MENTAL RETARDATION SERVICES

IN HENNEPIN COUNTY

September, 1974

Community Health and Welfare Council of Hennepin County, Inc.
404 South 8th Street
Minneapolis, Minnesota
55404

MENTAL RETARDATION SERVICES IN

HENNEPIN COUNTY

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CONCLUSIONS

A. RETARDED PERSONS/FAMILY NEEDS

1. Each mentally retarded person and his family needs to have a designated point of entry into the spectrum of services which would also be an ongoing contact point as the person family requires additional or new services.

2. Each retarded person/family should have available a total system of service options that work together efficiently and effectively. This interlinkage appears to function inadequately in Hennepin County at this time.

3. There is a need for better transitional procedures when a retarded person moves from one program to another, to avoid delay and neglect.

4. A basic need of parents still not adequately met is counseling and informational services, with stress on parenting skills, regardless of age of diagnosis of retarded person. Too much parent counseling does not include practical suggestions that take into consideration the day to day stresses of living with the retarded person.

5. Counseling by itself is seldom sufficient. The service recommendations developed through counseling must be available for the counseling to have any real meaning.

6. Parents need a mechanism that is supportive to them as long as the retarded person needs the service system. It is not enough that parents be informed of available services. They may need support in effective utilization of services.

7. Parents with early-diagnosed retarded children need more adequate information, referral help and support from the physicians. There still appears to be a general lack of: a) knowledge on the part of many physicians; as to current concepts of mental retardation and resources available to the child and, b) sensitivity and skills in supporting the emotional needs and Interpreting the Initial diagnosis the parents.

Conclusions - 2

8. For retarded children not diagnosed until school age, (5 years) there is a need for more complete and ongoing interpretation to the parents.

9. Once the retarded child leaves the school setting, most of the initiative for obtaining services falls back on the parent. There is need to strengthen the supportive services for this group of parents as well as a need for better interpretation of the social and personal needs and situations of adult retarded persons as contrasted with their needs when they were children.

10. There needs to be more comprehensive direct services for the adult retarded including special living arrangements, sheltered workshops, group homes, recreation, supervision, transportation and support for some financial benefits, that a retarded person loses when he becomes an adult.

11. The retarded person has the same basic needs as other people but because of his limited intelligence he needs special assistance to obtain them. Greater attention needs to be given to other aspects of the retarded person's development and functioning—health, other handicaps, the total person.

12. Families with multiple problems, of which mental retardation is just one, need to be referred to and receive help from other service systems in an effective and coordinated way.

B. ORGANIZATION AND SOCIETY NEEDS

1. Both the private and public sectors are needed in the delivery of services to mentally retarded persons, but there should be better communication and coordination between them.

2. Progress in prevention of mental retardation requires better education in all health areas, as well as more professional attention to:

Conclusions – 3

Organization and Society Needs (cont.)

2. (cont.)

   a. better prenatal and obstetrical care,
   b. better nutritional education and practice,
   c. more attention to infant health, innoculations, disease prevention,
   d. more attention to genetic analysis and genetic counseling.

3. Planning systems show duplication and poor coordination; they are too far removed from direct services and too divorced from accountability. Reorganization and shifting of responsibilities at the various planning levels often diminishes efforts already expended on direct services. Efforts for retarded persons should now be focused on direct services rather than on more planning activities.

4. There is a need for specific delineation of which responsibilities should be assigned to state institutions and local communities in providing services for the retarded person, with particular attention to reduction of the present overlap of services and the shifting of funds from state to community levels.

5. The educational system is mandated to assume educational responsibility for retarded children from 5 to 21. If this mandated responsibility is to be extended to include pre-school retarded children, there is need for additional financial support as well as planned sharing and participation of other public and private agencies.

6. The present service system does not adequately recognize the multiple goals and changing needs of retarded persons nor the wide range of individual differences they represent.

7. Retarded persons should be able to progress in some area of development or training. If the person becomes "dead-ended," then the program and the person need to be evaluated.

8. Basic medical and psychological evaluations are still not available to any child.

9. There is a need to recognize and develop better working relationships between poverty programs and mental retardation programs, recognizing the special significance of functional retardation related to social disadvantage.

10. Too often, the rights and needs of the child and family are subordinated to the convenience and rituals of the

11. Utilization of services by retarded persons and their families is frequently limited by the lack of transportation.

12. The expenses to families with retarded children often cause serious financial problems and provide an additional disruptive element in the family life situation.

13. More attention needs to be given to the education of the public, not just in sympathy or "theoretical acceptance," but in more practical terms, with an eye to community attitudes, zoning changes, job opportunities, better understanding of individual differences.

14. There is a constant need to make people more aware of information and referral sources, through every avenue available.

15. Many agencies are required by law to keep records and develop objectives for the retarded persons they serve, but there is very little evidence that these various plans of action are related to or coordinated with one another for the benefit of the retarded individual.

RECOMMENDATIONS

1. The former Mental Health/Mental Retardation Area Board and subsequently its staff, the Mental Health-Mental Retardation Area Program, should align its priorities more closely to its mandated responsibilities, with greater focus on the mentally retarded person.

2. Since the Mental Health/Mental Retardation Area Board no longer exists, the County Commissioners must designate an authoritative body to assume the mandated responsibilities for services to mentally retarded persons.

3. The public and private sectors jointly should immediately develop and implement an effective system of case management for retarded persons of all ages, to serve as an entry point, and provide follow along and information referral. The staff would become the facilitators for mentally retarded persons/families requesting help with any or all parts of the system. They would have the responsibility to convene group conferences of professionals providing services to mentally retarded persons, would have access to the reports on individual retarded clients, if requested by the clients, and could be the most appropriate determiners of gaps in services.

   The new County Welfare Department Case Management Division could serve this function in the public sector, with some modifications in their program. Minneapolis Association for Retarded Citizens could serve this function in the private sector. Both agencies should designate representatives who would work together in a closely interlinked communication system.

4. Input from the service level to the planning level is essential to effective planning, and should be sought and utilized on an ongoing basis by the planning agencies, and particularly the Mental Health-Mental Retardation Area Program. The Study Committee sees the recommended case management system as an extremely important means to this end.

5. Hennepin County Health and Social Services Administration Planning and Evaluation Section has the opportunity to broaden its base of contacts with the providers and recipients of services to mentally retarded persons, and should take responsibility for effective communication so that mental retardation planning will always reflect the needs of retarded persons.

Recommendations - 2

6. Physicians, particularly family doctors, when dealing with a retardation problem, have a responsibility to provide better support and attention to parents' emotional needs and to give them immediate referrals to services or professionals in the mental retardation field. Appropriate local medical societies and associations should undertake educational programs to upgrade their colleagues' knowledge of mental retardation.

7. Better parent counseling and education are a joint responsibility of public and private agencies. Agency staffs should be augmented to provide this service, particularly in hospitals, schools, day activity centers, vocational rehabilitation and residential care facilities, with special emphasis on expansion of services for the parents of the adult retarded, a hitherto neglected need.

8. Because the County Welfare Department purchases services from day activity centers, Hennepin County Board of Commissioners should assign responsibility for the monitoring and evaluating of program transitions for retarded persons among day activity centers which operate under independent boards. This could be implemented by Hennepin County through an organization such as Day Activity Center Association.

9. The professionals involved in making the diagnosis and service recommendations for mentally retarded children diagnosed in school settings, should participate in the counseling and interpretations to the parents. The schools should provide a written report as part of their interpretation and counseling sessions for parents.

10. The Mental Health-Mental Retardation Area Program should assume specific and direct responsibility for the development and implementation of programs and services for adult retarded persons. This responsibility would minimally include working with the state and county welfare departments to determine number of community placements needed, working with the communities to develop needed residential and other resources, becoming an intermediate link between local communities and State Division of Vocational Rehabilitation in the development of vocational rehabilitation opportunities, and initiating the coordination of agencies' program objectives for the retarded persons they serve.

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11. A brochure should be developed by the Mental Health-Mental Retardation Area Program in cooperation with other agencies. It should outline what mental retardation is and describe the entry points to the system of services. It should be given to all new parents and made available in every physician's office and every social service agency, dealing with families.

12. The Hennepin County Medical Society and professionals in mental retardation should enter into discussions with the Medical School of the University of Minnesota concerning the training of family physicians in the area of mental retardation.

13. Realizing the impact that National Health Insurance legislation may have on the availability of financing for programs for mentally retarded persons, private and governmental planning agencies should begin now, cooperately and together, to look at alternative ways of providing financial resources other than Title XIX and to consider how educational and social service programs now funded under Title XIX could be financed in the future.

14. There would be value in an annual report to the community and the professions in which the individual service agencies explain what is happening in their programs. This could take the form of an annual meeting, sponsored by the Mental Health-Mental Retardation Area Program, and should include verbal accounts by the agencies of the changes in program direction, goals, priorities, trouble areas. The report meeting would enable staffs in various parts of the service system to relate to the total care concept at least once a year.

15. Every agency involved with meeting human needs, including programs especially directed at the poverty problems, should be especially aware of problems of functional mental retardation and should be cognizant of the special needs of this group, described in the body of the report and in the section on conclusions.

INTRODUCTION

Society's views of mental retardation have undergone many changes in the last hundred years, and society's acceptance of persons with mental disabilities has greatly affected the way in which services have been provided. As the philosophy has changed from sheltering the retarded from society (and sheltering society from the retarded) and placing them in isolated institutions to today's concept of providing a wide range of services to enable the retarded to obtain an existence as close to normal as is possible for them, more and more sectors of the community have become involved in providing services. Today, a system exists in Hennepin County involving public and private agencies which influences the quality of life for most of the identified mentally retarded persons in the community.

The system is a dynamic one, responding to the needs and demands of its clientele, although not always in an organized or coherent method. The system is also a complex one, involving many levels of service by a wide diversity of agencies, holding onto traditional approaches while at the same time trying to develop changes which will bring about new direction and meaning into the life of mentally retarded persons.

The effectiveness of a community approach to providing services depends in part on the recognition and acceptance of

the roles each part of the service system plays, the responsibility each part accepts, and on how well all these parts are identified and coordinated in providing a total care concept.

As an expression of a concern for the effectiveness of this system, the Mental Health-Mental Retardation Area Program in Hennepin County requested the Community Health and Welfare Council to undertake a study of role clarifications and responsibility regarding the provision of services to mentally retarded persons in Hennepin County. The Council, after receiving support from a number of other agencies, agreed to accept the challenge of such a study and outlined the purposes as follows:

1. To determine where the responsibility and accountability currently falls for services to mentally retarded persons.
2. To determine if there are gaps in services and to make those gaps visible through identification and description.
3. To determine if there is a better way for responsibility to be assigned, and to make the appropriate recommendations.
4. To formulate plans to implement the recommendations.

The Council Board of Directors appointed an ad hoc study committee, under the leadership of Dr. Harriet Blodgett.

HISTORICAL BACKGROUND

Minnesota has a proud heritage of providing services to the mentally retarded. From the present point of view, we can make many criticisms of the philosophy and methods which prevailed in times past, but we can also find many attitudes expressed by earlier leaders in the field which sound surprisingly modern. For example, in Mildred Thomson's Prologue, there is a statement which applies just as well to the work of our current committee as it did to her work in 1924: "It was imperative that I have immediate knowledge of the laws under which I would function and of the policies established to carry them out." (p. 15) As early as 1918, the State Board of Control expressed a changing point of view of "feebleminded" persons: • "Not all the feebleminded can be placed or should be in institutions. In the first place the cost would be prohibitive, and in the second it is unnecessary. There are so many gradations, so many types, that supervision must range from little or none to very close. The experience under the new law, while only a beginning, shows that a large part of the problem can be solved by the development of community interest and care outside of the institutions. This will need time and education of the communities to a realization of the need and of their responsibilities." (Prologue, p. 49.) More than fifty years later, we are still working on the tasks of developing community interest and care.

Minnesota laws over the years have given county welfare departments the major responsibility for providing social services to the retarded. Over time, concepts of what those "social services" should be have changed and broadened, and many other agencies have appeared on the scene to perform some of the service functions.

Special classes in public schools were in existence in Minnesota as early as 1915, but these classes were only for the educable retarded, and were mostly restricted to the elementary age range. Even in the 1940-50 era, such classes were found chiefly in the larger communities. Public school classes for trainable retarded children existed in only a very few school systems. As recently as 1956, there were only about sixteen such classes in Minnesota, and nearly half of these were in Duluth, St. Paul, and Minneapolis.

Changes in state government organization made some shifts in placement of responsibility for the retarded, and changes in education laws have also occurred. The year 1957 was especially significant; the special education law passed in that year mandated public school programs for the educable retarded, and provided for state aid also for school programs for the trainable, if school districts wished to develop them. Not until 1972, however, did it become mandatory for public schools to serve trainable retarded children. Important developments in education have also taken place in programs of training for high school age retarded young people. Project 681, in Minne-

apolis, providing for job training for special class high school youngsters, paved the way for the development of the Cooperative School-Rehabilitation Center.

While developments for the retarded have taken place concurrently in the fields of general social welfare and of education, changes in the level of public information and in the climate of public attitudes have also occurred, as a result of myriad forces. Certainly one of the major forces has been the work of Associations for Retarded Citizens, on local, state, and national levels. These groups have been impressively successful in changing laws, encouraging provisions for needed service, encouraging research, setting up demonstration projects. There have been innumerable study groups, committees, and advisory groups over the past twenty years, including at least two study committees appointed by the Governor. The Community Health and Welfare Council has, over the years, sponsored several study committees to review, discuss, and make recommendations about aspects of mental retardation. One such committee, in 19 55, developed a tentative plan for the Sheltering Arms School program which was adopted by the Sheltering Arms Board of Directors. Another group studied the needs of trainable retarded children; still another focused on vocational training needs.

Earlier concerns, and the years of work of earlier professionals in mental retardation, have helped create better understanding of mentally retarded people and to clarify comprehension of their needs, some of which are the same as those of intellec-

tually normal people and some of which are different. The tasks this Study Committee has tried to accomplish will, to the extent we are successful, help to shape society's future performance in meeting these needs.

METHODOLOGY

To determine the responsibility and accountability for the wide variety of services provided to mentally retarded persons in Hennepin County is a large task. To undertake this task, the Council chose a study committee composed of people with various experiences and backgrounds from professional, consumer, and volunteer points of view. They included professionals who had long experience in the field, parents of retarded children, and lay-volunteers who had served the community in other capacities.

The Committee developed the following framework for its study:

Phase I: An assessment of the statutory responsibilities and policies as they apply to Hennepin County agencies.

Phase II: An assessment of existing programs in Hennepin County as they compared with the law:

1. A survey of agencies and organizations providing direct services to determine what services they provided, to whom, and how and why they felt those services should remain the same or should be changed.

2. Interviews with parents of retarded persons, to be selected from a sample of parents with preschool, school age, and

adult mentally retarded persons, to be interviewed by telephone.

3. A survey of agencies identified as planning agencies, to be asked to describe their planning activities and how they related to the provision of direct services.

The Committee planned to analyze the data and prepare specific recommendations for programming and financial responsibilities in Hennepin County, taking into consideration all developmental plans for a large, metropolitan-area program.

Finally, the Committee planned to consider how its recommendations could be implemented by the community.

PHASE ONE: LAW ANALYSIS

To conduct its analysis of existing laws pertaining to services for the mentally retarded, the Committee decided to utilize the services of law students. Two law students were employed with the cooperation of the Area Office. The students worked under the direction of the Committee, but were supervised under a special arrangement with the Developmental Disabilities Legal Project under the Legal Aid Society. The students had access to the Legal Aid Society's library materials and the previous work that had been done by the lawyers in assisting mentally retarded persons obtain their rights for service.

The law students' assignment was to make an analysis of those statutes involving federal, state, county, and municipal responsibilities for programs. They also took part in interviewing state and local agencies which had developed policy statements and regulations in accordance with the statutes.

Their findings were then shared with the Committee and a summary description of the statutes, regulations, and ordinances was prepared for the study report. The summary was based on an interpretation of applicable federal, state, and local laws through May, 1974, and the current policy statements of official state and local agencies. The analysis was divided into the following areas: State Policy, County Role, County Welfare Board, Area Mental Health-Mental Retardation Programs, Health and Social Services Advisory Board, State Comprehensive Programs, Guardianship, Education and Vocational Rehabilitation, Zoning, Minnesota Human Services Act, and Federal Legislation as it affects the delivery of services to mentally retarded persons. (See Appendix A)

PHASE TWO: ANALYSIS OF SERVICES

In trying to determine the direction the agencies are taking in delivering services to mentally retarded, and their philosophies in the delivery of services, the Committee decided to look at it from two points of view. First, the agencies themselves were surveyed and asked about their services, and then a selected

sample of parents of retarded persons was also asked about the same services.

Agencies

The Committee developed a list of agencies from the resource files of state, regional, county, and local organizations, and identified them as those that provided direct services and those that were planning agencies. Survey instruments were developed and tested. The direct service agency questionnaire was divided into two parts. The first part concentrated on statistical information which identified the agency, the kinds of people they served, and the kinds of services they provided. The second part asked the agency to respond to questions as a result of their experience in providing services to mentally retarded persons. The specific services listed in the questionnaire were taken from the list developed by the Developmental Disabilities Task Force of the Metropolitan Council. (See Appendices B-E.)

The questionnaires were mailed to the agencies and follow-up was done by telephone. Although there were several other questionnaires on mental retardation being sent to agencies at the same time, agency staff for the most part were very cooperative and supported this study.

Parents

A sample of 150 parents' names was drawn to be interviewed

by Committee members concerning services received by their children. The sample was drawn on the basis of four variables:

1. Occupation
2. Race
3. Age of child
4. Geographic location

The 1970 census population was used in conjunction with previous data gathered on the distribution of mentally retarded individuals in the population to determine percentages of cases to be selected within variables. Occupation ratios were broken out as 20% professional-managerial; 15% white collar; 60% blue collar; 5% unskilled. Race ratios were established at 82% white; 14% black; 4% other. The age of child component was broken out at 10% preschool; 40% school age; 50% adult. Geographic location was set at 45% Minneapolis; 55% suburbs.

Parents' names were selected at random from lists provided by the Minneapolis Association for Retarded Citizens, Sheltering Arms School, Opportunity Workshop, and the Minneapolis Public Schools. Persons drawn for the sample were first informed about the study by a letter describing the purposes of the study, asking their cooperation, and indicating that an interviewer, designated by name, would be calling them. Each Committee member then telephoned the names on his or her list, explained what they were trying to do, and asked if the parent would be willing to participate in the study. If the answer was affir-

mative, the interviewer then asked three basic questions and set a date and time for a phone interview. After the parent agreed to participate, the questionnaire was mailed to the parent with a reminder of the telephone interview date which had been set. It took approximately an hour and one-half to complete the interview once it was initiated. However, with some parents it took as many as 20 or more call-backs to actually begin the interviewing process. (See Appendix F.)

Each Committee member was given 15 to 17 different names to interview. The total time involved, the unavailability of some parents, and the unwillingness of some to participate meant that approximately 100 names of the 150 originally drawn actually did complete the total interview questionnaire. The significant difference between those parents who completed the questionnaire and those who did not was that more of those who did not fell in the unskilled occupational group and/or the "Black" or "other" racial categories. Most of the parents were very cooperative, interested in the study, and more than willing to supply the information being sought.

After analyzing the data from the various questionnaires, the Committee then interviewed staff in selected service categories to clarify particular points not adequately covered in the survey instrument. These included staff people involved

with state financing, state planning agencies, reorganization of the county advisory committees, day activity centers, County Welfare Case management Division, and others. The Study Committee also utilized its own resources of Committee membership to add further interpretation and definition to the data collected and to the understanding of the delivery system in Hennepin County.

FINDINGS

After analysis of all the data gathered, there did not seem to be any outstanding lacks or gaps in kinds of services available to the retarded. The overall impression is that both professionals and parents feel there is a wide range of services currently available and that the services, for the most part, are the ones required to meet the needs of retarded persons. The major difficulty appeared to be in getting retarded persons from one part of the service spectrum to another, or in a breakdown of interlinkages between the service components. This does not mean that individual people didn't have problems in getting service for a particular client. But, in general, the individual components of the service delivery system appeared to be adequate and appropriate.

Law Analysis

Minnesota counties are committed, by State law, to provide social services to mentally retarded persons in accordance with State plans, mandated by the Federal Social Security Act and approved by the Secretary of Health, Education and Welfare. Counties must provide the services under these State plans to all eligible persons in order for the State to receive federal reimbursement for a portion of the costs incurred.

In addition, State law imposes a duty on the county welfare departments to provide, to all persons in need, services

which are not mandated by the Federal Government. Although not federally reimburseable, costs of these programs are supported, at least in part, by State grants to the counties or to other approved local agencies.

Generally, programs for the mentally retarded are supervised by State agencies, but administered and implemented by local governmental units or specialized local agencies and authorized non-profit organizations. However, in certain circumstances, administration and implementation are retained at the state level—for example, in state institutions and state schools for the mentally retarded.

The State Department of Public Welfare in its policy statement indicates that its basic premise for providing service to the mentally retarded citizens in Minnesota is development and use of community-based resources. The State policy indicates that while State government has had and will continue to have a major responsibility, comprehensive programs must also develop from local community efforts.

In explaining the respective roles which state, county, and community units are to have in developing the needed resources for an effective comprehensive service program for the mentally retarded citizens in Minnesota, the Commissioner of Public Welfare has issued guidance to county welfare departments that the "initiative and leadership for area-wide cooperative planning, development, implementation, coordination, and evaluation...

rest with the Mental Health/Mental Retardation Board." The focus of responsibility for the Area Board is clearly on community development—the development of needed resources, cooperative agreements among agencies, and local financial support.

Under law, the County Welfare Board is held basically responsible for administering all forms of public assistance, child welfare, and other programs under the Federal Social Security Act, and has a duty to establish after-care plans under the Minnesota Hospitalization and Commitment Act. The County Welfare agency, when service is requested, shall in cooperation with the individual or family, develop a service plan that is realistic and that takes into account the needs of the individual and the family as a whole. This plan will be reviewed as often as necessary, but not less than quarterly.

Under provisions of State law, public school districts are required to provide education programs for mentally retarded children from age 5 through 21. No school board may exclude, expel, or excuse any person from school without sufficient cause. Special instruction for the mentally retarded may be provided in a number of ways, including services in connection with regular school programs or services provided by contract with public, private, or voluntary agencies.

Some of the problems which emerge from studying the statutes and policies are as follows:

1. Several state agencies have overlapping responsibilities for planning of services and facilities.

2. There is a multiplicity of required records in individual service plans on the county level, and no information system for putting these plans together for the benefit of the retarded person.

3. The current zoning codes are often a barrier to developing community-based alternatives to institutionalization. These codes represent a real problem in trying to implement the normalization concept.

4. The laws provide for the kind of responsibility necessary to develop programs and services which can meet the needs of the mentally retarded person in Hennepin County. The biggest problem, as usually is the case, is the selectivity with which these mandated responsibilities are carried out, which results often from lack of needed financing for the programs, but also from an apparent lack of real effort to determine what the retarded person wants the priorities to be.

5. The financing arrangements are often not compatible with current philosophies in providing services to mentally retarded persons. For example, many services are funded under Title XIX, which is in reality a medically oriented program, whereas the bulk of services required by mentally

retarded persons really fall under educational and social services concepts. Yet there is lack of adequate funding specifically for the latter types of programs.

6. The law provides for overall plans to guide the development of services. These plans, however, have not yet materialized in Minnesota, at either the state of county level.

Agencies

In trying to obtain statistical information on service to mentally retarded persons, there is some difficulty in being able to find out whether or not they are receiving services. Many of the agencies surveyed indicated that they do not keep their records according to a diagnosis of mental retardation. While this information, when known, is recorded in individual case files, it is not part of an overall information system and thus is not readily retrievable. This was particularly true of the diagnostic and evaluation services available in Hennepin County.

Most agencies feel that the services they are providing are the most appropriate services for them to provide. But there are a number of agencies which feel that some services they do provide could more appropriately be furnished by another agency, or that there are some services they should be providing which they currently are not offering. However, the services listed as the least appropriate are distributed over a wide range and do not fit into similar categories. Probably the agencies assumed responsibility for delivery of these kinds of services

because there was a need at a particular point in time, and no one else was meeting it. This raises the question of an adequate monitoring system to match up needs with the most appropriate resources.

Agencies generally believed that services should be delivered by a wide variety of public and private agencies, with the notable exceptions of education, diagnostic services, protective services, and personal care services, which were viewed as being best left in the public sector.

Most services were seen as being at a fairly high stage of development in Hennepin County. Three areas generally perceived as needing expansion were: community education, family support services, and service coordination. Other areas rated as being of high need of further development, but not universally so rated, were: programs for adults, including day activity centers; special living arrangements; additional special education programs.

Coordination of services was clearly a concern of agencies as repeated suggestions for modifications in the system appeared in the questionnaire. The service coordination system needed is seen as a more nearly centralized vehicle to include: monitoring, an initial contact and ongoing outreach of service for those requesting it, funds channeled through it to achieve services, a mechanism to insure continuous flow of services to mentally retarded persons. As part of the monitoring function,

a need is seen for clearly defined lines of agency responsibility with inter- and intra-agency accountability.

Although recognizing that some family counseling and support services are available in the community, and that these services are becoming more widely available, agencies re-emphasized the need for more extensive development of these services. Counseling should include both parent education and support, with emphasis on attention to total family needs, not just the needs of the individual with the mental retardation problem.

Early identification and diagnosis and early counseling and information-giving to parents can help the family handle its problems more adequately. Some of the agencies now involved in counseling were seen by the Committee as hot being well equipped to extend this service sufficiently to meet the need. Other resources in the community might be utilized more adequately.

As more educational programs have become available in the community, extending the options for service, there is increased emphasis on modifying the programs to improve quality rather than quantity. A particular concern was voiced by some agencies for the development of a child as he moves from the small, more personal and individualized program of the preschool years into the larger educational program of the public school system. These agencies expressed a need for the public schools to work

more closely with the preschool programs to improve continuity for the child. Some public school programs were seen as not providing all the challenges that the smaller preschool programs felt able to offer.

Few of the planning agencies could express their organization's objectives, and only a small minority expressed any objectives directly related to identifying the need for services to mentally retarded persons.

While the planning agencies and direct service agencies did share concern for further development of two areas—service coordination and community education—the other areas discussed above were either not ranked at all, or were not ranked highly or commented on by the planning agencies.

Parents

Parents generally found it very difficult to think about or consider the development of services other than those their own child might need. In responding to questions of how they would choose to redesign the delivery system and its component parts, most parents were unable really to visualize services as a system, or to comment on what changes or modifications in services would improve a total system.

Parents also seemed to find it difficult to rate services which they had received in the past but were not currently re-

ceiving. They tended to rate most of the services they had received as being good or adequate; very few were rated as poor. The Committee members unanimously felt, after having had long discussions with the parent interviewees, that the parents' ratings of services were usually based on experience with one particular agency. Committee members found it necessary to take copious notes during the interview process, in addition to recording the specific responses to questionnaire items. After reviewing these notes, the interviewers found that indeed many parents had experiences with particular agencies, offices, or organizations within the service system which could have been rated poor, fair, or unsatisfactory for their needs at the time.

One area in which parents felt that their needs were generally unmet was in the initial diagnosis of their child. This was particularly true when the diagnosis came from a physician and was made when the child was very young. Parents reported that the physicians generally did not provide support for the emotional needs of the parents, and were unable or unwilling to refer them to resources where they might have received more appropriate education and counseling. The parents indicated that often the physician seemed unaware of resources that might be available to help them or their child, and, more often than not, it had been recommended to them that it might be better if they did not attempt to keep the child.

Parents indicated that the services in greatest need of development were: educational services, diagnostic services,

and counseling services. They also mentioned residential care, special living arrangements, sheltered employment, and recreation services, but these were less frequently cited.

Parents also seemed to feel that the public sector should be more responsible for making sure that services are available. Even with an area such as advocacy, parents felt that the public sector should carry as much responsibility as the private sector.

Parents felt that, as part of the counseling and family support services needed, there should be more effective coordination of services with more guidance available. They recognize that meeting the needs of retarded persons requires services which come through a number of agencies, but they hope that services might be better developed so that the program runs smoothly from one stage or one aspect to another. They repeatedly mentioned that getting services for their child would be so much easier if there were one place where they could go which would provide access to information about available services and steer them to help in determining their own child's special needs so that they could help their child more effectively. Parents also pointed out the need for additional education programs in the community and for agencies so that they would receive better (more suitable) referral information and more immediate help.

Parents indicated also a need for help with financing; this was not seen as a crucial problem by agencies. Parents reported

that paying for services for a retarded child was often difficult for them, as a family, and that there was a real need for the development of better financial support for parents to avoid excessive depletion of family resources. They indicated that better public financial support would more adequately ensure the right of services for all.

The parents selected in the sample who subsequently could not or would not participate, either because of their own decision not to participate or because they could not be located after many, many attempts, were almost exclusively those parents who fell in the unskilled occupation category and who were in the "Black" or "other" racial category. The assumptions the Committee made about these parents were that they were among the most economically deprived, that by their own definition they were outside of the system in that many were unwilling to participate. The Committee speculated that among their reasons for not participating might be:

1. That the service organizations have not developed adequate approaches or techniques for reaching them.

2. That in their complex social problems, retardation appears to be rather minor-

3. That perhaps they did not have enough understanding of what mental retardation was and how it affected their family.

DISCUSSION

The mentally retarded person today is increasingly enveloped in language and planning concepts which are aimed at developing services for a much larger group of handicapped individuals, the developmentally disabled. While recognizing that there are real and valid reasons for developing service plans for a large identifiable population group when the kinds of services needed overlap, particularly on a regional and state level, the Study Committee nevertheless felt that currently there is still a need to identify services which are specifically designed for mentally retarded persons. The nature of this disability is such that it requires specialized programs and techniques in order to develop to the maximum the potential of retarded persons. For this reason, the Committee chose to confine its recommendations to those services specifically geared to the mentally retarded person and to accept as its working definition for the design of those services this statement: "Mental retardation refers to significantly sub-average intellectual functioning which manifests itself during the developmental period and is characterized by inadequacy in adaptive behavior."

A statement of philosophy which was developed for a study 12 years ago seems as applicable today in trying to determine the parameters which any service system must consider in meeting the total needs of the mentally retarded person. "Mental retardation is a multiple problem. Its dimensions are bounded

only in part by degree of intellectual defect although this is an important boundary. They are also formed by: patterning of intellectual abilities, patterning of emotional reactions, patterns of behavioral adjustment, aspects of physical health and added sensory or motor handicaps, patterns of family climate and by patterns of societal attitude and provision for retardates which affect opportunity for education, recreation, employment, and which broadly shape the environmental climate for retarded individuals."

The system of services which adequately meets or tries to meet the many-faceted problems of the retarded is necessarily a complex system. The complexity itself and the bureaucratic workings of such a system, as often as not produces confusion and barriers in the most effective use of resources by the professional for his client, and most certainly offers a perplexing maze for a great many parents seeking services for their child.

If a community is to establish a care system which meets the needs of the retarded person and his family, it is hoped that such a system would have, as an integral part, a planning and coordinating mechanism to provide for: identifying needs, facilitating the planning and implementation of a full range of services, establishing a delivery system, setting priorities for expenditure of funds, reviewing applications for governmental funds and for construction of new facilities, and coordinating its activities with other planning bodies.

Currently, in Hennepin County, these functions are not all centered in one source, although legislative mandates provide for a pooling of several functions. The split in responsibility is often between the program planning aspects and the financing aspects. The closer the interlinkages between these two facets of the care system, the more effectively quality care can be controlled and the more effective a community can become in providing the full spectrum of required services and continuity
of care.

An essential element in a good helping system is a mechanism which facilitates the most effective utilization of services that a person needs. The Hennepin County system needs to provide a way in which a client can tap the variety of options available to him in his community with ongoing consultation with someone who knows his situation. Without this assistance the family may approach its decision-making inappropriately sometimes too far in advance of the need, often not until the time of the need, and many times—regretably—too late to meet the need.

Other communities have wrestled with this same problem and have developed different models to solve it. The Committee feels sure that our community can do so too. One concept which the Committee discussed at great length is the regional center mechanism. Typically, a regional center serves the following functions. It serves:

1. As an entry point to community services.

2. As the "gate-keeper" which determines the flow of persons to state hospitals and/or facilitates their return to the community.

3. As the mechanism which links state resources with local community resources to bring maximum benefits to the retarded person.

4. As the fiscal control of funds for the purchase of essential services which could not otherwise be pro vided.

The regional center concept blends private and public sectors of service and utilizes resources in the community without necessarily housing them under one roof- The Committee felt that the regional center was a feasible way of providing a continuity of service to the community and would encourage our own regional and state planning offices and organizations to pursue this idea.

It appears to the Committee that a central element in the potential success and the potential problem of this regional center program are one and the same: the marriage of the financial mechanism to the provision of services which is inherent in the approach. Such a marriage would require a great deal of time and effort in the State Legislature and on other fronts to make this alternative possible in Hennepin County.

Committee members felt that there are some needs apparent in Hennepin County that demand immediate attention and cannot wait for the investment of time and effort necessary to achieve

a regional center concept. The Committee therefore recommended an alternative: an intake, service coordination mechanism one step below the regional center concept. The mechanism would remain part of the dual system of public and private providers, but at the same time offer an entry point, a "gate-keeper" concept for the client requesting those services, and a mechanism to link together all the community resources.

The Committee also examined the role of the educational system in the delivery of services to mentally retarded persons under the age of 21. Philosophically, there are many reasons why it would be feasible to have an educational system assume responsibility for the provision of services for children from birth to 21. Most of the services rendered to the young retarded individual are educational in nature; consequently, it would seem logical to have planning, delivery, and financial mechanisms all centered in one sector of our community which could be held clearly accountable for provision of those services.

However, the Committee recognized that there are often wide differences between what would be ideally sought after and what is realistic to obtain. The school systems in Hennepin County are not seen as having either the resources or, in many cases, the capabilities to provide the wide variety of services that the retarded person needs in his stages of development from birth to 21. Nor, perhaps, is it advisable for all services in this age span to be developed under a single philosophy that might

emanate from a single school district. However, the Committee encourages examination of what might be accomplished through the regional vocational education district.

It would make sense to have some better way of financing programs for mentally retarded persons than the current system of allocating those funds through separate departments of the state, and to have closer coordination between those programs which deal with the preschool child and those programs affecting his later developmental stages. Even if the system were changed so that education were to assume overall responsibility for mentally retarded children, the most effective delivery of these services is likely to be accomplished through the school system's utilization of resources already existing in the community, rather than assuming that the educational system can provide all of these resources by itself.

Among the families of retarded children, there is a subgroup composed of diverse kinds of people who share one characteristic—poverty. Much of the work which is being done with them and for their children is happening in Model City types of child care programs, usually not employing the label of "mental retardation". Conversations with some of the professional workers in these programs have given Committee members some impressions and ideas which have significance to the total problem of mental retardation. Many of these families have multiple problems, and multiple relationships with multiple agencies. Many of these parents are limited in their skills to cope with their life situations. Some are limited in ability, many are limited in

educational background and skills, many have complex difficulties of social and personal adjustment. Meeting survival needs is so difficult that problems a retarded child is having may occupy a low place on the list of family priorities.

Many of these parents are deeply fearful of officialdom, even while they are dependent on some aspects of it. They are easily threatened; they often are fiercely rejecting of the label of mental retardation applied to their child or, perhaps to them. Often they are very resistant to making any changes in how they do things—perhaps because, or partly because, they feel trapped in their situations.

Establishing good working relationships with them involves more flexibility, more willingness on the part of the professional worker to accept wide differences in value systems and life style, and more effort to establish a basis of trust which is meaningful to the family involved.

It seems to the Committee that the children of these families are an important subgroup. Many of them probably do fall in the borderline or high educable ability range; many of them are probably also adversely affected by all the specific lacks subsumed under the terms "cultural deprivation" and "social disadvantage". Many of them could be salvaged to become more adequate—if we were more skillful in reaching their families and in alleviating some of their basic living problems.

They may not be in the population recognized as retarded when they are adults, although they may appear as educationally retarded during their school years. Without adequate attention and services during their childhood years, many of them will, as adults, contribute to the social problems of crime and delinquency, court systems and prison systems, chemical dependency, child abuse, financial dependency.

The study conducted by this Committee is one of several studies carried out over the years in an effort to create a better system of services. The Committee examined the different kinds of information which became available to it through this study, and there were certain areas that appeared to have shown little improvement since former studies were done. Two areas particularly were discussed: the planning and decision-making role, and "what is best for the client" concept.

The system that exists currently in Hennepin County and its corresponding regional and state levels appears to be dichotomized. On the one hand are the individual agencies giving service who have become over-identified with their clients, and on the other hand are the "paper planning" agencies who have become under-identified with the clients. There appears to be a real need for a professional bridge among the planning bureaucracy, the direct services agencies, and the families. This bridge is seen not only as an advocate for the retarded person and his or her problems, but also as an advocate of the system.

The advocate would need to have a composite, comprehensive view of the client and available services. As society is organized today, parents are assumed to be the ones who should fill the advocacy role, but parents really can't walk the complicated fragmented route of fractionated service systems alone nor do they always have a realistic view of their retarded child. Parents wear out and children end up not being able to get the services they need because of practical problems. In many cases more could be done, but the parents' energy and time have been exhausted.

In analyzing the resources available in the community to assume this responsibility, the Committee felt that the Minneapolis Association for Retarded Citizens had a unique capability to fill this role, to be effective monitors of the system, to advocate for that which is good in the system and to push for changes where there is dissatisfaction and inadequacy. MARC is not seen as accomplishing this role alone or in isolation, but rather through working with and utilizing all of the resources in the community. This agency is seen as being able to become the crucial bridge which allows the monitoring and advocacy role to be undertaken effectively in Hennepin County.

There were many areas of concern that the Committee discussed and contemplated. Some are reflected in the conclusions and others in specific plans of action suggested in the recommendations. The Committee realized that many other groups are in the process of planning for new services and the expansion of existing

services for the handicapped population as a whole in Hennepin County. It recognized the work that has already been undertaken by the Metropolitan Transit Committee for the Disabled which studied transportation needs of the disabled. Consequently, it did not make any specific recommendations on transportation, but supports the concepts and the direction that the Metropolitan Committee is pursuing.

In summary, the Committee felt considerable concern about the apparent over-development of planning activities which often seem to have little or no relationship to one another. The Committee felt that although many of the planning structures were developed in good faith and with the objective of improving specific parts of the system, today those planning activities may bear little relationship to what is actually happening to or needed by the retarded persons themselves. The Committee strongly felt that the time has come once again in Hennepin County and in the related governmental sections of the community, to put more emphasis on the development of direct services to meet effectively the already identified, yet ever-changing needs of the mentally retarded persons within specified time periods.

A P P E N D I X E S

APPENDIX A

MENTAL RETARDATION STUDY

LAW SUMMARY AND ANALYSIS

Statutory Responsibilities

APPENDIX A-1

MENTAL RETARDATION STUDY

Law Summary and Analysis

Statutory Responsibilities

I. Scope:

This report is a summary of the basic responsibilities for the provision of services to mentally retarded citizens of Hennepin County, Minnesota. It is based on interpretation of: 1) applicable federal, state, and local laws (where appropriate) through May, 1974; and 2) policy statements of official state and local agencies.

A Directory of Federal Programs for the Handicapped is at Appendix 1. Excerpts from the 0E0 Catalog of Federal Domestic Assistance Programs is at Appendix 2. Summary comments and problem areas identified by the authors is at Appendix 3.

II. Background:

Minnesota counties are committed by the State to provide social services to the mentally retarded in accordance with State plans mandated by the Federal Social Security Act and approved by the Secretary, United States Department of Health, Education and Welfare. Counties must provide the services under these State plans, to all eligible persons, in order for the State to receive federal reimbursement for a portion of the costs incurred.

In addition, State law imposes a duty on the county welfare departments to provide, to all persons in need, services which are not mandated by the Federal Government. Though not federally reimburseable, the costs of these latter programs are supported at least in part by State grants to the counties or other approved local agencies.

III. The Statutory Scheme:

Generally, programs for the mentally retarded are supervised by State agencies but administered and implemented by local government units or specialized local agencies and authorized non-profit organizations. However, in certain circumstances, supervision and implementation is retained at the State level, e.g., state institutions and state schools for the mentally retarded.

IV. The State Policy:

The basic premise for providing services to the mentally retarded citizens of Minnesota is the development and use of community-based resources. This policy finds expression at the State level as follows:

"A basic orienting fact is that persons and families live in villages, towns, cities, and counties—not in institutions. When institutionalization is called for, it will generally be temporary. Therefore, a comprehensive program must be based in communities—not institutions. Institutions will continue to serve as important resources in a comprehensive program, but they can no longer be the core of the program, as they have been in the past. State government has had and will continue to have a major responsibility, but comprehensive programs must also develop from local community efforts." [Department of Public Welfare Social Service Manual II-8420, 7April72].

A. The State Role:

The Commissioner of Public Welfare:

1) administers and manages the state institutions for the mentally retarded; [Minn. St. '246.01]

2) licenses residential facilities for the care and treatment of the mentally retarded; [Minn. St. 252.28]

3) provides cost of care for residents of state institutions for the mentally retarded from funds provided by the legislature; [Minn. St. 252.27]

4) supervises mentally deficient wards; [Minn. St. 256.01]

5) supports programs of the Area Mental Health/ Mental Retardation Board with grants-in-aid; [Minn. St. 245.61]

6) assists communities in ascertaining local needs in planning and establishing community Mental Health/Mental Retardation programs; [Minn. St. 245.69]

7) supports daytime activity centers (DAC) for the mentally retarded with grants-in-aid; [Minn. St. 252.21]

8) reviews and evaluates Area Mental Health/Mental Retardation Board programs and makes recommendations to the Area Mental Health/Mental Retardation Board; [Minn. St. 245.69]

9) evaluates the extent to which regional facilities, agencies and boards are carrying out their plans for delivery of services and reduction of mental retardation programs; [DPW Soc. Svc. Manual II-8241(6)]

10) assesses the efficiency and effectiveness of programs established to carry out the provision of state law governing the Department of Public Welfare legal responsibilities pertaining to mentally retarded persons; [DPW Soc. Svc. Manual II-8241(7)]

11) assures that changes in the law and programs are accomplished and based on those assessments; [DPW Soc. Svc. Manual II-8241(8)]

12) assures that methods of monitoring programs, including licensing, are developed and carried out to help determine why the program is working where it appears to be effective and to determine where the law and the system are not working and why. [DPW Soc. Svc. Manual II-8241(10)]

B. The County Role - Hennepin County Welfare Board:

The Hennepin County Board of Commissioners is also the Hennepin County Welfare Board. [Minn. St. 391.03(3)]

The County Welfare Board is basically responsible for administering all forms of public assistance and public child welfare or other programs within the purview of the Federal Social Security Act (except for public health nursing and home nursing care) which are imposed on the State Commissioner of Public Welfare by law for both children and adults. [Minn. St. 393.07(3)] The County Welfare Board is responsible for organizing, staffing, and administering the Hennepin County Welfare Department in a manner to best provide the required social service programs of the State. [Dept. Public Welfare Soc. Svcs. Manual I-2110, 7Feb72]

In addition to the duties derived through the State's responsibility for administering federally mandated services, the County Welfare Board has a duty to establish "after care" plans under the Minnesota Hospitalization and Commitment Act. [Minn. St. 253A.14] Specifically,

the county of the patient's residence must, prior to a patient's release, discharge, or partial discharge from the hospital, establish a continuing plan for after-care services for such patient. The plan will be developed in cooperation with the head of the hospital, the patient's physician, and the director of the Community Mental Health Center service. The plan must include provisions for medical and psychiatric treatment, nursing care, vocational assistance, and such other aid as the patient shall need. The County Welfare Department has a mandatory duty to supervise and assist the patient in finding suitable shelter, employment, medical and psychiatric treatment, and to aid in his readjustment to the community. [Minn. St. 253A.15 Subd 12]

C. The Community Role - Area Mental Health/Mental Retardation Program:

Communities and/or non-profit corporations may establish, subject to the approval of the Commissioner of Public Welfare, a community (or "area") Mental Health/ Mental Retardation program pursuant to the provisions of the Minnesota Community Mental Health Service Law; [Minn. St. 245.61 to 245.69]. Such a program is intended to fulfill the following service responsibilities:

1) cooperate with public health and other groups for programs to prevent mental retardation;

2) provide information and education services to the general public, and lay and professional groups;

3) provide consultative services to public and private schools, courts, and public and private health and welfare agencies;

4) provide outpatient diagnostic and treatment services ; and

5) provide rehabilitative services for persons suffering from mental retardation, particularly those who have received prior treatment in an in-patient facility. [Minn. St. 245.61]

Before qualifying for any State financial aid provided by the Community Mental Health Service Law, any community or non-profit corporation establishing a Mental Health/Mental Retardation program must appoint a Community Mental Health/Mental Retardation Board. [Minn. St. 245.66] This Board is more commonly known as the "Area Mental Health/Mental Retardation Board," and when established it has the following statutory duties:

1) implement programs in mental retardation to as sure delivery of services;

2) review and evaluate community mental health services provided pursuant to the Community Mental Health Service Law, [Minn. St. 245.61 - 245.69] and report to the Commissioner of Public Welfare, the administrator of the program, and, when indicated, the public together with recommendations for additional services and facilities;

3) recruit and promote financial support for the program for private sources...and promote public support for municipal and county appropriations;

4) promote, arrange, and implement working agreements with other social service agencies, both public and private, and with other educational and judicial agencies;

5) advise the administrator of...the program on the adoption and implementation of policies to stimulate effective community relations;

6) review the annual plan and budget and make recommendations thereon;

7) appoint advisory committees in at least the areas of...mental retardation...a committee shall consist of residents of the area served who are interested and knowledgeable in the area governed by such committees. These advisory committees shall report regularly to the Board. [Minn. St. 245.68]

In explaining the respective roles which state, county, area (community) are to have with respect to developing the needed resources for an effective comprehensive service program for the mentally retarded citizens of Minnesota, the Commissioner of Public Welfare has issued guidance to County Welfare Departments that the "... initiative and leadership for area-wide cooperative planning, development, implementation, coordination, and evaluation..." rest with the Mental Health/Mental Retardation Board. [DPW Soc. Svcs. Manual II-8151.02]

A similar policy notion is inherent in the statutory provisions of the Community Mental Health Service Law noted above [Minn. St. 245.61]. The focus of responsibility for the Area Board is therefore "...clearly on community development—the development of needed resources, cooperative agreements among agencies, and local financial support..." [DPW Soc. Svcs. Manual II-8243].

D. The Hennepin County Mental Health/Mental Retardation Board was constituted by resolution of the County Commissioner on July 2, 1968, "...to act as the Hennepin County Mental Health (and Mental Retardation) Board pursuant to Minnesota Statutes 245.66-69, as amended..., and to serve as the advisory body to the Board of Commissioners on all matters pertaining to mental health and mental retardation;" and (by resolution of the Commissioners) "... all matters pertaining to mental health and mental retardation [were to] be referred to the Hennepin County Mental Health and Mental Retardation Board for its report and recommendations... "

It was not until March of 1974, however, that the County Mental Health/Mental Retardation Board acknowledged the full range of its statutory powers and duties under Minnesota Statutes 245.61-69 amended, and the advisory role delineated for it by the County Commissioners. Section I and II of the Hennepin County Mental Health/ Mental Retardation Area Program Operating Manual clearly reflect, in writing, the functions which the County (Area) Mental Health/Mental Retardation Board is to perform:

"1. Functions Performed;

a) To advise the County Board on the development of Mental Health/Mental Retardation policies and programs.

b) To serve as the comprehensive coordination and planning agency for Mental Health/Mental Retardation programs.

c) To negotiate for the purchase of such programs and services as may be necessary to develop a comprehensive Mental Health/Mental Retardation program for the County of Hennepin, as authorized by the County Board.

d) To serve as an advocacy body for Mental Health/ Mental Retardation matters."

The instructions further expressly state that the Mental Health/Mental Retardation Board "...must..." carry out the specific statutory responsibilities identified "...Under Minnesota Statutes 245.61 - 245.69, as amended," and in addition the instructions give recognition to the fact that other, broader advisory duties have been assigned by the Hennepin County Board to the effect that the County (Area) Mental Health/Mental Retardation Board is to advise the County Commissioners on all Mental Health/Mental Retardation programs and policies, not just those funded through the Community Mental Health Service Act. [Minn. St. 245.61 - 245.69]

Section II of the Mental Health/Mental Retardation Area Program Operating Manual identifies expressly, for the first time in the Mental Health/Mental Retardation Board's six-year existence, priorities for the delivery of services, "based on [the Mental Health/Mental Retardation Board's] best judgment of service delivery need presently existing in Hennepin County," and ranked in the following order: (approved by Mental Health/Mental Retardation Board, 7May74)

1. Community Care, including appropriate residential facilities and programs for former hospital residents, both mentally ill and mentally retarded.

2. Better screening (diagnosis and assessment) and appropriate alternatives to state hospital psychiatric care.

3. School-related mental health programs.

4. Residential facilities and programs for adolescents and adults with severe mental retardation and mental health problems.

5. Public education about available services.

6. Development and implementation of county-wide consultation and education objectives.

7. Expanded services for under-served geographic areas."

These priorities are established for the express purpose of preparing the 1975 Hennepin County Mental Health/ Mental Retardation budget.

Although the Community Mental Health Service Act, [Minn. St. 245.61 - 245.69] provides discretionary funding authority to local governmental units establishing community mental health programs under the Act, this special tax levy authority has never been used by the Hennepin County Board of Commissioners. Prior to 1973, the levy limit was 2 mills annually on all taxable property. The levy is authorized specifically "...to provide the necessary funds to establish and operate a mental health services program..." [Minn. St. 245.62]. By amendment in 1973, the 2 mill limit is continued on cities, towns and villages but counties are excepted from the 2 mill ceiling. [Laws 1973, Chap. 583, Sec 14]. The levy is authorized in excess of any statutory or charter limitations, and arguably is exempt from any state-imposed budget ceilings tied to property tax levies for general funds. A county welfare board could allocate general welfare funds to the Community Mental Health/Mental Retardation Board for the purpose of expanding Mental Health/Mental

Retardation services in the county, and such allocation would be employed as a source of funds in addition to the funds provided by the special tax levy under Minn. St. 245.62. [Op. Att. Gen. 125a-64, HSeptl968] .

E. Hennepin County Health and Social Services Advisory Board (HSSAB):

The Hennepin County Commissioners approved the establishment of a County Health and Social Services Advisory Board on 20May74. This agency is not organized pursuant to the Human Services Act [Minn. St. 402.01 - 402.10] for several reasons:

a) The County Health and Social Services Advisory Board does not include any Court Services, which is a requirement of the Human Services Act [Minn. St. 402.02, Subd2(d)].

b) The Human Services Act does not authorize planning grants to individual counties and thus Hennepin County would receive no financial aid from the State for planning human services development. [Minn. St. 402.08]

c) The HSSAB is a purely advisory body, which makes it "acceptable" to the majority of county commissioners, while a Human Services Board would exercise broad statutory management responsibilities and receive funding from the State. [Minn. St. 402.02, Subd 2]

In its present form, the County Health and Social Services Advisory Board replaces the County Mental Health/ Mental Retardation Board as the advisory body to the County Commissioners. The Mental Health/Mental Retardation Board becomes a Standing Committee of the HSSAB.

V. The State Comprehensive Program:

The Department of Public Welfare Comprehensive Program for Mental Retardation consists of a system of relationships between the following organizations: the state agency, state institutions for the retarded, the county welfare board, the area MH/MR board, and the daytime activity center board(s). Their respective duties, which together comprise the comprehensive program and service plan, are mandated by statute, either state or federal. The focus of responsibility for each differs in important ways, however.

The state agency, state institutions, and the county welfare board predominantly address their service efforts toward persons who currently fit statutory descriptions of categories of eligibility for service. While the State Department of Public Welfare has a broad responsibility to assess statewide needs and make appropriate legislative recommendations, [Minn. St. 246.06, 256.01], the county welfare board concentrates on delivery of service to categorically defined eligible persons, and is not so directly involved with assessments of overall need for community service.

The state institutions are operated and administered under the supervision of the Commissioner of Public Welfare and her state agency. These facilities are used as regional resource centers by the County Welfare Department on behalf of eligible clients. They are used as a community resource by the Area Mental Health/Mental Retardation Board in its assessment and development of needs and services for the mentally retarded throughout the community.

Daytime Activity Centers, (DAC's) are established upon approval by the state agency. These centers provide daytime activity programs and services directly toward:

1) mentally retarded children who can benefit from the program of services offered and who are excused or excluded from attending school;

2) mentally retarded children and adults unable to attend school because of chronological age or inability to independently engage in ordinary community activities;

3) providing counseling services to the parents or guardians of mentally retarded persons who may register at the DAC. [Minn. St. 252.23]

The County Welfare Board uses DAC's as a resource for the service needs of eligible individual clients. The Area Mental Health/Mental Retardation Board also uses the DAC's as a resource to provide contractual service to members of the community and to assist in service planning for community-wide support of mental retardation programs.

VI. Determination and Assessment of Resource Needs in the Comprehensive Mental Retardation Program:

As noted in the prior delineation of statutory responsibilities for providing social services to the mentally retarded, State law and agency policy recognizes the importance of coordinated, area-wide need assessments as the

essential first step in the development of a comprehensive plan and program to provide services. But the practical administration and implementation of statutory provisions and state agency guidance is both time consuming and cumbersome.

The Area Mental Health/Mental Retardation Program Office is the planning, coordinating, and evaluating unit for the community's program and service needs. However, the County Welfare Department is charged with planning duties and resource need determinations as well.

A. Social Service Plan and Case Record - County Welfare Department:

State policy requires that when service is requested or an offer of service is accepted, the "County Welfare agency shall, in cooperation with the individual or family, develop a service plan that is realistic and that takes into account the needs of the individual and the family as a whole. The plan shall describe the specific services to be provided and shall ensure the maximum feasible effort to assist the individual or family to achieve the specific objectives of the plan." [DPW Soc. Svcs. Manual I-2440, 5April73].

This plan will be reviewed as often as necessary but not less than quarterly.

It is the express responsibility of the County Welfare Director to ensure that a separate service record is maintained for each social service case, and that the record include both an assessment of the need for the service and the plan as well as other administrative data. [DPW Soc. Svcs. Manual I-2460, I-2470].

Other records, which are prepared by the County Welfare Department as needs, assessments and service plans include:

1) cost of care plan and developmental plan for placement in residential facilities for the retarded outside the home; [Minn. St. 252.27, DPW Soc. Svcs. Manual II-8459 - 8464]

2) after-care service plan for patients returning from institutions for mentally retarded. [Minn. St. 253A.15 Subdl2]

B. Individual Program and Treatment Plans - Licensed Residential Facilities:

Facilities providing residential and day care, or services, for more than four retarded persons of all ages,

including state institutions under control of the Commissioner of Public Welfare and serving mentally retarded persons, must be licensed under DPW Rule 34. [Minn. St. 252.28]

The program and licensing standards under Rule 34 require the preparation and maintenance of detailed and records for each person residing in, or receiving services from, the licensed facility or program.

Responsibility for the individualized program and treatment plan of each resident is placed upon the facility staff. [DPW Rule 34, III-C] The program and treatment plan is a detailed statement of developmental objectives and service needs. In effect it is an individual comprehensive program for social and rehabilitative services because it mandates the utilization of the following developmental services: DAC's, education, recreation, religious, sheltered workshops, social work, and vocational rehabilitation. Moreover, Rule 34 envisions the use of individual program plans as the basis for evaluating not only the individual but the services provided, and also as a basis for the development of services provided by the facility. The record will further serve as a means of communication among all persons contributing to the resident's program. (DPW Rule 34, V-E4a-f]

C. Individual Program Record - Day Activity Center:

Day Activity Centers are administratively independent of both the County Welfare Board and the Area Mental Health/ Mental Retardation Board. [Minn. St. 252.22] The DAC's provide services under contracts (or purchase-of-service agreements) to these agencies, however. In Hennepin County, the thirteen DAC's have formed an association to provide centralized administrative, planning, advocacy, evaluation, and programming activities for the member DAC's and under contract to the Area Mental Health/Mental Retardation Program Office [Hennepin County Soc. Svc. Plan 1974, p.40]. The Commissioner of Public Welfare has responsibility to closely supervise the operation of licensed DAC's receiving state grants. [Minn. St. 252.24]. Under State regulations, each licensed DAC shall maintain a case record for each person participating in its program. The record must include a statement of the goals to be accomplished at the center and a plan for training, education and treatment. The case record must also include a periodic individual progress evaluation and a plan for family involvement with a record of conferences held. [DPW Rule 31(g) (1) (aa-ff)]. Moreover, when an applicant is refused or terminated from participation in the DAC program, a record of such action must be put in the minutes of the DAC Board with reasons therefore and a record of efforts made to assist those applicants refused or excluded, to find other services. [DPW Rule 31(f) (3) (bb)].

The DAC is thus another source of information which may be useful in assessing needs and developing resources to serve the mentally retarded in the community.

VII. Guardianship - Guardianship and Commitment:

A. The Minnesota guardianship law is contained in the Minnesota Hospitalization and Commitment Act (MHCA), which is the means for bringing an individual under state guardianship.

A person who is committed as "mentally deficient" under the MHCA is not automatically put into a hospital. Upon commitment, the Commissioner of Public Welfare is appointed by the court as a guardian of the mentally deficient person. [Minn. St. 253A.07 Subdl8.] The Commissioner acts through the County Welfare Department.

A mentally deficient person is defined in the MHCA as "any person other than a mentally ill person, so mentally defective as to require treatment or supervision for his or for the public welfare." [Minn. St. 253.A.02, Subd5]. A person can be committed for mental deficiency merely by meeting the statutory definition.

The commitment is indefinite and may only be removed by a court hearing. Persons placed in an institution for the mentally retarded may be released by agreement by the Commissioner but release from the facility has no effect on the commitment to state guardianship. The legal disabilities suffered by a person who is committed to the guardianship of the Commissioner and thus a "ward," are the same as those of a person adjudged legally incompetent:

1) the committed person may be placed in a home, hospital, or institution [Minn. St. 253A.07(18)];

2) the committed person cannot be adopted without the Commissioner's approval [Minn. St. 259.25(1)];

3) the Commissioner may hold limited sums of the ward's estate and expend them for the ward's benefit [Minn. St. 256.93];

4) in certain conditions, the ward may be sterilized [Minn. St. 256.07];

5) the ward cannot marry without the Commissioner's consent [Minn. St. 517.03];

6) the ward cannot make contracts [Minn. St. 525.543];

7) the ward cannot sue or defend himself in any court action nor can he buy insurance or invest [Minn. St. 525.56(3)];

8) the ward cannot vote [Act 7, Sec 2, Minnesota Constitution];

9) the ward may be denied the right to apply for a driver's license [Minn. St. 171.04(5-9)];

10) the ward may not operate a boat or vessel [Minn. St. 361.12];

11) the ward may be challenged for jury selection [Minn. St. 631.29];

12) if a mentally deficient person is adopted without his condition being known, the adoption may be annulled by the parents if the condition is discovered within five years of the adoption [Minn. St. 259.30].

Public guardianship for the mentally deficient ward may be removed by petition for discharge on the initiative of the Commissioner under a probate proceeding [Minn. St. 525. 611], because the ward is no longer in need of supervision. This kind of action discharges the Commissioner's power to act with general supervisory powers over the person, but it does not change the person's status of mentally deficient. The discharge action is significant in terms of freedom to move about and to exercise choices in jobs, education, and residence. The person still has limited legal rights.

The other method for removing public guardianship is by bringing an action for restoration to capacity. [Minn. St. 253A.10]. Any interested adult may bring this action, but there must be a showing that the person seeking restoration is no longer mentally deficient, often a difficult fact to prove in court. [Handbook on Guardianship and Commitment, Minneapolis Legal Aid Society, Minneapolis, Mn.]

A new law has been proposed to the Minnesota legislature concerning guardianship and protection of mentally retarded persons. According to proponents, the "purpose of the proposed guardianship law is to maximize the civil rights of persons who are placed under the guardianship of the welfare commissioner by tailoring the guardianship to reflect the needs, abilities and disabilities of the individual.

To accomplish this the proposed Act:

1. Removes the guardianship law from the Minnesota Hospitilization and Commitment Act and creates a separate guardianship statute. With the growing number of retarded individuals now living in the community there is a need for very different legal and factual considerations in judicial appointment of a guardian and the judicial commitment of a person to an institution. The present statute takes that critical distinction into account for the mentally ill, but not the retarded. The proposed statute would extend the same right to the retarded.

2. Creates a "guardianship" with plenary supervisory powers for those persons who require total supervision, and a more limited "conservatoryship" for those with more capacity to function independently but who still need some supervision.

3. Provides the appointing court with flexibility to grant the conservator a range of specified powers and responsibilities so as to tailor the conservatorship to the needs and abilities of the individual.

4. Provides for a comprehensive social, medical, and psychological evaluation to assist the court in ordering the appropriate form of conservatorship or guardianship.

5. Provides for both an annual review of the developmental progress of the ward or conservatee and an annual review of the legal status of the individual to insure that his legal status properly reflects any changes in his development.

6. Provides procedural due process protections at the hearing to appoint the guardian or conservator.

7. Charges the Commissioner of Welfare with affirmative duties on behalf of the ward or conservatee to protect the retarded person's interests and to maximize his potential for social and financial independence.

8. Gives parents or other relatives the option of informally nominating the Commissioner as guardian or conservator without having to personally petition the court for appointment of the Commissioner as guardian.

The concept of a limited form of guardianship for the mentally retarded was first proposed in 1963 by the Task Force on Law of the President's Panel on Mental Retardation. That Task Force was headed by Chief Judge David Bazelon of the United States Court of Appeals for the District of

Columbia. The proposed Minnesota guardianship act builds upon the Task Force recommendation and adapts it to the local needs and long experience which we've had with public guardianship in Minnesota." [Summary of the Proposed Minnesota Mental Retardation Guardianship and Protection Act, furnished by the staff of the Legal Advocacy Project, Minneapolis Legal Aid Society].

VIII. Education and Vocational Rehabilitation:

A. Under the provisions of State law, local school districts are required to provide education programs to meet the needs of all children of school age. [Minn. St. 120.01] Public school districts are further required to provide education programs for mentally retarded children age 5 through 21. [Minn. St. 120.17]. No school board may exclude, expel, or excuse any person from school without sufficient cause. [Minn. St. 127.071]

Special instruction for handicapped children, e.g., mentally retarded, may be provided in a number of ways ranging from services in connection with attending regular elementary and secondary school classes to services provided by contract between the school district of the child's residence and public, private, or voluntary agencies. [Minn. St. 120. 17(2)]

The State Board of Education is responsible for promulgating the rules and regulations relative to:

> Qualification of personnel; courses of study and training; pupil eligibility; size of classes, rooms; equipment; supervision; parent consultation; and other rules and standards necessary for the instruction of handicapped children. [Minn. St. 120.17(3)]

B. The State Department of Education must provide vocational rehabilitation services for individuals in the State whose capacity to earn a living was destroyed or impaired in accidents or otherwise. [Minn. St. 212.29]

In order to improve rehabilitation services for the severely disabled (individuals who are unable to participate in competitive employment as result of physical or mental disability) the Minnesota Legislature has provided for the development and continuation of long term sheltered workshops and work activity programs. [Minn. St. 121.71 through 121.714]

The governing body of any city, village, borough, town, or county may expend money which may be available for such purposes in the general fund, and may levy a tax which, except when levied by a county, shall not exceed in any one year the following amounts per capita of the population, based on the last federal census: Cities of the first class, villages, boroughs, and towns, not to exceed thirty cents per capita. [Minn. St. 121.712.(2)]

Every city, village, borough, town, county, non-profit corporation, or combination thereof establishing a community long term sheltered workshop or work activity program shall appoint a long term sheltered workshop board.

The chief executive officer of the governmental unit(s) and non-profit corporation(s) shall appoint the board. If a non-profit corporation singly establishes such a workshop or work activity program the corporation shall appoint the board.

Membership of the Community long term sheltered workshop board shall be representative of the community served and shall include a disabled person. One-third to one-half of the board shall be representative of industry or business and remaining membership should be representative of lay associations for the handicapped; labor, the general public, and education, welfare, medical, and health professions. [Minn. St. 121.713]

Subject to the rules and regulations of the State Board of Education and existing state law, each community long term sheltered workshop board shall:

1) Review and evaluate the need for long term sheltered workshop services or work activity programs provided pursuant to Minn. St. 121.71-121.714 and report thereon to the Commissioner of Education, the administrator of the program, and, when indicated, the public together with recommendations for additional services and facilities;

2) Recruit and promote local financial support for the program from private sources... and promote public support for municipal and county appropriations;

3) Promote, arrange, and implement working agreements with other educational and social service agencies both public and private and any other allied agencies;

4) Advise the administrator of the long term sheltered workshop program on the adoption and implementation of policies to stimulate effective community relations;

5) Review the annual plan and budget and make recommendations thereon;

6) When so determined by the authority establishing the program, act as the administrator of the program. [Minn. St. 121.713(3)]

The Commissioner of Education is responsible for promulgating rules and regulations in regard to state certification of the programs, eligibility of the programs to receive state grants (which may not exceed an amount— equal to 75% of the normal operating expenses excluding wages paid to clients or long term workers), standards as to types and kinds of severely disabled persons eligible for program services, and other necessary rules to carry out the provisions of Minn. St. 121.71-131.713 [Minn. St. 121. 714 (5)(4)]

C. Minnesota Commission of the Handicapped:

The Minnesota Legislature established a thirty-member Commission For The Handicapped appointed by the Governor, effective in July 197 3. The legislation defines a "handicapped person" as one who, because of a substantial physical, emotional, or mental disability or dysfunction requires special services in order to enjoy the benefits of our society. [Minn. St. 256.481]

The Commission membership must include at least fifteen handicapped persons or parents or guardians of handicapped persons. One-third of the Commission must be appointed from the organizations providing services for the handicapped, and two-thirds from the general public. Serving as ex-officio members without voting power are the Commissioners or their representatives of the State Departments of Public Welfare, Education, and Manpower Services, and the Chief Executive Officer of the State Board of Health. Additional ex-officio representation without voting power is required from the division of vocational rehabilitation (Department of Education) and divisions of mental retardation services and services for the blind (Department of Public Welfare) as well as from other divisions and sections which are directly concerned with services for handicapped persons.

The Commission is to organize itself functionally and must establish councils and committees to give detailed at-

tention to the special needs of each category of handicapped persons.

The Commission has the following mandatory duties and powers:

1) To advise the Governor, appropriate state agencies and the public on matters pertaining to public policy and the administration of programs, services, and facilities for handicapped persons in Minnesota-

2) To encourage the development of coordinated, interdepartmental goals and objectives and the coordination of programs, services, and facilities among all state departments and private providers of service as they relate to handicapped persons.

3) To serve as a source of information to the public regarding all services to handicapped persons.

4) To review and make comment to the Governor, state agencies, the Legislature, and the public concerning adequacy of state programs, plans and budgets for services to handicapped persons and for funding under the various federal grant programs-

5) To research, formulate, and advocate plans, programs, and policies which will serve the needs of handicapped persons. [Minn. St. 256.482(5)]

D. Head-Start

1972 amendments to the Economic Opportunity Act P.L. 92-424 were designed "... to assure that not less than ten per centum of the total number of enrollment opportunities in the nation in the Head-Start Program shall be available for handicapped children... and that services shall be provided to meet their special needs."

Subsequent policy directives to the local programs became effective in February, 1973. These directives included "mentally retarded" in the definition of handicapped children. Recruitment procedures were to give priority to handicapped children in filling vacancies. Programs not serving handicapped children were to begin doing so immediately. Local programs (Head-Start Local Programs) were to begin a continuing investigation of community needs and program capabilities to meet those needs. Head-Start program directors must maintain- records of outreach, recruitment and services to handicapped children.

IX. Zoning:

The zoning issue is regarded by many advocates of the mentally retarded as "the last petcock" in the path from institutionalization into implementation of the normalization principle. Proponents of the latter, along with the State Department of Public Welfare [DPW Rule 8 (g) (1)], regard an everyday life style in a "normal" type home within a family residential neighborhood as the most effective component of development measures for a mentally retarded person. The zoning ordinances or positions of cities and municipalities operate to frustrate manifestation of this normalization endeavor either by flatly refusing to allow existence of group homes, day activity center, and all types of residential facilities in residential areas, or by requiring that special permits be obtained through compliance with extensive procedural requirements. Justifications offered for these restrictive ordinances range from a belief that property values would be adversely affected to apprehension over allegedly dangerous physical activities of the new home's residents.

Until approximately three years ago the City of Minneapolis allowed group homes and other small residential facilities for the mentally retarded only in industrial settings or in the downtown area. At that time the view on classification of group homes changed. They are presently viewed as "rooming houses" and are allowed in R4 apartment building areas or less attractive areas and then only after the grant of conditional use permit by the City Council. [Minneapolis Code of Ordinances, Chapters 263-285]. They are denied access to the more favorable Rl, R2 and R3 residential areas even if a conditional use permit could be obtained. [Minneapolis Code of Ordinances, Chapters 256 and 262].

However, proposed changes are presently under consideration by the Minneapolis City Planning Commission and should result in zoning ordinance changes within the year. It is likely that the new ordinances will allow group homes and other residential facilities for the mentally retarded to be established in all residential areas, including the Rl single family dwelling areas. However, it will certainly be necessary to obtain a conditional use permit for entry into any of these favorable residential areas.

The present procedures for a conditional use permit require formal application and hearing with the City Planning Commissioner with strong measures for notification of the neighborhood residents. The hearing is held by the Planning

Commission which then reports to the Zoning and Planning Committee of the City Council with their recommendation on the permit request. The Planning Commission will not recommend that a permit be granted unless it is shown inter alia, that the establishment of the home facility will not hamper or harm:

1) the health, safety, morals, comfort, or general welfare of the community,

2) the use and enjoyment of property,

3) the property values in the area, and

4) the development and improvement of the neighborhood. [Minneapolis Code of Ordinances 253.100 through .112]

While the proposed zoning changes open the possibility for a facility in the favorable Rl and R2 residential areas, they also increase the procedural burden placed on the applicant for a conditional use permit. The present procedural requirements, including the burdensome standards listed above, are retained. The proposed changes add requirements which force the applicant to complete extensive communication campaigns with the area residents at least 30 days before the formal notice of the Planning Commission hearing is sent out. The applicant is required to present an extensive list of information items to the area residents along with explanation of the zoning ordinances and licensure requirements.

The proposal providing for the opening of the Rl through R3 residential areas and the concomitant burdensome permit procedures are not facing serious dispute at the present time. The immediate issue under consideration by the City Planning Commission is the spacing or density requirements to be enacted. Due to even greater difficulty in establishing residential facilities in surburban areas, many facilities of Hennepin County are located in the City of Minneapolis, especially in the inner areas near downtown. Four alternative means of regulating the density of residential facilities have been proposed by the Planning Committee and sent out for public reaction:

1) no requirements other than the conditional use permit;

2) a ratio system of one facility per 4,000 community populations;

3) only those facilities that are community supported and occupied only by eligible residents of that neighborhood or area:

4) two new facilities would be permitted for every one that was established in the suburban communities of Hennepin County.

X. The Minnesota Human Services Act:

A. In 1973, the Minnesota Legislature authorized the establishment and development of coordinated and fully integrated programs to deliver "human services" on a county-wide, multiple county, or regional basis. Minn. St. 402. 01 to 402.10, effective July, 1973, allow one or more contiguous counties having an aggregate population of 50,000 or more persons, or all the counties within a "region" designated by Minn. St. 462.381 to 462.396 [e.g., those established pursuant to the Regional Development Act of 1969] by resolution of the county board(s) concerned, designation of a human services board.

The Board shall be composed of at least one county commissioner and citizen members comprising not less than one-third of the total Board membership. A citizen member of the Board shall be Chairman of the Human Services Advisory Committee, appointed in a manner prescribed by the county board(s) participating. Board members shall serve a term of three years so arranged that the terms of one-third of the Board will expire each year. Vacancies will be filled in the same manner as original appointments.

B. The Human Services Board shall possess all the powers and duties now assigned by law to:

1) Manage the existing public resources to human services delivered or purchased by the counties, which are subsidized or regulated by the departments of corrections, health, and public welfare. (emphasis supplied)

2) Employ staff to carry out the purposes of Sections 402.01 to 402.10 Minn. St.

3) Deliver services directly or through contract with other government and non-government providers.

4) Develop a plan for the delivery of services, which shall include court services, public health services,

public assistance, mental retardation services (emphasis supplied), social services, mental health services, and other similar classification, and shall show evidence or participation in the development of the plan my major private sector providers

5) Receive and expend for the purposes of Sections 402. 01 to 402.10 funds from the departments of corrections, health and public welfare, or from other lawful source, including any government source.

Each county shall be subject to applicable requirements of law concerning funding, and to existing limitations upon the authority to levy taxes, for any particular program or service.

The departments of corrections, health, and public welfare shall provide funds from any grant or subsidy program on authorized source to the Human Resources Board, based upon a plan which satisfies the standards and regulations of the individual state agency, and which represents all subsidy money for human services which each agency commits to programs with county(ies) comprising the Human Services Board.

C. The Advisory Committee is appointed by the Human Services Board. The Committee may not have more than 25 persons serving three-year terms. The Chairman of the Advisory Committee shall be appointed by the Human Services Board, but shall not be a member of a county board.

The Advisory Committee shall be comprised of one-third members representative of those persons receiving services provided by the Human Services Board, up to one-third will be providers or employees of providers of services and must include representatives of private providers if such providers exist in the county(ies) establishing the Human Services Board. The remaining Advisory Committee shall represent the citizens of the county(ies).

The Advisory Committee must establish at least three permanent task forces to assist it in its functions: corrections, mental health services, and public health. Each task force shall be chaired by a member of the Advisory Committee, but membership in task forces is limited to individuals not being members of the Advisory Committee. Task Force membership shall be constituted to fulfill state agency requirements for receiving categorical funds. These Task Forces may replace those advisory bodies required by statute and regulation to advise county welfare boards and other

county and area boards.

The Human Services Board shall provide staff assistance to the Advisory Committee.

D. The Act permits, but does not require, the Commissioners of corrections, public health and public welfare, to delegate any duty, authority, or responsibility vested in their respective department relative to any service or program presently provided by the State to any Human Services Board which has in effect an approved plan for the affected program or service. This authority to delegate includes express authority to transfer to the Human Services Board that portion of any unexpected appropriation which represents a savings to the State Agency concerned by the virtue of being relieved of the duty, responsibility, or authority so delegated. However, no state employee shall be involuntarily terminated from employment by such transfer of funds. (emphasis supplied)

The delegation functions and the transfer of funds associated with that function are subject to the conditions that the Human Services Board maintain the applicable standards prescribed by the department making the delegation. If the Human Services Board fails to maintain the standards prescribed, both function and funds shall automatically revert to the agency which had so delegated them. The Act requires that the department concerned give the legislature (House appropriations and Senate finance) immediate notice of any transfer of funds.

E. The Act provides that County employees whose functions are consumed by a Human Services Board shall continue as employees of the Human Services Board without loss of seniority, status, or benefits and shall be subject to any merit or civil service system. Not later than 30 days after approval of plan and budget by affected state agencies, any county board Committee or Commission have authorities or duties in the areas designated by the Act [402.02 Subd. 2 Clause d] and no per diem or expense reimbursements for members shall be paid there after.

F. The State Planning Agency selects pilot study Human Service Board's for the development of plans and programs pursuant to the Act. A board need not be formally designated as a Human Service Board to qualify as a pilot study Board. Any board selected as a pilot shall receive financial assistance to plan its responsibilities, but no grant shall be made to an individual county. [402.08 amended Ch 234, Sec. 5 1974 S.L.].

XI. Federal Legislation as it Affects Delivery of Services to the Mentally Retarded (Developmentally Disabled)

A. General

There are literally scores of federal programs which provide for services either directly or indirectly to mentally retarded persons. These range in scope from a Presidential Commission on national policy and goals to local grant programs for specific research on individual problems of the retarded citizen. Basic federal legislation which impacts on mental retardation services can be categorized functionally (e.g., education, vocational rehabilitation, health care and treatment, etc.) or by purpose (e.g., research, training of personnel, contruction of facilities, comprehensive planning for needs and services, financial assistance to states and communities and cash subsidies to individuals.) Most of the federal legislative programs encompass both approaches.

The key features of federal programs are:

1) Commitment of state financial participation as a requirement to receiving federal funds.

2) Identification and designation of a state agency(ies) to be responsible for administering the program

3) Comprehensive review of existing or proposed State plans for implementing the federal program.

4) Detailed regulations for determining conditions under which federal funds will be granted, eligibility criteria for applicants, standards for qualification of state plans, and procedures for submitting applications for funds and/or services.

Following is a brief description of the major federal legislation concerning mental retardation services.

B. Developmental Disabilities Services and Facilities Construction Act of 1970 - PL91-517 (DDA)

The DDA is one of the most significant recent federal programs because:

1) It defines developmental disability broadly, as a disability at tributed to mental retardation, cere-

bral palsy, or other neurological handicapping condition of an individual found to be closely related to mental retardation or to require treatment similar to that required by mentally retarded individuals;

2) it recognizes the indefinitely continuing nature of developmental handicaps and the need for specialized services over an extended period of time in order to rehabilitate the developmentally disabled;

3) it authorizes funds for a number of services, particularly grants to states and developing and implementing comprehensive, continuing plans to service a broad range of the human needs of the develop mentally disabled throughout their lifetimes;

4) it mandates State-level review of many existing federal and state plans for services currently provided in order specifically to identify gaps in existing state services and to enable expansion of services to developmentally disabled groups not now receiving services (emphasis supplied). The DDA Regulations, 45CFR Part 614, Sec. 416.10 specifically require as a minimum State review of the following federally assisted programs, to determine the quality, scope, and extent of services being provided or to be provided to the developmentally disabled: Education for the Handicapped, Vocational Rehabilitation, Public Assistance, Medical Assistance, Social Services, Maternal and Child Health, Crippled Children Services, Comprehensive Health, Mental Health and Mental Retardation and other related programs such as Aging; and,

5. it expressly prohibits the use of federal DDA money to decrease the level of services to the developmentally disabled now provided by state or local levels (because the thrust of the DDA is to enable states to expand and improve services).

C. The Rehabilitation Act of 1973 - PL93-112

This newly enacted federal law replaces the Vocational Rehabilitation Act and extends the authorization of grants to states for vocational rehabilitation services with special emphasis on services to those with the most severe handicaps as defined in Sec. 7 Clause (12) of the Act, the term "severe handicap" means a disability which requires multiple

services over an extended period of time and results from "...cerebral palsy...mental retardation...multiple sclerosis...muscular dystrophy...neurological disorders including strokes and epliepsy... and any other disability specified by the Secretary,(DHEW) in regulations he shall prescribe].

The Act authorizes a number of programs but there are three which particularly affect services for the mentally retarded citizen; programs to:

1) develop and implement comprehensive and continuing State plans for meeting current and future needs for providing vocational rehabilitation services to handicapped individuals and to provide such services for the benefit of such individuals, serving first those with the most severe handicaps, so that they may prepare for and engage in gainful employment;

2) conduct a study to develop methods of providing rehabilitation services to meet current and future needs of handicapped individuals for whom a vocational goal is not possible or feasible so that they may improve their ability to live with greater independence and self-sufficiency;

3) initiate and expand services to groups of handicapped individuals (including those who are home bound or institutionalized) who have been underserved in the past; (emphasis supplied).

A major provision in the Rehabilitation Act of 1973 is the authorization for states to submit a consolidated rehabilitation plan which includes its developmental disabilities program (emphasis supplied) provided that the agency administering the DD program in the State concurs and the consolidated plan meets all the requirements of both the Developmental Disabilities Act and the Rehabilitation Act - the Secretary DHEW may approve such a consolidated plan or advise the State to submit separate plans.

The Act authorizes funds for the provision of basic rehabilitation services. These include: individual rehabilitation written programs? evaluation of rehabilitation potential, counseling guidance, referral and placement; training services including personal and vocational adjustment services and family services; physical and mental restoration services; trade necessities; transportation; technological aids and services; and, when provided to groups of individuals, such services may also include management

services, equipment and initial supplies, and construction or establishment of rehabilitation facilities.

The Act also provides funds for training rehabilitation personnel, construction and planning facilities, vocational training services, and established an affirmative action program for hiring, placing, and advancing of handicapped individuals in federal employment.

D. Elementary, Secondary and Other Education Amendments of 1969 - PL91-230

Elementary and Secondary Education Act of 1965 (ESEA), Title I, Section 1039a, para. 5, pertaining to the use of Title I funds by state agencies directly responsible for providing free public education for handicapped children (including M.R.) was amended to provide a formula for determining the maximum federal grant available to the agency and mandating that such funds shall only be used for pro-grams and projects, including acquisition of equipment and where necessary construction of school facilities, which are designed to meet the special education needs of such handicapped children [P.L. 91-230, Sec. 105(a)].

Da. ESSEA Title VI - Education of the Handicapped Act

This Act authorizes grants to states, under federally approved state plans, for the purpose of assisting states in the initiation, expansion, and improvement of programs and projects for the education of handicapped children (includes M.R.) at preschool, elementary, and secondary school levels. Sec. 613 provides that the State plan give satisfactory assurance that federal funds paid to the state under Part B. of the Act will be expended:

1) solely to initiate, expand, or improve programs and projects -

   a) which are designated to meet the special educational and related needs of handicapped children throughout the State,

   b) which are of sufficient size, scope, and quality taking into consideration the special educational needs of such handicapped children) as to give reasonable promise of substantial progress toward meeting those needs; and,

2) for the proper and efficient administration of the State plan including State leadership activities and consultative services), and for planning on the State and local level. The amount expended for such administration and planning is limited to 5% of the amount allotted to the State for any fiscal year or $100,000, whichever is greater. There are a number of other mandatory requirements for the State plan involving administrative and fiscal controls, annual reporting requirements, use of federal funds to supplement rather than supplant State, local and private funds used for education and related services to handicapped children, and significantly the following two provisions:

   a) Sec. 613, a(2) "requires that the State plan shall provide satisfactory assurance that, to the extent consistent with the number and location of handicapped children in the State who are enrolled in private elementary and secondary schools, provisions will be made for participation of such children in programs assisted or carried out under this part;" (i.e., Part B, Title VI)

   b) Sec. 613 (a) requires that any State desiring to receive grants under Part B Title VI shall submit the State plan through its State educational agency to the U.S. Commissioner of Education, and that the State plan not be part of any other plan. (emphasis supplied)

This latter requirement strongly suggests that the State educational plan, thought tied to State Developmental Disabilities Act and Rehabilitation Act plan submissions, must remain a separate and distinct entity.

Part C of Title VI, ESSRA provides funds for establishing experimental projects and programs such as regional resource centers and services for deaf-blind children, and research activities to identify the special needs of handicapped children, develop or demonstrate new or improved methods which contribute to the adjustment and education of such children, training of professional and allied personnel engaged in or preparing to engage in programs specifically designed for such children, and dissemination of materials and information about practices found effective in working with such children. Moreover, Sec. 623 specifically authorizes the U.S. Commissioner of Education to arrange by contract, grant, or otherwise with public agencies and private non-

profit organizations for "the development and carrying out by such agencies and organizations" (emphasis supplied) of experimental preschool and early education programs for handicapped children - throughout the nation and in both rural and urban areas - including activities and services designed to:

1) facilitate the intellectual, emotional, physical, mental, social and language development of such children,

2) encourage the participation of the parents of such children in the development and operation of such programs;

3) acquaint the community to be served by any such programs with the problems and potentialities of such children; the federal government may pay up to 90% of the cost of developing, carrying out, or evaluation of such programs.

E. Social Security Act of 1935 as Amended:

Developmentally disabled are included in Social Security programs to the extend that they are needy and qualify under eligibility financial requirements, as determined by • either State or county definitions of "financial need." Such programs include:

1) Title XVI Supplemental Security Income for the Aged, Blind, and Disabled - PL92-603.

2) Title XIX Medical Assistance PL91-56.

3) Title V - Maternal and Child Health and Crippled Childrens Services PL90-248.

4) Title IVA Aid and Services to Needy Families with Dependent Children - AFDC PL90-248.

5) Title IVB Child Welfare Services PL90-248

Attached is Appendix 1, a Directory of Federal Program for the Handicapped, 1971, as it was entered into the Congressional Record by Senator Robert H. Dole.

Attached is Appendix 2, pertinent excerpts from the DEO Federal Catalog of Domestic Assistance Programs, detailing the programs available as of June 1972, to implement the federal legislation intended to service mentally retarded and other handicapped or developmentally disabled.

APPENDIX B

PLANNING AGENCIES

1. Association of Residence for the Retarded of Minnesota
2. Department of Special Education, University of Minnesota
3. Dowling School Parent-Teacher Association
4. Emerson School Parent-Teacher Association
5. Mental Health-Mental Retardation Area Program
6. Metro Council Developmental Disabilities Council.
7. Minneapolis Association for Retarded Citizens
8. Minnesota Administrators of Special Education
9. Minnesota Association for Retarded Children, Inc.
10. Minnesota Commission on the Handicapped
11. Minnesota Department of Public Welfare
12. Minnesota Division of Vocational Rehabilitation
13. Minnesota Office of Developmental Disabilities
14. North Minneapolis Association for the Retarded
15. St. Mary's Junior College - Human Services Program
16. School Districts (See Appendix B-7)
17. Suburban Hennepin County Area Vo-Tech Schools, Dist. 2 87
18. West Metro - Special Education Council

DIRECT SERVICE AGENCIES

1. Abiding Savior Lutheran Church
2. All Saints Nursery School for Exceptional Children
3. Anoka County Association for Retarded Children

4. Anoka County Day Activity Center
5. Anoka/Hennepin School District #11
6. Annunciation Catholic Church
7. Assumption CCD School of Religion
8. Big Brothers, Inc.
9. Big Sisters Association, Inc.
10. Blaine Recreation Department
11. Bloomington City Health Department
12. Bloomington Recreation Department
13. Boy Scouts of America
14. Brooklyn Buddies
15. Brooklyn Park Parks & Recreation Department
16. Camp Friendship
17. Camp Indian Chief
18. Calvery Lutheran Church of Golden Valley
19. Catholic Welfare Services of Minneapolis
20. Cerebral Palsy Clinic - Fairview Hospital
21. Charles Bronstein Home
22. Christ Lutheran Church
23. Christ Memorial M.R. Recreation Program
24. Christ the King Lutheran Church
25. Clara Doerr Residence
26. Clinton Club
27. Columbia Heights Recreation Department
28. Combined Nursing Services of Minneapolis
29. Community Involvement Program
30. Community Living, Inc.

31. Concerned Parents of Retarded
32. Congregational Church
33. Cooperative School - Rehabilitation Center
34. Crystal Recreation Department
35. Curative Therapeutic Pre-school
36. Day Activity Centers Association
37. Deaconess Hospital - Family Health Program
38. Diamond Skippers and Spinners
39. Dowling School for Crippled Children
40. Edina Recreation Department
41. Elim Lutheran Church
42. Epiphany Church of Coon Rapids
43. Forest View Children's Home
44. Foster Grandparents Program
45. Fraser School, Inc.
46. Fridley Recreation Department
47. Girl Scouts of America
48. Golden Valley Recreation Department
49. Goodwill Industries of Minneapolis
50. Hammer School
51. Hastings State Hospital
52. Hennepin County General Hospital
53. Hennepin County Welfare Department
54. Holy Cross Learning Center
55. Holy Nativity Lutheran Church - D.A.C.
56. Holy Trinity Lutheran Church - D.A.C.
57. Homecrafters

APPENDIX B-4

58. Homeward Bound, Inc.

59. Hopkins/Minnetonka Recreation Department

60. Jewish Family and Children's Service

61. Jewish Vocational Office

62. Kenny Rehabilitation Institute

63. Legal Advocacy for the Developmental Disabled of Minnesota

64. Legal Aid Clinic - University of Minnesota Law School

65. Legal Assistance to Minnesota Prisoners

66. Lutheran Church of the Redemption

67. Lutheran Social Services of Minnesota

68. Metropolitan Center for the Retarded

69. Minneapolis Hearing Society

70. Minneapolis Parks and Recreation Board

71. Minneapolis Public Schools - Psychological Services

72. Minneapolis Public Schools - School Rehabilitation Center

73. Minneapolis Rehabilitation Center

74. Minneapolis Society for the Blind

75. Minnesota Academy of Seizure Rehabilitation

76. Minnesota Association for Retarded Children

77. Minnesota Department of Public Welfare

    Administrative Section Division of
    Medical Assistance Division of Public
    Assistance Division of Rehabilitative
    Service Division of Retardation Services
    Division of Social Services

78. Minnesota Department of Health District Offices

79. Minnesota Learning Center - Brainerd State Hospital Campus

80. Minnetonka Child Psychiatric Clinic and Day Hospital

81. Mount Olivet Lutheran Church

82. Mount Olivet Rolling Acres

83. Muscular Dystrophy Association of America, Inc.

84. New Hope Park and Recreation Department - KID STUFF

85. New Hope Park and Recreation Department

86. North Minneapolis Association for Retarded

87. Northside Swingers

88. Outreach Community Center, Inc.

89. Opportunity Workshop

90. Opportunity Workshop Work Activity Center

91. Our Lady of Grace

92. our Saviour's Lutheran Church

93. Parkway United Church of Christ

94. Pillsbury-Waite Cultural Arts Center

95. Planned Parenthood of Minnesota

96. Plymouth Recreation Department

97. Reubin Lindh Learning Center

98. Richfield Lutheran Church

99. Richfield Parks and Recreation Department

100. RISE, Inc.

101. St. David's Day Activity Center - Episcopal Church

102. St. Helena Church

103. St. Josephs Church of Hopkins

104. St. Luke's Episcopal Parish

105. St. Louis Park Recreation Department

106. St. Matthew Lutheran Church

107. St. Raphael's Church

108. St. Stephen's Catholic Church

109. St. Timothy's Catholic Church

110. School for Social Development, Inc.

111. Sheltering Arms, Inc.

112. Southside Minneapolis Association for Retarded Children

113. Special Children's Recreation Association

114. Spring Lake Park Recreation Department

115. State of Minnesota, Department of Manpower Services

116. State of Minnesota, Division of Vocational Rehabilitation

117. Suburban Public Health Nursing Service

118. Suburban Recreation Association

119. Swimming Classes - MARC

120. Tasks Unlimited, Inc.

121. Tonka Teens

122. Twin Cities Opportunities Industrialization Center, Inc.

123. United Cerebral Palsy of Minneapolis

124. University Lutheran Church of Hope and Andrew Presbyterian

125. University of Minnesota Hospitals

Division of Child Psychiatry Division of Health Care Psychology

126. University of Minnesota - Psycho-Education Center

127. United Church Women of Greater Minneapolis - GADABOUTS

128. Washburn Child Guidance Center

129. Wesly Methodist Church - Sunshine Inn Cold Group

130. Westminister Presbyterian Church - In Group

131. Youth Minnesota Association for Retarded Children

132. Volunteers of America

133. Zion Lutheran Church

APPENDIX B-7
SCHOOL DISTRICTS

1. Anoka #11
2. Bloomington #2 71
3. Brooklyn Center #286
4. Burnsville #191
5. Chaska #112
6. Columbia Heights #13
7. Edina #273
8. Golden Valley #275
9. Voc-Tech District #287
10. Hopkins #274
11. Minneapolis Special School District #1
12. Minnetonka #276
13. Mound #277
14. Moundsview #621
15. Orono #278
16. Osseo #279
17. Richfield #280
18. Robbinsdale #281
19. St. Anthony Village #282
20. St. Louis Park #283
21. Spring Lake Park #16
22. Wayzata #284

COMMUNITY HEALTH AND WELFARE COUNCIL OF HENNEPIN COUNTY, INC.
STUDY OF SERVICES TO MENTALLY RETARDED PERSONS
AGENCY QUESTIONNAIRE

ORGANIZATION _____

APPENDIX C

SERVICES	TOTAL	ACTIVITY PROGRAM FOR ADULTS	BASIC DEVELOPMENTAL SERVICES FOR CHILDREN	CASE MANAGEMENT (SERVICE MANAGEMENT)	COUNSELING	DIAGNOSTIC SERVICES	DOMICILIARY CARE	EVALUATION SERVICES	FAMILY SUPPORT SERVICES (COUNSELING)	FOLLOW ALONG	INFORMATION & REFERRAL (PROFESSIONAL USE)	INFORMATION & REFERRAL (CLIENT USE)	JOB PLACEMENT SERVICES	PERSONAL CARE SERVICES	PROTECTIVE SERVICES	RECREATIONAL SERVICES	SERVICE COORDINATION	SHELTERED EMPLOYMENT	SPECIAL EDUCATION	SPECIAL LIVING ARRANGEMENTS	TRAINING SERVICES	TRANSPORTATION SERVICES	TREATMENT SERVICES	VOCATIONAL SERVICES	WORK ACTIVITY	WORK ADJUSTMENT
1. Number of clients served in year:																										
Pre-School																										
School Age																										
Post School																										
Retirement Age																										
2. What are your elibilitity requirements?		PLEASE SEND US A COPY OF YOUR ELIGIBILITY REQUIREMENTS FOR EACH SERVICE RENDERED.																								
3. a) How many applicants were you not able to serve?																										
b) What were the reasons?																										
c) What do you do with the applicants you're unable to serve?																										
4. a) How many clients have you terminated during the last year?																										
b) What were the reasons?																										
c) What do you do with the clients you have terminated?																										

SERVICES	TOTAL	ACTIVITY PROGRAM FOR ADULTS	BASIC DEVELOPMENTAL SERVICES FOR CHILDREN	CASE MANAGEMENT (SERVICE MANAGEMENT)	COUNSELING	DIAGNOSTIC SERVICES	DOMICILIARY CARE	EVALUATION SERVICES	FAMILY SUPPORT SERVICES (COUNSELING)	FOLLOW ALONG	INFORMATION & REFERRAL (PROFESSIONAL USE)	INFORMATION & REFERRAL (CLIENT USE)	JOB PLACEMENT SERVICES	PERSONAL CARE SERVICES	PROTECTIVE SERVICES	RECREATIONAL SERVICES	SERVICE COORDINATOR	SHELTERED EMPLOYMENT	SPECIAL EDUCATION	SPECIAL LIVING ARRANGEMENTS	TRAINING SERVICES	TRANSPORTATION SERVICES	TREATMENT SERVICES	VOCATIONAL EVALUATION	WORK ACTIVITY	WORK ADJUSTMENT
5. From What sources do you receive funds?																										
CITY																										
STATE																										
COUNTY																										
Voluntary-Private																										
Fees																										
Other																										
6. Answer this question ONLY if you are a funding source What funds do you provide? (amount by service)																										
7. Staff/Client Ratio																										

8. Do you offer systematic In-Service training for your staff?
____Yes ____No - If Yes, Describe:

9. Indicate level of staff training by number of staff in each catagory:

Education	Experience in Years 0 - 2	3 -5	6 and Over
0 - 12 Years			
13 - 15 Years			
College Graduate			
Graduate Degree			

APPENDIX C-2

SERVICES

ACTIVITY PROGRAM FOR AGING
ADVOCACY
COMMUNITY EDUCATION
CORRESPONDENCE EDUCATION
BASIC DEVELOPMENTAL SERVICES FOR CITIZEN
CASE MANAGEMENT (SER. SITE MANAGEMENT)
COUNSELING
DIAGNOSTIC SERVICES
DOMICILIARY CARE
EVALUATION SERVICES
FAMILY SUPPORT SERVICES (COUNSELING)
FOSTER HOMES
INFORMATION & REFERRAL (PROFESSIONAL USE)
INFORMATION & REFERRAL (CLIENT USE)
JOB PLACEMENT SERVICES
PERSONAL CARE SERVICES
PROTECTIVE SERVICES
RECREATIONAL SERVICES
RESPITE CARE
SHELTERED EMPLOYMENT
SPECIAL EDUCATION
SPECIAL LIVING ARRANGEMENTS
TRANSITIONAL SERVICES
TRANSPORTATION SERVICES
TREATMENT SERVICES
VOCATIONAL SERVICES
WORK ACTIVITY
WORK ADJUSTMENT

10. Which of the above listed services are in greatest need of development? (Rank order your answers - one being the greatest need).

11. Whether or not you offer the services, which of the above listed services do you feel are most appropriate for your agency to provide? (Rank order your answers - one being most appropriate).

12. Which of the above listed services do you feel is least appropriate for your agency to provide? (Rank order your answers - one being least appropriate).

13. Where is it most logical to invest the responsibility for delivering the above listed services? (Please check by service the appropriate responsible agency).

	PUBLIC	Health	Education	Welfare	VOLUNTARY/NON-PROFIT	PRIVATE
ACTIVITY PROGRAM FOR AGING						
ADVOCACY						
COMMUNITY EDUCATION						
CORRESPONDENCE EDUCATION						
BASIC DEVELOPMENTAL SERVICES FOR CITIZEN						
CASE MANAGEMENT (SER. SITE MANAGEMENT)						
COUNSELING						
DIAGNOSTIC SERVICES						
DOMICILIARY CARE						
EVALUATION SERVICES						
FAMILY SUPPORT SERVICES (COUNSELING)						
FOSTER HOMES						
INFORMATION & REFERRAL (PROFESSIONAL USE)						
INFORMATION & REFERRAL (CLIENT USE)						
JOB PLACEMENT SERVICES						
PERSONAL CARE SERVICES						
PROTECTIVE SERVICES						
RECREATIONAL SERVICES						
RESPITE CARE						
SHELTERED EMPLOYMENT						
SPECIAL EDUCATION						
SPECIAL LIVING ARRANGEMENTS						
TRANSITIONAL SERVICES						
TRANSPORTATION SERVICES						
TREATMENT SERVICES						
VOCATIONAL SERVICES						
WORK ACTIVITY						
WORK ADJUSTMENT						

14. If you could redesign the total delivery system of services for mentally retarded citizens, how would you do it?

PLEASE RETURN THIS QUESTIONNAIRE TO THE:

COMMUNITY HEALTH AND WELFARE COUNCIL OF HENNEPIN COUNTY, INC.
404 SOUTH 8TH STREET
MINNEAPOLIS, MINNESOTA 55404

RESPONDENT'S NAME _____

APPENDIX C-3

APPENDIX D

COMMUNITY HEALTH AND WELFARE COUNCIL

STUDY OF PLANNING SERVICES FOR MENTALLY RETARDED PERSONS

Name of Organization _____

1. Identify agency structure: (may check more than one answer)

   a. _____ Voluntary/non profit corporation
   b. _____ Private
   c. _____ Governmental
   d. _____ Other, explain:
   _____
   _____
   e. _____ Independent
   f. _____ Division of another agency, identify:
   _____
   _____

2. Under what authority do you operate (i.e., federal statute, agency cooperative agreement, grassroots, etc.): _____
   _____
   _____

3. What are the agency's planning objectives: (attach printed copy if available) _____
   _____
   _____

4. Briefly explain agency's planning activities for last year. (Include active or recent committees, studies, grant applications, comprehensive plan, etc., related to services for mentally retarded persons).
   _____
   _____
   _____
   _____
   _____
   _____

5. What specific program or service developments have been the direct result of the agency's activities during the last year: _____
   _____
   _____
   _____
   _____
   _____
   _____

6. What are the agency's funding sources and amounts. (Identify specific department or title).

a. Federal _____

b. State _____

c. County _____

d. City _____

e. Voluntary _____

f. Fees _____

g. Other _____

7. What is the level of staff training in your agency. (Identify number of staff in each category).

Education	Experience in Years 0 - 2	2 - 5	5 and Over
Less than college degree			
College degree			
Graduate degree			

	SERVICES	ACTIVITY PROGRAM SERVICES	ADVOCACY	COMMUNITY EDUCATION	COMPREHENSIVE PLANNING	BASIC DIAGNOSTIC SERVICES	CASE DEVELOPMENT AND MANAGEMENT	CASE DEVELOPMENT (CASE-WORK) COUNSELING	DIAGNOSTIC SERVICES	LEGAL AID	SOCIALIZATION SERVICES	FAMILY SUPPORT SERVICES (HOMEMAKER)	FOLLOW ALONG	INFORMATION & REFERRAL (GENERAL USE)	INFORMATION & REFERRAL (SPECIAL USE)	JOB PLACEMENT SERVICES	PERSONAL CARE SERVICES	PROTECTIVE SERVICES	RECREATIONAL SERVICES	SERVICE COORDINATION	SHELTERED EMPLOYMENT	SPECIAL EDUCATION PROGRAM	SPECIAL LIVING ARRANGEMENTS	TRAINING SERVICES	TRANSPORTATION SERVICES	TREATMENT SERVICES	VOCATIONAL SERVICES	WORK ACTIVITY
8.	What funds do you provide to other agencies (identify by amount).																											
9.	Whether or not you offer the services, for which of the listed services do you feel it is most appropriate for your agency to provide?																											
10.	Whether or not you offer the services, for which of the listed services do you feel it is least appropriate for your agency to provide?																											
11.	Which of the listed services are in greatest need of development?																											
12.	Where is it most logical to invest responsibility for delivering the above listed services? (Please check by service the appropriate responsible agency).																											
	PUBLIC																											
	Health																											
	Education																											
	Welfare																											
	VOLUNTARY/NON-PROFIT																											
	PRIVATE																											

13. If you could redesign the total delivery system of services for mentally retarded citizens, how would you do it?

APPENDIX E

DEFINITIONS OF SERVICES

Activity Program for Adults	day care services
Basic Developmental Services for Children	day care services
Case Management	coordination of all resources for a client
Counseling	solution of specific problems
Diagnostic Services	identify presence, causes, complications of disability
Domiciliary Care	24-hour supervision, out-of-home living quarters self contained
Evaluation Services	develop an individual service program
Family Support Services	outreach to the home
Follow Along	life-long monitoring relationship
Information and Referral (Professional Use)	provide list of resources to professionals, referral, public information about problems
Information and Referral (Client Use)	Response to client's inquiry face to face or otherwise
Job Placement Services	assistance in securing and settling into employment

APPENDIX E-2

Personal Care Services	food, clothing, personal interaction, bodily care
Protective Services	guardianship - can be adjunt system to parental responsibility
Recreational Services	social expression, enjoyment constructive leisure
Service Coordination	Administrative coordination of community services (planning functions]
Sheltered Employment	protective employment
Special Education	knowledge and basic skills through secondary level
Special Living Arrangements	out-of-home living with supervision
Transportation Services	individuals to services, services to individuals
Training Services	daily living, social, personal skills as part of society
Treatment Services	treat cause, aggravations, complications of disability
Vocational Evaluation	assessment of worker characteristics and potential
Work Activity	minimal productive employment with social-learning program
Work Adjustment	preparation work habits, skills, attitudes, etc. needed for employment

APPENDIX F

COMMUNITY HEALTH AND WELFARE COUNCIL

MENTAL RETARDATION STUDY

PARENT QUESTIONNAIRE

PART I.

FOR PARENTS WITH CHILDREN UNDER 18 AND/OR THOSE STILL IN SCHOOL

1. Have you made use of any of the following facilities?

   a. _____ Daytime Activity Centers - source _____

   b. _____ Public School Programs - academic year _____
      summer _____

   c. _____ Private Day School Classes - source _____

   d. _____ Residential Care-Private - source _____

   e. _____ Residential Care-State Institution - source _____

   f. _____ Boarding Home Care - source _____

   g. _____ Temporary or Respite Care - source _____

   h. _____ Other _____

2. What diagnostic and medical services have you used for your child?

   a. Major sources of medical attention:

   _____Family physician only _____University Hospital

   _____General Hospital _____Medical Clinic

   _____Public health services _____Other

   b. Specialized medical services

   _____Receiving medication
   (for what condition?) _____
   _____

   _____Hearing - source _____
   _____Vision - source _____
   _____Special health problems _____
   (Please describe.) _____

APPENDIX F-2

c. Psychological services

_____Public School - source _____

_____Clinic/Hospital - source _____

_____Private - source _____

3. What social, community and recreational services has your child used?

a. _____Special Sunday School classes or church related programs.
source _____

b. _____Evening recreational programs.
source _____

c. _____Summer park program.
source _____

d. _____Summer day camp.
source _____

e. _____Summer residential camp.
source _____

f. _____Other special recreational programs. (swimming, gymnastics etc)
source _____

APPENDIX F-3

COMMUNITY HEALTH AND WELFARE COUNCIL

MENTAL RETARDATION STUDY

PARENT QUESTIONNAIRE

PART II.

FOR PARENTS WITH CHILDREN OVER 18 AND/OR THOSE NOT IN A SCHOOL PROGRAM

1. In what program is your child currently involved?

   a. _____ Competitive Employment - Job
   Through what source did he get the job? _____
   What transportation does he use to get to work?
   _____

   b. _____ Sheltered Employment
   Name of employer _____
   Length of time employed _____
   How was placement secured _____
   Transportation _____

   c. _____ Job Training
   Name of school/firm/center _____

2. If not employed or in training, what are your child's activities?
   _____
   _____

3. Where does your child live?

   a. _____ In family home
   b. _____ In a group home
   c. _____ Other (Please explain) _____

4. What social or recreation activities does he/she participate in within the community?
   _____
   _____

5. What does he/she do during their leisure time?
   _____
   _____

6. To what extent does your child move within his community independently?
   _____
   _____

7. To what extent does your child handle money independently? (make change, make all purchases, etc.)

PART III.
FOR ALL PARENTS

1. What services have you, as a parent, received?
   a. _____ Information about services - source _____
   b. _____ Interpretation of services - source _____
   c. _____ Counseling - source _____
   d. _____ Financial assistance - source _____
   e. _____ Other (Please explain) _____

Below is a list of services that are available in some form for mentally retarded persons. Please answer each question relating to the services which you have received.

2. Please give the services which you have received a rating showing what you thought about the service.

	Good	Ade-quate	Use-ful	Poor	In-Ade-quate	Not Help-ful	Not Avail-able	Not Appli-cable
Diagnostic Services								
Evaluation Services								
Counseling								
Information and Referral								
Education Services								
Training Services								
Daycare Services								
Residential Care								
Special Living Arrangements								
Treatment Services								
Personal Care Services								
Protective Services								
Recreation Services								
Follow Along								
Transportation								
Sheltered Employ-ment Services								
Work Activity								
Work Evaluation								
Skill Training								
Legal Services								
Financial Services								
Advocacy								

APPENDIX F-5

Question #3 - Which services listed below do you believe are in the greatest need of development? (rank by order of importance-one being of greatest need).

Question #4 - Who should be responsible for seeing that the services listed below are available? (Indicate by service -
PUBLIC
Health
Education
Welfare
VOLUNTARY/NON-PROFIT
PRIVATE)

	Question #3	Question #4
Diagnostic Services		
Evaluation		
Counseling		
Information and Referral		
Education Services		
Training Services		
Daycare Services		
Residential Care		
Special Living Arrangements		
Treatment Services		
Personal Care Services		
Protective Services		
Recreation Services		
Follow Along		
Transportation		
Sheltered Employment Services		
Work Activity		
Work Evaluation		
Skill Training		
Legal Services		
Financial Services		
Advocacy		

APPENDIX F-6

5. If you could redesign the total delivery system of services for mentally retarded citizens, how would you do it?

6. Additional Comment.