

ROUGH DRAFT

WORKING PAPERS
ON MENTAL RETARDATION

Minnesota Mental Retardation
Planning Council

February, 1965

STATE OF MINNESOTA MENTAL
RETARDATION PLANNING COUNCIL
CENTENNIAL BUILDING ST.
PAUL, MINNESOTA 55101

The attached materials are designed to help the regional chairmen and their committees examine their particular regions by offering guidelines to compare services. The materials are gleaned from the workings of the task forces to date, as well as current literature in the field. They are by no means exhaustive, and much of the information is unidentified as to source. For these reasons, we would prefer that they would not be published and be used only for the purpose of regional planning. Some of the material is general, and is applicable state-wide. Other portions of it are quite specific, pertaining to the certain regions involved. Additional copies of any portion of it are freely available to individuals, sub-committees, and regional committees, as interest and need may require.

February, 1965

MINNESOTA MENTAL RETARDATION PLANNING COUNCIL

PROJECT PROPOSAL

Morris Hursh, Commissioner Minnesota
Department of Public Welfare Centennial
Building St. Paul 1, Minnesota

April 29, 1964

MINNESOTA MENTAL RETARDATION PLANNING COUNCIL

PROJECT PROPOSAL

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MINNESOTA MENTAL RETARDATION PLANNING COUNCIL

PROJECT PROPOSAL

I

Official Agency

1. It is our intention in Minnesota to operate the Minnesota Mental Retardation Planning Council as an inter-departmental agency. The Minnesota law requires that the State Department of Public Welfare be the official agency; however, to give the Council the proper inter departmental responsibilities and to make it broadly representative, the formation and the name of the Executive Committee and Council members has been by Governor Karl F, Rolvaag. He will also designate the Council Chairman. In selecting the initial Planning Committee (which also acts as the Executive Committee of the Planning Council), the Governor appointed five key department heads, in addition to a member of his own staff, the executive director of the Minnesota Association for Retarded Children, and the chairman of the Minnesota Advisory Board on Handicapped, Gifted, and Exceptional Children, which is a statutory board advisory to the Departments of Health, Education, and Welfare. The Governor feels that if this plan is to succeed and be truly inter departmental, all of the groups concerned with mental retardation must participate equally and have an equal voice in the proceedings and planning.
2. The Minnesota Department of Public Welfare is the official Minnesota agency which has the responsibility for the administration of Social Security funds in Minnesota. It will, therefore, be the applicant agency and will receive and disperse funds from the Mental Retardation Planning Grant.

H. Council

1. A council of twenty-five (25) members has been appointed by the Governor. In addition to the Executive Committee, it includes specialists in special education from college and community levels, experts in mental retardation from the University of Minnesota, county welfare workers with a direct responsibility for the program for the retarded, several lay members including the president of the Minnesota Association for Retarded Children, medical representatives, plus others knowledgeable about this problem. Appendix "A" lists experience and qualifications of the various Council members. It has been decided to limit council membership to 25 because of the unwieldiness of a larger group. The task force membership will be very broad and each council member will serve on a task force to provide liaison and direction,

III. Task Forces

1. Nine task force groups will be formed to study mental retardation and develop a Minnesota plan for serving the mentally retarded. Careful attention will be given to task force formation and purposes. Each group will include appropriate professionals, laymen, representatives of organizations concerned with mental retardation, and at least one member of the Planning Council. It is through the task forces that broad involvement will take place. Task forces will be:

III. Task Forces

1. (continued)

- a) Volunteer Services and Public Awareness
- b) Prevention, Diagnosis, and Treatment
- c) Education and Habilitation
- d) Residential Care
- e) Community-based Services
- f) Research
- g) The Law and Mental Retardation
- h) Staff Training and Recruitment
- i) Employment of the Retarded

- 2. Each task force will be provided with a consultant selected from the departments and agencies concerned with mental retardation. (See Appendix "B".)
- 3. Each task force will be given an individual assignment which relates to the total over-all plan. Assigning the responsibilities of the task forces will be one of the first duties of the Council as a whole. If necessary, additional task forces will be added. (Attached is an organization chart, Appendix "E", showing the present status of organization of the various task force groups.)

A. Volunteer Services and Public Awareness

1.) Assignment

- a) Assess present level of public awareness, present methods of creating awareness, and effectiveness of these methods, through surveys, use of present available materials, such as the 1962 "Survey of Public Attitudes", and any other means.
- b) Evaluate volunteer services both in the community and in residential facilities to identify the need for additional volunteer services and recommend additional ways in which in which volunteer can serve the retarded.

2) Membership of the task force

Social workers, community organizers, adult educators, religious leaders, volunteer coordinators, journalists, audio and visual experts and others.

3) Staff and Consultants

Miriam Karlins, Minnesota Department of Welfare, Director of Public Information and Volunteer Services; Jo Anne Bay, Director of Public Information, Minnesota Association for Retarded Children.

B. Prevention, Diagnosis, and Treatment

1) Assignment

- a) Assess services in Minnesota designed to diagnosis, prevention, and treatment of mental retardation, including study of Minnesota's prenatal care program, obstetrical services, post-natal care (especially in the low income areas).

II. Task Forces

3 - B (continued)

- b) Evaluate use of such well-known preventative methods as the Guthrie test and genetic counseling.
- c) Determine the need for additional diagnostic services throughout the state and evaluate effectiveness and efficiency of such services presently operated.
- d) Attempt to establish improved, effective case-finding methods.
- e) Examine the feasibility of an annual statewide examination of all four-year-old children for hearing, vision, mental retardation, orthopedic problems, speech difficulties, dental problems, emotional disturbance and malnutrition.
- f) Determine the possibility of establishing, on a county, district or regional basis, a committee to which will be reported for study and recommendation, all children of school age not enrolled in the school programs.
- g) Additional assignments will be made and the task force may also add to the above mentioned methods.

2) Membership of task force

Pediatrics, psychiatry, obstetrics, genetics, nursing, dentistry, neurology, speech pathology, otologist, oculist, and others.

3) Staff and Consultants

To be determined.

C. Education and Habilitation

1) Assignment

- a) Assess Minnesota's special classes, determine number and type of classes needed.
- b) Evaluate present services, including curriculum, quality and distribution of classes.
- c) Recommend necessary additional services, including those needed at the state level within the Department of Education.
- d) Determine the need for work training, sheltered workshops, school work programs, vocational training, counseling services, etc., and make recommendations to meet the needs.

2) Membership of task force

Special educators, vocational rehabilitation counselors, psychologists, employment counselors, employers, and others.

HI. Task Forces

3-C (continued)

3) Staff and Consultants

To be determined.

D. Residential Care

1) Assignment

- a) Assess the present residential care facilities of the state, both public and private.
- b) Develop or establish the machinery to develop standards of care and programs for such facilities.
- c) Evaluate all other types of residential care programs now in operation, such as group homes, boarding homes, use of nursing homes and homes for aged retarded. The appropriate use of such facilities shall be studied.
- d) Study placements from state institutions to community residential facilities and establish, if possible, an instrument to evaluate the value and effect of such placements.
- e) Attempt to determine Minnesota's long term need for state residential facilities and the future role of these facilities.
- f) Recommend such additional types of facilities as deemed wise, such as half-way houses, small sheltered living units, small state residential units, and others.

2) Membership of the task force

All medical, nursing, social work, psychologists, special education, psychiatric aides, administrators, and others.

3) Staff and Consultants

To be determined.

E. Community-Based Facilities 1)

Assignment

- a) This task force shall concern itself with camping, day activity, church programs, recreation, scouting, and all other community services. It will be especially necessary for this group to work closely with local groups.
- b) To tabulate present services, numbers served, location of services and evaluate these services regarding quality of program, staff, equipment, housing, etc.

F. Research (Medical and Behavioral) 1)

Assignment

- a) Compile a control record of all research of all types now being carried on in Minnesota at universities, colleges, institutions, and in other facilities.
- b) Study relationship of the various projects to each other, if any, and recommend coordination where possible.
- c) Tabulate and list sources of income for research in Minnesota, such as foundations, Associations for Retarded Children, State of Minnesota, and others.
- d) Recommend any special research projects it deems necessary to the various research facilities.

2) Membership of the task force

All branches of medicine, behavioral sciences, and others.

3) Staff and Consultants

To be determined,

G. The Law and Administration

1) Assignment

- a) Study Minnesota's Guardianship Law and recommend any-necessary improvements or changes.
- b) Study Minnesota's criminal code as it affects the retarded

H. Staff, Training and Recruitment

1) Assignment

- a) Cooperate and coordinate with other task force groups to determine need for additional trained staff in services and facilities for the retarded.
- b) Assess Minnesota's special education departments of the various teacher training institutions and determine ability of such programs to meet need for necessary additional staff.
- c) Study in-service training programs of state institutions for the retarded.
- d) Study and recommend improvements in Minnesota's staff recruitment methods.
- e) Study salaries as they relate to staff shortages.

2) Membership of the task force

All professions and representatives of specialized employees, such as psychiatric aides.

3) Consultants and Staff

To be determined.

III. Task Forces

3. (continued)

I. Employment of the Retarded

1) Assignment

- a) Tabulate the various types of jobs now filled by the retarded within state and federal civil service.
- b) Study additional ways that the retarded can be employed by governmental agencies.
- c) Study use of special vocational training schools for the retarded.
- d) Evaluate effectiveness of state employment offices in placing the retarded.
- e) Determine attitudes of employers toward employment of retarded.

2) Membership of the task force

Employment counselors, vocational school educators, employers, labor leaders, and others.

3) Consultants and Staff

To be determined.

IV. Staffing

Candidates for the position of project director of the Planning Council are currently being interviewed. It is our intention to employ a person who has both organizational experience and background in the field of mental retardation. We feel that the key to the proper functioning of the Planning Council rests with employment of a staff person able to involve the many people knowledgeable about mental retardation, to organize them at the state and local levels, and to extend the organization to the various regions. The proposed budget calls for a full-time project director with secretarial staff.

V. Regional Approach

1. There will be eight regional committees in the state of Minnesota established as a specific part of the Minnesota Mental Retardation Planning Council. Each of these regions will have a chairman. Membership on the regional committee will include representatives from the various direct services for the retarded, such as day activity centers, institutions, group care homes, etc., representatives from the Associations for Retarded Children, special education services, public health nurses, medical representatives, the regional vocational counselors, law enforcement officers, regional state employment service representatives, county welfare workers, representatives of private welfare agencies, and others. These eight regional committees will be further broken down into committees to consider various regional problems of the areas; for example, some regions in Minnesota are far removed from the

V. Regional Approach 1.

(continued)

present institutions for the retarded. A committee of the regional committee will consider this particular problem and make recommendations to the Minnesota Mental Retardation Planning Council. Each of these regional committees will be staffed in a manner similar to the use of consultants on the main task force bodies; for example, field representatives for the Minnesota Association for Retarded Children will be available as staff for several regions; other regions will be staffed by representatives of the Departments of Health, Education and Welfare.

2. Besides the committee activity in each region, one-day regional conferences will be held to permit members of the Minnesota Planning Council (the main body) to meet in each region to hear reports from the regional committees,
3. Under the direction of the State Department of Public Welfare, Regional Mental Health Coordinating Committees have been established to strengthen coordination between the state hospitals, the community mental health centers, and county welfare agencies, and services to the mentally retarded. These coordinating committees will be an important resource in achieving regional involvement, and in encouraging coordination between agencies.

VI. State-Wide Assessment of Existing Services

1. Through regional approach outlined above.
2. The Department of Welfare is now completing a statewide directory of services, including diagnostic facilities, special education, workshops; and day activity centers. Other directories are also available.
3. Special surveys of community-based services; i.e., type of service, number served, degree of mental retardation of client, cost, related services, financing, etc.
4. Special studies of residential care facilities for the mentally retarded.
5. A preliminary survey at state departments level is now underway. (See Appendix "C".)
6. Membership of key commissioners on the Planning Council will help assure an adequate assessment of services.
7. Probably the single most important phase of our assessment will be identification of the problems. This, of course, will also relate to all the above points.

With the background of the survey of existing services, an analysis will be made to identify problems or fundamental conditions, which presently limit progress toward desirable objectives. It is expected that some problems will be quite apparent but that others will become apparent only after careful study. For example, it may be quite evident that we have a special problem in trying to develop community services for the mentally retarded in small towns in rural areas. It may be less clear that this problem relates to needed re-organization of school districts, to our inadequate form of intermediate level

VI. State-Wide Assessment of Existing Services

7. (continued)

school organization, or to needs for more inter-agency coordination in development of services from central state offices.

It is in the context of careful problem analysis and careful specification of goals that creative approaches to solutions may be expected to emerge. The Council plans call for concentration of resources at this state of its studies.

VII. Selection of Goals Procedure

1. Workshop on Wheels. To acquaint Council members with existing facilities and programs, and to help Council members understand their role in determining goals, we are planning a series of bus tours of the facilities that serve the retarded. (We have just completed a series of four Governor's Bus Tours to residential and community facilities for the mentally retarded and the mentally ill. The tours were co-sponsored by the Minnesota Association for Retarded Children, Minnesota Association for Mental Health, and the Governor.)

The purpose of the Workshop on Wheels will be to have council and task force members visit facilities and programs for the retarded throughout the state. Participants will observe programs first hand and especially observe problems within programs and facilities visited. For example, Minnesota has some serious under staffing and overcrowding in state institution facilities, which should be seen by the Council members. Conferences will be held with staff, both professional and non-professional. These visits will help in establishment of goals and will also serve to create public awareness and concern.

2. Goals Seminar, conducted by top level Department staff. This has proven highly successful in Minnesota's mental hospitals administration and has resulted in major program goal changes.
3. The regional conferences outlined above will also be used for the purpose of developing goals.

VIII. Development of a Plan

1. The Executive Committee will have the responsibility for achieving effective state-level coordination. The Executive Committee will develop ways of accomplishing coordination at local level. Efforts to achieve coordination will be concentrated on use of present agencies including the 87 county welfare departments and the 20 community mental health centers.
2. Existing case finding methods in Minnesota include the "school census" of handicapped children and the special Four-County Project, which is developing and evaluating improved case finding methods.
3. The Council will ask each agency to re-evaluate its methods of providing services and coordination with other agencies. (See Appendix "D".)

VIII. Development of a Plan (continued)

4. Existence of the Planning Council and intensive study for 18 months in this field will help determine how we will provide essential planning (including continuing re-evaluation) for mentally retarded of all ages.
5. Use of the eight regional committees, the regional conferences of the seven mental health coordinating committees will provide a regional approach to the Council's considerations. (See V above.)

IX. Legislative Involvement

1. Use of a legislative advisory committee. Legislators in key positions, such as the chairmen of Senate and House Welfare and Health, Education, Labor, Judiciary Committees, and others, will be kept closely informed and along with other legislators, will be asked to make recommendations regarding goals to be accomplished through state legislation and appropriations.
2. Involvement of legislators in regional conferences.
3. Legislators participated in recent Governor's Bus Tours.

X. Coordination with the Mental Health Planning Council

1. Six members of the .Mental Retardation Planning Council are also on the Mental Health Planning Council.
2. Regional Mental Health Coordinating Committees, which are adjuncts of the Mental Health Planning Council, include representatives from programs for the retarded.
3. Because of the relationship between community facilities for the mentally retarded and those for the mentally ill in Minnesota, the facilities sub-committee of the Minnesota Mental Health Planning Council will serve as the advisory council for the development of a state plan for administering federal grants for construction of facilities for the mentally retarded. Members of the Minnesota Mental Retardation Planning Council serving on the facilities sub-committee are:

Gerald F. Walsh, Executive Director, Minnesota ARC
Dr. Robert Barr, Department of Health
Sally Luther, Administrative Asst., Governor's Office

In addition, it will be recommended that the following people be added to the facilities sub-committee to assure broad representation of people concerned with mental retardation:

Mrs. Betty Hubbard, Executive Director, St. Paul ARC
Howard Paulsen., Lutheran Social Services

APPENDIX "A"

COUNCIL MEMBERSHIP

Barr, Dr. Robert * Minnesota Department of Health University of Minnesota Campus Minneapolis, Minnesota	Secretary & Executive Officer Department of Health Member, Mental Health Planning Council Chairman of M.H.P.C. Facilities Sub- Comm.
Berman, H. D., President The Judy Company 310 North 2nd Street Minneapolis, Minnesota	Active in Minnesota in movements to urge employment of handicapped
Deno, Dr. Evelyn 807 M.E. Broadway Minneapolis, Minnesota	Consultant in Special Education and Rehabilitation, Minneapolis Public Schools Member, Advisory Committee on Handicapped, Gifted and Exceptional Children Vice-President, Minnesota Council for Special Education
Geary, James St, Paul Public Schools Court House St. Paul, Minnesota	Director of Special Education, St. Paul Public Schools Member of several regional planning bodies
Hect, Melvin D. Room 1430, Rand Tower Minneapolis, Minnesota	President, Minnesota Association for Retarded Children Attorney
Huston, Mrs. Alice Minnesota Council of Churches 122 West Franklin Minneapolis, Minnesota	Director of Christian Education Directs special program for training teachers of religious education classes for the mentally retarded
Hursh, Morris * Department of Public Welfare Centennial Office Building St. Paul, Minnesota	Commissioner of Public Welfare
Jensen, Dr. Reynold University of Minnesota Minneapolis, Minnesota	Director, Division of Child Psychiatry Member of numerous special committees on mental retardation Member, NARC Research Advisory Committee Consultant to Lakeland Mental Health Center,. Fergus Falls
Mattheis, Duane * Centennial Office Building St. Paul, Minnesota	Commissioner, Department of Education
Blodgett, Dr. Harriett 4330 West River Road Minneapolis, Minnesota	Director, The Sheltering Arms Chairman, Advisory Board on Handicapped, Gifted and Exceptional Children

LaFond, Dr. Edward M. 104 Doctors Park St. Cloud, Minnesota	Orthopedist
Lippman, Dr. Hyman Wilder Clinic 670 Marshall Avenue St. Paul, Minnesota	Vice Chairman, Governor's Advisory Council on Children and Youth Children's Mental Health Committee of the Mental Health Medical Policy Committee
Lohmann, Dr. Victor * St. Cloud State College St. Cloud, Minnesota	Member Advisory Board on Handicapped, Gifted and Exceptional Children
Luther, Sally * State Capitol St. Paul, Minnesota	Administrative Assistant to Governor, Karl F. Rolvaag Chairman, Executive Committee, M.R.P.C.
Mattson, Dr. Bruce Mankato State College Mankato, Minnesota	Department of Special Education Mankato State College, Mankato
McDonough, Father Michael Newman Club University of Minnesota Minneapolis 14, Minnesota	Leader in religious education for the mentally retarded in Minnesota
Mickelson, Harold F. Court House Annex Austin, Minnesota	Director, Mower County Welfare Department
Paulsen, Howard Lutheran Social Service of Minnesota 2414 Park Avenue Minneapolis, Minnesota	In charge of several facilities for the mentally retarded and staff to Lutheran Social Services' mental retardation committee
Quigley, Stephen T. * Room 120 - State Capitol St. Paul, Minnesota	Commissioner, Department of Administration
Reynolds, Dr. Maynard University of Minnesota Minneapolis, Minnesota	Director, Dept, of Educational Psychology Chairman of the 1961-63 Governor's Advisory Committee on Mental Retardation On numerous committees on mental retardation at both state and federal levels
Stahl, Judge Lucille Court House Windom, Minnesota	Judge of Probate Court (in Minnesota, the Probate Court handles all guardianship procedures of mentally retarded)
Tudor, Dr. Richard B. 316 Doctors Building Minneapolis, Minnesota	Pediatrician active in program to improve services for the mentally retarded

Walsh, Gerald F. * 2742
Hennepin Avenue
Minneapolis 8, Minnesota

Executive Director, Minnesota Association
for Retarded Children Chairman, Minnesota
Inter-Agency Committee
on Mental Retardation

Weatherman, Dr. Richard
Duluth Public Schools
Duluth, Minnesota

Assistant Superintendent of Duluth Public
Schools in charge of Duluth special class
programs

Worden, Guy
522 East Alcott Avenue
Fergus Falls, Minnesota

Board member, Lake Region Sheltered
Workshop Parent of a retarded child; also,
active
in local and regional activities for the
retarded

Brown, Robert J. *
369 Cedar Street
St. Paul, Minnesota

Commissioner, Department of Employment
Security

Lappegard, Raymond *
State Office Building.
St. Paul, Minnesota

Commissioner, Department of Corrections The
Department of Corrections operates a
special facility for young retarded, using
free space at one of its facilities. Also
has operated a special program on defective
delinquents

* Members of Executive Committee

APPENDIX "B"

COMMUNITY ORGANIZATIONS AND STATE AGENCIES TO BE INVOLVED ON

TASK FORCE GROUPS

I. State Departments

1. Department of Public Welfare

- a. Division of Medical Services, Section on Mental Retardation.
Volunteer Services, Others
- b. Division of Child Welfare: Licensing and Standards
- c. Division of Public Assistance
 - Aid to Disabled
 - General Relief
 - Aid to the Blind
- d. Division of Rehabilitation
 - Crippled Children Services
 - Consultant Services
 - Bureau of Psychiatric Services
- e. Institutions for the Mentally Retarded - Superintendents

2. Department of Education

- a. Special Education
- b. Division of Vocational Rehabilitation

3. Department of Health

- a. Division of Special Services
- b. Division of Local Health Administration, Section of
Public Health Nursing
- c. Division of Disease Prevention and Control
- d. **Division of Hospital Services**

4. Department of Corrections

5. Department of Employment Security

6. Attorney General

II. Other State of Minnesota Agencies

1. University of Minnesota

- a. Medical School, Child Psychiatry and Pediatrics
- b. Agricultural Extension Division
- c. Child Development
- d. Genetics
- e. Recreation
- f. Special Education Department

2. State Colleges

- a. Special Education Departments

III. Community Organizations

1. Associations for Retarded Children

- a. **Minnesota ARC Executive Director**
- b. **Minnesota ARC President**
- c. **Local Chapter Representatives (2)**

2. **American Legion and Auxiliary and other veterans' groups**

3. **Jaycees and Mrs. Jaycees and other service groups**

4. **Minnesota Psychological Association**

5. **Minnesota Medical Association**

6. **Minnesota Association of County Welfare Directors**

7. Minnesota Nurses Association

8. Minnesota Bar Association

9. Minnesota Welfare Council

10. Catholic Charities

11. Minnesota State Pastors Association

12. Lutheran Social Services of Minnesota

13, Minnesota Advisory Board for Handicapped, Gifted and Exceptional Children

14. Probate Judges

Appendix "B" - (continued)

15. Minnesota Association of County Commissioners
16. Mental Health Centers
17. Representatives of private and non-profit facilities for the retarded

APPENDIX "C"

MINNESOTA MENTAL RETARDATION PUNNING COUNCIL

PRELIMINARY DEPARTMENT*

SURVEY OF SERVICES TO THE MENTALLY RETARDED

1. Legal responsibilities
2. Number of mentally retarded in total case-load
3. Number served
4. How served
5. Special projects financed with federal funds
6. Number of special staff working with mentally retarded
at state level (give full and part-time figures)
7. List major problems regarding services to the retarded

* Submitted to Departments of Health, Education, Corrections, Welfare and Employment Security.

APPENDIX "D"

COORDINATING AND PLANNING GROUPS IN MINNESOTA

1. Minnesota Inter-Agency Committee on Mental Retardation

History: Organized in 1958, this Committee has representatives from the Departments of Health, Welfare, and Education and the Association for Retarded Children.

Purpose: Coordination, exchange of information.

Accomplishments: People concerned with the mentally retarded have become better acquainted with each other. There is assurance that these people will have opportunity to meet and be kept abreast of latest plans and developments.

2. Advisory Board on Handicapped, Gifted and Exceptional Children

History: Appointed by the Governor in 1956 for the purpose of advising the Departments of Health, Welfare, and Education. Provided for by law in 1957.

Purpose: To aid in formulating policies and encouraging programs for exceptional children. Continuous study of the needs of exceptional children.

Accomplishments: Activity has been primarily in the area of special education. The Committee has been active in almost all moves to improve special education laws and programs. Several special reports have been issued; one, a report on services to trainable retarded children.

3. Minnesota Council for Special Education, Inc.

History: Formed by groups and individuals who recognized the great need to improve special education programs.

Purpose: To coordinate and define services to exceptional children. To serve as a clearing house for information and ideas. To outline anticipated needs in special education.

Accomplishments: This group was to a great degree responsible for the adoption of major new special education legislation in 1957.

4. 1962 Governor's Advisory Committee on Mental Retardation

History: Because the State Legislature did not appoint a Legislative Interim Commission on Mental Retardation during the 1961 session, the Minnesota Association for Retarded Children asked the Governor to appoint this Committee.

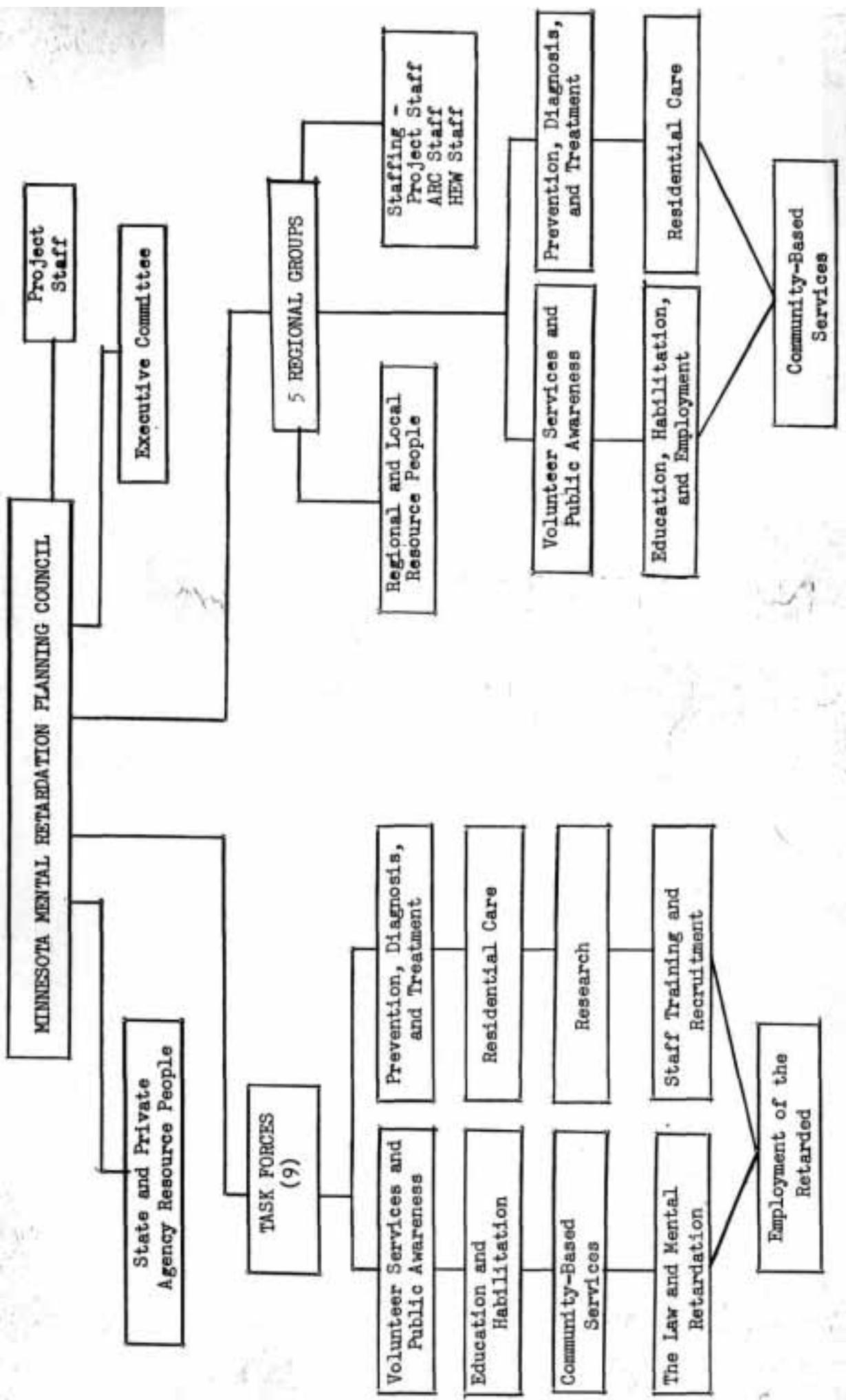
Appendix "D" (continued)

Purpose: To study Minnesota's program for the mentally retarded and make recommendations. No public funds were available; however, private funds were made available for staff work and a special filmed report.

Accomplishments; Day Activity Center legislation, improved institution staffing, increased public awareness,

FACTORS TO CONSIDER WHICH RELATE TO COORDINATION

1. Size of state.
2. Population - intensity, growth.
3. Leadership from state colleges and universities, private colleges, and state departments.
4. Structure of state departments.
5. Degree of coordination and cooperation within departments.
6. Degree of cooperation between departments.
7. **Duplication.**
8. Activity of Associations for Retarded Children.



The original project proposal calls for regional study of five areas of service to the retarded: Volunteer Services and Public Awareness; Prevention, Diagnosis and Treatment; Education, Habilitation, and Employment; Residential Care; and Community-Based Services. The supplemental request commits us to exploring interstate planning as well as planning in the seven-county metropolitan region. The following structure is suggested;

I. Philosophy and Goals

The goal of the Planning Council is to develop a plan to provide an array of services along a continuum of care which is available to any retarded person wherever and whenever he may need it. To be effective, the plan must be designed to properly meet needs. **Many** people who understand the problems and can weave solutions into the fabric of existing services must be involved.

Involvement of both individuals and organizations is a necessary ingredient. As the Planning Council and its task forces develop a plan for services on a state wide basis, it is essential to have "grass roots" involvement. Regional committees are the most practical approach.

H. Structure of Regional Committees

There will be seven regional committees in connection with the Minnesota Mental Retardation Planning Council. These are shown on the attached map and designated as follows:

- | | |
|------------------------|-----------------|
| 1. Northeast | 5. Metropolitan |
| 2. Northwest | 6. Southwest |
| 3. East Central | 7. Southeast |
| 4. <i>West</i> Central | |

Metropolitan Region-- Because of a proliferation of services, governmental units and local planning groups, this area is earmarked for special study in our supplemental grant. It should not be included in the foregoing. We must work out a special methodology.

A. Committee Organization

Membership on regional committees should include representatives from the various direct services to the retarded, such as day activity centers, workshops, institutions, etc., and Associations for Retarded Children, special education, public health, medicine, vocational, employment, welfare, private agencies and others.

It will be the responsibility of each regional committee to assess the present services and unmet needs to the retarded in their region, and point out special problems, Each regional committee's studies should include any services or facilities provided by bordering states and explore use of such facilities.

This will be accomplished as follows:

The regional chairman, using this guide, shall suggest committee members. These names are to be submitted to the Mental Retardation Planning Council office. After further consideration, nominees will receive a letter inviting them to serve on the regional committee. This will also set the date, time, and place of the first committee meeting.

B. Calendar

First meeting--- The first meeting should be held between February 22-27, 1965, at a central point with in the region. This will be a day long meeting.

Second meeting-- To be held between March 22-31. At this, a public meeting, members of the Minnesota Mental Retardation Planning Council will be present to hear sub-committee reports. Anyone else in the region who desires to make a presentation may do so. The public should be notified.

Final Reports will be sent by April 30 to the Minnesota Mental Retardation Planning Council for use in preparing its report.

III. Functioning of Committees

Upon convening, the entire group will discuss goals and purposes. Sub-committees will be formed to deal with the following areas.

- a. Volunteer Services and Public Awareness
- b. Prevention, Diagnosis and Treatment
- c. Education and Habilitation
- d. Residential Care
- e. Community-Based Facilities
- f. Employment of the Retarded

A staff member of either the Minnesota ARC or the Mental Retardation Planning Council will be assigned to assist the regional chairman and will be present at the full committee meetings.

Sub-committees will consider problems and unmet needs. These will be reported to the entire committee when it convenes later the same day. Members of sub-committees should take the responsibility for developing a more detailed report to be given at a second meeting in March.

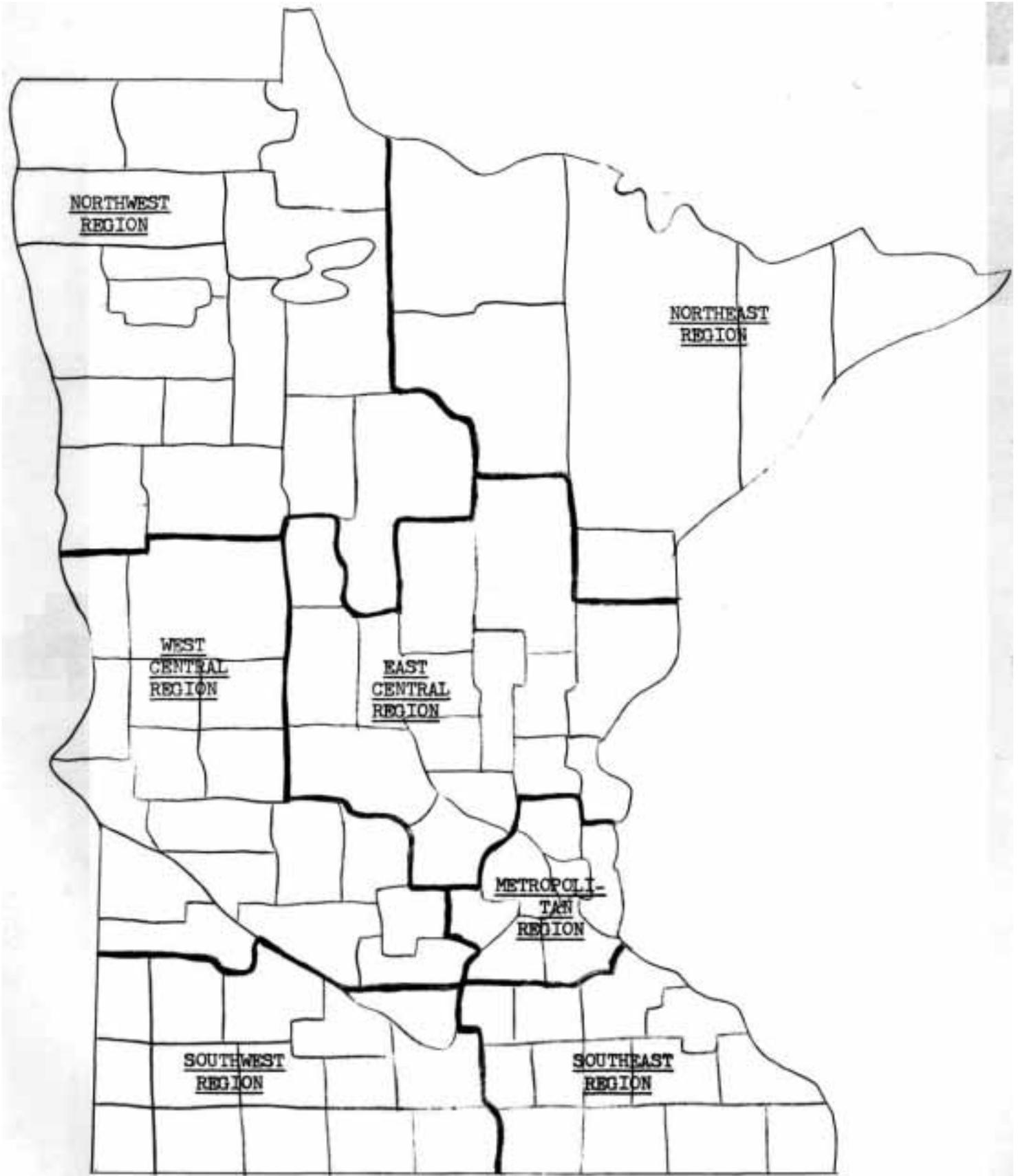
IV. Duties of Regional Chairmen

1. Select regional committee members; send list to State Planning Office.
2. Set meeting dates, time, place, and make other necessary arrangements.
3. Serve as chairman at meetings.
4. Appoint sub-committee chairmen and recorders.
5. Submit reports of findings and recommendations to the Minnesota Mental Retardation Planning Council.

January, 1965

MINNESOTA MENTAL RETARDATION PLANNING COUNCIL

REGIONAL PLAN



MINNESOTA MENTAL RETARDATION PLANNING COUNCIL
REGIONAL PLAN

NORTHEAST REGION

Carlton
St. Louis
Itasca
Koochiching
Lake
Cook

NORTHWEST REGION

Becker
Clay
Kittson
Marshall
Hubbard
Clearwater
Beltrami
Norman
Polk
Pennington
Red Lake
Roseau
Lake-of-the-Woods
Cass

Mahnommen

EAST CENTRAL REGION

Crow Wing
Kanabec
Mille Lacs
Pine
Morrison
Sherburne
Stearns
Benton
Todd
Wadena
Aitkin
Chisago
Isanti
Wright

METROPOLITAN REGION

Anoka
Dakota
Hennepin
Ramsey
Washington
Carver
Scott

WEST CENTRAL REGION

Chippewa
Renville
Douglas
Pope
Kandiyohi
Meeker
Lac qui Parle
Yellow Medicine
McLeod
Sibley
Otter Tail
Stevens
Big Stone
Swift
Traverse
Grant
Wilkin

SOUTHWEST REGION

Brown
Cottonwood
Faribault
Jackson
Blue Earth
Murray
Nobles
Pipestone
Redwood
Martin
Watonwan
Lincoln
Lyon
Nicollet
Rock

SOUTHEAST REGION

Dodge
Freeborn
Goodhue
Mower
Olmsted
Rice
Wabasha
Waseca
Steele
Winona
Fillmore
LeSueur
Houston

INTRODUCTION

It has been said that we are either pushed around by our problems or led by our dreams.

It is apparent to students of the problem of mental deficiency that we have all too frequently in the past attempted to develop programs on a piecemeal basis without attempting cooperative program planning. Numerous agencies and various professional disciplines are actively engaged in providing programs and services for the mentally retarded, yet no organized method has been attempted to bring all of these interests and disciplines together to delineate what constitutes a state's total program.

Three definitions of mental retardation are in common use:

The mentally retarded are children and adults who, as a result of inadequately developed intelligence, are significantly impaired in their ability to learn and to adapt to the demands of society.

(President's Panel, 1962)

Mental retardation refers to sub-average general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior. (AAMD)

The mentally retarded person is one who, from childhood, experiences unusual difficulty in learning and is relatively ineffective in applying whatever he has learned to the problems of ordinary living; he needs special training and guidance to make the most of his capacities, whatever they may be. (NARC)

The keystone to the development of effective services for the mentally retarded is comprehensive planning that takes into account state and local requirements, as well as the professional and voluntary resources of communities.

It is essential that local programs are coordinated and consistent with state programs and objectives. Communities cannot do the job alone. They need leadership, guidance, and consultation from the state level to assure that retarded children, wherever they live, have access to services. States must develop standards for care and the means for enforcement. Resources and facilities that transcend local capacity and responsibility, and financial subsidy for certain programs that cannot be supported from local tax avenues alone. Only as responsibilities between local, state and national agencies are fully shared, can comprehensive community programs become a reality; and it goes without saying, that to underwrite such programs, citizens' groups, fraternal organizations, business men, and the church must contribute their full and active support. The challenge confronting this group in translating these concepts into program reality is as difficult as any you are called upon to face; yet, if we pursue our efforts with vigor and conviction, the task is not insurmountable.

In order to prescribe for an individual in particular at any given time, and for the retarded, in general, there must be an inclusive array of services available. These are administered, for the most part, by, through, or within instrumentalities which administer to the non-retarded, that is, the family, the professions, and the Health, Education and Welfare, and other agencies which society has created for these purposes. Ideally, the elements in this array should be so intimately related to one another, and so accessible as to be readily marshaled into a continuum of care.

Continuum of care describes the selection, blending and use in proper sequence and relationship of the medical, educational, and social services required by a retarded person to minimize his disability at every point in his life span. A

continuum of care permits fluidity of movement of the individual from one type of service to another, while maintaining a sharp focus on his unique requirements. The ongoing process of assuring that an individual receives the services he needs when he needs them, and in the amount and variety he requires is the essence of planning and coordination.

Coordination is a necessary condition for the existence of a continuum of care, and the provision of continuity of care. Coordination is the process of bringing all necessary resources to bear in the appropriate sequence in order to accomplish a specific mission.

Basic Principles for Care of the Mentally Retarded

1. Early identification should be made of every person suspected of being mentally retarded. These individuals should have a complete and adequate diagnosis and evaluation made by qualified professional personnel representing medical, psychological, social, and educational services.
2. Close coordination of all medical resources, including, but not limited to, diagnostic centers, the Medical School, and state institutions caring for the mentally retarded, is essential for the development of research to determine the causes of mental retardation and to work toward the most effective treatment of the mentally retarded. Coordinated research is essential in attaining these goals.
3. Official agencies should cooperate with community groups to interpret to the public the needs of the mentally retarded.
4. Every mentally retarded person who can live in the community should be provided with family-oriented services to make this possible. These should include adequate health services, both private and public; counseling and casework services, educational services, recreation, vocational training, and specialized services for employment.
5. Provision should be made for institutional care at the optimum time for each mental retardate who needs this type of care. Institutional care includes both hospital and nursing care for those persons in need of such services, and educational and training services for the mentally retarded who need group care.

6. There should be close cooperation between institutions and community agencies so that the person able to leave group care can be received back into his community at the most favorable time. This program includes provision of living arrangements best suited to his needs, placement in employment, and provision of recreational and social opportunities appropriate for the particular individual.

From Everybody's Child, The Mentally Retarded
Report of the Subcommittee on Mental
Retardation to the Governor's
Inter agency Committee on Health,
Education and Welfare Program,
State of Washington, 1961.

Guidelines in Program Development

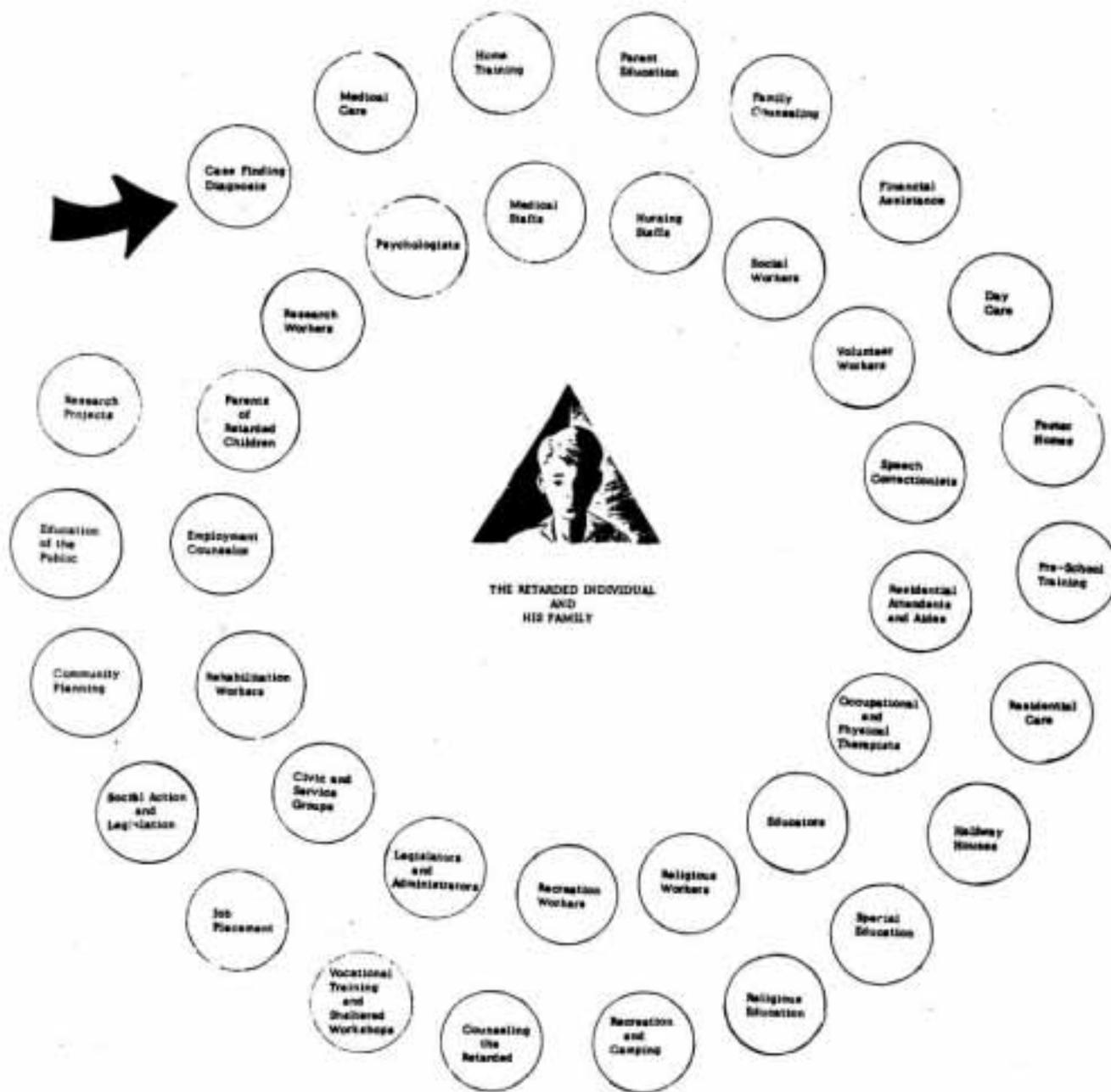
Philosophy and Concepts

1. The mentally retarded are entitled to opportunities for maximum development of their potentialities.
2. The integrity of the family unit should be preserved whenever possible.
3. A state and community should examine critically the total needs of the mentally retarded and develop blueprints for a comprehensive program.
4. A mentally retarded population is decidedly heterogeneous in composition and presents a diversity of needs requiring special attention.
5. A comprehensive program designed to meet the needs of the retarded should be composed of many essential interrelated parts.
6. The multiple needs of the retarded require the concern of numerous professional groups and agencies.
7. Since all the various aspects of a comprehensive program are never developed at the same time, consideration must be given to the question of priority of services developed.
8. The success of any one aspect of the existing program depends upon the presence and degree of success of other aspects.
9. A comprehensive program for the mentally retarded will give emphasis to services which are available during the early formative years.
10. The interest of the mentally retarded can best be served when there is maximum integration of programs and services for the retarded, both general and special, into the overall programs for both the handicapped and non-handicapped.

11. Meeting the needs of the retarded is basically a community problem, with both the state and community assuming responsible roles for various aspects of the comprehensive program.
12. It would be desirable for the state to assume leadership in the development of a comprehensive program, but with responsibility left with the community for actual administration of most service aspects of the program.
13. Since both the state and community have responsibility for certain aspects of a comprehensive program, there must be provisions at both levels for maximum communication and coordination.
14. No set pattern of organization for the many aspects of the comprehensive program can be outlined as best for any given state or community.
15. Legal provisions for programs and services for the mentally retarded should be set forth in broad and flexible descriptive terminology.
16. Although the chief responsibility for providing programs for the mentally retarded should rest with public (governmental) agencies, voluntary agencies will always assume a vital role in this endeavor.
17. Provisions must be made for an adequate evaluation of the needs of the retarded as a prerequisite to acceptance into a given program.
18. All persons once identified as mentally retarded will not require specialized assistance throughout life.
19. A wisely planned and well-integrated program for the mentally handicapped will give emphasis to both primary and secondary prevention.

For a discussion of each of these statements, see A Manual of Program Development in Mental Retardation, pp 33-48. American Journal of Mental Deficiency, January, 1962.

A WELL-ROUNDED PROGRAM FOR THE RETARDED



Cooperation

Coordination

Communication

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A Brief History of Mental Retardation

from

Hutt, Max L. and Gibby, Robert G. *The Mentally Retarded Child*, Boston: Allyn and Bacon, 1958

and

Davies, Stanley P. *The Mentally Retarded in Society*. New York: Columbia University Press, 1959.

Prior to the twentieth century, interest in mentally retarded children had waxed and waned for several hundred years. In the nineteenth century the nature of mental retardation was brought to spectacular public attention by Jean Itard. He undertook the task of educating "up to a civilized state" a young boy who had been living in a wild and savage-like condition in the woods of France. This boy, called the "Wild Boy of Aveyron," was about seventeen years of age at that time. Although Itard did not apparently meet with much success in his educative attempts, the publicity the case attracted served to stir up considerable interest in the problems of mental retardation. Several schools for the mentally retarded were established in Europe. The prevalent theory at that time was that mental defect was amenable to education. It soon became apparent, however, that even though the children placed in special schools did show remarkable growth and progress there were limits beyond which they could not reach.

The work of Itard was followed up in Europe by Edward Seguin, physician-psychologist, who founded in Paris in 1837 the first school for the education of "idiots." Seguin later migrated to the United States, where he became a leader in educating state legislatures and the public to the problems of the mental defective.

In 1875 Dugdale's book, The Jukes, appeared. He studied the social adaptations of five generations of a single family, whose members had extensive antisocial records. Although Dugdale concluded that "crimes against society" were transmitted along family lines, he did not believe that this transmission was necessarily on a hereditary basis. Society, however, jumped to the

conclusion that hereditary transmission of mental retardation was proved by Dugdale's study, despite the fact that only one out of the 709 subjects studied by Dugdale had a certified record of "feeblemindedness."

Many other misconceptions were held both by the general public and by professional workers during this period. Some of these were: that mental deficiency was a disease; that delinquent and criminal behaviors were a direct consequence of mental deficiency; that education was of no value in the treatment of mental deficiency; that mentally retarded individuals should be kept in prisons or in homes for paupers. Thus, whereas some attempt at segregation of mentally retarded individuals was made, there was very little provision for either their special education or training.

In the early part of the twentieth century some attempts at differentiation in the segregation and treatment of the mentally retarded began to appear. Institutions and special schools were established for their care and training. Probably much of this more desirable attitude was made possible by the development of intelligence tests. In 1904 Alfred Binet and Thomas Simon developed the now famous Binet-Simon test to identify mentally retarded children in the public schools. This test has been translated and revised for use in many countries throughout the world and is known in its most modern version as the Stanford-Binet. Intelligence tests made the measurement and detection of mental retardation more accurate, and their use stimulated important movements in planning more effectively for children in the public schools.

For example, in 1910 Dr. Henry H. Goddard recommended to the American Association for the study of the Feebleminded a system of classification according to test ratings as follows: idiots, those with a mental age of two years or less; imbeciles, those with a mental age of from three to seven years; morons, those with a mental age of from eight to twelve years. Today

the terms "idiot," "imbecile" and "moron" are no longer used and the word "feebleminded" is obsolete. Preferred terms are severely, moderately, or mildly retarded, or low grade, middle grade, and high grade types. The changing terms reflect profound changes in thought; once considered a threat to the social order, those today known as retarded are now seen not as liabilities but as potential assets, calling upon society not so much for control as for skilled help.

During World War I, intelligence tests, particularly those designed to be administered to groups of persons at the same time, were widely used in the armed forces. The country was shocked to hear that almost half of all the Army recruits had a mental age of twelve years or less. Later, surveys of school populations yielded similar results. This raised a storm of controversy regarding the whole issue of the nature of intelligence. It was first decided that something was wrong with the tests and the interpretations made of their results. Soon however, it became apparent that test results were invalidated by many conditions, such as educational and cultural experiences, that the intelligence quotient alone was not an adequate criterion of mental retardation and that there were many other problems concerning the proper use and interpretation of intelligence test scores.

Research was stimulated, and many studies were done on such problems as the inheritance of mental capacity, racial differences in intelligence, the relation of I.Q. to occupational level, and the like. Many previously held conceptions had to be discarded. The over-simplified concept that intelligence was transmitted on a hereditary basis had to be thrown overboard. It was seen that the apparent race differences in intelligence were often the result of the bias of the test in favor of one racial group over another. It was also evident that many factors other than intelligence were significant in predicting ultimate vocational and educational levels.

Figures from World War II give a picture even more in accordance with the modern view. The Selective Service System reported that of men rejected for service, some 4 percent were disqualified on grounds of mental deficiency. National distribution, however, suggested that the rejections for mental deficiency as determined by the Selective Service were strongly influenced by regional differences in educational and cultural background.

The over-all products of the ferment of the early part of the twentieth century were quite valuable. Probably the chief outcomes were the reorganization of attitudes and concepts in regard to mental retardation, and the establishment of more adequate provisions to meet the unique problems that retarded individuals present.

As long ago as 1908 Binet and Simon wrote, "A peasant, normal in ordinary surroundings of the fields, may be considered a moron in the city. In a word, retardation is a term relative to a number of circumstances which must be taken into account in order to judge each particular case." No sharp dividing line can be drawn between the subnormal and the normal simply because none exists. The mildly retarded on the one hand, and the dull normal on the other hand, do not represent wholly different groups of human beings, but rather a continuous series differing in degree but not in kind, and shading almost indistinguishably into one another. When the test of social competency is taken into account, who is retarded, and who is not, becomes a matter of relativity.

There have been three major phases in work with mentally retarded children. The first, from about 1850 to 1900, was characterized by the development of institutions; the second, from 1900 to 1950, was highlighted by an emphasis on day-school special classes. In the third period, from 1950 on, parent activity has been perhaps the most significant element.

Movement of the parents has resulted in three important gains: First, by education it has made mental retardation more respectable, and killed forever the idea that heredity is a major cause of retardation. The public is now more aware of the fact that mentally retarded children are entitled to treatment and a chance for happiness. Second, by getting together, the parents have themselves grown in their understanding of the problems of mental retardation. Third, by refusing to believe that the less able retarded children were doomed to lives of perpetual custody, the parents have conducted the most practical research of the last 15 years.

This is where we are at present—not only willing but eager to look at the assets of the retarded child in a positive manner. Many of the older misconceptions have been swept away and we are tending to substitute a more dynamic approach which is characteristic of twentieth century science. However, we still have a long way to go.

Chronology of Programs for the Retarded in Minnesota

1879 - First institution for the retarded established as unit of Faribault School for the Deaf, Dumb, and Blind.

1882 - Permanent building constructed at Faribault and filled with 41 children.

1885 - Dr. A. C. Rogers became superintendent of the new school. He employed a psychologist, the first in any institution in the United States. 1910 - \$5,000 legislative appropriation for research made possible the appointment of Dr. Fred Kuhlmann, famous for his version of the Binet-Simon intelligence test, to lead the psychology program.

1913 - Summer classes for training of teachers started at Faribault. 1915 - Special classes for the retarded in public schools subsidized by law. 1917 - First guardianship laws are passed, emphasizing public responsibility on both state and county levels.

1923 - "Club houses" for mentally retarded girls, who worked in the community for pay, were set up in Minneapolis, St. Paul, and Duluth (These were closed before 1940, possibly because of changes in work opportunities). 1925 - Colony for Epileptics established at Cambridge.

1925 - Permissive sterilization law passed, based on the erroneous idea that the "feeble-minded" must not have offspring.

1945 - Owatonna State School and the Annex for Defective Delinquents at St. Cloud were opened.

1946 - Publication of "Teach Me," the first booklet designed to help parents care for severely retarded children, by Bureau for the Feeble-minded and Epileptic of Minnesota State Division of Public Institutions.

1946 - Parents of children at Hammer School organized the Minneapolis Association of Parents and Friends of the Mentally Retarded. Within a few years, similar groups are organized throughout the state.

1947 - Dr. Sheldon Reed arrived in Minnesota to head the Dight Institute on Human Genetics.

1950 - National Association for Retarded Children organized.

1953 - Interim Commission on Youth Conservation and Mental Health Programs recommended that (a) steps should be taken to improve greatly the level of supervision of the mentally deficient in all counties, and (b) all committed mentally retarded in need of institutionalization should be admitted and no waiting list permitted to again develop.

1953 - Law passed by which parents, if able, were expected—though not required—to pay 52 per cent of the per capita cost of institutional care; if parents failed to pay, the charge to the county was doubled.

1956 - Community Health and Welfare Councils of Minneapolis and St. Paul recommended that private agency services to the retarded be increased, so that activities furnished for other individuals would also be furnished for the retarded.

1957 - Laws relating to special classes resulted in great expansion of special programs for the retarded in the schools such that the character of the institutional population changed somewhat—e.g., opening of trainable classes often means refusal of space in a residential institution if child is attending school.

1957 - Another new institution opened at Brainerd. Colony at Cambridge began accepting mentally retarded as well as epileptics, and Faribault, Cambridge and Brainerd were placed on a regional basis.

1961 - Law regarding parent payment changed to reduce portion paid by family but to retain the idea that, while the state should bear the greatest load, institutional care was not totally a state responsibility. 1951-1961 - Legislative progress based on needs of mentally retarded:

1. State aid for special classes in public schools raised
2. Classes for educable retarded made mandatory
3. Trainable classes came into being and state aid is granted them also
4. State subsidy granted to community mental health centers which provide services to mentally retarded.

5. Minnesota Advisory Board on Handicapped, Gifted, and Exceptional Children established to advise State Departments of Health, Education and Public Welfare,

6. Subsidies provided on pilot basis for day care centers.

1963 - Division of Vocational Rehabilitation entered into cooperative agreement contracts with local school districts to facilitate expansion of employment of retarded as they make the transition from school to community.

1963 - Number of special classes throughout state for trainable retarded increased from 21 (in 1957) to 49.

1964 - Special classes throughout the state for educable retarded increased to 523, serving 6,803 children.

PREVALENCE

Despite the importance of mental retardation as a major national health, social, and economic problem, exact figures as to numbers of retarded persons are not available, Gardner and Nisonger state, in their Manual on Program Development in Mental Retardation, that there are "presently no...data which permit a precise statement of the prevalence of mental retardation." Although incidence surveys have been conducted in various states, notably New York, Michigan and Illinois, it is generally agreed in the literature that no comprehensive survey of the number of mentally retarded in a community has ever been undertaken using satisfactory techniques for identification. Most authors attribute this deficiency to the diversity of definitions utilized in various inquiries, the difficulties of measurement and case-finding, and the generally limited scope of the prevalence studies which have been made.

It is commonly estimated that three per cent of the population, or about five and one-half million*, might be classified as mentally retarded.

(If a conservative population projection of 230 million Americans by 1980 is realized, this might mean as many as 6,900,000 persons who will by then be considered retarded.) Based on this customary three per cent figure, a breakdown frequently presented in terms of 126,000 annual live births is as follows:

Approximately 4,200, or 0.1% of all births, or one child out of every 1,000 born, who are severely or profoundly retarded, needing constant care or supervision throughout their lives;

approximately 12,600, or 0.3% of all births, or three children per 1,000 born, who are moderately retarded, capable of developing self-protection skills and limited skills for semi-productive effort and partial self support in a protected environment;

approximately 110,000, or 2.6% of all births, or about 26 children per 1,000 born, who are mildly retarded, capable of adjustment from a marginal role in society to complete assimilation.

as follows:

Mild Retardation	75%
Moderate Retardation	20%
Severe Retardation	5%

However, if we agree that mental retardation is not a life-long unalterable condition, but is a complex set of manifestations of some children's relationships with their immediate environment, then an overall incidence figure has little meaning. What the three per cent figure really seems to mean is "three per cent of the school population," since when the mentally retarded are not lumped together but are identified by age groups, prevalence estimates vary from 0.3% at pre-school age to 3% at school age to 1% post school.

Apparently the "visibility" of the retarded is different at different age levels, one reason being that our techniques for discovering these individuals, primarily based on academic standards which do not prevail at earlier and later ages, are most frequently utilized and are most effective during the school years.

Furthermore, the schools have access by virtue of mandatory attendance laws to a "captive audience", consisting of almost all persons of school age, whereas

it is harder to locate individuals in other age groups. In the past only a small number of pre-schoolers have been identified, most of them with gross physical defects—partly because physical and environmental factors have not yet had a chance to affect the child, partly because instruments for detection are not yet well developed for this age level, and partly because our standards of evaluation are less stringent. From ages 10 to 14, when the most rigid standards of school achievement are imposed, as many as eight to ten per cent of the school population have been labeled mentally retarded. Many of these individuals "disappear" after about age 14 to 16, when they are re-absorbed into the body of the community, presumably able to function at least marginally. Thus, prevalence rates change because society's standards of competency, programs, situations, and expectations vary for each of its members at various ages, and not necessarily because of a change in functioning level of the member. (Some of the severely and moderately retarded may have a shorter life span, helping to account for some of the drop in adult prevalence.)

Gardner and Nisonger suggest that at best "it would be safe to say that at some time in their lives about three per cent of the population could be classified as mentally retarded." Even more conservatively, it has been observed that "the best statement regarding prevalence that can be made at this time is that it may be sufficiently greater than the approximate one per cent now known to all agencies to suggest that the continued demand and need for service will exceed availability of such services for many years to come."

Even such well qualified. Careful statements have very little meaning unless we are in possession of far more particularized information. We have already mentioned age and degree of retardation in relation to shifting criteria and unacceptability of techniques and instruments for identification. It is becoming axiomatic

as studies proliferate that the majority of the mentally retarded are to be found in the disadvantaged strata of society. For example, a strong correlation between economic status and intellectual development is evidenced by studies such as one done in Chicago in 1952. Sixty-five per cent of pupils in special classes for the retarded came from eleven slum areas (out of seventy-five urban areas), in which the referral rate for school-age children ranged from ten to thirty per cent. To quote from the President's Panel:

"Extraordinarily heavy prevalence in certain deprived population groups suggests a major causative role...for adverse social, economic, and cultural factors...Whether the causes of retardation in a specific individual may turn out to be bio medical or environmental in nature, there is highly suggestive evidence that the root causes of a great part of the problem of mental retardation are to be found in bad social and economic conditions... and that correction of these fundamental conditions is necessary to prevent mental retardation successfully on a truly significant scale."

Accordingly a national Departmental Advisory Group on Cultural Deprivation has been appointed, with representation from all agencies of the Department of Health, Education and Welfare, in order to assemble pertinent facts and develop programs for preventive action on Federal-State locals. Since at present only a fraction of mental retardation cases can be prevented through bio medical means, it is crucial that we attack the bulk of cases through improving environmental factors in our culturally deprived groups.

Related to the above are geographical, racial, and demographic variations in prevalence of mental retardation. Although four per cent (716,000) of the draftees examined during World War II were rejected on the basis of "mental deficiency," the percentage varied regionally from one per cent in the Far West to nearly ten per cent in the Southeast; taken by state, rates ranged from one-half of one per cent in some states, to almost 14 per cent in others. Selective Service statistics indicate that draft rejection rates were six times as high for non-whites, suggesting the effects of lack of opportunity, educational deficits,

and other negative environmental factors.

It must be recognized that we are evaluating individuals for mental retardation on a primarily intellectual basis, in the school years as well as in the mass Army screenings, and that the psychological tests commonly used penalize the lower socio-economic strata unmercifully. Our tests are based on middle-class academic values, are formulated by middle-class professionals, are standardized on "representative" random samples of the population, with the result that the culturally disadvantaged person is likely to "fail." Later on, when socially adaptive rather than academic performance is the criterion, many of these individuals no longer appear to be retarded. As Heber puts it: "Mental retardation is a term descriptive of the current status of the individual with respect to intellectual functioning and adaptive behavior. Consequently, an individual may meet the criteria of mental retardation at one time and not at another. A person may change status as a result of changes in social standards or conditions, or as a result of changes in efficiency of intellectual functioning, with level of efficiency always being determined in relation to the behavioral standards and norms for the individual's chronological age group."

If we are interested in propagandizing (and this is certainly a legitimate interest), it is indeed dramatic to say, for example, that "mental retardation afflicts twice as many individuals as blindness, polio, cerebral palsy, and rheumatic heart disease, combined." If, instead, we are concerned with program planning, with building a framework of adequate services on a state and national level, then we need to research our figures carefully and to analyze them with respect to rates and degree of occurrence within various sub-groups of the population.

PREVENTION. DIAGNOSIS, AND TREATMENT

Prevention

In the long run the ultimate goal in working with mental retardation is prevention. Were all mental retardation prevented, the concomitant problems would no longer exist. Obviously this is a goal not easily realized, since the causes of mental retardation are so varied and, for the great bulk of cases, still unknown. However, as Gardner and Nisonger point out, "if incidence could be reduced by a small margin, the efforts would be justified." More important is the observation that "full application and utilization of existing; knowledge... would eliminate perhaps half or more of all new cases of mental retardation... Measured in economic as well as human values, the...high cost of mental retardation, warrants a maximum effort for prevention."

The task of prevention is difficult, because mental retardation is merely a symptom associated with a large number of defects which in turn are due to multiple causative factors. It is these causative factors which provide the key to correction of a complex problem. A beginning has been made, largely since 1950, when

a spurt of new medical discoveries generated fresh optimism; the war had demonstrated the vital contribution of the handicapped; new concepts of rehabilitation gained acceptance; and our responsibility for world leadership revitalized our belief that the manner in which our Nation cares for the less fortunate is a key to our future.

Many sources point out that the dynamic force mainly responsible for focusing attention on the retarded in the first place was the organized parent groups, whose patience and determination provided much needed leadership.

With present knowledge it is possible to identify precise causes in

approximately 15 to 25 percent of the cases of mental retardation. These are cases where

organic pathology as a result of disease or injuries is often demonstrable, most readily in instances where the degree of retardation is severe and there has been gross brain damage. There are a great many diseases and conditions which affect the brain and result in retardation, including infections or poisons in the mother's system during pregnancy, infection

of the central nervous system during infancy, injuries to the brain at birth, head injuries in childhood, metabolic disorders determined by heredity, and abnormal brain growths.

When causes are specified, effective preventive action can, in many instances, be taken. Examples include German measles in the first three months of pregnancy, RH blood factor incompatibility in newborn infants, lead poisoning, and dietary changes to overcome phenylketonuria, galactosemia, and other diseases of faulty body chemistry.

However, in from about 75 to 35 percent of the cases of mental retardation, consisting primarily of mildly retarded persons without gross abnormality of the brain, specific diagnosis is not yet possible. Yet, even here, research is casting light on a complex interaction of factors.

It seems reasonable to believe that some members in this group are affected by operation of genetic and hereditary factors which are not yet clearly identifiable or understood. Similarly, a significant role for bio medical causes is suggested by data which show clearly that children born of mothers without prenatal care have an incidence of retardation many times higher than children born with proper maternal care. For example, a variety of unfavorable health factors, including lack of prenatal care, poor nutrition, deficient postnatal care, and similar unfavorable factors, may produce damage to the brain or to the body which cannot be generally measured with present techniques but which will constitute a drag on physical and neurological development. Clearly, however, the incidence of mental retardation is heavily correlated with a lack of proper maternal and prenatal health care, which in turn is closely associated with unfavorable socio-economic status of families or whole neighborhoods or groups in the population.

The majority of the mentally retarded are the children of the more disadvantaged classes of our society. This extraordinarily heavy prevalence in certain deprived population groups suggests a major causative role...for adverse social, economic, and cultural factors.

Thus, prevention of mental retardation in all of its complexity requires simultaneous action on all fronts—biological, psychological, and sociocultural.

A complete discussion of bio medical causes, suspected causes, and corresponding preventive measures which are being or should be, taken is impossible here. A partial list appears below.

Causes of Retardation

Congenital syphilis

Anoxia, mechanical, and other brain injuries during delivery

Brain damage associated with blood incompatibilities between mother and infant

Inborn "errors" of metabolism, such as (1) phenylketonuria (PKU) and (2) galactosemia

Maternal infection during pregnancy, such as (1) German measles (rubella),

(2) Thyroid disease, diabetes, sub-clinical urinary tract infection in expectant mother

Prematurely

Health hazards after birth as anoxia, infection, diarrhea disease, inadequate diet, physical trauma (including "battered child syndrome"), lead poisoning

Genetic mutations during premarital and preconception period

Chromosomal aberrations

Preventive Measure

Systematic blood tests during pregnancy, followed by effective therapy

Improved obstetrical practice

Routine prenatal blood tests; prompt exchange transfusions

(1) Simple screening of newborn, laboratory blood tests on suspected cases, dietary change and (2) identification of carrier state in parents, galactose free diet pre - and post-natal.

(1) Voluntary exposure of girls prior to child bearing age; development of vaccines

(2) Better medical management and routine detection procedures

Adequate pre-natal care -

Adequate post-natal care, particularly efforts of public health nurses, etc. aimed at "high risk" mothers; early diagnosis and treatment of infection; public education and control

Strict enforcement of standards in use of x-ray and other equipment producing ionizing radiation

Laboratory detection and genetic counseling earlier pregnancy in certain instances.

To what use society puts knowledge such as that in the chart above, as well as the results of future research, will determine its benefit to all concerned. Obviously, Federal, State, and local public health programs, support of research, and health legislation, are required, with appropriate allocation of money and manpower--particularly in order to utilize fully improvements in pediatric and obstetrical practice. The President's Panel has developed a number of axioms which summarize preventive needs.

1. The prevalence of mental retardation is significantly higher in those population groups where maternal care is frequently inadequate; therefore, a nation-wide program should be launched by the Children's Bureau, Public Health Service, and State and local health departments concentrating on these high-risk groups.
2. It is recommended (1) that State departments of health and university medical centers collaborate in the development of regional genetic counseling services (by groups of States where possible and appropriate) so that young married couples and expectant parents in all parts of the Nation may have access to such consultation; and (2) that diagnostic laboratories for the performance of complex diagnostic procedures be developed on a regional basis.
3. The Food and Drug Administration, the National Institute of Health, and the pharmaceutical industry should develop and require the use of techniques for evaluating and assessing the effects of Pharmaceuticals on the fetus, infants, and young children.
4. A few States have enacted laws or established regulations providing for the registration, inspection, calibration, and licensing of x-ray and fluoroscopic machines and other ionizing radiation sources; it is strongly recommended that all States establish such provisions and that the Public Health Service continue to expand its program for radiological health protection, with special emphasis on provision of assistance to the States in establishing effective x-ray control programs.
5. Hospitals are urged to adopt and use every known procedure for prevention of prenatal and neonatal defect and brain damage; the joint hospital accreditation board should add criteria for prevention procedures to its present requirements for accreditation.
6. In view of the high percent of automobile and other accidents resulting in brain injury, it is recommended that the accident prevention activities of the United States Public Health Service be expanded and that it continue to encourage intensive research in the causes of accidents as a basis for more effective programs of prevention.

A rather special case of mental retardation engendered by environmental deprivation is that which is termed "psychogenic," originating in conditions in the environment or within the individual, or both. There seems to be a particular vulnerability during the first year of life; there is incomplete agreement as to the reversibility of this condition, which can result from institutionalization, separation of infants from mothering figures, and distortions in the mother-child relationship (the "unavailable mother"—working mothers, mothers who innately cannot fill the child's needs because of

illness or depression, rejecting or over protecting mothers). Changes in patterns of institutional and foster care can do much to remedy the occurrence of retardation based on inadequate post-natal stimulation. Certainly extensive public education, aimed at gaining acceptance and use of preventive measures, is mandatory, particularly among the disadvantaged, uninformed, uncooperative families from which the majority of the retarded come.

Such education is merely part of community programs which should be taken to modify conditions of environmental deprivation.

James Conant, in his book Slums and Suburbs, outlines the factors to which "cultural retardation" of slum area children is related:

- (1) Lack of motivation toward achievement and toward standards of high performance;
- (2) A home environment that fails to develop the modes of thinking and perceiving common to the middle and upper class child;
- (3) A family organization or structure that is emotionally crippling to the child;
- (4) Lack of adequate social facilities in health, education, and welfare.

It has been suggested that at least two major approaches to the problem be taken: general measures to correct fundamental social, economic, and cultural conditions with which mental retardation is so closely associated;

specific measures directed at groups of children, among whom the influence of mental retardation is heavy, to increase opportunities and provide experiences that will offset or alleviate adverse factors in their environment. General measures include strengthening of health and maternal and child welfare programs; strengthening our educational system at all levels as well as "bridging the gap" between schooling and employment; urban renewal and area redevelopment programs; "income replacement programs" for the indigent, such as social security, unemployment compensation, etc.

Specific measures might include establishing preschool enrichment centers in rural and urban "slum" areas; work with parents by schools, social agencies, etc., in promoting better child-rearing practices; public school adaptation of education to needs and capacity of deprived children.

A bold preventive approach is called for to interrupt...the adverse cultural and social ailments which are the root of many of our health and social problems, including mental retardation... These problems call for assistance to the passive and dependent or underprivileged families, many of whom are not reached by existing public or private community services. Their needs are great, but their financial and spiritual resources are meager.

However, even if our capacity to finance services through public funds were of no consideration, there is one critical factor which constitutes an almost impassible barrier..., the lack of trained people to work with children and families in disadvantaged communities...Voluntary service can help meet the needs...The creation of a domestic Peace Corps can provide leadership...and with appropriate state and local committees, can give new impetus to the volunteer spirit throughout the country.

Diagnosis

The Joint Expert Committee of WHO says:

Although some forms of mental subnormality, usually those of severe grade, are recognizable at birth, the majority of cases look much like normal children and are first distinguished by slowness of development. During the period of infancy, only cases of fairly gross handicap are likely to be diagnosed. In the preschool years, however, it becomes possible to discover a good deal of moderate sub normality and some mild cases.

In speaking about early detection and diagnosis, we are to a degree continuing the foregoing discussion of prevention, because "in an increasing number of instances, detection and diagnosis of an underlying biological abnormality can lead to the prevention of brain disease and consequent retardation." Physicians and nurses need to be trained to recognize the signs of normal, as well as aberrant, development of the newborn; systems of examination and observation should be instituted in all maternity and general hospitals, with data carefully recorded. The "high risk" group in terms of possible mental retardation should be identified and followed up by public health nurses, use of neurological and other screening procedures, and inclusion of suitable items on the "confidential medical data section" of birth certificates. For

example: history of genetic diseases in relatives or siblings, small premature infants, infants from low income families where emotional or sociocultural deprivation appears likely. Wall baby clinics could be utilized here to advantage in follow up.

Early case finding will minimize damage—partial prevention—caused by hearing impairment, speech disorders, deprivation of stimulation, epilepsy, and other handicaps, as well as reverse both phenylketonuria and galactosemia. Case-finding efforts must be continuous because many detectable symptoms of mental retardation are not apparent at earliest stages of development. Provision for each newborn infant of ongoing health supervision by a private physician, pediatrician, or well child clinic is the ideal. Biological, neurological and psychological screening tests should be incorporated, in pre-natal care, newborn, and later on in the child's development. Systematic examination of preschool children in the community would be a boon to schools and parent in planning for the optimum development of the child's potential. The continuous case finding process must be implemented by complete diagnostic work-up, laboratory tests, medical specialist consultation, and psychological evaluation—to support the "suspected" mental retardation. It would seem most expedient and economical if existing community services be utilized, since few parents can afford extensive diagnostic services. State Crippled Children's diagnostic services, community mental health clinics, state and local health department laboratory services, and interprofessional diagnostic centers in the community as well as at university and medical centers may be extended for this purpose. An even better reason for building on existing services stems from the difficulty of...deciding who is a subnormal child and who is not. Since the case finding and diagnostic problems range over the whole field of physical health, mental health, and educational guidance, and since the retarded child is not only retarded but also has the health, social, and educational needs common to all children...previous tenancies toward isolation of these children and segregation of services available to them should be terminated.

Comprehensive diagnosis requires a multi-disciplinary team approach—the primary physician, medical specialists, nurse, psychologist, social worker, audiologist, speech pathologist. Not all will be seen by every child, but they should be available if their contribution is needed. Often it is difficult to secure an adequate diagnosis because of limitations of present knowledge, limitations of diagnostic instruments, scarcity of well trained professionals in this field. However, the 97 interprofessional diagnostic clinical facilities presently operating throughout the nation are doing much to ameliorate this situation. Such clinics also provide a valuable setting for training and clinical experience of professional personnel.

An example of the interaction of the various specialties in making a diagnosis might be as follows: the medical disciplines would determine where a patient is physically able to attend school and whether there are remediable physical defects; the psychologist would decide whether the patient is mentally bright enough to profit from schooling, or whether the patient's capability for understanding language is such that he can profit from schooling; the otologist may contribute on the child's ability to hear; the social worker or public health nurse would provide information on availability of schools and data on the family; and the educator would select the most appropriate type of educational placement. The careful explanation of all findings to the patient's family is a major task in itself. Such is the team approach to diagnosis. Besides the special clinics mentioned above, retarded children are served diagnostically by out-patient clinics of general hospitals, out-patient clinics of state institutions, mental health clinics, traveling clinics, regional or local child guidance clinics, university out-patient clinics, and public school child study services. The list is long and varied, but the services provided are far from adequate. School health programs in particular have a vast potential for diagnosis of mental retardation and other handicaps, which in many instances has not been exploited.

The diagnostic role of the family physician or pediatrician merits special attention, whatever facilities may be available for referral, he is often the first person to see the mentally retarded infant after discharge from the hospital, or to make initial diagnosis at a later developmental stage. He is in a position to study the suspected retarded child longitudinally, to contribute valuable observations about growth and development, to initiate comprehensive diagnosis when needed. He can interpret diagnostic implications to the parents over the years. He can help to increase the child's total capacity by diagnosing other defects without delay, such as dental or orthopedic problems. He is in a sensitive position for noting and interpreting improvements or changes in the dynamic syndrome which is mental retardation, as these occur in a given individual. Treatment - Total Care

Medical supervision of the whole child is the primary physician's responsibility to the retarded, as to the normal, individual. He is the only professional who will maintain a continuous working relationship with the child and family during the individual's total life span. In the words of the A.M.A. Conference on Mental Retardation, "Good management, therefore, requires the development of a total life plan for each individual, insuring continuous care and enabling the retardate to achieve his maximum potential.

It is the responsibility of the physician—consulting with the family and professional colleagues — to devise this life plan and to mobilize the resources of the individual, the family, and the community to put it into effect."

The physician should provide a liaison between the family and the many specialists and clinics involved in total evaluation. He should be involved in long-range planning for the child and be responsible for seeing to it that the plans are carried out. He should treat associated physical handicaps to maximize the child's functioning level. He should take the initiative in

making periodic checks, as in the management of any chronic illness. He can counsel the parents most effectively, if he is sufficiently informed about retardation and community resources for coping with the problem. The size of that if which is the condition for all effective treatment by the individual physician, is described below:

Unfortunately, at the present time, physicians are not well educated as to the general problem of the retarded...Until the proficiency of the general physician, pediatrician or internist in the field of mental retardation is improved by further training...the director of a diagnostic and evaluation center will need to substitute for the individual physician. The physician who is familiar with the life of the family and the community should be the ideal focus. However, at present his knowledge of community resources, especially educational and vocational opportunities for the retarded, is woefully inadequate and requires concentrated upgrading.

* * * * *

Our Task Force on Prevention, Diagnosis and Treatment has drawn up an outline of ideal responsibilities for planning:

- I. To devise a full retinue of effective preventive measures; a continuing, authoritative review of advances in the field and a specific technique to ensure incorporation of appropriate new measures in the preventive program.
- II. To plan a method for total evaluation of any child suspected of mental retardation using up-to-date investigative techniques; multi-discipline consultations; effective interprofessional communication and imaginative techniques for informing and guiding parents, teachers, and others concerned with care of the child.
- III, This task force is uniquely constituted by virtue of its broad professional membership to plan or review all treatment of these children; to plan specifically for their general and special medical care; to review all other plans of treatment ("everything that comes after evaluation.")

Five overlapping areas of concern were likewise delineated.

1. Case finding. Several members stressed the need for earlier

recognition of the retarded. The school system catches more than any other community service, but much could be done prior to this. The need for education of physicians to be alert and check for known symptoms of retardation was emphasized. Many of these could be discovered through post-natal care and subsequent physical examinations, A difficulty here is that parents frequently do not return for regular examinations.

A centralized reporting of all children excused from compulsory school attendance for any reason would probably discover many retarded youngsters but would be difficult and costly to maintain. A project on early case finding is part of our supplemental grant (see below).

2. Prevention. The task force should evaluate present research for practical uses. Investigation of families where retardation has already occurred was also suggested. Investigation into social background, possible factors involved in pregnancy, etc, could evolve common denominators with which to identify future potentiality for retardation, A registry of defects could be set up but would be pointless unless specific follow-up service were created; the list would also have to be kept current. Congenital physical malformations will be recorded on birth certificates in the future.
3. Diagnosis. Continuing evaluation by a team of experts is desirable. This approach should be used in culturally deprived areas with good success. Family physicians must have a particular awareness of mental retardation or symptoms might easily be overlooked. A checklist of possible causes and symptoms to look for was suggested. Emphasis should be placed on the role of the public health nurse as a resource for identifying symptoms and getting information to doctors and other professional workers. The idea that a complete team was not necessary for every case was expressed. A hierarchy of services

might be employed; more sophisticated techniques might be provided at some central area for unusual cases which could not be served by community evaluation facilities.

Manpower shortages and recruiting problems are obstacles. For example, in staffing the Four-County Project in Owatonna, difficulties have been encountered because salaries were well under those paid by the community mental health center housed in the same building. Perhaps the mental health centers could do diagnostic work with additional staff; Owatonna would test this.

4. Parent Counseling. Initially, counseling is within the province of the person who suspects or diagnoses mental retardation. Most frequently this is the family doctor. However, doctors often are not informed on developments regarding retardation and do not have time or interest in many cases to attend diagnostic team staffing. Doctors might be seen in their offices and informed in detail of team findings. But it was pointed out that parents accept counseling better from those who have been involved in the team diagnosis rather than from another individual who merely summarizes the team findings. For this reason it would be ideal for the family physician to be a member of the evaluation team.

The school is an important counseling agent because of its legal responsibility for education and the psychological, health, and other services it offers.

5. Treatment. Treatment in a broad sense includes everything that happens after evaluation. (This task force is concerned primarily with medical management, since other aspects of care are being studied by other task forces). The need for better education across disciplines of professionals involved in treatment was pointed out. Mental health centers can be of value here because of their advisory

roles in the community. A specific project for the task force might be the matter of how to provide specialized professional education for those involved in team evaluation and community leadership. The task force has been divided into three sub-committees, Case-finding and Prevention, Total Evaluation, and Parent Counseling and Treatment. Their function is to propose a philosophical framework for the task force, develop specific approaches to problems discussed above, and determine what basic information is needed and how it can best be acquired. A summary of their work to date follows below. Repetition cannot be avoided, but all of the ideas expressed can bear reiteration.

Case-finding and Prevention.

The subcommittee is devoting its efforts to the design of a longitudinal study in which such variables as case-finding techniques, methods of evaluation, effects of preventive treatment, and the culturally deprived milieu will be systematically examined with respect to preschool children. Plans for the study arose from an examination of the feasibility of statewide diagnostic screening of all preschool children for retardation and other handicaps. Our overall goal is early provision of all available services; we are particularly concerned with developing and applying preschool enrichment programs for both children and parents from the culturally deprived milieu. Thus, we are not simply case finding in the usual sense, but aiming at a step-wise procedure whose logical and desirable outcome is prevention.

Initially it was decided by the group that it was desirable to include both rural and urban settings, emphasize existing community resources as much as possible, concentrate considerable attention on "high risk" groups, and examine both the individual and the milieu involved. Members felt that the following questions should be answered: (1) What can the maximum utilization of local resources be? (2) What other handicaps become visible in such a

survey? (3) What is the efficiency of currently available or developed diagnostic instruments? (4) What is the cost of finding additional cases? (5) What intervention could be taken which would warrant case-finding expenditure? (6) What are the milieu characteristics which are pertinent in "environmentally caused" mental retardation?

At our second sub-committee meeting, the question of responsibility for implementation of the research design arose. It was agreed that task forces should identify problems and outline specifically methods of implementation, but that carrying out the design was outside our province as a planning group.

There was much discussion of the feasibility of studying "high risk" populations. In Minneapolis, there is a considerable body of base-line data already available on the culturally deprived Grant School area and other high risk areas, set forth in the 1964 Profile of Minneapolis Communities prepared by the Community Health and Welfare Council. Well-baby clinics, as well as Dr. Evelyn Hartman's pre-natal clinic which has just been set up to study high risk mothers and infants, could be drawn upon for sample populations. There is preparation in Minnesota an adaptational curriculum guide, suitable for a tailor-made enrichment program to use with the children identified, at the preschool and at later stages. Problems arose as we tried to agree on a rural county or counties from which a comparable "deprived" sample might be drawn. Some members felt that rural cultural deprivation is not the same as the urban phenomenon which seems to be involved in the etiology of mental retardation; others held the view that even within a generally deprived rural population there were strata whose lack of environmental stimulus penalized them significantly. The thought was voiced that, in order for the study to have reliable implications for the entire state, our sample should be random rather than stratified. A

decision was reached that we were at this point more interested in a service-oriented project, which could serve a greater number if we draw stratified samples rather than a more representative random one. Although the committee recognized the need for a clearly formulated definition of mental retardation, members felt that a broad definition would evolve eventually, that for our purposes qualification for placement in a special class might meanwhile be used as an operational definition. In trying to make use of case-finding resources which are at hand, the possibility of upgrading present school census procedures and data to aid early case-finding was canvassed. It was pointed out that a research study had been done on improving the census, that a questionnaire form had been developed (these were distributed to sub-committee members) which might certainly help us to find some children early. Consideration might also be given to taking the school census at the age of 3 and again at 5, or perhaps to holding an annual clinic. The Health Department and/or other designated agency such as Crippled Children's Service, school professional screening personnel, etc., would then go in and examine the children identified. Another method of finding cases would be to utilize the kindergarten roundup, which apparently brings in almost 100% of school age children extant, to find the handicapped. We might "push back" this roundup to the age of 3 or even 2, possibly running it at consecutively earlier ages, to determine at what age we could locate the optimum number of individuals. The feasibility of a central agency, where a pool of information on handicapped children in the community would be repositied, was also explored. Such an endeavor would be impractical both from the point of view of expense and the continuous re-evaluation required to keep the information up to date. Furthermore, since mental retardation is always subject to change, a "permanent registry would be an injustice to the individuals involved.

It would also be interesting to know to what extent our present resources are being used by various strata of our population. We assume that these services, such as wall-baby clinics, are taken advantage of, but are they? Is there less gap between available services and use in the wealthy areas than in the deprived? This aspect of the study might also help us to upgrade the census in the sense of finding some more cases who are being served, but of whoa we were not previously aware. In this portion of our work, as in subsequent steps, we would be selecting our study populations around perceived problems, rather than limiting ourselves, as originally planned, to a comparison of culturally deprived groups in the various communities. We have simply expanded the scope of our plan to encompass a variety of samples of individuals, at the sane tine spelling out more precisely specific facets of the projected study.

The committee decided that our next meeting would involve setting forth clearly that part of our design which would deal with the Grant School district (urban culturally deprived) and Kandiyohi County (rural sample) in terns of improved school census techniques and earlier kindergarten roundup.

Total Evaluation. Again the concept of a continuing comprehensive evaluation by a team of specialists was stressed. Ideally total evaluation should be effected as early as possible, with emphasis on treatable diseases and those conditions having genetic implications.

Evaluation includes adequate history, physical examination and laboratory studies. Important aspects of the history are pregnancy and birth, developmental milestones, review of systems and socio-economic and educational background; consideration should be given to some type of check list which may be research related. Physical examination consists of general physical, neurological, psychological, and other specialized consultations (audiology, Otolaryngology, ophthalmology, orthopedic, dental) as needed. It might be useful to document physical status of patients by taking of photographs at

time intervals. Laboratory examination would comprise urinary screening tests, blood tests, electroencephalography and other neurological tests, spinal fluid examinations, and psychological screening tests (e.g., Vineland Social Maturity Scale, Goodenough Draw-A-Man Test and Peabody Picture Vocabulary Test). It is essential that data collected in such evaluations be coordinated to see if the diagnosis has been firmly established and to determine further needs. Reports should be made available to referring physicians and schools. Facilities available for total evaluation in the metropolitan area are: University Hospitals, Hennepin County General Hospital, Ancker Hospital, Sister Kenny Institute, Sheltering Arm, and others. Regional facilities might include Mayo Clinic (Rochester), Four County Projects (Owatonna and Fergus Falls), and interstate facilities at Fargo-Moorhead, Grand Forks, East Grand Forks, and Duluth-Superior. Determination of personnel considerations in these areas should be made to assess limitations and resources. It is important that total evaluation be integrated with case-finding, treatment, and research—from a personnel, financial, and communications standpoint. For example, patients might be available for research activities, in order to learn more about the etiologies of their conditions and to develop new screening tests. Highly specialized evaluation centers, set up perhaps at Mayo Clinic or University Hospitals, might be geared with research tools of a more sophisticated nature. Community mental health centers, interstate services, etc., might be important in regional integration. Professional education might be accomplished by means of referring physician participation in total evaluation conferences, total evaluation demonstration center with practicing physician participation, or mental retardation news bulletin including information regarding techniques in evaluation and research tools. Parent Counseling and Treatment.

The person most involved in Initial counseling, in informing the parents

and discussing with than the presence or possibility of retardation, is usually the family physician—be ha general practitioner, pediatrician, or obstetrician. When there is definite retardation the parents should be told and provisions made for definitive diagnosis. When there is uncertainty, it is a matter of recognizing the possibility and seeing to it that adequate diagnostic studies are obtained. Early referral is important, not only for pinpointing suspicion but also to provide a longer period of observation prior to definitive diagnosis.

Often times the family physician feels inadequate because of lack of training and limited exposure to the problems of retardation to handle the counseling. It would be well to include the subject matter of mental retardation as well as counseling techniques in the education of physicians; these problems could also be a part of post-graduate refresher courses in pediatrics and program of the Academy of General Practice. A questionnaire which would orient the family as to what questions to ask physicians might be developed.

Another problem in counseling arises after a child has been referred to a diagnostic center. When an evaluation is completed there should be a consultation between the family and that member of the team who is able to discuss problems and answer questions most authoritatively. After the consultation a report in lay language might be sent to the parents and to the referring physician; the latter should also receive any additional professional information which could be of value. The use of this direct routing may minimize confusion which often arises from relayed information. The family doctor will of necessity be most intimately involved with the retarded child, and any tendency to divest him of this involvement should be avoided. So far as is possible, treatment program should be worked out through him. In this way he will become more aware of the problems of retardation and more experienced in handling them.

Treatment possibilities should be presented to the family in the initial counseling session. Although there is a gross shortage of trained personnel to provide the many necessary facets of treatment, there is often in the community dormant professional or lay talent which with training could be utilized. The object of any public health activity should be to get the program back into the hands of the community as soon as possible, since by providing services the community is also improving itself and learning at the same time.

COUNSELING SERVICES FOR THE FAMILY

. . The matter of providing sympathetic and intelligent professional counseling to the families of the mentally retarded has been repeatedly cited as an urgent need. The anxiety and emotional tension put upon these families can hardly be comprehended by those who have not experienced this tragedy, and the parents particularly are concerned that few of them have skilled help at a time when they so critically need it. Over and over again strained relationships between husband and wife, or between family and neighbors are recounted—strains that ultimately result in separation or divorce, or physical, emotional, or social breakdowns within the family group. The still-prevalent stigma associated with mental retardation, as well as the heavy physical burdens of caring for a handicapped person, are experiences that undoubtedly take a heavy toll from the most competent and secure person. It is the opinion of parents and others that family counseling, both on a group and on an individual basis, is of first importance."

In the Children magazine for January-February, 1956, there appears an article entitled "Some Pointers for Professionals" by Leatha L. Patterson, a member of the National Association for Retarded Children and a mother, Excerpts from this article appear most appropriate.

One of the most heart-warming aspects of being the mother of a retarded child these days is in being a part of a profound partnership which is developing between lay and professional people. Of all life's problems, those presented by a handicapped child (and particularly a mentally handicapped child) required the utmost teamwork within professions, among professions, and between professional and lay people, especially parents. All over the country we parents are attempting to assume responsibilities appropriate to the partnership through helping to define our separate roles and enlightening our communications in order to save other families from unnecessary trauma.

Dr. Martha M. Elliott, Chief of the Children's Bureau, recently said: "When officials of public agencies ask what kinds of services should be provided for retarded children, my advice is, ask the parents. They all are often best qualified to say what help they need, where professional persons have to provide the

hows. Thus, we laymen and professionals are indispensable to one another in our efforts to make up for past neglect of the serious medical, emotional, social and educational problem. Here she brings together written and spoken insights which have come her way from both professional workers and parents. On the basis of these and her own experience she urges:

- (1) Tell us the nature of her problem as soon as possible.
- (2) Always see both parents. Both parents should be present whenever possible, and at least on first consultation regarding a child's handicap. It is difficult for a mother to go home and re-state, interpret, and answer questions about a problem she does not clearly understand herself. Often the problem with its fears has brought about a lack of communication between the mother and father; establishing adequate communication is difficult in any marriage.
- (3) Watch your language. Parents need to understand the implications of their problem but too often we are given professional gobbledygook, or at the other extreme plain talk of an obnoxious variety.
- (4) Help, us to see that this is our problem. Too many well-meaning professional people in the past have thought they knew what was good for us and have recommended, even insisted, on institutionalization. Only as we parents are helped to work through our problems, can we find any peace of mind. If we have not planned for our child ourselves, if someone else has made the decisions, we have not really made up our own minds and so must keep going over the ground again and again.
- (5) Help us to understand our problem. Parents differ in quantity and clinical quality of information they can absorb during different phases of this problem. What they want and need depends greatly on the individual but. many of us have no search for the knowledge that we needed in order to understand

our child.

- (6) Know your resources,
- (7) Never put us on the defensive.
- (8) Remember that parents who have retarded children are just people.
- (9) Remember that we are parents and that you are professionals.
- (10) Remember the importance of your attitude toward us. Sometimes I think your colleagues place too much emphasis on "objectivity" and not enough on "loving kindness." Certainly we expect you to be objective about our problem; but about us? Never. A really gifted professional person cannot help feeling being subjective, attempting to stand in our shoes and to look at our problem through our eyes, in the process of helping us. It is only through empathy that you can define the proper words and acts to help us. There are greater debts and breadths in helping parents of retarded children than many of you have realized in your initial attempts.

Dr. Harriet Blodgett presents a professional's point of view: I suggest that one of the factors which interferes with clear thinking on the part of society's professional representatives in this area is misguided sympathy with the misfortune of the parents of retarded children, which feeds into circular mismanagement of the total problem through "weaseling" methods of coming to grips with its interpretation and with action. Granted that to have a mentally retarded child is an unfortunate event, it is not the only unfortunate event that can and does happen to people, and action stemming from sympathy only is likely to be limited in value and not necessarily wise in judgment. I submit that parents need, first of all, information. They need this to be presented sympathetically but factually and honestly. They need it to be personalized for their own child and their own situation, but in the framework of broad professional knowledge and

experience with the total problem of retardation. They need practical kinds of help with behavior management, understanding, acceptance, fostering growth in independence and self-sufficiency, avoidance of secondary emotional and dependency problems of the retarded child, avoidance of circular dependency situations, avoidance of intra-family problems related to unequal distribution of parental attention and reward. They need informational steering toward sources of help—not only counseling and supportive kinds of help, but planning help, knowledge of resources, and help in selecting those resources appropriate to their needs and situation. I submit that we have often short-changed parents through trying to counsel them in accordance with what we think they want to hear, rather than what we know to be true. We have been fearful of putting our professional knowledge to the test of individual application.

HOME TRAINING

What is proving most meaningful to the parents is the help they receive in home training and every day living with their retarded child. At an evaluation conference short-term goals may be set such as learning self-feeding or toilet training. As one goal is reached the next is planned. The processes involved in guiding many children to achieve degrees of self-help are basically the same as in normal children. With an understanding of the child's potentiality for achievement and of the specific goals to be reached the public health nurse (for instance) is in a key position to assist the family in helping the child in reaching his goals. She is, however, dependent upon the mental retardation clinic for the evaluation of the child and his family. She needs to maintain a continuing relationship with the clinic staff in working with mentally retarded children in their homes in order to give understanding support to their parents and to participate in the training programs that are directed, to the total plan of care for each child."

From Lesser, Arthur J. "New Programs for Mentally Retarded Children" Paper given at the American Public Health Association, Cleveland, 1957.

EDUCATION AND REHABILITATION

The terms "education and habilitation" should be thought of as extending to all preschool, school, and post-school age experiences necessary for the maximum development and well-being of the retarded. These services ordinarily should supplement parental rights and responsibilities but not supplant them.

Education and habilitative agencies should avoid creating vacuums for less educable or trainable retardates by upgrading programs for the more educable retardates. I.Q. and C.A. criteria should be extended in favor of the retarded and not restricted. Well rounded programs must provide for the mildly retarded as well as the severely retarded; for those in the community as well as those requiring residential care. These programs must be of a continuing nature and should attempt to provide for the total needs of the retarded person.

Unesco in 1962, in its publication, Education and Mental Health stated: "Dull children are not likely to attain the same standing as their better in doubt contemporaries and their rate of educational progress, even under favorable conditions will be markedly slower. Attempts to force them to keep pace with the average meet with no success and result either in destroying completely their educational personal morale or at a range of more or less overly aggressive attitudes which may lead to delinquency. When, however, such children are from the earliest moment put into the charge of a sympathetic teacher who understands both their limitations of learning capacity and the techniques essential to enable them to progress socially and educationally, all but those who have additional difficulties can be educated to become self-supporting and self-respecting citizens and to live well-adjusted and satisfying lives." The subnormal and the dull, however, have special needs and make special demands upon the teacher's skill. Their most marked and general disability is in the verbal field and all those operations, which require abstract reasoning. Hence, in

varying degrees, according to an accurate assessment of their potentialities, and to a continued and well-informed study of their progress, the curriculum should be based upon concrete realizations, practical work, the development of manual skills and upon increasing social independence.

Since the turn of the century, public school systems in the United States increasingly have come to assume responsibility for the education of the mildly retarded or educable classification. At mid-century, moderately or trainable retarded have legal status in local school systems somewhat comparable to the position of the educable predecessors 50 or 60 years ago. Thus the legal principles underline educational services for retarded children may be viewed in historical perspective. One of the obvious conclusions that can be drawn from an inspection of the trends is the fact that the rights and privileges of the mentally retarded now are beginning to be regarded quite differently as compared with yesteryear. Under girding the evolvement of greater privileges and more freedom as well as better protection of personal rights under the law, are those constitutional guarantees which equally assure, for the retarded, the same justice and individual worth cherished by all of us. Such ideals can be achieved only through the enlightened instrumentalities of society and among the major tools of education.

A basic principle of the American school system is free education for all children, the right of the child to basic educational opportunities at public expense, and the obligation of the state to provide equal educational opportunities. Constitutional mandates do not specifically exclude children because of physical or mental limitations; exclusions or exemptions constitute action of boards of education based upon state statutes. The laws of the land must be compatible with

the constitution which they serve and local boards of education must act in accordance with the laws designed to implement the basic principles stated above. Whenever a child, able to profit from education is exempted from school solely on the grounds of his retardation, and whenever a local school system does not claim its responsibility for providing education to such a child, there emerges, at this time in history, the very serious question of abridgment of civil rights—the question of whether children can be denied equal educational opportunity because they are mentally retarded.

Preschool Centers

There is a need to establish preschool age centers for the socialization and stimulation of retarded children and for the counseling of parents relative to effective home training of the retarded. A major gap in community services is the lack of such things as homemaker services, working public health services and especially designed nursery and kindergarten activities for the retarded.

School Facilities

nationally, only one retarded child in four is in a special school. Both public and private special education facilities should be utilized to the fullest extent. There is a need of intensive curriculum research to devise the best suited curricula and courses of study for the retarded. There is immediate need of more effective instructional media with intensive research concerning proper textbooks, electronic learning devices, etc. For the trainable mentally retarded, there is great need of an honest answer to the question: whose responsibility is it to educate or train these youngsters? The school or a non-school agency? There is need to analyze the laws governing special education services for the retarded, so as to identify major gaps and inadequacies in existing legislation.

Occupational Preparation and Placement

In planning a comprehensive program of services for the mentally retarded, considerable emphasis should be placed on developing the capacity of each mentally retarded person for useful work. This principle should apply to services of all types and at all age levels. It is true that it would be unrealistic to expect every mentally retarded person to become self-supporting or even partially self-supporting to gainful work activity. However, a series of investigations of the social and occupational adjustment of adult mentally retarded persons living in communities have revealed that many are capable of self-support. These studies disclose that substantial numbers of these persons had found and were holding jobs were married and fully meeting family responsibilities, abiding by the law and were otherwise maintaining an acceptable level of citizenry. Undoubtedly their numbers would be increased considerably if all mentally retarded persons were provided with adequate services directed toward developing the work potential. In addition to the first group, there are many other retardates who can work productively in sheltered workshops or in homebound activities. Even severely retarded persons can be taught to perform simple household tasks or self-care activities. When a retarded person is prepared for employment placement, job benefits are obvious. The individual enjoys a better income. He acquires a feeling of self-esteem. His status in the family and the community is improved. The family or the public as the case might be, is freed of the burden of his support. The goods or services which he produces add to our national wealth. The benefits while not as spectacular are analogous in the case of the more severely retarded person who is prepared for sheltered employment or self-care activities. We should keep before us the following principles: (1) The development of work potential is as important in the case of the severely retarded person as in the case of the less-severely retarded person; (2) a program of occupational preparation and placement which encompasses all retarded will

result in a greater number of persons rehabilitated into remunerative employment than a program which serves only a selected group.

The economic value of vocational rehabilitation for the retarded is clearly demonstrable. A study of 1,578 mental retardates who were rehabilitated in 1958 estimated that their total annual earnings rose from \$70,000 before rehabilitation to 2.5 million dollars after rehabilitation. Using \$1,500 as the average individual cost for the rehabilitation services, the total one time cost was estimated at under 2.4 million. The economic gain to the nation and to the individual is thus clearly evident--aside from the savings in public and private assistance costs which were being incurred on behalf of these individuals before their rehabilitation. Only 3 per cent of this group supported themselves, before rehabilitation, from their own earnings : eight per cent were supported by public assistance; and 89 per cent by their families and other sources.

In general, the teaching of specific work skills is less useful than the long-term development of good work attitudes. Most of the jobs which truly retarded people will fill are basically unskilled jobs. Their adequate performance is more dependent on responsibility, good habits of being on time, sticking to the task, not getting upset by minor interpersonal difficulties, staying out of trouble with the law and with the neighbors, than on specific job training. This points toward in-service training in the job situation, or in a simulated job situation, rather than long-term specific teaching of complex skills.

Essential Services

A truly adequate program for the occupational preparation *and* placement of the mentally retarded will require the development and operation of a comprehensive network of services and facilities throughout the country. Such a program can

be realized only by a wide-spread participation by both public and private agencies in all three levels of operation, national, state and local. The program should make provision for: (1) Vocational evaluation, counseling and job placement. (2) Training courses in appropriate vocational areas, (3) Joint schoolwork experience program that operated cooperatively by schools and vocational rehabilitation agencies. (4) Clearly defined and adequately supervised programs for on-the-job training of retarded workers. (5) Employment training facilities for those who require further vocational preparation after completion of the public school program. (6) Sheltered workshops for retarded workers capable of productive work in the supervised, sheltered setting. (7) Vocational rehabilitation services in conjunction with residential institutions. (8) Counseling services to parents to provide them with an adequate understanding of the employment potentials of their children and to provide guidance which will enable them to participate more fully in their rehabilitation process. (9) Supportive services and facilities such as supervised residential facilities, day by day counseling services, legal services and special recreational activities.

Coordinating; Education, Vocational Rehabilitation and Placement Services A

planned program of occupational preparation and placement should be developed and initiated for the employable retarded, while he is still in school and before he reaches the permissible age for leaving school. This plan should be developed cooperatively by the school and the vocational rehabilitation and placement agencies in the community. It should cover both the school and post-school periods. It should provide for optimum utilization of all available resources and for continuity of services. This approach necessarily assigns the school a key position in the area of occupational preparation and the placement of the mentally retarded.

EMPLOYMENT

Help for mentally retarded persons in gaining employment is one of the most important services that can be rendered to the nation and to those who are handicapped. Employment has both social and economic benefits and few aspects of life in our society are more important to the individual.

Suitability for employment has its origins in health, family life, and relationships outside the family such as religion and education. When more significant progress has been made by the mentally retarded in these other areas, the problem of gaining and holding a job more frequently can be surmounted successfully.

The mentally retarded have a hard time finding and holding jobs—even ordinary jobs—for many reasons. The skill demands of most jobs are beyond their ability. The non-skill requirements of many tasks are difficult for them to meet because of their mental requirements and consistent application of effort, the need to travel to a work place and arrive at a particular time, the need to accommodate to the demands of others, and so on. The mentally retarded person or his parents and friends do not know where to find a job that he can perform. Mentally retarded persons do not know about the training they need, the types of jobs they could perform, and the non-skill requirements of work both before and during employment.

Employers generally do not know how to use the limited skill of the retarded person, nor how to supervise him in such a way as to bring out his full potential. Many employers and fellow workers are not sympathetic to the needs of the mentally retarded nor capable of meeting them; some employers furthermore do not believe they can afford economically to be concerned with a retarded person.

In our complex industrial economy where technological progress and automation are eliminating more than one million unskilled jobs a year» the problem of employment for the retarded is accentuated. Automation is tending to throw the mentally retarded into competition with more capable persons who are displaced from ordinary jobs. It is fortunate that there is substantial expansion in some sections of the economy (for example, the service industries) which can employ individuals with lesser skills.

Every effort must be made and all available services used to equip and train the retarded and assist them in finding suitable employment.

Employment assistance for the mentally retarded seeks to meet the problems of employment through private and public arrangements that:

1. Relate the education and training of the mentally retarded to employment requirements, especially through expert evaluation and counseling.
2. Advise the mentally retarded and their employer about the kinds of jobs they can perform and how jobs can be redesigned so that the mentally retarded can perform them.
3. Refer the mentally retarded to jobs they can perform or to training opportunities.
4. Advise the mentally retarded and their fellow workers and employers about the best ways for working together.
5. Expose the mentally retarded to work in competitive situations and initiate them into the needs of competitive work situations.
6. Provide the mentally retarded employment in non-competitive situations if competitive employment is not possible.

It is the feeling of the task force on employment that an employer hires people for what they can do, not what they can't do. They are in business to make a profit and every worker must contribute his share. There is nothing paternalistic about the process. Competition being what it is, employers cannot afford to "carry" less than full capacity workers. The employers on the task force expressed their experience that handicapped persons, retarded and otherwise, when placed on jobs which they can perform, lose their label of retarded. Everyone is handicapped in some degree and mental retardation is only one. It is very important that a placing: agency follow through with supervision after a retardate is employed.

Work training programs and sheltered employment are separate concepts although they may be accomplished in the same work situation. Work training programs are discussed more thoroughly in the education and rehabilitation section of this material.

SHELTERED EMPLOYMENT

It is to the credit of the selection process that it results in an efficient placement of the vast majority of the workers in the national labor force. Nevertheless, it also results ultimately in the rejection of a sizeable group of persons from any type of employment. Because of physical, mental or social handicaps, these persons are unemployable by the standards of competitive enterprise. Yet frequently, they are persons who want to work and who possess considerable productive capacity. Many mentally retarded persons will be found in this group. If their productive capacity is not to be wasted and if they are not to be denied benefits enjoyed by their fellow citizens, it is essential that means be devised for providing employment opportunity which are in keeping with democratic principles and the national economy.

To provide opportunity for those persons who cannot be absorbed in existing work situations, there should be developed a system of sheltered work activities. This system should include (1) sheltered workshops and (2) sheltered work projects. These activities should be developed by both public and private agencies at all levels.

A predominant objective of each workshop or work project should be to rehabilitate the individual to a highest level of productivity of which he is capable. In many instances, the goal would be rehabilitation into competitive enterprise.

In the operation of each activity, there should be a plan for providing or securing whatever rehabilitation services might be indicated including medical, psychological, social and vocational services. Pay rates should be kept below prevailing industrial wage rates in order to provide monetary incentive for rehabilitation into competitive enterprise.

The term "sheltered work project" may require explanation. Traditionally, the workshop has been the medium for providing sheltered employment.

However, many opportunities for purposeful, productive work are to be found outside the workshop. A sheltered work project then, is a sheltered work activity which is carried on in a setting other than that of a workshop. Activities which lend themselves to the development of sheltered work projects include conservation, maintenance of parks, recreational areas, and grounds of public institutions, domestic service occupations, certain types of health service occupations, and

agricultural occupations. Sheltered work projects may also be operated in selected departments of industrial plants. Sheltered work projects should be under the guidance and control of work shops, rehabilitation centers, and other professional rehabilitation agents. Sheltered work projects should serve the relatively large numbers of disabled persons and clinical undertake a great variety of activities useful to the community. At the same time, they require smaller capital investment in buildings and equipment than do other types of employment, including those of the workshop.

Determining the Need for a Sheltered Workshop

Enthusiasm, interest and desire are excellent motivators for those considering the initiation of a sheltered workshop. Besides these incentives, there are legal considerations and other requirements necessary in the establishment of such a facility. There are a number of principles that experience has shown indispensable to the successful operation of a sheltered workshop for the mentally retarded. As a first step, it is essential to establish an active workshop committee. It is of utmost importance that the committee be composed of civic-minded persons of sound judgment and good knowledge of the community, who are in a position to be helpful and are interested in the project. If the workshop will serve several disabilities, a representative from each group to be served should be included in the committee. A committee should also include representatives from the State Department of Vocational Rehabilitation, Special Education, State Employment Service, Public Relations, and other workshops which may exist in the community, industry, labor, business, and civic organizations. In selecting the committee, it should be kept in mind that some or all of its members may function as a governing body after *the workshop* has been established.

The committee, in order to determine the need for a workshop, should obtain the following information:

1. "Whether other workshops in the community will accept the mentally retarded for evaluation, training, and sheltered employment.
2. How many mentally retarded persons need this service. A sufficient number of candidates, (at least five to start), should be available and in need of the new service to justify the establishment of a workshop. Public and private schools, social agencies, clinics, parents, physicians, and state rehabilitation or employment agencies are resources for this information.

Consultation with these agencies or persons, particularly during the early planning stages, can result in at least two things:

1. It may be possible to gain additional needed assistance which may extend initial interest in the new program to the workshop's advantage.
2. These resources can be used as the sounding board to clarify exactly what is essential in your local community to meet the needs of the group concerned. Should there be differing viewpoints on what is needed, or believed to be essential? It is far better to review such differences at the start than at a later date when any final plans are to be submitted.

The committee should plan its facility so that it continues to meet the needs of the community it serves, as well as the special interests of retarded persons. Workshops initiated by member units of an A.R.C. will discover a greater amount of community acceptance and willingness to financially support programs that keep the doors open to other handicapped persons. Those workshops interested in serving other handicapped persons referred by local, public, vocational rehabilitation agencies, find such agencies more interested in programs serving all persons with various handicaps as opposed to those only providing services to one special disability group.

The advantages of a mixed disability workshop include the following:

1. Larger groups of handicapped persons can be served.
2. Program content will be enriched, since different handicapped persons have varying abilities, permitting a wide range of work to be undertaken.
3. Cost to operate will be less when these can be shared.
4. Staff persons who are relatively hard to find might be more attracted because the workshop responsibilities will be broader and offer greater challenges.

There must be some sort of appropriate work available in the community, whether this be sub-contracting the production of an article, contracting for services, or other activities. There must also be a permanent and reliable source of subsidy. Workshops are not self-supporting. Attached to this material is a bill before the Legislature which would provide state subsidy for the development of sheltered workshops. Essential staffing elements are a director, a person to solicit business, counseling with retardates and parents, placement and continuing follow-up, a knowledgeable shop foreman and a variety of others, depending on the size and nature of the workshop.

The Working Plan for the Sheltered Workshop

Sheltered Workshop Program Phases:

1. Screening admissions. Each candidate for admission to a workshop is ideally considered on the basis of medical, psychological, social, educational, and vocational records. Individuals need to be physically able to participate in the program. The rehabilitation screening team includes professional consultants from related fields. These usually include the vocational counselors, the psychologist, the social worker, or special educator.
2. Evaluation. The workshop staffs observe each trainee in a variety of vocational or job activities. Interests, abilities, skills and potentialli-

ties are evaluated. Social and interpersonal factors in the vocational or job setting are tested. For example, job explorations and adjustment measures provide opportunities to evaluate trainee abilities and limits. It should be kept in mind that some established workshops have developed effective working relationships with public and private vocational rehabilitation agencies often provide "evaluations of work potential" for referred clients. After such evaluations are made, the client is referred back to the referring agency, who then assumes responsibility for either further training or job placement.

3. Personal adjustment training. Evaluation leads to an understanding of individual personal adjustment needs, the ability to meet normal work demands, adjust to a job, require integration and proper balancing of social, personal, and vocational experience.
4. Vocational or job training. Vocational or job training objectives are determined primarily by job interests and personal adjustment factors. The trainee's abilities and potentials provide bases for specific or general training. Extensive job analysis assures practical goals and vocational or job training.
5. Selective placement. Overall performance and adjustment in the sheltered workshop results either in job placement in the workshop or in competitive employment. Successful job placement utilizes each trainee's highest level of capability.
6. Follow-up. The sheltered workshop, or cooperating agency that places the workshop trainee, is responsible for the follow-up. The goal of follow-up is to insure that both employer and employee are satisfied. The need for follow-up decreases as the employer-employee, relationship becomes better established.

RESIDENTIAL CARE

Residential care includes any facility outside the home which provides care for patients 24 hours per day. It has an important place among the various services required for the retarded and for many years, it was practically the only service of any importance in this country. The view that a large institution is one of several rather than the main resource in the care of the retarded is not yet established in the United States as it is in the Scandinavian countries and in England, Holland, and other parts of Europe where significant community services are a part of their program. In this country, institutions represent the greatest investment of manpower, buildings, and funds and thus are highly visible. This is a consequence of the historical pattern of our concern for the retarded and a coincidence of the physical nature of residential facilities which are very large in many cases and frequently is some distance from centers of populations. The challenge to state institutions is how to accelerate the change from large isolated facilities to smaller units close to the home of the patients and to the health, education and social resources of the community; and the challenge to both state and private residential facilities is how to replace the old concept of custodial care wherever it still exists with modern programs of therapy, education, and research. Institutional care should be restricted to those whose specific needs can be met best by this type of service.

Institutions are one facet in the continuum of care. The decision to place a retarded person in residential care must be made on the basis of careful review of the diagnosis and symptoms of the individual, the needs of his family, and other resources available in this community. Professional judgment and recommendations are indispensable, but the decision-making process must also include members of the family if they are at all competent to participate.

Because of the tremendous variations in the problem presented, it is unwise to generalize with respect to the desirability of keeping retarded children in their own homes. The attitude of parents on this matter ranges all the way from determination to retain the child whether or not it is wise for them to do so - to the despair that results from carrying an intolerable burden. The financial capabilities of families covers an equally wide range, thus what is "best" for the retarded child, his family, and the community can properly be determined only by adequate professional evaluations, skillful counseling, and an objective point of view on the part of local and state authorities.

There will always be some retarded individual for whom a residential setting for a short or long period will be the treatment choice. In making this decision, the emotional stability of the family and the degree of dependence of the retarded person involved are key factors. If the total well-being of the retarded person depends on the care of trained personnel and if his presence in the home conflicts with a fulfillment of the needs of other members of the family, he probably should not remain at home. If a retarded person is to live at home, it is important to determine whether the community has the supplementary facilities he needs.

Age is an important and sometime controlling factor. Studies have shown consistently that infants and even young children up to six and seven years of age are usually better served in their own or in an adequate foster home or in boarding home group care. The need for schooling alone rarely calls for admission to an institution today except in rural areas where facilities are scarce. Most often, admission is necessitated by unmet medical, nursing, or behavioral needs, by death of the parents, or by lack of stability in the family.

Many retarded people have a critical need not being met in the community; the need may be a foster home, an educational opportunity, or only routine medical and dental care. Every effort should be made to satisfy needs such as these through available or new resources rather than resorting in a routine fashion to institutional care.

The following objectives for residential care should be considered by boards of private institutions, appropriate authorities of the states, and clinical the council of state governments:

1. Every such institution including those that care for the seriously retarded should be basically therapeutic in character and emphasis and closely linked to appropriate medical, education, and welfare programs in the community.
2. Every institution has some unique quality or potential that can be developed for the benefit of the entire field. No institution should be regarded as merely "custodial", those caring for the profoundly retarded offer unusual opportunities for the application of new methods of treatment and care and for research.
3. Diagnosis and evaluation should take place before admission and be followed promptly by treatment when the patient is received.
4. The institution should extend its services beyond the traditional boundaries of its own campus and reach out to assist the patient and his family before his actual admission; this facilitates visits by parents and friends after admission and is an important factor in early adjustment.
5. Flexible admission and release policies and out-patient programs similar to those in the hospital or school are essential in meeting the needs of the retarded and their families.
6. The goal of every residential program should be the elimination or amelioration of as many symptoms as possible and the achievement of independent, semi-dependent or even a sheltered extramural life for every person under care in accordance with his potential. This can be accomplished only by a devoted staff with a variety of professional skills and a competent administration. Indoor and outdoor recreations; social activities; programs of physical fitness; opportunities for self-expression through music, painting, worship; and other creative outlets are essential aspects to a sound institutional program.
7. No child or adult shall remain in residential care any longer than necessary. Regular and frequent re-evaluations must be scheduled to reveal any possibilities that may have been developed in his community and to determine whether the individual himself has reached the point where he may profit by some other form of care.

8. If and when the child or adult is ready for return to the community, adequate resources and services for support should be made available. It may not be vase or possible for some to return to their own families, hence the importance of developing foster or boarding home placements or homes for small groups similar to those in several European countries.
9. Responsibility for the care of persons returned to the community should not be relinquished by the institution until assistance is assured from some other source; efforts should be made to see that community services are made avail able to him before he leaves.
10. Many residential populations lend themselves to certain unique research under- takings particularly of a clinical nature. Continued clinical evaluation of the institution program itself requires personnel with a research point of view,
11. The future of residential care must be viewed in the context of state and regional needs and resources; i.e., more than one state should be included in planning in many instances as the geographic characteristics and resources of some states are such that they cannot meet the needs alone. Joint planning and development of interstate facilities is particularly important in providing facilities for such combinations of handicap as the blind and the deaf-mentally retarded.

As the states and the boards of public and private institutions plan for the future, problems of the size of institutions, program, and personnel are paramount. Bring- ing the provision of services as close as possible to the local community is a basic tenet on which the Panel's recommendations rest. This would be consistent with the general movement of health and mental health services in this direction, in itself and important and key movement in developing new services for the retarded.

Private Institutions

Unique opportunities are open to the private institutions in the country. There are many ways in which they can serve as important links in a continuum of community services and cogent reasons why they should become increasingly strong factors in programs for the retarded; First is the fact that our society believes in and profits by a fruitful partnership of public and private services in every area of endeavor; second and more explicit, it is the opportunity that the high quality institution offers to the states by way of a spearhead or vehicle for demonstration and experimentation in residential care. A great deal of value

could accrue to both voluntary and public programs for the retarded if more states would apply in carefully selected instances, "the purchase of care" plan whereby a private institution for the retarded is conducting or can conduct for a state institution or other state programs, a unique service of special value. It is suggested that this possibility be thoroughly explored by those states which have not yet considered or used this resource. It is important that in any such plan, the purchase of care should be made on a cost accounting rather than a flat basis and that the amount paid by the state in any year should not exceed the total amount of the budget of the institution for that year. Otherwise, the institution would in a sense lose its private status and be subject to state control.

States have the responsibility to maintain effective licensing and inspection of all private facilities offering residential care for the retarded. Private institutions of appropriate standards and clinical level of patient care that meets state requirements should be eligible for all support and subsidies outlined in these recommendations. The mission to the Netherlands sponsored by the panel made the following recommendations among others which are germane to the future of residential care in the United States.

1. Impetus should be given in the United States to the development of a wider range of diversified residential arrangements for those retarded persons who, for whatever reason, cannot live with their own or foster families; that is, small units designed in program and structure meet different needs.
2. Emphasis should be directed to the development of group homes in urban and suburban areas for small homogeneous groups of retarded persons who can use the various community opportunities for work, recreation, and education and to the design, construction, staffing, and use of living units for six of ten children within larger institutions.

One of the best hopes for the improvement of both public and private institutions in the states may come from interdepartmental committees and equally strong citizen's committees, both appointed by the Governors and responsible to them.

If the membership of a citizen's committee includes knowledgeable and militant

people who will acquaint themselves with the problems of the retarded in the state and help to determine what is needed to improve and develop the program, there will be substantial progress; in fact, it is doubtful whether fundamental improvements in residential care where it is needed the most can take place without an organized and sustained citizen effort.

Our own task force on residential care feels that we need everything we have today plus much more in both state institutions and smaller community institutions. We must interweave the institution with the total program of services and upgrade all of them.

Institutions basically furnish three services: custodial care, training, and medical services. People are committed because institutions meet the needs of the individual, his family, or the community. Sometimes it is questionable whether they aren't committed because there is no other service for them in the community. The task force feels placement in a residential facility outside the home is a basic decision which should be based primarily on the needs of the patient and family, and should be based on adequate diagnosis which would include future planning and type of service needed.

I. Goals of our state institutions

- A. To create an atmosphere in which every patient can develop to their full potential.
- B. To establish a standard of physical, nursing and medical care which, at the very minimum, is as good as that available to a non-retarded person in the community.
- C. To become sufficiently flexible so as to be able to play a full coordinated part in the comprehensive state planning for mental retardation.

II. Evaluative programs to meet those goals:

- A. To find out what the needs of an individual patient are.
- B. To meet these needs as fully as possible
These needs will vary with:
 - 1. Degree of mental retardation.
 - 2. Degree of physical handicap.
 - 3. Age of the patient.
- C. Even amongst these three broad groups, retardates differ from each other in personality and personal characteristics and needs as much as any large groups of non-retarded persons would.

III. Having established the needs, programs can be designed for certain large groupings, e.g.

- A. Bedfast - physically handicapped.
- B. Children.
- C. Adolescents.
- D. Non-working adults.
- E. Working adults who will stay in the hospital.
- F. Working patients with a prospect of living outside of the hospital.
- G. Geriatric patients.
- H. Further subdivisions e.g., Psychiatric Unit; Independent Living Unit; Unit for Brain Injured Children.

IV. Intake procedures

- A. Person advising admission should have first hand knowledge of
 - 1. What the institution can do.
 - 2. What the institution can not do.
 - 3. What alternative prospects there are,
- B. Committed or voluntary admission.

V. Placement procedures

- A. Need for preplanning at hospital and County Welfare level before patient is placed out.
- B. Better if welfare worker can attend hospital planning sessions.
- C. Perhaps better if hospital worker would visit patient in placement situation several times during first year.
- D. Many patients will never leave hospital, for others the institutional stay- can be a transitory phase in their life history in response to some stressful situation.

VI. New functions

- A. Sheltered workshop within the institution
- B. Evaluation and teaching of work habits and skills to retardates, come in by the day, or 5 days a week and go home at week ends.
- C. Similar resource for adult chronic mental patients in the community.
- D. Mother and child units to help normal mother with retarded child become used to handling the child or infant.
- E. Problem family training - mother and father both inadequate with child. Should be possible to structure a useful plan for, say, two such families at a time. Father working in hospital, mother receiving instruction in Home Economics, etc.

COMMUNITY SERVICES FOR THE MENTALLY RETARDED

Almost 95% of the mentally retarded live in their home communities and will continue to do so. This in itself is desirable but community facilities must be adequate if the retarded who remain in their home communities are to develop their potentialities most profitably for themselves, their families and society.

The retarded vary widely in their capabilities and needs. Some require total care from infancy throughout their lives, while others will need services during only part of their lifetime, such as special education during the school years. A comprehensive program will be outlined but it must be understood that all parts of this program will not apply to every retarded person. Responsibility for development of community programs in Minnesota has been divided and indefinite, leading to overlap in some areas and some serious gaps in services. The following basic recommendations were developed by the Governor's Advisory Committee on Mental Retardation in its 1962 report. They are to be used as a guide in establishing responsibilities in this area.

Responsibility for community services for the mentally retarded:

- I. Mentally retarded persons are entitled to all the services normally provided to other children and adults. A, These services should be provided by the governmental body
institution or private agency that normally provides such services to others; for example:
 - (1) Education and training should be provided by the public schools.
 - (2) Vocational training and placement should be offered by the office of vocational rehabilitation
 - (3) Recreation when provided by a local governmental body should be extended to the retarded.

(4) Camping and religious nurture should be in the hands of non-public institutions and agencies.

(5) Preschool training should be provided by other agencies up to the age when the school's responsibility begins.

B. There should be a recognition of the excess cost factor in providing public service with reimbursement by the state to the local public body providing such service.

Community responsibility and intervention begins when adaptive behavior becomes beyond a parent's control. Actual referral may be through parents, physicians, school, the police, or other communications. A definite diagnosis and evaluation should be the first step to determine limitations and future planning. Based on this appropriate services should be available to parents as well as agencies. Realizing that not all retarded persons will use every service, the following are identified as being necessary:

1. Prenatal and postnatal care. (See Prevention, Diagnosis & Treatment)
2. Diagnosis, including medical, psychiatric and social services.
3. Counseling and parent education.
4. Nursery and nursery school.
5. Day care.
6. Special education at elementary and secondary levels for both trainable and educable retardates.
7. Work training and job placement.
8. Sheltered workshops.
9. Boarding homes, both temporary and permanent.
10. Sheltered living for adults.
11. Religious classes.

12. Recreation services and camping,
13. Social activities for adults.
14. Half-way houses.
- 15- Various special treatment services, such as speech, hearing, sight,
physical therapy, etc,
16. Nursing homes.

These services should be available as needed by individuals and families regardless of cost, commitment to guardianship, or other prerequisites. There is a very direct relationship, of course, between services assumed by the community and the effective functions of the state institutions. Regional committees must evaluate what services they already have in these many areas. Can they realistically develop a whole gamut of services? If not, how can they be furnished? Many of the necessary ingredients for these services are discussed in various places throughout these materials. They can be used as yard sticks against which the regions can measure themselves.

Sub-committees in this area should concentrate on nurseries and nursery schools, day care, boarding homes both permanent and temporary, sheltered living for adults, religious classes, recreation services including character building organizations and clinical camping, social, activities for adults, half-way houses and nursing homes.

The task force on Community-based Services has discussed day activity centers at considerable length. They should have the following general purposes:

1. To offer a developmental program for the individual.
2. To facilitate adjustment in the family and community.
3. To offer counseling and case finding, with emphasis on discovery of and management of remedial conditions.
4. To integrate agency services for the retarded so that the continuum of appropriate services is available to the retarded in the community at all stages in his life.
5. To re-evaluate and to make long range diagnostic studies of the individual.
6. To free parents from constant care of the retarded, so that they may allocate more time to other essential family needs. There are funds available from the state on the matching basis to communities. There is a proposal before the legislature for substantially more to stimulate day care centers. Standards for programs are being prepared, and may be available for regional meetings. If available, these will be part of the materials.

Transportation is a major item. The federal guidelines for the construction of facilities suggest that day care centers should not be more than one hour's driving time from the person receiving the service. The feeling of the task force was that transportation should be a budgeted item of the day care center, and contracted for by an outside facility, such as school bus, taxi cab service, or community-owned station wagon. The matter of insurance when using parents' automobiles is a major item.

The first step in measuring need for a daytime activity center is the identification of retardates who would use the service. Interested civic groups, and getting general community recognition of need are essential ingredients. Soliciting agencies which may know of retardates, and contacting parents directly or through the agency, are a means of involving additional persons. It appears that activity centers will develop where there is community pressure of this sort, rather than looking at our presently very unreliable incidence figures and planning where one ought to be. It frequently is the case that as services are provided, a lot of people eligible to use them seem to appear,

Recreation

Recreation is a long neglected area of service for retardates.

Borderline and mildly retarded may well be absorbed into their recreational planning programs for the normal population with the exception of those persons who need specialized techniques due to multiplicity of handicaps, emotional disturbance or brain injury. A moderately, severely and profoundly retardate requires specialized services, training techniques and leadership in institutions, public and private. Such a program should include a recreational program dealing with the preschool and continuing through elementary school age adolescence and adulthood. In such a program, the inter-disciplinary approach is mandatory.

Recreational programs should be extended to all persons within this category, whether the placement be in institutions, public and/or private schools, resident and rehabilitation centers, hospitals or homes. Continuous active family participation is basic in recreational programs for these children. Such a program can be achieved through parent training classes initiated by private and/or public

agencies. The range of activity may well include these types:

- (1) Leisure time activities for persons as members of a family constellation as individuals.
- (2) Organized group activity to include social experiences within the group structure.
- (3) Incidental activities that may develop into
 - (a) hobbies, with the possibility of (b) developing vocational skills.
 - (c) The stimulation of creative abilities, and (d) the development of good human relationships. Such a program should be an "all year-round" one with emphasis on quality rather than quantity.

A review of the present situation of recreation for the mentally retarded reveals a tremendous lack of knowledge. Very little has been published in this field. The limited amount of material deals almost exclusively with children's activities or group experiences, that is discounting camping and so forth. The material available is primarily descriptive in nature and not based upon research or the evaluated process.

Recreation for the retarded requires definition and clarification. Public awareness of the need of the mentally retarded for constructive leisure time activity and participation and recreation must be stimulated. Recreation as an integral productive part of the life of the individual should be recognized. Likewise desired is recognition of the demonstrated ability of the mentally retarded to participate in wholesome leisure activities. Responsibility for recreational programs with the federal, state, and local levels needs to be defined and accepted. Agencies providing recreational programs and services should be encouraged to include the mentally retarded.

Counseling Centers for Adult Retardates

Counseling centers are necessary to help orient retarded adults and to direct them to appropriate facilities for service. As time goes on and the philosophy of community integration begins to operate more in the care and training of the retarded, there will be greater numbers of retarded adults in the community who will need continuing guidance and help. Counseling centers realistically planned and operated would seem to be the answer to the problem of helping the retarded and his family maintain satisfactory social and economic relationships.

Religious Training

Specific denominational religious training for the retarded can be of great advantage to them. Limited as they are in natural talents, they can draw a great measure of internal strength and personal security from a belief in the fatherhood of God and the brotherhood of man.

Further, it is well to realize that appropriate religious and moral training of the retarded is a great asset in helping them acquire maximum self-control and is a counter-acting influence against delinquency. This training is essential to their social acceptance and adjustment. Hence, the provision of religious training and instruction to the retarded through private denominational instruction, release time program, week-end instructions, and so forth is a matter of serious and practical moment.

Very little has been standardized in programming for camping and recreation facilities, religious training, social activities for adults and half-way houses. We need much detailed information on organization, specific activities,

frequency of opportunity, leadership, public acceptance, etc. on existing services to develop a body of useful materials.

VOLUNTEER SERVICES AND PUBLIC AWARENESS

Volunteer Services

Volunteer service is that voluntary effort given without pay by any individual in the community who wishes to share therein the responsibilities of those democratic institutions concerned with the advancement of human welfare. The opportunities of citizen participation are the privilege and obligation of all. The highest potentialities of citizen participation can be reached when a coordinated, volunteer service program is regarded as an integral phase of the total community organization. Recognition of a reciprocal relationship built on mutual respect and responsibility between the volunteer and the professional, each with individual areas of competence, defined and understood, is necessary to the best development of a social attitude and an intellectual technique with which to approach common objectives.

The variety of activities that volunteers do, and the personalities doing them defy description, and categorizing in any but the most general terms. Attached is a list of services received from a survey made of state institutions. These suggest only a portion of those services which volunteers conceivably might perform. With the rapid growth of community based services, opportunities for volunteers are steadily increasing, and are available to an ever larger segment of the population. Both agencies, volunteers, and organizations which sponsor volunteers, should look at their communities for opportunities.

There are basic principles fundamental to giving and to receiving volunteer services.

Giving

Volunteer service is no polite gesture casually made at the cost of a few odd hours. It is a responsibility requiring:

1. Substantial and definite blocks of time, sincerity of interest, conviction of purpose, exercise of intelligence, and energy; and a businesslike approach to work assigned, regardless of the fact that it is done without pay.

2. A knowledge of community strengths and weaknesses, and the existing objectives, problems, needs, and resources of the program with which the volunteer is identified.

3. A willingness to prepare adequately for work to be done under proper supervision, according to standards for training, conduct, quality of service; to adapt special skills and experience to various required activities, and to accept change of assignment when, after objective evaluation, it is deemed advisable.

4. A capacity for growth in leadership which will determine the value of volunteer service to the giver and the receiver in terms of personal satisfaction, creative contribution, and intelligent interpretation.

Receiving

Working with volunteers is not an extracurricular activity, but is a fundamental part of a professional worker's responsibility. The two groups, while performing widely separated functions, can, together, do more than either one alone. In putting this philosophy into practice, organizations and clinical agencies using volunteers have the responsibility of:

1. Accepting -the role of volunteers, recognizing their contribution, respecting their needs and abilities, and taking the time to do something positive about these factors as they relate to the program of the agency.

2. Analyzing the organization's work, defining specific jobs involved in the total plan, determining the division of work between professional and volunteer, deciding the skills, abilities and qualifications desirable for the best performance of the task and the amount of specific training required, informing professional staff on the program for volunteers, and a development among them of essential attitudes necessary to good supervision and a working partnership relationship, making adequate arrangements for necessary recruiting, screening, training, and placing of volunteers; developing methods of recognition and promotion that may be deserved because of unusual service, providing satisfactory working conditions, and all possible opportunities for enriching experiences consistent with sound policy.

3. Taking advantage of the responsibility for developing confidence and self-assurance of volunteers in their own ability to contribute worth while service to the community, thereby helping them to become practicing citizens and community leaders who are able to take an active and constructive part in shaping social programs. .

Volunteers, in giving direct service to retarded persons, perform three major functions:

1. Useful work which cannot be done by a professional to lessen the dehumanization process, and. broadening the retarded outlook,, making him feel important and loved.

2, *By supplementing, not supplanting, professional services.* Volunteers should never be used in jobs or services for which money has been provided for paid personnel, or for which money could be secured through proper channels and actions. Exceptions might be made in essential jobs impossible to fill with paid personnel because of manpower conditions, provided the particular effect of these conditions does not result directly from poor personnel practices in comparison with similar operations; in situations where money might be made available for initiation or extension of services upon demonstration by volunteers of the need for and value of such services.

3. Filling gaps in the continuum of care where no professional service is available, such as religious education, camping, recreation, leisure time programs, and some areas not yet thought of. Many of our present programs were started by volunteers, and, after proving their value, became too large to handle and have been accepted as public and private responsibilities. They are now integral parts of our services. There is no need for this to stop simply because we have developed many services; gaps still remain in our continuum of care. Parents and those persons residing in the region should be able to point these out.

The need for volunteers from an agency point of view can be determined by the staff sitting down and making a list of the needs of the community, and specific services of the agency where a volunteer could be useful. Then make a list of the agencies in the community that are already doing, or should be doing, some volunteer work. This would include service clubs, veterans' organizations, churches, and the many other groups which make up the community. You will find volunteers doing many things already, and when you put these tools together, you should have a good starting point.

Selection of volunteers is a two-way street. Agencies should outline jobs to be done by volunteers and actively recruit them. Groups who sponsor volunteers should request them to complete an application blank which indicates their particular interests, background, availability, and other items. A sample blank is attached. This can be adapted to whatever agency or group may be using it. Complete job descriptions should be made for every job for which a volunteer can and should be used.

Volunteers should agree to enter an appropriate training program which will also indicate their abilities and maturity, as well as sharpen their interest. This training should include orientation to mental retardation, and specific agency programs, goals, ground rules, philosophy, and procedures. Good materials are necessary and available. National, state and local associations for retarded children, the Mental Health Association, the State Department of Public Welfare, the Federal Department of Health, Education and Welfare, and others, have, or can produce, appropriate materials. Periodic training programs on a regional basis might be a continuing program of the associations for retarded children, using both professional staff and experienced volunteers as faculty. Through this selection and training program, unmotivated volunteers will perhaps be discouraged, and the fewer volunteers remaining will be much better ones.

Supervision of volunteers requires several elements. In addition to a job being defined specifically, it should be useful and necessary, and the volunteer should see where it fits into the accomplishment of total agency goals. It should give him a responsibility and a recognition of his services. He should be responsible to one person in the agency. The sponsoring group from which he was recruited should also know who this person is. The responsibility for supervision should rest with whoever has the responsibility for getting the work accomplished, not necessarily the agency director or the volunteer services coordinator, if there is one. Any agency which uses as many as one volunteer should have one individual in charge of the program.

VOLUNTEER APPLICATION FORM

Agency _____

Please read instructions. This form, which should be filled out before the interview, will help us to better know you, your interests, and qualifications as a prospective volunteer. Please fill in every line unless it does not apply to your experience, in which case draw a line through the space so we will know this fact.

Date: _____ Age: (Please Circle) 12-15 16-19 20-39 40-59 60+

1. Miss _____
Mrs. _____
Mr. _____

2. Address _____ Phone: _____
Street City Zone Home Business

3. Education: Grade School ___ High School ___ College ___ Business ___ Other ___

4. Employment; _____

5. Church Affiliation: _____

6. What foreign language do you speak? _____

7. Have you teaching ability or experience? _____

8. Name any societies, clubs, church, or organizations of which you are now a member _____

9. List your particular interests, skills, and hobbies (This might include certain games, dancing, music (instrumental or vocal), dramatics, hobbies (stamp collecting, sketching, etc., art and craft work, etc.)) /: _____

10. List any interest, skill in office and organization work (typing, mimeographing, committee events, etc.): _____

11. In what type of discussion groups, if any, have you participated: _____

12. Do you like to read aloud? _____

13. Do you drive? ___ Is a car available? ___ Insurance Coverage _____
Yes No

14. What kind of volunteer services have you done? _____

Where? _____

15. What kind of volunteer services would you like to do? _____

16. What is desired schedule of services?

a. Contemplated duration of your offer of volunteer services:
1 to 3 mos. _____ 3 to 6 mos. _____ 6 to 12 mos. _____ Indefinitely _____

b. Time of day available:
Morning _____ Afternoon _____ Evening _____ All Day _____

c. Days of week available:
Sun. _____ Mon. _____ Tues. _____ Wed. _____ Thurs. _____ Fri. _____ Sat. _____

d. Schedule of visits:
Weekly _____ Monthly _____ Twice a mo. _____ Occasionally _____

17. Organization to receive credit? _____

Return to: _____

What Kinds of Work do Volunteers do?

1. They work in the following departments: social service, recreation, handicraft, ward services, beauty shop, barber shop, lab technology, sewing, tour guiding, clerical, and in the patient canteen (operated entirely by volunteer workers).
2. They serve as friendly visitors in foster, nursing and boarding homes.
3. They serve in individual homes as escorts, drivers, volunteer big Sisters (Brothers),
4. They plan and execute parties, social and recreational events.
5. They serve as tutors.
6. Sew, mend and sort clothes.
7. Write letters.
8. Read and tell stories to patients.
9. Take patients shopping, to games, parks, etc.
10. Teach organ and music lessons.
11. Conduct classes.
12. Work in the library, conduct tours, assist in medical records office, central supply office.
13. Assist with occupational therapy.
14. Give bridge, art, sculpture, cooking lessons.
15. Act as attendants for infants in transit.
16. Counseling in management and financial management.
17. Publicity.
18. Handle Boy Scout, Cub Scout, and Girl Scout programs.
19. Administer tests under direction of Psychology Department.
20. Conduct religious services.

Public Awareness

It is axiomatic that effective social action begins with heightened public awareness. Mental retardation is no exception. Rather, in the words of the American Association on Mental Deficiency,

Broad public awareness, understanding, and acceptance of mental retardation and its many personal and social implications are essential features of a community and state program for the retarded...First, without a recognition and acceptance of the needs of the retarded by at least a substantial part of the community, programs will not be provided...Second, if the retarded is to obtain community adjustment, a wide segment of the community must understand the nature of the difficulties which the retarded face and assume an understanding and accepting attitude...

A misinformed public...can drastically reduce the effectiveness of an enlightened scientific program of training and education...

Not only is there a need to inform the lay public about the nature of mental retardation, but, perhaps more important, the professional elements must become better informed. Public attitude as a whole suffers unduly when those persons whose work brings them in contact with the retarded and his family are poorly informed as to the essential facts of mental retardation and modern thinking as to what can be done to lessen the handicap. The physician, social worker, educator, lawyer, psychologist, nurse, clergy, all must know mental retardation and have an intimate knowledge of community resources available to the retarded.

The President's Panel states emphatically that educating the public

is vital to any real progress in every aspect of the retardation problem because public awareness plays a key role in helping to . shape the attitudes of legislators and potential workers in the field, as well as helping to stimulate community support and financial backing for the needed expansion and improvements necessary in a wide variety of programs,

but that

filling the needs of various professional groups for information and educational materials, and preparing and disseminating more general material for the benefit of special interest groups and lay publics, is a huge task.

Part of this task is being carried out nationally by the National Association for Retarded Children, the American Association on Mental Deficiency, the Council on Exceptional Children, and the U.S. Department of Health, Education and Welfare. This year the major health campaign conducted by the Advertising Council will be concerned with mental retardation. The campaign is jointly sponsored by the Department of Health, Education and the Joseph P. Kennedy, Jr. foundation, with

the NARC paying the cost of printing pamphlets distributed during the campaign. Every advertisement used in the campaign calls attention to "six things you can do now to help prevent mental retardation and bring new hope to the 51/2 million persons who are mentally retarded":

1. If you expect a baby, stay under a doctor's or a hospital's care. Urge all expectant mothers to do so.
2. Visit local schools and urge them to provide special teachers and special classes to identify and help mentally retarded children early in their lives.
3. Urge your community to set up workshops to train retardates who are capable of employment.
4. Select jobs in your company that the mentally retarded can fill, and hire them,
5. Accept the mentally retarded as American citizens. Give them a chance to live useful, dignified lives in your community.
6. Write for free booklet to President's Committee on Mental Retardation, Washington, D.C.

On the state and local level, the Jaycees, Mrs. Jaycees, and United Commercial Travelers have each taken mental retardation as a major project for the year. Other groups who concentrate considerable effort and resources here in Minnesota are Civitan, VFW auxiliary, American Legion auxiliary, and Epsilon Sigma Alpha philanthropic sorority.

Nevertheless only the surface has been scratched. Many people are not even sure what a mentally retarded person is.

The American public seems to lump all the mentally retarded into one commonly held stereotype: the person with absolutely not one whit of intelligence. Even the slightly retarded are thought of in this manner.

Intensive public information and re-education is needed before the negative failure stereotype concept of mental retardation is eradicated and the new positive hopeful approach is substituted. This will involve a public awareness of the new dimensions of mental retardation as a fluid, relative concept, rather than as a static, immutable one.

A 1962 survey of public information and attitudes sponsored by the Minnesota Association for Retarded Children revealed that, in a random sample of 900 respondents, most Minnesotans had a limited understanding of mental retardation. Only one person in ten demonstrated specialized information about retardation, as compared with one-fifth of the people who directly confused retardation with other mental and physical disorders. Further, many respondents were confused about the origins of mental handicaps and had little accurate information about physical and mental capabilities of retardates. Those who were able to relate mental retardation to some kind of mental sub normality displayed a superficial knowledge, "frequently made remarks indicating misunderstandings or vague suppositions." Nearly one-third of the people sampled could not identify a single state or local service for the retarded.

On the professional level, the situation is not too much better. Consider:

"Communicating information to the practicing physician is not... simple... Any educational effort faces the build-in resistance of many physicians, both because of their pessimistic attitude toward the disease in general and because of the personal feelings of anxiety and guilt such patients may arouse." (From the A.M.A. Conference on Mental Retardation, 1964)

"Employers with the highest levels of education tended to have the least favorable opinions of the job abilities of the retarded. The amount of factual knowledge employers had of mental retardation seemed to have little bearing on their attitudes toward the retarded. Somehow employers have to be made to feel that the retarded can work, and work well."

"The shortage of adequately trained teachers is a major deterrent to the expansion of programs for the retarded. Colleges training such persons report 10-20 positions available per graduate. At least 50,000 new teachers are needed. Three out of four retarded children are not in special classes due *in part* to lack of adequately trained teachers."

It is not surprising, then, that the task force on Public Awareness has decided to base its endeavors on two assumptions: (1) efforts to inform the public, or specific publics, about mental retardation up until now have not been too successful, and (2) better methods of communication must be devised. It was agreed that,

although what we want to communicate to what kinds of people must be carefully worked out, at this stage content is not as important as development of effective methods.

Members felt that it -was desirable for planning purposes to prepare an ideal, even utopian, public awareness and education campaign and to modify it later-if necessary-in line with practical considerations. The plan should be as specific and detailed as possible, with clearly stated directions for implementation. The project staff will at that point make every effort to locate resources with which to translate the plan into action after the termination of the planning year.

It was decided that, while it is certainly important to reach "the people," we would concentrate our attention first and foremost on specific professional publics. For one thing, the public as a whole is being approached through the national campaigns mentioned above. Second, we agree with the National Education Task Force that "intensive indoctrination for specific professional personnel would lay a broad base for future public education in this area." In the back of our minds, placed there by voluminous public opinion research, is the notion that,

It is a common mistake to think of the Public as one massive, monolithic assemblage. No money-spending, vote-casting, goods-buying unit of more than 100 million adult Americans waits as one vast audience to be molded into 'public opinion. (We the People' consist of many publics, of many kindred interest groups, and of unorganized groups with like and unlike preferences...

Accordingly, we have drawn up a tentative list of key professional publics as follows:

1. Physicians
2. Clergymen
3. Employers and labor representatives
4. Teachers of teachers) students will be
5. Teachers) dealt with here
6. Teachers of psychologists, social workers, and other members of service professions
7. School superintendents and administrators
8. School boards
9. Public health nurses
10. Public officials (especially county commissioners)
11. Lawyers and judges
12. Church groups throughout the state
13. Homemaker clubs (reached through extension division)
14. Parents not being reached
15. Volunteers
16. Non-white minority group representatives (particularly Indian)
17. Mass media

Our intention is to whittle this list down to a workable number of "priority publics," and to plan how to deal most effectively with each in the public education sphere.

Some of this information we seek is available in attitude surveys, public opinion literature, and books and articles concerning mental retardation; these the project staff is presently researching. Feed-back to the project staff from our other task forces concerning public education needs will likewise be incorporated into our assessment. The task force on Prevention, Diagnosis and Treatment has already given us a good idea of some of the needs of physicians, particularly in the areas of improved parent counseling and more informative education in mental retardation for physicians and medical students. For example, consideration is being given to development of a questionnaire which will "tell parents the right questions to ask doctors;" this would facilitate productive, anxiety-relieving communication between doctor and parent.

It was decided that the best way to canvass professional publics was to set up a series of information workshops at which leaders from various publics will speak to the sub-committee in a kind of round table discussion. We anticipate that a mutual "brainwashing" will take place.

We will try to find out from representative leaders of these key publics what their group knows about mental retardation; what kinds of information they need or wish to know; effectiveness of public education, past or present, in getting the message to them; how they can help us in evolving messages and methods; how we can best help them. It was pointed out that this type of involvement on the part of participating leaders would in itself be a potent beginning at fostering awareness and interest in the public which was represented. (The effect of "influential" in molding opinion within their groups has been well documented in public opinion research including the Minnesota A.R.C. attitude survey mentioned above.)

Because of their obviously crucial role with relation to the mentally retarded person and his family, physicians have been designated as our first key public. Three physicians—a pediatrician, a general practitioner, a university affiliated neurologist—will meet with us on February 18, 1965 for our first public information workshop. Such an exchange of ideas, carried on with a variety of professional groups, should result in a rich pool of knowledge. In this way a broad, but specific, basis for comprehensive planning will be created. This is our beginning.

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5. What facilities are there for diagnosis and how are they utilized?

6. Who refers patients for diagnosis? How is the referral channeled?

7. Who is responsible for counseling parents? What has been the personal experience of families with diagnosis and counseling?

8. Where do parents obtain continuing assistance in planning for the needs of their retarded child? What information do they feel they need?

9. Is counseling an integral part of the diagnostic process?

Volunteer Services and Public Awareness

1. What are the possibilities for volunteer services in the region,
and are they being used?

2. What are the problems involved, how serious are they, and how can
they be met?

3. What are the reactions of some of the volunteers to the way they were
recruited, the work they are doing, their relationship with professionals
the satisfaction and recognition of the work they are doing?

4. Each agency should be asked how they use volunteers, whether or not they could use them if they were available, and what kinds of jobs might they do? If this is done conscientiously, in view of the philosophy described, it would seem we would be able to have a pretty good picture of the need and extent of volunteer services in a community, and, at the same time, would serve as an instrument for stimulating further services.

5, How well does the public in your county understand the concept of mental retardation? How many people still think of the retarded as "sick?" What can be done to replace outmoded notions about mental retardation with a constructive attitude toward the retarded and his potential for growth?

6. To what extent are legislators kept informed about mental retardation—facts, problems, issues? How can they be persuaded to take a greater interest (visits, etc.) in various types of facilities for the mentally retarded? How can communications with them be expanded?

7. How well informed about mental retardation are the professional groups in your region? What specific publics need most to be focused on in a public awareness campaign? What do they need to know? How are they being reached? How can they be reached?

Education and Habilitation

1. What is the structure of special classes? What are their goals? Are special students integrated with the rest of the school population?

2. Are trainable children being accommodated in the school system?

3. What, if any, provision exists for preschool programs for the retarded?

4. To what extent are schools aware of employment possibilities for the retarded? Is there job follow-up after the individual leaves school?

5. Has consideration been given to work-training programs?

Residential Care

1. What is community attitude toward state and private institutions for the retarded?

2. Is there community understanding of their purpose and goals?

9. How many boarding homes are there in the county?
10. How many are available to serve the retarded?
11. Of what ages?
12. Are they short term or permanent?

Community Based Services

1. What programs exist which might offer service to the retarded, e.g.,
Boy Scouts, 4-H clubs, Sunday school classes, etc.?

2. Do these serve the retarded in the community? How many are served?
Are there special programs for the retarded?

3. What recreational facilities are available to the retarded? Who sponsors them?

4. Do daytime activity centers meet the standards suggested in the attached material?

5. Are more centers needed?

6. To what extent are other agencies and services being made aware of the needs of mentally retarded, e.g., old age programs, adult activity centers, etc?

SUBMITTED BY: _____
Address: _____

REGION: _____