Attachment 2

Report Update for

State Mental Retardation Facilities

As required by Part 1. Health and Safety Code - Title 7
Mental Health and Mental Retardation
Subtitle A. Chapter 533. Subchapter B. Section 533.032c
On Long Range Planning

FISCAL YEARS 2004-2005

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Texas Department of Mental Health and Mental Retardation

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Report on

State Mental Retardation Facilities

Introduction and Charge

In addition to the long-range (or strategic) plan required of state agencies, the Texas Department of Mental Health and Mental Retardation (TDMHMR) is required by statute to prepare a report containing information and recommendations regarding the most efficient long-term use and management of the Department's campus-based facilities. [Part 1, Health and Safety Code – Title 7, Subtitle A, Chapter 533, Subchapter B, Section 533.032-(c) (d) (f) (g)].

Due to the different audiences that may be interested in state mental health facilities and state mental retardation facilities, the Department prepared two reports in fiscal year 2004, one for state mental health facilities and one for state mental retardation facilities. The current report contains updated information for state mental retardation facilities as required by the statute.

Overview of Report

The approach to updating this report was shaped by the oral and written input received at public hearings on state mental retardation facilities held on November 4, 2003 and March 3, 2004. (Summaries of the comments received pursuant to these public hearings are provided in Appendix A and Appendix B.)

As the comments received at these hearings indicate, there continue to be distinct, disparate, and occasionally opposing perspectives about the future role and function of state mental retardation facilities. One point of view expressed by commenters is that for many persons a state mental retardation facility is an appropriate home where high quality services can be provided in a safe environment. In contrast, other commenters presented a perspective that any person with mental retardation – regardless of the intensity or extent of their need – can and do live in the community, and funding for community services should be increased to respond to this need and demand.

The report starts with the "big picture," describing national and state trends related to state mental retardation facilities, and then describes the characteristics of persons served in state mental retardation facilities.

Next the report presents the methodology used, first presenting the conceptual approach and then the actual processes for obtaining and analyzing the data. Results based on this analysis are presented and the limitations of the data and analysis are recognized. (The report recognizes that the conclusions regarding the

future direction of all state facilities will be a policy decision directed by the state legislature and recommendations in this report may need to be continually revisited as the information base is developed and refined.) This analysis also includes projections related to maintenance of the infrastructure.

Criteria for Admission to State Mental Retardation Facilities

There are four statutory criteria established by the Persons with Mental Retardation Act that an individual must meet in order to be committed to a state mental retardation facility (PMRA, Sec. 593.052):

(1) the proposed resident is a person with mental retardation;
(2) evidence is presented showing that because of mental retardation, the proposed resident:
(A) represents a substantial risk of physical impairment or injury to himself or others; or
(B) is unable to provide for and is not providing for the proposed resident's most basic personal physical needs;
(3) the proposed resident cannot be adequately and appropriately habilitated in an available, less restrictive setting; and
(4) the residential care facility provides habilitative services, care, training, and treatment appropriate to the proposed resident's needs.

To determine if an individual meets the second criterion above, the Department established two objective standards which took effect January1, 2001. The individual must meet one of these two standards to meet the criterion.

(1) The individual has an IQ that is four or more standard deviations below the mean (in the severe or profound range of mental retardation); or
(2) The individual has an Inventory for Client and Agency Planning (ICAP) service level of 1 – 4 or an ICAP service level of 5 or 6 and also has extraordinary medical needs or has exhibited incidents of dangerous behavior.

The Department convened a Task Force, which met between June 11 and August 28, 2003, to evaluate criterion 3 above. The Task Force's recommendations included an instrument to be used by the local mental retardation authorities to standardize the process for determining if an integrated setting could provide adequate and appropriate services to an individual seeking admission to a state mental retardation facility. The Department has incorporated the Task Force's recommendations into the proposed Chapter 412 Subchapter K Governing Access to Mental Retardation Services and Supports which was published for comment in the January 9, 2004 edition of the Texas Register. Adoption of this rule is anticipated during the April 14-15, 2004 meeting of the TDMHMR Board.

National Data Related to Mental Retardation Facilities

The use of and need for residential settings for persons with developmental disabilities continues to grow. As reported in *The State of the States in Developmental Disabilities: 2004*, there was a seven percent increase nationally in the number of individuals served in all types of residential settings between 2000 and 2002. When broken down by size of facility, people living in settings of six or fewer individuals increased by 15%. In settings of seven to 15 persons there was a two-percent increase. However, there was a six percent decrease in the number of individuals living in public and private facilities serving 16 or more persons with developmental disabilities. These data continue the trends of a steady decline in reliance on large residential facilities and an increased use of community services and supports.

Texas continues to be ranked 42nd in the nation for overall fiscal effort (based on spending per $1,000 of total state personal income) as reported in 2004 edition of *The State of the States in Developmental Disabilities*. Table 1 below depicts the total mental retardation/ developmental disabilities spending of the top ten states as reported in fiscal year 2002 (in billions of dollars) and the fiscal effort rankings for mental retardation/developmental disabilities spending in three categories: community, congregate (institutional) and overall.

Table 1 Fiscal Effort Rank, FY 2002

	NY	CA	PA	OH	TX	IL	MA	MN	NJ	FL
Total Spending (Billions)	4.786	3.746	1.965	1.733	1.611	1.358	1.204	1.196	1.155	1.024
Community Ranking	4	34	14	17	44	42	16	3	40	49
Congregate Ranking	22	32	17	9	25	8	23	37	10	34
Overall Ranking	4	39	12	11	42	40	15	2	34	49

Definitions:

1) Congregate includes congregate/institutional settings serving 16 or more persons. Nursing home spending is included.
2) Community includes residential settings for 15 or fewer persons and day programs (such as sheltered workshops, day care, case management, and other non-residential community services).

In the June 2002 survey conducted by the University of Minnesota entitled *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002*, of the 42 states that still have state-operated large congregate facilities (16+ residents), Texas ranks 36th in average per resident daily expenditures. A comparison of the previously referenced ten states using their 2002

average per resident daily expenditures as reported in the University of Minnesota study is shown below in Table 2.

Table 2 Average per Resident Daily Expenditures of Large State-Run Facility Services in 2002

	NY	CA	PA	OH	TX	IL	MA	MN	NJ	FL
Avg Daily Expenditure	536.15	459.33	411.00	294.31	253.41	334.00	494.37	778.00	385.25	262.91
Avg Daily Population	2293	3726	1652	1954	5150	3160	1194	36	3365	1351
Rank	5	9	14	33	36	28	8	1	18	35

Of the ten states that spend the most dollars on mental retardation/developmental disabilities services, Texas has the lowest average per person daily expenditure in state-operated facilities.

State Mental Retardation Facility Trends

Enrollment

The enrollment numbers for individuals served in the state mental retardation facilities continue their downward trend. At the beginning of fiscal year 2001, the enrollment in state mental retardation facilities was 5,413. By the end of fiscal year 2001, the enrolled number of individuals was 5,274. By the end of fiscal year 2002, the enrollment number was down to 5,039 and by August 31, 2003, enrollment in the state mental retardation facilities stood at 4,996.

Admissions and Separations

Since 2001, separations from state mental retardation facilities have exceeded the number of admissions. Table 3 details the movement within the state mental retardation facilities during the previous two biennia. The Department's efforts to comply with the Promoting Independence initiative has eliminated the "backlog" of individuals in state mental retardation facilities waiting for services in the community, as evidenced by fewer individuals moving into the community in fiscal year 2003. The category "Discharges" includes other reasons for separation from the state mental retardation facilities, such as interstate transfers, discharge from a temporary emergency admission, and minors found fit to proceed and/or not eligible for commitment during the 90-day placement order under the family code.

Table 3 State Mental Retardation Facilities

Admissions, Movement into the Community and Deaths

Fiscal Year	Admissions	Movement to Community	Deaths	Discharges	Net Movement
2000	314	141	106	42	25
2001	203	160	130	45	-132
2002	171	249	123	34	-235
2003	214	111	114	32	-43

On August 31, 2003, there were 34 Texas state mental retardation facility residents recommended for movement into the community. Utilizing the Living Options process, the decision to seek placement into the community is made by the Interdisciplinary Team (IDT). The IDT consists of the consumer, the consumer's family member(s), the legally authorized representative/guardian, and the remaining members of the Interdisciplinary Team (facility/MRA staff with special training and

experience in the diagnosis, management and assessment of the needs of persons with mental retardation). When an individual living in a state mental retardation facility has a guardian or other legally authorized representative (LAR), the final decision about movement from the facility setting to the community rests with the guardian or LAR, when that decision is for the consumer to remain in the facility. The LAR/guardian does not have the authority to require a community placement over the recommendation of the IDT. Of those recommended for moves into the community, 73% (25) have intermittent or limited levels of need. Persons with extensive levels of need comprise 21% (7) of this group with the remaining 6% (2) categorized as having pervasive levels of need.

Demographics

A seven-year trend analysis of demographic data on persons living in state mental retardation facilities revealed that adaptive behavior levels have remained static. Persons with severe and profound adaptive behavior levels comprised 87% of the state mental retardation facilities population in 1997, compared with 86% in 2003. The percentage of persons with severe and profound levels of mental retardation likewise has remained constant: 77% in 2000 and 76% in 2003. In 1997, persons aged 36 and older made up 63% of the population in the state mental retardation facilities. By 2003, this age group had increased and accounted for 75% of the population. In 1997, 42% of the individuals had behavioral management needs in the moderate, severe and profound ranges. This percentage had grown to 50% in 2003. In reviewing health status, 30% of individuals served in 1997 had moderate, severe or profound health needs; in 2003 this same group accounted for 35% of the population.

Level of Need

An individual's Level of Need describes the result of an assessment the state uses to determine the intensity of services a person may need. There are five levels of intensity: intermittent, limited, extensive, pervasive, and pervasive plus. Appendix C contains a description of each of the levels of need. Individuals are classified at a higher intensity of need when they have more severe medical or behavioral problems. Pervasive and pervasive plus intensity levels refer to constant support needs across all environments and life areas. The characteristics of the individuals residing in state mental retardation facilities on level of need assessments appears to have shifted since 2000. In 2000, people with extensive and pervasive needs accounted for almost 75% of the facilities' population. In 2003, this same group of individuals accounts for less than 60% of the population. A closer look reveals that there has been a 14% decline in the number of individuals served with pervasive needs. During the same time, there has been an increase of 13% in the number of individuals with limited needs being served in the state mental retardation facilities.

Table 4 Comparison of Level of Need in SMRFs

	FY 2000	FY 2003
Intermittent	3.35%	4.7%
Limited	22%	35%
Extensive	36%	35%
Pervasive	38%	24%
Pervasive Plus	0.23%	0.12%

This shift in percentages of level of need characteristics reflects the admission of more capable individuals who exhibit significant behavioral challenges that providers in the community have not been able to appropriately serve.

Initiatives Affecting State Mental Retardation Facilities

House Bill 2292 (78th Regular Legislative Session)

Among the efforts to streamline government and create efficiencies in the delivery of social services, the Texas Legislature passed HB 2292, which restructures all of health and human services. As part of this restructuring, the current Department of Mental Health and Mental Retardation will be abolished. Services for people with mental retardation, including the operations of state mental retardation facilities, will be transferred to the newly created Department of Aging and Disability Services. According to the H.B. 2292 Transition Plan developed by the Health and Human Services Commission and submitted to the Governor on November 3, 2003, the commissioner of the new department (Jim Hine) was appointed in December 2003. The new Department of Aging and Disability Services will begin operations September 1, 2004. The future of the state mental retardation facilities will be influenced by the mission, vision and values developed by the new department.

In Article II of the same bill, the Legislature will allow the department, after August 31, 2004 and before September 1, 2005, to contract with a private service provider to operate a state school only if the following conditions can be met:

(1) the Health and Human Services Commission determines that the private service provider will operate the state school at a cost that is at least 25 percent less than the cost to the department to operate the state school;

(2) the Health and Human Services Commission approves the contract;

(3) the private service provider is required under the contract to operate the school at a quality level at least equal to the quality level achieved by the department when the department operated the school; and

(4) the state school, when operated under the contract, treats a population with the same characteristics and need levels as the population treated by the state school when operated by the department.

In December 2003, a request for proposals from entities interested in operating a state mental retardation facility was issued. The results of the request yielded no proposal that met the conditions of the legislation.

Health and Human Services Commission Rider 55

In the General Appropriations Act for the Health and Human Services Commission, the Legislature attached a rider that calls for the study of facility closures and consolidations during the 2004-2005 biennium at the Department of Mental Health and Mental Retardation. The Commission will then provide a report with site specific recommendations on closures and consolidations when the 2006-2007 Legislative Appropriations Request is submitted to the Legislature.

The criteria for identifying facilities for closure include:

a. proximity to other facilities and geographical distribution of remaining facilities;

b. administrative cost of the facility;

c. availability of other employment opportunities in the area for employees displaced by the closure;

d. condition of existing facility structures;

e. marketability of the property where the facility is located when considering the possible sale of the property or alternate use possibilities;

f. ease of client transfer capability;

g. capacity at remaining facilities to accommodate persons transferred from a facility identified for closure; and

h. identification of specialty programs or services.

Factors Affecting Future Needs for State Mental Retardation Facility Beds

According to the Texas mental retardation system policy, the primary role of the state mental retardation facilities is to serve persons with mental retardation who have intensive needs, including persons with severe and profound mental retardation and persons with mental retardation who have severe physical or medical needs or significant behavioral or psychiatric problems. Such needs can often be met in community settings but, because of an individual's/family's/legally authorized representative's circumstances, resources, or preference, the state mental retardation facility many times continues to be the choice of consumers/family.. This is an important aspect in considering the future needs for state mental retardation facility beds. The characteristics or needs profile of a person with mental retardation is not enough by itself to establish the need for state mental retardation facility placement. Other factors also have to be considered.

Some factors that affect the future needs for state mental retardation facility beds are:

1. Values/Principles-
   Values and principles applied to community services and supports, permanency planning, and person-directed planning will shape the demand for state mental retardation facilities.

2. Availability of Community Service Options-
   The Department continues to develop resources and expand community services and supports, thus enabling those persons with mental retardation who would like to live with their families or in nearby community settings to receive their services in the community.

3. Population Growth-

   Prevalence studies demonstrate that the proportion of the population consisting of persons with mental retardation who have intensive needs is constant. Therefore, as the population increases–as it has done in Texas–the number of persons needing mental retardation services also increases. If services and supports for persons with mental retardation are not available or are not being provided in community settings, this potentially increases the demand for state mental retardation facility placement.

4. Preferences of consumers and family members-

   The Department strives to assure that a person's and/or the legally authorized representative/guardian's choice is honored.

5. Capacity Issues-

   At the end of Fiscal Year 2003, there were 890 vacant certified beds within the state mental retardation facilities system. Of these vacant certified beds, approximately 115 are being used as temporary sleeping areas when large-scale building renovations at the facilities require that alternate sleeping areas be used, and approximately 50 are located in buildings that are now primarily used for day program services rather than for residential living. The remaining 725 vacant certified beds are being held in reserve for emergency and other operational needs.

Assumptions Related to Projections and Estimates of Potential Demand for State Mental Retardation Facility Admissions

Potential demand for state mental retardation facility admissions and resources may be estimated based on historical trends. However, actual demand is not known until it occurs. Therefore, assumptions must be made in order to estimate potential demand. The key assumptions used for this report are:

1. Projections include regular, emergency and court-ordered admissions, and the continued and expanded availability of funding for community services, including waiver services.

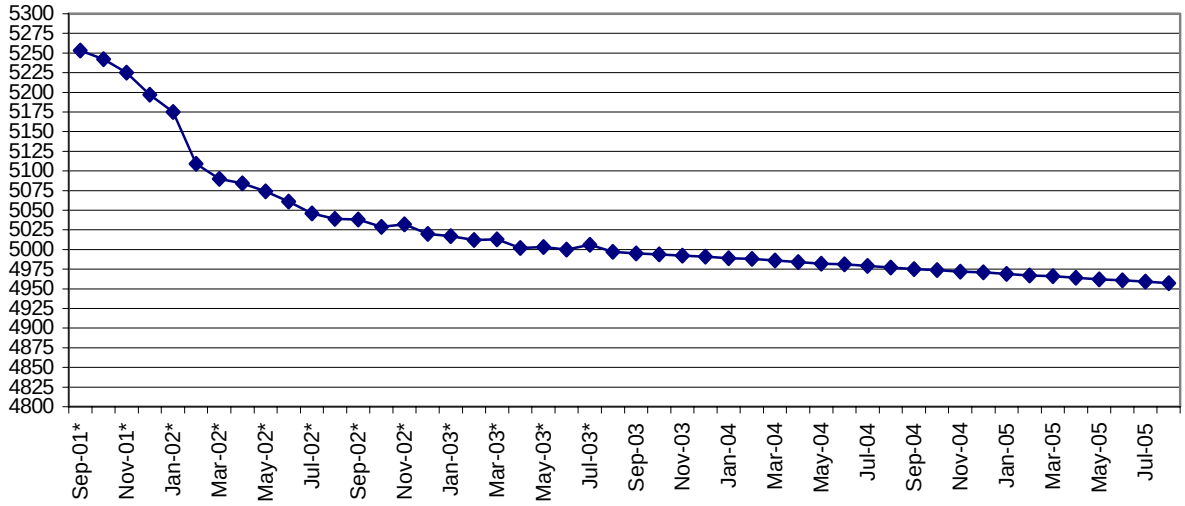
2. The potential demand for state mental retardation facility placements will be addressed within the context of personal choice, permanency planning and the Promoting Independence Initiative.

3. The estimates of demand assume that the mission of state mental retardation facilities will focus on those persons with severe and profound mental retardation with intensive needs and persons with mental retardation who have severe physical or medical needs or significant behavioral or psychiatrics problems for whom community services are not available or are not preferred.

Projection of Future Enrollment Trends

Based on their most recent data, the State Mental Retardation Facilities office has prepared the following projection of future enrollment trends using a simple linear regression model. Using an estimate of 19 admissions per month and anticipating approximately 21 separations per month, the average enrollment of the state mental retardation facilities will continue its downward trend., albeit at a much slower pace than in previous years due to the assumption that community based services and supports for persons with mental retardation continue to receive no expansion in appropriations to meet the waiting list needs.

Enrollment Projections in State Mental Retardation Facilities
(Actual Data 09/01 through 08/03; Projected Data 09/03-08/05)
A Month by Month Reporting



Data on Residential Services Preference

During fiscal year 2003, the local authorities completed a survey of individuals on the waiting list for community services to determine which services were being requested. The local authorities were able to contact 100% of these individuals. As of August 31, 2003 there were 6,528 people who had requested and were still waiting for a residential service. Of those still waiting for a residential service, 16 have requested services in a state mental retardation facility.

Projection of SMRF Maintenance Costs: 2004 - 2009

In addressing projections of maintenance costs for state mental retardation facilities, estimates were developed assuming that buildings would be maintained at current conditions. Projections of these costs were done using the Department's Computer-Aided Facility Management (CAFM) system. To maintain buildings in their current condition, two types of activities are necessary: (1) anything that needs replacement must be replaced and (2) anything that needs repairing must be repaired. The estimated costs reflect the assumption that the backlog of maintenance needs will be addressed so there is no further deterioration in the condition of the buildings.

Using CAFM, the projected costs for maintaining state mental retardation facilities at industry standards are shown below for each of the next six years.

Table 5 Projections of Needed Maintenance Costs for State Mental Retardation Facilities

Year	Projected Costs
2004	$68,493,652
2005	$72,946,638
2006	$65,598,666
2007	$72,521,566
2008	$57,876,455
2009	$72,678,485
TOTAL	**$410,115,463**

Note that these projections are for all state mental retardation facility buildings. Different priorities are assigned to buildings depending on their use. For the purposes of prioritization, buildings are categorized into five classes: consumer sleeping buildings; consumer use buildings; administration buildings; support buildings (e.g. warehouse, kitchen, maintenance); and site buildings (e.g. gutters, sewers). Maintenance costs for all building categories are available. Cost projections for consumer use and consumer sleeping buildings in state mental retardation facilities are presented below.

Table 6 Projections for Maintenance of Consumer Use and Consumer Sleeping Buildings in Mental Retardation Facilities FY 2004 - 2009

	Consumer Use Building	Consumer Sleeping Buildings	TOTAL	% of Total Maintenance Costs
2004	$11,728,741	$35,507,538	$47,236,279	69.0%
2005	$10,259,178	$33,828,443	$44,087,621	60.4%
2006	$10,141,699	$30,131,221	$40,272,920	61.4%
2007	$11,089,556	$36,079,865	$47,169,421	65.0%
2008	$11,127,400	$27,514,790	$38,642,190	66.8%
2009	$12,990,439	$37,716,573	$50,707,012	69.8%
TOTAL	**$67,337,012**	**$200,778,431**	**$268,115,443**	**65.4%**

Note that these projections are based on industry standards and do not represent the actual projected expenditures for maintenance.

For several years, resources have been limited for facility infrastructure maintenance resulting in a significant backlog of deferred maintenance. The 78th Texas Legislature appropriated $35.3 million dollars in general obligation bonds to be used for repair and maintenance projects at the state mental retardation facilities and state mental health facilities during the 2004 – 2005 biennium. These projects will be prioritized by facility, with the highest priorities given to projects addressing Life Safety Code issues.

Future Use and Management of State Mental Retardation Facilities

Summary

The goal of the state mental retardation facilities is "to promote the well-being and abilities of persons with mental retardation who require the most intensive, specialized long-term care." To this end, the Texas Legislature continues to provide funds for these facilities. For fiscal years 2004-2005, an average monthly enrollment of 4,977 persons is anticipated.

As shown in this report, the trend in state mental retardation facilities is to serve persons with mental retardation with intensive needs. Seventy-six percent of the persons residing in state mental retardation facilities have severe or profound levels of mental retardation. The proportion of persons with mental retardation in state mental retardation facilities who have severe health problems or have high levels of needs related to behavior management is increasing. These findings continue to reinforce the future role of the state mental retardation facilities. The facilities will continue to serve people with the most intensive needs who meet eligibility criteria and who choose or have legally authorized representative/guardians who choose to receive services in state mental retardation facilities, and those individuals who are court committed to a state mental retardation facility.

Demand for state mental retardation facility services is slowly and steadily declining. Nationally, it is noted that the overall fiscal effort for mental retardation services has been increasing, and the part of that fiscal effort devoted to congregate living situations continues to decrease. Taking the national trend a step further, it is noted that for congregate living situations, the emphasis is on settings of less than 16 beds. Throughout the nation, the number of facilities with 16 or more beds has steadily declined. In Texas, a definite trend has been identified toward declining enrollments in the state mental retardation facilities.

The future of the state mental retardation facilities in Texas will ultimately be determined by the state legislature. Operation of the state mental retardation facilities will be under the new Department of Aging and Disability Services as of Fiscal Year 2005. Therefore, their future role may be changed to reflect the mission, vision, values and priorities of the new department.

Future Direction

Based on the analysis and discussion in previous sections of the report, the key features related to the future of state mental retardation facilities are summarized below.

- The current and future role of state mental retardation facilities is to serve persons with mental retardation and intensive needs who meet eligibility criteria and who choose or have legally authorized representative/guardians who choose

to receive services in state mental retardation facilities, and those persons who are court committed.

- Except for emergency and court-ordered services, children and adolescents are not admitted to state mental retardation facilities.
- State mental retardation facilities will be maintained in a manner that assures the safety and well being of persons receiving services.
- The current capacity of the state mental retardation facilities appears to be sufficient to meet future/projected demands.

Appendix A

Summary of Comments on State Mental Retardation Facilities
Received from First Public Hearing
(Including Written Comments)
on
November 4, 2003

State Mental Retardation Facilities First Public Hearing

November 4, 2003

As legislatively mandated, a public hearing was held on this date to receive comments on the long-term use and maintenance of the state facilities. Notice of this hearing (in English and Spanish) was provided to each state facility to distribute to their parent/family groups, was distributed to each of the local MHMR centers to be posted for interested parties, and was published in the Texas Register in late September.

The hearing convened at 9:00 a.m. with Robert Kifowit, Director of State Mental Retardation Facilities receiving the comments along with Barry Waller, Director of Long-Term Services and Supports.

There were 18 individuals attending and 12 gave comments. Four speakers represented three advocacy groups, seven speakers were parents/family members of individuals in state mental retardation facilities, and one individual receiving services spoke. Additionally, there were 14 written comments submitted — seven from individuals who spoke at the hearing and seven from stakeholders who were unable to attend.

The following is a summary of all the comments received.

In Support of State Mental Retardation Facilities:

1. A family member urged continued use of state facilities, saying they provide services and benefits in the most efficient and economical way. They stated that Texas should learn from the mistakes of other states that have closed institutions, saying that a large percentage of the medically-fragile individuals in those states died soon after being moved into the community. They advocated for the building of additional cottages on the state school campus, as they would provide a more comfortable way to live as compared to a dorm setting. The speaker indicated that families of severely and profoundly retarded individuals believe strongly that the state school is the best place for their family members, for their healthcare, security, happiness and well being.

2. This speaker relayed her daughter's story of living in privately owned six-bed ICF/MR for years and developed very bad behaviors that the staff was not trained to deal with. The family contacted and visited many other private facilities, but were told that their daughter did not fit into their program. With luck and help from the local MHMR center, they got their daughter into a state school. She is very happy, comfortable and safe, and the staff is well trained and can handle any problem, health or otherwise. The speaker urged that state schools not be privatized or closed, but instead open the doors so that thousands of individuals with severe and profound mental retardation can have good homes.

3. Another speaker said the HCS program has been a total disaster this year with changes that have come about. They reported that there are many individuals who would like to get into a state school, but no one will accept their packets. In their huge rural community there are literally no services unless you live right in the city or you travel to another big city…no doctors, no dentists, no psychiatrists, no services willing to treat our sons and daughters. State schools offer this help and are a safety net. As to possible closures, the speaker said that it was immoral to literally rip someone out of a surrounding where they are very happy and put them hundreds of miles away from family and friends.

4. The next speaker has a daughter who has lived in a state school for 35 years. Prior to entering the state school, she had lived in three private facilities, but due to behavior problems, they proved unsuccessful. At the state school, the daughter has shown significant improvement due to the many behavioral-type programs at the school and recently, due to new medications. The speaker commented that the staff are very dedicated and caring and take wonderful care of the residents.

5. This speaker also has a child that has been in a state school for 35 years, and reports the family is very satisfied with the facility. The speaker indicated that everyone should have a choice of service and if Texas has as big a heart as it is a state, there would be money for both areas (state schools and community services). In expressing concern about future admissions to state schools being only emergency-based admissions, the speaker said the most important thing is to retain choice.

6. Stating they provided care for their son at home until his behavior became dangerous to himself and to them, the speaker said their son is now in a state school, and they make the 80-mile trip to visit him every week. The speaker reported that they had tried two other facilities in the community, but one closed down due to lack of funding and the other could not provide adequate care. The speaker urged the department to remember their son and hundreds like him when planning the future of state schools.

7. This speaker's son has been in a state school since 1976. Their son is very happy and the staff is excellent. They stated their son requires 24-hour care and that is not available in community-based services. Calling their son a "runner," the speaker noted that if he were moved into the community, he would run and probably get injured or worse…the state school gives us security and watches over him.

8. This commenter wrote that neither the Department nor the local MHMR centers honor the choice of the legally authorized representative when that choice is for state school placement.

9. This writer noted that with the aging of caregivers and consumers, the department should rethink its assumption that the future demands for state school beds will decline. They also suggest that the report address the impact of "deferred maintenance" at the state schools, and that the department should survey individuals/families of new admissions to state schools from the community for their level of satisfaction with state school services.

10. This writer is very pleased with the care her sister receives at the state school, a choice they made over a community ICF/MR group home. They urge the maintenance of the state school system in Texas and are ardently opposed to any plan to close a state school. They believe that community based services are of questionable quality and that state school placement should be offered to those on the HCS waiting list.

11. Another writer indicates that the family members of clients in state schools depend on these facilities – no other place offers similar care.

In Support of Community Services:

1. One speaker urged the department to use the most recent data available. They indicated that there is tremendous amounts of money being spent to maintain state facility buildings when currently there are only 14 individuals waiting to get into state schools. They said there will never be appropriate funding for community services because the state is strapped to an antiquated system from which it cannot fiscally escape. They stated that it is a myth that someone leaving a state facility would have a hard time in the community. They cited the 2003 Consumer/Family Satisfaction Survey that indicated 92% of the consumers surveyed were supported through the Medicaid waiver, and that over half of the family members reported increased contact with the consumer since their move to the community. Finally, the speaker commented on the study for closure and consolidation of state schools, hoping that the study will demonstrate that Texas cannot afford outdated state school care any longer.

2. The speaker indicated that state mental retardation facilities are an antiquated and more costly way of delivering services and supports to individuals with mental retardation. They indicated that segregation and institutionalization are no longer the preferred manner of care and that the large majority of persons with mental retardation and their families are seeking support to help them live successful lives in the community. The speaker noted the current reorganization and consolidation of the health and human services system gives the department a great opportunity to make significant contribution regarding the future of mental retardation services. The speaker said that admissions to state schools have increased rather than decreased as projected, and that a lack of HCS slots is a factor.

3. This speaker indicated that many people with disabilities are more than capable of living in the community, but noted it's a constant battle to get needed services. They urged continued funding for community services and asked that people not be forced back into institutional settings.

4. Another speaker said that large congregate care facilities for people with mental retardation (state schools and large community facilities) are an outdated mode of service delivery. They indicated that the national trend is less and less of the ICF/MR system and more of the HCS. They also relayed that individuals in waiver services have additional rights not available to persons in the ICF/MR programs. They

expressed support for the Comptroller's recommendation to downsize the institutions and offer community based service supports and options. The speaker noted that there are over 900 vacant beds in the state mental retardation facilities – equivalent to two state schools essentially closed, but still open and costing taxpayers money. They stated that it needs to be clear that the majority of parents of individuals with mental retardation don't want state school placement, and those people on the waiting list are not waiting for slots in a school but for community-based services. Finally, the speaker expressed disappointment that in spite of public hearing and such, no major systemic changes ever result.

This commentor also requested an update of Executive Order RP-13 and on the HHSC Rider 55 be included in the report.

5. Expressing frustration, this speaker noted that with the last legislative session tens of thousands of people in the community lose services and tens of thousands are denied services while the state schools end up with an increase in funding. The speaker stated of the 5,000 or so people in state schools, 1,000 – 1,500 are there under court commitment or some legal thing, and another bunch are there who want to get out and can't get out, so we're talking about not having to inconvenience a small group of people. The speaker indicated that some families were forced to place their loved one in a state facility as that was the only way to get services. The speaker questioned why there will be an enhancement of state facilities – pumping more dollars into antiquated and dying buildings and services. The speaker concluded with a statement that state schools are immoral, fiscally irresponsible, unfair, and unfathomable, and this continues year after year. Studies and reports, committees and task forces all for nothing when it gets to decision-making because nothing changes.

6. This writer is in favor of supporting people with disabilities living in their home communities.

7. This commentor requested the results of the satisfaction survey of individuals moved into community services be incorporated into this report. They also want to see detailed in the report a description of the Living Options process (SB 367, 77th Legislature); an update on the volunteer advocate system (SB 368, 77th Legislature); detailed information on Rider 70 relating to alleged offender services and a discussion of the Rider 65 report relating to cost of Medicaid funded services (both from 77th Legislature). They further indicate a desire to see information on HHSC Rider 16 related to a study of developing a five and six bed model for HCS, and a discussion of the study called for in HB 966 (77th Legislature) on money follows the person from institutional to community care included in the report. As a last comment, they believe that the maintenance/repair costs should be included as a factor that effects the need for state school beds.

8. This writer's comments included recommendations to change Departmental rules related to state school admissions and to the interdisciplinary team staffing process in the state schools. Another recommendation called for the reconfiguration of the Department's data collection and reporting system. They recommended that the Department close the 900 currently vacant beds in state schools and close at least

two additional facilities during this biennium. They wanted additional funding for the Promoting Independence initiative so that the 500 people in large community ICFs/MR recommended for community placement can be moved. They recommended using commercial vendors for wheelchair and other seating/positioning equipment as those produced in the state school shops were of questionable quality. They asked the Department to consider best practices model for the delivery of mental retardation services in the newly designed health and human services system. They also recommended that the Department develop and implement a pilot of money follow the person within the state school and community ICFs/MR population.

Appendix B

Summary of Comments on State Mental Retardation Facilities
Received from Second Public Hearing
(Including Written Comments)
on
March 3, 2004

State Mental Retardation Facilities Second Public Hearing

March 3, 2004

As legislatively mandated, a public hearing was held on this date to receive comments on the long-term use and maintenance of the state facilities. Notice of this hearing (in English and Spanish) was provided to each state facility to distribute to their parent/family groups, was distributed to each of the local MHMR centers to be posted for interested parties, and was published in the Texas Register in early February 2004.

The hearing convened at 9:00 a.m. with Robert Kifowit, Director of State Mental Retardation Facilities receiving the comments along with Barry Waller, Director of Long-Term Services and Supports.

There was 1 individual attending and speaking as the parent of an individual residing in a state school. Additionally, there were 4 written comments submitted.

The following is a summary of all the comments received.

In Support of State Mental Retardation Facilities:

1. The speaker stated that the Mental Retardation Authorities "just don't get it". The legislators are very supportive of state schools and that is expected to continue. The strategic plan should be written with a positive perspective of the state schools. Rules and regulations should not make it difficult to get into the state schools. The speaker concluded that she hopes it will become as easy to obtain information about the state schools as it used to be to see a doctor.

2. The organization wrote that this report has not been used for the purposes cited in the legislation but has been used for opposite purposes. They related that the report is written based on minority comments rather than the comments made by the majority of commenters. The reduction in state school census is stated as the result of forcing persons out of the state schools and disregarding the individuals and legally authorized representative's choice of state schools. The organization concludes by stating: "TDMHMR continues to ignore our input and support for 'CHOICE' of state school residential services in these reports and in their continued restrictive state school admission/eligibility in their 'Continuity' policy."

3. The same document as in #2 above was submitted by one individual.

In Support of Community Services:

1. An advocacy organization defined their position regarding state schools as: "Adults should have access to the services and supports they need to live in the community. The state of Texas must allocate the requisite resources to support community living for people with developmental disabilities. In addition, the state must rapidly expand the availability of individualized community options, transition all individuals in state schools to community living, commit to a transition plan to close state schools and transfer any cost savings to quality community programs. "

   This organization also requested that the results of the "Consumer/Family Satisfaction Survey of Community Placements from State Mental Retardation Facilities" be included in the report.

2. Another advocacy organization wrote:
   "Thank you for the opportunity to submit comments on the Report Update for SMRFs. The (organization) appreciates your having updated the data using the most recent reports (i.e., *The State of the States in Developmental Disabilities*). Other than the updated figures, no new information is being presented in this document. To that end, I would like to underscore the comments made by advocates in support of community services to Robert "Kif" Kifowit and Barry Waller on November 4, 2003." (See Appendix A, *In Support of Community Services*, comments 1, 2, 4, and 5.)

Appendix C

Description of Level of Need Categories

Level of Need (LON)

This is a five tiered assignment system that is derived from two sources: (1) the results of the administration of the *Inventory for Client and Agency Planning* (ICAP), a validated and standardized assessment designed to predict the amount/intensity of services and supports an individual would require from a mental retardation service system; and (2) documentation on the ICF-MR Level of Care assessment form which relates specifically to the need for extraordinary levels of service provider intervention resulting form an individual's demonstration of maladaptive behaviors which seriously threaten the safety and welfare of the individual or of others. The five levels are as follows:

- **Intermittent (LON 1)** is generally associated with mild to moderate deficits in intellectual functioning and mild deficits in adaptive behavior. The individual does not demonstrate significant maladaptive behaviors and requires limited personal assistance and/or regular to infrequent supervision.

- **Limited (LON 5)** is associated with mild to moderate deficits in intellectual functioning and in adaptive behavior. Staff support to individuals ranges from close supervision and guidance to direct assistance in accomplishing personal care.

- **Extensive (LON 8)** is associated with moderate to severe deficits in intellectual functioning and adaptive behavior. Individuals require direct physical assistance and/or constant supervision due to extremely limited personal care skills which may be associated with physical disabilities, medical conditions, or maladaptive behaviors.

- **Pervasive (LON 6)** is associated with severe to profound deficits in intellectual functioning and adaptive behavior and the presence of maladaptive behaviors requiring increased levels of staff supervision.

- **Pervasive Plus (LON 9)** is associated with the verifiable presence of extremely serious maladaptive, life-threatening behaviors requiring the constant provision of a formalized, systematic behavioral intervention/treatment program; and of the constant, one-to-one supervision by the service provider in order to assure the individual's safety or the safety of others. ALL requests for LON 9 assignment are reviewed by the UR Division of the Medicaid Office at TDMHMR.

An individual in ICF-MR services may qualify for the next higher LON based on serious medical issues as well as behavioral issues. Pervasive Plus is only available through a behavioral need "bump up."