Closing the Gap in Texas:

Improving Services for People with Intellectual and Developmental Disabilities

October 2008

Human Services Research Institute

7420 SW Bridgeport Road Suite #210
Portland Oregon 97224
Voice: 503-924-3783 Fax: 503-924-3789
www.hsri.org

[Page left intentionally blank for double-sided copying]

Closing the Gap in Texas:

Improving Services for People with Intellectual and Developmental Disabilities

October 2008

Prepared for the

Texas Council for Developmental Disabilities
6201 East Oltorf, Suite 600
Austin, Texas 78741-7509
512-437-5432

Prepared By

John Agosta, Jon Fortune, Drew Smith, Kerri Melda,
Robert Gettings and Valerie Bradley

Human Services Research Institute
7420 SW Bridgeport Road, Suite 210
Portland, Oregon 97224
503-924-3783
www.hsri.org

All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Texas Council for Developmental Disabilities or any other government authority.

[Page left intentionally blank for double-sided copying]

About the Authors

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

This report was prepared by the following staff:

John Agosta, Ph.D., is an 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 has studied specific facets of the field (e.g., trends in supported employment, managed care, self-determination). He 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., is a Policy Associate at HSRI. Dr. Fortune has solid research skills as well as hands on experience as a state administrator. In 1990, he 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. Dr. 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, Dr. Fortune managed a community agency in Wyoming and held other positions in Colorado and Texas and is currently working on financial architecture in DD statewide services 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., is a 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.

[Page left intentionally blank for double-sided copying]

Kerri Melda, M.S., is a 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 the Human Services Research Institute since 1992. Her primary responsibilities at HSRI include project leadership, policy and statistical analyses, program evaluation, and provision of training and technical assistance. Ms. 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 is the 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 fifty 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, Mr. 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 national 26 state initiative on performance measurement, the National Core Indicators. Ms. 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 Mental Retardation.

[Page left intentionally blank for double-sided copying]

Table of Contents

[Page left intentionally blank for double-sided copying]

Charts and Tables

[Page left intentionally blank for double-sided copying]

1. Introduction

The Texas Council for Developmental Disabilities (TCDD) engaged the Human Services Research Institute (HSRI) to examine selected aspects of the present system in Texas serving people with mental retardation and related conditions (MR/RC).[1] In response, HSRI has completed a "gap analysis" that is intended to serve as a discussion point for state staff and others pertaining to the current state of the Texas system. In addition, HSRI has developed a series of "action steps" that can be used to guide needed systematic reform.

In completing this work, HSRI is aware that circumstances are not stagnant. We acknowledge several steps that the Texas Department of Aging and Developmental Services (DADS) has taken to move in a new direction. For instance:

- The *HHS 2009 to 2013 Strategic Plan* and the 2006 Promoting Independence Advisory Committee Stakeholder Group demonstrates a vision for improving the system so that it effectively addresses the needs of people with mental retardation and related conditions.
- Texas has, since 2001, pursued action, through its *Promoting Independence Plan*, to relocate people with disabilities and seniors from nursing homes and institutions to community alternatives. The plan was in response to the 1999 *Olmstead vs. LC & EW* Supreme Court decision and currently involves several actions within Texas' "Money Follows the Person" initiative.
- Texas joined the National Core Indicators Project, a 30 state collaboration that has resulted in the identification of common performance indicators, uniform data collection protocols, and the generation of data sets that allow states to compare their results with national norms. Overall, Texas has achieved average quality outcomes (http://www.hsri.org/nci/) when compared to the other 29 states participating in the project.
- In August 2008, Texas was recognized for its pilot efforts in self-determination in an article published by the National Association of State Directors of Developmental Disabilities Services (NASDDDS)[2].
- The Texas Legislature allocated funds for the fiscal year (FY 2008-2009) biennium to serve 8,902 more individuals in its Medicaid waiver-funded programs. These include individuals with MR/RC and others as well.

[1] The title of this report makes reference to "people with intellectual and developmental disabilities" (ID/DD). Yet, in relevant Texas statute (Title 7; Subtitle A; Chapter 531) and related administrative codes refer to this general population as people with "mental retardation and related conditions" (MR/RC). The two reference points (ID/DD and MR/RC) are not exactly interchangeable, but do overlap significantly. 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 national trends, terminology keyed to "developmental disabilities" is used. More information to illustrate the difference between these terms is provided on page 3.

[2] NASDDDS, (2008). Texas Launches New Self-Directed Services Option. *Community Services Reporter*. *15*, 2

This report, however, does identify significant weaknesses that exist within Texas' MR/RC service system that must be addressed. The report is divided into three parts:

1. **Gap Analysis**: We present findings resulting from an analysis to appraise circumstances in Texas against three performance benchmarks.

2. **Action Steps**: We present eight (8) Action Steps that Texas must undertake to close the gaps in performance that we identify. These actions involve: (a) increasing opportunity for individuals to live in the most integrated settings; (b) increasing capacity to address present un-met expressed service demand; and (c) strengthening community system infrastructure to improve services.

3. **Concluding Remarks**: We present a summary of our observations and parting remarks.

A Glossary of Key Terms is presented on the following pages in advance of presenting the major findings of our inquiry. Understanding the meaning of these terms is critical if the reader is to grasp the findings, conclusions, and recommendations in this report.

Glossary of Key Terms

In this report, services and housing arrangements for people with 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.

Developmental Disabilities: The U.S. Developmental Disabilities Assistance and Bill of Rights Act of 2000 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 developmental 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[3] 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.

[3] Texas Health and Human Services Department, The Long Term Care Plan for People with Mental Retardation and Related Conditions Fiscal Years 2006 - 2007. Retrieved September 2008, from http://www.dads.state.tx.us/news_info/publications/planning/Proposed_DRAFT_LTC_Plan_06_07_04.pdf

Glossary of Key Terms (Continued)

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, the 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 "noninstitutional" services for Medicaid-eligible individuals. The Medicaid Home and Community-Based Services (HCBS) waiver program was designed to provide noninstitutional, community services to people who are aged, blind, disabled, or who have ID/DD (intellectual or developmental disabilities) and who, in the absence of alternative noninstitutional 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.[4]"

[4] Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2007). *Residential Services for People with Developmental Disabilities: Status and Trends Though 2006*. Page 92. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

Glossary of Key Terms (Continued)

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 provide 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; intervenor; 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 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.

Glossary of Key Terms (Continued)

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) This waiver 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 of $10,000 per year in 2007.

2. Gap Analysis

A *gap analysis* compares an enterprise's actual to its potential or desired performance. It is an assessment of the distance between what an enterprise is currently doing and what it seeks to do in the future. A gap analysis flows from benchmarking the level of performance achieved and other assessments of requirements as well as current system capabilities.

The gap analysis begins with defining key expectations for desired system performance. These expectations serve as the basis for appraising current performance. We recognize that a primary and overarching goal in Texas is that everyone supported by the system has a quality service. In addition, and for the purpose of this gap analysis, HSRI, has identified three fundamental, top-level performance benchmarks against which 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). As illustrated by the graphic below, the benchmarks are related to service access, service delivery, system efficiency, and associated outcomes.

Benchmarks

1. **People with mental retardation and related conditions have access to and receive necessary publicly-funded services and supports with reasonable promptness**. Publicly-funded systems should operate in a fashion to ensure that those who need services receive such services and supports within a reasonable period of time. This requires sound system infrastructure in order to ensure a diverse and agile service delivery capacity. When services are not furnished promptly, individuals and families experience negative life outcomes
2. **Services and supports are provided in the most integrated setting appropriate to the needs of the individual**. The U.S. Supreme Court's *Olmstead* decision has established the clear benchmark that publicly-funded services must be furnished in the most integrated setting. The decision mandates that states operate services so that individuals are not unnecessarily institutionalized.
3. **The system must promote economy and efficiency in the delivery of services and supports**. This means that the state must seek out the most cost effective services and supports, building on the supports that families and communities provide, and effectively utilizing federal funding. Systems that do not stress economy and efficiency are not sustainable.

These three essential benchmarks serve as the framework for the HSRI gap analysis. The following sections of this report contain information comparing Texas' current performance against these benchmarks.

The analysis is based primarily 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. Annually, RTC conducts a 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. All states, including Texas, participate in this survey. In general, RTC survey data serve as the source of information that compares Texas performance to the nation as a whole as well as selected other states.[5] We also draw from data compiled by the Coleman Institute on Cognitive Disabilities at the University of Colorado.[6] The Coleman Institute collects annual data primarily related to financial and programmatic information from states on a yearly basis. The Coleman Institute now has a 30-year trend for each state spanning back to 1977. The data collected is done so in cooperation of state agency officials to ensure accuracy within the information presented.

Using these data sources, we were able to compare the performance of the Texas MR/RC system to that of systems in other states, as well as the national averages. Such comparisons help pinpoint areas of strengths and weaknesses in system performance. The gap analysis also draws upon previous studies of the Texas MR/RC service delivery system, and consultation with national experts about critical dimensions of system performance.

As illustrated later, in some instances, we compare Texas' performance to the performance of selected states. 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 of 8 million or more[7]. The states selected for this comparison include:

CMS Region 6	2006 State Population
Arkansas	2,809,111
Louisiana	4,243,288
New Mexico	1,942,302
Oklahoma	3,577,536
Texas	23,407,639

Large Population States	2006 State Population
California	36,249,872
Florida	18,057,508
Georgia	9,342,080
Illinois	12,777,042
New Jersey	8,666,075
New York	19,281,988
North Carolina	8,856,505
Ohio	11,463,513
Pennsylvania	12,402,817

5 Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2007). *Residential Services for People with Developmental Disabilities: Status and Trends Though 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

6 Braddock, D. et al. (2008). *The State of the States in Developmental Disabilities: 2008*. Boulder, Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

7 Michigan, while having a 2006 population over 8,000,000, was not included as a comparison state for this analysis. Michigan's developmental disability service system operates under a managed care framework, making direct comparisons problematic.

Benchmark #1: Serving Individuals with Reasonable Promptness

Assessment: Texas does not furnish services with reasonable promptness to its citizens with mental retardation and related conditions.

Background

Most of the 5 million people with developmental disabilities in the United States are supported by their families or live independently without specialized publicly-funded developmental disabilities services. Public developmental disabilities service systems provide services and supports to a relatively small percentage (about 20-25 percent) of all individuals with developmental disabilities. Public systems focus principally on people who have significant 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.

Demand for publicly-funded developmental disabilities services is growing nationwide. Generally, demand has been increasing at a rate greater than population growth alone. This increase in demand is the product of several factors. One of the most important factors is the increased longevity of people with developmental disabilities. 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 among individuals receiving services is reduced (and, consequently, there is less capacity to absorb new demand); and (b) there is a growing cohort 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. Increased demand also is the result of other factors, including the development of community services and supports that better meet the needs of individuals and families.

The demand for developmental disabilities services is dynamic. Each year, significant numbers of youth with developmental disabilities exit special education systems and need ongoing services and supports as young adults. Other people seek services because their families cannot continue to support them or need extra assistance. Based on the work completed elsewhere and national comparisons by the Research and Training Center on Community Living, it is not uncommon to observe year-over-year increases in the expressed demand for developmental disabilities of 4 percent[8] or more.

States generally operate their developmental disabilities service systems under fixed capacity limits. Only a handful of states (e.g., AZ and CA) provide for automatic annual caseload increases to accommodate additional eligible individuals. System capacity is managed by

[8] Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2007). *Residential Services for People with Developmental Disabilities: Status and Trends Though 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.

capping dollars or "slots" (service openings), or a combination of both. Likewise, capacity is regulated by changes in funding from year to year.

Capped system capacity, coupled with rising demand for services, has resulted in individuals spilling over onto "waitlists." The number of people on a waitlist measures the gap between current system capacity and expressed service demand. This gap grows when the expansion of system capacity does not keep pace with growth in service demand. The waitlist queue will lengthen even though there may have been some growth in system capacity.

Federal court decisions have clearly indicated that responding to service needs with reasonable promptness means that individuals who have emergency or crisis needs must receive Medicaid-funded services within 90 days. It follows then that people who have critical near-term needs should be able to count on receiving services within 6-9 months[9]. If they do not, their needs can rapidly turn into an emergency or crisis situation.

Texas Status

Until recently, Texas did not compile systematic information about people with mental retardation and related conditions who need and would qualify for, but are not receiving, services and supports. As a consequence, little was known about where the state stood in meeting the needs of its citizens with MR/RC. Legislation was enacted in 2001 (Senate Bill 368, 77th Texas Legislature (R) to require the state to compile information about unmet service demand of children and has lead to the compilation of information about more people with unmet need within the state of Texas. Given our review of the information available, however, we find that:

- Texas serves far fewer individuals with MR/RC than reasonably might be expected, suggesting that significant numbers of individuals do not receive the services they need.
- Individuals in need who are known to the state by their status on a service "interest list" have waits ranging from 0 to over 9 years, with typical wait times being three or more years for services.
- Present methods of collecting information on unmet expressed service demand does not provide the state with an accurate means of forecasting demand or the costs associated with meeting such demand.
- Texas has acted to reduce the level of unmet need, but these actions thus far have been insufficient to reduce substantially the number of people waiting for services.

Texas Service Utilization Patterns

Our review of service use patterns in other states suggests that Texas does not serve as many people as might reasonably be expected. Consider that:

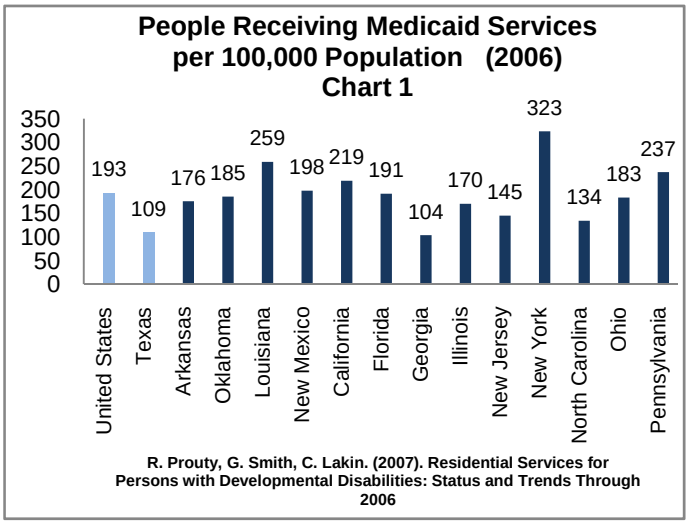
- Texas spends significantly less than other states on MR/RC services. On average, in 2006, states spent $131.29 per citizen on residential services for this population, while

[9] Federal Medicaid Act 42 C.F.R. § 435.930(a)

Texas spent 69 percent below the national average: $53.91 (Braddock et al., 2008)[10]. Note that:

- 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.

- In 2006, the number of people receiving residential services (i.e., all residential settings) 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 100K. 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).



- Regarding the fuller spectrum of Medicaid-funded services for people with MR/RC in 2006, Texas furnishes these services at a rate that is 43.3 percent below the nationwide average (109 per 100K population in Texas vs. 193 per 100K population nationwide as can be seen in Chart 1). For Texas to have served the national average in 2006 of people per 100K population, the state would have had to provide residential services to roughly 19,662 more people with Medicaid waiver services in that year.
- The chart also illustrates that among the comparison states, only Georgia serves fewer people per 100K (i.e., 109 in Texas to 104 in Georgia).

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. 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.

[10] Texas, in 2006, had a Cost of Living Index of 88.9, which was among the lowest in the nation and 10.1% below the nation average (reported ACCRA Cost of Living Index at the Council for Community and Economic Research). Second, according to the Bureau of Labor and Statistics the Consumer Price Index for Texas in 2006 was 190.1 and the national average was 201.6, a difference of 6 percent. Finally, in 2006-2007, the US Census Bureau ranked Texas 21st in Personal Income per Capita.

Texas maintains "interest lists" for people who are un-served and seeking services, or underserved and seeking additional (or a change in) services. As shown by Table 1,on the following page, as of June 30, 2008, DADS reported that 79,925 individuals were on the Interest List for six of seven HCBS waiver programs operated by the department. This number is unduplicated and does not include participants in the STAR+PLUS waiver program, with 37,187 of those individuals on the HCS Interest List alone.

The number of people with MR/RC on the DADS Interest List cannot be accurately determined.

Note that the table, in showing numbers on Interest Lists and totals served (i.e., 47,527 overall), includes people with MR/RC as well as others who may qualify due to other types of disabling conditions. We cannot determine how many of the numbers shown have MR/RC or other potentially qualifying conditions. We understand, however, that primarily individuals with MR/RC are served within the HCS and TxHmL waiver funded programs.

The CBA waiver serves the most people (21,050 people) and presently has the second largest interest list. 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 highest interest list. Further, projections show the HCS Interest List to grow to 40,000 individuals by 2010[11].

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 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 1: Individual 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 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

[11] Health and Human Services System, (2008). Strategic Plan 2009-13. *Chapter VI, 162.*

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

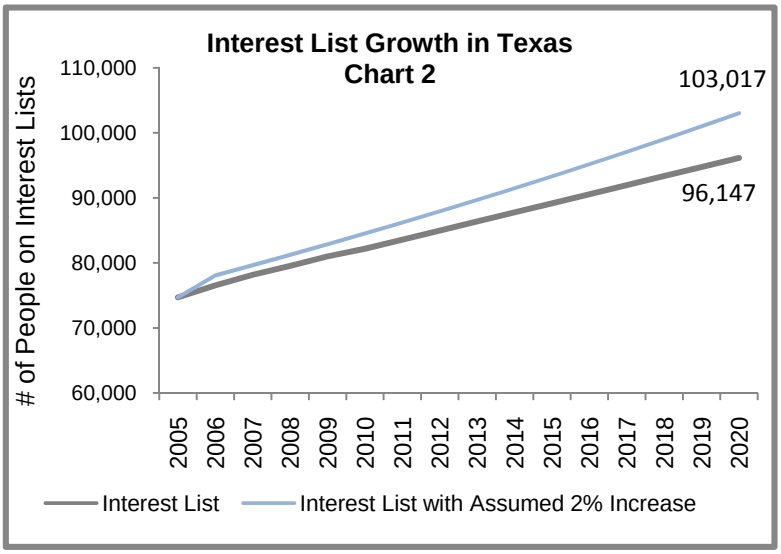
*Some people on the DBMD Interest List have reached the top of the list multiple times and declined services, yet choose to remain on the list. Additionally, the list includes individuals under the age of 18 not yet eligible to receive services.

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

If nothing is done to intervene, these numbers, no doubt, will grow larger due to the expected growth in the state population. Texas, for several decades, has been one of the fastest growing states in the nation, with no immediate end to this growth spurt in sight. According to the Texas State Data Center, the population of the state is likely to reach 25 million by 2010 and could reach 51.7 million by 2040.

According to the US Census Bureau, the Texas population is growing faster than the national population, as has happened every decade since Texas became a state. Between 1990 and 2007, the Texas population grew by 41 percent, from 17.0 million to 23.9 million. In comparison, during this same period, the United States population increased by only 21 percent, from 249 million to 302 million. 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, we find that in most states, waitlists grow at a rate greater than population growth alone. As can be seen in Chart 2, projected growth in the population of Texas also leads to growth in the Interest List. The 2006 Texas state population is estimated at 23,407,629. If nothing were done and if the Interest List were simply to keep pace with



population growth, it would likewise grow to 93,353 people by 2018, or 1,400[12] people per year. As mentioned earlier, based on the work HSRI has done in other states, and national comparisons, it is not uncommon to observe year-to-year increases in expressed demand of four percent and 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 new people per year.

Difficulties with Using Interest Lists to Assess Unmet Service Demand

All states struggle to keep pace with rising service demand. Typically, people who need residential services need them urgently. Without such supports their circumstances can deteriorate quickly, creating life crises for all involved. Likewise, individuals may have needs for other types of services (e.g., day supports, transportation) that, if left unattended, may also lead to serious life repercussions. As a result, being able to forecast demand and reduce waitlists are top priorities in most states.

When forecasting demand, several types of demand must be taken into account:

- Potential Demand refers to the total number of people who are or would be eligible for services. Calculating the exact prevalence rates of developmental disabilities is extraordinarily difficult. Definitions vary by state, with several states using their own instead of the federal definition. Further, the federal definition of developmental disabilities is not easily applied to children. Finally, national surveys of disability do not specifically target developmental disabilities in their inquiries. Still, HSRI conducted prevalence studies in several states (e.g. NM, OR, MI, AR, IA) and generally estimated prevalence to range between 1-2 percent. In Texas, this would amount to between approximately 234,076 and 468,152 people. State systems, however, serve only a small portion of those who may be eligible.
- Expressed - Met (Satisfied) Demand refers to those individuals served by the system. Some of these individuals may want services different from those they are currently receiving.
- Expressed-Unmet Demand refers to individuals who have come forward, requested services, are on waitlists and would accept services if offered. This group does not include individuals who seek services but would not accept them presently, if offered.
- Latent Demand refers to individuals who are interested in receiving services though not immediately. They may anticipate needing services in the near future, say within 3-5 years.
- Hidden Demand refers to individuals who would come forward if their life circumstances changed or if the services offered better matched their preferences.
- Compensated Demand refers to individuals whose needs are accommodated through other means and may never come forward for services.

[12] A rise in Interest Lists of 1,400 people per year is calculated by reviewing year-to-year growth in the list over the past five years and then projecting the growth forward, given the anticipated increase in population.

In this context, to plan effectively, state policy makers must have reliable and accurate information pertaining to the number of people who have requested services and need them presently (expressed unmet demand) and others who would likely seek services in the near future (latent demand). Doing so requires diligent data collection over several years to examine how demand trends behave over time.

At issue, always, is the accuracy of the information collected and the biases that may be inherent within the data. For example, in systems where resources are scarce individuals may rush to express a service need whether it is presently needed or not simply to "get on the list." Such behavior tends to overstate numbers on a waitlist.

In addition, states can confound their findings by establishing waitlists for pre-defined services that individuals may or may not want. For instance, 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 the true preference. Likewise, if an individual sought supported apartment living but can only choose between ICF/MR services or a community group home, then the forced choice would also be inaccurate. Put another way, in constructing waitlists states 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.

States can confound their findings by establishing waitlists for pre-defined services that individuals may or may not want. ... 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.

Other State Approaches to Address Waitlists

States approach issues like these differently and with varying success. Colorado, for example, works from a platform based in these principles:

- "A primary consideration of any requirement for waitlists must be fairness.
- The system needs to be reasonable, defensible to families and make sense to regular citizens.
- Persons waiting for services need to have the ability to move from one service area to another without 'penalty.'
- The system should make it unnecessary for people to be on a waitlist for years prior to wanting or needing the service. It would be desirable if only people who want services now or in the near future are on a waitlist."[13]

Based in these guiding principles, Colorado compiles a registry to track demand for services throughout the state. Likewise, Pennsylvania and Illinois gather information on service demand

[13] Smith, G. (1999). *Closing the gap: Addressing the needs of people with developmental disabilities waiting for supports*. Alexandria, VA: NASDDDS.

through the systematic use of a standardized protocol called the Prioritization of Urgency of Need for Services (PUNS). PUNS classifies individuals based on an assessment of how soon services must be provided or, in other words, the urgency of need. Individuals are classified as to whether the service need is an "emergency" (i.e., services are needed right away), "critical" (supports are needed within one year) or "planning" (services are needed within a 1-5 year time frame).

In contrast to practices like these, Texas seeks to assess service demand through the compilation of multiple "Interest Lists" associated with several Medicaid waiver options. There are four fundamental flaws with the approach:

1. Individuals can express an interest in receiving a service and be placed onto an Interest List without first being determined eligible for the service. Where waitlists are used elsewhere, states typically determine service eligibility before placing the individual on a list for particular waiver programs. In Texas, those who are on the Interest List are deemed as being "interested," but not necessarily eligible, for specific services. Further, we cannot determine if the individuals seeking services have MR/RC or some other disabling condition. Individuals seeking services are mixed together and reported in aggregate. By not determining eligibility initially, the Interest List is difficult to interpret. Planners cannot tell who on the list may actually be eligible for services, and so cannot accurately forecast the cost of addressing the Interest List.
2. Individuals can be on multiple interest lists, yielding various duplicated and unduplicated counts for services. Individuals may well seek to be placed on multiple lists, given the varying waiting times for service start up. As a result, planners cannot be certain of the number of people truly desirous of participating in particular waiver programs.
3. Data are not gathered on an individual's "urgency of need." Individuals instead are offered services generally on a "first come first serve" basis. Without such information, planners cannot systematically apply resources to those most in need or forecast such need going forward.
4. The range of waiver options and the protocol for being placed on interest lists presses individuals to get on interest lists whether they particularly need or want to participate in a particular waiver program. This dynamic may lead to an overstating of the numbers on a list, and just as importantly provide a skewed view of the services individuals actually seek.

Overall, while Texas has taken steps to gather information on those seeking services, referring again to Senate Bill 368, from a strategic perspective the resulting Interest Lists do not provide the data needed to understand present demand and forecast demand going forward.

Actions to Address Unmet Service Demand

The Texas leadership is aware of the pressing need for services. The Health and Human Services System Strategic Plan notes that:

> "These substantial Interest Lists and waiting lists continue to exist despite expanded state investments in addressing such lists in the last two legislative sessions.
>
> The continued existence of sizable Interest Lists and waiting lists for programs in the HHS System clearly illustrates the need for further substantial investments in these services. Even with the recent progress in expanding services, these lists do not necessarily decline in size, due to several factors. These factors include population growth, changing demographics (e.g., an aging population) that affect the demand for services, and the phenomenon that public awareness of expanding services sometimes encourages people who had given up hope of the availability of services to express an interest in receiving services. Nevertheless, regardless of how fast or whether the Interest Lists or waiting lists are reduced as services are expanded, additional investments in expanding services will greatly improve the health and quality of life of many more Texans with these critical needs" (p. 19-20 2008). [14]

In response, steps have been taken to accommodate service preferences or reach additional individuals needing support. For example:

- The 79th Legislature provided additional funds for the 2006-07 biennium making it possible to serve an additional 9,360 individuals through the Medicaid waiver programs, as well as, non-Medicaid-funded services.
- The 80th Legislature 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 will allow DADS to serve 8,902 more individuals, according to the following breakdown:

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

It is important to note that HSRI does not assume that all of these additional service openings will be filled by people with MR/RC. For the purposes of this report, we assume that only the openings allocated to HCS and In-Home Family Support can be determined to be filled by people with MR/RC[15] (n=4,050).

[14] Health and Human Services System, (2008). Strategic Plan 2009-13. *Chapter III, 78.*

[15] Though the CLASS waiver is open to serve individuals with mental retardation, it is important to note that HSRI is unable to identify the number served with mental retardation compared to related conditions.

These actions, no doubt, are welcome among the thousands seeking services in Texas. Still, they are insufficient for addressing present un-met service demand. The new individuals served represent only a portion of those in need. Recall that unduplicated counts of interest lists (excluding the STAR+PLUS waiver count) totals 79,925 people. Moreover, each year new individuals come forward seeking services. If this rate is pegged simply to population growth, we estimate that the Interest List would grow at about 1,400[16] people per year. In addition, using service utilization metrics based on experiences in other states, we noted (see Chart 1) that for Texas to reach the national average of people served per 100,000 in 2006, it would need to enroll roughly 19,662 more people in Medicaid waiver and other state-funded services (Lakin et. al., 2007).

Overall, we find that 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. Simply put, individuals cannot count on getting services right away. In the meantime, their situation may deteriorate and caregivers can buckle under the stress of long-term unassisted care giving.

This shortfall in system capacity has additional ramifications. People are limited to receiving services in settings where there are openings rather than with agencies that they prefer. This undermines individual choice. Also, 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 over behavioral challenges that many other states manage in their community services systems.

Conclusion

Texas is not alone in grappling with the steady increase in the demand for MR/RC services. Gaps between system capacity and service demand are present in nearly every state, although the relative size of the gap varies considerably state-to-state. Other states (e.g., OR, CT, KY, NY and PA) have adopted multi-year plans to reduce their waitlists. There is no doubt that furnishing services to individuals with mental retardation and related conditions and families who have urgent needs with reasonable promptness is a major challenge facing all states.

Yet, the present gap in Texas between system capacity and service demand is extremely large. While the protocol for compiling the Interest Lists may be flawed, the sheer magnitude of the lists is alarming. Our review suggests that due to the increase in services available and the greater increase in the Interest List, service demand as tabulated by the present protocol is growing at a rate of about 1,400 people each year, and will likely grow more rapidly than what population growth alone would predict. Add to this information comparisons between service

[16] A rise in Interest Lists of 1,400 people per year is calculated by reviewing year-to-year growth in the list over the past five years and then projecting the growth forward, given the anticipated increase in population.

utilization rates in Texas and elsewhere. These comparisons illustrate that Texas serves fewer people than are served in other states

Taking these data together, it is reasonable to conclude that there is a large cohort of people with mental retardation and related conditions in Texas who have urgent or critical unmet needs. Texas has recently sought to accommodate unmet service demand by allocating funds for system expansion. These efforts have certainly helped thousands more people. These allocations, however, are insufficient. In addition, Texas presently has no long-range plan for closing the gap between system capacity and service demand. No targets have been established to secure a year-by-year reduction in this gap. Nor does Texas employ an accurate and reliable means for tracking demand over time. Absent such strategies, there is every danger that the current gap will worsen.

[Page left intentionally blank for double-sided copying]

Benchmark #2: Serving Individuals in the Most Integrated Setting

Assessment: Texas relies on large congregate care facilities to serve people with mental retardation and related conditions to an extraordinary extent. Opportunities for individuals to receive services in the most integrated setting are abridged.

Background

In its landmark *Olmstead v. LC & EW* decision, the United States Supreme Court affirmed that, under Title II of the Americans with Disabilities Act, states are obliged to operate their programs for people with disabilities in a manner that ensures that individuals receive services in the *most integrated setting* appropriate to their needs. The *Olmstead* decision established a clear benchmark for the operation of public programs for people with disabilities.

As a practical matter, "most integrated setting" means that individuals are supported in community settings that are as similar as possible to typical living arrangements for people without disabilities. The *Olmstead* decision sent the strong message that people should not be unnecessarily institutionalized. The decision also established affirmative expectations for the transition of people from institutional settings to the community.

Twenty years ago in the developmental disabilities field, the majority of individuals were served in large congregate settings (i.e., settings where seven or more people are served). According to RTC, in 1987, only 27.3 percent of all people who received residential services were supported in living arrangements for six or fewer people. About one-half of all individuals were served in very large settings accommodating sixteen or more individuals, including 95,000 people who resided in very large, state-operated public institutions.

The contemporary benchmark for supporting people with developmental disabilities in the most integrated setting is a living arrangement that supports six or fewer individuals in the community.

By 2006, 70.5 percent of all people nationwide were supported in living arrangements for six or fewer people. In eleven states (AK, AZ, HI, IN, ME, MD, NV, NH, NM, RI, VT), 90 percent or more of individuals were served in small living arrangements. Nationwide, only 15.3 percent of all people were served in very large settings with sixteen or more beds. The number of people served in very large public institutions fell to under 39,000 in 2006. The average community living arrangement supported 2.7 individuals versus 7.5 people in 1987 (Lakin et. Al. 2007). The steady, marked decline in the use of large and very large residential settings over the past twenty years is the product of several factors, including litigation focused on sub-standard conditions in very large public facilities, the expansion of community services, and a community integration imperative that presses for people to be given opportunity to live life in the community with the support they need much like any other citizen.

Today, in the United States, the best practice benchmark for supporting people with developmental disabilities in the most integrated setting is to employ settings where six and frequently fewer people share a living arrangement in community-based settings, not ICF/MR facilities. Most states have reconfigured their service systems so that the vast majority of individuals are now supported in settings that meet this benchmark.

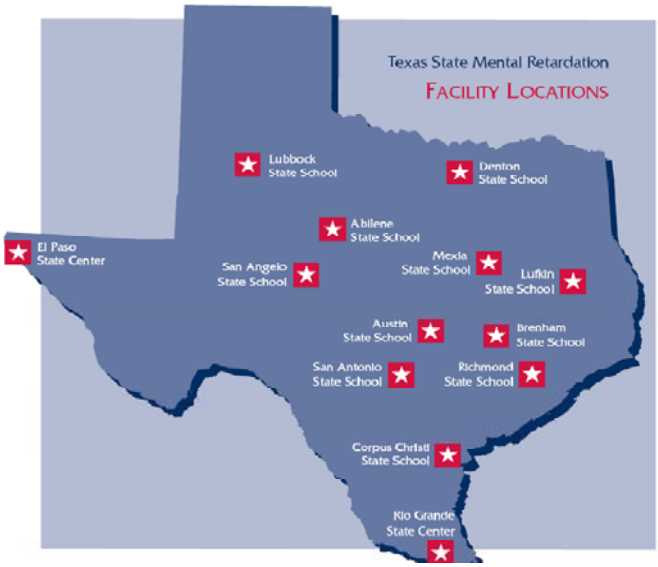
Texas Status

In 2006, 21,720 people received residential services in Texas. In supporting these individuals, Texas relies much more heavily on large congregate care facilities than most states. Moreover, the state continues to place children in state schools/centers and to rely on ICF/MR services options, even within services used to support smaller groups of people. While Texas is taking action to alter this pattern, the pace of such change is slow.

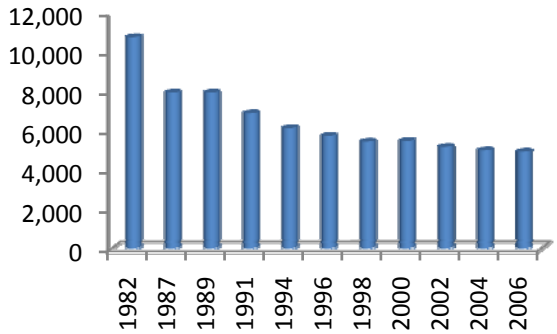
Reliance on Large Congregate Care Facilities

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



Number of People Living in State Schools/Centers from 1982-2006 in Texas
Chart 3

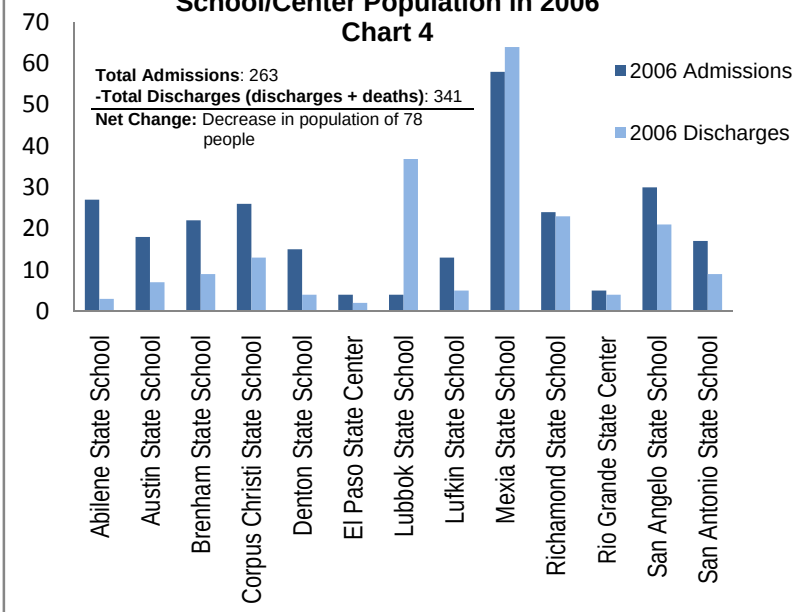


R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006

As illustrated by Chart 3, Texas has relocated individuals from state schools/ centers into community alternatives, reducing the population from 7,933 in 1989 to 4,924 in 2006. Still, since 1989, Texas has been considerably slower at reducing the use of large facilities, such as the state schools/centers when compared to national trends. Since 1989, Texas reduced the census in large state facilities by 32.6 percent compared to 53.9 percent nationally.

As can be seen in Chart 4, the net change in state school/center population did decrease by 78 people. However, when comparing only admissions and discharges (not including deaths) there was a net increase in population of 55 people. The chart also shows that all 13 state schools/centers still actively admit individuals. Mexia State School had the largest admission of 58 people, but also the largest discharge of 64 people.

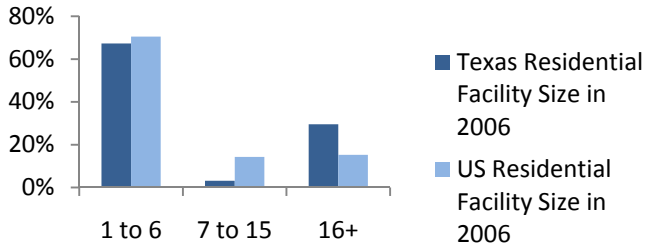
Admissions and Discharges of Texas State School/Center Population in 2006
Chart 4



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

Chart 5 shows the percentage of people living in residential settings of three size ranges. As illustrated, the state generally funds a bi-modal residential system. In 2006, people receiving residential services generally lived in housing options of 1-6 people (n=14,623), or in facilities housing 16 or more people (n=6,414). Relatively few people (n=682) lived in intermediate-size residences of 7-15 people.

Percentage of Individuals by Setting Size
Chart 5



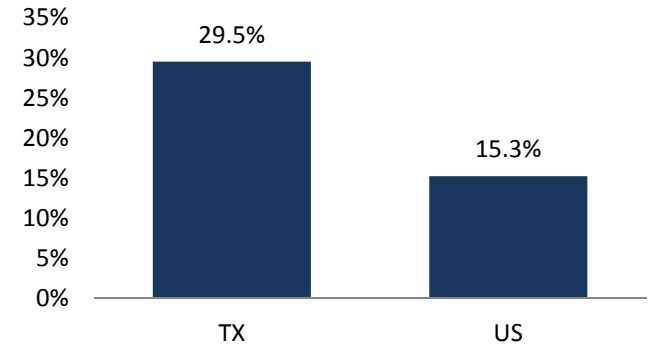
R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006

Based on these figures, 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 6).

Overall, such performance does not compare well with practices in other states. Consider that:

- Texas is the 7th highest ranking in the nation in percentage of people served in residential facilities with 16 or more beds.

Percentage of Individuals Living in Large Settings (16+) Compared to Total Population Served
Chart 6



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

- Texas ranks 8th highest in the nation in people served in state institutions per 100,000 population.
- In 2006, Texas made up nearly 13 percent of the total number of individuals living in state institutions, nationally.
- Overall, Texas served twice as many individuals in large settings as the national average in 2006, as can be seen in Chart 6.
- Texas continues to invest heavily in its state schools/centers with a FY 2008-2009 biennium appropriation of $1.04 billion. This appropriation includes funding for DADS to hire 1,690 new FTEs, including 1,211 medical professional and direct care positions and 479 positions to support state school/center operations. DADS reports that 1,139 of the new staff positions had been filled by mid-August, 2008.

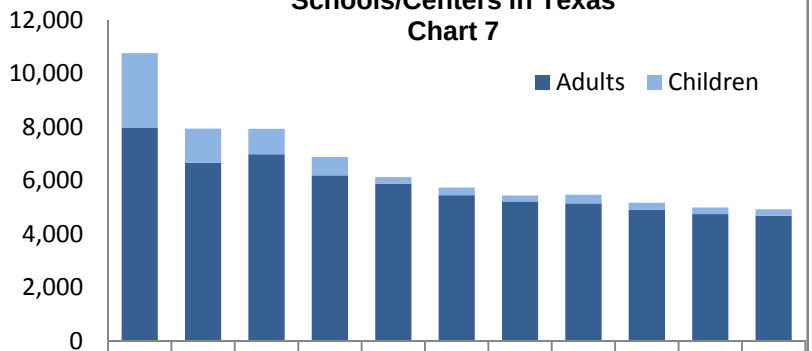
Placements of Children into State Schools/Centers

Though the state has closed two state schools (both in 1996), in 2006, there were 263 new admissions into state schools/centers in addition to 208 discharges and 133 deaths, yielding an overall modest census reduction of 78 people.

The population of children in state schools/centers has remained virtually constant since 1994 (see Chart 7). In 2006, roughly 5 percent of the residents in state schools were children, ages 0-21. This amounts to 246 children in state schools/centers, which places Texas roughly one percent (1%) higher than the national average of child occupancy in state institutions.

Yet, in 2006, 43 percent (114 out of 263) new of admissions into Texas state schools/centers were children. This is twice the national average of 21.7 percent. And as shown by Chart 8, many of these children have no to moderate levels of need.

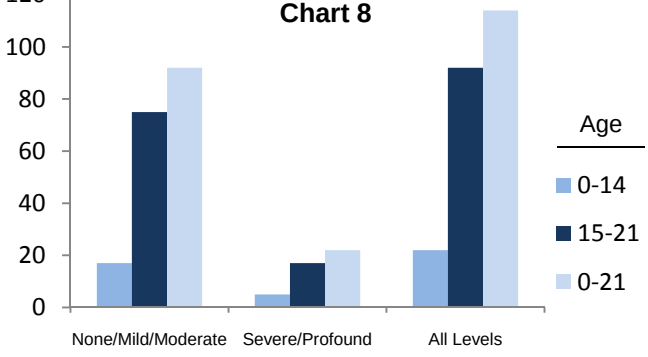
Distribution of Children and Adults Living in State Schools/Centers in Texas
Chart 7



	1982	1987	1989	1991	1994	1996	1998	2000	2002	2004	2006
Children	2,798	1,270	952	688	245	287	217	328	258	250	246
Adults	7,963	6,666	6,981	6,192	5,879	5,448	5,219	5,142	4,911	4,741	4,678

R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006
*Numbers based on end of year totals, not monthlyaverages

Admissions into State Schools/Centers by Age and Level of Need in Texas
Chart 8



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

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 12 children/youth moved out of state schools and into community settings.

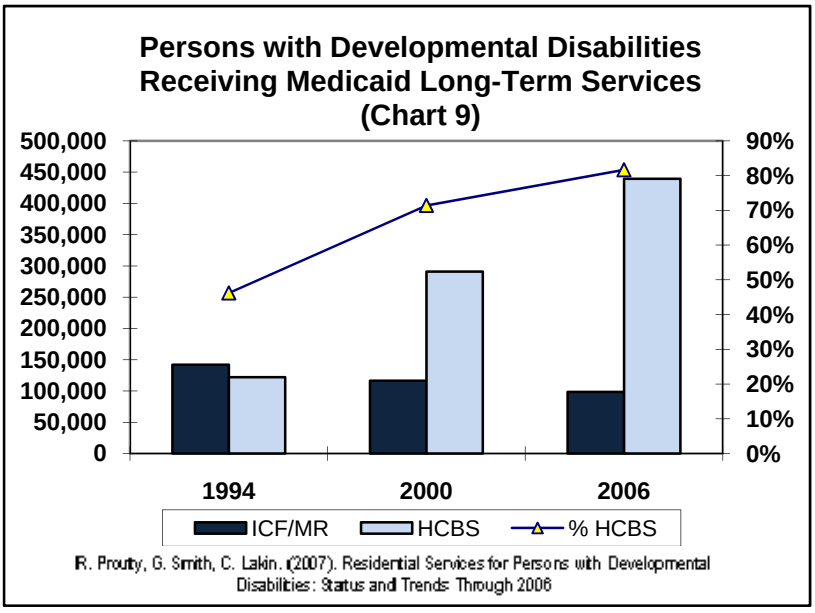
The workgroup listed five main pressures for increased admissions among children:

- Previous reductions in community-based services due to cuts in General Revenue Allocations (GRA) to Mental Retardation Authorities.
- Continued lack of timely available appropriate alternatives due to long waiver interest lists.
- Lack of comprehensive and readily available supports for families of children with challenging behavior or co-occurring mental health diagnoses, sometimes leading to court involvement.
- Forensic/court-ordered placement.
- Parental choice, given the alternatives available.

We recognize that the legislature has taken some action on this issue. Senate Bill 368 was passed during the 77th Texas Legislature Regular Session (2001) that requires all individuals under the age of 22 who reside at a state school/ center to be placed on an Interest List. The new provision is meant to expedite the placement of children out of state run schools/centers. Yet, by allowing children to be admitted into the state schools/centers, the state continues to replenish the population making it almost impossible transition away from the state's reliance on large congregate facilities.

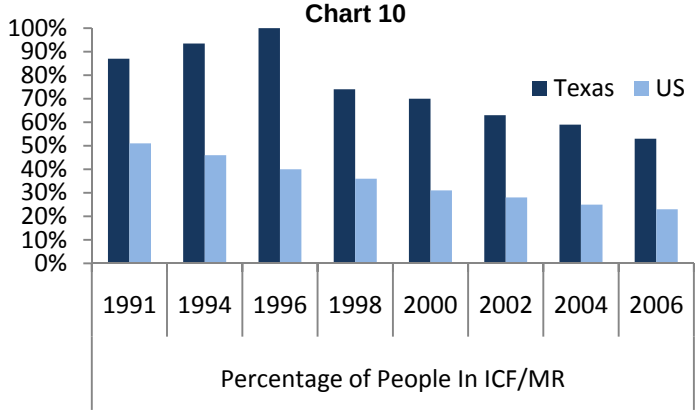
Reliance on ICF/MR Service Options

In most other states, people with extensive support needs are served by HCBS services in the community. 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 state residential institutions for people with developmental disabilities at all. The trend is reflected by Chart 9 showing a steady decrease in ICF/MR use nationally and dramatic increases in the use of HCBS options.



In Texas, there is relatively modest use of HCBS waiver funding. Instead, the state continues to support larger residences licensed as ICFs/MR, as can be seen in Chart 10. Trend lines show that many states have come to rely almost entirely on HCBS services and very little on ICFs/MR. In 2006, nationally, 83.0 percent of those served in developmental disability systems participated in an HCBS waiver program, compared to 54.7 percent in Texas. Further, the trend nationally to transition away from ICFs/MR gained momentum in the 1990's once waiver use became more common. Texas has not kept pace with this national trend.

Individuals Living In ICFs/MR As a Percentage of theTotal Individuals in Residential Facilities
Chart 10

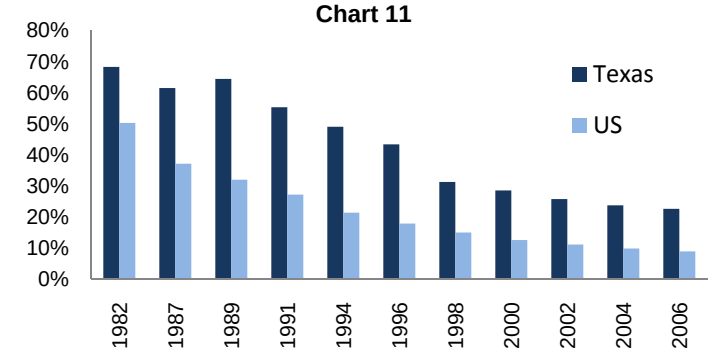


R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006

Consider that:

- As illustrated by Chart 11, the percentage of people served in large state run institutions has steadily decreased nationally and in Texas since 1982. Texas, however, has always served a greater percentage of people in such facilities than the national average. Further, in 1982 the national rate of 50 percent was 3/4 of the rate in Texas. And in 2006, the national rate of 9 percent was 2/5 of the rate in Texas. When it comes to the percentage of people residing in state institutions, the gap between Texas and the rest of the nation has continued to widen.

People Served in State Run Institutions as a Percentage of Total People Served in Residential Settings
Chart 11



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

- Texas still has more than twice as many individuals living in ICFs/MR than is the national average.

- Consider again the percentage of people living in residential settings of various sizes (See Chart 5). Of those living in settings of 1-6 individuals, 31 percent (4,519[17]out of 14,623) are in ICFs/MR, compared to 6 percent nationally.
- Texas has made very little progress in transitioning away from ICFs/MR over the past 20 years. In 2007, 6,608 individuals lived in ICFs/MR; this is a very small change from the 6,649 individuals in 1987[18].

Level of Need

Texas uses the Inventory for Client and Agency Planning (ICAP) to assess individual functional characteristics and to, in turn, arrive at a level of service and dollar allocation to provide needed support. Using an assessment tool allows a state to more accurately determine a person's level of need and resource requirements. It is often argued that those with the most significant support needs should be served in more costly and service intensive options, such as ICFs/MR.

Texas assigns an individual to one of five Level of Need (LON) categories that are based on an individual's scores generated from ICAP scores. An individual's ICAP score may be adjusted upward to account for special medical or behavioral conditions. DADS defines the LON categories as follows:

- Intermittent: This individual does not need 24-hour care, demonstrates very independent living skills, with no significant maladaptive behaviors noted. Staff intervention is typically reminders with some guidance required.
- Limited: Skill level ranges from fairly independent to some personal care reminders/guidance needed. Behavior intervention or hands-on personal care assistance may be required. Individuals may have psychiatric disorders, which may be fairly well controlled with medication. Staff intervention ranges from reminders to 24-hour guidance and support.
- Extensive: Skill level ranges from no self-help skills (due to physical limitations) to demonstrating some basic self-help skills. Staff intervention includes personal care assistance utilizing hands-on techniques and/or implementation of behavioral interventions.
- Pervasive: These individuals may have some basic self-help skills and demonstrate challenging behavior requiring intervention. Individuals at this level may even require one-on-one supervision or care for safety reasons, but not 16 hours a day.

Pervasive Plus: These individuals require one-on-one supervision within arm's length of the individual during all waking hours due to their life-threatening behavior

[17] 4,509 are in non-state 1-6 bed ICFs/MR and 10 are in state run 1-6 bed ICFs/MR. R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006

[18] Texas Department of Aging and Disability Services. (April 25, 2008). *Letter of Response to 02/15/2008 House Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services*

Individuals Served by Service Type and Their Level of Need

Table 3

Level of Need	State Schools		Community ICF/MR		Total ICF/MR		HCS		TxHmL		Total Waiver	
	People	Percent	People	Percent	People	Percent	People	Percent	People	Percent	People	Percent
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

As shown by Table 3, it appears that in Texas there is a modest tendency to support people with more significant disabilities in ICF/MR settings. The trending, however, is not absolute. The percentage of people with a Limited LON served in either ICFs/MR or waivers is roughly equivalent (44.8 percent ICFs/MR to 42.9 percent in waivers). However, 2,768 individuals (24.8 percent) of all those served in community waivers have extensive, pervasive or pervasive plus support needs compared to 38.36 percent or 1,085 people in ICFs/MR. Meanwhile, 13.5 percent or 1,573 of those with intermittent needs are served in ICFs/MR settings, compared to 32.31 percent or 3,605 in waivers. These data raise issues over why so many people with intermittent (low levels) needs are in ICFs/MR. Likewise the data show that community-based waivers serve significant numbers of people with extensive (moderate to high) levels of need.

Actions to Alter Present Patterns

Texas is taking some steps to alter this pattern of reliance on large facilities to deliver residential services. In 2002, for example, Governor Rick Perry signed Executive Order RP13. This order was meant to further develop the Promoting Independence Plan (Olmstead) within Texas. The aim of the executive order was to remove barriers to transitioning children and adults from institutions into community living settings.

More recently, in fiscal year (FY) 2007, DADS began to refer more individuals living in state schools/centers to community settings. In the last six months of FY 2007, DADS referred 127 state school residents to community settings, compared with 48 referrals in the first six months of FY 2007. That trend continued in the first six months of FY 2008, when DADS referred 125 state school/center residents to community settings.

Still, it is increasingly apparent that Texas is not moving fast enough to alter present service patterns. Consider the following passages in the July 2008 Texas State Auditor Report 08-039:

> "Intermediate Care Facilities for people with Mental Retardation (ICF/MR) is a state- and federally-funded program under Medicaid. The ICF/MR program provides residential care and treatment for people with mental retardation or severe related conditions. As of Aug. 31, 2007, there were 4,884 residents in the state schools. There are more than 800 community ICF/MR facilities in Texas, with a population of 6,620 at the end of August 2007. Fiscal year 2008 appropriations to state schools (9/07-8/08) totaled $518.9 million, compared to $351.5 million for community ICF/MR facilities.
>
> The average daily cost to serve a state school resident in FY 2006 was about $335 compared to about $165 for community ICF/MR facilities. The State Auditor's Office found that greater costs in state schools are driven by higher costs in direct care staffing, administration and comprehensive medical care" (page 3).

The July 2008 Texas State Auditor's report further notes that:

> "DADS should improve the 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's documentation often does not include information about the individuals' awareness of available community living options. Documenting the individuals' awareness of living options is significant given that 52 percent of state school/center residents had expressed no preference for specific living arrangements as of the end of fiscal year 2007. Though ICF/MR settings are more integrated than state schools/centers, they are less integrated than HCBS community waiver services.
>
> In addition, the summary of the report states that DADS should improve its monitoring to help ensure that (a) it discusses community living options adequately with individuals; and (b) it has sound and sufficiently documented reasons for its decisions about individuals' living arrangements. DADS's monitoring efforts also are hindered by weaknesses in the automated case management system that contains information about individuals' needs and preferences. These issues are significant because Texas has the nation's largest population of individuals receiving mental retardation services living in large, state-run institutions." (page 2)

Conclusion

By all measures, Texas relies more heavily on state schools/centers and privately-operated ICFs/MR than most other states. In fact, its investment is extraordinary. Further, in spite of its actions to decrease such reliance, stronger actions have been taken to maintain and buttress its investment in ICF/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.

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 saps resources that might be invested in more integrated community options, weakening the community system and its potential for serving a wider range of individuals.

Benchmark #3: Economy and Efficiency

Assessment: Texas' financial level of effort in supporting services for people with mental retardation and related conditions is subpar. The present system overemphasizes the use of costly service models.

Background

There is no doubt that appropriately supporting people with developmental disabilities requires a substantial financial commitment on the part of a state. Developmental disabilities are lifelong. People with developmental disabilities have significant functional impairments and many require day-by-day services and supports throughout their life. Developmental disabilities services are among the most-costly long-term services. Therefore, it is important that a state employ effective financial management strategies and practices that promote economy and efficiency in the delivery of services.

There is significant variability among the states with respect to their level of financial effort in supporting services for people with developmental disabilities. State fiscal capacity varies due to underlying economic and other differences. However, all other things being equal, states where there is a relatively low level of financial effort in support of developmental disabilities services usually have large waitlists for services. Service providers struggle to survive in the face of low payment rates that, in turn, result in major problems in meeting basic quality standards and in workforce stability.

Effective financial management of developmental disabilities services is complex and multi-faceted. Key facets include:

- **Managing the Use of Federal Medicaid Financing**. To the extent that a state can qualify services for federal Medicaid financing, it can stretch its own dollars to serve more people with developmental disabilities. In developmental disabilities services, Medicaid is the principal source of federal financial assistance to help states finance services. In general, maximizing federal Medicaid dollars is a practical necessity in all states. Medicaid financing can play a major role in underwriting the expansion of system capacity to meet service demand. However, Medicaid is a complex program that operates under federal parameters. It presents to states alternative pathways for securing federal dollars to pay for services. As a consequence, there are major differences among the states in their utilization of Medicaid dollars to finance services.
- **Promoting Economical Service Delivery**. It is in a state's best interest to channel service demand into lower cost, more economical service delivery alternatives. Some models of developmental disabilities service delivery are extremely costly due to regulatory and other requirements. For example, in 2006, the average nationwide cost of serving an individual in a public or private Intermediate Care Facility for the Mentally Retarded (ICF/MR) was $124,969. In contrast, the average cost of supporting a person through the Medicaid HCBS waiver program was $39,818. In an environment of limited

budgets, reliance on high cost service models obviously will foreshorten a state's ability to meet current and future service demand.

- **Purchase of Service**. Government is the principal purchaser of developmental disabilities services. Consequently, state purchase-of-service policies and practices have major market place ramifications. The rates that a state pays for services affect the viability, quality and availability of services. For example, if state payments for personal assistance services are based on below market wage rates, then individuals and families will experience major difficulties in locating workers who are willing to provide supports. To the extent that state payments are not based on a realistic appraisal of legitimate provider costs, quality will suffer and there will be an insufficient supply of providers to support individuals.

How a state addresses these facets of financial management of developmental disabilities services has major consequences for the state's ability to support its citizens with developmental disabilities.

Among the states, there have been several noteworthy national trends and developments in the financial management of developmental disabilities services. With respect to Medicaid financing of developmental disabilities services, the trend for more than 20 years has been for states to concentrate on expanding HCBS waiver programs for people with developmental disabilities while concurrently reducing the utilization of more costly ICF/MR services.

Chart 9 (shown earlier) illustrates the number of people nationally served in ICFs/MR and through HCBS waivers for people with developmental disabilities. As shown, ICF/MR utilization has been declining since 1994. A substantial proportion of the reduction in ICF/MR utilization is the result of the ongoing downsizing and closure of very large state-operated institutions. However, about 40 percent of the reduction in ICF/MR utilization stems from a decline in the number of people served in private, non-state run ICF/MR services. In contrast, the number of people served in HCBS waiver programs has grown substantially, nationwide. In 2006, 83.0 percent of the 577,607 people with developmental disabilities nationwide who received Medicaid-funded long-term services were served through HCBS waiver programs. As previously noted, the de-emphasis by states on ICF/MR services in favor of waiver services is due in significant part to the very high costs of ICF/MR services and the relatively lower costs of waiver HCBS.

Between 2000 and 2006, states increased the overall number of individuals with developmental disabilities in the United States receiving Medicaid-funded long-term services by a little over one-third. In most states, this expansion was fueled by more aggressive leveraging of community developmental disabilities services to capture increased federal Medicaid dollars. Leveraging, including converting community-based ICFs/MR to waiver funding, helped states to weather the downturn in state revenues and, in some cases, expand services to additional individuals. The HCBS waiver program now is the principal source of federal financial assistance to states to underwrite the costs of specialized developmental disabilities services. In terms of expenditures, in 2006 federal-state spending for HCBS waiver services accounted

for 59.5 percent of the $30.8 billion in Medicaid spending nationwide for specialized developmental disabilities long-term services.

States are launching supports waivers to channel demand away from very costly 24/7 residential services.

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. Faced with a rapidly rising demand for developmental disabilities services, most states simply cannot afford to respond by scaling up comprehensive services. Instead, many states have launched what are termed "supports waivers" that operate under fixed dollar cost limits and pay for services that complement family care giving.

For example, confronted by a lengthy waiting list, Oregon has implemented a Medicaid HCBS supports waiver program that provides a foundation benefit package to eligible individuals and families. Individuals and families can exercise considerable decision-making authority in selecting the waiver-funded services and supports that will best meet their needs. The supports waiver program has enabled Oregon to channel demand away from high cost comprehensive services. As a result, Oregon has been able to reduce its overall per person HCBS waiver costs from $39,000 in 2002 to $37,746 in 2006 and expand the number of people receiving services by 35 percent. Oregon expects to eliminate its community waiting list by 2009 through the further expansion of its supports waiver program. There are sixteen other states[19] that have designed and implemented similar types of supports waivers for people with developmental disabilities.

Another important development has been the emergence of new approaches to purchasing services. Several states have implemented or are designing relatively sophisticated rate-setting systems. These systems are designed to ensure that payments for services match up with underlying service delivery requirements along with provider agency costs in securing labor and other inputs in the market place. For example, Arizona has implemented a rate system that takes into account market wages, difficulty of care, geographic and other factors that affect provider costs. States also are abandoning their conventional purchase of service systems in favor of umbrella service authorization limits that are based on the usual and customary costs of serving people with developmental disabilities who have similar support needs and life circumstances. For example, Connecticut has designed a system that establishes cost limits based on statistically significant factors that affect the overall costs of supporting individuals. States are moving toward greater standardization of payment rates based on market factors and assessed individual needs. Matching dollars to the support needs of individuals and using standardization promotes efficiency and encourages the entry of new providers into the market place.

[19] Alabama, Colorado, Connecticut, Florida, Georgia, Indiana, Louisiana, Missouri, Montana, Nebraska, Oklahoma, Pennsylvania, South Dakota, Tennessee, Texas and Washington.

Texas Status

In comparison to the nation and other states, Texas funding for MR/RC services is well below the national average. This is evident through review of its overall fiscal effort and spending on Medicaid services. Moreover, the pattern of spending in Texas, which emphasizes the use of more expensive ICF/MR services, is inefficient.

Financial Level of Effort

There are two ways to measure a state's overall level of financial effort in supporting its citizens with mental retardation and related conditions:

- **Fiscal Effort**. This method appraises a state's level of financial effort by measuring its overall spending for developmental disabilities services relative to state personal income. This method takes into account underlying differences in the relative strength of state economies and therefore a state's capacity to fund developmental disabilities services. All other things being equal, the higher a state's personal income, the greater a state's capability to fund developmental disabilities services. By this measure, the Coleman Institute in 2006 ranked Texas 49th among the states with respect to its overall level of fiscal effort. Among the 13 comparison states, Georgia was the only state to rank lower at 50th. In 2006 and 2004, Texas fiscal effort was 51 percent below the nationwide average. Considering only community services, Texas ranked 50th among the states.

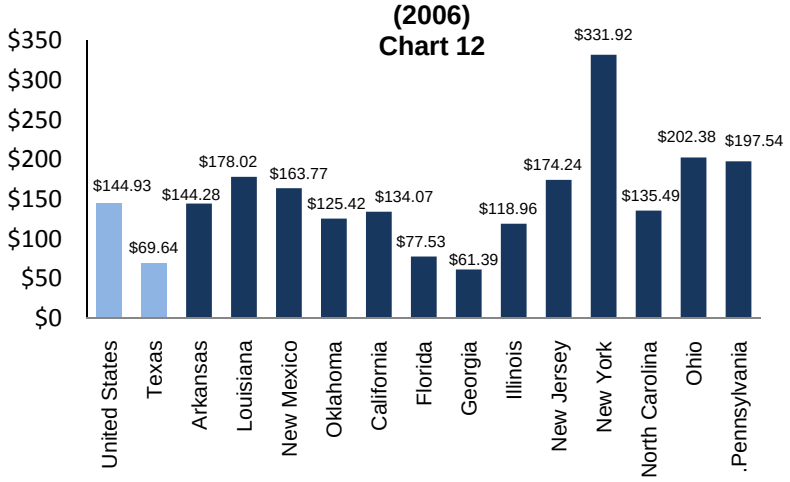
Ranking of Overall Fiscal Effort (Table 4)

State	Ranking
TX	49
AR	16
LA	8
NM	13
OK	29
CA	37
FL	47
GA	50
IL	40
NC	25
NJ	31
NY	2
OH	9
PA	14

Braddock, D. et al. (2008). *The State of the States in Developmental Disabilities: 2008* . Boulder, Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

- **Expenditures per Citizen**. Another way to measure a state's level of financial effort is its expenditures per citizen – that is, total MR/RC expenditures divided by the state's population. Chart 12 compares Texas' expenditures per citizen to the nation as a whole and

Developmental Disabilites Spending Per Citizen (2006)
Chart 12



Braddock, D. et al. (2008). *The State of the States in Developmental Disabilities: 2008*. Boulder, Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

selected other states. In 2006, Texas spent $69.64 per citizen for MR/RC services. The nationwide average ($144.93 per citizen) was more than double that figure. Texas' 2006 spending for MR/RC services would have had to have been $1.762 billion higher in 2006 to match the nationwide average. As also can be seen, nearly all the other selected states exhibited a stronger level of financial effort than Texas[20].

Measured by either fashion, Texas' level of financial effort for MR/RC services has been comparatively meager. It is worth noting that, in 2006-2007, the U.S. Census Bureau ranked Texas 21st in Personal Income per Capita. The state's relatively low level of financial effort has important ramifications regarding the resources available per person and associated provider service reimbursement rates.

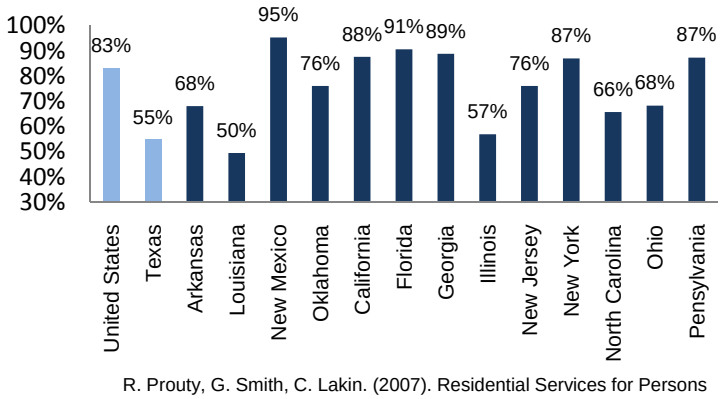
Utilization of Medicaid Financing

In 1996, 81 percent of funding was pegged to Medicaid with the proportion growing to 89 percent in 2006. This was achieved principally by shifting services to the HCBS waiver program. However, these additional federal Medicaid dollars were used to sustain current service levels rather than expand services.

With respect to Medicaid financing of MR/RC services, Texas is noteworthy in two respects:

- A larger proportion of individuals in Texas who receive Medicaid long-term services are served in ICFs/MR (state schools/centers) than is typical nationwide or in most states. According to the RTC, in 2006, 54.7 percent of individuals were supported through the HCBS waiver in Texas versus 83.0 percent nationwide. As can be seen from Chart 13, all the other selected states, except for Louisiana, served a higher proportion of individuals through the HCBS waiver programs than Texas. The steps taken by HHS to capture additional federal Medicaid dollars have resulted in an increase in the number and proportion of people participating in the Texas HCBS waiver programs. However, this proportion is still well below the national norm.

% of Medicaid Beneficiaries Receiving HCBS (2006)
Chart 13

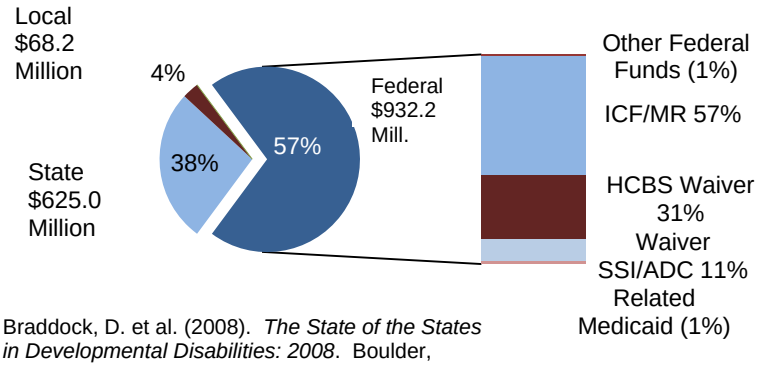


R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006

[20] Note: In the second quarter of 2006, Texas had the third lowest cost of living in the United States (surveyed by ACCRA). Missouri Economic and Research Information derives the cost of living index for each state by averaging the indices of participating cities and metropolitan areas in that state. Texas' cost of living for the second quarter of 2006 was 88.9. The U.S. average is 100.0.

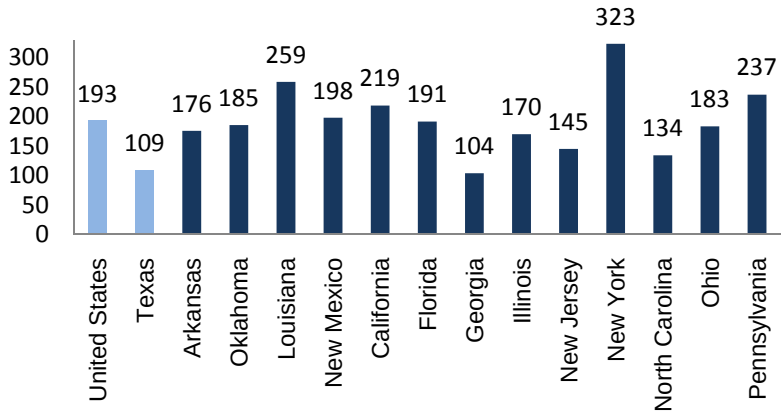
- The second major difference is that Texas expends a greater proportion of its Medicaid dollars on ICF/MR services than the nation as a whole or most other states. According to the Coleman Institute, in 2006 (as shown by Chart 14), 57 percent of the $1.63 billion in Texas Medicaid spending for people with MR/RC underwrote ICF/MR services, compared to 29 percent nationally. In 2006, nationwide 47 percent of Medicaid spending for people with MR/RC was used to pay for home and community-based waiver services, compared to 31 percent in Texas.

MR/RC Revenue Sources (2006)
Chart 14



Braddock, D. et al. (2008). *The State of the States in Developmental Disabilities: 2008*. Boulder, Colorado: Department of Psychiatry and Coleman Institute for Cognitive Disabilities.

People Receiving Medicaid Services per 100,000 (2006)
Chart 15



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

Overall, Texas Medicaid spending for MR/RC services lags behind the national average. In 2006, Texas Medicaid spending per citizen for MR/RC services was 47 percent below the nationwide average.

Texas also lags behind the rest of the nation and most other selected states in the number of people who receive Medicaid MR/RC services. Chart 15 shows the number of individuals who received Medicaid ICF/MR or HCBS waiver services per 100,000 people in the population during 2006. Texas furnished Medicaid MR/RC services at a rate that was 43.3 percent below the nationwide average. Several other states (e.g., CA, LA, and NY) furnished Medicaid developmental disabilities services at an appreciably higher rate, relative to state population, than Texas.

While Texas has improved its performance in securing federal Medicaid dollars for MR/RC, the state lags behind the national norm and most of the other selected states in the proportion of dollars expended on HCBS waiver services, the proportional amount spent on Medicaid MR/RC services, and the number of individuals who receive such services. Texas is unusual for the high proportion of Medicaid dollars that are used to underwrite ICF/MR services.

Inefficient Spending

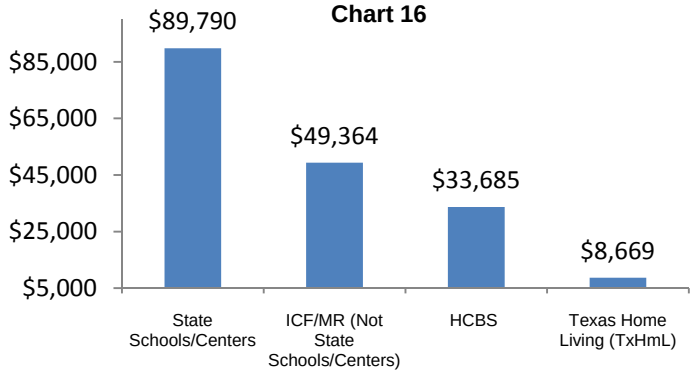
Texas concentrates its funding for MR/RC services on higher cost services furnished in state schools/centers and community ICFs/MR. Chart 16 shows 2006 annual per person costs for various types of services in Texas. This chart is based on figures provided by DADS and RTC. As can be seen, the cost of serving a person in a state school/center was about twice the cost of supporting a person in other types of (privately operated) ICFs/MR. Per person expenditures for HCBS services are lower than ICF/MR costs. Texas Home Living (TxHmL) services are the least costly. However, only a small proportion of individuals receive services through the TxHmL waiver program. Table 5 gives a brief comparison of services available in each of the two waivers (HCS and TxHmL).

Focus on Texas Home Living (TxHmL)

Texas' supports waiver, called Texas Home Living, allows for a low cost solution to providing home and community based services. The 2006 annual average cost was $8,669, and it served 1,933 people. The TxHmL Waiver was implemented in 2004 to provide a limited array of services and supports to individuals who are often on the general interest list for waiver services. The program was initially designed to be self-financing. That is, the enrollment of individuals already receiving state General Revenue waiver-like services would permit using those state funds to draw federal match for waiver services. Reductions in appropriations for GR funded services has curtailed expansion of TxHmL through conversions.

The TxHmL Waiver targets people with mental retardation who meet Level 1 ICF/MR level of care criteria. Such individuals have less intensive needs than other people who have a higher level of need. TxHmL offers day and other supports that complement natural and other community supports. Access to the waiver is through the state's network of Mental Retardation Authorities (MRAs). MRAs conduct intake and furnish service coordination, including assisting individuals and families in developing service plans. Individuals who accept TxHmL waiver services retain their position on the HCS waiting list. That is, individuals who receive TxHmL waiver services may transfer to the HCS waiver when their names rise to the top of the HCS list and slots are available.

2006 Expenditures Per Person in Texas
Chart 16



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

Comparison of Services Provided (Table 5)

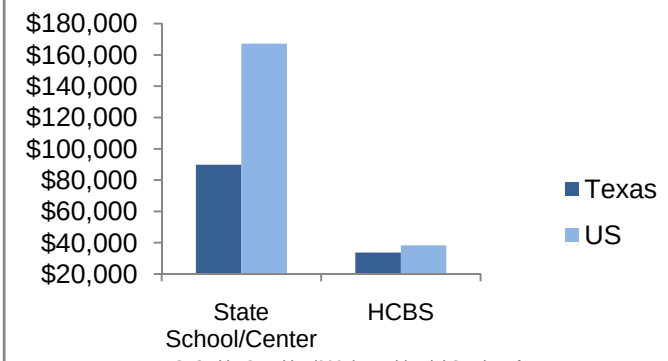
HCS Waiver	TxHmL Waiver
Residential Assistance (Foster/Companion Care, Residential Support, Supervised Home Living)	Adaptive Aids
Day Habilitation	Home Modifications
Counseling and Therapies	Community Supports
Audiology	Dental
Dietician	Supported Employment
Adaptive Aids	Employment Assistance
Home Modifications	Nursing
Nursing	Pathology, Audiology and Dietician
Respite	Therapy – OT, PT, ST
Supported Employment	Respite
Case Management	Day Habilitation
Dental	Behavioral Support

In considering these comparisons, it should be noted that there may be differences in the service needs of people served across these options. People living in state schools, for instance, may have more significant needs – on average –than people served in the Texas Home Living option. These service options, however, are not configured to serve people strictly according to their level of need. As a result, some people receiving ICF/MR services, for example, have needs on par with others receiving HCBS services.

Texas ICF/MR per person expenditures are generally lower than the cost of such services in other states. In 2006, per person ICF/MR expenditures were about 44 percent lower in Texas than the nationwide average for comparable facilities.

Chart 17 compares Texas 2006 per person expenditures to the national average for large ICF/MR (or Texas state schools/centers) and HCBS waiver per person costs. As can be seen, Texas ICF/MR costs were appreciably below the nationwide average. HCBS waiver per person expenditures also were about 13 percent lower than the nationwide average.

Per Person Expenditure Comparison of State Institution (State Schools) and Home and Community-BasedServices
Chart 17

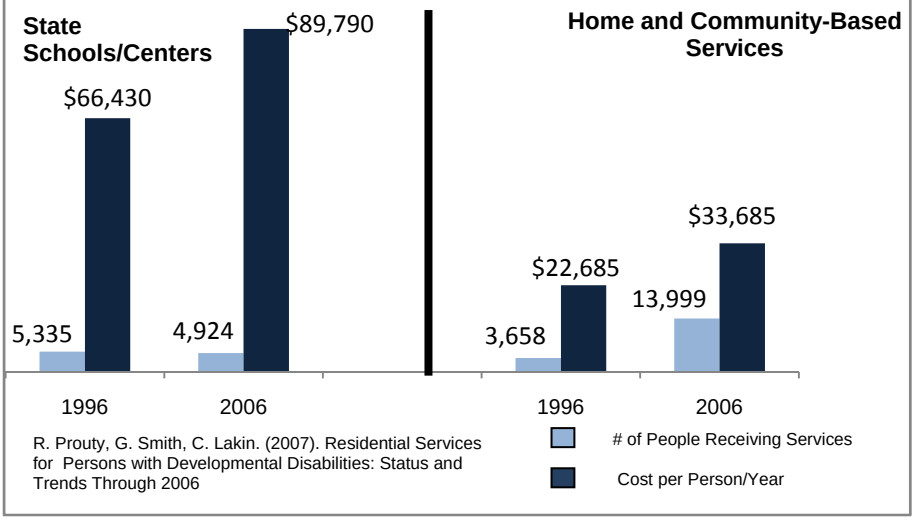


R. Prouty, G. Smith, C. Lakin. (2007). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006

Broadly, the situation in Texas is as follows:

- As Chart 18 illustrates, state school/center outlays are increasing even as the number of people served at the facilities is declining. More likely, state school expenditures per person will continue to track upward. To contrast, the numbers served by HCBS have increased significantly, while the cost per person has also increased, albeit more modestly. To the extent that Texas continues on this course, this means that the state schools/centers will claim an increasingly

Comparison of Cost per Person for State Schools/Centers and HCBS from 1996-2006
Chart 18



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

disproportionate share of available resources relative to the proportion of individuals that the state schools/centers serve.

- Due to the relatively low payments in Texas for ICF/MR services, the impact of placing greater emphasis on supporting people in the most integrated setting would generally be budget neutral on a per person basis. Reducing the number of people served in 16+ ICFs/MR will not yield significant budget savings, because Texas currently underfunds 16+ ICF/MR facility settings.
- Home-based services in Texas have proven to be the most economical to deliver on a cost per person basis. However, the proportion of people receiving home-based services is relatively low. Home-based services are akin to the types of services that other states are emphasizing through the operation of supports waivers. This suggests that the expansion of home-based services offers some promise in Texas for improving the overall economy and efficiency of MR/RC service delivery.

Payment Policies

The low per person costs of services in Texas are not so much indicative of economy and efficiency in service delivery as they are the byproduct of problematic payment policies. There is broad agreement in Texas that the rates that are paid for MR/RC services are insufficient to ensure the delivery of high quality, effective supports for individuals.

These enduring low rates in Texas are a major source of tension within the service delivery system. Funding for an annual cost-of-living-adjustment (COLA) often directly competes with expanding services to support additional individuals. In some years, the COLA has been skipped, resulting in provider agencies being squeezed between rising costs on one hand and flat state payments on the other. The outcomes of this squeeze are low worker wages, workforce problems and upsizing program sites.

Information provided in the Texas HHS 2009-2013 Strategic Plan states,

> "Many provider rates have not kept pace with routine inflation or medical costs. Additionally, minimum wage increases and increasing gasoline prices have had a tremendous impact on provider costs. Rates were restored and increased for the non-state operated ICFs/MR, HCS, TxHmL, and CLASS programs in June 2007. In September 2007, rates were increased for non-state operated ICFs/MR, NFs, and other community providers (CBA, PHC, DAHS, TxHmL, CLASS, HCS)
>
> The Department worked with the HHS System's Rate Setting office to implement provider rate increases approved by the Legislature for the current biennium. The Department will continue to work with the Rate Setting office to request increases as needed to address inflation-related costs." (p. 173-174. 2008)

Note that the rate setting process is an interactive partnership between HHSC and the Legislature. HHSC makes recommendations to the Legislature. The Legislature then amends and approves the final rates and appropriates the funds necessary to implement the specific rate proposals. Though this increase will help providers survive within the system, the HHS

System's Rate Setting office has not established a system that will update and change rates as time passes and costs increase. Without regular rate adjustments, the HHS Rate Setting Office aides in establishing a system that imposes hardship on providers and weakens the MR/RC service platform.

Contributing to this problem is the fact that Texas generally does not have payment rate determination systems that employ well-defined cost models that in turn are informed by solid information about provider and market costs. As a consequence, payments are adrift. Texas has not established explicit benchmarks for provider reimbursements for the services that the state is purchasing on behalf of people with mental retardation and related conditions.

Conclusion

Texas' average spending per citizen for MR/RC services was 47 percent below the national average in 2006. Over the years, Texas has stepped up its performance in securing Medicaid funding for MR/RC services. Unfortunately, these increased revenues have not been translated into a large expansion of services. Texas continues to devote a greater share of its Medicaid dollars to large congregate care services than is typical nationwide, but over the past 15 years, the state has ramped up its use of the HCBS waiver program. Even though there are long-standing and well-known problems in state payments for MR/RC services, there presently are no actions underway to reformulate payments to ensure that they are adequate.

The HSRI *Gap Analysis* revealed that a disproportionate number of Texas citizens with MR/RC are served in large and very large congregate care facilities. In 2006, one-third of the all the people (32.6 percent) in Texas who received MR/RC residential services were served in facilities that did not meet the most integrated setting benchmark – i.e., living arrangements that support six or fewer persons. Almost all (90 percent) of these individuals were located in very large facilities that served 16 or more persons, including 4,909 people who were living in the thirteen state schools/centers. Texas lags substantially behind nearly all other states in fostering the provision of services in the most integrated setting.

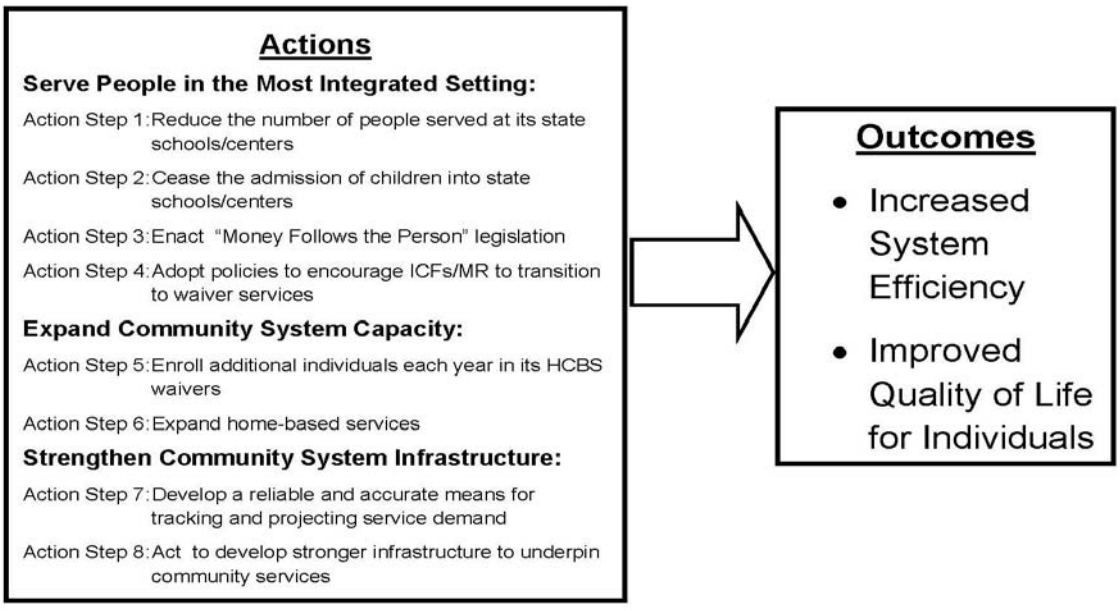
3. Action Steps

Texas is at a crossroads. HSRI's *Gap Analysis* reveals that Texas underperforms in three key benchmarks. These include serving individuals with mental retardation and related conditions (MR/RC) with reasonable promptness and in the most integrated settings, and in spending its resources most efficiently. Further, the state's present service system does not have adequate resources to meet the needs of all people who urgently require services, and it fails to ensure the consistent provision of high quality services.

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

Given these performance benchmarks, HSRI has identified **Eight Action Steps** that are keyed to three major system redesign Action Areas. These Action Areas relate to system's commitment to community integration, adequate capacity and the development of a strong, agile community infrastructure and are the recommendations of HSRI. These Action Steps, over a 10-year timeframe, require that Texas:

- Action Area 1: Embrace the principle of supporting people in the most integrated setting by reducing the role that large congregate care facilities and community ICFs/MR play in the Texas service system.
- Action Area 2: Expand system capacity so that by 2018 all people who have emergency or critical needs will be served with reasonable promptness.
- Action Area 3: Strengthen infrastructure in support of the community services system.



These areas are inter-related and should be regarded as a unified, intertwined series of actions that build and depend upon one another. The 10-year time horizon has been purposely selected in recognition of the fact that many of the system redesign action steps will take time and resources to put into motion and complete. System redesign is a complex endeavor. Since there are many action steps identified, the question inevitably arises as to how these steps should be sequenced. These Action Steps, however, do not offer a detailed implementation work plan. A comprehensive 10-year plan will need to be developed by Texas DADS and other stakeholders, defining the state's overall philosophy, approach and oversight mechanisms.

It is entirely feasible for Texas to implement each of these steps. Inaction will have serious negative consequences for people with mental retardation and related conditions.

It is important to emphasize that the Action Steps are based on practices and policies that have been successfully implemented in other states. It is entirely feasible for Texas to carry out each of these steps. Inaction will have serious negative consequences for people with mental retardation and related conditions. By not taking these steps, policy makers can expect that the state will: (a) continue spending substantial sums to maintain large facilities, such as the state schools/centers, which provide services that people increasingly do not want[21] and that increasingly have been criticized by federal and state oversight bodies, (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. In addition, forestalling action will likely make future action more costly and difficult to undertake. The time to act is now.

What follows is a description of the eight Action Steps. Subsequently, discussion is offered pertaining to how these steps may be implemented, including information on potential financing options.

[21] We recognize that judgment regarding what people may "want" can be a contentious issue. Self-advocacy groups, however, persistently indicate that they prefer normalized community life with support rather than service delivery requiring residence in large facilities. Self-Advocates Becoming Empowered (SABE), for example, is a leading national self-advocacy organization and has clear positions on this matter, calling for outright closing of institutions (http://www.sabeusa.org). Likewise, family advocacy groups very often take positions to favor community support systems, including "family support" service options, over facility-based service responses. Reflecting these preferences, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 states as its purpose to assure that "individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life." Consistent with these themes, states have steadily divested from congregate services in favor or more person-centered modes.

Eight Action Steps

Action Area 1: Serve People in the Most Integrated Setting

Action Step #1 Texas should reduce the number of people served at its state schools/centers to no more than the present nationwide utilization rate for these types of facilities.

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 21.0 individuals per 100,000 persons in the general population; the nationwide utilization rate was 12.8. In 2007, DADS developed plans to reduce state school/center population by 200 people[22]. Once this reduction is completed, Texas would still be using state schools/centers at a rate (19.8 individuals per 100,000 persons in the general population) that is well above the nationwide norm.

The substantial 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. This figure includes 25 facilities since 2000 and 61 since 1995. By 2009, there will be nine states and the District of Columbia that will not operate very large state-operated facilities. These states include: Alaska, Hawaii, Maine, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia. Other states are approaching this standard, with eleven other states having fewer than 200 people living in large state facilities.

Continuing this trend is New Jersey. In its plan entitled Path to Progress (New Jersey Department of Human Services, Division of Developmental Disabilities Olmstead Plan, May 2007), New Jersey announced that it intends to reduce the census of its developmental centers by 1,850 people over the next eight years. During this period, the census at its centers will drop from about 3,000 to 1,200 people by 2015. Of interest, in 2006 California and New York respectively had 2,000 and 2,770 fewer people living in facilities larger than 16 beds than Texas (Lakin, et.al., 2007).

There are several reasons why large public facilities are playing a diminishing role in developmental disabilities service systems. Community service systems have improved capabilities to support people with challenging medical and behavioral conditions. Large facilities also are extremely costly to operate, averaging $167,000 per resident per year nationwide in 2006. In many states, such facilities continue to encounter serious problems in meeting federal quality of care requirements. Compliance with federal requirements is an ongoing source of increased operating costs in such facilities, as illustrated by Texas' experience over the past 10 years. In some states, the role of state-operated facilities is shifting to furnishing high intensity, short-term services to small population segments (e.g., individuals

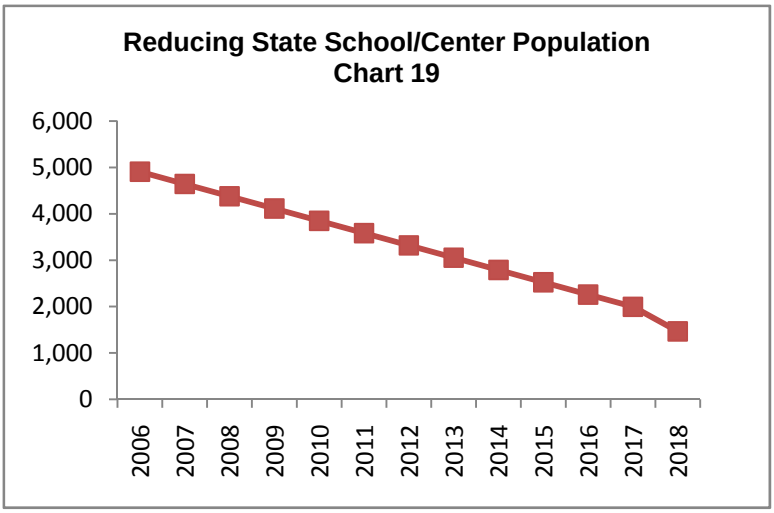
[22] An Audit Report on State Mental Retardation Facilities, the Department of Aging and Disability Services, and the Department of Family and Protective Services (July 2008). p ii.

who have clinically complex conditions and/or require forensic services). The role of large state-operated facilities in providing long-term residential services has been substantially reduced in most states.

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. However, it is clear that both political and economic considerations also figure into the equation.

Texas will make substantial progress in supporting people with MR/RC in the most integrated setting by reducing the number of people served at the state schools/centers to the nationwide norm and responsibly relocating individuals into the community. The fact that most other states rely far less than Texas on such facilities should serve as a signal that Texas need not maintain its present state schools/centers capacity.

The Texas state schools/centers presently command a disproportionate share of Texas MR/RC budget. The per person costs of supporting people in the state schools/centers will continue to ratchet upward in order to maintain compliance with federal requirements. Reducing the number of people served at the 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.



As shown by Chart 19, Texas should reduce its state school/center population to the predicted nationwide norm by 2018. Based on recent trends, by 2018, it is expected that nationwide, 5.1 individuals per 100,000 in the general population will be served in large state-operated facilities (in 2006, there already were 16 states that served 5.1 or fewer people per 100,000 in the general population in large state facilities). Taking into account projected Texas population growth during the *2006-2018 period*, state school/center population would have to be reduced to 1,465 individuals in 2018 to match the projected nationwide norm. This 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; alternatively it would mean placing about 22 individuals per month into appropriate community settings.

The result of such a placement plan would be a 70 percent census reduction over the eight-year period. This type of census reduction will result in higher per diem costs at the state schools/centers as fixed overhead costs are spread over fewer and fewer residents. As a

result, additional dollars will need to be invested in the community service system for people being placed out.

During the period that the state schools/centers population is being reduced, the amount of dollars that would become available for reinvestment as a result of downsizing are likely to be modest. It also will be important that Texas define more precisely the role that the state schools/centers will play going forward. Over time, the state schools/centers probably should concentrate on serving well-defined target populations and play a diminished role in furnishing long-term services. For example, the residual facilities in Michigan and Minnesota (as well as some other states) are largely devoted to providing short-stay services for people with very challenging behaviors, including individuals who have been diverted from the criminal justice system due to their inability to participate meaningfully in their own defense.

The transition of individuals from the state schools/centers to the community should incorporate the following best practices:

- Education and information for individuals and parents pertaining to community options. This can be achieved by utilization of the Community Living Options Information Process (CLOIP[23]).
- Full-featured person-centered planning to identify the best mix of community services to support the person in the community. Person-centered planning should include family members and others who know the individual well;
- Management of the planning/transition process by a team of state personnel who are intimately familiar with community services;
- Investment into a strong and dynamic community infrastructure;
- The placement of individuals only in community living arrangements that meet the most integrated setting benchmark;
- Free and informed choice by the individual of the provider agency that will furnish her/him services and supports in the community; and,
- Intensive monitoring of community placements for at least the first twelve months following state schools/centers discharge.

The experiences of other states in managing the community placement process should be drawn upon in mapping out a strategy for downsizing the census of state schools/centers in Texas. 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 a

[23] Responsibility for the CLOIP was delegated to local MRAs effective January 1, 2008 (and aggregate data re: impact of this new process is not available). *Prior to January 1, 2008, state school staff conducted CLOIP for adult state school residents.*

Through the CLOIP, state school residents (and their LARs) receive an explanation of the services and supports that are available in the community and an opportunity to visit community living options. This process occurs prior to the individual's annual planning meeting. During the annual planning meeting, the resident makes their living preference known (which is reported either as "prefers current living arrangement" or "prefers alternate living arrangement"). The individual only receives a "referral" for community placement, if their interdisciplinary team (IDT), which is their facility treatment team, agrees that such a referral is appropriate.

particularly apt example of how to integrate the above principles into a coherent long-range strategy for reducing a state's reliance on large, multi-purpose state institutions.

Community placements will be more durable and stable to the extent that they are individualized and planned carefully. However, as Texas pursues this goal, it will encounter problems unless the state concurrently addresses the major problems that affect community services. Unless these problems are addressed effectively, there will be continuing pressures to admit people to the state schools/centers.

Action Step #2 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 work group established by DADS to investigate youth admissions found that in FY 2007, 152 children/youth ages 0-21 were admitted into state schools, while 12 children/youths moved out of state schools and into community settings. If Texas is to push away from its reliance on state schools, it must take firm action to eliminate further admissions of children and youth to state school facilities.

A first order ideal is to assert plainly that children belong home with their families. If this ideal cannot be realized, then children and youth must have opportunity to be with another family or in live in small alternative residences in the community.

DADS agrees with that principle. The agency's "Message for Families"[24] states that:

> "Children and families go hand in hand. A nurturing family life offers a child a unique sense of security. All children need families who are consistently and actively engaged in their life, make sure they know they're loved, and make sure they're getting what they need to grow up to be the best they can be."
>
> "While institutional care may be a temporary solution, it is felt that it cannot meet the long term needs of the child." Hence Texas has had permanency planning laws in place since 2001. The nature of residential care is that staff come and go in the child's life as they change shifts and change jobs. Many aspects of family life are not possible with shift staff, no matter how caring and competent."

Yet the same message softens these statements to suggest that out-of-home placement in an institution can be a "best and only option:"

> "In an ideal world, the needed supports and services would be readily available. Unfortunately, there are often waiting lists for needed support services and families are not always able to get what they need, when they need it. In times like these, families may feel that placing their child in an institution is their best or only option."

[24] DADS (2208). *Message for Families*. Included as Attachment 13 in a letter posted April 25, 2008 from Adelaide Horn, Commissioner, to The House Select Committee on Services for Individuals Eligible for Intermediate Care Facility services.

Such statements raise the question of why services for individuals and families are not available to keep families intact, but are evidently available to support out-of-home institutional placement. As noted earlier, 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.

Taken together, circumstances like these maintain an "action bias" for placing children in state schools. If Texas is to take seriously a commitment to support individuals in the most integrated setting, it must face this issue squarely and take action to eliminate placement of children into state schools.

In 2006, 21 of 41 states (51%) with large state operated facilities had no children aged 0-14 years 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 in this age cohort living in large state facilities. Clearly, most other states have taken action to promote in-home or family support over placing children in institutions. Texas should do the same.

It may do so by refusing to enroll children aged 0-21 in state schools, with exceptions made under only the most challenging circumstances. To establish a "*Family First*" action bias, DADS should:

1. Grant 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.
2. Take affirmative action to accommodate any 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 (R). (2001),
3. Adopt a standardized risk assessment protocol that will be employed system wide 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 in 2008 and introduced into the service plan development process starting in 2009.
4. Develop a "diversion" protocol triggered by the risk assessment that systematically establishes and 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.

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

Action Step #3 Texas should further develop its "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.

In Texas, ICFs/MR constitute a distinct funding/service "silo." Once a person is placed in an ICF/MR, it is difficult for the individual to secure an alternative living arrangement. ICF/MR funding is not easily portable and cannot follow the person into the HCBS waiver. As a consequence, individuals are locked into ICFs/MR. This circumstance is at odds with the basic tenets of the U.S. Supreme Court's *Olmstead* decision.

Elsewhere, states are being challenged for maintaining such circumstances. In Illinois, a similar situation prompted the filing of a lawsuit (*Ligas v. Maram)* which claims the State of Illinois is violating the Americans with Disabilities Act (ADA) by not accommodating ICF/MR residents who would prefer to be supported in an alternative and more integrated living arrangement.

States are also taking steps to support the transition of individuals from ICFs/MR to more integrated settings in the community. For example, in the recent settlement of the *Martin v. Strickland* lawsuit, Ohio has agreed to accommodate ICF/MR residents who wish to move to a more integrated community setting. Over the past three years, Wisconsin has taken steps to accommodate non-state ICF/MR residents who can be served in more integrated community settings. Louisiana is working with the operators of large, private ICF/MR to transition their operations to supporting individuals in smaller community settings funded through a new HCBS waiver program.

Texas first responded to the *Olmstead* decision in 2001 through Executive Order GWB 99-2 to establish a plan for providing meaningful opportunities for people with disabilities and seniors to live in the most appropriate settings. Since then, the plan has been revised three times, the most recent in 2006[25]. The plan calls for systematic investment in helping people transition from congregate care settings into the community. In the 2006 plan revision, the Promoting Independence Advisory Committee made two issues their highest priority for the 2008-09 biennium: continued interest list reduction and workforce stabilization.

The Promoting Independence Advisory Committee's 2007 Stakeholders Report reports that since 1999 "14,393 individuals have transitioned back to the community as of December 31, 2007. Of that number, 6,685 continue to receive their long term services support in a community-based setting. Overall, 57 percent of the total population that relocates back into the community are 65 or older; 43 percent are 64 or younger" (page 22)[26].

[25] Texas Health and Human Services Commission (2007). The 2006 Revised Texas Promoting Independence Plan In Response to S.B. 367, 77th Legislative Session, Executive Order RP-13, and the *Olmstead vs. L.C*. Decision.

[26] Promoting Independence Advisory Committee. (2008). Promoting Independence Advisory Committee 2007 Stakeholders Report.

The Committee also reports that while MFP has proven successful for individuals living in nursing facilities, it does not provide people living in all ICFs/MR the same opportunity. For people with MR/MC, the original Promoting Independence Plan gave priority to relocation to individuals living in large ICF/MR settings. Relocation opportunity, however, is pegged to access to the HCS waiver program, given availability of HCS slots. The slots can come available through attrition or increased legislative appropriation for HCS. The Committee notes that the process is effective as long as there is new funding and attrition slots. From 1999 to 2007, 1,073 people have moved from the state school/center system. Interestingly, the State Auditor found that as of August 31, 2008, 70 percent (or 449) of state school residents who "preferred an alternate living arrangement" were not provided a community living arrangement. The SAO went on to recommend that DADS improve its monitoring of the Community Living Options Information Process (CLOIP) discussions to address these issues. Likewise, 734 more have moved from large ICFs/MR to HCS options. People in smaller setting sizes have not had the same opportunities.

In this context, under the Deficit Reduction Act of 2005, Congress – at the urging of the Bush Administration – set aside $1.75 billion in "Money Follows the Person" (MFP) funding over a five-year period to assist states in accelerating the transition of people from large settings to integrated residential settings. This funding provides states with enhanced federal matching funds to pay for community supports for persons who are transitioned to the community. Texas is one of 31 states to receive a federal Centers for Medicare and Medicaid Services (CMS) award to expand opportunities for people to secure alternative services in the most integrated living setting.

The Coleman Institute (2008) reports that the Texas initiative seeks 2,616 transitions in its plan, including 780 seniors, 420 people with physical disabilities, 160 people with mental illness, 1,216 people with mental retardation or related conditions, and 40 others. The commitment to people with MR/RC amounts to 46.5 percent of the total.

In addition, during the 80th Legislative Session (2007), the Legislature appropriated funds for 250 Promoting Independence (PI) HCS slots for people in state schools for the biennium. These Promoting Independence slots are available to state school residents *who receive a referral* to community; a resident can access these slots within six months of *receiving a referral.*

In addition, the 80th Legislature appropriated funds for 240 "PI" HCS slots for individuals in *large* community ICFs. These slots are available to residents within 12 months of a referral.

Also, 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 do not qualify for a nursing facility waiver program (e.g. CBA), but do meet the eligibility requirements of another waiver program (e.g. HCS).

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

1. Utilize MFP, consistent with Action Step 2 above, to keep children out off institutions, and to provide opportunities for children with MR/RC to leave institutional settings in favor of HCS alternatives. We recognize Texas's commitment to having children living in

their community with their families. Funding to back this commitment, however, has been insufficient. Further, the Promoting Independence Advisory Committee notes in its 2007 Stakeholders Advisory Report that often children cannot access the proper Medicaid waiver to meet their needs. Assuring that children with MR/RC have meaningful opportunity to relocate in the community will require additional appropriations.

2. Continue to utilize the MFP initiative, in support of Action Step 4 below, to encourage administrators of larger ICFs/MR to voluntarily close their facilities, to allow individuals to relocate to smaller HCS waiver alternatives. This action is consistent with DADS' Money Follows the Person Rebalancing Demonstration. This demonstration is an initiative focused on providers of community ICFs/MR with nine beds or more to help them take these beds off-line.
3. Expand opportunities within MFP for people with MR/RC to transition to HCS Medicaid waiver alternatives. This will require firm policy direction and appropriations to provide individuals with meaningful opportunity to transition. Such action is consistent with Senate Bill 27 (80th Legislature, 2007) to strengthen the process used to educate individuals about relocation opportunities.
4. Expand opportunities for relocation to 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 opportunity to transition to HCS funded living alternatives as well.
5. Continue to build upon CLOIP activities to educate individuals with MR/RC and their families about the choices they have for relocating from ICFs/MR. This should include:
    - A further developed "in-reach" program to identify individuals who would be apt candidates for transition to the community; and
    - Developing ongoing education for institution residents and their families, including opportunities to visit alternative community settings.

It is important to acknowledge that strong action to relocate individuals from ICFs/MR to HCBS waiver options has budgetary ramifications. People who leave ICFs/MR may, in some instances, be replaced by other individuals. Consequently, there would be no reduction in ICF/MR expenditures and HCBS waiver funding would have to increase to accommodate individuals who elect to transition to other alternatives.

It is difficult to predict how many individuals might avail themselves of the opportunities afforded by the enactment of MFP legislation. A conservative estimate is that about 5 percent of 11,616 ICF/MR residents in 2006, totaling 581 people, might seek to transition to alternative community living arrangements over a multi-year period.

Given an average waiver cost in 2006 of about $33,685 per person in the HCS Medicaid waiver, the cost would amount to at least $19.6 million in additional waiver funding would be necessary

to accommodate the transition of 581 individuals. We acknowledge, however, the amount would likely be more given that there is a general tendency for the state schools/centers to serve individuals with disabilities that are more significantly challenged, and so would result in per person waiver costs considerably above the current state wide average.

To avoid forcing individuals who want to transition from ICF/MR compete with other individuals for HCBS waiver openings, Texas should set aside or reserve waiver slots to accommodate such individuals. Texas also should provide additional funding to its agencies to facilitate the transition of individuals from ICF/MR to alternative community living arrangements.

Action Step #4 Texas should adopt policies to encourage organizations that operate ICFs/MR to transition to supporting individuals in the most integrated setting.

The large concentration of community-privately owned ICFs/MR in Texas is a historical artifact. DADS reports that by 1987, 6,649 individuals were served in such settings, and 20 years later, in 2007, the number holds steady at 6,608.

Texas saw ICF/MR services as a means of securing federal Medicaid funding to cover the costs of residential services before the HCBS waiver was a Texas option under federal law. Texas lagged behind other states in initiating a HCBS waiver program targeting to persons with mental retardation and related conditions. The Home Community Services waiver program was not initiated until 1993, or more than 10 years after the Medicaid HCBS waiver authority was established by Congress. And, until recent years, the state enrolled fewer individuals in the HCS waiver program than other states. As a consequence, Texas has an especially large concentration of ICFs/MR. In 2006, there were 865 community ICFs/MR operating state-wide.

For better or worse, Texas cannot roll back the clock. Instead, the state must pursue strategies to rebalance its MR/RC service system in collaboration with the organizations that operate community ICFs/MR. DADS has been working along these lines with some agencies that are interested in converting their large facilities (7 beds and greater) to HCBS community living arrangements. These efforts should be expanded to include facilities serving 6 or fewer residents.

Other states have launched rebalancing initiatives. For example, as previously mentioned, 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 worked collaboratively with ICF/MR providers to downsize and, ultimately, close their facilities.

More broadly, Texas should actively solicit proposals from agencies that operate ICFs/MR to convert such facilities to smaller settings. Starting in 2009, DADS should dedicate 1-2 staff positions to work directly with agencies interested in conversion. Funds should be appropriated to provide conversion grants of up to $100,000 to agencies that submit promising proposals to support their development of downsizing/conversion plans.

Summary

During the 10-year period between 2008 and 2018, Texas should take several steps to rebalance its MR/RC system and thus improve opportunities for people to receive services and supports in the most integrated setting. It is entirely feasible for Texas to bring the number of people served at the state schools/centers into alignment with nationwide norms for the operation of such facilities. A decision to move in this direction would entail relatively modest year-over-year levels of out-placements from state schools/centers. Additional action steps have been outlined that would contribute to rebalancing ICF/MR and HCBS services and move Texas toward a system where individuals have greater freedom to live in the most integrated setting.

Action Area 2: Expand Community System Capacity

An important goal for the Texas MR/RC system is to have sufficient capacity to respond with reasonable promptness to the legitimate needs to the people it is charged with serving. Yet, 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 capacity to meet the expressed demand for MR/RC services. In June 2008, there were 79,925 people on Interest Lists, of whom 37,187 were on the HCS Interest List. More to the point, the utilization rate per 100,000 in population is far lower than the national average.

To develop a sound strategy, a realistic projection of service demand is necessary. Owing to the difficulties in interpreting these Interest List data (see earlier discussion of this point), however, we pin our projections and recommendations on utilization rates compared with national rates.

Projected Service Demand in Texas

Total service demand is 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. Consider these three factors:

1. Uncertainty over general population growth projections. Texas has a fast-growing population that is difficult to predict accurately, given uncertainty over migration patterns. The Texas Population Projections and Estimates Program at The University of Texas – San Antonio has produced various projections based on four scenarios to account for migration. Each scenario yields different population projections. The US Census Bureau, however, projects that the Texas population will increase by 59.8 percent by 2030, or at 1.99 percent per annum. Under this projection, the state's overall population would increase by 12,465,924 people over 2000 census figure (i.e., 20,851,820 people). In projecting Texas population through 2018, this rate of increase was applied to the U.S. Bureau of the Census' July 2006 estimate, starting with a 2006 population of 23,407,629.
2. Added demand due to specific disability-related factors. The specific demand for MR/RC services is influenced by several factors. At a minimum, demand will grow at about the same rate as the general population. However, 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 example, California has experienced year-over-year increases in service demand that are 2-4 percent above the rate of population growth. Connecticut is another state that is experiencing continued growth in service demand despite a concerted effort to reduce the state's waiting list for community services.
3. Uncertainty over service utilization targets. DADS has compiled information about unmet service needs through the operation of the Interest Lists for the past six years.

Using this metric, the demand for MR/RC services is relatively high in comparison to many other states. Yet, there are difficulties with interpreting these data and, therefore, we have elected to pin service demand projections to measures of service utilization rates in Texas and nationally. More specifically, we key our estimates to:

- The difference in 2006 between the number per 100,000 in population that Texas serves (i.e., 109 people per 100K) and the number it would serve per 100K if it were to serve the people at a level commensurate to the national average is 193 people per 100K; and
- The service penetration rate that 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 (i.e., minimize or potentially eliminate the interest list) is 250 people enrolled in services per 100,000 in the general population.

For our purposes, we assume that the rate of demand for MR/RC services in Texas will grow at a pace somewhat faster than state population alone. HSRI set the rate at 2 percent each year above the rate of population growth, a relatively conservative assumption. Other states are experiencing higher year-over-year rates of increase in service demand, and so, a "Population Plus 2%"assumption is reasonable.

Based on the Plus 2% population estimates, two scenarios were developed, one keyed to a 193 person per 100K service utilization pattern, and the other to a 250 person per 100K rate. The technical note at the end of this section contains a more detailed discussion concerning how these projections were developed. For both scenarios, we factor in that:

- In 2006, a total of 25,615 people were served in ICF/MR certified settings or were HCBS waiver service recipients. These individuals are counted as "satisfied demand."
- DADS received appropriations to serve 8,902 more individuals during the 08-09 biennium. HSRI assumes that 4,050 of these individuals are people with MR/RC (this includes those slots allocated for HCS (n=2,676) and In-Home Family Supports (n=1,374) waivers). Therefore, 4,050 individual must be subtracted from our calculations.
- The state population in 2006 was 23,407,629, with growth estimated at 1.99 percent per year.

Projection #1: Service Use Rate of 193 people per 100K population. Texas serves 109 people per 100K in the general population. If it were to serve people at a level commensurate to the national average, it would need to serve 193 people per 100K. This results in a difference of 84 people per 100K population. Given a state population in 2006 of 23,407,629, this would amount to 19,562 people. As a result, the Texas level of total service demand in 2006 would be 45,177 (i.e., 25,615 + 19,562).

Projecting these numbers forward from 2008 through 2018, we find that to reach the present national average utilization rate of 193 people per 100K in population, Texas would need to serve an additional 32,826 people by 2018. Subtracting out the 4,050

DADS plans to serve in FY 2008-09 yields a total of 28,776, or 2,877 new people each year (or 5,754 per biennium).

Projection #2: Service Use Rate of 250 people per 100K population. Under this scenario, the target is set higher, at 250[27] people served per 100K. Again, noting that in 2006 a service utilization rate in Texas was 109 people per 100K, pushing to 250 people yields a difference of 141 more people per 100K. Given a state population in 2006 of 23,407,629, this would amount to 32,904 people. Using this service use target, the Texas level of total service demand in 2006 would be 58,519 (i.e., 25,615+32,904).

Again, projecting these numbers forward from 2008 through 2018, we find that to reach a utilization rate of 250 people per 100K in population, Texas would need to serve an additional 50,086 people by 2018. Subtracting out the 4,050 DADS plans to serve in FY 08-09 yields a total of 46,036 additional service enrollees, or the enrollment of 4,604 people each year (or 9,208 per biennium) on average.

Resources Needed to Meet Projected Service Demand

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 can underwrite 59.44 percent of these additional outlays. To estimate the volume of dollars that might be necessary, three alternative funding scenarios are used. Each scenario assumes that Texas will employ Medicaid financing to expand system capacity. These scenarios are:

- **Current Service Mix**. Under this scenario, it is assumed that 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) to estimate the cost of expanding system capacity moving forward.
- **HCBS Expansion Only**. It is assumed that Texas would rely exclusively on expanding its HCBS waiver for people with MR/RC to address current unmet and future service demand going forward. The baseline figure used under this scenario is $33,685 per person (the average HCBS expenditure of 2006).
- **ICF/MR Services Only**. Under this scenario, only ICF/MR services are used. In 2006 the average cost was $70,404 per person.

Table 4 illustrates these three cost scenarios by two service utilization standards, the first being at a rate of 193 people per 100,000 population, and the second at 250 people per 100K. As shown:

- Given a service use rate of 193 people per 100K, resources must be allocated to serve an additional 28,776 people by 2018. The most cost effective approach dictates the use of HCBS services to fund this expansion, which, according to our calculations, would run

[27] It is possible that this number will continue to increase as time goes on. Therefore, the 250 people per 100,000 is a conservative goal, and public policymakers should be aware that this number may be higher in 2018.

an additional $969 million annually. Alternately, if these individuals were served in ICFs/MR, the costs would be approximately $2.0 billion, over twice the cost of HCBS.

- Given a service use rate of 250 people per 100K, resources must be allocated to serve an additional 46,036 people by 2018. Again, the most cost effective approach requires the use of HCBS services, at an additional cost of nearly $1.6 billion annually. The cost here, by comparison, would be $3.2 billion if these people were served in ICFs/MR.

Overall, it would be substantially more economical for Texas to address service demand by relying exclusively on HCBS waiver services to finance the expansion. It also is worth noting that the funding necessary to eliminate unmet need is comparable to the difference between current Texas level of fiscal effort versus the nationwide norm.

Table 6
Resources Needed To Meet Service Demand ($ million)
Two Service Utilization Levels by Three Cost Scenarios

	Year	Additional Capacity Needed	Current Avg. Cost Per Person ($50,336/person)	HCBS Services Only ($33,685/person)	ICF-MR Services Only ($70,404/person)
193 per 100k	2009	2,878	$145	$97	$203
	2010	5,756	$290	$194	$405
	2011	8,634	$435	$291	$608
	2012	11,512	$579	$388	$810
	2013	14,390	$724	$485	$1,013
	2014	17,268	$869	$582	$1,216
	2015	20,146	$1,014	$679	$1,418
	2016	23,024	$1,159	$776	$1,621
	2017	25,902	$1,304	$873	$1,824
	2018	28,780	$1,449	$969	$2,026
250 per 100k	2009	4,604	$232	$155	$324
	2010	9,208	$463	$310	$648
	2011	13,812	$695	$465	$972
	2012	18,416	$927	$620	$1,297
	2013	23,020	$1,159	$775	$1,621
	2014	27,624	$1,390	$931	$1,945
	2015	32,228	$1,622	$1,086	$2,269
	2016	36,832	$1,854	$1,241	$2,593
	2017	41,436	$2,086	$1,396	$2,917
	2018	46,040	$2,317	$1,551	$3,241

Source of Cost Data: Prouty et al., 2007; based on 2006 data.

Given these findings, two action steps are recommended so that by 2018 Texas has sufficient system capacity to meet projected service demand.

Action Step #5 Starting in 2009 and each year thereafter through 2018, Texas should enroll an additional 4,604 individuals each year in its HCBS waivers.

As illustrated above, Texas policy makers can choose between policy options to address the unmet needs of people with MR/RC to varying degrees. A conservative choice would involve expanding capacity gradually until a service utilization rate commensurate with the national average is achieved. While attractive from a cost savings perspective, the approach would still leave thousands without the services they need.

More appealing is a strategy to accommodate most, if not all, unmet expressed demand. It is recommended that Texas expand system capacity at a steady pace by serving an additional 4,604 people each year between 2009 and 2018. Such action would result in another 46,040 individuals receiving services by 2018. By employing the HCBS waivers 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. Again, it is important to realize that by serving the additional 4,604 individuals per year would allow for a service utilization rate of 250 per 100K of general population. There is a significant possibility that by serving this number of people will strongly reduce and possibly eliminate the Interest Lists in Texas over time.

The cost for achieving this goal depends on the service mix that is applied. As illustrated by Table 4, the most cost effective approach involves the use of HCBS financing options. Though we estimate additional service expenditures of nearly $1.6 billion in 2018, we acknowledge that:

- The cost figure used to develop this estimate ($33,685 per person) should not be thought of as a fixed amount per person. It will likely cost much more to serve certain individuals in the community, especially if ICF/MR options are closed off. Others, however, will cost less.
- It should also be noted that Texas has chronically underfunded its entire service system for people with MR/RC. System expansion will also require bolstering various aspects of the community system infrastructure, thereby adding to the per person cost.
- The actual cost per person will also depend on the HCBS service options that are emphasized. For instance, options that rely on out-of-home residential placements will drive the cost up. In contrast, options that promote family based options will cost less. The actual mix of options selected will determine the final average per person cost for the proposed service expansion.

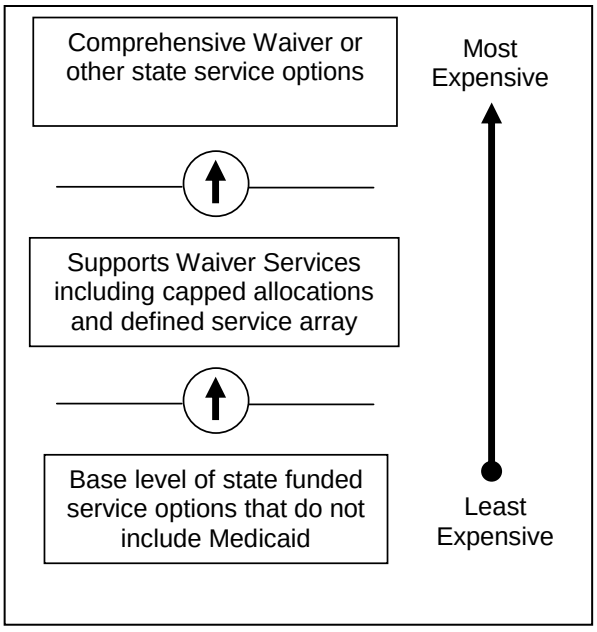
If system capacity is expanded at a slower rate during the period 2009 – 2018, Texas will be unable to serve all individuals with reasonable promptness. For example, if system capacity is expanded to serve only an additional 2,878 individuals (the target associated with 193 people per 100K population), many individuals with emergency or critical unmet needs would likely go without services, or necessarily displace people already enrolled in services. Though new individuals will be steadily added to the services, people with MR/RC would experience extensive waiting times.

Implementing this action step would entail scaling up 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 that is not dissimilar to 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.

Action Step #6 Texas should concentrate on expanding home-based services as the primary tool for addressing service demand. Consideration should be given to expanding the Texas Home Living (TxHmL) HCBS "supports" waiver.

Home-based services have proven to be an effective, economical means to support individuals with MR/RC in Texas. Through home-based services, services and supports are furnished to supplement and complement the supports that families furnish day-by-day to individuals. Families also have expressed a high level of satisfaction with home-based services.

Consistent with the previous Action Step, Texas should concentrate going forward on expanding home-based services as its primary tool for addressing unmet service demand. In crafting a strategy to eliminate its unmet demand for developmental disabilities services, Oregon decided to focus its efforts on the expansion of similar non-residential services. Other states have taken a similar approach. Focusing on home-based services is a less costly strategy than expanding licensed residential services. At the same time, provision must be made for some measure of expansion in residential service capacity outside the family home, especially to accommodate individuals who are living with aging caregivers.



Texas should consider the enlargement of the current Texas Home Living (TxHmL) HCBS waiver program. Currently, there are 18 states that operate separate "supports waivers" that provide roughly the same type of services as Texas' home-based services. Supports waivers in these states operate side-by-side with the traditional "comprehensive waivers" that provide more extensive services, including licensed residential services furnished outside the family home.[28] Supports waiver programs, in contrast, 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. As a result,

[28] Smith, G., Agosta, J. & Fortune, J. (2007). *Gauging the use of HCBS support waivers for people with developmental disabilities*. Washington, DC: Office of Disability, Aging and Long Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation.

the per waiver participant cost in comprehensive waivers is substantially greater than in supports waivers.

Aside from this cost advantage, recent changes in federal policies have also prompted states to set up separate supports waivers. Specifically, in 2001 the Centers for Medicare and Medicaid Services (CMS) issued a State Medicaid Director Letter #01-006 (a.k.a., Olmstead Letter #4). This letter addressed the question of whether a state could operate a single waiver program which restricted the benefit package certain waiver enrollees were eligible to receive. CMS made in clear in the letter that this practice is barred by federal Medicaid law. In essence the letter was intend to prevent a state from administering what is termed a "waiver within a waiver" – that is, a waiver that was internally partitioned to control the number of people who could access certain types of waiver services, typically 24-hour, out-of-home residential supports. The letter made clear that, once a person is enrolled in a particular waiver program, that individual must be able to obtain any service that is available through the waiver, if they need it. Furthermore, *Olmstead* Letter #4 made it clear that a state is at financial risk if it elects to provide the full range of waiver services that any given enrollee might require.

As a result, we conclude that operating a separate supports waiver, as Texas currently does, would: (a) assure that the state's waiver operations are consistent with *Olmstead* Letter #4; 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.

Note that presently there is a sizable gap between the range and intensity of services that can be funded under the state's supports waiver program (the TxHmL program) and the original MR/RC waiver program (the HCS program). Expenditures under the TxHmL program are capped at $13,000 per annum, while expenditure under the HCS program may not exceed 200 percent of the current ICF/MR reimbursement rate or 200 percent of the estimated annualized per capita cost of ICF/MR services, whichever is lower. That currently translates into a maximum of $151,490 a year for people at the most intensive level of care need (Level 9). While the state differentiates between HCS recipients who are eligible and ineligible for residential services, because of CMS' policy outlined in the Olmstead #4 Letter, it might make more sense for DADS officials to establish a separate waiver program for individuals who require a somewhat enhanced array of community supports to avoid an out-of-home placement.

Still, expanding the current Texas Home Living (TxHmL), the home-based services supports waiver, also would open up the opportunity to make other changes to home-based services that could prove beneficial. For example, individualized per person budgets informed by systematic assessment might be substituted for the current single funding limit, thus permitting additional services to be authorized when necessary to meet the needs of the individual or address changes in family circumstances. In addition, consideration should 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.

Summary

Absent an aggressive, multi-year initiative to reduce and eliminate unmet emergency and critical unmet service demand, Texas will find itself confronting an ever-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.

Technical Note

The service demand projections contained in this section start at the current base of "satisfied demand" (people who are presently receiving services) and "expressed but unmet demand." In particular:

- In 2006, a total of 25,615 people were served in the ICF/MR certified settings or were HCBS waiver service recipients. These individuals are counted as "satisfied demand."
- Because the Interest Lists kept in Texas are difficult to interpret, we key our estimates of un met or unsatisfied demand to the difference in 2006 between the number per 100,000 in population that Texas serves (i.e., 109 people per 100K) and the number it would serve per 100K if it were to serve the people at a level commensurate to the national average of people (i.e., 193 people per 100K). This results in a difference of 84 people per 100K population. Given a state population in 2006 of 23,407,629, this would amount to 19,562 people. The Texas level of total service demand in 2006 would be is 45,177 (i.e., 25,615+19,562).
- National experience, however, suggests, that when states reach about 250 people per 100,000 in population, most – if not all – unmet expressed demand is met. Keying to this service use rate, Texas would need to serve 141 more people per 100K population. Given a state population in 2006 of 23,407,629, this would amount to 32,904 people. Using this service use target, The Texas level of total service demand in 2006 would be 58,519 (i.e., 25,615+32,904)

Projected service demand rates are calculated when these numbers are considered in relation to changes in the overall state population. Texas is a fast growing state, but it is difficult to calculate exactly how fast the population will grow, given uncertainty over migration patterns.

The Texas Population Projections and Estimates Program in the Texas State Data Center and The Office of the State Demographer in the Institute for Demographic and Socioeconomic Research at The University of Texas – San Antonio has produced various projections based on four scenarios to account for migration. Each scenario yields different population projections. The US Census Bureau, however, projects that the Texas population will increase by 59.8 percent by 2030. This would total an additional 12,465,924 people over the number present in 2000 (i.e., 20,851,820 people). Given these figures, the Texas population is expected to grow at the rate of 1.99 percent per annum through 2030.

In projecting Texas population through 2018, this rate of increase was applied to the U.S. Bureau of the Census July 2006 estimate, starting with a 2006 population of 23,407,629.

We could pin our demand projection estimates to simple population growth, and not add in any other factor to presume demand rates higher than population growth alone. Projected unmet demand using the "no change" in the rate of demand assumption is calculated by applying the current service demand rate to Texas projected population each year and subtracting out the 26,615 individuals who currently receive services.

Projections of service demand employing the 2 percent year-over-year rate of demand growth assumption may also be calculated by increasing the base service demand rate by 2 percent each year and applying the calculated rate to projected state population for the year.

As a result, there are four analysis possibilities depending on whether we key projections to: (a) the 193 vs. 250 per 100K person service use rate, and (b) the "no change" vs. "plus 2%" population growth assumption.

Given that experience in other states consistently shows rates of demand in excess of population growth alone, we elected to develop our analyses to the "Plus 2%" assumption and present two scenarios based on the assumption to compare the 193 per 100K and 250 per 100K options.

The Table below provides a detailed breakdown of the data by option. As shown:

Presuming Demand Greater than Population Growth by 2%

Technical Note

Estimates at 193/100k

Year	Pop Growth at 1.99%/year	Service Util at 193/ 100k	Plus 2%	Number Served in 2006	Difference
2006	23,407,629	45,177	46,080	25,615	20,465
2007	23,873,441	46,076	47,002	25,615	21,387
2008	24,348,522	46,993	47,942	25,615	22,327
2009	24,833,058	47,928	48,901	25,615	23,286
2010	25,327,236	48,882	49,879	25,615	24,264
2011	25,831,248	49,854	50,876	25,615	25,261
2012	26,345,290	50,846	51,894	25,615	26,279
2013	26,869,561	51,858	52,932	25,615	27,317
2014	27,404,265	52,890	53,990	25,615	28,375
2015	27,949,610	53,943	55,070	25,615	29,455
2016	28,505,807	55,016	56,172	25,615	30,557
2017	29,073,073	56,111	57,295	25,615	31,680
2018	29,651,627	57,228	58,441	25,615	32,826
				Number in 2018	32,826
				DADS to serve in 2008	4,050
				Difference	28,776
				Need to Serve Each Year (2008-2018)	**2,878**

Estimates at 250/100k

Year	Pop Growth at 1.99%/year	Service Util at 250/ 100k	Plus 2%	Number Served in 2006	Difference
2006	23,407,629	58,519	59,689	25,615	34,074
2007	23,873,441	59,684	60,883	25,615	35,268
2008	24,348,522	60,871	62,101	25,615	36,486
2009	24,833,058	62,083	63,343	25,615	37,728
2010	25,327,236	63,318	64,610	25,615	38,995
2011	25,831,248	64,578	65,902	25,615	40,287
2012	26,345,290	65,863	67,220	25,615	41,605
2013	26,869,561	67,174	68,564	25,615	42,949
2014	27,404,265	68,511	69,936	25,615	44,321
2015	27,949,610	69,874	71,334	25,615	45,719
2016	28,505,807	71,265	72,761	25,615	47,146
2017	29,073,073	72,683	74,216	25,615	48,601
2018	29,651,627	74,129	75,701	25,615	50,086
				Number in 2018	50,086
				DADS to serve in 2008	4,050
				Difference	46,036
				Need to Serve Each Year (2008-2018)	**4,604**

Action Area 3: Strengthen Community System Infrastructure

Most Texas stakeholders agree that there are major shortcomings in the delivery of community MR/RC services. Provider agencies are struggling to acquire and retain a stable competent workforce. In turn, workforce instability spawns major problems in assuring the quality of services and supports. The extent of the oversight of community services is generally regarded as insufficient and is a continuing source of concern across the full spectrum of stakeholders. In addition, there are gaps in the capacity of the community system to address the needs of individuals with especially challenging conditions.

These shortcomings stand as major impediments to expanding services to individuals who have unmet emergency or critical needs as well as foster the delivery of services in the most integrated setting. Because of these problems, the present community system is not solid enough to serve as a platform for system expansion and reconfiguration. There are two principal action steps that must be taken to overcome these shortcomings.

Action Step #7 Texas must develop a reliable and accurate means for tracking and projecting 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." As illustrated in the *Gap Analysis*, the lists have grown to include nearly 80,000 individuals. 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 need services presently 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. Without such information, state leaders and advocates alike are virtually guessing at the accuracy of the lists and their implications for informing a reasoned systemic response.

To this point, however, the sheer size of the Interests Lists coupled with the chronic underfunding of the Texas system, allows policy makers to allocate additional sums of money to address unmet needs without worrying about overshooting their target. Any sum allocated by the legislature is welcomed, though routinely such allocations fall short of substantially reducing unmet need across the state.

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. Several other states have undertaken this task in recent years. For example, as noted earlier, 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.

We are not recommending that Texas adopt the PUNS. Other useful state systems exist. Texas state leaders, however, 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.

Action Step #8 Texas must take action to strengthen infrastructure to underpin its community service system.

We have recommended that Texas take significant action to reduce the census at the state schools, create incentives for ICF/MR providers to transition to HCBS options, and expand system capacity. In taking such action, we understand that Texas must simultaneously bolster its community services system.

Taking such action will no doubt require state leaders to rethink and reinforce several community system elements. For instance, what role should Mental Health and Mental Retardation Centers play? In accordance with state statute, these centers develop services for people with serious and persistent mental illness or have mental retardation, and may also provide substance addiction services. First established by statute in 1965, these centers may provide services, expand resources for their service areas, manage resources for state and local government, include the community in service assessment, planning and evaluation, and help coordinate local mental health, mental retardation, and substance addiction resources. Texas currently has 39 centers spread across the state.

Likewise, other infrastructure elements such as the functions and capacity of service coordinators might be reviewed. Overall capacity to gather and manage information pertaining to system operations might need to be upgraded, as might methods for monitoring service quality, including the health and well-being of service recipients.

Finally, with system reform comes the opportunity to restructure the supply of services and how they are delivered. Such action can be used to promote self-direction for individuals (e.g., choosing an appropriate and preferred living option) and to emphasize preferred system outcomes, such as expanded community employment opportunities for service recipients.

Discussion of what Texas might do in areas like these is well beyond the scope of this inquiry. We do, however, urge state leaders to take action to improve system infrastructure related to: (a) the workforce, (b) service reimbursement rates, and (c) assuring that extraordinary needs (i.e., LON 9) among service recipients are accommodated.

- **Workforce Concerns**. Community agencies in Texas, like many states, are plagued by high rates of turnover among direct support professionals. High worker turnover translates directly into major problems in assuring that services meet essential quality standards. It

A skilled, stable workforce is the cornerstone of an effective community services system.

also poses real problems in ensuring that people with MR/RC receive services and supports that enable them to achieve critical outcomes in their lives. An unstable workforce increases the underlying costs of services in the form of increased use of overtime, higher workers' compensation expenses, and training costs. These problems are not unique to Texas. Adding capacity to serve people with reasonable promptness will be difficult unless community agencies are able to hire more workers and retain the ones that they have for longer periods.

High worker turnover is attributable in part to the inability of provider agencies to pay competitive wages. The capacity of agencies to compete for and retain workers is directly affected by the level of state payments for community services. In Texas, payments for community services have not been regularly adjusted year-over-year 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.

Compounding matters, providers may not offer workers a satisfactory range of benefits (e.g., health insurance, vacation or holiday pay) or sustained training or education. Overall, working conditions like these add to low worker satisfaction, which in turn helps fuel further turnover.

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. While some advocate that community wages be benchmarked against state employee wages, the better approach is to benchmark wages against comparable types of jobs in the general labor market, providing geographic modifiers as warranted to reflect local labor market conditions.

Determining an appropriate level of compensation for community workers is not simple. To lay the proper foundation for making such a determination, a comprehensive study of current wages and benefits is necessary along with an analysis of general and local labor market conditions. For example, 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.

Texas should conduct a full-scale study of community worker wages and boost funding as necessary to ensure that workers can be paid competitive wages.

It is recommended that Texas take two steps to improve conditions for community workers:

1. In the short-term, "top line" payment rates for community agencies should be increased 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.

2. A full-scale study of community wages and benefits should be initiated this year and targeted 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. It should identify how much wages and benefits would need to be increased to be competitive. Finally, 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.

Should the recommended study of wages and benefits reveal that a substantial boost in funding is necessary for community wages and benefits to be competitive, then a multi-year funding strategy should be designed to provide the necessary additional dollars to boost wages and benefits to competitive levels within no more than three years.

- **Provider Reimbursement Rates.** Another study that would yield valuable information is a provider cost study. In many cases, providers are likely to know the amounts they pay for overhead and overall direct costs, but often do not have a clear understanding of what it costs to serve a particular person. A provider cost study is meant to look at how funds are allocated by actual costs associated with providing service. This allows a provider to know how much is being allocated to specific services as well as looking at factors such as per person costs. Oregon has completed a similar study for use in establishing its reimbursement rates for specialized developmental disability services. This type of study also allows a state to pair the information with a system wide payment reimbursement study to better manage the money allocated for individuals. Such studies and practices have been implemented in a number of states, and are leading to most sophisticated strategies for financing person-centered services and afford enhanced choices for individuals receiving services.

  Texas also has the opportunity to update and enhance its assessment of needs by replacing the aging Inventory for Client and Agency Planning (ICAP) tool with the Supports Intensity Scale (SIS). The SIS was published in 2004 and is in use in 14 states and 14 counties. It is easy to align with individual plans of care and, in an increasing number of states is being used as the basis of developing individual budgets or reimbursement levels for state waiver programs. Because the instrument is supports needs based, it captures some of the natural supports that Texas does not need to pay for. It is a nationally normed tool structured around client interviews. SIS assessment results would be very useful in matching available waiver dollars to the individual community support needs of waiver-eligible individuals.

  As Texas explores the costs within the system, it becomes vital that the state also considers strengthening the information technology systems that provides the basis for

resource allocation decisions. By doing so, the state is more capable of recognizing potential crisis situations, managing data, and projecting funding needs.

While Texas is obtaining further systems information, the state will develop a stronger understanding of where shortfalls are within the system. In turn, this information will help the state to manage crisis intervention services more effectively. This is often done by collecting data on the individuals who go in crisis situations and developing guidelines for predicting possible crisis situations and proactively managing the situation so a more catastrophic crisis can be avoided.

- **Individuals with Complex Needs.** A critical measure of the effectiveness of a community developmental disabilities service system is how well it supports individuals who have especially challenging behavioral or medical conditions. The capacity to meet the needs of these individuals without resorting to long-term institutionalization is vital. To the extent that the needs of such individuals can be appropriately addressed in the community, their lives will be more stable and the high costs of institutionalization will be avoided.

  Texas presently lacks a well-structured capacity in the community to respond to the needs of these people. As a consequence, *de facto* the state schools/centers play a crucial role of serving individuals whose needs cannot be met in the community due to their challenging conditions. Indeed, 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.

  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 (Pineland Center). 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.

  Obviously, the Texas MR/RC service system is far larger and more complex than the Vermont and Maine systems. However, the fundamental design principles that undergird the Vermont and Maine approaches to addressing the needs of individuals with challenging medical and behavioral conditions are relevant. These principles include:

- Establishing on-call capacity to rapidly provide technical assistance to providers that experience problems addressing the needs of those with challenging conditions;
- The capability to dispatch skilled personnel to community settings to identify effective practices in addressing challenging conditions and work with provider agency staff to implement such practices; and
- The operation of short-stay crisis residences to provide intensive services in order to stabilize a person who is experiencing a crisis.

The foregoing capacities and capabilities form the core of an effective approach to serving individuals with challenging behavioral and medical conditions. Such an approach features capacity to address the needs of such persons in the community rather than placing the person to a large congregate care setting.

Given the sheer size of Texas (from a geographic and population standpoint), two recommendations are offered:

1. Texas should contract with one or more private-sector organizations to furnish specialized behavioral services on an as needed basis for defined geographic areas of the state. These Behavioral Support Organizations can be linked to regional provider networks already in place as well as furnish ongoing training and education to community personnel in supporting people who present behavioral challenges.
2. DADS should craft a set of specifications for the operation of Behavioral Support Organizations, and, during 2009, issue a Request for Information to solicit proposals to operate such organizations. Assuming that one or more satisfactory responses to this solicitation are received, DADS should conduct a pilot of the behavioral support system during 2010. If the pilot is successful, this approach to furnishing services could be extended statewide starting in the 2011-2012 biennium. To complete these actions DADS may seek to establish an independent task force on behavioral intervention or develop a Behavioral Crisis Team.

In a similar vein, Texas should undertake an in-depth study of current system capabilities to meet the needs of individuals who have extensive medical support needs. At present, little is known the effectiveness of health care systems in meeting the needs of individuals with extensive, chronic health care needs in the community, although there is some evidence of problems in appropriately supporting individuals who have especially complex medical conditions. Some states (e.g., California and Pennsylvania) have launched major initiatives aimed at improving the quality of health care services for people with developmental disabilities in the community. These initiatives may suggest potential courses of action in Texas.

Summary

It is vital that Texas pursue the foregoing action steps in order to create a solid platform for the delivery of community services going forward. To the extent that Texas ignores these mission-critical areas, the feasibility of reducing the state's over-reliance on large congregate care

facilities and expanding system capacity to support people with unmet needs in the community will be undermined.

Implementing the Action Steps

The *Action Steps* lay out a complex, intertwined agenda for system redesign in Texas. System redesign is an exciting opportunity for the state to commit itself to achieving excellence in service system performance. Redesign also may generate concerns about the potential impacts on people with mental retardation and related conditions, their families, committed professionals, and other stakeholders. These concerns are entirely legitimate, and if not addressed can fuel strong resistance to system redesign. In addition, experience shows[29] that systems managers seeking to make major change can inadvertently make matters worse by:

- Failing to articulate and communicate a clear and unambiguous vision for the future that appeals to key stakeholders, and to take consistent policy action that advances the vision;
- Failing to establish a strong sense of urgency around the redesign effort that illustrates the consequences of inaction and the benefits of taking action;
- Failing to engage stakeholders in the redesign effort and forging a coalition among them to help shape the redesign process;
- Failing to remove policy, financing mechanisms or other structural barriers that may impede system redesign;
- Failing to plan systematically for redesign and to implement the plan step by step, building short-term successes along the way; and
- Failing to anchor the redesign to organizational cultures within agencies across the state and encourage learning communities among stakeholders to support the effort.

A successful redesign strategy involves purposeful action to avoid pitfalls such as these. In fact, several of the Action Steps that follow take these potential hazards into account. Steps may, for example, promote collaborative problem solving, remove policy barriers or improve systems infrastructure. Such action will inevitably improve service delivery, but also help build confidence in the community system and fuel momentum among stakeholders for additional change. Aside from implementing the specific action strategies called for in the *Action Steps*, however, DADS can improve its chances for success by:

1. **Launching the redesign effort with executive and legislative branch sponsorship and pursuing the redesign process through a collaborative process**. The success of system redesign will hinge on enlisting the collaboration of several stakeholders and constituencies from the start and sustaining their engagement throughout the planning and implementation process. In this context, because system redesign has both fiscal and legislative implications, policy makers must also be actively involved in the redesign process.

[29] Kotter, John (1998). *Leading change: Why transformation efforts fail*. Harvard Business Review (March-April) Reprint No. 95204.

In this context, we recommend that redesign be launched by enlisting executive and legislative branch sponsorship. A Redesign Steering Committee, with decision making authority, should be appointed to spearhead the effort. Care should be taken, however, to assure that the Committee is composed of participants who are committed to achieving the objectives set forth in the *Action Steps.* The Committee process should not be used to forestall or delay needed actions. Instead, 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. To ease the way, 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 Steps* 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.

2. **Engaging people with mental retardation and related conditions, the primary constituents of the system, in the redesign effort.** People with developmental disabilities themselves represent a primary, albeit too often neglected, stakeholder group that must also be effectively engaged. Toward this end, we recommend that DADS establish a position within its office that is staffed by a person with MR/RC to provide continual input into DADS' policy decisions. DADS should also encourage service providers to include self-advocates on the DADS Council. Moreover, DADS should direct funds annually toward training for self-advocates, and to help participants organize more effectively to convey their views regarding state and local policy and practice.

   In this context, several other states provide funds to self-advocacy organizations, including Alabama, Illinois, Oregon, New York, Pennsylvania, New Jersey, Massachusetts and others. To amplify their investment, in some states multiple sources of support are tied together. This may include teaming with the Texas Council on Developmental Disabilities, utilizing VISTA/AmeriCorps programs (e.g., Oregon, Missouri, New York, Utah), or through the creative use of Medicaid dollars to fund training (e.g., Minnesota, Wisconsin). In all such instances, participating agencies must take care to avoid conflicts of interest and assure that the voice of self-advocates stays free and unencumbered by agency policy preferences.

3. **Taking specific actions to help reduce potential resistance from stakeholders.** The Action Steps illustrate the policy decisions that must be pursued in order to achieve significant, and needed, system change in Texas. For various reasons, such change may spur strong resistance from particular stakeholders, such as parents of individuals currently residing in state schools and centers and , staff or administrators of community based ICFs/MR. The individuals being re-located may also be anxious about moving. Where concerns like these are not taken into account, the process can go awry and fuel resistance to future relocation efforts.

To promote success, it is essential that the opinions of these stakeholders not be discounted, but that their concerns be heard and addressed to the extent possible. Very often, within a systems change process, "resistance" is considered as undesirable. Instead, it should be treated as "data" that can be used productively to improve the change process and address concerns. In this context, DADS staff should create opportunities for affected stakeholders to voice their concerns and suggest means for resolving these concerns. Overall, success depends on effective communication between policy makers and those in the field charged with implementing the planned changes.

4. **Establishing an unambiguous action-bias that is consistent with the redesign effort.** Most likely, concerns or resistance from these and other sources can be accounted for and addressed before or during the transformation process. Still, no matter what is done in response, some may object to the planned changes. Their objections, however, should not be allowed to undermine the process. Once DADS commits to redesign, it must assure that the actions it takes promote the redesign effort. There may be instances where DADS must act in ways -- for the moment -- that are inconsistent with its commitment. Such decisions, however, should be carefully considered and increasingly rejected in favor of those that support redesign. By doing so, a clear and unambiguous path for redesign can emerge and an action-bias for change can take hold.

Overall, the *Action Steps* identify strategies to be adopted, but do not constitute a detailed implementation plan. The implementation of each action step will require considerable additional follow-up activities and more detailed planning. With guidance and oversight provided by a Redesign Steering Committee, implementation will proceed best, if it is conducted as a collaborative enterprise among constituencies that stresses full transparency. DADS can reinforce this emphasis on cross stakeholder collaboration by routinely taking actions consistent with the redesign.

Funding and Financing

It is useful to discuss the likely impacts of the Action Steps on the funding and financing of MR/RC in Texas.

- **Funding.** Implementing the *Action Steps* will require that Texas step up its funding of MR/RC services. As was pointed out in the *Gap Analysis*, Texas' present level of funding is sub-par in relationship to nationwide norms. Current funding is insufficient to meet present service demand or support the delivery of high quality services.

  There are only limited opportunities in Texas to shift dollars among services to secure meaningful savings that can be redirected toward expanding services and/or addressing problems such as low community worker pay. For example, while it is important that Texas increase opportunities for people served in ICFs/MR to transition to the community if they wish, the costs of community residential supports for these individuals may be roughly the same as the cost of serving a person in an ICF/MR because Texas

ICF/MR payments are relatively low in comparison to payments for such services in other states.

Where the *Action Steps* have fiscal implications, they have been identified as to their direction and general magnitude. The *Action Steps* stress the use of more economical services and supports to the extent possible. However, it would be misleading to suggest that these actions can be implemented without additional funding.

- **Financing.** As a general matter, the additional spending that is necessary to implement most of the *Action Steps* can be offset in part with federal Medicaid dollars. Certainly, expanding system capacity can and should be financed in large part through the expansion of HCBS waivers for people with MR/RC. Many of the costs associated with improving the service delivery system infrastructure also are appropriate candidates for Medicaid financing.

  In the Deficit Reduction Act of 2005, Congress added §1915(i) to the Social Security Act. This provision provides states with an alternative approach to securing federal Medicaid dollars to underwrite the costs of home and community-based services. Under this alternative, a state may elect to cover certain home and community-based services under its Medicaid State plan rather than having to seek periodic renewal of waivers to provide such services. States are permitted to establish limits on the number of people who may receive Section 1915(i) services in much the same way as they may set expenditure and utilization caps under Section 1915(c) waiver programs. States also may continue to operate HCBS waivers.

  In the near-term, however, this new Medicaid coverage option does not offer Texas any significant advantage over continuing to employ the HCBS waiver program to underwrite the costs of home and community services for people with MR/RC. Down the road, however, this alternative may warrant consideration as a tool to finance cross-disability service delivery strategies, especially in the arenas of integrated employment and personal assistance.

  There are other Medicaid financing alternatives to the HCBS waiver program that also are available. One such alternative includes what are termed 1915(b)/1915(c) combination waivers that permit a state to shift the delivery of developmental disabilities services to a managed care framework and integrate the delivery of Medicaid long-term care and other services. Texas, in fact, is currently piloting this option in the Dallas and Tarrant service areas through its Integrated Care Management (ICM) programs. ICM participants have their acute and long-term support needs managed and coordinated by a single contractor, having the same service options available to them as are offered through the CBA waiver. Wisconsin has also used this alternative to implement its Family Care program. In Wisconsin, community agencies have been established to manage the entry of individuals into long-term services (including developmental disabilities services) and channel people to the most appropriate services. Michigan also employs a combination waiver to channel funding to local entities for the delivery of developmental disabilities services. Yet another alternative is employing the broader

federal Section 1115 waiver authority to implement a broader restructuring of the delivery of services. For example, Vermont has employed this waiver authority to reconfigure long-term services for seniors and people with disabilities. In Vermont, individuals now have an entitlement to home and community services and admission to nursing facilities has been restricted.

Each of these alternative waiver authorities has attractive features. Either may serve as a vehicle to unify the delivery and funding of Medicaid services for people with developmental disabilities. However, there are major challenges associated with using either authority, including significant operational design issues. More importantly, each alternative has sweeping implications with respect to the flow of federal Medicaid dollars. For example, the Section 1115 authority imposes a “budget neutrality” requirement that limits the amount of federal Medicaid dollars a state may receive. This requirement means that this authority should not be used unless a state is reasonably confident that the present level of Medicaid funding is sufficient to underwrite current services. If applied to an under-funded system, the Section 1115 authority can have negative consequences. Both of these authorities are more properly applied to systems that are stable and do not have large pent-up service demand.

At present, the best option for Texas is to expand its HCBS waiver capacity and improve its operations. Texas should ensure that the design of the waiver aligns with the goals and objectives it has set for the service system. Additionally, the financial gains achieved through expansion of the waiver and/or refinancing current services should be reinvested in the community system. Later, once Texas has addressed some of the underlying problems in its MR/RC service system, other options may be considered.

[Page left intentionally blank for double-sided copying]

4. Concluding Remarks

> ***"A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the 'customers' are not to be left behind and to become hostages of an outdated way of doing things."***
>
> ***Alfred Dam***

It is said that everything is bigger in Texas. This includes the opportunity to improve the gap between current system performance for people with mental retardation and related conditions and performance that meets national benchmarks for quality.

Over the past 30-40 years, Texas has invested heavily in services for people with MR/RC. Yet, even as the state established a community services system, it has maintained an enduring commitment to ICF/MR facilities including the state school/center network. Now, Texas faces difficult policy choices in responding to the needs of its citizens with MR/RC. This circumstance is fueled by a growing unmet demand for services, changing expectations among people with MR/RC and their families, chronic under-funding and other factors.

We have reviewed the Texas service system against a series of three performance benchmarks. We find that:

- People with MR/RC 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. Service utilization rates in Texas are far below the national average. Insufficient funding also weakens the system's overall capacity to support individuals with complex medical needs or behavioral challenges, especially within the community.
- Many people with MR/RC do not receive services within the least restrictive setting appropriate to their needs. Texas ranks 7th highest in the nation in percentage of people with MR/RC living in residential facilities with 16 or more beds.
- The state's service system for people with MR/RC is not operated in a manner that promotes efficiency and economy.

The initial examination of information regarding Texas's 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.

In response, state leaders must decide what to do. In response, going forward state leaders have several policy options to consider. For instance, the state may:

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

The *Action Steps* presented earlier are pinned to the fourth option. These actions call for Texas to:

Serve People in the Most Integrated Setting:

Action Step 1: Reduce the number of people served at its state schools/centers

Action Step 2: Cease the admission of children into state schools/centers

Action Step 3: Enact "Money Follows the Person" legislation

Action Step 4: Encourage ICFs/MR to transition to serve people in the most integrated setting

Expand Community System Capacity:

Action Step 5: Enroll an additional 4,604 individuals each year in HCBS waivers

Action Step 6: Expand home-based services as the primary tool for addressing service demand

Strengthen Community System Infrastructure:

Action Step 7: Develop a reliable and accurate means for tracking and projecting service demand

Action Step 8: Strengthen infrastructure to underpin the community service system

These actions provide state leaders with definitive direction for addressing the challenges faced by the Texas MR/RC service system. By enacting these steps, Texas will increase system capacity, improve system efficiency, and improve the quality of life for thousands of Texans with MR/RC and their families.

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."

There is no reason to believe that people with mental retardation and related conditions in Texas will settle for anything less.