

TO DEVELOP PROGRAM STANDARDS FOR SERVICES  
TO THE MENTALLY RETARDED IN MINNESOTA

I. Introduction and Philosophic Rationale.

Minnesota has been seriously hampered, as have most other states, in caring for the mentally retarded by the absence of standards which could be used to structure programs to serve diverse groups of retarded persons in day or residential facilities. Such program standards are becoming a critical necessity as facilities which care for the retarded multiply and decentralize, under the added impetus of Federal construction moneys available under Public Law 88-164.

The Minnesota Mental Retardation Planning Council has strongly recommended that program standards be created and used as "enforceable guidelines" for all state and private facilities, that is, built into the licensing process. Further, the Council has recommended that program standards must be formulated in terms of well-defined needs of homogeneous groups of retarded persons. Were this the case, someone who wanted to build a facility to care for, say, fifteen non-ambulatory children aged 0 to 6 years, would have to meet certain criteria of programmatic effectiveness for this particular kind of patient group before the facility could be licensed. The appropriate question would be "What kinds of retarded persons are you thinking of serving?" rather than "What kind of facility are you planning to build?" A retarded person of a given age, degree of retardation, and handicapping condition must have certain services, regardless of whether he lives in his own home, in a state institution, or in a small boarding home - granted that the way in which these are provided and perhaps relative emphases among services may vary with the setting.

The "continuum of care" concept envisions that there will be available to each retarded person appropriate services, as needed, at any point in his life span. Ideally services should be available to the retarded to the extent that they are available to the non-retarded in the same community. Program standards are necessary if every retarded person is to be provided with a life-milieu as closely comparable

as possible to that of non-retarded persons. Designing facilities to encompass needed programs, rather than adapting programs to already structured facilities, will secure optimum movement of patients from facility (and service) to facility along a continuum of care.

## II. Purpose.

The purpose of the proposed project is to develop a body of program standards suitable for use in the provision of a variety of appropriate services to homogeneous groups of retarded persons in day and residential facilities. These standards will encompass a full range of services - evaluation, treatment, education, training, rehabilitation, sheltered employment, care and management, and recreation, all designed to maximize the personal and social effectiveness of each retarded individual.

## III. Implications.

The proposed project would have important national implications in its applicability in other states. A canvass of the 50 states revealed that only California and Louisiana have developed any standards specifically geared for the mentally retarded; both appear to be "bare bones." All of the responding states indicated a high degree of interest in a project to create standards. Mr. Herschel Nisonger, Director of Special Studies for the American Association on Mental Deficiency, has written in answer to our query that such a project is "urgently needed," and has promised every possible assistance in carrying it out.

Once the standards are developed their ultimate value will lie in their incorporation into the licensing process and enforcement thereof. An individual or group proposing to care for retarded persons would be required to structure the particular combination of services needed by the population to be served prior to licensure. Further, the state would be able to request that a private non-profit group which indicated an interest in serving the retarded to provide badly needed services for a clearly defined group of retarded persons, rather than permitting a proliferation of similar facilities offering undifferentiated services to heterogeneous populations.

It is hoped that an important long-term effect of the development of a unified body of standards will be the participation of each state department responsible for

service to the retarded in a concerted attempt to ensure that standards which fall within its area of concern are met in a given setting. Thus the Departments of Health and Public Welfare and the Divisions of Special Education and Vocational Rehabilitation would mount a coordinated effort, perhaps even to the extent that responsibility for licensing would eventually be a trilateral one. It should be explained that, at present, licensing of facilities to care for the retarded is somewhat arbitrarily divided between the Departments of Health and Public Welfare. Because clearly defined program standards have not been available, too often the left hand simply does not know what the right hand is doing. For example, the Department of Public Welfare has licensed a pediatric nursing home, despite the residence there of numerous patients requiring intensive nursing care. On the other hand, the Department of Health licenses a residence and sheltered workshop for retarded young adults, under its Hotel and Restaurant Division. (Even though one of the projects is making pizza, this licensure seems somewhat absurd!)

#### IV. Procedure.

- A. The Project will be developed as part of Minnesota's greater implementation effort under the aegis of the Mental Retardation Planning Council. The Department of Public Welfare will serve as fiscal agent, as it has for planning and implementation grants under Public Laws 88-156 and 89-97 and for administration of construction moneys under Public Law 88-164.
- B. A special committee of the Residential Care Task Force has held many meetings to explore various aspects of the "standards and licensing lag" in Minnesota. The Task Force, with its special committee as a nucleus, would serve as an advisory group during the project year. Other key individuals will be added, including the Director of Medical Services, Department of Public Welfare; at least one superintendent of a state institution for the retarded; and the Residential Care

chairman of the Minnesota Association for Retarded Children,

- C. The general methodology will be to conceptualize specific program needs of homogeneous groups of retarded persons, in consultation with organizations, agencies, planning bodies, and individuals throughout the state and private sector who are, and have long been, deeply committed to the welfare of the mentally retarded. Most of these agencies and individuals have been intimately involved in the comprehensive mental retardation planning and implementation process.
- D. Dr. Richard Bartman, formerly Director of Children's Mental Health Services, Medical Services Division, Department of Public Welfare, and presently Assistant Superintendent at Sonoma State Hospital in Eldridge, California, developed a system of patient groupings which have been in use in Minnesota's state institutions for the retarded since June, 1965.

Dr. Bartman structured six groupings (see attached) along the broad dimensions of age and ambulation and evolved a brief description of each group in terms of abilities, distinguishing intellectual and emotional characteristics and needs — ranging from total care to a high degree of independence and autonomy. These groupings will be the conceptual pivot around which program requirements will be elaborated.

- E. A variety of collected data will be utilized as applicable:

1. State Standards (Minnesota)

- a. Minnesota Statutes and Regulations for Licensing of Nursing Homes and Boarding Care Homes.
- b. Standards for the Licensing of Foster Boarding Homes for Children,
- c. Standards for Family Day Care Homes in Minnesota.
- d. Standards for the Licensing of Private Child-Caring or Placing Agencies.
- e. Standards for the Licensing of Child-Caring Institutions

2. State standards (Other states)

Standards pertaining to residential or day care were solicited from other states. Although, with the exception of California and Louisiana, these

do not apply directly to the retarded, they will nevertheless be carefully sifted for any useful material.

3. National standards

- a. Child Welfare League of America Standards for Day Facilities; for Residential Facilities
- b. AAMD Manual on Program Development
- c. AAMD Manual for Residential Care Facilities
- d. Joint Commission on Accreditation of Hospitals: Standards for Extended Care Facilities

4. Written material developed by members of the Residential Care Task Force

- a. MA Study of Foster Boarding Homes for Mentally Retarded Children in a Metropolitan County."
- b. "The Worlds OF --," an outline of the subjective milieu and the objective needs (services and staff) of children and adults in the six programs described in IV, D, above, together with an assesment of how well present private facilities are meeting these needs.

5. Important aspects of programming as described by administrators of state and private facilities in Minnesota. This data came in response to a letter from the project office soliciting useful information about programs in ongoing facilities.

V. Staff

A full-time staff would consist of a project director and a secretary. Consultants would be utilized as necessary, in addition to the advisory group and vast expert base described in IV, A, above.

On this basis, this project should take about one year to accomplish.

VI. Budget

Director	\$14,000
Secretary	4,200
Fringe Benefits	1,000
Supplies	2,000

Equipment	900
Travel	1,200
Other	1,700
Consultants	
Contractual Services	
	\$25,000

PROPOSAL  
TO DEVELOP PROGRAM STANDARDS FOR SERVICES  
TO THE MENTALLY RETARDED

I. Minnesota has been seriously hampered, as have most other states, in caring for the mentally retarded by the absence of standards with which to structure programs to serve diverse groups of retarded persons in day or residential facilities. Such program standards are fast becoming a critical necessity as smaller, decentralized facilities to care for the retarded multiply, as evidence of a burgeoning professional and popular awareness of modern concepts of caring for the retarded given strong practical impetus by the availability of Federal construction moneys under Public Law 88-164.

Although the Division of Child Welfare, Department of Public Welfare, has developed standards for foster boarding homes for children, family day care homes, child-caring institutions, and group day care of pre-school and school age children, these standards are necessarily too broad to be useful in trying to devise programs based on grouping retardates along various dimensions of similarity. Further, they are limited to children, a serious limitation when one considers the thousands of retarded adults whose need for imaginative programming is great, and whose ranks are ever growing as improved medical research and treatment enhances the life span. (It is worth noting that two new residential facilities for retarded adults are being constructed in Minnesota at this moment — one for 100 males, the other for 100 females. Those which already exist have experienced serious problems in attempting to program for their populations without appropriate guidelines.) Similarly, the Department of Health has published standards for nursing homes and boarding care homes; these apply to adults, but they encompass physical standards only and even then are largely unsuitable for care of the mentally retarded.

The Minnesota Mental Retardation Planning Council has strongly recommended that program standards be created and used as "enforceable guidelines," that is, built into the licensing process, for all who wish to care for the retarded on a day or residential basis. The Council's recognition of this urgency of this need was recently underscored by Dr. Robert Jaslow, Director of the Division of Mental Retardation, U.S. Department of Health,

Education, and Welfare, when he listed as one point in a six-point program model for balance and coordination of services to the retarded the following: "We must develop standards for services and training. Those to be utilized are determined by the community when appropriate to control and justify the expenditure of tax dollars, to help in program evaluation, to stimulate program improvement, and to use in determination of the need for continuance and modification of various programs. Standards are a quality control factor for the good of the community, the family, and, most important, the patient."

The "continuum of care" concept envisions that there will be available to each retarded person appropriate services, as needed, at any point in his life span. Ideally services should be available to the retarded to the extent that they are available to the non-retarded in the same community. Program standards are necessary if every retarded person is to be provided with a life-milieu as closely comparable as possible to that of non-retarded persons. Designing facilities to encompass needed programs, rather than adapting programs to already structured facilities, will secure optimum movement of patients from facility (and service) to facility along a continuum of care.

The Planning Council has recommended that program standards be formulated in terms of well-defined needs of homogeneous groups of retarded persons. Were this the case, someone who wanted to build a facility to care for, say, fifteen non-ambulatory children aged 0 to 6 years, would have to meet certain criteria of programmatic effectiveness for this particular kind of patient group before the facility could be licensed. The appropriate question would be "What kinds of retarded persons are you thinking of serving?" rather than "What kind of facility are you planning to build?" A retarded person of a given age, degree of retardation, and handicapping condition must have certain services, regardless of whether he lives in his own home, in a state institution, or in a small boarding home - granted that the way in which these are provided and perhaps relative emphases among services may vary with the setting.

Gardner and Nisonger explain the necessity for this type of theoretical framework as follows:

"A classification of mental retardation without further qualifications as to the degree of retardation, etiology, type and severity of accompanying physical, sensory, neurological, emotional, educational, or learning handicaps is only of limited value

in planning a program for a given individual...Needs within a retarded population vary as a function of chronological age as well as along various dimensions of severity of handicap (physical, social, educational, emotional, mental, and vocational). Different programs must be developed to provide for the various constellations of needs present...Since programs and services cannot be developed entirely on an individual basis, it becomes necessary to devise some method of grouping retardates in terms of outstanding characteristics or needs. Programs can then be developed to meet the needs which focus the basis of the groupings." 1(p.38)

## II. Purpose.

The purpose of the proposed project is to develop a body of program standards suitable for use in the provision of a variety of appropriate services to homogeneous groups of retarded persons in day and residential facilities. These standards will encompass a full range of services - evaluation, treatment, care and management, education, training, rehabilitation, sheltered employment, and recreation, all designed to maximize the personal and social effectiveness of each retarded individual. They will provide indispensable guidelines for both the providers and the consumers of services - that is, the agency or individual which wishes to serve, the architect (if one is involved), the placing agency, and the parent or family - as well as for the licensing agency.

## III. Implications.

The proposed project will have important national implications in its applicability in other states. A canvass of the 50 states revealed that only California and Pennsylvania are actually working in this area, and neither has progressed too far in its effort. The prospect of a project to create standards generated a high degree of interest and enthusiasm on the part of all respondents. Mr. Herschel Nisonger, Director of Special Studies for the American Association on Mental Deficiency, has written in answer to our query that such a project is "urgently needed," and has promised every possible assistance in carrying it out. Similar letters, which contain both awareness of the magnitude of the need and the assurance of support for any project which would help to remedy this need, have been received from the National Committee for the Daycare of Children and the

Child Welfare League of America, as well as from Dr. Arnold Cortazzo, Professor at the University of Florida who has been deeply involved in the problem of standard setting, and Otto Estes, Louisiana Commissioner of Mental Retardation, whose committees are also vitally concerned with the development of standards. Letters of support from individuals and agencies in Minnesota have also been received.

Once the standards are developed their ultimate value will lie in their incorporation into the licensing process and enforcement thereof. An individual or group proposing to care for the retarded persons would be required to structure the particular combination of services needed by the population to be served prior to licensure. Further, the state would be able to request that a private non-profit group which indicated an interest in serving the retarded provide badly needed services for a clearly defined group of retarded persons, rather than permitting a proliferation of similar facilities offering undifferentiated services to heterogeneous populations.

It is hoped that an important long-term effect of the development of a unified body of standards will be the participation of each state department responsible for service to the retarded in a concerted attempt to ensure that standards which fall within its area of concern are met in a given setting. Thus the Departments of Health and Public Welfare and the Divisions of Special Education and Vocational Rehabilitation would mount a coordinated effort, perhaps even to the extent that responsibility for licensing would eventually be a trilateral one. It should be explained that, at present, licensing of facilities to care for the retarded is somewhat arbitrarily divided *between* the Departments of Health and Public Welfare. Because clearly defined program standards have not been available, too often the left hand simply does not know what the right hand is doing. For example, the Department of Public Welfare has licensed a pediatric nursing home, despite the residence there of numerous patients requiring intensive nursing care. On the other hand, the Department of Health licenses a residence and sheltered workshop for retarded young adults, under its Hotel and Restaurant Division. (Even though one of the projects is making pizza, this licensure seems somewhat absurd!)

#### IV. Methodology.

- A. The project will be developed as a part of Minnesota's greater implementation effort. It was originally intended that this work take place under the aegis of the Mental Retardation Planning Council. However, since the grant under which the Planning Council functions will terminate in December, 1967, the State Planning Office would serve as administrative and fiscal agent for the project. This choice seems a fortunate one for two reasons: the project to develop standards is distinctively inter-departmental in nature and thus should be carried out independent of any one state department; state mental retardation planning (after December 1967) will be subsumed under Comprehensive Health Planning for which Dr. Ellen Fifer, Director of Health and Rehabilitation, State Planning Office, will be responsible.
- B. A special committee of the Residential Care Task Force has held many meetings to explore various aspects of the "standards and licensing lag" in Minnesota. This committee would serve as the nucleus of a Standards Advisory Board during the project year. The committee numbers among its members Dr. Robert Barr, Executive Secretary of the Minnesota Department of Health; Morris Hursh, Commissioner of the Minnesota Department of Public Welfare; Dr. Helen Knudsen, Director, Division of Hospital Services, Department of Health; Charles Fecht, Supervisor, Standards and Licensing, Division of Child Welfare, Department of Public Welfare; Arthur Jauss, Consultant, Standards and Licensing, Division of Child Welfare, Department of Public Welfare; Evelyn Carlson, Director, Hammer School; Frances Ames, Supervisor, Mentally Retarded, Division of Medical Services, Department of Public Welfare; Howard Paulsen, Director, Family Counseling Division, Lutheran Social Service of Minnesota; and Gerald Walsh, Executive Director, Minnesota Association for Retarded Children. Other key individuals will be added, including but not limited to the Director of Medical Services, Department of Public Welfare; the Director of Special Education, Department of Education; the Director of Vocational Rehabilitation, Department of Education; at least one superintendent of a state institution for the retarded; representatives of the Department of Special Education and Department of Pediatric Medicine, University of Minnesota; and the Residential Care chairman of the Minnesota Association for Retarded

Children.

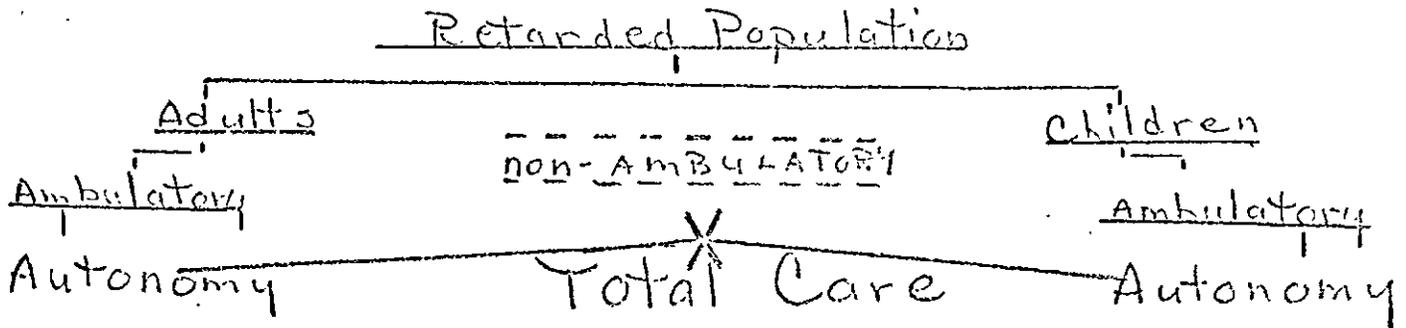
- C. The general methodology will be to conceptualize specific program needs of homogeneous groups of retarded persons, in consultation with organizations, agencies, planning bodies, and professional and lay persons throughout the public and private sector who are, and have long been, deeply committed to the welfare of the mentally retarded. Most of these agencies and individuals have been intimately involved in the three year comprehensive mental retardation planning and implementation process. Attached is a partial list of individuals with whom the project staff would consult.
- D. Two primary systems of organizing data into functional units will be used.
1. The American Association on Mental Deficiency has been working on standards for state residential institutions since 1960 and published a manual on standards in January, 1964. In early 1965 the AAMD received a grant from the Mental Retardation Division, Public Health Service, to convert these standards into evaluation instruments; this task was completed in December, 1966. Also in 1966, the Public Health Service approved another grant enabling the AAMD to provide evaluation services by professional teams to all state residential institutions desiring such service.

Mr. Herschel Nisonger, who directs the Institutional Evaluation Project for the AAMD, has generously offered to share any of his materials with us. The AAMD evaluation instruments, which contain hundreds of items pertinent to various aspects of programming for the retarded, will be used as a "jumping-off place" for our own compilation of data. We propose to extract from this material whatever relates to serving varieties of retarded persons in multifarious settings. Of course, many of these items are uniquely applicable to state residential institutions.

2. Dr. Richard Bartman, formerly Director of Children's Mental Health Services, Medical Services Division, Department of Public Welfare, and presently Assistant Superintendent at Sonoma State Hospital in Eldridge, California, developed a system of patient groupings which has been used to classify patients in Minnesota's

state institutions for the retarded since June, 1965.

Dr. Bartman structured six groupings (see attached) along the broad dimensions of age and ambulation and evolved a brief description of each group in terms of abilities, distinguishing intellectual and emotional characteristics, and needs - ranging from total care to a high degree of independence and autonomy. While this classification system is admittedly arbitrary, it does rest on certain established parameters, as indicated in the chart below:



Each of these groupings will be used to initiate discussion and consultation with individuals, groups and agencies, local, state, and Federal, which are knowledgeable, experienced, and responsible for dealing with the constellation of characteristics represented by that particular grouping. This process, which is both inclusive and selective, parallels that used in Minnesota's comprehensive mental retardation planning effort. Although sometimes laborious, it not only ensures the tapping of an enormous fund of expertise, but also prognosticates acceptance of the standards by those who have had such an important hand in preparing them.

The ideas so garnered will be sifted, worked in with the AAMD material as well as with pertinent data from sources listed in (E.) below, and synthesized into a written working draft for each of the six groups. At this point we would envisage a series of meetings with the Standards Advisory Board, some of whom may have been involved in the formative process as well, to review and modify the working draft and shape it into final form. This process would be repeated with each of the six Bartman groups, so that the end product would be a compilation of six program groupings. There would be many elements common to all, and many

elements unique to each.

E. In addition, a variety of collected data will be utilized as applicable:

1. State Standards (Minnesota)

- a. Minnesota Statutes and Regulations for Licensing of Nursing Homes and Boarding Care Homes.
- b. Standards for the Licensing of Foster Boarding Homes for Children.
- c. Standards for Family Day Care Homes in Minnesota.
- d. Standards for the Licensing of Private Child-Caring or Placing Agencies.
- e. Standards for the Licensing of Child-Caring Institutions.
- f. Standards for Group Day Care of Pre-School and School Age Children in Minnesota.

2. State Standards (Other states)

Standards pertaining to residential or day care were solicited from other states. Although, with the exception of California and Louisiana, these do not apply directly to the retarded, they will nevertheless be carefully examined for any useful material.

3. National standards

- a. Child Welfare League of America Standards for Day Facilities; for Residential Facilities.
- b. AAMD Manual on Program Development.
- c. AAMD Manual for Residential Care Facilities.
- d. Joint Commission on Accreditation of Hospitals: Standards for Extended Care Facilities.
- e. NARC Standards and Guidelines for Day and Residential Care.

4. Written material developed by members of the Residential Care Task Force

- a. "A Study of Foster Boarding Homes for Mentally Retarded Children in a Metropolitan County"
- b. "The Worlds OF -," an outline of the subjective milieu and the objective needs (services and staff) of children and adults in the six programs described in IV, D, above, together with an assessment of how well present

private facilities are meeting these needs.

5. Important aspects of programming as described by administrators of state and private facilities in Minnesota. A few responses came in reply to a letter from the project office soliciting useful information about programs in on-going facilities. With the existence of an ongoing funded project to develop standards, another letter should be sent and would probably elicit a greater number of replies.

V. Staff.

A full-time staff would consist of a project director and a secretary. In addition to the advisory group and vast expert base described in IV, C, above, we would anticipate using the services of the following consultants: Herschel Nisonger, Director of Special Studies for the American Association on Mental Deficiency; \_\_\_\_\_ Director, Joint Commission on Accreditation of Hospitals, Extended Care Committee; Owen Franklin, Mental Retardation Specialist, Children's Bureau; someone from NARC.

On this basis, this project should take about 18 months to accomplish.

VI. Budget.

Director	\$21,000
Secretary	6,300
Fringe Benefits	1,500
Supplies	3,000
Equipment	7 900
Travel	3,600*
Other	
Printing	3,000
Office Rental	1,800
Telephone	450
Postage Expense	1,120
	\$42,670

\*This figure includes travel to national consultants and to facilities in other states.

MINNESOTA MENTAL RETARDATION PLANNING COUNCIL

CHARACTERISTICS OF THE PATIENTS WHO WILL BE IN THE SIX BROAD PROGRAMS BEING ESTABLISHED IN THE INSTITUTIONS FOR MENTALLY RETARDED

July, 1965

Program No. 1

CHILD ACTIVATION PROGRAM This program is for children from birth to puberty who are non-ambulatory or bedfast. These children certainly usually suffer from major degrees of central nervous system damage, and also quite often have gross external physical abnormalities. When in a setting that provides a large amount of physical care and a high level of environmental stimulation quite often a significant number of these children become able to progress from bed to a wheeled conveyance, may become able to crawl or walk with assistance, and show the development of a high level of affective responsiveness to others.

Program No. 2

CHILD DEVELOPMENT PROGRAM This program is for ambulatory children up to the age of puberty. This is a varied group and includes children who may be withdrawn and passive, overly active, or show evidences of cerebral dysfunction, and who show all degrees of intellectual handicap. These children do not have gross physical anomalies but may have mild congenital malformations. This group to be worked with effectively needs to be broken down into a number of subgroups but all these children benefit greatly from warm understanding relationships with adults, and from various types of special education and activity programs.

Program No. 3

TEENAGE PROGRAM This program is for ambulatory children from puberty to approximately 16 years of age. This is a large and somewhat heterogeneous group including adolescents who have various degrees of cerebral dysfunction, a wide range of

Program No. 3 - (cont'd)

intellectual handicap, and, in a state institution, includes a high proportion who may be delinquent or borderline delinquent. These children require special programming because of the unique characteristics of adolescence but the basic treatment modalities are much the same as for those in the child development program.

Program No. 4

THE ADULT ACTIVATION PROGRAM This program is for bedfast and non-ambulatory patients who may be late adolescent, adult, and aged. These patients benefit greatly from care somewhat similar to that described for the Child Activation Program. This group includes "grownup" cerebral palsied children who may have had considerable assets overlooked because of their expressive difficulties. Needs in the orthopedic area may also be very great. Many of these patients are able to be physically habilitated to the point of not requiring total care in bed but being able to get about in wheeled conveyances.

Program No. 5

ADULT MOTIVATION PROGRAM This program is for ambulatory late adolescent, adult, and aged patients. The intellectual range of patients in this group is from "not testable" to around 35 to 40. They are characteristically passive, withdrawn, and manifest peculiarities of behavior such as rocking and making odd noises. Many of these patients show evidences of congenital cerebral underdevelopment and external congenital anomalies. They are, however, given adequate stimulation and opportunity, able to enjoy a large number of occupational therapy and recreational activities. Occasionally a patient in this group is found to be able to participate in a sheltered work program.

Program No. 6

ADULT SOCIAL ACHIEVEMENT PROGRAM This program is for active late adolescents, adults, and aged. It includes those residents who have become overdependent on the institution as a result of long term hospitalization, those who have various "character problems" such as antagonistic behavior or other difficulties in forming constructive interpersonal relationships, those who are able to achieve a high level of independence within the institution but have difficulty in developing social or work relationships outside the institution, and those who are potentially able to establish a satisfactory extramural adjustment but who have not acquired the skills required for such an adjustment.

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NOTE: Those patients who demonstrate clearly definable psychiatric symptoms but who otherwise clearly belong to one of the six programs will be placed on a psychiatric service for treatment. While on the psychiatric service their progress and general wellbeing will continue to be followed by the staff from the program to which they ordinarily would belong.