



**TEXAS COUNCIL ON AUTISM
& PERVASIVE DEVELOPMENTAL DISORDERS**

**Texas Council on Autism and
Pervasive Developmental Disorders**

2016 Report

As required by the
Texas Human Resources Code, Title 7 Rehabilitation of Individuals with
Disabilities, Chapter 114 Texas Council on Autism and Pervasive
Developmental Disorders Act of 1987, and as amended by the
77th Legislature, Regular Session, 2001, Senate Bill 361, and the
79th Legislature, Regular Session, 2005, Senate Bill 882

Texas Department of Assistive and Rehabilitative Services
August 2016

One in 68 children has autism spectrum disorder.¹

¹ "Autism Spectrum Disorder (ASD), Data and Statistics, Prevalence," Centers for Disease Control and Prevention, accessed June 30, 2016, <http://www.cdc.gov/ncbddd/autism/data.html>.

Table of Contents

Terminology	3
Mission Statement	3
Structure of the Texas Council on Autism and Pervasive Developmental Disorders ...	4
Governor-Appointed Public Members	4
Ex Officio Members.....	5
Funding for the Texas Council on Autism and Pervasive Developmental Disorders ...	5
Autism Spectrum Disorder in Texas	5
Facts about Autism Spectrum Disorder.....	6
Autism Services in Texas.....	6
Priorities for the 85th Legislative Session	8
Recommendations.....	9
Recommendation 1: Improve the services provided to children birth to three years old for early identification and expand the services provided for early intervention..	9
Recommendation 2: Continue and Increase Funding for the DARS Autism Program	10
Recommendation 3: Ensure that Medically Necessary Treatments Are Available to Texans	10
Recommendation 4: Improve Special Education (IDEA Part B).....	11
Recommendation 5: Improve Public Schools.....	13
Recommendation 6: Improve Transition Services and Post-Transition Opportunities	13
Recommendation 7: Increase Employment Rates for Adults with Autism Spectrum Disorder	14
Recommendation 8: Reduce the Medicaid Waiver Lists	15
Recommendation 9: Retain the Office of Autism Services and an Advisory Committee on Autism Spectrum Disorder	16
Conclusion.....	17

Terminology

For the purposes of this report, except when used in statute or other credited material, the term autism spectrum disorder is used to refer to all diagnoses considered to be on the autism spectrum.

Mission Statement

The mission of the Texas Council on Autism and Pervasive Developmental Disorders is to advise and make recommendations to state agencies and the Texas Legislature to ensure that the needs of persons of all ages with autism spectrum disorder and their families are addressed and that all available resources are coordinated to meet those needs.

Structure of the Texas Council on Autism and Pervasive Developmental Disorders

The Texas Council on Autism and Pervasive Developmental Disorders (TCAPDD) was established by [S.B. 257, 70th Legislature, Regular Session, 1987](#), adding [Chapter 114, Texas Council on Autism and Pervasive Developmental Disorders Act of 1987](#) to the Human Resources Code.

Administrative support to the TCAPDD was provided by the Department of Aging and Disability Services (DADS) from 2004 to August 31, 2014. Pursuant to the [2014-15 General Appropriations Act \(Article II, Special Provisions Relating to All Health and Human Services Agencies, Section 10, Limitations on Transfer Authority, 83rd Legislature, Regular Session, 2013\)](#), the executive commissioner of the Health and Human Services Commission (HHSC) transferred administrative support for the TCAPDD from DADS, Strategy C.1.1., Central Administration, to the Department of Assistive and Rehabilitative Services (DARS), Strategy A.3.1, Autism Program, on September 1, 2014.

At DARS, administrative support for the TCAPDD is provided by the DARS Office of Autism Services. Pursuant to S.B. 200, 84th Legislature, Regular Session, 2015, the TCAPDD will be abolished no later than September 1, 2016, with a new HHSC advisory committee (Texas Autism Council) assuming the responsibility prescribed by Texas Human Resource Code, Chapter 114, and previously performed by the TCAPDD.

Governor-Appointed Public Members

The TCAPDD is composed of the following governor-appointed public members:

Name	Designation
Dr. Stephanie Sokolosky, Interim Chair	Professional
Dr. Pamela Rollins, Secretary	Professional
Daniel Durany	Self-Advocate
Ann Hart	Parent

Ex Officio Members

The following agencies are members of the TCAPDD. A representative is appointed from each:

- Texas Health and Human Services Commission
- Texas Department of Aging and Disability Services
- Texas Department of Assistive and Rehabilitative Services
- Texas Department of Family and Protective Services
- Texas Department of State Health Services
- Texas Education Agency

Funding for the Texas Council on Autism and Pervasive Developmental Disorders

The Texas Council on Autism and Pervasive Developmental Disorders (TCAPDD) is financially supported by its six member agencies. During fiscal year 2016, each member agency contributed \$14,000, for a total TCAPDD budget of \$84,000.

Administrative support for the TCAPDD is provided by the DARS Office of Autism Services.

Autism Spectrum Disorder in Texas

Autism spectrum disorder (ASD) is a complex developmental disability. Signs typically appear during early childhood and impair a person's ability to communicate and interact with others.

ASD is defined by a certain set of behaviors and is a spectrum condition that affects individuals differently and to varying degrees. Some of the behaviors associated with autism include delayed learning of language; difficulty making eye contact or holding a conversation; difficulty with executive functioning, which relates to reasoning and planning; narrow, intense interests; poor motor skills, and sensory sensitivities. A person on the spectrum might display many of these behaviors, only a few, or many other behaviors besides.

There is no known single cause of autism, but increased awareness, early diagnosis and/or intervention, and access to appropriate support services lead to significant improvement.

The Health and Human Services Commission's Center for Strategic Decision Support estimated in 2014 that 399,915 Texans have an ASD diagnosis, including 130,316 children below 22 years of age. The estimate is based on prevalence data from the Centers for Disease Control and Prevention and on information from the U.S. Census Bureau.

Caring for a child with ASD can be a challenge. Disruptive behaviors, communication difficulties, ancillary medical problems, and issues related to intellectual deficits can tax the physical, emotional, and financial reserves of families. By providing early intervention and effective education, we can reduce the need for support services and, in turn, the cost of the services. However, it is imperative that we avoid thinking of autism as a childhood condition. We must plan to support individuals and families throughout their lives.

The lifetime cost of supporting an individual with ASD has been estimated to be \$1.4 million. If an individual with ASD also has an intellectual disability, the total rises to \$2.4 million.² The costs can jeopardize an individual's or family's ability to pay for treatment and care and can ultimately jeopardize an individual's or family's financial security.

Facts about Autism Spectrum Disorder

Autism spectrum disorder (ASD) affects 1 in 68 children.

ASD is almost five times more common among boys than girls (ASD occurs in 1 in 42 boys and 1 in 189 girls).³

ASD costs a family \$60,000 a year, on average.

Forty percent of people with ASD have average to above-average intellectual abilities.

ASD receives less than 5 percent of the National Institutes of Health's research funding.

ASD occurs in all racial, ethnic, and socioeconomic groups.

Autism is the fastest growing serious developmental disability in the United States.

No medical detection or cure exists for autism.⁴

More than 7 million children call Texas home and nearly 1 in 11 children in the United States lives in Texas, according to The Annie E. Casey Foundation.

Autism Services in Texas

A number of state agencies in Texas provide autism-specific services, including the following.

² "Raising an Autistic Child: Coping With the Costs," Chris Taylor, Money Magazine Online, June 24, 2014, quoting a study published in the Journal of the American Medical Association, <http://time.com/money/2918134/cost-raising-autistic-child>.

³ "Autism Spectrum Disorder (ASD), Data & Statistics, Prevalence," Centers for Disease Control and Prevention, accessed June 30, 2016, <http://www.cdc.gov/ncbddd/autism/data.html>.

⁴ "Facts about Autism, Did you know ...," autismspeaks.org, accessed June 30, 2016, <https://www.autismspeaks.org/what-autism/facts-about-autism>.

Department of Assistive and Rehabilitative Services

Texas Autism Research and Resource Center
Early Childhood Intervention
Autism Program (Applied Behavior Analysis: Children)
Vocational Rehabilitation

Department of Aging and Disability Services

State supported living centers
Intermediate care facilities for individuals with an intellectual disability or a related condition
Community Living Assistance and Support Services
Home and Community-based Services
Deafblind with Multiple Disabilities Services
Medically Dependent Children Program
Texas Home Living Program
Nursing facilities
Guardianship Services

Texas Education Agency

Special education programs for Texas independent school districts

Texas Higher Education Coordinating Board

Autism program grants to autism research centers at institutions of higher education that provide evidence-based behavioral services and training

Priorities for the 85th Legislative Session

Not later than November 1 of each even-numbered year, the Texas Council on Autism and Pervasive Developmental Disorders (TCAPDD) must submit a report to the governor, the lieutenant governor, and the speaker of the house. The report identifies all of the additional services or improvements required to meet the needs of persons with autism spectrum disorder (ASD) and their families.

Children and adults with ASD and their families face many challenges. The need for services is particularly evident in the areas of early identification and intervention; special education; transition, employment, and residential services; and other services for adults. A statewide system for delivering services could help ensure the effective and efficient planning, funding, delivery, and evaluation of ASD services. As the TCAPDD looks forward to the 85th Legislature, the TCAPDD's advocates increased funding for autism services.

Accordingly, the TCAPDD has made nine recommendations for legislative action that the council believes would be of greatest benefit to the ASD service system.

- Recommendation 1: Improve the services provided to children birth to three years old for early identification and expand the services provided for early intervention
- Recommendation 2: Continue and Increase Funding for the DARS Autism Program
- Recommendation 3: Ensure that Medically Necessary Treatments Are Available to Texans
- Recommendation 4: Improve Special Education (IDEA Part B)
- Recommendation 5: Improve Public Schools
- Recommendation 6: Improve Transition Services and Post-Transition Opportunities
- Recommendation 7: Increase Employment Rates for Adults with Autism Spectrum Disorder
- Recommendation 8: Reduce the Medicaid Waiver Lists
- Recommendation 9: Retain the Office of Autism Services and an Advisory Committee on Autism Spectrum Disorder

Recommendations

Recommendation 1: Improve the services provided to children birth to three years old for early identification and expand the services provided for early intervention

Acknowledgement: The TCAPDD is working closely with Act Early Texas! (AET!), a collaborative effort among nine university-based autism centers and stakeholders from the public and private sectors based at the Children's Learning Institute at The University of Texas Health Science Center in Houston. AET! is developing a comprehensive plan for providing services for children and youth with autism spectrum disorder (ASD). The TCAPDD supports AET!'s plan and has applied to receive federal funding from the Health Resources and Services Administration for innovative ASD-related projects. If approved, the funding would begin September 1, 2016, and would last for three years.

Diagnosing ASD early is critically important to receiving timely and appropriate intervention services. A 2007 Swedish study suggests that early diagnosis can reduce the cost of lifelong care by two thirds.⁵ There is a significant shortage of professionals qualified to diagnose a young child with ASD. No single agency in Texas is responsible, as yet, for identifying autism early in a child's life. All children should be screened for autism between the ages of 18- and 24-month, during their well-child visits, as recommended by the American Academy of Pediatrics.⁶

Autism screening and other developmental screening is provided as a Medicaid benefit. DARS Early Childhood Intervention performs routine interviews and developmental assessments to determine a child's eligibility and screens the child for autism, according to the recommendation.

Without a diagnosis of ASD, a child may not receive effective early intervention, and valuable time is lost. Effective early intervention by age three can increase the number of children who learn to talk and attend regular kindergarten by up to 40 percent. According to the U.S. Government Accountability Office, early intervention can reduce the cost of education by over \$10,000 per child, per year, compared to the cost for children who do not receive early intervention. In fact, the research brief [Proven Benefits of Early Childhood Interventions](#), published by the Rand Corporation, states

⁵ "The economic consequences of autistic spectrum disorder among children in a Swedish municipality," Krister Järbrink, *Autism* (September 2007, vol. 11, no. 5, 453-463), Sage Journals, http://aut.sagepub.com/search/results?fulltext=The+economic+consequences+of+autistic+spectrum+disorder+among+children+in+a+Swedish+municipality%2C%22+K.+J%3%A4rbrink&submit=yes&journal_section=spaut&src=selected&andexactfulltext=and&x=0&y=0

⁶ "How Pediatricians Screen for Autism," [healthychildren.org](http://www.healthychildren.org), accessed June 30, 2016, <https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/How-Doctors-Screen-for-Autism.aspx>.

that “well-designed early childhood interventions have been found to generate a return to society ranging from \$1.80 to \$17.07 for each dollar spent on the program.” The brief cites benefits across domains, including cognitive function, behavior, social interaction, self-regulation, and physical health. Further, research has shown that early intervention improves long-term results, which not only saves money, but leads to a higher quality of life for individuals and families.

The TCAPDD recommends funding initiatives, programs, and services designed to improve early diagnosis and expand autism-specific early interventions to include those identified in Recommendation 3.

Recommendation 2: Continue and Increase Funding for the DARS Autism Program

Acknowledgement: The TCAPDD expresses appreciation to the 84th Texas Legislature for increasing funding for the DARS Autism Program.

The TCAPDD is encouraged that DARS received funding to expand its Autism Program, which provides comprehensive and focused applied behavior analysis (ABA) to children ages three through fifteen. The total number of providers for the program increased from 8 to 21 in 2016, thereby expanding the availability of focused ABA to parts of the state that do not have adequate capacity. Focused ABA is now available in 10 of the Health and Human Services Commission’s eleven regions. (Comprehensive ABA is being phased out, as required by legislation.)

The TCAPDD supports continued expansion of the Autism Program. Increasing access to appropriate ABA therapy will improve the quality of life for families and individuals and save taxpayers money. Intensive early intervention, including ABA, has been shown to improve results, reduce lifelong costs for families, and save taxpayers money.⁷

The TCAPDD recommends that the Texas Legislature continue to increase funding for the DARS Autism Program to serve more children.

Further, the TCAPDD is pleased that the DARS Autism Program is working on a pilot program with Texas State University to study the effectiveness of an innovative treatment model. The pilot program is an example of a collaboration intended to improve the lives of children with autism spectrum disorder in a cost-effective way.

Recommendation 3: Ensure that Medically Necessary Treatments Are Available to Texans

⁷ Lifetime Distribution of the Incremental Societal Costs of Autism, Michael L. Ganz, Archives of Pediatrics and Adolescent Medicine journal, APRIL 2007, doi:10.1001/archpedi.161.4.343, <http://archpedi.jamanetwork.com/article.aspx?articleid=570087>.

Not all children who are diagnosed early receive appropriate, evidence-based therapies. Although Texas has one of the strongest autism insurance mandates in the country, children on Medicaid and families with health insurance that is self-funded by a parent's employer do not benefit. Families with excellent insurance coverage are often denied their claim, unless they make repeated appeals.

Adequate coverage of medically necessary treatments could help avoid issues with claims and could help address the educational issues and long waiting lists explained in Recommendation 8.

Another concern is that children on the autism spectrum will be negatively affected by the proposed reduction in Medicaid payments to pediatric therapists, as reported by the Texas Tribune and other media outlets. Considering that 43 percent of Texas's nearly 7 million children receive Medicaid or CHIP (the Children's Health Insurance Program)⁸, reduced access to therapy covered by Medicaid would negatively impact a huge number of children.⁹

The TCAPDD recommends that Texas not implement the proposed reduction in Medicaid payments to pediatric therapists. The TCAPDD also recommends that Texas provide Medicaid funding for autism treatments as required under Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program. Federal law already dictates that medically necessary treatment be provided for children on Medicaid.

Finally, most private therapists with expertise in autism live in the major metropolitan areas of the state, which may make it more difficult for families who live in other regions to find a therapist. Of the 1,202 board certified behavior analysts in Texas, 746 (or 62 percent) live within 100 miles of Houston, Dallas, Fort Worth, Austin, and San Antonio.¹⁰

Recommendation 4: Improve Special Education (IDEA Part B)

Acknowledgement: The Texas Council on Autism and Pervasive Developmental Disorders applauds the work of the Texas Statewide Autism Leadership for Autism Training (TSLAT) team based at the Region 13 Educational Service Center. TSLAT has published an extensive collection of free articles, videos, and classroom tools on the TSLAT website for use by teachers and administrators. No matter where an educator works, she or he can learn to teach students with ASD more effectively.

Acknowledgement: The TCAPDD also expresses appreciation to the 84th Texas Legislature for awarding \$8.1 million to the Texas Higher Education Coordinating Board to be used for evidence-based behavioral services and training over the next two years.

⁸ "Texas Medicaid and CHIP in Perspective," Tenth Edition, Texas Health and Human Services Commission, February 2015, <http://www.hhsc.state.tx.us/medicaid/about/PB/PinkBook.pdf>.

⁹ "Budget Cuts Hit Early Childhood Intervention Program," Edgar Walters, The Texas Tribune, May 3, 2016, <https://www.texastribune.org/2016/05/03/advocates-warn-cuts-early-childhood-intervention-p>.

¹⁰ Behavior Analyst Certification Board (BACB), accessed July 7, 2016, <http://info.bacb.com/o.php?page=100155&by=state>

The parent-directed treatment and the training for teachers and paraprofessionals will help several thousand children during the biennium, and the research funded by this appropriation will inform educators in the future.

The majority of children with autism spectrum disorder (ASD) ages 3 to 22 years are served by their local independent school districts. According to the Texas Education Agency, the number of students receiving special education services has increased to 442,476.¹¹ Of that number, 54,098 are students with a primary diagnosis of autism spectrum disorder, which is the fastest-growing diagnostic category in Texas public schools.¹² While Public Law 94-142, also known as the Individuals with Disabilities Education Act (IDEA), guarantees children with disabilities a free appropriate public education, the truth is that funding for educational services in Texas is significantly lower than most other states.¹³

The appropriate goals for educational services for children with ASD are the same as those for other children; that is, personal independence and social responsibility¹⁴. Students with ASD more often require explicit instruction and more support services to make progress, often requiring a lower staff-to-student ratio. In addition, an individualized education program tailored to meet each student's educational needs is required by federal law.

Furthermore, educational services for students with ASD should include social skills training. Researchers at Duke University promote the teaching of soft skills, such as self-control for all elementary-age students¹⁵. If this instruction is important for typical students, it is absolutely critical for students on the autism spectrum. Since social impairment is part of the disability itself, we cannot assume that children with ASD will learn to navigate the social world on their own; they must be taught that skill. Not only will teaching social skills prepare students for relationships and employment in adulthood, it will also help them master academic material while they are still in school.¹⁶

¹¹ Texas Public School Statistics for 2014-15, Texas Education Agency, accessed June 30, 2016, <http://tea.texas.gov/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=25769825081&libID=25769825178>.

¹² "Special Education Reports," Texas Education Agency, PEIMS Standard Reports, accessed June 30, 2016, <https://rptsrv1.tea.texas.gov/adhocrpt/adser.html>.

¹³ "Revenues and Expenditures for Public Elementary and Secondary Education: School Year 2012–13 (Fiscal Year 2013)," Stephen Q. Cornman, National Center for Education Statistics, U.S. Department of Education, January 2016, <https://nces.ed.gov/pubs2015/2015301/index.asp>.

¹⁴ "Educating Children with Autism," page 5, The National Academies Press, 2001, <http://www.nap.edu/read/10017/chapter/2#5>.

¹⁵ "How Does the Fast Track Intervention Prevent Adverse Outcomes in Young Adulthood?," Child Development journal, March/April 2016, Wiley Online Library, Child Development, <http://onlinelibrary.wiley.com/doi/10.1111/cdev.12467/abstract>.

¹⁶ "Social Thinking and Common Core Standards," Michelle Garcia Winner and Pamela Crooke, Social Thinking, accessed June 30, 2016, <http://www.socialthinking.com/Articles?name=Social%20Thinking%20and%20Common%20Core%20Standards%20Article>.

The TCAPDD recommends increasing funding for special education so that children with ASD receive appropriate instruction, an individualized education program, and social skills training to ensure that they are given the opportunity to be successful.

Recommendation 5: Improve Public Schools

Even though most students on the autism spectrum receive special education services, it is important to remember that they don't necessarily receive these services in self-contained classrooms. As public school districts strive to provide a free and appropriate education in the least-restrictive environment for students with disabilities, more and more students with autism spectrum disorder (ASD) spend at least part of their school day in inclusive environments and general education classes with nondisabled peers.

Taking a universal design approach to public education would help. In universally designed classrooms, thoughtful modifications are in place from the outset to ensure that the curriculum meets the needs of all children, in contrast to adapting the curriculum to meet the needs of an individual child with disabilities, which is often more costly and difficult for the teacher to manage.¹⁷

Education Week's 2016 report ranked Texas public schools 42nd in the nation, in regard to school performance.¹⁸ According to the Education Law Center, a legal advocacy organization in Pennsylvania, public school funding in Texas has remained low, on a nationwide scale, and basically flat in recent years. Texas invests "a very low percentage of state economic capacity in funding public education."¹⁹

The TCAPDD recommends increasing overall public school funding, so that children with ASD may excel in inclusive environments.

Recommendation 6: Improve Transition Services and Post-Transition Opportunities

Acknowledgement: Research indicates that many students with disabilities are leaving secondary school without having found competitive integrated employment or being enrolled in postsecondary education. There is a need to provide support services to such students as they make the transition from school to postsecondary life. Based on the findings, the Workforce Innovation and Opportunity Act (WIOA) was reauthorized to modify the Workforce Investment Act and the Rehabilitation Act. WIOA requires the Vocational Rehabilitation program to spend 15 percent of its federal funding

¹⁷ Pamela R. Rollins, *Facilitating Early Social Communication: From Theory to Practice* (Autism & Aspergers Publishing Company, 2014), page 10.

¹⁸ "Quality Counts Marks 20 Years, Report Explores New Directions in Accountability, Nation Earns C, Massachusetts Ranks First in 'State of the States' Report Card," edweek.org, Revised January 26, 2016, http://www.edweek.org/media/qualitycounts2016_release.pdf.

¹⁹ "Is School Funding Fair? A National Report Card," Dr. Bruce Baker, Rutgers Graduate School of Education; David Sciarra, executive director, Education Law Center (ELC); Danielle Farrie, ELC research director; Theresa Luhm, Esq., ELC managing director, March 2016, <http://www.schoolfundingfairness.org>.

(approximately \$36 million) on Pre-Employment Transition Services for individuals who meet the legal definition of “student with a disability.” WIOA also requires the program to spend 50 percent of its Supported Employment funds on individuals who meet the definition of “youth with a disability.” The program has increased its collaboration with school districts to supplement, not supplant, the districts’ services thereby helping them provide services earlier and provide more intensive services. Improving services in this way is one example of WIOA’s beneficial effect.

As more and more students with autism spectrum disorder (ASD) move into secondary school and transition to adult life, the question becomes “Transition to what, specifically?” Once the federal mandate to educate students with disabilities no longer applies, services are not guaranteed. According to researchers at Drexel University, over 60 percent of young adults on the autism spectrum do not find work or continue their education within two years after leaving high school. In fact, Drexel researchers found that young adults with ASD have the highest rates of disconnection (that is, the highest rates of being unemployed and out of school) compared to their peers with other disabilities.²⁰ Given that most individuals with an ASD diagnosis are currently under the age of 22, Texas is on the verge of the autism tsunami that has been widely reported in the media. In other words, the forecast will only get worse if we don’t take action.

The TCAPDD recommends increasing funding to improve transition services and improve post-transition opportunities such as employment and higher education.

Recommendation 7: Increase Employment Rates for Adults with Autism Spectrum Disorder

Acknowledgement: The TCAPDD supports DARS Vocational Rehabilitation Services collaboration with the University of North Texas to create an [autism-specific specialization credential](#). For each employment service that a DARS contractor wishes to provide, the contractor must earn a specialization credential through the Workplace Inclusion and Sustainable Employment at the University of North Texas (UNTWISE). DARS and UNTWISE worked together to create the first specialization available to contractors who are employment specialists. As of 2016, contractors who complete UNTWISE in-depth training can specialize in providing autism-related services. The contractors are also eligible for a premium placement and use of a new tool for assessing the job-readiness of individuals with autism. TCAPDD members are pleased with the new autism-related area of specialization. TCAPDD members are also pleased with the new Developmental Disorders Team of DARS counselors who provide ongoing and in-depth training on developmental disorders to all DARS Vocational Rehabilitation counselors statewide.

²⁰ “National Autism Indicators Report: Transition into Young Adulthood,” Roux, Shattuck, Rast, Rava, and Anderson, Philadelphia, PA, Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015. <http://drexel.edu/autisminstitute/research-projects/research/ResearchPrograminLifeCourseOutcomes/IndicatorsReport/#sthash.fi94tmIL.dpbs>

A high percentage of adults with ASD are unemployed or underemployed. It is common for employees with ASD to lose their jobs because they don't have the basic skills required to navigate the world of work. Not only does the situation take an emotional and financial toll on individuals and families, it also costs Texas and the United States in terms of wasted talent, lost revenue, and increased public assistance.

The LEAD Center, funded by the U.S. Department of Labor's Office of Disability Employment, calculated that, although Texas' overall unemployment rate for 2014 was a low 5.10 percent, only 37.97 percent of adults with disabilities were employed.²¹ ²² For adults with ASD, the national figures are much worse. A 2012 employment study from Washington University in St. Louis determined that people with ASD have the worst "no participation" rate of any disability group.²³

There are, however, encouraging developments in the employment arena. For example, at the national level, the U.S. departments of labor, education, and health and human services are working together to help states implement the Workforce Innovation and Opportunity Act, signed July 22, 2014, which promises to improve the public workforce system and serve more disconnected youth, including young people with ASD.

Here in Texas, DARS Vocational Rehabilitation and the Texas Education Agency have signed a memorandum of understanding to improve the transition from school to adulthood for people with disabilities. At the Department of Aging and Disability Services (DADS), the Employment First Task Force promotes competitive employment of people with disabilities. Software companies such as Microsoft and SAP have announced autism initiatives in recent years.²⁴ All of these efforts are steps in the right direction, but the TCAPDD does not believe that these developments alone can accommodate the growing number of adults with ASD.

The TCAPDD recommends increasing funding for support services intended to improve employment rates for adults with ASD.

Recommendation 8: Reduce the Medicaid Waiver Lists

Whether or not an adult with autism spectrum disorder (ASD) is employed, he or she needs residential support; that is, a place to live and guidance or assistance. Support services include attendant care, behavior management, and skills acquisition. The Community Living and Support Services (CLASS) program and the Home and

²¹ "Texas, State Data tab," Lead Center, National Disability Institute, Accessed on June 30, 2016, http://employmentfirst.leadcenter.org/texas#quicktabs-states_big_screen=1.

²² "Texas, Snapshot tab," Lead Center, National Disability Institute, Accessed on June 30, 2016, http://employmentfirst.leadcenter.org/texas#quicktabs-states_big_screen=0.

²³ "How These 4 Major Companies Are Tackling The Autism Unemployment Rate," Joseph Erbentraut, June 1, 2015, [huffington-post.com, http://www.huffingtonpost.com/2015/05/07/autism-employment_n_7216310.html](http://www.huffingtonpost.com/2015/05/07/autism-employment_n_7216310.html).

²⁴ "Diversity and Inclusion, Embracing differences drives our innovation and success," go.sap.com, "SAP Autism at Work Overview Video," SAP, accessed June 30, 2016, <http://go.sap.com/corporate/en/assetdetail/2016/04/9e6909ee-6a7c-0010-82c7-eda71af511fa.html>.

Community-Based Services (HCS) Medicaid Waiver programs offer individualized, community-based funding but, long waiting lists make them meaningless for tens of thousands of Texans with disabilities such as ASD. Children often become teenagers or adults before they qualify for the funding needed to attend the CLASS program because of waiting lists that can last as many as 12 years—even if the child’s family applies for the funding as soon as the child is diagnosed.

According to the report *The Case for Inclusion*, published by United Cerebral Palsy (UCP) in 2015, only Mississippi ranks lower than Texas when it comes to providing community-based support services for people with disabilities. UCP reports that 322,000 people with disabilities are on waiting lists for residential and community services throughout the United States and according to the Coalition for Texans with Disabilities over 127,000 of them live in Texas.

Even for those in the CLASS and HCS programs, the funding is not always sufficient to meet the needs of consumers with ASD, especially those with severe behavior challenges. For example, the daily reimbursement rate for day habilitation is so low that providers can’t afford to hire as many trained staff members as some adults with ASD require. In other words, individuals with severe behavior challenges are not always eligible to participate in day programs, even if they have received funding. Likewise, HCS group home companies can’t always afford to offer support services sufficient to accommodate residents who have severe behavior problems. Reducing the number of individuals with the most severe behavior problems through proactive intervention is an effective way to address the issue significantly, but it will not eliminate it.

We recognize that Senate Bill 7 of the 83rd Texas Legislature requires the Health and Human Services Commission (HHSC) and the Department of Aging and Disability Services (DADS) to design and implement a system to provide acute care and long-term support services to individuals with an intellectual and developmental disability (IDD). We also recognize that HHSC’s IDD System Redesign Advisory Committee, created by Senate Bill 7, will advise as well as consult and collaborate with HHSC and DADS on any necessary redesign of that system. We support the goals of this group as published on its website and remain hopeful that the hardworking members of this committee will help DADS and HHSC improve systems for Texans who have an IDD such as ASD.²⁵

The TCAPDD recommends increasing funding and strategies to reduce the Medicaid waiver lists.

Recommendation 9: Retain the Office of Autism Services and an Advisory Committee on Autism Spectrum Disorder

²⁵ “Intellectual and Developmental Disability System Redesign Advisory Committee,” Advisory Committees, About HHSC, Texas Health and Human Services Commission, accessed June 30, 2016, https://www.hhsc.state.tx.us/about_hhsc/AdvisoryCommittees/iddsrac.shtml.

The TCAPDD recommends that the Office of Autism Services be retained when DARS autism-related services transfer to the Health and Human Services Commission (HHSC). The Office of Autism Services centralizes the DARS Autism Program, the Texas Autism Research and Resource Center (TARRC), and the administrative support provided to the TCAPDD.

Retaining these functions under a single unit will allow consumers, policy makers, and HHSC employees to obtain and exchange information about autism spectrum disorder (ASD) and services efficiently.

Furthermore, the TCAPDD supports the continuation of TARRC initiatives, including:

- improving and maintaining the TARRC website;
- providing training programs for community professionals, such as law enforcement officers and firefighters;
- sponsoring an annual autism research conference; and
- providing information and referral services to inquirers statewide.

Additionally, given the abolishment of the TCAPDD no later than September 1, 2016, the TCAPDD supports HHSC's decision to develop a new advisory committee. The current governor-appointed members are willing and eager to help transition duties from the TCAPDD to the new advisory committee.

Conclusion

In summary, we, the current governor-appointed members of the Texas Council on Autism and Pervasive Developmental Disorders, believe the following:

- Autism spectrum disorder (ASD) is a complex neurodevelopmental disability that affects individuals differently and to varying degrees across their entire lifespan.
- Early diagnosis and appropriate intervention for children improve quality of life and result in significant financial savings.
- Increased national awareness has drawn attention to the millions of American families living with ASD, but that has not translated into sufficient treatment and support.
- There are encouraging trends in Texas; however, overall, funding for treatment, education, and long-term support of people with ASD is woefully inadequate.
- The TCAPDD respectfully requests that the Texas Legislature increase funding for all programs that help people with ASD, to reduce the burden that the disorder places on hardworking families.