



Research Paper

Services for Adults with Autism

September 2015

Autism spectrum disorder (ASD) is a range of complex neurobiological developmental disabilities which manifest as social skill impairments, communication impairments, and repetitive behaviors. ASD is also associated with intellectual disabilities—while about 40% of those with autism have above average intellectual abilities, 25% are nonverbal (Autism Speaks, 2015b). As the term “spectrum” denotes, symptoms can range from mild to severe and individuals will present with a wide variety of impairments depending upon the severity and combination of symptoms (CDC, 2015a). “The disorder emerges in early childhood and persists throughout the life of an affected person. The full range of cognitive abilities is represented, with approximately 55 percent of individuals with ASD having IQ scores below 70. In addition, many individuals with ASD have other disabilities, such as epilepsy or emotional or behavioral disorders, which impair their overall level of functioning” (Texas Council on Autism and Pervasive Developmental Disorders [TCAPDD], 2010).

The rate of children diagnosed with ASD has increased significantly in recent years. Between the years 2000 and 2010 the rate increased from 1 in 150 children to 1 in 68 children. Put another way, in 2000 there were 6.7 children diagnosed with ASD for every 1,000 children in the population. In 2010, the prevalence of ASD per 1,000 children was 14.7 – a 119.4% increase (CDC, 2015a). “There is not a full count of all individuals with ASD living in the United States. However... we can estimate that over 1% of children from birth to 21 years of age have

ASD” (CDC, 2015a, p.43). That means, based on current population estimates as of July 2014, there are 1.05 million children with ASD in the United States (U.S. Census Bureau, 2015a). Using the rate of 1:68, another 664,809 of the children born in the next ten years can be expected to be diagnosed with ASD (U.S. Census Bureau, 2015b). While the causes of ASD are unknown, “we do know that ASD are [*sic*] more common than we thought before and should be considered an important public health concern” (CDC, 2015b).

The vast majority of research on ASD has been child centered – focused on early detection and intervention as well as causes and treatments. “The number, characteristics, and needs of adolescents and adults living with ASD in the United States are understudied” (CDC, 2015a, p.44). Estimates of the number of adults with ASD who will need services and support over the next decade vary from 500,000 (Advancing Futures for Adults with Autism [AFAA], 2014) to between 700,000-800,000 (PBS Newshour, 2011). One study forecasts an increase of the number of adults with autism by over 600% because they are already born (Roger, 2011).

Thanks to the Individuals with Disabilities Education Act (IDEA) (U.S. Department of Education, n.d.) children diagnosed with autism are entitled to receive early intervention services (from birth to age 2) and special education and related services (ages 3-21). The majority of these services are provided at no cost to the family. Unfortunately, when a child ages out of the school system they also age out of

entitlement-based services. “There is no federal requirement for providing supportive services in adulthood” (Anderson, Rast, Rava, Roux & Shattuck, 2015, p. 8). Most young adults “begin their journey into adulthood by stepping off a services cliff. Access to needed supports and services drops off dramatically after high school – with too many having no help at all” (Anderson et al., 2015, p. 8). To obtain services as an adult, a “person has to apply and demonstrate that he or she is eligible for services according to a specific program's requirements” (Foden and Anderson, 2011). The autistic adult, or more often the parent, must navigate through a bewildering maze of services available through various programs and organizations.

Transition

Moving through adolescence to adulthood is oftentimes not easy even when there are no disabilities present. For a young person with autism this process can be especially daunting. Transition planning is part of the federally mandated special education services provided to children with disabilities. Each child is required to have an individual education program (IEP) that “must include appropriate measurable post-secondary goals based upon age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills” (Transition in Texas, 2012) by the age of 16. In Texas, that minimum age was lowered to 14 in 2011 (Transition in Texas, 2013). Autism Speaks, in its *Family Service Transition Tool Kit*, includes a timeline for each state that provides guidelines for when certain events should take place (Autism Speaks, 2015a). The Texas Education Agency (TEA) publishes a *Texas Transition and Employment Guide* which provides a plethora of information including recommended timelines for applying for additional services and supports (TEA, 2014). In essence, a transition plan should include:

- By the age of 14
 - Transition planning begins
 - IEP should include activities and courses the student will need to gain the knowledge

and experience necessary to complete their goals

- By the age of 16
 - Current skill set assessments should be conducted annually – both academic and functional living skills
 - Begin the Vocational Rehabilitation application process
- Before the age of 17
 - The age of majority in Texas is 18
 - If the family and student feel that the student lacks adequate decision-making capabilities, guardianship/conservatorship process should begin
 - If the family and student feel that the student possesses adequate decision-making capabilities, a statement of informed consent of the transfer of rights should be included in the IEP (i.e. student understands that they will be making their own decisions when they turn 18 years old)
 - Vocational rehabilitation process should begin
- Before the age of 18
 - Apply for benefits
 - Social Security
 - Supplemental Security Income
 - Medicaid
 - Add name to waiting list for residential placements
- At age 21 – Special education programs are terminated once the student fulfills their IEP goals or when they turn 21 years old (Autism Speaks, 2015a; TEA, 2014)

Independence

A recently published study (Taylor, Center, & Mailik, 2014) of the change in vocational and educational activities of adults with ASD over the course of 10 years revealed that there is significant cause for concern. 161 adults with ASD, ranging in age from 18 to 52, were evaluated at six points over the 10 years to determine whether they became more independent, stayed the same, or became less independent. The relationship of personal characteristics and contextual resources (family income, formal services received and needed, and parental social support) to independence level were examined. The study concluded that:

- Improvement in vocational and educational activities (measure of independence) was relatively rare
 - Less than 25% improved to any degree
 - Less than 5% had substantial improvements
 - 13.3% showed substantial decline
- Greater independence in activities of daily living was associated with more independent vocational and educational activities
- Diagnosis of intellectual disability (ID) was a strong predictor of vocational/educational activities
- Gender – the average woman’s decline was 15 times greater than the average man’s decline
- Greater number of services received related to improving vocational/educational activities over time

In their discussion of the results of this study, the authors pointed out that limited improvement might have been affected by declines in public funding which limited availability of services and “overall, our findings suggest that personal characteristics of adults with ASD are important factors that predict their vocational and educational activities throughout adulthood. It is important to note, however, that there are likely many other factors that could account for the lack of improvement overall in vocational and educational activities for adults with ASD. Although it was not modeled empirically in our study, when examining the case studies for those whose vocational activities improved over time, it appeared that improvements were often related to fierce and prolonged advocacy on the part of parents to procure and maintain better vocational activities for their son or daughter with ASD. As parents age, they might advocate less effectively, which could account for the lack of improvement in vocational activities” (Taylor, Center, & Mailik, 2014, pp.12-13).

Services available to autistic adults in Texas

It is estimated that in 2014 there were 399,915 individuals with an ASD diagnosis in Texas, 130,316 of whom were children below 22 years

of age (TCAPDD, 2014). The two primary state agencies providing assistance to autistic adults are the Texas Department of Assistive and Rehabilitative Service and the Texas Department of Aging and Disability Services. Many other statewide and local nonprofit organizations provide information and resources.

Texas Department of Aging and Disability Services (DADS)

DADS provides programs funded by both the state (General Revenue [GR] funded programs) and federal government (Medicaid programs). Many of the programs have long waiting lists and individuals are encouraged to place their name on the list as soon as possible. A person may be on more than one waiting list even if s/he is receiving other services. Another issue is that not all programs are available in all areas of the state (DADS, n.d.). General eligibility for these services include one or more of the following:

- Diagnosis of an intellectual disability based on
 - Measure of IQ
 - Determination of adaptive behavior level
 - Evidence that the disability was present before the 18th birthday
- Diagnosis of autism spectrum disorder
- Nursing facility resident who is eligible for specialized services for intellectual disability or a related condition
- Be eligible for early childhood intervention services

(DADS, n.d.)

DADS General Revenue services and supports include (DADS, n.d.):

- **Service coordination** – assistance with access to medical, social, educational, and other services through the Local Authority
- **Community support** – individualized activities provided in the home or community locations
 - Daily living habilitation
 - Family support to limit out-of-home placement

- Transportation between home and work or day habilitation sites
- **Respite** – short-term relief provided by trained staff to the unpaid caregiver
- **Employment assistance** – locate paid jobs
- **Supported employment** – individualized support services, supervision and training to sustain paid employment
- **Nursing** – when treatment required and prescribed by a physician
- **Behavioral supports** – specialized interventions to increase adaptive behaviors and/or modify maladaptive behaviors
- **Specialized therapies** – occupational, physical, speech and language, audiology, dietary, etc.
- **Vocational training** – to help get a job (includes sheltered workshops)
- **Day habilitation** – help with getting, keeping or improving self-help, socialization and adaptive skills (provided in group setting, not in the home)
- *GR services have an annual budget cap of \$4,000 per adult* (L. Abundis, personal communication, July 7, 2015)

Medicaid ICF/IID Programs include (DADS, n.d.):

- Intermediate care facilities for individuals with an intellectual disability or related conditions (ICF/IID) – 24-hour residential settings
 - State supported living centers (SSLC)
 - 13 campuses state-wide with one located in San Antonio (San Antonio State School)
 - Provide full range of behavioral treatment and medical care
 - Admissions limited by state law to individuals with intellectual disability – those with ASD and IQ >75 are not eligible
 - Community-based ICF/IID
 - Eligibility includes intellectual disability or a related condition such as ASD
 - Must have IQ 75 or below *OR* moderate to extreme deficits in adaptive behavior
 - Served in six-bed homes or larger settings
 - *There are no waiting lists for this program, however, community-based facilities can determine additional admission criteria*

- (age, gender, etc.) and maintain its own interest list based on occupancy rate
- Medicaid ICF/IID Waiver Programs – certain ICF/IID requirements are waived, services provided in home-like settings, eligibility determined by LA
- Home and Community-based services (HSC) program
 - Services similar to GR services
 - Individuals living in a host home/companion care setting or an HCS residence (group home) pay for their own room and board
 - No annual cost limit for services provided
 - *There is waiting list for this program*
- Texas Home Living (TxHmL) program
 - Services supplement but do not replace services and supports from other programs
 - Some services similar to GR services
 - *Annual cost limit of \$17,000 per person*
- Consumer directed services (CDS) – option available in waiver programs that allow individuals to recruit, hire, and train employees to deliver necessary services
- Community Living Assistance and Support Services (CLASS) program
 - Provides services to individuals without intellectual disability who have a qualifying disability that affects their ability to function in daily life (includes ASD)
 - Services similar to GR and includes adaptive devices and medical supplies
 - *There is a waiting list for this program*

DADS Interest Lists

Demand for services far outstrips the availability of funding to provide those services. Of the estimated 269,599 adults with ASD in Texas in 2014, almost half (approximately 49%) were on waiting lists for the services they needed. An applicant's name is placed on a waiting list on a first-come, first-served basis. Interest lists are managed either locally or statewide, depending on the program (DADS, 2015b). Services of interest to adults with ASD for which waiting lists exist include:

- Community-based alternatives (GR programs)
 - Interest lists maintained locally and reported statewide annually

- As of May 2015 there were 592 eligible individuals waiting for services in Bexar County
 - 2,955 total service interests
 - Most identified services included respite, community support, day habilitation, and behavioral support (L. Abundis, personal communication, July 7, 2015)
- Statewide, there were 8,162 on the list in August 2014 (most recent available) (DADS, 2015b)
 - *Time on the list ranged from 0 to 2 years*
- HSC programs
 - Interest lists maintained locally and by the state

- As of May 2015 there were 4,531 individuals waiting for services in Bexar County (L. Abundis, personal communication, July 7, 2015)
- Statewide, there were 72,821 on the list in May 2015 (most recent available) (DADS, 2015b)
 - *Time on the list ranged from 0 to 14 years*
- CLASS
 - Interest lists maintained by state
 - Statewide, there were 53,861 on the list in May 2015 (most recent available) (DADS, 2015b)
 - *Time on the list ranged from 0 to 11 years*

The following chart is a comparison of the ICF/IID, HCS, and TxHmL Programs from the Texas Department of Aging and Disability Services:

	ICF/IID Program	HCS Program	TxHmL Program
<i>Who's eligible?</i>	<ul style="list-style-type: none"> • Person must be Medicaid eligible.* • Person must have an intellectual disability or a related condition.* 	<ul style="list-style-type: none"> • Person must be Medicaid eligible.* • Person must have an intellectual disability or an IQ of 75 or lower with a related condition.* 	<ul style="list-style-type: none"> • Person must be Medicaid eligible.* • Person must have an intellectual disability or an IQ of 75 or lower with a related condition.*
<i>How is a provider selected?</i>	Person may select a particular ICF/IID; however, the ICF/IID must have a vacancy and the ICF/IID provider must approve the admission.	Person may select any provider that serves the area where they live or intend to live. If the person moves to another area in Texas, they may select any provider that serves that area. The waiver program provider is required to serve any eligible person who selects it.**	
<i>What's paid for?</i>	Rates pay for all services, as well as room and board and basic personal care items.***	Rates pay for all services, but do not pay room and board or any personal care items, which must be paid for by the person.***	
<i>Where must the person live?</i> <i>Who else would live there?</i>	<ul style="list-style-type: none"> • Person must live in the ICF/IID. • The number of people served by an ICF/IID can range from six to several hundred. 	Person must live: <ul style="list-style-type: none"> • in own home; • in family's home; • in a foster/companion care setting, or • in a program residence that has no more than four residents. 	Person must live: <ul style="list-style-type: none"> • in own home, or • in family's home.
<i>When would staff be available?</i>	Program provides staff 24 hours per day.	Staff availability depends on person's needs and the service option chosen.	Staff availability depends on person's needs and total cost of services.
<i>Is CDS available?</i>	No.	Yes, for certain services.	Yes, for all services.

*Specific eligibility criteria are described in 40 TAC Chapter 9, Subchapter E governing ICF/IID Programs — Contracting; 40 TAC Chapter 9, Subchapter D governing HCS; and 40 TAC Chapter 9, Subchapter N governing TxHmL.

**Providers who are operating at their contracted capacity level are not required to accept additional applicants.

***For a Medicare beneficiary in ICF/IID, HCS, or TxHmL, all prescription medications are provided through the Medicare Prescription Drug Program. (DADS, n.d., p.7)

Local Authorities

There are 39 local intellectual and developmental disability (IDD) authorities (LA) which serve as the DADS services point of contact for individuals in the counties they cover. Bexar County is served by the Alamo Local Authority and Bandera, Comal, and Kendall counties are served by the Hill Country MHDD Centers headquartered in Kerrville, TX (DADS, 2015c). The services provided by the Alamo Local Authority may be considered representative of services provided around the state of Texas and include:

- Determination of an Intellectual Disability – including psychological evaluation and testing
- Consumer Benefits screening to ensure maximum benefits (SSI, Medicaid, etc.)
- Home and Community Based Services (HCS) Interest List
- Community Living Options Information Process for residents of state supported living centers
- Permanency Planning (<23 yrs)
- Preadmission Screening and Resident Review
- Program enrollment
 - Intermediate Care Facilities (ICF/IID)
 - State Supported Living Center
 - General Revenue
 - Texas Home Living (TxHmL)
 - Home and Community Based Services (HCS)
 - Community First Choice
- Service Coordination (Targeted Case Management)
 - General Revenue
 - Texas Home Living (TxHmL)
 - Home and Community Based Services (HCS)

(AACOG, n.d.; L. Abundis, personal communication, July 7, 2015)

Texas Department of Assistive and Rehabilitative Service (DARS)

While the fairly new Autism Program offered through DARS currently only focuses on children, adults with ASD may qualify for other DARS programs. Eligibility for most programs is based on disability and need.

Vocational Rehabilitation

Those receiving Supplemental Security Income or Social Security Disability Insurance are presumed eligible for vocational rehabilitation services. To be eligible for vocational rehabilitation services a person must:

- Be present in the state of Texas
- Have a physical and/or mental condition that affects ability to work
- Need vocational rehabilitation services in order to get and/or keep a job
- Be able to get and keep a job after receiving services

DARS also specifies that “consumers can be served by only one DRS program at a time” (DARS, n.d.b).

Independent Living Services

To be eligible for this program, a person must:

- “Have a significant disability that results in a substantial impediment to their ability to function independently in the family and/or in the community, **and**
- There must be a reasonable expectation that ILS assistance will result in the ability to function more independently”

(DARS, n.d.a)

There are 27 Centers for Independent Living in Texas, 15 of which are funded by DARS. These centers provide advocacy, information and referral, peer counseling, and independent living skills training. San Antonio Independent Living Services (SAILS) is the DARS-funded center that services Bandera, Bexar, Comal, and Kendall counties, among others (SAILS, n.d.).

Employment and Independent Living

Getting a job and moving out of the family home are considered major milestones in the life of any young adult. For those with ASD, the challenges of establishing an independent lifestyle can be overwhelming. A recently published study found:

- 58% of young adults with ASD worked for pay outside the home
 - Much lower rate than those with other types of disabilities
 - Four in every 10 ASD adults never worked for pay

- Those with jobs tended to work part-time in low-wage jobs
- One in five young adults with ASD ever lived away from parents without supervision
 - 87% lived with their parents at some point between high school and their early 20s
 - Far higher percentage than in the general population
 - Only 19% of young adults with ASD ever lived independently after high school
 - Significantly lower percentage than their peers with other disabilities
 - Compared to 60% of those with speech-language impairment or emotional disturbance lived independently
 - 80% of those with learning disabilities
- 53% of young adults with ASD received no vocational or life skills services during their early 20s

(Roux, Shattuck, Rast, Rava, and Anderson, 2015, p.15)

Employment assistance is provided primarily through the DADS and DARS programs previously discussed. Housing assistance is also provided by those agencies but, aside from the state supported living centers, the wait is long and families often turn to alternative sources when searching for housing placements. Additionally, many families are unaware of what resources may be available to help them provide housing for their adult with ASD. A recent survey concluded that “76% of caregivers surveyed reported that despite the need for future supports, the individual with autism is not currently on a waiting list for housing or residential support services... Just one in four caregivers is currently saving for the future housing needs of the individual with autism” (Autism Speaks, 2013, p.19).

Types of residential placements available Medicaid ICF/IID program facilities

- Community-based residences
 - Vary in size from eight to 14 or more people
 - Provided by nonprofit organizations and private facilities
 - Currently list 44 spaces available in San Antonio

- State supported living center (in San Antonio)
 - Maximum capacity of 300
 - Currently lists 73 spaces available (DADS, 2015c)

Group Homes

- Traditional model for residential services for individuals with developmental disabilities
- Several unrelated individuals live together with onsite staff
- House is owned by a provider agency that also employs and supervises staff

Group Living/Ownership (Co-op)

- Similar to group home
- House is owned by a group of families or individuals
- Caregivers hired by the co-op

Teaching Family Model/Foster Home Living

- Family-style living with support services available 24/7 by professional teaching parents, usually a married couple
- The individual may be the only person with a disability living in the home, or there maybe others with or without disabilities

Supervised Living (Semi-Independent Living)

- Individuals may live in a house or apartment
- Functional life skills can be taught or supported by staff
- Support available 24 hours a day

Supported Living

- Individual lives in a house or apartment
- Minimal services based on specific needs
- Caregivers work under the direction of the individual

(Autism Speaks, 2011, p.13)

There appears to be no easy way to find appropriate permanent housing for an adult with ASD. Most agencies (private, nonprofit, and government) have individual eligibility requirements and an array of services to offer which must be waded through one at a time before a proper fit is found. What follows is a brief description of a representative sample of the types of funding and supports available in Texas and the San Antonio area.

U.S. Department of Housing and Urban Development (HUD)

HUD provides housing options, primarily for low income individuals, which can be accessed by adults with ASD to offset the cost of living alone. Use of HUD assistance is limited by strict income requirements (HUD, n.d.a):

- Privately owned subsidized housing
 - HUD helps apartment owners offer reduced rents
 - Individuals must find an apartment and apply to the apartment management office directly
 - There is a low-rent apartment search engine on the HUD website (HUD, n.d.b)
- Housing choice vouchers
 - Administered locally by public housing agencies (PHA) (San Antonio Housing Authority [SAHA] in San Antonio)
 - Participants find their own housing – apartment, townhouse, single-family residence
 - Once approved, the PHA pay the housing subsidy directly to the landlord
 - Participant must pay at least 30% of their monthly adjusted income to rent and utilities
 - In San Antonio, “due to limited funding and voucher availability, applicants should expect to remain on the waiting list for approximately three to five years” (SAHA, 2015)
- Homeownership assistance – Homeownership incentive program (HIP) in San Antonio
 - Assists eligible persons who are buying a new or existing home within the city

limits of San Antonio with up to \$12,000 for down payment and closing costs;

- Buyers must have stable employment, good credit and able to afford a mortgage payment
- Price and location restrictions apply (REnewSA, 2015)

Nonprofit organizations that provide residential options in San Antonio include:

- Reaching Maximum Independence, Inc. (n.d.)
 - Group homes
 - Supported apartment programs
 - Foster care services
- Autistic Treatment Center, Inc. (n.d.)
 - Group homes
- Mission Road Development Center (n.d.)
 - 13 community (group) homes
 - One assisted living home

All of the aforementioned facilities are part of the HCS and IFC network monitored and licensed by DADS. There are numerous private companies that also provide residential services. 18 of those organizations can be found through the DADS network (DADS, 2015c).

“There are other methods of funding services ... but the available funds are limited and usually unable to support the full scope of services that an adult with autism needs. These include: family support dollars, private funding, private health insurance...grants and foundations. Regardless of the funding mechanisms available, planning is crucial” (Autism Speaks, 2011, p.20). The need for supportive housing for low-income and disabled individuals, including those with ASD, is pressing.

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