Texas Biennial Disability Report

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Prepared by:
The Texas Council for Developmental Disabilities

Texas Council for Developmental Disabilities

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Dedication

This Report is Dedicated to:

Rene Requenez
Dec. 3, 1972 - Dec. 7, 2009

Rene Requenez of Edinburg was an active volunteer/advocate and founder of Access Granted, a non-profit organization whose goals revolve around empowering people to become productive, independent, and socially integrated into the world around them through the use of technology and special services. He was a member of the Consumer Directed Workgroup with the Health and Human Services Commission, and an accessibility tester for Adobe, the Microsoft Corporation and Ensemble Studios. Mr. Requenez received a bachelor's degree from The University of Texas Pan American, with a major in Rehabilitation Service. He was appointed to the Texas Council for Developmental Disabilities by Governor Perry in December 2008.

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About the Texas Biennial Disability Report

The *Texas Biennial Disability Report* regarding the state of services to individuals with disabilities was mandated by Senate Bill 374, passed by the 76th Texas Legislature (1999)(R). This legislation requires the Texas Council for Developmental Disabilities (TCDD) and the Texas Office for Prevention of Developmental Disabilities (TOPDD) to prepare a biennial report to the Legislature on the state of services to persons with disabilities in Texas; to outline present and future needs for consumer-friendly, appropriate, and individualized services and supports; and to make recommendations related to those services. Specifically, SB 374 directs TCDD and TOPDD to address the following:

- Fiscal and Programmatic Barriers to Consumer Friendly Services
- Progress Toward Individualized Service Delivery Based on Functional Needs
- Progress in Development of Local Cross-Disability Access Structures
- Projection of Future Long-term Care Service Needs
- Consumer Satisfaction and Consumer Preferences

TCDD and TOPDD are submitting separate reports for 2010. As directed in the government code, this report is focused on health and human services and does not address in detail the broader array of policy issues related to housing, education, transportation, and employment, that impact the lives of persons with developmental disabilities.

In each Biennial Report, TCDD has elected to focus a portion of the report on a key policy issue facing individuals with developmental disabilities. TCDD chose to focus the 2010 report on the *representative profiles of the needs and situations of people who are waiting for services in Texas.* Due to the current political and fiscal environment, the 2010 Biennial Disability Report incorporates both the advances and impasses of key policy initiatives that emerged in the 81st Texas Legislative Session (R) and over the most recent biennium (FY 2010-2011). In this report, the Council has also added statewide survey data to highlight the needs and situations of people with disabilities and their families who are waiting for services in Texas to the analysis TCDD conducted in 2008 addressing the state's allocation of resources for long-term services and supports. This report establishes a framework for legislative action during the 82nd Texas Legislative Session (2011).

The *Biennial Disability Report* is submitted to the Executive Commissioner of Health and Human Services, Governor, Lieutenant Governor, and Speaker of the House of Representatives no later than December 1st of each even-numbered year.

About the Texas Council for Developmental Disabilities

The Texas Council for Developmental Disabilities (TCDD) is a 27-member board appointed by the Governor. At least 60 percent of the members are individuals with developmental disabilities, parents of young children with developmental disabilities or family members of people with developmental disabilities who are unable to represent themselves. Members also represent the Department of Aging and Disability Services, the Department of Assistive and Rehabilitative Services, the Department of State Health Services, the Health and Human Services Commission, and the Texas Education Agency. Advocacy, Inc., the state's protection and advocacy program; the Texas Center for Disability Studies at The University of Texas; the Center on Disability and Development at Texas A&M University; and local organizations are also represented on the Council.

TCDD is established as a state agency by state and federal law to support and promote community inclusion and integration of people with developmental disabilities. The Council uses information about the service system, disability-related issues and people's needs, to develop projects and activities that focus on gaps and barriers in services and supports that help Texans with disabilities live in, work in and contribute to their communities. These activities, designed to impact the entire state, are developed in close collaboration with consumers, parents, advocates, state agencies, service providers, and policymakers.

COUNCIL MEMBERS

Public Members	Agency Representatives and Alternates
Brenda Coleman-Beattie, Austin	Mary Faithfull/Patty Anderson, Advocacy, Inc.
Rebecca Hunter Adkins, Lakeway	Penny Seay/Sandy Graham, Center for Disability Studies (The University of Texas at Austin)
Kristine K. Bissmeyer, San Antonio	Mike Benz/Amy Sharp, Center on Disability and Development (Texas A&M University)
Kimberly Blackmon, Fort Worth	Frank Genco, Texas Health and Human Services Commission (HHSC)
Kristen Cox, El Paso	Jeff Kaufmann, Texas Department of Aging and Disability Services (DADS)
Andrew D. Crim, Fort Worth	Kathy Griffis-Bailey, Texas Department of State Health Services (DSHS)
Mateo Delgado, El Paso	Kathy Clayton/Margaret Christen, Texas Education Agency (TEA)
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Executive Summary

In 2008, the Texas Council for Developmental Disabilities contracted with Human Services Research Institute (HSRI) to conduct a *Gaps Analysis* of the Texas service system for people with developmental disabilities. This research provided the foundation for recommendations made by TCDD in its 2008 Biennial Disability Report (available online at http://www.txddc.state.tx.us/resources/publications/biennial_report/biennialindex.asp). This external analysis evaluated Texas' performance with three performance benchmarks and found that:

- People with developmental disabilities in Texas do not have access to services with reasonable promptness;
- Many people with developmental disabilities do not receive services within the least restrictive setting appropriate to their needs; and
- The state's service system for people with developmental disabilities is not operated in a manner that promotes efficiency and economy.

Based on this analysis, TCDD presented the Legislature with four policy options to consider in response to this policy dilemma:

1. Do nothing and keep the current investment patterns and service array in place, which will continue the inefficient use of resources, the community service system will not meet local service needs and the interest lists for waiver services will continue to grow.
2. Increase funding significantly, but maintain the current system of organizing and delivering services. This approach may help marginally, but would perpetuate present inefficiencies, even if most of the new money were to be directed at community systems. Additionally, fewer people will be served than might otherwise be served in a more efficient system.
3. Keep funding relatively level, but de-emphasize the use of Intermediate Care Facility (ICF/MR) services in favor of Home and Community-based Services (HCBS). Under this approach, there may be a marginal impact on unmet service demand, but the state may achieve greater cost efficiencies.
4. Increase funding significantly and de-emphasize the use of ICF/MR services in favor of HCBS. This is the most forward-looking option that would provide a pathway toward increased efficiency while providing needed funds to strengthen the community system and address unmet service demand.

The 81st Texas Legislature increased funding for community and state operated ICF/MR services, but maintained the current system of delivering services. As a result, the gaps in the Texas service system that were previously identified in 2008 still remain. It is important to note that the 81st Legislature did, however, make significant legislative and funding improvements that impact the developmental disabilities services system in Texas. These 2010 Biennial Report Recommendations take that into account.

TCDD recognizes the state's current fiscal realities and therefore recommends that the 82nd Texas Legislature de-emphasize the use of ICF/MR services in favor of HCBS to achieve greater cost efficiencies. The Council recommends that Texas leaders look for ways to enhance home and community-based services as the ultimate long-term goal.

Strengthening Existing Community Services

1. Enroll an average of 4,604 additional individuals each year in HCBS waivers for individuals with ID/DD, increasing the 2006 capacity of 13,999 to approximately 64,085 individuals by 2018 in order to meet the service demand in Texas.
2. Provide sufficient funds to ensure that the Community Safety Net of community support services has the capacity to meet the needs of all individuals with intellectual and development disabilities (ID/DD) in the community. Including:
    2.1. Build capacity and fund the community mental health and substance abuse supports network to deter unnecessary placements in hospitals, criminal justice systems, and nursing facilities.
    2.2. Build capacity and fund the community infrastructure to support individuals with significant behavioral and/or medical needs in order to reduce reliance on institutional settings for specialized services and support.
3. Ensure that individuals are able to receive adequate amounts of needed services, based on their functional needs.
    3.1. Amend the eligibility requirements and service array of Medicaid waiver programs to serve individuals who have cognitive/emotional-behavioral/psychosocial disabilities with or without accompanying physical disabilities.
    3.2. Update the assessment of needs by replacing the Inventory for Client and Agency Planning (ICAP) tool with more current protocols such as the Supports Intensity Scale (SIS).
4. Use home-based services as the primary tool for addressing service demand, including modifying the Texas Home Living (TxHmL) HCBS “supports” waiver to include a broader array of services and a more robust level of services.
5. Enhance efforts to provide community respite alternatives.
6. Make necessary program changes to allow participants increased control over their individual service budget. Develop options for participant-directed services (CDS, SRO) in Medicaid and non-Medicaid programs (including waivers) that provide long-term services and supports including fee-for-service and managed care programs (STAR+PLUS). Extend participant-directed options to additional services beyond personal assistant services and respite services.
7. Develop specialized services and supports to allow individuals with developmental disabilities to age in place following the loss of a family caregiver.

8. Address insufficiencies in provider reimbursements that impact the availability and quality of community support services. Specifically:
    8.1. Increase rates and implement rate enhancements for community service providers to ensure that providers can recruit, train, and retain quality direct care staff and compete with other employers in the workplace.
    8.2. Create a hierarchical structure of reimbursement rates that recognizes case mix, complexity of care, family supports, and individual needs.
    8.3. Adjust reimbursement mechanisms to provide incentives for providers to enhance community supports and to implement innovative approaches in service delivery to improve quality and cost effectiveness.
    8.4. Use existing cost data as a basis for increases in payment rates for community agencies to catch up with underlying changes in the cost of doing business in Texas.
    8.5. Implement low-cost or no-cost workplace improvements to increase retention of direct care workers.
    8.6. Initiate a comprehensive study of community wages and benefits in 2011 and target for completion during 2012.
9. Explore quality-improvement strategies such as using self-advocates to provide peer support to consumers to increase safety, prevent abuse and neglect, and improve awareness of community living options.
10. Improve services and community living options for youth with disabilities transitioning from education settings to post-education activities.

Serving People in the Most Integrated Setting

11. Reduce the number of people served at state supported living centers. During the 2010-2018 period, the SSLC population should be reduced to not more than 1,465 individuals for Texas to simply meet the projected nationwide averages.
12. Cease admissions of children to state supported living centers. Continue and enrich efforts to accommodate all children under the age of 22 who are in state supported living centers and seek community placement using mechanisms such as in-home support services for children living at home with families and "Money Follows the Person" to provide opportunities for children to leave institutional settings in favor of HCBS alternatives.
13. Further develop the "Money Follows the Person" initiatives to accommodate a stronger transition of people living in ICFs/MR who prefer to receive services in the most integrated setting.

14. Modify the Community Living Options Information Process (CLOIP) to ensure that residents of state supported living centers who express interest in community living arrangements receive appropriate education about, and are able to access community options. Specifically:
    14.1. Improve the required documentation of mandated discussions with residents regarding their options for community supports and services, and include documentation concerning supports and services needed to successfully transition to a community setting, efforts to secure those services, and documentation of the reasons for not providing community living arrangements when requested.
    14.2. Revise procedures to require local authorities to provide choice options to residents in community ICFs/MR and fully reimburse local authority costs for those activities.
    14.3. Develop "transition assistance services" for participants in all HCBS waivers, including the HCS waiver program.
15. Improve and promote opportunities for ICFs/MR providers to transition to supporting individuals in the most integrated setting.

Projection of Future Long-Term Care Needs

16. Build expertise among service providers to assist individuals with developmental disabilities who are aging and their family caregivers in actively planning for their future long-term care needs.
17. Direct HHSC and its Departments (DADS, DARS, DFPS, DSHS) to develop the infrastructure to collect and share common information about individuals receiving services across access and intake systems at the state and local levels.
18. On a biannual basis, review and use data on the types of services selected by individuals with disabilities when they are offered Medicaid waiver supports to more efficiently fund future long-term supports based on consumer needs.
19. Continue and formalize the redesign of services and supports for people with ID/DD with executive and legislative branch sponsorship, to reduce the institutional bias in long-term services and support systems by 2018 and redirect funds to community services.
20. Pursue redesign through a collaborative process that engages people with intellectual and developmental disabilities and other appropriate stakeholders as primary constituents of the system.

Introduction

Every two years, the *Texas Biennial Disability Report* offers a snapshot of the strengths and weaknesses in the service delivery system for persons with disabilities and identifies opportunities for improvement and innovation in how the state provides supports to individuals and their families. In 2008, the Texas Council for Developmental Disabilities (TCDD) gathered and presented a detailed analysis of the gaps in the current system and opportunities for economic efficiencies that also meet consumer demands and life goals. The 2010 report builds on the discussion of the *Allocation of Resources for Long-term Services and Supports* that began in 2008 and offers recommendations based on progress in the last biennium, the challenges that remain, and the stated needs of people waiting for services. Recommendations are also based on statewide survey data that provide *representative profiles of the needs and situations of people with disabilities and their families who are waiting for services in Texas*.

Long-term services and supports are a priority for Texas when taking into consideration that:

- Individuals with disabilities and their families consistently report that accessing services and supports in their homes and communities is their greatest challenge;
- The Texas Legislature faces an estimated $20-25 billion shortfall, and state leaders are seeking strategies to reduce costs while continuing to meet essential needs;
- Legislators and other state leaders have a growing recognition that rebalancing the system of long-term services and supports is needed to meet service demands in a timely and efficient manner.

In many ways, Texas is better today than it was in 2008: a greater number of individuals with disabilities and their families have been offered home and community-based waiver services; the census at state supported living centers (SSLC) continues to decline; and the safety and protection of SSLC residents has markedly improved. Legislation passed during the last session also improved the process of informing residents in SSLC about community alternatives and made it easier for residents to move from large congregate settings using strategies such as "Money Follows the Person." Yet despite these accomplishments, Texas continues to face significant challenges with a growing number of children admitted to SSLCs and an interest list for waiver services that has exceeded growth projections despite additional waiver funds appropriated last session.

Strategies to rebalance the system of long-term services and supports must include actions that address its multiple segments simultaneously. Without a strong foundation in the home and community-based system of supports, Texas cannot expect to achieve its goal to serve individuals in the most integrated setting. Because the system components are dynamic and susceptible to ever changing federal regulations and state fiscal realities, leaders must establish a formal plan that outlines the vision for the Texas system that will live well beyond their tenure in office. The following review and recommendations outline the key components of the long-term support system and the modifications that will have the greatest impact in the lives of persons with intellectual and developmental disabilities and their families.

Report Methodology

To develop the recommendations in this report, TCDD reviewed and synthesized information from a variety of sources including research reports, demographic data and projections, and best practice models from other states. Texas specific data was obtained from state agencies including the Texas Health and Human Services Commission (HHSC) and its departments (DADS, DARS, DSHS, DFPS), and a review of actions taken by the Texas Legislature during the 81st Legislative Session (R)(2009). TCDD also obtained input from Council members, colleagues and advocates from disability groups throughout Texas.

In order to fully evaluate the state of services in Texas and make appropriate recommendations in 2008 on *The State's Allocation of Resources to Provide Long-term Services and Supports for Texans with Developmental Disabilities*, TCDD commissioned an external analysis of the current system including comparisons to other states in the nation. This external analysis came from two primary sources: The Coleman Institute on Cognitive Disabilities at the University of Colorado, and Human Services Research Institute (HSRI).

In 2008, TCDD engaged the Human Services Research Institute (HSRI) to examine selected aspects of the present system in Texas serving people with intellectual and developmental disabilities (I/DD). In response, HSRI completed a gap analysis to serve as a discussion point for state policy leaders and others pertaining to the current state of the Texas system, plus a series of action steps that can be used to guide systematic reform.

The gap analysis, action steps, and implementation strategies were presented in the *2008 Texas Biennial Disability Report* and in a more detailed report titled *"Closing the Gap in Texas: Improving Services for Persons with Intellectual and Developmental Disabilities.*" Both reports can be found on the TCDD website at http://www.txddc.state.tx.us.

In order to create *representative profiles of the needs and situations of people with disabilities and their families who are waiting for services in Texas*, TCDD partnered with The Institute for Organizational Excellence at The University of Texas at Austin and the Department of Aging and Disability Services to conduct a survey of individuals on the statewide interest lists for community-based waiver services. In the summer of 2010, a total of 10,000 surveys were distributed to individuals waiting for Home and Community-Based Services (HCS), and Community Living Assistance and Support Services (CLASS) waiver programs. Surveys were mailed in hardcopy and made available via the Internet. A total of 1,922 individuals responded (19.2%). Approximately 1,537 (15.4%) completed the hardcopy survey and 385 (3.9%) completed the Internet survey.

Individuals with disabilities and their families were asked about the services they currently receive, as well as the services they needed the most. Respondents reported what prompted them to place their name on the interest list for services, and to anticipate their future service needs. Demographic data pertaining to the age of the primary caregiver and financial resources were also a part of the survey. The complete survey is provided in Appendix B.

Disability Rates in Texas

The term "developmental disabilities" refers to a group of conditions or disabilities that occur prior to or at birth, or during childhood (i.e., before age 22), and result in substantial functional limitations in three or more life activity areas and reflect the individual's need for individualized supports and assistance. Individuals with limitations may have various diagnoses such as intellectual and developmental disabilities, cerebral palsy, epilepsy, autism, severe learning disabilities, head injuries, and others that may result in limitations in intellectual or physical abilities. People with such disabilities may need assistance throughout life in self-care, employment, housing, and social interaction. In the United States, approximately 1.8 percent of general population has a developmental disability, or approximately 446,081[1] individuals in Texas.

Most people with developmental disabilities receive key supports from their families or live independently with or without publicly-funded developmental disabilities services. Public developmental disabilities service systems provide resources and supports to a relatively small percentage (approximately 20-25 percent) of all individuals with developmental disabilities. Public systems focus principally on people who have functional limitations and require services over and above the supports that their families are able to provide or that they can obtain through generic human services programs.

Trends in Service Demand

Demand for publicly-funded developmental disabilities services is growing nationwide and has been increasing at a rate slightly greater than population growth alone. Increased demand is the product of several factors including the development of community services and supports that better meet the needs of individuals and families, and the increased longevity of people with developmental disabilities. The mean age at death for persons with intellectual disabilities or developmental disabilities rose from 19 years during the 1930s to 66 years in 1993, an increase of 247 percent.[2] Similarly, the life span of people with developmental disabilities has increased as the result of better health care and is approaching the average lifespan of the general population. This increased longevity has two ramifications for developmental disabilities service systems: (a) the "turnover" of individuals receiving services is reduced (and, consequently, there is less capacity to absorb new demand); and (b) there is a growing population of individuals who live in households in which the primary caregivers are themselves aging. About 25 percent of people with developmental disabilities reside in households in which the primary caregiver is age 60 or older. As caregivers grow older, their capacity to continue to support individuals with developmental disabilities diminishes.

[1] Administration on Developmental Disabilities and U.S. Census Bureau, Population Finder for Texas at http://www.census.gov/.

[2] Janicki, M.P., Dalton, A.J., Henderson, C.M., & Davidson, P.W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. Disability and Rehabilitation, 21, 284-294.

Over the past several decades, many states have reexamined the delivery of services to their citizens with developmental disabilities. During this timeframe, the general trend has been towards a decentralization of services where individuals can receive home and community-based services (HCBS) instead of "treatment" in state institutions. This trend is the result of research, advocacy and federal actions such as the *Americans with Disabilities Act*, the *Individuals with Disabilities Education Act,* and the Supreme Court decision in *Olmstead v. L.C.* These actions are consistent with providing services in the least restrictive manner possible and the philosophy that individuals should be supported to make their own decisions concerning their lives.

Texas' Ranking in Nation

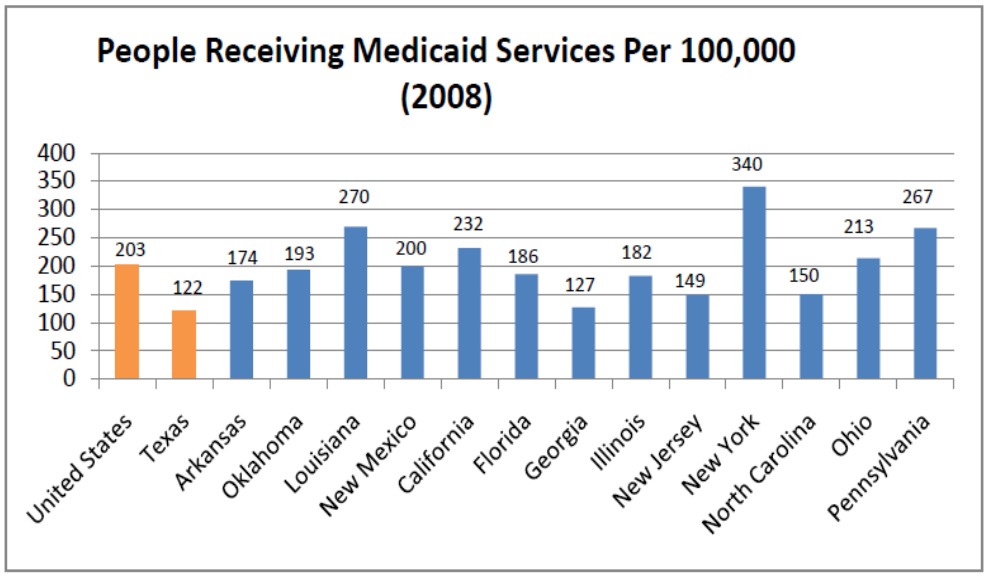
Texas has invested heavily in services for people with intellectual and developmental disabilities. Texas ranks 49th out of the 50 states in providing community-based services to individuals with developmental disabilities – above only Mississippi. Nearly 13 percent of the nation's individuals with disabilities that reside in large state facilities are located in Texas.[3] Yet, even as the state established a community services system, it has maintained an enduring commitment to Intermediate Care Facilities for Persons with intellectual and developmental disabilities (ICFs/MR) including the state supported living center network (previously called state schools). The current system of long-term services and supports in Texas falls significantly behind other states in several key areas:

- **Texas spends very little on Medicaid developmental disabilities services and provides services to fewer people than most states.**
    - ☑ Texas lags the nation, and nearly all comparison states, in the number of persons who receive Medicaid developmental disabilities services.
    - ☑ Texas spends **$69.07** per citizen on developmental disabilities services. Nationwide, on average, states spend **$144.93** per citizen.
    - ☑ Texas furnishes Medicaid developmental disabilities services to 122 persons per 100,000 population, compared to the national average of 203 – or 40 percent below the nationwide average.[4] (See Chart 1.)

- **Texas employs its fiscal resources inefficiently.**
    - ☑ The Texas system emphasizes the use of more expensive services more frequently than other states.
    - ☑ Texas spends a greater proportion of its Medicaid dollars on ICFs/MR compared to the national average.

[3] United Cerebral Policy. 2007. "The Case for Inclusion." Washington, D.C.
[4] R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008.

Chart 1



R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008

- **Texas and other states are seeing notable changes in the trends of where people choose to receive services, when they are allowed to choose.**
    - ☑ A higher percentage of individuals now prefer to receive services in the communities in which they live.
    - ☑ The characteristics of individuals receiving services in ICF/MR settings are similar to those receiving home and community-based waiver services. The analysis of DADS' data by HSRI revealed that approximately 29 percent of individuals with Pervasive Level of Need (LON) are in waiver programs and 40 percent of individuals with Extensive LON are in waiver programs.

People with developmental disabilities nationally argue strongly for support systems that look decidedly different than the current service system in Texas. As articulated in the Alliance for Full Participation Action Agenda (Alliance for Full Participation, 2005):

> "We [people with disabilities] do not belong in segregated institutions, sheltered workshops, special schools or nursing homes. Those places must close, to be replaced by houses, apartments and condos in regular neighborhoods, and neighborhood schools that have the tools they need to include us. We can all live, work and learn in the community."

Texas faces difficult policy choices in responding to the needs of its citizens with intellectual and developmental disabilities. This circumstance is fueled by a growing unmet demand for services, changing expectations among people with developmental disabilities and their families, diminished funding and other factors.

The most pressing issue facing the Texas service system is the lack of community capacity to meet current and future service demand. Texas lags considerably behind most states in terms of services offered to people with intellectual and developmental disabilities. For example:

- New York, with a total population of about 4 million less than Texas (TX: 23.5M vs. NY: 19.3M) serves more than twice as many people through its developmental disabilities service system as Texas (NY: approximately 100,000 vs. TX: approximately 43,000).
- California, with a total population 60 percent greater than Texas (CA: 38.0M vs. TX: 23.5M) provides services to 220,000 children and adults with developmental disabilities, or five times as many as Texas.

The situation is exacerbated by the fact that Texas, for several decades, has been one of the fastest growing states, with no immediate end to this population growth pattern in sight. According to the Texas State Data Center (The University of Texas, San Antonio), the population of Texas could reach 51.7 million by 2040. Given such growth, it will be an extraordinary challenge to address the backlog of unmet needs for long-term services while simultaneously keeping pace with population-driven growth in demand.

Texas Benchmark Performance

In 2008, the Texas Council for Developmental Disabilities (TCDD) contracted the services of the Human Services Research Institute to conduct an external analysis of the Texas service system and evaluate its performance against a series of three performance benchmarks:[5] Although Texas has made incremental steps towards improving some aspects of service delivery, those efforts were not significant enough to change the overall assessment of system performance, which has remained unchanged since 2008.

Benchmark 1: People with I/DD have access to and receive necessary publicly-funded services and supports with reasonable promptness.

Assessment: People with intellectual and developmental disabilities (I/DD) in Texas do not have access to services with reasonable promptness. Texas significantly and chronically underfunds its service system, resulting in significant numbers of people who do not receive the supports they need. This is evident in the service utilization rates in Texas that are far below the national average. Insufficient funding also weakens the system's overall capacity to support the most vulnerable individuals such as those with complex medical needs or behavioral challenges, within the community.

[5] For complete report on gap analysis, please see "Closing the Gap in Texas" report on the TCDD website at http://www.txddc.state.tx.us/public_policy/gaprpt/gaprpt.asp.

Benchmark 2: Services and supports are provided in the most integrated setting appropriate to the needs of the individual.

Assessment: Many people with I/DD do not receive services within the least restrictive setting appropriate to their needs. By all measures, Texas relies more heavily on state supported living centers (previously called state schools) and privately-operated ICFs/MR than most other states. In fact, the discrepancy in Texas' investment in institutions compared to its investment in community services is extraordinary. Texas ranks eighth highest in the nation in its percentage of people with developmental disabilities living in residential facilities with 16 or more beds. While there have been actions taken to decrease this reliance, stronger actions have been taken to maintain its investment in ICFs/MR options. The state admits children into state supported living centers at a pace more than twice the national average. In FY 2008-2009, the state added 1,690 positions to the state supported living center structure at a cost of approximately $1.04 million and in FY 2010-2011 the state increased the number of SSLC positions by 1,160, increasing the total number of funded, full-time equivalent positions in the SSLC network to 14,073.

Benchmark 3: The system must promote economy and efficiency in the delivery of services and supports.

Assessment: The state's service system for people with developmental disabilities is not operated in a manner that promotes efficiency and economy. Texas' average spending per citizen for I/DD services is well below the national average. Texas continues to devote a greater share of its Medicaid dollars to large congregate care services than is typical nationwide. Furthermore, there presently are no actions underway to reformulate payments to ensure that they are adequate.

Given the present fiscal environment and how these funds are applied, the state system is ill-positioned to address the present and future needs of its citizens with intellectual and developmental disabilities.

Policy Options

Based on the external analysis and comparison to other states, Texas leaders have four key policy options to consider:

1) **Do nothing.** Keeping the current investment patterns and service array in place will most likely result in more of the same – i.e., continued inefficient use of resources, a community system that cannot easily meet local service needs, and a growing unmet demand for services.
2) **Increase funding significantly, but maintain the current system of organizing and delivering services.** This approach might help at the margins, but it would tend to perpetuate present inefficiencies, even if most of the new money were to be directed at community systems. Overall, fewer people will be served than might otherwise be the case.
3) **Keep funding relatively level, but de-emphasize the use of ICF/MR services in favor of home and community-based services (HCBS) financing options.** The transition itself will require funding, but afterwards the state may drive down its "per participant cost" due to increased reliance on lower cost options. Under this approach, there may be marginal impact on unmet service demand. State leaders, however, must take into account the fact that the present overall fiscal effort is already well under the national average.
4) **Increase funding significantly and de-emphasize the use of ICF/MR services in favor of HCBS funding options.** This is the most forward-looking option. It would provide a pathway toward increased efficiency within the system while providing needed funds to strengthen the community system and systematically address unmet service demand. Further, it would place the state on a firmer footing in developing a system that can better address growing needs while systematically reducing the interest list for services.

The 81st Texas Legislature increased funding for community services and state supported living centers, but maintained the current system of delivering services. As a result, the gaps in the Texas service system that were previously identified in 2008 still remain. It is important to note that the 81st Legislature did make significant improvements to the developmental disabilities services system in Texas and the proposed 2010 Biennial Report Recommendations take those actions into account.

The Texas Council for Developmental Disabilities recognizes the fiscal realities of diminished funding and therefore recommends that the 82nd Texas Legislature de-emphasize the use of ICF/MR services in favor of HCBS waiver options to achieve greater cost efficiencies (Option #3). The Council also recommends that Texas leaders look for ways to increase funding for HCBS significantly (Option #4) as the ultimate long-term goal.

The state system of long-term services and supports was at the forefront of discussion during the 81st Texas Legislative Session (2009)(R). Legislation was passed that addressed the growing interest list for community-based services and system functions such as community living options and case management. There was a great deal of focus on the protection and safety of residents in state supported living centers (SSLCs) in the wake of a federal investigation by the Department of Justice and multiple incidents of abuse and neglect at specific centers. A summary of legislative actions in these areas is provided below.

Protection of Residents in State Supported Living Centers

A report from the federal Department of Justice (DOJ) stated that Texas' 13 state supported living centers fail to protect residents from harm. On June 4, 2009, Governor Rick Perry signed a resolution supporting a $112 million, five-year plan to address abuse and neglect claims at the 13 state centers, under an agreement to resolve problems identified by the DOJ in its four-year investigation of the residential institutions. Under the settlement, Texas must improve living conditions and medical care and more quickly investigate claims of abuse. The state must also ensure that residents are receiving individualized care and assist them in moving to the most integrated living settings when appropriate. This includes educating residents and families/guardians about available community placements so they can make informed choices. The Texas Senate and House of Representatives both unanimously approved Senate Current Resolution 77 by Senator Jane Nelson in 2009, (S.C.R. 77, 81th, (R)) supporting this settlement.

Also in 2009, the Texas Legislature approved a number of actions to improve care at the SSLCs, including the hiring of hundreds of new employees statewide, more staff training and creating complaint hotlines. Random drug tests and fingerprinting for employees are now required. S.B. 643 (81th, (R)) by Senator Nelson related to greater protection of SSLC residents and included measures such as installation of security cameras and increased background checks. This bill also created an independent ombudsman office for residents and families.

Baseline reviews conducted by independent monitoring teams selected jointly by DOJ and the state were completed at each of the state supported living centers from January-May, 2010. Based on the evaluations, each facility is working to improve services and care, such as reducing the use of restraints, including minimizing or eliminating the use of mechanical restraints. However, the evaluations also identified problems such as an inadequate number of psychiatrists on staff, needed improvements in transition of individuals to community settings, dental care and other issues.

Despite these reports and other problems, state supported living center proponents advocated vigorously to keep all 13 facilities open and gained support from legislators during the 81st legislative session. Several legislative proposals were introduced that called for state supported living center consolidation with the intent to bring Texas in line with the lower institutionalization rates of other states that provide more services for citizens in community settings, including programs for individuals with more intensive support needs.

Home and Community-Based Waiver Service Expansion

Special Provision Section 48 Contingency Appropriations of the General Appropriations Act (S.B. 1, 81st (R)) allocated funds for home and community-based programs and 1915(c) waivers in an effort to reduce the wait time for services, expand waiver related community services, and provide specific direction related to reshaping the system of care for persons with disabilities. Approximately $464.5 million was allocated in state and federal funds to reduce the interest lists for home and community-based programs and expand the number of individuals receiving waiver services in the community by 7,832 individuals by August 2011. Section 48 required DADS to increase the number of slots during fiscal years 2010-2011 for (1) individuals moving out of medium and large intermediate care facility for persons with intellectual and developmental disabilities (ICFs/MR), (2) children aging out of foster care services, (3) children who are at risk of being institutionalized, and (4) individuals at imminent risk of institutionalization. Unfortunately, the total numbers of new waiver services offered this biennium was significantly lower than the original 7,832 due to overall cost growth within each waiver. In 2008, TCDD recommended that waiver services be offered to no less than 4,604 individuals each year (9,208 in biennium) to simply meet the national averages of service delivery by 2018.

Section 48 further directed DADS to reduce the overall number of SSLC residents through census management, not closure, and to move residents into community programs through the community living options information process. In 2009, approximately 252 moved to an alternative living environment, while 177 new residents were admitted to SSLCs.[6] Additionally, DADS reported that in FY 2010, 330 SSLC residents moved into community programs and 170 individuals were admitted into the facilities.

Section 48 also required HHSC to study and recommend options for creating a managed care pilot for Texans with intellectual and developmental disabilities. The proposed options include capitated and non-capitated models and assume that the goal is to create additional waiver slots by delivering more cost-effective services; that long-term savings are possible, but immediate short-term savings are unlikely and all options will require some startup costs; and that significant service system redesign will be required. An entitlement to HCBS services would not be created. Each option creates incentives for more cost-effective management of I/DD services so that savings can be directed to serving additional clients.[7] A full report of recommendations is expected December 1, 2010.

[6] State Supported Living Center Update, Texas Department of Aging and Disability Services, June 2010.
[7] Managed Care Pilot Study Update, Presentation to Senate Finance Committee August 18, 2010 by Texas Health and Human Services Commission.

Case Management Transfer from Providers to Local Authorities

Under the direction of Special Provision Section 48, the Department of Aging and Disability Services (DADS) transferred case management services under the Home and Community-based Services (HCS) Waiver from service providers to local authorities on June 1, 2010. In addition to transferring responsibility for case management, the rule change developed service coordination activities for the local authorities under the state's targeted case management strategy. This transition, among other efforts, provided an ally for consumers and families and increased their ability to choose or refuse specific services and supports as desired; request alternate services and providers; and appeal decisions about the services and supports they receive. Over time, it will enhance local provider oversight and accountability while enabling service coordinators to maintain the integrity of their advocacy role on behalf of each service recipient.

Under the new process, there are three required service planning tasks for each individual in the HCS program. The first is developing a Person-Directed Plan (PDP) to explore the individual's goals, desires and supports needed to achieve the outcomes desired by the individual or legally authorized representative (LAR) and to ensure the individual's health and safety. Then an Individual Plan of Care (IPC) is developed which specifies HCS services to be provided, as well as non-waiver services to be accessed. Finally an Implementation Plan (IP) is developed by the program provider, with input from the individual or LAR, and approved by DADS. It details strategies the provider will use to deliver the HCS services and training the individual may need as indicated in the PDP and the IPC.

State Budget Shortfalls

Perhaps the greatest challenge facing the 82nd Texas Legislature is a budget shortfall estimated as high as $25 billion for the next two fiscal years (FY 2012-2013) – approximately 25 percent of current state (non-federal) spending. This deficit is mainly a result of the weak national economy, declining state income, population growth and recurring state expenses created by spending the federal stimulus money. This is expected to have devastating effects on the state's programs, including services and supports for people with disabilities. The budget shortfall could mean drastic reductions in current services as well as increases in waiting lists, cuts in provider rates and difficulty in receiving medical services.

Texas is struggling with how to handle the budget crisis while still meeting essential needs. Because of the financial shortfall, all state agencies were instructed to reduce their state funds by five percent this year and to include an additional 10 percent cut in state funds in their budget proposals for the next two years. Most baseline budget requests will severely reduce services. For example, the Department of Aging and Disability Services (DADS) baseline budget request would reduce the number of persons served in community-based Medicaid waivers in FY 2012-

2013 by 13,368 individuals. Other DADS programs potentially affected include state supported living centers, nursing facilities and intermediate care facilities for persons with intellectual and developmental disabilities (ICFs/MR). The DADS Exceptional Items request, if funded, would maintain existing services for Texans who receive waiver services and other community-based services. Additionally, state leadership announced in mid-November that agencies will be asked to make additional budget reductions of 2-3% for FY 2011.

Some programs are exempt from these reductions, such as funds to maintain eligibility in Medicaid entitlement programs, the Children's Health Insurance Program (CHIP) and foster care. However, this can put other programs at risk of even higher budget cuts. Several items that were exempt in the past were dropped from the protected list this time including prisons, adoption subsidies and an effort to diagnose toddlers' physical and mental disabilities.

Moving Forward

Several legislators have acknowledged that the measures taken in the last legislative session were aimed more at addressing immediate problems with health and safety issues than taking proactive steps to develop a comprehensive plan to reform and rebalance Texas' system of long-term services and supports for individuals with disabilities. Unfortunately, focusing the discussion on whether or not state supported living center should close rather than debating what is needed to enhance the current capacity of the community-based service system and to address over-spending in large congregate settings will not move Texas forward. In the 2011 environment of budget shortfalls and growing service demand, TCDD hopes that Texas leaders will once again engage in a meaningful, informed debate about what is needed to move the Texas long-term care system forward.

Strengthening Existing Community Services

Home and community-based services are the foundation of the long-term service and support system and a lifeline for persons with disabilities. There are thousands of individuals and family members in Texas who seek services and supports in the community as indicated by the state waiver interest lists which exceed projections and now consists of 103,145[8] individuals who wish to remain in their own homes or live with family and friends. There are also a significant number of individuals who reside in state supported living centers who wish to transition to a setting in the community. However, many of those transitions are delayed due to limited availability of community programs appropriate for individuals with more complex needs, particularly those who may need positive behavior intervention supports.

Texas faces a major strategic challenge: keeping pace with the rising demand for I/DD services, while simultaneously adding new capacity. The community system infrastructure in its present form may not support rapid system expansion and reconfiguration. If Texas is interested in rebalancing the long-term supports system, it is critical to have a more solid foundation in its community supports. Key areas that need immediate attention include workforce recruitment and training, service reimbursement rates, and a system that assures that individuals with complex needs are appropriately served.

Ideally, once an individual applies for services and is deemed eligible, he or she will start receiving services with reasonable promptness – a key benchmark for a state's performance. General standards indicate that individuals with emergency or crisis needs should receive services within 90 days or sooner. Likewise, those with critical near-term needs should receive services within 6-9 months.[9] When these standards cannot be met, Texas maintains interest lists for people who are un-served and seeking services, or underserved and seeking additional or changed services.

> Texas falls significantly below the national average in the number of individuals served per capita and the dollars spent per person.

There already is a substantial shortfall in Texas' current system to meet the expressed demand for I/DD services. In August 2010 there were 103,145 people on interest lists, including 45,756 on the HCS interest list.[10] (See Table 1.) Furthermore, individuals who are on the interest list must wait years to receive services. Some on the HCS interest list must wait 8-9 years. (See Table 2.)

[8] R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008.
[9] Federal Medicaid Act 42 C.F.R. § 435.930(a).
[10] Texas Department of Aging and Disability Services, Interest List and Caseload Summary, September 2010.

Table 1: Individuals on Interest Lists for Community-Based Waiver Services (2010)

Program	# on Interest List
Community-Based Alternatives (CBA)	35,220
Integrated Care Management (ICM) 1915(c) waiver	*2846
Community Living Assistance and Support Services (CLASS)	32,650
Deaf-Blind with Multiple Disabilities (DB-MD)	316
Medically Dependent Children Program (MDCP)	18,404
Home and Community-based Services Program (HCS)	45,756
STAR+PLUS 1915(c) waiver	*5,288
Total	****140,480**
Numbers as of September 2010	

* Individuals who are not SSI eligible and who want 1915(c) CBA-like waiver services are placed on an interest list. This interest list is managed by DADS and the numbers above reflect those non-SSI individuals on the interest list whose eligibility has not yet been determined.

** Count is duplicated. The unduplicated count is 108,433. **The unduplicated count without STAR+PLUS is 103,145.**

Source: Texas Department of Aging and Disability Services, Interest List and Waiver Caseload Summary, September 21, 2010

Table 2: Percentage of Individuals Waiting for Specific Waiver by Time Spent Waiting

Time on Interest List	CBA	ICM	CLASS	DBMD*	MDCP	HCS
0-1 years	48.3 %	99.9 %	22.0 %	80.0 %	30.7 %	20.7 %
1-2 Years	43.6 %	0.1 %	19.7 %	14.9 %	25.5 %	18.6 %
2-3 years	8.1 %	0 %	17.7 %	3.8 %	22.5 %	14.8 %
3-4 years	0 %	0 %	15.1 %	1.3%	18.6 %	12.2 %
4-5 years	0 %	0 %	9..6 %	0 %	2.7 %	9.6 %
5-6 years	0 %	0 %	7.7 %	0 %	0 %	7.6 %
6-7 years	0 %	0 %	7.5 %	0 %	0 %	7.5 %
7-8 years	0 %	0 %	0 %	0 %	0 %	6.9 %
8-9 years	0 %	0 %	0 %	0 %	0 %	2.1 %
9+ years	0 %	0 %	0 %	0 %	0 %	0 %

*Some people on the DBMD Interest List have reached the top of the list multiple times and declined services, yet choose to remain on the list. Additionally, the list includes individuals under the age of 18 not yet eligible to receive services.

***Source: Texas Department of Aging and Disabilities, (September 21, 2010). DADS Interest List and Waiver Caseload Summary*

Of particular concern is the recognition that Texas' interest lists are growing more rapidly than projected. For example, in 2008, DADS reported 79,925 individuals waiting for waiver services (unduplicated without STAR+PLUS). From that data, HSRI projected that Texas interest lists might grow to as many as 99,016 by 2018. Already in 2010, Texas has exceeded that projection and reports 103,145 individuals and families waiting for home and community- based services.

A similar pattern exists for the HCS interest list – in 2008, there were approximately 37,187 on the interest list for HCS services. HSRI projected that the list would grow to 40,000 by 2010. In 2010, a total of 45,756 were waiting for services – well over the projected levels.[11]

Future Demand for Services

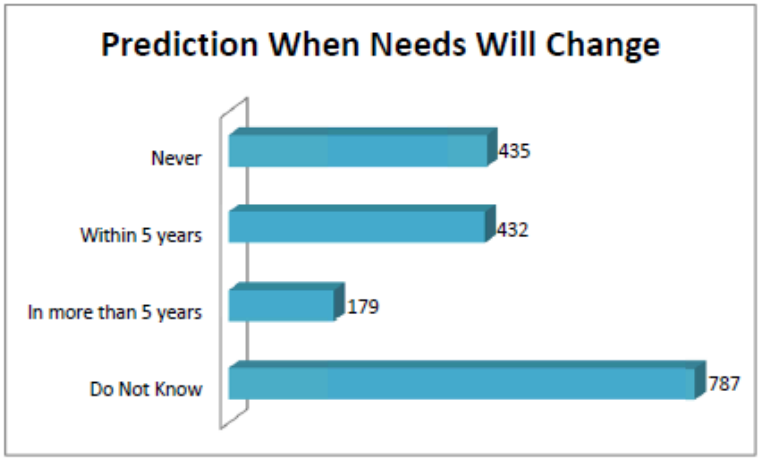
If nothing is done to intervene, the number of people seeking long-term care services and supports is expected to grow even larger due to the projected growth in the state population. The Texas population is growing faster than the national population. Between 1990 and 2007, the Texas population grew by 41 percent, from 17.0 million to 23.9 million, while the U.S. population increased by only 21 percent. According to the Texas State Data Center (The University of Texas, San Antonio), the population of Texas could reach 51.7 million by 2040. Given such growth, it will be an extraordinary challenge to address the backlog of unmet needs for long-term services, while simultaneously keeping pace with population-driven growth in demand. Complicating matters, HSRI finds that in most states, waiting lists grow at a rate greater than population growth alone.

Texas has recently sought to accommodate unmet service demand by allocating additional funds for waiver services (79th, 80th, and 81st Texas Legislatures). These efforts have helped thousands more people; however, these allocations are insufficient to keep up with the overall demand. Texas presently has no comprehensive, long-range plan for closing the gap between system capacity and service demand. No targets have been established to secure an annual reduction in this gap. Absent such strategies, the current gap is expected to worsen.

Many individuals and families find it difficult to anticipate at what point their needs for services and supports will change. In a survey of those on the state interest list for home and community-based waiver services, about one-quarter of respondents anticipate their needs will change in the next five years, however, almost half simply did not know when their service needs will change. (See Chart 2.) This survey provides only a snapshot of future demand – Texas does not employ an accurate and reliable means for tracking demand over time.

[11] 2008 Texas Biennial Disability Report, Texas Council for Developmental Disabilities, December 1, 2008.

Chart 2



Source: Biennial Report Survey of Individuals on Texas Interest Lists, Institute for Organizational Excellence, The University of Texas at Austin, 2010.

Impact of Diminished Community Capacity on Individuals with Disabilities

In Texas, the gap between present capacity and unmet needs means Texas does not operate its service system in a manner that ensures that individuals will receive services promptly – another state performance benchmark. People in need must wait for the next available service opening or HCBS waiver slot and cannot count on getting assistance soon. While waiting – most for years – their situation may deteriorate and caregivers experience exceptional burden under the stress of long-term unassisted caregiving.

Texas also requires individuals to seek programs with pre-defined services that individuals may or may not want. For example, if an individual is seeking supported employment services, but is only given a choice of day habilitation or sheltered work, the forced response would not reflect a person's true need or life goal. Likewise, if an individual wants supported apartment living but can only choose between ICFs/MR services or a community group home, then the forced choice would also be inaccurate. Thus, constructing interest lists may inadvertently allow the supply of services illustrated within their data gathering protocol to influence individual responses. The outcome is a skewed view of demand that reinforces expansion of the existing service supply without accounting for services individuals and families may truly be seeking. According to the survey of individuals on DADS waiver interest lists, the most needed services were respite, specialized therapies and behavioral support services.[12] Individuals currently enrolled in HCS selected residential supports (group homes) 30% of the time, which may

[12] Biennial Report Survey of Individuals on Texas Interest Lists, Institute for Organizational Excellence, University of Texas at Austin, 2010.

indicate that services chosen at the time of enrollment are not representative of the services needed at the time a person signs up for waiver services.[13]

Perhaps the most serious ramification is the fact that people are limited to receiving services in settings where there are openings rather than from providers that meet their true needs or life goals. This practice undermines individual choice. Openings may not be available near the individual's home community, making it difficult for an individual to maintain ties with friends and family. People needing services are often unable to select a community service and may have to choose an ICF/MR or state supported living center because it is available when they are having a crisis. Often in Texas, the crisis is due to behavioral challenges that many other states manage effectively in their community service systems.

For more detailed data on the Texas Community-based Service Delivery System, see *Closing the Gap in Texas: Improving Services for Persons with Intellectual and Developmental Disabilities* at http://www.txddc.state.tx.us/public_policy/gaprpt/gaprpt.asp.

[13] Texas Department of Aging and Disability Services, Analysis of Data Provided Over Time, 2010.

TCDD Recommendations for Strengthening Community Capacity

1. **Enroll an average of 4,604 additional individuals each year in HCBS waivers for individuals with ID/DD, increasing the 2006 capacity of 13,999 to approximately 64,085 individuals by 2018 in order to meet the service demand in Texas.**

   Currently, 103,145 Texans are waiting for services. In order to accommodate most, if not all, of the unmet demand, Texas should expand system capacity at a steady pace by serving a minimum of an additional 4,604 people each year between 2011 and 2018 in HCBS waivers for individuals with I/DD. Such action would result in another 46,040 individuals receiving services by 2018. Increasing the size of its waiver program would provide Texas with a HCBS waiver capacity relative to the size of its state population – the capacity other states already possess. By employing the HCBS waiver to finance this expansion in capacity, Texas will be able to secure federal Medicaid dollars to underwrite 59.44 percent of the cost of this expansion. Section 48 Contingency Appropriations (81st Texas Legislature (R)) allocated $464.5 million in state and federal funds to reduce the interest/waiting lists for home and community-based programs and expand waiver slots by 7,832 by August 2011. However, the total number of waiver slots was significantly reduced in programs such as CLASS, CBA, MDCP because appropriations were needed to fund the overall cost growth in these programs.

2. **Provide sufficient funds to ensure that the Community Safety Net of community support services has the capacity to meet the needs of all individuals with intellectual and development disabilities (ID/DD) in the community. Including:**

   2.1. **Build capacity and fund the community mental health and substance abuse supports network to deter unnecessary placements in hospitals, criminal justice systems, and nursing facilities**.

   An estimated 1,037,883 adult Texans have a serious mental illness. The Continuity of Care Task Force was convened by the Texas Department of State Health Services (DSHS) to study and make recommendations on improving care for individuals with behavioral health disorders who move through multiple state, local and other provider systems. The final report, completed in August 2010, states that, “In (fiscal year) 2009, more than 190,000 Texans received mental health treatment services funded by DSHS at community mental health centers, and over 15,000 persons were admitted to state mental health facilities. Over the past 50 years, people have been moved from institutions to incarceration at unprecedented rates. Community-based supports are needed to make recovery more feasible.”[14]

[14] September 2009 report by the National Leadership Forum on Behavior Health/Criminal Justice Services.

2.2. Build capacity and fund the community infrastructure to support individuals with significant behavioral and/or medical needs in order to reduce reliance on institutional settings for specialized services and support.

Supports for individuals with challenging behaviors through community programs are often not available, creating an unnecessary reliance on state supported living centers to provide these specialized services. Enhancing community-based capacity would include: supportive housing in the community, "step down" levels of care, including residential care and assisted living for individuals who do not need hospitalization, outpatient programs to restore competency in the community; and more judicial alternatives, including an option to order individuals to take psychotropic medications, with specific provisions. In the fall of 2010, DADS began convening focus groups around the state to identify specific needs of persons with behavioral and medical needs in the community. The need for behavioral support services is the second most needed service according to responses from people on the interest list.

3. Ensure that individuals are able to receive adequate amounts of needed services, based on their functional needs.

3.1. Amend the eligibility requirements and service array of Medicaid waiver programs to serve individuals who have cognitive/emotional-behavioral/psychosocial disabilities with or without accompanying physical disabilities.

Individuals who have disabilities due to conditions such as fetal alcohol spectrum disorders, traumatic or acquired brain injuries, autism, and others often find they are unable to successfully access the supports they need in the community. The Texas Health and Human Services Commission (HHSC) is requesting funding for an exceptional item in its 2012-2013 Legislative Appropriations Request (LAR) to create a pilot Medicaid Community Support Waiver for people with acquired brain injury (ABI). Two options were recommended in the *"Feasibility Study for Providing Community Support and Residential Services for Individuals with Acquired Brain Injury"*; however only one – for a Community Support Waiver – was proposed, due to the state's tight budget. This pilot waiver would provide supports for 200 individuals living in the community who have functional limitations resulting from ABI. The proposed client-directed waiver would allow individuals to choose from an array of services that best fit their individual needs within the annual limit of $15,000 per person, per year. The Department of State Health Services also initiated a pilot project for a Medicaid waiver for children with "serious emotional disturbances" (SED). The Youth Empowerment Services (YES) waiver is designed to allow more flexibility in funding intensive community-based services and supports for children with SED and their families, preventing custody relinquishment, and reducing or averting inpatient psychiatric hospital stays. This pilot began in Travis and Bexar counties, where it is expected to serve up to 300 children ages 3-18 over the course of the pilot. Detailed evaluation of the implementation and cost-effectiveness of these programs is needed.

3.2. Update the assessment of needs by replacing the Inventory for Client and Agency Planning (ICAP) tool with more current protocols such as the Supports Intensity Scale (SIS).

The SIS was published in 2004 and is in use in 14 states. It is easy to align with individual plans of care and, in an increasing number of states, is being used as the basis of developing individual budgets or reimbursement levels for state waiver programs. Because the instrument is supports needs based, it captures some of the natural supports that Texas does not need to pay for. It is a nationally normed tool structured around client interviews. SIS assessment results are grouped and would be very useful in matching available waiver dollars to the individual community support needs of waiver-eligible individuals.

4. Use home-based services as the primary tool for addressing service demand, including modifying the Texas Home Living (TxHmL) HCBS "supports" waiver to include a broader array of services and a more robust level of services.

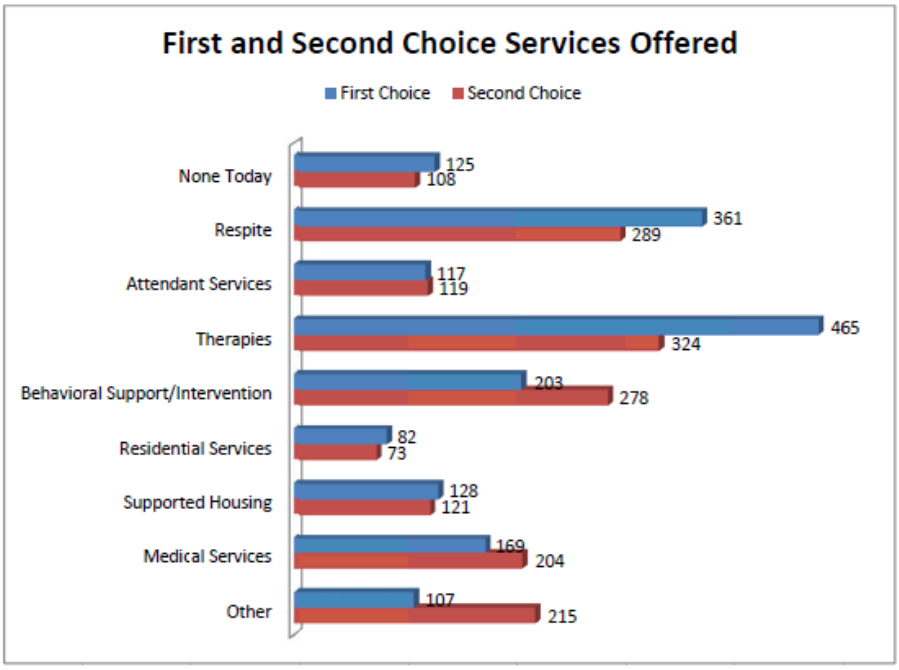
Comprehensive residential services are very costly to deliver, whether in an ICF/MR or another type of community residence. Home-based services have proven to be an effective, economical means to support individuals with I/DD in Texas. Families have expressed a high level of satisfaction with home-based services that complement rather than substitute for the family caregiver. Focusing on home-based services is a less costly strategy than expanding licensed residential services. Currently, there are 18 states that operate separate "supports waivers" that provide roughly the same type of services as Texas' home-based services. Supports waiver programs do not offer residential services and are characterized by a relatively low dollar cap on the total amount of HCBS services that may be authorized on behalf of a beneficiary. Expanding the number of TxHmL "slots" alone is not sufficient. Broadening the array of supports services would: (a) assure that the state's waiver operations are consistent with *Olmstead;* and (b) reduce budgetary risks for the state by enrolling some individuals into a supports waiver that can apply per person caps, as opposed to a comprehensive waiver with no such limits. Consideration should also be given to including full-featured self-direction of home-based services, including adding the coverage of "individual goods and services" to provide an extra measure of flexibility, and expanding respite services – one of the top two most needed services reported in a survey of individuals and families on the Texas Interest Lists.[15] In the most recent biennium, the majority of those who enrolled in HCS chose their own/family home or foster care option. Only 12.5% have chosen a group home arrangement.[16]

[15] Biennial Report Survey of Individuals on Texas Interest Lists, Institute for Organizational Excellence, The University of Texas at Austin, 2010.
[16] Texas Department of Aging and Disability Services, Analysis of Data Provided Over Time, 2010.

5. Enhance efforts to provide community respite alternatives.

Respite care provides a caregiver temporary relief from the responsibilities of caring for individuals with disabilities. Respite programs are a lifeline for families, yet these services are often unavailable in the community where families need them. In a statewide survey of families on the interest list for home and community-based waiver services (2010), respite services was reported in the top two most critical services needed. (See Chart 3.)

Chart 3



Source: Biennial Report Survey of Individuals on Texas Interest Lists, Institute for Organizational Excellence, The University of Texas at Austin, 2010.

For both first and second choice offerings for services they would like to receive, respondents across all waiver groups chose 1) Therapies which include specialized medical services to help a person treat a specific health problem (i.e., physical, occupational, speech therapy, etc.), and 2) Respite including taking care of someone during the day so the main caregiver can have a break.

Without community respite, many are forced to rely on institutional settings for respite support which is often an undesirable choice and can be disruptive to the individual with a disability. To address these issues, Texas was awarded one of 12 grants from the U.S. Administration on Aging under the federal Lifespan Respite Care Program. The Department of Aging and Disability Services (DADS) will use the $200,000 grant over a 36-month period to develop a Texas Respite Coordination Center to conduct respite forums around the state, develop statewide resources, and support the efforts by local entities working to increase respite services. In addition, the 81st Texas Legislature's House Bill 802 (in effect September 2009) authorized DADS to spend $1 million over the FY 2010-11 biennium to develop the

Texas Lifespan Respite Care Program (LRCP) for people who are not eligible for respite services from any other source. This program awarded three community-based pilot programs (North Texas, Central Texas and the Capital Area) to promote respite services for people who care for individuals of all ages with chronic conditions and disabilities in Texas. These pilot programs will work to expand the availability of respite services in their communities, including new and emergency respite services, and develop whenever possible, the use of volunteer respite programs. These grants also created the Texas Respite Coalition to provide advice and support to DADS on the LCRP grant. The coalition is comprised of representatives from 35 agencies and organizations that represent persons of all ages and disabilities and who are concerned about services for caregivers. While these efforts are an important first step, our surveys demonstrate how critical respite services are for individuals and families and should remain a funding and program priority among state leaders.

6. **Make necessary program changes to allow participants increased control over their individual service budget. Develop options for participant-directed services (CDS, SRO) in Medicaid and non-Medicaid programs (including waivers) that provide long-term services and supports including fee-for-service and managed care programs (STAR+PLUS). Extend participant-directed options to additional services beyond personal assistant services and respite services**.

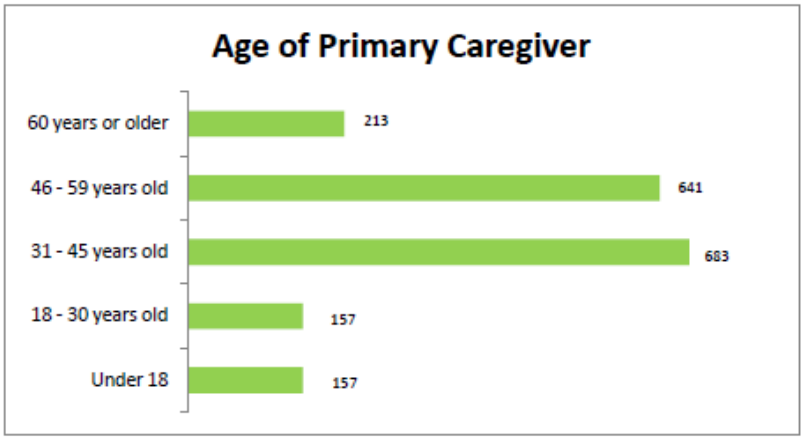
   Consumer Directed Services (CDS) and the Shared Responsibility Option (SRO) are vehicles of self-determination for people with disabilities which allow increased control over the services and supports that individuals receive and how those services are delivered. The 2008 Texas Health and Human Services System customer satisfaction survey data indicate that many DADS respondents would like to hire, train, and manage the people who are paid to help them. Similarly, the 2006 National Core Indicators Customer Survey and the Participant Experience Survey results indicate that most CLASS CDS respondents reported feeling that they had control over how they spent their money, feeling safe in their home, feeling satisfied with their personal life, and being independent of guardianship. In the past two years, Texas has expanded the services that may be self-directed and has seen participation triple from just over 2,000 individuals at the end of February 2008 to over 6,000 at the end of February 2010. During the past two years the Consumer Direction Workgroup provided direction and input to HHSC, DADS and the Texas Workforce Commission (TWC). Activities and accomplishments of the workgroup are: (1) acting on recommendations from its 2008 report, including significant expansion of the CDS option and preparing for expansion of the SRO option into all long-term services and supports; (2) identifying barriers to consumer direction such as liability insurance for CDS employers and the rate differential in the financial management services fee across programs that prevent a network of CDS agencies; and (3) assisting in education and outreach through improvement in web-based resources and participating in Town Hall meetings. Strategies to address current challenges such as access to criminal background checks, nursing services delivered through consumer direction, and differences in provider qualifications across programs should also be implemented to further the options for participant-directed services.

7. Develop specialized services and supports to allow individuals with developmental disabilities to age in place following the loss of a family caregiver.

The average age of an adult with a developmental disability living with parents age 60 and older is 38 years. Many family caregivers will age beyond the capacity to provide care in the next 10 to 20 years. Long waiting lists for home and community-based residential services make it difficult for persons with developmental disabilities who lose their family caregiver to maintain their independence.

In the 2010 Survey of Individuals and Families Waiting for Services, the majority of respondents indicated their primary caregiver is between age 31 and 59 years of age. Around 37% have a primary caregiver between 31 and 45 years and another 35% between 45 and 59 years of age. (See Chart 4.)

Chart 4



Source: Biennial Report Survey of Individuals on Texas Interest Lists, Institute for Organizational Excellence, University of Texas at Austin, 2010

8. Address insufficiencies in provider reimbursements that impact the availability and quality of community support services. Specifically:

8.1. Increase rates and implement rate enhancements for community service providers to ensure that providers can recruit, train, and retain quality direct care staff and compete with other employers in the workplace.

Wages play a critical role in determining workforce adequacy and the quality of services received. In addition to receiving relatively low wages, workers typically lack access to affordable benefits, receive minimal training, and are often employed on variable, part-time schedules. These factors can result in shortages of direct-care workers, high turnover rates, lack of qualified staff, inadequate backup for sick and vacation time, and difficulty retaining workers. DADS has modified its rules regarding rate enhancement to allow additional providers to participate, however without needed funding, these programs cannot be fully implemented.

8.2. Create a hierarchical structure of reimbursement rates that recognizes case mix, complexity of care, family supports, and individual needs.

Not all individuals with disabilities need the same level of care. The reimbursement rates for community care services should recognize case mix, complexity of care, and other caregiver supports available, based upon an appropriate assessment tool. The 80th Texas Legislature (2007) took a very important step towards this goal by authorizing a higher nursing rate for clients with ventilators and/or tracheotomies, but similar distinctions need to be made for other services, particularly attendant care and behavioral supports.

8.3. Adjust reimbursement mechanisms to provide incentives for providers to enhance community supports and to implement innovative approaches in service delivery to improve quality and cost effectiveness.

Consider setting rates per month or per diem to allow for options other than hourly direct service delivery to meet client needs. Funding should be provided to encourage providers to explore and implement innovations related to technology, tele-health, phone monitoring, case management fees, etc.

8.4. Use existing cost data as a basis for increases in payment rates for community agencies to catch up with underlying changes in the cost of doing business in Texas.

Wages are typically low, opportunity is minimal, and support is minimal. The result is high turnover, low retention, and significant worker recruitment costs for provider organizations. However, the demand for direct support workers is among the fastest growing in the country, with projections that it will be the second largest occupation in the U.S. by the year 2018, playing a vital role in job creation and economic growth, particularly in low-income communities. A catch-up funding increase would not only prevent further deterioration in already low wages, but would reduce strains on community services, and demonstrate recognition of the importance of the care provided by these workers now and in the future.

8.5. Implement low-cost or no-cost workplace improvements to increase retention of direct care workers.

Direct support workers often feel isolated and receive little recognition for their work. Not only are they isolated from their employer, they have very limited opportunity to network with each other for problem-solving and support. However, those whose work is valued and appreciated by their supervisors, and who are listened to and encouraged to participate in care planning decisions, have higher levels of job satisfaction and are more likely to stay in their jobs. While wages and benefits are a critical component of employment, there are other improvements that can be made that are low- or no-cost to the employer.[17] DADS has created a video on its website to

[17] Home and Community Based Services Workforce Advisory Council Preliminary Workforce Recommendations to HHSC, May 2010.

demonstrate realistic job previews, however other initiatives such as flexible work schedules, worker recognition, worker-consumer matches, a career ladder, networking and mentor opportunities that support existing workers is needed.

8.6. Initiate a comprehensive study of community wages and benefits in 2011 and target for completion during 2012.

The study should examine current community wages and benefits in relationship to comparable positions in the general labor market. It also should examine the extent of local/regional variations in worker pay. The study should build on the previous work of groups such as the Home and Community-based Services Workforce Advisory Council (2010) and provide policymakers with reliable, concrete information concerning the extent to which community wages and benefits are (or are not) competitive. The study should address parity issues, and suggest how wages and benefits can be indexed going forward so that they can be kept in alignment with services needs and labor market demands.

9. Explore quality-improvement strategies such as using self-advocates to provide peer support to consumers to increase safety, prevent abuse and neglect, and improve awareness of community living options.

The use of self-advocates who are independent of the service delivery system (functioning similar to ombudsmen) is an essential function to improve the quality of care received. Approximately 60 percent of state supported living center residents do not have guardians or others who can voice an opinion or communicate their interests. Peer advocates have experiences similar to those they assist which can increase trust and reliability. Self-advocates serve to provide individual support, peer-to-peer counseling, and education on issues such as preventing and reporting abuse and neglect, understanding community living options, and exercising self-determination. Several self-advocacy groups exist at some SSLCs and in some communities. It is essential that ICF/MR residents and waiver participants have access to peer support that is separate from the service provider.

10. Improve services and community living options for youth with disabilities transitioning from education settings to post-education activities.

Youth with a disability who are transitioning into post-schooling activities, services for adults, or community living should have the opportunity and necessary supports to seek individualized, competitive employment in the community. TWC could encourage local workforce development boards to explore available funding options (federal, state, local, public/private) to expand disability navigator positions within the workforce system to partner with local board business service representatives to assist transitioning youth with

disabilities to gain employment.[18] Funding should be allocated to DARS (2010-2011 LAR) for its Vocational Rehabilitation programs, which include services seeking to increase positive employment outcomes for youth with disabilities. Medicaid waiver programs offer supported employment and pre-vocational services, however many participants receive day habilitation services instead. These day habilitation services typically are provided in large, congregate settings that aren't integrated into naturally occurring communities. Youth with disabilities who transition from education settings should be able to access the employment services offered in waiver programs and not forced to choose day habilitation

[18] Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Community Living, Implementation of HB1230 Workgroup Recommendations, Submitted January 2009. Accessed http://www.hhsc.state.tx.us/news/presentations/HB1230_0109.pdf.

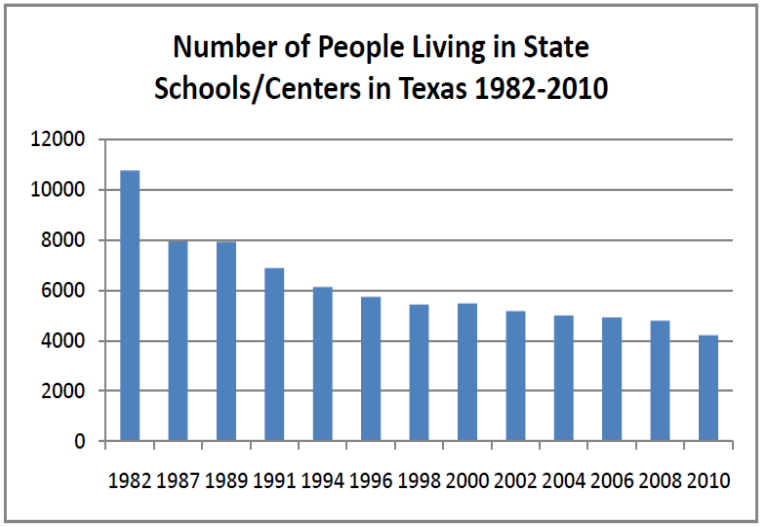
Reliance on Large Congregate Care Facilities

Texas has not kept pace with the national trend to transition away from ICFs/MR in favor of waiver services. Many states have come to rely almost entirely on HCBS services and very little on ICFs/MR. In fact, in 2009, ten states plus the District of Columbia did not have *any* state operated residential institutions for people with developmental disabilities. As a result of the DOJ settlement agreement and Section 48, Texas has taken steps to ensure SSLC residents are being served in the most integrated setting.

In spite of some actions to decrease the focus on state supported living centers, stronger legislative actions have been taken that maintain and expand the state's investment in ICF/MR options, including the slow pace of relocations from state supported living centers, sustained admissions of children into state centers at a pace twice the national average, and the addition of 2,850 positions to the state supported living center infrastructure since 2008.

This pattern ultimately results in individuals not being served in the most integrated setting possible. Moreover, the continued strong investment in state supported living centers and community ICF/MR service structure expends resources that might be invested in more integrated community options, weakening the community system and its potential for serving a wider range of individuals.

Chart 5

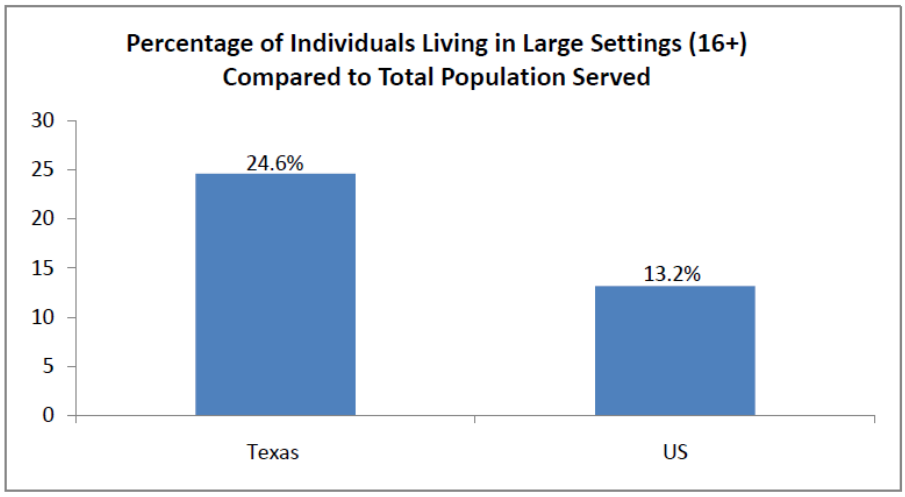


R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008 with FY 2010 data taken from DADS Report to PIAC, October 2010.

Texas has relocated many individuals from state supported living centers into community alternatives, reducing the population of state-operated facilities from 7,933 in 1989 to 4,207 in 2010.[19] (See Chart 5.) Yet, Texas has been considerably slower at reducing the use of state centers when compared to national trends. Since 1989, Texas reduced the census in large state facilities by only 32.6 percent compared to a 53.9 percent reduction in census nationally.

Texas continues to devote a greater share of its Medicaid dollars to large congregate care services than is typical nationwide and the cost of supporting a person in a state supported living center was almost twice the cost of supporting a person in other types of ICFs/MR. The state generally funds a bi-modal residential system. In 2008, most people receiving residential services lived in housing options of 1-6 people (17,894 individuals), or in facilities housing 16 or more people (6,041). Relatively few people (625) lived in intermediate-size residences of 7-15 people.[20] Chart 6 shows that Texas has almost twice the number of residents living in large congregate settings (16+ residents) than the United States average.

Chart 6



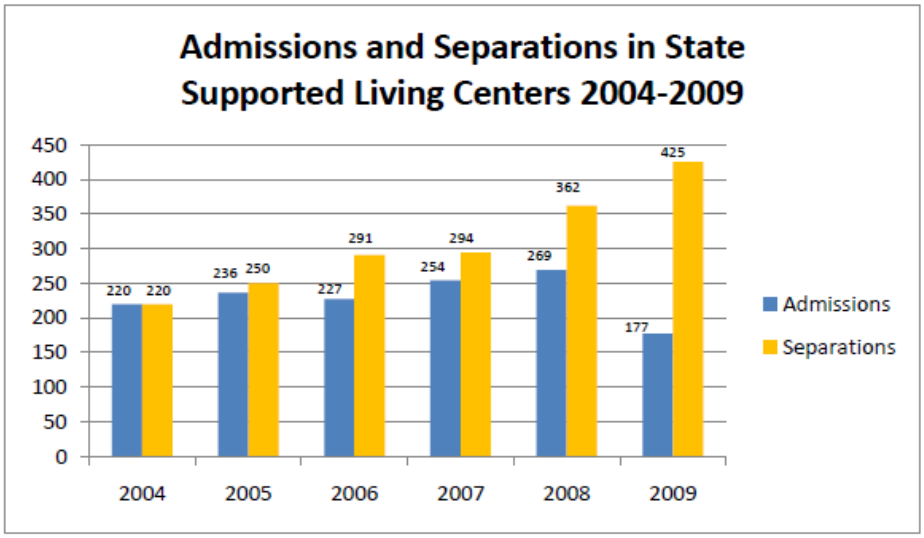
R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008

As seen in Chart 7, all 13 state supported living centers are actively admitting individuals. Since 2004, Texas SSLCs have been working to discharge more residents than they admit. While Texas has made progress in moving residents to other locations, the rate of admissions has not slowed until recently and a large number of individuals continue to be admitted each year. As noted previously, the number of SSLC residents who receive community placements has also increased in recent years, due in large part to the improvements to the Community Living Options Information Process, the implementation of Special Provisions Sec. 48 and the

[19] Report Update for State Supported Living Centers FY 2010-2011, Texas Department of Aging and Disability Services, July 2010.
[20] R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008.

agreement with DOJ. However, as long as the capacity is not present in the community to address the needs of people with challenging conditions, Texas will not be able to continue this trend in reducing the overall census in state supported living centers and meeting national norms.

Chart 7

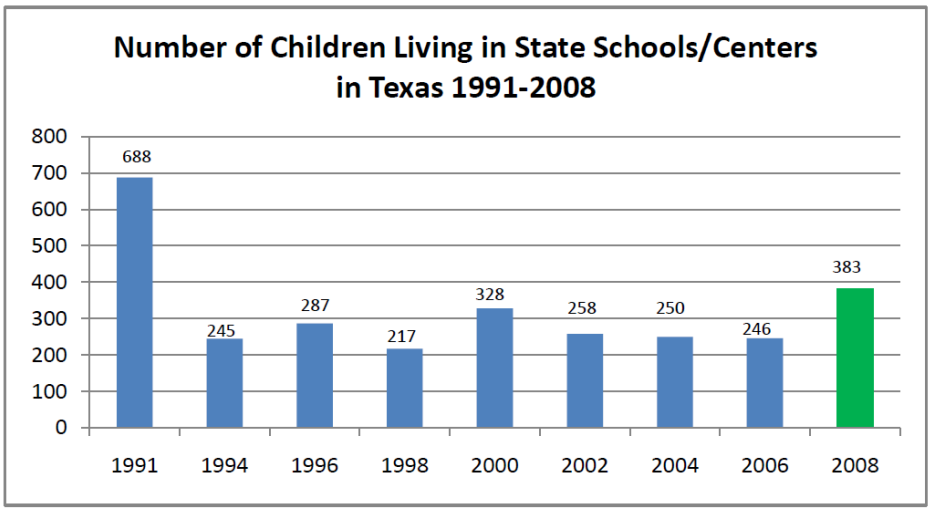


*Separations include: movement to alternative living environment, discharges, deaths
Source: Texas Health and Human Services Commission CARE System, Report Update for State Supported Living Centers FY 2010-2011, Texas Department of Aging and Disability Services, July 2010.

Children in State Supported Living Centers

The population of children in state supported living centers has remained relatively constant since 1994. (See Chart 8.) Yet, in 2008, the number of children living in state centers increased from 5% to 8% of all residents. This translates into 383 children currently living in state centers, up from 246 in 2006.

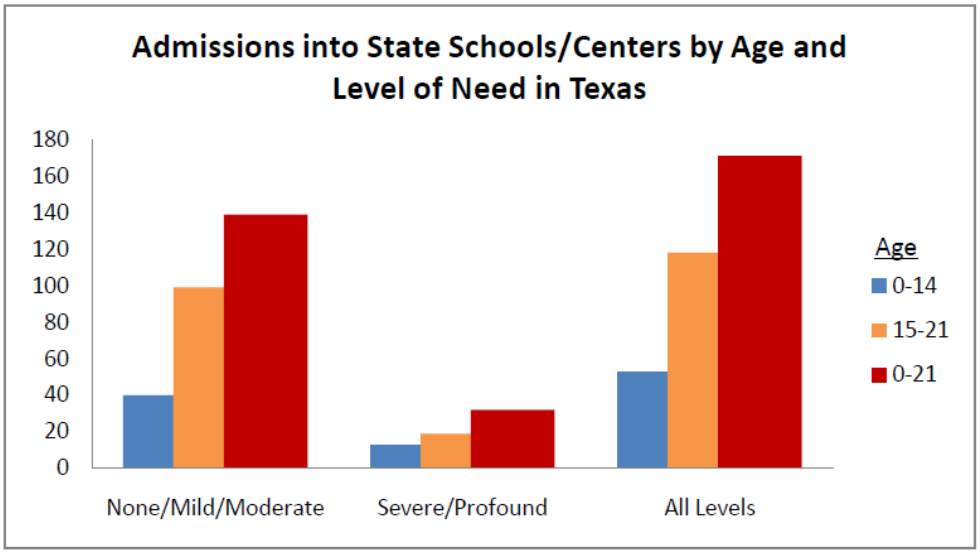
Chart 8



R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008

In 2009, 50 percent (88 out of 177) of new admissions into Texas state supported living centers were children (age 0-21). This is more than twice the national average of 21.7 percent. According to DADS, 91 children were admitted into SSLCs in FY 2010 out of 170 total admissions for the year. Not only has the number of children admitted to these facilities increased, but they are representing a greater percentage of all new admissions (53.5 percent). As shown by Chart 9, many of the children admitted in 2008 have none to moderate levels of need.

Chart 9



R. Prouty, G. Smith, C. Lakin. (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008

The Texas Legislature has taken some action by passing Senate Bill 368 (77th Texas Legislature, (R)(2001) that requires all individuals under the age of 22 who reside at a state supported living center to be placed on an interest list for community waiver support. The 81st Texas Legislature (R)(2009) appropriated funding for 196 "diversion" waiver slots, of which, 92 have been released to serve individuals in the community (41 children and 51 adults) as of September 1, 2010. An additional 310 "Promoting Independence" waivers (which, children can access) were also funded for the FY 2010-2011 biennium. The 81st Texas Legislature also approved Rider 32 (previously Rider 41) which specified that children under 21 who reside in nursing facilities may by-pass the interest list to receive services, however only 16 children were offered community services as a result of this provision. These provisions are meant to expedite the placement of children out of state run centers. Yet, children are limited by the number of waivers that are available. Furthermore, by allowing children to be admitted into the state supported living centers, the state continues to replenish the population making it almost impossible to transition away from the state's reliance on large congregate facilities.

After extensive public comment and discussion, the Texas Council for Developmental Disabilities (TCDD) approved a motion (August 6, 2010), to support a proposal by Advocacy, Inc. to call for a moratorium on new admissions to State Supported Living Centers (SSLCs). This proposal for a temporary suspension of admissions is based on ongoing concerns regarding the institutions and risks to the health and safety of residents. Advocacy, Inc. proposes a moratorium on new admissions until the state can demonstrate that the facilities, are meeting residents' constitutional rights to protection, health care and behavioral and mental health services, and other supports.

As the state's federally funded protection and advocacy system for people with developmental disabilities, Advocacy, Inc. asked other organizations to support a call for a moratorium on SSLC admissions. This proposal is based on ongoing concerns noted in the U.S. Department of Justice (DOJ) investigation and recent reports by monitoring teams reviewing services provided in each facility. The reports document serious concerns and deficiencies in care, including serious health and safety problems that continue to put residents at risk of imminent harm.

For more detailed analysis of residential and non-residential services, see "*Closing the Gap in Texas: Improving Services for Persons with Intellectual and Developmental Disabilities"* at http://www.txddc.state.tx.us/public_policy/gaprpt/gaprpt.asp.

TCDD Recommendations for Serving People in the Most Integrated Settings

11. Reduce the number of people served at state supported living centers. During the 2010-2018 period, the SSLC population should be reduced to not more than 1,465 individuals for Texas to simply meet the projected nationwide averages.

Based on Texas population growth estimates during the next 10-year period, reaching a census of 1,465 would entail a reduction of state supported living center population of a little over 3,444 people or a net reduction of approximately 265 people per year. This translates into placing about 22 individuals each month into appropriate community settings. Since FY 2008, the SSLC census has had a net reduction of 562 individuals. Although approximately 170 individuals were admitted into SSLCs in FY 2010, if the net census declines continue in the same manner, it is feasible for Texas to reach the nationwide average over time. Reducing the number of people served at state supported living centers and operating a smaller number of beds in such facilities is not only feasible but also a strategy central to avoiding the disproportionate drain such facilities place on the state's budget.

12. Cease admissions of children to state supported living centers. Continue and enrich efforts to accommodate all children under the age of 22 who are in state supported living centers and seek community placement using mechanisms such as in-home support services for children living at home with families and "Money Follows the Person" to provide opportunities for children to leave institutional settings in favor of HCBS alternatives.

DADS has supported the principle that children belong in a home with their families, yet services are often not available to keep families intact rather than causing out-of-home institutional placement. A DADS workgroup on the topic identified several pressures that combined to encourage increased admittance of children to the state supported living centers, including: (a) reductions in community-based services due to cuts in funding to local authorities; (b) lack of timely available appropriate alternatives; (c) lack of comprehensive and readily available supports for families of children with challenging behavior or co-occurring mental health diagnoses; (d) forensic/court-ordered placement; and (e) parental choice given the alternatives available. Given that 53.5 percent of new admissions to SSLCs are children, if Texas is to move away from its reliance on state supported living centers, it must take firm action to eliminate further admissions of children and youth to the centers.

13. Further develop the "Money Follows the Person" initiatives to accommodate a stronger transition of people living in ICFs/MR who prefer to receive services in the most integrated setting.

The MFP Demonstration is a federally funded program that provides states with money to move people from institutional settings into community settings. Texas is one of the first states to expand the MFP program, which originally focused on nursing home residents, to include state supported living centers, residents in large community ICF/MRs, and voluntary

closure of ICF/MR facilities. To date, 1163 individuals have transitioned to home and community-based services – 43% from state supported living centers and 57% from large (14+ bed) community ICF/MRs to their own home, foster care, or 3 or 4 bed group homes. These MFP initiatives should continue, as well as extending MFP options to all community ICF/MR residents and to children who reside in SSLCs.

14. Modify the Community Living Options Information Process (CLOIP) to ensure that residents of state supported living centers who express interest in community living arrangements receive appropriate education about, and are able to access community options. Specifically:

14.1. Improve the required documentation of mandated discussions with residents regarding their options for community supports and services, and include documentation concerning supports and services needed to successfully transition to a community setting, efforts to secure those services, and documentation of the reasons for not providing community living arrangements when requested.

DADS documentation often does not include information about the individuals' awareness of available community living options, nor the types of supports needed in a community program that may not currently be available. This information is critical given that 70 percent of state supported living center residents who "preferred an alternative living arrangement" were not provided one.[21] The federal Department of Justice investigation also raised concerns about discussions of community living options with residents. As part of the settlement agreement, Texas must ensure that residents are receiving individualized care and assist them in moving to the most integrated living settings when appropriate. This includes educating residents and families/guardians about available community placements so they can make informed choices. In the past three fiscal years DADS has increased the number of individuals placed in community settings: 206 individuals in FY 2008; 262 individuals in FY 2009; and 330 individuals in FY 2010. Improvement in this area is still needed to adequately identify the community support needs of SSLC residents who currently require more intensive supports, but would prefer to transition to the community.

14.2. Revise procedures to require local authorities to provide choice options to residents in community ICFs/MR and fully reimburse local authority costs for those activities.

Local authorities are the most appropriate agency to provide information on community living arrangements to individuals. Recently, the Legislature directed local authorities to provide community living options information to residents of state

[21] An Audit Report on State Mental Retardation Facilities, the Department of Aging and Disability Services, and the Department of Family and Protective Services, State Auditor's Office, July 2008.

supported living centers. Local authorities need to become more involved in the planning process for individuals residing in these settings and relevant procedures should be revised to ensure that representatives from local authorities are a permanent member of the planning team and have opportunities to discuss community living options with all residents. Local authorities are not providing this same information for people residing in community-based ICFs/MR and those residents also need unbiased information about community living options.

14.3. Develop "transition assistance services" for participants in all HCBS waivers, including the HCS waiver program.

Transition Assistance Services (TAS) assist Medicaid recipients who are nursing facility residents to set up a household when they are discharged from the facility. Eligible waiver programs include Community-Based Alternatives (CBA), Community Living Assistance and Support Services (CLASS), Medically Dependent Children Program (MDCP), Deaf Blind with Multiple Disabilities (DBMD) and Consolidated Waiver. TAS are currently not available to those transitioning from state supported living centers or ICFs/MR or those going into the Home and Community-based Services (HCS) waiver and should be expanded and made available to these individuals.

15. Improve and promote opportunities for ICFs/MR providers to transition to supporting individuals in the most integrated setting.

Texas must pursue strategies to rebalance its I/DD service system in collaboration with the organizations that operate community ICFs/MR. The Money Follows the Person Demonstration project in Texas is focusing on voluntary closure of privately owned facilities with nine or more residents. The largest privately owned ICF/MR in Texas has voluntarily chosen to close under the state's MFP Demonstration project (The Willows, San Antonio, 177 residents). Another large ICF/MR operator is coordinating with the MFP program to close its facility. As of May 2010, 10 private ICFs/MR have had plans approved to transition to HCS. These efforts should be expanded to include all public and private facilities, both large and small.

Projections for Future Long-term Service Needs

Absent an aggressive, multi-year initiative to reduce and eliminate unmet emergency and critical services demand, Texas will find itself confronting a widening gap between the capacity of the service system and service demand. Individuals and families will face longer and longer wait times before they can receive services. Moreover, it will be very difficult for Texas to reduce its over-reliance on large congregate care services so long as it is not fully meeting service demand in the community.

Texas seems to hold the view that rebalancing the system is not feasible – that the institutional system (both public and private) must be preserved and that the solution is to chip away at the lengthy and rapidly growing waiting list in the state. TCDD suggests that this strategy is flawed and will never allow Texas to achieve a truly cost-effective, consumer-directed system.

Legislators can respond by developing a plan to realign the current system by placing a greater emphasis on serving persons with disabilities in their communities, which is more cost efficient and responsive to what individuals continue to say they want. The transition may require time and funding in the immediate future, but in the long run will afford the opportunity to serve more individuals while keeping funding levels more stable.

System redesign is an exciting opportunity for Texas to commit itself to achieving excellence in service system performance. However, redesign also may generate legitimate concerns about the potential impacts on people with intellectual and developmental disabilities, their families, committed professionals, and other stakeholders. Any redesign efforts should have executive and legislative branch sponsorship, and be conducted through a collaboration that engages individuals with disabilities and other stakeholders in the development process.

As broad redesign efforts are discussed at the system level, there are immediate improvements to be made within today's system to assist individuals with disabilities and family members plan for their future service needs. In the TCDD 2010 survey of people on the interest lists for community services, approximately half (43%) did not know when their service needs would change.[22] Therefore, Texas should ensure that the state has the capacity, expertise, and infrastructure components to objectively assess and meet their needs over time.

[22] Biennial Report Survey of Individuals on Texas Interest Lists, Institute for Organizational Excellence, The University of Texas at Austin, 2010.

TCDD Recommendations for Future Long-term Support Needs

16. Build expertise among service providers to assist individuals with developmental disabilities who are aging and their family caregivers in actively planning for their future long-term care needs.

The total number of older adults with I/DD is expected to increase three-fold in the next 20 years. In the 2010 Survey of Individuals and Families Waiting for Services,[23] the majority of respondents indicated their primary caregiver is between age 31 and 59 years of age. Persons who are aging with developmental disabilities have unique long-term care planning needs in terms of finances, housing, health care, and family supports. Service providers must increase their knowledge and skills in assisting individuals with I/DD as they plan for the future. Similarly, cross-training between aging and disability networks must be established to help individuals and their caregivers with their unique planning needs.

17. Direct HHSC and its Departments (DADS, DARS, DFPS, DSHS) to develop the infrastructure to collect and share common information about individuals receiving services across access and intake systems at the state and local levels.

Improved communication between health and human services agencies is critical in serving individuals in a more efficient manner. This involves cross-training of staff on developmental disabilities, cross-referral of individuals to improve access to the right service at the right time, and innovative technologies to facilitate the sharing of information. Collaborative practices such as identifying crossover cases and sharing information about clients who receive services from multiple divisions should become usual business across the human service enterprise.

18. On a biannual basis, review and use data on the types of services selected by individuals with disabilities, when they are offered Medicaid waiver supports, to more efficiently fund future long-term supports based on consumer needs.

In the 2010 survey of approximately 1,500 individuals and families in Texas on the interest list for home and community-based services, respondents cited therapies, respite services, and behavioral supports as the services they needed most. DADS collects data on the types of services selected by new waiver enrollees, however this data is not used by legislative leadership in budget planning and policy development. A more routine study of service patterns selected by new enrollees and the stated support needs of individuals waiting for services can help leaders develop a greater understanding of the demand and choice for services in this state which is critical in accurately planning and financing the future long-term service and supports system in Texas.

[23] Biennial Report Survey of Individuals on Texas Interest Lists, Institute for Organizational Excellence, University of Texas at Austin, 2010.

19. **Continue and formalize the redesign of services and supports for people with ID/DD with executive and legislative branch sponsorship to reduce the institutional bias in long-term services and support systems by 2018 and redirect funds to community services infrastructure.**

    Legislators should formalize their commitment to serving individuals in the most integrated settings by developing a comprehensive plan to realign the current system by placing a greater emphasis on serving persons with disabilities in their communities, which is more cost efficient and responsive to what individuals continue to say they want. Groups such as a "Redesign Steering Committee" may be useful in helping state leaders define long-range goals and work out implementation details.

20. **Pursue redesign through a collaborative process that engages people with intellectual and developmental disabilities and other appropriate stakeholders as primary constituents of the system.**

    Individuals with disabilities and their families who are the recipients of long-term services and supports should be at the table when decisions are made regarding the benefits they receive. Any formal planning efforts or redesign initiative should focus on the participation and input from individuals with disabilities who can speak to the true impact these policy decisions can have on their own lives.

Summary

It is clear that Texas is at a crossroads. Today's state leaders must choose the path and set the course for action for the next five, 10, 20 years. Action will require risks, but the benefits for Texans with disabilities will be far greater. By not taking proactive steps, policymakers can expect that the state will: (a) continue spending substantial sums to maintain large facilities, such as the state supported living centers, that provide services that individuals with disabilities say they do not want, and that have been criticized by federal and state oversight bodies;[24] (b) find it increasingly difficult to accommodate new applicants for services so that interest lists will continue to grow; and (c) continue to oversee a community system that is continuously challenged to address the needs of people already receiving services. Forestalling action will likely make action later more costly and difficult to undertake.

Texas can significantly improve opportunities for people to receive services and supports in the most integrated setting. It is entirely feasible for Texas to reduce the number of people served at the state supported living centers and meet a significant portion of demand for services. It is up to policymakers to determine if this current funding trend will change and follow the pattern seen across the nation or whether Texas will continue to invest so heavily in ICF/MR facilities. A decision to move in this direction would require relatively modest annual levels of transition from state supported living centers.

The issue is the extent to which Texas leaders are willing to make fundamental and far reaching reform. The data clearly demonstrates that Texas currently spends its resources inefficiently, on too few individuals, in settings for which there is little demand from consumers. The debate is not simply whether or not state supported living centers should be closed. There is a real need in Texas to develop an earnest, comprehensive and informed long-term vision and plan for the system of services and supports for persons with disabilities. This discussion should involve not only legal issues, but account for the state's fiscal realities and moral obligations to persons with disabilities and their families that should drive true system reform.

Budget shortfalls should not be a reason Texas does not move forward with the recommendations outlined in this report. These issues can be addressed in the context of the state's fiscal realities. With crisis comes opportunity to change the way Texas does business, look to other states for innovations and best practices, and become a leader in providing services and supports to persons with disabilities and their families.

[24] State Auditor's Office (July 2008) "An Audit Report on State Mental Retardation Facilities, the Department of Aging and Disability Services, and the Department of Family and Protective Services" State Auditors Report Number 08-039 and Department of Justice (December 2006) "*Report Identifies Civil Rights Violations at Lubbock State School"* http://www.usdoj.gov/crt/split/documents/lubbock_sch_findlet_12-11-06.pdf.

Appendix A: Texas Government Code

GOVERNMENT CODE
Title IV, Chapter 531
Section 531.0235. BIENNIAL DISABILITY REPORTS

Sec. 531.0235. BIENNIAL DISABILITY REPORTS. (a) The commissioner shall direct and require the Texas Planning Council for Developmental Disabilities and the Office for the Prevention of Developmental Disabilities to prepare a joint biennial report on the state of services to persons with disabilities in this state. The Texas Planning Council for Developmental Disabilities will serve as the lead agency in convening working meetings, coordinating and completing the report. Not later than December 1 of each even-numbered year, the agencies shall submit the report to the commissioner, governor, lieutenant governor, and speaker of the house of representatives.

(b) The report will include recommendations addressing the following:

(1) fiscal and program barriers to consumer friendly services;
(2) progress toward a service delivery system individualized to each consumer based on functional needs;
(3) progress on the development of local cross-disability access structures;
(4) projections of future long-term care service needs and availability; and
(5) consumer satisfaction, consumer preferences and desired outcomes.

(c) The commission, Texas Department of Human Services, and other health and human services agencies shall cooperate with the agencies required to prepare the report under Subsection (a).

As enacted by SB 374, 76th Texas Legislature in 1999. The 76th Legislature also changed the name of the Texas Planning Council for Developmental Disabilities to the Texas Council for Developmental Disabilities (HB 1610).

Appendix B: Survey of Individuals and Families Waiting for Services

A total of 1,537 individuals and families on Texas Interest List for Waiver Services responded to this survey administered by mail and Internet in Summer of 2010. The statewide survey was administered by Institute for Organizational Excellence, The University of Texas at Austin, in partnership with TCDD.

Questions:

1. How many in your household (including family members and others living with you)?

2. What is the combined household monthly income?

3. What is the age of the primary person who provides you care/assistance?

4. Please indicate the Interest List you are currently on (CLASS, HCS, or BOTH).

5. Do you currently receive any of the following services?
   - Medicaid
   - Special Education
   - Public-funded Personal Assistance
   - Private funded Personal Assistance
   - Other Waiver Services
   - Medicare
   - Home Delivered Meals
   - No Services Received

6. If you were offered two services today, what would be your first and second choice?
   - Respite
   - Attendant Services
   - Therapies
   - Behavioral Support/Intervention
   - Residential Services
   - Supported Housing
   - Medical Services
   - None Today

7. When do you expect your service needs to change?
   - Never
   - Within 5 years
   - In more than 5 years
   - Do not know

8. What prompted you to sign up on the Interest List?
   - Through Local Authority
   - Through School
   - Need Waiver Services
   - Make too much for Medicaid
   - Current Insurance Does Not Cover Needs
   - Do not know
   - Other

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