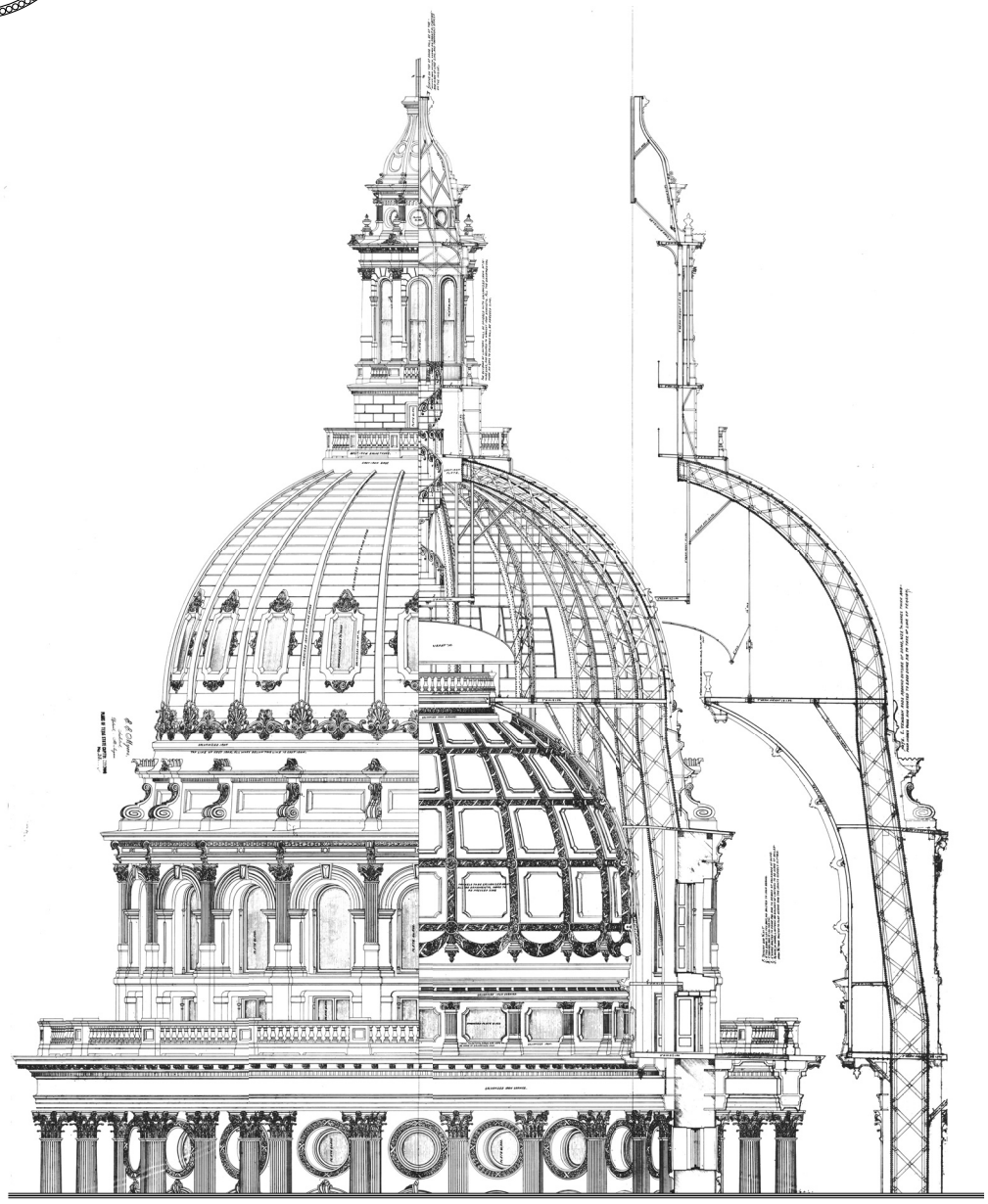
Interim Report to the 81st Texas Legislature



House Select Committee on
Services for Individuals Eligible for Intermediate Care Facility Services

December 2008

HOUSE SELECT COMMITTEE ON SERVICES FOR INDIVIDUALS ELIGIBLE FOR INTERMEDIATE CARE FACILITY SERVICES
TEXAS HOUSE OF REPRESENTATIVES
INTERIM REPORT 2008

A REPORT TO THE
HOUSE OF REPRESENTATIVES
81ST TEXAS LEGISLATURE

LARRY PHILLIPS
CHAIRMAN

COMMITTEE CLERK
DOISE MIERS

POLICY ANALYSTS
AMANDA BRANT
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Select Committee On
Services for Individuals Eligible for Intermediate Care Facility Services

December 11, 2008

Larry Phillips
Chairman

P.O. Box 2910
Austin, Texas 78768-2910

The Honorable Tom Craddick
Speaker, Texas House of Representatives
Members of the Texas House of Representatives
Texas State Capitol, Rm. 2W.13
Austin, Texas 78701

Dear Mr. Speaker and Fellow Members:

The Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services of the Eighty-first Legislature hereby submits its interim report including recommendations and drafted legislation for consideration by the Eighty-first Legislature.

Respectfully submitted,

Larry Phillips, Chairman

John Zerwas, Vice-Chairman

Myra Crownover

Susan King

Armando Martinez

Dora Olivo

Joe Pickett

Patrick Rose

Vicki Truitt

John Zerwas
Vice-Chairman

Members: Myra Crownover, Susan King, Armando Martinez, Dora Olivo, Joe Pickett, Patrick Rose, Vicki Truitt

HOUSE OF REPRESENTATIVES
Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services

December 1, 2008

Realizing the need for a comprehensive examination of the system of care for those with developmental and cognitive disabilities, Speaker Tom Craddick had the foresight to create the Select Committee on Individuals Eligible for Intermediate Care Facility Services in January 2008. The committee has worked extensively in researching this complex structure and now offers up the information and recommendations in this report as the basis to conduct a thorough review and transformation of this system.

I would like to thank the members of the committee for the hard work they have put in to understanding the intricacies of caring for those with developmental disabilities in this state. They exhibited such dedication while working on ideas for recommendations which will be put towards improving the system of care for some of our most fragile Texans.

I appreciate the lively discussions and feedback from the many parties interested in this subject matter. Though the opinions are quite diverse, I challenge all parties to continue working together to improve the developmental disability system while keeping in mind what is best for these individuals.

I would also like to thank the committee staff for their tireless efforts in traveling this great state to visit our community based services, state schools and MRA's. They did a superb job of keeping the committee well informed and on task.

The report and recommendations for the Select Committee for Individuals Eligible for Intermediate Care Facility Services goes beyond just state schools; it encompasses the entire system of care for anyone eligible an for ICF/MR including those in community care and those who have put themselves on an interest list because they anticipate needing services in the future. I challenge the 81st Legislature to become thoroughly familiar with these recommendations and have a healthy debate in passing legislation to improve the care for those in this state with developmental and cognitive disabilities.

Sincerely,

Larry Phillips
Chair, Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services

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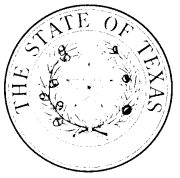

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Myra Crownover
District 64

December 3, 2008

As a member of the Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services, I have decided to attach this statement to the Official Report of the Committee.

I would like to thank the members of the Committee for their hard work during these past few months. I would also like to thank all of the people who took time to testify before the Committee, many of whom are parents and guardians of the individuals served by State Schools. Finally, I would like to commend the hard work of the staff of the Committee. The Official Report is thorough and well done.

The issue of appropriate care for the mentally retarded is complex and there is no "one size fits all" solution. The population served by community homes and State Schools is made up of individuals with unique needs. The Official Report attached hereto accurately reflects the complexity of developing a system of care for these individuals. At the heart of the debate is what is best for each person.

While I believe that every person involved truly wants to see what is best for these individuals, an institutional bias against State Schools pervades the Department of Aging and Disability Services (DADS) and the Health and Human Services Commission (HHSC). Over the past few months, I have heard privately from parents, employees, and others who are involved in State Schools. Many of whom testified before the Committee and many others who were not willing to testify publicly out of a fear of retribution by DADS. The consistent theme of what I heard was that HHSC and DADS are biased against State Schools, and have engaged in management practices that hinder the ability of State Schools to serve the individuals in their care.

The Department of Justice just released their findings into an investigation of all 13 State Schools and the findings are disturbing. The responsibility for conditions at our State Schools lies directly at the feet of DADS. The institutional bias and mismanagement at DADS is hard to expose but very real. For example, DADS requires that all State Schools pay the same rate for nurses (with a small cost of living adjustment for each school). However, the market rate for qualified nursing care varies greatly from school to school. DADS has standardized pay for almost every position within the State School system and the result has been to hamper each individual institution's ability to retain qualified staff. The high turnover rate of staff at State Schools is a direct cause for many of the problems at

the schools. In fact, the Department of Justice found that "The frequency and severity of critical incidents at the facilities are disturbingly high and often directly related to insufficient staffing."

Another problem highlighted in the Official Report of the Committee that I would like to add emphasis to is the lack of oversight of HCS Community Homes by DADS. The problems in State Schools are well documented and disturbing. However, there is no system set up to monitor the safety of individuals in HCS Community Homes. The oversight of these homes is left to private providers with little involvement from DADS and no reporting requirements. As noted in the Report, the federal Government Accountability Office recently found that Texas lacked sufficient oversight of Home and Community Based Waiver facilities and "did not have a systematic process for reviewing deaths to identify and address quality-of-care issues"[and] ..."did not currently aggregate mortality data." The individuals in these homes deserve the same degree of oversight and protection as the individuals in State Schools. Also, despite the recent problems at State Schools, most of the parents of State School patients that I spoke with feel quite strongly that the care provided to their children at State Schools is excellent and do not want their children moved into community homes with little State oversight. No one has a more vested interest in the well-being of a patient at a State School than the patient's parent.

Finally, I have great concern with the CLOIP process for State School residents that are profound or severely retarded. The basic idea behind this process has merit. However, in practice, individuals who do not have the capacity to make decisions about their care should not be asked to make decisions about their care. Currently, 60% of the residents in State Schools do not have a legal guardian. Without the protection of a guardian, severe or profoundly retarded individuals are not positioned to properly participate in the CLOIP process and the process itself is susceptible to manipulation.

Many people believe that closing or consolidating State Schools could eliminate the problems associated with State Schools. This is simply not the case. The responsibility for the conditions at State Schools is directly attributable to mismanagement by DADS. Furthermore, it is clear that DADS has failed to manage and protect the individuals living in community homes to an even greater degree than they have mismanaged State Schools. Transferring this very vulnerable population from one poorly managed institution to another institution with less oversight only serves to conceal the problem in a system with more layers of bureaucracy and less protection for the residents. Closing State Schools only serves to bury the problem, not to solve it.

As a result of my experience as a member of the Committee, I would like to make two additional recommendations:

1. Every aspect of management of State Schools by DADS should be evaluated with a focus on improving conditions across the board. Instead of favoring one type of care for the mentally retarded, DADS should focus on improving every aspect of the system so that community based care and State Schools have the necessary tools and oversight to serve the individuals in their care.

2. The removal of Severe or Profound mentally retarded individuals from State Schools without the involvement of a parent or guardian should be halted immediately.

Sincerely,

Myra Crownover

Myra Crownover
State Representative, District 64

The State of Texas
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Armando "Mando" Martinez
State Representative
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November 24, 2008

The Honorable Larry Phillips, Chairman
House Select Committee on Services for Individuals
Eligible for Intermediate Care Facility Services
P. O. Box 2910
Austin, TX 78768-2910

RE: Committee Report

Dear Chairman Phillips:

I am in receipt of the House Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services report and I would like to make the following statements:

1. As the Department of Aging and Disability Services (DADS) evaluate statewide improvements as recommended in the report, it is important that all State schools remain open to serve the citizens of Texas in the respective regions.

2. Additionally, because family involvement is important to those individuals who live in State schools, the State should consider expanding or establishing schools in underserved areas of the State.

I appreciate all of the hard work that you, the committee members, and the committee staff did during the past several months to prepare and write this report.

Sincerely,

Armando "Mando" Martinez
State Representative, District 39

DORA OLIVO
STATE REPRESENTATIVE
DISTRICT 27
FORT BEND COUNTY (PART)

The State of Texas
House of Representatives
Austin, Texas

COMMITTEES:
PUBLIC HEALTH
PUBLIC EDUCATION

December 4, 2008

The Honorable Larry Phillips
Chairman, Select House Cmte.
P.O. Box 2910
Austin, TX 78768

Dear Chairman Phillips:

Following are my comments on the committee report recommendations.

Recommendation 4:

Appoint a Quality Assurance Team for facilities that chronically receive a Quality Reporting System Score below 60 for more than three surveys.

It is not enough to just appoint a Quality Assurance Team (QAT) for facilities as mentioned above. That QAT must be one that is knowledgeable in doing quality assurance and one that is also not connected to the state schools in order to do more objective reporting. In addition to this, we need to review, if necessary, the efficacy of the current Quality Reporting System.

Recommendation 7:

Maintain state operated long-term care facilities for only the most medically fragile and hard to serve populations.

I am concerned with this recommendation because it seems to be leading to depopulating state schools. Currently, you also have people in state schools that cannot get out and about by themselves and cannot verbalize their wants and needs; and some that are bed ridden. Some of them are also people that require medical attention on a more frequent basis without being considered medically fragile. State schools would seem to be appropriate for these populations also. Of course the family member's preference should also be taken into consideration. We need to define "hard to serve populations" in the recommendations we are making.

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Recommendation 12:

Initiate a communicative devices pilot program in a State Mental Retardation Facility.

In favor, but should note such a pilot program exists at Denton State School, funded by a grant from Volunteer Services, and the program is successful.

Sincerely,

Dora Olivo

COMMITTEES:
HUMAN SERVICES, CHAIR
HIGHER EDUCATION

Patrick M. Rose
TEXAS STATE REPRESENTATIVE
DISTRICT 45

COUNTIES:
BLANCO
CALDWELL
HAYS

December 3, 2008

The Honorable Larry Phillips, Chairman
House Select Committee on Services for Individuals Eligible for Intermediate Care Facilities
P.O. Box 2910
Austin, TX 78768-2910

Dear Chairman Phillips:

When I began my work on this select committee, I subscribed to the conventional legislative wisdom that reforming our system of long-term services and supports was infeasible, and that the only way forward was preservation of our institutional system, both public and private, along with continued efforts to chip away at the seemingly intractable problem of lengthy waiting lists for community-based services. Over the past year, however, I have come to recognize that this is a flawed strategy that will never allow Texas to achieve a truly cost-effective, consumer-directed system.

This committee has done an excellent job of identifying strategies to provide better consumer protection against abuse, neglect, and exploitation, and I am confident that our recommendations will improve long-term care services in this regard. Reports of abuse and neglect in private institutions should be investigated by a state agency, not by the facility itself. More group and foster companion homes should be surveyed annually. Data systems should be refined so that trends in the incidence of abuse and neglect in the community can be monitored, and problems can be addressed. Direct care staff in institutions and community-based settings should receive adequate screening, training, and compensation to do their job. Individuals with intellectual disabilities should have guardians when absolutely necessary and access to supported decision-making services when guardianship is not appropriate. What's more, I strongly support the recommendations to invest in safety-net services and home and community-based waiver programs.

In contrast, I am not satisfied that the Texas Legislature has done its job to address the need for more fundamental and far-reaching reform. My office receives calls and letters on a regular basis from families who must make the difficult choice between placing their child in an institution and going without adequate services for years. Any serious analysis of the long-term care budget makes clear that we currently spend too much to serve too few in settings for which there is little demand. Advocates across the state who have worked tirelessly to educate our

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Legislature provide ample support for their argument that our current system, by accident rather than by design, promotes wasteful service utilization and institutionalization over efficiency and independence. Planning around the growing need for long-term services and supports is our responsibility.

I do not wish to deny that progress has been made since the Supreme Court's *Olmstead* decision in 1999, or that effective, hard-working, and well-intentioned legislators, agency staff, and advocates have brought about real changes and necessary improvements. As a result of these efforts, Texas is serving more individuals in the community than ever before. But we can do a much better job at spending our state dollars efficiently and, more importantly, meeting the needs and desires of a much larger proportion of the eligible population.

This is not and should not be framed as simply a debate over whether to close state schools. There is real need in this state to develop an earnest, comprehensive, and informed long-term vision and plan for our system of services and supports for persons with disabilities. The qualified staff at Texas' Health and Human Services Commission (HHSC) and Department of Aging and Disability Services (DADS) have the expertise to do this, but they cannot implement fundamental change absent legislative direction and leadership. While state school consolidation and closure should and must be on the table, we should also reconsider the very architecture of our ICF/MR program, both public and private. Ultimately, the legal, moral, and fiscal arguments for fundamental reform are compelling.

Legal Considerations

Texas has a legal obligation, as directed by the United States Supreme Court in *Olmstead*, to serve persons with disabilities in community settings whenever possible, yet the very structure of our long-term care system inhibits compliance with this directive. The Department of Justice's (DOJ) findings in its investigations of our state schools indicate that we are not fulfilling this legal obligation to the best of our ability.

As evidenced by trends in other states, improvements are possible. Texas relies much more heavily on institutional care than other states. We institutionalize individuals with intellectual and developmental disabilities at nearly twice the national rate. In fact, we operate more state-run institutions and place more individuals, including children, in large congregate settings than any other state.[1] Continuation of these trends leaves Texas vulnerable to litigation, which is an inefficient way to reform policy, often resulting in lengthy settlement negotiations and costly remedies. Furthermore, waiting for court mandates driven by the federal government is not a prudent road map for reform. The Texas Legislature can and should require the creation of a proactive rather than reactive plan to improve our system of long-term services and supports, informed by our own experiences, as well as the successes of other states.

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[1] Braddock, D., Hemp, R. & Rizzolo, M.C. (2008). *The state of the states in developmental disabilities.* Boulder, CO: The University of Colorado's Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

Moral Considerations
Legal issues aside, Texas also has a moral obligation to respect the life and dignity of persons with disabilities and their families and to honor their right to be served in home and community-based settings if they so choose. I, like other members of this committee, respect the desire of families who have been well served by dedicated state school staff for decades, as well as those who have chosen care in private institutions. Like other committee members, state agency leaders, and much of the advocacy community, I would find it unconscionable to force any individual to opt for community-based services should they prefer care in an institutional setting.

We would be remiss, however, if we failed to acknowledge that the reverse occurs on a daily basis. The choices of families who prefer community-based services and who represent the vast majority of persons with intellectual and developmental disabilities are not accorded the same respect. A family whose only alternative to institutionalization is an eight-year waiting list does not have a real choice.

This scenario would be troubling even if it were the case for only a handful of families eligible for services. The fact that it is the case for tens of thousands of Texans is inexcusable. Currently, there are nearly 70,000 names on interest lists for programs that waive off of intermediate care facilities. Fully one third of the names (representing 10,000 persons with disabilities) on the Home and Community-Based Services (HCS) interest list have waited five years for services. More than 1,000 have spent between eight and nine years on the interest list. Absent systemic change, the choice of one constituency will continue to be given more weight than that of another.

Fiscal Considerations
As chair of the House Human Services Committee, I am acutely aware of the needs that are met with health and human services dollars and recognize that critical programs compete biennially for a fixed amount of funding. While legislators tend to argue about whether the pot is big enough, no one denies that there is a limit to what the state can expend. Rarely do we have the opportunity to serve more Texans, do so in a more effective manner, and reduce the cost to the taxpayer in the middle and long run.

Texas' long-term care system for persons with intellectual and developmental disabilities fails to meet the critical standard of fair and efficient allocation of our finite resources. We spend twice as much today as in 1987 in inflation-adjusted dollars on long-term services and supports for individuals with intellectual and developmental disabilities, but the number served has grown by less than 20 percent.[2] Over this same two-decade period, the state's population increased by 44 percent. In other words, our state has doubled its investment and is still unable to keep pace with population growth—an unsustainable pattern.

A portion of inflated costs is attributable to improved services for persons in state schools and in community-based settings. Another portion is due to health care costs that have risen more

[2] In FY 1987, Texas spent $718 million (in 2007 dollars) to serve approximately 35,000 persons with disabilities. In FY 2007, the state spent $1.5 billion to serve approximately 41,000.

rapidly than overall inflation. There are, however, three systemic factors that drive up the cost of serving persons with disabilities without improving the quality of care or increasing consumer choice. Unlike health care inflation, changing these dynamics is within our direct control and should be a priority:

1. The cost to serve persons in state schools is substantial and growing. The number of individuals choosing care in a state school setting has declined over time, yet Texas continues to operate the same number of state-run institutions. Consequently, administrative and overhead costs are spread among fewer individuals, and the cost per person has increased.[3] As settlement agreements with the DOJ are finalized, these costs are likely to rise even more;

2. The structure of our waiver programs encourages overutilization and inefficient use of resources by focusing on a diagnosis rather than an individuals functional needs and preferences; and

3. Our system offers only the most expensive option—institutional care—as an entitlement, while making families wait years for the less costly and more integrated community-based services that most prefer.[4]

Despite significant changes over the past two decades, from the settlement of *Lelsz* and the *Olmstead* decision, to rapidly increasing demand for home- and community-based services, we have failed to realign the basic funding structure of Texas' long-term care system to match shifting demand. We continue to invest more money in institutions than the community, in spite of consumer demand and fiscal realities that should dictate otherwise. What's more, as we strive to serve more individuals in community settings, we add waiver after waiver program, each with its own eligibility requirements, service array, and reimbursement structure. In other words, the configuration of our system of long-term services and supports has magnified both its cost and complexity.

Given the resources that are likely to be available over the coming biennia, the Legislature has three options in moving forward:

1. We can do nothing. Under this scenario, interest lists will grow rapidly, institutional census will decline slowly, and the cost of serving persons with disabilities will increase as a result;

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[3] The average annual cost (inflation-adjusted) for a state school placement has risen from less than $60,000 in 1987 to more than $100,000 in 2007.

[4] Eligible individuals are entitled to receive care in a state school or in a private ICF at nearly twice the average annual cost of home and community-based care. According to DADS' *Rider 44 Report* (2006), the average annual cost of care for persons with disabilities, including acute care costs, differs dramatically by setting, ranging from $37,000 for community-based waiver services to $72,000 for institutional care (ICF and state school). HCS residential services average $58,000 per person per year.

2. We can continue to invest money on both sides of the system (community-based and institutional) as we did last session, ignoring its underlying inefficiencies and avoiding the need to make difficult decisions; or

3. We can take the prudent approach, developing a plan to realign the current system by placing a greater emphasis on serving persons with disabilities in their communities. This transition would certainly require both time and funding in the immediate future, but it would increase efficiency dramatically in the long run. Rather than serving fewer people at greater cost as we have been doing, we have the opportunity to serve more while keeping funding levels stable. This approach is only possible, however, if the consolidation and closure of state institutions is on the table.

Reform is always challenging, but we can no longer afford to ignore the need to change the way our state serves persons with disabilities. Texans place great stock in individual choice, fiscal responsibility, and the dignity of their fellow citizens, and I believe strongly that our system of long-term services and supports could do a much better job at reflecting these common-sense values. This is why I will propose legislation during the upcoming session that will give HHSC the directive and the authority to develop and implement a plan to grow our community capacity, downsize our institutions, make sense of our complex waiver system, reduce the average cost of care, and increase our ability to serve persons with disabilities effectively, efficiently, and in the setting of their choice.

I genuinely appreciate your leadership on these issues over the interim, as well as the opportunity to offer additional comments.

Sincerely,

Patrick M. Rose

Patrick M. Rose

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I. Introduction

The Select Committee on Services for Individuals Eligible for Intermediate Care Facilities was appointed by Speaker Tom Craddick in January 2008 and includes in its members Representatives Larry Phillips, chair; John Zerwas, vice-chair; Myra Crownover; Susan King; Armando Martinez; Dora Olivo; Joe Pickett; Patrick Rose; and Vicki Truitt. The Select Committee was granted jurisdiction over all matters pertinent to systems in this state for the care of persons with cognitive and developmental disabilities who are eligible for the services of intermediate care facilities. The select committee's jurisdiction included:

(1) investigating and recommending strategies to improve the quality of and availability of appropriate services for persons with cognitive and developmental disabilities who are eligible for the services of intermediate care facilities, while ensuring the safety and well-being of individuals being served in community settings and institutional settings;

(2) reviewing functional assessment tools used to assess persons with cognitive and developmental disabilities who are eligible for the services of intermediate care facilities;

(3) evaluating this state's ability to comply with federal regulations and directives regarding services for persons with cognitive and developmental disabilities who are eligible for the services of intermediate care facilities and this state's ability to implement generally accepted practices for those services;

(4) assessing the adequacy of the "community safety net" in this state's mental retardation authority system after considering the increased longevity of persons with cognitive and developmental disabilities and their aging parents and other caregivers;

(5) reviewing the waiting lists for Medicaid home and community waiver services; and

(6) assessing the risks to the health and well-being of persons with cognitive and developmental disabilities who are eligible for intermediate care facility services that are not currently being addressed by this state's current system of supports.

II. Overview of Current System

At present, an estimated 661,000 Texans live with mental retardation (MR). In FY 2008, an average of 41,553 individuals per month received MR services at a cost of over one billion dollars (all funds).[1] Numerous agencies, both public and private, provide services and supports to individuals eligible for ICF/MR's services. They work collaboratively to serve the needs of Texans with developmental disabilities/intellectual disabilities (DD/ID) and/or related conditions (RC). The entities that make up the system of care are:

- The Department of Aging and Disability Services (DADS);
- The Department of Family and Protective Services (DFPS);
- The Department of State Health Services (DSHS);

- The Department of Assistive and Rehabilitative Services (DARS);
- The Health and Human Services Commission (HHSC);
- The Texas Education Agency (TEA);
- Local Mental Retardation Authorities (MRA's);
- A network of private providers; and
- Faith-based and non-profit organizations.

The Department of Aging and Disability Services (DADS)

The Department of Aging and Disability Services administers most of the programs for individuals eligible for ICF/MR services. The agency provides long-term services and supports, regulates providers of long-term services and supports, and administers the state's guardianship program for elderly Texans and those with disabilities.[2] In addition, DADS administers Medicaid waiver programs, maintains the interest lists for the Medicaid waiver programs, operates State Mental Retardation Facilities (SMRF's), oversees community-based ICF/MR's, coordinates with other public agencies, and contracts with local MRA's and private providers.

Organizational Structure
DADS is under the direction of the Commissioner, who is appointed by the Executive Commissioner of Health and Human Services Commission, and approved by the Governor. The Commissioner oversees seven programmatic and support divisions: the Office of the Deputy Commissioner; Internal Audit; Chief Operating Officer; Chief Financial Officer; Access and Intake; Provider Services; and Regulatory Services.[3]

The Office of the Deputy Commissioner manages the Center for Policy and Innovation, the Center for Program Coordination, and the Center for Consumer and External Affairs. These centers are responsible for providing DADS with policy direction and technical assistance.[4] The Center for Policy and Innovation oversees the Quality Assurance and Improvement unit; this center manages the programs intended to improve provider performance.

The Internal Audit division conducts independent consulting meant to improve DADS functioning. The department employees report directly to the Commissioner to maintain independence and objectivity.[5]

The Chief Operating Officer (COO) is responsible for coordinating DADS activities with HHSC. This division also manages several departments within DADS: legal services; consumer rights and services; information technology; contract oversight and support; and executive and staff operations.[6]

The Chief Financial Officer (CFO) handles budget and data management as well as fiscal accounting.[7]

The Access and Intake division ensures services are locally accessible through a coordinated and efficient system. The division manages Area Agencies on Aging (AAA), MRA's, regional and local services, and guardianship services.[8]

Provider Services administers contracts with hundreds of community and in-home service providers. The division's responsibilities include residential services, community services, and State Mental Retardation Facilities (SMRF's).[9]

The Regulatory Services department ensures the safety of the facilities providing services to clients. The department has three tasks: state licensing and federal credentialing operations; survey operations; and enforcement operations.[10]

Programs and Services under DADS Authority
The programs and services provided through DADS to individuals with mental retardation (MR) and/or a related condition (RC) are divided into two categories, community services and residential services.

Community services are provided while an individual is living in their own home, a family home, or a small group home setting. Included in this category are Medicaid entitlement services, Medicaid 1915(c) waiver programs, and non-Medicaid community supports and services.[11] Medicaid 1915(c) waivers allow the Secretary of Health and Human Services to waive certain Medicaid requirements. This allows long-term care services to be delivered in a community-based setting as an alternative to services provided in an institutional setting.[12]

Residential services consumers reside in a facility to receive services and supports. DADS oversees three types of Medicaid entitlement residential facilities: nursing facilities, hospice, and ICF/MR's (community-based and SMRF's).[13]

The Department of Family and Protective Services (DFPS)

DFPS is responsible for protecting adults with disabilities, the elderly, and children.[14] The Adult Protective Services (APS) division investigates any allegations of abuse, neglect, or exploitation of individuals receiving services in SMRF's, MRA's, and some private providers.[15] APS also initiates in-home investigations when there are allegations of abuse, neglect, or exploitation in community settings such as private homes, adult foster care homes, and unlicensed board and care homes.[16] The agency coordinates its efforts with the state's other health and human service agencies.

The Department of State Health Services (DSHS)

DSHS promotes the health of individuals and communities while providing effective health services, particularly mental health (MH) services. The agency has some responsibilities relating to the care of Texans with MR. DSHS, in collaboration with HHSC, administers the Comprehensive Care Program (CCP). It serves individuals under age 22 with pervasive medical needs.[17] In addition, the operation of the Rio Grande State

Center, a SMRF, is managed by DSHS because it is a residential facility offering both MH and MR services.[18]

The Department of Assistive and Rehabilitative Services (DARS)

DARS works with individuals with disabilities and their families to enhance quality of life and enable full participation in society. Most of the programs offered by DARS focus on employment services and independent living. The agency is also responsible for making an individual's determination of disability prior to receiving Social Security Administration disability benefits. In addition, DARS administers the Early Childhood Intervention (ECI) program. ECI serves children under 3 years old with developmental delays.[19]

The Health and Human Services Commission (HHSC)

HHSC provides oversight for the operation and administration of the health and human services system. The commission is responsible for coordinating services between all five health and human services agencies. HHSC also directly administers the state Medicaid program and several other assistance programs.[20]

The Texas Education Agency (TEA)

TEA and local school districts provide all children, including those with MR and other RC, with a free and appropriate education. All children are entitled to public school services between the ages of 3 and 21.[21]

Local Mental Retardation Authorities (MRA's)

MRA's provide services and information to individuals with MR in their catchment area. They serve as the local authority for MR services in their region. There are 39 MRA's throughout the state. They provide services either directly to the consumers or through a network of local providers. The services and supports offered by each MRA vary depending on the specific needs of the population.[22] Community Mental Health and Mental Retardation (MHMR) Centers are the MRA's for every catchment area except Bexar County. The Alamo Area Council of Governments serves as the MRA in that region.[23]

Services provided by MRA's

The authorities act as the front door for individuals interested in accessing services. They inform every consumer about all of the available services and supports. The MRA's then determine a person's functional eligibility prior to enrollment in programs. Once a client is receiving services and supports, the authorities provide service coordination and case management.[24]

Depending on the type of services a consumer seeks, the MRA's can facilitate placement in an ICF/MR (SMRF's or community-based) or enrollment in a Medicaid waiver program.[25]

For most Medicaid waiver programs, the number of interested individuals exceeds the resources available. Therefore, those seeking waiver services must be placed on an interest list. Consumers are served on a first-come, first-serve basis. It is the MRA's responsibility to coordinate placement on interest lists.[26]

In addition, MRA's conduct permanency planning. Senate Bill 368 passed during the 77th Regular Session of the Texas Legislature states that all consumers under 22 years old living in nursing facilities, ICF/MR's, or in an HCS group home must have a plan that is reviewed every six months. The goal of the permanency planning is to provide children with a consistent, nurturing environment; have a positive parental relationship with an adult in a family setting; and have a person who will advocate on their behalf.[27]

Authorities perform the annual Community Living Options Information Process (CLOIP) for all adults living in a State Mental Retardation Facility. Senate Bill 27 passed during the 80th Regular Session of the Texas Legislature instructed DADS to shift the responsibility for informing residents about their community options from the SMRF's interdisciplinary team to the MRA's. It requires the MRA's to discuss all available living options with each adult resident of a state school or state center. The CLOIP became fully operational in January 2008 at an annual cost of $3,577,503 general revenue.[28] [29]

Additional services provided through MRA's include respite care and day habilitation. Some authorities choose to become a residential service provider contracting with DADS through either the HCS or ICF/MR programs. This function of the MRA's is very similar to that of the private providers.

MRA Relationships with other Agencies

MRA's coordinate their programs and services closely with DADS and with each other. Each MRA contracts with DADS to provide services to individual consumers. DADS then provides the oversight for the community programs and services delivered through these contracts.[30]

The Texas Council of MHMR's is a non-profit organization collaborating with MRA's to improve the effectiveness and efficiency of services delivered throughout the state. Each MRA has a representative on their board of directors except Bexar County. The Alamo Area Council of Government serves as the MRA in that region rather than an MHMR center.[31]

MRA Challenges and Issues

The local authorities have the difficult responsibility of ensuring that every resident in their area has access to the necessary services and supports. The MRA's have identified several challenges that affect their ability to provide efficient and effective care.

Many MRA's have expressed a need for an increase in their ability to provide respite services. The authorities must act as a safety net; any time an emergency occurs and an individual needs residential placement immediately, the MRA's provide respite services until alternative arrangements can be made. Increasing their ability to provide respite will prevent out-of-home placements by providing a break for caregivers and also improving the MRA's ability to provide crisis services.

MRA's are concerned about their dependence on general revenue funding. As the safety net provider for their local area, the MRA's must use GR funds to ensure an individual's needs are met by providing prevention and crisis services. Any decrease in funding would result in the MRA's ability to provide services to be weakened.

Another issue with the MRA's is their communication with DADS and with each other. Some MRA's have very effective communication; they are well informed and are providing extremely efficient and effective services to their consumers. However, other authorities have less effective communication resulting in misunderstanding and inadequate service provision. The ability of MRA's to provide information and services is inconsistent throughout the state.

MRA Catchment Areas

MRA Name	Location	Catchment Area
ACCESS	Jacksonville	Anderson and Cherokee
Andrews Center	Tyler	Henderson, Rains, Smith, Van Zandt, and Wood
Austin-Travis County MHMR Center	Austin	Travis
Betty Hardwick Center	Abilene	Taylor, Jones, Callahan, Shakelford and Stephens
Bexar MRA	San Antonio	Bexar
Bluebonnet Trails Community MHMR Center	Round Rock	Bastrop, Burnet, Caldwell, Fayette, Gonzales, Guadalupe, Lee, and Williamson
Border Region MHMR Community Center	Laredo	Webb, Jim Hogg, Zapata, and Starr
Burke Center	Lufkin	Angelina, Houston, Jasper, Nacogdoches, Newton, Polk, Sabine, San Augustine, San Jacinto, Shelby, Trinity, and Tyler
Camino Real Community MHMR Center	Lytle	Atascosa, Dimmit, Frio, La Salle, Karnes, Maverick, McMullen, Wilson, and Zavala
Center for Life Resources	Brownwood	Brown, Coleman, Comanche, San Saba, Mills, Eastland, and McCulloch
Central Counties Center for MHMR Services	Temple	Bell, Coryell, Hamilton, Lampasas, and Milam
Central Plains Center	Plainview	Hale, Lamb, Swisher, Bailey, Parmer, Castro, Floyd, Motley, and Briscoe
Coastal Plains Community MHMR Center	Portland	Aransas, Bee, Brooks, Duval, Jim Wells, Kenedy, Kleberg, Live Oak, and San Partricio
Community Healthcore	Longview	Gregg, Harrison, Marion, Panola, Rusk, Bowie, Cass, Red River, and Upshur
Denton County MHMR	Denton	Denton

Center		
El Paso MHMR	El Paso	El Paso
Gulf Bend MHMR Center	Victoria	Calhoun, DeWitt, Goliad, Jackson, Lavaca, Refugio, and Victoria
Gulf Coast Center	Galveston	Brazoria and Galveston
Heart of Texas Region MHMR Center	Waco	McLennan, Bosque, Falls, Freestone, Hill, and Limestone
Helen Farabee Regional MHMR Centers	Wichita Falls	Archer, Baylor, Childress, Clay, Cottle, Dickens, Foard, Hardeman, Haskell, Jack, King, Knox, Montague, Stonewall, Throckmorton, Wichita, Wilbarger, Wise, and Young
Hill Country Community MHMR Center	Kerrville	Bandera, Comal, Blanco, Edwards, Gillespie, Hays, Kendall, Kerr, Kimble, Kinney, Llano, Mason, Medina, Menard, Real, Schleicher, Sutton, Uvalde, and Val Verde
Lakes Regional MHMR Center	Terrell	Camp, Delta, Franklin, Hopkins, Kaufman, Lamar, Morris, Rockwall, Titus, Hunt, Ellis, and Navarro
LifePath Systems	McKinney	Collin
Lubbock Regional MHMR Center	Lubbock	Cochran, Crosby, Hockley, Lynn, and Lubbock
Metrocare Services	Dallas	Dallas
MHMR Authority of Brazos Valley	Bryan	Brazos, Grimes, Madison, Washington, Burleson, Leon, and Robertson
MHMR Authority of Harris County	Houston	Harris
MHMR of Nueces County	Corpus Christi	Nueces
MHMR of Tarrant County	Fort Worth	Tarrant
MHMR Services for the Concho Valley	San Angelo	Coke, Concho, Crockett, Irion, Reagan, Sterling, and Tom Green
MHMR Services of Texoma	Sherman	Cooke, Fannin, and Grayson
Pecan Valley MHMR Region	Stephenville	Erath, Somervell, Palo Pinto, Parker, Hood, and Johnson
Permian Basin Community Centers for MHMR	Midland	Brewster, Culberson, Ector, Hudspeth, Jeff Davis, Midland, Pecos, and Presidio
Spindletop MHMR Services	Beaumont	Jefferson, Orange, Hardin, and Chambers
Texana Center	Rosenberg	Wharton, Austin, Colorado, Fort Bend, Matagorda, and Waller
Tri-County MHMR Services	Conroe	Liberty, Montgomery, and Walker
Texas Panhandle MHMR	Amarillo	Dallam, Sherman, Hansford, Ochiltree, Lipscomb, Hartley, Moore, Hutchinson, Roberts, Hemphill, Oldham, Potter, Carson, Gray, Wheeler, Deaf Smith, Randall, Armstrong, Collingsworth, Donley, and Hall
Tropical Texas Behavioral health	Edinburg	Cameron, Hidalgo, and Willacy
West Texas Centers for MHMR	Big Spring	Andrews, Borden, Crane, Dawson, Fisher, Gaines, Garza, Glasscock, Howard, Kent, Loving, Martin, Mitchell, Nolan, Reeves, Runnels, Scurry, Terrell, Terry, Upton, Ward, Winkler, and Yoakum

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Private Providers

Private providers are non-profit and for-profit agencies licensed through a state health and human services agency. DADS licenses facilities providing care for individuals with MR. The services provided by these private entities are paid for through a reimbursement system using both federal and state funding. Non-profit providers also receive charitable contributions.

Types of Facilities
There are four types of services offered by private providers through state contracts: day habilitation, group homes for HCS clients, foster/companion care homes, and community-based ICF/MR facilities.[33]

III. Texas Population Eligible for ICF/MR Services

The state defines mental retardation as significantly sub-average general intellectual functioning that is concurrent with deficits in adaptive behavior and originates during the developmental period.[34] In practice three criteria are used to diagnose mental retardation:[35]

- Intellectual functioning lower than the majority of the general population represented by an IQ level below 70 on a standardized intelligence test. (About 2.7 percent of the Texas population has an IQ level of 70 or below.)[36]
- Limitations in adaptive behavior, or the inability to function independently in activities of daily living, as compared to other individuals of the same age and cultural background.
- Onset prior to 18 years of age.

Individuals with mental retardation often have a secondary related condition such as seizure disorders, physical disabilities, hearing impairment, visual impairment, mental illness, or medical fragility.[37]

Severity of Mental Retardation

Mental retardation is commonly divided into four ranges (mild, moderate, severe, and profound) based on intellectual and social factors.[38] An individual's level of mental retardation is correlated to the amount of assistance a person needs to carry out the activities necessary to lead a comfortable and productive life.

Individuals with mild mental retardation can usually live successfully in the community, either independently or in supervised settings, with appropriate supports. This group constitutes the largest segment (about 85%) of those with the disorder. Individuals with mild mental retardation typically undergo normal development of social and communication skills during the preschool years (ages 0-5 years) and have few sensorimotor impairments. These individuals may be indistinguishable from their

classmates until later in life. IQ scores for individuals in this range are from 50 to 70, and they can gain academic achievement to approximately a sixth-grade level by their late teens. As adults they usually possess adequate social and vocational skills for minimum self-sufficiency, but may need supervision.[39]

Persons with moderate mental retardation may require additional training and support to successfully achieve the same goals as those in the mild range.[40] They benefit from vocational training as well as training in social and occupational skills, and with some supervision can look after their own personal care. This group scores between 35 and 55 on IQ tests and constitutes about 10% of individuals with a mental retardation diagnosis. Most, but not all, of the individuals in this range of mental retardation develop communication skills during early childhood. Typically, their academic achievements are up to a second grade level. The majority of this group are able to work under supervision in sheltered workshops, or in the general workforce, performing unskilled or semiskilled tasks. This group may live successfully in the community, especially with supervision.[41]

Persons in the severe and profound ranges often experience disabilities in addition to their diagnosis of mental retardation.[42] The group with severe mental retardation constitutes three to four percent of individuals with mental retardation. These individuals acquire little to no language skills in early childhood, but may learn to talk during the school-age period. This group is capable of learning basic self-care skills, and limited pre-school skills, such as the alphabet and simple counting. As adults, they may be able to perform simple tasks in closely supervised settings. Unless they have an associated handicap or behavior issue that requires specialized nursing or other care, most are successful with supervision in community group homes or living with their families.[43]

Individuals with profound mental retardation constitute approximately one to two percent of individuals with mental retardation. Most individuals in this group have an identified neurological disorder that accounts for their diagnosis. Impairments in sensorimotor functioning become evident during early childhood. A highly structured environment and an individualized relationship with a caregiver who provides continuous aid and supervision create the optimal environment for this group. With training, self-care, communication, and motor skills may improve.[44]

Of the total population of Texans with a diagnosis of mental retardation, 95,000 persons are believed to be in the moderate, severe or profound ranges of the diagnosis.[45] Based on their functional abilities, persons in this group are likely to be eligible for ICF/MR's.

Pervasive Developmental Disorders & Related Conditions

Persons eligible for ICF/MR's may have a primary diagnosis other than mental retardation. The Department of Aging and Disability Services defines a priority population for mental retardation services. Individuals in this category must possess one or more of the following attributes:[46]

- A diagnosis of mental retardation as defined by Texas Health and Safety Code §591.003;
- A pervasive developmental disorder as defined in the current edition of the Diagnostic and Statistical Manual;
- A diagnosis of a related condition and eligibility for and enrollment in services in the ICF/MR, HCS, or TxHmL programs;
- Residing in a nursing home and eligible for specialized services for mental retardation or a related condition pursuant to Section 1919(e)(7) of the Social Security Act; or
- Current eligibility for Early Childhood Intervention Services through the Texas Department of Assistive and Rehabilitative Services.

Pervasive developmental disorders (such as Autism, Asperger's Disorder and Rett's Disorder) are typified by severe impairments in development.[47] Impairments occur in the areas of reciprocal social skills and communication skills. Individuals with pervasive developmental disorders also exhibit stereotypy in their behavior patterns, interests and activities. Onset of these disorders usually occurs before age 10. Of the 10,905 individuals residing in ICF/MR's, six have a primary diagnosis of an unspecified pervasive developmental disorder, and 44 have a primary diagnosis of autism.[48]

Related conditions that are severe and chronic disabilities that are closely related to mental retardation effect impairments of intellectual and adaptive functioning because they are similar to those of a person with mental retardation.[49] A related condition may result from a condition such as cerebral palsy, or epilepsy, but may not be attributable to mental illness. In order to be considered a related condition the disability must emerge prior to age 22, and must be expected to continue indefinitely. Related conditions are further defined as resulting in significant functional limitations in three or more life skills areas, including: self-care, language skills, learning ability, mobility, self-direction, and capacity for independent living. There are a total of 160 current ICF/MR residents who have a primary diagnosis of a related condition. [50]

The priority population of persons with mental retardation is projected to grow from 95,000 in 2008 to 102,000 in 2012.[51]

Level of Need (LON)

A level of need assessment is conducted for all individuals placed in ICF/MR's or waiver programs. An individual's level of need is the gauge used to determine the intensity of services an individual may need. Individuals with more severe medical or behavioral problems are classified at a higher level of need. DADS establishes an individual's level of need and uses this information as a payment category for reimbursement rates. [52] Information such as the individual's diagnosis, cognitive functioning, behavioral status, ICAP data, nursing needs, functional assessment, and physician's evaluation are considered in determining a level of need.[53] There are five levels of need intensity:[54]

- Intermittent (LON 1), This individual 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 required.
- Limited (LON 5), The skill level of a person at a Limited LON 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.
- Extensive (LON 8), The skill level of a person at an Extensive LON ranges from no self-help skills (due to physical limitations) to demonstrating some basic self-help skills. Staff intervention includes personal care assistance utilizing hands-on techniques and/or implementation of behavioral interventions.
- Pervasive (LON 6), This individual may have some basic self-help skills and demonstrates challenging behavior requiring intervention. Consumers in this level of need may even require one-on-one supervision or care for safety reasons.
- Pervasive Plus (LON 9), Individuals at this LON require one-on-one staff supervision within arm's length of the consumer during all waking hours due to their life threatening behavior. Pervasive plus applies to individuals who have significant behavior challenges including: self-injurious behavior, serious disruptive behavior, aggressive behavior, or sexually aggressive behavior.[55]

At the pervasive and pervasive plus levels of need an individual requires constant support across all environments.[56]

Medical Fragility

The term "medically fragile" is used to collectively describe individuals with moderate or severe health problems. Persons with moderate medical fragility have chronic health problems that require professional intervention beyond administration of medication, but less than daily. Persons with severe medical fragility have a health status that is unstable, or have multiple serious health problems which may be life threatening and require professional intervention on a daily basis.[57]

Dual Diagnosis

For the purposes of this report dual diagnosis refers to an individual's comorbid diagnoses of mental retardation and a psychiatric disorder. Instances of dual diagnosis are recorded increasingly; national data suggests 30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder and specialists believe this number remains valid in Texas as well.[58] Approximately 18% if individuals committed to a state school in Texas are admitted on discharge from a state hospital.[59]

Behavioral Management Needs

Individuals with difficult behaviors require specialized plans of care to maintain the well-being of the individual and others in their home environment. Behavioral assessments guide the development of these plans and include three levels of behavioral involvement:[60]

- Moderate - The individual exhibits problem behaviors that are disruptive, interfere with the carrying out of daily living activities, and cannot be ignored or easily redirected. These behaviors require direct intervention, usually in the form of a deceleration technique and/or psychotropic medication, in addition to procedures for teaching a more acceptable functional behavior.
- Severe - The individual exhibits problem behaviors that cause major disruption and threaten the health and safety of the individual, peers, or staff if allowed to continue. These behaviors are often not amenable to non-intrusive techniques and require more intense intervention to manage the situation.
- Profound - The individual exhibits problem behaviors that are of sufficient frequency and intensity such that the individual receives a "behavior bump" in his or her level-of-need or the individual's behavioral history is such that his or her initial commitment was under Chapter 46 of the state Code of Criminal Procedure or under Chapter 55 of the Family Code.

IV. Services and Supports

The services and supports available to individuals eligible for Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) are divided into three categories: Non-Medicaid services, entitlement services, and waiver services.

Non-Medicaid Services

Non-Medicaid services are supported entirely through state General Revenue (GR) funds. Unlike Medicaid programs, there is no federal funding match for these programs. Non-Medicaid services are provided through the local Mental Retardation Authorities (MRA's). The specific services provided by each MRA vary based on the priorities of each catchment area's population. Non-Medicaid services can be divided into two groups: Mental Retardation (MR) GR Services and In-Home Family Supports for Persons with Mental Retardation (IHFS-MR).[61]

Mental Retardation General Revenue Services
Most services offered through the MRA's are funded through state general revenue allocated to MR programs. These services are vital to the system of care because they act as a safety net, providing prevention and crisis services. They allow people to remain in their own home or a family home, avoiding institutional placement.

Eligibility

An individual is part of the priority population defined by DADS, and is, therefore, eligible for MR GR services if they meet one or more of the following five descriptions:

- A person with MR (defined by Health and Safety Code, §591.003);
- A person with a pervasive developmental disorder (defined in the latest edition of the Diagnostic and Statistical Manual);
- A person residing in a nursing home who is eligible for specialized MR services;
- A person with a related condition (RC) who is enrolling in ICF/MR, HCS, or TxHmL programs;
- A child who is eligible for ECI services.[62]

Array of Services

Prior to receiving services, an assessment is required and performed by the MRA's to determine individuals' eligibility prior to receiving services. An individual's IQ and adaptive behavior level (ABL) are assessed by a professional to establish functional eligibility.[63]

Service coordination is provided by an MRA staff person. This activity helps an individual improve quality of life and community participation by accessing and coordinating medical, social, educational, and other appropriate services.[64]

Community support services are personalized based on each consumer's person-directed plan. These supports can be provided in the client's home or in a community setting. The program offers activities focusing on an individual's ability to perform functional living skills. Family support services are also offered to prevent or limit out-of-home placement; transportation is provided to support an individual's participation in employment or community activities.[65]

Respite services are planned or emergency relief provided to an individual's unpaid caregiver on a short-term basis. MRA's claim to maintain that this is an important part of the safety net because it can prevent out-of-home placement by allowing caregivers to take a break. This service is provided by trained staff in an individual's home or in a facility setting.[66]

There are two programs that focus on paid, personalized, competitive employment in the community. The employment assistance program provides assistance locating an appropriate job. The supported employment program helps a person sustain a job once located.[67]

Day habilitation is intended to assist clients acquire, improve, or retain the necessary socialization and adaptive skills to participate in the community.[68]

Specialized therapies are provided by licensed professionals. The availability of specialized therapies through GR funding is limited and not offered by every MRA, but

can include psychology, nursing, social work, occupational therapy, speech therapy, physical therapy, dietary services, and certain behavioral services.[69]

Finally, limited residential services may be accessed using GR funding. Less than 50 individuals are currently receiving residential services using GR funding. Rider 19 directed Texas Department of MHMR to refinance all residential services for persons with MR eligible for Medicaid funding, through waiver programs or the ICF/MR program.[70] Because so few individuals are receiving residential services using GR funds, Rider 19 has little affect on DADS' operation. However, DADS will continue to submit a report to the Legislative Budget Board until all individuals no longer need these services.

In-Home Family Support for Persons with Mental Retardation (IHFS-MR)

IHFS-MR is meant to address an individual's short-term disability needs. This program is a grant program providing up to $2,500 annually to a rotating group of individuals eligible for these services. IHFS-MR is the resource of last resort; these funds are only used when another form of funding cannot be accessed.[71] This program is appropriated $5 million annually. [72]

Eligibility

To qualify for IHFS-MR four eligibility requirements (diagnosis, residency, financial and need) must be met.

- Diagnosis: An individual must have a diagnosis of MR, a pervasive developmental disorder, or qualify for ECI services.
- Residency: The consumer must reside in Texas, in their natural home (their own home or a family member's home).
- Financial: An individual receiving IHFS-MR services cannot have an income over 150% Texas median income. A co-pay is required for individuals making more than 105% Texas median income. The co-pay is based on a sliding scale related to family size and income.
- Need: The consumer may not be receiving funds through the IHFS for physical disability; may not be enrolled in a comprehensive support program such as a Medicaid waiver program; and must have a need that can be met through an item listed as allowable criteria with cost within statute, and not available through another support program.[73]

Array of Services

IHFS-MR offers a variety of services including respite care, specialized therapies, home care, counseling and training, special equipment, home modifications, and transportation.[74]

Medicaid Entitlement Services

Entitlement services include all programs and supports that have been written into the State Medicaid Plan. Because it is encompassed in the plan, the state cannot limit the number of people who enroll in the program. Every individual who meets the eligibility

requirements must be served. Medicaid (both state and federal funds) must pay for all services included in the State Medicaid Plan.[75]

To be eligible, an individual must meet both financial and functional requirements. Health and Human Services Commission is responsible for assessing financial eligibility; DADS contracts with MRA's to assess an individual's functional eligibility.[76]

Entitlement services include both community and residential programs. Community services including Primary Home Care (PHC), Community Attendant Services (CAS), Early Childhood Intervention(ECI) and Comprehensive Care Program(CCP) assist a person to remain in their natural home. Individuals in residential programs, including nursing facilities, hospice, and ICF/MR's, reside in facilities managed by either government agencies or private providers.

Primary Home Care (PHC)
PHC provides non-technical assistance to individuals whose disability limits their ability to perform activities of daily living (ADL). Individuals with disabilities as well as the elderly may enroll in this program. On average, a consumer receives about 16.6 hours of assistance per week. In Fiscal Year (FY) 2006, an average of 64,484 people received services per month at an average cost of $622.68 per client. In FY 2007, an average of 59,065 individuals were served at a monthly cost of $635.36.[77]

Eligibility
A person must meet five criteria to receive PHC services:

- Be at least 21 years of age;
- Have a monthly income of less than 100% the limit for Supplemental Security Income (SSI) ($637/month);
- Have countable resources less than $2,000;
- Have a functional assessment score of 24 or greater; and
- Have a statement from a professional documenting the medical condition causing functional limitations.[78]

Community Attendant Services (CAS)
CAS is similar to PHC; however, the clients served in CAS are ineligible for PHC because of the income requirements. CAS also provides non-technical assistance to individuals whose ability to perform ADL's has been impaired. Consumers receive approximately 16.4 hours of attendant services per week. In FY 2006, an average of 43,785 individuals were served a month at a cost of $609.69 per consumer. In FY 2007, an average of 42,089 people received services each costing $619.56 per month.[79]

Eligibility
CAS does not have any age restrictions. However, consumers must meet four requirements:

- Have a monthly income that is within 300% of the limit for SSI ($1,911/ month);
- Have countable resources less than $2,000;
- Have a functional assessment score of 24 or greater; and

- Have a statement from a professional documenting the medical condition causing functional limitations.[80]

Comprehensive Care Program (CCP)
CCP is an expanded portion of the Texas Health Steps Program (THSteps). THSteps is a program for children on Medicaid. It provides case management and regular dental and medical checkups. CCP covers services that are not ordinarily allowable under the Texas Medicaid Plan. Using CCP children under 21 years old are eligible for any medically necessary and appropriate health care service covered by Medicaid, regardless of the limitations of the state's Medicaid Program. Some of the services typically accessed using CCP include private duty nursing, augmentative communication devices, and treatment in psychiatric hospitals.[81]

Financial eligibility for CCP is determined based on parents' income. However, for children seeking Medicaid waiver services, financial eligibility is based on the income of the child. A child who would not be eligible for CCP due to their parents' income could be eligible for a waiver program based on their income. Once the child has enrolled in a waiver program, they are then automatically eligible for CCP because persons on a waiver program are eligible for Medicaid services. Of the 1,967 individuals enrolled in a waiver program and receiving CCP in FY 2006 and FY 2007, 1,153 enrolled in the waiver prior to receiving CCP and 814 people received CCP services prior to enrolling in a waiver.[82]

Early Childhood Intervention (ECI)
ECI offers services to families with children with disabilities and developmental delays. The program is intended to promote development and learning, provide support to families, coordinate services, and decrease the need for costly special programs. Services are provided throughout the state by a variety of local agencies.[83]

The program is funded through the Individuals with Disabilities Education Act (IDEA) using both state and federal funds. Some services are offered at no cost to the consumer or their family. Other services are provided on a sliding scale based on family size and income. No child or family is denied services due to an inability to pay.[84] In FY 2008, the total appropriation for ECI was $152,439,231 and 52,937 children were served.[85]

<u>Eligibility</u>
To receive ECI services a child must be under 3 years old and meet one of the following descriptions:

- A child delayed in one or more of the following areas of development: cognitive, motor, communication, social-emotional, or self-help skills;
- A child who may perform within their appropriate age range but whose patterns of development are different from their peers: atypical sensorimotor development, atypical language or cognition, or atypical emotional or social patterns; or
- A child who has a medically diagnosed condition with a high probability of developmental delays.[86]

Array of Service
ECI services include assistive technology (services and devices); audiology; developmental services; early identification, screening and assessment; family counseling; family education; medical services (diagnostic or evaluation services used to determine eligibility); nursing services; nutrition services; occupational therapy; physical therapy; psychological services; speech-language therapy; and vision services.[87]

Some services are provided at no cost regardless of the parent's income: evaluation and assessment; development of the Individual Family Service Plan (IFSP); service coordination; translation or interpretation services, if needed; services for children with auditory and visual impairments; and services for children in foster care or in conservatorship of the state.[88]

Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR's)
Residential programs are intended for individuals with a disability who cannot, or choose not to live in their own home. These programs include nursing facilities, hospice, and ICF/MR's. However, most individuals with MR and/or related condition (RC) seeking residential services through an entitlement program are placed in Medicaid ICF/MR's.

ICF/MR's are operated by both private companies (non-profit and for-profit) and public agencies (MRA's and DADS). Provision of active treatment is a central requirement of the ICF/MR program. Active treatment is required to include the aggressive, consistent implementation of health services, treatment and specialized training.[89]

In FY 2007, $130,547,839 GR funds ($332,775,526 all funds) and in FY 2008, $135,057,725 GR funds ($342,612,190 all funds) were allocated to the ICF/MR program. In FY 2007 an average of 6,624 people were served per month, decreasing to an average of 6,412 each month in FY 2008.[90]

There are two types of ICF/MR's: community-based ICF/MR's and State Mental Retardation Facilities.[91] The facilities range in size from four beds up to several hundred. Each provider may set specific criteria for admission into their facility. This provision helps protect the consumers' health and safety, ensuring that all residents are provided for appropriately.

Eligibility
To be eligible for placement in an ICF/MR, an individual must,

- Be in need of, and able to benefit from the active treatment provided in a 24-hour supervised facility;
- Be eligible for SSI or be determined to be financially eligible for Medicaid by HHSC; and
- Meet one of the following criteria:
    - Have an IQ score of 69 or below and an Adaptive Behavior Level (ABL) with mild to extreme deficits in adaptive behavior;

- Have an IQ score up to 75 and a primary diagnosis by a licensed physician of a RC and have an ABL with mild to extreme deficits in adaptive behavior; or
- Have a primary diagnosis of a RC regardless of IQ and have an ABL with moderate to extreme deficits in adaptive behavior.[92]

Array of Services

All ICF/MR facilities provide diagnosis, treatment, rehabilitation, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at their greatest ability.[93]

Community-Based ICF/MR's

Community-Based ICF/MR's include those managed by private providers and local MRA's. The consumers reside in group homes, which are divided based on size. Small homes have up to 8 beds. Medium ICF/MR's have between 9 and 13 beds, and large group homes have 14 or more beds.[94]

As of September 2008, there were 778 small community-based ICF/MR's serving 4,427 individuals. There were 4,692 certified beds in small group homes. Medium ICF/MR's accounted for 683 certified beds in 57 group homes serving 641 people. Finally, 18 large group homes served 1,254 individuals and had 1,592 certified beds.[95]

State Mental Retardation Facilities (SMRF's)

SMRF's are located across Texas and include 11 state schools and 2 state centers. Each facility serves between 100 and 600 individuals. These facilities differ from community-based ICF/MR's because they provide specialized services for persons with severe or profound MR, people with MR who are medically fragile, and people with MR who have maladaptive behaviors.

Department of Aging and Disability Services provides oversight for all of the facilities with the exception of the Rio Grande State Center. It is operated by Department of State Health Services because the facility also serves individuals with a primary diagnosis of a mental illness.[96]

SMRF's were allocated a total of $422,357,147 in FY 2006 and $458,397,793 in FY 2007. The average annual cost to serve an individual was $89,728 in FY 2006 and $93,838 in FY 2007. As of September 2008, SMRF's had 5,985 certified beds, 4,869 funded beds, and 4,817 occupied beds.[97] The number of certified beds is the maximum number of individuals DADS Regulatory Services has licensed each facility to serve. Funded beds are those with financial resources attached to them and occupied beds are those being used by residents.

All SMRF residents have an Interdisciplinary Team (IDT) meeting annually. It is used to assess an individual's needs for treatment, habilitation, and training. The IDT is also used to make recommendations for services including whether the individual is best served in

the community or in a facility. The individual; the individual's Legally Authorized Representative (LAR), if any; and persons specified by the MRA and SMRF are always included in the team. A LAR is a person authorized by law to act on behalf of an individual. A LAR can be a parent, guardian, or managing conservator of a minor. [98] The IDT may also include other concerned persons requested by the individual or the LAR; persons directly related to service provision; and representatives from the school district, if the individual is 21 or younger and is eligible for public school. If the IDT does not reach a consensus, the individual's situation is reviewed by the head of the SMRF and by the ombudsman in DADS' State Office.[99]

All SMRF residents also go through the Community Living Options Information Process (CLOIP) annually. DADS has contracted with the 13 MRA's with a SMRF in their area to provide this service. A representative from the MRA provides the resident and their family or LAR with information about every available community living option. The outcome of each CLOIP meeting is then discussed at the individual's IDT meeting.[100]

Waiver Services

DADS oversees eight waiver programs, which provide community-based services and supports to individuals with MR in their own home or in a home-like setting. Most individuals eligible for ICF/MR services are also eligible for Medicaid waiver programs. Waiver services are provided by private companies as well as MRA's.[101] Several waiver programs including Community Based Alternatives (CBA), Deaf Blind Multiple Disabilities (DBMD), Medically Dependent Children Program (MDCP), and Consolidated Waiver Program (CWP) serve individuals with MR as well as individuals with other disabilities. It is impossible to know the number of people enrolled in each program with a diagnosis of MR and/or RC because DADS does not record that information. However, most individuals with a diagnosis of MR and/or RC are enrolled in either HSC or CLASS. These two programs account for 72% of all individuals on ICF/MR waiver program interest lists.

With waiver programs, the state is allowed the flexibility to limit scope of eligibility, geographical location, scope of services, amount of services, and number of people served. The state can determine the amount of resources allocated to each program. Unlike entitlement services in which everyone who is eligible must to be served, if there are not adequate resources to support all persons interested, people are served on a first-come, first-serve basis. Those who cannot be served immediately are placed on an interest list until a waiver slot becomes available. In addition, waiver funds can move with the person to any provider in any part of the state and offer consumers more choice regarding service provision.[102]

Many individuals receive services while on the interest list for waiver programs. Individuals may be enrolled in an entitlement program, receiving non-Medicaid services, or getting support from faith-based or non-profit organizations prior to receiving a waiver slot. During the 80th Regular Session, the Texas Legislature appropriated $71.5 million General Revenue and $167.3 million All Funds to expand waiver and non-Medicaid

services. An estimated 8,902 additional people will be served using these resources including 2,676 more HCS slots.[103]

Community Based Alternatives (CBA)
CBA was developed to offer individuals a community alternative to nursing facility placement. In FY 2006, 26,763 individuals were receiving CBA services at an average cost of $1,293.99 per month. In FY 2007, CBA was serving 26,783 individuals costing an average of $1,288.86 per month[104]. As of June 2008, there were 29,316 individuals on the CBA interest list. Those currently receiving a waiver slot have been on the interest list between 2 and 3 years.[105]

Eligibility
To qualify for CBA services, an individual must,

- Be 21 or older;
- Meet medical necessity for nursing facility admission;
- Have a monthly income within 300% of the SSI limit ($1,911/ month);
- Have countable resources less than $2,000; and
- Have an Individual Service Plan (ISP) that does not exceed 200% of the reimbursement rate that would have been paid for that same individual to receive services in a nursing facility[106].

Array of Services
A range of services are offered through CBA including case management, adaptive aids, medical supplies, dental services, adult foster care, assisted living, emergency response, nursing, minor home modifications, occupational therapy, personal assistance, consumer-directed services, home delivered meals, physical therapy, respite care, speech pathology, and transition assistance services.[107]

Home and Community-Based Services (HCS)
HCS provides services and supports to individuals in the community as an alternative to ICF/MR placement. HCS recipients may live in their own home, a family home, in a foster care/companion care setting, or in a group home with no more than four individuals who receive similar services.[108] Unlike the ICF/MR program, HCS is a zero-reject program. Providers may not set their own specific enrollment criteria. If a consumer picks a provider, the provider must establish appropriate services if they are not already available.

In FY 2007, 11,798 people received services costing $179,146,848 GR ($456,657,781 all funds). In FY 2008, $217,811,648 GR ($552,540,965 all funds) was allocated to HCS and the number served increased to 13,349. As of June 2008, 37,187 people were on the interest list for HCS. Individuals who received a waiver slot in FY 2008 were placed on the list between October 1998 and April 2000.[109]

Eligibility
To be eligible for HCS an individual must,

- Have a determination of MR or have been diagnosed by a physician as having a RC;
- Meet the ICF/MR Level of Care I or VIII criteria;
- Have countable resources less than $2,000; and
- Have an Individual Plan of Care (IPC) that does not exceed 200% of the reimbursement rate that would have been paid for that same individual to receive services in an ICF/MR, or 200% of the estimated annualized per capita cost for ICF/MR services, whichever is greater.[110]

Array of Services

The HCS program offers case management, residential assistance, supported employment, day habilitation, respite, dental treatment, adaptive aids, minor home modifications, social work, psychology, occupational therapy, physical therapy, audiology, speech/language pathology, dietary services, and licensed nursing services. HCS funds can also be used to pay for the residential setting in which the HCS individual resides.[111]

Community Living Assistance and Support Services (CLASS)

CLASS provides services for individuals with a RC as an alternative to placement in an ICF/MR. People enrolled in this program reside in their natural homes. In FY 2007, 3,052 individuals were receiving CLASS with a total annual cost of $40,197,865 GR ($102,467,156 all funds). The number enrolled increased in FY 2008 to 3,901. The funds allocated increased to $54,877,244 GR ($139,211,679 all funds). In June 2008, there were 21,496 people on the CLASS interest list.[112] In 2008, individuals who had been placed on the interest list between November 2001 and June 2002 were given a waiver slot.[113]

Eligibility

An individual can start receiving CLASS at any age; however, they must meet several eligibility requirements:

- Have a RC prior to 22 years of age that requires habilitation and case management services;
- Have a monthly income that is within 300% of the monthly SSI limit ($1,911/month);
- Have countable resources less than $2,000; and
- Have an ISP that does not exceed 200% of the estimated annualized per capita cost of providing services in an ICF/MR to an individual qualifying for a Level of Care I or VIII.[114]

Array of Services

CLASS services include adaptive aids and medical supplies, case management, consumer-directed services, habilitation, minor home modifications, nursing services, occupational and physical therapy, psychological services, respite, specialized therapies, speech pathology, and transition assistance.[115]

Deaf Blind Multiple Disabilities (DBMD)
DBMD provides services and supports to individuals with deaf blindness and at least one other disability. The program is a community alternative to residing in an ICF/MR. Waiver recipients are able to reside in their own home, a family home, or a small group home.[116]

In FY 2007 and FY 2008, 138 individuals were receiving DBMD services. In FY 2007, DBMD cost $2,455,322 GR ($6,258,787 all funds). The costs increased in FY 2008 to $2,562,472 GR ($6,500,437 all funds). In June 2008, 28 individuals were on the interest list for DBMD.[117] Individuals receiving a waiver slot in FY 2008 were placed on the list between January 2007 and June 2008.[118]

Eligibility
To receive DBMD services an individual must meet the following requirements:

- Be 18 years of age or older;
- Have deaf blindness with one or more other disabilities that impair independent functioning;
- Have a monthly income within 300% of the monthly income limit for SSI ($1,911/month);
- Have countable resources less than $2,000; and
- Have an ISP that does not exceed 200% of the estimated annualized per capita cost of providing services in an ICF/MR to an individual qualifying for Level of Care VIII.[119]

Array of Services
Services offered through DBMD include adaptive aides and medical supplies; dental services; assisted living; behavioral support services; case management; chore provider; minor home modifications; residential habilitation; day habilitation; intervener; nursing services; occupational therapy; physical therapy; orientation and mobility; respite; speech, hearing and language therapy; dietary services; for the consumer-directed services option financial management is provided; and transition assistance.[120]

Medically Dependent Children Program (MDCP)
MDCP provides services to children in the community as an alternative to nursing facility placement. In FY 2006, 959 children were receiving MDCP at an average cost of $1,306.71 per month per child. In FY 2007, enrollment increased to 1,508 consumers each costing an average of $1,185.31 per month.[121] In June 2008, 9,920 children were interested in MDCP services. None of those individuals have been on the list more than 3 years.[122]

Eligibility
To be eligible a child must,

- Be under 21 years old;
- Meet medical necessity requirements for nursing facility admission;
- Have a monthly income within 300% of the limit for SSI ($1,911/month);

- Have countable resources less than $2,000; and
- Have an IPC that does not exceed 50% of the reimbursement rate that would have been paid for that same individual to receive services in a nursing facility.[123]

Array of Services
MDCP services include adaptive aids, adjunct support services, financial management services, minor home modifications, respite, and transition assistance services.[124]

Consolidated Waiver Program (CWP)
In November 2001, CWP began as a pilot program in Bexar County. This waiver was offered to individuals on the interest lists for other waiver programs. Because CWP was intended to serve clients eligible for various waiver programs, it has a larger and more diverse array of services.

In August 2008, 182 people were enrolled in CWP. The total expenditures in FY 2008 were $4,138,377.[125] There is currently no interest list for CWP.

Eligibility
In order to receive CWP services an individual must,
- Reside in Bexar County;
- Be on the interest list in Bexar County for STAR+PLUS, HCS, CBA, CLASS, DBMD, or MDCP waiver services;
- Have a monthly income within 300% SSI limit ($1,911/month);
- Have countable resources under $2,000; and
- Have an ISP that does not exceed 200% of the reimbursement rate that would have been paid for that individual to receive services in a nursing facility or an ICF/MR.[126]

Array of Services
A range of services are offered through the CWP: adaptive aids and medical supplies, adult foster care, assisted living/residential care, audiology, behavior supports, communication supports, child support services, dental services, dietary services, emergency response services, family surrogate services, habilitation, home delivered meals, independent advocacy, intervener services, minor home modifications, nursing services, orientation and mobility services, personal assistance services, transportation, psychological services, respite, social work, physical and occupational therapy, speech and language pathology, and transition assistance.[127]

Texas Home Living (TxHmL)
TxHmL is intended to be a community alternative for individuals eligible for ICF/MR placement who only need limited services. Unlike other waiver programs, the local MRA's provide coordination and case management for clients on TxHmL. In FY 2007, 1,404 individuals were receiving TxHmL waiver services costing $3,026,121 GR ($7,713,792 all funds). In FY 2008, the number enrolled decreased to 1,279. However,

the costs increased to $3,509,822 GR ($8,903,657 all funds). There is no interest list for TxHmL; every person interested is either currently being assessed for eligibility or is already receiving services.

Eligibility

An individual must meet five eligibility requirements to enroll in the program:

- Have a determination of MR;
- Live in their own home or a family home;
- Be Medicaid eligible;
- Meet ICF/MR Level of Care I requirements; and
- Have an ISP that does not exceed $13,000.[128]

Array of Services

The services provided through TxHmL are divided into two categories. Community Living Services are community support, day habilitation, employment assistance, supported employment, and respite services. Technical and Professional Supports include skilled nursing, behavioral support, adaptive aids, minor home modifications, dental treatment, and various specialized therapies.[129]

V. Residential Facilities

Intermediate Care Facility for Persons with Mental Retardation (ICF/MR)

An ICF/MR is a long-term residential facility serving four or more individuals with mental retardation or a related condition. Texas Health and Safety Code §252.002 (4), defines a "facility" as "a home or an establishment that: (a) furnishes food, shelter, and treatment or services to four or more persons unrelated to the owner; (b) is primarily for the diagnosis, treatment, or rehabilitation of persons with mental retardation or related conditions; and (c) provides in a protected setting continuous evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each resident function at the resident's greatest ability." These services are provided in two settings: community facilities and State Mental Retardation Facilities (SMRF's).[130] As of November 2008 there were 10,905 individuals residing in ICF/MR's in Texas.[131]

ICF/MR's are Medicaid benefit certified and funded under §1905(d) of the Social Security Act. Both private and public organizations operate ICF/MR's. All facilities must be in compliance with state and federal standards, laws, and regulations.[132] DADS is responsible for licensing all privately owned facilities. State-owned and other facilities serving Medicaid recipients must be certified by the Centers for Medicare and Medicaid Services.[133] In FY 2008, 748 private providers held 6,249 certified beds, 98 public providers (Community MHMR Centers) held 678 certified beds, and there were an additional 20 state-owned facilities including state schools and centers with a total of 6,025 certified beds.[134]

The main requirement for certification as an ICF/MR is the provision of active treatment. Active treatment is the aggressive and organized implementation of specialized and generic training, treatment and health services to individuals who are not able to function without consistent supervision or in the absence of such a program.[135] Examples of services provided to ICF/MR residents include nursing and prescriptions, habilitation, skills training, speech, occupational and physical therapies, adaptive aids, and 24-hour supervision and support.[136] Individuals in an ICF/MR also have an Interdisciplinary Team (IDT) that meets annually to assess his or her service needs. The IDT is comprised of the individual, persons and professionals involved in their treatment, a legally authorized representative or guardian (if available), active family members, advocates and/or persons whose presence is requested by the individual receiving services.

ICF/MR's are categorized by size according to the number of certified beds they operate. Large facilities are those with 14 or more beds. Medium facilities have nine to 13 beds. Small facilities have eight or fewer beds.[137] The most common model is a six-bed facility. Although ICF/MR's may be as small as four beds the structure of the reimbursement rates for small community ICF/MR's is insufficient to support the operation of homes with fewer than six beds.[138] Statewide, in FY 2008, there were 778 small ICF/MR's in operation, 57 medium ICF/MR's, and 31 large ICF/MR's (including the 13 state schools and centers).

FY 2008 numbers show a decline in the number of operational ICF/MR facilities of all sizes over the past few years.[139] Since FY 1999, the average number of individuals served in an ICF setting has decreased by 16%,[140] and since FY 2002 separations from SMRF's have exceeded admissions.[141] Meanwhile, the average number of HCS recipients has more than doubled.[142] As the number of community alternatives increases, demand for ICF/MR's, especially state school services, is expected to continue to decrease.[143] Under the administration of the Texas Department of Mental Health and Mental Retardation, the authorization of new medium and large ICF/MR's was phased out and this policy remains in effect under DADS.[144] The Texas Department of Mental Health and Mental Retardation was the provider of community mental health and mental retardation services until 2003 when HB 2292 consolidated its 12 health and human service agencies into five departments: Health and Human Services Commission, Department of Aging and Disability Services, Department of Assistive and Rehabilitative Services, Department of Family and Protective Services, and the Department of State Health Services.[145]

Among the 6,967 certified community ICF/MR beds (all privately and publicly owned, but not located at a State School or Center) available in FY 2008, there were 645 (9%) vacancies statewide.[146] MRA staff who met with the Committee attributed the openings to people's preference to receive general revenue services in their own homes with GR services until their HCS slot is available. However, there are regional variations, with some facilities in certain MRA
service areas not having sufficient openings to meet demand, and others having had open beds for periods of up to one year.

Providers may set their own criteria for admission to their facilities, and are not required to accept new applicants unless they can ensure the health, safety, and appropriate provision of services to all residents.[147] Providers may also eject an individual from an ICF/MR at any time for the same reason.

Medicaid-eligible individuals who meet certain requirements have a federal entitlement to receive care in an ICF/MR.[148] Individuals living in ICF/MR's may have a diagnosis of mental retardation or other disabilities. Persons of any age may be served in an ICF/MR. To be eligible for placement in an ICF/MR, an individual must:

- Be in need of, and able to benefit from the active treatment provided in a 24-hour supervised facility;
- Be eligible for SSI or be determined to be financially eligible for Medicaid by HHSC; and
- Meet one of the following criteria:
    - Have an IQ score of 69 or below and an adaptive behavior level with mild to extreme deficits in adaptive behavior;
    - Have an IQ score up to 75 and a primary diagnosis by a licensed physician of a RC and have an adaptive behavior level with mild to extreme deficits in adaptive behavior; or
    - Have a primary diagnosis of a related condition regardless of IQ and have an adaptive behavior level with moderate to extreme deficits in adaptive behavior[149].

In FY 2007, an average of 6,608 persons per month were served in community ICF/MR's,[150] at an average monthly cost of $4,096 per eligible consumer.[151] As of August 2008 there were a total of 6,431 individuals living in community ICF/MR's. Seventy percent (4,505) living in small facilities.[152] FY 2008 expenditures for community ICF/MR's totaled $342.6 million (all funds).[153]

The typical six bed facility is a three to four bedroom home. Individuals can personalize their rooms with furniture, décor, choice of paint color, and personal items such as posters, televisions, stereos, movies and CDs. More independent residents are able to make purchases with money earned at their place of employment, and may come and go as they please.

Medium ICF/MR's are limited in number. The structures are generally modified 5 to 6 bedroom homes, or were built specifically to house 9 to 13 people in a dormitory-like facility. Rooms are typically shared, but individuals can choose to decorate according to their preference.

Within the guidelines of ICF/MR regulations, individuals in small and medium facilities are able to participate in community activities such as attending dances at community centers, cultural events, trips to the library and places of worship. ICF/MR regulations specify menu plans, but residents take part in grocery shopping, and choosing from available menu options. Most homes also reserve one night of the week for residents to dine out. Direct care staff in these facilities range from young, untrained workers to

those with many years of experience and dedication to the population; most earn minimum wage with no benefits. ICF/MR's that are not directly operated by DADS are visited by DADS staff once a year to ensure compliance with ICF/MR regulations. If a private provider operates a large number of facilities DADS may elect to visit only a random sample of that provider's homes.

Structures for large ICF/MR's vary widely from resembling a hospital with wings set around nursing stations and dining halls to a high rise apartment complex. Daily activities and schedules, while established within ICF/MR regulations, are also variable.

Given the composition of the population, the regulations outlined by ICF/MR put in place a system of support for individuals who require greater assistance in the activities of daily living. While individuals with higher levels of ability may not need additional supervision to ensure their health and safety it is instrumental in the success of individuals with a higher level of need.

Conditions across the numerous ICF/MR facilities toured by the Committee varied greatly. While most of the facilities provide quality living arrangements some were clearly sub-standard. The lack of consistent oversight by DADS and self-investigatory authority of private providers are of particular concern. Ultimately, the quality of life for individuals residing in an ICF/MR of any size depends on the staff at that individual home and the guiding principles and philosophy of the provider.

Group Homes through Home and Community-Based Services (HCS)

One of the living options for individuals receiving HCS services is a small group home setting of no more than four individuals. If an individual receiving HCS services chooses a group home living option their provider of choice must make a home available to them. As of July 2008, 4,534 individuals (32% of all HCS recipients) are receiving long-term residential services in a group home for HCS recipients at an average monthly cost of $4,389 per person[154] ($1,730 state funds, $2,659 federal funds).[155] The group homes are operated according to HCS principles and regulations established by DADS in compliance with CMS; DADS regulatory visits the home once per year to inspect for adherence to licensing and regulation guidelines established by DADS and CMS. If a provider operates more than one home DADS may elect to visit only a randomly selected sample of the provider's homes.

HCS is often touted as offering a superior group home model to ICF/MR's because of its wide service array, smaller setting, and comparatively few regulations regarding the daily activities of residents. The Committee visited several group homes for HCS recipients and found that in physical appearance they are indistinguishable from small ICF/MR's. According to their preference, residents may have their own room, personalized to their liking, or choose to live with a roommate. Those who are capable may come and go as they like. Individuals residing in a group home for HCS recipients have more freedom of choice regarding their daily activities, and staff are responsible in encouraging residents to make healthy choices. Direct care staff in these group homes, just as in ICF/MR's,

range from young and inexperienced to those with a great deal of experience and dedication to working with individuals with developmental disabilities; most make minimum wage with no benefits.

As with ICF/MR facilities, conditions across the numerous HCS facilities toured by the Committee varied greatly; while most provide clean, safe living environments, some were sub-standard. Consistent oversight by DADS coupled with quality providers that employ well-trained staff ensure the well being of individuals residing in a group home for HCS recipients.

Foster/Companion Care

A foster or companion care option is a component unique to the HCS waiver program service array that allows individuals to receive services in a private residence. Individuals who choose HCS foster care services receive care from a single direct care giver (eliminating the need for shift staff) who is reimbursed on a per diem basis according to the individual's level of need. The direct care giver may be a family member, or non-related party who contracts with a certified private provider organization. The direct care giver may or may not have guardianship of the HCS recipient.

HCS providers are expected to comply with HCS program principles and regulations, and DADS conducts at least one on-site review of the foster home per year.[156] The private provider organization moderates the HCS recipient's financial accounts, ensures that required services are provided, and oversees that adequate care and supports are being maintained in the home by the direct care giver. The duties of the direct care giver vary according to the individual's abilities, but include ensuring that basic needs are met on a daily basis; assisting as needed with daily living skills; monitoring medications, diet or treatments under the delegation of a nurse or other health care provider; and providing or securing transportation for the individual.

The presence of a steady caregiver in an actual home setting placed the foster care homes toured by the Committee among the better residential placements visited. This program allows family members to directly care for their relatives and loved ones in their own homes, or participate in the family activities of an unrelated caregiver. Strong bonds between caregivers and the HCS recipient may form because of the consistency of the relationship. Usually no more than two HCS recipients reside in the same foster home (although up to four are allowed) and as a result individuals are given more personalized attention. However, unless policies are put in place to increase oversight and monitoring of the foster care model, the number and wide distribution of those homes may allow for abuses of the system and/or the individuals living there.

State Mental Retardation Facilities (SMRF)

State Mental Retardation Facilities, including 11 state schools and two state centers, provide 24-hour direct services and supports to developmentally disabled individuals

seeking residential placement. Each SMRF is a certified ICF/MR. Operating funds for the facilities are approximately 60% federal dollars and 40% State General Revenue or third-party sources.[157] In FY 2007 expenditures for the SMRF system totaled $458.4 million all funds ($243.5 million federal dollars, $171.5 million General Revenue, and $27.2 million in other funds) to serve an average of 4,909 persons per month.[158] State schools are located in Abilene, Austin, Brenham, Corpus Christi, Denton, Lubbock, Lufkin, Mexia, Richmond, San Angelo, and San Antonio. The state centers are located in El Paso and Harlingen.

The SMRF service array includes health care services (physician, nursing, and dental); behavioral treatment services; skills training and vocational programs; and occupational, physical, and speech therapies.[159] Vocational programs overwhelmingly include contract work with companies to assemble or package products, fold and sort shop rags or linens, secure labels, shred or tear paper, and pack items for transfer. Workers are paid piecemeal or at a rate established by a time study of what the average worker produces. Additionally, some facilities include creative outlets for the production of craft products that also generate income for the individual.

Forty-nine percent of the individuals residing in SMRF's in 2008 have lived there for 20 years or more; thirteen percent have lived in a state facility for 40 years or more. Since FY 2002 the number of separations from SMRF's has exceeded admissions. There were 254 new admissions to state schools/centers in FY 2007, and 294 separations including 118 transfers to a community placement, 140 deaths and 36 discharges. Discharges refer to separations due to the individual moving to another facility out of state, release of individuals found competent to stand trial or fit to proceed, and leaving after a temporary emergency admission.[160] Of the total 1,083 people who have moved out of a SMRF since FY 2000, 95% moved to the HCS waiver program, 2.5% moved to a community ICF/MR, and 2.5% moved to another setting such as nursing home, family residence, or another waiver service.[161]

The majority (73% in FY 2007) of SMRF residents are individuals with severe and profound levels of intellectual and developmental disabilities, and roughly half (53% in FY 2007) have behavioral management needs in the moderate, severe, or profound ranges.[162] In February 2007, 58% of the SMRF population had a Level of Need (LON) score of 8, 6, or 9.[163] As previously discussed in the Level of Need section, a LON 8, 6, or 9 are among the highest levels of need, with some individuals needing constant supervision and support.

In June 2008, 35% of SMRF residents were considered medically fragile, having moderate to severe health needs;[164] and in FY 2007 20% of the individuals in the facilities required 24-hour nursing services.[165] Twelve percent of state facility residents require enteral feeding tubes. Individuals who are non-ambulatory account for 31.6% of the SMRF population.[166]

Over three quarters (78% in June 2008) of the SMRF population is age 35 and older; 26% in June 2008 were age 55 and older. Residents age 0-21 made up 7% of the total

population as of June 2008[167], but also represent the fastest growing segment. Of the 251 new admissions to SMRF's in FY 2007 there were 111 (44%) under age 18[168]. Fifty-seven SMRF residents have been admitted under Chapter 55 of the Family Code.[169] Chapter 55, Family Code admissions are explained in detail below in the Involuntary Family Code Evaluation section.

Occurrences of dual diagnoses are also notable. As of June of FY 2008 there were 2,850 (59%) SMRF residents dually diagnosed with mental retardation and a mental health issue. Level of need assessments over the past six years indicate new SMRF residents are increasingly admitted at a lower intensity of service need than in previous years. This trend illustrates the rising admission of residents based on their significant behavioral challenges and co-occurring mental illness rather than more severe medical problems that require constant support across environments.[170] Fifty-two percent of SMRF residents in June 2008 were taking psychotropic medications,[171] and in FY 2007 62% of residents participated in a behavioral management plan.[172] In FY 2007 nearly a quarter (24%) of individuals committed to a SMRF through a regular involuntary admission were admitted on discharge from a state hospital, equal to 18% of all new admissions for that year.[173]

The 2008-2009 General Appropriations Act of the 80th Legislature provided $1.04 billion (all funds) for SMRF's in the 2008-09 biennium. This amount includes the funding necessary for DADS to enact a hiring project that will meet the national staffing quotient by adding an additional 1,690 full-time employees (FTEs) with emphasis on hiring medical and direct care staff.[174] A large proportion of the unfilled non-direct care staff positions are in the field of nursing. Although the 2008-2009 General Appropriations Act included an increase of 650 nurse positions to be filled during the biennium, a nationwide shortage of nurses in combination with the SMRF's inability to offer a competitive wage has made filling these vacancies difficult.[175]

Additional costs for SMRF operations include maintenance of the buildings.[176] The physical structures of the buildings are in need of repair and renovation. In order to replace capital items such as roofs, bedrooms, and living rooms and maintain compliance with the Life Safety Code DADS received $39.8 million in general obligation bonds. Projected costs for maintaining the buildings in their current condition through 2013 total $439.6 million, of which 55.4% will go toward maintaining resident use and sleeping areas, with the rest going toward administration buildings, support buildings such as warehouses and central kitchens, and site buildings such as gutters and sewers.[177]

For each SMRF, occupancy and capacity can be discussed on three levels: current enrollment, funded capacity, and ICF/MR certified capacity.[178] Current enrollment is the total population of residents in a facility at any given time including those assigned to certified and non-certified beds. Funded capacity is the number of beds for which the facility actually receives funding, ideally this number is equal to the current enrollment. ICF/MR certified capacity is the maximum number of beds a facility is authorized to operate as established by DADS. Currently, only 4,869 (81%) of the 5,985 certified ICF/MR beds in SMRF's are funded. Most SMRF's have an average enrollment at or

near their funded capacity, but the two facilities in Mexia and San Angelo are frequently at an enrollment above funded capacity.

Admission Categories and Criteria

Residential services in state schools and state centers are intended to serve individuals with severe or profound mental retardation and those individuals with a diagnosis of mental retardation who are also medically fragile or who have behavioral problems.[179] New admissions to state facilities are conducted under these guidelines, but some previously admitted residents may function at a higher level and may not display medical or behavioral complications.

The Persons with Mental Retardation Act (PMRA)(THSC, Title 7, Chapter 593) requires that four mandatory admission criteria be confirmed by an Interdisciplinary Team established by the individual's local MRA. The findings of the IDT must be submitted in a report to the county court or SMRF superintendent. The report must show that (1) the individual has a diagnosis of mental retardation; (2) the IDT has found that because of mental retardation the individual represents a substantial risk of physical impairment or injury to self or others, or is unable to provide for and is not providing for the adult's most basic personal needs; (3) the individual cannot be adequately and appropriately habilitated in an available, less restrictive setting; and (4) the state facility provides habilitative services, care training and treatment appropriate to the adult's needs. In this case, "a substantial risk of physical impairment or injury to self or others" or "is unable to provide for and is not providing for the adult's most basic personal physical needs" is represented by an IQ in the severe or profound range of mental retardation; an ICAP service level from 1 to 4, or 5 or 6 with either medical needs requiring direct nursing treatment for at least 180 minutes per week, or exhibition of dangerous behavior that requires intensive staff intervention and resources to prevent injury to self or others; or another objective measure determined by the department.[180]

Admission to a SMRF may take place under voluntary or involuntary circumstances; all involuntary admissions require a court commitment. There are three types of voluntary admission and four involuntary admission types:[181]

Voluntary Respite: This service is offered to provide temporary rest, relief and/or assistance to an individual, or his or her family. During a voluntary respite admission the individual is placed in the SMRF for a time period not to exceed 30 days. If needed, one additional 30-day extension may be granted. This type of admission requires the consent of the individual (if he or she is determined capable of giving legally adequate consent), or the consent of the individual's guardian, or parent in the case of a minor.[182] There were 41 voluntary respite admissions to a SMRF in FY 2007.[183]

Voluntary Emergency: An individual who has an urgent need for services may be admitted to a SMRF under voluntary emergency status for a time period not to exceed 12 months. This type of admission requires the consent of the individual (if he or she is determined capable of giving legally adequate consent), or the consent of the individual's

guardian, or parent in the case of a minor.[184] There were 5 voluntary emergency admissions to a SMRF in FY 2007.[185]

Voluntary Regular: This is a long-term placement option for an adult individual who requires habilitative services, on-going care, training, and treatment. Voluntary regular admission requires that the *adult individual* provide legally adequate consent. If an individual chooses to pursue voluntary regular placement in a SMRF their MRA will determine their eligibility and submit an application packet to the facility that serves the individual's home county. In accordance with Texas Health and Safety Code §593.003, 593.013, and 593.026 a person may only be admitted to a state facility under a regular voluntary admission if they have been determined to meet the mandatory admission criteria set out in the Persons with Mental Retardation Act, and the MRA has created an IDT report recommending the placement within the six months preceding the request.[186] If the eligibility criteria are met, the department determines if space is available in the facility servicing the individual's county of residence, and the facility superintendent determines that the facility provides services that meet the needs of the adult, the individual may be admitted. If no appropriate vacancy exists in the facility serving that individual's home county, the superintendent notifies DADS who will determine the availability of a matching vacancy at another facility.[187]

Effective January 1, 2001 SMRF's do not permit the regular voluntary admission of a minor.[188] The most recent regular voluntary admission to a SMRF was in FY 2002.[189]

Involuntary Regular: Under the Persons with Mental Retardation Act, an individual may be committed to long-term placement in a state facility if living at home is not possible.[190] Specifically, "a person must be admitted in accordance with basic due process requirements, giving appropriate consideration to parental desires if possible. The person must be admitted to a facility that provides habilitative training for the person's condition, that fosters the personal development of the person, and that enhances the person's ability to cope with the environment."[191] The guardian or parent (in the case of a minor) of a person with mental retardation, the court, or any other interested person may request an IDT report and recommendation for long-term placement in a residential care facility. The report must show that the IDT has determined that because of mental retardation the individual represents a substantial risk of physical impairment or injury to self or others, or is unable to provide for and is not providing for their most basic personal needs; cannot be adequately and appropriately habilitated in an available, less restrictive setting; and that the state facility provides habilitative services, care-training and treatment appropriate to the person's needs. The county court has original jurisdiction over all proceedings for involuntary commitment of a person with mental retardation to a state facility.[192]

There were 184 involuntary regular admissions to a SMRF in FY 2007; of these, 104 (57%) were admissions of individuals under age 22.[193]

Involuntary Criminal Code: In accordance with Chapter 46 of the Texas Code of Criminal Procedure, adults who meet eligibility criteria for admission to an ICF/MR and

who have been found incompetent to stand trial with no probability that the individual will gain competency to stand trial in the near future may be committed to a SMRF for long-term placement.[194] There were 16 involuntary criminal code admissions to a SMRF in FY 2007.[195]

Involuntary Criminal Code Evaluation: An adult may be admitted to a SMRF for a period of no more than 120 days in order to determine the competency of the individual to stand trial. The facility must provide treatment to the individual, determine through observation and evaluation whether the individual is competent to stand trial, and assess whether the individual meets SMRF commitment criteria. Once this information has been submitted in a report to the court and if, as a result of mental retardation, the individual is determined not competent to stand trial he or she may be committed to a SMRF for long-term placement.[196] There were 3 involuntary criminal code evaluation admissions to a SMRF in 2007.[197]

Involuntary Family Code Evaluation: Under Chapter 55 of Texas Family Code concerning judicial proceedings for youth with mental retardation or mental illness a minor may be admitted to a SMRF for a period of no more than 90 days to undergo an assessment of his or her ability to proceed. The facility must provide treatment to the individual, determine through observation and evaluation whether the individual is competent to stand trial, and assess whether the individual meets SMRF commitment criteria. This information is submitted in a report to the court. If the child is determined by the court to be unfit to proceed, and to meet eligibility criteria for placement in a SMRF then he or she may be committed to a SMRF for long-term placement.[198] There were 43 family code evaluation admissions in FY 2007.[199] Twenty-one of these evaluation admissions resulted in placement in the facility for an additional, indefinite period of time. As of August 2008, 3 of those 21 individuals had subsequently moved to a community setting.[200]

State Schools and Centers

Abilene State School

The Abilene State School service region includes the counties served by the Betty Hardwick MRA, Center for Life Resources MRA, and the Pecan Valley MHMR Region. The original physical plant was established in 1903 as an epileptic colony, but most of the structures were completed in 1943, just before the facility was repurposed in 1957 to care for individuals with mental retardation.[201] As of June 30, 2008 there were 511 residents at Abilene State School.[202]

Abilene State School provides intensive medical care in their infirmary, and maintains a special home for individuals with tracheostomy tubes. Of the total 137 SMRF residents with trachs 96 (70%) reside at Abilene State School.[203] The facility's OT/PT department creates a variety of custom communication books for individuals who have speech related issues. This service is also available to non-residents for a fee.

Direct care employees at Abilene State School have a 52% turnover rate, half of which leave during the initial 6-month probationary period.[204] As of August 2008 there were 55 vacant nursing positions, which had been unfilled for an average of 36 days.[205]

For Abilene State School the combined direct operating budget and "off the top" expenses such as worker's compensation, unemployment payments, and expenses associated with the Department of Justice, which are paid for by the State Office, but allocated to the individual facilities for cost reporting purposes, totaled $54.4 million in FY 2008.[206]

Austin State School

The Austin State School service region includes counties served by Austin-Travis County MHMR Center, Bluebonnet Trails Community MHMR Center, and the Hill Country MHMR Center. The facility, established in 1915 by House Bill 73, was the first specifically meant to house individuals with mental retardation. It opened its doors in 1925 and at its height housed over 2,000 residents.[207] As of June 30, 2008 there were 434 residents at Austin State School.[208]

Direct care employees at Austin State School have a 75% turnover rate, 58% of which leave during the initial 6-month probationary period.[209] As of August 2008 there were 61 vacant nursing positions, which had been unfilled for an average of 236 days.[210]

The combined direct operating budget and "off the top" expenses for Austin State School totaled $45.4 million in FY 2008. [211]

Brenham State School

The Brenham State School service region includes counties served by the MHMRA Brazos Valley and Tri-County MHMR Services. The facility opened in 1974 and was the first state school certified as an ICF/MR.[212] As of June 30, 2008 there were 385 residents at Brenham State School.[213]

Direct care employees at Brenham State School have a 44% turnover rate, 43% of which leave during the initial 6-month probationary period.[214] As of August 2008 there were 38 vacant nursing positions, which had been unfilled for an average of 206 days.[215]

The combined direct operating budget and "off the top" expenses for Brenham State School totaled $37.8 million in FY 2008. [216]

Corpus Christi State School

The Corpus Christi State School service region includes counties served by the Border Region MHMR Center, Coastal Plains Community MHMR Center, Gulf Bend MHMR Center, and MHMR Center of Nueces County. The facility opened in 1970 as an independent school district for youth with developmental disabilities. As of June 30, 2008 there were 356 residents at Corpus Christi State School. Twenty-seven of these individuals are adult alleged offenders, the third highest population of adult alleged offenders in a SMRF.[217]

Direct care employees at Corpus Christi State School have a 70% turnover rate, 62% of which leave within the initial 6-month probationary period.[218] As of August 2008 there were 15 vacant nursing positions, which had been unfilled for an average of 54 days.[219]

The combined direct operating budget and "off the top" expenses for Corpus Christi State School totaled $35.2 million in FY 2008. [220]

Denton State School
The Denton State School service region includes counties served by the Dallas MetroCare Services MRA, Denton County MHMR Center, Lakes Regional MHMR Center, LifePath Systems MRA, and MHMR Services of Texoma. The facility was opened in 1960 to serve persons with mental retardation.[221] As of June 30, 2008 there were 623 residents at Denton State School.[222]

Direct care employees at Denton State School have a 60% turnover rate, 56% of which leave within the initial 6-month probationary period.[223] As of August 2008 there were 77 vacant nursing positions, which had been unfilled for an average of 148 days.[224]

The combined direct operating budget and "off the top" expenses for Denton State School totaled $66.4 million in FY 2008. [225]

El Paso State Center
The El Paso State Center service region includes El Paso County, which is served by the El Paso Community MHMR center. The facility was opened in 1974 to provide residential services to individuals with both mental retardation and mental health issues.[226] As of June 30, 2008 there were 138 residents at El Paso State Center.[227]

Direct care employees at El Paso State Center have a turnover rate of 32%, 54% of which leave during the initial 6-month probationary period.[228] As of August 2008 there were nine vacant nursing positions, which had been unfilled for an average of 237 days.[229]

The combined direct operating budget and "off the top" expenses for El Paso State Center totaled $14.5 million in FY 2008. [230]

Lubbock State School
The Lubbock State School service region includes counties served by Central Plains MHMR Center, Helen Farabee Regional MHMR Centers, Lubbock Regional MHMR Center, and Texas Panhandle MHMR. The facility was opened in 1969.[231] As of June 30, 2008 there were 269 residents at Lubbock State School.[232]

Direct care employees at Lubbock State School have a 62% turnover rate, 50% of which leave during the initial 6-month probationary period.[233] As of August 2008 there were 31 vacant nursing positions, which had been unfilled for an average of 208 days.[234]

The combined direct operating budget and "off the top" expenses for Lubbock State School totaled $37.1 million in FY 2008. [235]

Lufkin State School
The Lufkin State School service region includes counties served by ACCESS MRA, Andrews Center, Burke Center, Northeast Texas MHMR Center, and Sabine Valley Center. The facility was opened in 1962 on the site of a former Air Force radar base.[236] As of June 30, 2008 there were 426 residents at Lufkin State School.[237]

Direct care employees at Lufkin State School have a 38% turnover rate, 51% of which leave during the initial 6-month probationary period.[238] As of August 2008 there were 33 vacant nursing positions, which had been unfilled for an average of 173 days.[239]

The combined direct operating budget and "off the top" expenses for Lufkin State School totaled $39.3 million in FY 2008. [240]

Mexia State School
The Mexia State School service region includes counties served by Central Counties Center for MHMR Services, Heart of Texas Region MHMR Center, and MHMR of Tarrant County. The facility also provides specialized treatment units for the statewide residential placement of juveniles committed under Chapter 55 of the Texas Family Code and adult alleged offenders committed under Chapter 46 of the Texas Criminal Code. Originally opened in 1946 as a German POW camp, additional structures were completed in 1960.[241] As of June 30, 2008 there were 518 residents at Mexia State School.[242]

Mexia has the largest population of residents under age 22 due in large part to the number of Chapter 55 juveniles committed with severe behavioral problems. Thirty percent of all youth housed in a SMRF reside at Mexia State School and these youth constitute 21% of the facility's total population. It also houses the largest population of adult alleged offenders, 37 in total as of June 2008.

Some of the alleged offenders are housed in a locked home with a total of 40 non-certified beds, which are supported solely by GR dollars at a daily rate of $381.26 ($5.6 million per year). The decision as to whether the beds in a locked home can be certified to receive Medicaid dollars seems to be at the discretion of the CMS regional offices; some states have been able to achieve certification for locked facilities. The combined direct operating budget and "off the top" expenses for Mexia State School totaled $57.2 million in FY 2008. [243]

New admissions to Mexia State School illuminate the rising trend of youth commitments to state facilities. In FY 2007, Mexia State School had nearly twice as many new admissions as any other facility, and 78% of these individuals were under age 18; and by June of FY 2008 the number of new admissions was nearly three times that of any other SMRF in the state, 63% of these individuals were under age 18.[244]

Nearly three quarters of the Mexia State School population is dually diagnosed with a comorbid mental heath issue.[245]

Direct care employees at Mexia State School have a 49% turnover rate, 46% of which leave during the initial 6-month probationary period.[246] As of August 2008 there were 41 vacant nursing positions, which had been unfilled for an average of 252 days.[247]

Due to the steady influx of residents from the court system Mexia is operating at an enrollment above its funded capacity.

Richmond State School

The Richmond State School service region encompasses one quarter of the population of the state of Texas and includes counties served by MHMRA of Harris County, Spindletop MHMR Services, the Gulf Coast Center, and Texana MHMR Center. The facility opened in 1968.[248] As of June 30, 2008 there were 494 residents at Richmond State School.[249]

Direct care employees at Richmond State School have the lowest turnover rate of all the SMRF's at 27%, with 27% leaving during the initial 6-month probationary period. They also have the highest retention rate with 37% staying three years or more.[250] As of August 2008 there were 58 vacant nursing positions, which had been unfilled for an average of 241 days.[251]

The combined direct operating budget and "off the top" expenses for Richmond State School totaled $54.8 million in FY 2008. [252]

Rio Grande State Center

The Rio Grande State Center is operated as a mental health facility by the Department of State Health Services. DADS has contracted with DSHS to provide residential services to adult individuals with mental retardation.[253] It is the only facility to provide both a mental health or mental retardation program. The service region for the Center includes counties served by Tropical Texas Center for MHMR, and Coastal Plains MHMR. The facility opened as a mental health clinic in 1962 and moved to its present location at an abandoned Harlingen airbase hospital in 1963. Residential services for persons with mental retardation were added in 1972.[254] As of June 30, 2008 there were 75 residents at Rio Grande State Center.[255]

Direct care employees at Rio Grande State Center have a 2.1% turnover rate, 58% of which leave during the initial 6-months of employment. In FY 2008 there were 2.3 vacant nursing positions, which had been unfilled for an average of 95 days.[256]
The combined direct operating budget and "off the top" expenses for Rio Grande State Center totaled $8.2 million in FY 2008. [257]

San Angelo State School

The San Angelo State School service region includes counties served by MHMR Services for the Concho Valley, Permian Basin Community Centers for MHMR, and West Texas

Centers for MHMR. The facility was opened in 1912 as a tuberculosis colony and served in this capacity until 1969 when the Legislature changed its function to provide residential services to individuals with mental retardation.[258] As of June 30, 2008 there were 300 residents at San Angelo State School.

As of June 2008, 87% of San Angelo State School residents were dually diagnosed.[259] The facility also houses the second largest population of adult alleged offenders, which account for 12% of the total number of residents.[260] Many of these individuals are served by the Specialized Treatment and Consultation Services (STACS) program developed at San Angelo State School to provide dually-diagnosed persons with severe behavioral challenges the supports needed to remain in less restrictive living environments. A newer program model, The Success Center, focuses on psychosocial rehabilitation of residents with dual diagnoses. The Success Center teaches skills for community living, achievement of personal fulfillment, and cognitive-behavioral therapies.[261]

San Angelo State School also includes a unique specialized treatment center specifically for female adolescents between ages 11 and 18 who have been committed to the facility under Texas Family Code, Chapter 55. The girls in this program are involved in on-site classroom education, daily living skills training, vocational and pre-vocational workshops, and counseling.[262]

Direct care employees at San Angelo State School have a 67% turnover rate, 60% of which leave during the initial 6-month probationary period.[263] As of August 2008 there were 23 vacant nursing positions, which had been unfilled for an average of 155 days.

Due to the steady influx of residents from the court system San Angelo State School is operating at an enrollment above its funded capacity. The combined direct operating budget and "off the top" expenses for San Angelo State School totaled $32.5 million in FY 2008. [264]

San Antonio State School

The San Antonio State School service region includes counties served by Camino Real Community MHMR Center and the Center for Health Care Services. The facility opened in 1978.[265] As of June 30, 2008 there were 288 residents at San Antonio State School.[266]

Direct care employees at San Antonio State School have a 75% turnover rate, 67% of which leave within the initial 6-month probationary period.[267] As of August 2008 there were 14 vacant nursing positions, which had been unfilled for an average of 190 days.[268]

The combined direct operating budget and "off the top" expenses for San Antonio State School totaled $30.4 million in FY 2008. [269]

In tours of the 13 SMRF's the Committee found the facilities to be largely outdated. Many were originally built for a purpose other than housing persons with developmental disabilities, and due to their age the costs of maintaining the physical plant are high. Most SMRF dormitories have floor plans similar to hospital layouts that are not

conducive to creating a home-like environment. Residents share a room with at least one other person, but often four or more individuals are assigned to one bedroom, and only in rare instances do people have the option of having their own room.

There continue to be shortages of full time employees, including nursing staff, and high turnover for direct care employees across the board. State school employees are often undertrained and overworked. Despite the many challenges of state school employment, the state school system has a group of employees who have dedicated many years of working tirelessly to meet the needs of the residents.

SMRF's provide excellent specialized services especially in fields such as orthotics and the production of customized wheelchairs; physical therapy; and occupational therapy. SMRF employees often possess a wealth of knowledge and experience regarding the particular needs of persons with developmental disabilities and are expert in finding ways to meet those needs.

VI. Quality Assurance

Two agencies within the Texas health and human services system of care serve regulatory and investigatory roles for long-term care facilities. Both the Department of Aging and Disability Services (DADS) and the Department of Family and Protective Services (DFPS) have responsibilities relating to ensuring the health and safety of facility residents.

DADS has two divisions with quality assurance responsibilities. DADS' Quality Assurance and Improvement unit has undertaken several projects and initiatives intended to improve service provision. DADS Regulatory Services division regulates facilities and is able to apply sanctions when appropriate. The Regulatory Services division also has an investigatory role in some types of facilities.

DFPS is responsible for investigating abuse, neglect, and exploitation allegations in some types of facilities for individuals eligible for Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR).

Quality Assurance and Improvements Unit Projects

The Quality Assurance and Improvements Unit (QAI) is part of the Center for Policy and Innovation. The unit is under the direction of the DADS' deputy commissioner. QAI is involved in, or oversees multiple projects intended to improve the quality of services and support programs. They are currently engaged in five types of projects: innovations and best practices, quality programs, quality strategy, surveys, and web resources.[270]

Innovations and best practices projects involve using pilot programs to integrate evidence-based best practice frameworks into long-term care facilities. DADS provided funding to establish an Evidence-Based Best Practice Fall Prevention Collaborative pilot. The QAI is coordinating another pilot program with the Texas Tech University Health

Science Center to evaluate the use of electronic medical records in long-term care facilities.[271]

DADS manages two quality programs. The Quality Consulting Program is intended to improve positive outcomes for individuals in SMRF's, ICF/MR's, and assisted living facilities. It promotes the use of evidence-based best practices by making technical assistance available to providers. The Quality Monitoring Program promotes quality service provision rather than simply compliance with regulations. The program offers technical assistance in a collaborative format to nursing facility providers.[272]

The quality strategy is the Quality Management Plan, a working document intended to provide a framework for a strategy focusing on participant-centered desired outcomes.

Two surveys are conducted annually by QAI. The Nursing Facility Quality Review is a statewide assessment of the quality of life, quality of care, and satisfaction of nursing facility residents. The findings act as a record of quality improvements and provide statewide performance benchmarks. The Long-Term Services and Support Quality Review is a survey given to individuals either receiving services in DADS institutions or through a home and community-based program.[273]

The Quality Matters website makes information available to providers intended to improve the resident's quality of life. The resources on the website include presentations from DADS provider trainings, evidence based frameworks, and links to other resources. The Quality Reporting System (QRS) is a web-based tool that is intended to provide consumers with consistent, accessible, and convenient information about long-term care facilities. This tool allows individuals to make informed decisions regarding their choice of providers. QRS information is also available by phone.[274]

Regulatory and Investigatory Responsibilities

DADS and DFPS share the responsibilities of regulating providers and investigating allegations of abuse, neglect, or exploitation in long-term care settings for people with disabilities. The type of provider determines the agency that performs investigations. If any investigation is concluded with a confirmed allegation, DADS has the ability to apply sanctions. The sanctions available also depend on the type of provider.[275]

In community-based ICF/MR's operated by private providers, the facility must report any incidents to DADS. The facility is in charge of investigating any allegations; then, DADS Regulatory Services evaluates the thoroughness of the investigation. DADS Regulatory Services is also responsible for evaluating the facility's compliance with state licensure and federal certification standards.[276]

The sanctions that may be applied to private community-based ICF/MR's include contract cancellation, decertification, vendor hold, directed plan of correction, administrative penalties, civil penalties, license revocation or suspension, denial of license renewal, emergency suspension and closing order, and appointment of a trustee.[277]

Any allegations of abuse, neglect, or exploitation of residents of community-based ICF/MR's operated by Community Mental Health Mental Retardation (MHMR) Centers are investigated by DFPS. DADS is responsible for ensuring the facilities are compliant with federal regulations. These facilities may be sanctioned with contract cancellation, decertification, vendor hold, and directed plan of correction.[278]

DFPS investigates all allegations involving residents of State Mental Retardation Facilities (SMRF's). DADS Regulatory Services ensures the facilities are compliant with federal regulations. Sanctions applicable to SMRF's include contract cancellation, decertification, vendor hold, and directed plan of correction.[279]

Home and Community-Based Services (HCS) providers are investigated by DFPS any time there is an allegation of abuse, neglect, or exploitation. The sanctions that may be applied to HCS providers include decertification, vendor hold, and contract termination.

DFPS investigates allegations of abuse of individuals receiving services from Texas Home Living (TxHmL) providers. These facilities may be sanctioned with decertification or vendor hold if the allegations are confirmed.[280]

DFPS, DADS Regulatory Services, and law enforcement share the responsibilities of investigating Community Living Assistance and Support Services (CLASS) and Deaf Blind Multiple Disabilities (DBMD) providers licensed as Home and Community Support Service Agencies (HCSSA). DFPS investigates allegations where the alleged perpetrator is an employee and the consumer is an adult. DADS Regulatory Services investigates if the alleged perpetrator is an employee and the consumer is a child. If the alleged perpetrator is not an employee, DFPS or law enforcement investigates. These facilities may be sanctioned with decertification (if applicable), contract sanctions (if applicable), administrative penalties, license revocation or suspension, denial of license renewal, recommendation to CMS to terminate Medicare participation, and injunction.[281]

DADS investigates DBMD providers licensed as assisted living facilities. Sanctions that may be applied to these facilities include civil penalties, administrative penalties, license revocation or suspension, license denial, emergency suspension and closing order, appointment of a trustee, and injunction.[282]

VII. Legislative and Legal Background

Legal Background

***Lelsz v. Kavanagh*, 1974**

Lelsz v. Kavanagh was filed by five families on behalf of individuals residing in Texas state schools.[283] The suit alleged that minimal constitutional standards for individuals with mental retardation who reside in state facilities were unmet, and sought

improvements in training and habilitation programs as well as an end to inappropriate institutionalization and the expansion of community service options.

As a result of the 1991 settlement two state schools were closed. No less than 600 individuals of the next two years were to be moved to community settings. Over the four year period of the settlement agreement 1,286 individuals moved from state schools to community settings.

The lawsuit was dismissed in November 1995 on the determination that the state had fulfilled the terms of the 1991 settlement agreement.

***Olmstead v. L.C.*, 1999**

In June 1999 the U.S. Supreme Court ruled that unnecessary institutionalization violates the 1990 Americans with Disabilities Act. [284] It was determined that states must provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when:

- The state's treatment professionals determine that such placement is appropriate;
- Affected persons do not oppose such treatment; and
- Placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state supported disability services.

The Court directed states to make modifications in programs and activities, unless such modifications would "fundamentally alter" the nature of the services, programs or activities.

Legislative Background

SB 700, 65th Legislature, 1977 (Persons with Mental Retardation Act)

The Persons with Mental Retardation Act provides that people with mental retardation have the rights, benefits, and privileges guaranteed by the constitutions and laws of the United States and Texas. [285]

Particular rights specified in the Act include the right to:

- Be protected from exploitation and abuse;
- Adequate treatment and habilitative services;
- Live in the least restrictive setting* appropriate to the individual's needs and abilities and in a variety of living situations; and
- A presumption of competency.

*The regulations implementing Title II of the Americans with Disabilities Act use the terminology "most integrated setting" instead of "least restrictive setting."

ICF/MR Waiver Program Established, 1985

Section 1915(c) of the Social Security Act was added in 1981 allowing the federal government to support states through Medicaid waiver programs to provide services in the home and community for Medicaid-eligible individuals who would be eligible for services in long-term care institutions.[286]

In 1985, the Texas HCS waiver was authorized offering a broader service array in both type and location of service delivery and a cost-effective alternative to institutionalization.

SB 257, 70th Legislature, 1987

SB 257 added Health and Safety Code Section 533.084(d) stating that the authority to close or consolidate a state school rests with the legislature. [287] DADS is not authorized to close or consolidate a facility providing mental retardation services without legislative approval.

HB 2377, 74th Legislature, 1995

HB 2377 codified the concept of a local Mental Retardation Authority (MRA) to which the state could delegate certain functions, such as planning, resource development, and allocation.[288] The central role of citizen participation in planning and evaluating supports and services was recognized, and the expectation that each MRA would consider public input was instituted. This legislation also established that the MRA would use principles of cost-benefit and appropriate client care to ensure consumer choice and the best use of public funds in assembling a provider network, and determining whether to provide a service or contract that service to another organization.

SB 367, 77th Legislature, 2001

SB 367 codified many of the recommendations made in the original Promoting Independence Plan, including the living options process designed to promote and ensure awareness of alternative living options for ICF/MR residents. [289] The living options process requires all providers of ICF/MR services to discuss living options with individual residents, legally authorized representatives, and/or family at least annually or upon request. The task force currently known as the Promoting Independence Advisory Committee was also codified in SB 367.

SB 368, 77th Legislature, 2001 (Permanency Planning)

Permanency planning for youth is a process that focuses on achieving family support by facilitating permanent living arrangements built on a philosophy that such arrangements should include an enduring and nurturing parental relationship. [290] SB 368 requires permanency planning for all individuals under age 22 who reside in ICF/MR's, including SMRF's; group homes for HCS waiver recipients; or another residential arrangement, other than a DFPS foster home, that provides care to four or more unrelated people under age 22. For individuals under age 22 placement in these settings is considered temporary and approval for the individual to continue to reside there must be obtained every six months.

Executive Order RP -13 (Promoting Independence)

In April 2002, Governor Rick Perry issued Executive Order RP-13 to further the state's efforts regarding the Promoting Independence Initiative and community-based alternatives for individuals with disabilities.[291] For example, the order directed the Health and Human Services Commission to:

- Review and amend state policies that impede moving individuals from institutions to the community;
- Incorporate the efforts of relevant state agencies to address housing and employment issues;
- Ensure permanency planning for children; and
- Implement a selected essential services waiver to provide community services for people waiting for services through the HCS waiver (Texas Home Living).

Rider 55, HB 1, 78th Legislature, 2003

Rider 55 directed HHSC to study the feasibility of closure and consolidation of state hospitals and state schools.[292] The study was conducted by a consulting group contracted by HHSC at a total cost of $161,812. No state facilities were recommended for closure or consolidation.

HB 2292, 78th Legislature, 2003

HB 2292 aimed to improve the delivery of health and human services for Texas by consolidating 12 state agencies into five.[293] Mental retardation programs, state school programs, community care programs, nursing home programs, and aging services were all merged to create the Department of Aging and Disability Services.

Rider 44, SB 1, 79th Legislature, 2005

Rider 44 directed DADS to prepare a report analyzing the costs of state operated and non-state operated ICF/MR's as well as the combined average monthly cost to the state per person participating in the HCS and TxHmL waivers.[294] The Rider also required a comparison of severity across settings by Level of Need.

Results of the cost comparison between community group homes and state schools illustrated the average monthly cost of state school operations to be higher. However, the report also noted these costs were not intended to be used for determining incremental effects of increasing or decreasing the number of consumers in that setting because state schools have certain operating costs that are not impacted with small fluctuations in the number of individuals served.

SB 27, 80th Legislature, 2007

SB 27 outlined requirements related to the community living options information process for adult residents of state schools. Living options for a state school resident are be to reviewed 30 days after admission, at least annually, and upon the request of the individual or his/her family members or guardian. Implementation of the Community Living Options Informational Process (CLOIP) for adult residents at state schools is delegated by DADS to local MRA's. A broad range of stakeholders were involved with

the development of CLOIP and tools for its administration as required by SB 27. In January 2008, CLOIP was fully operational in accordance with the bill.

HB 2439, 80th Legislature, 2007

HB 2439 addressed issues related to provider of last resort and the roles of local mental health and mental retardation authorities (MRA's). DADS is required to ensure that MRA's:

- Provide individuals with information to make informed decisions;
- Respect the rights of individuals; and
- Integrate individuals into the community.

2008-2009 General Appropriations Act, 80th Legislature, 2008

In 2008, HB 1 provided funds for HCS waiver program services allowing an additional 250 individuals to move from SMRF's within 180 days of the recommendation for transfer to the community, per the Promoting Independence Plan.[295]
The bill also appropriated $1.04 billion (all funds) for SMRF's for the 2008-09 biennium, an increase of $121 million over the 2006-07 biennium. This amount included the funding needed to bring staffing ratios at the SMRF's up to the national level by hiring an additional 1,690 new full-time employees.[296] As of February 2008, 677 of the new positions at state schools were filled.[297]

VIII. Interest Lists

DADS maintains interest lists for services and supports for which the demand is greater than the available resources. The unduplicated count of individuals on all ICF/MR waiver program interest lists totals 82,050 people. There are currently interest lists for the following ICF/MR waiver programs:[298]

Community Based Alternatives (CBA)
Integrated Care Management (ICM)
STAR+PLUS
Community Living Assistance and Support Services (CLASS)
Deaf/Blind with Multiple Disabilities (DBMD)
Home and Community Services (HCS)
Medically Dependent Children's Program (MDCP)

Individuals eligible for ICF/MR's are potentially eligible for any of the above services; however, the HCS and CLASS lists are given particular consideration in this report because they were specifically designed to waive off of the ICF/MR program by serving individuals with mental retardation or a related condition. HCS and CLASS lists account for 72% of all individuals on ICF/MR waiver program interest lists.[299]

Based on June 2008 interest list numbers, the cost to serve all eligible persons on the interest lists would be $2 billion all funds, $842.4 million state dollars, per year.[300] This amount would serve an estimated 48,208 individuals per month - the number who would be expected to be found eligible for services and accept them if offered.

HCS and CLASS Interest Lists

The HCS program in particular has been criticized for its extensive interest list. Individuals who were released from the list in FY 2008 had been placed on the list between October 1998 and April 2000.[301]

As of June 2008, there were 37,187 persons on the HCS interest list.[302] In FY 2008, 2,607 persons were released from the list. Of those released 1,338 (51%) were enrolled in the program, and 579 (22%) were either denied services due to ineligibility or declined services.[303] The remaining 654 (25%) individuals are "in the pipeline" awaiting determination of eligibility. Individuals who are denied or decline a slot at the time that the services become available to them often request that their name remain on the list should their circumstances change in the future. Their name will be returned to the bottom of the list, and the original date they were placed on the interest list is maintained. About 70% of individuals accept an HCS slot when it becomes available to them.[304]

To fully fund the HCS program and eliminate an HCS interest list would require $1.24 billion all funds ($517.6 million GR funds) and 145 new full time employees at DADS and at HHSC for determining Medicaid eligibility.[305]

As of June 2008, there were 21,496 persons on the CLASS interest list.[306] In FY 2008 approximately 1,122 persons were released from the list. Of those released 461 (41%) were enrolled in the program, and 537 (48%) were denied or declined services. The remaining 124 individuals are "in the pipeline."[307] To fully fund the CLASS program and eliminate a CLASS interest list would require $432.6 million all funds ($181 million GR funds) and 56 new full time employees.[308] Individuals who were placed on the CLASS list between November 2001 and June 2002 were released in June 2007 for FY 2008.[309]

The 80th Legislature appropriated $71.5 million in GR funds to DADS for the purpose of addressing the interest lists for community-based long-term care services.[310] This amount is to be released over the 2008-09 biennium in amounts of $18.1 million in FY 2008 and $53.3 million in FY 2009. In addition to creating slots for other waiver programs, these monies create 2,676 new HCS slots and 587 new CLASS slots.[311] Over $6.5 million in GR funds was specifically earmarked for the creation of 240 HCS waiver slots for individuals moving out of large ICF/MR's under the Promoting Independence Plan.[312]

Promoting Independence Plan

The Promoting Independence initiative began in January 2000 as a response to the U.S. Supreme Court decision in *Olmstead v. L.C.*[313]

HHSC began the Promoting Independence Initiative, as directed by Executive Order GWB 99-2, and appointed the Promoting Independence Advisory Board to develop the state's first Promoting Independence Plan as a response to the *Olmstead* ruling.[314] HHSC was directed to involve consumers, advocates, providers and relevant state agencies in a system wide review of services and supports available to individuals with disabilities in Texas. The resulting report included stakeholder recommendations for improving community-based programs for Texans with disabilities.[315] Recommendations in the original plan addressed: methods to identify and assess individuals for readiness to move to the community; access to services; system capacity; service coordination; and removal of the barriers to community support.

The Plan, which is in its third revision submitted to the Governor and Legislature in February 2007, provides a comprehensive and organized guide for achieving independent living for persons with developmental disabilities.[316] Additionally, the Plan addresses the requirements of Executive Order, RP-13, which required the state to review all long-term care services and supports, make appropriate recommendations, and implement specific gubernatorial directives. The Plan also reports the status of implementation of a plan to ensure appropriate care settings for persons with disabilities, and the provision of a system of services and supports that foster independence and productivity, including meaningful opportunities for a person with a disability to live in the most appropriate care setting. Finally, the Plan examines the availability, function, and effectiveness of existing community-based supports for people with disabilities.

Initiatives and policies in which the Promoting Independence Committee had an integral role include:[317]

- The engagement of HHSC and DADS in the "Money Follows the Person" (MFP) project in which select states receive federal funds to help persons who are elderly or have disabilities move from institutional settings back to community settings. The Money Follows the Person Demonstration will use enhanced funding allocated in the 2008-2009 General Appropriations Act to expand MFP over the next five years to move persons with intellectual and developmental disabilities, and persons with behavioral health needs from nine or more bed ICF/MR's.[318] Under the Promoting Independence Plan persons residing in large ICF/MR's (14 or more beds) or in SMRF's are provided expedited community services through dedicated HCS waiver slots.
- Riders which allow children aging out of foster care to access community services;

- The creation of the Texas Home Living 1915(c) waiver program for persons with intellectual disabilities;
- The creation of permanency planning policies for children residing in institutional settings; and
- Increased support of self-determination and consumer-directed services.

IX. Department of Justice Investigation

On March 17, 2005, the Department of Justice (DOJ) notified the Texas Governor's office of their intent to investigate Lubbock State School (LSS), in accordance with the Civil Rights of Institutionalized Persons Act (CRIPA).[319]

CRIPA was enacted in 1980 and gives the U.S. Attorney General the authority to conduct investigations and initiate litigation relating to conditions in government operated institutions, including Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR). The DOJ's investigations focus on broad reform of conditions in institutions, ensuring reasonably safe conditions of confinement, freedom from unreasonable bodily restraints, and such minimally adequate training as reasonably might be required by those interests. They do not address individuals' particular problems or seek money on behalf of individuals.[320]

Enforcing the Americans with Disabilities Act's (ADA) integration provision has become a DOJ priority. The provision requires that placement be offered in the most integrate setting appropriate to meet the needs of the individual. According to a 1999 U.S. Supreme Court case, *Olmstead v. Zimring*, a community setting is appropriate when treatment professionals determine community placement is appropriate, the individual does not oppose movement to a less restrictive environment, and placement can be accommodated considering the needs of other individuals and the state's resources.[321]

The DOJ has a history of investigating facilities throughout the U.S. At the end of Fiscal Year (FY) 2004, DOJ was investigating over 160 facilities in more than 30 states and territories. The DOJ monitors conditions in 22 facilities operated under court orders or settlement agreements. Most of the investigations have resulted in voluntary correction or judicially enforceable settlements. CRIPA authorized the U.S. Attorney General to file suit if the institutions being investigated fail to correct deficiencies or does not agree to a settlement.[322]

Lubbock State School Investigation

A number of consultants with expertise were involved in the investigation including psychiatry, psychology, general medical care, nursing, nutritional and physical management, protection from harm, and community placement. The DOJ conducted an on-site investigation the week of June 13, 2005. Medical and other records relating to the care and treatment of residents were reviewed before, during, and after the on-site investigation. Facility policies and procedures were reviewed. Administrators and staff were interviewed. Residents were observed in their residences, activity areas,

classrooms, workshops, and during meal time. DOJ's preliminary findings were expressed to facility staff in an exit conference.[323]

On December 11, 2006, DOJ released the LSS investigation findings in a report. The report indicates that LSS fails to provide adequate health care; protect residents from harm; provide adequate behavioral service, freedom from unnecessary and inappropriate restraints, and habilitation; and provide services in the most integrated setting appropriate. Negotiations with the DOJ are still ongoing; however, the Department of Aging and Disability Services (DADS) and LSS have begun to implement improvement strategies. The report included numerous recommendations that could improve LSS compliance with CRIPA. They are divided into four categories: health care; protection from harm; behavior programs, restraints, and habilitation; and serving persons in the most integrate setting appropriate.[324]

Health care recommendations include improvements in general medical services, occupational and physical therapy services/physical and nutritional management, and psychiatric services. General medical services should be enhanced by maintaining adequate staffing levels for trained nurses; maintaining and reviewing accurate medical records; monitoring and evaluating medication use and pharmacy services; and providing staff with training to avoid preventable medical issues.[325]

Occupational and physical therapy services could be improved by evaluating and documenting the status of residents that require therapy services. The Physical Nutritional Management Team should receive the proper training and staff should be trained to assist with dysphasia or choking risks. All individuals with physical or nutritional needs should be identified and assessed.[326]

A standard psychiatric and psychological evaluation process should be developed and each resident should be assessed for psychiatric needs. The procedures of administering, documenting, and reviewing the use of psychotropic medications need to be addressed. A collaborative relationship should be established between psychiatry and neurology to better serve individuals with both mental health needs and a seizure disorder.[327]

The DOJ indicated that LSS residents could be better protected from harm by training all staff and residents (to the best of their ability) on the process for reporting abuse and neglect. LSS and DADS should ensure appropriate steps are taken when an allegation is made; unusual incidents should be tracked and the root causes addressed.[328]

Behavior programs could be improved by developing individual plans for each resident, training staff on how to properly implement behavior plans, monitoring residents' progress, and revising programs when appropriate. A process should also be established to develop individual habilitation plans. The efficacy of each plan should be monitored.[329]

Policies need to be established discouraging the use of restraints in any non-emergency situation. Staff need to be trained in the proper way to restrain residents. Any incidents of repeated use of restraints should be evaluated and addressed.[330]

More people could be served in the most integrated setting appropriate if staff, residents, and their guardians were educated about community living options and procedures were developed to improve the transition process.[331]

Investigation Expansion

Since completing the LSS investigation, the DOJ has expanded its investigation to include other State Mental Retardation Facilities (SMRF). In March 2008, DOJ announced their intent to investigate Denton State School (DSS). Since then, an on-site investigation has been conducted. The DOJ has yet to release an investigation report.

In August 2008, the DOJ informed the Governor's office that the investigation would expand further to include all 11 state schools (including LSS and DSS) and 2 state centers. No information has been released regarding the scope of the investigation; it is unknown whether an on-site investigation will be conducted at every facility.

State-Wide Improvements

Shortly after the DOJ announced its intent to investigate, DADS began to implement system-wide initiatives to improve the quality of services provided in SMRF's. According to testimony before the Select Committee in February 2008, DADS has brought in new management to enhance operations. Since October 2005, eight new SMRF superintendents have been hired. In addition, there have been changes in the state office including new management, two new program liaisons, and the development of the Program Improvement Unit.[332]

After the DOJ announced its intent to investigate LSS, DADS began to meet weekly with staff from HHSC, Attorney General, and Governor's office. In addition, DADS developed and implemented a facility plan to address exit findings and hired the Columbus Organization to provide training and technical assistance.[333]

Competency-based and "train the trainer" training will be provided at all facilities focusing on identifying and reporting abuse, neglect, and exploitation; active treatment; client rights; nursing practices; and habilitation therapies and augmentative communication systems and devices. In addition, selected facilities will receive specialized training concentrating on active treatment, person-directed planning, positive behavior supports, and nursing services.[334]

Included in the FY 2008-09 biennial appropriation for SMRF's is an additional $48.8 million in GR funding ($124.9 million all funds), allowing DADS to hire additional staff. DADS hopes to hire an additional 1,690 FTE's to meet national staffing ratios. As of August 18, 2008 1,139 of the new positions had been filled including 1,211 medical

professionals and direct care staff, and 479 support staff positions. DADS is working to ensure that all of the new positions are filled over the next Fiscal Year.[335] The DOJ-related appropriation also provided resources for 250 additional Home and Community-Based Services (HCS) waiver slots for individuals transitioning out of SMRF's.[336]

Since the initiation of the DOJ investigation, DADS has begun implementing a number of initiatives intended to improve service provision and compliance with Civil Rights for Institutionalized Persons Act. Two initiatives focusing on person-centered values have been established. Values-based culture training teaches staff to treat individuals with dignity and respect. The Standardized Person-Directed Planning System was established to assist in the development of individualized plans based on what is important to the individual and their needs.[337]

DADS indicates there is an increased focus on ensuring individual rights within SMRF's. A standardized rights assessment has been established. SMRF's have also worked to transition individuals into the most integrated setting, set up positive behavior support, and reduce the use of restraints.[338]

DADS has also implemented several quality medical services initiatives and believes that access to, and quality of nursing services and specialized therapies have been addressed. DADS testified that medication management has improved by their use of a standardized assessment tool for medication side-effects and training staff in the area of Poly-Pharmacy.[339]

Finally, DADS has instituted continuous quality improvements including establishing health status committees, developing a standardized unusual incident trend analysis system, and practicing emergency code drills.[340]

The development and implementation of CLOIP has improved the SMRF's ability to inform residents and their families or guardians about community-based residential options. Senate Bill 27 passed during the 80th Regular Session of the Texas Legislature, instructed DADS to establish CLOIP. On January 2008, Mental Retardation Authority (MRA) staff began conducting CLOIP and discussing the outcome at each SMRF resident's Interdisciplinary Team (IDT) meeting.

X. The State Auditor's Report

In July 2008, the State Auditor's Office (SAO) released a report based on an audit of the Department of Aging and Disability Service (DADS) and the Department of Family and Protective Services (DFPS). The audit had three objectives: to determine whether DADS informs consumers in State Mental Retardation Facilities (SMRF's), or their Legally Authorized Representative (LAR) about community living options; to determine whether DADS and DFPS properly address allegations of abuse, neglect, or exploitation; and to compare the costs of providing care in a SMRF and in a community-based ICF/MR.[341]

The audit was based on DADS operation of SMRF's and community-based ICF/MR's from September 1, 2005 until December 31, 2007 and DFPS investigations at ICF/MR's from September 1, 2005 until November 30, 2007. The SAO conducted interviews with staff and consumers; reviewed policies and procedures, statues, and rules; examined ICF/MR cost reports; and examined data pertaining to community living options and investigations to test for compliance with requirements.[342]

Community Living Options Recommendations

The SAO identified some trends regarding DADS' process for informing SMRF residents of their community living options. More SMRF residents were referred for community placement in the last part of FY 2007 and the first part of FY 2008 than were in previous years.[343]

However, not everyone who expressed a preference for community placement was transitioned out of a SMRF. Only 13% of consumers expressed an interest in an alternative placement. "Alternative placement" meant a community living option 91% of the time. The rest of the time "alternative placement" referred to a different room within the same facility or another SMRF. Of that 13% who were interested in a living arrangement change, DADS did not provide the consumer's preference 70% of the time.

A large percentage, 52%, of consumers expressed no preference in living situation. In 29% of the cases audited, it was not specified whether the needs of the individuals could be met in the community. The files also did not specify the reason why an institutional setting was necessary, if it was.[344]

A reason for denying a person's request for an alternative placement was recorded 88% of the time. The number one reason was behavior management problems. The second most common reason a consumer who stated a preference for community placement was not referred, was a preference for an institutional setting by family or a guardian.[345]

The SAO report recommended that DADS improve its process for documenting and monitoring community living discussions and decisions. However, many of the issues identified by the report had already been addressed with the introduction of CLOIP. CLOIP had not yet started when the SAO concluded their audit; therefore, the changes made because of CLOIP are not reflected in the report.[346]

DADS and DFPS Investigation Recommendations

The audit report included several recommendations for ways to improve procedures for investigations of abuse, neglect, or exploitation. First, DADS should initiate investigations with a lower priority in a timely manner. The complaints and incidents classified as a priority 1 were investigated in a timely manner 99% of the time. Only 59% of priority 2 complaints and 75% of priority 3 complaints were initiated in a timely manner. DADS has begun to take steps to improve timeliness. Thus far in FY 2008, the number of investigations initiated outside of their timeframe has decreased by 46%.[347]

DADS should also ensure that they do not employ any persons with a history of abuse, neglect, or exploitation. The SAO identified 10 individuals who were employed at a facility and were listed as unemployable on either the Nurse Aide or the Employee Misconduct Registries. Once brought to DADS attention, the ten employees were immediately fired. DADS has also implemented a process that requires every employee to go through a registry check when they are hired and annually thereafter.[348]

Even though DFPS investigated most of the allegations and complaints filed in a timely manner, the report still identified several recommendations for how they could improve the investigation process. The SAO recommended that DFPS contact consumers and facilities as well as conduct investigations in a timely manner. DFPS should also ensure that the initial assessments of allegation priorities are accurate.[349]

Facility Cost Comparison

The SAO attempted to compare the costs of providing care in a SMRF with providing care in a community-based ICF/MR. The report stated that the average daily cost of a SMRF in FY 2006 was $335.63 per resident. The average daily cost of an individual living in a community-based facility in FY 2006 was $165.17.[350]

Three factors impacted the higher costs of SMRF's: direct care staffing, SMRF's have higher staff to consumer ratios and provide more benefits for their direct care staff; administration, SMRF's allocate more costs from the central office to the facilities; and comprehensive medical care, most health and pharmacy services are provided on campus in a SMRF.[351]

The usefulness of the cost comparison is questionable. Several factors impact the comparison's accuracy. It is impossible to determine if health status differences between the population at SMRF's and community-based ICF/MR's impacted the higher SMRF costs. The health status differences are not measurable because the codes are not tracked for community-based ICF/MR residents as they are for SMRF residents.

Another cost comparison complication is that DADS does not divide their reimbursement rates into cost categories. The auditors had to estimate the costs per cost category based on a single day rate.

Finally, health care and prescription medication costs were difficult to compare. They are provided in the SMRF's for consumers while community-based ICF/MR consumers do not receive these services at their facility.[352]

XI. Committee Work

In order to gain an understanding of the needs of Texans with developmental disabilities and the current system of services and options available to them the Committee met with a wide array of stakeholders. Committee undertakings included:

- Committee hearings held on February 12, May 21 and August 22, 2008 with dedicated time for public testimony. The February 12 hearing was an organizational hearing that included testimony from state agencies and other organizations instrumental in the ICF/MR system of care. Topics of the May 21 hearing included guardianship, dual diagnosis, and policies regarding state employees; public testimony was also taken. The August 22 hearing focused on the State Auditor's report, interest lists, and public testimony. Days before this hearing Governor Perry was notified that the Department of Justice had expanded its investigation to include all SMRF's.
- Dialogue with DADS, HHSC, DFPS and other state agencies.
- Visits to all 13 State Mental Retardation Facilities.
- Tours of numerous privately and publicly operated ICF/MR's; group homes and foster homes for HCS recipients; and non-profit and private pay residential models.
- Meetings with staff at Mental Retardation Authorities across the state.
- Discussions with advocacy groups from all points of view.
- Correspondence with concerned Texans.
- National research on systems of care for individuals with developmental disabilities including discussions with experts on service delivery nationwide.

XII. Committee Recommendations

After careful research and review of the system of care for individuals with developmental disabilities, the Committee decided on the extensive recommendations that follow. The top priority of the Committee is ensuring that no matter where a person resides, they are free of abuse, neglect, and exploitation. Many of the recommendations involve improving the quality of care for individuals in community-based and state-run facilities as well as making sure these individuals have access to appropriate services.

With the 81st Legislature convening soon, some of the recommendations can immediately get underway and be accomplished in a relatively short time period. Other recommendations include more legislative direction, will have to take into account the fiscal soundness of the state's budget, and involve a longer time frame to achieve.

The Committee asks that special priority be given to the following recommendations: require DFPS to investigate abuse and neglect allegations in all facilities; increase funding to MRA's for safety net services and programs that prevent individuals from needing more restrictive and costly services; move Regulatory and Quality Assurance responsibility to HHSC; continue to decrease the HCS Interest List and remedy obstacles within the HCS Program; create a joint committee to determine the viability and future direction of the State Mental Retardation Facility system.

Once safe environments have been established, appropriate services are accessible and the interest list continues to decrease, the Committee looks forward to establishing a

model system for those with developmental disabilities; a system that recognizes the uniqueness of individuals and enhances their quality of life.

Recommendations for DADS

Instruct DADS to evaluate the effectiveness of statewide improvements and report to the 81st Legislature.

Since the start of the DOJ investigation of Lubbock State School, the Department of Aging and Disability Services has implemented a number of quality improvement initiatives, or statewide improvements, throughout State Mental Retardation Facilities. DADS should now conduct an evaluation of these policies and programs measuring their effectiveness and submit a report of their findings to the 81st Legislature. Such an evaluation would also be a tool for deciding whether continued efforts are required to ensure that the changes recommended by the Department of Justice are achieved, or whether continued endeavors toward providing a high quality of care are needed. This is especially critical in an environment where there are high levels of staff turnover and exposing new employees to value-based training is necessary for creating a beneficial change.

Create a joint legislative committee to determine the viability and the future direction of State Mental Retardation Facilities.

A joint committee of House and Senate members, with input from experts in the developmental disabilities field, demographers, and architects, should be named to specifically examine the physical infrastructure needs of Texas' state schools and centers.

The committee would be tasked with a comprehensive evaluation of the SMRF system including: forecasting the population that will need state run facilities in the future and determining the services they will require; inspecting the existing physical plant at each facility and calculating projected expenditures to update the physical plant at each facility; evaluating each facility for energy efficiency; determining if each facility is operating at an optimal census; and determining if each facility is suitable for its intended purpose.

As an outcome of their analysis and research the committee would create a full report, including demographics and forecasts of future state facility usage, and propose legislation to address the issues identified by the joint committee. Creating this committee would be a proactive measure in addressing the recent announcement that the Department of Justice will be surveying SMRF's statewide. As the Department of Justice continues their review the committee may integrate findings from the DOJ reports into their own recommendations.

Create an Assistant Commissioner for State Mental Retardation Facilities.

Centralized jurisdiction over issues related to improvement of State Mental Retardation Facilities should be entrusted to an Assistant Commissioner for State Mental Retardation Facilities. The Assistant Commissioner for SMRF's would oversee operations of State Mental Retardation Facilities. One of the Assistant Commissioner's primary responsibilities will be ensuring the expedient, effective implementation of the recommendations and improvements stipulated by the Department of Justice. This position will report directly to the Commissioner of DADS and would allow for increased oversight of SMRF's as well as the systematic efficiency needed to make necessary changes and improvements to the system.

Appoint a Quality Assurance Team for facilities that chronically receive a Quality Reporting System Score below 60 for more than three surveys.

The Quality Reporting System assigns each facility a compliance score, which corresponds to one of six recommendations. The recommendations range from termination of certification within 23 days to recertification without conditions. The recommendation assigned to each facility is determined by the type and seriousness of violations and deficiencies identified during facility surveys completed by the Regulatory Services division of DADS[353].

All facilities listed in QRS are currently certified and therefore, either meet minimum standards or are monitored while problems are corrected. However, some facilities repeatedly have unfavorable ratings and still maintain certification. These facilities correct the problems identified in surveys and by the time they are resurveyed, the facility again has serious deficiencies and violations. This cycle continues without any long-term improvements to the facility[354].

If a SMRF receives a score of 60 (corresponding to a recommendation to invoke the automatic cancellation clause) or below on more than three consecutive surveys a team should be appointed by the commissioner of HHCS. The team will include representatives from a cross section of the health and human services agencies (HHSC, DADS, DSHS, DARS, and DFPS) and will have a team leader who is appointed by the HHSC commissioner. They will develop an immediate strategy to eliminate deficiencies as well as a long-term plan. The plan will identify ways to ensure the sustainable improvement of the poor performing facility. The team will be responsible for implementing the strategy in conjunction with the SMRF assistant commissioner and will report back to the HHSC commissioner. State Mental Retardation Facilities should be centers of excellence and chronic substandard ratings are unacceptable.

Address staffing needs within State Mental Retardation Facilities.

State schools and centers received funding during the 80th Legislative Session to enact a hiring project adding an additional 1,690 full-time employees (FTE's), including 650 nursing staff, to their workforce. However, direct-care staff turnover at SMRF's remains

extremely high, and many of the new nursing positions, as well as professional staff positions, remain unfilled. Consideration should be given to allowing the funds previously allocated for increasing the number of FTE's to be instead used for increasing pay and training for present employees and, therefore, hiring fewer employees, in an effort to boost retention and skill level within the current and future workforce. Furthermore, it should be established that DADS has implemented appropriate training and is commendably maintaining the current workforce prior to allocating additional FTE's in the future.

High levels of staff turnover often necessitate hiring unqualified workers with minimal training. The retention of full-time employees could be stabilized by offering competitive pay and benefits that suit the nature of the work. Providing direct care to SMRF residents can be a physically challenging task that often includes the frustrating assignment of determining the needs and desires of non-communicative residents and contact with emotionally disturbed or aggressive individuals. Staffing shortages often require unanticipated overtime for employees and often supervisors are unable to authorize holidays or vacation time because doing so will leave facilities understaffed. While employees of state-run ICF/MR's do receive benefit packages (something not frequently offered by private providers) their low wages and heavy workloads sometimes offset that advantage.

Several employment policies should be altered to ensure that only qualified and competent staff continue to work at SMRF's. Currently, SMRF staff are not at-will employees. Changing this policy would allow administrators to terminate employees when there is evidence they may be putting residents at risk without having to go through a review process. In addition, policies regarding random drug testing of SMRF employees should be modified. At present, employees may not be drug tested unless there is reasonable suspicion. Allowing for random drug testing of employees would help protect residents from harm by assuring staff are not under the influence of drugs while caring for a vulnerable population.

Shortages among professional medical and nursing staffing needs should be addressed by offering competitive salaries and flexibility in the salary DADS is authorized to pay. The Committee suggests that to activate this initiative a specific appropriation should be made to DADS for the designated purpose of hiring new professional medical and healthcare staff.

Additionally, the availability of professionals could be expanded through the creation and support of programs in fields such as nursing, behavioral management, and medical care for persons with developmental disabilities. This should include the development and expansion of stipend programs that allow current SMRF employees to gain education and training in exchange for committing to a certain period of employment after graduation. Further, university students who elect to complete internships in state facilities should be eligible for stipends to offset the costs of their tuition. By building bridges between the state facilities and medical centers and universities, the hiring pool for the entire system of care for persons with developmental disabilities widens to include a higher number of

more experienced workers. DADS needs to take advantage of the cutting-edge medical training institutions in the state to develop a more substantial compilation of well-trained medical staff.

To attract more qualified candidates to leadership roles at SMRF's, such as the Superintendent and Assistant Superintendents for Programs and Administration, salaries for these positions should be increased to make them more competitive with comparable positions in the private sector. Additionally, Recommendations from the State Auditor's Biennial Report on the State's Position Classification Plan should be used as a guide for salary increases. The report suggests increasing salaries for a number of positions including qualified mental retardation professionals, nurses, doctors, and psychiatrists.

Continue conducting value-based training to further instill a system-wide philosophical shift that focuses on the uniqueness of individuals.

Many of the theories underlying the programs DADS oversees for persons with a diagnosis of mental retardation stress normalization and are often so strictly enforced and regulated that the individual risks being lost in favor of adherence to programmatic expectations. DADS does provide training for staff that focuses on valuing the persons they serve as individuals. However, what is called for is a complete top-down philosophical shift toward appreciating an individual's need for personal expression, growth, and abilities in spite of their disability. Respect for the needs and abilities of each person should serve as the focal point for interactions and program development. All programs should be organized to recognize the uniqueness of these individuals and offer them the highest quality of life.

Maintain state operated long-term care facilities for only the most medically fragile and hard-to-serve populations.

There continues to be a need for state facilities that provide residential care for individuals in crises, or for those who need more medical care or structure than is available to them in a community setting. The highest quality of care for these individuals can also be provided in State Mental Retardation Facilities with smaller populations. Persons who could be served in the community, but prefer to remain in state care, should have the option of transitioning to small, community-based, state-run ICF/MR's. This arrangement ensures that the consistency of state involvement that concerned family members desire remains intact while offering a more integrated, home-like setting to individuals. These facilities would be open only to those moving out of SMRF's, and SMRF residents would have the option to first choose a home operated by a private provider.

Create specialized facilities for Criminal Code and Family Code commitments.

Individuals committed to State Mental Retardation Facilities under Chapter 46 of the Texas Code of Criminal Procedure as alleged offenders should be housed in a separate location rather than sharing a facility with general SMRF residents. They are often a

relatively high functioning group of individuals who may represent a security risk, and in some cases a threat to the safety of others. As such, alleged offenders should be housed in a locked facility that employs specially trained staff, and specialize in behavioral management and habilitation programs. The Regulatory Services division will need to work with Centers for Medicare and Medicaid Services (CMS) to establish ICF/MR certification and Medicaid reimbursement for such a facility. DADS should also review the campus leave policy for individuals committed to a state facility under Chapter 46. Presently, these individuals, in some circumstances, are allowed to leave the facility for home and community visits despite the fact that their behaviors are potentially dangerous; this has led to instances of the residents engaging in criminal behavior in the community during their commitment to the facility. Additionally, higher priority should be placed on establishing the competency of these individuals so they may access their right to due process.

Separate facilities should also be established for children who are placed in a SMRF under Chapter 55 of the Texas Family Code. This population is also relatively high functioning, tend to have high rates of elopement, and may represent a security and safety risk to themselves and others. They should be housed in a locked facility with special habilitative and educational programming, and specially trained staff.

Align ICF/MR and HCS Licensing and Employment standards.

Employment and licensing standards should be consistent across programs. Currently, the standards are more stringent for HCS than for ICF/MR providers.

Prior to 1993 it was possible for an individual with a criminal history to be licensed as an ICF/MR provider. In 1993, the Texas Administrative Code (TAC) enacted a rule preventing anyone who has been convicted of an offense with a penalty of incarceration from becoming a licensed provider. Every two years a provider's license must be renewed, at this time a criminal background check is done. The license will not be renewed if a provider has been convicted of an offense with a penalty of incarceration within the past two years. Because the TAC rule enacted in 1993 was not retroactive, it is possible for a provider to maintain and renew their license despite a previous criminal history.[355]

The TAC includes separate standards for licensing HCS providers. Criminal background checks are performed on all providers including any "indirect ownership interests" who wish to contract with Medicaid through the HCS program. Convictions for any of the 21 offenses listed in the TAC permanently prohibit providers from becoming licensed. ICF/MR licensing standards should be changed to align with those for HCS. This would protect the safety of individuals in ICF/MR's by ensuring providers do not have a criminal past.

Employment standards are also different in the ICF/MR program than in HCS. The Texas Health and Safety Code lists 23 offenses that permanently bar an individual from employment with an HCS provider. This rule also includes seven offenses that prohibit

an individual from employment for five years. This is not true for the ICF/MR program. The stringent employment standards of the HCS program should be adopted by ICF/MR. This would protect the well-being of vulnerable Texans by ensuring those working in facilities do not have a criminal history.

Install security cameras in common areas of State Mental Retardation Facilities and post a security guard at the entrance to each facility.

Cameras placed in hallways and common areas of SMRF's would protect individuals residing in those facilities by acting as a deterrent for inappropriate behaviors and would provide evidence to be reviewed in cases where an accusation of wrongdoing has been made. Frequently, staff members who are accused of abuse, neglect, or exploitation are either unfairly reprimanded or are retained as employees in spite of wrongdoing due to a lack of evidence to confirm or deny their role in the incident. The Regulatory Services division that establishes ICF/MR certification with the Centers for Medicare and Medicaid Services (CMS) will need to work with the CMS Regional Office to establish that the installation of cameras is necessary for the safety of each resident because cameras will act as a deterrent in abuse, neglect, and exploitation. Additionally, cameras will aid in the review of such cases and allow DADS to terminate employees who pose a threat to residents. Taking measures to ensure the safety of residents is especially important in the current state school environment, which is rife with accusations of improper treatment of individuals. Evidence from these cameras would be used strictly to investigate cases of purported abuse, neglect or exploitation and would be viewed only by law enforcement and approved employees of the Department of Family and Protective Services, the Health and Human Services Commission, and DADS.

For the additional safety of the residents, a gatehouse will be erected at the main entrance of each facility, if one does not already exist, and a security guard will be stationed at the gatehouse to ensure that persons entering the facility have proper identification and have signed a visitors log.

Develop expertise on vocational training and design an updated, meaningful work program for State Mental Retardation Facility residents.

DADS should explore more substantial work program models for individuals with developmental disabilities and incorporate these into State Mental Retardation Facilities as an alternative to the typical contract work carried out in state schools and centers. Horticulture, ceramics, and screen printing programs, which take into account the various skill levels of each individual, already exists in community-based facilities and can be used as examples for more meaningful activities for state schools residents.

Initiate a communicative devices pilot program in a State Mental Retardation Facility.

Communicative devices allow non-verbal individuals to express themselves. New technology is enabling individuals to use computers to communicate, including some

residents of State Mental Retardation Facilities. However, the limited scope and lack of data collection have called into question whether the individuals using the devices are truly able to express their desires to facility staff and if these devices are being used to their full potential to truly allow an individual to participate in their care and standard day-to-day activities.

DADS should establish a pilot program at one of the State Mental Retardation Facilities that focuses on using communicative devices in the most appropriate and effective manner and bring in experts to develop the program. The devices, when used appropriately, will enable individuals who have been unable to communicate with staff effectively to express their needs and desires. Increased communication between residents and staff will improve the quality of life and guarantee the well-being of individuals living in SMRF's.

Certify that all facilities are implementing CMS guidelines regarding the right to retain appropriate possessions as intended.

The Regulatory Services division should ensure that all CMS guidelines are implemented consistently and as intended. Some facilities may be implementing CMS guidelines inappropriately. CMS policy states that "clients have the right to retain and use appropriate personal possessions."[356] The guidelines further explain that individuals should be encouraged to use age-appropriate items. However, age-inappropriate items only become an issue when they are hindering the individual's development.

Some facilities have interpreted this policy to mean residents may only have items deemed appropriate based on their chronological age. When questioned, the facility's stated rationale behind their implementation had nothing to do with improving individuals' positive outcomes or functional skills. The facility stated the policy was implemented in that manner to reduce stigma against residents when they are in public. This particular facility was not implementing CMS policy as it was intended.

Some activities and items that would be classified as age-inappropriate may actually improve adaptive skills and would therefore be allowed under CMS rules. All facilities should reassess their implementation of this policy to ensure they are doing what is in the best interest of the residents.

Change titles "State School" and "Superintendent" to more appropriate terminology.

The designation "state school" is a misnomer that should be replaced with more illustrative language; the associated term "superintendent" reinforces confusion about the function of the facilities. While state schools do provide some educational services this is not their sole function. They are residential settings, primarily for adults, with a wide array of services, active treatments, and habilitation. The misleading "state school" label should be transitioned to a more appropriate moniker such as "Supported Living Center;"

superintendents and assistant superintendents should be referred to as "Directors" and "Assistant Directors."

Recommendations for Community-Based Systems and Services

Increase funding to MRA's for safety net services and programs that prevent individuals from needing more restrictive and costly services.

The safety net is a function performed by Mental Retardation Authorities (MRA's) to protect individuals' health and safety and respond to an intensive need or a crisis. The safety net should include both prevention and crisis intervention components; operate only as long as necessary to prevent or to stabilize a crisis; minimize or eliminate future service gaps; and avoid duplicating services available through other community programs.[357]

The individuals who access safety net services are at risk of being abused or neglected; demonstrate dangerous behaviors or threats; have health and safety needs not being met; are at risk of losing necessary functional skills; or are at risk of losing support systems. When an individual's caregiver becomes temporarily unavailable, often due to illness, these services can be used to support the individual until other arrangements are made. Safety net services are particularly useful for people who cannot use other community services to meet their needs, are on an interest list for Medicaid-funded services, or are ineligible for Medicaid services.[358]

Most of these individuals live in either their own home or a family home. Without access to safety net services, when a crisis occurs placement in an institutional setting is often the only option. Services such as respite, day habilitation, and behavioral supports assist in stabilizing difficult situations and prevent support systems from breaking down.[359]

Preventative interventions are arguably the most important group of safety net services. Because the purpose of prevention is to intervene prior to a crisis, these interventions have the most positive clinical results and are the most cost effective. Preventative interventions are divided into two categories: information/referral and proactive intervention. In many situations, issues can be resolved and crises averted if the individuals and their families are provided with information that allows them to understand their condition and access appropriate services. Proactive intervention services either reduce the severity of a crisis or prevent a crisis all together.[360]

If an individual does not access services in an appropriate or timely manner, the result is often a crisis. MRA's must then use crisis intervention strategies to respond, stabilizing the situation until long-term services and supports can be arranged.[361]

All MRA's offer safety net services but the quality and scope vary greatly; successful programs such as the New Day Treatment Program and the Behavior Training Program offered by The Mental Health and Mental Retardation Authority (MHMRA) of Harris County should be looked at as models for other MRA's to implement.

Expanding all MRA's ability to provide prevention and crisis safety net services will prevent individuals from needing more restrictive and costly services in the future including entering an institution. This is particularly important for children. In recent years the number of children being placed in State Mental Retardation Facilities (SMRF's) has been increasing. Providing families with appropriate services will allow children to remain in their own home. It will protect the health and safety of vulnerable Texans while minimizing the need for more costly interventions.[362]

Develop policies and regulations to improve oversight and service provision in community-based facilities.

Responsibility for investigating reports of abuse, neglect, and exploitation within facilities is not consistent across programs. DFPS investigates allegations in SMRF's, ICF/MR's managed by MRA's, group homes for individuals enrolled in HCS, TxHmL providers, and CLASS and DBMD facilities licensed as Home and Community Support Services Agencies (HCSSA's) when the alleged perpetrator is an employee and the victim is an adult or when the perpetrator is not an employee and the investigation is not appropriate for law enforcement. DADS investigates allegations in DBMD facilities licensed as assisted living facilities and CLASS and DBMD facilities licensed as HCSSA's when the perpetrator is an employee and the victim is a child. DADS is also responsible for evaluating the thoroughness of investigations done by private community-based ICF/MR's.

Policies and procedures should be augmented to create consistency across programs. All investigatory responsibility should be assumed by DFPS.

DADS Regulatory Services division is responsible for surveying each provider to ensure compliance with licensing and credentialing requirements. However, DADS does not visit every facility. Most providers operate numerous group homes. Instead of surveying each individual group home, DADS surveys a sample of each provider's homes annually. Regulatory services should begin to survey at least half of each provider's homes annually. This will not only improve the quality of services but will also increase confidence in the survey process.

Continue to decrease the HCS Interest List and remedy obstacles within the HCS Program.

The 80th Legislative session appropriated funds to support the HCS program and reduce the interest list. Such focus on the HCS program is pivotal to continued reduction of the interest list and the provision of HCS services to those who would like to receive them. The Legislature should continue efforts to support the provision of additional HCS slots.

Despite the increasing popularity of the HCS program, several issues have been identified by providers and consumers. Once an individual comes to the top of the HCS list, there are still obstacles preventing them from being placed in an appropriate residential setting.

Each HCS provider is capped; there is a predetermined maximum number of individuals each can serve. People receiving HCS slots have noted it is difficult to find a provider in some areas that have openings. This is preventing individuals from transitioning into the community. Strategies to increase provider capacity should be developed and implemented. This could be accomplished by increasing the maximum number of individuals who may reside in an HCS group home to six. Growing the provider base is especially important because of the continued interest in HCS.

In addition, HCS is a "zero-reject" program. Once an individual has chosen a provider, the provider must develop an appropriate care plan if they are not already serving their maximum number of clients. For example, if a 20 year old ambulatory female chooses provider X and provider X only has homes with elderly non-ambulatory males, then provider X will have to establish a home that would properly address her needs. This policy has both positive and negative effects. It prevents hard to serve individuals from being rejected by providers. However, it is often difficult and costly for providers to develop special programs for a single individual. The legislature should consider revising the "zero-reject policy" to encourage more providers to serve a larger number of HCS clients.

Reformulate reimbursement rates for direct care and administration for private providers.

Private providers are reimbursed by Medicaid for the services provided through contracts with DADS. Two reimbursement areas should be reformulated: administration and direct care.

Reimbursement rates for administration should be maintained to ensure provider's ability to offer quality case management services. Case management is particularly important in the foster care/companion care program. The meetings between the client and the case manager may be the individual's only interaction with a person outside the foster care home. In the foster care program, individuals have a single live-in caregiver rather than a rotating group of shift staff. In addition, not every foster home is visited by DADS Regulatory Services division because they only visit a sample of each provider's homes annually. The legislature should maintain or consider increasing reimbursement rates for foster care case management. This would improve quality of care by increasing communication between the provider and the service recipient.

Another issue related to the administration reimbursement rate is the large amount of paperwork required for the HCS program. HCS providers are required to record each individual's activities in 15 minute increments. This recordkeeping dictates high personnel costs without enhancing the quality of service. DADS should alter its HCS administrative requirement to reduce the paperwork burden. This would improve quality of care by allowing resources to be used to concentrate on caring for clients rather than on filing time consuming paperwork.

Revise the process for assessing Level of Need (LON).

Each individual receiving ICF/MR services is assessed and assigned a Level of Need. An individual with more severe medical and behavioral needs is given a higher LON. The payment rates given to the providers are based on LON.

Providers have expressed concern regarding improper LON assignment. Individuals with a LON 9 are required to have one-on-one supervision and therefore providers are paid accordingly. However, often when the proper supervision is provided problematic behaviors become less frequent. These individuals are then reassessed and because the one-on-one supervision is preventing maladaptive behaviors, the LON is decreased. When the supervision is scaled back, the problematic behaviors often return and LON goes back up.

Decreasing an individual's LON because intense supervision is doing what it is intended to do puts providers in a difficult position. The committee has met with high-quality providers who continue one-on-one supervision with residents whose LON has been decreased. The result is that the payment rate received by the provider is actually less than the cost of providing appropriate care. By serving this client, the provider is facing financial detriment. The provider's only alternative is to offer less supervision which puts the individual and other residents at risk.

The procedures for assigning LON should be addressed to ensure that providers are being compensated for the level of care they provide to each individual. This would stop the cycle of increasing LON when problematic behaviors occur and then decreasing LON when behaviors are controlled by one-on-one supervision.

Use the Texas Home Living (TxHmL) Waiver Program to serve some individuals currently using General Revenue services.

Texas Home Living is a Medicaid 1915(c) waiver program managed by the Department of Aging and Disability Services (DADS). It provides support in the community for those individuals eligible for Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) who only need limited services. TxHmL uses both state and federal funds to support the program.

Many of the services offered through the TxHmL program are the same services being accessed through Non-Medicaid Mental Retardation (MR) General Revenue (GR) programs. Respite, case management, specialized therapies, community supports, employment services, and day habilitation are accessible through TxHmL and MR general revenue services. Both programs even use the same provider, MRA's, for case management services.

Expanding TxHmL could decrease the number of individuals accessing services through MR general revenue programs. Individuals could receive the same services through

TxHmL as they are receiving now through MR general revenue services and the state could begin getting a federal funding match for services it is currently providing without the match. Use of this waiver program could allow more individuals to stay in their homes and avoid costly institutional placement by providing appropriate services in the community.

Allow community-based providers to share resources with State Mental Retardation Facilities.

Throughout the state, community-based providers have expressed difficulty accessing particular specialized services including physical therapy, wheelchair fabrication, speech therapy, assistive communication devices, psychiatry, dentistry, neurologists and other medical specialties, respite, day habilitation, and vocational training. Many of these services require professionals with expertise in working with individuals with disabilities. Finding professionals with the appropriate experience is difficult especially in more rural areas.

The same services that community-based providers are having difficulty accessing in the community are currently being provided in SMRF's. While community-based providers cannot find adequate services, SMRF's have professionals on staff with expertise. Community-based providers should be given flexibility to contract with SMRF's to provide specialized services on an "outpatient" basis.

This could be beneficial for both community-based providers and SMRF's. State Mental Retardation Facility resources would be utilized more cost effectively. Residents in community-based programs would have improved access to necessary specialized services.

Recommendations for System-Wide Services

Require DFPS to investigate abuse and neglect allegations in all residential facilities.

DFPS currently investigates all allegations of abuse, neglect, and exploitation in SMRF's, ICF/MR's managed by MRA's, HCS group homes, and TxHmL providers. However, for community-based ICF/MR's operated by private companies, the provider has investigatory responsibility. Unlike other facilities, DFPS is not involved in the investigation. After the facility completes their own investigation DADS reviews its thoroughness.

DFPS should assume investigatory responsibility for all facilities. DADS should not complete the investigations because it is not a neutral party either. The agency has the responsibility of contracting with providers and overseeing the program. DFPS does not have a conflict of interest because they do not operate facilities. Shifting the responsibility to DFPS would make the investigation process consistent across programs and types of providers.

Move Regulatory and Quality Assurance responsibilities to HHSC.

DADS Regulatory Services division has the responsibility of ensuring facilities are providing residents with a safe and healthy environment. This division conducts licensing and credentialing activities, surveys facilities, and provides enforcement for facilities with deficiencies.

The Quality Assurance and Improvement Unit (QAI), which is part of the Center for Policy and Innovation, manages and oversees a number of projects intended to improve the quality of services. Most QAI programs and initiatives involve studying and promoting best practices. However, there are two projects, surveys and web resources, which focus on client satisfaction and trust.

The QAI administers two surveys annually, the Nursing Facility Quality Review and the Long-term Services and Supports Quality Review (LTSS QR). These assessments allow individuals receiving services or their families to provide feedback about the quality of care, quality of life and client satisfaction.

The QAI also manages two web resources, the Quality Reporting System (QRS) and the Quality Matters website. QRS is a web-based tool providing individuals with information about specific providers. It is intended to allow people to compare facilities. It improves individuals' ability to make informed choices about which provider to use. QRS assigns a score to each facility based on their level of compliance with regulatory requirements. The website allows providers to access information about best practices and clinical literature reviews.

Moving the Regulatory Services Division and the survey and web-based resources sections of the Quality Assurance and Improvement Unit to HHSC will eliminate the appearance of impropriety and increase people's confidence in regulatory actions taken. It would increase transparency and trust in the system. HHSC should assume responsibility because it is an agency not directly involved in service provision and already oversees DADS' operations.

Notify DFPS and HHSC of all deaths in State Mental Retardation Facilities, ICF/MR's, and residences of HCS clients.

When any death occurs in a State Mental Retardation Facility, ICF/MR, or residence of an HCS client, DFPS and HHSC should be notified. Currently, if a death occurs in a SMRF and there are any indications the death is not due to natural causes, it is referred to DFPS for investigation. DFPS and HHSC should always be notified of any death. DFPS, an agency not involved in managing facilities, should then evaluate the situation and decide if an investigation is warranted.

HHSC should also be notified so they can begin to conduct a mortality review. The Long-term Services and Supports Quality Review (LTSS QR) should be expanded to

include a review of any deaths at State Mental Retardation Facilities, community-based ICF/MR's, or residences of HCS recipients. The review should include six components as suggested in the Government Accountability Office report on Medicaid Home and Community-Based Waivers: screen individual death with standard information; review unexpected deaths; include medical professionals in the reviews; document the review process, findings, or recommendations; use review information to address quality of care; and aggregate mortality data over time to identify trends. Notifying the Quality Assurance and Improvement section of HHSC (as recommended above) of any deaths occurring in any facility will allow them to collect the information necessary to complete the review.

Changing the notification procedures for resident deaths would eliminate the appearance of impropriety by increasing independence and transparency. Individuals would have more trust in the health and safety of residents because one agency would be responsible for administering the program; a second would be responsible for evaluating the circumstances of residents' deaths to determine if it was due to abuse, neglect, or exploitation; and a third agency would be performing a mortality review to identify any trends and address quality of care.

Improve and expand the Client Assignment and Registration system (CARE).

The ability to collect and analyze data about the system of services for individuals who are developmentally disabled is key to planning for service provision. DADS is frequently unable to provide requested information, particularly about community ICF/MR's and recipients of HCS, with the explanation that those data points are not among the numbers they track. For example, DADS does not track in a database instances in which an Interdisciplinary Team denies the exit of a state school resident requesting community placement, or the reason for which the request was denied. This information is entered into each client's file, but it cannot be easily retrieved or monitored remotely. Client file information should be stored electronically in a system that can be accessed by the department for auditing or data collection purposes. Additionally, DADS is unable to distinguish the number of individuals in particular waiver programs with a specific diagnosis, even though obtaining such information through the collection of a consumer's complete and updated medical history would ensure that individuals were enrolled in the waiver program that best meets their needs and would provide information key to planning for future needs.

MRA's state that the information they report to DADS is often not relevant to or useful in obtaining data on the people they serve. This makes it difficult to make valuable assessments and comparisons of the numbers of persons served per MRA, and the quality and appropriateness of services people receive statewide. The CARE system should have the capability to track individuals served by MRA's and those in community placements. At present, once an individual enters a home or facility owned by a private provider, neither DADS nor the MRA continues to account for the whereabouts or well-being of that individual beyond the initial 30 days after placement. For the safety and well-being of individuals, DADS should evaluate and enhance their data collection to

gather comprehensive, comparable, and relevant data for persons receiving services in all programs and settings.

Rejoin mental health services and mental retardation services under the authority of a single entity.

At the local level MH/MR services remain connected, but recent reorganization at the state level to separate departments by service provision means that while consumers have a single point of entry for either service type the local entities providing access to those services are required to report to two separate governing agencies and their related bureaucracies.

There is growing cross over between the population served by MR services who are also in need of MH services. While not all persons with a mental retardation diagnosis are in need of mental health services, the large percentage that are would be best served in a situation where the mental health and mental retardation service providers work together at the state level to establish wraparound services.

Create programs for increasing awareness of and care for individuals dually diagnosed with a psychiatric disorder and mental retardation.

As the number of individuals dually diagnosed with mental retardation and mental illness continues to increase, access to concurrent mental health and mental retardation services remains limited. In both SMRF's and community settings it is difficult to retain psychiatrists and psychologists willing, or experienced enough, to work with this particular population, and few providers operate specialized programs tailored to individuals with dual diagnoses. As a result, people may go undiagnosed, or receive inappropriate diagnoses and treatments. Persons experiencing a mental health crisis may have to be admitted to a state hospital, but individuals living in community-based ICF/MR's are at risk of losing their bed if their mental health needs require an extended stay in a specialized facility.

Public and private providers serving individuals with mental retardation must be equipped to meet their mental health needs. The San Angelo State School serves as a model for best practices in implementing programming and staff training for serving dually diagnosed individuals. A pilot project in the Concho Valley led by Project Janus attempts to address gaps in the service delivery system by building cooperative efforts between private and public providers of mental retardation services and mental health providers. Continued support of programs such as these is essential to educating providers on the prevalence and manifestation of dual diagnosis, and to establishing appropriate support services at all provider levels.

Continue to enhance and improve the Community Living Options Information Process (CLOIP).

The implementation of the Community Living Options Information Process in February 2008 has been a successful first step towards informing state school residents and their families about the residential and service options available. Feedback and information collected in this initial year of the program, as well as continued monitoring and assessment of the program, should be used to enhance and improve the process. All MRA staff, not just those directly involved in CLOIP, should be trained to have a full understanding of the service options available to their clients. Staff at the state schools should similarly be educated about the range of service options available in their region so they are able to take all the alternatives into account when making recommendations in Interdisciplinary Team meetings.

Conduct a comprehensive study of the guardianship system as it relates to those eligible for Intermediate Care Facilities for Person with Mental Retardation.

Significant concerns continue regarding the guardianship system as it relates to individuals living in both state-run and community-based settings. Complexities in the system arise from the unique needs and abilities of individuals that vary on a case by case basis and as such make it difficult to pass regulations that suit the needs of the whole population. There is concern that requiring the assignment of guardians impedes the rights of individuals who are competent to make many or most decisions independently, while failing to appoint a guardian in other situations may leave individuals vulnerable. The Judiciary Committee should perform a comprehensive review of the guardianship system as it relates to those eligible for an ICF/MR and sponsor legislation that ensures the protection of the rights of persons who are developmentally disabled; their review should have a particular focus on State Mental Retardation Facility residents, 60% of whom are purported to have no guardian.

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