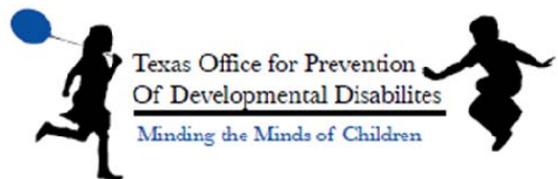

Texas Biennial Disability Report

December 1

2012

Prepared by: The Texas Council for Developmental Disabilities
in Collaboration with Texas Office for Prevention of
Developmental Disabilities.

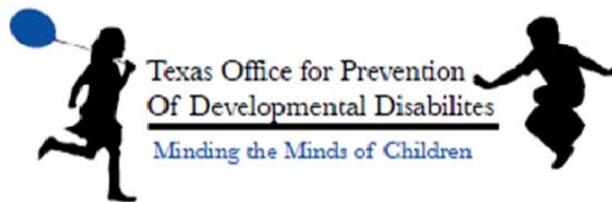




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About the Texas Biennial Disability Report (Background and Statute)

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 has elected to focus a portion of the report on a key policy issue faced by individuals with developmental disabilities. For 2012, TCDD chose to examine “the interconnectivity of education with employment for individuals with developmental disabilities, including measures of consumer satisfaction.” The *2012 Texas Biennial Disability Report* incorporates policy initiatives from the 81st and 82nd Texas legislative sessions, key interim charges, and considerations going into the 83rd Texas Legislative Session. This report establishes a framework for proposed legislative action during the 83rd Texas Legislative Session (2013).

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.

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 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.

About Preventable Developmental Disabilities

During the past 30 years, significant advances in research have allowed for the prevention of many cases of intellectual and developmental disabilities.

For example, every year our nation prevents:

- 250 cases of intellectual disability due to phenylketonuria (PKU) by newborn screening and dietary treatment;
- 1,000 cases of intellectual disability due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy;
- 1,000 cases of intellectual disability by use of anti-Rh immune globulin to prevent Rh disease and severe jaundice in newborn infants;
- 5,000 cases of intellectual disability caused by Hib diseases by using the Hib vaccine;
- 4,000 cases of intellectual disability due to measles encephalitis thanks to the measles vaccine; and
- Untold numbers of cases of intellectual disability caused by German measles during pregnancy thanks to rubella vaccine.¹

Other interventions have also reduced the chance of intellectual and developmental disabilities. Preventive interventions such as child safety seats and bicycle helmets reduce head trauma. Removing lead from the environment reduces brain damage in children. Early intervention programs with high-risk infants and toddlers have shown positive impacts on intellectual functioning and a reduction of the likelihood of secondary disabilities. Finally, early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of having a healthy child. Dietary supplementation with folic acid, taken before and during pregnancy, reduces the risk of neural tube defects. Women who have PKU are now encouraged to be counseled to go on a restricted phenylalanine diet three months prior to pregnancy to prevent intellectual disability in their baby.² The Texas Office for Prevention of Developmental Disabilities (TOPDD) builds on these accomplishments to move Texas to the forefront of the prevention of developmental disabilities.

¹ Alexander, D. "Prevention of Mental Retardation: Four Decades of Research." *Mental Retardation and Developmental Disabilities Research Reviews* 4. 2008:50-58.

² *Causes and Prevention of Intellectual Disabilities*. The Arc. 2011:1-3.

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 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 consist of Texas state agency representatives from the following agencies which provide key services and supports to individuals with developmental disabilities: Department of Aging and Disability Services, Department of Assistive and Rehabilitative Services, Department of State Health Services, Health and Human Services Commission, and Texas Education Agency. Disability Rights Texas, the state's protection and advocacy program; the Texas Center for Disability Studies at The University of Texas; the Center on Disability and Development at Texas A&M University; and other organizations are also represented on the Council.

TCDD is established as a state agency by state and federal law to support and promote community inclusion and integration of people with developmental disabilities. The Council uses information about the 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 Texans with disabilities live, work, and contribute to their communities. These activities, designed to impact the entire state, are developed in close collaboration with people with disabilities, parents, advocates, state agencies, service providers, and policymakers.

TCDD COUNCIL MEMBERS

Public Members

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Rebecca Hunter Adkins, Lakeway
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Joe Rivas, Denton
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Lora Trainer Taylor, Houston
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Agency Representatives and Alternates

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Frank Genco, Texas Health and Human Services Commission (HHSC)
Jeff Kaufmann, Texas Department of Aging and Disability Services (DADS)
Kathy Griffis-Bailey, Texas Department of State Health Services (DSHS)
Cindy Swain/Barbara Kaatz, Texas Education Agency (TEA)
Sara Kendall, Texas Department of Assistive and Rehabilitative Services (DARS)

About the Texas Office for Prevention of Developmental Disabilities

Texas Office for Prevention of Developmental Disabilities (TOPDD) is the designated state agency on the prevention of developmental disabilities and is administratively attached to the Health and Human Services Commission. TOPDD was created by the Texas Legislature in 1989 to coordinate prevention activities among the state's health and human services enterprises. The agency's mission is to help minimize the human and economic losses caused by preventable developmental disabilities. Much of TOPDD's work involves preventing fetal alcohol spectrum disorders and head injuries which are the largest causes of the most prevalent preventable developmental disabilities. TOPDD is also active in assessing the full range of preventable developmental disabilities to better position the state to implement targeted prevention strategies.

One major area of focus for TOPDD is injury prevention in children. In addition to the visible physical impact of childhood injuries is the impact on the brain. Recent studies show that even when misuse was considered, helmets prevented 68 to 85 percent of non-fatal head injuries. Injury is a common and costly childhood affliction, accounting for approximately 15 percent of medical spending from ages 1 to 19; for children ages 5 to 19, injury rivals the common cold in frequency.³ As a result, injury prevention is a leading cause of preventable disabilities and a priority for TOPDD. TOPDD's Child Safety and Injury Task Force brings together experts from across the state to organize initiatives to boost injury prevention work. This year, TOPDD launched an awards program to recognize the foremost leaders in injury prevention and to link them to build collaboration and increase the use of best practices throughout the state.

Over 50 organizations are involved in the work of TOPDD. These organizations include state agencies such as the Health and Human Services Commission (HHSC), the Department of State Health Services (DSHS) and the Department of Family and Protective Services (DFPS), as well as organizations active in health care, children's needs, prevention, chemical dependency, education and judicial issues. Our membership includes consumers, judges and lawyers, medical professionals, educators, prevention experts and human service leaders. These diverse participants are the driving force behind the work of the agency.

One of TOPDD's major accomplishments has been to engage organizations and leaders from throughout the state to develop the first statewide plan on Fetal Alcohol Spectrum Disorders (FASD). TOPDD and its partners are working on implementing this plan. The goals of the strategy include: 1) education for professionals and the community on FASD, 2) screening and brief intervention for alcohol use of pregnant women, 3) utilizing services that reach high risk groups (individuals in treatment) to educate them about FASD and 4) developing diagnosis and care for children already impacted by prenatal alcohol exposure. It is through this simple recipe for success, that Texas is implementing evidence-based strategies to address FASD.

³ Miller, T.R., Romano, E.O., and Spicer, R.S., "The Cost of Childhood Unintentional Injuries and the Value of Prevention." *The Future of Children*, 10(1). 2000:137-163.

The agency is also doing a comprehensive assessment of prevention work throughout the state and nation to build on the state's strengths and identify areas of growth.

The change in health care policies on a national and state level makes it imperative to integrate prevention tools at every level of service so that we can prevent disabilities before they occur and simultaneously prevent secondary disabilities which can occur later. The Texas Office for Prevention is proud to assume the leadership role in this endeavor.

These following committees convened during the 2011-2012 biennium:

TOPDD Executive Committee Members

Richard Garnett, Ph.D., Executive Committee Chair, Texas Office for Prevention of Developmental Disabilities

Angelo P. Giardino, M.D., Ph.D., Medical Director, Texas Children's Hospital

Ashley Givens, Chair, Director of Special Events-Public Relations, Texas Scottish Rite Hospital for Children

The Honorable Jim Jackson, Texas House of Representatives – District 15

Valerie Kiper, RN, MSN, NEA-BC, Corporate Quality Consultant, Accreditation and Regulatory, Universal Health Services

Joan Roberts-Scott, Directorate Manager, CE Scheduling Unit, Texas Department of Aging and Disability Services

Marian Sokol, Ph.D., Vice-Chair, Consultant, First Candle

Mary Tijerina, Ph.D., Associate Professor, Texas State University School of Social Work

The Honorable Vicki Truitt, Texas House of Representatives – District 98

Child Safety and Injury Prevention Task Force

Adrian Billings, M.D., Ph.D., Family Medicine/Obstetrics Physician, Pearce Clinic and Big Bend Medical Center

Sam Cooper III, LMSW-IPR, Director, Office of Title V and Family Health, Texas Department of State Health Services

Richard Garnett, Ph.D., Executive Committee Chair, Texas Office for Prevention of Developmental Disabilities

Angelo P. Giardino, M.D., Ph.D., Medical Director, Texas Children's Hospital

Ashley Givens, Chair, Director of Special Events-Public Relations, Texas Scottish Rite Hospital for Children

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Sonia Quintero, Deafness Resource Specialist, Region XI-B, Communications Access Ability Group of South Texas

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Shaun Barker, Director Performance Oversight, Texas Health and Human Services
Terry Beattie, Director Office of Program Coordination, Texas Health and Human Services
Melinda Benjumea, Program Director - STARS/ABA-Skip/CBS Team, MHMRA of Harris County
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Esther Betts, Prevention Team Lead/Child & Adolescent Services, Mental Health & Substance Abuse, Texas Department of State Health Services
Mike Bright, Executive Director, ARC of Texas
Kathleen Buckley, Social Worker, UT Health Science Center
Anjulie Chaubal, Program Director Prevention & Early Intervention Division, Texas Department of State Health Services
Cathy Cockerham, Program Operations Director, Texas CASA
Deborah Cortez, President, Texas Healthy Start Alliance
Barbara Crane, Nurse, University of Texas Health Science Center
Sarah Crockett, Education Coordinator, Texas Association of Infant Mental Health
Fran Dayal, Program Specialist, Early Childhood Intervention, Department of Assistive & Rehabilitative Services
Sheryl Draker, Lead Instructor of Attorneys, WJF Institute
Janie Dykes, Program Specialist V, Texas Department of State Health Services
David Evans, Executive Director, Austin Travis County Integral Care
Natalie Furdek, Coordinator ,Women's Substance Abuse Services , Mental Health & Substance Abuse, Texas Department of State Health Services
Sandra Galindo, Regional Nurse Consultant, Specialty Nursing Services, Department of Family & Protective Services
Angela Gil, RD, LD., Nutrition Education Consultant, Women, Infant and Children Program, Texas Department of State Health Services
The Honorable Ernie Glenn, Bexar County Felony Drug Court Judge
Stevie Hansen, Chief of Addiction Services, MHMR Tarrant County
The Honorable Bonnie Hellums, 247th District Court Judge
Susan Homan, M.D., FAAP, Physician, Developmental/Behavioral Pediatrics
Carole Hurley, J.D., Attorney at Law
Laura C. Jenkins, LCDC, CPS, Director of Program Compliance, Fort Bend Regional Council on Substance Abuse
Linda Kagey, Counselor, Linda Kagey Counseling
Shelley Koslan-Joiner, Mom and Baby Special Services Coordinator, JPS Health Network (Tarrant County)
Kathy Kramer, Ph.D., Director of Raising Texas, Office of Early Childhood Coordination, Texas Health and Human Services

Melanie Lane, Unit Coordinator, Center for Health Care Restoration, Haven for Hope
Margaret Larsen, Executive Director, Special Olympics Texas & Governor's Committee on People with Disabilities
Laura McCarty, Program Manager, Harris County STAR Drug Court
Mimi Martinez McKay, Chief of Staff, Information Services, Texas Department of State Health Services
Justin Mazzeo, Coordinator, Texas Alliance for Drug Endangered Children
Charly Meismer, Program Specialist, Family and Community Services, Texas Health and Human Services
Robert Miles, Legislative Liaison, Texas Association of Addiction Professionals
Diana Mitchel, Family First Program Director, Alpha Home Inc.
Gloria Moore, Community Advocate
Heidi Penix, CIP Program Director/CJA Grant Administrator, Texas Center for the Judiciary
Laura Peveto, Prevention and Intervention Manager, Office of Children Services, Travis County Health Human Services & Veteran Services
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Lisa Ramirez, Coordinator, Specialized Female Treatment Services, Women's Substance Abuse Services, Texas Department of State Health Services
Jerry Roberson, Ph.D., Senior Associate, United Associates
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Dori Wind, J.D., Senior County Assistant Attorney, Harris County District Attorney's Office
Ginny Woods, CJA Program Director/CIP Program Administrator, Texas Center for the Judiciary

Executive Summary

Every two years, the Texas Council for Developmental Disabilities (TCDD), in collaboration with the Texas Office for Prevention of Developmental Disabilities (TOPDD), prepares the *Texas Biennial Disability Report*. The report provides an overview of the strengths and weaknesses in the system of service provision for persons with developmental disabilities and to issues related to reducing the occurrence of preventable disabilities, and identifies opportunities for improvement and innovation in how the state provides supports to those persons and their families.

This report contains an overview of the services provided to persons with developmental disabilities in Texas, recent legislation impacting the provision of services, progress made toward three performance benchmarks, and a section focusing on the intersection of education and employment services provided to persons with developmental disabilities. Lastly, this report provides recommendations for action needed to improve and expand the services provided in Texas.

Texas residents with developmental disabilities are experiencing an increasing need for services due to increased longevity. The state is also experiencing population growth. Texas has made improvements in rebalancing the system of supports for persons with developmental disabilities by continuing to allocate funding to increase the number of people enrolled in home- and community-based services and reducing the number of persons in state supported living centers.

Despite these improvements, Texas continues to fund an institutional infrastructure by providing services to people in large state-operated facilities at higher rates than other states. The number of people requesting home- and community-based services continues to exceed growth projections indicating significant unmet need for services. Funding for these services has not kept pace with the need. Without a strong foundation of home- and community-based services, Texas cannot achieve its goal of serving individuals in the most integrated setting. Additionally, the number of Texans who are impacted by preventable developmental disabilities is truly significant. With a proactive approach, the state can indeed prevent many people from ever having a disability. This will not only make more funds available to assist people with disabilities, but will also improve the life trajectory of millions of Texans.

Texas faces difficult policy choices in responding to the needs of its citizens with intellectual and developmental disabilities. Challenges include a growing demand for services, changing expectations for service delivery among people with developmental disabilities, programmatic barriers to serving people in the least restrictive setting, and continued economic uncertainty. To address these challenges, Texas leaders have four key policy options to consider:

1. **Do nothing.** Keeping the current investment patterns and service array in place will most likely result in continued inefficient use of resources, a community system that cannot easily meet local service needs, and a growing unmet demand for services.

2. **Increase funding significantly, but maintain the current system of organizing and delivering services.** This approach might help at the margins, but it would tend to perpetuate present inefficiencies, even if most of the new money were to be directed at community systems. Overall, fewer people will be included than might otherwise be the case.
3. **Keep funding relatively level, but de-emphasize the use of state supported living centers in favor of home- and community-based services.** The transition itself will require funding, but afterwards the state may drive down the “per participant cost” due to the use of lower cost service options. Under this approach, there may be marginal impact on unmet service demand. State leaders, however, must take into account the fact that the present overall fiscal effort is already well under the national average.
4. **Increase funding significantly and de-emphasize the use of state supported learning centers in favor of home- and community-based services.** This is the most forward-looking option. It would provide a pathway toward increased efficiency within the system while providing needed funds to strengthen the community system and systematically address unmet service demand. Further, it would place the state on firmer footing in developing a system that can better address growing needs while reducing waiting lists for services.

In order to address increasing demand for services, Texas needs to take several actions to ensure appropriate and adequate prevention efforts and long-term service and supports systems. TCDD and TOPDD recognize the state’s current fiscal realities and therefore recommend that the 83rd Texas Legislature continue to de-emphasize the use of the state supported living centers and invest in home- and community-based services in the most integrated setting and to achieve greater cost efficiencies. TCDD and TOPDD recommend that Texas leaders strengthen prevention efforts and enhance home- and community-based services as the ultimate long-term goals.

Because Texas continues to experience economic uncertainty and growing service demand, TCDD and TOPDD hope that Texas leaders will once again engage in a meaningful, informed debate about what is needed to move the Texas long-term care system forward.

Report Methodology

This *2012 Texas Biennial Disability Report* updates and expands previous reports prepared by the Texas Council for Developmental Disabilities (TCDD) and the Texas Office for Prevention of Developmental Disabilities (TOPDD). In 2008, TCDD commissioned an external analysis of the current service delivery system including comparisons to other states across the country. TCDD examined the present system in Texas serving people with intellectual and developmental disabilities. The resulting gap analysis, action steps, and implementation strategies can be found in *Closing the Gap in Texas: Improving Services for Persons with Intellectual and Developmental Disabilities*.

For the *2010 Texas Biennial Disability Report*, TCDD contracted with The Institute for Organizational Excellence at The University of Texas at Austin and the Department of Aging and Disability Services to conduct a survey of individuals waiting to receive services through home- and community-based Medicaid waiver services. TCDD obtained input from Council members, colleagues, and advocates from disability groups throughout Texas.

This report updates the Texas specific data contained in the *2010 Texas Biennial Disability Report*. TCDD reviewed and synthesized information from a variety of sources including academic articles, research reports, and demographic data and projections. Data were obtained from Texas state 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. In addition, the actions taken by the 82nd Texas Legislature are summarized.

This report also includes a special focus on education and employment services for individuals with developmental disabilities. For this section of the report, information was obtained from the state agencies listed above as well as the Texas Education Agency and Texas Workforce Commission. Information from research reports produced by legislatively mandated councils, commissions, and audits is also included.

Overview of Services and Supports in Texas

Background

The service and support system for people with intellectual and developmental disabilities in Texas has improved over the past several decades but still faces many challenges. Disability rates in Texas and the corresponding demand for services continue to rise. The following sections discuss the trends in service demand and how Texas compares to other states in providing services to its citizens.

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. Individuals with substantial functional limitations may have various diagnoses such as intellectual and developmental disabilities, cerebral palsy, epilepsy, autism, severe learning disabilities, head injuries, and others that may result in limitations in intellectual or physical abilities. People with developmental disabilities may need assistance throughout life in self-care, employment, housing, and social interaction. Approximately 14.18 percent of the population of the United States and 11.4 percent of the Texas population has a disability.⁴ In Texas, about 475,265 people have a developmental disability.⁵

Most people with developmental disabilities receive key supports from their families or live independently with or without publicly funded developmental disabilities services. Public developmental disabilities service systems provide resources and supports to a relatively small percent (approximately 20 to 25 percent) of all individuals with developmental disabilities. Public systems focus primarily on people who have functional limitations and require services over and above the supports that their families are able to provide or that they can obtain through human services programs available to all individuals.⁶

Trends in Service Demand

Demand for publicly funded developmental disabilities services is growing nationwide and has been increasing at a rate slightly greater than population growth alone. Increased demand is the product of several factors including the development of community services and supports that

⁴ *American Community Survey*. United States Census Bureau. Web. 7 Aug. 2012. <http://www.census.gov/acs/www/>.

⁵ Texas Council for Developmental Disabilities. Web. 16 Aug. 2012. <http://www.txddc.state.tx.us/index.asp>.

⁶ 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. 2008:9.

better meet the needs of individuals and families, greater awareness about the existence of services and supports, and the increased longevity of people with developmental disabilities.

The most recent research available shows that the mean age at death for persons with intellectual disabilities or developmental disabilities rose from 19 years during the 1930s to 66 years in 1993, an increase of 247 percent.⁷ The life expectancy for people with intellectual and developmental disabilities is similar to that of the general population, with the mean age at death ranging from the mid-50s (for those with more severe disabilities or Down syndrome) to the early 70s for adults with mild or moderate intellectual and developmental disabilities.⁸ The number of adults with intellectual and developmental disabilities age 60 years and older is projected to reach 1.2 million by 2030.⁹

Increased longevity for people with developmental disabilities means that there is less turnover of service recipients and consequently reduced capacity to absorb new demand. Also, a growing population of individuals lives in households in which the primary caregiver is aging. Nationally, over 75 percent of people with intellectual and developmental disabilities live with their family.¹⁰ Twenty-five percent of family care providers are over the age of 60 and another 35 percent are between the ages of 41 to 59.¹¹ As caregivers age, their ability to continue to support individuals with developmental disabilities diminishes. Although most adults with intellectual and developmental disabilities live with their family, just 7.1 percent of funding for intellectual and developmental disability services is for state-provided community-based services for individuals living in the family home.¹²

Over the past several decades, many states have reexamined 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 family or in a community of their choice.¹³ This trend is the result of research, advocacy, and federal actions such as the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the 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

⁷ 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.

⁸ Bittles, A., Petterson, B., Sullivan, S., Hussain, R., Glasson, E., and Montgomery, P. "The Influence of Intellectual Disability on Life Expectancy." *The Journals of Gerontology Series A: Biological Science and Medical Science*, 57. 2002:470-472.

⁹ 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.

¹⁰ Braddock, David, Richard Hemp, and Mary C. Rizzolo. *The State of the States in Developmental Disabilities 2011*. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado. 2011:62.

¹¹ *Ibid.*

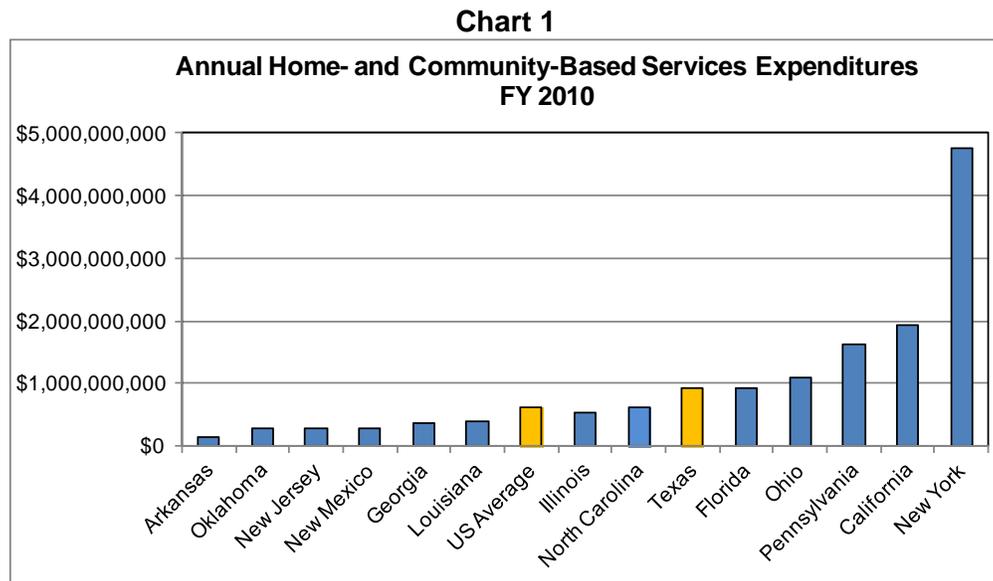
¹² *Ibid.*:75.

¹³ 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.

manner possible and the philosophy that individuals should be supported to make decisions concerning their own lives.

Texas' Rank in the Nation

While Texas continues to invest heavily in services for people with intellectual and developmental disabilities and has established a system of community services, state funding favors large institutional facilities over community-based care. Texas continues to expand home- and community-based services; 2010 annual expenditures per average daily recipient are close to the national average of \$45,550, but are less than several other large states. The average state per diem rates for institutional facilities for persons with intellectual and developmental disabilities have doubled since 2002.¹⁴ Seventeen percent of individuals with disabilities in Texas reside in large state facilities.¹⁵ Chart 1 shows the FY 2010 annual home- and community-based services expenditures compared to the national average.¹⁶



Source: Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:113.

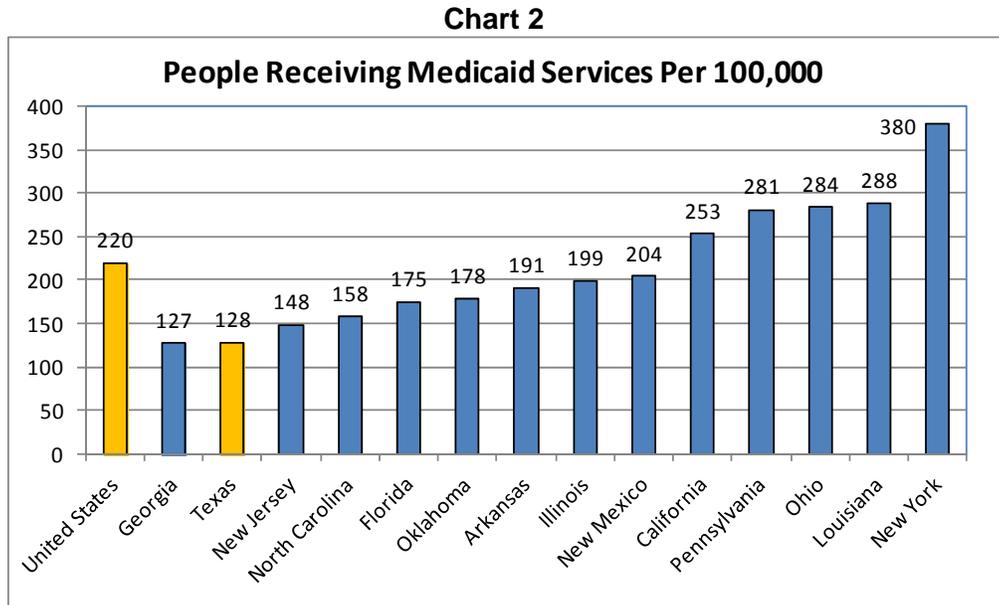
In FY 2010, Texas provided services and supports for 22,247 individuals with intellectual and developmental disabilities through the Medicaid home- and community-based service waiver programs and spent a total of \$912.6 million on home- and community-based service waiver

¹⁴ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:179.

¹⁵ Bragdon, Tarren. *The Case for Inclusion 2012*. United Cerebral Palsy. Washington, DC. 2012:2 of 7.

¹⁶ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:113,179.

programs.¹⁷ Four states have lower Medicaid utilization rates than Texas: Alabama, Georgia, Michigan, and Nevada (although Michigan has lower utilization than Texas, a significant portion of Michigan's services are provided as an entitlement via the Michigan Medicaid state plan). Chart 2 shows the utilization rates per 100,000 of state population.



Source: Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:120.

The current system of long-term services and supports in Texas falls significantly behind other states as evidenced by the following:

- Texas serves fewer people than other states, including New York and California:
 - New York, with a total population that is 23 percent less than Texas (25.1 million in Texas compared to 19.4 million in New York) provides services to more than twice as many people in intermediate care facilities for individuals with an intellectual disability (ICF/ID) and home- and community-based services as Texas (approximately 32,000 in Texas compared to approximately 74,000 in New York).¹⁸
 - California, with a total population 33 percent greater than Texas (37.3 million California compared to 25.1 million in Texas) provides services to approximately 94,000 people in ICFs/ID and home- and community-based services, nearly three times as many as Texas.¹⁹

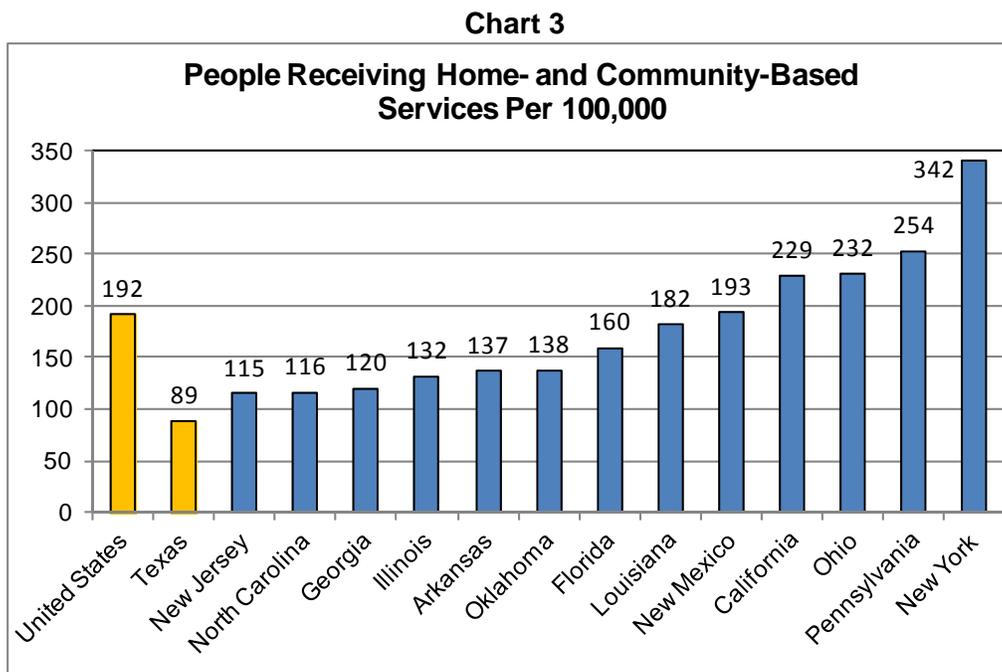
Although Texas has increased the number of people receiving home- and community-based services by over 15,000 from 2000 to 2010, it has a relatively low utilization rate of 88.5 per

¹⁷ Ibid:113.

¹⁸ Ibid:116.

¹⁹ Ibid.

100,000 of the state population.²⁰ This compares to the national average of 191.8 per 100,000 as shown in chart 3. Three states have lower home- and community-based services utilization rates: Michigan, Mississippi, and Nevada (although Michigan has lower utilization than Texas, a significant portion of Michigan’s services are provided as an entitlement via the Michigan Medicaid state plan).²¹



Source: Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:120.

- Texas has a higher proportion of Medicaid long-term care recipients in ICF/ID programs compared to the national rate. Of the 679,630 Medicaid long-term care recipients nationally, 87.1 percent received home- and community-based services and 12.9 percent received services in an ICF/ID;²² in Texas, 68.9 percent of Medicaid long-term care recipients received services from home- and community-based programs and 31.1 percent received services from an ICF/ID.²³
- Texas spends a greater proportion of its Medicaid dollars on institutional care compared to other states. Texas ranks second highest in the nation (after New York) with ICF/ID expenditures of \$974 million.²⁴

²⁰ Ibid:109, 120.

²¹ Ibid:120.

²² Ibid:114.

²³ Ibid:116.

²⁴ Ibid:125.

Texas annual expenditures per resident in a state supported living center (SSLC) were \$148,005 in 2010 and \$166,643 in 2012, a 12.6 percent increase.²⁵ Expenditures per home- and community-based services recipient were \$42,413 in 2010 and \$39,947 in 2012, a 5.8 percent decrease.²⁶ The situation is exacerbated by the fact that Texas, for several decades, has been one of the fastest growing states. Between 1990 and 2010, the Texas population grew by 48 percent, from 17.0 million to 25.1 million, while the U.S. population increased by 24.1 percent.²⁷ Data from the Texas State Data Center suggest that the population of Texas could grow from 25.1 million in 2011 to 44.9 million by 2040.²⁸ Given such growth, it will be an extraordinary challenge to address the backlog of unmet needs for long-term services while simultaneously keeping pace with population-driven growth in demand.

Consumer Satisfaction

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

Nationally, people with developmental disabilities argue strongly for support systems that look decidedly different than the current system of service provision in Texas. As articulated in the action agenda of the Alliance for Full Participation, a national organization that advocates for inclusion for people with developmental disabilities²⁹:

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

²⁵ “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.

²⁶ “3.A. Strategy Request: 82nd Regular Session, Agency Submission, Version 1 Automated Budget and Evaluation System of Texas (ABEST), Goal 1.3.2.” *Budget & Data Management*. Department of Aging and Disability Services. 2010:1; Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:125.

²⁷ *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>.

²⁸ *Texas Population Projections Program*. Texas State Data Center. Web. 10 Aug. 2012. <http://txsdc.utsa.edu/data/TPEPP/Projections/Index.aspx>.

²⁹ 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. 2008:77.

The Long-Term Services and Supports Quality Review (LTSSQR) is one of several key strategies the Department of Aging and Disability Services (DADS) uses to monitor the quality of long-term services and supports in the state. In addition to monitoring the quality of services and supports in assisted living facilities, ICFs/ID, SSLCs, and home- and community-based waiver programs, DADS uses LTSSQR to inform stakeholders about the status of long-term services and supports, including current observations and trends over time. DADS will continue to use LTSSQR to monitor the quality of long-term services and supports in Texas to measure customer satisfaction.³⁰

- *Services and supports improved health and well being.* In 2009, at least 94 percent of people reported that their services and supports helped their health and well being. The percentage of people who reported that their services and supports addressed their health and well being has remained high over the past three years.³¹
- *Services and supports helped people achieve their personal goals.* Similarly, a high percentage of people reported that their services and supports helped them achieve their personal goals. In 2009, at least 89 percent of people reported that their services and supports helped them achieve their personal goals. The percentage of people who reported that their services helped them reach their goals has remained high over time.³²
- *People were happy with their personal life.* At least three out of four people surveyed reported feeling happy in 2009. A decline in the percentage of people who were happy was only observed in the Community Living Assistance and Support Services (CLASS) Medicaid waiver program. An increasing percentage of people who received services from the Deaf Blind with Multiple Disabilities (DBMD) program or who resided in SSLCs reported feeling happy with their personal life from 2005 to 2009. Little or no change was observed among the remaining programs.³³

Consumer satisfaction with services for persons with intellectual and developmental disabilities is measured by the National Core Indicators (NCI) project, 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; Health, Welfare, and Rights; System Performance; Staff Stability; and Family Indicators. NCI is a voluntary effort used by agencies nationwide to evaluate and compare their performance across states. Survey respondents are consumers and their families. There are a number of measures showing comparisons between Texas and the average of the 29 states participating in the NCI survey (conducted in 2009 and 2010).

³⁰ *Long-Term Services and Supports Quality Review 2010*. Texas Department of Aging and Disability Services. January 2011:41.

³¹ *Ibid.*

³² *Ibid*:42.

³³ *Ibid*:42.

While 86 percent of the Texas respondents report that they do get the services they need, which is similar to the average of all NCI states (87 percent), Texas respondents report less choice than the average of responses from all 29 NCI states:

- 43 percent of Texas respondents choose their case manager or service coordinator, which is lower than the average of all NCI states (58 percent).
- 64 percent of Texas respondents reported that they decide their daily schedule, which is considerably lower than the average of all NCI states (83 percent).
- 15 percent of Texas respondents reported choosing their home, which is considerably lower than the average of all NCI states (45 percent).
- 74 percent of Texas respondents choose what to buy with their money, which is lower than the average of all NCI states (89 percent).

Other indicators include the following:

- Most people (between 81 and 87 percent) believe that their case manager or service coordinator asks them what they want and provides what they need, with Texas respondents reporting similar responses to those of all NCI states.
- Texas respondents are more likely than the average of all respondents to report that their case manager or service coordinator called them back right away (83 percent and 74 percent, respectively).³⁴

Consumer Directed Services (CDS) are a service delivery option in Medicaid community-based waiver programs that allow individuals or their legally authorized representatives to recruit, hire, train, and fire their service providers. In 2011, DADS implemented a broader awareness initiative including user-friendly information and materials about the CDS option.³⁵ Based on interviews with consumers and family members, more people who used the CDS option reported:³⁶

- That the people paid to help them listened carefully to what the person asked them to do.
- They had greater autonomy over their services and increased inclusion in the community compared to people who did not use CDS.

³⁴ “NCI State Report: Texas 2009-10.” *National Core Indicators*. Human Services Research Institute and The National Association of State Directors of Developmental Disabilities Services. Web. 11 Aug. 2012. <http://www.nationalcoreindicators.org/>.

³⁵ Taylor, Chris. “House Committee on Appropriations Subcommittee on Health and Human Services Charge #7.” Department of Aging and Disability Services. May 7, 2012:8.

³⁶ *Long-Term Services and Supports Quality Review 2010*. Texas Department of Aging and Disability Services. January 2011:67, 72.

Future Demand

When demand for the Medicaid community-based services and supports outweigh 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.³⁷ Service availability occurs when the legislature allocates funds to include more persons in a waiver or when services are vacated by a participant.

The expansion of Medicaid managed care has resulted in a decline in the number of people waiting for the Community Based Alternatives (CBA) waiver services. However, the number of people on waiting lists for other Medicaid waiver programs serving individuals with intellectual and development disabilities continues to increase. In Texas, home- and community-based services would have to grow by 334 percent on average to accommodate the need.³⁸

The CLASS program provides home- and community-based services to individuals with a related condition as an alternative to placement in an ICF/ID. The CLASS waiver program provided long-term services and supports to 4,719 individuals³⁹ and as of September 2012, has the second largest interest list, at 44,039 individuals.⁴⁰ Individuals can wait up to nine years before receiving CLASS services, with almost 72 percent waiting up to five years to receive services. The Home- and Community-Based Services (HCS) program provides residential services and supports to persons with intellectual and developmental disabilities. The HCS waiver provided long-term services and supports to 19,873 individuals as of June 2012,⁴¹ and presently has the largest interest list at 60,832.⁴² Individuals can wait over ten years before receiving HCS services, with 68 percent waiting up to five years to receive services.

Table 1 shows the number of individuals on the interest lists for six Medicaid waiver programs. These counts are duplicated and do not match unduplicated counts discussed on the previous page.

³⁷ *Interest List Reduction*. Department of Aging and Disability Services, Web. 11 Aug. 2012.

<http://www.dads.state.tx.us/services/interestlist/index.html>.

³⁸ Bragdon, Tarren. *The Case for Inclusion 2012*. United Cerebral Palsy. Washington, DC. 2012:6 of 7.

³⁹ *DADS Interest List and Waiver Caseload Summary*. Department of Aging and Disability Services. August 2012:6.

⁴⁰ *Interest List Reduction*. Department of Aging and Disability Services, Web. 27 Nov. 2012. Archives retrieved from: <http://www.dads.state.tx.us/services/interestlist/index.html>.

⁴¹ *DADS Interest List and Waiver Caseload Summary*. Department of Aging and Disability Services. August 2012:6.

⁴² *Interest List Reduction*. Department of Aging and Disability Services, Web. 27 Nov. 2012. Archives retrieved from: <http://www.dads.state.tx.us/services/interestlist/index.html>.

Interest List Counts	FY 2008*	FY 2010	FY 2011	FY 2012
CBA	29,316	35,220	30,148	11,172
CLASS	21,496	32,650	38,258	44,039
DBMD	28	316	420	537
HCS	37,187	45,756	52,676	60,832
MDCP	9,920	18,404	22,063	25,810
STAR+PLUS	2,125	5,288	10,741	11,056
Total	68,631	97,126	113,417	153,446

Source: *Interest List and Waiver Caseload Summary Archive*. Department of Aging and Disability Services.

20 Nov. 2012. Web. 27 Nov. 2012. <http://www.dads.state.tx.us/services/interestlist/archive>.

*Data for FY 2008 is from June 2008.

The time that individuals spend on interest lists has fluctuated. Table 2 shows the time on interest lists for six Medicaid waiver programs in 2010 and 2012. Wait times have increased from 2010 to 2012 for Medically Dependent Children's Program (MDCP), HCS, DBMD, and CLASS. Wait times have decreased for CBA.

Time on Interest List	CBA		STAR+ Plus*		CLASS		DBMD**		MDCP		HCS	
	2010	2012	2010	2012	2010	2012	2010	2012	2010	2012	2010	2012
0-1 years	48.3%	91.7%	65.8%	57.0%	22.0%	12.8%	80.0%	26.6%	30.7%	19.6%	20.7%	13.9%
1-2 Years	43.6%	8.3%	32.0%	24.1%	19.7%	15.8%	14.9%	21.8%	25.5%	22.2%	18.6%	14.6%
2-3 years	8.1%	10.0%	0.9%	18.0%	17.7%	16.1%	3.8%	25.1%	22.5%	19.8%	14.8%	15.2%
3-4 years	0.0%	0.0%	1.1%	0.7%	15.1%	14.5%	1.3%	26.4%	18.6%	16.6%	12.2%	13.3%
4-5 years	0.0%	0.0%	0.2%	0.0%	9.6 %	12.8%	0.0%	0.0%	2.7%	14.3%	9.6%	10.5%
5-6 years	0.0%	0.0%	0.0%	0.0%	7.7%	11.1%	0.0%	0.0%	0.0%	7.5%	7.6%	8.9%
6-7 years	0.0%	0.0%	0.0%	0.0%	7.5%	7.2%	0.0%	0.0%	0.0%	0.0%	7.5%	7.1%
7-8 years	0.0%	0.0%	0.0%	0.0%	0.0%	5.4%	0.0%	0.0%	0.0%	0.0%	6.9%	5.5%
8-9 years	0.0%	0.0%	0.0%	0.0%	0.0%	4.2%	0.0%	0.0%	0.0%	0.0%	2.1%	5.3%
9-10 years	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	5.1%
10-11 years	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.6%

Source: *Interest List and Waiver Caseload Summary Archive*. Department of Aging and Disability Services. 20 Nov. 2012. Web. 27 Nov. 2012. <http://www.dads.state.tx.us/services/interestlist/archive>.

* Integrated Care Management Services (ICM) are not shown on the chart for 2010 and are no longer offered due to the expansion of the STAR+PLUS program in the Dallas and Fort Worth areas effective Feb. 1, 2011.

**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.

The 2008 *Closing the Gaps in Texas* analysis provides more information regarding the complexity of using counts on interest lists to determine service demand.⁴³ In addition to the difficulty of projecting need and interest list growth, people on the interest lists may not know when and if their service needs will change. In a survey of those on the interest list for HCS waiver services, about one-quarter of respondents anticipate their needs will change in the next five years. However, almost half indicated that they did not know when their service needs will change.⁴⁴

⁴³ 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, October 2008:10.

⁴⁴ *2010 Texas Biennial Disability Report*. Texas Council for Developmental Disabilities. 2010:21.

Legislative Decisions and Direction

Since the Texas Council for Developmental Disabilities (TCDD) identified gaps in the Texas service system in 2008, TCDD has advocated for increased funding for programs and services for people with intellectual and developmental disabilities with 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 also for state supported living centers (SSLCs), which maintained significant expenditures for institutional care. In 2011 the 82nd Texas Legislature maintained funding for SSLCs and decreased funding for community intermediate care facilities for individuals with an intellectual disability or related condition (ICFs/ID) and Medicaid waiver programs. As a result, the imbalance in the Texas service system that favors institutional care remains despite some increases in community services.

Upon adoption, the FY 2012-2013 budget passed by the 82nd Texas Legislature was expected to be approximately \$4.8 billion less than is necessary to fund Medicaid programs through the 2012-2013 biennium.⁴⁵ The budget contained \$9 billion in cuts to general revenue and left almost \$5 billion in Medicaid services unfunded.⁴⁶ The reductions in funding, coupled with cuts in rates for ICFs/ID and Medicaid waiver programs, resulted in short-term cost savings for the state but negatively impacted clients through a reduction in services and longer waiting periods for services. Even in a program where funding was maintained, the interest list grew considerably: Although approximately 9 percent more clients were provided long-term services and supports in the HCS waiver between FY 2010 and June 30, 2012, the number of people on the interest list grew almost 30 percent, to 60,196 people in that time (interest lists are discussed in more detail in the previous section of this report).⁴⁷

The following sections provide an analysis of key decisions made by the 82nd Texas Legislature that impacts people with intellectual and developmental disabilities.

Budget Reductions

The 82nd Texas Legislature reduced funding for programs that affect service provision for people with developmental disabilities in both the short- and long-term and that have long-term consequences for future state budgets.

The FY 2012-2013 budget reduced funding for Department of Family and Protective Services (DFPS) prevention services, the Department of Assistive and Rehabilitative Services (DARS) Early Childhood Intervention program, and the Texas Education Agency (TEA) Early Childhood

⁴⁵ *General Appropriations Act 2012-2013 Biennium: The Budget and Texans with Developmental Disabilities*. Texas Council for Developmental Disabilities. July 2011:3.

⁴⁶ *Ibid*:2.

⁴⁷ *Interest List Reduction*. Department of Aging and Disability Services, Web. 11 Aug. 2012. <http://www.dads.state.tx.us/services/interestlist/index.html>.

School Readiness program.⁴⁸ Direct service hours provided to clients through DARS Early Childhood Intervention Services program is less than the amount recommended by early childhood experts and, according to DARS, is not sufficient for desired outcomes.⁴⁹ Funding for the TEA Early Childhood Readiness program was cut in half.⁵⁰

For both the ICFs/ID and the Medicaid waiver programs, appropriations for FY 2012-2013 were reduced, yet service provision is to remain at current levels. ICF/ID services experienced a two percent rate cut and Medicaid waiver programs a 1 percent rate cut.⁵¹ As part of the overall 1 percent rate reduction for Medicaid waiver programs, supported home living (SHL) rates - the most cost-effective of the three home- and community-based (HCS) service types - were cut by 26 percent.⁵²

The FY 2012-2013 budget includes funding to maintain all of the SSLCs. In order to maintain services in the facilities, funding was increased from the previous biennium. Legislators projected that the SSLC census would be reduced by 740 people to 3,595 by the end of FY 2013.⁵³ Attempts to close any SSLCs have not been successful. The initial (engrossed) version of HB 1 from the 82nd Texas Legislature contained Rider 43 directing the Department of Aging and Disability Services (DADS) to close one unspecified SSLC by January 1, 2013 and to monitor the health and well-being of the residents moved from the SSLC to community care. This provision was removed from the conference committee report and final version of the appropriations bill.

Expansion of Managed Care

Medicaid managed care is provided to six rural and seven urban service areas through the State of Texas Access Reform (STAR) and STAR+PLUS programs. The 82nd Texas Legislature expanded Medicaid managed care to the Lower Rio Grande Valley, an area of the state with historically high costs. Spending reductions are assumed to come from extending the reach of Medicaid managed care in Texas to these 10 new South Texas counties.

Beginning on March 1, 2012, The STAR Medicaid managed care program expanded into a total of 174 more Texas counties including 164 counties in rural areas and 10 counties in South Texas.⁵⁴ The STAR+PLUS program remains in seven service areas with sixty-three counties

⁴⁸ *General Appropriations Act 2012-2013 Biennium: The Budget and Texans with Developmental Disabilities.* Texas Council for Developmental Disabilities. July 2011:2-5.

⁴⁹ *Ibid*:4.

⁵⁰ *Ibid*:2.

⁵¹ Department of Aging and Disability Services. Message to Morningside Research and Consulting via TCDD. September 21, 2012. Email.

⁵² *Ibid*.

⁵³ *General Appropriations Act 2012-2013 Biennium: The Budget and Texans with Developmental Disabilities.* Texas Council for Developmental Disabilities. July 2011:1-3.

⁵⁴ *Medicaid Managed Care Changes Effective March 2012.* Texas Health and Human Services. 2011:2.

covering a mix of urban and rural areas in north, central and southeastern areas of the state.⁵⁵ STAR+PLUS integrates health care services and long-term service and supports for people who are over age 65, who are blind, or have disabilities.⁵⁶

Medicaid managed care reduced the amount of time people wait on the Community-Based Alternatives (CBA) interest list, because individuals who are eligible for home- and community-based services and have income at or below Supplemental Security Income (SSI) also are automatically eligible and enrolled in STAR+PLUS.⁵⁷ The program has the potential to support people with disabilities who would be able to live in the community through provider-initiated coordinated care and long-term care management. However, if a health plan does not have an adequate number of providers, the program also has the potential to restrict access to therapies, community services, and specialists. In such a case, the program may not improve access to long-term services and supports, and may reduce quality of care.⁵⁸ In addition, the state currently is left with little recourse when a Medicaid managed care organization makes certain business decisions, like reducing direct support wages across a region.

Increased Funding for the Texas Home Living Program

In the appropriations bill passed by the 82nd Texas Legislature, funding was increased for the Texas Home Living (TxHmL) waiver program.⁵⁹ The TxHmL program provides essential services and supports to Medicaid-eligible Texans with an intellectual or developmental disability so they can continue to live at home.

While funding for TxHmL was increased, funding for In-Home and Family Support (IHFS) for people with intellectual and developmental disabilities was eliminated.⁶⁰ The legislative intent in reducing funding for this DADS program was to move individuals from the IHFS program into the TxHmL waiver program.⁶¹ The IHFS program provided direct grant benefits to help people purchase services that enable them to live in the community. However, not everyone previously receiving IHFS is eligible for TxHmL.⁶² Specifically, children who received IHFS were most likely to go without services as a result of the refinance. TxHmL is the only waiver for which parental

⁵⁵ Ibid.

⁵⁶ Ibid:1.

⁵⁷ *Community Services 2008-2009 Projected Funds and 2010-2011 Requested Funds and Average Monthly Caseloads*. Department of Aging and Disability Services. Web. 5 Oct. 2012.

http://www.dads.state.tx.us/providers/pi/piac_reports/2008/projectedfunds.html

⁵⁸ Dunkelberg, Anne. "Texas Health Care 2011: What has Happened and the Work that Remains." Center for Public Policy Priorities, December 2011: 7.

⁵⁹ *General Appropriations Act 2012-2013 Biennium: The Budget and Texans with Developmental Disabilities*. Texas Council for Developmental Disabilities. July 2011:3.

⁶⁰ Ibid.

⁶¹ Ibid.

⁶² Ibid.

income can preclude a child's Medicaid eligibility. Likewise, it is the only waiver with an income eligibility threshold below 300 percent of SSI.⁶³

The legislature also reduced DADS Intellectual Disability Community Services funding by 26 percent, which is provided through local intellectual and developmental disability authorities and supports people living in the community by coordinating and providing a range of services for people on the interest lists who are waiting for services or for people who are not eligible for any other program.⁶⁴ Understating the challenge of coordinating services for persons with few options belies the systemic unmet needs of Texans with disabilities.

Transition Planning and Person First Language

Passed during the 82nd Texas Legislature, SB 1788 by Senator Patrick and Representative Huberty requires TEA to develop a model Individual Education Plan (IEP) for school districts to use in assisting students with transition planning and requires public student transition planning to begin when students are 14 years old rather than waiting until students are 16 years old. As the education and employment section of this report will show, the rate of former students who received special education services enrolling in higher education or being competitively employed within one year of leaving high school decreased from federal fiscal year (FFY) 2009 to FFY 2010. It is believed that beginning transition planning earlier will improve these outcomes.

HB 1481 by Representative Truitt and Senator Zaffirini requires health and human services agencies to use person first respectful language when referring to people with disabilities in state materials and communication, including statutes and policies.⁶⁵ Specifically, the legislation requires the removal of the word "retard" and all of its derivations from statute and state literature.

State Supported Living Centers and Promoting Independence

Medicaid Promoting Independence (PI) funding provides services and supports that allow people who are at risk of institutionalization, leaving institutions, or children aging out of foster care to receive community-based waiver services. Services that will be provided as a result of funding for Promoting Independence for the FY 2012-2013 biennium are:⁶⁶

- Home- and Community-based Services (HCS) Medicaid waiver services for 400 persons to

⁶³ *Texas Home Living (TxHmL) Program*. Department of Aging and Disability Services. Web. 13 Nov. 2012. <http://www.dads.state.tx.us/handbooks/txhtml/N/index.htm>.

⁶⁴ *General Appropriations Act 2012-2013 Biennium: The Budget and Texans with Developmental Disabilities*. Texas Council for Developmental Disabilities. July 2011:3.

⁶⁵ *Department of Aging and Disability Services: High Level Summary of DADS Budget for Fiscal Year 2012-13*. Department of Aging and Disability Services.

⁶⁶ *Ibid.*

transition from large intermediate care facilities (ICFs) and state supported living centers (SSLCs);

- Crisis/diversion services for 240 persons at imminent risk of institutionalization in a SSLC;
- HCS waiver services for 192 children aging out of DFPS foster care; and
- CBA waiver services for 100 persons at risk of institutionalization in a nursing facility.

SB 37 by Senator Zaffirini continues the Promoting Independence Advisory Council (PIAC) until 2017, to ensure there are continued recommendations made to the Health and Human Services Commission (HHSC) regarding the appropriate care settings for persons with disabilities.⁶⁷ The PIAC submitted the “2010 Revised Texas Promoting Independence Plan” to the Governor and to the Texas Legislature in February 2011 and released the *Interim 2012 Promoting Independence Advisory Committee Stakeholder Report* in June of 2012.

Several federal and state actions since 2009 have affected SSLCs and how they provide care to their residents including, but not limited to, the U.S. Department of Justice (DOJ) settlement agreement regarding the 13 SSLCs in Texas that seeks to: increase protections of SSLC residents; bring supports and services up to generally 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 82nd Texas Legislature passed additional legislation aimed at improving care at the SSLCs and for people who are currently receiving or would like to receive home- and community-based services, including:

- SB 41 by Senator Zaffirini and Representative Davis reduces the use of restraints and directs SSLC staff to use the least restrictive restraint.
- HB 2609 by Representative Guillen and Senator Uresti was passed to increase safety for SSLC and ICF/ID residents and staff by adding obstruction and retaliation to the list of offenses that bar a person from employment at these facilities.⁶⁸
- SB 222 by Senator Nelson and Representative Raymond requires DADS to inform individuals who are eligible for services about all of their program and service options and to educate the public about home- and community-based service options.⁶⁹ SB 222 also required HHSC to apply for and actively pursue amendments to the Community Living Assistance Support Services (CLASS) and HCS waivers to authorize the provision of personal attendant services through those waivers.

SB 7 by Senator Nelson and Representative Zerwas required DADS and HHSC to streamline and improve administrative and service delivery efficiencies of the 1915(c) Medicaid waiver programs. It also required the implementation of an electronic visit verification (EVV) system

⁶⁷ 82nd Regular and 1st Called Session Legislative Summary. Department of Aging and Disability Services. 2012:3.

⁶⁸ Ibid:4.

⁶⁹ Ibid:5.

that would allow providers to verify and document services provided to clients. EVV implementation has been particularly problematic because the required technology was originally designed for persons who primarily receive services from a provider in their homes and was not technologically accessible to all persons with disabilities who are active in their communities and those who employ their direct support workers. The bill also required a plan for the redesign of the long-term care services and supports system to increase access to patient-centered care in the most cost-effective manner.⁷⁰ Discussion regarding the topic of redesign was included in several interim hearings and DADS held a public input session, but no details regarding what the plan will include are available.

HB 3197 by Representative Coleman requires a pilot program to implement the culture change model of care at one SSLC. The policy is a result of a Legislative Budget Board (LBB) recommendation and includes implementing processes, policies, and practices that assist in shifting decision-making to the individual with the disability. DADS is directed to work with the Texas Long Term Care Institute at Texas State University to develop and implement training, assessments, and technical improvements that will inform the improvement of practices, services, and the workforce. The legislation required DADS to submit a report to the governor and the LBB regarding the pilot program no later than September 1, 2012.⁷¹

Texas received approval from the Centers for Medicare and Medicaid Services (CMS) on December 12, 2011, for a waiver that allows the state to develop the Texas Health Care Transformation and Quality Improvement Program. The program preserves funding for hospitals, provides incentive payments for health care improvements, and directs more funding to hospitals that serve large numbers of people without insurance.⁷²

⁷⁰ *Texas Legislature Online*. Web. 25 September 2012.

<http://www.capitol.state.tx.us/BillLookup/History.aspx?LegSess=821andBill=SB7>.

⁷¹ *82nd Regular and 1st Called Session Legislative Summary*. Department of Aging and Disability Services. 2012:3.

⁷² "FYI Monthly E-News." Texas Council for Developmental Disabilities. January 2012:1.

Texas Benchmark Performance

In 2008, the Texas Council for Developmental Disabilities (TCDD) contracted with the Human Services Research Institute (HSRI) to conduct an external analysis of the Texas service system and evaluate its performance against three performance benchmarks. HSRI provided an assessment of progress toward meeting each benchmark and the following section updates the progress that has been made since the 2008 report.⁷³

Texas Benchmarks

Benchmark 1: People with intellectual and developmental disabilities have access to and receive necessary publicly funded services and supports with reasonable promptness.⁷⁴

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

In Texas, as in many states, service system capacity is managed during the legislative process by capping dollars or service openings, or both. Capacity is determined by the budget passed by the Texas Legislature during each session. 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 or sooner and individuals with critical near-term needs should receive services within 6 to 9 months.⁷⁵ When demand for services exceeds the available service openings available, individuals are put on an interest list for services.

Benchmark 2: Services and supports are provided in the most integrated setting appropriate to the needs of the individual.⁷⁶

Assessment: **Many people with intellectual and developmental disabilities do not receive services within the least restrictive setting appropriate to their needs.** As discussed earlier in this report, Texas relies more heavily on state supported living centers (SSLCs) and privately

⁷³ 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.

⁷⁴ Ibid:9.

⁷⁵ Ibid:10.

⁷⁶ Ibid:21.

operated intermediate care facilities for individuals with an intellectual disability or related condition (ICFs/ID) than most other states.

Benchmark 3: The system must promote economy and efficiency in the delivery of services and supports.⁷⁷

Assessment: The state's service system for people with developmental disabilities is not operated in a manner that promotes efficiency and economy. Texas' average spending per citizen for home- and community-based intellectual and developmental disability services is below the national average. Texas continues to devote a greater share of its Medicaid dollars to large congregate care services than is typical nationwide.

Action Steps

Over the last several years, Texas has made incremental steps towards improving some aspects of service delivery; however, these efforts have yet to make a significant impact on interest list wait times and service system improvements. The 2008 *Closing the Gaps in Texas* analysis identified three action areas and eight action steps to guide Texas in a ten-year system redesign effort. This section lists those action steps and describes Texas' progress toward implementing them.

Action Area 1: Serve People in the Most Integrated Setting

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

In 2010, the average daily population of people with developmental disabilities living in residential facilities with 16 or more beds in Texas was 4,337. This compares to 2,149 for California and 2,019 in New York.⁷⁸ The daily population in Texas is 37 percent higher than New Jersey (2,711), the state with the second highest average daily population. As of August 2012 the SSLC census is 3,787.⁷⁹

It costs Texas significantly less money to provide needed services to an individual living in a community setting compared to an institutional setting. In state fiscal year (FY) 2013, the reimbursement rate per person per day in SSLCs will range from \$634.26 to \$656.00. The reimbursement rate per person per day in small state-owned community ICFs/ID will be

⁷⁷Ibid: 31.

⁷⁸ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:11.

⁷⁹ *Promoting Independence Advisory Committee Department Activity Report*. Department of Aging and Disability Services. October 2012:5.

\$625.18.⁸⁰ The cost of private, community-based ICFs/ID per person per day will range from \$109.86 to \$398.07 depending on facility size and the level of need.⁸¹

In 2010, the average annual nationwide cost of serving an individual in a public or private ICF/ID was \$144,695. In contrast, the average cost of supporting a person through the Medicaid home- and community-based programs was \$45,550.⁸²

As a result of the circumstances necessitating the U.S. Department of Justice's (DOJ) involvement in the state supported living centers system, TCDD continues to support a moratorium on new admissions to SSLCs.⁸³

Action Step #2: Cease admissions of children to state schools/centers.

The policy of the state 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.⁸⁴ As of February 2012, 134 young adults (18 to 22 years) and 119 minor children (age 18 or younger) were living in a Texas SSLC, almost 7 percent of the SSLC census.⁸⁵ This is a 4 percent decrease from February 2011, but is still 5 percent higher than the number in 2002.⁸⁶ Nationally, across all levels of disability, youth ages 15 to 21 years were 12.2 percent of admissions and 18.2 percent of readmissions.⁸⁷

Chart 4 shows the population of children in SSLCs. Texas has been working to ensure that children admitted to SSLCs have access to family-based alternatives in the HCS waiver program via Permanency Planning and Promoting Independence. The population of children in institutions had remained somewhat constant from 1994 until 2008, when the number of children living in SSLCs jumped to 383, an increase from 5 percent to 8 percent of all SSLC residents and a 36 percent increase in the number of children.⁸⁸

⁸⁰ *Rate Analysis for Long-Term Services and Supports: Intermediate Care Facilities for Individuals with an Intellectual Disability*. Texas Health and Human Services Commission Rate Analysis Department. September 2012:3-4.

⁸¹ *Ibid*:1.

⁸² Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:viii, ix.

⁸³ *Fact Sheet: Collaboration on Supporting a Moratorium on SSLC Admissions*. Texas Council for Developmental Disabilities. September 2010: 1.

⁸⁴ *Senate Bill 368 77 (R) Bill Analysis*. Texas Legislature Online. Web. 2 October. 2012.

<http://capitol.state.tx.us/tlodocs/77R/analysis/html/SB00368F.htm>.

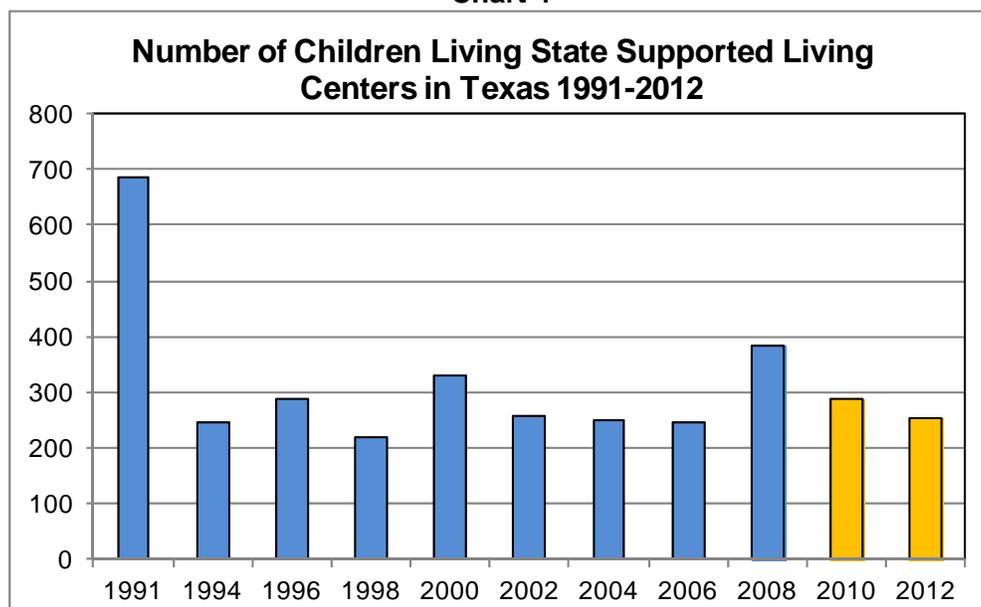
⁸⁵ *Permanency Planning Report: In Response to S.B. 368, 77th Legislature, Regular Session, 2001*. Texas Health and Human Services Commission. July 2012:6.

⁸⁶ *Ibid*:14.

⁸⁷ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:43- 44.

⁸⁸ *Ibid*:179.

Chart 4



Sources: 1991 through 2008 data are from Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:179. 2010 data are from Permanency Planning and Family-Based Alternatives Report. In Response to SB 368, 77th Legislature, Regular Session 2001. December 2011. 2012 data are from Permanency Planning Report. In Response to SB 368, 77th Legislature, Regular Session, 2011. July 2012.

In 2009, 50 percent (88 out of 177) of new admissions into Texas SSLCs were children (age 0 to 21). This is more than twice the national average of 21.7 percent. The Department of Aging and Disability Services (DADS) admitted 71 children 18 years or younger to an SSLC in FY 2010 and 51 in FY 2011.⁸⁹ The number of children admitted to these facilities has decreased and they represent a smaller percentage of all new admissions (40 percent).⁹⁰

Of 35 states reporting, 23 (including Texas) reported admitting or readmitting more children and youth to large state facilities in 2010 than were discharged from those facilities.⁹¹

In Texas in federal fiscal year (FFY) 2010, the majority of admissions and readmissions of children and youth to large state facilities had a “none/mild/moderate” level of intellectual disability.⁹² Ideally, children and youth with lower levels of need are provided supports in

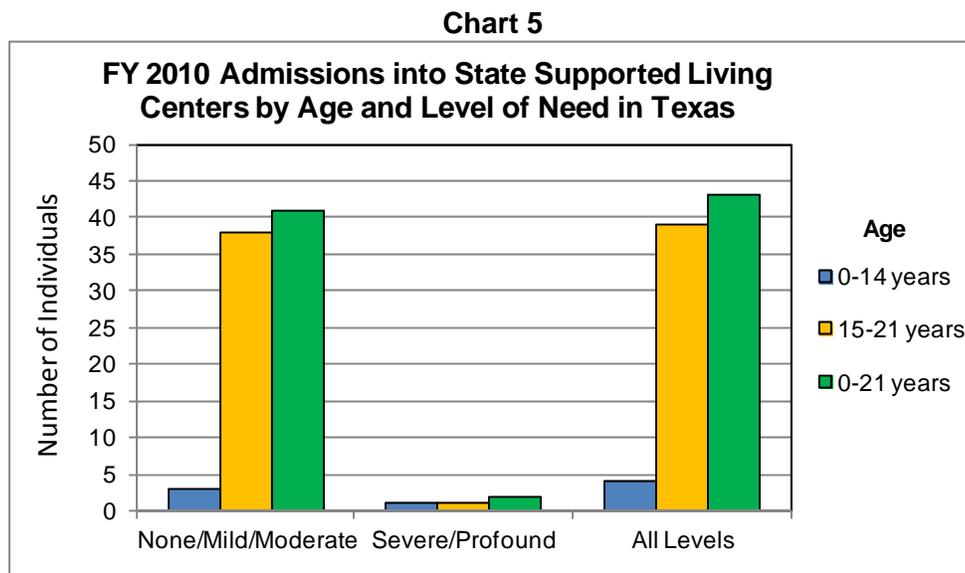
⁸⁹ Department of Aging and Disability Services. “TCDD Data Request.” Message to Morningside Research and Consulting. July 20, 2012. Email.

⁹⁰ Ibid.

⁹¹ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:48.

⁹² Ibid:49.

community settings rather than in an institutional setting.⁹³ As shown in Chart 5, many of the children admitted in 2008 had none to moderate levels of need.



Source: Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012: 49.

The Texas Legislature has taken some action to expedite the placement of children in the community rather than institutions. Senate Bill 368 (2001) requires all individuals 22 years and younger who reside at an institution to be placed on an interest list for community waiver support. The goal of the bill is to ensure that children grow up in families rather than institutions.⁹⁴ In addition to children, all SSLC residents have access to the HCS waiver program via Promoting Independence and should receive community placement within 180 days of a request.

Action Step #3: Texas should further develop its Money Follows the Person initiatives to accommodate a stronger transition of people living in ICFs/ID who prefer to receive services in the most integrated setting.

The Money Follows the Person (MFP) demonstration project began in September 2001 and has helped more than 20,300 Texans with disabilities living in institutions to transition back to the community to receive their long-term services and supports.⁹⁵ MFP helps states rebalance their long-term care systems to transition people with Medicaid from institutions to the community.

⁹³ 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. 2008:46.

⁹⁴ *Senate Bill 368 77 (R) Bill Analysis*. Texas Legislature Online. Web. 2 October. 2012. <http://capitol.state.tx.us/tlodocs/77R/analysis/html/SB00368F.htm>.

⁹⁵ "Money Follows the Person Demonstration Project." *Grants/Innovations Supporting Promoting Independence*. Department of Aging and Disability Services. 15 May 2012. Web. 16 Aug. 2012. http://www.dads.state.tx.us/providers/pi/mfp_demonstration.

Texas is considered a leader in this area and has developed and implemented a wide variety of creative strategies for maximizing its share of MFP opportunities. The following are some of the MFP project proposals of particular note:

- Refinance four Aging and Disability Resource Centers (ADRC) and fund the following: one additional ADRC Housing Navigator, two new ADRCs, supported employment training and technical assistance, Preadmission Screening and Resident Review (PASRR) Survey, sponsorship of individuals to attend Self-Advocate Conference, and a realistic job preview video.
- Training of Local Authorities, nursing facility staff, and referring entities on the PASRR redesign.
- Creation of Person Centered Thinking training for individuals who support people with developmental disabilities.
- Provide Positive Behavior Management workshops for individuals implementing behavior support plans, such as nurses, direct contact staff, caregivers, family members, behavior analysts, medical staff, home managers and supervisors, and other professionals who work with individuals who have developmental disabilities and engage in challenging behaviors.
- Create a pilot program to work with three Local Authorities, Austin State Supported Living Center (ASSLC) and state office staff for individuals living in ASSLC to receive support to achieve success in a community setting.⁹⁶

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

Texas has not kept pace with the national trend to transition away from ICFs/ID, especially large facilities, toward more home- and community-based settings. Many states have come to rely almost entirely on home- and community-based services and very little on ICFs/ID. In fact, 11 states plus the District of Columbia do not have any state-operated residential institutions for people with developmental disabilities.⁹⁷

As evidence of continued support for institutional care, the state added 1,690 staff positions to the SSLC structure in FY 2008-2009 at a cost of approximately \$1.04 million. This increased the total number of funded, full-time equivalents (FTEs) in the SSLC network to 14,073.⁹⁸

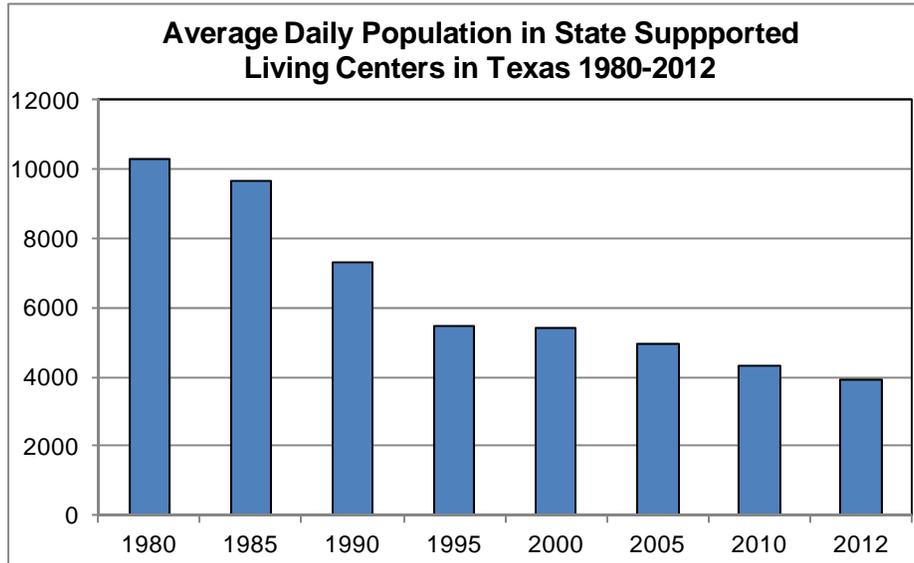
⁹⁶ “Brief Summary of Current Money Follows the Person Demonstration 100 Percent Administrative and Rebalancing Activities.” Message to Morningside Research and Consulting from TCDD. October 16, 2012. Email.

⁹⁷ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:17; *Indiana Governor’s Council for People with Disabilities*. National Association of Councils on Developmental Disabilities. 2011:1.

⁹⁸ Department of Aging and Disability Services. “TCDD Data Request.” Message to Morningside Research and Consulting. July 20, 2012. Email.

Many SSLC residents have transitioned to community alternatives, reducing the census of state-operated facilities from 10,320 in 1980⁹⁹ to 3,787 in 2012¹⁰⁰ as shown in Chart 6. Yet Texas has been considerably slower at reducing the population of SSLCs when compared to national trends. Since 1989, Texas reduced the census in large state facilities by only 32.6 percent compared to a 53.9 percent reduction nationally.¹⁰¹

Chart 6



Sources: Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:5. Data for 2012 are from Legislative Budget Board. Department of Aging and Disability Services 2012-2013 Legislative Appropriations Request.

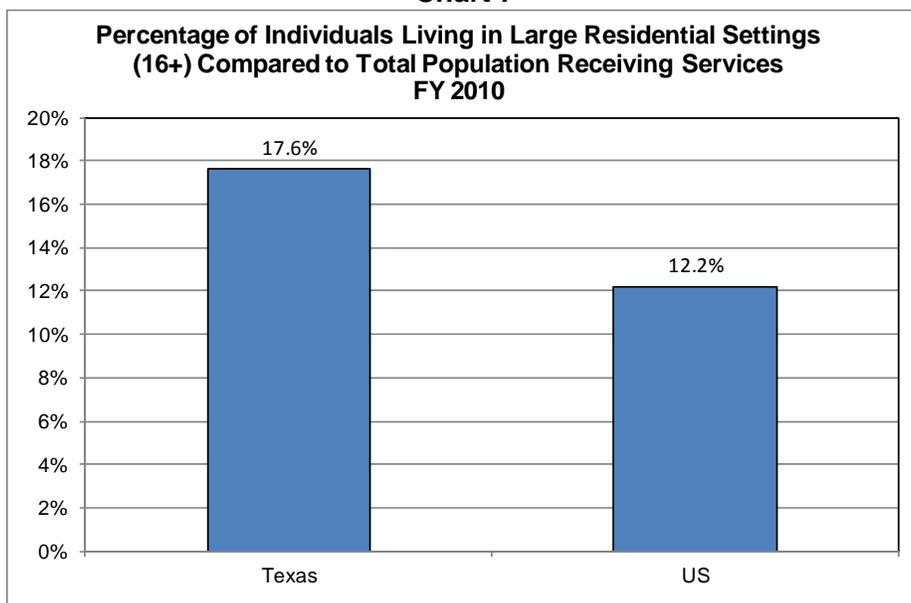
Texas continues to devote a greater share of its Medicaid dollars to large congregate care services than is typical nationwide, and the cost of supporting a person in a state supported living center was almost twice the cost of supporting a person in other types of ICFs/ID. Chart 7 shows the percentage of individuals living in large residential settings compared to the United States.

⁹⁹ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:5.

¹⁰⁰ *Promoting Independence Advisory Committee Department Activity Report*. Department of Aging and Disability Services. October 2012:5.

¹⁰¹ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:11.

Chart 7



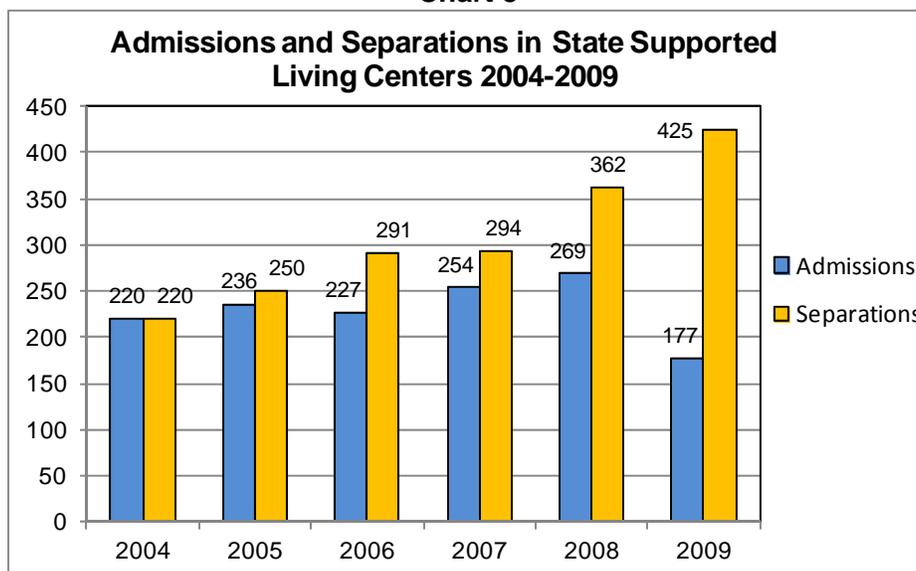
Source: Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:77.

As shown in Chart 8, SSLCs are continuing to admit individuals. Since 2004, Texas SSLCs have discharged more residents than they admit.¹⁰² While Texas has made progress in honoring the choice of residents to move to other locations, a large number of individuals continue to be admitted each year and the rate of admissions just recently slowed. As noted previously, the number of SSLC residents who receive community placements has also increased in recent years and the community has shown the capacity to provide appropriate services to individuals who have moved from institutional settings. During FY 2011, 204 individuals were moved from SSLCs into community placements, and only 3 (1 percent) returned to an SSLC. As of May 31, 2012, 123 individuals have moved from SSLCs into community placements, and only 3 (2 percent) returned to an SSLC.¹⁰³

¹⁰² *Texas Health and Human Services Commission CARE System, Report Update for State Supported Living Centers FY 2010-2011*. Department of Aging and Disability Services. July 2010.

¹⁰³ "Community Placements and Community Placement Returns." Department of Aging and Disability Services. June 08, 2012.

Chart 8



Source: Texas Health and Human Services Commission CARE System, Report Update for State Supported Living Centers FY 2010-2011. Texas Department of Aging and Disability Services, July 2010.

Action Area 2: Expand Community System Capacity

Action Step #5: Starting in 2009 and each year thereafter through 2018, Texas should annually enroll an additional 4,604 individuals in its home- and community-based services waivers.

Table 3 shows number of individuals enrolled for three Medicaid waiver programs: Home- and Community-based Services (HCS), Texas Home Living (TxHmL), and Community Living Assistance and Support Services (CLASS) programs for FY 2007 to FY 2011. All three programs provide services and supports to people with intellectual and developmental disabilities to move into or remain in the community. While the target of serving an additional 4,604 individuals per year was not met, there was an average increase of 2,162 individuals enrolled per year.

Waiver and Number Served	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
HCS	11,795	13,386	15,104	17,172	19,384
TxHmL	1404	1243	1051	914	913
CLASS	3,094	3,833	3,949	4,221	4,642
Total number enrolled	16,293	18,462	20,104	22,307	24,939

Source: Department of Aging and Disability Services. "TCDD Data Request." Message to Morningside Research and Consulting. July 20, 2012. Email.

Action Step #6: Texas should concentrate on expanding home-based services as the primary tool for addressing service demand. Consideration should be given to expanding the TxHmL home- and community-based supports waiver.

Texas' annual expenditures for home- and community-based intellectual and developmental disability services have increased from \$40,240 per average daily recipient in 2008¹⁰⁴ to \$43,414 per average daily recipient in 2010. Expenditures per day per state resident have increased from \$28.71 in 2008 to \$36.29 in 2010. These expenditures are below the national average of \$45,550 per average daily recipient and \$85.14 per state resident.¹⁰⁵

According to a survey of individuals on DADS waiver interest lists, the most needed services were respite, specialized therapies, and behavioral support services.¹⁰⁶ However, the needs of individuals may change over time as they remain on the interest lists. For example, while individuals may indicate that they would like to receive HCS waiver services so they can remain at home, new enrollees in the HCS waiver program selected residential supports (group homes) 30 percent of the time.¹⁰⁷

TxHmL is the only waiver for which parental income can preclude a child's Medicaid eligibility. Likewise, it is the only waiver with an income eligibility threshold below 300 percent of

¹⁰⁴ Lakin, K. Charlie, Sheryl Larson, Pat Salmi, and Naomi Scott. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2008*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2009:105.

¹⁰⁵ Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends Through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:113.

¹⁰⁶ Lakin, K. Charlie, Sheryl Larson, Pat Salmi, and Naomi Scott. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2008*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2009:105.

¹⁰⁷ Texas Department of Aging and Disability Services, Analysis of Data Provided Over Time, 2010.

Supplemental Security Income (SSI).¹⁰⁸ Consistent with other efforts to streamline the waiver system, TxHmL eligibility should be expanded.

Action Area 3: Strengthen Community System Infrastructure

Action Step #7: Texas must develop a reliable and accurate means for tracking and projecting service demand and associated trends.

Texas has relied on interest lists for waiver services counts and wait times and population projections to track and project service demand. Interest lists, however, have a number of methodological flaws which may lead to individuals signing up for multiple waivers interest lists that may meet their needs due to uncertainty regarding the best fit. As a result, using these lists to determine demand and reviewing trends may be misleading. To develop a more systemic view and response to meeting unmet needs, Texas must establish a more structured means of gathering information on individuals facing critical emergency need for services.¹⁰⁹ For more discussion about how future demand is projected, please see the “Overview of Services and Supports” section of this report.

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

The 2008 *Closing the Gaps in Texas* analysis identifies three areas that need to be addressed to support the community service system in Texas: workforce turnover, provider reimbursement rates, and establishing community services for individuals with complex needs.¹¹⁰

To address workforce shortage and turnover, Texas needs to attract and retain direct service workers. Research shows that wages and benefits are the driving factors for recruiting and attracting direct service personnel.¹¹¹ While the direct care turnover rate in Texas decreased from 56.2 percent in 2008 to 39.8 percent in 2010, it is still relatively high (fifth) compared to the national average of 24.4 percent.¹¹² The Promoting Independence Advisory Committee (PIAC) made two recommendations to address workforce turnover and provider reimbursement rates. Recommendation 4 in the *PIAC Interim 2012 Stakeholder Report* is to raise the base wage for

¹⁰⁸ *Texas Home Living (TxHmL) Program*. Department of Aging and Disability Services. Web. 13 Nov. 2012. <http://www.dads.state.tx.us/handbooks/txhtml/N/index.htm>.

¹⁰⁹ 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. 2008:63.

¹¹⁰ *Ibid*:65-67.

¹¹¹ *Interim 2012 Promoting Independence Advisory Committee Stakeholder Report*. Department of Aging and Disability Services. June 2012:5.

¹¹² Larson, Sheryl, Amanda Ryan, Patricia Salmi, Drew Smith, and Allise Wuorio. *Residential Services and Supports for People with Developmental Disabilities: Status and Trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 2012:64.

entry-level support workers in home- and community-based service programs.¹¹³ The report also recommends providing community services to individuals with complex behavioral support needs: “Develop a tiered training program for professionals and unlicensed para-professionals and family members providing in-home care to support individuals with challenging behaviors.”¹¹⁴ In the *Interim 2010 Report*, the PIAC recommended increasing provider rates to address inflation.¹¹⁵

¹¹³ *Interim 2012 Promoting Independence Advisory Committee Stakeholder Report*. Department of Aging and Disability Services. June 2012:4.

¹¹⁴ *Ibid.*

¹¹⁵ *Interim 2010 Promoting Independence Advisory Committee Stakeholder Report*. Department of Aging and Disability Services. March 2010:13

System Recommendations

Recommendations: Actions Needed for Systems Change

The following recommendations were provided by the Texas Council for Developmental Disabilities (TCDD):

1. Rebalance the system that serves persons with intellectual and developmental disabilities 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. Develop and implement strategies that address the needs of families in crisis to prevent the unnecessary placement of children in any institutional setting.
3. 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 set direct service wages at levels commensurate with the value and scope of the service.

Recommendations: Actions Needed for Prevention

The following recommendations were provided by the Texas Office for Prevention of Developmental Disabilities (TOPDD):

1. Build the capacity for and fund early childhood intervention programs, thereby reducing the need for more intensive services later in life.
2. Build the capacity for and fund children's mental health services to prevent secondary disabilities.
3. Increase access to prenatal and lifelong medical care – the first line of defense in preventing developmental disabilities.
4. Allow Texas Medicaid to pay for screening and brief intervention of pregnant women for alcohol and other substances, as other states currently do. This has proven to save millions and improve the lives of the participants.
5. Support evidence based programs, such as substance abuse treatment, domestic violence services and prevention services such as home visiting, injury prevention, teen pregnancy prevention, family violence, and child abuse/neglect prevention and services. These programs are crucial in heading off developmental disabilities and reducing their impact when they do occur.
6. Require all educators to obtain coursework in special education. Given that children with special needs are integrated into the regular classes, it is important that any and all teachers have at least a basic understanding of disabilities.

7. Expand licensing requirements for social workers, counselors, attorneys, nurses and physicians so that their advanced coursework will include information on developmental disabilities. Provide continuing education credits in these professions for topics related to developmental disabilities. Professionals need to understand the special needs of the people they serve in order to make informed decisions and plans that impact their clients/patients. With this information, serious mistakes can be avoided.
8. Integrate training on developmental disabilities for all state employees who provide direct services. Nearly every state agency works with some individuals with developmental disabilities including: DFPS, juvenile and criminal justice programs, behavioral health programs, public safety, and entitlement programs. An understanding of issues related to memory, emotional regulation, sensory integration and executive functioning is needed for employees to avoid serious and tragic consequences and to serve people appropriately.
9. Support statewide planning efforts on developmental disabilities, such as the FASD planning initiative developed by the Texas Office for Prevention of Developmental Disabilities. With a collaborative approach to this work, the state will achieve better outcomes for children.
10. Allow for Medicaid to pay for neuro-psychological exams for children upon referral by a pediatrician. The information from such exams can provide critical information to help the physician and the family to develop appropriate interventions which will prevent secondary disabilities and allow for the family to develop pro-active plans for the child.¹¹⁶
11. Develop and support mechanisms for the identification of developmental disabilities in Texas, including developmental disabilities caused by alcohol and other drug exposure. State specific prevalence figures will facilitate planning and prevention efforts and lead to improved services for these individuals and families.
12. Develop guidelines to support fetal infant mortality review committees to assess, link and track perinatal substance use and its impact on fetal infant deaths and illnesses.¹¹⁷ This information is crucial in obtaining a clearer picture for Texas in how and why children in Texas become ill or die and developing effective prevention strategies.
13. Require hospitals to demonstrate how they will implement the changes in the Child Abuse Prevention and Treatment Act (CAPTA,) legislation, which was reauthorized in 2010 and now requires children to receive referrals if they were prenatally exposed to alcohol or other drugs. This will allow children who have alcohol related disabilities to obtain needed services at birth and minimize the need for more expensive services later in life.
14. Avoid criminalization of a mother giving birth to a prenatally exposed infant. These measures discourage the women from obtaining potentially life-saving medical care.¹¹⁸
15. Utilize the 1115 waiver and the Affordable Health Care Act to support these important prevention efforts and thereby produce long-term cost savings for the state.

¹¹⁶ Chasnoff, IJ. "The Mystery of Risk: Drugs, Alcohol, Pregnancy and the Vulnerable Child." Chicago: NTI Upstream, 2011.

¹¹⁷ Ibid.

¹¹⁸ Ibid.

Special Focus Section: Education and Employment

The Texas Council for Developmental Disabilities (TCDD) chose to dedicate a section of the *2012 Texas Biennial Disability Report* to “the interconnectivity of education with employment for individuals with developmental disabilities, including measures of consumer satisfaction.” The following section of the report provides an overview of the education and employment services provided to individuals with a developmental disability in Texas, the trends in service provision over time, and reports on several measures of consumer satisfaction.

The Council supports the position that people with disabilities have the right to job training, employment at competitive wages, and career growth as lifelong learners. The Council further supports the position that employment opportunities should be available to people with disabilities in the community job market without discrimination or segregation.

Employing Persons with Disabilities

In June 2010, the Bureau of Labor Statistics (BLS) reported that 71 percent of Americans without disabilities under the age of 65 had jobs. For Americans with disabilities, 22 percent had jobs.¹¹⁹ The employment rate for people with developmental disabilities is even worse. The Arc, a national advocacy organization for individuals with intellectual disabilities, recently conducted a survey and found that 85 percent of individuals with developmental disabilities were not working.¹²⁰ These findings are consistent with the National Core Indicators (NCI) survey data (discussed in more detail later in this section), in which 74 percent of individuals with developmental disabilities do not have a community job and 47 percent of those without a job would like one.

The Arc conducted its *Family and Individual Needs for Disability Supports* (FINDS) survey in 2010. More than 5,000 people (4,962 caregivers and 558 people with disabilities) from all 50 states and Washington, D.C. completed surveys.¹²¹ While the majority of people with intellectual and developmental disabilities want to have a job in the community, the promise of integrated, community-based employment is not being met. Among the 15 percent of respondents who report that they or their family member is employed, jobs in the community with competitive wages remain elusive:

- Only 41 percent report that their family member works in a competitive job in the community.
- 54 percent work in sheltered workshops and enclave settings.

¹¹⁹“Data on the Employment Status of People with a Disability.” *U.S. Bureau of Labor Statistics*. U.S. Bureau of Labor Statistics, 2011. Web. 14 Sept. 2012. <http://www.bls.gov/cps/cpsdisability.htm>.

¹²⁰ *Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports*. The Arc. 2011:4.

¹²¹ *Ibid*:4.

For those who are unemployed, 52 percent report that they or their family member is unable to get the job training or other assistance they need to find and keep a job.¹²²

As indicated earlier in the report, approximately 11 percent of the Texas population has a disability.¹²³ About 475,265 Texans have a developmental disability.¹²⁴ Based on the information received from Texas state agencies and discussed in the following section, the number of people receiving post-secondary education and employment services from Texas state agencies is very small compared to the number of people with developmental disabilities in Texas.

Current Gaps in Data Collection and Information Sharing

In order to gain a better understanding about individuals with developmental disabilities who are receiving services and the outcome of those services, state agencies that provide education and employment services to individuals with significant disabilities were asked to provide information: the Department of Aging and Disability Services (DADS), the Department of Assistive and Rehabilitative Services (DARS), the Department of Family and Protective Services (DFPS), the Department of State Health Services (DSHS), the Texas Education Agency (TEA), and the Texas Workforce Commission (TWC). Responses were received from each of the agencies although a number of limitations to the available data were identified.

The federal definition of developmental disabilities refers to individuals with significant challenges that result in substantial functional limitations in at least three functional areas. As such, a “developmental disability” is not a diagnosis, and the presence of a substantial functional limitation may be more severe or less severe over time, or episodically. Several of the agencies from which data were requested collect and report data for individuals with a disability or diagnosis, but none of the agencies capture information about service recipients based on the federal definition of developmental disabilities.

TEA data includes all students receiving special education services but much of the data are not available by specific disability or diagnosis. TWC data includes persons with any self-identified disabling condition. DARS collects data about individuals receiving vocational rehabilitation (VR) services by “Primary Disabling Condition Category”, but those data do not coincide with the definition for developmental disabilities. DSHS is able to provide a dataset of individuals receiving employment services that includes all recipients of mental health services which could be separated by Diagnostic and Statistical Manual (DSM) diagnosis. However, DSM codes do not discretely represent “developmental disabilities”. Thus, understanding the services for individuals who have a developmental disability is challenging.

¹²² Ibid:5.

¹²³ *American Community Survey*. US Census Bureau. Web 7 Aug, 2012. <http://www.census.gov/acs/www/>.

¹²⁴ Texas Council for Developmental Disabilities. Web. 16 Aug. 2012. <http://www.txddc.state.tx.us/index.asp>.

Outcome data is also not readily available. Most agencies collect information from individuals receiving services only until those services are completed, or soon after. For example, DARS tracks service recipients for only a limited time after program completion. TEA is able to collect data from high school graduates but the data are limited to former students for whom TEA has contact information, which may be outdated.

Texas state agencies face significant technology and resource limitations that impact their ability to collect and report data. To improve data collection, state agencies should develop a methodology with broad agency and stakeholder input to track services and employment outcomes (during and after service provision) for persons with intellectual and developmental disabilities across agencies and programs.

Education and Employment Services and Program Enrollment

Service data reported by DADS, DARS, DFPS, DSHS, TEA, and TWC are detailed below.

Department of Aging and Disability Services. DADS provides services in the community to individuals with an intellectual or developmental disability, funded by General Revenue. An assessment is conducted in accordance with Texas Health and Safety Code to determine if an individual has a diagnosis of an intellectual disability or is part of the DADS priority population for individuals with an intellectual and developmental disability priority population.¹²⁵ Services are provided through the Local Authorities (LA) and LA contracted providers.

Table 4 shows the services that are provided through the community services program and the number of persons receiving services during the first two quarters of FY 2012 (ending February 29, 2012).¹²⁶

¹²⁵ *Access and Intake Services Community Options Booklet*. Department of Aging and Disability Services. May 2012:72.

¹²⁶ Department of Aging and Disability Services. "TCDD Data Request." Message sent to Morningside Research and Consulting via TCDD. June 12, 2012. Email.

Table 4

Intellectual Disability Community Services 1st and 2nd Quarters of FY 2012	
Service Title	Number of Persons Served
Eligibility Determination	363
Service Coordination	2,532
Community Support	1,846
Respite	1,169
Employment Assistance	129
Supported Employment	188
Vocational Training	289
Day Habilitation	939
Therapies	529
Behavioral Support	282
Total Number of Individuals Served by Service	8,264
Total Number of Individuals Served Unduplicated	5,753

Source: Department of Aging and Disability Services. "TCDD Data Request." Message sent to Morningside Research and Consulting via TCDD. June 12, 2012. Email.

The average number of individuals with intellectual or developmental disabilities receiving community services per month in FY 2012 (through April 2012) was 5,753. DADS estimates that 9,955 individuals will access services through the end of FY 2012.¹²⁷

Table 5 shows the number of individuals receiving employment assistance services from two DADS waiver programs: Deaf Blind with Multiple Disabilities (DBMD) and Texas Home Living (TxHmL). Employment assistance services assist individuals in obtaining competitive, integrated employment. This data includes any person who used the listed service for at least one day in the fiscal year. General Revenue data reflects people receiving employment assistance services without enrollment in a waiver program.

¹²⁷ Department of Aging and Disability Services. "TCDD Data Request." Message sent to Morningside Research and Consulting via TCDD. July 20, 2012. Email.

Table 5

Individuals Receiving Employment Assistance Services				
	FY 2010		FY 2011	
	All Ages	Under 26	All Ages	Under 26
CLASS	N/A	N/A	N/A	N/A
DBMD	0	0	0	0
General Revenue	722	335	611	275
HCS	N/A	N/A	N/A	N/A
ICF/ID Receiving Services from Local Authority	25	4	29	8
MDCP	N/A	N/A	N/A	N/A
TxHmL	35	6	57	22

Source: Department of Aging and Disability Services. "TCDD Data Request." Message to Morningside Research and Consulting. July 20, 2012. Email.

Table 6 shows the number of individuals receiving supported employment services from the following DADS waiver programs: Community Living Assistance and Support Services (CLASS), DBMD, Home- and Community-based Services (HCS), and TxHmL. Supported employment services assist individuals in maintaining competitive, integrated employment. The data includes any person who used the listed service for at least one day in the fiscal year. General Revenue data reflects people receiving supported employment services without enrollment in a waiver program. In FY 2011, approximately 3 percent of individuals in CLASS, DBMD, HCS, and TxHmL waivers received supported employment services.

Table 6

Individuals Receiving Supported Employment Services				
	FY 2010		FY 2011	
	All Ages	Under 26	All Ages	Under 26
CLASS	0	0	3	0
DBMD	0	0	0	0
General Revenue	723	202	661	199
HCS	525	40	535	42
ICF/ID Receiving Services from Local Authority	22	2	24	2
MDCP	N/A	N/A	N/A	N/A
TxHmL	62	3	90	21

Source: Department of Aging and Disability Services. "TCDD Data Request." Message to Morningside Research and Consulting. July 20, 2012. Email.

Table 7

Individuals Receiving Vocational Training Services				
	FY 2010		FY 2011	
	All Ages	Under 26	All Ages	Under 26
General Revenue	1,018	332	907	298
ICF/ID Receiving Services from Local Authority	172	23	137	19

Source: Department of Aging and Disability Services. "TCDD Data Request." Message to Morningside Research and Consulting. July 20, 2012. Email.

Table 7 shows the number of individuals receiving vocational training services from DADS. Vocational training services provide day training to people in industrial enclaves, work crews, sheltered workshops, or affirmative industry settings to help them get a job. This data includes any person who used the listed service for at least one day in the fiscal year. General Revenue data reflects people receiving vocational training services without participation in an intermediate care facility for individuals with an intellectual disability (ICF/ID) or waiver.

Table 8

Individuals Receiving Day Habilitation Services				
	FY 2010		FY 2011	
	All Ages	Under 26	All Ages	Under 26
CLASS	N/A	N/A	N/A	N/A
DBMD	17	5	16	5
General Revenue	2,898	1,198	2,699	1,040
HCS	13,802	2,726	15,224	2,602
ICF/ID Receiving Services from Local Authority	538	53	440	53
MDCP	N/A	N/A	N/A	N/A
TxHmL	708	154	1,399	402

Source: Department of Aging and Disability Services. "TCDD Data Request." Message to Morningside Research and Consulting. July 20, 2012. Email.

Table 8 shows the number of individuals receiving day habilitation services from DADS. Most waiver participants who are not enrolled in public education spend their days in a day habilitation program. The day habilitation service component assists an individual to acquire, retain, or improve self-help, socialization, and adaptive skills necessary to live successfully in

the community and participate in home and community life. Day habilitation services are provided in a group setting other than the individual's home for normally up to five days a week, six hours per day.¹²⁸ Though it is agreed that the intent is not to default waiver participants into day habilitation settings, provider rate models were designed such that participants are expected to be out of their home settings for six hours a day, five days a week.

There has been considerable frustration and confusion regarding the coordination of DADS and DARS employment services. Employment assistance (help to locate or develop paid employment) and supported employment (help to maintain a job) are not included as services in all of the waivers and there are different protocols for how different DADS services interact with DARS services. When employment services are included, a waiver is considered the payer of last resort.

Historically, DADS providers serving individuals for whom competitive employment is an identified goal were required by the state to refer those individuals to DARS to apply for VR services. For individuals determined by DARS to be ineligible for services, the DADS provider was required to obtain a copy of a letter of denial before assisting an individual in locating competitive employment. With the release of DADS Information Letter 10-122 in September 2010, this became optional for persons who receive services in an ICF/ID or with general revenue from a Local Authority, but not for waiver participants.¹²⁹ DADS clarified in Information Letter No. 12-60 in June 2012 that providers are no longer required to refer any already employed participants to DARS for services, as DARS services are for those seeking employment.¹³⁰

State supported living centers (SSLCs) are operated by DADS. The 13 SSLCs provide facility-based direct services and supports to 3,787 people with intellectual and developmental disabilities who are medically fragile or who have behavioral health needs.¹³¹ The SSLCs offer the following on and off campus paid work services for employment:

- Workshops: A non-competitive segregated work environment where people acquire job skills and experience.
- Client Worker Program: State paid employment on the state facility campus.
- Enterprise: Engaged in activities to create goods and services for direct sale to persons in the community.
- Enclave Work: Distinct work unit in a competitive work environment with staff assistance and supervision.

¹²⁸ *Texas Home Living (TxHmL) Program*. Department of Aging and Disability Services. Web. 20 Nov. 2012. <http://www.dads.state.tx.us/handbooks/txhtml/N/index.htm>.

¹²⁹ *Information Letter 10-122*. Department of Aging and Disability Services. 2010:1.

¹³⁰ *Information Letter No. 12-60*. Department of Aging and Disability Services. 2012:1.

¹³¹ *Promoting Independence Advisory Committee Department Activity Report*. Department of Aging and Disability Services. October 2012:5.

- Supported Employment: Staff supervised and assisted employment with a community employer that directly compensates the individual.
- Competitive Employment: Paid employment in the community with no or extremely limited support from staff.

Table 9 shows the number of individuals living in SSLCs who participated in paid work services both on and off campus.

Table 9

State Supported Living Centers Paid Work						
	On Campus			Off Campus		
	Workshops	Client Worker Program	Enterprise	Enclave Work	Supported Employment	Competitive Employment
As of August 31, 2011	1,641	227	18	72	12	4
As of August 31, 2010	1,795	421	29	55	12	5

Source: Department of Aging and Disability Services. "TCDD Data Request." Message to Morningside Research and Consulting. July 20, 2012. Email.

Department of Assistive and Rehabilitative Services. The federal VR Program coordinated by DARS helps people who have a mental or physical disability that results in a substantial impediment to employment to prepare for, find, and keep employment. VR services help individuals prepare for interviews, learn skills, and can provide assistance or accommodations needed to maintain employment. The VR program assists people with a wide variety of disabilities including persons with significant hearing loss including deafness, musculoskeletal impairments, substance abuse, emotional or mental health concerns, cardiac/respiratory/circulatory difficulties, cognitive or intellectual limitations, neurological disorders, spinal cord injuries, traumatic brain injuries, or other physical or mental disabilities that impact the person's ability to find and keep a job.¹³²

DARS has 1,257 staff in the Division for Rehabilitation Services.¹³³ In FY 2010 and FY 2011, 35,513 consumers under the age of 26 were served in the VR program. DARS provided post-secondary education services to 10,921 VR consumers. These services include assistance with tuition, books, and other related items to assist with learning. These data do not include services that are not directly related to post-secondary services, such as providing transportation or mobility training, personal attendants, a computer, or a wheelchair. VR programs consider services as successfully closed when the individual has been employed for 90 days or more. In

¹³² "Vocational Rehabilitation for Persons with Physical and Mental Disabilities." *Vocational Rehabilitation for Persons with Physical and Mental Disabilities*. Department of Assistive and Rehabilitation Services. Web. 10 Sept. 2012. <http://www.dars.state.tx.us/drs/vr.shtml>.

¹³³ *Department of Assistive and Rehabilitation Services: Annual Report 2011*. Department of Assistive and Rehabilitation Services. January 2012:6.

FY 2010 and FY 2011, the VR program successfully closed 5,323 cases. Of those, 2,854 individuals (53.6 percent) were earning \$1,000 or more a month at closure.¹³⁴

Of 5,853 individuals for whom services did not result in a successful employment outcome, the most common reasons were that the individual failed to cooperate, or the individual moved and could not be located. The following are definitions for the reasons a case is considered to be an unsuccessful closure and the number of cases closed for that reason in FY 2010 and FY 2011:

- Unable to locate, moved out of state: Contact with the consumer is lost after documented, repeated attempts by telephone and mail over a reasonable period have failed. Also used when the consumer moves out of state and gives little evidence of returning any time soon (1,340).
- Disability too severe: It is decided through clear and convincing evidence that VR services will not enable the consumer to achieve an employment outcome because of the severity of the disability (68).
- Refused services: The consumer clearly does not intend to follow through with the program of services (845).
- Death: (46).
- Institutionalized: The consumer is:
 - Admitted to an institution, and
 - Not expected to be available to pursue a DRS program (88).
- Referred to another agency or DARS program: The services of another agency are more appropriate than a DRS program (41).
- Failure to Cooperate: The consumer fails to follow through with the program of services (2,080).
- Transportation not feasible: Suitable transportation for accepting or maintain employment is either not available or not feasible (too costly, inaccessible, etc.) (20).
- Extended services not available: The consumer could benefit from supported employment services, but no source of extended services is available (7).
- Other: Services may be denied or ended for other reasons, such as the consumer has achieved employment without substantial VR services (1,318).¹³⁵

Department of Family and Protective Services. The Preparation for Adult Living (PAL) program was implemented in 1986 to ensure that older youth in substitute care (state custody) are prepared for independent living when they become adults and leave DFPS services. PAL program staff strive to provide each of these youth with skills and resources they will need to be healthy, productive adults.¹³⁶ In FY 2011, 93 percent (564 out of 607) of youth with disabilities

¹³⁴ Department of Assistive and Rehabilitative Services. "TCDD Data Request." Message to Morningside Research and Consulting. January 20, 2012. Email.

¹³⁵ *DRS Rehabilitation Policy Manual: Chapter 6 Closure*. Department of Assistive and Rehabilitative Services. Web. 4 Oct. 2012. <http://www.dars.state.us/drs/rpm/ch6.htm>.

¹³⁶ *Preparation for Adult Living (PAL) Program*. Department of Family and Protective Services. Web. 10 Sept. 2012. http://www.dfps.state.tx.us/Child_Protection/Preparation_For_Adult_Living/.

who exited foster care when they were ages 16 to 21 received PAL services, an increase from FY 2010 (90 percent).

Under the federal Promoting Safe and Stable Families Amendments of 2001, DFPS receives federal funding for a grant program to provide post-secondary educational and training vouchers (ETV) to both children in foster care and persons who have recently aged out of foster care who are between the ages of 16 and 23.¹³⁷ The ETV is based on need and provides up to \$5,000 in financial assistance each year. In FY 2011, 21 out of 735 (3 percent) youth with disabilities who exited substitute care received an education and training voucher, which is a decrease from FY 2010 with 30 out of 754 (4 percent) receiving a voucher.¹³⁸

Department of State Health Services. DSHS uses the Texas Recommended Assessment Guidelines (TRAG) to determine the level of need for adults with a severe mental illness and/or emotional disturbance. The TRAG determines need in nine dimensions based on a scale of 1 to 5 with 1 being the lowest need and 5 being the highest need. The nine dimensions for assessment include: Risk of harm; support needs; psychiatric-related hospitalizations; functional impairment; employment problems; housing instability; co-occurring substance use; criminal justice involvement; and depressive symptomatology. DSHS provided data on clients with a TRAG score of 3 or higher who are eligible for one of four service packages, with each package providing an increasing level of services.¹³⁹

- Service Package 1: Pharmacological management, medication training and supports, and routine case management.
- Service Package 2: Pharmacological management, medication training and supports, routine case management, and counseling.
- Service Package 3: Pharmacological management, medication training and supports, psychosocial rehabilitation, supported employment, and medical services.
- Service Package 4: Assertive community treatment (ACT) alternative. Individuals in ACT are provided pharmacological management, medication training and supports, psychosocial rehabilitation, supported employment, and medical services by a registered nurse. Services provided by an ACT team are focused on outreach, engagement, and stabilization, are all-inclusive, and made available 24 hours a day, 7 days per week.¹⁴⁰

Individuals with TRAG scores of 3 or higher are determined to have moderate to high needs, therefore all clients who DSHS provided data for were eligible to receive a service package. Chart 9 shows the number and the percentage of eligible clients ages 18 to 23 who were

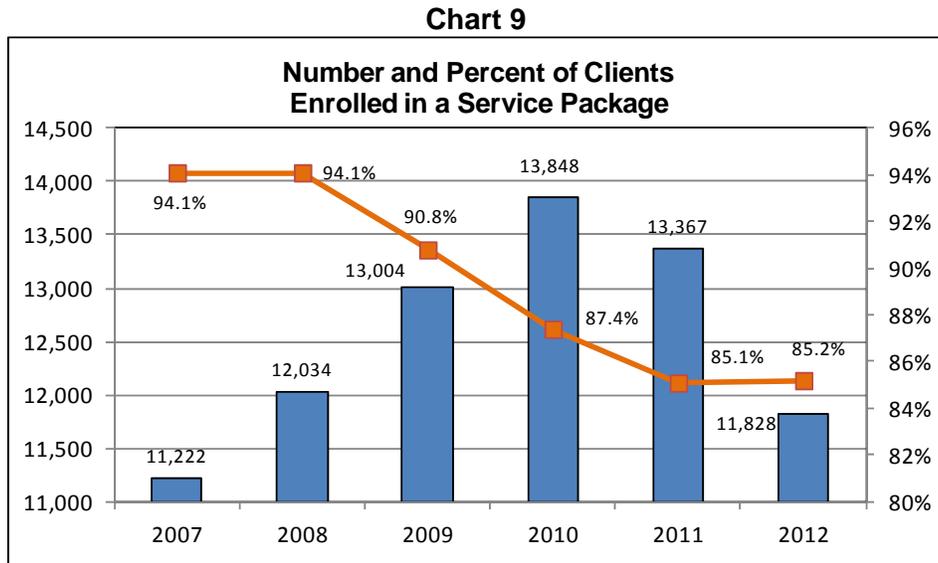
¹³⁷ *Education and Training Voucher Program (ETV)*. Department of Family and Protective Services. Web. 27 Nov. 2012. http://www.dfps.state.tx.us/Child_Protection/Youth_and_Young_Adults/Post_Secondary_Education/.

¹³⁸ Department of Family and Protective Services. "TCDD Data Request." Message to Morningside Research and Consulting. August 1, 2012. Email.

¹³⁹ *User's Manual for the Adult Texas Recommended Assessment Guidelines*. Department of State Health Services. September 2007:16.

¹⁴⁰ *Ibid*:16-21.

enrolled in a service package in FY 2007 through FY 2012, although FY 2012 data is only available through July 2012.



Source: Department of State Health Services. "TCDD Date Request." Message to Morningside Research and Consulting. July 31, 2012. Email.

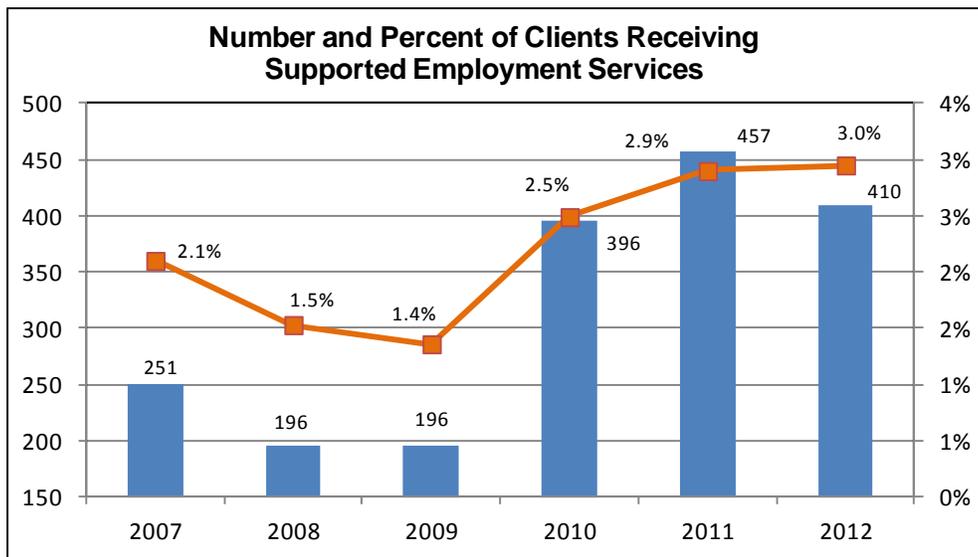
DSHS also provides supported employment services to assist individuals in maintaining competitive, integrated employment. The DSHS Supported Employment Model is an evidence-based practice and is based on the following principles:

1. Zero Exclusion
2. Integration of vocational and mental health treatment services
3. Competitive employment
4. Benefits counseling
5. Rapid job search
6. Follow-along supports
7. Preferences¹⁴¹

Chart 10 shows the number and the percentage of clients eligible for a service package (clients with a TRAG score of 3 or more on the employment dimension) who received supported employment services from DSHS from FY 2007 through FY 2012, although FY 2012 data is only available through July 2012.

¹⁴¹ Ita, Trina. *Supported Employment*. Department of State Health Services. 31 May 2011. Web. 13 Sept. 2012. <http://www.dshs.state.tx.us/Layouts/ContentPage.aspx?PageID=35583>.

Chart 10



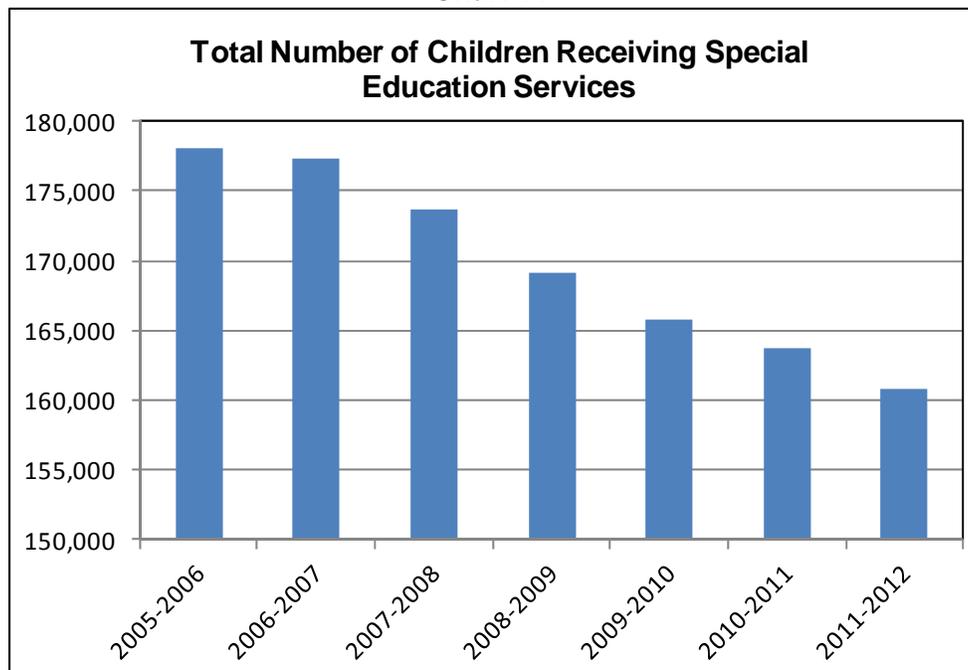
Source: Department of State Health Services. "TCDD Date Request." Message to Morningside Research and Consulting. July 31, 2012. Email.

Texas Education Agency. As established by the reauthorization of the Individuals with Disabilities Education Act (IDEA) of 2004, the TEA Response to Intervention (RtI) program is the framework for the general education program to include all students, including those who experience difficulties either academically or behaviorally. RtI helps to ensure that students have the opportunity to experience a full range of educational opportunities through the general education program.¹⁴²

As a result of the implementation of RtI, the total number of children with disabilities ages 14 and older receiving special education services has decreased approximately 10 percent since 2005. Chart 11 shows the total number of children receiving special education services since the 2005-2006 school year.

¹⁴² "2008-2009 Response to Intervention Guidance." *Division of Curriculum*, Texas Education Agency. Web. 14 Sept. 2012.

Chart 11



Source: Texas Education Agency. "Data Request for TCDD 2012 Texas Biennial Report." Message to Morningside Research and Consulting. May 25, 2012. Email.

According to TEA's State Performance Plan, 74 percent of youth with individual education plans (IEP) graduated from high school in federal fiscal year (FFY) 2010, lower than the graduation rate for all students (84 percent). The percent of youth with IEPs that dropped out of high school in FFY 2010 is 12 percent, which is higher than the dropout rate for all students (7 percent).¹⁴³ Graduation and dropout rates have improved slightly from 72 and 14 percent in FFY 2009.¹⁴⁴

Retention rates for students with disabilities in Kindergarten through grade 6 have shown a slight improvement. In school year 2009-2010, 8,732 out of 235,915 students (3.7 percent) receiving special education services were retained. This is a decrease from school year 2007-2008, in which 11,218 out of 246,689 students (4.5 percent) receiving special education services were retained.¹⁴⁵

Although graduation rates have increased, a post-school survey sponsored by TEA, administered to the exiting cohort of students within one year of leaving high school, found that there has been no consistent improvement in post-secondary education and employment rates. There was a 6 percent decrease from FFY 2009 to FFY 2010 in respondents who reported being enrolled in school, job training, or an education program. From FFY 2009 to FFY 2010

¹⁴³ *Part B State Performance Plan: 2005-2012*. Texas Education Agency Division of Federal and State Education Policy. February 2012:2,31.

¹⁴⁴ *Annual Performance Report FFY 2009*. Texas Education Agency Division of IDEA Coordination. February 2011:2,51.

¹⁴⁵ "Grade-Level Retention in Texas Public Schools, 2009-10." *Division of Research and Analysis*, Department of Assessment and Accountability Texas Education Agency. November 2011:54.

there was a four percent decrease in respondents who reported being employed since they left high school.¹⁴⁶ Table 10 shows the post-school outcomes from FFY 2007 to FFY 2010.

Table 10

Post School Outcomes		
Federal Fiscal Year	Education and Training	Employment
2007	54%	67%
2008	44%	63%
2009	52%	68%
2010	46%	64%

Source: *State Performance Plan Indicator 14: Extended Post Secondary Follow-up Survey: Final Statewide Report*. Texas Education Agency. 2008-2011.

Texas Workforce Commission. Local workforce development offices throughout Texas provide services to individuals who are seeking employment. Of the 127,026 individuals receiving services from April 2011 to March 2012, 53,378 or 42 percent were individuals who self-identify as having a disability.¹⁴⁷

Consumer Satisfaction

TEA Parent Survey. In 2010, TEA surveyed parents of students receiving special education services to obtain information regarding parent involvement with their child's school. Overall, parents expressed satisfaction with the special education services provided by schools.¹⁴⁸ Specific responses include:

- Of the 4,277 respondents, 78 percent of parents agreed that they are considered an equal partner with teachers and other professionals in planning their child's program.¹⁴⁹
- Of the 4,275 respondents, 78 percent of parents responded that the school always communicates regularly regarding IEP progress and other important issues regarding the child.¹⁵⁰
- Of the 4,248 respondents, 66 percent of parents responded that the teachers always understand the child's needs.¹⁵¹
- Of the 4,915 respondents, 84 percent of parents responded that their concerns are always considered by the Admission, Review, Dismissal (ARD) committee in the development of the child's IEP.¹⁵²

¹⁴⁶ *State Performance Plan Indicator 14: Extended Post Secondary Follow-up Survey: Final Statewide Report*. Texas Education Agency. 2008-2011.

¹⁴⁷ Texas Workforce Commission. "TCDD Data Request." Message to Morningside Research and Consulting. June 26, 2012. Email.

¹⁴⁸ *Part B State Annual Performance Report for FFY 2010*. Texas Education Agency Division of Federal and State Education Policy. February 2012:104.

¹⁴⁹ Ibid:110

¹⁵⁰ Ibid:110.

¹⁵¹ Ibid:111.

¹⁵² Ibid:112.

Though parents reported satisfaction with special education services, parents reported dissatisfaction with transitional services provided by schools. Twenty-two percent of parents in FFY 2010 either disagree or strongly disagree with the following survey items: “the school provides transition services to help my child reach his or her goals after high school,” “the school provides information on agencies that assist my child in the transition from high school,” and “special education services have helped my family and I get the services that my child needs outside of school.” Dissatisfaction increased from 20 percent in FFY 2009.¹⁵³ These three survey items scored among the lowest for questions regarding parent interactions with the school.¹⁵⁴

HB 1230 Monitoring Report. The 2009 *HB 1230 Monitoring Report* is a response to Section 1 of House Bill 1230 which was passed by the 80th Texas Legislature, Regular Session (2007), requiring the Health and Human Services Commission (HHSC) to monitor health and human service programs, consider whether or not programs or services for youth with disabilities in transition to adult living result in positive outcomes, and collect information regarding the outcomes of the transition process. The report includes the findings from a telephone survey:¹⁵⁵

- Of respondents who met with someone in high school to develop a transition plan, 85 percent were either very satisfied or somewhat satisfied with the assistance that they received.¹⁵⁶
- Of respondents who worked in some capacity since leaving high school, 76 percent were either very satisfied or somewhat satisfied with the *type of work* they do, and 60 percent were either very satisfied or somewhat satisfied with *how much* they have worked.¹⁵⁷
- Of respondents who sought education assistance from an agency 74 percent reported that the agency typically helped respondents get the needed resource to go to school.¹⁵⁸

Overall the results of the telephone survey were positive. However, 45 percent of respondents who were not working or going to school reported that the agency did not help them get the resources they needed to go to school.¹⁵⁹

National Core Indicators. NCI is a collaborative effort which began in 1997 between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). NCI consists of survey responses to five core indicators that measure the outcomes of services provided: Individual Outcomes; Health,

¹⁵³ *Annual Performance Report FFY 2009*. Texas Education Agency Division of IDEA Coordination. February 2011:94.

¹⁵⁴ *Part B State Annual Performance Report for FFY 2010*. Texas Education Agency Division of Federal and State Education Policy. February 2012:106.

¹⁵⁵ *H.B. 1230 Monitoring Report: Transition Experience of Texas Youth with Disabilities*. Health and Human Services Commission. May 2009:11.

¹⁵⁶ *Ibid*:26.

¹⁵⁷ *Ibid*:28,29.

¹⁵⁸ *Ibid*:36.

¹⁵⁹ *Ibid*:36.

Welfare, and Rights; System Performance; Staff Stability; and Family Indicators. NCI is a voluntary effort used for agencies to evaluate and compare their performance across states. Some of the results relevant to employment include:¹⁶⁰

- According to the latest NCI survey, individuals who are currently employed are satisfied with their work. However, there is still a high number of individuals who are not working or not working consistently.
- 89 percent of Texas respondents reported that they are satisfied with their day program/daily activity, which is consistent with the average of all NCI states (89 percent).
- 94 percent of Texas respondents reported that they are satisfied with their job, which is consistent with the average of NCI states (92 percent).
- 74 percent of Texas respondents reported that they do not have a job in the community, which is consistent with the average of all NCI states (73 percent).
- 47 percent of Texas respondents reported that they do not have a job in the community but would like one, which is consistent with the average of all NCI states (46 percent).
- Texas respondents reported the average length of time at their current community job as 32 months. This is much lower than the NCI average of 56 months.
- 77 percent of Texas respondents reported working 10 out of the last 12 months in a community job, which is lower than the average of all NCI states (82 percent).
- 83 percent of Texas respondents reported that they do not have integrated employment as a goal in their service plan, which is higher than the average of all NCI states (77 percent).¹⁶¹

Recommendations: Actions Needed to Address Barriers to Education and Employment

1. Develop a methodology to track services and employment outcomes for persons with intellectual and developmental disabilities across agencies and programs with broad agency and stakeholder input.
2. Ensure that the planning process for individualized education services and supports for students with disabilities is person and family centered and directed; information about real work options is discussed early and often during the transition process; and that options considered by students, families and school personnel include supported work-study, internships, community activities, mentoring programs, local and state post-graduation resources and community living options.
3. Identify systemic barriers that prevent some persons with disabilities from achieving competitive employment in integrated settings including agency policies and procedures, practices, and financing structures, and develop implementable strategies to remove those barriers and improve outcomes.
4. Expand the number of employers interested in hiring persons with developmental disabilities by continuing to disseminate information and training materials about common reasonable

¹⁶⁰ “NCI State Report: Texas 2009-10.” *National Core Indicators*. Human Services Research Institute and The National Association of State Directors of Developmental Disabilities Services. Web. <http://www.nationalcoreindicators.org/>.

¹⁶¹ Ibid.

accommodations, tax incentives, best practices and benefits of employing persons with developmental disabilities.

TOPDD Surveys on Education and Job Readiness: Raising the Voice of and for People with Developmental Disabilities

About the Surveys

TOPDD conducted two surveys to provide a voice for people with developmental disabilities, one for consumers and family members and one for key informants. These results will be shared with policy makers through the *2012 Texas Biennial Disability Report* that is a collaborative effort with the Texas Council for Developmental Disabilities and TOPDD.

A total of one hundred and sixty eight people participated in the surveys. The surveys were conducted in 2012. Sixty-six people participated in the Key Informant Survey and one hundred and two individuals completed the Consumer Survey. The participants covered a broad range of developmental disabilities and came from diverse geographical areas throughout Texas.

Key Informant Survey

General Education Issues

Participants seemed concerned 1) that educators lacked knowledge of developmental disabilities, 2) about access to services and 3) the impact of standardized testing on children with developmental disabilities.

- 52 percent said that educators understand the challenges associated with a disability “somewhat”, with 21.6 percent responding “a little bit” and 9.8 percent responding “not at all”.
- 7.7 percent said that some children they served never obtained special education.
- Only 2.2 percent thought that educators “very much” had adequate training in developmental disabilities, while 17.8 percent responded “not at all” and 35.3 percent responded “a little bit”.

Additional highlights of the survey as it relates to school:

- Schools were “very responsive” to the student’s special needs. 14 percent
- Early interventions are effective. 70.6 percent
- Clients needed more early intervention than they received. 63.5 percent
- Standardized testing did “not at all” help children with disabilities. 70 percent
- Parents are well informed about rights. 2 percent
- Schools are following guidelines regarding special education. 50 percent
- Due process is effective. 36 percent

Preparation for the Workforce

There seemed to be a great deal of concern about the preparation of children with disabilities for success in the workforce. The following is a sampling of responses:

- Only 5.8 percent said that they agreed that children with disabilities have adequate preparation to succeed in the workforce “very much”.
- 73 percent expressed a concern about the ability of the people they serve to live independently.
- 80.8 percent were “very much” concerned about the ability of the people they serve in obtaining/maintaining employment. 0 percent said that they were not at all concerned.
- The most common response on the employment status of clients-33.3 percent unemployed, and 30.3 percent intermittently employed.
- 97.5 percent agreed that students need more specialized skills training in high school.
- 94.1 percent responded that the children needed more preparation about how to operate in the world of work.
- 76.5 percent thought more job readiness skills were needed “very much”.

Accommodations in School and Qualifying for 504 Plans and Special Education

While it seemed that some schools were quite responsive in meeting the needs of children, overall respondents expressed frustration.

- A common theme was kids “falling through the cracks” because their “IQs aren’t low enough”, or if their disabilities were not physical.
- People went to great lengths getting children qualified for help. Getting a lawyer was described by respondent as a means to obtain services. After six years, one family was successful after hiring a lawyer, another family involved a congressman.
- Many respondents said it took years to determine eligibility. It sometimes took a year to begin the testing. Concerns were expressed regarding foster children who often have multiple disabilities and who often change schools.
- Non English speaking families seem to face even more delays and often receive no services.
- Respondents noted that cut backs to schools are negatively impacting children with special needs.
- One respondent described how it is common for families to keep children with medical conditions at home when the school won’t accommodate them and said that the schools are aware that the children are home and receiving no education.
- Backlash to children and parents who are seeking was described.

Improving Schools

- Access to services was the most common concern with quicker assessment and diagnosis.
- Once children have a 504 or an IEP, it seems that the challenge is getting the schools to follow it. There are no guidelines to enforce the 504 or IEP.
- Social skills training, vocational education, assistive technology and education for teachers on inclusion and developmental disabilities were highlighted.
- Increased collaboration with other systems of care was discussed-public mental health centers, Division for Blind Services, etc.

Consumer Survey

Consumers shared many similar concerns to key informants including concerns about educators' lack of knowledge of developmental disabilities, a system that seems to block access to services instead of facilitating it, the lack of preparation for the world of work that children with developmental disabilities receive, etc.

- 44.2 percent responded with “not at all” to the question of “do you think educators have adequate preparation and training in developmental disabilities”. Only 8.1 percent responded “very much”.
- Is standardized testing helpful to children with disabilities? 59 percent “not at all”
- Standardized testing hindered children with disabilities 43 percent “very much”

Eligibility and Due Process

It is noteworthy that consumers expressed concerns over the process of determining eligibility. In fact, only 6 percent thought that due process was “very much” effective.

	“Not at all”	“A little bit”	“Somewhat”
Parents well informed of rights	27.7%	41%	28%
Schools followed guidelines for special education.	20.7%	28%	20.7%
Effectiveness of due process	33.7%	22.9%	24.7%

Employment Preparation and Independent Living

Consumers seemed deeply concerned about obtaining and maintaining employment. They indicated in both open ended and multiple choice questions a concern that the educational experience was not providing preparation for the world of work.

- People with disabilities have adequate preparation to succeed in the workforce. 50 percent “not at all”
- Concern about the individual’s ability to live independently. 75.8 percent “very much”
- Concern about the individual’s ability to obtain employment. 74.4 percent “very much”
- Job readiness skills needed. 77.6 percent
- More specialized skills training in high school needed. 84 percent
- More preparation about the world of work needed. 86 percent “very much”
- Ongoing job coaching needed. 74 percent
- Vocational skills needed. 72 percent “very much”
- Other supports needed for employment. 77.2 percent “very much”
- Typically have had a full time job. 2 percent

Areas in which Schools Can Improve:

- Improve Knowledge of Staff about Specific Disabilities

Respondents described the impact of the lack of knowledge among staff:

- Uses ineffective, inappropriate discipline methods instead of effective positive behavioral supports and applied behavior analysis
- Insensitive to needs of students
- Ineffective teaching techniques

Respondents thought schools needed to strategically implement inclusion for higher functioning children and obtain and utilize specialized skills in helping lower functioning children educationally and proactively build social skills and support for children with developmental disabilities. One respondent wrote that teachers are “simply not trained in how to educate these students in the way they learn. Start by educating those who educate!”

Improve Access to services and enforcement of the IEPs:

It was pointed out that schools can use tax payer money to have a lawyer fight a case but parents cannot afford an attorney, so parents are at a complete disadvantage in the ARD process. One consumer wrote “This money could be better spent on the children.”

It was also pointed out that there is no mechanism for monitoring that the IEPs are followed and no consequences when a school does not fully implement the IEP. One respondent suggested that an ombudsman get assigned to each family to even the playing field. Many parents wrote about “receiving many accommodations on paper”.

Parents also wrote about the challenge of getting services for people who have disabilities that aren’t “visible”. While there was much discussion about funding, lack of knowledge about how to help children with disabilities seemed to be equally important.

The following were descriptions of the eligibility process:

“a constant battle”, “horrible, hell and a nightmare”, “very difficult”, “like pulling teeth”, “paperwork, paperwork, paperwork”.

Other comments:

“Words can’t fully describe the frustration, confusion, anger and disbelief” and described the eligibility process as one that produces “battle scars”.

“This box isn’t large enough to contain the anguish, blood, sweat and tears and the emotional roller coaster parents ride through a horrible system having to fight so hard for what should be inherently given to every child.”

“The public school system for those receiving special education services is more often than not, a joke.”

“You have to be a bully to get any help for your kids and God help those who are not educated enough.”

One parent described how they have taken loans to pay for services amounting to \$40,000 and now they are going to lose their home because the school wouldn’t pay and insurance wouldn’t cover it.

Develop Functional Learning and Vocational Education Opportunities:

The overwhelming need for more functional learning activities, vocational education, social skills, mentoring and transition planning was discussed. Respondents described how it was a waste of time to put a child in “an economics or science class” when the work is over their head and “they needed more practical education”.

It was mentioned that children with disabilities often are not given access to vocational programs that typical children access. One parent’s response about what kinds of support services were available to people with developmental disabilities was, “ha, ha, ha, when you get that answer, please pass it on to me.”

Implement Testing Appropriate for Students with Disabilities:

Consumers voiced many concerns on the impact of standardized testing on children with developmental disabilities. They described the pressure created by standardized testing requirements, how it impacts a sense of self-worth, was a “nightmare”, “pointless”, a “waste of tax payer money”, etc. The testing seemed to be a special concern for children with lower functioning skills.

Provide Adequate Funding for Services:

Respondents discussed the impact of cutbacks on children with developmental disabilities and all children. There was also concern expressed about how funds were used-for instance buying team uniforms when teachers are being cut. They also seemed positive about vocational services provided by DARS, but concerned that so few children could access these services.

Comparisons between surveys on questions:

Question: To what extent do you feel that educators and staff members have adequate training in developmental disabilities?	Key Informant	Consumer
Not at all	17.6%	44.2%
A little bit	35.3%	18.6%
Indifferent	3.9%	3.5%
Somewhat	41.2%	25.6%
Very much	2%	8.1%
N/A	0%	0%

Taken together, the majority of respondents on both surveys feel responded “not at all” or “a little bit”. This speaks to a lack of confidence level overall in the competency of the educators to meet the needs of children with developmental disabilities.

Question: Do you feel concerned about the individual’s ability to obtain/maintain employment?	Key Informant	Consumer
Not at all	0%	2.3%
A little bit	5.8%	10.8%
Indifferent	0%	12.0%
Somewhat	8.4%	12.8%
Very Much	80.8%	74.4%
Not applicable	0%	7.0%

Overall, an analysis of the results demonstrates that the difference between the two surveys was fairly minor when comparing key informants and consumers.

Findings

What was most striking about the results was how similar they were across the board. Regardless of what part of Texas people came from, or their role, the concerns were very similar. There is clearly consensus among people in the developmental disabilities community about what hurdles exist.

Access to Services

- It seemed commonplace for schools to delay the eligibility process for 504 and special education.
- Parents lack the information and knowledge to navigate the system. Even those with the knowledge seem to feel outnumbered and outgunned, especially when a district brings a lawyer into the process.
- There is no clear mechanism to require full implementation of IEPs and no clear consequences for schools that fail to do so. This is a serious gap.

Slightly under the surface of the comments was the stress that families experience in working with the system. Respondents were appeared angry and frustrating. Given that raising any child has its stressors, especially a child with developmental disabilities, it seems to add an unfair burden for families to struggle to navigate such a complex system alone. There is tremendous evidence of the impact of stress on children. The stress that was described by the families cannot be healthy for the well-being of the child and family. It appears that many school districts are not following the intent of IDEA or state law. The fact that only 2 percent of key informants felt that parents are well informed of their rights speaks volumes about the challenges families face when negotiating a system which was originally designed to provide for a fair and equal treatment, with parents having an equal voice to those professionals.

Education and Training of School Personnel

There was tremendous concern about the lack of knowledge of school personnel across the board on developmental disabilities. This seems to be impacting all aspects of the educational experience for the children. Only 2 percent of key informants and 8 percent of consumers felt that educators “very much” had adequate training on developmental disabilities. This demonstrates a resounding lack of confidence in the skill level of the people in the education system when it comes to children with developmental disabilities.

Functional Vocational Skills

With 80.8 percent of key informants and 74.4 percent of consumers expressing concerns about the ability of people with disabilities being able to obtain and maintain employment, and only 2 percent holding a consistent job according to the consumer survey, consumers and families have reason to be alarmed about this issue.

The clear consensus was that the focus on academics and testing was not providing children with special needs the kind of education that they needed and that children with developmental disabilities needed a more practical education that would prepare them for the world of work. Along with this, the need for social skills training was clearly an unmet need. The stress level of families who are so deeply concerned that children will not be prepared for the world of work has to be tremendous. It seems that overall that children with developmental disabilities are being asked to fit into a system that is built around the needs of typical children instead of one that addresses the needs of all children. Standardized testing, and a very academically oriented curriculum may be appropriate for some children but it is not appropriate for all children.

Funding

While funding is not the only barrier identified, it is clearly a major component of the deficits in the systems that children with developmental disabilities tap. As proactive programs such as ECI are cut, children will experience more needs as adults. In an increasingly competitive work environment, children with disabilities may become increasingly dependent on the crumbling "social net" and miss the opportunity to every individual deserves to be self-sufficient and successful in work.

Recommendations

1. Improve access to services:

All parents should obtain information about how to request testing for special education and what the IEP process entails. This should be done in writing, emailed to parents and on the school website.

Loopholes for schools that allow for delaying the eligibility process need to be addressed. Currently parents can report when a school doesn't meet the deadlines of the eligibility process. This puts the parents in an uncomfortable position. Instead a reporting process needs to be developed with each district and the state related to deadlines for testing, meetings, etc. There need to be consequences set up by the state related to missing deadlines.

Currently the only rating for schools relates to performance on standardized testing. Parents of children in special education need to be surveyed by the state and those results should be included in how the schools are rated. Unless the overall rating of school is influenced by parents of children in special education, there will be little accountability in how these children are treated.

The state legislature has been active in addressing bullying. Retaliation is indeed a form of bullying and the state needs to develop a reporting and hearing process that demonstrates a no

tolerance stance on retaliation along with clear consequences for staff that demonstrate any retaliatory action.

At the beginning of the eligibility process, parents should be connected with someone outside the school to provide information and answer questions.

A whistle blower program should be established to allow educators to file anonymous complaints when they suspect the school is skirting the law.

Increased access to legal counsel is needed for parents. Schools that miss deadlines or are found to be using retaliation should face financial consequences. A fund could be established to help parents pay for counsel.

2. Improve professional training:

It should be a requirement that to be certified teachers, school social workers, counselors, etc. obtain education in special education and that part of the testing that is done to certify them includes questions related to children with developmental disabilities. Continuing education requirements should include specific requirements about the types of classes taken and include requirements for classes on developmental disabilities and an ethic requirement which includes a focus on children with developmental disabilities.

3. Develop an education system that meets the actual needs of children with developmental disabilities:

The state should establish a task force which includes consumers, policy makers, school leaders and experts on vocational education to explore vocational education, transition issues and how the testing system should be addressed to meet the needs of children with developmental disabilities. The task force will make recommendations that can be implemented through legislation and at the district level.

4. Provide adequate funding:

While there are some low cost /no cost solutions to these problems, there is no question that these services need funding. Consumers, key informants and policy makers need to join together to adequately fund these services. Education and vocational services are far less costly in terms of both dollars and human losses than homeless shelters, prisons, and life- long support by the state. The Texas economy, which is important to all of us, can't possibly thrive in the long term without reasonable investment in education and vocational training.

Appendix A: Texas Government Code

GOVERNMENT CODE

Title IV, Chapter 531

Section 531.0235. BIENNIAL DISABILITY REPORTS

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

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

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

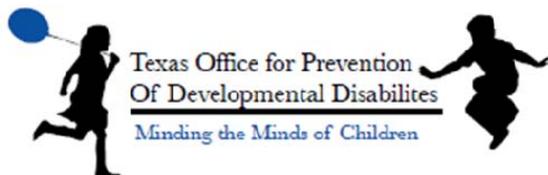
(c) The commission, Texas Department of Human Services, and other health and human services agencies shall cooperate with the agencies required to prepare the report under Subsection (a).

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



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