Planning of Facilities for the Mentally Retarded

Report of the Public Health Service Committee on

PLANNING FACILITIES

for THE MENTALLY RETARDED

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE Washington, D.C.  20201
MAJOR PRINCIPLES for Planning and Programing

Facilities for the Mentally Retarded

• Planning of services and facilities should involve full participation of all agencies having a major responsibility to the mentally retarded or having a significant potential for contributing to an overall program. These agencies should include both governmental and voluntary organizations and groups.

• General community services and facilities should be available to the mentally retarded to the fullest extent possible and existing services suitable for the retarded should be identified and considered in the planning of needed additional services.

• Planning of services and facilities should be related to other forms of community planning and to social and economic trends.

• Planning agencies and organizations should stimulate the development of programs for the prevention of mental retardation.

• Adequate data should be developed to provide a base for developing services and facilities needed in the continuum of care, and planning should be based on total and complete needs of the retarded rather than on the availability of financial support.

• Where feasible and appropriate, existing facilities should be improved and new services and facilities planned should meet or exceed existing standards.

6 Facilities should be located so as to be readily accessible to the population to be served.
FOREWORD

THE BROADENING INTEREST in and community concern with mental retardation and the resultant need for action have been heightened during recent years by the 1962 report of the President's Panel on Mental Retardation and the enactment by the 88th Congress of two major pieces of legislation: The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P.L. 88-164) and the Maternal and Child Health and Mental Retardation Planning Amendments of 1963 (P.L. 88-156). This new legislation provides the mechanisms for action on a broad front through Federal grants for the development of a comprehensive State plan to combat mental retardation and for the construction of facilities for the retarded.

The Public Health Service has an important role in the crusade against mental retardation. To assist it in carrying out its responsibilities, the Public Health Service, in consultation with several constituent members of the Secretary's Committee on Mental Retardation, appointed a Committee on Planning Facilities for the Mentally Retarded. This committee recognized the urgent need for guidelines for planning and assumed three major tasks:

- to develop basic definitions of services and facilities needed by the retarded
- to establish principles for planning
- to outline procedures for planning

The results of the committee's deliberations are contained in this report.

The committee believes that this report will be of interest to State, regional, and community planning agencies; to administrative, professional, and policy-making personnel involved in planning, constructing, and operating facilities for the mentally retarded; and to public and private agencies and organizations concerned with the utilization of facilities. The State agencies having the responsibility for developing the State plan under provisions of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 will, it is hoped, find this report particularly helpful.

The committee gratefully acknowledges the assistance provided by many individuals. Personnel from the Children's Bureau, Office of Education, Public Health Service, Vocational Rehabilitation Administration, and the National Association for Retarded Children, Inc., were consulted frequently by the staff in the preparation of various sections of the report. Thanks are due also to many committee members who gave special assistance to the staff.

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Summary

Concepts in Planning

Effective planning of services and facilities for the mentally retarded involves the understanding and utilization of several basic concepts. Foremost among these is that opportunities must be provided for each retarded individual to attain his fullest potential. The achievement of this goal presupposes participation of the retarded in community services to the extent appropriate and practicable and, where specialized services are required, making such services available at the community level. Under this planning concept, the types of services and facilities currently available, as well as the number of persons served, must be known, since patterns of availability and utilization differ from community to community.

Services and facilities must be planned in terms of levels of retardation and age groupings since the needs of the retarded vary accordingly. Needs for services and facilities are also conditioned by many sociocultural and economic conditions. High risk areas, i.e., areas of low income and cultural deprivation, generally have a greater incidence of retardation than areas of above-average income levels. High risk areas, too, have less resources for maintenance and support of needed services and facilities. Planning must also take into consideration the availability of professional personnel to adequately staff needed facilities.

All planning programs should recognize the importance of preventive services in combating mental retardation and in ameliorating its effects. Programs for prevention should be correlated with programs for care and treatment to insure full utilization of community resources and the fullest effort in attacking and solving the problem. In planning, too, mental retardation and mental illness should be recognized as separate problems. At the same time, however, planning for services and facilities in both areas should be correlated as may be feasible.

Public and private agencies engaged in the planning of services and facilities for the retarded face many situations which tend to become barriers impeding the success and effectiveness of planning. Lack of precise data makes the establishment of benchmarks for measuring need a nebulous undertaking. Other barriers are a lack of standards for programming and the unavailability of certain services for particular levels of retardation and age groupings. When these situations are coupled with inadequate utilization of existing facilities, the resultant incomplete understanding and acceptance of mental retardation as a community responsibility tends also to be accompanied by inadequate financial support.

Services and Facilities for the Retarded

Planning efforts should result in the availability of an array of services and facilities providing a continuum of care for the retarded. Basic services in this array essential to this continuum of care include the following: • diagnostic and evaluation services. These serv-
ices involve the diagnosis and evaluation of the individual; the appraisal of resources of the individual, his family, and the community; and the development of recommendations for a plan to help the individual realize his fullest potential.

- **treatment services.** These services include medical and appropriate related ancillary services and therapies to provide for the improvement of the individual: physically, psychologically, and socially.

- **education services.** Curriculums of instruction geared to the needs of the retarded at various levels of retardation in different age groupings are the bases of education services.

- **training services.** Included in these services are training in motor skills, self-help, and activities of daily living; vocational training; and socialization experiences conducive to personality development.

- **personal care services.** Personal care services cover food, shelter, clothing, and medical care. Also included are special medical and nursing services directed at the prevention of regression in the retarded individual and stimulation of his maturation.

- **sheltered workshop services.** These services include vocational evaluation, training, and paid work experience.

The primary types of facilities needed to house the basic services described above include:

- **diagnostic and evaluation clinic:** housing diagnostic and evaluation services.

- **day facility:** housing treatment, education, training, personal care, or sheltered workshop services on less than a 24-hour-a-day basis.

- **residential facility:** housing treatment, education, training, personal care, or sheltered workshop services on a 24-hour-a-day basis.

- **group home facility:** housing services needed by retarded individuals capable of independent living under a minimum of supervision.

**Principles for Planning and Programing**

Among the more important basic principles which should be considered in the planning and programing of services and facilities for the mentally retarded are:

- Planning of services and facilities should involve full participation of all agencies having a major responsibility to the mentally retarded or having a significant potential for contributing to an overall program. These agencies should include both governmental and voluntary organizations and groups.

- General community services and facilities should be available to the mentally retarded to the fullest extent possible and existing services suitable for the retarded should be identified and considered in the planning of needed additional services.

- Planning of services and facilities should be related to other forms of community planning and to social and economic trends.

- Planning agencies and organizations should stimulate the development of programs for the prevention of mental retardation.

- Adequate data should be developed to provide a base for developing services and facilities needed in the continuum of care, and planning should be based on total and complete needs of the retarded rather than on the availability of financial support.

- Where feasible and appropriate, existing facilities should be improved and new services and facilities planned should meet or exceed existing standards.

- Facilities should be located so as to be readily accessible to the population to be served.

**Planning Procedures**

The primary responsibility for planning of services and facilities for the mentally retarded should be vested in a State planning organization. Local planning agencies should assist the State planning organization wherever possible; for example, by providing detailed information relative to local conditions. The planning of services and facilities for the mentally retarded should be consistent and in harmony with the basic principles in the State’s comprehensive mental retardation plan. Facility planning should also be correlated with State plans for the construction of community mental health centers and hospitals and related health facilities.

A wide variety of data are needed in the planning process. These data cover various facets of existing services and facilities as well as population and socioeconomic characteristics of service areas. Sources of information include
various departments of the State Government and national voluntary agencies maintaining programs for the retarded; local units of State agencies and national voluntary organizations; and local government, voluntary, and private groups.

The developmental nature of mental retardation, the wide spectrum of services required to provide a continuum of care, the prevalence of retardation, and the variation in levels of retardation and age groupings must all be considered in measuring the need for specialized services and facilities within a given geographical area. To these factors must be added the extent to which community health, welfare, and educational services and facilities are available for the retarded. Availability should be measured in terms of adequacy and appropriateness of the services and facilities for the retarded and the interest which community facilities have in serving the retarded along with other segments of the population. In measuring the need in both types of situations, prime decisions must be based upon the empirical knowledge and judgment of persons experienced in making these determinations. Statistical data serve primarily as points of departure for such evaluations.

Delineation of areas is essential for effective programing of services and facilities. These planning areas should be large because of the variations in geographical territory covered by different types of services and facilities. For example, a community residential facility will serve a much larger territory than a community day facility. In delineating areas, consideration should be given to population factors, availability of professional personnel, travel patterns, and travel time.

Limited funds make it imperative for the planning organization to establish a priority system for the construction of needed facilities. Chief reliance must be made on qualitative factors such as the availability of community services and community support for programs for the retarded; the relative need for specific specialized services; the extent of cooperation of services with other mental retardation facilities or programs; and the potential quality of programs to be provided.

Quantitative data include information on services and facilities available and the utilization of existing services and facilities. They also include information on the size of population group for which services are to be planned, the levels of retardation and age groupings to be served, and the socioeconomic and cultural characteristics of the service areas.

The planning organization has a responsibility for continuing interpretation of planning recommendations to public and nonprofit agency personnel and to government officials and civic leaders. The ultimate test of all planning of services and facilities for the retarded is the effectiveness of action taken on recommendations. In view of this, the recommendations must be understood by key leadership within the planning area and be capable of implementation within the resources of the area, both current and potential. Effective action on the recommendations of the planning group includes, among many things, the following:

- establishment of a realistic program to carry out recommendations
- gaining and maintaining full support of community and professional leaders
- securing and maintaining adequate and sound financial support
- developing professional staff necessary to provide quality services.
Chapter I

Need for Planning

The growing need for programs to serve the mentally retarded is stimulating increased demand for action at State, community, and regional levels. A sense of urgency accompanies the determination to have appropriate services and facilities available for all levels of retardation and all age groups and for a wider geographic coverage in a more balanced pattern of distribution. From this urgency stems a need for effective, realistic, and practical planning for the development of services and facilities for the mentally retarded.

Concepts in Planning

The prime objective of all programs for the mentally retarded is to provide opportunities for each individual to attain his fullest potential. In the planning of services and facilities, cognizance of this objective calls for the establishment of specific goals for each individual in each program, periodic reassessment of program objectives in terms of individual potentials, and a built-in flexibility within programs to permit quick and easy adaptation to changing requirements.

In light of the objective described above, planning should involve utilization of community services insofar as feasible and practical. The values accruing to the individual and his family make it desirable to encourage the inclusion of the retarded within the framework of community programs. The effectiveness of these programs will depend upon the degree of understanding of the special needs of the retarded and the consideration given to these special needs by personnel administering the programs.

To the extent appropriate and practicable, services and facilities should be planned for availability within the community. This permits utilization of family and community resources, helps sustain family interest in the individual, and facilitates assimilation of the retarded into normal patterns of community life. Efficient planning for the retarded within this community orientation calls for correlation with other community planning activities in the areas of health, education, and welfare to assure full utilization of available resources and to avoid duplication wherever possible.

Those planning services and facilities for the mentally retarded must bear in mind that not all new services or expansions of existing services will require added facilities. Frequently, additional programs can be housed within facilities currently in operation. Efficient planning entails careful analysis of the potentials of existing facilities to provide adequate functional space for new programs to be developed.

A comprehensive attack on mental retardation should include preventive services as well as care and treatment services. Prevention is the most effective means of reducing the prevalence of mental retardation. A significant proportion of
this handicapping condition results from situations which are preventable with good medical care. It is estimated that full application and utilization of existing knowledge through action on a broad front to correct adverse community conditions, combined with specific preventive measures would eliminate at least half of the new cases of mental retardation.

The planning of services and facilities for the mentally retarded calls for the recognition that mental retardation and mental illness are separate problems. Although the two problems are related in that they may on occasion occur in the same person and may involve some of the same kinds of professional skills in diagnosis and in the care of the individual involved, there are basic differences between them which necessitate the establishment of and adherence to different concepts and objectives in the planning process. Planning in both areas, however, should be correlated to the fullest extent possible to insure maximum use of available community resources.

Effective planning includes a realistic assessment of mental retardation needs and an analysis of needs in terms of services and facilities required. This assessment starts with an evaluation of the existing services and facilities available for the retarded, both specialized and general, in terms of their capacity and potentials. It includes the formulation of a specific plan containing recommendations for the development of needed additional services and facilities and the translation of these recommendations into action.

Stimulation of interest in the planning of services and facilities for the mentally retarded must come from the understanding, support, and leadership of professional groups involved in the field of mental retardation such as physicians, special education teachers, psychologists, social workers, and members of many other professions. These groups, in turn”, must evoke the participation of leaders in commerce and industry, labor, and other facets of community life.

Factors Affecting Planning

Planning of services and facilities for the mentally retarded is affected by a wide range of factors and conditions. Some of the more important are: Planning will be conditioned by the number of retardates residing within the planning area. The larger the number of retarded, the greater the prospective need for services and facilities. Hence, in "high risk" areas—those areas of low income, cultural deprivation, and high density of population—considerable need for services and facilities may be anticipated. Frequently, these areas will show a substantial deficit in existing services and facilities.

The types of services and facilities required will be influenced by the numbers of individuals in the various levels of retardation—mild, moderate, severe, and profound—and in age classifications such as children (preschool and school age) and adults. The availability of existing services and facilities for these levels as well as the total numbers of the retarded served, must be known in order to determine the services and facilities required to adequately meet total needs. For example, the planning area may contain facilities providing educational services for the mildly retarded of school age but no training services for the moderately retarded adult.

The degree to which existing community services are available to the retarded will also have an impact on the planning of services and facilities. Most planning areas will have some type of generic services and facilities open to the mentally retarded. Efficient and realistic planning will necessitate identifying these services and facilities and analyzing programs which they provide, in terms of the total needs of the retarded individuals in the area.

Finally, planning for the retarded will be influenced by the range of specialized services and facilities currently available; the extent to which, when correlated with generic services, these complete the spectrum of needed programs; and the acceptance and support which they enjoy within the community or planning area. The planning of needed specialized services and facilities capable of maintaining quality programs requires public understanding and backing such as that accorded generic services.

Many barriers must be faced in planning services and facilities for the retarded, however. A few of them are mentioned below. For example, the availability of services and facilities does not necessarily imply adequate utilization; significant problems arise in bringing services and clientele together. Avoiding unnecessary service duplications and overlapping may also prove difficult. Furthermore, standards for programming have not been developed to insure adequate services for some levels of retardation or age groups. Techniques are not yet available
for estimating potential caseloads and evaluating demographic, cultural, and economic change.

Other problems have come to the forefront as the mental retardation horizon widens. Among these are the extent to which a given facility actually serves the needs of the area it is intended to serve, and its flexibility to meet a variety of changes. In addition, those planning for the development of services and facilities for the mentally retarded in required quantity face shortages of qualified personnel, problems of financial support, and the incomplete understanding and acceptance of mental retardation as a community problem.

Characteristics of the Mentally Retarded

From a medical point of view, "mental retardation" is not a disease entity. It is a syndrome which can be produced by many causative agents acting singly or in combination. Symptomatically, it is characterized by delayed or atypical developmental patterns accompanied by impairment of general adaptation. From an educational point of view, the mentally retarded child is characterized by subnormal intellectual function to an extent which prevents him from responding efficiently to the usual patterns of classroom instruction. From a social standpoint, the retarded child is slower in maturing and acquiring social and practical skills; as an adult, the retardate has less than the normally expected ability to manage his affairs and to progress in gainful employment.

Many definitions of mental retardation have been formulated. The one currently accepted by the American Association on Mental Deficiency is: "subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior." * "Mental retardation" thus encompasses a wide range of deviance, from minimal to profound. The distinction between normality and the mildest degree of mental retardation is arbitrarily denned. Mildly retarded persons are more comparable to those who are normal than they are to the most profoundly retarded. For this reason, although there are many more near-normal retarded than profoundly retarded, fewer specialized services and facilities are required for the mildly retarded.

1 See item 2, Suggested Reading List.

Generally speaking, categories of services are established according to the practical level of functioning and age, rather than the cause of retardation. Nevertheless, etiology may have to be considered in the specifics of treatment or education for a particular individual. Practical distinctions must, therefore, be based on extent of impairment, taking account of the various factors which contribute to intellectual and social functioning. The manifestations of these levels of function change with age. These are indicated in abbreviated and qualitative form in chart I (p. 4). Further descriptive material is presented in the section on measuring need which appears in chapter IV.

Scope of the Problem

As stated above, mental retardation is defined as impairment of ability to learn and to adapt to the demands of society. These demands are not the same in every culture. Even within our own society they vary with the age of the individual. Society as a whole does little to assess the intellectual or social accomplishments of the preschool child. During the school years, however, the individual is evaluated very critically in terms of social and academic accomplishment. In later life, the intellectual inadequacy again may be less evident if social performance meets minimal demands. Numerous surveys directed toward determining the frequency and magnitude of the problem of mental retardation have shown that the number of individuals reported as retarded is highest during the school years. Less than one-fifth as many children in the age group 04 were reported by these surveys as mentally retarded as were reported in the age group 10-14. Similarly, only one-fourth as many persons in the age group 20 and over were identified as mentally retarded as in the age group 10-14.

This variation by age is to some extent determined by differential survival rates and other demographic factors. The very high prevalence at ages 10 to 14 is due primarily to the increased recognition of intellectual handicap of children within the school systems, while the low number of infants from 0 to 1 year of age identified as retarded is in part attributable to the fact that their intellectual deficit is not yet apparent. Of striking significance is the fact that
Chart I.—Developmental Characteristics of the Mentally Retarded

<table>
<thead>
<tr>
<th>DEGREES of Mental Retardation</th>
<th>PRESCHOOL AGE 0-5 Maturation and Development</th>
<th>SCHOOL AGE 6-20 Training and Education</th>
<th>ADULT 21 and over Social and Vocational Adequacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROFOUND</td>
<td>Gross retardation; minimal capacity for functioning in sensorimotor areas; needs nursing care.</td>
<td>Some motor development present; may respond to minimal or limited training in self-help.</td>
<td>Some motor and speech development; may achieve very limited self-care; needs nursing care.</td>
</tr>
<tr>
<td>SEVERE</td>
<td>Poor motor development; speech is minimal; generally unable to profit from training in self-help; little or no communication skills.</td>
<td>Can talk or learn to communicate; can be trained in elemental health habits; profits from systematic habit training.</td>
<td>May contribute partially to self-maintenance under complete supervision; can develop self-protection skills to a minimal useful level in controlled environment.</td>
</tr>
<tr>
<td>MODERATE</td>
<td>Can talk or learn to communicate; poor social awareness; fair motor development; profits from training in self-help; can be managed with moderate supervision.</td>
<td>Can profit from training in social and occupational skills; unlikely to progress beyond second grade level in academic subjects; may learn to travel alone in familiar places.</td>
<td>May achieve self-maintenance in unskilled or semiskilled work under sheltered conditions; needs supervision and guidance when under mild social or economic stress.</td>
</tr>
<tr>
<td>MILD</td>
<td>Can develop social and communication skills, minimal retardation in sensorimotor areas, often not distinguished from normal until later age.</td>
<td>Can learn academic skills up to approximately sixth grade level by late teens. Can be guided toward social conformity.</td>
<td>Can usually achieve social and vocational skills adequate to minimum self-support but may need guidance and assistance when under unusual social or economic stress.</td>
</tr>
</tbody>
</table>


More than half of the individuals considered retarded during adolescence are no longer so identified in adulthood.

In view of these considerations, only gross estimates of the overall magnitude of the problem can be established. One such estimate may be derived through measures of intelligence. The numbers who are mentally retarded by this criterion can be calculated roughly on the basis of the experience with intelligence testing. Experience has shown that virtually all children with I.Q.'s below about 70 on most tests standardized nationally have significant difficulties in learning and in adapting adequately to their environment. About 3 percent of the school-age population score below this level. Based on the figure of 3 percent, it is estimated that about 5.6 million people in the United States are mentally retarded.
Chapter II

Services and Facilities for the Mentally Retarded

The mentally retarded require an array of services that provide a "continuum of care" or "spectrum of opportunity" for all levels of retardation and for all age groups. To meet the needs of the retarded as shown in chart I (p. 4) and also provide a continuum of care, a wide variety of patterns of services have been developed. Chart II (p. 6), taken from the Report of the President's Panel, shows both the variety and range of representative services needed by the retarded. Some of these services embody old traditional approaches to the problems of mental retardation, while others are comparatively recent developments.

To achieve a continuum of care requires an overall program of direct services covering: (1) identification and diagnosis; (2) treatment; (3) education; (4) training; (5) personal care; (6) placement and guidance; and (7) protective supervision. Once the problem is identified, all the essential elements of a complete program should be available either within the framework of existing generic services or as specialized services. All services should be correlated to provide maximum efficiency and use of available financial and personnel resources, to insure full coverage of needs of the retarded.

Among the more important services required by the mentally retarded in an overall program are the following:

Diagnosis (and evaluation)

Coordinated medical, psychological, and social services, supplemented where appropriate by nursing, educational, or vocational services and carried out under the supervision of personnel qualified to: (1) diagnose, appraise, and evaluate mental retardation and associated disabilities and the strengths, skills, abilities, and potentials for improvement of the individual; (2) determine the needs of the individual and his family; (3) develop recommendations for a specific plan of service to be provided with necessary counseling to carry out recommendations; and (4) where indicated, periodically reassess progress of the individual.

An adequate and thorough diagnosis and evaluation of all retarded persons is essential to the proper planning of individual programs to meet particular and specific needs. Both short-term and long-term planning for treatment,
## Chart II.—Array of Direct Services for the Retarded

<table>
<thead>
<tr>
<th>Life stage</th>
<th>Components of special need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant</td>
<td>Specialized medical follow-up . Residential nursery</td>
</tr>
<tr>
<td></td>
<td>Special diets, drugs or surgery . Sensory stimulation . Child welfare services . Home training</td>
</tr>
<tr>
<td></td>
<td>Home nursing . Environmental enrichment</td>
</tr>
<tr>
<td>Toddler</td>
<td>Correction of physical defects . Foster care . Nursery school . Physical therapy . Trained baby sitter</td>
</tr>
<tr>
<td></td>
<td>Classes for slow learners . Playground programs . Environmental enrichment</td>
</tr>
<tr>
<td></td>
<td>Boarding school . Speech training . Vocational counseling—Personal adjustment training</td>
</tr>
<tr>
<td></td>
<td>Selective job placement . Total disability assistance . Life annuity or trust</td>
</tr>
<tr>
<td></td>
<td>Bowling . Sheltered workshops . Guardianship of property . Life annuity or trust</td>
</tr>
<tr>
<td></td>
<td>Old age assistance . OASI benefits</td>
</tr>
<tr>
<td>Older adult</td>
<td>Medical attention to chronic conditions . Evening school . Social supervision .</td>
</tr>
</tbody>
</table>

1 Not included are diagnostic and evaluation services, or services to the family; the array is set forth in an irregular pattern in order to represent the overlapping of areas of need and the interdigitation of services. Duration of services along the life span has not been indicated here.

training, education, and personal care or supervision of the individual and counseling of his parents is dependent upon the quality of diagnosis and evaluation services provided for him. Hence, diagnostic and evaluation services are the keystone to the development of a complete array of services in any community or region.

Resources contributing to comprehensive diagnostic services for the retarded may be available from a variety of sources: physicians and other professional personnel in private practice; general clinics in medical centers and teaching hospitals; mental health centers; public health department clinics; and outpatient services of residential facilities for the retarded. In many areas, the spectrum of services required to provide complete diagnosis and evaluation may be dispersed among several organizations and agencies. For example, early identification of retardation may come from teachers in the public schools or from school psychologists, while such services as counseling may come from public and private agencies.

Mental retardation is frequently complicated by problems of associated physical disabilities, emotional disturbances, sensory defects, and the like. The existence of these correlative conditions emphasizes the need for comprehensive diagnosis and evaluation prior to the development of individual programs for treatment, education, training, personal care services, or sheltered employment.

**TREATMENT SERVICES**

*Services under medical direction and supervision providing specialized medical, psychiatric, neurological, or surgical treatment, including, where appropriate, dental therapy, physical therapy, occupational therapy, speech and hearing therapy, or other related therapies which provide for improvement in effective physical, psychological, or social functioning of the individual.*

The inclusion of the full range of specialized medical and related services contained in the definition above is predicated on the concept that the retarded will require the same basic medical care as the non-handicapped. The importance of developing and maintaining adequate treatment services for the retarded is also emphasized by the fact that a significant portion of retardates have associated disabilities such as impaired hearing, difficulty in perceiving, impaired vision, poor muscular coordination, and physical deformities. Increased survival rates will probably increase the number of retarded persons with associated physical handicaps in the future.

**EDUCATIONAL SERVICES**

*Services, under the direction and supervision of teachers qualified in special education, which provide a curriculum of instruction for preschool children, for school-age children, or for the mentally retarded beyond school age.*

The basic functions of educational programs for children of preschool age are to develop basic self-help skills such as dressing and grooming, develop preacademic skills, provide socialization and group training, and promote environmental enrichment for the culturally deprived to improve intellectual experience and motivation. Educational services for the retarded of school age encompass a curriculum of instruction for those unable to keep abreast of a normal public school program. The content of such a curriculum must relate to the capacities of the individuals whom it is to serve.

Many retardates are able to go from school to some type of employment without great difficulty. Others need postschool vocational training services for placement in the economic life of the community. A large number of these retardates have associated personal, social, and physical handicaps. These require specialized training under qualified personnel to develop the skills which will enable them to engage in competitive or sheltered employment.

Vocational training for older youth and adults includes vocational evaluation, counseling, systematic planned instruction for sheltered or competitive employment, placement, and followup services carried out under the supervision of personnel qualified to direct these services.

**TRAINING SERVICES**

*Services which provide (1) training in self-help and motor skills, (2) training in activities of daily living, (3) training in useful occupational skills, (4) opportunities for personality development and social skills, or (5) experiences conducive to social development, and which are*
carried out under the supervision of personnel qualified to direct these services.

This broad definition of training services also includes group activity services, as well as group home and halfway house services.

Group activity services are defined as: Coordinated programs of diversified activities providing opportunities for individual learning and participation including recreational activities.

Group home or halfway house services are defined as: Supervised housing arrangements which may include counseling and group activities for small groups of mentally retarded individuals capable of relatively independent living or for individuals needing opportunities to become oriented to community life.

Training services must be developed for a wide range of levels of retardation and for all age groupings. For example, training services for those in the lower levels of retardation should provide opportunities for the development of behavior patterns, self-care skills, social skills, health habits and attitudes, money management, and many others. Training may be provided on an individual or group basis. For instance, for the young retarded child home training programs are desirable to assist the mother in developing techniques and sequences of activity which contribute to self-help, motor development, and the like.

Training programs must be compatible with the present developmental levels, learning characteristics, and potentials for future development of the retardates involved. For the younger retarded person, training programs usually emphasize self-help, basic communication, and interpersonal skills. For the older or more capable individual, training programs will generally stress activities which provide opportunities to acquire skills enhancing participation in family, community, and economic life. Training services may include programs for adults who have completed various types of educational programs available during the school-age years but who are too handicapped to be acceptable in a vocational training or sheltered workshop program.

PERSONAL CARE SERVICES

Services which provide personal care (including food, shelter, and clothing), and special nursing and medical care directed at the prevention of regression and the stimulation of maturation.

Personal care services involve much more than programs designed solely to furnish food, clothing, and shelter. These services should only be maintained where treatment, education, and/or training services are provided within the same facility in order to bring the individuals involved to a higher level of function.

SHELTERED WORKSHOP SERVICES

Services involving a program of paid work which provides (1) work evaluation; (2) work adjustment training; (3) occupational training; and (4) transitional or extended employment and which is carried out under the supervision of personnel qualified to direct these activities.

Sheltered workshop services have two major aspects: transitional employment and extended employment. In transitional employment, the major goal is eventual placement in community employment. Such a program gives considerable emphasis to training, evaluation, and placement programs as well as to actual employment activities. In the extended employment program, the emphasis is upon a broad range of work activities for those who cannot function satisfactorily in competitive employment.

There are certain advantages in providing the mentally retarded with sheltered workshop services in programs which include other handicapped individuals. For some of the mentally retarded, such programs can permit broader opportunities for socialization experiences and widen the range of job contracts that can be fulfilled. These benefits can be realized, however, only if the staff of the multipurpose workshop recognizes the special needs of the retarded, particularly the longer training time frequently required.

In addition to the services defined above, many supplementary services are essential to the care and treatment of the retarded. Generally speaking, these services are components of generic community services available to the retarded and his family, as they are to any other individual or group within the community. Among these services are: preventive medical services, public health nursing, casework, counseling, homemaker services, foster home care, income maintenance services, legal aid services, and many others. Since these services are available to the total
community, they will usually be housed in the community facilities maintaining these programs. Occasionally it may be desirable, however, to provide housing of one or more of these services within a specialized facility for the retarded, particularly if the services are established primarily for that group.

Facilities

Although the various services for the mentally retarded, as described above, may be housed in many kinds of facilities, four major types may be distinguished.

**Diagnostic and Evaluation Clinic**

A facility housing coordinated medical, psychological, and social services, supplemented where appropriate by nursing, educational, or vocational services and carried out under the supervision of personnel qualified to: (1) diagnose, appraise, and evaluate mental retardation and associated disabilities and the strengths, skills, abilities, and potentials for improvement of the individual and his family; (2) determine the needs of the individual; (3) develop recommendations for a specific plan of services to be provided with necessary counseling to carry out recommendations; and (4) where indicated, periodically reassess progress of the individual.

Diagnostic and evaluation clinics may be operated as a part of or be associated with such facilities as a medical teaching center, a mental health facility, a general hospital, a residential or day facility for the mentally retarded, a public health center, or a State agency, or may be freestanding. Insofar as possible, diagnostic and evaluation clinics should be planned in proximity to general diagnostic services so as to avoid duplication and to assist in the recruitment of professional personnel. In many communities it is necessary to obtain diagnostic and evaluation services by utilizing the services of several different agencies or practitioners. To make effective use of such resources requires a high degree of cooperation among the agencies involved.

**Day Facility**

A facility housing treatment, educational, training, personal care, or sheltered workshop services on less than a 24-hour-a-day basis.

Day facilities provide many benefits to the retarded person, his family, and his community. Significant among them are: participation in supervised programs formally developed to meet individual needs, and maintenance of a controlled environment in which appropriate habit formation is a basic goal. These facilities also provide a wider range and type of experience than can be developed within the family. At the same time, the values of continuing participation in family life are retained. By using day facilities, parents are afforded some relief from the 24-hour task of care and, through participation in parent-counseling programs offered by such facilities, can obtain a better understanding of the problems of the retarded. Thus, day facilities make it possible to keep the retarded at home and in the community.

**Residential Facility**

A facility housing treatment, educational, training, personal care, or sheltered workshop services on a 24-hour-a-day basis.

Residential facilities have a long history of providing services for the mentally retarded. In the process of their development, they have changed from being largely custodial institutions to facilities maintaining broad-gaged programs. These programs include services for the severely retarded and totally dependent as well as services for the retarded who cannot be maintained in the home or community because of emotional or behavior problems. Residential facilities also meet the needs of communities unable to financially support the services required by the retarded or in which placement in generic services or facilities such as foster homes is impractical or inadequate.

**Group Home Facility**

A facility which provides housing services, personal counseling services, and group activity services for individuals capable of personal self-care and requiring only moderate or minimum supervision.

The major function of group home facilities is to provide opportunities for as much independence of living as can be maintained within a program framework which unobtrusively provides or makes available the services needed to sustain independence. These facilities may be satis-
factorily developed as homes for the adult retarded, young or old, living and working in the community. They may also be developed as halfway houses for the retarded in transition from residential to community life. These facilities may be established as freestanding institutions, independently owned or operated. Or they may be administratively associated with a residential facility, a day facility providing comprehensive services, or a State agency having administrative responsibility for programs for the mentally retarded.

Some of the varied patterns in which services and facilities needed by the mentally retarded may be combined are visualized on chart III below, adapted from the Report of the Task Force of the President's Panel on Mental Retardation dealing with Prevention, Clinical Services, and Residential Care.

Chart III.—Table of Community Care Services

<table>
<thead>
<tr>
<th>Home care 1</th>
<th>Home care 2</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care</td>
<td>+ Social worker and/or public health nurses visiting in home.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Treatment center.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Night care.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Day nursery.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Public school (special education).</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Special school (community).</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Training center.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Sheltered employment.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Competitive employment.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Recreation (activity) center.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Weekend residential care.</td>
<td></td>
</tr>
<tr>
<td>Home care</td>
<td>+ Residential care during parental vacation or illness (short-term care).</td>
<td></td>
</tr>
<tr>
<td>Boarding school or preschool+Home care—weekends.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boarding school or preschool+Home care—vacations.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group home (for adolescent + With or without employment or adult)</td>
<td>Residential sheltered employment+Home care—weekends and</td>
<td></td>
</tr>
<tr>
<td>Residential hospital vacation.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living+Occasional home visits.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living+Sheltered employment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living+Supervised employment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living+Recreational (activity) center.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living+0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 May exist or be planned in multiple combination.
2 Own home or foster home.
PLANNING OF SERVICES and facilities is a process through which all factors relating to the needs of the mentally retarded can be identified and considered as an integrated whole. In this process, adherence to basic principles is a fundamental requirement. These principles must be realistic, timely, and most important, productive of tangible results. The process necessitates definition of the nature and scope of the problem as manifested locally. It calls for awareness of the resources available to deal with the problem and identification of those aspects of the problem that remain to be solved. The process also enlists services and skills of professional and community leaders, including those with particular interest in the mentally retarded.

Planning affords opportunities for developing greater awareness of the needs of the retarded and for stimulating the action necessary to achieve a comprehensive pattern of services for them. Effective planning cannot be done in isolation. Plans for the development and coordination of appropriate resources must relate to other planning efforts and to other health, education, and welfare activities in the planning area. These efforts and activities have an important bearing on the need for services and facilities for the mentally retarded.

Principles sufficiently broad to encompass the needs of the mentally retarded, yet consonant with the cultural and economic patterns of the areas to be served, should be formulated. Factors to be considered include the types of services and facilities best suited to meet the particular needs of the retarded within these areas, based upon the best knowledge available, the feasibility of providing these services and facilities within the limitations of existing and anticipated community resources, and the degree to which acceptance and support can be expected.

Planning must address itself to the balancing of conflicting objectives. For example, the objective of making maximum use of scarce professional talent may be in apparent conflict with the objective of bringing services close to the homes of retarded individuals. The process of planning should be organized to identify explicitly and weigh the relative importance of such factors in a particular situation.

Once these basic determinations have been made, the development of the definitive plan to achieve specified objectives should take into account the following principles:
1. Planning of services and facilities for the mentally retarded should involve full participation of any governmental, voluntary, or other agency having a major responsibility to the mentally retarded, to the end that effective coordination be achieved. Any agency or group which is considered to have a significant potential for contributing some element to the overall program for the retarded should also be encouraged to participate in the planning process.

Only through coordinated effort can adequate programs providing the widest possible services be developed. In addition, effective use of available funds to support construction and operation of needed facilities and services can be fostered through cooperation and participation of all interested agencies and organizations in planning to meet the needs of the retarded. The extent of involvement will necessarily reflect the degree of responsibility and commitment of the particular agency toward the retarded.

2. General community services and facilities should be available to the mentally retarded to the fullest extent possible.

Many of the medical, health, educational, and social service needs of the mentally retarded are similar to those of the general population, and maximum use should be made of general services which meet such needs. In many cases, the usefulness of these services can be extended and enhanced with the advice of a person having special knowledge of the character and needs of the retarded, or through some minor modification of procedure. To the extent that general services and facilities are thus made more widely useful and adapted to the special needs of the retarded, it will be possible to avoid capital outlays and operational costs for separate services and facilities. Moreover, available professional staff, in many areas a scarce commodity, is utilized more fully.

Such provisions, however, do not obviate the need for certain specialized services and facilities. Even when maximum adaptation of general services has been achieved, there will remain in any community or area certain needs which can and should be met by services especially designed for the mentally retarded, either in association with other services or "freestanding."

3. Existing services suitable for the retarded (whether general or specialized) should be identified and considered in relation to one another; priority should be established for the organization of new services to complete the array necessary for a comprehensive program.

Since the needs of the retarded vary widely, planning agencies should recognize that a wide range of services will be required.

4. Planning of services and facilities for the retarded should be related to other forms of community planning and to social and economic trends.

The development and utilization of services and facilities for the retarded will be affected by many aspects of community life, such as trends in population growth, shifts in age composition, and changes in land utilization and patterns of commercial and industrial growth. The demand for services and facilities for the retarded may also be influenced by any shift in the content of programs of other health, education, and welfare agencies. Practical and realistic planning calls for an understanding of all potentially influencing factors.

5. Planning agencies and organizations should stimulate the development of programs for the prevention of mental retardation concurrently with programs providing facilities and services for the retarded.

The extent and impact of mental retardation can be minimized through preventive measures. Such programs as those providing maternal and child care, particularly in "high risk" areas, and programs for early diagnosis, evaluation, and case finding can do much to lessen the incidence of retardation. Through preventive programs, even today, individuals can be spared much mental and, frequently, physical damage, and their families will be spared great emotional stress. The cost of preventive programs will be far less than the total cost of providing the spectrum of facilities and services needed for those who might otherwise be retarded.

6. Adequate data should be developed to provide a base for projecting the extent, character, and location of services and facilities which will be needed.

The soundness of quantitative decisions and the effectiveness of evaluative interpretations in planning services and facilities for the mentally retarded are contingent upon the adequacy of available data. The development of long-range goals depends on knowledge of the broad needs. To proceed toward these long-range goals, the
planning body needs to project in detail the immediate steps to be taken. This requires data about needs, such as general information regarding number and distribution of retarded children under school age whose families could and would avail themselves of a nursery school situation, or the number of adult retardates who could be maintained in the community with minimal social supervision, for the lack of which they would be admitted to 24-hour residential care. The capacity of each existing service should be compared to the extent of need for that type of service.

Need should be distinguished from demand, however. Demand should be assessed with special reference to the way in which the existing service is perceived by those whose needs it is intended to meet. It is well-known that a good service tends to call forth the expression of need through demand for the service, whereas a poor service suppresses demand even where need exists.

In addition, the data should (1) provide criteria for interpreting potentials for expansion and upgrading of existing facilities and services, and (2) permit determination of resources available within the area to maintain quality programs at efficient levels.

7. **Planning should be based on the total and complete needs of the mentally retarded for services and facilities rather than on the availability of financial support.**

The primary objective in planning services and facilities should be consideration of the total and complete needs of the mentally retarded. The recognition of these needs should not be limited by existing policies of governmental or sponsoring agencies or the funds available. Priorities for meeting these needs must be established, and this involves the development of both long-range and short-range goals.

8. **Short-range planning involves the selection of the higher priorities in the long-range plan.**

Factors influencing the selection of high priority activities for inclusion in the short-range plans include urgency of needs and feasibility of meeting these needs quickly. Feasibility, in turn, is influenced by available resources of facilities, funds, personnel, leadership, and public acceptance. Attention should be given to cultivation of community resources through continuing involvement of community leaders and groups in the planning process. Short-range steps should not be taken which tend to defeat long-range goals.

9. **Where feasible and appropriate, existing facilities should be improved.**

A detailed evaluation of the effectiveness and efficiency of existing services and facilities should be an integral part of all planning activity. This evaluation should cover effectiveness of program, adequacy of staff, relation of size to objectives, suitability of structure and location, and potential for improvement or adaptation. New services may often be added to existing facilities rather than being established independently. Oversized institutions may often advantageously be reduced in capacity or made more versatile in their services. All such possibilities should be carefully weighed during the planning process.

10. **Facilities and services for the mentally retarded should be planned to meet or exceed existing standards.**

Facilities should be planned to meet or exceed any generally accepted minimal requirements which may already exist for accreditation, eligibility for licensure, or grants-in-aid or loan programs. If the accreditation or licensure standards are lacking or inadequate, the support for their development should be stimulated.

11. **As far as practicable, facilities for the mentally retarded should be located so as to be readily accessible.**

To the extent appropriate and feasible, services and facilities for the mentally retarded should be planned so as to be accessible to the population to be served and to professional staff. Travel time and expense for the retarded should be minimized, especially where daily travel is involved. Residential facilities should be located where families may visit easily. Careful consideration should also be given to the distribution pattern of needed professional personnel and the factors which attract and hold staff.

The location of facilities should be planned to permit effective coordination and interrelationships with other related health, education, and welfare services. Decisions on the location of facilities should be based not only on the present distribution of population but also on a consideration of population trends and growth and projected development of transportation systems.
To provide opportunities for research and training of personnel, the potential for productive interaction between facilities for the retarded and the higher education system should be cultivated. Accessibility of such resources will contribute notably toward the primary purpose of bringing the best possible service to all the retarded in the State in a community setting.

12. Projected needs for continuing inservice training of personnel should be explicitly considered as part of State and community planning for the retarded.

Some centralization of such training may be advantageous. Proximity to existing schools, colleges, and universities is a relevant factor. In any case, the possible need for suitable space for training activities in appropriate facilities should be considered.

13. Planning groups should develop procedures to evaluate their activities on a continuing basis.

By the process of continual evaluation, overall needs will be kept in constant focus and changes can be made whenever justified. This will also contribute to new and more effective means of meeting needs, particularly as consideration is given to new knowledge. Planning bodies should be alert to the significance of lessons to be learned from experience in other communities and in other areas of the country, as well as from their own activities. Pull use should be made of resources which may be mobilized from beyond the area directly under study.

The development of such procedures to evaluate their own activities will assist planning groups in withstanding undue influence by special interests, whether they are professional, religious, civic, or proprietary. It will also help restrain any tendencies toward rigidity on the part of planning personnel, especially in dealing with long-range plans. The planning process should be responsive to changing conditions.
Chapter IV
Planning Procedures

Planning services and facilities for the mentally retarded is a continuing process, oriented toward the attainment of both short-term and long-term goals. In this orientation short-term goals become the focal point of immediate action, the objectives of current programing within the limits of available financial and personnel resources. Long-term goals reflect overall needs toward which all action should be directed and encompass the full range of services and facilities required by the retarded. Thus, a plan for the construction of facilities for housing services for the mentally retarded must be conceived and developed as a flexible mechanism amenable to changes in concepts of treatment and care and also to changes in characteristics and needs of the population to be served.

Coordination of Planning Activities

A State plan developed in response to Public Law 88-164, the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, for the construction of facilities to house services for the mentally retarded should be consistent with the State's comprehensive mental retardation plan developed under Title XVII of the Maternal and Child Health and Mental Retardation Planning Amendments of 1963, P.L. 88-156. The basic concepts and goals for the development of needed services and facilities should be, to the extent practicable, the same in both plans.

Since planning for community facilities for the mentally retarded, community mental health centers, and hospitals and related health facilities present separate and distinct problems in most planning areas, it is essential that the planning efforts in each program be separate activities. However, the State plans for the construction of facilities for each of these programs should be correlated so as to more nearly assure efficient use of capital and other resources and to minimize unnecessary duplication of services and facilities. In addition, the planning of community facilities for the retarded should be correlated with the program for the construction of university-affiliated facilities for the mentally retarded, which authorizes project grants for facilities for clinical training of physicians and other specialized personnel in the field of mental retardation or for the demonstration of special services.²

Planning Organization

RESPONSIBILITY FOR PLANNING

The primary responsibility for planning services and facilities for the retarded should be vested in a State agency for several reasons. First, the geographic areas served by each of the various types of facilities required for the mentally retarded are not identical. For example, a diagnostic and evaluation clinic will ordinarily serve a larger geographic area than a day facility providing training services.

Second, a State agency will be aware of the broad considerations which must be given to major socioeconomic, cultural, and population problems in the planning of services and facilities for the retarded. Such factors as the impact on planning of "high risk" areas—areas of poverty and cultural deprivation—and metropolitan areas encompassing several political subdivisions can better be evaluated on a statewide basis than on a local or community basis.

Third, the legislation enacted by the 88th Congress authorizing Federal aid to assist in constructing facilities for the mentally retarded requires that a single State agency be designated to administer the program in each State. This agency is responsible for, among other things, the development of a State plan for constructing specially designed facilities for the retarded. This plan is to be directed toward the provision of services for all retarded within the State. To accomplish this objective, the State agency must inventory existing services and facilities throughout the State, evaluate this information, and develop a construction program designed to provide the additional services and facilities needed. Furthermore, statewide plans must be modified each year, as necessary, to assure a continuing program geared to changing concepts and needs.

Public Law 88-164 calls for the appointment of an Advisory Council to the State agency which shall include representatives of the following: (1) State agencies concerned with planning, operation, and utilization of facilities for the retarded; (2) nongovernmental organizations concerned with education, employment, rehabilitation, welfare, and health; and (3) consumers of services provided by mental retardation facilities. For effective planning of services and facilities for the retarded, the State Advisory Council for the mental retardation construction program should, in the opinion of this Committee, be separate from the State Advisory Council for the community mental health centers construction program and from the State Council for the Hill-Burton program.

LOCAL PARTICIPATION

The development of effective services and facilities for the mentally retarded also requires planning at the local level within the framework of statewide planning. From this local planning, based on first hand knowledge of various factors, can come concrete proposals for the upgrading or expansion of existing programs, services, and facilities or for the establishment of new services and facilities. Local planning activities have three functions: (1) to develop basic detailed data regarding the mental retardation needs in the local area, following methods and procedures set up by the State planning agency; (2) to make recommendations to the State agency and its Advisory Council regarding courses of action to meet local needs; and (3) to assist the appropriate State agency in locating sponsors to carry out recommendations.

ADEQUATE STAFFING ESSENTIAL

Adequate staff for the planning agency is essential to efficient planning of services and facilities for the mentally retarded. Of prime importance is the availability of professional personnel: (1) skilled in the various techniques of planning services and facilities to meet areawide needs; (2) with an understanding of the problems faced by the mentally retarded; and (3) with the ability to translate this knowledge into a program of action. In addition to the professional staff, the planning organization should have access to experienced consultants. Qualified consultants may be found among professional personnel of established facilities and from organizations and agencies involved in the planning of medical, educational, vocational, and related health and welfare services for the retarded.

Obtaining Needed Data

Projecting the need for services and facilities for the mentally retarded, whether on a state-
wide or local basis, will necessitate the collection and evaluation of all available data regarding existing programs. The data collected must include estimates of the number of retarded individuals needing assistance, the extent to which existing services and facilities meet the needs, and the level of demand for additional services and facilities.

The socioeconomic, cultural, population, and geographical factors affecting planning must also receive consideration. Such information is essential to provide a base for realistic evaluation of the effectiveness and adequacy of services and facilities already in existence and the potential for expansion. Only after such information has been collected and analyzed, will it be possible for a planning agency to project the need for additional services and facilities.

**Influencing Factors**

In estimating the number of retarded persons requiring assistance, every effort should be made to secure data covering levels of retardation and age groupings. As pointed out previously in this report, the degree of concentration of individuals in the various levels of retardation (e.g., mild, moderate, severe, and profound) and age groups (e.g., children, adolescents, and adults) will directly affect the type of services and facilities which must be programmed.

Data on all existing services and programs making a significant contribution to the retarded are fundamental to effective planning.

These include, among other things:

- numbers, type, size, sponsorship, structural and functional condition of facilities, and relationship with other services and facilities.
- utilization of facilities: e.g., numbers of retarded receiving various kinds of services.
- demand for services: e.g., waiting lists for existing facilities; known pressures for new programs.
- staffing: e.g., physicians, nurses, physical therapists, occupational therapists, vocational counselors, special education teachers, social workers, and psychologists.

Other desirable kinds of estimates and projections cover:

- Population: e.g., numbers, trends, age groups, concentration, and prevalence of mental retardation by levels of retardation and age groupings.

- Socioeconomic conditions: e.g., income, industrial and commercial patterns, and employment opportunities.
- Topography: e.g., transportation routes, natural barriers, shopping centers, and location of facilities and services.

**Sources of Information**

Agencies involved in planning and programming for the construction of facilities for the mentally retarded may be able to obtain a considerable amount of valuable data from several organizations and agencies. Among them are the following:

**Public Agencies**

State agencies for mental retardation (these may be administrative units within State agencies).

State departments having concern for the following functions:
- public health
- mental health
- public welfare
- institutions
- corrections
- economic planning
- education (administrative units for special education)
- State crippled children’s agency (if separate from the department of public health).

State agencies for vocational rehabilitation.

State employment agencies.

State planning organizations.

State universities.

**Voluntary Agencies**

State units of: National Association for Retarded Children, Inc.

United Cerebral Palsy Associations, Inc.

National Association for Mental Health.

**Local and Regional Agencies**

Health and welfare councils. Areawide planning organizations. Regional planning commissions. Colleges and universities.

Local units of State, public, and voluntary agencies.

**Professional Organizations**

American Association on Mental Deficiency.

State medical groups.
State educational organizations.
State rehabilitation associations.
State social welfare associations.

Measuring Need for Services

Full consideration must be given to the developmental nature of mental retardation, the wide spectrum of services required, and the effect of level of retardation and age grouping, in measuring need for specialized services and facilities for the retarded within a given geographical area. In addition to the utilization of available statistical data, considerable reliance must be placed upon the judgments of knowledgeable and experienced persons in making these determinations.

In measuring need for specialized services and facilities within an area, account should be taken of community health, education, and welfare facilities accommodating other segments of the population and the extent to which these can house certain specialized services.

Some specialized services do not require extensive housing. On the other hand, services that depend upon daily participation of the retarded for effectiveness may require more space. Thus, education and training services and facilities will require more in the way of housing than diagnostic and evaluation services.

Level of Retardation and Age Grouping

Some aspects of the impact of the level of retardation and age grouping on measuring needs are presented in the following:

Mildly Retarded

Children.—The successful melding of the more capable mentally retarded adults into the general population can be achieved only if an appropriate array of general and specialized services is available to them as children. The proportion of pupils sufficiently retarded to require a modified curriculum will vary from less than 1 percent to more than 10 percent of the total school enrollment, depending on the social, economic, and other local environmental conditions which tend to minimize or maximize mental retardation. Better health and social services might help to reduce this figure. Until a preschool training program is instituted, however, the majority of mildly retarded children are not likely to be detected.

It is estimated that approximately one million mildly retarded children should be receiving the benefits of special education. Of these, only about one-third are enrolled in public school special classes at the present time. However, the number for whom special class instruction is provided in the public schools has been increasing during recent years.

Most mildly retarded adolescents are aware of the difficulties they have in "keeping up" with their classmates and are also sensitive to the widening differences in aspirations between themselves and their normal classmates. This sensitivity accentuates cultural conflicts and other adolescent problems and, in some instances, precipitates emotional disturbance of a degree requiring psychiatric attention. The extent and character of psychiatric disturbance among the mildly retarded in a given community constitutes one of the variables to which attention should be given in the planning process.

In areas where unfavorable conditions prevail, the social problems of the retarded will be aggravated, especially for the adolescent and young adult. Antisocial behavior on the part of the retarded youth will be more likely than will such behavior by the normal young person to lead to insistence that he be removed from the community. Special residential facilities may be required for the rehabilitation of members of this group.

Adults.—Planning for mildly retarded adults should emphasize utilization of generic community services. Among the mildly retarded, some degree of subnormal intelligence usually persists into adult life. With adequate training and social guidance, however, the majority in this group can make a sufficiently good adjustment (adaptation of behavior) to maintain themselves socially and economically within the community. The achievement of such social and vocational independence depends in large measure on services providing guidance and training, including a "school-work" experience or a period of employment under sheltered conditions designed to ease the transition from school to work. Social and vocational counseling, which take account of the limitation of the retarded individual, must continue to be available, preferably within the agencies which offer such services to those who are not mentally retarded.
The Moderately and Severely Retarded

Children.—The total number of moderately and severely retarded children of school age in the nation is estimated to be between 150,000 and 200,000. Unlike the mildly retarded, the moderately and severely retarded are usually detected prior to school entrance, in the sense that parents and those close to them (e.g., family physicians) are usually aware that some problem exists. Experience has shown, however, that relatively few of these children come to the attention of agencies which give systematic or specifically identifiable service, even in areas where special clinics have been established. The children become conspicuous during school years because they are clearly unadapted to participation in the regular school program.

Children in these categories tend to be found in all social strata. Unless more reliable data are available to the State or local planning agency, it may be assumed for planning purposes that approximately one-third of 1 percent of the school enrollment may be used as a base for measuring needs for services and facilities for the moderately and severely retarded in children of school age.

Adults.—The total number of profoundly retarded adults is uncertain but probably does not exceed 35,000. Greater life expectancy may be expected to increase the numbers of the profoundly retarded and to influence the pattern of demands for both day and residential care in the next decade. A significant number of profoundly retarded children even now remain at home at least until adolescence. Some adults come to the attention of agencies only when age or infirmity of parents becomes a factor. In the past decade, a pronounced increase both in the total number and proportion of the profoundly retarded in residential care has been noted. At present they constitute somewhat more than one-fourth of the patients of all ages in public residential institutions for the retarded. Approximately one-sixth of these profoundly retarded patients are over 40 years of age.

Needs in Relation to Type of Service

Complete planning should include the full range of services and facilities as described in the report of the President’s Panel on Mental Retardation. This section focuses attention on general estimates of the extent of need for services for which facilities may be constructed under Public Law 88-164, the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963.

Diagnostic and Evaluation Services

Diagnostic services accept children and adults who have not yet been definitively classified as to disability and need. Generally speaking, however, most referrals tend to be made in terms of perceived need and perceived function of the service, rather than on the as-yet-to-be-made refined analysis. Thus, a specialized clinic for the retarded or handicapped tends to receive only those cases which are sufficiently marked so that retardation is fairly obvious to parents or referring physician.

See item 12, Suggested Reading List.
Whether a clinic is designed primarily for the retarded, for children with "developmental disorders," or for children with apparent neurological impairment, it may be expected that the number of new cases of mental retardation referred to the clinic will be 200 to 300 per million population per year. This figure does not include referrals which, on examination, turn out not to be mentally retarded. The caseload of a new clinic during the first years of operation may be higher than this figure because of a backlog not previously diagnosed or evaluated. Moreover, if the diagnostic clinic provides continuing review, counseling, reassessment, and interpretative services, the active caseload at any one time will be at least two or three times the number of referrals.

Initial diagnosis will require a complete workup and recurrent evaluations may be necessary. Some provisions should be made to have diagnostic and evaluation services available for all age groups. However, an identification and initial diagnostic service will, in practice, be supplied in a variety of settings, and not all mentally retarded of all types will be channeled through special diagnostic and evaluation clinics. For example, many mildly retarded children will not be referred to a specialized clinic but may be handled in a more general way, either in general pediatric clinics, through the school psychological services, or in mental hygiene clinics.

Treatment Services

Facilities for treatment, including surgical procedures, remediation of sensory defects, speech therapy, physical therapy, psychiatric treatment, and other appropriate therapies are likely to be provided for the retarded in settings where other activities are also provided. Among these settings are:

- Specialized diagnostic clinic, following diagnosis and evaluation.
- General or special purpose community hospital.
- Rehabilitation center.
- Residential center for the retarded.
- Day program providing education, training, or personal care services.
- Community mental health center or hospital.

Estimates of the extent of need for additional treatment services can be made only through an analysis of the caseload of the facilities described above to determine the extent to which treatment is or can be made a feasible part of their programs. A large portion of the need for treatment services will stem from the fact that many of the retarded, especially the severely and profoundly retarded, have multiple handicaps, including motor dysfunction and sensory impairments which may be amenable to proper treatment.

Education and Training Services

Preschool.—Preschool services may be described as group training for young retarded children designed to prepare them for successful entry into public school programs. These, in turn, fall into two main categories.

1. Preschool programs for children with mild functional retardation attributable to social or cultural inadequacies in the environment. Assuming identification of every mentally retarded child by age 15, it is estimated that between 300 and 800 new cases per million of total population would be found annually. It is only realistic to recognize, however, that this identification and initial diagnostic service will, in practice, have to be supplied in a variety of settings and that not all the mentally retarded of all types can be channeled through one type of diagnostic gateway.

2. Preschool programs for moderately retarded children with clinically recognizable forms of retardation, including organic syndromes, who need training in self-help and socialization experiences with other children. Assuming an average 2-year enrollment period, the need for this type of service may be estimated at approximately two per 1,000 of kindergarten enrollment in the area to be served.

School Programs.—The following school programs can be identified:

1. For the mildly retarded or "educable," a 5-days-a-week, full-day schooling oriented toward vocational goals is needed for an average of approximately 2 to 2.5 percent of the school enrollment.

2. For the moderately retarded and other "trainable," a 5-days-a-week full-school-day program is needed for approximately 2 to 3 per 1,000 of school enrollment. This may be divided between classes in day facilities and classes in residential settings.

3. For children of school age who do not qualify as "educable" or "trainable," day care with training in self-help is successful where population density makes it feasible. Between
and 1 per 1,000 of school enrollment may require this service.

Post-School Programs.—Sheltered workshop services should be included in post-school programs:

1. Continuation classes for retarded adults are needed. These have been relatively little developed except in residential settings where existing classroom facilities can usually be used for evening courses.

2. Rehabilitation workshops providing work training and experience as an intermediate between school and work have demonstrated their usefulness in conjunction with longer-term sheltered employment opportunities. These services are suitable in parts of the country where there are industries which can employ rehabilitants or provide the subcontracts for workshops for the retarded. Needs will vary with the employment market, and will range up to 1 per 1,000 of the adult population.

3. Adult activities and independent living centers for those incapable of productive work, competitive or sheltered, are essential in the community. Day care or day activity centers may be organized with training, treatment or recreational components. Due to the increasing span of life, the number of persons who could benefit from such services is probably lower today than it will be in 5 or 10 years hence.

Residential Care

Many factors will influence the demand or need for 24-hour-a-day care for the mentally retarded who cannot be cared for in their own or foster homes. Here, too, a range of services may be contemplated. Some short-term care is indicated, but the volume will be small. Some small residential units (group homes) with minimal supervision for more capable moderately retarded or more handicapped mildly retarded are being given increased consideration. In view of the many factors involved and the possible influence of changing patterns of community care, it is impossible to specify a "recommended" number of units of residential care on the basis of population. At present, there is a tenfold difference between the various States in terms of numbers for whom accommodation is now provided per 1,000 population, ranging from approximately .2 to 2 per 1,000 population with the average close to 1 per 1,000 population.

The needs of the following groups for residential care deserve particular attention from planning bodies:

Infants.—Additional facilities will be needed for the care of profoundly retarded, grossly malformed infants.

The Moderately and Severely Retarded of all Ages.—Despite expert opinion that many children in this category can and should be maintained in the community at least until adolescence, considerable pressure continues to be exerted for admission of the preschool or early school-age groups to the residential facility. The long waiting lists of school-age children for admission to residential facilities appears to be due, in part, to a failure by public school personnel to recognize the needs of this group. Another factor is the position taken by many private physicians that the public school system in their respective communities cannot handle the problem.

At the present time, residential facilities also provide sheltered care for the moderately retarded adult in the absence of immediate family. A successful change in this pattern could be produced with the development of concurrent long-range effective programs for supervision and guidance, as well as leisure time and work activity, for the moderately mentally retarded in the community.

The Profoundly Retarded Adult.—This category may be expected to increase significantly within the next decade as the postwar "baby boom" grows up. As a result of the improved postwar survivorship this increase will probably be more than proportionate to the increase in population with a resultant increase in the need for residential services.

The Mildly Retarded Adolescent and Young Adult.—Experience shows that, despite improved programs, a certain number of mildly retarded adolescents still exhibit behavior which is unacceptable in the community and which has resulted in their being committed to residential institutions when mental retardation is noted to be present. This occurs even though mental retardation may, in fact, be the secondary handicap. A sharp numerical increase in demand for this type of care may be anticipated between 1964 and 1970, reflecting the maturation of those born in post-war years.
Delineation of Regional Geographic Service Areas

Because of the relatively large geographic area covered by the State and the feeling of autonomy in certain areas, it is generally necessary for the State planning agency—and always necessary for a local planning organization—to delineate geographic areas for which adequate services for the mentally retarded are planned. These delineated areas should be of sufficient size and population concentration to permit the development of a full range of services consistent with the needs of the retarded and giving full consideration to all levels of retardation and age groupings. Delineation of large geographical areas permits flexibility in planning to meet the needs for all kinds of services and facilities.

As pointed out previously, the geographical area covered by specific services and facilities will vary. For example, the areas served by a diagnostic and evaluation clinic may be a region of the State or interstate area. On the other hand, it is generally recognized that a day facility should serve only a geographical territory which will insure that the facility will be within one hour's travel time of the homes of the retarded. The area served by residential facilities usually is larger than that for day facilities, but should be of a size that will permit weekend travel of residents to their homes and enable parents, relatives, and friends to visit the facility.

Many other factors should also be considered in the delineation of areas. Among them are availability of personnel to staff services, travel patterns, and location of medical centers and universities. Also, the patterns of geographic coverage already established by planning groups involved in health, education, and welfare may well be reviewed to determine the feasibility of delineating mental retardation areas in the same patterns. Such a procedure would permit optimum utilization of generic services by the retarded and provided opportunities for correlation of specialized services for the retarded with services for the general community. For example, the regional areas developed in connection with the Hill-Burton program might, in many States, provide an approach to the delineation of service areas in planning certain services and facilities for the mentally retarded. An example would be community residential facilities. Other facilities, such as day facilities, might follow more nearly the pattern established for consolidated school systems.

Analysis of Needs and Resources

A major task in planning is the determination of the mental retardation groups to be served, by levels of retardation and age groupings, and the services and facilities required. Based upon an analysis of the data obtained and an application of previously suggested measures of need, it should be possible for the planning organization to identify inadequacies in existing services and programs and also particular groups of the retarded not receiving service or inadequately served. In this connection, the judgment of individuals familiar with the needs of the retarded within the various delineated areas will be of utmost importance.

Following this analysis, recommendations regarding the development of new or expanded facilities or the remodeling and modernizing of existing facilities should be developed and incorporated in the State or local plan. Among the items to be considered in formulating these recommendations are the establishment of both short-range and long-range goals for construction, the ability of a service area to support the type of services and facilities needed, and the proper location of the facilities to house the services.

In establishing goals, the planning organization must recognize that many needed services for the retarded will not require construction of facilities. Recommendations should be made, first, as to the services and programs needed and, second, as to whether or not housing will be required. The determination of goals, both long-range and short-range, should be based on an evaluation of current patterns of use, effectiveness of existing units, proper utilization of staff, and other judgmental factors as well as upon a consideration of the services not presently available and the number of retarded persons not served. As pointed out in chapter I, short-range goals should include phasing of programs to accomplish the long-range objectives.
Priorities

Limited funds make it imperative for the State plan to establish a priority system for the construction of needed facilities. Such a system should be based on principles which will assure the most efficient utilization of the various resources which can be mobilized to the best advantage of the retarded. Basically, a priority system will show, first, the relative need among the various areas to be served and, second, the relative need for different types of facilities within the same service area.

Both quantitative and qualitative data must be utilized in determining relative need. Due to the developmental nature of mental retardation and the wide variety of services necessary to provide a continuum of care for each individual, judgmental factors will be extremely important in the establishment of a priority system. In most instances, these judgmental factors will be of greater significance than the quantitative data which may be available. Some of the more important factors in both categories include:

**Quantitative (Factual) Factors**

- size of the population group for which services are to be planned
- levels of retardation and age groups to be served
- socioeconomic and cultural characteristics of the area

**Qualitative (Value) Factors**

- availability of generic community services, such as health, education, and welfare activities, for the retarded
- availability of community support
- relative need for specific specialized services
- contribution to the comprehensiveness of programming within the area
- extent of cooperation of services with other mental retardation facilities or programs
- potential quality of programs to be provided
- extent to which funds (or facilities) will permit the mentally retarded to live in own home, in own community, or outside the community.

Carrying Out Recommendations

The members of the planning organizations have a major responsibility for continuing interpretation of planning recommendations to public and nonprofit agency personnel, government officials, and civic leaders. In this they should work cooperatively with those most concerned with ongoing general programs for the retarded in the State, especially the State agencies with major responsibilities for the retarded and the State Association for Retarded Children.

The ultimate test of all planning for services and facilities for the retarded is the effectiveness of the action taken on the recommendations. In view of this, the recommendations must be understood by the key leadership within the planning area and be capable of implementation within the resources of the area, both current and potential. It is at this point that the differentiation between short-range programming and long-range goals comes clearly into focus. The recommendations of the planning group involving short-range programming must be amenable to immediate action. Those involving long-range objectives should be based on the anticipated successful resolution of problems requiring first attention.

Effective action on the recommendations of a planning group regarding the needs for construction of facilities to house services for the retarded involves, among many things, the following:

*Establishment of a realistic program to carry out recommendations.*—The program (or programs) should be well conceived, practical, and its goals and objectives accepted and supported by the community.

*Gaining and maintaining full support of community and professional leaders.*—Full support is essential and must be sustained over a long period of time to accomplish the results anticipated in the recommendations.

*Securing and maintaining adequate and sound financial support.*—Financial support for both capital outlays and operating funds on a continuing basis is indispensable to effective action in providing needed services and facilities for the retarded.

*Developing professional staff necessary to provide quality services.*—Qualified and experienced professional personnel should be available in sufficient numbers to meet current and potential staffing requirements of existing and programmed services and facilities.
Developing Evaluation and Program Analysis Procedures

Keeping abreast of new demands and changing conditions will require the development of evaluation and program analyses procedures. The State planning agency should develop procedures for self-evaluation to maintain its activities at a high level of efficiency. Where feasible and appropriate, State planning agencies may find it desirable to engage in analysis in such areas as: (1) measurement of need for mental retardation facilities and services; (2) patterns of utilization of mental retardation facilities; and (3) financial support of facilities. In addition, procedures should also be designed to evaluate the activities of existing facilities in their efforts to meet the demands of new developments and needs in the field of mental retardation.
Appendix

Suggested Reading List

16. President's Panel on Mental Retardation. Report of the Mission to the Netherlands by the President's Panel on Mental Retardation. Wash-


RELATED AD HOC COMMITTEE REPORTS

PREVIOUS Ad Hoc Committee reports which are part of the series of publications concerned with hospital and related health facility planning are:


Free single copies of the above publications are available from—
Division of Hospital and Medical Facilities Public Health Service
U.S. Department of Health, Education, and Welfare
Washington, D.C. 20201.

The publications may be purchased at the above-cited prices from—
The Hospital and Medical Facilities Series now includes material under three general subdivisions: The Hill-Burton Program Health Professions Education Facilities for the Mentally Retarded.

The publications which have been issued under the first subdivision (the Hill-Burton Program) are briefly described in an annotated bibliography, "Hill-Burton Publications," Public Health Service Publication No. 930-G-3, which will be provided upon request. For a free single copy, write to: Division of Hospital and Medical Facilities, Public Health Service, U.S. Department of Health, Education, and Welfare, Washington, D.C., 20201.

The second and third subdivisions, Health Professions Education and Facilities for the Mentally Retarded, have just been instituted. As time goes on and publications are produced in the new fields, they will be included in subsequent issues of the bibliography.