DIMENSIONS OF THE TASK [1]

As indicated earlier, the materials in this section were prepared and distributed in advance of the work conference to serve as a background for discussion.

A. Rationale for State Planning

1. Program planning for the mentally retarded should be conceived as State-wide in scope. Approximately 96 per cent of the mentally retarded population reside in communities. Less than four per cent live in residential centers. State planners must face the problem of how to make adequate services readily available to the retarded and their parents regardless of where they live.

2. Although program plans may be conceived for groups in the retarded population, they must ultimately be focused upon the specific needs of individuals. These specific needs vary with the degrees of impairment and at different age levels. Most mildly retarded individuals will need specialized services only at certain periods in their lives while the severely retarded will need lifelong services. State planners must base the determination of program needs upon an intimate knowledge of the potential capacities and limitations of the retarded to be served.

3. Comprehensive State planning in mental retardation involves many interrelated areas or fronts such as prevention, clinical services, residential facilities, professional training, research, community services (diagnosis and evaluation, education and training, rehabilitation, sheltered workshops, home training and parent counseling, day care services, etc.), public education and legislation.

   In the initial stages it is not only logical but often necessary because of pressing conditions to concentrate planning efforts in one area at a time. But because of the interrelationships among areas, planning in any specific area should be conceived in its relationships to the total State program.

   For example, potential improvements and expansions in programs and services are largely dependent upon an adequate supply of well-trained professional personnel. The potential demands for residential facilities are closely related to the adequacy and availability of community services.

[1] Section II - State Planning in Mental Retardation. Report of a Work Conference Focused upon State-level Problems of Organization and Administration Involved in Program Planning in Mental Retardation. Sponsored by the American Association on Mental Deficiency, 1963.

As an approach to State planning it is only natural to begin with problems in areas which are most immediate and pressing, but State planners should also give due consideration to the long-term goals of a State program.

A. Many kinds of services (health, education, welfare, recreational, spiritual, and cultural) are available to the general public. Most of these services are presumed to be available to the retarded and their families, but in reality they are seldom designed to meet their specific needs. As a result, many types of specialized services have been established for the retarded.

This is inevitable because of the variety and specialized nature of needs of the retarded. To establish parallel specialized services for all types of human disabilities may become financially burdensome and may result in unnecessary duplication of services. When specific services for the retarded are needed they should be provided. In case a new or expanded specialized service is needed, the crucial problem becomes one of deciding whether an "existing agency or resource" is now equipped or with necessary adjustments can become equipped to render such specialized services effectively and economically.

Historically in this country, the tendency has been to exclude the retarded from many existing community services. Due to the recent upsurge of public interest in the welfare of the retarded this trend has gradually changed. In projecting future programs for the retarded, State planners should consider the possibilities of maximum utilization of existing services as well as the establishment of separate services.

5. State-wide program planning requires effective State administrative leadership. Within the framework of State government several departments and agencies are responsible for the administration of services to the retarded. These services include residential services, clinical services, education and training, rehabilitation, health services, welfare services, child labor and employment services.

Many States have established within a single department of State government a division, an office or a bureau with a chief administrator who is responsible for the administrative and supervisory duties relating to residential facilities for the retarded, specialized clinics for the retarded and to certain State supported community services not delegated by law to other units of State government. It must be recognized that the legal authority and responsibility of such a chief administrator is limited to services administered by his division. Usually no official provisions are

made for the planning and coordination of all State level services except in a few States where State interagency councils have been established by the governor or by legislative statute. Some chief administrators have achieved considerable progress through voluntary cooperation. State planners are faced with the problem of clarifying the central leadership role in State planning and in securing greater permanence and stability in the mechanism for planning and coordination of services at the State level.

6. With the many individuals, agencies and institutions involved in serving the retarded at the community level, effective leadership in planning and coordination of services is urgently needed. Community agencies, both public and private, tend to work independently and often new services are established with little regard for how they fit into a plan for meeting the total community needs of the retarded.

   As at the State level, responsibility for the central leadership role in community program planning for the retarded is not clearly defined in most communities. In some of the larger communities, health and welfare councils have provided the leadership and the mechanism for planning and coordination of services. In other communities, parents' councils for the retarded have assumed this role at least to some degree. Several comprehensive studies of program needs and services have been made in communities throughout the United States but have not been implemented. Most communities are not organized to provide the central leadership or the mechanism for continuous comprehensive program planning, implementation and coordination as, for example, has been underway in Monroe County (Rochester), New York since 1959.

   It is difficult to conceive how State planning can be effective in many areas of mental retardation without effective community planning units as components of the total State planning organization.

   How to develop dynamic community planning organizations and properly relate them to the State planning structure is one of the problems State planners must resolve.

B. Evidences of Need for State Planning

Judged on the basis of available knowledge and expert opinion there are many crucial weaknesses in the current programs and practices in the field of mental retardation. After an intensive study of this problem, the President's Panel on Mental Retardation issued a very significant report (October, 1962) which contains 95 specific recommendations designed to strengthen the programs and practices in this field. The

objectives implied in these recommendations cannot be achieved except through skillful planning at national, state and local levels.

While some States are beginning to make substantial progress in State-wide planning in specific areas of mental retardation, comprehensive State planning still remains to be developed in the future. Illustrations of inadequate provisions for State planning in the past may be Summarized as follows:

1. There are evidences of weaknesses in the organizational structure for effective planning in many States such as:

    a. Inadequate provisions within the structure of State government for an administrative unit (division, office, or bureau) equipped to provide leadership in State planning and coordination of State services to the retarded.

    b. Inadequate provisions for a qualified full-time chief administrator of such division, office, or bureau on an administrative level of authority and responsibility which is consistent with his needs for effective program planning, decision-making and administrative action.

    c. Inadequate provisions for a State interagency council to serve as a medium for planning and coordination of State services to the retarded. This is an essential part of the planning organization since several departments or agencies of State government are usually involved in serving the retarded.

    d. Inadequate provisions for citizen participation on an advisory basis in State program planning.

    e. Inadequate provisions for planning at the community level. Effective community planning facilities are of special importance in the areas of prevention and service programs.

    f. Lack of clarity in the definition of functions and responsibilities of State and local agencies (public and private) for services to the retarded.

2. There are evidences of weaknesses in past and present attacks upon the problems of prevention. There are those who believe that the incidence of mental retardation could be reduced by at least 50 per cent if current knowledge were applied effectively. To our knowledge, no State has made a frontal attack upon problems of prevention through a combination of possible approaches, such as:

a. Intensive case-finding programs in those areas where the causes, methods of prevention and/or treatment are known.

b. Increasing maternal and child health services in "low-income" areas which have been shown to be "high-risk" areas in terms of the incidence of mental retardation.

c. Strengthening community health, education and welfare services designed to counteract the retarding influences of impoverished environmental and cultural conditions (of home and community) upon the development of children.

d. Providing in-service training programs for those who serve the retarded, to acquaint them with the specific problems, programs and needs of the retarded. This should include physicians, psychologists, educators, nurses, social workers, and other specialized personnel.

e. Establishing through State departments of health and the medical profession preventive measures in hospitals involving obstetrical procedures, use of drugs and x-ray equipment.

3. There are evidences of lack of effective planning in the growth of residential facilities. Some of these evidences are:

a. As expanded facilities were needed there has been a tendency to add on to existing institutions rather than establish new ones. Consequently, many residential facilities have become extremely large. While there are differences of opinion among the experts on the optimal size for residential institutions, the President's Panel on Mental Retardation recommends that they should not exceed 1,000 beds. According to the 1962 AAMD Directory of Public and Private Institutions, of the 89 public institutions constructed prior to 1950, 26 per cent had a rated bed capacity of not to exceed 1,000, 70 per cent had a rated bed capacity of more than 1,000, and four per cent were not reported.

b. Most public residential institutions are seriously overcrowded. Many States report long waiting lists. For example, the Illinois Commission on Mental Retardation reported (1958) a bed capacity in the State institutions for the mentally retarded of 7,136 and a bed occupancy of 10,225 or an overcrowding of 43.3 per cent. The report also indicated a waiting list of 1,432. This is fairly typical of what many States have faced with respect to overcrowding and waiting lists.

c. The Biometrics Branch of the National Institute of Mental Health estimates that in 1960, approximately 40,000 mentally retarded individuals resided in hospitals for the mentally ill. This is approximately 20 per cent of the total mentally retarded in public institutions. How many were placed in hospitals for the mentally ill because of inadequate diagnostic evaluations or because of a lack of other facilities is unknown, but experts in the field appear to agree that a substantial number are misplaced.

d. Concepts of the primary functions of residential institutions have changed over the years. When public residential institutions were first established over a century ago, their admissions were restricted to retarded children and youth who showed promise of treatment, training and release to the community. gradually, due to social and legal demands, they were obligated to admit retarded individuals with few, if any, restrictions on age levels and degrees of impairment.

At present, the severely retarded constitute a large proportion of the new admissions to most public residential institutions. A large proportion of these retarded individuals have limited potentials for treatment, training and release and instead require long-time care. With the gradual development of a greater variety of community facilities, it may be possible for more of the severely retarded to remain in the community or to be released to the community after comparatively short periods of treatment in the residential institution.

e. Many public residential facilities for the retarded are poorly located for effective functioning. Their isolation from centers of population makes it difficult to attract, hold and house professional staff. Their geographic locations make it difficult for them to serve as regional centers and provide regional services to communities. Distances from colleges and universities often make it difficult for them to become involved in programs of professional training and research.

Until recently little attention has been given to the location of residential facilities adjacent to and closely affiliated with university centers for professional training and research. As a result, many students have had little opportunity for personal contacts with the mentally retarded during their training. Proposed Federal legislation (S. 1576—formerly S. 756) which has been passed by the Senate and is now before the House of Representatives is designed to strengthen this situation.

Residential institutions may be isolated by professional distance as well as geographic distance. Unless they maintain well qualified staffs and high program standards their participation in university training and research programs is not likely to be welcomed.

There are positive forces at work to correct some of the weaknesses of residential facilities indicated above. The fact that residential institutions established since 1950 tend to be smaller in size is encouraging if they are able to hold the line. The recent establishment of a few institutions adjacent to and in close affiliations with university centers for professional training and research is extremely promising. Experimental efforts toward the development of different types of residential placement facilities such as service-oriented multipurpose regional institutions, special purpose institutions, small community-based residential centers, small group-care residential centers or nursing homes, especially for the older residents and the increased use of foster and boarding care homes is also encouraging.

It is impossible at this time to conceptualize an ideal State system of residential placement facilities which will best serve all retarded in need of such services. Many signs indicate that public residential institutions face a period of transition. We need to mobilize and apply all possible resources of wisdom and skillful planning in this period of transition.

4. There are evidences of lack of adequate planning in the development of community programs such as:

   a. Limited provisions for early identification and diagnosis of the mentally retarded children. In most communities only those retarded with visible impairments are likely to be discovered and diagnosed before reaching school age and later.

   b. Limited provisions for complete diagnostic (clinical) services which are readily available to the retarded and their parents. Too frequently the diagnosis of mental retardation is made (especially for the mildly retarded) on the basis of intelligence and achievement tests administered by a school psychologist. Where community mental health clinics are available, the services to the retarded are often limited to diagnosis with little follow-up provisions for parent counseling and individual program planning for the retarded.

   c. Inadequate provisions for a planned and coordinated attack upon the problems of prevention.

d. While substantial progress has been made at the community level in providing special education programs for school age mentally retarded children and youth, relatively little has been done for pre-school age children and for older youth and adults. Nursery school, day care, home training and parent counseling services are being developed in some communities but as yet are quite limited.

   Likewise, sheltered workshops, recreational and other types of programs are being developed for older youth and adults in some communities but these are still limited in coverage.

e. Lack of definition of agency responsibility (public and private) for services to the retarded. Agency responsibilities for certain services such as education, health, welfare, and religion are fairly well established. Agency responsibilities for certain specialized services to the retarded such as diagnostic services, sheltered workshops, day care, home training and parent counseling services are not so well established.

f. Inadequate provisions for selective placement of those who must be removed from their natural homes. There is substantial evidence to indicate that retarded mental development is not the primary reason for institutional placement for many retarded individuals. Instead, the primary reasons may be because of emotional or personality disturbances, or because of inadequate casework services to find appropriate foster or boarding home care or limited local financial resources to support such placements.

g. Inadequate utilization of existing basic community resources for the retarded. When the needs for specific services for the retarded are recognized, the tendency has been to establish new agencies to provide these specialized services before exploring the possibilities of what existing agencies might be able to do in providing such services. Comprehensive community programs for the retarded are expensive and new specialized agencies should be established only after it has been determined that existing agencies cannot provide the services just as effectively and even more economically.

h. Limited provisions have been made in the communities for in-service training programs for those who serve the retarded. This includes physicians, psychologists, teachers, nurses, social workers and other specialized personnel. It also includes agency executives, board members of agencies and community leaders whether or not they are trained in the above disciplines.

In this section, an attempt has been made to cite some concrete evidences of the inadequate planning in the past, some of the complexities involved in program planning and hopefully some convincing reasons for more adequate planning in the future. Concrete evidences of need for planning could also be presented in other areas of State-wide planning such as research, professional training, public education and legislative reform.

Analysis of a Design for State Planning

Because of its many ramifications and complexities, State program planning in mental retardation is difficult to define. It is the process by which a State makes a systematic appraisal of the adequacy of its services and facilities in meeting the present day needs of its retarded population and makes concrete proposals for improvements and/or changes which are consistent with stated goals, are consistent with modern scientific knowledge and social practice and are within the framework of its potential resources.

The planning process involves (1) establishing the State organization for planning; (2) preparing the State design for planning; (3) delineating significant areas for planning; (4) securing statistics by age groups and by degrees of impairment in the retarded population; (5) assessing current services, practices and potential resources; (6) determining future program needs; (7) assembling and processing pertinent data; (8) setting up tangible goals; (9) projecting concrete plans for expediting program improvements and/or changes in line with stated goals; and (10) evaluating the results.

The different aspects of the planning process may be briefly outlined as follows:

1. Setting up the State Planning Organization

   In the development of an efficient and continuing organization, provisions should be made for the following:

   a. An official State planning authority (department, division or board).

   b. A State design for planning for the mentally retarded.

   c. Effective State administrative leadership.

   d. Qualified professional staff.

   e. A State interdepartmental advisory committee or council to assist in planning and coordination of State services to the retarded.

f. A citizens' advisory committee or council to assist the staff with policy decisions. This council should be representative of the various aspects (State and local) of mental retardation in the State. In addition, it may be advisable to set up ad hoc citizens' committees or task forces to make studies in special areas of the State plannig design.

g. An effective planning body in every community functioning as an integral part of the State planning organization.

2. Preparing the Design for Planning

In preparing the advanced blueprint or design for State planning in mental retardation, attention should be focused upon the following:

a. Delineation of significant areas of the planning process.

b. Securing statistics by age groups and by degrees of impairment in the State retarded population.

c. Assessing current services and practices.

d. Determining future program needs in the light of potential resources.

e. Setting up tangible goals.

f. Projecting concrete plans for achieving these goals.

g. Evaluating progress toward goals.

3. Securing Data on the State Retarded Population

In order to plan programs to meet the specific needs of groups in the retarded population it is necessary to secure data by age groups and by degrees of impairment. Since no exact figures are available it is necessary at this time to rely upon estimates based upon prevalence studies applied to age grouping of the U. S. Census.

4. Analyzing Program Needs

Assessment of the adequacy of existing State-wide services and projecting program plans into the future. Some of the factors which should receive emphasis in planning are:

a. **Delineation of Program Areas**

The areas involved in planning may be divided roughly into two groups: (1) those which deal with direct services to the retarded and their parents. These include facilities for residential care, clinical services, special education, rehabilitation, training and sheltered workshops, day care, home training, parent counseling and the like; and (2) those which deal with less direct services such as prevention, research, training of professional personnel, public education, financing, and legislation.

b. **Determination of Specific Needs of Individuals and Groups in the Retarded Population**

The mentally retarded population is quite heterogeneous in nature. The degrees of mental impairment range from mild to severe. Some require special services only at certain periods during their lives while others require a continuity of services throughout their lives whether they live in communities or in residential institutions.

c. **Assessment of Existing Services and Practices**

Many types of services are now available to the retarded and their parents at both State and community levels. Program planners must face such questions as: Are existing services soundly based and adequate or should they be changed? Is maximum use made of existing community health, education and welfare services? When should new special services be established? Are current practices based upon modern scientific information and social practice? What criteria should guide future practices?

d. **Assessment of Potential Resources**

Services to the retarded require finances, physical facilities and trained personnel. States vary widely in the availability of these resources. Each State should develop a State-wide plan which is sound, frugal, balanced and within the framework of its potential resources.

In addition, other possibilities should be explored such as cooperation among the States in pooling their resources on a regional basis. Examples of this are the southern states through SREB and the western states through WICHE, especially in the field of professional training. Types of Federal aid to the States as recommended by the President's Panel is another possible resource.

5. Setting up Program Goals

The most crucial aspect of the State planning process is involved in the determination of goals. While there will be many similarities among the general goals as determined by the different States, their specific nature will vary depending upon the particular needs and resources of the individual States. Some of the broad areas in which goals should be established are:

a. Prevention.

b. Clinical services.

c. Program development in communities.

d. Program development in residential institutions.

e. Research.

f. Training and utilization of personnel.

g. State laws.

h. Public education.

i. Financing State programs.

6. Assembling and Processing Data

Recording, assembling, analyzing and interpreting many kinds of data are required as a basis for the determination of program needs and for the projection of future State program plans in mental retardation. Future progress in State planning should be greatly facilitated by modern methods of data processing.

Many States are improving and expanding their data processing facilities. Much still needs to be done to refine diagnostic procedures, terminology, classification, records and methods of reporting in order to secure more complete, accurate and uniform national and State statistical data for use in program planning. Improved methods of assembling survey data is also greatly needed.