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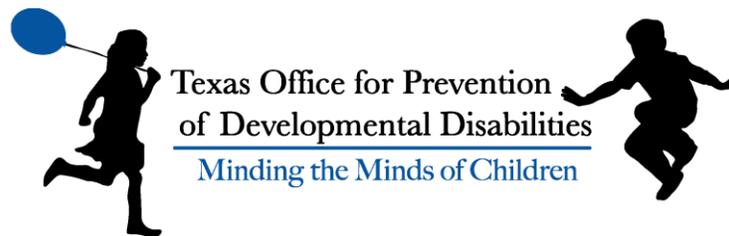
Texas Biennial
Disability Report

Prepared by the
Texas Council for Developmental Disabilities
in collaboration with the
Texas Office for Prevention of Developmental Disabilities



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About the Texas Biennial Disability Report

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

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

As directed by state law, this report is focused on health and human services and does not address in detail the broader array of policy issues that impact the lives of persons with developmental disabilities.

In each *Texas Biennial Disability Report*, TCDD and TOPDD have elected to provide additional detail on current state level policy discussions related to services for persons with developmental disabilities. This includes recently enacted state and/or federal legislation, or policy discussions with state agency partners about the delivery of health and human services.

The 2014 Report summarizes the key federal and state legislative actions that are changing the landscape of long-term services and supports in Texas. These include implementation of the Affordable Care Act, workforce innovation and employment, and new rules for Medicaid home and community based settings. At the state level, the system of services and supports for people with disabilities is impacted by the statewide expansion of managed care, implementation of Employment First policies, and the Sunset Commission review and recommendations for health and human service agencies, including TCDD and TOPDD.

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

Executive Summary

Texas statute (Title IV, Chapter 531, Section 531.0235) requires that every two years, the Texas Council for Developmental Disabilities (TCDD), in collaboration with the Texas Office for Prevention of Developmental Disabilities (TOPDD), prepare the *Texas Biennial Disability Report*. The report provides an overview and “State of the State” related to reducing the occurrence of preventable disabilities and the strengths and weaknesses in the state service delivery system. TCDD and TOPDD are also asked to make specific recommendations for improving how Texas supports individuals with developmental disabilities and their families.

TCDD and TOPDD evaluate the long-term services and supports (LTSS) system in Texas against national benchmarks to ensure that: 1) people with disabilities have access to and receipt of necessary publically funded services and supports with reasonable promptness, 2) services and supports are provided in the most integrated setting appropriate to the needs of the individual, and 3) the funding and delivery of services and supports is economic and efficient.

Unfortunately, Texas is not meeting these standards and benchmarks for service delivery. The demand for long term services and supports continues to rise as our state population grows and individuals with intellectual and developmental disabilities (I/DD) are living longer. The number of requests for home-and-community based services currently exceeds the state’s capacity leaving many individuals to wait years for needed support. While Texas has made improvements over the years to address these benchmarks, state contributions to institutions remain high and the investments in home and community based services have been too small to effectively rebalance the system.

Federal and state policies passed over this last biennium will ultimately strengthen the ability of individuals with developmental disabilities to live, work, be healthy, and participate in their community. The anticipated impact of federal policy related to affordable health care, workforce innovation, and home and community based settings will require Texas to change the way it does the business of long term services and supports. Similarly, Texas legislative action related to state supported living centers, expansion of Medicaid managed care, and employment first policies are shifting the types and manner in which individuals access needed supports. Those who need guardianship, individuals with complex needs, and individuals with both developmental disabilities and mental illness are particularly vulnerable and costly if not strategically addressed.

However, the current policy environment offers multiple opportunities for Texas to be proactive and lead with innovation. System recommendations include, but are not limited to:

- Rebalance the system that serves persons with I/DD by expanding cost-effective policies that honor the choices of individuals to live in the most integrated setting to meet their needs, identifying and providing supports and services to meet the needs of persons when and where they need them, and transferring the inevitable savings so that more persons with disabilities have the opportunity to be included in their communities.
- Define an overall vision and commitment to the prevention of developmental disabilities and develop an integrated plan across multiple disciplines to strengthen assessment and early intervention.
- Develop and implement strategies that address the needs of families in crisis to prevent the unnecessary placement of children in any institutional setting.
- Address the current and looming direct support workforce shortage by collecting and analyzing trends regarding workforce demographics and wages, developing and promoting a peer support workforce, expanding consumer direction, and restructuring payment methodologies to ensure that the Texas Legislature has the ability to set direct service wages at levels commensurate with the value and scope of the service.
- Support the expansion of Medicaid under the federal Affordable Care Act. The expansion would have covered an additional 1.2 million Texans by 2016.
- Empower self-advocates and their families to fully benefit from the new federal home and community based settings guidelines in areas of individual privacy, control over one's schedule and activities, money management, visitors, and community involvement.
- Explore less restrictive alternatives to guardianship, such as supported decision-making, and direct the courts to determine whether alternatives could meet the needs of the person rather than guardianship.
- Jointly adopt and implement the Employment-First policy by the Health and Human Services Commission, Texas Education Agency, and the Texas Workforce Commission.
- Establish goals to increase the number of individuals in integrated, competitive employment and to decrease the number of individuals in workshops earning sub-minimum wage.

The *2014 Texas Biennial Disability Report* outlines the details of current policies and the opportunities Texas has to strengthen the continuum of support for individuals with developmental disabilities and their families. TCDD and TOPDD look forward to engaging policy makers in a meaningful, informed discussion over the next biennium about what is needed to move the Texas long-term services and supports system forward to serve individuals and families with efficiency and promptness.

About Developmental Disabilities

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000 (P.L. 106-402) defines a developmental disability as a severe chronic disability of an individual five years of age or older that:

- ❖ is attributable to a mental or physical impairment or combination of mental and physical impairments;
- ❖ is manifested before the individual attains age 22*
- ❖ is likely to continue indefinitely;
- ❖ results in substantial functional limitations in three or more of the following areas of major life activity:
 - self-care
 - receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living
 - economic self-sufficiency
- ❖ 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.

*An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 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 those criteria later in life.

About Preventable Developmental Disabilities

Huge strides have been made in the prevention of intellectual and developmental disabilities (I/DD). Each year, our nation prevents thousands of developmental disabilities through increased screenings, dietary supplements, vaccines, preventative safety measures and early interventions. In an ever-changing society, these successes have established a solid foundation to build on and advance the charge of prevention. Texas is well positioned to focus on the future and strategically expand prevention efforts, thus improving outcomes for Texas children. The integration of prevention into the full range of existing health and human services is critical because it is cost effective, simple and provides opportunities to reach large populations with consistent messaging. Secondary disabilities, including mental illness, are those that are connected with a primary disability but were preventable. For instance, a child who has a speech/language disorder and receives appropriate and timely intervention could avoid serious reading problems in the future.

Research indicates that 95% of individuals with a primary developmental disability also experience secondary disabilities. Mental illness, disrupted school experiences, trouble with the law, confinement, inappropriate sexual behavior and alcohol/drug problems are all experiences and challenges commonly facing individuals with a developmental disability. Secondary disabilities can reasonably be avoided or mitigated through improved interventions and support for the individual and family. The needs of people with I/DD must be addressed holistically and integrated in the many areas of service available.

Research on epigenetics is revealing that genetics related to I/DD is far more complex than it was once considered. The good news in this research is it is demonstrating that genes can be "turned on" and "turned off," providing increased opportunities for prevention. This research is in its infancy but it promises to revolutionize prevention. As systems apply the new knowledge of protective and risk factors, they can mitigate risk. For instance, the research on the impact of stress and nutrition on a fetus, infant or child is demonstrating both the power of prevention and the consequences of missing prevention opportunities. Texas is working with national experts who can bring the latest research to guide the system in building a healthier future for the children of Texas.

About the Texas Council for Developmental Disabilities

The Texas Council for Developmental Disabilities (TCDD) is governed by a 27-member board appointed by the Governor. At least 60 percent of the members of the board are individuals with developmental disabilities, parents of young children with developmental disabilities, or family members of people with developmental disabilities who are unable to represent themselves.

Members also include Texas state agency representatives from agencies that provide key services and supports to individuals with developmental disabilities: the Department of Aging and Disability Services, the Department of Assistive and Rehabilitative Services, the Department of State Health Services, the Health and Human Services Commission, and the Texas Education Agency. Disability Rights Texas (the state's legal protection and advocacy agency), the Texas Center for Disability Studies at The University of Texas, and the Center on Disability and Development at Texas A&M University are also agency members.

TCDD is guided by the federal Developmental Disabilities Act (DD Act) that says that individuals with developmental disabilities and their families should participate in the design of, and have access to, needed community services, individualized supports, and assistance that promote self-determination, independence, productivity, and integration and inclusion in all areas of community life, through culturally competent programs. Specifically, the federal Developmental Disabilities Act (DD Act) directs TCDD to engage in:

- ❖ systems change (example: the way agencies and other organizations do business to improve outcomes for individuals with developmental disabilities (DD) and families),
- ❖ advocacy (example: educating policy makers about unmet needs), and
- ❖ capacity building (example: helping communities grow their resources).

TCDD is established as a state agency by state and federal law to support and promote community inclusion and integration of people with developmental disabilities. The Council uses information about the system of service provision, disability-related issues, and consumer needs to develop projects and activities that address gaps and barriers in services and supports in order to help the estimated 489,500 Texans with developmental disabilities live, work, and contribute to their communities.

Texas Council for Developmental Disabilities Members

| Member | City |
|---------------------------------------|---|
| Mary Durham (Chair) | Spring |
| Andrew Crim (Vice-Chair) | Fort Worth |
| Hunter Rebecca Adkins | Lakeway |
| Kimberly Blackmon | Fort Worth |
| Kristine Clark | San Antonio |
| Gladys Cortez | McAllen |
| Kristen Cox | El Paso |
| Mateo Delgado | El Paso |
| Stephen Gersuk | Plano |
| Diana Kern | Cedar Creek |
| Ruth Mason | Houston |
| Scott McAvoy | Cedar Park |
| Michael Peace | Poteet |
| Dana Perry | Brownwood |
| Brandon Pharris | Beaumont |
| David Taylor | El Paso |
| Lora Taylor | Houston |
| John Thomas | Abilene |
| Richard Tisch | Spring |
| Member (Alternate) | Agency |
| Mary Faithful (Patty Anderson) | Disability Rights Texas |
| Penny Seay | Texas Center for Disability Studies (UT Austin) |
| Michael Benz (Amy Sharp) | Center on Disability and Development (Texas A&M) |
| Nancy Walker (April Young) | Health and Human Services Commission |
| Penny Larkin | Texas Department of Aging and Disability Services |
| Sara Kendall | Texas Department of Assistive and Rehabilitative Services |
| Manda Hall, MD (Ivy Goldstein) | Texas Department of State Health Services |
| Cindy Swain (Barbara Kaatz) | Texas Education Agency |

About the Texas Office for Prevention of Developmental Disabilities

The Texas Office for Prevention of Developmental Disabilities (TOPDD) is administratively attached to the Health and Human Services Commission. TOPDD is a public-private partnership overseen by an executive committee with members appointed by the Governor, Lieutenant Governor, and the Speaker of the House.

Importance of the Structure of the Office:

- It is instrumental in the fundraising efforts of the Office.
- Since the Office began, the state has only paid for approximately 20% of TOPDD's budget, while the Office has raised 80%.
- It facilitates the active involvement and leadership of organizations in the state.
- Over 100 leaders representing diverse entities plan and organize the work of TOPDD.
- It allows TOPDD to facilitate the development of public policy to prevent developmental disabilities, which would not be possible without its independence.
- Public policy development is a core function of TOPDD.

Major Areas of Focus:

The majority of the Office's work focuses on fetal alcohol spectrum disorders, brain injury and co-occurring developmental disabilities with mental illness. TOPDD also assesses the full range of preventable developmental disabilities to better position the state to implement targeted prevention strategies. The Office develops reports and updates on these issues:

- Spearheading state planning
- Developing resources
- Educating and engaging stakeholders
- Convening leaders to facilitate collaboration
- Integrating prevention across systems
- Improving public policy

TOPDD is the only state entity building a coordinated and focused prevention approach that uses the latest research to minimize the incidence and severity of preventable developmental disabilities.

Texas Office for Prevention of Developmental Disabilities Members

| TOPDD Executive Committee Members: |
|--|
| Richard Garnett, Ph.D, Chair |
| Marian Sokol, Ph.D, MPH, Vice-Chair |
| Ashley Givens |
| Valerie Kiper, DNP, MSN, RN, NEA-BC |
| State Representative Elliott Naishtat |
| State Representative Ron Simmons |
| Mary Tijerina, PhD, MSSW |
| Joan Roberts-Scott |

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Report Methodology

This *2014 Texas Biennial Disability Report* is a collaborative report prepared by the Texas Council for Developmental Disabilities (TCDD) and the Texas Office for Prevention of Developmental Disabilities (TOPDD).

This report updates the Texas specific data contained in the *2012 Texas Biennial Disability Report* as directed by Texas Government Code Title V, Chapter 531 (See Appendix A) that asks for a summary of the state of developmental disability services in Texas. In responding to the state request for projections of future demand, TCDD and TOPDD reviewed national data comparing Texas and national spending on Medicaid residential facilities, intermediate care facilities, and home and community based services. The most recent national data was compiled in 2012 and is provided here.

TCDD and TOPDD reviewed and synthesized information from a variety of sources including peer-reviewed academic articles, state and national research reports, and demographic data and projections. Data were obtained from the Texas State Data Center, and Texas health and human service agencies including the Health and Human Services Commission, the Department of Aging and Disability Services, the Department of Assistive and Rehabilitative Services, the Department of State Health Services, and the Department of Family and Protective Services.

A detailed analysis is provided of the policy actions taken by the United States Congress, as well as the 83rd Texas Legislature that impact persons with developmental disabilities. The anticipated federal policy impact of federal health care, workforce innovation, and Medicaid home and community based settings are included. Texas policy related to state supported living centers, Medicaid managed care, employment first, guardianship, services for individuals with complex needs, and the co-occurrence of developmental disabilities and mental health are discussed.

This report summarizes information from the Sunset Advisory Commission, which conducted its review of health and human service agencies this year and made recommendations for each agency. The Sunset recommendations, if approved by the Legislature, will significantly change the way Texas provides long-term services and supports in our state moving forward.

State of the State for Developmental Disabilities

Demand for publicly funded developmental disabilities services is growing nationwide and has been increasing at a rate slightly greater than population growth alone. Increased demand is the product of several factors including a reduction in large congregate and institutional options, the increased utilization and capacity of community services and supports that better meet the needs of individuals and families, and the increased longevity of people with developmental disabilities. The following sections discuss these current and future trends in service demand and how Texas compares with other states providing services to those with intellectual and developmental disabilities (I/DD.)

Disability Rates in Texas

The term “developmental disabilities” refers to a group of conditions or disabilities that occur prior to or at birth, or during childhood (before age 22), and result in substantial functional limitations in three or more life activity areas (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency) and reflect the individual’s need for individualized supports and assistance.¹ Individuals with such functional limitations may have various diagnoses such as intellectual and developmental disabilities, cerebral palsy, epilepsy, autism, severe learning disabilities, brain injuries, and others that may impact intellectual or physical function. People with developmental disabilities may need assistance throughout life in self-care, housing, employment, and social interaction. It is estimated that the rate of developmental disabilities is 1.5-2.5% of the population.² In Texas with a population of 26.4 million, this translates to approximately 489,500 or more state residents with developmental disabilities.

Rates of Select Preventable Developmental Disabilities

Fetal Alcohol Spectrum Disorders

The Behavioral Risk Factor Surveillance System (BRFSS, 2011) found that 43.8% of women ages 18-44 in Texas drink, with 11.4% engaging in binge drinking (4 or more drinks in one sitting). Additionally, the Pregnant Risk Assessment and Monitoring (PRAMS, 2011) report found that 44.3% of women in Texas reported drinking three months before they were pregnant. These figures are similar to national figures for women. National studies indicate that one in eight

¹The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106 – 402106th Congress)

² *Intellectual Disability: Definition, Classification, and Systems of Supports*, 11th Edition. (2011). Washington, DC: American Association on Intellectual & Developmental Disabilities.

women continue to drink during pregnancy. The prevalence of Fetal Alcohol Spectrum Disorder (FASD) may be as high as one to five percent in the United States. This is higher than the prevalence of autism spectrum disorders. Given that the drinking rates in Texas are similar to national rates, it is a reasonable to assume that the national rates of FASD are reflected in Texas.

Brain Injury Prevention

According to the Texas Traumatic Brain Injury Advisory Council Report from 2007, approximately 3,500 children ages 0-19 suffer a brain injury each year, with about one third of those injuries resulting in a lifelong disability. Common causes of brain injury in children include transportation and bicycle accidents, along with sports related injuries, falls, and physical abuse/neglect. Leaders in Texas working on injury prevention could benefit from sharing and collaborating but they often do not know of each other's work. Texas needs to connect and recognize the outstanding leaders in child safety and is doing so through TOPDD.

Co-occurring Developmental Disabilities and Mental Illness

The prevalence of mental illness among individuals with developmental disabilities ranges from 30 to 40% (Quintero & Flick, 2010). Few systems are designed to identify and meet the needs of people with developmental disabilities and mental health disorders. Health and human services systems are not designed to identify or treat co-occurring developmental disabilities and mental illness. Consequently, individuals with these co-occurring disorders often are viewed as willfully non-compliant and "fail." This creates the revolving door and escalation of needs and services, along with further decline of the individuals. This leads to incredible costs for our systems and devastating results for the people being treated inappropriately. TOPDD recently launched a new, intensive study of this issue in Texas and is currently working on recommendations.

Trends in Service Demand

The movement toward community living for all persons with developmental disabilities has been gaining momentum. Being part of the community and living as independently as possible are among the most important values and goals shared by people with disabilities and their families. Individuals with disabilities continue to express a desire for access to services in a timely manner without having to wait for services; to receive services in the most integrated setting; and to have choice in deciding how services are delivered. Surveys indicate individuals with disabilities have the same goals as their neighbors — they want to have access to quality health care, have meaningful relationships, and be able to work and build assets needed to be independent and productive members of the community.

Despite this movement, Texas is one of the few remaining states that maintain a large system of public residential institutions for this population. Texas developed this system of centers over many years, housing as many as 13,700 residents when placing people with I/DD in institutions was the norm. Today, the vast majority of people with I/DD live in the community, and the 13 centers house only about 3,362 people. Yet maintaining this large system of state-run facilities is costly, involving a budget of \$661.9 million a year.³ Despite transitioning many residents into the community, Texas has not closed a facility since the 1990s.

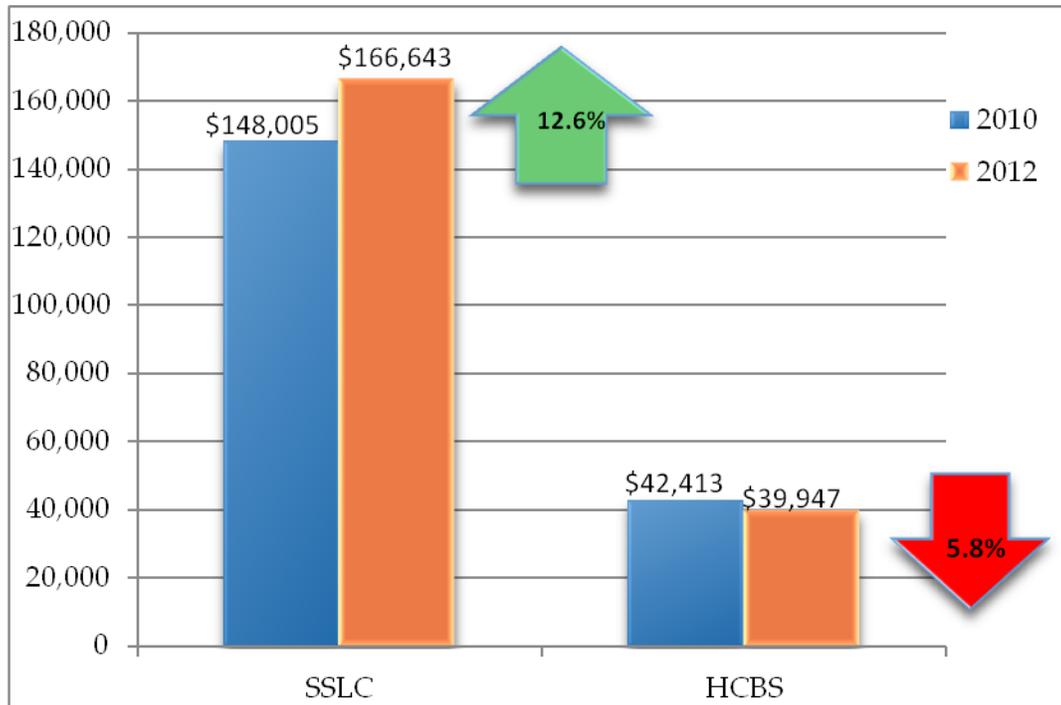
Although the service delivery system for people with I/DD has shifted to the community, Texas has chosen not to eliminate, but to only downsize the State Supported Living Centers (SSLCs), maintaining this costly infrastructure. Delivering services to a person for a year in an SSLC costs approximately \$113,000 more than serving people with similar levels of need in a community based program. In fiscal year 2013, DADS employed about 16,000 staff, 80 percent of whom worked in state supported living centers around the state.⁴

³ Sunset Advisory Commission Staff Report, Department of Aging and Disability Services, May 2014.

⁴ Ibid

Texas annual expenditures per resident in an SSLC were \$148,005 in 2010 and \$166,643 in 2012, a 12.6% increase.⁵ Expenditures for home and community based services participants were \$42,413 in 2010 and \$39,947 in 2012, a 5.8% decrease.⁶

Total Annual Expenditures Per Resident in a State Supported Living Center and Home and Community Based Service Recipient



The situation is exacerbated by the fact that Texas, for several decades, has been one of the fastest growing states. Between 2000 and 2010, the Texas population grew by 21%, from 20.8 million to 25.1 million⁷, while the U.S. population increased by 10%.⁸ Data from the Texas State Data Center suggest that the population of Texas could grow from 26.4 million in 2014 to 54.3 million by 2040.⁹

⁵ "3.A. Strategy Request: 82nd Regular Session, Agency Submission, Version 1 Automated Budget and Evaluation System of Texas (ABEST), Goal 1.8.1." *Budget & Data Management*. Department of Aging and Disability Services. 2010:1.

⁶ Ibid

⁷ 2014 Preliminary Population Projections by Migration Scenario for Texas – Report Texas State Data Center Projections Report (0.5 migration rate)

⁸ *U.S. and State Decennial Census Population Counts, 1990-2010*. Bureau of Business & Economic Research. 22 Dec. 2010. Web. 10 Sept. 2012. <http://bber.unm.edu/census/2010States.htm>.

⁹ 2014 Preliminary Population Projections by Migration Scenario for Texas – Report; Texas State Data Center Projections Report (0.5 migration rate)

Given such growth, it will be an extraordinary challenge to address the current backlog of unmet needs for long-term services while simultaneously keeping pace with population-driven growth in demand.

Trends in Home and Community Based Services

Nationally, the number of people with I/DD known to the state I/DD agencies or receiving residential services through a state I/DD agency increased from 693,691 in 1998 to 1,138,121 in 2012 (an average increase of 31,745 people per year). The number of people with I/DD living in a home they own or rent nearly doubled from 62,669 in 1989 to 122,664 in 2012. Similarly, the number of people living in the home of a family member also nearly doubled, increasing from 325,650 in 1998 to 634,988 in 2012.¹⁰

These trends have forced many states to reexamine how services are provided to people with developmental disabilities. Public policies increasingly support consumer choice and the rights of people with developmental disabilities to live with their families or in communities of their choice.¹¹ These policies are the result of research, advocacy, and federal actions such as the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the U.S. Supreme Court decision in *Olmstead v. L.C.* 527 U.S. 581 (1999). Initiatives in Texas have been consistent with these trends that promote the provision of services in the least restrictive manner possible and the philosophy that individuals should be supported to make decisions concerning their own lives.

To further reduce unnecessary institutionalization, Congress authorized the Money Follows the Person (MFP) program (2005) to help states decrease the number of people with disabilities living in Medicaid institutions. The legislation provided a system of flexible and supplemented financing for long-term services and supports to assist states in moving people to smaller more integrated, appropriate and preferred settings. Texas has been active in promoting independence and transition from institutional settings to the community for almost 15 years.

¹⁰ Larson, S.A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Pettingell, S., Anderson, L.L., Moseley, C., Sowers, M., Fay, M.L., Smith, D., & Kardell, Y. (2014). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

¹¹ Heller, T., Stafford, P., Davis, L.A., Sedlezky, L., and Gaylord, V. (Eds.). "Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities. Volume 23 (1)." Minneapolis: University of Minnesota, Institute on Community Integration and Research and Training Center on Community Living. 2010:2.

In response, the Medicaid program today includes multiple community-based mechanisms through which states can request funds. Medicaid long term services and supports are increasingly provided to people with I/DD living in the home of a family member, a host home or the person's own home, as well as various sizes and types of community group home settings. Medicaid community based long-term services and supports include but are not limited to service coordination/case management, homemaker, home health aide, personal care, adult day services, day and residential habilitation, and respite care.

Trends in Capitated Service Delivery and Managed Care

A most notable trend has been the growth in the delivery of long-term services and supports through capitated Medicaid managed care programs. Specifically, Medicaid (CMS) Section 1115 Research and Demonstration Projects allowed states the flexibility to test new or existing approaches to financing and delivering Medicaid services including the option to provide home and community based services through a Managed Care Organization (MCO). Similarly, states could amend their Medicaid State Plan under the 1932(a) federal authority to implement a managed care delivery system. Finally, Section 1915(a) and (b) Managed care waivers allow states to use managed care delivery systems. A joint program (between 1915(c) and 1915 (b) waivers – also referred to as 1915b/c waivers) allows states to implement two types of waivers at the same time as long as all federal requirements were met for both programs. As of 2014, 26 states have contracts with MCOs to deliver long-term care for seniors and individuals with disabilities.¹²

More states are now turning to Medicaid managed care to control long term services and supports (LTSS) costs. Although managed care organizations can make budgeting more predictable, there is little definitive evidence about whether they actually save money or improve outcomes for individuals with disabilities. Further, states must contend with rising expenses for those individuals who are “dual-eligible” — those who are covered by both Medicare and Medicaid.¹³ Poor coordination between the two programs has led to inefficient delivery of services and confusion among program recipients and providers. A detailed summary of Medicaid Managed Care Reform in Texas is provided later in this report.

¹² "States Turn to Managed Care To Constrain Medicaid Long-Term Care Costs". Agency for Healthcare Research and Quality. 2014-04-09. Retrieved 2014-04-14

¹³ Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers. National Council on Disability. March 18, 2013.

Trends in the Aging of Individuals with Disabilities and Their Caregivers

There are an estimated 641,000 adults age 60 and older with I/DD in the United States and the numbers are expected to double in the next two decades. The average life expectancy of people with I/DD was just 22 years in 1931 but is now 63 years for males and 69 years for females.¹⁴ The causes of death for all individuals with developmental disabilities are similar to those of the general population (i.e., coronary heart disease, type 2 diabetes, respiratory illnesses, and cancer). At these rates, the number of American adults with I/DD aged 60 years and older is projected to reach 1.2 million by 2030.¹⁵

As they age, people with I/DD seek the same outcomes as people without disabilities, such as maintaining their physical and mental health and the ability to function as independently as possible, actively engaging with life through friendships, contributing to society, and meaningfully participating in community life. However, older adults with I/DD are often more vulnerable to conditions that will make their old age potentially more difficult. In comparison with adults without long-term disabilities, adults with I/DD are more likely to experience earlier age-related health changes, limited access to quality health care, and fewer financial resources. In addition, they are more likely to be living with parents into adulthood and have more limited social supports outside the family.

Although most adults with I/DD live with their families, just 7.1% of funding for I/DD services is for state-provided, community-based services for individuals living in the family home.¹⁶ Without a mandate for support to adults with I/DD and their families, most will receive few support services and face long residential services waiting lists.¹⁷ An urgent need exists for aging adults with I/DD and their families to have access to quality supports that address their age-related health and social changes in the face of aging family caregivers who may no longer be available for care. Already, more than 25% of family care providers are over the age of 60 years and

¹⁴ Centers for Disease Control and Prevention: Faststats: Life Expectancy, 2014. Accessed <http://www.cdc.gov/nchs/faststats/life-expectancy.htm>

¹⁵ Janicki, M.P., Dalton, A.J., Henderson, C.M., and Davidson, P.W. "Mortality and Morbidity Among Older Adults With Intellectual Disability: Health Services Considerations." *Disability and Rehabilitation*, 21. 1999:284–294.

¹⁶ Ibid

¹⁷ Lakin, K.C., Larson, S., Salmi, P. & Scott, N. (2009). Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

another 38% are between 41-59 years¹⁸. With the growing life expectancy of the individual and the aging of the informal caregiver, the system will be stretched further to absorb the new demand.

Texas' Rank in the Nation

Among the more than 60 million citizens who rely on Medicaid are about 9 million nonelderly people with disabilities, including 1.4 million children. While people with disabilities constituted 16.5% of Medicaid enrollees in fiscal year (FY) 2008, expenditures on their behalf represented 44 percent of total Medicaid spending.¹⁹ The proportion of total Medicaid expenditures spent on long-term supports for people with I/DD declined from 12.0% to 9.0%. It has remained below 10.3% since 1992.²⁰ Nationally, there has been a fundamental rebalancing of spending on individuals with disabilities in institutions as compared to spending on HCBS in the years since the *Olmstead* decision.

Further, the population of individuals with disabilities under 65 in nursing homes actually increased between 2008 and 2012. This is true even though 38 studies over the past seven years have clearly demonstrated that providing HCBS is more cost-effective than providing services in an institution²¹ – it costs less money to provide needed services in a community setting than an institution.

Since the Texas Council for Developmental Disabilities (TCDD) detailed the gaps in the Texas service system in 2008²², TCDD has advocated for more investment in home and community based services and less emphasis on large congregate facilities. In 2009, the 81st Texas Legislature increased funding for community services, but simultaneously increased funds for SSLCs, which maintained significant expenditures for institutional care. Similarly, in 2011, the 82nd Texas

¹⁸ Braddock, D., Hemp, R., & Rizzolo, M.C. (2008). *The state of the states in developmental disabilities: 2008*. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry.

¹⁹ Medicaid and CHIP Payment and Access Commission, "MACStats, Table 9," in *Report to Congress: The Evolution of Managed Care in Medicaid* (Washington, DC: Medicaid and CHIP Payment and Access Commission, June 2011).

²⁰ Larson, S.A., et.al (2014). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

²¹ US Senate HEALTH, EDUCATION, LABOR, AND PENSIONS COMMITTEE, Tom Harkin, Chairman "Separate And Unequal: States Fail To Fulfill The Community Living Promise Of The Americans With Disabilities Act." July 18, 2013

²² Agosta, John, Jon Fortune, Drew Smith, Kerri Melda, Robert Gettings, and Valerie Bradley. *Closing the Gaps in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. Texas Council for Developmental Disabilities. Oct. 2008:7.

Legislature maintained funding for SSLCs and actually decreased funding for community ICF facilities and Medicaid waiver programs. Thus, the imbalance in the Texas system that favors institutional care remains strong, despite some relative increases in community services.

Children Living in Institutions

The stated policy of Texas is that all children should grow up in families whenever possible and that all institutional placements of children are to be considered temporary.²³ Texas has been successful in moving more than 2,100 children from institutions to families since 2003 and a similar number have moved to less restrictive environments.²⁴

Despite these successes, approximately 1,259 children and young adults with developmental disabilities still resided in long-term care institutions as of August 2013.²⁵ In SSLCs, there were 203 children (6% of total SSLC census). Of the 116 new admissions (September 2013 to August 2014), 42 were children (36%). This is down from 50% in 2009 (88 children of 177 new admissions). These numbers represent the efforts Texas is making to expand community supports. (See Table 1)

Table 1: Number of Children Residing in Institutions (2013)

| Nursing Facilities | Small ICF | Medium ICF | Large ICF | SSLC | HCS | DFPS Licensed Facility | TOTAL |
|--------------------|-----------|------------|-----------|------|-----|------------------------|-------|
| 70 | 233 | 48 | 16 | 203 | 640 | 49 | 1,259 |

*Data reflect the number of children residing in an institution as of August 31, 2013.

**Of the 1,259 children in institutions, 842 are ages 18-21

The Department of Aging and Disability Services (DADS) received federal approval last fall to create a new target group in the Home and Community-based Services waiver for children who live in General Residential Operations or group homes for children with I/DD in Child Protective Services. Thus, children living in congregate foster care settings will now have the opportunity to grow up in a family environment with the use of Home and Community-based Services Host Homes.

²³ *Senate Bill 368 77 (R) Bill Analysis*. Texas Legislature Online. Web. 2 October. 2014 <http://capitol.state.tx.us/tlodocs/77R/analysis/html/SB00368F.htm>.

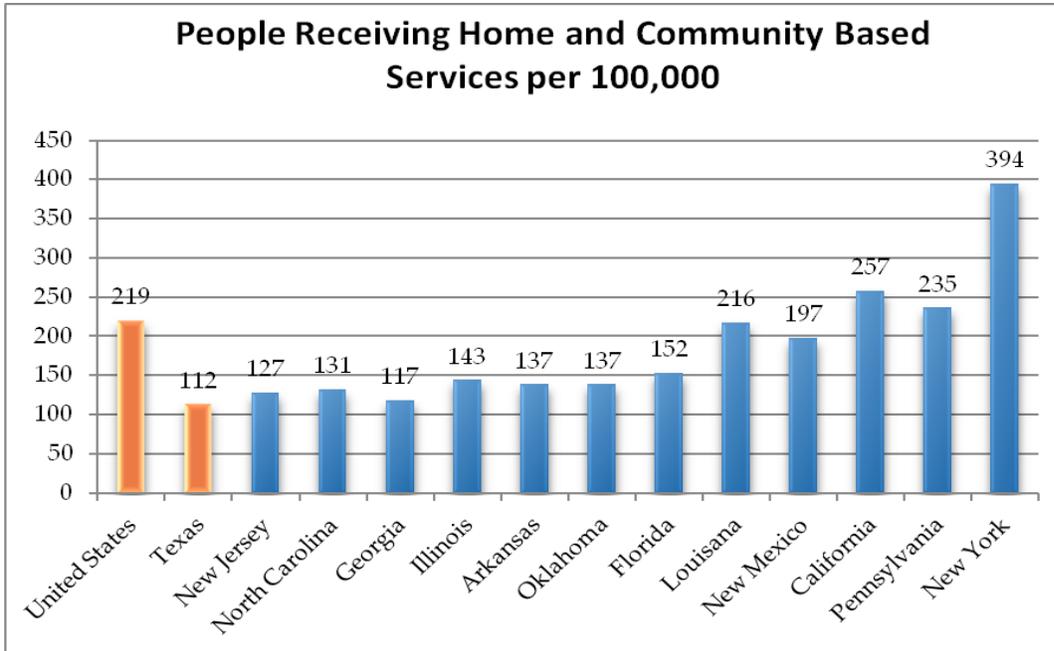
²⁴ Permanency Planning and Family-Based Alternatives Report, Texas Department of Aging and Disability Services, January 2013 www.hhsc.state.tx.us/reports/2014/SB368-Permanency-Planning.pdf Jan 14

²⁵ Ibid.

Home and Community Based Spending

Texas overall has a relatively low utilization rate for Medicaid home and community based services of 112 people per 100,000 of the state population.²⁶ This compares to the national average of 219 people per 100,000 (as shown in Chart 1). Only two states have lower home- and community-based services utilization rates than Texas – Mississippi and Nevada.²⁷

Chart 1. Home and Community Based Service Utilization



²⁶ I Larson, S.A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Pettingell, S., Anderson, L.L., Moseley, C., Sowers, M., Fay, M.L., Smith, D., & Kardell, Y. (2014). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

²⁷ Ibid

In FY 2012, Texas provided services and supports for 29,193 individuals with I/DD through the Medicaid home and community based service waiver programs and spent a total of \$1.05 billion on home and community based service waiver programs for persons with I/DD.²⁸

Table 2. Monthly Expenditures for Home and Community Based Waivers

| Medicaid Waiver | Population Served | Average Number Persons Served/Month | Monthly Cost Per Person | Annual Expenditures |
|---|--|--|--------------------------------|----------------------------|
| Community Based Alternatives | Age 21 and over with need for nursing home level of care | 9,553 | \$1,265 | \$146,496,512 |
| Community Living Assistance and Support Services | All ages with related condition such as cerebral palsy or epilepsy and eligibility for ICF/IID admission | 4,671 | \$3,610 | \$202,977,068 |
| Deaf Blind with Multiple Disabilities | All ages with deaf-blindness and eligibility for ICF/IID admission | 150 | \$4,257 | \$7,728,434 |
| Home and Community-based Services | All ages with intellectual disability or related condition with IQ of 75 or below, and eligibility for ICF/IID admission | 20,159 | \$3,489 | \$846,609,878 |
| Medically Dependent Children Program | Under age 21 with need for nursing home level of care | 2,291 | \$1,444 | \$39,818,738 |
| Texas Home Living | All ages with intellectual disability or related condition with IQ of 75 or below, and eligibility for ICF/IID admission | 4,611 | \$870 | \$48,308,518 |

²⁸ Larson, S.A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Pettingell, S., Anderson, L.L., Moseley, C., Sowers, M., Fay, M.L., Smith, D., & Kardell, Y. (2014). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Texas has a higher proportion of Medicaid long-term care recipients in ICF programs compared to the national rate.

- Of all Medicaid long-term care recipients nationally, 88.9% received home and community based services and 11.1% received services in an ICF²⁹
- In Texas, 75.5% of Medicaid long-term care recipients received services from home and community based programs and 24.5% received services from ICF.³⁰

Texas also spends a greater proportion of its Medicaid dollars on institutional care than almost all other states. Texas ranks second highest in the nation (after New York) with ICF expenditures now exceeding \$1.03 billion.³¹

Evidence Based Practices

Research advancements have changed the way that we understand the human brain. However, the majority of state systems and approaches were developed long before this critical research occurred. Today's research has tremendous implications for policy makers and many of the best researchers are located in Texas. Brain research has pinpointed where problems exist in the brain and behavior research has demonstrated what interventions are effective. The Infant and Toddler Courts in Texas are a great example of demonstrating how using more science-based approaches can boost success. Science based policies would reduce waste and improve outcomes to better meet the needs of the citizens of Texas.

Consumer Satisfaction

Section §2114.002 of the Texas Government Code, requires that Texas state agencies biennially submit to the Governor's Office of Budget, Planning, and Policy and the Legislative Budget Board information gathered from customers about the quality of agency services. The state compiles the results of over 119,000 individual survey responses from 34 surveys conducted by health and human service agencies.³²

²⁹ Larson, S.A., et.al.. (2014). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

³⁰ Ibid

³¹ Ibid

³² Texas Health and Human Service System 2014 Report on Customer Service, June 2014.

The Long-Term Services and Supports Quality Review (LTSSQR) is one of the largest surveys conducted to assess the satisfaction, quality of care, and quality of life of individuals who receive long-term services and supports. The most recent LTSSQR was published in January 2013, and is based on data collected in 2009 and 2010.³³

The following outcomes in services and supports were reported by consumers across programs:

- Most people received the services they needed and were satisfied with information about how to access services and support
- Long-term services and supports facilitate personal goals, health, and well being
- At least three of four people reported feeling happy
- Access to transportation
- Choice to decide how to spend free time

The following areas in need of improvement were reported by consumers across programs (*in no particular order*):

- Community inclusion
- Feeling lonely often
- Access to timely preventive care
- Autonomy to take risks
- Choice of staff or case manager
- Control over transportation and spending money
- Privacy when visiting with guests
- Work opportunities in the community

Consumer satisfaction with services among persons with I/DD is also measured by the National Core Indicators (NCI) survey, a collaborative effort that began in 1997 between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). NCI collects data on five core indicators: Individual Outcomes;

³³ *Long-Term Services and Supports Quality Review 2010*. Texas Department of Aging and Disability Services. January 2011:41.

Health, Welfare, and Rights; System Performance; Staff Stability; and Family Indicators. Texas has been an NCI State since 2005-06. NCI is a voluntary effort used by multiple states to evaluate and support efforts to improve system performance and better serve consumers. NCI survey respondents are individuals with developmental disabilities and their families. With approximately 29 states participating, Texas can examine its own outcomes, and measure its progress against national averages of the same measure. Specific results of the NCI survey³⁴ are highlighted below.

Approximately 81% of the Texas respondents report that they do get the services they need, which is similar to the average of all NCI states (82 percent).

Texas respondents report less choice than the average of responses from other NCI states³⁵:

- 46% of Texas respondents reported choosing or having input in choosing where they live, which is lower than the average of all NCI states (60%).
- 72% of Texas respondents reported that they choose or help decide their daily schedule, which is considerably lower than the average of all NCI states (81%).
- 74% of Texas respondents reported helping to make their service plan, which is lower than the average of all NCI states (85%).
- Approximately 59% of Texas respondents chose or were aware they could change their case manager or service coordinator, which is similar to the average of all NCI states (60%). Approximately 54% reported they could request a change if needed.
- 19% of Texas respondents use the Self-Directed Supports Option which is higher than the average of all NCI states (11%). **not all states offer this option*

NCI Indicators also suggest Texas respondents are less involved in community employment³⁶:

- Only 9% of Texas respondents reported being in a community paid job, which is lower than the average of all NCI states (15%).
- 69% of Texas respondents go to a day program or do other activities during the day. This is similar to the average of other NCI states (72%).

³⁴ National Core Indicators Adult Consumer Survey 2012-2013, National Association of State Directors of Developmental Disability Services and Human Service Research Institute, June 2014.

³⁵ Ibid

³⁶ National Core Indicators Adult Consumer Survey 2012-2013, National Association of State Directors of Developmental Disability Services and Human Service Research Institute, June 2014.

- Only 16% of Texas respondents reported having community employment as a goal in their service plan, which is much lower than the average of all NCI states (24%).

The quality management expectations for the operation of home and community based services (HCBS) continue to evolve. Most recently, the Centers for Medicare and Medicaid (CMS) issued new (effective March 2014) HCBS quality requirements for HCBS settings and person centered service planning. In addition, CMS revised the HCBS Quality Assurance and Sub-Assurance, which also became operative in March 2014.³⁷ A full description of the new HCBS rules are provided later in this report. The NCI Survey will serve as a resource to assist Texas with these and other service system reporting outcomes and service goals.

Future Demand

Texas faces difficult policy choices in responding to the needs of its citizens with intellectual and developmental disabilities in the future. This circumstance is fueled by overall population growth and the unmet demand for services, changing expectations among people with developmental disabilities and their families about where and how services are delivered, and diminished funding from state and federal sources. Texas has made significant strides and investments to ensure that individuals have the ability and right to live in the most integrated setting as required by the Americans with Disabilities Act and upheld by the U.S. Supreme Court's Olmstead decision in June 1999. Through Executive Orders GWB 99-2 and RP-13, Texas made a strong commitment to provide community-based services to individuals and ordered the development of a Texas Olmstead plan. Since the development of the Texas Promoting Independence Plan in 2001, over 41,000 Texans with disabilities, both old and young, have moved from institutions to the community, where services on average cost significantly less than in institutions. Legislative appropriations have consistently provided resources for expansion of home and community-based services; however, funds have not kept up with demand resulting in extensive interest lists for these programs.

³⁷ National Core Indicators Adult Consumer Survey 2012-2013, National Association of State Directors of Developmental Disability Services and Human Service Research Institute, June 2014.

Interest List for Home and Community Based Services

When demand for the Medicaid community-based services and supports outweighs available resources, consumers can choose to put their names on an interest list until services become available. Applicants are placed on interest lists on a first-come, first-served basis and will be contacted when services become available.³⁸ Service availability occurs when the legislature allocates funds to include more persons in a waiver or when an existing participant vacates services.

The Centers for Medicare and Medicaid Services (CMS) approved the use of managed care strategies in the provision of long term services and supports under the condition that all SSI eligible individuals with a medical necessity for nursing facility services were automatically enrolled in the STAR+PLUS LTSS waiver. This meant that as Medicaid managed care expanded across the state, all of the persons on the Community Based Alternatives (CBA) waiver waiting list were automatically assessed and, if eligible, enrolled in LTSS waiver services. The condition that resulted is the near elimination of the CBA waiting list is not anticipated in future managed care rollouts – specifically for people with I/DD. The number of people on waiting lists for other Medicaid waiver programs serving individuals with I/DD continues to increase. In Texas, it has been calculated that home-and community-based waiver services would have to expand by 334% above current spending to accommodate the needs expressed by the interest list.³⁹ TCDD and TOPDD recommend that in future rollouts, persons who are SSI eligible should receive long term services and supports across all waivers without a wait.

³⁸ Interest List Reduction. Department of Aging and Disability Services, Web. 11 Aug. 2012. <http://www.dads.state.tx.us/services/interestlist/index.html>.

³⁹ Bragdon, Tarren. *The Case for Inclusion 2012*. United Cerebral Palsy. Washington, DC. 2012:6 of 7.

Home and community based waivers provided long-term services and supports to 29,193 individuals as of June 2012,⁴⁰ and the HCS waiver presently has the largest interest list at 72,042.⁴¹ (See Table 3).

Table 3. Interest List Summary Fiscal Years 2013 – 2014

| | CBA | STAR+ | CLASS | DBMD | MDCP | HCS | Total |
|--|--------|--------|--------|------|--------|--------|-----------|
| Number of Clients on IL - September 1, 2013 | 6,579 | 5,034 | 48,169 | 543 | 27,012 | 67,201 | 154,538 |
| Total Released/Removed from IL* | 10,091 | 17,807 | 1,377 | 317 | 3,765 | 1,372 | 34,729 |
| Enrolled | 1,363 | 910 | 62 | 6 | 307 | 445 | 3,093 |
| In the Pipeline | 476 | 5,947 | 794 | 208 | 1,000 | 672 | 9,097 |
| Denied/Declined | 8,252 | 10,950 | 521 | 103 | 2,458 | 255 | 22,539 |
| Current IL - August 31, 2014 | 3 | 12,564 | 51,581 | 428 | 27,121 | 72,042 | **163,739 |

* The counts for CBA, CLASS, DBMD, and MDCP include releases from FY12-13 that were still in the pipeline as of August 31, 2013.

** Count is duplicated. The unduplicated count is 112,819. The Unduplicated count without Star+Plus is 100,255.

*August, 2014, Texas Department of Aging and Disability Services

⁴⁰ Larson, S.A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Pettingell, S., Anderson, L.L., Moseley, C., Sowers, M., Fay, M.L., Smith, D., & Kardell, Y. (2014). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

⁴¹ *Interest List Reduction*. Department of Aging and Disability Services, August 2014. Archives retrieved from: <http://www.dads.state.tx.us/services/interestlist/index.html>.

Individuals can wait over 10 years before receiving HCS services, with 68% waiting up to five years to receive services (See Table 4).

Table 4. Average Wait Times on Interest List - Fiscal Years 2014

| Average Wait Times on Interest List | CBA | STAR+ | CLASS | DBMD | MDCP | HCS |
|-------------------------------------|-----|--------|-------|------|-------|-------|
| 0-1 years | 3 | 12,415 | 4,572 | 126 | 4,181 | 6,472 |
| 1-2 Years | N/A | 141 | 5,233 | 105 | 4,769 | 7,923 |
| 2-3 years | N/A | 3 | 5,574 | 140 | 4,735 | 8,471 |
| 3-4 years | N/A | 2 | 6,828 | 57 | 5,253 | 8,584 |
| 4-5 years | N/A | N/A | 6,967 | N/A | 4,617 | 8,939 |
| 5-6 years | N/A | N/A | 6,243 | N/A | 3,566 | 7,834 |
| 6-7 years | N/A | N/A | 5,504 | N/A | N/A | 6,162 |
| 7-8 years | N/A | N/A | 4,779 | N/A | N/A | 5,210 |
| 8-9 years | N/A | N/A | 3,083 | N/A | N/A | 4,143 |
| 9-10 years | N/A | N/A | 2,348 | N/A | N/A | 3,209 |
| 10-11 years | N/A | N/A | 450 | N/A | N/A | 3,132 |
| 11-12 years | N/A | N/A | N/A | N/A | N/A | 1,959 |
| 12-13 years | N/A | N/A | N/A | N/A | N/A | 3 |
| 13-14 years | N/A | N/A | N/A | N/A | N/A | 1 |

*Some persons on the DBMD interest list have reached the top of the list multiple times and declined services, yet choose to remain on the list.

August 2014, Texas Department of Aging and Disability Services

In evaluating Texas benchmarks, individuals with developmental disabilities do not receive services with reasonable promptness. This is evident in the service utilization rates in Texas that are far below the national average. When an individual applies for services and is determined eligible, ideally that individual will receive services with reasonable promptness. General standards indicate that individuals with emergency or crisis needs should receive services within 90 days and individuals with critical near-term needs should receive services within six to nine months.⁴² In Texas, demand for services exceeds the available service openings, as evident in its large interest list for services.

Promising opportunities exist for Texas to continue to rebalance the LTSS system and assist people to move into the community. Texas was awarded a Balancing Incentives Program grant from the Centers for Medicare and Medicaid Services that is assisting the state in developing the structural changes necessary to support people to live in the community. The grant allows the state to receive a two percent increase in the Federal Medical Assistance Percentage (FMAP) on community services through 2015. Texas also continues to participate in the Money Follows the Person Demonstration that provides enhanced match for eligible populations transitioned from nursing facilities (NF) and large and medium sized intermediate care facilities for individuals with an intellectual disability or related conditions (ICFs/IID). In addition, Texas is developing the Community First Choice option in the Medicaid State Plan and will receive a six percent increase in FMAP for services that support people in their homes once the option is implemented.⁴³

Texas Sunset Review of Health and Human Service Agencies

Under state law, the Sunset Advisory Commission regularly reviews state agencies to determine effectiveness, duplication, and ways to make improvements. This biennium, all of the state's health and human services agencies, including the Texas Council for Developmental Disabilities, and the Texas Workforce Commission were reviewed.

The review process began the summer of 2014 and will continue through the 84th Texas Legislative Session in 2015.

⁴² Agosta, John, Jon Fortune, Drew Smith, Kerri Melda, Robert Gettings, and Valerie Bradley. *Closing the Gaps in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. Texas Council for Developmental Disabilities. Oct. 2008:

⁴³ Ibid

The Recommendations of the Sunset Commission⁴⁴ have significant implications if approved by the Texas Legislature by ultimately changing the way Texas provides long-term services and supports. While a list of all Sunset Review Recommendations is beyond the scope of this report, it is important to mention the following components of the recommendations that may impact persons with disabilities.

Advisory Roles and Meaningful Stakeholder Input

The Sunset Commission reported that statutory advisory groups are often difficult to administer, inflexible, and not fully accessible to the public. The review also found that many of HHSC's advisory committees are unnecessary, duplicative, and not truly accessible to the public. As these recommendations are discussed, TCDD and TOPDD strongly encourage HHSC to maintain a strategic and robust stakeholder involvement process in long-term care services and supports. The Texas service delivery system cannot be designed, implemented, or effectively evaluated without meaningful input from the individuals and families who receive services. As the Sunset Commission makes its final recommendations, HHSC must seek input that maintains a consumer voice.

System Level Expertise in Developmental Disabilities

The Sunset Commission recommended the consolidation of the current five HHS system agencies into one agency called the Health and Human Services Commission.⁴⁵ While this approach may improve administrative function, there is great potential to impact quality by diluting the already limited expertise in I/DD in the state system. Long term care services and supports must be administered and delivered by those who understand the unique aspects of I/DD and how to achieve meaningful outcomes in the service delivery system.

The Texas Council on Developmental Disabilities (TCDD) and the Texas Office of Prevention of Developmental Disabilities (TOPDD) were also reviewed by the Sunset Commission this year. TCDD and TOPDD support the continuation of TOPDD. A detailed analysis of the Sunset Recommendations and rationale for continuation are included in Appendix B.

⁴⁴ Health and Human Services Commission: Special Report. Texas Sunset Commission Staff Report Summary. October 6, 2014

⁴⁵ Ibid.

Role of Preventive Services

While the state offers many prevention services, it lacks an overall vision for prevention and an integrated plan that brings together the strengths of different disciplines in the system to provide consistent messaging and to build on each other's strengths. The state funds substance abuse prevention, child abuse prevention, child safety, tobacco cessation, etc. State agencies involved in prevention go far beyond those that are under the HHSC umbrella. While cross agency/system advisory groups exist, there does not appear to be requirements for cross-discipline and cross-agency collaboration or coordination or any accountability system to ensure collaboration. Requiring the development of a comprehensive, integrated plan for the integration of prevention would demonstrate a true commitment to prevention. Texas needs to map out measurable goals and strategies so that policy makers can demonstrate to constituents when progress is being made on these important issues.

TOPDD Action on Special Topic Areas

TOPDD facilitates two active task force groups in Texas: a Fetal Alcohol Spectrum Disorder Task Force, known as the FASD Collaborative, and the Child Safety and Injury Prevention (CSIP) Task Force. The membership of these task forces is extremely diverse and includes professionals from the following disciplines: medical, legal, mental health, education, substance abuse treatment and recovery, business, policy and others.

The FASD Collaborative

The FASD Collaborative is implementing the first-ever statewide plan on FASD, which TOPDD created through its FASD Collaborative in 2011. The plan was developed by exploring prevention needs and resources across Texas related to FASD and is a document that guides the work of the Collaborative. It addresses needs on a local, regional and statewide level. The FASD Collaborative has mobilized three active workgroups that are focusing on the following:

- Workgroup 1 Focus: The provision of FASD training and technical assistance to targeted professionals, such as medical and behavioral health providers who work with women of childbearing age
- Workgroup 2 Focus: The identification of existing and development of new Texas based epidemiology and surveillance information
- Workgroup 3 Focus: The development of policies that are guided by both Texas based and national research.

Through this work, TOPDD has engaged local and regional communities to take leadership on these goals and develop local initiatives.

Highlights of Local/Regional Initiatives

- San Antonio: TOPDD partnered with Alpha Home (a chemical dependency treatment center) to implement Project CHOICES, an evidence-based FASD prevention program, building a model that can be utilized across Texas to improve outcomes for children.
- Central Texas: TOPDD has partnered with the Central Texas Perinatal Coalition, to educate medical providers and other professionals who work with pregnant women.
- Houston: TOPDD partners with a host of organizations in Houston, including the Infant and Toddler Court, Houston Area Partnership on FAS, and the Santa Maria Hostel (a treatment facility). TOPDD has hosted several planning sessions targeting the child welfare system, has an ongoing intervention program in partnership with Santa Maria Hostel and has conducted several specialized education sessions in the region. Additionally, TOPDD has coordinated with the court system on educational projects (including as a sponsor the Keeping Infants and Toddlers Safe Conference) and has partnered with the community on several grant applications.
- Cross-Regional Initiatives: In collaboration with the Centers for Disease Control and Prevention and funding through the Meadows Foundation, TOPDD developed the FASD Training Center, a volunteer network of 160 professionals that TOPDD has trained to provide education on FASD on a regional level across Texas.

TOPDD's work on a local level has catapulted the topic of FASD to the top of larger regional and statewide training agendas, including major training events for state agencies. TOPDD's staff must increasingly rely on volunteers to conduct trainings because of the continuous increase in demand for training.

Child Safety and Injury Prevention Task Force

The Executive Committee of TOPDD conducted a needs assessment around child safety and organized key informant interviews to determine what the most pressing issues are in this field. This would help TOPDD to better target the membership for the task force. Several important issues emerged from these discussions:

1. Typically safety organizations focus either on "intentional and unintentional injury." However, this is a false separation. Parents who are accused of maltreatment seldom

intentionally harm their children. The area between intentional and unintentional injuries is extremely gray. In order to increase effectiveness, safety organizations must develop more comprehensive initiatives on prevention. As a result, TOPDD is convening organizations that are traditionally tied to either focus area. TOPDD's child safety award program brings together leaders from diverse communities working on a broad spectrum of child safety areas.

2. There is very little information-sharing or collaboration among safety organizations. Safety leaders need to learn what others are doing in the field, what research-based programs in safety exist in Texas and how to share data and information across systems. TOPDD is using Facebook and developing new communication tools to connect safety leaders on information sharing and data collection.
3. Safety leaders have tremendous knowledge and experience that would be invaluable to policy makers. However, because safety leaders are often grass roots, community-based initiatives, they often lack knowledge about how policies are made and/or changed. TOPDD is developing information that will educate safety advocates how to address policy.

One of the exciting ways that the CSIP is promoting and recognizing injury prevention work in the state of Texas is by honoring individuals and organizations that engage in this work with the J.C. Montgomery Child Safety Award, which was established by TOPDD in 2011.

Highlights of Safety Leaders

TOPDD has honored safety leaders who work in a wide-range of areas such as child protection, law enforcement, water safety, public policy related to safety, medical services, etc. Child safety is an incredibly diverse field and it is important for the state to recognize the many ways that individuals and organizations can promote safety.

Co-occurring Developmental Disabilities and Mental Illness Initiative

TOPDD has launched a new initiative on this issue through a grant from the Hogg Foundation. The goal of this work is to examine systems and policies in Texas to develop strategies that better meet the needs of this population. Many health and human services professionals have no training in identifying and working with people who have both developmental disabilities and mental illness. This can lead to recidivism, the removal of children from a family, incarceration and dangerous, life-threatening outcomes. Too often these problems become multigenerational. This is especially tragic, given that these outcomes are often preventable because they are the result of multiple failures to respond to the array of needs of the individuals.

With a staff of five people, TOPDD has educated over 2,500 professionals across the state and

facilitated over 55 trainings in the past two years. The work of preventing I/DD is extremely important for every Texan. In the coming years, Texas and the nation will experience tremendous growth of the population of older Americans. This will clearly put pressure on our health and human services systems. If Texas can be strategic about preventing disabilities in children, it will have an immediate and long-term impact on the state budget. The numbers related to prevalence and costs per incidence of preventable disability speak volumes.

TOPDD is reaching thousands of Texans and working with a wide range of systems to reduce these costs. Many children with preventable disabilities have tremendous talents, but have life dreams that can never be realized because of their disabilities. Ultimately, the Office seeks to make it possible for all children in Texas to reach their full potential and build a stronger, healthier Texas for generations to come.

Benchmarks for Service Delivery Performance

The goal of the Texas Council for Developmental Disabilities is to create system level change so that all people with disabilities are fully included in their communities and exercise control over their own lives. The Council works to ensure that people with developmental disabilities have opportunities to live in the community of their choice, be independent, have jobs, and have other services and supports needed for full participation in community life.

TCDD evaluates the long-term services and supports system in Texas against the following benchmarks:

1. People with developmental disabilities have access to and receive necessary publically funded services and supports with reasonable promptness.
2. Services and supports are provided in the most integrated setting appropriate to the needs of the individual.
3. The system must promote economy and efficiency in the funding and delivery of services and supports.

This report includes recommendations for how to improve the service delivery system to meet these benchmarks and better serve individuals with developmental disabilities (TCDD), and how to prevent developmental disabilities when possible (TOPDD).

Federal Policy: Impact on Persons with Disabilities

The 83rd Texas Legislature made significant changes to the system of long-term services and support. Most notable legislation includes the implementation of Medicaid managed care and the adoption of Employment First policies. Over the next biennium, Texas must also implement budget and spending changes, respond to Sunset Review recommendations, and work to implement new federal guidelines related to workforce innovation and home and community based services. A summary of how these federal and state policies will impact persons with developmental disabilities follows.

Federal Legislation

Over the 2013-2014 biennium, the United States Congress passed several pieces of legislation that specifically relate to individuals with disabilities. These policies will ultimately strengthen the ability of individuals with developmental disabilities to live, work, be healthy, and participate in their community. The following section describes the impact of these new federal policies.

Affordable Care Act

The Patient Protection and Affordable Care Act⁴⁶, has been referred to as the most significant change to the United States health care system since the implementation of Medicare and Medicaid in 1965. While this bill was originally passed by Congress in 2010, the state level implementation of this legislation began January 1, 2014. A recent study found that among adults age 18-64 with cognitive decline, 32.1% had private insurance, 41% Medicaid, and 27% Medicare, leaving 13.6% with no insurance.⁴⁷

Without adequate health care, individuals with I/DD who often have multiple health conditions are at risk for developing secondary disabilities. Compared to adults without disabilities, adults with I/DD are more likely to lead a sedentary lifestyle, have inadequate emotional support, and be in fair or poor health. The Affordable Care Act increases access to insurance coverage for individuals with developmental disabilities, places a greater focus on prevention, improves measurement of patient outcomes and quality of care, and structures a greater commitment to addressing underlying mental health and substance abuse problems.

⁴⁶ Pub.L. 111-148, 124 Stat. 119, codified as amended at scattered sections of the Internal Revenue Code and in 42 U.S.C. and Public Law 111-148. *111th United States Congress*. Washington, D.C.: United States Government Printing Office. March 23, 2010. Retrieved 2014.

⁴⁷ Altman, B. and Bernstein, A. *Disability and Health in the US 2001-2005*. Hyattsville MD National Center on Health Statistics 2008

Key provisions of the Affordable Care Act that impact people with disabilities include:

- ❖ Allows parents to cover children on their health insurance plans until the child reaches age 26
- ❖ Insurance providers may not discriminate against individual on the basis of their preexisting health status
- ❖ Increases coverage for habilitative or long-term services and supports
- ❖ Provides greater opportunities to access home and community based services through the Community First Choice Option, State Balancing Incentive programs, and Money Follows the Person
- ❖ Establishes patient centered medical homes
- ❖ Integrates primary care and mental health/substance abuse services
- ❖ Requires development of new standards for medical diagnostic exam equipment to ensure it is accessible for people with disabilities
- ❖ Requires new standards for data collection in national surveys on disability
- ❖ Potential for new funding to develop model curricula to increase ability of health professionals to work with people with disabilities

Rehabilitation versus Habilitation

As mentioned above, a key provision of the ACA is the inclusion of habilitative services. Yet, the scope of habilitation versus rehabilitation for persons with developmental disabilities is not yet defined. The U.S. Department of Health and Human Services (HHS) defines rehabilitation as: “Health care services that help a person keep, get back or improve skills and functioning for daily living that have been lost or impaired because a person was sick, hurt or disabled. These services may include physical and occupational therapy, speech-language pathology and psychiatric rehabilitation services in a variety of inpatient and/or outpatient settings.” Other services and devices that are often included are physician and nursing services; recreational therapy; music therapy and cognitive therapy for people with brain injuries and other conditions; psychiatric, behavioral and other developmental services and supports; durable medical equipment (DME), including complex rehabilitation technologies; orthotics and prosthetics; low vision aids; hearing aids and augmentative communication devices; and other assistive technologies and supplies.

These services and devices need to be provided in an array of settings, such as inpatient rehabilitation hospitals and other inpatient or transitional rehabilitation settings, outpatient therapy clinics, community provider offices, at a person’s home, and at various levels of intensity, duration and scope, depending on the severity of the condition and the functional impairment presented by the particular individual.

Definitions of habilitation are taken from the National Association of Insurance Commissioners (NAIC): “Health care services that help a person keep, learn or improve skills and functioning for daily living. Examples include therapy for a child who isn’t walking or talking at the expected age. These services may also include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings.”⁴⁸ The key difference is that habilitation usually refers to acquiring or learning skills whereas rehabilitation usually involves regaining skills that have been lost or improving or preventing deterioration of skills. Habilitative services are listed in the Affordable Care Act as an essential benefit, yet many insurance companies do not currently recognize habilitative services for coverage.

Advocates for people with disabilities nationwide have expressed support for the NAIC definition plus the Medicaid definition: “Services designed to assist individuals in acquiring, retaining and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings.”⁴⁹ Ensuring that habilitation includes learning a new skill or function is a critical aspect of the definition and coverage for persons with disabilities.

Medicaid Expansion in Texas

The Affordable Care Act offered states the opportunity to expand its Medicaid enrollment to cover more of the uninsured population. New policies would increase eligibility to low-income adult citizens at a higher rate of 133% of the federal poverty level (approximately \$15,282 for an individual; \$31,322 for a family of four). Many people with disabilities fall into the gap between traditional Medicaid eligibility and the requirements to participate in the insurance exchanges under the Affordable Care Act, and would likely be covered if Medicaid eligibility was expanded.

⁴⁸ NAIC Glossary of Terms for the Affordable Care Act (PDF)

⁴⁹ Social Security Act, Section 1915(c)(5)(A)

Medicaid expansion in Texas would extend coverage to an estimated 1.2 million uninsured Texans by 2016. Federal funds would cover 100% of the expansion for the first three years, and no less than 90% in subsequent years. This expansion, however, is optional for each state and Texas is not likely to expand coverage.

The expansion does not change current eligibility rules for home and community based services individuals – must meet current rules for determining financial eligibility including any asset test in Texas and the standards for having a disability and qualifying for services. However, Texas would have the opportunity to create new benefits packages for the people newly eligible as a result of the expansion and could add home and community, personal care, and habilitation services that are important to those with long term support needs.

TCDD supports reform measures and principles that provide individuals with consistent access to patient centered, timely, unencumbered, affordable and appropriate health care. Therefore, TCDD supports the expansion of Medicaid for Texas under the federal Affordable Care Act that would have covered an additional 1.2 million Texans by 2016. The Council supports the position that in any consideration of changes to the healthcare financing and delivery system in the United States, the well-being of the patient must be the highest priority.

The Autism CARES Act

One in 68 U.S. children has an autism spectrum disorder (ASD), a 30% increase from 1 in 88 just two years ago, according to the Centers for Disease Control and Prevention.⁵⁰ In 2000 and 2002, the autism estimate was about 1 in 150 children. Two years later 1 in 125 8-year-olds was believed to have autism. In 2006, the number grew to 1 in 110, and then the number went up to 1 in 88 based on 2008 data.

The increased prevalence of Autism in the United States led to the reauthorization of the Combating Autism Act of 2011, now called the Autism CARES Act.⁵¹ This bill was signed into law in

⁵⁰ "Prevalence of Autism Spectrum Disorder among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010," Centers for Disease Control and Prevention, March 2014.

⁵¹ Combating Autism Reauthorization Act of 2014 or Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 or Autism CARES Act of 2014 (H.R. 4631; Pub.L. 113–157)

August 2014. The Act authorizes \$1.3 billion over five years for research into autism while calling for federal agencies to examine and anticipate the needs of children with autism who are “aging out” of current programs and need different assistance as adults.

Other changes in the Autism CARES Act include the designation of a new deputy under the Department of Health and Human Services to oversee federal autism research and services. The bill requires a new government report on the needs of children with autism as they transition to adulthood. The bill also increases the number of family and self-advocate representatives on the Interagency Autism Coordinating Committee (IACC), which guides research on autism.

Achieving a Better Life Experience (ABLE) Act

American families face challenges in saving money for the long-term support needs of a family member with a disability. Perhaps the greatest is the fear of disqualifying a family member from eligibility for much-needed public benefits, such as supplemental income or long-term services and supports through the Medicaid system, through the buildup of assets. The federal legislation known as the Achieving a Better Life Experience (ABLE) Act (S.313 / H.R.647) would give people access to specialized savings accounts. People with disabilities and their families would be able to invest up to \$100,000 in these accounts without losing access to Supplemental Security Income, Medicaid services, or other important federal benefits for people with disabilities.⁵²

The purpose of the act is to provide secure funding for disability-related expenses on behalf of designated persons with disabilities that will supplement, but not replace, benefits provided through private insurance, the Medicaid program, the Supplemental Security Income program, employment, and other sources. Any person who is receiving SSI or disability benefits under Title II of the Social Security Act would be eligible to use an ABLE account. As a form of a 529 Account, funds in ABLE Act accounts could be spent on tuition and education expenses, housing, transportation, employment support, health expenses, assistive technology, personal assistance, and financial management services. These savings accounts would represent another tool that people and families can choose to avail themselves of; they would not replace other specialized long-term planning tools, such as Supplemental Needs Trusts. The ABLE Act has not yet passed

⁵² Adapted from “Achieving a Better Life Experience (ABLE) Act: Fact Sheet” created for the Disability Policy Seminar, available at: <http://www.thearc.org/document.doc?id=4638>

Congress, but has the support of over 380 co-sponsors and is expected to receive a vote by the end of the 2014 session.

Advancing Fetal Alcohol Spectrum Disorder (FASD) Research, Prevention, and Services Act

Senator Lisa Murkowski introduced S237 “Advancing Fetal Alcohol Spectrum Disorder (FASD) Research, Prevention, and Services Act” in February 2013 and it was assigned to the Senate Committee on Health, Education, Labor, and Pensions, where it did not receive a hearing. The bill directed the Secretary of Health and Human Services (HHS) to: (1) establish and carry out a research agenda for FASD; (2) facilitate surveillance, public health research, and prevention of FASD; and (3) continue the Interagency Coordinating Committee on Fetal Alcohol Syndrome. It also required the Secretary to provide financial assistance to: (1) establish or expand state FASD programs; (2) implement best practices to educate children with FASD, educate members of the criminal justice system on FASD, and educate adoption or foster care agency officials about services for children with FASD; (3) provide transitional services for those affected by prenatal alcohol exposure; (4) develop public service announcements to raise awareness of the risks associated with alcohol consumption during pregnancy; (5) increase awareness and identification of FASD in federally qualified health centers; and (6) provide respite care for caretakers, recruit mentors, and provide educational and supportive services to families of individuals with FASD. The bill has not yet passed, but will be proposed again in the 2015 session.

Workforce Innovation and Opportunity Act

The 2014 passage of the Workforce Innovation and Opportunity Act (WIOA) will improve employment opportunities and economic prospects for all Americans, including those with disabilities. This bill represents a reauthorization of the Workforce Investment Act of 1998 (WIA), including the Rehabilitation Act, through 2020. WIOA has the potential for significant advancement in employment of people with disabilities.

With only 20% of people with developmental disabilities represented in the general community workforce, the bill is designed to help workers with disabilities increase access to jobs, education, job-driven training, and support services that give them the chance to secure jobs, advance their careers, and build assets needed for independent living.

Primary provisions of the WIOA that impact persons with disabilities include:

- ❖ A much larger role for public vocational rehabilitation (VR) as people with disabilities make the transition from school to adult life.

- ❖ Required agreements between state VR systems and state Medicaid systems, and state intellectual and developmental disability (I/DD) agencies.
- ❖ A definition of “customized employment” in federal statute, and an updated definition of “supported employment” that includes customized employment.
- ❖ A definition for “competitive integrated employment” as an optimal outcome.
- ❖ Enhanced roles and requirements for the general workforce system and One-Stop Career Centers in meeting the needs of people with disabilities.
- ❖ A number of disability agencies moving from the Department of Education (DOE) to the Department of Health and Human Services, including the Independent Living Program.
- ❖ Changes in performance measures to include entering and retaining employment wages, education, skills and training, and serving employers.
- ❖ Requires that VR agencies allocate at least 15% of their federal funding toward transition efforts.

Sub-minimum Wage

The new policies of the WIOA specifically include efforts intended to limit the use of sub-minimum wage employment. Specifically, individuals age 24 and younger are prohibited from working jobs that pay less than the federal minimum of \$7.25 per hour unless they first try vocational rehabilitation services. This updated rule will take effect two years after the law’s enactment. Though the bill requires most young people to try competitive employment before working for less than minimum wage, there are exceptions for those who are deemed ineligible for vocational rehabilitation and to allow individuals already earning less than the federal minimum to continue in their jobs. In cases where individuals with disabilities do earn less than minimum wage, the WIOA policy establishes requirements that the individual periodically be provided career counseling by the state and are informed about other work opportunities.

New Rules for Home and Community Based Settings

Over the past five years, the Centers for Medicare and Medicaid Services (CMS) has engaged in ongoing discussions with stakeholders, states and federal partners about the qualities of community-based settings that distinguish them from institutional settings. As a result, CMS issued a final rule to ensure that Medicaid’s home and community-based services programs provide full access to the benefits of community living and offer services in the most integrated settings. These new rules, issued in January 2014, significantly change the way home and community-based services will be defined and delivered moving forward.

These new rules apply, or will apply, to all long term services and supports options in Texas.⁵³ The rule, as part of the Affordable Care Act, supports the Department of Health and Human Services' Community Living Initiative launched in 2009 to develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to participate in meaningful community living.

The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics. The final rule excludes certain settings as permissible settings for the provision of Medicaid home and community-based services. These excluded settings include nursing facilities, institutions for mental disease, intermediate care facilities, and hospitals. Other Medicaid funding authorities support services provided in these institutional settings. The rule supports enhanced quality, and adds protections for individuals receiving services.

Under the final rule, and to be eligible for continued federal funding, home and community-based services must be provided in settings that have the following community qualities based on the needs of the individual included in their person-centered plan⁵⁴:

- ❖ The setting is integrated in and supports full access to the greater community;
- ❖ Is selected by the individual from among setting options;
- ❖ Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- ❖ Optimizes autonomy and independence in making life choices; and
- ❖ Facilitates choice regarding services and who provides them.
- ❖ In addition, the final HCBS rules⁵⁵:
 - Define and describe the requirements for home and community-based settings appropriate for the provision of HCBS;
 - Define person-centered planning requirements across the section 1915(c) and 1915(i) HCBS authorities;

⁵³ Home and Community-based Services (Final Regulation CMS-2249-F/CMS-2296-F; see www.Medicaid.gov/HCBS)

⁵⁴ Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F). Centers for Medicare and Medicaid: January 2014

⁵⁵ Ibid

- Provide states with the option to combine coverage for multiple target populations into one waiver under section 1915(c), to facilitate streamlined administration of HCBS waivers and to facilitate use of waiver design that focuses on functional needs;
- Allow states to use a five-year renewal cycle to align concurrent waivers and state plan amendments that serve individuals eligible for both Medicaid and Medicare, such as 1915(b) and 1915(c); and
- Define and describe the requirements for community employment services.

The Texas Legislature has instructed state agencies on a number of occasions to make program modifications in the interest of moving the system toward more efficiency and uniformity. The federal HCBS rule gives the state the opportunity to comply with these directives more meaningfully and systematically improve all of the waivers by streamlining their rules and requirements through assessing and developing remediation plans across all of the waivers by topic/service through extensive stakeholder input for each waiver. Many waiver features substantially meet expectations in the federal HCBS rule, but there is great variation in the degree to which each of the waiver's services complies.

Integrated Community Employment

The new HCBS rules offer multiple opportunities to use waiver supports to increase employment opportunities for individuals with disabilities within current policy. While specific guidelines have yet to be released, CMS is asking states questions about waiver participants: Is the individual employed or active in the community outside the setting? Does the individual work in an integrated community setting? If the individual would like to work, is there activity that ensures the option is pursued? Does the individual participate regularly in meaningful non-work activities in integrated community settings for the period of time desired by the individual? These questions demonstrate CMS's commitment to the importance of community based employment for waiver participants.

Implementation Timeline

The implementation of the Home and Community Based Services settings rule is an ongoing process. CMS is currently working with states to provide detailed guidance on each waiver and each component of these new rules. All states must submit to CMS a plan for transitioning their current HCBS system into compliance with the new rule by March 17, 2015. States, like Texas, submitting a 1915(c) waiver renewal or amendment before March 17, 2015, must include a

transition plan in that submission. States then have 120 days from that submission date to submit a transition plan for the remainder of their HCBS system. Texas had one 1915(c) waiver expire before the March 17, 2015, deadline. The CLASS waiver was scheduled for renewal on August 31, 2014.

The Texas Department of Aging and Disability Services (DADS) held an HCBS Rules Stakeholder Meeting in October 2014 and plans to engage stakeholders, including program participants and providers, more meaningfully in the coming months.

Recommendations for Implementation of HCBS Rules

The following section outlines recommendations for how Texas should take advantage of the opportunities offered to individuals through the new HCBS rules:

1. Texas has the opportunity to assess and remediate the waivers in advance of the transition of long-term services and supports into managed care. For this reason, the STAR+PLUS waiver and its accompanying rules, policies and procedures must be included in the purview of a broader HCBS Settings Transition Workgroup.
2. Require the development of a person-centered plan across all home and community based waiver programs. Increase the enforcement to ensure providers are accountable and held to the principles of person centered planning.
3. Texas transition plans for each HCBS program that pays for day habilitation should include strategies that move toward Employment First and Community-based Non-Work (CBNW) and away from the current facility-based day habilitation programs and sheltered employment. Texas day habilitation programs do not typically, but could, provide much more community engagement for participants if required and reimbursed.
4. Prohibit the use of respite in an institutional setting in all home and community based waivers. Texas has prohibited the use of respite in an institutional setting in the HCS waiver. A similar exclusion should be included in the CLASS waiver and Medically Dependent Children Program (MDCP).
5. Engage in an educational campaign regarding the HCBS guidelines to empower self-advocates and their families to fully benefit from the new guidelines. This includes individual privacy, choice of roommates, control over one's schedule and activities, money management, visitors, and community involvement.

6. Ensure that people may have visitors of their choosing at any time, which may conflict with some providers' practices and routines.
7. Residential settings should build capacity for visitability. This barrier should be focused on in the current transition plan.
8. Expand individual options to ensure right to privacy, dignity and respect. Individuals in group homes do not have consumer directed options, which is contrary to the HCBS settings rule that requires individuals receiving Medicaid HCBS to have independence in making life choices, including but not limited to daily activities, physical environment and with whom to interact.

Other considerations for persons with disabilities that should be addressed in the implementation of the HCBS rules include:

- ❖ Co-location and spacing requirements that discriminate against persons with disabilities;
- ❖ Rules that encourage the development or maintenance of maximum self-reliance and independence with a goal of self-sufficiency;
- ❖ A community living options information process that encourages the most integrated settings and includes ongoing information to people in group homes and host homes, not just for those in institutions; and
- ❖ Uniform mandatory participation (program termination) requirements without sufficient due process protections.

The federal HCBS settings rule provides Texas with the opportunity to truly assess and make improvements to waiver programs so that waiver participants will be integrated in and have support for full access to services in the greater community, including opportunities to seek employment and work in competitive integrated settings, to control personal resources, and to engage in community life in the same way as people who are not waiver participants.

Texas State Policy: Impact on Persons with Disabilities

The 83rd Texas Legislature made significant changes to the way long term services and supports are funded and delivered in our state. The following sections provide an analysis of policy decisions made in the past biennium.

Texas State Budget

The 83rd Texas Legislature passed and the Texas Comptroller certified SB 1, the 2014-2015 biennial budget. It includes \$94.6 billion in General Revenue (GR), and \$197 billion in All Funds. Combined with the supplemental appropriation, the \$95 billion GR budget is an increase of less than 8% compared to 2012-13 GR spending. However, after adjusting for population and inflation, the GR for 2014-2015 is 8.4% below the levels in the 2010-2011 budget. For people with disabilities the budget funds many of the requested health and human services Exceptional Items to restore or expand services. The following summarizes the budget decisions made for selected health and human service programs important for people with developmental disabilities.

Department of Aging and Disability Services (DADS)

Medicaid Waiver Programs

DADS requested funding to provide services to 20% of the persons waiting on HCS and CLASS interest lists who are likely eligible for services. The legislature funded services for about 24% of the request for HCS and CLASS services.

| Community Expansion | | |
|---------------------|---------------|------------------|
| Waiver | Request | Funded 2014-2015 |
| HCS | 5,566 | 1,324 |
| CLASS | 3,056 | 712 |
| TxHmL | 574 | 3,000 |
| CBA | 982 | 100 |
| STAR+PLUS | 1,116 | 490 |
| MDCP | 238 | 120 |
| DBMD | 16 | 100 |
| Total Svcs | 11,548 | 5,846 |

Promoting Independence

The budget fully funded the DADS request for diversions and transitions from institutions into community waiver programs. New this biennium are HCS services for persons with I/DD to transition from nursing facilities and Child Protective Services group homes. The \$28.1M for promoting independence will be used to:

- Transition 400 people from large and medium ICFs into HCS services
- Transition 192 children aging out of foster care into HCS services
- Provide HCS services to 300 persons in crisis to prevent SSLC placement

- Provide CBA services to 100 persons in crisis to prevent nursing home placement
- Provide HCS services to 360 people with I/DD in nursing homes
- Provide HCS services to 25 children living in Child Protective Services group homes

Community First Choice

The budget includes a new basic attendant and habilitation service for 11,902 people with I/DD that would be delivered by managed care organizations (insurance companies). The new service will be made available to persons with a functional need who are also Medicaid eligible in March 2015.

Department of Assistive and Rehabilitative Services (DARS)

Early Childhood Intervention (ECI)

ECI provides services to eligible children with developmental delays that assist them to gain skills or improve development. The ECI request was fully funded to address the increase in the average cost of services that occurred as a result of the 82nd Legislature’s decision to narrow eligibility. The budget also included a rider that made \$63M of the total ECI appropriation contingent on a requirement that families earning above 400% of the federal poverty level pay 100% of the cost of ECI services. That means that a family of four earning more than \$94,200 is required to pay approximately \$400 per month for ECI services.

| Department of Assistive and Rehabilitative Services (DARS) General Revenue | | |
|---|----------------|-------------------------|
| Exceptional Items | Request | Funded 2014-2015 |
| 1. Maintain ECI Current Services | \$10.8M | \$10.8M |
| 2. Expand Autism Services to Unserved Areas | \$4.8M | \$2.4M |
| 3. Expand Independent Living Centers | \$2M | \$0 |
| 4. Access to Interpreter Services for the Deaf | \$1.3M | \$700K |
| 5. Deaf & Hard of Hearing Resource Specialists | \$840K | \$200K |
| 6. Comprehensive Rehab Services for 206 persons | \$11.8M | \$5.9M |

Autism Program

The DARS Autism Program provides intensive, evidence-based treatment to children ages 3-8 with a diagnosis of Autism Spectrum Disorder. The budget funds \$2.4M to establish two additional autism service locations and made the funding contingent upon a plan to provide services more efficiently to more children.

Comprehensive Rehabilitation Services

Individuals with a traumatic brain injury or spinal cord injury can receive post-acute rehabilitative services in the CRS program. The budget included added funding to provide CRS services to an additional 103 persons.

Independent Living Centers

The Legislature did not fund the DARS request for \$2M for three new Independent Living Centers (ILCs). Instead, a rider was added to require DARS to report on the actual and projected numbers of recipients served by each center and the types of services provided and make recommendations to improve the measurement, collection, and reporting of outcome data related to the centers.

Deaf and Hard of Hearing Services

The legislature funded about 42% of the DARS combined requests for Access to Interpreter Services and Access to Deaf and Hard of Hearing Services.

Department of State Health Services (DSHS)

Children with Special Health Care Needs

The CSHCN program covers services for children with extraordinary medical needs, disabilities, and chronic health conditions across the state. The program pays for medical care, family support services, and related services not otherwise covered. The budget included an additional \$6.6M.

Mental Health Funding

The budget included an additional \$154.8M to address mental health. This includes funds to eliminate the adult and children's waiting lists for mental health services.

| Department of State Health Services (DSHS) | |
|--|-------------------------|
| Workgroup Initiatives | Funded 2014-2015 |
| Public MH Awareness Campaign | \$1.6 M |
| School-based training for teachers and staff in prevention and early identification of MH. | \$5 M |
| Crisis Services | \$25 M |
| Expand Community MH for 6,242 Adults and 286 Children | \$20 M |
| Youth Empowerment Service (YES) Waiver Statewide Expansion | \$24.4 M |
| Collaborative Public-Private Partnerships | \$25 M |
| Expand Local MH Authorities to Serve Persons Who Are Underserved | \$17 M |
| Expand NorthSTAR to Serve Persons Who Are Underserved | \$6 M |
| Fund MH Services for Veterans | \$4 M |
| 1915i Home & Community Based Services Including Rental Assistance | \$24.8 M |
| 10 beds in private residential treatment centers (RTCs) for youth at risk for parental relinquishment of custody to DFPS | \$2 M |
| NEW Investment in Mental Health Services | \$154.8 M |

Health and Human Services Commission (HHSC)

Acquired Brain Injury

The budget provided \$2.1M to the Office of Acquired Brain Injury and to increase services and supports for persons with an acquired brain injury.

Attendant Wages

121,000 attendants received wage increases. The lowest wages were raised to \$7.50 per hour in FY 2014 and to \$7.86 per hour in FY 2015. The \$88.7M GR appropriation to increase wages also included \$20 million for provider rate enhancement. The original request was for \$176M for a \$0.50 per hour across-the-board wage increase.

Texas Department of Housing and Community Affairs

\$3.8M of the \$11.8M appropriated to the Housing Trust Fund was for the Amy Young Barrier Removal Program. This funding is available to fund architectural accessibility modifications in individual homes or rental units.

Prevention of Developmental Disabilities

Funding for prevention is a small fraction of the HHSC budget. Costs for prevention services during childhood are small in comparison with costs associated with caring for people who become more disabled because they did not receive the services that were needed early in life. These costs include juvenile justice or incarceration. Preventable disabilities (especially FASD and preventable mental illnesses), including those caused by trauma and/or abuse/neglect, are often factors in crimes that push children into these systems in the first place.

As the Sunset Commission noted in its report, the state has a tendency to pay for services downstream. The only way to change this is through prevention and to make prevention a priority on a system-wide basis and fund it accordingly. Policies that transform system and funding structures to prioritize funding are recommended.

Study on Alcohol and Controlled Substances Statistics

Current law includes the possession and use of certain drugs among the conduct that constitutes an offense of abandoning or endangering a child. However, these provisions do not apply to an unborn child. Interested parties have expressed concern for the unborn children of mothers who abuse alcohol and certain illegal substances during their pregnancy, specifically noting the long-term health consequences that can be directly attributed to prenatal alcohol or drug abuse.

HB 1396 (83R) adds temporary provisions, set to expire September 1, 2015, to require the Department of Family and Protective Services (DFPS) and the Department of State Health Services (DSHS), using existing resources, to conduct a study on alcohol and controlled substance statistics. The bill requires the study to determine whether either state agency currently compiles the following information: the number of children reported to the department who at birth tested positive for the presence of alcohol or a controlled substance and the controlled substances for which they tested positive; the number of such children who were removed from their homes and have been diagnosed as having a disability or chronic medical condition resulting from the presence of alcohol or controlled substances; and the number of parents who test positive for the presence of a controlled substance during a department investigation of a report of abuse or neglect of the parent's child.

The Co-Occurrence of Developmental Disabilities and Mental Illness

Individuals with co-occurring developmental disabilities and mental illnesses are a particularly vulnerable population of people served by the state mental health and developmental disabilities systems. While their numbers are relatively small, these individuals pose significant service delivery and funding challenges, requiring a coordinated array of treatment interventions and supports that necessitate the collaborative involvement of providers of both public systems.

People with developmental disabilities are three-to-four-times more likely to experience a mental health disorder than the general population.⁵⁶ This may be related to chemical imbalances, structural issues in the brain, or problems with connections between structures. Individuals with a co-occurring mental illness and developmental disability are at increased risk of homelessness, institutionalization and incarceration.⁵⁷ While early intervention is recommended for children with co-occurring conditions, factors such as poverty, education, and lack of insurance can result in less opportunity for early intervention support.

Despite these needs, services are often organized as mental illnesses or developmental disabilities – but not both. Thus, individuals with co-occurring conditions face specific barriers related to a lack of coordination and collaboration across service systems, as well as gaps in research, clinical expertise, and access to appropriate programs.⁵⁸ One service provider describes, “The idea of dual diagnosis (intellectual disability and mental illness) is complex because the diagnosis involves teasing out which portions of the individual’s problems are due to intellectual disability, which are due to mental illness, and which are due to learned behavior in a family system. Treatment involves specialized techniques that are sometimes adapted from mental health models to work with people with intellectual disabilities. This specialized treatment is not always attractive to providers given the current funding streams and reimbursement rates in Texas.”

⁵⁶ Cooper, S., Smiley, E., Morrison, J., Williamson, A., & Allen, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry*, 190, 27-35.

⁵⁷ The Importance of Integrated Services in a Downturned Economy, NADD Bulletin, Vol. XII, Number 4 (2009).

⁵⁸ Silka, V. R., & Hauser, M. J. (1997). Psychiatric assessment of the person with mental retardation. *Psychiatric Annals*, 27(3).

Through a grant from the Hogg Foundation, TOPDD has launched a new initiative to improve coordination and planning of policy efforts across systems to address the needs of people with co-occurring developmental disabilities and mental illness. This is the first time that a state entity has been awarded this two-year, renewable grant. The goals are to: 1) support policy efforts to provide universal and systematic surveillance and screenings for early identification of developmental disabilities and potentially co-occurring disorders; 2) promote incorporation of prevention efforts into all integrated care systems; 3) enable continuous access to integrated services for children at high-risk for co-occurring problems; and 4) develop recommendations for a collaborative response to dual diagnosis and tenets of integrated care across systems. Products of this program will include policy analysis and opportunities for prevention, an analysis of gaps and strengths in the current system, and development of recommendations of how systems can work together to improve prevention and treatment practices.

Recommendations for Serving Individuals with Both Mental Illness and I/DD

1. Increase collaboration between the mental health and developmental disabilities systems and primary care in order to better identify and track individuals with high risk needs, share expertise among providers, increase education for families, and translate research into practice.
2. Increase access to early intervention services and supports for children with co-occurring conditions.

State Supported Living Centers

The state supported living centers (SSLCs) provide campus-based direct services and supports to people with intellectual and developmental disabilities who are medically fragile or have complex behavior support needs at 13 locations — Abilene, Austin, Brenham, Corpus Christi, Denton, El Paso, Lubbock, Lufkin, Mexia, Richmond, Rio Grande, San Angelo and San Antonio. The Texas Department of Aging and Disability Services (DADS) operates state supported living centers. (Note: The Rio Grande State Center is operated by the Texas Department of State Health Services and provides services through a contract with DADS.) State supported living centers provide 24-hour residential services, comprehensive behavioral treatment services and health care services, including physician services, nursing services and dental services. Other services include skills training; occupational, physical and speech therapies; vocational programs; and services to maintain connections between residents and their families and natural support systems.

Today, the vast majority of people with I/DD live in the community, and the 13 centers house about 3,362 people,⁵⁹ down from the 4,337 reported here in 2010.⁶⁰ Yet Texas continues to rely more heavily on SSLCs and privately operated intermediate care facilities for individuals with I/DD or related condition (ICFs/ID) than most other states. As of 2012, 12 states reported no state operated facilities serving individuals with I/DD with more than 16 residents. Of the 38 states operating I/DD facilities with 16 or more residents, 20 had 1 or 2 facilities, 16 had 3 to 10 facilities, and 2 had 11 or more facilities (New York with 14 and Texas with 13 I/DD facilities with 16 or more residents).⁶¹

In Texas, community capacity is managed during the legislative process by capping dollars, service opportunities, or both. Texas has chosen not to eliminate, but to slowly downsize the large SSLCs, maintaining this costly infrastructure in lieu of strengthening capacity to serve people in the community. Despite transitioning many residents out of institutions, Texas has not kept pace with the national trends to reduce the number and size of SSLCs — Texas has not closed a facility since the 1990s.

In evaluating current benchmarks, Texans with I/DD do not receive services within the least restrictive setting appropriate to their needs. TCDD has made similar recommendations in recent biennia to rebalance the system that serves persons with I/DD by expanding cost-effective policies that honor the choices of individuals to live in the most integrated setting to meet their needs, and transferring savings to serve more persons with disabilities in their communities. In 2008, TCDD published an analysis of Texas spending on Medicaid and I/DD services as compared to other states.⁶² The trends today are similar as they were in 2008.⁶³

- Texas average spending per person for home and community based services was below the national average.

⁵⁹ Promoting Independence Advisory Committee Department Activity Report Texas Department of Aging and Disability Services, October 2014.

⁶⁰ Agosta, John, Jon Fortune, Drew Smith, Kerri Melda, Robert Gettings, and Valerie Bradley. *Closing the Gaps in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. Texas Council for Developmental Disabilities. Oct. 2008:7

⁶¹ Larson, S.A., et.al (2014). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

⁶² Agosta, John, Jon Fortune, Drew Smith, Kerri Melda, Robert Gettings, and Valerie Bradley. *Closing the Gaps in Texas: Improving Services for People with Intellectual and Developmental Disabilities*. Texas Council for Developmental Disabilities. Oct. 2008:7

⁶³ Ibid.

- Texas admits a higher proportion of children to SSLCs than the national average.
- Texas is reducing its census in SSLCs at a slower rate than reduction nationally.
- Texas must enroll a significant number of individuals in HCBS waivers in order to keep up with population growth and increased service demand.

From 2013 to 2014, there were 116 new admissions to SSLCs. Approximately 36% of these were children (42). Although African Americans only make up 11.4% of the Texas population, they make up 30% of admissions to SSLCs (See Table 5). Their disproportionate representation in institutional admissions bears further review.

Table 5. New Admissions to SSLCs by Ethnicity

| Ethnicity | Total Number | Percent |
|----------------------------------|--------------|---------|
| White | 53 | 46% |
| American Indian or Alaska Native | 1 | 1% |
| Asian | 1 | 1% |
| Black or African American | 35 | 30% |
| Multiracial | 1 | 1% |
| Hispanic or Latino Origin | 24 | 21% |
| Other/Unknown | 1 | 1% |
| Total Annual Admissions | 116 | |

*Texas Department of Aging and Disability Services, as of March 31, 2014

In 2014, the Texas SSLC system is responding to three specific policy initiatives to improve the quality of services, build community capacity in order to serve people in the most integrated setting, and deliver services in a cost efficient manner. These include: 1) US Department of Justice Settlement Agreement, 2) Department of Aging and Disability Services SSLC long range plan, and 3) the Sunset Commission Review of the Texas Department of Aging and Disability Services.

US Department of Justice

In June 2009, the State of Texas and the United States Department of Justice (DOJ) entered into a Settlement Agreement regarding services provided to individuals with I/DD in SSLCs as well as the

transition of such individuals to the most integrated setting appropriate to meet their needs and preferences. The Settlement Agreement covers all State Supported Living Centers (SSLCs).

Pursuant to the Settlement Agreement, the SSLCs must be routinely monitored for compliance with the settlement. The parties agreed to delay the Four-Year Report until June 2014. The Settlement Agreement states: "...The parties anticipate the State will have implemented all provisions of the Agreement at each Facility within four years and sustained compliance with each such provision for at least one year..." This expectation was not met, and all facilities had many provisions not yet in compliance.⁶⁴

The DOJ settlement agreement regarding the 13 SSLCs in Texas sought to:

- increase protections of SSLC residents;
- bring supports and services up to accepted professional standards of care;
- provide the most appropriate level of care to SSLC residents; and
- provide residents with information about, and the choice to, transition to the most integrated community placement possible.

The Settlement Agreement with the DOJ required the monitors to provide an assessment of the status of compliance. The assessment provides explicit recommendations about how to improve SSLC services. In Section T – Providing Services in the Most Integrated Setting Appropriate to Meet a Person’s Needs, monitors questioned whether the state has the capacity to develop an acceptable community living discharge planning process and specifically recommends that the state work with facilities on the development and implementation of formal process for transition. With respect to Section U – Consent, the assessment discusses the conflict relating to facility directors making decisions for individuals without guardians and considered to be incapacitated.

State Supported Living Center Long-term Plan (DADS)

The Department of Aging and Disability Services Rider 39⁶⁵ requires DADS, in coordination with DSHS, “to develop a 10-year plan for the provision of services to individuals residing in SSLCs,

⁶⁴ United States v. State of Texas (State Schools) Settlement Agreement. Four Year Report. Texas Department of Aging and Disability Services, June 23, 2014

⁶⁵83rd Texas Legislature, State Appropriations Request, Department of Aging and Disability Services

considering cross agency issues impacting both SSLCs and state hospitals. Texas Health and Safety Code (HSC), Title 7, Subtitle A, Chapter 533, Subchapter B, Section §533.032(c) also requires development of a long-range plan for SSLCs. In September 2014, though a draft plan was not provided to make comments on, DADS provided an opportunity for public comment on what should be included in it.

TCDD continues to commend DADS for implementing proposals from community advocates that represent improvements to the SSLC system. For example, DADS has made a significant commitment to provide Person Centered Thinking training at all of the SSLCs. Overall transitions are improving, but compared to national averages, the pace is slow and investment too small to truly rebalance the long-term service system.

Texas Sunset Advisory Commission: State Supported Living Centers

The Texas Sunset Advisory Commission adopted final recommendations for the Department of Aging and Disability Services (DADS) that will be proposed during the 84th Texas Legislative Session that begins January 13, 2015. Noting declining enrollment, increasing costs and questionable quality, the Sunset staff made significant and clear recommendations regarding SSLC consolidation.

Sunset Commission staff made the following SSLC specific recommendations:

1. Require DADS to close the Austin SSLC by August 31, 2017.
2. Establish an SSLC Closure Commission to determine an additional five SSLCs to close no later than August 31, 2022.

The Sunset Commission adopted the Austin SSLC closure recommendation and modified the SSLC Closure Commission recommendation by making it an SSLC Restructuring Commission that would be tasked with ‘right-sizing’ the number of SSLCs required to meet the need for services in Texas. The Restructuring Commission would evaluate SSLCs and submit a final report with recommendations to the 85th Legislature by December 1, 2016. Recommendations of additional SSLC closures would be possible, but that is not a requirement of the Restructuring Commission. Sunset staff also made rebalancing recommendations that would require DADS to invest savings from SSLC closure to “address the need for more consistent crisis support, adequate rates for people with more complex needs, [and] ensuring the safety of DADS' clients in day habilitation facilities ...”⁶⁶

⁶⁶ Texas Department of Aging and Disability Services Sunset Staff Report with Hearing Material, Sunset Advisory Commission, June 2014

Recommendations for State Supported Living Centers

The Sunset Advisory Commission's staff recommendations are consistent with TCDD's longstanding rebalancing recommendations and provide substantial supporting evidence that should be used as a primary resource in the development and implementation of the DADS State Supported Living Center Long-term (10-year) Plan.

1. Rebalance the system that serves persons with I/DD by expanding cost-effective policies that honor the choices of individuals to live in the most integrated setting to meet their needs, identifying and providing supports and services to meet the needs of persons when and where they need them, and transferring the inevitable savings so that more persons with disabilities have the opportunity to be included in their communities.
2. Define an expectation for fewer institutions and to bring services up to generally accepted professional standards of care for those remaining. TCDD continues to support a moratorium on new admissions to SSLCs based on the circumstances necessitating the U.S. DOJ involvement in the SSLC system. The Council also supports the position that people with I/DD should have access to high-quality services and supports wherever they live.
3. Develop and implement a peer support program for individuals with I/DD to foster supported decision-making and community transition, and encourage more empowerment and choice. Peer support is currently being used by DSHS at state hospitals.
4. Expand home and community based services as the primary mechanism for addressing the increased service demand in our state. As the population grows, so does the demand for services. Individuals should not be unnecessarily placed in an institution because the state has not funded adequate community supports.
5. Increase funding to reduce waiver interest lists. Waiver interest lists mean that individuals who need community services are not receiving them. Waiting without needed support can increase risk for negative health outcomes, crisis, and unnecessary institutionalization.

Medicaid Managed Care

As Texas and other states continue to transition individuals with I/DD from large congregate SSLC settings to home and community based services, the challenge of how to meet the current and future demand within the state's budget is tremendous. Medicaid Managed Care models offer a financial structure designed to increase savings, provide greater access to services, and serve more people (reduce interest lists for services). The model is also designed to promote higher-quality services, person-centered planning and self-direction to ultimately improve outcomes for people with I/DD. Capitated payment rates are central to improving the cost-effectiveness of services within a managed care environment because they allow the managed care organization (MCO) wide latitude in utilizing available dollars to design interventions that both save money and improve outcomes.

Yet with respect to people with life-long disabilities who will need services for decades, it is important to think in the very long term when determining whether services are cost effective. Cost savings in long-term services and supports may be realized outside the life cycle of a managed care contract. For instance, attention to supports for family caregivers to reduce the stress of care-giving increases the likelihood that families will be able to continue to provide support over extended periods of time, even multiple decades. Upfront investment in employment services may not result in more independence during the contract period but can significantly reduce the need for public resources for many decades into the future. Person-centered services include an aspect of planning beyond the here and now with an eye to the future. People with I/DD have support needs that are not always predictable – any system redesign needs to incorporate considerable flexibility to support each individual as their needs change.

2014 Expansion of Medicaid Managed Care in Texas

In 2013, SB 7 (83R) was passed that requires the transfer of Medicaid long term services and supports for people with I/DD into a single managed care system by 2020. This includes HCS, CLASS, DBMD and TxHmL waivers and the ICF program, but not State Supported Living Centers. As of September 1, 2014, about 84% of Medicaid clients' healthcare services were coordinated

by managed care organizations and by fiscal year 2017, more than 90% of all Medicaid clients are likely to receive services through managed care organizations.⁶⁷

The specific elements of the managed care system as outlined in SB 7 include:

- Acute Medical Services: Medicaid acute care services would be provided through a capitated managed care program (STAR, STAR Kids, or STAR+PLUS) operated by a Managed Care Organization.
- Medically Dependent Children’s Program (MDCP): MDCP would be eliminated. MDCP would be replaced by a mandatory STAR Kids capitated managed care program for children.
- Texas Home Living (TxHmL): TxHmL would be transferred to the managed care system first – no later than Sept. 1, 2017. HHSC would be required to determine whether to cease operating the TxHmL waiver because all of the waiver’s services are provided via managed care as an entitlement, whether to continue operating the TxHmL waiver to provide those services that are not included in managed care, or eliminate a portion of the services currently available to people receiving services.
- Residential Changes to Reduce Costs: SB 7 would require prior authorization before a person could receive services in a group home in order to restrict access to only those that cannot be served in a less restrictive setting. SB 7 would also require the development of housing options, including the most restrictive settings, to reduce the cost of residential services.
- Voluntary Transition to Managed Care: HCS, CLASS and DBMD waiver participants would not be required to transition to managed care for LTSS but would be offered an option to transition to managed care. However, participants who choose to transition from their waiver program to managed care are not permitted to transfer back to their previous waiver program.
- The Commission would decide whether to continue to operate the waivers and the ICF program for the purpose of providing supplemental services not available in managed care (STAR+PLUS) or for only those who choose to remain in a waiver program.

⁶⁷ Sunset Advisory Commission Staff Report, Department of Aging and Disability Services, May 2014. Accessed <https://www.sunset.texas.gov>.

- Pilot Capitated Managed Care Strategies for Persons with Intellectual and Developmental (I/DD): DADS may test capitated, managed care strategies with a private provider by Sept. 1, 2016 for no longer than two years. The pilots would coordinate services provided through community ICFs and Medicaid waiver programs, and integrate long term services and supports with acute care services.
A waiver program recipient's pilot participation would be voluntary.
- Community First Choice: A basic attendant and habilitation service for 11,902 people with I/DD was authorized that will be administered by managed care organizations. Cost projections indicate that wages would be about 25% less than current HCS habilitation wages. I/DD Local Authorities will coordinate the new CFC service, but cannot provide the CFC service. Current CLASS, HCS and TxHmL providers will be eligible to provide the new I/DD service.
- Comprehensive Assessment: SB 7 requires DADS to implement a comprehensive assessment and resource allocation process that is intended to provide a uniform mechanism to provide recommendations relating to type, intensity and duration for appropriate and available services based on each person's functional needs.

Implementation Timeline

- September 2014: Acute (medical) care rolled into STAR+PLUS program
- March 2015: Nursing facilities will roll into STAR+PLUS program
- September 2016: MDCP will roll into STAR Kids program;
- September 2017: TxHmL will roll into STAR+PLUS program
- September 2020: All other LTSS waivers will roll into STAR+PLUS program

Opportunities for Prevention in Managed Care

Currently, there are very few places in Texas where children can receive a diagnostic assessment for the disabilities under the FASD umbrella and other complex neurodevelopmental disabilities. Developing reimbursement policies for medical providers that expand their ability to provide assessments of complex disabilities is an essential tool in connecting individuals with services that mitigate their current disabilities and prevent secondary disabilities from developing.

Education, along with system-wide integration of Education, Screening, Brief Intervention and Referral to Treatment (SBIRT) has proven to be an effective tool in the prevention of

developmental disabilities. Education related to the prevention of developmental disabilities could be mandated by the legislature in state operated and state funded programs, and included in contract requirements and MOU's among state entities. Precedence has been set in this area by DSHS, which now requires all state funded chemical dependency treatment agencies to provide education about FASD. This approach is a cost effective and efficient means to reach a large number of people.

The research on SBIRT as a tool to prevent FASD is impressive. Studies across the country (including Texas) demonstrate that Project CHOICES has a 69% success rate in reducing the risk of an alcohol-exposed pregnancy. TOPDD has partnered with several treatment agencies in Texas, where similar positive results were found. Through simple rule changes, SBIRT can become available to all Medicaid clients of childbearing age. Additionally, the multiple systems under the HHSC umbrella could provide countless opportunities for SBIRT. Policies that facilitate the integration of SBIRT and education regarding prevention can pave the way to a healthier state.

Capacity of Managed Care System to Serve Individuals with I/DD

Managed care organizations may not be truly ready to adequately assist people with I/DD in the current model.⁶⁸ The MCO must have expertise on how to serve individuals with long term support needs outside of the medical model. MCOs must also be able to recruit and maintain the needed workforce of direct support professionals to assist individuals with daily tasks, support them at home and in the community, and advocate and encourage communication of personal goals. A sustainable and efficient system must also communicate with, and be responsive to, the diverse members of the I/DD community themselves. Decisions about the future service delivery system should be made with the perspectives and active involvement from individuals and family members who are receiving services.

For the most part, discussions regarding the expected benefits of state managed care proposals are limited to "reducing costs" and "coordinating care." However, for people with disabilities, coordinating care should be focused on the outcomes desired for people receiving services, such as a better quality of life, control over their services and supports, full participation in community life, protection of individual rights, employment options for working age adults, etc. In addition to

⁶⁸ Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities. National Council on Disability. 2012.

making services more cost-effective, the aim of such systemic transformations should be to help people with disabilities live better, richer lives and gain access to the opportunities outlined by the Americans with Disabilities Act.

While managed care offers potential for reducing the institutional bias of Medicaid policy, Texas has made the decision to take state supported living centers services out of the state managed care program. Taking the most expensive support alternative out of the cost calculation not only will decrease any savings that might otherwise occur, but also will provide the option (and incentive) for managed care programs to divert high cost individuals to institutional services, thus potentially increasing the number of people provided services in the most costly support option.⁶⁹ This action removes the most significant opportunity to achieve system-wide savings and improve participant outcomes.

If resources are to be managed effectively to ensure that everyone receives services, including those still on waiting lists, all resources must be managed under the same program structure.

Recommendations for Systems Change in Medicaid Managed Care

1. Services system reform should include the whole system that serves persons with I/DD, including all institutions and all waivers for which persons with I/DD are eligible. For significant cost efficiencies to be realized, the most expensive services (institutional services) must be included.
2. Address the current and looming direct support workforce shortage by collecting and analyzing trends regarding workforce demographics and wages, developing and promoting a peer support workforce, expanding consumer direction, and restructuring payment methodologies to ensure that the Texas Legislature has the ability to set direct service wages at levels commensurate with the value and scope of the service.
3. Individuals with I/DD and family members receiving services must participate at the design and implementation stage and on an ongoing basis, review information made available about the performance of the managed care program.

⁶⁹ Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities. National Council on Disability. 2012 Policy Brief.

4. The role of the local authority should be maintained. Local authorities are responsive to their local communities and have access to local resources, and have demonstrated ability to improve quality.
5. The Person Directed Planning (PDP) process and tool developed with substantial stakeholder input should be included in the future I/DD system. As part of the ongoing implementation of Sec. 48 Rider provision (2009), stakeholders have developed and refined a PDP process and tool that should be expanded to the other programs in the system (including SSLCs).
6. Housing options should be fully integrated in the community, in close proximity to goods and services and not in congregate living environments. TCDD does not support including larger residential options in systems redesign, and notes that providers indicate the cost of retrofitting existing homes to accommodate more residents is generally cost prohibitive.
7. Ensuring that identification and diagnostic services for neurodevelopmental disabilities are accessible to all Texas families will mitigate the impact of preventable disabilities.
8. Policies requiring state agencies to develop an education and SBIRT plan in collaboration with TOPDD would allow Texas to use existing resources to make a significant impact in the incidence of developmental disabilities.

Employment First

Work is a fundamental part of adult life for people with and without disabilities. It provides a sense of purpose, shaping who we are and how we fit into our community. Meaningful work has also been associated with positive physical and mental health benefits and is a part of building a healthy lifestyle as a contributing member of society. Because it is essential to people's economic self-sufficiency, as well as self-esteem and well-being, people with disabilities who want to work should be provided the opportunity and support to work competitively within the general workforce. Individually tailored and preference based job development, training, and support should recognize each person's employability and potential contributions to the labor market.

Individuals with disabilities are much less likely to have a job than individuals without disabilities. In June of 2014, about 63% of working-age Americans were employed.⁷⁰ By contrast, only 36% of people with disabilities in the United States are employed and only 23.4% of people with cognitive disabilities.⁷¹ Data for Texans with disabilities is similar. Yet, the majority of non-employed people with disabilities would like to be working, and their job preferences are well within the mainstream – 80% said they would like a paid job now or in the future, which is comparable to the 78% of nondisabled, working-age people who are not employed. And like all workers, individuals with disabilities value job security, income, flexibility and chances for advancement and career. These numbers challenge the idea that the low employment rate of people with disabilities is due to low motivation or job preferences – this data suggests the supply is there. With the coming labor shortages as baby boomers retire, people with disabilities represent a valuable and underutilized resource. Technology advances foster greater ease in integrating workers with disabilities in the workplace.

When individuals with disabilities are provided the appropriate supports to earn competitive wages alongside their non-disabled peers, they are given the opportunity to build wealth and assets which lead to a higher quality of life and a greater degree of independence. The poverty rates of people with disabilities are much higher than that of the general population. Approximately 34% of people with disabilities live on a household income of less than \$15,000 per year, compared to 12% of people without disabilities. High levels of poverty lead to people with disabilities being dependent on government funded programs. An Employment First policy that holds individuals with disabilities to the same employment standards and responsibilities of any working-age adult can help individuals with disabilities be independent in the community, build assets, reduce dependence on public funds and services, and avoid the costs associated with current programs.

Data from the National Core Indicators Project suggest that only 14.7% of working age adults supported by state I/DD agencies participated in integrated employment.⁷² Community

⁷⁰ According to the U.S. Bureau of Labor Statistics: “In June, the civilian labor force participation rate was 62.8 percent for the third consecutive month.” United States Department of Labor, Bureau of Labor Statistics, Employment Situation Summary, available online at: <http://www.bls.gov/news.release/empsit.nr0.htm> (accessed on July 30, 2014)

⁷¹ Smith, F.A., & Clark, D.M. 2007. Disability and Occupation. DataNote Series, Data Note XIII. Boston, MA: Institute for Community Inclusion

⁷² Human Services Research Institute, National Core Indicators Annual Summary Report 2011-2012

rehabilitation providers (CRPs) reported that only 27% of individuals with I/DD supported by their organization worked in integrated jobs, including both individual jobs and group supported employment.⁷³ Those who are employed typically work limited hours with low wages.⁷⁴ At the same time, participation in facility-based and non-work services has grown, suggesting that employment services remain an add-on rather than a systemic change.

Employment First

Employment First is the principle that integrated competitive employment should be the expected outcome for people with developmental and other disabilities. The 83rd Texas Legislature (2013) passed a statewide Employment First Policy (SB 1226) which establishes that it is the policy of Texas that earning a living wage through competitive employment in the general workforce is the priority and preferred outcome for working-age individuals with disabilities who receive public benefits. Texas joins at least 42 other states with Employment First efforts. SB 1226 requires the Health and Human Services Commission (HHSC), the Texas Education Agency, and the Texas Workforce Commission (TWC) to jointly adopt and implement an Employment First Policy.

The Employment First Task Force developed and approved recommendations outlined in their first report to the Texas Legislature.⁷⁵ The recommendations address a broad range of matters regarding policy, procedures, and rule changes that are necessary to allow the Employment First Policy to be jointly adopted and implemented by HHSC, TEA, and TWC. The Task Force's work is integral to understanding policy barriers and opportunities across state agencies to increase innovation and get people to work.

Day Habilitation Services

Day habilitation facilities provide services in a group setting during weekday work hours and are offered to DADS clients through community-based I/DD waiver and intermediate care facility programs. Day habilitation services are designed to help individuals make connections within their communities. Texas and other states developed day habilitation programs, work activities centers and sheltered workshops recognizing the need to have viable day program options for

⁷³ Butterworth, et al., StateData: The National Report on Employment Services and Outcomes, 2013

⁷⁴ Human Services Research Institute, National Core Indicators Annual Summary Report 2011-2012

⁷⁵ Texas Employment First Policy And Texas Employment First Task Force Report, Texas Health and Human Services Commission, Fall 2014 <http://www.dads.state.tx.us/providers/supportedemployment/EFTFReport.pdf>

individuals with I/DD. While these programs were developed to meet real needs, there is debate about whether these services are truly inclusive or can isolate individuals from meaningful involvement in community activities as currently designed.

In fiscal year 2013, Texas spent more than \$96 million on day habilitation services. DADS requires program providers to ensure their subcontractors, including day habilitation facilities, provide safe and adequate services. However, these requirements vary across programs, and contracts between facility owners and providers are not required to include basic quality and safety measures.⁷⁶

Despite rising use of these facilities, DADS does not have basic information on how many of its clients attend day habilitation, where the facilities are located, or problems at these facilities. Directing providers to include basic requirements in day habilitation contracts may improve services and add a layer of protection for clients who attend the facilities; however, it is important to note that some long term services and supports providers also operate day habilitation facilities. Thus, the improvement would be minimal if a provider is put in a position to hold itself accountable to contract requirements. Tracking day habilitation information would allow the agency to identify trends and problems at these facilities and help its clients and providers choose a day habilitation facility.

Sub-minimum Wages

Texas currently has more than 100 employers that utilize certificates from the Department of Labor to pay sub-minimum wages to individuals with disabilities working in sheltered workshops or enclaves. Sheltered workshops typically do not promote full inclusion; do not generally teach readily transferrable or relevant work skills; and usually do not provide wages which allow workers to break the cycle of poverty. Some workers with disabilities in Texas earn as little as 1½–10 cents per hour despite working for a profitable local business. In some cases, providing job coaches for individuals to be successfully employed can be less expensive than paying for the costs of sheltered employment.

The new policies of the federal Workforce Innovation and Opportunity Act (WIOA) include efforts intended to limit the use of sub-minimum wage. Specifically, individuals age 24 and younger are prohibited from working jobs that pay less than the federal minimum of \$7.25 per hour unless

⁷⁶Ibid.

they first try vocational rehabilitation services. In cases where individuals with disabilities do earn less than minimum wage, the measure requires that they periodically be provided career counseling by their state and are informed about other work opportunities.

Day habilitation and congregate employment programs are incredibly important in the lives of many individuals, but they are considered a model of the past. Agencies and providers must work together with self-advocates and families to design program options that people want and the resources and incentives for providers to make that transition. It is an opportunity for Texas to proactively move forward by ensuring that day programs provided in all Texas waivers align with the principle and the spirit of the Employment First Policy now adopted by the Legislature.

Recommendations for Employment

1. Develop recommendations for policy, procedure, and rules changes that are necessary to allow the Employment First Policy required to be jointly adopted and implemented by the HHSC, TEA, and TWC.
2. Develop a methodology, with broad agency and stakeholder input, to track services and employment outcomes for people with disabilities across agencies.
3. Develop information for students, adults and families about the impact of employment on benefits and how work incentives can be utilized (including Social Security work incentives).
4. Examine potential changes to day habilitation services based on recent federal CMS guidelines (42 CFR 441.301) that define the settings in which states may provide services in home and community-based waivers for people with IDD.
5. Identify a provider payment structure that incentivizes a collaborative approach to integrated, competitive employment outcomes.
6. Establish goals to increase the number of individuals in integrated, competitive employment and to decrease the number of individuals in workshops earning sub-minimum wage.

Guardianship

The Texas Council for Developmental Disabilities supports protecting the civil rights and well-being of people with developmental disabilities. The vast majority of people with disabilities, including those with I/DD, are able to make important decisions without the need for a guardian. With the provision of supports and services, most persons with disabilities are capable of making important decisions such as where they want to live and the type of care they want to receive without the need for a full or limited guardian.

Guardianship is a legal tool that allows a person to make decisions for another person. As a result, it removes the civil rights and privileges of a person by assigning control of their life to someone else. Although state law in Texas directs a court to encourage the development or maintenance of maximum self-reliance and independence, it is not uncommon for courts to create full guardianships that deprive individuals with disabilities of the right to make fundamental decisions about their lives. The broad definition of “incapacity” in Texas Estates Code has a discriminatory impact by enabling a court to appoint a guardian if an adult has a physical or mental condition and is substantially unable to provide food, clothing, or shelter, to care for their physical health, or manage their own financial affairs. Even though individuals with a disability may need supports and services or assistance from others to provide for such needs, they should still be afforded the right to make choices about these aspects of their lives.

There has been an increase in guardianships throughout Texas in part because resources in some communities have not kept pace with needs. In limited cases, DADS serves as the guardian of last resort for persons with diminished capacity. DADS must be appointed a person’s guardian by the courts. Guardian services include ensuring appropriate living arrangements, managing estates, and making medical decisions for the person. In fiscal year 2013, DADS provided guardianship services either directly or through contracts to 1,366 persons. Texas has about 46,000 guardianships statewide. In fiscal year 2013, the DADS guardianship program had 99 staff and a budget of about \$6.3 million.

Since 1993, legislation favored tailored, limited guardianships. However, year after year, plenary (full) guardianships have been established. Less-restrictive alternatives are being developed and tailored to individual need; yet, the law does not instruct investigators or guardians ad litem to exhaust possible alternatives. If the need can be filled by a guardianship, the process is

abbreviated. The law promotes building capacity of the individual to make their own decisions. Yet, the requirements to dissolve a guardianship are extremely difficult, expensive and/or impossible for most.

The law presumes all people have capacity for decision-making – this includes people with intellectual and developmental disabilities. People with disabilities should be given the opportunity to avoid or limit guardianship through a variety of alternatives to guardianship such as:

- Power of attorney, medical power of attorney, durable power of attorney
- Limited power of attorney for education decisions
- Medicaid waiver home and community based services and supports
- Surrogate Decision Making program for people in ICFs
- Special needs trusts
- Joint checking accounts or debit cards
- Money management programs
- Social Security's Representative Payment Program
- The Consent to Medical Treatment Act lists those family members and other persons, including a clergy member, who can act as surrogate decision-makers in health care decisions when the person lacks the capacity to make a major medical and dental treatment decisions. (Texas Health and Safety Code, Chapter 313)
- Volunteer Supported Decision Making allows people with limited disabilities to choose a supporter to help them understand information, options, responsibilities and consequences in order to make decisions. Supported decision-making is being piloted in Texas

Parents of children with complex neurodevelopmental disabilities may face financial challenges with the costs of providing care. In some instances, neurodevelopmental disabilities can cause the child to become violent and cause safety concerns for the child, family and community. The behavioral and financial factors may result in families facing the difficult decision of relinquishment. It is important that families are not forced to make this choice. Policies that support families in raising children with complex neurodevelopmental disabilities are needed.

Texas Guardianship Reform and Supported Decision-Making Group

The Texas Guardianship Reform and Supported Decision-Making (GRSDM) workgroup came together in June 2013 to look at the need for policy reforms and less restrictive alternatives to guardianship. GRSDM includes individuals and representatives of the legal profession, family members and advocacy organizations that cross age and disability. Some GRSDM participants also contribute to the Working Interdisciplinary Network of Guardianship Stakeholders, a project of the Texas Supreme Court administered by the Office of Court Administration. Both groups are working to improve guardianship and advance alternatives, such as supported decision-making.

The following recommendations were identified by the GRSDM work group to the guardianship system in Texas that would promote the well-being and protect the rights of people with disabilities:

1. Change Term from “Ward” to “Person” would change the impersonal term “ward” to “person under guardianship.”
2. Bill of Rights for Wards and Proposed Wards lists rights that individuals under guardianship get to keep, such as the right to live, work and play in the most integrated setting, visit with people of their choice, and appear before the court to express their preferences or concerns. Rights for a proposed ward include the right to petition the court and due process.
3. Supported Decision-Making Agreement would establish an informal alternative to guardianship where individuals could choose people they trust to help them understand the decisions they need to make and to communicate their decisions to others.
4. Alternatives to Guardianship lists less restrictive alternatives to guardianship, such as a power of attorney or representative payee and directs the court to determine whether alternatives could meet the needs of the person rather than guardianship.
5. Duties of Guardians would improve protections for individuals committed to institutional settings. This proposal calls for guardians to visit a person in an institution every month and provide timely responses to calls, emails or letters about the person.
6. Limits of Guardianship with Services and Supports requires the court to determine if formal and informal supports are in place or available that enable individuals to meet their needs for food, clothing, or shelter, care for their physical or mental health,

manage financial affairs and/or make decisions so that guardianship may be averted or limited.

7. Guardianship and Decisions about Residence states individuals under guardianship should, if possible, be able to make decisions about where they reside.

TCDD supports the DOJ's recommendation for the state to employ an expert to focus on alternatives to guardianship that will support community living for people with disabilities. These alternatives should include the supported decision making methods that were reported to be working well in at least one SSLC.

Individuals with Complex Needs

While many people continue to believe that people with the most complex behavioral and medical support needs require the services provided by state supported living centers, considerable evidence and experience in Texas and other states demonstrates otherwise. In fact, as many as eight times the number of individuals with the highest level of need live in home and community settings than SSLCs.⁷⁷ Thus, Texas clearly has both the capability and the capacity, and is currently serving individuals with complex needs in the community. However, the state system can do more to strengthen its capacity to address crisis, prevent unnecessary institutionalization, and provide ongoing behavior support through integrated service models.

People with more complex health care needs often require more intensive medical services coordinated across multiple providers, as well as a wide range of social supports to maintain health and functioning. In 2013, DADS identified obstacles to community placement for people residing in SSLCs, including the need for supports for people with significant challenging behaviors, specialized mental health supports, environmental and transportation modifications, the availability of specialized medical supports, and meaningful employment.⁷⁸

Individuals with I/DD are three-to-five-times more likely to demonstrate challenging behaviors⁷⁹ that can result in self-harm, injury to others, destruction of property, and limited community involvement. Many consumers with complex behavioral issues benefit from the extra support of a crisis management team. Crisis support can include respite services, and a clinical team to provide consultation and coordination with the existing service and support system. Some crisis services are offered as a mobile unit where professionals go into the community to conduct assessments, evaluate for appropriate services that may be needed, and provide crisis stabilization. However these strategies may require additional staffing that is not included in current reimbursement levels. TCDD supports the development and implementation of strategies that address the needs of families in crisis to prevent the unnecessary placement of children in any institutional setting.

⁷⁷ Texas Department of Aging and Disability Services Sunset Staff Report with Hearing Material, Sunset Advisory Commission, June 2014

⁷⁸ Texas Department of Aging and Disability Services Obstacles to Community Referral and Transition. State Supported Living Centers. 2013

⁷⁹ What Do NCI Data Reveal About Individuals With Intellectual and Developmental Disabilities Who Need Behavior Support? NASDDDS and HSRI, September 11, 2014

Current community systems often lack integrated clinical and behavioral services. Few counselors and therapists are available in the community with both the experience and desire to provide services to individuals with I/DD. Because of the range and intensity of services needed, individuals with complex needs tend to be the most costly. States must effectively coordinate the full range of medical, mental health, and social services in order to best support the individual. Service delivery systems must be flexible and integrated to deliver better value to these high-need beneficiaries. The state's recent expansion of managed care models provides an opportunity to strengthen the integration between physical and behavioral to address those Individuals with complex needs.

The Department of Aging and Disability Services makes the following recommendations to build the state's capacity to serve individuals with complex needs within the home and community based system:

1. Access to physical and behavioral health services: Improve access to physical and behavioral health services; especially in rural areas (e.g., explore use of telemedicine).
2. Number of physical and behavioral health providers in the community: Increase the number of physical and behavioral health service providers available in the community by undertaking activities to recruit and retain providers.
3. Transition issues: Address issues encountered just before and following transition from an institution to the community to ensure successful transition and prevent re-institutionalization (e.g., crisis response, faster access to Medicaid coverage in the community).
4. Quality of data collected: Improve the accuracy and completeness of data that inform the appropriateness of interventions and quality of services.
5. Education to help people understand what services and supports individuals need: Help individuals, families, and providers understand I/DD and the appropriate services and supports individuals need.
6. Program rules related to service delivery: Review Medicaid waiver program rules to identify ways to improve service delivery, increase efficiency, reduce costs, increase quality, and improve opportunities for self-determination.

7. Evidence-based practices: Implement evidence-based practices that promise the best outcomes.
8. Workforce training: Provide training to create a highly-skilled provider workforce to satisfy the needs of persons with complex needs in the community (e.g., person-centered thinking, behavior management strategies).

Summary

As transition of SSLC residents to more integrated settings continues, further identification, exploration, and expansion of collaboration efforts between SSLCs and local I/DD authorities to both strengthen the transition process and to expand and improve community-based services for persons with complex behavioral and healthcare needs is necessary. Texas is not alone in facing the challenges of serving individuals with developmental disabilities and their families. Over the years, Texas has demonstrated innovation that is improving the experience of those receiving services. Yet, opportunities remain to further integrate prevention into the full range of health and human services, and to improve the service delivery system consistent with the needs and preferences of individuals seeking support, and that meet national performance benchmarks.

Individuals with disabilities want to have access to services in a timely manner without having to wait for services; to receive services in the most integrated setting; and to have significant input and choice in deciding how those services are delivered. Individuals with disabilities have the same goals as their neighbors — they want to have access to quality health care, have meaningful relationships, and be able to work and build assets needed to be independent and productive members of the community.

Both federal and state policies passed this biennium demonstrate efforts to achieve these goals. The prevention goals, policy review, and system recommendations made in this report offer opportunities for Texas to rebalance the long term services and supports system to focus on the outcomes most important to individuals and their families. TCDD and TOPDD offer evidence based practices and other resources of their agencies to state leaders and policy makers over the next two years as they make decisions on how to conduct the business of supporting Texans with developmental disabilities and their families.

Appendix A: Texas Statute on Biennial Disability Report

Government Code

Title IV, Chapter 531

Section 531.0235. Biennial Disability Reports

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

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

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

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

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

Appendix B: Sunset Advisory Commission Recommendations for TCDD and TOPDD

Texas Council on Developmental Disabilities

The Sunset Advisory Commission issued a report that recommends the continuation of the Texas Council for Developmental Disabilities (TCDD) for 12 years until 2027. Sunset staff found that TCDD and its functions are necessary to ensure that Texas meets the needs of people with developmental disabilities (DD). The report states that TCDD fulfills the critical role of identifying the most pressing needs of Texans with DD. Once the needs are determined, TCDD works to advance public policy and systems change to allow people with DD to gain more control over their own lives.

The report also recommends that TCDD improve its process for tracking grant project outcomes. Specifically, the report recommends that TCDD establish clear expectations for grant project outcomes and track the progress of five-year grant projects designed to continue beyond the TCDD funding period. The report suggests this information will help TCDD to better identify successful outcomes, increase the effectiveness of future efforts, and ultimately improve the long-term impacts on services offered to people with I/DD.

Texas Office for Prevention of Developmental Disabilities

The HHSC Sunset Staff Report recognized that the state has a reactive approach to services and often addresses issues "downstream." Strengthening prevention across agencies and developing a statewide prevention plan would provide a tremendous positive impact. While the state offers many fine prevention services, it could strengthen all of these efforts by creating an overall plan for integrating prevention, providing consistent messaging and building on each other's strengths.

Policies that require state agencies to work with TOPDD to develop a prevention plan, along with the support to do this, would maximize the impact of the state's individual prevention program and position Texas to obtain increased federal funding.

The Sunset Commission staff report has proposed the removal of TOPDD's Executive Committee, along with TOPDD's independence as being "administratively attached to HHSC." It would allow for the functions of the Office to be maintained, but not necessarily the office itself.

There are several reasons why this proposal is problematic:

- It would seriously diminish and possibly eliminate the Office's ability to fundraise (TOPDD has traditionally raised 80% of its funds). In all of its grant applications, TOPDD emphasizes its independence and structure. While technically some foundations are allowed to give to government entities, the fact is that HHSC does not receive foundation support. TOPDD does because of its unique status.
- It would provide complete and absolute power over an organization (TOPDD) to an entity (the state), which provides only 20% of the funding. This is clearly a poor governance structure.
- It would eliminate the Office's public policy work, which is a major part of its mission. Internal HHSC entities have very strong restrictions regarding public policy efforts. Indeed, HHSC employees are required to engage the HHSC external relations department when speaking to legislators. Whereas TOPDD has legislators on the executive committee (that the Sunset proposes to eliminate). These legislators can shepherd policy change. Policy change is absolutely critical to the prevention of developmental disabilities. Public policies can impact all Texans and take immediate effect. To eliminate this would severely limit effectiveness.
- The purpose of the Office is to provide a coordinated, comprehensive approach to the prevention of developmental disabilities. Since Sunset's recommendations only allows the "functions of TOPDD" to exist, these functions may be assigned to various state entities. This would compromise and fragment the prevention of developmental disabilities. Additionally, these entities would not be able to raise the funds that TOPDD does. This could eliminate the progress that Texas has made in integrating the prevention of developmental disabilities across systems.
- If the Office is not in statute, the rider granting the Office an exception to Article IX, Section 8.01 regarding limits in acceptance of monies would be eliminated. According to Article IX, Section 8.01. "(d) An unexpended balance, from a gift or bequest, existing at the beginning of this biennium or at the end of a fiscal year of this biennium is appropriated for use during this biennium for the purpose provided by the grantor." This exception is extremely important to TOPDD since donors do not time donations in relation to the state's fiscal year.

- TOPDD has a 2-year renewable grant with the Hogg Foundation. The contract it has is with TOPDD, not with HHSC. The Foundation would have no obligation to pay the second year of the grant if there is no TOPDD in legislation. Thus the state would be walking away from over \$60,000 that had been obligated to TOPDD.
- The Sunset Commission staff report affirmed the need for TCDD, yet it recommended subsuming the prevention of developmental disabilities into HHSC. The voice for prevention of developmental disabilities, provided by TOPDD is just as needed as the voice for the needs of people with developmental disabilities. Without a strong voice for the prevention of developmental disabilities, the increase in the percentage of people who have developmental disabilities that is described in this report is sure to continue.

This would be a serious step backwards when the state is developing mechanisms for the prevention of developmental disabilities through TOPDD. TOPDD needs to maintain its independence and executive committee.

TOPDD's executive committee requested that the Sunset Commission expand TOPDD's mission beyond the prevention of developmental disabilities so it could use its structure to develop more integrated prevention services across systems and build bridges between prevention initiatives statewide.

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