DEVELOPMENTAL DISABILITIES ACT EXTENSION AND RIGHTS OF MENTALLY RETARDED, 1973

HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON LABOR AND PUBLIC WELFARE UNITED STATES SENATE

NINETY-THIRD CONGRESS

FIRST SESSION

ON

S. 427

TO PROVIDE FOR THE EXTENSION OF THE DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT

S. 458

TO PROVIDE FOR THE HUMANE CARE, TREATMENT, HABILITATION AND PROTECTION OF THE MENTALLY RETARDED IN RESIDENTIAL FACILITIES THROUGH THE ESTABLISHMENT OF STRICT QUALITY OPERATION AND CONTROL STANDARDS AND THE SUPPORT OF THE IMPLEMENTATION OF SUCH STANDARDS BY FEDERAL ASSISTANCE, TO ESTABLISH STATE PLANS WHICH REQUIRE A SURVEY OF NEED FOR ASSISTANCE TO RESIDENTIAL FACILITIES TO ENABLE THEM TO BE IN COMPLIANCE WITH SUCH STANDARDS, SEEK TO MINIMIZE INAPPROPRIATE ADMISSIONS TO RESIDENTIAL FACILITIES, AND DEVELOP STRATEGIES WHICH STIMULATE THE DEVELOPMENT OF REGIONAL AND COMMUNITY PROGRAMS FOR THE MENTALLY RETARDED WHICH INCLUDE THE INTEGRATION OF SUCH RESIDENTIAL FACILITIES, AND FOR OTHER PURPOSES

FEBRARY 8, 1973

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CONTENTS

Page

Bills:
S. 427, text **of** 2
S. 458, text **of** 4
S. 1654, text of 726

CHRONOLOGICAL LIST OF WITNESSES

THURSDAY, FEBRUARY 8, 1973

Humphrey, Mrs. Hubert H., wife of Hon. Hubert H. Humphrey, a U.S. Senator from the State of Minnesota 251
Boggs, Elizabeth M., chairman, National Advisory Council on Services and Facilities for the Developmentally Disabled 259
Cooke, Robert E., M.D., chairman, scientific advisory board, the Joseph P. Kennedy, Jr., Foundation 323
Tarjan, George, M.D., professor of psychiatry and programs, Director, Council on Mental Retardation 470
Jordan, Robert G., M.D., president, Association of University Affiliated Facilities 478
Watson, James MacDonald, M.D., member, national board of directors, Epilepsy Foundation of America, and associate clinical professor of neurology, University of Oregon Medical School, Portland, Oreg 491
Bowling, John, board of directors, National Association of Retarded Children 499
Messner, Sherwood A., director, professional services program department, United Cerebral Palsey Associations, Inc 506
Schneier, Max, chairman, Federation of Parents Organizations for New York State Mental Institutions 561
Rivera, Geraldo, station WABC-TV, New York, N.Y. 562
Hartman, David, national vice president, Muscular Dystrophy Association of America 567
Charash, Leon I., M.D., chairman, medical advisory committee, Muscular Dystrophy Association of America 570
Weingold, Joseph T., executive director, New York State Association for Retarded Children, Inc 572
Haggerty, Dennis E., Esq., member, National Advisory Council of Development Disabilities 585
Bartlette, Donald, director, program and social work service, Outreach Community Center, Minneapolis, Minn 587
Poetz, Clifford, apartment living program resident, Outreach Community Center, Minneapolis, Minn., president, Client Council; member at large, region No. 1, Minnesota Youth Association 590
Rimland, Bernard, M.D., founder, National Society for Autistic Children; director, Institute for Child Behavior Research; accompanied by Mrs. Mary Akerley, chairman of the National Society for Autistic Children- 590
Rupp, Joan, president, Maryland Association, Children With Learning Disabilities, Inc 594
Smith, Mrs. Vernon B., member, Childhood Mental Illness Committee, National Association for Mental Health, Inc 600
Moss, James W., Ph. D., University of Washington, Seattle, Wash., special consultant to the National Easter Seal Society for Crippled Children and Adults 602
Shurman, Jack, president, Spina Bifida Association of America 616

Akerley, Mrs. Mary, chairman of the National Society for Autistic Children ..... Page 644
Crosby, Kenneth 6., program director, Accreditation Council for Facilities for the Mentally Retarded 644
Boyer, Donald A., president, National Association of Private Residential Facilities for the Mentally Retarded 655
Kott, Maurice G., Ph. D., director, Division of Mental Retardation, New Jersey Department of Institutions and Agencies 666
Scheerenberger, R. C, Ph. D., president-elect, National Association of Superintendents of Public Residential Facilities for the Mentally Retarded 691
Schnibbe, Harry C, executive director, National Association of State Mental Health Program Directors 696
Kinnealey, Moya, director, occupational therapy training, Eunice Kennedy Shriver Center, Walter E. Femald State School, Waverly, Mo 698
Healey, William C, Ph. D., associate secretary for school affairs, American Speech and Hearing Association 705

STATEMENTS

Akerley, Mrs. Mary, chairman of the National Society for Autistic Children. 644
Bartlette, Donald, director, program and social work service, Outreach Community Center, Minneapolis, Minn 587
Boggs, Elizabeth M., chairman, National Advisory Council on Services and Facilities for the Developmentally Disabled 259
Prepared statement 263
Bowling, John, board of directors, National Association of Retarded Children 499
Prepared statement 501
Boyer, Donald A., president, National Association of Private Residential Facilities for the Mentally Retarded 655
Prepared statement 657
Charash, Leon I., M.D., chairman, Medical Advisory Committee, Muscular Dystrophy Association of America 570
Cooke, Robert E., M.D., chairman, scientific advisory board, the Joseph P. Kennedy, Jr., Foundation 323
Prepared statement (with attachments) 327
Crosby, Kenneth G., program director, Accreditation Council for Facilities for the Mentally Retarded 644
Prepared statement 647
Haggerty, Dennis E., Esq., member, National Advisory Council of Development Disabilities 585
Hartman, David, national vice president, Muscular Dystrophy Association of America 567
Healey, William C, Ph. D., associate secretary for school affairs, American Speech and Hearing Association 705
Prepared statement 706
Hollings, Hon. Ernest F., a U.S. Senator from the State of South Carolina, prepared statement 721
Humphrey, Mrs. Hubert H., wife of Hon. Hubert H. Humphrey, a U.S. Senator from the State of Minnesota 251
Jordan, Robert G., M.D., president, Association of University Affiliated Facilities 478
Prepared statement 482
Kinnealey, Moya, director, Occupational Therapy Training, Eunice Kennedy Shriver Center, Walter E. Femald State School, Waverly, Mass 698
Prepared statement 700
Kott, Maurice G., Ph. D., director, Division of Mental Retardation, New Jersey Department of Institutions and Agencies 666
Prepared statement 668
Messner, Sherwood A., director, professional services program department, United Cerebral Palsey Associations, Inc 506
Prepared statement 509

Moss, James W., Ph. D., University of Washington, Seattle, Wash., special consultant to the National Easter Seal Society for Crippled Children and Adults ... Page 602
Prepared statement ... 603
Noland, Royce P., executive director, American Physical Therapy Association, prepared statement ... 723
Poetz, Clifford, apartment living program resident, Outreach Community Center, Minneapolis, Minn.; president, Client Council member at large, region 1, Minnesota Youth Association ... 590
Rimland, Bernard, M.D., founder National Society for Autistic Children; director, Institute for Child Behavior Research; accompanied by Mrs. Mary Akerley, chairman of the National Society for Autistic Children ... 580
Rivera, Geraldo, station WABC-TV, New York, N.Y ... 562
Rupp, Joan, president, Maryland Association, Children with Learning Disabilities, Inc ... 594
Scheerenberger, R. C, Ph. D., president-elect, National Association of Superintendents of Public Residential Facilities for the Mentally Retarded ... 691
Prepared statement ... 692
Schneier, Max, chairman, Federation of Parents Organizations for New York State Mental Institutions ... 561
Schnibbe, Harry C, executive director, National Association of State Mental Health Program Directors ... 695
Prepared statement ... 696
Shurman, Jack, president, Spina Bifida Association of America ... 616
Prepared statement ... 618
Smith, Mrs. Vernon B., member, Childhood Mental Illness Committee, National Association for Mental Health, Inc ... 600
Tarjan, George, M.D., professor of psychiatry and program director, Council on Mental Retardation ... 470
Prepared statement ... 472
Watson, James MacDonald, M.D., member, national board of directors, Epilepsy Foundation of America, and associate clinical professor of neurology, University of Oregon Medical School, Portland, Oreg ... 491
Prepared statement ... 494
Weingold, Joseph T., executive director, New York State Association for Retarded Children, Inc ... 572
Prepared statement ... 577

ADDITIONAL INFORMATION

Articles, publications, etc.:
Federal legislation on rights of mentally retarded, proposed ... 697
Residential services for the mentally retarded: An ACTION policy proposal, by the President's Committee on Mental Retardation, Washington: 1970 ... 288
Communications:
"Bill of Rights for the Mentally Retarded," letters commenting on ... 231-248
Randolph, Hon. Jennings, a U.S. Senator from the State of West Virginia, chairman, Subcommittee on the Handicapped from Louis A. Saporito, DDS, president, American Dental Association, Newark, N.J., March 2, 1973 ... 716
Symington, Hon. Stuart, a U.S. Senator from the State of Missouri from Daniel Henroid, regional director, the Easter Seal Society, St. Louis, Mo., March 6, 1973 ... 719
Miscellaneous :
Advice to the Secretary of HEW on the Extension of the Developmental Disabilities Act by the National Advisory Council on Services and Facilities for the developmentally disabled ... 278
National Advisory Council on Services and Facilities for the developmentally disabled, members of ... 263

DEVELOPMENTAL DISABILITIES ACT EXTENSION AND RIGHTS OF MENTALLY RETARDED, 1973

THURSDAY, FEBRUARY 8, 1973

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
OF THE COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met at 10:30 a.m., pursuant to recess, in room 2228, New Senate Office Building, Senator Jennings Randolph (chairman of the subcommittee) presiding.

Present: Senators Randolph, Kennedy, Javits, and Hathaway.

Senator KENNEDY (presiding pro tempore). The Subcommittee on the Handicapped will come to order.

Today we will take testimony on two pieces of legislation which affect those of our citizens with developmental disabilities: S. 427, the Developmental Disabilities Services and Facilities Construction Act Extension, and S. 458, the Bill of Eights for the Mentally Retarded. I want to thank the distinguished senior Senator from West Virginia, Senator Jennings Randolph, for giving me the opportunity to chair these hearings.

[The texts of S. 427 and S. 458 follow:]

93D CONGRESS
1ST SESSION

S.427

IN THE SENATE OF THE UNITED STATES

JANUARY 18,1973

Mr. KENNEDY (for himself, Mr. RANDOLPH, Mr. WUJJAMS, Mr. JAVITS, Mr. BEALL, Mr. CRANSTON, Mr. HATHAWAY, Mr. MONDALE, Mr. PELL, Mr. SCHWEIKER, and Mr. TAFT) introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

A BILL

To provide for the extension of (The Developmental Disabilities Services and Facilities Construction Act.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That (a) section 121 (a) of the Developmental Disabilities Services and Facilities Construction Act is amended by striking the word "five" and inserting in lieu thereof "eight", and by striking out "June 30, 1973" and inserting in lieu thereof "June 30, 1976".

(b) Section 122 (b) of such Act is amended to read as follows:

" (b) For the purpose of making grants under this sec-

tion, there are authorized to be appropriated such sums as may be necessary.".

(c) Section 131 (c) of such Act is amended to read as follows:

"(c) For the purpose of making grants to carry out the purpose of section 130, there are authorized to be appropriated such sums as may be necessary.".

93D CONGRESS
1ST SESSION

S.458

IN THE SENATE OF THE UNITED STATES

JANUARY 18, 1973

Mr. JAVTTS (for himself, Mr. WILLIAMS, Mr. KENNEDY, Mr. BROOKE, Mr. BURRDICK, Mr. CRANSTON, Mr. HARTKE, Mr. HUGHES, Mr. HUMPHREY, Mr. MCGEE, Mr. METCALF, Mr. PASTORE, Mr. PERCY, Mr. RIBICOFF, Mr. SCHWEIKER, Mr. STEVENS, Mr. STEVENSON, Mr. TAFT, Mr. TOWER, Mr. TUNNEY, Mr. Moss, Mr. PELL, Mr. RANDOLPH, and Mr. DOLE) introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

A BILL

To provide for the humane *care,* treatment, habilitation and protection of the mentally retarded in residential facilities through the establishment of strict quality operation and control standards and the support of the implementation of such standards by Federal assistance, to establish State plans which require a survey of need for assistance to residential facilities to enable them to be in compliance with such standards, seek to minimize inappropriate admissions to residential facilities and develop strategies which stimulate the development of regional and community programs for the mentally retarded which include the integration of such residential facilities, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

That this Act shall be known as the "Bill of Eights for the Mentally Retarded".

SEC. 2. (a) The Congress finds that—

(1) there are more than two hundred thousand mentally retarded persons in the United States currently living in publicly and privately operated residential facilities for the mentally retarded;

(2) the prime purpose of residential services for the mentally retarded is to protect and nurture the mental, physical, emotional, and social development of each individual requiring responsible full-time services and to provide those experiences which will enable the individual (A) to develop his physical, intellectual, and social capabilities to the fullest extent possible; (B) to develop emotional maturity commensurate with social and intellectual growth; (C) whenever possible, to develop skills, habits, and attitudes essential for return to contemporary society; and (D) to live a personally satisfying life within the residential environment for whatever period he may need to remain there;

(3) the basic obligation of residential services is to assure to the mentally retarded the same constitutional rights and guarantees as every other American citizen;

(4) voluntary and involuntary admissions to a residential facility should be based on sound professional

considerations that include a comprehensive assessment of mental ability, physical health, and adaptive behavior which demonstrate a handicap sufficiently severe to justify placement;

(5) legal guardians should be appointed for both adults who are incompetent because of the severity of their mental retardation and minors who are deprived of parental guardianship, prior to their admission to a residential facility and, also, for each such individual who is in residential facilities at the date of enactment of this Act;

(6) residential facilities for the mentally retarded should provide a warm, stimulating setting devoid of dehumanizing conditions, the living quarters should be designed for optimum safety and to insure the provision of basic needs, including the right to privacy, and the location of the residential facility should where appropriate be within the community served and provide for normal contacts within the community life;

(7) the protection of the human dignity, the integrity and the life, of the mentally retarded must be realized as the first consideration in research and planning for the mentally retarded; and

(8) residential facilities should consist of small, homelike units located within, coordinated with, and

integrated into existing community living situations and although the demand for resources to build these new facilities may seem to conflict with the demand for resources to upgrade the old ones to humane care, treatment and protection standards, the two objectives are equally necessary.

(b) The purpose of this Act is to establish standards which assure the humane care, treatment, habilitation, and protection of the mentally retarded in residential facilities and improve the system for the provision of services to the mentally retarded through the encouragement of and support for the planning and development of strategies to implement such standards, minimize inappropriate admissions to residential facilities and stimulate the development of regional and community programs integrating such residential facilities which conform to such standards. It is the further purpose of this Act to encourage and support planning and development of strategies which survey and analyze residential facilities and their compliance with the standards established under title XII of the Public Health Service Act and stimulate regional and community programs and services for the mentally retarded which integrate such residential facilities.

AMENDMENT TO PUBLIC HEALTH SERVICE ACT

SEC. 3. The Public Health Service Act is amended by inserting after title XI the following new title:

"TITLE XII—SUPPORT OF RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

"PART A—STATE STRATEGY PLANNING

"SEC. 1201. (a) In order to assist the States in comprehensive surveys and analyses of the cost of bringing existing residential facilities into compliance with the standards established under part C of this title, review existing State plans concerned with providing services and programs for the mentally retarded and develop strategies which include implementation and monitoring mechanisms which minimize inappropriate placement in residential facilities particularly through the provision of alternative programs of care and coordinate and integrate existing residential facilities with existing and future regional and community mental retardation programs and services, which shall be done in cooperation with the National Advisory Council on Standards for Residential Facilities for the Mentally Retarded established under section 1209 of this Act, and to study administrative relationships, including the identification of legal, economic, social and other barriers to compliance with the standards established under part C of this Act and financing of programs and services from both public and private sources among Federal, State, and local governments in the field of mental retardation with recommendations for improvement, the Secretary may make grants, to such applicants and upon such terms and conditions as he shall by regulations prescribe.

" (b) In order to assist the States in improving existing residential facilities for the mentally retarded so as to contribute more effectively in providing the resident with experiences which will enable such individual (1) to develop his physical, intellectual, and social capabilities to the fullest extent possible; (2) to develop emotional maturity commensurate with social and intellectual growth; (3) whenever possible, to develop skills, habits, and attitudes essential for return to contemporary society; and (4) to live a personally satisfying life within the residential environment and to otherwise conform to the standards established under part C of this title, the Secretary may, in accordance with the provisions of this part, make grants, not to exceed $300,000 per institution, to cover costs of administering and operating demonstration facilities and training programs to render services in the care of mentally retarded persons in residential facilities and reduce excess residential facility population, which shall be evaluated for effectiveness in improving residential care for the mentally retarded.

" (c) For the purpose of making grants under section (a) of this part there are authorized to be appropriated $15,000,000 for the fiscal year ending June 30, 1974, and for each of the next two succeeding fiscal years and for the purpose of making grants under section (b) of this part there are authorized to be appropriated $15,000,000 for the fiscal

year ending June 30, 1974, and for each of the next two succeeding fiscal years.

"**PART B**—DELIVERY OF MENTAL RETARDATION PROGRAMS AND SERVICES

"GRANTS TO ASSIST INSTITUTIONS FOR THE MENTALLY RETARDED

"SEC. 1202. (a) For the purpose of assisting States in meeting the expenses, directly or indirectly, for bringing publicly operated facilities and publicly assisted facilities into conformity with the standards established under part C of this title, which seek to assure the humane care, protection, habilitation, and treatment of the mentally retarded in residential facilities, there are authorized to be appropriated such sums as are necessary to enable the Secretary to make grants under this title.

"(b) In considering applications for such grants, the Secretary shall give priority to those applicants whose publicly operated residential facility or publicly assisted facilities are in the greatest need of assistance to comply with such standards.

"STATE PLANS

"SEC. 1203. (a) Any State desiring to receive a grant under this title shall submit a plan to the Secretary:

"(1) setting forth a schedule for compliance with the standards established under part C of this title for each facility for which assistance is requested;

"(2) designating a State planning and advisory council, which shall include representatives of local agencies and nongovernmental organizations concerned with services for mentally retarded persons and at least one-third of the membership of such council shall consist of representatives of consumers of such services from publicly operated and publicly assisted residential facilities for the mentally retarded;

"(3) assuring reasonable State financial participation in the cost of carrying out the plan to comply with the standards set forth in this title and how the residential facility for the mentally retarded will complement and augment rather than duplicate or replace other community services for the mentally retarded or meet the requirements of part C of this title;

"(4) setting forth a schedule of costs to achieve compliance with the standards established under part C of this title; and

"(5) designating how placement in residential facilities shall be minimized through alternative regional and community programs and services for the mentally retarded.

"(b) The Secretary shall approve a plan which sets forth a reasonable time for compliance with the standards established under this title, and he shall not finally dis-

approve a plan except after reasonable notice and opportunity for a hearing to such State.

"AMOUNT OF GRANTS; PAYMENTS

"SEC. 1204. (a) The total of the grants with respect to any project under this part may not exceed 75 per centum of the necessary cost thereof as determined by the Secretary.

"(b) Payments of grants under this part shall be made in advance or by way of reimbursement, and on such conditions as the Secretary may determine.

"MAINTENANCE OF EFFORT

"SEC. 1205. Applications for grants under this part may be approved by the Secretary only if the application contains or is supported by reasonable assurances that the grants will not result in any decrease in the level of State, local, and other non-Federal funds for services for mentally retarded which would (except for such grant) be available to the applicant, but that such grants will be used to supplement, and, to the extent practicable, to increase the level of such funds.

"WITHHOLDING OF GRANTS

"SEC. 1206. (a) Whenever the Secretary, after an opportunity for a hearing on the record finds—

"(1) that there has been a failure to comply substantially with any requirement set forth in the plan of that State approved under section 1203; or

"(2) that in the operation of any program assisted under this title there is a failure to comply substantially with any applicable provision of this title;

the Secretary shall notify such State of his findings and that no further payments may be made to such State under this Act for any project connected with the program until he is satisfied that there is no longer any such failure to comply, or that the noncompliance will be promptly corrected.

"(b) In any case where a State has received a grant under section 1202 and has not complied with the standards of this title within a reasonable period of time prescribed by the Secretary, such State shall not be eligible for any further Federal funds on behalf of any individual who is a resident of any public or private residential facility for the retarded which does not meet the standards set forth in part C of this title. The funds to which any individual would otherwise be entitled to have paid on his behalf to any vendor of residential services, public or private, shall be reserved for him and administered by the Social Security Administration in the same manner as benefits under title II of the Social Security Act would be administered on his behalf were he entitled to same.

"(c) Five years after the date of enactment of this Act, no residential facility for the mentally retarded shall be eligible to receive payments either directly or indirectly

under any Federal law, unless such facility meets the standards promulgated under part C of this title.

"EXTENSION OF TIME TO MEET STANDARDS

"SEC. 1207. Where in any fiscal year the appropriation for grants under section 1202 does not meet the amount authorized, the Secretary may extend the time for recipients of such grants and other residential facilities for the mentally retarded to meet the standards established by this Act.

"ALTERNATIVE PROGRAMS OF CARE

"SEC. 1208. (a) The Secretary is authorized to make grants to any public or private non-profit agency, organization or institution to meet the costs of development, improvement, extension, or expansion of community resources and community living situations for the mentally retarded other than living-in residential facilities for the mentally retarded.

"(b) Applications for grants under this section shall contain such information and be in such form as the Secretary may prescribe.

"(c) In considering applications for grants under this section the Secretary shall give priority to those applicants whose proposal he determines are of special significance because they demonstrate new or relatively effective or efficient methods of delivery of sen-ices to the mentally retarded.

"(d) There are authorized to be appropriated to carry out the purpose of this section such sums as may be necessary for the fiscal year ending June 30, 1974, for each of the next two succeeding fiscal years.

"(e) Each recipient of a grant under this title shall keep such records as the Secretary may prescribe, including records which fully disclose the amount and disposition by such recipient of the proceeds of such grant, the total cost of the project or undertaking in connection with which such grant is made or used, the amount of that portion of the cost of the project or undertaking supplied by other sources, and such records as will facilitate an effective audit.

"(f) The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipient of any grant under this title which are pertinent to such grant."

"NATIONAL ADVISORY COUNCIL ON STANDARDS FOB RESIDENTIAL FACILITIES FOB THE MENTALLY RETARDED

"SEC. 1209. (a) Effective ninety days after the date of enactment of this Act, there is hereby established a National Advisory Council on Standards for Residential Facilities for the Mentally Retarded (hereinafter referred to as the 'Council'), which shall consist of fifteen mem-

bers, not otherwise in the regular full-time employ of the United States, to be appointed by the Secretary without regard to the provisions of title 5, United States Code, governing appointments in the competitive civil service. The Secretary shall from time to time designate one of the members of the Council to serve as Chairman thereof. The members of the Council shall be selected from representatives of the American Association on Mental Deficiency, the American Psychiatric Association, the Council for Exceptional Children, the National Association for Retarded Children, the United Cerebral Palsy Association, consumers (for example, parents of the mentally retarded) of services from publicly operated and publicly assisted residential facilities for the mentally retarded, and leaders in the fields of service to the mentally retarded, including a representative of the National Association of Coordinators of State Programs for the Mentally Retarded, of the National Association of Superintendents of Public Residential Facilities for the mentally retarded, and other persons (for example, parents of the mentally retarded) in organizations representing consumers of such services. A majority of the Council shall be representative of the interests of consumers of such services.

"(b) It shall be the duty and function of the Council to (1) advise the Secretary with respect to any regulations promulgated or proposed to be promulgated by him in the implementation of the standards established under part C of this Act, (2) study and evaluate such standards authorized by this Act through site visits and other appropriate methods with a view of determining their effectiveness in carrying out the purposes for which they were established, and (3) based upon site visits or other studies, evaluations or reviews recommend to the Secretary any changes, revisions, modifications, or improvements in the standards established under part C of this Act.

" (c) Members of the Council, while attending meetings or conferences thereof or otherwise serving on the business of the Council, including site visits shall be entitled to receive compensation at rates fixed by the Secretary, but at rates not exceeding the daily equivalent of the rate provided for GS-18 of the General Schedule for each day of such service (including traveltime), and, while so serving away from their homes or regular places of business, they may be allowed travel expenses, including diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons in the Government service employed intermittently."

"PART C—STANDARDS FOR RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

"Chapter 1.—ADMINISTRATIVE POLICIES AND PRACTICES

"Subchapter I—Philosophy, Location and Organization

"SEC. 1210. (a) The ultimate aim of the facility shall be to foster those behaviors that maximize the human qualities of the resident, increase the complexity of his behavior, and enhance his ability to cope with his environment.

"(b) The facility shall accept and implement the principle of normalization, defined as the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible, taking into account local and subcultural differences.

"SEC. 1211. (a) The names of facilities, the labels applied to their users, and the way these users are interpreted to the public should be appropriate to their purposes and programs and services should not emphasize 'mental retardation' or 'deviancy'.

"(b) Residents should not be referred to as 'patient' except in a hospital-medical context; as 'kids' or 'children' if they are adults; or as 'inmates'.

"SEC. 1212. (a) The facility should be located within, and conveniently accessible to, the population served,

so as to have access to necessary generic community services.

"(b) The facility should not be isolated from society or community by factors such as:

"(1) difficulty of access, due to distance or lack of public transportation;

"(2) architectural features;

"(3) socio-cultural or psychological features; and

"(4) rules, regulations, customs, and habits.

"(c) Protection devices (such as fences and security windows), where necessary, should be inconspicuous, and should preserve as normal an environmental appearance as possible, so as to permit the pursuit of normal activities.

"(d) The facility should be in scale with the community in which it is located.

"(e) The facility and the surrounding community should be encouraged to share their services and resources on a reciprocal basis.

"(f) The community in which the facility is located should be capable of meeting the needs of the facility's residents for generic and specialized services.

"(g) The community in which the facility is located should be capable of absorbing, and encouraged to absorb, into its cultural life those residents capable of participation in that life.

"(h) The facility shall have available a current descriptive directory of community resources.

"SEC. 1213. (a) Residents should be integrated to the greatest possible extent with the general population. To this end, generic and specialized community services, rather than facility services, should be used extensively or, if possible, completely. For example, the residents should—

"(1) attend (special) classes or programs in regular schools;

"(2) attend religious instruction and worship in the community;

"(3) utilize medical, dental, and all other professional services located in the. community;

"(4) use community rather than facility recreation resources, such as bowling alleys, swimming pools, movies, and gymnasia;

"(5) shop in community stores, rather than in facility stores and canteens; and

"(6) work in as integrated a fashion as possible: sheltered employment should be in regular industry, and among nonretarded workers; sheltered workshops should be in the community; and work that must be on the campus of the facility should afford maximal contact with nonretarded persons.

There shall be evidence of professional and public education to facilitate the integration of residents, as outlined above.

"(b) The facility should be divided into groupings of program and residence units, based upon a rational plan to meet the needs of the residents and fulfill the purposes of the facility.

"SEC. 1214. The facility shall make every attempt to move residents from—

"(1) more to less structured living;

"(2) larger to smaller facilities;

"(3) larger living units to smaller living units;

"(4) group to individual residence;

"(5) dependent to independent living; and

"(6) segregated to integrated living.

"Subchapter II—General Policies and Practices

"SEC. 1215. (a) The facility shall have a written outline of the philosophy, objectives, and goals it is striving to achieve, that is available for distribution to staff, consumer representatives, and the interested public, and that shall include but need not be limited to:

"(1) its role in the State comprehensive program for the mentally retarded;

"(2) its concept of the rights of its residents;

"(3) its goals for its residents;

"(4) its concept of its relationship to the parents of its residents, or to their surrogates;

"(5) its concept of its relationship to the community, zone, or region from which its residents come;

"(6) its concept of its responsibility (through research, training, and education) for improving methods, understanding, and support for the mental retardation field;

"(7) the facility shall have a plan for evaluation and modification to maintain:

"(A) the consistency of its philosophy, objectives, and goals with advancements in knowledge and professional practices; and

"(B) the consistency of its practices with its philosophy, objectives, and goals.

"(b) The facility shall have a manual on policies and procedures, describing the current methods, forms, processes, and sequence of events being followed to achieve its objectives and goals.

"(c) The facility shall have a written statement of policies and procedures concerning the rights of residents that—

"(1) assure the civil rights of all residents;

"(2) are in accordance with general and special rights of the mentally retarded as defined by the Secretary in accordance with section 2 of this Act; and

"(3) define the means of making legal counsel available to residents for the protection of their rights.

"SEC. 1216. (a) The facility shall have a written statement of policies and procedures that protect the financial interests of residents and that provide for—

"(1) determining the financial benefits for which the resident is eligible;

"(2) assuring that the resident receives the funds for incidentals and for special needs (such as specialized equipment) that are due him under public and private financial support programs; and

"(3) when large sums accrue to the resident, providing for counseling of the resident concerning their use, and for appropriate protection of such funds.

"(b) Procedures in the major operating units of the facility shall be described in manuals that are current, relevant, available, and followed.

"(c) The facility shall have a summary of the laws and regulations relevant to mental retardation and to the function of the facility.

"(d) The facility shall have a plan for a continuing management audit to insure compliance with State laws and regulations and the effective implementation of its stated policies and procedures.

"SEC. 1217. (a) A public facility shall have documents

that describe the statutory basis of its existence, and describe the administrative framework of the governmental department in which it operates.

"(b) A private facility shall have documents that include its charter, its constitution and bylaws, and its State license.

"SEC. 1218. (a) The governing body of the facility shall exercise general direction and shall establish policies concerning the operation of the facility and the welfare of the individuals served.

" (b) The governing body shall establish appropriate qualifications of education, experience, personal factors, and skills for the chief executive officer. The chief executive officer shall have had training and experience in the administration of human services. The chief executive officer shall have administrative ability, leadership ability, and an understanding of mental retardation. Where the chief executive officer is required also to have had training in a professional service discipline, such training shall be in a discipline appropriate to the facility's program.

" (c) The governing body shall employ a chief executive officer so qualified, and shall delegate to him authority and responsibility for the management of the affairs of the facility in accordance with established policies.

" (d) The chief executive officer shall—

"(1) designate an individual to act for him in his absence;

"(2) make arrangements so that some one individual is responsible for the administrative direction of the facility at all times;

"(3) when an assistant chief executive officer is employed, the qualifications required for this position shall be in compliance with those stated above for the chief executive officer; and

"(4) there shall be on the premises of the facility at all times a person designated by the chief executive officer, or the person acting for him, to be responsible for the supervision of the facility.

"SEC. 1219. (a) The facility shall be administered and operated in accordance with sound management principles.

"(b) The type of administrative organization of the facility shall be appropriate to the program needs of its residents.

"(c) The facility shall have a table of organization that shows the governance and administrative pattern of the facility.

"(d) The table of organization shall show the major operating programs of the facility, with staff divisions, the administrative personnel in charge of the programs and di-

visions, and their lines of authority, responsibility, and communication.

"(e) The organization shall provide for the judicious delegation of administrative authority and responsibility among qualified members of the staff, in order to distribute the administrative load of the facility and to accelerate its operating efficiency.

"(f) The organization shall be such that problems requiring ongoing decisionmaking regarding the welfare of the resident are handled primarily by personnel on the lowest level competent to resolve the problem.

" (g) The organization shall provide for the utilization of staff with different levels of training by using those with more adequate training to supervise and train those with lesser training.

" (h) The organization shall provide effective channels of communication in all directions.

" (i) The facility shall have a plan for improving die quality of staff and services that shows how the staff functions by programatic responsibilities in establishing and maintaining standards of quality for services to residents. The plan shall show how the facility's organizational structure enables the following functions:

"(1) determination of standards for quality of services to the residents;

"(2) establishment of qualifications for personnel;

"(3) recruitment of qualified personnel;

"(4) initiation of preservice and inservice training and staff development programs;

"(5) work with administrators, superviors, and staff of the administrative units of the facility to secure and assign qualified personnel to such units;

"(6) annual evaluation of staff performance;

"(7) continuous evaluation of program effectiveness; and

"(8) development and conduct of appropriate research activities.

"SEC. 1220. (a) The administration of the facility shall provide for effective staff and resident participation and communication. Staff meetings shall be regularly held. Standing committees appropriate to the facility, such as records, safety, human rights, utilization review, research review, and infection and sanitation, shall meet regularly. Committees shall include resident participation, whenever appropriate. Committees shall include the participation of direct-care staff, whenever appropriate.

"(b) Minutes and reports of staff meetings, and of standing and ad hoc committee meetings shall include records

of recommendations and their implementation, and shall be kept and filed. Summaries of the minutes and reports of staff and committee meetings shall be distributed to participants and to appropriate staff members. Various forms of communication (such as meetings, minutes of meetings, directives, and bulletins) shall be utilized to foster understanding among the staff, among the residents, between staff and residents, and between facility, community, and family.

"SEC. 1221. The facility shall designate a percentage of its operating budget for self-renewal purposes, such as:

"(1) development of operational data records;

" (2) research on its own programs;

"(3) evaluation by qualified persons who are not part of the facility;

" (4) elicitation of feedback from consumers of the facility's services, or from their representatives;

"(5) staff education;

"(6) the findings generated by the foregoing activities shall be actively and broadly disseminated to:

" (A) all members of the facility's staff;

"(B) consumer representatives, when appropriate;

" (7) the facility shall have a continuing system for collecting and recording accurate data that describe its population, in such form as to permit data retrieval and

usage for description, programming of services, and research. Such data shall include, but need not be limited to:

"(A) number by age-groups, sex, and race;

"(B) number grouped by levels of retardation (profound, severe, moderate, mild, and borderline), according to the American Association on Mental Deficiency Manual on Terminology and Classification in Mental Retardation;

"(C) number grouped by levels of adaptive behavior, according to the American Association on Mental Deficiency classification;

"(D) number with physical disabilities;

"(E) number ambulatory and nonambulatory (mobile and nonmobile) ;

"(F) number with sensory defects;

"(G) number with oral and other communication handicaps; and

"(H) number with convulsive disorders, grouped by level of seizure control.

"SEC. 1221. The facility shall have a description of services for residents that is available to the public and that includes information such as:

"(1) groups served;

"(2) limitations concerning age, length of residence, or type or degree of handicap;

"(3) the plan for grouping residents into program and living units;

"(4) preadmission and admission services;

"(5) diagnosis and evaluation services;

"(6) means for individual programing of residents in accordance with need;

"(7) means for implementation of programs for residents, through clearly designated responsibility;

"(8) the therapeutic and developmental environment provided the residents; and

"(9) release and follow-up services and procedures.

"SEC. 1222. The facility shall provide for meaningful and extensive consumer-representative and public participation, by the following means:

"(1) the policymaking or governing board (if any) shall include consumers or their representatives (for example, parents), interested citizens, and relevantly qualified professionals presumed to be free of conflicts of interest;

"(2) when a facility does not have a governing board, its policymaking authority shall actively seek advice from an advisory body composed as described above;

"(3) the facility shall actively elicit feedback from those consumers of its services (and their representatives) who are not members of the aforementioned governing or advisory bodies;

"(4) there shall be an active program of ready, open, and honest communication with the public. In structuring visits to the facility by persons not directly concerned with a resident, however, steps shall be taken both to encourage visiting and to consider the sensibilities and privacy of the residents. Undignified displays or exhibitions of residents shall be avoided, and normal sensibility shall be exercised in speaking about a resident;

"(5) personnel shall be permitted to communicate their views about a resident and bis needs and program to his relatives. Personnel shall be trained to properly and competently assume this responsibility;

"(6) the facility shall maintain active means of keeping residents' families or surrogates informed of activities related to the residents that may be of interest to them;

"(7) communications to the facility from residents' relatives shall be promptly and appropriately handled and answered;

"(8) close relatives shall be permitted to visit at

any reasonable hour, and without prior notice. Steps shall be taken, however, so that the privacy and rights of the other residents are not infringed by this practice;

"(9) parents and other visitors shall be encouraged to visit the living units, with due regard for privacy. There shall be facilities for visiting that provide privacy in the living unit (but not special rooms used solely for visiting) ;

"(10) parents shall be permitted to visit all parts of the facility that provide services to residents;

"(11) frequent and informal visits home shall be encouraged, and the regulations of the facility shall encourage rather than inhibit such visitations;

"(12) there shall be an active citizens' volunteer program; and

"(13) the facility shall acknowledge the need for, and encourage the implementation of, advocacy for **all** residents.

"SEC. 1223. A public education and information program should be established that utilizes all communication media, and all service, religious, and civic groups, and so forth, to develop attitudes of understanding and acceptance of mentally retarded persons, in all aspects of community living.

"Subchapter III—Admission and Release

"SEC. 1224. No individual whose needs cannot be met by the facility shall be admitted to it. The number admitted as residents to the facility shall not exceed—

"(1) its rated capacity; and

"(2) its provisions for adequate programing.

"SEC. 1225. (a) The laws, regulations, and procedures concerning admission, readmission, and release shall be summarized and available for distribution. Admission and release procedures shall—

"(1) encourage voluntary admission, upon application of parent or guardian or self;

"(2) give equal priority to persons of comparable need, whether application is voluntary or by a court;

" (3) facilitate emergency, partial, and short-term residential care, where feasible; and

" (4) utilize the maximum feasible amount of voluntariness in each individual case.

" (b) The determination of legal incompetence shall be separate from the determination of the need for residential services, and admission to the facility shall not automatically imply legal incompetence.

"SEC. 1226. (a) The residential facility shall admit only residents who have had a comprehensive evaluation, cover-

ing physical, emotional, social, and cognitive factors, conducted by an appropriately constituted interdisciplinary team.

"(b) Initially, service need shall be defined without regard to the actual availability of the desirable options. All available and applicable programs of care, treatment, and training shall be investigated and weighed, and the deliberations and findings recorded. Admission to the residential facility shall occur only when it is determined to be the optimal available plan. Where admission is not the optimal measure, but must nevertheless be recommended or implemented, its inappropriateness shall be clearly acknowledged and plans shall be initiated for the continued and active exploration of alternatives.

"(c) The intended primary beneficiary of the admission shall be clearly specified as—

"(1) the resident;

"(2) his family;

"(3) his community;

"(4) society; and

"(5) several of the above.

"(d) All admissions to the residential facility shall be considered temporary, and when appropriate admissions shall be time-limited. Parents or guardians shall be counseled, prior to admission, on the relative advantages and disadvan-

tages and the temporary nature of residential services in the facility. Prior to admission, parents or guardians shall, and the prospective resident should, have visited the facility and the living unit in which the prospective resident is likely to be placed.

"SEC. 1227. (a) A medical evaluation by a licensed physician shall be made within one week of the resident's admission. Upon admission, residents should be placed in their program groups, and they should be isolated only upon medical orders issued for specific reasons.

"(b) Within the period of one month after admission there shall be:

"(1) a review and updating of the preadmission evaluation;

"(2) a prognosis that can be used for programing and placement;

"(3) a comprehensive evaluation and individual program plan, made by an interdisciplinary team;

"(4) direct-care personnel shall participate in the aforementioned activities;

"(5) the results of the evaluation shall be recorded in the resident's unit record;

"(6) an interpretation of the evaluation, in action terms, shall be made to:

" (A) the direct-care personnel responsible for carrying out the resident's program;

" (B) the special services staff responsible for carrying out the resident's program; and

" (C) the resident's parents or their surrogates

" (c) There shall be a regular, at least annual, joint review of the status of each resident by all relevant personnel, including personnel in the living unit, with program recommendations for implementation. This review shall include—

" (1) consideration of the advisability of continued residence and alternative programs;

" (2) at the time of the resident's attaining majority, or if he becomes emancipated prior thereto:

" (A) the resident's need for remaining in the facility;

" (B) the need for guardianship of the resident;

"(C) the exercise of the resident's civil and legal rights;

" (3) The results of these reviews shall be:

"(A) recorded in the resident's unit record;

"(B) made available to relevant personnel;

" (C) interpreted to the resident's parents or surrogates;

"(D) interpreted to the resident, when appropriate; and

"(4) parents or their surrogates shall be involved in planning and decisionmaking.

"SEC. 1228. A physical inspection for signs of injury or disease should be made in accordance with procedures established by the facility:

"(A) within twenty-four hours prior to a resident's leaving the facility for vacation, placement, or other temporary or permanent release; and

"(B) within twenty-four hours following a resident's return to the facility from such absence.

"SEC. 1229. (a) At the time of permanent release or transfer, there shall be recorded a summary of findings, progress, and plans.

"(b) Planning for release shall include provision for appropriate services, including protective supervision and other followup services, in the resident's new environment. Procedures shall be established so that—

"(1) parents or guardians who request the release of a resident are counseled concerning the advantages and disadvantages of such release; and

"(2) the court or other appropriate authorities are notified when a resident's release might endanger either the individual or society.

"(c) When a resident is transferred to another facility there shall be—

"(1) written evidence that the reason for the transfer is the welfare of the resident; and

"(2) a transfer process that shall insure that the receiving facility will meet the needs of the resident.

"(d) Except in an emergency, transfer shall he made only with the prior knowledge, and ordinarily the consent, of the resident and his guardian.

"SEC. 1230. (a) In the event of any unusual occurrence, including serious illness or accident, impending death, or death, the resident's next of kin, or the person who functions in that capacity (a guardian or citizen advocate) shall he notified promptly and in a compassionate manner. When appropriate, the wishes and needs of the resident, and of the next of kin, concerning religious matters shall be determined and, insofar as possible, fulfilled.

"(b) When death occurs:

" (1) with the permission of the next of kin or legal guardian, an autopsy shall be performed;

"(2) such autopsy shall be performed by a qualified physician, so selected as to be free of any conflict of interest or loyalty;

"(3) the family shall be told of the autopsy findings, if they so desire; and

" (4) the facility shall render as much assistance as possible in making arrangements for dignified religions services and burial, unless contraindicated by the wishes of the family.

" (c) The coroner or medical examiner shall be notified of deaths, in accordance with state law.

"Subchapter IV—Personnel Policies

"SEC. 1231. (a) Adequate personnel services shall be provided by means appropriate to the size of the facility. If the size of the facility warrants a personnel director, he. shall have had several years of progressively more responsible experience or training in personnel administration, and demonstrated competence in this area.

"(b) The facility's current personnel policies and practices shall be described in writing;

" (1) The hiring, assignment, and promotion of employees shall be based on their qualifications and abilties, without regard to sex, race, color, creed, age, irrelevant disability, marital status, ethnic or national origin, or membership in an organization.

" (2) Written job descriptions shall be available for all positions.

"(5) Licensure, certification, or standards such as are required in community practice shall be required for all comparable positions in the facility.

"(4) Ethical standards of professional conduct, as developed by professional societies, shall be recognized as applying in the facility.

"(5) There shall be a planned program for career development and advancement for all categories of personnel.

"(6) There shall be an authorized procedure, consistent with due process, for suspension and/or dismissal of an employee for cause.

"(7) Methods of improving the welfare and security of employees shall include:

"(A) a merit system or its equivalent;

"(15) a salary schedule covering all positions;

"(C) effective grievance procedures;

"(D) provisions for vacations, holidays, and sick leave;

"(E) provisions for health insurance and retirement;

"(F) provisions for employee organizations;

"(G) opportunities for continuing educational experiences, including educational leave; and

"(H) provisions for recognizing outstanding contributions to the facility.

"(c) A statement of the facility's personnel policies and practices shall be available to all its employees.

"(d) All personnel shall be initially screened to determine if they are capable of fulfilling the specific job requirements. All personnel shall be medically determined to be free of communicable and infectious diseases at the time of employment and annually thereafter. All personnel should have a medical examination at the time of employment and annually thereafter. Where indicated, psychological assessment should be included at the time of employment and annually thereafter.

"(e) The performance of each employee shall be evaluated regularly and periodically, and at least annually. Each such evaluation shall be—

"(1) reviewed with the employee; and

"(2) recorded in the employee's personnel record.

"(f) Written policy shall prohibit mistreatment, neglect, or abuse of residents. Alleged violations shall be reported immediately, and there shall, be evidence that—

"(1) all alleged violations are thoroughly investigated;

"(2) the results of such investigation are reported to the chief executive officer, or his designated representative, within twenty-four hours of the report of the incident; and

"(3) appropriate sanctions are invoked when the allegation is substantiated.

"SEC. 1232. (a) Staffing shall be sufficient so that the facility is not dependent upon the use of residents or volunteers for productive services. There shall be a written policy to protect residents from exploitation when they are engaged in productive work. A current, written policy shall encourage that residents be trained for productive, paid employment. Residents shall not be involved in the care (feeding, clothing, bathing), training, or supervision of other residents unless they—

"(1) have been specifically trained in the necessary skills;

"(2) have the humane judgment required by these activities;

"(3) are adequately supervised; and

"(4) are reimbursed.

"(b) Residents who function at the level of staff in occupational or training activities shall—

"(1) have the right to enjoy the same privileges as staff; and

"(2) be paid at the legally required wage level when employed in other than training situations.

"(c) Appropriate to the size and nature of the facility, there shall be a staff training program that includes:

"(1) orientation for all new employees, to acquaint

them with the philosophy, organization, program, practices, and goals of the facility;

" (2) induction training for each new employee, so that his skills in working with the residents are increased;

" (3) inservice training for employees who have not achieved the desired level of competence, and opportunities for continuous inservice training to update and improve the skills and competencies of all employees ,*

"(4) supervisory and management training for all employees in, or candidates for, supervisory positions;

" (5) provisions shall he made for all staff members to improve their competencies, through means such as—

"(A) attending staff meetings;

" (B) undertaking seminars, conferences, workshops, and institutes;

"(C) attending college and university courses;

"(D) visiting other facilities;

"(E) participation in professional organizations;

"(F) conducting research;

"(G) publishing studies;

"(H) access to consultants;

"(I) access to current literature, including books, monographs, and journals relevant to mental retardation;

"(6) interdisciplinary training programs shall be stressed;

"(7) the ongoing staff development program should include provision for educating staff members as research consumers.

"(8) where appropriate to the size and nature of the facility, there shall be an individual designated to be responsible for staff development and training, and such individual should have—

"(A) at least a master's degree in one of the major disciplines relevant to mental retardation;

"(B) a thorough knowledge of the nature of mental retardation and associated disabilities, and the current goals, programs, and practices in this field;

"(C) a knowledge of the educational process;

"(D) an appropriate combination of academic training and relevant experience;

"(E) demonstrated competence in organizing and directing staff training programs; and

"(9) appropriate to the size and nature of the facility, there should be adequate, modern educational media equipment for the conduct of an inservice training program, such as: overhead, filmstrip, motion picture, and

slide projectors; screens; models and charts; and video tape systems.

"(d) Working relations should be established between the facility and nearby colleges and universities for the following purposes:

"(1) making credit courses, seminars, and workshops available to the facility's staff;

"(2) using facility resources for training and research by colleges and universities; and

"(3) exchanging of staff between the facility and the colleges and universities for teaching, research, and consultation.

"Chapter 2.—RESIDENT LIVING

"Subchapter I—Staff-Resident Relationships and Activities

"SEC. 1240. (a) The primary responsibility of the living unit staff shall be to devote their attention to the care and development of the residents as follows:

"(1) each resident shall receive appreciable and appropriate attention each day from the staff in the living unit;

"(2) living unit personnel shall train residents in activities of daily living and in the development of self-help and social skills;

"(3) living unit personnel shall be responsible for

the development and maintenance of a warm, family- or home-like environment that is conducive to the achievement of optimal development by the resident;

"(4) appropriate provisions shall he made to ensure that the efforts of the staff are not diverted from these responsibilities by excessive housekeeping and clerical duties, or other non-resident-care activities; and

"(5) the objective in staffing each living unit should be to maintain reasonable stability in the assignment of staff, thereby permitting the development of a consistent inter-personal relationship between each resident and one or two staff members.

"(b) Members of the living unit staff from all shifts shall participate with an interdisciplinary team in appropriate referral, planning, initiation, coordination, implementation, followthrough, monitoring, and evaluation activities relative to the care and development of the resident.

"(c) There shall be specific evaluation and program plans for each resident that are—

"(1) available to direct care staff in each living unit; and

"(2) reviewed by a member or members of the interdisciplinary program team at least monthly, with documentation of such review entered in the resident's record.

"(d) Activity schedules for each resident shall be available to direct care staff and shall be implemented daily as follows:

"(1) such schedules shall not permit 'dead time' of unscheduled activity of more than one hour continuous duration; and

"(2) such schedules shall allow for individual or group free activities, with appropriate materials, as specified by the program team.

"(e) The rhythm of life in the living unit shall resemble the cultural norm for the residents' nonretarded age peers, unless a departure from this rhythm is justified on the basis of maximizing the residents' human qualities. Residents shall be assigned responsibilities in the living unit commensurate with their interests, abilities, and developmental plans, in order to enhance feelings of self-respect and to develop skills of independent living. Multiple-handicapped and nonambulatory residents shall—

"(1) spend a major portion of their waking day out of bed;

"(2) spend a portion of their waking day out of their bedroom areas;

"(3) have planned daily activity and exercise periods; and

"(4) be rendered mobile by various methods and devices.

"(f) All residents shall have planned periods out of doors on a year-round basis. Residents should be instructed in how to use, and, except as contraindicated for individual residents by their program plan, should be given opportunity for, freedom of movement—

"(1) within the facility's ground; and

"(2) without the facility's grounds.

Birthdays and special events should be individually observed. Provisions shall be made for heterosexual interaction appropriate to the residents' developmental levels.

"(g) Residents' views and opinions on matters concerning them should be elicited and given consideration in defining the processes and structures that affect them.

"(h) Residents should be instructed in the free and unsupervised use of communication processes. Except as denied individual residents by team action, for cause, this should typically include—

"(1) having access to telephones for incoming and local outgoing calls;

"(2) having free access to pay telephones, or the equivalent, for outgoing long distance calls;

"(3) opening their own mail and packages, and generally doing so without direct surveillance; and

"(4) not having their outgoing mail read by staff, unless requested by the resident.

"(i) Residents shall be permitted personal possessions, such as toys, books, pictures, games, radios, arts and crafts materials, religious articles, toiletries, jewelry, and letters.

"(j) Regulations shall permit normalized and normalizing possession and use of money by residents for work payment and property administration, as for example, in performing cash and check transactions, and in buying clothing and other items, as readily as other citizens. In accordance with their developmental level—

"(1) allowances or opportunities to earn money shall be available to residents; and

"(2) residents shall be trained in the value and use of money.

"(k) There shall be provision for prompt recognition and appropriate management of behavioral problems in the living unit. There shall be a written statement of policies and procedures for the control and discipline of residents that is—

"(1) directed to the goal of maximizing the growth and development of the residents;

"(2) available in each living unit; and

"(3) available to parents or guardians.

"(l) Residents shall participate, as appropriate, in

the formulation of such policies and procedures. Corporal punishment shall not he permitted. Residents shall not discipline other residents, except as part of an organized self-government program that is conducted in accordance with written policy.

" (m) Seclusion, defined as the placement of a resident alone in a locked room, shall not be employed.

" (n) Except as provided in subsection (p), physical restraint shall be employed only when absolutely necessary to protect the resident from injury to himself or to others, and restraint shall not be employed as punishment, for the convenience of staff, or as a substitute for program. The facility shall have a written policy that defines the uses of restraint, the staff members who may authorize its use, and a mechanism for monitoring and controlling its use. Orders for restraints shall not be in force for longer than twelve hours. A resident placed in restraint shall be checked at least every thirty minutes by staff trained in the use of restraints, and a record of such checks shall be kept. Mechanical restraints shall be designed and used so as not to cause physical injury to the resident, and so as to cause the least possible discomfort. Opportunity for motion and exercise shall be provided for a period of not less than ten minutes during each two hours in which restraint is employed.

Totally enclosed cribs and barred enclosures shall be considered restraints.

"(o) Mechanical supports used in normative situations to achieve proper body position and balance shall not be considered to be restraints, but shall be designed and applied—

"(1) under the supervision of a qualified professional person; and

"(2) so as to reflect concern for principles of good body alinement, concern for circulation, and allowance for change of position.

"(p) Chemical restraint shall not be used excessively, as punishment, for the convenience of staff, as a substitute for program, or in quantities that interfere with a resident's habilitation program.

"(q) Behavior modification programs involving the use of time-out devices or the use of noxious or aversive stimuli shall be:

"(1) reviewed and approved by the facility's research review and human rights committees;

"(2) conducted only with the consent of the affected resident's parents or surrogates;

"(3) described in written plans that are kept on file in the facility;

"(4) restraints employed as time-out devices shall

be applied for only very brief periods, only during conditioning sessions, and only in the presence of the trainer; and

"(5) removal from a situation for time-out purposes shall not be for more than one hour, and this procedure shall be used only during the conditioning program, and only under the supervision of the trainer.

"Subchapter II—Food Services

"SEC. **1241.** (a) Food services shall recognize and provide for the physiological, emotional, religious, and cultural needs of each resident, through provision of a planned, nutritionally adequate diet. There shall be a written statement of goals, policies, and procedures that—

"(1) governs all food service and nutrition activities;

"(2) is prepared by, or with the assistance of, a nutritionist or dietition;

"(3) is reviewed periodically, as necessary, by the nutritionist or dietitian;

"(4) is in compliance with State and local regulations;

"(5) is consistent with the facility's goals and policies; and

"(6) is distributed to facility personnel.

"(b) When food services are not directed by a nu-

tritionist or dietitian, regular, planned, and frequent consultation with a nutritionist or dietitian should be available. Records of consultations and recommendations shall be maintained by the facility and by the consultant. An evaluation procedure shall be established to determine the extent of implementation of the consultant's recommendations.

"(c) A nourishing, well-balanced diet, consistent with local customs, shall be provided all residents. Modified diets shall be—

" (1) prescribed by the resident's program team. with a record of the prescription kept on file;

" (2) planned, prepared, and served by persons who have received adequate instruction; and

" (3) periodically reviewed and adjusted as needed.

"(d) Dietary practices in keeping with the religious requirements of residents' faith groups should be observed at the request of parents or guardians. Denial of a nutritionally adequate diet shall not be used as a punishment. At least three meals shall be served daily, at regular times, with—

"(1) not more than a fourteen-hour span between a substantial evening meal and breakfast of the following day, and

" (2) not less than ten hours between breakfast and the evening meal of the same day.

" (e) Resident's mealtimes shall be comparable to those normally obtaining in the community. Provision should be made for between meal and before bedtime snacks, in keeping with the total daily needs of each resident. Food shall be served—

" (1) as soon as possible after preparation, in order to conserve nutritive value;

"(2) in an attractive manner;

"(3) in appropriate quantity;

"(4) at appropriate temperature;

" (5) in a form consistent with the developmental level of the resident; and

" (6) with appropriate utensils.

When food is transported, it shall be done in a manner that maintains proper temperature, protects the food from contamination and spoilage, and insures the preservation of nutritive value.

" (f) All residents, including the mobile nonambulatory, shall eat or be fed in dining rooms, except where contraindicated for health reasons, or by decision of the team responsible for the resident's program. Table serviee shall be provided for all who can and will eat at a table, including residents in wheelchairs. Dining areas shall—

"(1) be equipped with tables having smooth, impervious tops or clean table coverings may be used;

"(2) be equipped with tables, chairs, eating utensils, and dishes designed to meet the developmental needs of each resident;

"(3) promote a pleasant and home-like environment that is attractively furnished and decorated, and is of good acoustical quality; and

"(4) be designed to stimulate maximum self-development, social interaction, comfort, and pleasure.

"(g) Dining arrangements shall be based upon a rational plan to meet the needs of the residents and the requirements of their programs. Dining and serving arrangements should provide for a variety of eating experiences (for example, cafeteria and family style), and, when appropriate, for the opportunity to make food selections with guidance. Unless justified on the basis of meeting the program needs of the particular residents being served, dining tables should seat small groups of residents (typically four to six at a table). preferably including both sexes.

"(h) Dining rooms shall be adequately supervised and staffed for the direction of self-help eating procedures, and to assure that each resident receives an adequate amount and variety of food. Staff members should be encouraged to eat with those residents who have semi-independent or independent eating skills. For residents not able to get to dining

areas, food service practices shall permit and encourage maximum self-help, and shall promote social interaction and enjoyable experiences.

"SEC. 1242. (a) Residents shall be provided with systematic training to develop appropriate eating skills, utilizing adaptive equipment where it serves the developmental process.

" (b) Residents with special eating disabilities shall be provided with an interdisciplinary approach to the diagnosis and remediation of their problems, consistent with their developmental needs.

" (c) Direct-care staff shall be trained in and shall utilize proper feeding techniques. Residents shall eat in an upright position. Residents shall eat in a manner consistent with their developmental needs (for example, infants should be fed in arms, as appropriate). Residents shall be fed at a leisurely rate, and the time allowed for eating shall be such as to permit adequate nutrition, to promote the development of self-feeding abilities, to encourage socialization, and to provide a pleasant mealtime experience.

"(d) Effective procedures for cleaning all equipment and all areas shall be followed consistently. Handwashing facilities, including hot and cold water, soap, and paper towels, shall be provided adjacent to work areas.

"Subchapter III—Clothing

"SEC. 1245. (a) Each resident shall have an adequate allowance of neat, clean, fashionable, and seasonable clothing.

" (b) Each resident shall have his own clothing, which is, when necessary, properly (inconspicuously) marked with his name, and he shall use this clothing. Such clothing shall make it possible for residents to go out of doors in inclement weather, to go for trips or visits appropriately dressed, and to make a normal appearance in the community.

"(c) Nonambulatory residents shall be dressed daily in their own clothing, including shoes, unless contraindicated in written medical orders.

"(d) Washable clothing shall be designed for multi-handicapped residents being trained in self-help skills, in accordance with individual needs.

"(e) Clothing for incontinent residents shall be designed to foster comfortable sitting, crawling and/or walking, and toilet training.

" (f) A current inventory should be kept of each resident's personal and clothing items.

" (g) Residents shall be trained and encouraged to:

" (1) select and purchase their own clothing as independently as possible, preferably utilizing community stores;

"(2) select their daily clothing;

"(3) dress themselves;

"(4) change their clothes to suit the activities in which they engage; and

"(5) maintain (launder, clean, mend) their clothing as independently as possible.

"SEC. 1246. Storage space for clothing to which the resident has access shall be provided. Ample closet and drawer space shall be provided for each resident. Such space shall be accessible to all, including those in wheelchairs.

"SEC. 1247. The person responsible for the facility's resident-clothing program shall be trained or experienced in the selection, purchase, and maintenance of clothing, including the design of clothing for the handicapped.

"Subchapter IV—Health, Hygiene, and Grooming

"SEC. 1250. (a) Residents shall be trained to exercise maximum independence in health, hygiene, and grooming practices, including bathing, brushing teeth, shampooing, combing and brushing hair, shaving, and caring for toenails and fingernails.

"(b) Each resident shall be assisted in learning normal grooming practices with individual toilet articles that are appropriately available to that resident.

"(c) Teeth shall be brushed daily, with an effective dentifrice. Individual brushes shall be properly marked, used,

and stored. Dental care practices should encourage the use of newer dental equipment, such as electric toothbrushes and water picks, as prescribed.

"(d) Residents shall be regularly scheduled for hair cutting and styling, in an individualized, normalized manner, by trained personnel.

"(e) For residents who require such assistance, cutting of toenails and fingernails by trained personnel shall be scheduled at regular intervals.

"(f) Each resident shall have a shower or tub bath at least daily, unless medically contraindicated. Residents' bathing shall be conducted at the most independent level possible. Residents' bathing shall be conducted with due regard for privacy. Individual washcloths and towels shall be used. A bacteriostatic soap shall be used, unless otherwise prescribed.

"(g) Female residents shall be helped to attain maximum independence in caring for menstrual needs. Menstrual supplies shall be of the same quality and diversity available to all women.

"(h) Every resident who does not eliminate appropriately and independently shall be engaged in a toilet training program. The facility's training program shall be applied systematically and regularly. Appropriate dietary adaptations shall be made to promote normal evacuation and urination. The program shall comprise a hierarchy of pro-

cedures leading from incontinence to independent toileting. Records shall be kept of the progress of each resident receiving toilet training. Appropriate equipment shall be provided for toilet training, including equipment appropriate for the multiply handicapped. Residents who are incontinent shall be immediately bathed or cleansed, upon voiding or soiling, unless specifically contraindicated by the training program in which they are enrolled, and all soiled items shall be changed. Persons shall wash their hands after handling an incontinent resident.

"(i) Each living unit shall have a properly adapted drinking unit. Residents shall be taught to use such units. Those residents who cannot be so taught shall be given the proper daily amount of fluid at appropriate intervals adequate to prevent dehydration. There shall be a drinking unit accessible to, and usable by, residents in wheelchairs. Special cups and noncollapsible straws shall be available when needed by the multiply handicapped. If the drinking unit employs cups, only single-use, disposable types shall be used.

"(j) Procedures shall be established for:

"(1) monthly weighing of residents, with greater frequency for those with special needs;

"(2) quarterly measurement of height, until the age of maximum growth;

"(3) maintenance of weight and height records; and

" (4) every effort shall be made to assure that residents maintain normal weights.

" (k) Policies and procedures for the care of residents with infections and contagious diseases shall conform to State and local health department regulations.

" (l) Orders prescribing bed rest or prohibiting residents from being taken out-of-doors shall be reviewed by a physician at least every three days.

" (m) Provisions shall be made to furnish and maintain in good repair, and to encourage the use of, dentures, eyeglasses, hearing aids, braces, and so forth, prescribed by appropriate specialists.

"Subchapter V—Grouping and Organization of Living Units

SEC. 1255. (a) Living unit components or groupings shall be small enough to insure the development of meaningful interpersonal relationships among residents and between residents and staff. The resident-living unit (self-contained unit including sleeping, dining, and activity areas) should provide for not more than sixteen residents. Any deviation from this size should be justified on the basis of meeting the program needs of the specific residents being served. To maximize development, residents should be grouped

within the living unit into program groups of not more than eight. Any deviation from this size should be justified on the basis of meeting the program needs of the specific residents being served.

"(b) Residential units or complexes should house both male and female residents to the extent that this conforms to the prevailing cultural norms. Residents of grossly different ages, developmental levels, and social needs shall not be housed in close physical or social proximity, unless such housing is planned to promote the growth and development of all those housed together. Residents who are mobile-non-ambulatory, deaf, blind, epileptic, and so forth, shall be integrated with peers of comparable social and intellectual development, and shall not be segregated on the basis of their handicaps.

"(c) The living unit shall not be a self-contained program unit, and living unit activities shall be coordinated with recreation, educational, and habilitativc activities in which residents engage outside the living unit, unless contraindicated by the specific program needs of the particular residents being served. Each program group should be assigned a specific person, who has responsibility for providing an organized, developmental program of physical care, training, and recreation.

"(d) Residents shall be allowed free use of all living

areas within the living unit, with due regard for privacy and personal possessions. Each resident shall have access to a quiet, private area where he can withdraw from the group when not specifically engaged in structured activities.

"(e) Outdoor active play or recreation areas shall be readily accessible to all living units.

"Subchapter VI—Resident-Living Staff

"SEC. 1256. (a) There shall be sufficient, appropriately qualified, and adequately trained personnel to conduct the resident-living program, in accordance with the standards specified in this document. Resident-living personnel shall be administratively responsible to a person whose training and experience is appropriate to the program. The title applied to the individuals who directly interact with residents in the living units should be appropriate to the kind of residents with whom they work and the kind of interaction in which they engage. The personnel who staff the living units may be referred to by a variety of terms, such as attendants, child care workers, or cottage parents. The term 'psychiatric aid' may be appropriate for a unit serving the emotionally disturbed, but not for a cottage of well-adjusted children. The title of "child care worker" may be appropriate for a nursery school group, but not for an adult unit. Nurses' aides are appropriate for units serving sick residents but not well ones.

"(b) The attire of resident-living personnel should be

appropriate to the program of the unit in which they work, and consistent with attire worn in the community.

"(c) When resident-living units are organized as recommended in subchapter V, and designed as stipulated in subchapter VII, the staff-resident ratios for twenty-four-hour, seven-day coverage of such units by resident-living personnel, or for equivalent coverage, should be as follows:

"(1) for medical and surgical units, and for units including infants, children (to puberty), adolescents requiring considerable adult guidance and supervision, severely and profoundly retarded, moderately and severely physically handicapped, and residents who are aggressive, assaultive, or security risks, or who manifest severely hyperactive or psychotic like behavior—

"(A) first shift, 1 to 4;

"(B) second shift, 1 to 4;

"(C) third shift, 1 to 8; and

"(D) overall ratio (allowing for a five-day workweek plus holiday, vacation, and sick time), 1 to 1;

"(2) for units serving moderately retarded adolescents and adults requiring habit training—

"(A) first shift, 1 to 8;

"(B) second shift, 1 to 4;

"(0) third shift, 1 to 8; and

"(D) overall ratio, 1 to 1.25;

"(3) for units serving residents in vocational training programs and adults who work in sheltered employment situations—

"(A) first shift, 1 to 16;

"(B) second shift, 1 to 8;

"(C) third shift, 1 to 16; and

"(D) overall ratio, 1 to 2.5.

"(d) Regardless of the organization or design of resident-living units, the overall staff-resident ratios should be as stipulated above. Regardless of the organization or design of resident-living units, the overall staff-resident ratios for the categories defined above shall not be less than 1 to 2, 1 to 2.5, and 1 to 5, respectively.

"Subchapter VII—Design and Equipage of Living Units

"SEC. 1257. (a) The design, construction, and furnishing of resident-living units shall be—

"(1) appropriate for the fostering of personal and social development;

"(2) appropriate to the program;

"(3) flexible enough to accommodate variations in program to meet changing needs of residents; and

"(4) such as to minimize noise and permit communication at normal conversation levels.

"(b) The interior design of living units shall simulate

the functional arrangements of a home to encourage a personalized atmosphere for small groups of residents, unless it has been demonstrated that another arrangement is more effective in maximizing the human qualities of the specific residents being served. There shall be a minimum of eighty square feet of living, dining, or activity space for each resident. This space shall be arranged to permit residents to participate in different kinds of activities, both in groups and singly. Furniture and furnishings shall be safe, appropriate, comfortable, and home-like.

"(c) Bedrooms shall:

"(1) be on or above street grade level;

"(2) be outside rooms;

"(3) accommodate from one to four residents;

"(4) provide at least sixty square feet per resident in multiple sleeping rooms, and not less than eighty square feet in single rooms.

"(5) partitions defining each bedroom shall extend from floor to ceiling;

"(6) doors to bedrooms—

"(A) should not have vision panels;

"(B) should not be lockable, except where residents may lock their own bedroom doors, as consistent with their program;

"(7) there shall be provision for residents to mount

pictures on bedroom walls (for example by means of pegboard or cork strips), and to have flowers, artwork, and other decorations;

"(8) each resident shall be provided with—

"(A) a separate bed of proper size and height for the convenience of the resident;

"(B) a clean, comfortable mattress;

"(C) bedding appropriate for weather and climate;

"(9) each resident shall be provided with—

"(A) appropriate individual furniture, such as a chest of drawers, a table or desk, and an individual closet with clothes racks and shelves accessible to the resident;

"(B) a place of his own for personal play equipment and individually prescribed prosthetic equipment; and

"(10) space shall be provided for equipment for daily out-of-bed activity for all residents not yet mobile, except those who have a short-term illness, or those very few for whom out-of-bed activity is a threat to life.

"(d) Suitable storage shall be provided for personal possessions, such as toys, books, pictures, games, radios, arts and crafts materials, toiletries, jewelry, letters, and other articles and equipment, so that they are accessible to the

residents for their use. Storage areas shall be available for off-season personal belongings, clothing, and luggage.

"(e) Toilet areas, clothes closets, and other facilities shall be located and equipped so as to facilitate training toward maximum self-help by residents, including the severely and profoundly retarded and the multiple handicapped as follows:

"(1) water closets, showers, bathtubs, and lavatories shall approximate normal patterns found in homes, unless specifically contraindicated by program needs;

"(2) toilets, bathtubs, and showers shall provide for individual privacy (with partitions and doors), unless specifically contraindicated by program needs;

"(3) water closets and bathing and toileting appliances shall be equipped for use by the physically handicapped;

"(4) there shall be at least one water closet of appropriate size for each six residents;

"(A) at least one water closet in each living unit shall be accessible to residents in wheelchairs;

"(B) each water closet shall be equipped with a toilet seat;

"(C) toilet tissue shall be readily accessible at each water closet;

"(5) there shall be at least one lavatory for each

six residents and one lavatory shall be accessible to and usable by residents in wheelchairs;

"(6) there shall be at least one tub or shower for each eight residents;

" (7) there shall be individual racks or other drying space for washcloths and towels; and

" (8) larger, tilted mirrors shall be available to residents in wheelchairs.

" (f) Provisions for the safety, sanitation, and comfort of the residents shall comply with the following requirements:

" (1) each habitable room shall have direct outside ventilation by means of windows, louvers, air conditioning, or mechanical ventilation horizontally and vertically;

" (2) each habitable room shall have at least one window, and the window space in each habitable room should be at least one-eighth ($12^{1/2}$ per centum) of the floor space;

" (A) each resident unit of eight shall have at least one glazed area low enough so that a child in normal day activities has horizontal visual access to the out-of-doors;

"(B) the type of glass or other glazing material used shall be appropriate to the safety needs of the residents of the unit;

"(3) floors shall provide a resilient, comfortable,

attractive, nonabrasive, and slip-resistant surface. Carpeting used in units serving residents who crawl or creep shall be nonabrasive;

"(4) temperature and humidity shall be maintained within a normal comfort range by heating, air conditioning, or other means. The heating apparatus employed shall not constitute a burn hazard to the residents;

"(5) the temperature of the hot water at all taps to which residents have access shall be controlled, by the use of thermostatically controlled mixing valves or by other means, so that it does not exceed 110 degrees Fahrenheit. Mixing valves shall be equipped with safety alarms that provide both auditory and visual signals of valve failure;

"(6) emergency lighting of stairs and exits, with automatic switches, shall be provided in units housing more than fifteen residents;

"(7) there shall be adequate clean linen and dirty linen storage areas for each living unit. Dirty linen and laundry shall be removed from the living unit daily; and

"(8) laundry and trash chutes are discouraged, but if installed, such chutes shall comply with regulations proscribed by the Secretary.

"Chapter 3.—PROFESSIONAL AND SPECIAL PROGRAMS AND SERVICES

"Subchapter I—Introduction

"SEC. 1258. (a) In addition to the resident-living services detailed in section 2, residents shall be provided with the professional and special programs and services detailed in this section, in accordance with their needs for such programs and services.

"(b) The professional and special programs and services detailed herein may be provided by programs maintained or personnel employed by the residential facility, or by formal arrangements between the facility and other agencies or persons, whereby the latter will provide such programs and services to the facility's residents as needed.

"(c) In accordance with the normalization principle, all professional services to the retarded should be rendered in the community, whenever possible, rather than in a residential facility, and where rendered in a residential facility, such services must be at least comparable to those provided the nonretarded in the community.

"(d) Programs and services provided by the facility, or to the facility by agencies outside it, or by persons not employed by it, shall meet the standards for quality of service as stated in this section. The facility shall require that services provided its residents meet the standards for quality

of services as stated in this section, and all contracts for the provision of such services shall stipulate that these standards will be met.

"SEC. 1259. (a) Individuals providing professional and special programs and services to residents may be identified with the following professions, disciplines, or areas of service:

"(1) audiology;

"(2) dentistry (including services rendered by licensed dentists, licensed dental hygienists, and dental assistants);

"(3) education;

"(4) food and nutrition (including services rendered by dietitians and nutritionists);

"(5) library services;

"(6) medicine (including services rendered by licensed physicians, whether doctors of medicine or doctors of osteopathy, licensed podiatrists, and licensed optometrists);

"(7) music, art, dance, and other activity therapies;

"(8) nursing;

"(9) occupational therapy;

"(10) pharmacy;

"(11) physical therapy;

"(12) psychology;

"(13) recreation;

"(14) religion (including services rendered by clergy and religious educators) ;

"(15) social work;

"(16) speech pathology;

"(17) vocational rehabilitation counseling; and

" (18) volunteer services.

"(b) Interdisciplinary teams for evaluating the resident's needs, planning an individualized habilitation program to meet identified needs, and periodically reviewing the resident's response to his program and revising the program accordingly, shall be constituted of persons drawn from, or representing, such of the aforementioned professions, disciplines, or service areas as are relevant in each particular case.

" (c) Since many identical or similiar services or functions may competently be rendered by individuals of different professions, the Standards in the following subsections shall be interpreted to mean that necessary services are to be provided in efficient and competent fashion, without regard to the professional identifications of the persons providing them, unless only members of a single profession are qualified or legally authorized to perform the stated service. Services listed under the duties of one profession may, therefore, be rendered by members of other professions who are equipped by training and experience to do so.

" (d) Regardless of the means by which the facility

makes professional services available to its residents, there shall be evidence that members of professional disciplines work together in cooperative, coordinated, interdisciplinary fashion to achieve the objectives of the facility.

"SEC. 1260. Programs and services and the pattern of staff organization and function within the facility shall be focused upon serving the individual needs of residents and should provide for—

"(1) comprehensive diagnosis and evaluation of each resident as a basis for planning programing and management;

"(2) design and implementation of an individualized habilitation program to effectively meet the needs of each resident;

"(3) regular review, evaluation, and revision, as necessary, of each individual's habilitation program;

"(4) freedom of movement of individual residents from one level of achievement to another, within the facility and also out of the facility, through training, habilitation, and placement; and

"(5) an array of those services that will enable each resident to develop to his maximum potential.

"Subchapter II—Dental Services

"SEC. 1261. (a) Dental services shall be provided all residents in order to maximize their general health by—

"(1) maintaining an optimal level of daily oral health, through preventive measures; and

"(2) correcting existing oral diseases.

"(b) Dental services shall be rendered—

"(1) directly, through personal contact with all residents by dentists, dental hygienists, dental assistants, dental health educators, and oral hygiene aides, as appropriate to the size of the facility; and

"(2) indirectly, through contact between dental staff and other personnel caring for the residents, in order to maintain their optimal oral health.

"(c) Dental services available to the facility should include—

"(1) dental evaluation and diagnosis;

"(2) dental treatment;

"(3) comprehensive preventive dentistry programs;

"(4) education and training in the maintenance of oral health;

"(5) participation, as appropriate, by dentists and dental hygienists in the continuing evaluation of individual residents by interdisciplinary teams, to initiate, monitor, and follow up individualized habilitation programs;

"(6) consultation with, or relating to—

"(A) residents;

"(B) families of residents;

"(C) other facility services and personnel;

"(7) participation on appropriate facility committees; and

"(8) planning and conducting dental research; cooperating in interdisciplinary research; and interpreting, disseminating, and implementing applicable research findings.

"(d) Comprehensive diagnostic services for all residents shall include—

"(1) a complete extra and intraoral examination, utilizing all diagnostic aids necessary to properly evaluate the resident's oral condition, within a period of one month following admission;

"(2) provision for adequate consultation in dentistry and other fields, so as to properly evaluate the ability of the patient to accept the treatment plan that results from the diagnosis; and

"(3) a recall system that will assure that each resident is reexamined at specified intervals in accordance with his needs, but at least annually.

"(e) Comprehensive treatment services for all residents shall include—

"(1) provision for dental treatment, including the dental specialties of pedodontics, orthodontics, periodon-

tics, prosthodontics, endodontics, oral surgery, and oral medicine, as indicated; and

"(2) provision for emergency treatment on a twenty-four-hour, seven-days-a-week basis, by a qualified dentist.

"(f) Comprehensive preventive dentistry programs should include—

"(1) fluoridation of the facility's water supply;

"(2) topical and systemic fluoride therapy, as prescribed by the dentist;

"(3) periodic oral prophylaxis, by a dentist or dental hygienist, for each resident;

"(4) provisions for daily oral care, as prescribed by a dentist or dental hygienist, including:

"(A) Toothbrushing and toothbrushing aids, such as disclosing wafers;

"(B) tooth flossing;

"(C) irrigation;

"(D) proper maintenance of oral hygiene equipment;

"(E) monitoring the program to assure its effectiveness; and

"(5) provision, wherever possible, of diets in a form that stimulates chewing and improvement of oral health.

"(g) Education and training in the maintenance of oral health shall include:

"(1) continuing inservice training of living-unit personnel in providing proper daily oral health care for residents;

"(2) providing dental health education to direct-care personnel;

"(3) a dental hygiene program that includes:

"(A) discovery, development, and utilization of specialized teaching techniques that are effective for individual residents;

"(B) imparting information regarding nutrition and diet control measures to residents and staff;

"(C) instruction of classroom teachers and/or students in proper oral hygiene methods;

"(D) motivation of teachers and students to promote and maintain good oral hygiene;

"(E) instruction of residents in living units in proper oral hygiene methods; and

"(4) instruction of parents or surrogates in the maintenance of proper oral hygiene, where appropriate (as in the case of facilities having day programs, or in the case of residents leaving the facility).

"(h) A permanent dental record shall be maintained

for each resident. A summary dental progress report shall be entered in the resident's unit record at stated intervals. A copy of the permanent dental record shall be provided a facility to which a resident is transferred.

"(i) When the facility has its own dental staff, there should be a manual that states the philosophy of the dental service and describes all dental procedures and policies. There shall be a formal arrangement for providing qualified and adequate dental services to the facility, including care for dental emergencies on a twenty-four hour, seven-days-a week basis. A dentist, fully licensed to practice in the State in which the facility is located, shall be designated to be responsible for maintaining standards of professional and ethical practice in the rendering of dental services to the facility. Where appropriate, the facility should, in addition, have available to it, and should utilize, the program-development consultation services of a qualified dentist who has experience in the field of dentistry for the retarded.

"(j) There shall be available sufficient, appropriately qualified dental personnel, and necessary supporting staff, to carry out the dental services program. All dentists providing services to the facility shall be fully licensed to practice in the State in which the facility is located. All dental hygienists providing services to the facility shall be licensed to practice in the State in which the facility is located. Dental assistants

should be certified by the American Dental Assistants Association, or should be enrolled in a program leading to certification. Dental health educators shall have a thorough knowledge of—

"(1) dental health; and

"(2) teaching methods.

"(k) Oral hygiene aides, who may supplement and promote the proper daily oral care of residents, through actual participation and development of new methods in the toothbrushing program, or in the dissemination of oral hygiene information, should be—

"(1) thoroughly trained in current concepts and procedures of oral care; and

"(2) trained to recognize abnormal oral conditions.

"(l) Supporting staff should include, as appropriate to the program—

"(1) receptionists;

"(2) clerical personnel to maintain current dental records;

"(3) dental laboratory technicians certified by the Dental Laboratory Association;

"(4) escort aides; and

"(5) janitorial or housekeeping personnel.

"(m) All dentists providing service to the facility shall

adhere to the code of ethics published by the American Dental Associatfon.

"SEC. 1262. (a) Appropriate to the size of the facility, a continuing education program shall be provided that is designed to maintain and improve the skills and knowledge of its professional dental personnel, through means such as—

"(1) preceptor or other orientation programs;

"(2) participation in seminars, workshops, conferences, institutes, or college or university courses, to the extent of at least sixty clock hours annually for each dental professional, in accordance with the standards of the American Dental Association and its component societies;

"(3) study leave;

"(4) participation in the activities of professional organizations that have as their goals the furtherance of expertise in the treatment of the handicapped;

" (5) access to adequate library resources, including current and relevant books and journals in dentistry, dental hygiene, dental assisting, and mental retardation;

"(6) encouragement of dentists to qualify themselves for staff privileges in hospitals; and

"(7) sharing of information concerning dentistry in its relationship with mental retardation, as by publication.

"(b) To enrich and stimulate the facility's dental program, and to facilitate its integration with community services, the facility should affiliate with, and provide educational experiences for the dental-career students of, dental schools, universities, colleges, technical schools, and hospitals, whenever the best interests of the facility's residents are thereby served.

" (c) There shall be adequate space, facilities, and equipment to meet the professional, educational, and administrative needs of the dental service. General anesthesia facilities for dental care shall be available. The services of a dental laboratory certified by the Dental Laboratory Association shall be available. Appropriate dental consultation shall be employed in the planning, design, and equipage of new dental facilities, and in the modification of existing facilities. All dental facilities shall be free of architectural barriers for physically handicapped residents.

"Subchapter III—Educational Services

"SEC. 1263. (a) Educational services, defined as deliberate attempts to facilitate the intellectual, sensorimotor, and affective development of the individual, shall be available to all residents, regardless of chronological age, degree of retardation, or accompanying disabilities or handicaps. There shall be a written statement of educational objectives that are consistent with the facility's philosophy and

goals. The principle that learning begins at birth shall be recognized, and the expertise of early childhood educators shall be integrated into the interdisciplinary evaluation and programing for residents.

"(b) Educational services available to the facility should include—

"(1) establishment and implementation of individual educational programs providing:

"(A) continuous evaluation and assessment of the individual;

"(B) programing for the individual;

"(C) instruction of individuals and groups;

"(D) evaluation and improvement of instructional programs and procedures;

"(2) participation in program development services, including those relating to:

"(A) resident habilitation;

"(B) staff training;

"(C) community activities;

"(3) consultation with, or relating to:

"(A) other programs for residents and staff;

"(B) parents of residents;

"(C) administration and operation of the facility;

"(D) the community served by the facility; and

"(4) research relating to educational programs, procedures, and techniques; and the interpretation, dissemination, and application of applicable research findings.

"(c) Where appropriate, an educator shall be a member of the interdisciplinary teams or groups concerned with—

"(1) the total programing of each resident; and

" (2) the planning and development of the facility's programs for residents.

" (d) Individual educational evaluations of residents shall:

" (1) commence with the admission of the resident ;

"(2) be conducted at least annually;

" (3) be based upon the use of empirically reliable and valid instruments, whenever such tools are available;

" (4) provide the basis for prescribing an appropriate program of learning experiences for the resident;

" (5) provide the basis for revising the individual prescription as needed;

" (6) the reporting and dissemination of evaluation results shall be done in such a manner as to—

"(A) render the content of the report meaningful and useful to its intended recipient and user; and

"(B) promptly provide information useful to staff working directly with the resident.

"(e) There shall be written educational objectives for each resident that are—

"(1) based upon complete and relevant diagnostic and prognostic date;

"(2) stated in specific behavioral terms that permit the progress of the individual to be assessed; and

"(3) adequate for the implementation, continuing assessment, and revision, as necessary, of an individually prescribed program.

"(f) There shall be evidence of educational activities designed to meet the educational objectives set for every resident. There shall be a functional educational record for each resident, maintained by, and available to, the educator.

"(g) There shall be appropriate programs to implement the facility's educational objectives. Wherever local resources permit and the needs of the resident are served, residents should attend educational programs in the community. Educable and trainable residents shall be provided an educational program of a quality not less than that provided by public school programs for comparable pupils, as regards:

"(1) physical facilities;

"(2) qualifications of personnel;

" (3) length of the school day;

" (4) length of school year;

" (5) class size;

"(6) provision of instructional materials and supplies ; and

" (7) availability of evaluative and other ancillary services.

" (h) Educational programs shall be provided severely and profoundly retarded residents, and all other residents for whom educational provisions may not he required by State laws, irrespective of age or ability.

"(i) Appropriate educational programs shall be provided residents with hearing, vision, perceptual, or motor impairments, in cooperation with appropriate staff.

" (j) Educational programs should include opportunities for physical education, health education, music education, and art education, in accordance with the needs of the residents being served.

"(k) A full range of instructional materials and media shall be readily accessible to the educational staff of the facility.

" (1) Educational programs shall provide coeducational

experiences. Learning activities in the classroom shall be coordinated with activities of daily living in the living units and with other programs of the facility and the community. The facility shall seek reciprocal services to and from the community, within the bounds of legality and propriety. An educational program operated by a facility shall seek consultation from educational agencies not directly associated with the facility.

"SEC. 1264. (a) There shall be available sufficient, appropriately qualified educational personnel, and necessary supporting staff, to carry out the educational programs. Delivery of educational services shall be the responsibility of a person who is eligible for—

"(1) certification as a special educator of the mentally retarded; and

"(2) the credential required for a comparable supervisory or administrative position in the community.

"(b) Teachers shall be provided aides or assistants, as needed. The facility's educators shall adhere to a code of ethics prescribed by the Secretary. Appropriate to the nature and size of the facility, there shall be an ongoing program for staff development specifically designed for educators. Staff members shall be encouraged to participate actively in professional organizations related to their responsibilities.

"(c) To enrich and stimulate the facility's educational

program, and to facilitate its integration with community services, opportunities for internships, student teaching, and practicum experiences should be made available, in cooperation with university teacher-training programs, whenever the best interests of the residents are thereby served.

"Subchapter IV—Food and Nutrition Services

"SEC. 1265. (a) Food and nutrition services shall be provided in order to—

"(1) insure optimal nutritional status of each resident, thereby enhancing his physical, emotional, and social well-being; and

"(2) provide a nutritionally adequate diet, in a form consistent with developmental level, to meet the dietary needs of each resident.

"(b) There shall be a written statement of policies and procedures that—

"(1) describes the implementation of the stated objectives of the food and nutrition services;

"(2) governs the functions and programs of the food and nutrition services;

"(3) is formulated and periodically reviewed by professional nutrition personnel;

"(4) is prepared in consultation with other professional staff;

"(5) is consistent with the facility's goals and policies;

"(6) is distributed and interpreted to all facility personnel; and

"(7) complies with State and local regulations.

"(c) Whenever appropriate, the following services should be provided—

"(1) initial and periodic evaluation of the nutritional status of each resident, including—

"(A) determination of dietary requirements and assessment of intake and adequacy through—

"(i) dietary interview;

"(ii) clinical evaluation;

"(iii) biochemical assessment;

"(B) assessment of food service practices;

"(C) assessment of feeding practices, capabilities, and potential;

"(2) maintenance of a continuing and periodically reviewed nutrition record for each resident;

"(3) incorporation of recommendations drawn from the nutrition evaluation into the total management plans for the resident;

"(4) periodic review of implementation of recommendations and of need for modification;

"(5) participation in the continuing interdiscipli-

nary evaluation of individual residents, for the purposes of initiation, monitoring, and follow up of individualized habilitation programs;

"(6) provision of—

"(A) counseling services to the individual resident;

"(B) reciprocal consultation services with facility staff and students;

"(C) counseling service to residents' families or their surrogates;

"(D) nutrition education, on a continuing basis, for residents, families or surrogates, staff, and students, and development of such programs in coordination with various education programs within the facility and the community;

"(7) coordination of nutrition programs between the facility and the community, including—

"(A) development of awareness of available programs in nutrition;

"(B) development of needed nutrition programa;

"(C) encouragement of participation of professionals and students in nutrition programs for the mentally retarded; and

"(8) development, coordination, and direction of

nutrition research, as well as cooperation in interdisciplinary research.

"(d) Food services shall include—

"(1) menu planning;

"(2) initiating food orders or requisitions;

"(3) establishing specifications for food purchases. and insuring that such specifications are met;

"(4) storing and handling of food;

"(5) food preparation;

"(6) food serving;

"(7) maintaining sanitary standards in compliance with State and local regulations; and

"(8) orientation, training, and supervision of food service personnel.

"(e) The food and nutrition needs of residents shall be met in accordance with the recommended dietary allowances of the food and nutrition board of the national research council, adjusted for age, sex, activity, and disability, through a nourishing, well-balanced diet. The total food intake of the resident should be evaluated, including food consumed outside of as well as within the facility.

"(f) Menus shall be planned to meet the needs of the residents in accordance with subsection (e). Menus shall be written in advance. The daily menu shall be posted in food preparation areas. When changes in the menu are

necessary, substitutions should be noted and should provide equal nutritive values. Menus shall provide a sufficient variety of foods served in adequate amounts at each meal, and shall be: (1) Different for the same days of each week; (2) Adjusted for seasonal changes. Records of menus as served shall be filed and maintained for at least thirty days. At least a one-week supply of staple foods and a two-day supply of perishable foods shall be maintained on the premises. Records of food purchased for preparation shall be filed and maintained for at least thirty days. A file of tested recipes adjusted to appropriate yield should be maintained.

" (g) Foods shall be prepared by methods that—

" (1) conserve nutritive value;

" (2) enhance flavor; and

"(3) enhance appearance.

" (h) Food shall be prepared, stored, and distributed in a manner that assures a high quality of sanitation. Effective procedures for cleaning all equipment and work areas shall be followed consistently. Dishwashing and panwashing shall be carried out in compliance with State and local health codes. Handwashing facilities, including hot and cold water, soap, and paper towels, shall be provided adjacent to work area.

" (i) When food is transported, it shall be done in a

manner that maintains proper temperature, protects the food from contamination and spoilage, and insures the preservation of nutritive value. Food storage procedures shall meet State and local regulations. Dry or staple food items shall be stored at least twelve inches above the floor, in a ventilated-room not subject to sewage or waste water backflow, or contamination by condensation, leakage, rodents, or vermin. Perishable foods shall be stored at the proper temperatures to preserve nutritive values. Food served to residents and not consumed shall be discarded.

"(j) There shall be a sufficient number of competent personnel to fulfill the objectives of the food and nutrition services, including—

"(1) nutritionists or dietitians;

" (2) other food service personnel;

"(3) clerical personnel;

" (4) depending upon the size and scope of the facility, food and nutrition services shall be directed by one of the following—

"(A) a dietitian who is eligible for membership in the American Dietetic Association, and preferably eligible for registration by the association, or a nutritionist who has a master's degree in foods, nutrition, or public health nutrition, who is eligible for membership in the American Dietetic Associa-

tion, and preferably eligible for registration by the association, and who, unless employed by a facility that also employs a dietitian, has had experience in institutional food management;

"(B) a food service manager who has a bachelor's degree in foods, nutrition, or a related field, and who receives consultation from a dietary consultant;

"(C) a responsible person who has had training and experience in meal management and service, and who receives consultation from a dietary consultant; and

"(D) the person responsible for food.and nutrition services should have had training or experience in providing services to the mentally retarded, and should be sensitive to their needs;

" (5) the dietary consultant shall—

" (A) be eligible for membership in the American Dietetic Association, and preferably eligible for registration by the association;

"(B) serve on a regularly scheduled and frequent basis when no full-time dietitian is available; and

" (6) every person engaged in the preparation and serving of food in the facility shall have a valid food handler's permit, as required by State or local regu-

lations. No person who is afflicted with a disease in a communicable stage, or who is a carrier of a communicable disease, or who has an open wound, shall work in any food service operation. Every person engaged in the preparation and serving of food in the facility shall annually be medically determined to be free of any disease in a communicable stage. All dietitians and nutritionists shall adhere to the code of ethics of the American Dietetic Association.

"(k) Appropriate to the size of the facility, an ongoing inservice training program shall be conducted that is designed to improve and maintain the skills of its food and nutrition services staff, through means such as—

"(1) seminars, workshops, conferences, and institutes;

"(2) college and university courses;

"(3) participation in professional organizations;

"(4) participation in interdisciplinary groups;

"(5) visitations to other facilities; and

"(6) access to adequate library resources, including current and relevant books and journals in nutrition and mental retardation.

"(1) Opportunities should be provided, in cooperation with university and other training programs, for students to obtain practical experience, under appropriate supervision,

whenever the best interests of the residents are thereby served.

"(m) There shall be adequate space, facilities, and equipment to fulfill the professional, educational, administrative, operational, and research needs of the food and nutrition services. Dining areas and facilities for food storage, preparation, and distribution shall be—

"(1) designed in cooperation with a dietitian and, when appropriate, with assistance from a qualified food service and equipment consultant;'

"(2) adequate for the storage and preservation of food;

"(3) in compliance with State and local sanitation and other requirements;

"(4) adequate for the preparation and serving of food; and

"(5) adequate for sanitary storage for all dishes and equipment.

"Subchapter V—Library Services

"SEC. 1266. (a) Library services, which include the location, acquisition, organization, utilization, retrieval, and delivery of materials in a variety of media, shall be available to the facility, in order to support and strengthen its total habilitation program by providing complete and integrated multimedia information services to both staff and residents.

Library services shall make available to the facility the resources of local, regional, State, and National library systems and networks. Library services shall be available to all residents, regardless of chronological age, degree of retardation, level of communication skills, or accompanying disabilities or handicaps.

"(b) Library services to residents shall be rendered—

"(1) directly, through personal contact between library staff and residents;

"(2) indirectly, through contact between librarians and other persons working with the residents, designed to—

"(A) maintain an atmosphere that recognizes the rights of the resident to access to information and to personal use of library materials appropriate to his level of development in communication skills or to his desire to conform to peer groups; and

"(B) enhance interpersonal relationships between direct-care workers and residents, through the mutual enjoyment of written, recorded, or oral literature appropriate to the resident's level of development and preference.

"(c) Library services available to residents should include—

"(1) assistance in team evaluation and assessment

of the individual's level of development in communication skills, such as listening, comprehension, reading, and ability to respond to stimuli in a wide range and variety of media;

"(2) provision of informational, recreational, and educational materials appropriate to individual residents at all stages of development in communication skills, including media to stimulate sensory development, both in the library and in the living unit. Such materials should include, but need not be limited to—

"(A) books, including picture, juvenile, adult, high interest-low vocabulary, large print, and talking books;

"(B) magazines, including juvenile, adult pictorial, and magazines on talking books;

"(C) newspapers;

"(D) audiovisual media, including films, filmstrips, slides, video tapes, audio tapes, and records, and appropriate equipment;

"(E) graphics;

"(F) experiant materials, such as manipulative materials, toys and games, realia, and animals;

"(3) development of programs for individual or group enjoyment, for development of communication skills, for encouragement and satisfaction of natural hu-

man curiosity about anything, including sex and the facts of life, and for general enhancement of self-image. These programs should include, but need not be limited to—

"(A) storytelling, with listener participation through games or other activities;

"(B) reading aloud, including 'reading' pictures;

"(C) film or filmstrip programs;

"(D) listening to recorded media;

"(E) media discussion groups;

"(F) library clubs;

"(G) touching, browsing, exploring, or naming sensory stimuli;

"(H) creative writing, including group composition through dictation, tape recording, etc.;

"(I) puppetry, including the making of puppets;

"(J) creative dramatics;

"(4) opportunities to visit, and make use of, community library services and facilities in the same manner, and on the same terms, as any resident of the community;

"(5) referral services to the community library most convenient to place of residence or employment, when the resident leaves the facility; and

"(6) active participation in, and encouragement of, library programs related to the educational and habilitative services of the facility, including the supplementation, support, and reinforcement of school programs.

" (d) Librarians providing service to residents should act as advocates on their behalf if facility policies or community library policies interfere with the retarded person's freedom to read materials of his own choosing or if they deny or abrogate his right to information or access to library services of any kind, in accordance with the Library Bill of Rights adopted by the American Library Association.

" (e) Library services to staff should include—

" (1) selection, acquisition, organization, classification, cataloging, procurement through interlibrary loan, and dissemination of informational, educational, and instructional library materials and audiovisual equipment;

" (2) provision of reference and bibliographic materials and services, literature searches, bibliography compilation, indexing and abstracting services, and other guides to the literature relevant to mental retardation;

" (3) acquisition of material for evaluation for purchase;

" (4) provision of a current awareness program to alert staff to new materials and developments in their fields;

" (5) orientation to library services and functions, including continuing instruction and assistance in the use of informational sources, and participation in general orientations to the facility;

" (6) provision of written and oral translation services; and

" (7) cooperation in inservice training programs by working with subject specialists and by recommending, providing, or producing materials in various media.

" (f) Library services to the facility may include—

" (1) provision of informational materials about the facility and mental retardation in general, through an organized collection of resources;

"(2) assistance with such public relation functions as preparing brochures, program statements, annual reports, writing news releases and feature stories, and offering editorial and research assistance to staff preparing professional books and papers; and

" (3) assistance in preparing grant applications and report writing.

" (g) When library services are provided in the facility—

" (1) there shall be a written statement of objectives that make possible a well-conceived, comprehensive, long-range program of library development, consistent with the overall goals of the facility, adapted to the needs

and aptitudes of the residents, and designed to be modified as the program of the facility changes;

"(2) there shall be a separate budget, adequate to carry out the program in accordance with stated goals and objectives;

"(3) library services shall be placed within the organizational structure of the facility in such a way as to be available to, and maximally utilized by, all relevant services and programs;

"(4) there shall be written policies covering the library's day-to-day activities, and the coordination of these activities with those of other services of the facility and with related activities in the community;

"(5) there shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the program in accordance with stated goals and objectives;

"(6) a qualified librarian shall be responsible for all library services. Where the level of need for services does not require the full-time employment of a professional librarian, coverage may be through the use of consultant service or supervisory personnel, through the pooling of resources and the sharing of services by two or more facilities in a geographic area, or through service supplied through a regional library system;

"(7) the librarian shal participate, when appropriate, in the interdisciplinary planning, development, and evaluation of facility programs;

" (8) the librarian should coordinate the purchasing of all print and nonprint materials for the facility, and act as the facility's informed agent in initiating the purchase of print and nonprint materials, and the library should serve as clearing house for such holdings;

"(9) librarians should participate in—

"(A) educating appropriate members of the community, concerning the library needs of residents;

" (B) planning, with community librarians, the utilization of library resources to optimize resident adjustment:

"(C) developing appropriate expectancies and attitudes within community libraries that residents will use;

" (10) appropriate relationships with other libraries and community agencies shall be established to more effectively accomplish the library's service functions;

"(11) appropriate to the size of the facility, there should be a staff development program designed to maintain and improve the skills of library services stall' through means such as—

"(A) staff meetings and inservice training;

"(B) seminars, workshops, conferences, and institutes;

"(C) college and university courses;

"(D) professional organizations;

"(E) participation in interdisciplinary groups;

"(F) visits to other facilities;

"(G) access to relevant professional literature;

"(12) whenever appropriate, the library should provide training for beginning librarians, further the orientation and training of library assistants, technicians, or volunteers, and serve as a training center for library institutes or workshops;

"(13) library services should be located so as to be convenient and accessible to all users;

"(14) all library functions should be integrated within a centralized location, whenever this does not act as a barrier to accessibility for any group;

"(15) space, physical facilities, and equipment shall be adequate to carry out the program, and shall comply with the standards for library services in health care institutions published by the Association of Hospital and Institution Libraries of the American Library Association;

"(16) the hours during which the library is open

should meet the requirements of the majority of the library's users, and should be as generous as possible; and

"(17) users of library services shall participate in the planning and evaluation of library programs, by means such as advisory committees.

"(h) If library services are provided outside the facility, there shall be a formal agreement that stipulates lines of communication, areas of responsibility, and kinds of service.

"(i) The individual responsible for maintaining standards of professional and ethical practice in the rendering of library services to the facility—

"(1) shall have a master's degree in library science from a school accredited by the American Library Association; and

"(2) should have preparation in a field relevant to work with the mentally retarded.

"(j) Individuals rendering library services, including librarians, media specialists, library and media technicians, supportive staff, and volunteers, shall have qualifications appropriate to their responsibilities and duties.

"Subchapter VI—Medical Services

"SEC. 1267. (a) Medical services shall be provided in order to—

"(1) achieve and maintain an optimal level of general health for each resident;

"(2) maximize normal function and prevent disability; and

"(3) facilitate the optimal development of each resident.

"(b) Medical services shall be rendered—

"(1) directly, through personal contact between physicians and residents; and

"(2) indirectly, through contact between physicians and other persons working with the residents, which is designed to maintain an environment that recognizes and meets the health, hygiene, sanitary, and nutritional needs of the residents.

"(c) Medical services available to the residential facility should include—

"(1) evaluation and diagnosis;

"(2) treatment;

"(3) program development services, including those relating to—

"(A) resident habilitation;

"(B) staff training;

"(C) community participation;

"(4) consultation with, or relating to—

"(A) residents;

"(B) families of residents;

"(C) the administration and operation of the facility;

"(5) medical and ancillary staff training; and

"(6) preventive health services for residents and staff.

"(d) The services of medical and surgical hospitals that are accredited by the Joint Commission on Accreditation of Hospitals shall be available to residents. Only pathology, clinical laboratory, and radiologic services that meet the hospital accreditation standards of the Joint Commission on Accreditation of Hospitals shall be utilized. Electroencephalograph services shall be available as necessary. There shall be evidence, such as may be provided by a record of the deliberations of a utilization review committee, that such hospital and laboratory services are utilized in accordance with proper professional standards.

"(e) Physicians shall participate, when appropriate—

"(1) the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs;

"(2) the development for each resident of a detailed, written statement of—

"(A) case management goals, encompassing

the areas of physical and mental health, education, and functional and social competence; and

"(B) a management plan detailing the various habilitation or rehabilitation modalities that are to be applied in order to achieve the specified goals, with clear designation of responsibility for implementation.

"(f) The management plan shall ordinarily include, but not necessarily be limited to—

"(1) the resident's day-to-day activity program;

"(2) physical rehabilitation to prevent and correct deformity, to enhance mobility, and to facilitate training in self-help skills;

"(3) provision for adaptive equipment necessary to the rehabilitation plan;

"(4) an educational program;

"(5) a vocational and occupational program;

"(6) stated intervals for review of the management plan; and

"(7) short- and long-term goals, including criteria for release.

"(g) Statement of treatment goals and management plans shall be reviewed and updated—

"(1) as needed, but at least annually; and

"(2) to insure continuing appropriateness of the

goals, consistency of management methods with the goals, and the achievement of progress toward the goals.

"(h) Special attention shall be given those residents who, without active intervention, are at risk of further loss of function, by means that include—

"(1) early diagnosis of disease;

"(2) prompt treatment in the early stages of disease;

"(3) limitation of disability by arresting the disease process;

"(4) prevention of complications and sequelae; and

"(5) rehabilitation services to raise the affected individual to his greatest possible level of function, in spite of his handicap, by maximizing the use of his remaining capabilities.

"(i) Preventive health services to residents shall include—

"(1) means for the prompt detection and referral of health problems, through adequate medical surveillance, periodic inspection, and regular medical examination;

"(2) annual physical examinations, that include—

"(A) examination of vision and hearing;

"(B) routine screening laboratory examina-

tions, as determined by the physician, and special studies when the index of suspicion is high;

"(3) maintenance of a graphic record of height and weight for each resident, in a form that permits ready reference to standardized norms;

"(4) immunizations, using as a guide the recommendations of the United States Public Health Service Advisory Committee on Immunization Practices and of the Committee on the Control of Infectious Diseases of the American Academy of Pediatrics;

"(5) tuberculosis control, in accordance with the recommendations of the American College of Chest Physicians and/or the section on diseases of the chest of the American Academy of Pediatrics, as appropriate to the facility's population; and

"(6) reporting of communicable diseases and infections in accordance with law.

"(j) Preventive health services to staff shall include—

"(1) preemployment physical examinations; and

"(2) surveys for the detection and prevention of communicable diseases.

"(k) There shall be a formal arrangement for qualified medical care for the facility, including care for medical emergencies on a twenty-four-hour, seven-days-a-week basis. A physician, fully licensed to practice medicine in the State

in which the facility is located, shall be designated to be responsible for—

"(1) maintaining standards of professional and ethical practice in the rendering of medical services in the facility; and

"(2) maintaining the general health conditions and practices of the facility and/or system of health services.

Each resident shall have a personal (primary) physician, who maintains familiarity with his state of health and with conditions within the residential living unit that bear on his health. Qualified medical specialists of recognized professional ability shall be—

"(1) available for a broad range of specialized care and consultation; and

"(2) appropriately used.

" (1) Appropriate to the size of the facility, an ongoing inservice training program shall be conducted that is designed to maintain and improve the medical skills of its physicians and their knowledge of developmental disabilities. through methods such as staff seminars, outside speakers, attendance at professional medical meetings, and informational exchanges with universities and teaching hospitals.

"(m) There shall be adequate space, facilities, and

equipment to fulfill the professional, educational, and administrative needs of the medical service.

"Subchapter VII—Nursing Services

"SEC. 1268. (a) Residents shall be provided with nursing services, in accordance with their needs, in order to—

"(1) develop and maintain an environment that will meet their total health needs;

"(2) foster optimal health;

"(3) encourage maximum self-care and independence; and

"(4) provide skilled nursing care as needed.

"(b) There shall be a written statement of nursing philosophy and objectives that are consistent with the purpose of the facility and that given direction to the nursing program. Nursing personnel shall be responsible for the formulation, review, and revision of the philosophy and objectives. The philosophy and objectives shall be—

"(1) distributed to all nursing personnel; and

"(2) made available and interpreted to all other personnel.

"(c) Nursing services should be provided through—

"(1) direct nursing intervention;

"(2) instruction and supervision of facility staff rendering nursing care;

"(3) supporting, counseling, and teaching the resi-

dent, Ms family, and his direct-care staff, at the facility or in the home;

"(4) consultation and followthrough in the interest of the resident; and

"(5) participation on appropriate facility committees.

"(d) Nursing services to residents shall include, when appropriate—

"(1) professional nurse participation in—

"(A) the preadmission evaluation study and plan;

"(B) the evaluation study, program design, and placement of the resident at the time of admission to the facility;

"(C) the periodic reevaluation of the type, extent, and quality of services and programing;

"(D) the development of discharge plans;

"(E) the referral to appropriate community resources;

"(2) services directed toward the promotion of health, including—

"(A) observation and assessment of the developmental function of the resident, within his environment;

"(B) training in habits of personal hygiene;

"(C) family life and sex education;

"(D) safety education;

" (E) control of communicable diseases and infections, through—

" (i) identification and assessment;

" (ii) reporting to medical authority;

"(iii) implementation of appropriate protective and preventive measures;

"(F) development of a written plan for nursing action, in relation to the total haibilitation program;

"(G) modification of the nursing plan, in terms of the resident's daily needs, at least annually for adults and more frequently for children, in accordance with developmental changes;

" (3) participation in the prevention of disability for all residents, with special attention to those residents who exhibit the lowest level of functional development, including—

" (A) nursing assessment of the functional level of development;

"(B) development, implementation, and coordination of a plan to maintain and encourage optimal level of function, with written provision for direct and indirect nursing intervention; and

"(4) planned, intensive nursing care for every resident who is medically determined to be acutely ill.

"(e) A professional nurse shall participate, as appropriate, in the planning and implementation of training of facility personnel. Direct-care personnel shall be trained in—

"(1) detecting signs of illness or dysfunction that warrant medical or nursing intervention;

"(2) basic skills required to meet the health needs and problems of the residents; and

"(3) first aid in the presence of accident or illness.

"(f) Qualified nurses shall be encouraged to become involved in—

"(1) initiating, conducting, and evaluating nursing research;

"(2) evaluating and applying relevant research findings for the benefit of residents;

"(3) formulating the policies governing research in the facility; and

"(4) serving as resource persons to schools of nursing, and to public health nursing and related agencies.

"(g) There shall be available sufficient, appropriately qualified nursing staff, which may include currently licensed practical nurses and other supporting personnel, to carry out the various nursing service activities. A registered professional nurse shall be designated as being responsible for

maintaining standards of professional, legal, and ethical practice in the delivery of nursing services according to the needs of the residents. The individual responsible for the delivery of nursing services—

"(1) should have at least a master's degree in nursing; and

"(2) shall have knowledge and experience in the field of developmental disabilities.

"(h) Nursing service personnel at all levels of experience and competence shall be—

"(1) assigned responsibilities in accordance with their qualifications;

"(2) delegated authority commensurate with their responsibility; and

"(3) provided appropriate professional nursing supervision.

"(i) Organized nursing services and professional nurse practitioners should have recourse to qualified and appropriate consultation as needed. All professional nurses shall be familiar with, and adhere to, the code of ethics published by the American Nurses' Association.

"(j) Appropriate to the size of the facility, there shall be an educational program designed to enhance the clinical competencies and the knowledge of developmental disabilities of its professional nursing staff, through means such as—

" (1) staff meetings and inservice training;

"(2) "seminars, workshops, conferences, and institutes;

" (3) college and university courses;

" (4) participation in professional organizations;

" (5) participation in interdisciplinary groups;

"(6) visits to other facilities; and

" (7) access to relevant professional literature.

" (k) To enrich and stimulate the facility's nursing program, and to facilitate its integration with community services, educational experiences for students of all types of professional and vocational nursing schools shall be encouraged and defined by a contractual agreement, whenever the best interests of the residents are thereby served.

" (1) There shall be adequate space, facilities, and equipment to fulfill the professional, educational, and administrative needs of the nursing service. Professional nursing consultation shall be included in the design and modification of areas and facilities that will be used by the ill and the physically handicapped.

"Subchapter VIII—Pharmacy Services

"SEC. 1269. (a) In order to contribute to improved resident care and to promote optimal response to drug therapy by the residents, through the full utilization of the knowledge and skills of the pharmacist, pharmacy services

shall be provided under the direction of a qualified pharmacist. There shall be a formal arrangement for qualified pharmacy services, including provision for emergency service, by means appropriate to the facility. Such means may include the services of a pharmacist in a local community or hospital pharmacy that meet the standards listed herein, as well as the operation of its own pharmacy by the facility. There shall be a current pharmacy manual that—

"(1) includes policies and procedures, and defines the functions and responsibilities relating to pharmacy services; and

"(2) is revised annually to keep abreast of current developments in services and management techniques.

"(b) There shall be a formulary system, approved by the responsible physician and pharmacist, and by other appropriate facility staff. Copies of the facility's formulary and of the American Hospital Formulary Service shall be located and available, as appropriate to the facility.

"(c) Upon admission of the resident, a medication history of prescription and nonprescription drags used shall be obtained, preferably by the pharmacist, and this information shall be entered in the resident's record for the information of the staff. The pharmacist shall—

"(1) receive the original, or a direct copy, of the physician's drug treatment order;

"(2) review the drug regimen, and any changes, for potential adverse reactions, allergies, interactions, contraindications, rationality, and laboratory test modifications, and advise the physician of any recommended changes, with reasons and with an alternate drug regimen;

"(3) maintain for each resident an individual record of all medications (prescription and nonprescription) dispensed, including quantities and frequency of refills;

"(4) participate, as appropriate, in the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs;

"(5) participate in any of the following activities that are undertaken in the facility:

"(A) drag research;

"(B) drug utilization review;

"(C) infection and communicable disease committee;

"(D) safety committee;

"(E) patient care incident review; and

"(6) establish quality specifications for drag purchases, and insure that they are met.

"(d) The pharmacist should—

"(1) prepare a drag treatment plan, as prescribed

by the attending physician, for inclusion in the resident's record and for use by the staff, that includes—

"(A) the drag product, dosage form, route of administration, and time of administration, including, when appropriate, the time with respect to meals, other drugs, and activities;

"(B) a schedule of laboratory tests necessary to detect adverse reactions;

"(C) nothing of any potential adverse reactions for the staff's information;

"(2) regularly review the record of each resident on medication, and have contact with selected residents with potential problems, noting in the residents' records and reporting to physicians any observations of response to drug therapy, and of adverse reactions and over or underutilization of drugs;

"(3) provide instructions and counseling on the correct use of his drugs, as prescribed by the attending physician, to each resident on home visit and discharge, and/or to this parents;

"(4) provide education and counseling to residents in independent living units on the correct use of their drugs, as prescribed by the attending physician, and on the results expected from correct use and from over or underuse;

"(5) participate in programs for sex education and drug abuse education;

"(6) provide information on the resident's drug regimen to the receiving facility pharmacist, when the resident is transferred, and, with the approval of the resident or his guardian, to the resident's community pharmacist, his private physician, and/or the community mental retardation service when the resident is discharged from the facility, so as to insure continuity of care;

"(7) participate in inservice education programs for professional and direct-care staff;

"(8) orient and teach students in pharmacy and other professions, regarding pharmacy's services to the residents and regarding drugs and their uses; and

"(9) participate in public education and informational programs on mental retardation.

"(e) Where appropriate to the facility, there shall be a pharmacy and therapeutics committee, that includes one or more pharmacists, to develop policy on drug usage in the facility, and to develop and maintain a current formulary. This committee shall meet not less than once every three months. Minutes of the committee meetings shall be kept on file.

"(f) Written policies and procedures that govern the

safe administration and handling of all drugs shall be developed by the responsible pharmacist, physician, nurse, and other professional staff, as appropriate to the facility. The compounding, packaging, labeling, and dispensing of drugs, including samples and investigational drugs, shall be done by the pharmacist, or under his direct supervision, with proper controls and records. Each drug shall be identified up to the point of administration. Procedures shall be established for obtaining drugs when the pharmacy is closed.

" (g) The unit dose or individual prescription system of drag distribution should be used. Wherever possible, drugs that require dosage measurement shall be dispensed by the pharmacist in a form ready to be administered to the patient.

" (h) There shall be a written policy regarding the administration of all drugs used by the residents, including those not specifically prescribed by the attending practitioner. There shall be a written policy regarding the routine of drug administration, including standardization of abbreviations indicating dose schedules. Medications shall not be used by any resident other than the one for whom they were issued. Only appropriately trained staff shall be allowed to administer drugs.

" (i) There shall be a written policy governing the self-administration of drugs, whether prescribed or not.

"(j) Drags shall be stored under[1] proper conditions of sanitation, temperature, light, moisture, ventilation, segregation, and security. All drugs shall be kept under lock and key except when authorized personnel are in attendance. The security requirements of Federal and State laws shall be satisfied in storerooms, pharmacies, and living units. Poisons, drugs used externally, and drugs taken internally shall be stored on separate shelves or in separate cabinets, at all locations. Medications that are stored in a refrigerator containing things other than drugs shall be kept in a separate compartment with proper security. A perpetual inventory shall be maintained of each narcotic drug in the pharmacy, and in each unit in which such drugs are kept, and inventory records shall show the quantities of receipts and issues and the person to whom issued or administered. If there is a drug storeroom separate from the pharmacy, there shall be a, perpetual inventory of receipts and issues of all drags by such storeroom.

"(k) The pharmacist should review the drugs in each living unit monthly, and should remove outdated and deteriorated drugs and drugs not being used. Discontinued and outdated drugs, and containers with worn, illegible, or missing labels, shall be returned to the pharmacy for proper disposition.

" (1) There shall be automatic stop orders on all drugs. There shall be a drug recall procedure that can be readily implemented. Medication errors and drug reactions shall be recorded and reported immediately to the practitioner who ordered the drug. There shall be a procedure for reporting adverse drug reactions to the Federal Food and Drug Administration. The pharmacist shall be responsible for the storage and dispensing of investigational drugs. The pharmacist shall provide the residential staff with pharmacological and other necessary information on investigational drugs, including dosage form, dosage range, storage, adverse reactions, usage, and contraindications.

" (m) There shall be an emergency kit—

"(1) readily available to each living unit; and

" (2) constituted so as to be appropriate to the needs of its residents.

"(n) Pharmacy services shall be—

"(1) directed by a professionally competent and legally qualified pharmacist who is a graduate of a school of pharmacy accredited by the American Council on Pharmaceutical Education, or its equivalent, and who serves on a full-time or part-time basis, as the activity of the service requires;

"(2) staffed by a sufficient number of competent

personnel, consistent with the facility's needs, and including—

"(A) pharmacists necessary to provide comprehensive pharmacy services;

"(B) technicians and clerical personnel to relieve the pharmacist of nonprofessional and clerical duties;

"(3) pharmacists should have had training and/or experience in providing services to the mentally retarded, and should be sensitive to their needs; and

"(4) all pharmacists shall be familiar with, and adhere to, the code of ethics of the American Pharmaceutical Association.

"(o) Appropriate to the size of the faculty, there should be a staff development program, designed to maintain and improve the skills of its pharmacy staff through means such as—

"(1) staff meetings and inservice training;

"(2) seminars, workshops, conferences, and institutes;

"(3) college and university courses;

"(4) participation in professional organizations;

"(5) participation in interdisciplinary groups;

"(6) visits to other facilities; and

"(7) access to relevant professional literature.

" (p) The pharmacy serving the facility shall—

" (1) have sufficient space for necessary compounding, dispensing, labeling, and packaging functions;

"(2) have the equipment necessary for compounding, dispensing, issuing, storing, and administrative functions;

"(3) be clean and orderly; and

" (4) contain current pharmaceutical reference material to provide adequate information concerning drugs.

"(q) Space for the storage of drags in the storeroom, pharmacy, and living units shall be sufficient to prevent crowding of the drugs. There shall be adequate drug preparation areas, that are—

"(1) properly secured;

"(2) well lighted; and

"(3) located so that personnel will not be interrupted when handling drugs.

"(r) If the facility operates its own pharmacy, there should be—

" (1) an office for the pharmacist; and

" (2) a private area for instructing and counseling residents and/or parents on the correct use of drugs.

"Subchapter IX—Physical and Occupational Therapy Services

"SEC. 1270. (a) Although this subsection combines standards for physical and occupational therapy, each is a discrete service that complements the other in a manner similar to their relationships with all other health and medically related services. Both services, therefore, shall be provided, or made available to, residents on a continuing basis, as needed. Physical and occupational therapy services shall be provided in order to—

"(1) prevent abnormal development and further disability;

"(2) facilitate the optimal development of each resident; and

"(3) enable the resident to be a contributing and participating member of the community in which he resides.

The facility shall have a written statement of its physical therapy and occupational therapy objectives for its residents, consistent with'—

" (1) the needs of the residents;

" (2) currently accepted physical therapy and occupational therapy theories, principles, and goals;

"(3) the philosophy and goals of the facility; and

" (4) the services and resources provided.

Physical and occupational therapy services shall be provided—

"(1) directly, through personal contact between therapists and residents;

"(2) indirectly, through contact between therapists and other persons involved with the residents, to:

"(A) create and maintain an atmosphere that recognizes the physical and psychosocial needs of residents and is conducive to the development and maintenance of optimal physical and psychosocial functioning;

"(B) maximize the effectiveness of all programs for residents, through the application of knowledge concerning the development and maintenance of motor performance and behaviors; and

"(C) implement programs for the improvement of physical and psychosocial functioning in all environmental settings.

Physical and occupational therapists shall have a responsibility for organizing and implementing programs to achieve physical and occupational therapy goals throughout the resident's daily activities.

"(b) Physical and occupational therapy services available to the facility should include—

"(1) screening and evaluation of residents;

" (2) therapy with individuals and groups;

" (3) program development services, including those relating fro;

" (A) resident habilitation;

"(B) inservice training of professional, direct-care, and other staff;

"(C) community participation;

" (4) consultation with, or relating to—

"(A) residents;

" (B) families of residents;

"(0) medical, dental, psychological, educational, nursing, and other services;

"(D) the administration and operation of the facility;.

"(E) the community served by the facility;

" (5) training of therapy staff;

" (6) training of physical and occupational therapy graduate and/or undergraduate students, interns, supportive staff, and volunteer workers;

" (7) assessment of program effectiveness; and

" (8) conduct of, or participation in, research, and dissemination and appropriate application of research findings.

" (c) Therapists should screen residents, in order to—

"(1) determine the characteristics of the facility's population;

"(2) identify resident needs and establish program priorities; and

"(3) determine the administrative, budgetary, and personnel requirements of the service.

"(d) Evaluation of individual residents by physical and occupational therapists should include—

"(1) observing and testing performance and motivation in sensorimotor, perceptual, behavioral, and self-care activities;

"(2) assessment and analysis of findings, to determine level of function and to identify deviations from accepted norms;

"(3) providing information for interdisciplinary staff use, in determining diagnosis, functional capacities, prognosis, and management goals; and

"(4) physical and occupational therapists shall participate, when appropriate, in the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs.

"(e) Physical therapy and occupational therapy staff

shall provide treatment-training programs that are designed to—

"(1) preserve and improve abilities for independent function, such as range of motion, strength, tolerance, coordination, and activities of daily living;

"(2) prevent, insofar as possible, irreducible or progressive disabilities, through means such as the use of orthotic and prosthetic appliances, assistive and adaptive devices, positioning, behavior adaptations, and sensory stimulation;

"(3) the therapist shall function closely with the resident's primary physician and with other medical specialists;

"(4) treatment-training progress shall be—

"(A) recorded regularly;

"(B) evaluated periodically; and

"(C) used as the basis for continuation or change of the resident's program.

"(f) Evaluation results; treatment objectives, plans, and procedures; and continuing observations of treatment progress shall be—

"(1) recorded accurately, summarized meaningfully, and communicated effectively;

"(2) effectively used in evaluating progress; and

"(3) included in the resident's unit record.

" (g) Consumers and their representatives, including residents, families, other disciplines, and community groups, shall be utilized in the planning and evaluation of physical therapy and occupational therapy services. There shall be available sufficient, appropriately qualified staff, and supporting personnel, to carry out the various physical and occupational therapy services, in accordance with stated goals and objectives. Physical and occupational therapists shall be—

"(1) graduates of a curriculum accredited by the Council on Medical Education of the American Medical Association in collaboration with the American Physical Therapy Association or the American Occupational Therapy Association;

"(2) if a physical therapist, eligible to practice in the State in which the facility is located; and

" (3) if an occupational therapist, eligible for registration by the American Occupational Therapy Association.

"(h) A physical therapist and an occupational therapist shall be designated as being responsible for maintaining standards of professsional and ethical practice in the rendering of their respective therapy services in the facility. Each such therapist shall be qualified as in subsection (g) and, in addition, shall—

"(1) have had three years of professional experience, two years of which should have been in working with mentally retarded persons;

"(2) have demonstrated competence in administration and supervision, as appropriate to the facility's program; and

" (3) preferably have a master's degree, in an area related to the program.

" (i) Therapy assistants shall—

"(1) be certified by the American Occupational Therapy Association or be graduates of a program accredited by the American Physical Therapy Association; and

"(2) work under the supervision of a qualified therapist.

" (j) Therapy aides shall—

"(1) be provided specific inservice training; and

"(2) work under the supervision of a qualified therapist or therapy assistant.

" (k) Physical and occupational therapy personnel shall be—

" (1) assigned responsibilities in accordance with their qualifications;

" (2) delegated authority commensurate with then-responsibilities ; and

"(3) provided appropriate professional direction and consultation.

"(l) Physical and occupational therapy personnel shall be familiar with, and adhere to, the Code of Ethics and standards of practice promulgated by their respective professional organizations, the American Physical Therapy Association or the American Occupational Therapy Association.

"(m) Physical Therapy and occupational therapy services operated by a facility shall seek consultation, at periodic intervals, from experts in physical therapy and occupational therapy who are not directly associated with the facility. Appropriate to the nature and size of the facility and to the physical and occupational therapy services, there shall be a staff development program that is designed to maintain and improve the skills of physical and occupational therapy personnel, through methods such as—

"(1) regular staff meetings;

"(2) an organized inservice training program in physical and occupational therapy;

"(3) visits to and from the staff of other facilities and programs;

"(4) participation in interdisciplinary meetings;

"(5) provision for financial assistance and time for attendance at professional conferences;

" (6) provisions for encouraging continuing education, including educational leave, financial assistance, and accommodation work schedules;

"(7) career ladders and other incentives to staff recruitment and development;

" (8) workshops and seminars;

" (9) consultations with specialists; and

"(10) access to adequate library resources, which include current and relevant books and journals in physical and occupational therapy, mental retardation, and related professions and fields.

" (n) Space, facilities, equipment, supplies, and resources shall be adequate for providing efficient and effective physical and occupational therapy services, including, but not necessarily limited to—

" (1) facilities for conducting administrative aspects of the program;

" (2) facilities for conducting screenings and evaluations ;

" (3) facilities for providing treatment and training for individuals and groups;

"(4) such other space, staff, and services as are essential to support and maintain effective programs; and

" (5) appropriate physical and occupational therapy

consultation shall be employed in the design, modification, and equipage of all physical and occupational therapy areas and facilities required to meet the specific goals of physical and occupational therapy services.

"Subchapter X—Psychological Services

"SEC. 1271. (a) Psychological services shall be provided, in order to facilitate, through the application of psychological principles, techniques, and skills, the optimal development of each resident. Psychological services shall be rendered—

"(1) directly, through personal contact between psychologists and residents;

"(2) indirectly, through contact between psychologists and other persons involved with the residents, designed to—

"(A) maintain an atmosphere that recognizes the psychological needs of residents and that is conducive to the development and maintenance of constructive interpersonal relationships; and

"(B) maximize the effectiveness of all programs for residents, through the application of knowledge concerning the understanding and change of behavior.

"(b) Psychological services available to the residential facility should include—

"(1) evaluation and assessment of individuals and programs;

"(2) therapy with individuals and groups;

"(3) program development services, including those relating to:

"(A) resident habilitation;

"(B) staff training;

"(C) community participation;

"(D) resident, staff, and community motivation;

"(4) consultation with, or relating to—

"(A) residents;

"(B) parents of residents;

"(C) the administration and operation of the facility;

"(D) the community served by the facility;

"(5) psychology staff training; and

"(6) conduct of research, consultation on research design, and dissemination of research findings.

"(c) Psychologists shall participate, when appropriate, in the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs—

"(1) psychologists shall conduct evaluations necessary to—

"(A) meet legal requirements;

"(B) meet research needs; and

"(0) provide data for biostatistical reporting;

"(2) methods of data collection employed in evaluation and assessment shall include, as appropriate—

"(A) standardized tests and techniques;

"(B) observations in natural and experimental settings, using standardized or generally accepted techniques;

"(C) interviews with—

"(i) the resident (or prospective resident);

"(ii) members of the resident's family and other informants; and

"(D) review of all pertinent records, including the comparison of current and previous status;

"(3) collation, analysis, and interpretation of data shall—

"(A) be performed in accordance with standards generally acceptable in professional psychology;

"(B) provide, as appropriate, both intra- and interindividual comparisons, by reference to normative data; and

"(C) utilize appropriate equipment, which is made available for the purpose;

"(4) the reporting and dissemination of evaluation results shall be done in such a manner as to—

"(A) render the content of the report meaningful and useful to its intended recipient and user;

"(B) enhance clinical understanding of the individual;

"(0) promptly provide information useful to staff working directly with the resident;

"(D) facilitate use of data for research and professional education;

"(B) facilitate use of data for statistical reporting; and

"(F) maintain accepted standards of confidentiality;

"(5) there shall be developed and maintained for each resident a continuing evaluation record that is frequently updated and that includes, but is not limited to, psychometric data.

"(d) Psychologists shall participate, when appropriate, in the development of written, detailed, specific, and individualized habilitation program plans that—

"(1) provide for periodic review, followup, and updating;

"(2) are designed to maximize each resident's development and acquisition of—

"(A) perceptual skills;

"(B) sensorimotor skills;

"(C) self-help skills;

"(D) communication skills;

"(B) social skills;

"(F) self direction;

"(G) emotional stability;

"(H) effective use of time (including leisure time);

"(I) basic knowledge;

"(J) vocational-occupational skills; and

"(K) socio-economic values relevant to the community in which he lives.

"(e) Psychologists should provide individual, and/or groups of, residents with therapy designed to develop, modify, and maintain behavior and attitudes that are rewarding and effective in meeting the demands of their intrapersonal and interpersonal situations. Psychologists should provide consultation and training services to program staff concerning:

"(1) principles and methods of understanding and changing behavior, to the end of devising maximally effective programs for residents;

"(2) principles and methods of individual and program evaluation, for the purposes of assessing resident

response to programs and of measuring program effectiveness;

"(3) psychologists should participate in the development of incentive systems designed to maximize motivation and to optimize, by means of provision for feedback, performance, and learning on the part of—

"(A) residents enrolled in habilitation programs;

"(B) staff engaged in resident habilitation programs; and

"(C) personnel involved in resident habilitation resources in the community.

"(f) Psychologists should provide assistance and/or consultation relative to—

"(1) developing and conducting evaluations designed to select and maintain appropriate and effective staff;

"(2) developing job analyses;

"(3) psychological problems of staff, including the making of appropriate referrals;

"(4) data concerning staff, and reports of evaluations of staff, shall—

"(A) be provided in appropriate form, and only to clearly appropriate supervisory staff;

"(B) enable data to be used for classification and reporting purposes;

"(C) enable data to be used for research purposes; and

"(D) maintain acceptable standards of confidentiality.

"(g) Psychologists should participate in—

"(1) educating appropriate members of the community, concerning the domiciliary, vocational, and recreational needs of residents who return to the community;

"(2) planning with community officials the adaptation of domiciliary, vocational, and recreational resources, to optimize resident adjustments; and

"(3) developing appropriate expectancies and attitudes within the community into which residents go.

"(h) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the various psychological service activities, in accordance with the needs of the following functions:

"(1) psychological services to residents, including evaluation, consultation, therapy, and program development;

"(2) administration and supervision of psychological services;

"(3) staff training;

"(4) research;

"(5) the facility should have available to it the services of at least one doctoral-level psychologist who is—

"(A) a diplomate of the American Board of Professional Psychology, or is licensed or certified by a State examining board, or is certified by a voluntary board established by a State Psychological Association;

"(B) knowledgeable and experienced in the area of mental retardation;

"(6) a psychologist, qualified as specified in subsection (h) (5) shall be designated as being responsible for maintaining standards of professional and ethical practice in the rendering of psychological services in the facility;

"(7) all psychologists providing service to the facility shall—

"(A) possess the educational and experiential qualifications required for membership in the American Psychological Association;

"(B) have demonstrated knowledge in the area of mental retardation;

"(8) all psychological technicians, assistants, and clerks employed by the facility shall work under the direct supervision of a psychologist who is qualified as specified in subsection (h) (8) ;

" (9) all members of the psychological services staff shall have and be familiar with, the Ethical Standards of Psychologists and the Casebook on Ethical Standards of Psychologists, published by the American Psychological Association, and all shall adhere to the ethical standards stated therein;

"(A) all new psychology service employees shall receive this material, and be familiarized with it, as a part of their orientation; and

"(B) the application of the ethical standards to practice with the mentally retarded in residential facilities shall be emphasized.

" (i) Appropriate to the size of the facility, an ongoing inservice training program shall be conducted that is designed to maintain and improve the skills of its psychology staff, through methods such as—

"(1) staff seminars;

"(2) outside speakers;

" (3) visits to and from the staff of other facilities;

"(4) attendance at conferences;

" (5) participation in interdisciplinary groups;

" (6) informational exchanges with universities, teaching hospitals, community mental health and mental retardation centers, and other community resources; and

"(7) adequate library resources, including current and relevant books and journals in psychology and mental retardation shall be available.

"(j) The training of interns and graduate students in psychology shall be encouraged, and appropriate supervision shall be provided. There shall be appropriate space and equipment for psychological services, including—

"(1) offices for professional and clerical staff;

"(2) testing and observation rooms;

"(3) interviewing, counseling, and training/treatment rooms;

"(4) play therapy rooms;

"(5) access to conference rooms; and

" (6) access to research and data analysis facilities.

"Subchapter XI—Recreation Services

"SEC. 1272. (a) Recreation services should provide each resident with a program of activities that—

"(1) promotes physical and mental health;

"(2) promotes optimal sensorimotor, cognitive, affective , and social development;

"(3) encourages movement from dependent to independent and interdependent functioning; and

" (4) provides for the enjoyable use of leisure time.

" (b) The facility shall have a written statement of its recreation objectives for residents, consistent with—

"(1) the needs of its residents;

"{2) currently accepted recreation principles and . goals;

"(3) the philosophy and goals of the facility; and

" (4) the services and resources the facility offers.

"(c) Recreation services available to the residential facility should include—

"(1) recreation activities for the residents;

"(2) recreation counseling;

"(3) individual and group instruction of residents in recreation skills, to achieve maximum proficiency and develop leadership potential;

" (4) therapeutic recreation;

" (5) education and consultation; and

" (6) research and evaluation.

"(d) Recreation activities available to the residents should include, as appropriate to the size and location of the

facility, and as adapted to the needs of the residents being served—

"(1) excursions, outings, and other trips to familiarize the residents with community facilities;

" (2) spectator activities; such as movies, television, sports events, and theater;

" (3) participation in music, drama, and dance, such as rhythmics, folk dancing, community sings, group music sessions in the living units, performance in music or dramatic productions, performance in choral or instrumental groups, and informal listening to records or tapes;

"(4) outdoor and nature experiences, including activities such as camping, hiking, and gardening;

" (5) team sports and lead-up activities;

" (6) individual and dual sports, such as bowling, archery, badminton, horseshoes, miniature golf, bicycling, and shuffleboard;

"(7) hobbies, such as collecting, photography, model building, woodworking (including use of power tools) cooking, and sewing;

" (8) social activities, such as clubs, special interest and discussion groups, social dancing, cookouts, parties, and games;

" (9) service clubs and organizations, such as lead-

ers clubs, scouting, 4-H, Junior Red Cross, Junior Chamber of Commerce, Hi-Y, Tri-Hi-Y, resident councils, and senior citizens clubs;

"(10) aquatics, including waterplay, swimming, and boating;

"(11) arts and crafts, including a wide range of activities from simple to complex, from reproductive to creative, and consistent with activities found in the community;

" (12) physical fitness activities designed to develop efficient cardiovascular and cardiorespiratory functions, strength, endurance, power, coordination, and agility, sufficient for both usual and extra demands;

"(13) library services for reading, listening, and viewing, such as looking at books, listening to records and tapes, and viewing film strips and slides;

" (14) celebration of special events, such as holidays and field days;

"(15) winter activities, including snow sculpture, snowplay, games and sports;

" (16) opportunities to use leisure time in activities of the resident's own choosing in an informal setting under minimal supervision, such as a 'drop-in center';

"(17) frequent coeducational experiences, to pro-

mote acceptable social behavior and enjoyment of social relationships; and

"(18) activities for the nonambulatory, including the mobile and nonmobile.

"(e) Maximum use should be made of all community recreation resources. Recreation counseling should be a continuous process that provides for—

"(1) modification of resident's recreation behaviors;

"(2) guidance to residents on how to find, reach, and utilize community recreation resources;

"(3) family counseling in relation to recreation activities; and

"(4) interpretation of residents' needs and abilities to community agencies.

"(f) Therapeutic recreation, defined as purposive intervention, through recreation activities, to modify, ameliorate, or reinforce specific physical, emotional, or social behaviors, should include, as appropriate—

"(1) participation on an interdisciplinary team, to identify the habilitation needs and goals of the resident;

"(2) determination of appropriate recreation intervention, to achieve the stated habilitation goals;

"(3) a written plan for implementing the therapeutic recreation objectives, consistent with the recommendations of the evaluation team; and

"(4) evaluation of the effectiveness of such interventions, and subsequent redefinition of the resident's habilitation needs and goals.

"(g) Education and consultation services should include—

"(1) provision of stimulation, leadership, and assistance with recreation activities, conducted by the direct-care staff;

"(2) staff training and development;

"(3) orientation and training of volunteers;

"(4) training of interns and students in recreation;

"(5) consultation to community agencies and organizations, to stimulate the development and improvement of recreation services for the retarded; and

"(6) public education and information, to encourage acceptance of the retarded in recreation activities.

"(h) Recreational services shall be coordinated with other services and programs provided the residents, in order to make fullest possible use of the facility's resources and to maximize benefits to the residents. Activities in health, music, art, and physical education shall be coordinated with recreation activities relevant to these areas.

"(i) Records concerning residents should include—

"(1) periodic surveys of their recreation interests;

"(2) periodic surveys of their attitudes and opinions regarding recreation services;

" (3) the extent and level of each resident's participation in the activities program;

"(4) progress reports, as appropriate;

" (5) reports on relationships among peers, and between residents and staff; and

"(6) evaluations conducted by personnel at all levels and, where appropriate, by staff from other services.

" (j) Established procedures for evaluating and researching the effectiveness of recreation services, in relation to stated purposes, goals, and objectives, should include—

" (1) utilization of adequate records concerning residents' interests, attitudes, opinions, participations, and achievements;

"(2) time schedules for evaluation that are appropriate to the service or program being evaluated;

"(3) provision for using evaluation results in program planning and development;

" (4) provision for disseminating evaluation results in professional journals and in public education and information programs; and

"(5) encouragement of recreation staff to initiate,

conduct, and participate in research studies, under the supervision of qualified personnel.

" (k) There shall be sufficient, appropriately qualified recreation staff, and necessary supporting staff, to carry out the various recreation services in accordance with stated goals and objectives.

" (1) Scheduling of staff shall provide—

"(A) coverage on evenings, weekends, and holidays; and

"(B) additional coverage during periods of peak activity.

" (2) Recreation personnel shall be--

"(A) assigned responsibilities in accordance with their qualifications;

"(B) delegated authority commensurate with their responsibility; and

"(C) provided appropriate professional recreation supervision.

" (3) Personnel conducting activities in recreation program areas should possess the following minimum educational and experiential qualifications:

" (A) a bachelor's degree in recreation, or in a specialty area, such as art, music, or physical education; or

"(B) an associate degree in recreation and one year of experience in recreation; or

"(C) a high school diploma, or an equivalency certificate; and two years of experience in recreation, or one year of experience in recreation plus completion of comprehensive inservice training in recreation; or

"(D) demonstrated proficiency and experience in conducting activities in one or more program areas.

"(4) Personnel performing recreation counseling or therapeutic recreation functions should possess the following minimum education and experiential qualifications, and should be eligible for registration with the National Therapeutic Recreation Society at the Therapeutic Recreation Specialist level:

"(A) a master's degree in therapeutic recreation and one year of experience in a recreation program serving disabled persons; or

"(B) a master's degree in recreation and two years of experience in a recreation program serving disabled persons; or

"(C) a bachelor's degree in recreation and three years of experience in a recreation program serving disabled persons; or

"(D) a combination of education and experience in recreation serving disabled persons that totals six years.

" (5) Education and consultation functions in recreation should be conducted by staff members, in accordance with their education, experience, and role in the recreation program.

" (1) Appropriate to the size of the recreation program, there shall be a staff development program that provides opportunities for professional development, including—

" (1) regular staff meetings;

"(2) an organized inservice training program in recreation;

"(3) access to professional journals, books, and other literature in the fields of recreation, therapeutic recreation, rehabilitation, special education, and other allied professions;

" (4) provisions for financial assistance and time for attendance at professional conferences and meetings;

" (5) procedures for encouraging continuing education, including educational leaves, direct financial assistance, and rearrangement of work schedules;

" (6) provision for workshops and seminars relating to recreation, planned by the recreation and other professional and administrative staff; and

"(7) provision for staff consultation with specialists, as needed, to improve recreation services to residents.

" (m) Recreation areas and facilities shall be designed and constructed or modified so as to—

" (1) permit all recreation services to be carried out to the fullest possible extent in pleasant and functional surroundings;

" (2) be easily accessible to all residents, regardless of their disabilities;

"(3) appropriate recreation consultation shall be employed in the design or modification of all recreation areas and facilities;

"(4) toilet facilities, appropriately equipped in accordance with the needs of the residents, should be easily accessible from recreation areas; and

" (5) appropriate and necessary maintenance services shall be provided for all recreation areas and facilities.

" (n) Indoor recreation facilities should include, as appropriate to the facility—

" (1) a multipurpose room;

"(2) a quiet browsing room;

" (3) access to a gymnasium;

"(4) access to an auditorium;

"(5) access to suitable library facilities;

"(6) access to kitchen facilities;

"(7) adequate and convenient space for storage of supplies and large and small equipment; and

"(8) adequate office space for the recreation staff.

"(o) Outdoor recreation facilities should include, as appropriate to the facility—

"(1) access to a hard-top, all-weather-surface area;

"(2) access to gardening and nature activity areas;

"(3) access to adequately equipped recreation areas; and

"(4) the facility's residents should have, as appropriate and feasible, access to year-round swimming and aquatic facilities.

"(p) Adequate transportation services for recreation programs shall be provided. Recreation equipment and supplies in sufficient quantity and variety shall be provided *to* carry out the stated objectives of the activities programs. Toys, games, and equipment shall be—

"(1) selected on the basis of suitability, safety, durability, and multiplicity of use; and

"(2) adapted as necessary to the special needs of the residents.

"(q) If a music therapy program is provided, it should include—

"(1) participation by the music therapist, when

appropriate, on an interdisciplinary evaluation team to identify the resident's needs and ways of meeting them;

"(2) determination of music therapy goals for the resident and development of a written plan for achieving them;

"(3) periodic progress reports, reevaluations, and program changes, as indicated;

"(4) direction by a therapist eligible for registration with the National Association for Music Therapy; and

"(5) appropriate space, facilities, and equipment, with special consideration of the acoustical characteristics of rooms used for performing and listening.

"Subchapter XII—Religious Services

"SEC. 1273. (a) Religious services shall be made available to residents, in accordance with their needs, desires, capabilities, and in accordance with their basic right to freedom of religion, in order to—

"(1) develop and enhance their dignity;

"(2) provide for the most meaningful and relevant practice of their religion; and

"(3) provide spiritual programs designed to aid their development and growth as persons.

"(b) Implementation of religious services should utilize community resources, whenever and wherever this is possible

and in the best interests of the residents. The objectives of the facility's religious services for its residents shall be directed toward full integration into, and membership in, their faith, and should include—

"(1) upholding the dignity and worth of the individual;

"(2) building moral and ethical standards of behavior;

"(3) preparing for religious growth in their faith groups;

"(4) establishing healthy self, world, and God concepts;

"(5) establishing constructive value systems;

"(6) giving direction toward greater personal maturity;

"(7) strengthening interpersonal relationships; and

"(8) contributing to growth in personal adequacy and happiness.

"(c) Religious services shall be made available to all residents, regardless of their degree of retardation. Participation in religious programs shall be voluntary, in accordance with the wishes of the resident, if he expresses them, or with the wishes of his parent or guardian.

"(d) Religious services to residents should include—

"(1) worship opportunities, sacraments, and reli-

gious rites, according to the needs and abilities of the residents and consonant with the practices of their respective faiths;

"(2) religious education programs geared to the needs and abilities of the residents;

"(3) observation of dietary practices in keeping with the religious requirements of residents' faith groups;

"(4) observation of religious holidays and holy days in keeping with the religious requirements of residents' faith groups;

"(5) pastoral counseling, both individual and group, to residents and their families;

"(6) pastoral visits to residents, with special emphasis on the care of the troubled, the sick, and the dying;

"(7) pastoral consultation with persons concerned with the resident's welfare; and

"(8) referral and communication between religious workers in the facility and in the community.

"(e) Those who serve the religious needs of the residents, including clergy, religious educators, and volunteers, should whenever possible—

"(1) assert and safeguard the full human and civil rights of the residents;

"(2) participate, as appropriate, in team and other

interdisciplinary planning regarding programs for individual residents, as well as in facility-wide or community programs;

"(3) keep appropriate records of significant religious events in the lives of each resident;

"(4) participate in training programs for facility personnel, including orientation of direct-care personnel in how they *may* help to further the religious programs for residents;

"(5) participate in training programs for community clergy, theological students, and others;

"(6) become involved with community clergy, and with religious and other groups, in their concerns for the spiritual care of the retarded;

"(7) promote public understanding and acceptance of the retarded; and

"(8) participate in their own faith group meetings, as required to maintain their standing.

"(f) There shall be available sufficient, appropriately qualified personnel, which may include clergy or religious leaders, religious educators, volunteers, and clerical and supporting personnel, to carry out the various religious programs—

"(1) religious services to residents shall be under

the direction of a person who, in keeping with the size and nature of the facility, may be one of the following:

"(A) a chaplain certified for work with the mentally retarded by a recognized certifying agency;

"(B) a clergyman or religious leader in good standing in his religious body;

"(C) a religious educator; or

"(D) a responsible person, who secures the services of qualified persons in carrying out the worship and education aspects of the program;

"(2) chaplains serving residential facilities for the retarded, on a full- or part-time basis, should—

"(A) be clergymen or religious leaders in good standing in their religious bodies; or

"(B) be endorsed or assigned by their recognized religious bodies; or

"(C) have B.A. and B.D. degrees, or their equivalents; and

"(D) be certified for work with the mentally retarded by a recognized certifying agency;

"(3) professional religious educators serving residential facilities for the retarded, on a full- or part-time basis, should—

"(A) be endorsed or assigned by their recognized religious bodies; or

"(B) have a bachelor's degree, or its equivalent; and

"(C) be certified for work with the mentally retarded by a recognized certifying agency;

"(4) nonprofessional religious services personnel, including volunteers, should—

"(A) be screened for ability to perform their assigned duties;

"(B) be oriented to, and trained for, their assignments; and

"(C) be provided ongoing supervision by a clergyman, religious leader, or religious educator of the respective faith.

"(g) Appropriate to the size of the facility, there shall be an educational program designed to enhance the competencies of religious services personnel, through means such as:

"(1) staff meetings and inservice training;

"(2) seminars, workshops, conferences, and institutes;

"(3) college and university courses;

"(4) participation in professional organizations;

"(5) participation in interdisciplinary groups;

"(6) visits to other facilities;

"(7) access to relevant professional literature; and

"(8) religious services personnel should have access to qualified and appropriate consultation, as needed.

"(h) Religious services personnel should be encouraged, when possible, to involve themselves in activities such as—

"(1) offering clinical pastoral education programs;

"(2) providing educational experiences for students;

"(3) developing innovative religious education materials;

"(4) developing innovative worship services;

"(5) conducting specific research and development projects; and

"(6) exploring and expanding citizen advocacy programs.

"(i) Residents shall have access to places appropriate for worship and religious education that are adequate to meet the needs of all. Religious services personnel shall be provided with office and other space, equipment, and supplies adequate to carry out an effective program.

"Subchapter XIII—Social Services

"SEC. 1274. (a) Social services shall be available to all residents and their families, in order to foster and facilitate—

" (1) maximium personal and social development of the resident;

"(2) positive family functioning; and

" (3) effective and satisfying social and community relationships.

" (b) Social services shall be provided, directly and indirectly, to—

" (1) the resident;

"(2) his family;

" (3) individuals or groups who represent different aspects of the social environment of the resident; and

" (4) the community.

" (c) Consumers and their representatives, including residents, families, other disciplines, and community groups, shall participate in the planning and evaluation of social service programs. Social services, as part of an interdisciplinary spectrum of services, shall be provided through the use of social work methods directed toward—

" (1) maximizing the social functioning of the resident;

"(2) enhancing the coping capacity of his family;

"(3) modifying environmental influences leading to, or aggravating, mental retardation;

" (4) increasing public understanding and acceptance of mental retardation and its associated problems;

" (5) creating a favorable climate to assist each retarded person to achieve as nearly normal living as is possible for him;

"(6) asserting and safeguarding the human and civil rights of the retarded and their families; and

"(7) fostering the human dignity and personal worth of each resident.

" (d) Social services available to the facility should include, as appropriate—

" (1) preadmission evaluation and counseling, with referral to, and use of, other community resources, as appropriate;

" (2) psychosocial assessment of the individual resident and his environment, as a basis for formulating an individual treatment plan;

"(3) implementation of an individual social work treatment plan for the resident and his family;

" (4) planning for community placement, discharge, and followup;

" (5) participation in policy and program development within the facility in relation to—

" (A) the residents' psychosocial needs and development;

" (B) serving the families of the resident;

"(C) use of community supportive and habilitative services;

" (D) staff training and development;

" (6) consultation with, or in relation to—

" (A) programs offered by other disciplines;

" (B) administration and operation of the facility;

" (C) agencies and individuals in the community served by the facility;

"(7) collaboration with other service delivery systems in planning and implementing programs for residents ; and

"(8) participation in social work and interdisciplinary program evaluation and research.

" (e) During the evaluation process, which may or may not lead to admission, the resident and his family should be helped by social workers to—

" (1) know the rights and services to which they are entitled, including the means of directing their appeals to the proper sources;

" (2) obtain advocacy on their behalf if rights and services are denied them; and

" (3) consider alternative services, based on the retarded person's status and salient family and community

factors, and make a responsible choice as to whether and when residential placement is indicated.

"(f) During the preadmission process, the resident and his family should be helped by social workers to—

"(1) cope with problems of separation inherent in placement;

"(2) initiate planning for the resident's return to his family and/or community;

"(3) begin involving themselves as partners with the residential facility staff in developing a treatment/habilitation plan;

"(4) become oriented to the practices and procedures of the facility; and

"(5) share information about themselves that will provide the facility's staff with maximum understanding of their situation, so that effective services can be delivered.

"(g) Social workers shall participate, when appropriate, in the continuing interdisciplinary evaluation of individual residents for the purposes of initiation, monitoring, and followup of individualized habilitation programs.

"(h) During the retarded person's admission to, and residence in, the facility, or while he is receiving services from the facility, social workers shall provide liaison between him, the facility, the family, and the community, so as to:

"(1) help the resident to—

"(A) cope with problems accompanying separation from family and community;

"(B) learn the roles and use the resources that will enable him to maximize his development;

"(C) participate in programs, in accordance with his individual treatment plan, that will maximize his ability for independent living, in or out of the residential facility;

"(2) help the staff to—

"(A) individualize and understand the needs of the resident and his family in relation to each other;

"(B) understand social factors in the resident's day-to-day behavior, including staff-resident relationships;

"(0) prepare the resident for changes in his living situations;

"(3) help the family to develop constructive and personally meaningful ways to support the resident's experience in the facility through—

"(A) counseling concerned with problems associated with changes in family structure and functioning;

"(B) utilization of the family's and the resident's own strengths and resources;

"(C) referral to specific services, as appropriate; and

"(4) help the family to participate in planning for the resident's return to home or other community placement.

"(i) After the resident leaves the facility, social workers shall provide systematic followup, including—

"(1) counseling with the resident;

"(2) counseling with family, employers, and other persons significant to the resident's adjustment in the community; and

"(3) referral to appropriate community agencies.

"(j) Social services shall help to integrate residential and other community services, through—

"(1) providing liaison between the residential facility and the community;

"(2) providing consultation to community agencies to facilitate the identification of needed resources for the retarded and his family;

"(3) interpreting the residential facility and its program to relevant sectors of the community;

"(4) collaborating with other disciplines to help the community develop appropriate resources; and

(5) involvement with social policy issues that affect the retarded.

"(k) Social services shall develop and maintain comprehensive, current records, useful for its own programs and those of other services. There shall be available sufficient, appropriately qualified staff and necessary supporting personnel to carry out the various social service activities.

"(1) The facility should have available to it a social worker who—

"(A) has a master's or doctoral degree from an accredited school of social work;

"(B) has had three years of post-master's experience in the field of social welfare;

"(C) meets the educational and experiential qualifications for certification by the Academy of Certified Social Workers; and

"(D) is knowledgeable and experienced in mental retardation.

"(2) A social worker having the qualifications specified in subsection (k) (1) shall be designated as being responsible for maintaining standards of professional practice in the rendering of social services to the facility, and for staff development.

"(3) Social workers providing service to the facility shall—

"(A) have a master's degree from an accredited school of social work; or

"(B) meet the educational qualifications required for full membership in the National Association of Social Workers and shall have had three years of experience in the field of social welfare.

"(4) Social work assistants or aides employed by the facility shall work under the supervision of a social worker having the qualifcations specified in subsection (k)(3).

"(5) Social service personnel, at all levels of experience and competence, shall be—

"(A) assigned responsibilities in accordance with their qualifications;

"(B) delegated authority commensurate with their responsibilities; and

"(C) provided appropriate professional social work supervision.

"(6) A full-time supervisor should be responsible for the direct supervision of not more than six staff members, plus related activities.

"(7) All social service personnel shall be familiar with, and adhere to, the code of ethics of the National Association of Social Workers.

"(l) Appropriate to the size of the facility's social serv-

ice program, an ongoing program of staff development shall be provided to improve the skills of the social work staff through such means as—

" (1) inservice training;

" (2) affiliation with schools of social work;

"(3) staff consultation with specialists, as needed, to improve social services to residents;

"(4) conference attendance, and other educational opportunities and forms of professional exchange; and

" (5) career ladders and other incentives to staff recruitment and development.

" (m) Space, facilities, equipment, supplies, and resources shall be adequate for providing effective social services, including—

" (1) offices for social service and clerical staff;

" (2) private interviewing rooms;

"(3) rooms suitable for conferences and group activities ;

"(4) dictating and transcribing equipment;

"(5) telephone service;

" (6) travel provisions;

"(7) provision for recordkeeping and information retrieval; and

" (8) library services.

"**Subchapter XIV—**Speech **Pathology and Audiology** Services

"SEC. 1275. (a) Speech pathology and audiology services shall be available, in order to—

"(1) maximize the communication skills of all residents; and

"(2) provide for the evaluation, counseling, treatment, and rehabilitation of those residents with speech, hearing and/or language handicaps.

"(b) The specific goals of speech pathology and audiology services shall be—

"(1) appropriate to the needs of the residents served;

"(2) consistent with the philosophy and goals of the facility;

"(3) consistent with the services and resources offered by the facility; and

"(4) known to, and coordinated with, other services provided by the facility.

"(c) Speech pathology and audiology services shall be rendered through—

"(1) direct contact between speech pathologists and audiologists and residents;

"(2) participation with administrative personnel in designing and maintaining social and physical environ-

ments that maximize the communication development of the residents; and

"(3) working with other personnel, such as teachers and direct-care staff, in implementing communication improvement programs in environmental settings.

"(d) Speech pathology and audiology services available to the facility shall include, as appropriate—

"(1) audiometric screening of—

"(A) all new residents;

"(B) children under the age of ten, at annual intervals;

"(C) other residents at regular intervals;

"(D) any resident referred;

"(2) speech and language screening of—

"(A) all new residents;

"(B) children under the age of ten at annual intervals;

"(C) all residents, as needed;

"(3) comprehensive audiological assessment of residents, as indicated by screening results, to include tests of pure-tone air and bone conduction, speech audiometry, and other procedures, as necessary, and to include assessment of the use of visual cues;

"(4) assessment of the use of amplification;

"(5) provision for procurement, maintenance, and

replacement of hearing aids, as specified by a qualified audiologist;

"(6) comprehensive speech and language evaluation of residents, as indicated by screening results, including appraisal of articulation, voice, rhythm, and language;

"(7) participation in the continuing interdisciplinary evaluation of individual residents for purposes of initiation, monitoring, and followup of individualized habilitation programs;

" (8) treatment services, interpreted as an extension of the evaluation process, that include—

" (A) direct counseling with residents;

" (B) speech and language development and stimulation through daily living activities;

"(C) consultation with classroom teachers for speech improvement and speech education activities;

" (D) direct contact with residents to carry on programs designed to meet individual needs in comprehension (for example, speech reading, auditory training, and hearing aid utilization) as well as expresssion (for example, improvement in articulation, voice, rhythm, and language) ;

" (E) collaboration with appropriate educators

and librarians to develop specialized programs for developing the communication skills of multiple handicapped residents, such as the deaf retarded and the cerebral palsied;

"(9) consultation with administrative staff regarding the planning of environments that facilitate communication development among residents in—

"(A) living areas;

"(B) dining areas;

"(C) educational areas;

"(D) other areas, where relevant;

"(10) participation in inservice training programs for direct-care and other staff;

"(11) training of speech pathology and audiology staff;

"(12) training of speech pathology and audiology graduate and/or undergraduate students, interns, supportive staff, and volunteer workers;

"(13) consultation with, or relating to—

"(A) residents (for example, self-referral);

"(B) parents of residents;

"(C) medical (octological, pediatric, and so forth), dental, psychological, educational and other services;

"(D) the administration and operation of the facility;

"(E) the community served by the facility; and

"(14) program evaluation and research.

"(e) Comprehensive evaluations in speech pathology and audiology shall consider the total person and his environment. Such evaluations should—

"(1) present a complete appraisal of the resident's communication skills;

"(2) evidence concern for, and evaluation of, conditions extending beyond observed speech, language, and hearing defects;

"(3) consider factors in the history and environment relevant to the origins and maintenance of the disability;

"(4) consider the effect of the disability upon the individual and the adjustments he makes to the problem as he perceives it; and

"(5) consider the reaction of the resident's family, associates, and peers to the speech and/or hearing problem.

"(f) Evaluation and assessment results shall be reported accurately and systematically, and in such manner as to—

"(1) define the problem to provide a basis for formulating treatment objectives and procedures;

"(2) render the report meaningful and useful to its intended recipient and user;

"(3) where appropriate, provide information useful to other staff working directly with the resident;

"(4) conform to acceptable professional standards, provide for intraindividual and interindividual comparisons, and facilitate the use of data for research and professional education; and

"(5) provide evaluative and summary reports for inclusion in the resident's unit record.

"(g) Treatment objectives, plans, and procedures shall—

"(1) be based upon adequate evaluation and assessment;

"(2) be based upon a clear rationale;

"(3) reflect consideration of the objectives of the resident's total habilitation program;

"(4) be stated in terms that permit the progress of the individual to be assessed;

"(5) provide for periodic evaluation of the resident's response to treatment and of treatment effectiveness;

"(6) provide for revision of objectives and procedures as indicated; and

"(7) provide for assistance or consultation when necessary.

"(h) Continuing observations of treatment progress shall be—

"(1) recorded accurately, summarized meaningfully, and communicated effectively; and

"(2) effectively utilized in evaluating progress.

"(i) There shall be established procedures for evaluating and researching the effectiveness of speech pathology and audiology services, including—

"(1) utilization of adequate records concerning residents' response and progress;

"(2) time schedules for evaluation that are appropriate to the service being evaluated;

"(3) provision for using evaluation results in program planning and development;

"(4) encouragement of speech pathology and audiology staff to participate in research activities; and

"(5) provision for dissemination of research results in professional journals.

"(j) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry

out the various speech pathology and audiology services, in accordance with stated goals and objectives—

"(1) A speech pathologist or audiologist, who is qualified as specified in paragraph (2) of this subsection, and who, in addition, has had at least three years of professional experience, shall be designated as being responsible for maintaining standards of professional and ethical practice in the rendering of speech pathology and audiology services in the facility.

"(2) Staff who assume independent responsibilities for clinical services shall possess the educational and experiential qualifications required for a Certificate of Clinical Competence issued by the American Speech and Hearing Association (ASHA) in the area (speech pathology or audiology) in which they provide services.

"(3) Staff not qualified for ASHA certification shall be provided adequate, direct, active, and continuing supervision by staff qualified for certification in the area in which supervision is rendered.

"(A) Supervising staff shall be responsible for the services rendered by uncertified staff under their supervision.

"(B) Adequate, direct, and continuing supervision shall be provided nonprofessionals, volunteers,

or other supportive personnel utilized in providing clinical services.

" (4) Students in training and staff fulfilling experience requirements for ASHA certification shall receive direct supervision, in accordance with the requirements of the American Boards of Examiners in Speech Pathology and Audiology.

"(5) All speech pathology and audiology staff shall be familiar with, and adhere to, the code of ethics published by the American Speech and Hearing Association.

" (k) Appropriate to the nature and size of the facility and to the speech pathology and audiology service, there shall be a staff development program that is designed to maintain and improve the skills of speech pathology and audiology staff, through methods such as—

" (1) regular staff meetings;

"(2) an organized inservice training program in speech pathology and audiology;

" (3) visits bo and from the staff of other facilities and programs;

" (4) participation in interdisciplinary meetings;

" (5) provision for financial assistance and time for attendance at professional conferences;

" (6) provisions for encouraging continuing educa-

tion, including educational leave, financial assistance, and accommodation of work schedules;

"(7) workshops and seminars;

" (8) consultations with specialists; and

" (9) access to adequate library resources, which include current and relevant books and journals in speech pathology and audiology, mental retardation, and related professions and fields.

" (1) Space, facilities, equipment, and supplies shall be adequate for providing efficient and effective speech pathology and audiology services, in accordance with stated objectives, including—

" (1) adequate and convenient evaluation, treatment, counseling, and waiting rooms;

"(2) specially constructed and sound-treated suites for audiological services, meeting U.S.A.S.I, standards;

"(3) design and location such as to be easily accessible to all residents, regardless of disability;

" (4) specialized equipment needed by the speech pathologist;

" (5) specialized equipment needed by the audiologist, including an audiometer, with provisions for sound field audiometry, and equipment capable of performing at least the following procedures: hearing screening, pure-tone air and bone conduction with con-

tralateral masking, speech audiometry, site-of-lesion battery, nonorganic hearing loss battery, and hearing aid evaluation;

"(6) provisions for adequate maintenance of all areas, facilities, and equipment, including—

"(A) electroacoustic calibration of audiometers at regular, at least quarterly, intervals;

"(B) calibration logs on all audiometers; and

"(7) appropriate speech pathology and audiology consultation shall be employed in the design, modification, and equipage of all speech pathology and audiology areas and facilities.

"Subchapter XV—Vocational Rehabilitation Services

"SEC. 1276. (a) The facility shall provide all its residents with habilitation or rehabilitation services, which includes the establishment, maintenance, and implementation of those programs that will ensure the optimal development or restoration of each resident, physically, psychologically, socially, and vocationally—

"(1) The facility shall have a written, public statement of its rehabilitation objectives for its residents, consistent with—

"(A) the needs of its residents;

"(B) currently accepted rehabilitation principles and goals;

"(C) the facility's philosophy and goals; and

"(D) the services and resources the facility offers.

"(2) While the habilitation/rehabilitation concept and process embrace all efforts to achieve the optimal development of each resident, specific habilitation/rehabilitation services shall focus on the maximum achievement of—

"(A) self-help skills;

"(B) social competence, including communications skills;

"(C) vocational competence; and

"(D) independent living.

"(b) The ultimate objective of vocational rehabilitation services shall be to assist every resident to move as far as he can along the continuum from vocational afunction to remunerative employment and entry into the mainstream of society as an independent citizen and worker. Vocational rehabilitation services shall be rendered--

"(1) directly, through personnel contact between vocational rehabilitation personnel and residents; and

"(2) indirectly, through contact between vocational rehabilitation personnel and other persons working with the residents, designed to enhance and facili-

tate the development and maintenance of a rehabilitative environment.

"(c) Vocational rehabilitation services available to the residents, in accordance with their needs, shall include—

"(1) vocational evaluation;

"(2) the formulation of written vocational objectives for each resident;

"(3) the formulation of a written plan to achieve the stated objectives;

"(4) implementation of the vocational plan through—

"(A) individual counseling;

"(B) prevocational programs;

"(C) vocational training;

"(D) vocational placement;

"(E) referral to appropriate sources for other services; and

"(F) followup.

"(d) Vocational evaluation of each resident shall—

"(1) be initiated within one month after admission to the facility;

"(2) arise out of a written comprehensive interdisciplinary evaluation (medical, psychological, social, and educational) that generates data relevant to vocational objectives and goals, such as information concerning—

"(A) aptitudes and abilities;

"(B) self-help and independent living skills;

"(C) interests;

"(D) self and vocational perception;

"(E) sensorimotor coordination;

"(F) communication skills;

"(G) current social adjustment;

"(H) educational history; and

"(I) vocational and avocational history;

"(3) be adequate for the formulation of vocational goals and of a detailed plan for the achievement of such goals;

"(4) be adequate for the assessment of current vocational status and for the prediction of possible future status; and

"(5) provide for periodic, but at least semiannual, reevaluation, consistent with the progress of the resident toward the stated goals.

"(e) The written vocational plan for each resident shall—

"(1) be consistent with the vocational evaluation;

"(2) specify the program to be undertaken to achieve his vocational objectives;

"(3) indicate the order in which the program is to be undertaken;

" (4) provide for the implementation of the evaluation team's recommendations; and

" (5) assign the responsibility to carry out the plan.

"(f) The resident shall be fully involved in his vocational evaluation, and in the formulation of his program plan. Prevocational services shall contribute to the development of work readiness in the resident, and shall provide—

" (1) vocationally relevant academic instruction;

"(2) instruction in the self-help and social skills necessary for vocational success;

"(3) instruction and practice in the social skills necessary for maximally independent functioning in the community, such as travel, handling of money, and use of community resources;

" (4) an orientation to the world of work;

" (5) development of work attitudes needed for vocational success;

"(6) rotated exploration and try-out of job tasks;

" (7) continuous evaluation of vocational potential; and

" (8) any necessary supportive services, including physical and mental restoration.

"(g) Vocational training programs shall meet all applicable legal requirements, and shall be provided through means such as:

" (1) work training stations;

"(2) work activity centers;

"(3) transitional sheltered workshops;

"(4) work-study programs;

"(5) on-the-job training;

" (6) trade training, in the classroom or on the job;

" (7) vocational training programs shall—

"(A) provide for an evaluation of training progress at least every three months;

"(B) make maximum use of job training resources—

" (i) within the facility;

"(ii) within the community;

"(8) facilities conducting vocational training programs shall have vocational training personnel assigned, in such numbers and for such times as are necessary and appropriate to the situation, to supervise the training in each training area; and

" (9) written, detailed training guides and curricula shall be available for all vocational training areas.

" (b.) Job placement services shall assist the individual to enter into appropriate kinds of employment, such as:

"(1) competitive, remunerative employment;

" (2) trade training programs;

"(3) transitional or extended sheltered workshops;

"(4) sheltered employment;

"(5) homebound employment;

"(6) homemaker; and

"(7) in conjunction with job placement services, the individual shall be provided assistance related to off-the-job needs, activities, and resources, such as—

"(A) living arrangements;

"(B) social and recreation activities;

"(C) medical services;

"(D) educational resources;

"(E) religious activities;

"(F) transportation;

"(G) legal affairs;

"(H) financial affairs; and

"(I) counseling.

"(i) Systematic follow-up services shall be provided that—

"(1) continue to be available to the individual for at least one year following placement;

"(2) involve contact with—

"(A) the individual;

"(B) the individual's family or family-substitute; and

"(C) The individual's employer, if appropriate;

" (3) generate data concerning vocational outcomes to evaluate and improve the effectiveness of vocational rehabilitation programs.

" (j) There shall be a clearly designated person or team responsible for the implementation, evaluation, and revision of the facility's vocational rehabilitation program.

" (1) There shall be available to each resident in a vocational rehabilitation program a counselor who is responsible for seeing that the resident's vocational rehabilitation program is effectively carried out.

" (2) A vocational rehabilitation counselor shall—

" (A) have a master's degree in rehabilitation counseling, or a master's degree in a related area plus training and skill in the vocational rehabilitation process; or

"(B) have a bachelor's degree and work under the direct supervision of a person qualified as in (A).

"(3) Vocational rehabilitation personnel providing training to residents in vocational areas shall be—

" (A) vocational instructors certified by the appropriate state agency; or

"(B) tradesmen who have attained at least journeyman status.

" (k) Appropriate to the nature and size of the facility, provisions shall be made for vocational rehabilitation staff development, through such means as—

" (1) inservice training;

"(2) short-term workshops;

"(3) seminars;

" (4) attendance at conferences; and

" (5) visits to other facilities.

" (1) Every facility that has a vocational rehabilitation program shall seek to establish working relationships with public and private rehabilitation agencies in the community. Each facility should have working relationships with university training programs in rehabilitation, including provision for—

" (1) research opportunities;

"(2) practicum experiences;

"(3) internships; and

"(4) consultation.

"Subchapter XVI—Volunteer Services

"SEC. 1277. (a) Volunteer services shall be provided in order to enhance opportunities for the fullest realization of the potential of each resident by—

" (1) increasing the amount, and improving the quality, of services and programs; and

"(2) facilitating positive relationships between the facility and the community which it serves.

"(b) The facility shall have a written statement of the goals and objectives of its volunteer services program that are—

"(1) appropriate to the needs of the residents;

"(2) consistent with the philosophy and goals of the facility;

"(3) developed in collaboration with the facility's staff;

"(4) specific and measurable; and

"(5) continuously assessed and periodically revised.

"(c) Volunteers shall provide services, which may be direct or indirect, that are based on resident needs, staff requests, and volunteer skills, and that enhance programs, develop social competence, and build self-esteem—

"(1) volunteer services shall supplement, but shall not be used in lieu of, the services of paid employees;

"(2) volunteer participation shall comply with State laws, such as those relating to labor and insurance;

"(3) volunteer participation shall be open to persons of both sexes, and of all ages, races, creeds, and national origins; and

"(4) volunteer services shall be available to all residents, regardless of age, ability, or handicaps.

"(d) Direct services provided to residents by volunteers, as appropriate to the facility's program and in cooperation with its staff, may include, but are not limited to—

"(1) physical, occupational, and music therapy assistance;

"(2) psychological testing assistance;

"(3) behavior modification and programed instruction assistance;

"(4) teacher or classroom assistance;

"(5) religious instruction;

"(6) recreation and leisure time activities;

"(7) social skills development;

"(8) library services;

"(9) nursing services;

"(10) transportation and escort assistance;

"(11) visits, vacations, and trips;

"(12) job and home finding; and

"(13) citizen advocacy.

"(e) Indirect services provided by volunteers, as appropriate to the facility's program and in cooperation with its staff, may include, but are not limited to—

"(1) conducting tours;

"(2) clerical and laboratory assistance;

"(3) gift shop and canteen operation;

"(4) public relations and community education; and

"(5) contributions.

"(f) Volunteer services staff should provide the following services—

"(1) to the facility's staff—

"(A) orientation in the need for, and philosophy of, volunteer services;

"(B) identification of how and where volunteers can be utilized; and

"(C) assistance in developing training for volunteers;

"(2) to the volunteers—

"(A) orientation, training, and placement;

"(B) opportunities to participate in planning and evaluating their experiences; and

"(0) appropriate recognition of their services and contributions.

"(g) Volunteer services staff functions shall include—

"(1) development and implementation of a plan for recruitment, selection, deployment, orientation, training, supervision, evaluation, recognition, advancement, and separation of volunteers;

"(2) development, in collaboration with appropriate staff, of job descriptions for volunteers;

"(3) maintenance of complete and accurate records, including, not not necessarily limited to—

" (A) hours of volunteer service rendered;

"(B) individuals and organizations providing services;

" (C) materials and moneys received; and

"(D) operational budget.

" (h) The staff members responsible for facility programs utilizing volunteers shall be responsible for providing such volunteers with on-the-job training, supervision, and consultation.

" (i) The cooperation and involvement of staff and community, which is essential to a successful volunteer services program, should be achieved by means such as—

" (1) a standing staff committee on volunteer services, to foster communications and cooperation, to evaluate and coordinate existing programs, and to stimulate new programs;

" (2) a volunteer services advisory committee, composed of representatives of appropriate community organizations;

"(3) encouragement of, and involvement with, parents groups;

" (4) collaboration with appropriate agencies ana community groups; and

" (5) recruiting volunteers representative of the community served by the facility, in respect of age, sex, socioeconomic, religious, racial, and ethnic groups.

"(j) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the volunteer services program, in accordance with stated goals and objectives.

" (1) A facility staff member shall be designated to be responsible and accountable for volunteer services—

" (A) where the size of the facility and scope of the program warrant, the person responsible for volunteer services shall devote full time to this area;

"(B) volunteer services shall be organized within the administrative structure of the facility in such a way as to be available to, and maximally utilized by, all relevant services and programs; therefore, the staff member responsible for volunteer services should report to an individual with facility-wide administrative responsibility; and

"(C) the staff member responsible for volunteer services should have the same relationship to volunteers as a personnel officer has to paid employees.

" (2) The staff member responsible for volunteer services shall have—

" (A) the necessary interpersonal, consultative, leadership, and organizational and administrative skills and abilities;

"(B) demonstrated ability to identify, mobilize, and deploy volunteer resources to meet the needs of residents;

"(C) knowledge of community organization;

"(D) knowledge of current practices and concepts in mental retardation; and

"(E) training and/or experience in organizing and administering volunteer services; as appropriate to the nature and size of the facility, and preferably—

" (i) a baccalaureate degree in a behavioral science; and

" (ii) three years of experience in volunteer services or related area.

" (k) Appropriate to the size of the facility, there should be a staff development program designed to maintain and improve the skills of volunteer services staff, through means such as—

" (1) seminars, workshops, and conferences;

"(2) college and university courses;

" (3) participation in professional organizations;

" (4) participation in interdisciplinary groups;

" (5) visits to other facilities; and

" (6) access to relevant professional literature.

" (1) There shall be adequate and accessible space, facilities, equipment, and supplies for providing efficient and effective volunteer services. If a canteen is operated by the facility, it shall—

" (1) be operated for the benefit of the residents;

"(2) be open to residents, staff, families, and visitors, without segregation by space or hours of use, so as to facilitate interaction;

" (3) provide opportunities for residents to purchase items for their personal needs;

" (4) provide opportunities for the training of residents; and

" (5) be operated so that any profits derived are utilized for the benefit of residents.

"Chapter 4.—RECORDS

"Subchapter I—Maintenance of Residents' Records

"SEC. 1278. (a) A record shall be maintained for each resident that is adequate for—

"(1) planning and continuous evaluating of the resident's habilitation program;

"(2) providing a means of communication among

all persons contributing to the resident's habilitation program;

"(3) furnishing documentary evidence of the resident's progress and of his response to his habilitation program;

"(4) serving as a basis for review, study, and evaluation of the overall programs provided by the facility for its residents;

"(5) protecting the legal rights of the residents, facility, and staff; and

"(6) providing data for use in research and education.

"(b) All information pertinent to the above-stated purposes shall be incorporated in the resident's record, in sufficient detail to enable those persons involved in the resident's program to provide effective, continuing services. All entries in the resident's record shall be—

"(1) legible;

"(2) dated; and

"(3) authenticated by the signature and identification of the individual making the entry.

"(c) Symbols and abbreviations may be used in record entries only if they are in a list approved by the facility's chief executive officer and a legend is provided to explain

them. Diagnoses should be recorded in full and without the use of symbols or abbreviations.

"Subchapter II—Content of Records

"SEC. 1279. (a) The following information should be obtained and entered in the resident's record at the time of admission to the facility:

" (1) name, date of admission, date of birth, place of birth, citizenship status, marital status, and social security number;

" (2) father's name and birthplace, mother's maiden name and birthplace, and parents' marital status;

"(3) name and address of parents, legal guardian, and/or next of kin;

" (4) sex, race, height, weight, color of hair, color of eyes, identifying marks, and recent photograph;

" (5) reason for admission or referral problem;

" (6) type and legal status of admission;

" (7) legal competency status;

" (8) language spoken or understood;

" (9) sources of support, including social security, veterans' benefits, and insurance;

"(10) provisions for clothing and other personal needs;

"(11) information relevant to religious affiliation;

"(12) report(s) of the preadmission evaluation (s) ; and

" (13) reports of previous histories and evaluations.

" (b) Within the period of one month after admission there shall be entered in the resident's record—

"(1) a report of the review and updating of the preadmission evaluation;

" (2) a statement of prognosis that can be used for programing and placement;

"(3) a comprehensive evaluation and individual program plan, designed by an interdisciplinary team; and

" (4) a diagnosis based on the American Association on Mental Deficiency (AAMD) Manual on Terminology and Classification in Mental Ketardation and, where necessary, the Diagnostic and Statistical Manual of Mental Disorders, second edition (DSM-II), published by the American Psychiatric Association.

"(c) Records during residence should include—

" (1) reports of accidents, seizures, illnesses, and treatments thereof, and immunizations;

" (2) record of all periods of restraint, with justification and authorization for each;

" (3) report of regular, at least annual, review and

evaluation of the program, developmental progress, and status of each resident;

"(4) observations of the resident's response to his program, recorded with sufficient frequency to enable evaluation of its efficacy;

"(5) record of significant behavior incidents;

"(6) record of family visits and contacts;

"(7) record of attendance and leaves;

"(8) correspondence;

"(9) periodic updating of the information recorded at the time of admission; and

"(10) appropriate authorizations and consents.

"(d) At the time of discharge from the facility, a discharge summary shall be prepared that should—

"(1) include a brief recapitulation of findings, events, and progress during residence, diagnosis, prognosis, and recommendations and arrangements for future programing;

"(2) be completed and entered in the resident's record within seven days following discharge; and

"(3) with the written consent of the resident or his guardian, be copied and sent to the individual or agency who will be responsible for future programing of the resident,

"(e) In the event of death—

" (1) a copy of the death certificate should be placed in the resident's record; and

"(2) when a necropsy is performed, provisional anatomic diagnoses should be recorded within seventy-two hours, where feasible, and the complete protocol should be made part of the record within three months.

"Subchapter III—Confidentiality of Records

"SEC. 1280. (a) All information contained in a resident's records, including information contained in an automated data bank, shall be considered privileged and confidential—

" (1) the record is the property of the facility, whose responsibility it is to secure the information against loss, defacement, tampering, or use by unauthorized persons;

" (2) the record may be removed from the facility's jurisdiction and safekeeping only in accordance with a court order, subpena, or statute;

"(3) there shall be written policies governing access to, duplication of, and dissemination of information from the record; and

" (4) written consent of the resident or his guardian shall be required for the release of information to persons not otherwise authorized to receive it.

"Subchapter IV—Central Record Service

"SEC. 1281. (a) The facility shall maintain an organized central record service for the collection and dissemination of information regarding residents. A centralized or decentralized system of record keeping may be used, in accordance with the needs of the facility—

" (1) there shall be a unit record that contains all information pertaining to an individual resident for all admissions to the facility;

" (2) where particular professional services require the maintenance of separate records, a summary of the information contained therein shall be entered in the unit record at stated intervals;

"(3) records shall be readily accessible to authorized personnel;

" (4) where a centralized system is used, appropriate records shall also be available in the resident-living units; and

" (5) a periodic review of the content of the records should be made by—

" (A) record personnel, to assure that they are current and complete; and

"(B) a committee of appropriate staff, in-

eluding the record librarian, to assure that they meet the standards set forth in section 1278;

"(6) there shall he a master alphabetical index of all residents admitted to the facility; and

"(7) records shall he retained for the period of time specified by the facility, but at least for the period of time consistent with the statute of limitations of the State in which the facility is located.

"Subchapter V—Statistical Records

"SEC. 1282. (a) While the type and amount of statistical information will depend upon the facility's particular needs, such information should include at least the following:

"(1) number of residents by age groups, sex, race, and place of residence;

"(2) number of residents by level of retardation, according to the AAMD classification;

"(3) number of residents by level of adaptive behavior, according to the AAMD classification;

"(4) number of residents with physical disabilities;

"(5) number of residents who are ambulatory and nonambulatory (mobile and nonmobile) ;

"(6) number of residents with sensory defects;

"(7) number of residents with oral and other communication handicaps;

"(8) number of residents with convulsive disorders, grouped by level of seizure control;

"(9) number of residents by etiological diagnoses, according to the AAMD, and, where necessary, the DSM-II classifications;

"(10) movement of residents into, out of, and within the facility; and

"(11) length of stay.

"(b) Data shall be reported to appropriate Federal and other agencies as requested.

"Subchapter VI—Records Personnel

"SEC. 1283. (a) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to facilitate the accurate processing, checking, indexing, filing, and prompt retrieval of records and record data.

"(b) The record system should be supervised, on a fuller part-time basis, according to the needs of the facility, by an individual who—

"(1) is a registered record librarian; or

"(2) is an accredited record technician; or

"(3) has demonstrated competence and experience in administering and supervising the maintenance and use of records and reports,

" (c) Record personnel should—

"(1) be involved in educational programs relative to their activities, including orientation, on-the-job training, and regular inservice education programs; and

"(2) participate in workshops, institutes, or correspondence education courses available outside the facility.

" (d) There shall be adequate space, facilities, equipment, and supplies for providing efficient and effective record services.

"Chapter 5.—RESEARCH

"Subchapter I—Encouragement of Research

"SEC. 1284. (a) Recognizing that the understanding, prevention, and amelioration of mental retardation ultimately depends upon knowledge gained through research, the administration and staff of the facility (and, in the case of public facilities, the appropriate governmental agency) shall encourage research activity.

"(1) opportunities and resources should be made available to members of the staff who are equipped by interest and training to conduct applied and/or basic research. Research resources and/or necessary research assistance should be made available to all staff members who have identified researchable problems related to the programs for which they are responsible;

"(2) research by qualified investigators who are not staff members of the facility shall be encouraged. There shall be a written policy concerning the conduct of research in the facility by investigators who are not staff members. Outside researchers shall fulfill the same obligations relative to staff information and feedback as do facility staff members. Consideration should be given to the assignment of a facility staff member to each research project conducted by outside investigators; and

"(3) where feasible, there shall be ongoing, cooperative programs of research and research training with colleges, universities, and research agencies.

"(b) The administration of the facility shall make provision for the design and conduct, or the supervision, of research that will objectively evaluate the effectiveness of program components and contribute to informed decisionmaking in the facility.

"Subchapter II—Review of Research Proposals

"SEC. 1285. (a) An interdisciplinary research committee shall review all proposed studies to insure—

"(1) adequacy of research design; and

"(2) implementation of ethical standards in the design.

"(b) Facility staff members shall be consulted regard-

ing the planning of research and the utilization of research findings in their areas of competence and interest.

"Subchapter III—Conduct of Research

"SEC. 1286. (a) The facility shall follow, and comply with, the appended Statement on the Use of Human Subjects for Research of the American Association on Mental Deficiency, and with the statement of assurance on research involving human subjects required by the United States Department of Health, Education, and Welfare for projects supported by that Agency.

"(b) Investigators and others directly involved in the research shall—

"(1) adhere to the ethical standards of their professions concerning the conduct of research; and

"(2) have access to the record of informed consent.

"Subchapter IV—Reporting Research Results

"SEC. 1287. (a) The principal investigator of each research project shall be responsible for communicating to the staff of the facility the purpose, nature, outcome, and possible practical or theoretical implications of the research. Copies of the reports resulting from research projects shall be maintained in the facility.

"(b) Where research findings are made public, care shall be taken to assure the anonymity of individual residents and parents.

" (c) Clearly defined mechanisms shall exist for informing staff members of new research findings that have applicability to the programs and administration of the facility. There shall be evidence that currently applicable research results are being implemented in the facility's programs.

"Chapter 6.—SAFETY AND SANITATION

"Subchapter I—Safety

"SEC. 1288. (a) The requirements of the Secretary shall be met, with specific reference to the following—

" (1) provision of adequate and alternate exits and exit doors;

" (2) provision of exit ramps, with nonskid surface and slope not exceeding one foot in twelve; and

" (3) provision in handrails on stairways.

"(b) There shall be records that document strict compliance with the regulations of the state or local fire safety authority that has primary jurisdiction over the facility—

" (1) aisles and exits shall be free from all encumbrances and floors shall be uncluttered;

"(2) flammable materials shall be properly stored and safeguarded;

" (3) attics and basements shall be kept orderly and free of rubbish; and

" (4) there shall be records of periodic fire safety inspections and reports.

" (c) There shall be a written staff organization plan and detailed, written procedures, which are clearly communicated to, and periodically reviewed with, staff, for meeting all potential emergencies and disasters pertinent to the area, such as fire, severe weather, and missing persons.

" (1) The plans and procedures should include—

" (A) plans for the assignment of personnel to specific tasks and responsibilities;

" (B) instructions relating to the use of alarm systems and signals;

" (C) information concerning methods of fire containment;

" (D) systems for notification of appropriate persons;

" (E) information concerning the location of firefighting equipment; and

"(F) specification of evacuation routes and procedures.

"(2) the plans and procedures shall be posted at suitable locations through the facility.

"(d) Evacuation drills shall be held at least quarterly, for each shift of facility personnel and under varied conditions, in order to—

" (1) insure that all personnel on all shifts are trained to perform assigned tasks;

" (2) insure that all personnel on all shifts are familiar with the use of the firefighting equipment in the facility;

" (3) evaluate the effectiveness of disaster plans and procedures;

" (4) evacuation drills shall include actual evacuation of residents to safe areas during at least one drill each year, on each shift. There shall be special provisions for the evacuation of the physically handicapped, such as fire chutes and mattress loops with poles; and

" (5) there shall be a written, filed report and evaluation of each evacuation drill.

"(e) An active safety program shall be maintained by a multidisciplinary safety committee that investigates all accidents and makes recommendations for prevention. Records of the activities of the safety committee shall be kept. There shall be adequate safety shields on the moving parts of all dumb waiters, elevators, and other machinery, as provided for in applicable standards and codes.

" (f) All buildings and outdoor recreation facilities constructed after 1971 shall be accessible to, and usable by, the nonambulatory and shall meet standards of the Secretary for making buildings accessible to, and usable by, the physically handicapped—

" (1) all existing buildings and outdoor recreation

facilities shall be modified so as to conform to the above standards by December 31, 19TG; and

" (2) existing facilities shall provide—

" (A) entrance ramps wide enough for wheelchairs, not exceeding a rise of one foot in twelve, with nonslip surfaces, and with rails on both sides;

"(B) doorways and corridors wide enough for wheelchairs; and

" (C) grab bars in toilet and bathing facilities.

" (g) Paint used in the facility shall be lead free. Old paint or plaster containing lead shall have been removed, or covered in such manner that i. is not accessible to residents.

" (h) Appropriate provisions shall be made for emergency auxiliary heat by means of alternate sources of electric power, alternate fuels, and/or standby equipment.

"Subchapter II—Sanitation

"SEC. 1289. (a) There shall be records that document strict compliance with the sanitation, health, and environmental safety codes of the State or local authorities having primary jurisdiction over the facility. Written reports of inspections by State or local health authorities, and records

of action taken on their recommendations, shall be kept on file at the facility.

"(b) The holding, transferring, and disposal of waste and garbage shall be done in a manner that will not create a nuisance, nor permit the transmission of disease, nor create a breeding place for insects or rodents—

"(1) waste that is not disposed of by mechanical means shall be—

"(A) kept in leakproof, nonabsorbent containers with close-fitting covers; and

"(B) disposed of daily.

"(2) containers shall be thoroughly cleaned inside and out, each time they are emptied; and

"(3) impervious plastic liners should be used.

"(c) Handwashing facilities shall be available in, or immediately adjacent to—

"(1) bathrooms;

"(2) toilet rooms;

"(3) sleeping areas; and

"(4) kitchens.

"(d) There shall be adequate insect screens on all windows and doors, where needed and adequate janitorial equipment and storage space in each unit of the facility.

"Chapter 7.—ADMINISTRATIVE SUPPORT SERVICES

"Subchapter I—Functions, Personnel, and Facilities

"SEC. 1290. (a) Adequate, modern administrative support shall be provided to efficiently meet the needs of, and contribute to, program services for residents, and to facilitate attainment of the goals and objectives of the facility. Such support shall make available a variety of resources, which may include, but need not be limited to, the following kinds of services; clerical, communication, dietary, financial, housekeeping, laundry, personnel, physical plant, records, safety and security, and supply and purchasing.

"(b) Administrative support functions should be directed by a qualified administrator, trained and experienced to provide skilled and efficient coordination of these services, to adequately meet the facility's program objectives. In larger facilities, provision may be made for both executive direction, via a chief executive officer (superintendent, director, and so forth), and administration of support services (via a business manager, and so forth). In smaller facilities, a single person may provide both program direction and administration of support services—

"(1) the administrator of support services should—

"(A) have at least a baccalaureate degree and

three years of experience in a responsible and relevant administrative position; or

"(B) have completed formal graduate education in health administration or its equivalent.

" (2) all administrative support personnel shall have sufficient understanding and appreciation of the nature and behavior of the mentally retarded resident, to assure that each employee's work and his relations to the residents contribute positively to their welfare.

"(c) There shall be adequate office space, facilities, equipment, and supplies for the efficient conduct of all administrative support functions.

"Subchapter II—Fiscal Affairs

"SEC. 1291. (a) Funds shall be budgeted and spent in accordance with the principles and procedures of program budgeting.

" (1) the budget requests submitted by the facility shall—

"(A) adequately reflect the program needs of the residents, as developed by program staff; and

"(B) be adequately documented and interpreted.

" (2) budget preparation shall be the product of team management;

"(3) budget preparation and implementation shall

include active participation of professional team members;

"(4) budget development shall include incorporation of effectiveness measures; and

"(5) there shall be sufficient latitude to permit rebudgeting of funds in response to changing program needs, and in accordance with the principles and procedures of program budgeting.

"(b) Individuals acting on the facility's budget requests (board members. State budget officials, members of appropriations committees, and so forth) should have firsthand knowledge of its operation and needs, obtained by regular visitation and observation of its programs.

"(c) Budget performance reports shall be prepared at appropriate intervals and submitted to those individuals participating in budgeting and management responsibilities.

"(d) Funds for community (that is, nonresidential) programs and services shall not be included in computing the per capita (that is, per resident) cost of operation. The per capita expenditure for residential services, divided by the cost of living index for the State or area, should compare favorably with the same ratio for the Nation as a whole, that is, come within 90 per centum of the Nation as a whole or, preferably, exceed 100 per centum. Maintenance expendi-

tures should be at least the same as would be required by age peers in the community.

" (e) There shall be a formal system of internal control in handling the fiscal affairs of the facility. The facility shall have an adequate 'responsibility' accounting system.

" (f) A full audit of the facility's fiscal activities shall be performed regularly, preferably annually, by a qualified accountant independent of the facility.

" (g) Fiscal reports shall be prepared and communicated to the facility's public at least annually.

" (h) Facilities charging for services shall have a written schedule of rates and charge policies, which shall be available to all concerned.

" (i) Where the size of the facility's operation warrants a fiscal officer, he shall have appropriate training and experience in accounting and auditing. Sufficient accountants, account clerks, and clerk-typists shall be provided to assure maximum support to the efforts of personnel directly involved in services to resident.

"Subchapter III—Purchase, Supply, and Property Control

"SEC. 1292. (a) There shall be written purchasing policies regarding authority and approvals for supplies, services, and equipment.

" (b) There shall be adequate documentation of the purchasing process, including, where appropriate, requisitions, bids from a number of suppliers, purchase orders, and receiving reports.

"(c) The inventory control system and stockroom operation shall be adequate for—

" (1) receiving supplies;

" (2) issuing supplies as needed in programs;

" (3) maintaining necessary stock level;

" (4)' establishing responsibility for stocks; and

"(5) there shall be appropriate storage facilities for all supplies and surplus equipment.

" (d) Where the size of the facility's operation warrants, the person responsible for directing purchase, supply, and property control should have had several years of progressively more responsible experience in these fields, and/or related training. There shall be sufficient trained and experienced personnel to accomplish the necessary purchase, supply, and property control functions.

"Subchapter IV—Communications

"SEC. 1293. (a) There shall be adequate communication service, including adequate telephone service, whenever residents are in the facility.

" (b) The communication system shall assure—

"(1) prompt contact of on-duty personnel; and

"(2) prompt notification of responsible personnel in the event of emergency.

"Subchapter V—Engineering and Maintenance

"SEC. 1294. (a) The facility shall have an appropriate and written preventive maintenance program.

"(b) Where the size of the facility warrants, engineering and maintenance shall be directed by an engineer who—

"(1) has had at least three years of progressively more responsible experience in institutional engineering and maintenance;

"(2) is licensed or certificated, as appropriate to the nature of the facility; and

"(3) there shall be sufficient trained and experienced personnel to accomplish the required engineering and maintenance functions.

"Subchapter IV—Housekeeping Services

"SEC. 1295. Appropriate to the size and nature of the facility, the person responsible for directing housekeeping services should have had—

(1) several years of progressively more responsible experience in this field, and/or related training;

(2) formal training in short courses or vocational schools; and

(3) experience and training in supervision and management.

"Subchapter VII—Laundry Services

"SEC. 1296. (a) Laundry services shall be managed so that—

(1) daily clothing and linen needs are met without delay; and

(2) there is minimum loss and damage to clothing.

"(b) Appropriate to the size and nature of the facility, the person responsible for directing laundry services should have had several years of progressively more responsible experience in this field, and/or related training. The person responsible for directing laundry service shall have the ability to supervise residents who work in the laundry.

"Chapter 8.—DEFINITIONS

"SEC. 1297. As used in this part the term—

"(1) 'Advocacy' means that which is done by an advocate.

" (2) 'Advocate' means an individual, whether a professional employed by a private or public agency, or a volunteer (a citizen advocate), who acts on behalf of a resident to secure both the services that the resident requires and the exercise of his full human and legal rights.

"(3) 'Ambulatory' means able to walk independently, without assistance.

" (4) 'Chief executive officer' means the individual ap-

pointed by the governing body of a facility to act in its behalf in the overall management of the facility. Job titles may include, but are not limited to, superintendent, director, and administrator.

" (5) Developmental disabilities' means disabilities that originate in childhood, are expected to continue indefinitely, constitute a substantial handicap to the affected individual, and are attributable to mental retardation, cerebral palsy, epilepsy, or other neurological condition closely related to, or requiring treatment similar to that required by, mental retardation.

"(6) 'Direct-care staff means individuals who conduct the resident-living program; resident-living staff.

" (7) 'Facility' means a residential facility for the mentally retarded.

" (8) 'Generic services' means services offered or available to the general public, as distinguished from specialized services intended only for the mentally retarded.

" (9) 'Governing board' means a group of individuals that constitutes the governing body of a facility; one form of a governing body. A governing board may be called a board of trustees, board of directors, or board of governors.

"(10) 'Governing body' means the policy-making authority, whether an individual or a group, that exercises

general direction over the affairs of a facility and establishes policies concerning its operation and the welfare of the individuals it serves.

"(11) 'Guardian' means an individual who has legal control and management of the person, or of the property or estate, or of both the person and the property, of a resident. A natural guardian is a parent lawfully in control of the person of his minor child; natural guardianship terminates when the child attains his majority. A legal guardian is one appointed by a court. A guardian of the person is one appointed to see that the resident has proper care and protective supervision in keeping with his needs. A guardian of the property is one appointed to see that the financial affairs of the resident are handled in his best interests. A guardian ad litem is one appointed to represent a resident in a particular legal proceeding, without control over either the resident's person or his estate. A public guardian is a public official empowered to accept court appointment as a legal guardian. A testamentary guardian is one designated by the last will and testament of a natural guardian.

"(12) 'Legal incompetence' means the legal determination that a resident is unable to exercise his full civil and legal rights, and that a guardian is required.

"(13) 'Living unit' means a resident-living unit that includes sleeping, dining, and activity areas.

" (14) 'Mobile nonambulatory' means unable to walk independently or without assistance, but able to move from place to place with the use of devices such as walkers, crutches, wheel chairs, wheeled platforms, and so forth.

"(15) 'Nonambulatory' means unable to walk independently, without assistance.

" (15) 'Nonmobile' means unable to move from place to place.

"(17) 'Normalization principle' means the principle of letting the mentally retarded 'obtain an existence as close to the normal as possible,' making available to them 'patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.' Specifically, 'the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible'

"(18) 'Public financial support programs' include, but are not limited to, services for crippled children; aid to the disabled, old age, survivors, and disability insurance, and other benefits available under the Social Security Act; and benefits administered by the Veterans' Administration.

"(15)) 'Residcnt' means the general term used in the standards to refer to an individual who receives service from a residential facility, whether or not such individual is actu-

ally in residence in the facility. The term thus includes individuals who are being considered for residence in a facility, individuals who were formerly in residence in a facility, and individuals who are receiving services other than domiciliary from a facility. (A residential facility, on the other hand, may use the term 'resident' to refer only to those individuals actually in residence, and may thus distinguish between resident and nonresident recipients of its services.)

" (20) 'Resident-living' means pertaining to residential or domiciliary services provided by a facility.

" (21) 'Residential facility' means a facility that provides twenty-four-hour programing services, including residential or domiciliary services, directed to enhancing the health, welfare, and development of individuals classified as mentally retarded. While the facility must provide twenty-four-hour programing for residents, in accordance with their needs, it need not itself operate any programs or services other than residential or domiciliary.

"(22) 'Rhythm of life' means relating to the normalization principle, under which making available to the mentally retarded 'patterns and conditions of everyday life which are as close as possible to the norms and patterns of the main-

stream of society' means providing a normal rhythm of the day (in respect to arising, getting dressed, participating in play and work activities, eating meals, retiring, and so forth), normal rhythm of the week (differentiation of daily activities and schedules), and normal rhythm of the year.

"(23) 'Surrogate' means an individual who functions in lieu of a resident's parents or family.

"(24) 'Time out' means time out from positive reinforcement. A behavior modification procedure in which, contingent upon the emission of undesired behavior, the resident is removed from the situation in which positive reinforcement is available.".

SEC. 4. (a) Section 1 of the Public Health Service Act is amended by striking out "titles I and XI" and inserting in lieu thereof "titles I, II, and XII".

(b) The Act of July 1, 1944 (58 Stat. 682) is further amended by renumbering title XI (as in effect prior to the date of enactment of this Act) as title XII and by renumbering sections 1101 through 1114 (as in effect prior to such date) and references thereto sections 1201 through 1214 respectively.

Senator KENNEDY (presiding pro tempore). The consideration of this legislation comes at a time of vigorous debate about the kind of Nation we are and the kind of Nation we want to become. President Kennedy said:

> The manner in which our Nation cares for its citizens and conserves its manpower resources is more than an index to its concern for the less fortunate—it is a key to its future.

It is that manner which is now in question. At stake is the nature of the Federal role—the degree to which the Federal Government will assure equity to its citizens and provide assistance to those who need help pulling themselves up by the bootstraps. We have, in the recent past, provided that assistance, recognizing that we do not all stand on level ground in this society, and that in many instances such inequity is an accident of birth and not a sign of personal deficiency.

This current debate is of special significance to the developmentally disabled, for until recently, they endured the consequences of the Federal Government's indifference. Our society first recognized its obligations to the developmentally disabled in 1935, when the Social Security Act created a crippled children's program within the Children's Bureau. Except for restricted income maintenance programs, the only other expression of Federal responsibility in this area was the Vocational Rehabilitation Act of 1943, which provided job counseling and placements for the mentally retarded. In his first year in office, President Kennedy called attention to the long neglected problems of both the mentally retarded and the mentally ill. He established a President's Panel on Mental Retardation, and out of their recommendations grew two significant pieces of Federal legislation: a special Federal program *of* comprehensive maternity and infant care projects aimed at high risk mothers, which also authorized grants to the States for comprehensive planning in the field of mental retardation; and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, which launched the first major Federal program for the construction of Federal facilities for the mentally retarded and the mentally ill.

The Developmental Disabilities Services and Facilities Construction Act was the next major legislative advance; it was enacted in 1970. The focus of the Federal effort was enlarged from an exclusive concentration on the mentally retarded to encompass a wider range of victims of developmental disabilities. The thrust of the act was to expand the role of the States in the development and implementation of comprehensive service programs. It was, and is, a piece of pioneering legislation, designed to supplement existing State programs, to develop new innovative "projects of national significance" as demonstration efforts, and to enable a wide variety of comprehensive resources to be brought to bear on the problems of the developmentally disabled for the first time.

On November 16, 1971, in a statement on mental retardation, President Nixon pledged "continuing expansion" of Federal spending in order to fulfill a national commitment to two major goals: First, to reduce by one-half the incidence of mental retardation in the United States before the end of this century, and second, to enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community. The President eloquently said:

Beyond any question, the effort is worth making. For at the present rate of occurrence, more than 4 million of the 142 million children whom demographers estimate will be born in America between now and the year 2,000 will grow up retarded. Their future is in our hands.

The President's words when viewed against enactment of the Developmental Disabilities legislation in 1970, raised the hopes not only of the developmentally disabled, but of their families and friends, of the health professionals and volunteer workers associated with them. It seemed that our society, which had shunned and ignored the developmentally disabled for so long, was finally ready to cope compassionately with their problems.

How disheartening it is to look back now on the President's actions since that November 16 statement. The President's fiscal year 1973 and fiscal year 1974 budgets both request appropriations for the formula grant portion of the Developmental Disabilities Act at levels identical to the fiscal year 1972 appropriation of $21.7 million. Authorizations are more than five times that level. The fiscal year 1973 and fiscal year 1974 budgets request only $4.2 million for university-affiliated facilities demonstration and training grants. This too is the exact amount appropriated by the Congress in fiscal year 1972. Authorizations are more than four times that figure. The President's budget has never requested 1 cent for the construction of facilities within which the university projects would be carried out.

Later this morning, we will hear of administrative foot dragging which delayed the establishment of this program, and even today, hinder its becoming maximally effective.

Failure to more responsibly fund this effort has had a significant impact on the States. New York State in fiscal year 1972 received $1.4 million out of budget request for $70 million, Massachusetts requested $6 million in fiscal year 1971, but received only $246,000.

One of the issues before us this morning will be definition of developmental disability. This is a critical question, because it will determine which groups are eligible for benefits under the program. A commitment to expand eligibility must be accompanied by an equally vigorous commitment to increase the appropriation for the program. To do one without the other would be to make a commitment that couldn't be met and decrease the benefits to those currently eligible.

The bill of rights of the mentally retarded focuses on the establishment of standards for residential facilities for the mentally retarded. The Developmental Disabilities Act would extend all the provisions of the 1970 law for 3 more years. We expect that the testimony we receive today will help us to improve those authorities. But unless the President is fully willing to implement them, they will not solve the problems. It is easy to find compassionate things to say about the plight of the developmentally disabled. It is more difficult to act compassionately. It is my hope that we will follow through on our commitment to the developmentally disabled; both wisdom and humanity dictate that we do.

Senator HATHAWAY (presiding pro tempore). I would like to say, first of all, that I am very happy to be able to fill in for Senator Kennedy this morning. A last minute change in the Senate calendar has necessitated his appearance on the Senate floor at this time. He will join me as soon as possible.

As the newest member of the subcommittee, I certainly welcome the opportunity to take testimony on the two important pieces of legislation before us today; S. 427, the Developmental Disabilities Services and Facilities Construction Act, and S. 458, the bill of rights for the mentally retarded.

Although only 2 years old, the developmental disabilities legislation has already shown a great deal of promise, being a new and innovative vehicle for the coordination and integration of the various Government program on behalf of the handicapped. The thrust of the act was to expand the role of the States in comprehensive service programs.

Unfortunately, however, appropriations for this legislation have been far below authorization figures. President Nixon's 1974 budget would hold the budget at the fiscal 1972 level.

At the present time, only 43,000 people out of a potential of 5 million has been served under this legislation. It is unlikely that additional numbers can be served if the appropriation is not increased.

The bill of rights for the mentally retarded is a new piece of legislation which attempts to set standards. The goal of the legislation is to correct the inhumane treatment in facilities.

This morning, we will get a look at these conditions in a film that will be shown by one of our witnesses, Mr. Geraldo Eivera, of ABC news.

I look forward to receiving the testimony of the many witnesses who will appear before us this morning.

I would like to add a personal note of my own. I have been very interested in the problems of the mentally retarded for many, many years, having served on the board of directors of an association in Maine for the mentally retarded ever since 1954.

At this time, I welcome to the subcommittee table Senator Javits of New York who, I understand, would like to make an opening statement at this time.

Senator JAVITS. Mr. Chairman, the prompt hearings on my bill of rights for the mentally retarded—S. 458—and the extension of the expiring Developmental Disabilities Services and Facilities Construction Act—S. 427—which you have introduced and of which I am a cosponsor—both measures introduced just 2 weeks ago—reflect the continuing deep concern of all the members of the Committee on Labor and Public Welfare to provide improved services and insure equal rights for the mentally retarded and other developmentally disabled, the children and adults in our society whose handicaps originate in childhood and continue in some measure throughout life. Although the mentally retarded form the largest group of the developmentally disabled, similar disabilities are also attributable to other neurological impairments, of which cerebral palsy and epilepsy are prime examples, but not the only related handicapping conditions.

The two main thrusts of my bill of rights for the mentally retarded are: (1) To provide for the humane care, treatment, habilitation, and protection of the mentally retarded in residential facilities through the establishment of strict quality operation and control standards, support of the implementation of such standards: and (2) To seek to minimize inappropriate admissions to residential facilities and stimulate States to develop alternative programs of care for the mentally retarded.

The goal of both bills is to launch a creative State/Federal partnership which would effectively utilize and develop resources to provide a full range of services—including the areas of health, education, welfare, rehabilitation, employment, and recreation for the mentally retarded and other developmentally disabled. Thus, by hearings on both measures, we will assure a complimentary approach, targeting in on the problems of the mentally retarded and other developmentally disabled.

I am pleased to welcome Geraldo Rivera. It is in great measure due to his creativity and leadership that as a public service, WABC-TV in New York first focused attention on the tragic conditions at the Willowbrook State School in New York, a residential facility for the mentally retarded. Since that first television broadcast, all the media have rendered a great public service in stirring the conscience of society and calling attention to the critical need to improve the care of the institutionalized retarded and expand alternative programs of community care.

I personally viewed the tragedy of Willowbrook. At the request of Governor Rockefeller, I urged special Federal crisis intervention to assist the State of New York in improving the situation at Willowbrook and any other New York State institutions with similar difficulties and pledged myself to the introduction of a bill of rights for the mentally retarded. I regret that the HEW report failed to provide urgently needed Federal leadership to the Willowbrook crisis and the plight of all mentally retarded.

My bill and its companion measures in the House would for the first time establish strict high quality standards to protect the human rights of the mentally retarded and, at the same time, stimulate the development of alternative programs of community care. Although these measures which would establish a benchmark in the effective care and treatment of the mentally retarded are cited in the HEW report as expressions of congressional concern, the report regrettably fails to take a position on the legislation. Thus, the force and effect upon Congress and the Nation, of HEW support to establish a national commitment for a bill of rights for the mentally retarded is forfeited. I will work for passage of this bill and believe that the bill of rights for the mentally retarded will be enacted into law this year.

Mr. Chairman, professional organizations interested in the plight of the mentally retarded have made excellent suggestions which affect the standards, the relationship of the bill with existing law and voluntary standards continuation. I believe these matters should be determined by the committee during its hearings and executive consideration of the measure. However, there was one common theme that ran throughout the need for and approval of the bill and I ask unanimous consent that these comments be printed in the hearing record.

Senator HATHAWAY. Without objection, so ordered.

[The information referred to follows:]

LETTERS COMMENTING ON "BILL OF RIGHTS FOB THE MENTALLY RETARDED"

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
OFFICE OF EDUCATION,
May 12, 1972.

To: Senator Jacob K. Javits.
Attn: Mr. Jay Cutler, Minority Staff Counsel, New Senate Office.
From: Edwin W. Martin, Associate Commissioner, Bureau of Education for the Handicapped.
Subject: Bill of Rights for the Retarded.

Thank you for the opportunity to review the proposed legislation to establish and implement a bill of rights for retarded children. The attached comments were developed by my staff. I thought you might be interested.

As you know, we have been quite concerned about the problems of children in institutions for the mentally retarded. Jim Moss, on my staff, was with the Federal team which visited Willowbrook. After that, he made a visit to the Rosewood State Hospital in Maryland. We are going to spend more time visiting these places in order to get a better understanding of the problem. This is going to become a special concern and priority item for this office.

We have in mind developing technical assistance and training programs to help improve the skills of professionals and other personnel in such institutions. We find that people managing educational and rehabilitation programs are not always up to date on what can and should be done. We will also be continuing our efforts to create more community programs so that these children will not have to be sent to such facilities.

The process of reconstructing the lives of institutionalized children will be difficult, and costly. It will take time. Your bill of rights is a good beginning.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
OFFICE OF EDUCATION,
April 28, *1972.*

To: Dr. Edwin W. Martin, Jr., Associate Commissioner, BEH.
From: R. Paul Thompson, Policy and Procedures Officer, ASB.
Subject: Bill of Rights for the Mentally Retarded.

The "Bill of Rights for the Mentally Retarded" (Mr. Javits, April 10, 1972) is a very comprehensive piece of legislation which provides humane care, treatment, and protection of the mentally retarded in residential faculties, and for the development of regional, and community programs for the mentally retarded which include the integration of such residential facilities. There is evidence of considerable expertise in the writing of the bill. In general, it is a carefully worded document, establishing strict standards for residential services, leaving little to chance or imagination with the exception of the educational component. Observations are as follows:

TITLE XI

Part A—State Strategy Planning: Provides for a review of all existing State plans concerned with providing services and programs for the mentally retarded. Emphasizes coordination of existing facilities. Provides not to exceed $300,000 per institution to cover costs of administering and operating demonstration facilities and training programs for MR.

Part B—Delivery of Mental Retardation and Services: Requires development of a State plan, which includes the designation of a State planning and advisory council. I would recommend that membership on this council must include the State Director of Special Education and State Administrator of the PL 89-313 program. (See Sec. 1103 (2).)

Part C—Standards for Residential Facilities for the Mentally Retarded: Detailed and adequate. No suggestions.

Sec. 1124. Significant—"No individual whose needs cannot be met by the facility shall be admitted to it."

Sec. 1126. Excellent—"The residential facility shall admit only residents who have had a comprehensive evaluation . . . by an appropriately constituted interdisciplinary team."

Sec. 1127(c). Significant—"There shall be a regular, at least annual, joint review of the status of each resident by all relevant personnel . . ."

Sec. 1132. Provides regulations concerning staff training, and inservice training for employees who have not achieved the desired level of competence. Specifies use of modern educational media equipment and development of working relations with nearby colleges and universities.

Sec. 1155(a). Specifics living components or groups or residents.

Sec. 1155(b). Indicates that residents who are mobile nonambulatory, deaf, blind, epileptic, and so forth, shall be integrated with peers of comparable social and intellectual development *and shall not be segregated on the basis of their handicaps.* This seems idealistic but not necessarily practical in all cases, i.e., persons who are deaf probably should not be placed with residents who are blind, since communication barriers could easily arise.

Chapter 3—Professional and Special Programs and Services

Sec. 1159. Specifies that individuals providing professional and special programs and services to residents include those in education; library services; music, art, dance and other activity therapies; occupational therapy; and vocational rehabilitation. I would suggest the addition of "Vocational Education and Vocational Habilitation (as contrasted to vocational rehabilitation).

Sec. 1163. Concentrates on educational services, indicating that such services, "defined as deliberate attempts to facilitate the intellectual, sensorimotor, and effective development of the individual shall be available to all residents regardless of chronological age, degree of retardation, or accompanying disabilities or handicaps." Could more clearly state that not only will such services be made available, but that all residents, to the maximum extent possible, be *enrolled or included,* in such programs.

Sec. 1166. Deals with Library Services Very Adequate.

Subchapter IX—Physical and Occupational Therapy Services. Specifies that physical and occupational therapy be provided, or made available to, residents on a continuing basis, as needed. Very adequate.

Subchapter X—Psychological Services. Provides for both direct and indirect psychological services. Appropriate and seem to be comprehensive.

Subchapter XI—Recreation Services. Specifies quite complete recreational services for each resident, which includes a variety of activities such as outings, performances in dramatic or musical productions, camping, team and lead-up activities, individual and dual sports, hobbies, etc. Specifies provision of "opportunities to use leisure time in activities of the resident's own choosing in an informal setting under minimal supervision." This subchapter appears to be excellent.

Subchapter XIII—Social Services. Specifics that social services shall be available to residents and their families, and shall so be provided, directly, and indirectly. Comprehensive.

Subchapter XIV—Speech Pathology and Audiology Services. Well designed; there seem to be no problems with this subchapter.

Subchapter XV—Vocational Rehabilitation Services. This subchapter could be reviewed critically to determine if all necessary aspects of a comprehensive vocational education and/or career education program are included. Seems oriented principally to *rehabilitation* rather than *habilitation* or initiatory training. (". . . services which includes the establishment, maintenance, and implementation of those programs that will ensure the optimal *development or restoration* of each resident, physically, psychologically, socially, and vocationally.")

Chapter 5—Research

This chapter charges the administration and the staff to encourage research activity. This chapter might be strengthened to assure that research activities are in fact conducted, and that funds are made available for such studies. The apparent permissiveness of this chapter could result in no research being conducted.

Chapter 8—Definitions

Significant definition—"Resident" means the general term used in the standards to refer to an individual who receives service from a residential facility, *whether or not such individual is actually in residence in the facility."* However a residential facility may use the term "resident" to refer only to those individuals actually in residence and may thus distinguish between resident and nonresident recipients of its services.

Summary Statement

This is a most significant piece of legislation, designed to ensure quality services to the mentally retarded. It is particularly strong in the medical health, social services, therapy, and residential living services. Areas possibly needing strengthening include the educational, vocational educational and research components.

Mr. Robert Gettings, of the National Association of Coordinators of State Programs for Mental Retardation, has indicated to me that he feels the bill exceeds the necessary detail for a law. His preference, which apparently reflects the thinking of many in his association, would be to have a less restrictive and comprehensive law, with the minute details being spelled out in policy statements, regulations, etc. Such statements would lend themselves more readily to changes as might be dictated by time and place.

ASSOCIATION FOR CHILDREN WITH
RETARDED MENTAL DEVELOPMENT, INC.,
New York, N.Y., May 8, 1972.

Senator JACOB K. JAVITS,
New York, N.Y.

DEAR SENATOR JAVITS: Please accept our thanks for sending us a copy of your "Bill of Rights for the Mentally Retarded."

At your request we are going to review this proposed legislation and if we have any recommendations we will communicate them to Mr. J. Cutler.

Of course, we will also alert our membership and all interested friends and professionals in the field about your bill. May we suggest that at the time you feel we can be of additional help in ensuring adoption of your bill, would you alert us and I am sure we can get many people to use their good offices for this purpose? All of us recognize the unquestionable need for the Federal Government to adopt a stance which will guarantee the elimination of conditions which treat our children in an inhuman way. We are with you in this, all the way.

IDA RAPPAPORT,
Executive Director.

ASSOCIATION FOR CHILDREN WITH
RETARDED MENTAL DEVELOPMENT, INC.,
New York, N.Y. May 31, 1972.

Mr. JAY CUTLER,
Minority Counsel to the Senate Health Subcommittee, New Senate Office Building, Washington, D.C.

DEAR MB. CUTLER : Early last month we received a copy of a proposed "Bill of Rights for the Mentally Retarded," to be introduced by Senator Javits. We have examined the Bill in its entirety and find it to be an outstanding document covering every aspect of the need for continuity of care and concern of the rights of the mentally retarded.

In the covering letter you encouraged comments and suggestions on this proposed legislation. We wish to offer some recommendations which do not alter in any way the intent of the "Bill of Rights," but we hope you will accept them in the friendly spirit in which they are being offered. Inasmuch as there are a number of comments, we thought it would be appropriate to list them on a separate sheet relating specifically to the sections of the Bill directly involved.

Please understand that we do not intend to be the ultimate experts on all phases' of this kind of legislation and so, perhaps some of our suggestions may not be completely appropriate from everybody's viewpoint. But, you invited us and we are taking the liberty of advising you to the best of our experience and ability.

Sincerely yours,

HARRY KAMISH,
Director, Public and Human Relations.

ASSOCIATION FOR CHILDBEN WITH
RETARDED MENTAL DEVELOPMENT, INC.
New York, N.Y., May 31, 1972.

COMMENTS AND SUGGESTIONS ON SENATOR JACOB JAVITS' "BILL OF RIGHTS FOE THE MENTALLY RETARDED"

INTRODUCTION UNDER SUBHEAD "A BILL"

Include in the first sentence, "to provide for the humane care . . ." *education and training.*

In same Introduction following "seek to minimize inappropriate admissions ..." and to *maximize necessary admissions.*

At the end of same Section, following "integration and such families . . ." *which provide for a full spectrum of necessary services to the mentally retarded in facilities conducted and administered by public and voluntary agencies.*

PART B, PAGE 8, LINE 6

Specific provision should be made for the inclusion of parents of the mentally retarded in the membership of a planning and advisory council.

PAGE 11, LINE 19-20

Again, provision should be made for the specific inclusion of parents on the National Advisory Council.

PAGE 12, LINE 2

Parents should be definitely specified as the consumers of such services.

PAGE 12, LINE 5-14

The Council should be required to make on-the-spot surveys on examinations and facilities.

CHAPTER I, PAGE 13

Line 6.—Sec. 1110 (a) to read "the ultimate aim of the *residential facility for the mentally retarded "hereinafter to be called the 'facility'* shall be to foster those behaviors that maximize the human qualities of the resident increase the *adaptability and development . . ."*

"(b)"—this section relating to the principle of normalization should be clarified beyond the profesisonal terms used with spiecifics.

"SEC 1111." We have been grappling for years with the development of names for such facilities which would eliminate "mentally retarded" in its title. Up to the present, the best we could come up with are euphemisms. We believe, any effort to avoid retardation as a descriptive term is an illusion.

CHAPTER 1, PAGE 13, LINE 20

Residents—additionally be referred to as clients and trainees.

CHAPTER 1, PAGE 14, LINE 13

"(c)"—The words normal activities should be changed to *activities suitable to their capabilities.*

LINE 16

"(e)"—There should be a more specific definition of the responsible agencies and population of the community.

PAGE 15, LINE 19

"(6)"—Sheltered employment in regular industry, among non-retarded workers, from our experience, is not a realizable goal. Sheltered employment, as we know it, refers to work opportunities provided for the trainable mentally retarded person who, while not having the development necessary for competitive industry, can still function in a work training and work activities environment. Of course, in exceptional cases some persons in this category may be able to hold down jobs in gainful employment, but this is not generally the case. We find, for example, a

growing accretion in our own workshops of those who can function and perform to the best of their ability in a sheltered setting but would find it difficult to perform in outside industry.

PAGE 18, LINE 12

" (3)"—Provision to be made specifically for trusteeships for residents described in this Section. New York State has developed good guidelines in this respect.

PAGE 25, LINE 14

"Sec. 1122."—Parents should be included specifically as participants.

PAGE 25, LINE 17

"(1)"—Parents and surrogates of residents should be specifically included on the policy making or governing Board.

PAGE 25, LINE 22

" (2)"—We recommend that all facilities have governing Boards.

PAGE 27, LINE 16

"(13)"—A mechanism for advocacy for all residents should be specifically spelled out.

PAGE 29, LINE 22

"(d)"—Why the emphasis on admission as temporary . . . especially, in view of the fact that severely and profoundly retarded clients require permanent placement.

PAGE 33, LINE 19

"(1)"—Recommend that autopsies be performed only with the permission of the next of kin or legal guardian.

PAGE 36, LINE 7

"(d)"—Recommend psychological assessment be a necessary part of all personnel applications, not only "where indicated" . . . full knowledge of all personnel is desirable.

PAGE 37, LINE 7

"Sec. 1132" (a)—Add after first word on Line 7 "employment . . . add the following words and *paid prevailing rates when providing such services.*

PAGE 37, LINE 15

" (4)"—Recommend this line read, "are adequately reimbursed."

PAGE 42, LINE 11

"(e) "—The word non-retarded in the context of this Section is unrealistic. Anyone familiar with the rhythm of life of the mentally retarded must recognize the special needs of this population and the ways in which they can enjoy their lives to the utmost of their capabilities. To attempt to cast this in a form where it "shall resemble the cultural norm" for chronological-age peers who are non-retarded is reaching very far.

PAGE 45, LINE 8

"(n)"—It is recommended that requirement be included that reports be made regularly to facility heads on incidences of use of restraint.

PAGE 46, LINE 15

"(p)"—Recommend that this sub-section have an addition as follows, "all use of chemical restraint shall be approved by appropriate facility supervisors under the direct orders of a physician."

PAGE 51, LINE 21

"(d)"—Recommend after the first *two* words, "effective procedures . . ." *consistent with State, municipal, and/or other local regulations.*

PAGE 53, LINE 1

"(2)"—Recommend facility staff discuss clothing needs and problems with parents or guardians wherever feasible.

PAGE 58, LINE 6

Recommend addition of a sub-section (f)—facility staff shall periodically discuss with parents or guardian of residents all living unit problems."

PAGE 100, LINE 23

"Sec. 1167."—Recommend that all members of the medical staff be qualified as medically competent to perform duties in the following sub-sections 1, 2, and 3.

While provision is made for the regularizing of staff-resident relationships, it is recommended that explicit provision be made for parent-guardian relationships with the facility's staff. There should be defined the avenues of approach to staff on various levels and also provision for periodic discussions of resident problems with those in the family who relate immediately to such residents.

ASSOCIATION FOR THE HELP OF
RETARDED CHILDREN,
New York, N.Y., June 12, 1972.

Mr. JAY CUTLER,
Minority Counsel to the Senate Health Subcommittee, Washington, D.C.

DEAR MR. CUTLER: I have reviewed Senator Javits' "Bill of Rights for the Mentally Retarded," and I would like to assure you of my complete support of this fine legislation. Please advise me when it is introduced so that I can inform our members.

Sincerely,

I. JOSEPH HARRIS,
Executive Director.

AMERICAN FEDERATION OF LABOR
AND CONGRESS OP INDUSTRIAL ORGANIZATIONS,
Washington, D.C., June 2, 1972.

HON. JACOB K. JAVITS,
U.S. Senate
Washington, D.C.

DEAR SENATOR JAVITS: I am replying to your letter inviting comments on your proposed "bill of rights for the mentally retarded." The mentally retarded are a neglected minority which rarely receive the treatment which other citizens take for granted. It is essential that the rights of these too often forgotten Americans be protected.

Although the AFL-CIO may not be in full agreement with every provision of your bill, in general, the bill represents a major step forward toward the goal of fully protecting the rights of millions of handicapped citizens of whom the mentally retarded are the most vulnerable. Your bill will do much to stimulate informed public debate and action to guarantee the rights of these innocent victims of heredity, disease and accidents.

Sincerely,

KENNETH YOUNG,
Assistant Director,
Department of Legislation.

DIXON-STATE SCHOOL,
Dixon, Ill., May 18, 1972.

Hon. JACOB K. JAVITS,
U.S. Senate,
Washington, D.C.

DEAR SENATOR JAVITS: Mr. T. K. Taylor of the Accreditation Council for Facilities for the Mentally Retarded, has generously shared with us a copy of your proposed Bill of Rights for the Mentally Retarded.

As a superintendent of a 2,700 bed facility serving the mentally retarded of all ages and all handicapping conditions, may I state that this is the most excit-

ing, promising, encouraging and all-encompassing proposal that has ever been made. You are obviously well acquainted with the tremendous needs and problems that exist in the field of residential care for the mentally retarded. Your proposal will do much to "provide for the humane care, treatment, habilitation and protection of the mentally retarded in residential facilities."

I, my colleagues, and the parents of our residents can only hope and, indeed, pray that your proposed Bill be enacted and implemented in the very near future.

We are, indeed, most grateful.

Sincerely,

David EDELSON,
Superintendent.

DEPARTMENT OF MENTAL HYGIENE,
Albany, N.Y., May 9, 1972.

Mr. JAY CUTLER,
Minority Counsel, Senate Health Subcommittee,
Washington, B.C.

DEAR MB. CUTLER: Senator Javits asked me in his May 1 letter to comment on his revised "Bill of Rights for the Mentally Retarded" which he plans to introduce this month.

I understand that you have already had an opportunity *to* exchange ideas on this bill last Friday with Fred Grunberg, our Deputy Commissioner for Mental Retardation and Children's Services.

I certainly appreciate Senator Javits' efforts to provide Federal legislation to increase the quality of residential care for the retarded and to stimulate the development of community services which will integrate residential care. However, I am apprehensive about the impact of the Bill on the Developmental Disabilities Act.

Although the level of funding does not reflect the importance of the Developmental Disabilities Act, this legislation also stimulates the Statewide plans for comprehensive community services for the developmentally disabled, including the mentally retarded.

Both have similar purposes and both include the mentally retarded in their target group. I would anticipate not only duplication, but also conflict in having two Councils in each state, as well as the National level, both developing plans and policies for services for the retarded.

I am very much in accord with the intent of Senator Javits' "Bill of Rights for the Mentally Retarded", and with its excellent provisions for providing better services for our retarded citizens. However, I do feel that the effectiveness of both the Bill and the Developmental Disabilities Act would be increased if some mechanism were developed for integrating and coordinating the two.

Thank you for giving me the opportunity to comment on Senator Javits' much-needed Bill. Please call either me or Dr. Grunberg if we can be of further help.

Sincerely yours,

ALAN D. MILLER, D.D.,
Commissioner

FEDERATION OF PARENTS ORGANIZATIONS FOR
THE NEW YORK STATE MENTAL INSTITUTIONS,
New York, N.Y., June 6, 1972.

MR. JAY CUTLER,
Minority Counsel to the Senate Health Subcommittee,
Washington, D.C.

DEAR JAY: Here are some comments on Senator Javits' bill.

On the whole, except for the minimal amount of money envisioned to help do the job, this bill is the best one I've ever seen. I hope I can be of some help in seeing that it becomes the law of the land.

Sincerely,

MAX SCHNEIER,
Chairman.

FEDERATION OF PARENTS ORGANIZATIONS OF
THE NEW YORK STATE MENTAL INSTITUTIONS,
New York, N.Y., May 16, 1972.

Senator JACOB JAVITS,
V.8. Senate,
Washington, D.C.

DEAR SENATOR JAVITS: I have reviewed your bill in the U.S. Senate regarding the mentally retarded. I find your bill excellent and very far reaching. There are some points of confusion and perhaps a slight degree of disagreement. The areas follow:

Page 6, lines 19 and 22 . . . These sums are very low and would not cure the ills of the New York State Institutions.

Page 7, line 12 . . . Talks about "such sums as are necessary" but it is my opinion that "such sums" will not materialize unless explicitly appropriated.

Page 8, line 40 . . . One-third consumer representation would not be enough for effective counter control.

Page 8, lines 20 and 21 . . . Who will support the community services? State or the Federal Government?

Page 9, Line 5 . . . If the Federal Government pays 75%, that would be excellent! But previous sections of the bill indicate a much lower percentage ($30,000,000.)

Page 10, lines 15 and 19 . . . Sounds great! A real prod to action.

Page 12, line 3 . . . Why will the Federal Advisory body be mostly consumers, and the state body be mostly providers?

The standards which are described in the remainder of the bill are excellent. In order for New York State to meet these standards, it will have to "shuffle" the deck of their program and redeal it—It would mean a total change! My only concern is that this may not be enforced, especially if only $30,000,000 is appropriated.

I heartily endorse this bill and would like to testify on its behalf, if that is possible.

Thanks again for all of your efforts on behalf of the retarded. I hope that the same will be done for the mentally ill.

Sincerely yours,

MAX SCHNEIDER,
Chairman.

THE JOHN F. KENNEDY INSTITUTE FOR HABILITATION OF
THE MENTALLY AND PHYSICALLY HANDICAPPED CHILD,
Baltimore, MA., May 9, 1972.

Mr. JAY CUTLER,
Minority Counsel to the Senate Health Subcommittee,
Washington, D.C.

DEAR MR. CUTLER: I recently received a letter from Senator Javits and a copy of the Bill which outlines the provision of humane care, treatment, habilitation, and the protection of the mentally retarded in residential facilities.

I was extremely impressed by the scope of this Bill. Such a comprehensive, obviously well-searched Bill for updating of our residential facilities is, of course, long overdue. I certainly should like to compliment you and the staff who were responsible for compending such an encompassing Bill.

I should like to make several comments about this Bill, after reading it several times and with some experience in the field. I should hope that my comments and criticisms are taken in a truly constructive sense.

In the preamble of the Bill, it is very clearly suggested that efforts should be made to "seek to minimize inappropriate admissions to residential facilities". It is my feeling that much of what is alluded to in this Bill would be geared to the educably retarded individual. As you are aware, most institutions in this country that deal with the retarded have many inappropriate admissions in which I would include the educably retarded. It is my feeling that small units for these individuals would be most functional for them if they were organized within the respective communities.

On Page 15 of the Bill, it is mentioned that residents should be integrated to the greatest possible extent with the general population. Attendance in classes or programs within regular schools, attending places of worship, using community resources for swimming and bowling, and so on, as well as shopping in stores and gainful employment are all things that I would think would be most

apropo to the educably retarded. In addition, on Page 28, in the subchapter entitled number III, there are regulations as to admission and release. Once again. I was unable to find any wording that might dissuade the admission of the mildly retarded to an institution.

I have said all this because I feel that most institutions, many of which are good, spend most of their efforts, both from the service standpoint and professionally, to the habilatation of the mildly retarded. These are the people that need it the least. I think with a minimum of professional guidance and good residential facilities within the community these people can be habilitated with ease.

I, therefore, would concern myself more with the moderately and severely retarded. I think that all of the services and professional input that has been described in this Bill should be guided towards the diagnosis, management, and habilitation of these individuals.

The description of the goals of the professionals working with the retarded in this Bill is truly outstanding. My one concern is as follows: when so many different professionals are working with the retarded, oftentimes sight is lost of the goal, and various services that should have been applied are not. I should like to suggest to you an alternative. After a resident has been known to the staff for some time, perhaps one month, a total habilitation conference could be held. This might set forth the goals for that individual. At this time, perhaps one or two major managers could be named for that individual. For example, a cerebral palsied patient, who is retarded might benefit from (1) education, (2) physical therapy, and (3) vocational training. If these services then have the responsibility or are the main manager for that resident, they may assume the responsibility of having under services for that resident whenever it seems appropriate, such as hearing and speech, religion, social services, and so on. It has been my experience that with many different disciplines concerned with a resident, oftentimes very little is accomplished unless there is a major manager or two.

I should also like to suggest that residential facilities for the retarded make every effort to share facilities. I feel best qualified to comment on the professional services aspects. I am convinced that a resident of a residential facility would get much better diagnostic service if he had a complicated problem, if this were *to* be done in a hospital setting, for example, which had great expertise in the metabolic and/or anatomic diagnosis of a particular problem. This would prevent the installation of costly equipment and so on in many institutions. The investigation period may last for only a few days at which time the individual would reassume his residency in the institution from whence he came. All information that was gained at the consultation unit could be made available to the institution. In this fashion, I truly believe that the costs for diagnosis could be kept down and probably the reliability of the tests would be greater.

On page 24, line 19, (H) number with convulsive disorders, grouped by level of seizure control. I think it would be more meaningful, particularly for research purposes, to have that sentence read "number with convulsive disorders, grouped by level of seizure control, and type of seizure".

On page 77, line 10, General anesthesia facilities for dental care shall be available. I would disagree with this concept. I am concerned about major dental and medical surgical activities occurring in any institution that does not have a good operating room, cardiac massage unit, cardiac arrest unit, including anesthetist available. I think we are asking for trouble if general anesthesia is to be encouraged in facilities that do not have excellent medical backup. What would one do if there was a cardiac arrest? Would the appropriate drugs and personnel, including any surgeons, be on hand? Once again, I think that you should consider making arrangements for any major dental or medical and/or surgical services for your residents at well-equipped, established hospital and/or dental units.

In the nursing section, particularly page 110, line 17, which states "formulating the policies governing the research in the facility", I would suggest that nursing might take part in governing research policies, but certainly in consultation with others in the unit. It seems to me that the best research in any facility is done by those who have the most expertise, whether they are nurses, physicians, or psychologists.

On page 115, line 9, (C), I wonder whether the sentence should not begin with noting rather than nothing.

The section on Subchapter VIII—Pharmacy Services, beginning on page 112, is indeed very comprehensive. I should like to make a plea, however, in your regula-

tions for including a sentence or two on the safety packaging of medications that are given to the families of the residents or residents themselves. (Poison Prevention Packaging Act of 1970) I think that younger residents of institutions may be readily exposed to various medications if left in drawers or on top of desks of older residents unless these are safety-packaged, I would be concerned about the possibility of accidental poisonings amongst residents who did not know the consequences of their actions.

Finally, let me say how happy I am to see such explicit and comprehensive regulations on the horizon. I should be happy to help in any way. Please feel free to call upon me at any time if I can offer you any further assistance.

Sincerely,

ROBERT H. A. HASLAM, M.D.,
Director.

JOINT COMMISSION ON
ACCREDITATION OF HOSPITALS,
Chicago, Ill., May 31, 1972.

Mr. JAY CUTLER,
New Senate Office Building,
Washington, D.C.

DEAR MR. CUTLER: I want to share with you my report to the Councilors concerning our discussion on Senator Javits' bill, which is item (3) in the enclosed memo.

It was very nice to have a chance to talk with you, and I hope that we will be able to keep in touch as this matter progresses.

Sincerely,

Ken Crosby,
KENNETH *G.* CROSBY, Ed. D.
Program Director.

MEMORANDUM NO. 63

To: Councilors.
From: Kenneth G. Crosby, Ed. D., Program Director.
Subjects: (1) Memorandum of Agreement, (2) June 19-20 Council Meeting, (3) Javits' Bill.
Date: May 31, 1972.

(1) The Memorandum of Agreement approved by the Joint Conference Committee and by the Board of Commissioners has been sent *to* the chief executive officers of Council Member Organizations with the enclosed letter. A copy of the Memorandum and other materials was sent you earlier with the Minutes of the Joint Conference Committee Meeting.

(2) The preliminary agenda for the June 19-20 meeting is enclosed. The meeting will begin at 9:00 A.M. on Monday, June 19, and from the length of the agenda I would expect it to last all day on Tuesday. Councilors should plan accordingly. Reservations for arrival Sunday, June 18, have been made at the Sheraton-Chicago for all Councilors. If there is any change in your arrival plans, please let us know at once, so that we will not have to pay for unused rooms.

(3) A copy of Dr. Porterfield's letter to Mr. Jay Cutler of Senator Javits' staff was sent you earlier. During our interview with Mr. Cutler on May 26, Dr. Shotick and I attempted to make the following points;

1. The Accreditation Council wholeheartedly supports the Senator's objective of improving the services provided mentally retarded persons, which is also the Council's goal.

2. AC/FMR believes that there is great value in the voluntary accreditation approach to setting standards and assessing compliance with them, especially when this approach is supported by government.

3. In order to be an effective means of improving services, standards have to be continually reviewed and revised in the light of increased knowledge, changing practice, and experience with their application and implementation. The Council's standards are expected *to* need revision soon, and they should not, therefore" be written into law. Whatever body sets standards must have the flexibility to change them.

4. As a voluntary agency that includes both provider and consumer representation, the Accreditations Council has the requisite flexibility to change both stand" ards and organizational participation in standard-setting, in response to chang

ing needs. The Council will consider next month the membership application of five additional organizations. The Accreditation Council's purview, moreover, is not limited to public residential facilities, but includes private facilities and non-residential community programs, and this broader perspective enhances the Council's capability to develop effective standards for public residential facilities.

5. The Accreditation Council recognizes the need for governmental overseeing of programs expending governmental funds. Rather than creating, in a National Advisory Council on Standards for Residential Facilities for the Mentally Retarded, yet another government agency, especially one that replaces an already-functioning voluntary body, however, consideration should be given to assigning this overseeing role to an existing group, such as the National Advisory Council on Services and Facilities for the Developmentally Disabled.

6. As important as standard-setting in improving services is the assessment of compliance with Standards. For effective results, this should not be left to the diverse means that might be employed by the fifty states. Since assessment of compliance necessarily involves interpretation and judgment in respect to the standards that have been set, and since feedback from assessment of compliance is essential for the continued improvement of standards, the dual, complementary functions of standard-setting and compliance-assessment should not be separated. Such separation would weaken the capacity to perform each function effectively.

7. The laudable intent of Senator Javits' bill can be achieved more effectively by encouraging facilities to comply with standards set and assessed by an independent, voluntary, national organization composed of both providers and consumers, which is what AC/FMR is. Certifiability of a facility for participation in the financial provisions of the bill should be presumed to exist if the facility is accredited by AC/FMR.

JOINT COMMISSION ON
ACCREDITATION OF HOSPITALS,
Chicago, IV,., May 18, 1972.

Senator JACOB K. JAVITS,
U.S. Senate, New Senate Office Building,
Washington, D.C.
Attention: Mr. Jay Cutler

DEAR SENATOR JAVITS: Since receipt on May 3 of a copy of your proposed Bill of Rights for the Mentally Retarded, the draft has been examined with meticulous care, particularly 'by the staff of the Accreditation 'Council for Facilities for the Mentally Retarded. I report now on the conclusions drawn from this review for your consideration.

Your strong and sincere interest in the welfare of the mentally retarded is well demonstrated by your conception of this legislative proposal. All of us on the staff, as well as the members of the Accreditation Council for Facilities for the Mentally Retarded and the Board of Commissioners of the Joint Commission, support your objective wholeheardtedly. The following comments are directed only at a consideration of the means by which this objective may be met.

There is, of course, a basic difference in approach. It is the position of the Joint Commission and of this Accreditation Council that there is great inherent value in the voluntary approach. When this is recognized and supported by government, the highest potential is created. For government to replace voluntary effort is no particular gain. We are attempting to instill the capability and the will for self-reliance in the mentally retarded. We should do no less for all of our citizens.

(1) The proposed National Advisory Council to the Secretary (Sec. 1108) essentially replaces the Accreditation Council for Facilities for the Mentally Retarded. This voluntary body was created in 1969 after three years of organizing negotiation, feasibility trials, and developmental effort. That it has been worth the effort is evidenced by the cooperative total commitment of five national organizations representing both professional and consumer interests *to* produce residential standards and, in the very near future, standards for community programs. Each of the signatory organizations contribute support, as does the Joint Commission and as will the institutions and programs to receive services. Government has provided substantial support in the form of grants. The gains and losses resulting in conversion to a federal operation must be carefully assessed. Without attempting to offer this assessment at this moment, it is our view that the losses would be greater. To mention only one point, the organizations participating in standard-setting would be relatively fixed by statute. The organizations which should participate may change from time *to* time—several others have pres-

ently applied for membership on the Accreditation Council—and the flexibility of an independent, national, voluntary body is requisite to making appropriate changes.

(2) Sections 1110 through 1197 identify, with a few minor variations, the present standards of the Accreditation Council. If standards are to be effective in improving services to the retarded, they must not be static, as they tend to be in statute, but must change in response to increased knowledge, improved practice, and experience with their application and implementation. These present standards of the Council are now being field-tested. Some standards have already been found to be unclear and in need of revision. Further experience can be expected to identify more needed changes. Again the flexibility of a voluntary body is requisite to effective results.

(3) The draft bill is silent on any program to evaluate institutional conformance to the standards. A chore, as critical as the derivation of the standards themselves, is the creation of a perceptive evaluation tool which can measure conformance, test the validity of the standards themselves, and offer a consultative mechanism for improvements in institutional performance. A proper accreditation program does more than categorize from time to time. It also offers a motivational force for change. Presumably the Secretary would find it necessary to utilize the services of state agencies for this phase. We submit that the Accreditation Council is closer by years to the effective implementation of this activity on an equitable national basis.

(4) Sections 1101 through 1107 do provide the kind of incentive and support which can facilitate early improvement in the condition of the mentally retarded. Were it geared to the program of the Accreditation Council for Facilities for the Mentally Retarded (or any comparable organization determined by the Secretary), it would be directed more effectively toward its objective. However, rather than a total delegation as was provided in the Medicare Act, certifiability of a facility for federal support should be *presumed* (rather than *deemed*, as in the Medicare Act) to exist if the facility is accredited by the Joint Commission on Accreditation of Hospitals through its Accreditation Council for Facilities for the Mentally Retarded. This would permit a reexamination or a resurvey or both at the instigation of the Secretary where substantial challenge has been made and, when indicated, a withdrawal of certification. This leaves the work in voluntary hands, the final decision for federal aid in federal hands. By this device, the constitutionality of the legislation is better assured.

(5) There does not appear to be a Section 1109.

The staff, the Accreditation Council, the Board of Commissioners, and all of the participating national organizations stand ready to be of help to you in any further consideration of this legislation. Again may we compliment you on your empathy with this too often forgotten segment of our population. We are very grateful for this opportunity to comment on your plans.

Sincerely,

JOHN D. PORTERFIELD, M.D.,
Director.

THE JOSEPH P. KENNEDY, Jr. FOUNDATION,
Washington, D.C., May 25, 1972.

Senator JACOB JAVITS,
Old Senate Office Building,
Washington, D.C.

DEAR SENATOR JAVITS: I have read your bill on the Bill of Rights for the Mentally Retarded and am very impressed. Congratulations for working so quickly and with such expertise in such a sad and difficult area.

I have attached a memo prepared by me and Dr. Cooke, our Scientific Advisor to the Kennedy Foundation. Let me know if we can help further.

Sincerely,

EUNICE KENNEDY SHRIVEB.

MEMORANDUM TO SENATOR JAVITS

The purpose is excellent and the proposals are certainly very worthwhile. Title XI, which is supported residential facilities, includes the development of some state strategies, including review of existing plans and the like. In addition, a relatively small amount of money, $300,000 per institution, is authorized to study the administration and financing of such programs.

There seems to be a priority for the institutions which are the worst, and this would seem on the surface to be very reasonable, but unfortunately, it could lead to some horrendous places simply being patched up rather than completely abandoned. The National Advisory Council on Standards for the Mentally Retarded is obviously a good idea if it has some authority; otherwise, it will simply be another group that writes out the standards which no one is able to follow because they don't have any money.

We have very serious concern about this bill of rights since it provides some money for residential services, but absolutely none for the enormous job of providing services for individuals who do not get into institutions. The best way to improve state institutions is to reduce the case load. The best way to do that is to provide much more money for noninstitutional activities so that patients in the institutions may be discharged and new patients will not be admitted because there will be community activities for them.

The section on integration of the patients with the community is very worthwhile and there are six points which are emphasized that the community should be used rather than the institution. The only trouble is that a good deal of money is required for these community activities and I do not see that at all in the authorization.

In Section 1160 on page 69 is listed the need for programs and services which provide for comprehensive diagnosis and evaluation, design and implementation of an individualized rehabilitation program, regular review, freedom of movement and an array of services that allows each resident to develop to his maximum potential. All of these are very worthwhile but it is fair to say that many institutions cannot mount and will never be able to mount adequate comprehensive diagnosis and evaluation because there is a shortage of physicians and particularly a shortage of people who want to be pinned down to a remote institution. Every effort should be made to have such services provided by excellent groups in the community, particularly university-affiliated facilities. A mention should be made in this legislation that these resources exist and should be used on a regional basis as much as possible for the kind of consultation and diagnostic evaluation that is spoken to in other parts of the legislation.

Again, much of the material in regard to nursing services, library services and the like speak to the large institution and after reading this legislation, one would get the feeling that the biggest place can provide the best program. We believe that this has not been shown to be the case and in the legislative history of this bill, it must be stressed that the great bulk of the services should be directly provided within the institution and worked out with the community and not that every effort be made to bring the residents into the institution on a full time basis.

Section IX on Recreation Services is excellent. The distinction between Recreation and Physical Education Services and Rehabilitation Services is important as illustrated in your bill. Both the personnel and the goals are quite different and should be so recognized.

ROBERT F. COOKE, M.D.,
EUNICE KENNEDY SHRIVER.

NATIONAL ASSOCIATION FOR RETARDED CHILDREN,
Arlington, Tex., May 15, 1972.

Mr. JAY CUTLER,
Minority Counsel to the Senate Health Subcommittee, New Senate Office Building, Washington, D.C.

DEAR MR. CUTLER : I am responding to Senator Javits letter to me of May 1 requesting a review of the proposed "Bill of Rights for the Mentally Retarded." I have had an opportunity to study this Bill with much interest, and I hope that the following comments may be of interest to you.

My first reaction is one of admiration for Senator Javits obvious concern for the welfare of retarded persons living in state institutions. The proposed Bill addresses itself to one of the really critical issues facing states in serving the needs of the mentally retarded today. I am in complete agreement with the philosophy expressed in this proposed legislation.

Although I am in general agreement with the standards included in Part C, I have some serious questions that these standards should be incorporated in law. Those of us who developed the accreditation standards for residential facilities for the mentally retarded strongly felt the standards should remain flexible and should continually reflect changing knowledge and philosophy regarding

services for the mentally retarded. The following quotation from the Standards Manual makes this position explicit: "The *Standards for Residential Facilities for the Mentally Retarded* are to be subject to continuous review and revision, in order to maintain currency with the best thinking and with changing knowledge and practice in the field, and in order to keep them clear, comprehensive, and challenging." The spirit of the Bill could be better served, I feel, by insisting compliance with the Accreditation Council for Facilities for the Mentally Retarded, rather than by stipulating specific standards. A second alternative might be to include the Standards, as outlined in Part C, in regulations rather than in the Bill itself.

Turning now to specific aspects of the Bill, I feel there is some danger that the emphasis on "optimum safety" of living quarters mentioned in lines 13 and 14 on page 3, may permit the establishment of, or justification for, a highly controlled, sterile, and developmentally inappropriate environment. Historically, we have seen concern for safety used as a rationalization for neglecting the developmental needs of individual residents. Perhaps the statement could include the intent that safety considerations should hot be overly restrictive and should take into account the need for freedom to explore and the freedom to sustain the normal minor injuries associated with child development.

I fear that the statement made at the bottom of page 3 that "residential faclities should be small, home-like units. . . ." may be overly limiting, in that the statement might be interpreted to prevent innovative environmental modifications designed to facilitate the training of retarded persons. It might be possible to incorporate the language on page 61 of the Bill which states "the interior design of living units shall simulate the functional arrangements of a home to encourage a personalized atmosphere for small groups of residents, unless it has been demonstrated that another arrangement is more effective in maximizing the human qualities of the specific residents being served."

In reviewing the proposed composition of the "National Advisory Council on Standards for Residential Facilities for the Mentally Retarded," I note that the members of the Council are selected from those agencies currently represented in the Accreditation Council for Facilities for the Mentally Retarded. Since the Council has been considering the possible inclusion of additional organizations, I wonder whether it might not be more appropriate to indicate that members shall be selected from the agencies represented on the Accreditation Council for Facilities for the Mentally Retarded, rather than limit membership to the specific agencies currently comprising the Accreditation Council.

I hope these comments are helpful. If I can be of any additional assistance, I hope you will not hesitate to contact me again.

With all best wishes.

Sincerely,

PHILIP Roos, Ph.D.
Executive Director.

NATIONAL ASSOCIATION OF SUPERINTENDENT
OF PUBLIC RESIDENTIAL FACILITIES,
Lansing, Mich,., May 9, 1972.

Hon. JACOB K. JAVITS,
U.S. Senate Committee on Labor and Public Welfare, Washington, D.C.

DEAR SENATOR JAVITS: I reviewed the "Bill of Rights for the Mentally Retarded" and have contacted Jay Cutler of your staff.

As Chairman of the National Association of Superintendents of Public Residential Facilities, I would like to take this opportunity to say our entire organization wishes you success in your endeavor to alleviate the highly unsatisfactory conditions that exist in so many of America's institutions for the retarded. We look to you as a champion, not only of the rights of the retarded but others who have made the field of Mental Retardation a career.

Sincerely yours,

DAVID ROSEN,
Chairman.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.,
New York, N.Y., May 1, 1972.

Mr. JAY CUTLER,
Committee on Labor and Public Welfare, New Senate Office Building, Washington, D.C.

DEAR JAY : I have examined very carefully the proposed bill by Senator Javits to provide for human rights of mentally retarded especially in the institutions.

I think the concept of the bill is superb as, indeed, are most of its terms. May I make some special comments on the bill itself.

Page 21 of the first version. Under subchapter III, section 1124 the statement is made "No individual whose needs cannot be met by facilities shall be admitted to it." I do not, however, see any alternatives to this in the bill itself. I think there must be some provision for this, other than the confusing and almost inoperable developmental disabilities services act (91-517).

Page 22. Section 1126(a) The statement is made "The residential facilities shall admit only residents who have had comprehensive evaluation . . ." There is no provision for who will give this evaluation.

Page 26. Section 1129(d) The statement is made *"except in an emergency* (italics mine) transfer shall be made with prior consent and order of resident or his guardian." I think the term *except in emergency* should be eliminated.

No transfers should be made without prior knowledge and not "ordinarily the consent", but absolute consent and this should be an informed consent.

Page 27. Section 1130, subsection (a) : "In event of any unusual occurances including serious illness and accidents, impending death, etc., resident's next of kin, etc., shall be notified, etc." I think this should state "Should be notified within 24 hours".

Page 31. Section 1132: "(a) Residents shall not be involved in the care, training or supervision unless they (4) are reimbursed". This should state "are reimbursed in accordance with minimal federal wage laws".

Page 37. Section 1140, Subsection "(h) Residents shall be permitted personal possessions".—should read—Shall be permitted and encouraged to have personal possessions.

These may seem minor changes, but my experience with "Development Disabilities" makes me very wary to imprecise language.

Now, one other matter, Jay. We in the field of mental retardation think the Developmental Disabilities Services Act an abortion. It is imprecise in language and, while opening the door to unrelated handicaps, shuts it on the mentally retarded.

The whole concept of throwing all handicaps together is, perhaps, well intentioned, but misguided. Our whole experience for over 100 years is that where the mentally retarded are in a mix with other handicaps for service, the mentally retarded end up with the short end of the stick.

The N.Y. State Association for Retarded Children calls on our senior senator to undertake a revision of this law in 1973 and go back to serving the retarded. The physically handicapped, without mental retardation have numerous laws for their protection and service. The retarded have this only.

I am ready to meet with you to help draft new legislation. We feel it is a must.

Sincerely,

JOSEPH T. WEINGOLD,
Executive Director.

UNITED CEREBRAL PALSY ASSOCIATION, INC.,
New York, N.Y., May 16, 1972.

Hon. JACOB K. JAVITS,
U.S. Senate, Washington, D.C.

DEAR SENATOR JAVITS : The "Bill of Rights for the Mentally Retarded," which you sent me, would be a lasting landmark in the restoration of full citizenship for the mentally retarded of our country. The emphasis placed on efforts to locate facilities that prepare a person to achieve normalization within the content of their family and community is excellent. A special dislike of mine is covered by the improved terminology for facilities and residents (Section 1111) and location of facilities, etc. (Sections 1112, 1113 and 1114). I resist regularly the tendency to call Palsy a "disease" or an "affliction," and those attending centers as "patients," etc.

No effort shall be made to comment on those subchapters about medical or related professional standards and requirements. I lack the qualifications to do

so. It is noted that the major part of the standards follow those adopted by the Accreditation Council for the Facilities for the Mentally Retarded, which was chaired by Dr. Elsie Helsel who heads our Washington office. The method for transforming their exceptionally fine report into an Act of Congress does raise a few questions.

Although the data requirements of Section 1121(7) are not limitations, I suggest the desirability of including a category for those with multiple handicaps, or to require appropriate cross-references for the identity of this group. The specialized needs of the multiple handicapped is recognized in Sections 1140(e), 1150(i) and 1157(e). In this connection, would not "or multiple handicapped" in place of "and so forth" more clearly set forth the intent of Section 1155 (b) at line 12?

While in accord with the concept and objective of Section 1132, I have concern about the practical results. The desirable requirement of 1132(b) (2) could become a deterrent to moving a resident out of "training situations." The attitude, I fear, would be why not hire a non-resident if the wage of a resident must be "at the legally required wage level." The need would appear to be for a pay incentive system that would enable a resident to progress from "training situations" to a position or performance level that would result in a full wage level. Whether Section 1132(b) (1) and (2) will accomplish the desired goal seems doubtful to me.

A major thrust of the Bill for residential-type and community related facilities appears to be defeated by application of this Act to existing facilities. As much as the need exists for changes and improvements in existing "institutional prisons," they would have to be moved and rebuilt entirely to begin to meet the full concept expressed in the Bill. In this regard the Bill appears to undertake two inconsistent objectives. In so doing the basic philosophy and essential goals will have to be excepted away with each grant in one way or another because nearly all existing facilities were constructed to provide diametrically different objectives. How any amount of grants can make it possible to provide "a personally satisfying life within the residential environment" (Section 1101 (b) (4) in most existing structures consistent with the Bill's standards and objectives escapes me.

My own State (Mississippi) is a glaring example of what is still occurring. The legislature funded last month the construction of a $5,000,000, 500-bed multi-story "mastaba to madness." This "monster-structure" will be located at Oxford, Mississippi, and (according to the State official under whose jurisdiction it would have operated) will be obsolete and overflowing before the foundation is laid.

My thoughts concerning this aspect of the Bill are too involved to detail here. For this reason that I have talked with Mr. Jay Cutler and have arranged to come to Washington on May 23, 1971, to explore other means of accomplishing the desired results while avoiding the obvious weakness of the present duality.

Sincerely,

GEORGE J. SCHWEIZER, JR.,
President.

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.,
New York, N.Y., May 24, 1972.

Mr. JAY CUTLER,
Counsel, Minority Staff, Committee on Labor and Public Welfare, New Senate Office Building, Washington, D.C.

DEAR JAY: It was sheer joy meeting you at long last. I guess the world is filled with beautiful people whose paths never cross. Fortunately ours did.

As Mr. George Schweizer, President of UCPA and I indicated in our meeting with you on May 23rd, we applauded what Senator Javits is attempting to do for the retarded and other developmentally disabled who must reside in our public institutions.

Although we are sympathetic to the problems of the states in operating such systems—old buildings, inadequate budgets, and insufficient staff, we agree with the Senator that we can no longer tolerate the conditions such systems impose. We can no longer accept rational reasons for why we cannot provide decent places to live and appropriate programs for our severely handicapped citizens.

Appropriate services for this group must be available not as a charitable gift-but as a constitutional right. Miracles must happen. Conditions must change!

Fortunately several forces are impacting on the problem of improvement of care in institutions. Each in its own way will be helpful.

Accreditation of residential facilities by the Accreditation Council for Facilities for the Mentally Retarded, a consortium of voluntary agencies with priority concerns for quality care. The actual accreditation of facilities for the mentally retarded is just starting. Development of standards and survey procedures is a complicated process. We are now open for business and we have high hopes;

Litigation in the courts in Alabama, New York, Georgia, South Carolina, Missouri and Massachusetts;

Developmental Disabilities Act Planning and Advisory Council which with consumer involvement are drafting and implementing total state plans for the developmentally disabled including alternatives to institutional care ;

The mood of the professional and lay community which will no longer tolerate warehousing conditions for human beings.

Our concerns with the Senator's proposed bill, which we were pleased *to* be asked to comment on, are primarily :

(1) Standards Problems—by creating a new National Advisory Committee, the bill would in essence create *two* groups of standard setters—the members of the Accreditation Council and the National Advisory Council. We also have a concern with getting locked into standards which are minimal and which we are trying *to* strengthen as quickly as it is pragmatically possible.

(2) Survey Problem—as the bill is presently written with states having the responsibility for surveying institutions in order to determine compliance, there is an unacceptable conflict of interest. States operate the institutional systems. States should not be judging whether or not they are doing a good job in operating the institutional system.

(3) Accreditation Process—those of us who have been working for six years to develop standards and procedures for accrediting institutions for the mentally retarded feel that as the bill is presently written it would weaken or liquidate the accreditation process.

It is my understanding that we have come to an accommodation on these concerns in the following manner.

(1) By changing the language on Page 11, Section 1108 to establish a National Advisory Council which will consist of representatives of agencies as represented on the Accreditation Council. These are presently AAMD, APA, CEC, NARC, and UCPA). However, the Accreditation Council is considering enlarging this group. The Secretary would have the responsibility for naming the agencies whose representatives are to serve on the National Advisory Council. The individual agencies would have responsibility for naming the specific councilors. In this way the same group of individuals would be serving as the National Advisory Council that are presently serving as Councilors on the Accreditation Council. Unless these two groups of individuals are identical, we could see mass confusion in the proliferation of standards which might not be compatible.

As I explained to you the Accreditation Council has made provision for the continuous revising and strengthening of standards. This process needs to have flexibility and not be locked into law. The bill language should therefore indicate that the standards in the bill are minimal and states will be expected to comply with additional standards approved by the Accreditation Council for Facilities for the Mentally Retarded.

(2) On Page 5, Section 1101 by adding language that says states in conjunction with the Accreditation Council will survey institutions for compliance. You might want to consider assigning this survey process entirely to the survey teams from the Accreditation Council. Surveyors would be performing *two* functions. They would be looking for the states for situations which should be improved in order to bring the services into compliance. Wearing another hat they would be deciding whether an institution was presently complying with enough of the standards in order to get the Seal of Accreditation.

One problem which we did not have an opportunity to discuss at our meeting was the problem posed by Page 8, line 1, State Advisory Councils. These Councils would seem to duplicate the efforts of the present Developmentally Disabilities Planning and Advisory Councils which are already functioning and which have one-third consumers.

Granted that such Councils are having "growing pains", from my own experience in the State of Ohio where I serve as Chairman of such a Council, I can assure you that we are moving very rapidly into the development of communitv alternatives for institutional care. We are putting in place a Protective Service-

Case Management System which will be an entry point for all candidates for residential care, institutional or community. We also have built into that system a resource which we feel is absolutely essential if we are going to move in the direction of community based residential facilities, namely a protective services system.

I have enclosed a copy of the Ohio Law and a copy of a speech given in Minnesota describing the System. I have also enclosed a copy of my letter to Congressman Ryan commenting on a bill which he plans to introduce. The Mentally Disabled Protection Act.

On behalf of United Cerebral Palsy I should like to thank you again for being so generous with your time in meeting with Mr. Schweizer and myself. If we can be of help in any further way, please call.

Sincerely,

ELSIE D. HELSEL, Ph. D.,
"Washington Representative.

UNITED CEREBRAL
PALSY ASSOCIATIONS, INC.,
New York, N.Y., January 12, 1973.

Mr. JAY CUTLER,
Counsel, Minority Staff, Committee on Labor and Public Welfare, Washington, B.C.

DEAR JAY: Attached are some suggested changes for S. 3759 "Bill of Rights for the Mentally Retarded."

First off of course I would be a lot happier if you would say this was a "Bill of Rights for the Mentally Retarded and Other Developmentally Disabled."

The enclosed changes do the following things:

(1) Make some minor additions and changes in the language.

(2) Utilize the State DDA Planning and Advisory Council as the "State Planning and Advisory Council" so that efforts are coordinated and not duplicated.

(3) Utilize the Accreditation Council for Facilities for the Mentally Retarded in much the same way that JCAH is used in the Medicare program so that there is not duplication of effort in the promulgation of standards and the determination of compliance.

Following our meeting on January 11th I called Dr. Kenneth Crosby who drafted the language concerned with standards and determination of compliance. He will be forwarding to you a letter including the same language so that you have an official communication from the Accreditation Council.

If you have any questions or if we can help in any further way please call. My home phone in Athens, Ohio is (614) 593-8775. My "Washington office number is 638-6169.

Warmest personal wishes,

ELSIE D. HELSEL, Ph. D.,
Washington Representative.

CHANGES FOR S. 3759

Section 1101. (a), Line 15-16—Delete (Page 5) : "which shall be done in cooperation with the National Advisory Council on Standards for Residential Facilities for the Mentally Retarded established under section 1109 of this Act,"

Section 1101. (a), Insert after line 26. (Page 5) : "Surveys to determine the the compliance of facilities with the standards established under part C of this title shall be conducted by the national accrediting body for such facilities, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals."

Section 1103, "State Plans", Suggested Change (Page 7) : "(a) Any State desiring to receive a grant under this title submit a plan to the Secretary:

"(1) setting forth as one of its priority goals the improvement of residential services;

"(2) setting forth a strategy and a schedule for compliance with standards under part C;

"(3) having in operation a properly constituted developmental diabilities planning and advisory council with duties and responsibility as set forth in section 134 of the Developmental Disabilities Act;

"(4) assuring reasonable state financial participation . . . ;

"(5) setting forth a schedule of costs . . . ;

"(6) designating how placement . . . ;

Section 1103 (2), Suggested Change To Read (Page 8) : "designating the State developmental disabilities planning and advisory council as the planning and advisory body.

Section 1106. Add after point (c) (Page 11) : "(d) A facility shall be deemed to meet the standards promulgated under part C of this title if it is accredited by the national accrediting body for such facilities, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, provided that the Secretary may cause an independent survey of compliance with the standards to be made in any facilities surveyed by the Accreditation Council whenever he finds such an independent survey to be necessary to validate the findings of the Accreditation Council survey.

Re: Section 1108.—"Alternative Programs of Care (Page 11) :

As you know the Accreditation Council is also developing standards for community programs. If these community programs are residential programs they should meet the same standards as are established in your bill under part C. Otherwise as we create alternatives to institutional care in the community they may be no better, or even worse, than our present institutions. The recent experience in Pennsylvania confirms this fear. You should know that the present standards were drafted in such a way that they would be appropriate for any residential facility of any size. A group of operators of small group homes in California reviewed the standards in order to give the Council assurance that the standards would be applicable to small facilities.

Suggested Change for Section 1108.—"Alternative Programs of Care:

"Community resources and community living situations for the mentally retarded receiving grants under this section shall comply with the applicable standards established by the national accrediting body for such programs, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals. A program shall be deemed to be in compliance with such standards if it is accredited by the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, provided that the Secretary may cause an independent survey of compliance to be made of any programs surveyed by the Accreditation Council whenever he finds such an independent survey to be necessary to validate the findings of the Accreditation Council survey.

Section 1109. (Page 12), Delete "National Advisory Council on Standards for Residential Facilities for the Mentally Retarded"

Replace with "Revision of Standards and the following material:

"(a) The Secretary shall seek and receive the advice of the national accrediting body for facilities and programs for the mentally retarded, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, in respect to (1) recommendation for any changes, revisions, modifications, or improvements in the standards established under part C of this title, (2) any regulations promulgated or proposed to be promulgated by him in the implementation of the standards established under part C of this title, provided that nothing herein shall limit the authority of the Secretary to seek and receive advice and respect to the above matters from any source he deems appropriate.

SUGGESTED CHANGES FOE S. 3769

Version submitted June 28, 1972.

Re: Page 3, Line 5: We have learned in Ohio that having legal guardians is just not enough protection for incompetent individuals whether they reside in State institutions or in the community. We have therefore set up a statewide Protective Advocacy System under law.

Suggested Change for Line 5: (5) a protective advocacy service including but not limited to guardianship should be available and replace this material with the following: "Revision of Standards. Sec. 1109. The secretary shall seek and receive the advice of the national accrediting body for facilities and programs for the mentally retarded, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, in respect to (1) recommendations for any changes, revisions, modifications, or improvements in the standards established under part C of this title, (2) any regulations promulgated or proposed to be promulgated by him in the implementation of the standards established under part C of this title, provided that nothing herein shall limit the authority of the Secretary to seek and receive advice in respect to the above matters from any source he deems appropriate."

The Council shares, as you know, the Senator's objectives of discouraging inappropriate admission to institutions and encouraging the exploration of alternatives to institutional care. As you also know, however, there is a great deal of concern among both providers and consumers regarding the establishment of alternatives to institutional care that may be no better—or even worse—than the institutions, unless relevant standards are met. The Council, indeed, has seen clear justification for this concern during the surveys it has conducted: residents have been placed in living situations that are even less desirable than the institution from which they came.

For the past two years the Council has been engaged in the development of standards for community agencies serving the retarded. As was the case with the standards for residential facilities, the development of these standards has involved the participation of administrators, practitioners, researchers, and consumers, representing a wide cross-section of the population concerned with programs for the mentally retarded and developmentally disabled. These national standards are currently being field tested by representative agencies, and they are expected to be adopted by the Council and published later this year. With this accomplishment the Council will have made available standards for all facilities and programs serving the retarded and developmentally disabled, and this wider purview and perspective, of course, will enhance the Council's ability to maintain effective standards for each segment of the field.

In the light of the foregoing, the Council suggests that Senator Javits' bill might be strengthened further by adding the following to Section 3:

(4) Add the following paragraph to Sec. 1108, "Alternative Programs of Care," of Title XI of the Public Health Service Act: "Community resources and community living situations for the mentally retarded receiving grants under this section shall comply with the applicable standards established by the national accrediting body for such programs, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals. A program shall be deemed to be in compliance with such standards if it is accredited by the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, provided that the Secretary may cause an independent survey of compliance to be made of any program surveyed by the Accreditation Council whenever he finds such an independent survey to be necessary to validate the findings of the Accreditation Council survey."

This Accreditation Council represents, as you know, a partnership of providers and consumers, brought together for the sole and express purpose of improving services to the mentally retarded. The Council is, of course, highly gratified that its first efforts in this endeavor—its standards for residential facilities for the mentally retarded—have received the acceptance indicated by their incorporation in Senator Javits' bill. The Council trusts that its subsequent and future efforts will be equally successful. Further indication of the Council's success is the fact that for additional national organizations concerned with programs for the retarded and developmentally disabled have applied and been approved for membership in the Council: the American Academy of Pediatrics, American Nurses' Association, American Psychological Association, and National Association of Private Residential Facilities for the Mentally Retarded. The participation of these organizations will, of course, further enhance the Council's ability to serve our mentally retarded citizens.

Sincerely,

KENNETH G. CROSBY, Ed. D.,
Program Director.

Senator JAVITS. Also, I ask unanimous consent that, in order for all to have the benefit of these recommendations, the full text of the letters from which these comments have been prepared and other letters of comment, the full text of the bill, and the section-by-section analysis prepared by the Library of Congress Congressional Research Service be printed in the hearing record.

I recognize the pending Willowbrook suit and the numerous other court cases across the Nation which have put in issue the constitutional right to adequate treatment of high quality and effectiveness. I believe we must finally, at this point in time, accept the responsibility that is ours. Ours, not only as legislators, but as citizens in this country that has at its roots the political doctrine of equal rights for all people.

We must act now to insure these basic human rights to the mentally retarded, and that is why we must enact into law the "bill of rights for the mentally retarded."

I think we have a great responsibility as legislators to accept our responsibility and I deeply believe that the "bill of rights for the mentally retarded," if enacted into law substantially in its present form, will be a great step forward in that regard.

I wish to welcome and thank the witnesses who are going to appear on both of these bills and thank Senator Kennedy for his work in this field. Thank you, Mr. Chairman.

Senator HATHAWAY. At this time, for the record, I would like to mention that Senator Walter Mondale has asked me to express his regret that, due to previous commitments, he is unable to be with us today. However, he wants to emphasize his intention to do everything he can to see that developmental disabilities legislation is enacted into law during this Congress.

Our first witness today is Mrs. Hubert Humphrey, who needs no introduction to anyone on the panel. Mrs. Humphrey's great involvement in and contributions for the improvement of the plight of the mentally retarded is well known.

Ever since it was discovered that the Humphrey's grandchild, Vicki, suffered from Down syndrome, Mrs. Humphrey has missed no opportunity to do whatever she could to help the mentally retarded and other handicapped as well. Through her travels with her husband throughout this country and the world, she has taken the opportunity to study various methods of dealing with those problems and thus has the benefit of firsthand knowledge of the most advanced thinking in the field. In 1966 she was appointed to the President's Committee on Mental Retardation and she has served on the boards of myriad other organizations concerned with the handicapped.

Mrs. Humphrey, we welcome you to the subcommittee.

Senator JAVTTS. I join the chairman in welcoming Mrs. Humphrey to the witness table. She is a very old friend and very well-respected by my wife and myself.

Senator HATHAWAY. You may proceed with your statement, Mrs. Humphrey.

STATEMENT OP MRS. HUBERT H. HUMPHREY

Mrs. HUMPHREY. I am Muriel Humphrey. I also would like to introduce Mr. Albert Saunders to the committee.

Mr. Chairman and members of this subcommittee, I am appearing today not as a representative of any organization or facility but as an individual who is actively involved on behalf of the handicapped, especially those who are mentally retarded.

It behooves the Congress and those of us who are deeply committed in this area to be firm in obtaining the best possible programs—and to seek high goals.

While it is necessary, of course, to be practical, to reevaluate the amount of money which should be spent on programs for the handicapped, we should not pull back from giving the required attention to their pressing needs.

People have high expectations for quality legislation. Senators and Congressmen are aware of this, I know, and I am confident that you will give thoughtful study and scrutiny to the provisions for the handicapped in the two measures now before your subcommittee: S. 427, extending authorizations under the Developmental Disabilities Services and Facilities Construction Act through June 30, 1976, and S. 458, which basically provides for the humane care, treatment, habilitation, and protection of the mentally retarded in residential facilities.

I strongly believe that the enactment of Federal programs on behalf of millions of persons with developmental disabilities is of critical importance today. The time has come to arouse public concern, when the handicapped in this country remain the victims of profound social neglect.

The time has come for the citizens of this great land of opportunity to unite in firm opposition to any regression in national policies and any reduction in Federal assistance that will consign children and youth to live without hope or promise.

The historic legislation enacted over the past decade to protect the health and affirm the human dignity of the mentallly ill, the mentally retarded, and other developmentally disabled must not be undermined in the decade of the 1970's.

However complex and clouded may be the arithmetical comparisons in the proposed budget of the U.S. Government for fiscal 1974, it is at least clear the present administration is not living up to previous commitments made to millions of mentally and physically handicapped Americans.

Overall, Congress is confronted with a budget which projects an increase of almost $19 billion in Federal outlays for fiscal 1974, while still managing to cut $10 billion from social programs designed to help the poor and underprivileged overcome barriers to meaningful participation in American society.

More specifically, the proposed budget for social and rehabilitation services calls for a cutback of almost $10 million in grants for developmental disabilities, and the administration is proposing an immediate recision of almost $43 million from current appropriation levels for social and rehabilitation services.

These actions offer no encouragement that this vital law for the developmentally disabled will ever be given the chance to do the job that is needed.

As you know, the developmentally disabled are the children and adults in our society whose handicaps originate in childhood and continue in some measure throughout life.

The 1970 act purposely establishes a broad definition of developmental disabilities to include victims of mental retardation, cerebral palsy, epilepsy, and similar disabilities attributable to neurological impairments.

Such neurological handicapped conditions could very well include autism, learning disabilities, dyslexia, spina bifida, childhood schizophrenia, and minimal cerebral dysfunction.

Yet the Department of Health, Education, and Welfare continues to apply the narrowest possible definition under regulations imple-

mentmg the 1970 act—which, in the end, simply comes down to still another means of keeping appropriations limited, by ignoring the scope of the problem to be addressed.

Several harsh examples of proposed cutbacks in funds for the physically and mentally handicapped can be cited to illustrate the scope of regressive measures planned in this area under the Federal budget for fiscal 1974:

No new starts in the construction of community health centers would be authorized for the next fiscal year.

Funds for staff at the existing 515 community health centers would be reduced by $10 million.

Programs for the mental health of children would be cut from $10 million to $8.4 million.

Under the proposed programs of education revenue sharing, funds for the education of the handicapped will be reduced, along with other programs directed at special needs—such as basic school lunch, vocational and adult education, and elementary and secondary education.

The Institute of Dental Health faced a recision of $3.7 million in appropriations for fiscal 1973 and a decline of some $6 million from the present funding level in fiscal 1974.

The National Institute of Child Health and Development will face a similar sharp decline in funding authority, both for the remaining months of the current fiscal year and a cutback of some $20 million in fiscal 1974.

The time has come to call a halt in this retreat from national responsibility. We must maintain programs on behalf of the developmental disabled and insist upon funding these programs at the full level of authorizations.

Residential facilities for the mentally retarded represent a major area for decisive national action without further delay. And it is clear that S. 458, introduced by Senator Javits and jointly sponsored by Senators Kennedy, Williams, Humphrey, and others, marks a major initiative in addressing these critical needs.

The legislation calls for residential facilities that are humane and safe; that provide for basic human needs; and that are community oriented.

Certain facts must be reiterated to emphasize the importance of this legislation. Some 275,000 mentally retarded persons in this country live in public and private residential facilities. For some it is their only home for most of their lives.

But too often in the past these facilities have been constructed to isolate, rather than to integrate these people into our communities. They were simply repositories for human beings, offering little or no opportunity to learn the skills or patterns of living which would equip them to live outside the institution.

Also, let us not forget that the President's Committee on Mental Retardation—on which I was privileged to serve—reported in 1968 that "The average age of institutions is 44 years old. Some have reached the century mark. At least 50 percent are functionally inadequate for the care, growth, learning and rehabilitation programs that can be successfully carried out with the retarded."

The number of institutions have increased 76 percent over the past decade—to 190 in 1970. Over the same period the average daily cost per resident went from $4.25 to $11.65—a 174-percent increase.

Let us not overlook the fact, however, that the largest portion of staff costs are for attendants, matrons and maintenance employees. Only about 11 percent of the 117,327 fulltime personnel at public institutions in 1970 were teachers and nurses.

And it is further discouraging to note that psychiatrists, psychologists, and social workers make up less than 2 percent of this force. Simultaneously, there has been an extremely high rate of turnover in personnel, primarily because of low wages.

The result has been the dehumanizing conditions given press attention last year at such institutions as the Willowbrook State School in New York and at Rosewood State Hospital in Maryland.

Meanwhile, we have received the shocking report from the American Psychiatric Association that the number of children in State and county mental health hospitals has doubled since 1963, to 55,000.

These harsh statistics ought to shock this Nation into action. Something is profoundly wrong, when an affluent and supposedly compassionate society allows thousands upon thousands of people to be shut away, forgotten, left simply to exist. Yet, with comprehensive care services and intensive habilitation a substantial majority could be enabled to participate in society.

At least one-third of the 6 million persons who are retarded today are capable of earning a living and being self-supporting, productive members of the community if adequate training and residential facilities are provided for them. It is time to cease talking about what the retarded cannot do and concentrate on what they can do.

Over the years that I have worked on behalf of the retarded, it has been my great privilege to visit programs for the retarded in every State in our Nation and many in other countries.

This past December, I visited a school in Moscow for retarded children—one of a number of daytime and boarding schools for handicapped children maintained by the Soviet Union. This was a boarding school for 150 children, described by the principal as having "weak and strong manifestations of mental retardation."

The children, aged 7 to 16, attend the first through the eighth grades at this school. There are 15 children per class. And there is special emphasis given to occupational training, a common feature of such schools. The staff included a psychiatrist, a psychiatric nurse, and 30 specially trained teachers and instructors.

I was informed that all newborn children in the Soviet Union are examined at birth and 18 times in the first year—and that further medical examinations are conducted if there are signs of developmental disabilities. Then, if so, the child may be sent to a special school, such as the one I was visiting.

Later, in a visit to a Moscow kindergarten for retarded children, I noted clean and brightly colored rooms, full of toys and with various activity centers. I was informed that much attention is given to the environmental conditions of the child as an important part of his development.

At the kindergarten there was a music room, a gym, a physical therapy room, and a good sized play yard, where the children have their

own vegetable garden. Complete laundry and kitchen facilities are also on the premises.

The emphasis in the Soviet Union upon the maximum habilitation of retarded, children was strongly impressed upon me in a subsequent visit to the Institute of Defectology in Moscow, which has achieved great progress in the establishment of special schools and the provision of carefully designed curriculums for retarded children by the Ministry of Education.

I could cite many similar observations from visits to schools, workshops and hospitals for retarded children in Warsaw. But the predominant impression I carried away was the substance of a conversation with Mrs. Ewa Garlicka, of the Polish Association for the Mentally Handicapped.

Mrs. Garlicka told me that 10 years ago there were no schools in Poland for the severely retarded child. Now there are state schools for mildly, moderately and severely retarded which begin with the lower grades. There are also cooperatives organized by the handicapped for the handicapped.

There are voluntary parent groups through which knowledge is gleaned about their children's problems and education. And teachers in Poland—as well as in Russia—are paid more to work with retarded children. In Russia, it is 25 percent more; in Poland, 10 to 15 percent more salary than other teachers receive.

I cannot help but be struck by the contrast in priorities given to assisting the developmentally disabled in Moscow and Warsaw—and what I confront in Washington today.

No one knows better than I that "the fight against retardation and other developmental disabilities will not be won in Washington. This day-to-day battle will be waged, as always, on the local front.

But these forces need logistical support. They need effective Federal assistance. They need to see a demonstrated commitment in Washington to establishing programs for the developmentally disabled on a sustained basis, effectively coordinated at all levels and truly comprehensive. And they need major new initiatives for the present decade launched under Federal legislation.

But most of all the people across America, who are committed to helping children and adults with developmental disabilities know a better and fuller life, need leadership.

They need the leadership which only this Congress can provide—in firmly establishing the rights of millions of handicapped Americans to decency and to hope in the future.

Thank you, Mr. Chairman.

Senator HATHAWAY. Thank you for your very impressive testimony. I was particularly impressed by some of the statistics you cited, such as the 18 examinations given to Russian children in their first year of life. Many of our children don't get that many examinations in 18 years of life.

Mr. HUMPHREY. I know. I was very impressed by the prenatal treatment given to mothers, by how many times and in what different ways they are examined. There is complete prenatal care and followup with the mother and nutritional care for the child. That was a very brief sentence I had in my statement, but I was impressed by the amount

of care given for prevention as well as teaching and rehabilitating all children, but especially the retarded.

Senator JAVTTS. I would like to address this question to Mrs. Humphrey and the other witnesses who will appear this morning.

We have a major emergency in the strike on the Penn Central and I am called to the floor now for a special committee meeting. However, I would first like to express my regrets for this morning but that I will preside for these hearings this afternoon and stay as late as it takes to hear the last witness.

I have just one question. Do you think—if you are prepared to answer it, if not, we will take your answer in writing later—that the provisions of the "Bill of Eights for the Mentally Retarded" can be and should be implemented and extended to other developmentally disabled? In other words, should they, too, have the protection of a basic rights structure?

Mrs. HUMPHREY. This bill is something that I have longed to see passed. Over my years of work in this field and through my many visits to facilities around the country, I find that the standards set in this bill are excellent. I am proud to support it. I understand there are some difficulties, that perhaps it is too detailed, but I don't want to get into that.

As far as its overall goals and standards I do think they should be set for other facilities, especially residential facilities for the other disabled.

Senator JAVITS. Thank you so much, Mrs. Humphrey.

Mrs. HUMPHREY. Thank you, Senator.

Senator HATHAWAY. I would like to ask you a few questions.

You visited a great many facilities for the retarded, including, I presume, many residential facilities. I wonder if you could tell us over the period of time that you have been active in this field, whether or not you have noticed anv improvement in the care that is being given throughout the United States?

Mrs. HUMPHREY. Yes, I have Senator Hathaway. It is always hard to generalize in our country—it is so big—each of the States in its philosophy and care influences the type of programs which are operating in its jurisdiction. Sometimes, we have made great progress in the programs, only to have a legislator cut back on a budget in the State. I am thinking particularly of our own State of Minnesota, which cut back on personnel. This had a devastating effect to the programs that were underway and had a tremendous negative effect on these problems—economic as well as human—one that will probably be irreparable for several years.

It is hard, once a program of this sort is started, to cut back. It should be maintained because a cutback like this is costly.

Senator HATHAWAY. It is regrettable that those who can't lobby on their own don't fare as well before either the Federal legislature or the State legislatures. Hopefully, we can do something about that here, through this vehicle.

I take it that you are pretty enthusiastic about the present emphasis on community-oriented facilities for the mentally retarded?

Mrs. HUMPHREY. Yes, I am.

Senator HATHAWAY. Are they working pretty well, from your observation?

Mrs. HUMPHREY. I think all of the States across the country have established new facilities in day-care centers as well as special education classes. I know that a great many of the private institutions and private day-care center facilities have been aided in recent years. This will eventually result in the lowering of the number of people who are being assigned to State institutions and public institutions, so that these programs in the small towns, the community areas and in the cities, will cost less in the long run.

Senator HATHAWAY. Do you find any problems with public attitudes toward the retarded?

Mrs. HUMPHREY. There are still some, but it is hard to pinpoint them. Some of them are just there. You sense them and you have to work with them. I found one that was quite devastating to my knowledge. I thought that, of course, in the special education classes we would have the best *of* teachers. However, I find that in my visits, sometimes the special education classes are having to accept the teacher who can't seem to find a place anywhere else. They can't seem to find a place for them to be put.

Actually, the whole program suffers when this happens. The public school program and the special children who need this special education all suffer. The children, themselves, suffer the most.

Senator HATHAWAY. I suppose in some areas there is public resentment toward mixing these children with the other children in the school?

Mrs. HUMPHREY. Yes, indeed. They really should be able to live in an apartment or in a residential home, where there are other community facilities available to them. We have found that when they are first placed in a residential area, they are looked down upon. As a matter of fact, there have been all kinds of problems with zoning.

Sometimes it has taken time to increase public awareness and change public attitudes toward these people. As soon as a facility is settled in a residential area, they become fully accepted and the neighborhood becomes very proud of them.

I think these two problems have devastating effects on the retarded and the parents of the retarded.

When we talk about the retarded, I think, we often refer only to the individual who is being helped by funding. However, we must remember that when we help a disabled person, we help not only that person but his family as well. So that if we help say an estimate of 5.5 million to 6 million retarded individuals we are probably helping 20 million people in our country.

Senator HATHAWAY. How about the problem of the availability of supportive services, such as recreational facilities?

Mrs. HUMPHREY. I think we are doing a great deal more in this field. I think the special olympics, which were supported by the Kennedy Foundation and the Kennedy family, have helped a great deal. I am a strong supporter of this type of activity because when we upgrade the activity of these young people and adults, they are able to do more, and this activates them tremendously.

Senator HATHAWAY. I have witnessed them. It is a heartening experience to see these people performing.

How about in the employment field? Do you find that employers are more willing to take on children who have disabilities?

Mrs. HUMPHREY. Yes, we have progressed a great deal in this area. I think it is well to remember, though, that there is always the danger that the first person to be laid off will be a retarded person, regardless of his comparative abilities in his job area. The difficulty here is that quite often, these are the people who can't pull themselves up by their own bootstraps. They need our help.

Senator HATHAWAY. YOU mentioned programs in Russia and Poland. Is there any country that is outstanding in this area?

Mrs. HUMPHREY. I hate to generalize about these countries because I only saw a few facilities and there is always difficulty in interpretation. However, in reading and discussing these problems with some of the members of the Institute of Defectology in the U.S.S.R., I was most impressed with their programs and with the unique constant care that they have. In Poland, there was a more relaxed atmosphere, but with equally good programs. I still think we would probably have to go back to the Scandinavian countries of Denmark, Norway, and Sweden for the greatest examples of care in this field.

Senator HATHAWAY. Thank you very much, Mrs. Humphrey. We have greatly appreciated your testimony.

Mrs. HUMPHREY. I have appreciated being here.

Senator HATHAWAY. The administration has refused to send any witnesses up to testify today. Therefore, our next witness will be Mrs. Elizabeth Boggs, who is the chairman of the National Advisory Council on Services and Facilities for the Developmentally Disabled.

Mrs. Boggs, we welcome you here this morning. I understand that you have been an advocate for the handicapped for nearly a quarter of a century.

In 1958, President Eisenhower appointed Mrs. Boggs to the President's National Committee for the 1960 White House Conference on Children and Youth. In 1961, she was appointed by President Kennedy to the President's Panel on Mental Retardation. During the Johnson administration, she was appointed and served as a member of the National Advisory Child Health and Human Development Council.

In addition to her present services as Chairman of the National Advisory Council on Services and Facilities for the Developmentally Disabled, she is presently vice chairman of the New Jersey Developmental Disabilities Council.

Mrs. Boggs, I welcome you to the subcommittee and would appreciate hearing your testimony.

Mrs. BOGGS. Thank you very much, Mr. Chairman. When I think back over the 25 years that you have mentioned, and as I look forward to another 25 years of what we hope will be rapid change, I am reminded of the passage in President Kennedy's inaugural address in which he spoke of "the long twilight struggle against the common enemies of man," against disease, hunger, and death itself. I think if the well-rounded cadences which characterized his address had permitted inclusion of developmental disabilities among these common enemies of man, it would also have been very apt.

There are many people in this room who know this problem very intimately and know that it is indeed a long, continuing, lifetime struggle. So also is the struggle to attain social justice and recognition for a group whose members, as you, yourself have said, have little chance to speak on their own behalf.

Senator HATHAWAY. I would like to welcome the chairman of the Subcommittee on Health to the hearing.

Senator KENNEDY (presiding pro tempore). I have just extended my apologies to Mrs. Humphrey for failing to hear her testimony. I think all of us who are interested in the field of retardation know of her tremendous interest in, dedication to, and understanding of the issue. She has been one of the greatest activists in this area, and I look forward to reading her testimony with great interest.

Elizabeth Boggs, with whom we have worked, has also been one of the great leaders in the area of developmental disabilities. I want to join in welcoming her here.

STATEMENT OF ELIZABETH M. BOGGS, CHAIRMAN, NATIONAL ADVISORY COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

Mrs. BOGGS. I am delighted to appear before you as chairman of the. National Advisory Council on Services and Facilities for the Developmentally Disabled, a council which was created by the 1970 act. I am happy, also, to know that one other among the 15 remaining members of our council, Mr. Dennis Haggerty, is to appear later as a witness.

Mr. Haggerty is an attorney who has been outstanding in his championship of the rights of the retarded in the legal field and in other fields as well.

I am here at the invitation of the committee and I am happy to account to you for the activities of the council.

The National Advisory Council was first authorized by the legislation in 1970. However, the legislation called for the establishment of the council on July 1, 1971. The first meeting of the Council was held barely a year ago.

I have submitted formal testimony, which I hope you will enter into the record. I know that there are many witnesses remaining to be heard and I will therefore make only a very brief statement.

Senator KENNEDY. Without objection, your full statement will be entered into the record at the conclusion of your testimony.

Mrs. BOGGS The act laid several responsibilities on the council which we have done our best to discharge in the relatively brief time we have had to work. In addition to that, the secretary invited us to advise him concerning extension of the act.

The council is governed by the Federal Advisory Committee Act in addition to the Development Mental Disabilities Act. Our proceedings are open to the public and the actions and advice that we give is also a matter of public record.

I want to make it clear that we advise and the Secretary disposes and that nothing I say should be in any way construed as reflecting the administration's position, officially or unofficially.

We have had quite a busy time and we have considered the functioning of the act. We are very well aware that many things are not going as smoothly as we might have hoped and wished, but we are also aware that some of these very rough spots are indicative of the dynamic character of the legislation and the appropriate involvement of many people in its implementation.

There was a report, recently, by a psychologist who did a study on characteristics of people who are successful in effecting changes in mental institutions. He found they were persistent and tolerant of confusion. I think those caracteristics must also characterize the many people who are now engaged in implementing change on all fronts for the develomentally disabled.

We made a number of specific recommendations on the extension of the act that have been before you and the public and are set forth in my statement. I don't propose to enumerate them, but I would be very happy to answer questions concerning the position of the Council.

Senator KENNEDY. The recommendations have been made a part of the record. Let me ask you a few questions. Mrs. Boggs, what were the consequences of delaying your appointment and those of the other members of the council?

Mrs. BOGGS. I think that one of the indirect consequences was that the Governors, not seeing a national model, often dallied in appointing the State councils. Since they should have been appointed at the earliest opportunity, the delay of more than a year in our getting underway did have a psychological deterrent effect.

The second consequence was that we were not drawn into session for the first time until after the major regulations; namely those affecting the State programs, had already been published. We had a relatively late input and a relatively short time in which to acquaint ourselves with the problems and carry out our responsibility to advise the Secretary.

Senator KENNEDY. If the charter is renewed, do you think speedier appointments would be advisable?

Mrs. BOGGS. Yes, but I think it raises a question that has to be considered by the Congress, because the charter renewal phenomenon is something that the Department is ascribing to the Federal Advisory Committee Act, which was enacted into law last fall and which has only recently become operative. Our Council held our first meeting under this act only last week. We have been advised that no advisory council continues for more than 2 years (even though it is created by statute with the intent that it be a continuing body), unless its charter is specifically renewed before the expiration of the 2-year term. We are looking for clarification of this.

Senator KENNEDY. Would you eliminate this provision for renewal of the charter every 2 years from the law?

Mrs. BOGGS. I, personally, feel that when the Congress creates an advisory council to be associated with what appears to be ongoing legislation and intends that body to have continuity, it should be sure that it does not pass a subsequent piece of legislation which denies that intent.

I think this is a technical question that should be addressed in the Federal Advisory Committee Act.

Senator KENNEDY. It would certainly have an adverse effect upon the program if it is allowed to lapse?

Mrs. BOGGS. I would think so. Our Council, in spite of its short life, has developed a strong sense of purpose and an intent to be as helpful as possible in maintaining momentum for this legislation. Should our Council go out of existence or be held in a state of un-

certainty or limbo for a period of weeks or months, I think this would operate adversely on the perception of the program.

Senator KENNEDY. I presume that you would like to obtain additional funds. Should you be able to do so, what would you recommended to be done with these funds?

Mrs. BOGGS. One of the difficulties we have had with this act is that the need is so tremendously more than the act contemplates; hence it is difficult to narrow the focus of the funds that are actually appropriated. Even the funds that are authorized are inadequate to the unmet need.

Let me give you one more example. We have spoken of this legislation as being interstitial—as filling gaps in between other Feedral programs. There is a clause in the bill which is essentially an automatic nonduplication clause. If you can do it someplace else, you don't do it here. There are many ways in which the small amounts of money in this legislation could be used to facilitate other services paid for out of other funds.

However, there are certain substantial areas of service which are important if we want to "deinstitutionalize" and for which the gaps to be filled are still quite large. An example of this is the adult activities center, a day program for severally handicapped adults who are not suited to the production-type workshop. There has recently been a study done of the rapid growth of these activity centers; in 1971 there were about 700 of them, which represented a tenfold increase over 7 years. The State that has the largest number of these centers is Minnesota. There are 84 of them in Minnesota. I did a little calculation and if the rest of the States were to do as well as Minnesota, it would cost about $250 million simply to have that one type of service in place throughout the country. That is, $250 million for one presently scarce component of the service system; by comparison we are getting $19 million allotted among all the States under the present DD formula. This is, perhaps, some indication of the need.

I also did a little quick calculation relative to the figures you gave in your opening statement about the numbers that are served. I figured that of those who are now getting some direct service under the act, the average annual per capita cost (Federal portion) is running about $200 or something of that order, which is less than we spend on people served under the Vocational Rehabilitation Act. Thus the small number served is a direct consequence of the small amount of money made available.

Now, I don't want to be caught playing the numbers game/because you can talk about taking a person on one bus ride one afternoon and call that a service and count it the same as getting someone to work every day, 5 days a week for a year. Sometimes, we play games of this kind. If we are going to have quality services, we have to be able to spend a substantial amount on each person.

Senator KENNEDY. HOW much should be spent per capita?

Mrs. BOGGS. I would prefer not to answer your question in such a broad global way, because the more severely handicapped a person is, the larger the per capita cost is likely to be in providing adequately for him, but needs vary. I just gave the example to identify what

"persons served" may mean. This could be anything from a week at camp to a year in a sheltered workshop.

We have a great variety of people with a great variety of needs slotted in under this act. The full burden of the cost of a comprehensive program for an individual should not and need not fall just on this act. It must be made up of a package of social services, education or whatever is applicable. This can be anything from a few hundreds to tens of thousands per person per year.

Senator KENNEDY. Mrs. Boggs, you mention in your statement that you made several recommendations to the administration with respect to this legislation. Have you had any response from them?

Mrs. BOGGS. I have had the opportunity to discuss the recommendations with Mr. Kurzman and others in the administration. It should be noted and it is a matter of record that, in a very difficult budget year, the administration has held in the 1974 budget the same amount for 1974 as was requested for this act in 1973. This signals to me an intent that the act be extended. I think that I can say without abusing any confidences that the administration will support renewal.

I would like to add that my associations with people in the administration around this act have been very affirmative. However, I feel that it is incumbent on the administration to speak for itself.

Senator KENNEDY. HOW many of the Council members are parents of developmentally handicapped children?

Mrs. BOGGS. There are three that I know of, including myself. I have never really asked all the members what their particular line of entry into this field of endeavor was. I do know the professional backgrounds of those who are professionally involved, and those are indicated in the sheets that I submitted to you as attachments to the prepared statement. You will see they are varied.

Senator KENNEDY. Thank you, Mrs. Boggs.

Mrs. BOGGS. Thank, you Senator.

[The prepared statement of Mrs. Boggs and other information sub-

STATEMENT

ON EXTENSION OF THE

DEVELOPMENTAL DISABILITIES SERVICES AND

FACILITIES CONSTRUCTION ACT

by

Elizabeth M. Boggs, chairman

National Advisory Council on Services and

Facilities for the Developmentally Disabled

before

Sub Committee on the Handicapped

Senate Committee on Labor & Public Welfare

February 8, 1973

As Chairman of the National Advisory Council on Services and Facilities for the Developmentally Disabled, I am happy to accept the invitation of this Committee to participate in this hearing and to account to you for the activities of the Council as created by the Congress.

History

The NACDD was first authorized on October 30, 1970, by P.L. 91-517. Antecedent legislation contained no such provision, although state level advisory councils were provided for in Title I of P.L. 88-164 relative to the construction of mental retardation facilities. The Developmental Disabilities Act specified July 1, 1971, for the establishment of the NAC and the Secretary did issue, at that time, an order establishing the Council; no members were appointed, however, until October 1971; the Council's first meeting was held in January 1972, barely more than a year ago.

Since then we have held three more meetings and convened a national conference of state council members and their staffs and state administering agency staff. Our meetings are open to the public. Our records are maintained for inspection by the public in Room 3062 of the Mary E. Switzer Memorial Building. The Council meeting of February 2nd thru the 3rd, 1973, was our first under the Federal Advisory Committee Act (P.L. 92-463).

Mr. Francis X. Lynch, a regular federal employee, is our Executive Secretary, More importantly, he is Director of the Division of Developmental Disabilities in the Rehabilitation Services Administration; the Division is charged with the administration of the Developmental Disabilities Act, the subject of today's hearings. Mr. Lynch was appointed to this post in the Spring of 1971.

Federal Advisory Committee Act

Under the Federal Advisory Committee Act, each advisory council is required to have a charter. A copy of our charter is attached. You will note that even though the NACDD was created by statue, it cannot function unless chartered by the Secretary and that it is subject to renewal of charter every two years. The renewal date in our case is July 1, 1973, since this is two years from the official date of our establishment. It appears from the charter that, should the charter be allowed to lapse at that time, all appointments to the Council would become void.

Composition of NACDD

The DDSA (Section 133) calls for twenty members appointed for four year staggered terms. The terms have been established as ending on December 31st of each year, I am attaching a list of the members initally appointed with brief biographical material, as originally prepared for the HEW publication. Programs for the Handicapped, December 31, 1971, # 71-10. Since original appointment. Dr. Bransford has moved to Denver, where he serves as Component Director for the Utilization and Research Component to the Federation of Rocky Mountain States, and Mrs. Hamilton has moved to Houston. Otherwise, our geographical distribution remains unchanged. Five of our original appointees have already rotated off after one year and have not been replaced. They served with vigor and effectiveness and we hope to continue to engage them in, our work.

You will note that a variety of interests and professional skills are represented on the Council. These include consumers, state agencies, voluntary agencies, universities, and a range of relevant professions. Since 1971, several of our members have been appointed by their respective governors to the advisory councils at the state level; three have been assigned state level administrative responsibilities under the Act. Incidentally, the three states involved, Massachusetts, South Carolina and Wisconsin, have very different structures, all of them effective, which demonstrates to me the: value of pluralism and the importance of leaving open administrative options at the state level, a principle which your Committee wisely built into the original 1970 Act.

We have had an excellent attendance record at regular Council meetings. In addition. Council members have addressed themselves conscientiously to the work of special committees which we found necessary. Among our sub-committees are the Committee on the Future of the University Affiliated Facilities <Part B of the Act), a Committee on Standards, a Committee on Evaluation, and a Committee on Technical Assistance to the State Councils.

Duties of the Council

The functions of the Council as prescribed by law are specified in the Charter and in Section 133(c) of the Act: to advise the Secretary on regulations and to determine the effectiveness of the programs authorized in accomplishing the purposes of the Act. In addition, in July 1972, Secretary Richardson asked us to advise him on extension of the Act.

With respect to regulations, the Council has done its job, I believe. We responded to "proposed rule making" on Part c (state formula grants) in January 1972, and reviewed our own and the public's responses in

April 1972. Much of our advice was accepted. The opportunity for a group Of knowledgeable people outside of the federal government to review together the problems and alternative solutions has demonstrated value, in my opinion. The final regulations for Part C were issued in September 1972, to take effect in December. This action followed enactment of the bill by two years; by federal standards this is speedy action. At our most recent meeting we considered the possible impact of the recently issued OMB Circular 102.

With respect to regulations for the new authority (demonstration and training) in Part B - University Affiliated Facilities, we were able to have earlier input, i.e., prior to publication of proposed rules. Proposed rules were issued in September. We considered the public's comments in November. The draft for final regulations is now in the Office of General Counsel HEW.

With respect to impact evaluation, a year has proved too short a time to develop formal evaluation strategies. Some specific evaluation projects have been funded. Our Council is of the opinion that resources within the Department are not optimally structured or supported to achieve, the kinds of evaluation we need. If the Council is permitted to continue its work, we hope to develop some more valid longer range strategies, as well as better indicators.

In this connection, I would like to mention affirmatively the cooperation we have recently received from the Office of the Assistant Secretary for Planning and Evaluation. In addition to the. indices developed in their quick study, there are many informal and anecdotal indications that the impact of the Act is already far reaching, in proportion to its dollar size. The very fact that this Committee will hear pleas from additional constituencies desiring to participate in the processes and benefits of the Act stands as testimony to positive perceptions of it. More broadly, we consider that the Developmental Disabilities Act is very well designed to support the HEW departmental goals of non-dependency and service integration. For the record you will find attached abstracts from the SRS Five Year Plan for 1974-78 (DHEW Publication #(SRS) 73-25200.) DDSA can complement the various health, education and rehabilitation programs so insightfully developed by this Committee in other bills', and enhance their delivery to the developmentally disabled who are so often the last to benefit.

Many states are undertaking new and creative approaches or firming up those for which only pilot programs have been in place to date. No state has a monopoly on good ideas and practices. One of the most important functions which the Division can perform, with the support

and participation of the Council, is to facilitate communication, among the states, of good models. Several activities promoted by the Council and the Division are already contributing to this end. These include the National Conference held last November, a technical assistance project funded at the University of North Carolina, the dissemination grant made to the National Association of Coordinators of State Programs for the Mentally Retarded (most of whom also have responsibility for new Developmental Disabilities programs). In short, our Council is of the opinion that evaluation without action is sterile, and we intend to maintain continuous feed-back as part of our contribution to achieving the purposes of the Act.

An essential ingredient in communication is the HEW Regional Office. Most Regional Commissioners have designated one or two staff members to carry prime responsibility for providing consultation to State Developmental Disabilities staffs and councils, and the zeal of these men and women has been much appreciated.

Extension of the Legislation

With respect to advising on legislation to extend the Act, the Council responded to the Secretary's request. The resulting material is in no way binding on the Secretary, but it is in the public domain. A copy is attached. We recommend extension of the Act for five years, with some modifications which I will be glad to discuss with you. At the time our recommendations were drawn up, we were not privy to the position of the Administration. We are indeed heartened that the President's budget anticipates extension of the Act; we hope this presages prompt action in both Houses. This new program requires continuity and deserves affirmation now.

Attachments: Council Charter
List of Members
Advice to the Secretary on Extension of Legislation
SRS Five Year Plan

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

C H A R T E R

NATIONAL ADVISORY COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

Purpose

The Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517) is designed to provide the States with broad responsibility for planning and implementing a comprehensive program of services and construction of facilities for persons affected by mental retardation, cerabral palsy, epilepsy, and other developmental disabilities originating before age 18 and constituting a substantial handicap for such individuals. It is designed to assist the States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs. Federal aid is authorized to support diagnosis, evaluation, treatment, personal care and other specialized services and to construct facilities to house these services. The Act gives States and local communities a strong voice in determining needs, establishing priorities and developing a system for delivering services to the developmentally disabled. The Council will assist the Secretary in the discharge of his responsibilities by advising him on regulations and by studying and evaluating programs to determine their effectiveness.

Authority

42 U.S.C. 2673. The council is governed by provisions of Executive Order 11671 which sets forth standards for the formation and use of advisory committees.

Function

Advises the Secretary, or his designee, with respect to any regulations promulgated or proposed to be promulgated by him in the implementation of Title I of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, as amended. Studies and evaluates programs authorized by such title with a view to determining their effectiveness in carrying out the purposes for which they were established.

Structure

The Council consists of twenty members, including the chairman, not otherwise in the regular full-time employ of the United States. The members are selected by the Secretary from among leaders in the fields of service to the mentally retarded and other persons with developmental

disabilities, including leaders in State or local government, in institutions of higher education, and in organizations representing consumers of such services. At least five members shall be representative of State or local public or non-profit private agencies responsible for services to persons with developmental disabilities, and at least five shall be representative of the interests of consumers of such services.

Members are invited to serve for overlapping 4-year terms; terms of more than two years are contingent upon the renewal of the Council by appropriate action prior to its expiration.

Management and staff services are provided by the Director of the Division of Developmental Disabilities, who serves as Executive Secretary.

Meetings

Meetings are held three times a year at the call of the chairman, with the advance approval of a government official who also approves the agenda. A government official is present at all meetings.

Meetings are open to the public except as determined otherwise by the Secretary; notice of all meetings is given to the public.

Meetings are conducted, and records of the proceedings kept, as required by applicable laws and Department regulations.

Compensation

Members who are not full-time Federal employees are paid at the rate of $100.00 per day, plus per diem and travel expenses in accordance with Standard Government Travel Regulations.

Annual Cost Estimate

Estimated annual cost for operating the committee, including compensation and travel expenses for members but excluding staff support, is $28,500. Estimate of annual manyears of staff support required is 1.3, at an estimated annual cost of $14,750.

Reports

An annual report is submitted to the Secretary through the Administrator, Social and Rehabilitation Service, not later than December 31 of each year, which shall contain as a minimum a list of members and their business addresses, the dates and places of meetings, and a summary of committee activities and recommendations made during the fiscal year. A copy of the report is provided to the Department Committee Management Officer.

Termination Date

Unless renewed by appropriate action prior to its expiration) the National Advisory Council on Services and Facilities for the Developmentally Disabled will terminate on July 1, 1973.

APPROVED:

JAN 1973
Date

Elliot L. Richardson
Secretary

MEMBERS OF THE NATIONAL ADVISORY COUNCIL
ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

Chairman

Elizabeth M. Boggs (Mrs. Fitzhugh W.) of Hasp top., View Jersey, received her Bachelor's Degree from Bryn Mawr College summa cum laude, and her Ph.D. from Cambridge University, England.

Her activities on behalf of exceptional children are numerous and include Past-Presidency of NARC of which she participated in the founding, Past-Presidency of the New Jersey Association for Retarded Children, memberships in Pennsylvania Advisory Council on Construction of Mental Retardation Facilities, President's Panel on Mental Retardation, United Cerebral Palsy of Pennsylvania, Council for Exceptional Childran, and the Governor's Advisory Council on Life-Time Disability (N.J.)

Among her awards are the 50th Anniversary of Rehabilitation Medallion (RSA), and the Kennedy International Award for Outstanding Leadership in Mental Retardation. 1974

Executive Secretary

Francis X. Lynch is the Director of the Division of Developmental Disabilities, Rehabilitation Services Administration, Social and Rehabilitation Service, Department of Health, Education, and Welfare, Washington, D.C. He was formerly Deputy Executive Director of the President's Committee on Mental Retardation. Prior to his work there, he was Supervisor of Special Education for the Quincy, Massachusetts public schools, and Executive Director of the Pennsylvania Association for Retarded Children.

He holds a Master's Degree in Special Education from State College, Boston, Massachusetts.

Charles D. Barnett, Ph.D., is Commissioner of the South Carolina Department of Mental Retardation in Columbia, South Carolina.

Dr. Barnett received his Ph.D. degree in psychology from George Peabody College for Teachers. Besides having university teaching experience, he served in State Schools for the Mentally Retarded in Louisiana and Texas, as psychological consultant to several organizations, and from 1965-1959 as Deputy Cormissioner of Mental Retardation.

He has or now holds offices in the American Association on Mental Deficiency, the National Association of Coordinators of State Programs for the Mentally Retarded, the United Cerebral Palsy Association of Texas, and the Council for Exceptional Children of Texas. He is the author or co-author of numerous publications. 1973

Jill D. Beckman, LL.B., is Commissioner, South Carolina Vocational Rehabilitation Department, Columbia, South Carolina.

Dr. Beckman was graduated from Presbyterian and Wofford Colleges and also has an honorary LL.D. from Presbyterian College. After a stint in education he entered the rehabilitation field.

He is a member of the South Carolina Rehabilitation Association, the National Rehabilitation Counseling Association, the Council of State Administrators of Vocational Rehabilitation, Mid-Carolina Retarded Association and Advisory Council, the Easter Seal Society for Crippled Children and Adults of South Carolina, Inc., and a member and past-president of the National Rehabilitation Association. He is currently Chairman of the Governor's Committee on Employment of the Handicapped. 1975

Louis A. Bransford, Ed.D., is Associate Professor of Guidance and Special Education at the University of New Mexico, Albuquerque, New Mexico.

Mr. Bransford holds degrees from the College of Santa Fe and Colorado State College. He began his "teaching experience as a teacher of the mentally retarded, moved on to teach adult migrant workers, than on to university teaching at Colorado State College and the University of New Mexico.

He has been a leader in work with Mexican-Americans and Indians, with the Head Start, Upward Bound, and Child Advocacy programs, and it; developing special education materials and evaluating projects.

Besides serving as a consultant to the president's Committee on Mental Retardation and several agencies within DHEW, his work has taken him to Japan, Hawaii, and Columbia 1973

Dale McCoy Engstrom, Lt. Col., U.S. Army (Ret.) C.L.U., is a member of the House of Representatives, State of Tennessee, Nashville, Tennessee.

Representative Engstrom attended the University of Wisconsin and several schools for officers in the U.S. Army. Besides being a Certified Life Underwriter and commercial pilot, he found time to he President of the Board of Directors of United Cerebral Palsy of Greater Chattanooga, and is now a member of the Board of Directors of United Cerebral Palsy of Tennessee, and is on the Governor's Advisory Council on Mental Retardation. 1974

Doris S. Fraser, Ph.D., is Director of the Bureau of Developmental Disabilities, State Executive Office for Administration and Finance, Boston, Massachusetts.

Miss Fraser attended McGill University, the Boston University School of Social Work, and received her Ph.D. from Brandais University. She has been in State Government since September 1967. Prior to entering public service, she was coordinator of the Massachusetts Mental Retardation Planning Project.

She is a member of the Academy of Certified Social Workers and the National Association of Social Workers. For her work in special education, mental health, and mental retardation, she has been honored by the Governor General of Canada, the National Association of Mental Health, and the Massachusetts Association for Retarded Children. 1972

Leonard J. Ganser, M.D., is Administrator of the Division of Mental Hygiene, Wisconsin Department of Health and Social Services.

Or. Ganser received his medical training at the University of Wisconsin Medical School, and received his Diplomate from the American Board of Psychiatry and Neurology.

He is a Fellow of the American Psychiatric Association, Past-President of the Wisconsin psychiatric Association and National Association of State Mental Health Program Directors. He is also a member of the Association for Retarded Children, and on the Board of Directors of the Wisconsin Epilepsy Association. 1974

Virginia Could (Mrs. R. B.) of Camarillo, California.

Mrs. Gould attended several universities, and holds a life teaching certificate from the State of Colorado. She was Director, Assistance League School for Child Development for nine years. She is a consultant on curriculum to the Hospital Improvement Project at Pacific State Hospital in Pomona, California. 1973

George V. Gray, American Institute of Architects, of Watervliet, New York.

Mr. Gray is Director of Mental Hygiene Facilities Planning for the State of New York. A graduate of Reusselaer Polytechnic Institute in architecture, he later taught architecture and still later was the recipient of a Millbank Fellowship to study European mental health and mental retardation facilities and programs. At present he is a doctoral candidate at Colombia University.

His interest in handicapping conditions is reflected in his activities in many associations concerned with mental retardation, cerebral palsy, and other handi capping conditions.

Mr. Gray serves as a consultant to the President's Comittee on Mental Retardation, the United Cerebral Palsy Association, and the Division of Developmental Disabilities. 1972

Dennis E. Haggerty of Delaware County, Pennsylvania.

Mr. Haggerty, a graduate of Temple Law School and a practicing attorney in Philadelphia, is a consultant to the President's Committee on Mental Retardation, a member of the Governor's Advisory Council for Construction of Facilities for the Retarded of Pennsylvania, a Board member of the Pennsyivania Association for Retarded Children, and ha has been requested to chair a new Committee for the Mentally Retarded and the Law of the American Bar Assocition. 1975

Jewell B. Hamilton (Mrs. W.. Ed) of Frankfort, Kentucky.

Mrs. Hamilton, a former administrative assistant to Governor Louie B. Nunn of Kentucky, earned degrees from Baylor University and the University of Houston. She was Kentucky Chairman of the 1970 White House Conference on Children and Youth, and of the Kentucky Commission on Children and Youth. She is a member of the Woman's Commission of Kentucky, of the Advisory Committee of the Kentucky Department of Child Welfare, and a Past President of the Kentucky Fedaration of Women's Clubs. 1975

Martin Kelp, Supervisor of the Rocky River Sheltered Workshop, Rocky River, Ohio.

Mr. Kelp was graduated from Case Western Reserve University in 1969, and since then has been associated with the Cuyahoga County Board of Mental Retardation as Supervisor of a sheltered workshop. 1972

Margaret 0. Murray (Mrs. Clark 0., Sr.) of Shawnee Mission, Kansas.

Mrs. Murray attended Kansas City Junior College and has been active since in organizational and church work.

A member of the Board of Directors of the National United Cerebral palsy Association since 1954, she is presently Secretary of the Board of Officers and Corporations. She is a member of the Board of Directors or the United Cerebral Palsy Association (UCPA) of Greater Kansas City, and a Past-President.

She represented UCPA on the Rational. Health Counci and served as a Board member for the Crippled Children's Nursery School. **1974**

Paul K. Pearson, M.D., M.P.H., C. Louis Meyer Professor of Child Health, University of Nebraska College of Medicine, 0.?.aha, Nebraska.

Dr. Pearson is Director of the Meyer Children's Rehabilitation Institute. He has served in the USPHS as Special Assistant to the Surgeon General on child health aspects, Assistant Program Director of the Mental Retardation Program, NICHD, and Chief, Mental Retardation Branch, DCD.

Board certified in pediatrics, he is a graduate of Northwestern University School of Medicine, University of California School of Public Health. He is active on numerous committees at Federal, State, and local levels on mental retardation, handicapped children, cerebral palsy, day care, and cultural deprivation. 1975

Marcile L. Perrin, R.N. (Mrs. Hal G.), Executive Secretary of the Nebraska Epilepsy League, Inc., Omaha, Nebraska.

Mrs. Perrin, mother of two and grandmother of five, received her nursing education at Research Hospital School of Nursing, Kansas City, Missouri.

She has been active as a volunteer in church, hospital, and civic programs for years, and has been. employed as Executive Secretary of the Nebraska Epilepsy League-since 1969. -1974

R. R. Remboldt, M.D., Director of the University Hospital School, University of Iowa.

Dr. Remboldt received his medical degree from the University of Nebraska. He is a Fallow in the American Academy of Pediatrics and of the American Academy of Cerebral Palsy, and an Associate Member of the American Academy of Neurology.

He is presently a full professor in both the Department of Pediatrics, College of Medicine, and in the College of Education.

He is a member of the Professional Advisory Council, Rational Easter Seal Society; Professional Services Program Committee of United Cerebral Palsy; and past-Presidont of the Iowa Society for Crippled Children and Adults. 1972

Edward L. Taylor, East Kent Kave School, of Philadelphia, Pennsylvania.

Mr. Taylor holds degrees in Special Education and Educational Administration, and has been working in special education since 1958. He has been active in the affairs of the Neighborhood Youth Corps, Day Nursery, and North Philadelphia Recreation Planning Committee. He is now Job Coordinator for Special Education at the school. 1973

Clara F. Tubby, Epilepsy Society of Massachusetts, Boston.

Miss Tubby, a graduate of Syracuse University, is Public Information and Program Director for the State Epilepsy Society. 1975

Raymond W. Vowall, Commissioner; State Department of Public Welfare, Austin, Texas.

Mr. Vowall holds degrees from Mississippi Southern University and the University Texas, to which he returned as Vice Chancellor for. Federal and State Affairs after serving in the public school system special schools as director, superintendent, and executive director.

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Board certified in Neurological Surgery and Diplomats of the National Board of Medical Examiners, Br. Ward is active in numerous scientific societies dealing with problems of the davelopmentally disabled. Shortly after graduation from Yale Medical School, he entered the field of neurology and neurosurgery.

He is on Advisory Committees on Epilepsy, Neurology, and Spinal Cord Injury, and holds editorial board appointments to several scientific journals. 1973

NATIONAL ADVISORY COUNCIL
ON SERVICES AND FACILITIES
FOR THE DEVELOPMENTALLY DISABLED

ADVICE TO THE SECRETARY ON THE EXTENSION
OF THE DEVELOPMENTAL DISABILITIES ACT

On July 24, 1972 Secretary Richardson requested the National Advisory Council to submit to him recommendations regarding the extension and modification of the Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517). The Council addressed this request at its meeting on November 19, 1972.

The National Advisory Council recommends and advises that the Developmental Disabilities Act be renewed with clarification of the statutory definition of developmental disabilities, minor amendments to streamline program operation, and extension and continuation of the program direction in force under current legislation.

In anticipation of Congressional action on the Developmental Disabilities Act the Secretary should be prepared to submit to the Congress a bill which fully reflects Administration policy regarding the developmentally disabled. Just as significant as the exact specifications and amendments which the Department advocates is the Department's general posture regarding developmental disabilities. The National Advisory Council believes that it is imperative at this critical stage of DD program's development, for the Administration's legislative initiative to demonstrate:

- Support of the Developmental Disabilities concept as a viable strategy for achieving national goals of non-dependency (de-institutionalization) and institutional reform as they relate to substantially handicapped citizens.

- Support of fledgling Governor's State Advisory Councils on Developmental Disabilities.

- Recognition of the importance of State planning and resource development mechanisms to complement and enhance the existing payments and services systems for developmentally disabled persons encompassed under federally assisted programs of Education for the Handicapped, Vocational Rehabilitation, Public Assistance, Medical Assistance, Social Services, Maternal and Child Health, Crippled Children's Services, Comprehensive Health, Mental Health and other related programs.

The National Advisory Council's recommendations on specific aspects of the Developmental Disabilities Act are as follows:

1. The Developmental Disabilities Act should be extended for a five year period. All authorization levels, except authorizations for construction of University-Affiliated Facilities, should be extended in progressive increments from the current authorization based on projected needs for planning, service system reform, administration, construction and services for the developmentally disabled.

Rationale: The Developmental Disabilities program is still in its infancy and would benefit greatly from the stability inherent in the recommended extension. At the State level especially, the perception of the Governors' Councils as ongoing bodies with the potential for continuity in planning and implementation will have a positive impact on State utilization of the DD program and approach.

While refraining from recommending specific authorization levels, the Council believes that authorization levels reflecting program needs provide an important benchmark and should be specified to guide administrators, both at the State and Federal level, in setting priorities, evaluating programs and long range planning. Since UAF construction has been abated and the Council realizes the difficulty of projecting need for construction at this time, the UAF construction autnorization should be extended for such sums as necessary.

2. The State allotment formula under Part C of the Developmental Disabilities Act should be revised to:

   a. retain the minimum State allotment at $100,000.

   b. modify the formula so that the allotment is composed of a core grant to each State of $75,000 to which is added a pro rata share of the residual amount. Each State's incremental share would reflect population and need as under the present formula.

   c. provide a minimum allotment of $50,000 for the Virgin Islands, American Samoa, Guam, and Trust Territory of the Pacific, with an incremental share as indicated above.

Rationale: The Council believes that the current allotment formula is sound and has served to achieve a fair distribution of funds. However, in considering projections under various levels of appropriation a more equitable distribution will be assured by setting a minimum of $75,000 as the essential core for planning and administration and distributing the

balance on the basis of per capita income, population and need. In most cases, States now receiving the minimum allotment will experience an increased above $100,000. For example, at a funding level of $24 million, all States except Alaska, would show an escalation above $100,000 and no State would receive less than in 1972. (See attached - Table I)

Just as core funding is necessary in the States, it is necessary in the four above mentioned territorial jurisdictions. Testimony from representatives of these jurisdictions has convinced the Council that it is unrealistic to expect more than token efforts without a specified minimum allotment.

3. The Federal Share for Part C should be established at 80% on a continuing basis, with the distinct understanding that the non-Federal share is a block match; the requirement for the State plan to give priority for financial assistance to rural and urban poverty areas should be enforced but the explicit reference to 90% for poverty areas should be eliminated.

Rationale: This carries with it the distinct understanding that under Part C the States will be under a mandate to give preference to areas of rural and urban poverty and that they have internal variable matching perogatives. The language in the Act should clearly indicate that the urban and poverty areas have a top priority and a possibility of going to 100% Federal funds

The Council believes that the present declining Federal per centum (75% in FY 71 and 72, 70% in FY 73) is inappropriate for a formula grant program. The Federal per centum should be equivalent to other SRS grant programs for planning and services. While strongly endorsing the preference for areas of urban and rural poverty, there is some evidence that the mechanism of a specific 10% Federal share differential is inadequate and in certain cases self defeating. A block grant approach with a mandated priority for poverty areas would allow the State a great deal of flexibility in setting matching requirements and have a positive influence on the quantity and quality of projects submitted for funding.

4. The 75% maximum Federal share under Part B of the Developmental Disabilities Act should be maintained for construction but eliminated for demonstration and training grants.

Rationale: The 75% Federal share for demonstration and training is more restrictive than similar discretionary authorities within DREW. Where the purposes of grants are innovation, expansion, and demonstration rather than core support, matching requirements should be flexible to allow for Department funding decisions to be based on the value and suitability of the applicant rather than the ability to contribute 25% of the cost of the project.

5. All existing project grant authority administered by the Division of Developmental Disabilities should be consolidated under a single authority with assurances that a significant portion be allocated to projects of national scope.

Rationale: Currently the Division of Developmental Disabilities administers four separate project grant authorities under various pieces of legislation (HIP and HIST grants under sec. 303 Public Health Service Act, projects for the mentally retarded under sec. 4(a)(1) of the Vocational Rehabilitation Act and Projects of National Significance under sec. 132(e) Developmental Disabilities Act). In the interest of sound grants management) and increased accountability the Council considers it appropriate to consolidate these granting authorities within the Developmental Disabilities Act to enable the Division to make grants to States, public and other nonprofit agencies to increase efforts toward the goal of adequate programs for the care, training and habilitation of the Developmentally Disabled.

The Council endorses the concept of projects of national significance and would anticipate that a continued commitment to these projects would be an integral element of project grant consolidation.

6. Federal review of construction projects funded under Part C, should be eliminated and States should be permitted to approve construction projects in conformance with State PLANS AND FEDERAL REGULATIONS.

Rationale: The current construction requirements under P.L. 91-517 are a carry over from the provisions of the Mental Retardation Facilities Construction Act (P.L. 88-164). The Council believes these requirements are inappropriate in a formula grant program and that elimination would be consistent with other formula grant authorities such as section 2 of the Vocational Rehabilitation Act.

7. The Developmental Disabilities Act should provide for • advance funding.

Rationale: Under the advance funding provision, appropriations under the Act are authorized to be included in the appropriations Act for the fiscal year preceding the year for which they are available for obligation. The Council believes that advance funding will be a valuable aid in planning and funding services by providing notice of actual fund availability a year ahead of time.

8. The definition of developmental disabilities should be revised to eliminate etiological factors, to focus on the most substantially handicapped and to define the target population based on objective characteristics. The new definition should be consistent with and referable to lega1 definitions which set forth eligibility criteria for services and payments to disabled persons in other

established federal programs. The following language would meet this criterion.

> Developmental Disabilities means a. disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen a handicap of comparable severity).

'As an alternative subparagraph (1) above could read:

> "(1) is attributable to mental retardation, cerebral palsy, epilepsy, or other medically determinable physical or mental impairments."

In addition to a revised definition, the Developmental Disabilities Act should provide for service eligibility for all substantially handicapped persons who can benefit from a service being provided for persons with developmental disabilities as defined in the primary target group. The following language is suggested:

> developmental disability or a person with another substantial handicap who has similar service needs and who is considered eligible for such similar services by an agency or a facility which is providing services primarily intended for persons with developmental disabilities.

Rationale: From the inception of the Developmental Disabilities Act, there has been a great deal of controversy as to the basic question, "Who are the developmentally disabled?" Questions arose as to the coverage of the primary groups, the nature of substantial handicap and the intended relationship between mental retardation and other conditions. The major issue concerns the inclusion or exclusion of other neurological conditions. The Council has considered a wealth of testimony on this issue and heard from various groups supporting and opposing changes in the definition. While there is little agreement on proper interpretation of the present law and on specific language for a new law, there is widespread support for a functional definition as opposed to a definition which relies on diagnostic labels. There is also agreement that regardless of the legal definition, service eligibility should be based on similar service needs.

The Council's suggested definition builds upon these areas of agreement and incorporates language used in the definition of disability under the Social Security Amendments of 1972 (P.L. 92-603[1]) and anticipates new definitions for "severely handicapped" under the new Rehabilitation Act (HR 8395). The shift from the concept of "condition" (neurological or otherwise) to the concept of physical or mental impairment provides the definition with a functional basis which has been used in the Social Security disability insurance program, and which will be further developed (especially in regard to children) as DHEW prepares to implement H.R. 1. The existing statutory linkages to social services and rehabilitation services in the supplementary income program make it important to develop common approaches to the definition, whereever possible.

Inasmuch as blindness is defined separately in all Social Security Act titles, the possibility of excluding blindness per se from the above definition should be considered.

The Council recognizes the complexity of the definitional issue and the near impossibility of developing a solution satisfactory to all. However, the Council urges that the suggested approach be given serious consideration as a way to begin to rationalize our services and payments programs for the developmentally disabled within the context of the other major service systems.

9. Legislative initiatives in the area of reform and improvement of public residential facilities and institutions for mentally retarded persons should be consistent with Presidential and DHEW goals of de-institutionalization and should be reflected in the developmental disabilities program.

P.L. 92-603 Title XVI Supplementary Security Income for the Aged, Blind, and Disabled defines disabled individual in sec. 1614(3)(A) and further defines physical or mental impairment in sec. 1614(3)(C) as "an impairment that results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques." This definition is in turn based on the definition of disability heretofore applied to disabled beneficiaries under Title II of the Social Security Act. Thus there is 15 years of experience in applying this definition to adults disabled in childhood. See: Social Security Regulations, Rights and Benefits based on Disability T1B-6-HEW SSA May 1969. See also: Section 404. 1501 Regulations #4 sub-part P.

Rationale: Institutions for the mentally retarded are under attack. Willowbrook, Partlow, Belchertown and a number of other State institutions have been cited as overcrowded, understaffed, isolated outmoded dehumanizing facilities. Congressional concern is evidenced by a number of bills introduced in the House and Senate. S. 3759 a "Bill of Rights for the Mentally Retarded," introduced by Senator Javits for himself and 21 other Senators, mandates standards for residential facilities; imposes sanctions for non-compliance with standards; establishes grants for comprehensive facilities planning, grants to assist institutions and grants for alternate programs of care.

Without commenting on the specific provisions of S. 3759 or the advisability of their incorporation in the-Developmental Disabilities Act, the Council advises that DHEW take a firm position that new programs in this area relate to and utilize the existing Developmental Disabilities structure. The Council's concern about the possibility of a separate authority for planning and improvement of residential care is twofold. Firstly, a concern that enactment of new residential services support independent of Developmental Disabilities Act will create parallel and duplicative administrative structures. Secondly, a concern that a residential improvement program independent of Developmental Disabilities Act may counteract DHEW movement toward community care. If additional legislative mandate is required to bring about improvement of residential facilities for the mentally retarded, the Council believes that the Developmental Disabilities Act provides an appropriate vehicle for such mandate and in conjuction with other SRS authorities could have a significant impact on residential care.

10. The cost of land should be included in the definition of cost of construction.

Rationale: This technical amendment would bring the Developmental Disabilities Act cost of construction definition in conformance with the definition in RSA's Vocational Rehabilitation Act. This definition was recommended in the 1969 Administration bill (H.R. 15160, 91st Congress 1st Session).

In developing the ten recommendations above, the Council considered other issue areas and decided that administrative approaches are more appropriate than legislative change. Thus, on the issue of clarification of the roles of State Councils and State Agencies, the Council recommends that regulations be clarified and guidelines be issued especially regarding the staffing of State Councils.

Rather than recommend new statutory authority to establish low interest loans and mortgage insurance for developmental disabilities facilities, the Council requests that administrative action be pursued to make existing loan and mortgage insurance authorities available to developmental disabilities facilities.

Proposed Formula based on $24,000,000

	need	support & planning	total		FY 72 Allotment
TRUST TERRITORIES	10362	50,000	60362		9,905
AMERICAN SAMOA	2763	50,000	52763		2,676
TOTALS					
1. Alabama	460814	75,000	535814		439,030
2. Alaska	25000	75,000	100000		100,000
3. Arizona	167920	75,000	242920		159,998
4. Arkansas	258137	75,000	333137		245,977
5. California	1156247	75,000	1531247		1,387,494
6. Colorado	191334	75,000	266334		182,314
7. Connecticut	237945	75,000	312945		226,680
8. Delaware	46848	75,000	121848		100,000
9. District of Columbia	48210	75,000	123200		100,000
10. Florida	648371	75,000	723371		617,761
11. Georgia	506151	75,000	581151		482,220
12. Hawaii	67119	75,000	142119		100,000
13. Idaho	79373	75,000	154373		100,000
14. Illinois	893341	75,000	968341		851,062
15. Indiana	502829	75,000	577829		479,033
16. Iowa	290365	75,000	365365		276,547
17. Kansas	215584	75,000	290584		205,408
18. Kentucky	426915	75,000	501915		406,641
19. Louisiana	420808	75,000	495808		400,911
20. Maine	120453	75,000	195453		114,744
21. Maryland	318753	75,000	393753		303,757
22. Massachusetts	489799	75,000	554799		466,622
23. Michigan	806385	75,000	881385		768,122
24. Minnesota	376942	75,000	451942		359,108
25. Mississippi	320544	75,000	395544		305,408
26. Missouri	469925	75,000	544925		447,609
27. Montana	74440	75,000	149440		100,000
28. Nebraska	156163	75,000	231163		148,767
29. Nevada	33220	75,000	108220		100,000
30. New Hampshire	72808	75,000	147808		100,000
31. New Jersey	574287	75,000	649287		547,134
32. New Mexico	108498	75,000	183498		103,415
33. New York	1483805	75,000	1558805		1,413,340
34. North Carolina	624001	75,000	699001		594,422
35. North Dakota	78816	75,000	153816		100,000
36. Ohio	983897	75,000	1058805		937,362
37. Oklahoma	261718	75,000	336718		272,220
38. Oregon	196388	75,000	271388		187,154
39. Pennsylvania	1170838	75,000	1245838		1,115,313
40. Rhode Island	86654	75,000	161654		100,000
41. South Carolina	3320400	75,000	407400		316,718
42. South Dakota	80448	75,000	155448		100,000
43. Tennessee	481323	75,000	556323		458,558
44. Texas	1120069	75,000	1195069		1,067,287
45. Utah	111084	75,000	186084		105,845
46. Vermont	48996	75,000	123996		100,000
47. Virginia	484169	75,000	559169		461,271
48. Washington	276201	75,000	351201		263,160
49. West Virginia	259988	75,000	334988		247,591
50. Wisconsin	446571	75,000	521571		425,408
51. Wyoming	32465	75,000	107465		100,000
52. Guam	8851	50,000	58851		8,444
53. Puerto Rico	444999	75,000	519999		423,909
54. Virgin Islands	7498	50,000	57498		7,155

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
LONG RANGE GOALS AND STRATEGY:

A FRAMEWORK FOR SRS PLANNING

****

DHEW GOALS

The Department is in a process or evolving a comprehensive strategy the broad dimensions of which are contained in the goals of non-dependency and institutional reform. The major planning Task for FY 74-78, for Agencies and the Department, is to translate this evolving strategy into consistent and coherent programmatic choices throughout the Department,

Non-Dependency. The Department's major goal for FY 74-78 is to foster non-dependency, through the accomplishment of the following objectives:

1. To create preventive mechanisms which identify the likelihood of people sliding down the scale of personal freedom of choice and reliance on others, and which remove dangers that threaten the status of those people.

2. to create the conditions necessary to achieve earning capacity, self-care, and personal freedom of choice.

3. To assist those who are not self-supporting to progress to the highest level of self-sufficiency that is within their capability.

4. T6 ensure the adequacy of income and services, qualitatively as well as quantitatively,' and the preservation of human dignity, for those who are unable to progress up the scale of self sufficiency.

Institutional Reform. One of the major means to bring about non-depehdency is through institutional reform the elimination of obstacles to n6n-dependency that arise from institutional practices and attitudes. Institutional reform implies working with the institutions to assure that they are accessible, responsive, and effective.

DHEW STRATEGY

Putting non-dependency and institutional reform together dictates the removal of barriers to the achievement of self-support and the strengthening of incentives for movement toward higher conditions of independence. There are three component's in this task:

, 1. Assuring that people have the financial resources to purchase necessities on a sustained basis.

2. Assuring that individuals have access to services and facilities. Barriers to individual access which are based upon race, sex, ago, income distribution or handicapping conditions must be reduced.

3. Assuring that adequate services are available. This requires thirst the quantity of services be distributed roughly according to need, and that the quality of services meet standards of adquacy. Quality should be measured in part by the attitudes of client groups toward the institutions that serve them.

SOCIAL AMD REHABILITATION SERVICE GOALS

Non-Dependency

The Secretary's announcement of the overarching Departmental Goals of Non-dependency gave impetus to the development of an SRS program goal framework. The goal framework is a vehicle for specifying human welfare outcomes of all SRS programs in common terms. It defines five possible categories of an individual's "state of being" in terms of his dependency on income maintenance and social services, These five categories have - tentatively been defined as:

1. Full Self-Support--An individual for whom income maintenance and related services are no longer required.

2. Partial Self-Support—An individual who has some earnings, but is partly dependent upon SRS programs for subsidized services and/or income supplementation.

3. Family Self-Care—An individual who has attained physical and/or emotional independence, within their own homes, and may be dependent upon income maintenance. (This goal has an important prevention focus attached to it. Services are provided to prevent an individual or family from deteriorating and thereby requiring out-of-home care).

4. Alternative Care—An individual who requires care in a community-based facility (e.g., half-way houses, foster homes," group homes) but does not require full-time supervision of his daily activities.

5. Institutional Care—An individual who requires full-time supervision. of his daily activities or who requires special settings to assist in the development of an individual's ability to function in another goal. (E.g., spinal cord centers or acute mental hospitals.)

It is hoped that over the plan period (FY 74-78) the goal framework will provide a basis for:

a. Defining clearly the target group populations capable of attaining and maintaining different levels of independence. (E.g., what should be the goal status of mothers with dependant children under school age.)

b Assessing the barriers to full and efficient goal attainment. ('What factors prohibit public assistance recipient:; from gaining full employment?)

c. Planning for services and programs felt to reduce these barriers. (What services, in what mix, would remove the barrier? Would these programs be cost-effective in comparison with programs that would raise the goal status of other target groups?)

Residential Services For The Mentally Retarded:

AN ACTION POLICY PROPOSAL

The President's Committee on Mental Retardation, Washington: 1970

A major priority of the President's Committee on Mental Retardation since its establishment has been to promote improvement in standards of residential service for the retarded and to develop a national policy on improved living conditions for those mentally retarded citizens who live in public and private residential facilities.

This booklet offers for public and professional review a proposed policy statement on residential services for the mentally retarded. The statement was prepared with the assistance of the National Association of State Coordinators of Programs for the Mentally Retarded and in cooperation with the National Association for Retarded Children, the American Association on Mental Deficiency, and the International League of Societies for the Mentally Handicapped. The President's Committee on Mental Retardation has approved the statement as a baseline for planning.

PCMR Work Group on Residential and Family Living

Raymond W. Vowell, *Chairman*

Bess Harris Jones

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Thomas A. Tucker

David K. Udall

Fred J. Krause, *Staff*

Residential Services For The Mentally Retarded

AN ACTION POLICY PROPOSAL

The President's Committee on Mental Retardation
Washington, **D.C. 20201**

Robert H. Finch, *Chairman;* Robert A. AIdrich, M.D., *Vice Chairman*
David B. Ray, Jr., *Executive Director*

May **1970**

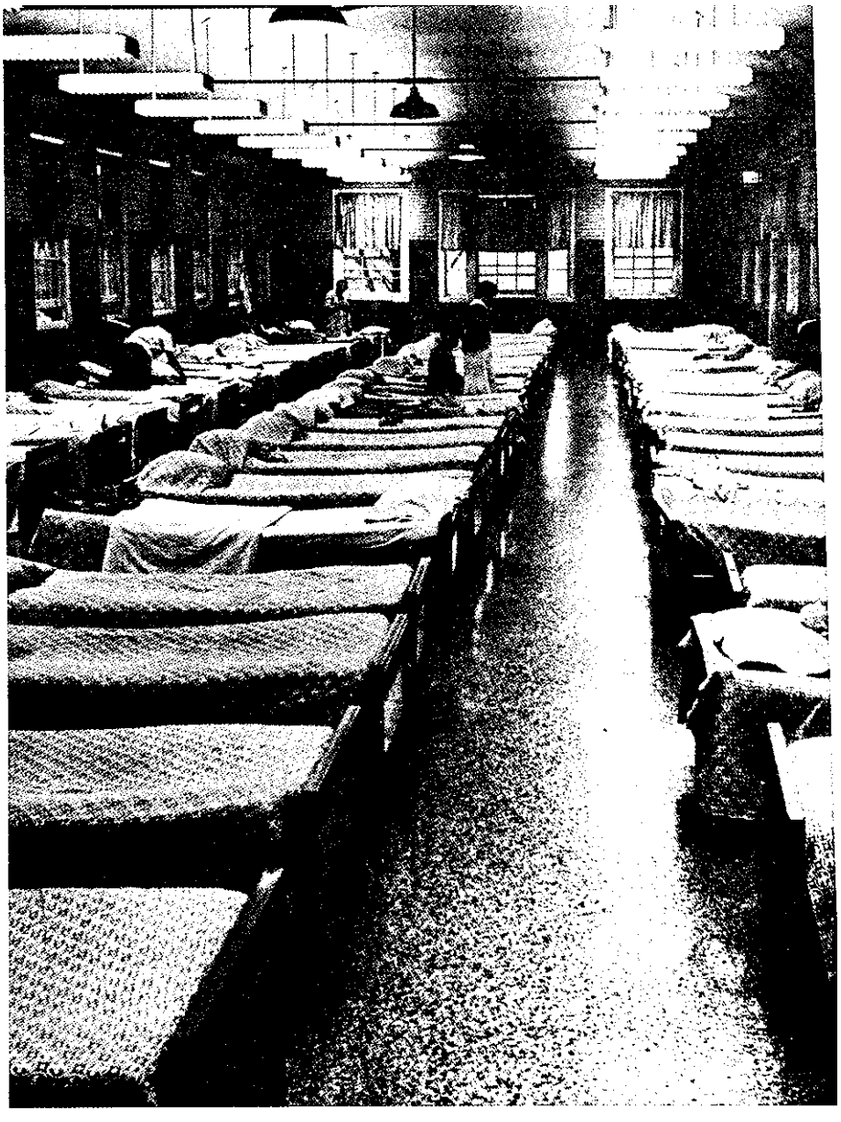


TABLE OF CONTENTS

Introduction iv

Definition 1

Statement of Purpose 1

Conditions Under Which Residential Care Is Appropriate 2

Legal Eights of the Individual 2

Residential Services 4

Regional and Community Resources 6

Residential Living Environment 7

Architectural Considerations 9

Residential Programs and Research 10

Administrative and Management Services 12

Advisory Committee 13

Advanced Technology and Methodology in Improving Residential Services 13

Parent and Citizen Volunteers 14

References 15

INTRODUCTION

History tells us that the separation point in philosophy regarding the weak, the crippled, and the infirm is well depicted by the divergent practices of the Spartans and the Athenians. While the ancient Spartans purportedly left the malformed to languish and die, the Athenians chose the road of care, haven, and nurture for the ill.

On the surface, it would appear that we in the United States have chosen the Athenian way. But realistic evaluation of our practices in housing and caring for the mentally retarded in residential facilities should give us reason to pause. Indeed, we must pause and reflect openly and honestly among ourselves. For administrative systems in public facilities for the retarded are rife with make-do arrangements that have grown up to compensate for bone-bare budgets and general indifference to the facilities' needs.

Many residential services and programs as they exist within the 50 states comprise a tragic paradox for the wealthiest nation in the world. On the one hand, our knowledge of environmental design and care for the retarded has never been greater and increases daily. On the other hand, the gap between what we know how to do and what we actually are doing seems to increase at an even more rapid rate.

Among the major causes of failure to provide proper housing and program are public apathy to the problem, misunderstanding of the condition, overcrowding, understaffing, and inadequate financial support. Despite the enlightened concepts of many leaders in the field of retardation, the inherited philosophy is too often one of isolation, coupled with disease-oriented treatment. The result is mass housing, built and administered on an outmoded model,

usually removed from community life and society. Almost all public institutions for the retarded are overcrowded, many seriously. Yet, nearly every state has long waiting lists of individuals waiting for admittance to a residential facility for the retarded.

There are few physical cures for mental retardation; therefore an attitude of hopelessness often exists toward these residents despite the good intentions of the staff. A reorientation in thinking will require considerable effort as public officials, administrators, professional workers, and the lay public all come to understand that the retarded can be helped by training, education, and habilitation.

Today, concerned professionals, government agencies, and parents of the retarded are demanding a complete departure from dehumanizing custodial care. Some administrators have already adopted a new approach; others are seeking to make such changes. This new philosophy calls for a variety of decentralized residential services, and a recognition of the human and civil rights of the retarded, among them programing according to the nature and degree of the individual's handicap. In short, the trend is toward normalization, a principle emerging as an entire new approach to management and programing for the retarded. This principle refers to allowing the retarded to obtain an existence as close to the normal way of life as possible in a residential setting.

The following policy statement is intended to be a major step toward realizing the goal of normalization for the retarded, especially for those in residential facilities. The goals in programing and housing cited here will not all be achieved overnight. The volume of activity to improve residential services must be sufficiently increased. We no longer can be satisfied with the often deceiving evaluation of the progress of the past or the vague promise of improvement in the future.

Today, more than 200,000 citizens of the United States who are mentally retarded are living in public residential facilities. The cost of operation of these facilities each day is in excess of 82.3 million, which is more than $1 billion a year for direct services alone. Far too many of these facilities consist of an impoverished living environment that is not distinctly different from the environment experienced by prisoners of war during the past three decades. The general public becomes highly incensed and concerned—and rightly so—when learning of abuses to prisoners of war. Unfortunately, the same public expresses little or no concern about inhumane living conditions that exist in their own communities.

We must begin, continue, and intensify in the nation and each of our 50 states a movement to improve our residential facilities for the mentally retarded. We must make residential facilities and their programs cost effective in terms of human lives salvaged from the limbo of neglect and given, to the fullest individual degree possible, the dignity of place and value in daily life and work.

The policy proposed in this booklet is offered both as a goal and a guideline. Its implementation, we believe, will be a *saving* act—in human resources, in program effectiveness, and in financial cost per individual served through human service programs.

The welfare of the mentally retarded should be the concern of all Americans. Their hope for the future is in our hands.

"The proper use of behavioral management should involve appropriate motivation and training reinforcement, reflecting an understanding of human development. There is no place for excessive use of physical restraints, abusive use of drugs and prolonged periods of isolation for the sole purpose of controlling behavior . . ."

Proposed Action Policy on Residential Services for the Mentally Retarded

Definition

A residential facility for the mentally retarded is any housing facility other than the individual's natural home, which provides supervised living with appropriate services related to the individual's needs.[1]

Statement of Purpose

The prime purpose of residential services for the mentally retarded is to protect and nurture the mental, physical, emotional and social development of each individual requiring fulltime responsible services. Inherent in this commitment is the responsibility to provide those experiences which will enable the individual (1) to develop his physical, intellectual, and social capabilities to the fullest extent possible; (2) to develop emotional maturity commensurate with social and intellectual growth; (3) whenever possible, to develop skills, habits; and attitudes essential for return to contemporary society; and (4) to live a personally satisfying life within the residential environment.

The definition here stated and the ensuing policy statement may be considered in the context of private residential facilities if they are comparable to public residential facilities in terms of residential population.

"Individuals who function at the level of staff in certain occupational or training activities have the right to enjoy the same privileges as staff and, when used in other than training situations, should be paid at the legally required wage level."

Considerations Under Which Residential Care Is Appropriate

Mental retardation in itself is rarely sufficient cause for the removal of an individual from his natural home. Nonetheless, more than 200,000 retarded persons in the United States currently live in publicly operated residential programs. These residential facilities should offer services to retarded individuals, specifically to those severely and profoundly retarded, and those with multiple handicapping conditions, who require highly specialized programs.

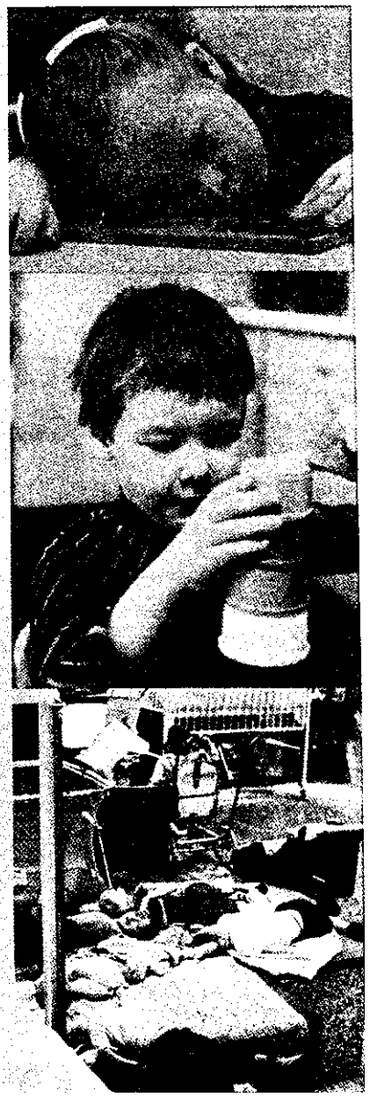
Less severely retarded persons may profit by short-term residential services for the amelioration or modification of specific problems such as emotional instability, asocial behavior, physical disabilities, or for specialized educational and training programs.

Legal Rights of the Individual

A basic obligation of residential services is to assure the rights of the individual. Each retarded person, regardless of the degree of retardation or additional disability, should be treated with respect and given every opportunity to exercise his own judgment in conducting his affairs and should be given the right to own and control property.

The responsible person concerned with and involved in program planning for the retarded should make an impar-

"The interrelationship of design and architecture to residential programming is vital . . ."



tial case review as often as deemed necessary but no less than annually.

The mentally retarded shall have the same constitutional rights and guarantees as every other American citizen.

The use of residential facilities for punitive purposes or for long periods of incarceration violates not only the rights of the individual but also the principles of residential care. The residential facility should be used for programming, not punishment.

Voluntary and involuntary admissions should be based on sound professional considerations. The reason for placement must depend on the individual's need for residential services, not on what is expedient or convenient at the time.

The integrity of the individual's family must be preserved and a close relationship between the family, the retarded individual and the staff should be encouraged. The admission of a mentally retarded person to a residential program should in no way be construed either by parents or staff as a termination of parental responsibilities to said individual unless legal action has occurred to sever these ties. It should be the philosophy of the residential program that parental involvement and participation in all aspects of services to a given mentally retarded person is normal, desirable, and expected, and that a cooperative, communica-

". . . a close relationship between the family, the retarded individual and the staff of the residential service facility should be encouraged . . ."

tive relationship between the facility and the parent will result in decisions and services which place the retarded persons' interests and welfare as a mutual responsibility and concern.

Family members or their official representatives should be allowed to visit and be free to communicate with their relatives by correspondence or telephone at any reasonable time.

Legal guardians should be appointed, whenever necessary, for both minor and adult retarded persons to insure full protection under the law.[2] The responsibility of the guardian is primarily to insure the retarded person civil and human rights (including termination of residential services) ; the protection of his property; and to assure determination and representation under criminal and civil law.

Residential Services

The best residential services meet individual needs. They combine the attributes of a positive home life with modern management techniques and skills available from the behavioral and medical sciences.

A residential service should be conducted in an atmosphere of warmth and affection, dignity and respect, with programs designed for each person's individual needs.

[2] It is advisable for each state to study and develop its own set of laws governing guardianship of the person and his estate.

The proper use of behavioral management should involve appropriate motivation and training reinforcement, reflecting an understanding of human development. There is no place for excessive use of physical restraints, abusive use of drugs and prolonged periods of isolation for the sole purpose of controlling behavior or for punitive reasons. An active and effective program will serve in many cases to improve behavior.

Good residential programs provide both long-term and short-term services and are governed by the goal of helping each mentally retarded person develop and make the best use of his capabilities.

Long-term services usually are required by the more severely and profoundly retarded whose needs—medical, physical, social, educational and psychological—frequently require continual attention. Programs need to be planned for maximum adjustment, since each individual has potential for some progress, no matter how severely impaired.

Ideally, short-term programs should be made available to the retarded with emotional, social, and/or medical problems who require intensive treatment or training within a sheltered environment. Further, model short-term programs should include temporary, reserved space and respite care to relieve critical family situations.

It is the obligation of the residential facility to develop each individual's economic potential as well. The work and training settings should train him to perform meaningful remunerative work outside of the residential facility.

Individuals who function at the level of staff in certain occupational or training activities have the right to enjoy the same privileges as staff, and when used in other than training situations, should be paid at the legally required wage level.

In addition to providing services to the retarded, residential facilities should offer a variety of programs to the family. Every effort should be made to maintain family integrity through intensive counseling and supportive services for the individual and his family before, during, and following residential placement. Alternatives to residential placement should be explored thoroughly with parents and community agencies.

Regional and Community Resources

It is essential that a residential facility cooperate and coordinate its programs with other regional and community mental retardation services, in order for the development of a full range of comprehensive services.

Residential services will vary considerably depending on the residents' needs and the availability of alternative

"It is the obligation of the residential facility to develop each individual's economic potential . . . The work and training settings should train him to perform meaningful remunerative work outside of the residential facility."

resources. Residential services should be but one identifiable service coordinated with the general and specific regional and community programs available to all citizens. A high percentage of the retarded are capable of being integrated into community living situations, when supportive generic services are available.

The comprehensive residential facility can take an active role in serving a region or community by providing, when appropriate, diagnostic and counseling services, outpatient services, special treatment centers, and in general, participating in all phases of comprehensive planning. Administrators and program staff need to become actively involved in regional and community health, education, rehabilitation and welfare planning.

In addition to developing a needed program within the residential facility, the administrator should plan for residents to participate in educational, social, and recreational activities in the community. Residential personnel should be encouraged to stimulate the development of regional and community programs when they are not otherwise available.

Residential Living Environment

The model residential environment should provide a warm, stimulating social setting, devoid of any form of dehumanizing conditions. The retarded should be helped

"Large dormitories should be remodeled to give privacy and individuality to the residents . . ."

"The model residential environment should provide a warm, stimulating social setting, devoid of any form of dehumanizing conditions . . ."

to live as normal a life as possible in safety. While those of similar behavior and chronological age may be grouped together, the practice of rote separation based on sex, clinical classification, or handicapping conditions is seldom justified. Small groupings designed to promote maximum social and emotional growth appropriate to the retarded person should be effected.

The staff must reflect attitudes and behaviors consistent with the concept that they are family surrogates, i.e., that they are providing services on a daily basis in lieu of the retardate's actual family. However, the continuing prerogatives and responsibilities of the child's true parents should also be recognized and respected, even though they may exercise these only on a periodic basis.

It is desirable for direct-care personnel to possess at least a high school education (or its equivalent) and to have access to an extensive inservice training program. A "career ladder" should be instituted, enabling qualified staff to take relevant college or university courses when specialized training needs arise.

The residential facility and college or university should be interrelated in such a way that the institution of higher learning contributes directly to inservice training of residential personnel, and residential staff and resources should

"The staff must reflect attitudes and behaviors consistent with the concept that they are family surrogates, i.e., that they are providing services on a daily basis in lieu of the retardate's actual family . . ."

be used in professional training and recruitment. Joint appointments should be considered.

Architectural Considerations

Facilities preferably should be designed to serve and maintain programs for a specific population. In planning the facility, attempts should be made, through flexible design, to accommodate advancements and changes in program techniques and methods. The interrelationship of design and architecture to residential programming is vital. Consequently, the use of facilities constructed for other purposes, e.g., tuberculosis sanitaria, military installations and obsolete nursing homes should be studied carefully before a decision is made to adopt them for the mentally retarded.

Design and construction of new facilities should adhere to a number of basic principles:

1. The location should be within the community served and provide for normal contacts with the life of the community.

2. The size and type of units should be based upon the residents' needs in a comprehensive program.

3. The living quarters should provide maximum opportunity for privacy, with closets, lockers, etc., for personal possessions. Living quarters should be consistent with cultural norms, with due regard to health, safety and conformity to accepted community standards.

"The best residential services meet individual needs. They combine the attributes of a positive home life with modern management techniques and skills available from the behavioral and medical sciences."

4. In new design and construction, consideration should be given to flexibility of programming and, at the same time, to the concept that the structure should be in harmony with the program.

Existing facilities should be studied carefully so that antiquated buildings can be scheduled for demolition and remaining buildings converted to specific programatic units. Facilities can be divided into small program-administrative units which are relatively autonomous and self-contained. Large dormitories should be remodeled to give privacy and individuality to the residents.

The yearly budget should include a realistic maintenance factor, plus an emergency or contingency fund.

In summary, existing facilities as well as proposed facilities should attempt to establish a total environment-physical, psychological, and social—that will provide effective programming for small groups of individuals in a highly personalized atmosphere.

Residential Programs and Research

It is important that research and data collection be a part of the total residential program. To date, outside agencies do much of the research conducted within residential facilities. The use of residential populations by various research agencies is not to be discouraged. However, each residential

facility should examine its own research potential and, when realistic, establish its own mechanisms for conducting such research programs. It is important that the principles promulgated in "Use of Human Subjects for Research," published by the American Association on Mental Deficiency,[3] be followed. In essence, this statement declares: "Research in mental retardation must conform to the scientific, legal and moral principles which justify all research and should emerge out of sound theoretical basis or follow previously accepted research design." The protection of human dignity, integrity and life must be recognized as the first consideration in research planning.

Administrators of residential facilities need to be concerned with studies aimed at improving programming and treatment. Every effort should be made to use new knowledge and techniques in programming for all levels of retardation, with emphasis on preventive research in all areas of mental retardation—biomedical and environmental.

The results of all research conducted within residential facilities which are pertinent to continued programming should be discussed with residential staff so that the findings can be applied. Such research not only will increase

[3] "Use of Human Subjects for Research." Policy Statement of American Association on Mental Deficiency, Compiled by Planning Board, AAMD May 13, 1969.

knowledge of the condition of mental retardation and the role of residential services, but will also provide understanding of many phases of human development.

Administration and Management Services

It is the responsibility of the appropriate and designated agency of state government to develop a philosophy and purpose of residential services for the mentally retarded. The philosophy should be consistent with the current status of knowledge and information available on residential services. The agency responsible for residential services should have a director or coordinator of programs for the mentally retarded. He should be authorized to provide executive direction and administration for all levels of residential services.

The administrator of the facility should implement program and staff policy, and direct and coordinate all phases of residential services. Staff should be able to identify ineffective programming and suggest improvements.

The administrator and professional staff should have training and experience in administration and human welfare services. Administrators should not be required to have academic training in any one special discipline, but must have administrative abilities, the quality of leadership and an understanding of the condition of mental retardation.

"Administrative policies should recognize the importance of the interrelationship of parents, volunteers, staff, and residents . . ."

"Each retarded person, regardless of the degree of retardation or additional disability, should be treated with respect and given every opportunity to exercise his own judgment in conducting his affairs . . ."

Advisory Committee

Officially constituted professional and lay advisory committees have proved to be highly beneficial to both public and private institutions in health, education and related fields. The committee members should be appointed by the governing board, commission or a duly constituted authority. Appointments should be made irrespective of political affiliation and should be based on both broad knowledge of the human welfare field and demonstration of public service.

The advisory committee may provide direct consultation and assistance to either the administrator and professional staff of the specific residential facility or to an official authority. There should be a clear description of purpose and function of the committee, leaving no doubt as to its limitations in an advisory role. At least annually, the advisory committee should prepare a report or meet directly with the appropriate state official on the progress and effectiveness of the residential services programs.

Advanced Technology and Methodology In Improving Residential Services

When applied to residential services, advances in technology may prove to be both economical and efficient. Industrial and management studies have provided advanced

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systems to modernize laundries, food service and general services. Data processing may be used in record systems and inventories. Program budgeting should make allowances for innovative planning.

Parent and Citizen Volunteers

The aid given by parents and citizen volunteers is very supportive to the mentally retarded and the staff of a residential facility. Administrative policies should recognize the importance of the interrelationship of parents, volunteers, staff and residents. Parent associations should be encouraged to meet at the facility and review with staff the program and budget needs for providing services to the mentally retarded. Volunteer services should always be regarded as additional service and not as replacement of paid professional staff.

A staff coordinator of volunteer services is necessary for the recruitment, training, and placement of volunteers in positions that will be most helpful to personnel and meaningful to the volunteer.

Youth and senior citizen volunteer groups should be encouraged to organize and participate in the over-all program for the retarded.

This statement is intended as a guideline for policy-makers, not as a final policy statement on residential services.

"The prime purpose of residential services for the mentally retarded is to protect and nurture the mental, physical, emotional, and social development of each individual requiring full-time responsible services . . ."

The intent is to provide direction so that administrators, staff and personnel, as well as parents and the retarded residents themselves, can adapt its philosophy to particular situations.

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Senator KENNEDY. Our next witnesses are a panel of three. They are Dr. Cooke, Dr. Tarjan, and Dr. Jordan.

Gentlemen, I welcome you to the hearings. Dr. Robert Cooke is the chairman of the scientific advisory board of the Joseph Kennedy, Jr., Foundation. He is presently on sabbatical leave from Hopkins University. He is the director, through Dr. Frederick Richardson, of the design of the first university-affiliated clinical facilities for the mentally retarded, which is to be completed.

Dr. George Tarjan is the program director of the Neuropsychiatric Institute of the U.C.L.A. School of Medicine. Among many other things, Dr. Tarjan is the Chairman of the Vice President's Council on Mental Retardation. He is on the advisory group of the Joseph P. Kennedy Memorial Foundation.

Our third witness on the panel is Dr. Robert Jordan, who is the president of the Association of University Affiliated Facilities. Dr. Jordan has, for 20 years, been involved in the assistance of programs to work with the handicapped and inservice programs for the developmentally disabled.

I welcome you on behalf of the subcommittee. We will start with you, Dr. Cooke.

STATEMENT OF ROBERT E. COOKE, M.D., CHAIRMAN, SCIENTIFIC ADVISORY BOARD, THE JOSEPH P. KENNEDY, JR., FOUNDATION

Dr. COOKE. I would like to submit for the record a rather long statement.

Senator KENNEDY. I would appreciate your holding your testimony to about 5 or 6 minutes each, so that we will have an opportunity to question you.

Dr. COOKE. I have a long statement which I would like to submit for the record.

Senator KENNEDY. Without objection, your printed statement will be inserted in the record.

Dr. COOKE. I would also like to submit a statement from the Executive Vice President of the Council, Mrs. Eunice Kennedy Shriver.

Senator KENNEDY. That statement also will be entered into the record at the end of your testimony.

Dr. COOKE. The Joseph P. Kennedy, Jr., Foundation has had an interest in the problems of the mentally retarded for many years. It is essentially the only private foundation which has been concerned almost completely with programs for the retarded beginning with the residential facilities and now progressing through research support to a new area of law.

The points which I should like to make in relation to the Developmental Disabilities Services and Facilities Construction Act and the bill of rights for the mentally retarded are essentially for these programs.

This is a particularly critical time for the Developmental Disabilities Act. It seems essential that it should continue. We are in a phase of transition from planning to an operational phase. This act permits the use of noncategorical generic funds in a way which has made possible the appplication of increased amounts of money from these non-

categorical funds to be applied to the disabled in a far more effective manner.

In a sense, the Developmental Disabilities Act has acted much like a conductor in a symphony, not providing the major music, but essential m the coordination of the activities of the various instruments.

A second reason that this is a critical time, is that there is a court mandate which will move the mentally retarded from institutions into the community. Hence, there will be a marked increase in the need for community resources and services far greater than simply an increase in the population.

The principle of least restrictive therapy, which is the basis for this court action, will demand a great increase in community programs.

Also, I think it is not a proper time for marked broadening of the coverage simply because of two points: the inadequacy of dollar support, which has been brought out by a number of witnesses and also because this program is very much in its infancy.

If there is a broadening of the coverage. I believe that this Developmental Facilities Act will be disabled in its own right because of the difficulties in extending these coverages. So that the definition which seems to make some sense is that of mental retardation and epilepsy and other closely related conditions which have similar service needs.

In relation to the university affiliated portion, which is also an essential element of the Devolpmental Disabilities Act, I can say from the broad perspective of many years of work in the field, that these university facilities have provided a number of functions which, I think, have kept the field moving in an appropriate direction.

They have served as regional service centers—our own Kennedy unit at Hopkins providing services to a larger number of handicapped than the other facilities combined. They have been regional quality control centers. They have functioned effectively as information centers in the Nation. They have developed programs which are providing personnel to people the service needs in the community.

They have been innovators and they are now moving into new fields, such as law and ethics and new areas that are essential for the retarded and disabled. They have very importantly provided a link between universities and communities.

Any statements I have with regard to the Bill of Eights for the Mentally Retarded are essentially pro, also. I think the principles are excellent and represent a real demonstration of the humanity of the authors.

I have concern about some of the details. The philosophy is that of large institutions. There are requirements in the bill for standards for nursing services, dental care, and so forth. This implies very large institutions rather than small community-based ones.

There also tends to be an emphasis on services for individuals that do not really belong there, such as the mildly retarded. Shopping, community recreation, worship, and so forth in the community is probably much more likely for the mildly retarded. They do not belong in residential institutions.

I think it is also important to point out that there should be no duplication of councils and no duplication of plans.

Essentially, there should be a continuum of services in the home to the residential, without separation of community and institution.

I should like to make one other point. That is, that there should be, I believe, many more options open to parents than presently exist. At the present time, most parents of retarded children requiring residential care have only State-run and State-supported institutions.

I should like to include in the record the defranchised opinion in the care of the mentally retarded.

Senator KENNEDY. Without objection, it should be included in the record.

Dr. COOKE. I believe that the Bill of Rights for the Mentally Retarded should be expanded to a comprehensive bill of rights for the handicapped. I request that the material that has just been prepared by Miss Rowan be included with my testimony as, essentially, a statement of what a truly comprehensive bill of rights for the handicapped might be.

Senator KENNEDY. Without objection, that will be included. Thank you very much, Dr. Cooke.

[The information referred to follows:]

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TESTIMONY OF ROBERT E. COOKE, M.D.

CHAIRMAN, SCIENTIFIC ADVISORY BOARD

ON SENATE BILL S.427 DEVELOPMENTAL DISABILITIES SERVICES

AND FACILITIES CONSTRUCTION ACT

AND ON SENATE BILL S.458 BILL OF RIGHTS

FOR THE MENTALLY RETARDED

AT HEARINGS BEFORE

THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

February 8, 1973

For over 20 years the Joseph P. Kennedy, Jr. Foundation has served as essentially the only private foundation concerned with the problems of mental retardation. The Foundation pioneered in the building of hospitals for the retarded, then established at Harvard, Johns Hopkins, the University of Chicago, Stanford, Wisconsin, Peabody, and Miami, mental retardation centers which served as models for the Federal mental retardation research programs and the University Affiliated Facilities for the Mentally Retarded. It established the first nationwide and even international Special Olympics' physical education programs for the mentally retarded. It is now moving to fill other gaps not met by government by establishing ethics research and training programs and centers at Harvard and Georgetown. Throughout this period the Foundation has had the advice and support of the leading professionals and scientists in the field. It is thus uniquely qualified to speak in support of the Developmental Disabilities Act and the Bill of Rights for the Mentally Retarded. The views expressed also represent my own as Professor and Chairman of the Department of Pediatrics and Pediatrician-in-Chief of the Johns Hopkins Hospital, Visiting Professor of Preventive and Social Medicine at Harvard University School of Medicine, and Vice Chancellor

Designate for the Health Sciences of the University of Wisconsin. I am presently an adviser to the National Institute of Child Health and Human Development and have completed an assignment as Chairman of a Task Force to upgrade residential institutions in the State of Maryland.

During this period of time we have had the opportunity to observe first-hand the impact of constructive Federalism on the care, treatment, and prevention of mental retardation. In 1960 parent activities were widespread, but almost no scientific interest existed within universities. Through the creation of research centers in mental retardation by the Kennedy Foundation and by the governmental establishment of 10 research centers under part I of the Mental Retardation Facilities Construction Act research interest was kindled. As a consequence, a number of new disorders have been discovered and treatment or prevention has been developed. The role of viral agents in producing prenatal injury is now understood. The effects of bilirubin on the brain and its prevention and the prevention of injury are now established. Metabolic diseases in increasing number are under attack and analysis, and therapy in some is now possible. I will not discuss these developments at this time because they seem more appropriate for dicsussions of research support relating to the National Institute of Child Health and

Human Development and the National Institute of Neurological Diseases and Stroke.

In 1960 there were no training programs whatsoever in the field of mental retardation except for limited activities in special education. Social workers, physical therapists, occupational therapists, psychologists, dieticians, nutritionists, medical students, psychiatrists and pediatricians had no first-hand experience other than a rare visit to a large and usually depressing institution. The creation of the University Affiliated Facilities immediately provided a major resource in the United States for manpower development for service to the mentally retarded. In 1960 habilitation services for the mentally retarded were provided only on a very limited scale in the diagnostic and evaluation centers established by the Children's Bureau. Although cases were well-studied at these facilities, essentially no treatment programs existed to permit the carrying out of their multiple recommendations. The establishment of the University Affiliated Facilities provided for the first time model treatment programs as well as diagnosis. Between 1960 and the enactment of the Developmental Disabilities Act in 1970, there was an improvement in the provision of services. Clinical programs in behavior modification made it possible

to make socially acceptable the behavior of very seriously retarded and disturbed children. Recreation activities for the retarded were enormously expanded with the model Special Olympics program of the Kennedy Foundation. Camps were established and a number of treatment programs scattered throughout the cities and states of this country came into being. These programs were established essentially by a number of independent agencies bearing little relationship to each other and with no relationship whatsoever to the training given by centers in our universities. In addition, there were serious gaps in services in many geographic areas although on a nationwide scale the services and resources for the retarded were markedly improved throughout the past decade.

In 1970 the passage of the Developmental Disabilities Act presented each state with an opportunity to develop an in-depth plan for the developmentally disabled child and adult. In the first year of the program the major effort of the community programs was dedicated to the development of such planning activities. A careful analysis of all available services was carried out. Prevalence data and frequency of occurrence of various problems were gathered as well as careful distributions of age groups affected to make systematic planning of services possible for the first time.

In the next year of the program there was a movement on the part of most states to fill existing gaps in services to an extent although the amounts of money available were extraordinarily small. Cooperative area-wide transportation systems were worked out among public and other nonprofit agencies. These services included transporting of individuals to and from daily routine activities, including delivery of goods to sheltered workshops and activity centers. In this way resources already established were made acceptable to the whole community. In another community the severely handicapped were served by a life enrichment program through the development of services in an activity center to permit a more reasonable adjustment of older retarded and cerebral palsied in their own home settings, thus sparing the cost of residential care in a state or private institution. Hostels for severely and profoundly handicapped were developed in another community. Funds were made available to another private, nonprofit community agency to assist the local churches and clergy in developing innovative religious programs for the developmentally disabled older children and adults. Training programs for work in gasoline stations were developed in another community, thus making it possible for the disabled to become more self-sufficient.

These various examples illustrate how useful the Developmental Disabilities funds may be. Instead of being the major financial resource, they are essentially the glue or adhesive material which binds together the larger programs of a noncategorical variety. That is, they make possible the use of large funds such as Medicaid, Medicare for the older retarded, vocational rehabilitation funds, welfare service funds, educational funds, so that the developmentally disabled may profit maximally from all that government has to offer, both state and local, as well as assuring the optimal use of private agencies.

Our testimony in strong support of extension of the Developmental Disabilities Act for at least a five-year period is based on the conclusions cited. These derive from a review of Developmental Disabilities activities on a national level, as well as participation of myself and my staff to a degree in the State activities in Maryland and in that region, as well as personal participation in the review of problems of institutions in the State of Maryland. The extension of the legislation is absolutely essential since these programs are just attaining a critical mass that permits the translation of plans into new operations. A failure to extend support would lead to a rapid return of the care of the disabled to the pre-1960 period. Even though

there is considerably more money available in generic services now than existed in 1960, the retarded and the other groups served by the Developmental Disabilities Act require a multiplicity of services which are not available in most communities as a part of usual health care, usual educational activities or rehabilitation services. As a consequence, the retarded are easily left out of community activities, or they are confined in institutions as a secondary means of meeting so-called humanitarian needs.

The extension and expansion of the Developmental Disabilities Act is absolutely critical at this particular time. As a result of class action suits in several states, with the Partlow case in Alabama being the model, residential institutions are being required in a number of states, and soon on the national level, to discharge from the institutions residents who do not require residential care as the most effective means of treatment. *The principle of least restrictive treatment* has been thoroughly endorsed and promulgated by this court action. However, community programs will be overwhelmed if they are not increased and expanded to meet the present community demand as well as the additional load that will come from the institutions.

Although the first three years of the Developmental Disabilities Act has unquestionably led to a broadening of geographic coverage, an increase in public interest and concern, and an improved identification of needs, the funding patterns have been inadequate to permit any large expansion of available services. Group homes, activity centers, and workshops are still badly needed in the community. And funding is certainly insufficient to build the necessary community-based services required by individuals removed from institutions. The State of Massachusetts, for example, has developed a planning process which has been copied by a number of other states. The resources are still grossly inadequate to meet the needs of the retarded, cerebral palsied, and epileptic who are in the community at the present time, let alone those who may be displaced from institutions by appropriate review.

In the process that will be occurring in the next few years, as there is a transfer of interest, hopefully, from institutions to communities, the Developmental Disabilities State Councils can be of enormous assistance in the coordination of the spectrum of services that range from full-time home activities to full-time residential institutional activities. These councils can develop detailed strategies to obtain full use of all available funds and, if given additional

monies, can fill gaps and provide resources to complement the training, education, and research activities in the University Affiliated Facilities. The coordinating roles of these Developmental Disabilities Councils will not cease as programs develop, but will have to continue indefinitely. An extension is therefore most important. Domiciliary and special living opportunities for young and old dependents are needed; day care opportunities for the young and severely retarded within the community are in short supply; protective and social legal services are needed that provide advocacy for the retarded when the parent no longer is able to participate. There is still great need for long-term sheltered employment opportunities and continued interagency cooperation and coordination is necessary to obtain maximum benefits for the multiply handicapped.

In the extension of part C of the Developmental Disabilities Act it is essential that there not be a diminishing Federal participation. Any further reductions below the authorized levels would be interpreted as mere tokenism. When a state with multiple problems, with many poor and underprivileged children and adults, and with many minority groups receives less than $300,000 per year for all of its community Developmental Disabilities activities, there is no great opportunity to accomplish the wonders that are expected.

It is also hoped in this extension that there be the least possible change in procedures and definitions. If the Developmental Disabilities program had been operating for many years, then inclusions at this time would seem to be appropriate, but the Act indeed is in the developmental stage and further additions and complications would simply lead to its disabling.

Testimony in support of part B related to the University Affiliated Facilities is easily mounted. These facilities have become resources for the whole region in which they are located, either diagnostic or therapeutic. They have been responsible for extensive manpower development which is heavily weighted quantitatively toward nonphysicians, although some physician experience has been provided. At the time of the hearings in 1969, I discussed in detail the educational opportunities provided by the University Affiliated Facilities for the retarded in many disciplines. I would hope that this statement might be reviewed because it is as applicable now as then. During this past three years it has been possible with the Developmental Disabilities core support to move into new areas such as increased parent education, new careers programs with associated support from the Department of Labor which have made possible the training of life managers out of the poor and previously unemployable of the inner city.

A copy of a training manual of this new careers program developed at the Kennedy Institute in Baltimore is available for inspection by the Committee. This successful program has converted social dropouts to productive members of society.

These University Affiliated Facilities have become resources for the whole region in programs of moral, ethical and legal education for law enforcement personnel. In our Kennedy Institute at Hopkins the Developmental Disabilities core support has made it possible to develop special educational programs for profoundly and severely retarded and for community teacher education. A computer related data collection system is now possible. One of the major achievements has been the development of dental care and a dental training program -- dental care being one of the most seriously neglected of the services for the developmentally disabled. Pharmaco-therapy of the Developmental Disabilities is now much improved over a few years ago as a consequence of work under this core support. A resource which certainly would be completely forgotten in most programs as a community resource is that of library development. The Developmental Disabilities Act has made it possible to have under one roof literature in relation to occupational therapy, physical therapy, speech and hearing, psychology, education of the

developmentally disabled and many other topics. Volunteer programs have been created with the establishment of a hotline from the community so that information can be provided for parents so that they can obtain optimal services for their children or young adults. This has led to the development of an information service center manned by volunteers who have produced an information referral manual for the whole State of Maryland. Media development has been possible with over 400 hours of videotape material concerned with patients so that the knowledge gained and the new techniques developed can be exported to other groups in the community or other University Affiliated Facilities.

The University Affiliated Facilities have been invaluable in providing consultative services to other mental retardation agencies, either public or private. For example, with the unfortunate death of the director of the Developmental Disabilities Planning Program in Maryland, the Kennedy Institute staff were able to step into the breach and develop an acceptable State plan. Three years ago the University Affiliated Facilities were thought of as the mental retardation arm of a single university; on the other hand, most have now developed multiple ties with many organizations. The Kennedy Institute at Hopkins, for example, is actively affiliated or associated with over 30 colleges and universities.

The University Affiliated Facilities have conducted training sessions for regional Developmental Disabilities Councils and have provided considerable assistance not only with the state planning but with the actual coordination of activities and the provision of many services that were missing. Unfortunately, there are only a relatively few of these compared with the number of states and efforts must be continued to expand their numbers and support so they can meet the needs of whole regions.

As regards the definition of developmental disability, again in relationship to the University Affiliated Facilities section the least change in definition would seem to be the most desirable. Unless there is a marked increase in funding, the additional categories cannot be properly served and at the present time professionals do not have difficulty with the classification system that is provided.

Bill of Rights for the Mentally Retarded

Although quantitatively, I have devoted the bulk of my testimony to the Developmental Disabilities Act, we support also the principles expressed in S.4S8. In these principles, Senator Javits has truly demonstrated his humane concerns. The institutionalized mentally retarded are the most neglected of all persons in our society. They have been subjected to ethical and legal abuses, with loss of rights, both civil and personal, frequently occurring without even a semblance of due process. Such abuses have recently been recognized by class action suits through the courts and some change can be expected. Some of the dehumanizing aspects result from gross inadequacies of institutional facilities, programs and personnel, and are not a necessary consequence of residential care. Some would do away with all residential care but this is obviously not feasible.

There is no question but that residential care outside the parents' home is necessary in some instances. Families for a host of reasons may not be able to cope. Families may disintegrate from illness, physical, mental or social. The retarded or disabled may present management problems far greater than any parents can take care of, or the retarded

may age and move into adult life without parental care. Thus, we will need residential care for many, many years to come.

If one compares the availability of medical care to the general public with the availability of residential care to the mentally retarded, serious differences come to light. In the creation of Medicaid as well as Medicare, free choice of physicians and hospitals was an essential ingredient. Since the enactment of Medicare and Medicaid, free choice has moved the consumer away from public medicine as it previously existed. The poor in many areas have rejected inadequate clinic care because of the long lines, massive facilities, and a degree of impersonality which they are unwilling to tolerate. The poor have demanded a middle-class system. In response to this demand for private-type medical services, facilities are being built or altered to provide more acceptable environments for patient care. City hospitals are undergoing face lifting operations that are transforming the long benches to more private-like clinics. On the other hand, in the care of the retarded, particularly the residential care, there is essentially no choice. If residential care is required, the only available choice except for the wealthy is the state-run institutional system. If day care out of the home is needed, essentially no funds are available for

young couples unless they are medically indigent. Extended care and private facilities for the mentally retarded are almost never met by private insurance, not even by Major Medical benefits. A few states contract with some private facilities to provide residential services, but here again there is almost no choice available to the parent. Usually, this public care is located many miles away, sometimes even across state lines. The facilities are usually large, old and planned many years before modern concepts of handling the retarded were developed. They are impersonal; they are crowded. Yet these facilities represent a major capital investment for the state - large physical plants, large civil service payrolls and large commitments which minimize change as a result of the enormous inertia of such monolithic systems. Even now many of these excessively large facilities are being enlarged still further. Although this proposed legislation is an effort to improve existing residential facilities; it should represent only a stop-gap measure, and very serious consideration must be given as to whether or not the support of the existing facilities as such is the best answer.

The principles of care enunciated in the Bill of Rights are absolutely correct and merit the attention of all interested citizens. The implementation, however, must not lead to a

permanent continuation of the monopolistic, monolithic system that presently exists. What if these public institutions do not satisfy parents? What if care is poor? What if monitoring by Federal agencies is impossible, as I believe it is? What if distances are too great? What if legislatures limit appropriations? Under our present system, families have no options, no more free choice than the medically indigent several years ago, only the "city hospital" for the retarded. Some may be good but many are bad.

The present system is totally noncompetitive; there is no free choice and indeed there may be a degree of competition of the residential facilities in the state with community activity. Each dollar given to community activities may be regarded by the bureaucracy running the state programs as a dollar less for expansion or improvement of its institutional programs. It is not surprising, therefore, that there is relatively little pressure at times from state agencies to improve community activities which are frequently voluntary and not operated by the state, although at times state supported. If one used the same principles in the care of the retarded as applied to acute medical care, a new basis for reimbursement would be developed, namely an insurance supported scheme on the widest possible basis to meet unexpected and catastrophic burdens.

The application of this free choice principle as found in the Medicare Act to the care of the severely and profoundly handicapped would make possible payments through a voucher system to families to assist in providing care where families prefer rather than public officials prefer care. With consumer demand increased and consumer capability to pay made possible, a multiplicity and variety of facilities to meet a variety of needs would be created, just as followed the Medicare/Medicaid Act. Small size of facilities would be inevitable because of the limits on local capitalization for such a venture. Small size, intimacy, personal involvement, volunteer and parent participation would result. New job ladders, new job opportunities would arise close to home, since these facilities would be accessible as well as available to the married women and the volunteers, young and old, of urban and suburban society. Nonprofit, or proprietary, both could flourish, regulated more by consumer satisfaction and competition, by parent boards and community leaders, than by legislative committees, or even boards of trustees that "visit the institution once a year."

How would an infant, child, or adult enter this system? By application from the family or an agency acting for the family. Determination of disability would be made by medical,

psychological and other disciplines, utilizing the University Affiliated Facilities, if they existed, the diagnostic and evaluation centers that have been set up by the Maternal and Child Health Service, or other programs that exist in the community. Appropriate study for each child would be guaranteed as a by-product of this system, since thorough evaluation would be required before reimbursement. The statewide Developmental Disabilities Councils referred to in the Developmental Disabilities Act could develop an advocacy system that would assure protection of parents and subjects to avoid exploitation. The creation of life managers behind the scenes by such Councils would be an important contribution to the care of the dependent. Some may say that this is a step down the road to more socialized medicine or more socialized care. To those I would say that the present system, particularly residential care, is the ultimate in socialized medicine. The facilities are owned and operated by the state; they are state controlled and state regulated.

Sooner or later parents of the retarded will demand options, options that they control, not options controlled by others. In a free society sooner or later free choice is inevitable, even for our least privileged, the retarded. Again, the methods of funding which I suggest are no longer

as radical a step as it seemed a few years ago. Our Social Security System now takes responsibility for the totally disabled whether they have been workers or not. The development of a voucher system for such activities would permit purchase of care where appropriate and should be considered seriously in the formulation of this legislation.

My concern for the more flexible approach is heightened by some of the language of this bill. Statements such as that on page 16 pertaining to attendance in regular schools, worship, community recreation and shopping indicate that the residential facilities referred to would be used primarily by the mildly retarded, and this group is the one that does not belong in residential care whatsoever. The profoundly and severely retarded would not attend regular school and would not participate in regular community activities in general. If the principle of least restrictive treatment and care is followed, except for the profoundly or severely retarded, the community can find a far better place than the residential institution. Many of the standards described in this Bill of Rights sound as though the institutions will have to be large and simply an upgrading of the present facilities. There are described such activities as nursing services, library services, food preparation services, facilities for general anesthesia and for dental care.

These indicate that the drafting of this legislation was geared toward the very large facility and not the small community facility as a model.

It would be hoped that, rather than develop a duplicative system that is concerned solely with residential care, every effort be made to have a single spectrum of services, not a separation of services, and that the activities in the community are integrated fully with the residential activities. There should be a single advisory council which is concerned with Developmental Disabilities in institutions and in the community. There should be a single state plan and a continuum of services rather than a separation of services. If this is truly to be Bill of Rights for the Mentally Retarded then there are many other considerations which should be included that relate to the civil and personal rights of the retarded. One of the Kennedy Scholars at the University of Miami, Miss Beverly Rowan, has developed model legislation which could serve as a Bill of Rights for the Retarded and it is hoped that this model legislation might be included with this testimony to provide some guidance for the drafting of a comprehensive Bill of Rights in the future.

In closing, it is again a great privilege and pleasure to appear before this Committee that is truly concerned with the well being of the less fortunate in our society.

PROPOSED REVISION OF CHAPTER 393

(1) Short title. Chapter 393 shall be known as "The Florida Law on Mental Retardation."

(2) Purpose. It is the purpose of this act to authorize and direct the department of health and rehabilitative services to evaluate, research, plan, and recommend to the governor and to the legislature, programs designed to reduce the occurrence, severity, and disabling effects of mental retardation. The department is directed to implement and administer programs through the division of retardation as authorized and approved by the legislature, based on the department's annual program budget. It is the further purpose of this act that the deparment shall coordinate the development, maintenance, and improvement of all programs and facilities for the mentally retarded in this state. Programs for the proper habilitation and treatment of the mentally retarded shall include, but not be limited to, comprehensive medical care, education , • recreation , training, and psychological, social work, and rehabilitative services suited to the needs of the individual, regardless of his age, degree of retardation, or handicapping condition. The department is further directed to fully effectuate the normalization principle through the establishment of community services for the mentally retarded as a viable and practicable alternative to institutional care at each stage of an individual's life development. Finally, it is the clear and unequivocal purpose of this act to guarantee the individual dignity and to protect the legal rights of all mentally retarded persons in accordance with the requirements of the law strictly construed.

(3) Definitions. As used in this act:

(a) "Mental retardation" refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior;

(b) "Habilitation" refers to the process by which an individual

is assisted to acquire and maintain those life skills which enable him to cope more effectively with the demands of his own person and of his enviornment and to raise the level of his physical, mental and social efficiency. Habilitation includes but is not limited to programs of formal, structured education and treatment;

(c) "Normalization principle" refers to the principle of letting the mentally retarded obtain an existence as close to the normal as possible, making available to them patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. Specifically, this principle involves the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible.

(d) "Treatment" refers to the prevention, amelioration, and/or cure of an individual's physical and mental disabilities or illnesses;

(6) "Facility" means any public or private residential or nonresidential institution, training center, hospital, clinic, school, group living unit, or similar facility serving the mentally retarded.

(f) "Institutional care" means habilitation and treatment in a public or private residential facility for the mentally retarded;

(g) "Community services" means-all, community based residential and nonresidential services necessary for the habilitation and treatment of mentally retarded persons outside an institution and includes, but is not limited to, medical treatment, education, recreation, training, and psychological and social work. services;

(h) 'Resident" means a person of any age who is receiving institutional care or community residential care in a facility for the mentally retarded;

(i) "Applicant" means a mentally retarded person of any age for whom admission to institutional care or community services provided by the division is sought whether such person seeks it of his own initiative or upon the initiative of his parent or legal guardian;

(j) "Legal guardian" means the court appointed, legal guardian of the person and/or property of a mentally retarded person of any age;

(k) "Disinterested expert" means an appropriately licensed or certified professional not employed by the state, not associated with an institution engaged in custodial care of the applicant, not previously engaged in professional care of the applicant, and not personally related to the applicant;

(l) "Clinical record" means all parts of the record relative to each resident required to be maintained and includes all information pertaining to the resident's admission, legal status, treatment, individualized habilitation plan, and all other information recorded by the facility which pertains to a particular resident;

(m) "Department" means the department of health and rehabilitative services;

(n) "Secretary" means the secretary of the department of health and rehabilitative services;

(o) "Division" means the division of retardation of the department of health and rehabilitative services;

(p) "Director" means the director of the division of retardation;

(q) "Regional center" refers to one of eleven administrative regions in the state through which the division of retardation provides institutional care and community services for mentally retarded persons;

(r) "Regional director" means the director of a regional center under the division of retardation;

(s) "Director of regional client services" means the director of institutional care in each region;

(t) "Director of regional special services" means the director of community services in each region;

(u) "Court" means the circuit court; and

(w) "Judge" means a judge of the circuit court. *

(4) Operation and Administration.

(a) Administration. The department, by and through the division of retardation, is designated the mental retardation authority of Florida. The department shall exercise executive and administrative supervision over all division facilities, programs, and services. The department shall forthwith assign or transfer to the division all state functions directly related to the supervision of, or responsibility for, all services and facilities for the habilitation and treatment of mentally retarded persons. In addition, the division of retardation is hereby designated the state administering agency for the receipt and expenditure of funds under the developmental disabilities services and construction act.

(b) Responsibilities of the Department. The department, through the division, shall be responsible for the preparation, development, evaluation, and coordination of a complete and comprehensive state-wide plan for the mentally retarded. The department shall likewise be responsible for the implementation of programs and coordination of efforts with other departments and divisions of the state government, federal, county and municipal governments, and private agencies and associations concerned with and providing services for the mentally retarded. It shall be responsible for the administration and operation of all state-operated facilities established for the diagnosis, care, treatment, habiliation, and training of the mentally retarded. It shall be responsible for establishing and monitoring standards for, providing technical assistance to, and exercising general program supervision of all state-operated facilities for the mentally retarded. It shall be

(x) "Physician" means a person licensed and qualified to practice medicine in the State of Florida.

responsible for licensing and monitoring all private facilities for the mentally retarded in this state on the basis of comprehensive standards and the requirements of this Chapter. It shall be responsible for establishing comprehensive community services for the mentally retarded to promote the habilitation and treatment of such persons in their home communities. It shall be responsible for stimulating research by public and private agencies and associations, institutions of higher learning, and hospitals and medical facilities in the interests of the amelioration and elimination of mental retardation and the proper habilitation and treatment of mentally retarded persons.

(c) State-operated facilities. State-operated facilities to provide institutional care and community services for mentally retarded persons shall be established in the eleven administrative regions of the state and shall include the existing sunland training centers, hospitals, and regional community centers. All state-operated facilities for the mentally retarded shall be under the supervision and control of the department, by and through the division, and administered through the regional centers. The regional centers shall provide community based alternatives to institutional care so that mentally retarded individuals may continue to live and function in their home communities. Specifically, the regional centers shall provide a pattern of facilities, programs, and community services to meet the needs of each mentally retarded person at each stage of his life's development regardless of his age, degree of retardation, or handicapping condition and shall include, but not be limited to: diagnostic and evaluative services; day care and training services; community residential services such as group living units, half-way houses, and foster homes; transportation services incidental to training and rehabilitative services; medical care and. psychological and social work services; specified home services; and institutional care.

(d) State-licensed facilities. All private, non-profit and proprietary facilities for the care, habilitation and treatment of mentally retarded persons shall be licensed by the department through the division. A license shall be issued for one year on the basis of comprehensive standards adopted and promulgated by the department and after a comprehensive inspection of the facility to be licensed. The department shall at regular and frequent intervals examine all state-licensed facilities in order to ascertain whether each facility continues to meet department standards. To this end, the department shall inquire into conditions of the physical plant, qualifications of personnel, methods of administration, program, and management of all persons served therein. The division may further inquire of and receive information from any person connected with the facility including, but not limited to, employees, residents, and parents. If, after due notice to the facility and opportunity for it to be heard, it is in the best interests of the mentally retarded persons serviced by the facility, the department may for just and reasonable cause amend, suspend, or revoke any license issued by it.

(e) Power to contract. The department, through the division, may contract with other agencies to provide, and be provided with, services and facilities in order to carry out its responsibilities under this act including, but not limited to: public and private hospitals; clinics and laboratories; departments, divisions, and other units of the state government; counties, municipalities, and other governmental units; units of the federal government; institutions of higher learning; and any other public or private entity which provides or needs facilities or services. The department shall make periodic audits, inspections and reviews to assure that the contracted services and facilities continue to meet the highest standards of the department.

(f) Application for and acceptance of gifts and grants. The department, through the division, may apply for and accept any

funds, grants, gifts, and services made available to it by any agency or department of the federal government or any other public or private agency or individual in aid of mental retardation programs undertaken, maintained, or proposed. All such moneys shall be deposited in the state treasury and disbursed as provided by law.

(g) Rules and regulations; personnel.

1. The department shall adopt rules and regulations necessary for the administration of this act in accordance with the administrative procedure act, chapter 120, provided that all rules and regulations so adopted shall be periodically reviewed no less frequently than every six months.

2. The director of the division, subject to the approval of the secretary of the department, shall appoint regional directors to manage, supervise, and administer division programs and services in each of the eleven administrative regions of the state. Regional directors so appointed shall be qualified for their respective positions. They shall be trained and experienced in fields related to mental retardation and in the management and administration of residential and nonresidential programs and services.

3. The director of the division, subject to the approval of the secretary of the department, shall appoint directors of regional client services and directors of regional special services in each of the eleven administrative regions of the state. Such directors shall be qualified for their respective positions and trained and experienced in fields related to mental retardation.

4. Bureau chiefs, regional directors, directors of regional client services, and directors of regional special services shall be exempt from the provisions of state career service. The director of the division may freely suspend or transfer such personnel when in the best interests of mentally retarded persons and approved by the secretary of the department. In the event that one such position becomes vacant for any reason, the director shall appoint a temporary replacement immediately and a permanent replacement within

sixty (60) days.

(h) Financing community services and residential care.

1. Primary financial responsibility for the habilitation and treatment of mentally retarded persons in this state shall lie with the State of Florida.

2. The department, by and through the division shall utilize appropriate federal funds and assistance as well as other public and private grants and gifts to the maximum available.

3. The department, through the division, may initiate a system of family contribution to the cost of institutional care and/or community services provided children under twenty-one (21) years of age by the division. The exact amount of family contribution shall be indicated on a sliding fee schedule and shall be dependent upon the cost of care or services provided and each family's ability to pay. The fee schedule shall take into account the basic public entitlements which the child would receive if he were not mentally retarded and lived at home. In no case, however, shall the amount of family contribution exceed the cost of caring for a normal child at home.

4. Subject to the previous subsection on family contribution, the department shall pay the cost of habilitation and treatment in a privately operated facility or through a private organization or agency where appropriate community services or institutional care is unavailable through the division.

(i) Review of community services and residential care.

A Human Rights Advocacy Committee shall be established by the department in each region of the state. Each committee shall be composed of sixteen (16) members, at least ten of whom shall be private citizens not employed by the division of retardation or any agency funded by it. Parents of retarded persons shall have representation on the committee. The remaining members shall include at least one retarded person, a representative of non-professional employees, and the remaining four to be selected from the regional

director, director of client services, director of social services and director of residential programs. The citizen members of the committee shall be representative of the geographical area served by the region. The principal responsibility of each committee shall be to review institutional care provided at state-operated facilities within the region and to perform such other duties as prescribed in this chapter. In addition, each committee shall review institutional care provided at state-licensed facilities within the region and community services provided by the division within the region. Committee members shall serve on a volunteer basis. Committee members shall be authorized to enter, with or without pre-arrangement, any state-operated or state-licensed facility in the region to determine whether department standards and the requirements of this chapter are being met. Also, committee members shall receive inquiries and complaints concerning services and care within the region. Each regional Human Rights Advocacy Committee shall meet at regular intervals and shall report on a periodic basis to the facilities involved and to the department any observations, comments, complaints, or possible violations of department standards or of the provisions of this chapter regarding any given facility.

(5) Legal rights of mentally retarded persons.

(a) Legal rights generally.

Notwithstanding any other provision of law, no person shall be denied any of the rights enjoyed by citizens of Florida and of the United States solely by reason of his admission to institutional care or receipt of community services for a condition of mental retardation, except as expressly determined by an appropriate court of law. No person shall be denied the full exercise of any and all of his civil rights including but not limited to the right to dispose of property, execute instruments, make purchases, enter into contracts, vote, marry, have children, and hold a driver's license unless adjudicated incompetent to do so by a court of law. No person shall be

declared or adjudicated incompetent except after a full hearing to determine his competency. All parties shall be given notice in writing not less than twenty (20) days before the scheduled hearing. The person alleged to be incompetent shall be physically present throughout the entire proceeding, effectively represented by counsel, and provided the right and opportunity to be confronted with and to cross examine all witnesses alleging his incompetency. In such proceedings, the burden of proof shall be on the party alleging incompetency.

(b) Right to individual dignity.

The individual dignity and worth of a mentally retarded person shall be respected at all times, upon all occasions, and by all persons.

(c) Right to education and training.

Each mentally retarded person shall have an equal educational opportunity and shall receive publicly supported education and training suited to his needs regardless of chronological age, degree of retardation, accompanying disabilities or handicaps, or admission to institutional care.

(6) Legal Rights of Residents.

In addition to the above listed legal rights of mentally retarded persons, each resident of an institution or community residential program serving mentally retarded persons shall enjoy the legal rights enumerated below.

(a) Right to habilitation and treatment.

1. Each resident shall receive proper habilitation and treatment, including medical treatment, education, recreation, training, and psychological and social work services suited to his needs, regardless of his age, degree of retardation, or handicapping condition.

2. Each resident shall participate in a habilitation program which will maximize his human abilities and enhance his ability to cope with his environment. The facility shall recognize that each resident, regardless of ability

or status, is entitled to develop and realize his fullest potential. The facility shall implement the principle of normalization so that each resident may live as normally as possible, including appropriate opportunities for the resident's interaction with members of the opposite sex.

(b) Right to individualized habilitation plan.

1. Prior to his admission to institutional or residential care, each resident shall have comprehensive social work, psychological, educational, and medical diagnoses and evaluations by licensed and qualified specialists to determine if admission is appropriate. These specialists shall appear and testify in person before the court at any admission proceeding.

2. Each resident shall have an individualized habilitation plan formulated by the facility. This plan shall be developed by appropriate qualified and licensed professionals and be implemented as soon as possible but no later than fourteen (14) days after the resident's admission to the facility.

3. Each habilitation plan shall be reviewed monthly by an interdisciplinary review team of qualified and licensed professionals and such resident care workers as are directly involved in the particular resident's habilitation and care. The resident's habilitation plan shall be modified as necessary or appropriate. Six months after admission and at least every six months thereafter, each resident shall receive comprehensive psychological, social work,' educational, and medical diagnoses and evaluation by qualified and licensed specialists to determine:

i. the value and appropriateness of present habilitation and treatment;

ii. future habilitation and treatment goals and needs;

iii. the necessity of continued institutional or community residential care and treatment; and

iv. the appropriateness of alternative nonresidential programs of care and treatment.

Such periodic re-examiniations and re-evaluations shall be made with a view toward discharge from institutional or community residential care as soon as practicable.

(c) Right to medical treatment and care.

1. Each resident shall receive prompt and appropriate medical treatment and care for any physical ailments and for the prevention of any illness or disability. Such medical treatment shall meet the highest standards of medical practice in the community.

2. No medication shall be administered unless at the written order of a physician. Notation of each individual's medication shall be kept in his clinical record. At least weekly the attending physician shall review the drug regimen of each resident under his care. All prescriptions shall be written with a termination date, which shall not exceed thirty (30) days.

3. Each resident shall be free from unnecessary or excessive medication. Medication shall not be used as punishment, for the convenience of staff, as a substitute for a habilitation program, or in quantities that interfere with the resident's habilitation program.

4. No resident shall be subjected to experimental research without the express and informed consent of the resident, if the resident is over twenty-one (21) years of age and is able to give such consent, or of the parent of a resident under twenty-one (21) years of age or of the legal

guardian of a resident of any age, and after consultation with independent specialists and legal counsel. Such proposed research shall first have been reviewed and approved by the division and then by the regional Human Rights Advocacy Committee before such consent shall be sought.

5. No resident shall be subjected to any unusual or hazardous treatment procedures without the express and informed consent of the resident, if the resident is over twenty-one (21) years of age and is able to give such consent, or of the parent of a resident under twenty-one <21) years of age or of the legal guardian of a resident of any age, and after consultation with independent specialists and legal counsel. Such proposed procedures shall first have been reviewed and approved by the division and then by the regional Human Rights Advocacy Committee before such consent shall be sought.

6. No resident shall have any of his organs removed for purpose of transplantation without the express and informed consent of the resident, if the resident is over twenty-one (21) years of age and is able to give such consent, or of the parent of a resident under twenty-one (21) years of age or of the legal guardian of a resident of any age, and after consultation with independent specialists and legal counsel. In addition, a court hearing to determine the appropriateness of such transplantation shall be held at which the resident is physically present, effectively represented by counsel, and provided the right and opportunity to be confronted with and to cross examine all witnesses alleging the appropriateness of transplantation. In such proceedings, the burden of proof shall be on the party alleging the appropriateness of transplantation. The requirements of this subsection shall also apply to

any other surgical procedure, including a sterilization procedure, which is undertaken for reasons other than clear therapeutic benefit to the resident.

7. As used in this section, "express and informed consent" means consent freely and. intelligently given in writing. Free and intelligent consent shall require that the person whose consent is sought be adequately and effectively informed as to:

i. Method of experimental research, unusual or hazardous treatment, transplantation, sterilization, or other non-therapeutic surgery;

ii. Nature and consequence of such procedures;

iii. Risks, benefits, and purposes of such procedures; and

iv. Sources of funding such procedures.

The express and informed consent of any person may be revoked prospectively at any time with or without cause. Also, all experimental research and unusual or hazardous treatment procedures upon a particular resident shall be discontinued immediately where the resident shows signs of adverse reaction to such research and procedures.

8. The absence of express and informed consent notwithstanding, a licensed and qualified physician may render emergency medical care or treatment to any resident who has been injured in an accident or who is suffering from an acute illness, disease, or condition, if within a reasonable degree of medical certainty delay in initiation of emergency medical care or treatment would endanger the health of the resident and provided such emergency medical care or treatment is authorized and approved by the administrative head of the facility involved.

(d) Right to humane care and treatment.

1. Corporal punishment shall not be permitted.

2. The facility shall prohibit mistreatment, neglect, or abuse of any resident in any form. All alleged violations shall be reported immediately to the regional director and to the regional Human Rights Advocacy Committee. Each alleged violation shall be thoroughly investigated. The results of each such investigation shall be reported to the regional director and to the director of the division within twenty-four (24) hours of the incident.' A written report shall be filed with the director within three days after the incident. The regional Human Rights Advocacy Committee shall conduct a similar investigation of its own.

3. Each resident shall enjoy a humane physical environment within the facility. The facility shall be designed to make a positive contribution to the efficient attainment of the habilitation goals of each resident.

4. Each resident shall be attended to by qualified staff in numbers sufficient to provide appropriate habilitation.

5. Seclusion, defined as the placement of a resident alone in a closed room for the purpose of punishment, shall not be employed. Legitimate "time out" procedures, defined as separation from other residents and group activities, may be utilized under close and direct professional supervision as a technique in behavior-shaping programs.

6. Behavior modification programs involving the use of noxious or aversive stimuli shall be reviewed and approved by the regional Human Rights Advocacy Committee and shall be conducted only with the express and informed consent of the affected resident, if the resident is over twenty-one (21) years of age and able to give such consent, or of the parent of a resident under twenty-one (21) years of age or of the legal guardian of a resident of any age, and

after consultation with independent specialists and legal counsel. Such behavior modification programs shall be conducted only under the supervision of and in the presence of a licensed and qualified professional who has had proper training and experience in such techniques.

7. Physical restraint shall be employed only when absolutely necessary to protect the resident from injury to himself or to prevent injury to others. Restraint shall not be employed as punishment, for the convenience of staff, or as a substitute for a habilitation program. Restraint shall be applied only if alternative techniques have failed and only if such restraint imposes the least possible restriction consistent with its purpose. Only the administrative head of the facility may authorize the use of restraints. Orders for restraints shall be in writing and shall not be in force for longer than six (6) hours. Mechanical restraints shall be designed and used so as not to cause physical injury to the resident and so as to cause the least possible discomfort. A resident placed in restraint shall be checked at least every thirty (30) minutes by staff trained in the use of restraints and a record of such checks shall be kept. Opportunity for motion and exercise shall be provided for a period of not less than ten (10) minutes during each two (2) hours in which restraint is employed. A monthly report shall be made to the regional Human Rights Advocacy Committee by the administrative head of the facility summarizing all uses of restraint, the types used, the duration, and the reasons therefor. The regional Human Rights Advocacy Committee shall have authority to review any restraint imposed by the administrative head.

8. All physical injuries to any resident, all incidents of mistreatment, neglect or abuse, and all uses of physical restraint or other methods of punishment shall be recorded in log books established and maintained by each facility for this purpose. All entries shall be dated, signed by the reporting party, and reflect all remedial action taken by the facility. The regional Human Rights Advocacy Committee shall regularly inspect and review these log books and take such action as it deems appropriate.

(e) Right to religious worship.

The opportunity for religious worship shall be accorded to each resident. Provisions for religious worship shall be made available to all residents on a nondiscriminatory basis. No individual shall be coerced into engaging in any religious activity.

(f) Rights to communications and visits.

1. Each resident has the right to communicate freely and privately with persons outside the facility. This right may be restricted only where there is clear reason to believe that such communication will be substantially harmful to the resident or to others.

2. Each resident has the right to receive and send sealed, unopened correspondence. No resident's incoming or outgoing correspondence shall be opened, delayed, held, or censored by the facility except where there is clear reason to believe that such correspondence will be substantially harmful to the resident or to others. However, correspondence addressed to public officials, attorneys, clergymen, or members of the regional Human Rights Advocacy Committee shall be absolutely privileged and shall be sent along promptly without being opened.

3. Each resident shall have the right to received and send packages. No resident's outgoing packages shall be

opened, delayed, held, or censored by the facility except where there is clear reason to believe that sending such package will substantially harm the resident or others. However, incoming packages may be opened and inspected by a representative of the facility in the presence of two witnesses. The contents of each package shall be itemized and noted in the resident's clinical record. An item so noted may be seized only where there is clear reason to believe that it will be substantially harmful to the resident or to others.

4. Each resident shall have reasonable and frequent opportunities to leave the facility to visit in the community.

5. Each resident shall have reasonable access to telephones and shall be afforded reasonable and frequent opportunities to meet with visitors.

6. The facility shall provide, under appropriate supervision, suitable* opportunities for the resident's interaction with members of the opposite sex.

7. A resident's rights to communications and visits, as provided in subsection 1 - 7 of this section, may be restricted only with the knowledge and approval in writing of the administrative head of the facility. Written notice of such restriction shall be immediately served on the resident, on his parent or guardian, and on the regional Human Rights Advocacy Committee. Also, such restrictions and the reasons therefor shall be recorded on the resident's clinical record. The restriction of a resident's right to communications and visits shall be reviewed at least every thirty (30) days. The regional Human Rights Advocacy Committee shall review and have authority to remove restrictions imposed by the administrative head of the facility.

(g) Right to fair employment practices.

1. No resident shall be required to perform labor which involves the operation and/or maintenance of the facility or for which the facility is under contract with an outside organization. Privileges or release from the facility shall not be conditioned upon the performance or nonperformance of labor covered by this subsection. Residents may voluntarily engage in such labor if the labor is compensated in accordance with applicable state and federal minimum wage laws.

2. No resident shall be involved in the care (feeding, clothing, bathing), training, or supervision of other residents unless he: has volunteered; has been specifically trained in the necessary skills; has the humane judgment required for such activities; is adequately supervised; and is reimbursed in accordance with the applicable state and federal minimum wage laws.

3. Each resident may perform vocational training tasks which do not involve the operation and/or maintenance of the facility, subject to a presumption that an assignment longer than three (3) months to any task is not a training task, and provided the specific task or any change in task assignment is an integral part of the resident's habilitation plan. If the resident performs vocational training tasks for which the facility is receiving compensation from any outside source, he shall be compensated in accordance with the applicable state and federal minimum wage laws.

4. Each resident may voluntarily engage in habilitative labor at non-program hours for which the facility would otherwise have to pay an employee, provided the specific labor or any change in labor is an integral part of the

resident's habilitation plan and is compensated in accordance with the applicable state and federal minimum wage laws.

5. Each resident may be required to perform tasks of a personal housekeeping nature as to himself only such as the making of his own bed.

6. Payment to residents pursuant to this section shall not be applied to defray the costs of maintenance of residents in the facility.

(h) Right to vote.

Each resident who is eligible to vote according to law has the right to vote in all primary and general elections. The department, through the division, shall establish rules and regulations to enable residents to register to vote and to obtain applications for absentee ballots and absentee ballots; to comply with other requirements which are prerequisite to voting; and to vote.

(i) Right to a clinical record.

A clinical record for each resident shall be diligently maintained. The record shall include information pertaining to the resident's admission, legal status, treatment, and individualized habilitation plan. The clinical record shall not be a public record and no part of it shall be released, except:

1. The record may be released to physicians, attorneys, and government agencies as designated by the resident, his parent, guardian, or attorney.

2. The record shall be produced in response to a subpoena or released to persons authorized by order of court. Matters privileged by other provisions of law shall not be so produced or released.

3. The record or any part thereof may be disclosed to a qualified researcher, staff member of the facility, or employee of the department or division when the secretary,

director, or regional director deems it necessary for the proper treatment of the resident, maintenance of adequate records, compilation of treatment data, or evaluation of programs.

4. Information from the clinical records may be used for statistical and research purposes if the information is abstracted in such a way as to protect the identity of individual residents.

Right to personal property.

1. Each resident has the right to the possession and use of his own clothing and personal effects. The superintendent may take temporary custody of such effects when it is essential to do so for medical or safety reasons. Custody of such personal effects shall be promptly recorded in the resident's clinical record and notice of such custody shall be immediately given to the resident, his parent or legal guardian, and to the regional Human Rights Advocacy Committee.

2. All money belonging to a resident held by the facility for the resident shall be held in a separate trust account for each individual resident and protected by bond or insurance. Each such account shall be audited annually by an independent auditor.

3. All interest on money received and held for a resident shall be the property of the individual resident and shall not accrue to the general welfare of all residents in the facility or be used to defray the cost of residential care. Interest so accrued shall be used or conserved for the benefit of the individual resident.

4. Upon the discharge or death of a resident, a final accounting shall be made of all personal effects and money belonging to the resident held by the facility.

All such personal effects and money including interest shall be promptly turned over to the resident or his heirs.

5. All canteen goods and services shall be available to residents at cost. Canteen employees shall be general revenue positions, not reimbursed from the canteen fund.

(k) Right to resident government.

Each facility shall initiate and develop a program of resident government to hear the views and represent the interests of all residents in the facility. The resident government shall be composed of residents elected by other residents, staff advisors skilled in the administration of community organizations, and a representative of the regional Human Rights Advocacy Committee. The resident government shall work closely with the regional Human Rights Advocacy. Committee to promote the interests and welfare of all residents in the facility.

(1) Right to habeas corpus.

1. At anytime and without notice; any person detained in a facility or his parent, guardian, or friend in his behalf is entitled to a writ of habeas corpus to question the cause,' legality, and appropriateness of the resident's detention upon proper application. Each person admitted to a facility for the mentally retarded and his parent or guardian shall receive specific written notice of the right to petition for a writ of habeas corpus. Such notice shall explain this right and how it may be invoked in plain and simple language.

2. Upon return of a writ of habeas corpus, a judge of the circuit court shall conduct a hearing to examine the facts concerning the person's mental condition and detention in the facility. All parties shall be given notice in writing not less than ten (10) days before the scheduled

hearing. The resident shall be physically present during the entire proceeding, effectively represented by counsel, and provided the right and opportunity to be confronted with and to cross examine all witnesses against him. The evidence shall include the resident's clinical record and such medical or other testimony as required by the court. The court shall review the admission and detention of the person in light of the requirements of this chapter and the rules, regulations, and standards of the department. The court shall discharge the resident if it finds that he is not an appropriate subject for institutional or community residential care. If it finds that the resident is receiving improper care and treatment or inadequate habilitation, the court shall either discharge the resident or order remedial measures implemented forthwith.

3. In a subsequent application for a writ of habeas corpus, any party to the proceeding may introduce evidence on record from a prior judicial proceeding. Such evidence shall have the same force and effect as testimonial evidence.

4. The resident or his parent, guardian, or friend in his behalf may petition the circuit court in the county where the resident is detained alleging that the resident is being unjustly denied a right or privilege granted by this chapter or that a procedure authorized herein is being abused. Upon the filing of such petition the court shall authorize and/or conduct a full judicial inquiry and issue any appropriate order aimed at remedying the situation.

(m) Right to notice.

1. The parent or guardian of each resident shall promptly, upon the resident's admission, receive a

written copy of these legal rights of residents including the legal rights of mentally retarded persons. Each resident, unless the resident is manifestly unable to comprehend, shall promptly upon his admission be orally informed in clear language of the above legal rights and, except where manifestly inappropriate, be provided with a written copy.

2. The administrative head of the facility shall report in writing to the parent or guardian of the resident at least every three months on the habilitation of the resident including his educational, vocational, psychological, social work, and living skills progress, and his medical condition.

(n) Liabilities for violations.

Any person who violates or abuses rights or privileges of residents provided by this chapter shall be liable for damages as determined by law.

(7) Admissions.

(a) Purpose of admissions generally.

1. No applicant shall be admitted to institutional care unless a prior determination shall have been made that institutional care in a residential facility is the least restrictive habilitation setting feasible for that person.

2. No applicant shall be admitted to institutional care if services and programs in the community can afford appropriate habilitation to such person.

3. Each applicant shall have the least restrictive conditions necessary to achieve the purposes of habilitation. To this end, the division shall make every effort to move applicants from a)more to less structured living; b) larger to smaller living' units; c) group to individual residence; d) segregated from the community to integrated

into the community living; e) dependent to independent living.

4. No mentally retarded child under six (6) years of age shall be admitted to institutional care unless such child is in need of constant medical supervision and full-time nursing care.

5. No borderline or mildly mentally retarded person shall be admitted to institutional care. For purposes of this subsection, a borderline retarded person is defined as an individual who is functioning between one and two standard deviations below the mean on a standardized intelligence test such as the Stanford Binet Scale and on measures of adaptive behavior such as the American Association on . Mental Deficiency Adaptive Behavior Scale. A mildly retarded person is defined as an individual who is functioning between two and three standard deviations below the mean on a standardized intelligence test such as the Stanford Binet Scale and on a measure of adaptive behavior such as the American Association on Mental Deficiency Adaptive Behavior Scale.

6. No person shall be admitted to residential care for the sole or principal reason that he is emotionally disturbed or a behavior problem.

7. Prior to his admission to community services or institutional care, each person shall have comprehensive psychological, social work, educational, and medical diagnoses and evaluations by licensed and qualified specialists in each such discipline to determine if admission is appropriate. Unless such preadmission evaluation has been conducted within three (3) months prior to his admission, each person admitted to community services or institutional care shall have a new evaluation to determine if admission is appropriate.

(b) Admissions to community services.

1. The department shall have authority to accept applications for voluntary admission to community services provided by the division. Applications shall be made to the department in writing on forms approved by the department.

2. For purposes of this section, "voluntary admission" means with the express and informed consent of the applicant for community services, if he is over twenty-one (21) years of age and is able to give such consent, or of the parent of an applicant under twenty-one (21) years of age or of the legal guardian of an applicant of any age.

3. Upon accepting an applicant for voluntary admission to community services, the department shall enter into a written contract with the applicant, or his parent or legal guardian as appropriate, whereby the department describes the community services to be provided by the division, describes the goals and objectives of such services, presents an individualized habilitation plan for the applicant, and agrees to provide the community services and habilitative program as described. The applicant, or his parent or legal guardian as appropriate, shall agree to cooperate with the department and pay such amount of family contribution to the costs of the community services received as may be specified by the deparment, subject to the requirements of section (4)(h)3 of this act. A contract for community services shall be fully enforceable for a limited period of time specified in the contract itself, but not to exceed one year.

(c) Admissions to institutional care.

1. ' The court shall have jurisdiction and authority to order that a mentally retarded person of any age may be

admitted to institutional care provided by the division where it is medically essential to do so or where the person is clearly dangerous to himself or others.

2. An admission to institutional care is medically essential only if clearly necessary to preserve the life or physical health of the applicant.

3. A mentally retarded person is clearly dangerous to himself or others if he has attempted suicide or serious self-injury, or if he has inflicted or attempted to inflict serious bodily harm on another within six (6) months prior to his application for insitutional care.

4. If the court determines that an admission is medically essential or that the mentally retarded person is clearly dangerous to himself or others, the court shall order that the applicant may be admitted to institutional care provided by the division. If the court determines that an admission is not medically essential or that the mentally retarded person is not clearly dangerous to himself or others, the petition for admission shall be dismissed.

5. Upon order that an applicant may be admitted to institutional care provided by the division, the department shall review the application as forwarded to it by the court. The department may admit such applicant to institutional care provided by the division if it determines that such is the most appropriate habilitative setting for that individual. Or, alternatively, the department may admit such applicant to community services provided by the division. In no case, however, shall the department refuse to serve a mentally retarded person that the court has ordered may be admitted to institutional care provided by the division.

6. Upon accepting a court-referred applicant for admission to institutional care, the department shall enter into a

written contract with the applicant, or his parent or legal guardian as appropriate, whereby the department describes the institutional care to be provided by the division, describes the goals and objectives of such care, presents an individualized habilitation plan for the applicant, and agrees to provide the institutional care and habilitative program as described. The applicant, or his parent or legal guardian as appropriate, shall agree to cooperate with the department and pay such amount of family contribution to the costs of institutional care received as may be specified by the department, subject to the requirements of section (4)(h)3 of this act. A contract for institutional care shall be fully enforceable for a limited period of time specified in the contract itself, but not to exceed one year.

7. In no case shall an order authorizing an admission to institutional care be considered an adjudication of mental incompetency or its equivalent; nor shall the matter of competency be properly raised or considered in an admission to institutional care hearing.

(d) Admission to institutional care proceedings.

1. Any applicant, the parent or legal guardian of any applicant, or the department may file a petition for admission to institutional care provided by the division.

2. The petition shall be executed under oath and set forth:

a. Name, birth date, sex, and residence address of the applicant;

b. Name and residence addresses of the applicant's parents and/or legal guardian;

c. A short and plain statement of the applicant's mental condition;

d. A short and plain statement of the facts rendering applicant's admission medically essential or the

applicant clearly dangerous to himself or others;

e. A short and plain statement of the institutional care for which admission is sought; and

f. A short and plain statement explaining the inappropriateness of admission to community services.

3. Copies of the petition and notices of the time and place for a hearing on the petition shall be served on the applicant, his parents and/or legal guardian, and the department not less than ten (10) days before the scheduled hearing.

4. Upon the filing of a petition, the court shall immediately fix a time for a hearing to determine the appropriateness of the applicant's admission to institutional care in a state-operated facility for the mentally retarded. The court shall appoint no fewer than three disinterested experts, qualified in the field of mental retardation, including at least one licensed and qualified physician, one licensed and qualified psychologist, and one licensed and qualified social worker to examine the applicant and to testify in person at the admission to institutional care hearing. Such expert testimony shall include, but not be limited to: the degree of applicant's retardation; the purpose to be served by institutional care; and the appropriate habilitation and treatment. Other evidence regarding the appropriateness of the applicant's admission may be introduced at the hearing by any interested party.

5. A full hearing on the petition shall be held as soon as practicable after the petition is filed. The applicant shall be physically present throughout the entire proceeding, effectively represented by counsel, and provided the right and opportunity to be confronted with and to cross examine all witnesses alleging the appropriateness of

his admission to institutional care. All evidence shall be presented according to the usual rules of evidence. All stages of each proceeding shall be stenographically reported. The burden of proof shall be on the party alleging the appropriateness of the applicant's admission to institutional care. In all cases, the court shall issue findings to support its decision and the basis for such findings.

6. An applicant shall be represented by counsel at all stages of a judicial admission proceeding. In the event that an applicant cannot afford counsel, the court shall appoint an attorney not less than twenty (20) days before the scheduled hearing. In all cases, a court appointed or otherwise procured attorney shall represent the rights and legal interests of the applicant regardless of who may initiate the proceedings and/or pay the attorney's fee. An attorney appointed pursuant to this section shall be entitled to a reasonable fee to be determined by the court.

7. Appeal of a final order in a judicial admission proceeding shall be by right in accordance with Article V of the Florida Constitution and the Florida Appellate Rules. Pendency of an appeal pursuant to this section shall stay admission until a final determination is made.

(e) Criminal or juvenile commitment.

Notwithstanding any other provision of this section, the court shall have jurisdiction and authority to commit a mentally retarded person of any age to the custody of the department for institutional care or community services provided by the division and the department shall accept such person, provided such commitment is in accordance with the requirements of the applicable criminal or juvenile court law.

(f) Validity of prior admissions.

No admission of a mentally retarded person for community

services or institutional care provided by the division, lawful before January 1, 1973, shall be deemed unlawful because of the enactment of this section. Within ninety (90) days of the enactment of this section, the department shall review the status of all persons presently admitted to community services or institutional care to insure that the requirements of this act have been fully complied with. Any person whose admission is not valid under the provisions of this act ninety (90) days after its enactment shall be discharged forthwith.

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(8) Discharge.

(a) Discharge after admission to community services.

1. Any person voluntarily admitted to nonresidential community services provided by the division may revoke his consent to such services prospectively and be immediately granted a voluntary discharge by the department.

2. Any person voluntarily admitted to community residential care may revoke his consent to such care prospectively and, within forty-eight (48) hours after giving written notice to the regional director of his desire and intention to leave the facility, be granted a voluntary' discharge by the department.

3. For purposes of this section, "voluntary discharge" means with the express and informed consent of the applicant for community services, if he is over twenty-one (21) years of age and is able to give such consent or of the parent of an applicant under twenty-one (21) years of age or of the legal guardian of an applicant of any age.

(b) Discharge after admission to institutional care.

1. If at any time after any person has been admitted to institutional care provided by the division, the resident, his parent or legal guardian, or the department is of the opinion that the resident's admission is no longer appropriate,

the court shall immediately fix a time for a hearing to determine the appropriateness of continued institutional care for the resident.

2. A discharge hearing shall be held as soon as practicable and in accordance with the requirements of section (7)(c) - (d) of this chapter dealing with admission to institutional care proceedings.

3. If the court determines that the resident's continued admission to institutional care is not medically essential or that the resident is not dangerous to himself or others, the resident shall be immediately discharged by the department. If the court determines that the resident's continued admission is medically essential or that the resident is dangerous to himself or others, he shall remain admitted to institutional care provided by the division.

4. Nothing in this section shall in any way limit or restrict the resident's right to a writ of habeas corpus, nor the right of the department to transfer a resident receiving institutional care to a program of community services provided by the division where such is the appropriate habilitative setting for the resident.

(c) Discharge after criminal or juvenile commitment.

Any mentally retarded person committed to the custody of the department pursuant to the provisions of the applicable criminal or juvenile court law shall be discharged in accordance with the requirements of the applicable criminal or juvenile court law.

(9) Competency.

(a) The issue of competency shall be separate and distinct from a determination of the appropriateness of admission to community services or institutional care for a condition of

mental retardation. No person shall be presumed incompetent solely by reason of his admission to community services or. institutional care; nor shall any such person be denied the full exercise of all legal rights guaranteed to citizens of Florida and of the United States except as expressly determined by an appropriate court of law.

(b) Where there is clear reason to believe that a person is incompetent by reason of a condition of mental retardation, proceedings to determine the competency of the individual may be initiated in accordance with the provisions and requirements of section 744.31, Fla. Stats. Such proceedings shall be initiated only if an adjudication of incompetency is essential for the appointment of a legal guardian of the person and/or property of the mentally retarded person.

(c) The effect of an adjudication of incompetency and the procedures for restoration to competency shall be as provided in section 744.31, Fla. Stats.

(10) Miscellaneous provisions.

(a) Custody of residents.

The department shall be the legal custodian of all persons admitted to institutional care or community residential care in a state-operated facility for the mentally retarded. The department shall not be the legal guardian of the person and/or property of such persons.

(b) Transfer of residents.

The department shall not under any circumstances transfer any person in a state-operated facility for the mentally retarded to any other state-operated facility not specifically for the habilitation and treatment of the mentally retarded.

(11) Severability.

It is declared to be the legislative intent that if any section, subsection, sentence, clause, or provision of this Florida law on mental retardation is held invalid, the remainder of the law shall not be affected.

PROPOSED STERILIZATION STATUTE

1. Legislative Intent.

(a) The legislature recognizes that sterilization is a drastic measure which should be resorted to only if clearly justified in light of all the facts. It is the intent of the legislature that both voluntary sterilizations and involuntary sterilizations upon court order shall be performed only in accordance with recognized standards of professional competency and as authorized by the provisions of this act strictly construed.

(b) This Legislature recognizes that any person over twenty-one (21) years of age who is competent to consent and who does in fact consent to be sterilized is entitled to have a voluntary sterilization performed - in accordance with the requirements of this act strictly construed. This Legislature recognizes that many mentally retarded persons are capable of considerable self control and self governance and that many have the capacity to make significant decisions about their own welfare. It is the intent of this Legislature that to the extent that voluntary sterilization may be considered a right,' it is one to which mentally retarded persons shall have equal access if capable of voluntary consent. The Legislature finds, however, that the voluntariness of consent of any institutionalized person, or person arguably mentally retarded, is subject to serious question and should, therefore, be determined by judicial processes provided in this act, and not as a matter of independent medical judgment between doctor and patient.

(c) This Legislature recognizes that various arguments have been made to promote involuntary sterilization of mentally retarded persons. This Legislature finds that eugenic arguments are, at best, of dubious scientific validity. This Legislature recognizes that noneugenic

arguments to promote involuntary sterilization of mentally retarded persons, such as unfitness for parenthood, possible illegitimacy, and possible burden on public welfare funds, are equally questionable and are lacking in sociological validity and are, further, speculative, vague, and constitute a deprivation of constitutional rights. This Legislature has concluded that the only valid and constitutional justification for involuntary sterilization is medical essentiality, as defined in this act.

2. Definitions.

As used in this act:

<a) "Sterilization" means any surgical or other medical procedure to render a person permanently incapable of reproduction, and includes both voluntary sterilizations and involuntary sterilizations upon order of the court;

(b) "Petitioner" means any person for whom a sterilization upon order of the court is sought whether such person seeks such order of his own initiative or upon the initiative of his parent or legal guardian;

(c) "Mental retardation" refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behaviour;

(d) "Mentally retarded person" means any person suffering from mental retardation;

(e) "Disinterested expert" means an appropriately licensed or certified professional not employed by the state, not associated with an institution engaged in custodial care of petitioner, not previously engaged in professional care of petitioner, and not personally related to petitioner;

(f) "Physician" means any person licensed and qualified to practice medicine in this state; and

(g) "Court" means the circuit court.

3. Voluntary Sterilization.

(a) A physician may perform a sterilization upon any person over twenty-one (21) years of age who is competent to consent and who does in fact consent to be sterilized. Such consent shall be freely and intelligently given in writing. Free and intelligent consent shall require that a physician adequately and effectively inform such person as to:

1. Method of sterilization;
2. Nature and consequences of such sterilization;
3. Likelihood of success;
4. Alternative methods of sterilization; and
5. Alternative methods of birth control and family planning

and be satisfied that such consent has been given after full and fair deliberation of these matters.

(b) Where a person seeking voluntary sterilization is under twenty-one (210 years of age, a physician shall not perform sterilization except upon order of the court.

(c) Where a person of any age seeking voluntary sterilization is a mentally retarded person, a physician shall not perform sterilization except upon order of the court.

(d) Where a physician has reason to believe that a person of any age is mentally retarded, he shall not perform sterilization except upon order of the court.

4. Sterilization upon Order of the Court.

(a) Jurisdiction and authority. — The court shall have jurisdiction and authority to order that a sterilization may be performed upon:

1. A petitioner who has attained puberty but is not yet twenty-one (21) years of age, regardless of mental retardation, if a sterilization is

determined to be medically essential; and

2. A mentally retarded petitioner over twenty-one (21) years of age either if a sterilization is determined to be medically essential or if the petitioner is found to be competent to consent and does in fact consent to be sterilized.

(b) Court proceedings. --

1. Any petitioner, or a parent or legal guardian of any petitioner, may file a petition for a sterilization upon order of the court.

2. The petition shall be executed under oath and set forth: name, age, and residence of the petitioner; names and residences of any parents, spouse, legal guardian, and/or custodian of the petitioner; petitioner's mental condition, if appropriate; a statement that competency to consent is the only issue for court determination if voluntary sterilization is sought; and a short and plain statement of the medical reasons for sterilization if involuntary sterilization upon order of the court is sought.

3. Copies of the petition and notices of the time and place for a hearing on the petition shall be served on the petitioner, his parents, spouse, legal guardian and/or custodian not less than ten (10) days before the scheduled hearing. If the existence or residence of any of the foregoing is unknown, an affidavit to that effect shall be filed in lieu of service.

4. A full hearing on the petition shall be held as soon as practicable after the petition is filed. The petitioner shall be physically

present throughout the entire proceeding, effectively represented by counsel, and provided the right and opportunity to be confronted with and to cross examine all adverse witnesses. All stages of each sterilization proceeding shall be stenographically reported. The burden of proof shall be on the party -seeking to establish that a sterilization is medically essential. In all cases, the court shall issue findings to support its decision and the basis for such findings.

5. A petitioner shall be represented by counsel at all stages of a sterilization proceeding. In the event that a petitioner cannot afford counsel, the court shall appoint an attorney not less than twenty (20) days before the scheduled hearing. In the event that a petitioner is under twenty-one (21) years of age and/or alleged to be mentally retarded, the court shall appoint counsel to represent the petitioner.. A court-appointed or otherwise procured attorney shall represent the rights and legal interests of the petitioner regardless of who may initiate the proceedings and/or pay the attorney's fee. An attorney appointed pursuant to this act shall be entitled to a reasonable fee to be determined by the circuit judge.

6. Appeal of a final order in a sterilization proceeding shall be by right in accordance with Article V of the Florida Constitution and Florida Appellate Rules. Pendency of an appeal pursuant to this act shall stay proceedings until, a final determination is made.

(c) Procedure to determine competency to consent. —

1. Upon petition that a petitioner is over

twenty-one (21) years of age and competent to consent to be voluntarily sterilized, the court shall immediately fix a time for a hearing to determine the petitioner's competency to consent to be voluntarily sterilized. If voluntary sterilization is sought, the only issue for court determination is competency to consent. For this purpose, the court shall appoint no fewer than two disinterested experts experienced in the field of mental retardation, including at least one licensed and qualified psychologist, to examine the petitioner and to testify at the hearing as to his mental condition. " Other evidence regarding the petitioner's mental condition may be introduced at the hearing by any party.

2. A petitioner is incompetent to consent to be sterilized if at the time of such sterilization as a result of mental retardation he lacks substantial capacity either to understand the nature and consequences of a sterilization or to give free and intelligent consent to a sterilization as required in subsection (a) of section 3 of of this act.

3. If the court determines that a petitioner is competent to consent, the court shall order that a voluntary sterilization may be performed on the petitioner if, in fact, the petitioner does so consent. If the court determines that a petitioner is incompetent to consent to be sterilized, a sterilization may not be performed unless the procedures set forth in subsection (d) below are followed for involuntary sterilization after finding of medical essentiality.

(d) Procedure to determine whether a sterilization is medically essential. —

1. Upon petition that a petitioner is under twenty-one (21) years of age or a mentally retarded person of any age and that a sterilization is medically essential, the court shall immediately fix a time for a hearing to determine the petitioner's mental and physical condition. The court shall appoint no fewer than three disinterested experts, including at least one licensed ' and appropriately qualified physician and one qualified psychologist experienced in the field of mental retardation to examine the petitioner and to testify at the hearing as to the petitioner's mental and physical condition. Other evidence regarding the petitioner's mental and physical condition may be introduced at the hearing by any party.

2. An involuntary sterilization is medically essential if clearly necessary to preserve the life or physical health of the petitioner. The court shall hear and consider evidence as to the psychological consequences of a sterilization upon order of the court, including the possibility of psychological harm to the petitioner. The likelihood of pregnancy, sexual promiscuity, or sexual exploitation shall not be sufficient for a finding that a sterilization is medically essential and therefore evidence of these factors shall be excluded in a sterilization proceeding. Evidence that a female petitioner requires continuous care and supervision during menstruation, that she is unable to learn basic techniques of

menstrual hygiene, and that she will never be able to learn such techniques, may properly be-considered.

3. If the court determines that a sterilization is medically essential, the court shall order that an involuntarily sterilization may be performed. If the court determines that a sterilization is not medically essential, the petition for sterilization shall be dismissed.

(e) Confidentiality of proceedings and records. —

1. All sterilization proceedings shall be confidential and closed to the public unless requested to be open to the public by the petitioner or his attorney.

2. Records of sterilization proceedings shall not be open to inspection by the public. On special order of the circuit judge, appropriate disclosure may be made for use in connection with the treatment of the petitioner or for purposes of significant research relating to sterilization. The circuit judge shall not permit such disclosure unless application is made by a researcher or research agency of professional repute and unless adequate assurances are given that the petitioner's name and other identifying information will not be disclosed by the applicant.

5. Limitations.

(a) Consent to a sterilization shall not be made a condition for release from any institution nor shall it be made a condition for the exercise of any right, privilege, or freedom.

(b) The fact that a person of any age has not been

sterilized shall not be a ground for confinement in any institution.

(c) Nothing in this act shall require any hospital or any person to participate in any sterilization, nor shall any hospital or any person be civilly or criminally liable for refusing to participate in any sterilization.

6. Penalty.

(a) Anyone knowingly or wilfully violating the provisions of this act shall be guilty of a felony in the third degree punishable as provided in sec. 775.082 or 775.083.

(b) Anyone knowingly or wilfully falsifying a petition for sterilization or otherwise aiding or procuring the performance of an unlawful sterilization shall be guilty of a misdemeanor in the first degree punishable as provided in sec. 775.082 or 775.083.

7. Severability.

If any section, subsection, sentence, clause or provision of this act, or the application thereof to any person or circumstance is held invalid, the invalidity shall not affect other provisions or portions thereof or applications of the act which can be given effect without the invalid provision or portion thereof or application, and to this end the provisions or portions of this act are severable.

A bill to be entitled AN ACT relating to the abuse of developmentally disabled persons; providing definitions and purpose; prescribing procedure for reports to be made; establishing a central registry; prescribing the transmittance of reports; and providing for immunity, privileges, and penalties.

(1) Definitions. – As used in this act:

(a) "Developmentally disabled person" includes any person who suffers from a condition of mental retardation, epilepsy, cerebral palsy, or other disability which causes the person to be substantially unable to protect himself from the abusive conduct of others.

(b) "Abuse" or "maltreatment" includes neglect, malnutrition, severe physical or psychological injury inflicted other than by accidental means, and failure to provide necessary treatment, habilitation, care, sustenance, clothing, shelter, supervision, or medical services.

(c) "Abused person" means any developmentally disabled person who has been subjected to abuse or whose condition suggests that he has been abused.

(d) "facility" means any public or private hospital, training center, clinic, school, or other program or service for developmentally disabled persons.

(e) "Department" means the department of health and rehabilitative services.

(2) Purpose. – The purpose of this act is to provide for the detection and correction of the abuse or maltreatment of developmentally disabled persons whose health and welfare are adversely affected and/or further threatened by the abusive conduct of others.

Such abuse or maltreatment includes neglect, malnutrition, the infliction of severe physical or psychological injury other than by accidental means, and failure to provide necessary treatment, habilitation, care, sustenance, clothing, shelter, supervision, or medical services. It is intended that the mandatory reporting of such cases will cause the protective services

of the state to be brought to bear in an effort to prevent further abuse and to protect and enhance the welfare of developmentally disabled persons.

(3) Considerations preliminary to submission of report. ___

(a) In consideration of physical injury, the following items shall be considered evidence of maltreatment before the report is required.

1. Characteristic distribution of fractures;
2. Disproportionate amount of soft tissue injury;
3. Evidence that injuries occurred at different times or are in different stages of resolution;
4. Cause of recent trauma in question;
5. Family or facility history;
6. History of previous episodes;and
7. No new lesions occurring during the abused person's hospitalization or removal from custody of parent, custodian, or facility.

(b) In consideration of abusive conduct in facilities for the developmentally disabled, in addition to those items enumerated in sub-section (a) above, the following items shall be considered evidence of maltreatment before the report is required:

1. Cruel and unusual disciplinary practices and procedures, including but not limited to corporal punishment, seclusion or excessive "time out" procedures, unnecessary or excessive medication and unnecessary or excessive use of physical restraints;
2. Evidence of inappropriate or harmful- program, habilitation, and/or treatment;
3. Cause of the recent abusive conduct in question;
4. Individual or facility history; and
5. Evidence of degrading and dehumanizing practices and procedures.

(4) Reports required. ___

(a) Any physician, psychologist, nurse, teacher, social worker, employee of a public or private facility serving developmentally disabled persons, or parent of such person, who has reason to believe that a

developnentally disabled person has been subjected to abuse, shall report or cause reports to be made to the department. When the attendance of any person with respect to a developnentally disabled person is pursuant to the performance of services as a member of a staff of a hospital, training center, clinic, school, or similar facility, he shall notify the person in charge of the facility or his designated delegate, who shall also report or cause reports to be made in accordance with the provisions of this act.

(b) Any facility serving developnentally disabled persons shall inform residents of their right to report abusive practices and shall establish appropriate policies and procedures to facilitate such reporting.

(5) Mature and content of report. - - to oral report shall be made immediately by telephone or otherwise to the department followed as soon thereafter as possible by a report in writing. Such reports shall contain, if known, the names and addresses of the developnentally disabled person and his parents or other persons responsible for his care, other developnentally disabled persons threatened by abusive conduct, the abused person's age, the nature and extent of his disability, the nature and extent of the injuries, and any other information that the reporter believes might be helpful in establishing the cause of the injuries, abuse, or maltreatment and the identity of the perpetrator.

(6) Responsibilities of public agencies. - - Upon receipt of a report of abuse of a developnentally disabled person, the department shall cause an immediate investigation to be made and shall in turn, where appropriate, notify the state attorney. All state, county, and local agencies have a duty to cooperate fully with the department, to transmit reports of abuse to the department, and to protect and enhance the welfare of abused developnentally disabled persons and developnentally disabled persons potentially subject to abuse detected by a report made pursuant to this act.

(7) Establishment and maintenance of central registry. — Reports of abuse shall be recorded in central registries established and maintained by the department as required by Section 828.041 dealing with abuse of children. Each registry shall contain information as to the name of the abused developmentally disabled person and the name of the family or other persons responsible for his care, the facts of the investigation, and the result of the investigation. The information contained in the registry shall not be open to inspection by the public. However, appropriate disclosure may be made for use in connection with the treatment of the abused person, or the person perpetrating abuse, and to counsel representing either person in any criminal or civil proceeding. Appropriate disclosure may also be made for use in connection with the hiring and/or employment of persons to serve developmentally disabled persons. In addition, information contained in the registry may be available for purposes of research relating to the abuse of developmentally disabled persons. The department shall make such information available upon application by a researcher or research agency of professional repute, and provided the need for the records has been demonstrated to the satisfaction of the department. Records shall not be opened under this provision unless adequate assurances are given that names and other information identifying developmentally disabled persons will not be disclosed by the applicant.

(8) Transmittal of records. ——With respect to any case of reported abuse of a developmentally disabled person, the department shall transmit all reports received by it to the state attorney of the county where the incident occurred, which shall contain the results of the investigation.

(9) Immunity. ——Anyone participating in the making of a report pursuant to this act or participating in a judicial proceeding resulting therefrom shall be presumed prima facie to be acting in good faith and in so doing shall be immune from any liability, civil or criminal, that otherwise might be incurred or imposed. Also, no resident or employee of a facility serving mentally disabled persons shall be subjected to reprisal or discharge because of his actions in reporting abuse pursuant to the requirements of this act.

(10) Privileges. — The physician-patient privilege, husband-wife privilege, or any privilege except the attorney-client privilege provided for or covered by law, both as it relates to the compentency of a witness and to the exclusion of confidential communications, shall not pertain in any civil or criminal litigation in which the abuse or maltreatment of a mentally disabled person is an issue or in any judicial proceedings resulting from a report submitted pursuant to this act.

(11) Penalty. Anyone knowingly and willfully violating the provisions of this act shall be guilty of a misdemeanor of the second degree punishable as provided in Sec. 775.082 or Sec. 775.083.

Diversion of Mentally Retarded or Mentally Ill Juveniles.

A. If at the time of taking the juvenile into custody or at any subsequent stage of the proceedings, there is reasonable ground to believe that the juvenile is mentally retarded or mentally ill, the intake officer, counsel for the juvenile or any interested party shall immediately move the court for the appointment of three qualified experts to examine the juvenile. The judge shall, within 24 hours of the filing of the motion, order the juvenile to be examined by three qualified experts, including a psychologist and a psychiatrist, either on an inpatient or outpatient basis, as specified in section B hereof.

B. A juvenile as described in the foregoing section shall not be detained in a detention or correctional facility.

(1) In the event he is considered to be a danger to himself or others, he may be placed in a mental hospital, training center for the retarded or other appropriate facility for a period not to exceed ten (10) days from the date of the order and examined therein. In this event the judge shall have the authority to make placement of the child in an appropriate facility, and said facility shall accept custody of the child. Within the ten-day time period provided for such placement, each of the examinations ordered by the judge shall be completed.

(a) A juvenile shall not be considered a danger to himself or others unless he has attempted suicide or has inflicted or attempted to inflict bodily harm on another within six months prior to his being taken into custody.

(b) An appropriate facility for the purposes of this act shall be one employing and containing, as integral parts thereof, psychological and psychiatric professional personnel and resources capable of providing the necessary habilitation and treatment appropriate to the condition of the child, and includes mental hospitals

and training centers and hospitals for the retarded.

(2).. In the event the juvenile is not considered to be a danger to himself or others, he shall be released to the custody of his parents or guardian and examined on an outpatient basis at a mental hospital, training center for the retarded, or other appropriate facility, or he shall be placed in a residential or community-based program of habilitation and treatment appropriate to his condition, and examined either within the program or on an outpatient basis. Said outpatient examinations or examinations provided within the residential or community-based program shall be completed within a period not to exceed twenty (20) days from the date of the order.

C. Within ten (10) days from the date of the order placing a juvenile considered dangerous in a mental hospital, training center for the retarded or other appropriate facility, or within twenty (20) days after the date of the order releasing the juvenile to the custody of his parents or guardian or placing him in a residential or community-based program of habilitation and treatment, a hearing shall be held on the issue of the juvenile's mental condition. At such hearing each examining psychologist , psychiatrist, and other qualified expert as provided in section A shall appear and testify in person as to the juvenile's mental condition. Other evidence regarding the juvenile's mental condition may be introduced at the hearing by any interested party.

(1) In the event the child is found to be mentally retarded or mentally ill, the petition alleging delinquency, if same has been filed, shall be promptly dismissed.

(2) In the event the child is considered to be a danger to himself or others, the court shall have the authority to transfer custody of such juvenile to the division of mental health, the division of retardation or such other agency or facility as is appropriate to the condition of the child for a period not to exceed one year from the date of the hearing. The juvenile shall be re-examined and

re-evaluated by a psychologist and a psychiatrist no less frequently than every six months. Re-evaluation hearings shall be held by the court no less frequently than every six months on the issue of the juvenile's mental condition and the necessity for continued inpatient treatment. The division of mental health, the division of retardation or other agency or facility shall accept custody of the child and shall not discharge him without a full hearing before the court.

(a) The court shall, for a period not to exceed one year from the date of the hearing, retain jurisdiction over every such juvenile for the purpose of transferring custody of the juvenile and conducting hearings.

(3) In the event said juvenile is not considered to be a danger to himself or others, he shall be released to the custody of his parents or guardian or placed in a residential or community-based program of habilitation and treatment appropriate to his condition for a period not to exceed one year from the date of the hearing. The juvenile shall be re-examined and re-evaluated by a psychologist and a psychiatrist no less frequently than every six months. Re-evaluation hearings shall be held by the court no less frequently than every six months on the issue of the juvenile's mental condition and the necessity for continued treatment.

(a) The court shall, for a period not to exceed one year from the date of the hearing, retain jurisdiction over every such juvenile for the purpose of ordering outpatient and other treatment appropriate to the child's condition and conducting hearings to ensure compliance with such orders for treatment.

D. At all stages of every proceeding provided in this act, the juvenile shall be effectively represented by counsel; if counsel is not retained for the juvenile, the court shall appoint such counsel, and if the juvenile cannot afford legal fees, the public defender or other counsel shall be appointed to represent him; and the right to counsel shall not be waived by the juvenile or on his behalf.

E. All proceedings provided in this act shall be stenographically reported;.

LEGISLATION ON THE MENTALLY RETARDED OR

MENTALLY ILL ADULT OFFENDER

(1) Definitions.—As used in this act:

(a) "Mental retardation" refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior}

(b) "Mental illness refers to a mental, emotional, or behavioral disorder which substantially impairs a person's mental health;

(c) "Disinterested expert" means an appropriately licensed or certified professional not employed by the state, not associated with an institution engaged in custodial care of mentally retarded or mentally ill persons, not previously engaged in professional care of the defendant, and not personally related to the defendant

(d) "Appropriate facility" means a mental hospital, training center for the retarded, or other facility employing and containing, as integral parts thereof, psychological and psychiatric professional personnel and resources capable of providing the necessary habilitation and treatment appropriate to the condition of the defendant; and

(e) "Court" means the criminal division of the circuit court or county court.

(2) Competency to stand trial.—

(a) If before or during trial the court, of its own motion or upon notion of the state or counsel for the defendant, has reasonable ground to believe that the defendant is mentally retarded or mentally ill, the court shall immediately fix a time for a hearing to determine the defendant's mental condition. The court shall appoint three disinterested experts including at least one psychiatrist and one psychologist to examine the defendant and to testify in person at the hearing as to his mental condition. Other evidence regarding the defendant's mental condition may be introduced at the hearing by either party.

(b) A defendant is incompetent to stand trial if at the time of trial as a result of mental retardation or mental illness he lacks substantial capacity either to understand the proceedings against him or to meaningingfully assist counsel in his defense. In making such determination, the court shall not consider evidence as to the offense with which the defendant has been charged.

(c) If the court determines that the defendant is competent, it shall proceed with the trial.

(d) If the court determines that the defendant is incompetent to stand trial, it shall commit him to an appropriate facility for treatment for a reasonable period of time not to exceed six months, and said facility shall accept the defendant. If, at any time within six months after a defendant has been committed to an appropriate facility for treatment, the superintends)* of said facility is of the opinion that the defendant is no longer mentally retarded or mentally ill, the court shall fix a time for a hearing to determine the defendant's mental condition. The hearing shall be conducted in the same manner as the original hearing to determine the defendant's mental condition. If found competent, the trial shall proceed. If, however, after spending a reasonable period of time not to exceed six months in an appropriate facility for treatment the defendant remains mentally retarded or mentally ill, the court shall declare the defendant permanently incompetent to stand trial and remand Mm to the custody of the proper division of the circuit court for possible involuntary admission to an appropriate facility. The court shall order all criminal charges against the defendant dismissed.

(3) Criminal responsibility.—

(a)"A person is not criminally responsible for his unlawful conduct if at the time of such conduct as a result of mental retardation or mental illness he lacked substantial capacity either to appreciate the wrongfulness of his conduct, to conform his behavior to the

requirements of the law, or to cope with the demands and responsibilities of normal adult life. *In* making such determination the court shall not consider evidence as to the offense with which the defendant has been charged.

(b) When in any criminal case the defendant intends to rely upon the defense of mental retardation or mental illness, no evidence offered by the defendant for the purpose of establishing this defense shall be admitted unless advance notice is given.

(c) Upon arraignment or prior thereto, the defendant shall notify the court that he will rely upon mental retardation or mental illness as one of his defenses. The defendant shall, within such time as . may be fixed by the court, file a statement of particulars showing as nearly as he can the nature of the mental retardation or mental illness he expects to prove and the names and addresses of the witnesses by whom he expects to prove such mental condition.

(d) Upon the filing of said statement of particulars by the defendant, the court shall cause the defendant to be examined, in the presence of attorneys for the state and for the defendant, if they choose to be present, by three disinterested experts including at least one psychiatrist and one psychologist appointed by the court, at such time and place as may be designated in the order of the court. The disinterested experts shall be summoned to testify in person before the court as to defendant's mental condition at the time of the commission of the alleged offense and subsequent thereto. The disinterested experts may be examined by the court and by counsel for the state and the defendant. Other evidence regarding the defendant's mental condition may be introduced at the trial by either party.

(e) Upon good cause shown for the amission of the notices and procedures as to the defense of mental retardation or mental illness, as herein set forth, the court may permit the introduction of evidence of such defense.

(£) If a defendant has been acquitted because of mental retardation or mental illness at time of offense, the court may remand the defendant to the custody of the proper division of the circuit court for possible involuntary admission to an appropriate facility.

(4) Competency to confess or make an incriminating statement.—

(a) If when a confession or incriminating statement is sought to be introduced the court, of its own motion or upon notion of either party, has reasonable ground to believe that the defendant was mentally retarded or mentally ill at the time of such confession or statement, the court may appoint disinterested experts to examine the defendant and to testify in person as to his mental condition. Other evidence regarding the defendant's mental condition may be introduced by either party.

(b) A person is incompetent to confess or make an incriminating statement if at the time of such confession or statement as a result of mental retardation or mental illness he lacked substantial capacity either to freely and intelligently waive his right to counsel and his right to remain silent or to accurately and reliably inform his interrogators regarding the alleged crime.

(c) If the court determines that the defendant is competent to confess or make an incriminating statement, it shall permit the introduction of the confession or statement offered, provided such confession or statement otherwise meets the requirements of the law.

(d) If the court determines that the defendant is incompetent to confess or make an incriminating statement, it shall not permit the introduction of the confession or statement offered.

(5) Sentencing.—

(a) If at time of sentencing the court, of its own motion or upon motion of either party, has reasonable ground to believe that the defendant is mentally retarded or mentally ill, it shall hear evidence regarding the defendant's mental condition. The court may appoint disinterested qualified experts to examine the defendant and to testify in person as to his mental condition. Other evidence regarding the defendant's mental condition may be introduced by either party. Such evidence shall be heard to determine if the defendant is in need of special

habilitation and/or treatment.

(b) If it determines that such is needed, the court shall order the department of health and rehabilitative services, through the division of corrections, mental health, retardation or any other division, to provide any special habilitation and/or treatment needed by the defendant for the duration of his sentence, and the department shall provide such special habilitation and/or treatment.

GUARDIANSHIP

Relatively little attention is being paid to matters of protecting the person as opposed to protecting his property. Consideration should be given to the possibility of having separate procedures — one for the protection of the person, the other for the protection of his property — as well as combined procedures. In the case of a retarded adult whose disabilities do not preclude the conduct of every-day affairs but are sufficiently severe to make unlikely the prudent management of substantial business or financial interests, it is recommended that conservators be considered — the handling of property problems only. Indeed, even when the person must be placed under guardianship, the handling of any substantial amount of property might well be vested in a conservator especially qualified to handle the assets involved rather than in a personal guardian. In other words, the two functions should be severable when the occasion warrants.

Overprotection is a constant threat. Merely because a retarded person is in need of various forms of assistance does not mean that he needs a guardian. In addition to the institution of formal guardianship, parallel services are required, such as personal counseling to be available to mentally handicapped persons who, with appropriate guidance and advice on a continuing basis, may not require formal guardianship. If all that is required in the particular case is help on a voluntary basis involving friendship and support, consideration should be given to the further development of programs offering these features through voluntary and service organizations. No laws should be required for these services.

When the protection required involves the exercise of legal rights, powers, duties and responsibilities, we must look to a formalized system of guardianship. Perhaps the creation of a new agency or an extension of an existing agency should be considered to deal with guardianship in these matters. This agency could be called the Guardianship Authority.

Mere intellectual ability or disability is an inadequate determinant as to the necessity for guardianship, as it does not necessarily correspond to social adaptation. Determination of the need for guardianship must be a process considering intelligence but pursuaded by functioning ability. Thus it is behavior which is the crucial determinant.

The ability of all institutionalized mentally retarded persons should be evaluated to determine which program or programs best suit the needs of the individual, and referral made to the appropriate source.

The underlining goal of a guardian should be to do everything possible to help the ward stand on his own feet in all respects. Once this is accomplished, if it can be accomplished in the particular instance, the guardian should, in conjunction with the ward, take whatever steps are necessary to terminate the guardianship arrangement. A guardian should not be able to apply for a voluntary or involuntary admission to an institution on behalf of the incompetent. This would make the incompetent person subject to compulsory institutionalization at his guardian's discretion and without the customary statutory and constitutional safeguards.

Guardianship should be subject to revision as the needs of the individual change. In all cases it should be designed to meet the needs of the individual and to fully utilize his abilities and capabilities. We need a mechanism which keeps the options open for the individual. There is a great temptation for parents to wrap everything up in a package in advance — to sign, seal and deliver a retarded person to a total institution — before the parent passes on. The parent wants to make all the decisions in advance. In the future even more than in the past such action will work an injustice for the mentally retarded person. At the same time that the retarded person needs to have his options kept open, he needs to have a person on hand who has the right and the duty to see that these options are optimally exercised when and as they occur.

The authority of parents to act and make decisions for their retarded children over twenty-one should be more clearly defined. Perhaps all parents of the mentally retarded could have their legal position vis-a-vis their adult retarded offspring clarified in a legal proceeding going to the appropriateness of parental or parent-guardian supervision. Many mentally deficient adults live for years as dependent or semi-dependent members of their family, without the formal protection of guardianship. Parents frequently assume the functions of guardians of the adult person without any judicial procedure. This omission produces an ambiguous situation and leaves the retarded person vulnerable on two counts. In the first place, there is the hazard of encouraging the assumption by one adult of an attitude of control over another, except when the justification for this relationship has been impartially reviewed and sanctioned and when in fact the sanctioning authority has considered not only the need for protection but the qualifications of the protector. Secondly, by postponing the formal enunciation of the need for such protection, parents leave the retarded adult exposed until such time as the informal parental supervision is interrupted. By seeking judicial recognition of the retarded adult's incapacity and securing appointment of himself or another suitable person as guardian of the person of the adult and establishing a relationship with a person or agency that can provide at least transitional continuity in an emergency, the parent can obviate this situation.

The natural guardianship of parents is to be preferred for minor retarded children. Judicial substitution of another guardian, public or private, should be only when circumstances make it necessary to replace parents in this function. Where guardianship of the person of one child rests in two distinct and separate guardians — for example, a parent and a public guardian — a basic conflict in authority arises. Such a conflict should be avoided. Those under parental guardianship should have equal access to other services, public and private, including counseling, care outside the home and continuing evaluation, as do those under judicially created private or public guardianship.

Since all children enjoy the legal protection of minority, it is fortunately possible in most instances to avoid giving judicial recognition to mental disability until late adolescence, when predictions of social viability can be made with greater accuracy. However, the legal problems associated with attainment of majority must be understood and anticipated.

An adult must be presumed legally capable of directing his own life unless and until adjudicated otherwise. It is sound to approach the years of chronologic maturity with this presumption, but it is unsound not to challenge it in the face of contrary evidence. The retarded adult, even when under guardianship, should not be regarded merely as a child who never grew up. He is usually biologically mature, has the experience of living even though he has not gained wisdom from it to the fullest, and has many of the needs of an adult. Although in certain respects he remains childish, to represent him as having exactly the same status as a minor is misleading and may encourage overprotection which is not in his best interest. As a general rule, services of a guardian should be supportive in character.

There should be a separation of the issues of institutionalization and competency, and this should be duly revised in Chapter 393. In addition, guardianship in 393 should be changed to custodianship. The fact of institutionalization, whether by admission or commitment, should not be a sufficient basis for appointment of a guardian. It should also, in appropriate situations, not preclude the appointment of a guardian.

Today there is an increasing need for the service of guardianship to be available independent of institutionalization. In addition, there is reason to advocate that even when a person is in residential care he should have a guardian who is not part of or subordinate to the apparatus of the care, training or treatment that he is receiving. It is not enough, however, simply to designate some public official as public guardian by statute. Guardianship is a personal relationship and depends on some degree of continuity and active partisanship as well as authority. Such

guardianship should therefore be exercised and implemented by individuals who have a continuing responsibility for a limited number of specific wards.

An order of involuntary hospitalization or institutionalization should have the effect only of depriving the individual of his personal freedom and providing him with proper care and remedial aid, not of rendering him incapable of exercising his civil rights. Care should be taken to insure that the institutionalized retardate is permitted to enjoy all the legal rights he is capable of exercising. In fact, an individual who becomes a ward (not necessarily institutionalized) should not lose or surrender his civil rights.

Competency determination should be tied in with and essential only to plenary guardianship, and be clearly inapplicable in regard to other protective or custodial situations. Incompetency must be adjudicated through a court hearing.

Elizabeth Boggs has outlined seven principles that must be taken into account in planning for guardianship services for the retarded:

(1) There must be a social institution that is primarily directed to the needs of the retarded person, not his estate.

(2) There must be a public agency to assume responsibility when the family can no longer provide the necessary protection for its retarded members.

(3) The plan must be flexible enough to allow adaptation to the degree of disability of each individual.

(4) The protective function must be available to the retarded person regardless of where he is. Admission to an institution, for example, should not terminate this service.

(5) The guardianship role must be independent of the agencies that provide services to the retarded. The individual acting as public guardian should have his own staff, accountable directly to him.

(6) The procedure for appointment of the public guardian should be respectful of due process and should seek ways to provide meaningful review of the individual's capacities.

(7) The service of protection should be available to all who need it, without regard to age or degree of retardation.

It is important that recognition be given to varying degrees of competency. Guardianship should be adpatable to the specific requirements of the case. For some individuals comprehensive guardianship will be required. However, as far as possible, mentally retarded adults must be allowed freedom — even freedom to make their own mistakes. The development of limited guardianships for adults should be pursued, with the scope of the guardianship specified in the judicial order. Plenary guardianship must be reserved for those who are judicially determined to be incapable of undertaking routine day-to-day decisions and who are found to be incapable of basic self-management.

PUBLIC GUARDIANSHIP

Public guardianship services should be available to every retarded person who needs them. Any such service should provide, in addition to legal and fiscal protection of property, a continuing concern for the retarded person as an individual.

Consideration should be given to creation of a comprehensive guardianship service that would afford a variety of plans to the parents of retarded children, be administered outside existing state agencies, and offer a personal service to retarded wards close to their place of residence.

Public guardianship would be vested in a state agency, with duties carried out by individual staff members. This would apply to persons living in institutions, who should have outside guardians (aside from the custodianship of the institution) to check on their treatment, care and release possibilities. The guardian

would have responsibility for maintaining contact with the ward and for reviewing his progress with those who have professional responsibility for him. The public guardian would function as guardian of the person and/or estate, and would meet the same requirements and have the same responsibilities as an individual or private guardian.

Outside of the institutions, the court would appoint a public guardian only if a suitable guardian is not available or willing to assume responsibility for such services or if other appropriate arrangements are not available for the performance of such services.

The petition for appointment of a public guardian should include a detailed written plan prepared in accordance with the specific needs of the alleged mental retardate. Perhaps another term to be considered would be public conservator (in those cases where merely property interests are protected).

The appointment of a state agency as guardian or conservator should not constitute a judicial finding that the mentally retarded person is legally incompetent. Such appointment shall be by the title of the office involved, and the authority of such person as guardian or conservator shall cease upon termination of his term of office and his authority shall vest in his successor or successors without further court proceedings. Such individual shall not resign as guardian or conservator unless his resignation is approved by the court.

Employees of the agency acting as public guardian should receive no direct compensation, profit or benefit from a ward or any other source, except the agency for services. The public guardian should be reimbursed for any personal expenditures made in the ward's behalf out of the ward's estate, when properly evidenced before the court. Claims for services rendered by state agencies, including the guardianship agency, must be submitted to the court for approval before payment.

The agency as public guardian shall furnish bond in the

amount of $25,000 for each of its employees performing the functions and duties of public guardian.

The public guardian may be removed by the court for cause or discharged because no longer needed. Provision should also be made for reviewing the case of every person for whom a public guardian has been appointed by means of an annual report to the court.

The courts need the support of a well-staffed public and permanent agency which would concern itself with the general subject of guardianship, the supervision of guardianship, seeing that the system works, and seeing that persons who would not otherwise fall under guardianship but who need it would be appropriately referred. This agency should have the power to bring before the courts some of the information on which action should be taken. It should not be in any government agency responsible for direct services for the care, training or treatment of the retarded.

The proposed public agency would have the authority and the means to carry out the following functions:

(1) Gather information on the overall system for the purpose of evaluating its effectiveness and proposing necessary changes.

(2) Review reports filed by the guardians.

(3) Investigate individual cases, either in response to a complaint or on its own initiative, including direct contact with wards on a random sample basis.

(4) Bring to the attention of the courts pertinent information on which court action is necessary.

(5) Review the work of professional guardians in relation to the number of wards accepted by each and advise court relative to limiting the number of wards any one guardian can properly serve.

(6) Identify persons needing guardianship who might not otherwise have an application made on their behalf.

(7) Initiate the necessary legal action where families or other concerned persons do not do so.

(8) Advise courts on criteria for the selection of guardians.

(9) Provide interim services by assigning a person to act as a temporary mentor in emergencies or while a new guardian is being selected.

(10) Secure competent professional persons to assist in court as expert witnesses, members of the evaluating team, etc.

Although the public guardian is a state official in charge of a state agency, he must work independently of state departments and/or divisions which provide direct services to the retarded. He should be available upon request to:

(1) Act as advisor for the mentally retarded who request his advice and guidance or for whose benefit it is requested. He may provide advice and guidance to the individual without prior appointment by a court.

(2) Accept court appointment as protector of the person and/or property of a mentally retarded person not adjudicated legally incompetent.

(3) Accept court appointment as guardian of the person and/or property of a retarded individual who has been adjudicated legally incompetent.

The provision of the above services should not be dependent upon a finding of incompetency, nor should it abrogate any civil right otherwise possessed by the retarded person.

Public guardianship, or public conservatorship, can be used to protect the property of retardates from excessive costs involved in private estate guardianships. The public conservator should be permitted to hold personal property, insurance or other regular

payments for wards and disburse them for the ward's benefit. Without this public conservatorship it would be necessary for the court to appoint a guardian or conservator, usually a bank or trust company. The small amounts involved in most retardates estates are insufficient to make it profitable for most corporate trust offices to act as guardian of the property.

LIMITED GUARDIANSHIP

Some retarded persons are wholly or substantially self-supporting. Although such persons may be in a position to manage themselves or their earnings, they may not be able to manage other assets such as property received by way of gift or inheritance. When it appears to the satisfaction of the court that a mentally retarded person for whom an application for guardianship has been made is over the age of twenty-one years and is wholly or substantially self-supporting by means of his wages or earnings from employment, the court should be authorized and empowered to appoint a limited guardian of the property only of such mentally retarded person who would receive, manage, disburse and account for only such property of such mentally retarded person as is received from other than the wages and earnings of said person. The retarded person could receive and expend his wages or earnings, and would also have the power to contract or legally bind himself for an amount not to exceed his wages or earnings for one month or the amount of three hundred dollars, whichever is greater.

Limited guardianship as applied to property situations should be called limited conservatorship. The term limited guardianship should apply to those situations involving guardianship of the person in particular well-defined areas and circumstances.

ADVOCACY

An advocacy program should be established (perhaps through the Florida Association for Retarded Children) to provide indivi-

dualized voluntary personal services to the retarded. These services should be coordinated with those offered by the Division of Family Services and the Division of Retardation. The purpose of such a program would be to recruit for each child or adult who does not have parents, relatives or friends, a citizen to act in a special individualized relationship. The needs of retarded individuals will vary, and the resources of the advocate should be matched to the special needs of the individual. Other advocacy services should be provided to individuals residing in institutions. Many of them have no contact with the community and require someone to visit them, to write or to send gifts on holidays. Persons being habilitated from institutions to the community need emotional support, practical guidance and follow-up which the advocate could provide.

The private agency delegated the responsibility of developing an advocacy program should perform the following functions:

(1) Insure a continuing advocacy program by appropriate planning, budgeting and the pursuit of funds.

(2) Define a desirable advocacy advisory committee.

(3) Attempt to define desirable advocacy characteristics.

(4) Develop procedures for recruiting advocates.

(5) Develop procedures for screening advocates.

(6) Develop rules of conduct for citizen advocates.

(7) Arrange and monitor advocacy relationships between retarded and advocate candidates.

(8) Conduct appropriate public education programs, disseminate information, and popularize the concept of citizen advocacy.

PROTECTIVE SERVICES

Protective services should be provided by the Division of Family Services with coordination and liaison with the Division of

Retardation. It should be the responsibility of the Division of Retardation to provide orientation and continuing training to the staff of the Division of Family Services in supplying these services. The Division of Retardation should also function in the role of consultant to the Division of Family Services staff.

The Division of Family Services should have the responsibility of providing professional services, including coordination and referral of the retarded person to appropriate legal, medical, social and financial sources.

Protective services are preventive and supportive services to the mentally retarded person, aimed toward achievement and maintenance of his maximum level of competency to manage his own affairs. These services should include, but not be limited to, assistance in obtaining the following:

(1) Food, shelter and clothing.

(2) Financial benefits to which the retarded person is entitled.

(3) Financial advice and services.

(4) Medical care.

(5) Legal services.

(6) Education and/or vocational training.

(7) Employment.

(8) Cultural, recreational and social activities and services.

(9) Protection of property.

(10) Protection from exploitation.

The possibility that the client's self-determination may be limited by protective services imposes the need for an extremely carefully detailed analysis of his abilities and inadequacies. The fact that certain decisions are not to be left to him must not

automatically mean that the right to make other decisions is also removed. The evaluation must insofar as possible specify areas in which the individual can function independently and those in which his self-determination must be restricted. Only that degree of intervention required to maintain or augment the individual's capability for self-management is to be allowed. Primarily the evaluation must seek to identify the client's need for services, presently and in the near future. The services identified should be limited to the provision of such things as food, clothing and shelter, but should also include companionship, friendly advice, assistance in getting about town, and other such daily needs.

Protective services should be primarily case management or advocacy services, and secondarily decision-making services.

Protective services would have the following responsibilities in case management or advocacy:

(1) To develop means by which people in need of protection can readily be identified and referred for services.

(2) To develop relationships with other agencies so that persons in need of services and eligible for them can receive them within a reasonable time, including emergency services.

(3) To develop with clients relationships of mutual trust and understanding so that they will cooperate in decision-making and carrying out plans.

(4) To protect the civil and human rights of the disabled and to call on legal and other resources as needed when these rights are endangered or infringed.

Protective services would have the following responsibilities in decision-making:

(1) To evaluate carefully the individual's ability to represent his own interests, in which evaluation an attorney should be meaningfully involved.

(2) To make necessary temporary arrangements to safeguard the person or his property in an emergency.

(3) To make appropriate longer term arrangements, taking into account as much as possible the wishes of the client.

(4) As a last resort, but nevertheless as needed, to apply to a court for guardianship.

The protective services staff should not take on the roles and responsibilities of conservators or guardians.

Malpractice insurance should be provided for members of the protective services staff. Otherwise the staff may postpone accepting the decision-making role, to the client's detriment.

The protective services agency should be responsible for periodic review of each client throughout his lifetime until his request for termination has been approved. Such a request should be evaluated in a way similar to that by which the client was accepted for services in the first place.

A state-wide system of protective services could be developed by the Division of Retardation. Through such program the division could:

(1) Provide direct services to the retarded.

(2) Enter into contracts with any responsible agency, public or private, for provision of protective services.

COUNSELING SERVICES

There is a need for well-organized counseling services for retarded adults, as well as for the families of retarded individuals, children or adults. Such counseling should help them make life decisions and would forestall the necessity for formal guardianship in their cases. In addition, functions of the proposed agency would include the development of training programs for prospective guardians, including parents; the establishment of a

roster of qualified guardians from among whom the association or agency can make recommendations to the appointing authorities; and the retention of a panel of experts who can assist guardians as needed — legally, financially or socially.

STAND-BY GUARDIANSHIP

Upon application or consent of both parents, natural or adoptive, if living, or of the surviving parent, a stand-by guar-,dian of the person or property or both of a mentally retarded person could be appointed by the court. The court could also, upon application or consent of such parent or surviving parent, appoint an alternate to such guardian to act if the guardian should die or renounce or become incapacitated after the death of the last surviving parent of such retarded person. Such stand-by guardian, or alternate in the event of such guardian's death or renunciation or incapacity, would automatically and without further proceedings be empowered to assume the duties of his office immediately upon the death or adjudication of incom-petency of the last surviving of the natural or adoptive parents of such mentally retarded person, subject only to confirmation of his appointment by the court within sixty days following assumption of his duties of such office. If the mentally retarded person is over the age of twenty-one, the court, before confirm-ing the appointment of the stand-by guardian, shall conduct a hearing at which the retarded person must be present and must be represented by counsel.

RECOMMENDATIONS BY THE PRESIDENT'S PANEL ON MENTAL RETARDATION AND THE 1963 TASK FORCE REPORT

The recommendations urged the development of a variety of guardianship plans for the retarded:

(1) Protective services for the retarded should be esta-blished in an appropriate state agency to supervise the activities

of private guardians.

(2) A program of limited guardianship of the person should be developed for the mentally retarded adult, with the scope of the guardian's authority carefully defined in the court's order.

(3) Plenary guardianship should be reserved only for those persons incapable of self-management and routine day-to-day decision-making.

(4) Guardianship of the property should be clearly differentiated from guardianship of the person. Where guardianship is required it is to be carefully adapted to the specific needs and abilities of the individual.

(5) Conservatorship of property should be available for those adults capable of conducting their own daily affairs, but whose disabilities prevent management of substantial business or financial interests.

(6) Public guardianship services are necessary to make these alternatives available to those for whom private guardianship is unavailable or not desired.

CUSTODIANSHIP

Institutions for the retarded should not be considered guardians of the person and/or property of those individuals committed or admitted to the institution. The institution should be specifically termed custodian in all such situations.

HEARING

The filing of the petition in Circuit Court to initiate guardianship proceedings should be by the individual himself, his parents, siblings, husband or wife, children, or next of kin. Consideration should also be given to filing of a petition by any interested party, including relatives or friends of the individual or an officer of the guardianship agency.

The individual against whom the proceedings are taken shall be represented by counsel at all stages of all proceedings involved, and if he cannot afford counsel, counsel shall be appointed to represent his interests.

Upon filing of a petition for determination of competency, the attorney representing the individual alleged to be retarded should notify the Division of Retardation, which would have responsibility for arranging an evaluation of the alleged retardate by a multidisciplinary team composed of, but not limited to, the following: (1) the Director of the Division of Retardation or his representative; (2) a certified psychologist; (3) a licensed practicing physician; (4) a certified teacher in the field of special education; (5) a social worker from the Division of Family Services.

Notice of hearing should be given to all parties concerned, including the potential ward, the person then having his charge, if any, the members of his family specifically designated to receive notice, and the guardianship agency, which should as a matter of law be a necessary party to the proceedings. Notice to the potential ward should be personal notice, and to the other individuals can be by mail. The notice should be in simple language and explain the rights involved.

The allegedly retarded individual should be present at all stages of all proceedings unless excused by the judge for good cause, in which event the judge shall see the retarded person and the reason for his non-attendance at the proceedings shall be specified in the record.

The hearing should be held in the judge's chambers or some other private place. Provision should be made for the confidentiality of court proceedings and records.

Although the hearing should be a full evidentiary hearing, the proceedings should be as informal as possible consistent with fairness and the preservation of civil rights.

There should be no loss of civil rights under the act.

All testimony adduced at the hearing should be stenographioally reported.

The court should be required to avail itself of the expertise of behavioral scientists. A comprehensive clinical evaluation should be undertaken covering medical, psychological, educational, social and vocational factors. This evaluation should be utilized in determining the extent of the guardianship programs, as well as their appropriateness. The potential ward should be consulted as to his wishes. In the event that he does not wish to become a ward, then through his legal representative he should have full opportunity to oppose any declaration that he is in need of guardianship or other protective services.

The evaluation report shall include a current diagnosis of the individual's physical condition prepared under the direction of a licensed medical practicioner, as well as reports of his current mental condition, social adjustment and educational factors, prepared by licensed and qualified psychologists, social workers and certified teachers in the field of special education. The evaluation report shall not be part of the public record and shall be open to inspection only by court personnel, the subject of the proceeding, his parents, guardian or conservator, the attorney for such parties and such other persons as may be designated by the court.

The criteria for guardianship must not extend beyond the realm of basic standards for a reasonable life. Advanced education, marked social graces and skills, and affluence are not goals which would satisfy the imposition of guardianship. Therefore, lack of such advantages should not be included in any formulation of criteria. The social circumstances of the individual, his organic disabilities, if any, and his intellectual standing would be factors vitally important to an understanding of the reason for his behavior and his apparent capacity to change it alone. The existence of parents should not be considered a contradiction for appointment of a guardian, nor should the existence of agencies or friends rendering advice or assistance be a bar to

guardianship.

Careful evaluation and expert advice at the time of a formal hearing on the appointment of a guardian for an adult will reveal the probabilities of changes in the subject's condition and capabilities, as well as the significance of future court reviews and their optimum frequency. Provision should be made for periodic review by the court to determine the continued need for guardianship. To require automatic review of every case with equal frequency is to do injustice both to those who need it and those who do not. There should be a wide range of choices from which the ward may draw the most appropriate. The latest date for the next review of guardianship should be specified in the order. The court shall conduct a full hearing on review, at which the retarded person shall be present and shall be represented by counsel. If he cannot afford counsel, counsel shall be appointed to represent his interests. Re-evaluation by the evaluation team or by private physicians, psychologists, social workers and certified teachers in the field of special education should be available at any time on the request of counsel for the retardate. The ward should be able to appeal to the court on issues regarding the guardian or the guardianship at any time.

The guardianship order should extend no further than supported by evidence of dysfunction. For those persons who are competent to handle certain matters it would be a serious mistake to impose unlimited guardianship. The order should remain in force until terminated by a further order of the court, for which application must be made by the ward, any person having an interest, the guardian or the guardianship agency.

There should be a right to appeal from any order, judgment or decree of the court in the determination of rights of any party in any proceeding in guardianship matters to the appropriate district court of appeal, except those appeals which may be taken to the Supreme Court as provided by law.

GUARDIAN

In appointing guardians, courts should look first to parents and other close relatives, but not necessarily in the order of formal kinship. The person most able, best situated and best motivated should be sought. The guardian should express in his will his choice as successor.

There are some persons who should not be considered guardians because of the possibility of conflict of interests. These include persons performing some professional or other service for the ward — such as a physician, teacher, attorney, landlady, superintendent of an institution, or one who is employed in one of the service systems in which the ward is enrolled.

Among the factors to be considered in the selection of a guardian is accessibility. If the guardian is to give the necessary time and maintain direct contact with the ward, he cannot live too far away or be too busy with other responsibilities. Much will also depend on whether the guardianship is plenary or limited. Even if he is a full-time professional guardian, he should not have too many wards; in addition, the issue of continuity must be considered. Strong preference is expressed for vesting guardianship in an individual person rather than an agency.

If during the course of a guardianship order the guardian dies or becomes incapacitated from performing his functions, or is unwilling to continue as guardian, the guardianship agency should automatically and without further court order become guardian until such time as another guardian is available. Where the guardianship agency is of the opinion that the guardian is not exercising his duties properly, it should be its duty to move the court for a change of guardian. In emergency circumstances, the guardianship agency should have the power to intervene and assume guardianship of a person who is a ward on the condition that within a prescribed period of time it apply to the court for ratification of this step.

A basic responsibility of all guardians is to maintain close contact with the retarded person or persons for whom they are responsible. They should visit them regularly and get to know them as individuals, with their own potentials, abilities, shortcomings and needs. The guardian should seek to develop an atmosphere of mutual confidence and trust, and make an active effort to see that the retarded person participates as much as possible in the life of his community. The wishes of the retarded person should be respected and he should be allowed to make his own choices whenever possible. The guardian has the responsibility to recruit, when necessary, expert services such as those of attorneys or physicians. A guardian should also see to it that any civil duties are performed by or on behalf of the ward, such as securing an identity card, registering for military service, etc. The guardian should also see that the appropriate authorities are informed of the relevant special circumstances arising from the condition of retardation. Also, the guardian should advise or assist or act for the ward in relation to securing his personal and civil rights. The guardian should insure that all possible benefits such as pensions, allowances, social security payments, VA payments, etc. are applied for and received. The guardian should assist the ward in administration of these benefits. The guardian should arrange appropriate insurance protection for the ward, taking full advantage of any special benefits available to a person in the ward's category. The guardian should assist the ward in completing and submitting the appropriate income tax form, making sure that all benefits that accrue to him are sought. If completion of the forms is too complicated for the guardian, professional advice should be obtained.

As one of his most important functions, the guardian should select and mobilize appropriate community resources, drawing on services for education, rehabilitation, health care, recreation, employment, social services and specialized day or residential care. To do so he must necessarily familiarize himself with the range of applicable services and programs offered by public, voluntary and proprietary agencies. Even when the retarded person is

enrolled in a well-organized program of daily activity or in a residential facility, public or private, the guardian has a responsibility to keep track of his progress and to review the appropriateness of the placement, to assure himself that the service is as represented and that the retarded person is not being mistreated or neglected. He should concern himself particularly with the curtailment of personal liberties which often occur in institutions, the use of restraints or corporal punishment, or simple failure to provide the retarded person with opportunities for sufficient activities to maintain his physical and emotional health. Where the ward is enrolled in a comprehensive service system, the guardian should insist on being advised of any significant plans for changing his ward's program.

The guardian of the person would be responsible for annual examinations of the ward's mental and physical condition by a qualified psychologist and a licensed physician, except in cases where the ward is in an institution. He may expend up to $50 of the ward's estate without prior court approval for each such examination. He may petition the court to use additional funds, and if funds have *been* exhausted, for financial relief from state or county funds.

Should there be a need for consent to treatment or surgery, the guardian of the person could provide the consent under certain circumstances.

If the guardian has the responsibility of looking after the ward's finances as well as guiding his personal decisions, his role as personal advocate must transcend the fiscal management role. Where the guardian has aptitude for the role of personal advocate but not for financial management, he should be instructed to use professional fiduciary services as necessary. Consideration should be given to the possibility of divided guardianship, separating guardianship of the person and of the estate when special circumstances justify it.

The guardian of property must maintain a watch on the assets of the ward and protect them from exploitation or dissipa-

tion. He should always be prepared to provide evidence that the ward's assets are in his possession or under his control. If the guardian cannot show that he has fully administered according to the law, he and his sureties would be personally charged to the extent of the assets not duly administered. He is to collect rents, incomes and issued and profits therefrom for the payment of debts, taxes, claims, charges and expenses of guardianship, and for the care, support, education and maintenance of the ward.

Every guardian, before exercising his authority as guardian, would be required to take oath that he will faithfully perform his duties as guardian and that he will render true accounts, whenever required by law, but no less frequently than annually.

In addition to taking oath, the guardian of property would be required to execute and file in the judge's office a bond to cover the amount of the ward's assets, including the total value of his personal property and the probable annual rents, profits and incomes receivable by him from any of the ward's real or personal property. This bond would have two or more sureties to be approved by the judge, or an authorized surety company. Such bond would be payable to the Governor and his successors in office, conditioned on faithful performance of all duties as such guardian according to law. Banks and trust companies authorized to do business in Florida would not be required to comply with the above rule. The bond given by any guardian, upon breach thereof, may be put in suit and prosecuted until the whole penalty sum of the bond has been recovered.

The penal sum of the bond of a guardian of the person only shall be double the probable expenditures to be made by such guardian for the ward during one year. Such bond shall be in a form approved by the court and signed by two or more personal sureties or by one or more corporate sureties approved by the court, and shall be conditioned that the fiduciary shall faithfully and honestly discharge the duties devolving upon him as such fiduciary; provided that if an instrument creating a trust

dispenses with the giving of bond the court shall appoint a fiduciary without bond unless the court i of the opinion that the interest of the trust demands it, in which event the court may require bond to be given in such amount as shall be fixed by the court.

The public guardian shall file an official bond in an amount not less than $50,000,which bond shall inure to the joint benefit of the several guardianship or conservatorship estates in the State of Florida, and the public guardian shall not be required to file bond in additional cases.

The court through which a fiduciary is appointed may reduce the amount of the bond of such fiduciary at any time for good cause shown. When two or more persons are appointed as joint fiduciaries, the court may take a separate bond from each or a joint bond from both or all.

No instrument authorizing the fiduciary therein named to serve without bond shall relieve a successor fiduciary from the necessity of giving bond, unless the instrument clearly evidences such an intention.

Within 60 days after appointment, the guardian of property should file with the judge a complete verified inventory of the ward's real and personal property which has come to his knowledge and of any cause of action which his ward has the right to sue or which he has the right to sue in behalf of his ward. The judge, if he deems it necessary, may appoint two persons of discretion, not related to the ward or to the guardian and not interested in the ward's property, authorizing them to appraise the property of the ward. If the ward's estate consists only of money, no appraisal is necessary. An inventory or appraisal may be used as evidence in any suit, by or against the guardian, but is not conclusive evidence as to the real value of the estate.

Every guardian shall file annually, and as often as otherwise ordered, in the court making said appointment, a full accounting of the administration of the estate. The guardian shall present

his accounting to the court in debit and credit form, and shall petition the court to have it examined, approved and confirmed. In these returns the guardian of property shall render a full and correct account of the receipts and disbursements of his ward's property and shall include a statement of his ward's assets. He will also include evidence that the sureties on his bond, if individuals, are alive and solvent. If a guardian neglects or refuses to file his annual return without good cause, the judge shall issue an order for him to be held in contempt of court until the return is made. Perhaps a provision should be included for regular review of accounts by the Clerk of the court, plus sanctions for the Clerk's failure to review.

The guardian of the person would be required to file annually a report with the court, which report must include, among other things:

(1) The names and addresses of all places where the ward was maintained during the preceding year.

(2) The length of stay of the ward at each place.

(3) A resume of medical and other professional treatment given the ward, including educational, vocational and social services.

(4) A resume of the guardian's activities and Visits to check on the progress and condition of the ward.

(5) An evaluation by the guardian as to whether or not the ward is competent enough that he should be restored.

(6) Written reports and evaluations from examining physicians, qualified psychologists and social workers regarding the physical, mental and social condition of the ward, including among other things recommendations for treatment and prognoses and indications for restoration.

Six month or annual reports should be required concerning the care, treatment and needs of the ward, including rehabilitation, education, vocational training, etc. There should be a requirement

that a social worker periodically visit the ward and report on his condition and surroundings.

The guardian of the person may apply by petition to the court for an order directing the guardian of property to pay an amount, at specified intervals, for the support, care, maintenance and education of the ward.

The guardian of property may receive an order, by petition to the court, authorizing the settlement or compromise of any claims, questions or disputes arising as result of personal injury or otherwise. The order will operate to relieve the guardian of responsibility in connection with such matters. The guardian is authorized and empowered to execute any release or waiver which may be necessary to effect the compromise or settlement in accordance with the law.

The mentally retarded person over the age of twenty-one should be able to petition the court at any time to have a guardian discharged and a successor appointed or to have the guardian of his property designated as a limited guardian. At the time the nomination is accepted or when an appointment is made by the court, the mentally retarded person and any person who made application for service on his behalf shall be informed by the court of the procedure for terminating the service or appointment. The public agency shall cease to provide protective services pursuant to nomination by the individual himself, by any interested person making application in his behalf, or by his parents when a written request for termination is received by the agency from or on behalf of the mentally retarded person. If the agency believes the person to be in need of protective services, it may file an application for guardianship or protectorship with the court. Termination of any court appointment as guardian or protector must be by order of the court.

Guardianship may also be terminated upon removal of the ward's incapacity of, in the case of guardianship of property only, upon exhaustion of the ward's assets.

A guardian, upon petition to and approval of the court, may resign and be relieved of his guardianship. He will be required to make and file a true account of his guardianship and to deliver to his successor guardian any and all records and property of the ward. The successor guardian must be appointed and duly qualified before a guardian is relieved of his duties and obligations.

A guardian may be removed from his position for any of the following reasons:

(1> Fraud in obtaining his appointment.

(2) Failure to discharge his duties.

(3) Abuse of his powers.

(4) Insanity or other incompetency.

(5) Habitual drunkenness or continued sickness rendering him incapable of discharging his duties.

(6) Failure to comply with any order of the judge.

(7) Failure to return schedules of property sold or accounts of sales of property or to produce and exhibit the ward's assets when so required.

(8) Mismanagement of the ward's property.

(9) Failure to give bond or security for any purpose when so required by the judge.

(10) Conviction of a felony.

(11) Appointment as a receiver or liquidator for any corporate guardian.

(12) Failure of a resident guardian who removes from Florida to designate a resident agent.

Proceedings for removal may be instituted by the judge on his own motion, by any surety, by the ward, or by any other interested person. A removed guardian must file; within 20 days of his

removal, a true, complete and final account of his guardianship in the office of the judge removing him. He shall surrender upon removal all assets and records of the ward to the successor guardian. In any case when a guardian is removed and when he is in default, his bond may be put in suit.

A parent presumably remains the natural guardian of the person of his committed minor child, but custody of the child's person is transferred by order to the institution. If no parent is present or able to serve, even nominally, as guardian of the child's person during his institutionalization, the institution appears to assume that function, in fact if not in law. Patients who are twenty-one or older no longer remain under the natural guardianship of their parents. The question of restoration upon discharge should be considered. If a guardian has been appointed, the discharge has no effect upon the status of the guardian. Upon discharge the patient's legal status should be clarified. Requirement of official documentation and explantion of the patient's competency, incompetency or partial incompetency should be provided as he leaves the institution. This will clarify matters concerning the right to vote, marry, enter into contracts, make a will, operate a motor vehicle, etc.

Restoration proceedings should be instigated by the verified petition of the ward, his guardian or any friend or relative. Medical and all other pertinent evidence and testimony should be received by the court in a full hearing. The ward shall be present at any restoration proceedings and he shall be represented by counsel. If he cannot afford counsel, counsel shall be appointed to represent his interests.

Guardianship instituted during the ward's minority shall terminate at the age of twenty-one or upon marriage or upon order of the court. At the age of twenty-one the person for whom a guardian has previously been appointed or anyone on his behalf may petition the court which made such appointment or the court in his

county of residence for the continuation of the guardianship, consideration being given to changes in the ward's condition.

Regional centers are apparently being set up throughout the State of Florida. These centers should be more fully and expeditiously developed so that they can serve the needs of the retarded in the community. The Division of Retardation should be authorized to contract with appropriate agencies, public and private, for the provision of services. These services would include diagnosis, counseling, maintenance of a registry and case records, follow-up services, assistance and hospital placement when necessary, calling attention to unmet needs in community care services for the retarded, maintaining appropriate staffs, and providing state funds to vendors of services to the retarded when failure to provide such services would result in institutionalization. The center should be used to purchase services for the retarded from whatever source is appropriate.

REVISION OF JUVENILE COURT ACT

SECTION 1. - PURPOSE OF ACT.

This act shall be construed and applied to effectuate the following purposes:

1. To preserve the unity of the family whenever possible and to provide for the care, protection and sound mental, physical and emotional development of children coming within the provisions of this act;

2. Consistent with the protection of the public interest, to remove from children committing delinquent acts the consequences of criminal behavior, and to substitute therefor a program of supervision, care and rehabilitation;

3. To achieve the foregoing purposes in a family environment whenever possible, separating the child from his parents only when necessary for his welfare or in the interests of public safety;

4. To provide judicial procedures through which the provisions of this act are executed and enforced and in which the parties are assured a fair hearing and their constitutional and other legal rights recognized and enforced.

SECTION 2. - DEFINITIONS.

When used in this act:

1. "Child" means an individual who is under the age of eighteen (18) years.

2. "Adult" means an individual eighteen (18) years of age or older.

3. "Juvenile court" means any court the name of which includes the word "juvenile," heretofore or hereafter established in any county or in any district consisting of two or more counties, and the county judge's court in every county in which no separate

juvenile court is established either for that county or for a district including that county within its limits. If any separate juvenile court is hereafter established, each county judge's court in the county or district wherein the separate juvenile court is established shall cease to be a juvenile court, and if any separate juvenile court heretofore or hereafter established shall be abolished, each county judge's court within the county or district wherein the separate juvenile court was established shall become a juvenile court.

4. "Separate juvenile court" means a juvenile court other than one presided over by a county judge acting as juvenile court judge.

5. "Court" means the juvenile court, unless express reference is made to another court.

5A. "Intake attorney" means attorney charged with responsibility of prosecuting cases in juvenile court;

6. "Detention care" means the temporary care of children in secure custody pending court disposition.

7. "Shelter care" means the temporary care of children in physically unrestricting facilities.

8. "Legal custody" means a legal status created by court order which vests in a custodian the right to have physical custody of the child and to determine where and with whom he shall live within the State; and the right and duty to protect, train, and discipline him and to provide him with food, shelter, education and ordinary medical care, all subject to the powers, rights, duties and responsibilities of the guardian of the person of the child and subject to any residual parental rights and responsibilities. An individual granted legal custody shall exercise the rights and responsibilities personally unless otherwise authorized by the court.

9. "Residual parental rights and responsibilities" means those rights and responsibilities remaining with the parent after the transfer of legal custody or guardianship of the person, including but not necessarily limited to the right of visitation, consent to adoption, the right to determine religious affiliation, and the responsibility for support.

10. "Probation" means a legal status created by court order following an adjudication of delinquency, or need for supervision, whereby a child is permitted to remain in his home subject to supervision and return to the court for violation of probation at any time during the period of probation.

11. "Protective supervision" means a legal status created by court order in cases whereby the child is permitted to remain in his home under supervision, subject to return to the court during the period of protective supervision.

12. "Delinquent act" means an act designated a crime under the law of this State, or of another State if the act occurred in another State, or under Federal law. A "delinquent act" includes the violation of municipal or chartered county ordinances. Traffic offenses shall not be deemed delinquent acts except for violation of the following statutes or ordinances: prohibiting driving while under the influence of alcoholic beverages, narcotics, barbiturates or other stimulants; driving without or during suspension of a driver's license; fleeing or attempting to elude a police officer; leaving the scene of an accident; and reckless driving.

13. "Neglected child" means a child:

(a) who has been abandoned by his parents, guardian, or other custodian;

(b) who is without proper parental care and control, or subsistence, education, medical or other care or control necessary for his well-being because of the faults or habits of his

parents, guardian, or other custodian or their neglect or refusal, when able to do so, to provide them, or

(c) whose parents, guardian, or other custodian are unable to discharge their responsibilities to and for the child because of incarceration, hospitalization, or other physical or mental incapacity; or

(d) who has been placed for care or adoption in violation of law.

14. "Custodian" means a person, other than a parent or legal guardian, to whom legal custody of the child has been given by court order or who is acting in loco parentis.

15. The singular includes the plural, the plural the singular, and the masculine the feminine, when consistent with the intent of this act.

SECTION 3. - INTAKE AND PROBATION SERVICES.

1. The department of health and rehabilitative services shall establish a statewide program of intake services and a statewide program of probation and other casework and clinical services to serve the court. The two programs shall be separate and apart from each other. The intake services program shall provide intake attorneys for the juvenile court. Whenever possible, the intake services shall be provided on a neighborhood basis in order that the causal effects relating to the child's actions or neglect may be more immediately diagnosed and, if possible, corrected without further court action.

2. The cost of these programs shall be paid out of the general revenue funds of the State. All employees shall be selected, appointed and promoted through a State merit system.

SECTION 4. - JURISDICTION.

1. The juvenile court shall have exclusive original jurisdiction of:

(a) proceedings in which a child is alleged to be delinquent or neglected;

(b) the termination of parental rights;

(c) proceedings for the adoption of an individual of any age.

(d) proceedings under the Interstate Compact on Juveniles;

2. The juvenile court shall have concurrent jurisdiction with the county judge's court of:

(a) proceedings for treatment or hospitalization of a mentally retarded or mentally ill child;

(b) proceedings to appoint a legal custodian or a guar-: dian of the person of a minor.

3. The juvenile court shall have jurisdiction of traffic offenses according to the terms of this act.

SECTION 5. - VENUE.

Proceedings under this act shall be commenced in the county where the child resides, if delinquency is alleged, they may also be commenced in the county where the acts constituting the alleged delinquency occurred. If neglect is alleged, they may also be brought in the county where the child, is present when the proceedings are commenced.

SECTION 6. - TRANSFER TO ANOTHER FAMILY COURT WITHIN THE STATE.

If the child resides in a county of the State and the proceeding is commenced in a court of another county, that court, on its own motion or a motion of a party made at any time prior to final disposition, may transfer the proceeding to the county of the child's residence for such further action or proceedings as the court

receiving the transfer may deem proper. Like transfer may be made if the residence of the child changes pending the proceeding. The proceeding shall be so transferred if the child has been adjudicated delinquent and other proceedings involving the child are pending in the family court of the county of his residence.

Certified copies of all legal and social records pertaining to the case shall accompany the transfer.

SECTION 7. - FILING OF PETITION ALLEGING DELINQUENT ACTS.

1. Complaints alleging delinquent acts or neglect shall be referred to the intake department. The intake department shall conduct a preliminary inquiry to determine first:

(a) In case of an alleged delinquent act, if there is probable cause to believe that a delinquent act has been committed and that the child committed the delinquent act;

(b) In case of alleged neglect, if there is probable cause to believe that the circumstance alleged to constitute neglect exists.

2. If the intake department determines that such probable cause exists, it shall then determine whether the best interests of the child or of the public require that a petition be filed. If the intake attorney determines that a petition should be filed, the intake attorney shall prepare, countersign and file the petition. When the intake department determines that a petition should not be filed, the court, upon application of the complainant, shall review this decision.

3. When a child is in detention or shelter care and the filing of a petition is not approved by the intake attorney, the child shall be immediately released.

4. The intake department shall have the authority to refer the case to an appropriate public or private agency or to conduct

conferences for the purposes of effecting adjustments or agreements which will obviate the necessity for filing a petition. During such inquiries, a party may not be compelled to appear at any conference, to produce any papers, or to visit any place. Such inquiries and conferences shall not extend for a period beyond 30 days from the date the complaint was made.

5. On motion by or in behalf of a child, a petition shall be dismissed with prejudice if it was not filed within 10 days from the date the complaint was referred to the intake department.

SECTION 8. - FORM OF PETITION.

1. Subject to subsection 2 of this section, petitions initiating court action and probation revocation petitions may be signed by any person who has knowledge of the facts alleged or is informed of them and believes that they are true.

2. The intake attorney shall represent the petitioner in all proceedings where the petition alleges delinquency or neglect.

3. Petitions shall be entitled, "In the Matter of_____, a Child," and shall be verified by affidavit.

4. Petitions shall set forth with specificity:

(a) the facts which bring the child within the provisions of subsection 1 (a) of section 4, and that the child is in need of care, supervision and rehabilitation;

(b) the name, birth date) and residence address of the child;

(c) the names and residence addresses of his parents, guardian or custodian, and spouse if any. If neither of his parents, guardian or custodian resides or can be found within the State, or if their residence addresses are unknown, the name of any known adult relative residing within the State, or, if there be none, the known adult relative residing nearest to the court;

(d) whether the child is in custody, and, if so, the place of detention and the time he was taken into custody; and

(e) when any of the facts required in paragraphs (b)-(e) are not known, the petition shall so state.

SECTION 9._- SUMMONS.

1. After a petition has been filed, the court shall immediately but not later than 24 hours direct the issuance of summonses, one directed to the child, and another to the parents, guardian, or other custodian, and such other persons as appear to the court to be proper or necessary parties to the proceedings, requiring them to appear personally before the court at the time fixed to answer the allegations of the petition. Where the custodian is summoned, the parent or guardian or both shall also be served with a summons. If the child is married, the spouse shall also be served with a summons.

2. The summons shall advise the parties of their right to counsel as provided in section 14. A copy of the petition shall be attached to each summons.

3. The judge may endorse upon the summons an order directing the parents, guardians, or other custodian having the custody or control of the child to bring the child to the hearing.

4. If it appears, from affidavit or sworn statement presented to the judge, that the child needs to be taken into custody pursuant to section 12, the judge may endorse upon the summons an order that an officer serving the summons shall at once take the child into custody and take him to the place of detention or shelter care designated by the court.

5. A party, other than the child, may waive service of summons by written stipulation or by voluntary appearance at the hearing.

SECTION 10. - SERVICE OF SUMMONS.

1. If a party to be served with a summons can be found within the State, the summons shall be served upon him personally at least 24 hours before the hearing. If he is within the State and cannot be found, but his address is known or can with reasonable diligence be ascertained, the summons may be served upon him by mailing a copy thereof by certified mail at least 5 days before the hearing. If he is without the State but he can be found or his address is known, or can with reasonable diligence be ascertained, service of the summons may be made either by delivering a copy thereof to him personally or by mailing a copy thereof to him by certified mail.

2. It shall not be necessary to the validity of any juvenile court proceedings concerning a child that the parents or legal custodians of the child be present, if diligent search and inquiry have been made without success by the court to ascertain their identity and residences, or if the parents and legal custodians evade service of or ignore summons, but in that event the judge, or authorized agent of the department of health and rehabilitative services who made the search and inquiry shall file in the case a certificate as to those facts, and the judge shall appoint a guardian ad litem for the child.

3. All process, orders, commitments to the division of health and rehabilitative services, and other papers issued out of the juvenile court or by the judge thereof in the capacity of committing magistrate may be served or executed, as the judge may direct, by the counselor or an assistant counselor of that juvenile court, or in the same manner as process issued out of a circuit court. Authorized agents of the department of health and rehabilitative services are also authorized to serve process, orders, commitments to the department of health and rehabilitative services,

and other papers issued out of the court or by the judge in the capacity of committing magistrate regarding cases under active supervision of the department.

SECTION 11. - TIME LIMITATIONS.

1. On motion by or in behalf of a child, a delinquency petition shall be dismissed with prejudice where the allegations of the petition are not determined by an admission, or a hearing on the allegations of the petition not commenced within:

(a) 10 days from the date the petition is filed where a child in custody is denied unconditional release at his detention hearing;

(b) 20 days from the date the petition is filed where a child, once in custody for the offense charged in the petition or an offense based upon the same conduct, is released at or before his detention hearing;

(c) 20 days from the date the petition is filed where the child was never in custody for the offense charged in the petition or an offense based upon the same conduct; or

(d) within either 10 days or 20 days from the time the child was taken into custody as provided in subsection 1 (a) or 1 (b) in cases where the summons directs that the child be taken into custody by the officer serving the summons, and the child has not previously been in custody for the offense charged in the petition or an offense based upon the same conduct.

2. The following periods shall be excluded in computing the time for a hearing on the allegations in the petition:

(a) The period of delay resulting from other proceedings concerning the child, including but not limited to an examination and hearing related to mental health, prehearing motions, waiver motions, and hearings on other matters.

(b) The period of delay resulting from a continuance granted at the request or with the consent of the child and his counsel.

(c) The period of delay resulting from a continuance granted at the request of the (title of appropriate prosecuting official) if the continuance is granted because of the unavailability of evidence material to his case, when the (title of appropriate prosecuting official) has exercised due diligence to obtain such evidence and there are reasonable grounds to believe that such evidence will be available at the later date; or the continuance is granted to allow the (title of appropriate prosecuting official) additional time to prepare his case and additional time is justified because of the exceptional circumstances of the case.

(d) The period of delay resulting from the imposition of a consent decree.

(e) The period of delay resulting from the absence or unavailability of the child.

(f) A reasonable period of delay when the child is joined for a hearing with another child as to whom the time for a hearing has not run and there is good cause for not hearing the cases separately. In all other cases, the child's case shall be separated from the hearing of another child alleged to have participated in the same offense so that a hearing may be held within the time limits applicable to him.

SECTION 12. - TAKING INTO CUSTODY.

No child shall be taken into custody except:

1. For a delinquent act pursuant to the laws of arrest;

2. By a law enforcement officer or authorized agent of the department of health and rehabilitative services when he has reasonable grounds to believe that the child is in immediate danger,

and that his being taken into custody is necessary to protect him from that danger;

3. Pursuant to an order of the court, rendered pursuant to the provisions of this act.

SECTION 13. - CRITERIA FOR DETAINING CHILDREN.

A child taken into custody shall not be placed or retained in detention or shelter care prior to the court's disposition unless detention or shelter care is required:

1. to protect the person or property of others or of the child; or

2. because he has no parent, guardian, custodian, or other person able to provide supervision and care for him; or

3. to secure his presence at the next hearing.

SECTION 14. - PLACE OF DETENTION OR SHELTER.

1. A child alleged to be delinquent may be detained, pending trial, in the following places:

(a) a licensed foster home or a home otherwise authorized by law to provide such care;

(b) a facility operated by a licensed child welfare agency;

(c) a detention home for children alleged to be delinquent operated by the department of health and rehabilitative services; or

(d) any other suitable place designated by the court, provided that no place of detention or shelter care may be designated if it is a facility to which children adjudicated delinquent may be committed under this act.

2. No child alleged to be delinquent may be placed in a jail or other facility for the detention of adults.

3. The official in charge of a jail or other facility for the detention of adult offenders or persons charged with crime shall

inform the court immediately when a child, who is or appears to be under the age of 18 years, is received at the facility, and shall deliver him to the court upon request, or transfer him to a detention facility designated by the court.

4. A child alleged to be neglected may be detained or placed in facilities for shelter care enumerated in subsections 1 (a), 1 (b), and 1 (d), and shall not be detained in a jail or other facility intended or used for the detention of adults charged with criminal offenses or for children alleged to be or who are delinquent.

SECTION 15. - RIGHTS OF CHILD.

1. Every child shall be presumed innocent until proven guilty.

2. A child shall be represented by counsel at all stages of any proceeding including any contact with the intake attorney and his office. If counsel is not retained for the child, the court shall appoint counsel for the child and if the parent or legal guardian or the child's estate cannot afford counsel, the public defender or other counsel shall be appointed to represent the child, and the right to counsel shall not be waived by the child or on his behalf.

3. With respect to a child charged with a delinquent act:

(a) such child shall not be compelled to be a witness against himself.

(b) such child shall be accorded all the rights guaranteed by Article I, section 12 of the Florida Constitution.

(c) Unless advised by counsel and accorded all constitutional rights, the statements of a child made while in custody to police or law enforcement officers or made to the intake attorney or probation officer during the processing of the case, including statements made during a preliminary inquiry, predisposition study

or consent decree, shall not be used against the child prior to a determination of the petition's allegations in a delinquency case or in a criminal proceeding prior to conviction.

(d) An extra judicial statement which would be constitutionally inadmissable in a criminal proceeding shall not be received in evidence against such child.

(e) An admission or confession made by such child out of court is insufficient to support a finding that the child committed the acts with which he is charged unless it is corroborated by other evidence.

(f) Such child shall not be put in jeopardy twice for the same offense. Criminal proceedings and other juvenile proceedings based upon the offense alleged in the petition or an offense based on the same conduct are barred where the court has begun taking evidence or where the court has accepted a child's plea of guilty to the petition.

(g) Such child shall be entitled to a trial by an impartial jury on the issues of whether the act with which he was charged was committed and whether the child committed it.

(h) Such child shall have the right to have compulsory process for witnesses, to confront at trial or final hearing adverse witnesses, and to be heard in person, by counsel or both.

(i) Any child charged with a delinquent act shall be entitled to release on reasonable bail with sufficient surety unless charged with what would be a capital offense or an offense punishable by life imprisonment if he were an adult, and the proof of guilt is evident or the presumption great, or unless his detention is necessary to protect the person or property of others or of the child.

SECTION 16. - CONDUCT OF TRIAL OR HEARING.

1. All proceedings shall be reported.

2. All hearings shall be open to the public, except those involving unwed mothers, custody or placement of illegitimate children.

SECTION 17. - SUBPOENA.

Upon application of a party, the clerk of the court shall issue, and the court on its own motion may issue, subpoenas requiring attendance and testimony of witnesses and production of records, documents or other tangible objects at any hearing.

SECTION 18. - PREDISPOSITION STUDY AND REPORT.

1. After a petition has been filed pursuant to section 4, 1 (a), the court shall direct that predisposition study and report to the court be made in writing by a probation officer or another agency authorized by law, concerning the child, his family, his environment, and other matters relevant to the need for treatment or disposition of the case. The study and report shall not be made prior to a finding with respect to the allegations in the petition unless a notice of intent to admit the allegations is filed, and the party consents thereto.

2. If, at the time of taking the juvenile into custody or at any subsequent stage of the proceedings, there are indications that the juvenile is mentally retarded, mentally ill, emotionally disturbed or otherwise suffering from a mental and/or emotional handicap, neurological disorder or chemical imbalance which could have an effect on his mental functioning, emotional functioning or behavior, the intake officer, Counsel for the juvenile, or any interested party shall immediately seek an emergency hearing before the judge on the issue of mental incapacity, which hearing shall be held within 3 hours of the emergency application; and the judge

shall order the juvenile to be examined by a psychiatrist, a psychologist, a physician and a social worker; but said juvenile shall not be detained in a detention facility, in the event he is considered to be a danger to himself or the community, he shall be placed in a mental hospital, training center for the retarded or other appropriate facility, and examined/therein. In this event the judge shall have the authority fab make placement of the child in a mental hospital, training center for the retarded, or . other appropriate facility; and said mental hospital, training center for the retarded or other appropriate facility shall accept custody of such child. An appropriate facility for the purposes of this section shall be one employing and containing, as integral parts thereof, medical, psychiatric and or psychological professional personnel and resources capable of providing the necessary care and treatment appropriate to the condition of the child. In the event the juvenile is not considered to be a danger to himself or the community, he shall be examined on an outpatient basis at a mental hospital, training center for the retarded or other appropriate facility as defined herein, and shall be released to the custody of his parents or guardian.

3. In 1:he event the child is found to be mentally retarded, mentally ill, emotionally disturbed, or otherwise suffering from a mental and/or emotional handicap, neurological disorder or chemical imbalance which could have an effect on his mental functioning, emotional functioning or behavior, the petition alleging delinquency, if same has been filed, shall be promptly, and no later than 24 hours after diagnosis, dismissed. In the event the juvenile is considered/to be a danger to himself or the community, the court shall have the authority to, and shall, transfer custody of such juvenile to the division of mental health, the division of retardation or such other agency or facility as is appropriate to

the condition of the child, an appropriate agency or facility being one as defined in subsection 2 hereof, said division of mental health, division of retardation or other appropriate agency or facility shall accept custody of such child, and shall not discharge him without a full hearing before the judge. The court shall retain jurisdiction over every child found to be mentally retarded, mentally ill, emotionally disturbed, or otherwise suffering from a mental and/or emotional handicap, neurological disorder or chemical imbalance which could have an effect on his mental functioning, emotional functioning or behavior, if said child is also considered to be/a danger to himself or the community, for the purposes of transferring custody of such juvenile and conducting a full hearing prior to said child's discharge from the division of mental health, division of retardation or other appropriate agency/or facility, as provided in this section and defined in subsection 2 hereof. In the event said juvenile is not considered to he a danger to himself or the community, he shall be released/to the custody of his parents or guardian; and the court shal retain jurisdiction over each said juvenile for the purpose off ordering outpatient treatment appropriate to the child's condition at a mental hospital, training center for the retarded or/other appropriate agency or facility, as defined in subsection 2 hereof, and for the purpose of conducting hearings to ensure compliance with such orders for outpatient treatment.

SECTION 19. - PRELIMINARY BEARING FOR CHILD ALLEGED TO BE DELINQUENT.

1. A child taken into custody, shall immediately but no later than twelve (12) hours after being taken into custody:

(a) be released to his parents, guardian, or custodian and be given verbal counsel or warning as may be appropriate;

(b) be released to his parents, guardian, or custodian upon their promise to bring the child before the court when requested by the court, unless his placement in detention or shelter care appears required as provided in section 12, or

(c) brought to the intake department or delivered to a place of detention or shelter care designated by the court or to a medical facility if the child is believed to be suffering from a serious physical condition or illness which requires either prompt treatment or prompt diagnosis for evidentiary purposes, and promptly give written notice thereof, together with a statement of the reason for taking the child into custody, to a parent, guardian, or other custodian and to the court.

2. When a child is delivered to the intake department or to a place of detention or shelter care designated by the court, an intake officer shall, prior to admitting the child for care, review the need for detention or shelter care and shall release the child unless detention or shelter care is required under section 12 or has been ordered by the court. When the intake officer determines such detention or shelter care is required, immediately but not later than 12 hours after delivery the child shall be taken before the court for a preliminary hearing.

3. Notice of the preliminary hearing, either oral or written, stating the time, place, and purpose of the hearing shall be given to the parent, guardian, or custodian if they can be found and to the child;

4. When a child charged with a delinquent act is brought before the court for a preliminary hearing, the court shall immediately inform him:

(a) of the charge against him and the contents of the petition;

(b) of the purpose of a preliminary hearing;

(c) of the fact that he shall be represented by counsel at all stages of the proceedings and of his other rights guaranteed by this act;

(d) of his right on the advice of counsel to waive the preliminary hearing;

5. The child upon advice of counsel may waive a preliminary hearing, and if he does so such waiver shall be in writing and signed by the child and his counsel. If the child waives preliminary hearing, the court shall set a time for the trial of his cause and either release him as provided in this section, admit him to bail or commit him to custody.

6. The court shall allow the child or his parents, legal guardian or custodian a reasonable time to send for counsel and shall, if necessary, postpone the hearing for such purpose. If the parent, legal guardian, custodian or the child's estate is unable to afford counsel, the court shall appoint the public defender to represent the child.

7. The court may for good cause postpone the hearing. If no postponement is ordered, the hearing shall be completed in one session. No postponement shall be for more than two days, nor shall the postponements in all exceed six days, except for exceptional circumstances.

8. If a postponement is ordered, unless the child is already admitted to bail or released in the custody of his parent, legal guardian or custodian, the court, if the child is bailable as of right, shall admit him to bail for his appearance at the time to which the hearing is postponed or, whenever possible, release him to the custody of his parent, legal guardian or custodian, who shall be responsible for the child's appearance at the postponed hearing. If bail is not furnished, or the child is not released, the court

shall commit him to custody for further hearing of the case.

9. The court shall issue such process as may be necessary to secure attendance of witnesses within the state, for the state or the defendant.

10. All witnesses shall be examined in the presence of the child and may be cross-examined.

11. Prior to the examination of any witness in the cause, the court may and on the request of the child's counsel shall exclude all other witnesses. He also may cause the witnesses to be kept separate and to be prevented from communicating with each other until all are examined.

12. If from the evidence it appears to the court that there is probable cause to believe that the act alleged to be a delinquent act was committed, that the child committed said act and that the child needs care or rehabilitation, the court shall forthwith hold the child to answer. Otherwise, the court shall discharge him.

13. If the child is held to answer, the court shall if the child is bailable, admit the child to bail, or whenever possible, pursuant to section 12 of this act release him on such terms and conditions as the court deems appropriate to the custody of his parent, legal guardian or custodian who shall be responsible for the child's appearance at trial.

14. If the child is held to answer and if no petition has been filed with respect to said child, a petition shall be filed within twenty four (24) hours after the preliminary hearing.

SECTION 20. - SHELTER HEARING FOR CHILD ALLEGED TO-BE NEGLECTED.

1. When a child alleged to be neglected is detained pursuant to section 12 of this act, a detention or shelter care hearing shall be held within 24 hours from the time he was taken into custody to determine whether continued detention or shelter care is required pursuant to section 12.

2. Notice of the shelter care hearing, either oral or written, stating the time, place, and purpose of the hearing shall be given to the parent, guardian, or custodian if they can be found and to the child.

3. The parties shall be informed of the contents of the petition, and shall be given an opportunity to admit or deny the petition's allegations.

4. When the judge finds that a child's shelter care is not required, the court shall order his release, and in so doing, may impose one or more of the following conditions singly or in combination:

(a) place the child in the custody of a parent, guardian, or custodian under their supervision, or under the supervision of an organization agreeing to supervise him;

(b) place restrictions on the child's travel, association, or place of abode during the period of his release; or

(c) impose any other condition deemed reasonably necessary and consistent with the criteria for detaining children specified in section 12, including a condition requiring that the child return to custody as required.

5. An order releasing a child on any conditions specified in this section may at any time be amended to impose additional or different conditions of release or to return the child to custody for failure to conform to the conditions originally imposed.

6. All relevant and material evidence helpful in determining the need for detention or shelter care may be admitted by the court even though not competent in a hearing on the petition.

SECTION 21. - TRIAL OF PETITION ALLEGING DELINQUENT ACT.

1. If the allegations of a petition alleging a delinquent act are denied, the court shall set the cause for trial. If the

court or jury finds on proof beyond a reasonable doubt, based upon competent, material, and relevant evidence, that a child committed the acts by reason of which he is alleged to be delinquent, the judge, without jury, may in the absence of objection, proceed immediately to hear evidence as to whether the child is in need of care or rehabilitation. If the burden of proof is not sustained on the issue of whether the alleged acts were committed, the court shall dismiss the petition and order the child discharged from any detention or temporary care theretofore ordered in the proceeding. If the court finds that the child is not in need of care or rehabilitation, it shall dismiss the proceedings and discharge the child from any detention or temporary care theretofore ordered. If the child is found to have committed an act which constitutes a felony, such a finding is sufficient to sustain a finding that the child is in need of care or rehabilitation in absence of evidence to the contrary.

If the court finds from clear and convincing evidence, relevant, competent and material in nature that the child is in need of care or rehabilitation, the court may proceed immediately or at a postponed hearing to make proper disposition of the case.

SECTION 22. - HEARING OK PETITION ALLEGING CHILD TO BE NEGLECTED.

The court without jury shall hear evidence on the petition alleging the child to be neglected. If the court finds from clear and convincing evidence, competent, material and relevant in nature, that the child is neglected, the court may proceed immediately *or* at a postponed hearing to make proper disposition of the case. Otherwise, the court shall dismiss the petition and order the child discharged from any detention or temporary care theretofore ordered in the proceeding.

SECTION 23. - DISPOSITION HEARINGS.

1. In disposition hearings all relevant and material evidence helpful in determining the questions presented, including oral and written reports, may be received by the court and may be relied upon to the extent of its probative value, even though not competent in a hearing on the petition. The parties or their counsel shall be afforded an opportunity to examine and controvert written reports so received and to cross-examine individuals making reports when reasonably available.

2. On its motion or that of a party, the court may continue the hearings under this section for a reasonable period not to exceed ten (10) days to receive reports and other evidence bearing on the disposition or need for care or rehabilitation. In this event, the court shall make an appropriate order for detention or temporary care of the child or his release from detention or temporary care subject to supervision of the court during the period of the continuance.

SECTION 24. - CONTINUANCE UNDER SUPERVISION WITHOUT ADJUDICATION.

1. At any time after the filing of a delinquency petition and before the entry of an adjudication order, the court may, on motion of the intake attorney or that of counsel for the child, suspend the proceedings, and continue the child under supervision in his own home, under terms and conditions negotiated with probation services and agreed to by all parties affected. The court's order continuing the child under supervision shall be known as a consent order. 2. Where the child objects to a consent order, the court shall proceed to findings, adjudication and disposition. Where the child does not object, but an objection is made by the intake attorney after consultation with probation services, the court

shall, after considering the objections and reasons therefor, proceed to determine whether it is appropriate to enter a consent order.

3. A consent order shall remain in force for 6 months unless the child is discharged sooner by probation services. Upon application of probation services or other agency supervising the child, made before expiration of the 6-month period, a consent order may be extended by the court for an additional 6 months.

4. If prior to discharge by the probation services or expiration of the consent order, a new delinquency petition is filed against the child, or the child otherwise fails to fulfill express terms and conditions of the order, the petition under which the child was continued under supervision may, in the discretion of the court following consultation with probation services, be reinstated and the child held accountable just as if the consent order had never been entered.

5. A child who is discharged by the probation services, or who completes a period of continuance under supervision without reinstatement of the original delinquency petition, shall not again be proceeded against in any court for the same offense alleged in the petition or an offense based upon the same conduct.

6. A judge who, pursuant to this section, elicits or examines information or material about a child which would be inadmissible in a hearing on the allegations in the petition shall not, over the objection of the child, participate in any subsequent proceedings on the delinquency or in need of supervision petition if:

(a) a consent order is denied and the allegations in the petition remain to be decided in a hearing where the child denies his guilt; or

(b) a consent order is granted but the delinquency petition is subsequently reinstated under subsection 4.

SECTION 25. - DISPOSITION OF CHILD.

1. The court shall enter a disposition order as soon as reasonably practicable after a petition is filed, but not later than twenty (20) days after the petition is filed if the child is detained in custody except for exceptional circumstances.

2. If a child is found to be neglected, the court may make any of the following orders of disposition to protect the welfare of the child:

(a) permit the child to remain with his parents, guardian, or other custodian, subject to such conditions and limitations as the court may prescribe;

(b) place a child, under the supervision of the counselor or authorized agent of the division of rehabilitative services either in the child's own home, or, the prospective custodian being willing, in the home of a relative of the child, or in some other suitable place, under such reasonable conditions as the judge may direct.

(c) transfer legal custody of the child to a licensed child caring institution willing to receive the child or a public child caring institution.

(d) transfer legal custody of the child to the department of health and rehabilitative services. The department shall have exclusive control of all children committed to it for the purpose of providing care, custody, treatment and placement.

(e) permanently transfer legal custody of the child to a licensed child placing agency, or the department of health and rehabilitative services, willing to receive the child, for subsequent adoption, if the court finds that the child has been abandoned by the natural parent or parents, and legal guardian if any, of the child; or that the parent or parents, and legal guardian if any, have substantially and continuously or repeatedly refused, or though

financially able have neglected, to give the child parental care and protection; or that the parent or parents, and legal guardian if any, are unfit by reason of their conduct or condition, which is seriously detrimental to the child's welfare; and if the court finds that it is manifestly to the best interest of the child to do so.

(f) transfer legal custody of the child to a relative or other individual who, after study by the probation services or other agency designated by the court, is found by the court to be qualified to receive and care for the child.

(g) if the court determines the child shall be hospitalized for medical or psychological treatment, it shall order such hospitalization or placement at an appropriate licensed institution.

2. unless a child found neglected shall also be found to be delinquent, he shall not be committed to or confined in an institution established for the care and rehabilitation of delinquent children.

3. If a child is found to be a delinquent, the court may make any of the following orders of disposition for his supervision, care, and rehabilitation:

(a) any order which is authorized by subsection (a) (b) (c) or (d) of this section for the disposition of a neglected child;

(b) place the child on probation under such conditions and limitations as the court may prescribe.

4. No delinquent child by virtue of such adjudication shall be committed or transferred to a penal institution or other facility used for the execution of sentences of persons convicted of a crime.

5. Whenever the court vests legal custody in an agency, institution or department, it shall transmit with the order copies of the clinical reports, predisposition study, and other information it has pertinent to the care and treatment of the child.

SECTION 26. - ORDER OF ADJUDICATION.

An order of disposition or other adjudication in proceedings under this act shall not be deemed a conviction of crime or impose any civil disabilities ordinarily resulting from a conviction or operate to disqualify the child in any civil service application or appointment.

The disposition of a child and evidence given in a hearing in the court shall not be admissible as evidence against him in any case or proceeding in any other court whether before or after reaching majority except in sentencing proceedings after conviction of a felony for the purposes of a presentence study and report.

SECTION 27. - LIMITATION OF TIME OH DISPOSITIONAL ORDERS.

1. An order vesting legal custody of a child in a department, agency, or institution shall remain in force for an indeterminate period not exceeding 1 year from the date entered, provided, however, that the child shall be released within the 1-year period by the department, institution, or agency when it appears that the purpose of the order has been achieved.

2. An order vesting legal custody of a child in an individual shall remain in force for 1 year from the date entered unless sooner terminated by court order.

3. An order of probation or protective supervision shall remain in force for an indeterminate period not exceeding 1 year from the date entered, provided, however, such probation or supervision shall be terminated within the 1-year period by probation services or agency providing the supervision where it appears that the purpose of the order has been achieved.

4. Prior to the expiration of an order transferring legal custody, the court may extend the order for an additional period of 1 year if it finds after a hearing, pursuant to section 23, that

the extension is necessary to safeguard the welfare of the child or the public interest.

5. Prior to the expiration of an order of probation or protective supervision, the court may extend it for an additional period of 1 year after a hearing pursuant to section 23 if it finds that the extension is necessary to protect the community or to safeguard the welfare of the child.

6. When a child reaches 18 years of age, all orders affecting him then in force terminate.

7. A release or termination, and the reasons therefor, made under subsections 1 and 3 of this section shall be promptly reported to the court in writing.

SECTION 28. - MODIFICATION, TERMINATION OR EXTENSION OF COURT ORDERS.

1. At any time prior to expiration, an order vesting legal custody or an order of protective supervision made by the court in the case of a child may be modified, revoked, or extended on motion by:

(a) a child, whose legal custody has been transferred to an institution, agency, or person, requesting the court for a modification or termination of the order alleging that he is no longer in need of commitment and the institution, agency, or person has denied application for release of the child or has failed to act upon the application within a reasonable time; or

(b) an institution, agency, or person vested with legal custody or responsibility for protective supervision requesting the court for an extension of the order on the grounds that such action is necessary to safeguard the welfare of the child or the public interest.

2. The court may dismiss a motion filed under subsection 1 of this section if, after preliminary investigation, it finds that

it is without substance. If it is of the opinion that the order should be reviewed, it may, upon due notice to all necessary parties as prescribed by rules of court, proceed to a hearing in the manner provided for in this act. It may thereupon terminate the order if it finds the child is no longer in need of care, supervision, or rehabilitation, or it may enter an order extending or modifying the original order if it finds such action necessary to safeguard the child or the public interest.

SECTION 29. - PROBATION REVOCATION.

1. A child on probation incident to an adjudication as a delinquent who violates a term of his probation may be proceeded against in a probation revocation hearing.

2. A proceeding to revoke probation shall be commenced by the filing of a petition labeled "Petition to Revoke Probation." Except as otherwise provided, petitions to revoke probation shall be screened, reviewed and prepared in the same manner and shall contain the same information as provided in sections 7 and 8. The petition shall recite the date that the child was placed on probation and shall state the time and manner in which notice of the terms of probation were given.

3. Probation revocation proceedings shall require clear and convincing evidence. In all other respects, proceedings to revoke probation shall be governed by the procedures, rights and duties applicable to delinquency cases contained in this act.

4. If a child is found to have violated a term of his probation pursuant to a probation revocation hearing, the court may extend the period of probation or make any other order of disposition specified for a child adjudicated delinquent.

SECTION 30. - GUARDIAN AD LITEM; GUARDIAN OF THE PERSON.

1. The court, at any stage of a proceeding under this act, shall appoint a guardian ad litem for a child who is a party to the proceeding, if he has no parent or guardian or custodian appearing on his behalf or their interests conflict with those of the child. A party to the proceeding or his employee or representative shall not be so appointed.

2. The court, in any proceeding under this act, shall appoint a guardian of the person for a child in any case where it finds that the child does not have a natural or adoptive parent in a position to exercise effective guardianship or a legally appointed guardian of his person. No officer or employee of a State or local public agency, or private agency or institution which is vested with legal custody of a child shall be appointed guardian of the person except when parental rights have been terminated and the agency or institution has been authorized to place the child for adoption.

3. In any case arising pursuant to section 4, 1 (a) the court, after finding that a child is neglected or delinquent, may also determine as between parents whether the father or mother shall have legal custody of the child, regardless of whether any other court shall have previously awarded custody.

SECTION 31. - PROTECTIVE ORDER.

In any proceeding commenced under this act, on application of a party or the court's own motion, the court may make an order restraining the conduct of any party over whom the court has obtained jurisdiction, if:

1. an order of disposition of a delinquent or neglected child has been made in a proceeding under this act; and

2. the court finds that the person's conduct is or may be

detrimental or harmful to the child, and will tend to defeat the execution of the order of disposition made; and

3. due notice of the application or motion and the grounds therefor and an opportunity to be heard thereon have been given to the person against whom the order is directed.

SECTION 32. - CONTEMPT.

The juvenile court shall have the same power to punish for contempt as do the circuit courts, and may punish for contempt any person interfering with the administration of or violating any provision of this chapter or order of the court relative thereto.

SECTION 33. - CONTINUANCES.

Continuances shall be granted by the court only upon a showing of good cause and only for so long as is necessary, taking into account the request or consent of the intake attorney, or the child, but also the interest of the child and the public in the prompt disposition of cases.

SECTION 34. - TRAFFIC OFFENSES.

No child shall be taken into custody for the violation of any traffic offense except those defined as delinquent acts pending determination of the matter and no child shall be placed in any penal institution or other facility used for holding persons convicted of a traffic offense.

SECTION 35. - APPEAL.

1. Any child, and any parent or legal custodian of any child, affected by an order of the juvenile court may appeal to the appropriate appellate court within the time and in the manner prescribed by the Florida appellate rules. The attorney general shall represent the state.

2. The taking of an appeal shall not operate as a supersedeas except:

(a) pursuant to the order of the juvenile court;

(b) a permanent order of commitment to a licensed child-placing agency or to the department of health and rehabilitative services for subsequent adoption shall be suspended while the appeal is pending, but the child shall continue in custody under the order until the appeal is decided.

3. The case on appeal shall be docketed, and any papers filed in the appellate court shall be entitled, with the initials but not the name of the child and the juvenile court case number, and the papers shall remain sealed in the office of the clerk of the appellate court when not in use by the appellate court and shall not be open to public inspection. The decision of the appellate court shall be likewise entitled, and shall refer to the child only by initials and juvenile court case number.

4. The original order of the appellate court, with all papers filed in the case on appeal, shall remain in the office of the clerk of the said court, sealed and not open to inspection except by order of the appellate court. The clerk of the appellate court shall return to the juvenile court all papers transmitted to the said court from the juvenile court, together with a certified copy of the order of the appellate court.

SECTION 36. - FINGERPRINTS; PHOTOGRAPHS.

1. If latent fingerprints are found during the investigation of an offense and a law enforcement officer has reason to believe that they are those of the child in custody, he may fingerprint the child regardless of age or offense for purposes of immediate comparison with the latent fingerprints. If the comparison is negative, the fingerprint card and other copies of the fingerprints taken

shall be immediately destroyed. If the comparison is positive and the child is under 14 years of age and referred to court, the fingerprint card and other copies of the fingerprints shall be delivered to the court for disposition. If the child is not referred to court, the print shall be immediately destroyed.

2. If the court finds that a child 14 or more years of age has committed a felony, fingerprints may be taken and retained in a local file or sent to a central State depository provided that they shall be kept separate from those of adults under special security measures limited to inspection for comparison purposes by law enforcement officers or by staff of the depository only in the investigation of a crime.

3. A child in custody shall not be photographed for criminal identification purposes without the consent of the judge.

4. Any fingerprinting and photographing of juveniles, pursuant to the above provisions, will be accomplished at the juvenile court by juvenile authorities. No child shall be fingerprinted or photographed at any jail, police station, or any other place of detention for adults.

5. Any person who willfully violates provisions of this section is guilty of a misdemeanor.

SECTION 37. - SEAL.

The juvenile court is a court of record, having a seal, and the judge, counselor, assistant counselors, clerks, deputy clerks, or authorized agents of the department of health and rehabilitative services shall each have power to administer oaths and affirmations. The seal shall be prescribed and furnished by the board of county commissioners of the county in which the court is established.

SECTION 38. - RECORDS; PRIVILEGED INFORMATION.

1. The court shall make and keep records of all cases brought before it and shall preserve the records pertaining to a child until ten years after the last entry was made and shall then destroy them, except that records of cases where orders were entered permanently depriving a parent of the custody of a child shall be preserved permanently. The court shall make official records, consisting of all petitions and orders filed in a case and any other pleadings, certificates, proofs of publication, summons, warrants and other writs which may be filed therein and shall make social records, consisting of records of investigation and treatment and other confidential information not forming part of the official records. In addition to the foregoing, the court shall keep a record to be designated "juvenile court statistical card" as to each child on whom a referral has been filed in the court, which card shall refer to the child only by initials and juvenile court case number setting forth full statistical data concerning such child and the grounds for the proceedings involved. The statistical card shall be in such form as provided by the department of health and rehabilitative services. Said card shall on or before the tenth day of each month be delivered to the department of health and rehabilitative services and shall be used by the department only for the purpose of obtaining the statistical information. The cards shall not be public records and shall be confidential information while in the possession of the department. The department shall not take or retain any names or addresses from any such cards or other information that would identify a child. It may publish the statistical data so obtained as to any or all counties reporting under this law.

2. On motion by a person who has been the subject of a petition filed pursuant to this act, or his parent or legal guardian, the

court, upon finding that the public's interest will not be adversely-affected, shall expunge any records relating to said child.

3. Court records except records of traffic violations, shall not be open to inspection by the public. All records, except those for traffic violations, shall be inspected only upon order of the judge, by persons deemed by the judge to have a proper interest therein, except that a child and the parents or legal custodians of the child and their attorneys shall always have the right to inspect and copy any official record pertaining to the child. The judge may permit authorized representatives of recognized organizations compiling statistics for proper purposes to inspect and make abstracts from official records, under whatever conditions upon their use and disposition the judge may deem proper, and shall punish by contempt proceedings any violation of those conditions.

4. All information obtained in discharge of official duty by any judge, counselor, assistant counselor, employee of any juvenile court, any authorized agent of the department of health and rehabilitative services shall be privileged, and shall not be disclosed to anyone other than the authorized personnel of the juvenile court, the department and others entitled under this chapter to receive that information.

5. All orders of the court shall be in writing and signed by the judge, except that the counselor, assistant counselor, clerk, deputy clerk or authorized agent of the department of health and rehabilitative services may sign a summons, or notice to appear.

6. No juvenile court record shall be admissible in evidence in any civil or criminal proceeding in any other court, except that:

(a) orders permanently depriving a parent of the custody of a child and committing the child to a licensed child placing agency or the department of health and rehabilitative services for adoption shall be admissible in evidence in subsequent adoption proceedings relating to the child;

(b) orders transferring a child to another court for trial shall be admissible in evidence in the other court, but shall create no presumption as to the guilt of the child, nor shall same be read to or commented upon in the presence of the jury in any trial in the other court.

(c) orders binding an adult over for trial on a criminal charge, made by the judge as a committing magistrate, shall be admissible in evidence in the court to which the adult is bound over;

(d) juvenile court records forming a part of the record on appeal shall be used in the appellate court in the manner hereinafter provided;

(e) juvenile court records necessary therefor shall be admissible in evidence in other courts in any case where a person is being tried upon a charge of having committed perjury in testifying in the juvenile court.

SECTION 39. - PAYMENT OF COST AND EXPENSES.

1. The court shall order the natural or adoptive parents of such child, or the natural father of an illegitimate child who has acknowledged his paternity in writing before the court or guardian of such child's estate, if possessed of assets which under law may be disbursed for the care, support and maintenance of such child, to:

(a) pay court costs and the costs of medical and other examinations and treatment of a child ordered by the court;

(b) pay the person or institution having custody of such child reasonable sums of money at such intervals as the court may consider adequate and proper for the care, support, maintenance, training and education of such child.

2. The court, in making such order, shall consider the circumstances and ability of such parents, or the natural father

of an illegitimate child, to pay, and the value of assets of the guardianship estate of such child, and where such order affects the guardianship estate, a certified copy of such order shall be delivered to the county judge having jurisdiction of such guardianship estate.

SECTION 40. - SEVERABILITY.

If any provision of this act, or the application thereof to any person or circumstances is held invalid, such invalidity shall not affect other provisions or applications of this act which can be given effect without the invalid provision or application. To this end the provisions of this act are declared to be severable.

SECTION 41.

This act shall take affect January 1, 1973.

Senator KENNEDY. Dr. Tarjan?

STATEMENT OF GEORGE TARJAN, M.D., PROFESSOR OF PSYCHIATRY AND PROGRAM DIRECTOR, COUNCIL ON MENTAL RETARDATION

Dr. TARJAN. Thank you, Mr. Chairman. First, I would like to thank you for the privilege of being invited to testify here. Second, I would like to assume that my written statement will be included in the record.

Senator KENNEDY. Without objection, it will be included at the end of your testimony.

Dr. TARJAN. I would simply like to add that I am a child psychiatrist who has spent his past 25 years in the area of mental retardation and some 18 years of it as the director of a large State institution. You have heard much about one such instiution recently.

Since 1965, I have been a full-time faculty member of U.C.L.A.

I should like to say that the lot of the mentally retarded is much better than it was 15 years ago. The Congress can, indeed, take pride for its leadership to authorize innovative programs and authorize the necessary funds.

It is true that many of my colleagues believe that the funds did not come fast enough. The fact is that several options are now open for the mentally retarded whereas, not long ago the only care was institutional care.

If I were to describe the present scene, I would say it could be best characterized by emphasizing its changing nature from the institutional to the community approach and I fully subscribe to that. However, we have a long way to go. Many community resources are still greatly missing.

This brings me to the Developmental Disability Act and some recommendations which I would like to focus on. I consider it absolutely essential that the Developmental Disability Act be continued. I expect that the possibility might arise that groups would like to specifically include certain conditions in addition to those which are now specifically included. In this case, problems would arise.

If this is not the case, then in my judgment, they would not exist. If on the other hand, new additional specific categories are added, then my concern is that the currently available moneys would be further diluted and I would plead for additional appropriations.

Again, if the latter situation arises, let me add from clinical experience that the most common single diagnosis that I found in developmentally disabled children is that of mental retardation. Therefore, I am urging you and your colleagues to include that particular term in any language that might be forthcoming.

In this time of changing patterns of care, I would like to urge that sufficient moneys be made available to enable the Nation to collect information and data on the fortunes or misfortunes of the mentally retarded or other disabled who are no longer in institutions or do not even enter.

We have reasonably good information on institutionalized individuals where this outcome may be good or bad, but we have no information as far as the noninstitutionalized are concerned. This was brought to my attention when I had the privilege of serving as one of the civilian consultants to the Federal task force that visited Willowbrook.

Again, I would like to emphasize the need for human resources. This brings me to the second part of the Developmental Disabilities Act, the one that refers to the University Affiliated Facilities.

I think that the University Affiliated Facilities are really the reservoir, the energy source, for making it possible for the Nation to develop the personnel needed in community care. As my good colleague, Dr. Cooke, emphasized, they can contribute much more than manpower development.

I strongly want to call attention to the need for continued vigorous support of research in all areas since, in spite of our advances, much of the knowledge necessary for good care is missing.

I would like to close by commending the Bill of Rights for the Mentally Retarded as a first step and only as a first step in the development of human dignity for the mentally retarded and those with other disabilities. I don't think that the bill is currently funded to the extent that can make a major impact, but I think the intent is not only laudable but essential.

Thank you, Senator.

Senator KENNEDY. Thank you, Dr. Tarjan. Dr. Jordan?

[The prepared statement of Dr. Tarjan follows:]

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February 1, 1973

The Honorable Edward M. Kennedy
United States Senate
Washington, D. C. 20510

Dear Senator Kennedy:

I feel greatly privileged that the Subcommittee has invited me to testify in connection with the hearings pertaining to Senate Bills 427 and 458, and has given me this opportunity to state my views concerning handicapping conditions. To a large extent, my comments will be based on those which I expressed on a recent occasion when, in one of our sister countries in the Americas, I was asked to review the progress our country has made in helping our retarded citizens over the past 25 years, to review the current scene, and to make some recommendations for future actions.

In sequence, I will first give you some information about my background so that you can judge the relevance and pertinence of my statements accordingly, then speak about some historical trends and accomplishments, describe the current situation and the current problems, and close with some selected general recommendations.

I am a psychiatrist, more specifically a child psychiatrist who has spent his professional time over the past quarter-century in caring for retarded children and adults, in teaching, research, and program administration, all related to mental retardation. Probably most importantly, I have had frequent opportunities to consult with a host of planning groups at the local, state, national and international levels. During the first 18 years of this time span, I was Superintendent and Medical Director of a traditional, large state institution for the mentally retarded: Pacific State Hospital in Pomona, California; and during the past 7-1/2 years I have been on the full-time faculty of the University of California at Los Angeles, in charge of the mental retardation program of that campus.. My expertise vis-a-vis handicapping conditions is probably greatest in the area of mental retardation, therefore I will focus, primarily on this syndrome.

When I started my work in mental retardation, shortly after the end of the Second World War, the main, if not sole, resource for "out-of-home" care for the retarded were the large residential facilities. Hence, my first extensive contact with retardation took place in such a setting. In those days, the Federal Government had, essentially, no special funds earmarked for the retarded. The institutions were supported by the states, and community programs were practically nonexistent. During the war, the construction of new facilities was halted, and the end of the war found the institutions overcrowded, underbudgeted, understaffed, and in disrepair. The level of care varied greatly from one institution to another, but in general was either poor or worse. In spite of this fact, there were long waiting lists for admission.

Retarded individuals were institutionalized neither with a therapeutic plan in mind nor out of real necessity, but simply because no other alternatives were available. Little was known either about newly admitted individuals or those in residence. Their development, their adjustment or the lack of it went unmonitored. Releases were rare and turnover rates were low. No estimates were on hand even pertaining to death rates. The addition of new beds was considered to be the simplest answer shortly after the war. Most states embarked on a program of institutional construction and accomplished this aim by enlargement of the existing institutions. Even the few new facilities followed the traditional models.

The first major breakthrough in community programming occurred when the education of the retarded, in state after state, moved from a voluntary and rare arrangement to become mandatory and more widespread. As a consequence, many school-age children who just a few years previously would have been institutionalized, remained at home and attended classes for the educable or trainable retarded.

In the 1950s and 1960s, a crescendo of progress took place. Several forces contributed significantly to this advance. They included the establishment of local parent organizations and that of the National Association for Retarded Children, the leadership of several members of Congress and of the various state legislatures, the enthusiastic participation of a number of governmental and professional leaders, the revitalization of some professional associations, the initiation of a few targeted research programs, and the establishment of a network of diagnostic and rehabilitational centers.

In the early 1960s, the role of the Joseph P. Kennedy, Jr. Foundation began to exert its major impact, and at the same time the Panel appointed by the late President John F. Kennedy began its work on its well known blueprint for the mentally retarded. I am sure you are well aware of the some one-hundred recommendations contained in the document, entitled A Proposed Program for National Action to Combat Mental Retardation.

The laws which resulted provided for the construction of university-based research centers, university affiliated facilities and community facilities, the support of staffing, the training of special teachers, the expansion of maternal, child health and crippled children's services, the planning of comprehensive services, and the upgrading of institutional programs, and inservice training in these settings. Most importantly, from the viewpoint of the issues before us, the laws pertaining to the university affiliated and community facilities became the antecedent of the Developmental Disabilities Act, the continuation of which you are now considering. Other developments not directly focusing on retardation, also benefitted the field. Two examples should suffice: the creation of the National Institute of Child Health and Human Development and the Head Start Program.

It should be obvious that the lot of the mentally retarded today is incomparably better than it was, let us say, 15 years ago. The Congress can indeed take pride for its leadership, its wisdom to authorize innovative programs, and its willingness to appropriate the necessary funds. It is true that many of my colleagues and I often felt that the advances were somewhat slow in coming and that the appropriations were insufficient to make our nation the international model for all the world to emulate. In many respects, other nations are still ahead of us, a situation which those of us professionally involved in mental retardation are reluctant to accept. Yet, new vistas and options have been opened for the mentally retarded and their families. The institutions are increasingly becoming only an alternative among an array of services. Public education has been expanded and teachers have been trained. There are some clinics available in the communities as well as sheltered workshops, foster programs, and other places where the retarded person can receive board and care whenever it is impossible for him to remain at home. As a consequence, in 1968, for the first time, the number of retarded individuals residing in public institutions declined, and this trend has continued since then.

The present scene is probably best characterized by emphasizing its highly transitional and changing nature. The retarded are cared for in a variety of settings, ranging from their own home to a residential institution. In addition, the private sector, the traditional mainstay of American enterprise, is increasingly becoming involved in the care of the retarded.

We have a long way to go, however, before we can pride ourselves that we are providing adequately individualized and fully humanitarian services to each and every one of our retarded citizens. The institutional programs are still far from ideal and still vary greatly in quality and availability. The recent events which focused on a large public institution in one of our most populous states, clearly attest to this fact. Public education still does not reach all the mentally retarded students. Rehabilitation and job opportunities are still in short supply. Sheltered workshops are few and far

between. Many clinics and programs still exclude the retarded. The emphasis is now on community care, but lack of funds and lack of human resources have kept us a long way from providing, at least in each major community, the array of services the retarded child and adult need. As far back as ten years ago, the President's Panel outlined the necessary network, but one can look at any community in our country and one is struck by the deficiencies. All in all, the fortune or misfortune of a retarded individual still depends as much upon the geographical locale in which he happens to live, than on his intrinsic special needs. I firmly believe that further progress depends as much upon the leadership of Congress as on the humanitarian understanding of the public at large.

This, then, brings me to a few recommendations. I know that others will testify on specifics; I will, therefore, restrict myself to some generalities.

The continued development of community resources must be very high on any priority list. The extension of the Developmental Disabilities Act is of obvious relevance in this respect. I would consider the passage of the necessary authorization and appropriation of utmost importance. I am aware of the fact that some discussions will take place pertaining to the definition of developmental disabilities, on the one hand, and the specific inclusions or exclusions of various syndromes by name, either in the bill or in the regulations, on the other hand. I know that you will hear testimonies on these matters.

Speaking from my own experience, I would like to state, our science of diagnosis and classification has not yet progressed sufficiently to enable us to assign each child into one specific category with absolute exclusion of the others. Many of the children suffer from several disabilities, therefore they qualify for inclusion in more than one category. One example would be a child who, as a consequence of German measles acquired during the fetal phase of development, is severely impaired in vision, hearing, muscular functions, and is also mentally retarded. In some instances, classification is more dependent on the inclinations of the examiner and on the recommendations of those who established the classificatory system than upon the symptoms of the child. The relationship between autism and mental retardation is probably the best example in this respect.

I believe, however, that in spite of overlaps, occasional indistinct demarcations and varying philosophies in diagnosis, most clinicians can make meaningful distinctions among categories and are able to rank-order the disabling conditions in a fashion that the etiologically primary one is given major emphasis. For example, a child with mental retardation and harelip is generally classified first as being mentally retarded and only secondarily as having a congenital physical defect.

I have found that the most common diagnostic label applicable to developmentally disabled children is that of mental retardation because most such children show significant impairment in intellectual development and in general adaptation. As a consequence, I strongly urge the inclusion of the term "mental retardation" in the language of the law.

One practical solution vis-a-vis the inclusion of other disabling conditions not currently specified in the language of the law, could be based on the following model. The mentally retarded, the cerebral palsied, and the epileptic could be combined into one group. Those with physical disabilities of prenatal origin could represent the second group. The autistic children and those with severely disabling and lasting learning disorders, a third one. What is imperative under these circumstances is the authorization and appropriation of sufficient funds for each group. Certainly it is essential that in this process the support for the mentally retarded, the cerebral palsied, and the epileptic group be maintained and increased in accordance with the need. As I mentioned earlier, I believe that clinicians would not encounter any major difficulties assigning children to one or another of these categories and that, basically, all children with developmental disabilities would be covered.

Of equal importance is the establishment of data collection systems pertaining to the mentally retarded and/or other developmentally disabled individuals, as the care of these people is becoming dispersed from a few settings to many. We have just about reached a point of sophisticated data collection and data analysis capacity to monitor the retarded in public institutions, but the proportion of those residing in these settings is declining. We know very little about those who leave or those who do not even enter. We have practically no information concerning their way of life, their adjustment, or the lack of it, in the communities. I doubt that a nationwide monitoring system could become an immediate reality, but I hope that model systems can be developed and maintained from centralized discretionary funds. This issue was brought squarely into my thinking when I realized that a state, roughly, of the same size in population as my own, had two-and-a-half times as many individuals in its public institutions than we have in California. Among the many questions which arose in my mind, one pertained to the fate of those who in New York are visible as residents of public institutions, but who in my state are dispersed in the general population and are therefore not fully followed.

No meaningful community programs can be established on a significant scale without the development of the necessary human resources. If the developmentally disabled are to be cared for through specialized programs, such specialists from a variety of disciplines must first be trained. If they are to obtain services through more general channels, an even larger number of human care-giving personnel must be acquainted with the special

needs of the developmentally disabled. This is one of the critical roles the university affiliated facilities must assume. They have similar capabilities for the development of new treatment methods, for clinical research, and for the rapid transfer of new knowledge into clinical practice. The continued support of the university affiliated facilities is, therefore, a keystone of future advancement or even the maintenance of our gains. These facilities have the capability to involve themselves with the two new major categories if their resources are sufficiently increased.

My statement in regard to mental retardation would not be complete or honest without it calling attention to our large gaps in knowledge. A continued vigorous support of research is as essential as the development of human resources. Much must yet be discovered. Any discovery postponed, even temporarily, condemns thousands of suffering people, proportionately, to the lag necessitated by lack of funding. We have a network of research centers; upon their vitality depends much of our success.

Last but not least, I would like to make a plea that we recognize, once and for all, the right of the retarded to human dignity. One of the bills under consideration provides a major step in the right direction. The institutional programs must be upgraded and standards must be fully developed for institutions as well as other community programs. Standard setting and monitoring can be done through various channels. I feel confident that professionals, worthy to be so designated, would support the enforcement of standards.

In closing, it is my hope that my comments will add to your deliberations and that your Subcommittee will support the bills before it.

Sincerely yours,

George Tarjan, M. D.
Professor of Psychiatry
and
Program Director, Mental Retardation

STATEMENT OF ROBERT G. JORDAN, M.D., PRESIDENT, ASSOCIATION OP UNIVERSITY AFFILIATED FACILITIES

Dr. JORDAN. We appreciate the invitation to testify here on behalf of the Association for the University for the Affiliated Facilities. I hope that our more formal statements, which we have submitted to you, will become a part of the record.

Senator KENNEDY. Without objection, it will be entered into the record at the end of your testimony.

Dr. JORDAN. I also might point out that my slow method of speech has automatically provided me with a time handicap. I will limit my remarks.

Senator KENNEDY. We have saved a few minutes on the other witnesses. I will give them to you.

Dr. JORDAN. We have with us

Senator KENNEDY. Excuse me. I would like you to introduce to the subcommittee the young lady sitting beside you. I presume she is with you?

Dr. JORDAN. I was just in the process of doing that. Actually, there are two others with me, representing our association. On my right is Dr. Margaret Griannini, Director of the New York Medical Clinic. Also with me is Mr. Don McNamee, who is with the Eunice Kennedy Shriver Center in Waltham, Mass.

Senator KENNEDY. Thank you.

Dr. JORDAN. We would focus a few remarks on the title II portion of the bill, although we heartily endorse the recommendations being made today in regard to title I, the purpose of the UAF. We concur with the remarks of my colleagues in this regard.

I would like to reemphaize the primary purpose, that being to try to answer the tremendous manpower needs. The retarded and the developmentally disabled are not yet nearly adequately served, as has been pointed out several times this morning.

The recruitment and interdisciplinary training of administration, direct care and other personnel, who provide the spectrum of services required by the target population is our primary purpose. In addition, assistance in the establishment of State and regional objectives evaluating the effectiveness with which these are being met and providing technical assistance to community agency personnel are primary goals.

The university affiliated facilities are making their presence felt in the field. Some recent research has found that 85 percent of some previous trainees' time is being spent in working directly with the developmentally disabled. A great potential is being realized in the interaction of the university affiliated facilities with regional and State facilities for improvement of the quality of services available to the disabled and their families.

Students are able to see and understand how other disciplines function and how they may be used with each other most effectively. We feel very strongly about this concept.

As another aspect of this effort, the prevention of institutionalization has been emphasized with programs designed to assist parents and community agencies in maintaining developmentally disabled individuals within their communities.

A considerable proportion of the activity of the UAF is directed to providing consultation to service agencies. Unlike many university

programs, the university affiliated concept has included a very strong community outreach component marked by a number of significant efforts. Models of service established permits a great involvement of community agencies and personnel.

When the UAF, in spite of continued support from some other agencies—such as local child united funds and local philanthropic funds—continued to be insufficient, operating and equipping funds have created gaps in our programs which disproportionately limit the productivity of university affiliated training centers.

We would like to emphasize two of the recommendations which have been included in our formal statement. First of all, the extension for 5 years of the authority for titles I and II in the increasing levels which are stated. Second, to remove the 25-percent matching requirement for title II, which was in the first authorization.

If I may, I would like to turn to Dr. Giannini for a few comments.

Senator KENNEDY. Certainly. Dr. Giannini.

Dr. GIANNINI. Thank you, Mr. Chairman. Prior to my remarks, which will be limited, because most of what I was going to underscore has been said already, I would like to say that I, too, have long been in the field of retardation, as George has been; 23 years of my 28-year professional life has been in the field of retardation. We have made a lot of mistakes and learned a lot along the way.

I think it really warrants some underscoring in terms of the serious commitment that was made when the plan to construct university affiliated facilities was designed. I would like to speak to that for a minute.

On the 19 constructed UAF's that at that time, the Federal Government and the universities seriously made a commitment to house the area that professional and paraprofessionals would be trained in, in order to service the mentally retarded.

The Federal Government committed something near the figure of $40 million and the universities had to go beyond their original commitment in many instances because, during construction, there was escalation of costs. I think the serious commitment is there in order to carry out this program of professionals and paraprofessionals dealing with the mentally retarded and the developmentally disabled from the very beginning.

I do think that we must be realistic, that the universities cannot completely carry on the support of these programs because of the continuing increase of annual expenditures and expansion of programs. There has to be some planning and some inclusion for the corps for the support of the university affiliated program for this program.

The UAF has become so involved by virtue of a strong service teaching program, that many basics are covered so that there would probably be the elimination of double fundings, such as in training and service and community programs and community kinds of consultations.

I was going to make a comment on the relationship of manpower programs for the developmentally disabled and the mentally retarded on a regional basis; but I think Dr. Cooke covered that so eloquently that I would simply like to emphasize that and say that it has so far been quite effective and, in the New England area, that the Eunice Kennedy Shriver UAF and Children's Hospital has too, in what it has undertaken.

I think there is a tremendous interest on the part of the young people in this country who wish to dedicate their lives in human services for

handicapped people. We are all being deluged with young people that wish to be trained. We cannot train them in programs of academic excellence because these programs do require expertise and they are so complex. There is a need for expansion for supervision.

I hope we will be able to meet this need for this potential source of manpower.

Lastly, I think we are all aware that UAF's have become recognized as one of the major national resources for training and service and outreach programs for the mentally retarded and other developmentally disabled. In this area, there has been a great deal of input within the regions to assess and to plan and to implement the final product and that is, after all, the training and all the implementation and planning of quality services to the mentally retarded and the developmentally disabled within the community so that they can live somewhat of an existence that they can become assimilated into the population.

Thank you, Senator.

Senator KENNEDY. Thank you, Doctor. Let me continue on the same point in questioning. The appropriation request for university-affiliated facilities for fiscal year 1974, $4.2 million, is the same as the one requested for the fiscal year 1973 budget. What does this mean for the future of the university-affiliated facilities? I also understand that this money is used for research in addition to training; is that correct?

Dr. JORDAN. NO, sir.

Senator KENNEDY. NO Part of it is used for research?

Dr. JORDAN. NO, sir. We had asked for considerably more in the conference committee. They came out with a $9.5 million recommendation for title 2 in the bill that was vetoed. At least that much is needed if we are going to proceed to implement our programs and grow.

Senator KENNEDY. Do you know offhand how much costs have increased over the last 2 or 3 years?

Dr. JORDAN. No, sir. I couldn't give you a percentage figure nationwide on that. We never have been able to implement our full programs in most instances. We have limped along on the parent program with partially empty buildings, for example.

Senator KENNEDY. If additional funds were appropriated and expended for this year, what plans would you have for the use of the additional funds, just to buttress the same planning?

Dr. JORDAN. We would carry out our original projections for expanding both service and training and would then be able to include some research in the training centers, anyway, more than we have.

Senator KENNEDY. YOU mean that although you are entitled to use the funds for research, you haven't been doing so?

Dr. JORDAN. In most instances, no.

Dr. COOKE. May I interject a remark?

Senator KENNEDY. Yes, sir.

Dr. COOKE. The centers were built with very detailed programs that were anticipated. I think it is fair to say that less than half of the 18 or so facilities are operating on more than a marginal existence as a result of the limited funds.

The services to these areas in which the university-affiliated facilities exist are, with very few exceptions, very inadequate as compared to the kind of programs that could be mounted.

Senator KENNEDY. I presume that is with no other funds budgeted?

Dr. COOKE. Some of the facilities have even been questioned as to whether or not they are complying with the legal requirements for their construction. There is a 25-year agreement for the purpose for which they were constructed. They have no funds to carry out these facilities. As a consequence, many of them are essentially with large amounts of empty space, which is a terrible waste of resources in this country.

We are not talking about huge sums of money. It is a matter of $3 or $4 million to make it possible for these facilities to operate on a 100-percent capacity rather than a 30-percent one.

Dr. JORDAN. If the amount of funding remains at exactly the same dollar figure, we would have to trim the program because of increasing costs.

Senator KENNEDY. Dr. Cooke, in regard to the level of funding remaining the same, if this were to be the case, what would be the effect on the implementation of these programs?

Dr. COOKE. This would be seriously crippling, also. There are two phenomena that go on. You have not only an increase in the number of individuals that are serviced because of better detection methods, but as you make progress in the care of individuals, the cost of these services increases. I think the analogy to the Defense Department is a particularly appropriate one. It costs much more now to kill a person than it did 100 years ago. It also costs very much more to cure and care for a person than it did 100 years ago. This is because of new technologies which can be applied.

Senator KENNEDY. YOU mean, as the patient progresses, the cost is greater?

Dr. COOKE. AS one develops new technologies to be applied, you have to pay for these additional technologies. Take, for example, one of the real additions to the care of the severely and profoundly handicapped has been that of behavior modification in which one can, essentially through conditioning methods, eliminate what is totally socially unacceptable behavior.

Children who could not have any contact with the rest of the community now can. That is a new development, but behavior modification costs a good deal in manpower. If you are going to apply this new technology, somebody is going to have to pay for it. It costs more as you made progress.

Senator KENNEDY. Thank you. Dr. Tarjan, you suggested in your testimony that there be a breakdown in eligibility into three classes and have urged three separate appropriations. This implies that there are not significant functional overlaps between the groups. Is this really so?

Dr. TARJAN. There is significant overlap. If the definition of "developmental disabilities" stays as it is, I think the whole issue disappears. Under those circumstances, I think we could take care of them all, if the funds are sufficient.

My suggestion was that if the definition is broadened, then the funding must be increased.

[The prepared statement of Dr. Jordan follows:

Testimony of

Robert G. Jordan, M.D.
President
Association of University Affiliated Facilities

Before The

SENATE SUBCOMMITTEE ON THE HANDICAPPED
The Honorable Edward M. Kennedy
Chairman

on

EXTENSION OF THE AUTHORIZATION OF P.L. 91-517 (The Developmental Disabilities Services and Facilities Construction Act of 1970)

February 2, 1973

The Developmental Disabilities Services and Facilities Construction Act of 1970, P.L. 91-517, is comprised of two major sections. Title I addresses itself to the problems of devising direct services to the developmentally disabled by creating a mechanism for establishing priorities and planning to meet the needs of this group. Title II, the University Affiliated Facility portion of the law, utilizes the concept of interdisciplinary training to deal with the complex manpower requirements of the field. These two components—service needs of the developmentally disabled and the manpower for delivering them—although related, are not inexorably intertwined and can be best implemented through consideration of their individual requirements.

The primary mission of the University Affiliated Facilities (UAFs) is to serve the needs of the developmentally disabled by providing: (1) interdisciplinary training of administrative, professional, technical, direct care, and other personnel who provide the spectrum of services required by the target population, (2) assistance in the establishment of state and regional objectives, evaluating the effectiveness with which these are being met, and (3) technical assistance to community agency personnel.

While the University Affiliated Facilities originated in direct relationship to mental retardation programs, they, in fact, adopted the developmental disabilities concept as a training reality prior to the language change in P.L. 91-517.

A recent suggested change, which we endorse, has been proposed for the definition in the new authorization, as follows:

> Developmental disability means a disability which (1) is attributabe to a medically determinable Physical or mortal impairment, (2) originates before the individual attains the age of l8 and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial, gainful activit" (or in the case of a child under ape l8, a handicap of considerable severity,).
>
> In addition to a revised definition, the Developmental Disabilities Act should provide for service eligibility for all severely handicapped persons who can benefit from service being provided for persons with developmental disabilities as defined in the primary target group. The following language is suggested: "eligible person" means a person with a developmental disability or a person with another substantial handicap who has similar service needs and who is considered eligible for such similar services by an agency or a facility which is providing services primarily intended for persons with developgental disabilities.

The University Affiliated Facilities are beginning to make their presence felt in the field. One center found that 85% of its previous trainees were working directly with the developmentaily disabled. The funds allocated to Title II of P.L. 91-517 are not drawn from Title I, but, in fact, nay be the means to achieve the intentions of Title I through the manpower trained by the University Affiliated Facilities.

A great potential is being realized in the interaction of University Affiliated Facilities with state and regional planning agencies for improvement in the quality and quantity of services available to the developnentally disabled and their families.

The University Affiliated Facility is a valuable asset for the state and region where it is located. The most important

characteristic of a Facility is its concentration of a number of highly skilled individuals from a wide variety of disciplines who have common interests in the field of developmental disabilities. This collection of individuals with shared concerns may be seen as a critical mass, by its very presence stimulating activities in the area and attracting additional resources, students and community practitioners, as well as the general citizenry, to the needs and accomplishments of the field. The interdisciplinary mix of staff and students goes beyond merely providing additional training, to serve as a basis for improved community service. That is, students trained in conjunction with other students from other disciplines are able to see and understand how other disciplines function and how they may be used with each other most effectively. In general, the University Affiliated Facility maintains a very strong outreach effort seeking to provide in-service, continuing and adult education to the wide variety of practitioners, volunteers, family and other interested citizens. This effort is significant in upgrading the skills of personnel in the field and also in providing them with models of service which they can adapt to their own practice.

In response to the requirement in P.L. 91-517 that the University Affiliated Facilities involve themselves with community college programs, most programs have developed curricula for students in these institutions planning careers as support personnel in community programs. A significant portion of this effort has been with paraprofessional workers in residential facilities as well as other personnel involved in a wide variety of connunity-based programs. The formalization of the relation-

ships with the community colleges has enabled community college students to obtain part of their training at a University Affiliated Facility, and, probably even core important, has provided professionals-in-training the opportunity to work directly with support personnel as part of their training experience.

Unlike many university programs, the University Affiliated Facility concept has included a very strong community outreach component narked by a number of significant efforts. Rather than merely providing pre-service training for professionals, in-service and community education has become an important part of most UAF activities. Moreover, the models of service established permit a great involvement of community agencies and personnel within the UAFs. For example, in several of the University Affiliated Facilities which are servicing rural, sparsely populated areas, a number of approaches have been designed to assist local practitioners in obtaining the more complete services of the developmental disabilities team. Videotape traveling teams and telephone consultation have been extensively used to demonstrate what can be done in these areas and to provide a backup support for the local practitioner.

To further the national goal of returning as many institutionalised residents as possible to the community, the UAFs have focused on two areas of activity. The first has been a major effort to address the needs of institutional personnel and to upgrade institutional programs and services to enhance the livelihood of residents returning to the community. At the sane time, out of concern for the lack of community support

agencies, the UAFs have worked to demonstrate the kinds of local services needed and the ways of more effectively and efficiently training personnel from a wide variety of community agencies to meet the needs of individuals once they return home. As another aspect of this effort, the prevention of institutionalization has been emphasized, with programs designed to assist parents and community agencies in maintaining developmentally disabled individuals within their communities.

While the major concern of the University Affiliated Facilities is the training of personnel for the field, a considerable proportion of their activity is directed to providing quality service and consultation to service agencies. A significant number of individuals and their families are served by the programs. Because of the depth and the variety of staffs, the UAFs frequently are called upon for consultation and/or service in specific cases and for assistance in developing management plans for "difficult to diagnose individuals." In this regard they work with state residential facilities as well as with a wide variety of community programs.

Much emphasis is placed on work with individuals with multiple handicaps who present particularly challenging problems for service agencies. For example, many University Affiliated Facilities are working with deaf-blind-retarded persons; others with severely and profoundly retarded who also have major physical limitations. UAFs provide consultation and referral services for regional mental retardation clinics. In some instances they operate field teams which maintain liaison with community programs, provide consultation in the field and make

provision for continuing the education of the staff of local agencies. This in-service training is an important adjunct to clinical service activities and demonstrates an optimum use of cases to improve practice.

The interdisciplinary training approach reflected in the development of UAFs has been in existence for almost a decade. During that tine major efforts have been put forth in formulating programs, constructing facilities, and organizing a substantial funding base for operations.

During the past several years there has been an increasingly strong thrust by the UAFs. Their efforts to assist state developmental disability councils in identifying and meeting the needs of the state and region have represented one of the most significant advances in the field. The close association with the various state Developmental Disability Councils is an important factor in the attainment of UAF goals. This mutually beneficial relationship will continue to produce best possible results for all concerned, especially if it is left unimpaired by formal controls such as vetoe power over funding by any state agency. The training of pre-service students at all levels, in-service training to upgrade and modify the patterns of practice, and service in the development and utilization of a wide variety of teaching approaches have started showing results. Pre-service and in-service training has a long-range ripple effect which may take years to fully assess. The University Affiliated Facilities are willing and able to become full partners in the implementation of the Developmental Disabilities Act. The greatest progress will bo shown primarily by the close coordination of the needs that are being addressed under Title I and

the manpower which can be provided by the UAFs under Title II. UAFs need to be represented on developmental disability councils. This will help to ensure close, coordinated effort. The UAF is a singular resource in many states and regions which must be utilized to the fullest possible extent.

In spite of continued support from the Maternal and Child Health Service, local school boards, United Funds and local philanthropic funds, continuing insufficient operating and equipping funds have created gaps in our programs which disproportionately limit the productivity of University Affiliated training centers. The Association of University Affiliated Facilities strongly recommends a five-year extension of the authorization for Title II of the Developmental Disabilities Services and Facilities Construction Act of 1970 in the following amounts:

> $30 million for fiscal year 1974; $35 million for fiscal year 1975; $40 million for fiscal year 1976; $45 million for fiscal year 1977; and $50 million for the fiscal year ending June 30, 1978.

The Association of University Affiliated Facilities also endorses the extension of the authorization for Title I of the Developmental Disabilities Act. We concur in the recommendations offered today in testimony by other involved organizations for a five-rear program of increasing annual authorizations--$l50 million for the first year. $200 million each for the second and third years, up to a maximum of $250 million by the fifth year.

To ensure the optimum use of appropriated funds, the Association of University Affiliated Facilities therefore endorses the language change, as also recommended in other

testimony today, for Section 124 (a) of Title II (under subtitle "Demonstration and Traininn Grants") to read as follows:

> "The total of the grant with respect to any construction project under this part may not exceed 75% of the necessary cost thereof as determined by the Secretary."

The Association also feels very strongly that it is not in the test interests of regional centers such as University Affiliated Facilities to empower a state council to vetoe funding. We therefore recommend that there by no state sign-off exercised by any state agency or council over Title II funding.

And, again, for a durable foundation from which not only the University Affiliated Facilities, but all other interested and involved public and private agencies may build, we heartily endorse the proposed amendment for a broadened and non-categorical definition of a "developmental disability" as already mentioned above in our testimony.

Armed with this mandate, we can reach out to tap the abilities of the disabled that we, and I know, this Subcommittee, so earnestly desire to serve.

Senator KENNEDY. There are many more questions I would like to ask, but we have a full room of witnesses and a shortage of time, I want to thank you and I hope you would answer any questions that the members of the committee might want to ask of you in writing.

The next panel of witnesses includes Mr. Messner, Mr. Bowling, and Mr. Watson. Would they come to the witness table, please?

The first member of the panel, representing the United Cerebral Palsy Association, is their director, Mr. Messner. Before holding his present position, Mr. Messner was executive assistant in the New York hospital of the Cornell Medical Association. He is a fellow of the American Public Health Association and has been a member of the Joint Commission Accreditation Council for facilities of the mentally retarded.

Mr. Messner, we welcome you to the subcommittee.

The second panel member is Mr. John Bowling of Alabama. Mr. Bowling is representing the National Association of Retarded Children, of which he is a member of the board of directors. He is presently involved in the Marshall County Association of Retarded Children. He is the past senior president, and is now president of the Jackson and Marshall Counties Mental Health Board in Alabama.

The third member of the panel is Dr. James M. Watson of Oregon, representing the Epilepsy Foundation of America, of which he is a member of the board of directors. Dr. Watson is a member of the boards of many professional organizations, including the Epilepsy League of Oregon, Inc., and the Multiple Sclerosis Society of Portland. He is also a member of the Governor's Planning Council on Developmental Disabilities.

We welcome all three of you to the panel. Mr. Messner, would you proceed with a summary of your statement please? All of the statements which are in writing can be submitted for the record.

Mr. MESSNER. With your permission, we would like to change the order and let Dr. Watson go first.

Senator KENNEDY. We are very glad to accommodate you.

STATEMENT OF JAMES MACDONALD WATSON, M.D., MEMBER, NATIONAL BOARD OF DIRECTORS, EPILEPSY FOUNDATION OF AMERICA, AND ASSOCIATE CLINICAL PROFESSOR OF NEUROLOGY, UNIVERSITY OF OREGON MEDICAL SCHOOL, PORTLAND, OREG.

Dr. WATSON. I would like to say thank you for your forbearance in having so many special advocates of so many special individuals come before you.

I speak both as a physician and as, fundamentally, one interested in epilepsy, both in law and in hope. I would like to say that the fact that developmental disabilities legislation exists is probably the reason that I and my two colleagues are able to sit here in peace and harmony. We have been able to form a coalition of effort and interest.

If developmental disability is to succeed in any other field, it will have some going to go, because it has been a unique accomplishment. The bills we serve are far better served by the fact that the three voluntary agencies are able to work together.

The success of the legislation in getting that done is enormous. I have submitted, as has the executive vice president of the Epilepsy Founda-

tion, a statement which I would like to request would be part of the record.

Senator KENNEDY. Without objection, it will be made a part of the record following your testimony.

Dr. WATSON. I would like to make an amendment to that statement and change some of the data. The sense of it is that the Developmental Facilities Act is welcomed by the Epilepsy Foundation of America and the physicians heartily endorse its continuation.

As far as Senator Javits' intentions in the bill which he submitted, we obviously equally support that. Epilepsy, per se, is not specially mentioned in his legislation. It would be my assumption, finally, to join the two—mentally handicapped and the mentally retarded—and make of this a package.

Simply speaking as an epileptologist—if that is a good word—half our epilepsy population is badly served in the sense that at least 50 percent of the people who have epilepsy continue to have epileptic attacks. Many of those individuals will never require institutionalization or that kind of care, but of that segment of the epileptic population that does, that legion that Senator Javits had addressed, I think we would be very happy to participate in it.

I stress the fact that the epileptic affliction is rather different, perhaps, than those of mental retardation. It isn't as easily seen until the seizure occurs. The degree of affliction of an epileptic is not easily demonstrated in the usual ways with a physical examination or an EG in office time.

In the social sense, there is a great barrier that is not visible instantly, but is great. We welcome being included in this kind of approach, because a great share of the epileptic problem has never been properly addressed by the physician or the others who served him.

Years ago there were institutions which were called colonies for epileptics. They were there simply because it was a place to keep the patients reasonably safe from outside harm, largely because there was no satisfactory method of treatment. Suitable treatment has diminished that population.

To go back to the percentages, 50 percent still remain inadequately treated. Therein lies our problem.

Speaking apart from epilepsy and the Epilepsy Foundation, I would like to express not only some pleasure at how far and fast we have gone. but also some frustration for the future.

In November, I took part in the national council's meeting of the State councils held here in Washington to discuss common problems. I had the pleasure of listening to a great number of individuals talking about the delivery of services in rural areas as opposed to urban areas. Every time I made a point as an Oregonian representing a rural population, the man sitting next to me from South Dakota made two points. He had less money and more rural area. As soon as he finished, a lady from Alaska rose and put us both on the floor. The enormity of the problem in Alaska with the reduction in funds with which they must deal is such that she had many points to make. After she made her points, a man rose from the back of the room and said he was from American Samoa.

What happens to you then, you see, is that the order of funding for transportation and simply the delivery of any minute service becomes

a problem. I suppose if the appropriations were magically increased, there would still be a problem.

The second frustration that I would like to point out is one that is currently rampant all over Washington—the reduction of funds for all programs.

The happy thing about developmental disabilities is that we have, indeed, been able to find other programs to pick up what we have started. The intent of the program to marry others, and, as Dr. Boggs said, interdigitate to other programs. We have a very good brood of epileptic children of pre-school age.

The other two agencies are to pick it up and make it better. Each of the three of these agencies are dependent on obtaining Federal funds; each of which look like they will be diminished if they do not totally disappear. We have something good started and the frustration of not being able to expand what we have got but also facing the future by diminishing in momentum what has been started is the point to which I speak.

Again, thank you for your forbearance in listening with us. My colleagues will add some special points to their cause. We are very glad to be here.

Senator KENNEDY. Thank you, Doctor.

[The prepared statement of Dr. Watson follows*:]*

Epilepsy
FOUNDATION OF AMERICA

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Statement of James MacDonald Watson, M.D.

Member, National Board of Directors
Epilepsy Foundation of America

and

Associate Clinical Professor of Neurology
University of Oregon Medical School
Portland, Oregon

RE:

S. 427 Developmental Disabilities Services and Facilities Construction Amendments

S. 458 Bill of Rights for the Mentally Retarded

Submitted by Epilepsy. Foundation of America
1828 L Street, N.W., Suite 406
Washington, D.C. 20036

January 30, 1973

STATEMENT OF JAMES MacDONALD WATSON, M.D.

Mr. Chairman, Members of the Committee, on behalf of Epilepsy Foundation of America and the approximately four million Americans with convulsive disorders, let me express our appreciation for this opportunity to present our views to you. It is Indeed an honor.

At the risk of appearing mawkish, permit me the opportunity to initially speak to a rather provincial point: that of the gratitude of our organization and its volunteers and afflicted constituencies for so promptly acting on a proposal to extend the first public law in recent history to attempt to provide a modicum of service to a profoundly needy population.

35 years ago, we had centers for the care, treatment and habilitation of persons with epilepsy. Then a new medication — diphenylhydantoin, usually known as dilantin — was developed for control of convulsive seizures. We thought that solved the problem, so we eliminated the centers, or "epileptic colonies." Our action, however, was premature; we then discovered that about half of our patients could not achieve complete seizure control. It is to this half, the severely handicapped, that the Developmental Disabilities Services and Facilities Construction Act addresses itself. Programs authorized by DD have served a high percentage of this two million. It is the only public law providing specific services to do so.

That 1t has been effective is exemplified, for instance, by our San Antonio, Texas, Epilepsy Association. Stimulated by a $14,000 DD grant — a small enough sum ~ this brand new voluntary association moved from virtually no services to a cooperative agreement with a conmunity hospital from which it was able to obtain space and resources for financial assistance, mental health and employment counseling services. It developed a public relations department through which its new activities are promoted, formed a speaker's bureau, and introduced a

teacher information program, School Alert, to the community. Today, an average of 60 persons attend monthly organized meetings and a number of patients have received the benefits of professional counseling designed specifically for their needs.

With the increased resources provided by yet a smaller DD grant of only $10,200, the Louisiana Epilepsy Association was able to expand its case load from 300 to an average of 1,200 in a nine-month period. Counseling services were added for parents and teenagers; and the development of a system of public information exhibits, media packages and a speaker's bureau were made possible. Building on the base provided by DD, and using its volunteer initiative, this chapter was also able to obtain an additional $23,225 to provide a gas liquid chromotography unit in its community hospital. Of the first forty epilepsy patients to have blood serum levels of anti-convulsants analyzed by this method, ten were determined to require an adjustment of medication.

I could go on with examples to document the needs and the progress this legislation has made toward the solution of the needs, but my point in summary is that this program has served to provide help to countless hundreds of people who have for 35 years lacked access to an understanding counselor's ear, a job, a method of determining what kinds and how much medication they require, and protection of the "inalienable" rights of a constitutional person in our society.

My second point requires a brief review of the historical base of S. 427. From its inception 10 years ago when its purposes were to (1) stimulate the development of a network of facilities for service delivery to the mentally retarded; (2) develop needed manpower; and (3) encourage research into the problems of mental retardation, the program has grown. Initial staffing grants for community mental retardation facilities were added in 1967, as well as provisions for construction of facilities for major programs of interdisciplinary training of mental retardation

medical and allied manpower. In 1970, when it became apparent that a great deal of effort was being expended in programs for the mentally retarded, with a total dollar figure of $606,970,000 in HEW alone, the legislation was wisely expanded to include services to persons with epilepsy and cerebral palsy — other neurological handicaps with a need indeed as great.

This expansion brought new emphases: (1) the marriage of several neurological disorders; (2) concentration on the most severely handicapped; and (3) stress on accessing existent community resources and facilities.

This continued expansion proved the health of the concepts; but as with all maturation processes, growing pains are beginning to be felt. While we are yet only three years into the new philosophy — with insufficient time to have adequately evaluated its propriety and progress -- attempts to fertilize it perhaps too much are being made by various interest groups and organizations.

This is a danger we must avoid. Too many government programs have forgotten their mission; too many have strayed from the path leading to the original goals established; and as a result, too many have not been successful — indeed are being phased out. DD must not go this way. Let us, then keep it — essentially as it is.

With the wide discrepancies between authorizations and appropriations for DD, the minimal sums it is likely to secure can help develop innovative attacks on a set of neurological problems. It <u>can</u> provide much assistance to an underserved, brain damaged population. It cannot -- without massive injections of money — also attempt to service groups which are no less needy, but which may receive their own tailor-made services through crippled children's programs, mental health programs, maternal and child health services, handicapped education programs, services for the blind, the deaf, and many others.

Those concerned with Developmental Disabilities need to remember its mission: to serve the neurologically handicapped. It needs to grow — but not too far, too fast. It needs to assess the validity of its yet new concept. It needs to retain its well-considered emphasis on those in our society who most need its services. And it needs time to adjust to its new clothes.

In short, the Developmental Disabilities Services and Facilities Construction Act is needed -- and essentially just as it is.

Mr. Chairman, Members of the Committee, I thank you.

STATEMENT OF JOHN BOWLING, BOARD OF DIRECTORS, NATIONAL ASSOCIATION OF RETARDED CHILDREN

Mr. BOWLING. I am honored to testify before this committee on Senate bill S. 427, the Extension of the Developmental Disabilities Services and Facilities Construction Act of 1969, and Senate bill, S. 458, the bill of rights for the mentally retarded. I do so as a representative of the National Association for Retarded Children and as the parent of a mentally retarded daughter, and as chairman of one of the State planning and advisory councils created by the Developmental Disabilities Act.

Incidentally, we have submitted more extensive testimony in writing which I would like to request be entered into the record.

Senator KENNEDY. "Without objection, it will be entered into the record following your testimony.

Mr. BOWLING. The National Association for Retarded Children, when testifying before this committee in 1969, indicated its full support of the concept and philosophy of the Developmental Disabilities Act. that support has not diminished during the intervening two and a half years since its enactment.

We are pleased with the progress that has been made to date and we believe there is ample evidence that developmentally disabled citizens are beginning to reap significant benefits from effective, well-planned, and coordinated services.

Progress has been made despite lengthy delays in implementation caused by the absence of Federal regulations until late 1971 and inadequate funding. For example, the lack of Federal guidelines at the State level resulted in many State councils being appointed during mid- to late-1971. In the case of my State the council was not officially appointed until December 1971, and held its first organizational meeting in January 1972, just slightly more than 1 year ago. Even though funding levels have permitted only minimal implementation of gap-filling services, the act has given States the mechanism through which comprehensive and long-range plans can be developed for the most effective service delivery systems attainable within the limits of local, State, and Federal funding constraints.

A most significant provision of the act is the composition of the State councils which includes consumers, volunteer advocate organizations, and the State agencies responsible for the delivery of services to reduce overlap and duplication, which was a major concern of the administration when it testified in opposition to this act in 1969.

Other concerns of the administration at that time were related in most part to the fiscal considerations inherent in broadening the target population to include disabilities other than mental retardation. The administration representative related their firm commitment to curb inflation through strict control of Federal spending. The President's budget request for the developmental disabilities programs and his subsequent veto of the Health, Education, and Welfare appropriations that exceeded his budget, has indeed demonstrated his commitment to spending controls.

While the National Association for Retarded Children supports in principal the provision of needed services for all developmentally disabled people, we fear that the lack of a commitment to this goal

by the President and the Congress will result in programs of diminishing quality for the mentally retarded in order to feint effective programs for a broader target population. The executive committee of NARC voted on January 20 of this year to endorse a noncategorical definition of developmental disabilities. I am sure they did so with the full realization that implementation of this definition cannot be accomplished without substantial increases of Federal spending in this area.

Our association also supports the extension of the university affiliated facilities section of the act. These centers are most important, particularly in training of professional personnel in the various service fields of developmental disabilities. Without this manpower resource, States will be hard pressed to meet the needs of the handicapped.

We are all familiar with the President's pledge to work toward returning one-third of the more than 200,000 mentally retarded people in public institutions to more useful and productive lives in the community. We submit that this goal can best be obtained through well planned and coordinated programs implemented through priorities established by the various developmental disabilities planning and advisory councils. This approach is not inconsistent with the intent of Senate bill, S. 458, the bill of rights for the mentally retarded. Thanks to the media most Americans are familiar with the deplorable conditions that exist in public institutions for the mentally retarded.

Names such as Willowbrook, Partlow, Rosewood, and Forest Haven bring to mind scenes of neglect and deprivation that make us shudder. But the litigation in *Wyatt* v. *Stickney*, in Alabama, is a lesson in frustration. Nine months after the full weight of the Federal courts were brought to bear on that institution, progress has been slow and discouraging. Few of the ACFMR standards included in the court's order have been met.

The National Association for Retarded Children fully supports the intent of Senate bill 458, but we have strong reservations regarding the inclusion of standards in the law, or even in regulations. This would tend to solidify the standards and make them difficult to change and update as new knowledge and new truths become apparent.

Mr. Chairman, we are most appreciative of this opportunity to share with you our concerns and thoughts regarding these bills. We thank you for your efforts and support of programs benefiting our developmentally disabled citizens.

[The prepared statement of Mr. Bowling follows:]

TESTIMONY ON

THE DEVELOPMENTALLY DISABILITIES SERVICES AND

FACILITIES CONSTRUCTION ACT OP 1973

(S. 427)

AND

THE BILL OF RIGHTS OF THE MENTALLY RETARDED

(S. 458)

Respectfully Submitted to:

THE SUBCOMMITTEE ON HEALTH

of the

SENATE LABOR AND PUBLIC WELFARE COMMITTEE ,

by the

NATIONAL ASSOCIATION FOR RETARDED CHILDREN

February 8, 1973

Mr. Chairman:

I am honored to testify before this Committee on Senate Bill, S. 427, the Extension of The Developmental Disabilities Services and Facilities Construction Act of 1969, and Senate Bill, S. 458, the Bill of Rights For The Mentally Retarded. I do so as a representative of the National Association For Retarded Children and as the parent of a mentally retarded daughter, and as Chairman of one of the State Planning and Advisory Councils created by the Developmental Disabilities Act.

The National Association For Retarded Children, when testifying before this Committee in 1969, indicated its full support of the concept and philosophy of the Developmental Disabilities Act. That support has not diminished during the intervening two and a half years since its enactment.

We are pleased with the progress that has been made to date and believe there is ample evidence that developmentally disabled citizens are beginning to reap significant benefits from effective,' well planned, and coordinated services. Progress has been made, despite lengthy delays in implementation caused by the absence of federal regulations until late 1971, and inadequate funding. For example, the lack of federal guidelines at the state level resulted in many state councils being appointed during mid to late 1971. In the case of ray state the council was not officially appointed until December, 1971, and held its first organizational meeting in January, 1972, just slightly more than one year ago. Even though fund-

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Other concerns of the Administration at that time were related in most part to the fiscal considerations inherent in broadening the target population to include disabilities other than mental retardation. The Administration representative related their firm commitment to curb inflation through strict control of federal spending. The President's budget request for developmental disabilities programs and his subsequent veto of the Health, Education and Welfare Appropriations that exceeded his budget, has indeed demonstrated his commitment- to spending controls.

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for a broader target population. The Executive Committee of the National Association For Retarded Children voted on January 20th of this year to endorse the non-categorical definition of develop-. mental disabilities. I am sure they did so with the full realization that implementation of this definition cannot be accomplished without substantial increases of federal spending in this area.

Our Association also supports the extension of the University Affiliated Facilities section of the Act. These centers are most important, particularly in the training of professional personnel in the various service fields of Developmental Disabilities. Without this manpower resource, states will be hard pressed to meet the needs of the handicapped.

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The National Association For Retarded Children fully supports the intent of S. 458, but we have strong reservations regarding the inclusion of standards in the law, or even in regulations. This would tend to solidify the standards and make them difficult to change and update as new knowledge and new truths become apparent.

We are most appreciative of this opportunity to share with you our concerns and our thoughts regarding these bills. We thank you for your efforts and support of programs benefiting our development-' ally disabled citizens. Thank you.

STATEMENT OP SHERWOOD A. MESSNER, DIRECTOR, PROFESSIONAL SERVICES PROGRAM DEPARTMENT, UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

Mr. MESSNER. I, too, have submitted a longer document which I request be entered into the record.

Senator KENNEDY. Without objection, it will be so included at the conclusion of your testimony.

Mr. MESSNER. I would like to highlight a few of the things that are in that document and supplement some of the things that my colleagues have mentioned.

First of all, we obviously support the extension of the Developmental Disabilities Act legislation and we urge that it be extended for 5 years rather than for 3.

This has been probably the most important piece of legislation in the last couple of decades with regard to services for the severely and substantially handicapped. We are already able to document that this is happening despite some of the difficulties that have been mentioned by other witnesses.

I want to highlight more specifically the gap-filling role this legislation provides and to raise several areas of concern about the future of the DD program.

This legislation has provided a unique approach that makes it possible for the State councils on developmental disabilities to review the various other Federal and State programs and to insure to a great extent that these do, indeed, serve the substantially handicapped. I am sure that this effort will improve as we gain more experience.

My particular concern is with what appears to be happening in the present administration in terms of revenue sharing. Specifically to the proposed revenue sharing for education.

If, indeed, we eliminate some of the categorical programs that are presently funded through the Bureau for the Education of the Handicapped of the Office of Education and turn over this money to the several States, we are concerned not only that the programs that may be supported by these States will not be of the quality as presently supported by the Federal Establishment, but also the review by developmental disabilities councils at the State level will be lost.

I would hope Congress, in considering revenue sharing, will provide some safeguards in this respect so there would be an opportunity for State councils on developmental disabilities to review these programs that are earmarked to become part of revenue sharing.

I would like to address the problem of the definition of the target population. We have heard various views of this today. United Cerebral Palsy Associations, Inc., has traditionally—because of the nature of the disability we are dealing with—tried to provide services broadly to individuals, whether or not they carry the diagnosis of cerebral palsy or not. In fact, it is very difficult to establish, sometimes, exactly what is meant by cerebral palsy. At least two-thirds of our local programs are serving people with other kinds of developmental disabilities. Persons that have other labels on them.

Therefore, we feel that the emphasis of the definition, the target population, should be as broad as possible. The specific wording that we are proposing is:

Developmental disabilities means a disability which (1) is attributable *to* a medically determinable physical or mental impairment, (2) originates before the individual attains the age of 18 and, (3) constitutes a severe handicap to a substantial gainful activity (or in the case of a child under age 18, a handicap of comparable severity).

We feel that this emphasis on substantially handicapped or severely handicapped protects the target population from being overwhelmed by the large numbers of people that might otherwise be served under this legislation.

We also emphasize the importance of continuing, in this legislation, some authority for funding programs of national significance.

We recognize that the funding up to the present has been inadequate. There is pressure to get as much money allocated to the States as possible, yet we feel that only through projects of national significance can some kinds of activities be undertaken. For example, demonstration of models of delivery services and exemplary services.

We have one specific model that we have been able to develop which is applicable to residents of State institutions and, more specifically, to those residents who are multiple and severely related to the so-called pretzels that we usually find being treated in the back wards and kept in bed most of the time.

Through grants from the DDA and from section 4(a)(1) of the Vocational Rehabilitation Act, we were able to train teams in five different residential institutions that have been able to mobilize a great many of these severely and multiple handicapped individuals. We have been able to mobilize them to the extent that they are now able to relate to their environment and to participate in the other programs that operate in these institutions, such as recreation programs, whereas previously they were eliminated from these.

This model could not have been demonstrated in any one State. It is a project of national significance which now desperately needs to be extended and teams need to be trained, hopefully through UAF's to extend this approach to many institutions throughout the country and also to community agencies that are serving these same kinds of individuals.

We could cite many examples of the way in which developmental disabilities funds have helped to fill gaps in communities where our facilities were able to become operational.

I want to highlight three areas that have been particularly important. One of these is adult services. The second is an outreach into the rural areas by home service workers. A third area of great need is transportation. We are seeing some new models of transportation developed through DD funds.

I would also like to mention the fact that at least three of our local affiliates have been able to secure developmental disabilities facilities funds from their State agencies to initiate programs for infants. This has become part of a network of infant program centers that we have established through a grant from the, Bureau for the Education of the Handicapped.

We have here a good example of the way Federal funds are combined with State funds and voluntary dollars to provide new and important areas of service.

Now, I would like to turn the subcommittee's attention to the bill of rights for the mentally retarded. We support this bill and endorse its

concepts. We feel that it is time for the Federal Government to take the leadership in overseeing the establishment of standards and overseeing the compliance by institutions of those standards.

We have some differences with the present bill. Specifically, we feel that it probably is not wise to include the present standards of the Council for the Accreditation of Facilities for the Mentally Retarded into legislated statute.

I speak now as a member of that council, having been a member for 3 years and on the planning committee for it for another 2 years. While these standards represent a great amount of work on the part of a lot of people and they do represent the consensus of many, many professional people and consumers in the field. They still are not perfect and probably never will be.

In fact, in the less than a year they have been field tested, already some 20 changes have been made. We feel it unwise to lock these into legislation.

Second, we would hope that the present structure—represented by the Council on Accreditation of Facilities—both in the making of standards and in the reviewing, whether institutions are in compliance with these standards, would be designated as the body to oversee this rather than set up a new National Advisory Council to develop standards. We feel it is inappropriate for the State agencies to foe given the responsibility for monitoring the projects. This represents, to us, conflict of interest.

We also urge that the already existing developmental disabilities councils be utilized. The standards as they now exist for institutions are not only for the large institutions but have been designed, hopefully, to be applicable to any institution serving more than five people.

It may be of interest to the committee to know that the standards have been reviewed by a group of private residential facilities in California and they feel that these are appropriate for small private institutions.

Also, I would like to emphasize that they are applicable to others, not just the mentally retarded. We were part of the process all during the development of these standards and we saw to it that the standards were applicable to those individuals who have physical handicaps as well as mental retardation.

I think that summarizes our position, Mr. Chairman. The fact that three agencies are together at this table and are getting together on a lot of other bases is commendable.

Senator KENNEDY. Thank you very much, Mr. Messner. We have a vote on the floor, so we are going to recess for about 15 minutes. I have a brief question for you gentlemen, then we will move ahead. We will be back in about 15 minutes.

[The prepared statement of Mr. Messner, along with other information, follows:]

Statement

Respectfully Submitted

to

The Subcommittee on the Handicapped

of the

Senate Committee on Labor and Public Welfare

on

S. 427, Extension of the Developmental Disabilities Services and Facilities Construction Act

In Behalf Of

United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, New York 10016

February 8, 1973

Witness

Mr. Sherwood A. Messner, Director, Professional Services Program Department, United Cerebral Palsy Associations, Inc.

Accompanied By

Dr. Elsie D. Helsel, UCPA Washington Representative and her assistant, Mr. E. Clarke Ross, Federal Programs Consultant to the Washington Office.

UCPA, Inc., appreciates very much the opportunity to appear before the Subcommittee on the Handicapped in support of S. 427 The Developmental Disabilities Services and Facilities Construction Amendments of 1973.

INTRODUCTION

DDA: Success In Meeting The Needs of the Substantially Handicapped

Definition of the Target Population

Philosophy of Programming Under DDA

Service Problems and Operational Difficulties Encountered During the First Years of DDA

1) Continued Need for Grants of National Significance
2) Role of the State Advisory Councils
3) Interpretation of Definition of Target Population in the Field
4) Communication Problems

UCPA Affiliate Programs Help Fill Service Delivery Gaps

Technical Changes

Conclusion

Appendixes

1) UCPA affiliate use of 1972 State DD Grants
2) UCPA affiliate use of 1971 State DD Grants
3) Technical Changes of Present Statutory Language

STATEMENT

ON

S. 427, EXTENSION OP THE DEVELOPMENTAL

DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT

PDA: Success in Meeting the Needs of the Substantially Handicapped

Of all the legislation enacted during the past decade, this particular piece has, in our opinion, the greatest potential for providing for our most substantially and often multi handicapped citizens, the services they need in order to develop their fullest potential and to live out their lives. It makes possible the translation from philosophy to practice of the recommendations made by the President's Panel on Mental Retardation to provide a continuum of services for all individuals regardless of the degree and complexity of the handicap.

In a speech before the National Conference of State Planning and Advisory Councils on Services and Facilities for the Developmentally Disabled in November, 1972 George J. Schweizer, Jr., President of UCPA, Inc., stated:

"UCPA is firmly committed to the position that comprehensive services should be available to every handicapped child and adult to the extent that he needs services in order to achieve his maximum potential, make his contribution to society and live a full and satisfying life with dignity.

"We feel every human life has meaning and value to society.

"We do not feel there are individuals whom society should write off as 'non-feasible' because of the severity or multiplicity of their handicap or because they were not able to contribute economically to society.

"We simply do not accept the position that a country cannot afford to habilitate or rehabilitate severely handicapped people.

Because the Act addresses itself and is concerned for our most severely handicapped and because of the tremendous potential this Act has for efficiently and effectively coordinating services, for the putting in place of new resources, and for accessing existing services for the development of new patterns for the delivery of services, UCPA enthusiastically endorses this legislation.

Through the requirement that the DDA Plan review and describe the "quality, extent and scope of services being provided, or to be provided, to persons with developmental disabilities under such other state plans for federally assisted state programs as may be specified by the Secretary" an even more powerful tool for providing additional needed services is forged. Through careful scrutiny and analysis of these federal state plans and through the use of Developmental Disabilities Act funds to glue together, supplement, or shore up services in those plans that are appropriate for developmentally disabled individuals, many new services can be accessed.

In those instances where developmentally disabled individuals are found clearly to be eligible in the plans but are denied access,

DM Councils, at which heads of the state agencies sit across the table from consumers and representatives of the voluntary agencies serving the handicapped, provide an unusual and formidable opportunity to not only get answers to "Why are these individuals denied access," but to work out solutions to the problem.

UCPA, Inc., is a strong advocate of consumer representation on governmental advisory councils such as the Developmental Disabilities Planning and Advisory Council. Such Councils must play a dynamic leadership role, giving guidance and direction to the administrators of programs. Such leadership will add both accountability and trust into the governmental system.

Comprehensive services to the substantially handicapped have been advanced and upgraded throughout the country since the creation of the DD Act three years ago.

Definition of the Target Population:

UCPA came into existence because cerebral palsied individuals with severe multiple dysfunctions were being written off and denied services. We have therefore used as our operating definition for cerebral palsy, a very broad one. Since cerebral palsy usually is accompanied with one or more other handicaps, our centers tend to be non-exclusionary in their admissions. We are therefore by tradition accustom to dealing with a wide spectrum of disabilities. We also know fully well that such terms as "cerebral palsy," "mental retardation," and "epilepsy" are not neat descriptive terms which communicate even reasonably well the etiology, treatment and program needs, and expected outcomes. These terms alone tell you really nothing about a specific individual and his program needs. Much additional information is needed in order to design a program — information such as severity of the handicap,

multiplicity of associated handicaps, degree of mobility and the ability of the family to cope. Even with all of this knowledge it is not always possible to predict with any degree of certainity what the response of the individual will be to treatment and training and what the outcomes will be. Therefore programming in terms of categorical labels does not make sense.

What we do know is that certain kinds of programs are essential for people with certain functional problems. Functional needs tend to cluster and they are appropriate for individuals with common needs regardless of the etiological diagnostic label attached. For example, stimulatory programs for babies that are identified early as lagging in development are equally appropriate whether the baby is subsequently diagnosed as cerebral palsied, mentally retarded or neurologically damaged or something else.

Hence, because of our programming experience UCPA has tended to favor an open-ended interpretation of the term "developmental disabilities."

A coordinated functional approach to services rather than an approach based on diagnostic categories makes good sense to us.

UCPA's position concerning the definition of "developmental disabilities" and the programming concepts promulgated in the Developmental Disabilities Act is a commitment to the philosophy of integration of handicapped individuals into the mainstream of society wherever possible. Our advice to affiliates has long been that they should offer a segregated service only when it is neither possible or feasible to integrate our cerebral palsied individuals into generic programs.

Philosophy of Programming Under DDA

As we understand the philosophy of programming under the Developmental Disabilities Act, the approach to comprehensive services is to use DD money to fill in gaps or shore up basic

federal-state programs serving the handicapped. Only where this is not possible are DD funds to be used in providing specialized service. If DD funds are used in this way — to put resources in place rather than fund specific segregated services -- such programs would be open to all substantially handicapped developmentally disabled individuals regardless of diagnostic label, provided the service is appropriate for them.

An excellent example of how DDA funds were used to put a state-wide resource in place is Ohio's Protective Service - Case Management - Personal Advocacy System.

Ohio has been divided into 10 planning and service delivery districts. The Ohio Division of Mental Retardation and Developmental Disabilities, which is the State agency responsible for administering the DD Act has set up or is in the process of setting up 10 District Offices which will be the central points of referral for services for the developmentally disabled. Screening, needs assessment, and referral take place here. If the need is for a residential placement a case manager is assigned. Every effort is then made to find a community placement with community based services. Institutional placement will be made only in emergencies or for treatment or training and will be time limited. As individuals are returned to the community from institutions after care supervision will be done by the District Office. Protective Service workers will be responsible for monitoring and follow-along services with the individuals to see that placements and program services remain appropriate.

Protective Service workers are assigned to every individual seeking services from the District Offices. They can provide a wide range of services from such simple things as counseling an individual or helping the family plan ahead for residential care to providing guardianship services under court order. This is a flexible system statutorially authorized under Ohio H. B. 290.

A developmentally disabled person can enter the system voluntarily or can be assigned by the courts. At the time of enrollment in the system the individual and his family are informed concerning how to terminate service if they so desire. The law requires that at least annually the protective worker must file with the Division of Mental Retardation and Developmental Disabilities a report on the status of each of his clients, how they are responding to their programs, whether there are problems that need attention. In times of crisis, protective workers can intervene legally. Already, our probate courts are using these workers as a resource. Parents feel they at long last have an answer to that haunting question "What will happen to this child when I die?" The Protective Services program began operation July 1, 1972 and already over 500 clients are enrolled.

DDA funds were co-mingled with state MR-DD funds to get the system in place state wide. Shortly, social services funds will be added to round out the system. DDA funds are also being used to train the new protective workers with the training being done by the UAF in Columbus — the Nisonger Center.

Although it is felt that the Protective Services - Case Management System is the best we can devise at this time, we realize it is a state system and hence subject to the ills and whims of the bureaucracy. It can become a very impersonal system as case loads get large. It cannot provide human relationships on a day-to-day basis. While parents are alive and functioning, they can watch dog the system. When parents are no longer able to function in this capacity, then there is being put into place another voluntary system — again with DDA funds — a personal advocacy system. An incorporated consortium of EFA, OARC, and UCP of Ohio has hired and will be responsible for supervising a consultant on personal advocacy to

work with voluntary agencies at the local levels in order to mount a personal advocacy program state wide. Initially some project monies will be used to help agencies get their personal advocacy programs off the ground. However in the long run these programs will be expected to be staffed by the agencies themselves with volunteers serving as advocates.

Thus DDA monies have been used to put in place a state wide resource that any substantially handicapped Individual or his family can use.

Service Problems and Operational Difficulties Encountered by UCP Affiliates During the First Years of PDA

1) Continued Need for Grants of Rational Significance

UCPA, Inc., believes there exists an on-going need for the grants of national significance authorized under Section 132 (e) for the purpose of demonstrating new or improved techniques for provision of services for developmentally disabled individuals. UCPA has had some difficulty understanding the Administration's position concerning the 10% set aside fund.

UCPA opposes the HEW regulation permitting these funds to revert to the states, if unallocated by April 1, 1973. We are deeply distressed at the Administration's withholding of $2.5 million in national significance grant monies. $2.5 million, divided between 55 states and territories for direct services means little but $2.5 million to develop service delivery models for demonstrating exemplary methods to states could mean a great deal.

National significance funds can have a tremendous import upon the development of new techniques for providing services. For example, the UCPA Mini-Team Project, funded by Title IV (a) of the Vocational Rehabilitation Act, is the type of project that DD national significance grants should be funding. The Mini-Team Project was concerned with

developing a curriculum to train institutional care taking personal in management skills and techniques which, when further implemented, virtually eliminate the need for bedfast care of severely and multiply handicapped residents. The "cross modality" approach to utilizing professional skills, which was forged and clearly demonstrated as effective in the Mini-Team Project, not only can provide a more normalized life style for the substantially handicapped but it is cost effective. It reduces markedly the need for costly one-to-one therapy.

The Project's success has been demonstrated in five locations: Atlanta Retardation Center, Georgia; Faribault State School, Minnesota; Denton State School, Texas; Mansfield Training Center, Connecticut; and Central Colony, Wisconsin.

Another example of how national significance money is being used is the UCPA Child Advocacy Project which is partially funded by DD national significance funds, and attempts to demonstrate how all services required by the developmentally disabled children in New York State; Milwaukee; Wisconsin; and San Mateo and Santa Clara counties, California are made available to these clients.

A final example of how these demonstration grants may be used is the Jointly sponsored UCPA - NARC - EFS DOIR Project (Developing Opportunities for Individual Responsibility) presently being considered for DD funding. The project will attempt to foster non-institutional housing for adult developmentally disabled adults, in five geographic areas of the country, based upon the choice of those adults.

Complicating the issue of the grants of national significance is the role that the National Advisory Council on Services and Facilities for the Developmentally Disabled has played in the decision making process. During its early days, the Council was merely advised of

the action taken by the Administration and no recommendations were asked for by the Administration. As the Council became more and more critical of its passive role, it slowly was granted more and more influence in the planning and review procedures of national significance grants. Though the responsibility of the Council is growing, its responsibility must be reinforced through legislation and/or regulations. To demonstrate this need for Council responsibility in this process, UCPA suggests that the Council be renamed, in the statute, as the "Planning and Advisory" Council.

2) Role of the State Advisory Councils

A great deal of confusion exists throughout the country on the proper role of the State Advisory Councils. UCPA believes that its role of planning; reviewing state plans; setting policy and priorities; and evaluating should be further clarified through federal regulation. The state council must assume a dynamic leadership role if the DD program is to reach its potential of fulfilling the service needs of the developmentally disabled.

The "cross-agency" coordination of human resources role of State Councils could be improved, we believe, by the creation of a direct line of authority between the Council and Governor — Massachusetts and Colorado are states whose reorganization have permitted the Councils to report directly to the Governor. Greater competence and responsibility both in planning and coordination have resulted from these reorganizations.

3) Interpretation of Definition of Target Population in the Field

A history of difficulty in many states has developed over the interpretation of the definition of who is "developmentally disabled?" This confusion in the field has caused disagreements between voluntary health agencies, both among themselves and with state agencies. California, Maryland, and New York are specific examples of the

confusion and disorientation that results from misunderstandings of interpretation.

A major problem seems to have arisen because the state mental retardation departments, usually the designated state developmental disability agencies, have sometimes interpreted the definition so as to exclude the non-mentally retarded developmentally disabled clients. We recognize this is a diminishing problem but we thought it should be called to the Subcommittee's attention.

It has been brought to our attention that some HEW regional offices have, at times, given confusing interpretations. The recent appointment of Mental Retardation Regional Consultants, to work along side of Developmental Disability Regional Consultants, demonstrates HEW's MR orientation. This is clearly an unnecessary duplication of manpower which are a step backward to reinforcement of the categorical approach.

4) Communication Problems

Communication problems exist at all levels of administration of the DD program. There seems to be no clear cut, consistent method to channel information from the HEW central office to the Regional Offices and then to the state offices and state councils

For example, there is still confusion at the state council level concerning such points as sign offs on UAF, Title II Grants; membership on State Councils re: consumers and heads of state agencies; requirements for 1974 Plans; and hold over authorization for 1972 funds.

The headquarters meeting (Communications in the DD World) called recently for Regional Office DD Representatives and Central Office staff involved in the DD program to which representatives of the voluntary sector were invited — was a step in the right direction to clear up some of the confusion.

During the National Conference of State Planning and Advisory Councils on Services and Facilities for the Developmentally Disabled, State Councilors expressed their dissatisfaction at the lack of communication between the state councils and the National Council. Specifically, the State Councilors requested that all minutes of National Council meetings he distributed to the states and that a monthly newsletter be prepared for distribution by the National Council.

UCPA Affiliate Programs Help Fill Service Delivery Gaps

The DDA program has clearly demonstrated that broad gaps exist in the delivery of services to the developmentally disabled. Some of these services are in existence, authorized under other federal-state programs, but denied to the developmentally disabled because of their severity and multiplicity of handicapped. Other needed services are non-existent — especially in the adult area.

Attached, in appendices 1 and 2, are surveys demonstrating the use of State DD funds by UCPA affiliates in 1971 and 1972. These surveys, by showing the use of DD funds, clearly demonstrate service delivery gaps.

A frequent use of DD funds by UCPA affiliates is for adult services. The substantially handicapped adult individual is by far the most neglected of the nation's developmentally disabled population. They are too old for presently operating educational programs. They are too severely handicapped to be accommodated in vocational rehabilitation centers. DDA has the potential for and is demonstrating that residential care in large institutions is not the only way in which substantially handicapped adults may be cared for. Community alternatives for residential services are more appropriate and less costly.

Another frequent use of DD funds by UCPA affiliates is for transportation, especially for non-educational purposes and in rural areas. Many, although not nearly all, school districts provide transportation either to publicly supported special educational classes or privately sponsored educational programs but no transportation is provided for the non-school age handicapped population or for non-educational services such as physical therapy. In many rural areas of the country no publicly supported transportation is available to the handicapped for any services.

Regarding rural locations, an important mechanism for delivering services is through home service workers. With the cut back in social services appropriations, authorized under the Social Security Act, some home services were provided to the developmentally disabled (and those were generally in rural areas) were in many cases terminated. DDA funds have permitted UCPA affiliates to provide these types of services.

Several UCPA affiliates in Pennsylvania, New York, Illinois, Ohio, and Washington State have mobile service units that make it possible for a professional worker — usually a therapist, nurse, or teacher to go into homes with cerebral palsied individuals and help the family in various ways.

Many other service gaps exist but the most crucial ones have been mentioned.

Technical Points of Extension

In order to promote greater improvement of the existing legislation and correct some of the problems encountered by UCPA affiliates, we suggest the Subcommittee's consideration of several technical changes of statutory language. Appendix 3 contains the exact wording of the proposed changes next to the present statutory language.

1) Page 300

The act should be extended for a five year period to encourage stability and continuity in the program. This, we believe, would have a positive impact on the states' utilization of the DD program. The DD program is a new concept and thus the necessity of continued

gearing up to develop a more sophisticated and effective mechanism of implementation must be recognized.

Specifically, Section 121 (a) should be amended by striking out the term "five" after "for each of the next" and inserting the term "eight" and by striking out "1973" after "fiscal years through the fiscal year ending June 30" and inserting 1978.

2) Page 301

The demonstration and training grant authority for University Affiliated Facilities should be extended until 1978 with increasing authorizations for each fiscal year by amending Section 122 (b). The needs of the developmentally disabled are so great, yet the numbers of trained professionals and their level of expertise is inadequate to meet these needs.

3) Pages 304-306

An editorial change is suggested in Section 130 fa) by inserting after the word "grant" and before the term "to assist" the phrase "in aid."

UCPA, Inc., believes that construction of community facilities should be a purpose of the state formula grant program and thus we propose in Section 130 (a) the insertion of "construction of community facilities." We suggest the word "community" to reinforce the trend toward deinstitutionalization.

Project Grants of National Significance - UCPA is firmly committed to the idea of an on-going need for the project grants of national significance now authorized under Section 132 (e) for the purpose of demonstrating new or improved techniques for provision of services for developmentally disabled individuals. In accordance with this belief, we believe the authorizing provisions for these grants should be given greater emphasis and greater visability by writing sub-headings into the statute earmarking these sections.

We also believe that by consolidating the grants of national significance with the authority established in Section 4 (a) (1) of the Vocational Rehabilitation Act, better accountability, increased coordination, and sound grant management may be promoted. For the purpose of achieving such consolidation, we propose deleting sub-sections (b), (c), (d), (e), and (f) of Section 130 and rewriting them as Section 130 (b).

Deinstitutional Incentives - In keeping with S. 458 and the present trend toward deinstitutionalization, UCPA suggests the establishment of a special supplemental grant to any State which includes in its State plan a specific supplemental plan directed toward reducing institutionalization and improving residential care for the developmentally disabled. As such, new language in Section 131 and Section 132 is proposed.

To clarify the orders and inter-relationships of the three grant authorities, we purpose the following placement with sub-headings be inserted into the law:

- Section 130 - Declaration of Purpose

  fa) State Formula Grants

  (b) Project Grants of National Significance

- Section 131 - Authorization of Appropriations

  (a) State Formula Grants
  (b) Projects of National Significance

  (c) Deinstitutional Incentives

- Section 132 (a) - State Allotments

  1) (no subheading)
  2) (no subheading)
  3) Projects of National Significance
  4) Deinstitutional Incentives

In keeping with the proposed five year extension, the appropriate language with corresponding dates should be inserted.

4) Page 305

A minimum allotment of $25,000 each is proposed for the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific. Their present allotment hardly covers administrative costs.

5) Page 306

The old subsection (e) of Section 132 (Section 132 (a) (4) in accordance with our suggestion) is revised to insure that a substantial portion of the project grant funds will be used for grants of national significance.

6) Page 307

In keeping with the non-categorical definition of developmental disability, the phrase "the mentally retarded and" in Section 133 (a) (3) should be deleted.

Corresponding to our commitment for enlarged consumer representation, the term "representative of the interests of" should be deleted from Section 133 (a) (3).

7) Page 309

Section 133 (b) (5) is amended by deleting the phrases which have become obsolete about "developmemtal disabilities associated with mental retardation."

To place increased emphasis on representation of non-governmental organizations and less emphasis on local agencies, the term "local agencies" is rearranged in the text of Section 133 (b) (8).

8) Page 310

UCPA suggests consideration of the provisions relating to the construction plan by placing them into the single Section 133 (b) (14) and making them optional with the state and to be included only if the state decides to use some of its funds for construction.

We also propose a new Section 133 (d) to give the Secretary of HEW authority to write additional regulations for the special deinstitutionalization add-on.

9) Page 346

The new definition, already discussed in our statement earlier, broadening the language so as to guarantee access by all developmentally disabled individuals, is written in Section 401 (1) and (m).

Conclusion

In conclusion, UCPA feels that the Developmental Disabilities *Act*, despite its slow start-up, its pathetically low level of funding, and its administrative problems, has accomplished a great deal in the short time it has been in effect. What it needs *now* is a period for settling in. Where state councils have been given authority and encouragement and umhampered opportunity to plan, set priorities, and act, new programs for previously unserved handicapped individuals have evolved.

The DDA has enabled states to experiment in microcosm with the Human Resources concept. It encourages state and local, voluntary and public agencies to develop new approaches lineing up diagnosis, referral, treatment, follow-up and follow-along. It makes possible the building of new statewide service systems to serve an up to now underserved group.

The public-private partnership created on State DDA Councils has not only done the Job assigned to it but has had many spin off benefits. The consumers on these councils have shown themselves to be valuable resources. The citizen representatives on the councils are learning first hand about bureaucratic red tape — and many are lending a hand to eliminate some of it from state government. Voluntary agencies have joined together in cooperative ventures no one would have believed possible three years ago.

Truly this is landmark legislation with powerful — and as yet unfulfilled — potential.

We should like to close with a quote from President Kennedy's statement regarding the need for a national plan in mental retardation since it is equally applicable today concerning the developmentally disabled:

> "The **manner in which our nation** cares for its citizens and conserves its manpower resources is more than an index to its concern for the less fortunate. It is a key to its future."

Statement

Respectfully Submitted

to

The Subcommittee on the Handicapped

of the

Senate Committee on Labor and Public Welfare

on

3. 458, the "Bill of Rights for the Mentally Retarded"

In Behalf Of

United Cerebral Palsy associations, Inc.

66 East 34th Street

New York, Mew York 10016

February 8, 1973

Witness

Mr. Sherwood A. Messner, Director, Professional Services Program Department, United Cerebral Palsy Associations, Inc.

Prior to joining United Cerebral Palsy, Mr. Messner was for six years Executive Assistant in the New York Hospital Cornell Medical Center. Mr, Messner is a member of the American Association on Mental Deficiency, a Fellow of the American Public Health Association and has been a member for three years o the Joint Commission on Accreditation of Hospital's Accreditation' Council for Facilities for the Mentally Retarded.

Accompanied By

Dr. Elsie D. Helsel, UCPA Washington Representative an,i her assistant, Mr. E. Clarke Ross, Federal Programs Consultant to the Washington Office.

United Cerebral Palsy Associations, Inc., stands foursquare behind the purposes and concepts in S. 458, the Bill of Rights for the Mentally Retarded, namely:

1) The establishment of standards which assure the human care, treatment, habilitatlon and protection of the mentally retarded in institutions;

2) Improvement of the institutional system by implementating standards and requiring compliance;

3) Minimizing inappropriate admissions;

4) Stimulation of the development of regional and community alternatives for residential care and services.

UCPA, Inc., deplores the disgraceful conditions still in existence in the back wards of some of our large institutions. We are particularly concerned because many of the residents of these back wards are victims of cerebral palsy. Most of them have *never* known a day of therapy or education in their lives. Many of them came from homes where they were functioning, before they were institutionalized, at much higher levels and where they were much more independent in their activities of daily living — feeding, dressing, and toileting. Some of them at one time, as a result of many hours of therapy, much effort and the expenditure of many thousands of dollars were once ambulatory or mobile with the use of braces, crutches or wheelchairs. All of them with proper treatment, management and equipment could be out of bed, on wheels, out of the ward participating in programs in the institution or out in the community. With the skills and

technology we now have, there is no longer any excuse for bed fast care for the cerebral palsied.

It is particularly distressing to us to visit the adult wards of institutions for the retarded and recognize an individual whom we have known as a happy, bright, promising child in one of our UCP centers — severely handicapped but responsive to therapy and with potential for some measure of independent living and work under sheltered conditions. There he lies — his contractures have been allowed to take over and his body is pulled into a weird non-functional position. His muscles have atrophied through disuse Ms decubiti are ulcerating; his sad eyes stare at the celling with nothing to look forward to but an endless succession of purposeless tomorrows. What a waste of human potential, of time, of money What an indictment of a society that would allow this to happen to a fellow human being!

So UCPA understands only too well the need for the Bill of Rights and we will do everything we can to support legislation that will eliminate forever inappropriate, dehumanising care — in institutions or out in the community.

We approve wholeheartedly of what the sponsors of S. 458 are trying to do. We have serious reservations concerning how they propose to get the Job done.

Major Concerns

UCPA has three major concerns with the legislation as presently drafted:

1) Duplication of effort and problems of coordination relative to the proposed State Planning and Advisory Council and the already functioning state planning and advisory councils for the Developmental Disabilities Act;

2) Duplication of effort of the proposed National Advisory council on Standards with the already functioning Accreditation Council for Facilities for the Mentally Retarded;

3) Conflict of interest in the proposed mechanism for state or federal determination of compliance with the proposed standards.

Let us share the reasons for these concerns.

Duplication of Effort — State Plans

The bill requires any state seeking a grant under Section 1203 "State Plans" for funds for bringing any publicly operated or essisted facility into conformity with the standards, to designate a State Planning and Advisory Council presumably to assist with accomplishing this goal. Although the duties of this Council are not spelled out in the bill, they would appear to duplicate the present efforts of the State Developmental Disabilities Act Planning and Advisory Councils charged with seeing that quality comprehensive services — including residential services — be made available for all of the developmentally disabled, including the mentally retarded. Almost all state DDA plans reflect concern for the development of quality community alternatives for residential care. Most plans reflect the philosophy that institutions should not operate in isolation but should be part of the community continuum of services. It would appear that another Planning and Advisory Council would add confusion as to responsibilities and role and would be a duplication of effort.

He are therefore suggesting that the bill designate the Developmental Disabilities Planning and Advisory Council as the Council rather than authorize the creation of a new Council.

Duplication of Effort of the Proposed National Advisory Council on Standards for Residential Facilities with the On-going Accreditation Council for Facilities for the Mentally Retarded

Since 1966, a group of voluntary agencies with a primary concern for improving residential care, have been working together to develop standards and set up procedures for surveying for compliance with the standards and for accreditation. This group originally included American Association on Mental Deficiency, American Psychiatric Aosociatlon, Council for Exceptional Children, National Association for Retarded Children and United Cerebral Palsy Associations, Inc. With the help of a grant from the Division of Mental Retardation (not the Division of Develpomental Disabilities) these agencies formed the National Planning Committee on Accreditation. They reviewed existing standards and decided that what was needed was not a revision of the old standards but the development of new standards reflecting new concepts and new approaches to residential care and services. With this decision and a recognition of the magnitude of the task ahead, the National Planning Committee felt they needed all the expertise and experience they could get. Work of the Joint Commission on Accredition of Hospitals was well known to the group.

Professor Herschel Nisonger, a member of the national Planning Committee had approached the Joint Commission concerning taking over the task of accrediting facilities for the mentally retarded but had been turned down. At that time the Joint Commission was in the process of setting up the accreditation program for nursing homes and extended care facilities and felt they could not take on another new area at that time.

The JCAH was approached again by the National Planning Committee with a proposed Memorandum of Agreement which would leave the decision making concerning standards and accreditation with the National Planning Committee but would link the operation administratively

and legally to the Joint Commission.

The Memorandum of Agreement under which the National Planning Committee and the Joint Commission on Accreditation of Hospitals agreed to Join forces included guarantees that a proposed Accreditation Council for Facilities for the Mentally Retarded would:

1) Develop, and regularly review and revise, standards to be used in the accreditation of facilities for the mentally retarded.

2) Develop, set procedures, and hire staff for surveying institutions requesting accreditation for compliance with the standards.

3) Make decisions concerning which institutions were to be accredited and which were to be denied.

Actions of the Accreditation Council are subject to final approval by the Joint Commission. The Memorandum of Agreement makes perfectly adequate provision for the withdrawal of the Accreditation Council from JCAH if, at any time, they feel it is not in the best interests of the program to continue this relationship.

To date the decision of the Planning Committee to place the program with JCAH has proved sound. This has been a most rewarding and fruitful association. The accreditation program has developed on schedule and is in operation. Standards were developed with the assistance of administrators, practitioners, researchers and consumers representing a wide cross section of the population concerned with programs for the mentally retarded and developmentally disabled. Standards were written so that they would be applicable to a residential facility of any size. They have been checked with a group of operators of private residential facilities of all sizes.

Of the five institutions used in a field test of the standards and survey procedures for accreditation, one institution has already

been accredited. The Council refuses to listen to statements that these standards are unreasonably high and consequently it will be difficult to get institutions to apply for accreditation. Dr. Kenneth Crosby, Program Director for the Accreditation Council for Facilities for the Mentally Retarded reports that as of January 12, 1973 there are paid applications for 40 facilities requesting accreditation with 53 other facilities involved at some prior step in the application process.

UCPA, Inc., has been a member of the group planning and working for accreditation of facilities for the mentally retarded since the group first began to work together back in 1966. In our opinion it would not only be duplication of effort to generate other standards than the ones developed by the Accreditation Council but such standards might not be of as high a quality as those we now have. Wo know full well that these Standards are not perfect but we feel they are the best that professional consensus and present knowledge can evolve at this time.

Indeed the Accreditation Council feels so strongly that any standards must be flexible and responsive as new knowledge and improved techniques of care come into being, that provision has been made for a permanent subcommittee of the Accreditation Council charged with regularly reviewing, revising, and making recommendations to full Council for changes. As a result of the field testing operations . with the standards about 20 change have already been approved.

We have therefore serious concerns about locking standards into lav; without some provision for regular review, updating and modification.

Conflict of Interest if States do the Surveying for Compliance

At the present time, state licensure is supposed to provide- some measure of protection to mentally retarded residents In state operated facilities. Obviously protection through licensure has failed or our

institutions would not have been allowed to reach the present deplorable state.

The track record of states policing their own operations has not been good. Indeed many states do not even require their state operated facilities to meet their own state licensure requirements!

Hence we have no confidence in the provision in the bill that would permit states to review their status with respect to compliance with standards. We feel strongly that this review should be done by a group outside government —- federal or state — preferably a voluntary group. State and federal governments should stand by as watchdogs to be sure that standards remain adequate and appropriate and that survey procedures are properly done.

UCPA feels very strongly that since the Accreditation Council for facilities for the Mentally Retarded is already in the business of accreditation, it would be logical to designate this group as the primary surveyor for compliance, with appropriate procedures for an additional independent survey if the Secretary wishes to validate the findings of the survey team of tie Accreditation Council for Facilities for the Mentally Retarded.

Standards and Accreditation Alone Will Not Do the Total Job

UCPA has enthusiastically supported the standard setting and accreditaion movement with the hope that this would provide a major impetus for the improvement of residential care and services. However, we know full well that this is not the total answer to the problem of provision of adequate and appropriate residential care. We need other initiatives including the cutting off of the flow of residents into the institution by the development of community alternatives.

We also feel that the role of the institution should change.

It should become a part of a total habilitative – rehabilitative system. It should be one of the alternatives for residential services. It should function as a treatment-training facility and all placements should be time limited. It should not become a repository for the non-ambulatory or for rejects that no one else wants to serve.

UCPA also well realizes that just the existence of a comprehensive system of community based services – including residential services – will not guarantee that all individuals who need such services get them.

The target group of both the Developmental Disabilities Act and the Bill of Rights namely, the substantially handicapped who will be dependent to some degree all of their lives – need an additional service to protect their civil and human rights and to guarantee that they get appropriate programs at appropriate times.

The State of Ohio has recently put into place statewide just such a system ~ a Protective Service - Case Management - Personal Advocacy System. The Ohio Division of Mental Retardation and Developmental Disabilities has established a network of 10 District Offices where developmentally disabled individuals and/or their families can apply for services. All entrys and exits from the state institutional system will henceforth be made through these District Offices. Protective Service is a voluntary service and if it is desired, a comprehensive diagnostic and evaluation procedure is required in order to determine if the person actually needs the protective service and in order to determine to what degree he needs the service. Under Ohio H.B. 290, a Protective Service ranging from minimal counseling to maximal full guardianship under court assignment can be provided by the Division of Mental Retardation and Developmental Disabilities. At time of acceptance into the service, the individual and/or his family are fully informed concerning how to get out of the system if they so desire. The law further stipulates that if the Division

of Mental Retardation and Developmental Disabilities accepts an individual for protective service, they are accountable for filing at least annually a full report in writing of the physical, mental and social condition of each mentally retarded or other developmentally disabled person for whom the Division is acting as guardian, trustee or protector.

If the individual or his family is requesting residential care anil services, every effort must be made to find a suitable community placement. Only if this is not possible, or an institution has a treatment-training program not available in the individual's community of residence will placement in an institution by made.

Already the institutional population in Ohio is dropping. Already over 600 clients are enrolled in the Protective Service System with more applications pouring in each week as parents become fully aware of what is available under the system. As a result of experience gained in a pilot protective service project in the State, it is anticipated that only about 10% of those applying will require court guardianship.

The Protective Service - Case Management System is a State system where accountability is assigned and can be insisted upon. However, since it is a State system it can become very impersonal. To watch-dog this system and to provide the badly needed personal touch, a companion volunteer system, a personal advocacy system, has been pilot tested and is being put in place under an incorporated consortium of the three primary voluntary agencies serving the developmentally disabled in Ohio — Ohio Association for Retarded Children, Epilepsy Foundation of America, and United Cerebral Palsy of Ohio. Developmental Disability Act funding is being provided to help set this resource in place.

Conclusion

UCPA feels very strongly that unless changes such as those we have indicated are made in the bill in order to coordinate its thrust with efforts already underway by the Accreditation Council for Facilities for the Mentally Retarded and the Developmental Disabilities Act Planning and Advisory Councils, the bill will not-only miss its mark of improving residential services for the developmentally disabled but may very well interfere negatively with progress already being made.

Specific Changes for S. 458

References are to S. 3759 dated June 28, 1972 since copies of S. 458 introduced January 18 were not available.

First of course we would like to see the language in the title and throughout the bill changed to "mentally retarded and other developmentally disabled."

RE: Page 3, Line 5

We have learned in Ohio that having legal guardians is just not enough protection for incompetent individuals whether they reside in State institutions or in the community. We have therefore set up a statewide Protective Advocacy System under law.

Suggested Change for Line 5

(5) a protective advocacy service including but not limited to guardianship should be available for both adults who are incompetent because of the severity of their mental retardation and minors who are deprived of parental guardianship, prior to their admission to a residential facility and, also, for each of who are in residential facilities at the date of the enactment of this Act;

Section 1191. (a), Line 4. Suggested Change (Page 5)

"In order to assist the States in bringing existing residential facilities into compliance with standards under part C of this Act, the Secretary shall make grants to the several states who have an approved developmental disabilities plan meeting the following criteria:

(1) setting forth as one of its priority goals the improvement of residential cervices;

(2) setting forth a strategy and a schedule for working toward compliance with the standards in part C;

(3) setting forth strategies which minimize inappropriate placement particularly through the provision of alternative programs of care;

(4) setting forth strategies for the coordination and integration of existing residential facilities with existing and future regional and community mental retardation programs and services;

(5) providing for the study of administrative relationships, including the identification of legal, economic, social, and other barriers to compliance with standards established under part 0 of this Act;

(6) providing for the financing of programs and services from both public and private sources among Federal, State and local governments in the field of mental retardation with recommendation for improvement, the Secretary may make grants to such applicants and upon such terms and conditions as he shall by regulations prescribe.

Section 1101. (a), Line 15-16 — DELETE (Page 5)

"which shall be done in cooperation with the National Advisory Council on Standards for Residential Facilities for the Mentally Retarded established under section 1109 of this Act,"

paction 1101. (a), INSERT After line 26. (Page 5)

"Surveys to determine the compliance of facilities with the standards established under part C of this title shall be conducted by the national accrediting body for such facilities, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals."

Section 1103, "State Plans," Suggested Change (Page 7)

"(a) Any State desiring to receive a grant under this title submit a plan to the Secretary:

"(1) setting forth as one of its priority goals the improvement. of residential services;

"(2) setting forth a strategy and a schedule for compliance with standards under part C;

"(3) having in operation a properly constituted developmental disabilities planning and advisory council with duties and responsibility as set forth in section 134 of the Developmental Disabilities Act; .

"(4) assuring reasonable state financial participation...;

"(5) setting forth a schedule of costs...;

"(6) designating how placement...;

Section 1103 (2), Suggested Change To Head (Page 8)

"designating the State developmental disabilities planning and advisory council as the planning and advisory body.

Section 1106. ADD AFTER POINT (c) (Page 11)

"(d) A facility shall be deemed to meet the standards under part C of this title if it is accredited by the national accrediting body for such facilities, the Accreditation *Council* for Facilities for the Mentally Retarded of the Joint commission on Accreditation of Hospitals, provided that the secretary may cause an independent survey of compliance with the standards to be made in any facilities surveyed by the Accreditation Council whenever he finds such an independent survey to be necessary to validate the findings of the Accreditation Council survey.

RE: Section 1108. -- "Alternative Programs of Care (Page 11)

As you know the Accreditation Council is also developing standards for community programs. If these community programs are residential programs they should meet the same standards as are established in your bill under part C. Otherwise as we create alternatives to institutional care in the community they may be no better, or even worse, then our present institutions. The recent experience in Pennsylvania confirms this fear. You should know that the present standards were drafted in such a way that they would be appropriate for any residential facility of any size. A group of operators of small group homes in California reviewed the standards in order to give the Council assurance that the standards would be applicable to small facilities.

Suggested Change for Section 1108. — "Alternative Programs of Care

"Community resources and community living situations for the mentally retarded receiving grants under this section shall comply with the applicable standards established by the national accrediting body for such programs, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, provided that the Secretary may cause an independent survey of compliance to be made of any programs surveyed by the Accreditation Council whenever he finds such an independent survey to be necessary to validate the findings of the Accreditation Council survey.

Section 1109. DELETE "National Advisory Council on Standards for Residential Facilities for the Mentally Retarded (Page 12)

REPLACE WITH "Revision of Standards and the following material

"(a) The Secretary shall seek and receive the advice of the national accrediting body for facilities and programs for the mentally retarded, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, in respect to (1) recommendation for any changes. revisions, modifications, or improvements in the standards established under part c of this title, (2) any regulations promulgated or proposed to be promulgated by him in the implementation of the standards established under part C of this title, provided that nothing herein shall limit the authority of the Secretary to seek and receive advice and respect to the above matters from any source he deems appropriate.

TITLE I[1]—SERVICES AND FACILITIES FOR THE MENTALLY RETARDED AND PERSONS WITH OTHER DEVELOPMENTAL DISABILITIES

SHORT TITLE

SEC. 99.[2] This title may be cited as the "Developmental Disabilities Services and Facilities Construction Act".

PART A—GRANTS FOR CONSTRUCTION OF CENTERS FOR RESEARCH ON MENTAL RETARDATION AND RELATED ASPECTS OF HUMAN DEVELOPMENT

* * * * *

PART B[3]—CONSTRUCTION, DEMONSTRATION, AND TRAINING GRANTS FOR UNIVERSITY-AFFILIATED FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

AUTHORIZATION OF APPROPRIATIONS

42 U.S.C. 2661

SEC. 121.[4] [5] (a) For the purpose of assisting in the construction (and the planning for the construction) of facilities which will aid in demonstrating provision of specialized services for the diagnosis and treatment, education, training, or care of persons with developmental disabilities or in the interdisciplinary training of physicians and other specialized personnel needed for research, diagnosis and treatment, education, training, or care of persons with developmental disabilities, including research incidental or related to any of the foregoing activities, there are authorized to be appropriated $5,000,000 for the fiscal year ending June 30, 1964, $7,500,000 for the fiscal year ending June 30, 1965, $10,000,000 each for the fiscal year ending June 30, 1966, the fiscal year ending June 30, 1967, and the fiscal year ending June 30, 1968, and $20,000,000 for each of the next ~~five~~ ten fiscal years through the fiscal year ending June 30, 1978. Except as provided in subsection (b), the sums so appropriated shall be used for project grants for

[1] The heading of title I amended by sec. 101(a) of P.L. 91-517.
[2] Sec. 100 amended by sec. 207(a) of P.L. 91-517.
[3] Section 601 of P.L. 91-296 provides in part that unless expressly limited by later enactment, funds appropriated for any fiscal year ending prior to July 1, 1973, for any program under this Act shall remain available for obligation and expenditure for such fiscal year.
[4] The heading of pt. B amended by sec. 207(b) of P.L. 91-517.
[5] Sec. 125 amended by secs. 2 (a), (b), and (d) (1) of P.L. 90-170, and sec. 201 (a) and (b) of P.L. 91-517.
[6] Sec. 513 of the Public Health Service Act authorizes in part, that, such portion as the Secretary may determine, up to 1 per centum, of any appropriation under any provision of the Mental Retardation Facilities Construction Act shall be available for evaluation of any program authorized thereunder.

construction of public and other nonprofit facilities for persons with developmental disabilities which are associated with a college or university.

(b)* (1) Of the sums appropriated pursuant to subsection (a) for any fiscal year, beginning with the fiscal year ending June 30, 1968, an amount equal to 2 per centum thereof (or such smaller amount as the Secretary may determine to be appropriate) shall be available to the Secretary for the purpose of making grants to cover not to exceed 75 per centum of the costs of the planning of projects with respect to the construction of which applications for grants may be made under this part. Not more than $25,000 shall be granted under this subsection with respect to any project. Appropriations.

(2) Planning grants under this subsection shall be made by the Secretary to such applicants and upon such terms and conditions as he shall by regulations prescribe. Payment of grants under this subsection shall be made in advance or by way of reimbursement, as the Secretary may determine.

(3) Whenever, in the succeeding provisions of this part, the term "grant", "grants", or "funds" is employed, such term shall be deemed not to include any grant under this subsection or any of the funds of any such grant.

DEMONSTRATION AND TRAINING GRANTS

SEC. 122.* (a) For the purposes of assisting institutions of higher education to contribute more effectively to the solution of complex health, education, and social problems of children and adults suffering from developmental disabilities, the Secretary may, in accordance with the provisions of this part, make grants to cover costs of administering and operating demonstration facilities and interdisciplinary training programs for personnel needed to render specialized services to persons with developmental disabilities, including established disciplines as well as new kinds of training to meet critical shortages in the care of persons with developmental disabilities.

(b) ** For the purpose of making grants under this section, there are authorized to be appropriated $15,000,000 for the fiscal year ending June 30, 1971; $17,000,000 for the fiscal year ending June 30, 1972; and $20,000,000 for the fiscal year ending June 30, 1973; $30,000,000 for the fiscal year ending June 30, 1974; $35,000,000 for the fiscal year ending June 30, 1975; $40,000,000 for the fiscal year ending June 30, 1976; $45,000,000 for the fiscal year ending June 30, 1977; and $50,000,000 for the fiscal year ending June 30, 1978.

* Subsec. 121 (b) added by sec. 2(c) of P.L. 90-170.
* Sec. 122 added by sec. 202 of P.L. 91-517.
** See footnote 7 on p. 386.

MAINTENANCE OF EFFORT

SEC. 127.[14] Applications for grants under this part may be approved by the Secretary only if the application contains or is supported by reasonable assurances that the grants will not result in any decrease in the level of State, local, and other non-Federal funds for services for persons with developmental disabilities and training of persons to provide such services which would (except for such grant) be available to the applicant, but that such grants will be used to supplement, and, to the extent practicable, to increase the level of such funds.

PART C—[15] GRANTS FOR PLANNING, PROVISION OF SERVICES, AND CONSTRUCTION AND OPERATION OF FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

DECLARATION OF PURPOSE

SEC. 130. The purpose of this part is to authorize—

(a) grants to assist the several States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services to persons with developmental disabilities;

~~(b) grants to assist public or nonprofit private agencies in the construction of facilities for the provision of services to persons with developmental disabilities, including facilities for any of the purposes stated in this section;~~

~~(c) grants for provision of services to persons with developmental disabilities, including costs of operation, staffing, and maintenance of facilities for persons with developmental disabilities;~~

~~(d) grants for State or local planning, administration, or technical assistance relating to services and facilities for persons with developmental disabilities;~~

~~(e) grants for training of specialized personnel needed for the provision of services for persons with developmental disabilities, or research related thereto; and~~

~~(f) grants for developing or demonstrating new or improved techniques for the provision of services for persons with developmental disabilities.~~

AUTHORIZATION OF APPROPRIATIONS

SEC. 131. In order to make the grants to carry out the purposes of section 130, there are authorized to be appropriated $60,000,000 for the fiscal year ending June 30, 1971, $105,000,000 for the fiscal year ending June 30, 1972, and $130,000,000 for the fiscal year ending June 30, 1973.

[14] Sec. 127 added by sec. 206 of P. L. 91-517.
[15] Part C amended by sec. 101(b) of P.L. 91-517.

in aid

including construction of community facilities;

(b) Project grants for activities of national significance which will contribute to improving the condition of persons with developmental disabilities including but not limited to grants for demonstrating exemplary services to persons with developmental disabilities who are especially disadvantaged, for technical assistance relating to services and facilities for persons with developmental disabilities, including assistance in state and local planning or administration, for training of specialized personnel needed for the provision of services for persons with developmental disabilities, or for research directly related thereto, for developing or demonstrating new or improved techniques for the provision of services to persons with developmental disabilities, or for gathering or disseminating information relating to developmental disabilities.

(a) STATE FORMULA GRANTS

$150,000,000 for the fiscal year ending June 30, 1974, $200,000,000 for each of the two fiscal years ending June 30, 1975 and June 30, 1976, $250,000,000 for the fiscal year ending June 30, 1977, and $300,000,000 for the fiscal year ending June 30, 1978.

(b) PROJECTS OF NATIONAL SIGNIFICANCE

In order to make grants to carry out the purposes of subsection 130 (b) there are authorized to be appropriated $25,000,000 for the fiscal year ending June 30, 1974, $30,000,000 for the fiscal year ending June 30, 1975, $35,000,000 for the fiscal year ending June 30, 1976, $40,000,000 for the fiscal year ending June 30, 1977, and $45,000,000 for the fiscal year ending June 30, 1978.

(c) DEINSTITUTIONAL INCENTIVES

To supplement the amount specified in subsection 131 (a) there are further authorized to be appropriated $30,000,000 for fiscal year ending June 30, 1974, $40,000,000 for the fiscal year ending June 30, 1975, $50,000,000 for the fiscal year ending June 30, 1976, $60,000,000 for the fiscal year ending June 30, 1977, and $70,000,000 for the fiscal year ending June 30, 1978, to be alloted to the several States by the Secretary in accordance with subsection 132 (a) (4).

STATE ALLOTMENTS

SEC. 132(a) (1) [see] From the sums appropriated to carry out the purposes of section 130 for each fiscal year, other than amounts reserved by the Secretary for projects under subsection (c), the several States shall be entitled to allotments determined, in accordance with regulations, on the basis of (A) the population, (B) the extent of need for services and facilities for persons with developmental disabilities, and (C) the financial need, of the respective States; except that the allotment of any State (other than the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands) for any such fiscal year shall not be less than $100,000 plus, if such fiscal year is later than the fiscal year ending June 30, 1971, and if the sums so appropriated for such fiscal year exceed the amount authorized to be appropriated to carry out such purposes for the fiscal year ending June 30, 1971, an amount which bears the same ratio to $100,000 as the difference between the amount so appropriated and the amount authorized to be appropriated for the fiscal year ending June 30, 1971, bears to the amount authorized to be appropriated for the fiscal year ending June 30, 1971.

~~(2) In determining, for purposes of paragraph (1), the extent of need in the State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified pursuant to section 134(b)(5), in the State plan of such State approved under this part.~~

(3) Sums allotted to a State for a fiscal year and designated by it for construction and remaining unobligated at the end of such year shall remain available to such State for such purpose for the next fiscal year (and for such year only), in addition to the sums allotted to such State for such next fiscal year: *Provided*, That if the maximum amount which may be specified pursuant to section 134(b)~~(4)(A)~~ for a year plus any part of the amount so specified pursuant thereto for the preceding fiscal year and remaining unobligated at the end thereof is not sufficient to pay the Federal share of the cost of construction of a specific facility included in the construction program of the State developed pursuant to section 134(b)~~(4)(A)~~, the amount specified pursuant to such section for such preceding year shall remain available for a second additional year for the purpose of paying the Federal share of the cost of construction of such facility.

(b) Whenever the State plan approved in accordance with section 134 provides for participation of more than one State agency in administering or supervising the administration of designated portions of the State plan, the State may apportion its allotment among such agencies in a manner which, to the satisfaction of the Secretary,

[see] See footnote 2 on p. 500.

The allotment for the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific shall be not less than $25,000 each.

(4) Deinstitutional Incentives

From the supplementary sums appropriated in accordance with the subsection 131 (c) the Secretary shall make allotments to the several States to assist them in carrying out specific goal oreinted plans acceptable to the Secretary and designed to reduce and eventually eliminate inappropriate institutional placement of persons with developmental disabilities, to improve the quality of care and habilitation of those for whom institutional care is appropriate and to protect the human rights of all persons with developmental disabilities, especially those without familial protection. Such specific supplemental plans shall be part of the State plan submitted in accordance with Sec. 134.

(13)

(14)

is reasonably related to the responsibilities assigned to such agencies in carrying out the purposes of this part. Funds so apportioned to State agencies may be combined with other State or Federal funds authorized to be spent for other purposes, provided the purposes of this part will receive proportionate benefit from the combination.

(c) Whenever the State plan approved in accordance with section 134 provides for cooperative or joint effort between States or between or among agencies, public or private, in more than one State, portions of funds allotted to one or more such cooperating States may be combined in accordance with the agreements between the agencies involved.

(d) The amount of an allotment to a State for a fiscal year which the Secretary determines will not be required by the State during the period for which it is available for the purpose for which allotted shall be available for reallotment by the Secretary from time to time, on such date or dates as he may fix, to other States with respect to which such a determination has not been made, in proportion to the original allotments of such States for such fiscal year, but with such proportionate amount for any of such other States being reduced to the extent it exceeds the sum the Secretary estimates such State needs and will be able to use during such period; and the total of such reductions shall be similarly reallotted among the States whose proportionate amounts were not so reduced. Any amount so reallotted to a State for a fiscal year shall be deemed to be a part of its allotment under subsection (a) for such fiscal year.

~~(e)~~ Of the sums appropriated pursuant to section 131, such amount as the Secretary may determine, but not ~~more than 10~~ less than 35 per centum thereof, shall be available for grants by the Secretary to public or nonprofit private agencies to pay ~~up to 90 per centum~~ part of the cost of projects for carrying out the purposes of section 130 which, in his judgment are of special national significance because they will assist in meeting the needs of the disadvantaged with developmental disabilities, or will demonstrate new or improved techniques for provision of services for such persons, or are otherwise specially significant for carrying out the purposes of this title.

(3) PROJECTS OF NATIONAL SIGNIFICANCE

(b)

NATIONAL ADVISORY COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

SEC. 133. (a)(1) Effective July 1, 1971, there is hereby established a National Advisory Council on Services and Facilities for the Developmentally Disabled (hereinafter referred to as the 'Council'), which shall consist of twenty members, not otherwise in the regular full-time employ of the United States, to be appointed by the Secretary without regard to the provisions of title 5, United States

Code, governing appointments in the competitive civil service.

(2) The Secretary shall from time to time designate one of the members of the Council to serve as Chairman thereof.

(3) The members of the Council shall be selected from leaders in the fields of service to ~~the mentally retarded~~ *and other persons with* developmental disabilities, including leaders in State or local government, in institutions of higher education, and in organizations representing consumers of such services. At least five members shall be representative of State or local public or nonprofit private agencies responsible for services to persons with developmental disabilities, and at least five ~~shall be representative of the interests~~ of consumers of such services.

CROSS OUT "the mentally retarded and"

CROSS OUT "representative of the interests of"

(b) Each member of the Council shall hold for a term of four years, except that any member appointed to fill a vacancy occurring prior to the expiration of the term for which his predecessor was appointed shall be appointed for the remainder of such term, and except that, of the twenty members first appointed, five shall hold office for a term of three years, five shall hold office for a term of two years, and five shall hold office for a term of one year, as designated by the Secretary at the time of appointment.

(c) It shall be the duty and function of the Council to (1) advise the Secretary with respect to any regulations promulgated or proposed to be promulgated by him in the implementation of this title, and (2) study and evaluate programs authorized by this title with a view of determining their effectiveness in carrying out the purposes for which they were established.

(d) The Council is authorized to engage such technical assistance as may be required to carry out its functions, and the Secretary shall, in addition, make available to the Council such secretarial, clerical, and other assistance and such statistical and other pertinent data prepared by or available to the Department of Health, Education, and Welfare as it may require to carry out such functions.

(e) Members of the Council, while attending meetings or conferences thereof or otherwise serving on the business of the Council, shall be entitled to receive compensation at rates fixed by the Secretary, but at rates not exceeding the daily equivalent of the rate provided for GS–18 of the General Schedule for each day of such service (including travel time), and, while so serving away from their homes or regular places of business, they may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons in the Government service employed intermittently.

able to other public or nonprofit private agencies, institutions, and organizations; (C) such funds will be used to supplement and, to the extent practicable, to increase the level of funds that would otherwise be made available for the purposes for which the Federal funds are provided and not to supplant such non-Federal funds; and (D) there will be reasonable State financial participation in the cost of carrying out the State plan;

(5) (A) provide for the furnishing of services and facilities for persons with developmental disabilities ~~associated with mental retardation~~, (B) ~~specify the other categories of developmental disabilities (approved by the Secretary) which will be included in the State plan, and~~ (C) describe the quality, extent, and scope of such services as will be provided to eligible persons;

(6) provide that services and facilities furnished under the plan for persons with developmental disabilities will be in accordance with standards prescribed by regulations, including standards as to the scope and quality of such services and the maintenance and operation of such facilities, except that during fiscal year 1971, the Secretary may waive, in whole or in part, the requirements of this paragraph;

(7) [1] provide such methods of administration, including methods relating to the establishment and maintenance of personnel standards on a merit basis (except that the Secretary shall exercise no authority with respect to the selection, tenure of office, and compensation of any individual employed in accordance with such methods), as are found by the Secretary to be necessary for the proper and efficient operation of the plan;

(8) provide that the State planning and advisory council shall be adequately staffed, and shall include representatives of each of the principal State agencies and representatives of ~~local agencies and~~ nongovernmental organizations and groups, concerned with services for persons with developmental disabilities: *Provided*, That at least one-third of the membership of such council shall consist of representatives of consumers of such services; ——, including local agencies,

(9) provide that the State planning and advisory council will from time to time, but not less often than annually, review and evaluate its State plan approved under this section and submit appropriate modifications to the Secretary; Annual review.

[1] Sec. 203(a)(3) of P.L. 91-648 transfers to the U.S. Civil Service Commission all functions, powers, and duties of the Secretary insofar as they relate to the prescription of personnel standards on a merit basis.

Records and reports availability.

(10) provide that the State agencies designated pursuant to paragraph (1) will make such reports, in such form and containing such information, as the Secretary may from time to time reasonably require, and will keep such records and afford such access thereto as the Secretary finds necessary to assure the correctness and verification of such reports;

Urban or rural poverty area, special consideration.

(11) provide that special financial and technical assistance shall be given to areas of urban or rural poverty in providing services and facilities for persons with developmental disabilities who are residents of such areas;

(12) describe the methods to be used to assess the effectiveness and accomplishments of the State in meeting the needs of persons with developmental disabilities in the State;

(13) provide for the development of a program of construction of facilities for the provision of services for persons with developmental disabilities which (A) is based on a statewide inventory of existing facilities and survey of need; and (B) meets the requirements prescribed by the Secretary for furnishing needed services to persons unable to pay therefor;

(14) set forth the relative need, determined in accordance with regulations prescribed by the Secretary, for the several projects included in the construction program referred to in paragraph (13), and assign priority to the construction of projects, insofar as financial resources available therefor and for maintenance and operation make possible, in the order of such relative need;

~~(15)~~ specify the per centum of the State's allotment (under section 132) for any year which is to be devoted to construction of facilities, which per centum shall be not more than 50 per centum of the State's allotment or such lesser per centum as the Secretary may from time to time prescribe; (13)

~~(16)~~ provide for affording to every applicant for a construction project an opportunity for hearing before the State agency; (15)

~~(17)~~ provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of and accounting for funds paid to the State under this part; and (16)

~~(18)~~ contain such additional information and assurances as the Secretary may find necessary to carry out the provisions and purposes of this part. (17)

(c) The Secretary shall approve any State plan and any modification thereof which complies with the provisions of subsection (b). The Secretary shall not finally disapprove a State plan except after reasonable notice and opportunity for a hearing to the State.

(14) if federal funds are allocated for construction as provided, in sub paragraph (13) of this subsection, outline a program of construction of facilities for the provision of services for persons with developmental disabilities which (A) is based on a statewide inventory of existing facilities and survey of need; (B) meets the requirements prescribed by the Secretary for furnishing needed services to persons unable to pay therefore; (C) sets forth the relative need, determined in accordance with the regulations prescribed by the Secretary for the several projects included in the construction program; (D) assigns priority to the construction of projects, insofar as financial resources available therefore and for maintenance and operation make possible, in the order of relative need; (E) assigns priority to construction of small group living facilities in the community to place emphasis on Section 132 (a) (4); and (F) restricts the use of construction funds for the construction of large residential facilities.

(d) in order to develop the fullest possible national impact of the optional specific goal oriented plans authorized by subsection 132 (a) (4), the Secretary is authorized to specify by regulations such additional requirements as he may find necessary which are consistent with the requirements of this section.

even-numbered year, on the basis of the average of the per capita incomes of the States and of the United States for the three most recent consecutive years for which satisfactory data are available from the Department of Commerce. Such promulgation shall be conclusive for each of the two fiscal years in the period beginning July 1 next succeeding such promulgation: except that the Secretary shall promulgate such percentages as soon as possible after the enactment of this Act, which promulgation shall be conclusive for the fiscal year ending June 30, 1965.

(2) The term "United States" means (but only for purposes of this subsection and subsection (i)) the fifty States and the District of Columbia.

(k) The term "Secretary" means the Secretary of Health, Education, and Welfare.

~~(l)[1] The term "developmental disability" means a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, which disability originates before such individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individual.~~

(l) "Developmental Disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen a handicap of comparable severity."

~~(m)[1] The term "services for persons with developmental disabilities" means specialized services or special adaptations of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with such a disability, and such term includes diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling of the individual with such disability and of his family, protective and other social and socio-legal services, information and referral services, follow-along services, and transportation services necessary to assure delivery of services to persons with developmental disabilities.~~

(m) the term "eligible person" means a person with a developmental disability or a person with another substantial handicap who has similar service needs and who is considered eligible for such similar services by an agency or a facility which is providing services primarily intended for persons with developmental disabilities

~~(n)[2] The term "regulations" means (unless the text otherwise indicates) regulations promulgated by the Secretary.~~

STATE STANDARDS FOR VARIABLE FEDERAL SHARE

SEC. 402.[2] * * *

[1] Sec. 401 amended to add new subsecs. (l), (m), and (n), by sec. 102(b) of P.L. 91-517.
[2] Sec. 402 repealed by sec. 104 of P.L. 91-211.

UNITED CEREBRAL PALSY ASSOCIATIONS, INC. • 66 EAST 34th STREET • NEW YORK, NEW YORK 10016

ELSIE D. MELSEU PH. **D.**
WASHINGTON REPRESENTATIVE:
THE **DODGE House, 20 E Street, N. *W.***
WASHINGTON, D. C. 20001
(203) 638-6169

December 26, 1972

TO : Elsie D. Helsel, Ph. D.

FROM : E. Clarke Ross

SUBJECT: 1972 State DO Grants

Attached is a chart summarizing our survey to date of UCPA affiliates and their applications for 1972 State Developmental Disabilities grants.

Of 300 affiliates, less than half, 144, have responded. Of those 144, 56 (or 38%) were awarded DD grants totalling $1,718,055.

This type of material should be made available to affiliates in the form of our "Analysis" publication as advertised in the "Word From Washington". These statistical surveys encourage non-involved affiliates to become involved in the State DD funding process and they also demonstrate the impact the DD Act has had upon serving the cerebral palsied population.

1972 State DP Grants

1)	UCPA Affiliates Responding to Survey	144
2)	UCPA Affiliates Applying for DDA Funds	80
3)	UCPA Affiliates Receiving DDA Funds	56
4)	UCPA Affiliates Hot Applying For DDA Funds	64
5)	Dollar Amount of DDA Funds Received By UCPA Affiliates	$1,798,255
	a) Largest Single DDA Grant awarded to a UCPA affiliate	$ 113,974
	b) Smallest single DDA Grant awarded to a UCPA affiliate	$ 2,265
	c) Average $ amount of 56 grants awarded to UCPA affiliates	$ 32,111

UCPA Affiliate Use of DP State Funds

1)	Programs for Children	21
2)	Programs for Adults	12
3)	Sheltered Workshops	8
4)	Transportation	8
5)	Home Service - Case Service	9
6)	Additional Professional Staff	6
7}	Studies	5
8)	Building and Equipment Needs	5
9)	Recreation and Emergency Respite	2
10)	Non-specification of fund use	7
	Total	83

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F.I.3IS D. HELSEL, PH. D.
WASHINGTON REPRESENTATIVE

15 E St., N.W.

MEMORANDUM

January 29, 1973

TO: Elsie D. Helsel, Ph.D.

FROM: E. Clarke Ross

SUBJECT: 1971 State DP Grants

I have reviewed the summary prepared by Mrs. Weinberg of UCPA affiliate use and application for 1971 State Developmental Disabilities grants. The totals follow.

1971 State DP Grants

1)	UCPA Affiliates Responding to Survey	144
2)	" Applying for DDA Funds	63
3)	" Receiving DDA Funds	24
4)	" Not Applying for DDA Funds	81
5)	Dollar Amount of DDA Funds Received By UCPA Affiliates	$587,279
6)	Average $ amount of grants awarded to UCPA Affiliates	$ 24,469

UCPA Affiliate Use of DP State Funds

1)	Programs for Children	4
2)	Programs for Adults	2
3)	Sheltered Workshops	2
4)	Transportation	7
5)	Home Service - Case Service	2
6)	Additional Professional Staff	0
7)	Studies	4
8)	Building and Equipment Needs	1
9)	Recreation and Emergency Respite	0
101	Special Living Arrangements	2
11)	Psychological Program	1
12)	Non-specification of fund use	6
		31

MEMORANDUM

June 16, 1972

TO: State Executive Directors
District Office Managers
National Staff

FROM: Elsie D. Helsel, Ph.D.
Washington Representative

RE: DDA Grants to UCP Affiliates

Attached is a summary prepared by Phyllis Weinberg, Assistant to the Washington Representative, of funds received by UCPA affiliates under the Developmental Disabilities Act for fiscal 1971.

We feel our affiliates are to be congratulated on their fine showing in getting involved in this program. We also know that many good projects were not funded because of inadequate appropriations for the Developmental Disabilities Act. (Authorization for l971 was $60 million. Appropriations Were $11.2 million.)

Fortunately, for fiscal 1972, the DDA appropriations wore doubled. We will shortly be sending a questionnaire to pull together data on 1972 state grants to UCPA affiliates.

Unfortunately, the states have been slow in getting their State Plans for fiscal 1972 approved and funds obligated from the federal level to the states, increased funding for DDA for 1973 is in jeopardy.

On April 28, the House overwhelmingly defeated two amendments to the fiscal 1972 Supplemental Appropriations Bill for HEW which would have increased DDA funds. Congressman Daniel Flood of Pennsylvania, Chairman of the Subcommittee on Labor and HEW of the House Committee on Appropriations pointed out that significant amounts of both 1971 and 1972 DBA funds remain unobligated in the federal treasury.

An amendment introduced by Congressman Jonathan Bingham of New York would have appropriated an additional $8.3 million for Title I. An amendment by Congressman Edward Koch of New York would have provided $6.5 million for hospital improvement and hospital in-service training (HIP and HIST) funds.

In arguing against additional DDA money for fiscal 1972, Congressman Flood pointed out:

1) $900,000 for fiscal 1971 still remains unobligated.

2) $15 million remains unobligated for 1972.

UCPA should make every effort to press their State DBA Councils and state agencies administering DBA to get their 1972 Plans in and approved immediately.

Otherwise it will be difficult, if not impossible, to get the 1973 DDA budget presently being considered, increased to the $65 million level that is being requested by UCPA and other agencies in their Appropriations Testimony.

The following affiliates have received funds from the state agency administering the DDA program in their state. (After the affiliate's name is the type of activity which will be funded and the amount of funds received.)

1.	UCP of Arkansas	- Dev. Day Care for Adults, Trans., Sheltered Workshop, Sp. Living Arrangements and for all phases of an adult program	$ 10,000
2.	UCP of Central Ark.	- Dev. Day Care for Children, Trans.	20,000
3.	UCP of Denver, Colo.	- Developmental Day Care for Adults	11,250
4.	UCP of Muscogee Cty., Georgia	- Transportation	14,625
5.	Beacon School of Wabash Valley, Ind.	- Dev. Day Care for Children, Trans., Sheltered Workshop	14,900
6.	UCP of Kansas	- Trans., Sp. Living Arrangements	78,400
7.	UCP of NE Maine	- Prevelence Study	9,285
8.	UCP of Michigan	- Evaluate High Risk Infants	40,000
9.	UCP of Detroit, Mich.	- Eval. Treatment Techniques for Infants	8,745
10.	UCP of Detroit, Mich.	- Eval. Services for Adults with CP	19,919
11.	UCP of Flint, Mich.	- Identify and Evaluate High Risk Infants	40,321
12.	UCP of Gr. St. Louis,Mo.	- Transportation	14,662
13.	UCP of Kansas City,Mo.	- Transportation	71,710
14.	UCPA of New Jersey	- Home Service Program	13,000
15.	UCP of Nassau Cty., N.Y.	-	65,000
16.	UCP of Utica Area, N.Y.	-	14,000
17.	UCP of North Carolina	- 1 bus for Charlotte - Equip. for 2 Centers	18,229
18.	UCP of Ohio	-	44,250
19.	UCP of Akron & Summit Ctys., Ohio	- Psychological Program	25,875
20.	UCP of Metro. Dayton, Ohio	-	10,313
21.	UCPA of Youngstown, Mahoning Ctys., Ohio	- Developmental Day Care for Children	8,500
22.	UCP of Knox Cty., Tenn.	-	22,900
23.	UCP of Cap. Area, Texas	-	7,495
24.	UCP of Dane Cty., Wisc.	- Home Craft Program	3,900
		TOTAL	$ 587,279

The following affiliates have not received their funds, but they have been notified that they will be getting DDA Funds from their state agency administering the DDA program. (After affiliates name is the type of activity which will be funded and the amount of funds asked for.)

1.	UCP of Central California	- Dev. Day Care for Children, Trans., $100 monthly for 23 treinees.	
2.	UCP of Central Iowa	- Dev. Day Care for Adults, Trans., Sheltered Workshop	$ 36,000
3.	UCP of the Bluegrass, Ky.	-	30,000
4.	UCPA of Sullivan Cty. Inc., N.Y.	- Cerebral palsy school addition.	

The following affiliates are still being considered for DDA funds from the agency administerings these funds. (After affiliates name is the type of activity they want funds for.)

1. UCPA of Colorado, Inc. - To expand current occupational therapy home program.
2. UCPA of Greater Hartford, Connecticut - Developmental day caw; for adults and transportation
3. UCP of Illinois - For a mobile team.
4. UCP of Cedar Rapids, Iowa - For outreach workers and an identification study.
5. UCP of Central Maryland - Funds for hiring social worker.
6. UCP of New Mexico - For a sheltered workshop.
7. UCP of New York City - For construction.
8. UCP of Queens, New York - For a sheltered workshop.
9. UCP of North Jersey, New Jersey - Developmental day care for children, developmental day care for adults and a sheltered workshop.
10. UCP of North Carolina - Developmental day care for children and transportation.
11. UCP of Lackawanna County, Pennsylvania.
12. UCP of Philadelphia and Vicinity, Pennsylvania - Developmental day care for adults, transportation, special living arrangements and infant stimulation program.
13. UCP of Lehigh Valley, Pennsylvania - Construction for child development center.
14. UCP of Pittsburgh District, Pennsylvania.
15. UCP of Southwest Pennsylvania, Inc., - Special Living Arrangements.
16. UCP of Pennsylvania - Employ rehabilitation or public health nurse.
17. UCP of Delaware County, Pennsylvania - Day care program.
18. UCP of Lebanon County, Pennsylvania - Expansion of early education program.
19. UCP of Delaware County, Pennsylvania - Day care for children and behavior modification/social service program.

The following affiliates have applied for DDA funds but have been turned down for funds from the state agency administering these funds. (*After* affiliates name is the type of activity they wanted funds for.)

1. Mid-State UCP, Inc., Maine - Renovations for facilities.
2. UCP of Minnesota, Inc. - Diagnostic and evaluation clinic.
3. UCP of Greater St. Paul, Minnesota - Developmental day care for adults and a sheltered workshop.
4. UCP of Boone County, Missouri.
5. UCP of Southwest Missouri - Transportation.
6. UCP of Sac Osage Area, Inc., Missouri - Developmental day care for children and transportation.
7. UCP of Tri-County, Missouri.
8. UCP of Middlesex County, New Jersey - Sheltered workshop.
9. OCPA of East Central, Ohio (Stark, Ohio) - Developmental day care for adults.
10. UCP of Columbus and Franklin Counties, Inc., Ohio.
11. UCP of northwest Oregon - Developmental day care for children, transportation, and a referral system.
12. UCP of Wyoming Valley, Pennsylvania - Developmental day care for adults, and transportation
13. Salt Lake and South Davis County UCP, Utah.
14. UCP of Utah.
15. UCP of Salt Lake County, Utah - Developmental day care for children transportation and sheltered workshop.
16. UCP of Metropolitan Hampton Roads, Virginia.

[A brief recess was taken.]

Senator KENNEDY. The subcommittee will come to order.

I have some questions for these gentlemen. Then, we are going to do the best we can to try to move the hearing along. The witnesses have been extremely patient and kind with the changing of the chairs.

We have had some matters of considerable importance come up this morning. Now we have the action by the full Labor Committee on the railroad strike legislation. We have gotten permission to continue our hearing. Usually, it cancels such other hearings, but since we were necessarily interrupted by former President Johnson's death, and since people have come from out of town, we want to move ahead.

We will try to keep the questions short and the answers responsive and we will move along as best we can.

Let me ask you—and I would like each of you to respond briefly—to what extent the limited appropriations of this act have limited your programs. The second part of the question is, if you had additional funds, how would they be used?

Mr. BOWLING. Mr. Chairman, I think particularly in my State, the limited amount of funds has been a severe constraint in filling the gap in services. I don't feel that our State is alone in this regard. Many of the gaps in services are really complete voids. The absence of small community-based residential facilities and supportive services, such as workshops and day-care centers, are voids in services that cannot be effectively filled with the meager funding available.

Another problem is transportation. We have been able to use limited funds to fill this gap by extending the services that are available to more developmentally disabled individuals. Additional funds will be used to extend the wider range of services to more developmentally disabled people.

Dr. WATSON. It is a reciprocal problem. In Oregon, for instance, with 140-odd thousand dollars and the request for $1.5 million, it makes no difference where you start. Projects of merit never got off the ground.

The frustration of this is always with us. We are able, by the invocation of programs, to move them into other sources of funding. If we had more money, perhaps, and if there had been sufficient funds available for a UAF, developmental facilities people would not have had to work on it. So that children who came from remote areas of the State, who had no other means of access to such facilities, might have had.

The idea of developmental facilities having to fund a university-affiliated program, which is a similarly funded organization, is simply to make part of it work. As Dr. Cooke was saying earlier, the dreadful under-use of such funds means that we all become equally handicapped.

Mr. MESSNER. I think to date all we have been able to do with funds available in the States is to establish a few demonstration or model projects. These have been pitifully few, only partially filling gaps or voids.

If greater funding were available, it would certainly allow expansion of these pilot demonstration projects to other areas, and it would also enable us to establish a network—which is something that very few States have even addressed at all.

In our testimony, you will find a network in Ohio that involves case management of the protective service workers and of personnel and advocates that would seem to be an ideal that might be established in every State. However, without additional funding, it seems unlikely to happen.

Dr. WATSON. I think if greater funds were available at the National and State levels, the two features which I think are nationwide still neglected, could be amplified. One is the retrieval of intelligence data, so that ultimately the several evaluation principles for the developmental disability concept could be legitimate. This obviously needs increased funding.

Second, the role of advocates as in the Javits' bill is minimally funded if it exists at all in our States simply because of the role of the advocates, because advocates might be our greatest use.

Senator KENNEDY. Mr. Bowling, what has been the general reaction within the local groups about the endorsement of, seeking greater funding levels?

Mr. BOWLING. Many local ARC's use a noncategorical definition of developmental disabilities with some apprehension simply because the lack of funds for the developmentally disabled means that services must be spread thinner to accommodate a broader target population. ABC people feel that the effect and scope of programs for the mentally retarded will be diminished as a result.

Senator KENNEDY. The fact remains, as I understand it, that only 43,000 out of the potential 5 million are being served. I think it shows that there is an under-commitment of resources at the Federal level to do the job that all of us believe should be done. Thank you, very much.

Our next witness is Max Schneier, chairman of the Federation of Parents' Organizations for New York State Mental Institutions. Mr. Schneier is also on the Commissioners' Task Force for Committee Involvement and Consumers' Protection.

He is accompanied by Mr. Geraldo Rivera, the distinguished filmmaker who produced the film on the Willowbrook Institution. This serious documentary has contributed greatly to the dialog on this issue.

Gentlemen, we welcome you to the committee.

STATEMENT OF MAX SCHNEIER, CHAIRMAN, FEDERATION OF PARENTS' ORGANIZATIONS FOR NEW YORK STATE MENTAL INSTITUTIONS

Mr. SCHNEIER. Senator Kennedy, though your introduction of Mr. Rivera was very generous, I would like to add that Mr. Rivera is the foremost social issues TV reporter in the Nation. Mr. Rivera, by his efforts, has brought to the public's attention the plight of the retarded in the State of New York.

His stinging commentaries have helped to galvanize the legislature in the State of New York into action on behalf of the retarded. He has just been awarded the Northeast Emmy for the best TV program and has been nominated for the National Emmy in the same area.

STATEMENT OF GERALDO RIVERA, STATION WABC-TV, NEW YORK, N.Y.

Mr. RIVERA. Frankly, Senator, when I first started reporting on the problems of the retarded, I had absolutely no experience in the area. Unlike all of the previous witnesses, I am still relatively inexperienced in the technical aspects of the care of the retarded.

The purpose of my testimony, I think, is just to talk about some conditions that exist. I can only describe them in laymen's terms, I don't know about developmental disabilities and I don't know about the differences in the distinction between the moderately and mildly and profoundly retarded, but I do know when you walk into a room that is about half the size of this one that has 200 children in it and those children are smeared with their own feces and they are naked and dressed in rags and knocking their heads against the wall and there are only three or four attendants to take care of these kids, I don't have to be a specialist to know there is something wrong there.

When somebody tells me that the Federal requirement is 80 square feet for each patient, I know they are not getting 80 square feet per patient.

I want to show a part of a documentary film that we made on Willowbrook almost a year ago. Before we show it, I would like to add that we have been back to Willowbrook many times. The last time was about a couple of weeks ago. It really hasn't changed much despite the publicity of the problems of the retarded and the publicity that the institution has gotten.

That is probably the most frustrating thing of all. Again, because I asked the Federal Government to act and because I urged the passage of the Javits' bill of rights for the mentally retarded. I do so just because what I saw wasn't right.

I want to read something that I wrote, my first reaction to Willowbrook a year ago.

When Dr. Wilkins slid back the heavy metal door of B Ward, building number six, the horrible smell of the place staggered me. It was so wretched that my first thought was that the air was poisonous and would kill me. I looked down to steady myself and I saw a freak: a grotesque caricature of a person, lying under the sink on an incredibly filthy floor in an incredibly filthy bathroom. It was wearing trousers, but they were pulled down around the ankles. It was skinny. It was twisted. It was lying in its own feces. And it wasn't alone. Sitting next to this thing was another freak. In a parody of human emotion, they were holding hands. They were making a noise. It was a wailing sound that I still hear and that I will never forget. I said out loud, but to nobody in particular, "My God, they're children." Wilkins looked at me and said, "Welcome to Willowbrook."

Again, I am not a doctor or a psychologist, I just know that is not right. Willowbrook is in the city of New York, the largest city in the richest State in the 20th century and those conditions just aren't supposed to be that way. The ball has to stop some place. People have been evading responsibility. The fingers all point to the Federal Government. I came here because it has to stop here with the Javits' bill of rights for the mentally retarded.

What you are going to see is about a 7-minute excerpt from that 30-minute piece. After that, I will say a few things and that is about it.

[The film was shown.]

Mr. Rivera. In the course of making that film and over the last several months, we have toured the facilities in several States and found

the philosophies and the conditions were wildly different as we traveled around.

Over the course of those travels and as I have spoken to more and more people in the field of mental retardation, almost everybody agrees that the way to take care of people like Bernardo, who spent 18 years in Willowbrook, is not in the human warehouse, but rather in the small community-based facilities for the mentally retarded.

I have no faith, frankly, in the energy or the physical capabilities of the State to enact what is best for the mentally retarded citizens within their borders. I point, again, to New York, which has 750,000 retarded people. I think it is not right.

The Javits' bill, I think, would certainly be a step in the right direction. It might not be a perfect document, but it is the best we can get at this point. Pass it and amend it as you see fit, but conditions now are intolerable.

Mr. SCHNEIEE. I come before you today as the chairman of the Federation of Parents' Organizations for New York State Mental Institutions to plead with this Senate subcommittee to do all in your power to help S. 458 become the law of the land.

There have been and there are crimes against humanity being committed every day in the retarded institutions throughout the **United** States that have no parallel in American history.

The plight of our Nation's retarded is well known to the Congress. It was graphically brought to their attention by the late Senator Robert Kennedy after his visit to the Willowbrook State School on September 1, 1965.

That visit revealed the inhuman conditions under which the large majority of our retarded existed into national prominence and visibility. On February 28 and 29 of 1972, just about a year ago today, the Secretary of the Department of Health, Education, and Welfare sent a special Federal team to New York City to hear testimony concerning conditions at the Willowbrook State School and the New York State mental retardation program.

The team then visited Willowbrook for a firsthand inspection tour. The human conditions it found are stated on page 12 of that report and, I quote:

> Furthermore, many of the wards that the teams visited, the care was substandard and inadequate to take care of the basic health and hygiene needs of the residents. Eye examinations seem to be particularly nonexistent. Dental care was primitive and medical services available only when crises occurred.
>
> Perhaps most disheartening of all was that there were no large number of individualized treatment plans for most of the residents. Residents who had rehabilitation potential were left in wards without sufficient or well-trained staff to care for them.
>
> Furthermore, since there were so few social workers on staff, there could be no real effort to work with families or residents to plan foster care and other possible alternatives to institutionalization.

The findings of this team were as follows: (1) There was an urgent need to develop more community-based facilities as opposed to institutions. (2) There was a need for immediate action for commencing immediate screening of all residents in institutions and to develop and implement adequate standards of care for treatment and training. There should be more consumer parent participation in the planning and implementation of services to the retarded.

One year later, today, the same conditions exist. You have been shown what it is really like by Mr. Rivera. The only thing that is missing is the sickening stench which never fails to make those of us who visit these institutions experience a deep depression and also fills us with a sense of hopelessness and despair because of our inability to accept these atrocities against our fellow human beings.

The very fact that a special task force could make recommendations and that such recommendations were not carried out, points to the absolute necessity for the passage of bill S. 458, which would set Federal standards to provide for the human care, treatment, and rehabilitation of and protection of the mentally retarded.

It would be one thing if this situation had to be, if the retarded American citizens could not be helped. Even then we would have at least a moral obligation to provide the best custodial care that was possible.

Senator Kennedy, most of what you have seen need not have been. Most of the retarded can be helped back to society as productive taxpaying citizens within the limits of their habilitative capabilities. To support this statement, I quote from the 1969 Third Report by the President's Committee on Mental Retardation.

> Some three-quarters of this Nation's retarded people could become self-supporting if given the right kind of training early enough. Another 10 to 15 percent could become partially self-supporting.

The key, therefore, is to start habilitation programs early enough, before the debilitation and the dehumanization process sets in. The scenes which we have all now witnessed are the results of that debilitation and dehumanization.

The greatest potential arguments for bill S. 458, which you are considering, are contained in the 1970 Report of the President's Committee on Mental Retardation, titled "Residential Services for the Mentally Retarded," an action policy proposal.

I have given this committee several copies of this report. Some of the key statements are restated for your consideration. Despite the enlightened concepts of many leaders in the field of retardation, the inherited philosophy is too often one of isolation coupled with disease or insufficient treatment.

A reorientation of thinking will require considerable efforts as public officials and professional workers and the lay public all come to understand that the retarded can be helped by training, education, and habilitation.

The report continues: To date, concerned professionals, Government agencies, and parents of the retarded are demanding a complete departure from the dehumanizing custodial care. This new philosophy calls for a variety of decentralized residential services and a recognition of the human and civil rights of the retarded according to the nature and the degree of the individual's handicap.

In short, the trend is toward normalization, a principle emerging as an entire new approach to management and programing for the retarded. This principle refers to allowing the retarded to obtain an existence as close to the normal way of life in the residential setting.

Far too many of our present facilities consist of an impoverished living environment that is not different from the environment experienced by the prisoners of war during the past three decades.

We must begin, continue, and intensify in the Nation and in each of our 50 States, a movement to improve our residential facilities for the mentally retarded. We must make residential facilities and their programs cost-effective in terms of human life and salvage from the limbo of neglect and give the dignity of place and value in daily live and work to these people.

Does not bill S. 458 recognize and seek to begin to effectively deal with the problems just outlined and lay the foundations of a structure of services and habilitation that will implement the suggestions contained in the report of the President's Committee on Mental Retardation? We know that it does and, I am sure, that you will all ultimately reach the same conclusion.

Senator, this bill will go a long way in eliminating the psychiatric model of warehousing our retarded citizens which has been responsible for so much harm, suffering, and anguish, not only to the residents of our State retarded institutions, but also to the parents and the relatives of these people. Yes, they too have also been brutalized in mind and spirit in the process.

Parents all over the country have recently turned to the courts for needed assistance since the Congress of the United States has not felt, until this point, the necessity to set basic standards and procedures for the States to follow. The Congress, by its inaction, had advocated its responsibility to the courts.

This bill gives the Congress the opportunity to fully shoulder these responsibilities and legislate the needed standards and procedures that will forever end the intolerable conditions in our State schools for the retarded.

You have left the job in prior years to the States. They have shown for the most part that they cannot and will not do what is necessary without Federal assistance and Federal supervision. Bill S. 458, except for the inadequately contemplated funding, effectively addresses itself to this problem of State failure and inaction and certainly gives the States sufficient time to comply with the standards and procedures contained therein, 5 long years.

However, we would like to amend page 10, paragraph C, beginning with line 23, to include the necessity of a State to submit to the Secretary of Health, Education, and Welfare a 5-year plan to meet the standard promulgated under part C, 180 days after the passage of this act with a yearly timetable of anticipated progress.

Such a plan would have to be approved by the Secretary. The failure to submit such a plan, the failure to gain the Secretary's approval of a plan and the failure to make progress according to the submitted plan, would terminate the eligibility of any residential facility to receive payments, either directly or indirectly under any Federal law.

In conclusion, Senator, there have been several great societies and civilizations in the history of mankind. Most of them have disappeared from the face of the Earth. Their decline and fall have one mutual set of circumstances. That is, they all stop or significantly decreased their programs to provide for the sick, their needy, and their handicapped.

It seems that no civilization of peoples can continue to prosper and flourish if they forsake those who cannot help themselves. The very moral fiber of a society erodes when this happens with the resultant decay and collapse.

Our President and our Congress would do well to remember this lesson from history which also follows the God-given directive, "Thou shalt be your brother's keeper."

Thank you.

Senator KENNEDY. Thank you, very much. It is a very moving film that we have seen. Mr. Rivera, I want to thank you very much for your willingness to share it with us here in the committee as you have shared it with millions of people who have seen it on the television program.

I commend the network for permitting and encouraging you to work in this area. In these days when the networks are under fire, it is a credit to the network for encouraging and pursuing it.

Here, when we are supposed to be asking you questions, you have asked the $64 one and that is "Why?" We are wondering why and also where the responsibility lies. Obviously, there is enough blame for all of us, but I can't let the occasion go by without pointing out that in spite of the request for the administration spokesman to come down here and help us with the development of this legislation, they chose not to testify today.

Had the administration testified, I would have asked them why it has taken 27 months from the enactment of the legislation for the first National Advisory Council to be held. I would also have asked what steps, if any, are being taken to assure prompt renewal of the charter. I would have asked why the budget level has been held at a level affecting 43 million when we have 5 billion to be served. I would have asked who would meet the needs of the people and I would have had those questions responded to.

We are going to take those and others and request the administration's answer in writing. If they can't come down here, we will go to them.

We see the enormous kinds of frustrations that many of the States are feeling. My own State requested some $6 million in programs and received $240,000. New York received 1.4 million.

We have seen authorization in excess of 120-odd million dollars and still the same figure comes back in this year.

Perhaps there is a good deal of blame for us all, in the sense that we haven't been able to get the people really aroused and interested in these problems. For the life of me, I wonder why we can't when we see a film like the one we have just seen; however, it is tragically true.

There are so many other different problems that are of tremendous importance as well. Mr. Rivera, you have said it in the film, and Mr. Schneier has spoken of it. This says a great deal about our society. I think that is really an indictment of our times. Mr. Schneier, I would like to address a question to you as someone who has tried to work in the entire health area and who last year tried to develop some legislative approach to our health maintenance legislation. It seems that the specific requirements of standards are very precise in Senator Javits' bill. The question is whether they are sufficiently flexible to take advantage of the newer kinds of treatments for those afflicted by developmental disabilities.

Do you have a feeling as to whether we ought to have as much precision on this as we have? The bill goes to the extent of suggestions about the number of times people must brush their teeth. That will be one of the arguments we will hear.

I would be interested in your feelings on that.

Mr. SCHNEIBR. No doubt, the input from the different professional disciplines is evident in that in every area every "t" was crossed and every "i" was dotted.

We have a crying need at this moment for two things: An improvement in the basic custodial care and the immediate institution of individualized treatment plans. These are the two basic needs, as I see them, (1) Better custodial care immediately, because lives are at stake. In one building in Willowbrook, there were 10 women who died in 1 year, which was 5 times the normal death rate in the city of New York. So, we have a need for help immediately in that area. (2) Each resident must be thoroughly evaluated and given an individualized treatment plan. That, to me, would be the important thing to follow through on.

Senator KENNEDY. Thank you, very much. We appreciate your testimony and we are grateful to you for allowing us to share your experience with us.

Our next witness is Mr. David Hartman. Mr. Hartman is best known as an actor of great reputation, particularly, in his role on "The Bold Ones" television series. In the process of doing research, for a segment of "The Bold Ones" which dealt with muscular dystrophy, Mr. Hartman became interested in the problem of the handicapped. He has worked closely with Jerry Lewis, national chairman of the Muscular Dystrophy Association, and I am sure his testimony will be of great help to the committee.

Accompanying Mr. Hartman is Dr. Leon Charash. He is the chairman of the Medical Advisory Committee of the Muscular Dystrophy Association of America.

STATEMENT OF DAVID HARTMAN, NATIONAL VICE PRESIDENT, MUSCULAR DYSTROPHY ASSOCIATION OF AMERICA

Mr. HARTMAN. Thank you and good afternoon, Mr. Chairman. On behalf of all the members of the Muscular Dystrophy Association of America, I would like to thank the committee for inviting us here today.

I would like to introduce Dr. Charash who is, as you said, the chairman of the medical advisory committee. He is an assistant clinical professor of pediatrics of the handicapped children's committee. He is a senior consultant to the Bureau of Handicapped in the city of New York and Nassau County Medical Center.

For the past 4 years, it has been my privilege and a challenge *to* have not only played the role of a doctor on television, but to have become deeply involved in the basic medical research for our show. Perhaps the most important part of my education has been to get a firsthand and deeply personal understanding of the desperate needs of hundreds of thousands of people in our country stricken with many forms of chronic disabling diseases.

Perhaps no episode in "The Bold Ones" series had as much meaning for me in this regard as the one we did dealing with muscular dystrophy in which children actually suffering from this tragic, handicapping, neuromuscular disorder appeared. The episode was directed by a talented man of extraordinary sensitivity—Jerry Lewis—who for

23 years has led America's volunteer battle against muscular dystrophy and related neuromuscular diseases as national chairman of Muscular Dystrophy Associations of America. The weeks I spent working with Jerry and the youngsters he refers to as "his kids" made me a convert to his cause.

As am MDAA volunteer at first, and later as a vice president of the association, I've gained a keen understanding of the tremendous problems faced by handicapped youngsters and their families—and just as keen an understanding of the importance of voluntary health agencies like the one I serve.

MDAA performs a vital dual function for the hundreds of thousands stricken by the diseases covered by its programs—most of whom are children. It supports a worldwide research effort aimed at discovering effective treatments or cures for dystrophy and related diseases and—through some 300 chapters and more than 110 comprehensive clinics across the Nation—it provides patients with a wide range of free services which lengthen and enrich their lives—including diagnosis, medical management, physical therapy, counseling, orthopedic equipment, and educational, recreational, and transportation programs. To finance these lifesaving programs, the association annually mounts one of the most ambitious and effective fundraising efforts on the American scene—public response to which has been so great that it has been possible for us to double program service expenditures in the last 4 years alone.

The Muscular Dystrophy Association of America is one of the finest examples of American voluntary action which exists today, and yet—as an increasing number of volunteer organizations like ours are discovering—voluntarism alone, as vitally important as it is, just isn't enough. It is especially ironic that MDAA's own effectiveness is one of the principal factors which is making it increasingly difficult for it to do its job.

Improved medical management techniques and expanded clinical programs have increased patient longevity and activity; rehabilitation and education programs have raised patient's expectations. Or, to put it most succinctly, hope has been created where, once, there was none—the hope of our patients that they may know the same educational, occupational, and social opportunities that health Americans look upon as a birthright.

Add to this an increase in our patient population proportional to that of the population at large and it becomes easy to understand why—as dedicated as we are to the concept of individual responsibility and private sector action—we have come to believe that fulfilling our growing responsibilities in the future must involve help from the public Sector.

It is in recognition of this inescapable fact that we believe it of the utmost importance to continue, and moreover, to expand the Developmental Disabilities Services and Facilities Construction Act. This law has done so much for so many in the decade of its existence. The rug cannot be pulled out from under its beneficiaries now. And there is solid precedent in the amendment of 1970 for ending the present law's arbitrary limitations to certain neurologic disorders—precedent for extending its benefits once again—this time to all children suffering from chronic neurologic, neuromuscular, and muscular diseases which have a major disabling effect on their overall development.

Muscular dystrophy and those related conditions embraced by the Muscular Dystrophy Association of America's programs are characterized by disabilities which have associated pathology in both the peripheral and central nervous systems. Affected children are unable to ambulate, play, attend school, or socialize in a normal manner. These youngsters frequently manifest learning difficulties as a result of poor eye-hand coordination, impaired visual perception, and other defects in their cognitive processes and cerebration.

The child with dystrophy attends the same day camps, seeks help at the same treatment centers, must go to the same special schools, and participate in the same other medical, social, and vocational programs as children with cerebral palsy. Just like the youngster with cerebral palsy, the young muscular dystrophy victim suffers severe physical, experiential, and scholastic problems resulting in chaotic damage to growth and development.

And yet dystrophy and related neuromuscular diseases of childhood are not—like cerebral palsy or epilepsy—specified in the 1970 amendment, despite this functional identity. It is, therefore, unclear whether MDAA could qualify for a Federal grant under the existing law. But the welfare of the hundreds of thousands of children to whom our association is committed, who face the same problems and require the same services as those whom the law specifies, makes it vitally important that their eligibility for help be unambiguously stated in the law.

In the fiscal year ending March 31, 1972, MDAA spent $4,900,888 on direct medical services to patients, and $3,563,881 on scientific research. This is an extraordinary achievement. However, there are many additional needs which remain unmet—residential and custodial care, intensive nursing attention, rehabilitative surgery, and hospitalization for other than diagnostic purposes are just a few. In addition, new research leads demand the speediest possible followup and projected new service programs cry out for funding. With medical costs spiraling, the only source of funds of the magnitude require to breach this widening gap is the Federal Government.

On behalf of my fellow officers and the board members of our association, who include such national leaders, in addition to Jerry Lewis, as Dr. Michael E. DeBakey, UNESCO Ambassador Louis Gore, North Carolina Governor Robert W. Scott, Congressman Herman Badillo, AFL-CIO president George Meany and national union presidents James T. Housewright, William H. McClennan, James H. Rademacher, and Frank E. Fitzsimmons; on behalf of the legions of volunteers who have been inspired by their leadership; on behalf of the voiceless children we serve and their families; and on behalf of the millions of Americans in communities across the Nation who have rallied to our cause, I urge you to continue this Nation's commitment to hundreds of thousands of children mentally retarded and handicapped by cerebral palsy and epilepsy. But we urge you, as well, to frame the amended designed to accomplish this end in such a way as to guarantee our commitment to the additional hundreds of thousands of developmentally disabled children we serve—youngsters functionally identical to those specifically covered by the existing law whose arbitrary disenfranchisement would be wholly without logical, social, medical, or moral justification.

Senator KENNEDY. Thank you, Mr. Hartman. You are to be commended to take the time to come here as well. I understand you came in last night from the west coast for this hearing. I think it is an indication of your own deep concern for the program.

Mr. HARTMAN. Thank you, sir.

Senator KENNEDY. I am sure you have a lot of other responsibilities as well, and I know of the great scheduling difficulties which you had to resolve in order to be with us today. I think you are rendering a great service.

Let me ask you about the other governmental funds that you receive. Do you get any other governmental funds?

Mr. HARTMAN. No, sir; we don't.

Senator KENNEDY. Have you made any kind of assessment about funds that would be necessary to meet the needs of the organization?

Mr. HARTMAN. The problem is this. We have achieved a great deal in the past 23 years. As a result of having made great strides in patient care and research, the problem is now compounded. We now need more funds to find the answers sooner.

The two basic areas that are most important are basic medical care and research. The fact is that the sooner we find an answer to the basic problems of neuromuscular disease, the sooner we will be able to spend less on patient care.

At this point, we desperately need immense amounts of money for research until we find the answers.

I think it boils down, briefly, to the two basic areas of research and patient care. The sooner we find the answer, the sooner we wouldn't have to spend that money.

Senator KENNEDY. It is generally considered that your organization has one of the most effective groups of volunteers in the Nation. How do you account for that?

Mr. HARTMAN. I think, basically, it is just over a number of years and that a great many people caring so much that they spend and are willing to spend and care enough to spend the amount of time and effort involved to get other people involved.

It really is incredible. When I started 3 or 4 years ago, I could not believe the mobilization—if you will—of literally millions of people in this country. The fact that is exciting to me is that everybody doesn't have to give all of their time, every day, every week. You can give a few minutes a year or a day a year.

There have been created by the Muscular Dystrophy Association, so many ways for people to get involved that it has worked beautifully.

Senator KENNEDY. Do you require some residential treatment for young people in this area? Do you have any view about trying to establish some standards?

Mr. HARTMAN. I would defer that question to Dr. Charash.

STATEMENT OF LEON I. CHARASH, M.D., CHAIRMAN, MEDICAL ADVISORY COMMITTEE, MUSCULAR DYSTROPHY ASSOCIATION OP AMERICA

Dr. CHARASH. Yes, Senator Kennedy, the unique thing about muscular dystrophy is that, for the most part, in contrast to some of the other problems that have been described, it is relentlessly progressive and

leads to death. So that the ultimate outcome is one of a fatal result from the inception.

This modifies, to some extent, the question of the requirement for long-term custodial care. I think Mr. Hartman has indicated very comprehensively the concern of the association.

There is one very brief item I would like to ask you to address your attention to, sir. That is paragraph V of section 102 of the amendment of 1972. In this legislation it states that the term "developmental disabilities" means the disability attributable to mental retardation, cerebral palsy, epilepsy, or other neurological diseases found by the Secretary to be closely related to mental retardation or to require treatment similar to that required by mentally retarded individuals, which disability originated before such individual attains age 18 which has continued or can be expected to continue indefinitely and which constitutes a substantial handicap to such individual.

MD begins and gets progressively worse. It produces great hardships on the patient, as Mr. Hartman stated. The child in a clinic or in a regional or vocational center with cerebral palsy or MS in a wheelchair are indistinguishable. They require identical services.

Our own people, including Dr. H. Huton Merit—Dr. Merit, as you know, is the chairman of the Department of Neurology at Columbia Medical Center

Senator KENNEDY. A quorum is needed to get the antistrike bill out of committee. I am going to have to go up to the floor. Again, I apologize.

We will recess now until 3:30. Senator Javits will be coming back at 3:30. He has pledged that he will stay here until the last witness has had a chance to offer testimony. It shows a sense of bipartisanship. I regret very much that we did not have the other people on the committee here.

This has happened because of the national strike situation. There is no reflection or indication of lack of interest of this committee in this area.

I want to thank all of you very much for being here and for your testimony and comments. We are going to get a bill and we are going to pass it into law. When you get out with all those volunteers we want you to just raise the roof. That is how to get the job done. If you have any other information, we will be glad to receive that for our further review.

There may be some of you who cannot stay. If you will submit your statements and any other information you might have, we will put it in the record and make it a part of the record.

The committee will recess until 3:30.

[Whereupon, at 2 p.m., the subcommittee recessed, to reconvene at 3:30 p.m., the same day.]

AFTERNOON SESSION

Senator RANDOLPH [presiding]. The subcommittee will be in order.

In 1970 the enactment of the development disabilities program marked a new approach to a pressing and complex problem: The need to provide adequate services and facilities to mentally retarded and other developmentally disabled persons. The Federal Government undertook at that time a responsibility to participate in the planning

and implementation of such a program. The partnership in this endeavor is not only Federal, State, and local in the usual sense of the words, but also a coalition of many diverse federally funded programs that provide services to persons in need. The extent to which these other programs can serve the developmentally disabled form a crucial part of the total purpose of this legislation; the act requires the coordination and integration of all Federal activities that can contribute to the well-being of these severely handicapped persons whom we have categorized as developmentally disabled.

The act is designed to place a greater than usual share of the responsibility for planning and priority-setting with the States. Local communities have a strong voice in determining needs and developing service delivery systems. The effective implementation of the act contributes to goals shared by all of us who are concerned with providing a better life for the severely disabled:

Participation at every level of government—all concerned groups;

Elimination of narrow diagnostic categories that deny services to persons in need;

Recognition of the United States of our severely disabled citizens, who cannot benefit from the usual service programs designed to prepare them for the job market;

Recognition of the fact that all social welfare and education programs must contribute to the development of a comprehensive and meaningful service program for the seriously handicapped.

This act also recognizes the important role of higher education in any national effort to serve the handicapped. The university-affiliated facilities program is training service workers and cutting across disciplinary lines to assure the preparation of adequately trained professional personnel who can work in local communities. These universities are also working closely with the States in order to assure the development of a coordinated, effective program for all the severely handicapped.

The President has urged us to implement two major goals of his administration: Reduction of the incidence of mental retardation and reduction of the number of persons confined to mental retardation institutions. Legislation such as the Developmental Disabilities Act is one of the cornerstones to the construction of programs that will meet those goals. It is for that reason that this Congress, this committee and these Senators have taken the initiative in introducing an extension of the Developmental Disabilities Act. Be assured that we will make every effort to do our part to improve the well-being of the disabled, and assure the rightful place in this society for all our severely handicapped citizens.

The next witness represents the New York State Association for Retarded Children.

Will you please proceed.

STATEMENT OF JOSEPH T. WEINGOLD, EXECUTIVE DIRECTOR, NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

Mr. WEINGOLD. Senator, I am Joseph T. Weingold, executive director of the New York State Association for Retarded Children Inc.

This is an organization of parents and friends of the mentally retarded in existence since 1948.

It has always been our contention that the institutional problem as we know it, cannot be solved by amelioration of institution conditions only. If we are ever going to solve the problem of institutionalization, it must go together with community services.

As for myself, I would be glad to submit to the committee a plan for the phasing out of all institutions for the mentally retarded over the next 10 or 15 years.

As for S. 458, the so-called Javits bill of rights for the mentally retarded, I think this is a brilliantly conceived piece of legislation. I think we would be wasting time to carp about the standards that it sets up.

As I understand and read it, those standards are minimal. I certainly don't see how anybody can object to minimal standards for this kind of situation. There are those who have come before the subcommittee and said we should leave it to the Secretary of Health, Education, and Welfare to write those standards.

I can only say that my past experience is that it will be 27 months before they are written and then they will be so imprecise that we won't know what he is talking about.

I think it is a good idea if the legislature has taken the time and the effort and the staff to think of standards; to once and for all put them into legislation. I think it is just as easy to change legislation as it is to change the regulations written by the Secretary.

I have only one suggestion. Section 1208 A. of the act reads, "the Secretary is authorized to make grants to any private or public nonprofit agency to meet the costs of development, et cetera, of community resources and community living situations for the mentally retarded other than living-in residential facilities as alternatives to institutional placement for the mentally retarded."

I don't see why living-in residential facilities were excluded. I think that should read, community living situations for the mentally retarded "including living-in residential facilities such as hostels, half-way houses or community residences."

In my opinion, this is the first real ray of hope we have seen for getting the States to do what they really ought to do for the mentally retarded, who are now in institutions and will have to be there for some years to come. We are heartily in favor of this bill as written with this small change that we have suggested.

As for S. 427, this bill, as I understand it, merely provides for the extension of the Developmental Disabilities Services and Facilities Construction Act, Public Law 91-517. As such, of course, we must be in favor of this bill because, as the saying goes, this is the only game in town; so, we must play it.

On the other hand, I think we have to take a hard look at what this bill tried to do in the past and what has happened to it, and maybe what we ought to do with the bill.

When the original bill was introduced, our association was not in favor of it as it was written. We were told that, unless we went along with this, we were going to get nothing in spite of the fact that the mental health part of that bill was not touched at all. So, we went along with it.

It is interesting to note that the administration, testifying on the first bill, said, "Do not add other categorical handicaps to this bill because we haven't even got enough money for the retarded. If you are going to add other handicaps as well, we are not going to get half enough money."

This, of course, was not heeded. The bill passed and the President signed it.

What have we gained? In my opinion, we have a bill here which, because of its imprecise language and regulations—which are badly drawn and as imprecise as the bill itself—we have a situation where the handicapped, themselves, don't know whether they belong in it or they don't belong in it.

In the new regulations of 1972 that the Secretary promulgated, he lists I don't know how many disabilities who want to get in on the act. I used that word in its technical sense. He said, "I am going to appoint a task force to tell me all about this." That is the way it was left.

Let's see what has happened with this bill as it was written. In New York State, we received $1,400,000. We had a committed $300,000 for the previous year grants. So, we had $1,100,000 and, although discouraging everybody from putting in applications, we still had $14 million of applications.

What happened was that we had disability at the throat of every other disability and my Disabilities Council, all trying to get the limited buck.

Even if, for mental retardation, epilepsy, and other neurologically caused conditions, we had 5 times or 1 times or 20 times this money, we would still have a problem.

As I see it, from the realistic point of view, all we can expect is what we are told we are going to get, which is about the same as last year, or maybe a little more if there is a real hard fight in the Congress. I don't see what else we can do except to leave it as it is, as imperfect as it is, and see, in the future, whether, indeed, we are going to include everybody under this umbrella, and then close the umbrella on all the children, or whether we are going to go the road of categorical disabilities, as we have in the past.

It is interesting to note that only mental retardation was taken out of the original bill. Mental health was left strictly alone. I wonder why mental retardation only is lumped with other disabilities in one bill. It is a rhetorical question.

To be perfectly frank, as the bill now stands, it means very little to us in my State. My association in 1971 served 16,000 mentally retarded persons. They were blind; they were deaf; they were autistic; but the presenting problem was mental retardation. We spent over $14 million. We shall continue to serve all these disabilities if they are retarded, with or without this act.

I would like to make several suggestions. One, that a real hard look be taken at this bill in terms of what disabilities are, and should be, included. From what I have said, you can see that I feel that mental retardation as a category must be prominent in this. It is greater than all the rest combined.

The second thing is, I think, we ought to take a hard look at the carryover from previous bills of 1970 on reducing amounts of Federal

aid, as the grants go on. This is nonsense. We have organizations who can't afford to put up the matching 30 percent. We have organizations who are low on funds and should have programs, but didn't apply because they couldn't put up the matching money.

It seems to me, therefore, that a bill like this may well say to a State: "If you want *x* million Federal dollars, you must put up *y* amount of State dollars." In other words, there must be a partnership between the State and the Federal Government.

I don't want to be negative about other disabilities, but the problems of the physically handicapped are especially different indeed from the mentally retarded. If this is recognized, I think we then can go into programs, examine the Federal programs, how they relate to all these disabilities, and make sure everybody gets what he needs—but not necessarily under this one umbrella.

I think we have found here a dumping ground which has resulted, I think, in very bad public relations between the agencies, in spite of the fact that we had three national organizations represented here in all sweetness and light.

I am on the frontline of services in my State. So is cerebral palsy and so is epilepsy. We get together and talk about this. I might say that none of us is very happy about what is happening with this. Nevertheless, we heartily support the extension of the bill, but because that is all that is before this Congress. However, we also suggest a very hard look be taken at what this bill says, what it should say, and how we are going to find it. Thank you, Senator.

Senator RANDOLPH. And I thank you. You talked about the broadened definition that would result in reduced services to the mentally retarded. Can you give to the subcommittee members a figure, or an idea, of the magnitude of that reduction?

Mr. WEINGOLD. I don't know whether I follow you.

Senator RANDOLPH. I thought you said a broader definition would result in reduced service programs to the mentally retarded.

Mr. WEINGOLD. Yes; that is right. It is very simple arithmetic. If we have $21 million for three handicaps and the same for nine handicaps, it is obvious that each one of the original three is going to get less of that $21 million.

I dont see how we can escape it. The magnitude of that depends on how specific the bill is, and who has the clout to get the money. I don't think that is the way handicaps should be served.

Senator RANDOLPH. YOU mean the wheel that squeaks the loudest is the one that gets the grease? Is that what you are saying?

Mr. WEINGOLD. Yes. It is unfortunate because it puts us in the position of concentrating more on organization than on services.

Senator RANDOLPH. One final question, Mr. Weingold. What technical assistance does the Department of Health, Education, and Welfare offer to the States in the implementation of this complex authority which we are discussing?

Mr. WEINGOLD. In *my* region of New York, region 2, the people in HEW have been very nice and very helpful. However, I might say that I don't think they can read the English language any **better than** we can, and the regulations are confusing, imprecise, and **no** one can say for sure what they mean. **So,** they come **to us and we** sit **down together, and try to** see **what the thing is saying.**

Furthermore, in the regulations and in the bill itself, there are about 14 or 15 or 16 categories of services. We, the advisory council, are supposed to pick out those that we think most important. It is curious to note that we picked out four or five in New York State; but, when Dr. Boggs, who is the head of the National Advsory Council, come to see us, she stressed a category that we never picked; transportation.

How can HEW tell us that this is more important than the other? She could. She was more help to us than HEW, I must say.

Senator RANDOLPH. Thank you very much, Mr. Weingold. As you know, I am as concerned as you are, and you are a leader and policy-maker in this field of the mentally retarded.

In whatever we attempt to do, we must not have it too heavily weighted in one direction. I think your tesimony is helpful and you add a point of controversy, which is not bad at all. Thank you, sir.

Mr. WEINGOLD. Thank you, Senator.

[The prepared statement of Mr. Weingold follows:]

An organisation of parents and friends to help all the mentally retarded. wherever they are, regardless of race; color, creed or age

NEW YORK STATE
ASSOCIATION FOR RETARDED CHILDREN, INC.

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JOSEPH T. WEINGOLD, Executive. Director

STATEMENT OP

JOSEPH T. WEINGOLD, EXECUTIVE DIRECTOR
N.Y.S. ASSOCIATION FOR RETARDED CHILDREN, IDC.
ON S. 427 and S. 458
FEBRUARY 8, 1973

SENATOR KENNEDY AMD MEMBERS OF THE SENATE SUBCOMMITTEE ON THE HANDICAPPED, I am Joseph T. Weingold, executive director of the New York State Association for Retarded Children, Inc. This is an organization of parents and friends of the mentally retarded in existence since 1948. Included in our 56 chapters are groups of parents and friends representing the retarded residents of the institutions of the State of New York. We have about 27,000 family members. I am also a member of the Advisory Council on Developmental Disabilities of the State of New York and of the Board of Visitors of Willowbrook, State Sohool.

X think it is a happy circumstance that this Committee is considering S. 427 and S. 458 together. The latter deals with standards, rights, and improvement of conditions in the various residential institutions for the mentally retarded and the former purports to deal with some federal aid for community services for the same group, as well as others. These must go hand-in-hand. Too often do we see isolated pieces of legislation dealing with the problem that is uppermost at the moment. Generally speaking, this

is the plight of the retarded in the institutions. The answer, however, lies not only in the institution itself and the services offered to the residents there, but in the vast array of services that must be implemented in the community (a) to prevent institutionalization, and (b) to provide that climate of acceptance and programs which will facilitate the return to the community of those in the institutions who are there only because of the lack of community alternatives.

I shall address myself first to the Bill of Rights of the Mentally Retarded, S. 458. This is a brilliantly conceived piece of legislation drafted with consummate skill and would, if implemented properly, indeed create the possibility for a new world for those unfortunate mentally retarded who must be separated from their homes and live, perhaps for long periods of time, if not for life, in institutions.

There are those I understand, who feel that the standards that have been provided by this bill don't go far enough. To those perfectionists I can only say that these are, as I understand them, minimum standards, and certainly for almost every institution in this country, represent vast advances over what now exists. We must dismiss this cavil.

I am delighted to see under Section 1208 that the Secretary is authorized to make grants for alternate programs of care, alternate to institutionalization. I have one direct suggestion to make that Section 1208 A. that now reads "the Secretary is authorized to make grants to any public or private non-profit agency, etc. to

meet the costs of development, etc. of community resources and community living situations for the mentally retarded other than living-ln residential facilities (emphasis mine) for the mentally retarded" be amended to read "and community living situations for the mentally retarded including living-in residential facilities as alternatives to institutional placement for the mentally retarded."

I cannot understand the omission of living-in residential facilities in the community, such as hostels, half-way houses, group homes, etc. which are an absolute necessity for the adult retardate who still needs some supervision, and who, without it, will go into an institution. These should be included absolutely if we are going to think of alternative programs for the care of the mentally retarded.

I could, of course, go into detail about this or that word, but it would serve no useful purpose. All I can say is that in my experience this is the first real bright ray of light that we have seen for the 200,000 mentally retarded who unfortunately must be in state institutions. The inclusion of alternative programs of care is most salutary and indicates an awareness of the totality of the problem that we can only commend without reservation.

I wish we could say as much and as well for S. 427. This bill merely provides for the extention of the Developmental Disabilities Services and Facilities Construction Act, the well known, if not notorious, P.L. 91-517. We must be in favor of this bill, but only because it is the only game in town and we must play it if we are

going to play at all. Having said that, however, we must repeat our opposition to the concept of a Developmental Disabilities Services and Facilities Construction Act that we voiced when it was first presented to the Congress.

When the original bill was introduced we were told by our National Association for Retarded Children and others that unless we went along with this extension of services to handicaps other than the mentally retarded we would get nothing. It is interesting to note, however, that in the testimony on the original bill the administration warned very strongly that the extension of the original bill to handicaps other than the mentally retarded would spread a limited amount of money to more and more handicaps under one umbrella and that, in fact, the mentally retarded would end up getting less than before. This is an historical fact. For the last 100 years we have seen that when the mentally retarded are included in an overall or umbrella approach with other handicapped they end up with the short end of the stick and I can say categorically that under the Developmental Disabilities Services Act the retarded are ending up with the short end of the stick as well.

This warning of the administration was not heeded. The bill passed and the President signed it. As a matter of fact exactly this has taken place. We do not see double, triple or quadruple money that was previously appropriated for the retarded now being spent on developmental disabilities; on the contrary if we include the other developmental disabilities there is less money spent per child

or person than before.

What then have we gained? Nothing but an arena for handicapped to fight with handicapped for a limited dollar, ending in dissatisfaction all around. The imprecise language of the bill together with the apparent reluctance of the Secretary to define it properly in regulations leaves all of us up in the air. It is well and good to talk about "children" but the term leaves me cold. I am interested in the child because when we speak of children we are creating the umbrella which we can close over them and hide them from view. As for mental retardation, which is my primary concern, this is an act which takes away from them their birthright. The mentally retarded in numbers are twice as many as all the other crippling conditions of childhood put together, ten times as many as cerebral palsy, fifteen times as many as blind, almost ten times as many permanent polio. But under the Developmental Disabilities Act, all are treated equally no matter what their needs, and so the most needy of the needy and the lowliest of the lowly and the most neglected of the neglected, the mentally retarded, are further relegated to a limbo of developmental disabilities.

If only the authorizations and appropriations and release of funds had been at least 10 times as much as we now have, perhaps we would not have had what almost to a life and death struggle for the buck, but we know this is not so. And we can anticipate that we are going to have more of the same this coming year, and for some years to come .

(statement on S. 427 ana S. 458 - Sen. Subcommittee on the Handicapped)

In New York State we received $1,400,000 for this year under the Developmental Disabilities Services Act. We had a carryover of $300,000 from the year before for previous grants, leaving $1,100,000 to distribute. We received $14,000,000 worth of applications but because of the imprecise language of the law and the regulations all kinds of disabilities with no real connection with the language of the law clamored for this limited dollar. It is interesting to note that mental retardation does not limit itself to mental retardation without cerebral palsy or epilepsy or other neurological conditions. In New York State our 56 chapters served in 1971 - 16,119 mentally retarded individuals and spent $14,161,813. Very little of this, a mere pittance, came out of developmental disabilities money. Of these 16,000 served there were also blind retarded, deaf retarded, cerebral palsy retarded, retarded with epilepsy, brain injury and any number of a hundred other accompanying handicapping conditions. On the other hand, if a mentally retarded child wanted physical restoration services under the Crippled Children's act they could not get it although cerebral palsy could. It was not until we enacted legislation in New York State stating that no child shall be deprived of a physical restoration service under the Crippled Children's Act solely by reason of the degree of mental retardation that any semblance of services for this deprived population was possible. I do not think I have to labor this point except to say one more word. Under the guise of serving many disabilities, in effect we have a bill here that offers in one bill categorical aid to the handicapped.

We know that was not its purpose, but that is the way it is being implemented. If we are going to serve categories then we should have separate legislation for similar or identical categories and mental retardation should not be submerged into nice nelly terms such as developmental disabilities putting it back into the closet from whence it took us so many decades to extract.

When we add to this the fact that mental health was not touched at all; that it was left as it was in the original bill, then we really have to wonder what the devil is going on.

I urge, therefore, on behalf of the parents and friends of the retarded in my state, on the basis of our experience with developmental disabilities, the law, the regulations, the implementation by the Secretary, and the Division of Developmental Disabilities in Washington - that a hard look be taken at this law; that it be re-written in the future and give to mental retardation as a discrete category the tools with which to create and foster those community services which are of absolute necessity if we are to make a dent in the institutional problem. Nor would the other handicaps be deprived - as all would be included if functioning at a retarded level.

The institution is a confession of society that it has failed to provide in the community what it should have provided. The Javits bill at least tries to make a better life for those who have been condemned to this existence but what I consider the companion bill, the Developmental Disabilities Services Act does not do what it should

do for the mentally retarded. I do not wish to be negative about other disabilities but the problems of the physically disabled without mental retardation are far different from those of the mentally retarded with physical disabilities or without physical disabilities. If this is recognized, we will not have what I consider to be the nightmare of the Developmental Disabilities Services Act. We have not seen the end of this. We have but to look at the regulations the Secretary put out in 1972 when he lists the various disabilities that went into this Act such as autism, learning disabilities, whatever that is, dyslexia (inability to read) spina bifida, childhood schizophrenia, and minimal cerebral dysfunction, whatever that is. Nor is this the end. I could name 20 or 30 others who might want to get into this. Where is it going to end and what will happen to the mentally retarded. This legislation was not intended to be a catchall, but that's what it is. We must have the courage to say it was a mistake, a well intentioned mistake by well meaning people who just did not understand the dynamics of community response for the needs of the mentally retarded.

Senator RANDOLPH. May we have the next witness?

STATEMENT OF DENNIS E. HAGGERTY, ESQ., MEMBER, NATIONAL ADVISORY COUNCIL ON DEVELOPMENTAL DISABILITIES

Mr. HAGGERTT. My name is Dennis Haggerty and I am a member of the National Advisory Council. My remarks today are to be directed toward S. 458 and not the former bill S. 427. The reason for that is we began this morning with the chairlady of the National Advisory Council, Elizabeth Boggs, and she covered that very well.

On my right is Donald Bartlette from Minneapolis, Minn., and Clifford Poetz. The latter represents one of the consumers of the bill we are talking about. I think he is the only consumer to have appeared before this committee today.

Thank you for the opportunity of my appearing and presenting some brief remarks on Senate bill 458. This bill represents legislation whose time has come. Just as a Bill of Rights for citizens was necessary after colonial oppression was experienced by our forefathers, so now is a bill of rights for the mentally retarded necessary. This latter group has experienced oppression including dehumanization, loss of liberty, sometimes loss of life for many years. There is one difference however, the retarded cannot speak for themselves, they must have others speak for them.

In 1961, President John F. Kennedy said: "The true measure of a society can be seen in what it does for its members who are least endowed." It is difficult to imagine any group in society who fit the description of "least endowed" more appropriately than the retarded.

I speak to you today on Senate bill 458, wearing several hats. One, as a member of the National Advisory Council on Developmental Disabilities and a consultant to the President's Committee on Mental Retardation, a successor committee to President Kennedy's panel. I am now serving in the latter capacity into a third administration.

The other hat is more personal, if that be possible, as a parent of a mentally retarded boy now aged 14; and as a lawyer. A parent who placed his child in an institution for the mentally retarded and watched as his will to exist seemed lost—a lawyer who spearheaded an investigation of one of the larger institutions for retarded in the Northeast United States and experienced the frustrations when unable to match conduct of institutional personnel against a norm in order to demand accountability. In fact, the only accountable areas in which one could find comfort were those provided by the Federal legislation under the hospital improvement project (HIP) and the hospital in-service training (HIST) programs.

This failure to hold people accountable for conduct where standards did not exist was the reason for opting for a class action suit to establish the right to education. State standards for the delivery of education were available. In a class action, we felt it better to go with the educational first.

The now pioneering effort of the right to education suit in the Federal court in Pennsylvania has blossomed into approximately 32 legal actions throughout the Nation involving right to treatment, right to education, or prevention of peonage.

Legislative action would prevent most of this litigation—litigation which has resulted from frustration wrought by unkept promises.

Legislative activities in the area of reform and improvement of public and residential facilities for the mentally retarded should be consistent with Presidential and Health, Education, and Welfare goals on institutional reform which results in deinstitutionalization. New programs in this area should relate to, but not duplicate, existing developmental disability structure.

The proposals contained in Senate bill 458 would provide for the humane care, treatment, and habilitation of the mentally retarded in residential facilities through the establishment of quality standards and Federal support for the implementation of those standards.

In recent years, public attention has focused on the conditions which existed in a number of State residential treatment facilities for the mentally retarded. Many of these facilities are understaffed, overcrowded, and isolated from the community. The publicity generated by these developments, that is investigations and litigation, has awakened the public to the need for immediate drastic improvements in all our States providing services to retarded children and adults.

I have heartily endorsed the proposed legislation but have just two caveats: (1) the participation of the volunteer/parent should be assured in stronger language than it now is; and (2) while I hold some reservations about inclusion of standards in regulations supporting legislation because they sometimes defeat the very legislation that they were adopted to support, in this case I would opt for the exclusion of specific standards from the bill itself and include them in supporting regulations. The Joint Accreditation Commission Standards represent 5-year effort but field testing is necessary and may result in many changes which could much more appropriately be handled by changing regulations than by amending legislation.

Thank you very much, Senator.

Senator RANDOLPH. Thank you very much, Mr. Haggerty. I have only one question. We know that according to you and others there are poor conditions in the residential treatment centers.

Apparently, the States have been unable to cope with this problem. Would you specify why you believe the States have failed to meet this challenge? Has it been a lack of money or personnel, lack of leadership, failure to assess priorities within the mentally retarded complex? What is your feeling?

Mr. HAGGERTY. If I might, Senator, in the late 1700's, when men were discussing the first Bill of Eights, black people could be bought and sold like tables or chairs. They could not vote and had no clout. Therefore, they were not considered in the national scope of things.

Most of your retarded people do not vote. In all of the instances that I know of, I dare say most of them do not vote. Without the legislative clout to enable them to have people represent them, we have a failure to consider a group that can't make any difference in whether they are elected or not elected and whether they could vote for any specific improvement which would improve their lot.

Senator RANDOLPH. YOU feel on the balance that this is a good bill, that the Javits approach is appropriate?

Mr. HAGGERTY. I do, sir; with that reservation. I feel the regulations should be where the in-depth standards should be. Whether or not a person takes a shower twice a day should not be in legislation, it should be in regulations.

Senator RANDOLPH. Perhaps I am in agreement with you on that. I am not sure. You feel that you can encumber a bill so heavily that it becomes overregulatory, isn't flexible, and doesn't take into account the fact that certain conditions vary from place to place and situation to situation; is that what you are saying?

Mr. HAGGERTY. More than that, Senator. This is an issue where the imposition of Federal standards on States which run their institutions involves the 11th amendment. It involves the question by the States of whether or not the Federal Government is going too far in telling them how to run their in-house affairs. It is not that objectionable in the way of regulations that are tied with money grants. In other words, if you do not perform, you do not get money.

Senator RANDOLPH. We appreciate your viewpoint, and it will certainly be kept in mind by the subcommittee as the legislation moves forward.

Mr. WEINGOLD. Would it be in order to make a comment?

Senator RANDOLPH. Yes. You know that I will think a little later on about what you have said. You go right ahead.

Mr. WEINGOLD. It is obvious that I don't agree with Mr. Haggerty on where the standards should be. All I can say is that if this bill is going to be reconsidered in terms of whether there should be standards in the bill or whether it should be written by HEW, we just must take a good look at who in HEW and how standards are going to be written.

Senator RANDOLPH. I understand Senator Javits is on his way over. We will continue to go through the testimony in the interim, so that everybody will get a chance to speak today. We will now hear from Mr. Donald Bartlette.

STATEMENT OP DONALD BARTLETTE, DIRECTOR, PROGRAM AND SOCIAL WORK SERVICE, OUTREACH COMMUNITY CENTER, MINNEAPOLIS, MINN.

Mr. BARTLETTE. First of all, I would like to introduce the young man who is with me today. We are happy to be here today because it is the first time that a retarded person is here in his own behalf. I would like the committee to meet Mr. Poetz, who has been treated and trained as a mentally retarded person, yet only a week ago, when we were summoned to Washington to testify, we found out through new psychological evaluations that he is not mentally retarded at all, but has the very normal IQ that we felt he had all along.

Due to the failure on the part of community facilities to evaluate him, for 23 years he lived the life of a mentally retarded person. Going along with that, I would like Senator Javits to know that Cliff is now living in an independent living program in Minneapolis, Minn., which is operated by Outreach Community Center.

He happens to be the president of our client council. He is a member of our consumers' panel, which has now traveled around Minnesota and we have plans to take part in many conventions. He is the first "retarded" member at large for region 1 of the Minnesota Youth Association for Retarded Children.

I am Don Bartlette, the director of program and social work services, Outreach Community Center, and the adviser to the client coun-

cil; moderator of the consumer panel. I am here today representing the residential care committee and the poverty committee for the Minneapolis Association of Retarded Workers; the American Association on Mental Deficiency, and the American Academy on Mental Retardation.

In relation to extending the Developmental Disabilities Act, Cliff and I reviewed the act thoroughly for several evenings. We feel it is an excellent device for providing services that aren't available to those who are developmentally disabled. The act, in its own title, does much to reduce the amount of stigma attached to the terms "mentally retarded" "cerebral palsied," and "epileptic." It emphasizes a more humanizing approach to serving those who happen to be developmentally disabled. The act also promotes the normalization concept of providing services to these persons.

We do feel that a stronger emphasis be placed in the area of consumer involvement in DDSA. Developmentally disabled persons—not only advocates—should be on planning councils, governing bodies, and advisory committees. In our agency, the staff and the board of directors think changes should be made in our residential facilities. Only as a result of listening to our clientele many changes have been made that would never have been made had we not listened to the people. Mr. Poetz has been instrumental in proposing many changes in the Minnesota Association for Retarded Children.

We very much support the act's emphasis on providing services in rural poverty areas as it is readily apparent that gaps in services therein continue to be great. In fact, in some areas of the Nation, no services are available to developmentally disabled persons.

Because of this, Cliff and I feel that the two should become more interrelated. In fact, if the two acts could be intertwined, there seems to be logic for developing and coordinating existing services in direct relation to filling the gaps where needed services are not provided as yet.

We sincerely hope, on behalf of all developmentally disabled persons, that DDSA can be extended through June 1975 so that more persons who need services can be given such assistance. Also, the DDSA would further promote the development of regional and community-based services that are so urgently needed.

In reviewing the bill of rights for the mentally retarded we again strongly support passage of this act. Because of the thousands of persons living in residential facilities who are being treated inhumanely and unjustly, we feel this act surely promotes a normalizing, humane way of life for residents of such facilities.

Again, we would urge that the act provide for a strong measure that will insure consumer participation by those residents living in all facilities, not only by representatives or advocates. Consumer involvement should be required on all governing bodies, advisory committees, and other planning groups. For example, in our residential facility, we have consumers—retarded, cerebral palsied, and epileptic residents—on our client council, recreation council, food committee, and building committee. The number of consumers on each of those advisory committees outnumbers the staff. Consumers are also involved in case conferences as a part of their treatment program.

We question the use of the term "mentally retarded" as it is too restrictive, too dehumanizing, too misunderstood by the general public, and it turns off opportunities for those who happen to be labeled as such. We suggest that S. 458 be a bill of rights for the developmentally disabled living in residential facilities. Because of the many problems inherent in labeling persons as "mentally retarded," we feel it would be more just to use a more humanizing term. In reviewing part C, chapter 1, subchapter 1, section 1111(a), page 14, definite reference is made not emphasizing "mental retardation" or "deviancy."

In (b) of the same section, our support is wholeheartedly for doing away with referring to adults, regardless of their handicap, as "kids" or "children." We hope that, by the passage of this act, the local, State, and National Associations for Retarded Children would be refrained from use of the word "children" as such.

We definitely support the act's reference to legal rights for the retarded, because, as yet, there are State laws prohibiting the mentally deficient—referred to as State ward commitments—from using their natural and legal rights as citizens of our Nation.

We feel that, in the area of advocacy, we would like the act to insure that each residential facility be required to have a staff advocate assigned to assure residents that their concerns and rights are made known and dealt with. We know of one facility where there is a newly appointed staff advocate and it is working out quite well.

Finally, we support the concept of having a national system of standards that all residential facilities must meet and keep in order to provide the best possible services to its residents. We feel these standards should be flexible and reevaluated periodically so that the needs of the residents can be the key to provision of services.

In Minnesota there is a new law titled "The Department of Public Welfare Rule No. IV," which affects all residential facilities, large and small, in Minnesota. These are standards indicating what type of services, what kind of consumer involvement must be had in order to operate.

We support standards like that.

In conclusion, I would like to refer you to the young man who, I think, is the most important person invited to your meeting today. If you have questions that you would like to ask Mr. Poetz, I am sure he would be happy to respond.

Senator JAVTTS [presiding pro tempore]. Let me say that I have apologies to make. We have a major railroad strike and action had to be taken today. As I am the ranking member of the Labor Committee, I had to attend. We have spent all day working for the passage of a bill which brings the strikers back to work. That bill just passed in the Senate about 25 minutes ago. It was a situation beyond my control.

I apologize to anyone who has transportation problems and if anyone wishes to submit a statement in lieu of testimony, it will be accepted.

Mr. Poetz, I gather you are a developmentally disabled person?

STATEMENT OF CLIFFORD POETZ, APARTMENT LIVING PROGRAM RESIDENT, OUTREACH COMMUNITY CENTER, MINNEAPOLIS, MINN.; PRESIDENT, CLIENT COUNCIL; MEMBER AT LARGE, REGION 1, MINNESOTA YOUTH ASSOCIATION

Mr. POETZ. Yes, I am, Senator.

Senator JAVITS. DO you feel that a "bill of rights," such as we are contemplating, should protect not only those classified as "mentally retarded" but also the "developmentally disabled."

Mr. POETZ. It should cover everybody under that label. I feel that would do a lot more good. In order to make it work, there should be standards set by Congress to say, "Here, you meet these standards before any money is given out through regional councils."

Senator JAVTTS. I gather you join Mr. Bartlette in the feeling about consumer satisfaction?

Mr. POETZ. Very strongly. I would like to recommend that it be mandatory that a consumer be on the regional boards for **DDA** for one reason. We have been sitting here all day, listening to parents who say, "Here, the retarded shouldn't be put under mandatory regulations because the parents feel that they can be more objective." I don't buy that one bit. The money is going to effect us and, as you know, as soon as it leaves Washington, it can disappear into a program and you can't find where it went.

If we can't have some idea of where the money is going, it won't do one bit of good. I think that a retarded consumer should be mandatory on these regional committees no matter who says what, because we have a bigger stake in it than anybody else does.

Senator JAVITS. I can understand why Mr. Bartlette said you were the most important witness we have today. Thank you very much for your testimony. It appeals to me very deeply. Thank you, both.

Our next panel is composed of Mrs. Rupp, Dr. Rimland, Mr. Shurman and Dr. Moss. Would you identify yourself to the stenographer?

STATEMENT OF BERNARD RIMLAND, M.D., FOUNDER, NATIONAL SOCIETY FOR AUTISTIC CHILDREN; DIRECTOR, INSTITUTE FOR CHILD BEHAVIOR RESEARCH, ACCOMPANIED BY MRS. MARY AKERLEY, CHAIRMAN OF THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

Dr. RIMLAND. I am Dr. Rimland. I would like to introduce Mrs. Mary Akerley, who is the chairman of the National Society for Autistic Children. My own specialty is research. As I know very little about these legislative matters, Mrs. Akerley is far more qualified in that area than I.

Senator JAVITS. Dr. Rimland, I am told that our subcommittee chairman, Jennings Randolph, was very anxious to hear your testimony. He was here awhile ago, but he is engaged now. He wanted me especially to bring that to your attention.

Dr. Rimland, we will start with you. If you would be good enough to proceed with your testimony? We have to limit each of the witnesses to 5 minutes. It is the best we can do without being unfair to everyone. If you will forgive me, I will stop you when 5 minutes are over.

Dr. RIMLAND. I would like to mention that both myself and Mrs. Akerley are parents of children who have been diagnosed as autistic or retarded.

I am Bernard Rimland, director of the Institute for Child Behavior Research in San Diego, author of the text, "Infantile Autism," and the founder of the National Society for Autistic Children, on whose behalf I am testifying today. We appreciate this opportunity to present our views on S. 427, the extension of the Developmental Disabilities Services and Facilities Construction Act.

The National Society for Autistic Children (NSAC) is an organization of parents, professionals and other interested citizens dedicated to improving the welfare of the estimated 80,000 autistic persons in the United States. Because they are so small a minority (only 4 in 10,000), they have not received the legislative and administrative attention necessary for their habilitation. Even so, one-third recover sufficiently to function independently as adults and another third make sufficient progress to avoid institutionalization—provided, of course, there is an alternative at hand. One can only imagine what the prognosis would be if sufficient therapeutic resources were available.

The Developmental Disabilities Act is the first piece of Federal legislation directed specifically to the needs of autistic persons as part of its target population. While they are not many, they are all substantially handicapped. And because they are not many, they can be planned for and served best as part of a group with similar service needs. We urge strongly that the inclusion of children be on the basis of their needs rather than on the basis of their labels.

We therefore support wholeheartedly the concept of the DDA and respectfully urge the subcommittee's favorable consideration of S. 427, which would extend the act for 3 years.

The old method of dealing with disabled people according to diagnosis has not proved particularly effective, especially when applied to the substantially handicapped. Where there is a major impediment to normal development, there are usually multiple handicaps, and rarely professional consensus on the proper label for any one of them. Yet when severely disabled people are evaluated according to their level of functioning and planned for accordingly, it becomes plain that their needs are not at all dissimilar.

For example, almost all require speech or language therapy; all require special education services; a great many will need vocational training and/or residential services at some point. Responsibility for providing these services rests with various agences in DHEW, and the DDA is the only Federal legislation with the potential for the necessary coordination of planning and services so that gaps may be filled and wasteful duplications avoided.

However, this approach is not valid for the mildly or moderately handicapped: a visually impaired person does not require the service that an orthopedically handicapped individual does, and the needs of a mildly retarded person are different yet.

We therefore recommend that great emphasis be placed on the severity of the handicap in defining the target group and in determining eligibility for planning and service. This would keep the target population to that small segment who require intensive therapeutic intervention.

We further urge that the subcommittee strongly recommend that in the regulations for implementation, planning and service priorities be given to those eligible groups heretofore unserved. For three years they have patiently waited their turn; we feel their time has come.

We are aware that in the past autistic children have been regarded as not suffering from the same disabilities as other handicapped children. We have demonstrated clearly that these children are biochemically and biologically impaired and are not merely emotionally impaired. They were formerly mis-diagnosed as suffering from mental retardation.

We respectfully suggest that to base the renewal of the DDA on its effectiveness is premature. In many States the program is just beginning to function as it should. Delays in local implementation, while regrettable, are understandable in view of the newness of the basic concept, the confusion over the regulations, especially regarding the target group, and the inadequate funding.

The first problem has an automatic solution: time has made and will continue to make all of us more familiar and comfortable with generic planning. The solution to the second difficulty is almost as easy: the definition of "developmental disability" should be reworded to remove the ambiguities. We support without reservation the wording proposed by the National Advisory Council and the Ad Hoc Coalition:

> Developmental Disabilities means a disability which (1) Is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age of eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen, a handicap of comparable severity).

This definition also has the support of at least one of the groups specifically named in the act, United Cerebral Palsy Associations, an organization which has consistently urged a comprehensive application of the law.

It should be noted that this definition does not in any way alter the nature or scope of the target group; it simply clarifies the language and adds a functional determinant to conform with congressional intent.

Senator JAVITS. Dr. Rimland, your time has expired. If Mrs. Akerley will yield her time to you, you may continue.

Mrs. AKERLEY. Certainly.

Dr. RIMLAND. I must borrow from Dr. Martin. When a family has a new baby, they don't wait for daddy to get a raise before they feed it. The same applies to the developmentally disabled. Whatever funds there are should be shared by the entire family.

As one who has spent a great deal of time in research on improving the methods of diagnosis, I can say with great assurance that diagnosis is usually a very arbitrary matter.

Senator Tunney, on June 23, 1972, in a letter to Secretary Richardson, suggested the administration include a process for identification of the other disabilities so that Congress could enact a revised and expanded program.

Congressman Rogers, in 1970 while DDA was still pending, in a letter to our National Affairs Committee, assured us that the intent was broad: "to include other mental impairments" were his words.

Senator Cranston, on March 15, 1972, in a letter to Administrator Twiname said:

As a co-sponsor of the bill and a member of the Subcommittee on Health, it is my clear impression that the intent of Congress was to broaden the dimensions of the mentally retarded to include other developmental disabilities such as autism.

Senator Humphrey, on October 13, 1972, during the Senate debate on the priorities for revenue sharing, said:

The whole subject of development for physically, mentally and emotionally disabled is of tremendous importance. I think it is wrong for us to differentiate between these different categories. I hope we can treat them all alike—include them all—they should be given the same treatment. I hope the proper officials take notice of the record that is being made here.

Senator Dole expressed similar sentiments during the debate, as did Congressmen Hall and Mills during the House debate on revenue sharing.

We therefore urge this subcommittee to so amend S. 427, including such other technical and conforming amendments as may be necessary for consistency. (For example, in sec. 134(b) (A), the phrase "associated with mental retardation" should be deleted.)

At the very least the current definition should be changed as follows:

(1) Deletion of the phrase "found by the Secretary": first of all, his failure to "find" any disabilities in the fourth category has caused most of the difficulty; and second, the phrase is now meaningless as the problem of determining which are the eligible disabilities has been turned over to the National Academy of Sciences;

(2) Deletion of the phrase "closely related to mental retardation or requiring services similar to those required by mentally retarded individuals," since this phrase has placed undue emphasis on one illustrative disability and has therefore caused distortion in the interpretation of the law; and

(3) Deletion of the three disabilities specifically named for the same reason.

The third difficulty is not so easily solved. Although not the primary responsibility of this subcommittee, the problem of adequate funding is one that should at least be touched upon here, as this has been the excuse tendered by the administration and others for the exclusion of the fourth category. While such a reason for exclusion has no legal basis, it certainly has a practical one, and NSAC is neither unaware of or unsympathetic with the resultant difficulties.

We therefore suggest two minor strategies which we believe will gain the favorable attention of the Subcommitttee on Appropriations:

(1) No increase in the sums authorized in the law itself; clearly this is not a good time to request increases for health programs. Actually, funding at the levels currently authorized instead of meager sums heretofore appropriated, would be a fantastic improvement; and

(2) The title of the act could be changed to "the Developmental Disabilities Revenue-Sharing Act, "which is actually a more accurate description as well as more in line with the administration's stated fiscal policy and philosophy.

One way to make maximum use of the limited funds would be to enforce the sanctions in the law against States which are using funds improperly.

In spite of the disappointing appropriations, we believe that with what has been one of its major difficulties cleared up, the develop-

mental disabilities program will prove itself an effective and efficient catalyst for service to the substantially handicapped. It should be given that chance. If it is not, not only will those in need be left without help, but a terrible injustice will have been wrought against the mentally retarded, whose spokesmen were the generous advocates for the rest of us.

There are children who are autistic and children with cerebral palsy.

I again would like to urge that the benefits of the Developmental Facilities Act be shared on the basis of the need and not on the basis of the label.

SENATOR JAVITS. Thank you, very much. We will now move to the next witness, Mrs. Rupp.

STATEMENT OF JOAN M. RUPP, PRESIDENT, MARYLAND ASSOCIATION, CHILDREN WITH LEARNING DISABILITIES, INC.

Mrs. RUPP. Mr. Chairman, we are very happy to have been invited to be here today. I would ask that the written testimony be submitted in the record.

Senator JAVITS. It will be so included in the record at the end of your testimony.

Mrs. RUPP. My name is Joan Rupp. As a parent and an educator, I am speaking on behalf of the National Association for Children With Learning Disabilities (ACLD). ACLD is a federated organization with affiliates in 41 States and the District of Columbia. The representation is 75 percent parent and 25 percent professional. It is parent oriented and parent directed. While the percentage of persons afflicted with the handicap which ACLD represents is quite significant, it is felt that only a small percentage of that group, probably under 1 percent, is severely enough handicapped to fall under the provisions of the Developmental Disabilities Act. However, we are vitally concerned with the needs of this group, albeit small.

The interest of ACLD is in preventing, by means of proper diagnosis and remedial measures, the strong possibility that, whether by behavioral, psychological, or educational mismanagement, this small group may end up with a substantial enough handicap to result in needs which would require continuous and serious intervention of various kinds.

On behalf of this group, and in the interest of meeting their needs, ACLD is fully behind the renewal of S. 427. The renewal, at the present level of funding, would be most significant in meeting large and still unmet needs of these individuals. ACLD is particularly in favor of the recommended revision of the present definition, supported by the National Advisory Council on Developmental Disabilities and the ad hoc coalition, as follows: "Developmental disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age 18 and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity, or in the case of a child under age 18, a handicap of comparable severity," for the following reasons:

First, this is a generic definition, whereas the existing definition depends on labels. The children who are of concern in this instance may, because of the limitations of testing mechanisms, lack of adequate professional personnel, and overlapping physical and/or emotional problems, be labeled mentally retarded, emotionally disturbed, et cetera. These are children who, research has shown, may be identified at an early age, due to their inability to develop a proper body image without help.

Because they fail to encode sensory data properly, they are bombarded, and everyday living becomes too much for them. In order to enable these children to achieve their fullest potential, proper medical and educational intervention is needed, which sometimes is denied as a result of improper labeling.

Labeling also tends to result in a self-fulfilling prophecy; that is, because the child is so labeled, everyone expects too little and/or the wrong thing from him/her, thereby creating a larger problem. A proper diagnosis in this area is difficult but not impossible. It does, however, require a multidisciplinary approach, which at the present time is not available except at great cost, and which might be made available through existing or planned mental health facilities. Such an approach would utilize such specialists as pediatricians, neurologists, speech and hearing specialists, diagnostic teachers, opthalmologists, and optometrists, and others.

Second, the thrust of current research, and current educational practice is toward an emphasis on identifying needs, and working toward remediation of those specific needs, rather than pinning a label on a child. This is due to recognition of the fact that present means of identification are inadequate, that some children represent multihandicaps, and that each child is an individual who represents unique needs, and so needs a highly individualized approach.

In summary, we are asking for (1) renewal of S. 427, with (2) the revised definition, and (3) the recognition that some of our children need the help which this act would provide.

Respectf ully submitted.

[The proposed statement of Mrs. Rupp and other information submitted for the record follows:]

STATEMENT OF

THE NATIONAL ASSOCIATION FOR CHILDREN WITH LEARNING DISABILITIES

IN TESTIMONY BEFORE

THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

ON

THE DEVELOPMENTAL DISABILITIES ACT

BY

MRS. JOAN M. RUPP, DUNKIRK, MARYLAND

FEBRUARY 5, 1973

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On behalf of this group, and in the interest of meeting their needs, ACLD is fully behind the renewal of S. 427. The renewal, at the present level of funding, would be most significant in meeting large and still unmet needs of these individuals. ACLD is particularly in favor of the recommended revision of the present definition, supported by the Administration, the National Advisory Council on Developmental Disabilities, and the Ad Hoc Coalition, as follows: "Developmental Disabilities means a disability which l)is attributable to a medically determinable physical or mental impairment, 2)originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and 3)constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen a handicap of comparable severity", for the following reasons.

First, this is a generic definition, whereas the existing definition depends on labels. The children who are of concern in this instance may, because of the limitations of testing mechanisms, lack of adequate professional personnel, and overlapping physical and/or emotional problems, be labelled mentally retarded, emotionally disturbed, etc. These are children who, research has shown may be identified at an early age, due to their inability to develop a proper body image without help. Because they fail to encode sensory data properly, they are bombarded, and everyday living becomes too much for them. In order to enable these children to achieve their fullest potential, proper medical and educational intervention is needed, which sometimes is denied as a result of improper labeling. labeling also tends to result in a self-fulfilling prophecy: i.e. because the child is so labeled, everyone expects too little and/or the wrong thing from him/her,thereby creating a larger problem. A proper diagnosis in this area is difficult, but not impossible. It does however, require a multi-disciplinary approach, which at the present time is not available except at great cost, and which might be made available through existing or planned mental health facili-

ties. Such an approach would utilize such specialists as pediatricians, neurologists, speech and hearing specialists, diagnostic teachers, opthalmologists and optometrists, and others.

Secondly, the thrust of current research, and current educational practice is toward an emphasis on identifying needs, and working toward remediation of those specific needs, rather than pinning a label on a child. This is due to recognition of the fact that present means of identification are inadequate, that some children represent multi-handicaps, and that each child is an individual who represents unique needs, and so needs a highly individualized approach.

In summary, we are asking for l)renewal of S.427, with 2)the revised definition, and 3) the recognition that some of our children need the help which this Act would provide.

Respectfully submitted,

Joan M. Rupp, President MACLD
for the
National Association for Children with Learning Disabilities

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Senator Edward Kennedy
c/o Dr. L. Horowitz
Room 4226, New Senate Office Building

STATEMENT OF CONCERN RE: S.458

THE NATIONAL ACLD RESPECTFULLY REQUESTS INCLUSION OF THIS STATEMENT INTO THE RECORD OF THE HEARINGS OF THE SENATE SUBCOMMITTEE ON THE HANDICAPPED.

To: Senator Edward Kennedy

From: Mrs. Joan M. Rupp, for the NATIONAL ASSOCIATION FOR CHILDREN WITH LEARNING DISABILITIES

Subject: Statement of Concern on S.458, Bill of Rights for the Mentally Retarded

Since we (National Association for Children with Learning Disabilities - ACLD) were given only five minutes to speak for the more than 20000 concerned parents, as well as educators, psychologists, physicians, and others professionally interested in children with learning disabilities, it was felt that our time must be concentrated on the Developmental Disabilities Act, which most concerns our particular target group. However, we would not want it to go unnoted that we do not recognize the absolute need for a bill such as S.458; particularly in view of the desperate need of these individuals for humane treatment: and in light of the fact that some individuals have been found at the Rosewood State Hospital in Maryland who had severe learning disabilities and had been mistakenly labeled mentally retarded. (This is one more reason for changing the existing definition in the Developmental Disabilities Act to a generic one, rather than one which depends on labels.) It is also a reason for changing the title of S.458 to the BILL OF RIGHTS TOR TIP! DEVELOPMENTALLY DISABLED.

We are submitting this statement of concern in view of the fact that our panel, which consisted of representatives for the Autistic Society, the National Association for Children with Learning Disabilities, the Spina Bifida Organization, the Easter Seal Society, and the Mental Health Association, was given a very short time in which to present our statements, as compared with the time given every other panel representing other developmental disabilities.

Senator JAVITS. Thank you very much, Mrs. Rupp. We are very grateful for your testimony. We now call on Mrs. Smith.

STATEMENT OF MRS. VERNON B. SMITH, MEMBER, CHILDHOOD MENTAL ILLNESS COMMITTEE, NATIONAL ASSOCIATION FOR MENTAL HEALTH, INC.

Mrs. SMITH. My name is Mrs. Vernon B. Smith. I reside in the State of Indiana and am the parent of a handicapped child. I am a member of the National Association for Mental Health Childhood Mental Illness Committee and am former chairwoman of the Childhood Mental Illness Committee of the Indiana Association for Mental Health. In addition, I have been actively identified with the Association for Retarded Children in my home State.

The National Association for Mental Health is a lay citizen's organization serving as advocate on behalf of the mentally ill, including mentally ill children, some of whom, but not all of whom, qualify for consideration as developmentally disabled within the definition of the Developmental Disabilities Act. We are deeply concerned by the fact that the legislation designed to serve the needs of those with developmental disability has been interpreted to cover only a part of the total population fitting the definition included in the law.

It was certainly appropriate that the legislation in question should have referred to three specific examples of developmental disability in order to clarify the kind of dysfunction to be covered. However, it is clear in reading the law that it was not intended that its benefits should be limited to those three disorders, but should be extended to disorders resembling in certain respects the three named examples.

Difficulty arises, however, with reference to an interpretation of the words "found by the Secretary." This language has been construed by those who would prefer to approach the problem on a selective basis to mean that the Secretary of Health, Education, and Welfare has been accorded the privilege of "electing" which among the total of developmental disabilities are to be eligible to benefit from the legislation. It is our contention that such a construction should not be put upon those words. It is not the privilege of the Secretary to determine which among many developmental disabilities are to be covered by the law, but rather to determine what disabilities are developmental and meet the criteria set down in the law.

Those who advise us professionally have indicated that childhood schizophrenia, autism and some forms of learning disability certainly meet the requirements of the law. Until this is at least disputed by the Federal agency responsible to administer the legislation, we will consider that the children to whom we have referred are being arbitrarily excluded from equal consideration under a law which clearly describes their condition of need.

It should be clear to all of us who have an interest in the developmentally disabled that this is the only Federal legislation which has the potential to coordinate planning for services to all those who fall within the definition of developmentally disabled.

If we are to be persuaded to wait longer for reasons which are strategic before pressing our claim for attention, the Secretary must make a definitive statement indicating what forms of developmental disability do, in his opinion, fit the definition of the law. If, for exam-

pie, the Secretary were to indicate that childhood schizophrenia is a developmental disability as denned by the law, then it would make sense for us to begin even now to join in the strategies involved in achieving full implementation. If, on the other hand, the Secretary were to rule that childhood schizophrenia is not a disability falling with the definition of the law, we would no longer lose valuable time standing idly by waiting for benefits which would never be provided and we would be free to take such other courses of action as might be required to benefit those excluded.

It is our hope, however, based on the professional advice available to us, that the children for whom we speak will be judged to fall within the definition of the developmentally disabled. It is also our hope that the present definition, which has caused so much misunderstanding because of its inherent ambiguities, will be amended. We would recommend a new definition which simply seeks to clarify the language of the definition. The definition we recommend is as follows:

Developmental disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age 18 and has continued or can be expected to continue indefinitely, and (3) constitutes, a severe handicap to substantial gainful activity (or in the case of a child under age 18, a handicap of comparable severity).

In conclusion, let me repeat the following points: (1) We contend that the Developmental Disabilities Act was adopted to serve the needs of all children who could qualify under the definition of the law and that the three specifically named categories were illustrative of the kind of disability intended; (2) the language of the law is not intended to give to the Secretary of HEW the right to decide which of the developmentally disabled he prefers and chooses to include as beneficiaries of the law, but instead gives him the authority to determine which disabilities other than those named are included within the legal definition, with all disabilities falling within the definition equally entitled to consideration; (3) the present practice of limiting the effect of the law to the three named disabilities represent an unwarranted discrimination against other children who by definition are eligible for consideration; and (4) those who are in authority should act promptly and decisively to clarify the issues involved, so that all of us who are concerned with the needs of the developmentally disabled can begin to work in concert on behalf of all children who are the victims of developmental disability irrespective of the form which it takes.

Thank you.

Senator JAVTTS. Thank you, Mrs. Smith. I understand you missed your plane and I humbly apologize. We will do anything we can to help you.

I have explained the reasons for the inconvenience.

Mrs. Smith, we recognize the problem you raise is a serious one. We will address ourselves to it in marking up the bill, which will probably occur more in the developmental disabilities bill than it does in my own bill, the bill of rights for the mentally retarded. We have a serious interest in what you have said and we will do our best to try and put it into legislation.

Our next witness is Dr. Moss.

STATEMENT OF JAMES W. MOSS, PH. D., UNIVERSITY OF WASHINGTON, SEATTLE, WASH., SPECIAL CONSULTANT TO THE NATIONAL EASTER SEAL SOCIETY FOR CRIPPLED CHILDREN AND ADULTS

Dr. Moss. I have a prepared statement that I would submit for the record.

Senator JAVITS. It will be so included, without objection, following your testimony.

Dr. Moss. If you look at what has been happening in this country in the field of the handicapped, I wonder what kind of a country it is. It is incredible that in 1973 we are still debating the issue of whether we will help disabled people or not.

Even more incredible is that we are debating which type of children with disabilities we are not going to help. It is going to be autistic children or the mentally retarded that we are going to neglect next? I believe our country has a responsibility to provide appropriate services for all disabled individuals without neglecting any.

We are one of the few countries left that is still debating this issue. The main problem, of course, is money. There is not enough to go around. The only way we have gotten where we are today, however, is because people have worked together to make it possible to pass laws, to get appropriations, and to bring about changes in programs.

The fact that we are fighting among ourselves is going to split us apart. We will lose the opportunity we have had to build better programs and attract more money.

The Easter Seal Society is in favor of the definition that has been promoted already here at the table. We are not 100 percent happy with it, but it is a better definition that the one we have now. We would rather see one that did not require a medical definition, because that could just raise the cost of the services without substantial benefit.

We are not committed to a belief that a handicap is forever. Our job is to remove disabilities and make it possible for people to get jobs and to interact successfully in society. Nevertheless, we believe that the conditions which result in disabilities and handicaps are permanent conditions and that only through successful treatment can people overcome their handicaps and achieve a degree of success.

If there is not enough money to go around, there will be more. We have proven this many, many times. We have worked together for the last 15 years to get the resources we need. Today we are using the same arguments among ourselves to differentiate the very children we all tried to help before.

Let me make one comment about the bill of rights for the mentally retarded. That bill is sufficiently complex that people could knit-pick it to death for the next 5 years. I would like to see you pass that bill immediately. I would like to see the House pass it and have it become law as soon as possible.

The circumstances are not going to change overnight. There is plenty of time to come back, 2 years from now and make amendments. It is worth getting off the ground and getting it started.

Senator JAVITS. I certainly appreciate your support for the "bill of rights for the mentally retarded." As you say, the definition which is being put forth is not the optimum, but it certainly will accomplish an improvement upon the Developmental Disabilities Act's previous definition.

(The prepared statement of Dr. Moss follows:)

Testimony of Dr. James W. Moss

Special Consultant for Developmental Disabilities

National Easter Seal Society for Crippled Children and Adults

Before the Subcommittee on the Handicapped

of the Senate Committee on Labor and Public Welfare

February 8, 1973

BACKGROUND

I am Dr. James W. Moss, a special consultant to the National Easter Seal Society for Crippled Children and Adults. I am here today to speak on behalf of that Society. I am also a professor at the University of Washington in Seattle, and the Director of Planning, Evaluation and Development at the University Affiliated Facility for Mental Retardation on that campus. Prior to assuming that position in Seattle last September, I was director of Research for the Bureau of Education for the Handicapped in the U.S. Office of Education—a position I held for eight years. For part of that time, I also served as Acting Deputy Associate Commissioner of Education for the Handicapped. I first became involved with the mentally retarded in 1953 when I was a teacher in a special class in California. I have had experience as a psychologist in a state school for the mentally retarded for two years, have studied with mental retardation specialists in England, and have been involved in research with the mentally retarded and other handicapped children for over 15 years.

The Easter Seal Societies have a direct relationship with the legislation under consideration. For more than half a century, the National Easter Seal Society's concern has been the, rehabilitation of physically

disabled persons, including those with developmental disabilities resulting from accidents, diseases or congenital defects. Service is extended by 2000 affiliated Easter Seal Societies without regard to the cause, the diagnostic label, the age, or the economic status of the physically disabled individual. Clients include those with orthopedic, neuromuscular, communicative and sensory disorders; for example, cerebral palsy, cleft lip and palate, spina bifida, paraplegia, stroke, arthritis, muscular dystrophy, multiple sclerosis, amputation, and speech and hearing disorders.

In 1972, 338,759 people were served either through continuing or one-time service. Over 36,000 people with neurological conditions received help. This figure includes those with cerebral palsy, epilepsy, spina bifida, Friederich's ataxia, hydrocephalus, Huntington's chorea, and tumor of the brain or spinal cord.

Examples of services are physical restoration for all age groups including infants, preschool services to ready youngsters for the public schools, camping and recreation for the young and old, training and workshop adjustment services for youth and adults, and information, referral and follow-up to help patients and their families locate and make use of available community resources. Other services include transportation in specially equipped vehicles and loan of equipment. Support for this vast network of rehabilitation services comes from bequests, contributions from the public, and fees from individuals and third parties, including government agencies.

The Easter Seal Society is a voluntary health organization which recognizes that some people have serious problems which they cannot solve by themselves. When a child who does not speak comes to an Easter Seal clinic no one says to him, If your lack of speech is due to mental

retardation we can help you, but if it is due to something else, we can't." Definitions and classification systems sometimes build walls to keep people away. We are interested in building bridges which bring services to people who need them. It is for this reason that the Society would like to see this Committee give some special thought to the definition of Developmental Disabilities.

Definition

In my opinion, the most significant legislation ever passed to promote the welfare of the mentally retarded was Public Law 88-164. This law, enacted 10 years ago, authorized the construction of research facilities and the construction of clinical facilities for the mentally retarded. It also authorized the use of federal funds for the construction of facilities for the mentally retarded and for the construction of community mental health centers.

Public Law 88-164 was the beginning of a national commitment which will eventually see the mentally retarded children and adults of our society participating fully in the benefits and obligations of this society. It was only the beginning of a long, difficult, and tortuous path to freedom for these people who have so few resources to help themselves. We are a long way from reaching the end of that path; nothing could have brought that point home more clearly than an experience I had last summer as a member of a federal team that toured the Willowbrook State School in New York.

Although we have not reached our goal, the path to that goal is clear and we are securely on that path. We know what has to be done; we have the skills and the technology to accomplish that goal. It is only a matter now of main-

taining our commitment and providing the resources to complete the journey started 10 years ago.

Public Law 88-164 was a good law but it was an imperfect law. It provided for the construction of research facilities before we had the talent or the money to carry out the research that was needed. It provided for the construction of clinical service facilities at a time when we didn't know for certain what services could accomplish what purposes. But that was 10 years ago. The Developmental Disabilities Act, enacted in 1970, made some very significant and very important changes in the original law. The most important change was the addition of the concept of services into the title of that Act. We learned quite clearly that buildings alone were no answer to the problems of the mentally retarded. The Developmental Disabilities Act authorized money to provide the services so desperately needed for these children, and has done so at a time when we think we know what services are necessary and how to deliver them.

At the same time that the concept of services was amended into the Title of Public Law 88-164, the concept of services entered into the definition relating to the recipient's eligibility for such services. We had, for the first time it seemed, stopped talking only about the mentally retarded and their problems and started talking about providing services and help to members of a population who could not help themselves but who had a fundamental right to the benefits of this society. In a very subtle but important way, the Developmental Disabilities Act shifted the burden of responsibility for failure from the shoulders of the mentally retarded to those of us responsible for changing our society to make it appropriate for all of our citizens. We can no longer say that a person has a problem because he is mentally retarded. We can only say that if a retarded person has a problem, it Is because we have failed to help him solve it.

The change in philosophy which occurred between the enactment of Public Law 88 164 and the enactment of the Developmental Disabilities Act came about because of what we learned about the provision of services for a group of handicapped individuals. We were able to show that the services we offer can significantly improve the lives of handicapped people. We know what can be done, and what must be done, for the mentally retarded, for the deaf, for the blind, for the emotionally disturbed, for the autistic, for the epileptic, for the cerebral palsied. We are no longer taking shots in the dark with the hope that some will hit home, that some success can be found.

The broadening of the concept of mental retardation to include other similar conditions requiring similar treatment was a remarkedly important move. That act alone could well change the way we think about the handicapped in the years to come. One consequence of this has been a refocusing of attention on the problems of definitions. Another consequence, unfortunate and hopefully temporary, is the scramble between the "ins" and the "outs."

I am deeply depressed today to hear some of the arguments which set one disabled person's welfare against another's. I am depressed when one handicapped child is left on the doorstep of a service facility while another is admitted. I am discouraged by the idiocy which forces practitioners to attempt to differentiate the cause of a child's malfunctioning as a prerequisite for excluding some children from help. It is too easy to convince ourselves that we need precise categories in order to provide more meaningful help to some of our handicapped individuals, when In fact we use these categories as a justification for rejection.

I have a very high regard for those people who, 10 years ago, spoke up for the mentally retarded and led them on a path out of darkness. These few people set a course of action for this country which will see the Javits Bill of Rights for the Retarded enacted, which will change the Willowbrooks and the Partlows, and which will see the development of group homes and community services for the retarded. But that course of action carried with it help for other handicapped as well. It is just not possible to go backward in time to that callous era where society cared so little about any of these people. Concern for the mentally retarded was the spearhead which broke the wall of resistance. That wall has now been cracked and a door must now be widened to assure that all of our handicapped individuals receive the services they need.

The Developmental Disabilities Act as introduced appears to be making a last ditch stand to hold onto the spearhead after the wall has been cracked. I know the sincerity of those who stood on those original ramparts to fight for services for the mentally retarded. I cannot be critical of the intensity of purpose which causes them to want to hold the line today on the Developmental Disabilities Act, because it was that very intensity of purpose which these same people showed 10 years ago which brought us to where we are today. But the wall has been cracked—the wall of prejudice, the wall of neglect, the wall of indifference. We must carry through that wall all of the neglected and forgotten disabled people of our society. The crack in that wall is not permanent and those who are left behind today will be left behind for a long time to come. We have not achieved a full commitment to equality in our society, and the commitments that we have made are easy to forget when the pressures change. One need only to look at the Administration's 1974 budget for confirmation of this.

The voices I heard 10 years ago were proclaiming sincere interest in the mentally retarded while decrying the lack of funds to provide them with services. "There is not enough money," they said, "to provide for the normal child," and therefore the mentally retarded had to wait. I hear almost the same voices today. "Of course we are interested in all the handicapped," they say, "but there is not enough money in DDA to provide for the mentally retarded. The rest will have to wait."

The Developmental Disabilities Act, as presently written, has the best of intentions but it could have disastrous effects. It has set the welfare of one handicapped child against another, one parent against another, one organization against another. If we have learned anything from the last 10 years, it is that the gains we have made in changing public opinion, in promoting legislation, in obtaining appropriations, have all been made because we have worked together in the service of a common cause. What is happening to us now is as if someone who doesn't want us to succeed has deliberately set us working one against the other in the hope that we would create sufficient confusion to block our own progress.

The Developmental Disabilities Act is a powerful tool but it must be reset to cut through the wall Which separates some of our citizens from all the others.

The problem is with the definition. The current definition does more than just separate the favored from the neglected. The definition simply doesn't mean what we mean it to mean. The current definition confuses the physical condition with the behavioral consequences of the condition. I would like to see us stop talking about mental retardation,

cerebral palsy, epilepsy, and such conditions as disabilities which have "continued or can be expected to continue indefinitely." Such conditions are not disabilities. They are conditions which lead to a number of behavioral disabilities. It is the inability to engage in certain activities highly valued by our society which constitutes the disability. For example, it is the inability to dress oneself, to talk, to walk, to care for one's needs, to engage in competitive employment, which constitutes the disability. The condition which is responsible is essentially untreatable with today's knowledge, but the disability itself is subject to remediation and treatment. When we talk about a disability which will continue throughout a person's life, we are promoting a fatalistic attitude which suggests that nothing that we can do will be of any help. On the other hand, if we talk about a person's inability to do something, then we have set the stage properly for finding ways to make that person more effective.

Furthermore, in confusing the underlying condition with the behavioral consequences of that condition, we put everyone given the same general physical diagnosis in the same bag in spite of differences in ability. For example, a person with epilepsy is developmentally disabled according to this act. Some people who have epilepsy are seriously disabled and require special help. Others with the same diagnosis may have no disabilities at all, sail right through school, get college degrees, marry, and live happily ever after. Both of these individuals would be considered disabled because the epilepsy condition originates prior to the age of 18 and can be expected to continue indefinitely; because both required similar treatment; because both would have been unable to achieve in a competitive

society had they not received treatment. The fact that the treatment was successful in controlling seizures with minimal side effects, thereby allowing the person to perform without behavioral deficits, does not allow him to escape the label "developmentally disabled".

1 am not going to promote a new definition at this time. That is because we are not ready to move that rapidly away from the security of the past. The National Easter Seals Society has examined the definition suggested by the National Advisory Council for Developmental Disabilities and we are willing to settle for that rather than further fractionate the forces concerned with the welfare of our handicapped people. However, if I were to suggest a different definition, it would go like this.

> A developmentally disabled person is one with a physical or mental condition, originating before age 18, which is not responsive to treatment, which therefore can be expected to exist during the life of the individual, and which leads (or has led) to behavioral deficits which substantially interfere with the individual's ability to acquire normal skills and knowledge, to engage in competitive employment, or to manage his own affairs without public assistance.

Such a definition would not make reference to a medically determined impairment or to a category of individuals. These are hardly oversights. It is only through an analysis of one's functioning ability that we can determine whether or not a person is disabled; therefore, the person who makes that determination should be one experienced in the remediation of such disabilities. At the University Affiliated Facility at the University of Washington we have a school with over 100 disabled youngsters. Our job is to identify those disabilities and modify them in order to provide those children with the skills they need to make the most of their education and to perform at the most independent level as adults. We do

a very careful analysis of the skills of each child, we identify specific objectives for each child, and we set out to achieve those objectives. The physical classification into which each child falls has essentially no value to us at all. If anything, it can be detrimental. As much as we try to avoid it, the knowledge that an individual has Down's syndrome could still have some effect on the specific objectives we set for that person. We really don't need to pay a physician to label a child for us. We would rather use that money to help us understand the child's disability and do something about it.

I have talked too much about definitions and the problems they cause. There are some other elements of the Developmental Disabilities Act which require attention.

Other Considerations

The original Act (88-164) might have made a mistake in providing funds for services without providing funds for the training of clinical personnel to provide such services. The Inevitable result was that the cost of services increased as the demands for scarce personnel became even greater. It is important that the training of professional personnel bear some relationship to the amount of services required. Also, the original Developmental Disabilities Act did not give sufficient guidance to the functioning of state Developmental Disability Boards. This has caused confusion and in some states has prevented these Boards from functioning in an effective way. It would be useful if the amended legislation could provide more guidance about the functions of these Boards.

The definition of a University Affiliated Facility has always been unclear. It was the intention of Public Law 88-164 to establish a limited

number of highly specialized, clinical service centers to work with the mentally retarded. These centers were clearly to be multidisciplinary centers which could focus the latest knowledge of a variety of disciplines on the particular problems of the retarded. The operation of such centers is complex and expensive. It requires a critical mass of Individuals from many disciplines who have learned to work together. However, the law, as presently defined, suggests that almost any organization which has some form of University affiliation and which provides some of several listed services can be considered a UAF and be supported through these funds. If this happens, the funds will be dissipated to the point where it is impossible to create the critical mass of interdisciplinary talent necessary to achieve the purpose of the program. It might be of some value for this Committee to study the definitions of a University Affiliated Clinical Center for the Developmentally Disabled.

The legislation, as it is currently proposed, says nothing about funding levels but there are those who would want to see service funds increased while holding constant that portion for UAFs. This would probably be a mistake. UAFs should serve a strong technical assistance role to the states and the regions as they attempt new and improved services for the Developmentally Disabled. At the University of Washington, we are now developing a strong consumer education program to put us in touch with parents of the disabled throughout the state, to help them to know what services they need, and to help them to obtain services. We will be working very closely with our Developmental Disabilities Board to analyze the problems of Washington State and to develop new services.

It is our intention to use the resources of the UAF to provide technical assistance in order to establish the most effective programs for disabled individuals. This service will become more and more important as funds for services increase for the Developmentally Disabled. The UAFs should, therefore, become more important *over* the *next* few years and not less important.

Time is extremely valuable at the Congressional Hearing. I wish it were possible to talk about the state of Washington and its success in reducing the population of State Institutions by one third. With your permission, I would like to submit for the record a brief statement about that program. I also wish there were time to talk about the programs of the National Easter Seal Society to show more about the workings of a voluntary health agency. We hear so much today about federal, state and local programs and about what is happening to our tax dollars that we sometimes forget the important roles played by the voluntary agencies.

The National Easter Seal Society for Crippled Children and Adults wants to go on record as being thankful for the Developmental Disabilities Act in any form. It is a very important piece of legislation. It is our belief that the Act could be strengthened by making clear that a disability need not be permanent except through our neglect and that it is not the condition which makes a person disabled, but rather the society in which he lives. We would like to see a differentiation between that which is a physical condition and that which constitutes a disability. We would like to see the focus on services and not on handicaps. We would like to see these services available to any substantially disabled person who needs them.

And, finally, we would like to see as much federal money as possible funneled into these programs so that the impaired in our society need not be permanently disabled.

Thank you for the opportunity to appear here today. I would be pleased to respond to any questions.

Senator JAVITS. Our next witness is Jack Shurman.

STATEMENT OF JACK SHURMAN, PRESIDENT, SPINA BIFIDA ASSOCIATION OF AMERICA

Mr. SHURMAN. This testimony is submitted by the Spina Bifida Association of America in support of Senate bill S. 427, the renewal of Public Law 91-517, commonly known as the Development Disabilities Act, as well as a revised definition of the target group to be served by this legislation. The feelings presented here are supported by a large group of citizens, both parents of children born with spina bifida and individuals with spina bifida themselves.

Within the first few weeks of life, 75 percent or 80 percent of the spina bifida children are identifiable and successfully treated by running a tube from the abdomen to drain off excess fluid.

In spina bifida one or more of the individual bones or vertebrae fail to close into a tube around the spinal cord. Through such an abnormal opening the contents of the spinal canal slip out much like a hernia. This forms a fluid filled sac the size of a small orange under the skin and is generally located in the region of the waist. The vital nerves so contained are protected only by the skin rather than by the tough bony structure of the spinal column.

This disarrangement of the nerves of the lower spine usually results in a loss of both movement and sensation of the lower extremities and in severe cases, paralysis from the waist down.

Another common complication can result from disturbances of the spinal fluid which ordinarily bathe the brain and spinal cord. An abnormal amount of fluid collects within the skull leading to excess pressures and enlargement of the head. This is known as hydrocephalus.

Only in most recent years have medical advances been such that a baby born with spina bifida could safely be surgically treated to return the spinal cord nerve bundle to within the protective spinal column. This does not eliminate the damage already done but tends to protect the individual from possible future injury and infection. This early attention to this defect is essential and is usually advised within 24 hours of birth, and requires the skills of a neurosurgeon.

Likewise, early detection and treatment of the hydrocephalus is equally as important to prevent brain damage and even possibly death. The surgical procedure prescribed here is to bypass the restricted cerebrospinal fluid routes by means of a "shunt." This is a small tube inserted into the fluid chambers within the skull which allows the excess fluid to be redirected to other parts of the body. No external devises are involved and one would be totally unaware of its use without specific reference to it.

Prior to these two medical advances only individuals with less severe forms of spina bifida were spared lifelong institutionalization and that at great expense to the citizenry. This proper initial medical attention so described can actually establish the difference between a lifetime burden on the tax-paying public and a human being with a potential of being a contributing, self-supporting member of society.

As illustrated, the treatment of spina bifida requires a great deal of teamwork between many medical specialties. The habilitive spirit of the Development Disabilities Act truly can provide for the nonmedical

teamwork and therefore, hope for many persons with spina bifida that they will have a better chance of becoming productive citizens rather than burdens on society.

Because of its multimedical aspects a person with spina bifida will experience handicaps which truly can be classified as restricting normal development of that individual, therefore a developmental disability.

Another consideration is that a clearly visible physical handicap may often overshadow another disability, which could indeed go undetected and therefore untreated. This lack of coordination of professional efforts could result in permanent mental and social scars and a gross reduction in one's ability to be a contributing member of society.

The renewal of the Developmental Disabilities Act is important, as it is to date the best legislation designed to coordinate and render more efficient many programs with the end result of improving the life style and productivity of many individuals with either physical or mental handicaps. The early diagnosis and treatment by coordination of disciplines will avoid more burdensome services later.

We are not seeking to extend the target group definition but to make equitable by adopting the new one proposed by, and approved by the administration, Ad Hoc Coalition, and Advisory Council. The original definition excluded most handicaps by emphasizing the three illustrative handicaps. This in effect is discrimination by omission.

It is urged that the new definition, specificially: "Developmental Disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen, a handicap of comparable severity)," be adopted in place of the present grossly misunderstood definition.

All children, being in their developmental years, are entitled to an opportunity to achieve their fullest potential no matter what their mental or physical limitations are. Achieving that potential cannot be guaranteed, but the opportunity should be.

Children have only one chance at life and delays in implementing the Developmental Disabilities Act will only result in a greater population of permanently handicapped.

In conclusion, the description of what spina bifida is and how it results in a multifaceted handicap was presented mainly to focus your attention to this question: "How can a definition of a developmental disability remain in the present law which could exclude consideration of children with spina bifida as the present definition does?" The proposed definition provides for objective medical judgment and is clearly more suitable. The coordinating spirit of the Development Disabilities Act bridges the many gaps presently unattended, the end result will be a citizenry that has been more fairly served and is more productive in the social scene. The country needs the act and we support its renewal.

Here in the United States, the infant mortality rate in 1965 provides genuine grounds for pride. Those should be gratifying statistics.

[The prepared statement of Mr. Shurman with attachments follows :

STATEMENT OF THE

SPINA BIFIDA ASSOCIATION OF AMERICA

IN TESTIMONY BEFORE

THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

ON

THE DEVELOPMENTAL DISABILITIES ACT

BY

JACK SHURMAN, WOODMERE, NEW YORK

FEBRUARY 8, 1973

My name is Jack Shurman, I reside in the state of New York, am the parent of a disabled child and am the president of the Spina Bifida Association of America.

The Spina Bifida Association of America membership is made of approximately 10,000 families of persons born with spina bifida. I speak today for them and, confidently, for more than 100,000 other spina bifida children and adults.

Spina bifida is a birth defect leading to multiple disabilities in one in every five hundred newborn for a total of about eleven thousand live births in the United States each year. Spina bifida has probably existed as long as the history of man and yet only recently has there been any public awareness of its existence much less its consequences. There is a simple explanation. Host spina bifida infants used to die within weeks of birth, far too soon for society to acknowledge their presence. Within the past decade or so surgical techniques have been perfected which have increased the survival rate of these infants. Each year forward until the cause of spina bifida can be found and eliminated, an estimated eleven thousand spina bifida babies will be born, will live, will mature, and for better or for worse will enter the mainstream of American life. They all start out in this world much for the worse.

For the sake of brevity I would simply state that they are born with a mal-formation of the vertebrae and spinal cord. Spina Bifida is often euphemistically referred to as "open spine". At best, the spina bifida child will experience reduced sensation and muscle control below the waist.

It is most likely that he will be paraplegic. The spina bifida child is incontinent of bowel and bladder. He is the frequent victim of kidney infections which threaten his life.

Within the first few weeks of life seventy-five to eighty percent of the spina bifida children will develop hydrocephalus, a serious neurosurgical emergency which is now treated quite successfully by running a tube from the brain cavities to the heart, chest or abdomen to drain off excess cerebrospinal fluid. Failure to initiate this procedure promptly will result in brain damage.

Spina bifida requires the skill and constant attention of a neurologist, neurosurgeon, orthopedist, orthopedic surgeon, urologist, physical therapist, often times an ophthalmologist, dermatologist and psychologist. Except for a handful of major medical centers in large metropolitan cities, there is no single place for a spina bifida child to go obtain all these services. He travels from doctor to doctor, hospital to hospital, city to city. He is very much like my own son with spina bifida who in the first nine years of his life suffered through seventeen major operations. Under these circumstances there is no way for a spina bifida child to view the world as you and I see it. He is developmentally disabled from the moment the obstetrician spots the tell-tale protrusion of the spinal cord and asks the attending nurse to call the neurosurgeon and alerts the operating room. From that moment on he is a person with a substantial handicap as defined for the Developmental Disabilities Act.

"A disability of such severity that it prevents the individual from participating in and benefiting from the social, economic, educational, recreational or other opportunities generally available to his peers in his community who are not similarly handicapped."

From the moment of birth the struggle begins to convert a potential welfare dependent and ward of the State into a productive contributing citizen and taxpayer. To this end, the Developmental Disabilities Act, is the best, albeit, the only program that addresses itself to all the social and rehabilitative problems of the disabled person — recognizes that each of his many problems are related to all of the others — cannot be treated in a vacuum.

The Spina Bifida Association of America urges the Congress to renew and implement the Developmental Disabilities Act. This association also recommends the revision of the definition of developmental disabilities as stated in the act.

Some of the problems of the multiple-disabled are unique and each case of spina bifida is unique unto itself. Given almost any definition of a disability, we can find thousands of individuals with spina bifida who fit it perfectly.

We do not, however, believe the plight of the person with spina bifida is more tragic nor more critical than that of any other severly disabled person. We believe that the present definition of "developmental disabilities" which includes reference to specific disabilities can be interpreted to exclude or discriminate against those disabilities not mentioned by name. The Spina Bifida Association of America recommends adoption of the definition proposed

SUPPLEMENT TO

STATEMENT OF THE

SPINA BIFIDA ASSOCIATION OF AMERICA

IN TESTIM0NY BEFORE

THE SENATE SUBCOMMITTEE ON THE HANDICAPPED

ON

THE DEVELOPMENTAL DISABILITIES ACT

BY

JACK SHURMAN, WOODMERE, NSW YORK

FEBRUARY 8, 1973

This testimony is submitted by the Spina Bifida Association of America in support of Senate Bill S-427, the renewal of Public Law 91-517. commonly known as the Developmental Disabilities Act, as well as a revised definition of the target group to be served by this legislation. The feelings presented here are supported by a large group of citizens, both parents of children born with spina bifida and individuals with spina bifida themselves.

The Spina Bifida Association of America is predominantly an organization of parents with a unified purpose to help all persons with the birth defect SPINA BIFIDA achieve their maximum potential. The association feels it can speak for the interests of over 100,000 individual citizens with spina bifida, the majority being young children. Although spina bifida is the second most prevalent handicapping birth defect involving the nerve and muscle systems, affecting about 11,000 newborns each year in the United States alone, the public is generally uninformed as to its manifestations.

It is important to present in oversimplified terms what spina bifida is and how it results in a significant population with a physical handicap, one that confronts an individual with many challenges.

The words spina bifida literally mean "cleft spine" or "open

V

spine". During gestation of the infant the back bone remains open untill about the twelfth week. At this time it normally begins to close into* a tube around the nerve core called the spinal cord.

In spina bifida one or more of the individual bones or vertebrae fail to close into a tube around the spinal cord. Through such an abnormal opening the contents Of the spinal canal slip out much like a hernia. This forms a fluid filled sac the size of a small orange under the skin and is generally located in the region of the waist. The vital nerves! so contained are protected only by the skin rather than by the tough bony structure of the spinal column.

This disarrangement of the nerves of the lower spine usually results in a loss of both movement and! sensation of the lower extremities and in severe cases, paralysis from the waist down.

Another common complication can result from disturbances of the spinal fluid which ordinarily bathe the brain and spinal cord. An abnormal amount of fluid collects within the skull leading to excess pressures and enlargement of the head. This is known as hydrocephalus. |

Only in most recent years have medical advances been such that a baby born with spina bifida could safely be surgically treated to return the spinal cord nerve bundle to within the protective spinal column. This does not eliminate the damage already done but tends to protect the individual from possible future injury and infection. This early attention to this defect is essential and is usually advised within 24 hours of birth, and requires the skills of a neurosurgeon.

Likewise early detection and treatment of the hydrocephalus is equally as important to prevent brain damage and even possibly death. The surgical procedure prescribed here is to bypass the restricted cerebrospinal fluid routes by means of a "shunt". This is a small tube inserted into the fluid chambers within the skull which allows the excess fluid to be redirected to other parts of the body. No external devises are involved and one would be totally unaware of its use without specific reference to it.

Prior to these two medical advances only individuals with less severe forms of spina bifida were spared life long instituion-alization and that at great expense to the citizenry. This proper initial medical attention so described can actually establish the difference between a lifetime burden on the tax-paying public and a human being with a potential of being a contributing, self-supporting member of society.

As illustrated, the treatment of spina bifida requires a great deal of teamwork between many medical specialties. The habilitive spirit of the Developmental Disabilities Act truly can provide for the non-medical teamwork and therefore, hope for many persons with spina bifida that they will have a better chance of becoming productive citizens rather than burdens on society,

Because of its multi-medical aspects a person with spina bifida will experience handicaps which truly can be classified as restricting normal development of that individual, therefore a developmental disability.

Another consideration is that a clearly visible physical handicap may often overshadow another disability, which could indeed go undetected and therefore untreated. This lack of co-ordination of professional efforts could result in permanent mental and social scars and a gross reduction in one's ability to be contributing member of society.

The renewal of the Developmental Disabilities Act is important, as it is to date the best legislation designed to co-ordinate and render more efficient many programs with the end result of improving the life style and productivity of many individuals with either physical or mental handicaps. The early diagnosis and treatment by co-ordination of disciplines will avoid more burdensome services later.

We are not seeking to extend the target group definition but to make equitable by adopting the new one proposed by, and approved by the Administration, Ad Hoc Coalition, and Advisory. Council. The original definition excluded most handicaps by emphasizing the three illustrative handicaps. This in effect is discrimination by omission.

It is urged that the new definition, specifically:

> "Developmental Disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen a handicap of comparable severity)."

be adopted In place of the present grossly misunderstood definition. All children, being in their developmental years, are entitled to an opportunity to achieve their fullest potential no matter what their mental or physical limitations are. Achieving that potential can not be guaranteed, but the opportunity should be.

Children have only one chance at life and delays in implementing the Developmental Disabilities Act will only result in a greater population of permanently handicapped.

In conclusion— the description of what spina bifida is and how it results in a multi-faceted handicap was presented mainly to focus your attention to this question: "how can a definition of a developmental disability remain in the present law which could exclude consideration of children with spina bifida as the present definition does?". The proposed definition provides for objective medical judgement and is clearly more suitable, The co-ordinating spirit of the Developmental Disabilities Act bridges the many gaps presently unattended, the end result will be a citizenry that has been more fairly served and is more productive in the social scene. The country needs the Act and we support its renewal.

Respectfully submitted,

Jack Shurman

Jack Shurman

President
Spina Bifida Association
of America

Spina Bifida

—a birth defect

hope through research

Spina Bifida

—a birth detect

hope through research

Pronunciations: SPI-na BIF-i-da; me-NIN-go-cele; me-NIN-go-MY-e-lo-cele.

Children were playing happily in a kindergarten for the handicapped. Two of them had *spina bifida* (also occasionally called *rachischisis),* but this birth defect of the nervous system was concealed by their clothing, and the children appeared normal to casual visitors.

The words, spina bifida, literally mean "cleft spine." Every infant's backbone, while developing in the mother, remains open until about the 12th week of the mother's pregnancy. In spida bifida, one or more of the individual bones of the back (vertebrae) fail to close completely, leaving a cleft or defect in the spinal canal.

Through such an abnormal opening, part of the contents of the spinal canal can slip like a hernia. This produces a *meningocele* or a *meningomyelocele.*

What are the common symptoms and complications?

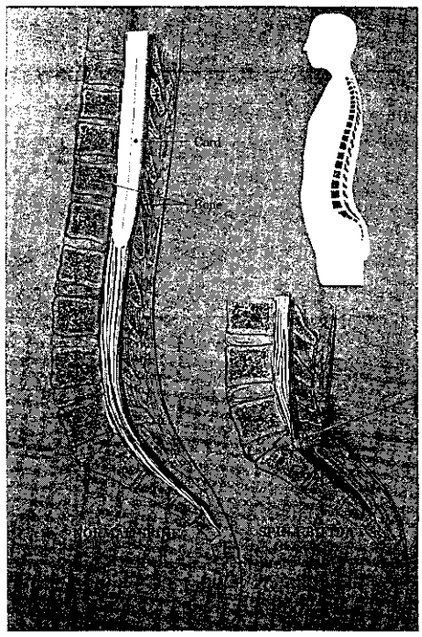
In its slightest form, called *spina bifida occulta,* the abnormality causes no symptoms at all, and may never be discovered. Or an X-ray of the spine which is taken for some other purpose reveals a small, unclosed portion of the spinal canal. A depression or dimple in the backbone over the defect, or a tuft of hair, sometimes leads to discovery of this harmless type of spina bifida.

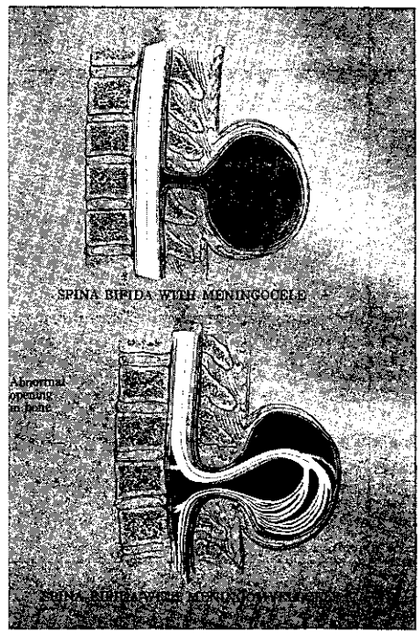
Mild or serious symptoms appear in some of the forms of spina bifida. In these, a sac, perhaps as small as a nut or as large as a grapefruit, protrudes from the backbone, usually at the lower end of the spine. At birth such a sac sometimes is completely covered with skin, but in other cases the nerve tissue is exposed.

When the sac contains some of the coverings *(meninges)* of the spinal cord, the ailment is called a meningocele. In more complicated cases, called a meningomyelocele, the coverings and some of the spinal cord *(myelo* means marrow and often refers to the spinal cord) have slipped through the bony opening as a sac *(cele),* which often contains some spinal fluid.

Since the sac most commonly contains portions of the lower end of the spinal cord, it is the legs of the patient which are most likely to be affected. In mild forms, the only difficulty might be weak muscles and inadequate skin sensation. If the injury to the spinal cord is more serious, the patient could have leg paralysis and no skin sensation on legs. Even in relatively mild spina bifida, bladder control is likely to be a troublesome complication.

Such symptoms are ordinarily present from the time of birth. However, symptoms may develop for the first time during adolescence. Rapid growth of the body at this time may overstretch the shortened nerves, leading to a progressive weakness.





Serious complications often occur. Where there is a large sac, especially one with a thin surface, friction from the baby's movements or clothing is likely to make the tissues raw. Infection of the spinal cord and brain coverings can result. In former days, meningitis frequently was a fatal complication. For this reason the sac must be carefully protected from undue injury, and surgical repair usually is recommended early.

Another common complication results from disturbances of the spinal fluid which ordinarily bathes the brain and spinal cord. In patients with meningocele, abnormal collections of fluid may take place not only in the spinal sac but also in the cavities within the brain. When an abnormal amount of fluid collects within the skull, this leads to an enlargement of the head called *hydrocephalus*.

What causes spina bifida?

Causes of spina bifida in humans are presently unknown, although more cases occur within some families than chance alone would account for. One of the goals of spina bifida research is the discovery of the cause or causes.

How common is spina bifida?

Estimates of the present number (the prevalence) of persons having spina bifida are difficult to make. When spina bifida and hydrocephalus or other nerve problems occur together, the ailment can be classified under any of these abnormalities. Sometimes spina bifida is included in the larger heading of birth abnormalities; of these about 60 percent are defects of the central nervous system.

The estimated number of new cases (incidence) in the United States for spina bifida alone or with hydrocephalus runs close to 3 for every 1,000 live births. Based on this rate, more than 11,000 children are estimated to be born with this birth defect every year. In addition, spina bifida appears in some miscarriages and stillbirths, but whether it acts as one of the causes of this loss remains for researchers to discover.

Recent statistics of the Department of Health, Education, and Welfare showed 1,151 deaths from spina bifida (including meningocele) in one year. This is less than the total deaths from acute appendicitis, but approximately ten times the deaths from polio since the polio vaccine became available. The survival rate for children with spina bifida is rising, probably due to research and its application in modern medical, surgical, and nursing care.

All these figures apply to relatively severe cases. Patients with minor degrees of spina bifida who die from other diseases would not be included within these mortality figures.

Treatment depends upon the situation

In the slightest cases of spina bifida, no treatment is required. The moderate cases require judgment as to whether surgery is advisable. Surgery prevents worsening of the condition in some instances, but cannot restore the lost functions. In those extreme cases where the sac of spina bifida breaks or appears about to break, immediate surgery becomes essential if the patient's condition permits.

Surgeons have operated on spina bifida patients of all ages beginning from a few hours after birth. Where hydrocephalus is or threatens to be a complication, surgery to shunt the extra fluid away from the brain is saving many patients whose condition would have been hopeless a few years ago. Investigators are developing and testing a variety of drugs with the goal of controlling hydrocephalus without surgery.

Infections can be a serious complication, whether in the bladder, the brain, or the spinal cord. Antibiotics are saving many patients with infections.

Because of the paralysis of some muscles in the legs, it is quite common for patients with spina bifida to develop stiffening of the joints and actual abnormalities of posture of the legs and feet. It is important from an early age that a child with spina bifida should have any necessary orthopedic measures to prevent such "contractures."

The family doctor, the orthopedic specialist, or the physiatrist (doctor of physical medicine and rehabilitation) frequently prescribes corrective shoes, braces, crutches, or other devices. These help the patient to make the most effective use of the weakened muscles, and to prevent the extremity from being maintained in an improper or awkward position. Crippling from "frozen" ankles, knees, or hips often can be prevented by "range-of-motion" exercises. Some doctors order these started for 3 or 4 times daily when the baby is a couple of days old. The goal is to keep joints movable and leg muscles from shortening (contracture). Mothers and fathers can learn these simple movements, always with their doctor's advice.

In some instances, operations for the transfer of tendons to restore proper muscle balance are helpful. Public health nurses or physical therapists in some communities will come into the home to give treatments the doctor orders.

Like all children, those with spina bifida need love and acceptance.

The future of these babies

Persons with spina bifida occulta ordinarily live normal lives. Some of those with moderate symptoms of spina bifida may have a shortened life span. Because of modern surgical and medical progress, even babies born with severe spina bifida have an improved chance to survive.

What is the risk of a second child with spina bifida?

According to investigators, "The genetic counselor takes a complete family history before he gives counseling about the risk of having a second child with spina bifida." The risk appears to be low in most families, but higher in some as shown by a family history of spina bifida or related birth abnormalities.

Some helpful voluntary associations

The Easter Seal Research Foundation of the National Society for Crippled Children and Adults awards research grants for studies on spina bifida and other ailments. The Society also has publications and information on spina bifida and other topics for the public. For information, contact the Library of the Society, 2023 West Ogden Avenue, Chicago, Illinois 60612. Information on services for children with spina bifida, including their special kindergartens and other facilities, may be obtained from State and local Easter Seal Societies.

A large nongovernmental source of leadership and financial support in the field of spina bifida is The National Foundation-March of Dimes. Public contributions to this national voluntary health organization finance more than 110 birth defects centers at major medical institutions where teams of specialists collaborate in programs of treatment, research, and teaching. Information may be obtained from The National Foundation-March of Dimes, 800 Second Ave., New York, N.Y. 10017 or from your county chapter.

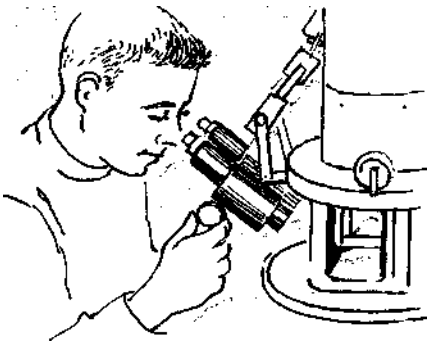
RESEARCH—the hope for spina bifida

Research in spina bifida is conducted by many medical centers including the National Institute of Neurological Diseases and Stroke (NINDS). This Institute is one of the National Institutes of Health, main medical research arm of the U.S. Department of Health, Education, and Welfare, at Bethesda, Md. NINDS and several other medical centers in America and other countries are conducting research, also, in the related abnormalities of meningocele, meningomyelocele, and hydrocephalus.

Since spina bifida occurs as a result of some disturbance of the normal growth before birth, there may be a genetic cause an in-

herited disturbance. It is also possible that factors operating during pregnancy could have a harmful influence on the developing child, leading to spina bifida. Current research seeks to determine the nature of such unfavorable influences in the environment.

In research projects with animals, spina bifida defects in baby rats have been produced by exposing the mother rats to chemical and physical agents. Studies investigate the effects on animals of drugs, toxins, and incomplete diets. Experimental animals have been produced with a hereditary form of spina bifida.



Specialists at NINDS who study the behavior of a disease in a population (epidemiologists) have investigated spina bifida and related ailments. Recognizing the gaps in present knowledge, epidemiologists have called for: more research for improved classification of spina bifida and commonly related birth defects; more study of the roles of heredity and environment; and further studies of close relatives of affected babies, including adequate studies of twins, where one or both have spina bifida.

As the result of a big NINDS project studying some 60,000 mothers and their offspring, conditions leading to spina bifida and other abnormalities of the newborn are expected to be understood more clearly. The Institute is cooperating with 14 medical centers throughout the Nation in collecting and analyzing detailed information.

More research is needed

Already, progress in research has produced improved treatment, but further discoveries are sought. A flow of new antibiotics is helping to control complicating bladder and spinal cord infections, but improved antibiotics are needed. Research in surgery of the nervous system has produced lifesaving techniques, but here, also, much remains to be accomplished.

However, basic research, such as that on the spinal fluid and nerve cells, is essential if the causes of abnormalties are to be located and controlled. Support of training of scientists for research is part of the program of attack on spina bifida and related ailments by NINDS.

From these many approaches, further progress is assured. Hope for conquest of birth abnormalities is stronger than ever before in history.

Other pamphlets

THE CHILD WITH SPINA BIFIDA, by Chester A. Swinyard, M.D., Ph.D. Helpful information for parents and friends; from Association for the Aid of Crippled Children, 345 East 46 Street, New York, N.Y. 10017. 1966. Free.

SPINAL CORD INJURY, Hope through Research, PHS Publication No. 1747. Problems, sources of help; from the Information Office. NINDS, National Institutes of Health, Bethesda, Md. 20014. 1969. Free.

Prepared by the Infortnation Office
National Institute of
Neurological Diseases and Stroke
NATIONAL INSTITUTES OF HEALTH
Bethesda, Maryland 20014

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FROM THE FIRST DAY

The Baby with Myelomeningocele

Newington Children's Hospital — Newington, Connecticut 06111

The material for this booklet was prepared by members of the Myelomeningocele Parents' Group at Newington Children's Hospital.

It is our hope that by offering this information, gained through our own experiences, we may be able to bring understanding and hope to other parents who have had a baby born with this condition, and to help them to feel less alone.

FROM THE FIRST DAY

In talking with one another, we have found that most of us had never heard of spina bifida or myelomeningocele until our own babies were born with this birth defect. Few of us had any understanding of the many medical terms with which we were confronted during the baby's first year. In addition, we were faced with the need to explain these complex problems to concerned relatives and friends. Hopefully, the following definitions, written in layman's language, will spare you some of the confusion we have known, and give new meaning to terms you will hear again and again.

THE IMMEDIATE MEDICAL PROBLEMS

Spina Bifida

The spine, which encases and protects the spinal cord, is made up of 31 bony segments, called vertebrae, which normally are well developed about the 12th week of pregnancy. If one or more of these vertebrae fail to develop fully, it leaves an abnormal opening or cleft in the spine, and a birth defect known as spina bifida results. This bone defect can be present with no trace of abnormality in the overlying skin and with no symptoms affecting the child. This is the mildest form of the condition and is called spina bifida occulta.

Spina Bifida with Meningocele

This is a condition in which some of the contents of the spinal canal have slipped out through the abnormal opening in the spine and are enclosed in a sac (cele), which protrudes from the backbone. Because this sac contains meninges (membranes of the spinal cord), in addition to spinal fluid, it is called a meningocele. An operation is necessary to remove the sac, but since there are no nerves involved, there is no paralysis. A baby born with a meningocele can **usually** be expected to live a normal life after surgery.

Spina Bifida with Myelomeningocele

This is the most serious and complicated form of spina bifida, as the sac which protrudes from the baby's back contains portions of the spinal cord, as well as meninges and spinal fluid. (Myelo means marrow and refers to the spinal cord.) You may occasionally hear this condition referred to as meningomyelocele or spina bifida cystica.

Nerve function is usually impaired from the defect downward, resulting in varying degrees of deformity and paralysis of the lower limbs, and lack of bowel and bladder control.

An immediate or early operation to repair the defect and prevent infection is usually recommended. Although

this surgery cannot restore the lost functions, it prevents worsening of the condition and improves the child's chances for rehabilitation.

Hydrocephalus

This is a serious complication which develops in a majority of the babies who are born with myelomeningocele. Sometimes called "water on the brain", hydrocephalus is caused by a blockage which interferes with the normal circulation and absorption of cerebrospinal fluid. This exerts pressure on the brain and there is an abnormal and rapid increase in head size.

The development of hydrocephalus is an emergency which could result in permanent brain damage or death. An operation, called a shunting procedure is usually necessary to relieve the pressure and prevent further enlargement of the head. The neurosurgeon inserts a slender, flexible tube in the baby's head to drain the cerebrospinal fluid into the heart where it then circulates with the blood. A valve inside the tube regulates the flow of the fluid. Shunts sometimes need revision due to the child's growth or other factors. If your child has had this surgical procedure, the neurosurgeon will tell you of any symptoms you should watch for that might indicate that the shunt is not functioning properly.

If your baby has not had a shunting procedure, you should be alert to the fact that any noticeable change in his head size should be reported to the neurosurgeon immediately.

Immediate or early repair of the myelomeningocele and surgical intervention to prevent or arrest hydrocephalus are essential to your baby's life and health. It is very frightening when you learn that your baby must have such major surgery, but thousands of newborns have had these operations with good results.

SECONDARY MEDICAL PROBLEMS

We mentioned earlier that impaired nerve function below the defect causes lack of bowel and bladder control (incontinence), and varying degrees of paralysis of the lower limbs (paraplegia). Although these problems are not usually of such immediate concern as those just discussed, they will require early medical attention. It is very important that you realize your child's life span may be dependent on the medical care he receives for his urinary system, and that his potential for ambulation is dependent on proper orthopaedic management and care. The neurosurgeon or your pediatrician will probably refer your baby to a special clinic, such as the Myelomeningocele Clinic at Newington Children's Hospital, where he will be examined on a regular basis by specialists in neurosurgery, urology, and orthopaedics.

In addition to the many things you have already learned about your baby's condition, at the clinic the urologist

will talk with you about the problems which may develop with the baby's urinary system, so you will understand why certain tests must be repeated at specific intervals to make sure the kidneys are functioning properly. The urologist may prescribe medication or institute other treatment to prevent infection and damage of the urinary tract.

The orthopaedic surgeon will discuss the baby's leg and muscle problems with you, and advise as to the type of treatment necessary to correct deformities of the spine and lower limbs. He will tell you about casting or bracing if your baby requires either. He may send you to the physical or occupational therapist to learn some simple exercises to help prevent joint contractures and strengthen the baby's leg muscles.

All of the babies and children followed in such clinics share common medical problems, but no two of them have identical conditions. Therefore, the team of specialists will coordinate their recommendations and establish an immediate and long-range treatment plan to best meet your child's particular needs, and help him to develop to his fullest potential.

You must resolve to follow the medical planning, as outlined, as only you can make it work. The doctors tell us that cooperative parents, participating in their child's rehabilitation program, are the most important members of the team.

If there are any aspects of your baby's treatment program that you do not understand, discuss them with the doctors. They are always ready to answer your questions and realize that it is important for you to "know why" if medical planning is to have real meaning for you.

The social worker at the clinic can answer other questions for you, and will help you with any problems you may have in following through with recommendations made by the doctors. Many of us have found it helpful to talk with the social worker about our concerns for the child's future, and our own feelings about having a handicapped child.

You should take your baby to your own pediatrician, of course, for his immunizations and for any problems related to his general health and development. It is well to request that copies of clinic notes on your baby be sent to your pediatrician so that he is kept informed at all times of the treatment program.

CARING FOR YOUR BABY AT HOME

You may have worried that your baby will be difficult to care for, but once he has had his initial surgery and is home with you, you will find that he may generally be handled much like any other baby. Unless the doctor has told you differently, the baby may lie on his back. He can, and should, be held and cuddled.

We do not feel that our babies had any abnormal pain. They cried when they were hungry, had gas pains, or wanted attention, as all babies do.

Your baby's lower extremities and all the area below the defect will probably be insensitive to heat, cold, and pressure. Because of this, his skin may blister or break down easily. You must make sure that his bath water is not too hot, and that his clothing and shoes are not too tight. Since he cannot move his legs normally, do not leave him lying in one position for long periods of time. Make sure that his diapers are changed regularly, as dampness also contributes to skin breakdown. You may avoid further medical problems by making it routine to check the lower part of the baby's body every day to see if there are any red marks from pressure or dampness, as these may quickly develop into open sores. The doctors will tell you if there are any other special precautions you should take.

If you have been taught an exercise program, do it as routinely as you do feeding the baby, as it is very important.

You will find that your baby can move the upper part of his body normally, and when he outgrows the infant stage, he should be stimulated and encouraged to use his arms and hands. He will enjoy the kind of toys other babies do, and will like being taken outdoors and seeing new things and other people and children. Keep him

upright as much as possible so he does not always view his world from a lying-down position.

It is important for all parents to go out for an evening together now and then, and most of us had little trouble in finding a friend, relative, or teenager to babysit so that we did not have to forego that pleasure. By locating a reliable sitter when the baby is small, there is usually no problem in her adjusting to changes in routine care as the child grows older.

YOU, THE PARENTS

So far, we have been concerned mainly with your baby, his problems, and care. But as parents of children born with myelomeningocele, we well remember the initial shock we suffered and the emotional adjustments we had to make after learning that our babies had serious physical problems.

We know that you, too, may well be struggling with strong, underlying feelings of despair, grief, and loneliness. It may still not be possible for you to believe that the baby you had anticipated so eagerly has come into the world with a complex medical problem. You may both be worrying that one of you is somehow responsible for the baby's condition. Or, you may be so overwhelmed that you feel it would have been better if the baby had not survived.

Perhaps it will help you to realize that all parents who are faced with this situation struggle with such thoughts and feelings. We have talked about our own initial reactions and they were all similar to those we have just mentioned. However, we have learned that these were normal reactions and that we need not feel ashamed for having felt as we did. Somehow these feelings must be resolved or they may lead to a strained marital relationship and prevent the development of normal parent-child relationships with your baby.

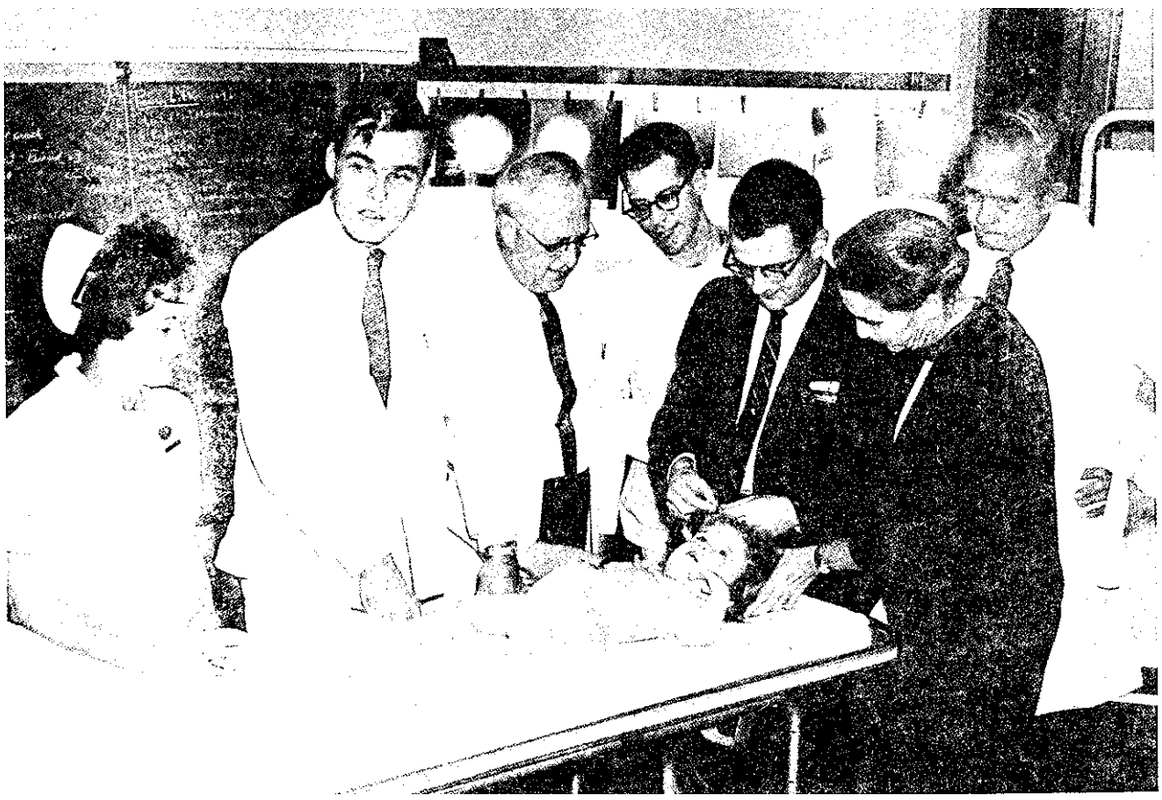
There is no one solution to this problem, of course. Many of us found that once we really understood the facts about the baby's physical condition, we were less frightened and better able to cope with the situation. Learning that the exact cause of myelomeningocele is not known helped us overcome the fear that we were responsible for the baby's problems. Attending Parent Meetings, talking with other parents at Clinic, and seeing the progress their children had made, showed us that we were not alone with our problems and encouraged us about our own babies' potential for rehabilitation. Many of us found that frank discussions of our feelings with a social worker or an understanding friend were helpful.

As we began to resolve our own feelings and came to realize that the baby's potential was of more importance than his handicap, we were better able to cope with other people's reactions. We know now that our acceptance

of the child's handicap has a positive effect on other people and their attitudes, and we want love and encouragement for our children, not pity.

Your child's potential for accepting and successfully adjusting to his handicap will depend in great part on your combined energies and ability in understanding his problems. The most vital factor leading to maximum growth and development, both physical and mental, is a stable home, with parents Who want and love their child. We know that you will be as proud of your child and his accomplishments as we are of ours.

At Newington Children's Hospital the combined skills of all specialties and necessary paramedical disciplines are available to contend with the complex medical, psychosocial and other problems associated with myelomeningocele.



Senator JAVITS. Thank you very much. I appreciate the contribution you have made. All of these witnesses have called our attention to categories not covered, and which we believe should be covered.

I wish to assure you we will give them the most earnest attention.

Mrs. Akerley, if you would like a minute to make any statements, please do.

STATEMENT OP MRS. MARY AKERLEY, CHAIRMAN OF THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

Mrs. AKERLEY. Yes, I would. I have one thing I would like very much to say. We think this bill has received very disappointing appropriations. If these major difficulties are cleared up, that is, the difficulties that center around who is included and who is not included, we believe that the developmental disabilities programs will prove themselves as effective catalysts in the service of the severely handicapped. I hope that the disagreements about the target population will not jeopardize the renewal.

If it is not given that opportunity, not only will those in need be left without help, but additional injustice will have been done to the mentally retarded, whose spokesmen were the generous advocates three years ago for the rest of us.

I would also ask that our formal statements be made a part of the record.

Senator JAVITS. That is ordered to be made a part of the record.

Even if it means forgoing my whole bill, this is going to happen in a constructive and an appropriate way.

Our next witness is Dr. Crosby. If you would put your statement in the record, then you could simply sum it up or comment on it, if you choose. We will give you a time limit of 8 minutes.

STATEMENT OF KENNETH G. CROSBY, Ed. D., PROGRAM DIRECTOR, ACCREDITATION COUNCIL FOR FACILITIES FOR THE MENTALLY RETARDED

Dr. CROSBY. Thank you, Mr. Chairman. The Accreditation Council for Facilities for the Mentally Retarded very much appreciates this opportunity to testify concerning Senate bill 458.1 am Dr. Kenneth G. Crosby, and I have been the Program Director of the Accreditation Council since it began operation in January of 1970.

The Accreditation Council is a consortium of national organizations that represent both the professional providers and the consumers of services to the retarded. The sole purposes of the Council are the improvement of services for the retarded and the protection of the consumer of such services through the identification of facilities and agencies that do provide high quality programs.

The Council seeks to fulfill these purposes by developing standards for quality services, devising survey techniques to assess compliance with standards, conducting surveys of facilities to determine the extent of their compliance, and awarding accreditation to those facilities that are found to be in compliance and to provide high-quality programs. The Council's Standards for Residential Facilities for the mentally retarded are, as you know, incorporated in Senate bill 458.

The Council is now conducting surveys of facilities to assess their compliance with these standards. The Council will soon publish standards for community agencies providing services to persons with mental retardation, and it will subsequently offer surveys of such agencies.

The Accreditation Council wholeheartedly supports the objective of S. 458. The statement which I will file with you for the record indicates the conclusions reached by the Council in its consideration of the bill.

At this time, I would like to summarize the major points in that statement.

The Council believes that the right of mentally retarded citizens to receive adequate treatment and habilitation should be expressly stated in statute. The fundamental requirements for realizing this right are the implementation of an individualized habilitation plan and its accomplishment within a normalizing and least restrictive environment. These are enduring requirements, and think it would be appropriate to fix them in law.

Detailed standards for the operation of habilitation programs, however, must be continuously subject to review and revision in the light of increased knowledge, changing practice, and experience with their application and implementation if they are to remain an effective means of impoving services, and if they are to encourage the exploration of new approaches. The Council's standards, though quite new, have already required revision.

For these reasons, the Council believes that, in the interest of improving services to the mentally retarded, its standards should not be put into law.

The Accreditation Council possesses and has already demonstrated the necessary flexibility and the necessary will to change and upgrade standards to make them more effective means of improving services. Through its liaison relationships with other organizations, the Council also possesses the ability and the determination to assure appropriate participation in standard setting. The Council's concern with standards for community programs as well as with standards for residential facilities also enhances its capability to develop effective standards in both areas.

Information derived from surveys to assess compliance is essential to the maintenance of currently effective standards. Conversely, assessment of compliance necessarily involves interpretation and judgment, based on an intimate knowledge of the fundamental intent of the standards, plus ready access to the means of effecting modification when necessary for the achievement of that intent. The dual, complementary function of standard setting and compliance assessment cannot be separated without weakening the capacity to perform each function.

Just as national standards are necessary for the effective improvement of services, so is a uniform method of compliance assessment essential for optimal results. Even if State-conducted surveys of State-operated facilities did not represent a conflict of interest, an accurate assessment of compliance with uniform standards could not be achieved with the diverse methods that might be employed by the 50 States.

Such surveys can best be done by an independent group. The Council's unique survey procedures, moreover, are necessary for the meaningful assessment of compliance with its standards and for gaining assurance that a facility does, in fact, provide adequate services to its clients.

The Council also shares the bill's objectives of discouraging inappropriate admission to institution and encouraging the exploration of alternatives to institutional care. There is, however, much concern among both providers and consumers regarding the establishment of alternatives that may be no better than the institutions unless relevant standards are met.

In the light of these considerations, the Council has suggested, in the statement that has been filed, changes in the bill that would, in its opinion, contribute to more effective achievement of the bill's objectives. These changes would provide that facilities comply with standards established by the national accreditation body for such facilities; that surveys of facilities to assess compliance with standards be conducted by this accrediting body; and that the alternative programs of care encouraged in the bill also comply with the standards established by the accrediting body.

The Accreditation Council represents a partnership of providers and consumers, which has been supported by Government and brought together for the sole purpose of improving services to the retarded. The Council believes that the acceptance of its standards by the authors of this bill supports its conviction that there is great value in the voluntary approach to setting standards and assessing compliance with them, especially when the potential exists, as it clearly does in S. 458, for effective support of this voluntary approach by complementary governmental activity.

Thank you, Mr. Chairman.

Senator JAVTTS. Thank you, Dr. Crosby. Your statement will be ordered to be made a part of the record.

[The prepared statement of Mr. Crosby follows:]

United States Senate, Subcommittee on Health of the Committee on Labor and Public, Welfare—Hearings on S.458, February 5, 1973.

STATEMENT of Kenneth G. Crosby, Ed.D., Program Director, Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals.

Mr. Chairman, Members of the.Subcommittee. The Accreditation Council for Facilities for the Mentally Retarded appreciates this opportunity to testify concerning Senate Bill 458, the Bill of Rights for the Mentally Retarded. X am Dr. Kenneth G. Crosby. I have been the Program Director of the Council since it began operation, in January, 1970.

The Accreditation Council for Facilities for the Mentally Retarded is a categorical council of the Joint Commission on Accreditation of Hospitals, established by agreement between the Joint Commission and a consortium of national organizations that represent both the professional providers and the consumers of services to the retarded. The current organizational-members of the Council are: the American Academy of Pediatrics, the American Association on Mental Deficiency, the American Nurses' Association, the American Psychiatric Association, the National Association for Retarded Children, the National Association of Private Residential Facilities for the Mentally Retarded, and the United Cerebral Palsy Associations. The American Psychological Association is expected to become a member, and additional applications for membership are anticipated. Each of the Member Organizations of the Council makes a financial contribution to its operation and appoints two representatives to sit on the Council and conduct its affairs. In addition, the Council has established liaison with thirty-three other national organizations interested in services for persons with mental retardation and other developmental disabilities. Since its inception the Council has received grant support from

the Division of Developmental Disabilities, Social and Rehabilitation Service, U.S. Department of Health, Education, and Welfare.

The sole purposes of the Council are the improvement of services for the mentally retarded, and the protection of the consumer of such services through the identification of facilities and agencies that do provide high quality programs. The Council seeks to fulfill these purposes by developing standards for quality services, devising survey techniques to assess compliance with standards, conducting surveys of facilities to determine the extent of their compliance, and awarding accreditation to those facilities that are found to be in compliance and to provide high-quality programs. The Council's Standards for Residential Facilities for the Mentally Retarded, which were published in September, 1971, are, as you know, incorporated in Senate Bill 458. The Council is now conducting surveys of residential facilities to assess their compliance with these Standards. The Council will soon publish standards for community agencies providing services to persons with mental retardation and other developmental disabilities, and it will subsequently offer surveys of such agencies.

The Accreditation Council wholeheartedly supports the objective of Senate Bill 458, which, like the Council's own goal, is the improvement of services to persons with mental retardation. The Council is pleased that this Bill has been introduced. Anticipating this event, the Council discussed, at its last meeting, how its own activities could most effectively further the achievement of the Bill's intent. I am pleased to be able to report to you today the results of the Council's deliberations.

Considering recent developments affecting services for the retarded on the voluntary, legislative, and judicial fronts, the Council believes, first of all, that the time is at hand when the right of mentally retarded citizens to receive adequate treatment and habilitation should be expressly stated in statute. The fundamental requirements for realizing this right are the implementation of an

individualized habilitation plan, and its accomplishment within a normalizing, humane, and least restrictive environment. These are enduring requirements, and it would be appropriate to fix them in law.

The ways in which treatment and habilitation must be provided in order to be effective, and the environmental features that are required for habilitation, however, necessarily change with increasing knowledge, and especially as new and innovative programs may be shown to be better and more effective methods of delivering services. In order to be an effective means of improving services, therefore, and in order to encourage innovation and the exploration of new approaches, programmatic standards must be continuously subject to review and revision in the light of increased knowledge, changing practice, and experience with their application and implementation. The Council's Standards for Residential Facilities, though quite new, have already required revision in order to make them more effective instruments for assuring quality services. Although the Council recognizes that laws are subject to change, and that legislation is a dynamic process, it has some concern about the speed of response to changing needs that may be achieved if detailed standards for the operation of facilities are incorporated in statute. For these reasons, the Council believes that, in the interest of improving services to the mentally retarded, detailed, programmatic standards for the operation of habilitation programs—such as the Council's Standards for Residential Facilities, which are included in the Bill before us—should not be put into law.

As a national, voluntary agency that includes both provider and consumer participation, the Accreditation Council possesses and has already demonstrated both the necessary flexibility and the necessary will to change and upgrade standards to make them more effective means of improving services. Through its liaison relationships with other national organizations, the Council also possesses the ability and the determination to assure appropriate participation in standard setting.

Finally, the Council's concern and experience with standards for community programs for the mentally retarded, as well as with standards for residential facilities, enhances its capability to develop effective standards in both areas.

As 1 have suggested, information derived from surveys of facilities to assess compliance with standards is essential to the maintenance of currently effective standards. Conversely, assessment of compliance with standards necessarily involves interpretation and judgement based upon an intimate knowledge of how the standards have been developed and of their fundamental intent, plus ready access to the means of effecting modifications when these are necessary for the achievement of that intent. To illustrate, surveys of several facilities by the Council indicated that a number of the Council's standards were not understood by the facilities in the way that was necessary to achieve their intent. This information was immediately presented to the Council, and the standards were modified forthwith so as to express their intent more clearly. Again, surveys revealed lacunae in the standards, in that the surveyors observed practices that they knew to be inconsistent with the Council's conception of an adequate program, but that were not stated explicitly in the standards. This intelligence, too, was presented to the Council, and the gaps in the standards were immediately filled. The conclusion is clear: the dual, complimentary functions of standard setting and compliance assessment cannot be separated without weakening the capacity to perform each function effectively.

Just as the Bill (and the Council) holds the promulgation of nation-wide standards to be necessary for the effective improvement of services, so is a uniform method of compliance assessment essential for optimal results. Even if state-conducted surveys of state operated facilities did not represent a fundamental conflict of interest, an accurate assessment of compliance with uniform national standards could not be achieved with the diverse methods, judgements, and interpretations that might be employed by the fifty states. Such surveys can best be done by an

independent national body representing both the providers and the consumers of services for the retarded, which, of course, is exactly what this Accreditation Council is.

Rather than focusing, in the more usual way, on the administrative organization and structure of a facility, the Council's survey concentrates on assessing compliance with standards in the individual programs and in the daily lives of a representative random sample of facility residents. The surveyor's assessment is derived from reviewing the record of each resident in the sample; from observing the resident, in the living unit and in program areas; from talking to him (when that is feasible); and from observing and talking with the direct-care contact personnel who are responsible for the resident's daily care. Only by conducting such a "program audit" of a sample of residents can compliance with the Council's standards be meaningfully assessed and assurance be gained that the facility does in fact provide adequate services to its clients.

The Council also shares the Bill's objectives of discouraging inappropriate admissions to institutions and encouraging the exploration of alternatives to institutional care. There is, however, a great deal of concern among both providers and consumers regarding the establishment of alternatives to institutional care that may be no better—or even worse—than the institutions, unless relevant standards are met. The Council, indeed, has seen clear justification for this concern during the surveys it has conducted: residents have been placed in living situations that are even less desirable than the institution from which they came.

For the past two years the Council has been engaged in the development of standards for community agencies serving the retarded. As was the case with the standards for residential facilities, the development of these standards has involved the participation of administrators, practitioners, researchers, and consumers, representing a wide cross section of the population concerned with programs for the mentally retarded and developmentally disabled. These national standards are

currently being field tested by representative agencies, and they are expected to be adopted by the Council and published later this year. With this accomplishment the Council will have made available standards for all facilities and programs serving the retarded and developmentally disabled.

In the light of these considerations, the Council suggests that the objectives of Senate Bill 458 may be more effectively achieved by making the following changes in Section 3:

(1) Delete the words "which shall be done in cooperation with the National Advisory Council on Standards for Residential Facilities for the Mentally Retarded established under section 1109 of this Act" from Sec. 1101 (a) of Fart A of Title XI of the Public Health Service Act, and insert at the end of Sec. 1101 (a) the following: "Surveys to determine the compliance of facilities with the standards established under part C of this title shall be conducted by the national accrediting body for such facilities, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals."

(2) Add the following paragraph to Sec. 1106 of Title XI of the Public Health Service Act: "(d) A facility shall be deemed to meet the standards promulgated under part C of this title if it is accredited by the national accrediting body for such facilities, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, provided that the Secretary may cause an independent survey of compliance with the standards to be made in any facility surveyed by the Accreditation Council whenever he finds such an independent survey to be necessary to validate the findings of the Accreditation Council survey."

(3) Delete the title "National Advisory Council on Standards for Residential Facilities for the Mentally Retarded" and Sec. 1109 of Title XI of the Public

Health Service Act, and replace this material with the following: "Revision of Standards. Sec. 1109. The Secretary shall seek and receive the advice of the national accrediting body for facilities and programs for the mentally retarded, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, in respect to (1) recommendations for any changes, revisions, modifications, or improvements in the standards established under part C of this title, (2) any regulations promulgated or proposed to be promulgated by him in the implementation of the standards established under part C of this title; provided that nothing herein shall limit the authority of the Secretary to seek and receive advice in respect to the above matters from any source he deems appropriate."

(4) Modify part C to provide that facilities must recognize the right of each resident to receive adequate treatment and habilitation; that this right shall be realized through the implementation, for each resident, of an individualized habilitation plan, accomplished within a normalizing, humane, and least restrictive environment; and that facilities must further comply with the standards established by the national accrediting body for such facilities, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals.

(5) Add the following paragraph to Sec. 1108, "Alternative Programs of Care," of Title XI of the Public Health Service Act: "Community resources and community living situations for the mentally retarded receiving grants under this section shall comply with the applicable standards established by the national accrediting body for such programs, the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals. A program shall be deemed to be in compliance with such standards if it is accredited by the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals,

provided that the Secretary may cause an independent survey of compliance to be made of any program surveyed by the Accreditation Council whenever he finds such an independent survey to be necessary to validate the findings of the Accreditation Council survey."

The language of the Bill makes it clear that its provisions apply to both publicly operated institutions for the mentally retarded and to those privately operated facilities that receive public support. The Council assumes that the Bill is also intended to apply to the significant and growing number of units for the mentally retarded that are located within state mental hospitals, as such units fall within the Council's concern. Should there be any doubt about the inclusion of such units in the Bill's provisions, the Council would further recommend that their inclusion be made explicit.

The Accreditation Council truly represents a partnership of providers and consumers, supported by government and brought together for the sole and express purpose of improving services to the mentally retarded. The Council is, of course, highly gratified that its first efforts in this endeavor—its Standards for Residential Facilities for the Mentally Retarded—have received the acceptance indicated by their incorporation in Senate Bill 458 (although, for the reasons given, the Council believes this incorporation to be unwise). The Council believes this acceptance supports its conviction that there is great value in the voluntary approach to setting standards and assessing compliance with them, especially when the potential exists, as it so clearly does in Senate Bill 458, for effective support of this voluntary approach by complimentary governmental activity directed to the same end: the improvement of services to our disabled citizens.

Senator JAVTTS. I have a comment to make about what you have said, but I will wait until Mr. Boyer is through. You have 8 minutes, Mr. Boyer.

STATEMENT OF DONALD A. BOYER, PRESIDENT, NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

Mr. BOYER. YOU have shown an interest and concern for the handicapped, today. Our group, the National Association of Private Residential Facilities for the Mentally Retarded is represented by Mr. Wayne Nielsen, and Mr. Manny Hall, who is our executive director.

You have in your hands a document that we have formulated. For that reason, I will not go over it. Senator, because the hour is getting late, I would request that we have the opportunity of submitting a more comprehensive recommendation at a later time.

Senator JAVTTS. Yes, you may do that. The record will be left open for 10 days.

Mr. BOYER. Thank you. I think it might be important to make a couple of comments without taking advantage of your time.

The National Association of Private Residential Facilities represents 271 facilities at this point, with approximately 13,000 handicapped people being involved in those programs.

We, of course, as a private association have been very excited about the trend toward deinstitutionalization, since this appears to us to be a very causitive step.

We would point out, however, that in order to implement that requires a great deal of coordinated planning by all agencies involved in order to attain the goals of deinstitutionalizing. This goal and these programs at this point pose a number of problems because real attention has to be given to the delivery system of service.

We are very concerned about this issue and you have had a good deal of testimony on it. As to types of handicaps that may not be included and just exactly how people do get services, standards are very important yet those standards are not worth very much if there is not an appropriate funding mechanism with the standards. I think this point has been made a number of times before. We have gotten ourselves into the position of becoming quite program oriented and yet no one is really in a position to pay for the program.

There are real gaps, and I think that many of us in the field were convinced that the DDA bill would fill some of those gaps. That has not come to pass.

One of the issues that has not been raised today, but one that I know is important to a number of the other people that have appeared, is the changes that have occurred in internal revenue regulations as relates to foundations and individual charities. Consideration must be given to this problem. I would want to simply call that to your attention and maybe we can supply more information in a more detailed report as we go along.

I would like to point out the need of incentive measures for loans for both profit and nonprofit organizations for the construction of the kinds of facilities that the deinstitutionalization concept proposes.

Phase III of the price-wage freeze is having a real impact on the private residential facilities. Social security increases, minimum wage increases and, of course, the fact that we are competing for the same staff as everyone else adds to our concerns. That this segment of our society continues under the price-wage freeze, phase III, is of great concern to all of us.

I think, sir, that those are the things that I would like to point out and you have said that we may submit our statements, which I would now do.

Senator JAVITS. It will be ordered included in the record.

[The prepared statement of Mr. Boyer with supplemental testimony follows:]

TESTIMONY FOR THE SENATE SUBCOMMITTEE ON THE HANDICAPPED ON S427 AND S458

FROM THE

NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

MR, DONALD A. BOYER - PRESIDENT

We appreciate the opportunity to appear before the Committee as representatives of the two hundred and sixty nine members of the National Association of Private Residential Facilities for the Mentally Retarded. Our Association consists of urban and rural facilities, both large and small, across the United States, which offer many levels of care to the developmentally disabled and multiply handicapped. I would like to preface my remarks by stating that for many years the accepted answer to the problem of the developmentally disabled and multiply handicapped was institutionalization. Fortunately, there were those who began to question the dehumanizing treatment, and urged a more normalizing way of life and pushed for deinstitutionalization. Deinstitutionalization sounds very good and is a very positive step; however, it calls for coordinated planning by all agencies to ensure that the Qoals for individualization are obtained. What I would like to convey to the Committee are those problems which are being created, and address myself to some of the items that would aid in the creation of a delivery system for the developmentally disabled and multiply handicapped.

Few persons would debate the idea that handicapped persons should be involved in meaningful activities during their waking hours and few people would debate the merits of providing good care for the handicapped, yet it becomes increasingly evident that a birth to death funding mechanism is necessary, not only to! provide care, but to pay for and provide the necessary programs which will meet the individual needs of the handicapped. There exist today wide gaps

in the funding mechanisms for the early childhood years, for adult and aged handicapped persons. We have become proponents for programs, but we are not funders. The Developmental Disabilities Act and the "Bill of Rights for the Mentally Retarded" have the potential for alleviating this problem - the potential to provide what many realize has been needed for so long.

Along with funding for services is the need for flexible national standards for those services. These standards must relate to the full spectrum of the multiplicity of service needs of the developmentally disabled and multiply handicapped. Firs standards which do not permit the evolvement of various levels of care in small as well as large facilities must be reviewed and altered to implement a more normalizing and humanizing care. We have been working with the National Safety to Life Code personnel to reflect these needed changes; however, in the interim, we are at a standstill in trying to provide innovative programming which will better meet individual needs.

National standards need to allow ample time for the improvement of existing services during implementation of the accreditation process. Existing programs must have sufficient time to bring their programs and facilities within the guidelines, or the ever increasing crisis of services will become even more critical than it is currently. The developmentally disabled and multiply handicapped are entitled to the same rights as others; however, a problem of this magnitude cannot be rectified immediately without causing further suffering and hardship. Through a flexible set of national standards, which would include building, safety and program standards; new and existing programs could better plan to meet the individual needs of handicapped persons.

Incentive measures in the form of low down payment, low interest loans are needed for proprietary as well as non-profit concerns. These measures would assist with developing the alternatives to institutionalization. Once standards

of service are realized nationally, such incentive measures would ease greatly the problems of initiating or expanding the much needed programs for all levels of the developmentally disabled and multiply handicapped. Special concern must be given to the needs of severely afflicted young children as well as adult and aged individuals. The initiation and expansion of programs which will result in direct services to the individual are badly needed.

Current governmental restrictions in Phase III present a nearly facility closing crisis. Social Security increases, the pending minimum wage increase, and other rising costs absorb the small margin on which most programs in the private sector operate. The current freeze on fees for services has forced some facilities to curtail services and may force others to completely close their doors unless rectified immediately. In this same vein, Foundation and individual giving have, in the past, been positive sources of funds for the private sector; however, with the current tax law ruling being unfavorable to charitable giving, this too has given rise to the increasing financial concern of the private facility.

In viewing this testimony, we would appreciate your consideration of the points mentioned. It is our feeling that all of us are very concerned about comprehensive services to meet the needs of developmentally disabled and multiply handicapped persons, and we are encouraged by your willingness to work together to find a workable, uniform program for our nations' handicapped citizens.

Thank you,

Donald A. Boyer, President
National Association of
Private Residential Facilities
for the Mentally Retarded

TESTIMONY FOR THE SENATE SUBCOMMITTEE ON THE HANDICAPPED ON S427 AND S4S8

FROM THE

NATIONAL ASSOCIATION OF PRIVATB RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

MR. DONALD A. BOYER - PRESIDENT

Addendum:

Mr. Chairman, our Association had a meeting last night and we would like to ask your permission to make an additional statement.

It was the consensus of opinion that the "Bill of Rights for the Mentally Retarded" directs itself toward larger institutions and facilities. He feel that strong standards must also be adopted for the kinds of persons who reside in small community residential settings, who require codes that will provide them with a more normalizing environment in which to live and develop.

We further feel that we represent a larger number of handicapped persons in this type of setting, and over a wider geographic range, than any other organization. We therefore request that our Association be given membership on the new National Advisory Board so that we may use our vast experience to help develop sufficient regulations to provide this segment of the developmentally disabled and multiply handicapped population with adequate protection.

National Association of Private Residential Facilities for the Mentally Retarded

1645 Jonquil Street, N.W., Washington, D.C 20012

Donald A. Boyer, *President*
Manford A. Hall, *Executive Director*

SUPPLEMENT TO THE TESTIMONY GIVEN FEBRUARY 8, 1973
TO THE
SENATE SUBCOMMITTEE ON THE HANDICAPPED

Prepared by: Donald A. Boyer, President
Wayne G. Nielsen, Chairman Legislative Committee

The National Association of Private Residential Facilities for the Mentally Retarded enthusiastically supports the objective of improved services provided the developmentally disabled, which includes the mentally retarded. Standards of care and effective funding for high quality of service have been of vital concern to the Association over the years. It is in keeping with the objectives of improving services for the developmentally disabled and multiply handicapped that the Association would like to share its concerns and make the following points:

1. NAPRFMR believes there is great value in the voluntary approach to setting standards and assessing compliance with them, especially when this approach is supported by government. The voluntary approach would create a system of effectively approving standards while at the same time provide a means for updating and revising such standards, which appears vital after making initial assessment surveys. It is therefore the strong recommendation of the Association that the "Bill of Rights for the Mentally Retarded" is a very positive steps however, the standards contained in S458 would have a

greater impact in improving the services for the mentally retarded if they were not put into law, but were placed in rules and regulations. Such rules and regulations could be reviewed and modified to better accomplish the desired objective of improving services for the mentally retarded on an ongoing basis.

2. If S4SS were put into law with the specific standards included, the National Association of Private Residential Facilities for the Mentally Retarded would feel it vital to have representation on the proposed National Advisory Council to the Secretary (Section 1108). This would replace the positive voluntary effort that has been demonstrated by the Accreditation Council for Facilities for the Mentally Retarded since 1969. It is the feeling of the Association that it has in the past, and must continue in the future, to play an instrumental role in improving services for the mentally retarded. In this way the mutual concern for improved services could be more widely and appropriately realized.

3. The National Association of Private Residential Facilities for the Mentally Retarded has a very real concern that there be established a group for control of care. It is with this in mind that the Association would recommend that this be vested in the Accreditation Council for Facilities for the Mentally Retarded.

4. The National Association of Private Residential Facilities for the Mentally Retarded; in support of improved services to the developmentally disabled, which includes the mentally retarded, urges that funding for care and programs be substantially upgraded and that the standards be tied to appropriate funding. Without an appropriate funding system, the practice of inappropriate and inadequate placement of the developmentally disabled and multiply handicapped will continue just as it has for so many years. Unfortunately, in so many instances, placements for the handicapped have been effected by following lines of available funding without regard for the adequacy of care or program. Care of the handicapped can be found in nearly every conceivable type of residence

which has led to an unfortunate situation of warehousing - thousands of handicapped in minimal care situations. The vastness of this practice creates a situation which will require an appropriate birth to death funding situation or the very intent of the legislation may make more tragic an already deplorable situation. Availablilty of funding tied to standards must be a key factor in realizing any improvement of services.

5. As a national policy, NAPRFMR endorses and supports equal treatment of profit and nonprofit facilities. This Association is comprised of nonprofit as well as profit private facilities and it is our belief that the quality of service must be the criteria of funding. Incentive measures for both kinds of programs should be available to all segments of the private sector to help meet the needs of the handicapped. Rules and barriers need to be removed which discriminate between the public, private nonprofit, and private profit programs. The private sector has assisted greatly in providing alternatives of care through the years. A more permissive attitude must be realized to stimulate further involvement and expansion of the role of the private sector. The private sector has in the past counted on charitable giving and foundations for support in operating high quality programs; however, with the recent rulings by the Internal Revenue Service, these sources are fast disappearing and require a broader funding for services to simply maintain the level of programs that currently exists.

6. It is recommended that a plan to upgrade existing facilities must go on concurrently with the development of community based programs. There is a continuing need for alternative levels of care; however, if serious attention is not rendered to existing services during the process of developing the alternative programs, the total care of the developmentally disabled will be further minimized. Movement to the community in many instances requires special service to prepare an individual for movement. If existing services are not

upgraded, movement of many persons may be minimized by chronic institutionalization without appropriate programs,

7. As national standards are realized, steps must be taken to (a.) insure that those standards do not impede the innovative programing that is necessary and (b.) insure where federal standards are *in conflict* with existing state statutes, rules and regulations, that the federal standards shall supercede the existing rules. Several cases in point are the state licensing responsibilities which are vastly different in various states and many times preclude the possibility of adequate housing and programs to meet specific needs. State fire standards also vary in many instances and in many instances do not reflect the national Safety to Life Code which permits alternative types of residential services designed to meet the needs of the individual being served. Antiquated commitment laws also serve many times as barriers to effective placement.

If the standards are to accomplish the objective of improved services for the developmentally disabled and multiply handicapped, the inhibitors to actual implementation must be removed.

8. It is recommended that the funds from the Developmental Disabilities Act extension be specifically designated for programs of a direct service nature as well as initiation of a new service. Unfortunately, many of the funds are being spent conducting surveys which have already been done. Though surveys have been helpful in the past, they are now used to delay service initiation. The millions of handicapped and developmentally disabled have been counted often enough and are still awaiting services which will help them live a more normalizing life with human dignity. Let's stop spending our money on surveys and begin to provide money for direct services. Treatment can be realized if there are funds to pay for it.

9. The multiplicity of support services at the community level are badly needed. Funds for the development of support services will aid greatly in

achieving some of the major points made by the "Bill of Rights for the Mentally Retarded". Programs at the community, college and university level are needed to assist in training para-professionals as well as professionals in the newer alternative types of care. It is anticipated that if the standards were implemented today, the staff needs would be quadrupled over night. Trained persons are simply unavailable without some type of assistance program at the college level.

In conclusion, NAPRFMR supports the extension of the Developmental Disabilities Services and Facilities Construction Act of 1970 and urges that the intent of S458 be inacted; however, we feel that the standard setting portion of S458 should be made a part of the rules and regulations with the assignment and enforcement going to the Accreditation Council for Facilities for the Mentally Retarded which has demonstrated its positive efforts in this area since 1969. The intent of these pieces of legislation is most laudable and it is with the highest regard for improved services for our developmentally disabled and multiply handicapped citizens that our Association makes the above recommendations. Again, the National Association of Private Residential Facilities for the Mentally Retarded appreciates the opportunity to share with other persons in improving services to those in our society who are handicapped.

Senator JAVITS. Thank you very much. I appreciate that and it was certainly helpful testimony. It is highly factual and in an area that we are trying to reach.

I might make just one comment to Dr. Crosby. I appreciate what you say, however, we must establish criteria which will not invalidate this legislation as being too general to stand the test of constitutionality and equal protection of the law. Bearing in mind what you have said, the desirability for the highest degree of flexibility in the rights, I assure you we will consider how to achieve that result that most carefully and probably come back to you and other witnesses in an effort to get your expertise on this subject.

Again, thank you both, very much.

Our next panel consists of the three State mental health directors, Dr. Kott, Mr. Scheerenberger, and Mr. Brain. Mr. Brain will be representing the National Association of State Mental Health Program Directors. These are associations of State officials.

We will hear first from Dr. Kott.

STATEMENT OF MAURICE G. KOTT, PH. D., DIRECTOR, DIVISION OF MENTAL RETARDATION, NEW JERSEY DEPARTMENT OP INSTITUTIONS AND AGENCIES

Dr. KOTT. I am representing the National Association of Coordinators of State Programs for the Mentally Retarded. We have filed with the committee a statement of testimony with respect to S. 427 and S.458.

Senator JAVITS. Without objection, that will be ordered included printed in full at the end of your testimony.

Dr. KOTT. I would appreciate the opportunity to outline some **of** the major points raised in our testimony. With respect to the Developmental Disabilities Act extension, we are in favor of it. We are in favor of a change in the definition to open eligibility to clients on the basis of functional need rather than categories of disability with the caveat that unless there is additional money available for the program, there will be less money available for each case.

Secondly, we are in favor of establishing in the bill a fixed Federal matching ratio rather than a decreasing one. There are current patterns of funding in the areas of social services and rehabilitation programs which do not diminish funding to applicants in successive years. We suggest that a similar approach be adopted in the developmental disabilities program.

This is particularly important because in our experience in funding local agencies, they collect money by nickels and dimes through volunteers. A reliable rate of Federal aid is all the more important to them because of the built-in fluctuations in community donations.

In terms of newspaper stories about the reduction of funds which possibly will effect OEO-sponsored agencies and other nonprofit organizations, the amount of money which will be available by way **of** community fund-raising councils to local agencies will be restricted; therefore, it will be harder to come up with the local matching share **for** DDSA grants. We recommend a flat 80 percent matching ratio in this legislation.

With respect **to the Bill of Eights for the Mentally Retarded, we feel the** need is **legitimate and** we **applaud the initiative of the bill's**

sponsors. However, this committee should consider a number of factors.

The first of these is that the focus of the proposed program should not be restricted to institutions. Otherwise, there is likely to be an increase in isolation of residential facilities. That is, the bill might create official boundaries between institutional and community based programs for the mentally retarded.

In many States, people are admitted to residential services in conjunction with other kinds of services which take place in the community. Followup and review is necessary if you are going to have good residential facilities. Guardianship is critical. We suggest the bill permit interdigitation between community and residential services.

We subscribe, second, to some of the comments of the previous speakers with respect to the dangers inherent in incorporating program standards in the legislation. We feel that it may be premature at this point to encumber the bill with standards of a regulatory nature.

Our suggestions include the following: First, that the Senate should contemplate the Bill of Rights for the Mentally Retarded not as a separate bill, but as a logical part of the Developmental Disabilities Act extention. We question the wisdom of establishing separate State councils for institutional improvements and developmental disabilities. The existence of two councils may make for conflict at best and lack of integration at worst.

We recommend that the States be required to submit a State plan to insure that there will be improvement in residential facilities. This plan should contain about five elements. First, it should contain clearly defined objectives which make residential services a part of the total service delivery system. Second, the plan should convey clearly the State's intentions of providing alternatives to large facilities. Third, it should provide for analyzing individual case needs in terms of the feasibility of utilizing alternatives to residential placement. Fourth, the plan should incorporate a mechanism to assure integration with community services. Fifth, the plan should include a yardstick which will be applied to the measurement of progress. The critical thing is not whether standards are attained, but really what happens to the individuals in residential services.

We suggest that it should be possible at this late date in history to clearly identify what one intends to happen to children and adults in institutions. It should be required that the State demonstrate that such change has taken place.

Senator JAVITS. Your time has expired. Would you please bring your statement to a conclusion?

Mr. Kott. If I may return to the first point, about consolidation. I deal each day with the title XIX program and intermediate care benefits, with vocational rehabilitation, with elementary and secondary education, and so forth, and can tell you that obtaining integration at a State capital level is extremely difficult. This problem is difficult enough without the morass of overlapping and often contradictory program regulations and guidelines issued by HEW. With this thought in mind we respectfully urge Congress to direct HEW to put together at least their aspects of the goals and the objectives of these programs as they hinge upon the mentally retarded and developmentally disabled so that it will be somewhat easier at the State level to make effective use of the multiplicity of Federal funding sources available.

Thank you, sir.

[The prepared statement of Dr. Kott follows:]

STATEMENT OF TESTIMONY
ON LEGISLATION TO

Extend and Amend the
Developmental Disabilities
Services and Facilities
Construction Act of 1970

and on

The Bill of Rights For"
The Mentally Retarded

S. 427 and S. 458

Respectfully Submitted
to the

SUBCOMMITTEE ON THE HANDICAPPED
COMMITTEE ON LABOR AND PUBLIC WELFARE
UNITED STATES SENATE

The Honorable Jennings Randolph, Chairman

by

Maurice G. Kott, Ph.D..

NATIONAL ASSOCIATION OF COORDINATORS OF STATE
PROGRAMS FOR THE MENTALLY RETARDED, INC.

February 8, 1973

The National Association of Coordinators of State Programs for the Mentally Retarded, Inc. is a non-profit organization dedicated to expanding and improving services to over six million mentally retarded citizens in the United States. The major aims of the Association are to facilitate nationwide communication among state and local agencies providing programs for mentally retarded and other developmentally disabled persons and to represent the interests of state program officials on issues of national significance.

The members of our Association are the primary focal point within state government for delivery of services to the mentally retarded and developmentally disabled in the fifty states and territories. In most states our members are responsible for directing state operated mental retardation institutions, stimulating the development of a wide range of community services for retarded children and adults and administering state allocations under Title I of the Developmental Disabilities Act. Thus, the reasons for our interest in the legislation under consideration today are self-evident.

Since the Subcommittee has before it two distinct legislative proposals, we have divided our statement today into two sections. In the first section, we will deal with the proposed extension of the Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517) and suggest several ways in which the Committee might amend this legislation in order to strengthen and clarify the existing statutory authority. The latter part of our testimony comments in general on the special challenges presented by the provisions of 24-hour, residential services to mentally retarded children and adults and more specifically on the initiatives proposed in Senator Javits' "Bill of Rights for the Mentally Retarded" (S. 458). Although, for convenience of presentation, We have divided our testimony into two parts, we want to stress at the outset that our Association recognizes and supports the need for an integrated approach to serving the mentally retarded and other developmentally disabled persons in both community-based and institutional settings.

I. Extending and. Amending the Developmental Disabilities Act

A. Extention of the Act. The new thrust toward the creation of a broad continuum of community-based services for the mentally retarded has stimulates a growing awareness of the need for a creative partnership between federal, state and local government as well as the private sector in developing and financing mental retardation services. The federal government took its first important step in this direction when Congress enacted the Community Mental Retardation Facilities Construction Act of 1963 (P.L. 88-164). However, it was not until 1970, largely through the initiative of this Committee, That Congress agreed to enter into a full partnership with the states by enacting the Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517). In taking this action, Congress expanded P.L. 89-164 in three essential ways. First, the scope of the

former program was broadened to include not only the mentally retarded, but also persons suffering from other developmental disabilities originating in childhood including cerebral palsy, epilepsy and other neurological handicapping conditions. Second, the program was broadened to include support for a full array of service programs as well as construction of community facilities. And finally, states were granted greatly expanded responsibility for planning and implementing a comprehensive program of services under a new formul a grant program.

Although the Developmental Disabilities program has been in actual operation for less than eighteen months in most jurisdictions, we believe that the wisdom of Congress in initially enacting the legislation has been amply demonstrated. There are many examples of ways in which states are using the limited funds available under DDSA to fill existing gaps in service and extend services to substantially handicapped children or adults who, until recently, were either unserved or inappropriately served. For the Subcommittee's information, we are attaching a few typical examples of DDSA projects (Appendix A).

Some jurisdictions encountered initial frustrations in getting the program off the ground because of delays in issuance of federal regulations and guidelines, internal conflicts, difficulties in organizing state councils and completing initial state plans, and the low level of federal funding. However, these are the types of problems often associated with new', ground-breaking legislation, "and now that they have been ironed out, all jurisdictions appear to be progressing well.

In view of the complexity of the legislative mandate spelled out in the Act and the need for long-range continuity in federal funding, the Association recommends that Part C of the Act be extended for a period of five years. Authorization levels should reflect the magnitude of the task before us in delivering quality services to all developmentally disabled persons. We recommend, therefore, that authorization levels be permitted to grow from $150 million in FY 1974 to $250 million in the fifth year of the program.

Last year, NACSPMR undertook a survey of state agencies responsible for administering planning, service and construction grants under Title I of the Developmental Disabilities Act. The purpose of this survey was to determine the general magnitude of need for federal support under P.L. 91-517 and how states planned to put such funds to use in expanding and improving services.

The results clearly substantiated the tremendous unmet need for services to developmentally disabled persons and indicated that the states are in a position to put significantly increased federal funds to wise use. While time and space will not permit a detailed analysis of the survey findings, it might be helpful to the Subcommittee if we outlined several of the general conclusions we reached.

1. State Governments Continue to Carry the Lion's Share of the Financial Burden of Providing Services for Developmentally Disabled Persons. Historically, states have assumed the major portion of the financial responsibility of providing residential care for the mentally retarded. Today, over one billion dollars annually is spent on the operation of state institutions for the mentally retarded alone.[1] This figure constitutes a 282 percent increase in state spending over the past nine years. In addition, states budgeted between 300 and 500 million dollars for community services to the mentally retarded last fiscal year.[2] While comparative figures from previous years are unavailable, it is safe to say that the general area of community services for the developmentally disabled constitutes the fastest growing portion of the budget in many states.

   The above stastistics make one point very clear: the federal government is still a junior partner in financing services for the developmentally disabled. In fact, there is some evidence that the federal government's commitment to this program has actually declined over the past five years relative to the states. Thus, in FY 1967 Congressional appropriations for programs operated by the Division of Mental Retardation3 constituted 5.0 percent of state operating expenditures for public mental retardation institutions. If the President's budget figures are accepted in the current fiscal year, this percentage will have dropped to 4.0 percent...

2. State and Local Agencies Continue to Face a Tremendous Backlog of Unmet Needs. Despite the sharp increase in programs and facilities over the past few years, all states face a staggering demand for more and better services to meet the needs of developmentally disabled citizens. A few examples of the magnitude of unmet service requirements may help to convey the sense of urgency involved:

1 This figure does not include state expenditures for care of the retarded in mental hospitals, nursing homes, boarding homes, schools for the deaf and the blind and a variety of other settings. For example, the National Association of State Mental Health Program Directors, Inc. has reported that some 33,246 retarded individuals were residents in state mental hospitals in forty-two reporting states. If we assume an average annual per resident cost of $5,000, then estimated state expenditures for retarded residents in public mental hospitals would total approximately $183 million.

2 It is important to note that this figure does not include additional millions of state dollars budgeted for special education, rehabilitation, social services, etc. to mentally retarded children and adults; nor does it encompass services to non-retarded, developmentally disabled persons and the important contributions of local communities and the private sector.

3 Redesignated the Division of Developmental Disabilities in 1971.

o A 1969 survey indicated that two-thirds of the over 70,000 retarded citizens in New Jersey were not receiving all the diagnostic, treatment, educational, day training or vocational services they needed.

o In 1972, Arkansas had a capacity for 1,371 retarded individuals in state operated residential facilities with another 128 beds under construction. However, an estimated 3,120 retarded children and adults - or well over double the number of beds available - required residential services. In addition, only 6 to 12 percent of the 10,039 retarded individuals who could benefit from community services were receiving them.

o An additional $37.2 million annually would be needed just to provide for the top priority needs of the developmentally disabled in Iowa according to the state Division of Mental Retardation". Among the most pressing problems are the shortage of community residential services, day care for children, work activity programs for retarded adults and work training and placement facilities.

o Less that 350 of the estimated 8,455 retarded individuals requiring sheltered workshops and work activity services in Oklahoma are presently enrolled in programs. The state estimates that it would cost $31,084,800 annually to provide such services to all clients. In addition, $37.8 million is needed to provide residential services to some 9,000 developmentally disabled persons in a variety of community and institutional settings.

Similar examples of service needs could be cited in almost every state; however, we hope that the above illustrations will give the Subcommittee an idea of the tremendous problems which face state and local providers of service.

3. Most State Agencies Are Using DDSA Funds to Stimulate and Reinforce the Trend Toward Community-Based Services. While DDSA funds are only a small portion of the total service budgets in all states, this assistance is vitally important because it helps financially strapped state agencies to demonstrate innovative techniques of delivering services. Several illustrations of how states are making use of DDSA funds can be found in Appendix A.

In addition, despite the frustrations often associated with inter agency coordination , the DDSA Councils in many states have proven to **be** effective common meeting grounds for planning and integrating public **and private** services to developmentally **disabled persons. These activities are beginning to pay off in more effective and economical delivery of client-centered services.**

States Could Put Sharply Increased Federal Funds to Wise Use. Appendix B provides a state-by-state comparison of FY 1973 allotments and the amounts agency officials in the various states feel they could wisely use in FY 1973. While these estimates range from ultra-conservative to ultra-liberal based on the perspective and observations of the individual administrator, the important point is that almost every state felt that it could use three to ten times the amount presently available. In fact, many states provided detailed plans on how they would go about using increased federal funds. Interestingly, all of these proposals emphasized the need for increased attention to the development of locally based services.

For example, Georgia reported that an additional 12,844 retarded children and adults are in need of day care and training services which would cost a total of $25.7 million. Massachusetts estimates that it would cost approximately $20.3 million to purchase or construct the 225 group homes that are needed to serve some 2,250 retarded adults - a considerable number of whom are currently residents in antiquated state . institutions. The cost of providing sheltered workshop services or home industries for the l,500 developmentally disabled adults in New Mexico would run $2,100,000 in the first year. Rhode Island could use $1,360,000 to provide services to 447 infants, transportation for 885 children and adults, community group living for 450 clients and information, referral and related services for over 5,000 epileptic and cerebral palsied individuals.

Several states cited the large number of requests for DDSA funds they have received during the first year of the program. The following table illustrates the tremendous demand for funds during the initial phase of the program. In interpreting these figures, it is important to keep in mind that: (1) since the program was so new, many potential applicants did not receive word in time to apply; (2) the relatively small amount available to each state discouraged many potential applicants from applying; and (3) due to funding restrictions, many states placed strict limits on the purposes for which funds could be used and/or the amount that could be requested. Despite these facts, each of the states reported that they were able to fund only 1/4 to 1/25 of the projects requested.

Comparison of Funds Requested and State Allotments Under Title I of the Developmental Disabilities Act, FY 1971.

STATE	FY 1971 ALLOTMENT	TOTAL AMOUNT REQUESTED (est.)
Illinois	? 477,111	$ 1,996,163
Massachusetts	246,124	6,000,000
New Jersey	304,000	1,800,000
New York	1,413,340*	13,400,000*
Oregon	100,000	1,500,000

B. Amendments to Existing Statutory Authority. While strongly endorsing extension of the legislation, we would like to suggest to the Subcommittee several amendments which, in our view, would strengthen the basic thrust of the program. These proposals are based on the collective experience of our membership who, as we indicated earlier, are directly responsible for administering state DDSA allotments in most states:

1. Definition of "Developmental Disabilities. Certainly, one of the most controversial issues surrounding the legislation ha» been the use of the term "other nuerologioal disorders" in the definition of developmental disabilities. Thus far, the Secretary of HEW has refused to recognize any disabling conditions besides mental retardation, cerebral palsy and epilepsy (which are specifically referred in the statute) as coverable under **the** Act. In reaching this decision, the Secretary apparently took into account: (1) the minimal appropriations initially available under the program and (2) the lack of unanimity among experts concerning handicapping conditions which can be considered neurologically-based and also meet the other criteria in the definition. On the other hand, organizations representing other substantially handicapped children and adults - most notable, learning disabled and autistic children - understandably have strongly petitioned to have their groups recognized as developmentally disabled.

   One of the basic tenets underlying the Developmental Disabilities legislation is that a significant degree of overlap exists among the etiological conditions and service needs of children and adults suffering from substantial, continuing disabilities originating in childhood. Convinced of this fact, in 1970, Congress took an initial step toward mandating a functional approach to serving the population in need, by enacting the Developmental Disabilities Act. At the time, our Association supported this step. Now, based on our experience with the program, we agree that further modification in the definition of the term "developmental disabilities" is needed. At the same time, we do not feel that the program's primary focus on the most substantially disabled clients should be abandoned, since such individuals whether they are labelled mentally retarded, cerebral palsied, autistic, epileptic, or whatever - are the ones most frequently rejected by other generic and specialized service systems. With these thoughts in mind, we endorse the recommendation made recently by the National Advisory Council on Developmental Disabilities in regard to the definition. Under this proposal, the definition of developmental disabilities would be revised to coincide with the definition of disability used in the Social Security Amendments of 1972 (P.L. 92-603)*, thus, eliminating all references

* i.e. "a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful employment (or in the case of a child under eighteen, a handicap of comparable severity)."

to specific etiological conditions. This approach would have the advantage of opening up the program to certain autistic, learning disabled and other persons handicapped in childhood who met the tests of severity and chronicity. It would also allow for close continuity with other federal programs based on determination of disability such as social security for dependents disabled in childhood, the new federalized cash assistance program for the aged, blind and disabled and social services authorized under Titles IVA, XIV and XVI of the Social Security Act. Finally, by tying the definition to the social security criteria, we have reasonable assurances, based on existing social security data covering some fifteen years, that the revised definition will not dissipate the program's present focus on the most substantially disabled children and adults.

2. Authorization of a Consolidated Project Grant Authority. The Association supports the creation of a consolidated project grant authority for the Developmental Disabilities program. At the present time, the Division of Developmental Disabilities in RSA administers four small project grant programs - initial staffing grants ($4.4 million in FY 1973) which are being phased out, Hospital Improvement and Hospital Inservice Training grants ($4.3 million in FY 1973) which also are being phased out, Rehabilitation Services project grants ($9.8 million in FY 1973) and DDSA set-aside grants of national significance ($2.1 million in FY 1973). Consolidating these project grant programs into a single broad-purposed authority would not only eliminate a good deal of administrative red tape and a source of confusion to state and local program administrators, but would also provide an excellent opportunity to clarify the purposes for which these project funds should be used to reinforce and strengthen the basic formula grant program.

3. Deinstitutionalization and Institutional Reform. The Association strongly supports the addition to the Act of a targeted program to stimulate the placement of mentally retarded institutional residents* into more homelike, community-based settings and to minimize the need for care in large, congregate living facilities. We will have more to say about this proposed program later in our testimony.

4. Establishment of a Fixed Federal Matching Ratio. P.L. 91-517 provided for a federal matching ratio of 75 percent in the first two years of the program and 70 percent in the third

* Although most of these individuals have a primary diagnosis of mental retardation, **it is important to note that** many **suffer from** other secondary **or overlapping handicapped, such as cerebral palsy,** epilepsy, etc.

year. This declining federal matching ratio is a carry-over from the old M.R. staffing grants program. When viewed in the context of the severe, continuing handicaps faced by developmentally disabled persons, continuity of federal, state and local aid to a habilitative service program becomes absolutely crucial. Unlike agencies serving clients with short-term, acute health or mental health conditions, programs for the developmentally disabled have a relatively slow turnover of clients and, therefore, benefit little from private insurance, Medicaid or other third party health payments. Thus, any decline in federal support must be compensated for by increases in already over-committed state and local, public and private sources.

Assurance of a continuing level of federal support over a period of years is often a prerequisite for reaching the most underserved areas of a state. Without such assurance, agencies in areas which have a relatively rich array of services and local matching sources often capture the lion's share of a state's allocations and the underdeveloped sections of a state suffer. The lessons learned under the former mental retardation staffing grants program were quite instructive in this regard.

For this reason, the Association recommends that a continuing 80 percent matching ratio be established for this program. This ratio coincides with the matching terms used in the federal-state rehabilitation program and other similar grant programs.

5. Definition of "Construction." The Act should be amended to include the cost of land in the definition of construction. At present, land is not defined as a reimbursable cost for purposes of federal construction grants. This exclusion, sometimes serves as a significant barrier to raising local matching funds for a new facility, especially in heavily urbanized settings where the cost of land is often exorbitant. This proposed amendment would draw the Act into conformance with the definition of construction used in the Vocational Rehabilitation Act.

6. Mortgage Insurance and Annual Interest Grants. The Association endorses the idea of mortgage insurance and annual interest grants to cover the costs of constructing facilities for the developmentally disabled. Experience with the program since 197.0 indicates that only about 12 percent of formula grant funds under Title I of P.L. 91-517 have gone to financing construction projects. Given the pressing need for expanded services, the relatively low priority given to construction is, in our view, a wise and rational allocation of resources. Nonetheless, this voluntary "moratorium" on federally financed construction is leading to an ever growing backlog in need for new and remodeled program space. Church basements and run-down, second-hand buildings will not suffice much longer.

Authorizing mortgage insurance and annual interest grants is one low cost way for the federal government to stimulate needed new construction. We favor this approach. However, we do not see it as a replacement for continuation of existing construction authority under Part C of the legislation. Because of the dearth of

local matching sources, a grant mechanism may be the only effective means of stimulating the construction of a facility in a rural or urban poverty area, for example.

7. Approval Authority for Construction Grant. Since the initial Mental Retardation Facilities Construction Act was passed by Congress in 1963, the federal government has always retained final approval authority over construction grants. In the early days of the program, when state agencies had little experience in dealing with the unique space needs of community mental retardation programs, this requirement undoubtedly was a wise precaution. Today, however, the states have been administering and processing construction grants for close to a decade and federal review and approval does little but add to the reams of red tape and time involved in processing construction grant applications. For this reason, we recommend that final approval authority for construction grants be delegated to the states.

8. University Affiliated Facilities. The Association recommends that authority for construction and demonstration and training grants to university affiliated facilities, authorized under Section 121 and 122 of the Act, be extended for five additional years. In addition, the Association feels that the Act should be amended to require that all future OAF grants be reviewed and found by the state DDSA agency to be in conformance with the comprehensive state plan developed under Section 134. Such a requirement would help to assure that the UAF's activities were relevant to the service goals and objectives established in the state plan and that this important training and service resource was working in concert with the state advisory council and designated state agency.

II. New Initiatives in the Area of Residential Services

Over the past few months, public attention has been focused on the deplorable conditions which exist in a number of state residential treatment facilities for the mentally retarded across the United States. Feature newspaper articles, magazine stories and television news reports and documentaries have uncovered the tragic fruits of decades of public and professional neglect. Understaffed, overcrowded, isolated from the community and inadequately funded, these facilities offer residents little more than a substandard level of custodial care.

The publicity generated by these developments has awakened the public to the need for immediate, drastic improvements in our system of providing services to retarded children and adults. Words such as "Willowbrook","Partlow", "Belchertown" and "Orlando" cogger up in the public's mind scenes of almost unspeakable human degradation. However, in the furor of the moment, it is important that we not lose sight of the advances that have taken place over the past decade and find ways of building upon this experience.

Many states have developed over the past decade or so an array of community-based, daytime services to reduce the long-range need for institutional placement. These programs, coupled with greater public understanding and awareness of the problem of mental retardation, are making it possible for more and more parents to maintain their children at home. In addition, several states have begun to establish a variety of alternative living facilities in the community to relieve the pressures on and reduce the size of traditional state institutions.

It is also important to recognize that a growing number of state institutions for the retarded are no longer the "snakepits" we have recently seen depicted in the press and on television. There have been notable improvements in many established institutions.

Nonetheless, we, who are so intimately involved in the operation of public institutional facilities, would be the first to admit that there is a serious need to improve residential services for the mentally retarded in this country. Despite the wide disparity in the quality of services rendered from state to state and institution to institution, almost without exception public residential facilities in all jurisdictions - even those with apparently the "best" programs - have deficiencies which should be corrected. The worst facilities present us with crises of major dimensions.

Senator Javits and other Senators who joined him in co-sponsoring the so-called "Bill of Rights for the Mentally Retarded" (S. 458) are to be complimented for taking the initiative in tackling a major problem which society has swept under the rug for too long. Our Association wishes to thank the Senator as well as his colleagues in both Houses of Congress who joined with him in casting[1] a national spotlight on the problems of residential services and suggesting ways in which the federal government might help to alleviate the present situation.

While warmly backing Senator Javits' initiative and his recognition of the need for positive federal intervention, we wish to express some reservations concerning the provisions of S. 458 and offer some suggestions for improvement.

First, the bill tends to read as if institutions exist in a virtual vacuum. With the exception of Section 1208 (Alternative Programs of Care), S. 458 deals exclusively with improving existing public residential facilities. While we can appreciate the need to focus in on an identifiable legislative target, the failure of the bill to adequately address the need for simultaneous improvements in community services to the retarded could result in an unfortunate program emphasis. In its present form, the legislation runs the danger of conveying to applicants for funds and recipients of services that the institution is an end unto itself. This is the very attitude - i.e., viewing the institution as the **only** service alternative available to the **retarded** - **which forms the core of** the

dilemma faced by the field today. As indicated earlier, the states and local communities have only begun to offer parents of retarded persons viable alternatives to the residential institution. However, these alternative residential and daytime services are currently in woefully short supply in most states. A federal initiative directed exclusively at improving existing facilities could only tend to impede the development of additional- alternatives and, thus, reinforce a monolithic model of services which has been largely discredited in the professional community.

From a practical point of view, it is becoming increasingly difficult in many states to identify the boundary lines between institutional and community services. We see regional centers for example, assuming responsibility for institutional intake, placement, and aftercare, and institutions developing strong community placement teams and other outreach efforts. Most experts agree that this evolutionary change in the role of the institution, so that it is viewed as only one piece in a continuum of services, is a very healthy trend. We hope this Subcommittee will attempt to reinforce this trend in whatever legislation it prepares.

Second, in our view, the incorporation of residential standards in statutory law would tend to make it more difficult to adapt the 'standards to changing program needs. The JCAH Accreditation Council for Facilities for the Mentally Retarded wisely took the attitude in initially promulgating residential standards that new standards should be subject to change as additional experience was obtained. We agree that any set of professional standards must be a "living" document which can be readily adapted to changes in the state-of-the-art. To lock any set of intricately detailed program standards into statutory law is likely to destroy the flexibility necessary to meet changing program needs.

Although the JCAH residential standards were published only a little over a year ago, already amendments to the basic document have been approved by the Council. This is as it should be with any enterprise as new and untested as residential service standards,

One illustration might help to demonstrate the rigidity which could result from statutory standards. Section 2.4.1.5.4 (Section 1150(f) of S. 458) states that a "bacteriostatic soap shall be used unless otherwise prescribed." The most commonly used soap with this characteristic contains hexachlorophene which is presently under attack by the Food and Drug Administration. If bacteriostatic soap were to be completely banned by FDA and the JCAH standards were made part of federal statutory law, would: (1) every resident need a prescription for non-bacteriostatic soap; or (2) would we continue to use soap with a hexachlorophene base despite a possible FDA ban on manufacture and sale - having to bootleg it in to meet standards; or (3) would we have to ask Congress to amend the law and run the full gauntlet of the legislative process?

Third, the establishment of state advisory councils which are separate and distinct from the state DDSA planning and advisory councils, would create, at best, a serious problem of coordination and integration of functions. The role of the present state DDSA councils encompass both community and residential services. Creation of a separate council could only lead to further isolation of the residential facility.

Fourth, for sometime the members of our Association have looked forward with great anticipation to the issuance of residential service standards and, therefore, were delighted when JCAH standards were promulgated in late 1971. However, it is important to recognize that these JCAH standards are new and untried. To date, they have been applied to only a few residential facilities (N.B. It is worth noting that only one of the six facilities initially surveyed was able to achieve even provisional accreditation.)

The feedback our Association has received from officials at the surveyed facilities suggests that there are still a number of bugs in the accreditation process and, perhaps, even some basic philosophic hurdles which will have to be overcome before the standards are generally embraced by practitioners in the field of residential services. Among the specific concerns which have been expressed to us about the JCAH Standards are the following: (1) They deal with items in a rather specific and precise manner which may be advantageous in evaluating a facility against a "standard" but still fail to disclose, with any degree of confidence, the quality of service delivered. Standards should be guides toward the attainment of specific objectives rather than dicta imposing rigid legal or programmatic concepts; (2) It remains to be demonstrated that the staffing requirements included in the JCAH standards, of and by themselves, assure adequate services. If we use "net releases alive," "deaths," and "admissions" as possible indicators of quality, it soon becomes apparent that this data is hardly covarient with per resident daily expenditures* (see Tables 8, 9 and 10, Mental Retardation Source Book, Department of Health, Education, and Welfare, 1972, pp. 15-20). Even if one wishes to avoid the question of the validity of such indicators and deals instead with reputation for quality, some states which appear to have a relatively high quality program are spending less on no more (or have a lower ratio of staff to institutional residents) than other states which have distinguished themselves in a most negative fashion; (3) likewise, there is no clear evidence to date that the precise physical and space standard applicable to the design and equipping of living units equates with the delivery of quality services. Even if staffing requirements were up to par, a strict interpretation of the physical standards alone would preclude most public residential facilities in the United States from meeting JCAH accreditation requirements. The replacement cost of these facilities, which now house thousands of retarded children and adults, would be astronomical. For example, six of New Jersey's seven institutions probably would not meet JCAH space requirement and would have to be taken "off the line" and replaced at a cost of approximately $120 million.

* Variation in per resident expenditures are mainly attributable to increased personal costs.

Fifth, while we agree in principle to the proposition that the federal government should not encourage substandard programs by continuing to finance the "bad" along with the "good," we have some reservations about the mechanism for cutting off federal funding which is built into S. 458. In essence Section 1206 of the bill would permit the Secretary of HEW to terminate all federal assistance to any institution which failed to meet the JCAH standards within five years after the date of enactment. However, Section 1207 would extend the required time for compliance if "in any fiscal year the appropriation for grants under Section 1202 (institutional improvement) does not meet the amount authorized...."

The problem is that no specific authorization levels are established in Section 1202. Yet, the ultimate success of the venture envisioned would rest largely on the willingness of Congress to commit the federal government to full participation in the cost of the upgrading of residential facilities. Estimates on the costs involved are not readily available but, given the magnitude of the task, we would guess that federal aid totally in the neighborhood of $1 billion annually would be required.

If only minimal authorization levels were set in Section 1202, the end result might be that the most backward facilities, with relatively limited sources of federal funds, might have little incentive to improve and might end up losing all federal aid. And so the poor institutions would only tend to get poorer.

Let us now turn to a few suggestions for structuring an alternative to S. 458. It is our view that such a program should contain some of the following elements:

1. A clear, targeted new authority is needed which will assist the states in reforming their present system for delivering residential services to the mental retarded. Such a program, which might incorporate the major goals of the Javits proposal and take the form of an additional title to the Developmental Disabilities Act, is required to assist the states in reforming their present systems for delivering residential services. The focus of this effort should not be directed primarily toward the improvements in existing residential facilities; rather it should encompass a full range of alternatives to traditional institutional placements and the necessary community support systems needed to sustain former and potential residents in community settings.

   Even if the federal government were willing and able to make a commitment under Section 1202 of the Javits bill, of the magnitude contemplated above, we doubt that using such funds simply to shore up an institutional service model would be the wisest possible allocation of resources.

Many exciting new developments are taking place, on an exploratory basis across the country in creating alternative residential situations for the retarded in group homes, foster homes, nursing care facilities, hostels, etc. Some of these programs already have demonstrated that services can be provided more effectively - and often at significantly less cost - for many present institutional residents in small, community-based settings. The federal government should attempt to reinforce this trend through a program of grants to the states.

In structuring such a new grant program. Congress should require states to submit a state plan spelling out how the money will be used to: (a) to reduce the overall size of existing state operated facilities; (b) to stimulate the development of small, community-based living alternatives for those requiring out-of-home care; (c) to develop more effective screening and referral mechanisms to assure that only those clients who can not be served in any alternate setting are admitted to the institution; (d) to begin intensive short-term habilitative programs which are designed to prepare retarded individuals and their families for successful adjustments to life in their home communities (thus, eliminating or delaying the need for residential placement); (e) to stimulate the development of supportive community services needed to successfully maintain retarded individuals in the community; and (f) to recruit and train the new professional and especially para-professional to provide and monitor the delivery of high quality residential and supportive services in community-based settings. Funds under this program should be allotted among the states in accordance with the existing DDSA formula, and the program should be tied to the same administrative mechanism as Developmental Disabilities so that community and institutional services will be seen; as essential and interrelated parts of a total service delivery system.

Care should be taken to build into this new system a strong evaluation, component. While we have a growing body of evidence which suggests that a significant segment of mentally retarded persons requiring out-of-home care function best in individual or small group settings, there is still a great deal we do not know about the types of residential situations which work best for given groups of clients, the most cost effective ways of providing such services, and the general factors involved in the success or failure of placements. To assist us in profitting from experience under this proposed new program, it is important that an evaluative feedback mechanism be incorporated as an integral part of the system.

Congress should establish broad statutory guidance for the operation of programs under the proposed new title. One such specification, for example, might be that the state would be

required to provide assurances that all programs - both community-based and institutional - which receive support under the Act would achieve minimum standards acceptable to the Secretary of HEW by a given future date {say four to five years after enactment). Periodic evidence also might be required to show that such agencies and facilities are making reasonable progress toward meeting such standards.

States should be permitted the choice of developing their own residential and/or community standards or accepting those developed by an outside standard-setting agency, such as JCAH. The Secretary of HEW would be given the authority to approve or reject any particular set of standards. In any event, we believe that some leeway ought to be left to the states to develop; their own program standards until we have had additional experience with the JCAH Accreditation process.

Congress should require the states to develop a detailed plan - not simply another "boiler plated" set of standard assurances - outlining how the funds provided under this new title will be used as part of the state's broader stategy to improve and reform the state's system for delivering residential services to the mentally retarded. The plan should specify all existing and new state and federal resources available to accomplish the desired goals and objectives and show how these resources will be used as part of a coordinated, goal-oriented structure.

A hard look should be taken at the deployment of existing federal resources which impact on the delivery of residential services to the retarded. At the grass roots level, there are many existing barriers to fully utilizing, in a coordinated fashion, the range of federal assistance programs available to aid in reforming the present system for delivering residential services to the retarded. For example, four of the six major agencies in the Social and Rehabilitation Services are now funding various aspects of residential services for the retarded. In addition, following the lead of President Nixon, SRS has established as one of its major goals deinstitutionalization of the developmentally disabled. Yet, it is almost impossible at the state and local levels to put resources from these four agencies together in an effective and coordinated funding package because each has its own basic goals and objectives and services to the retarded are incidental to the accomplishment of these overriding goals:

We recommend that Congress specifically direct HEW, perhaps through the soon-to-be-established Office of the Handicapped, to come up with a Department-wide plan for carrying out the President's deinstitutionalization goal and report back to Congress within eighteen months. Specific attention should be given in the plan to identifying the legislative and administrative steps necessary to more effectively deploy existing HEW resources to accomplish this objective.

One of the basic purposes of the Developmental Disabilities Act was to require the states to make more effective use of existing federally funded health, education and welfare programs in serving the developmentally disabled. Many states have faced great frustrations in carrying out this mission because of the diverse objectives, statutory authorities, regulations and guidelines governing each program. What we, in a sense, are suggesting is that, perhaps, it is time that the federal establishment took a look at its own house.

In conclusion, we deeply appreciate this opportunity to present the Association's views to this Subcommittee. We certainly recognize the very real problems you face in handling the legislation before you today. However, based on the extraordinary record of this Committee over the last decade, we feel confident that you will draft legislation which is progressive and fair to all interests involved. If our members can be of any assistance in this process, we stand ready to help.

APPENDIX A

ILLUSTRATIONS OF USE OF STATE ALLOTMENTS
UNDER TITLE I OF THE DEVELOPMENTAL DISABILITIES ACT*

The following are several examples of the way in which states are utilizing federal formula grant funds appropriated under Title I of the Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517):

Washington Offers Aid to Deaf, Blind Retarded

Until three years ago Washington, like many other states, offered virtually no specialized services for blind-retarded and deaf-retarded children. The state schools for the deaf and blind, in practice, refused to serve the sensory handicapped with subnormal intellect and state institutions for the retarded provided no special aid for such children.

In recent years, however, this picture has begun to change. Three M.R. institutions have started programs for, blind-retarded residents and the state schools for the deaf and blind gradually have begun to admit the retarded. In addition, the Washington Legislature in 1968 appropriated funds for the construction of a 20-bed cottage for blind-retarded children at the state school for the blind. This building, completed in April, 1970, contains sufficient space for all the program and living needs of the residents including classrooms, dining and activity rooms and bedrooms.

Through the use of federal Developmental Disabilities funds, the state now plans to open the new facility in January, 1972. Earlier efforts to launch the program were frustrated by a lack of state appropriations. Once the program is underway, state officials plan to ask the legislature to appropriate state funds to operate the new facility so that future DDSA allotments can be released for other priority purposes.

Federal project grant funds have also been obtained to provide a focal point for professional services to the retarded at the state schools for the deaf and blind which are both located in Vancouver. The task of the project team will be to: (1) assist the staffs of the two schools to develop adequate selection and placement criteria for retarded children; (2) insure that such children receive adequate services; (3) aid in identifying the existing retarded population; (4) instruct the education and care staff of the two schools in the specialized needs of the retarded child; and (5) provide community placement and counseling services. Officials estimate that 15% of the resident population of the two schools are mentally retarded.

Louisiana Begins Information-Referral Network

Since the report of President Kennedy's Panel on Mental Retardation was issued in 1962, there has been a growing national awareness of the need for improved access to information on generic and specialized services available to mentally retarded children and adults.

Louisiana has recognized the importance of timely, accurate information on service resources and is now in the process of developing a statewide information and referral system through the use of federal developmental disabilities funds. The key to the new system will be the designated staff members in a variety of generic health, social and educational agencies throughout the state who will be trained to serve as their agency's Specialist in information and referral services for the developmentally disabled and their families.

In addition to training generic agency staff, DDSA funds are being used to: (1) prepare and publish a statewide directory of services available to the developmentally disabled; (2) develop a standardized referral and follow-up process; (3) establish a computerized case registry system; and (4) utilize available data to evaluate management, provide feedback to individual workers, and assure that individuals gain better access to services.

The state Division of Mental Retardation, which is the agency responsible for administering DDSA funds in Louisiana, has contracted with a private management consulting firm to design and implement the new information and referral system. This firm will be responsible for the initial training and development activities involved in instituting the system described above.

The concept of a strong system of information and referral service is not new in Louisiana. A state directory of services for the mentally retarded was prepared several years ago as a result of the initial comprehensive mental retardation planning legislation (P.L. 88-156) . In addition, two local information and referral centers were established around the same time. The results of these activities have demonstrated conclusively both the need and the feasibility of creating a statewide information and referral network.

Texas, Florida Serve Epileptics

The overall purpose of the Developmental Disabilities Services and Facilities Act of 1970 was to fill existing gaps in services to persons afflicted with mental retardation, cerebral palsy, epilepsy, and other neurological handicaps. Texas recently provided one example of how a little bit of DDSA money can go a long way towards achieving this goal.

In July, 1971 the Dallas Epilepsy Association received a $5,000 DDSA "mini grant" to co-host, with the Texas Rehabilitation Commission, a one-day symposium on epilepsy for vocational rehabilitation counselors. The 100 VR counselors attending the session were instructed in the medical aspects of epilepsy as well as the day-to-day problems encountered by epileptics in their pursuit of a normal life. The highlight of the session was a panel discussion involving four epileptics who were interviewed by Dr. Anthony Arangio, Professor and Chairman, Community Planning and Administration, at the University of Texas in Arlington. These individuals gave symposium participants an inside look at epilepsy from the consumer standpoint. . .

This meeting was an important stage in the development of a cooperative program to upgrade statewide rehabilitation services for the epileptic.

The Houston Epilepsy Association later received a $90,000 grant from the Moody Foundation which was matched on an 80-20 basis by TRC to employ the state's first VR epilepsy specialists. There are currently six full time specialists on the TRC staff serving exclusively epileptic clients in five Texas cities.

Florida is another example of how DDSA money is being used to benefit. epileptics. The. Epilepsy Association of Central Florida was recently awarded a $35,000 DDSA grant to open and staff a state office for promoting a comprehensive, statewide epilepsy program. In addition, staff members will work to create new chapters of volunteers throughout the. state. At present there are six local epilepsy chapters operating in Florida.

Ohio Develops Protective Services

As the number of retarded and other developmentally disabled persons in community-based settings continues to grow, the need for intensified follow-up and follow-along services increases. Ohio is one state which has recognized this need and is developing a system designed to insure continuity of services to substantially disabled citizens. The Ohio Division of Mental Retardation and Developmental Disabilities is using DDSA funds to develop and implement a statewide case management, protective service and personal advocacy system. The development of the system was authorized late last year when Governor Gilligan signed a comprehensive protective services bill (H.B. 290).

Implementation is in progress. The Division is presently establishing and staffing twelve district offices located in key cities which serve • ... as the natural hub of service activities and the focal point of transportation routes for each of the areas. Each office will contain a corps group of case managers whose chief functions include intake, counseling, diagnosis and evaluation, prescriptive programming, referral to appropriate services, regular assessment of outcomes and modification of program prescriptions. In addition, protective service workers, also based in the district offices, will be responsible for monitoring, tracking, appraising, counseling and advocating for individuals enrolled in the system who need help in managing themselves and/or their affairs.

Apart from the case managers and protective service workers is the personal advocacy system where one individual assumes responsibility for looking after, as if they were his own, the interests, rights and personal needs of a developmentally disabled individual. A coordinator for personal advocacy has been hired who is administratively responsible to a Citizen Board of a new consortium, Ohio Developmental Disabilities, Inc. The Board is made up of representatives from the three primary . voluntary agencies serving the developmentally disabled in the state - Ohio Association for Retarded Children, United Cerebral Palsy of Ohio and Epilepsy Foundation of America.

DDSA monies have been involved in the development of all parts of this three-part system. Initially, the funds are being used to train workers for the system through contracts with the university affiliated facility

in Columbus, the Nisonger Center. Plans are, however, to eventually fund the case management and protective service aspects of the system with social service funds through a contract with the State Department of Welfare. The *DDSA* project monies will then be used to assist agencies at the local level get their advocacy service off the ground, and to pay, on an ongoing basis, for the coordinating service for personal advocacy at the state level.

* Based on information which originally appeared in New Directions, published by the **National Association of Coordinators of State Programs** for the Mentally Retarded, Inc.

APPENDIX B

Preliminary Estimates on Need for State Formula Grant Funds Under Title I of the Developmental Disabilites Act (P.L. 91-517)

STATE	FY 1973 ALLOTMENT (Tentative)	ESTIMATED NEED FY 1973*
Alabama	$ 439,030	a
Alaska	100,000	b
Arizona	c	c
Arkansas	245,977	$1,500,000
California	1,387,494	4,100,000[d]
Colorado	183,314	1,450,000
Connecticut	226,680	a
Delaware	100,000	1,000,000
District of Columbia	100,000	5,000,000
Florida	617,761	4,045,000[e]
Hawaii	100,000	b
Idaho	100,000	500,000
Illinois	851,062	1,996,000[f]
Indiana	479,033	b
Iowa	276,547	3,700,000
Georgia	482,220	5,500,000[g]
Kansas	205,408	2-3 Million
Kentucky	406,641	a
Louisiana	400,911	12-15 Million
Maine	114,744	300,000
Maryland	303,757	b
Massachusetts	466,622	2,300,000[h]
Michigan	768,122	1,500,000
Minnesota	359,108	510,000
Mississippi	305,408	b
Missouri	447,609	1,000,000
Montana	100,000	a
Nebraska	148,767	b
Nevada	100,000	a
New Hampshire	100,000	b
New Jersey	547,134	1,876,000[i]
New Mexico	103,415	2,500,000
New York	1,413,340	10,400,000[j]
North Carolina	594,422	1,000,000
North Dakota	100,000	b
Ohio	937,362	a
Oklahoma	272,220	772,220
Oregon	187,154	1,300,000
Pennsylvania	1,115,313	30,000,000
Rhode Island	100,000	1,000,000
South Carolina	316,718	1,500,000
South Dakota	100,000	400,000
Tennessee	458,558	5,000,000
Texas	1,067,287	1,500,000[k]
Utah	105,845	b

STATE	FY 1973 ALLOTMENT (Tentative)	ESTIMATED NEED FY 1973*
Vermont	100,000	375,000
Virginia	461,271	1,500,000
Washington	263,160	1,000,000
West Virginia	247,591	a
Wisconsin	425,408	1.5-3 Million
Wyoming	100,000	500,000
Guam	8,444	b
Puerto Rico	423,909	b
Virgin Islands	7,155	b

* All estimates are based on the preliminary results of a survey of state DDSA officials conducted by the National Association of Coordinators of State Programs for the Mentally Retarded, Inc.

a. No specific estimate provided. In most instances, however, other descriptive information supplied in the questionnaire would tend to suggest a level of need comparable to states of similar size.

b. Not reporting.

c. Not participating in the Developmental Disabilities program.

d. This estimate includes only the amount necessary to meet the immediate need for expansion of one aspect of state services - the network of thirteen regional centers. The state estimates that approximately 100,000 retarded children and adults need services but are not presently receiving them. In order to provide such services the state's present budget would have to be supplemented by an estimated $180 million.

e. The Florida Division of Retardation estimates that $40,450,000 would be needed from all federal sources to provide a full array of services to the mentally retarded alone. The assumption is made that about 1/10 of this amount could be effectively used in FY 1973.

f. Based only on the total amount requested in FY 1971 when the state's allotment was $477,111.

g. The state estimates that the total cost of providing needed community services to all mentally retarded citizens would be an additional $31,325,500 annually. It's worth noting that this figure does not include the cost involved in improving care in state institutions nor does it encompass the costs of providing services to other developmentally disabled (the cerebral palsied, the epileptic, etc.).

h. Estimates based on service needs only; does not include amounts required for construction of facilities.

i. This figure reflects only the total amount requested for service and construction projects in FY 1971 (when the state's allotment totalled $304,000). A 1969 survey indicated that two-thirds of the over 70,000 retarded citizens in New Jersey were not receiving the diagnostic, treatment, educational, day training or vocational services they needed

j. This figure reflects the total amount requested in FY 1972.

k. This amount reflects only the amount requested for service grants during FY 1972 when the state committed $620,000 for this purpose. The remainder of the state's allotment was used for administration, planning and construction projects.

Senator JAVITS. Thank you, very much.
Our next witness is Dr. Scheerenberger.

STATEMENT OP R. C. SCHEERENBERGER, PH. D., PRESIDENT-ELECT, NATIONAL ASSOCIATION OP SUPERINTENDENTS OP PUBLIC RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

Dr. SCHEERENBERGER. Thank you, Senator.
Senator JAVITS. Your statement will be included in the record at the conclusion of your testimony.
Dr. SCHEERENBERGER. AS a superintendent of a residential facility and a representative of the National Association of Superintendents of Public Residential Facilities, we fully appreciate the significance of your bill from the point of view of recognizing that retarded citizens are fully entitled to their civil rights.
Unfortunately, over the past few years this seems to be an uphill battle, but we will accomplish it.
We hope that the message contained in this bill will filter down to those agencies—Federal and State—who seem determined to convert residential facilities into nursing homes.
[The prepared statement of Dr. Scheerenberger follows :

The Honorable Edward Kennedy, Chairman
Subcommittee on the Handicapped
Committee on Labor and Public Welfare, U. S. Senate
The Capitol
Washington, D.C. 20510

Bill of Rights for the Mentally Retarded

Testimony of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded

First, the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded wishes to record its appreciation to Senator Javits for developing a bill which recognizes a very critical situation affecting 200,000 - 300,000 retarded persons in the United States, many of whom are living in inappropriate or inadequate environments. The intent of the bill is excellent for a number of reasons, including its full recognition of the mentally retarded as citizens, its recognition of the need for standards, and its recognition that residential facilities must be integrated into the total scheme of comprehensive community programming.

There are, however, several major concerns with regard to procedures for implementing the bill's intent:

(1) It is recommended that standards be deleted from the bill. While there is no question as to the need for standards, and relatively high standards, they must be readily modifiable. For example, it is anticipated that there will be a significant change in populations served by residential facilities in the near future, and that numerous Innovative programs and approaches will be developed. Subsequently, any existing standards would need to change in, order to remain meaningful.. Historically, legislative standards become rigid and rapidly outdated.

(2) According to the bill's provisions (Section 1106 c), facilities not in full compliance with the standards within five years will no longer be eligible to receive any Federal funding for the mentally retarded. Physical plant, location of residential facility, difficulty in recruiting professional staff, overcrowded conditions with no alternative community services available, and other such factors may make it impossible for some residential facilities to attain the level of full compliance within the stated period of time. The results would be disastrous to retarded persons living in such a facility. We do not believe that this provision in the bill is consistent with the intent to provide better living circumstances and programs for retarded residents.

If the standards were deleted, the need for a National Advisory Council for Residential Facilities for the Mentally Retarded would still exist. This Council could serve in the capacity of keeping the Secretary constantly alert to the status, needs, and trends of residential programming throughout the United States, and submit recommendations concerning proposed standards. Activities of the Council either should be integrated with those of the National Advisory Council on Developmental Disabilities or, at least, their efforts should be closely allied in order to assure comprehensive planning and development of strategies. As clearly indicated in the bill, the problem of inadequate residential programming as well as the inappropriate placement of retarded persons in residential facilities can never be resolved without strong community services.

We appreciate the opportunity of being able to contribute our thoughts and deliberations with regard to this bill.

R. C. Scheerenberger, Ph.D., President-Elect
National Association of Superintendents of Public
Residential Facilities for the Mentally Retarded
January 26, 1973

Extension of Public Law 91-517

Testimony of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded supports the proposed extension of Public Law 91-517. It is essential that each state continue to have a council for the developmentally disabled which can serve as a planning and resource development mechanism to complement and enhance existing service systems and payment for developmentally disabled persons encompassed under various Federally assisted programs,

We do recommend, however, that the definition of developmentally disabled persons be modified to eliminate present ambiguity and confusion, and that the state councils as well as the National Advisory Council become more concerned with problems involving thousands of disabled persons presently in residential facilities. Alternative community programming must be developed for many such residents. To date, this area has not been extensively considered.

R. C. Scheerenberger, Ph. D., President-Elect
National Association of Superintendents of Public Residential Facilities for the Mentally Retarded
January 26, 1973

Senator JAVTTS. Our next witness is Harry C. Schnibbe.

STATEMENT OF HARRY C. SCHNIBBE, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

Mr. SCHNIBBE. I have a prepared statement.

Senator JAVITS. It is hereby received and will be included in the record at the end of your testimony.

Mr. SCHNIBBE. Mr. Chairman, 57 percent of all developmentally disabled persons in public facilities in the United States are under the care of the directors of State mental health agencies.

It follows, naturally, that the commissioners of State mental health programs have a substantial concern about the progress and success of the Federal assistance program for the developmentally disabled.

Mr. Chairman, we participated in the creation of this law, we have been deeply involved in the past 3 years in implementing it at the State level, and we want to see it extended and expanded.

We endorse and support S. 427 provided it is amended as follows:

(1) The first amendment relates to clarifying the definition of developmental disability, because we would like to see the category broadened and we would add a new paragraph into section 401, paragraph 1. "The term 'developmental disability' means a disability attributable to mental retardation, cerebral palsy, or epilepsy, which disability originates before such individual attains age 18, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individual."

We would add a new paragraph (m) as follows:

The term "eligible person" means a person with a developmental disability originating in childhood who has similar service needs and who is considered eligible for such similar services by an agency or a facility which is providing services primarily intended for persons with developmental disabilities.

(2) Second, we would provide assistance to the States for institutional reform. In section 131, of Public Law 91-517, add a paragraph (b) providing authorizations for assistance to the States for reform of institutional programs and for deinstitutionalization. Recommendation:

To supplement the amount specified in Sub. Sec. 131(a) there are further authorized to be appropriated $20 million for fiscal year ending June 30, 1974, $30 million for the fiscal year ending June 30, 1975 and $40 million for the fiscal year ending June 30, 1976 to be allotted to the several States by the Secretary in accordance with Sub. Sec. 132(a) (2).

In section 132(a) add a new paragraph (2) as follows:

From the supplementary sums appropriated in accordance with the subsection 131(b) the Secretary shall make allotments to the several States to assist them in carrying out specific goal oriented plans acceptable to the Secretary and designed to reduce and eventually eliminate inappropriate institutional placement of persons with developmental disabilities, to improve the quality of care and habilitation of those for whom institutional care is appropriate and to protect the human rights of all persons with developmental disabilities, especially those without familiar protection. Such specific plans shall be part of the State Plan submitted in accordance with Section 134.

(d) Bring granting percentage into conformance. In section 137 (b) (1) change "75 percent" to "80 percent." This will bring the Federal matching percentage into conformance with most other Federal health and social service grant programs. This will help reduce "shop-

ping around" for Federal support with the most favorable matching percentage.

Mr. Chairman, various other amendments are being recommended here today. Most of them would have our concurrence. However, we consider that the three amendments that we have just recommended are of a specially high priority nature.

We urge their acceptance by you and your subcommittee and we urge that S. 427 (as amended), extending the developmental disabilities program for 3 years, be quickly passed by both Houses of the Congress.

As far as your particular bill, Senator, we find the standards in S. 458, on the rights of the mentally retarded, to be highly acceptable. We find no deviations from the "Standards for Residential Facilities for the Mentally Retarded" from the Joint Commission on Accreditation of Hospitals as adopted May 5,1971.

However, we do have a great deal of question as to whether this kind of detailed standard should become part of Federal statute. Standards need to be changed frequently and changing of Federal statutes is sometimes very difficult.

It is also our opinion that the amount of Federal money intended is extremely small. If the Federal statutes are going to impose standards, we are certain that there will be a great clamor from the States for the Federal Government to pay much more of the bill.

We intend to provide your committee with further comments from the States on S. 458.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Schnibbe follows:]

PREPARED STATEMENT OF HARRY C. SCHNIBBE, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS, WASHINGTON, D.C.

Mr. Chairman, fifty-seven percent (57%) of all developmentally disabled persons in public facilities in the United States are under the care of the directors of State mental health agencies.

It follows, naturally, that the commissioners of State mental health programs have a substantial concern about the progress and success of the Federal assistance program for the developmentally disabled.

Mr. Chairman, we participated in the creation of this law, we have been deeply involved in the past 3 years in implementing it at State level, and we want to see it extended and expanded.

We endorse and support S. 427 provided it is amended as follows:

1. Clarify definition of "Developmental Disability"

In section. 134(b) of PL 92-517, strike the present paragraph (5) and add a new (5) as follows:

"Describe the quality, extent and scope of such services as will be provided to eligible persons".

In Section 401 of PL 91-517 strike paragraph (1) and add a new paragraph (1) as follows:

"Developmental Disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age 18 and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity or in the case of a child under age 17, a handicap of comparable severity."

Add a new paragraph (m) as follows:

"the term 'eligible person' means a person With a developmental disability or a person with another disability originating in childhood who has similar service needs and who is considered eligible for such similar services by an agency or a facility which is providing services primarily intended for persons with developmental disabilities."

2. Provide assistance to the States for Institutional Reform

In Section 131, of PL 91-517, add a paragraph (b) providing authorizations for assistance to the States for reform of institutional programs and for deinstitutionalization.

Recommendation: "To supplement the amount specified in Sub. Sec. 131(a) there are further authorized to be appropriated $20,000,000 for fiscal year ending June 30, 1974, $30,000,000 for the fiscal year ending June 30, 1975 and $40,000,000 for the fiscal year ending June 30, 1976 to be allotted to the several States by the Secretary in accordance with Sub. Sec. 132(a) (2)."

In Section 132(a) add a new paragraph (2) as follows:

"From the supplementary sums appropriated in accordance with the sub. sec. 131(b) the Secretary shall make allotments to the several States to assist them in carrying out specific goal oriented plans acceptable to the Secretary and designed to reduce and eventually eliminate inappropriate institutional placement of persons with developmental disabilities, to improve the quality of care and habilitation of those for whom institutional care is appropriate and to protect the human rights of all persons with developmental disabilities, especially those without familiar protection. Such specified plans shall foe part of the State plan submitted in accordance with Sec. 134."

S. Bring granting percentage into conformance

In Section 137(b)(1) change "75%" to "80%". This will bring the Federal matching percentage into conformance with most other Federal health and social service grant programs. This will help reduce "shopping around" for Federal support with the most favorable matching percentage.

Mr. Chairman, various other amendments are being recommended here today. Most of them would have our concurrence. However, we consider that the three amendments that we have just recommended are of a specially high priority nature.

We urge their acceptance by you and your subcommittee and we urge that S. 427 (as amended), extending the Developmental Disabilities program for 3 years, be quickly passed by both Houses of the Congress.

In re. S. 458 (Sen. Javits).

PROPOSED FEDERAL LEGISLATION ON RIGHTS OF MENTALLY RETARDED

We find the standards in S. 458, on the rights of the mentally retarded, to be highly acceptable. We find no deviations from the "Standards for Residential Facilities for the Mentally Retarded" from the Joint Commission on Accreditation of Hospitals as adopted May 5,1971.

However, we do have a great deal of question as to whether this kind of detailed standard should become part of Federal statute. Standards need to be changed frequently and changing of Federal statutes is sometimes very difficult.

It is also our opinion that the amount of Federal money intended is extremely small. If the Federal statutes are going to impose standards, we are certain that there will be a great clamor from the States for the Federal Government to pay much more of the bill.

We intend to provide your committee with further comments from the States on S. 458.

Thank you, Mr. Chairman.

Senator JAVITS. Thank you very much. The record will remain open for 10 days and any additional information on State provisions for S. 458 will be included in the record as part of your statement. Thank you very much for appearing here.

The last panel today is that of Moya Kinnealey, director of occupational therapy training at the Eunice Kennedy Shriver Center of the Walter E. Femald State School in Waverly, Mass., and William C. Healey, associate secretary for school affairs of the American Speech and Hearing Association.

Miss Kinnealey, would you proceed ?

STATEMENT OF MOYA KINNEALEY, DIRECTOR, OCCUPATIONAL THERAPY TRAINING, EUNICE KENNEDY SHRIVER CENTER, WALTER E. FEMALD STATE SCHOOL, WAVERLY, MASS.

Miss KINNEALEY. I would submit my statement for the record.

Senator JAVITS. Your statement will be included in the record in its entirety at the end of your testimony.

Miss KINNEALEY. I appreciate this opportunity to present the views of the American Occupational Therapy Association. I will be brief.

The American Occupational Therapy Association represents some 14,000 registered occupational therapists and certified occupational therapy assistants. All of our members work with disabled people and probably a third of our members are directly involved in providing evaluation, treatment, training, and consultation for the mentally retarded and developmentally disabled.

The American Occupational Therapy Foundation has recently established as its first priority, the promotion of research and its application to problems of children with neurological dysfunctions, and in particular, with learning disabilities.

Occupational therapy is not a life-saving service. It is, however, a service dedicated to helping the disabled to reestablish both the will and the physical and mental means they need to lead as satisfying and as productive a life as possible.

These bills, therefore, are a vital concern to our members, and we strongly support both measures. The bill of rights for the mentally retarded should assure further extension and improvement of services to the children so greatly benefited by President Kennedy's leadership and initiatives in the last decade. Continuation and expansion of the Developmental Disabilities Act should bring, in the decade of the 1970's, long overdue services to the millions of children with equally handicapping conditions, but who have received little help to date in overcoming them and having the opportunity to achieve their maximum potential.

Many people have urged that the definition of developmental disabilities be expanded. I would like to concur with this recommendation. In the evaluation center in which I work, I believe that about one-seventh of the children that we evaluate have a nonspecific diagnosis. They are multiple-handicapped.

Numerous groups have asked to be included in a revised definition of developmental disabilities in order to be eligible for services under this law. I agree with this and would like to suggest that the revised definition include any "disability related to a medically determinable physical or mental impairment."

There is always a large group of high-risk infants and children—those subjected to severe deprivations in early life, such as nutritional deficiencies; exposure to overcrowded, unsanitary or unstable living conditions; and those with genetic and metabolic disorders—who experience an abnormally high rate of developmental disorders.

Premature infants, especially boys, and full-term infants with extremely low birth weights belong to this high-risk population. Case-finding among these youngsters and early intervention, before more extensive rehabilitation of their handicaps is required, will pay substantial dividends. Among them may be the avoidance of more costly

medical, educational, and related services as well as the prevention of behavioral disorders and delinquency.

Turning to S. 458, the proposed bill of rights for the mentally retarded, we should like to commend Senator Javits and the cosponsors for an extremely comprehensive bill directed to the improvement of residential facilities for the mentally retarded. We are concerned, however, by the absence of standards for nonresidential facilities and for community programs, or even any reference to the need for such standards in S. 458 as it is presently written.

In many instances we find that sending children from the Fernald School to institutions, including nursing homes, does not offer much promise for improvement of their conditions. They receive a bare minimum of custodial care without any therapeutic or educational programs.

The standards for professional services that are outlined in the several subchapters of chapter 3, part C of the bill include standards for occupational therapy. However, this section fails to identify several crucial concerns of occupational therapy in the evaluation and training of mentally retarded residents. These include the skills they need to engage in the self-care, work and leisure time activities that together constitute so large a part of people's lives.

We would also like to suggest the possibility of the separation of standards for the two disciplines, occupational therapy and physical therapy. Each has a unique focus and utilizes different skills to evaluate and treat disabilities.

In summary, the American Occupational Therapy Association cannot endorse the inclusion of the standards for physical and occupational therapy as presently written in S. 458. However, we are prepared to work with the committee to adapt existing occupational therapy standards and principles of organization to the proposed framework of standards for residential facilities for the mentally retarded contained in S. 458. We shall be glad to submit our specfic recommedations for revisions in the near future.

Senator JAVITS. Thank you very much, Miss Kinnealey. I have instructed the staff to take advantage of that offer and to work with your organization in an effort to improve the bill by developing those standards.

Miss KINNEALEY. Thank you.

[The prepared statement of Miss Kinnealey follows:]

STATEMENT OF

THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION

Before the

Senate Committee on Labor and Public Welfare,
Subcommittee on the Handicapped
on S. 427 and S.458

Thursday, February 8, 1973

Mr. Chairman:

I am Moya Kinnealey, O.T.R., Director of Occupational Therapy Training at the Eunice Kennedy Shriver Center of the Walter E. Femald State School in Waverly, Massachusetts. The Center has several functions; it is the screening unit for admissions to the School, a residential facility for the mentally retarded, and it is the evaluation center for one of seven Massachusetts catchment areas designated by the State Department of Mental Health. As a university-affiliated facility, the Kennedy Center provides graduate training for occupational therapists and other health-related professions in a multi-disciplinary setting and an interdisciplinary manner.

I am indeed grateful to you and the members of the Subcommittee for this opportunity to present the views of the American Occupational Therapy Association on S.427, which seeks to extend for three years the Developmental Disabilities Services and Facilities Construction Act of 1970 (Public Law 91-417), and S.458, which would establish standards to insure the humane care, treatment, habilitation and protection of the mentally retarded in residential facilities.

The American Occupational Therapy Association represents some 14,000 registered occupational therapists and certified occupational therapy assistants. Approximately

one-third of our membership, I would estimate, have had some experience, during their professional careers, in programs that render services to children with developmental disabilities. Today, several hundred occupational therapists are directly involved in providing evaluation, treatment, training, and consultation for mentally retarded individuals in residential and other facilities. In addition, the American Occupational Therapy Foundation has recently established as its first priority the promotion of research and its application to the problems of youngsters with neurological dysfunctions, in particular, those with learning disabilities.

These bills, therefore, are a vital concern to our members, and we strongly support both measures. The Bill of Rights for the Mentally Retarded should assure further extension and improvement of services to the children so greatly benefited by President Kennedy's leadership and initiatives in the last decade. Continuation and expansion of the Developmental Disabilities Act should bring, in the decade of the '70s, long overdue services to the millions of children with equally handicapping conditions, but who have received little help to date in overcoming them and having the opportunity to achieve their maximum potential.

In support of our position on this legislation, Mr. Chairman, may I briefly describe our profession's role and concern for the children it serves. Occupational therapy is not a life-saving service. It is, however, a service dedicated to taking those lives saved by others and helping to re-establish both the will and the physical and mental means of making them more satisfying to the individual, acceptable by the family, and productive for the community.

Only three years have elapsed since the passage of P.L. 91-517, too short a time to permit proper evaluation. More significant, however, has been the lack of adequate appropriations for the programs authorized. While we strongly endorse the enactment of S.427 with appropriate amendments, we feel that appropriation of the necessary funds to

carry our the essential purposes of this legislation is of equal importance. Neither the minimal support afforded the Developmental Disabilities Program in fiscal 1973, nor the reduced level in the President's Budget for fiscal 1974, is sufficient to meet the needs. Recognizing that appropriations are not within the jurisdiction of this Committee, we call attention to this problem simply because it has severely restricted the development of operating programs.

During the consideration of this legislation in 1970, the Congressional Committee reports noted that a substantial number of persons suffering from epilepsy, cerebral patsy, and related neurological impairments were "falling between the cracks insofar as programs designed to provide aid for them" were concerned. For that reason, the 91st Congress saw fit to broaden the law, including not only mental retardation but also these other specific categories of disabling conditions.

Mr. Chairman, we find a similar situation today. The specific categories enumerated in P.L. 91-517 have, in effect, limited programs to these groups. Thus, substantial numbers of children with a developmental disability (that is a disability related to a medically-determinable physical or mental impairment) are not considered eligible for the services funded by this legislation. We hope, therefore, that in extending the Act, the Committee will give favorable consideration to a revised definition which will permit coverage for all those with developmental disabilities.

We offer our support for a broadened definition because as 0 health profession closely identified with services to children, we are aware of the tremendous need and the potential benefit to be derived from the earliest possible detection of developmental deficits and intervention to minimize their effects. It seems inefficient and wasteful to establish a program for only certain types of disabilities, excluding those children with other developmental disabilities who could benefit enormously from the same services.

There is, for example, a large group of high-risk infants and children - those subjected to severe deprivations in early life, such as nutritional deficiencies; exposure to overcrowded, unsanitary or unstable living conditions; and those with genetic and metabolic disorders - who experience an abnormally high rate of developmental disorders. Premature infants, especially boys, and full-term infants with extremely low birth weights belong to this high-risk population. Case-finding among these youngsters and early intervention, before more extensive rehabilitation of their handicaps is required, will pay substantial dividends. Among them may be the avoidance of more costly medical, educational, and related services as well as the prevention of behavioral disorders and delinquency.

Just as proper and timely prenatal care for expectant mothers has been demonstrated to reduce infant mortality, so also early detection and treatment of developmental deficits before they are compounded by the pressures and problems which arise when school-age is attained or when higher levels of school-age are reached will be less costly than subsequent correction of more severe disabilities.

Turning to S.458, the proposed Bill of Rights for the Mentally Retarded, we should like to commend Senator Javits and the co-sponsors for an extremely comprehensive bill directed to the improvement of residential facilities for the menially retarded. We are concerned, however, by the absence of standards for non-residentail facilities and for community programs, or even any reference to the need for such standards in S.458 as it is presently written. The emphasis on alternative programs of care and greater utilization of non-residential facilities and community resources for the mentally retarded is highly commendable. The desirability of standards for these programs should be considered.

The standards for professional services that are outlined in the several subchapters of Chapter 3, Part C of the bill include standards for occupational therapy (Subchapter IX, Physical and Occupational Therapy Services). However, this section (Sec. 1270) fails

to identify several crucial concerns of occupational therapy in the evaluation and training of mentally retarded residents. These include the skills they need *to* engage in the self-care, work and leisure time activities that together constitute so large a part of people's lives. Since the major focus of occupational therapy is the development, maintenance or restoration of an individual's ability to perform these daily activities in a manner which is as productive and satisfying as possible, it is vital that this focus be articulated in the standards.

It might also be wise to consider the separation of standards for the two disciplines, occupational therapy and physical therapy. Each has a unique focus and utilizes different skills to evaluate and treat disabilities.

We are aware that many groups have suggested that detailed standards such as those contained in Part C not be "locked into law". We are equally aware that without specific standards, the mentally retarded will continue to receive much less than optimal care. We shall rely upon the Committee's wisdom and judgment to strike a balance between unnecessary detail and essential requirements.

In summary, the American Occupational Therapy Association cannot endorse the inclusion of the standards for physical and occupational therapy as presently written in S.458. However, we are prepared to work with the Committee to adapt existing occupational therapy standards and principles of organization to the proposed framework of standards for residential facilities for the mentally retarded contained in S.458. We shall be glad to submit our specific recommendations for revisions in the near future.

We wish to commend the members of this Subcommittee for their leadership and commitment to improvement of services for the Nation's handicapped. We greatly appreciate the opportunity to present our views on these legislative proposals.

Senator JAVITS. Thank you, very much. Now, Dr. Healey. Do you want your statement included in the record ?

STATEMENT OP WILLIAM C. HEALEY, PH. D., ASSOCIATE SECRETARY FOR SCHOOL AFFAIRS, AMERICAN SPEECH AND HEARING ASSOCIATION

Dr. HEALEY. Yes.

Senator JAVITS. We will order your statement to be printed in the record at the conclusion of your testimony.

Dr. HEALEY. I would like my full written statement included because I have been rewriting it in deference to the hour. I should just encourage you to railroad through S. 427 and S. 458.

We certainly want the fiscal appropriation of S. 427 brought up to the levels authorized if at all possible. We support Senate bill 458 and especially the standards for speech pathology and audiology services.

We have found in a recent study, that residential facilities are sorely lacking in speech, hearing, and language specialists. There is a high prevalence of speech, hearing, and language problems among the mentally retarded population, as I am sure you are aware.

We know that the development of communications skills is a key factor in the business of deinstitutionalization and social integration into the community. We hope you will note in our prepared statement the modifications that we are recommending.

In deference to the time and your schedule, which we appreciate, we will terminate this testimony on that note.

Senator JAVITS. Dr. Healey, you are very kind. I thank you very much. You have been so gracious to me, I promise you we will examine very carefully your specific suggestions and do our best to give them every consideration.

Dr. HEALEY. We are extremely concerned, Senator, with the number of deaf and hearing impaired among the mentally retarded who are in these facilities. They represent a large population who have fallen through the cracks of existing services. We want comprehensive programs for this population as well.

Senator JAVITS. I assure you we will take a careful look into this.

[The prepared statement of Dr. Healey follows :]

ASHA
9030 Old Georgetown Rd., Washington, D. C. 20014

AMERICAN SPEECH AND HEARING ASSOCIATION

STATEMENT OP THE AMERICAN SPEECH AND HEAPING ASSOCIATION

BEFORE THE SUBCOMMITTEE OH THE HANDICAPPED

OP THE SENATE LABOR AND PUBLIC WELFARE COMMITTEE

REGARDING

S. 427, THE DEVELOPMEHTAL DISABILITIES SERVICES AND CONSTRUCTION ACT

AND

S. 458, THE BILL OF SIGHTS FOR THE MENTALLY RETARDED

Presented by
William C. Healey, Ph.D.
Associate Secretary for School Affairs
American Speech and Hearing Association

February 8, 1973

Mr. Chairman, I an Dr. William Healey, Associate Secretary of the American Speech and Hearing Association (ASHA). ASHA is a scientific and professional society comprising more than 15,000 speech pathologists and audiologlsts. The speech pathology and audiology profession is the primary discipline concerned with the systems, structures, and functions that make human communication possible; with the causes and effects of delay, maldevelopment, and disturbance in human communication; and with the identification, evaluation, and rehabilitation of individuals with speech, language, and hearing disorders.

The work of ASHA and its members is consumer-oriented, and the consumer market is a very large one indeed. Research completed in 1969 termed a population of 236,000 deaf Americans "a conservative total." The same study estimated that some 8,500,000 Americans have "hearing problems of one type or another which are less severe than deafness but which impair communication and hence social efficiency." Americans plagued by central communication disorders (e.g., impairments of speech and language resulting from stroke or mental retardation) were estimated at 2,100,000, and those with speech disorders at an astonishing 10 million.[3]

It is true that some of these communication disorders go unperceived, and that many which are perceived go untreated. It is also true that the treatment of some of these disorders is administered by health professionals other than speech pathologists and audiologlsts. But the fact remains that close to 21 million Americans, about one-tenth of our national population, are in some way and to some degree speech, language and/or hearing handicapped. And service to these Americans is the primary mission of ASHA and its membership.

1 Report of the Subcommittee on Human Communication and Its Disorders, national Advisory Neurological Diseases and Stroke Council (NIH), Human Communication and Its Disorders — An Overview, Bethesda, Md. (1969), p. 11.

2 Ibid., p. 13.

3 Ibid., pp. 16-17.

I appreciate the opportunity to appear before the Subcommittee on the Handicapped to express support for S. 427, the proposed Developmental Disabilities Services and Facilities Construction Act of 1973. Although fiscal appropriations have never reached the levels authorized in the 1970 Act, we feel the limited number of programs and services implemented have made significant contributions in meeting previously unmet needs of many developmentally disabled persons.

Likewise, our Association supports S. 458, the Bill of Rights for the Mentally Retarded. We recognize the need for standards that help insure improved services for persons with mental retardation. Whether to legislate standards or simply to enable their establishment and enforcement through appropriate regulations is a question best answered, perhaps, by the Committee after input from the several organizations which are more directly concerned with the total operation of residential facilities.

We know the need for quality standards and programs. The prevalence of speech hearing, and language disorders among persons with mental retardation is considerably higher than that found in the normal population (about 4 to 1). For example, the prevalence of hearing loss in institutionalized persons often exceeds 25%. More than 90% of young children in residential facilities require speech and language habilltatlon and as high as 50% of the adult population have speech and language handicaps.

Members of our profession and others have demonstrated that qualified personnel in speech pathology and audiology can significantly improve the mentally retarded person's ability to communicate for social, educational, and vocational purposes. Unfortunately, many persons in residential facilities for the mentally retarded have been denied the special services of qualified speech pathologists and audiologists and have not had the full opportunity to develop maximum communication competence. Data from a 1972 study sent to 169 facilities indicated that only 35%

of the 137 programs responding had services for mentally retarded persons who are deaf or hearing impaired.[4]

We know from research and experience that improving the ability of the mentally retarded to communicate is a key factor in the deinstitutionalization and societal integration of many mentally retarded persons. He realize that these are the primary goals of S. 453. We believe they are commendable objectives and necessary in an absolute sense if America's mentally retarded are to receive the services and opportunities they so greatly need and deserve.

Members of ASHA's Committee on Mental Retardation have actively promoted and sought improved speech, hearing, and language services for the mentally retarded. In 1971, the Committee developed and the Association endorsed "Standards for Speech Pathology and Audiology Services in Facilities for the Retarded." (Copy attached) More recently ASHA organized a cooperative program with the American Association on Mental Deficiency and the Council of Educators of American Schools for the Deaf to develop guidelines for expanding the quality of services for mentally retarded individuals who are also deaf or hearing impaired.

The ASHA recognizes the need for this unprecedented legislation, supports the intent of its provisions, commends the Committee for its foresight and competence in preparing the proposal, and strongly recommends its enactment.

Mr. Chairman, it is our belief that the two bills now before this Subcommittee should each serve to complement the other, in the interest of a truly comprehensive approach to meeting the needs of the mentally retarded and otherwise developmentally disabled. In this direction, we hope that a significant portion of the funds called for by Senator Kennedy's S.427 will be utilized to encourage the kind of swift and smooth shift S. 458 calls for in the method of delivering health services to the mentally retarded — i.e., from a predominant reliance on residential facilities to

[4]Hall, S.M. and Talkington, L.S.: "Trends in Programming for Deaf Mentally Retarded in Public Residential Facilities," Mental Retardation, 10(2): 50-52, April, 1972.

a new primary reliance on community services and facilities.

We believe further that definitions of "developmental disabilities" appearing in both bills should be both uniform and capable of accommodating the hearing, speech, and language needs of the thousands of Americans who are developmentally disabled.

Mr. Chairman, there are three issues which the American Speech and Hearing Association believes should be clarified in the Subcommittee's final version of S. 458. One clarification can be made by a simple technical amendment; the other two require either additional language in two of the bill's sections or appropriate mention in the Subcommittee's final report on S. 458.

First, the needed technical amendment. The acronym "U.S.A.S.I.," which appears in section 1275 (1) (2) of S. 458, refers to a nationally-recognized standard-setting organization which no longer calls itself the "United States of America Standards Institute." The Institute, concerned that it might be mistaken for a federal agency, changed its name to "American National Standards Institute, Inc. several years ago and began using the acronym "ANSI.'' The standard to which the subject section refers, entitled "American Standard Criteria for Background Noise in Audiometer Rooms," has already been provided to the Committee. The Institute has informed us that the standard is currently being updated and otherwise revised, and that this should take between one and two years. But the prospective change should not affect the wording of the bill's section (except for the changed acronym). There is only one soundtreated-room standard now and there will still be but one after the revision is accepted by the Institute.

Second, it is our hope that section 1231 (b) (3) be amended to read (or the Subcommittee's report comments on that section indicate that):

> Licensures, certification, or standards such as are required in community practice shall be required for all comparable positions in the facility, <u>except as otherwise provided by this Act</u>.

Such an amendment (or appropriate report language) will satisfactorily resolve existing inconsistencies between the subsection referred to above and both sections 1231(b)(4) and 1275(j). Section 1275(j), in effect, sets forth that the speech pathology and audiology services provided under the Act must be provided or supervised by professionals who have attained at least a master's degree in one or both of the disciplines (or its equivalent), who have satisfactorily performed clinical services for at least one year under the supervision of an appropriately certified professional, and who have passed a national examination in their discipline. Persons providing speech pathology and audiology services, in any setting, who do not meet these experiential and educational criteria violate "ethical standards of professional conduct" [section 1231(b)(4)]. Requirements of community practice in some areas, however, permit (e.g., by licensure in the State of Louisiana) the rendering of speech pathology and audiology services by persons who, for a variety of reasons, fail to meet these criteria. Toward assuring that appropriately qualified speech, language, and hearing professionals are the ones who will deliver services to the mentally retarded, we urge adoption of the amendment (or report language) suggested above.

Third, Mr. Chairman, it is our hope that report language relative to section 1209(b)(3) indicate that it is the intent of the Subcommittee that the Advisory Council on Standards for Residential Facilities for the Mentally Retarded be required, whenever it recommends to the Secretary of Health, Education, and Welfare 'any changes, modifications, or improvements in the standards under part C of this Act, to additionally transmit to the Secretary all relevant recommendations of appropriate standard-setting professional organizations and societies.

Thank you again, Mr. Chairman, for this opportunity to present our views.

Special Reports

THE ESTABLISHMENT OF STANDARDS FOR SPEECH PATHOLOGY AND AUDIOLOGY SERVICES IN FACILITIES FOR THE RETARDED

The purpose of this report is to provide the ASHA membership with information about the standards for accrediting facilities for the mentally retarded adopted by the Accreditation Council for Facilities for the Mentally Retarded (AC/FMR) of the Joint Commission on Accreditating Hospitals (JCAH) in May, 1971. In addition to the immediate relevance to all speech pathologists and audiologists working in (or serving as consultants to) facilities for the mentally retarded, these standards provide operational guidelines that have implications for speech pathology and audiology services in other types of facilities. Although the ABESPA Professional Services Board's 1970 guidelines were generally incorporated and ASHA was officially represented in the final drafting of the guidelines, publication in *Asha* at this time does not represent official endorsement of the Association.

The AC/FMR standards relate to all professional and special services needed by the retarded. This report presents the standards of direct relevance to speech pathology and audiology services quoted directly from the total standards document titled *Standards for Residential Facilities for the Mentally Retarded.* This has been published in two editions: (D a soft-cover bound edition including all standards adopted by the AC/FMR in May 1971 may be obtained from AAMD. 5201 Connecticut Avenue. WW., Washington, D.C. 20015 for 51-00; and (2) a loose-leaf binder edition including all standards and a two-year updating service of revisions as issued may be obtained from AC/FMR, 645 North Michigan Avenue, Chicago, Illinois for $6.00. (Both editions are sent postpaid, but repayment is requested. The price covers only partial cost, since the publication is partiallv supported by the Federal grants.) The AAMD edition is for general information, but the AC/FMR edition is needed for accreditation and self-survey use.

A brief history of the establishment of these standards seems indicated. In 1952 the American Association on Mental Deficiency (AAMD) first published the report of its special committee on standards for institutions. Seven years later AAMD, supported by a grant from the National Institute of Mental Health, undertook a major standards development project which culminated in the 1964 publication of *Standards for State Residential Institutions for the Mentally Retarded.*

The 1964 AAMD Standards were presented as minimal, as generally attainable within five to ten years, and as a oasis for evaluation and accreditation activities. Concurrent with their publication, the AAMD established a committee to continue review and revision of the standards and to encourage their implementation by developing an evaluation instrument based upon them, by providing an evaluation service to institutions requesting it and by planning for the eventual establishment of a formal accreditation program. In 1965 a grant from the Mental Retardation Branch of the U.S. Public Health Service (subsequently the Division of Mental Retardation and recently the Division of Development Disabilities in the Social and Rehabilitation Service) enabled development of the evaluation instruments. A second grant, in 1966, pro vided for the evaluation, over the ensuing three years, of 134 state institutions for the mentally retarded, which represented three-quarters of such institutions and housed 90% of the residents of public facilities in the United States. Along with this project the AAMD instigated the formation of the National Planning Committee on Accreditation of Residential Centers for the Retarded, composed of representatives of AAMD, the American Psychiatric Association, the Council for Exceptional Children, the United Cerebral Palsy Associations (the five national organizations that now constitute the AC/MRF), plus toe American Medical Association (which is a member organization of the JCAH). The National Planning Committee continued the review and revision of the 1964 standards and developed the structure of an accrediting agency, which in 1969 culminated in the establishment of the AC/FMR within the JCAH.

The AC/FMR enlisted participation of over 200 individuals representing 42 organizations (in addition to the five member organizations of the AC/FMR) working in 20 committees. These committees, representing all the disciplines and interests that must be involved in providing fully adequate programs for the retarded, were selected and functioned according to the five fundamental principles as stated in the standards document as follows:

1. Since all of the problems associated with mental retardation do not fall within the purview of any

LYLE L. LLOYD, Ph.D., Chairman of the ASHA Mental Retardation Committee, prepared this Special Report.

one discipline, but require for their alleviation the knowledge and skills of many professions, the philosophy of the entire project, and of all its associated committees, must be thoroughly interdisciplinary in concept.

2. Consequent to this philosophy, while each committee should be charged with primary responsibility for that section of the Standards pertaining to the activities of its particular discipline, no area of the Standards is the exclusive property of any discipline and, therefore, the Standards as a whole must be subject to review and criticism by every committee.
3. Since standards for services to the mentally retarded must, at this point in time, be derived from the consensus of experienced leaders in the field as to what constitutes an adequate program, rather than from empirical data relating program provisions to desired outcomes, representation on committees must be as broad as possible in terms of variety of current viewpoints and program approaches, as well as in terms of levels of administrative responsibility.
4. Inasmuch as identical standards must apply to the level of professional services rendered, whether within or without a residential setting, and since the Standards are intended to be applicable to both public and private facilities, representatives of nonresidential as well as public facilties must be included on committees.
5. In order to broaden participation in standards development, to obtain the latest information and thought, and to secure the widest possible consensus while, at the same time, maintaining continuity with earlier endeavors, committees should include representatives of college and university programs and of research activity, as well as representatives of operating programs, and no more than one member of a committee should have served on previous standards committees. ,

The AC/FMR extended committee membership invitations to individuals on the basis of their known expertise, experience, and viewpoints in addition to asking national professional organization to name official representatives to the committees pertinent to their areas of interest. Twenty committees were selected with concern for administration, architecture, business management, dentistry, dietetics and nutrition, education, library services, medicine, nursing, pharmacy, physical and occupational therapies, psychology, records, recreation, religious services, resident living, social work, speech pathology and audiology, vocational rehabilitation, and volunteer services. In keeping with the interdisciplinary philosophy, most of the committees were multidisciplinary in composition.

The committee for speech pathology and audiology consisted of: Gerald G. Freeman, Alfred Hirschoren, Edwin A. Leach, John R. Olson, Paul A. Rittmanic, Boyd V. Sheets, Joseph E. Spradlin, and Lyle L. Lloyd, Chairman. The committee's audiologists, educators of the deaf, educators of the retarded, psychologists, and speech pathologists represented administrative, classroom, clinic, and research experience in community clinics, day schools, hospitals, residential facilities, and university settings. This committee's drafting of standards represents several years of activity of the AAMD's Speech Pathology and Audiology Subdivision and the ASHA Mental Retardation Committee. In addition to AAMD and ASHA representation, the CEASD and CEC were officially represented on the committee.

Audiologists and speech pathologists responsible for programs in facilities for the retarded should become familiar with the total standards document, but those standards of most direct relevance to speech and hearing services for the retarded and with general implications for all service-oriented ASHA Members are presented below:

SECTION 3. PROFESSIONAL AND SPECIAL PROGRAMS AND SERVICES

3.1 Introduction

3.1.1 In addition to the resident-living services detailed in Section 2, residents *shall* be provided with the professional and special programs and services detailed in this Section, in accordance with their needs for such programs and services.

3.1.1.1 The professional and special programs and services detailed herein may be provided by programs maintained or personnel employed by the residential facility, or by formal arrangements between the facility and other agencies or persons, whereby the latter will provide such programs and services to the facility's residents as needed.

3.1.1.2 In accordance with the normalization principle, all professional services to the retarded should be rendered in the community, whenever possible, rather than in a residential facility, and where rendered in a residential facility, such services *must be* at least comparable to those provided the nonretarded in the community.

3.1.1.3 Programs and services provided by the facility, or to the facility by agencies outside it, or by persons not employed by it, *shall* meet the Standards for quality of service as stated in this Section.

3.1.1.3.1 The facility shall require that services provided its residents meet the Standards for quality of services as stated in this Section, and all contracts for the provision of such services *shall* stipulate that these Standards will be met

3.1.2 Individuals providing professional and special programs and services to residents may be identified with the following professions, disciplines, or areas of service:

a. Audiology [see 3.14];
b. Dentistry (including services rendered by licensed dentists, licensed dental hygienists, and dental assistants) [see 3.2];
c. Education [see 3.3};
d. Food and Nutrition (including services rendered by dietitians and nutritionists) [see 3.4];
e. Library Services [see 3.5];
f. Medicine (including services rendered by licensed physicians, whether doctors of medicine or doctors of osteopathy, licensed podiatrists, and licensed optometrists) [see 3.6];
g. Music, art, dance, and other activity therapies [see 311];
h. Nursing [see 3.7];
i. Occupational Therapy [see 3.9];

j. Pharmacy [see 3.8];
k. Physical Therapy [see 3.9];
l. Psychology [see 3.10];
m. Recreation [see 3.11];
n. Religion (including services rendered by clergy and religious educators) [see 3.12];
o. Social Work [see 3.13];
p. Speech Pathology [see 3.14];
q. Vocational Rehabilitation Counseling [see 3.15];
r. Volunteer Services [see 3.16].

3.1.2.1 Interdisciplinary teams for evaluating the resident's needs, planning an individualized habitation program to meet identified needs, and periodically reviewing the resident's response to his program and revising the program accordingly, *shall* be constituted of persons drawn from, or representing, such of the aforementioned professions, disciplines, or service areas as are relevant in each particular case.

3.1.2.2 Since many identical or similar services or functions may competently be rendered by individuals of different professions, the Standards in the following subsections *shall* be interpreted to mean that necessary services are to be provided in efficient and competent fashion, without regard to the professional idenificataions of the persons providing them, unless only members of a single profession are qualified or legally authorized to perform the stated service. Services listed under the duties of one profession may, therefore, be rendered by members of other professions who are equipped by training and experience to do so.

3.1.2.3 Regardless of the means by which the facility makes professional services available to its residents, there *shall* be evidence that members of professional disciplines work together in cooperative, coordinated, interdisciplinary fashion to achieve the objectives of the facility.

3.1.3 Programs and services and the pattern of staff organization and function within the facility *shall* be focused upon serving the individual needs of residents and should provide for:

3.1.3.1 Comprehensive diagnosis and evaluation of each resident as a oasis for planning programming and management;

3.1.3.2 Design and implementation of an individualized habituation program to effectively meet the needs of each resident;

3.1.3.3 Regular review, evaluation, and revision, as necessary, of each individual's habilitation program;

3.1.3.4 Freedom of movement of individual residents from one level of achievement to another, within the facility and also out of the facility, through training, habilitation, and placement;

3.1.3.5 An array of those services that will enable each resident to develop *to* his maximum potential.

3.14 Speech Pathology and Audiology Services

3.14.1 Speech pathology and audiology services shall be available, in order to:

3.14.1.1 Maximize the communication skills of all residents;

3.14.1.2 Provide for the evaluation, counseling, treatment, and rehabilitation of those residents with speech, hearing and/or language handicaps.

3.14.2 The specific goals of speech pathology and audiology services *shall* be:

3.14.2.1 Appropriate to the needs of the residents served;

3.14.2.2 Consistent with the philosophy and goals of the facility;'

3.14.2.3 Consistent with the services and resources offered by the facility;

3.14.2.4 Known to, and coordinated with, other services provided by the facility.

3.14.3 Speech pathology and audiology services *shall* be rendered through:

3.14.3.1 Direct contact between speech pathologists and audiologists and residents;

3.14.3.2 Participation with administrative personnel in designing and maintaining social and physical environments that maximize the communication development of the residents;

3.14.3.3 Working with other personnel, such as teachers and direct-care staff, in implementing communication improvement programs in environmental settings.

3.14.4 Speech pathology and audiology services available to the facility shall include, as appropriate:

3.14.4.1 Audiometric screening of:

3.14.4.1.1 All new residents;

3.14.4.1.2 Children under the age of ten, at annual intervals;

3.14.4.1.3 Other residents at regular intervals;

3.14.4.1.4 Any resident referred;

3.14.4.2 Speech and language screening of:

3.14.4.2.1 All new residents;

3.14.4.2.2 Children under the age of ten at annual intervals;

3.14.4.2.3 All residents, as needed;

3.14.4.3 Comprehensive audiological assessment of residents, as indicated by screening results, to include tests of puretone air and bone conduction, speech audiometry, and other procedures, as necessary, and to include assessment of the use of visual cues;

3.14.4.4 Assessment of the use of amplification;

3.14.4.5 Provision for procurement, maintenance, and replacement of hearing aids, as specified by a qualified audiologist;

3.14.4.8 Comprehensive speech and language evaluation of residents, as indicated by screening results, including appraisal of articulation, voice, rhythm, and language;

3.14.4.7 Participation in the continuing interdisciplinary evaluation of individual residents for purposes of initiation, monitoring, and follow-up of individualized habilitation programs;

3.14.4.8 Treatment services, interpreted as an extension of the evaluation process, that include:

3.14.4.8.1 Direct counseling with residents;

3.14.4.8.2 Speech and language development and stimulation through daily living activities;

3.14.4.8.3 Consultation with classroom teachers for speech improvement and speech education activities;

3.14.4.8.4 Direct contact with residents to carry on programs designed to meet individual needs in comprehension (e.g., speech reading, auditory training, and hearing aid utilization) as well as expression (e.g., improvement in articulation, voice, rhythm, and language);

3.14.4.8.5 Collaboration with appropriate educators and librarians to develop specialized programs for developing the communication skills of multiply handicapped residents, such as the deaf retarded and the cerebral palsied;

3.14.4.9 Consultation with administrative staff regarding the planning of environments that facilitate communication development among residents in:

3.14.4.9.1 Living areas;

3.14.4.9.2 Dining areas;

3.14.4.9.3 Educational areas;

3.14.4.9.4 Other areas, where relevant;

3.14.4.10 Participation in inservice training programs for direct-care and other staff;

3.14.4.11 Training of speech pathology and audiology staff;

3.14.4.12 Training of speech pathology and audiology graduate and/or undergraduate students, interns, supportive staff, and volunteer workers;

3.14.4.13 Consultation with, or relating to:

3.14.4.13.1 Residents {e.g., self-referral);

3.14.4.13.2 Parents of residents;

3.14.4.13.3 Medical (otological, pediatric, etc.), dental, psychological, educational and other services;

3.14.4.13.4 The administration and operation of the facility;

3.14.4.13.5 The community served by the facility;

3.14.4.14 Program evaluation and research.

3.14.5 Comprehensive evaluations in speech pathology and audiology *shall* consider the total person and his environment Such evaluations should:

3.14.5.1 Present a complete appraisal of the resident's communication skills;

3.14.5.2 Evidence concern for, and evaluation of, conditions extending beyond observed speech, language, and hearing defects;

3.14.5.3 Consider factors in the history and environment relevant to the origins and maintenance of the disability;

3.14.5.4 Consider the effect of the disability upon the individual and the adjustments he makes to the problem as he receives it;

14.5.5 Consider the reaction of the resident's family, associates, and peers to the speech and or hearing problem.

3.14.6 Evaluation and assessment results shall be reported accurately and systematically, and in such manner as to:

3.14.6.1 Define the problem to provide a basis for formulating treatment objectives and procedures;

3.14.6.2 Bender the report meaningful and useful to its intended recipient and user;

3.14.6.3 Where appropriate, provide information useful to other staff working directly with the resident;

3.14.6.4 Conform to acceptable professional standards, provide for ultra-individual and interindividual comparisons, and facilitate the use of data for research and professional education;

3.14.6.5 Provide evaluative and summary reports for inclusion in the resident's unit record.

3.14.7 Treatment objectives, plans, and procedures *shall:*

3.14.7.1 Be based upon adequate evaluation and assessment;

3.14.7.2 Be based upon a clear rationale;

3.14.7.3 Reflect consideration of the objectives of the resident's total habilitation program;

3.14.7.4 Be stated in terms that permit the progress of the individual to be assessed;

3.14.7.5 Provide for periodic evaluation of the resident's response to treatment and of treatment effectiveness;

3.14.7.6 Provide for revision of objectives and procedures as indicated;

3.14.7.7 Provide for assistance or consultation when necessary.

3.14.8 Continuing observations of treatment progress *shall* be:

3.14.8.1 Recorded accurately, summarized meaningfully, and communicated effectively;

3.14.8.2 Effectively utilized in evaluating progress.

3.14.9 There *shall* be established procedures for evaluating and researching the effectiveness of speech pathology and audiology services, including:

3.14.9.1 Utilization of adequate records concerning residents' response and progress;

3.14.9.2 Time schedules for evaluation that are appropriate to the service being evaluated;

3.14.9.3 Provision for using evaluation results in program planning and development;

3.14.9.4 Encouragement of speech pathology and audiology staff to participate in research activities;

3.14.9.5 Provision for dissemination of research results in professional journals.

3.14.10 There *shall* be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the various speech pathology ana audiology services, in accordance with stated goals and objectives.

3.14.10.1 A speech pathologist or audiologist, who is qualified as specified in Item 3.14.10.2, and who, in addition, has had at least three years of professional experience, *shall* be designated as being responsible for maintaining standards of professional and ethical practice in the rendering of speech pathology and audiology services in the facility.

3.14.10.2 Staff who assume independent responsibilities for clinical services *shall* possess the educational and experiential qualifications required for a Certificate of Clinical Competence issued by the American Speech and Hearing Association (ASHA) in the area (speech pathology or audiology) in which they provide services.

3.14.10.3 Staff not qualified for ASHA certification *shall* be provided adequate, direct, active, and continuing supervision by staff qualified for certification in the area in which supervision is rendered.

3.14.10.3.1 Supervising staff *shall* be responsible for the services rendered by uncertified staff under their supervision.

3.14.10.3.2 Adequate, direct, and continuing supervision *shall* be provided nonprofessionals, volunteers, or other supportive personnel utilized in providing clinical services.

3.14.10.4 Students in training and staff fulfilling experience requirements for ASHA certification *shall* receive direct supervision, in accordance with the requirements of the American Boards of Examiners in Speech Pathology and Audiology.

3.14.10.5 All speech pathology and audiology staff *shall* be familiar with, and adhere to, the Code of Ethics published by the American Speech and Hearing Association.

3.14.11 Appropriate to the nature and size of the facility and to the speech pathology and audiology service, there *shall* be a staff development program that is designed to maintain and improve the skills of speech pathology and audiology staff, through methods such as:

3.14.11.1 Regular staff meetings;

3.14.11.2 An organized inservice training program in speech pathology and audiology;

3.14.11.3 Visits to and from the staff of other facilities and programs;

3.14.11.4 Participation in interdisciplinary meetings;

3.14.11.5 Provision for financial assistance and time for attendance at professional conferences;

3.14.11.6 Provisions for encouraging continuing education, including educational leave, financial assistance, and accommodation of work schedules.

3.14.11.7 Workshops and seminars;

3.14.11.8 Consultations with specialists;

3.14.11.9 Access to adequate library resources, which include current and relevant books and journals in speech pathology and audiology, mental retardation, and related professions and fields.

3.14.12 Space, facilities, equipment, and supplies *shall* be adequate for providing efficient and effective speech pathology and audiology services, in accordance with stated objectives, including:

3.14.12.1 Adequate and convenient evaluation, treatment, counseling, and waiting rooms;

3.14.12.2 Specially constructed and sound-treated suites for audiological services, meeting U.S.A.S.I. standards;

3.14.12.3 Design and location such as to be easily accessible to all residents, regardless of disability;

3.14.12.4 Specialized equipment needed by the speech pathologist;

3.14.12.5 Specialized equipment needed by the audiologist, including an audiometer, with provisions for sound field audiometry, and equipment capable of performing at least the following procedures: hearing screening, pure-tone air and bone conduction with contralateral masking, speech audiometrv, site-of-lesion battery, nonorganic hearing loss battery, and hearing aid evaluation;

3.14.12.6 Provisions for adequate maintenance of all areas, facilities, and equipment, including:

3.14.12.6.1 Electroacoustic calibration of audiometers at regular, at least quarterly, intervals;

3.14.12.6.2 Calibration logs on all audiometers.

3.14.12.7 Appropriate speech pathology and audiology consultation *shall* be employed in the design, modification, and equipage of all speech pathology and audiology areas and facilities.

AMERICAN DENTAL ASSOCIATION

LOUIS A. SAPORITO • PRESIDENT
570 BROAD STREET
NEWARK, NEW JERSEY 07102

March 2, 1973

The Honorable Jennings Randolph
Chairman
Subcommittee on Handicapped Workers
Committee on Labor and Public Welfare
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

The American Dental Association is pleased to have this opportunity to present its views on S. 458, a bill to provide humane care, treatment, habitation and protection of the mentally retarded in residential facilities.

The Association is intensely interested in the unique dental health needs of the mentally retarded. The Association is pleased to note the inclusion of extensive dental provisions in S. 458.

During the past few decades, the dental health of the nation has advanced considerably. In spite of these advances, however, the incidence of dental disease today is still nearly universal and it is a rare individual who is not in need of dental care. The mentally retarded are no exception to the rule. On the contrary, their dental health needs often exceed those of the community as a whole.

Sections 1261 and 1262 delineate a comprehensive dental services program for individuals who are residing in mental retardation facilities. Undoubtedly, comprehensive dental care such as is described in these sections is badly needed by many of the mentally retarded.

Of particular concern to the Association is the fact that dentists and dental auxiliaries treating special patients have need of careful training. We are pleased to note that section 1262 recognizes this problem and should, through the establishment of continuing education programs, meet this requirement.

We respectfully request that this letter be included in the Subcommittee's hearing record on S. 458.

Sincerely,

Louis A. Saporito

Louis A. Saporito, D.D.S.
President

Senator JAVITS. At this point I order printed all statements of those who could not attend and other pertinent material submitted for the record.

[The material referred to follows:]

"THE EASTER SEAL SOCIETY"
FOR CRIPPLED CHILDREN AND ADULTS
The St. Louis Society for Crippled Children, Inc.

4108 LINDELL BOULEVARD • ST. LOUIS, MISSOURI 63108 • Area Code 314 662-7342

March 6, 1973

The Honorable Stuart Symington
Senate Office Building
Washington, D.C. 20510

Subject! Public Law 91517
Extension of Developmental Disabilities Act

Dear Senator Symington:

This is to record my personal as well as the Easter Seal Society St. Louis Region's endorsement of an extension of the Developmental Disabilities Act, Public Law 91517, which is due to expire on June 30, 1973. We at the Easter Seal Society feel very strongly that the Developmental Disabilities Act has been an important piece of legislation which has helped significantly many disabled in the past two years. The Easter Seal Society has served on an Advisory Council in developing a local regional plan to implement the Developmental Disabilities Act and the services it provides for our citizens.

We strongly support the position of the National advisory Council for the Developmentally Disabled and the position as stated by James W. Moss, Ph.D., in testimony before the Subcommittee on the Handicapped of the Senate Committee on Labor and public Welfare. Dr. Moss supported the recommendation of the National Advisory Council which deletes any reference to the categorical groups listed in the original Act, "mental retardation, cerebral palsy, epilepsy and other neurological conditions". We strongly endorse the proposal of the Advisory Council for a change in legislation which reads:

> *"Developmental Disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age of eighteen and has continued Or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen a handicap of comparable severity).*

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AFFILIATED WITH THE MISSOURI AND NATIONAL EASTER SEAL SOCIETIES FOR CRIPPLED CHILDREN AND ADULTS, INC.

"In addition to a revised definition, the Developmental Disabilities Act should provide for service eligibility for all substantially handicapped persons who can benefit from a service being provided for persons with developmental disabilities as defined in the primary target group. The following language is suggested:

" 'eligible person' means a person with a developmental disability or a person with another substantial handicap who has similar service needs and who is considered eligible for such similar services by an agency or a facility which is providing services primarily intended for persons with developmental disabilities."

In these times in which there is considerable tumult and indecision regarding the provision of services for the disabled, it is especially important that focus be put on provision of these necessary services and not on emphasizing diagnostic categories, strict eligibility guidelines, etc. We would endorse the recommendation of the National Easter Seal Society which states that the Act be strengthened by making it clear that a disability need not be permanent except through our neglect, and it is not the condition which makes a person disabled, but rather the society in which he lives. We would definitely like to see federal money channeled into programs so that the impaired in our society need not be permanently disabled.

The Easter Seal Society St. Louis Region continues its efforts as a private voluntary non-profit agency in serving the needs of the disabled child and adult in a region encompassing the City of St. Louis and the Missouri Counties of St. Louis, St. Charles, Jefferson, Franklin, Lincoln and Warren. We are especially interested in all public and private efforts made to coordinate services for the disabled and their families.

Sincerely,

Daniel Henroid

Daniel Henroid
Regional Director

STATEMENT BY SENATOR ERNEST F. HOLLINGS BEFORE THE SUBCOMMITTEE ON THE HANDCIAPPED ON THE DEVELOPMENTAL DISABILITIES ACT, S. 427.

I appreciate this opportunity to present my views to the Subcommittee on the Handicapped and to suggest that during its consideration of the Developmental Disabilities Act, the Subcommittee amend this act to include the provisions of S. 34, the Autistic Children's Research Act, which I introduced on January 4.

I originally introduced this legislation during the 92nd Congress after learning of the severe needs of autistic children across the nation. In my own state of South Carolina, 1200 children needing residential treatment are competing for the 44 beds which we have available, and only ten of these beds are available for the severely disturbed child. My state is not an exception. Because of the finely drawn definition covering the mentally ill and the mentally retarded, many of the estimated 80,000 autistic Americans are unserved by schools, residential facilities, and vocational programs. Very few states have a comprehensive program for the autistic child. Without treatment and education, these children will end up in a state institution, receiving nothing but custodial care at a cost to the taxpayer of $250,000 for each individual so interned.

To turn our backs on this problem is not only inhumane, it is also costing us money. It has been shown that autistic children can be helped by education and treatment programs similar to those existing for mentally retarded and other developmentally disabled individuals. This education and care enables the autistic person to become a more self-sufficient and productive member of society and helps to free him from dependence on custodial care.

S. 34 would establish loans and grants to any public or nonprofit entity operating a residential or non-residential center with education programs for autistic children. This would rectify the problem that we have in South Carolina, and which exists in many other states as well, where parents must go outside the state to obtain the needed facilities for their autistic child. Further, S. 34 would initiate a coordinated, comprehensive research effort. At this point, there is no known cause or cure for autism. I feel it is essential to face this problem head-on and to lift the curtain of ignorance.

I note that services provided by S. 427 are similar to the grants and loans that are included in S. 34. Hence to include the autistic in the definition of S. 427 would include this group in the coverage of the bill and would incorporate the concept which I had in mind when I proposed S. 34.

I note that S. 427 does not contain provisions for research. I would suggest to the Subcommittee that they consider the merits of initiating and encouraging research in the developmental disabilities field. In the area of autism, I know that there has been abundant evidence in the past ten years that autistic children can benefit, often dramatically, from special education suited to their needs. The same fact is true of the other categories of developmentally disabled. If we can increase our knowledge of the causes of developmental disabilities, and if we can increase our experience and our experimentation in different programs of special education and other treatment, we certainly can make great strides in helping these people help themselves. Hence, in the long run a research effort will more than pay for itself, and it would certainly enrich the developmental disabilities program.

Recognizing the potential for coordinating services for all the substantially handicapped, I feel it is particularly appropriate to include the autistic in the program established by S. 427. To proceed with various bills, each directed toward a specific disability would encourage duplication and unnecessary competition. This amendment represents the most effective and economical approach to the problems faced by all substantially disabled Americans, and it enables us all to work together to enact and fund legislation to provide the help these people so desparately need.

I appreciate the opportunity which this Subcommittee has afforded me to express my views.

american physical therapy association

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STATEMENT OF

THE AMERICAN PHYSICAL THERAPY ASSOCIATION

BEFORE THE SENATE COMMITTEE ON

LABOR AND PUBLIC WELFARE

SUBCOMMITTEE ON THE HANDICAPPED

ON S. 427 AND S. 458

Presented by
Royce P. Noland, Executive Director
American Physical Therapy Association

February 21, 1973

Physical Therapy is a profession which develops, coordinates, and utilizes selected knowledge and skills in planning, organizing, and directing programs for the care of individuals whose ability to function is impaired or threatened by disease, or injury. The profession requires knowledge in depth of human growth and development, human anatomy and physiology , neuro anatomy, neuro physiology, biomechanics of motion, manifestations of disease and trauma, normal and abnormal psychological response to injury and disability, and the ethnic, cultural, and socio-economic influences on the individual. It also includes principles of learning and teaching, administration, supervision, the consultive process, and communication, knowledge of the role and function of other health professions, and the planning for and development of community health service and facilities. The profession incorporates a large spectrum of activities such as direct patient care, supervision, teaching, consultation, administration, research, and community service. The American Physical Therapy Association as a professional society consists of more than 18,000 physical therapists throughout the United States and its territories, and one of its objects is, "To meet the physical therapy needs of the people through the development and improvement of physical therapy education, practice, and research."

The American Physical Therapy Association is grateful *to* the members of the Subcommittee for an opportunity to present its views

on S. 427, The Developmental Disabilities Services and Facilities Construction Act of 1970 (Public Law 91-417) and on S. 458, which would establish standards to insure humane care, treatment, habilitation and protection of the mentally retarded in residential facilities. S. 427, which seeks to extend for three years the Developmental Disabilities Services Act, should be commended for its foresight in realizing that only by continuing such legislation can the proper facilities for children with handicaps be adequately and continually upgraded in the future. We strongly endorse the enactment of S. 427 with appropriate amendments.

We commend Senator Javits on his proposed "Bill of Rights for the Mentally Retarded," S. 458. This is a fine example of a very comprehensive bill attempting to provide for humane care, treatment, habilitation, and protection of the mentally retarded in residential facilities. We would like to also compliment Mr. Javits on the thoroughness of Chapter 3, Part C of the bill which relates to standards for physical therapy services, Subchapter IX, Section 1270. This section is exceptionally well-detailed and parallels without conflict those standards for physical therapy services and practice as defined by the American Physical Therapy Association.

In summary, the American Physical Therapy Association does endorse S. 427 and S. 458 and strongly asks for a favorable consideration by the committee. Certainly, this type of legislation indicates another great step forward in the committment to improvement of services to the handicapped and we sincerely appreciate this opportunity to present our views on this proposed legislation.

93D CONGRESS
1ST SESSION

S. 1654

IN THE SENATE OF THE UNITED STATES

APRIL 18, 1973

Mr. JAVITS introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

A BILL

To provide for the extension of the Developmental Disabilities Services and Facilities Construction Act, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act he cited as the "Developmental Disabilities Amendments of 1973".

EXTENSION OF AUTHORIZATIONS

SEC. 2. (a) Section 121 (a) of the Developmental Disabilities Services and Facilities Construction Act is amended by inserting after the first sentence thereof the following new sentence: "There are also authorized to be appropriated for such purpose such sums as may be necessary for the fiscal

year ending June 30, 1974, and for each of the next two fiscal years."

(b) Section 122(b) of the Developmental Disabilities Services and Facilities Construction Act is amended by striking out "and" before "$20,000,000" and by inserting before the period at the end thereof ", and such sums as may be necessary for the fiscal year ending June 30, 1974, and for each of the next two fiscal years".

(c) Section 131 of the Developmental Disabilities Services and Facilities Construction Act is amended by striking out "and" before "$130,000,000" and by inserting before the period at the end thereof ", and such sums as may be necessary for the fiscal year ending June 30, 1974, and for each of the next two fiscal years".

MINIMUM ALLOTMENT FOE TERRITORIES

SEC. 3. Section 132 (a) (1) of the Developmental Disabilities Services and Facilities Construction Act is amended by striking out "any State (other than the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands)" and inserting in lieu thereof "the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands for any such fiscal year shall not be less than $50,000, and the allotment of each other State".

ELIMINATION OF REQUIREMENT OF FEDERAL APPROVAL OF EACH CONSTRUCTION PEOJECT

SEC. 4. (a) (1) The Developmental Disabilities Services and Facilities Construction Act is amended by striking-out sections 135 and 136, and by redesignating sections 137, 138, and 139 as sections 135, 136, and 137, respectively.

(2) Section 123 (a) (2) of such Act is amended by striking out "139" and inserting in lieu thereof "137".

(3) Section 134 (b) of such Act is amended by striking out "and" after the semicolon at the end of paragraph (17), by redesignating paragraph (18) as paragraph (20), and by inserting the following new paragraphs after paragraph (17):

"(18) provide reasonable assurance that adequate financial support will be available to complete the construction of, and to maintain and operate when such construction is completed, any facility, the construction of which is assisted by funds made available pursuant to section 132;

"(19) provide reasonable assurance that all laborers and mechanics employed by contractors or subcontractors in the performance of work on any construction project assisted with funds made available pursuant to

section 132 will be paid wages at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the Davis-Bacon Act, as amended (40 U.S.C. 276a-276a-5) ; and the Secretary of Labor shall have with respect to the labor standards specified in this paragraph the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.E. 3176; 5 U.S.C. 133z-15) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c) ; and".

(4) The heading of the section of such Act redesignated as section 135 by paragraph (1) of this subsection is amended by inserting "CONSTRUCTION," after "PLANNING,".

(5) The heading of the section of such Act redesignated as section 136 by paragraph (1) of this subsection is amended by inserting "CONSTRUCTION," after "PLANNING,".

(6) The section of such Act redesignated as section 135(a) (1) by paragraph (1) of this subsection is amended by striking out ", other than expenditures for construction,".

(7) Section 140 of such Act is amended by striking out so much thereof as precedes subsection (b) (other than the section heading), by striking out "(b)" and inserting in lieu thereof "SEC. 138.", and by inserting "construction," after "planning,",

(8) Section 142 (a) (2) (A) of such Act is amended by inserting "which was used by the State in which the facility is located" before "to assist in financing the construction of the facility".

(b)'(l) Section 401 (h) (1) of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 is amended by striking out "part C of title I or".

(2) Section 401 (h) (2) of such Act is amended by striking out " (A) for any project under part C of title I may not exceed 66 2/3 per centum of the costs of construction of such project; and (B) ".

(3) Section 401 (h) (3) of such Act is amended by striking out "under part C of title I or".

(4) Section 403 (a) of such Act is amended by striking out "section 134 in the case of a facility for the mentally retarded or persons with other developmental disabilities, or" and by striking out "section 136 or" and "as the case may be," from clause (2) thereof.

(5) Section 403 (b) of such Act is amended by striking out "135 or".

(6) Section 404 of such Act is amended by striking out "135 or" and "136 or" from the first sentence thereof.

(7) Section 405 of such Act is amended by inserting "or section 135" after "section 403".

(8) Section 405 (1) of such Act is amended by striking out "135 or" from clause (A) thereof and by inserting "(in the case of a community mental health center)" after "205" in such clause.

AMENDMENTS TO FEDERAL SHARE PROVISION

SEC. 5. The section of the Developmental Disabilities Services and Facilities Construction Act redesignated as section 135(b) by section 4(a) (1) of this Act is amended to read as follows:

" (b) The 'Federal share' with respect to any State for purposes of this section shall be 70 per centum for the fiscal year ending June 30, 1974; 60 per centum for the fiscal year ending June 30, 1975; and 50 per centum for the fiscal year ending June 30, 1976."

INCLUSION OF LAND ACQUISITION COSTS

SEC 6. Section 401 (e) of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 is amended by inserting ", for purposes of title II of this Act only," before "the cost of the acquisition of land.".

INCLUSION OF AUTISM

SEC. 7. Section 401 (1) of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 is amended by inserting "(including autism)" after "condition of an individual".

EFFECTIVE DATE

SEC. 8. The amendments made by this Act shall become effective with respect to appropriations for fiscal year beginning after June 30, 1973.

Senator JAVITS. The subcommittee will now stand adjourned until the call of the Chair.

[Whereupon, at 5:45 p.m., the subcommittee recessed, to reconvene subject to the call of the Chair.]