

ED 027 655

EC 002 975

The New Jersey Comprehensive Plan to Combat Mental Retardation.
New Jersey Div. of Mental Retardation, Interdepartmental Committee on Lifetime Disability.
Spons Agency-Public Health Service (DHEW), Washington, D.C.
Pub Date Jun 66

Note-180p.

EDRS Price MF-\$0.75 HC-\$9.10

Descriptors-Clinical Diagnosis, Community Programs, Cooperative Planning, Counseling, Day Care Programs, Educational Programs, *Exceptional Child Services, Incidence, Legislation, *Mentally Handicapped, Personnel Needs, Preschool Programs, Prevention, Program Costs, Research Needs, Residential Programs, State Agencies, *State Programs, Vocational Rehabilitation, Welfare Services

Identifiers-New Jersey

Recommendations to combat mental retardation in New Jersey are made in the following areas: coordination; research; prevention, detection, and treatment; clinical, social, recreation, and religious services; residential care; education; vocational rehabilitation; law; manpower and training; and public awareness. Additional information is given concerning the scope of the problem, including definition, measurement and classification, and prevalence. Services in 21 areas are described, as are state programs in the Departments of Institutions and Agencies, Health, Education, Labor and Industry, and State (the Division on Aging). Cost of program implementation, community programs, the State construction plan, and new project proposals are also treated. Nine charts, four appendixes, a bibliography, and information on making this report are provided. (JD)

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THE NEW JERSEY

COMPREHENSIVE

PLAN

TO COMBAT MENTAL RETARDATION

JUNE 1966

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**THE
NEW
JERSEY
COMPREHENSIVE
PLAN
TO
COMBAT MENTAL
RETARDATION**

**THIS PROJECT WAS SUPPORTED IN PART BY A MENTAL
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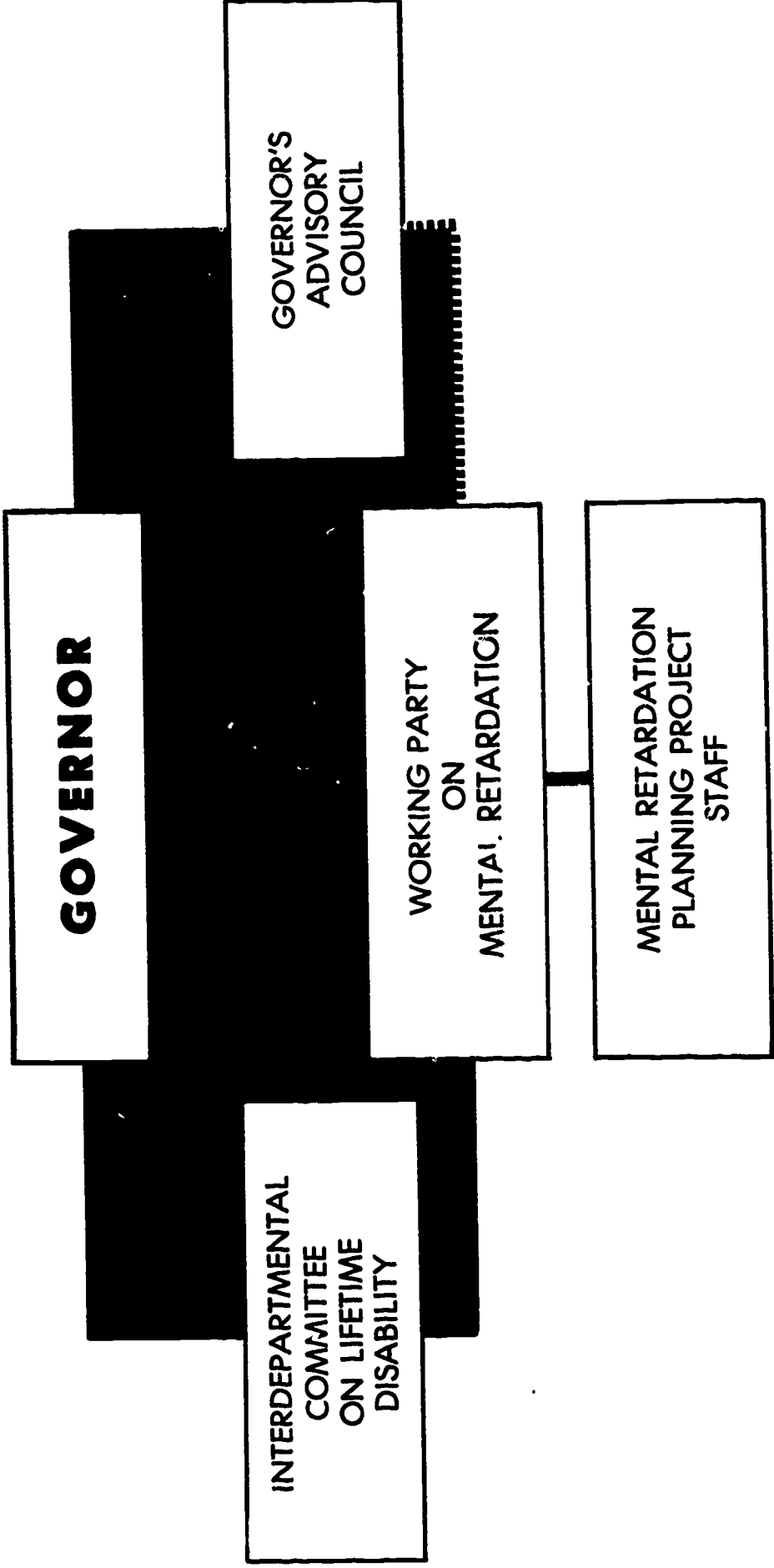
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PREFACE

There was a time when planning of a most rudimentary sort was, to a great extent, sufficient and adequate in meeting the primary needs of the mentally retarded in New Jersey. Such planning apparently has proven appropriate as evidenced by the dramatic increase over the past ten years in the number and types of programs available to the retarded.

The spectrum of opportunity for the retarded has broadened, resulting in more service to more people. The over-all program for the retarded in New Jersey is now so large, diverse, and interrelated, involves so many independent institutions and agencies, and has acquired so much momentum, that to maintain the *status quo* is to harbor the misconception that what appears adequate will remain adequate. What is necessary is systematic and essential planning in some detail.

First, all the various segments that comprise the total program to the retarded should be pulled together to determine their inter-relatedness. Each element should be evaluated in terms of its contribution to the total program. The nature, scope, and responsibility of each element in relation to each other and the total program should be clarified. Second, a single master plan for the retarded of New Jersey should be developed. This plan should be flexible so as to incorporate unforeseen future findings in an ever-developing tenable pattern of implementation. Since program results are frequently unpredictable, the plan should provide for possibilities of both gross disappointment in some ventures and for useful chance findings in others. Thus, as experience with the plan is acquired and as findings become known, new avenues for further research and exploitation will be disclosed.

Some events, however, can be predicted and scheduled. Any viable plan for the state should aim to (1) marshal these predictable trends in a concrete way so that existing measurable needs can be met, and (2) utilize "unpredictable" new knowledge whenever and wherever it comes to light. Perhaps an example of predictable events would involve population projections while, on the other hand, a rapid breakthrough in prevention or new concepts in program development would be an example of the unpredictable.

As the primary instrument for combatting mental retardation, a

comprehensive plan for the state would provide many other benefits. It is anticipated, for example, that its existence would tend to reassure the legislature, the Association for Retarded Children, and the interested public that effective persistent planning is occurring. Moreover, the anxieties of those who are rightfully concerned with the continuity of statewide planning for the retarded should be somewhat allayed by the general acceptance and constant evaluation of a plan that looks beyond the next fiscal year.

Although no single individual can be the chief author or judge of the master plan, one person might be required to devote full attention to the plan, with consultation of an advisory body. This "mental retardation planner" would be responsible for attending to new ideas as they develop. He would assess these new concepts for possible incorporation in the plan. To accomplish this task he must become and remain fairly familiar with staff, physical facilities, and existing programs for the retarded within the state so that program implementation can be undertaken with maximum utilization of available resources. Regular visits to the sites of functional services may be required to discuss current and future programming and explore new modes of operation for possible immediate implementation. From time to time consultation with experts may be necessary.

In any event, the "mental retardation planner" would prepare statements of program intent or change, including: (1) curriculum development, program procedures, and nature of population to be served, (2) techniques of implementation with regard to locus, required changes in facilities and staff, (3) evaluation of current programs with particular attention to innovations or services developed on a research and demonstration basis. In effect, the planner represents a readily available channel for the appraisal and consequent movement of innovations and discoveries from the literature to the program; while the plan, in turn, represents a systematic central structure to which inputs of newly occurring ideas and concepts would apply.

Five years from now some pattern of disposition or allocation of services will certainly exist. That pattern will undoubtedly reflect in some measurable degree the plan as it exists today, however inconsistent or incomplete it may be. Therefore, the development of a plan under continual systematic examination for consistency and completeness would serve substantially to insure that the pattern of activities a few years hence is the "best" pattern possible.

This document is an initial step forward in the direction of formulating an ongoing, comprehensive plan. To meet *all* the needs of *all* the mentally retarded is the ultimate goal. It is in this spirit that the New Jersey Comprehensive Plan to Combat Mental Retardation is presented.

INTRODUCTION

In October 1962, the report of the President's Panel on Mental Retardation, "A Proposed Program for National Action to Combat Mental Retardation", recommended that "the Secretary of Health, Education and Welfare should be authorized to make grants to States for comprehensive planning in mental retardation." The report also recognized that, since the multi-faceted problems of mental retardation typically involve the concern of several divisions of state government, "each State should make arrangements through such means as an interdepartmental committee, council or board, for joint planning and coordination of State services for the mentally retarded."

In partial implementation of the Panel's recommendations New Jersey Governor Richard Hughes created an Interdepartmental Committee on Lifetime Disability on June 26, 1963. In addition, a "Governor's Advisory Council" to this Committee was formed with broad representation of lay and professional citizens.

As a reflection of governmental and private concern at all levels, the Committee's first stated objective was to develop a comprehensive plan to combat mental retardation in New Jersey. Toward this end, a Working Party on Mental Retardation was established. From various state agencies representatives who have a particular competence in this area were designated by the appropriate Commissioners. The charge of the Working Party was to "review the present available State Services to the retarded, identify the Executive Department which is or should be discharging responsibility and report to the Interdepartmental Committee the extent and manner in which each function should be strengthened. This Working Party will, as well, develop a comprehensive plan involving public and private, state-wide and local activities to combat mental retardation."

With the passage of Public Law 88-156, federal funds were made available for states to undertake comprehensive planning in mental retardation. New Jersey was awarded an initial grant of \$30,000 and a supplemental grant of \$33,000 for comprehensive planning. The Mental Retardation Planning Staff was secured and began its work in September, 1964.

The Working Party initiated planning by developing a *list of services* which any retarded individual might need at any given time

in his life. An *ideal description* of each listed service was developed from the available literature and in consultation with authorities in the field. After identifying the array of services a retarded person might need, and after determining what these services should be ideally, the Project Staff then gathered data relative to what services and programs *actually* exist for the retarded in the state. Concurrently the Project Staff held a series of meetings with professional and voluntary organizations in health, education, and welfare fields* to elicit a broad representation of opinions regarding perceived deficits in services and recommendations regarding the most appropriate and effective ways of discharging public and private responsibilities for the mentally retarded. From the data, opinions, and suggestions offered at these meetings, in addition to the determination of deficits by comparing ideal services against existing programs, recommendations were developed.

A series of regional meetings were held throughout the state to elicit public reaction to the plan in general and the proposed recommendations in particular. Also professional and voluntary organizations were reconvened at a State Conference on Mental Retardation Planning for the same purpose. As reaction to the proposed recommendations resulted in constructive criticism with a view toward strengthening the plan, the recommendations were revised and submitted to the Working Party and the Governor's Advisory Council for final approval.

The core of this plan can be found in Section I, Recommendations. Data, reports, and other information from which the recommendations were developed are contained in the remaining sections.

* See Appendix D.

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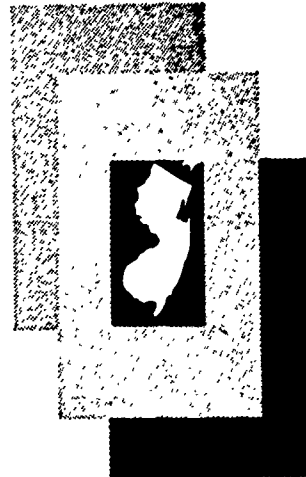
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Section I

RECOMMENDATIONS



DISCUSSION OF RECOMMENDATIONS

A plan to combat mental retardation must, of necessity, take into account the present structure of existing services. Only by the careful evaluation of services to the retarded as they are presently constituted can cogent, meaningful recommendations be made. This plan, therefore, is intended to (1) identify essential services for the retarded, (2) clearly fix responsibility for providing these services, and (3) indicate deficits and gaps in present programs for the intensification and expansion of existing services and the creation of necessary new programs for the retarded.

Recommendations are made in the following areas:

COORDINATION	EDUCATION
RESEARCH	VOCATIONAL
PREVENTION, DETECTION, & TREATMENT	LAW
CLINICAL, SOCIAL, RECREATIONAL, AND RELIGIOUS SERVICES	MANPOWER & TRAINING
RESIDENTIAL CARE	PUBLIC AWARENESS

Coordination

Mental Retardation is a complex health, education, social, and economic problem. To combat mental retardation a multidisciplinary approach is needed. The numerous and varied problems created by this condition require effective interagency and inter-

professional collaboration of a high order. In New Jersey, services for the retarded are administered by different agencies and organizations. No single department has the over-all responsibility for the total public program for the retarded in the state. Furthermore, no single department or agency can or should be responsible for the total needs of the retarded. Rather, a coordinating interagency mechanism is needed to marshal together in a bond of common continuing concern those various official and voluntary, statewide and local segments of the total program for the retarded in New Jersey. Only through such a permanent coordinating body can the state insure effective implementation of all services and provide for continuous planning to integrate existing programs and develop necessary new ones. Therefore, it is recommended:

That a Mental Retardation Planning Board, responsible to the Governor through the Interdepartmental Committee on Lifetime Disability, be created as a permanent advisory body.

Members of this Board should include representation from state departments having responsibility for services to the retarded (Institutions and Agencies, Health, Education, Labor and Industry, and State), and at least four persons of whom at least one shall represent a non-governmental agency providing services to the retarded. Specific responsibilities of the Board would be to review and make recommendations in relation to:

1. coordinating the activities of all state departments having responsibility to the mentally retarded,
2. setting standards for services and standard setting responsibility,
3. establishing program priorities,
4. assigning or re-assigning program responsibility,
5. calling attention to long-term needs and commenting on related budgetary requests,
6. stimulating planning at the community level,
7. proposing training programs and scholarships to prepare professionals to work with the mentally retarded,
8. reviewing laws and practices relating to the mentally retarded,
9. assuring maximum utilization of federal funds,
10. publishing a directory of resources, and
11. initiating a public awareness campaign in mental retardation.

To accomplish the above, funds should be available to secure personnel and other services required.¹

In essence, the Board would act as the permanent "guardian" of

¹Initial funding by way of federal appropriations seems possible.

the New Jersey Comprehensive Plan to Combat Mental Retardation. It would press for the implementation of recommendations in this plan and modify the plan as needed in the light of future knowledge. The Board should identify and clarify various issues in retardation and establish a priority system which would give emphasis to those crucial and pressing problems which require immediate attention and solution.

Research

Research in mental retardation is of paramount importance. It is the key to understanding the causes of retardation and to providing new and improved methods for assisting the retarded. The ultimate discovery of methods for preventing mental retardation is made possible only through the diligent pursuit of research.

New Jersey has never made any extensive provisions for continuous research into the myriad medical, psychological, social, and educational aspects of mental retardation. Since new knowledge is the foundation of prevention as well as effective services, state government should make a more substantial commitment to the support of research related to human development and human disability not only within its operating agencies but also in its institutions of higher learning.

Vital research, both basic and applied, is needed in many areas. The responsibility for research cannot and should not be assumed by any single department or agency. Therefore, it is recommended:

That the Interdepartmental Committee on Lifetime Disability establish a permanent Working Party on Research to stimulate and coordinate research efforts among state departments.

A charge to this body might include the following:

1. that the facilities, staff resources, and experimental populations available in any one department be made accessible to other departments;
2. that there be established by the Department of Institutions and Agencies a "storehouse" of information on the clinical and social characteristics of the mentally retarded that could be shared by all service agencies concerned for research samples, predictions on caseloads, and similar uses;
3. that appropriate state departments should apply for and utilize to a maximum degree federal and private funds available for research in mental retardation;
4. that state departments undertake a program of public information to support the need for research projects in mental retardation;

5. that detailed and extensive epidemiological studies be undertaken to measure more accurately the incidence and prevalence of mental retardation in New Jersey; and
6. that a register of research projects be developed.

At present, research by public agencies is undertaken generally at residential facilities. Research efforts should take into account in an ever increasing degree the philosophy that, wherever possible, the retarded should remain in his natural social environment and be viewed as an integral part of society. Future research projects should be consistent with this philosophy so as to undertake practical endeavors which will produce useful results that can be applied in community and school settings as well as in institutions. It is recommended:

That, in addition to more research at residential facilities, there should be an expansion of community and school centered research concerning the mentally retarded.

Basic research needs to be carried out to a greater extent at universities, colleges, and medical schools. More complete understanding of neurological, bio-chemical, and genetic factors in retardation is needed, in addition to studies pertaining to the learning processes, intellectual structure, and personality characteristics of the retarded.

Although research costs money, it is such research, however, that saves untold sums of money in the future. With the conviction that continuous study and research will ultimately benefit the people of New Jersey, the state through financial support, should demonstrate its good faith in scientific achievement. It is recommended:

That institutions of higher learning and medical facilities in the state expand research in the area of mental retardation, and that the state provide a financial base of support for such research activity.

Past assumptions of non-modifiable behavior of the retarded are being questioned today. Agencies have the responsibility to continually assess the philosophy under which they operate and their requirements for service. They should seek to up-date their techniques and strive to service cases previously conceived to be "difficult." Working closely on a day-to-day basis with the retarded, all agencies are in an ideal position to undertake investigation leading to new concepts of feasibility and improved services. Therefore, it is recommended:

That service agencies include soundly-structured research activities in their programs.

With the advent of new and increasing federal legislation directed

at economically depressed and urban areas, new programs and services have come into being. Since 90% of New Jersey's population lives in urban areas and since studies indicate a greater prevalence rate of retardation in cities and among the culturally and socially deprived, the effects of these federally sponsored programs on the mentally retarded need to be evaluated. Furthermore, these programs present an excellent opportunity for joint social research endeavors. Therefore, it is recommended:

That cooperation and communication be established between the new anti-poverty programs and research programs in mental retardation for the exchange of information and indications of the effects of deprivation on mental development.

Prevention, Detection, and Treatment

Mental retardation can be caused by various conditions that hinder or interfere with development before birth, during birth, or in the early childhood years. Specific identified causes are: German measles in the mother during the first three months of pregnancy, meningitis, Rh-factor incompatibility between mother and infant, lead poisoning in young children, chromosome abnormalities, as well as others. Inborn errors of metabolism, if untreated, can cause damage to the nervous system and hence result in mental retardation. Among the retarded, there are many whose development has been adversely affected by inadequate diet, inadequate prenatal and perinatal care, and lack of adequate stimulation. Having the responsibility to "promote improved general public health" services in the state, the Department of Health should provide leadership in this area. Since prevention is directly related to adequate maternal and child care, it is recommended:

That the Department of Health stimulate an overall effort to provide optimal medical care to every expectant mother and newborn infant.

In addition to optimal prenatal delivery and post-partum care, the medical program should include (1) protection from harmful drugs and unnecessary radiation, (2) health education to expectant mothers, particularly concerning nutrition and prenatal hygiene, and (3) early screening procedures and preventive treatment for the newborn.

Since prevention of mental retardation is socially desirable, programs which can make a significant contribution to prevention, whether specifically or generally, should be promoted by public agencies and be publicly supported to the extent necessary to make them effective. Examples of public promotion and support in

health areas include accident prevention, control of noxious substances, vaccination for measles, surgery for hydrocephalus, and control of rubella. It is, therefore, recommended:

That more programs of prevention through public education be undertaken by the Department of Health.

To emphasize the importance of health supervision, it is recommended:

That continued program expansion, including protective immunization, be undertaken by the Department of Health for the systematic and continuous health supervision of infants and young children.

Early detection is vital to early treatment. For example, if the diagnosis of phenylketonuria (PKU) is made sufficiently early, mental retardation can be prevented through proper diet. In 1965, New Jersey passed permissive legislation encouraging PKU testing. Although this represents a step in the right direction, New Jersey needs to expand programs of screening and detection of inborn metabolic errors. It is recommended:

That the Department of Health expand services for early detection of conditions arising from inborn errors of metabolism.

A number of causative factors of retardation have been identified. Various other conditions are closely associated with mental retardation. Physicians should be alert to "high risk" infants, who by virtue of certain demonstrated criteria are more likely to develop serious handicapping conditions (including mental retardation) than would the general population. The Department of Health should identify such infants for careful medical surveillance and supervision. A roster of "high risk" cases should be maintained and constantly evaluated for early and appropriate treatment. It is recommended:

That the Department of Health develop a high risk register indicating those children needing immediate supervision and follow-up.

Once identified and registered as "at risk", a child would receive early needed treatment services in an effort to prevent or reduce disability and ameliorate concomitant handicaps. As a corollary to the above, it is also recommended:

That the Department of Health encourage medical personnel caring for infants and young children to maintain detailed developmental records particularly on high risk groups.

The oral hygiene needs of the retarded are often overlooked. Studies indicate a relationship between mental retardation and

dental problems. The behavior of the retardate in the dental chair may pose a management problem for the dentist. As a result, parents often experience extreme difficulty in obtaining needed dental services for their retarded child. Therefore, it is recommended:

That the Department of Health and the New Jersey State Dental Society seek to assure that dental services be made available to all retarded.

The site of many aspects of an effective program of prevention, detection, and treatment will be the general hospital, particularly its prenatal and pediatric services. Standards for hospital accreditation provide a means of insuring at least minimal acceptable quality of patient care and management. Criteria for hospital approval presently in force do not include, however, certain basic diagnostic procedures necessary for improved services to the mentally retarded. Therefore, it is recommended:

That the Joint Commission for Accreditation of Hospitals should require the availability of facilities for prenatal care, screening for inborn errors of metabolism, and other preventive measures.

Related to the issue of medical care is the matter of payment for a full range of hospital services. Since disorders of the newborn period are apparent in many cases of mental retardation and since disabilities of prenatal origin constitute an unforeseeable risk, the following is recommended:

That health and hospital insurance programs should cover infants, including those with congenital defects, from birth for all necessary medical and surgical treatment.

That insurance laws should be amended to require continued inclusion in group hospital and medical family coverage of disabled adults who are dependent members of such families.

Clinical, Social, Recreational, and Religious Services

Given dramatic advances in research and prevention in the future, there will always be some children and adults in society who will be handicapped to some degree by mental retardation. Therefore, the general and special needs of the retarded must be provided for by available programs and services. Moreover, the retarded should be viewed as a part of, rather than apart from, their fellow human beings. Toward this end, every effort should be made to keep those retarded in the community when other protective services are not required. Whenever a general service can effectively embrace the retarded, it should do so.

There are a number of reasons why clinical services for the retarded should be a part of existing services for other children. First, difficulty frequently arises in making a definite decision as to whether a child is intellectually subnormal. Second, the case-finding process should include the whole field of physical and mental health and education. Third, agencies need clinical information to particularize their service to retarded clients.

Thus, the retarded should have access to all generic type facilities. Initial diagnostic and evaluation services for the retarded should be carried out in comprehensive "all purpose" facilities serving a broad variety of handicapped children. Attached to and fully utilizing the services of pediatric clinics in general hospitals, these comprehensive diagnostic facilities should (1) diagnose, appraise, and evaluate an individual, (2) determine the strengths, skills, abilities, and potentials for improvement of the individual and his family, (3) develop a specific plan of services to be provided with necessary counseling to carry out a program prescription, and (4) where indicated, periodically reassess progress of the individual. Travel time and population to be served should be considered in establishing such facilities. Therefore, it is recommended:

That the Department of Health be responsible for the orderly development of diagnostic facilities for handling all disorders of a developmental nature, including mental retardation.

Furthermore,

That there should be a minimum of one comprehensive diagnostic and evaluation facility in each region, with special attention given to major population areas in the state².

Diagnostic facilities should be closely associated with general hospital facilities so that pediatric, neurological, psychiatric, laboratory, and other services can be utilized in formulating diagnoses. Genetic counseling services should be made available to parents of individuals considered to be "at risk".

In New Jersey there are diagnostic and evaluation clinics serving particularly the retarded. By virtue of trained professional personnel and the knowledge and techniques developed in serving the retarded over the years, these clinics are well qualified to evaluate in depth the special needs of the retarded. Thus the existing

²The following regions have been delineated for planning and construction in mental retardation: METROPOLITAN—Bergen, Essex, Hudson, Passaic, Union counties. NORTHERN—Hunterdon, Morris, Somerset, Sussex, Warren counties. CENTRAL—Burlington, Mercer, Middlesex, Monmouth, Ocean counties. SOUTHERN—Atlantic, Camden, Cape May, Cumberland, Gloucester, Salem counties.

pattern of service suggests that while comprehensive clinics might make initial diagnoses in relation to developmental disorders, special clinics for the retarded would engage in a detailed analysis of the needs of the retarded to develop an appropriate program prescription. Such special clinics need to include a network of associated activities which are vital to the welfare of the retarded and his family. It is recommended:

That clinics providing diagnostic and/or other services essentially to the mentally retarded, seek to include related activities, such as: family evaluation, counseling, life planning, providing for continuity of services, and assuring that remedial treatment is being provided.

Special clinics for the retarded should be looked to by health and welfare agencies as a resource for consultation and referral of the more difficult cases of diagnoses and treatment.

In addition to comprehensive clinics for disorders of a developmental nature and specialized clinics for the retarded, certain agencies must make a medical diagnosis, educational evaluation, or vocational appraisal to determine eligibility for admission to programs. Since the bulk of retarded are detected upon entrance to school, the importance of diagnosis in the total system of educational services must be recognized. Early detection of learning disabilities is required and appropriate school placement is needed to avoid secondary handicaps. It is, therefore, recommended:

That the Department of Education develop a uniform method to identify each retarded child in need of special education and promote the expansion of educational diagnostic and evaluation services to provide for the early detection of learning disabilities.

Emotional problems often accompany retardation. Likewise, it is often hard to determine if a person's difficulties stem primarily from mental illness or mental retardation. At any rate, psychiatric disorders whether primary or secondary to the handicap deserve the particular attention of professionals in the mental health field. Experience has shown that, with the proper approach and within the limits imposed by the degree of retardation, emotional difficulties among the retarded are amenable to intervention.

The retarded person and his family has every right to expect that the same psychiatric facilities and resources available to others will be available to them. In some instances, this may necessitate the addition of a psychiatric consultant to the staff of a clinic for the retarded. In others, it may require that the staff of a mental hygiene clinic become more knowledgeable about mental retardation. The administrators of mental health services should orient their

personnel to the mental health problems of the mentally retarded. It is, therefore, recommended:

That mental hygiene clinics and community mental health centers provide services to mentally retarded persons requiring psychological and psychiatric treatment.

Families have many fears about seeking early advice regarding their handicapped child. No family, however, should be deterred from seeking such service because of the added fear of cost. It is, therefore, recommended:

That state and/or federally aided diagnostic and counseling services be available in all parts of the state, either without cost or at nominal cost to the family.

Amid the array of services which should be available to the retarded and their families, there should be a single place—a “fixed point”—to which those in need of counsel could turn and return for authoritative advice and guidance, or for referral to appropriate general and special resources. Too often, parents of the retarded are shuffled around from agency to agency. The confusion that results leads to frustration, heartbreak, and sometimes despair. Division of Mental Retardation regional offices and clinics for children with developmental defects will have a high degree of continuity and visibility so that an ongoing relationship between the case and the agency may be developed to be used by the client on a recurring basis. Therefore, it is recommended:

That, within each region, division of mental retardation offices and diagnostic clinics for children with developmental defects serve as “fixed points of referral” to provide information, consultation, and referral services for the retarded and their families.

Presently, the Division of Mental Retardation has three regional offices providing “field services”. With the establishment of a fourth Division of Mental Retardation regional office in the Northern Region, any family in New Jersey would have access to a Field Services’ office within one-hour travel time. In partial implementation of the above, it is recommended:

That a Field Services’ office be established in the northern region.

Many retarded come to the attention of social agencies not directly concerned with retarded persons. Such agencies have an excellent opportunity to assist in determining whether the retarded are receiving all necessary services. To accomplish the end of providing the retarded the specialized services he requires, the following is recommended:

That all social agencies identify those persons in their caseload known or suspected to be mentally retarded and consult the regional "fixed points of referral" for recommendations.

That all social agencies determine that their retarded clients are receiving all services to which they are entitled and make special provisions for those unable to benefit from existing services.

The retarded child needs opportunities for physical development and play. Recreational experiences, moreover, provide the retarded with valuable social interaction which will help in overcoming the social isolation apparent in the case of limited development. The determination and discipline learned in sports and games also can be applied to other problems of living. Since most mentally retarded live at home, recreational activities in the past have been dependent largely upon the interest, skills, and available resources of their families and of the community. Public and private agencies providing recreational programs should be encouraged to include the mentally retarded. They should take advantage of funds available for such programs. It is recommended:

That local groups, both public and private, continue to expand their activities in the field of recreation for the mentally retarded.

The more capable retardate will be able to take advantage of opportunities which exist for non-retarded individuals, if provided the encouragement to participate. The specific physical and psychological characteristics of other retarded require special programs of activity. However, for those adult retarded who are not capable of sheltered or competitive employment, a program providing constructive training, some work, and an opportunity for social interaction is needed. It is recommended:

That the Department of Institutions and Agencies establish activities centers for the adult mentally retarded who are not capable of sheltered or competitive employment and who do not require care in an institution.

The activities centers and other social agencies can identify those more competent adults whose vocational potential has been underestimated. Other retarded adults may "grow" in programs to the point of apparent vocational potential. Therefore, it is also recommended:

That social agencies refer those adult retarded who might profit from vocational services to the Rehabilitation Commission.

It is the obligation of religious leaders of all faiths to provide opportunities for religious instruction and worship to retarded persons living in the community. Religious organizations, also, should make available to state and private institutions clergy for conducting services of worship and providing religious instruction. Parents, moreover, often seek help from spiritual leaders. To counsel effectively, clergy must be available and should have sufficient understanding of aspects of mental retardation. It is recommended:

That religious organizations offer religious instruction and worship to the retarded as well as counseling to the retarded and their families in the community and provide the means for religious programs at state and private institutions.

Public welfare agencies need personnel qualified to counsel families having a retarded member. All public welfare agencies, therefore, should either employ such personnel or contract for such service. It is recommended:

That public welfare agencies make available the services of professional persons qualified to counsel families having a retarded member.

Residential Care

For many years, residential care was practically the only service available to any degree in New Jersey and in the country as a whole. In the recent past, however, community services and facilities have become more readily available to the retarded. Institutionalization, therefore, now represents but one of several service alternatives open to the retarded and one facet in the "continuum of care" services which the retarded need.

The extent of individual variations among the retarded and the variety of complex problems which they present make it unwise to generalize that it is always desirable to keep the retarded at home. What is "best" for a retarded child, his family, and the community should be determined through adequate professional evaluation and skillful counseling. The total well-being of the entire family should be the major concern. As a general rule, however, institutional care should be restricted to those whose specific needs can be met best by this type of service.

In New Jersey there are six institutions for the retarded with a resident population of approximately 6,500. Ideally these institutions should service a resident population not in excess of 6,000 persons. Overcrowding exists. Vineland State School, for example, is operating at 126% of capacity, and Woodbine State Colony is functioning at 120% of capacity. Furthermore, outmoded structures

which are still in use present management difficulties and care problems. To alleviate this condition, it is recommended:

That the Department of Institutions and Agencies systematically reduce overcrowding in state residential institutions for the retarded, particularly Vineland State School and Woodbine State Colony, and replace outmoded structures presently in use.

Implicit in this recommendation is the understanding that none of the existing institutions be expanded for the sole purpose of accommodating an increased number of retarded. The practice in New Jersey to restrict future institutional size to 1,000 residents conforms with the concept of the maximum size of such facilities.

The development of community programs will reduce to some extent the percent of retarded who will need institutionalization. It is difficult to estimate the effect of more available Day Care facilities throughout the state on those requiring institutionalization. More effective services in the institutions will result in returning some residents to the community thereby making space available for others.

Future expansion in institutional facilities, however, must be anticipated if the state is to meet its obligations to the retarded who require residential service. While the present population of New Jersey is expected to increase from 6.8 millions to 8.9 millions in 1980, of major significance for future planning is the greater accelerated increase of that segment of the population between the ages of 5 to 18. It is anticipated that the present 1.7 millions in this age group will increase to 2.3 millions by 1980. From this group the retarded who will require residential care represent probably a substantial yet, nevertheless, undetermined factor. Caseloads, however, will grow requiring more institutional space. In addition, the following factors have a bearing on residential capacity: (1) 1,513 mentally retarded persons on the waiting list, (2) an excess of 500 individuals in overcrowded institutions, and (3) approximately 1,620 mentally retarded reported in state and county hospitals. Therefore, it is recommended:

That the Department of Institutions and Agencies make diligent efforts to provide sufficient institutional capacity to speedily accommodate all retarded persons requiring residential care.

It is anticipated that when Woodbridge State School and the proposed Hunterdon State School (1,000 beds) are filled to capacity, the remaining need for residential care will be of such magnitude that still another institution will be needed by 1972.

It may be unrealistic, however, to believe that the state can move

fast enough or with such accuracy that it can anticipate the future requirements of an expanding child population and thus to be ready at all times for urgent needs as they arise. A waiting list of mentally retarded persons may always exist, regardless of the best efforts on the part of many. Other types of 24-hour care such as family care, group living homes, half-way houses, selected placement in private boarding homes, and special residential institutions should be part of the Department of Institutions and Agencies' total program.

Emphasis has been given to the need for a variety of community-centered programs for the retarded. There are those retarded who can function well in the community but require group shelter and special recreational programs. It is recommended:

That for those retarded whose needs could be met best in a semi-sheltered environment, the Department of Institutions and Agencies develop community-oriented small group living centers to provide shelter, and other required services.

The Purchase of Care Program provides suitable interim care for those on the waiting list, whose needs are immediate and urgent. Placement in private licensed institutions, however, should be considered as a long-term program for appropriate individuals as well as the present concept of temporary placement. It is recommended:

That the Department of Institutions and Agencies continue the present Purchase of Care Program and extend the scope of the program to purchase care on both a group-residential and individual-home basis.

Upgrading the quality of service in institutions is a major responsibility of the Department of Institutions and Agencies. Institutions should seek continually to incorporate proven methods and effective approaches to residential care. Standards applied in New Jersey should reflect current thinking in the field, provide appropriate care and training, and eliminate former attitudes which led to the social isolation of the retarded. It is, therefore, recommended:

That the Department of Institutions and Agencies develop a comprehensive set of standards for residential and hospital care for state institutions, and apply such standards in the routine evaluation of the care and training services in institutions.

To this end, the following two suggestions are made: (1) the AAMD's *Standards for State Residential Institutions* be considered as a basis for the establishment of standards for New Jersey State Institutions, and (2) the standards of the Joint Commission for

Accreditation of Hospitals be the goal of hospitals and infirmaries at institutions.

Because a retarded person is in a state operated residential or day facility, it should not be assumed that he cannot benefit from existing community services. By definition, services available to all retarded should be available to those in residential and day facilities. Institutions should utilize related health, education, rehabilitation, and social services which would benefit the retarded resident. Those in institutions or day facilities should not be barred from such services. Therefore, it is recommended:

That no retarded person be denied the advantages of generally available health, education, rehabilitation, and social services because of inclusion in any state operated residential or day facility.

New Jersey's institutional classification system differs from most other states. The present system is based on age, sex, and degree of retardation. This traditional system of "specialized" institutions has served New Jersey for many years. With Woodbridge State School and the proposed residential facility at Hunterdon, seven state institutions for the mentally retarded will be available in this small geographic but highly populous state. The Department of Institutions and Agencies has reached a cross-road where it must decide what type of institutional classification system would best serve the needs of the retarded and their families. A regionalized system of residential care would keep the retarded close to the community and his family. On the other hand, the present system allows for the handling of segments of the retarded population in "special" ways. There are cogent arguments on both sides. In any event, it is recommended:

That the Department of Institutions and Agencies make an intensive study of the institutional classification system to determine whether an extension of the system of "specialized" institutions or a regionalized system of residential care would best serve the retarded and their families.

When a "crisis" situation arises in a family necessitating the placement of the retarded family member for a short period of time, such opportunity should be available. For example, in instances when the mother must undergo minor surgery or when parents plan a vacation, there should be someone to care for the retarded child. In all such situations it can be assumed that families will make every effort to utilize their own resources. The state, however, should assist families by offering short-term placement at state institutions or by way of other alternatives. It is recommended:

That, for those retarded needing temporary residential care, the Department of Institutions and Agencies make provision for short-term placement.

A decision in regard to residential placement should not be achieved on the basis of cost to local or county government. Equitable distribution of costs would assure consideration of placement in a residential facility on need rather than apparent economy. The expenses to the county should be the same, for instance, whether a case is in an institution or on categorical assistance. Therefore, it is recommended:

That the net cost of residential care of the retarded, after federal aid and private payments are allowed for, should be shared between the state and counties in the same proportions as categorical aid to the permanently and totally disabled, and that residence requirements be established on the same basis.

Education

New Jersey was one of the first states to pass mandatory legislation providing educational services and school attendance for both the educable and trainable mentally retarded. The 1954 "Beadleston Act" has served as a model for other states. Over the ten-year-span there has been an increase of 647 classes for educable retarded children. The present number of such classes is 934. During the same period, classes for the trainable retarded increased from 5 to 217. This represents a total increase of 859 special classes over a ten year period.

Although New Jersey has made great strides in providing special education services, there are apparently over 5,800 children who are in need of but are not receiving such services. The increasing number of retarded children, moreover, who will emerge upon the educational scene presents a challenge calling for superior leadership and administrative prowess. Since the Department of Education is responsible for supervising education services for all children of school age, it is recommended:

That the Department of Education provide and stimulate state and local leadership in the development, administration, and supervision of special education services for retarded children.

A recent report *The Education of Handicapped Children in New Jersey 1954-1964* has evaluated the progress of special education and made recommendations to meet present and future needs. It is urged that the recommendations set forth in that report be adopted and where necessary translated into legislative action. The two

specific recommendations pertaining to the mentally retarded in the report are worthy of repetition here:

That there be (1) intensification of efforts to establish sound vocationally oriented secondary school programs for the mentally retarded, and (2) stricter enforcement of present laws regarding the establishment of needed services and classes and the placement of eligible children.

Deprivation of adequate learning opportunities for children contributes to and complicates the problem of mental retardation. Educational opportunities, therefore, should be made available to these children prior to school and at earliest possible ages. Through formal preschool programs the positive development of all children may be accelerated. In New Jersey, private and voluntary groups have "pointed the way" by initiating projects to provide preschool training. Such organizations should continue to expand their efforts in this area. It is time, however, for the state to play a vital role in these crucial, formative preschool years. A mechanism for developing such projects is already available under the Elementary and Secondary Education Act of 1965 and by way of Project Headstart. It is recommended:

That the Department of Education stimulate the development of projects to broaden the learning opportunities of preschool children, particularly those who reside in homes where such opportunities are lacking or limited.

Since education services to preschool children would be provided at the local level, school districts should be offered the added incentive of state aid. Therefore, it is recommended:

That state aid be made available to local school districts which provide approved education services to preschool children on the same basis as for children between five and twenty.

The public schools have the responsibility to prepare each retarded child entrusted to them for maximum usefulness in post-school life. This implies establishing realistic goals for every child. Various kinds of educational experiences would assist the retarded in living a balanced life at home and in the community. Such educational experiences should be an integral part of the curricula for the mentally retarded. Therefore, it is recommended:

That the Department of Education seek to enrich the curricula for mentally retarded children to include physical education, recreation, music, art, crafts, science, and other experiences.

Special education programs are no longer confined to large cities

as they generally were prior to 1954. Many small districts face difficulties establishing homogeneous classes for the mentally retarded. This has implications for supervision which often cannot be provided adequately by individual districts. Often teachers and administrators must look to state level consultants for assistance. The county child study supervisors can serve in this role and, in fact, have devoted a great deal of their time in providing guidance and assistance in the development of these programs. Therefore, it is recommended:

That the Department of Education expand supervisory and consultative services through the child study teams, while the responsibility for the administration and supervision of programs must be accepted by local boards of education.

The state has a responsibility for the *continuous* educational appraisal of its physically and mentally handicapped students. There are school districts which fulfill the minimum requirements of the law yet fail to make provision for the ongoing needs of handicapped and normal children as well. The Department of Education should provide services for continuing evaluation of special programs as they relate to learning and the general well-being of the child. It is, therefore, recommended:

That the Department of Education require that needed services of school psychologists, speech correctionists, health personnel, school social workers, remedial educators, guidance workers, and other specialized personnel for continuous educational appraisal be available within each local school district.

The need for school instruction for the retarded beyond childhood is often overlooked. Many adult retarded can benefit from instruction in filling out applications, simple budgeting, use of leisure time, and other practical activities. It is, therefore, recommended:

That courses of instruction be made available to the adult retarded by way of education programs under local sponsorship.

The absence of adequate instructional materials is one of the major barriers to efficient classroom instruction of the retarded. Special education teachers frequently receive little guidance in assembling and adapting material for use in their classrooms. Teachers and other education personnel should be provided with competent consultation on the use of instructional material. Instructional materials centers should be developed. These centers would evaluate, distribute, and disseminate information concerning available instructional materials, and would consult with producers, or prospective producers, of special instructional materials for the retarded. Further, they could adapt and modify materials now

available for use with normal children so as to be of maximum use in teaching the retarded. Therefore, it is recommended:

That instructional materials centers be established in the Department of Education and institutions of higher learning.

Not all children can be taught or trained in the public schools. Those who are too handicapped are entitled to the equivalent of free public education provided to the more capable child. The service, therefore, should be available without cost to families. It is recommended:

That children too immature or too severely handicapped to be eligible for admission to approved special education programs be provided with a daily program of care and habilitation designed to foster maximum development of their potential.

The Department of Institutions and Agencies seems the appropriate state agency to organize and implement such a program for children of school age. The preschool group may be incorporated in preschool programs operated by local boards of education or by private and voluntary organizations.

Vocational

Society has an obligation to marshal together all the resources necessary to assist the retarded in becoming self-supporting citizens. Greater effort must be placed on training and employing the retarded. The therapeutic value of work and the feeling of independence enhance the retardate's self-concept. The fact that most moderately and mildly retarded individuals can hold some form of responsible employment has particular economic implications. The Rehabilitation Commission and the Division of Employment Security should work together to develop more job opportunities. Jointly, they should investigate vocational areas suitable for the retarded. It is recommended:

That the Rehabilitation Commission and the Division of Employment Security make a joint effort to identify and develop more job opportunities for the mentally retarded.

Vocational training centers and sheltered workshops provide the retarded with (a) necessary training and self-confidence to enable him to earn a living with a minimum of outside supervision and (b) an opportunity to work productively under supervision before engaging in competitive employment. The greatest gap in many communities is the absence of a sheltered workshop geared to the needs of the mentally retarded. Prior to 1954, there was only one

workshop serving the retarded in the entire state. Today there are approximately 15 workshops offering significant service to the retarded. The development of workshops, however, has been sporadic. Vocational training facilities have sprung up mainly where local public interest was demonstrated. As a result, there are areas in the state where vocational training facilities are needed but do not presently exist. Seven counties in New Jersey do not have workshop facilities at all.

The Rehabilitation Commission should assume the responsibility for the orderly development of workshop facilities. Utilizing presently available federal funds for systematic planning, this development should provide for adequate coverage in all areas of the state, and should include special provision with public subsidy to those facilities serving persons unable to engage in remunerative employment. Furthermore, suitable standards for sheltered workshops are sorely needed. All agencies concerned should continue to stimulate the orderly growth of vocational rehabilitation facilities and the establishment of needed standards. It is, therefore, recommended:

That the Rehabilitation Commission be responsible for the orderly development and/or operation of sheltered workshop facilities.

As a corollary, it is recommended:

That suitable standards for vocational rehabilitation facilities be established and enforced by the Rehabilitation Commission.

The transition from school to work is often difficult for the retarded. A program combining vocational and academic skills not only enhances the placement prospects of the retarded but also familiarizes the retarded with the demands of work. Cooperative work study programs make this difficult transitional period easier for the retarded. At the present time, a few work study programs are in operation in New Jersey. Special class teachers and vocational counselors should work together to assist the retarded to bridge the gap from school to employment. It is recommended:

That present work study programs, suitably designed for the needs and abilities of the retarded, be expanded and new ones developed by the Rehabilitation Commission and the Department of Education.

The Department of Civil Service can make a valuable contribution by increasing employment opportunities for the retarded in state service. The Federal Civil Service program may serve as a model. Active programs of training and public employment would relieve some persistent fears held by parents i.e., that their children will have nothing to do once they leave public school or come home from

institutions or are left uncared for in the event both parents die. It is, therefore, recommended:

That the Department of Civil Service maximize opportunities for the employment of the mentally retarded in state service.

Law

New legal as well as social concepts regarding the retarded are needed. Laws must take into account the pervading chronic character of mental retardation. Equality before the law is predicated on the assumption that everyone has roughly comparable capacities to invoke the law's protections and to abide by its proscriptions. Because of inadequate intellectual development and impairment in the ability to learn and adapt to the demands of society, the retarded generally do not have the capacity to take advantage of, much less understand, their rights nor to fulfill their obligations under the law. Special attention should be given to (1) the protection of civil rights, (2) life guardianship, and (3) a theory of responsibility in criminal acts, as these apply to the retarded.

Current New Jersey laws often reflect outdated concepts and terminology in reference to the retarded. "Idiots, imbeciles, feeble-minded, mental deficient, defective, incompetent, and non compos mentis" are but a few of the terms found in New Jersey laws to refer to the mentally retarded. In fact, Article 2 Para. #6 of the New Jersey Constitution provides that no "idiot" shall enjoy the right of suffrage. Many of the laws, themselves, are obsolete, awkward, difficult to implement, and to an extent disregarded. The mentally retarded must be assured full human and legal rights and privileges under New Jersey law. Therefore, it is recommended:

That New Jersey laws and practices relating to the mentally retarded be reviewed, examined, and up-dated.

In this regard, the proposed Mental Retardation Planning Board should take the initiative in seeing that such a study be undertaken. It is suggested that the Board invoke the assistance of the State Bar Association and maintain close liaison with (1) the study group "The Mentally Retarded and the Law" at the National Law Center, George Washington University, and (2) the Rutgers University School of Law study of juvenile courts. Also, various state departments should be encouraged to review systematically the statutes under which they operate with respect to mental retardation and suggest amendments as required.

Specifically with regard to Chapter 59, P.L. 1965 (amendments to Title 30), the Department of Institutions and Agencies should make

diligent efforts to implement its provisions as quickly and efficiently as possible. In order to do this, it is recommended:

That the Department of Institutions and Agencies obtain sufficient funds to implement fully the provisions of Title 30, especially in the area of guardianship services to the mentally retarded.

Generally, the special problems of the mentally retarded offender are not sufficiently understood by law enforcement and by court officials. Therefore, police and court officials should be able to draw upon the knowledge of professional workers in matters pertaining to retarded individuals. Much needs to be done in this area, and the Department of Institutions and Agencies can play an important role. The following is, therefore, recommended:

That the Department of Institutions and Agencies make its Division of Mental Retardation regional social work staff available as "friends of the court" to be used as consultants on court matters relating to retarded persons.

That a review board be established within the Department of Institutions and Agencies to deal with those mentally retarded juvenile offenders committed or entrusted to the care and custody of the Commissioner of Institutions and Agencies.

There is an apparent relationship between statutory provisions on maintenance charges and full acceptance of service by families. It is recommended:

That the Statutes pertaining to financial liability of relatives for care in residential institutions for the retarded should be amended.

Serious consideration should be given to the following:

- (1) For retarded persons under 21 receiving residential care under a state program, liability should be limited to parents, with the amount of liability established on the bases of net taxable income. An applicable statewide scale should be developed reflecting the concept that the maximum charge to parents should not exceed the cost of caring for a child at home. In no case should maintenance charges exceed the actual per capita cost of food, clothing, lodging, personal and medical care rendered in the institutions.
- (2) The liability of parents should cease when retarded persons attains age 21.
- (3) The liability of retarded resident for his own maintenance should be limited to food, clothing, lodging and personal care, including medical care.

Since appropriations are always a function of statute and legislative action, concerns relating to funding are included under recommendations on law. Local communities may find the cost of service a valid hindrance to providing service. Liberalization of state aid provisions would have a beneficial effect in stimulating local communities to provide and expand needed service to the retarded. Local *health* and *education* services are two significant areas where such provisions are needed. Therefore, it is recommended:

That legislation be enacted to provide a program of state aid to local health agencies.

In order to emphasize the equalization principle inherent in Title I of the Federal Elementary and Secondary Education Act of 1965, it is recommended:

That local school districts be permitted to count federal funds used for personnel or programs for the handicapped as their own in matching for state aid.

Manpower and Training

There is a shortage of personnel to work with the mentally retarded. Sufficient and skilled manpower must be provided to meet the needs of New Jersey's expanding population. An extensive study is required to estimate precisely the number of people needed in various fields to serve all the disabled, including the retarded. Toward this end, a study group should be formed as soon as possible. Therefore, it is recommended:

That the Interdepartmental Committee on Lifetime Disability establish a working party to study in depth present and future manpower needs in the area of lifetime disability.

Salaries directly influence patterns of recruitment and turnover. Despite a sincere desire to serve humanity, career men and women are discouraged by inadequate or low salaries. In general, New Jersey salaries do not compare favorably with those of neighboring states. Consequently, persons trained in or employed by New Jersey are lured away by the higher salaries of other states. For New Jersey to attract and retain needed manpower to overcome present and anticipated crucial shortages, the entire area of salaries pertaining to recruitment and employee retention should be studied thoroughly. It is recommended:

That the Department of Civil Service undertake a study to determine to what extent difficulty in recruitment and employee retention is related to present salary structures.

Shortages in personnel, however, are not due entirely to inade-

quate salaries offered to career men and women. Colleges and universities have not provided sufficient meaningful opportunities to interest students in the field of mental retardation. Despite the obvious relevance of the study of learning, developmental processes, social behavior and measurement to mental retardation, there has been a long-standing, general disinterest on the part of many university departments to stimulate the interest and imagination of students to consider the field of mental retardation. As a result, many students, as well as professionals, are unaware of the intrinsic human values and rewards in working with the mentally retarded. Since the availability of professional personnel to meet the various needs of the retarded is contingent upon the degree to which colleges and universities provide stimulating and successful programs, the following is recommended:

That all institutions of higher learning provide courses at the undergraduate level and programs of specialized instruction at the graduate level in the area of mental retardation.

That medical and dental schools in particular provide instruction in mental retardation as part of the regular curriculum, and offer post-graduate and refresher courses to practicing physicians and dentists.

Students must be encouraged to seek careers in the social, psychological, and physical sciences. New Jersey should make such choices more appealing by providing funds to attract the best students. Stipends, grants, and annual scholarships should be provided to persons preparing for service in health, education, social work, rehabilitation, recreation, public administration, and other fields directly related to human services. It is, therefore, recommended:

That the state scholarship fund be extended to provide stipends, tuition, grants, and awards for both graduate and short-term training in fields relevant to mental retardation.

Appropriate executive departments can, also, play a significant role in stimulating the expansion of various training programs. It is, therefore, recommended:

That the Department of Health make available special training in mental retardation to pertinent public health personnel.

That the Rehabilitation Commission, in the Department of Labor and Industry, continue to develop and expand training programs and scholarships to prepare professional personnel for service in vocational rehabilitation.

That the Department of Education encourage institutions of higher learning to develop and expand programs for the training of teachers, supervisors, school psychologists, and other special education personnel.

That the Department of Institutions and Agencies encourage and assist its employees on all levels to improve their knowledge and techniques in the service of the mentally retarded.

State departments will be unable, however, to provide necessary and extensive special training to personnel working with the retarded without sufficient funds to undertake such training. Departments should be allocated special budgetary appropriations for this purpose. Therefore, it is recommended:

That the Legislature provide sufficient funds to stimulate additional and specialized training to personnel working with the mentally retarded.

One of the most neglected approaches to the eventual recruitment of potential personnel in the field of mental retardation is providing information on career opportunities to young people. High school students should be made aware of the needs, opportunities, and challenges in the field of mental retardation. Such information should be given at a time when career notions are being formulated. Likewise, more specific information should be provided at the time of a career decision. Generally, guidance personnel have been slow to get the message of mental retardation across early enough to suggest a career possibility. The State can render a real service in this area by making information on career openings in state programs available to key guidance and counseling personnel on a continuous basis. Therefore, it is recommended:

That the Department of Civil Service periodically advise high schools, colleges, and public and private guidance agencies of career opportunities in the field of mental retardation.

Faced with shortages of personnel in fields germane to retardation, common sense dictates the judicious utilization of existing manpower. In addition, highly trained professionals should be free from routine tasks which could be handled adequately by others. In this regard, the use of volunteers has not been explored fully. There are, for instance, persons in the community with time, talents, and skills to devote to the mentally retarded. Although some volunteers are being used in a few programs, the potential volunteer group represents a relatively untapped resource. Also, there is a large available labor force of retired persons. Many of these older men and women

have the skills and the understanding to help public and private agencies who are waiting for colleges and universities to turn out specialists with basic education, but comparatively little practical experience. Such retired persons could be used in the care and training of the retarded in various public and private facilities. Agencies should make effective use of these resources to supplement professional staffs. Therefore, it is recommended:

That the use of volunteers be explored by all program administrators.

Public Awareness

If plans for the retarded are to succeed, public attention must be focused on mental retardation. Only as the general public becomes aware of the problem will it take positive action on behalf of the retarded. The lack of systematic, continuing efforts by many public and private organizations to adequately inform the public has contributed to misconceptions, misinformation, and public apathy regarding the retarded. New and improved programs for the retarded, moreover, require public understanding, acceptance, and support. If people know, they will help. Thus to combat mental retardation effectively, the citizens of New Jersey must press for the translation of meaningful plans into purposeful action.

A total campaign to inform the general public about mental retardation should include a clear description of the problems, current programs, and additional services needed. The responsibility of citizens and community groups should be clarified. Special voluntary and professional organizations should promote understanding about the mentally retarded. A well-planned, integrated, continuous, and coordinated public awareness program with statewide coverage cannot, however, be fully discharged by a single organization or group. The cooperation of all public and private, voluntary and official organizations is required.

The proposed Mental Retardation Planning Board, however, would be in position to initiate a statewide comprehensive public awareness campaign in mental retardation with the cooperation of other agencies. In addition, appropriate state departments should stimulate public information and education programs at the state and local level. Efforts should be directed toward strategic personnel such as ministers, general medical practitioners, teachers, and others in positions which bring them into close contact with problems associated with the mentally retarded. The following, therefore, is recommended:

That the proposed Mental Retardation Planning Board initiate a statewide comprehensive public awareness campaign in mental retardation.

That state departments offering service to the retarded stimulate public awareness at the state and local level.

That every voluntary and official, public and private organization concerned with mental retardation make public awareness of the problem an integral part of its program.

Since the problems of the retarded are more likely to be noticed if they are brought to the attention of the public, mass communications media must be fully utilized. Radio, television, news articles, filmstrips, and the like could carry the mental retardation "story" to the public. More specifically, state publications should be used to a greater degree to inform professional and lay people of developments in the field. Also, a directory of information indicating services and programs available to the retarded in New Jersey should be compiled and widely distributed. Therefore, the following is recommended:

That greater use be made of mass communications media, in addition to official state publications, to better enhance public and professional knowledge and understanding of the latest developments in the field of mental retardation in New Jersey.

That a directory of information regarding services and programs now available throughout the state to the mentally retarded be developed and periodically reviewed and revised.

Although the use of mass communications media will help to increase public awareness, plans for the retarded will move forward as community leadership interprets the problem of mental retardation as basically local in nature and one which, so far as possible, the community should assume.

SUMMARY OF RECOMMENDATIONS

Coordination (see p. 13)

- 1. That a Mental Retardation Planning Board, responsible to the Governor through the Interdepartmental Committee on Lifetime Disability, be created as a permanent advisory body.**

Research (see p. 15)

- 2. That the Interdepartmental Committee on Lifetime Disability establish a permanent Working Party on Research to stimulate and coordinate research efforts among state departments.**

3. That, in addition to more research at residential facilities, there should be an expansion of community and school centered research concerning the mentally retarded.
4. That institutions of higher learning and medical facilities in the state expand research in the area of mental retardation, and that the state provide a financial base of support for such research activity.
5. That service agencies include soundly-structured research activities in their programs.
6. That cooperation and communication be established between the new anti-poverty programs and research programs in mental retardation for the exchange of information and indications of the effects of deprivation on mental development.

Prevention, Detection, and Treatment (see p. 17)

7. That the Department of Health stimulate an overall effort to provide optimal medical care to every expectant mother and newborn infant.
8. That more programs of prevention through public education be undertaken by the Department of Health.
9. That continued program expansion, including protective immunization, be undertaken by the Department of Health for the systematic and continuous health supervision of infants and young children.
10. That the Department of Health expand services for early detection of conditions arising from inborn errors of metabolism.
11. That the Department of Health develop a high risk register indicating those children needing immediate supervision and follow-up.
12. That the Department of Health encourage medical personnel caring for infants and young children to maintain detailed developmental records particularly on high risk groups.
13. That the Department of Health and the New Jersey State Dental Society seek to assure that dental services be made available to all retarded.
14. That the Joint Commission for Accreditation of Hospitals should require the availability of facilities for prenatal care, screening for inborn errors of metabolism, and other preventive measures.
15. That health and hospital insurance programs should cover

infants, including those with congenital defects, from birth for all necessary medical and surgical treatment.

16. That insurance laws should be amended to require continued inclusion in group hospital and medical family coverage of disabled adults who are dependent members of such families.

Clinical, Social, Recreational, and Religious Services (see p. 19)

17. That the Department of Health be responsible for the orderly development of diagnostic facilities for handling all disorders of a developmental nature, including mental retardation.
18. That there should be a minimum of one comprehensive diagnostic and evaluation facility in each region, with special attention given to major population areas in the state.
19. That clinics providing diagnostic and/or other services essentially to the mentally retarded, seek to include related activities, such as: family evaluation, counseling, life planning, providing for continuity of services, and assuring that remedial treatments is being provided.
20. That the Department of Education develop a uniform method to identify each retarded child in need of special education and promote the expansion of educational diagnostic and evaluation services to provide for the early detection of learning disabilities.
21. That mental hygiene clinics and community mental health centers provide services to mentally retarded persons requiring psychological and psychiatric treatment.
22. That state and/or federally aided diagnostic and counseling services be available in all parts of the state, either without cost or at nominal cost to the family.
23. That, within each region, Division of Mental Retardation offices and diagnostic clinics for children with developmental defects serve as "fixed points of referral" to provide information, consultation, and referral services for the retarded and their families.
24. That a Field Services' office be established in the northern region.
25. That all social agencies identify those persons in their caseload known or suspected to be mentally retarded and consult the regional "fixed points of referral" for recommendations.
26. That all social agencies determine that their retarded clients are receiving all services to which they are entitled and make

special provisions for those unable to benefit from existing services.

27. That local groups, both public and private, continue to expand their activities in the field of recreation for the mentally retarded.
28. That the Department of Institutions and Agencies establish activities centers for the adult mentally retarded who are not capable of sheltered or competitive employment and who do not require care in an institution.
29. That social agencies refer those adult retarded who might profit from vocational services to the Rehabilitation Commission.
30. That religious organizations offer religious instruction and worship to the retarded as well as counseling to the retarded and their families in the community and provide the means for religious programs at state and private institutions.
31. That public welfare agencies make available the services of professional persons qualified to counsel families having a retarded member.

Residential Care (see p. 24)

32. That the Department of Institutions and Agencies systematically reduce overcrowding in state residential institutions for the retarded, particularly Vineland State School and Woodbine State Colony, and replace outmoded structures presently in use.
33. That the Department of Institutions and Agencies make diligent efforts to provide sufficient institutional capacity to speedily accommodate all retarded persons requiring residential care.
34. That for those retarded whose needs could be met best in a semi-sheltered environment, the Department of Institutions and Agencies develop community-oriented small group living centers to provide shelter and other required services.
35. That the Department of Institutions and Agencies continue the present Purchase of Care Program and extend the scope of the program to purchase care on both a group-residential and individual-home basis.
36. That the Department of Institutions and Agencies develop a comprehensive set of standards for residential and hospital care for state institutions, and apply such standards in the routine evaluation of the care and training services in institutions.

37. That no retarded person be denied the advantages of generally available health, education, rehabilitation, and social services because of inclusion in any state operated residential or day facility.
38. That the Department of Institutions and Agencies make an intensive study of the institutional classification system to determine whether an extension of the system of "specialized" institutions or a regionalized system of residential care would best serve the retarded and their families.
39. That for those retarded needing temporary residential care, the Department of Institutions and Agencies make provision for short-term placement.
40. That the net cost of residential care of the retarded, after federal aid and private payments are allowed for, should be shared between the state and counties in the same proportions as categorical aid to the permanently and totally disabled, and that residence requirements be established on the same basis.

Education (see p. 28)

41. That the Department of Education provide and stimulate state and local leadership in the development, administration, and supervision of special education services for retarded children.
42. That there be intensification of efforts to establish sound vocationally oriented secondary school programs for the mentally retarded.
43. That there be stricter enforcement of present laws regarding the establishment of needed services and classes and the placement of eligible children.
44. That the Department of Education stimulate the development of projects to broaden the learning opportunities of preschool children, particularly those who reside in homes where such opportunities are lacking or limited.
45. That state aid be made available to local school districts which provide approved education services to preschool children on the same basis as for children between five and twenty.
46. That the Department of Education seek to enrich the curricula for mentally retarded children to include physical education, recreation, music, art, crafts, science, and other experiences.
47. That the Department of Education expand supervisory and consultative services through the child study teams, while the

responsibility for the administration and supervision of programs must be accepted by local boards of education.

48. That the Department of Education require that needed services of school psychologists, speech correctionists, health personnel, school social workers, remedial educators, guidance workers, and other specialized personnel for continuous educational appraisal be available within each local school district.
49. That courses of instruction be made available to the adult retarded by way of education programs under local sponsorship.
50. That instructional materials centers be established in the Department of Education and institutions of higher learning.
51. That children too immature or too severely handicapped to be eligible for admission to approved special education programs be provided with a daily program of care and habilitation designed to foster maximum development of their potential.

Vocational (see p. 31)

52. That the Rehabilitation Commission and the Division of Employment Security make a joint effort to identify and develop more job opportunities for the mentally retarded.
53. That the Rehabilitation Commission be responsible for the orderly development and/or operation of sheltered workshop facilities.
54. That suitable standards for vocational rehabilitation facilities be established and enforced by the Rehabilitation Commission.
55. That present work study programs, suitably designed for the needs and abilities of the retarded, be expanded and new ones developed by the Rehabilitation Commission and the Department of Education.
56. That the Department of Civil Service maximize opportunities for the employment of the mentally retarded in state service.

Law (see p. 33)

57. That New Jersey laws and practices relating to the mentally retarded be reviewed, examined, and up-dated.

58. That the Department of Institutions and Agencies obtain sufficient funds to implement fully the provisions of Title 30, especially in the area of guardianship services to the mentally retarded.
59. That the Department of Institutions and Agencies make its Division of Mental Retardation regional social work staff available as "friends of the court" to be used as consultants on court matters relating to retarded persons.
60. That a review board be established within the Department of Institutions and Agencies to deal with those mentally retarded juvenile offenders committed or entrusted to the care and custody of the Commissioner of Institutions and Agencies.
61. That the statutes pertaining to financial liability of relatives for care in residential institutions for the retarded should be amended.
62. That legislation be enacted to provide a program of state aid to local health agencies.
63. That local school districts be permitted to count federal funds used for personnel or programs for the handicapped as their own in matching for state aid.

Manpower and Training (see p. 35)

64. That the Interdepartmental Committee on Lifetime Disability establish a working party to study in depth present and future manpower needs in the area of lifetime disability.
65. That the Department of Civil Service undertake a study to determine to what extent difficulty in recruitment and employee retention is related to present salary structures.
66. That all institutions of higher learning provide courses at the undergraduate level and programs of specialized instruction at the graduate level in the area of mental retardation.
67. That medical and dental schools in particular provide instruction in mental retardation as part of the regular curriculum, and offer post-graduate and refresher courses to practicing physicians and dentists.
68. That the state scholarship fund be extended to provide stipends, tuition, grants, and awards for both graduate and short-term training in fields relevant to mental retardation.
69. That the Department of Health make available special training in mental retardation to pertinent public health personnel.

70. That the Rehabilitation Commission, in the Department of Labor and Industry, continue to develop and expand training programs and scholarships to prepare professional personnel for service in vocational rehabilitation.
71. That the Department of Education encourage institutions of higher learning to develop and expand programs for the training of teachers, supervisors, school psychologists, and other special education personnel.
72. That the Department of Institutions and Agencies encourage and assist its employees on all levels to improve their knowledge and techniques in the service of the mentally retarded.
73. That the Legislature provide sufficient funds to stimulate additional and specialized training to personnel working with the mentally retarded.
74. That the Department of Civil Service periodically advise high schools, colleges, and public and private guidance agencies of career opportunities in the field of mental retardation.
75. That the use of volunteers be explored by all program administrators.

Public Awareness (see p. 38)

76. That the proposed Mental Retardation Planning Board initiate a statewide comprehensive public awareness campaign in mental retardation.
77. That state departments offering service to the retarded stimulate public awareness at the state and local level.
78. That every voluntary and official, public and private organization concerned with mental retardation make public awareness of the problem an integral part of its program.
79. That greater use be made of mass communications media, in addition to official state publications, to better enhance public and professional knowledge and understanding of the latest developments in the field of mental retardation in New Jersey.
80. That a directory of information regarding services and programs now available throughout the state to the mentally retarded be developed and periodically reviewed and revised.

Section II

SCOPE OF THE PROBLEM



Definition

Understanding the nature of mental retardation is complicated insofar as the disorder is not a specific disease entity, but rather a constellation of many different symptoms arising from numerous causes. At present, over one hundred causes, representing 15 to 25 percent of all known cases of mental retardation, have been identified. In such cases, a physiological basis for the condition can be demonstrated. Nevertheless, the causes of the remaining 75 to 85 percent of cases remain an enigma. This group consists mainly of the mildly retarded who show no gross cerebral abnormality. Social and hereditary factors are believed to be responsible for much of the disorder in this group. The evidence, however, is inconclusive.

In general, mental retardation is viewed as a social problem. When an individual fails to meet the behavioral standards and norms of his chronological age group, he is often considered retarded. However, a change in the individual's level of intellectual functioning or in prevailing cultural standards may alter his status. In other words, a person viewed as mentally retarded at one time in his life may not be considered retarded at another time. This is supported by the findings of prevalence studies which report children between the ages of ten and fourteen as more likely to be identified as mentally retarded than during any other period in their lives (Lewis, 1921, Lemkau, Tietze and Cooper, 1941, 1942a, 1942b, and 1943; Onondaga County, 1955; and Levinson, 1962).

Mental retardation elicits the interest of many disciplines in-

cluding education, medicine, psychology, and sociology. As a consequence, the disorder is viewed from various different theoretical orientations. Many definitions of mental retardation representing these theoretical orientations are reported in the literature. No one definition, however, has received universal acceptance. With few exceptions, the definitions incorporate concepts of intellectual deficit and inadequate social adaptation as salient features of the disorder.

The two most quoted definitions are those of the President's Panel and the American Association on Mental Deficiency (AAMD).

President's Panel:

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

American Association on Mental Deficiency:

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

With the enactment of Chapter 59, Public Law 1965*, New Jersey has a statutory definition of mental retardation.

"Mental retardation shall mean a state of significant subnormal intellectual development with reduction of social competence in a minor or adult person; this state of subnormal intellectual development shall have existed prior to adolescence and is expected to be of life duration."

This definition is similar to the AAMD's with the exception that it refers to mental retardation as "expected to be of life duration." Since the AAMD definition seems to have been most frequently used in identifying the persons involved in this study it most nearly describes the population identified as mentally retarded.

Measurement and Classification

Because mental retardation is a relative concept depending on the prevailing cultural and educational standards, and since the

* On May 27, 1965, Chapter 59 of Public Law 1965 was signed by Governor Hughes. Chapter 59 incorporated a major portion of the recommendations of the State Commission on Mental Health; it pertained to institutions and agencies which amended, supplemented and repealed parts of Title 30 of the Revised Statutes. The definition, can be found in section 30:4-23. Also, Chapter 59 defines mental deficiency as "that state of mental retardation in which the reduction of social competence is so marked that persistent social dependency requiring guardianship of the person shall have been demonstrated or be anticipated."

retarded exhibit behavioral variations which defy a uni-dimensional measurement, there is no completely satisfactory measure for identification and classification of the mentally retarded. *Measured intelligence* and *adaptive behavior*, however, are currently in use. *Measured intelligence* refers to the individual's current level of intellectual functioning in relation to his chronological age group as determined by objective tests. The conversion of raw IQ scores to standard deviation values gives levels of deviation of measured intelligence.*

Table I
Measured intelligence levels and conversion of IQ scores to standard deviation ranges

<i>Level</i>	<i>Classification</i>	<i>Approximate Score</i>	<i>Standard Deviation</i>
I	Borderline	70-84	-1.01 to -2.00
II	Mild Retardation	55-69	-2.01 to -3.00
III	Moderate Retardation	40-54	-3.01 to -4.00
IV	Severe Retardation	25-30	-4.01 to -5.00
V	Profound Retardation	0-24	< -5.01

Adaptive behavior refers to the ability of the individual to act in accord with requirements of behavior as determined by society. The standard deviation ranges corresponding to levels of adaptive behavior should correlate with measured intelligence. As with measured intelligence, adaptive behavior is determined in relation to the individual's chronological age group.

Table II
Levels of adaptive behavior corresponding to standard deviation ranges

<i>Level</i>	<i>Classification</i>	<i>Standard Deviation</i>
0	No Deviation	equal or greater than -1.00
I	Mild Deviation	-1.01 to -2.25
II	Moderate Deviation	-2.26 to -3.50
III	Severe Deviation	-3.51 to -4.75
IV	Profound Deviation	< -4.75

Behavioral correlates of mental retardation for given age groups can be found in Table III.

* For a thorough discussion on the conversion of measured intelligence and adaptive behavior scores to standard deviations, the reader is referred to: Heber, R., *A Manual on Terminology and Classification in Mental Retardation*, AAMD, 1961, pp. 55-64.

Table III*

Behavioral correlates of degree of retardation for given age groups.

	<i>Pre-school age 0-5 years</i>	<i>School age 5-21 years</i>	<i>Adult age 21 and over</i>
P R O F O U N D	Gross retardation; minimal capacity for functioning in sensori-motor areas; needs nursing care.	Obvious delays in all areas of development; shows basic emotional responses. May respond to skillful training in use of legs, hands and jaws; needs close supervision.	May walk, need nursing care, have primitive speech; usually benefits from regular physical activity; incapable of self-maintenance.
S E V E R E	Marked delay in motor development; little or no communication skill; may respond to training in elementary self-help e.g. self-feeding.	Usually walks barring specific disability; has some understanding of speech and some response; can profit from systematic habit training.	Can conform to daily routines and repetitive activities; needs continuing direction and supervision in protective environment.
M O D E R A T E	Noticeable delays in motor development, especially in speech; responds to training in various self-help activities.	Can learn simple communication, elementary health and safety habits, and simple manual skills; does not progress in functional reading or arithmetic.	Can perform simple tasks under sheltered conditions; participates in simple recreation; travels alone in familiar places; usually incapable of self-maintenance.
M I L D	Often not noticed as retarded by casual observer, but is slower to walk, feed self and talk than most children.	Can acquire practical skills and useful arithmetic and reading to a 3rd to 6th grade level with special education. Can be guided toward social conformity.	Can usually achieve social and vocational skills adequate to self maintenance; may need occasional guidance and support when under social or economic stress.

Most currently used systems of classification take into account both measured intelligence and adaptive behavior, and most range from "borderline" at the high end to "profound" at the low end. The many systems in use prevent an absolute conversion to the AAMD system used in this document, but such a conversion was attempted in developing the data on prevalence which follows.

* Adopted from Chart book on mental retardation, President's Panel.

Prevalence

Knowledge of the prevalence of mental retardation in New Jersey would be of value in demonstrating needs and for comprehensive planning of services. As an initial step to this end, the literature was reviewed to gain familiarity with thinking in this regard. Studies concerned with the prevalence of mental retardation in defined populations were evaluated (Lewis, 1921; Lemkau, Tietze & Cooper, 1941, 1942a, 1942b, & 1943; Roth & Luton, 1943; Onondaga County, 1955; Wishik, 1956; Levinson, 1962; and Jastak, Mac Phee & White-man, 1963).

No one study, however, was found satisfactory in methodology. Definitions, size of sample, tests used and methods of data collection were not consistent. The lack of uniformity of these variables is responsible, in part, for differences in prevalence shown in Table IV. Reported prevalence ranged from a low of .68% to a high of 8.83%.

Table IV
Studies of gross prevalence of mental retardation

<i>Year</i>	<i>Author</i>	<i>Prevalence</i>
1929	Lewis	.857
1941-43	Lemkau et al.	.68
1943	Roth & Luton	.82
1955	Onondaga County	5.33 ^a
1956	Wishik	3.7
1962	Levinson	3.15 ^b
1963	Jastak et al.	8.83

a. between ages of 5 and 17

b. between ages of 5 and 20

A description of the different approaches used in the survey follows.

Lewis' criteria for mental retardation consisted of a combination of social inadequacy and lack of school and test ability. Generally, only persons with an IQ below 70 were included. If, however, an individual scored greater than 70, but was diagnosed as having "temperamental abnormality" (p24) to such a degree that he was considered incapable of social adjustment, he was also counted as retarded. Lemkau et al. used an objective IQ criterion similar to Merrill's (1938) for children, and a determination of social competence, at times inferred only from social data for adults.

Roth & Luton and Wishik do not report clearly the criteria used. Onondaga County included as retarded "all children under 18 years of age, residents of Onondaga County on March 1, 1953, identified as definitely mentally retarded or suspected of mental retardation on the basis of developmental history, poor academic performance, IQ score, or social adaptation when contrasted with their peers (p87)." Levinson used the essentially educational criterion of an objective IQ score. Jastak used multiple criteria consisting of 15 psychometric tests, indices of occupational and educational achievement, and social data. Persons scoring in the lower quartile on all measurements were classified as retarded.

These studies cover quite different geographic locations. Lewis surveyed six areas in England and Wales. Lemkau used the Eastern Health District in Baltimore, Maryland. Roth & Luton and Onondaga County each used county delineated areas located in Tennessee and New York, respectively. Wishik's population consisted of two counties in Georgia, while Maine and Delaware were used by Levinson and Jastak, respectively.

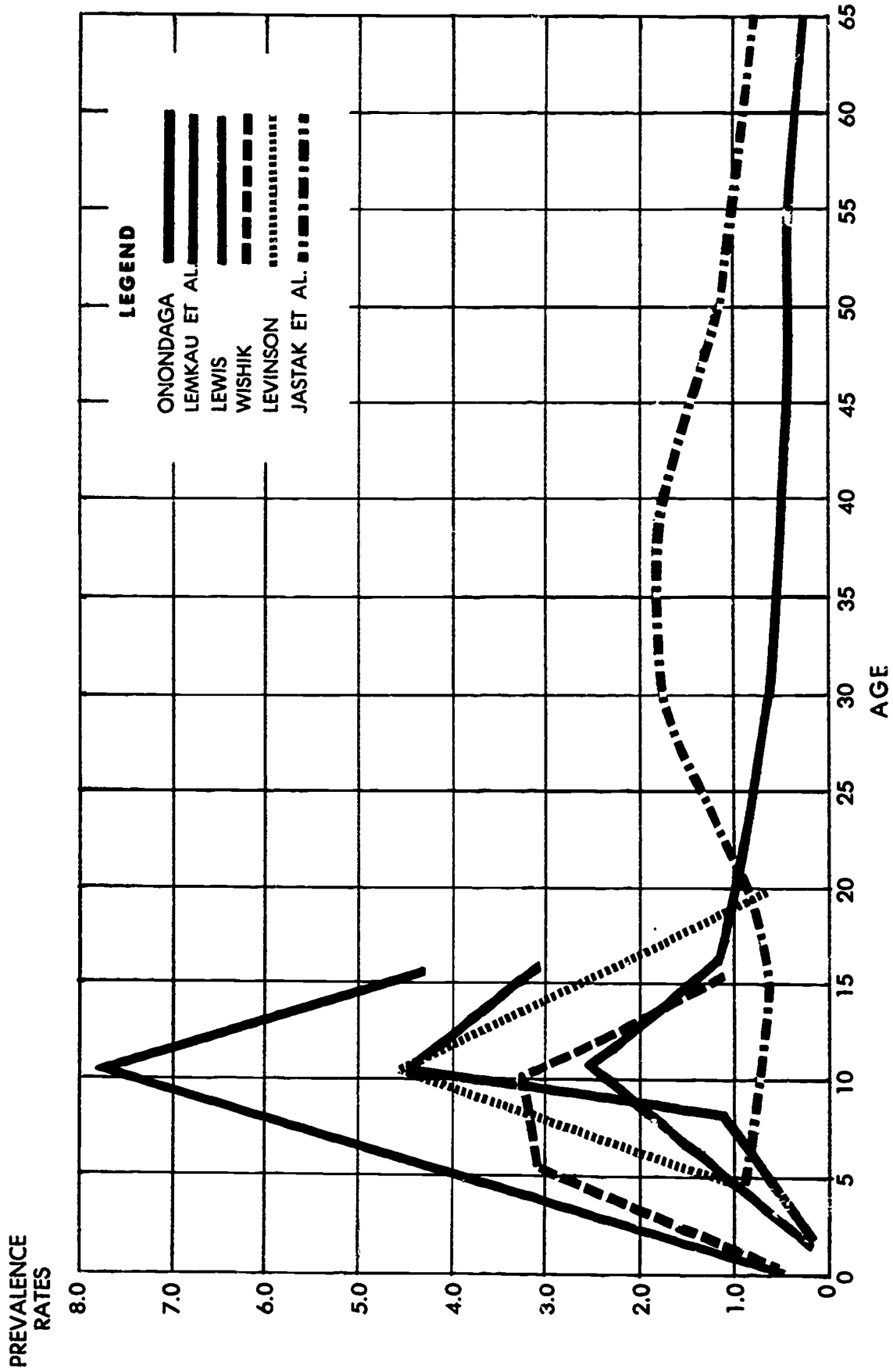
Methods of data collection also differed. Lewis had school teachers refer children performing in the lower 15% of their class. IQ tests were administered to these children. The lower scoring 2% to 7% were individually tested by Lewis with Binet-type scales standardized on an English population. Teacher's reports and school records supplemented this data. To determine the number of mentally retarded persons not in school, health and social agencies were contacted for referral.

Lemkau and Onondaga examined the caseloads of official and voluntary agencies. Roth & Luton also used this approach, but supplemented their investigation with requests for referrals and a house-to-house survey in three sub-sample areas. Wishik requested community referrals for a three-week period and then sampled every tenth household. Levinson elicited referrals by mail inquiry addressed to schools and institutions, and Jastak randomly sampled "family units."

In the studies of Lemkau, Roth & Luton, and Wishik, the prevalence of many different handicaps was considered. It is possible, therefore, that in some instances a retardate concealed under a different diagnostic classification, may have escaped detection.

Regardless of the approach used, a pattern is found in all studies other than Roth & Luton's and Jastak's. Figure I shows reported prevalence rates for separate age groups. (Roth & Luton, however, did not report separate rates). Prevalence is found to vary as a function of age. The number of identified retarded persons is low during the first few years of life. With increasing age, it rises

FIGURE I
REPORTED PREVALENCE OF MENTAL RETARDATION
FOR GIVEN AGE GROUPS



markedly. There is a peak at approximately ages 12 to 15. As the individual approaches late adolescence and early adulthood, known prevalence decreases. Since studies showing this phenomenon were based primarily on a case referral method of data collection, several explanations appear plausible.

1. During the first few years of life, mild retardation is not apparent because behavior demands made on the child are within his capability. Prevalence during this time might reflect the more severe levels of retardation where gross symptomatology is evident.

2. High prevalence during the school years may be attributed to high academic expectations and required standards of behavior beyond the capability of the retardate.*

3. As schooling ends, known prevalence decreases. The mildly retarded apparently are capable of satisfying a non-academic, less demanding adult society

Jastak's higher prevalence for the 30 to 40 year old group is probably a function of the case finding technique, i.e. a random sampling approach as opposed to eliciting referrals or inspecting caseloads of agencies. The gross prevalence of 8.83%, which he found, can be explained, only in part by his "experimental criteria of retardation (pp63-73)." Since other studies have not used Jastak's approach, his findings cannot be corroborated or refuted.

The studies reviewed, being limited in scope, were evaluated in conjunction with data from other authoritative sources. The President's Panel (1962) refers to a gross prevalence rate of approximately 3%. Approximately .1% are profound and severe; .3% are moderate; and 2.6% mildly retarded. The Panel also notes greater prevalence among the ten to fourteen age group. Stevens and Heber (1964) state that mental retardation "effects from 2% to 3% of the total population (p2)." Masland, Sarason and Gladwin (1958) state that "to be specific, of the 4,200,000 children born annually in the United States, 3% (126,000) will never achieve the intellect of a 12-year-old child, 0.3% (12,600) will remain below the 7-year intellectual level, and 0.1% (4,200), if they survive, will spend their lives as completely helpless imbeciles, unable even to care for their own creature needs (p3)."

This information indicates a gross national prevalence rate of 3%. If the sole criterion for mental retardation was an IQ score, this approximate 3% rate would be corroborated. For example, in standardizing the 1937 revision of the Stanford-Binet, IQ ranges and percentages were as follows: 79-70 IQ, 5.6%; 69-60 IQ, 2.0%; 59-50 IQ, 0.4%; 49-40 IQ, 0.2%; 39-30 IQ, 0.03%. Assuming an IQ of 69 or less

* The President's Panel reported prevalence rates found by surveys as high as 8 to 10% in the 10 to 14 age group.

as criterion for mental retardation, the prevalence rate (i.e. 69-30 IQ) would be 2.63% (Merrill, 1938). Although mental retardation is not determined by the sole criterion of IQ alone, measured intelligence does indicate an individual's probable capacity for social adaptability. Heber (1961) states, "Since the behavior sampled by current intelligence tests contributes to total adaptation, level of function in the Measured Intelligence dimension will (usually) correlate with level of adaptive behavior (p61)."

Data supporting the national prevalence estimates at the mild, moderate, and severe levels of mental retardation were found in the literature. In the 1937 standardization of the Stanford-Binet, Merrill reported 2.4% of the standardization group as falling within the 69-50 IQ range. Levinson, however, has questioned the validity of using Merrill's data in estimating prevalence. Levinson states, "children with IQ's below 50 are not usually found in the schools, from which the standardization group at the lower school ages (apparently from about age 6 to 14) was almost entirely drawn (p5)." Although Levinson's point is valid, one may assume that the mildly retarded were adequately represented. This group usually scores in the 69-55 IQ range and is not excluded from school.

Nickell (1954) studied selected areas in Illinois to determine the prevalence of the trainable mentally retarded (TMR).^a A prevalence of .235% was reported. The criterion used was an IQ score 50-20. A study by the Department of Mental Hygiene, New York State (1956) reported a .33% rate for children with IQ's below 70. Since approximately 70 percent of all cases were in the 49-25 IQ range, the TMR rate would be about .23%. The remaining .1% would fall into the severely retarded category. Wirtz & Guenther (1957) elicited a prevalence of .298% of TMR in a study conducted in Illinois and Michigan. These recent findings are in relative agreement with those reported by Lewis. In the 7 to 14 age group, he reported 2.47% "feebleminded", .38% "imbeciles", and .1% "idiots".

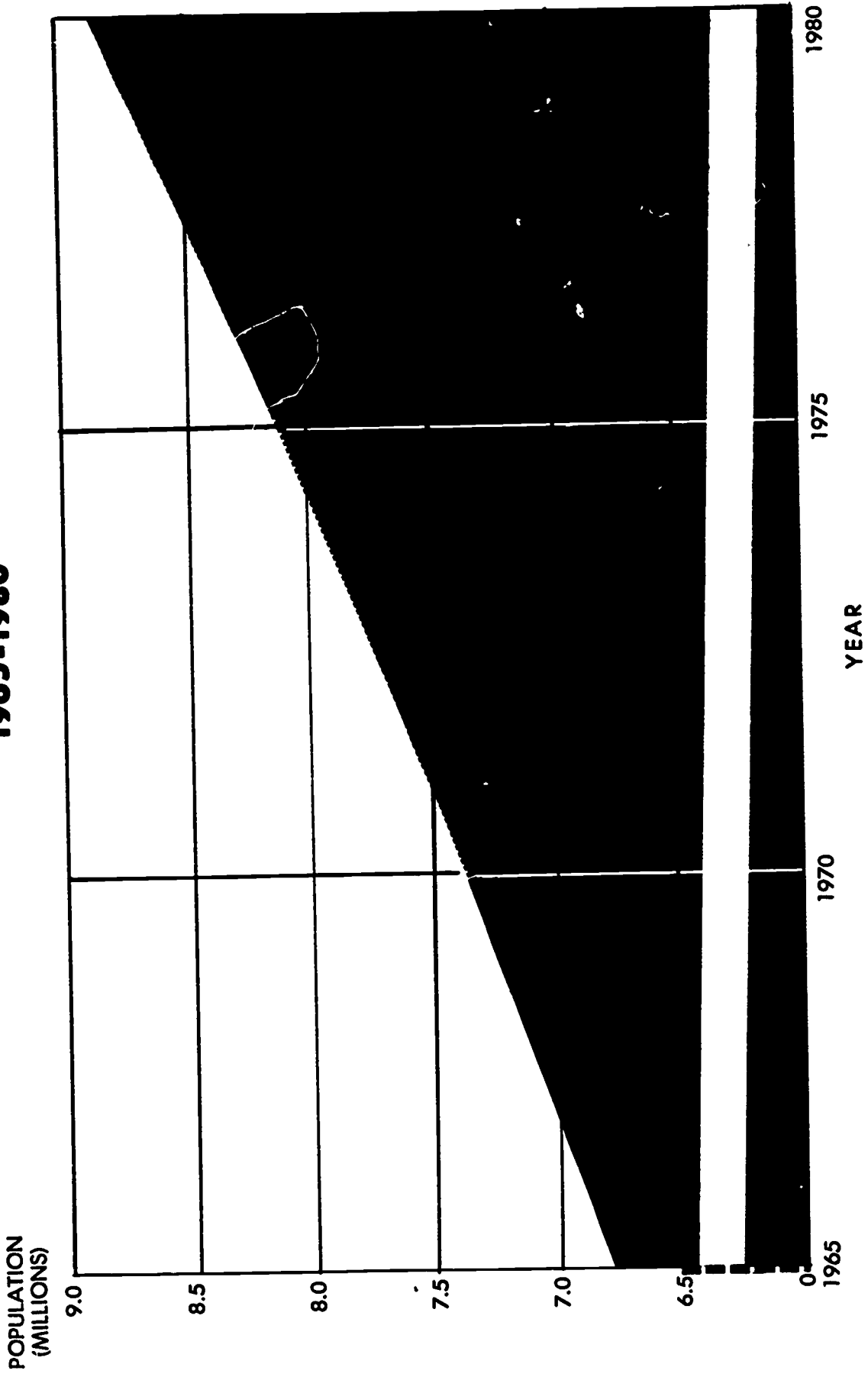
No study concerned only with mental retardation at the severe level was found in the literature. The estimate, however, that .1% of the population is severely retarded appears accurate. Since the severely retarded require constant supervision and care, they compose the greater proportion of the 200,000 persons residing in institutions for the mentally retarded. Furthermore the .1% estimate is supported by data from New Jersey. The 6,259 retarded persons in New Jersey institutions represent approximately .1% of the state's population.

The exact prevalence of mental retardation in New Jersey is not

^a One cannot assume, however, that all moderately retarded persons are trainable. The TMR figures must be interpreted as rough indices of moderate retardation.

CHART I

**ESTIMATED POPULATION - NEW JERSEY
1965-1980**



2

known. The most valid approach to determine prevalence would be through a study of a carefully selected sample of the state's population. Until such a study is undertaken, however, national prevalence figures will be applied to New Jersey's population. (Chart I indicates the predicted population growth in New Jersey.)

Table V lists the estimated prevalence of mental retardation in New Jersey for given years and levels of retardation. The estimations for 1970, 1975 and 1980 are made with reservation.

Table V

Estimated prevalence of mental retardation in New Jersey*

	1965	1970	1975	1980
Severe & Profound	6,760	7,442	8,112	8,892
Moderate	20,363	22,326	24,346	26,675
Mild	176,245	192,385	210,635	231,184
Total	203,368	222,153	243,093	266,751

As Table V shows, approximately 203,368 persons were estimated to be mentally retarded in New Jersey during 1965. To determine what proportion of this number was receiving service, the number of cases served by public and private agencies, institutions, and schools in New Jersey was tabulated. As shown in Table VI, 32,802 cases were reported.

* These estimates are based on overall population growth and do not take into account the accelerated growth rate of the 5 to 18 age group.

Table VI
Location of the known population of mentally retarded persons
in New Jersey.

1. Special Education ^a	16,430
2. State Residential Institutions ^a	6,259
3. Diagnostic and Evaluation Clinics ^b	1,118
4. Field Services ^b	2,762
5. State & County Mental Hospitals ^c	1,615
6. Vocational Rehabilitation Commission ^a	1,435
7. County Welfare Rolls (total disability) ^c	1,288
8. Private Residential Institutions ^b	805
9. Sheltered Workshops ^b	415
10. Pre-School Classes ^b	235
11. Commission for the Blind ^b	200
12. Day Care ^b	177
13. State Penal Institutions ^d	63
	32,802

a. data 1966. b. data 1965. c. data 1964. d. data 1963.

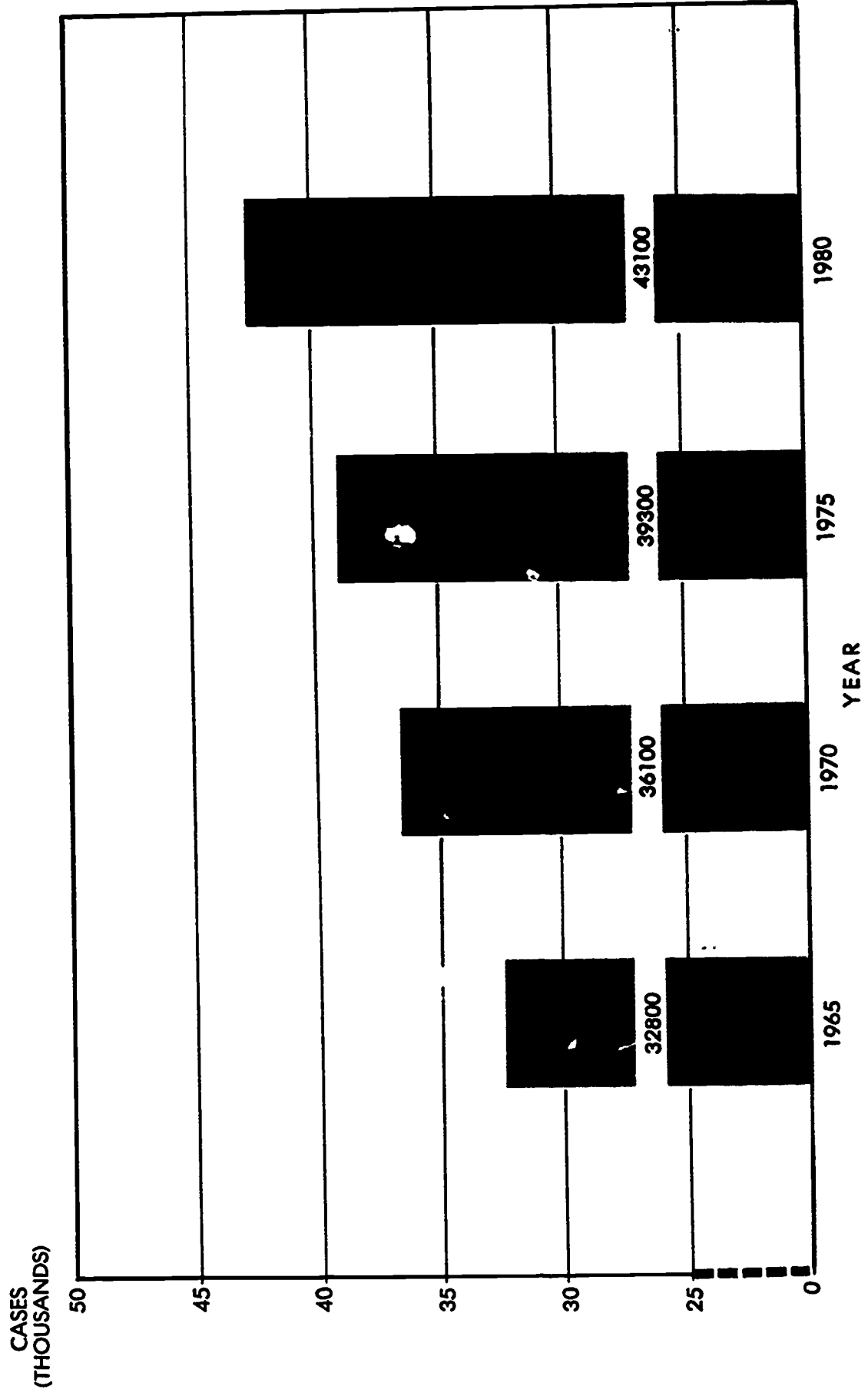
The number of cases represents *units of service* rendered. Each individual case record was not inspected; only the total number of cases serviced by an agency was made known. The data collection procedure, therefore, does not indicate if an individual is carried on the caseloads of more than one reporting agency.

From a review of the literature, the following conclusions relating to the prevalence of mental retardation can be drawn:

- (a) prevalence estimates are influenced by the method of assessment;
- (b) children between the ages of ten and fourteen are more likely to be identified as mentally retarded than during any other period in their lives;
- (c) prevalence is significantly higher in areas characterized by low family income and education;
- (d) a greater concentration of mental retardation is found among the unemployed;
- (e) mental retardation is higher among non-whites than whites; and,
- (f) differences in prevalence between rural and urban areas can not be assumed without question.

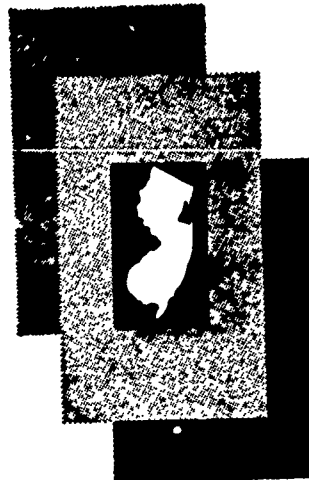
^a Based on U.S. government estimates of 17.6% retarded of those receiving aid for permanent disability.

ESTIMATED GROWTH IN CASES SERVED 1965-1980



Section III

**DESCRIPTIONS OF
SERVICES**



The retarded individual is at a disadvantage in nearly all areas of living. During his lifetime he will need services from a wide range of professions and organizations. These services must be readily available to the retarded and their families. Such services should, therefore, be conspicuously publicized so that individuals will know where to find the services they need.

Whenever a general service can effectively include the retarded, it should do so, regardless of the obstacles entailed. Since the retarded vary widely in their capabilities and needs, however, an inclusive array of specialized services are also required.

Whether general or specialized, services should be so related to each other that the ideal concept of a "continuum of care" can be realized. This concept is clearly defined in the President's Panel report. Continuum of Care describes the selection, blending, and use in proper sequence and relationship of the medical, educational, and social services required by a retarded person to minimize his disability at every point in his lifespan. Thus "care" is used in its broadest sense and the word "continuum" underscores the many transitions and liaisons, within and among various services and professions, by which the community attempts to secure for the retarded the kind and variety of help and accommodation he requires. A "continuum of care" permits fluidity of movement of the individual from one type of service to another while maintaining a sharp focus on his unique requirements. The ongoing process of assuring that an individual receives the services he needs when

he needs them and in the amount and variety he requires is the essence of planning and coordination.

This section describes 21 major service areas for the retarded. Each description attempts to (1) define the service area, and (2) include those elements which would comprise an "ideal service".

PREVENTION

Mental retardation is a symptom complex—the expression of a large variety of causes, many of which are as yet unknown, others only in rather broad terms and only in a few instances do we have a fairly precise knowledge of cause and effect. Our ability to prevent mental retardation is directly correlated with the precision and specificity of our knowledge concerning its causation.

Generally, the etiologies of mental retardation can be grouped into the following categories:

1. bio-physical,
2. socio-cultural, and
3. psychogenic-emotional.

Often these groups are inter-acting. For instance, a child with an unrecognized hearing defect or uncorrected visual defect will have difficulties in communication and learning and thus may function on a retarded level. A youngster who lives in a socially deprived and culturally limited environment may act on a retarded level, due to insufficient stimuli. In addition, the frustration he experiences through inability to compete with others more fortunate, may lead to emotional disturbance and further functional retardation. There is a high correlation between prematurity and the incidence of mental retardation. Also the rate of premature births is much higher in the low socio-economic group.

This discussion will be limited to the prevention of mental retardation resulting from bio-physical causes. These can be grouped into those operating *pre-natally*, *para-natally*, and *post-natally*. They may result in mental retardation as the only effect, or they may be associated with specific physical characteristics or other physical defects.

*Clinical Classification**

The classification which is based, when possible, on etiology. Only those conditions are included that occur often enough to have practical importance. It should be noted, however, that there are probably more than a hundred different etiologic factors and recognizable syndromes associated, either always or only oc-

* Textbook of Pediatrics; Waldo E. Nelson, M.D.; pp 1232 - 1233, W. B. Saunders Co., 1964

asionally, with mental retardation. The following clinical conditions are grouped according to the period of life during which the causative factor or mechanism is established or operative, namely prenatal, natal, and postnatal.

I. Prenatal

A. Genetically determined

1. Familial or subcultural,
2. Phenylketonuria,
3. Galactosemia,
4. Cerebral Lipodoses,
5. Cerebral demyelinating diseases,
6. Gargoylism,
7. Cranial anomalies (primary microcephaly, craniosynostosis, hypertelorism, congenital hydrocephalus).
8. Congenital ectodermoses (tuberous sclerosis, neurofibromatosis, cerebral angiomas),
9. Hereditary cerebral maldevelopment, not clinically classifiable, and
10. Chromosomal aberrations (mongolism, Klinefelter's syndrome, triple X syndrome, hermaphroditism, and other miscellaneous conditions).

B. Prenatal, of known cause

1. Infection (syphilis, German measles, toxoplasmosis, cytomegalic inclusion disease),
2. Fetal irradiation,
3. Kernicterus (Rh and ABO maternal isosensitization; non-specific neonatal hyperbilirubinemia),
4. Cretinism.

C. Prenatal, of unknown or indefinite cause and not clinically classifiable

1. Associated with placental abnormalities, toxemias of pregnancy, prematurity, maternal medication, nutritional deficiencies, anoxia, poisoning, trauma, etc., (congenital cerebral maldevelopment).

II. Natal

- ### ***A. Birth injuries (direct cerebral trauma, hemorrhage, anoxia).***

III. Postnatal

- A. Cerebral infections (meningoencephalitis, abscess),
- B. Cerebral trauma,
- C. Poisoning (lead, carbon monoxide, and others),
- D. Cerebrovascular accidents, occlusions and hemorrhages of varying or unknown causes, and
- E. Postimmunization encephalopathies (pertussis, smallpox, rabies, and others).

Primary Prevention is prevention of the basic cause leading to mental retardation (e.g. the prevention of lead poisoning). *Secondary Prevention* is the prevention of mental retardation resulting from the basic cause (e.g. prompt treatment of plumbism to prevent lead-encephalopathy with resulting mental retardation). In some instances more is known about primary prevention (e.g. provision of comprehensive prenatal care will decrease the incidence of toxemias, prematurity and thus the risk of resulting mental retardation) and in other instances more knowledge exists concerning secondary prevention (e.g. nutritional treatment of PKU, calactosemia or shunt operation for hydrocephalus).

Preventive Measures

I. Genetic Counseling

Development of genetic counseling services

This requires very specialized skilled personnel as well as facilities for biochemical and chromosomal studies. Probably best developed in conjunction with a university medical school, possibly in cooperation with a neighboring state (regional). Consideration must be given to training of personnel in genetic counseling and to the development of a well-functioning referral system, so that diagnostic centers, hospitals, institutions, and physicians can obtain the services for selected couples as expediently as possible. Self-referral is not recommended, in order to avoid inappropriate utilization of a limited and expensive new service. Genetic counseling services should be available for a variety of genetically determined conditions and not exclusively for mental retardation cases.

Suggested model: Regional center (Medical School or Research Centers).

Trained counselors (geneticists or physicians with special training) strategically distributed throughout state, attached to selected hospitals with diagnostic clinics, who have access to

the regional center for necessary consultation, laboratory services and referrals.

Physicians, diagnostic centers, hospitals, institutions, etc.

Epidemiological follow-up of families with known or suspected hereditary disease

- a. For early case finding among siblings, cousins, etc. and prompt institution of preventive measures, if available (e.g. PKU, galactosemia).
- b. For development of better data, including a state-wide registry for selected conditions. Reporting by hospitals and physicians (similar as reporting of CC cases) is desirable. Better data may eventually lead not only to better follow-up but to better control measures, perhaps, as a result of epidemiological investigation.

II. Family planning

This service including referrals, should be made freely available to all who can accept them, when indicated: e.g.

- a. hereditary disease in family,
- b. ill health of mother, which may adversely affect woman or offspring,
- c. for the purpose of adequate child spacing (too frequent pregnancies often result in fetal death, prematurity and poor reproductive performance in general), and
- d. for emotional or socio-economic reasons, which may interfere with the healthy development of the child.

III. Prevention of damage to the developing fetus

Preconceptional care is a type of health care of great importance and should begin long before the inception of pregnancy, e.g.

- a. promotion of optimal physical health, including optimal nutritional status. (Correlation exists between poor nutritional status of mother and prematurity, thus susceptibility of child to anoxia with resultant brain damage.) Woman should enter pregnancy in good nutritional status and good health in general.
- b. exposure of young girls to rubella, in order for them to develop immunity prior to child bearing period,
- c. diagnosis and treatment of toxoplasmosis, and
- d. education toward seeking early prenatal care, avoidance of exposure to infections and possible injurious agents.

Provision of comprehensive prenatal care in sufficient quantity and of high quality and convenient accessibility to all pregnant women, with special concern and provisions for the high-risk groups, such as the socio-economically disadvantaged, the grand old multiparas, the very young primiparas, unmarried mothers, women with previous disastrous outcome of pregnancy (fetal death or damaged child), and with previous complications of pregnancy (toxemias, premature births, Rh or ABO sensitivity, etc.):

- a. early and periodic obstetrical check-up,
- b. careful medical control of use of hormones, drugs, radiation, anesthesia, and other agents which may be potentially harmful,
- c. prevention and control of infections (e.g. syphilis, toxoplasmosis), and
- d. careful attention to optimal health maintenance during pregnancy, including nutrition.

IV. *Provision of optimal delivery care* to avoid brain injury to the infant.

- a. prevention of obstetrical trauma and accidents,
- b. prompt recognition and treatment of complications and abnormal conditions, and
- c. judicious use of analgesia and anesthesia (none in premature deliveries) to avoid anoxia in the infant.

V. *Expert care of the newborn* to avoid anoxia with resultant brain damage:

- a. apgar score for every newborn,
- b. immediate post-delivery care to assure adequate breathing,
- c. special care of prematures,
- d. avoidance of infections, and
- e. avoidance of Kernicterus (e.g. exchange transfusions in Rh or ABO sensitized infants, caution in Vitamin K administration).

VI. *Early recognition and prompt treatment of conditions leading to mental retardation:*

- a. screening of infants for PKU (and for other inborn errors of metabolism, when this becomes practical), and
- b. careful physical diagnosis. Early recognition and prompt treatment of hydrocephalus, microcephalus, cretinism.

VII. *Institution and development and follow-up of a high-risk infant registry*

VIII. Systematic and continuous health supervision of young infants and children including protective immunizations (e.g. pertussis, measles may lead to encephalitis and mental retardation).

IX. Prompt treatment of certain conditions and infections which may lead to Meningo-encephalopathies with resultant mental retardation; e.g. febrile convulsions, dehydration, TB, influenza, Meningococcal meningitis, etc.

X. Accident prevention (head injuries, lead poisoning may result in brain damage) program should be geared to developmental stage of the child and the adult:

- a. intensive accident prevention education for the public,
- b. network of diagnostic and treatment facilities open 24 hours a day,
- c. epidemiological and environmental follow-up of lead poisoning,
- d. provision of supporting legislation, and
- e. continuous research.

CASE FINDING AND DIAGNOSIS

The primary element in an adequate "continuum of care" is that of "case finding," i.e. discovering the infant or child with suspected mental retardation and referring him to an agency having special professional competence for diagnosis and evaluation.

Because of the almost universal practice of in-hospital deliveries in this country, opportunity exists for the observation and examination of almost every newborn child. Some forms of mental retardation, usually those of severe degree, are recognizable at birth; others are suspected as "high-risk infants" or "vulnerable candidates." The majority of cases, however, are not immediately apparent but are first distinguished by deviations from the normal patterns of growth and development. It is essential, therefore, for members of professions who see children at an early age to be familiar with normal expectancies. The responsibility for early identification of the mentally retarded child rests with physicians, psychologists, nurses, social workers, and other paramedical personnel.

There is urgent need to institute in all general and maternity hospitals a more meticulous system of examination and observation of the newborn. There should be special efforts at referral, follow-up by public health nurses, flagging of records in physicians offices and clinics, use of special neurological and other screening procedures, and appropriate items on record forms. The inclusion

of suitable items on the "confidential medical data section" of birth certificates also has value as a case-finding mechanism.

There needs to be identification for more frequent and intensive examination of the high-risk group of infants, i.e. those who for certain demonstrated reasons have greater likelihood of mental retardation than the general population. Criteria for the selection of such infants are increasing in number as more conditions or findings are positively correlated with the presence of mental retardation. Means should be developed for establishing and maintaining a "risk register" in order to bring such infants to the services they need.

Case-finding efforts should be continuous rather than sporadic. The ideal method is to provide for each newborn infant continuous health supervision by a private physician, pediatrician, or well-child clinic. This process should be fully backed by diagnostic laboratory, medical specialist consultation, and psychological testing service to confirm or refute the suspicion of mental retardation. Existing services should be used for this purpose and should be improved and extended to meet the total need. A mechanism for coordinating all needed diagnostic services both clinical and laboratory is essential.

Comprehensive diagnosis and evaluation of a mentally retarded child and his family requires an interprofessional approach. The diagnostic clinic or center should serve as a "fixed point of referral and information" to which the family can go to learn about their child's condition and to begin to formulate a lifetime plan. In addition to definitive diagnosis, a center should also offer professional counseling to the family on a continuing basis and should act as the intermediary between the family and other services in the community. (The concept of a diagnostic center does not necessarily mean a single structure or even a group of buildings. It is intended to convey a group of services, accessible and coordinated.)

The elements needed for good diagnosis and program planning are the following:

1. A complete social and medical history must be taken, including information on prenatal care, genetic factors, birth, development, relationships and attitudes of the family, reason for referral, current condition, illnesses, etc.
2. There should be a complete appraisal of the general health and physical condition of the child, noting any abnormalities, and providing clues for further medical investigation.
3. There should be a laboratory examination, including certain routine screening techniques such as urinalysis, blood count, X-rays, and electroencephalogram. Based on the findings in

the case history and physical examination, the physician should order any additional tests that are needed to refine the diagnosis.

4. The psychologist's evaluation and test procedures should be concerned with two broad areas: (a) determining the child's intellectual capacity and (b) analyzing the child's personality and patterns of behavior. It is essential that this information not be isolated, but correlated with other diagnostic data.

When the entire diagnostic procedures are completed the child should have a comprehensive diagnosis which relates to his total functioning. It should be developed on a team basis with some opportunity for the principal participants to confer and discuss the implications of the case. Findings must then be interpreted to the parents through skilled counseling. This is the initial step in a process which should include periodic re-evaluation, follow-up in counseling, and formulation of a lifetime plan for the retarded individual.

RESTORATIVE SERVICES

As a group, the mentally retarded have a high rate of concomitant physical defects and malformations. Many of these conditions are amenable to physical, social, and psychological treatments of various types. The aim of restorative services for the retarded is to alleviate the effects of such conditions through treatment in order to promote and maintain the greatest possible potential of self-sufficiency of the individual.

In general, the most severe physical defects coincide in incidence and degree with the severity of mental retardation. As they affect different systems and organs, these defects are of varying types and origins. They may be purely congenital or acquired; they may be aggravated and progressive. Many cases are handicapped by multiple defects. Some prominent physical defects are:

1. orthopedic conditions, such as muscular rigidities, fixed contractures, bone deformities and anomalies,
2. eye abnormalities and disturbances of vision,
3. defects of speech,
4. defects of hearing and balance,
5. general surgical conditions, such as hernias, hydrocoeles, glandular and vascular disorders,
6. general medical conditions, such as heart, lung, kidney, and blood disorders,
7. neurological disorders, such as hyperactivity,
8. psychiatric conditions,

9. dental defects, such as malformations of teeth and jaw,
10. defects of metabolism, such as phenylketonuria galactosemia and aminoaciduria, and
11. dietary deficiencies.

In programming restorative services, early diagnosis and determination of need are most important. Immediately following, a plan of early restorative measures should be formulated on the basis of a complete evaluation of the individual. The medical aspects of the plan must be coordinated with social, educational, and vocational considerations. Planning and treatment should begin in the hospital (or place in which need is first recognized) and should be continued in the home, school, clinic, institution, day-care center, or wherever. The physician should be involved, not only in planning, but also in insuring that plans are fulfilled, working in cooperation with other professionals.

Restorative services are of such a variety that all areas cannot be covered in this brief description. Several general observations, however, merit consideration:

- a. Practically all operative surgical treatment must be done in general hospitals. For best results, skilled specialized personnel should be utilized both for treatment and after-care, including plans for physiotherapy and occupational therapy coordinated with training, use of prosthetics, etc.
- b. Physicians and allied professionals should increasingly receive the benefits of education and instruction in mental retardation, including information on availability and locations of restorative services.
- c. Adequate provision for restorative services should be incorporated in plans for schools, home training, and care programs, day-care centers, diagnostic and evaluation centers, and new institutions. These plans should include provision for adequate numbers of skilled physicians, nurses, physiotherapists, speech therapists, and occupational therapists, with necessary space and equipment to service an expected caseload.
- d. Within existing institutions, medical services should be expanded to include more restorative services in addition to day-to-day care of emergent medical and surgical problems.

HOME TRAINING AND CARE

Home training is basically an educational service by professionals in the home designed to assist families in the development of an objective approach to everyday problems presented by a retarded

child, and to develop adequate training and care techniques primarily for the early formative years.

For most retarded children, early institutionalization is less desirable than a satisfactory family environment. Most parents want to keep their children at home, even though they sometimes need help in fulfilling their parental responsibility. By home visits and demonstrations, the public health nurse or other professional persons can help start proper training and care of the retarded child and relieve the parents' anxiety as well. Such services also enable parents to more objectively decide on the best plan of care for the future of their child, especially if it develops that the family cannot adapt its living pattern to include the needs of a retarded member.

Although usually concerned with the retarded infant or pre-school child, home training may also be needed in later developmental stages of life. In addition to the public health nurse, various situations may require the skills of the social worker, teacher, or other professional persons from the education, health, and welfare fields. These professionals should be available on a referral basis.

The retarded adult, who achieves or is forced into independent living, often lacks the ability to manage adequately. Home training should be available to him for assistance in budgeting, buying, general home maintenance, child care, and similar needs.

In those cases where mental retardation is complicated by the presence of additional handicaps, home nursing service should be available as needed. Nurses should be trained in the special aspects of home instruction for the retarded as part of their over-all health program.

The agency responsible for providing home training and care to families should bear the cost of this service, if the family does not have the means. (As public health services are available free of charge in many areas of New Jersey, cost for the purchasing agency would be minimal. Costs for more specialized professionals would need to be handled on a consultant basis.)

PRE-SCHOOL TRAINING

A pre-school training program is one in which mentally retarded children are assisted in their social, physical, and emotional development to prepare them more adequately for admittance to educable and trainable classes in the public school system. It is the initial step in group adjustment and educational play experiences for retarded children.

Prior to entering a pre-school training program, most retarded children have little or no contact with other children. Often such children are inadequately prepared for public school. The purposes of pre-school training, then are (1) to avoid early failure and

rejection, (2) to prepare these youngsters for acceptance into public education, and (3) to prepare them better for living at home and in the community.

Retarded children are often discovered after they have been admitted to school. The great challenge, at the pre-school level therefore, is to identify and assist these children in the community prior to formal public education. Some ways of locating such children are: publicity of the pre-school program within the community; referrals by pediatricians, public health organizations, and social agencies; referrals by parents, relatives and friends of children who are believed to be slow in mental development; and examination of younger siblings of children who are in special classes.

Upon referral a thorough case study of each child should be made. This should include a medical examination, a social history, a history of the development and problems of the child, the attitudes of the parents and siblings toward the child, his eating and playing habits, and a diagnosis of particular disabilities in intellectual or emotional traits. This data should (1) aid in the diagnosis of mental retardation, and (2) aid in determining the kind of educational program the child needs, pre-school or otherwise.

The criteria for admission to pre-school training should remain flexible. While certain broad criteria may be established and applied, each child should be judged individually regarding his potential for placement in special education classes. In doubtful cases, the child may be admitted provisionally and evaluated at the end of a probationary period, perhaps six weeks in duration.

If a child's need for pre-school training is indicated, such secondary factors as geographic bounds, age, or inability of the parents to pay should not be considered barriers to fulfilling the need.

As its major objectives, pre-school training should:

1. provide an environment for each child which will foster emotional health by promoting feelings of security, belongingness, and accomplishment;
2. foster good physical health;
3. provide opportunities for maturation through self-help throughout the day;
4. offer opportunities for the development of imagination and the expression of ideas and feelings;
5. offer opportunities for social development;
6. offer opportunities for the development of motor skills;
7. offer opportunities to develop intellectual abilities;
8. offer opportunities for parent education; and

9. provide for special clinical education for special disabilities found in the children.

In establishing programs for the pre-school mentally retarded, consideration should be given to the difficulty involved in organization, the cost of operation, the difficulties of discovering the children, and the lack of experience of professional personnel in this area. These are some of the problem areas that require further study and solution.

Pre-School education of the mentally retarded has been a long-neglected field. Although considerable research is currently under way in this area, it is clear that even more research should be undertaken in order to meet the need. Projects of cultural enrichment are needed for those pre-school children who are deprived of adequate opportunities for learning. Research is needed in determining what procedures and techniques are most effective in reducing the extent and degree of mental retardation.

Future research efforts should also attempt to establish the significance of pre-school training in the development of the mentally retarded. This phase in the education of retarded children is of utmost importance. It is possible that many children who are unable to adjust to society, would have been able to make an adequate adjustment after a well-rounded program of pre-school education. The cost of such a program may be insignificant when compared to the cost of support and care at a later age.

SPECIAL EDUCATION

Every child is entitled to instruction and guidance appropriate to his needs so that his intellectual, physical, and social potentials may be developed to the fullest. This premise is as true for handicapped children as it is for normal children. A child who bears the burden of a condition such as mental retardation, which prevents him from profiting from ordinary educational procedures, should be offered special educational opportunities to the extent necessary, and in whatever setting may be most suitable in the light of his medical, social, and educational needs.

The responsibility for providing such educational opportunity for mentally retarded children of school age rests with the public school systems. Each local Board of Education has the responsibility for identifying mentally retarded children of school age within the district and providing suitable educational services. In turn, the State Department of Education has responsibility for providing leadership, including expert consultation, for setting standards, for approving programs, for sharing their cost, and for enforcing pertinent laws and regulations which pertain to public education.

Help and encouragement on the part of educators at state and

county levels and of local educational administrators should be given to school districts in establishing several types of well-supervised programs to assist the mentally retarded—secondary school programs, work-study programs, sheltered workshop programs, and adult education programs. The total objective would be to make special education as much as possible part of a continuum that is related to vocational education and vocational rehabilitation.

Ideally, educational programs for the retarded should be designed to meet the particular needs and abilities of each child. Educational opportunities, facilities, and services provided by regular school programs should also be provided for special education programs.

Realistic requirements for admission to special classes should be determined and used. Psychological testing and counseling services should be made available to parents of suspected mental retardates, as a preliminary to classification and consideration for placement in special classes.

Teachers of the mentally retarded should be highly qualified individuals. Methods should be developed to provide for more effective training and use of personnel for teaching retarded pupils. National standards of special teacher qualifications and reciprocal certification agreements should be established. Also, means should be developed for more professional communication among teachers and other school personnel working with the mentally retarded.

Existing special education services should be reviewed and if necessary, be extended and improved to provide adequate and appropriate educational opportunity for retarded children, including children of pre-school age and children in local community or state-supported facilities.

COUNSELING THE RETARDED

Although case counseling of the retarded has been slow to develop, many professionals now feel that it is an appropriate tool in promoting the personal and social adjustment of a retarded client, and that it is an indispensable element for those experiencing situations of social or emotional stress. Though it cannot be applied to all segments of the retarded population, it can be selectively used with beneficial results for those with milder retardation and even some with more severe disabilities.

The impairment in judgment and verbal communication of the mentally retarded will usually make it necessary for the counselor to modify his customary techniques. To be effective, the counselor should also have a recognition and an understanding of the special nature of his client, and a conviction of his intrinsic human value and suitability for services.

In general, counseling the retarded should strive to:

1. promote the adjustability of the individual,
2. modify the environment by effecting change in attitudes and expectations, and/or
3. determine the environment best suited to the needs of the individual.

Service should be focused on that area most responsive to professional intervention and constructive change.

In promoting the adjustability of a retarded individual, i.e. making him more adaptable to new and changing conditions, there are three major steps or stages: (1) establishing rapport, (2) identifying problems, and (3) working out solutions to problems.

It is recognized that, in counseling the retarded, intellectual factors will impede to some extent the problem-solving process and complicate the individual's adjustment. The counselor must make special effort, therefore, to foster comprehension in his client and to rely on direct advice and guidance techniques. If and when the client is prepared to act on his own, the skillful counselor should modify his participation and encourage his client to make choices and decisions while also helping him to understand the alternatives and consequences.

While some retarded clients can be helped to become better adjusted through problem-solving, the successful adjustment of others will depend on the degree to which the environment can be "tailored" to their social capacities. The counselor should be cognizant of parental attitudes, living conditions, vocational opportunities, community services, and other supportive factors. He must try to determine if the retardate has a realistic chance of functioning in his present situation, or he must determine what surroundings will compensate for the liabilities of the person and make suitable recommendations.

The setting of the counseling function should be determined by need. In the community, for example, it might come under the auspices of the agency designed to assist with a management plan after diagnosis. Within the institution, it might be the special task of a qualified staff member in order to assist the retarded towards self-management and the constructive use of institutionalization.

In addition to individual counseling consideration should be given to group counseling. Members of group, when carefully selected, can contribute significantly to each other's social competence and feelings of contribution and fulfillment, in addition to providing observers an opportunity for insight.

RESIDENTIAL CARE

Residential facilities should be available to serve all retarded children and adults who are in need of long- or short-term care. They should be equipped to provide for the therapeutic needs of each individual. Institutions are one element in the total spectrum of services. Residential care should be community based and should be limited to those whose specific needs can be met best by this type of service.

The challenge to state institutions is how to accelerate the change from large isolated facilities to smaller units close to the homes of the patients and to the health, education, and social resources of the community; and the challenge to both state and private residential facilities is how to replace the old concept of custodial care, wherever it exists, with modern programs of therapy, education, and research.

Every institution should be basically therapeutic in character and emphasis, and closely linked to appropriate medical, educational, and welfare programs in the community. No institution should be regarded as merely "custodial"; those caring for the profoundly retarded offer unusual opportunities for the application of new methods of treatment and care, and for research. Diagnosis and evaluation should take place before admission. The institution should extend its services beyond the traditional boundaries of its own campus and reach out to assist the patient and his family before admission. This would facilitate visits by parents and friends after admission which is an important factor in early adjustment.

Flexible admission and release policies and outpatient programs similar to those of a hospital or school are also essential.

The goal of every residential program should be the elimination or amelioration of as many symptoms as possible and the achievement of independent, semi-dependent, or even a sheltered extramural life for every person under care in accordance with his potential. This can be accomplished only by a devoted staff with a variety of professional skills and a competent administration. The support and leadership of a competent and interested state department and board of trustees is necessary.

Indoor and outdoor recreation, social activities, programs of physical fitness, and opportunities for self-expression through music, painting, and worship, as well as other creative outlets are essential aspects of sound institutional programs.

No child or adult should remain in residential care any longer than necessary. Regular re-evaluations should be scheduled to determine if the individual has reached a point where he can profit from other programs of care available in the community. When the

Retarded person is ready for return to the community, adequate resources and services for his support should be made available. It may not be wise or possible for some to return to their own families, hence the importance of developing foster or boarding home placements, or homes for small groups similar to those in several European countries. Responsibility for the care of persons returned to the community should not be relinquished by the institution until assistance is assured from some other source. Efforts should be made to see that community services are made available to him before he leaves.

Many residential populations lend themselves to certain unique research undertakings, particularly of a clinical nature. Continued critical evaluation of the institutional program requires personnel with particular interest in research. It is important, that research in some form be a part of the institutional program.

DAY CARE

Retarded children have the same basic needs, as do normal children. Parents of retarded children, therefore, have the same right to educational services for their children as parents of mentally adequate children.

Day Care is a community-centered program designed to provide for the training and social adjustment of severely and profoundly retarded children of school age who cannot fit into public school programs and who are not in an institution. Thus, retarded children excluded from public school by virtue of a classification as neither educable nor trainable are provided with service.

The need for this program is based on the following fundamental beliefs:

1. that the retarded individual has worth and dignity as a person;
2. that he has a right to the kind of help he needs; and
3. that, with proper training, he can be helped to achieve his optimal performance level.

The specific aims of a Day Care program are:

- a. to stimulate the child's awareness of himself and his environment;
- b. to aid the child in developing habits of self-help, cleanliness, and personal care;
- c. to aid the child in achieving optimal social and emotional adjustment;
- d. to aid the child in developing his communicative ability to his maximum potential;

- e. to encourage the child's interest and awareness of his surroundings;
- f. to aid the child in learning to develop control of his body movements;
- g. to aid the child in learning to understand and follow directions;
- h. to aid the child in learning to identify familiar persons and objects;
- i. to provide the child with the opportunities for self-expression;
- j. to promote the child's independence and social acceptance;
- k. to aid the child in developing acceptable habits of social behavior; and
- l. to provide the child with acceptable outlets for tension reduction.

The Day Care child is usually unable to care for his own basic needs. He may not be toilet trained, unable to feed himself and to talk, and suffering from one or more physical or emotional handicaps. His total social experience generally has been limited to his parents and siblings.

For such a child, Day Care provides a controlled environment, highly structured with schedules and routines, in order to help him reach his maximum potential for self-efficient functioning. Self-help and self-care activities are stressed on a habit formation basis. Socialization, that is, the training in proper habits of social living, is also stressed. Learning, in the usually accepted sense, is denied the person of extremely limited intellectual capacity; therefore, acceptable behavior and performance on a habit basis rather than a thinking basis is instilled in the individual.

Day Care is also a parent-oriented program. It affords real relief several hours a day to mothers who often face tremendous burdens with the daily care of severely or profoundly retarded children. The program offers assistance to families through parental counseling prior to a child's admission into a center and subsequent to enrollment in a program. Through relief from the task of 24-hour care and the other helps afforded by the program, tensions within the home decrease and the mental health of families improves considerably.

Many retarded begin and end their lives in the community. Their care frequently presents many and grave problems, especially for those of the more severe levels of retardation. Many families desire to keep their retarded at home rather than in an institution. Day Care programs render real assistance to such families in enabling

them to keep the retarded at home and in the community. Furthermore, these programs provide a wider range of experience than can be developed within the family. At the same time, the values of participation in family life are retained.

In addition to the benefits that Day Care programs provide to the retarded person, his family, and his community, these programs also reduce the need for institutionalization. Consequently, institutions are able to reduce their waiting lists and to some extent their over-crowded conditions.

RECREATION

The mentally retarded need opportunities for recreation. Their need is frequently intensified by isolation resulting from parental over-protection, failure in school and occupational pursuits, and exclusion from normal group activities. From participation in appropriate recreational activities, mentally retarded persons can derive important physical, social, and educational benefits.

Physically, recreation promotes good health, growth, fitness and strength, coordination, and athletic ability. Socially, it teaches teamwork, competition, self-esteem, self-confidence, and response to leadership. Educationally, it aids the learning process by providing opportunity to relate words to objects and actions. The rules of the game are visualized in actual situations. Then, through repetition, all of the elements are continuously associated with each other and with the actions of the learner. Hence a principle is established that can be applied also in the classroom or training situation.

Within the framework of existing recreational and social programs, the needs of the retarded should be provided. State and community services should be available without discrimination against the retarded. This may require inclusion in a regularly scheduled program or modified and specialized programs structured for their specific needs.

Thus, many retarded children and adults can, if they are allowed, participate in existing services. They can use the parks, golf course, tennis courts and swimming pools; attend day and over-night camps; utilize commercial resources such as theaters and bowling alleys; take part in Boy Scouts, Girl Scouts, Camp Fire Girls, YMCA, YWCA and CYO; and join community organizations on trips to sports events, county and state fairs, the circus, and places of historic or scenic interest. Perhaps more than any other age group, the retarded adolescent and young adult need social programs.

In the case of the more severely retarded, other services are needed. Specialized programs should be soundly geared to their physical, intellectual, and social characteristics. Skilled leadership

is needed for such programs. Information on recreation should be available to assist individuals and groups in developing programs; information about successful programs should be collected and shared with others. Within residential care facilities, existing recreational programs should be reviewed and expanded where necessary.

Since most mentally retarded individuals live at home, recreational activities are largely dependent upon the interests, skills, and available resources of their families and of the community. Families having mentally retarded children need assistance in understanding the development and play activities of the retarded child. They also need motivation and encouragement to bring their children to recreational activities. Community agencies providing recreational programs and services should be encouraged to include the mentally retarded. Likewise, the churches and synagogues should make their resources available for recreation and other group activities involving the retarded. Consideration should be given to providing transportation. Recreation is essential for the development of the retarded since it can be one of the most constructive means of teaching them how to live together with others.

VOCATIONAL REHABILITATION

Vocational rehabilitation services are designed to assist the handicapped individual to develop his work capabilities so that he can adequately function in the employment world. Rehabilitation services to the mentally retarded in New Jersey have largely been through the Federal-state program administered by the New Jersey Rehabilitation Commission. Certainly, many public and private agencies have been and are currently involved in the total picture. Without the cooperation of special education, the private non-profit sheltered workshop, the Association for Retarded Children, the public institutions, and other governmental and non-governmental agencies, the Rehabilitation Commission could not perform its function.

The vocational rehabilitation process incorporates the following steps: (1) identification of adults and young adults in need of services; (2) a diagnostic evaluation to determine the current mental and physical status of the individual; (3) corrective medical measures when needed such as hearing aids, orthopedic appliances, psychotherapy, etc.; (4) vocational training when indicated in a sheltered workshop, private training facility, or on-the-job; (5) job placement at a level commensurate with the individual's capacities and interests; and (6) vocational counseling.

Ideally, vocational rehabilitation is viewed as that part of the continuum of services which comes into play prior to the termina-

tion of the individual's public school experience or institutional experience and bridges the gap between this experience and ultimate self-support. The vocational counselor is viewed as an essential part of the school or institutional team which begins community planning before the individual reaches an employable age. It is felt that a vocational rehabilitation function should be incorporated into each school district and into each institution.

For the retardate who needs extensive work evaluation, work training, or work experience prior to competitive employment, the non-profit sheltered workshop serves a vital function. Typically, the individual client is provided with a prevocational evaluation designed to elicit his interests and to estimate his ultimate work potential. Following an evaluation, the workshop frequently provides a period of personal adjustment services including intensive counseling. Vocational training opportunities to provide work skills needed in the performance of specific jobs should be available. As part of the total workshop process, competitive job placement is seen as the basic and primary objective for the upper-level retardate.

For the retardate who has some capacity to contribute to his self-support, but who lacks ability to function in competitive employment, the non-profit sheltered workshop also provides long-term paid employment through sub-contract work, prime manufacturing, or salvage activities. Remuneration is commensurate with the individual's productivity.

Workshops need to maintain a secure financial base in the light of the number of clients who require this type of setting for many years. Government, it would appear, can afford stability and security to this group of clients either by subsidy to the workshop or through the establishment of publicly operated workshop services as part of a comprehensive community based facility for the mentally retarded.

Basic requirements needed to round out an ideal picture of vocational rehabilitation in New Jersey are additional (1) funds to service more cases, (2) counselors to handle special caseloads of mentally retarded, and (3) university-based programs to train the many vocational counselors who will be needed.

JOB PLACEMENT

Job Placement means assistance that is provided to the mentally retarded in:

1. choosing a suitable field of employment,
2. securing a specific job, and
3. solving difficulties that arise in the employment situation.

Since a number of community agencies presently have contact with

the retarded and their families, it would seem to be a natural development for such agencies to help retardates in the area of employment. Specifically, these agencies should include:

1. school personnel who develop part-time job opportunities for special class students;
2. rehabilitation counselors who endorse and subsidize work programs;
3. field service workers who assist the retarded in after-care programs as well as in programs which offset the need for institutional placement;
4. selective placement counselors who evaluate retardates for placements and job referrals;
5. job counselors who have job leads for the retardates or, who can supply such information to other agencies;
6. social workers who seek to motivate a person as well as to provide help or referral;
7. workers in special projects, e.g. war on poverty, retraining drop-outs, etc., who come in contact with the retarded; and
8. volunteers who may be helpful to any of the above.

A wide range of work opportunities should be available to the retarded. Ideally this should include:

1. terminal workshops,
2. training workshops,
3. sheltered employment with sleep-in facilities,
4. sheltered employment without sleep-in facilities,
5. halfway houses from which retardates grow into independent living situations, and
6. competitive (full) employment at (a) on-going rates of pay and (b) part-time (day work) opportunities.

One must understand the requirements of the situation as well as the applicant's possibilities. He must know what a job requires in terms of physical capacities, mental abilities, interests, and personality traits. This knowledge should then be measured against all that the counselor knows about the retarded client, i.e. his school records, test results, interviews, personality traits, abilities, interests, stability, alertness, and willingness to accept direction. Only then, can an adequate judgment regarding job placement be made.

In general, the single act of getting a retarded individual a job is far from fulfilling his total need. The person involved should assure that the retardate is sufficiently encouraged and helped.

Attention to details cannot be overemphasized in the case of the retarded seeking a job. Experience suggests that many potentially successful job placements have resulted in frustration and failure because of minor reasons. Help should be provided in filling out forms, securing a Social Security card, locating and using public transportation, and in other details. An on-going supportive relationship is needed to guide the individual during the employment period. The retarded individual should be encouraged toward more independence in living and afforded more opportunity for making judgments and solving problems. In the last analysis, it is the retardate who makes or breaks a job situation, yet the efforts of those who assisted him in job placement are of considerable significance.

Families of the retarded play an important role in successful job placement. Through recognition and encouragement, they can help the retardate achieve a degree of security, responsibility, and independence.

In the community, much needs to be done to foster the interest of potential employers and civic groups. Toward this end, the employer who has hired the retarded can be a valuable asset in influencing other employers to utilize the abilities of the retarded.

FAMILY COUNSELING

A plan of treatment for a mentally retarded person cannot be considered complete without a meaningful explanation to the family and a consideration of their problems and emotional involvements. Families of the retarded should not be considered as merely passive recipients of authoritatively presented wisdom, but rather as deeply concerned persons who need to become better prepared for the task that faces them. Family counseling should be an indispensable part of the over-all clinical procedure.

The physician, psychologist, counselor, social worker, and teacher play major roles in guiding the efforts of parents. All should be well trained in interviewing techniques and counseling methods, and should be well informed about sources of referral.

The most valid and practical guide to family counseling originates from the questions of parents. An authority in this field¹ identifies five major areas of parental concern:

1. the features of the diagnosis,
2. the etiology of the disturbance,
3. the prognosis,
4. the child's place in the family structure, and
5. therapeutic management.

¹ Dr. Leo F. Kanner, professor emeritus of child psychiatry, Johns Hopkins University, "Parent Counseling" from "Mental Retardation", Rothstein

The questions vary, of course, depending on many factors such as the family group, religious and ethnic background, economic circumstances, social status, personality characteristics. Often, questions are asked not solely for obtaining factual information but with recognizable psychological overtones. A further complication is introduced by the fact that families bring to the counseling situation a network of earlier information, misconceptions, advice, and so on.

Let us consider separately each of the above concerns in some detail, although in practice they are overlapping and interdependent.

Any diagnostic formulation that is offered to the family of the retarded should be based on clear knowledge of the patient's status, derived from a thorough physical, psychological, and social investigation. In addition, the form of disclosure should be adapted to the pattern of the family's orientation toward the child, their environment, and themselves. Obviously, much tact is required of the counselor. The different types of attitudes that he will encounter are deeply grounded in the emotional backgrounds of the parents. But when the parents have been brought to accept the child as he really is, with full knowledge of his strengths and weaknesses, the first step of effective family counseling has been taken.

Once the issue of diagnosis has been settled, parental solicitude converges on the problems of etiology and genetics, areas where much is still to be learned. Typically, parents want to know the cause of the retardation, its relation to heredity, and the risk involved in future reproduction by themselves or their normal children. Not all such questions can be answered unequivocally, but knowledge that is certain should be separated from statistical odds, and such information imparted to parents. When false beliefs are uncovered, the counselor has a responsibility to correct them. He should not, of course, make decisions for the parents but can give them the biological facts they need in order to make decisions themselves. In addition, he can provide authoritative reassurances to persons whose belief in human and parental competence has been badly shaken.

A correct diagnosis is the basis for any prognostic evaluation. In family counseling there are situations, especially when the patient involved is in the early years of life, which call for caution in arriving at a definite conclusion. If results are uncertain, it is advisable for the counselor to hold his judgment in abeyance until a clear picture emerges. When he has obtained an adequate estimate of the child's present and future potentialities, he has an obligation to transmit this information to the parents. If the parents are too distressed about the future outlook, they can be helped to perceive the child in stages of progress.

Another important area of family counseling is the place of the retarded child in the family structure. Few parents can escape the initial trauma that accompanies the diagnosis of mental retardation. They can, however, be helped to understand the child's condition and his place in the family. In adapting their living patterns to the child's special needs, families will vary considerably. The counselor must consider the predominant characteristics and values of the group to which the family belongs as being an influence on their attitudes and responses. Parents can be helped to perceive characteristics that the retarded child may have in common with his normal brothers and sisters. Parents should be helped to set realistic goals for their retarded child, thereby saving themselves and him needless frustration. They should be assured that continuing guidance will be available to them as new situations arise.

All of these concerns are an indispensable prelude to formulating a plan of therapeutic management for the retarded child. Hopefully, the parents, having come to terms with their own feelings, will act as collaborators with the counselor in effective long-range planning. The counselor can suggest to parents specific management techniques, as well as ways in which the parents can contribute to the growth and development of the child. Because of his knowledge of the family, the counselor can often point out to parents the strengths and weaknesses of their particular approaches to the problem. Together, the counselor and the parents, in cooperation with appropriate disciplines and services, should objectively consider a variety of arrangements as indicated by the needs of the child, whether they be of a medical, psychological, sociological, or educational character. The counselor can also encourage parents to look for further help from their community resources and local parent organizations.

PARENT EDUCATION

Parent education means helping parents to accept and understand the problems of their mentally retarded child. It is one of the most important parts of the child's management.

A Parent Education Program should be one which helps the parents to accept responsibility for carrying out a total program of rehabilitation and therapy for their child, plus fulfilling their child's needs in the home. In general, there are three major directions which can be taken in establishing a parent education program:

- a. those parent education programs developed in cooperation with and utilizing the service of professional specialists;
- b. those group education programs for parents which utilize the service of both the professional specialist as well as the parents in interaction; and

- c. those parent education programs developed primarily through interaction and inter-participation with other parents.

The content of such parent education programs depends in great measure upon the parents' needs and the available resources within the community. In general, parents should receive basic information on the various aspects of mental retardation—medical, psychological, social, educational, vocational, personal—especially as particularly related to the family environment.

In addition to programs, various services should be available to parents and should achieve the following:

- a. to assist parents through counseling to understand the nature of retardation and the developmental potentials and limitations of their retarded child;
- b. to assist parents with home-training problems of retarded children in basic habits of self-care, self-control, communication, and socialization;
- c. to assist parents in planning for the future of their retarded children;
- d. to acquaint parents with community resources and how community services can be obtained;
- e. to assist parents in securing other services, such as nursery school, day care, social and recreational services.

HOMEMAKER SERVICE

As defined by the National Conference on Homemaker Services (1959), a homemaker is "a mature, specially trained woman with skills in homemaking who is employed by a public or voluntary health or welfare agency to help maintain and preserve family life that is threatened with disruption by illness, death, ignorance, social maladjustment, or other problems. A pleasant personality, physical and mental well-being, experience, and training enable her to assume full or partial responsibility for child or adult care, for household management, and for maintaining a wholesome atmosphere in the home. She does these things under the general supervision of a social worker, nurse, or other appropriate professional person connected with the sponsoring agency. She exercises initiative and judgment in her performance of her duties, recognizes the limits of her responsibility, works cooperatively with family members, and shares her observations and problems with those responsible for the homemaker service program."

Homemaker service is primarily a temporary service in the home for the purpose of supplementing parental care and maintaining family unity. It is necessitated by any situation which is considered

a "crisis" in a family's life, e.g. illness or death of a parent, serious illness of a child, birth of a new child, absence of a parent, etc.

For the family with a retarded member, the fact of mental retardation itself frequently requires major adaptation in family life. Because of the type and amount of care required, what may be a routine problem in many families can become a "crisis" situation for the family with a retardate. At such a time, bringing a homemaker into the home can insure proper care of the retarded member and direct assistance for the daily life needs of all members of the family.

An important secondary function of the homemaker is that of teacher. Many parents of retarded children are socio-economically deprived and some are of limited mentality. Although these parents may want to give proper care to their child, they often lack the maturity, know-how, and resources to do so. The homemaker, with the supportive help of a social caseworker, can teach these parents how to budget, plan meals, market, keep house, and care better for their children.

The homemaker that is assigned to provide service to a family with a retarded member should have specialized training. Where possible, professional personnel should be utilized to instruct homemakers in the special problems of retardation as related to their service. The homemaker should have an interest and aptitude for work in this type of home situation. The homemaker's participation in staff discussion of individual case situations can be an additional training experience.

Homemaker service should function in close cooperation with other agencies and services in the community. (In New Jersey, this service is available in 16 of the 21 counties. Most of these are independent agencies, having their own boards and fund-raising committees; a few are connected with health or counseling agencies. Homemaker service is purchased from these agencies on an hourly basis.) The cost of homemaker service should be assumed by the family if possible, or by the agency purchasing this service for its client.

WELFARE

Welfare departments provide services to neglected and dependent children, the aged, the totally disabled, and others in difficulty. The services provided to these groups include financial assistance, homemaker services, foster care placement, guardianship, and protective services. Many mentally retarded persons and their families may need these services. They should, therefore be available and geared to the special needs of the retarded.

While some state agencies have undertaken program responsibilities for the mentally retarded, many more seem unaware of the impact of mental retardation on their caseloads and have made a limited or a reluctant response to this problem. In comprehensive planning there is a unique opportunity to promote an appreciation of the welfare implications for the problem and to chart a course for program development and for cooperation with other agencies.

The following services and provisions merit careful consideration:

1. identifiable services for the mentally retarded with adequate staff;
2. that present regulations and practices do not discriminate against the mentally retarded;
3. services be related in a positive manner with employment, rehabilitation, vocational education, health, residential care, and other services to reduce dependency and protect the retarded;
4. good programs of case finding to locate and provide social services to the retarded and their families;
5. programs providing information and referral services, financial assistance, counseling services, and protective services in order to meet the needs of the retarded and their families;
6. child placement programs for those requiring suitable substitute homes as well as for the return of the child to his own home and community;
7. coordination of clinical and program services for the retarded individual in the community in order to obtain maximum development of the child;
8. provision of day care programs which are suitably licensed and supervised.

FOSTER HOME AND FAMILY CARE

Foster home and family care are welfare services which provide substitute family life for a planned period of time for a child or adult who has been separated from his natural or legal family, together with casework and other treatment services needed by the individual and his family. (Both terms are frequently used synonymously, although foster home care is usually understood to be for infants and children, while family care is for adults.) These programs offer the individual a closer approximation to normal family living than other types of substitute care. The foster home program is particularly adapted to meet a child's developmental needs in a family-centered society.

Normally, the mentally retarded person's own family offers the best environment for management and social adjustment. But whenever individual responsibility fails and circumstances are such that

his needs cannot be met in the home, the community becomes responsible for his welfare. The placement of retarded individuals outside their natural homes should be determined on the basis of their specific needs. This approach should include the following:

- a. systematic evaluation (medical, psychological, educational, social, etc.) of each individual by an interdisciplinary team;
- b. an appraisal of the kind of placement facilities available (foster home, boarding home, public or private residential institution, nursing home, etc.); and
- c. a survey of the kinds of programs (community-based and institutional) which will meet the specific needs of the individual under consideration for placement.

For those retardates who must be cared for outside their own homes, their needs should be determined by social study, and subsequently by continuous study and supervision. The ultimate welfare of the individual should be the main consideration guiding all decisions. These decisions, based on his objectively-determined needs, should provide him the fullest opportunity for emotional, spiritual, mental, and physical growth.

The retardate and those with whom he has significant relationships should be carefully prepared for placement. Efforts should be made to conserve a child's relationship to his parents, to involve the parents and relatives in constructive planning for the child, and, if possible, eventually to re-establish the child in his own home. Sometimes the home environment can be improved (perhaps by a social worker) while the individual is away, permitting him to return to his home eventually. In those instances where destructive parental relationships are clearly established, efforts should be devoted toward clarifying those relationships so that separation may pave the way for constructive ongoing planning.

Foster home and family care must be planned accordingly when there is no foreseeable possibility of a child's return to his own home or adoption. The duration of care should depend upon the ultimate outcome of this service in accordance with the needs, age, and problems of the child, the degree of his retardation, the nature of his relationships with his family, and the extent of parental incapacity.

Foster home and family care should be available for all ages. On a short-term basis it can (1) relieve the family of the burden of caring for a retarded child, (2) aid the family in case of sickness, and (3) give parents an opportunity to leave their retarded child well cared for while absent from home. The service should be available for those retarded who no longer need the protective care of an institution, as well as for those who no longer can be cared for in the family because of the death or incapacity of

parents. In both situations, placement can be on short- or long-term basis, depending on the specific needs of the retardate and the home situation. All retardates so placed help to reduce the number requiring institutionalization.

RELIGION

To the extent that mentally retarded persons can benefit from religious training and activities, their participation should be encouraged. Religious denominations of the community have an obligation to provide both church services and instruction geared to the special needs of the retarded.

Religious groups should work in cooperation with parents' associations to provide such service. Religious leaders should take the initiative in establishing or improving special classes, Sunday school classes, and special religious services. They should be aware of current information on basic aspects of mental retardation—medical, psychological, educational, social, and recreational—in order to better serve the retarded.

Religious organizations should provide state and private institutions with the services of a clergyman. Whenever possible the parents of children residing in institutions should be allowed to take their children to local religious services.

Some denominational colleges presently have cooperative programs with nearby institutions for the retarded. These programs provide a good opportunity for students to work with young people in institutions. Seminaries should include instruction in mental retardation as part of the regular curriculum.

The clergy can significantly assist parents through counseling and guidance, and in providing spiritual solace. The clergy can also help parents achieve emotional and social stability.

Some excellent publications on mental retardation by various religious groups should be continued and given wider circulation. The retarded of all faiths should receive religious education through regular means or by special programming. Major religious groups should confer on ways of enlarging their activities to help the mentally retarded.

RESEARCH

Research, as a generic term, refers to the application of scientific methods to carefully defined problems so as to insure attaining minimally ambiguous solutions to these problems. In relation to mental retardation, research may be conceived of as falling into two main categories: basic and applied research. In the psychological area, basic research includes studies designed to increase the

understanding of the mentally retarded child's basic learning processes, intellectual structure, personality characteristics, and perceptual characteristics. In the medical research area, a greater understanding of the neurological, bio-chemical, and genetic characteristics of mentally retarded individuals is the primary focus.

Yet, basic research studies are only a first step in the development of a total research program for the mentally retarded. Such studies may provide us with advanced knowledge of intellectual structure, the principles of learning, perceptual processes, and inborn metabolic errors. The next logical step, however, would be the initiation of an applied research program. This program would make use of improved theoretical understanding of the nature of mental retardation in designing studies to find better educational methods, more reasonable curricula, improved techniques for psychological treatment, better institutional management, and perhaps ultimately the prevention and cure of certain types of mental retardation through medical intervention.

In an ideal research program, then, basic research provides understanding and increased knowledge while applied research would put new understanding to work in a constructive and beneficial way.

The history of both public and private efforts in New Jersey to advance knowledge in the field of mental retardation through research is a long and productive one. From the establishment of the Research Laboratory at the Training School at Vineland, under the direction of Dr. Henry Goddard, to the state supported research program within the Department of Institutions and Agencies initiated at the Edward R. Johnstone Training and Research Center in 1956, New Jersey has been identified with the best in psychological and educational research.

Evolving from the original premise that the state had a responsibility to subsidize research into the many problems associated with mental retardation, the research program at the Johnstone Center has grown in staff, scope, and consequence. Several federal agencies have supplemented the state's investment by awarding research, development, dissemination, and construction grants to the institution. The production of quality research in this area has been and continues to be a trademark of the Johnstone program. Few professional meetings in the behavioral sciences have been held since 1956 which have not presented contributions from the Johnstone research staff.

There is compelling evidence to the effect that Institutions and Agencies' venture into research in mental retardation has been an unqualified success. With advances in this research area being made across many disciplines, it is proposed that the Johnstone program requires supplementation. Institutions and Agencies must continue

to facilitate research in mental retardation by the development of appropriate research centers in some of its other institutions, based on the Johnstone model. The Johnstone research unit is exclusively concerned with the behavioral sciences. Perhaps a well staffed medical research unit, in collaboration with a medical school program, might be installed at Vineland, Woodbine, or Woodbridge. A unit stressing social factors in mental retardation might be placed at Totowa or New Lisbon.

The successful research program within the Department of Institutions and Agencies described above raises the question as to whether other public agencies within the state also have some responsibility for research—if not the active operation of research programs then at least the provision of research consultation and facilitation services.

For example, it would appear reasonable that some types of badly needed research in teaching methodology should be carried on under the auspices of the State Department of Education. Some of the alternative strategies for accomplishing this purpose might include: (1) a centrally located research staff that would carry on its program in the public schools; (2) a research consultant on the central office staff that would work with State Department personnel to identify critical issues and then stimulate the development of appropriate research programs utilizing the resources available in the state college system or elsewhere; or (3) follow the model of the University of Illinois where the State Department of Public Instruction has helped to establish an Institute for Research on Exceptional Children. This Institute, in addition to initiating and conducting its own research program, also acts as the research arm of the State Department. Perhaps, the State Department of Education in New Jersey could help to underwrite a similar program at one of the state colleges or at Rutgers University.

The New Jersey Rehabilitation Commission has long been an approver and transmitter of research applications going to the Vocational Rehabilitation Administration for support. With its burgeoning program, the Rehabilitation Commission might wish to consider the establishment of a research program that would relate itself programmatically to issues that the Commission deems important rather than delegating the responsibility for research initiative entirely to scattered individuals in the universities.

The arguments for local research efforts applied to the Department of Education and the Department of Labor and Industry can also be applied to the Department of Health as well as other units of state government. A cautionary note should be sounded at this point to make it clear that although a systematic research program

of some type is being proposed for all appropriate divisions of state government, there is no intention to foster the idea that these should be discrete and isolated programs. On the contrary, many of the research programs developed in the different departments will overlap conspicuously in content as well as methodology. It is suggested, therefore, that any widespread awakening of research interest in the various divisions of state government should be followed immediately by the establishment of an Interdepartmental Committee on Research. This Committee would facilitate integration and avoid duplication of research efforts. It would make facilities, staff resources, and experimental populations available in any one department accessible to all.

The findings of good research and their appropriate application have long been acknowledged as the bellwether of good service. If research is deemed to be a legitimate and important concern of state government, then it should be encouraged, in all its ramifications, through administrative and financial support.

LAW

Equality before the law is based on the assumption that every person has a comparable capacity to invoke the law's protections and abide by its proscriptions. Such a capacity, requiring a minimum set of personal characteristics, may not be altogether present in certain handicapped persons, but also may not be totally absent.

In recent times, the law has become aware of this variability and has expressed its concern for "naturally disabled" individuals in a rapidly expanding body of statute and opinion. In dealing with this group, which includes the mentally retarded, the law recognizes a very difficult and complex problem. Summarily, the problem is threefold: (1) to recognize conditions which depart from the norm and to differentiate among them, (2) to take account of the provision which society already makes for its disabled members, and (3) to prepare to adapt to the problems and to take advantage of alternatives in disposition.

In its efforts to cope with this vast problem, the law appropriately calls upon the expanding knowledge and resources of other professions, such as medicine, psychology, education, and social work. It is the law's responsibility to develop and refine the legal provisions and practices which affect the lives of the mentally retarded in a number of areas: residential care (public and private, voluntary and involuntary), civil incompetency and restoration, guardianship, adoption, marriage, annulment and divorce, eugenic sterilization, the validity of contracts, deeds and wills, suing and being sued, juvenile court determinations, and areas of criminal law (including the ad-

missibility of statements made to the police under questioning, competency to stand trial, and criminal responsibility).

Determining the total relationship of the law to the mentally retarded requires the best resources of current legal knowledge and judicial opinion. The following general principles should be considered:

1. Legislation relating to the mentally retarded must be primarily protective. For example, the child must be protected against ill treatment and neglect; the adolescent and adult must be protected against exploitation; the family must be protected against dissolution and unnecessary hardship; and the community must be protected against antisocial actions.
2. Protective legislation should be reviewed regularly to determine that it is fulfilling its intent, and that it has not become self-protective, that is, guarding the rights of those with vested interests in the retarded rather than the persons themselves. Overprotection should also be avoided.
3. Legislation covering the needs of the mentally retarded should as far as possible be made within the framework of more general legislation on the rights and needs of all persons, or, more specifically, of all disabled persons.
4. Where possible, legislation should be of a positive rather than a negative character. That is, legislation which imposes statutory duties on authorities is likely to be a greater benefit and advancement to the mentally retarded than that which emphasizes penalties for failure to carry out responsibilities.
5. Legislation relating to the mentally retarded should deal with the issue of guardianship. The scope of the guardianship should be specified and carefully adapted to the requirements of each case. Guardianship of property must be clearly distinguished from guardianship of the person.
6. There should be legislation that ensures adequate supervision of institutions caring for the mentally retarded.
7. There should be legislation that deals with commitment procedures and voluntary admissions, as well as the particular circumstances pertinent to each.
8. There should be legislation that distinguishes between mental retardation and mental illness and deals separately with each condition. There must be definition and consistent use of these and similar terms.

9. The courts should recognize the chronic character of mental retardation as well as individual differences among the retarded. Such recognition should be reflected in regulations regarding criminal responsibility.

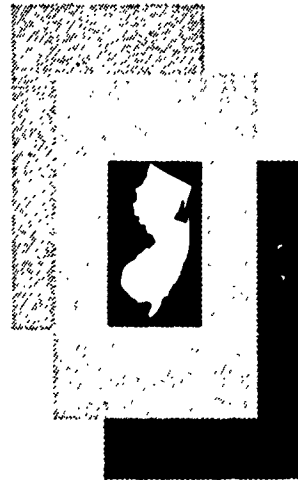
PUBLIC AWARENESS

Future progress in mental retardation is largely dependent upon public awareness and public understanding. These are the foundations for community support and financial backing so necessary for the success of mental retardation programs. Also, they help to shape the attitudes of legislators, administrators, and workers in pertinent fields. Public education programs should focus attention on the nature, scope and social implications of mental retardation. It is recognized that a public education program of the scope and content needed for mental retardation is such a huge task that it cannot and should not be the responsibility of any single organization, but should become the joint responsibility of several.

The use of mass communications media should be employed: such as articles in professional journals, newspapers, and magazines; press kits, films, television "spot announcements;" exhibits at professional meetings, talks to civic and fraternal organizations, visits to state facilities, institutes for professionals in related fields, a central information service for both professionals and laymen, and so on. Most of these are being utilized to some degree at present, but they should be expanded, perfected, and coordinated for fuller impact.

A coordinating group should work closely with those presently active in informing and educating the public on mental retardation. The objective would be to strive towards an ideal climate of widespread public acceptance and understanding of mental retardation.

Section IV
STATE PROGRAMS



In order to determine the extent to which needed services are presently being provided to the retarded and their families, studies were made of current state programs in those departments having direct responsibilities concerning the mentally retarded, that is, the Departments of Institutions and Agencies, Health, Education, Labor and Industry, and State.

Brief descriptions of these departments and programs are contained in this section of the report.

A. DEPARTMENT OF INSTITUTIONS AND AGENCIES

1. Division of Mental Retardation

An important development in the administrative structure of government in New Jersey took place with the formation in 1919 of the State Department of Institutions and Agencies; an "omnibus" department which encompasses mental, correctional, and welfare institutions, with associated out-patient and community service, together with the state's public and child welfare programs. Common administrative and professional services were centralized within this department even though certain aspects of the direct management of the institutions continue to be vested in the individual boards of managers. The entire department is governed by the unpaid "Board of Control" which appoints the commissioner as its chief executive officer.

Between 1952 and 1959, the general administration and coordination of the state's intramural program and the development of extra mural supervisory and consultant services to the mentally

retarded and their families in the community was vested in the Bureau of Mental Deficiency within the Division of Mental Health and Hospitals. In December 1959, on recommendation of the Governor's Commission to study the Department of Institutions and Agencies, the bureau was superseded by the new Division of Mental Retardation, whose director is responsible directly to the commissioner.

The Division of Mental Retardation has the responsibility for the supervision of the activities of six institutions for the mentally retarded. The department cooperates with other state agencies and community groups for the development of needed programs for the retarded. The division has been organized into five programs: Admission and Classification, Institutional Service, Purchase of Care, Field Services, and Day Care.

a. Admission and Classification

The Admission and Classification Service of the Division of Mental Retardation is located within the central coordinating unit of the division—its central office. The Coordinator of Admission and Classification and his staff are responsible for the following:

- a. determination of eligibility for placement in state institutions for the retarded. In implementing this function, the coordinator works in conjunction with Field Services. Data of a psycho-social and developmental nature are secured by Field Services, and with other related information, forwarded to Admission and Classification for evaluation. Field Services can be requested, if necessary, to secure additional data. If eligibility is determined in the affirmative, classification to the appropriate state institution is made on the basis of age, sex, programs available, and other variables. Recommendations for interim community programming are forwarded to Field Services, if necessary. If the client be found not eligible, alternative programming is recommended. In either case, Field Services notifies the family or referral source as to the determination;
- b. maintenance of the waiting list for institutional placement, and communication with interested agencies;
- c. selection from the waiting list for admission to appropriate institutions when vacancies become available. Institutions have the responsibility of identifying bed space within their settings to the Coordinator of Admission and Classification;
- d. classification with respect to transfer among institutions for the retarded or from other institutions within the Department of Institutions and Agencies;

- e. demographic functions in terms of resident populations, case movement, waiting list, Field Service referrals, etc.;
- f. effecting the transfer of clients from the Purchase of Care Program to the appropriate state institution;
- g. effecting interstate transfers under the Interstate Compact on Mental Health;
- h. in the role of a consultant, the Coordinator of Admission and Classification, in conjunction with the Bureau of Community Institutions, inspects private domiciliary facilities for the retarded; and
- i. dissemination of information as to the Administration and Classification procedure for institutionalization.

The Coordinator of Admission and Classification reports directly to the Director of the Division of Mental Retardation.

b. Residential Care

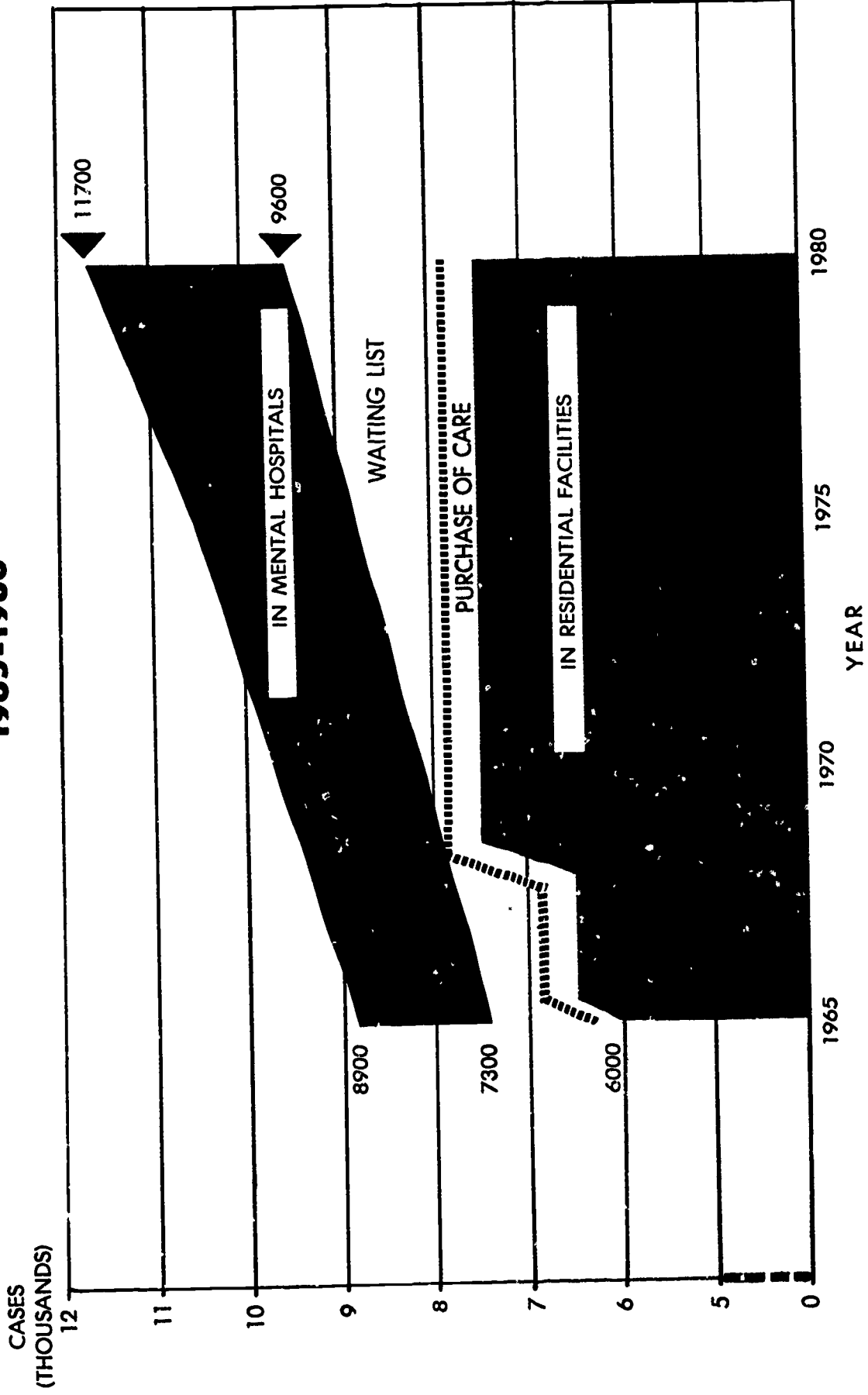
Although the first legal provisions for the care of the mentally retarded in New Jersey were enacted in 1730, it was not until 1860 that the Legislature appropriated \$3,000 a year to cover the maintenance of approximately 27 New Jersey children at the Pennsylvania Training School. In 1888, the state established its own institution, The Vineland State School, just across the street from The Training School, privately established four years earlier.

As early as 1873 a "Report of the Commissioners of the Deaf and Dumb, Blind and Feeble in the State of New Jersey" had recommended "a system of institutions which shall be schools for education and training . . . in preference to the plan of institutions which are asylums merely." The premise that on education and training depends the salvation of the mentally retarded was also uppermost in the minds of those who directed The Training School at Vineland. The present State Colony at New Lisbon was originally established in 1913 as an outpost of The Training Schools.

The emphasis on education had one unfortunate consequence in that it did delay assumption by the state of a direct responsibility for the protection and training of the "unimprovable defective." These were left to the care of the counties until 1921 when the State Colony at Woodbine was established. The colony accepted the most severely retarded boys and men and made history by improving the "unimprovable." Results achieved at Woodbine have thrown new light on the whole problem of training in basic self-care for children of low mental level.

The North Jersey Training School, the only public institution for the retarded in the northern half of the state, was opened in 1928. Its nursery unit, established in 1948, and now housed in a

ESTIMATED NEED -- RESIDENTIAL FACILITIES 1965-1980



modern sunlit building, is New Jersey's partial answer to the increased need for pediatric nursing care for retarded infants.

For nearly 30 years expansion of New Jersey's institutional capacity took place only through the addition of dormitories rather than new buildings.

The Johnstone Training and Research Center was opened in 1955. This Center, originally constructed as a manual training school, was extensively renovated between 1956 and 1958 to provide the students with the physical facilities for a campus life much like that of a college or boarding school. Under construction at Johnstone is the Readjustment Unit, a facility for the "defective delinquent." Specialized programming will be instituted at this unit to meet the needs of this special group.

The most recent addition to New Jersey's Institutional Program is the Woodbridge State School. The first residents were received at Woodbridge during January of 1965. Since recent trends indicate that more severely retarded individuals are seeking institutionalization, a seventh institution is being planned at Hunterdon with criteria for admission similar to Woodbridge State School.

All institutional programming is subject to the approval of the Director of the Division of Mental Retardation. The institutional aspects of the Division's program include the following: (1) review and approval of current institution programs and consultation with superintendents and their staffs on the innovation and development of educational, training, medical, and cottage life programs; (2) planning and conducting of regular meetings with the superintendents and staffs of the institutions around policy, practice and procedure; (3) consultation with the institutions and with the commissioner of the department with respect to budget and capital construction. The Division also acts as "approval officer" for expenditure of funds appropriated to various accounts at the institutions (i.e. education and library supplies, recreational equipment, and industrial and vocational supplies); (4) attendance at meetings of the institutional Boards of Managers to interpret the position of the State Board of Control, the Commissioner, and the Division of Mental Retardation; and (5) supervision of state wards in non-departmental facilities and assisting the Bureau of Community Institutions (which has an inspection function) in the review of the private domiciliary facilities for the retarded.

The Vineland State School, established in 1888, is New Jersey's oldest residential facility for the mentally retarded. The School consists of a main campus and an ancillary unit, the Almond Road Colony, located four miles away. This unit accommodates approximately 800 girls. Although Vineland accepts females of all levels

of retardation, the resident population is generally severely and moderately retarded. The Almond Road Colony accommodates primarily the severely retarded.

At Vineland State School each resident is provided the opportunity to achieve her highest potential for return to the community or for optimum adjustment to institutional living. Students are enrolled in diversified programs commensurate with their ability and need. Effective programming has made it possible to increase the usefulness of low-level residents to care for themselves to a degree.

Research activity remains at a high level at Vineland. Many studies are supported, in part, by federal funds. The areas of investigation are quite diversified. At present, research staffs representing medical and behavioral disciplines are involved with: inservice training for attendants; heredity factors in phenylketonuria; physio and speech therapy for retardates; the efficacy of play therapy in retardates; and maximal stimulation for the multiple-handicapped, severely retarded.

In conjunction with Glassboro State Teachers College, the Vineland State School offers an internship in special education (mental retardation) to students enrolled in the major area of study.

The State Colony at New Lisbon, established as a county colony in 1914, was assumed under the jurisdiction of the State of New Jersey in 1916. New Lisbon primarily accommodates educable and trainable males from the age of five. Although the Colony has no facilities for "bed patients," semi-ambulatory males of higher levels of intelligence are acceptable.

New Lisbon promotes a deep sense of responsibility for giving its residents living experiences. The highest priority is to develop every resident's ability to his highest potential and teach him to apply himself as broadly as possible. New Lisbon is striving for better programming and facilities. In fact, federal funds are presently being requested to accelerate the means necessary to achieve these ends. Research methods aimed at habilitating the New Lisbon resident are presently in effect.

Regarding plant structure, the first phase of a \$9,000,000 institutional reconstruction program was completed on March 1, 1965. Twelve new 52-bed cottages complete with facilities for care, recreation and training are under construction. Included in the construction plan will be a multi-purpose building (gymnasium, religious center, assembly hall, special purpose therapy rooms, and barber shop) and a new 50-bed hospital.

The Woodbine State Colony, established in 1921, accepts males over five years of age who are profoundly and severely retarded. Although with most residents eventual community placement is

not expected, programming for intra-institutional living has been most encouraging.

Constructive work with the severely retarded is particularly difficult. The idea that mere custody was the only feasible type of care for such a group was generally accepted. In 1924, however, Woodbine instituted a limited program of activity, especially recreational, in the belief that it would be beneficial to the residents. Initial success far exceeded expectations. As a result, activities were expanded greatly. Increasing patient activities have so changed the whole atmosphere of the institution that it is difficult to believe that Woodbine boys are chiefly the severely and lower-middle-grade mentally deficient types.

The term "diversional occupation" best describes the program which emphasizes the training value of all patient activities with the aim of increasing self-reliance and self-help. Such activities as training to control bodily functions, to eat without assistance, and to dress and undress are painstakingly taught to seriously handicapped patients. The Woodbine plan seeks to develop habit formation and to attempt to establish acceptable standards of behavior.

The North Jersey Training School was established in 1928. The school consists of a main campus for females over five years of age and young adult women of moderate and mild degrees of retardation, and a nursery unit for both male and female non-ambulatory children (under five years of age). Institutional programming is focused on returning residents to the community. Retarded girls of a mental capacity not conducive to ultimate community placement are given training to their maximum level of ability so they may live usefully and happily within the institution.

Each girl may progress through successively higher levels of academic and vocational education. Some pupils, particularly younger ones, attend school both morning and afternoon. For others instruction provided during a half day in school is correlated with occupational training and various types of maintenance work. Some girls who have reached the limit of their academic education devote the whole day to training for work in the community. The school is in proximity to a population center, and use is made of this resource to give many girls experience on day placement in domestic and other types of work.

The Edward R. Johnstone Training & Research Center was established in 1955 as a co-educational facility accommodating mildly and moderately retarded adolescents (age range from 12 to 21). Physically the Center resembles a small college campus. Students reside in dormitories; two in each room. Residents are admitted to

Johnstone on a temporary basis, from other institutions or directly from the community. Upon completing his course of study, the student is returned to independent community living or transferred to another institution. The curriculum reflects an inter-disciplinary approach to education. Practical course work is given to prepare students for vocational and social responsibility in the community.

Research and professional training are also considered important functions of the Johnstone Center. A full-time research staff has made numerous contributions in widening the range and knowledge of the processes of learning, memory, and perception in the mentally retarded.

The center is frequently a host to various short-term institutes and conferences. It has developed a close relationship with the State College at Trenton, which conducts courses, as well as demonstrations and student teaching, at Johnstone. The center also has an APA approved internship program in clinical psychology, and in conjunction with the Graduate School of Social Work of Rutgers University, offers a practicum in social work with the retarded.

The Woodbridge State School is New Jersey's sixth and newest residential facility for the mentally retarded. First admissions were received during January, 1965. Woodbridge accommodates the profoundly and severely mentally retarded of both sexes, and of a minimum age of five. Upon achieving full residential capacity, it is estimated that one-half of the residents will have multiple handicaps and be non- or semi-ambulatory.

Although full implementation of programming is not expected for sometime, a philosophical groundwork to programming has been conceived. In essence, Woodbridge will provide a home and training school that offers its residents not only adequate but the best possible care in which they can live in happiness, contentment and security; a living experience which is suited to their needs and which offers them opportunities and help to develop and function to their maximum level of ability. In partial fulfillment of this goal, a research proposal for federal funds to develop an improved inservice training for personnel working directly with the residents has been approved.

Programming at New Jersey's six residential facilities provides the resident with an array of services which will insure a living situation conducive to maximum growth and development. The following program areas are available at all state institutions:

1. medical services,
2. psychiatric services,
3. educational and training,
4. therapies and activities,

5. recreation services,
6. psychological services,
7. social services,
8. speech and hearing services,
9. chaplaincy services, and
10. cottage life activities.

c. Purchase of Care

The Purchase of Care Program of the Division of Mental Retardation was established to offer residential placement services to mentally retarded clients declared eligible for state residential placement, but for whom a current vacancy did not exist in a state institution. Prior to the Purchase of Care Program, most clients who attain waiting list status had no recourse but to be kept at home. Families often experienced increased strains and threatened disorganization, particularly in the needs of the severely retarded. It became apparent that until state institutional vacancies were made available, suitable interim programming had to be devised.

An appropriation of \$1,000,000 was granted by the State Legislature in order to place these clients in private, licensed, residential facilities for the retarded. Purchase of Care became operational during July of 1964. The appropriation will expire during June of 1965, but an additional appropriation, also for \$1,000,000, has been requested for the 1965 fiscal year and is most certain to be approved.

Families and guardians of the retarded, who have achieved waiting list status, and where the need for placement is more pronounced, now have a choice to either participate in the program or await a state vacancy.

Coordinating this program is a supervisor of Purchase of Care. The supervisor is informed as to client needs by social workers located in the three Field Services district offices. The social workers forward data to the coordinator of Purchase of Care whereby a priority system based upon urgency and length of time on the waiting list is maintained. Placements are based upon this priority and private vacancies available.

In essence, placement under Purchase of Care effects commitment to the institution to which the client has been classified. The client's name is entered upon the residence roll at the respective institution with a notation indicating his Purchase of Care status. When a state vacancy becomes available, the superintendent of the respective institution indicates this to the coordinator of classification. A decision is then made as to whether the institution is best able to care for a client's needs. The client can, therefore, be transferred from the private placement to the institution if appropriate.

Clients are placed only in private facilities equipped to render services commensurate with client need. In fact, most placements

are out of state. Families contribute to the cost of the client's care similarly as if he were in a state institution. As of April 7, 1965, 315 clients were on Purchase of Care. The program has been viewed by those involved with problems of retardation as most timely. The most pressing cases for institutional placement have been extended services from this program.

d. Day Care

The Day Care Program is a community-centered program designed to provide training and social adjustment to profoundly and severely retarded children of school age, who, classified as neither trainable nor educable, have been excluded from participation in a public school program. Children in this category are between the ages of four and-a-half and twenty-one. It has been estimated that in New Jersey there may be as many as 1200 children who qualify for and are in need of a Day Care Program.

The availability of Day Care services was limited until a state legislative appropriation of \$25,000 was allotted in the fiscal year 1963-1964. Initial grants were made to the Essex and Union units of the NJARC, and by March of 1964, three additional units were participating in Day Care (Burlington, Gloucester, and Bergen-Passaic). For the fiscal year 1964-1965, a legislative appropriation of \$75,000 was granted. Three additional county units of NJARC entered into contracts to provide Day Care services (Monmouth, Warren and Morris) bringing the total to eight NJARC units offering service in 15 Day Care Centers as of September, 1964.

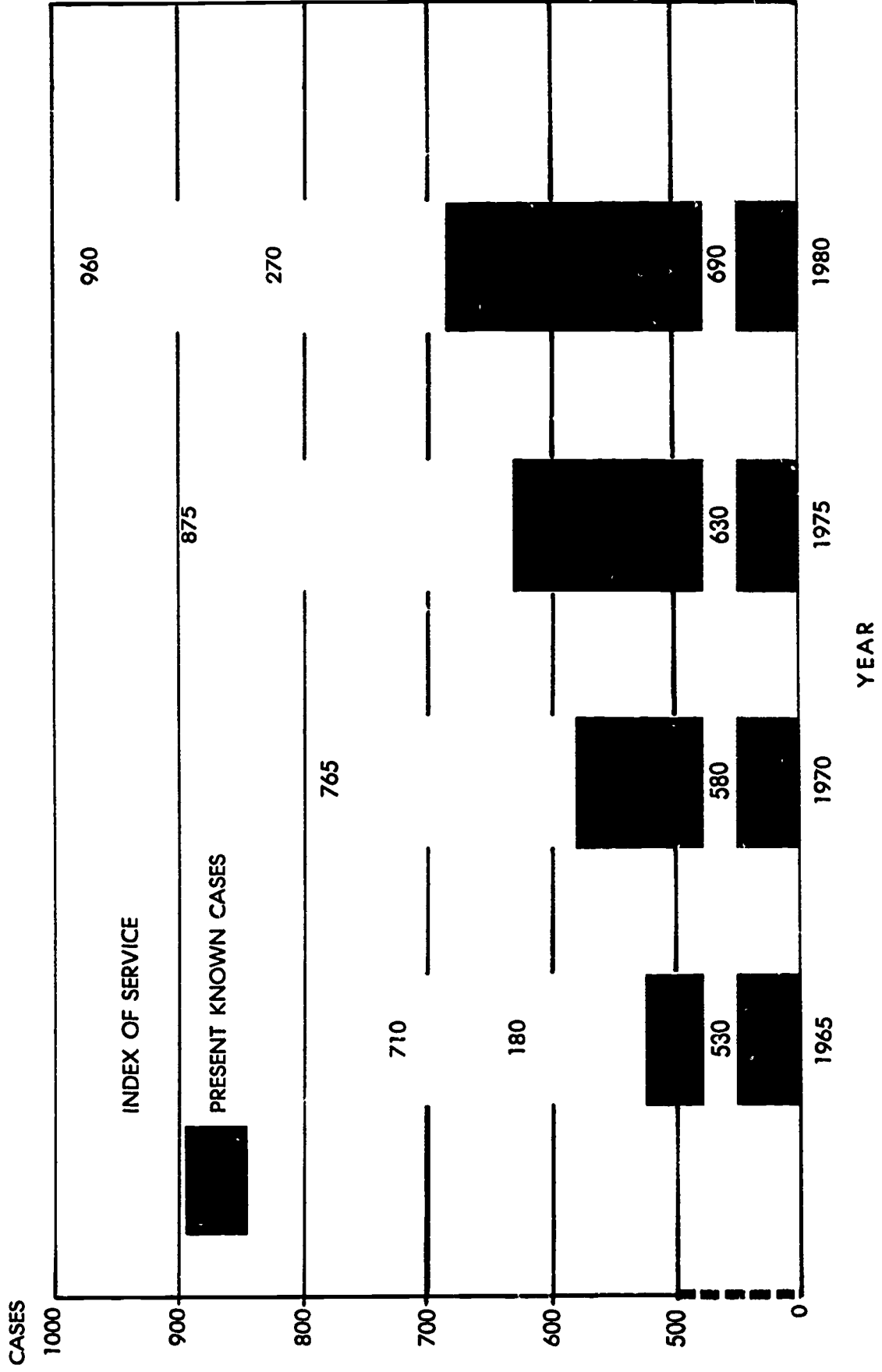
Experience with Day Care during the past two and a half years has indicated that with effective programming specifically designed to meet the social and physical needs of these children, growth heretofore unexpected can be achieved. The program is highly structured. Learning in areas of self-help and socialization is emphasized.

Day Care in New Jersey is in an early stage of development. At present, the program is carried out in conjunction with NJARC. However, complete state operation is soon expected. The Division of Mental Retardation is presently funding NJARC units which are operating Day Care Centers in all of New Jersey's 21 counties. A legislative appropriation for \$225,000 for the fiscal year 1965-1966 has been made to the Division of Mental Retardation. Presently, there are 276 children in Day Care.

e. Field Services

The Field Services program is a service area of the Division of Mental Retardation in the New Jersey Department of Institutions

CASE LOAD-DAY CARE SERVICES - 1965 - 1980
COMPARISON OF ESTIMATES FROM PRESENT KNOWN CASES AND INDEX OF SERVICE



and Agencies. Field Services provides social work services to the mentally retarded individual and his family. Social workers are the only discipline represented on the staff. Information and consultative services are available to various organizations interested in programs for the mentally retarded.

Prior to Field Services, individuals released from state institutions for the retarded, other than New Lisbon, were supervised by institutional social workers. Retardates from New Lisbon received post-institutional supervision from parole officers of the Division of Correction and Parole. Since the use of parole officers for this purpose was open to question, the State Board of Control authorized study into new approaches for supervision. Accentuating this problem was the need for an accelerated program of release of institutionalized retardates. As a logical consequence to accelerated release to the community, an expanded program of supervision would be needed. Therefore, the establishment of a state sponsored, community situated agency, whose responsibility would be to provide post-institutional supervision, was approved by the State Board of Control.

Rationale for locating this agency in the community proper as opposed to the institution was in part due to admission procedure. Admission to an institution was made not in terms of the geographic residence of the retardate, but in terms of age, sex and degree of retardation. Located in the community the agency would be in closer proximity to the released retardate's home.

Based on case load projections and areas of high population, three Field Services' were established in Northern, Central, and Southern New Jersey in March, 1956. The Initial caseload consisted of individuals already residing in the community on extended leave status from institutions. Referrals to district offices for supervision were made by institutions. Initial assignments to Field Services were, therefore, in the area of post-institutional placement and supervision. Field Services thereby became the vehicle for return of the retardate to the community; a liaison role was achieved between institutions and the community.

Since institutions needed additional information of a socio-familial and developmental nature to formulate alternative programming of both an intramural and extramural type, Field Services was assigned the responsibility of securing these data during 1956-57. In order to provide for an annual review of all waiting list cases, Field Services was assigned the responsibility of securing data relative to socio-familial-medical and developmental history. This assignment was delegated during 1957-58. This was also a service to classification functions and gave an indice as to present need (degree of urgency) for admission to institutions. During 1961,

Field Services was assigned the function of intake (application) for Divisional services. Requests for services has greatly increased; in fact, the general case load has more than doubled during the past three years.

The following list describes services presently provided by Field Services. Service areas cannot be assumed to be mutually exclusive; when dealing with the complexity of human needs, areas tend at times to overlap.

1. **Intake for Divisional Services:** Intake involves a study process in which comprehensive data of a psycho-socio-familial and developmental nature are gathered. This provides the basis for eligibility and classification determinations when institutional placement is deemed the appropriate alternative.
2. **Community Based Planning:** Dissemination of information; assistance to family in selecting a community program for the retardate (e.g. pre-school, Day Care, public school classes, vocational rehabilitation services, etc.); consultative services to agencies; and casework service as needed.
3. **Referral Service:** Lines of communication remain open with many community agencies. When study indicates that Field Services cannot meet a specific need the retardate is referred to an appropriate agency. An example would be referring a convulsive retardate to a convulsive disorder clinic.
4. **Pre-admission Planning:** Interim programming is offered to individuals awaiting admission to a state institution.
5. **Pre-release Planning:** Field Services, in its liaison role, plans with both the institution and family for the retardate's return to the community.
6. **Post-institutional Supervision:** Upon release to the community, the retardate is assigned a social worker who supervises the retardate and assists in job-finding, social programming, etc.
7. **Family Care Placements in Sheltered Boarding Homes:** Many of the elderly retarded released from the institution are placed (usually in original county of residence) in state licensed, sheltered boarding homes. Field Services arranges and supervises placement of the individual. His cost of care is paid by the institution. Field Services also assists families and agencies in securing boarding placement for the retardate who needs a sheltered home rather than institutionalization. Cost of care in this situation is borne by the individual, his family, or an interested community agency.
8. **Out-of-State Services:** In 1956, New Jersey ratified the Interstate Compact on Mental Health, thus entering into reciprocal

relationships with other party states. Field Services assists the Compact Coordinator in securing information and providing supervision to out-of-state cases—where an individual is on the residence rolls of an out of state institution, yet is presently residing in New Jersey. Progress reports are forwarded to the institution.

The Northern District Office services Warren, Sussex, Passaic, Union, Essex, Bergen, Morris, and Hudson counties; the Central District Office services Middlesex, Hunterdon, Somerset, Monmouth, Ocean, Mercer, and Burlington counties; the Southern District Office services Camden, Atlantic, Salem, Cumberland, Cape May, and Gloucester counties. A supervisor of Field Services, who reports directly to the director of the Division of Mental Retardation, coordinates policy making and implementation of procedures at the district level. An assistant supervisor of Field Services reports to the supervisor. At the Northern District Office there is one supervisor, one assistant supervisor and twelve social workers; at the Central District Office there is one supervisor and seven social workers; and the Southern District Office personnel consists of one supervisor and four social workers.

2. DIVISION OF PUBLIC WELFARE

a. Bureau of Assistance

The Bureau of Assistance of the Division of Public Welfare, Department of Institutions and Agencies, is the state agency assigned the responsibility of supervising the administration of public assistance programs to persons in need of financial aid. The administering agencies are the county welfare boards for categorical assistance and the municipal welfare departments for general assistance.

There are five categorical assistance programs: Old Age Assistance, Medical Assistance for the Aged, Disability Assistance, Aid for Dependent Children, and Blind Assistance. There is also a program of General Assistance. When responding to requests for service from the mentally retarded (where mental retardation is considered a diagnostic criterion upon which to base an evaluation), the programs usually concerned are either Disability Assistance or Aid for Dependent Children (ADC).

Under Disability Assistance, eligibility is based upon the condition of "permanent physical or mental defect, disease or impairment (other than blindness) which is not likely to improve in the foreseeable future, and which prevents the person from performing a useful occupation (including homemaking) which exists in the community and for which he is qualified."^a If found eligible for assistance, pay-

^aDivision of Public Welfare, Bureau of Assistance, Form PA-191

ment is received from the welfare board of the county of residence. A further requirement is that the applicant pledge all or part of his property, either real or personal, as a guaranty for the reimbursement of the assistance received. When the recipient's condition allows him to function in gainful employment, payments are discontinued.

If a special circumstance arises requiring residential placement, the retarded recipient can be placed with payment for his care made by Disability Assistance. If long-term placement is needed, the welfare board usually refers the case to the Division of Mental Retardation for determination regarding appropriate institutional placement. If the recipient is placed in a state institution for the retarded, his assistance terminates and all responsibility is transferred to the Division of Mental Retardation. Since county welfare boards do not maintain staff personnel trained in the field of mental retardation, consultations with Field Services regarding matters related to community programming for the retarded is not infrequent.

Under ADC, payments are made by the county welfare boards in behalf of children under age 18, to their needy parents or other relatives. Since the program is concerned with strengthening family life, ADC makes it possible for the child to remain in the care and protection of his family. Regarding eligibility criteria, a family must include one or more children "under age 18 who have been deprived of support or care by reason of the death, physical or mental capacity, or continued absence from the home of one or both natural or adoptive parents."^b Eligibility is based upon the status of the parents. In given cases, children on ADC are mentally retarded. Care needs of a professional nature might be needed and can be provided for under ADC.

If deemed the appropriate alternative, a child can be placed in a private institution for the retarded under ADC. To be eligible for this placement, however, the child must have a sibling on ADC presently living at home. If there is only one child, he cannot be maintained in such a facility under ADC. The case would in all probability be referred to Field Services for disposition.

A number of retarded children under ADC are in private placements for the retarded. Presently in evaluation stages at the departmental level is the proposal that the Purchase of Care Program assume financial responsibility for these children. To date, no definite statement has been made. Participating in the costs of maintaining these assistance programs are the Federal, state and municipal governments.

^bDivision of Public Welfare, Bureau of Assistance, Form ADC-9

b. Bureau of Children's Services

The Bureau of Children's Services (BCS) of the Division of Public Welfare, Department of Institutions and Agencies, is the state's child welfare agency. It provides a variety of services designed to maximize opportunities of children in need to develop, physically and mentally, to their fullest potential. Children from birth to age 21 are eligible for service. BCS extends all available services deemed appropriate to any retarded child referred.

Historically, Governor Foster M. Voorhees, signed into law on March 14, 1899 a statute creating the State Board of Children's Guardians. As time passed, assignment responsibility changed commensurate with public awareness. Today, BCS has the authority to engage in many activities, including a protective service program; the establishment of standards to regulate the purchase of service from private and voluntary agencies; and authorization to extend services to unmarried mothers. There are 16 BCS district offices strategically located throughout the state. Casework treatment is the primary tool of the agency. Services are provided under three categories: *Care*, *Guardianship*, or *Protective Services*. *Care* implies service rendered with the voluntary consent of the parent or legal guardian. *Guardianship* implies that by court order, all parental rights are severed, and BCS is made guardian. *Protective Service* is where a parent refuses to permit investigation which is necessary to protect a child from abuse, hence, the court is requested to intervene and order such an investigation.

Major services provided by BCS to the retarded are listed below:

1. Casework services conducted in the child's home, including:
 - a. arranging for diagnostic testing (e.g. psychological testing) and social study,
 - b. assisting parents in having the child appropriately classified with the Division of Mental Retardation, if necessary,
 - c. consultation with school personnel to establish a school program for the child,
 - d. effecting placement out of own home where necessary,
 - e. counseling with child's family and community resources regarding the needs of the child, and modes of handling these needs, and
 - f. protective service, if necessary.
2. Casework service rendered on behalf of a child out of his home:
 - a. seeing that the child is classified with the Division of Mental Retardation, if necessary.
 - b. foster home or group family care placement and supervision

where indicated. (This would include payment of increased board rates, if essential.) Group family care is for children too disturbed to remain in their own homes or regular foster homes, but whose behavior does not warrant institutionalization.

- c. if advisable, placement and supervision of a child in a private institution for the retarded until such time as the child is classified by the Division of Mental Retardation, and commitment papers are filed. In some instances responsibility is then transferred to the Division of Mental Retardation.
3. Children released from an institution for the retarded may be provided any of the above services.
4. Services to unmarried retarded mothers: BCS can offer services on behalf of an unborn child. Such services include consultation, counseling, expenditure of funds for board, medical care, etc. Adoption services are also considered.

c. Commission for the Blind

The Commission for the Blind of the New Jersey Department of Institutions and Agencies, has throughout its history, maintained a program of education and welfare for the blind and partially sighted. The philosophy of the commission reflects the belief that programming for the blind should take into consideration the immediate problem, as well as a comprehensive view of the individual, his family, and the community.

The commission maintains services for the blind in many related areas, e.g. counseling to parents of blind pre-school children; enrollment in nursery and grade schools; educational counseling for children; inter-disciplinary diagnostic services; vocational guidance; and provision for special tools for learning. A conservative estimate of the number of clients registered with the commission's educational service who have handicaps in addition to visual deficiency is 40% to 50%. Many of these multiple handicapped clients are mentally retarded. The blind and visually handicapped retardate has always been extended the services of the commission. His eligibility for services is determined by an evaluation of his intellectual and adaptive abilities.

At present (March, 1965), 100 children under age 21 are enrolled in both educable and trainable classes in public schools. About 130 clients are in state institutions for the retarded; an additional 30 are in private placement awaiting transfer to state institutions. In addition to the 100 children in educable and trainable classes in public school, 15 children are in classes for other handicaps, e.g. cerebral

palsy. Another 25 are in classes for the visually impaired, usually referred to as "sight saving classes". Thirty children are in parochial schools for the blind and multiple handicapped. Sixty children are maintained at various private facilities, e.g., cerebral palsy centers and nursery schools. Ten children are in Day Care Centers. The commission pays part or all of the tuition for these ten children. Also, the commission has 20 children on a voluntary basis at the Johnstone Training and Research Center. In a relatively self-contained unit, intensive training and treatment is afforded the residents. A highly individualized program stressing academics and social skills is promoted. Thirty children are also in out-of-state residential schools where programs at the educable and trainable level are provided. Children are also afforded diagnostic services at the Center for Blind Children in Boston.

There are presently 40 children over age seven for whom there are no programs.

Children in public school classes for the retarded are assigned an educational counselor from the commission who checks on the client's school progress. The counselor confers with the public school teacher and offers advice regarding special problems of the blind. If specialized instruction appears beneficial, the counselor will offer this service to the retardate as an adjunct to his school program. Services which are also available to the older blind retardate include vocational counseling and instruction, home care, and related services.

B. DEPARTMENT OF HEALTH

The Department of Health, assigned the responsibility to "formulate comprehensive policies for the promotion of public health and the prevention of disease within the State,"¹ has its legal foundation largely, but not exclusively, in Chapter 177, Laws of 1947 (Title 26, New Jersey Statutes Annotated). The many services provided by this department assist local health departments to strengthen their ability to prevent, detect and control disease and to restore to maximum well-being and usefulness those whose health is impaired. The administrative head of the department is the State Commissioner of Health. His appointment to this position is made by the Governor with the advice and consent of the Senate.

This department has been organized into the following eight divisions: the Division of Chronic Illness Control; the Division of Constructive Health; the Division of Environmental Health; the Division of Laboratories; the Division of Local Health Services; the Division of Preventable Diseases; the Division of Special Consultation Services; and the Division of Vital Statistics and Administra-

tion. The commissioner and his staff coordinate the work of the divisions and districts; and the staff includes specialists in law and public relations.

Although no specific statement has been formulated regarding the extent of the department's responsibility for the mentally retarded, a direct commitment is realized to the mentally retarded through the Division of Constructive Health. Within this division is the Maternal and Child Health Program and the Crippled Children's Program.

Under the *Maternal and Child Health Program*, the department underwrites the expense of a diagnostic evaluation and follow-up for the mentally retarded and/or physically handicapped with particular emphasis on the pre-school child. This evaluation is given by a professional team coordinated by a designated medical director and consisting of at least the following: a pediatrician, psychiatrist, psychologist, medical social worker, and Public Health Nurse. Consultation services are available by board certified specialists in the following disciplines: orthopedics, ophthalmology, physiatry, otolaryngology, urology, neurosurgery and plastic surgery. An evaluation of the client's physical, emotional, and social capacities and a determination as to methods and goals of restorative services are forwarded to the referring physician. This program neither provides nor underwrites the cost of treatment. At present, four diagnostic and evaluation centers are under the auspices of the Department of Health. They are: 1. Morristown Memorial Hospital, Morristown, 2. Babies' Hospital, Newark, 3. Hackensack Hospital, Hackensack, and 4. Bancroft School, Haddonfield. The program also provides PKU testing of newborns in hospitals throughout the state. The program affords phenylalanine testing and diagnostic evaluation of phenylalanine cases up to three years of age, and when necessary, underwrites the cost of therapeutic dietary measures (Lofenalac). With responsibility for prevention, detection, and control of disease, the program has submitted a project through the Children's Bureau covering a five-year period to provide for prenatal and obstetrical services for some 2,000 medically indigent cases in the City of Newark. These services are to be provided through four participating hospitals and will enhance the types of services now being provided at the Newark City Hospital.

The Program has provided migrants with complete prenatal and obstetrical services for the past two years. The Maternal and Child Health Program also provides obstetrical, nursery and pediatric consultation services to hospitals throughout the state in an attempt to raise the standards of such services as a preventative measure.

¹Revised Statutes Annotated 26: 1A-37

The *Crippled Children's Program* provides hospitalization, convalescent care, braces, appliances, prosthetic devices, and nursing services to all handicapped children who might profit from rehabilitation services. The departmental share of the costs of the Crippled Children's Program is 40% (consisting of state and federal monies). Counties provide the other 60%. Some counties have had difficulty in meeting their share and some have been hesitant to add new diagnostic categories of crippled children because of the extra costs involved.

In 1964, 9,198 children received service through the Crippled Children's Program.

C. DEPARTMENT OF EDUCATION

Legislative Framework

The establishment of special classes for the educationally retarded was first mandated by state legislation passed in 1911. In 1954, comprehensive new legislation, known as the "Beadleston Act", clarified and affirmed the responsibility of local school districts for identifying and providing appropriate educational programs for physically handicapped and mentally retarded pupils, and increased the state aid to local districts for this purpose. Chapter 178-P.L. 1954 describes the classification of mentally retarded children under three groups, as follows:

- a. "educable mentally retarded children, who are those who may be expected to succeed with a minimum of supervision in homes and schools and community life and are characterized particularly by reasonable expectation that at maturity they will be capable of vocational and social independence in competitive environment;
- b. trainable mentally retarded children, who are so severely retarded or socially immature that they cannot be classified as educable but are, notwithstanding, potentially capable of self-help, of communicating satisfactorily, of participating in groups, or directing their behavior so as not to be dangerous to themselves or others and of achieving with training some degree of personal independence and social and economic usefulness within sheltered environments;
- c. children who are so mentally retarded as to be neither educable nor trainable."

The law requires that school boards obtain the services of state-approved psychologists and clinics to examine and evaluate all suspected mentally retarded children referred to them by the schools. Once a child is classified, it becomes the duty of each board of edu-

cation to provide suitable facilities and programs of education or training, according to the following:

- a. "by establishing a special class or classes in the district; or
- b. by sending pupils to a special class in the public schools of another district; or
- c. by agreement with one or more school districts to provide joint facilities; or
- d. by individual instruction or training at home or in school whenever, in the judgment of the board of education with the consent of the Commissioner, there are too few mentally retarded pupils to form a class in the district, or whenever it is impracticable to transport a child because of distance or other good reason to a class referred to in subsections a, b, and c . . ."

No class conducted for educable mentally retarded children may contain more than 15 pupils, and no class for the trainable may contain more than 10 pupils.

Commission on Education of the Handicapped

The Commissioner of Education's Commission on the Education of the Handicapped was appointed in September 1963 to study the effectiveness of the 1954 "Beadleston Law", also the second Beadleston Act (1959) and the Grossi Bill (1964). (The latter two laws are concerned with providing educational services for emotionally disturbed and socially maladjusted children.) In the Introduction to the Commission's report "The Education of Handicapped Children in New Jersey 1954-1964," the following points are made: "With increased emphasis upon education of the handicapped at federal, state, and local levels, the Commission members are convinced that it is time for the State of New Jersey to respond to these changing circumstances. Rather than enact more and more piecemeal laws dealing with more narrowly defined categories of the handicapped in more and more diverse patterns of financing, and more and more administrative patterns, it is time to unify previous diverse laws into a single law. A consistent pattern of support for education for all handicapped children regardless of category should be instituted. . . . Therefore, this Commission finds that the review of the effectiveness of the 'Beadleston Acts' as implemented, and the consideration of possible revision of legislation, as requested by the Commissioner of Education, is very timely and that major changes in the structure, including the statutory basis of special education services in New Jersey, are urgently needed. . . . The Commission believes that if the recommended unification of laws, administration, services and financing become a reality, local authorities would be made more fully aware of the identification

and numbers of handicapped children residing in their communities, and would more readily supply appropriate programs. This unification would, in our judgment, change the pattern of educational services toward increased effectiveness and the overall financial economy as well as contribute to the preservation of human resources."

One of the major recommendations made by the Commission in their report is that "the Office of Special Education Services should be organized as a Division of the State Department of Education with the head of that division having the rank of Assistant Commissioner." Other recommendations pertain to the responsibilities of local school districts, expanded programs for the training of professional personnel, and increased financial aid. In the area of mental retardation, the Commission makes the following specific recommendations:

1. "Intensification of efforts to establish sound vocational oriented secondary schools programs for the mentally retarded, and
2. Stricter enforcement of present laws regarding the establishment of needed services and classes and the placement of eligible children."

Special Education

The Office of Special Education Services in the Division of Curriculum and Instruction, Department of Education, reports the following services for the mentally retarded in the public schools of New Jersey, 64-65 school year:

Number of Approved Classes for Educable	
Mentally Retarded	1,024
Number of Approved Classes for Trainable	
Mentally Retarded	256
Total Number of Classes for Mentally Retarded	1,280
Number of Children in Classes for Educable	
Mentally Retarded	13,000
Number of Children in Classes for Trainable	
Mentally Retarded	2,200
Total Number of Children in Classes for Mentally Retarded	15,200
Total Number of Mentally Retarded sent to Classes in a Receiving District	1,493
Number of Educable Mentally Retarded Receiving Individual Instruction	142

Number of Trainable Mentally Retarded Receiving Individual Instruction	51
Total Number of Mentally Retarded who Received Individual Instruction	193
Total Number of Children Classified as Retarded but in no Special Education Program	1,285
Total Number of Children Enrolled in New Jersey Public Schools	1,254,625
Three per cent of Total Number of Children Enrolled in New Jersey Public Schools	37,639
Expected Increase in Number of Mentally Retarded Children in New Jersey (1963-1968)	4,110

Growth of Special Education Services

In recent years there has been a tremendous increase in the number of classes for educable and trainable children. A study of the growth pattern shows that special education programs are no longer confined to large cities as they were in 1954 (the year of the Beadleston Act). It is now the large cities which report the most serious shortage of classes for the mentally retarded. Geographic expansion now makes the special education program more accessible to trainable and educable children any place in New Jersey. Tables I and II show the growth of special education classes for educable and trainable children, by county, over the past twelve years.

The Educable Child in Secondary School

As a result of a series of conferences involving the Commissioner of Education, the Assistant Commissioners, and the Directors of the Division of Curriculum and Instruction, a statement of policy was released in 1957 which describes responsibilities of secondary schools in regard to retarded children. "The elementary school, after consultation with the County Supervisor of Child Study, may certify that a mentally retarded child has completed the offerings of the elementary special education program and that the child then becomes the responsibility of the secondary school." In arriving at this statement, it was agreed that the general purposes of education do not change for the mentally retarded but the methods of achieving the purposes must be designed to fit their needs and capacities. It is the responsibility of schools to provide those types of education for retarded children as required by law. The law does

SPECIAL CLASS ENROLLMENT - 1965
COMPARISON OF ESTIMATES FROM PRESENT ENROLLMENT AND INDEX OF SERVICE

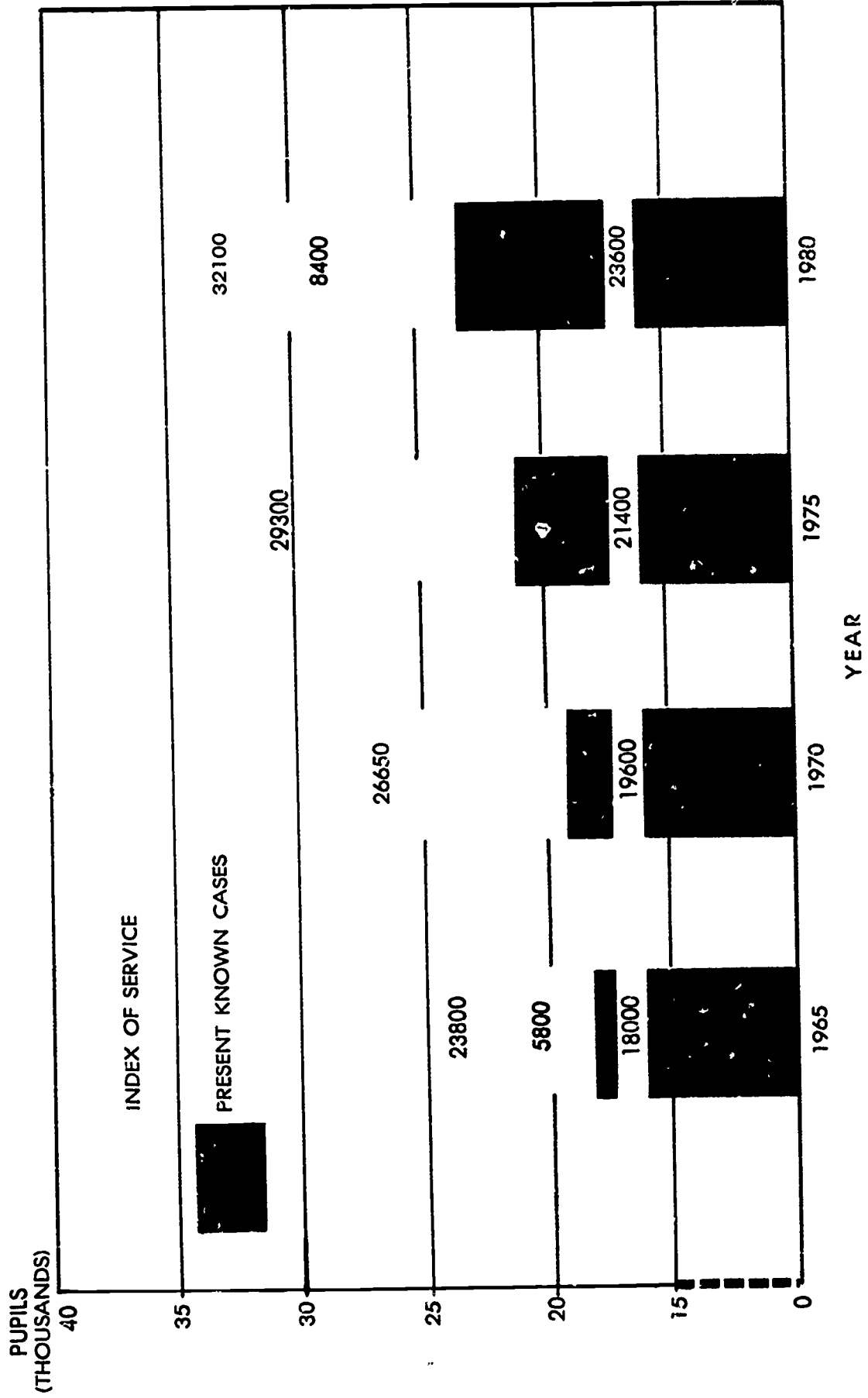


Table I
APPROVED CLASSES FOR THE EDUCABLE MENTALLY RETARDED FOR THE PERIOD

	1953-54 to 1964-65											
	53-54	54-55	55-56	56-57	57-58	58-59	59-60	60-61	61-62	62-63	63-64	64-65
Atlantic	5	12	18	20	26	27	26	28	31	36	39	39
Bergen	12	16	26	29	41	46	51	56	59	67	71	77
Burlington	5	4	8	12	19	27	31	35	36	38	38	45
Camden	13	17	30	35	33	40	44	48	49	54	55	62
Cape May	-	-	1	-	1	6	7	10	11	13	13	13
Cumberland	6	9	20	25	27	32	34	38	41	44	47	51
Essex	90	115	121	124	127	139	151	148	166	175	179	178
Gloucester	1	6	10	11	21	21	21	25	26	26	29	33
Hudson	50	52	46	47	48	43	45	47	49	48	56	52
Hunterdon	-	-	-	3	5	6	6	9	9	8	7	7
Mercer	14	31	65	87	80	79	81	80	87	96	97	92
Middlesex	7	13	20	25	31	38	44	48	50	54	59	61
Monmouth	8	10	15	21	26	30	39	43	44	47	49	57
Morris	3	10	13	13	17	17	21	26	31	35	40	42
Ocean	-	-	-	3	4	7	14	14	18	23	27	26
Passaic	27	27	31	37	38	39	42	48	46	49	53	55
Salem	-	-	2	4	7	8	9	11	12	14	14	16
Somerset	6	7	7	8	8	10	11	11	14	17	17	17
Sussex	2	2	3	8	9	11	12	12	13	13	13	14
Union	36	35	40	47	50	53	56	64	65	69	74	75
Warren	2	2	5	6	7	7	8	6	7	8	10	12
GRAND TOTAL	287	368	481	565	625	686	753	807	864	934	987	1024

Table II
**APPROVED CLASSES FOR THE TRAINABLE MENTALLY RETARDED FOR THE PERIOD
 1953-54 to 1964-65**

	53-54	54-55	55-56	56-57	57-58	58-59	59-60	60-61	61-62	62-63	63-64	64-65
Atlantic	-	1	3	3	4	4	4	4	5	4	4	4
Bergen	-	2	10	13	14	14	14	17	22	26	26	29
Burlington	-	-	2	2	4	5	5	7	8	9	10	13
Camden	-	2	4	6	9	11	10	9	11	14	14	14
Cape May	-	-	-	-	-	-	-	-	2	2	3	3
Cumberland	-	-	5	5	6	8	9	9	9	9	9	9
Essex	-	6	16	18	18	21	23	27	27	28	34	38
Gloucester	-	-	2	2	2	3	4	6	6	5	5	6
Hudson	-	3	12	15	15	17	18	19	21	22	22	23
Hunterdon	-	-	-	1	2	3	3	3	3	3	3	3
Mer ^{cap}	-	-	6	9	6	6	7	8	9	10	11	12
Mid ^{sex}	-	-	6	8	11	11	13	13	14	17	18	19
Monmouth	-	1	2	6	7	7	8	9	9	10	13	15
Morris	-	3	5	6	6	7	7	7	7	9	9	10
Ocean	-	-	2	5	7	6	5	8	8	7	8	9
Passic	-	2	5	5	7	9	10	12	13	13	14	15
Salem	-	-	-	1	1	3	3	3	3	3	3	3
Somerset	-	-	1	2	3	3	3	4	5	5	6	6
Sussex	-	-	1	1	1	1	1	1	1	1	1	1
Union	-	7	12	13	14	15	15	17	18	18	22	22
Warren	-	-	1	1	1	1	2	2	2	2	2	2
-	27	95	122	138	155	164	185	203	217	237	256	GRAND TOTAL

not distinguish between the responsibilities of elementary and secondary schools.

The most recent figures reported by the Office of Special Education Services on secondary classes for the mentally retarded are the following:

	<i>Total</i>
Orientation to Work Experience (part-time on job training)	48
Integrated with Total School Program (no on job training)	145
Self-contained classroom (not integrated with total program)	44
TOTAL	237

Financing Special Education Services

At present there are two principal ways of financing special education services for mentally retarded children in local school districts, as follows:

CLASSIFICATION	STATE AID
For mentally retarded children who receive instruction in a class comprised of similarly handicapped children in their district	The local district receives \$2,000 annually from the state for each such class. Class size is limited according to category of handicap. No reimbursement is given for supplementary instruction given to children in these special classes
For mentally retarded children who attend a class in another school district.	Sending districts receive 50% of the tuition cost above \$200.

Training of Teachers

At present there are training programs for the preparation of teachers of the mentally retarded at the following state colleges: Glassboro, Jersey City, Newark, Paterson, and Trenton. There continues to be a severe shortage of qualified teachers in this area of special education. It is estimated that the need is presently met by only one-third. Statistics on the number of certificates issued by the Department of Education to teachers of the mentally retarded for 1964-65 school year are as follows:

<i>Emergency</i>	227
<i>Provisional</i>	230

Elementary and Secondary Education Act of 1965

One of the earliest pieces of administration legislation to be enacted by the 89th Congress has become Public Law 89-10, the Elementary and Secondary Education Act of 1965. This act will give impetus to the development of educational services for the retarded, as well as for children with other handicaps.

Title I of the Act authorizes a three-year effort to encourage and support the creation, expansion, or improvement of special programs, including the construction of facilities, to meet the needs of culturally deprived children from low income families.

Title II, provides funds for the acquisition by public education agencies (for use by children in both public and non-public schools) of "library resources", which would include audio-visual as well as published materials.

Title III authorizes appropriations for such activities as counseling, remedial instruction, health, recreational and social work services, vocational guidance, and specialized instruction and equipment.

Title IV authorizes the training of research personnel and the development of improved methods of disseminating research findings to other education centers and local school districts. Private non-collegiate research organizations and professional associations become eligible to participate in this training effort.

Title V authorizes a five-year program to assist in strengthening the leadership resources of state education departments.

All types of grants available under this act must be applied for. The estimated amounts to be available to New Jersey during 1965-1966 are as follows:

	<i>Millions</i>
Title I (to districts with Low Income Families)	\$20.2
Title II (Library Resources)	3.2
Title III (Supplemental Centers and Services)	3.2
Title IV (Cooperative Research)	Project Basis
Title V (Strengthening State Department)7 and projects
TOTAL	<u>\$27.3 estimated</u>

D. DEPARTMENT OF LABOR AND INDUSTRY

The Department of Labor and Industry is concerned with the following: (1) to improve the general welfare through programs designed to meet the needs of workers and employers; (2) to make manifest optimum skill potential of all workers—young and old, including the handicapped; (3) to insure protection of the

health of workers (and decreasing operating costs for employers) by innovating methods to improve industrial safety; (4) to maintain minimum wage standards for workers and to provide unemployment benefits, temporary disability insurance and workmen's compensation, and (5) to maximize a state of harmonious relations between labor and management. The divisions, bureaus, and commissions that comprise the department are concerned with the plight of the retarded in his quest to secure and maintain employment. The experience of public and private agencies has shown that with assistance the retarded can prepare for, secure, and maintain employment. The department assists the retarded in securing appropriate employment.

1. Rehabilitation Commission

History

Vocational rehabilitation represents the sum total of services designed to restore a mentally or physically handicapped individual to a level of vocational activity consistent with his physical and mental capabilities. The vocational rehabilitation process incorporates the following steps: (1) location and identification of those adults and young adults in need of services; (2) a diagnostic evaluation (medical and vocational) to determine the current mental and physical status of the individual and to help in arriving at a suitable vocational objective; (3) corrective medical measures, when needed, such as hearing aids, orthopedic appliances, psychotherapy, etc.; (4) vocational training, when indicated, in the form of training in a sheltered workshop, private school or on-the-job training; (5) job placement at a level commensurate with the individual's capacities and interests; (6) vocational counseling, as indicated, throughout the total process, not only with the individual but in many cases with the family. The federal-state program for vocational rehabilitation, which provides these services, has always had, as one of its principal functions, coordination of all services necessary for an individual to become vocationally rehabilitated. Ancillary services, such as funds for maintenance and transportation, are also available.

With the mentally retarded, the definition and process of vocational rehabilitation is essentially the same as for other disabilities. (The term vocational habilitation more appropriately applies to the mentally retarded.) The six steps described above generally occur in the course of serving the vocational rehabilitation needs of the retarded. Emphasis will vary according to the assets, interests, and liabilities of the individual and availability of resources.

Since 1920 the public vocational rehabilitation program has served the physically disabled. In 1943 legislation permitted service to the

mentally retarded, mentally ill, and epileptic. It was not until passage of Public Law 565 in 1954, however, that funds were made available to implement service for these groups. This is the enabling law which provides for grants to public and private facilities for training, research and demonstration, and extension and improvement of programs.

New Jersey Rehabilitation Commission's Program for the Mentally Retarded

The New Jersey Rehabilitation Commission began development of its Mental Health Program for the mentally retarded and mentally ill in October of 1956 when a new position was created for this purpose. Shortly thereafter, Professional Advisory Councils for the Mentally Retarded and for Mental Health were established.

During the following eight years the commission's program for the mentally retarded was improved and expanded. Emphasis was placed on staff training, public education, establishment of cooperative relationships with other agencies, experimentation, and assistance to sheltered workshops and other facilities through consultation and grants, as well as provision of services to clients. The following represent some of the specific activities of these years:

1. Training

- a. complete staff and special counselors of the commission;
- b. inter-agency and inter-discipline;
- c. the commission also acted as consultants to universities for VRA grants to increase the number of qualified professionals to serve the mentally retarded. This involved grants to universities and fellowships to individuals to train;
 - (1.) social workers by Rutgers University at the Johnstone Training and Research Center,
 - (2.) rehabilitation counselors at Seton Hall University, and
 - (3.) speech therapists and audiologists at Seton Hall University.

2. Cooperative agreements and procedures with other agencies—Department of Education, Special Education of Catholic Newark Diocese, Division of Mental Retardation, State Employment Service, Division of Welfare, and Sheltered Workshops.

3. Appointment of special counselors.

4. Extension and Improvement Grants for the commission—

- a. Assignment of a counselor to work with the Newark school system which had the largest number of classes for the mentally retarded. Three counselors now serve this school system and there are two others in Essex County.

- b. Assignment of a counselor to the Camden district for direct services in this territory and for consultation and development work in the rest of South Jersey. Two other counselors now serve in South Jersey.
 - c. Assignment of a counselor to the Trenton school system and the Johnstone Training and Research Center. Although the School had asked for this earlier, assignment was not made until a sheltered workshop was established in Mercer County with the commission acting as a catalytic agent and consultant and providing funds for extension and improvement and fees for services to clients.
5. Extension and Improvement Grants to sheltered workshops. Prior to 1957 there was only one sheltered workshop—the Occupational Center of Essex County—providing services to the mentally retarded. Since then 18 sheltered workshops have received grants from the commission as well as fees for services to individual clients. Commission personnel have also encouraged development of these facilities and served as consultants in establishing programs.
 6. Coordination of Sheltered Workshops *
 7. Demonstration and Research Grants to other facilities through VRA—The Commission has served as consultant to and is cooperating with the
 - a. Johnstone Training and Research Center, and
 - b. Bancroft School.
 8. Work-Study Demonstration Grants through VRA—The commission has acted as consultant and is cooperating with the:
 - a. Occupational Center of Essex County and Newark school system,
 - b. Southern Gloucester County School, and
 - c. East Orange, Montclair, and West Essex Regional Schools.

Referrals during this period were accepted from any source. However, actual case finding was carried out on a limited basis in selected areas to which special counselors were assigned. Control of referrals to some extent was exercised since the commission was not in a position—from the standpoint of staff, service funds, know-how, or available facilities for service—to open the flood gates.

During this period the commission's program for the mentally retarded grew rapidly. A survey of the states, conducted by the

* (Recognizing the importance of sheltered workshops, on 6/24/63 the NJRC appointed an administrative supervisor to the position of workshop coordinator. He works closely with workshops on a day to day basis providing consultation & assisting in development of programs and grant applications.)

Office of Vocational Rehabilitation, indicates that the growth of rehabilitation services to the mentally retarded in New Jersey for the period 1955-1959 exceeded that of the nation; New Jersey's average increased 7.3%—national average 1.6% New Jersey ranked 4th among the states for fiscal 1959 in the numbers of mentally retarded rehabilitated and exceeded most of the states of comparable population. For fiscal years 1963 and 1964 New Jersey's rank for rehabilitations of the mentally retarded, based on a percentage of all rehabilitations, was sixth in the nation. The chart below, which shows this growth, represents the number of mentally retarded rehabilitated as compared to the total number of individuals rehabilitated in New Jersey:

	1957	1958	1959	1960	1961	1962	1963	1964
MENTALLY RETARDED								
REHABILITATED	31	43	114	99	165	203	267	334
TOTAL REHABILITATED	781	1030	1316	1362	1521	1888	2242	2890
PER CENT OF TOTAL	3.9	4.1	8.6	7.3	10.0	10.7	11.9	11.5

During the first nine months of the present fiscal year, the growth has continued. The mentally retarded receiving services has increased each month as shown below:

	July	Aug.	Sept.	Oct.	Nov.	Dec.	Jan.	Feb.	March
MENTALLY RETARDED									
RECEIVING SERVICES	757	758	792	816	828	888	881	916	933

An increase of 176 receiving services has occurred. The 933 clients in the active caseloads is already above the 907 projection previously established for the entire year, and if the trend continues the 1966 projection of 1073 will be reached before the end of the present fiscal year.

The increased number of mentally retarded receiving services has been due to (1) the addition of special counselors to serve this group, and (2) the total expansion of staff. Since 1957, 44 new rehabilitation counseling positions have been added, a 250% increase.

INCREASE IN REHABILITATION COUNSELORS

1957	1958	1959	1960	1961	1962	1963	1964	1965
28	37	38	41	48	50	55	67	73

Included in this expansion has been nine special counselors working exclusively with the mentally retarded. This departure from

3

the traditional general caseloads in which a counselor works with all types of physical and mental impairments has had a profound impact on the program. In the first nine months of this year, of the 486 mentally retarded individuals found eligible for services, 325, or 67%, were handled by special counselors for the retarded. Of the 236 rehabilitated in this period, 129, or 55%, were handled by special counselors.

Special counselors for the retarded function in the northern, central, and southern parts of the state. In Essex County there are five such counselors. One is on a Vocational Rehabilitation Administration Research and Demonstration Work-Study Project involving the Montgomery School in Newark and the Occupational Center of Essex County. Two other counselors serve the mentally retarded in the City of Newark. Another handles the suburban area of Essex County. The fifth counselor is involved in a recently initiated Vocational Rehabilitation Administration sponsored work-study project involving school systems of East Orange, Montclair, West Essex Regional, and the New Jersey Rehabilitation Commission.

In Mercer County, through an Extension and Improvement Project, the New Jersey Rehabilitation Commission has assigned a special counselor to work with the Trenton School System and the Johnstone Training and Research Center. The counselor also serves clients in the Johnstone Halfway House Project for the mentally retarded.

In South Jersey there are three counselors for the retarded. One serves the Camden County area; the second handles Cumberland County; and the third is in a recently started Vocational Rehabilitation Administration sponsored work-study project at the Delsea Regional High School in Gloucester County.

Planning for the Future

Now with the impetus given by federal legislation, it is possible and necessary for the commission to plan for a greatly expanded program for the mentally retarded in cooperation with the State Plan for the Mentally Retarded and public and private agencies. In order to plan on a long- and short-term basis, statistics have been gathered from sources which have the most meaningful information for vocational rehabilitation. It should be recognized that figures which have been compiled are intended to give a rough estimate of the size of the problem. Statistics have not been sought, or were not available, from the Veterans Administration, private physicians, clinics for the mentally retarded, or the State Employment Service.

ESTIMATED NUMBER OF REFERRALS FOR VOCATIONAL REHABILITATION

<i>Referral Sources</i>	<i>Estimated Mentally Retarded for Vocational Rehabilitation</i>
Department of Education	3,720
Classes for high school age educable students	
Senior and junior high schools 237 classes	
Elementary schools 11 classes	
Total classes	<u>248</u>
Total students (15 per class) ..	3,720
Institutions and Agencies—Schools for Mentally Retarded as of 7/1/63-6/30/64	253
Discharges from institution	25
Extended visit from institution	<u>228</u>
TOTAL	<u>253</u>
Disability Assistance as of 6/30/64	819
Total of disabled recipients	
over 16 yrs. of age	8,390
11.5% mentally retarded	965
Estimated 85% educable	819
	<u>4,792 TOTAL</u>

Since experience has shown that 29% of all referrals (all types of disabilities) are screened out as ineligible for services, it is estimated that of the possible 4,792 individuals who might currently be referred for vocational rehabilitation, 3,402 would be eligible for services. The Commission's caseload of March, 1965 projected to 6/30/65 shows 10,000 cases. Of this total, 14.35%, or 1,435 are mentally retarded. Thus, the Commission could presently be serving more than twice as many mentally retarded at this time.

In order to serve clients adequately, it is reasonable to expect the counselor with a general caseload to serve 135 clients (90 active, 35 in investigation) and a specialist to serve a caseload of 90 (60 active, 30 in investigation). Even with conservative estimates, the Commission is understaffed.

Based on the Commission's experience with referrals, caseloads and potential clients in the community, the following chart indicates present and future caseloads and counselors needed.

<i>Fiscal Year</i>	<i>Total Caseload</i>	<i>Mentally Retarded</i>	<i>% of Total</i>	<i>Counselors Needed</i>
7/1/66	10,000	1,435	14.35	16
7/1/67	15,098	2,417	16.01	27
7/1/68	20,712	3,509	16.94	39
7/1/75	30,000	6,000	20.00	66

This chart will assist the Commission during the next decade when extensive expansion of program will take place. Consideration must be given, however, to other factors and variables that will affect these figures—such as population growth, automation, new knowledge through research and developments brought about by the State Plan for the Mentally Retarded. The Commission will also be active in designing new methods and techniques for locating and serving this disability group more effectively.

In order to develop the program of vocational rehabilitation of the mentally retarded, the New Jersey Rehabilitation Commission considers the following necessary:

1. cooperation and participation in the State Plan for the Mentally Retarded;
2. more adequate funds for public and private vocational rehabilitation purposes, including salaries adequate enough to attract and maintain qualified staff;
3. one special counselor for each local office and more for highly populated areas;
4. closer cooperation with Special Education in public and parochial schools—including an agreement of cooperation with the Trenton and Camden Catholic Diocese. (One is in existence with the Newark Catholic Diocese);
5. Work-Study Programs—development of the role of the Department of Education and that of the Commission including new methods of funding in these programs, (also possible involvement of Sheltered Workshops);
6. closer cooperation with the Division of Mental Retardation including matching funds for expanded programs;
7. stepped-up training for Commission Staff—inter-agency and inter-disciplinary training for more coordinated and effective services to clients;
8. sheltered workshops;
 - a. increase in number—see that there is adequate coverage in all areas of the state;
 - b. above may involve regional workshops with support by state agencies—I & A and NJARC—either directly or by delegation of management to community agencies. Co-operative planning would involve discussion with the N. J. Association for Retarded Children;
 - c. standardization for staffing and services to insure quality of service;

- d. consideration for other types of workshops and other programs for existing workshops to provide for interests and aptitudes of clients (possible farm type) and to meet labor needs in the community;
9. employment opportunities—expansion of present commission program of training and placement in jobs other than the stereotyped, routine and service jobs. Enlist cooperation of the Labor Department re: labor trends and the Department of Education in training to meet future needs;
 10. group counseling—expansion of the present commission program;
 11. related family services—cases are sometimes rejected and closed non-rehabilitated because the family environment is not conducive to rehabilitation. Although this can happen in other severe disabilities, it occurs more frequently with the mentally retarded. A family often needs guidance and support in handling a mentally ill or retarded child. Yet, Family Service Agencies are either non-existent in many communities or have such a long waiting list that little help is available. If service could be extended to a family member or members, perhaps the entire family would benefit. Psychiatric treatment, counseling (individual and group), and social work services for the family are some ways in which this could be accomplished;
 12. social workers—added to the staff of the N. J. Rehabilitation Commission (if not made available through other sources) to provide needed case work;
 13. auxiliary service—there will be an increasing need for availability of professional staff. To working clients or parents, other agencies have long recognized the need for having services available at specified times other than usual hours. Objective thought and planning will be given to this aspect of service;
 14. Multi-disciplinary Agency Center—it is important for agencies and disciplines to understand each other and work selflessly in the interest of the client. This would involve having a psychiatrist, psychologist, social worker, and counselor—all from different agencies—functioning in one center—each helping the client and family at a given time.
 15. on-going evaluation of present and future program for the mentally retarded—new methods and techniques will be developed to meet the service needs of this disability group.

2. Other Programs

Wage and Hour Bureau

The Wage and Hour Bureau allows mentally retarded employees to receive wages lower than the prevailing minimum wage. This permits the mentally retarded to engage in remunerative employment at home and more often in sheltered workshops. They, therefore, can work at their own speed and earn wages commensurate with their ability. Permission for this wage variance is applied for by the individual employee. In some instances, the employer or sheltered workshop facilities applies for a permit to cover all handicapped employees.

Division of Employment Security

This division offers selective placement services to all applicants including the physically and mentally handicapped. In local offices throughout the state, the mentally retarded applicant is offered a variety of specialized services (counseling, aptitude testing, etc.) to insure maximum opportunity for employment. The division, however, does not maintain a staff of counselors who work only with the retarded.

Division of Workmen's Compensation

The mentally retarded worker injured in the course of employment is as eligible as any other industrially injured employee in the state to receive Workmen's Compensation benefits. The Second Injury or One Percent Fund provides benefits for employees who become totally disabled as a result of successive injuries, each of which alone would cause only partial disability. In such cases of subsequent injury, the employer is obligated to pay compensation only for the disability which resulted from the second injury; the Fund is obligated to pay the remainder of the compensation. By removing the employer's fear of increased Workmen's Compensation, the Second Injury Fund enhances employment opportunities for disabled workers, including the mentally retarded, who might subsequently suffer a comprehensible accident.

E. DEPARTMENT OF STATE

Division of Aging

The health of the general population has greatly improved during this past half century. With health improvement came a life expectancy hitherto unrealized. In 1850, the life expectancy of the average American was 39 years. By 1957 this figure rose to an unprecedented

*Dept. of Conservation and Economic Development, Bureau of Commerce, Research and Statistics

69 years. It is estimated that by 1970, approximately 663,000* residents of New Jersey will be aged 65 or older. Medical advancements, notably in the areas of public health and pediatrics, have been primarily responsible for this new longevity.

Some aged individuals lose the capacities necessary for independent living, but at any given time this is only a very small percentage of those over 65—something under 5%. However, many older people face problems because society as a whole, as well as individuals, have failed to plan for the extension of life at a time when the employment as a lifelong expectation is decreasing.

The Division on Aging was created in New Jersey to systematically study the problems related to aging. Its legal foundation can be found in Chapter 74, Public Laws of 1957. The Division, in a generic sense, is responsible for maintaining a continuous study, analysis and interpretation of all information, data, and program developments pertaining to the aging processes and the needs of the older residents of New Jersey. Divisional policy is developed with the advice of a Commission on Aging. Membership in the Commission consists of the Director of the Division, who serves as Chairman, six members who represent six designated state departments, and four citizens. Program activity consists of maintaining a continuous inventory of resources; disseminating information through various communications media; providing consultant services to community and professional organizations; assisting state agencies and volunteer groups in programming and experimentation related to aging; initiating legislation; organizing and participating in professional conferences; and encouraging research by making grants-in-aid available.

Under present legislation, the Division does not provide direct services to individuals. Although no statement of responsibility to the mentally retarded has been promulgated, the Division does have the responsibility for identifying the needs of older people in whatever area they may arise. Areas of immediate interest insofar as mentally retarded aging individuals are concerned include:

1. Placement of such individuals in a community setting, especially approved boarding homes;
2. Provision for mentally retarded adults cared for by their aging parents who are concerned with the future of these individuals.

The Division can be of assistance in developing approaches to the above mentioned two areas of concern, as well as other areas specific to the aging mentally retarded through their program activity.

Section V

**COST OF
PROGRAM
IMPLEMENTATION**



Total implementation of a comprehensive plan for the mentally retarded will undoubtedly require a great expenditure of funds. The complexity of present and proposed programs of both a service and administrative variety, however, makes accurate estimation of future costs formidable. Public and private agencies may provide similar services, often in competition with each other—yet rarely operating within a similar fiscal structure. The availability of other services is contingent upon financial support from federal, state, and local government agencies, and matching arrangements are complex and differ significantly from service to service. Numerous community programs exist where operating expenses vary significantly. During 1965, for example, the cost per child for Day Care ranged from a low of \$865 to a high of \$2,232 at different county centers. To some extent, such variation results from the fact that in some programs volunteer services predominate, and programs are made available in structures which may be rent free or partially subsidized by county funds or parent or other voluntary groups.

To insure adequate provision of future service, cost estimation should not reflect present inadequate service levels, but be based upon the assumption that future services will be available to all retarded persons requiring such services. The cost estimates contained herein pertain to Residential Care, Special Education, Vocational Rehabilitation, Disability Assistance, and Day Care—programs either partially or totally supported by state departments.

Cost estimates are predicated on two factors: (1) an increase in the units of service required; and (2) increased costs for providing

a given unit of service. In estimating future caseloads in Special Education, Vocational Rehabilitation, and Day Care, the Index of Service¹ methodology was used. Future caseloads for Disability Assistance and Residential Care were estimated on the assumption that present levels of service need will rise in proportion to the growth of that segment of the population eligible for the service. During 1965, for example, 8,640 retarded persons out of New Jersey's population aged 18-65 received disability assistance. The present ratio was used as an index of need for disability assistance in future years.

With regard to the cost for units of service, the method of estimating was as follows: In each area of programming, the average cost of rendering service to one person during 1965 was calculated. This figure, the average cost of rendering service to one person during 1965, was considered the base datum. This base cost per unit of service was then increased by 5% per annum to anticipate inflation factors and the cost inherent in increasing the quality of service. The adjusted cost per unit of service was then multiplied by the appropriate caseload estimate.

All cost estimates, therefore, reflect the increase in both mounting caseloads and the increased costs for providing a given unit of service. The cost estimates, however, pertain only to the operating expenses of the programs. Funds needed for the construction of new facilities or expansion of existing structures are not included.

Residential Care

New Jersey's residential caseload was approximately 6,400 during 1965.² The cost of providing services to these persons during 1965 was \$13,052,000, or approximately \$2,040 per person. Although this number was provided service during 1965, an additional 900 persons were awaiting residential placement on waiting list status. Had the total cohort received residential care, \$14,900,000 would have been necessary to provide adequate services.

It is estimated that by 1970, approximately \$20,502,000 will be needed to provide services for 8,040 persons. The estimate rises to \$38,880,000 by 1980 when an approximate caseload of 9,600 is anticipated.

The actual extent of residential care is contingent upon the capacity of the plant structure to accommodate retarded persons. The Woodbridge State School, opened during January, 1965, will

¹For a detailed description of the Index of Service statistical technique, the reader is referred to Appendix A.

²This approximate residential caseload does not include the Purchase of Care caseload of approximately 300 persons.

accommodate 1,000 residents. In addition to the expanded caseload made possible by Woodbridge, the construction of the readjustment unit and the research evaluation facility of the Johnstone Training and Research Center will make available an additional 164 beds. Still another facility, the Hunterdon State School, with a rated capacity of 1,000, is scheduled for operation during the latter part of 1968.

It should be noted that the number of retarded persons estimated to be in mental hospitals were not included in the service-need cohorts. During 1965, for example, 1,620 retarded persons were reported to be patients in state and county mental hospitals. It is difficult to determine at this time just what percent of this number should be transferred to a residential facility for the retarded. If one assumes, however, that persons hospitalized in psychiatric facilities with either a primary or secondary diagnosis of mental retardation should be transferred to residential schools for the retarded, a total of 8,920 persons would have needed this character of service during 1965; and the cost of providing service to these persons would have approximated \$18,197,000. By 1980, (including the number of persons estimated to be in mental hospitals), \$47,507,000 would be needed to provide residential care for approximately 11,700 persons.

Special Education

For the 1964 school year, the State Department of Education funded special education services to 2,232 trainable and 14,123 educable mentally retarded children (the number of mentally retarded children who received this specialized instruction during 1965 has as yet not been reported). The cost* of providing services during 1964 was approximately \$13,500,000.

Approximately 23,800 retarded children were in need of special education during 1965. Had full implementation of service existed, and the 23,800 children estimated to need this service received it, the cost would have approximated \$19,600,000 (assuming average 1964 costs). By 1970, it is estimated that 3,100 trainable and 22,500 educable mentally retarded children will be in need of special instruction at a cost of \$24,500,000. By 1980, moreover, \$32,400,000 will be required to provide adequate services to 32,100 children who will be expected to need this type of program.

Vocational Rehabilitation

The Vocational Rehabilitation Commission of the Department of Labor and Industry reported that 470 mentally retarded persons

*This cost reflects both state and local school district contributions.

were rehabilitated during 1965. The cost of rendering services to these individuals approximated \$254,800, of which the state paid 49% with federal support for the remainder. Estimates, however, indicated that although 470 persons were rehabilitated, an additional 1,470 retarded persons needed this service during 1965. If rehabilitation services were made available to the total estimated caseload, the cost would have approximated \$1,053,000.

By 1970, need for service is expected to rise to 2,140 cases, and the cost of providing service to this caseload will be \$1,450,000. The estimate rises to 2,330 by 1980 with \$2,727,000 being required to provide adequate services. It is recognized that the scope of existing service will expand as funds become available to New Jersey as a result of the passage of the Vocational Rehabilitation Amendments of 1965.*

Day Care

Day Care services were rendered to 239 children during F.Y.66 at a cost of approximately \$258,000. Of this total, \$225,000 was provided by the Department of Institutions and Agencies. The remaining financial support came from the local NJARC units who operate Day Care. Although 239 children received Day Care service, it was estimated that an additional 472 children in need of this service did not receive it. If the total cohort had been accommodated, the cost would have approximated \$775,000.

By 1970, it is estimated that 765 children will require this character of service at a cost of \$1,016,000; and this service need will rise to 955 by 1980 with \$2,039,000 needed to provide an adequate program.

Bureau of Assistance

The Bureau of Assistance of the Department of Institutions and Agencies reported that during 1965, 8,640 persons received \$10,580,000 in disability assistance. Of that number, approximately 1,290 retarded persons received \$1,613,000 of which the federal government contributed \$772,400 (48%), with state and local governments equally sharing the remainder (26% each).¹ By 1970, it is estimated that 1,350 retarded persons will need this financial assistance at a cost of approximately \$2,070,000; and by 1980, 1,680 persons will be in need of disability assistance because of inadequacy resulting from mental retardation. The cost of maintaining this caseload will approximate \$4,043,000.

*On January 1, 1966 the federal contribution will rise to 66%, and by July, 1966 the federal matching will increase to 75%.

¹On January 1, 1966 the matching arrangement will change with the federal share increasing to approximately 50% and state and local contributions each approximating 25%.

Table I

Summary of costs necessary to maintain caseloads in Residential Care, Special Education, Vocational Rehabilitation, Day Care, and Disability Assistance. The 1965 "Actual" column refers to the amount of money expended on serviced caseloads during 1965. All "Required" columns refer to the estimated costs necessary to provide services to anticipated caseloads.

	1965 <i>Actual</i>	1965 <i>Required</i>	1970 <i>Required</i>	1975 <i>Required</i>	1980 <i>Required</i>
Residential Care	13,052,000	14,900,000	20,502,000	28,382,000	38,880,000
Special Education	13,500,000*	19,600,000	24,500,000	30,600,000	32,400,000
Vocational Rehabilitation ..	254,800	1,053,000	1,450,000	1,978,000	2,727,000
Day Care	258,000	775,000	1,016,000	1,495,000	2,039,000
Disability Assistance	1,613,000	1,613,000	2,070,000	2,914,000	4,023,000
TOTAL	28,667,800	37,941,000	49,538,000	65,369,000	80,069,000

*actual cost during 1964

Section VI
COMMUNITY
PROGRAMS



The term "community" in respect to resources for the mentally retarded seems to be used in two different, but sometimes overlapping, ways. In some instances sponsorship appears to be the major criterion; community in this sense seems to mean non-governmental sponsorship. Location would appear to be the other commonly used criterion; services provided outside congregate institutions are considered community under this definition. The overlap comes about as a result of the fact that most governmental services have traditionally been available on a congregate, residential basis. For the purpose of the present discussion of resources the term is used in the "overlapping" sense, excluding governmentally sponsored congregate facilities. The two major resources thus excluded would be the large-scale residential facilities operated by the state, and special classes operated by local school districts.

Most of the community programs presently in operation in New Jersey are either operated by or affiliated with county components of the New Jersey Association for Retarded Children. Consequently, most of the information regarding such programs was obtained from the state office of the organization. Additional data was developed by the project staff in its inventory of resources for the state construction plan.

Day-Care Centers

New Jersey's State Plan for the Construction of Mental Retardation Facilities identifies a day care center as one which offers a program of social-developmental training to severely and profoundly

retarded children between the ages of 4½ and 21. The children served should not be eligible for special classes operated by local school districts. The construction plan identified 15 such centers; however, there are at least 13 additional centers which conform to some but not all of the criteria mentioned above. There seems to be a trend towards a stricter interpretation of what constitutes a day care center, and many of the 13 additional centers are in the process of being converted to day care centers as defined in the construction plan. Eligibility for state and federal financial assistance is undoubtedly a major factor in determining this trend. Almost all counties in the state have at least one day care center.

Activity Centers

Although less strictly defined than day care centers, activity centers offer programs for "graduates" of day care programs, and for other adults too severely retarded to be considered for competitive employment. In some instances persons in the activity center might be so handicapped that an extension of training in activities of daily living would be the most that could be offered. For those somewhat less severely handicapped, sheltered employment within the center would seem to be a legitimate goal. Nine such activity programs serving nine counties have been identified. Additional programs with some aspects of an activity center are available in conjunction with the sheltered workshops discussed below.

Sheltered Workshops

There are at least 20 facilities in 12 counties identified primarily as sheltered workshops. Programs available in these facilities range from intensive vocational training for competitive employment to basic activity programs. Most workshops emphasize preparation for competitive employment. Many workshops, however, are concerned about the increasing numbers for whom they are expected to provide sheltered employment, the so-called "terminal" cases. Most centers also serve a variety of handicaps, and sponsorship of clients by the New Jersey Rehabilitation Commission seems to be of great assistance in their operation. The term "sheltered workshop" is somewhat misleading since it tends to imply a place of sheltered employment rather than training. Since the term is so commonly used to include both sheltered employment and training, a change in terminology seems unlikely.

Diagnostic and Evaluation Centers

At least six such centers devoted almost exclusively to the mentally retarded are available. Exact county coverage is difficult to deter-

mine. Some centers restrict intake to a few counties; some extend services to counties not otherwise covered by a diagnostic center; and others theoretically offer services to the entire state. The source of financial support is frequently a factor in determining geographical coverage. If a clinic operation is supported almost entirely from funds collected within a particular county, services rendered to non-residents of that county may require full payment, while fees for county residents are on a sliding scale. In general, fees are based upon ability to pay.

Services seem to be more readily available in the northern half of the state. Facilities in New York City are also used by persons in the northeastern sector of the state. Similarly, facilities in Philadelphia are used by families in the midwestern and southern parts of the state. There seems to be a renewed interest on the part of Child Guidance clinics to offer evaluation services to the mentally retarded. In some areas of the state such clinics may be the only resource readily accessible. For children of school age, evaluation services available through the public schools are sometimes overlooked. Local school districts do provide evaluation services to determine whether children might be eligible for special class placement. Parents, however, sometimes fail to take advantage of this service because (1) they do not know it is available, or (2) they feel that the child may be too severely handicapped to be considered for special class. Many school districts will provide an evaluation even for those children for whom gross observation reveals profound retardation.

Parent Counseling

Counseling parents of the retarded is probably the most widespread and least clearly defined of all the community activities under discussion. There are few organized programs for this function (less than a dozen could be identified) and it is somewhat difficult to distinguish between the rather common "giving of advice" on a short-term basis and a more extended program offered specifically for parents of the retarded. Most diagnostic clinics offered some form of counseling as part of their program. In addition, four county units of NJARC list parent counseling as part of their program. Mental Health clinics, family service agencies, and private practitioners serve parents of the retarded as well as others, but very few of these are able to offer services to meet the often unique problems of the parent of a retarded child. Group counseling has been offered in some areas on-and-off for the last 10 years, and seems to be on the increase. "Crisis counseling" is becoming a more popular concept, and many units of the parents' organization have

aspirations along these lines. Efforts should be made to assist physicians and clergy since they are frequently called upon to offer advice to parents of retarded children.

Counseling the Retarded

This is usually done as part of other programs, most frequently in vocationally oriented settings, and generally with the more mildly retarded. Some clinics for the retarded offer counseling services to more moderately retarded persons, but this service is apparently not used very often. Child Guidance clinics service borderline cases when mental retardation may be in doubt, but the likelihood of service seems to be in inverse proportion to the degree of mental retardation.

Recreation Programs

Recreation programs seem generally available throughout the state. Fifteen canteen programs in 12 counties offer specific programs for the teen-age retardate, and additional recreation programs for younger children extend this type of program to 15 counties. Activities include swimming, bowling, social dancing, and other similar recreational pursuits. Seven counties have special scout troops for retarded youngsters of both sexes. Fourteen counties have summer day camps sponsored by local units of NJARC. There are some regular day camps which also take retarded youngsters, in addition to a few overnight camps which take a limited number of retarded children. Many of the milder retardates take advantage of regular programs of the Scouts, Y's, the social organizations of the churches and the neighborhood, and many others. Of this group many participate in commercially available sources of entertainment and recreation.

Other

At least five counties have special provisions for the religious needs of retarded persons. These counties have organized religious classes, but retarded persons throughout the state undoubtedly take advantage of the regular programs offered by the various denominations.

The availability of speech and physical therapy is rather difficult to determine. At least two counties have special speech programs for the retarded, but no county was found to have a physical therapy program for this group. Such therapy is available, however, in cerebral palsy clinics. Many retarded children who also have cerebral palsy are undoubtedly served through such centers.

Summary

Since most retarded persons remain in the "community" as defined, the availability of community resources to meet their needs is a vital factor in a soundly structured program. Many such persons have minimum deficit and are capable of taking advantage of programs developed for the general population. Others cannot profit from these since the programs may not meet their needs. Special programs have grown tremendously in the last two decades, but coverage is "spotty". All too frequently the development of a program is dependent upon a small group of interested persons who have the dedication and the "know-how" to get such a program started. This generally coincides with the needs in a particular area, but not always. A "master plan" for the development of community resources would seem to be needed, with provision for the development of facilities, where needed, by other than strictly local persons.

Section VII
ADDITIONAL
INFORMATION



CONSTRUCTION PLAN

Under Public Law 88-164 Federal matching funds were made available to states for the construction of mental retardation facilities. The New Jersey Construction Plan was developed in conformity with this law to include: (1) delineation of planning areas, (2) description of regions, (3) inventory of existing services and facilities, (4) determination of relative need, and (5) a system of priorities. *The New Jersey State Plan for the Construction of Mental Retardation Facilities* was approved by the U.S. Surgeon General in August, 1965. The plan represents the best local attempts to secure data on the availability of facilities and the best attempts developed in conjunction with the Advisory Council on Construction and the State Board of Control to meet state need for comprehensive planning to combat mental retardation. Since the needs of the retarded in comprehensive planning are reflected in the construction plan, salient features of the construction plan are abstracted and presented here.

This construction program conforms with the requirements of Section 133 and 134 of the Act and Section 54.109 of the Regulations.

Delineation of Planning Areas

The State of New Jersey has been divided into four major regions for planning purposes. Justification for this delineation is as follows:

1. The regions are of sufficient size and 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.

2. The regions permit programming of needed services and facilities without unnecessary and costly duplication.
3. Access within each region is well maintained by a system of highways and freeways. For the most part, travel time between urban centers in each region and their contingent suburban areas does not exceed one hour.
4. The regions are appropriate for various administrative purposes. Because this delineation has been developed along county boundaries, the mechanism for effective coordination with other county-based departments and agencies is available and operable.
5. The regions are identical with the public health regions of the state which permits effective coordination between these departments.
6. The population in each region tends to share an identifiable economic base.
7. The regions tend to be urban areas with their tributary suburban and rural development.

Socio-Economic Characteristics by Region¹

Region I—Bergen, Essex, Hudson, Passaic, Union
 Region II—Hunterdon, Morris, Somerset, Sussex, Warren
 Region III—Burlington, Mercer, Middlesex, Monmouth, Ocean
 Region IV—Atlantic, Camden, Cape May, Cumberland, Gloucester, Salem

	I	II	III	IV
1. Population—1960	3,225,407	572,115	1,367,389	901,871
2. Pop. density per sq. . mi—1960	4,588	273	553	402
3. Pop. Estimate—1963	3,338,550	640,050	1,529,670	961,730
4. Pop. Projection— 1970	3,493,760	767,918	1,836,905	1,072,362
5. Median Age—1960 ..	33.7	31.8	29.9	32.3
6. % under 5 yrs—1960	9.9	11.4	11.6	10.9

¹Data provided by the Department of Conservation & Economic Development

MENTAL RETARDATION REGIONS

2

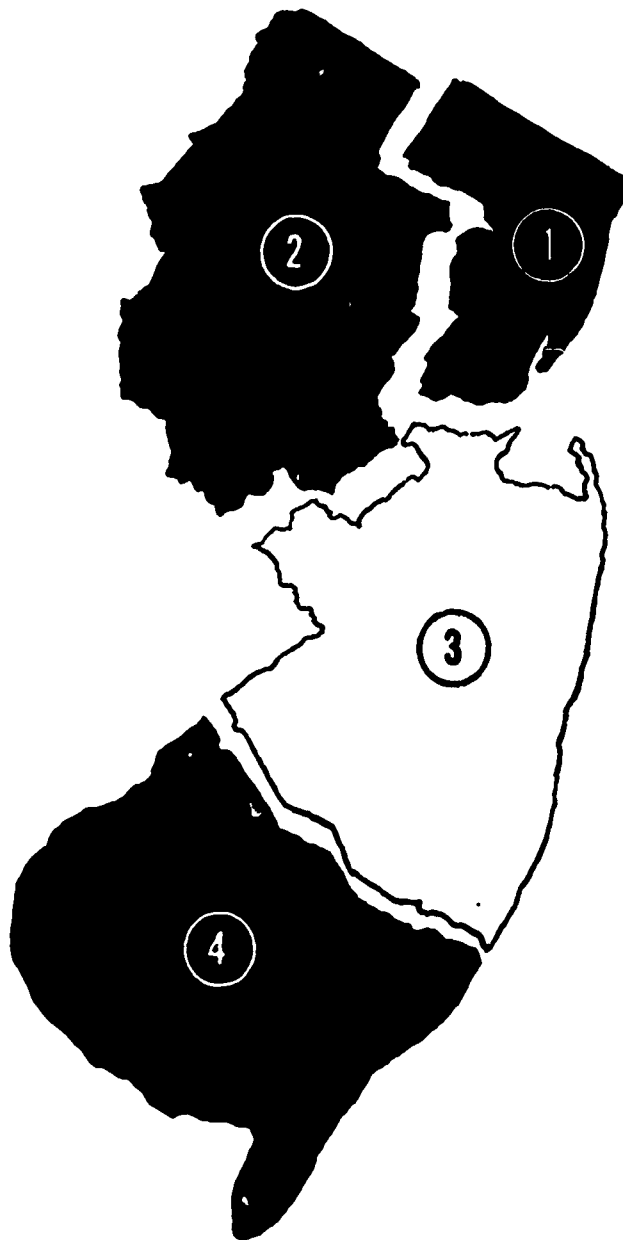
NORTHERN

WARREN
SUSSEX
MORRIS
SOMERSET
HUNTERDON

1

METROPOLITAN

BERGEN
HUDSON
PASSAIC
ESSEX
UNION



4

SOUTHERN

CAMDEN
ATLANTIC
CAPE MAY
GLOUCESTER
SALEM
CUMBERLAND

3

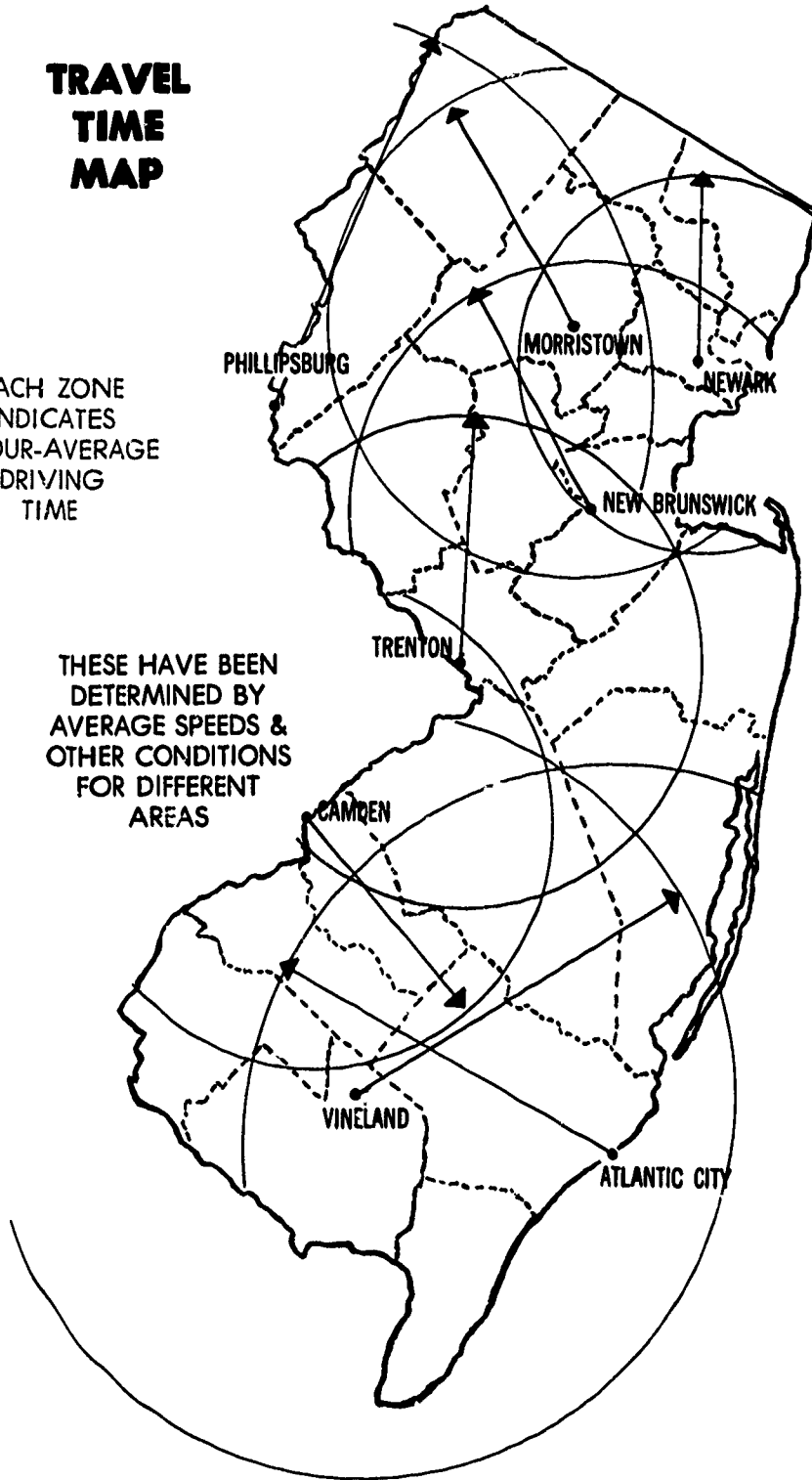
CENTRAL

MIDDLESEX
MONMOUTH
MERCER
BURLINGTON
OCEAN

TRAVEL TIME MAP

EACH ZONE INDICATES 1-HOUR-AVERAGE DRIVING TIME

THESE HAVE BEEN DETERMINED BY AVERAGE SPEEDS & OTHER CONDITIONS FOR DIFFERENT AREAS



	I	II	III	IV
7. % 5-19 yrs-1960	24.9	26.7	27.0	26.0
8. % over 65 yrs-1960	9.4	9.0	8.4	10.1
9. % over 25 with high school education	40.4	47.4	44.5	35.3
10. Average Household size-1960	3.20	3.36	3.37	3.22
11. Median Family Income-1960	\$6,992	\$6,515	\$6,437	\$5,843
12. % of households with income under \$2500	7.2	9.5	12.9	12.6
13. Total Land Area sq. mi.	703	2,099	2,475	2,245
14. % undeveloped land -1960	33.4	42.6	42.1	44.4
15. % Agricultural land -1959	4.3	34.0	27.6	29.9
16. % Industrial land -1960	5.9	0.6	1.3	0.8
17. % of single family dwelling units of total dwelling units-1960	44.8	87.5	84.5	83.8
18. % of pop. un-employed-1963 ..	6.3	6.1	6.8	8.5
19. % of pop. on general public assistance	3.0	1.2	1.9	3.1

Quantitative and Qualitative Factors

In the determination of priorities for the construction of needed facilities for the mentally retarded the relative needs among planning regions and among different types of facilities within the same region must be considered. There must also be established short-term goals, predicated upon the possibility of immediate or early implementation as well as pressing needs, in consonance with long-term goals reflecting the conceptions of comprehensive planning to combat the problem of mental retardation. The order in which both long and short term priorities are cast is a function of quantitative data and qualitative (or judgmental or subjective) factors which may be of greatest significance in establishing short term goals.

This section of the plan will, in the main, address itself to short-term goals. It may be sufficient for long-term planning to indicate that New Jersey requires expansion of more diagnostic and evaluation services and more treatment, education and training, and residential care services for the purpose of overcoming present shortages in service, to develop new approaches, and to meet increased demand as the state population grows from the 6,066,000 persons determined in the 1960 census to the 8,112,000 predicted for 1975.

During the next three or four years, in contrast to the entire program to be realized over the long haul, specific priorities can be designated. Present relative need among regions may be a function of the degree to which services actually exist and the waiting list (actual or inferred) for presently conceptualized and/or offered services. There will be little attention paid here to the socio-economic and age differentials among regions since the differences may not be significant. New Jersey may be a state relatively homogeneous when one considers the regions referred to previously. Differences between regions (as totals for regions) do not reflect similarity for components among regions. For instance, the relatively great density of Region I is matched by density in particular localities in other regions. The weighting, moreover, to give to various components in the establishment of difference between regions is not available from the experience in New Jersey or the literature. It is not known whether the greater density in Region I should be considered as more or less important than the younger age of persons in Region III or the undeveloped land in Region IV or the lowest percent of industrial land in Region II.

The manifestations of present need by regions in terms of required versus available units of service are presented in the Construction Plan. (Estimates of required need derived from "Planning of Facilities for the Mentally Retarded," United States Department of Health, Education and Welfare, Public Health Service and from "index of service" as developed for "comprehensive" planning in New Jersey.)

These data led to the following order of priority among the Regions in New Jersey:

<i>Order of Priority</i>	<i>Region</i>
First	II
Second	III & IV
Third	I

It will be noted, however, that the difference in met needs among regions is slight and certainly hardly significant. The need is appar-

ent in all regions. As a consequence, it is New Jersey's intention to select projects for funding predicated primarily on the basis of *type of facility* rather than any regional priority. The order of the regional priority will be used only in such instances where there may be competition between two regions for funds of similar types of construction.

It will be apparent that no reference is made to custodial residential services as traditionally provided on a 24-hour a day basis in a residential facility. New Jersey's relatively small area and tradition of classified institutions makes the existing facilities appropriately and easily available to all citizens regardless of in which region they may live. In 1965, a new 1000-bed facility was opened and will take care of a significant portion of the list of those awaiting residential service. There is, moreover, presently available an appropriation to construct another residential facility which should meet needs in this kind of service until 1970 or 1972. This aspect of service, consequently, should have a low or the lowest priority. Some recognition, however, should be given to the absence in New Jersey of Community Group Living Centers for the retarded who require housing and "company" (such as might not be available in a foster home) while they pursue relatively independent living in the community.

In regard to the estimated service-load for Community Group Living Centers (hostels), local opinion suggests that this service may be required for as many as 140 retarded persons in the state.

The qualitative factors, perhaps of greater importance to short term priority than quantitative factors, include:

1. availability of generic services,
2. apparent feasibility,
3. contribution to comprehensiveness of total program,
4. community readiness, and
5. extent to which the construction will house a service that will continue family integration and life (for the retarded) in the community.

The question of availability of generic services poses again for all in the field the issue of advisability of "tooling up" specialized services for the retarded. Even should the philosophical question be disregarded, certain trends may be apparent in regard to various types of facilities. The tendency in regard to *treatment services* via specific kinds of treatment services in general or all purpose hospitals or clinics should be encouraged. The comprehensive planning in New Jersey, while recognizing all need for *diagnostic and evaluation* services in relation to all kinds of services, seems

to be in the direction of "all purpose" clinics for handicapped children connected with pediatric services in general hospitals. All purpose *sheltered workshops* have to some extent been made available to the retarded. There, however, has been no development of generic *Day Training and Custodial Services* for pre-school children, for school age children unable to participate in public schools, and for the mentally retarded beyond school age.

The issue of apparent feasibility is complex and contains, at least, the following aspects: clarity of purpose, antecedent demonstration or trial and availability of sponsorship in both administrative and fiscal terms. The purpose of all the types of services discussed previously is relatively clear. In New Jersey, however, antecedent demonstration by which newly started programs can begin with a minimum of floundering is to be noted more in the *diagnostic and evaluation* area, the *day training* area, and the *sheltered workshop* area. There is comparatively less local (and probably national) experience in regard to *treatment* and *pre-school services*. As far as availability of sponsorship in administrative and fiscal terms, responsibility and intent is apparent in regard to *day training and custodial services* and somewhat vague in the other areas. With particular regard to *sheltered workshop* programs, moreover, legislation presently pending in Congress may change the character of "eligibility" to rehabilitation services and establish a Federal Construction Program similar to PL 88-164. A serious matter remains to be resolved (at least in New Jersey) in regard to *pre-school training services*. Further discussion will be required before there will be a clear conception of whether this service shall be sponsored by public agencies or voluntary associations, and if the former, by which state department or by what level of government (e.g. state, county, municipal).

All of the previously listed services will contribute to the comprehensive character of New Jersey's program for the retarded. As far as can be judged there is undifferentiated community readiness for all. The NJARC, in a statement to New Jersey's Planning Staff, emphasized the need for gestures of service and construction support in all previously listed areas.

The final qualitative factor involves support of family integration and the extent to which the service would permit continued residence by the retarded in the community. All of the listed services, especially in view of the disclaimer of a high priority for residential facility construction, will be in support of this important value. The attainment of this aspiration, however, may be less directly a function of *diagnostic and evaluation services* than of the others which

are in the character of direct services to improve the quality of social and physical adjustment to the community.

Perhaps a final, previously unmentioned, qualitative factor should be mentioned—highest priority should be given to facility construction which provides (for a region or subdivision of a region) a number of services which are not contradictory in a medical, social, or administrative sense. A day training and custodial service may be housed in the same facility as a pre-school center. The former, however, in the same structure as a training workshop may develop an unfortunate public image as the community can invest the mildly retarded adolescent or young adult with the degree of handicap apparent, for instance, in adolescents who are so retarded that they cannot attend public schools.

System of Priorities

Based on the aforementioned quantitative and qualitative factors, in addition to the analysis and evaluation of existing and suitable facilities for the retarded, and with the advice and consultation of the Advisory Council on Construction, the following system of priorities has been developed:

<i>Order of Priority</i>	<i>Type of Facility within Regions</i>
1	Training and Custodial Day Center
2	Sheltered Work Training Center
3	Pre-School Center
4	Training and Custodial Residential Center
5	Diagnostic Center
6	Treatment Center

The establishment and eventual completion of these priorities, which will bridge presently existing gaps, are viewed as an important and necessary step toward completing the array of necessary services and facilities for the mentally retarded in New Jersey.

Perhaps some repetition of the philosophy regarding the low ranking of diagnostic and treatment facilities may be required. First, the extent to which treatment may be supplied the retarded in New Jersey is undisclosed by the inventory. Second, in the opinion of the Advisory Council and Planning Staff such services do exist to a significant degree in facilities not developed exclusively for the retarded. Third, it is our belief that additional diagnostic and treatment facilities should not be developed for exclusive service to the retarded but created as part of generic programs to service all handicapped individuals.

In evaluating requests for funds, priority will be given to replacement of inadequate physical structures so that the quality of programs may be increased and greater numbers of retarded may be served.

NEW PROJECT PROPOSALS

In the course of comprehensive planning, three project proposals were developed and submitted to the U.S. Public Health Service. Federal funds were approved for the *Implementation of New Jersey's Comprehensive Plan to Combat Mental Retardation*. Brief summaries of these proposals follow.

Development of a High Risk Register for Mental Retardation

This project is being submitted on behalf of New Jersey's Interdepartmental Committee on Lifetime Disability. The intention of the project is to demonstrate the feasibility and usefulness of a register of newborn children who might be considered "at risk," i.e. by reason of certain criteria demonstrated by them or by their mothers, those infants who have greater likelihood of mental retardation than the general population. Project staff is to collect data, register high-risk individuals, and transmit data to the medical personnel responsible for their health supervision. By means of visiting nurses' case work and follow-up pediatric examination, prevention will be effected on two levels: (1) on the primary level, to prevent the occurrence of mental retardation; (2) on the secondary level, to modify or reverse the course of the condition through diagnosis and treatment, and through treatment of superimposed handicaps. Project staff will act as a "focal point" of referral to community resources and as liaison between parents and appropriate social agencies. There will be follow-up on the accomplishments of treatment and services, and a continuous flow of data to and from the register. The locus is to be two hospitals, each serving differently comprised populations. The socio-economic characteristics of a rural area and of an urban area, as related to the criteria for high risk, will provide a basis for comparative study and analysis. Project staff will publish a report of the techniques and achievements of the project.

Health and Activities Centers

This project is also being submitted on behalf of New Jersey's Interdepartmental Committee on Lifetime Disability. The purpose of the project is to demonstrate the feasibility of extra-institutional programs for severely retarded, older adolescents, and adults, who are living in the community and are not involved in any existing

service. Basic to the project is the premise that, if a retardate is to attain his maximum potential, he must be treated as an organic whole. Accordingly, the project will organize a center in an urban area at which a gamut of services will be provided, such as medical (diagnostic and corrective), dental (evaluative and corrective), psychological, social, recreational, instructional, etc. The program is designed to (1) prevent the physical, social, and intellectual decomposition commonly found among this group who are retained in the community, (2) provide the individual with a program commensurate with his abilities, and (3) enhance the possibility of retaining the retardate in the community by developing his ability to care for himself. Case records maintained on all clients participating in the project will be periodically reviewed and evaluated in terms of the changes and benefits derived from the program. At the end of the five-year demonstration period, a narrative summary report on the values of the program will be prepared.

Implementation of New Jersey's Comprehensive Plan to Combat Mental Retardation

This project provides a mechanism for implementing the recommendations made in this plan. Primary emphasis is placed upon coordinating the efforts of the various agencies assigned program responsibility under the plan, and upon stimulating these agencies to follow through on these responsibilities. Provisions are also made to allow the project staff to initiate activities in mental retardation in those instances when no other resource is available.

It recognizes that the recommendations made in the plans do not provide specific procedures, and sets as its first task the translation of each recommendation into a program of action. Technical assistance will also be made available to all agencies having program responsibilities under the plan. Recognition is also given to the rapid change in programs for the mentally retarded, and to the need for continuous planning if an integrated program of total service is to be established and maintained.

A Mental Retardation Planning Board, with broad representation is proposed, with the expectation that such a board would achieve official status within state government. Similar boards on a regional basis are also to be considered in recognition of different program needs in the four identified regions within the state.

The Project staff will also undertake more intensive study of certain problems for which no recommendations were made in the original plan. A continuous inventory of resources will be maintained, and will be made available to all interested persons. Public information programs will also be undertaken as well as training

programs oriented towards those likely to have contact with mentally retarded persons and their families. A directory of resources for the retarded will be developed, and a genetically oriented "risk register" will be maintained.

APPENDICES

APPENDIX A

SERVICE INDEX METHODOLOGY

To estimate present and future caseloads and the magnitude of the mental retardation problem in New Jersey, an Index of Service methodology was developed. The service index is based on the known retarded need in selected important service areas such as Special Education, Residential Care, etc. After consultation with experts in each service area a figure is obtained for the number of retarded being served in a district which the expert feels has the best rate of implementation.

This means that the person in the field judges, for example, district "A" as:

1. being best known to the population served,
2. most utilized by the population served,
3. has the most appropriate screening for the service offered

District "A" then, is a model for all districts in Service Area "5" in giving a figure which can be used to determine a ratio or index in Service Area "5". This does not mean that District "A" has the highest quality of service since the index deals with quantity not ideal quality. The figure for District "A" would be the numerator of a fraction whose denominator would be the population served (county, municipality, State, etc.). This fraction would yield a resultant decimal which would be the Service Index for all districts in Service Area "5".

Below is an example using the Day Care Service Area
1964 exhibited need in District "C" 60
1964 population estimate for age range 5-18 in District
"C" 141,852

Service Index for Day Care $\frac{60}{141,852} = .000423$ or .0423%

Highest 1964 figure for known need in 1964 = 533
Service Index Estimate of 1964 Day Care Need = 720

APPENDIX B

FINANCIAL RESPONSIBILITY: GENERAL PRINCIPLES

Most of the mentally retarded require most of the different elements in the range of human services—education, health, welfare—which society has generally recognized should be available as needed by all citizens. In addition, the special needs of the retarded require that some of these services be rendered with special expertise, and that there be a few additional types of service specifically designed to meet the most atypical needs within the group designated as retarded. This leads to affirmation of a first principle:

1. *The retarded should have at least as free access to needed services, however financed, as other citizens.*
2. *As a second principle: No retardate should be barred from full utilization of a needed service by virtue of his financial status, or that of his family.*

This applies equally to the well-to-do, those in the middle income group, and the poor. Congress has recently underlined this principle by classing handicapped children as "disadvantaged" from an educational viewpoint regardless of their economic status.

The "formula" by which financial responsibility for providing a given service is assigned strongly influences patterns of service. Thus if preventive services appear too costly to the individual he evades them, and eventually not only he but society loses. If a community agency must pay out its own funds to secure the most appropriate service for an individual client, but can secure another service at less cost to itself by referring the client to another agency which derives its support from some other source, there is at least latent pressure to take the second course. This pressure exists even though the easier course may not be the most effective or the most economical, when the general rather than agency interest is considered. Such pressures arise not only between agencies at the local level, but between levels of government. Hence a third principle:

3. *Patterns of financial responsibility should be such as to encourage the course of action which is socially and individually the most desirable.*

And a fourth:

4. *Patterns of support and eligibility for service should be determined according to functional need rather than according to any universal diagnostic category.*

Children need special education when their mental retardation is such that it interferes with learning in a normal classroom. Adults may need a source of income and support when their mental retardation is such that it prevents them from supporting themselves. Mental retardation may be combined with other kinds of impairment which modify or accentuate needs. The total functional result rather than the "label" alone should be paramount.

Under our American system, certain patterns of financial responsibility have developed in which personal and social ideas have been somewhat differentiated. Society has assumed responsibilities through tax support for services which are more efficiently rendered under public administration,—as for example with police protection or sewage disposal—or where private initiative alone might leave socially undesirable gaps as was the case in education before the advent of free public schools open to all.

More generally stated:

5. *To the extent that the needs of the retarded approximate ordinary needs for health services, education services, and the like, it is generally desirable that similar patterns of support be followed.*

This means free public education for all retarded children, and medical care according to family means through public agencies or private insurance coverage. However, our society is increasingly recognizing that the burden of extraordinary needs, natural disasters, and exceptional adversity should not fall unmitigated on a few; thus a sixth principle:

6. *To the extent that extraordinary risks cannot be spread through the usual mechanisms of private insurance, some form of social insurance of public aid should be applied.*

Nowhere is this need more vividly seen than in respect to adults who were permanently and totally disabled from childhood, among whom many are mentally retarded. These persons through no fault of their own never attain a period of remunerative employment and thus never establish for themselves a base of insurance against unemployment, sickness, disability, or old age. The full impact of their disaster, not only in childhood but in adult life, falls primarily upon their parents. The most recent amendments to the Social Security Act establish the principle that the aged are entitled to support and medical care without regard to the means of their children or other relatives. This principle is equally applicable to persons who reach adulthood without the capacity to support themselves. More specifically stated as principle seven:

7. *Disabled adults, without sufficient resources for their own support should be eligible for maintenance benefits or aid from an appropriate public source without reference to resource of relatives.* This aid should be a personal entitlement and not be limited by the type of care required or type of facility rendering it, provided services for which public funds are applied, directly or indirectly, meet minimum standards of efficacy which protect the client.

APPENDIX C

THE HISTORY OF MENTAL RETARDATION

1. Early Period

Mental retardation is as old as man. The record of concern and care for the less fortunate prior to 1800, however, represents one of the most pathetic chapters in the history of man. Living in societies where the majority of people were unschooled and untrained, the "feble-minded" did not appear significantly different from their neighbors.

The severely retarded, however, have been recognized since ancient times. The Spartans exposed their handicapped offspring to the elements to die. The retarded were left to perish in the mountains or drown in the rivers. By the Middle Ages the plight of the retarded had not improved. At the pleasure of the lords and their ladies, the retarded were exploited as "fools" and "jesters." During the Protestant Reformation, the mentally ill and retarded were thought to be "possessed with the devil." The unusual behavior of the retarded, the convulsive, and the mentally ill was interpreted with mystical, religious overtones. For the most part such "strange" individuals were considered human aberrations possessed with unusual demoniacal powers. As such, they were tortured, tormented, punished, and ostracized. Even Luther and Calvin regarded them as "filled with Satan."

The Church provided the only hope for the less fortunate prior to 1800. From the thirteenth century on, the churches of Europe began rather systematically to provide asylums for the less fortunate members of society, including the intellectually handicapped. These "asylums" were intended solely to provide a sanctuary for those unable to survive in a cruel, competitive society. No attempt was made at treatment or education. In the sixteenth century, St. Vincent de Paul and his "Sisters of Charity" established the Bicetre of Paris for the care and protection of those with behavior disorders.

The unfortunate status of the retarded was further complicated by the prevailing philosophy which influenced the thinking of most professionals of that day. The relative effects of heredity and environment on the growth and development of the individual were being considered. The "nature-nurture controversy," which is still with us today, was dominated primarily by the "naturalists" school of thought. They believed that heredity was the primary cause of mental retardation. As such, they thought that the condition was incurable. This pessimistic and defeatist point of view precluded

treatment and education. The prevailing belief was "Once retarded, always retarded; nothing can be done."

In retrospect, the mentally subnormal were punished or largely ignored prior to 1800. At any rate, they did not come within the social arena of human concern.

2. After 1800

Around the turn of the 19th century, experimental psychology, which had not influenced professional thinking to any discernable degree, received a forward thrust with discoveries in neurology, physics, mathematics, and physiology. A discovery of another sort, however, influenced the course of mental retardation. In 1798 hunters chanced upon a 12-year-old boy, naked, untrained, and inarticulate, who had been living in the forest of Aveyron, France. Jean Itard took charge of Victor, "The Wild Boy of Aveyron." Itard had been influenced by the teachings of John Locke of England and Jean Rousseau of France who believed that learning came only through the senses and that all persons could develop the ability to learn if given adequate stimulation. The Golden Rule that "practice makes perfect" was in direct opposition to the pessimistic teachings advanced by the "hereditarians" and "naturalists." The effects of environment on learning were coming into play. From this perspective, Itard proceeded to teach Victor intensively, emphasizing sensory and motor training. With courage, enthusiasm, and vigor Itard struggled valiantly to produce changes in the behavior of this boy. While his efforts resulted in marked behavioral changes in Victor, Itard was unable to teach him to talk or to live independently in Parisian society. Even though some progress was made, he considered his experiment a failure. Nevertheless, it represents the first scientific attempt at training a retarded child. It marked a radical change of emphasis from incurability and isolation to treatment and education. It stimulated a new movement in which professionals began to assume responsibility from the Church for the retarded.

The residential school program in the United States can be traced directly to Itard's work, through his student Edward Seguin. He expanded and formalized his teacher's techniques into a complex, systematic, sequence of training which he called the "physiological method." To test his procedures, Seguin established the first residential school for the retarded in Paris in 1837 as part of the famous Bicetre Hospital. With the success of this training school, in addition to his classical contributions, *The Moral Treatment, Hygiene and Education of Idiots and Other Backward Children* (1846), Seguin was recognized as an international figure in

the field prior to his arrival in America. He was the guiding force in establishing the first American residential institution at South Boston in 1848. He became the first president of the organization which is known today as the American Association on Mental Deficiency.

Inspired by Seguin's method and his "model" school in Massachusetts, other states followed rapidly. New York opened a school at Albany in 1851, Pennsylvania in 1852, Ohio in 1857. By 1890, fourteen states had separate facilities for the retarded. By 1900, residential schools were established in most of the states of New England, the Great Lakes Area, and in California, with a total number of patients approximating 14,000. The twentieth century has witnessed a rapid spread of public and private residential institutions throughout the country. According to the *President's Panel Report* (1962), there are more than 300 public and private institutions for the mentally retarded in the country. It states, "Based on 1960 data, approximately 160,000 are in 108 public residential institutions specifically designed for the mentally retarded, 10,000 are in 200 private institutions."

With the exception of the small beginning of the special class movement in the public schools, mental retardation appeared almost entirely as an institutional problem in 1900. The outstanding accomplishments and success which Seguin demonstrated in particular cases of retardation resulted in a philosophy of unrestrained optimism. The first schools emphasized education and training. They were begun as "experimental laboratories" to test Seguin's methods and the effects of environment on retardation. Intended as training schools and not asylums, state institutions were developed with the motivating belief that most all the mentally deficient could be "cured" through education and training and returned to the community as average citizens. Seguin (1866, pp. 249-50) emphasized this approach by stating: "We are aware that the appellation of asylum has been attached to several of the most important schools. But this term conveys exclusively the idea of a custodian, life-long place of retreat, whereas the institution or school is only temporarily open for educational and physiological treatment. In it, idiots and their congeners are expected to remain during the period assigned by nature for progress in young persons, unless it sooner becomes manifest that they cannot be improved at all or any more, in which case their parents should take them out to make room for new pupils."

State institutions were created for the trainable pupils of school age who through training could assume a normal place in society. The untrainable were relegated to the asylum. New Jersey sub-

stantiated this view when the 1873 Commission recommended that "the counties should be required to protect and care for the unimprovable defective especially of the feeble-minded class while the state gathers into these institutions by a gradual process all those who are susceptible to the influences of education and capable of being so improved by its agency as to be elevated in the scale of intelligence, raised from a condition of hopeless dependence and fitted to become useful to society and measurably or wholly self-supporting."

With increasing numbers of the less trainable being admitted to institutions and the unsuccessful adjustments of those released from state schools, residents were being retained beyond school age and the philosophy of "curing through training" or "restoring to a normal life" was gradually substituted by the concept of permanent custody. A number of factors effecting this major change of emphasis by state residential schools has been suggested. "First, experience soon taught professional persons in the field that the extreme claims of the environmentalists were ill-founded. Second, society was seldom prepared to provide needed funds for professional persons in the quality and quantity needed to provide intensive training programs. Too often, states, considering their responsibilities terminated with the construction of elaborate physical plants, were content to see the retarded removed from society and placed in a setting where only custodial care could be provided. Third, professional persons themselves must accept part of the responsibility for the neglect of retardates; until recently, few have been prepared to devote their lives to the study or treatment of this group of citizens. Fourth, a new development began in this country about 1900, aimed at educating a larger and larger percentage of moderately retarded boys and girls through public day schools and classes (Dunn, 1961, pg. 16)."

Such was the thinking during the first quarter of this century. As new institutions sprang rapidly into being, with them came new ideas. The belief that all the retarded must be forever institutionalized was rejected in part. By the third decade it was generally agreed that many would not require the specialized services of an institution; that of those who had been institutionalized, a selected group could be returned to the community under controlled conditions; and that all social anomalies were not solely or directly traceable to retardation. Three major developments followed. First was the Colony Plan whereby competent individuals were employed extra-institutionally during the day and were supervised by school personnel. In New Jersey an example of this was the Red Bank Colony established in 1925 for girls from Vineland. Second,

a parole system was evolved. Previously, the community failure of many retardates upon leaving the institution was due in great measure to the fact that there was little post-institutional supervision and guidance. Third, local school systems accelerated the establishment of special classes for the slow learner in accordance with statutes enacted in 1911.

In the more recent past, the day-school movement has played an ever-increasing role. The first class for "backward children" was started in Providence, Rhode Island in 1896. Since individual intelligence tests had not been devised at that time, it is likely that this class and others established before 1915 enrolled pupils who were "problem children" because of educational, social, and/or intellectual difficulties. With the advent of efficient psychometric devices, especially the original Stanford-Binet Test of Intelligence in 1916, all retardation was translated into numbers. With the introduction of intelligence tests, the I.Q. became an idol. The number of retarded appeared to increase markedly for it was believed there was definite, incontestable proof in the intelligence test. In any event, educators became more aware that various levels of intellectual functioning among children warranted the development of special classes to deal with individual differences. As a result, special day schools and classes have increased fairly rapidly. In 1922, 23,000 retarded pupils were enrolled in such facilities; by 1940 the number had increased to 99,000; in 1953 it was up to 114,000. The 1953 U.S. Office of Education survey revealed a new trend. Almost 5,000 of the 114,000 retarded pupils in day classes were "trainable" children. Very few facilities for this group existed in day school before 1953. Day-school facilities are restricted largely to urban communities. Children in rural areas, by and large, continue to be neglected.

The impetus which the "mental retardation movement" received in the early years of the twentieth century was hampered by the pressures of the depression followed by World War II. Immediately after the war, interest spread rapidly. There was a resurgence of effort and purpose. The phenomenal growth and development of interest in mental retardation after World War II can probably be attributed to four events: (1) a thorough revulsion toward the Nazi mass slaughter of retarded persons; (2) a re-awakening of interest on the part of biological and social scientists; (3) renewed public awareness of how little had been done for these "forgotten people"; and (4) an adamant, unashamed, and well-organized parent movement.¹

¹ Jerome Rothstein, *Mental Retardation*, 1961, preface.

In 1950, the National Association for Retarded Children was formed. Composed chiefly of parents of mentally retarded children, this organization has done much to develop and stimulate public awareness of the problems of mental retardation. Initially, NARC conducted educational programs on a demonstration basis. Responsibility for many of these pilot enterprises was subsequently assumed by the public schools. As concern developed for those who did not meet the requirements of the public school program, parents expanded their efforts to include groups beyond school age, the pre-schoolers, and the more severely retarded. With a membership of more than 95,000 persons, NARC has grown from a few isolated individual groups scattered over the country to more than 1,000 units in 50 states. It has been most effective in urging state legislatures to enact laws fostering new improved programs and services for the mentally retarded. It has been instrumental in creating several state commissions to delineate total, comprehensive, and state wide plans of service for the mentally retarded. Increased interest on the part of the Federal Government is due partly to their efforts.

Other organizations have played an important role in the field. The American Association on Mental Deficiency, organized in 1876, draws its members from the professional disciplines of medicine, education, psychology, social work, and administration. In recent years, through its committee for "technical planning in mental retardation," it has developed and conducted numerous conferences and studies in the broad areas of (1) research, (2) training of personnel, and (3) programming. Also, the Council for Exceptional Children of the National Education Association has stimulated the development of teacher-training programs, assisted in delineating the qualifications of teachers of the mentally retarded, and encouraged the dissemination of scientific information in the broad field of special education through state, regional, and national conferences and publications. Also, numerous private organizations conduct a variety of programs and services for the retarded. Efforts of these groups have contributed to a better understanding of mental retardation and to the growing philosophy that the mentally retarded person should be served with as little dislocation from his normal environment as is consistent with the special character of his needs.

Based on this philosophy, the development of day-care centers represents an identifiable trend in the history of mental retardation. The operation of day-care centers as a function of the units of NARC began as early as 1953, but the majority of the programs were started within the past four years. The developing pattern

of this embryonic program appears similar to that of the early day classes for trainable retarded children. In 1957, Delaware passed legislation establishing daytime care centers for severely retarded children; the first of several state-supported, state-operated programs of care for severely retarded children was opened in 1958. In 1957, Massachusetts started a program of pre-school classes for mentally retarded children. Several other states have enacted legislation providing financial support for day-care services for the mentally retarded since 1957.

A recent survey of day-care centers operated by NARC units indicated that there were 3,948 children attending 100 of these centers. This number did not include any state operated or supported programs. Of concern are the 750 children reported to be on waiting lists and the additional undeclared number in the 12 centers reporting only the presence of waiting lists. The services offered in these programs varied from supervision of a small number of children for two hours twice a week to complete clinical, educational, and social welfare programs. Some centers reported group therapy for parents, diversified programs for children, and complete health services. Other centers indicated that they have none of these services. The need to secure inspection and licensing procedures of the barest minimal standards is evident. In any event, it is still too early to determine the relative impact of the "day-care movement" on the history of mental retardation.

3. Mental Retardation in New Jersey

In 1846 Stephen A. Garrison, assemblyman from Cumberland County and father of the Reverend Stephen O. Garrison who was to found the Vineland Training School, introduced a bill in the legislature to create a state school for the feeble-minded.² This failed to pass, but in 1860 New Jersey consented to support a limited number of its retarded at the Elwyn Training School in Pennsylvania. In 1873 a commission was appointed "On the Deaf and Dumb, Blind and Feeble-minded in the State of New Jersey." The commission's report of 1874 estimated that there were 1,000 retarded persons in the state and concluded that one or more institutions for defective classes were needed. Not until 1888 however, did New Jersey open its first State School at Vineland, simultaneously with the Vineland Training School, private but closely entwined with New Jersey history.

A second state commission on the care of the feeble-minded was appointed in 1913. Meanwhile, the Vineland Training School was

² A partial reprint of "Institutions—a Brief Summary through the Mid-Twentieth Century", by VonBulow, *Welfare Reporter*, Oct. 59, pp. 151-153.

investigating social delinquencies in the rural areas of Burlington County and set up a county colony at New Lisbon in 1914. In 1916 New Jersey inherited this as its second state institution. Recommendations of the commission of 1913, together with those of the Prison Inquiry Commission, caused the legislature to enact laws in 1918 which created a Board of Control and The Department of Charities and Corrections, renamed the following year the Department of Institutions and Agencies. Charged with the operation and responsibilities of a new welfare and correctional system, the department proceeded to integrate the then existing institutions and agencies and to expand services and facilities. At that time there were two state schools for the retarded, the State School at Vineland and the State Colony at New Lisbon. A number of wards, however, were maintained by the state at the Vineland Training School.

New Jersey approached the problem of residential care for the feeble-minded rather uniquely. Small in size, it apparently saw no need for a geographical division in which institutions served certain areas. Rather, sex was the determinant, males being sent to New Lisbon and females to the Vineland State School. With the State Colony at Woodbine, established in 1921, a more refined and then radical criterion was added, namely, degree of retardation. Woodbine was planned as an institution for males who, for the most part, were severely retarded. This was an innovation and the system of classifying institutional population by sex and degree of retardation has remained peculiar to New Jersey as schools in other states are for both sexes of all grades. One result of the New Jersey plan has been more aggressive training for, and a greater emphasis upon, the severely retarded.

New Jersey now had two state schools for males—Woodbine for the seriously retarded, and New Lisbon for the educable and the defective delinquent. Classification at the central office level became a more significant task. The laws of 1918, however, had adequately included methods and authority for the interchange of residents, so that if an individual had been improperly classified or had progressed or regressed as to demand different programming, he could be readily transferred between these two schools or the Vineland Training School.

The Vineland State School was the only institution for female retardates of all grades (excluding the relatively small number at the Training School) until 1928, when the North Jersey Training School at Totowa was opened for girls ranging in age from six to 20 years who could profit from comparatively advanced training and be returned to the community. Thus, the younger, more competent girls were classified for Totowa and the situation at Vin-

land changed over the years in that the percentage of higher grade females diminished while those of middle and lower grades increased. As the Vineland State School was gradually outgrowing its physical resources, in 1925 the Almond Road Colony about four miles west of the main school was started. Today this adjunct cares for about one third of Vineland's population, primarily the more seriously retarded.

For 28 years these four residential schools served but did not meet all of the demands. There was little expansion either in facilities or program during the depression and World War II. One pressing need, however, was eased. None of the four schools accepted children below five and there were many tragic situations where families required assistance before the child reached that age. In 1948 a nursery for 100 children of both sexes below five was established in Totowa, one of the first such units in the country.

Since the turn of the century, New Jersey has been a leader in the field of mental retardation. Garrison, Goddard, E.R. Johnstone, Earle, Ellis, Doll, and Yepsen are some of the names engraved in the state's history. Their contributions have been recognized far beyond the boundaries of New Jersey. As the mid-century mark approached, however, a new force began to exert itself. This was the Association for Retarded Children. In this organization parents banded together to arouse public concern and to foster greater understanding and awareness of public responsibility. A vital, determined, inspired organization, it stimulated efforts on the local, state, and national level on behalf of the retarded. As 1950 approached there was a revival of interest in this field.

Special education in New Jersey received its greatest impetus with the passage of the Beadleston Bills in 1954. This legislation came as a result of the many unmet educational needs of handicapped children and youth. For the first time in the history of New Jersey, the classification and special education of mentally retarded and physically handicapped children were made mandatory. The law specifies that each board of education must ascertain which children between the ages of five and 20 in the public schools of the district cannot be properly accommodated through the school facilities usually provided because of the extent of their mental retardation or physical handicaps. Mentally retarded children must be classified as educable or trainable. Suspected cases of mental retardation must be classified by psychological examiners approved by the State Department of Education. Mentally retarded children are placed in special classes with limited enrollments. *The Education of Handicapped Children in New Jersey 1954-64* indicates the

progress that has been made in providing educational services to the mentally retarded during the past decade:

"New Jersey was one of the first states to pass mandatory legislation providing educational services and school attendance for the mentally retarded. The 1954 legislation has served as a guide for other states. In spite of the fact that many administrators were not fully prepared to undertake such a program at its inception, a good job has been done. Over the ten-year span there has been an increase of 647 classes for educable children. The present number of such classes is 934. The classes for the trainable increased in number during the same period from five to 217. A study of the growth pattern shows that special education programs are no longer confined to large cities as they were in 1954. Indeed it is now the large cities which report the most serious shortage of classes for the mentally retarded. Geographic expansion now makes the special education program more accessible to trainable and educable children any place in New Jersey Despite these gains, as of June 1963, there were 1380 educable pupils reported as classified but not attending educable classes. Thirty-one were reported as not attending school. One hundred and seventy-two trainable children were excluded pending placement and twenty-eight were in regular classes."

Although the establishment and acceleration of institutional and educational programs represented substantial advances in meeting the needs of the retarded, obvious gaps still remained. In an attempt to bridge these gaps a number of new programs were initiated. First, in 1955, the Field Services Program of the Division of Mental Retardation was begun. Its initial responsibility was to provide post-institutional supervision. The decision to locate its offices in the community rather than at institutions reflects the trend toward integrating the retarded in the community as opposed to a life of isolation apart from society. Over the years, the scope of this agency has expanded. It now provides a host of social services for the retarded and their families. Second, in 1963, the Public Day Care Program was established to meet the needs of those retarded children who, classified as neither "trainable" nor "educable," are excluded from public school. As a community-centered program designed specifically to provide for the social-developmental adjustment of these children, it enables the severely and profoundly retarded to remain at home and in the community. It affords real relief several hours a day to mothers who face the tremendous burdens of daily care of these children. Although 15 Day Care Programs are now in operation, they are housed in unsuitable

physical structures. To meet this need, the construction of physically suitable Day Care Centers has been designated as the first priority in the *New Jersey State Plan for the Construction of Mental Retardation Facilities 1964-1965*. Third, in January 1965, the Woodbridge State School for severely retarded boys and girls was opened. This brings the total number of institutions for the retarded to six. Plans for the development of a seventh institution, the Hunterdon State School, are underway.

On June 26, 1963, Governor Richard J. Hughes created an Interdepartmental Committee on Lifetime Disability composed of the Commissioners of Education, Health, Institutions and Agencies, Labor and Industry, the Secretary of State and a representative of the Governor's office. Also, a "Governor's Advisory Council" to this Committee, with broad representation of lay and professional citizens, was formed. As a reflection of governmental and private concern at all levels, the Committee's first stated objective was the development of a comprehensive plan to combat mental retardation. Toward this end, a Working Party on Mental Retardation was established. From various state agencies representatives having a particular competence in this area were designated by appropriate Commissioners. The charge of the Working Party was to "review" the present available State Services to the retarded, identify the Executive Department which is or should be discharging responsibilities and report to the Interdepartmental Committee the extent and manner in which each function should be strengthened. This Working Party will, as well, develop a comprehensive plan involving public and private, statewide and local activities to combat mental retardation."

4. The Present

Three distinct periods of development in the history of mental retardation care in the United States have been noted: (1) 1850-1900 saw the growth of institutions; (2) 1900-1950 witnessed the development of public school classes for retardates and the development of intelligence and personality tests; and (3) 1950 to the present has seen an emphasis on research and the rise of community resources.

The role of the Federal Government represents the beginning of a new chapter in the history of mental retardation. In 1961, President Kennedy appointed a panel of experts to prepare a national plan to combat mental retardation. In 1962, the panel presented its report. In 1963, Congress responded with new major legislation. Also the White House Conference on Mental Retardation was held. In 1964, comprehensive planning by every state in

the union was underway. In its report, "National Action to Combat Mental Retardation," the panel summarizes its almost 200 recommendations in the following eight broad areas:

1. *Research* in the causes of retardation and in methods of care, rehabilitation, and learnings.
2. *Preventative health measures* including (a) a greatly strengthened program of maternal and infant care directed first at the centers of population where prematurity and the rate of "damaged" children are high; (b) protection against such known hazards to pregnancy as radiation and harmful drugs; and (c) expanded diagnostic and screening services.
3. *Strengthened educational programs generally and extended and enriched programs of special education* in public and private schools closely co-ordinated with vocational guidance, vocational rehabilitation, and specific training and preparation for employment; education for adult mentally retarded and workshops geared to their needs.
4. *More comprehensive and improved clinical and social services.*
5. *Improved methods and facilities for care*, with emphasis on the home and the development of a wide range of local community facilities.
6. *A new legal, as well as social, concept of the retarded*, including protection of their civil rights; life guardianship provisions when needed; an enlightened attitude on the part of the law and the courts; and clarification of the theory of responsibility in criminal acts.
7. *Helping overcome the serious problems of manpower* as they affect the entire field of science and every type of service through extended programs of recruiting with fellowships and increased opportunities for graduate students and those preparing for the professions to observe and learn at first hand about the phenomenon of retardation. Because there will never be a fully adequate supply of personnel in this field and for other cogent reasons, the panel has emphasized the need for more volunteers in health, recreation, and welfare activities and for a domestic Peace Corps to stimulate voluntary service.
8. *Programs of education and information to increase public awareness* of the problem of mental retardation.

In addition to a strong emphasis on *research* and *prevention*, the report recommends the following:

1. That programs for the retarded, including modern day care, recreation, residential services, and ample educational and vocational opportunities, be *comprehensive*.
2. That they operate in or close to the communities where the retarded live—that is, that they be *community-centered*.
3. That services be so organized as (a) to provide a central or fixed point for the guidance, assistance, and protection of retarded persons if and when needed, and (b) to assure a sufficient array or *continuum* of services to meet different types of need.
4. That private agencies as well as public agencies at the local, state, and federal levels continue to provide resources and to increase them for this worthy purpose. While the Federal Government can assist, the principal responsibility for financing and improving services for the mentally retarded must continue to be borne by the states and local communities.

There is no doubt that through the active and immediate implementation of the panel's recommendations, one will witness increased co-ordinated efforts on behalf of the Federal Government, all directed toward "a search for solutions to the problems of mental retardation (President's Panel, pg. 196)."

The attack on mental retardation has gained tremendous momentum. President Johnson has stated, "Today we can say objectively that more has been done by the government in the past two years than in the previous 200 years to meet the challenge of mental retardation." Significant advancements have been made in many areas, ranging from genetics and biochemistry to special education and vocational rehabilitation. Dr. Stafford Warren, who served as the President's Special Assistant on Mental Retardation said that "The toll of mental retardation could be reduced by fully one half if all we know today could be applied successfully everywhere." Much, however, remains to be accomplished. This is where we stand today. The future belongs to those who, through coordinated effort and planned action, will bring to the mentally retarded a brighter tomorrow.

APPENDIX D

ACKNOWLEDGEMENTS

The following organizations were invited to participate in a series of meetings held to secure a broad range of professional opinions regarding the service needs and program requirements of the mentally retarded.

Organizations:

AFL - CIO

American Psychiatric Association—New Jersey District Branch
International Association of Personnel and Employment
Service Workers—New Jersey Chapter
Licensed Nursing Homes of New Jersey
National Association for Social Workers—North Jersey Chapter
National Association for Social Workers—South Jersey Chapter
New Jersey Academy of General Practice
New Jersey Academy of Pediatrics
New Jersey Association of Childhood Diseases
New Jersey Association of Children's Institutions
New Jersey Association of Chosen Freeholders
New Jersey Association of Chiefs of Police
New Jersey Association of County Welfare Directors
New Jersey Association of Mental Hygiene Clinics
New Jersey Association for Retarded Children
New Jersey Association of Sheltered Workshops
New Jersey Association of State College Facilities
New Jersey Association for Brain Injured Children
New Jersey Conference on the Handicapped
New Jersey Council on Family Agencies
New Jersey Education Association
New Jersey Educators of the Mentally Retarded
New Jersey Hospital Association
New Jersey League of Municipalities
New Jersey League of Nursing
New Jersey Medical Society
New Jersey Mental Health Association
New Jersey Neuro-Psychiatric Association
New Jersey Personnel and Guidance Association
New Jersey Psychological Association
New Jersey Recreational Society
New Jersey Rehabilitation Association

New Jersey Society for the Brain Injured
New Jersey Society for Crippled Children and Adults
New Jersey State Bar Association
New Jersey State Board of Dentistry
New Jersey State Federation for Districts Boards of Education
New Jersey Welfare Council
United Cerebral Palsy of New Jersey

Participants:

Mr. Kenneth Adams	Mrs. Aaron Hirschorn
Mrs. Amy Atchley	Mrs. Jeanette Hodge
Mr. Frank Ball	Dr. Walter Jacobs
Dr. Jack Bardon	Dr. Joseph Jehl
Dr. John M. Bartram	Mr. Oscar Knade, Jr.
Dr. Franklin Behrle	Dr. Joseph Konzelman
Mr. Arthur Bierman	Mr. Theodore Lucas
Dr. Victor Boogdanian	Mr. Joseph Maloney
Mr. Jack Breakstone	Dr. Bernard Millner
Mr. John Conover	Dr. Nellie Mitchell
Mr. John Crowley	Mr. John Monaghan
Mr. H. Bert DiPaul	Mr. Clifford E. O'Connor
Mr. Raymond Dougherty	Dr. Doris C. Perry
Mrs. Elizabeth Easton	Mr. Robert Rice
Dr. Irving Feldman	Mr. James Robins
Dr. Robert Fisher	Mr. Joseph Ruddley
Dr. Irwin Friedman	Mr. Robert Russell
Dr. Edwin M. Gold	Dr. Winifred Scott
Dr. Bernard Goldberg	Dr. Nellie Stone
Mr. Charles Hambright	Mr. Matthew Treihart
Msgr. John Hourihan	Dr. Henry Zanzalari

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