

STATE OF TEXAS
DEPARTMENT OF AGING AND DISABILITY SERVICES

STUDY ON THE COSTS AND BENEFITS
OF INITIATING A PILOT PROJECT TO PROVIDE SERVICES
TO ADULTS WITH AUTISM SPECTRUM DISORDERS AND
RELATED DISABILITIES

AS MANDATED BY HB 1574

PREPARED BY:

BURNS & ASSOCIATES, INC.
3030 NORTH THIRD STREET
PHOENIX, ARIZONA 85012

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EXECUTIVE SUMMARY

Last year, 4,300 adults with autism spectrum disorders (ASD) received services from the Department of Aging and Disability Services (DADS), the Health and Human Services Commission (HHSC), and/ or the Department of Assistive and Rehabilitative Services (DARS). An estimated 4,000 adults with ASDs have requested DADS services, but have been placed on an interest list due to a lack of funding. Nearly half of these 8,300 adults either receiving services or on an interest list are between 18 and 25 years of age. The costs of providing supports to these individuals will only increase as they, and their caregivers, age. The decisions that Texas makes in response to the unmet demand for services, the aging of the population, and increasing diagnoses of autism will have significant human and financial consequences.

To address the wave of children with ASD who will become adults in the coming years, the 81st Texas Legislature passed H.B. 1574, which was signed into law by Governor Rick Perry in May 2009. The legislation mandated a study to determine the costs and benefits of a pilot program to provide services to adults with ASD and related disabilities. Pursuant to that requirement, DADS contracted with Burns & Associates, Inc. (B&A) to provide recommendations on options for pilot programs.

To aid in the development of options to meet the needs of adults with ASDs in Texas, B&A researched best practices across the country. Drawing from findings from task forces in other states, service evaluations, and advocacy group reports, several best practices emerged, including:

- the need for services specifically designed to meet the needs of individuals with ASDs including training programs and outreach campaigns;
- a team-based, person-centered planning process that focuses on the individuals' strengths, interests, and goals to develop seamless service plans;
- a resource clearinghouse that provides a one-stop shop for families seeking information;
- a continuum of services that reflect the varied needs of individuals across the autism spectrum;
- early and comprehensive transition planning to prepare young adults for life after high school;

- a behavioral plan that is implemented across the consumer's range of services; and,
- employment supports that maximize individual's abilities.

B&A also inventoried existing programs that provide services to adults with ASDs and related disabilities in Texas, which include:

- special education services delivered through the State's 1,700 high schools;
- vocational rehabilitation supports provided by DARS;
- home and community-based service waiver programs operated by DADS;
- health care services through HHSC; and,
- other programs that provide housing, workforce, and other supports.

To evaluate the effectiveness of existing programs, B&A engaged consumers, parents, providers, and other stakeholders across the State through telephone interviews, in-person focus groups, site visits, and online surveys. In total, more than 200 individuals shared their perspective on existing services, unmet needs, and potential solutions. Service claim data from DADS, DARS, and HHSC were also analyzed. Combining these quantitative and qualitative analyses and comparing the data to the identified best practices, several gaps in Texas' existing systems of supports for adults with ASDs were identified. These include:

- Insufficient resources result in individuals being unable to access services. More than 78,000 individuals are currently on interest lists for DADS' waiver services including an estimated 4,000 adults with ASDs. Without supports, families report that young adults regress and lose gains they made in school, are less likely to sustain employment, and are less engaged in their communities.
- Services are not designed for adults with ASDs. For example, services lack behavioral components that are critical to individuals with ASDs, day habilitation programs provide "baby-sitting" rather than meaningful activities, and jobs in which consumers are placed are beneath their abilities.
- The existing system is fragmented. Unlike in school when services for children with disabilities are primarily the responsibility of their school, responsibility for providing services to adults with ASDs is spread across multiple state agencies, local authorities, and

contracted providers. This can overwhelm families and result in consumers not receiving services they need.

- Employment outcomes are poor. Adults with ASDs are chronically unemployed, having difficulty in both obtaining and retaining a job.

Despite these gaps, Texas stakeholders identified several positive features in the existing systems of supports for adults with ASDs including, adoption of strategies to promote self-determination, a large group of committed and knowledgeable parents, and a number of excellent providers across the State.

B&A has designed three pilot programs that aim to build on these strengths and incorporate best practices from across the country to address the identified gaps. In particular, the pilot options incorporate DADS' person-centered planning principles. Although the pilots have different structures and goals, each provides a framework within which individual service and behavioral plans are customized for every consumer according to his/ her strengths, interests, and goals.

The first pilot – Specialized Support Coordination and Community Connections – is designed primarily to address system fragmentation and the lack of ASD expertise among case managers and providers. This pilot establishes a foundation of several core elements that would be incorporated in the other pilot options. The first option includes specialized support coordinators who are specifically trained in working with individuals with ASDs; are experts in community, state, and federal benefits; and carry an ASD-only caseload. A total of 210 consumers at three sites would be enrolled. Complementing specialized support coordination, participants would receive peer support from caregivers of adults with ASDs who have experience in navigating existing systems of support. This pilot option also includes a \$2.0 million pool of matching funds to create and expand local service capacity. Over two years this option would require \$4.6 million in total funding, including \$4.4 million in general revenue funds.

The second pilot would establish a full ASD-appropriate continuum of home and community-based services, from in-home supports through independent living and residential alternatives. This option is envisioned as a traditional comprehensive Medicaid waiver program that

incorporates elements of DADS' existing waiver programs as well as the specialized support coordination and peer support from the first option and adds or expands services to meet the needs of adults with ASDs, such as more residential options, greater employment services, and expanded behavioral supports. The pilot would be operated at 3 sites with 100 consumers each. Particular care would be given to ensuring that individuals across the spectrum are enrolled, from high-functioning individuals that currently receive few services to severely disabled consumers with co-occurring intellectual disabilities for whom there is an over reliance on institutional care. The estimated cost of this option is \$34.9 million over two years, including \$14.25 million in general revenue funding.

The third pilot option – Transition and Employment Centers – would move away from the traditional service delivery model based on a network of contracted providers. Rather, it would establish center-based programs responsible for coordinating care for adults with ASDs. This option, also operated under a Medicaid waiver, would emphasize strategies to address deficiencies associated with post high school transition planning and employment outcomes. The centers would provide life-skills training to adults with ASDs so that they can successfully transition to the community. To improve employment opportunities, the centers would utilize an innovative model that has been used elsewhere in the country and internationally in which specialized work is in-sourced following a consulting firm model. Out-of-center employment placements and other more traditional services would also be coordinated by the centers. All services would be geared towards improving consumers' ability to be successful within the community. The pilot would include three centers with 50 consumers each, costing \$22.1 million over the two-year duration of the project, including \$11.05 million in general revenue funds.

Each of the pilots will be operated by a contract provider and start-up activities will require between six and 24 months. Financial considerations and the need to carefully evaluate the programs require that each be limited initially to only a few geographic areas. Each pilot is then proposed to last for two years, during which the outcomes of the projects will be evaluated and reported to the Legislature. If demonstrated to be effective, each pilot program has the potential to be expanded incrementally as resources become available. Considering procurement and

start-up timelines and the two-year evaluation period, there is likely to be only limited data available for the legislative session beginning in January 2013. More comprehensive outcome data will be available for the session beginning in 2015.

After exploring funding possibilities, B&A concluded that a new Medicaid Section 1115 research and demonstration waiver would be the best option for the second and third pilots. To provide matching state funds, it is suggested that the State explore an expansion of the private insurance autism mandate to generate Medicaid savings as well as opportunities to shift some existing general revenue-only services provided through the local MR authorities to Medicaid.

The number of adults with ASDs is only going to increase in the coming years. This report provides options through which the State can prepare for this wave and assist its residents with ASDs in achieving their potential.

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Options for Pilot Programs for Adults with Autism Spectrum Disorders and Related Disabilities

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SECTION 1: INTRODUCTION

H.B. 1574, (81st Texas Legislature, Regular Session, 2009) signed into law by Governor Rick Perry in May 2009, requires the Health and Human Services Commission (HHSC) to conduct a study to determine the costs and benefits of a pilot program to provide services to adults with autism spectrum disorders (ASD) and related disabilities. HB 1574 outlines several elements to be included in a pilot program, including:

- specialized supports coordination and vocational assessment, training, and support to encourage sustainable employment and community integration;
- meaningful community-based activities for individuals for whom competitive employment is not a goal;
- promotion of individual development, self-determination, and independence;
- coordination of services and behavioral supports across all areas of need; and,
- flexible funding and a flexible array of services to meet individual needs.

In addition to these requirements, HB 1574 also outlines the process to conduct the study, including researching best practices from other states, consulting with key stakeholders, identifying gaps and barriers, and describing potential federal sources of funding. Appendix D specifies these requirements and notes how they are incorporated in this report.

As the state agency primarily responsible for delivering services to individuals with developmental disabilities including ASDs, the Department of Aging and Disability Services (DADS) was tasked with coordinating this project. DADS subsequently awarded a contract to Burns & Associates, Inc. (B&A) to provide recommendations on options for pilot programs.

Study Methodology

B&A sought to gather information from a wide variety of resources, both within and outside of Texas. Within the State, B&A spoke with or received comments from more than 200 consumers, parents, providers, and other stakeholders; analyzed claims data from DADS, HHSC, and the Department of Assistive and Rehabilitative Services (DARS); received information from the Texas Education Agency, Texas Workforce Commission, and Texas Department of Housing and

Community Affairs; and reviewed guidelines, manuals, and other materials relating to existing services.

Multiple strategies were employed to encourage consumers, parents, providers, and other stakeholders in the State to provide input regarding their perceptions of existing services for adults with ASDs, identify gaps in the system, and solicit suggestions for potential pilot programs. These efforts included focus groups with parents held in Austin and Houston, a provider focus group in Houston, and a mixed focus group (parents and providers) in El Paso. B&A conducted onsite visits with four local MR authorities as well as an onsite visit to a group home and day program provider. Additionally, B&A conducted dozens of one-on-one telephone interviews with consumers, parents, providers, and advocates. Two electronic surveys were also created. The first was sent to the local MR authorities; 21 of 39 responded. The second was an online survey, available in both English and Spanish, which could be completed by anyone with an interest in the project. The link for this survey was sent to a number of groups across the State with a request that they forward it to their membership. A total of 160 useable responses were received.

Overall, input was received from a diverse group of stakeholders, including consumers and caregivers, providers, community advocates, and state agency staff. Feedback was received from each of the State's 11 health and human services geographic regions (see Appendix C for a map). References in this report to stakeholder input refer to those individuals who shared their opinions and suggestions through any of the forums cited above.

After a preliminary assessment of the existing state of services for adults with an ASD in Texas, B&A researched national trends. External sources were evaluated to identify potential best practices and models that could be emulated in the state. Specifically, B&A reviewed research literature, reports authored by autism task forces established in other states, and programs providing services to adults with ASDs in other states.

Structure of This Report

Following this introduction, the report is divided into six parts.

- *Background on Autism Spectrum Disorders* provides an overview of the characteristics of ASDs, a historical perspective on incidence rates, and information about the number of Texas residents with ASDs receiving services.
- *Best Practices in Systems and Services* discusses select reports from autism task forces in other states as well as published evaluations of services for adults with ASDs, and outlines the best practices and recommendations found in these sources. Appendix B provides brief overviews of programs operating in three states – Pennsylvania, Connecticut, and Arizona – and how these programs address barriers and incorporate best practices.
- *Programs Currently Providing Services to Adults with ASDs* summarizes the roles that various Texas state agencies have in delivering services to this population.
- *Gap Analysis* identifies deficiencies in the existing systems of supports for adults with ASDs in Texas based on a review of program materials and claims data, stakeholder input, and comparisons to the best practices previously identified.
- *Pilot Programs* suggests possible initiatives to mitigate or eliminate services gaps based on best practices and programs found across the country and outlines the elements that would be common to all of the pilots as well as those specific to each. Appendix A provides a table that further details, compares, and contrasts the three options.
- *Possible Funding Opportunities* highlights potential sources of federal and state funding to support the pilot programs.

Acknowledgements

Burns & Associates thanks all those who assisted in this study and worked diligently to provide background information and requested data, including representatives from the Health and Human Services Commission, the Department of Aging and Disability Services, the Department of Assistive and Rehabilitative Services, and the Texas Education Agency. The professionalism and commitment to this project shown by agency staff will serve Texas well in the implementation of any pilot program.

B&A also acknowledges the consumers, family members, and service providers who helped shape this report by sharing their opinions, experiences, and recommendations for pilot programs to serve adults with autism spectrum disorders. Their collective dedication to systems improvement is an inspiration.

SECTION 2: BACKGROUND ON AUTISM SPECTRUM DISORDERS

Characteristics of Autism Spectrum Disorders

The term autism spectrum disorder (ASD) currently includes five distinct pervasive developmental disorder diagnoses: autistic disorder, Asperger's Syndrome, Rett's Syndrome, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS). Persons with an ASD diagnosis present with core symptoms in three areas:

- social interactions and relationships, symptoms of which may include significant difficulty developing nonverbal communication skills such as eye contact and facial expressions, lack of seeking to share enjoyment and interests with others, and difficulty establishing friendships;
- verbal and nonverbal communication, symptoms of which may include deficits in the comprehension and/ or use of language, presence of stereotyped and repetitive language, and difficulty initiating, joining, maintaining and closing a conversation; and,
- limited interests in activities or play, symptoms of which may include focus on parts of an object rather than the whole object and how it is meant to be used, an apparent need for preservation of sameness and routine, a preoccupation with topics, and stereotyped motor behaviors (e.g., hand-flapping, body rocking).

A number of other clinical conditions can co-occur with the diagnosis of ASD. It is estimated that between 25 and 70 percent of persons with ASDs have mental retardation. This wide range underscores the difficulty in assessing intelligence in persons with autism. Anxiety disorders and epilepsy are also relatively common among individuals with ASDs.

For the purposes of the data analysis included in this report, ASD and related disorders are defined as the following International Classification of Diseases (ICD) diagnosis codes:

- 299.0 – autistic disorder;
- 299.1 – childhood disintegrative disorder;
- 299.8 – other specified pervasive developmental disorders;
- 299.9 – other specified developmental disorders; and

- 315.9 – unspecified delay in development.

H.B. 1574 requires that the pilots developed through this project target adults with related disabilities with similar support needs. Due to this requirement, the pilot options will not rely only on a diagnosis for participants and instead will include a functional behavioral assessment that can identify adults with similar support needs.

Incidence

According to the federal Centers for Disease Control and Prevention (CDC), between 1 in 80 and 1 in 240 children, with an average of 1 in 110, meet the criteria for an ASD diagnosis.

Diagnoses are made across racial, ethnic, and socioeconomic groups but males are four-to-five times more likely to be diagnosed than females.

The estimated incidence of ASDs has increased steadily since the 1970s and 1980s when it was believed to be 1 in 10,000. The CDC has identified a number of factors that may account for the increase, including greater community awareness, earlier identification, increased availability of developmental disability services, and broadened diagnostic criteria that include milder cases.

The increase in autism diagnoses remains a topic of controversy. At issue is whether actual prevalence has increased (and, if so, why) or whether the increase in cases can be fully explained by the factors listed above.

There has been comparatively little research conducted regarding the prevalence of ASDs in the adult population. A recent study conducted in the United Kingdom and published in September 2009 concluded that autism is as common in the adult population as it is in children.¹

Specifically, the study found that roughly one out of 100 adults are on the spectrum of autism, the same rate reported in children. If accepted, this study contradicts the notion that the incidence of autism has increased since the 1980s because the study found no significant differences in the prevalence of autism in adults surveyed in their 20s through 70s. It has been noted that the study had a relatively small sample size. Additionally, this study has yet to be

¹http://www.ic.nhs.uk/webfiles/publications/mental%20health/mental%20health%20surveys/APMS_Autism_report_standard_20_OCT_09.pdf

replicated since it was only recently published. As with children, the prevalence of autism in adults remains far from settled.

There are no reliable national estimates of the prevalence of ASDs among adults and very few state-level estimates. The state data that are available rely on caseloads from developmental disabilities programs and, at times, projections based on special education counts. Since services for adults with an ASD are generally not an entitlement and because some adults with an ASD may be able to function without services, such estimates likely undercount the actual prevalence of autism within the states. None come close to approaching one percent, but these estimates do provide useful benchmarks regarding the demand for services.

Surveying existing state programs for individuals with ASD and other intellectual and developmental disabilities, Arizona stands out as one of the few without waiting lists (Arizona's program is discussed in greater detail later in Appendix B). Since Arizona does not utilize waiting lists, the caseload should closely reflect the demand for services among those individuals meeting the eligibility criteria. As of July 2010, there were 1,157 adults with an ASD diagnosis receiving services (125 of whom were receiving state-only funded services). This represents 0.024 percent (*24 thousandths* of one percent) of Arizona's estimated adult population of 4.86 million.

The Delaware Legislative Task Force Report on Adults with Autism Spectrum Disorders reviewed service numbers to determine the number of adults with an ASD. In its 2008 report, the report's authors reported that there were 207 adults receiving services from the state's developmental disability program and 47 students over the age of 18 years old receiving special education services. The total of 254 is 0.038 percent of the state's estimated adult population of 676,000.

Extrapolating from special education caseloads, Pennsylvania's 2005 autism census estimated that there would be 3,800 adults with an ASD diagnosis by 2010, or 0.039 percent of the state's estimated 9.8 million adult residents. Since this estimate was derived from special education

services, it is unknown what proportion of this total would require or request state or other publicly-funded supports after high school.

Current Service Numbers in Texas

The Department of Aging and Disability Services, Department of Assistive and Rehabilitative Services, and the traditional Medicaid programs administered by the Health and Human Services Commission are the programs that serve the greatest number of adults with ASDs. To evaluate caseload figures, service utilization, and expenditure totals, service claims data from these agencies were analyzed. DADS and DARS provided all claims data for state fiscal years 2008 and 2009 regardless of diagnosis while HHSC provided only those claims that had an ASD diagnosis attached. Combining this data, 4,330 adults with an autism spectrum disorder received some services between July 1, 2008 and June 30, 2009. Figure 1 provides the numbers by program.

Figure 1: Adults with an ASD Receiving Services by Agency, 7/1/08-6/30/09	
<u>Received Services From:</u>	<u>Count</u>
DADS only	1,664
DARS only	847
HHCS only	582
DADS and DARS	76
DADS and HHSC	1,093
DARS and HHSC	39
DADS, DARS, and HHSC	29
Total	4,330

Source: B&A analysis of service claims data provided by DADS, DARS, and HHSC

This total represents 0.023 percent of Texas’ adult population, estimated at 18.8 million by the Texas Department of State Health Services’ Center for Health Statistics. This figure does not include everyone who is in need of services. In particular, due to funding restrictions the Medicaid waiver programs administered by DADS place individuals on an “interest list” when a funded slot is not available. According to records provided by

DADS, for the two programs that serve the greatest number of adults with an ASD, there were more than 78,000 individuals on the interest lists as of July 2010.

Eligibility for these individuals has not yet been determined so it is unknown how many have an ASD, but if the distribution of diagnoses among these consumers is comparable to the enrolled population there would be approximately 10,000 children and adults with an ASD on the interest list. According to DADS, 46 percent of those on the interest list, more than 35,000 individuals,

are 18 years of age or older. If this proportion is true for the estimated ASD population, there would be almost 4,000 adults with an ASD on these interest lists.

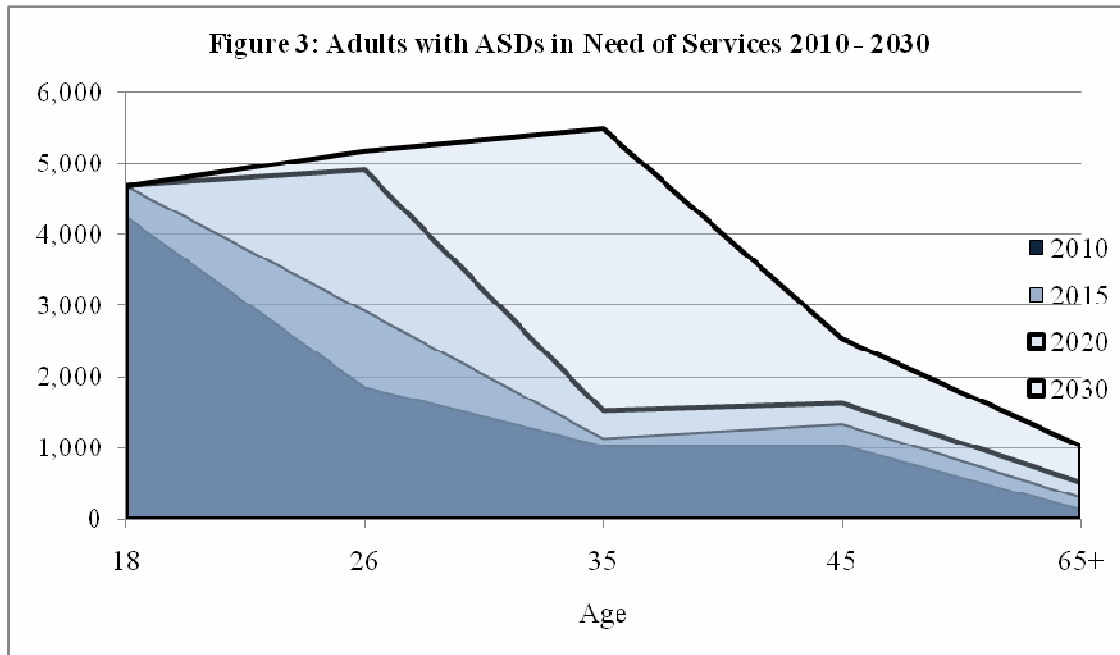
Adding this estimate to the current service number yields a total of about 8,300 adults with ASDs requesting services. This is 0.044 percent of the State's adult population, which is slightly higher than the range suggested by the Arizona, Delaware, and Pennsylvania estimates, but generally consistent with those findings.

The current caseload of adults with ASDs skews heavily to young adults as illustrated by Figure 2. A similar distribution is seen in the overall interest list numbers. Given the increase in diagnoses in recent years this distribution is not surprising, but it does have profound implications for the overall demand for assistance as well as the type of services that will be needed as these individuals age.

<u>Age Range</u>	<u>Count</u>
18-25	2,046
26-34	1,091
35-44	609
45-64	507
65+	77

Source: B&A analysis of service claims data provided by DADS, DARS, and HHSC

Figure 3 demonstrates how the age distribution of adults with ASDs will look in five, ten, and twenty years if the incidence does not change (the number of individuals with ASDs turning 18 years old is held constant from year-to-year).



Source: B&A analysis of service claims data provided by DADS, DARS, and HHSC, and DADS interest list data

This chart illustrates a conservative scenario to show the effect that the simple aging of the existing caseload will have on the demand for services. Even if the number of new adults in the system remains constant the number of individuals requesting services will increase from about 8,300 today to more than 10,000 in five years and almost 19,000 by 2030.

Over this period, there will be dramatic growth in the number of adults in their 30s and 40s. This will alter the character of the services that are required as both consumers and their parents and caregivers age. Currently, many adults with an ASD continue to live with their parents who also often serve as de facto case managers. These are roles that parents will be unable to fill forever. The current system of supports will need to adapt to ensure that appropriate housing options and other services are available to meet the needs of these aging consumers and provide peace of mind to their families.

SECTION 3: BEST PRACTICES IN SYSTEMS AND SERVICES

The growing incidence of autism spectrum disorder diagnoses has resulted in a significant body of research on service interventions with an overwhelming emphasis on children with an ASD. As the children diagnosed over the past two decades have reached adulthood, a nascent focus on the needs of adults with an ASD has emerged.

States have established task forces to issue recommendations for state systems and advocacy groups have emerged to represent the needs of adults with ASDs. Notable efforts include:

- Delaware's Adult Autism Task Force's report published in June 2008²;
- New Jersey's Adults with Autism Task Force's report released in October 2009³;
- The Nevada Autism Task Force's July 2008 report⁴;
- The Pennsylvania Department of Public Welfare's Autism Task Force's December 2004 report⁵;
- Kentucky's Commission on Autism Spectrum Disorders' October 2006 report⁶;
- The Organization for Autism Research's *Current State of Services for Adults with Autism* study produced for Advancing Futures for Adults with Autism, a national consortium of 12 organizations⁷; and,
- IMPAQ International's environmental scan of published evaluations of services for adults with autism⁸.

These state task forces represent states large and small with varying size, population, density, geography, and wealth. Despite the differences, these reports show considerable consistency in recommendations for an effective system of supports for adults with autism spectrum disorders.

²<http://legis.delaware.gov/LIS/TaskForces.nsf/59da77da7c06f47485256ff6006f8346/c491ae16f86b1906852571a3006cdfa5?OpenDocument&TableRow=1.5.2#1.5>.

³ <http://www.state.nj.us/humanservices/dd/board/AATFrpt.pdf>

⁴ http://dhhs.nv.gov/autism/TaskForce/2008/2008_NV_Autism_Task_Force_Report.pdf

⁵ <http://www.dpw.state.pa.us/About/Secretary/AutismTaskForce/003670890.htm>

⁶ <http://chfs.ky.gov/kcdd/KB+296+KY+Commission+on+Autism+Spectrum+Disorders.htm>

⁷ http://www.mofeat.org/files/oar_survey_11309.pdf

⁸ <http://www.impaqint.com/files/4-Content/1-6-publications/1-6-2-project-reports/FinalASDRpt.pdf>

Best Practices in System Design

The reports issued by the advocacy groups and state task forces cited above found that systems and services with an ASD-specific focus are necessary. Despite the increase in ASD diagnoses, the number of individuals, particularly adults, with ASDs is much smaller than the developmental disabilities, mentally ill, and physical disabilities populations. The socialization, communication, and behavior characteristics of ASD differ from these conditions significantly enough to warrant individualized services, but it is usually through programming for these other populations that individuals with ASDs receive services. The reports conclude, though, that systems designed for other populations do not effectively address the needs of individuals with autism spectrum disorders and related disabilities.

The state task forces propose several strategies to develop an ASD emphasis, including:

- establishment of a new office or bureau on autism services, frequently within the developmental disabilities department, to ensure dedicated staffing, funding, and services;
- development of training programs for individuals who work with individuals with autism spectrum disorders, including case managers, vocational rehabilitation counselors, teachers involved in transition planning, and service providers;
- public education campaigns targeting the general public, business community, law enforcement, and health care professionals; and
- creation of autism-specific Medicaid waivers for a system of home and community-based services designed for individuals with ASDs. Currently ten states have Medicaid waivers specific to individuals with autism, but only two cover services for adults, including the Pennsylvania waiver, which is the only one limited to adults (see Appendix B for a description of this waiver).

An ASD-focused system needs to recognize the significant variability in the needs and abilities of individuals across the autism spectrum. This variability is evidenced in a number of domains including behavioral, social, vocational, independent and adaptive functioning, and academic success. To recognize the unique needs of individuals, a person-centered focus is necessary with

service plans tailored to each consumer. The task forces and reports noted above suggest that person-centered plans incorporate several elements:

- age and developmentally appropriate self-determination to allow individuals to be actively engaged in planning their supports;
- a strength-based emphasis that builds on an individual's abilities, goals, and interests, and sets the highest expectations appropriate given the individual's level of functioning;
- a team-based approach including the consumer's family and others who know and care about the individual;
- identification and utilization of natural supports; and,
- seamless service plans that integrate supports to create a comprehensive individual plan focused on consumer goals rather than fragmented service silos.

An ASD-focused system must be accessible. Adults with ASDs and related disabilities and their families are often overwhelmed by the complexity of existing systems of support. While their children are still in school, parents typically look first to their school district for support and resources, but responsibility for services for adults is more diffuse, spread across multiple state agencies. Task force recommendations often begin with organizing available resources and information. The information clearinghouse required by H.B. 1574 is an example of Texas acting to implement this best practice. Building on such a clearinghouse as a first step, a number of task forces recommend establishment of a system with a single point of entry for all available services.

Best Practices and States Task Force Recommendations in Service Design

The state task forces and advocacy groups referenced in the beginning of this section suggest a number of considerations when delivering services, training, and education to adults with ASDs. For example, there should be recognition that services will need to be ongoing, particularly for those who are not higher functioning. This is a different mindset for some programs, such as vocational rehabilitation, which are time-limited. Structured environments and managing changes within those environments are also important for adults with ASDs. These include educational, work, and home environments. Important elements in structured milieu include the

physical organization, the provision and use of predictable schedules, and individualized/differentiated use of teaching methods.

These foundational best practices should be incorporated in the design of specific services and supports, including transition from high school, housing, and employment and other day activities. Additionally, when considering service design it is important to recognize that a one-size-fits-all approach will not be effective; a range of options is necessary to accommodate those across the entire spectrum of autism disorders.

Transition

The transition out of the public education system can present a host of difficulties for young adults with ASDs. The federal Individuals with Disabilities Education Act (IDEA) requires that individuals with disabilities receive special education services through the age of 21 years. To prepare students with disabilities for the time when this entitlement to services ends, IDEA requires that transition planning begin at age 16.

The loss of the familiar routine of school and, at times, the friends they had in high school can be particularly jarring for an individual with an ASD. Without transition to appropriate supports, individuals aging out of the school system may regress, losing many of the gains that they made while in school. Effective transition strategies are critical to supporting adults on the autism spectrum in achieving their potential.

Consistent with established best practices the transition plan must be person-centered and strengths-based, focusing on what the individual can accomplish rather than what they cannot. Employment is often the focus of transition planning, but the plan should cover all aspects of the individual's life, including housing, community participation, leisure, and health. The process should be inclusive, involving the transitioning consumer, his/ her family, and the agencies that will be providing services to facilitate development of an integrated and seamless plan. Those participating in the planning should have a familiarity with ASDs and the services that are available.

Other best practices include recognition of the continuing benefit of behavioral therapy and skills training interventions throughout the teen years that are focused specifically on the skills necessary for successful community living and employment. These skills include reacting to and managing changes in the environment such as work schedules, money management, writing checks, filling prescriptions, safety, socialization, relationships in the work place, etc.

Housing

As young adults with ASDs transition from the public education system, many will continue to live with their parents for some period of time. In its 2008 *Living with Autism Study*⁹, Easter Seals found that more than 80 percent of individuals with autism between the ages of 19 and 30 years live with family compared to about one-third of individuals without special needs in this age group. As will be discussed in the following section, the extent to which this is true in Texas is unknown. Supporting an individual in his/ her family home is far less costly than providing residential supports so states should provide assistance to those caregivers who need it. These services may be directed at both the consumer, such as therapies and behavioral support and access to employment supports and day activities, as well as to the caregivers. In particular, a number of the task forces and researchers stress the need for training for family members to support the consumer's behavioral plan as well as respite for caregivers.

Continuing to live with family is not an option for all adults with ASDs, however. In some instances, the consumer may no longer wish to live at home and, in others, family may be unable to provide care due to age, infirmity, or other reasons. Housing options are needed for the entire autism spectrum; providing too little support may result in harm to a consumer while too much may shortchange his/ her ability to be independent and result in unnecessary costs for the state. The range of options should include transitional models that are short-term and aim to build skills necessary to live independently; supported living in which the consumer lives in their owned or leased home but receives some assistance in areas of need such as budgeting or community engagement; supervised living in their owned or leased home that is more intensive than supported living such as, for example, models in which several adults with ASDs live in

⁹ http://www.easterseals.com/site/PageServer?pagename=ntlc8_living_with_autism_study_home

different apartments within the same complex so that staff may provide oversight; and community-based group homes.

Whether in their family home, living independently, or in a group home setting, housing supports should be tailored to the unique needs of adults with ASDs. For example, many individuals with ASDs lack awareness of dangerous situations. A housing plan, then, should include safety training for consumers and the appropriate level of supervision for each individual. The characteristics of ASDs can also have an impact on the necessary physical environment, which may require home adaptations and assistive technology such as soundproofing and devices that enable consumers to communicate and manage sensory and motor challenges. In all instances consumers should be provided an opportunity to “design” their home environment by participating in major home decisions, meals, household routines, etc.

One promising practice is family consortiums, in which two to four consumers choose to live in a shared home purchased by the consumers’ families. The consumers and family members set the direction of the home and actively work together for its successful operation either directly or through contracted service providers. Families hire staff, set the staffing patterns, and decorate and maintain the home. Services provided in the home include personal care, counseling, nutrition,

Best Practices in Practice:
*Autism Treatment Center,
Dallas and San Antonio*

ATC provides a variety of services to individuals with ASDs. Operating these services under one (organizational) roof, ATC is able to deliver seamless supports. ATC operates schools for children and young adults, vocational and day programs, and therapy services. ATC also owns and operates 20 community-based group homes.

The group homes are single family homes and duplexes. Generally three or four residents live in a home and are matched for compatibility. Residents are contributing household members (e.g. doing chores) and make decisions about their home such as how to decorate their room.

Providing meaningful activities is an important element of ATC’s residential model. During the day, residents are usually out of the home working, volunteering, or participating in other day activities. In the evenings and on weekends, there are outings for shopping, entertainment, etc. Group homes are frequently located near each other providing more opportunities for socialization.

ATC’s residential model provides a framework for one housing option for adults with ASDs that works within existing programmatic and funding constraints (private fundraising does play an important role in addressing remaining gaps)

transportation, and medical supplies and adaptive equipment. Ohio has 87 of these consortiums.

Employment Supports

Most adults with an ASD are capable of working so employment should be an expectation. For example, the Delaware task force, which focused on young adults transitioning from high school as well as older, generally higher-functioning adults, stated their assumption that “each individual will spend approximately 40 hours per week engaged in meaningful activity outside of the home, with at least 20 hours of this being gainful employment. This is regardless of where an individual may live, or what he or she may do across the day.”

Supported employment programs can take a variety of forms. In an individualized placement model, a job coach provides one-on-one onsite support, assisting the consumer with learning both the functional and social aspects of the job. Due to the cost of this model, intensive support is often time-limited. Group supported employment models include enclaves and mobile work crews in which a job coach works with several consumers. Group supported employment is generally less integrated with less opportunity for transitioning to competitive employment and is, therefore, more appropriate for consumers who are less likely to be able to work in an individual placement without intensive support.

Best Practices in Practice: *nonPareil Institute, Dallas*

The national Autism Society reports that 90 percent of adults with autism are unemployed. Many have marketable skills, but cannot navigate the workplace. Interpersonal relationships, training methods, even the physical environment (e.g. light and noise) can be barriers to success.

In response, the founders of nonPareil Institute created a model in which work is brought to the individual who “work in an environment suited to THEIR needs rather than forcing them to adapt to environments more suited for those without autism.”

This ASD-specific program uses an interests- and strengths-based approach to the work itself. nonPareil trains its employees in various aspects of technology development, an area in which a number of adults with ASDs have an aptitude. Employees receive competitive wages for their work.

Long-term nonPareil hopes to build a “community within a community” with living facilities for adults in the program (living onsite will not be mandatory). The community would seamlessly incorporate housing, employment, socialization, and other needs.

The program’s name illustrates the founders’ belief in their consumers: “A person so excellent as to have no equal.”

In recent years, there has been an emphasis on offering more opportunities to adults with ASDs and related disabilities through customized employment and entrepreneurial models.

Customized employment seeks to create an individualized job through negotiation with an employer. The resulting job, of course, must meet an employer's needs and make financial sense. An entrepreneurial model is similar except the individualized job that is created is used as the basis to form a corporation to pay the consumer and support staff rather than the consumer working for another employer. Such models are particularly attractive options in rural communities without center-based day or employment programs. The entrepreneurial model may take one of two paths – a micro-board or self-employment.

A governing micro-board is created around the consumer and is made up of family members, friends, community members, and others. Typically the micro-board encompasses all of the consumer's lifelong support needs, including habilitation and residential needs in addition to employment. The micro-board incorporates and becomes a qualified Medicaid provider. There are currently several successful micro-boards in Texas.

Self-employment is generally a less resource-intensive model than micro-boards. The focus is limited to employment and incorporation may or may not be necessary and a governing board is not necessary. The consumer runs the corporation him/ herself after having received training in marketing, billing, paying taxes, and the actual work. As an example, one Texas parent reported her son with an ASD and mental retardation formed a corporation to clean windows.

Evaluations of supported employment programs find that those that are effective provide employment specialists with an understanding of ASD, align jobs with consumers' interests, provide ongoing support to maintain the job, and work closely with employers. It has been shown that consumers involved in supported community employment experience improved quality of life compared to those in sheltered workshops.

With the exception of the entrepreneurial models, employer participation is key to a consumer's successful employment. This, in turn, requires that job coaches be familiar with the business community in their area and reach out to potential employers to discuss the benefits of hiring an

Best Practices in Practice:
The Coffeehouse, Houston

Recognizing the need for services tailored to individuals with ASDs and the lack of services for high-functioning adults, the Harris County local MR authority established the Coffeehouse program for adults with Asperger's Disorder to provide an enriching environment during the day.

The Coffeehouse is a voluntary drop-in program with a mission "to provide an opportunity and atmosphere for people with Asperger's Disorder to work on social and related issues that affect their independence and community living." Limiting the focus to Asperger's rather than the entire autism spectrum or an even broader group with developmental disabilities has resulted in a program that is tailored to the unique needs of this population including social skills training and college/employment readiness.

Participants discuss with their peers issues relevant to having Asperger's. The group is led by a trained facilitator, but the participants largely determine what will be discussed.

These ingredients – specialized services, self-determination, high expectations, and a sense of community – have created a meaningful program for its attendees. In the words of one consumer, "Despite all the challenges Coffeehouse and its staff are pulling miracles daily in that program."

individual with an ASD. To further encourage employer participation, several task forces have recommended the establishment of tax credits for those that provide jobs to adults with ASDs and other disabilities.

Day Activities

Activities other than employment should also be available.

For some consumers these activities will fill time when they are not working; for others, employment may not be an immediate option and so these activities will comprise a more significant portion of their day.

Effective day habilitation programs facilitate learning with a focus on skills related to activities of daily living, pre-vocational training, or preparing for continued education. The program should be appropriate to the functional level of those participating, rather than serving as an adult day care program. To the greatest extent possible, an employment focus should include a goal of graduating the consumer to community employment rather than emphasizing a sheltered workshop approach that is not individualized, provides little training, expects minimal production, and has high staff-to-client ratios. Day habilitation programs should include a community integration emphasis by providing consumers opportunities to spend time in the community through volunteer activities, shopping trips, entertainment excursions, etc.

Behavioral Supports

Certain services have historically been provided for children with ASDs but not adults, including behavioral programming

and therapies. In many states, these services continue to be restricted to children because it has been believed that they are not effective for adults, but recent evaluations on the effectiveness of these services have found that adults with ASDs can continue to benefit. A specific example of this type of service is applied behavior analysis (ABA). ABA is a structured, empirically based behavioral/ educational intervention. ABA aims to: increase on-task behaviors/ attention, teach skills not currently in the consumer's behavioral repertoire, maintain positive behaviors already in the individual's repertoire, generalize positive behaviors and skills across settings, restrict or narrow conditions under which interfering behaviors occur, and reduce or eliminate maladaptive behaviors.

The recommendations from the state task force reports and research literature described earlier in this section demonstrate a high degree of consensus on a number of best practices related to meeting the needs of adults with ASDs and related disabilities. Appendix B includes descriptions of systems in Pennsylvania, Connecticut, and Arizona that put many of these principles into practice. Few, if any, programs currently incorporate all of these practices, but these standards provide a guidepost both for measuring existing systems and constructing new programs.

SECTION 4: PROGRAMS CURRENTLY PROVIDING SERVICES TO ADULTS WITH ASDS

Many state entities are responsible for providing various services to adults with autism spectrum disorders. This fragmented approach is historic and driven in large measure by federal requirements and funding streams. Each of the 1,700 high schools in the State must provide transition services to any individual qualifying for special education services. Employment services may be provided through programs administered by the Department of Assistive and Rehabilitative Services, Department of Aging and Disability Services, or Texas Workforce Commission. DADS is responsible for administering several different Medicaid waiver programs that may serve individuals with an ASD (each of which has different requirements and service packages), while the Health and Human Services Commission administers the traditional Medicaid program. In addition to the number of state agencies that are involved, in many instances responsibility for coordinating and delivering services for these programs is delegated to local authorities or contractors, creating further fragmentation.

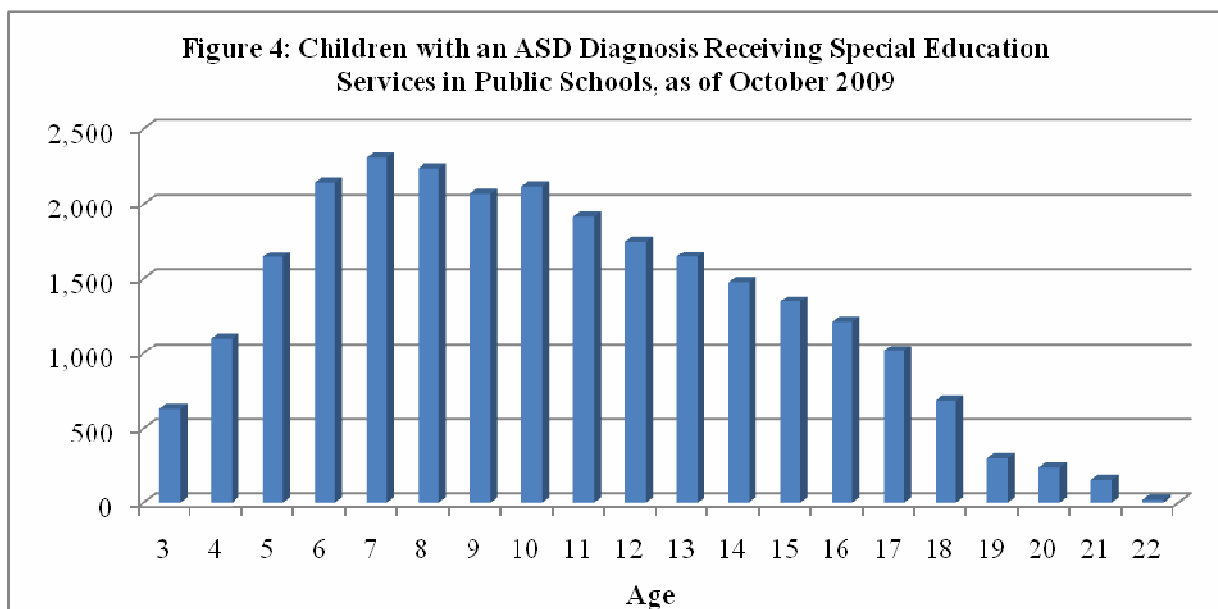
Each state entity is responsible only for the specific services that it delivers. No single agency is responsible for coordinating services for individual consumers.

Independent School Districts

There are more than 1,200 independent school districts (ISD), including charter school operators, and more than 1,700 high school campuses in Texas. The public education system plays an important role in preparing individuals with autism spectrum disorders and related disabilities for adulthood.

The Texas Education Agency reports that there were more than 4.7 million children (and young adults) in public schools as of October 2009. Approximately 456,600 (about 9.6 percent of the total) were receiving special education services. Of these, 26,003 individuals had an autism spectrum disorder diagnosis, representing 0.55 percent of the total number enrolled in public schools.

Figure 4 illustrates the total ASD population by age as of October 2009. Although a static portrait, the chart demonstrates a clear trend. The number of children with ASD diagnoses rises until the age of seven years old as children who are not keeping pace with their peers are identified, screened for a learning or developmental disability, and enrolled in special education services as appropriate. After the age of seven years, the decline in the number of students with ASDs receiving special education services presumably reflects children who are mainstreamed back into regular classrooms. Children with more severe disabilities continue to receive special education services until they graduate from high school or age out of the public education system at 22 years of age.



Source: Figures provided by TEA

As noted previously, federal law requires that schools develop a transition plan for students with disabilities to prepare for life after high school. Texas regulations require that transition planning include postsecondary education options, a functional vocational evaluation, employment goals and objectives, independent living goals and objectives, and referrals to appropriate services. The transition plan is discussed in admission, review, and dismissal (ARD) meetings, which include the student, his/ her parent(s), and school personnel, and may also

include, at the parents' option, representatives from the local MR authority and/ or DARS. Local MR authorities and DARS are not, however, obligated to attend ARD meetings.

Department of Assistive and Rehabilitative Services

After exiting the public education system, a number of young adults with autism spectrum disorders and related disabilities begin to receive vocational rehabilitation services from DARS. Vocational rehabilitation is intended to assist individuals with disabilities obtain and retain jobs. In order to be eligible for services, an individual must present a physical or mental disability that affects their ability to work, require services in order to obtain or retain employment, and have the ability to maintain their job after receiving services.

Once an individual is determined eligible, DARS, the consumer, and the consumer's family as appropriate develop an individualized plan for employment (IPE). The IPE includes an employment goal, a plan for achieving that goal, the frequency with which the DARS counselor meets with the consumer, a description of the services to be received, and the consumer's responsibilities in achieving the employment goal. DARS does not have an order of selection (waiting list) in place; all consumers determined eligible receive services.

Case management for vocational rehabilitation services is performed by DARS employees, referred to as counselors. The program contracts with vendors to deliver various services, which may include training, job placement assistance, job coaching, tuition assistance, assistive devices, and other services. Federal funds received through the Vocational Rehabilitation Act cover 78.7 percent of most vocational rehabilitation expenses. This law, however, limits the use of federal funds for supported employment services (which generally encompass most of the services noted previously) to 18 months.

According to DARS' 2009 annual report, more than 86,000 individuals received vocational rehabilitation services at a total cost of \$206.6 million. Individuals with developmental disabilities, including autism spectrum disorders represent a minority of these totals. Reviewing claims data provided by DARS for the twelve month period ending June 30, 2009, only 951 individuals had a primary or secondary impairment caused by autism and another 6,481 had

mental retardation, cerebral palsy, or a congenital condition/ birth injury. Overall, individuals with a developmental disability comprised less than 10 percent of the vocational rehabilitation caseload. Similarly, the \$18.4 million of spending related to this population was only a fraction of the program's overall budget.

Figure 5 displays vocational rehabilitation caseloads and spending for individuals with ASDs.

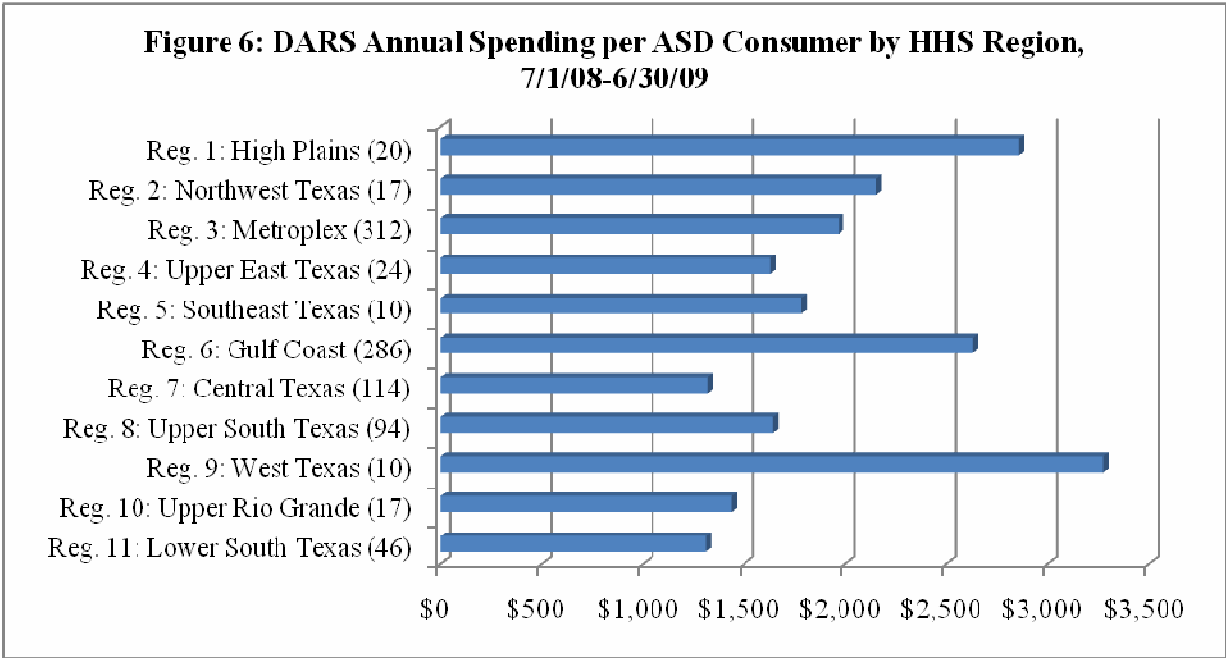
On average, the vocational rehabilitation program expends about \$2,200 for each consumer with an ASD. The largest categories of spending are services leading to supported employment and tuition

assistance. Individuals with an ASD are more likely than other disability populations to receive evaluations, psychological testing, and counseling services.

The vocational rehabilitation program is available statewide, operating out of more than 120 offices. There are, however, significant differences in spending and services across the State. Figure 6 compares spending across the State organized by health and human services region.

Figure 5: Vocational Rehabilitation Spending for Individuals with ASDs, 7/1/08-6/30/09			
Autism Spectrum Disorders			
Age	Consumer	Expend.	Avg. Spending
Age 13-17	9	\$ 9,738	\$ 1,082
Age 18-21	532	950,941	1,787
Age 22-25	263	757,974	2,882
Age 26-34	96	255,374	2,660
Age 35-44	34	55,571	1,634
Age 45-64	17	41,884	2,464
Age 65+	-	-	-
Total	951	\$ 2,071,482	\$ 2,178

Source: B&A analysis of service claims data provided by DARS



Source: B&A analysis of service claims data provided by DARS

The figure excludes costs associated with vehicle modifications and halfway houses to avoid skewing figures in the smaller regions and focus on tuition and training costs. Average per consumer spending by region ranges from a low of \$1,313 in the Lower South Texas region to a high of \$3,273 in the West Texas region. Reviewing service level details shows that there is a broader array of available services in metropolitan areas compared to more rural areas.

Department of Aging and Disability Services

DADS is responsible for funding and overseeing a number of programs to provide residential and home and community-based services for adults with autism spectrum disorders and related disabilities. The most significant of these programs are public and private intermediate care facilities for the mentally retarded (ICF/ MR), two Medicaid waiver programs, and general revenue (GR) funding contracted through the local MR authorities.

ICF/ MR services and the waiver programs receive federal matching funds through the Medicaid program. The federal share of costs is based upon the state’s per capita income compared to the national average. In Texas, the historic federal share of Medicaid costs is about 60 percent (the

matching rate has been temporarily enhanced under the federal American Recovery and Reinvestment Act). The GR-only services do not receive any federal financial participation.

Intermediate Care Facilities for the Mentally Retarded

ICF/ MRs are Medicaid-funded institutions that provide 24-hour residential services. Additionally, consumers residing in ICF/ MRs may receive comprehensive behavioral treatment services; skills training; occupational, physical, and speech therapies; vocational programs; and services to maintain connections between individuals and their families and natural support systems. According to United Cerebral Palsy's (UCP) *The Case for Inclusion Report* for 2010¹⁰, in 2008 Texas had more consumers in state-run and private ICF/ MRs than any other state.

In Texas there are 13 state-operated ICF/ MRs, referred to as State Supported Living Centers (SSLC). According to the DADS website, the censuses for these facilities range from approximately 75 to 580 consumers¹¹. According to the UCP report there were 4,789 consumers in these "large state facilities" in 2008, nearly twice as many as in any other state. All of the consumers placed in the SSLCs have mental retardation, but a number also have co-occurring diagnoses. In the 12-month period ending June 30, 2009, 357 adults with an ASD diagnosis resided in a SSLC at some point during the year. Providing ICF/ MR services is expensive. The average cost of supporting an adult with an ASD (who also has a mental retardation diagnosis) in an SSLC was more than \$133,000 in the twelve-month period ending June 30, 2009.

The State also has an extensive network of private ICF/ MRs. The DADS website lists more than 800. These homes are substantially different from the state-run institutions because, although some are medium or large facilities, most private ICF/ MRs are single-family homes licensed to house six consumers. Claims data for the 12-month period ending June 30, 2009 indicate nearly 7,000 consumers resided in private ICF/ MRs, including 382 adults with an ASD.

The historic reliance on ICF/ MRs was primarily a result of the manner in which the federal government funded services for individuals with intellectual and developmental disabilities.

¹⁰ http://medicaid.ucp.org/pdf/Case_For_Inclusion_Report_2010.pdf

¹¹ <http://www.dads.state.tx.us/services/stateschools/> (retrieved August 23, 2010)

State-run ICF/ MRs have been an optional state plan service under federal Medicaid law since 1972 (private ICF/MRs were not added until 1977) allowing costs to be shared between the federal government and the states. Prior to the advent of Medicaid waivers, home and community-based alternatives were not eligible for federal funding so states had a financial incentive to place individuals in ICF/ MRs rather than less restrictive options.

Medicaid Waivers

To facilitate a shift away from ICF/ MR placements, in 1981 the federal government established a “waiver” option for states. In brief, Medicaid waivers authorized under Section 1915(c) of the Social Security Act permit states to provide home and community-based services that are generally not available through the traditional Medicaid program.

DADS administers several 1915(c) Medicaid waiver programs, including Community Based Alternatives, Consolidated Waiver Program, Deaf-Blind Multiple Disabilities, Medically Dependent Children Program, Texas Home Living, Community Living Assistance and Support Services (CLASS), and Home and Community-based Services (HCS). Although there are individuals with autism spectrum disorders enrolled in each of these waivers, the largest numbers of adults with ASDs are enrolled on either the CLASS or HCS waiver.

The HCS waiver is a “comprehensive” waiver that provides both home and community-based services and residential support through small group homes. About 80 percent of the consumers enrolled in the HCS waiver live in a paid residential placement, either in a group home, adult foster care, or another supervised living environment.

In order to be eligible for the HCS waiver, a consumer must have mental retardation or a related condition that results in an IQ of 75 or below. Thus, an ASD diagnosis alone will not make an individual eligible for this waiver. Of those with an ASD (in addition to mental retardation) 65 percent had a “current or active state” autistic disorder (ICD-9 diagnosis code 299.00) and 32 percent had another current or active state specified pervasive developmental disorders (299.80), which are more severe diagnoses on the autism spectrum. A consumer must also meet ICF/ MR

level of care criteria, meaning that, in the absence of home and community-based supports, they would require institutional care.

Nearly 16,000 consumers received services through the HCS waiver between July 1, 2008 and June 30, 2009; a little more than 1,200 of these individuals had an ASD diagnosis (with more than 1,000 who are at least 18 years of age). Due to funding limitations, not everyone who is eligible for the program is able to enroll. As of July 2010, 46,650 individuals were on an interest list meaning that they have applied for services, but have not yet received an eligibility determination for the HCS waiver. Some individuals have been on the interest list for as long as nine years. Assuming the distribution of diagnoses for the existing caseloads is similar to the distribution within the interest list, an estimated 2,100 are adults with ASDs. Using current spending averages, enrolling these individuals would cost approximately \$140 million, of which \$56 million would come from the State.

The CLASS waiver is a “supports” waiver that provides home and community-based services, but not residential supports, to individuals with intellectual and developmental disabilities. Like the HCS waiver, an individual must meet ICF/ MR level of care criteria in order to be eligible for the CLASS waiver. Unlike the HCS waiver, however, individuals do not need to have mental retardation to qualify and a consumer with an ASD diagnosis without a co-occurring condition may be eligible.

Between July 1, 2008 and June 30, 2009, more than 4,100 individuals, including more than 800 with an ASD (about half of whom were 18 years of age or older), were served through the CLASS waiver. Most of the adults with an ASD in CLASS have the same two diagnosis that comprise the majority of the HCS caseload, “current or active state” autistic disorder and current or active state specified pervasive developmental disorders, but about 12 percent have an unspecified developed delay (315.9), which is typically a less severe diagnosis.

As with the HCS waiver, the CLASS waiver does not have sufficient funding to enroll all eligible consumers and, as of July 2010, 31,486 individuals were on an interest list. Some individuals have been on the interest list for as long as seven years. Working from the

distribution of diagnoses within the existing caseload, an estimated 1,900 of the individuals on the interest list are adults with ASDs. Enrolling them in the waiver would cost about \$60 million, of which \$24 million would be state funds.

Figure 7 compares the services offered by the two waivers. In addition to the lack of residential supports in the CLASS waiver, one of the more notable differences between the two service packages is the availability of certain specialized therapies in the CLASS waiver that are not covered by the HCS waivers. This category of service includes massage, music, hydro-, aquatic, hippo- (equine), and recreation therapy; therapeutic horseback riding; auditory integration training; and nutritional services. These specialized therapies are frequently utilized by individuals with ASDs, but the HCS waiver covers only audiology and dietary services.

Both waiver programs rely on contracted entities for case management. Within the CLASS waiver, case management is provided by an independent case management provider agency. As of June 1, 2010 case management for consumers enrolled in the HCS waiver is provided by the local MR authority as a state plan service (previously case management was provided by the direct service agency as a waiver service). Case managers are responsible for assisting in the development of an individual service plan that is expected to consider each consumer's unique needs, strengths, goals, and natural supports.

Figure 7: HCS and CLASS Waiver Covered Services		
	HCS	CLASS
Residential Support	✓	
Supported Home Living	✓	
Supervised Living Services	✓	
Foster Care Services	✓	
Support Family Services		✓
Transition Assistance (\$2,500 max.)		✓
Day Habilitation	✓	
Habilitation Attendant/ Training		✓
Prevocational		✓
Supported Employment (HCS-\$3,000/ yr. max.)	✓	✓
Respite Care (30 day/ yr. limit)	✓	✓
Occupational Therapy	✓	✓
Physical Therapy	✓	✓
Speech/ Language Pathology	✓	✓
Specialized Therapies		✓
Audiology (Spec. therapy in CLASS)	✓	
Dietary (Spec. therapy in CLASS)	✓	
Nursing Services	✓	✓
Psychology (Behavior Support)	✓	✓
Dental (\$1,000/ yr. max.)	✓	
Social Work	✓	
Adaptive Aids (\$10,000/ yr. limit)	✓	✓
Minor Home Modifications (lifetime limit—HCS: \$7,500; CLASS: \$10,000)	✓	✓

The service plan provides for an authorization of a specific amount of the various services that the consumer will receive. The CLASS and HCS waivers utilize direct service agencies to deliver the services identified during the planning process. These agencies cannot also provide case management services.

Both programs emphasize self-determination and consumer choice to empower consumers with greater control over aspect of their lives. Consumers may select any direct service provider or CLASS case management agency contracting with DADS to serve their area. Additionally, consumers have the option of selecting the consumer-directed services (CDS) option. In CDS, the consumer or his/ her designated representative hires, trains, and supervises direct support workers. Within the CLASS waiver, CDS is an option for habilitation services, respite, nursing, physical therapy, occupational therapy, speech/hearing therapy, and support consultation. Approximately 58 percent of the consumers with an ASD enrolled in the CLASS waiver utilized the CDS option. Within the HCS waiver, self-direction was added only about two years ago and is only available for supported home living, respite services and support consultation. Due to the recent addition of the CDS option in the HCS waiver and limited services for which it is available, it is utilized much less frequently by consumers in the HCS waiver.

DADS pays providers according to a published fee schedule. The rates are intended to account for wage, benefit, and administration costs and are set, in part, using information from provider cost reports. In general, the same services receive the same reimbursement across the CLASS and HCS waiver though supported employment is a notable exception. Rates are the same across the State; there are no differentials to account for regional variances in the labor market. With the exception of residential services, foster and companion care, supported home living, and habilitation, there are no rate differentials based on consumers' level of need.

Many provider reimbursement rates have received several increases in recent years. For example, since August 2007 supervised living and residential support service rates increased between 32 and 64 percent; HCS day habilitation rates other than pervasive-plus (which decreased three percent) increased between 17 and 57 percent, CLASS habilitation rates

increased between 11 and 12 percent, therapy rates increased between 17 and 25 percent, and behavioral support rates increased 11 percent.

Between July 1, 2008 and June 30, 2009, DADS expended more than \$1.0 billion to provide services to individuals enrolled in the HCS waiver and more than \$140 million to support those enrolled in the CLASS waiver. Figure 8 summarizes caseloads and costs across the two programs.

The table shows that the average annual per-consumer cost is significantly higher for adults compared to children, particularly in the HCS waiver. This

Figure 8: CLASS and HCS Caseloads and Spending, by Age and ASD, 7/1/08-6/30/09

	Consumers	Expenditures	Avg. Cost
CLASS	4,112	\$144,542,051	\$35,151
w/ ASD	844	25,800,761	30,570
<18	440	12,473,656	28,349
18+	404	13,327,105	32,988
w/o ASD	3,268	118,741,290	36,335
<18	1,070	31,487,114	29,427
18+	2,198	87,254,176	39,697
HCS	15,953	\$1,025,240,935	\$64,266
w/ ASD	1,239	82,182,004	66,329
<18	192	8,394,034	43,719
18+	1,047	73,787,971	70,476
w/o ASD	14,714	943,058,931	64,093
<18	563	24,175,885	42,941
18+	14,151	918,883,046	64,934

Source: B&A analysis of service claims data provided by DADS

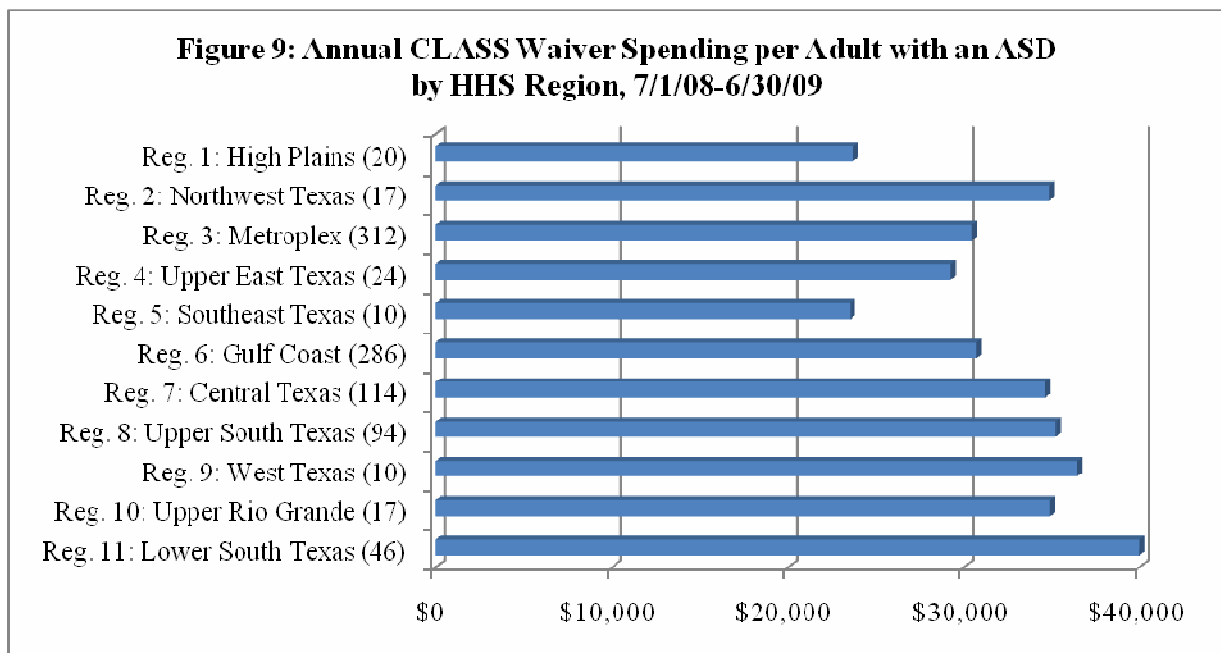
increase coincides with exit from the public education system. Without ISD services funded through IDEA, consumers and their families rely on the waivers for day habilitation services. Comparing the 18 to 21 age group to those between the ages of 26-34, day habilitation costs per consumer are nearly 250 percent higher in the CLASS waiver (\$6,500 to \$22,698) and almost 350 percent higher in the HCS waiver (\$5,226 to \$23,117). Additionally, a number of young adults exiting high school transition to paid residential placements, including HCS group homes, adult foster care, or supervised living environments. Less than 40 percent of the HCS consumers between the ages of 13 and 17 are in a paid residential placement. This percentage grows to almost 74 percent for those between 18 and 21 years of age. After the age of 22, more than 90 percent of HCS consumers are living in a paid residential placement.

This differs greatly from the 2008 Easter Seals report cited previously, which found that 80 percent of adults between the ages of 19 and 30 years live with family. This may be partially explained by parents providing paid foster care in the family's home. DADS reports that, anecdotally, this occurs frequently and may explain much of this increase in paid residential

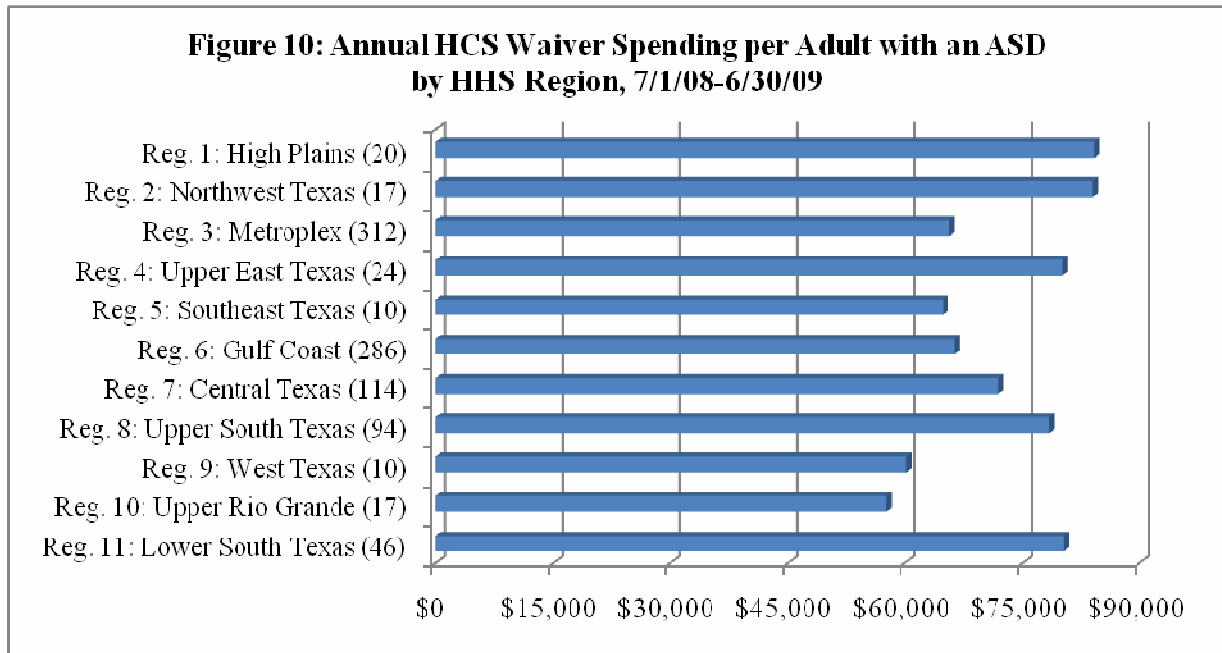
placements when consumers reach the age of 18 years. However, DADS does not have data that quantifies this assumption and the proportion of consumers in adult foster care still living in their family home is unknown.

Within both waiver programs, a small number of service categories account for the bulk of total spending for adults with an ASD. Of the \$73.8 million expended to support adults with an ASD enrolled in the HCS waiver, three categories of services comprised more than 96 percent of the total: case management (36.5 percent), out-of-home residential supports (32.0 percent), and day habilitation services (27.6 percent). Similarly, four categories of service account for nearly 86 percent of the more than \$13 million of CLASS waiver spending for adults with an ASD: habilitation (34.9 percent); client-directed services, which can include a number of different services (32.0 percent); specialized therapies (13.5 percent); and case management (5.2 percent).

As in the vocational rehabilitation program, significant differences in per capita spending are evident across the HHSC regions (see Appendix C) as illustrated by Figures 9 and 10.



Source: B&A analysis of service claims data provided by DADS



Source: B&A analysis of service claims data provided by DADS

As the charts demonstrate, some regions may have relatively high per-capita spending in one waiver and comparatively low per-

capita spending in the other waiver. Figure 11 ranks each region by spending for the CLASS and HCS waivers. Analyzing utilization of individual services reveals differences between regions.

Figure 11: Per-Capita Waiver Spending on Adults with ASD Ranks by Region, 7/1/08-6/30/09

	CLASS	HCS
Region 1: High Plains	10	1
Region 2: Northwest Texas	5	2
Region 3: Metroplex	8	8
Region 4: Upper East Texas	9	4
Region 5: Southeast Texas	11	9
Region 6: Gulf Coast	7	7
Region 7: Central Texas	6	6
Region 8: Upper South Texas	3	5
Region 9: West Texas	2	10
Region 10: Upper Rio Grande	4	11
Region 11: Lower South Texas	1	3

Within the CLASS waiver, the regions with the highest utilization of

specialized therapies correspond to the State’s largest metropolitan areas: Austin, Dallas/ Fort Worth, Houston, and San Antonio. In

each of these regions, a majority of consumers received specialized therapies, while in several of the less populous regions, one-third or fewer of the consumers utilized these services. Similarly, consumers in these regions – plus

Source: B&A analysis of service claims data provided by DADS

the El Paso area – are more likely to use the consumer-directed option. These facts imply that the more rural areas of the State lack choice in providers and, particularly, specialized providers. These areas appear to compensate by relying much more heavily on day habilitation services.

The highest per-capita spending in the HCS waiver occurs in the more rural areas of the State. In general, consumers in these regions are more likely to live in paid residential placements and, since these services are costly, these areas have higher average costs. As with the CLASS waiver, one of the likely drivers of the higher incidence of paid residential placements in rural areas is the lack of alternative services. Also similar to the CLASS waiver, HCS consumers in rural areas utilize more day habilitation services than individuals in more populous areas.

General Revenue Services

As noted, the CLASS and HCS waivers are not sufficiently funded to enroll everyone who is eligible and more than 78,000 are on an interest list waiting for services, which is more than any other state according to the 2010 UCP *The Case for Inclusion* report. To provide some level of services to individuals who are not enrolled in one of the waiver programs, Texas provides general revenue (GR) dollars to provide state-only funded services.

In fiscal year 2010, \$110 million in general revenue funding was distributed to the local MR authorities in amounts ranging from \$509,000 to \$13.1 million. The funds are intended to be used to help consumers remain in their own home. Individuals eligible for GR funded services are those that have mental retardation or a pervasive developmental disorder including autism, certain nursing facility residents, and children eligible for early intervention services. DADS directs the local MR authorities to give priority to individuals with the “most intense needs”, including those at risk of losing his/ her support system, especially the living arrangement or supports needed to maintain self; at risk of abuse or neglect; whose basic health and safety needs are not being met through current supports; at risk for functional loss without intervention or preventive or maintenance services; or who demonstrates repeated criminal behavior.

Allowable services are generally those covered by the CLASS waiver, including case management, habilitation, transportation, employment assistance and supported employment,

respite, nursing, behavioral support, specialized therapies, vocational training, and in-home family support. Home modifications and adaptive aids are not permissible. Though covered services are similar to those in the CLASS waiver, an individual receiving GR funded services receives much less support than consumers enrolled in the waiver. The local MR authorities report spending between \$3,000 and \$6,000 per consumer compared to the CLASS waiver's average per-capita spending of \$35,000.

Health and Human Services Commission

The Health and Human Services Commission administers the traditional Medicaid program in Texas to provide medical insurance to low-income individuals. HHSC delivers services on a fee-for-service basis as well as through capitated managed care plans. HHSC utilizes more than one fee-for-service model, but the common feature is that hospitals and providers contract directly with HHSC and are reimbursed on a per-service basis. In the STAR and STAR+PLUS programs, in contrast, HHSC contracts with health plans and pays them a monthly capitation rate for each enrolled consumer and the health plan is responsible for ensuring that individuals receive the services that they need.

The STAR+PLUS program is operated under a Medicaid Section 1915 (b)/ (c) waiver. This program for individuals with physical or mental disabilities who qualify for supplemental security income (SSI) places responsibility for all of a consumer's medical needs – acute care, long term care, and behavioral health – with a single managed care organization (MCO). Participation in the program is mandatory for qualifying individuals in the Bexar, Harris, Harris Expansion, Nueces, and Travis service areas (Dallas and Tarrant service areas will be added in 2011). Individuals in ICF/ MRs or enrolled in a DADS waiver program are ineligible. Consumers may select any MCO contracting in their service area, and that MCO is paid a fixed monthly rate for each consumer.

Other Programs

There are other programs that reach more limited numbers of adults with ASDs, including higher education support, employment services, and housing programs.

Higher Education

Community colleges and universities must make accommodations for individuals with disabilities, including those with ASDs. These accommodations could include assistance with note taking or additional time to complete an exam, but generally do not include supports in daily living or socialization that young adults with ASDs often need in order to be successful in college. There are programs at some colleges, however, that have been designed specifically to support individuals with ASDs.

For example, Midwestern State University started its Autism Support Program (ASP) in 2008. The program provides a residence for 2-3 students with an ASD and a like number of students without an ASD who are special education majors and who serve as peer mentors. This model provides mutual benefits; the peer mentors gain experience working with individuals with special needs while the individuals with ASDs receive counseling, socialization assistance, study hall, and experience living more independently. Of the original participants with an ASD, one student now lives with a peer mentor in a campus apartment and another is in a traditional residence hall. ASP continues to provide supports to these students as needed. The Texas Legislature has provided funding for the program through May 2011.

Similar programs are not available at all Texas institutions of higher learning and even this program is currently reaching only five consumers so few young adults with ASDs have access to such comprehensive supports in college.

Workforce Programs

The Texas Workforce Commission (TWC) is responsible for coordinating a number of employment programs, most of which are funded by the federal Department of Labor (DOL) and delivered through employment one-stops in 28 local workforce investment areas. In general vocational rehabilitation programs are partners in the one-stop system, but most of the services delivered through the system are designed for “traditional” low-income job-seekers rather than individuals with disabilities.

To address the difficulty that individuals with disabilities have historically had in accessing services through the one-stop system, the federal government began funding the disability program navigator initiative in 2003. The intent of the initiative was to increase access to employment and training services and employment opportunities for individuals with disabilities, strengthen relations between one-stop programs and community organizations to better coordinate service delivery, provide information and support to businesses to improve their capabilities in hiring and retaining job seekers with disabilities, and act as liaisons between individuals with disabilities and the one-stop system by assisting individuals to access one-stop services. There is currently a navigator in each of the 28 local areas across the State. Beginning in fiscal year 2009, TWC began fully funding the statewide initiative after DOL eliminated disability navigator grant funding. Despite progress made through the navigator initiative, one-stop systems across the nation continue to struggle with providing services to individuals with disabilities.

Housing Programs

Most housing-related programs are federally funded. In some instances the funds are granted directly to local governments or service providers. For programs administered through the State, the funds are handled by the Texas Department of Housing and Community Affairs (TDHCA). As is the case for TWC, most TDHCA programs do not specifically target individuals with disabilities although much of the focus is often on individuals with physical disabilities, which is a larger group than those with intellectual and developmental disabilities.

There are some funds that are earmarked for individuals with disabilities. For example, the federal Section 811 Supportive Housing for Persons with Disabilities grant provides capital grants and project rental assistance to nonprofit developers of housing for individuals with disabilities. Several Texas nonprofits have received funding from this grant, including programs serving adults with ASDs. A portion of Section 8 funding is set aside for housing vouchers for individuals with disabilities and the HOME and Community Development Block Grants may be used to construct or rehabilitate housing for persons with disabilities. TDHCA reports that incentives are provided in certain programs to serve priority populations, which may include individuals with disabilities.

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SECTION 5: GAP ANALYSIS

While there are a number of positive features of programs available to adults with autism spectrum disorders and related disabilities, such as the person-centered focus and consumer directed options under DADS' waiver programs as well as a large core group of parents, providers, and others who are dedicated to improving outcomes for all adults with ASDs, there are significant gaps in the type and amount of services available for adults with ASD as well as the comparability of services across regions of the State.

Many Texas stakeholders who provided input for this study, particularly parents and caregivers, express dissatisfaction with the existing system. Some of these gaps, such as waiting lists, a lack of services for young adults transitioning out of the public education system, and system fragmentation are applicable to all individuals with intellectual and developmental disabilities. Others are more unique to individuals with autism spectrum disorders including programs that lack services needed by the consumers such as behavioral supports and providers without experience working with adults with ASDs. Families spoke passionately about the failures that these system deficiencies are causing across the autism spectrum: young adults that are regressing after leaving the public school system, poor employment outcomes, and consumers that do not have opportunities to lead enriching lives.

Insufficient Resources

There are more than 78,000 individuals with intellectual and developmental disabilities waiting for home and community-based services through the CLASS and HCS waivers. An estimated 4,000 of these individuals are adults with an ASD.

The number of individuals that are unable to access services correlates directly with the resources invested in programs for individuals with intellectual and developmental disabilities. According to the annual *Residential Services for Persons with Developmental Disabilities* study (Lakin, et al.)¹², spending for home and community-based services (such as those provided through the HCS and CLASS waiver programs) per Texas resident was \$28.71 in 2008.

¹² <http://rtc.umn.edu/docs/risp2008.pdf>

Compared to the other states, this is the second-lowest per capita contribution to these services ahead of only Mississippi.

Insufficient funding was an issue that was mentioned by the vast majority of stakeholders, whether consumers, families, providers, or local MR authorities. Figure 12 reports the responses received for the online survey question relating to the adequacy of system funding. More than half of both provider and family respondents chose the lowest ranking, very inadequate. Almost 90 percent of providers responded negatively to this question.

Figure 12: Responses to the Question “How would you rate the adequacy of funding allocated to services for individuals with ASDs?”

	Family (n=60)	Providers (n=38)
Very Adequate	5%	3%
Somewhat Adequate	8%	5%
Neutral	12%	5%
Not Very Adequate	20%	37%
Very Inadequate	55%	50%

Source: Compilation of B&A’s online survey, open from June 9 to July 19, 2010

When their adult child is unable to access services due to waiver funding limitations, parents report that their adult children do not reach their potential. They are unable to obtain a job and do not have other meaningful activities to occupy their day. This can lead to frustration and acting out.

“My son... was put on a waiting list in 2007. We are still waiting for services, and it is my understanding we will be waiting several years. In part due to this, he has spent time in a mental health commitment and in jail.”
-Mother of a 23 year-old with an ASD

Caregivers are also affected when their family member is unable to access services. If the adult with an ASD is unable to be at home for an extended period of time without supervision, the caregiver may have to stop working or pay out-of-pocket for attendant care. If these are not options, the consumer may need to be placed in residential care at a greater cost to the State.

For those individuals who do have a waiver slot, per consumer spending in the CLASS waiver compares favorably to supports waivers in other states, but HCS spending is on the low side for a comprehensive waiver. Common complaints of families with relatives in the HCS waiver are the

lack of coverage of the specialized therapies that are available in the CLASS waiver, the low spending cap for supported employment, and the omission of coverage for prevocational services. Further, since HCS requires consumers to have a mental retardation diagnosis and CLASS does not provide housing supports, there are no significant residential options for higher-functioning adults with ASDs.

Services Are Not Designed for Individuals with ASDs

Even for those fortunate enough to be enrolled in a waiver program, there are a number of gaps in the system. A frequent frustration expressed by stakeholders was that existing services do not “fit” adults with autism spectrum disorders. Individuals with ASDs generally receive services through programs designed for persons with mental illness or other intellectual or physical disabilities. These populations are much larger than the number of individuals with ASDs, at times resulting in less focus on the unique needs of this group. In Texas, consumers with an ASD are barely one percent of the vocational rehabilitation caseload and adults with an ASD are only 16 and 7 percent, respectively, of the CLASS and HCS adult caseloads.

Consequently, it is not surprising that the services that are provided to adults with ASDs are often ill-fitting, leading to frustration amongst

*“Providers want individuals with ASD to ‘fit’ into their existing programs.”
-Mother of a 28 year-old with an ASD*

consumers and families. This is true for many of the individuals who shared their thoughts on this study. As part of the online survey and during interviews and focus groups, questions were asked regarding various services, including employment, day activities, housing, and case management, etc. The most common complaints related to the structure of services and the expertise of the staff delivering these services. At the same time, many parents whose adult children received services from providers that specialize in ASD expressed satisfaction with these agencies. This dichotomy – a general sense that services and providers overall are not meeting the needs of adults with ASDs, but that there are a relative handful of exceptional providers – is reflected in responses to the online survey, which asked for respondents’ perceptions of providers’ knowledge.

Figure 13 shows that, although both families and providers were as likely to say that professional staff and direct support workers are very or somewhat knowledgeable as they were to report that they were not very or not at all knowledgeable, approximately 40 percent provided a negative response.

Figure 13: Responses to the Question “How would you rate the knowledge and skills of the [staff type] who deliver services to individuals with ASDs?”

	[“professional staff”]		[“direct support worker”]	
	Family (n=59)	Providers (n=41)	Family (n=51)	Providers (n=39)
Very Knowledgeable	19%	20%	16%	15%
Somewhat Knowledgeable	20%	20%	24%	21%
Neutral	24%	17%	22%	18%
Not Very Knowledgeable	27%	39%	24%	33%
Not at All Knowledgeable	10%	5%	16%	13%

Source: Compilation of B&A’s online survey, open from June 9 to July 19, 2010

Probing these responses, several consumers and families felt that programs were not meaningful enough for adults with ASDs or did not take into account their abilities. They stated that too many day habilitation programs provide little more than “baby-sitting” with activities that were “appropriate for pre-schoolers but not for disabled adults”. Similarly they feel that many of the jobs in which adults with ASDs are placed are beneath their skills levels. Although similar comments were made in relation to services for adults across the autism spectrum, most of this feedback was concentrated among consumers with an ASD but without mental retardation and their families. The consensus among this group was that day programs and employment opportunities were designed for individuals with mental retardation and may be appropriate for this population, but do not meet the needs of adults with ASDs, particularly those with high-functioning autism or Asperger’s.

At the other end of the spectrum several families reported that some providers are unwilling to work with adults with challenging behaviors. One parent reported that her son tried three different residential placements and was asked to leave all three because of challenging behaviors. The lack of behavioral supports in general and as components of other services is another example that parents noted to illustrate a system that is not designed for individuals with ASDs. Families, local MR authorities, and providers reported that adults with ASDs can benefit

from such services, including applied behavioral analysis. However, in the CLASS waiver program only four adults with ASDs received behavioral support services between July 1, 2008 and June 30, 2009. In the HCS program 233 adults with ASDs received this service, but these

*“My adult son is athletic and had a job reflecting this interest after he got out of high school. And then they changed his work schedule. The employer called the police because of his aggressive reaction. Now he is on the couch.”
-Mother of a 24 year-old with an ASD*

consumers received, on average, fewer than five hours over this 12-month period. Expanding access to applied behavioral analysis, especially through board certified behavior analysts (BCBA), was identified by the local MR authorities and families as one of the most pressing needs in the existing menu of supports.

There are structural impediments to the development of autism-specific services identified by study participants, including:

- wages, particularly for day habilitation workers and attendants, that are too low;
- an HCS waiver requirement that providers serve everyone that requests their services discouraging specialization (which a number of stakeholders oppose, due to concerns about disadvantaging other disability populations); and
- lack of providers in general, and professionals such as BCBAAs in particular, in rural areas of the State, resulting in part from the lack of differentiated reimbursement rates that may be discouraging providers from locating in hard-to-serve regions.

Existing System Is Fragmented

For many consumers and their families, navigating the various programs can be overwhelming. When faced with major decisions – what will happen after high school? what resources are available? what waiver program is best for my/ my child’s situation? – consumers and their families often do not know where to turn. There is no single clearinghouse of information and resources. Also, with multiple state agencies and providers responsible for various components of the system, families report that the lack of overarching coordination is a hindrance to their adult child. Providers do not have a holistic view of the consumer so, rather than working together to help the individual achieve his/ her goals, services are delivered in a vacuum. Two of

the prominent examples that stakeholders identified are transition from the public schools and case management.

Transition from the Public Schools

Nearly every stakeholder participating in this study expressed negative sentiments regarding transition services as summarized in Figure 14. More than 90 percent of the families responding to this question answered that transition services were not very or not at all effective; no other question received a higher proportion of negative responses. Although providers were somewhat less negative, 80 percent still rated transition services as not very or not at all effective.

	Family (n=46)	Providers (n=35)
Very Effective	2%	9%
Somewhat Effective	2%	6%
Neutral	4%	6%
Not Very Effective	44%	49%
Not at All Effective	48%	31%

Source: Compilation of B&A's online survey, open from June 9 to July 19, 2010

Without appropriate supports to replace the school environment, an individual may lose many of the gains they made while in school. A number of parents reported that this is exactly what has occurred with their adult child, sharing personal stories about their children who did not have meaningful activities to fill their day after high school, and instead watched television or played video games. Even in instances in which employment was secured after high school, a number of parents reported that an absence of appropriate supports led to the loss of a job. Due to the resulting turmoil in their lives, these young adults became less happy and displayed more negative behaviors.

Stakeholders identified a number of causes for failures during the transition out of the public school system:

- schools are more focused on “paperwork” than on helping young adults to be successful post-high school;
- school staff without adequate knowledge of services that may be available; and
- local MR authority and DARS representatives that are not available to participate in ARD meetings to discuss transition planning.

*“Transition was really just a few meetings during which I figured out that my son’s post-school programming would be totally up to me. I was right.”
-Mother of a 24 year-old with an ASD*

Transition planning is further complicated because there is often “nothing to transition to.” Federal law provides an entitlement for services through the public schools until an individual’s 22nd birthday, but no similarly broad entitlement exists for services after public school. Thus, if a consumer is not already enrolled on one of the DADS waivers, he/ she will not have access to a broad array of support once they leave high school.

Many parents reported that a lack of post high school supports to maintain their children at home resulted in the need for out-of-home placements. Maintaining consumers in paid residential placements is very costly. Between July 1, 2008 and June 30, 2009, annual HCS costs for an adult with an ASD receiving residential supports were almost \$30,000 greater than those living with family. Although some post-high school residential placements will continue to be necessary and at times desirable, even small reductions to the proportion in an out-of-home setting could produce large savings.

Case Management

Assisting families in navigating the various systems is, or should be, the responsibility of the consumer’s case manager. Several families that shared their opinions over the course of this study spoke about how much they appreciated their case manager or counselor and the help that they provide. However, a number of others expressed just the opposite, that although they are generally nice people they do not have the skills, knowledge, or institutional support that are necessary to be effective. Figure 15 illustrates the mixed opinions that families have.

Figure 15: Responses to the Question “How effective is Case Management for adults with an ASD?”

	Family <u>(n=59)</u>	Providers <u>(n=45)</u>
Very Effective	17%	24%
Somewhat Effective	20%	31%
Neutral	25%	20%
Not Very Effective	22%	16%
Not at All Effective	15%	9%

Source: Compilation of B&A’s online survey, open from June 9 to July 19, 2010

An equal number of family members report negative opinions as those with positive impressions. Providers had much more favorable perceptions of case management.

Respondents most often noted that failures occur because the case manager does not have experience in working with individuals with an autism spectrum disorder or even an understanding of the condition because no specific training geared towards ASDs is required.

*“Case managers work for one agency, but we have to deal with three agencies, and it seems that none of the three knows what the other two are really doing”
-Mother of a 17 year-old with an ASD*

Additionally, many families stated that a case manager may know the details about their program, but they frequently lack knowledge of other services that may be available. For example, a DARS counselor can facilitate vocational rehabilitation services but does not

know what is available from the waiver programs, or a CLASS case manager can assist a consumer with waiver services but is unaware of community resources.

Stakeholders identified a number of systemic barriers that make it difficult for case managers to be effective in meeting the needs of adults with ASDs:

- no specialized training to familiarize case managers with ASDs and how to work with people with these conditions;
- high caseloads make it difficult for case managers to spend much time with the individuals to whom they are assigned;
- low pay; and
- high turnover, which prevents case managers from gaining practical experience.

A surprising number of parents reported that they abandoned their careers to, effectively, become their child’s case manager. For most families, this is not a feasible option. Even for those that are currently filling this role, in addition to the personal sacrifices that are required they expressed concerns about how their children will fare when the parents are no longer able to care for them.

Employment Outcomes Are Poor

When discussing specific services, consumers and their families were most critical of employment supports. Consumers and family

*“Employment services were not at all effective!”
-Mother of a 28 year-old with an ASD*

members believe that adults with ASDs and related disabilities can, and should, work. Doing so provides a meaningful way for consumers to spend their day, builds self-esteem, and allows them to contribute to the economy and the cost of their care. Stakeholders report broad dissatisfaction with employment services as summarized in Figure 16.

Figure 16: Responses to the Question “How effective are Employment Services for adults with an ASD?”

	Family (n=50)	Providers (n=45)
Very Effective	8%	11%
Somewhat Effective	14%	16%
Neutral	6%	11%
Not Very Effective	32%	53%
Not at All Effective	40%	9%

Nearly three quarters of families felt that employment services are not very or not at all effective. The majority of providers also reported a negative impression, though were far less likely to state that employment services were not at all effective.

Source: *Compilation of B&A’s online survey, open from June 9 to July 19, 2010*

Vocational rehabilitation programs across the country have struggled to generate successful employment outcomes for adults with ASDs. According to George Washington University’s Institute on Rehabilitation Issues’ 2007 *Rehabilitation of Individuals with Autism Spectrum Disorders*¹³ report, individuals with ASDs were 1.5 times more likely to have an unsuccessful closure than a successful closure, which means that of 100 average closures only 40 were successful. During that same period, out of 100 average closures for the entire vocational rehabilitation population, 57 were successful. Consumers and parents shared numerous stories about how vocational rehabilitation programs have not met their needs.

In fact, of all the agencies providing any services to adults with ASDs, respondents were most critical of DARS, stating that the agency is too likely to determine that an adult with an ASD will not benefit from services and determine them ineligible, too often does not participate in ARD meetings and transition planning, provides supports that are too limited, and places individuals in

¹³ <http://gwcre.org/images/uploads/32IRI.pdf>

inappropriate jobs. Parents are also troubled by the time-limited nature of DARS supports, which are generally limited by federal law to 18 months.

DADS also reports poor employment outcomes. In a recent letter¹⁴, the Department noted that of the nearly 35,000 individuals with an intellectual or developmental disability to whom DADS delivered day services only eight percent received employment supports. The letter also stated that the national average was 24 percent. Several stakeholders noted that the rates that DADS pays for employment supports through the CLASS waiver are considerably less than DARS, which makes it difficult to find a qualified (or any) provider. The CLASS rate may be appropriate for attendant care types of employment supports, but is inadequate for services requiring greater provider skills, such as job development. Additionally, although paying competitive rates, the HCS waiver limits supported employment to \$3,000 per year.

Stakeholders suggested a handful of other factors contributing to poor employment outcomes. As discussed earlier, providers' lack of expertise in working with individuals with ASDs was mentioned frequently. Even those families who have worked with the TWC disability navigators reported that these specialists do not understand autism and are ineffective. Respondents also noted that the employer community does not understand autism spectrum disorders and are therefore reluctant to hire and make accommodations for adults with ASDs. Reliable transportation to and from a job was also noted as an impediment to employment. All of these barriers are exacerbated in rural parts of the State.

¹⁴ <http://www.dads.state.tx.us/providers/communications/2010/letters/IL2010-99.pdf>

SECTION 6: PILOT PROGRAMS

The following three pilot options for adults with autism spectrum disorder and related disabilities are designed to meet the requirements of HB 1574 and other criteria established by DADS, and evolved directly from analyses of best practices, existing systems in the State, and identified service gaps. Appendix A provides a table that details, compares, and contrasts the three options.

Placement of the pilot projects is a key decision. Funding limitations require a limited geographic focus for the three pilot options. There are significant disparities in the availability of services across the State, which is not surprising given the diversity of the State. Although not strictly designed to address underserved areas, the location of pilot projects should consider opportunities to simultaneously begin to address these gaps. Directing a portion of any investment of funds to underserved areas would yield substantial benefits beyond the pilot participants as local capacity is expanded and a more comprehensive array of services becomes available. Selection of pilot sites should be driven by:

- the diversity of geographic regions across Texas (population density, ethnicity, strength of the school district, etc.);
- the demand for services (e.g., enough consumers to justify pilot implementation);
- existing capacity in the community; and,
- community interest.

The pilot options assume that DADS will issue a request for proposals (RFP) for development and implementation of one or more of the selected pilots. There is a wide range of need along the autism spectrum and the different regions of the State have varying needs, strengths, and capacity. As a result, there is not a one-size-fits-all approach that will be right for everyone everywhere. The pilots, therefore, are intended to provide an overall framework through which individualized services may be provided. The pilots are broadly designed to include enough flexibility to encourage innovation through the RFP process. Such innovations should be evaluated to determine their applicability on both large and small scales.

Start-up time for the pilots will be between six and 24 months and each is then proposed to operate for a two year evaluation period. During and after the period, the outcomes of the projects will be evaluated and reported by DADS to the Legislature to determine whether to expand the programs to other parts of Texas. If demonstrated to be effective, each pilot program has the potential to be expanded incrementally as community and state resources become available. Considering procurement and start-up timelines and the two-year evaluation period, there is likely to be only limited data available for the legislative session beginning in January 2013. More comprehensive outcome data will be available for the session beginning in 2015.

Common Elements

Although distinct, the three pilots share several common elements.

Administering Agency

While a number of agencies are involved in providing services to adults with ASDs, the success of the pilot programs will depend to a great extent on the designation of a single entity to pull together all of the State's resources. DADS is the logical administering agency for any pilot project for a number of reasons:

- administration of existing home and community-based services waiver programs;
- understanding of ASD and related conditions;
- involvement with the ASD resource center also established by HB 1574;
- oversight of and contracting with local MR authorities and Aging and Disability Resource Centers; and
- expertise in soliciting federal grants.

Assessment

Participation in the three pilots will not rely on diagnosis per se, but each will require the use of an assessment tool:

- to determine which adults with ASDs and related disabilities with similar support needs are eligible to participate;
- to guide care planning;

- to ensure Medicaid waiver level of care requirements are met; and
- in Pilots 2 and 3, to align resources to assessed needs.

The Adaptive Behavior Assessment System-Second Edition (ABAS-II) is recommended for the pilot projects. The ABAS-II is a norm-referenced instrument that provides a comprehensive evaluation of an individual's strengths and weaknesses in ten adaptive skill areas across three key domains (conceptual, social, and practical). Scores can be derived for the three adaptive domains and a General Adaptive Composite (GAC). It is appropriate across the life span and yields standard scores and age-based percentile ranks. This is a simple tool to administer, requiring only 15 to 20 minutes, and allows for multiple raters. Prior to implementation DADS will develop the score thresholds that pilot participants must meet.

Training Requirements

The lack of ASD-specific expertise in existing programs was identified as a deficiency in the current system. To address this gap, each of the pilots include training requirements for all stakeholders – consumers, support coordinators, providers (both professionals and direct support workers), community organizations, etc. Both the Connecticut and Pennsylvania programs discussed in Appendix B include similar requirements. DADS would import or develop training guidelines and materials appropriate for Texas. Additionally, organizations selected as pilot sites should be required to have a consumer or family member on the Board of Directors or as staff to advise the organization on pilot policies and procedures.

Facilitating Employment

Poor employment outcomes is one of the critical gaps identified by stakeholders. In addition to specific employment strategies embedded in the pilot options, there are two overarching strategies.

The first is the establishment of a tax credit for private employers that employ adults with ASDs and related disabilities. The credit would be modeled after Texas' existing TANF and Medicaid credit for employers with workers that formerly received assistance from these programs. The credit against franchise, sales and use, and other taxes is equal to 20 percent of the wages paid to

the employee with a maximum credit of \$2,000. A credit for employing adults with ASDs and related disabilities would not have the wage and benefit requirements included in the TANF and Medicaid tax credit.

The second strategy is an increase in DADS' reimbursement rate for supported employment services in the CLASS waiver. The current supported employment provider rate under the CLASS waiver is a maximum of \$13.85 per hour while the hourly rate paid through the HCS waiver is \$33.83. In most instances, the CLASS and HCS waivers pay the same rate for the same service; this is one of the exceptions. Parents of adults in the CLASS waiver report that this rate creates a significant barrier to finding quality employment supports, particularly compared to the HCS rate and a reported DARS rate of more than \$30 per hour. It is possible that the rate is appropriate for some types of services (e.g., training and supervision), but not others (e.g., job development). DADS and HHSC should conduct a study of service specifications, provider requirements, and market rates for various supported employment services (e.g., assessment, job development, and training and supervision), to determine a rate or rates that will improve the quality and availability of services.

Reviewing the federal Bureau of Labor Statistics Occupational Employment Statistics, the employment category educational, vocational, and school counselors (occupation code 21-1012) best approximates the supported employment service. Though wages vary across the State, the May 2009 median hourly wage for this classification is typically \$25 or \$26 in Texas¹⁵. When combined with benefits, administrative, and other costs, the HCS and DARS rates provide reimbursement comparable to this median, but the CLASS rate significantly lags the market. The fiscal impact of increasing CLASS supported employment reimbursement would depend on the rate or rates to be adopted. If a single rate was maintained, at current utilization levels every 10 percent increase would cost about \$27,000 in total funds (\$11,000 in general revenue); adopting the HCS rate would increase costs by \$390,000 (\$156,000 in general revenue). If a higher rate led to greater utilization, costs would be greater.

¹⁵ <http://www.bls.gov/oes/current/oessrcma.htm>

Community Collaborations and Partnerships

A key component of all pilot options is collaborations and partnerships. While the specific relationships that need to be established differ by pilot design, each pilot and pilot site must enlist community participation and commitment to meet the needs of adults with ASDs. These collaborations and partnerships could include:

- Aging and Disability Resource Centers
- Housing Authorities
- Employers
- State Supported Living Centers
- Primary Care Physicians
- Mental Health Agencies
- Arcs
- Autism Societies
- Foundations
- Providers
- Universities
- Graduate Training Programs
- Centers for Independent Living
- Parent and Consumer Groups
- Nonprofits
- Religious organizations

Evaluation

Decisions regarding pilot continuations or expansions would be based on a quantifiable evaluation to ensure that public dollars are used effectively. Key measures include:

- consumer and family satisfaction;
- number of consumers in competitive employment, hours worked, wages and benefits, etc.;
- number of consumers in various living situations, including with family, independently, group home, etc.; and
- average cost per consumer.

To compare these variables, DADS would develop a baseline profile of each participating consumer. Additionally, there should be an attempt to identify a comparison population. These consumers could include CLASS or HCS waiver participants or individuals receiving services through the local MR authorities. The comparison population should mirror the participating group as closely as possible in terms of region (given the significant service variability that currently exists across the State), age, diagnosis, and functional status. At six month intervals, the measures of the participating consumers would be compared to their own baselines as well as to the comparison group allowing for early and ongoing identification of any trends or issues.

Pilot Differences

Though sharing these foundation elements, the pilots differ in the gaps that are addressed, programs structure and services, anticipated benefits, and funding requirements. The following summaries outline each of the options, which are further detailed in Appendix A.

Pilot 1: Specialized Support Coordination and Community Connection

The first pilot option is intended to benefit consumers through enhanced connections to local, state, and federal assistance programs facilitated by specialized support coordinators and “peer support” as well as a funding pool to assist development or expansion of local capacity.

Gaps Addressed

This pilot is intended to address the following system gaps:

- a fragmented system of programs and services;
- lack of specific knowledge and expertise related to ASDs among case managers; and
- insufficient resources to meet the needs of adults with ASDs.

Program Structure and Services

Three sites serving a total of 210 consumers would be selected for this pilot option. Each pilot site would have two support coordinators for 70 adults with ASDs, 35 who are currently receiving DADS waiver services and 35 who are not. For those enrolled in a waiver, specialized support coordination offered through this option would replace the case management they currently receive. A variety of organizations may be interested in participating, including ADRCs, local MR authorities, Arcs, and universities.

Specialized support coordinators would receive training on working with adults with ASD and would have an ASD-only caseload. Specialized support coordinators would be experts on state and community resources as well as federal benefits such as Supplemental Security Income (SSI) and supplemental nutritional assistance (formerly called food stamps).

Each pilot site would be expected to:

- assess community needs and monitor service gaps and unserved and/or underserved adults within the geographic area covered by the pilot;
- expand service capacity through development of a network of partners and providers committed to serving adults with ASDs;
- expand community resources by identifying non-State spending on Medicaid-eligible services that the State would certify in order to allow Medicaid funds to be claimed for these local expenditures;
- provide network, resource, and referral services for adults with ASDs in the area who are not receiving specialized support coordination;
- provide estate planning for older caregivers and/ or link families to professionals trained and willing to provide such services at low cost;
- support families who are able and willing to privately pay for appropriate services; and
- operate community education and outreach programs.

Additionally, a new “peer support” service would be established to connect participants with caregivers who have successfully pieced together an appropriate array of services for their adult relative with autism. This service would complement specialized support coordination by connecting consumers and families with caregivers who have practical experience in navigating the various systems of support. Caregivers providing peer support would be compensated according to a statewide rate to be developed by DADS and HHSC.

Finally, this pilot option includes \$2.0 million in general revenue funding designated as a pool to incentivize pilot sites to obtain private and federal contributions for program services. The funding pool establishes a public-private partnership designed to motivate foundations and private citizens to make donations that will be “doubled” with a dollar-for-dollar state contribution. Funds may also may be used to provide match for federal grants where required. The timing of initiatives associated with the funding pool will be dependent on federal and private grant cycles so it will take time to build this capacity.

Program Benefits

- Designating a single support coordinator to be responsible for all services that a consumer receives, regardless of the entity providing funding or delivering the services, addresses the issues of fragmentation and creates a seamless support plan for pilot participants.
- Based on individuals' person-centered plans, support coordinators will assist consumers and their families in identifying resources that, while not as robust as the waiver programs, will provide greater support than they current receive.
- Establishment of linkages to community resources.
- The funding pool, which when matched will total at least \$4 million; will build capacity in the areas in which the pilot is operating (which could be anything from organizing a picnic or other community event to purchasing a van to provide transportation).
- Increased consumer and family satisfaction.

Funding Requirement

The estimated total cost of this pilot over two years is \$4.6 million, including \$4.4 million in general revenue. Other than support coordination provided to consumers already enrolled on a Medicaid waiver program, all of the costs would be borne by general revenue dollars. The matching pool is projected to generate at least \$2 million in new non-State resources.

Pilot 2: Full Service Continuum

The second pilot includes a significantly more expansive approach than Pilot 1. This pilot builds on the foundational elements of the first option, including specialized support coordination and peer support services, and adds a comprehensive continuum of home and community-based services from in-home supports to independent living to residential alternatives. This pilot is envisioned as a Medicaid waiver program with a service package that builds on the service packages covered by the HCS and CLASS waivers.

Gaps Addressed

The pilot would begin to address many of the gaps identified by stakeholders including:

- insufficient resources to meet the needs of adults with ASDs;

- lack of residential alternatives;
- lack of specialized services; and
- poor employment outcomes.

Program Structure and Services

The second pilot option utilizes an assessment-informed resource allocation model that considers an individual's needs and strengths as measured by his/ her ABAS-II score. This score, coupled with consumers' living environment (e.g. living at home, independently, in a group home) and natural supports, would be used to assign budgets for services. Individuals with greater needs would receive larger budgets and individuals with similar needs would receive similar budgets. Using person-centered planning principles, consumers would then have the flexibility to direct their budgets to the services that are most important to them.

All services currently offered by either the HCS or CLASS waiver would be covered and reimbursed according to existing fee schedules, but service definitions and provider qualifications would be revised to meet the needs of adults with ASDs. The service package would include the following features.

- Rather than service level limitations (e.g. specific unit limits for each service in an individual's plan), control would occur at the budget level; generally, consumers would be able to purchase whatever covered services they wish, up to the cumulative budget limit (limitations on respite, dental services, environmental modifications, and assistive devices would remain).
- All participants would have a behavioral therapy plan and there would be expanded coverage of behavioral supports and therapies appropriate for adults with ASDs.
- An emphasis on supported employment services (job development, individualized assessment and job search, and training and supervision) as well as self-employment planning and support.
- Expansion of residential options through new supported and supervised living alternatives such as models in which several individuals each have their own apartment (or share with a roommate) in a complex, but share common space and supports, as well as permitting parents

to purchase and own a residence while allowing a contracted provider to staff and run the home.

- Addition of crisis intervention services including designation of emergency home placements.
- Inclusion of a rate modifier for non-emergency transportation.
- Addition of specialized pharmacology counseling.
- Availability of self-direction for all services.

Through a procurement process, DADS would select a single entity to manage this pilot option in three sites across a range of geographic areas of the State. The selected organization would be responsible for building a network of providers qualified to deliver specialized services and providing training to all participants (support coordinators, providers, and families) for each of the sites.

A total of 300 consumers would participate. Consumers across the spectrum would be enrolled so that the pilot's effectiveness can be evaluated for individuals with varying support needs:

- approximately one-third would be high functioning adults, including those with Asperger's, to fill the significant gaps in access to services post high school.;
- another third should be lower functioning adults with ASDs who are either in residential care or likely to become candidates for State Supported Living Centers placement; and,
- the remaining third would be between these two ends of the spectrum.

These percentages are guidelines and would be adjusted as necessary based on community need.

Program Benefits

- Increase in the number of adults with ASDs accessing comprehensive supports.
- Incorporates the specialized support coordination benefits from the first pilot option, including a more seamless system of supports.
- Services specifically designed to meet the unique needs of adults with ASDs .
- Reduction in intensive residential placements (e.g. SSLCs) resulting in future cost avoidance.
- Improved employment outcomes.

- Increased consumer and family satisfaction.

Funding Requirement

The estimated total cost of this pilot over two years is \$34.9 million, including \$14.25 million in general revenue, which is comparable to the cost of providing services to consumers through the CLASS and HCS waivers.

Pilot 3: Transition and Employment Centers

Like the second pilot, the third option includes the specialized support coordination and peer support components of the first option, but this pilot moves away from the traditional service delivery model based on a network of providers. Instead, center-based programs would provide intensive employment and college preparation as well as independent living skills training to equip consumers with the skills they need for community living.

Gaps Addressed

This pilot option differs from the second pilot in terms of the model to deliver services, but seeks to address many of the same gaps:

- poor employment outcomes, particularly a lack of quality jobs for higher-functioning individuals;
- system fragmentation, with an emphasis on transition from the public school system;
- lack of residential alternatives; and,
- lack of specialized services.

Program Structure and Services

Three pilot sites would be selected to develop transition and employment centers with each serving 50 adults with ASDs. The centers would be responsible for participating in the development of a person-centered service, behavior, employment/ college, and transition plan for each individual that is designed to help consumers achieve their maximum level of independence and integration within the community.

Ten to 20 participants at each site should be older teenagers and young adults still in high school to target poor outcomes often resulting from the lack of behavioral therapy supports for adolescences with ASDs still in school and the absence of ASD appropriate services after high school. Center representatives would be expected to build relationships with area ISDs and attend ARD meetings for participating consumers. To the extent possible, ISDs should provide financial support for the services provided to their students through the centers.

Transition goals will vary from consumer to consumer; for some it will be a transition to college, for others independent living will be the goal, and for still others it will be a supervised setting. Participants will generally not be able to receive services through the employment and transition centers indefinitely. Time limits would be based on each consumer's individual transition plan, which could be 12 months for some individuals, but a longer period for others if the pilot is extended past the initial two-year authorization. Ongoing supports would be delivered through the second pilot option (or, if not available, though an existing DADS waiver program).

As in the second pilot, this option allocates resources for adult participants based on their assessed needs and strengths and the availability of natural supports. Using DADS' existing person-centered planning concepts, the consumer, their family, and the center would develop a service plan to meet the individual's objectives. The center would receive the individual's monthly budget allocation and use the funds to pay for services, outlined in the individual plan, provided by the center as well as services that the center does not provide directly, such as group home placement. This payment mechanism maximizes flexibility in the use of funds and provides cash flow for the center. Centers are also expected to obtain private and non-Medicaid federal dollars; a total of \$1.5 million is set as a target across the three sites.

A particular emphasis in assisting consumers to successfully transition to the community is addressing poor employment outcomes for adults with ASDs, including job placements that are below the abilities of many higher-functioning individuals. This pilot option includes an innovative employment program modeled after the Danish company Specialisterne, Chicago-based Aspiritech, Community Services for Autistic Adults and Children in Maryland, and the nonPareil Institute in Dallas. A key feature to this model is in-sourcing specialized work

following a consulting firm model and outsourcing work in a more traditional supported employment model. For in-sourced work, actual jobs would be based on the individual strengths of the consumers participating in the program and opportunities in the community. Examples could include publishing, graphics, and specialized computer work (companies elsewhere specialize in fields such as beta testing software and gaming, as well as data entry and more repetitive work for those with fewer skills). Work is priced at competitive rates, which is significantly greater than what most adults with ASDs are currently paid, and a portion of the income goes to support the center and provide employment opportunities to lower-functioning individuals.

Adults with vocational skills other than the specialized work to be performed in the center would be supported in jobs outside the center. Self-employment is a viable option for some adults with ASDs and the centers would help these consumers design and implement self-employment plans. Although it is an expectation that employment would be an option for the large majority of participants, for those consumers for whom competitive employment is not an option, the centers will support individualized meaningful day activities offered outside of the center. These activities could include quality day habilitation programming, volunteer work, or another community-based activity.

Coupled with assistance in developing skills necessary for the workplace (showing up on time, interacting with coworkers, etc.), the center would offer life skills training to provide consumers with the abilities they need to live independently as possible. Such skills training could include money management, accessing transportation, shopping, meal preparation, etc. The centers would work with area colleges and universities to develop supports for students with ASDs and provide appropriate behavioral, social, and communication training for those who wish to attend college. Behavioral, communication, and social support services as well as non-emergency transportation would be provided through the center.

The centers would also provide family home support and identify other living options. One of the three pilot centers will include onsite apartments with common space for some of the consumers in the program as they prepare to transition.

Program Benefits

- Increase in gaining and sustaining employment and higher wages for consumers.
- Incorporates the specialized support coordination benefits from the first pilot option, including a more seamless system of supports.
- Services specifically designed to meet the unique needs of adults with ASDs.
- Increased consumer and family satisfaction, and young adults and families transitioning into the pilot from school report less fragmentation of services.
- Successful, sustainable transition into the community after center participation.

Funding Requirement

Including an estimated per consumer cost of \$50,000 annually, capital start-up, and administrative expenses, the estimated total cost of this pilot over two years is \$22.1 million, including \$11.05 million in general revenue.

SECTION 7: POSSIBLE FUNDING OPPORTUNITIES

Funding the second and third pilot programs outlined in this report will be difficult given Texas' ongoing budget challenges. Availing itself of federal funds can help the State reduce the financial burden.

Nearly all federal grants are restricted in the purposes for which they may be expended. Various federal grants could be used to fund individual components of the pilot options. For example, certain Department of Labor grants could be utilized to support employment services and Department of Housing and Urban Development grants for housing supports. However, each of these grants is "capped" meaning that the total amount received by the State is fixed. These funds are currently fully allocated so redirecting dollars to the pilot options would result in an existing program losing funding. Further, these grants are administered by other state agencies, which would inhibit seamlessness. Due to these considerations, the aforementioned grants were excluded as options.

Medicaid Waivers

Medicaid is the one federal funding source that could be used to for most of the expenditures envisioned in the pilot programs and Texas will want to take advantage of these federal funds to support the cost of the pilots. There is not a cap on the amount of Medicaid funding that the State can receive; the federal government will continue to pay for Medicaid covered services provided to Medicaid eligible individuals so long as the State funds the non-federal share of costs. The services included in the pilots generally cannot be provided through traditional/ state plan Medicaid. However, Medicaid allows for waiver programs to provide for such services (and, as previously noted, Texas already has several authorized waiver programs). There are three primary types of waiver programs, which are described on the federal Centers for Medicare and Medicaid Services' (CMS) website¹⁶:

¹⁶ <https://www.cms.gov/MedicaidStWaivProgDemoPGL/>

Section 1115 Research & Demonstration Projects: This section provides the Secretary of Health and Human Services broad authority to approve projects that test policy innovations likely to further the objectives of the Medicaid program.

Section 1915(b) Managed Care/Freedom of Choice Waivers: This section provides the Secretary authority to grant waivers that allow states to implement managed care delivery systems, or otherwise limit individuals' choice of provider under Medicaid.

Section 1915(c) Home and Community-Based Services Waivers: This section provides the Secretary authority to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings.

States may also combine 1915(b) and 1915(c) waivers, resulting in the ability to waive freedom of choice in provider as well as all of the provisions that may be waived under standalone 1915(c) waivers. These combination waivers, however, do not formally permit waiving eligibility requirements.

The first pilot option is not envisioned as a waiver program and it is assumed that it would be entirely state-funded except for support coordination provided to individuals already enrolled in an existing waiver program. The State could consider amending the existing Medicaid waivers to cover peer support services as well as non-state-funded services that are identified and not currently covered by the existing waivers, but may not be able to limit these services to pilot participants, which would make it more challenging to manage costs.

The second and third pilot options are envisioned as Medicaid waiver programs, specifically requiring waivers of:

- comparability of services to provide supports to participants that differ from state plan services;
- state wideness so that the pilots can be limited to specified geographic areas; and,

- freedom of choice of provider so that consumers may be assigned to specific providers (Medicaid participants are otherwise permitted to choose their own providers).

Additionally, to be successful the State would need waivers that allow special treatment of income. The specific elements that would be necessary include:

- exclusion of supported employment related income from Medicaid eligibility determination;
- a maintenance needs allowance of 300 to 400 percent of the federal poverty level for individuals earning significant wages and living independently or in their family home;
- establishment of a share of cost for income greater than the maintenance needs allowance that may exceed the cost of services (for the third option this provision would remain in place until the center is self-sustaining but would not apply to adults who have transitioned to the community); and,
- allowing individuals participating in the pilots to maintain Medicaid waiver eligibility (provided they were eligible at the time of enrollment in the pilot) regardless of income.

There are several waiver strategies that have been considered for the second and third options.

Option 1: New 1915(c) Waiver

Ten states have developed autism-specific 1915(c) waivers. In only two of these states, Pennsylvania and Indiana, do the waivers cover adults (Indiana's waiver covers all ages while Pennsylvania's is limited to adults over 21 years of age). These states opted for separate waivers in order to:

- provide a specified number of slots for individuals with ASDs;
- develop a different cost-effectiveness test not reliant exclusively on the ICF/ MR level of care;
- include autism specific services without expanding coverage of those services to participants in other waivers;
- overcome the hurdle in their existing waivers requiring a mental retardation diagnosis; and,
- facilitate a specialization focus in autism spectrum disorders by support coordinators, the provider network, vocational rehabilitation, schools, and mental health agencies.

A separate, autism-specific 1915(c) waiver is strongly supported by some Texas stakeholders and equally strongly opposed by others. Option 1 was rejected because the 1915(c) waiver vehicle does not include the waiver authority for all of the provisions required by the pilots.

Option 2: Amendments of Existing Waivers

Consideration was also given to amending the existing CLASS and HCS waivers. This option was rejected for several reasons.

- The CLASS and HCS programs are both authorized under 1915(c), which, as noted in the first waiver option, do not include the authority for all of the provisions required by the pilots.
- Both waivers would have to be amended and negotiated with CMS, requiring added effort.
- The federal government may not approve a resource allocation model (as called for by the second and third pilot options) for a subset of the population (i.e. this change would affect only consumers with ASDs and not those with intellectual and developmental disabilities).
- Expanded and new services could not be limited to adults with ASDs.

Option 3: New Combination 1915(b)/(c) Waiver and

Option 4: Section 1115 Research and Demonstration Waiver

The two most viable options for the second and third pilot options (alone or in combination) are a new combination 1915(b)/(c) waiver or an 1115 waiver. Texas has experience with a 1915(b)/(c) waiver as this is the authority under which STAR+PLUS operates.

However, in keeping with the research and demonstration focus of the pilots, Texas should attempt to secure an 1115 waiver. The second and third pilots require waivers specifically related to eligibility determination and only an 1115 waiver has the clear authority to waive eligibility requirements. Both Arizona and Vermont utilize research and demonstration waivers to waive certain eligibility requirements. STAR+PLUS has a limited ability to do this out of profits under its 1915(b)/(c), but 1115 waivers are the most likely vehicle for facilitating these eligibility requirements. A research and demonstration waiver can also accommodate the other required elements summarized above, including waivers of freedom of choice of providers, state wideness, and comparability of services as well as authorizing the provision of home and

community-based services. Though an 1115 is the most likely option, selection between Options 3 and 4 should be based on a concept paper provided to the federal government and their resulting advice.

Non-Federal Funding

Increasing the number of individuals receiving services will require additional resources. Assuming that Medicaid will provide for 60 percent of the costs, Texas will still need to cover the other 40 percent. There are a few options for generating a portion of this revenue.

General Revenue Funded Services

As described earlier, the local MR authorities collectively receive \$110 million to provide services to individuals who are not enrolled in a Medicaid waiver. Many of these individuals are likely Medicaid-eligible; although they are not enrolled in a waiver because they are on the interest lists due to a lack of funding. Further, the GR funded services are often Medicaid waiver eligible. As a result, some portion of this \$110 million in general revenue is being used to provide Medicaid eligible services to Medicaid eligible individuals without receiving any Medicaid contribution.

If some or all of these consumers could be enrolled in a Medicaid program, the resulting federal financial participation would generate savings for the State. Creating savings would require that the cost of the services that consumers are receiving not exceed the current spending level. The goal of such an initiative, therefore, would be to continue to provide the same services to the same individuals with the only difference being that federal Medicaid funds would support 60 percent of the costs. Any resulting GR savings could be used to fund the pilot programs.

Capturing Medicaid funding for these services would require use of a limited supports Medicaid waiver with costs comparable to the \$3,000 to \$6,000 in supports that consumers receive in GR-only services. Texas pursued a similar strategy through the Texas Home Living Program (TxHmL), which was established in 2004 to provide community services for consumers receiving GR-only services. Converting GR-only consumers to Medicaid funding provided the

State the opportunity to expand services to these individuals or increase the number of consumers served.

To be eligible for TxHmL, a consumer must have a mental retardation diagnosis; an individual with an ASD but without mental retardation will not qualify. As with the HCS and CLASS waivers, an individual must also meet ICF/ MR level of care criteria. TxHmL case management is provided by the local MR authorities. The service package is similar to that of GR-funded services, with the waiver program also providing minor home modifications, adaptive aids, and dental treatment. The most frequently utilized services are employment assistance, respite, and day habilitation. TxHmL currently has a \$15,000 annual limit, which exceeds current average GR-funded services spending, but average per-capita spending is only about \$5,200, which is comparable to the cost of GR-funded services.

Transitioning current GR-funded consumers to a Medicaid-supported program could be accomplished either by enrolling individuals in the TxHmL program (if per-capita spending could be maintained near the GR-only funding level rather than the \$15,000 cap) or through the establishment of a new, more limited supports waiver. In the latter strategy, the service package would mirror those that are currently provided through GR-only funding. According to a study published by the federal Department of Health and Human Services, 17 states had supports waivers in 2006¹⁷. Most of these waivers had caps in excess of the current funding level that a consumer receives through GR-only services. There was, however, at least one exception: Washington's Basic Waiver had spending caps of \$1,425 to \$6,500. If Texas opted to pursue a new supports waiver to leverage existing GR spending, there is this precedent for a program with a cap equivalent to current spending levels.

Several local MR authority representatives expressed some concern with this proposal if it would result in a loss of funding. The State could alleviate this concern by tasking the local MR authorities with serving the additional TxHmL slots or new waiver participants. This strategy would also minimize disruption for consumers since they are already receiving services through the local MR authorities. This structure would maintain the same consumers receiving the same

¹⁷ <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm>

services from the same providers with the same amount of total funding; the only difference would be the funding split – Medicaid would be covering 60 percent of the costs.

If the entire \$110 million of GR-funded services were shifted to a Medicaid waiver program, the State would achieve savings of \$66 million. It is unlikely that every dollar could be shifted to a Medicaid program, however, and additional analysis is necessary. The intent of such a review would be to leverage federal funds without disadvantaging current consumers or impairing the local MR authorities' ability to maintain existing programs to provide emergency services or assistance to support consumers in their homes.

Expansion of Private Insurance Autism Mandate

During its 81st session the Texas Legislature expanded an existing mandate that private group insurers provide coverage of "generally recognized services" for individuals with ASDs, which include applied behavioral analysis; speech, occupational, and physical therapy; medications; and nutritional supplements. HB 451 increased the required coverage period from between the ages of two and six years to the date of diagnosis through the age of nine years old. However, the age limit is still less than what most other states with autism mandates require.

According to the National Conference of State Legislatures, 21 states had some mandate for coverage of autism-related services¹⁸. For the 17 states for which age limits were readily available, all were greater than Texas' limit with the lowest being 15 years of age. Seven states mandate coverage through the age of 21 (generally if the individual is still in school), and another five have mandates through 18 or 19 years of age.

Though generally not the primary purpose of such mandates, requiring private insurers to cover these services can reduce costs to the Medicaid program. For a Medicaid-eligible child or young adult who also has access to private insurance, Medicaid will only pay claims for services that are not covered by the private insurer. By expanding coverage requirements, additional costs are shifted to private insurers. It is unknown how much Texas would save by expanding the autism mandate. Reviewing HCS and CLASS claims, expenditures for psychological/ behavioral

¹⁸ <http://www.ncsl.org/?tabid=18246>

support services and occupational, physical, and speech therapy for those through the age of 21 years old is only about \$150,000. Specialized therapies total another \$3.0 million, but it is unclear what portion of these services would be covered. Additionally, comparable data from HHSC would have to be reviewed to determine how much is being expended for these services under Early Periodic Screening, Diagnosis, and Treatment.

Not all Medicaid expenditures on services that would fall under the autism mandate would be shifted to private insurance because a number of these children and young adults will not have access to private insurance. Conversely, a number of children and young adults who are not eligible for Medicaid would benefit as their insurers would now cover additional services. Thus, it is not anticipated that this strategy would result in a significant windfall, but it would generate some revenue while expanding coverage for children and young adults with ASDs.

SECTION 8: CONCLUSION

About half of the adults with ASDs receiving state-funded services or on a waiver interest list are between 18 and 25 years of age. Investing in these individuals now will yield dividends for the State. With appropriate supports, these adults will be able to achieve their full potential to live more independently, be involved in their communities, and work and contribute to the economy. Any delay in action will increase the human and economic costs of addressing the needs of this population.

Texas faces several challenges in addressing these needs. More than 78,000 individuals are on the interest list for the CLASS and HCS waivers, including an estimated 4,000 adults with ASDs, due to a lack of funding to serve these consumers. The existing system of supports is fragmented amongst numerous state agencies, local entities, and contracts, and generally lacks ASD-specific services. Despite these gaps, the State does have several strengths on which to build.

DADS has embraced the concepts of person-centered planning and, although some stakeholders report that its promise has not been fully realized due in large part to the barriers mentioned above, the foundation has been laid. Additionally, Texas has a sizable core group of self-advocates, caregivers, and providers that is committed to improving outcomes for adults with ASDs and could be a champion of systems change.

Based on research of best practices across the country and feedback from Texas stakeholders, this report outlines three pilot program options. Taken together, these pilots are designed to address each of the systems gaps that have been identified while expanding the number of adults with ASDs that are receiving home and community-based supports. These options are intended to serve as a framework to test new methods of connecting consumers to needed services.

Adjustments to the pilot outlines presented in this report will likely be necessary as DADS and HHSC work with the Texas Legislature. Once legislative approval is granted, DADS should move forward on two fronts. First, requests for proposals need to be written and released and responses must be scored to determine the entities that will operate the pilot programs. Second,

given the importance that federal funding will play in the second and third pilots, HHSC and DADS should engage CMS to determine which waiver option is most likely to be approved.

Each pilot is proposed to last for two years to ensure that evaluation outcomes are achieved prior to program expansion. If the pilots are achieving the desired results, including increased consumer and caregiver satisfaction, improved employment outcomes, more consumers living independently, and cost avoidance and savings, subsequent expansions incorporating program adjustments based on lessons learned can be pursued as funding and regional capacity becomes available.

New service delivery systems are not created overnight and establishment, evaluation, and potential expansion of any pilot program will occur over a period of years. The pilot options outlined in this report mark the beginning of this effort.

APPENDIX A: OVERVIEW AND COMPARISON OF COMPONENTS OF PILOT OPTIONS

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Administration and Purpose			
Appropriate Agency To Design and Administer	Department of Aging and Disability Services		
Start-up Time	6-12 months	12-18 months	18-24 months
Pilot Duration	Two years		
Gaps Addressed	<ul style="list-style-type: none"> • Insufficient resources <ul style="list-style-type: none"> • Consumers placed on interest lists due to a lack of funding • Services not designed for the unique needs of adults with ASDs • Limited expertise among case managers, professionals, and direct service workers in working with adults with ASDs • Lack of specialized training for case managers, professional staff, and direct service workers • Fragmentation in existing system • Lack of comprehensive case management 	<p>The gaps identified for Pilot 1 plus:</p> <ul style="list-style-type: none"> • Insufficient resources <ul style="list-style-type: none"> • Over reliance on public and private ICF/MRs due to the absence of residential alternatives and independent living supports • Un-served and underserved higher functioning adults • Poor employment outcomes 	<p>The gaps identified for Pilot 1 plus:</p> <ul style="list-style-type: none"> • Fragmentation in existing system <ul style="list-style-type: none"> • Ineffective post high-school transition planning • Poor employment outcomes • Insufficient resources <ul style="list-style-type: none"> • Over reliance on public and private ICF/MRs due to the absence of residential alternatives and independent living supports

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Requirements of HB 1574			
Encourage Sustainable Employment	<ul style="list-style-type: none"> The support coordinator will develop and execute with the adult and family the individualized plan of employment The support coordinator provides linkages to community resources after 18 months of DARS services 	<ul style="list-style-type: none"> The support coordinator will develop and execute with the adult and family the individualized plan of employment Expanded supported employment services 	<ul style="list-style-type: none"> The support coordinator will develop and execute with the adult and family the individualized plan of employment Center recruits work performed at the center and placements outside the center Expanded job-related training and monitoring College support and monitoring
Encourage Community Integration and Meaningful Community-Based Activities	<ul style="list-style-type: none"> Emphasizes community resources to support adults in their homes Provides access to resources for adults not receiving waiver services that will prevent some ICF/ MR admissions 	<ul style="list-style-type: none"> Directly targets reduction in SSLCs and ICF/ MRs Expands independent living supports and community residential alternatives 	<ul style="list-style-type: none"> Provides both independent living and family home supports as well as independent living skills training Offers employment opportunities at integrated employer work sites Transitions residents to independent living in the community based on each consumer's transition plan Provides community socialization Supports college placements
Promotion of Continued Individual Development and Avoidance of Regression	<ul style="list-style-type: none"> Provides linkages to services for adults not otherwise not receiving support that can contribute to avoidance of behavior regressions 	<ul style="list-style-type: none"> Builds services on the philosophy that all adults with ASDs with mental retardation can learn Allows the adult to use their intellectual and work skills in gainful employment 	<ul style="list-style-type: none"> Builds services on the philosophy that all adults with ASDs with mental retardation can learn Allows the adult to use their intellectual and work skills in gainful employment Develops social and independent living skills Provides supports for adults

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
			transitioning from school to reduce behavior regression
Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Requirements of HB 1574 (cont.)			
Promote of Self-Determination and Independence	<ul style="list-style-type: none"> • Requires person centered planning 	<ul style="list-style-type: none"> • Requires person centered planning • Allocation of annual funding level based on assessed need promotes self-direction • Allows for all services to be self-directed 	<ul style="list-style-type: none"> • Requires person centered planning • Provides support for independent living arrangements • Enhances opportunities for sustainable gainful employment
Coordinate Services and Behavioral Supports Across All Areas of Need	<ul style="list-style-type: none"> • Support Coordination provided to adults with ASD at all levels of need 	<ul style="list-style-type: none"> • Support Coordination provided to adults with ASD at all levels of need • All participants receive a behavior therapy plan • 	<ul style="list-style-type: none"> • Support Coordination provided to adults with ASD at all levels of need • Center provides services to adults with ASD at all levels of need
Allow for Flexible Funding and for a Flexible Array of Services	<ul style="list-style-type: none"> • Builds community partnerships • Monitors and fills gaps in service array • Uses private funding sources to maximize flexibility 	<ul style="list-style-type: none"> • Expanded ASD appropriate services • Allocation of annual funding level based on assessed need promotes self-direction 	<ul style="list-style-type: none"> • Dollars are distributed based on a funding level that can be use for services and supports that are appropriate to the needs of each adult

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Consumers			
Target Population	<p>210 consumers (70 each at three local sites) receive specialized support coordination</p> <ul style="list-style-type: none"> • Half currently receiving services through the CLASS or HCS waivers • Half not receiving waiver services <p>Resource directory and referral to network partners to any adult with an ASD</p>	<p>300 consumers (100 at each site)</p> <ul style="list-style-type: none"> • Approximately 100 who are high-functioning/ Asperger's • Approximately 100 who are lower-functioning (e.g. with mental retardation, significant assessed needs, and/ or minimal or no communication abilities) • Approximately 100 between the two ends of the spectrum <p>All must be Medicaid waiver eligible Excludes individuals with co-occurring substance abuse or psychotic conditions</p>	<p>150 consumers (50 each at three sites)</p> <p>All must be Medicaid waiver eligible</p> <p>Excludes individuals with co-occurring substance abuse or psychotic conditions</p>
Participant Recruiting Strategies	<ul style="list-style-type: none"> • New enrollees to either CLASS or HCS waivers • Existing waiver recipients identified by case managers as having unmet needs • On a waiver interest list • Receiving GR services through a local MR authority • 	<ul style="list-style-type: none"> • On a waiver interest list • Receiving GR services through a local MR authority • State Supported Living Center residents with ASDs • Adults transitioning or recently transitioned from high school • A portion of enrollment (e.g. 25 percent) can include adults who voluntarily withdraw from CLASS or HCS 	<ul style="list-style-type: none"> • On a waiver interest list • Receiving GR services through a local MR authority • Adults transitioning or recently transitioned from high school • A portion of enrollment (e.g. 25 percent) can include adults who voluntarily withdraw from CLASS or HCS •
Number who may benefit statewide	By 2015, there will be an estimated 10,000 adults with an ASD receiving services or on an interest list; each waiver has the potential to be scaled to provide services to these individuals		
Assessment Process and Assessment Tool	Facilitating entity conducts assessment using ABAS-II	Independent assessors in DADS and/or local MR authorities conduct assessments using ABAS-II	

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Support Coordination and Services			
Support coordination	<ul style="list-style-type: none"> • All participants have a person-centered service, employment, and behavior plan • Facilitating entity provides designated support coordinator for each participant • Support coordinator qualifications are BA in related area and 2 years experience working with individuals with ASDs or five years of ASD-specific experience • All support coordinators must complete the modular training and testing process 	<ul style="list-style-type: none"> • All participants have a person-centered service, employment, and behavior plan • Pilot organization provides designated support coordinator for each participant • Support coordinator qualifications are BA in related area and 2 years experience working with individuals with ASDs or five years of ASD-specific experience • All support coordinators must complete the modular training and testing process • Care planning guidelines developed for resource allocation model 	<ul style="list-style-type: none"> • All participants have a person-centered service, employment, and behavior plan • Support coordination provided through the center • Support coordinator qualifications are BA in related area and 2 years experience working with individuals with ASDs or five years of ASD-specific experience • All support coordinators must complete the modular training and testing process • Care planning guidelines are developed for resource allocation model
Services offered	<ul style="list-style-type: none"> • Development of a specialized ASD network of partners/providers • Resource directory • Referral to network partners • Peer support • Monitoring of service gaps • Solicitation of funds • Services offered by community partners and funded through private/federal resources or allowable Medicaid match • Provider, consumer, and family training • Volunteer network 	<ul style="list-style-type: none"> • All current CLASS and HCS waiver services (limit on supported employment services eliminated) • Expanded coverage of adult behavioral therapies • Expanded supported employment services – job finding, counseling, training, monitoring and coaching; and self employment planning, support, and implementation • Expanded coverage of meaningful day activities in the community – planning, training, and monitoring 	<ul style="list-style-type: none"> • Provision of work site and equipment • Solicitation of in-sourced work • Network of employers for external job placement • Work specific skills training • Behavioral, social, and communication training for work and college • Work and college performance monitoring and intervention • Community socialization

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Support Coordination and Services (cont.)			
Services offered (cont.)		<ul style="list-style-type: none"> • Expanded residential alternatives including adult/ family owned apartments/ homes and independent cluster apartments • Non-emergency transportation with rural area modification • Peer support • Crisis intervention including maintenance of temporary emergency placement home • Specialized pharmacology counseling specific to ASD and frequently occurring co-morbid conditions 	<ul style="list-style-type: none"> • Center based independent living alternative – apartments with common space (one site only) for a limited number of participants • Identification and support for independent living alternatives (not center based) • Family home support • Transportation – work related and community activities • Independent living skills (e.g. money management) • Self employment planning, support and implementation • Transition planning
Service/Funding Limitations	State funded pool establishes total dollars available for the three pilot sites	Based on assessment informed resource allocation levels, each participant receives an annual dollar amount for support needs	
Payment for Services/Rates	<ul style="list-style-type: none"> • Peer support rate established by DADS using an independent rate model • To the extent other services are offered, rates will follow waiver fee schedules 	<ul style="list-style-type: none"> • Rates for existing services will follow the HCS and CLASS fee schedules • New or expanded service rates will be set using an independent rate model 	Center receives a per-person payment for each individual based on their assessed needs

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Evaluation of Outcomes			
Expected Outcomes	<p>Community capacity is expanded to fill gaps in service</p> <p>Service sites successfully solicit private and public funds</p> <p>Increased consumer and family satisfaction</p> <p>Higher consumer and family ratings for the program</p> <p>Increased specific experience and knowledge of support coordinators and providers</p> <p>Increased center group home and ICF/MR admissions</p>	<p>Decrease in gaining and sustaining employment</p> <p>Decrease in center group home and ICF/MR admissions</p> <p>Behavior regression is reduced</p> <p>Decrease in incidents with ASD and mental retardation</p> <p>Clear demonstrable improvement in communication, ADLs, and IADLs</p> <p>Increased consumer/families rate the appropriateness of services higher</p> <p>Decrease in incidents and families transitioning into the program from school report less fragmentation of services</p>	<p>Decrease in gaining and sustaining employment</p> <p>Increased center wages</p> <p>Increased consumer and family satisfaction</p> <p>Behavior regression is reduced</p> <p>Decrease in center group home admissions</p> <p>Increased consumers living independently with supports</p> <p>Decrease in incidents and families transitioning into the program from school report less fragmentation of services</p> <p>Successful, sustainable transition into the community after center participation</p>
Evaluation	<p>Evaluations of each of the measures above conducted every six months and compared to:</p> <ul style="list-style-type: none"> • The pilot participants' baseline (prior to enrollment in the pilot) • A comparison group of similarly situated individuals (e.g. functional status, waiver participation, demographics, etc.) <p>Cost data will also be collected</p>		

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Contractors to Operate the Pilots			
Contracting Strategy and Requirements	RFP issued with requirements such as: <ul style="list-style-type: none"> • Management and business plan • Assessment approach • Support coordinator selection, wage and benefits, and training • Partner network commitment • Referral process • IT capacity • Provider, consumer, and parent training strategy and implementation schedule • Plan for monitoring service gaps • Funding plan inclusive of private, local, state, and federal dollars • Plan for peer supports • Experience with ASD • Staffing plan 	RFP issued with requirements such as: <ul style="list-style-type: none"> • Management plan • Network of providers who have agreed to complete training • Support coordinator selection, wage and benefits, and training • Proposed interface with related agencies • Proposed community partnerships • Proposed interface with health and mental health systems, etc. • IT capacity • Experience with ASD • Staffing plan 	RFP issued with requirements such as: <ul style="list-style-type: none"> • Business plan for enterprise • Capital required • Nonpublic fund sources • Development time frame • Experience with ASD • Staffing plan • Proposed interface with health and mental health systems, etc. • Evidence of employer support • Plan for matching work to participant skills • Work and college performance monitoring and intervention plan • Fund management • Payroll and accounting experience • Plan for transitioning center residents into the community
Preferred Information Technology Capabilities	<ul style="list-style-type: none"> • Electronic assessment • Support coordination/ care planning and tracking system • Referral tracking • Interface with and encounter reporting from network partners • DADS, DARS, and HHSC claims • Web based resource directory 	<ul style="list-style-type: none"> • Electronic assessment • Support coordination/ care planning and tracking system • DADS, DARS, and HHSC claims 	<ul style="list-style-type: none"> • Electronic assessment • Support coordination/ care planning and tracking system • DADS, DARS, and HHSC claims
Potential Organizations Interested	<ul style="list-style-type: none"> • ADRCs, Autism Society, Local MR authorities • Universities • Nonprofits (CILA, ARC, etc.) 	<ul style="list-style-type: none"> • Local MR authorities • Provider based organizations • Parent/ Community collaborative • Nonprofits (CILA, ARC, etc.) 	<ul style="list-style-type: none"> • Local MR authorities • Nonprofits (CILA, ARC, etc.) • Parent/ Community collaborative • Experienced out-of-state companies

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Collaborations and Partnerships			
Important Collaborations	<ul style="list-style-type: none"> • ADRC • DARS • Local MR authorities • Housing authorities • Workforce development boards 	<ul style="list-style-type: none"> • Medicaid • Primary care physicians • Mental health agency and network of providers for adults with mental health co-occurring conditions 	<ul style="list-style-type: none"> • Medicaid • Primary care physicians • Mental health agency and network of providers for adults with mental health co-occurring conditions
Important Community Partnerships	<ul style="list-style-type: none"> • Employers • Universities • Graduate training programs • Physicians • Work programs • HUD • Autism Societies • ARC • Centers for Independent Living • Parent groups • Providers • Foundations • Consumer groups 		

Component of Pilot	Pilot 1: Specialized Support Coordination and Community Connections	Pilot 2: Full Service Continuum	Pilot 3: Transition and Employment Centers
Cost Impacts – Start-Up through Initial Two-Year Evaluation			
DADS administration (train, contract, monitor, evaluate)	\$500,000 (GR)	\$800,000 (\$400K GR)	\$800,000 (\$400K GR)
Contractor operations (support coordination and administration)	\$1,800,000 (\$1.6M GR) \$300,000 per site/ yr	\$2,100,000 (\$1.05M GR) \$100 startup \$1.0M/ yr ongoing	\$3,300,000 (\$1.65M GR) \$100K per site startup \$500,000 per site/ yr
Services	\$300,000 (GR) 4 hours/ month of peer support per consumer	\$32,000,000 (\$12.8M GR) 100 high - \$30K/ yr 100 med - \$50K/ yr 100 low - \$80K/ yr	\$15,000,000 (\$6.0M GR) 150 at \$50K/ yr
Other	\$2,000,000 (GR) pool to match private and federal funds		\$3,000,000 (GR) Capital start-up 2 at \$750,000 1 at \$1,500,000
Total	\$4,600,000 (\$4.4M GR)	\$34,900,000 (\$14.25M GR)	\$22,100,000 (\$11.05M GR)
Community Resources Utilized/Incentivized	\$2,000,000 in private and federal funds generated	No specific target	\$1,500,000 set as target for three sites
Estimated Cost/Savings of the Pilot	<ul style="list-style-type: none"> \$2,000,000 in supports purchased without state dollars Lower admission rates to SSLCs and group homes 	Lower admission rates to SSLCs and group homes	<ul style="list-style-type: none"> Wage offset of expense through share of cost Lower admission rates to SSLCs and group homes

APPENDIX B: CASE STUDIES OF PROGRAMS IN OTHER STATES

The gaps identified in Texas' system of supports for adults with autism spectrum disorders and related disabilities are not unique to the State. These are issues with which state governments across the country struggle. A number of states have established programs that seek to address these gaps. There are a number of innovative programs across the states and three are profiled here – Pennsylvania, Connecticut and Arizona. While not profiled, innovative programs focusing on transition from school in Delaware¹⁹ and employment in Maryland²⁰ were mentioned by several stakeholders.

Pennsylvania's Medicaid Waiver for Adults with Autism

Pennsylvania was the first, and is still the only, State with a Medicaid waiver specifically created to meet the needs of adults with an autism spectrum disorder. The waiver arose from the work of the Pennsylvania Autism Task Force, which was established by the Secretary of the Pennsylvania Department of Public Welfare (DPW) in 2003. The Task Force was divided into twelve subcommittees, each of which was tasked with evaluating a specific facet of the systems in place to provide services to individuals with an ASD. One of the subcommittees assessed the needs of adults over 21 years of age. The Task Force reports were published in December 2004.

The Task Force reported that there were almost no community-based services for adults with an ASD. In particular, the report noted that those services that are provided to adults with an ASD were typically delivered through the mental health/ mental retardation system, which has a “caretaker sensibility” rather than a skill-building or supportive approach. The Task Force additionally identified other areas of concern, include inadequate provider rates leading to turnover, lack of coordination amongst providers, and the short duration of vocational rehabilitation services. These conclusions are very similar to the gaps in Texas as identified through stakeholder surveys, interviews, and focus groups.

¹⁹ <https://www.cms.gov/PromisingPractices/Downloads/DelawarePromisingPractices6-11.pdf>

²⁰ www.csaac.org

In response to the Task Force's recommendations, Pennsylvania created the Adult Autism Waiver, which was approved by the federal Centers for Medicare and Medicaid Services in May 2008.

The waiver is directly administered by the Bureau of Autism Services (BAS), which was also created based on Task Force recommendations, within DPW. Direct administration differs from most mental health and mental retardation services in Pennsylvania, which are administered by county-operated Offices of Mental Retardation and Mental Health. The Task Force recommended that administrative control be retained at the State level, reporting that the county system "drains a significant percentage of the \$1.2 billion spent annually." The waiver has an enrollment capacity of 200 at an annual cost of approximately \$100,000 per individual, or \$20 million total.

To be eligible, individuals must be at least 21 years of age and have received from a licensed psychologist or physician a diagnosis before the age of 22 of autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified, Asperger's syndrome, or Rhett's disorder. IQ is not an eligibility factor. Consumers must have substantial functional limitations in three or more major life activities, including self-care, receptive and expressive language, learning, mobility, self direction and/or capacity for independent living. Further, individuals must meet the clinical eligibility for intermediate care facilities for the mentally retarded (ICF/ MR). Finally, consumers cannot have income that exceeds 300 percent of the federal benefit rate, which in 2010 is \$2,022 per month. Reassessments are conducted annually.

Consistent with identified best practices, the waiver utilizes a person-centered approach. BAS contracts with private providers for support coordination. Consumers are able to select their support coordinators. The support coordinator meets with the consumer and/ or their family to identify strengths and needs. The Parental Stress Scale (PSS), Scales of Independent Behavior-Revised (SIB-R) assessment, and Quality of Life Questionnaire (QOL.Q) are used to assist in the evaluation of need. The support coordinator then works with individuals, their families, and others that the consumer wishes to include to develop an individual service plan (ISP) and then

monitors consumers' services to ensure alignment with the ISP. The ISP includes information about who the consumer likes and admires, the activities that he/ she prefers, allergies or other health concerns, a record of fire and traffic safety knowledge, and other important information that is a part of the participant's everyday life. The ISP outlines the services that the consumer needs and the plan is submitted to BAS for approval and authorization.

The waiver covers 18 services as shown in Figure B-1.

Figure B-1: Services Covered by Pennsylvania's Medicaid Waiver for Adults with Autism	
Assistive Technology	Behavioral Specialist Services
Community Inclusion	Community Transition Services
Counseling	Day Habilitation
Environmental Modifications	Family Counseling
Family Training	Job Assessment
Job Finding	Nutritional Consultation
Residential Habilitation	Respite
Supported Employment	Temporary Crisis Services
Therapies (Occupational, Physical, Speech and Language)	Transitional Work Services

Most of the services covered by the Adult Autism Waiver are also included in Pennsylvania's Consolidated Waiver for individuals with mental retardation. However, in response to the Task Force's findings regarding the lack of provider expertise in serving individuals with an ASD, BAS requires that service providers complete a nine module training program that address the multiple needs of adults with autism before they begin delivering services. Separate training is required for support coordinators and behavior specialists.

In its waiver application, the State estimated that nearly one-third of participating consumers would receive residential habilitation services and that related expenditures would comprise 36 percent of total estimated waiver spending. Residential habilitation is primarily provided in licensed community homes (group settings) though licensed family living homes (adult foster care) are also included in this service. Individuals receiving residential habilitation require awake support staff 24 hours per day, seven days per week. The stated goal of the services is to "teach skills to give the participant more independence so that the participant will be able to

move to a private home setting in the future.” A participant receiving Residential Habilitation services must contribute 72 percent of his/ her monthly Supplemental Security Income (SSI) payment to the provider for room and board.

About 80 percent of consumers were estimated to receive community inclusion services, which were projected to represent 28 percent of total expenditures. The service provides assistance to individuals to improve their activities of daily living and participation in the community. Specific examples include assistance with bathing, dressing, and eating, as well as socializing, getting to know their neighborhood, and participating in community activities.

The waiver application assumes that nearly every consumer will utilize behavioral specialist services, which are estimated to total 13 percent of expenditures. A behavioral specialist creates a behavioral support plan, which helps those in regular contact with the consumer to support the individual. The behavioral specialist trains family members and providers in how to support the consumer to become more independent.

The majority of the remaining expenditures is associated with day habilitation (provided in adult training facilities) and supported employment. Both services are estimated to serve 40 percent of waiver consumers.

BAS, through a consultant, established a prospective provider rate schedule. These rates do not include regional variation. This differs from the methodology used for services reimbursed through Pennsylvania’s Consolidated and Person/ Family Directed Support Waivers for individuals with developmental disabilities. For those waivers, reimbursement rates for most services were established by DPW through its own analysis of cost data submitted by its providers. Rates for services under these waivers, then, vary from provider to provider. The State has reported that it will survey providers regarding their costs and evaluate utilization data to adjust the fee schedule as necessary. Currently, however, the overall result of these differing methodologies is that services provided under the Adult Autism Waiver are usually reimbursed at a lesser rate than comparable services delivered under other waiver programs for individuals

with developmental disabilities despite the additional requirements of the Adult Autism Waiver (i.e. more training).

With only 200 slots the waiver does not have the capacity to enroll all adults with an ASD in Pennsylvania. Two priority groups were established. Priority 2 includes individuals who are already receiving services through a waiver or in an ICF/ MR, nursing home, or hospital. Everyone else is in Priority 1.

BAS held a lottery for admission in the program. Priority 1 individuals who requested an application between July 1, 2008 and August 11, 2008 were assigned a random order. After the initial lottery, individuals are placed on an interest list in the order in which the request is received. Potential consumers do not receive an eligibility application until a waiver slot is available. Priority 2 individuals, regardless of whether they participated in the lottery, are not sent an application until all Priority 1 individuals who expressed an interest in receiving an application.

Enrollment in the waiver, which began in December 2008, has been slow. In a May 2009 update posted on its website, BAS stated that its goal was to have filled the 200 slots by June 30, 2009. However, according to a November 30, 2009 update, 100 individuals were enrolled and 61 of these consumers had approved plans.

Much of the delay has been related to registering providers for the program. As noted, existing providers delivering services to individuals with developmental disabilities and related disorders, including autism, must complete the training course developed by BAS. Additionally, it is likely that the lower reimbursement rates offered under the Adult Autism Waiver has contributed to the difficulty the State has had in attracting providers.

Given the relative newness of the program, little has been published on its outcomes. As the first and only Medicaid waiver specifically targeting adults with ASDs, it will continue to be closely watched.

Connecticut Autism Spectrum Disorder Pilot

Recognizing the lack of appropriate supports for adults with autism spectrum disorders, the Connecticut Assembly mandated the Autism Pilot Program (APP) in 2006. Like Pennsylvania, Connecticut has established a Division of Autism Services within its developmental disabilities department, which administers APP. The program was designed with a strong evaluation component so that any expansion would be evidence-based. The evaluation was conducted by the University of Connecticut in December 2008. At that time, there were a total of 52 enrolled consumers in the two counties in which the program was operating.

Similar to findings from Texas stakeholders, Connecticut identified particular gaps in services for individuals once they graduate from high school and for higher-functioning individuals. Thus, the program is limited to individuals over 18 years of age with substantial functional limitations in at least three areas of major life activity. Consumers could no longer be receiving services through the school system. Individuals with mental retardation are ineligible for the program and, after initial implementation, APP excluded those with co-occurring mental health issues. Intake was conducted in the consumer’s home.

In addition to case management, the pilot program covered five services. These services, the rate paid for each, and the expected utilization are included in Figure B-2. Life, social, educational, and employment

skills services include instruction, implementation of individual service plan strategies and therapeutic recommendations,

Service	Rate (hour)	Expected Utilization
• Life, Social, Educational, and Employment Skills	\$35.47	2-15 hours/ week
• Community Mentor	\$26.09	2-10 hours/ week
• Job Developer/ Career Counselor	\$55.32	2-6 hours/ week for 6 months
• Consultative Services	\$67.60 (\$72.95 for clinical psychologists)	\$3,000/ year limit
• Interpreter Services	\$52.00	

and assistance with activities of daily living and community access. Community mentors provide social interaction, assistance and supervision of household chores, and access to leisure activities. Job developers in partnership with the Bureau of Rehabilitation Services provide assessments, job analysis, and training to secure and sustain employment. Consultative services

include a range of professional services such as nutrition, counseling, behavior management and training, nursing, communication, and therapy. Residential supports are not covered by APP.

To address the gaps related to a lack of provider expertise in working with individuals with ASDs, APP incorporated two key best practices. First, dedicated case managers were assigned to the program so that they were only working with individuals with ASDs. These case managers had caseloads of approximately 30 consumers, to ensure that they had adequate time to devote to each individual. Second, providers selected to deliver these services were required to complete a training video series developed specifically for this program.

Participants were provided an individual budget based on their unique needs, which is another best practice. Of those consumers included in the evaluation, budgets ranged from \$762 to \$76,230 with a mean of \$30,378. Four individuals had budgets of less than \$12,000, nine had budgets between \$12,000 and \$24,000, eight were allocated budgets of \$24,000 to \$48,000, and three had budgets in excess of \$48,000. Spending was substantially less than budgeted allocations and averaged 59 percent of the total, or \$18,014. It was reported that this difference was due to the ambivalence of some participants. APP was entirely state-funded.

The evaluation of the program was based on interviews with 28 consumers in the program as well as caregivers, case managers, and other stakeholders. Eight of these individuals were living independently, 19 lived with their parents or other relatives, and one was in a supervised living program apartment funded by the Department of Mental Health and Addiction Services. The results of the evaluation were somewhat mixed, but largely positive.

Employment outcomes for individuals with ASDs are exceedingly poor across the country. During the course of the evaluation, the utilization of employment supports increased from 10 to 21 individuals. At the baseline period for APP eleven consumers were employed, but after one year only six of them were still employed. However, of the ten that did not have jobs but had been employed in the past, seven were working after one year and, of the six who had never worked two were employed after one year. Overall, there was a net employment increase of four consumers and 56 percent of the 27 consumers included in this analysis were employed, which is

higher than national estimates of employment rates among individuals with ASDs. APP participants worked in jobs ranging from clerical and service (e.g. grocery stores) positions to illustrators. Most earned less than \$10 per hour. The evaluation also found significant increases in job satisfaction with many fewer consumers reporting that they did not like the people with whom they worked, the environment, the location of the job, and their pay and hours.

The number of adults using social groups, community mentors, and support groups increased from 2 to 19. This may help explain a modest decrease in “screen time” – the time spent watching television, using a computer, and playing video games – from 7.8 hours to 7.1 hours. Strangely, however, consumers reported fewer close relationships with family and friends after one year in the program.

Consumers were also evaluated using the Scales of Independent Behavior (Revised), which is a norm-referenced assessment of adaptive and maladaptive behavior. The evaluation found improvement on the broad independence scale and each of the subscales: motor skills, social interaction and communication skills, personal living skills, and community living skills. Additionally, improvement was found on each of the maladaptive indices (generalized, internalized, asocial, and overall support score) except for externalized, which was already in the normal range.

When asked whether APP helped them achieve their goals, consumers had generally positive responses. Figure B-3 summarizes these results.

	% with goal	Were your goals met?			How helpful were the services?		
		totally	partially	did not	very	somewhat or little	not at all
Life Skills	81%	9%	77%	14%	22%	65%	13%
Employment Skills	74%	15%	60%	25%	31%	50%	19%
Community Involvement	33%	33%	44%	22%	33%	47%	20%

The table shows that most consumers said their goals were “partially” met and that services were “somewhat or little helpful”. Participants were most satisfied with having met their goals in

community involvement and least satisfied with progress in life skills, which include communication and social skills and performing activities of daily living.

Figure B-4 notes the responses of APP case managers asked whether pilot program participants met their goals. The most interesting finding is the dichotomy on employment skills. Case managers were three times more likely to respond that consumers totally achieved their goals compared to the responses of the consumers themselves, but also were more likely to report that employment goals were not met.

	Were consumers' goals met?		
	totally	partially	did not
Life Skills	6%	81%	12%
Employment Skills	45%	20%	35%
Community Involvement	30%	65%	4%

Caregivers were also asked about their perceptions of the program. Families were most concerned about what will happen when they are no longer able to care for their loved one with an ASD. They also expressed specific concerns related to socialization, employment, housing, and safety. After one year in the program, 39 percent of the interviewed caregivers reported that they were less concerned.

The evaluation noted several difficulties experienced over the first year of the program as well as best practices. The researchers found that the program was most effective for younger participants recently involved in services through the school system, underscoring the importance of effective transition services. Provider staff expectations were at times too low as they were not accustomed to working with higher-functioning adults highlighting the need for specialized training to build ASD-specific service capacity. Conversely, the evaluation authors stated that some parents' expectations were too high, particularly regarding employment.

Overall, the program generated overall positive outcomes in its first year of operation while filling a gap in services for higher-functioning adults with ASDs who previously had few services.

Arizona Long Term Care System

Unique in the country, Arizona operates its entire Medicaid program under a single Section 1115 demonstration waiver. Most of the State’s Medicaid program is operated on a capitated managed care basis. The Arizona Department of Economic Security (ADES) contracts with the State Medicaid Agency as the managed care organization to provide services to individuals with developmental disabilities in the Arizona Long Term Care System (ALTCS).

To be eligible for ALTCS, an individual must meet the institutional level of care determined by three age-specific preadmission screening instruments. Autism spectrum disorders are a qualifying condition; an individual does not need to have co-occurring mental retardation to qualify for ALTCS. ADES is responsible for all aspects of an individual’s care, including acute care and behavioral health services as well as long term care services. Support coordination, service authorization, and utilization review functions are performed by state staff.

ALTCS offers an array of traditional service options as listed in Figure B-5. None are unique to individuals with ASDs.

Habilitation (under which ABA is often provided)	Person centered planning facilitation
Specialized habilitation (music, behavioral, and communication)	Center based employment
Group homes	Group supported employment
Nursing supported group homes	Individual supported employment
Community protection and treatment homes	Housekeeping
Developmental homes (foster care)	Respite
Individually designed living arrangements	Attendant care
Speech, physical therapy, and occupational therapy	Day habilitation
	Independent living support

Like Texas but unlike the Pennsylvania and Connecticut programs discussed previously, Arizona generally does not have autism-specific programming or specialized support coordination for adults with ASDs. Applied behavioral analysis is specifically covered for children, but not for adults. ALTCS, however, does incorporate several best practices that are informative.

Arizona is a leader in consumer choice. ADES utilizes an “open and continuous” procurement that permits providers that meet the service requirements to enter the system at any time. The

system has a large network of qualified independent providers for home based supports (habilitation, attendant care, respite, housekeeping, etc.) and one of the largest fiscal intermediary programs in the country with more than 4,000 consumers and families operating as the employer of record. Consumers and their families direct the supports delivered by independent providers, maximizing self-direction and services tailored to the needs of each consumer/family. Family members (other than spouses) are permitted to provide and receive reimbursement for attendant care. In fact, among adults with ASDs, nearly 75 percent of all attendant care services are provided by family members. Taken together, these program features maximize opportunities for self-determination.

In order to reimburse independent providers based on the needs of consumers they serve, DDD developed a rate adjustment tool. The rate adjustment tool evaluates both environmental factors (the safety of the home, the availability of natural supports) as well as behavioral, functional, and medical needs of the individual. A base rate for each service is modified based on the scores for the individual served by the independent provider. Providers who are in continued service for two or more years also receive a supplement to the rate.

Similar to Texas, Arizona has both large, urban areas as well as expansive rural areas. To encourage providers to deliver services in these areas, ALTCS uses geographic modifiers to certain provider rates, such as therapies and transportation (the underlying rate schedule is established using an independent cost model). In the case of therapies, for example, three tiers are established depending on population densities with the highest tier providing a 50 percent bonus on the base rate. This strategy has helped to build capacity in rural areas.

Arizona state law establishes an entitlement to ALTCS services for those who meet the eligibility criteria; waiting or interest lists are not permitted. In fiscal year 2009 Arizona provided services to 1,006 adults with ASD diagnoses and expended \$42.6 million on services for these consumers. The average annual per person spending was about \$42,300. This is between the average amounts expended by Texas in the CLASS and HCS waiver programs, which is to be expected since ALTCS is essentially a combination of a comprehensive waiver and a supports waiver.

Of the \$42.6 million in ALTCS spending for adults with ASD more than 48 percent, \$20.5 million, is associated with group homes. As is the case in Texas there is a significant jump in the percentage of consumers living in a paid residential placement as an individual ages. Group home utilization increases from 11 percent in the 18 to 21 year old age group to 31 percent in the 26 to 34 year old age group. The lack of waiting lists in ALTCS has resulted in a smaller percentage of individuals in out-of-home placements compared to other states because of the availability of supports to maintain individuals in their home.

Additionally, ADES utilizes group home placements in lieu of ICF/ MRs. Arizona has only one state-run institution remaining, but no longer admits new consumers to the facility. Arizona has a medium-sized private ICF/ MR whose residents generally are medically fragile (e.g. ventilator dependent). Few, if any, individuals with ASDs are in ICF/ MRs. Overall, the availability of support services and the use of the community-based placements rather than ICF/ MRs resulted in Arizona receiving the top ranking from UCP for community inclusion this year. Additionally, since home and community-based services are more cost effective than institutional placements, Arizona per-resident costs are significantly lower than the national average (though higher than Texas’).

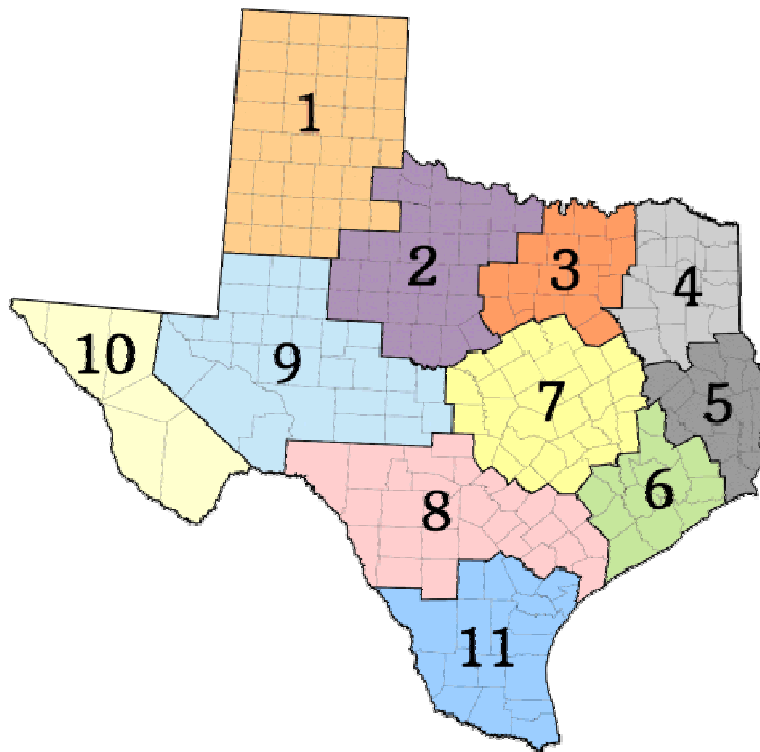
Like most of the country, Arizona struggles with helping individuals obtain meaningful employment. Of the 1,006 adults with ASDs receiving services in fiscal year 2009, 22 received individual supported employment or an employment support aide and 56 were in group supported employment. In contrast, 44 were in center based employment and 456 were in day treatment programs. To attempt to resolve the system fragmentation issues resulting from both ALTCS and the state vocational rehabilitation program having responsibility for employment supports, ADES several years ago moved the money associated with services for individuals with development disabilities from the vocational rehabilitation program to ALTCS.

Arizona provides a model of how certain best practices can be implemented system-wide to benefit all individuals with developmental disabilities. However, without a survey of consumers

with ASDs and their families it is unknown whether they feel that they believe that the system is meeting their unique needs.

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APPENDIX C: TEXAS HEALTH AND HUMAN SERVICES REGIONS



Region	Counties Serviced
Region 1: High Plains	Armstrong, Bailey, Briscoe, Carson, Castro, Childress, Cochran, Collingsworth, Crosby, Dallam, Deaf Smith, Dickens, Donley, Floyd, Garza, Gray, Hale, Hall, Hansford, Hartley, Hemphill, Hockley, Hutchinson, King, Lamb, Lipscomb, Lubbock, Lynn, Moore, Motley, Ochiltree, Oldham, Parmer, Potter, Randall, Roberts, Sherman, Swisher, Terry, Wheeler, Yoakum
Region 2: Northwest Texas	Archer, Baylor, Brown, Callahan, Clay, Coleman, Comanche, Cottle, Eastland, Fisher, Foard, Hardeman, Haskell, Jack, Jones, Kent, Knox, Mitchell, Montague, Nolan, Runnels, Scurry, Shackelford, Stonewall, Stephens, Taylor, Throckmorton, Wichita, Wilbarger, Young
Region 3: Metroplex	Collin, Cooke, Dallas, Dallas, Denton, Ellis, Erath, Fannin, Grayson, Hood, Hunt, Johnson, Kaufman, Navarro, Palo Pinto, Parker, Rockwall, Somervell, Tarrant, Wise
Region 4: Upper East Texas	Anderson, Bowie, Camp, Cass, Cherokee, Delta, Franklin, Gregg, Harrison, Henderson, Hopkins, Lamar, Marion, Morris, Panola, Rains, Red River, Rusk, Smith, Titus, Upshur, Van Zandt, Wood
Region 5: Southeast Texas	Angelina, Hardin, Houston, Jasper, Jefferson, Nacogdoches, Newton, Orange, Polk, Sabine, San Augustine, San Jacinto, Shelby, Trinity, Tyler

Region 6: Gulf Coast	Austin, Brazoria, Chambers, Colorado, Fort Bend, Galveston, Harris, Liberty, Matagorda, Montgomery, Walker, Waller, Wharton
Region 7: Central Texas	Bastrop, Bell, Blanco, Bosque, Brazos, Burleson, Burnet, Caldwell, Coryell, Falls, Fayette, Freestone, Grimes, Hamilton, Hays, Hill, Lampasas, Lee, Leon, Limestone, Llano, Madison, McLennan, Milam, Mills, Robertson, San Saba, Travis, Washington, Williamson
Region 8: Upper South Texas	Atacosa, Bandera, Bexar, Calhoun, Comal, DeWitt, Dimmit, Edwards, Frio, Gillespie, Goliad, Gonzales, Guadalupe, Jackson, Karnes, Kendall, Kerr, Kinney, La Salle, Lavaca, Maverick, Medina, Real, Uvalde, Val Verde, Victoria, Wilson, Zavala
Region 9: West Texas	Andrews, Borden, Coke, Concho, Crane, Crockett, Dawson, Ector, Gaines, Glasscock, Howard, Irion, Kimble, Loving, Martin, Mason, McCulloch, Menard, Midland, Pecos, Reagan, Reeves, Schleicher, Sterling, Sutton, Terrell, Tom Green, Upton, Ward, Winkler
Region 10: Upper Rio Grande	Brewster, Culberson, El Paso, Hudspeth, Jeff Davis, Presidio
Region 11: Lower South Texas	Aransas, Bee, Brooks, Cameron, Duval, Hidalgo, Jim Hogg, Jim Wells, Kenedy, Kleberg, Live Oak, McMullen, Nueces, Refugio, San Patricio, Starr, Webb, Willacy, Zapata

APPENDIX D: CROSSWALK OF HB 1574 REQUIREMENTS TO REPORT SECTIONS

HB 1574 Requirement	Report Section
<p>Sec. 2(b) – outlines requirements of pilot programs, including:</p> <ul style="list-style-type: none"> • Encourage sustainable employment and community integration • Develop meaningful community-based activities for persons for whom competitive employment is not a goal • Promote continued individual development and avoid regression • Promote self-determination and independence • Coordinate services and behavioral supports across all areas of need • Allow for flexible funding and for a flexible array of services to meet individual needs 	<p>Section 6 outlines the three proposed pilot options, which are designed to address these requirements. Appendix A provides further detail for each of the specified requirements</p>
<p>Sec. 2(c)(1) – requires that pilots provide a seamless system of supports to provide:</p> <ul style="list-style-type: none"> • Options for independent living, if appropriate • Community-based housing • Individualized supports 	<p>Section 6 outlines the three proposed pilot options, which are designed to address the requirements. In particular:</p> <ul style="list-style-type: none"> • Specialized support coordinators are expected to serve as systems navigators to provide a focal point for consumer and family contact • Pilots 2 and 3 provide a continuum of services, including housing supports, to reflect the varying needs of adults across the spectrum • Each pilot option includes DADS’ existing person-centered planning philosophy
<p>Sec. 2(c)(2) – requires that the report include research and analysis of best practices and programs from other states</p>	<p>In preparing this report, autism task force reports from three dozen states were reviewed with the recommendations of the five most thorough reports, along with findings from other national advocates, synthesized to isolate common best practices. These conclusions are summarized in Section 3. Appendix B includes summarizes of programs in three states that incorporate many of these best practices</p>
<p>Sec. 2(c)(3) – requires that the report authors consult with and solicit feedback from key stakeholders</p>	<p>Utilizing telephone interviews, in-person focus groups, site visits, and an online survey, B&A spoke with or received comments from more than 200 individuals across the State including:</p> <ul style="list-style-type: none"> • Key agency representatives • Consumers and self-advocates • Parents and caregivers • Providers • Local MR authority staff <p>This input informed the entire study, most particularly the gap analysis in Section 5 and pilot program design discussed</p>

	in Section 6 and Appendix A
<p>Sec. 2(c)(4) through Sec. 2(c)(6) requires that the report</p> <ul style="list-style-type: none"> • Address barriers that may prevent consumers from living in their local community • Identify the existence and cause of service gaps • Develop recommendations to eliminate the gaps 	<ul style="list-style-type: none"> • The report relied on analysis of service claims data from DADS and DARS as well as stakeholder input to identify barriers and gaps, the most significant of which are summarized in Section 5 • The pilot option described in Section 6 and Appendix A are designed to address these gaps
<p>Sec. 2(c)(7) requires that the report identify potential benefits to persons who would receive services from the pilot program</p>	<p>The expected outcomes are discussed in Section 6 and Appendix A</p>
<p>Sec. 2(c)(8) requires that potential federal sources of funding for the pilot programs be identified</p>	<p>Potential federal funding opportunities are summarized in Section 7, which concludes that Medicaid (through an 1115 waiver) is the most viable option. The section also provide potential sources of State funding to match the federal funds</p>
<p>Sec. 2(e) requires that the report include:</p> <ul style="list-style-type: none"> • A recommendation for the structure of the pilot programs • A recommendation on the choice of an appropriate agency to design and administer the pilot programs • An estimation of the number of persons who may benefit if a program similar to the pilot were instituted statewide • An estimation of the potential cost of the pilot program and whether the pilot program may lead to savings • A method of determining which persons would be eligible to participate in the pilot programs • Which Medicaid waiver programs are appropriate to the pilot programs and whether new Medicaid waiver programs may be required 	<ul style="list-style-type: none"> • Elements related to the structure, scope, and administration of the pilots is included in Section 6 and Appendix A • Discussion of Medicaid waiver options is included in Section 7