

THE NEED FOR RESIDENTIAL PLACEMENTS FOR THE
MENTALLY RETARDED IN MINNESOTA

INTRODUCTION

This memorandum reports several estimates of the need for community residential beds for the mentally retarded in Minnesota. In assessing need, we have tried to determine that number of beds which could and probably would be used to benefit retarded citizens of the State. We have therefore focused on probable demand for such services, and tried to identify sources of that demand. We have asked ourselves and our informants the following question: "If Minnesota were to provide community residential beds for all retarded persons who could reasonably be expected to use them, how many such beds would be utilized?"

We have consulted several sources in compiling this report: each source's estimate is given below, and includes (1) the number of residential beds considered necessary. (2) the growth necessary to meet this need, and (3) an explanation of how we derived each estimate. Finally, we offer our conclusion as to the best estimate.

This information was compiled and this memorandum written for three reasons. First, through informal contacts we had received widely varying estimates of the need for residential services for the retarded. It seemed logical to investigate these estimates to clarify the situation for ourselves, and to distribute our findings to inform all interested parties of each others' thoughts on the matter. Second, this information is a necessary input to planning. Since planning proceeds on assumptions and predictions of future conditions, widely varying estimates of need can result in very different policies. Comprehensive information and discussion of the factors involved here should be a valuable input to Area and Statewide planning bodies. Finally, information on future needs will be useful as background material elsewhere in this office's study of regulation of human service facilities, especially in evaluating the overall impact of regulation on the care delivery system for mentally retarded persons.

Governor's Planning Council
on Developmental Disabilities
Minnesota State Planning Council
300 Centennial Building
658 Cedar Street St. Minnesota 55155

POTENTIAL USE

An important factor in assessing the number of beds utilizable in the future is the potential use for MR residential services, that is, the number of people who can be expected to come forth and seek services. Potential use refers to the process by which people who previously were outside of and unknown to the residential care system come forth to obtain services from it. This process is exactly the same thing as the process commonly referred to as the "woodwork phenomenon." We have avoided this phrase lest it be construed as insulting to persons now seeking services or MR persons in general.

Potential use refers to the process by which people previously unknown to the care delivery system come to seek services from the system. Persons who come forth via this process are believed to have remained in relative obscurity due to ignorance, or because they believed that the system could not or would not do anything for them even if they attempted to avail themselves of it. Under circumstances of limited services and residential placements for MR persons, such an assumption is probably warranted. Knowledge of the existence of the system dispels ignorance, and knowledge that the system is expanding to accommodate larger numbers of people enhances the confidence of persons previously outside the system to the point that they now seek services from it. Undiagnosed and diagnosed MR persons now residing in nursing homes or other facilities constitute another source of MR persons who would seek services from an expanded delivery system.

THE ESTIMATES

A. The Estimate of the Minnesota House Appropriations Committee

The House Appropriations Committee of the Minnesota State Legislature draws on information from the President's Committee on Retardation for its premises and methodology. The President's Committee posits that 3% of the population is retarded, but that only 1% of the population is severely enough retarded to require services. Of these, only one-fifth require residential placement and services. Applied to the approximately

4,000,000 citizens of Minnesota, these percentages yield 120,000 retarded, 40,000 requiring services and 8,000 requiring residential care and services. According to the Appropriations Committee's sources, as of April, 1976, there were 6,016 MR persons in state hospitals and community facilities and another 667 persons in Skilled Nursing Facilities and general Intermediate Care Facilities. (These two types of facilities are generally known as nursing homes.)

Assuming that the MR population in state hospitals will not increase, the current data indicate that there is a need for 1,984 more community MR beds ($8,000 - 6,016 = 1,984$). The existing stock of MR beds will have to be expanded by 32.98% ($1,984 \div 6,016 = .3298$) to meet this need. These figures are shown in Table 1. One potential source of these beds is the conversion of SNF and ICF beds to ICF-MR beds, although this might prove to be a problem because the nursing homes are generally large and not readily adaptable to the programming and environmental needs of MR persons. The data indicate that there will be some 1,317 new persons ($8,000 - 6,016 - 667 = 1,317$) seeking services from the system.

B. The Estimate of the Department of Public Welfare Mental Retardation Program Division

Mr. Ardo Wrobel, Director of the DPW Division of Retardation Services, believes that by 1980 there should be 7,000 to 7,500 MR beds in the State. His estimate is obtained as follows: There are approximately 3,375 MR persons in the state hospitals, and about 3,000 more persons in community facilities for the retarded. There is a "waiting list" for placement in community residential facilities of 601 persons, of which an estimated 50% are in state hospitals. Adding 300 (the 50% of those on the waiting list who are not currently in residential facilities) to the previous figure gives 6,675 MR persons, and an allowance for 325 to 825 people latently coming forth to seek services makes up the balance of this estimate. This indicates that the number of people seeking placement will increase by between 4.9% ($325 \div 6,675 = .049$) and 12.4%. Correspondingly, the total number of beds will have to increase from the present 6,375 by 3.8% ($625 \div 6,375 \times 100 = 9.8$) to 17.6%. Mr. Wrobel believes that the potential use process has definitely slowed recently, and that this is an indication that it is nearing the end of its course,

In reaching this estimate, Mr. Wrobel considered several

factors. He wanted to be conservative and to avoid overbuilding of facilities and system capacity. Since current expansion is aimed primarily at the ambulatory, relatively uncomplicated mainstream of the MR population, he is specifically concerned that the community care delivery system will overdevelop its capacity to serve this group while ignoring groups with special needs.

Further, there is the potential problem that a large expansion of beds in the short run will result in excess capacity later. The system is intended to offer a continuum of levels of care and to move people within it as far toward normal living as possible. If the system works well, then a significant number of MR persons will move through and out of the supervised residential service stage of the system into independent living situations. There is no guarantee that there will be persons waiting to move into the vacated places on a continuous basis. Thus, it is possible that beds will lie empty. This problem is compounded by the possibility that facility operators may try to retain residents, however inappropriately, in order to keep themselves in business. These two considerations further mandate that care be taken to avoid overdevelopment of residential facilities.

Mr. Wrobel feels that the most appropriate course to follow is to allow development to about 7,500 total beds by 1980 and to exercise rigorous control in permitting development beyond that, to assure that gross excess capacity is not developed for any group of the MR population. An incorrect decision leading to a shortfall in construction of beds would be less costly and more easily rectified than one leading to significant over-construction.

To fulfill its responsibility of sound planning, the Department is in the process of promulgating Rule 185 relating to assessment of local need and planning for the development of facilities on a local basis. The Department now has the authority to approve or reject applications to operate MR facilities according to the overall needs of the system and the MR population; Rule 185 is intended to be the strong, clear rule necessary to back up the exercise of this discretionary authority. The successful implementation of this rule will depend on the efforts of the Area Boards.

Mr. Wrobel further believes that by the time the system has developed to a capacity of 7,000 beds, a rigorous process of review of applications to operate facilities must be established. As one element of that process, he advocates that applicants should

be required to specifically identify approximately 75% of their intended clientele. This is determined and obtained from Area Board Need Assessment and Plan documents, County Welfare Departments, and the waiting lists of existing facilities. The unidentified remainder of the facility's capacity would allow for people coming forth via the potential use process. This specific identification procedure in the need determination process will guard against over-building and also against arbitrary placement of persons.

A very important consideration is the distribution of total MR beds between state hospitals and community-based facilities. Mr. Wrobel estimates that there are roughly 1,800 persons who require the intensive and comprehensive care available only at very large institutions (i.e., state hospitals). Placing the rest in community facilities will require 2,200 to 2,700 new beds in community facilities in addition to the 3,000 currently licensed. (As of May, 1976 there were 1,991 beds licensed in certified community ICF-MR facilities and 898 in facilities licensed under DPW Rule 34 and funded by Cost of Care Grants for MR children, a total of 2,889 beds. The most recent update from the Technical Assistance Project staff showed 2,999 licensed beds in the State.)

Mr. Wrobel believes that the State should aim to achieve a total capacity slightly greater than (approximately 102% of) total need. Such a situation would enable the State and counties to put competitive pressure on all providers to upgrade quality, lest they lose referrals and thus be forced out of business. The idea here is to use the fact of slight excess capacity to provide an incentive to facility operators to deliver higher-quality services in order to obtain and keep (revenue-producing) residents.

To recapitulate, Mr. Wrobel does not disagree with our estimate, developed in F below, of 9,000 beds as total need for MR residential placements. He is uncertain whether it will be that great, but readily acknowledges that it may be. His argument is that the system should aim to develop to 7,500 total beds over the next four years, with development beyond that subject to rigorous scrutiny of the needs of the system and of the served population at that time. The key issues, as he sees them, are the course which the development of the system will take and the roles which responsible parties will play in directing that development.

Kathryn Roberts of the DPW Division of Retardation

Services is presently reviewing the Community Mental Health Area Boards assessments of need for MR residential services. Unfortunately, the data received from the Area Boards thus far are unreliable. Ms. Roberts generally agrees with the figure of 8,000 beds as an accurate estimate of required capacity for MR residential services.

Ms. Roberts voiced two concerns which are important here. The first is that indiscriminate development of facilities will have undesirable impact in that residents will be inappropriately placed in them. She is concerned that once residential placements are created, persons will be found to occupy them, even if their characteristics and needs are not appropriate to the services offered by the facility in which they are placed. This is likely to affect higher-functioning MR persons, including those coming forth via the potential use process, more seriously than other groups. For example, persons who would most appropriately be placed in apartment training programs or living entirely independently may be placed in group homes by social workers or coaxed into them by providers. Social workers and providers are likely to proceed on the premise that since there are beds, there must be persons to fill them. This underscores the need for sound planning by responsible parties.

Her second concern is over the absence of a monitoring mechanism to assure that persons in the system continue to progress through the continuum of care until they attain their highest level. Ms. Roberts is concerned that providers hold attitudes which are contrary to resident progress in accordance with the normalization principle, and that there is nothing in the present regulatory structure to assure that the spirit of that principle is observed.

C. The Estimate of the Metro Council

The Metro Council derived its estimate via the following reasoning. Three percent of the general population is mentally retarded. One-third of this three percent will need residential placement. The estimated population of the Metropolitan Area for 1975 is 1,927,600. One per cent of this yields the estimate of 19,276 persons needing residential services in the Metropolitan Area in 1975. Doubling this, which is standard procedure when extending population data for the Twin Cities to the entire State, yields an estimated need of 38,552 beds. Given the fact

there are 6,375 beds presently in service in the State, and assuming that the census of state hospitals will not increase, the apparent necessary growth is 504.7%, or 32,177 new community beds.

In fairness, it should be pointed out that the Metro Council did not make this extension, inasmuch as they are concerned only with the needs of the metropolitan area. We made the extension to show the implications of their estimate for the State. Furthermore, a straight doubling of the estimate for the metro area probably yields a high estimate for the State because the metro area tends to have a higher concentration of retarded persons owing to the concentration of major treatment centers there.

That 3% of the general population is retarded is a statistical, definitional fact based on IQ tests. Those who score in the third percentile or lower are defined as retarded. Many of these are borderline cases who live normal lives in society without ever requiring services of any kind. It appears that the Metro Council has confused the group who need residential placement with the group who require services of any kind. This confusion has caused the Council to err greatly on the high side of actual need (by a factor of four, roughly).

D. The Estimate of the St. Paul Association of Retarded Citizens

Mr. Bob Tuttle, Director of the St. Paul Association of Retarded Citizens (SPARC) agrees with our methodology in deriving the estimate given in E below. An advocate of community based residential services for the retarded, Mr. Tuttle says that 10,000 beds is the absolute maximum need for Minnesota. (This top-end estimate from an MR advocate is a very strong indication that the Metro Council's estimate is much too high.)

Important consideration must be given to the types of residential services provided and to the proper mix of services to best serve the MR population. Special needs cited by Mr. Tuttle are for mentally retarded-mentally ill teenagers and for physically handicapped, multiply involved children. These persons are presently inappropriately situated, either at home, in foster homes, or in child caring institutions. For this latter group, approximately 320 beds would be needed in the Twin Cities, and an additional 215 out-state. There is also a need to identify and relocate ME persons in nursing homes who are as yet undiagnosed. Though these special needs groups are mentioned here, the

overall point is that careful consideration must be given to the range of types of care required to serve the MR population appropriately.

E. A Synthetic Estimate

This estimate uses information from Dennis Bogen, MR Program Coordinator at Fergus Falls State Hospital, the Medical Assistance survey of MR persons and their placements in 1975, DPW, and internally generated assumptions. Mr. Bogen, via contacts with county social workers and welfare departments in the area served by Fergus Falls State Hospital, has a solid estimate of 3,000 known MR persons who have required services of some kind in that area. There are approximately 300 MR persons in the hospital. This indicates that approximately 10% of the known MR are in state hospitals. Roughly another 10% are in community facilities. This brings us, coincidentally, to the 20% figure cited by the President's Committee on Retardation.

Now, if approximately 20% of the known MR are in residential facilities, then the number of MR persons requiring services of any type is five times the number in facilities. That is, $\text{Number in Facilities} = .2 \times \text{Number Requiring Services}$, or $\text{Number Requiring Services} = \text{Number in Facilities} \times 5$. The 1975 Medical Assistance survey indicates that there are approximately 6,330 MR persons now in facilities. The DPW estimate as of May, 1976, is 6,375 persons. Adding the 300 who are awaiting residential placement to this latter figure yields 33,375 persons ($6,675 \times 5$) needing services of any sort, or 33,375 MR known to the care delivery system.

Next we consider some alternative assumptions of growth in potential use of residential services. If we allow that half again the number (50%) presently in facilities or awaiting residential placement will come forth as services become more readily available and residential placements more easily attainable, we arrive at an estimate of need of 10,013 beds ($6,675 \times 1.5$). Alternatively, assuming total growth of only 25% of the number currently in facilities or awaiting placement, we estimate a total need of 8,344 beds ($6,675 \times 1.25$). Table 1 summarizes the five estimates just presented.

F. Further Considerations: A Refined "Best" Estimate

There are several factors affecting the number of people expected to come forth from the potential use group and seek placement in residential facilities. Operating to limit the number still to come forth is the fact that Minnesota, relative to the rest of the U.S., is more committed to quality care for the MR and has better-developed funding and administrative institutions through which to fulfill its commitment. Medical Assistance (via Title XIX of the Social Security Act) pays for adults and eligible children in ICF-MR facilities and State Cost of Care Grants pay for MR children who are not eligible for aid via Title XIX funds. The point to be made here is that it is relatively easy for MR persons to receive care in Minnesota; given this relative ease, it could be expected that most persons requiring care will already have come forth to seek it.

Three main factors operate to expand the number of MR persons who will seek residential services: First, there are very probably a significant number of undiagnosed and/or inappropriately placed MR persons in nursing homes, foster homes and child caring institutions who will be identified as the overall MR care delivery system is expanded. Second, there are unidentified persons either living at home with parents or living marginally or sub-marginally in society who can benefit from placement in a community residential facility. The absence of placements and services and ignorance of opportunities for such services will have limited those seeking them in the past. Further dissemination of information and seeking out of those who could benefit from residential services by public and private medical and social agents will expand the number of MR seeking residential care. Finally, there are some MR who will seek temporary placement in residential facilities. These are generally known as "respite care" residents or clients. The time period involved with this category can vary from one week up to six months. There are two classes of respite care: The first is care intended to give the parents or caretakers of persons living at home a break from the intensive effort they must put forth for their MR children, or to provide parents with free time necessary to manage an emergency in the household. The second type is residential placement for specific, short-term training. On balance, we believe that these expansionary factors will outweigh those tending to limit the number of persons seeking residential services.

Current opinion has it that maintaining an inventory

state hospitals and community residential facilities. This is a question which must be addressed by further study.

All of the estimates except that of the Metro Council are in the range of 7,000 to barely over 10,000 beds.

Special attention must be paid to the needs of the various care groups within the overall MR population. This does not mean that priority should be assigned to "special needs" groups, but that there are numerous groups with different care needs and that these differences must be considered in planning the mix of programs and facilities for the MR in Minnesota. Further study along these lines is warranted. Furthermore, future study will have to take account of different conditions of need and system capacity in specific geographic regions of the State.

CONCLUSIONS AND RECOMMENDATIONS

We conclude that 9,000 beds could be utilized to significant benefit by mentally retarded persons in Minnesota by 1980. We believe that this takes fair account of natural growth due to population increase, expansion of the number seeking services via the potential use phenomenon and relocation of those now inappropriately placed.

Special attention must be paid to conditions of need and system capacity both for specific needs sub-groups of the total MR population and also for specific geographic areas. The attitude that all applications to operate MR facilities must be approved will have to be replaced with more specific planning goals and policies as specific geographic and care-type niches in the delivery system become filled. The variation in observed regional population growth rates highlights this point. Between 1970 and 1975, these rates varied from -1% for Region 6W to +18.3% for Region 7E. Also, with the current emphasis on expansion for special needs groups, it is likely that program capacity for persons with certain special needs will be reached relatively soon. Planners must heed these factors in setting priorities for further development of the system. In some cases, they must begin to set priorities and to promote actively the development of residential services in areas not adequately served under the present regime of general, permissive policies.

This need for specific planning cannot be stressed

strongly enough. The consequences of failure to meet it are not only the potential waste and inefficiency of surplus beds, but also the injustice of inappropriate placement of MR persons. Responsible parties - the County Welfare Departments and their social workers, the Area Boards, providers, and the Department of Public Welfare - must act to assure sound planning and the appropriate, organized development of the care system for mentally retarded persons.

Finally, the experiences which led us to undertake this project lead us now to suggest better communications among relevant and interested parties to promote better coordination of the developing MR care system.