

**INSTITUTIONAL AND COMMUNITY SERVICES
REPORT TO THE
78TH LEGISLATURE**

APRIL 20, 2003

**Presented by the Task Force on State Schools and
Community Services Programs for Texans with Mental Retardation**

STATE PROVIDED AND COMMUNITY PROVIDED RESIDENTIAL SERVICES IN TEXAS

A Compendium of Reports, Research, and Objective Data
Related to Texas State Schools and Community Based Services for People with
Mental Retardation

INTRODUCTION:

Texas currently supports a dual system of services for people with mental retardation and related conditions: an institutional, or state school model, and a community-based service delivery model ⁽¹⁾.

Under the current economic climate, debates over the philosophical and moral issues underlying these two models have been complicated with the growing demand for fiscal responsibility and legislative integrity in managing public tax dollars. Recently, advocates for services for people with mental retardation have called for an examination of the economic arguments of maintaining, as is, the current system of state-owned and operated large institutional facilities in the face of escalating demands for services in the community.

Currently, less than 1% of the population of individuals with mental retardation in need of residential services chooses institutional care. The 78th Texas Legislature must consider the practicality of continuing to maintain, without change, Texas' massive system of institutional care when the vast majority of citizens with mental retardation and their families are requesting and waiting for community-based services. Texas continues to lag behind the trend among states across the country to close large institutional facilities and redirect savings to support more efficient and cost-effective services in the community.

On April 7, 2003, Comptroller Carol Keeton Strayhorn issued a report in which she recommended that two as yet unidentified state schools be closed to achieve economies within the institutional system ⁽¹⁴⁾.

PURPOSE:

The purpose of this report is to assist the Legislature with their deliberations on this issue and to aid in their process of coming to factual and objective decisions regarding the design and funding of the public system of services for people with mental retardation. Unfortunately, most Legislators do not have the ability to personally confirm the veracity of the many anecdotal, albeit emotional, stories that are presented on both sides of this complicated issue. Often these

stories and anecdotal “evidence” that are presented by zealous advocates, at best, shade the facts, and at worst misrepresent the details on important issues. A need exists for validated and objective data, from known, reliable and objective Texas-based and nationally recognized sources, upon which legislators and other state officials may rely.

This report will present research findings, reports from various state and local agencies, and other objective findings that will clarify issues often discussed in the institutional services versus community services debate. This report will attempt to cover these issues and findings in the following categories:

- TDMHMR Waiting List
- State Institution Statistics and Data
- Comparisons of Statistics Between State Schools and Community Programs
- Relevant Research Findings
- Misconceptions and Myths

References will be given for all fact statements. Source documents referred to in this report are available upon request.

It is recognized that establishing an order or priority for the various topics can only be a subjective process. Accordingly, the sections that follow are in no priority order.

THE TDMHMR WAITING LIST:

(1) Current service delivery facts:

Using the accepted estimate that 3% of the general population will be affected, approximately 632,000 people with mental retardation live in Texas. The Texas Department of Mental Health and Mental Retardation (TDMHMR) define the legislatively mandated mental retardation services priority population to be 111,156 persons ⁽²⁾. The TDMHMR service delivery system, including both community and campus-based mental retardation services, served 41,417 Texans in fiscal year 2001.

Recognizing some duplication in the number of customers across services:

- 5,645 persons were served in State Mental Retardation Facilities (State Schools)
- 22,368 persons were served in mental retardation community programs
- 7,748 persons were served in ICFMR programs
- 6,057 persons were served in Medicaid waiver services (HCS, HCS-O, and MRLA) ⁽²⁾.

With only approximately 37% of the priority population currently receiving services, it is clear that the need for mental retardation services in Texas is not being met. With an estimated additional 6,000 Texans being born annually who have or will develop mental retardation, the need continues to grow.

The TDMHMR Waiting List is a significant barometer of the known demand for, and the availability of, mental retardation services. Due to the birth rate, expanding awareness of the waiting list, an increasing assertiveness on the part of consumers and their families, and an improved system of documenting that waiting list, the number of persons on the TDMHMR Waiting List grows more than 20% annually. There is no guarantee that the current Waiting List includes all persons now waiting for services. It reflects only known need. Evidence suggests that many more are in need who simply don't ask to be put on the list knowing that some wait as many as seven to ten years for services.

However, the most recent Waiting List figures documented by TDMHMR are as follows:

- 21,067 documented people waiting for mental retardation services
- 11,196 (54%) of those individuals receive no services at all
- 9,871 (47%) receive some services ⁽³⁾
- Approximately 19,230 wait for Home and Community-Based Services (HCS)
- Additional reports document an average of 9 persons per month are waiting for services in a state school ⁽⁴⁾

It should be noted that TDMHMR asserts that most of the people on the Waiting List who receive "some services" often receive only case management oversight with no actual services delivered, minimal in-home contacts, or sporadic and minimal clinical contacts. Although often discounted by those not familiar with the system, those on the Waiting List receiving "some services" have documented need for services and interventions far exceeding those currently received.

A deeper analysis of the Waiting List reveals that 29% do not want services immediately. The needs of these families may be driven, for example, by:

- A family having a 19 year old child in school that does not need those services until s/he graduates in two years.
- Families who, knowing that many others wait for more than 7 years for services, add their child to the Waiting List simply to ensure seniority on the list at such time when the family member will need services.
- Some individuals are added to the Waiting List in anticipation of a decreasing life span for the parents or aging caregivers. An aging parent might sign their adult child up for services anticipating they, the parents, will be dead by the time their adult child comes up on the list although they are willing to continue to care for him/her until the parents' death.

(2) Accuracy of the Waiting List:

Confusion exists regarding who the people are that are on Waiting Lists. Some have recently asserted that the TDMHMR Waiting List is vague and undocumented and that it does not project needed services or eligibility for services. This assertion is incorrect.

The Texas Health and Safety Code 533.038 (d) requires that: "...a person with mental retardation, or a person's legally authorized representative (LAR), seeking residential services shall receive a clear explanation of programs and services for which the person is determined

eligible, including state schools, community ICF/MR programs, waiver services under section 1915(c) of the federal Social Security Act, or other services” (5).

Following the enactment of the foregoing requirement (re: Senate Bill 358, 76th Legislature), TDMHMR incorporated language into departmental rules requiring that local Mental Retardation Authorities (MRAs) inform all individuals, and their LARs, regarding all programs and services for which the individual may be eligible. These rules are cited in the TDMHMR’s “Explanation of Residential Options: Elements of Rule Requirements”. Every year each MRA (in most cases, Community Mental Health and Mental Retardation Centers) must contact every individual on the list and determine:

- If they continue to be interested in services
- Which specific services they anticipate needing
- When they might need those services if they had a choice
- Their current address and contact information.

The TDMHMR Performance Contracts with MRAs for FY 2002 include requirements that each local MRA maintain Waiting List information in the state TDMHMR data system data for all persons requesting/needing services that will not be available for at least 30 days.

(3) Eligibility for services:

Estimates that as many as 40% of individuals on the Waiting List are “ineligible” for services are wholly incorrect. Due to the un-reimbursed cost of the eligibility determination process and the fact that services may not be available to the individual for 7-10 years, local Mental Retardation Authorities (MRAs) do not formally determine eligibility for services until such time as services actually become available to the individual. However, because most adults with mental retardation meet financial criteria for SSI (Supplemental Security Income), when evaluated, as many as 98% of those on the Waiting List are found to be eligible for services.

TDMHMR has taken effective steps to ensure the accuracy and integrity of the Waiting List. Therefore, while the Waiting List might have been suspect five years ago, the current Waiting List is validated and accurate to every extent possible. Accordingly, TDMHMR has information of high quality and validity regarding what persons are waiting for services, when they expect to need those services and what specific services and service environments are needed and requested.

(4) Waiting Lists vs. Interest Lists:

Another area of confusion is the common misunderstanding of how the TDMHMR Waiting List compares to the “interest list” of other state agencies. The “Waiting List” of TDMHMR is a documented, specific, and personally validated list of people who have asked for specific services they need but are not able to access, who have indicated their preference for a community-based or institutional environment and who have indicated when they expect services to be needed.

The Department of Human Services “interest list” is simply a list of people who have expressed interest in a particular DHS service. This list does not have the detailed data structure or required verification processes noted in the TDMHMR Waiting List.

STATE INSTITUTION STATISTICS AND DATA:

Since 1999, The Texas Legislature has required TDMHMR to take specific and concrete steps to improve efficiency, reduce costs, and maximize federal funding to enhance the cost-effectiveness of its Home and Community-based Services (HCS) program. In 2003, the current economic, political, and social environment now demands that all budgets of all sectors of the service delivery system, including state schools, undergo the same scrutiny in our attempt to compensate for severe budget shortfalls and increasing waiting lists for community services. Community services advocates have said that there simply is no more “fat” to cut and that further reductions will mean terrible human consequences by the reduction and elimination of community services.

State School advocates suggest that residents of those state programs do not wish to have their system changed, and express their concern that the state schools only deal with the most severely impaired who cannot function outside the state school facilities. Arguments tend to be passionate and emotional, but concerns have been expressed that many of the state school arguments have been based on inaccurate data or have been presented with ill-informed and erroneous conclusions. Community advocates argue that cuts in community funding means reduction or elimination of services, while a closure of one or more state schools merely means those residents will be inconvenienced by a move to another facility with no reduction in services.

(1) National trends:

To have a perspective and reference by which to interpret data, it is helpful to have a broad perspective of what is happening nationally. National data show:

- As recently as 1982, about one-half of all individuals with mental retardation who received residential services were served in large, state-operated facilities. However, between 1990 and 2000, the number of persons served in large, state-operated facilities decreased by 42.8% (8).
- During 1990-2000, the number of residents in public and private institutions for 16 or more persons declined 34%. Public institutions alone declined 44% (9).
- Studies have indicated almost 200 state institution closures will have occurred by the end of 2003. There are currently 10 states that have closed all of their state facilities (19).
- During the years from 1980 to 2001, 20 states have reduced their average daily population of residents in state mental retardation institutions by over 60%, with ten actually reducing by 100% (closure of all state institutions) (19).

As noted before and with some duplication in the number of consumers across services, in 2001, 5,645 persons were served in State Mental Retardation Facilities while some 36,000 persons were served in a variety of community-based mental retardation service environments (2).

(2) Cost Comparisons:

Note: Public policy makers and others interested in comparing costs of institutional and community-based services for people with mental retardation should beware certain “national cost-comparison studies”. Such studies are often not credible in that they draw conclusions on the basis of:

- data that may be collected and classified in radically different ways from state to state,
- significant variations in state approved program elements and service definitions, and
- dissimilar service system infrastructures.

Instead, to obtain relevant, accurate and objective perspective on cost issues, Texas leaders should examine Texas-based cost data which is collected, analyzed and certified for accuracy by Texas authorities.

According to a recent TDMHMR report to the Legislature and the TDMHMR 2004-05 Legislative Appropriations Request, the total annual cost for the state schools is approximately \$360 million, or approximately \$71,555 per resident (10). It should be noted that this figure does not include a pro rata share of the \$349 million projected as being required for facility maintenance costs for 2002 through 2007. It is unclear, but it has been suggested, that the annual cost figure also does not include various other costs such as retirement, health insurance, and workers compensation, which are reported to be over \$30 million in GR funds annually (\$70 million in all funds annually) (11). When all costs are considered, total budget for state institutional care for people with mental retardation is estimated to be over \$460 million per year (or over \$92,000 per year per resident).

The same MHMR sources referenced above document the total state budget for HCS/MRLA waiver services is approximately \$279 million in all funds, approximately \$46,055 per consumer (10). This total is spent via contracts through which private providers deliver the contracted package of services without supplement or emergency subsidy.

(3) Level of Need:

Much misunderstanding exists regarding the Level of Need (LON) of those residing in both institutional and community based services. Advocates for state institutions often testify in legislative and other forums that state schools are for the most impaired those who “could not survive in the community”. However, even the Voice of the Retarded, the national organization of institutional advocates, has publicly stated (16) that “VOR acknowledges the importance of mainstreaming community services for people with mental retardation who can benefit from this level of care”. Recent Level of Need research by TDMHMR documents that community service

programs can and are serving persons with even the most significant levels of disabilities. (10) In its report to the Legislature, TDMHMR presented the following comparison between the LON's of state school residents and of those residing in community-based HCS/MRLA programs for the period of September 1999 through August 2000.

	<u>State Schools</u>	<u>HCS/MRLA</u>
Intermittent	228	1,300
Limited	1,404	2,229
Extensive	2,001	1,144
Pervasive	2,005	575
Pervasive Plus	<u>8</u>	<u>52</u>
	5,646	5,300

The Intermittent LON is defined as “does not need 24 hour care, demonstrates very independent living skills, with no significant maladaptive behavior noted. Staff intervention is typically reminders with some guidance.”

The Limited LON is defined as “ranges from fairly independent to some personal care reminders/guidance needed. Behavior intervention or hands-on personal care assistance may be required. Individuals may have psychiatric disorders, which may be fairly well controlled with medication. Staff intervention ranges from reminders to 24-hour guidance and support.”

Community services advocates often ask state TDMHMR officials why any of these two relatively mildly disabled LON groups are in a state school at all.

The report documents that individuals with more severe disabilities, those with Extensive and Pervasive LONs, can and are being served in community programs as well as in state schools. It should be noted that there are actually more individuals with the Pervasive Plus LON, reflecting those with the most severe disabilities, living in community programs than in state facilities. It is clear from this state-generated data that people with even the most significant impairments can and, in large numbers are, being served in community programs and research supports that conclusion (22, 23, 24, and 28).

(4) Infrastructure Cost Projections:

Many question the efficacy of the state continuing to maintain an aging system of facilities which, in the immediate future, will require hundreds of millions of state funds to simply maintain. A recent report from TDMHMR on its Computer Aided Facility Management (CAFM) System (11) noted that the MHMR infrastructure has 23 statewide facilities, 1425 buildings, 105 million square feet of space, and 7,500 acres of land. In a 1999 report, TDMHMR reported that the CAFM had determined a Facility Cost Index (FCI) for each of the state schools. It showed that five of the 12 campuses were “significantly impaired”.

The FY03 bond-financed appropriation for TDMHMR facility repair and rehabilitation listed \$20,086,677 as needed for immediate repairs. The TDMHMR FY04-05 Capital Construction

Request asked for \$37,955,748 for immediately needed facility repairs and rehabilitation. (Note that \$2.5 million of this amount was listed for new construction). According to these data, almost \$60 million is needed just to meet immediate crisis maintenance needs of state school facilities. That figure does not include costs for regular, ongoing facility maintenance.

Projected total facility maintenance needs are projected to cost \$349 million through 2007. Private providers of community programs complain that there are no state subsidies to help with their maintenance needs. If a proposal now before the Legislature is adopted requiring the private sector HCS programs to expand from the current 3 and 4 bed model to a 6 bed model, their needs for “maintenance/reconstruction” will be massive and un-reimbursed, placing the continuing operations of some in jeopardy.

Finally, the above noted CAFM report notes that to reduce the Facility Cost Index across the system to a “good” level TDMHMR would have to spend \$350 million dollars over five years, \$20-30 million per year thereafter, and \$500 million over the next fifteen years. These figures do not include inflation or expansion and only refer to maintenance and repair ⁽¹⁵⁾.

FACILITY DEMAND:

Demand for state-operated institutional services has fallen dramatically. As previously noted, only a fraction of 1% of individuals on the TDMHMR Waiting List have stated a desire for placement in a state school. Meanwhile, the demand for community-based alternatives is rising and has become the subject of lawsuits in Texas and many other states.

A February 2003 report from TDMHMR ⁽¹³⁾ identified 930 empty beds in the 10 state schools for persons with mental retardation, an overall 10 % vacancy rate. This number of vacancies, scattered among the facilities, exceeds the total capacity of the largest state school, Denton State School (716 beds) ⁽¹⁴⁾. The Comptroller’s office has recommended that TDMHMR identify, close and sell at least two state schools and achieve at least \$20.4 million in General Revenue savings in the 2004-5 biennium ⁽¹⁴⁾.

MISCONCEPTIONS AND FACTS:

Concerns regularly expressed when closure is discussed include:

- State School residents who have severe or profound mental retardation or who have multi-handicaps cannot live in the community

Fact: Much evidence is available to show that all residents of state institutions for people with mental retardation can live and be served in the community with appropriate and sufficient supports. Many community services advocates who have children with even the most severe level of mental retardation and concomitant physical, emotional and

medically fragile conditions have testified that they feel their children are ably served in the community even though the services they receive, on average, cost one-half or less than that provided by state schools.⁽¹⁷⁾

- Some advocates of institutional services assert that persons currently served in state schools, and/or their parents or LARs, would be unhappy and their quality of life would diminish if they were to be transferred to community-based residential placements.

Fact: On March 23, 2003, TDMHMR released a Draft Executive Summary for a “Consumer/Family Satisfaction Survey, Placements from State MR Facilities” conducted by local MRA staff. Regarding overall consumer/satisfaction with the community placement, 81% of respondents replied that they were “Very Satisfied” or “Somewhat Satisfied” with the placement, while an additional 11% rated supports as being “Adequate”. Only 8% of the respondents were “Somewhat Dissatisfied” or “Very Dissatisfied”.

This concrete and objective evidence of the Texas experience is commanding and significant. Typical stories about community dissatisfaction from state school advocacy groups such as PART (Parents Association for the Retarded of Texas), VOR (Voice of the Retarded) and TSSS (Texans Supporting State Schools) are often anecdotal and unsubstantiated. The documented evidence from this study shows conclusively that state school placements to the community are overwhelmingly considered positive by the consumers and families involved.

- Some state school advocates suggest that community services push a “one size fits all” approach to service delivery.

Fact: Contrary to the uniform regimentation found in most institutional programs which must cater efficiently to the disparate needs of hundreds of residents, community-based waiver services are, by rule, designed to meet the unique needs, abilities, and interests of each individual consumer. TDMHMR rules require a person-centered planning approach that determines the appropriate nature, scope, amount and duration of services and supports that will best meet the unique needs of the individual.⁽²⁹⁾ Likewise, services can be delivered in a variety of service environments including small group homes, “foster family”-type placements, or individualized supported living arrangements. Far from a “one size fits all”, cookie-cutter approach, community-based mental retardation services offer a range of services and supports in a variety of environments which best suit the unique and individual needs of the consumer.

RELEVANT RESEARCH FINDINGS:

A survey of the professional, objective and typically university-based research on community mental retardation services, there are undeniable and broad conclusions supporting expansion

of community services. In a response to the need for the elaboration of findings in the field, a communication from Charlie Lakin, Ph.D., Director of the Institute on Community Integration (University Affiliated Program) at the Research and Training Center on Community Living, University of Minnesota, stated that there “is strong and remarkably consistent evidence of relative detriment to the development of functional daily living skills (“adaptive behavior”) associated with institutional living when compared with community living” (17). This finding, he reports, has been replicated repeatedly by many different professional research teams.

The research is overwhelmingly clear that consistent and substantial benefits in the development of functional daily living skills tend to accrue to people afforded the opportunity to live in community settings and that, conversely, consistent and substantial developmental detriments tend to accrue to people who are retained in institutional settings.

Dr. Lakin reports that a substantial majority of studies conducted in the United States over the past 20 years show statistically significant benefits in adaptive behavior accruing to people who leave institutions. He postulated that whether the community homes offered better environments for learning adaptive behavior or whether the people who worked in those homes were better at teaching them, all we really know is that their adaptive skills improved when they left the institutions and moved to homes in the community (17). Dr. Lakin felt that “...there really seems to be no question from the available research about which ways the effects run, nor is there much question that their magnitude is substantial”. Dr. Lakin “personally see(s) no moral alternative but to respond to the reality that community living is by nature a more beneficial option for people than institutionalization”.

A report on deinstitutionalization by Dr. David Mank, Director of the Indiana Institute on Disability and Community (19), reports that more than 20 detailed studies have been conducted across the country about what happens to people when they leave large congregate settings. All of these studies tell the same story. People with disabilities, including people with severe and multiple disabilities, show increases in independence, fewer problem behaviors, increases in choice making, increases in relationships with people without disabilities, and increases in employment and earnings. The studies also show an increase in participation in community activities and that neighbors develop positive attitudes about their neighbors with disabilities. Dr. Mank goes on to report that by every measure, living in the community shows clear increases in quality of life compared to living in larger, congregate settings.

The closing of an institution presents great concern for people with disabilities and their families. More than 20 studies of such families tell us that before deinstitutionalization, most families were reasonably satisfied with the situation for their loved one. Most did not want their loved one to leave the institution. However, within one to two years following the community placement, the vast majority of family members changed their attitude about community living for their loved one and was happy with the placement. According to Dr. Mank, the vast majority of families have noted and been pleased about the improvements in quality of life for their loved one (19).

Other similar and related studies are found in the literature.

- Hayden & DePaepe, 1991 ⁽²¹⁾, found that persons with significant medical conditions are living in community settings, and medical supports can be and are being provided to community members with complex medical needs.
- Brown, 1998 ⁽²²⁾, found that over four years people who were discharged and moved into new community living arrangements experienced overall health as improvements. They also saw the quality of medical services as better or unchanged. They viewed the movers' overall welfare and well being as better. Moreover, the majority of respondents believed that access to special therapies and medical services had improved since the individuals moved to the community.
- Conroy, 1995 ⁽²³⁾, followed 520 people with extensive and severe medical needs who moved from a state-operated institution to the community, and found that less than 2% indicated they had "occasional or frequent problems in receiving medical services".
- Noll & Desmond, 1993 ⁽²⁴⁾, studied 256 participants in community homes with 97% needing a primary care physician. 99% saw the physician within the past two years, and the majority of their families rated the quality of their overall medical care between good and excellent.
- South Dakota Division of Developmental Disabilities, 1996 ⁽²⁵⁾, examined the status of 75 adults who were discharged from a state-operated institution and found that none of them experienced significant health concerns as a result of moving to the community.
- Brown & Bretting, 1998 ⁽²⁶⁾, reported that over time, more community residents saw a doctor they liked. Movers consistently indicated that they saw a doctor when needed. A greater percentage of post-move staff members exhibited an excellent level of knowledge about health and medical needs of residents.
- Litziner, 1993 ⁽²⁷⁾, compared the health status of a group of adults who lived in an institution to their health status one year out of the institution. They were considered "medically fragile" and to have "complicated seizure disorders". The study found fewer seizures, a decrease in emergency room visits, and an increased level of functioning for those who left the institution.
- Tyler & Bourguet, 1997 ⁽²⁸⁾, followed a group of people from institutions to the community. Overall, the descriptive studies indicated that the health of people with intellectual disabilities who moved from an institutional setting to the community improved. Additionally, medical services received were rated as being either better or unchanged and access to services improved. Medical services received were rated as being either better or unchanged.

In an extensive review of the literature, the Center on Residential Services and Community Living, regarding Health Status, Health Care Utilization Patterns, and Health Care Outcomes ⁽²¹⁾, authors Drs. Mary Hayden and Shannon Kim concluded that there is evidence to indicate that:

- (a) there are individuals with varying degrees of intellectual disability and medical care needs living in the community;
- (b) people with significant medical conditions can be placed and maintained in more normalized community settings; and
- (c) medical supports can be and are being provided to people with intellectual disabilities and allied medical conditions to enable them to live in the community.

CONCLUSIONS:

The data on institutions and community programming are clear. Community integration seems, in every respect, preferable. Community advocates believe that all people, however severe their disabilities, must be permitted opportunities to live in their home community, close to family and friends, and with their non-disabled peers. It is commonly believed among advocates for community services that people who have been classified as “retarded” should have available to them the patterns and conditions which characterize the mainstream of society. Indeed, support services should be available to promote the fullest possible integration of people with disabilities.

To protect state institutions from efforts to “right size” forces only community services to remain a vehicle for managing the state budget through reducing community resources. The resulting termination, delay, reduction or denial of services to people in the community is inherently discriminatory, unfair, fiscally irresponsible, and short sighted. A significant body of evidence and knowledge concludes that community services are the most efficient, cost effective, healthiest, and most preferred option.

It is simply time for the Texas Legislature to consider and scrutinize institutional as well as community services within the context of the current economic and pro- “government reorganization” environment. It is time for the Legislature to act on the Comptroller’s recent recommendations for the closure of two state schools in the immediate future and, as recommended by community service advocates, to consider additional closures in years to come. It is time not only to “right-size” the institutional system to the realities of the current environment, but also to commit proceeds from sale of property and operational savings to the expansion of community-based mental retardation services.

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