



2008 Annual Report

Texas Council on Autism
and Pervasive Developmental Disorders

Recommendations to the 81st Texas Legislature

November 1, 2008

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

2008

Annual Report:

Recommendations to the 81st Texas Legislature

Submitted to the
**Governor, Lieutenant Governor,
Speaker of the House
and Executive Commissioner of the
Texas Health and Human Services Commission**

As required by
Texas Human Resources Code, Chapter 114

November 2008



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

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November 1, 2008

To the Governor, Lieutenant Governor, Speaker of the House and Executive Commissioner of the Health and Human Services Commission:

The Texas Council on Autism and Pervasive Developmental Disorders (Council) respectfully submits its 2008 Annual Report, as required by Texas Human Resources Code, Chapter 114.

This report offers five recommendations the Council has identified as requiring priority attention by the 81st Legislature, all resultant of 12 months of input from consumers, family members, local and state agency stakeholders, community representatives, and advocates.

Each of the five recommendations addresses one of the four stages-of-life areas (early childhood, school-age years, school-age to adult transition, and adult services) this report employs as a platform from which to create a seamless system of services that is lacking for children and adults with autism spectrum disorder (ASD) in Texas:

- Establish a statewide Autism Research and Resource Center.
- Develop and implement a state plan to ensure a continuum of services from screening to diagnosis and treatment for all Texas children with ASD.
- Implement recommendations in the “Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Adult Living” as required by HB 1230.
- Create multiple pilot programs to adapt and provide evidence-based services to adults with autism.
- Fully fund the Department of Assistive and Rehabilitative Services’ legislative appropriations request for the continuation of its Autism Project which provides therapy services to children with autism, ages three to eight.

The Council is intent upon working collaboratively with all parties to maximize existing resources and identify unmet needs in order to create an effective, evidence-based continuum of services for children and adults with autism in Texas. This report provides evidence that deferring early services to children with ASD will cost Texas billions of dollars in future costs and offers solutions to begin addressing the myriad of issues confronting Texans with autism.

The Council sincerely appreciates your efforts to improve the lives of children and adults with ASD and respectfully requests your serious consideration of and support for the recommendations included in this report.

Respectfully,

Frank McCamant
Chair



TABLE OF CONTENTS

Foreword.....	2
Texas Council on Autism and Pervasive Developmental Disorders	5
Values and Assumptions.....	5
Strategic Planning.....	6
Autism in Texas	7
2008 State Progress in Serving Persons with Autism.....	10
Recommendations	
I: Texas Autism Research and Resource Center.....	13
II: Screening, Diagnosis and Treatment.....	15
III: HB 1230 Recommendations	21
IV: Adult Services Pilot Projects.....	23
V: DARS Autism Project.....	27
Glossary	28
Appendices	30
A: Texas Council on Autism and PDD Membership.....	33
B: FY 2008 Texas Council on Autism Public Meetings	37
C: DADS Interest Lists	38
D: DARS Texas Early Childhood Intervention Dissemination of CDC Materials.....	40
E: Texana Center Day Habilitation Programs	42
F: Statewide Initiative for Autism Training.....	44



Foreword

The 2008 Annual Report of the Texas Council on Autism and Pervasive Developmental Disorders marks a new approach to presenting the Council's perspective on autism issues to state leadership. This document provides updates on state-level programs serving Texans with autism and recommendations to state leadership as the 81st Texas Legislature prepares to convene in January 2009. The recommendations in this report focus on policy issues and proposed initiatives which may require legislation.

During calendar year 2009 the Council will create a long-term strategic plan to provide coordinated services to adults and children with autism as required by Texas Human Resources Code, Chapter 114. The three to five year strategic plan will lay out a comprehensive framework to deliver services in an efficient and effective manner. Further information on the Council's strategic planning process can be found on page 6.

The Council extends its gratitude to the many consumers, family members, providers, educators, elected officials and representatives of all agencies¹ taking the time to attend one of the Council's 12 town hall forums or business meetings during the past year² to offer their valuable insights on people living with autism in Texas.

The views and life experiences shared with the Council richly inform each recommendation in this annual report and the Council's strategic plan now under development.

¹ Parents of Autistic Children of Texas, Partners Resource Network, Center for Autism, Texas Center for Disability Studies, Autism Society of Greater San Antonio, Children's Policy Council, MHMRA, Harris County, University of Texas Health Science Medical School of Houston, University of Texas Medical School at Houston, Avondale House, Houston, Texas Tech University Burkhart Center, Lubbock ECI DEBT, MHMR Tarrant County, Education Service Center 17, Lubbock MHMR, Greater Dallas League of Women Voters Women's Council HHS Coordinator, Autism Council of Educational Support and Scientific Studies, Harlingen Consolidated Independent School District, San Benito Consolidated Independent School District, Tropical Texas Behavioral Health.

² See Appendix B: FY 2008 Texas Council on Autism Public Meetings.



Texas Council on Autism and Pervasive Developmental Disorders

The Texas Council on Autism and Pervasive Developmental Disorders (Council) was established in 1987 by legislation that added Chapter 114 to the Texas Human Resources Code. The Council is composed of seven public voting members appointed by the governor, ten Regional Advisory Committee Chairs and six ex-officio state agency members. Four appointed members of the Council have a family member with an autism spectrum disorder.

The **mission** of the Council is to advise and make recommendations to state agencies and the Legislature to ensure that the needs of persons of all ages with Autism Spectrum Disorder (ASD)³ are addressed and that all available resources are coordinated to meet those needs.

The Council holds the vision that individuals with ASD will have adequate resources and supports to ensure their maximum personal, educational, and vocational potential throughout their lifetime.

In June 2008, Governor Perry named Frank McCamant (Austin) presiding officer of the Council for a term to expire at the pleasure of the governor. He also appointed four new members to the council including Michael R. Bernoski (Cedar Park), Mirella Garcia (El Paso), Stephanie Sokolosky (Lubbock), and Pam Rollins (Dallas). Previously-appointed members are Anna Hundley (Dallas) and Manuel Vela (Harlingen).

The Council also includes one representative from Texas Education Agency (TEA), Texas Health and Human Services Commission (HHSC), Texas Department of Aging and Disability Services (DADS), Texas Department of State Health Services (DSHS), Texas Department of Assistive and Rehabilitative Services (DARS), and

Texas Department of Family and Protective Services (DFPS).

The Council's website (<http://www.texasautismcouncil.org>) maintains notices of upcoming meeting, agendas, and the notes of all Council meetings. Also available are the Council's bylaws, policies and procedures, council reports, enabling legislation, resources, third party research reports and recent news.

All meetings held by the Council are announced in the Texas Register. The Council meets at least four times per year and may have additional public hearings throughout Texas as necessary. Written or in-person testimony is welcome at all meetings and public hearings. In addition, all interested individuals and groups are encouraged to contact the Council at any time.

Values and Assumptions

In preparing this annual report, the Council offers the following statements of fact and values which provide a basis for this annual report.

³ Autism is one of five disorders coming under the umbrella of pervasive developmental disorders (PDD). The disorders within the category of PDD are: Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder (CDD), Rhett's Disorder, and PDD-Not Otherwise Specified (PDD-NOS). This report uses the terms "autism spectrum disorder" or "ASD" to refer to all five categories of PDD.

- ASD is a spectrum disorder with tremendous variability within the population.
- ASD occurs in all geographic, ethnic, racial and socio-economic groups.
- Every child in Texas with ASD deserves an accurate and timely diagnosis.
- Texas children with a diagnosis of ASD deserve appropriate and timely treatment.
- People with ASD benefit from individualized and coordinated personal care, education, and vocation/ employment / community support throughout their lifetime.
- Families and caregivers of persons with ASD deserve and benefit from supportive services.
- Health, transportation, education and law enforcement personnel provide services more effectively when appropriately educated about ASD.
- Adults with ASD benefit from a community living option they choose, if there are appropriate supports.

Strategic Planning

Previous state plans issued by the Council have been more of a compilation of recommendations rather than a comprehensive long-term planning document. While the recommendations themselves had merit, there was no framework to set them into an organized work plan that focused on key outcomes and goals. The Council has acknowledged this and is going to undertake a planning process that will develop such a long-term strategic plan. The beginnings of this process were initiated in September 2008 and a true strategic state plan should be available in 2009.

Building on input received by the Council over recent years and the foundation of work so far by the Council and its Advisory Task Force, the strategic planning process will articulate the Council's long-term goals, as well as prioritize the work elements necessary to achieve these goals over time. The plan will serve as the strategic focus for the Council's work over the next several years.

Autism in Texas

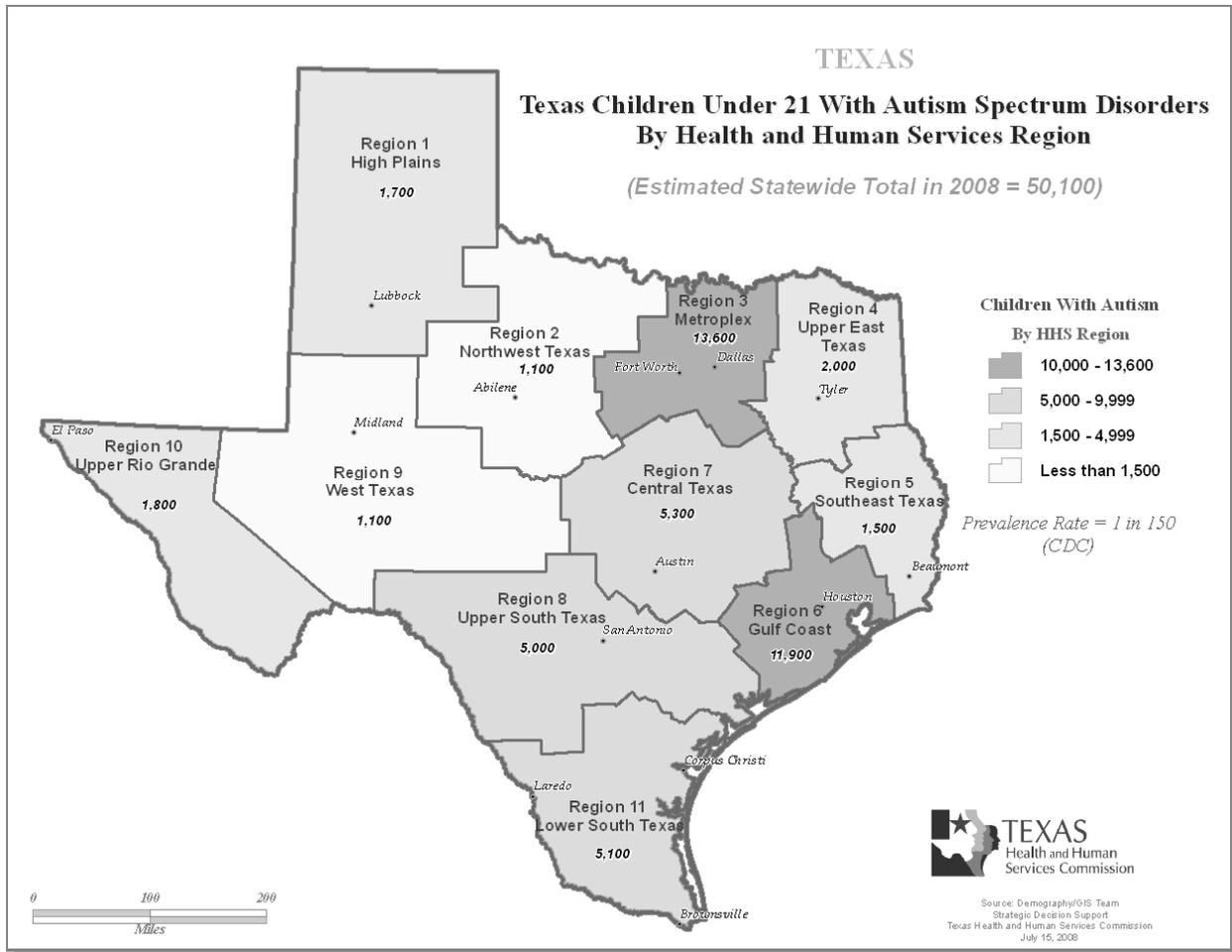
Autism spectrum disorders (ASD) are lifelong developmental disabilities, characterized by marked difficulties in social interaction, communication skills, and restricted, repetitive and stereotyped patterns of behavior, interests and activity.

The following graphic, produced by the Texas Health and Human Services Commission Strategic Decision Support Demography/GIS Team, utilizes U.S. Centers for Disease and Control Prevention (CDC) data to show the estimated numbers of people living with autism within each of the 11 health and human services regions.

The data are generated by applying research findings from CDC indicating that that one in every 150 children may have an autism spectrum disorder,⁴ to each region's population. These data are not the result of a prevalence or incidence study specifically for Texas, and are presented for planning purposes only.

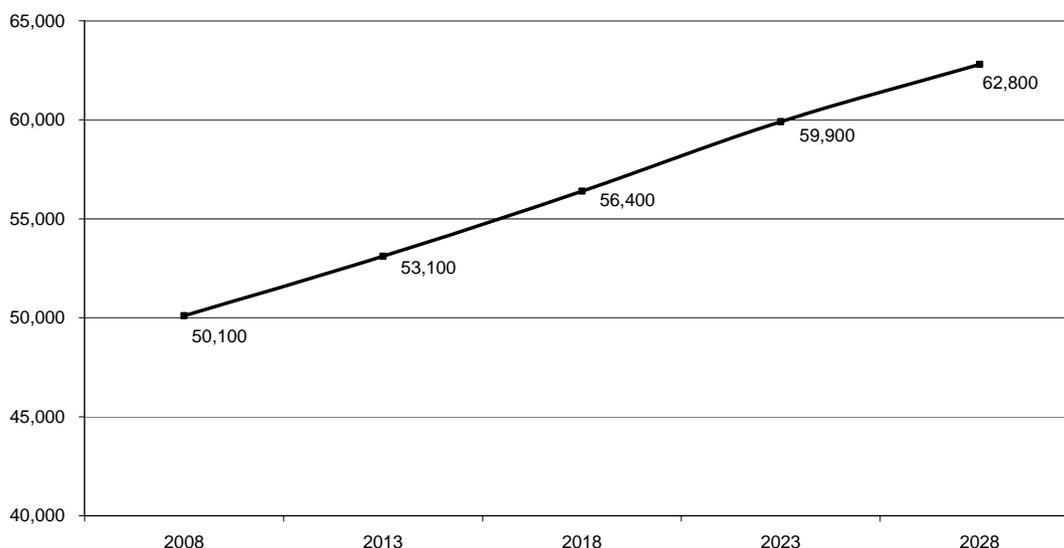
ASD is the fastest-growing serious developmental disability in the United States, impacting an estimated 1 in 150 children.¹ In 2008, over 23,000 children with ASD were served in Texas schools, more than a 15% increase from 2007.¹

⁴ Centers for Disease Control and Prevention "CDC Releases New Data on Autism Spectrum Disorders (ASDs) from Multiple Communities in the United States." Website news release February 8, 2007. See: <http://www.cdc.gov/od/oc/media/pressrel/2007/r070208.htm>



The chart on the following page, using the same CDC data, projects that the number of Texas children under age 21 with autism will increase to 62,000 by 2028.

Texas Children Under Age 21 With Autism Spectrum Disorders



Source: Demography Team. Strategic Decision Support. Texas Health and Human Services Commission. July 2008.

Assumes CDC-cited prevalence rate of 1 in 150 among children under age 21.

The increased number of children and adults diagnosed with ASD is a growing and urgent concern for families, service providers, and policy-makers as existing health, education, and social service systems struggle to respond to the service needs of this population in a comprehensive manner.

Though a number of services and funding options for individuals with ASD exist, they are scattered, fragmented, and often difficult to access. There are no widely implemented service guidelines for ASD in Texas, and there are significant gaps in knowledge about ASD among professionals serving these individuals.

It is widely recognized that early intervention services are key to improving outcomes. In response, CDC has embarked on a nationwide early screening, diagnosis and treatment campaign. In addition, the American Academy of Pediatrics recently released new treatment guidelines recommending that screening for ASD begin at 18 months.

2008 State Progress in Serving Persons with Autism

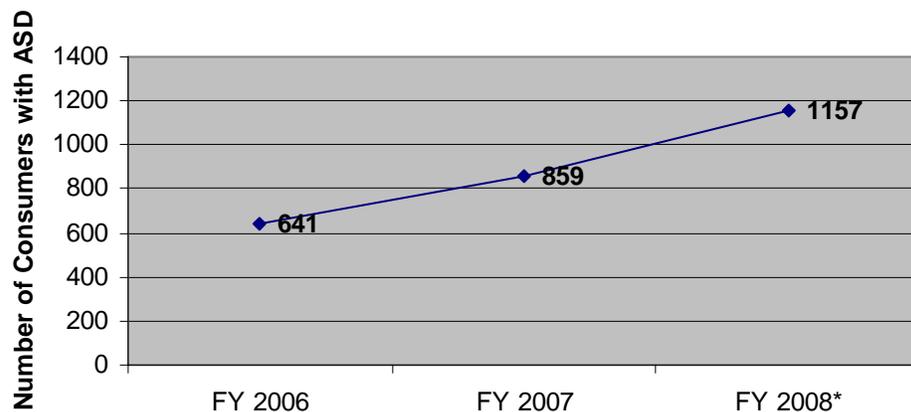
The following is a list of initiatives and activities seeking to improve state services and supports to persons with ASD during state fiscal year 2008:

- DARS Early Childhood Intervention (ECI) is pursuing avenues to share pertinent information on the early signs of autism developed by the CDC. By targeting the primary referral sources for ECI services including physicians, allied health professionals and child care providers, ECI can capture the attention of a broad array of professionals that intersect with families with infants and toddlers. To further expand this network ECI is disseminating this information to the ECI provider community and guiding them on local distribution opportunities.
- DADS has included a service component called “Behavioral Support” in the Community Living Assistance and Support Services Program (CLASS), Home and Community Services (HCS) and Deaf-Blind Multiple Disabilities (DBMD) waivers. Since September 1, 2008, board-certified behavior analysts have been added to the list of qualified providers able to provide this service.
- The Autism Project is a limited program through the DARS established after the 80th Legislative session, which provides funding for four projects around the state to provide services to up to 300 children ages 3 to 8 with ASD. The contracts include a requirement that the providers make Applied Behavioral Analysis (ABA) services available. DARS has requested continued funding for this project in its 2010-11 LAR.⁵
- TEA designated Education Service Center Region (ESC) XIII to provide the leadership for the Statewide Initiative for Autism Training in public schools across Texas. ESC XIII and TEA created and implemented a plan regarding ASD during 2007-08, and are currently implementing the approved plan for the 2008-09 school year. (For more information, see Appendix F: Statewide Initiative for Autism Training.)
- ESC XIII, on behalf of TEA, submitted an application to the National Professional Development Center on ASD program funded by the U. S. Department of Education, Office of Special Education Programs. Although a grant was not awarded to TEA, the agency is planning to implement the initial phase of the proposed project and is considering re-applying for the grant next round. The project will: 1) promote evidence-based practices for early identification, intervention, and education; 2) provide sustainable, outcome-based professional development and technical assistance; and, 3) evaluate child, family, practitioner, and system level outcomes.
- DFPS has created and filled one position for an ASD specialist to serve both Child Protective Services and Adult Protective Services.
- DADS has released a Request for Qualifications seeking a contractor to conduct a study on the feasibility and costs of establishing a statewide autism research and resource center.

⁵ HHS System Strategic Plan 2009-13 Chapter X: Goals, Objectives, and Strategies, page 318. Published online: http://www.hhs.state.tx.us/StrategicPlans/HHS09-13/StrategicPlan_FY2009_2013.pdf

- Autism Spectrum Disorders Service Delivery Innovations: from September 2006 through March 2008, the Council was a partner in the “Autism Spectrum Disorders Service Delivery Innovations” project funded by the Texas Council on Developmental Disabilities, managed by DADS, and implemented by Texas Tech University Burkhart Center for Autism Education and Research. The project produced a statewide survey that examined perceptions concerning the effectiveness and usage of ASD interventions and supports.
- The Texas A&M Center for Disability Studies is increasing the capacity of their Directory of Community Services to include a searchable directory of providers serving all persons with disabilities, including over 2000 provider resources for people with autism and their families.
- HHSC (at the request of the Council) is conducting the *Survey of Agency Programs Serving Individuals with Autism Spectrum Disorders*. This survey is intended to develop an “inventory” of state agency programs that serve people with ASD.⁶
- DARS vocational rehabilitation programs are serving increasing numbers of consumers with ASD, as shown in the following table:

**Consumers with ASD Served in
DARS Vocational Employment Programs**



* as of July 31, 2008

- DARS vocational rehabilitation programs have put several systems in place to enhance employment of consumers with ASD.
 - an outcome based supported employment system that utilizes customized upfront planning to identify and implement the unique employment support needs of each consumer.

⁶ Very few programs are targeted specifically to meet the needs of people with ASD. However, many agencies offer programs that provide services that are essential to the care, support, or treatment of individuals with autism. The survey is gathering information on programs that would be of interest to families of individuals with ASD were they to ask “what programs or services do you offer that could help my family member with ASD?” The survey seeks information on how many people with ASD these programs serve. The survey will also provide the basis for the Council to carry out its legislative charge to ensure the services are well coordinated and ‘the full range of services that are available through existing state agencies is offered to those persons throughout their lives to the maximum extent possible’.

- an on-line Autism training module available to all DARS counselors statewide. This training provides guidance to counselors regarding assisting consumers with ASD through the Vocational Rehabilitation process.

Recommendations to the 81st Texas Legislature

I: Texas Autism Research and Resource Center

***Establish a statewide
Autism Research and Resource Center.***

In an effort to standardize the quality of information and services delivered to their citizens with ASD, three states have proactively sought to coordinate autism-related research, education and training of professionals interacting with people with autism, and outreach and community education. Below are synopses of two successful model programs in Illinois and Indiana.⁷

The Autism Program of Illinois Service Network consists of over 27 agencies and universities committed to addressing the needs of people with autism and their families. The program describes itself as a systems development initiative intended to support access to evidence-based programs throughout Illinois. In addition to promoting statewide collaborations and best practices, the program's goals are to provide a framework for the state's activities around diagnosis, intervention and research needs. This includes a strategy for education, coordination and support for healthcare providers and academic programs across the state. Research activities include collaborations with university programs in Illinois, North Carolina and Tennessee. The development of this infrastructure has won national attention as a model for system development.

The Indiana Resource Center for Autism (IRCA) engages in research, develops and disseminates information and education to local communities, organizations, agencies, and families dealing with ASD. Activities related to education and training include statewide conferences and workshops, university courses and practicum opportunities, and training and support to school-based professionals. IRCA maintains a data base for use by researchers and program evaluators and serves as an information clearinghouse which monitors and distributes information about resources, services, policies, and education opportunities. Applied research activities are focused on ways to improve the quality of available programs and inform policy development. A university-based program, the IRCA develops effective research strategies and also supports doctoral and other graduate students in their related individual research and

⁷ The third state is New York: The State Autism Consortium is seen as a "brain trust" which coordinates collective research by the state's scientific community to treat and address autism and autism related disorders. Initial interest for participation in the New York consortium was voiced by: Columbia University, Mount Sinai Medical Center, the University of Rochester, New York University Medical School, Nathan Kline Institute, NYS Institute for Basic Research/CUNY College of Staten Island, Wadsworth Center, Psychiatric Institute of New York State, Albert Einstein College of Medicine, the State University at Albany and the University at Buffalo. Working with the Office of Mental Retardation and Developmental Disabilities, the New York consortium provides infrastructure, resources and collaboration to advance basic and applied research and inform the development of initiatives called for by the growing autism crisis.

service interests. IRCA routinely surveys and reports on the status of programs and services, statewide policy and legislative actions⁸.

A primary goal of a Texas Autism Research and Resource Center (TARRC) would be to foster an inclusive multi-university environment in which autism resource information and evidence-based research are coordinated among and supported by all Texas universities. The functions of the Center would also include:

- education and training of professionals interacting with people with autism (police, EMS and other medical, public transit workers, teachers, etc.),
- outreach and community education,
- autism-related research,
- coordination of autism research activities among Texas universities,
- hosting research symposia and other meetings for information and data sharing,
- establishing and maintaining a web-based repository of accurate information on autism research and interventions,
- supporting the mandated activities of the Council.

The TARRC will play a major role in strengthening the statewide infrastructure through improvement of communications and collaboration among state agencies, service providers and consumers. The center will complement and coordinate the efforts of the multiple Texas universities which have established autism services and research activities.

DADS currently has the authority to create an Autism Research and Resource Center through the 2008-09 General Appropriations Act (H.B. 1, 80th Legislature, Regular Session, 2007), Rider 6 and S.B. 52, 79th Legislature, Regular Session, 2007. Further, DADS has issued a request for proposals to conduct a study on the feasibility of establishing and operating the TARRC. That feasibility study will be available in early calendar 2009.

⁸ See <http://www.iidc.indiana.edu/irca/fAbout.html>

II: Screening, Diagnosis and Treatment

Develop and implement a state plan to ensure a continuum of services from screening to diagnosis and treatment for all Texas children with ASD.

The creation and implementation of a state plan to ensure a continuum of services from early screening to treatment for all Texas children with ASD must be legislatively-mandated. The Council will convene a state plan work-group and direct its efforts, but requests the support of the 81st Legislature to engender the sense of urgency that is demanded of this issue.

Screening and Diagnosis

Demonstrating the need for routine developmental screenings, diagnostic services and treatment has benefited from a body of independent research and recommendations from both the American Academy of Pediatrics (AAP) and the CDC calling for developmental screening and surveillance for all children.

Early identification of developmental disorders is critical to the well-being of children and their families.

*American Academy of Pediatrics
2006 Policy Statement*

AAP recommends developmental surveillance and standardized developmental screening for every well-child visit and has issued updated guidelines and policy statements in an effort to overcome the challenges to early detection of developmental disorders.⁹

According to the AAP, delayed or disordered development may be associated with a higher risk for behavior disorders or associated developmental disorders. Identification of a developmental disorder and its underlying etiology is essential for early medical, social and behavioral treatment planning by both health care professionals and the families.¹⁰

CDC supports the AAP guidelines and recommends developmental screening and surveillance for all children during the 9-month, 18-month, and 24 or 30-month well child visits. The CDC urges parents to request these screenings if not initiated by their physician and advises additional screening if a child is at risk for ASD (has a sibling or parent with an ASD) or if symptoms warrant.

Title V of the Social Security Act¹¹ and the Individuals with Disabilities Education Improvement Act (IDEA)¹² strengthen the call for health professionals to provide early screening and

⁹ American Academy of Pediatrics, Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An algorithm for Developmental Surveillance and Screening. *Pediatrics*. 2006;118: 1:405-420

¹⁰ American Academy of Pediatrics, Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An algorithm for Developmental Surveillance and Screening. *Pediatrics*. 2006;118: 1:405-420

¹¹ See Title V of the Social Security Act (42 USC Chapter 7, Subchapter V 701-710 [1989])

¹² See Individuals With Disabilities Education Improvement Act (IDEA) of 2004 (Pub L No. 108-446)

intervention for children with developmental disabilities. Interventions to address the needs of children diagnosed with ASD should be initiated as early as possible.¹³

Yet there remain barriers to children receiving screening and, as appropriate, a diagnosis. While many parents recognize abnormalities in their child's development prior to 24 months of age,¹⁴ a diagnosis is often not made until much later. Many children diagnosed with ASD in preschool do not meet the full criteria for ASD before age 3 but they may show signs of social communication delays prior to 12-18 months, an age when significant changes to the child's brain and nervous system can be made.

The resources available to help parents at the time of diagnosis may include some of the following depending on the family's income, proximity to service providers and ability to learn about these resources:

- ECI services from DARS for children with a medical diagnosis affecting development including an ASD diagnosis, developmental delays or atypical development
- Texas Health Steps (THSteps) for children on Medicaid or THSteps–Comprehensive Care Program
- Children's Health Insurance Program (CHIP)
- Private health insurance
- TEA services after aging out of ECI at age three
- Mental retardation (MR) community services through DADS-funded community centers

Clearly, the state's intent is to create a seamless continuum of services from a parent's first observation that their child may not be developing typically through diagnosis and treatment. Unfortunately, there is no continuum of services and the services that do exist are inadequate and under funded.

Treatment

There is no single treatment protocol for all children with ASD, but most individuals respond best to highly-structured behavioral programs. The National Institute of Child Health and Human Development¹⁵ lists behavioral therapy, including ABA among the recommended treatment methods for autism spectrum disorders.^{16, 17} Behavior analysis is a scientific approach to understanding behavior and how it is affected by the environment. The science of behavior analysis focuses on principles about how behavior works, or how learning takes place.

Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may be harmful or that interfere with

¹³ Ibid.

¹⁴ De Giacomo A, Fombonne E. Parental recognition of developmental abnormalities in autism. *Eur Child Adolesc Psychiatry*. 1998;7:131-136

¹⁵ See National Institute of Child Health and Human Development website: <http://www.nichd.nih.gov/health/topics/asd.cfm>

¹⁶ Other interventions provided by speech therapists, physical therapists, occupational therapists, registered dietitians and mental health providers often benefit a family with a child with ASD. These therapies are not the focus of this discussion because they are typically reimbursed by Medicaid and private insurance, unlike ABA.

¹⁷ Currently there is not an adequate supply of speech therapists, physical therapists, occupational therapists, registered dietitians and mental health providers who are trained to work with the ASD population in Texas and nationally.

learning. ABA uses those techniques and principles to address socially important problems, and to bring about meaningful behavior change.¹⁸ Today, ABA is widely recognized as a safe and effective treatment for autism. It has been endorsed by a number of state and federal agencies, including the U. S. Surgeon General.

A recent survey in Texas found ABA as the scientifically-based intervention that most professionals are familiar with and find most helpful.¹⁹ ABA and related services are typically provided by psychologists and Board Certified Behavioral Analysts (BCBA). Although the field is relatively young, there are high demands for professionals and there are now six state universities in Texas with accredited BCBA programs. However, ABA services are not readily available in schools or in the health and human services system in Texas.

Texas Medicaid does not cover ABA services. Although these services are often costly, the benefits appear to be significant, both in terms of well-documented individual outcomes, and potential long-term care cost savings.

¹⁸ Glen O. Sallows and Tamlynn D. Graupner. 2005: Intensive Behavioral Treatment for Children With Autism: Four-Year Outcome and Predictors. *American Journal on Mental Retardation*: Vol. 110, No. 6, pp. 417-438. Twenty-four children with autism were randomly assigned to a clinic-directed group, replicating the parameters of the early intensive behavioral treatment developed at UCLA, or to a parent-directed group that received intensive hours but less supervision by equally well-trained supervisors. Outcome after 4 years of treatment, including cognitive, language, adaptive, social, and academic measures, was similar for both groups. After combining groups, we found that 48% of all children showed rapid learning, achieved average post-treatment scores, and at age 7, were succeeding in regular education classrooms. Treatment outcome was best predicted by pretreatment imitation, language, and social responsiveness. These results are consistent with those reported by Lovaas and colleagues (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993).

¹⁹ Burkhart Center for Autism Education and Research, Texas Tech University, 2008: Service Delivery Innovations for Autism Spectrum Disorders in the State of Texas, May 2008. Online <http://www.dads.state.tx.us/autism/servicedeliveryinnovations/service-delivery-innovations-asd-june2008.pdf>

Benefits of Early Diagnosis and Treatment

The use of Early Intensive Behavioral Intervention services would save Texas \$208,500 per child across eighteen years of education, a total savings of \$2.09 billion.

Journal of Child and Family Studies, 2007

A recent study indicated that the State of Texas would save \$208,500 per child across eighteen years of education with Early Intensive Behavioral Intervention (EIBI) services for a total savings of \$2.09 billion.²⁰ Of note is that the authors were using 2002 prevalence data of school age children in Texas. That number has since doubled.

Over forty percent of children with ASD receiving EIBI as prescribed by a qualified professional are indistinguishable from their school peers after the full scope of therapy.

Alternatively, without early diagnosis and treatment a child with autism may require 24/7 services of HCS or CLASS waiver programs. A very conservative estimate of the cost to maintain one child for the rest of their life exceeds \$3 million.²¹

Workgroup Outcomes

As mentioned above, the creation and implementation of a state plan to ensure a continuum of services from early screening to treatment for all Texas children with ASD must be legislatively-mandated if the issue is to receive the attention and sense of urgency that is required.

The state plan workgroup, lead by the Council, should identify gaps in state services delivering early screening, diagnostic and treatment services and develop an actionable plan to maximize existing resources. The group should be composed of consumers and family members, government and private-sector subject matter experts, stakeholder groups and advocates.

Issues the workgroup should consider addressing include:

- ECI is required to provide only diagnostic medical evaluations to determine eligibility for ECI services. Because children who are on the autism spectrum most often qualify for ECI services based on having “atypical development” or “developmental delays,” they may not receive a specific diagnosis of ASD which may delay or limit access to other services the child may require.
- Service coordination for children receiving ECI services ends when the child turns three, which means that there is not a designated case manager to assist the family with identifying and accessing services.
- Independent school districts do not provide service coordination to children transitioning to independent school districts from ECI services. Service coordination is not a requirement of IDEA, Part B; nor is it prohibited. In Texas, only after an Admission, Review and Dismissal (ARD) committee determines that an eligible student needs service coordination in order to receive a free appropriate public education (FAPE) is that service provided by the local school district.

²⁰ G.S. Chasson, G.E. Harris, et. al., *Journal of Child and Family Studies*, Volume 16, p.401-413 (2007).

²¹ This assumes that a child begins receiving CLASS waiver services at age 10, dies at age 70, and costs \$50,000 per year to be maintained in the community. \$50,000 is well below the current annual cap for an individual on CLASS. The cost would increase if this individual lived in a state-run ICF/MR.

- Families without private health insurance and not eligible for Medicaid Texas Health Steps (THSteps) or Children's Health Insurance Program (CHIP) often postpone seeking screening and diagnostic services for their child.
- Medicaid is unable to reimburse Board Certified Behavior Analysts for the treatment of children with autism.
- There is not an adequate supply of speech therapists, physical therapists, occupational therapists, registered dietitians and mental health providers who are trained to work with the ASD population in Texas.

The Council recommends that the workgroup explore the efficacy of the following specific recommendations:

- Utilize Frew v. Hawkins Medicaid lawsuit settlement funds to develop multiple pilot projects evaluating the delivery of behavioral therapy services using a consultative model for Medicaid-eligible children with autism.
- Increase Texas Medicaid reimbursements for developmental screenings and well child care visits.
- Reimburse BCBA's for ABA therapy services through Texas Medicaid.
- Independent school districts should maximize opportunities to utilize behavioral analysts in consultative roles in schools and classrooms.
- Federally Qualified Health Centers and other public clinics should provide the option of ABA and related services to children of all ages in underserved areas.
- All public clinics should incorporate CDC and American Academy of Pediatrics screening, diagnosis and treatment guidelines and focus primarily on young children to ensure behavioral services are provided, as appropriate, shortly after diagnosis.

The statewide coordination of services from screening to diagnosis and treatment for children with ASD is critical. Intensive and early behavioral therapies will complement existing ECI services providing a foundation as the child transitions at age three into local school services.

Without timely treatment many children will lose the hope of a more independent life; without early screening and diagnosis, they will not timely treatment that can truly make a difference.

State Plan Implementation

It is anticipated that the state plan to ensure a continuum of services from early screening to treatment can be completed by December 2009. As its mandate requires, the Council will then present the state plan recommendations to the appropriate state agencies. The Council's governing statute states:²²

On approval of the governing body of the agency, each agency affected by a council recommendation shall implement the recommendation. If an agency does

²² See Texas Human Resources Code, Chapter 114 (Texas Council on Autism and Pervasive Developmental Disorders Act of 1987). Online: <http://tlo2.tlc.state.tx.us/statutes/docs/HR/content/pdf/hr.007.00.000114.00.pdf>

not have sufficient funds to implement a recommendation, the agency shall request funds for that purpose in its next budget proposal.

As each agency's 2012-13 strategic plan and legislative appropriations request s (LAR) are developed, the Council will confer with agency leaders on state plan elements that may require action by the Texas 82nd Legislature. Identified elements requiring legislative consideration will be included in each agency's strategic plan, LAR and in the Council's 2010 Annual Report to be submitted on November 1, 2010.

III: HB 1230 Recommendations

Implement recommendations in the “Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Adult Living.”

As stated in the *Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Adult Living* (created in response to House Bill 1230 80th Legislature, Regular Session, 2007):²³

“The unemployment rates for adults with disabilities are staggering, and far exceed the rates for adults without disabilities. While many adults with disabilities want to work, the supports to find and retain employment are frequently not available. To change this trend, we need to begin by preparing our transition-age youth with disabilities for employment. We can do so by providing them with employment and supported employment services that will help them obtain and maintain meaningful employment in integrated settings, as opposed to the current practice of placing them in sheltered workshops and enclaves.

DADS, DARS, DSHS, Texas Workforce Commission, TEA and the local Independent School Districts are all part of the complex employment support puzzle with little coordination taking place to improve access to services. The fragmented system of employment services and supports for youth with disabilities has created a system in which many individuals and families struggle to identify and access needed services. Additionally, mutually exclusive agency requirements add to the confusion. The many barriers in this system result in significant delays or the total inability to obtain services.”

Until recently, ensuring effective employment services for youth with disabilities who are transitioning to adulthood had not been addressed in Texas state policy. In the 80th Legislative Session, House Bill (H.B.) 1230 was enacted to improve the services provided to Texas youth with disabilities as they transition from school to adult living. H.B. 1230 was based largely on recommendations from an October 2006 report from the Children’s Policy Council.

In the 80th Legislative Session, H.B. 1230 was enacted to improve the services provided to Texas youth with disabilities as they transition from school to adult living. This *Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Adult Living* fulfills the requirements of Section 3 of the bill that directs the establishment of a workgroup to develop a plan to:

- ensure that a youth with a disability who is transitioning into post-school activities, services for adults, or community living has choices about work and career, and the

²³ The text of this section is largely taken from the *Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Adult Living* (As required by House Bill 1230 80th Legislature, Regular Session, 2007), presented to HHSC Executive Commissioner Hawkins, September, 2008.

- opportunity with necessary supports, to seek individualized, competitive employment in the community;
- improve the collaboration between HHS agencies, other state agencies, the community, and local service providers to maximize existing supported employment resources; and
 - increase the quality and quantity of available supported employment services and opportunities.

The workgroup's efforts resulted in five major goals for the delivery of employment/supported employment services to youth with disabilities and recommendations designed to accomplish those goals. The goals address Program Changes, Infrastructure Model Reform, Capacity Building, Outreach and Public Awareness, and TEA Transition Services and Employment Programs.

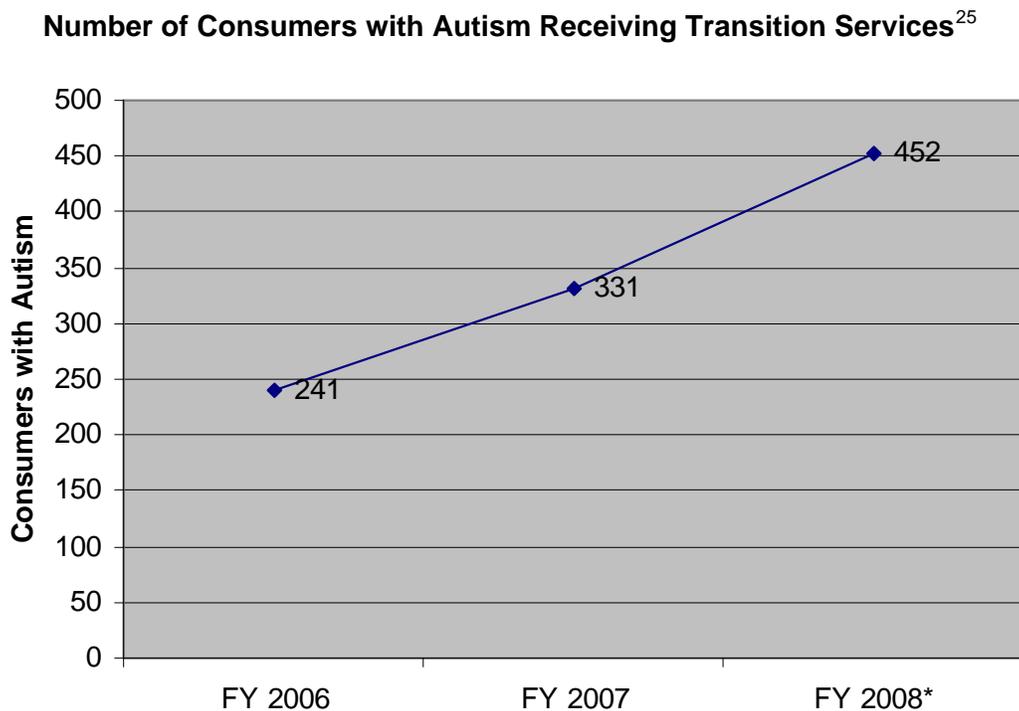
On August 13, 2008, the *Plan for Improving Employment Services for Texas Youth with Disabilities Who are Transitioning to Adult Living* was delivered to HHSC Executive Commissioner Hawkins. HHSC has convened a workgroup of the involved state agencies to inventory individual agency implementation activities and plans, and to develop strategies for those components requiring coordinated implementation. In turn, a report based on HHS agency implementation activities and plans will be submitted to the legislature by January 1, 2009.

The Council urges the 81st Legislature to act decisively in its response to the Executive Commissioner's report to appropriate funds and give direction for creating a seamless, effective transition from school to meaningful work in appropriate settings for all Texas youth with disabilities.

IV: Adult Services Pilot Projects

Invest \$10 million to fund five two-year residential adult services pilot projects to provide comprehensive services to adults with autism.

In June 2008, a query was conducted by DARS to view trends related to consumers with ASD receiving transition services. The graph below shows an 87% increase in the number of those receiving transition services²⁴ from FY 2007 to FY 2008 and clearly demonstrates the need to address the critical shortage of services for adults with ASD in Texas.



* projected using the 3rd quarter service level of 294.

People with ASD must have viable opportunities to live, work and enjoy life in their community through residential options, employment and vocational opportunities, access to medical and other community services, and individual support services. A coordinated system of comprehensive service delivery is needed to ensure that skills gained in school are maintained

²⁴ From 2004 reauthorized Individuals with Disabilities Education Act (IDEA): The term "transition services" means a coordinated set of activities for a child with a disability that 1) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education; vocational education; integrated employment (including supported employment); continuing and adult education; adult services; independent living or community participation; 2) Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and 3) Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives and, when appropriate, acquisition of daily living skills and functional vocational evaluation.

²⁵ June 2008 data collection by DARS Division for Rehabilitation Services (DRS) and Division for Blind Services (DBS).

and enhanced throughout adult life. This is essential for the ever-growing population of adults with autism to be integrated into the workforce and to fully contribute their skills and interests to society.

A best practices study²⁶ written by the Autism Society of Delaware examined nationally recognized programs and found that the behavioral and communication skills attained during K-12 school years deteriorated if these supports were not continued throughout a person's life. This study concluded that successful projects serving adults with autism must include:

- services and activities that are integrated rather than compartmentalized,
- a common philosophy for support and service delivery,
- coordinated and sustained funding and non-fiscal resources
- local program administration rather than distant or hierarchical systems,
- a family centered approach, and
- program and system accountability and evaluations.

A Delaware legislative task force on autism reports:

“Around the country states are becoming more aware of the increasing number of children and young adults with autism and are identifying the issues that this increase in population brings. They are first looking at children’s needs, creating Medicaid waivers for services for children, creating autism registries, promoting early diagnosis and improving early intervention programs. Fewer states have fully addressed the needs of adults, but a handful of states are proposing pilot projects to support adults who do not have accompanying cognitive disabilities with specific supports designed for adults on the spectrum at home, in the workplace and community.”²⁷

In 2007, the New Jersey legislature, for example, funded \$5 million to increase services to people with autism. Of this, \$3 million is to increase services to 62 adults with autism. Other new or expanded programs include increased respite care and family support, an autism registry, and medical services. New Jersey is also considering an Asperger's Pilot Initiative to provide vocational, educational, and social service training to individuals with Asperger's Syndrome. New Jersey has the highest rate of autism in the nation (1 in 95).

The State of Maryland supports a program that is specific to adults with autism, Community Services for Autistic Adults and Children. Services include employment, residential, day habitation programs, individual support, and family support. Approximately 250-300 people are currently being served. Funding sources include: Developmental Disabilities Administration, Maryland State Department of Education, Autism Waiver, and privately paying adults and/or families.

²⁶ Autism Society of Delaware. Best Practices for Serving Adults with Autism: Results of the study on services and supports for adults on the autism spectrum across the United States, Full Research Report (available online: S:\Center for Policy and Innovation\Autism Council\State Plan\2008 Plan\References- Resources-Input\Adult Pilot Program\De_State Plan_Best Practices.htm)

²⁷ Riegel, Kent, Esq., Ellis, Theda, M.B.A., M.Ed., Keyes, Joseph, Ph.D. Summer 2008, Delaware Legislative Task Force Report on Adults With Autism Spectrum Disorders (available online: <http://www.delautism.org/TaskForce.pdf>)

Currently in Texas, eligible adults with autism desiring to live in the community most commonly receive services through CLASS or HCS. Both of these funding sources have very low reimbursement rates and provide limited services. HCS, which has 37,187 people on its interest list and for which the wait time is 8-9 years, requires a diagnosis of mental retardation. Many individuals with ASD are not diagnosed with mental retardation and would not be eligible for HCS services. CLASS does not provide residential services and has a wait time of 7-8 years.

Organizations in Texas providing services under the current reimbursement rate structure simply cannot provide the proven “best practice” services an adult with ASD deserves and needs. Funding for vocational activities is so limited that adults most frequently participate in group activities which have no meaningful relationship to employment. DARS Outcome Based Supported Employment Services is very time limited, making it inappropriate for most adults with ASD. If adults with ASD are to be successfully employed, most will require ongoing support to maintain a job.

A recent survey by the National Association of Residential Providers for Adults with Autism found that adults in nine other states surveyed are funded at an average per person rate that is from \$20,000 to \$50,000 (33% to 83%) **more** than adults receiving services in Texas.

Texas was ranked last, well below Alabama.

Texas adults with ASD deserve options and opportunities to live, work and enjoy life in their community setting which employs standards of best practices. To that end the Council recommends the following options be considered when developing an individualized program for every adult with ASD:

- I. Community Living Options
 - Natural home with support.
 - Community group home (3-4 people)
 - Supported apartments
 - Foster Placements

- II. Employment/ Vocational opportunities
 - Work training sites
 - Supported employment
 - Enclave
 - Competitive employment
 - Volunteer opportunities

- III. Medical and other community options
 - Recreation, social activities, and medical facilities
 - Access community health agencies
 - Access and train to use community transportation
 - Shopping/ religious activities
 - Community colleges

- IV. Individual Service Options
 - Case management
 - Person centered planning
 - Behavior Supports
 - Therapy Services
 - Counseling
 - Employment Opportunities

While Texas does not have a statewide infrastructure of providers to immediately begin serving the thousands of adults with autism requiring tailored community based-services, it does have a network of local non-profit agencies and for-profit providers eager to implement and adapt the best practices now in place in New Jersey, Maryland, Delaware and other states.

The Council recommends that the Legislature invest \$10 million to fund five two-year adult-services pilot residential projects to implement and adapt evidence-based best practices to provide comprehensive services to adults with ASD.

V: DARS Autism Project

Fully fund DARS' legislative appropriations request for continuation of its Autism Project.²⁸

In August of 2007, the Legislative Budget Board, in conjunction with the Governor's Office, instructed the HHSC to transfer \$5 million in general revenue to DARS to fund autism services, such as ABA, for children ages three through eight with ASD.

After a competitive procurement process, four contractors were awarded grants of \$1.25 million to provide services beginning 4/1/08 and ending 8/31/09:

- Child Study Center, in collaboration with the University of North Texas Department of Applied Behavior Analysis, anticipates serving over 80 children at its facility in Fort Worth.
- Easter Seals North Texas, in collaboration with the University of North Texas Department of Applied Behavior Analysis, projects serving 50 children at its facilities in the Oak Cliff and Carrollton.
- MHMRA of Harris County, in collaboration with the University of Houston at Clear Lake, anticipates serving over 140 children and will provide services in western Harris County and in eastern Harris County at the University of Houston at Clear Lake.
- Texana Center will provide services to 40 children at its Behavior Treatment and Training Center Day Treatment Program in Rosenberg.

As of July 31, 2008, seventy-nine children had received services under the grants. The program is intended to complement services outlined in a child's Individualized Education Plan, if a plan exists, and to bill Medicaid, Children's Health Insurance Program (CHIP), private insurance, and any other available third party source before using DARS funding. Current funding will provide for the services through August 2009.

DARS' base legislative appropriations request for the 2010-11 biennium includes continued funding for autism services. The Council recommends full funding and continuation of the DARS Autism Project.

²⁸ DARS Autism Project online information: <http://www.dars.state.tx.us/stakeholders/autism/index.shtml>



Glossary

Autism Spectrum Disorders (ASDs): collective term indicating Autistic Disorder (AD), Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), and Asperger's Disorder (AS) as defined by the American Psychiatric Association's (APA) Diagnostic and Statistical Manual, Fourth Edition (DSM-IV-TR).

Applied Behavior Analysis (ABA): the design, implementation, and evaluation of systematic environmental changes to produce socially significant change in human behavior through skill acquisition and the reduction of problematic behavior. ABA includes direct observation and measurement of behavior and the identification of functional relations between behavior and the environment.

Board Certified Behavior Analyst (BCBA): conducts descriptive and systematic (e.g., analogue) behavioral assessments, including functional analyses, and provides behavior analytic interpretations of the results. The BCBA designs and supervises behavior analytic interventions. The BCBA is able to effectively develop and implement appropriate assessment and intervention methods for use in unfamiliar situations and for a range of cases.

Behavior Plan: a plan designed to modify behavior using evidence-based practices and techniques; it is based on the direct observation and measurement of behavior as well as a functional behavioral assessment.

Developmental delay: the condition in which a child is not developing and/or achieving skills according to the expected time frame.

"Developmental disorder" and "developmental disability:" refer to a childhood mental or physical impairment or combination of mental and physical impairments that result in substantial functional limitations in major life activities.

Evaluation: a complex process aimed at identifying specific developmental disorders that are affecting a child.

Functional Behavioral Assessment and Analysis: the process of identifying the variables that reliably predict and maintain problem behaviors. The functional behavioral assessment and analysis processing typically involves: (1) identifying the problem behavior(s), (2) developing hypotheses about the antecedents and consequences likely to trigger or support the problem behavior, and (3) performing an analysis of the function of the behavior by testing the hypothesis.

Surveillance: the process of recognizing children who may be at risk of developmental delays.

Screening: the use of standardized tools to identify and refine a recognized risk.



Appendices



Appendix A: Texas Council on Autism and PDD Membership

Public Members	
<p><u>Frank Christian McCamant</u> Chair P.O. Box 26921 Austin, TX 78755 Phone: 512- 794-8024 (home) 512- 422-4704 (cell) E-mail: fmccamant@austin.rr.com Represents: Parent/Professional</p>	<p><u>Anna Penn Hundley</u> Vice Chair 6415 Brook Lake Drive Dallas, TX 75248 Phone: 972-644-2076 (work) 972-661-0500 (home) 972-489-0527 (cell) Fax: 972-644-5650 E-mail: Ahundley@ATCoftexas.org Represents: Professional</p>
<p><u>Mike Bernoski</u> 1109 Del Roy Cedar Park, TX 78613 Phone: 817-230-4550 Fax: 888-335-3416 Email: mike@bernoski.net Represents: Parent</p>	<p><u>Mirella "Millie" Garcia</u> 908 Ash Lane El Paso, TX 79925 Phone: 915-449-0628 (work) Fax: 915-975-8295 Email: millie_garcia@sbcglobal.net Represents: Parent</p>
<p><u>Pamela Rollins</u> 6511 Lakewood Blvd Dallas, TX 75214 Phone: 214-821-7655 (home) 214-905-3153 (work) Fax: 214-905-3006 Email: rollins@utdallas.edu Represents: Professional</p>	<p><u>Manny Vela</u> 2101 Pease St., Suite 501 Harlingen, TX 78550 Phone: 956-389-4028 Fax: 956-389-1129 E-mail: Manuel.vela@valleybaptist.net Represents: Parent/Professional</p>
<p><u>Stephanie Sokolosky</u> P.O. Box 93367 Lubbock, TX 79493 Phone: 806-368-5242 (home) Email: stephanie.sokolosky@ttu.edu Represents: Professional</p>	

State Agency Members	
<p style="text-align: center;">Bobby Alexander 701 W. 51st St. Austin, TX 78751 Phone: 512-438-5421 (work) Email: bobby.alexander@dfps.state.tx.us Represents: Department of Family Protective Services</p>	<p style="text-align: center;">Terry Beattie 4900 North Lamar Blvd. Austin, TX 78751-2399 Phone: 512- 424-6528 (work) E-mail: Terry.Beattie@hhsc.state.tx.us Represents: Health and Human Services Commission (HHSC)</p>
<p style="text-align: center;">Donna Elmore 1100 West 49th St. Austin, TX 78756-3199 Phone: 512- 458-7111, Ext. 3060 (work) E-mail: donna.elmore@dshs.state.tx.us Represents: Department of State Health Services (DSHS)</p>	<p style="text-align: center;">Debra Emerson 701 W. 51st St. Austin, TX 78751 Phone: 512- 438-4760 (work) E-mail: Debra.Emerson@dfps.state.tx.us Represents: Department of Family and Protective Services (DFPS)</p>
<p style="text-align: center;">Don Henderson 701 W. 51st St. Austin, TX 78751 Phone: 512- 438-4507 (work) E-mail: Don.Henderson@dads.state.tx.us Represents: Texas Department of Aging and Disability Services</p>	<p style="text-align: center;">Barbara Kaatz 1701 Congress Ave. Austin, TX 78701-1494 Phone: 512-463-9241 Fax: 512-463-9560 E-mail: Barbara.Kaatz@tea.state.tx.us Represents: Texas Education Agency (TEA)</p>
<p style="text-align: center;">Marc Mullins 4900 N. Lamar Blvd. Austin, TX 78751-2399 Phone: 512-377-0717 (work) E-mail: marc.mullins@dars.state.tx.us Represents: Department of Assistive and Rehabilitative Services (DARS)</p>	

Regional Advisory Committee Chairs

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<p>HOUSTON</p> <p>Cynthia Singleton 3103 Garrow St. Houston, TX 77003 Phone: 832-615-6053 E-mail: houstonchair@kadenastrategies.com</p>	<p>LUBBOCK</p> <p>David Jenkins 5809 3rd St., Apt. 304 Lubbock, TX 79416 Phone: 806-438-1276 E-mail: David.Jenkins@esc17.net</p>

<p style="text-align: center;">PANHANDLE</p> <p style="text-align: center;">Ed Hammer, Ph.D. 3905 Huntington Drive Amarillo, TX 79109 Phone: 806-353-1114 E-mail: Ed1hammer@nts-online.net</p> <p style="text-align: center;">26 Counties of the Texas Panhandle Main Cities: Amarillo, Pampa, Dumas, Borger, Perryton, Dalhart, Canyon, and Childress</p>	<p style="text-align: center;">RIO GRANDE VALLEY</p> <p style="text-align: center;">Dagoberto Garza 2520 South I Road Edinburg, Texas 78535 Phone: 956-627-0458 Fax: 956-316-8338 E-mail: dago.garza@hhsc.state.tx.us</p>
<p style="text-align: center;">SAN ANTONIO</p> <p style="text-align: center;">Theresa Diaz 6914 Forest Park San Antonio, TX 78240 Phone: 210-256-6698 Fax: 210-567-7823; Attn: Theresa E-mail: autismtdiaz@hotmail.com</p>	<p style="text-align: center;">WACO</p> <p style="text-align: center;">Anita Karney 9101 Wolf Creek Waco, TX 76712 Phone: 254-666-8846 214-766-3260 (cell) E-mail: akarney@swbell.net akarney@hotmail.com</p> <p style="text-align: center;">McLennan, Bosque, Hamilton, Lampasas, Coryell, Bell, Falls, and Limestone counties</p>

Appendix B: FY 2008 Texas Council on Autism Public Meetings

Council Public Hearings and Quarterly Meeting Locations

- September 8, 2007 -Corpus Christi
- November 7, 2007- Austin
- December 12, 2007-Austin
- January 24, 2008-Houston
- April 1-2, 2008-Lubbock
- May 6-7, 2008- Harlingen
- June 10, 2008-Austin
- July 1, 2008-Austin
- August 5, 2008-Austin

These meetings have included documented attendance of over 50 self-advocates, parents, consumers and direct care providers, and the participation from 44 representatives of the following organizations:

1. Parents of Autistic Children of Texas;
2. Partners Resource Network;
3. Center for Autism;
4. Texas Center for Disability Studies;
5. Autism Society of Greater San Antonio;
6. Children Policy Council;
7. MHMRA, Harris County;
8. University of Texas Health Science Medical School of Houston;
9. University of Texas Medical School at Houston;
10. Avondale House, Houston;
11. Texas Tech University to Burkhart Center, Lubbock, TX;
12. ECI DEBT;
13. MHMR Tarrant County;
14. ESC 17;
15. Lubbock MHMR;
16. Greater Dallas League of Women Voters Women's Council HHS Coordinator;
17. Autism Council of Educational Support and Scientific Studies
18. Harlingen Consolidated Independent School District;
19. San Benito Consolidated Independent School District;
20. Tropical Texas Behavioral Health;

Since September 1, 2007 Anna Hundley (Council Vice Chair) has given 14 presentations to approximately 8850 audience members. She has participated in 3 documentary and Discovery Channel film productions, and is scheduled to speak over the summer at conferences with large audiences.

Appendix C: DADS Interest Lists

The below information is excerpted from a document presented by DADS House Select Committee on Services for Individuals Eligible for Intermediate Care Facility Services on August 22, 2008

Interest Lists

- Demand typically outweighs the availability of community services, so names of interested individuals are placed on interest lists and are assessed on a first-come, first-served basis
- When an individual comes to the top of a list, the eligibility determination process begins
- While on an interest list, many individuals' needs may be met through other programs
- Service levels are impacted by federal appropriations and funding appropriated by the Legislature
- The 80th Texas Legislature appropriated \$71.5 million General Revenue and \$167.3 million All Funds for expansion of the Medicaid waiver and non-Medicaid community services programs at DADS. With the additional authorized funding, we anticipate serving an additional 8,902 persons during the 08-09 biennium:
 - Community Based Alternatives (CBA) – 1,607
 - Community Living Assistance and Support Services Program (CLASS) – 586
 - Home and Community Services (HCS) – 2,676
 - Medically Dependent Children's Program (MDCP) – 415
 - Deaf-Blind with Multiple Disabilities Waiver Program DBMD – 16
 - Non-Medicaid – 2,228
 - In-Home Family Support (IHFS) – 1,374

CBA

Number Currently Served	21,050
Number on Interest List	29,316
Longest Time on Interest List 2-3 years	

ICM 1915 (c) Waiver

Number Currently Served	2,540
Number on Interest List	263*
Longest Time on Interest List 1-2 years	

CLASS

Number Currently Served	3,929
Number on Interest List	21,496
Longest Time on Interest List 7-8 years	

DBMD

Number Currently Served	153
Number on Interest List	28
Longest Time on Interest List 1-2 years	

MDCP

Number Currently Served	2,541
Number on Interest List	9,920
Longest Time on Interest List 2-3 years	

HCS

Number Currently Served	13,889
Number on Interest List	37,187
Longest Time on Interest List 8-9 years	

STAR+PLUS 1915 (c) Waiver

Number Currently Served	3,425
Number on Interest List	2,916*
Longest Time on Interest List 2-3 years	

TOTAL

Number Currently Served	47,527
Number on Interest List	100,335**
Longest Time on Interest List N/A	

These counts reflect data as of June 30, 2008.

* Individuals who are not SSI eligible and who want 1915(c) CBA-like waiver services are on an interest list. This interest list is managed by DADS and the numbers above reflect those non-SSI individuals on the interest list whose eligibility has not yet been determined.

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

Appendix D: DARS Texas Early Childhood Intervention Dissemination of CDC Materials

June 2008

Texas Early Childhood Intervention Dissemination of CDC Materials for Autism Spectrum Disorders (ASDs)

Texas ECI is pursuing multiple avenues to share pertinent information on the early signs of autism developed by the Centers for Disease Control and Prevention (CDC). By targeting the primary referral sources for ECI services including physicians, allied health professionals and child care providers we can capture the attention of a broad array of professionals that intersect with families with infants and toddlers. To further expand this network we are disseminating this information to the ECI provider community and guiding them on local distribution opportunities.

The following represents current and planned activities:

CDC 'Learn the Signs. Act Early.' Fact Sheet & Campaign Materials

a.) Primary Referral Sources & families:

- Fact Sheet to be distributed at the ECI exhibit at statewide conferences scheduled throughout the year for allied health professionals, family practice & pediatric physicians, nurses, child care providers, parent/family organizations, foster care families, state conference on autism, and other related organizations. See attached list of conferences for remainder of 2008.
- ECI Developmental Check List Brochure identifies developmental milestones including social-emotional.
 - Brochure is available on website.
 - Brochure is broadly disseminated by service providers to parents, primary referral sources and general public.
 - Brochure is currently being revised and will include additional milestones from CDC.
- Will include information in 'ASK ECI' column in Texas Child Care Quarterly.

b.) ECI Providers

- CDC Fact Sheet on ASDs along with information to access the CDC Campaign materials will be disseminated to ECI providers.
- Provide information on CDC Campaign materials at the October meeting of all ECI Program Directors.
- Include CDC Campaign materials as a resource for ECI training on Autism Spectrum Disorders by ECI trainers.
- Provide information on CDC Campaign materials in Child Find Bulletin, a quarterly publication to all Child Find Coordinators in Texas.

c.) ECI 'Library Matters' a statewide HHSC resource available to professionals and Texas residents.

- Provides journal, research and informational materials, including autism.
- ECI Providers can request a topic search from the Librarian.
- Texas ECI works with the Librarians to develop the 'Library in a Box' which is provided to the provider network. This is a collection of library resources on specified topics. Texas ECI will develop a 'Library in a Box' utilizing the CDC materials on autism.
 - The CDC Campaign materials were ordered by Texas ECI a month ago and have not been received. It takes 4-6 weeks for delivery.

d.) ECI Website – Information available

- ECI Developmental Brochure Checklist
- ECI 'Library Matters'
- Link to CDC Campaign materials (to be added)

Appendix E: Texana Center Day Habilitation Programs

Texana Center delivers day habilitation services for six counties in South East Texas. The following is a synopsis of a model program developed and implemented for all Texans with disabilities.

Summary

Communication and development of relationships with the families and communities we serve is crucial to our success. Also critical to our success is the use of the principles of applied behavior analysis as the basis for teaching skills and the use of board certified behavior analysts to train staff and shape our service environments. Our partnerships with local ARCs and Parent Advisory Committees provide additional support to our day habilitation centers and allow us to continue to develop new programs and activities. We promote buy-in with our staff by asking for their input in developing programs and providing skill building trainings.

Program Philosophy

Texana's day habilitation programs are designed to promote independence of the individuals we serve. We provide a full-day program that offers our individuals a variety of activities in a safe setting while giving the family unit a break. The goal of our program is to move our individuals towards independence in the areas of personal, home, community and employment skills. We encourage parent participation and have several successful parent groups that advocate for us and provide much needed additional support in developing programs. We develop our staff through targeted training that gives them the skills needed to be effective in their job.

Our training model is based on the Science of Behavior Analysis. Utilizing behavioral teaching techniques we can ensure our individuals make progress on their objectives within a reasonable time frame. We have set standards for the number of teaching trials completed, the use of positive reinforcement and accurate data collection. The core of our program is on identifying functional training objectives that will have a great impact on the individual's life. We focus on developing independence within the wide range of abilities we serve. While the science of applied behavior analysis has been prominent in the world of Autism, it has an equal impact on individuals with other disabilities such as downs syndrome, cerebral palsy, mental retardation and dual diagnoses. Our training model has proven to be highly effective with all individuals we serve.

Additional programs offered throughout the day were developed through a series of surveys delivered to our individuals, their families and our staff. With this broad array of input we were able to identify programs that are of interest to those we serve as well as valued by the families and staff. Examples of additional programs include: exercise, computer, vocational, social and enrichment.

Structure-

Our seven day habilitation centers are integrated into the communities we serve and range from 25 to 90 individuals. Below is a summary of some key positions in our centers.

Center Manager: Oversees the daily operations of the center ensuring compliance with all standards & regulations. Center managers are responsible for hiring & managing of staff as well as promoting buy-in of our mission to provide quality day habilitation services.

Board Certified Behavior Analysts: Officed in our Day Habilitation Centers, the BCBA assesses & manages problem behavior. The BCBA provides technical support in using behavioral techniques and staff training on a day to day basis. This has a great impact on the overall running of the centers. The BCBAs have been a driving force in the progress made at the centers.

Training Specialist: A key player in the implementation of our training programs. With special training from behavior analysts, our training specialists have the skills to assess our individuals and pinpoint functional training objectives. They write training objectives, train staff & families, monitor implementation of programs and make needed modifications.

Voc/Hab Trainer: Recognized as the movers in our day programs. Our staff strive to be positive role models for our individuals. They implement training programs, take data and develop the additional programs with support from the center managers. They act as coaches to our individuals following a prompting sequence that facilitates progress on training objectives.

Job Coach: Works with individuals utilizing our supported employment services. Job coaches provide the needed training & support to individuals working in community jobs. They develop relationships in the community and open up new opportunities for future employment.

Appendix F: Statewide Initiative for Autism Training

ESC XIII provides the leadership for the Statewide Initiative for Autism Training in public schools across the state of Texas. Region XIII and the Texas Education Agency created and implemented a plan regarding autism during 2007-08, and have approved a new plan for the 2008-09 school year. This short report covers the plans for both years.

The current plan calls for the development of a Recommended Practices Manual for Students with Autism in Texas. The manual will provide information about assessment and intervention to help guide the evaluation and program issues in the public school system. Dr. Brenda Smith Myles of the University of Kansas has been contracted to provide the manual. Prior to publication two groups will formally review the draft product. Members of the first group are the designated autism contacts from the 20 ESCs across the state. The second group will be comprised of parents and educators from across the state. Results of feedback from the two groups will be incorporated into the final draft which is due in November 2008. The manual is scheduled to be online in December 2008. The plan calls for updating the manual on an annual basis through contract with a university program charged with reviewing evidence-based practices and research produced within the scholastic year. The results will be incorporated into the manual.

The second element of the plan outlines the development of statewide training resources. The intent is to provide training information that is consistent, easy to access, and available when needed. The twenty autism contacts at the ESCs have identified seven core training topics that should be provided to all persons interested in autism in Texas: Autism 101, Asperger's Syndrome 101, Classroom Organization, Communication Issues in ASD, Behavior Issues in ASD, Socialization Issues in ASD, and Futures Planning. Each topic will be available as a Training of Trainers program to the twenty ESC contacts for face-to-face presentations as regional need dictates. In addition, the first six training modules will be available as an online training through the ESC at the learner's convenience. At this time, the training is for Texas educators, parents of children with autism, and service providers in Texas who serve students with autism spectrum disorders. All training will be offered in both Spanish and English versions by the end of the 2008-09 school year. The first module, Autism 101 should be online in English in September 2008. ESC autism contacts can provide additional information on availability and access.

The third component of the plan is the development of a website to facilitate access to information and resources related to autism. The website is open and under development at www.txautism.net. The site will provide access to information about training provided at various ESCs, the Recommended Practices Manual, a toolbox for educators, and connections to other resources for individuals with autism, educators, parents and agencies.

The fourth piece of the plan involves collaboration with other agencies which includes the Texas State Conference on Autism, statewide groups established in the various ESCs, the Texas Council on Autism and Pervasive Developmental Disorders, and the Texas ACT Early Group. This collaboration will be supportive and varied, ranging from direct participation to sharing of information, and will vary according to changing needs and requests.

The Texas State Conference on Autism is planned and hosted by ESC, Region 2 in Corpus Christi. This project will work closely with the conference project as yet another venue for

training and information dissemination to parents and educators directly affected by Autism Spectrum Disorders.

Collaboration with the Texas Council on Autism and Pervasive Developmental Disorders involves information sharing to assure development of services that are consistent and effective for all individuals directly affected by ASD. The Council identifies and monitors apparent gaps in services currently available from various state agencies for persons with autism or other pervasive developmental disorders and advocates improvements on behalf of those persons. In addition, the Council advises the legislature on legislation that is needed to develop further and to maintain a statewide system of quality intervention and treatment services for all persons with autism or other pervasive developmental disorders. While our direct connection to the Council is for educational purposes, we recognize the need for collaboration to foster effective and consistent services of all kinds for Texans.

A major initiative springing from the Texas ACT Early Group was the application to the National Professional Development Center on Autism Spectrum Disorders. This program is designed to support statewide efforts to develop evidence-based services for students with autism, with a focus on early detection and services. The grant application proposed the development of 9 model sites around the state to focus on evidence-based practices in Preschool Programs for Children with Disabilities programs, elementary school programs, and secondary programs with strong ties to agency services available to the model site. While Texas' application was not accepted for the national grant, the Region XIII/TEA plan calls for the proposed elements of the grant that were the responsibility of the Texas Education Agency to be implemented, including the selection of the model sites that represent the three levels of service along with geographic and population diversity as well. This multi-year project should result in a model site relatively near to most Texans. The intent of the project is that all Texans will have virtual access to programs in some form as well. The first year (2008-2009) involves developing guidelines for model site selection and development, along with intensive training for the model site teams. The proposed second year (2009-2010) will see the development of the sites with direct support from various ESCs and the third year (2010-2011) will begin the dissemination phase of the project.

Collaboration with the other ESC statewide groups, such as the Statewide High School/Transition Leadership at Region 11, meets the need to provide consistent information related to education in Texas. Students with Autism Spectrum Disorders are found in every educational setting in the state. Students with autism may be found in instructional settings from self contained classrooms to Advanced Placement classes. The elements of this statewide autism project are designed to provide useful and needed information to parents, students, educators, and other interested and affected Texans.

