HOUSING THE UNSERVED MENTALLY RETARDED IN MASSACHUSETTS

by

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ABSTRACT

In recent years, legal obligations and reduced funding have limited the Massachusetts Department of Mental Health's ability to adequately service the mentally retarded. As a result, it is now believed that a large number of mentally retarded are in critical need of state housing assistance. These individuals include mentally retarded living with parents who are no longer able to care for them and mentally retarded living in inappropriate environments, such as mental institutions. Because of a lack of data, however, it is not known how many individuals require housing or what type of housing they need.

To assist the state in developing services for these individuals, this thesis presents information on which a housing plan can be based. A discussion of national and state issues that influence planning for the mentally retarded first sets the groundwork from which estimates can be developed. Following this, a methodology for developing estimates on the basis of incomplete and conflicting data is presented. This methodology uses both mental retardation prevalence rates and data from surveys or counts of the unserved to estimate the number in need of any form of state services by age, the number in need of housing by age, and the type of housing needed. Using these estimates, policy issues regarding who the state should serve and recommendations for housing the unserved mentally retarded are discussed.

The results of my analysis indicate that between 3,200 and 5,000 mentally retarded adults currently require DMH services. Approximately 2,500 of these require housing, with the majority needing independent living services or housing with light staff assistance. Estimates also indicate that between 9,200 and 16,500 mentally retarded children will be requiring services over the next twenty years. Between 5,800 and 9,700 of these will be requesting housing assistance at approximately the same rate that retarded adults will be leaving the DMH service system because of death or other circumstances. The majority of these children also require housing with only limited staff supervision. Thus, DMH plans should focus on this type of housing. In the first phase of planning, however, the state should also provide more specialized housing in order to address the needs of those with more severe disabilities.

Thesis Supervisor: J. Mark Davidson Schuster, Lecturer
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INTRODUCTION

In 1972, the first of several class action lawsuits was filed against the Commonwealth of Massachusetts on behalf of residents of state schools for the mentally retarded. Parents, guardians and advocates for the mentally retarded living in Belchertown state school were the first to claim that residents were not receiving care and treatment that met minimal constitutional requirements. Between the years 1972 and 1975, four other class action suits were filed against the state alleging similarly unconstitutional conditions at the remaining state schools.

In response to these suits, the state entered into consent decrees, legally binding agreements that protected all those who lived at the schools for thirty consecutive days on or after the date lawsuits were filed. In these decrees, the state agreed to renovate physical conditions, increase the number of staff and improve the quality of services at the schools. To control capital outlay costs, the state and plaintiffs further agreed that only a limited number of school beds would be renovated. The remaining need for beds would be met by moving some residents into smaller facilities in the community. (1)

In conjunction with consent decree plans, the state also decided to bring the schools and some community facilities into compliance with Title XIX (Medicaid) standards. These standards, in combination with consent decree mandates, regulate "staffing levels and policies, client rights, health and safety standards, program plans, and the provision of private and comfortable space" in state facilities for the mentally retarded. (2) By upgrading facilities to Title XIX standards, the state would receive federal reimbursement for about 50% of the costs of
treating eligible clients and 50% of construction costs.(3)

Since the signing of consent decrees, the Massachusetts Department of Mental Health, Division of Mental Retardation (DMH/MR) has been struggling to implement the state's plan for school renovations and community placements. This process, however, has not proceeded smoothly. DMH's efforts to develop or sponsor residences in the community, for example, soon met with local resistance, and sites for community placements became hard to find. In addition, "concerns were raised about the quality and scope of community services" since most new programs were operated by private or non-profit vendors rather than the state.(4)

Legislative frustration with the high costs of bringing facilities into compliance with Title XIX and consent decree mandates further slowed the process. Unhappy with the expense of renovations and new construction, the legislature funded no additional capital improvements for the schools and no new community programs in fiscal years 1982 and 1983. In fiscal year 1984, funding was appropriated for only eighty community placements.(5)

As a result of these problems, DMH fell behind in its schedule for meeting both consent decree and Title XIX requirements. This, in turn, led to further outside involvement in DMH planning and to further complications. Following a personal inspection of the schools in 1983, U.S. Secretary of Health and Human Services Margaret Heckler, threatened to cut off federal reimbursements for the schools if they were not brought into full compliance with Title XIX soon. The Judge responsible for overseeing consent decrees also indicated that court involvement in the operations of schools would continue until consent decree and Title XIX mandates were met. Meanwhile, the plaintiffs in the class action
suits became increasingly frustrated and convinced that the state was incapable of addressing its responsibilities in a timely fashion.

The result of these circumstances was the development of a "dual system of care" for the mentally retarded, that is, care provided on one level for those who are protected by consent decrees ("class clients"), and on another level for those who are not ("non-class clients"). Because of difficulties in meeting consent decree agreements, DMH has been unable to adequately address the service needs of non-class clients. Since the signing of consent decrees, most of the funding appropriated to DMH has been for class clients only, and no new residents have been admitted to the state schools. DMH attempted to address this problem by admitting non-class clients to regional centers, which are not covered under the decrees. However, space in these facilities is limited. While developing new community residences under consent decrees, DMH also attempted to initiate an "80-20" policy whereby 20% of all new community beds would be allocated to non-class clients. This policy, however, was cut short as community opposition and reduced funding limited DMH's ability to provide even enough beds for class clients.

This dual system of care has persisted, in part, because of the state's legal obligations under consent decrees. According to these decrees, class clients have "special eligibility" for DMH/MR services. As a result, if class clients need services that are not currently available, the state must fund and create services on their behalf. There is no such obligation, however, for persons who are not protected under the decrees. The provision of services to non-class clients is instead dependent on the results of screening assessments, the determination of need by DMH Area Directors, and the availability of needed services.(6)
In recent years, DMH has been widely criticized for neglecting the needs of non-class clients. Parents, who chose to care for their children at home prior to the class action suits, now feel they are being punished for having done so. Having endured the emotional and financial difficulties of providing for a disabled child, many of these parents now require state assistance. They are, however, frustrated by long waiting lists for a limited amount of DMH/MR services. The situation of these parents is the topic of frequent debate in the Commonwealth and was the focus of a report to the state legislature's Committee on Human Services and Elderly Affairs which argued:

The current policy punishes those families who have initially accepted responsibility for their mentally retarded child instead of rewarding them. This is unjust because these families have done the State a service. Institutionalization in a state school for retardation is currently estimated by the Department of Mental Health to have an annual operational cost of about $41,000 for each mentally retarded individual. By keeping their children at home and having them attend public schools instead of institutionalizing them in a state school, it has cost the State a minimal amount. 

In addition to leaving the retarded at home without adequate services, DMH's lack of attention to non-class clients may also have caused some to be placed in inappropriate environments outside the home. A current item of controversy, for example, concerns mentally retarded who were placed in nursing homes after admissions to state schools were closed. According to their families, these individuals are receiving services inferior to those available at the schools, and are losing important skills and opportunities as a result. Similar claims are made with respect to retarded residents of state mental institutions. DMH itself acknowledges that these individuals are not receiving adequate services and recently established a special task force to evaluate and
address their needs.

Wherever they now live, the greatest service need of non-class clients is for placement in DMH/MR facilities. This need is reflected in DMH/MR waiting lists, which indicate that 68% of those requesting Department services require housing assistance. A survey of students in state special education programs, many of whom live at home, also indicates that 66% will need specialized housing upon graduation. The demand for housing among those living at home is further evidenced in a study of parents of retarded adults. According to this study, "more than half of the parents [surveyed] indicated that the one service they most wanted was a group home or supervised apartment for their adult offspring...."(8)

This year DMH has once again received substantial funding from the legislature and many are looking to the Department for increased services to non-class clients. Included in this funding appropriation was $79.5 million for the renovation of state schools and the establishment of community residences for the retarded. This funding is considered to be sufficient to meet all consent decree and Title XIX requirements. In addition, the Fiscal Year 1983 capital budget allocation provided $18 million to the Executive Office of Communities and Development (EOCD) for the development of "alternative model community residences for...plaintiff class members of certain consent decrees...and...other appropriate handicapped persons who are not class clients...."(9) It is this latter amount that will be used to address the housing needs of non-class clients, once the terms of consent decree mandates are met.

Unfortunately, it will not be easy to develop a housing plan for unserved mentally retarded individuals. Despite strong support and
adequate funding for such an effort, there is not a wealth of data on
which such a plan could be based. Further, what little information that
is available tends to be incomplete, out of date, or, in some cases,
baised by the political perspectives of those who collected the
information. Thus, DMH does not know with any certainty how many non-
class clients require state services, or the type of services they
require.

To assist the state in its planning, this report presents
information on which a housing plan for unserved non-class mentally
retarded individuals can be based. This report addresses (1) how many
mentally retarded persons require state services, (2) how many of these
require housing services, (3) what type of housing they need, and (4)
when they will need it. The report also sets forth a methodology for
developing estimates on the basis of inadequate and conflicting data. The
estimates derived are then used to evaluate three options the state could
pursue in housing the unserved.

This report begins with a discussion of the various issues that must
be considered in estimating the unserved mentally retarded population.
Chapter One addresses both national and state issues that influence
planning for the mentally retarded in order to help DMH understand the
implications of various approaches to the problem. In the second chapter
a methodology for estimating the number of unserved mentally retarded
individuals and their service needs is developed. This methodology uses
both mental retardation prevalence rates and and data from surveys or
approximate counts of the unserved to estimate the number in need of
state services, the number in need of services by age and the number in
need of housing by age. In the third chapter, these estimates are further
broken down according to the type of housing the unserved mentally retarded require. Policy issues regarding who the state should serve are discussed in the final chapter and recommendations for housing the unserved mentally retarded are presented.

(2) Massachusetts Department of Mental Health, Division of Mental Retardation. Orientation to the Mental Retardation Service System "Fact Sheet: State School" (Boston: Massachusetts Department of Mental Health, no date) p. 1.


(5) Frank T. Keefe, Secretary, Massachusetts Executive Office of Administration and Finance. Letter to Chester G. Atkins, Chairman, Massachusetts Senate Ways and Means Committee and Michael C. Creedon, Chairman, Massachusetts House Ways and Means Committee (Boston, September 26, 1983).

(6) Massachusetts Department of Mental Health, Division of Mental Retardation. Department of Mental Health Mental Retardation Regulations 104 CMR 20.00 - 23.00 (Boston: Massachusetts Department of Mental Health, 1979) Sections 21.07-21.09, pp. 5-6.


ISSUES IN ESTIMATING THE MENTALLY RETARDED POPULATION
When the President's Committee on Mental Retardation reported its findings in 1977, it cited five methods of estimating the number of mentally retarded living in the United States. Each of these methods implied different conclusions as to the prevalence of retardation among different age and income groups. Adding further to the complexity, the Committee noted differences in the definition and diagnosis of mental retardation which also influence estimates of this population. As a result of these difficulties, the Committee concluded its report with only a tentative estimate of the size of the retarded population and a call for more research on the subject.(1)

Estimating the number of mentally retarded in need of services is even more problematic. On the state level, estimates of the unserved differ according to which definition of mental retardation is used and how the population is studied. But, even if the same definition were employed, estimates would still diverge because of differences in the way agencies serving the retarded define the term "unserved." Because there is a lack of data on the unserved mentally retarded population, these differences are not easily resolved.

The Massachusetts Department of Mental Health currently needs to begin planning for the unserved mentally retarded. As a result of difficulties in meeting consent decree mandates, it is now believed that a large portion of the state's mentally retarded are in critical need of services. Yet, the inability to estimate the number in need and the type of services they require is a serious barrier to the provision of appropriate services. Without this information, the state cannot engage in effective planning on behalf of unserved non-class mentally retarded clients.
This chapter sets the groundwork from which estimates of mentally retarded service needs can be developed. Because the estimation process is not straightforward, the state must understand the various ways in which the problem can be approached. With this background, and a sense of the way different assumptions can affect the estimate, DMH will be better able to develop its own estimates.

ISSUES IN ESTIMATING THE NUMBER OF MENTALLY RETARDED RESIDING IN THE STATE OR NATION

Definitions of Mental Retardation

Perhaps the most important issue in the field of mental retardation is that of how the condition should be defined and diagnosed. While it is generally agreed that mental retardation involves some kind of intellectual deficit, professionals disagree on how this deficit can be measured. Because of this disagreement, three different measures are currently used to determine the presence of mental retardation. These measures and the definitions that they lead to are discussed below.

(1) Measures of Intelligence

Intelligence tests are the most widely known and widely used method of detecting mental retardation. The mean score on these tests is 100, and mental retardation is considered to be present if the score falls below 70 (three standard deviations below the mean). Among those with scores below 70, the degree of retardation is further defined by the range in which the score falls. While the exact range varies according to which test is used, an individual is generally considered to be mildly retarded if their score is 50-70; moderately retarded if 35-50; severely retarded if 20-35; and profoundly retarded if 0-20.
In recent years, the usefulness of IQ tests as a measure of intelligence has been widely questioned. This discussion has focused on the biases of the tests and their inability to measure actual intellectual ability. Because of these problems, intelligence tests are believed to identify proportionately more low income or minority persons as mentally retarded. This leads to an inflated estimate of the mentally retarded population. As a result, the use of intelligence tests as a single measure of retardation has diminished significantly.

(2) Measures of Adaptive Behavior

Problems with intelligence tests have led to the development of other methods of detecting and evaluating mental retardation. One of these assesses an individual's adaptive behavior, or "the way in which an individual performs those tasks expected of someone his age in his culture." For a child, expected adaptive behavior includes the ability to dress or attend school. For adults, appropriate adaptive behavior includes the ability to work or live independently.

In addition to overcoming the problems associated with intelligence tests, adaptive behavior assessments lead to a better understanding of mental retardation. Mental retardation is a complex condition involving not only intellectual deficits, but also behavioral problems and physical disabilities. Adaptive behavior evaluations, therefore, result in a more thorough understanding of an individual's abilities and needs. Adaptive behavior measures also assist in early diagnoses of mental retardation since behavioral, not intellectual, problems are the first symptoms recognized by parents.

An important user of adaptive behavior measures is the American Association on Mental Deficiency (AAMD). This organization sets a
standard for the way many professionals evaluate and treat the retarded.

The AAMD definition of mental retardation reads:

Mental Retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the development period.(7)

(3) Measures of Functional Disability

The AAMD definition was accepted by the majority of professionals in the field until 1978, when Amendments to the Developmental Disabilities Legislation (Public Law 95-602) were passed.(8) Although these amendments did not specifically refer to mental retardation, they did include a definition of developmental disabilities that changed the way in which these and other disabilities were viewed:

The term "developmental disability" means a severe, chronic disability of a person which:

(1) is attributable to a mental or physical impairment or combination of mental and physical impairment;

(2) is manifested before the person attains age 22;

(3) is likely to continue indefinitely;

(4) results in substantial functional limitations in three or more of the following areas of major life activity: (a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, (g) economic self-sufficiency;

(5) reflects the person's need for a combination of special interdisciplinary or generic care, treatment or other services which are (a) of lifelong or extended duration and (b) individually planned and coordinated.(9)

Public Law 95-602 changed the outlook on mental retardation by emphasizing the functional rather than categorical nature of disability. Prior to these amendments, disabilities were largely defined in terms of
diagnostic categories, e.g. epilepsy, cerebral palsy. Public Law 95-602 went beyond these categories to address the way disabilities affect an individual's ability to function in society. In so doing, the law considered not only the physical and mental status of the disabled, but also their economic and vocational capabilities. (10)

Even more important was the law's emphasis on the severity of disability and the need for services "which are of lifelong or extended duration." Under these requirements, the mere presence of mental retardation was not sufficient to establish eligibility for services, unless that condition also substantially limited an individual's ability to function throughout life.

The Developmental Disabilities Legislation of 1978 was written to direct limited federal dollars to those disabled with the most severe needs. (11) For the mentally retarded population, the legislation reduced the number eligible for services to the most severely and profoundly retarded. Because the law had this effect, its definition of disability has still not been accepted by all who work on behalf of the mentally retarded.

Estimates of the Prevalence of Mental Retardation

In mental health planning, a common procedure for estimating the number of mentally retarded in need of services is to use estimates of the prevalence or incidence of the condition. Prevalence refers to "the proportion of persons in a population who are considered mentally retarded at a given time," while incidence is "the frequency of occurrence of new cases of mental retardation." (12) These estimates are derived from epidemiological surveys and statistical approximations.
But, these surveys and approximations are necessarily influenced by the criteria used to detect and define mental retardation. Thus, like the definitions used to realize them, estimates of the prevalence or incidence of mental retardation are very controversial.

However, difficulties in realizing estimates of the mentally retarded are not solely the fault of differences in definitions of retardation. Mental retardation is a condition that is still not fully understood nor easily diagnosed. As a result, attempts to estimate its prevalence are hindered by a lack of information.

A good example of the difficulties of estimating the mentally retarded population lies in the history of the commonly used 3% prevalence rate. This estimate of the prevalence of mental retardation was first reported in 1959 and later gained national importance when it was employed by the President's Panel on Mental Retardation. The derivation and use of this estimate points to all the complexities resulting from how mental retardation is detected and defined.

The 3% estimate was derived by using intelligence tests as a measure of retardation. Researchers assumed that any intelligence test score falling more than three standard deviations from the mean (e.g. any score below 70) corresponded to the presence of mental retardation. Because intelligence test scores are standardized such that they are distributed normally, this analysis led to the prediction that approximately 3% of the population is mentally retarded.(13)

Although the 3% prevalence rate was initially embraced by many in the mental health field, it has since been contested. The items of contention vary from questions regarding the method used to define mental retardation, to observed differences in the prevalence of retardation.
among certain sectors of the population.

A primary criticism of the 3% estimate is that it is based solely on intelligence tests as a measure of retardation. Researchers who have devoted a great deal of their work to this issue argue that measures of adaptive behavior must also be considered when developing prevalence estimates. Tarjan, Wright, Eyman and Keeran explain that most of those serving the retarded use both intelligence tests and adaptive behavior evaluations to diagnose the condition, and that both measures therefore influence the number of individuals identified as mentally retarded.(14) Echoing this theme, another researcher, Jane Mercer, writes that the effect of looking at only this measure of retardation may be to overestimate its prevalence:

The 3% prevalence model is based on a unidimensional definition of mental retardation and generalizes directly from the normal distribution of IQ test scores. However, most definitions of mental retardation require a double criterion, subnormality in adaptive behavior as well as intelligence. When a double criterion is used, rates for mental retardation are cut approximately in half.(15)

Tarjan, Wright, Eyman and Keeran also argue that the 3% estimate is misleading because it does not take into account variations in the prevalence of retardation among different age groups. According to these researchers, there is a much higher prevalence of retardation among school age children because this is the age when the condition is most likely to be recognized. In school, children are the object of a great deal of attention and required to engage in analytical tasks which expose any learning or intellectual difficulties they might have. In later years, this is not the case, and only those with the most obvious disabilities are diagnosed as retarded. As a result, the prevalence of
retardation is much lower among very young and older populations, with most of those identified being severely retarded.(16)

Based on their studies, Tarjan and his co-authors estimate that only 1% of the population is mentally retarded. As might be expected, this prevalence varies considerably according to the age of the population. This variation is depicted in Figure 1.1. Figure 1.2 shows how the prevalence of different levels of retardation also varies among different age groups.

A related criticism of the 3% estimate is that it does not consider strong evidence of a higher prevalence of mental retardation among low income and minority communities. A study cited by the President's Committee on Mental Retardation, for example, claims that mild retardation is "six to seven times more prevalent among non-whites than whites; thirteen times more prevalent among poor than middle or upper income groups; and found most frequently in rural, isolated areas and inner city ghettos."(17) According to a report prepared for the City of Philadelphia, 75% of the cases of mental retardation are the result of "adverse socio-environmental factors...[including] poverty, poor medical care, improper dietary habits, poor sanitation and cultural deprivation."(18)

In this case, variations in the prevalence of mental retardation result from methods used to identify the condition and economic factors. If intelligence tests are employed as the sole measure of mental retardation, then disadvantaged individuals are more likely to be diagnosed as having this condition. These tests, after all, are criticized for being biased toward the middle class and for identifying individuals with insufficient learning opportunities, as well as
FIGURE 1.1
PREVALENCE OF MENTAL RETARDATION IN GENERAL POPULATION BY AGE GROUP

FIGURE 1.2
LEVEL OF RETARDATION AMONG MENTALLY RETARDED BY AGE GROUP

LEVEL OF RETARDATION
- PROFOUND
- SEVERE-MODERATE
- MILD


intellectual deficits. The actual economic situation of persons living in poverty can also lead to problems, such as inadequate health care, that result in a higher incidence of mental retardation.

For the most part, state agencies serving the retarded ignore these difficulties when estimating the size of the mentally retarded population. According to a recent study, nearly 50% of the state agencies surveyed employ prevalence rates of 3%, and all but three use a one-factor approach (e.g. the use of IQ tests exclusively) to realize their estimates. Further, only twenty-four of the forty agencies responding were able to breakdown their estimates by age and/or level of retardation. Thus, despite evidence of problems with the 3% prevalence rate and the importance of considering the distribution of mental retardation by age, the majority of those serving the retarded are content to use the simplest methods of estimation available. This approach leads them to plan for more mentally retarded than may actually require services.

Definitions and Prevalence Estimates Used in Massachusetts

In Massachusetts, the situation with regard to estimating the number of mentally retarded mirrors the confusion at the national level. Massachusetts agencies serving the retarded employ three different definitions of the condition, two of which correspond to definitions described above. These definitions lead to prevalence rates that are different from one another, and also different from those used on the national level because they are state-specific.

(1) American Association on Mental Deficiency (AAMD) Definition

In this state, the AAMD definition of mental retardation is used by
the Massachusetts Association for Retarded Citizens (MARC). MARC is an advocacy group for the retarded and is active in promoting the deinstitutionalization of treatment for the retarded. The organization was named as a plaintiff in two of the class action suits brought against the state, and has recently been advocating for the provision of more community residences for the retarded.

MARC estimates that 2.3% of the Massachusetts population is mentally retarded. (20) While this prevalence rate is lower than the commonly used 3% figure, it is also the highest estimate employed in the state. The estimate is high because the AAMD definition includes all persons who might be labelled as mentally retarded, whatever their level of retardation. Other definitions used in the state do not include persons with mild mental retardation, leading them to smaller estimates.

Given its role and activities, it is understandable that MARC chooses to use the AAMD definition. In so doing, the organization is recognizing well established evidence that mental retardation consists of both intellectual and adaptive behavior deficits. However, by employing the AAMD definition, the organization also assists its cause, proving the need for its existence by maximizing its estimate of the retarded population.

(2) Developmental Disabilities Definition (P.L. 95-602)

The developmental disabilities definition is the definition used by most state agencies serving the disabled. One of the most important users of this definition is the Massachusetts Developmental Disabilities Council (MDDC). The role of this agency is to develop a state plan that addresses gaps in services to the developmentally disabled and to "influence agency policy and budget processes for improved services for
developmentally disabled persons."

The Massachusetts Developmental Disabilities Council estimates that approximately 1.52% of the population is developmentally disabled. This estimate is based on data from a nationwide survey of the population conducted in 1976. From this survey, researchers determined that 1.39% of the Massachusetts population was developmentally disabled. The MDDC realized its estimate of 1.52% by adding on another 8,000 developmentally disabled residents of state schools and institutions who were not included in the nationwide survey.

Because it includes all persons with developmental disabilities, and not just the retarded, the MDDC estimate is not really comparable to the MARC estimate. The MDDC prevalence estimate also excludes many of the mildly retarded who are not severely disabled enough to fall under the P.L. 95-602 definition.

However, the Developmental Disabilities Legislation definition is representative of a changing outlook on state services to the disabled. A number of state agencies have adopted this definition, in part, because it expands the provision of services to a much larger cross section of the disabled population. Under this one definition, persons with cerebral palsy, muscular distrophy, mental retardation and other serious disabilities are all provided for. For this reason, the MDDC believes that the developmental disabilities definition will become increasingly popular among state agencies serving the disabled.

(3) Definition Used by the Department of Mental Health

Unlike other agencies serving the retarded, the Department of Mental Health has formulated its own definition of the population it serves. The definition used by the Department's Division of Mental Retardation is:
A "Mentally Retarded Person" means a person with inadequately developed or impaired intelligence which substantially limits ability to learn or to adapt as judged by established standards available for the evaluation of a person's ability to function in the community.(24)

The definition adopted by the Department of Mental Health is something of a cross between the AAMD and P.L. 95-602 definitions. Like the AAMD definition, DMH's definition includes mention of intellectual deficits and, in a less explicit way, behavioral impairments. The definition also hints at the developmental disabilities definition by referring to "a person's ability to function in the community."

In practice, this definition comes even closer to the P.L. 95-602 definition since DMH uses a prevalence rate taken from this legislation. Under the developmental disabilities definition, 0.5% of the population is presumed to be both mentally retarded and developmentally disabled. This prevalence rate is used by DMH to estimate the number of mentally retarded eligible for its services.

The definition formulated by DMH is an attempt to acknowledge the importance of both the AAMD and the developmental disabilities definitions. It is also an attempt to limit the provision of services to only those with the most severe needs. By drawing from both definitions, DMH excludes both developmentally disabled persons who are not mentally retarded and the mildly retarded from eligibility for services.

On the basis of the three definitions used in the state, three different prevalence rates, and three different estimates of the population eligible for services are realized. Given that the Massachusetts population is about 5.8 million, the estimated number of mentally retarded or developmentally disabled residing in the state
varies in the following way:

MARC (2.3% prevalence): 133,400 mentally retarded
MDDC (1.52% prevalence): 88,160 developmentally disabled
DMH (0.5% prevalence): 29,000 mentally retarded/developmentally disabled

The differences in these estimates cannot be resolved until each of the agencies serving the retarded decide on one definition. This, however, is not likely to happen in the immediate future. The Massachusetts Association for Retarded Citizens is an advocacy group for the retarded only, and unlikely to switch to a definition that includes other disabled populations. The MDDC is probably correct in assuming that the developmental disabilities definition will become more widely used by state agencies, but it will be some time before DMH makes this transition. The Department has indicated that it would consider using this definition, but that it cannot do so until it succeeds in meeting the needs of the even smaller population that fits within its current definition.
ISSUES IN ESTIMATING THE NUMBER OF MENTALLY RETARDED IN NEED OF STATE SERVICES

For all the problems associated with estimating the total mentally retarded population, estimating the number in need of services is even more difficult. In this case, estimates vary according to the way both mental retardation and "unserved" are defined. Definitional problems are further complicated by the fact that the unserved are, for the most part, not known to the state and, therefore, little information is available from which to estimate their numbers.

The unserved population can be broken down into two groups: (1) mentally retarded receiving no services from the state, and (2) mentally retarded receiving inappropriate or inadequate services. For those receiving no services, problems in realizing estimates arise because of difficulties in locating and evaluating these individuals. In the case of the underserved, estimation problems result from different views on what constitutes inappropriate services, and which state agency should meet the need. These problems are discussed in greater detail below, with a focus on individuals believed to require DMH/MR residential services.

Unserved Mentally Retarded

The largest group of mentally retarded regarded as unserved are those living at home. According to a report from the office of Massachusetts State Senator Backman, this population is comprised of three sub-groups:

(1) Mentally retarded who were not placed in state schools because of "the infamous reputation of most state institutions,"

(2) Mentally retarded who remained at home because their families felt that "they should handle the
responsibilities of their relatives," and

(3) Mentally retarded "who were able to stay at home" because of special education programs provided to them in their own communities.(25)

In many ways, these three groups reflect the history of treatment of the retarded. The second group, for example, emerged as a result of a growing national adherence to the "normalization principle". This principle states that "the patterns and conditions of everyday life for disabled individuals should be as close as possible to the norms and patterns of the mainstream of society."(26) The effect of this principle has been to encourage the provision of community and home-based care for the retarded.

On a state level, the normalization principle was translated into special education programs such as those for the third group identified above. In Massachusetts, the Department of Education's Chapter 766 program enabled many of the retarded to remain at home during their school years by requiring that local school systems to provide special education programs in the communities where special needs children lived. Prior to Chapter 766, educational opportunities for the disabled were generally limited to private and state schools which required children to live away from home.(27)

A final, less positive incentive for families to keep the retarded at home was the condition of the state schools for the mentally retarded. Before the class action suits were filed against the state, the unfavorable conditions at the schools were fairly well known and families were reluctant to place children in these institutions. After the class action suits, parents no longer had a choice since DMH stopped admitting new clients to the schools.
For each of these groups there is likely to be an eventual need for residential services. Those who remained at home because of conditions in the schools, or because families provided for them, will need housing once relatives are no longer able or willing to provide care. This often happens because families experience marital problems, emotional stress and financial difficulties as a result of providing for the disabled. In other cases, the parents are aging and no longer physically able to care for the retarded.

For these groups, the difficulty in estimating the number needing services results from a lack of information. Many of the retarded living at home do not use state services and therefore have not been identified. They become known to the state only if they identify themselves, usually when there is a crisis in the family. As a result, the data that are available on this group are heavily weighted toward those whose families are most vocal, or most in need.

For students of special education programs, services are needed once they graduate. The Chapter 766 program serves only children ages 3-22 and is responsible for meeting both their educational and residential needs. In this regard, the mentally retarded using special education programs do not become "unserved" until they lose eligibility for Chapter 766 programs. Once this happens, individuals continue to need the same services, but often do not receive them.

The number of students now in Chapter 766 programs is well documented. Because these individuals are served by the state, they have been counted and their needs have been evaluated. However, not all those served in special education programs are mentally retarded and the exact number with this condition is not known. In addition, many who graduated
from the program never obtained substitute services and are now no longer known to the state.

**Underserved Mentally Retarded**

In the broadest sense, the "underserved" population includes developmentally disabled individuals who do not receive DMH assistance and DMH clients who need alternative residential placements. To narrow this range, the term underserved, as used in this chapter, refers only to those mentally retarded who are not currently receiving, and are presumed to require DMH/MR residential services. This definition excludes some developmentally disabled individuals and others who need day services, but focuses on those DMH is most concerned about. Major groups that fall within this definition of underserved are discussed below.

(1) Mentally Retarded Living in Mental Institutions

DMH currently acknowledges that the mentally retarded living in state mental institutions are inappropriately housed. These individuals are known as "dual diagnosis" clients because they suffer from both mental retardation and mental illness. DMH describes the problem with the current system of care to this population in this way:

...the Department of Mental Health, with its myriad and wide ranging service options, has not adequately developed programs and treatment modalities for those mentally ill and mentally retarded individuals residing in both our institutions and in the community. Because of the dual diagnosis, clients have been shuffled among Divisions, and no clear focus of responsibility has ever been established for the development of treatment options.(28)

Because of this problem, a special DMH task force was organized to identify dual diagnosis clients and evaluate their needs. As a result of this task force's work, the mentally retarded/mentally ill persons
residing in state mental institutions have been identified. However, questions still remain as to what type of housing these individuals need as an alternative to mental institutions. DMH believes that, while they are not the best environment in the long run, state schools are the only settings where there is sufficient expertise to develop appropriate programs for these clients. MARC, however, believes that these individuals should be placed in community settings. As a result of this disagreement, available estimates of the service needs of dual diagnosis clients are inconsistent.

(2) Mentally Retarded Living in Nursing Homes.

The mentally retarded residing in nursing homes actually consist of two groups (1) individuals living in state pediatric nursing homes, and (2) adults living in geriatric nursing homes, rest homes, skilled nursing facilities, and chronic care hospitals.

Ironically, the mentally retarded came to live in pediatric nursing as a result of DMH's early efforts to deinstitutionalize the retarded. In the early 1970's, DMH decided to emphasize community based care and stopped admitting children to the state schools. Unfortunately, alternative residences for severely retarded children were in limited supply at the time and many could not obtain the care they needed. To address this problem, the state built four pediatric nursing homes designed to serve both multiply handicapped and severely retarded children.(29)

Although pediatric nursing homes were initially intended to provide short term care, the continued lack of alternative housing for disabled children has led to longer terms of service. The problem with this is that the children are growing older and nursing homes are only licensed
to serve individuals under age 21. Unless alternatives for individuals over age 21 are found, further residential services for retarded children could be lost. (30)

Estimates of the mentally retarded living in pediatric nursing homes differ depending on who is determined to be "underserved". DMH is obviously most concerned with the over 21 population since this group is at risk of losing all services. MARC, however, argues that institutional settings are rarely appropriate for the treatment of the retarded, and that the majority of all the retarded living in pediatric nursing homes should be moved.

Mentally retarded adults living in nursing homes, chronic care hospitals, skilled nursing facilities and rest homes are even more the subject of policy debates. Many of these individuals are former residents of DMH state schools. Others are believed to have been placed there as a result of DMH's inability to provide adequate residential services to the mentally retarded. A good portion of both groups are elderly or suffering from illnesses, and regarded as needing specialized residential care. (31)

Estimates of the underserved mentally retarded residing in nursing homes vary because of uncertainty about how many require alternative housing. First, DMH does not believe that all the mentally retarded need its services to realize better care. According to the Department, many of these clients require the skilled nursing care that is available in hospital-like settings. DMH also feels that many of these individuals would be adequately served if the care provided in their current residence were improved. This perspective differs somewhat from that taken by MARC, which believes that most of those in adult nursing homes
should be transferred to DMH community residences.

A second issue concerns some 200 former residents of state schools. As with other mentally retarded living in nursing homes, DMH has yet to determine that these clients need alternative housing. However, families of these clients argue that since their transfer, individuals living in nursing homes "have received no services and have been left isolated and forgotten, resulting in loss of skills and physical deterioration."(32) These parents are now fighting to get their children placed back in the schools where they believe the care is better. To complicate the problem, their efforts are being challenged by another group of parents who do not want any more state funds spent on the schools. As a result of these conflicts, estimates of the underserved living in nursing homes are politically volatile. (3)

Mentally Retarded in Custody of the Department of Social Services

A final group of individuals sometimes regarded as underserved are mentally retarded children in the custody of the Department of Social Services (DSS). These children receive foster care and group home residential services through DSS. MARC has indicated that most of these children are well served, but that some could benefit from DMH residential programs. MARC is particularly concerned about "older adolescents or young adults who are unlikely to find an adoptive family and for whom family reunion is unrealistic."(33)

The Department of Mental Health has not really addressed itself to the needs of these individuals, except to express some concern for those who lose DSS eligibility once they reach age 22. Problems with estimating the number of underserved in this group are therefore the result of a lack of attention to their needs which, in turn, results in a lack of
CONCLUSIONS

Estimating the number of mentally retarded residing in the state or nation is by no means a simple task. As has been discussed, estimates vary according to the way mental retardation is detected and defined. Prevalence rates are the customary means of realizing estimates of the retarded population, but these also vary depending on which sector of the population is studied. In Massachusetts, three different definitions are used to establish eligibility for services, leading to estimates that range from 29,000 to 133,400.

Estimating the number of mentally retarded in need of services is equally difficult. In this case, estimates differ according to how both mental retardation and "unserved" are defined. For those receiving no services from the state, estimation is further complicated by a lack of data on the population. For individuals regarded as "underserved," estimates can only be made after some agreement is reached on what constitutes an appropriate level of care, what kinds of services are required to meet the need and which agency should address the problem.

These problems do not make it easy for state agencies to develop services for the mentally retarded. It is always difficult to develop plans on the basis of insufficient data and in the face of controversial and conflicting information. Yet, because it is the state's responsibility to meet the needs of retarded citizens, and because plans must be made to address their needs, these problems must be confronted. In the following chapters, an attempt is made to do just that.
FOOTNOTES


(3) At the time of its report, the President's Committee noted these criticisms of intelligence tests: "they are based on the values of white, middle-class persons...measure achievement based on differences in opportunity to learn, rather than native intelligence...[and] are used arbitrarily as a means for excluding persons of minority cultures from opportunities to learn." (President's Committee. Mental Retardation: The Known and the Unknown, p. 5.)

(4) President's Committee. Mental Retardation: The Known and the Unknown, p. 6.

(5) President's Committee. Mental Retardation: The Known and the Unknown, p. 6.

(6) President's Committee. Mental Retardation: The Known and the Unknown, p. 6.

(7) Massachusetts Department of Mental Health, Division of Mental Retardation. Orientation to the Mental Retardation Services System "Fact Sheet: Mental Retardation" (Boston: Massachusetts Department of Mental Health, no date) p. 1.

(8) Mark J.D. Mills, Commissioner, Massachusetts Department of Mental Health. Memorandum to Manuel Carballo, Secretary, Massachusetts Executive Office of Human Services (Boston, January 24, 1983) p. 3.

(9) Mills, Memorandum to Manuel Carballo, p. 3.


(12) President's Committee. Mental Retardation: The Known and the Unknown, p. 8.


(15) Mercer, pp. 15-16.


(22) Massachusetts Developmental Disabilities Council, p. 4. (See United States Department of Commerce, Bureau of the Census. Survey of Income and Education (SIE), 1976). This survey was not an effort to identify individuals with developmental disabilities but did ask respondents to report the presence of any such condition.


(24) Mills, Memorandum to Manuel Carballo, p. 4.


(26) Lash, p. 5. (See Massachusetts Department of Mental Health. Orientation to the Mental Retardation Services System "Fact Sheet: Normalization" Boston: Massachusetts Department of Mental Health, 1981).

(27) Lash, p. 10.

(28) Mills, Memorandum to Manuel Carballo, p. 20.

(29) Mills, Memorandum to Manuel Carballo, pp. 15-16.
(30) Mills, Memorandum to Manuel Carballo, p. 16.


(33) Moriearty, p. 22.
ESTIMATES OF THE NUMBER OF MENTALLY RETARDED
IN NEED OF HOUSING
Before plans can be made on their behalf, estimates of the number of mentally retarded in need of state provided housing must be developed. While the previous chapter described the problems of realizing such estimates, this chapter addresses those problems by employing a methodology for planning with inadequate and conflicting data. Because different definitions of mental retardation and of "unserved" and "underserved" can influence estimates, this methodology is designed so that definitions can be easily changed and their implications tested. The methodology also uses two approaches to develop estimates in order to check the appropriateness of assumptions and realize greater accuracy.

This methodology is based on approaches others have used to estimate the number of mentally retarded in need of services. Based on a study I conducted, other states and localities generally use one of three methods to develop estimates. These methods and their advantages and disadvantages are described below. (See Appendix A for a more complete description of approaches used by other states and localities.)

1. **Estimates Based on Prevalence Rates**
   In this approach, estimates of the unserved are derived by multiplying mental retardation prevalence rates times the population and subtracting the number served. Its advantage is that it is fairly easy to implement. Its disadvantage is that prevalence rates vary depending on how mental retardation is defined and which sector of the population is studied.

2. **Estimates Based on Surveys**
   This approach involves using surveys of the general population or agencies serving the retarded to estimate the number in need of assistance. The approach thereby assists in actually
identifying the unserved and generates detailed information on their characteristics and needs. Unfortunately, estimates realized through this approach can be less than accurate if survey questions are ambiguous or not enough people are surveyed. In addition, when agencies serving the retarded are surveyed, only those who are known to require assistance are identified, and not the total unserved population.

(3) **Estimates Based on Prevalence Rates and Surveys**

This approach uses both prevalence rates and surveys to estimate the need for services. By using prevalence rates, individuals who might not be identified in surveys can be estimated. However, because prevalence rates vary, surveys provide more precise data on the unserved and their needs. Thus, this approach offers an opportunity to improve the accuracy of results derived by either method. Its disadvantage is that using two methods leads to a confusing situation in which two estimates of the number in need of services result.

Despite this limitation, the methodology I use in this report employs both prevalence rates and surveys. This approach is used because it resolves some of the problems discussed in Chapter One. For example, under this methodology, uncertainty regarding the accuracy of estimates based on prevalence rates is compensated for by drawing from information in surveys of the retarded. Similarly, problems such as a lack of data on the unserved are addressed by comparing estimates based on surveys against prevalence-based estimates. This approach thereby leads to a more accurate set of estimates by using all the available information on the unserved mentally retarded.
Figure 2.1 depicts the process by which estimates are developed using this methodology. At the top of the figure, estimates of the prevalence of mental retardation in Massachusetts are used to develop one set of estimates. At the bottom of the figure, surveys or approximate counts of the unserved and underserved retarded lead to a second set of estimates. Because no comprehensive survey of the unserved mentally retarded has been conducted in Massachusetts, this second set of estimates is based on studies conducted by a variety of agencies. This information, combined with estimates based on prevalence rates, then leads to an estimated range of the number of mentally retarded requiring state services.

In developing either set of estimates, I use an approach which allows information to be changed or added in order to improve the results. If, for example, the prevalence rate used to derive estimates is considered inappropriate, it can be easily substituted with another. Similarly, the assumptions I make in resolving conflicting survey data on the unserved can be altered. Additional information on the unserved can also be added into the analysis as it becomes available. In this way, problems with different definitions and prevalence rates or incomplete and inconsistent data on the mentally retarded are also addressed.

Using this methodology, estimates of the unserved/underserved retarded in need of housing are developed in three steps. As depicted in Figure 2.2, the first step is to estimate the number of mentally retarded requiring any form of state services. In the second step, this estimate is broken down into two age groups, children and adults. Finally, in step three, estimates are narrowed to include only those who need state provided housing.
FIGURE 2.1
PROCESS FOR ESTIMATING THE UNSERVED/UNDERSERVED MENTALLY RETARDED

ESTIMATE
BASED ON MENTAL RETARDATION PREVALENCE RATES

ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED

ESTIMATE BASED ON SURVEYS OR COUNTS OF THE UNSERVED/UNDERSERVED MENTALLY RETARDED
FIGURE 2.2

STEPS IN ESTIMATING THE UNSERVED/UNDERSERVED MENTALLY RETARDED

ESTIMATE
BASED ON MENTAL RETARDATION PREVALENCE RATES

STEP ONE
ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED

STEP TWO
ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED BY AGE GROUP

STEP THREE
ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED IN NEED OF HOUSING BY AGE GROUP

ESTIMATE BASED ON SURVEYS OR COUNTS OF THE UNSERVED/UNDERSERVED MENTALLY RETARDED
In each of these steps, I make certain assumptions regarding definitions and prevalence rates. Although the methodology proposed can be used under a variety of assumptions, the development of estimates in this report requires that some be made at this time. The benchmark assumptions I use are described below.

(1) **Definition of Mental Retardation**

I use the Department of Mental Health, Division of Mental Retardation definition of mental retardation. This definition is chosen because DMH/MR is the state's primary provider to the retarded and the agency responsible for meeting the needs of most of the unserved.

(2) **Estimates of the Prevalence of Mental Retardation**

For the same reasons as those mentioned above, the DMH prevalence rate of 0.5% is employed in this analysis. This rate includes only mentally retarded individuals who are eligible for DMH/MR services.(2)

(3) **Definition of Unserved Mentally Retarded**

In this report, the unserved mentally retarded are defined as individuals who are currently or potentially, eligible for and in need of, and not now receiving services from the Department of Mental Health, Division of Mental Retardation. In step three, the definition is narrowed to include only those who require housing services from DMH/MR.

This definition focuses on individuals who meet DMH/MR eligibility requirements and are in greatest need of services. The definition includes clients who are served by DMH, but not by the Division of Mental Retardation (e.g. dual diagnosis clients in state mental institutions). The definition does not include developmentally disabled persons who are not also mentally retarded, nor does it include residents
of DMH/MR facilities who need alternative placements.

(4) Definition of Underserved Mentally Retarded

The underserved are defined as individuals who are not now receiving, and who the Department agrees should be receiving, services from DMH/MR. In step three, this definition is changed to include only persons who need DMH/MR housing.

Unfortunately, this definition cannot be applied to all mentally retarded who are potentially underserved. This is because DMH has not yet determined how many individuals require additional services. In some cases, there is not enough information on which to base such a decision. As a result, estimates reported in this document are based on the information that is available and my own assumptions regarding the need for DMH/MR services.

STEP ONE: ESTIMATE OF THE UNSERVED/UNDERSERVED MENTALLY RETARDED POPULATION

Figure 2.3 depicts how the proposed methodology is used to develop two estimates of the number of unserved and underserved mentally retarded residing in the state. At the top of the figure, the DMH prevalence rate of 0.5% leads to an estimate of 19,657 unserved mentally retarded. At the bottom of the figure, the lower estimate of 14,239 is based on studies that have identified the unserved and underserved. The sources and limitations of each of these estimates are described below.

Prevalence-Based Estimate of Unserved Mentally Retarded: 19,657

The first estimate of unserved mentally retarded is derived by multiplying the DMH prevalence rate by the Massachusetts population and then subtracting individuals currently served by the Department of Mental
FIGURE 2.3
ESTIMATED RANGE OF UNSERVED/UNBERSERVED MENTALLY RETARDED

TOTAL MENTALLY RETARDED POPULATION IN MASSACHUSETTS = DMH/MR PREVALENCE RATE X MASSACHUSETTS POPULATION = 0.5% X 5.8 MILLION = 29,000

LESS POPULATION SERVED BY STATE:
IN DMH/MR INSTITUTIONS: 3,880
IN DMH/MR COMMUNITY RESIDENCES: 3,350
RECEIVING DAY SERVICES: 2,113
TOTAL 9,343

PREVALENCE-BASED ESTIMATE = 19,657

ESTIMATED RANGE OF UNSERVED/UNBERSERVED MENTALLY RETARDED = 14,200 - 19,700

SURVEY OR COUNT BASED ESTIMATE = 14,239

ESTIMATE OF UNSERVED = 10,365
ON DMH/MR WAITING LISTS: 2,467
IN CH. 766 PROGRAMS: 7,898

ESTIMATE OF UNDERSERVED = 3,874
IN STATE MENTAL INSTITUTIONS: 570
IN NURSING HOMES: 2,554
IN DSS CUSTODY: 750

SURVEYS OR COUNTS OF THE UNSERVED/UNBERSERVED MENTALLY RETARDED
Health. Aside from difficulties with the DMH prevalence rate, this estimate is affected by uncertainty about (1) the number of clients currently housed by DMH/MR and (2) the housing needs of other DMH/MR clients and mentally retarded served by other state agencies.

Tables 2.1 and 2.2 report data collected from DMH on residents of institutional or community-based facilities by class or non-class status. These tables show that data on residents of DMH facilities are very inconsistent. According to Table 2.1, between 3,800 and 4,100 persons are reported to live in DMH state schools and regional centers. Estimates of the number of clients served in community residences are even more wide ranging. In this case, one set of estimates shows a majority of class clients, while another shows a majority of non-class clients.

These inconsistencies result from the way data are collected and used. The Massachusetts Service Coordination Battery (MSCB), for example, is used to monitor services provided to clients protected by consent decrees. Thus data from the MSCB do not include all non-class clients served by DMH/MR. Other data reported in the tables are similarly incomplete. For example, calls to DMH institutions provide data on the number of clients in residence on the day calls are made, while data reported in budget documents indicate the average number of residents over different periods of time.

Because they are the most recent and complete, I use data from the DMH's Fiscal Year 1985 capital budget request. These data indicate that about 3,500 class clients reside in state schools while 400 non-class clients live in regional centers. In DMH community residences, the estimated number of clients served is 3,350. This estimate is lower than others reported in Table 2.2, but regarded by the Department to be the
### TABLE 2.1
CLIENTS SERVED IN DMH/MR INSTITUTIONS BY CLASS STATUS

<table>
<thead>
<tr>
<th>PLACE OF RESIDENCE/CLIENT STATUS</th>
<th>CALLS TO INSTITUTIONS (JANUARY)</th>
<th>CALLS TO INSTITUTIONS (FEBRUARY)</th>
<th>MASS. SERVICE COORDINATION BATTERY</th>
<th>FY 85 OPERATING BUDGET</th>
<th>DMH FY 85 CAPITAL BUDGET REQUEST</th>
</tr>
</thead>
<tbody>
<tr>
<td>IN STATE SCHOOLS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CLASS CLIENTS</td>
<td>3,455</td>
<td>3,389</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NON-CLASS CLIENTS</td>
<td>-0-</td>
<td>-0-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SUBTOTAL</td>
<td>3,455</td>
<td>3,389</td>
<td></td>
<td>3,381</td>
<td>3,466</td>
</tr>
<tr>
<td>IN REGIONAL CENTERS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CLASS CLIENTS</td>
<td>68</td>
<td>310</td>
<td></td>
<td>394</td>
<td>414</td>
</tr>
<tr>
<td>NON-CLASS CLIENTS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SUBTOTAL</td>
<td>378</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>3,523</td>
<td>3,790</td>
<td></td>
<td>3,775</td>
<td>3,814</td>
</tr>
<tr>
<td>CLASS CLIENTS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NON-CLASS CLIENTS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GRAND TOTAL</td>
<td>3,833</td>
<td>4,106</td>
<td></td>
<td>3,775</td>
<td>3,814</td>
</tr>
</tbody>
</table>

### TABLE 2.2
CLIENTS SERVED IN DMH/MR COMMUNITY FACILITIES BY CLASS STATUS

<table>
<thead>
<tr>
<th>CLIENT STATUS</th>
<th>MASS. SERVICE COORDINATION BATTERY</th>
<th>FY 85 OPERATING BUDGET</th>
<th>DMH FY 85 CAPITAL BUDGET REQUEST</th>
<th>DMH FY 83 COMMUNITY SERVICE REPORT</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLASS CLIENTS</td>
<td>1,797</td>
<td></td>
<td>1,948</td>
<td></td>
</tr>
<tr>
<td>NON-CLASS CLIENTS</td>
<td>3,121</td>
<td></td>
<td>1,402</td>
<td></td>
</tr>
<tr>
<td>GRAND TOTAL</td>
<td>4,918</td>
<td>5,400</td>
<td>3,350</td>
<td>4,414</td>
</tr>
</tbody>
</table>

CLIENTS IN DAY PROGRAMS ONLY

| CLASS CLIENTS       | 216                                |
| NON-CLASS CLIENTS   | 1,897                              |
| TOTAL               | 2,113                              |

(SEE ATTACHED)
SOURCES: TABLES 2.1 - 2.2

1 Massachusetts Department of Mental Health, Division of Mental Retardation. Special Report on Self-Preservation Status for the Division of Capital Planning and Operations: Self-preservation Status by Class Member Status and Residential Setting Based on the Massachusetts Service Coordination Battery (Boston: Massachusetts Department of Mental Health, January 1984) pp. 1-3.


3 Massachusetts Department of Mental Health. Long Range Capital Facilities Development Plan and Capital Outlay Budget Request, Fiscal Year 1985 (Boston: Massachusetts Department of Mental Health, October 1983) "Agency Narrative" pp. 45, 63.

4 Lorre Seagren and Barbara Lepidus. Department of Mental Health Fiscal Year 1983 07 Community Services Report (Boston: Massachusetts Department of Mental Health, November 1983) p. 9.
most accurate.

To supplement these estimates, data on DMH clients now receiving day services only are also included. The data are again drawn from the DMH capital budget request and indicate that approximately 200 class clients and 1,900 non-class clients receive day services only. By adding these individuals to the estimate of clients housed in community residences, the percentage breakdown of class/non-class clients served outside of institutions is 40% class clients and 60% non-class clients. This compares well with data from the MSCB, which indicate that 37% of those served in the community are class clients while 63% are non-class clients.(3)

Unfortunately, the estimates derived above do not accurately reflect the actual service needs of DMH clients. Some DMH clients receiving day services only, for example, need residential placements and might therefore be considered underserved. On the other hand, many individuals receiving DMH respite care and support services do not need housing assistance and should be included among the served. Because there is a lack of data on the service needs of either of these groups, I use the total population served in day programs only to represent all DMH clients who are not now receiving and do not require DMH/MR housing.

Finally, a number of clients are served by other state agencies and should be subtracted from the estimate of 19,657 unserved. This includes mentally retarded persons receiving assistance from any of the twelve state agencies that serve the retarded. However, because accurate counts of these individuals are difficult to obtain, and because their housing needs have not been assessed, they are included in the estimate as unserved.
Survey or Count-Based Estimate of Unserved/Underserved Mentally Retarded: 14,239

Estimates of the mentally retarded actually identified as unserved or underserved are based on data collected by a number of agencies serving the retarded. Because this step of the estimation process considers the total unserved and underserved population, estimates presented below include mentally retarded individuals who may not need DMH/MR housing.

(1) Mentally Retarded Identified as Unserved: 10,365

(a) Mentally Retarded on DMH Waiting Lists: 2,467

Persons on the DMH waiting list have either contacted DMH Area Offices themselves, or been identified by Area Office staff through some other means since September 1982. The waiting list indicates that 1,678 of these individuals need housing assistance, while 789 need day services only.(4)

I assume that most individuals on DMH waiting lists are now living at home. This is because mentally retarded individuals living at home usually become known to the state only when they identify themselves, and waiting lists constitute a primary means by which they make their needs known. In addition, data from the waiting list compare relatively well with other estimates of retarded individuals living at home. For example, the waiting list indicates that 1,678 persons need housing, while MARC estimates that 1,106 mentally retarded living at home require DMH/MR housing.(5)

At the same time, the DMH waiting list may overestimate the degree of unserved need in Massachusetts. According to one DMH Area Officer,
waiting lists are used by the Department to determine how funds should be allocated throughout the state. Area Offices are therefore inclined to inflate their waiting lists in order to receive more funding. They do this by seeking out retarded individuals who are not in immediate or critical need of assistance. As a result, the DMH waiting list is "more a political statement than a rational planning statement" and not entirely reliable.(6)

(b) Mentally Retarded in Chapter 766 Programs: 7,898

The estimate of unserved mentally retarded using special education programs is based on data from the Department of Education's "After 22" survey conducted in 1982. This survey identified nearly 4,000 special needs children who will need "continuing services from one or more Human Service Agencies" once they lose Ch. 766 eligibility at age 22.(7) While the survey did not specifically identify potential DMH/MR clients, it did provide enough information on which to base a rough estimate:

(1) The survey reports that an average of 445 individuals per year will lose Chapter 766 eligibility in 1984, 1985 and 1988. In 1986 and 1987 an average of 623 individuals per year will lose eligibility. (The increase is the result of a rubella epidemic in 1964-65.)(8)

(2) The best indicator of need for DMH services in the survey is the prevalence of cognitive disability among all students. Of those graduating in 1984, 1985 and 1988, 86% are reported to have cognitive disabilities. Among those losing Ch. 766 eligibility in 1986 and 1987, the percentage prevalence of cognitive disability is 81%.(9)

(3) Multiplying the prevalence of cognitive disability times the
population size, estimates of students who will need DMH/MR services in the future are:

-- Students turning 22 in 1984-85, 1988: 1,148 (383/yr)
-- Students turning 22 in 1986, 1987: 1,009 (505/yr)

Total Population needing services 1984-88: 2,157

(4) Individuals turning 22 between the years 1989-2003 (e.g. individuals now aged 3-17) were not identified by the survey. However, the Department of Education estimates that there are approximately 383 students at each age with cognitive disabilities for a total of 5,741 students.(10)

(5) The total number of students now using Chapter 766 programs and potentially in need of DMH/MR assistance over the next twenty-two years is therefore: $2,157 + 5,741 = 7,898$.

Importantly, this estimate represents only a rough count of mentally retarded individuals now in state special education programs. Because it is based only on the prevalence of cognitive disability among students, the estimate probably includes some mentally ill and mildly retarded individuals who are not eligible for DMH/MR services. The estimate also includes individuals who are now living at home and on DMH waiting lists.

Based on this analysis, the total unserved mentally retarded population is 10,365. This estimate is high in comparison to others. A survey conducted by the office of Massachusetts State Senator Backman, for example, identified only 3,300 mentally retarded known by DMH Area Offices to require services.(11) The Backman survey, however, probably did not identify Chapter 766 students between the ages of 3-17 since they are not yet eligible for DMH services. If these children are subtracted from the estimate of 10,365 unserved, 4,600 remain. This is still higher
than the estimate reported in the Backman survey, probably because some individuals on both waiting lists and in Ch. 766 programs are double counted.

(2) Mentally Retarded Identified as Underserved: **3,874**

(a) Mentally Retarded in State Mental Institutions: **570**

The estimate of underserved mentally retarded residing in state mental institutions is based on the following information:

(1) **MARC estimate: 400**

This estimate of mentally retarded persons living in DMH state hospitals is based on "agency projections of this population which have ranged over the past few years from 235 to 735."(12)

(2) **1978 DMH estimate: 781**

This estimate is from the Department's Five Year Plan for Mental Retardation Services developed in 1978. In this report, DMH estimated that only 551 of these individuals require alternative housing.(13)

(3) **1984 DMH estimate: 529**

This estimate is based on data collected by DMH's special task force on the mentally retarded/mentally ill. The estimate includes dual diagnosis clients living in only three of the Department's seven district areas. It also includes individuals living in a variety of residences, of which 167 are in state mental institutions and in need of alternative housing.(14)

These estimates differ in part because of the way the data were collected and in part because the size of the population living in state mental institutions changes over time. Differences also result from
difficulties in determining whether an individual's primary disability is mental retardation or mental illness and, on that basis, whether they should be served by DMH's Division of Mental Retardation.

Because the dual diagnosis task force conducted the most recent and thorough evaluation of the mentally retarded/mentally ill, their estimate is probably the most accurate. However, this estimate does not include all dual diagnosis clients residing in the state. Because other estimates are out of date, I use the mean of the three estimates of the total dual diagnosis population. The resulting estimate therefore includes dual diagnosis clients living outside of mental institutions, but also takes into account past and possible future changes in the population size.

(b) Mentally Retarded in Nursing Homes: 2,554

As with the dual diagnosis population, estimates of the underserved mentally retarded residing in pediatric and adult nursing homes vary. Table 2.3 reports estimates derived by MARC and DMH on the number of mentally retarded living in nursing homes, and the number estimated to need alternative housing. According to this table, estimates of the mentally retarded in pediatric nursing homes are the major source of differences between the two agencies. For this group, DMH reports two estimates, each of which are lower than the MARC estimate.

In this report, I use the lower DMH estimate of mentally retarded in adult and pediatric nursing homes. The DMH estimate is chosen because it includes only those persons that the Department believes are underserved. The lower estimate is used because it appears to include only the mentally retarded, while the higher estimate may include other multiply handicapped individuals as well.(15)
<table>
<thead>
<tr>
<th>Place of Residence</th>
<th>SOURCE OF ESTIMATE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Massachusetts Association for Retarded Citizens¹</td>
</tr>
<tr>
<td></td>
<td>Mentally Retarded</td>
</tr>
<tr>
<td>In Adult Nursing Homes</td>
<td>2,360³</td>
</tr>
<tr>
<td>In Pediatric Nursing Homes</td>
<td>350</td>
</tr>
<tr>
<td>TOTAL</td>
<td>2,710</td>
</tr>
</tbody>
</table>


²Mark J.D. Mills, Commissioner Massachusetts Department of Mental Health. Memorandum to Manuel Carballo, Secretary, Massachusetts Executive Office of Human Services. (Boston, January 24, 1983) pp. 11, 18.

NOTES

¹Includes Residents of Chronic Hospitals, Intermediate Care Facilities, Skilled Nursing Facilities (2,110) and Non-Medicaid Eligible Rest Homes (250).

²Includes only those estimated by MARC to need placement outside their current residence (984). MARC does not estimate housing need of residents of non-medicaid eligible rest homes. I assume that, as with others in nursing homes, one-half require additional services (125). MARC estimates also do not break down clients' housing need by age or current place of residence.

³Includes residents of Adult Nursing Homes and Rest Homes only.

⁴DMH reports two estimates in the same document.
(c) Mentally Retarded in DSS Custody: 750

This estimate is taken from a study conducted by MARC. The estimate is based on the assumption that one-half of the 1,500 children served by DSS are mentally retarded. According to MARC, many of these individuals could benefit from DMH respite care and support services. Only 100 older adolescents, however, are assumed require DMH residential placements.(16)

Analysis of Estimates Developed in Step One

Using the methodology proposed, approximately 14,200-19,700 mentally retarded individuals in the state are estimated to be unserved or underserved. The sources are used to develop these estimates are summarized on Tables 2.4 and 2.5.

Both of these estimates are probably high because they include persons who do not require additional assistance or are not eligible for DMH/MR services. For example, the prevalence-based estimate of 19,700 unserved includes individuals receiving adequate services from DMH and other state agencies. The estimate of 14,200 unserved and underserved is also high because it includes mentally ill and mildly retarded individuals in Ch. 766 programs. For other groups, however, such as mentally retarded in nursing homes, this estimate may be low. Further detail on the limitations of the estimates is also provided in Tables 2.4 and 2.5.

Finally, the estimated range of unserved/underserved mentally retarded reported here is not appropriate for use in developing a housing plan. The estimate of 19,700 unserved, for example, includes DMH clients who do not need residential placements. Data from surveys of the unserved and underserved also indicate that not all of these individuals
TABLE 2.4

SOURCES USED TO DETERMINE PREVALENCE-BASED ESTIMATE OF UNSERVED

<table>
<thead>
<tr>
<th>Population</th>
<th>Estimate Used</th>
<th>Source of Estimate</th>
<th>Limitations of Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mentally Retarded Residing in Mass.</td>
<td>29,000</td>
<td>DMH Prevalence Rate (.05%) Multiplied by Mass Population (5.8 Million)</td>
<td>Prevalence Estimate is Lower Than That Used by Other Agencies</td>
</tr>
<tr>
<td>Mentally Retarded Now Served by the State</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) In DMH/MR State Schools and Regional Centers</td>
<td>(3,880)</td>
<td>DMH FY 85 Capital Budget Request</td>
<td>Contradicts Other Data on Mentally Retarded Served in Institutions</td>
</tr>
<tr>
<td>b) In DMH/MR Community Residences</td>
<td>(3,350)</td>
<td>DMH FY 85 Capital Budget Request</td>
<td>Same as Above</td>
</tr>
<tr>
<td>c) Receiving Other DMH/MR Services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day Services</td>
<td>(2,113)</td>
<td>DMH FY 85 Capital Budget Request</td>
<td>Includes Some Persons Who Require Housing Placements</td>
</tr>
<tr>
<td>Respite Care</td>
<td>(?)</td>
<td></td>
<td>Number of Individuals Now Served and in Need of Housing Not Known.</td>
</tr>
<tr>
<td>Support Services</td>
<td>(?)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Served by Other State Agencies</td>
<td>(?)</td>
<td></td>
<td>Same as Above</td>
</tr>
<tr>
<td>Prevalence-Based Estimate of the Unserved Mentally Retarded</td>
<td>19,657</td>
<td>Massachusetts Mentally Retarded Population Less Those Served by the State</td>
<td></td>
</tr>
<tr>
<td>Population</td>
<td>Estimate Used</td>
<td>Source of Estimate</td>
<td>Limitations of Estimate</td>
</tr>
<tr>
<td>------------</td>
<td>---------------</td>
<td>--------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Estimate of Unserved</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) On DMH/MR Waiting Lists</td>
<td>2,467</td>
<td>DMH/MR Waiting List, Includes Persons Identified Since 9/82</td>
<td>Waiting lists tend to over estimate need.</td>
</tr>
<tr>
<td>b) In Ch. 766 Programs</td>
<td>7,898</td>
<td>Dept. Education &quot;After 22&quot; Survey, 1982. Based on averages of student population and prevalence of cognitive disability among students.</td>
<td>May include mentally ill, mildly retarded. Persons 3-17 were not identified by survey; but estimated.</td>
</tr>
<tr>
<td>Subtotal Unserved</td>
<td>10,365</td>
<td></td>
<td>double counts persons on waiting lists &amp; in Ch. 766 Programs</td>
</tr>
<tr>
<td>Estimate of Underserved</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) In State Mental Institutions</td>
<td>570</td>
<td>Average of estimates reported by MARC and DMH.</td>
<td>Includes dual diagnosis clients not in mental institutions; more recent data indicates smaller numbers.</td>
</tr>
<tr>
<td>b) In Nursing Homes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Nursing Homes</td>
<td>2,329</td>
<td>Estimate Reported by DMH/MR.</td>
<td>Lower than estimates reported by MARC.</td>
</tr>
<tr>
<td>Pediatric Nursing Homes</td>
<td>225</td>
<td>Lower estimate reported by DMH/MR.</td>
<td>Same as Above</td>
</tr>
<tr>
<td>c) In DSS Custody</td>
<td>750</td>
<td>Estimate by MARC</td>
<td>Based on questionable assumption that one-half of DSS clients are mentally retarded.</td>
</tr>
<tr>
<td>Subtotal Underserved</td>
<td>3,874</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Unserved/Underserved</td>
<td>14,239</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
require DMH/MR housing. Perhaps most important, both sets of estimates include children who are not currently eligible for services. In this regard, two further steps are necessary to estimate the number of mentally retarded individuals who need residential services now and in the future.
STEP TWO: ESTIMATE OF THE UNSERVED/UNDERSERVED MENTALLY RETARDED BY AGE GROUP

In this step, the estimated range of unserved and underserved mentally retarded is broken down into two age groups, children and adults. This analysis is conducted prior to estimating the number in need of DMH/MR housing for two reasons. First, because research indicates that the prevalence and severity of mental retardation is different for children and adults, their housing needs are also likely to be different. Second, since DMH's Division of Mental Retardation does not officially serve children, breaking down the unserved by age gives a sense of the number currently in need of services (adults) and the number in need of future assistance (children).

The methodology used in this step is the same as that used in step one. As depicted in Figure 2.4, estimates of the prevalence of mental retardation by age lead to estimates of 3,191 unserved adults and 16,466 unserved children. At the bottom of the figure, data from surveys or counts of the unserved and underserved indicate that 4,992 of these are adults and 9,247 are children.

Prevalence-Based Estimate of the Unserved Mentally Retarded:

3,191 Adults 16,466 Children

This estimate of the unserved and underserved is based on estimates of the prevalence of mental retardation by age. The problem with this approach is that estimates of the prevalence of retardation by age vary depending on how the population is studied. This variation is depicted in the Tables 2.6 and 2.7 which report estimates developed by Tarjan, Wright, Eyman and Keeran and by Baroff. As shown in Table 2.6, these researchers use different estimates of the overall prevalence of mental
FIGURE 2.4
ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED BY AGE GROUP

ESTIMATED PREVALENCE OF MENTALLY RETARDED ADULTS IN MASSACHUSETTS
= 0.2% X 5.8 MILLION
= 11,600

LESS ADULTS SERVED BY STATE: 8,409
PREVALENCE-BASED ESTIMATE OF UNSERVED ADULTS: 3,191

ESTIMATED PREVALENCE OF MENTALLY RETARDED CHILDREN IN MASSACHUSETTS
= 0.3% X 5.8 MILLION
= 17,400

LESS CHILDREN SERVED BY STATE: 934
PREVALENCE-BASED ESTIMATE OF UNSERVED CHILDREN: 16,466

ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED BY AGE GROUP:
ADULTS 3,191-4,992
CHILDREN 9,247-16,466

SURVEY OR COUNT-BASED ESTIMATE OF UNSERVED/UNDERSERVED:
ADULTS 4,992
CHILDREN 9,247

ESTIMATE OF UNSERVED:
ADULTS 2,131
CHILDREN 8,234

IN CH. 766 PROGRAMS:
ADULTS 0
CHILDREN 7,898

IN STATE MENTAL INSTITUTIONS:
ADULTS 532
CHILDREN 38

IN NURSING HOMES:
ADULTS 2,329
CHILDREN 225

IN DSS CUSTODY:
ADULTS 0
CHILDREN 750

SURVEYS OR COUNTS OF THE UNSERVED/UNDERSERVED MENTALLY RETARDED
### Table 2.6
ESTIMATES OF THE PREVALENCE OF MENTAL RETARDATION BY AGE

<table>
<thead>
<tr>
<th>Source of Estimate</th>
<th>Children (under age 20)</th>
<th>Adults</th>
<th>Overall Prevalence in Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tarjan, Wright, Eyman, and Keeran&lt;sup&gt;1&lt;/sup&gt;</td>
<td>.76%</td>
<td>.24%</td>
<td>1%</td>
</tr>
<tr>
<td>Baroff&lt;sup&gt;2&lt;/sup&gt;</td>
<td>.17%</td>
<td>.24%</td>
<td>.4%</td>
</tr>
</tbody>
</table>

### Table 2.7
ESTIMATES OF THE PREVALENCE OF MENTAL RETARDATION BY AGE AND LEVEL OF RETARDATION

<table>
<thead>
<tr>
<th>Source of Estimate</th>
<th>Mildly Retarded</th>
<th>Moderate to Severely Retarded</th>
<th>Profoundly Retarded</th>
<th>Mildly Retarded</th>
<th>Moderate to Severely Retarded</th>
<th>Profoundly Retarded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tarjan, Wright, Eyman, and Keeran&lt;sup&gt;1&lt;/sup&gt;</td>
<td>.62%</td>
<td>.11%</td>
<td>.03%</td>
<td>.13%</td>
<td>.09%</td>
<td>.02%</td>
</tr>
<tr>
<td>Baroff&lt;sup&gt;2&lt;/sup&gt;</td>
<td>--</td>
<td>.16%</td>
<td>.02%</td>
<td>--</td>
<td>.22%</td>
<td>.02%</td>
</tr>
</tbody>
</table>


<sup>2</sup>Baroff, George S. "Predicting the Prevalence of Mental Retardation in Individual Catchment Areas." *Mental Retardation* 23(3) June 1982, pp. 134-135.
retardation and of the prevalence of mentally retarded children in the population. These differences are explained in Table 2.7, which shows that Tarjan and his co-authors include the mildly retarded in their estimates, while Baroff does not. This leads Tarjan to a higher overall prevalence estimate and, since many of the mildly retarded are children, a proportionately higher estimate of retarded children.

A further problem with these prevalence estimates is that they are not based on the DMH/MR definition of mental retardation. The DMH/MR prevalence estimate of 0.5% is based on a definition that includes mildly retarded individuals only if they have other severely handicapping conditions. The 1% prevalence estimate used by Tarjan and his co-authors, however, includes all the mildly retarded, while Baroff's prevalence estimate of 0.4% does not include any of the mildly retarded.

Because of these problems, I adjusted the estimates reported by Tarjan, Wright, Eyman and Keeran to make them compatible with the DMH/MR prevalence rate.(17) This was done by reducing mildly retarded population reported by Tarjan and his co-authors by two-thirds. The one-third remaining are assumed to represent mildly retarded individuals who have other disabilities that make them eligible for DMH/MR services. On the basis of these assumptions, approximately 0.2% of the Massachusetts population is estimated to be mentally retarded adults, and 0.3% mentally retarded children.

These prevalence rates imply that 11,600 mentally retarded adults and 17,400 mentally retarded children reside in Massachusetts. Subtracting off children and adults currently served by DMH/MR gives estimates of the unserved mentally retarded population by age. Unfortunately, data on the age of DMH/MR clients were not available, so
estimates were used instead. Because DMH/MR serves children only in cases of emergency, I assume that, at most, 10% of those served by DMH/MR are children. Based on this assumption, 3,200 adults are estimated to be currently in need of services, while 16,500 children are estimated to require services over the next twenty years.

Survey or Count-Based Estimate of Unserved/Underserved Mentally Retarded:

<table>
<thead>
<tr>
<th>Adults</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>4,992</td>
<td>9,247</td>
</tr>
</tbody>
</table>

According to surveys or counts of the unserved, some 5,000 adults and 9,200 children require DMH/MR services. These estimates are, for the most part, based on the same data and assumptions as those used in step one. The only exception is the estimate of mentally retarded residing in mental institutions. In this case, estimates are based on data from DMH's dual diagnosis task force because this is the only source which reported information on the population's age. Sources used to develop other estimates are listed on Table 2.8.

Table 2.8 shows that proportionately more children are unserved, while proportionately more adults are underserved. This is because the unserved population includes a large number of students who are not yet eligible for DMH services. The underserved population includes proportionately fewer children because mental institutions serve children only in emergency cases, and because most of those in nursing homes are adults.

_analysis of Estimates Developed in Step Two_

In this step, prevalence rates lead to a lower estimate of unserved mentally retarded adults than do data from surveys or counts. On the other hand, prevalence rates lead to an estimate of unserved children
<table>
<thead>
<tr>
<th>Population</th>
<th>Total</th>
<th>Adults</th>
<th>Children</th>
<th>Source of Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimate of Unserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) On DMH/MR Waiting Lists</td>
<td>2,467</td>
<td>2,131</td>
<td>336</td>
<td>DMH/MR Waiting List (indicates age of Individual)</td>
</tr>
<tr>
<td>b) In Ch. 766 Programs</td>
<td>7,898</td>
<td>-0-</td>
<td>7,898</td>
<td>&quot;After 22 Survey&quot; (all are under 22)</td>
</tr>
<tr>
<td>Subtotal Unserved</td>
<td>10,365</td>
<td>2,131</td>
<td>8,234</td>
<td></td>
</tr>
<tr>
<td>Estimate of Underserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) In State Mental Institutions</td>
<td>570</td>
<td>532</td>
<td>38</td>
<td>Report by DMH MR/MI task force indicates that 6.6% dual diagnosis clients are under age 22.</td>
</tr>
<tr>
<td>b) In Nursing Homes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Nursing Homes</td>
<td>2,329</td>
<td>2,329</td>
<td>-0-</td>
<td>DMH Estimate</td>
</tr>
<tr>
<td>Pediatric Nursing Homes</td>
<td>225</td>
<td>-0-</td>
<td>225</td>
<td>DMH Estimate</td>
</tr>
<tr>
<td>c) In DSS Custody</td>
<td>750</td>
<td>-0-</td>
<td>750</td>
<td>Estimate by MARC (all children or adolescents)</td>
</tr>
<tr>
<td>Subtotal Underserved</td>
<td>3,874</td>
<td>2,861</td>
<td>1,013</td>
<td></td>
</tr>
<tr>
<td>Total Unserved/Underserved</td>
<td>14,239</td>
<td>4,992</td>
<td>9,247</td>
<td></td>
</tr>
</tbody>
</table>
that is 78% higher than that reported in surveys of the unserved and underserved. This disparity may be the result of two factors. First, assumptions made regarding estimates of the prevalence of retardation by age and the percentage of children served by DMH/MR may have led to an overestimate of unserved children. Second, surveys or counts may underestimate the number of retarded children in need of services since surveys identify only those who are known to require services and children are not yet eligible for DMH/MR assistance.

Both sets of estimates show a higher proportion of children than is found in the general population. According to the 1980 census, 34% of the Massachusetts population is under age 22. In contrast, estimates based on prevalence rates indicate that 84% of the unserved mentally retarded are children, while data from surveys and counts indicate that 65% are children. The percentages of unserved retarded children are higher because, as has been discussed, most of the mentally retarded population is comprised of children.

For planning purposes, estimates of unserved retarded adults are of more critical importance than estimates of unserved children. This is because children are not currently eligible for, nor in need of, DMH/MR services. Furthermore, not all the 9,200 to 16,500 children estimated will be requiring services at one time. Instead, they will be demanding services incrementally over the next twenty to twenty-two years. It can also be assumed that children will be requesting assistance at approximately the same rate that adults will be leaving the DMH service system because of death or other circumstances. Thus, when planning services for the mentally retarded, only the estimates of unserved adults should be considered. Estimates of children are important to the
planning process only because they indicate how the demand for state services might change in the future.

**STEP THREE: ESTIMATE OF THE UNSERVED/UNDERSERVED MENTALLY RETARDED IN NEED OF HOUSING BY AGE GROUP**

The final step is to estimate the number of mentally retarded adults and children who require DMH/MR housing. The results of this analysis are presented in Figure 2.5, and indicate that between 2,465 and 2,474 mentally retarded adults are currently in need of housing while some 5,837 to 9,699 mentally retarded children will need housing in the future.

**Prevalence-Based Estimate of Unserved Mentally Retarded in Need of Housing:**

2,474 Adults 9,699 Children

Estimates developed in this step are based on the prevalence of a single characteristic among mentally retarded individuals currently served by the state. They are not based on national statistics or more general prevalence rates because these sources do not specifically address the need for publically provided housing among the mentally retarded.

The characteristic studied in this analysis is the same one DMH/MR uses to assess the housing needs of its clients. This characteristic concerns clients' "capability of self-preservation", or ability to evacuate a building quickly and without assistance in cases of emergency. Not all clients served by DMH are capable of self-preservation, and the degree of assistance needed to evacuate determines the type of facility in which they should live. For example, persons able to evacuate with verbal instruction require housing with lower staff-client ratios than persons who need physical assistance to evacuate. To determine specific
FIGURE 2.5
ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED IN NEED OF HOUSING BY AGE GROUP

DMH/MR CLIENTS' LEVEL OF SELF-PRESERVATION CAPABILITY
PREVALENCE-BASED ESTIMATE OF UNSERVED ADULTS IN NEED OF HOUSING: 2,474

CH. 766 STUDENTS' LEVEL OF SELF-PRESERVATION CAPABILITY
PREVALENCE-BASED ESTIMATE OF UNSERVED CHILDREN IN NEED OF HOUSING: 9,699

ESTIMATED RANGE OF UNSERVED/UNDERSERVED MENTALLY RETARDED IN NEED OF HOUSING BY AGE GROUP:
ADULTS 2,465-2,474
CHILDREN 5,837-9,699

SURVEY OR COUNT-BASED ESTIMATE OF UNSERVED/UNDERSERVED IN NEED OF HOUSING:
ADULTS 2,465
CHILDREN 5,837

ESTIMATE OF UNSERVED IN NEED OF HOUSING:
ADULTS 1,442
CHILDREN 5,546

ESTIMATE OF UNDERSERVED IN NEED OF HOUSING:
ADULTS 1,023
CHILDREN 291

ON DMH/MR WAITING LISTS:
ADULTS 1,442
CHILDREN 236

IN CH. 766 PROGRAMS:
ADULTS 0
CHILDREN 5,310

IN STATE MENTAL INSTITUTIONS:
ADULTS 348
CHILDREN 25

IN NURSING HOMES:
ADULTS 675
CHILDREN 166

IN DSS CUSTODY:
ADULTS 0
CHILDREN 100

SURVEYS OR COUNTS OF THE UNSERVED/UNDERSERVED MENTALLY RETARDED
housing needs, DMH classifies its clients according to four general levels of "capability":

(1) **Unimpaired**: "capable of exiting the facility without physical assistance and/or supervision or instruction by staff, within two and one-half (2 1/2) minutes."

(2) **Ambulatory/Partially Impaired**: able to walk without assistance, and able to evacuate within 2 1/2 minutes "without any physical assistance but with supervision or instruction."

(3) **Ambulatory/Impaired**: able to walk without assistance, require physical assistance to evacuate the facility in 2 1/2 minutes.

(4) **Non-Ambulatory/Impaired**: same as (3) above, except unable to walk without assistance.(19)

Data on the relative capability of the mentally retarded now served by the state are available from two sources, the Massachusetts Service Coordination Battery (MSCB) used by DMH/MR, and the "After 22" survey conducted by the Department of Education. I use the MSCB to represent characteristics of the adult mentally retarded since most of those served by DMH/MR are adults. Data from the "After 22" survey are used to represent the characteristics of mentally retarded children under age 22.

The following tables summarize data from the MSCB on the relative capability of clients served by DMH. The data are organized according to clients' current residence and class status.(20) Table 2.9(a) shows that the majority of class clients are not capable of self-preservation without some assistance. According to Table 2.9(b), non-class clients show a much higher level of capability. These differences are expected since most of the housing available to non-class clients is designed for
### Tables 2.9(a) & (b)

**Self-Preservation by Class Member Status and Residential Setting Based on Massachusetts Service Coordination Battery**

#### (a) Class Clients

<table>
<thead>
<tr>
<th>Level of Self-Preservation Ability</th>
<th>RESIDENTIAL SETTING</th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
<th>Overall %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Living By Self/With Family</td>
<td>Group Living Arrang.</td>
<td>Congregate Care</td>
<td>School/Regional Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unimpaired</td>
<td>456</td>
<td>862</td>
<td>146</td>
<td>832</td>
<td>2,296</td>
<td>41.1%</td>
</tr>
<tr>
<td>Ambulatory/Partially Impaired</td>
<td>34</td>
<td>152</td>
<td>24</td>
<td>1,333</td>
<td>1,543</td>
<td>27.6%</td>
</tr>
<tr>
<td>Ambulatory/Impaired</td>
<td>9</td>
<td>42</td>
<td>14</td>
<td>746</td>
<td>811</td>
<td>14.5%</td>
</tr>
<tr>
<td>Non-Ambulatory/Impaired</td>
<td>13</td>
<td>25</td>
<td>20</td>
<td>879</td>
<td>937</td>
<td>16.8%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>512</strong></td>
<td><strong>1,081</strong></td>
<td><strong>204</strong></td>
<td><strong>3,790</strong></td>
<td><strong>5,587</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

#### (b) Non-Class Clients

<table>
<thead>
<tr>
<th>Level of Self-Preservation Ability</th>
<th>RESIDENTIAL SETTING</th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
<th>Overall %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Living By Self/With Family</td>
<td>Group Living Arrang.</td>
<td>Congregate Care</td>
<td>School/Regional Center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unimpaired</td>
<td>1,341</td>
<td>701</td>
<td>388</td>
<td>79</td>
<td>2,509</td>
<td>73.0%</td>
</tr>
<tr>
<td>Ambulatory/Partially Impaired</td>
<td>196</td>
<td>119</td>
<td>64</td>
<td>93</td>
<td>472</td>
<td>13.7%</td>
</tr>
<tr>
<td>Ambulatory/Impaired</td>
<td>100</td>
<td>27</td>
<td>35</td>
<td>66</td>
<td>228</td>
<td>6.6%</td>
</tr>
<tr>
<td>Non-Ambulatory/Impaired</td>
<td>97</td>
<td>13</td>
<td>40</td>
<td>78</td>
<td>228</td>
<td>6.6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1,734</strong></td>
<td><strong>860</strong></td>
<td><strong>527</strong></td>
<td><strong>316</strong></td>
<td><strong>3,437</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

---

1. Massachusetts Department of Mental Health, Division of Mental Retardation. *Special Report on Self-Preservation Status for the Division of Capital Planning and Operations: Self-Preservation Status by Class Member Status and Residential Setting Based on Massachusetts Service Coordination Battery* (Boston: Massachusetts Department of Mental Health, January 1984) pp. 1-3.
persons with high levels of capability.

To develop estimates of the number of unserved mentally retarded adults in need of housing, data from the MSCB are applied to the prevalence-based estimate of the unserved. A weighted average of the relative capability of class and non-class clients is used to account for differences in the overall size of each group and differences mentioned above regarding their capabilities. These averages are listed below. (See Appendix B for calculations.)

(1) % Clients Unimpaired: 53.2%
(2) % Clients Ambulatory/Partially Impaired: 22.3%
(3) % Clients Ambulatory/Impaired: 11.5%
(4) % Clients Non-Ambulatory/Impaired: 12.9%

Applying these percentages to the prevalence-based estimate of 3,191 unserved mentally retarded adults, the following estimates result:

(1) # Unserved adults Unimpaired: 1,699
(2) # Unserved adults Ambulatory/Partially Impaired: 713
(3) # Unserved adults Ambulatory/Impaired: 367
(4) # Unserved adults Non-Ambulatory/Impaired: 412

To estimate the number of adult unserved mentally retarded requiring DMH/MR housing, I make several adjustments to the estimates reported above. Each of the estimates developed so far includes persons who live by themselves or with family. I assume that unimpaired or ambulatory/partially impaired persons who live alone or with family are, at least for the time being, adequately housed. Because of their condition, persons classified as ambulatory/impaired or non-ambulatory/impaired are considered to require housing regardless of their current living situation. (21) These assumptions lead to lower estimates of unserved
mentally retarded adults in need of DMH/MR housing. (For detailed calculations see Appendix B.)

1. # Unserved adults Unimpaired in need of housing: 1,064 (33.3%)

2. # Unserved adults Ambulatory/Partially Impaired in need of housing: 631 (19.8%)

3. # Unserved adults Ambulatory/Impaired in need of housing: 367 (11.5%)

4. # Unserved adults Non-Ambulatory/Impaired in need of housing: 412 (12.9%)

A total of 2,474 or 78% of the unserved mentally retarded adults are thereby estimated to need DMH/MR housing.

To estimate the future housing needs of unserved mentally retarded children, I use a similar procedure based on comparable data from the Department of Education's survey of Chapter 766 students. These data, reported in Table 2.10, indicate that children in Ch. 766 programs are somewhat more capable of self-preservation than DMH/MR clients. Estimates of the number in need of housing are derived by multiplying the percentages reported in Table 2.10 times the prevalence-based estimate of 16,466 unserved mentally retarded children. As with the adult population, persons classified as unimpaired or ambulatory/partially impaired are excluded from the calculation if they are considered capable of independent living. This leads to the following estimates:

1. # Unserved children Unimpaired in need of housing: 4,296 (26.1%)

2. # Unserved children Ambulatory/Partially Impaired in need of housing 3,175 (19.3%)

3. # Unserved children Ambulatory/Impaired in need of housing: 1,073 (6.5%)

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### TABLE 2.10

**LEVELS OF SELF-PRESERVATION ABILITY AND PROJECTED LIVING SITUATION AMONG CHAPTER 766 STUDENTS**

<table>
<thead>
<tr>
<th>Level of Self-Preservation Ability</th>
<th>Level of Living Situation Projected</th>
<th>Overall %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Independent Living (no on-site assistance)</td>
<td>Group Living (on-site supervision and assistance)</td>
</tr>
<tr>
<td>Unimpaired</td>
<td>1,421</td>
<td>915</td>
</tr>
<tr>
<td>Ambulatory/Partially Impaired</td>
<td>143</td>
<td>649</td>
</tr>
<tr>
<td>Abulatory/Impaired</td>
<td>37</td>
<td>129</td>
</tr>
<tr>
<td>Non-Ambulatory/Impaired</td>
<td>35</td>
<td>56</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1,636</strong></td>
<td><strong>1,749</strong></td>
</tr>
</tbody>
</table>

---

1. Massachusetts Department of Education, Division of Special Education. The "After 22" Survey, Survey Report #1: Statewide Summary (Quincy: Massachusetts Department of Education, July 1982) Table 10 "Incidence of levels of self-preservation ability and levels of projected living situation", p. 28.

### NOTES

Survey only identified 3,625 students. Some students are therefore double counted on this table. According to the survey, "respondents, in some cases interpreted the independent living item...as a possibility - if available - but also checked the group living items...as a parallel possibility," (p. 9).
The estimate of unserved mentally retarded children requiring housing assistance in the future is therefore 9,699 or 59% of the unserved population under the age of 22.

These estimates assume that the unserved mentally retarded have the same characteristics and capabilities as mentally retarded individuals currently served by the state. Unfortunately this assumption cannot be tested since sample data on the relative capabilities of unserved mentally retarded are not available. However, it can probably be assumed that many of those who are unserved are so because they do not need services. As a result, estimates reported in this analysis may again overestimate the actual number in need of state services.

These estimates also do not take into account the fact that some of those included in the prevalence-based estimate of the unserved do not require state housing services. In step one, persons receiving respite care and support services from DMH and retarded served by other state agencies were counted as unserved even though some do not need housing placements. However, because data on the housing needs of these individuals are not available, they have only been subtracted from the estimate if they are classified as unimpaired or ambulatory/partially impaired and living by themselves or with family.

Survey or Count-Based Estimate of Unserved/Underserved Mentally Retarded in Need of Housing: 2,465 Adults 5,837 Children

If the same percentages derived above are applied to the survey or count-based estimates of 4,992 adults and 9,247 children, the following estimates result:
(1) # Unserved/underserved adults in need of housing: 3,869
   (78% unserved/underserved adults)

(2) # Unserved/underserved children in need of housing: 5,446
   (59% unserved/underserved children)

In contrast, data on the actual service needs of the unserved/underserved mentally retarded indicate that fewer adults and more children require state housing assistance:

(1) # Unserved/underserved adults in need of housing: 2,465
   (49% unserved/underserved adults)

(2) # Unserved/underserved children in need of housing: 5,837
   (63% unserved/underserved children)

This second set of estimates is based on data from the same sources used in steps one and two. For each group of mentally retarded individuals identified as unserved or underserved, estimates are available on the number in need of state provided housing. These estimates are suggested by the agencies that collected data on the unserved or underserved, or, as in the case of Chapter 766 students, developed on the basis of other relevant information. The sources of estimates used in this step are summarized in Table 2.11.

In comparison to estimates based on the capabilities of clients served by the state, data from surveys of the unserved and underserved indicate that a higher percentage of children and lower percentage of adults need housing. For children, the estimates are higher because they are largely based on "After 22" survey data which show a greater need for housing among students than is indicated by their level of capability.(22) For adults, estimates of the number in need of housing may be lower for political reasons. Most of the adults are "underserved" and state agencies are unlikely to admit that a large number of individuals fall into this category.
<table>
<thead>
<tr>
<th>Population</th>
<th>Total Unserved/Underserved</th>
<th>Adults In Need of Housing</th>
<th>Children In Need of Housing</th>
<th>Source of Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimate of Unserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) On DMH Waiting Lists</td>
<td>2,467</td>
<td>1,442</td>
<td>236</td>
<td>DMH/MR Waiting Lists</td>
</tr>
<tr>
<td>b) In Ch. 766 Programs</td>
<td>7,898</td>
<td>-0-</td>
<td>5,310</td>
<td>&quot;After 22&quot; Survey; based on data that indicates that 68% of all students graduating in 1984, 1985, 1987, will need housing. This percentage also applied to graduates in years 1989-2003. Of those graduating in 1986, 1987, 62% need housing.¹</td>
</tr>
<tr>
<td>Subtotal Unserved</td>
<td>10,365</td>
<td>1,442</td>
<td>5,546</td>
<td></td>
</tr>
<tr>
<td>Estimate of Underserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) In State Mental Institutions</td>
<td>570</td>
<td>346</td>
<td>25</td>
<td>Housing need based on average of individuals reported to need housing by DMH and MARC. Age breakdown same as Table 2.8.</td>
</tr>
<tr>
<td>b) In Nursing Homes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Nursing Homes</td>
<td>2,329</td>
<td>675</td>
<td>-0-</td>
<td>DMH Estimate</td>
</tr>
<tr>
<td>Pediatric Nursing Homes</td>
<td>225</td>
<td>-0-</td>
<td>166</td>
<td>DMH Estimate</td>
</tr>
<tr>
<td>c) In DSS Custody</td>
<td>750</td>
<td>-0-</td>
<td>100</td>
<td>MARC Estimate</td>
</tr>
<tr>
<td>Subtotal Underserved</td>
<td>3,874</td>
<td>1,023</td>
<td>291</td>
<td></td>
</tr>
<tr>
<td>Total Unserved/Underserved</td>
<td>14,239</td>
<td>2,465</td>
<td>5,837</td>
<td></td>
</tr>
</tbody>
</table>

¹Massachusetts Department of Education, Division of Special Education. The "After 22" Survey, Survey Report #1: Statewide Summary (Quincy: Massachusetts Department of Education, July 1982) Table 9: "Reported number of individuals in need of specialized group living, nursing homes, or hospital situation”, p. 27.
Analysis of Estimates Developed in Step Three

In this third step, three estimates of the number of unserved and underserved mentally retarded in need of housing were developed. These three sets of estimates indicate that between 2,465 and 3,869 mentally retarded adults currently require housing assistance while 5,446 to 9,699 children may need housing once they reach age twenty-two.

For planning purposes, I consider estimates based on surveys or counts of the unserved more representative of actual housing need because they generally consider more than one indicator of housing need and are based on evaluations conducted by trained professionals. For example, estimates of the housing needs of children under DSS custody are based not only on the client's level of impairment, but also on the willingness of adoptive or natural families to care for these children. In the case of persons on DMH waiting lists, determinations of housing need are made by DMH Area Office staff who are experienced in needs assessment and familiar with the criteria used to place clients.

In addition, both estimates of the number of unserved children requiring housing are less accurate than estimates of unserved adults. This is because estimates for children are based largely on data from the "After 22" survey which only identified students aged 17-22. In this analysis, I assume that students between the ages of 3 and 17 will have the same housing needs as older students who were identified by the survey. However, whatever problems that result from this assumption are again not of critical importance since children are not in immediate need of services.
CONCLUSIONS

To address the difficulties of estimating the unserved and underserved mentally retarded, a methodology was developed based on approaches other states and localities have used. This methodology uses both mental retardation prevalence rates and data from surveys or counts of the unserved and underserved mentally retarded. On the basis of this methodology, three ranges of estimates were developed:

(1) Estimate of the unserved/underserved mentally retarded population in Massachusetts: 14,239-19,657

(2) Estimate of the unserved/underserved mentally retarded by age:
   adults currently in need: 3,191- 4,992
   children in need of services over the next twenty years: 9,247-16,466

(3) Estimate of the unserved/underserved mentally retarded in need of housing by age (23):
   adults currently in need: 2,465- 2,474
   children in need of services over the next twenty years: 5,837- 9,699

Each of these ranges probably overestimates the number of individuals in need of DMH/MR services. This is especially true for estimates of unserved and underserved mentally retarded children. The reason estimates are high are summarized below.

(1) Prevalence-Based Estimates
   * Include mentally retarded served by DMH and other state agencies who do not require housing placements.
   * Are based on assumptions regarding the prevalence of retardation by age and the age of DMH/MR clients which seem to inflate estimates of unserved children.
   * Use data on the relative capability of mentally retarded
served by the state to estimate housing need. This assumes that the unserved share characteristics similar to those currently receiving assistance. In reality, the unserved probably have less severe needs and require fewer services.

(2) **Survey or Count-Based Estimates**

* Use data from DMH waiting lists which tend to exaggerate unserved need.

* Includes individuals not eligible for DMH/MR services, such as mildly retarded and mentally ill students of Ch. 766 programs.

* Are based on the assumption that Ch. 766 students aged 3-17 will have the same housing needs as older students upon turning 22. In fact, their future housing needs are not yet known.

* Use the mean of available data to estimate the number of mentally retarded in mental institutions. The resulting estimate is higher than recent estimates.

These estimates are further limited in that they present only a static picture of the mentally retarded in need of state services. For example, these estimates do not consider mortality rates of the retarded, nor changes in clients' capability of self-preservation over time. In estimating the need for housing, I have also not addressed the possibility that some individuals now living at home will eventually require housing. While these factors will certainly change the demand for housing services, they have not been considered because available data do not provide this level of detailed information on the unserved.
Despite these problems, I believe my estimates are within 10 to 20% of an accurate number for two reasons. First, because they consider all the available information on the unserved, these estimates are the best that can be developed at this time. Second, given that estimates are based on incomplete data and wide ranging assumptions, information on clients' mortality or changes in their capability and family situation would not substantially improve the results.

The estimates presented here provide a basis on which state plans can be developed. Estimates indicate that approximately 3,200 to 5,000 mentally retarded adults currently require some form of state services. Of these, some 2,500 adults require placement in DMH/MR housing facilities. Estimates also indicate that between 9,200 and 16,500 children will be demanding services over the next twenty years. Between 5,800 and 9,700 of these will require housing at approximately the same rate that retarded adults will be vacating units as a result of death or need for other services.

To develop a workable housing plan, however, further information on the unserved mentally retarded is required. This information concerns the type of housing the unserved mentally retarded require. The following chapter breaks down the estimates developed here according to the type of housing needed by the unserved mentally retarded adults and children.
(1) This process of adding or substituting information into the analysis has been facilitated by setting up the estimation model using microcomputer spreadsheet software.

(2) See Chapter One, page 28 for description of DMH prevalence rate.

(3) In fact, the comparison is a fair one since MSCB data also includes persons who live at home or with family and receive day services from DMH/MR.

(4) Massachusetts Department of Mental Health, Division of Mental Retardation. 5016-0104 Summary Report: Non-Class Clients Requesting Services, First Quarter, 7/1/83 - 9/30/83 (Boston: Massachusetts Department of Mental Health, December 1983).


(6) Interview with DMH Area Officer, February 16, 1984.


(8) Massachusetts Department of Education. The "After 22" Survey. Survey Report #2, p. 5. The Department of Education specifically suggests that averages, rather than actual counts, be used to estimate the student population. These are considered to be more accurate and reliable (see p. 14).


(10) Massachusetts Department of Education. The "After 22" Survey. Survey Report #2, p. 3. The figure reported here is based on an estimate of 382.7 students per year (86% x 445 = 382.7 x 15 = 5740.5).


(12) Moriearty, p. 17.
(13) Mark J.D. Mills, Commissioner, Massachusetts Department of Mental Health. Memorandum to Manuel Carballo, Secretary, Massachusetts Executive Office of Human Services (Boston, January 24, 1983) p. 11.

(14) James J. Callahan, Jr., Commissioner, Massachusetts Department of Mental Health. Memorandum to Frank T. Keefe, Secretary, Massachusetts Executive Office of Administration and Finance (Boston, January 31, 1984) pp. 5-7, 18-24.

(15) Mills, Memorandum to Manuel Carballo, pp. 11, 18.

(16) Moriearty, pp. 20-22.

(17) Estimates developed by Tarjan, Wright, Eyman and Keeran are used as a basis because they more accurately reflect variations in the prevalence of mental retardation by age. Unlike those developed by Baroff, these estimates take into account the mortality rates of the retarded and the different ways in which mental retardation is diagnosed. (See Chapter One, pp. 22-24.)


(19) Massachusetts Department of Mental Health, Division of Mental Retardation. Regulation Filing and Publication Form: 104 CMR 22.00 Mental Retardation/Facility Standards (Boston: Massachusetts Department of Mental Health, August 1983) p. 1. DMH/MR actually uses five categories: (1) Impaired, (2) Partially Impaired, (3) Unimpaired, (4) Ambulatory, (5) Non-Ambulatory. Categories are combined in this report to make them consistent with categories used in the MSCB and the "After 22" Survey.

(20) Note that the number of clients reported on the MSCB is different from the estimate used in step one. This is because the MSCB does not include data on all non-class clients served by DMH/MR (see step one, p. 50.)

(21) Certainly, not all those who are unimpaired or ambulatory/partially impaired have family able to provide care. Others may also have secondary impairments that limit their ability to live their own. Thus, my assumption that all these individuals are adequately housed may underestimate their actual housing need. This, however, is balanced by the fact that some ambulatory/impaired and non-ambulatory/impaired persons may be able to live alone or with family. For these individuals, my assumption that all require DMH/MR housing may overestimate actual housing need.

(22) Massachusetts Department of Education. The "After 22" Survey. Survey Report #1, pp. 27, 28. Estimates of students' levels of capability are from table 10, "Incidence of levels of self-preservation ability and levels of projected living situation." Estimates of students' need for specialized housing are from table 9, "Reported number of individuals in
need of specialized group living, nursing home, or hospital situations."

(23) Does not include estimates based on capabilities of those served by the state as applied to the 14,239 unserved identified in surveys or counts.
ESTIMATES OF THE TYPE OF HOUSING NEEDED
BY THE UNSERVED MENTALLY RETARDED
The cost of housing DMH/MR clients varies considerably according to the type of facility in which they are placed and the level of services they receive. In general, the most expensive housing is that which is built specially for the mentally retarded, has high staff-client ratios and provides medical care on-site. Serving individuals in these types of facilities currently costs between $47,100 and $80,300 per client, per year.\(^1\) Less expensive housing services use existing facilities adapted for the retarded and have fewer staff and services. The cost of serving clients in these facilities averages about $22,000 per year, but can be as low as $2,000.\(^2\)

In planning services for the unserved mentally retarded it is therefore important to know what type of housing they need. Given the variation in costs of providing housing, this information will enable the state to allocate its funds most effectively. Estimates of the unserved population's housing need will also help the state to avoid expensive mistakes, such as building highly specialized facilities that will be underutilized, and ensure that the unserved mentally retarded receive the type of assistance they need and deserve.

The ideal method of determining housing needs of the unserved retarded would be to develop Individual Service Plans (ISPs) for each individual. These plans are currently used for all DMH/MR clients as a means of deciding which services they need to realize "...the most self-fulfilling, independent, and socially integrated style of living possible...."\(^3\) Plans are developed only after clients have undergone comprehensive evaluations conducted by a number of health professionals. Plans are also updated annually to account for changes in an individual's
condition and need.(4)

The principal advantage of the ISP is that it takes into consideration all aspects of a client's condition and how they affect client's service needs. In planning housing services, then, not only are clients' self-preservation capabilities considered, but also their physical health, living skills and behavioral condition. In this way, the thorough evaluation that forms the basis of the ISP leads to the provision of the most appropriate services.

Obviously, Individual Service Plans have not been developed for the unserved mentally retarded. Unfortunately, the detailed information that goes into the preparation of these plans is also not available. While the unserved population's level of self-preservation capability can be estimated, there is not sufficient data from which to estimate the prevalence of other impairments among these individuals. Thus, of the 1,064 unserved adults estimated to be capable of exiting a facility without assistance, it is not known how many have other conditions (e.g. epilepsy, cerebral palsy, cancer) that indicate need for a higher level of housing service.

Even knowing what percentage of the mentally retarded have secondary impairments would not help in this matter because the individual's capability of self-preservation and the likelihood of having secondary impairments are not independent of one another. Rather, individuals are less likely to be capable of self-preservation if they have significant additional impairments.

Because of this lack of information, estimates of the type of housing needed by the unserved will necessarily be rough. Given that the prevalence of multiple impairments among the unserved is not known,
estimates of their need for any of the more than twenty housing services offered by DMH/MR cannot be generated. Instead, I derive estimates for four general types of facilities which are representative of the range of housing services provided by DMH/MR. These four general types of housing services are described below. (See Appendix C for a detailed description of DMH/MR facilities.)

(1) **Independent Living Services**

This category includes housing in which residents are responsible for their own care and are visited by DMH staff only occasionally. The category also includes the provision of respite care and support services to individuals in their own home. DMH/MR housing services in this category are specialized home care and cooperative apartments.

(2) **Group Living Situations with Light Staff Assistance**

This category includes housing in which staff-client ratios are relatively low and clients are able to care for themselves with some assistance. DMH/MR community residences and staffed apartments are examples of facilities in this category.

(3) **Group Living Situations for Individuals Who Require Moderate Staff Assistance and Some Medical Care**

Facilities included under this category have high staff-client ratios and medical care available. Residents of these facilities may require physical and/or medical assistance as a result of mobility impairments or illness. Facilities that provide services appropriate for these individuals include nursing homes and Intermediate Care Facilities for the Mentally Retarded, Type B (ICF/MR-B).

(4) **Housing for Individuals who Require Substantial Staff Assistance and Medical Care**

These facilities can serve individuals with more severe medical,
behavioral or physical conditions. They have, in the past, tended to be institutions, rather than community residences, and generally meet Title XIX Medicaid standards. They also have very high staff-client ratios. Examples of facilities in this category are hospitals, skilled nursing facilities, and DMH/MR State schools. Also included are Intermediate Care Facilities for the Mentally Retarded, Type A (ICF/MR-A), facilities which provide highly specialized services in a community-based setting.

To estimate the unserved population's need for any of these four housing types, I use a methodology similar to that used in the previous chapter. This methodology first uses information on individuals' ability to evacuate a building to generate one set of estimates and then data from surveys or approximate counts of the unserved/underserved to develop a second set. These two estimates, broken down by age, are summarized in Table 3.3 at the end of this chapter.

**ESTIMATES OF THE TYPE OF HOUSING NEEDED BY THE UNSERVED/UNDERSERVED MENTALLY RETARDED BY AGE GROUP**

**Prevalence Based Estimates**

Using information on the unserved mentally retarded population's capability of self-preservation, I developed estimates of their housing need. Drawing from estimates derived in Chapter Two, step three, I assume that the four levels of self-preservation capability correspond exactly to the four categories of housing. Thus, I assume that all those who are unimpaired and in need of DMH/MR housing require independent living services. Similarly, persons who are ambulatory/partially impaired are assumed to need housing with light staff assistance. Applying these assumptions to the prevalence-based estimate of unserved mentally retarded...
retarded adults results in the following distribution of housing need:

(1) # Unserved adults in need of independent living services: 1,064 (43%)

(2) # Unserved adults in need of housing with light staff assistance: 631 (25%)

(3) # Unserved adults in need of housing with moderate staff assistance and some medical care: 367 (15%)

(4) # Unserved adults in need of housing with substantial staff assistance and medical care: 412 (17%)

Estimates of the housing need of unserved mentally retarded children are derived using the same assumptions and data from the "After 22" survey. Since mentally retarded children are expected to take the place of adults as they pass away, these estimates again reflect only future trends in housing need. Based on estimates developed in Chapter Two, mentally retarded children will require the following types of housing over the next twenty years:

(1) # Unserved children in need of independent living services: 4,296 (44%)

(2) # Unserved children in need of housing with light staff assistance: 3,175 (33%)

(3) # Unserved children in need of housing with moderate staff assistance and some medical care: 1,073 (11%)

(4) # Unserved children in need of housing with substantial staff assistance and medical care: 1,155 (12%)

These two sets of estimates indicate that a majority of unserved mentally retarded require independent living services or housing with light staff supervision. Among adults currently in need, 69% are largely able to care for themselves, while 31% require moderate to heavy staff assistance and medical care. The need for housing with limited staff
assistance can also be expected to increase since estimates show that 77% of retarded children will likely require this type of housing upon turning twenty-two. On the basis of these estimates, the state's plan for housing the unserved should emphasize less specialized types of housing and include a capacity to expand this level of service.

However, the estimates developed above are only a very rough approximation of the actual housing need of the unserved mentally retarded. While the individual's self-preservation capability is a valuable indicator of housing need, it is not the only measure of importance. If, for example, an unimpaired person had a severe medical condition, then he or she would require housing that provided medical care on-site. Similarly, a non-ambulatory/impaired person with a family able to provide care could live at home if adequate support services were provided. Thus, these estimates reflect only general tendencies in the housing need of the unserved mentally retarded and must be checked against surveys and counts of the unserved/underserved.

Survey and Count-Based Estimates

Using information from surveys and counts of the mentally retarded identified as unserved or underserved, the following estimates of their housing need result:

<table>
<thead>
<tr>
<th>HOUSING TYPE</th>
<th>ADULTS</th>
<th>CHILDREN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent living services</td>
<td>338 (14%)</td>
<td>607 (10%)</td>
</tr>
<tr>
<td>Housing with light staff asst.</td>
<td>1,560 (64%)</td>
<td>4,352 (75%)</td>
</tr>
<tr>
<td>Housing with moderate staff asst.</td>
<td>230 (9%)</td>
<td>674 (12%)</td>
</tr>
<tr>
<td>Housing with heavy staff asst.</td>
<td>329 (13%)</td>
<td>204 (3%)</td>
</tr>
</tbody>
</table>

These estimates are, for the most part, drawn from the same sources as those used in steps one through three in Chapter Two. For example, estimates of housing needed by the unserved mentally retarded are again
based on data from DMH/MR waiting lists and the "After 22" survey. Sources used to develop other estimates are listed on Tables 3.1 and 3.2. These tables also present estimates of the housing needed by each subgroup of unserved and underserved mentally retarded by age.

In two cases, estimates are developed using an approach different from that used previously. In this analysis, for example, estimates derived for mentally retarded living in state mental institutions are no longer based on a mean of three estimates. In addition, estimates of the housing need of mentally retarded individuals living in nursing homes are based on data collected by MARC rather than DMH. These changes were made because approaches used earlier were not sufficient to develop estimates of housing need. The means by which these two estimates were developed are described below.

(1) Mentally Retarded in State Mental Institutions:

As stated in the previous chapter, there are three sources of information on the mentally retarded living in mental institutions. These sources and the information they provide on the housing need of mentally retarded living in mental institutions are as follows:

(1) MARC Estimate

According to MARC, 400 mentally retarded living in state mental institutions require alternative housing. Of these, MARC estimates that 40 need placement in housing with heavy staff assistance, 90 need housing with moderate staff supervision and 270 need housing with light staff supervision.(5)

(2) 1978 DMH Estimate

In 1978, DMH estimated that 551 of 781 mentally retarded in
<table>
<thead>
<tr>
<th>POPULATION</th>
<th>Independent Living Services</th>
<th>Housing with Light Staff Asst.</th>
<th>Housing with Moderate Staff Asst., Some Medical Care</th>
<th>Housing with Substantial Staff Asst., Medical Care</th>
<th>TOTAL</th>
<th>Source of Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimate of Unserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) On DMH/MR Waiting List</td>
<td>277</td>
<td>1,021</td>
<td>51</td>
<td>85</td>
<td>1,434</td>
<td>DMH/MR waiting list. (Housing need of 8 adults not indicated)</td>
</tr>
<tr>
<td>b) In Ch. 766 Programs</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>&quot;After 22&quot; Survey (all are children).</td>
</tr>
<tr>
<td>Subtotal Unserved</td>
<td>277</td>
<td>1,021</td>
<td>51</td>
<td>85</td>
<td>1,434</td>
<td></td>
</tr>
<tr>
<td>Estimate of Underserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) In Mental Institutions</td>
<td>-0-</td>
<td>144</td>
<td>48</td>
<td>156</td>
<td>348</td>
<td>DMH dual diagnosis task force and MARC estimates.</td>
</tr>
<tr>
<td>b) In Nursing Homes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Nursing Homes</td>
<td>61</td>
<td>395</td>
<td>131</td>
<td>88</td>
<td>675</td>
<td>DMH &amp; MARC estimates.</td>
</tr>
<tr>
<td>Pediatric Nursing Homes</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>(All are children)</td>
</tr>
<tr>
<td>c) In DSS Custody</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>(All are children or adolescents)</td>
</tr>
<tr>
<td>Subtotal Underserved</td>
<td>61</td>
<td>539</td>
<td>179</td>
<td>244</td>
<td>1,023</td>
<td></td>
</tr>
<tr>
<td>TOTAL UNSERVED/UNDERSERVED ADULTS</td>
<td>338</td>
<td>1,560</td>
<td>230</td>
<td>329</td>
<td>2,457</td>
<td></td>
</tr>
</tbody>
</table>
### TABLE 3.2

**SOURCES USED TO DETERMINE SURVEY OR COUNT-BASED ESTIMATE OF TYPE OF HOUSING NEEDED BY UNSERVED/UNDERSERVED CHILDREN**

<table>
<thead>
<tr>
<th>POPULATION</th>
<th>Independent Living Services</th>
<th>Housing with Light Staff Asst.</th>
<th>Housing with Moderate Staff Asst., Some Medical Care</th>
<th>Housing with Substantial Staff Asst., Medical Care</th>
<th>TOTAL</th>
<th>Source of Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimate of Unserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) On DMH/MR Waiting List</td>
<td></td>
<td>49</td>
<td>158</td>
<td>16</td>
<td>13</td>
<td>236</td>
</tr>
<tr>
<td>Subtotal Unserved</td>
<td></td>
<td>592</td>
<td>4,145</td>
<td>638</td>
<td>171</td>
<td>5,546</td>
</tr>
<tr>
<td>Estimate of Underserved</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) In Mental Institutions</td>
<td></td>
<td>-0-</td>
<td>10</td>
<td>4</td>
<td>11</td>
<td>25</td>
</tr>
<tr>
<td>b) In Nursing Homes</td>
<td></td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>-0-</td>
<td>(All are adults)</td>
</tr>
<tr>
<td>Adult Nursing Homes</td>
<td></td>
<td>15</td>
<td>97</td>
<td>32</td>
<td>22</td>
<td>166</td>
</tr>
<tr>
<td>Pediatric Nursing Homes</td>
<td></td>
<td>15</td>
<td>97</td>
<td>32</td>
<td>22</td>
<td>166</td>
</tr>
<tr>
<td>c) In DSS Custody</td>
<td></td>
<td>-0-</td>
<td>100</td>
<td>-0-</td>
<td>-0-</td>
<td>100</td>
</tr>
<tr>
<td>Subtotal Underserved</td>
<td></td>
<td>15</td>
<td>207</td>
<td>36</td>
<td>33</td>
<td>291</td>
</tr>
<tr>
<td>TOTAL UNSERVED/UNDERSERVED CHILDREN</td>
<td></td>
<td>607</td>
<td>4,352</td>
<td>674</td>
<td>204</td>
<td>5,837</td>
</tr>
</tbody>
</table>

1. Massachusetts Department of Education, Division of Special Education. The "After 22" Survey. Survey Report #1: Statewide Summary (Quincy: Massachusetts Department of Education, July 1982) Figure 7: "Reported individuals in need of group living or specialized living situations by age groups" (p. 10).
mental institutions needed alternative housing. The type of housing needed by these individuals, however, was not identified.(6)

(3) 1984 DMH Estimate
According to DMH's dual diagnosis task force, 167 individuals in mental institutions should be moved to state schools for the retarded. This task force also identified another 362 mentally retarded/mentally ill individuals, but did not indicate their housing needs.(7)

In Chapter Two, differences between these estimates were resolved by taking a mean, leading to the estimate that 373 mentally retarded living in mental institutions require alternative housing. Unfortunately, because not all these sources provide data on the type of housing clients need, the same approach cannot be used to estimate housing need.

To determine housing needs of these individuals, several assumptions were made based on the available information. First, because the dual diagnosis task force conducted a thorough evaluation of the mentally retarded in mental institutions, their estimate is assumed to be the most accurate. Thus, 167 individuals are estimated to require housing with heavy staff supervision and medical care. Second, the housing needs of the 206 remaining individuals are estimated using information reported by MARC. This information indicates that, of those who do not need housing with heavy staff assistance, 75% would be more appropriately served in housing with light staff supervision, while 25% require housing with moderate staff supervision. Thus, I estimate that 154 persons now living in mental institutions need housing with light staff assistance, and that 52 need housing with moderate staff assistance and some medical care.
To break down these estimates by age, I use the same assumption as that used in step two. This assumption is based on information from DMH's dual diagnosis task force which reported that 6.6% of the mentally retarded in mental institutions are under age 22. I apply this percentage to the estimates derived above to estimate the housing need of both children and adults in mental institutions.

(2) Mentally Retarded in Nursing Homes

In Chapter Two, estimates of the mentally retarded living in adult and pediatric nursing homes were based on data reported by DMH. Unfortunately, the source from which these data were drawn did not indicate where clients should be placed as an alternative to nursing homes. Thus, estimates of this population's housing need are based on the only other source of information available, estimates developed by MARC.

MARC estimates indicate that approximately 1,109 individuals now living in nursing homes should be re-housed in smaller facilities in the community. According to MARC, the housing needs of these individuals are as follows:

(1) % In need of independent living services: 9 %

(2) % In need of housing with light staff assistance: 58.5%

(3) % In need of housing with moderate staff assistance and some medical care: 19.5%

(4) % In need of housing with substantial staff assistance and medical care (9): 13%

These percentages are applied to DMH's estimates that 675 mentally retarded in adult nursing homes and 166 in pediatric nursing homes need alternative housing. This assumes that adults and children have the same housing needs, an assumption that cannot be checked since MARC estimates...
are not broken down by clients' age or current place of residence.

Based on these assumptions, most of the unserved/underserved mentally retarded are estimated to require housing with only limited staff assistance. Using information from surveys or counts of the unserved/underserved, estimates indicate that 77% of the unserved adults need independent living services or housing with light staff supervision (Table 3.1). Mentally retarded children who will be requiring services in the future also appear to have a greater need for less specialized housing (Table 3.2). In this set of estimates, however, more children are expected to demand housing with light staff assistance than independent living services.

As with estimates based on levels of self-preservation capability, these estimates are limited in some respects. Because some of the sources used did not provide complete information on the type of housing needed by the unserved, estimates are based on potentially inaccurate assumptions. Moreover, those sources which did include detailed information are not entirely reliable. DMH/MR waiting lists, for example, indicate the specific types of housing requested by the unserved, but are probably more reflective of the types of facilities people are familiar with than the facilities they actually need. Estimates based on "After 22" survey data are also limited since only students aged 17 to 22 were studied and it was assumed that younger students would have the same housing needs as older students upon turning twenty-two. These problems reduce the accuracy of survey or count-based estimates but are not so significant as to limit their usefulness for planning.
CONCLUSIONS

In this chapter, I developed two sets of estimates of the type of housing needed by the unserved mentally retarded, first by using information on their capability of self-preservation and then by using data from surveys or counts of the population. These estimates indicate that a majority of unserved mentally retarded adults require independent living services or housing with light staff supervision. Children who will be requiring state assistance over the next twenty years will have an even greater need for these same types of housing. Thus, the focus of state planning, both in the present and the future, should be on these types of housing.

Determining how many units of housing are needed is more difficult. While the two sets of estimates reveal the same general tendencies, they show very different numbers in need of each particular type of housing. These differences are evident in Tables 3.3 (a) and (b) which present estimates developed in this chapter organized by age.

The greatest difference between estimates of unserved adults' housing need is in the categories of independent living and housing with light staff assistance. Estimates based on levels of self-preservation capability, for example, indicate that 1,064 unserved adults require independent living services, while estimates based on surveys or counts suggest only 338 adults need this type of housing. For housing with light staff assistance, estimates based on capability of self-preservation show 929 more individuals in need than that based on surveys or counts. Thus, even as both sets of estimates indicate that a majority of unserved adults (1,695 or 1,898) need independent living services or housing with light staff assistance, they differ with regard to how many individuals...
### TABLES 3.3 (a) and (b)

**Comparison of Estimates of Type of Housing Needed by Unserved/Underserved by Age Group**

#### Table 3.3(a)

**Estimates of Unserved/Underserved Adults**

<table>
<thead>
<tr>
<th>Source of Estimate</th>
<th>Independent Living Services</th>
<th>Housing with Light Staff Asst.</th>
<th>Housing with Moderate Staff Asst., Some Medical Care</th>
<th>Housing with Substantial Staff Asst., Medical Care</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence-Based Estimate (Based on Levels of Self-Preservation Capability)</td>
<td>1,064 (43%)</td>
<td>631 (25%)</td>
<td>367 (15%)</td>
<td>412 (17%)</td>
<td>2,474</td>
</tr>
<tr>
<td>Survey or Count-Based Estimate</td>
<td>338 (14%)</td>
<td>1,560 (64%)</td>
<td>230 (9%)</td>
<td>329 (13%)</td>
<td>2,457</td>
</tr>
<tr>
<td>Difference</td>
<td>726 (30%)</td>
<td>929 (34%)</td>
<td>137 (6%)</td>
<td>83 (3%)</td>
<td></td>
</tr>
</tbody>
</table>

#### Table 3.3(b)

**Estimates of Unserved/Underserved Children**

<table>
<thead>
<tr>
<th>Source of Estimate</th>
<th>Independent Living Services</th>
<th>Housing with Light Staff Asst.</th>
<th>Housing with Moderate Staff Asst., Some Medical Care</th>
<th>Housing with Substantial Staff Asst., Medical Care</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence-Based Estimate (Based on Levels of Self-Preservation Capability)</td>
<td>4,296 (44%)</td>
<td>3,175 (33%)</td>
<td>1,073 (11%)</td>
<td>1,155 (12%)</td>
<td>9,699</td>
</tr>
<tr>
<td>Survey or Count-Based Estimate</td>
<td>607 (10%)</td>
<td>4,352 (75%)</td>
<td>674 (12%)</td>
<td>204 (3%)</td>
<td>5,837</td>
</tr>
<tr>
<td>Difference</td>
<td>3,689</td>
<td>1,177</td>
<td>399</td>
<td>951</td>
<td></td>
</tr>
</tbody>
</table>
require each specific type.

The reason for these differences is that each set of estimates uses different criteria to evaluate housing need. Estimates based on levels of self-preservation capability do not take into account all the factors that affect housing need. If, for example, an individual had family able to provide care, or a serious secondary impairment, then their housing need would be different from that estimated on the basis of their capability of self-preservation. Estimates based on surveys or counts generally do consider the effect that these other factors have on housing need and thereby lead to different results.

Estimates differ the most for the two less specialized types of housing because factors other than self-preservation capability play a much more important role in determining need for these services. These two housing services are so closely related that both the unimpaired and ambulatory/partially impaired could live in either. Deciding which one they need is therefore more dependent on the presence of secondary conditions or their family situation. This is not the case, however, for more specialized housing. Levels of impairment are better indicators in these cases because families are less likely to have the skills (or finances) needed to provide care. Secondary impairments are also of less importance given the severity of individuals' primary disability. Thus, in determining the need for housing with moderate to heavy staff assistance, both sets of estimates are based on the most significant criterion, and thereby closer.

Table 3.3(b) also shows that the two sets of estimates of unserved children's housing need differ even more than those developed for adults. These estimates differ the most under the categories of independent
living or housing with light staff assistance. There is also a difference of 951 individuals between estimates of the of children needing housing with substantial staff assistance and medical care. For housing with moderate staff supervision, however, each set of estimates report approximately the same percentage of children in need.

These differences are not only due to differences in the criteria used to evaluate housing need, but also to difficulties in predicting children's future housing need. As with adults, factors such as the family's ability to provide care and the presence of secondary impairments affect estimates of the number in need of less specialized housing. The age of the population, however, also leads to problems across all categories of housing. Most of the unserved children, particularly those in Chapter 766 programs are still very young and will not be requiring services for many years. At this point in time, it is hard to say exactly what type of housing they will need upon turning 22. Because children's service needs are not as well known as adults inconsistencies that result from using different criteria to evaluate housing need are exaggerated.

In developing a housing plan for the unserved mentally retarded, I suggest that the state use the lowest estimate for each category of housing. These estimates indicate the smallest number of individuals who require each type of housing services. DMH plans should also include enough flexibility so that services could be expanded to meet the needs of those represented by the higher estimates. Thus, while at least 338 adults in need of independent living situations should be planned for, DMH should keep in mind that some 700 more persons may eventually require similar services. DMH/MR plans should also consider the future needs of
mentally retarded children who will gradually add to the housing demand even as older retarded adults pass away.

In most cases, using the lowest estimates means that housing plans will be based, initially, on data from counts or surveys of the unserved and underserved. This approach makes sense because these estimates include individuals who have actually been identified and are known to require services. In contrast, estimates based on prevalence rates reflect latent demand which may or may not be expressed in the future. These estimates include persons who may have been missed in surveys or censuses of the unserved and are thereby important to consider. Using them as a basis for developing a housing plan, however, would not be appropriate since individuals included in these estimates may never actually request state services, or be identified in some other way.

This analysis provides information sufficient to begin planning for the unserved mentally retarded but is still missing one important component, an analysis of the state's ability to provide housing services. Even though funds are currently available to develop housing for the unserved, they are inadequate to address the needs of those represented by even the lowest estimates. Thus, at least in the initial phases of housing development, policy decisions must be made regarding who the state should serve. These policy decisions are discussed in the final chapter of this report, along with recommendations for planning.
FOOTNOTES

(1) These costs are based on the following information:
- $47,100 is the average annual cost per client in FY 84 for housing in an Intermediate Care Facility for the Mentally Retarded, Type A. Cost quoted by the Massachusetts Department of Public Welfare, April 1984.
- $80,300 is the cost of services provided by a chronic hospital. Cost quoted by Sandra Michaels in An Analysis of the FY83 Massachusetts DSS Respite Care Program for the Developmentally Disabled (Boston: Massachusetts Department of Social Services, May 1983) p. 48. Michaels' cost figure is based on MARC projections.

(2) These costs are based on the following information:
- $22,000 per year is the average annual cost of housing mentally retarded clients in facilities with less than 24-hr care. Cost based on information provided by the Massachusetts Rate Setting Commission, April 1984. According to this source, the cost of providing this housing service currently ranges from $50 to $70/day per client.
- $2,000 is the lowest cost of providing residential services indicated on DMH/MR waiting lists. The cost was listed for independent living services.

(3) Massachusetts Department of Mental Health, Division of Mental Retardation. Orientation to the Mental Retardation Service System "Fact Sheet: Individual Service Plan and the Annual Review" (Boston: Massachusetts Department of Mental Health, no date) p. 1.

(4) Massachusetts Department of Mental Health. "Fact Sheet: Individual Service Plan."

Moriearty's evaluation of housing need uses categories different from my own and are as follows:
# In need of housing in an ICF/MR: 40
# In need of Community Personal Care Assist. Program for Severely Handicapped: 90
# In need of Community Personal Care Assist. Program for Moderately Handicapped: 270

These categories are similar to my own. (See Moriearty, pp. 4-6).

(6) Mark J.D. Mills, Commissioner, Massachusetts Department of Mental Health. Memorandum to Manuel Carballo, Secretary, Massachusetts Executive Office of Human Services (Boston, January 24, 1983) p. 11.

(7) James J. Callahan, Jr., Commissioner, Massachusetts Department of Mental Health. Memorandum to Frank T. Keefe, Secretary, Massachusetts

(8) Moriearty, p. 19. Moriearty estimates that 1,230 mentally retarded in Skilled Nursing Facilities, Chronic Hospitals and Intermediate Care Facilities are underserved. This represents one-half of the mentally retarded population in long term care nursing homes. Of these, 246 are estimated to require additional services in their current place of residence. These individuals are therefore not included in my calculation, leaving 984 in need of alternative housing.

Moriearty also identifies another 250 residents of non-medicaid eligible nursing homes in need of assistance, but does not evaluate their housing need. I assume that, as with others in nursing homes, one-half of these will require alternative housing. Thus, Moriearty's estimates imply that approximately 1,109 (984 + 250/2) mentally retarded in nursing homes require alternative housing.

(9) Moriearty, p. 19. Again, Moriearty's housing categories are different from my own. According to her report, mentally retarded in nursing homes require the following types of housing:

- # In need of housing in an ICF/MR: 130
- # In need of Community Personal Care Assist. Program for Severely Handicapped: 192
- # In need of Community Personal Care Assist. Program for Moderately Handicapped: 576
- # In need of in Home Supplement or Respite Care: 86

(10) DMH Area Officer, Personal Communication, March 1984.
OPTIONS AND POLICY DECISIONS FOR HOUSING THE UNSERVED MENTALLY RETARDED
Thus far, this report has focused almost exclusively on estimating the unserved mentally retarded and their service needs. While these estimates are certainly integral to the development of services for non-class clients, they do not provide sufficient information on which to base long range housing plans. Instead, the estimates presented in this report represent only a rough approximation of the number of individuals who need DMH/MR services. Further, because only limited funds are currently available, not all of those estimated to require housing can be served at this time.

Because they are sometimes based on debatable assumptions and incomplete data, the estimates reported in this document may not accurately reflect the actual number of individuals in need of assistance. A sensitivity analysis that I conducted also shows that estimates would change if different assumptions were used. According to this analysis, if a 1% rather than 0.5% prevalence rate is used to develop estimates, then the prevalence-based estimate of the total population in need of services increases by 148%. If MARC data on the mentally retarded living in nursing homes is substituted for DMH data, then survey or count-based estimates of the total population increase by 1%. In both cases, estimates of the number in need of housing increase, while the percentage in need of each type of facility remains the same. (See Appendix D for a more thorough discussion of the sensitivity analysis.)

This analysis points out the importance of gaining better data on non-class clients who are potentially in need of DMH services. If changing only one assumption leads to an increase of 148%, then the need for further research is certainly indicated. At the same time, however,
uncertainty surrounding the accuracy of estimates of the unserved mentally retarded should not preclude planning on their behalf. While the sensitivity analysis shows that the actual number of individuals in need may be different from that estimated, this difference would not affect the provision of services over the next few years. Because the state can only serve a limited number of individuals at any one time, any change in estimates would only affect future plans. Thus, the estimates presented in this report can be used to develop preliminary plans for housing the unserved, with future plans based on estimates that are refined and improved as more data becomes available.

Another reason why long range plans cannot be developed at this time is that the funds currently available are not adequate to address the needs of all those estimated to require housing. While the Fiscal Year 1983 capital budget includes $18 million for the development of housing that serves both non-class and class clients, this money could be quickly and easily spent on non-class clients alone. For example, if estimates based on individual's capability of self-preservation are used, then providing housing to the 412 unserved adults requiring housing with heavy staff assistance could potentially cost the state $20.6 million. The actual cost would be even higher, since this figure does not include the cost of providing ongoing services. If estimates based on surveys or counts of the unserved are used, then the expense of providing housing services to those currently in need would be somewhat lower, but still leave less than $2 million for the provision of services to other individuals.(1)

It is unlikely, then, that the state will be able to meet the housing needs of all non-class clients in the immediate future. Instead,
plans for housing the unserved mentally retarded must be developed in phases. The first phase consists of using the $18 million currently available to house some of the non-class clients estimated to require assistance. During this phase, DMH should seek additional funding for housing development and attempt to improve estimates of the number in need and the type of services they require. In this way, DMH will be able to begin addressing the needs of non-class clients without having to wait for better data or additional funding.

In preparing plans for the initial phase, DMH must also decide its priorities with regard to who should receive state housing services. This decision is necessary because available funds limit the Department's ability to meet the needs of all those estimated. To assist the state in this decision-making process, this chapter explores the various options that could be pursued in the first phase of housing the unserved mentally retarded. These options reflect only the state's larger policy choices and not decisions that will have to be made between particular individuals. To clarify the options, each is evaluated according to criteria relevant to the development of housing plans. These criteria are used to expose the consequences of making various choices so that DMH will be able to make an informed decision regarding which type of housing it should provide in the initial planning stages.

OPTIONS FOR HOUSING THE UNSERVED MENTALLY RETARDED

DMH's options for housing the unserved mentally retarded can be simplified such that they fall into three broad categories. These options are as follows:

(1) The state could emphasize the provision of housing for those who
are largely able to care for themselves, e.g. persons who need independent living services or housing with light staff assistance.

(2) The state could focus its efforts on housing the most severely disabled, e.g. individuals who need moderate to substantial staff assistance and medical care.

(3) The state could provide a balanced mix of housing, serving a relatively equal number or fixed proportion of individuals who need only limited staff assistance and persons who need moderate to heavy staff assistance and medical care.

These options reflect the range of opportunities now before the state. By emphasizing housing for those who need only minimal staff assistance, for example, the state would provide housing which is in the greatest demand. Because this type of housing is the least expensive to provide, pursuing this option would also allow the state to serve the largest number of individuals in need. On the other hand, if the state allocated the majority of its funds to those who need moderate to heavy staff assistance, it could serve all of those with the most critical housing need. This type of housing is very expensive, however, and following this option would mean that most of those with less severe disabilities would not be served. Thus, the third option presents an opportunity for the state to provide housing to a relatively large number of individuals while still serving those with more severe disabilities.

Because each option has its advantages and disadvantages, deciding between them is a difficult task. This decision is made only more difficult by the fact that pursuing any one option means that some persons will have to wait for the services they need. Ultimately, the state should be able to provide housing for all the unserved. But in the
interim, with only limited funds available, a decision must be made as to which type of services should be provided in the first phase of housing development.

CRITERIA FOR EVALUATING OPTIONS

One way of deciding between these options is to evaluate them according to a set of criteria which reflect the state's interests. These criteria should encompass a broad range of concerns so that the implications of choosing any one option will be as explicit as possible. They should also be practical, emphasizing the state's ability to provide services, and address both long and short range planning issues. Perhaps most important, the criteria should be sensitive to the needs of individuals who are being planned for since the choice of any option will mean that some will not immediately receive services.

The criteria that I suggest will enable the state to evaluate its options using information that is currently available on the unserved mentally retarded. These criteria are as follows:

(1) Severity of Individual's Needs

Current DMH policy indicates that individuals with the most severe housing needs should be given priority for services. For the unserved mentally retarded, evaluations of severity of need can be based on estimates of the type of housing individuals need and their capability of self-preservation. In addition, the families' ability to provide care in lieu of state housing services should be considered.

(2) Cost of Providing Housing Services

Since only limited funds are available, initial plans for housing the
unserved mentally retarded should consider the cost of providing services. By providing the least expensive types of housing, the state could serve more individuals. Some services also offer the potential for saving the state money, either because they are less costly than comparable alternatives, or because they can prevent need for more expensive services in the future. These services should therefore be given strong consideration in the early stages of housing development.

(3) **Gaps in Planned Services**

Preliminary plans for spending available funds will provide only a limited amount of services to the unserved mentally retarded. In addition, plans emphasize the provision of housing to only certain groups of individuals. Persons whose needs are not addressed in these plans should therefore receive priority for housing with the remaining funds.

(4) **Availability of Non-Profit/Private Sector Alternatives**

Ideally, the state should only provide for those whose housing needs cannot be met by the non-profit or private sector. This would allow the state to focus its efforts on those who cannot afford the available alternatives or those who need services that only the state can provide.

(5) **Future Needs of the Mentally Retarded**

Initial housing plans should also consider the changing needs of the mentally retarded. For example, if the mentally retarded require more medical care as they grow older, or if the next generation is expected to be more severely disabled because of higher survival rates, then state planning should focus on housing that provides
medical care. In this way, the housing provided would be used both in the future and the present.

**EVALUATION OF OPTIONS**

Table 4.1 evaluates each of the state's options based on the criterion described above. The option of emphasizing housing for those who need independent living services or housing with light staff assistance is clearly favored with respect to the cost of providing services. Under other criteria, pursuing this option in the early stages of planning offers fewer advantages. This option would provide housing which is available in the non-profit or private sector, and serve individuals who generally do not have a critical need for housing. Option 2, emphasizing more specialized housing, is preferable across all criteria, except those of costs and future needs. By pursuing this option, the state would serve the most severely disabled, but also leave a large percentage of those in need without services. The third option, providing a balanced mix of housing, would best address the future needs of the mentally retarded, but also provide housing which is available from the non-profit or private sector and potentially leave unserved 73% of those with the most severe disabilities. The basis for these evaluations is described below.

**OPTION 1: Emphasize Independent Living Services and Housing With Light Staff Assistance**

(1) Severity of Individual's Needs:

In general, individuals who require housing with only limited staff assistance can be assumed to have the least severe need for DMH/MR housing. Most of these individuals are not severely disabled and are
<table>
<thead>
<tr>
<th>OPTIONS</th>
<th>Severity of Individual's Needs</th>
<th>Cost of Providing Services (Range of annual cost per client)</th>
<th>Gaps in Planned Services (% left unserved under option)\textsuperscript{a}</th>
<th>Availability of Non-Profit/Private Sector Alternatives</th>
<th>Future Needs of the Mentally Retarded</th>
</tr>
</thead>
<tbody>
<tr>
<td>OPTION 1: Emphasize Independent Living Services, Housing with Light Staff Asst.</td>
<td>Serves less severely disabled, likely to be cared for at home. Some might have critical need if with aging parents.</td>
<td>$18,250-$25,550</td>
<td>57% needing ind. living or hsg. with light staff</td>
<td>Provides hsg. available in non-profit, private sector.</td>
<td>Provides hsg. in greatest demand in future. Does not meet needs of elderly retarded or severely retarded.</td>
</tr>
<tr>
<td>OPTION 2: Emphasize housing with moderate staff asst., some medical care, housing with subst. staff asst., medical care</td>
<td>Serves severely disabled unlikely to be cared for at home. Some already receiving state services.</td>
<td>$35,000-$80,300</td>
<td>92% needing ind. living or hsg. with light staff</td>
<td>Provides hsg. not available or affordable in non-profit, private sector.</td>
<td>Provides hsg. appropriate for elderly and severely retarded. Does not meet needs of majority requiring hsg. in future.</td>
</tr>
<tr>
<td>OPTION 3: Provide a Balanced Mix of Housing</td>
<td>Serves both severely disabled and less severely disabled, retarded at home with aging parents, others receiving no services.</td>
<td>$18,250-$80,300</td>
<td>73% needing ind. living or hsg. with heavy staff</td>
<td>Provides some hsg. available in non-profit, private sector</td>
<td>Provides hsg in levels proportionate to future demand, most responsive to future needs</td>
</tr>
</tbody>
</table>

\textsuperscript{a} These percentages are based on models for each option, presented in tables 4.2 through 4.4.
largely able to care for themselves. Because they do not require highly specialized care, these individuals are also more likely to have family members who are able and willing to provide for them.

In some cases, however, these individuals may be regarded as having severe housing needs for other reasons. Persons living at home with aging parents, for example, have a critical need for state services. Unfortunately, the exact number of persons who are in this situation and would be served under this option is not known. There is, however, some evidence that the number may be large. According to a recent survey the average age of parents with retarded adults living at home was 60, while more than 15% were age 70 or older. The survey also indicated that 30% of those living at home were mildly retarded. Thus, many of those who would be provided for under this option may have severe housing needs in the near future.

(2) Cost of Providing Housing Services:

Because these types of services are the least expensive to provide, this option would enable the state to serve the largest number of individuals in need. According to the Massachusetts Rate Setting Commission, the cost of housing mentally retarded clients who need less than 24 hour care ranges from $18,250 to $25,550 per year. I assume that these costs include leasing expenses (most of these facilities are leased rather than purchased) as well as the cost of providing basic services.

Services that would be emphasized under this option can also prevent the need for more expensive forms of state services. A good example is respite care, a service now offered by DMH and the Department of Social Services (DSS). This program provides temporary relief and ongoing
support to families who care for the disabled and disabled individuals who are attempting to live on their own.

According to the Department of Social Services, respite care saves the state money in two ways. First, because the program is relatively inexpensive, it serves more people for the same amount of money. Based on its cost estimates, DSS argues that for the cost of housing one person in an ICF/MR, thirty-nine persons can receive respite care. (6) Second, respite care can reduce the likelihood that individuals will be placed in more expensive, state operated housing. While data supporting this claim have not been generated in Massachusetts, DSS sites evidence from a study conducted in California. This study found that respite care helped to prevent 7.3% of the children served from being placed outside the home. (7) DSS thereby concludes that its own program, and a similar one provided by DMH, also saves the state money by encouraging the disabled to remain in their own homes.

Respite care is not the only program included under this option which serves a preventive function. By housing individuals in facilities with light staff assistance now, the state may be able to provide them with skills that will enable them to live on their own in the future. Thus, in terms of both cost per client and potential for cost savings, this option should be given strong consideration.

(3) Gaps in Planned Services:

DMH has already begun to develop plans for housing unserved non-class clients using funds available from the fiscal year 1983 capital budget. Thus far, plans have only been prepared through fiscal years 1986 and 1987. These plans indicate that the following number of units will be provided per housing category (8):
Independent Living Services: 0
Housing with Light Staff Assistance: 375 (94%)
Housing with Moderate Staff Assistance: 16 (4%)
Housing with Heavy Staff Assistance: 8 (2%)

Not all these units will be available to non-class clients. Instead, the capital budget stipulates that housing developed under the $18 million appropriation serve class clients as well. Assuming that, as in previous years, at least 20% of the units will go to non-class clients, they would receive the following services:

Independent Living Services: 0
Housing with Light Staff Assistance: 75
Housing with Moderate Staff Assistance: 3
Housing with Heavy Staff Assistance: 2

The units planned to date are not sufficient to meet the unserved population's needs, regardless of what type of housing they require. Nonetheless, $11 million in funds will still be available after these units become available. These funds can be expected to serve an increasing number of non-class clients since most class clients are provided for under current plans.

Pursuing option 1 would mean that the remaining funds would be spent largely on independent living services and housing with light staff supervision. This would not be unreasonable given that many individuals who require this type of housing would not be served under current plans. Based on the lowest estimates reported in the previous chapter, 92% of those in need of independent living services or housing with light staff assistance are not served under current plans. However, there is an even greater gap between planned services and estimated need for housing with moderate to heavy staff assistance and medical care. In this case, 99% of those in need are left unserved under current plans. Thus, on the basis of this criterion, housing provided in the early phases of development...
should not exclusively emphasize independent living services or housing with light staff assistance.

(4) Availability of Non-Profit/Private Sector Alternatives:

Persons capable of living independently or in housing with light staff supervision could be served by the private or non-profit sector. The type of housing these individuals need is not so specialized that only the state can provide it. Indeed, DMH often adapts ordinary homes when providing this type of housing service. Ancillary services offered by DMH in these facilities could also probably be provided by the non-profit or private sector or in collaboration with such agents. Based on this criterion, this option should not be pursued in the early stages of planning.

(5) Future Needs Of the Mentally Retarded:

In preparing long range plans, future as well as current service needs of the mentally retarded should be considered. This involves evaluating the changing needs of clients now served by DMH/MR as well as the needs of persons who will be requiring housing in the future.

A major factor that will influence changes in the housing need of DMH/MR clients is the aging process. Many of DMH/MR's clients are now middle aged, and in the state schools some are already elderly. While few studies have been conducted on the effect of aging on the mentally retarded, it can be assumed that elderly retarded require at least the same services as non-retarded elderly. This means that individuals will need increasing medical care and staff assistance as they grow older. Because of their condition, DMH/MR clients may also require services above those normally provided to the elderly.(10)

The next generation of retarded individuals is also expected to
require specialized services and medical care. According to DMH, medical advances have helped to increase the life span of individuals born with significant, multiple impairments. In the future, then, there will likely be more mentally retarded with severe disabilities requiring state services.

In the immediate future, however, this trend will not significantly affect housing needs of the unserved mentally retarded. According to estimates developed in the previous chapter, mentally retarded children who will be requiring services over the next twenty years appear to have less severe housing needs than adult mentally retarded. Thus, despite the fact that persons with severe impairments are living longer, the majority of children now residing in the state appear to be capable of living independently or in housing with light staff supervision.

Given this situation, the option of emphasizing housing with limited staff assistance would address the future needs of only one group: children who are estimated to need housing in the near future. This population, however, represents the largest group of persons who will need services in the future. While the number of elderly mentally retarded and retarded with severe disabilities may be increasing, it is still small in comparison to the number of children needing housing with limited staff assistance. Thus, pursuing this option would enable the state to provide housing that will be in the greatest demand in the future.

OPTION 2: Emphasize Housing with Moderate Staff Assistance and Some Medical Care and Housing with Substantial Staff Assistance and Medical Care

(1) Severity of Individual's Needs:
Persons who require moderate to substantial assistance probably have the most severe housing need. These persons have the most severe disabilities and probably cannot be provided for at home by their family. Parents are not likely to have the skills required to care for these individuals, nor could they easily afford the costs of providing medical care in the home.

There is, however, one exception. Persons now living in mental institutions or nursing homes and would be more appropriately served in other heavily staffed facilities are not, in my opinion, in critical need of housing. While they may not be receiving the best care possible, they are at least receiving some approximation of adequate housing and services from the state. Certainly they are better off than persons who are capable of living independently, but have no family to care for them and no available alternatives. Thus, not all individuals who would be housed under this option have more severe needs than those who would be housed under option 1.

(2) Cost of Providing Housing Services:

Under this option, the state would be emphasize the most expensive types of housing and thereby serve fewer people. The actual amount of state expenditure would vary depending on the type of facilities provided. For housing with moderate staff assistance and medical support, the cost per client would be about $35,000 per year.(12) For housing with heavy staff supervision, the cost would range from $47,100 for placement in an ICF/MR-A to $80,300 for services provided by a chronic hospital.(13)

These costs do not include the cost of constructing facilities. This, however, is not a factor for facilities which are already in
existence, such as hospitals and state schools. Other facilities, such as ICF/MRs would have to be developed. At most, this would cost the state about $50,000 above the cost of providing basic services to each client.

The costs reported above also do not account for reimbursements the state receives in providing housing services. Under Title XIX (Medicaid) the state is reimbursed for about 50% of the cost of constructing ICF/MRs and rehabilitating the state schools. The state also receives back about 50% of the cost of providing services to Medicaid eligible clients in these facilities.(14) State expenses may be further offset by SSI benefits for eligible clients.(15) The actual cost of providing services under this option is thereby substantially reduced, but still higher than the cost of providing less specialized housing.

The potential for cost savings under this option would vary depending on which type of facilities were used. Because they are expensive to maintain, state schools are probably the least cost effective method of providing hospital level care. These facilities are also underutilized and have inordinantly high staff-client ratios. On the other hand, facilities such as ICF/MRs can be very cost effective. Despite the fact that they are expensive to build, these facilities provide very high level services for less than it costs to serve clients in state schools or hospitals. They also provide a valuable opportunity for individuals with severe impairments to live in the community.

Given the variation between facilities, it is difficult to determine whether pursuing this option would save the state more money than option 1. It probably would if DMH focused on services which cost less than other comparable alternatives. But, even under this scenario, the expense of providing housing would be so high that many persons with less severe
disabilities could not be served. Without appropriate care, these persons might eventually require services more expensive than those they currently need. Thus, the cost savings realized by providing housing under this option would be reduced in the long run.

(3) Gaps in Planned Services:

The housing plans presented earlier indicate that the current emphasis is on housing with limited staff assistance. Of the 400 planned units, only five will provide moderate to heavy staff assistance and medical care to unserved non-class clients. Clearly, the focus of future plans must be on housing that provides more specialized services. However, because the needs of those who need other types of housing are also not adequately addressed in current plans, the focus should not be exclusively on highly specialized housing. As a result, the option of emphasizing housing with moderate to heavy staff supervision is therefore only slightly preferred to option 1.

(4) Availability of Non-Profit/Private Sector Alternatives:

Because they require highly specialized care, it is unlikely that individuals who would be provided for under this option could be served by the non-profit or private sector. In addition, many facilities included under this option (particularly Intermediate Care Facilities) are designed according to such strict standards, that only the state would be willing to build them.

In cases where there is alternative housing available, it is too expensive. Private hospitals, or residential schools, for example, could potentially serve persons with severe impairments as well as state operated facilities. However, many families of the retarded probably could not afford the cost of this care. Many have already spent a great
deal of money obtaining proper medical care for their children and have limited funds remaining. Because there are few affordable alternatives available, this option is preferable to option 1 on the basis of this criterion.

(5) Future Needs of the Mentally Retarded:

Both DMH/MR clients and the next generation of mentally retarded individuals will require housing with high staff levels and medical care in the future. Pursuing this option would thereby enable the state to provide housing to meet this demand. The housing emphasized under this option, however, would not address the needs of the majority of those requiring services in the near future. Instead, most mentally retarded children appear to need housing with limited staff supervision. On this basis, option 2 would not be the best option to pursue in the initial stages of housing development.

OPTION 3: Provide a Balanced Mix of Housing

Providing a balanced mix of housing can mean a number of different things. On the one hand, this option could mean that the state would spend equal amount funds on each of the different types of housing. Because housing those with less severe needs is also less expensive, this would mean that proportionately more individuals in this category would receive housing. Obviously, this does not result in a "balanced mix" of housing, but a mix which has already been discussed as option 1.

Another interpretation of "balanced mix" is that the state provides an equal number of beds in each category of housing. Because there are varying degrees of demand for each housing type, however, this would result in disproportionate services to some groups of individuals. For
example, estimates developed in the previous chapter show that at least 970 adults need independent living services or housing with light staff supervision. If 100 units of housing were provided to this group, only 10% of those in need would be served. However, if an equal number of units were provided to adults in need of housing with moderate to heavy staff assistance and medical care, then 18% would be served. This again, is not a "balanced mix" and is closer to that which has been discussed as option 2.

Another approach is to provide housing in levels proportional to demand and serve approximately the same percentage of individuals in need of each type of housing. Since both the cost and demand for each type of housing is different, the actual funds and units provided under each type would also be different. Relative to need, however, both funds and units would be distributed equally among the different types of housing. In fact, even as more funds would be spent on housing with moderate to heavy staff assistance, this would be balanced by the fact that more independent living services and housing units with limited staff supervision would be provided. This mix of housing would be the most politically favorable and is thereby used as the basis for evaluation.

(1) Severity of Individual's Needs:

Perhaps the greatest disadvantage of the balanced mix option is that the state would have to sacrifice serving some individuals with the most severe needs in order to provide housing to a larger number of people. Indeed, it is very difficult to find support for a plan that does not make every effort to serve persons who are severely disabled, require medical care and are not capable of self-preservation.

On the other hand, persons who are largely able to care for
themselves, but have no family and no other alternatives available, also have a severe need for housing. Because their need is not so dramatically evident as those with severe disabilities, these people are often forgotten when state policy is developed. Providing a balanced mix option therefore has the advantage of giving the state an opportunity to recognize and address the needs of these people.

A balanced mix option could potentially provide services only to those who have the most critical need for housing. With both limited funds and limited beds available, this would almost have to be the case. Thus, the unserved severely disabled would have priority over those who are "underserved". Similarly, of those who need housing with limited staff supervision, persons with no family to care for them would have priority over those who do. A conscious effort to provide a balanced mix of housing might therefore, under the best of circumstances, force the state to look more critically at clients' severity of need than it would otherwise. Because this option could leave many severely disabled without services, however, it should still be considered a lower priority than option 2.
(2) Cost of Providing Housing Services:

Under this option, the state would serve fewer individuals than under option 1, but more than under option 2. The cost of providing services would vary depending on the exact mix provided, ranging from $18,250 per client for housing with light staff assistance to $80,300 for services provided by a chronic care hospital.

The potential for cost savings under this option is somewhat more difficult to assess. By providing for individuals who need housing with limited staff assistance, the state might be able to prevent some from needing more expensive services in the future. In absolute numbers, however, many people in this category would still remain unserved. With regard to persons who need moderate to heavy staff supervision and medical care, the state could again save money by providing services at a lower cost than hospitals or skilled nursing facilities. Many in this group, however, would also remain unserved. If these severely disabled persons truly have a critical need for housing, then the state will eventually have to serve them, regardless of any "balanced mix" policy. In this case, a more cost effective approach would be to emphasize housing that meets their needs from the start.

In terms of both cost and potential for cost savings, I believe this option should be given strong consideration. This option offers an opportunity to provide preventive services which can save the state money and allow the state to serve a relatively large number of people while still addressing the needs of some of the severely disabled. Because this option would not serve the largest number of people possible, nor a majority of those with severe disabilities, it should not, however, be preferred above options 1 or 2.
(3) Gaps in Planned Services:

DMH/MR's plans for spending available capital funds do not fully address the unserved populations' need for any type of housing. In this regard, a balanced service system would enable the state to distribute its remaining funds among all those in need. Since plans place greater emphasis on housing for those who need limited staff assistance, however, future plans should probably allocate fewer funds to this type of housing. Thus, Option 3 would not be the best approach for addressing gaps in planned services.

(4) Availability of Non-Profit/Private Sector Alternatives:

Because there are more alternatives for those who need only limited staff assistance this option is less than perfect. If persons with this level of need are more likely to be provided services by some non-public entities, then the state should place emphasis on meeting their needs. The provision of housing to serve both persons who need housing with limited staff assistance and to those who need moderate to heavy staff assistance on an equal level should thereby be given lower priority than option 2.

(5) Future Needs of the Mentally Retarded:

This option best addresses the future housing needs of the mentally retarded. A "balanced mix" of housing would meet the future needs of aging DMH/MR clients, an increasing number of severely disabled individuals and children who will need housing in the near future. Furthermore, a mix that is based on current demand would also provide housing on levels proportionate to clients' future needs. For example, estimates of the housing need of unserved adults indicate that a majority require housing with limited staff supervision. Similarly, a majority of
those requiring services in the future will need this type of housing. Thus, a balanced mix option is the most responsive to both the present and future needs of mentally retarded individuals.

CONCLUSIONS

The Department of Mental Health currently has an opportunity to serve a large number of mentally retarded individuals in need of state services. Given the capital funds available, the consent decree mandates that have influenced the Department's provision of services over the past ten years can finally be met. With that accomplished, the mentally retarded who have not been protected under these decrees can become the focus of DMH planning. Having waited so long for services, these non-class clients deserve the state's attention and can be housed, at least in part, with funds provided under the recent capital budget.

The estimates developed in this report can help the state to prepare a plan that meets the needs of these individuals. While developing accurate estimates of the unserved mentally retarded is a difficult task, this report has pieced together all the information that currently is available on the unserved to arrive at a reasonable approximation of the number in need of services and their level of need. The estimates that resulted indicate that approximately 2,500 mentally retarded adults are currently in need of DMH/MR housing. A majority of these need housing with only limited staff assistance, while at least 560 need housing with moderate to heavy staff supervision and medical care.

While these estimates give a sense of current housing need, estimates of mentally retarded children offer information on services that will be needed in the future. Assuming that children's service needs
will not change significantly over the next twenty-two years, they will require less specialized housing with fewer staff present. These children can be expected to fill housing units vacated by retarded adults as they pass away. Because children have somewhat different needs than adults, however, the state's long range housing plan for the mentally retarded should build in a capacity to meet increasing demand for housing with little or no staff supervision.

These estimates of the unserved population's service need, however, are not sufficient to use as a basis for long range planning. First, because estimates are based on sometimes inappropriate assumptions and inadequate data, further research on the unserved mentally retarded is required. In addition, even as $18 million has been allocated for the development of community based housing for the mentally retarded, these funds could be spent by providing housing only to those who need housing with substantial staff assistance and medical care. Thus, for the time being, the state can only develop preliminary plans for housing a limited number of non-class clients in need of assistance.

This final chapter has attempted to provide DMH with a basis for deciding priorities of service in the first phase of housing development. Using criteria which address both the state's ability to provide services and the severity of individual's needs, three options that DMH could pursue with regard to housing the unserved have been evaluated. As Table 4.1 shows, none of the options is clearly preferred, since each could be considered a high priority under one guideline, and a lower priority under others.

To decide between these options, the state must determine the relative importance of each criteria, and on that basis, which option is
the most satisfactory. Choosing any one option must mean that the state serves some individuals at the expense of not serving others. By deciding which criteria should be given the most weight, a decision can be reached as to which individuals the state feels most (or least) responsible for serving in the initial phases of planning.

To further clarify the implications of choosing any one option, I have developed models to show how each could be carried out using the remaining $11 million in funds. These models, presented on Tables 4.2 through 4.4, are based on estimates of the least number of people in need of each type of housing. Using this information, as well as data on housing currently planned, the models give examples of (1) the total number of people that could be served under each option, (2) the number that could be provided with each type of housing, (3) the amount of funds that would be allocated to each type of housing and, (4) the number in need of each type of housing that would remain unserved. To simplify the models, only one type of housing is used to represent each category. In reality, the provision of housing under each model would be much more complex, with varying amounts of different types of services provided under each category.

These tables further reinforce the conclusion that option 1 could serve the largest number of persons in need. Based on the models presented, this option would serve 76% more persons than option 2 and 25% more than option 3. However, option 1 would also leave unserved 75% of those in need of moderate staff assistance and 85% of those in need of heavy staff assistance and medical care. Option 2 would allocate a larger percentage of funds and units to those in need of more specialized housing, but, compared to option 1, serve 81% fewer persons in need of
TABLE 4.2
MODEL FOR OPTION 1:
EMPHASIZE INDEPENDENT LIVING SERVICES AND HOUSING WITH LIGHT STAFF ASSISTANCE

<table>
<thead>
<tr>
<th>Housing Category</th>
<th>Representative Housing Service</th>
<th>Cost per Client</th>
<th>Est. # In Need(^a)</th>
<th># Served In Model (%)</th>
<th>TOTAL COST TO SERVE</th>
<th># Left Unserved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Living Services</td>
<td>Specialized Home Care-Out of Home</td>
<td>$11,400(^b)</td>
<td>338</td>
<td>186 (55%)</td>
<td>$2,120,400</td>
<td>152</td>
</tr>
<tr>
<td>Housing with Light Staff Assistance</td>
<td>Staffed Apartment</td>
<td>$22,000(^c)</td>
<td>556</td>
<td>195 (35%)</td>
<td>$4,290,000</td>
<td>361</td>
</tr>
<tr>
<td>Housing with Moderate Staff Assistance, Some Medical Care</td>
<td>ICF/MR-B</td>
<td>$37,400(^d)</td>
<td>227</td>
<td>57 (25%)</td>
<td>$2,131,800</td>
<td>170</td>
</tr>
<tr>
<td>Housing with Substantial Staff Assistance, Medical Care</td>
<td>ICF/MR-A</td>
<td>$50,400(^e)</td>
<td>327</td>
<td>49 (15%)</td>
<td>$2,469,600</td>
<td>278</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td>1,448</td>
<td>487 (34%)</td>
<td>$11,011,800</td>
<td>961</td>
</tr>
</tbody>
</table>

NOTES

\(^a\) Based on lowest estimate reported in Chapter Three, less those served under current plans.

\(^b,c\) These costs are the mean cost of providing services. (See: Massachusetts Department of Mental Health, Division of Administration and Finance. Per Client Annualized Cost: Mental Retardation Services, Boston: Massachusetts Department of Mental Health, no date.) I assume these costs include the expense of leasing facilities.

\(^d\) The cost of serving clients in an ICF/MR-B is $35,400 per the Massachusetts Department of Public Welfare (April 1984). The cost of constructing facilities is $30,000 per client, per the Massachusetts Division of Capital Planning and Operations (April 1984). I assume these facilities have a depreciable life of fifteen years. Thus, for construction, the annual cost per client = $30,000/15 = $2,000. This is added to the cost of serving clients.

\(^e\) The cost of serving clients in an ICF/MR-A is $47,100 per the Massachusetts Department of Public Welfare (April 1984). The cost of constructing facilities is $50,000 per client, per the Massachusetts Division of Capital Planning and Operations (April 1984). Assuming again a depreciable life of fifteen years, the annual construction cost per client = $50,000/15 = $3,300. This is added to the cost of serving clients.
### TABLE 4.3
**MODEL FOR OPTION 2:**
EMPHASIZE HOUSING WITH MODERATE STAFF ASSISTANCE, SOME MEDICAL CARE
AND HOUSING WITH SUBSTANTIAL STAFF ASSISTANCE AND MEDICAL CARE

<table>
<thead>
<tr>
<th>Housing Category</th>
<th>Representative Housing Service</th>
<th>Cost per Client</th>
<th>Est. # In Need</th>
<th># Served In Model (%)</th>
<th>TOTAL COST TO SERVE</th>
<th># Left Unserved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Living Services</td>
<td>Specialized Home Care-</td>
<td>$11,400$^b</td>
<td>338</td>
<td>17 (5%)</td>
<td>$193,800</td>
<td>321</td>
</tr>
<tr>
<td></td>
<td>Out of Home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housing with Light Staff Assistance</td>
<td>Staffed Apartment</td>
<td>$22,000$^c</td>
<td>556</td>
<td>56 (10%)</td>
<td>$1,232,000</td>
<td>500</td>
</tr>
<tr>
<td></td>
<td>ICF/MR-B</td>
<td>$37,400$^d</td>
<td>227</td>
<td>57 (25%)</td>
<td>$2,131,800</td>
<td>170</td>
</tr>
<tr>
<td>Housing with Substantial Staff Assistance, Some Medical Care</td>
<td>ICF/MR-A</td>
<td>$50,400$^e</td>
<td>327</td>
<td>147 (45%)</td>
<td>$7,408,800</td>
<td>180</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td>1,448</td>
<td>277 (19%)</td>
<td>$10,966,400</td>
<td>1,171</td>
</tr>
</tbody>
</table>

**NOTES**

- See Notes, Table 4.2
### TABLE 4.4
MODEL FOR OPTION 3: PROVIDE A BALANCED MIX OF HOUSING

<table>
<thead>
<tr>
<th>Housing Category</th>
<th>Representative Housing Service</th>
<th>Cost per Client</th>
<th>Est. # In Need&lt;sup&gt;a&lt;/sup&gt;</th>
<th># Served In Model (%)</th>
<th>TOTAL COST TO SERVE</th>
<th># Left Unserved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent Living Services</td>
<td>Specialized Home Care- Out of Home</td>
<td>$11,400&lt;sup&gt;b&lt;/sup&gt;</td>
<td>338</td>
<td>91 (27%)</td>
<td>$1,037,400</td>
<td>247</td>
</tr>
<tr>
<td>Housing with Light Staff Assistance</td>
<td>Staffed Apartment</td>
<td>$22,000&lt;sup&gt;c&lt;/sup&gt;</td>
<td>556</td>
<td>150 (27%)</td>
<td>$3,300,000</td>
<td>406</td>
</tr>
<tr>
<td>Housing with Moderate Staff Assistance, Some Medical Care</td>
<td>ICF/MR-B</td>
<td>$37,400&lt;sup&gt;d&lt;/sup&gt;</td>
<td>227</td>
<td>61 (27%)</td>
<td>$2,281,400</td>
<td>166</td>
</tr>
<tr>
<td>Housing with Substantial Staff Assistance, Medical Care</td>
<td>ICF/MR-A</td>
<td>$50,400&lt;sup&gt;e&lt;/sup&gt;</td>
<td>327</td>
<td>88 (27%)</td>
<td>$4,435,200</td>
<td>239</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td></td>
<td>1,448</td>
<td>390 (27%)</td>
<td>$11,054,000</td>
<td>1,058</td>
</tr>
</tbody>
</table>

**NOTES**

<sup>a,b,c,d,e</sup> See Notes, Table 4.2
independent living services or housing with light staff assistance. In contrast, under option 3, 27% of those in need of all types of housing would be served, with funds slightly weighted toward more specialized housing. In terms of the actual number of people served, option 3 would serve more persons in need of independent living or housing with light staff assistance.

My own recommendation is that DMH develop a plan which falls between option 2 and option 3, that is, one which is slightly weighted toward housing for those who need specialized care but not so much so that persons with less severe disabilities are neglected. I suggest an emphasis on housing with moderate to heavy staff supervision and medical care because I believe that the individual's severity of need is the most important consideration. In all respects -- level of disability, ability of parents to provide care and the availability of affordable housing alternatives -- persons who need this type of housing have the most severe needs and should be DMH's first priority.

Persons who require less specialized housing, however, should be served in near equal proportions because their need for housing may be just as critical. Many of these persons may be living with aging parents who are concerned about finding a secure home for their children. Others are with parents whose energies and finances have been spent providing care for children who required, but could not receive, state services. Rather than assume that these families should and will continue to house the retarded indefinitely, the state must begin to be more attentive to the needs of those who have been saving it money by taking care of their own.

At the same time, DMH should emphasize housing services that have a
preventive function. By offering these services on in the early stages of planning, the number of individuals in need of state operated housing might actually be reduced. For example, the provision of respite care to some families might encourage them to continue caring for their retarded children at home. Similarly, if the severely disabled who are now underserved are provided more appropriate care in their current place of residence, perhaps they would not require alternative housing. Offering preventive services would thereby enable the state to allocate its funds to more people and focus on the development of housing for those who most truly need it.

For several years now, DMH/MR planning has been crisis oriented, responding to lawsuits, legislative demands and funding reductions. It cannot be emphasized enough that the Department now has an opportunity to change that system of service. While consent decree mandates have not yet been met there is beginning to be some room for DMH to be creative, rather than defensive, in its planning. Hopefully, the information provided in this report will enable the Department to meet that challenge.
FOOTNOTES

(1) These cost estimates assume that all those who require hospital-like settings are housed in ICF/MR-As. $50,000 cost per client quoted by Massachusetts Division of Capital Planning and Operations (April 1984).

(2) See Massachusetts Department of Mental Health, Division of Mental Retardation. Department of Mental Health Mental Retardation Regulations 104 CMR 20.00 - 23.00 (Boston: Massachusetts Department of Mental Health, 1979) Section 21.07(4), p. 5.


(4) Fein, p. 73.

(5) Costs quoted by Massachusetts Rate Setting Commission, April 1984.

(6) Sandra Michaels. An Analysis of the FY 83 Massachusetts DSS Respite Care Program for the Developmentally Disabled (Boston: Massachusetts Department of Social Services, May 1983) p. 57. DSS estimates annual cost of housing clients in an ICF/MR as $36,135. Respite care was estimated to cost $915 per client (see Executive Summary of the same report).

(7) Michaels, p. 61. See, Office of Child Abuse Prevention, Department of Social Services "Respite Care Demonstration Project, Second Year Evaluation, Final Report" (Sacramento, California: Department of Social Services, January 1982.)

(8) Mary McCarthy, Massachusetts Executive Office of Human Services. Memorandum to George A. Zitnay, Assistant Commissioner for Mental Retardation, Massachusetts Department of Mental Health (Boston, April 4, 1984). The specific types of housing provided under current plans are:

- Staffed Apartments: 367 units
- Community Residences: 8 units
- ICF/MR-As: 8 units
- Limited Group Residences: 16 units

(9) McCarthy, Memorandum to George A. Zitnay, p. 1. Current plans estimate a cost of $30,000 per bed, regardless of the housing type. Thus, approximately $11,970,000 will be spent on the 399 units planned, leaving $6 million of the $18 million appropriated for future housing development. However, the state also has funds available from previous years which will be used to house the mentally retarded. These funds bring the total available for future development to $11 million.
(10) Currently there is some debate regarding what type of services the elderly mentally retarded require. For further information see:

(11) Mills, Memorandum to Manuel Carballo, p. 27.

(12) This cost estimate is based on several sources:
- DMH/MR waiting lists indicate that the cost of housing clients in facilities which fit under this category ranges from $12,000 to $35,000 per client.
- According to the Massachusetts Department of Public Welfare (April 1984), the cost of serving clients in an ICF/MR-B in FY84 averaged $35,405.

(13) ICF/MR cost based on information received from Massachusetts Department of Public Welfare (April 1984). Chronic hospital cost based on estimates reported by Michaels, p. 48. Michaels' estimate is based on MARC projections.


(15) Michaels, p. 47.
APPENDIX A

Methods Used by Other States and Localities to Estimate Unserved Mentally Retarded Housing Need

A number of other states in addition to Massachusetts have been guided by consent decrees in planning for the mentally retarded and found it difficult to serve those not protected under these decrees. These states have also faced problems, such as those discussed in Chapter One, in trying to estimate the number in need of services. The way these governments overcame these problems provides an example which Massachusetts might follow in planning for its unserved retarded citizens.

My own study of other state and local governments reveals three approaches to estimating the housing needs of unserved mentally retarded: (1) the use of prevalence rates, (2) the use of surveys, and (3) the use of both prevalence rates and surveys.

(1) Estimates Based on Prevalence Rates

In one of the five studies consulted, estimates of the prevalence of retardation were used almost exclusively to predict the housing needs of unserved mentally retarded. This study, conducted for the City of Philadelphia, used research on the prevalence of mental retardation among different income groups to estimate a 7% prevalence in neighborhoods with the lowest median family income and 2% in neighborhoods with the highest median family income. These assumptions were then checked against data on the mentally retarded attending public schools, which also revealed a higher prevalence of retardation in low income neighborhoods. With this information, the estimate of unserved mentally retarded was derived by subtracting the number served by the
city from the overall prevalence estimate.

To determine the number in need of housing, authors of the Philadelphia study analyzed relevant characteristics of the retarded. For example, research reported by the President's Committee on Mental Retardation was used to break down the unserved mentally retarded population by age and level of retardation. The authors then assumed that the youngest and most severely retarded had the greatest need for housing.(2)

Although only one study was found to use prevalence rates as the primary means of determining unserved housing need, the approach is not that uncommon. A survey of state agencies referred to in Chapter One indicated that many states use this method to estimate the number of mentally retarded requiring services.(3) The advantage of this approach is that it makes estimating unserved housing need a relatively simple task. The disadvantages of the approach, however, are that prevalence rates vary and that housing need may depend on factors that cannot be estimated based on this information alone, for example, families' ability to provide care.

(2) Surveys of the Unserved Mentally Retarded

Three states used surveys to estimate the number of unserved mentally retarded in need of housing. In DuPage County Illinois, two studies were conducted, one a door-to-door census of the general population, the other a survey of known handicapped individuals. The first study was used to estimate the prevalence of disability in the area, while the second provided information on the various types of impairments and needs of the disabled.(4) Alternatively, a study conducted for the state of Ohio surveyed agencies serving the disabled,
asking them to identify disabled individuals in need of services and to indicate their current place of residence, age, and level of disability. In Montana, a similar survey was used and additional information was obtained from interviews, on-site visits to residences for the disabled and existing studies.

There are two primary advantages to using surveys to estimate unserved housing need: (1) surveys assist in actually identifying the unserved, and (2) surveys provide detailed information on the characteristics and needs of the unserved. In this regard, surveys overcome some of the problems associated with prevalence estimates and provide better data on which to develop plans. Survey data are especially valuable in cases where estimates cannot be based on prevalence rates, for example, in estimating the type of housing the unserved require.

Despite these advantages, surveys do not provide perfect information on the unserved. As with estimates based on prevalence rates, survey results can vary depending on how respondents determine whether an individual is mentally retarded or "unserved". Biases in the survey procedure, ambiguous questions or incomplete responses can also lead to unreliable results. When a census of the general population is used, additional problems arise if the individuals polled do not share characteristics similar to the larger population. If agencies serving the disabled are surveyed, results are limited because agencies can only identify those they know to be unserved.

(3) Statistical Estimates Combined with Surveys

The last study I consulted used both statistical estimates and surveys to estimate the number of mentally retarded in need of housing. In research conducted for the State of Rhode Island, a prevalence rate of
1.6\% was used to estimate the number of mentally retarded/developmentally disabled in need of state services. Results from a survey of public agencies serving the disabled were then employed to determine trends among the disabled with regard to age, level of disability, current place of residence and severity of need.\(^8\)

The Rhode Island approach attempts to balance the advantages and disadvantages of using prevalence rates and surveys. By employing prevalence estimates, the state realized an estimate that included unserved individuals who might not be known to providers and thereby might not be reported in any survey. Because prevalence rates vary, however, survey data were used to develop a more precise count of the unserved and their actual needs. In this way, estimates of the unserved mentally retarded were double-checked and made more useful for planning.

Unfortunately, using both statistical estimates and surveys to estimate unserved housing needs does not resolve the problems associated with either method. Instead, estimates realized through this approach are subject to problems associated with both prevalence rates and surveys. In addition, the use of both methods means that two estimates of the unserved in need of housing are developed. In Rhode Island, this confusion was resolved by assuming that the survey identified individuals with the most immediate and verifiable need, while estimates based on prevalence rates included persons with future service needs.
FOOTNOTES


(2) Stonorov and Haws, p. 27.


(8) Rhode Island Department of Mental Health, Retardation and Hospitals. Division of Retardation State Plan FY83 (State of Rhode Island, no date).
APPENDIX B

Applying Information on Mentally Retarded Served by DMH/MR to the Prevalence-Based Estimate of Unserved Retarded Adults

According to Tables 2.9 (a) and (b), the level of self-preservation capability among DMH/MR class and non-class clients is as follows:

<table>
<thead>
<tr>
<th>Level of Capability</th>
<th>Class</th>
<th>Non-Class</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unimpaired</td>
<td>41.1%</td>
<td>73.0%</td>
</tr>
<tr>
<td>Ambulatory/Partially Impaired</td>
<td>27.6%</td>
<td>13.7%</td>
</tr>
<tr>
<td>Ambulatory/Impaired</td>
<td>14.5%</td>
<td>6.6%</td>
</tr>
<tr>
<td>Non-Ambulatory/Impaired</td>
<td>16.8%</td>
<td>6.6%</td>
</tr>
</tbody>
</table>

Clearly, class and non-class clients have different levels of capability. As indicated by data from the MSCB, most class clients require some form of assistance to evacuate while most non-class clients are unimpaired. Tables 2.9(a) and (b) also indicate the mix of class and non-class clients served by DMH. Non-class clients comprise 38.1% of those served by DMH/MR, while class clients comprise 61.9% of the served population.

Before percentages from tables 2.9(a) and (b) can be applied to the prevalence-based estimate of unserved adults, these differences must be accounted for. This is done by weighting the capability breakdown by the percent of class or non-class clients served by DMH/MR. The results of this computation are then added to realize the expected percent of unserved adults who are unimpaired, ambulatory/partially impaired, ambulatory/impaired and non-ambulatory/impaired. This computation leads to the following estimates:

(1) **Unimpaired**:

41.1% of the class clients are unimpaired. Weighting this by the percent of class clients clients in the population served by DMH/MR =
41.1% X 61.9% = 25.4%

73.0% of the non-class clients are unimpaired. Weighting this by the percent of non-class clients in the population served by DH/MR =

73.0% X 38.1% = 27.8%

These two results are then added to realize the expected percent of unserved mentally retarded adults who are unimpaired:

25.4% + 27.8% = 53.2%

Applying this to the prevalence-based estimate of unserved mentally retarded adults, the number estimated to be unimpaired =

53.2% X 3,191 = 1,699

(This and other calculations were performed using a computer program which multiplied out to several decimal points. The results presented here are therefore different from those that would be realized if calculations were performed using the percentages listed.)

(2) Ambulatory/Partially Impaired:

27.6% X 61.9% (class clients) + 13.7% X 38.1% (non-class clients)

= 17.1% + 5.2%

= 22.3%, or 713 of the unserved adults are estimated to be ambulatory/partially impaired.

(3) Ambulatory/Impaired:

14.5% X 61.9% (class clients) + 6.6% X 38.1% (non-class clients)

= 9.0% + 2.5%

= 11.5% or 367 of the unserved adults are estimated to be ambulatory/impaired.

(4) Non-Ambulatory/Impaired:

16.8% X 61.9% (class clients) + 6.6% X 38.1% (non-class clients)

= 10.4% + 2.5%

= 12.9% or 412 of the unserved adults are estimated to be non-ambulatory/impaired.

To estimate the number of unserved adults in need of DH/MR housing, a similar procedure is followed. In this case, however, estimates of the unimpaired or ambulatory/partially impaired are derived by subtracting off individuals who are living by themselves or with family. Estimates of ambulatory/impaired and non-ambulatory/impaired persons are the same as
those realized above. This leads to the following estimates:

(1) **Unimpaired in Need of Housing:**

2,296 class clients are unimpaired. Of these, 456 are living by themselves or with family. Thus, 1,840 or 32.9% of the class clients are both unimpaired and not living by themselves or with family. Weighting this by the percent of class clients in the population served by DMH/MR =

\[ 32.9\% \times 61.9\% = 20.4\% \]

2,509 non-class clients are unimpaired. The number living by themselves or with family is 1,341. Thus, 1,168 or 34.0% of the non-class clients are both unimpaired and not living by themselves or with family. Weighting this by the percent of non-class clients served by DMH/MR =

\[ 34.0\% \times 38.1\% = 12.9\% \]

These two results are then added to realize the expected percent of unserved mentally retarded adults who are unimpaired and not able to live by themselves or with family:

\[ 20.4\% + 12.9\% = 33.3\% \]

Applying this to the prevalence-based estimate of unserved mentally retarded adults, the number estimated to be unimpaired and in need of DMH/MR housing =

\[ 33.3\% \times 3,191 = 1,064 \]

(2) **Ambulatory/Partially Impaired in Need of Housing:**

1,509 or 27.0% of the class clients are both ambulatory/partially impaired and not living by themselves or with family. Among non-class clients, 276 or 8.0% are ambulatory/partially impaired and not living by themselves or with family. Substituting these percentages into the formula used above:

\[ 27.0\% \times 61.9\% \text{(class clients)} + 8.0\% \times 38.1\% \text{(non-class clients)} = 16.7\% + 3.1\% = 19.8\% \text{ or 631 of the unserved adults are estimated to be ambulatory/partially impaired and in need of DMH/MR housing.} \]

(3) **Ambulatory/Impaired and in Need of Housing:**

All unserved adults estimated to be ambulatory/impaired are assumed to require housing regardless of their current living situation. Thus, 367 ambulatory/impaired unserved adults are estimated to need DMH/MR housing.

(4) **Non-Ambulatory/Impaired and in Need of Housing:**

All 412 unserved adults estimated to be non-ambulatory/impaired are
assumed to require DMH/MR housing regardless of their current living situation.
APPENDIX C

Description of DMH/MR Housing Services by Category of Housing

The services listed below include all housing related programs now used by DMH/MR. Most of these services are provided directly by the Department. In some cases, however, DMH pays for services provided to clients by other state agencies or private vendors.

(1) Independent Living Services

- Living with Parents or Kin

- Other Family Living Situation (Foster Care)

- Specialized Home Care: This program provides services to clients in their own home or a private residence where room and board is paid for. Clients receive training in daily living skills, support and/or respite services.(1)

- Independent Living Apartments: These apartments have no staff in residence and are used only for those who are capable of self-preservation.(2)

- Independent Living with Minimal Supervision

- Cooperative Apartments: Residents in these facilities receive regular services, but on a less than 24-hour basis.(3)

(2) Group Living Situations with Light Staff Assistance

- Community Residence: This facility is a "...supervised, residential setting for six to twelve clients capable of self-preservation...with not more than a one to eight staff to client ratio. One staff person must be present when clients are asleep. There must be a full-time residence manager."(4)

- State Operated Community Residence

- Other Group Home Type Community Residence

- Staffed Apartment: In these apartments residents' skill levels can vary considerably. Residents receive 24-hour staff supervision and need not be capable of self-preservation.(5)

(3) Group Living Situations for Individuals who Require Moderate Staff Assistance and Some Medical Care

- Limited Group Residence: This facility can serve clients with varying degrees of impairment. When used for clients who are not
capable of self-preservation there must be one staff member present for each client and "...sleeping facilities for these residents...[must be]...on a floor from which both exits lead directly to grade." When used for clients who are capable of self-preservation, "...there must be staff present for every four residents...."(6)

- Residential Schools other than DMH/MR State Schools

- ICF/MR-B: This facility houses eight to fifteen individuals who are capable of self-preservation. "These programs are funded...under the Medicaid program and are licensed by the Department of Public Health. The physical facility and the program must meet the requirements of Title XIX of the Social Security Act. The first floor must be accessible to the physically handicapped...."(7)

- Rest Homes

- Nursing Homes

(4) Housing for Individuals who Require Substantial Staff Assistance and Medical Care

- ICF/MR-A: This facility houses eight clients who are not capable of self-preservation. Like ICF/MR-Bs, these programs are licensed and certified by the Department of Public Health and meet Title XIX requirements. These facilities are also accessible to the physically handicapped.(8)

- State Schools for the Mentally Retarded: These institutions are governed by Title XIX and Consent Decree mandates. Services provided in schools "...include but are not limited to: training and habilitation, medical, nutritional, adaptive equipment, social and recreational services, and a wide range of clinical services."(9)

- Regional Centers for the Mentally Retarded: These facilities are similar to the state schools but are smaller in scale, generally "...serve geographically limited areas and are not subject to the mandates of consent decrees. They are, however, subject to Title XIX regulations."(10)

- Skilled Nursing Facility

- General Hospital

- Rehabilitation Facility/Hospital

- Psychiatric Hospital

- Other Health Related Facilities
FOOTNOTES

(1) Massachusetts Department of Mental Health, Division of Mental Retardation. Orientation to the Mental Retardation Service System "Fact Sheet: Community Residential Services for Mentally Retarded Persons" (Boston: Massachusetts Department of Mental Health, no date.) p. 2.


(9) Massachusetts Department of Mental Health, Division of Mental Retardation. Orientation to the Mental Retardation Service System "Fact Sheet: State School" (Boston: Massachusetts Department of Mental Health, no date.) p. 1.

(10) Massachusetts Department of Mental Health, Division of Mental Retardation. "Fact Sheet: State School," p. 2.
APPENDIX D

Sensitivity Analysis of Estimates of the Unserved Mentally Retarded

One advantage of the mathematical model I use to develop estimates is that the assumptions on which estimates are built can be easily changed and new information incorporated. Since the estimates presented in this report are sometimes based on debatable assumptions and incomplete data, this is an important attribute. By substituting new information into the model, better estimates of the unserved mentally retarded can be developed. In addition, the relative importance of each piece of information used to derive estimates can be tested through a sensitivity analysis. This analysis is conducted in this appendix, showing how estimates would change if some of the more important assumptions used in the model were altered.

Prevalence-Based Estimates

Key assumptions used in the development of prevalence-based estimates are those which affect the largest number of estimates. In this regard, the assumption that 0.5% of the Massachusetts population is mentally retarded is critical because all prevalence based estimates are derived from this rate. Another important assumption is that only 10% of DMH/MR clients are children. While this assumption does not affect estimates of the total population in need of services, it does seem to lead to an overestimate of unserved retarded children and, thereby, an underestimate of mentally retarded adults currently in need of services.

To test the reaction of the model to the prevalence rate, I developed estimates of the unserved mentally retarded based on the 1%
prevalence rate suggested by Tarjan, Wright, Eyman and Keeran in their research. In substituting this rate into the model, estimates of the prevalence of mental retardation by age also change. In this case I again used Tarjan and his co-authors' estimates that 0.2% of the population is mentally retarded adults and 0.8% mentally retarded children. (1)

Table D.1 reports estimates that result from implementing this change. As evidenced in this table, changing the prevalence rate to 1% has the effect of increasing the estimate of the total unserved population by 29,000 or 148%. This increase, however, only affects estimates of unserved retarded children. This is because estimates based on a 0.5% and 1% prevalence rate both assume that 0.2% of the population is mentally retarded adults. In contrast, estimates derived from the 0.5% prevalence rate assume that 0.3% of the Massachusetts population are children, while estimates derived from the 1% rate assume 0.8% are children. (2) As Table D.1 shows, using the 1% prevalence rate thereby leads to higher estimates of children in need of housing over the next twenty years. However, the percentage of unserved children requiring each type of housing remains the same.

With regard to the mentally retarded served by DMH/MR, I developed estimates based on the assumption that 25%, rather than 10%, are children. This change was not based on any additional information concerning the age of DMH/MR clients. Instead, I chose 25% because it would reduce the estimate of unserved retarded children while still reflecting DMH's policy of serving children only in cases of emergency.

Table D.1 also shows that by changing only the assumption regarding children served by DMH/MR, estimates of the total unserved population are not affected, but differences in estimates of the unserved by age do
<table>
<thead>
<tr>
<th>ESTIMATE</th>
<th>Estimate Reported (Based on 0.5% Prevalence Rate, assumption that 25% of DMH/MR's Clients are Children)</th>
<th>Estimates based on 1% Prevalence Rate</th>
<th>Estimates based on Assumption that 25% of DMH/MR's Clients are Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Unserved Population</td>
<td>19,657</td>
<td>48,657</td>
<td>19,657</td>
</tr>
<tr>
<td>Unserved by Age Group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults</td>
<td>3,191</td>
<td>3,191</td>
<td>4,593</td>
</tr>
<tr>
<td>Children</td>
<td>16,466</td>
<td>45,466</td>
<td>15,064</td>
</tr>
<tr>
<td>Unserved Needing Housing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults</td>
<td>2,474</td>
<td>2,474</td>
<td>3,561</td>
</tr>
<tr>
<td>Children</td>
<td>9,699</td>
<td>26,783</td>
<td>8,874</td>
</tr>
<tr>
<td>Type of Housing Needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Ind. Living</td>
<td>1,064</td>
<td>1,064</td>
<td>1,331</td>
</tr>
<tr>
<td>- Housing with Light Staff</td>
<td>631</td>
<td>631</td>
<td>908</td>
</tr>
<tr>
<td>- Housing with Moderate Staff</td>
<td>367</td>
<td>367</td>
<td>529</td>
</tr>
<tr>
<td>- Housing with Substantial Staff</td>
<td>412</td>
<td>412</td>
<td>593</td>
</tr>
<tr>
<td>Children:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Ind. Living</td>
<td>4,296</td>
<td>11,862</td>
<td>3,930</td>
</tr>
<tr>
<td>- Housing with Light Staff</td>
<td>3,175</td>
<td>8,768</td>
<td>2,905</td>
</tr>
<tr>
<td>- Housing with Moderate Staff</td>
<td>1,073</td>
<td>2,963</td>
<td>982</td>
</tr>
<tr>
<td>- Housing with Substantial Staff</td>
<td>1,155</td>
<td>3,190</td>
<td>1,057</td>
</tr>
</tbody>
</table>
result. By assuming that 25% of DMH/MR's clients are children, estimates of unserved adults increase by 44%, while estimates of unserved children decrease by 9%. Similarly, estimates based on this assumption show 1,087 more adults and 825 fewer children in need of housing than estimates based on the assumption that 10% of DMH/MR's clients are children. Estimates of the percentage of children and adults requiring each type of housing are again unchanged.

Survey or Count-Based Estimates

For survey or count-based estimates, the most critical assumptions are those which are based on controversial or conflicting data. Two groups of unserved/underserved mentally retarded for which the data conflict the most are (1) mentally retarded living in mental institutions, and (2) mentally retarded residents of nursing homes. For the first group, three estimates are available, one reported by MARC and two reported by DMH. For mentally retarded living in nursing homes there are two sources of information. These sources are estimates reported by MARC and estimates used by DMH.

In Chapter Two, differences between estimates of the mentally retarded living in mental institutions were resolved by taking a mean. In this analysis, I change the estimate to coincide with data reported by DMH's special task force on the mentally retarded/mentally ill. According to this source, approximately 529 dual diagnosis clients currently reside in the state. Of these, 167 living in mental institutions are estimated to require placement in DMH state schools.

By developing survey or count-based estimates based on these data, results change only slightly. As shown on Table D.2, changing the
estimate of mentally retarded living in mental institutions reduces estimates of the total unserved/underserved population by only 0.3%. This decrease largely affects estimates of the unserved adults since most of those in mental institutions are over age 22. In addition, estimates of mentally retarded requiring housing are also lower as a result of substituting data from the dual diagnosis task force for the mean three estimates. Estimates of the type of housing needed also change, but only under the categories of housing with light staff assistance and housing with moderate staff supervision and medical care.(3)

For mentally retarded residents of nursing homes, I substituted MARC's estimates for DMH's. According to MARC, approximately 2,360 retarded adults and 350 children currently live in nursing homes. MARC also estimates that 1,109 of these individuals require alternative housing. Unfortunately, this latter estimate is not broken down by clients' age. In this analysis, I assume that the proportion of adults and children requiring housing is the same proportion as that reported by MARC for the total population living in nursing homes. Thus, 965 retarded adults (87%) and 144 children (13%) are estimated to need DMH/MR housing. MARC estimates that these individuals need the following types of housing:

(1) % In need of Independent Living Services: 9.0%
(2) % In need of Housing with Light Staff Asst.: 58.5%
(3) % In need of Housing with Moderate Staff Asst. and Some Medical Care: 19.5%
(4) % In need of Housing with Substantial Staff Asst. and Medical Care (4): 13.0%

Table D.2 shows that by using MARC data on the retarded living in nursing homes, estimates of the total unserved/underserved population
### TABLE D.2

**COMPARISON OF SURVEY OR COUNT-BASED ESTIMATES UNDER DIFFERENT ASSUMPTIONS**

<table>
<thead>
<tr>
<th>ESTIMATE</th>
<th>Estimates Reported</th>
<th>Estimates Based on DMH's Dual Diagnosis</th>
<th>Estimates Based on MARC's Estimates of Retarded in Mental Institutions</th>
<th>Estimates Based on MARC's Estimates of Retarded in Nursing Homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Unserved/Underserved Population</td>
<td>14,239</td>
<td>14,198</td>
<td>14,395</td>
<td></td>
</tr>
<tr>
<td>Unserved/Underserved By Age Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults</td>
<td>4,992</td>
<td>4,954</td>
<td>5,023</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>9,247</td>
<td>9,244</td>
<td>9,372</td>
<td></td>
</tr>
<tr>
<td>Unserved/Underserved Needing Housing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults</td>
<td>2,465</td>
<td>2,273</td>
<td>2,755</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>5,837</td>
<td>5,823</td>
<td>5,815</td>
<td></td>
</tr>
<tr>
<td>Type of Housing Needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Ind. Living</td>
<td>338</td>
<td>338</td>
<td>364</td>
<td></td>
</tr>
<tr>
<td>- Housing with Light Staff</td>
<td>1,560</td>
<td>1,416</td>
<td>1,730</td>
<td></td>
</tr>
<tr>
<td>- Housing with Moderate Staff</td>
<td>230</td>
<td>183</td>
<td>287</td>
<td></td>
</tr>
<tr>
<td>- Housing with Substantial Staff</td>
<td>329</td>
<td>329</td>
<td>366</td>
<td></td>
</tr>
<tr>
<td>Children:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Ind. Living</td>
<td>607</td>
<td>607</td>
<td>605</td>
<td></td>
</tr>
<tr>
<td>- Housing with Light Staff</td>
<td>4,352</td>
<td>4,342</td>
<td>4,340</td>
<td></td>
</tr>
<tr>
<td>- Housing with Moderate Staff</td>
<td>674</td>
<td>670</td>
<td>670</td>
<td></td>
</tr>
<tr>
<td>- Housing with Substantial Staff</td>
<td>204</td>
<td>204</td>
<td>201</td>
<td></td>
</tr>
</tbody>
</table>

**NOTES**

- Housing need of 8 adults on waiting list not indicated.
increase by 1%. This increase affects estimates of both unserved children and adults. Estimates of the number in need of housing also increase by 12% for adults, but decrease 0.4% for children. A similar pattern is found in estimates of the type of housing needed by the unserved/underserved. Once again, however, approximately the same percentage of adults and children are estimated to require each type of housing.

Conclusions

This appendix shows how the proposed model can be used to develop estimates based on different assumptions and data on the unserved mentally retarded. It also shows the degree to which certain assumptions affect estimates of this population.

Based on this analysis, estimates are the most sensitive to assumptions regarding the prevalence of mental retardation. By changing this one assumption, estimates of the number in need of any form of state services more than double. This indicates that the DMH/MR prevalence rate should be carefully evaluated before it is used to estimate the unserved population. While DMH believes that this rate is appropriate for estimating the number of mentally retarded with the most severe needs, it may be too conservative. The 1% estimate developed by Tarjan, Wright, Eyman and Keeran is based on extensive research of the mentally retarded, their mortality rates, and variations of the prevalence of mental retardation by age. This estimate may therefore be more appropriate for use in the estimation process.

Changing the assumption regarding the percentage of children served by DMH/MR also has a significant impact on estimates of the unserved
mentally retarded. In this case, estimates of the unserved mentally retarded adults increase by 1,402 individuals while estimates of children decrease by the same amount. Uncertainty surrounding the accuracy of this assumption, however, is less problematic. By checking its own data on the age of clients served, DMH should be able to resolve differences between the estimates rather easily.

Assumptions made in the development of survey or count-based estimates appear to have less of an influence on estimates. By substituting data from DMH's dual diagnosis task force, or MARC data into the model, estimates of the total unserved/underserved mentally retarded change by only 0.3% or 1% respectively. This, however, does not mean that data on these groups should not be more carefully checked. Instead, the differences that result are small only because the changes I made were also minor. For example, MARC's estimate of the number of mentally retarded residing in nursing homes is only 6% larger than DMH's.(5) If neither of these estimates are accurate, then actual differences may be greater than that indicated by this analysis.

The results of this analysis have important implications for planning housing for the unserved mentally retarded. For example, estimates based on the assumption that 25% of DMH/MR's clients are children indicate that 1,087 more adults require housing than estimated in Chapter Two. Under this assumption, then, DMH plans for housing the unserved mentally retarded would have to be expanded. Similarly the DMH dual diagnosis task force estimates of mentally retarded in mental institutions indicate that a number of adults need housing with light staff assistance, or housing with moderate staff supervision and medical care. This implies that DMH plans should place less emphasis on these
types of housing.

In the immediate future, however, policy decisions are not affected by these differences. Because of funding constraints, DMH is only able to serve a limited number of clients at any one time. Thus, the difference between developing housing for 19,700 or 48,700 adults would not affect the provision of services in the initial stages of planning. The estimates presented in the main body of this report can therefore be used to develop initial housing plans, with future plans based on data that are refined and improved over time.
(1) See Chapter Two, Table 2.6.

(2) In Chapter Two, estimates of the unserved by age were derived by making Tarjan, Wright, Eyman and Keeran's estimates compatible with DMH's 0.5% prevalence rate. This was done by reducing the mentally retarded population reported by Tarjan and his co-authors' by two-thirds. This lead to the following estimates:

-- ADULTS
Tarjan, Wright Eyman and Keeran estimate that .13% of the population is mildly retarded adults, .09% moderately to severely retarded adults and, .02% profoundly retarded adults (see Chapter Two, Table 2.7). Thus, Tarjan and his co-authors estimate that the overall prevalence of mentally retarded adults in the population =

\[ .13\% + .09\% + .02\% = .24\% \]

After reducing the mildly retarded population by two thirds, my estimate of the overall prevalence of retarded adults in the population =

\[ .13\% \text{ (33\%)} + .09\% + .02\% = .04\% + .09\% + .02\% = .15\% \text{ or } .2\% \]

Thus, after rounding, the estimate of the prevalence of mentally retarded adults in the population does not change by adjusting Tarjan and his co-authors' estimate to coincide with the DMH 0.5% prevalence rate. Differences do result, however, in estimates of the prevalence of retarded children.

-- CHILDREN
Tarjan, Wright, Eyman and Keeran report that .62% of the population is mildly retarded children, .11% moderately to severely retarded children, and .03% profoundly retarded children. Their estimate of the overall prevalence of retarded children in the population is therefore =

\[ .62\% + .11\% + .03\% = .76\% \]

In this case, reducing the mildly retarded population by two-thirds leads to the following estimates:

\[ .62\% \text{ (33\%)} + .11\% + .03\% = .20\% + .11\% + .03\% = .34\% \text{ or } .3\% \]

Thus, for children, making Tarjan and his co-authors' estimates compatible with DMH's 0.5% prevalence rate leads to a rate that is 0.5 percentage points lower than that reported by the authors.
(3) Estimates of dual diagnosis clients requiring independent living services do not change because estimates derived by both MARC and DMH indicate that none of these individuals require this type of housing. Similarly, estimates based on the mean of available data and those reported by the dual diagnosis task force both assume that 167 mentally retarded/mentally ill individuals require housing with substantial staff assistance and medical care. Estimates of dual diagnosis clients requiring housing with light or heavy staff supervision do change because DMH's dual diagnosis task force reports no individuals need this type of housing, while MARC estimates that 360 individuals require placement in these facilities. (See Chapter Three, pp.95-99).

(4) See Chapter Three, p. 99.

(5) MARC estimates that the total mentally retarded population living in nursing homes is 2,710. DMH estimates 2,554 mentally retarded are currently residing in nursing homes (see Chapter Two, Table 2.3).
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