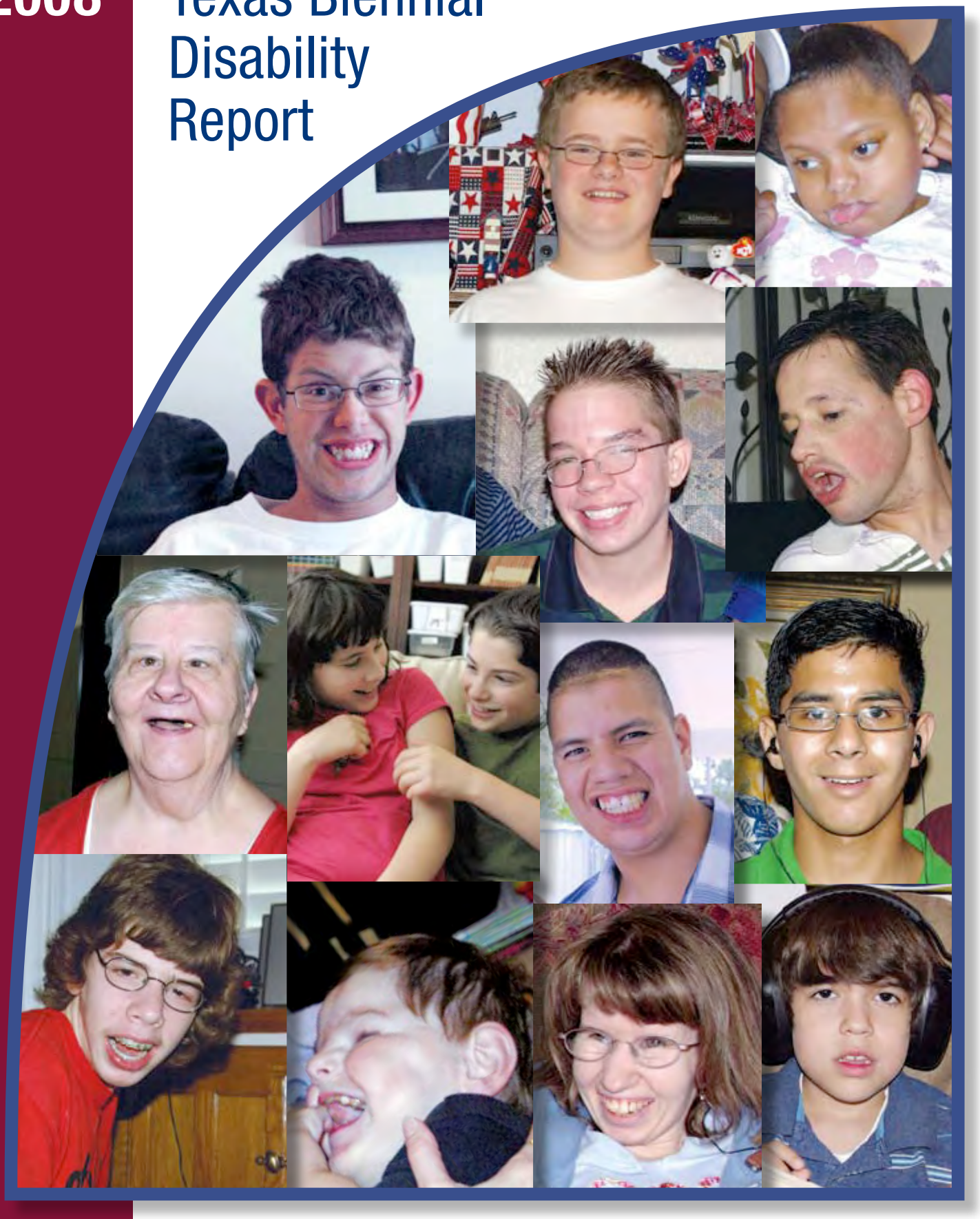
2008

Texas Biennial Disability Report



Texas Council for Developmental Disabilities

Texas Office for Prevention of Developmental Disabilities

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For their time, energy and expertise in preparing this report

2008

Texas Biennial Disability Report

December 2008

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This Report is Dedicated to:

Raul "Rudy" Acosta

Nov. 25, 1964 - Feb. 18, 2008

"During my 18 years stay in the nursing home, I was isolated from the community. Since moving into the community, I have become integrated into mainstream life and have become a contributing member of society.

As I have thrived, so has my belief that everyone with a disability has a right to be seen and participate rather than isolated in institutions. People have a right to take the risk to move from institutions into community life."

– Rudy Acosta, 2005

Rudy Acosta was separated from his mother at age 8 and placed in a nursing facility at age 12 because of the severity of his disability and a lack of community-based resources. Eighteen years later, he obtained the services and supports he needed to move into his own apartment. Mr. Acosta devoted the rest of his life to a passionate and powerful campaign to create community alternatives to nursing homes and state institutions, and he demonstrated to numerous policymakers and other people that anyone, with appropriate supports, can live a good life in the community.

Mr. Acosta had a rare form of muscular dystrophy that caused him to be totally paralyzed with difficulty breathing. Even so, he earned a Bachelor's Degree in Psychology at Texas Tech University, in Lubbock in 1998, and eventually moved to Austin where he was closer to the legislators and decision-makers he wanted to influence. He also graduated from Partners in Policymaking in 1998 and served on the Texas Council for Developmental Disabilities from February 2000 - September 2005. Mr. Acosta was a member of the Advocacy, Inc., board of directors at the time of his death.

"I hope my experience will inspire people who are institutionalized to seek their dreams, and I encourage everyone to support individuals who choose to move to an independent life in their community," Mr. Acosta told legislators.

Table of Contents

Executive Summary 1
About the Biennial Disability Report 9

Section One: Recommendations of the TCDD

About the Texas Council for Developmental Disabilities 10
Methodology 11
Glossary of Key Terms 16
State of Services and Supports 21
- Disability Rates in Texas 21
- Trends in Service Demand 21
- Texas' Ranking in Nation 22
- Interest Lists: Time Spent Waiting for Services 24
- Reliance on Large Facilities 29
- Placement of Children in State Schools/Centers 32
- Serving Individuals with Complex Needs in the Community 33

Recent Progress in Texas 37
TCDD Recommendations for Systems Change 44

Special Focus

Allocation of Resources to Provide Long-Term Services and Supports for Texans with Developmental Disabilities 54
Recommendations 57

Section Two: Recommendations of the TOPDD

About the Texas Office for Prevention of Developmental Disabilities 77
Focus on Fetal Alcohol Spectrum Disorders 78
- Characteristics of FASD 78
- Problems of FASD 79
- Needs of Population Affected by FASD 80
- Obstacles Faced by the Population Affected by FASD 80

TOPDD Recommendations for Addressing FASD 82

Appendix

Appendix A: Texas Government Code §531.0235 83
Appendix B: References 84

Personal/Family Stories; Charts & Tables

Personal/Family Stories

Alba Family 23
Caster Family 26
Betty Gage 28
Sparks Family 36
Aune Family 41
May Family 46
Munoz Family 49
Perez-Walker Family 50
Olive Family 59
Noel Family 62
Johnson Family 66
Harmon Family 69
LeMaster Family 73
Yaemon Family 75
Dotts Family 78
Lane Family 81
Thetford Family 82

Charts

1. People Receiving Medicaid Services per 100,000 Population 22
2. Number of People Living in State Schools/Centers 29
3. Admissions and Discharges of Texas State School/Center Population 30
4. Percentage of Individuals by Setting Size 30
5. Percentage of Individuals Living in Large Settings (16+) 31
6. 2006 Expenditures per Person in Texas 31
7. New Admissions to State Schools in Texas and U.S. 32
8. Admissions to State Schools/Centers by Age and Level of Need 32
9. Individuals in ICFs/MR Compared to Total in Residential Facilities 33
10. ICF/MR vs. HCBS Wavier Spending in U.S. and Texas 34

Tables

1. Individuals on Interest Lists by Longest Time Waiting for Services 24
2. Percentage of Individuals Waiting for Waivers by Time Spent Waiting 25
3. Individuals Served by Service Type and their Level of Need 33

Executive Summary

Over the past 30-40 years, Texas has invested heavily in services for people with intellectual and developmental disabilities. Yet, even as the state established a community services system, it has maintained an enduring commitment to Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) including the state school/center network. 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 109 persons per 100,000 population, compared to the national average of 193 – or 43.3 percent below the nationwide average.
- **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.
- **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: 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, chronic under-funding and other factors.

The most pressing issue facing the Texas mental retardation and related conditions (MR/RC) 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 MR/RC. 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 growth pattern in sight. According to the Texas State Data Center (The University of Texas, San Antonio), the population of Texas is likely to reach 25 million by 2010 and 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 Performance

The Texas Council for Developmental Disabilities solicited an external analysis of the Texas service system to evaluate its performance against a series of three performance benchmarks:

Benchmark 1: People with mental retardation and related conditions have access to and receive necessary publicly-funded services and supports with reasonable promptness.

Assessment: People with MR/RC 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.

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

Assessment: Many people with intellectual and developmental disabilities (I/DD) do not receive services within the least restrictive setting appropriate to their needs. By all measures, Texas relies more heavily on state schools/centers 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 seventh 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 pace of relocations from state schools is modest at best. Meanwhile, the state admits children into state schools at a pace twice the national average. And, in FY 2008-2009, the state added 1,690 positions to the state school structure at a cost of approximately $1.04 million.

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 MR/RC services was 47 percent below the national average in 2006. 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.

The initial examination of information regarding Texas' current system suggests the following observation:

Given the present fiscal effort and how these funds are applied, the state system is ill-positioned to address the present and future needs of its citizens with mental retardation and related conditions.

Policy Options

Moving forward, state leaders have several policy options to consider. For instance, Texas may:

- ☑ **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.
- ☑ **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.
- ☑ **Keep funding relatively level, but de-emphasize the use of ICFs/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.
- ☑ **Increase funding significantly and de-emphasize the use of ICFs/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 present needs while systematically reducing the interest list for services.

While some progress has been made in recent years, the pace of change is slow. The following recommendations are offered to improve the service delivery system for persons with intellectual and developmental disabilities.

TCDD Recommendations for Systems Change

Fiscal and Programmatic Barriers to Consumer Friendly Services

1. Develop and implement a comprehensive plan to reduce the institutional bias in long-term services and support systems and redirect funds to community services infrastructure by 2018.
2. Require regulated health insurance policies to provide coverage for mental and behavioral disorders for children and adults equal to coverage for other medical conditions.
3. Address insufficiencies in provider reimbursements that impact the availability and quality of community support services. Specifically:
   - **3.1** Increase rates and expand 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.
   - **3.2** Create a hierarchical structure of reimbursement rates that recognizes case mix, complexity of care, family supports, and individual needs.
   - **3.3** Adjust reimbursement mechanisms to provide incentives for providers to implement innovative approaches to service delivery to improve quality and cost effectiveness.

Progress Toward Individualized Service Delivery Based on Functional Needs

4. Modify the Community Living Options Information Process (CLOIP) to ensure that residents of state schools who express interest in alternative living arrangements receive appropriate education about, and are able to access community options. Specifically:
   - **4.1** Improve the required documentation of mandated discussions with residents regarding their options for community supports and services, as well as the documentation of the reasons for not providing community living arrangements when requested.
   - **4.2** Require community ICFs/MR to utilize Mental Retardation Authorities (MRAs) to provide choice options to ICFs/MR residents. Provide funding to fully reimburse the MRA costs to ensure informed choices.
   - **4.3** Expand "transition assistance services" for consumers in all HCBS waivers, including the Home and Community-Based Services (HCS) waiver program.
5. Invest in community respite alternatives to avoid reliance on state institutions for support, including an expansion of respite services to include caregivers under the age of 65.

6. Enhance the capacity of the community services infrastructure to better support individuals with complex needs. Specifically:

   6.1 Remove barriers and create incentives for providers to provide services and supports to individuals with complex needs in the community.

   6.2 Require the Department of Aging and Disability Services (DADS) to collect and analyze data that identifies factors driving admissions to state schools (particularly children) and report those findings to the Legislature.

Progress in Development of Local Cross-Disability Access Structure

7. 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 developmental disabilities (I/DD). Specifically:

   7.1 Build capacity and fund the Mental Retardation (MR) safety net services to support individuals with I/DD in the community.

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

   7.3 Build capacity and fund the community mental health and substance abuse supports network to deter unnecessary placements in hospitals and nursing facilities.

   7.4 Increase the number of waiver slots authorized for children aging out of Child Protective Services custody.

8. 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.

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

10. Direct the Health and Human Services Commission (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 level.

11. Ensure that individuals with developmental disabilities, specifically children with special health care needs, are not negatively impacted in efforts to reform the Texas Medicaid system, expand managed care initiatives, and/or restructure the service eligibility infrastructure.

Projection of Future Long-Term Care Service Needs

12. Require a formal study in Texas to gather data on the types of services selected by individuals with disabilities when they are offered Medicaid waiver supports, and use this data to more efficiently fund future long-term supports based on consumer needs.

13. Develop specialized services and supports to allow individuals with developmental disabilities to age in place following the loss of a family caregiver. Assist individuals with developmental disabilities who are aging and their family caregivers in planning for their future long-term care needs.

Consumer Satisfaction and Consumer Preferences

14. Expand options for Self-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 self-directed options to additional services beyond personal assistant services and respite services.

15. Transfer the responsibility for quality monitoring of state mental retardation facilities (SMRFs) from DADS to an entity with more administrative autonomy.

16. 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.

17. Ensure participation of people with disabilities and family members on state and local level committees that make recommendations regarding policy and the development and implementation of service programs.

Recommendations on Rebalancing the System of Long-Term Care Services and Supports

18. Reduce the number of people served at state schools/centers.

    18.1 During 2008-2018, the state school/center population should be reduced to 1,465 individuals to simply meet the projected nationwide norm.

    18.2 Concurrently and effectively address the major problems that affect community services to reduce pressures to admit people to the state schools/centers.

19. Cease admissions of children to state schools/centers.

    19.1 Provide resources to bolster in-home support services for children living at home with families.

    19.2 Take affirmative action to accommodate all children under the age of 22 who are in state schools/centers and seek community placement.

    19.3 Adopt a standardized risk assessment protocol that will be employed systemwide to identify potential risks and risk mitigation strategies as part of the individual service plan development process.

    19.4 Develop a “diversion” protocol triggered by the risk assessment that systematically implements alternatives to out-of-home placement of children in the state schools or community ICFs/MR.

20. 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.

- **20.1** Utilize MFP to keep children out of institutions and to provide opportunities for children to leave institutional settings in favor of HCS alternatives.
- **20.2** Expand opportunities within MFP for people to transition to HCS Medicaid waiver alternatives.
- **20.3** Expand opportunities for relocation of people with MR/RC living in smaller ICFs/MR of eight beds or fewer.
- **20.4** Implement activities to educate individuals who are eligible for MR/RC services and their families about the choices they have for relocating from ICFs/MR.

21. Adopt policies to encourage ICFs/MR providers to transition to supporting individuals in the most integrated setting.

- **21.1** Promote incentives to encourage administrators of both large and small ICFs/MR to voluntarily close their facilities and to allow individuals to relocate to HCS waiver alternatives.
- **21.2** Starting in 2009, DADS should dedicate staff positions to work directly with agencies interested in conversion.
- **21.3** Appropriate funds to provide conversion grants of up to $100,000 to agencies that submit promising proposals to support their development of downsizing/conversion plans.

22. Starting in 2009, enroll a minimum of 4,604 additional individuals each year in HCBS waivers for individuals with I/DD increasing the 2006 capacity of 13,999 persons to approximately 64,085 individuals by 2018.

23. Expand home-based services as the primary tool for addressing service demand, including consideration of expanding the Texas Home Living (TxHmL) HCBS "supports" waiver.

- **23.1** Enlarge the current TxHmL waiver program.
- **23.2** Expand TxHmL to include a broader array of services and a more robust level of services.

24. Develop a reliable and accurate means for tracking service demand and associated trends.

25. Strengthen the infrastructure to underpin the state community service system.

Workforce

25.1 Increase payment rates for community agencies to catch up with underlying changes in the cost of doing business in Texas.

25.2 Implement low-cost or no-cost workplace improvements to increase worker retention.

25.3 Initiate a comprehensive study of community wages and benefits in 2009 and target for completion during 2010.

Reimbursement Rates

25.4 Implement a provider cost study to examine how funds are allocated by actual costs associated with providing service.

25.5 Update and enhance 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).

Serving Individuals with Complex Needs

25.6 Contract with one or more organizations to furnish specialized behavioral services for individuals living at home on an as-needed basis for defined geographic regions.

25.7 Undertake an in-depth study of current system capabilities to meet the needs of individuals who have extensive medical support needs.

26. Launch the redesign effort with executive and legislative branch sponsorship and pursue redesign through a collaborative process that engages people with intellectual and developmental disabilities and other appropriate stakeholders as primary constituents of the system.

TOPDD Recommendations for Addressing Fetal Alcohol Spectrum Disorders (FASD)

1. Increase services for awareness, prevention, and intervention for individuals at risk for FASD.
2. Develop and offer pre-service education and continuing education training for paraprofessionals and professionals in a wide range of disciplines.
3. Establish supervised living arrangements for adults affected by FASD.
4. Advocate recognition of FASD by Medicaid and insurance companies, so that all diagnostic and treatment work are reimbursable.
5. Support community services to assist families with children affected by FASD to remain in a stable and caring environment, i.e. home.

About the 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 jointly 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

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

The recommendations included in the *Biennial Disability Report* are focused on key policy initiatives that have emerged in the most recent biennium (2007-2008). This report serves to establish a framework for legislative action during the 81st Texas Legislative Session (2009).

In each Biennial Report, TCDD has elected to focus a portion of the report on a key policy issue facing individuals with developmental disabilities. This year, the Council directed a special focus for the 2008 Biennial Disability Report on *The State's Allocation of Resources to Provide Long-Term Services and Supports for Texans with Developmental Disabilities*.

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 1 of each even-numbered year.

Section One of this Report includes recommendations from the Texas Council for Developmental Disabilities. Section Two includes recommendations from the Texas Office for Prevention of Developmental Disabilities.

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 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
Jan R. Newsom, Chair, Dallas	Mary Faithfull/Patty Anderson Advocacy, Inc.
Brenda Coleman-Beattie, Vice-Chair, Austin	Penny Seay Texas Center for Disability Studies at The University of Texas at Austin
Kristine Bissmeyer, San Antonio	Michael Benz/Amy Sharp Center on Disability and Development at Texas A&M University
Melonie Caster, Bedford	Kathy Clayton/Richard Poe Texas Education Agency (TEA)
Mary Durheim, McAllen	Audrey Deckinga/Clare Seagraves Texas Health & Human Services Commission (HHSC)
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Richard Tisch, Spring	
Raul Trevino, Palmhurst	
Susan Vardell, Sherman	

To develop the recommendations included in Section One of this report, TCDD reviewed and synthesized information from a variety of sources. Specific information was obtained from research reports, demographic data and projections, and best practice models from other states. Data was obtained from Texas state agencies including the Texas Health and Human Services Commission and its Departments (DADS, DARS, DSHS, DFPS), and a review of actions taken by the Texas Legislature during the past biennium. TCDD also obtained input from Council members, and colleagues and advocates from disability groups throughout Texas.

External Review

In order to fully evaluate the state of services in Texas and make appropriate recommendations on this year's special focus area, *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).

Coleman Institute on Cognitive Disabilities, University of Colorado

TCDD engaged David Braddock, Ph.D., of the Coleman Institute on Cognitive Disabilities to provide: **1**) a review of current national trends in developmental disabilities through 2006 (most recent data) and beyond with Texas as the benchmark; and **2**) a discussion of factors influencing service demand for developmental disabilities in Texas and the U.S.

The Coleman Institute collects annual data primarily related to financial and programmatic information from states on a yearly basis. Texas has participated in this survey for multiple years. The Coleman Institute has a 30-year trend for each state spanning back to 1977.

David Braddock, Ph.D.

Associate Vice President of the University of Colorado (CU) System and Executive Director of the Coleman Institute for Cognitive Disabilities. He has contributed to cognitive disability research, public health and social policy for more than 35 years. Braddock received Bachelor's and Master's degrees in Government and a Doctorate in Special Education from The University of Texas at Austin. He also completed additional graduate work in the Graduate School of Business at the same institution. Braddock was at the University of Illinois at Chicago (UIC) from 1979-2001 as Professor of Human Development and Public Health, as the founding head of the Department of Disability and Human Development and of its research institute, and as an associate dean. He was instrumental in the establishment of the nation's first Ph.D. program in disability studies at UIC. Prior to UIC, he held positions with the Council for Exceptional Children, the Secretary's Committee on Mental Retardation in the U.S. Department of Health, Education and Welfare, and with state developmental disabilities agencies in Texas, Missouri and Illinois.

Professor Braddock has over 200 publications and monographs in four areas: 1) the comparative study of the demography and financing of services to people with disabilities in the 50 American states; 2) long-term care; 3) health promotion and disease prevention;

and, 4) public policy toward people with disabilities. He has testified in congressional hearings on numerous occasions and in the legislatures of 12 states. He received international career research awards from The Association for Retarded Citizens (Arc) of the United States (1987), the American Association on Mental Retardation (1998), and the University Scholar Award from the President of the University of Illinois (1998). Braddock is a former president of the American Association on Mental Retardation (1993-94) and a recipient of The Arc-United States Franklin Smith Award for Distinguished National Service to the Field of Mental Retardation (2000), The Arc's highest honor. He edited the American Association on Mental Retardation's Research Monographs and Book Publication Program during 1997-2002 and currently sits on the Board of Directors of the International Special Olympics.

Human Services Research Institute

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 results are included in the Special Focus of this year's report: *The State's Allocation of Resources to Provide Long-Term Services and Supports for Texans with Developmental Disabilities*. The gap analysis, action steps, and implementation strategies have been synthesized in this report. The full HSRI analysis and report can be accessed through the TCDD Web site at www.txddc.state.tx.us/public_policy/news.asp#gap.

HSRI was founded in 1976 and is a non-profit, tax-exempt corporation with offices in Cambridge, Massachusetts and Portland, Oregon. For more than 30 years, HSRI has assisted states and the federal government to enhance services and supports to improve the lives of vulnerable citizens such as people with developmental disabilities or mental illness, or low income families. HSRI has provided consultation in such areas as strategic planning and organizational change, funding strategies, systems integration, quality management and assurance, program evaluation, evidence-based practices, family support, self-advocacy, self-determination, and workforce development.

The analysis conducted by HSRI and presented in this report is based on data provided or published by the Texas Department of Aging and Disability Services (DADS) and on information assembled by the Research and Training Center on Community Living (RTC) at the University of Minnesota. RTC conducts an annual comprehensive nationwide survey of state developmental disabilities agencies to obtain comparative information and data on residential and other services and supports for people with developmental disabilities and reports that information in *Residential Services for Persons with Developmental Disabilities*[1]. All states, including Texas, participate in this survey. HSRI also draws from data compiled by the Coleman Institute on Cognitive Disabilities at the University of Colorado.

Comparison states were selected using two main criteria: (a) states within the same federal Medicaid region as Texas (Region 6); and (b) states with large populations (8 million or more in 2006) to pinpoint areas of strengths and weaknesses in system performance. Using these data sources, HSRI was able to compare the performance of the Texas MR/RC system to that of systems in other states, as well as the national averages.

The analysis was prepared by the following HSRI staff:

John Agosta, Ph.D.

HSRI Vice President. He completed his doctorate in Rehabilitation Research at the University of Oregon, specializing in research methods and community supports for people with disabilities. Employed at HSRI since 1983, he has been involved with nearly all efforts at HSRI surrounding family support issues, facilitated development of strategic plans, conducted analyses of state systems for people with developmental disabilities (e.g., Arkansas, Idaho, Oregon, Hawaii), and studied specific facets of the field (e.g., trends in supported employment, managed care, self-determination). Dr. Agosta is a nationally recognized expert in topic areas such as family support, self-directed supports and community systems regarding policies that affect individuals with developmental disabilities.

Jon Fortune, Ed.D.

Policy Associate at HSRI. He has solid research skills as well as hands on experience as a state administrator. In 1990, Dr. Fortune joined the Wyoming Department of Health Developmental Disabilities Division where he has held senior management positions. He was instrumental in designing and implementing Wyoming's system of community services for people with developmental disabilities and acquired brain injury, including developing Medicaid HCBS waivers for both populations. During his tenure in Wyoming, the state substantially reduced the number of people served in its large state facility and built an especially strong system of quality community supports. Fortune was also the chief architect of the precedent-setting Wyoming DOORS model through which people with disabilities are assigned individual budgets based on their assessed needs and other factors. Prior to joining the Wyoming Department of Health, he managed a community agency in Wyoming and held other positions in Colorado and Texas and is currently working on financial architecture in DD statewide service systems in Colorado, Florida, Louisiana, Michigan, Missouri, Oregon, Rhode Island, and Virginia. He also has had a lifetime interest in the research regarding the Alamo.

Drew Smith, B.S.

Policy Assistant at HSRI. He is a graduate of Portland State University in Business Administration and currently works on several HSRI projects tied to developing person-centered funding strategies, assessing the impacts of service changes and reductions, and supporting self-advocacy.

Kerri Melda, M.S.

Policy Associate at HSRI and works on several of HSRI's person-centered funding and gap analysis projects. Ms. Melda holds a Master's Degree in Public Policy and Administration (University of Oregon) and a Bachelor's Degree in Special Education (Indiana University). She has been employed with HSRI since 1992. Her primary responsibilities at HSRI include project leadership, policy and statistical analyses, program evaluation, and provision of training and technical assistance. Melda currently serves as Director of HSRI's Juntos Podemos (Together We Can) Family Center, connecting Latino families who have children with disabilities to community services and supports, and as Director of HSRI's National Center for Family Support. She also oversees all family support related activities of the National Core Indicators project, which aggregates, analyzes and compares family support satisfaction data across 30 states.

Bob Gettings

Former Executive Director of the National Association of State Directors of Developmental Disabilities Services. Mr. Gettings served as NASDDDS' chief executive officer for nearly 37 years. In this capacity, he was responsible for representing the interests of the 50 state developmental disabilities agencies in Washington, D.C., and facilitating communication among the states concerning the most effective means of serving citizens with lifelong disabilities. A Life Member of the American Association on Intellectual and Developmental Disabilities, Gettings was recognized in 2000 by the National Historic Trust on Mental Retardation as one of 36 major contributors to the field during the 20th Century.

Valerie Bradley, M.A.

Has been the President of HSRI since its inception in 1976. She has a Master's Degree from the Eagleton Institute of Politics at Rutgers University. Ms. Bradley has directed numerous state and federal policy evaluations that have contributed to the expansion, enhancement and responsiveness of services and supports to people with disabilities and their families. She helped to design skills standards for human services workers, conducted a study to translate the experience with decentralization in Scandinavia to an American context, is the principal investigator of a national technical assistance initiative in quality assurance, and co-directs a 26-state initiative on performance measurement, the National Core Indicators. Bradley is the recent past Chair of the President's Committee on Mental Retardation. She is also the Immediate Past President of the American Association on Intellectual and Developmental Disabilities.

Personal Stories

When reviewing the analysis of Texas policy related to access and delivery of health and human services, it is important to understand the impact the current policies and future decisions have on the daily lives of individuals with intellectual and developmental disabilities (I/DD). Therefore, TCDD contacted individuals with I/DD and their families throughout the state and invited them to share their experiences in obtaining needed services and supports. Individuals were asked about the specific challenges they face on a daily basis and the services they need most. Individuals answered questions regarding the application process for Medicaid and non-Medicaid programs and the time spent waiting for needed services. Individuals who ultimately received services were asked to describe how the services affected their daily life. Families were also asked to speak directly to Texas policymakers and offer suggestions for change.

Individuals who willingly told their story represented all geographic regions of the state — both urban and rural areas. Each family was unique in terms of income level, ethnicity, gender, cultural background, and disability. Some were receiving Medicaid waiver services while others have been on the state's Interest List for years. TCDD engaged an independent consultant, Therese Palombi, to talk with individuals with developmental disabilities and their family members and summarize their stories in their own words. The recommendations in this report are offered to make a difference in the lives of people who were interviewed and the many other families in Texas in need of support.

Therese Palombi

Has more than 25 years of experience working with people with disabilities in Texas. She started her career as a direct care employee and has worked in the private and public sectors for people with disabilities. She has worked for a Mental Retardation Authority (MRA) and for the Department of Aging and Disability Services (DADS) Provider Services Division. Palombi has managed various Medicaid programs and is currently doing contract work in the field. She serves as a Board member for The Arc of Texas and is on the Project Advisory Committee for EveryChild, Inc., in Austin.

Intellectual and Developmental Disabilities vs. Mental Retardation and Related Conditions

The two reference points throughout this report (I/DD and MR/RC) are not exactly interchangeable, but do overlap significantly. A reference to "people with intellectual and developmental disabilities" (I/DD) is preferred terminology when making reference to this population and is consistent with national trends. Yet, in relevant Texas statute (Title 7; Subtitle A; Chapter 531) and related administrative codes, the reference to this general population who access services are people with "mental retardation and related conditions." For the purposes of this report, the term "mental retardation or related conditions" is used when there is reference to the Texas service system. When referencing the broader population of individuals, the term "intellectual and developmental disabilities (I/DD)" is used.

Glossary of Key Terms

In this report, services and housing arrangements for people with mental retardation and related conditions (MR/RC) within the State of Texas are examined. Below, is a list of key terms used commonly throughout this report, as well as their meaning/definition.

Federal Definition of Developmental Disabilities:

The U.S. Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402) reads as follows:

A. "In general, the term ´developmental disability´ means a severe, chronic disability of an individual that:

- **i.** is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- **ii.** is manifested before the individual attains age 22;
- **iii.** is likely to continue indefinitely;
- **iv.** results in substantial functional limitations in three or more of the following areas of major life activity: (a) self care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, and (g) economic self-sufficiency; and
- **v.** reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

B. Infants and young children: An individual from birth to age nine, inclusive, who has a substantial delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting these criteria later in life."

It is worth noting that states do not have to use the federal definition of developmental disabilities and many have their own variation of the definition.

Mental Retardation and Related Conditions:

DADS defines Mental Retardation and Related Conditions as follows:

Mental Retardation[2] is defined by 25 Texas Administrative Code (TAC) §415.153 as:

> Consistent with THSC, §591.033, significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

Related Condition is defined by 25 TAC §415.153 as: As defined in the Code of Federal Regulations (CFR), Title 42, 435.1009, a severe and chronic disability that:

A. is attributable to:

- cerebral palsy or epilepsy; or
- any other condition, other than mental illness, found to be closely related to mental retardation because the condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with mental retardation, and requires treatment or services similar to those required for persons with mental retardation;

B. is manifested before the person reaches the age of 22; and

C. is likely to continue indefinitely; and

D. results in substantial functional limitation in three or more of the following areas of major life activity:

- self-care;
- understanding and use of language;
- learning;
- mobility;
- self direction; and
- capacity for independent living.

State School/Center:

State schools/centers are large state-run facilities for people with intellectual disabilities. These facilities are Intermediate Care Facilities for the Mentally Retarded (described below) and provide round-the-clock care to facility residents. These settings are typically referred to as "very large" settings, housing 75 to 620 individuals in Texas. Nationally, these facilities are referred to as "large state-run institutions." Texas currently has 13 state schools/centers serving individuals with intellectual disabilities. The Office of the State Auditor concluded in its July 2008 report that Texas has the nation's largest population of individuals receiving mental retardation services in large state-run institutions.

Intermediate Care Facility for the Mentally Retarded (ICF/MR):

The designation of ICF/MR refers to a type of residential setting that is supported through the federal Medicaid program and jointly funded through state and federal match. The ICF/MR program provides highly-regulated residential care and treatment for people with mental retardation or severe related conditions. In Texas, ICFs/MR range from smaller residential facilities for 1 to 6 individuals up to large facilities housing 16 or more individuals, and in many cases provide 24 hour care. Many of the small ICFs/MR are privately owned and were in operation before HCBS waiver (described below) services became an alternative funding option in Texas. There are 60 medium sized (7-15 bed) ICFs/MR in the state along with 19 larger private ICFs/MR.

Home and Community-Based Services (HCBS) Waiver:

The University of Minnesota, Research and Training Center on Community Living defines home and community-based services as follows:

"Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), passed on August 13, 1981, granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance 'non-institutional' services for Medicaid-eligible individuals. The Medicaid Home and Community-Based Services (HCBS) waiver program was designed to provide non-institutional, community services to people who are aged, blind, disabled, or who have I/DD (intellectual or developmental disabilities) and who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid facility (i.e., a Nursing Facility or an ICF/MR). Final regulations were published in March 1985 and since then a number of new regulations and interpretations have been developed, although none have changed the fundamental premise of the program, that of using community services to reduce the need for institutional services.

A wide variety of non-institutional services are provided in state HCBS programs, most frequently these include service coordination/case management, in-home support, vocational and day habilitation services, and respite care. Although not allowed to use HCBS reimbursement to pay for room and board, all states provide residential support services under categories such as personal care, residential habilitation, and in-home supports.[3]"

Texas Home and Community-Based Services (HCBS) Waivers

- **Community Based Alternatives (CBA)** – The CBA waiver serves older adults and adults with disabilities as a cost-effective community alternative to living in a nursing home. DADS provides case management services to participants in this waiver program. Services available through this waiver include: adaptive aids and medical supplies, adult foster care, assisted living residential care services, consumer directed services, emergency response services, home delivered meals, minor home modifications, nursing services, occupational and physical therapy, personal assistance services, prescription drugs (if not covered through Medicare), respite care, and speech and/or language pathology services. While a handful of older individuals with MR/RC are involved in this program, the primary target population consists of elderly and non-elderly individuals with physical disabilities.
- **Community Living Assistance and Support Services (CLASS)** – Serves people with mental retardation or related conditions as a cost-effective community alternative to placement in an intermediate care facility. Services available through this waiver include: adaptive aids and medical supplies, case management, the Consumer Directed Services (CDS) option, habilitation, minor home modifications, nursing services, occupational and physical therapy, prescription drugs (if not covered through Medicare), psychological services, respite care, specialized therapies, and speech pathology. The CLASS waiver does not provide habilitation services in community facilities with 24-hour care responsibilities and, as such, does not address the residential support needs of many individuals on the interest list for HCS waiver services. CLASS services are available in specific geographic catchment areas.

- **Deaf-Blind with Multiple Disabilities (DB-MD)** – The DB-MD waiver serves individuals who are deaf and/or blind with multiple disabilities as a cost-effective alternative to institutional placement. The program focuses on increasing opportunities for consumers to communicate and interact with their environment. Clients can choose from among three options for residential support: **1**) live in their own home or apartment with support; **2**) live with a parent or guardian with support; or **3**) live in a group home with support. Services available through this waiver include adaptive aids and medical supplies; assisted living (licensed up to six beds); behavior communication services; case management; chore provider; the Consumer Directed Services (CDS) option; day habilitation; dietary services; environmental accessibility/minor home modifications; intervener; nursing services; occupational and physical therapy; orientation and mobility; prescription drugs (if not covered through Medicare); residential habilitation; respite care; speech, hearing, and language therapy; and transition assistance services.
- **Home and Community-based Services Program (HCS)** – Serves people with mental retardation as a cost-effective community alternative to placement in an intermediate care facility. HCS serves individuals who are living with their family, in their own home, or in other community settings, such as small group homes. Services available through this waiver include case management, adaptive aids, minor home modifications, counseling and therapies (includes audiology, speech/language pathology, occupational therapy, physical therapy, dietary services, social work, and psychology), dental treatment, nursing, residential assistance (e.g., supported home living, foster/companion care, supervised living, residential support), respite, day habilitation and supported employment.
- **Integrated Care Management (ICM) 1915(c) waiver** – This program is a non-capitated primary care case management model of Medicaid managed care. ICM is available only in the Dallas and Tarrant county service areas. ICM Program participation is mandatory for individuals who are 21 years of age and older who receive Supplemental Security Income (SSI) or are SSI-related, receive SSI and are dually eligible for Medicaid and Medicare, and participate in Community-Based Alternatives (CBA) and who wish to receive the same services they now receive in CBA. ICM is voluntary for SSI children under 21 years of age in the ICM Service Areas. Individuals in institutional settings and those in waiver programs other than CBA are excluded from the ICM Program.

  ICM members will remain eligible for the full set of Medicaid benefits they currently receive. ICM members who are not dually eligible for Medicaid and Medicare are eligible to receive unlimited medically necessary prescriptions. They also will have access to an annual adult wellness check. ICM long-term services and supports (LTSS) include Primary Home Care (PHC) and Day Activity and Health Services (DAHS). ICM members may also be eligible for the ICM 1915(c) waiver services. The ICM 1915(c) waiver offers the same array of services as the CBA waiver.

- **Medically Dependent Children Program (MDCP)** – This waiver provides services to support families caring for children who are medically dependent and to encourage de-institutionalization of children in nursing facilities. DADS' employees provide case management services to MDCP eligible children. Services available through this waiver include: respite care, adjunct support services, adaptive aids, minor home modifications, and assistance with nursing facility to community transition.
- **STAR+PLUS 1915(b)(c) waiver** – STAR+PLUS is a Texas Medicaid program that provides health care as well as acute and long-term services and support through a managed care system. It is administered by the Texas Health and Human Services Commission (HHSC). Services are provided through health maintenance organizations (HMOs), which are health plans operating under contract with DADS. Through these health plans the STAR+PLUS program combines traditional health care (such as doctor visits) and long-term services and support, such as providing help in your home with daily activities, home modifications, respite care (short-term supervision) and personal assistance. People with MR/RC who require ICF/MR level of care are not eligible to participate in this program
- **Texas Home Living (TxHmL) waiver** – This is a cost-effective community alternative to placement in an intermediate-care facility that provides selected essential services and supports to children and adults with mental retardation who live in their family homes or their own homes. Services available through this waiver include adaptive aids, minor home modifications, specialized therapies (audiology, speech/language pathology, occupational therapy, physical therapy, and dietary services), behavioral support, dental treatment, nursing, community support, respite, day habilitation, employment assistance and supported employment. Unlike the HCS waiver program, the TxHmL program operates under a per participant spending cap, which was $10,000 per year in 2007.

Trae Caster

Read his family's story on page 26.

State of Services and Supports for Persons with Developmental Disabilities

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 (e.g., 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 mental retardation, 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 1.7 percent of general population has a developmental disability, or approximately 411,500[4] 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[5]. The life span of people with developmental disabilities has increased as the result of better health care and is approaching average lifespan of the general population. This increased longevity has two ramifications for developmental disabilities service systems: (a) "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.

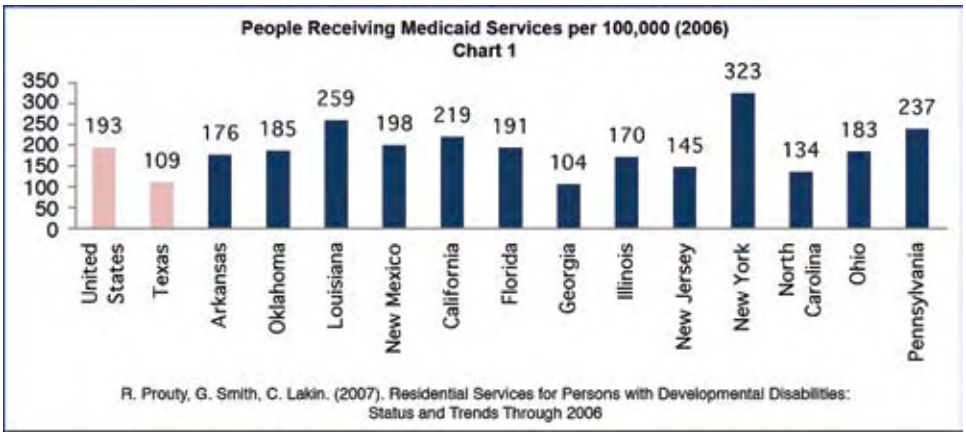
Over the past several decades, many states have reexamined the delivery of services to their citizens with developmental disabilities. During this timeframe, the general trend has been towards a decentralization of services where individuals can receive home and community-based services (HCBS) instead 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 *Olmstead v. L.C.* Two common themes running through these items are the need to provide 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 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.[6]

In comparison to other states, Texas falls significantly below the national average in many areas. Consider that:

- Texas spends significantly less than other states on Medicaid services to people with mental retardation or a related condition (MR/RC). On average, in 2006, states spent $131.29 per citizen on residential services for these individuals, while Texas spent just 41 percent of the national average: $53.91 (Braddock et al., 2008).
- In 2006, the number of Texans receiving community residential services per 100,000 people in the state's overall population was 35 percent less than the national average. (Texas serves 92 people per 100,000 versus the national average of 142 per 100,000). This means that Texas would need to provide residential services to 50 more people with MR/RC per 100,000, or 11,704 individuals, just to reach the national average (Lakin et al., 2007).
- In 2006, Texas furnished Medicaid-funded services at a rate that is 43.3 percent below the nationwide average (109 persons per 100,000 population in Texas vs. 193 persons per 100,000 population nationwide as can be seen in Chart 1). For Texas to serve the national average of people per 100,000 population, the state would need to provide Medicaid services to roughly 19,662 more people.
- Chart 1 also illustrates that among the comparison states, only Georgia serves fewer people per 100,000 population (i.e., 109 in Texas to 104 in Georgia).



Alba Family: Vandi, Elias, Alexis, Lorenzo & Jackie

Jackie and Lorenzo

Vandi and Elias Alba have three children: 12-year-old Alexis and 11-year-old twins Lorenzo and Jackie who were born with autism. After giving birth to twins, Vandi thought she would take a little time off from her $55,000 a year job. This "little time off from work" soon stretched to 10 years off work so that she could provide her children with autism with the support they needed. The Albas would end up spending $10,000 a year for services for Lorenzo and Jackie. For the Alba family, 10 years on the waiting list cost them an estimated $650,000.

It wasn't long before the Albas were faced with a difficult realization. The specialized services their twins would require were unavailable in Red Oak, Texas. They began researching options and discovered that behavioral services were available in Collin County from providers with extensive experience in childhood autism. Determined to obtain the best possible opportunity and services for their children, Vandi and Elias decided to leave the home in which they had planned to spend the rest of their lives. Elias quit his job, and the family moved to Plano. Once the Albas had relocated, their twins began receiving the services they needed.

Lorenzo was enrolled in specialized speech services designed to increase his auditory functioning, and Jackie was enrolled in behavior training. The Albas were only able to afford these services with assistance from Vandi's parents in the form of a $20,000 loan.

As the wait continued for waiver services, the Albas were considering a move out of state to seek better options for their children; however, Vandi's parents both became very ill. As an only child, she took on the task of caring for her father who had Parkinson's disease and her mother who had cancer. This all took place during the first four years of the twins' life.

In October of 2007 after spending 10 years on the waiting list, the Albas finally received services for Jackie under the Medicaid Community Living Assistance and Support Services (CLASS) waiver. They chose the Consumer Directed Services (CDS) option which allows them to decide who comes into the family home. Vandi has since returned to work.

Vandi states that what haunts them the most is, "The greatest loss is the loss we will never know. We will never know what 10 years of appropriate therapies and services could have done for our children." Being interviewed for this report was a very difficult decision for the Albas as they would be forced to relive this difficult experience. However, they knew it was something they had to do because, "We have to change the future. We *have* to."

Interest Lists: Time Spent Waiting for Services

Ideally, once an individual applies for services and is deemed eligible, he or she will start receiving services with reasonable promptness. 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[7].

When these standards cannot be met, Texas maintains "interest lists" for people who are unserved and seeking services, or underserved and seeking additional or changed services. As shown by Table 1, (as of June 30, 2008) DADS reported that 79,925 individuals were on the Interest Lists for six of seven Medicaid HCBS waiver programs operated by the department. This does not include participants in the STAR+PLUS waiver program, with 37,187 (duplicated) of those individuals on the HCS Interest List alone.

It is not known how many of the 47,527 individuals currently receiving waiver services have intellectual and/or developmental disabilities or other potentially qualifying conditions. However, individuals with I/DD are primarily served within the HCS, CLASS and TxHmL waiver funded programs. The HCS waiver, which is used to fund several community residential support options, serves the second highest number of people (i.e., 13,889) and has the largest interest list. Projections indicate the HCS Interest List will likely grow to 40,000 individuals by 2010[8].

Table 1: Individuals on Interest Lists by Longest Time Waiting for Services

Program	# Currently Served *	# on Interest List	Longest Time on Interest List
Community Based Alternatives (CBA)	21,050	29,316	2-3 years
Integrated Care Management (ICM) 1915(c) waiver	2,540	*263	1-2 years
Community Living Assistance and Support Services (CLASS)	3,929	21,496	6-7 years
Deaf-Blind with Multiple Disabilities (DB-MD)	153	28	1-2 years
Medically Dependent Children Program (MDCP)	2,541	9,920	2-3 years
Home and Community-based Services Program (HCS)	13,889	37,187	8-9 years
STAR+PLUS 1915(c) waiver	3,425	*2,916	2-3 years
Total	**47,527**	****100,335**	**N/A**

These counts reflect the end of June 2008.

* 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 82,050.The unduplicated count without STAR+PLUS is 79,925.

Source: Texas Department of Aging and Disability Services, Presentation to House Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services, August 22, 2008

Table 2 illustrates the time people generally spend waiting to receive services by waiver program. As shown, waiting time varies by waiver, with waits for the HCS and CLASS waivers being longest. Texans with MR/RC can wait up to nine years to receive HCS services with, 30.1 percent waiting for five years or more and the average wait being 3.5 years.

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	82.6 %	99.2 %	27.0 %	46.4 %	47.1 %	17.9 %
1-2 Years	10.7 %	0.8 %	22.6 %	53.6 %	38.4 %	17.5 %
2-3 years	7.0 %	0 %	13.9 %	0 %	14.4 %	13.4 %
3-4 years	0 %	0 %	12.3 %	0 %	0 %	10.7 %
4-5 years	0 %	0 %	12.0 %	0 %	0 %	10.3 %
5-6 years	0 %	0 %	11.9 %	0 %	0 %	9.9 %
6-7 years	0 %	0 %	0 %	0 %	0 %	9.4 %
7-8 years	0 %	0 %	0 %	0 %	0 %	7.7 %
8-9 years	0 %	0 %	0 %	0 %	0 %	3.1 %
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, (2008, June 30). DADS Interest List. Retrieved September 2008, Web site: http://www.dads.state.tx.us/services/interestlist/index.html

Future Demand for Services

If nothing is done to intervene, the number of people on interest lists is expected to grow 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, from 249 million to 302 million. According to the Texas State Data Center (The University of Texas, San Antonio), the population of Texas is likely to reach 25 million by 2010 and 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. Based on national comparisons, it is not uncommon to observe annual increases in demand of four percent or more. Thinking more conservatively, if the number of individuals on Texas' Interest Lists were to grow by two percent per year (over population growth), the list would swell to 99,016 people by 2018, or by an average of 1,966 additional individuals per year.

"Every decision we make is based on these Medicaid waiting lists. I would rather go to war than lose my place on the waiting list. I am willing to leave my family if I can get services for my child."

– Master Sergeant Stephen Spark, (one year from retirement)

Caster Family: Melonie, David, Madisen, Wyatt, Elizabeth & Trae

Madisen, Trae, David, Melonie, Wyatt and Elizabeth

Parents who have a child with a disability can spend much time questioning what caused their child's disability. Bedford resident Melonie Caster, however, can pinpoint the exact date and cause of her son's disability. When her son, Trae, was nine weeks old, he was injured by a licensed in-home caregiver. Shaken baby syndrome caused severe trauma to his head and neck when the caregiver probably threw Trae against a wall.

For the next three years, Melonie didn't know if their son would survive. Melonie was faced with the decision to unplug Trae from his life support systems as doctors told her that he was in pain and would not recover. During what she thought was the last night of Trae's life, she held him all night in the hospital room.

Once the support systems were unplugged, Trae immediately began to breathe on his own. However, the doctor told Melonie that Trae would always be in a vegetative state and she replied, "You're right, I'm going to have a little sweet pea."

Once he recovered from his immediate injuries, Trae was diagnosed with traumatic brain injury. Melonie states, "I no longer had a child with shaken baby syndrome, I have a child with a disability." She then added Trae's name to the Medicaid waiver program waiting lists.

Over the next nine years of their lives, Trae's parents were falsely accused of his injuries and threatened with prosecution for a crime they did not commit. They also had their parental rights terminated temporarily, and Trae was placed in foster care for nine months.

Melonie created an international support group for shaken baby syndrome. Also, because Trae's abuser was unable to be prosecuted due to legal limits, Melonie worked to enact legislation that was passed in her son's name to increase the statute of limitations related to injury of a child.

Melonie remarried and her second husband, David, and his three children, Madisen, Wyatt and Elizabeth, began a journey together caring for Trae while they waited to receive Medicaid waiver services.

They received Community Living Assistance and Support Services (CLASS) services in 2006 when Trae was 13 years old. While grateful for the services, the Casters report that CLASS does not cover medications related to Trae's diagnosis of traumatic brain injury. As a result, their out-of-pocket expenses have not been reduced since enrollment in the waiver program.

Now that Trae has services, he goes into the community with his attendants and gets the therapies he needs. Melonie states, "Now, Trae is just a kid. Before the program, he was a person with a disability on a waiting list."

Texas has recently sought to accommodate unmet service demand by allocating funds for system expansion – specifically allocating additional funds for waiver services (79th and 80th Texas Legislature). These efforts have helped thousands more people; however, these allocations are insufficient to meet 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. Nor does Texas employ an accurate and reliable means for tracking demand over time. Absent such strategies, the current gap is expected to worsen.

Impact of Texas Interest Lists on Individuals with Disabilities

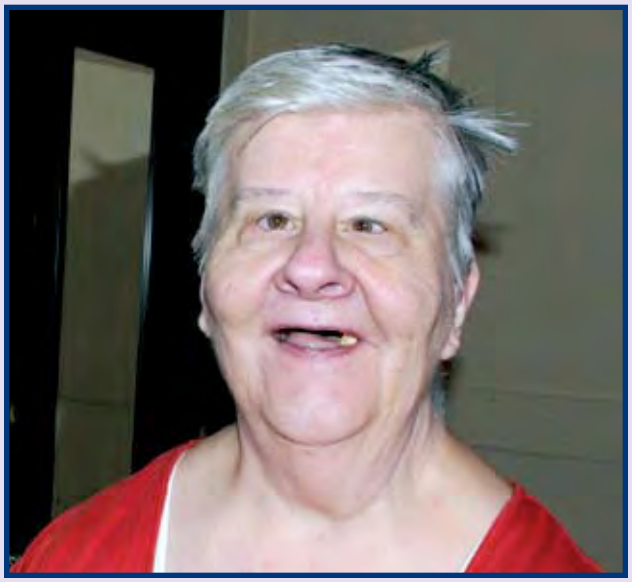
In Texas, the gap between present capacity and unmet needs means Texas does not operate its service system in a manner that ensures that individuals will receive services promptly. People in need must wait for the next available service opening or HCBS waiver slot and cannot count on getting assistance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

Texas also requires individuals to enter an interest list for waiver 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 preference. 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.

> "We try to fit the individual to the program vs. fitting the program to the individual. Everyone is different."
>
> – Pat Munoz

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 they prefer. 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 school/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.

Betty Gage



Betty Gage

Betty Gage currently lives in an Intermediate Care Facility for persons with Mental Retardation (ICF/MR) group home in Corsicana, Texas, but she wants her own apartment. Betty is 68 years old and has been on the Home and Community-Based Services (HCS) waiting lists for the past eight years. She has mild mental retardation and lives with five roommates.

For the majority of her life, Betty lived with friends in Arkansas and Texas. Her friends now live in Alaska, and she flies up to see them on a yearly basis.

Betty says she wants to be in the HCS program because “I want my own apartment and I want a different job.” She wants more space and privacy for her personal items. She also wants to be able to go to the store and shop on her own.

“I’m ready to go!” Betty reports. In keeping with her desire to move, Betty has storage bins full of items she has purchased for an apartment. She has decorative items, kitchen and bath items and at least half a dozen pillows.

Betty visits the administrator’s office at the group home almost every day and asks “When am I going to get the call?” Betty and the administrator call frequently to check the status of her place on the list. Betty’s current number for the HCS program is 414, down from 616 in 2006.

Betty was asked to think, “What if it took another five years before (your) name comes up on the list?” She replied, “It’s not going to work for me. I can’t wait five more years. I don’t want to.” She added, “When am I going to get HCS, when I die?”

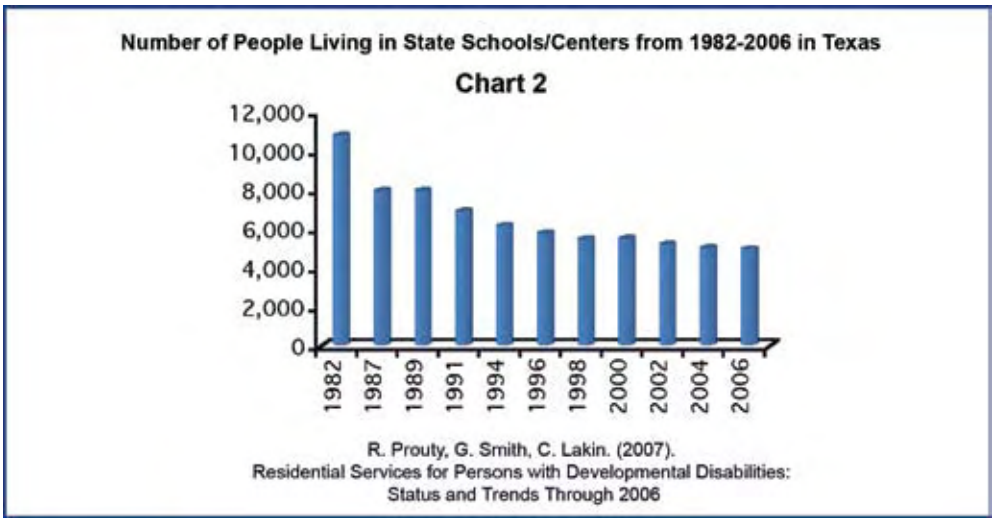
Reliance on Large Congregate Care Facilities

Texas relies much more heavily on large congregate care facilities than most other states. The state continues to place children in state schools/centers and to rely on ICF/MR service options, even within services used to support smaller groups of people. While Texas is taking some action to alter this pattern, the impact is small and the pace of change is slow.

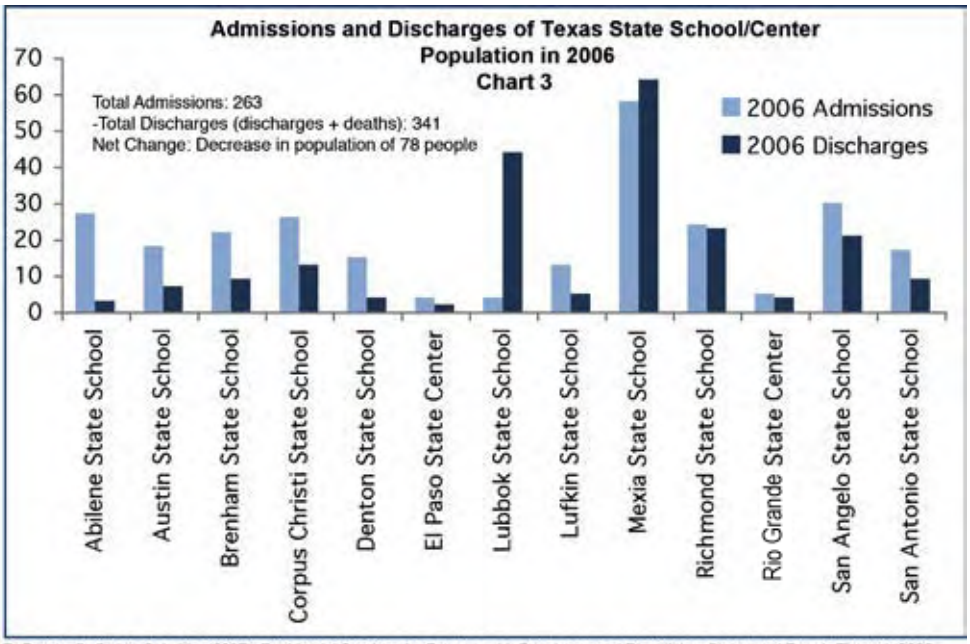
Texas operates 13 state schools/centers across the state. These facilities include sites in:

Abilene
Austin
Brenham
Corpus Christi
Denton
El Paso
Harlingen (Rio Grande)
Lubbock
Lufkin
Mexia
Richmond
San Angelo
San Antonio

Texas has relocated many individuals from state schools/centers into community alternatives, reducing the population of state-operated facilities from 7,933 in 1989 to 4,924 in 2006. Yet, Texas has been considerably slower at reducing the use of state schools/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.



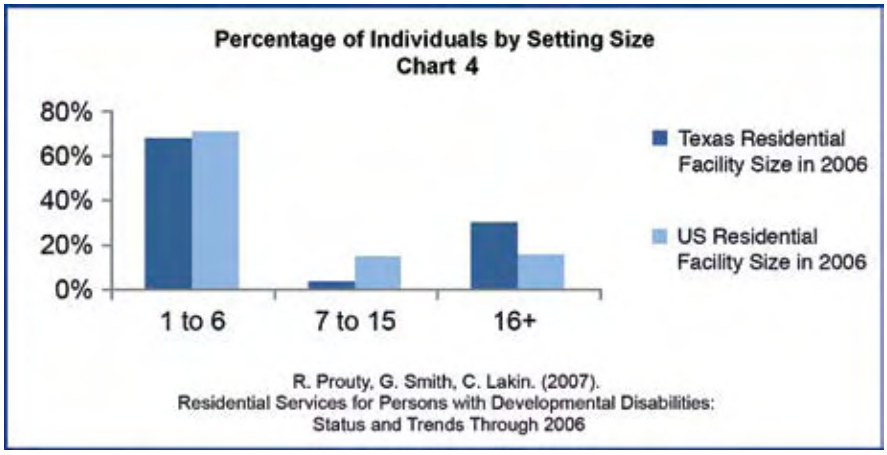
As can be seen in Chart 3, the state school/center population decreased by 78 people in 2006. However, when comparing only admissions and discharges (not including deaths) there was a net increase of 55 people. The chart also shows that all 13 state schools/centers still actively admit individuals. In 2006, Mexia State School had the largest admission of 58 people, but also the largest discharge of 64 people.



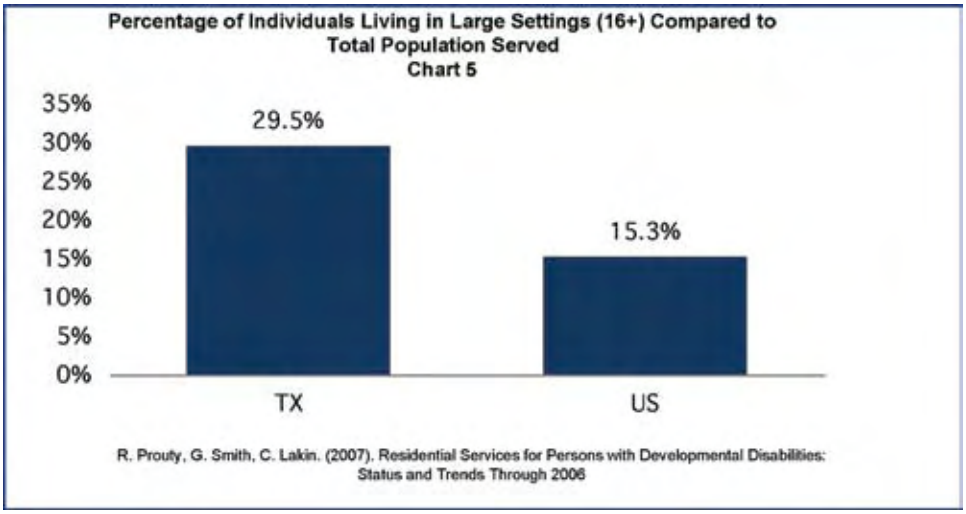
R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006

Rio Grande

Chart 4 shows that the state generally funds a bi-modal residential system. In 2006, most people receiving residential services lived in housing options of 1-6 people (14,623 individuals), or in facilities housing 16 or more people (6,414). Relatively few people (682) lived in intermediate-size residences of 7-15 people.

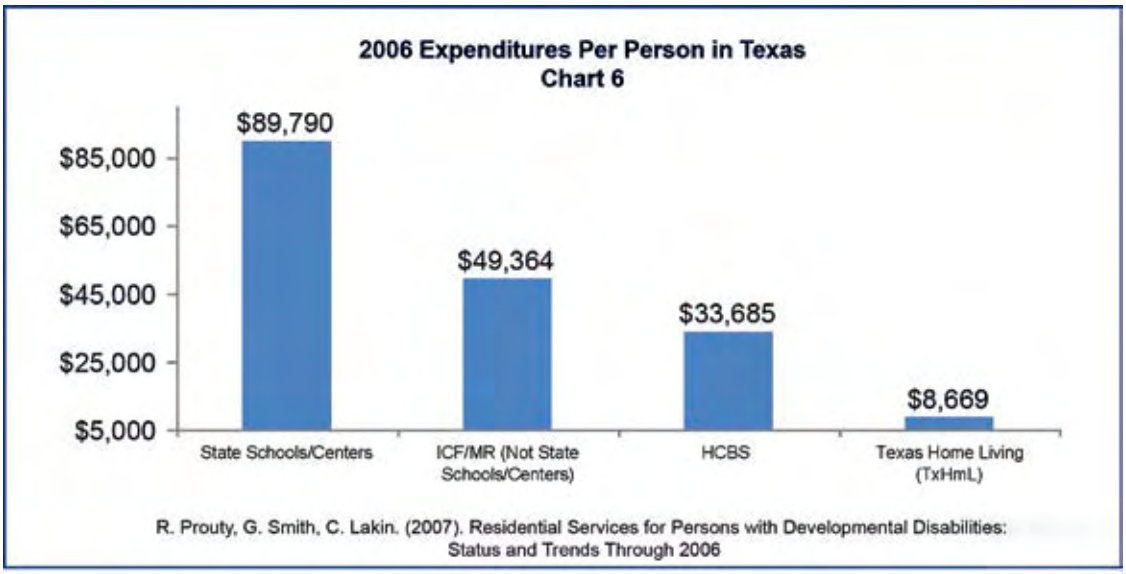


Based on the figures in Chart 4, Texas serves about the same percentage of individuals as other states in residences of 1-6 people (67 percent in Texas versus 71 percent nationally). However, in Texas, about 29.5 percent receiving residential services are in facilities serving more than 16 people, compared to 15.3 percent nationally (see Chart 5).



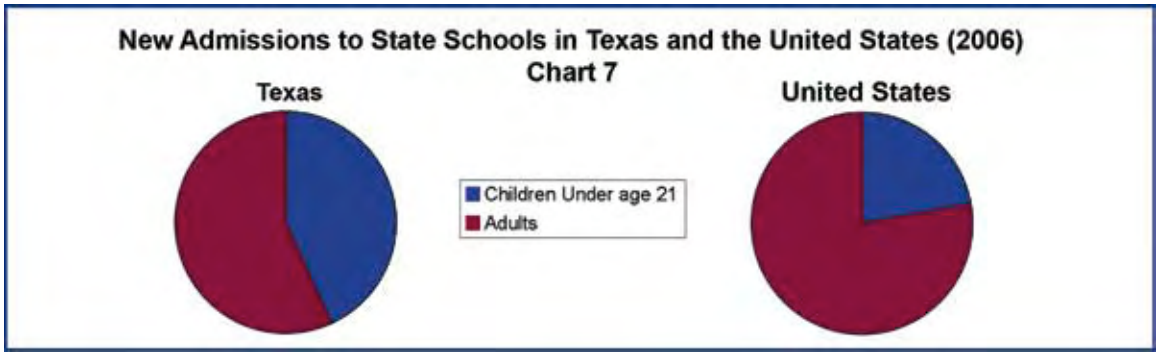
Texas closed two state schools in 1996. Despite this, there were 263 new admissions into state schools/centers in 2006, in addition to 208 discharges and 133 deaths, yielding an overall modest census reduction of only 78 people.

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 school/center was almost twice the cost of supporting a person in other types of ICFs/MR.



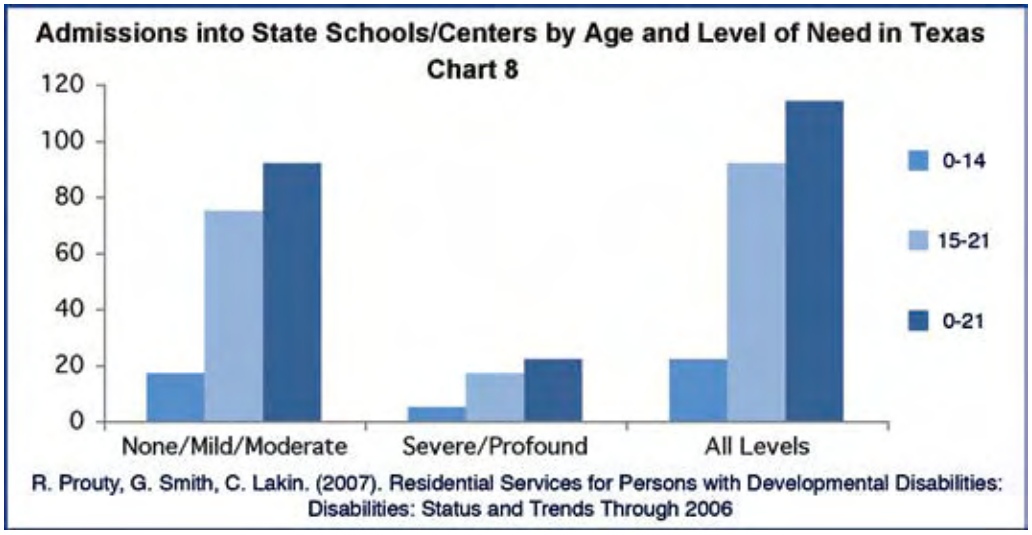
Placements of Children into State Schools/Centers

The population of children in state schools/centers has remained virtually constant since 1994 (see Chart 7). In 2006, roughly five percent of the residents in state schools were children, ages 0-21. This amounts to 246 children in state schools/centers.



In 2006, 43 percent (114 out of 263) of new admissions into Texas state schools/centers were children. This is twice the national average of 21.7 percent.

As shown by Chart 8, many of these children have none to moderate levels of need.



Due to recent increases in state school/center admissions involving children, DADS established a workgroup to investigate the current intake of new children into state schools/centers and the current discharge rate. The workgroup found that in fiscal year 2007, 152 children/youth ages 0-21 were admitted into state schools, while only 12 individuals moved out of state schools and into community settings.

The Texas Legislature has taken some action by passing Senate Bill 368 (77th Texas Legislature, 2001) that requires all individuals under the age of 22 who reside at a state school/center to be placed on an Interest List for community waiver support. The provision is meant to expedite the placement of children out of state run schools/centers. Yet, children are limited by the number of waivers that are available. Furthermore, by allowing children to be admitted into the state schools/centers, the state continues to replenish the population making it almost impossible to transition away from the state's reliance on large congregate facilities.

Serving Individuals with Complex Needs in the Community

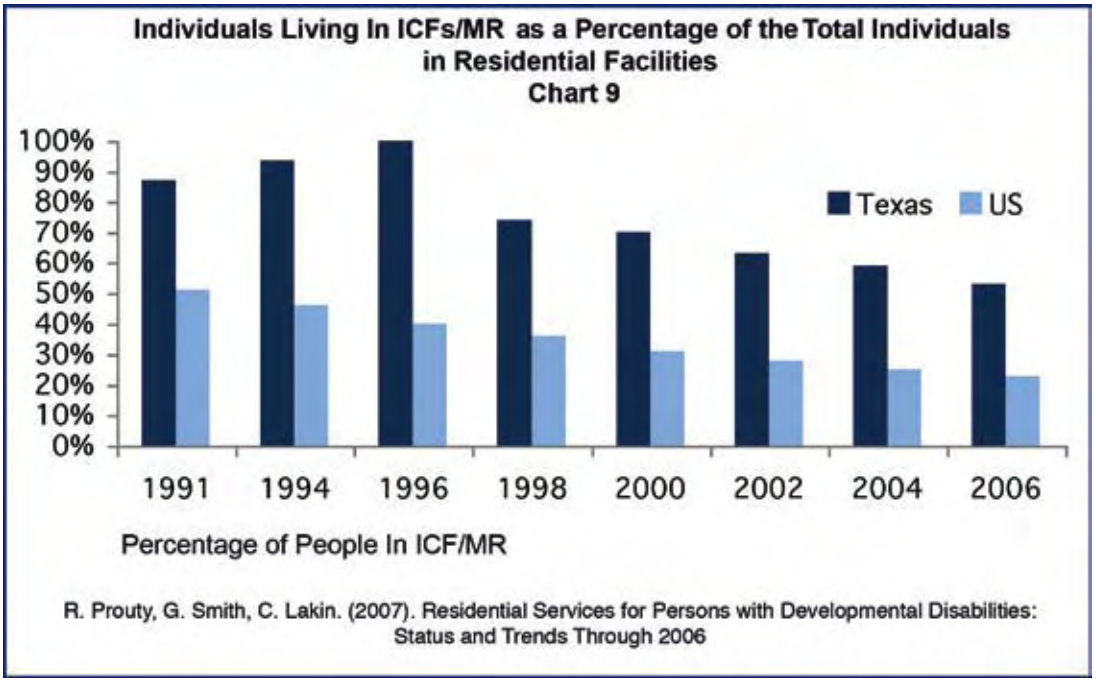
In Texas there is a tendency to support those with more significant disabilities in ICF/MR settings. However, as shown in Table 3, the percentage of people with a Limited Level of Need (LON) served in ICFs/MR is roughly equivalent to the percentage served in waivers (44.8 percent ICFs/MR to 42.9 percent in waivers).

Table 3: Individuals Served by Service Type and Their Level of Need

	State Schools		Community ICF/MR		Total ICF/MR		HCS		TxHmL		Total Waiver	
Level of Need	People	%	People	%	People	%	People	%	People	%	People	%
Intermittent	249	5.10%	1,324	19.55%	1,573	13.50%	2,719	29.28%	886	47.35%	3,605	32.31%
Limited	1,862	38.16%	3,362	49.65%	5,224	44.84%	4,046	43.57%	738	39.44%	4,784	42.88%
Extensive	1,689	34.62%	1,289	19.04%	2,978	25.56%	1,797	19.35%	198	10.58%	1,995	17.88%
Pervasive	1,062	21.77%	775	11.45%	1,837	15.77%	700	7.54%	49	2.62%	749	6.71%
Pervasive Plus	17	0.35%	21	0.31%	38	0.33%	24	0.26%	0	0.00%	24	0.22%
Total	4,879	100%	6,771	100%	11,650	100%	9,286	100%	1,871	100%	11,157	100%

Source: DADS response to questions posed by the House Select Committee for Individuals Eligible of Intermediate Care Facility Services; April 25, 2008; Attachment 11

The national trend is to rely more heavily on HCBS options for individuals of all levels of need, including those with significant support needs. In fact, by 2009, nine states plus the District of Columbia will not have any state operated residential institutions for people with developmental disabilities.

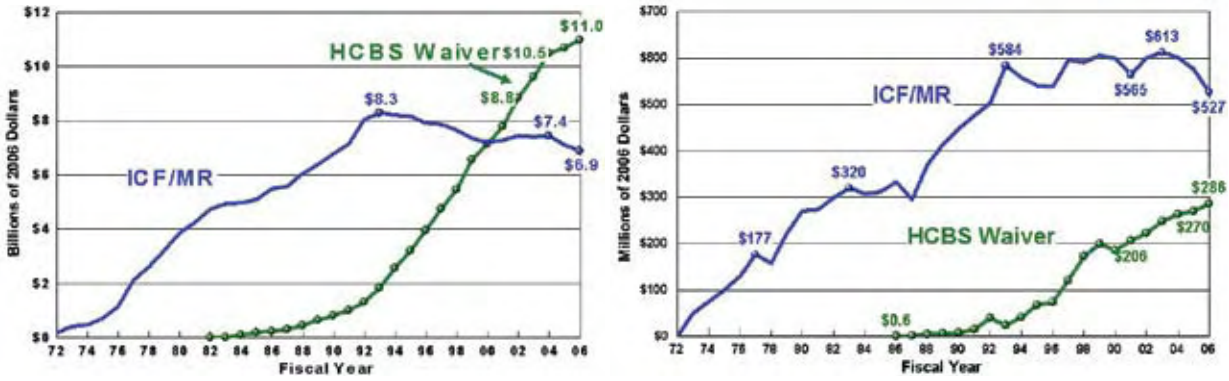


The national trend to transition away from ICFs/MR gained momentum in the 1990s once waiver use became more common. Yet Texas has not kept pace with this national trend (Chart 10). Many states have come to rely almost entirely on HCBS services and very little on ICFs/MR. In 2006, nationally, 83 percent of those served in developmental disability systems participated in an HCBS waiver program, compared to only 54.7 percent in Texas. In 2007, 6,608 individuals lived in ICFs/MR; a small change from the 6,649 individuals in 1987[9].

Chart 10 (below) shows an important trend in spending for services. In past years, total spending nationally for ICFs/MR facilities has been greater than spending for home and community based services (HCBS). However, around the year 2000, this national trend changed. As seen in the first graph (A), the amount of funds spent on HCBS waiver services nationwide met and then exceeded the amount spent on ICF/MR services. Yet as the second graph (B) shows, Texas has not made this fundamental shift in the manner in which individuals receive needed services. As of 2006, the amount spent on ICF/MR facilities in Texas remains significantly higher than the amount spent on HCBS services.

ICF/MR vs. HCBS Waiver Spending in the U.S. and Texas
Chart 10

United States (A) **Texas (B)**



Source: Braddock, D., State of the States in Developmental Disabilities, 2008.

It is not known what the future will hold – 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 ICFs/MR.

Summary

By all measures, Texas relies more heavily on state schools/centers and privately-operated ICFs/MR to serve individuals with complex needs than most other states. In spite of actions to decrease such reliance, stronger actions have been taken that maintain and expand the state's investment in ICF/MR options, including:

- The slow pace of relocations from state schools.
- Sustained admissions of children into state schools at a pace twice the national average.
- The addition of 1,690 positions to the state school infrastructure in FY 2008-2009.

This pattern ultimately results in individuals not being served in the most integrated setting possible. Moreover, the continued strong investment in state school 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.

Nick Aune

Read his family's story on page 41.

Sparks Family: Stephen, Leesa, Tyler & Jason

Leesa, Jason, Stephen and Tyler Sparks

Master Sergeant Stephen Sparks and his wife, Leesa, have 30 years of combined service in the military. Stephen is currently one year from retirement. Leesa quit her job to take care of their sons, 11-year-old Jason and 13-year-old Tyler, who has autism. Tyler was first diagnosed with developmental delays while the Sparks were serving in Turkey. The military's Exceptional Family Member Program (EFMP) requires that if you have a family member with a disability, you must return immediately to the United States. The Sparks family moved to Massachusetts for five years, then Converse, Texas, where they currently reside.

Tyler attends a school in the San Antonio area that specializes in applied behavior analysis, which is essential if Tyler is to meet his full potential. The school provides individualized work/training skills which are important to Tyler for future community living. He wants to go to a cooking school and become a famous chef. He is currently taking cooking classes at the school.

The Sparks' military insurance covers Tyler's $2,500 a month expense for school tuition and transportation. But, if Stephen retires and Tyler is still on the waiting list for Medicaid services, Tyler will lose all of the services he currently has. Tyler has been on the waiting lists for five years; he is number five on the Home and Community-Based Services (HCS) waiting list.

This dilemma is further exacerbated by Stephen's recent deployment orders which are to report by December 31, 2008, to go to the Middle East for a year of duty. Thus far, he has had six tours of active duty in the Middle East for a total of 522 days in active combat. Upon completion of this tour, his orders are to report to one of three bases, all of which are outside of Texas. To avoid losing his son's placement on the waiting list, he plans to retire upon return from the Middle East.

The Sparks have met with several state legislators regarding how the waiting list affects military families, with one expressing an interest in exploring such during the next Legislative Session. While Stephen will not be here during the 81st Texas Legislature, he says he would like legislators to know that "Every decision we make is based on these Medicaid waiting lists. I would rather go to war than lose my place on the waiting list. I am willing to leave my family if I can get services for my child."

During the last biennium, Texas has made some progress to improve services and supports for individuals with intellectual and developmental disabilities. Specific policy and program improvements have been made in the areas of transitioning from institutional settings to community living, accessing home and community-based waiver supports, and Medicaid system reform. While progress has been made, there are still significant areas for improvement.

Transition from State Schools to Community Living

Home and Community-based Waiver Expansion

The 79th Texas Legislature (2005) provided funds for the 2006-07 biennium making it possible to serve an additional 9,360 individuals through the Medicaid waiver programs as well as through non-Medicaid-funded services.

Similarly, the 80th Texas Legislature (2007) appropriated $71.5 million in General Revenue and $167.3 million in All Funds for expansion of Medicaid waiver and non-Medicaid community services. The additional funding allowed DADS to serve 8,902 more individuals according to the following breakdown:

Community Based Alternatives (CBA)	1,607
Community Living Assistance and Support Services (CLASS)	586
Deaf-Blind with Multiple Disabilities (DB-MD)	16
Home and Community-based Services Program (HCS)	2,676
Non Medicaid Services	2,228
In-Home Family Support	1,374
Medically Dependent Children Program (MDCP)	415
Total	**8,902**

DADS also began to refer more individuals living in state schools/centers to community settings. While these funds have provided needed services to thousands of individuals, Texas is not moving strategically or quickly enough to meet the current and future demand for services.

Community Living Options Information Process

Senate Bill 27 passed by the 80th Texas Legislature (2007) has changed the way that residents of state schools and state centers and their Legally Authorized Representatives (LARs) are informed about options for living in the community. The new Community Living Options Information Process (CLOIP) aims to minimize any conflicts of interest between the state school/center, resident, LAR or local Mental Retardation Authority (MRA) in helping residents and LARs understand community options. Local MRAs now have the responsibility for providing this information for adults, 22 or older, who live in a state school/center in the MRA's service area. Despite these efforts, many residents do not get the information about the community living options they choose.

Institution to Community Relocation Efforts

As part of the state's response to the *Olmstead* decision, several initiatives have been undertaken to help people relocate from institutions to the community. In September 2001, Rider 28 was implemented, which has helped more than 12,030 Texans in nursing facilities transition back to the community to receive their long-term services and supports. Rider 28, also known as "Money Follows the Person" or "MFP" established a method-of-financing whereby an individual's service dollars "follow" them when they move from an institution to the CBA waiver program. This allows nursing facility residents to return to the community without having to be placed on a community service interest list.

While the MFP financing mechanism has proven successful for individuals living in nursing facilities, it does not provide people living in state schools/centers and ICFs/MR with the same opportunity. During the 80th Texas Legislature (2007), funds were appropriated for 250 "Promoting Independence" HCS slots for people in state schools. These slots are available to state school residents who receive a referral to community. In addition, the 80th Legislature appropriated funds for 240 Promoting Independence HCS slots for individuals in large community ICFs. Rider 41 (General Appropriations Act, 80th Legislature, 2007) allows DADS to provide waiver services to an individual under the age of 22 moving from a nursing facility who does not qualify for a nursing facility waiver program (e.g. CBA), but does meet the eligibility requirements of another waiver program (e.g. HCS). Additionally, Rider 43 (General Appropriations Act, 80th Legislature, 2007) allows DADS to provide waiver services to 50 individuals under the age of 22 moving from a small or medium community ICF/MR. While these slots are critical in relocating individuals to the most integrated setting, individuals in ICFs/MR who wish to move to the community are limited by the relatively low number of slots made available to them.

Additionally, the Texas Health and Human Services Commission (HHSC) and the Texas Department of Aging and Disability Services (DADS) will receive approximately $17.9 million in new funding over the next five years, which will be paired with existing state and federal funding for a total of $143 million under the Federal MFP Demonstration Grant, awarded to Texas by the Centers for Medicare and Medicaid Services.

The agency will use the money to enhance the MFP initiative and expand efforts for persons with intellectual and developmental disabilities, and persons with behavioral health needs. Specifically, DADS will develop a pilot project to transition adults with behavioral health (mental health or substance abuse) needs from nursing facilities to the community. Up to 50 individuals will be served each year in the San Antonio area.

This demonstration project will also enable DADS to allow up to 400 individuals currently receiving ICF services to transition to HCS, but only if their provider decides to convert their program to provide HCS services. While this strategy is a notable step forward, it is inconsistent with the principle of self-direction, one of the core principles of Money Follows the Person.

Permanency Planning

While improvements have been made in informing residents of community options, the transition of individuals from facilities – particularly children – has been slow. Permanency planning efforts are designed to assure a permanent family living situation for children. Recent reports on permanency planning for children in Texas indicates there has been a small decrease over the past five years in the number of children/individuals under age 22 who receive residential services through DADS. Generally speaking, since 2002 there has been an increase in the number of individuals moving into smaller facilities with fewer children living in the larger facilities. Two exceptions are in the number of individuals under 22 who live in state schools, which has increased by 23 percent (up from 241 to 297), and the number of individuals under 22 who live in medium ICFs/MR; a 49 percent increase (up from 39 to 58). Overall, there has been a decrease from 1,508 in August 2002 to 1,434 on February 28, 2007; a total of only 74 children in five years.

Study on Intermediate Care Facilities

On January 16, 2008, the Speaker of the Texas House of Representatives, Tom Craddick (Midland), announced the creation of the *House Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services.* The committee was charged to evaluate the state's infrastructure for serving persons with cognitive disabilities and to make recommendations for new ways to improve the quality and availability of care in multiple settings. The committee focused on people who are eligible for services of intermediate care facilities including state schools. In addition to an investigatory role, the committee was charged to assess the risks to the health and well-being of persons eligible for state ICFs/MR services that are not being addressed by the state's current system. The committee is directed to review the assessment process used in determining eligibility for ICF/MR services and to evaluate the state's ability to comply with federal regulations regarding services and supports for individuals with cognitive and developmental disabilities.

Home and Community-based Services and Supports

Consumer Directed Services

The Consumer Directed Services (CDS) option was expanded and made available to individuals enrolled in the Home and Community-based Services (HCS) and Texas Home Living (TxHmL) waiver programs in 2008. The CDS option allows individuals or their legally authorized representative (LAR) to hire, train, supervise and fire the persons who provide their services. Financial management services, such as processing payroll and taxes, are provided by a CDS agency. Individuals enrolled in HCS may now self-direct their supported home living and respite services. Individuals enrolled in TxHmL now have the opportunity to self-direct some or all of their services. This expansion allows a greater number of individuals with developmental disabilities to self-direct their support services. People who prefer the traditional agency model continue to have that option to obtain services.

The CDS option was already available in programs such as Primary Home Care, Family Care (FC), Community Attendant Services (CAS), Community-Based Alternatives (CBA), Community Living Assistance and Support Services (CLASS), Deaf-Blind with Multiple Disabilities (DBMD), Medically Dependent Children Program (MDCP), and Consumer-Managed Personal Attendant Services (CMPAS). People in these programs can now use the CDS option to self-direct some waiver services such as nursing, physical therapy, occupational therapy, speech/hearing/language therapy, attendant services, and respite. However, CDS is not available for all waiver services in all programs.

Medicaid Waiver Expansion

The Department of Aging and Disability Services (DADS) expanded the Community Living Assistance and Support Services (CLASS) program statewide in 2008. The CLASS program is a Medicaid waiver that provides home and community-based services to adults and children with related conditions as a cost-effective alternative to placement in an Intermediate Care Facility. People with "related conditions" have a qualifying disability, other than mental retardation, which originated before age 22 and which affects their ability to function in daily life. CLASS was previously offered in only about half of the state's counties. Unfortunately, the choice of providers remains limited in some areas.

Pilot Program for Children with Autism Spectrum Disorders

It is estimated that one of out every 200 children in public schools in Texas is diagnosed with autism[10]. In efforts to further expand supports for children, the Department of Assistive and Rehabilitative Services (DARS) has implemented a pilot program to serve Texas children with autism spectrum disorders. The $5 million initiative will expand services for an estimated 300 children 3 to 8 years of age.

Aune Family: Jim, Miriam, Daniel & Nicola (Nick)

Jim, Daniel, Nicola (Nick) and Miriam

It is obvious when you meet Jim and Miriam Aune that what has kept their marriage together for 22 years is their sense of humor. Since Jim and Miriam each have a doctorate degree in Speech and Communication, they believe that having two children with severe speech and language problems is "proof that God really does have a sense of humor." Their two sons, Daniel, 17, and Nick, 19, were both born with autism.

When their sons were born, the parents were told to put both of their children in an institution and forget about them. Miriam still asks, "How do you forget about your children?" The Aunes moved from Minnesota to Bryan in 1996 because both had been hired by Texas A&M University as professors in the Communication Department. Miriam ultimately quit her professorship to stay home and take care of their children while Jim carried the financial burden. This was very difficult as they also managed $10,000 a year in out-of-pocket expenses for their sons' medications.

The Aunes credit the Bryan school system with their sanity during the nine years they waited for Community Living Assistance and Support Services (CLASS). "The schools have always been our last defense," says Miriam. One day, Nick hit Miriam so hard that she was almost knocked out. She called the school's Autism Director for help and within 20 minutes, she had four professionals at her door. They stayed with her for four hours until Nick had calmed down.

The Aunes began receiving CLASS services one year ago, and say that it has been both a blessing and a challenge. "CLASS allows you to put together your own kids' program based on their needs. The biggest difference in our lives since we have had the CLASS program is that for the first time in our lives, we can just parent our children. We are not their therapists, and we don't have to be their teachers."

The challenge for the Aunes is the Consumer Directed Services (CDS) option under CLASS. Miriam stated, "That was scary. It's like running a small business. It took us more than four months just to deal with the paperwork. CDS means you are doing it all. It's been forced upon us." One of the most frustrating aspects of CDS for Miriam was the hiring process. As she explained, "How do I write an ad for someone to come into my home and take care of the most important thing in my life and be sweet, nice and love my babies?"

After receiving CLASS services, Miriam says, "The changes in our lives have been indescribable. We can go to a movie at night now. Before CLASS, we could only attend matinees while the boys were in school." Daniel and Nick are both going to camp for one week this summer, and Jim and Miriam are going to take their first vacation in 21 years.

The Aunes report that both Nick and Daniel have made tremendous progress over the past year, but, "CLASS would have been the biggest miracle of our lives had we gotten it when they were young. We're not asking for a Cadillac. We just wanted early intervention." Miriam adds jokingly, "Can you be late to be early?"

Mental Health System Redesign

The 80th Texas Legislature (2007) allocated $82 million in new funds to redesign the community mental health crisis safety net to reduce the number of people who are admitted to emergency rooms, jails, and state hospitals. Changes include creating a 24-hour, seven-day-per-week telephone crisis service with trained staffers, creating local outreach teams that go to the consumer's home, and mobile psychiatric emergency units that will travel to local hospitals as needed. This is part of a larger Mental Health Transformation project initiated in 2005. A 21-member Mental Health Transformation Working Group consisting of state leaders, agency officials, and mental health consumers provides strategic guidance and direction for mental health transformation.

State Medicaid System Improvements

The 80th Texas Legislature (2007) passed and the governor signed Senate Bill 10, which calls for improvements to the Texas Medicaid program by focusing on prevention and better planning to help Texans to live longer, healthier lives. Specifically, this program calls for a Health Opportunity Pool that would provide federal dollars to reimburse hospitals for uncompensated care, premium payments for employees who are Medicaid eligible but enroll in employer-sponsored insurance plans, an extension of Medicaid coverage for foster children to age 23 if they are attending college, and a tailored benefits package for populations such as children with special health-care needs.

Integrated Care Management

Individuals in 13 counties began receiving Medicaid services through the new Integrated Care Management (ICM) program in 2008. ICM combines regular health care, such as doctor visits, with long-term services and supports, such as in-home attendant care. Key components of the fee-based model include the use of service coordinators, consumer advocates, community groups and providers, in-home services, and electronic health records. ICM provides coverage primarily for people who receive Medicaid and Supplemental Security Income (SSI), and are age 21 or older, and those who receive services through the CBA waiver program. Children under the age of 21 who receive SSI may choose to participate in ICM or stay in traditional fee-for-services Medicaid. People who are in institutional settings (nursing homes) and people in waiver programs other than CBA are not eligible for the ICM program. Medicaid recipients who meet this criteria and live in Collin, Dallas, Denton, Ellis, Hood, Hunt, Johnson, Kaufman, Navarro, Parker, Rockwall, Tarrant and Wise counties are included in the program. Individuals with I/DD do not currently receive ICM services.

Access to Children's Medicaid Services

The 80th Texas Legislature (2007) approved $150 million for strategic initiatives to expand children's access to Medicaid services. Most of the funding is being used to increase payment rates for dentists, physicians, and specialists to encourage more health care providers to accept Medicaid patients. The state's Medicaid program covers more than 2 million children — or one out of every three children in Texas. The Early Periodic Screening, Diagnosis and Treatment (EPSDT) service, known as the Texas Health Steps (THSteps) in this state, includes the Comprehensive Care Program and Medical Transportation Program for beneficiaries under the age of 21.

Medicaid Infrastructure and Competitive Employment Support

The Department of Assistive and Rehabilitative Services (DARS), in collaboration with the Health and Human Services Commission, has been awarded a four-year Medicaid Infrastructure Grant (MIG). The grant from the federal Centers for Medicare and Medicaid Services (CMS) will be used to develop the infrastructure for a comprehensive system of competitive employment support for persons with disabilities. The goals of the project are to increase enrollment in the statewide Medicaid Buy-In (MBI) program and expand the MBI program statewide to support its effectiveness as a work incentive. The Medicaid Buy-In program allows workers who have a disability to receive Medicaid by paying a monthly premium in order to maintain access to the same Medicaid services such as office visits, hospital stays, X-rays, vision services, hearing services and prescriptions. The project will also improve public and private employment resources for persons with disabilities, increase partner collaboration among those who provide employment resources (e.g., Vocational Rehabilitation (VR) and One-Stop Workforce Centers), and educate consumers about work incentives and workforce system services to enhance their use.

Missy and Mac Olive

Read their family's story on page 59.

TCDD Recommendations for Systems Change

While some improvements have been made during the past biennium, there are several key areas in which the 81st Texas Legislature must take action. The following section outlines TCDD recommendations.

Fiscal and Programmatic Barriers to Consumer Friendly Services

Recommendations

1. **Develop and implement a comprehensive plan to reduce the institutional bias in long-term services and support systems and redirect funds to community services infrastructure by 2018.** Texas presently has no comprehensive, long-range plan for closing the gap between system capacity and service demand. While principles supporting community-based services are cited in the Health and Human Services Strategic Plan (2009-2013), no specific actions are identified. The Texas Legislature should direct efforts to reduce its over-reliance on state schools/centers, to better manage the interest list, and to increase community spending. Specific components of this 10-year plan are outlined in the special focus area on rebalancing the long-term services and supports system.

2. **Require regulated health insurance policies to provide coverage for mental and behavioral disorders for children and adults equal to coverage for other medical conditions.** Persons with mental disorders generally do not have equal access to health insurance. Many health plans limit mental health and substance abuse services. Texas has enacted laws that require insurance parity only for a small set of specified diagnoses or serious mental illnesses (schizophrenia, bipolar disorder, and/or major depression), but these requirements have not included other conditions such as fetal alcohol spectrum disorder (FASD). These laws discriminate against children and adults whose illnesses can be as disabling as those specified in statute, but do not fit neatly within the statute's diagnosis or current criteria.

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

    3.1 **Increase rates and expand 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.

3.2 **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 Legislature 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.

3.3 **Adjust reimbursement mechanisms to provide incentives for providers to implement innovative approaches to 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.

Progress Toward Individualized Service Delivery Based on Functional Needs

Recommendations:

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

4.1 **Improve the required documentation of mandated discussions with residents regarding their options for community supports and services, as well as the 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 school residents who "preferred an alternative living arrangement" were not provided one.[11]

4.2 **Require community ICFs/MR to utilize Mental Retardation Authorities (MRAs) to provide choice options to ICFs/MR residents. Provide funding to fully reimburse the MRA costs to ensure informed choices.** MRAs conduct intake and furnish service coordination including assisting individuals and families in developing service plans. As a lead agency in the community service system, MRAs are the most appropriate agency to provide information on community living arrangements to individuals. Recently, the Legislature directed the MRAs to provide community living options information to residents of state schools/centers. This resource needs to be extended to residents of community ICFs/MR as well. Funding should be provided to MRAs to cover the cost of these activities.

"One of the biggest challenges I face is to get staff to think outside the box. Staff should be taking Tony into the community and teaching him how to navigate in this world. He'll never be able to work if he can't do this, and there needs to be consistent services if it is to be beneficial."

– Pat Munoz

May Family: Kathy & Sara

Kathy and Sara May

Sara May has a rare condition called Cockayne syndrome. At the time she was diagnosed, only 50 other children in the United States had this condition. Cockayne syndrome is an inherited disorder which typically includes growth retardation, abnormal sensitivity to light, a prematurely-aged appearance and developmental delays. Now, at 23 years old, Sara is going through menopause.

Kathy fears that her daughter will pass away before her number ever comes up on the waiting list. When Sara was diagnosed with this syndrome at age 5, Kathy was told by a geneticist that Sara had 10 years to live. Sara has lived 13 years beyond the normal life expectancy of a person with this syndrome. But, it has come with great cost. She lost her hearing, and she is losing her vision and her ability to walk.

While seeking help for her daughter, Kathy attended a “boot camp” for families sponsored by state agencies, advocates, MRA representatives and providers. The purpose of the boot camp was to educate families who were seeking services about the long term care service system. She was told if she would “lock up” Sara in a nursing home or a State School, she would immediately be number one on the waiver. This is not the route they wanted to go. Sara’s choice and desire is to remain in her home and be safe and comfortable for the remainder of her life. She wants to be a part of her community, not separated from it.

Kathy said the biggest dream they have is to have resources in their hometown for people with special needs so they can give back to the community. Sara wants to do something meaningful and be able to come home from that experience and have something to talk about.

Sara has decided she’d like to remain living with her mom, but she wants a normal life in the community. When asked what she would like to do if she had an attendant, Sara laughed and said “Go to a bar.”

4.3 **Expand "transition assistance services" for consumers 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 (MDC), Deaf Blind with Multiple Disabilities (DBMD) and Consolidated Waiver. TAS services are currently not available to those transitioning from state schools/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.

5. **Invest in community respite alternatives to avoid reliance on state institutions for support, including an expansion of respite services to include caregivers under the age of 65.** Respite care provides a caregiver temporary relief from the responsibilities of caring for individuals with chronic physical or mental disabilities. Respite programs are a lifeline for families, yet these services are often unavailable in the community where families need them. As a result, 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. Funding should be allocated to strengthen the community based respite service system to better support informal caregivers. Policy changes should also be made to allow respite services to be available to all parents, siblings, and loved ones who provide care – not just for those over age 65.

6. **Enhance the capacity of the community services infrastructure to better support individuals with complex needs. Specifically:**

6.1 **Remove barriers and create incentives for providers to provide services and supports to individuals with complex needs in the community.**

6.2 **Require DADS to collect and analyze data that identifies factors driving admissions to state schools (particularly children) and report those findings to the Legislature.** Information obtained on children and other individuals with I/DD at the time of admission to a state school is collected and maintained by the individual facility. As a result, there is no statewide information on the factors that lead to the admission such as medical or family crisis. State data indicates that almost half of individuals with complex needs are currently served in the community. If DADS collected and maintained admission information, state leaders could better evaluate the specific factors precipitating a crisis leading to placement, identify possible community supports, and avoid unnecessary institutionalization.

Progress in Development of Local Cross-Disability Access Structure

Recommendations:

7. **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 developmental disabilities (I/DD). Specifically:**

   7.1 **Build capacity and fund the Mental Retardation (MR) safety net services to support individuals with I/DD in the community.** Gaps in the community infrastructure often include the lack of skilled providers, rate structures that fail to reimburse costs for the services, limited availability of services, and providers that are unwilling to develop programs due to liability issues.

   7.2 **Build capacity and fund the community infrastructure to support individuals with behavioral needs in order to reduce reliance on institutional settings for specialized services and support.** Supports for individuals with challenging behaviors are often not available through community programs, creating an unnecessary reliance on state schools to provide these specialized services.

   7.3 **Build capacity and fund the community mental health and substance abuse supports network to deter unnecessary placements in hospitals and nursing facilities.** The 80th Texas Legislature (2007) allocated $82 million in new funds for community mental health crisis to reduce the number of people who are admitted to emergency rooms, jails, and state hospitals. Additional funds should be allocated to strengthen the community infrastructure to serve individuals in the most integrated setting.

   7.4 **Increase the number of waiver slots authorized for children aging out of Child Protective Services custody.** Many children are being unnecessarily placed in institutions when no other option is available when they "age out" of CPS conservatorship at age 18 and have a continued need for residential services. Priority has been given to provide community options to children aging out of Child Protective Services, however this opportunity is only offered if the waiver slots are available. Additional allocation of home and community based waivers set aside for these individuals are needed.

> "Legislators need to know how important the Medicaid waiver programs are and that they need to be tailored to suit a family's needs. They can look good on paper, but not work in the community."
>
> – LaChandra Noel

8. **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. There are no appropriate placements for individuals who require 24-hour supervision since facilities are designed for individuals with cognitive disabilities (IQ less than 70) or those requiring nursing care. There are no Medicaid waiver services for individuals who were injured as adults, who do not have a medical condition requiring skilled nursing and who are able to live in the community with supports. Many are inappropriately institutionalized in nursing homes, generally contrary to the intent of the *L.C. and E.W. v. Olmstead* Supreme Court Decision. Modification of the eligibility requirements and service array of Medicaid waivers would allow individuals with these functional needs to be more appropriately served.

Pat and Tony Munoz

Pat Munoz is a quiet force of nature when it comes to providing the best opportunities for her 25-year-old son, Tony. They live in El Paso, and Tony is diagnosed with moderate mental retardation and a psychotic disorder. Pat had family support early on, but that changed as Tony's behavior became more difficult to manage. The family environment was too stimulating for Tony which resulted in acts of aggression. This behavior, coupled with a lack of understanding, alienated many people — but most importantly, Pat's family. "The hardest thing I've had to deal with was to educate my family," she said.

Pat revealed that at times she was scared that Tony would hurt her. She felt she had no other choice but to institutionalize Tony for one week at the El Paso State Center. It was a very negative experience for both since he came home with unexplained bruises and minor injuries.

Tony was on the waiting list for nine years before receiving Texas Home Living (TxHmL) services. While on the waiting list, respite and habilitation services were provided through the El Paso MHMR. Shortly after his enrollment in the TxHmL waiver, Tony was offered and accepted services through the Home and Community-Based Services (HCS) waiver.

In analyzing services, Pat said that "There are major problems with HCS, and it's not what it's cracked up to be." She explained that she had to give up her job due to inconsistent staff coverage from the providers. She became Tony's foster parent after her provider suggested this, but she took a decrease in pay and lost her medical and dental benefits.

According to Pat, "One of the biggest challenges I face is to get staff to think outside the box. Staff should be taking Tony into the community and teaching him how to navigate in this world. He'll never be able to work if he can't do this, and there needs to be consistent services if it is to be beneficial."

Pat also expressed concern about the day habilitation (day hab) component of HCS. "This is a major place where HCS is lacking. We try to fit the individual to the program vs. fitting the program to the individual. Everyone is different. My son does not do well in a day hab environment. This is something we need to work on with the HCS program."

When asked to identify the three top services Tony still needs that he is not getting, Pat said, "Employment, Employment, Employment." She added that "Transportation is also a big problem as the HCS program does not cover the cost of this service."

Regarding options for Tony's future, Pat said, "We are exploring the possibility of opening up our own business, a shredding paper business." She wants Tony to be employed and part of his community, even if she has to be the one to create the opportunities for him.

Pat noted that Tony volunteered at a nursery while he was in high school but due to not having HCS services when he graduated, he lost his job. She believes that if he had the transition services at that time (HCS), he could have maintained employment. She feels this was a missed opportunity for him.

Perez-Walker Family: Gloria & Aiden Villasenor-Walker

Gloria Perez-Walker and Aiden Villasenor-Walker

For Austin resident Gloria Perez-Walker, waiting years for Medicaid waiver services can only be measured in losses. Her nine-year-old son, Aiden, was born with autism and living with this condition is extremely stressful for a family. Aiden needs constant prompting to complete his daily living tasks. As Gloria explains, "I will ask Aiden to get ready for school and he will come downstairs with his books and back pack on, but he will be completely naked. I feel like I've had a two year old child for nine years."

Aiden can be very aggressive. He has even choked Gloria on several occasions. He also is extremely sensitive to noises, particularly to dogs barking and birds chirping. When he hears these noises, he mimics them and then runs out the door and into oncoming traffic. He wears headphones to help screen out sounds that trigger this flight behavior.

Gloria's relationships with family and friends have changed since she's had Aiden. "I have to constantly explain autism to all of them, and it is tiring," she revealed. "They want to protect and shelter him, and they don't understand the need for him to be independent." Her family and friends expect her to keep Aiden with her for the rest of her life. Gloria states that "If I had a typical child, I would still be married."

Gloria's career and educational goals have suffered as well. She had to give up school and work at times in order to maintain Aiden's Medicaid health insurance coverage and Supplemental Security Income (SSI) benefits.

"I feel like a bad person because I talk poorly about my child just so he can get services," Gloria confided. "The only way to get services for Aiden is to constantly point out how bad he is or all that he can't do so I can get the services he needs. I feel like I have to always look at my child in a negative light."

She added that "Everything is from a needs perspective, so if you're going to get anything for your child, you have to be prepared to state everything he needs in front of a group of therapists and professionals at the drop of a hat. I feel like I'm always fighting for him and that takes up my life. I haven't had a chance to enjoy him."

Despite all she faces, Gloria has great aspirations for Aiden. She wants him to have his own life, become as independent as possible and live in his own home. For this to be possible, however, Gloria needs services now while Aiden is still in the early developmental stage of his life.

They have been waiting for Medicaid waiver services for five years. Aiden came up for the Medically Dependent Children Program (MDCP) but was denied because autism is not considered a medical disorder. Despite this, Gloria knows that early intervention for children with autism is critical if they are to meet their full potential. Each year that goes by without services is another loss for the Perez-Walker family and more critically, another loss for Aiden.

9. **Expand 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. The *"Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Community Living,"* directed by the 80th Texas Legislature (R)(2007) includes recommendations to remove existing barriers and to build a more comprehensive, coordinated system of employment supports and services for youth with disabilities as they make choices about their work and career.

10. **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 level**. Improved communication between HHS departments 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. In 2006, DFPS and DSHS worked to share information about people with a mental health diagnosis who also experienced abuse, neglect, and exploitation to identify problem areas and identify opportunities for change. DFPS and DADS have assembled a workgroup to identify crossover cases. Such collaborative practices should become usual business across the human service enterprise.

11. **Ensure that individuals with developmental disabilities, specifically children with special health care needs, are not negatively impacted in efforts to reform the Texas Medicaid system, expand managed care initiatives, and/or restructure the service eligibility infrastructure**. Texas has made significant progress in recent years to improve the state Medicaid system. Demonstration projects that promote managed care, integrated care management, as well as modifications to the TIERS eligibility system are a few examples. While individuals with developmental disabilities are not the current target population for these demonstration projects, this population does rely heavily on Medicaid services and supports. As policy changes continue, leaders must ensure that the system changes will not negatively impact the ability of individuals with developmental disabilities to access needed services.

Projection of Future Long-Term Care Service Needs

Recommendations:

12. **Require a formal study in Texas to gather data on the types of services selected by individuals with disabilities when they are offered Medicaid waiver supports and use this data to more efficiently fund future long-term supports based on consumer needs**. In the past two Legislative sessions (79th, 2005) and (80th, 2007), leaders have allocated additional funds for waiver services through programs such as HCS. This year's target for HCS enrollment was 1338. As of August 1, 2008, 1259 individuals have been enrolled. Of those, 646 have chosen a foster care model, 484 have chosen "own home/family home" and only 129 have chosen a group home/residential setting. This translates to approximately 90 percent who have selected a non-residential model. This information was collected for the most recent waiver expansion; however, this data is not collected on a systematic basis across all waivers. A formal study will develop a stronger understanding of the demand and choice for services in our state which is critical in accurately planning and financing the future long-term service and supports system in Texas.

13. **Develop specialized services and supports to allow individuals with developmental disabilities to age in place following the loss of a family caregiver. Assist individuals with developmental disabilities who are aging and their family caregivers in planning for their future long-term care needs**. 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 and be active members of their communities. Resources are needed to ensure that these individuals are able to remain in their homes and age in place. Persons who are aging with developmental disabilities have unique long-term care planning needs. In addition to planning for their own aging in terms of finances, housing, and health care, many may find themselves in a position of seeking public services for the first time. Specialized assistance must be developed to help families with these unique planning needs.

Consumer Satisfaction and Consumer Preferences

Recommendations:

14. **Expand options for Self-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 self-directed options to additional services beyond personal assistant services and respite services**. Consumer Directed Services (CDS) and Shared Responsibility

Option (SRO) are vehicles of self-determination for people with disabilities which allow increased control over the services and supports 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. Participation in CDS is low in both fee-for-service and managed care (STAR+PLUS) areas of the state, with the exception of the CLASS program where 41 percent of service recipients are participating in CDS.

"CLASS allows you to put together your own kids' program based on their needs. The biggest difference in our lives since we have had the CLASS program is that for the first time in our lives, we can just parent our children. We are not their therapists, and we don't have to be their teachers."

– Miriam Aune

15. **Transfer the responsibility for quality monitoring of state mental retardation facilities (SMRFs) from DADS to an entity with more administrative autonomy.** In a report published in July of 2008, the State Auditors Office cited gaps in the investigation of complaints and incidents involving state school residents. Approximately 41 percent of priority complaints were not investigated within the required 14 days. Furthermore, state schools are both monitored and evaluated by the Department of Aging and Disability Services (DADS) which operates the facilities. Changes should be made to the oversight system to ensure that incidents are investigated properly, that state schools/centers who do not meet safety standards receive appropriate consequences, and that potential conflicts of interest are reduced.

16. **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 ombudsman) is an essential function to improve the quality of care received. Approximately 60 percent of state school 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.

17. **Ensure participation of people with disabilities and family members on state and local level committees that make recommendations regarding policy and the development and implementation of service programs**. Individuals receiving services should be at the table when decisions are made regarding the supports they receive. Appropriate funding must be provided within service programs (e.g., long-term care, employment, transportation, etc.) to allow individuals with disabilities to attend task force and committee meetings and participate in the planning process.

Allocation of Resources to Provide Long-Term Services and Supports for Texans with Developmental Disabilities

As previously discussed, Texas has invested heavily in services for people with intellectual and developmental disabilities (I/DD) over the past 30-40 years. Yet, even as the state built a community services system, it has maintained an enduring commitment to ICFs/MR facilities including the state school/center network. With a growing unmet demand for services, changing expectations among people with I/DD and their families, chronic under-funding and other factors, Texas faces difficult policy choices in responding to the needs of its citizens. There is great opportunity to reduce the gaps between current system performance in serving persons with disabilities and performance that meets national benchmarks for capacity and quality.

Texas Current Performance

A *gap analysis* compares an enterprise's actual performance to its potential or desired performance — an assessment of the distance between what an enterprise is currently doing and what it could do in the future. The gap analysis begins with defining key expectations for desired system performance. These expectations, or benchmarks, serve as the basis for appraising current performance. A primary and overarching goal in Texas is that everyone supported by the system has a quality service.

TCDD engaged the Health Services Research Institute (HSRI) to conduct an external analysis of how Texas is doing relative to three fundamental, top-level performance benchmarks which were used to gauge the provision of publicly-funded services and supports for people with mental retardation and related conditions. These benchmarks were derived from HSRI's nationally recognized work in developing quality assurance indicators (i.e., the "Quality Framework" for the Centers for Medicare and Medicaid Services, and the National Core Indicators utilized by over 30 states including Texas). The complete Gap Analysis, Action Steps, and Implementation Strategies can be found on TCDD's Web site at www.txddc.state.tx.us/public_policy/news.asp#gap. A summary of HSRI's assessment of Texas follows:

Benchmark 1: People with mental retardation and related conditions have access to and receive necessary publicly-funded services and supports with reasonable promptness.

Assessment: People with MR/RC 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.

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

Assessment: Many people with intellectual and developmental disabilities (I/DD) do not receive services within the least restrictive setting appropriate to their needs. By all measures, Texas relies more heavily on state schools/centers 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 seventh 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 pace of relocations from state schools is modest at best. Meanwhile, the state admits children into state schools at a pace twice the national average. And, in FY 2008-2009, the state added 1,690 positions to the state school structure at a cost of approximately $1.04 million.

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 MR/RC services was 47 percent below the national average in 2006. 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.

The initial examination of information regarding Texas' current system led to the following observation:

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

In response, fundamental system redesign is necessary for Texas to improve its performance in supporting its citizens with intellectual and developmental disabilities. Absent redesign, system performance will not change appreciably, and will likely deteriorate over time. System redesign is a complex, challenging endeavor, especially in large service delivery systems like the one in Texas.

Policy Options

Moving forward state leaders have several policy options to consider. For instance, the state may:

- ☑ **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.
- ☑ **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.
- ☑ **Keep funding relatively level, but de-emphasize the use of ICFs/MR services in favor of 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.
- ☑ **Increase funding significantly and de-emphasize the use of ICFs/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 present needs while systematically reducing the interest list for services.

The following recommendations are related to the fourth option. TCDD concurs that Texas can take several steps to rebalance its MR/RC system and make significant progress in serving people in the most integrated setting, expanding system capacity, and strengthening existing community services in the next 10 years.

Tyler Sparks

Read his family's story on page 36.

Recommendations to Rebalance the Long-Term Services and Supports System

It is important to note that the following recommendations are based on practices and policies that have been successfully implemented in other states. By not taking these steps, policymakers can expect that the state will: (a) continue spending substantial sums to maintain large facilities, such as the state schools/centers, that provide services that individuals with disabilities say they do not want, and that have been criticized by federal and state oversight bodies[12]; (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. The time to act is now.

Serving People in the Most Integrated Setting

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 schools/centers and not just meet nationwide norms for the operation of such facilities, but exceed the averages by meeting a significant portion of demand for services. A decision to move in this direction would require relatively modest annual levels of transition from state schools/centers. Additional action steps have been outlined that would contribute to rebalancing ICFs/MR and HCBS services and move Texas toward a system where all individuals have greater freedom to live in the most integrated setting.

18. **Reduce the number of people served at state schools/centers.** It is TCDD's position that individuals with developmental disabilities do not belong in institutional settings and must have access to the full range of accommodations necessary to ensure that living in their natural community is possible. The fact that most other states rely far less than Texas on such facilities should serve as a signal that Texas' practice of maintaining its present state schools/centers capacity is outdated. As in other states, community providers in Texas have the ability to provide quality services and supports to individuals with the most challenging support needs. However, Texas has not developed the capacity to meet those demands and therefore relies on state schools/centers to meet those needs.

In 2006, Texas served 67 percent more individuals at its state schools/centers than the nationwide norm for utilization of such facilities. The Texas utilization rate for state schools/centers services was 21 individuals per 100,000 persons in the general population; the nationwide utilization rate was 12.8. Today, Texas is still using state schools/centers at a rate significantly higher than the nationwide norm (19.8 individuals per 100,000 persons in the general population).

18.1 **During the 2008-2018 period, the state school/center population should be reduced to 1,465 individuals to simply meet the projected nationwide norm.** While TCDD advocates that the total state school/center population be reduced to zero as quickly as possible, we recognize that achieving this goal will take significant commitment and effort over time. Based on Texas population growth estimates during the next 10-year period, reaching a census of 1,465 would entail a reduction of state school/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. These projections confirm that this is a feasible goal in the short-term to move Texas towards its long-term goal of community living for all individuals with developmental disabilities.

As shown in the charts presented earlier in this report, Texas state schools/centers presently command a disproportionate share of Texas' MR/RC budget. The per person costs of supporting people in state schools/centers will continue to move upward in order to maintain compliance with federal requirements. Reducing the number of people served at state schools/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.

18.2 **Concurrently and effectively address the major problems that affect community services to reduce pressures to admit people to the state schools/centers.** HSRI comments that the persistence of the operation of large facilities in many states is explained in part by material shortcomings in the capabilities of community service systems, especially the capacity to serve individuals requiring extensive behavioral supports or those with complex, chronic medical needs. Ultimately, community placements will be more durable and stable to the extent that they are individualized and planned carefully.

She was told if she would "lock up" Sara in a nursing home or a State School, she would immediately be number one on the waiver.

– Kathy May

Missy and Thomas "Mac" Olive

Missy Olive is the oldest of five children and has had guardianship of her 29-year-old brother, Thomas "Mac" Olive, since he was 18. "I thought I knew everything and I wanted to give my parents a break," Missy said. She has a doctoral degree in educational psychology and works at The University of Texas at Austin. Mac is diagnosed with autism, profound mental retardation, mild cerebral palsy and a seizure disorder. They moved to Texas in 2000, and Mac has been on the waiting list since then. He is currently number 2,100.

Missy and Mac previously lived in Nevada and Tennessee where Mac received personal attendant and respite care hours. They were able to live together while Missy worked and went to school. When she was offered a job at UT-Austin, they moved to Texas and were surprised that Mac had to be placed on a waiting list. Since they lost attendant care, Missy placed Mac into a community ICF/MR group home where he lived for six years.

Missy reports that Mac suffered numerous injuries while under the care of the group home, and she was often not notified of these incidents. Missy attributes the problems to the high rate of staff turnover. She filed numerous complaints and says nothing was done. The provider forced Mac out of the community ICF/MR, and there was no place for him to go.

With no community support and no other choice, Mac had to move to Austin State School or else he would have no services at all and Missy would have to quit her job. "We could have remained as a family if we had waiver services," she stated.

"I want (legislators) to know that if I was given just 25 percent of the cost of placing Mac in a State School, I could have him at home living with me," Missy disclosed. "Our state has not only caused Mac physical harm due to the multiple injuries he suffered while living in an ICF/MR, they forced Mac to move out of my house. There is no family choice."

Her biggest challenge, she said is the stress she feels when Mac cries every time she takes him back to the State School after spending time at her home. "I never know if they're going to give him his meds properly, if he going to the bathroom or if they will know if he is hurt."

Missy recognizes that "There is a convenience to state schools because doctors are right there, they can do blood draws, etc., but," she said, "I am not sure if we should be using tax dollars for convenience."

Other States

The majority of other states have significantly reduced or eliminated their utilization of very large state-operated facilities. The Coleman Institute (2008) shows that by 2010 a total of 140 state-operated institutions will have closed since 1970. ***By 2009, there will be nine states and the District of Columbia that will not operate large facilities.*** These states includes: Alaska, Hawaii, Maine, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia. Other states are approaching this standard, with 11 more states having fewer than 200 people living in large state facilities. The steps being taken in New Jersey to systematically reduce the number of persons served in its seven state developmental centers as part of the state's Olmstead initiative offers an example of how to develop a long-range strategy for reducing a state's reliance on large, multi-purpose state institutions.

19. **Cease admissions of children to state schools/centers.** In 2006, 43 percent (114 out of 263) of admissions into Texas state schools/centers were children. This was twice the national average of 21.7 percent. Further, a workgroup established by DADS to investigate youth admissions found that 152 children/youth ages 0-21 were admitted into state schools in FY 2007, while only 12 individuals moved out of state schools and into community settings. If Texas is to move away from its reliance on state schools, it must take firm action to eliminate further admissions of children and youth to state school facilities.

    DADS has supported the principle that children belong home with their families[13]. Yet services are not available to keep families intact, but are evidently available to support 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 schools, including: (a) reductions in community-based services due to cuts in funding to Mental Retardation 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.

Kris Valera

Read his family's story on page 69.

To establish a "*Family First*" strategy, DADS should:

19.1 **Provide resources to bolster in-home support services for children living at home with families.** Children in critical or emergency need of services should not have to endure long wait lists that place their families in crisis.

19.2 **Take affirmative action to accommodate all children under the age of 22 who are in state schools/centers and seek community placement.** This includes children on the Interest List for community placement resulting from Senate Bill 368 that was passed during the 77th Texas Legislature (2001).

19.3 **Adopt a standardized risk assessment protocol that will be employed systemwide to identify potential risks and risk mitigation strategies as part of the individual service plan development process.** Several states (e.g., Oregon and Massachusetts) have developed such protocols and integrated them into their service plan development processes. An appropriate protocol should be selected during FY 2009 and introduced into the service plan development process starting FY 2010.

19.4 **Develop a "diversion" protocol triggered by the risk assessment that systematically implements alternatives to out-of-home placement of children in the state schools or community ICFs/MR.** This may include placement with another family, or secondarily placement in an alternative community residence. Placement in state schools must be considered a last alternative after all others are exhausted.

Other States

In 2006, 21 of 41 states (51 percent) with large state operated facilities had no children under age 15 living in such facilities. (Note that the remaining nine states have no state institutions.) At 5 percent, Texas had the eighth highest percentage of children under age 15 living in large state facilities. Clearly, most other states have taken action to promote in-home or family support over placing children in institutions.

"We could have remained as a family if we had waiver services,"

– Missy Olive

Noel Family: LaChandra, Mia, Ashley & Aaliyah

LaChandra, twins Mia and Ashley and sister Aaliyah

At 21-years-old, LaChandra Noel was a bright, beautiful young woman with her whole life ahead of her. She was in college working on a criminal justice degree, modeling and on her way to the Miss America pageant. Then, in an instant, everything changed. At five and a half months pregnant, she was hospitalized and discovered that her twins, Ashley and Mia, had a condition known as cytomeglo virus. The virus left Ashley with severe mental, physical and medical impairments. She is unable to walk, feed or dress herself and has no communication skills. Mia was affected by the virus later on in her life and, over time, has lost a great deal of her hearing.

LaChandra's husband began physically and psychologically abusing her. But, where does a mother who is expecting her third child and already has twins, one of whom has severe disabilities, go when her life is threatened? Initially, she moved in with her mother, but her husband continued to threaten her and physically attacked her. She filed charges against him and moved to a battered women's shelter. The shelter was not set up for a family of four and particularly not for a child with a disability.

After the twins were born, LaChandra received social security benefits and, as required, she turned in her pay check stubs. It was not until a year later that LaChandra discovered that the benefits counselor had provided inaccurate information about required income thresholds. As a result, she had been overpaid and was required to pay back an entire year's worth of benefits. She had to quit her job so she wouldn't lose her Medicaid coverage for Ashley.

In 2006, while living in another shelter, Ashley's name came up on the Medically Dependent Children Program (MDCP) waiting list. It took two months before anyone came to interview her and assess Ashley's eligibility. During the visit, however, not only was LaChandra told she may not receive services because she was homeless, the service coordinator forgot to bring the nurse to conduct the assessment.

Finding a "real" home seemed out of reach at this time and Ashley was hospitalized due to illness, so LaChandra felt her only option was to place Ashley in a nursing facility. For the next two and a half months, she called every nursing facility on the list, but to no avail. During this time, she found a place for her family to live, but enrollment in MDCP was still pending with hopes of services ever starting beginning to fade. In fact, they never got MDCP services.

"Legislators need to know how important the Medicaid waiver programs are and that they need to be tailored to suit a family's needs," LaChandra said. "They can look good on paper, but not work in the community."

Then, in January 2007, LaChandra was notified that Ashley's name came up on the Community Living Assistance and Support Services (CLASS) waiting list. By June, she was reenrolled and receiving services. She chose the Consumer Directed Services (CDS) option. Now that Ashley has the services she needs and the family has a home they can call their own, their longing for security and stability has been realized. Moreover, LaChandra, whose goals were put on hold many years ago, has since returned to work and is four classes away from graduating from college.

20. **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.** Once a person is placed in an ICF/MR, it is difficult for the individual to secure an alternative living arrangement primarily because ICFs/MR funding is not easily portable and cannot follow the person into the HCBS waiver. As a consequence, individuals often have little choice but to remain in ICFs/MR until their turn comes up on the waiver interest list – currently many years. This circumstance is at odds with the basic tenets of the U.S. Supreme Court's *Olmstead* decision. Texas was one of the first states to utilize the "Money Follows the Person" (MFP) concept. This policy has allowed for individuals residing in institutional settings to relocate back to a community setting and utilize that funding to receive community-based services.

For people with developmental disabilities, the original Promoting Independence Plan gave priority to relocation to individuals living in large ICFs/MR settings. However, relocation opportunity is only effective as long as there is new funding and/or attrition. From 1999 to 2007, 1,073 people moved from the state school/center system. Likewise, 734 more have moved from large ICFs/MR to HCS waiver programs. However, the 6,000 or more individuals residing in smaller community ICFs/MR should also have opportunities to transition to HCS waiver living alternatives as well. Texas has expressed a commitment to having children living in their community with their families. Funding to support this commitment should be demonstrated by extending permanent budget transfers through MFP for children as well.

To avoid forcing individuals who want to transition from ICFs/MR from competing with other individuals for limited HCBS waiver openings, Texas should set aside or reserve waiver slots to accommodate individuals who want to transition out of ICFs/MR. Texas also should provide additional funding to cover the business expenses that facilitate the transition of individuals from ICFs/MR to alternative community living arrangements.

Texas should build on its historical commitment to MFP by taking the following five actions:

20.1 **Utilize MFP to keep children out of institutions and to provide opportunities for children to leave institutional settings in favor of HCS alternatives.** Texas has expressed a commitment to having children live in their community with their families. Funding to back this commitment, however, has been insufficient. Often, children cannot access the waiver services that meet their needs. Assuring that children have meaningful opportunities to relocate in the community will require additional appropriations.

20.2 **Expand opportunities within MFP for people to transition to HCS Medicaid waiver alternatives.** This will require firm policy direction and appropriations to provide individuals with meaningful opportunities to transition. Such action is consistent with Senate Bill 27 (80th Legislature, 2007) to strengthen the process used to educate individuals about relocation opportunities.

"I want (legislators) to know that if I was given just 25 percent of the cost of placing Mac in a State School, I could have him at home living with me."

– Missy Olive

20.3 **Expand opportunities for relocation of people with MR/RC living in smaller ICFs/MR of eight beds or fewer.** Current emphasis focuses on larger ICFs/MR of nine or more beds. A mainstay of the Texas system, however, includes over 6,000 people living in smaller community ICFs/MR. These individuals should have opportunities to transition to HCS funded living alternatives as well.

20.4 **Implement activities to educate individuals who are eligible for MR/RC services and their families about the choices they have for relocating from ICFs/MR.** The processes of permanency planning and the Community Living Options Information Process (CLOIP) should be expanded to ensure that individuals and families have the resources they need to transition to the community if they so choose. Mental Retardation Authorities (MRAs) are well positioned in the community to provide such information.

21. **Adopt policies to encourage ICFs/MR providers to transition to supporting individuals in the most integrated setting.** Texas must pursue strategies to rebalance its MR/RC service system in collaboration with the organizations that operate community ICFs/MR. In addition to MFP initiatives, DADS has been working with some organizations that are interested in converting their large facilities (seven beds and greater) to HCBS community living arrangements. These efforts should be expanded to include facilities serving six or fewer residents.

21.1 **Promote incentives to encourage administrators of both large and small ICFs/MR to voluntarily close their facilities and to allow individuals to relocate to HCS waiver alternatives.** This action is consistent with DADS' Money Follows the Person Rebalancing Demonstration. This demonstration is focused on providers of community ICFs/MR with nine beds or more to assist those providers to take these beds off-line.

21.2 **Starting in 2009, DADS should dedicate staff positions to work directly with agencies interested in conversion.**

21.3 **Appropriate funds to provide conversion grants of up to $100,000 to agencies that submit promising proposals to support their development of downsizing/conversion plans.**

Other States

Louisiana is working with the operators of large, private ICFs/MR to facilitate the conversion of several facilities to smaller living arrangements. Over the years, Minnesota has also worked collaboratively with ICFs/MR providers to downsize and, ultimately, close their facilities.

Expanding system capacity

Texas faces a major strategic challenge: keeping pace with the rising demand for MR/RC services, while simultaneously adding new capacity. There already is a substantial shortfall in Texas' current system to meet the expressed demand for MR/RC services. In June 2008 there were 79,925 people on Interest Lists in 2008, of which 37,187 are on the HCS Interest List.

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

HSRI defines total service demand as the sum of "met" or "satisfied" demand (i.e., people who are receiving services) and "expressed but unmet demand" (i.e., people who seek services and have emergency or critical unmet needs). It is difficult to pinpoint year-over-year service demand trends in Texas. Texas has a fast-growing population that is difficult to predict accurately due to uncertainty over migration patterns. The U.S. Census Bureau projects that the Texas population will increase by 59.8 percent by 2030, or at 1.99 percent per annum.

There is considerable evidence from other states that the demand for MR/RC services is growing at a rate that significantly exceeds the rate of general population growth. For our purposes, it is assumed that the rate of demand for MR/RC services in Texas will grow at a pace somewhat faster than state population alone. HSRI analysis suggests a rate of two percent each year above the rate of population growth as a relatively conservative assumption.

Based on these figures, HSRI offers two calculations:

- The difference in 2006 between the number per 100,000 in population that Texas serves (i.e., 109 people per 100,000) and the number it would serve per 100,000 if it were to serve the people at a level commensurate to the **national average** (i.e., 193 people per 100,000); and
- The service penetration rate Texas would have to reach in order to address, based on the experiences of other states, **most, if not all, expressed demand** for MR/RC services (250 persons enrolled in services per 100,000 in the general population).

"People need to get off the waiting lists earlier so they can get the therapies, home modifications, and equipment they need for their children sooner."

– Kim Johnson

Johnson Family: Kim, Chad & Blake

Kim and Blake Johnson

"When I first got home, I felt more like a nurse than a mom," Kim Johnson explained, talking about her experiences in taking her son, Blake, home after he spent the first 14 months of his life in the hospital. Blake was born premature weighing 1 pound 6 ounces, was blind and had numerous surgeries for heart and lung problems.

While he was in the hospital, they received Medicaid due to Blake's low birth weight. Once he gained enough weight, the threat of losing his Medicaid coverage was eminent. Medicaid coverage continued for awhile because of his blindness, but he lost it when he was sent home from the hospital.

Quitting her job in order to care for her son, Kim has waited for services for 3 ½ years. "I would be working if I didn't have a disabled child," she said. "No daycare will take a child that is so medically fragile."

Life on a Medicaid waiting list is not easy, and the difficulties are numerous. Kim and her husband have to financially balance the deductibles on their private health insurance and the co-payments with the services Blake so greatly needs. They make daily decisions such as weighing the need for a swallow study or whether to wait another year so they can put their resources toward the cost of physical or speech therapy. Their insurance only covers 20 visits per year, per discipline.

Early intervention is essential for children born with severe physical and medical issues because there are often delays in their development. People on the waiting list frequently go without the care and services they know would greatly improve the quality of their lives.

"People need to get off the waiting lists earlier," Kim said, "so they can get the therapies, home modifications, and equipment they need for their children sooner."

Even with supportive family and friends, life can be very isolating while waiting for the Medicaid waiver program. Despite all of their struggles, Kim reports that "Blake has changed our entire family. We don't take things for granted, and we look at life in a different way. He has been such a good thing for us, and we're so lucky to have him."

There is no doubt that additional dollars will be needed for Texas to address current unmet service demand as well as keep pace with projected additional demand through 2018. Federal Medicaid dollars currently can underwrite 59.44 percent of these additional outlays. To estimate the total dollars that might be necessary, HSRI offers three funding scenarios. Each scenario assumes that Texas will employ Medicaid financing to expand system capacity. These scenarios are:

- **Current service mix.** Unmet service demand would be addressed by expanding system capacity in about the same proportion as the present mix of services. This scenario employs the 2006 average per person cost of serving a person in Texas ($50,336 per person).
- **HCBS Expansion Only.** If Texas would rely exclusively on expanding its HCBS waiver to address current unmet and future service demand going forward, the baseline figure would be $33,685 per person (the average HCBS expenditure of 2006).
- **ICFs/MR Services Only.** Under this scenario, only ICFs/MR services are used. In 2006 the average cost was $70,404 per person.

Overall, it would be substantially more economical for Texas to address service demand by relying exclusively on HCBS waiver services to finance the expansion. In addition to the overall cost comparisons offered above, DADS data indicates that HCS residential services averaged $52,663 annually in FY 2006 compared to average annual costs for 8-person or less ICFs/MR of $54,924. Given these findings, two specific recommendations are made so that by 2018 Texas has sufficient system capacity to meet projected service demand:

22. **Starting in 2009, enroll a minimum of 4,604 additional individuals each year in HCBS waivers for individuals with I/DD increasing the 2006 capacity of 13,999 persons to approximately 64,085 individuals by 2018.** 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 2009 and 2018 in HCBS waivers for individuals with I/DD. Such action would result in another 46,040 individuals receiving services by 2018. 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.

    Such action would increase the number of HCBS waiver enrollees from the 2006 capacity of 13,999 persons to serve approximately 64,085 individuals 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. In 2018, Texas would be serving 250 individuals with mental retardation and related conditions in its waiver programs for every 100,000 persons in the general population – the estimated utilization rate needed to become "above average" and meet most, if not all, expressed service demand.

"When am I going to get HCS, when I die?"

– Betty Gage, Age 68

23. **Expand home-based services as the primary tool for addressing service demand, including consideration of expanding the Texas Home Living (TxHmL) HCBS "supports" waiver.** Another important national development is a reduction in the use of 24/7 "comprehensive" residential services in favor of services that complement rather than substitute for family caregiver and other supports that are available for individuals with developmental disabilities. 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.

    23.1 **Enlarge the current Texas Home Living (TxHmL) HCBS waiver program.** 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.

    23.2 **Expand TxHmL to include a broader array of services and a more robust level of services.** 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 incorporating full-featured self-direction of home-based services, including adding the coverage of "individual goods and services" to provide an extra measure of flexibility for individuals and families to purchase non-traditional services and supports.

"The only way to get services for Aiden is to constantly point out how bad he is or all that he can't do so I can get the services he needs. I feel like I have to always look at my child in a negative light."

– Gloria Perez-Walker

Harmon Family: Connie, John & Grandson Kris

Connie and John Harmon with grandson Kris Valera

The Harmons are a mix of cultures, generations and family structure that don't meet the typical norms of a family caring for a child with a disability. Connie and John Harmon live in Sugar Land. They are in their 60s and thought they'd be retired and living comfortably by now.

They adopted a little girl when she was just 6 days old. At the age of 15 years old, their adoptive daughter gave birth to son Kris, who has autism. Unfortunately, she was unable to care for Kris, and the Harmons have had custody of him since he was 18 months old.

For the first 10 years of Kris' life, he had severe behavioral issues. He had tantrums every hour that would last up to 15 minutes per episode. Connie had to apply restraints on a daily basis just to control his outbursts. He hit and physically abused her for years. Managing Kris' behavioral episodes has taken a toll on Connie's health. She has high blood pressure, four torn disks in her back and chronic chest pains. As Kris frequently ran off, she had to carry him almost everywhere for the first eight years of his life, resulting in a significant deterioration of her spine.

The Harmons have spent thousands of dollars out of their own pockets to care for Kris while they waited for services. They spent $1,000 a month for eight years on attendant services and $3,000 a month for more than 47 medications he took until they found the right combination for him to be able to function and live his life.

Like many other families who are caring for a child with a disability, the Harmons had no support available to them. In fact, Connie was not able "to build relationships with other people" or even go to church, an activity that was very important to her. Caring for Kris also alienated her from the rest of her family and resulted in suffering of her other children and grandchildren. The Harmons have sacrificed their spiritual, physical and mental health, as well as their financial security. They both work 12-15 hours a day to replenish the funds they have used caring for Kris.

They considered institutionalizing Kris because they were so emotionally and physically drained. Connie states, "We almost turned him over to the State as I couldn't hold on. The thought of doing this almost put me in a mental hospital." When Connie discussed this with her case manger, the Texana Mental Retardation Authority (MRA) offered them a Texas Home Living (TxHmL) slot to provide some relief as she got a few hours a week of respite. With the support of TxHmL, the Harmons decided against institutional placement.

After nine years on the waiting list, Kris' name came up for Home and Community-Based Services (HCS) services. He now has an attendant whom Connie calls a "life skills coach" to teach him daily living skills and ensure his participation in the community.

Connie explains that she had "given up everything in (her) life so Kris could have one." His enrollment in HCS has allowed her to return to the life she once had. She now has "time to take care of errands, pay bills" and, more importantly, "attend church."

Strengthening Existing Community Services

The infrastructure of Texas' community system in its present form may not fully support manageable but rapid system expansion and reconfiguration. If Texas is to implement these actions to rebalance the system, it is vital that leaders create a solid platform for the delivery of community services going forward.

24. **Develop a reliable and accurate means for tracking service demand and associated trends.** Over the past several years Texas has gathered information on unmet service needs and compiled it in a series of "Interest Lists." Currently, the lists have grown to include nearly 80,000 individuals (unduplicated count). These lists, however, are troubled by a number of methodological flaws which make them difficult to interpret and likely drive individuals to sign up whether they presently need services or not. As a result, their utility for forecasting demand and reviewing associated trends is severely limited.

    From a strategic standpoint, the Interest Lists fail to provide state leaders with the information they need to systematically allocate available resources or to plan ahead to prepare for emerging demand preferences. In Texas, those who are on the Interest List are deemed as being "interested," but not necessarily eligible, for specific services. Further, agencies cannot determine if the individuals seeking services have MR/RC or meet functional and/or diagnostic eligibility requirements. Individuals seeking services are mixed together and reported in aggregate, and can be on multiple interest lists, yielding various duplicated and unduplicated counts for services. Individuals may seek to be placed on multiple lists, given the varying waiting times for service start up. Data are not gathered on an individual's "urgency of need" or the types of service they requested. Individuals instead are offered services generally on a "first come first serve" basis. Without more information, state leaders and advocates are virtually guessing at the accuracy of the lists and their implications for informing a reasoned systemic response.

> "CLASS would have been the biggest miracle of our lives had we gotten it when they were young. We're not asking for a Cadillac. We just wanted early intervention. Can you be late to be early?"
>
> – Miriam Aune

To develop a more systematic view and response to meeting unmet needs going forward, Texas must establish a more structured means of gathering information on individuals facing critical or emergency need for services. Texas state leaders should undertake a review of other waiting list management systems and take action to establish a more reliable, accurate and useful means for collecting data on unmet service need.

Other States

Several other states have undertaken this task in recent years. For example, Pennsylvania and Illinois utilize the Prioritization of Urgency of Need for Services (PUNS) waiting list management system. PUNS classifies individuals based on an assessment of urgency of need and how soon services must be provided. It allows state staff to track what services are needed by urgency category. In addition, because uniform demographic information is gathered about each individual and their family caregivers (e.g., age), the data set also reveals other information useful to planners. HSRI advises that the PUNS is not necessarily the recommended choice – there are also other useful state systems that could be reviewed.

25. Strengthen the infrastructure to underpin the state community service system. If Texas is to be successful in reducing the census in state schools, the state must commit to simultaneously strengthening its community services system. Taking such action will require state leaders to rethink and reinforce several community system elements. Key areas that need immediate action include workforce, service reimbursement rates, and a system that assures that individuals with complex needs are appropriately served.

> "We are just trying to survive here."
>
> – Steve LeMaster

Workforce

Community agencies often experience high worker turnover which can pose significant challenges in their ability to deliver quality care. In Texas, payments for community services have not been regularly adjusted annually to reflect changes in the "cost of doing business." As wages increase in the general labor market, community agencies encounter more and more difficulties in hiring and retaining competent workers. At present, there is little in the way of up-to-date, systematic information to gauge the extent to which community worker wages should be boosted so that community agencies can be reasonably competitive in the market place.

Three recommendations are offered to improve conditions for the community worker:

25.1 **Increase payment rates for community agencies to catch up with underlying changes in the cost of doing business in Texas.** A catch-up funding increase would reduce strains on community services and avoid further deterioration in wages.

25.2 **Implement low-cost or no-cost workplace improvements to increase worker retention.** 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. These include flexible work schedules, realistic job previews, worker recognition, worker-consumer matches, a career ladder, networking and mentor opportunities.[14]

25.3 **Initiate a comprehensive study of community wages and benefits in 2009 and target for completion during 2010.** 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 be designed so that it provides policymakers with reliable, concrete information concerning the extent to which community wages and benefits are (or are not) competitive. The study also should suggest how wages and benefits can be indexed going forward so that they can be kept in alignment and competitive with general labor market levels.

Other States

Wyoming undertook a comprehensive study of this type several years ago. The study revealed that community worker wages needed to be boosted by about 20 percent to be competitive with other employers. Based on this study, the Wyoming Legislature appropriated the necessary funds to increase wages; a follow-up study determined that the increase in wages resulted in a marked reduction in workforce turnover.

Reimbursement Rates

Wages, benefits, and services are ultimately tied to the amount the provider is reimbursed. It is not simply the total amount of the reimbursement, but how efficiently the service can be provided with the funds allocated.

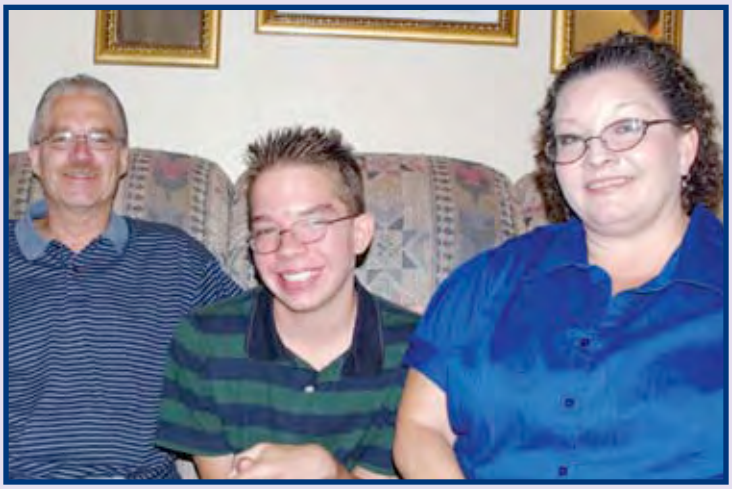
Two recommendations are offered to improve reimbursement rates:

25.4 **Implement a provider cost study to examine how funds are allocated by actual costs associated with providing service.** This study would allow a provider to know how much is being allocated to specific services as well as look at factors such as per person costs. This type of study also allows a state to pair the information with a systemwide payment reimbursement study to better manage the money allocated for individuals.

25.5 **Update and enhance 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 for developing individual budgets or reimbursement levels for state waiver programs. Because the instrument is support 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 would be very useful in matching available waiver dollars to the individual community support needs of waiver-eligible individuals.

LeMaster Family: Karen, Steve & Brandon

Steven, Brandon and Karen LeMaster



Karen and Steve LeMaster have been married for more than 25 years. Despite being encouraged every step of the way to separate their family for the sake of their son, they chose to stay together. Karen explains that staff at "The Social Security department in El Paso constantly told me to divorce my husband and quit my job. That way I could have everything I need for Brandon."

Their 16-year-old son Brandon is diagnosed with autism, Asperger's syndrome and obsessive compulsive disorder. They placed Brandon on the Home and Community-Based Services (HCS) waiting list when he was 3 years old, and it was 13 years before they received services.

During the 13 years spent on the waiting list, the family suffered severe financial strain and declared bankruptcy twice due to high medical bills and the inability to earn more money because of financial restrictions associated with the Medicaid eligibility requirements. When Brandon was five, Karen and Steve had to change their respective jobs to intentionally earn less money to reduce their salaries by $14,000 a year. This action resulted in a combined take home pay of $2,000 a month.

These job changes, coupled with Brandon's preexisting medical conditions, resulted in higher monthly premiums ($420 a month) for medical insurance. The LeMasters spend $500 a month in prescription and therapy co-payments for Brandon. They are not able to afford the co-payment for Steve's prescriptions related to his diabetes, so he goes without so that his son's needs are fully met. Steve states, "We're just trying to survive here."

Despite their personal sacrifices, the LeMasters frequently lose Brandon's Social Security and Medicaid due to earning as little as $12 over the monthly threshold. When this occurs, they stop all of Brandon's therapies since they cannot afford the expense. Karen states, "Dealing with the Social Security office has been the greatest stressor of our lives." They gave up Social Security benefits for Brandon for two years because they didn't have the energy to fight with them anymore. When they came off the waiting list, they had to re-apply for Social Security and Medicaid to qualify Brandon for waiver services.

Now that they have had HCS services for a year, the LeMasters both comment, "It is severely lacking." Brandon needs social skills and vocational training if he is to be prepared for community living, but the HCS program is not providing these essential services. Additionally, the HCS providers are unable to secure consistent staff coverage to meet Brandon's needs.

The LeMasters point out that "Brandon thought all his staff was leaving because they didn't like him." When he begins to bond with staff, they often leave to earn a higher rate of pay elsewhere, and Brandon loses yet another person in his life. At one point, he threatened suicide because this was so difficult for him to deal with; his parents got him into therapy.

Karen adds, "We're struggling to make a better life for our son; that's all. We've never been on a family vacation and the future is scary for us. It never stops for our family."

Steve and Karen both hope that Brandon will have the opportunity to live in his own home and receive the support services for job training and independent living. Brandon wants to graduate high school and college so he can become a crime scene investigator or a chef.

Serving Individuals with Complex Needs

Texas presently lacks a well-structured capacity in the community to respond to the needs of individuals with complex needs. As a consequence, the state schools/centers become the provider of serving individuals whose needs cannot be met in the community due to their challenging conditions. This is one of the rationales for maintaining state schools/centers.

So long as the capacity is not present in the community to address the needs of people with challenging conditions, Texas will face ongoing pressures to admit people to the state schools/centers.

Two specific actions are suggested:

25.6 **Contract with one or more organizations to furnish specialized behavioral services for individuals living at home on an as-needed basis for defined geographic regions.** This would strengthen the community infrastructure to support individuals in their homes and community. DADS should conduct a pilot of behavioral support system during 2010. If the pilot to contract with organizations to provide community support for behavioral crisis is successful, this approach to furnishing services could be extended statewide starting in the 2011-2012 biennium.

25.7 **Undertake an in-depth study of current system capabilities to meet the needs of individuals who have extensive medical support needs.** Approximately half of individuals with complex needs in Texas are being served in the community. However, little is known about the effectiveness of the system in meeting the needs of individuals with extensive, chronic health-care needs in the community.

"I would be working if I didn't have a disabled child. No day care will take a child who is so medically fragile."

– Kim Johnson

Other States

States that have closed their large public facilities or substantially reduced their capacity have had to confront the question of how to meet the needs of individuals whose challenging conditions would otherwise lead to institutionalization. Some of these states (e.g., Maine and Vermont) recognized that reducing institutionalization required the development of capacity in the community to respond quickly and expertly to the needs of individuals with challenging conditions. For example, Vermont sponsored the development of a statewide crisis intervention network that can respond to the needs of such individuals in a variety of ways. Establishing this crisis network cleared the way for Vermont to close its only public institution. Maine found itself caught in a revolving door situation, with individuals in crisis cycling into and out of its one remaining public institution. In response, Maine created capacity in the community to meet the needs of these persons. This enabled Maine to proceed with its closure of Pineland Center, its only large public institution.

Karen and Lathom Yaemon

While the Yaemons waited for Medicaid waiver services for seven years, they sought help from the school districts and private pay facilities around the state. Their 17-year-old son, Lathom, has been diagnosed with autism, Attention Deficit/ Hyperactivity Disorder (ADHD), speech impairment and mild mental retardation. He has severe behavior problems which include biting, kicking, choking and destroying property. When Lathom was home, the family was in a constant state of crisis.

Lathom attended school in Dripping Springs, but as he got older, his behavior worsened. He was striking out 20-50 times a day, and the school staff were restraining him and putting him in time out where he spent most of his day. Since the school was unable to assist with his behavioral episodes, they removed him and placed him in a residential facility in 2002. But, they had to bring him home after nine days because they could no longer afford the $500 a day cost.

Lathom was enrolled in a private Applied Behavior Analysis (ABA) school in Houston, and Karen lived with her mom to provide oversight of Lathom's care. She was away from her husband and daughter who remained in Dripping Springs to tend to their family business. The lack of Medicaid services forced the family to live apart and cost them thousands of dollars.

After exhausting their financial resources and after seven years on the waiting list, Lathom reached number 657 on the HCS list. The family was faced with no other option but to place him in Austin State School. The lack of community Medicaid services was a significant gap, and there wasn't any resource available between the family and a State School placement.

The Yaemons worked with the team at the State School to develop a plan for getting Lathom's medications and behavior more manageable. After living at Austin State School for one year, Lathom received a community slot. He got an HCS placement and is now living in a Home and Community-Based Services (HCS) group home in Austin.

Comprehensive 10-Year Plan to Rebalance the Long-Term Services and Supports System

System redesign is an exciting opportunity for Texas to commit itself to achieving excellence in service system performance. However, redesign also may generate concerns about the potential impacts on people with intellectual and developmental disabilities, their families, committed professionals, and other stakeholders. These concerns are entirely legitimate, and if not addressed can fuel strong resistance to system redesign.

26. **Launch the redesign effort with executive and legislative branch sponsorship and pursue redesign through a collaborative process that engages people with intellectual and developmental disabilities and other appropriate stakeholders as primary constituents of the system.** A *Redesign Steering Committee*, with decision making authority, should be appointed to lead the effort. The Steering Committee should be charged with helping state officials to push forward by working out implementation details and generating support for planned system changes. This Steering Committee should have its own budget to defray meeting and other expenses, including support for the meaningful participation of people with disabilities and families. The Steering Committee should have ongoing, *independent* staff support during the duration of the action period. The Steering Committee should be required to prepare periodic reports about its activities and these reports should be widely disseminated across all stakeholder groups. South Carolina has the authority to direct its health and human service commission to take specific action to implement rebalancing efforts. Committee members should also include individuals with developmental disabilities and their families to provide input into the design of the system in which they receive services.

"The greatest loss is the loss we will never know. We will never know what 10 years of appropriate therapies and services could have done for our children."

– Vandi Alba

Conclusion

Absent an aggressive, multi-year initiative to reduce and eliminate unmet emergency and critical unmet service 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.

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."

It is clear that Texas is at a crossroads. Today's state leaders must choose the path and set the course for action in the next five, 10, 20 years. Action will require risks, but the benefits for Texans with disabilities will be far greater. The time to act is now.

About the Texas Office for Prevention of Developmental Disabilities

The Office for Prevention of Developmental Disabilities was created by the Texas Legislature in 1989 to coordinate prevention activity among the state's health and human services enterprise. The governor and legislature directed the agency to address substance abuse, teen pregnancy, and childhood head and spinal cord injury. The agency's mission is to help minimize the human and economic losses caused by preventable developmental disabilities.

A nine member, executive committee consisting of experts in medicine, business, academia, and mental health governs the agency and establishes policy directed toward its priorities: preventing fetal alcohol spectrum disorders (FASD) and head and spinal cord injury.

Executive Committee

J.C. Montgomery, Jr., Chair (Dallas)

Marian Sokol, Vice-Chair (San Antonio)

Valerie Kiper (Amarillo)

Joan Roberts-Scott (Austin)

Mary S. Tijerina (San Marcos)

Representative Jim Jackson (Carrollton)

Richard Garnett (Ft. Worth)

Representative Vicki Truitt (Keller)

Carolyn A. Smith, Executive Director

The agency strives to coordinate activity among private and public organizations to address preventable developmental disabilities. The goals directing this work include:

- Educate the public about FASD and head and spinal cord injury.
- Train professionals to provide services to individuals affected by brain injury.
- Implement public health strategies that emphasize prevention using evidence-based interventions.

Two task forces actively advise the agency on 1) prevention of alcohol-exposed pregnancy, the cause of FASD and 2) educating parents and young children about using helmets, safely riding bicycles, and avoiding common childhood injuries.

The focus of this year's report is on policy improvements for individuals with FASD.

Focus on Fetal Alcohol Spectrum Disorders (FASD)

FASD is not a diagnosis, but rather a combination of birth defects and behavioral challenges in children whose mothers drink alcohol during pregnancy. FASD is highlighted in this report to increase awareness about the condition and make recommendations regarding needed improvements in the service delivery system to better support individuals and their families.

Characteristics of FASD

FASD is the leading cause of developmental disabilities. Children affected by FASD typically have a reduced head size and brain damage. As a direct result of mental retardation and brain damage associated with FASD, children also have immature social skills and behavior. Some of the facial characteristics are small nose bridge, flat midface, thin upper lip and a smooth philtrum. Children with these disorders may also have low birth weight and continue to be small through puberty. Many children have a lower than normal IQ and face numerous learning and behavior problems. Exposure to alcohol during prenatal development may increase the incidence of hyperactivity and short attention spans. Many children affected by FASD experience multiple health problems. Another complication is they often lack health insurance to cover their medical needs.

Dotts Family: Betty, Ted & adopted son

The Dotts Family

Betty and her husband, Ted, are in their 70s and live in Lubbock. Ted is a pastor. They have a 41-year-old son who has been diagnosed with fetal alcohol syndrome disorder (FASD). The Dotts adopted their son when he was 13 days old and were unaware of his condition until he was diagnosed at age 31.

Their son has a normal IQ; however, he suffers frontal lobe damage that primarily affects his judgment. He was diagnosed as having a learning disability as a child with symptoms including dyslexia, disgraphia (deficiency in the ability to write but not due to intellectual impairment), and dyscalculia (difficulty in visual processing and severe mathematical problems). These symptoms are typical for persons diagnosed with FAS.

He has been in and out of the judicial system and lacks the ability to understand the consequences of his behavior. He became addicted to drugs and alcohol when he went to college. This further impaired his judgment and ability to follow through with his life's goals and expectations.

"There are no services (specifically) available for kids and adults who have FASD," Betty said. "They basically fall through the cracks and often end up in jail. The average lifetime cost of caring for a person with FASD is $3 million each to manage health problems, special education, psychotherapy and counseling, welfare, crime and the justice system." Betty says the biggest problem was getting him diagnosed. For moms who have children with FAS, there is an enormous stigma to this diagnosis.

Problems of FASD

The estimate for lifetime care for a person with FASD is in the millions, while 2003 estimates indicate that prevention can cost as little as $5,000.[15] State services available to individuals with developmental disabilities often do not include persons affected by FASD. The structural brain damage unique to prenatal alcohol exposure often results in cognitive and/or functional disabilities that do not meet current Medicaid program eligibility.[16] FASD is not recognized as a disability in schools for IDEA assistance, thus many states are currently working on a FASD diagnostic code.

The damages created by alcohol during the nine months of pregnancy are very devastating to the unborn child. Many children struggle through the day to day frustration of inconsistent mastery of skills and spotty memory. They often have trouble generalizing information and perceiving similarities and difference. Many children affected have impaired impulse control. Children with FASD may have episodes of rage, the inability to make good judgments, eating and sleeping problems, and trouble distinguishing truth from fiction.[17] Because of the serious and irreparable brain damage caused by alcohol use during pregnancy many children are not self-sufficient in adulthood. They are unable to obtain or maintain sustainable employment. They may also experiment with drugs and alcohol or be involved in the criminal justice system.

Diagnoses pose a greater set of problems and obstacles for families with a child who has prenatal alcohol exposure. FASD is rarely covered in medical school curriculum; according to a recent study only about 17 percent of recent obstetric-gynecologic textbooks recommend abstinence from alcohol during pregnancy.[18]

Physicians may be reluctant to diagnose this condition, after birth, partly to avoid inducing guilt in the mother and labeling the child. One physician's statement may help explain why children are not identified, "If we diagnose it, we have to treat it, and we don't have the resources to do that".[19] Quite often children with FASD are misdiagnosed with other disabilities because it so often mimics other disorders such as ADHD. Many physicians hesitate to diagnosis FASD without proof of alcohol use during pregnancy. Many obstacles impede the discovery of alcohol use in pregnancy, such as the birth mom may not be around, she may be unwilling to admit use of alcohol, and she may not remember her alcohol use during that time.

According to experts, physicians are not the only professionals who should know about FASD. There is practically no training on FASD in disciplines such as education, social work, health professions, juvenile justice, and other systems responsible for the care of people at risk.

Needs of Population Affected by FASD

1. There is a need for resources for both prevention and treatment, and collaboration across State agencies.
2. Proper diagnosis and comprehensive services are in great demand but not readily available.
3. Increased public awareness that there is no safe level of alcohol use during pregnancy.
4. Educators have indicated a need for support and training regarding educating students with FASD. A 1995 survey of special education divisions in each of the 50 states revealed that none recognized or specifically served the needs of students based on a diagnosis of FAS, nor did they have plans to do so (Wentz, 1997). [20]

Obstacles Faced by Population Affected by FASD

Children with FASD face a lifetime of problems. They are at an increased risk for secondary effects such as mental illness, drug and alcohol addiction, dropping out of school and incarceration.[21] According to the Florida Center for Child and Family Development, Inc., about 70 percent of individuals with FASD will have problems with employment. About 82 percent will not be able to live independently. Fewer than 10 percent of individuals with FAS are able to live on their own regardless of their IQ.[22]

Texas lacks resources to offer specialized services, such as a training curriculum to learn how to better serve this population, inpatient residential treatment, transitional housing for adults, and medical and mental health services.[23] With the current lifetime care estimates as high as $5 million,[24] many families will not have the money to provide long term allocation of resources to support their children into adulthood.

The Lane Family

Melanie is a 51-year-old, single parent of a 27-year-old daughter, Natalie, who has fetal alcohol effects (FAE). Melanie was an alcoholic throughout her pregnancy and for eight years after the delivery of her daughter. Then she entered Alcoholics Anonymous (AA) and became clean and sober. Melanie is now a substance abuse counselor for women.

Natalie was not diagnosed until she was 10 years old. She has a normal IQ however; she has problems with impulse control, difficulty with mathematical problems (dyscalculia), severe dental problems, hearing loss and chronic ear infections. These types of symptoms are what define fetal alcohol effects, but she does not have the full blown syndrome. She did graduate from high school.

Early on in Natalie's education, she received speech therapy through the public school system. "These kids often go undiagnosed or misdiagnosed," Melanie said, "so there isn't a lot of intervention to help them address issues they may face." The mental health system doesn't even acknowledge FASD/FAE as an issue, therefore education is severely lacking. This is very frustrating as Mental Retardation Authorities (MRAs) need more training, she said.

Melanie was so guilty and full of shame that she did not tell her daughter about FAE until she was older. She found an article that had a photo of what FAS looks like in children and showed it to her daughter. She said that Natalie took the picture and went into the bathroom and placed the photo next to her face to compare herself to the picture. This was very difficult for them both.

It is common for these children to be misdiagnosed with oppositional defiant disorder or bi-polar, etc. and be placed on heavy anti-psychotic medications which often are contraindicated for FASD or FAE syndromes. The medications can actually cause more damage to the children, Melanie said. She suggests a mandatory FASD screening for all children entering the system via Child Protective Custody. However, this must be done in conjunction with education. Even if FASD is diagnosed, there are limits in what the service system can do. More education and training is needed at the front door.

Canada is the world leader in treating FASD, Melanie said, and she suggested that Texas look at their system and use what is working there to help these children and their families.

Recommendations

TOPDD Recommendations for Addressing Fetal Alcohol Spectrum Disorders (FASD)

1. Increase services for awareness, prevention, and intervention for individuals at risk for FASD.
2. Develop and offer pre-service education and continuing education training for para-professionals and professionals in a wide range of disciplines.
3. Establish supervised living arrangements for adults affected by FASD.
4. Advocate recognition of the disorder by Medicaid and insurance companies, so that all diagnostic and treatment work are reimbursable.
5. Support community services to assist families with children affected by FASD to remain in a stable and caring environment, i.e. home.

Thetford Family: Denese & Skyler

Denese Thetford and Skyler

Denese Thetford has a 19-year-old son, Skyler, who has been diagnosed with alcohol-induced static encephalopathy. She adopted him when he was 2 days old, and he wasn't diagnosed until he was 15-16 years old. In school, he was diagnosed with learning disabilities and attention deficit/hyperactivity disorder (ADHD), but he has a normal IQ. He has dysgraphia (difficulty with writing), as well as problems with anger and impulse control, cause and effect, and consequences, etc.

"He would be better off if he had mental retardation as he would have more services available to him," Denese says. She states that there are no services for older children. Skyler is intelligent enough to know that he doesn't want to be stigmatized by going to the Mental Retardation Authority (MRA) for any type of services.

Her goal is to spread information about the damaging effects that alcohol has on a fetus. "More awareness needs to be done," she said. "Alcohol does more damage than cocaine, crack, pot, etc." Denese said it costs Lubbock County about $14,000 a day to care for a person diagnosed with FASD, including judicial, social services, and medical costs, etc.

The hope is for Skyler to live and function independently. He is going to welding school one night a week at college and is fitting in better as he is doing what his peers do — going to college. He is also a volunteer fireman.

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).

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