# Assessment of Area Adults with Autism Spectrum Disorder and Other Intellectual and Developmental Disability

Community Information Now
Prepared for the Kronkosky Charitable Foundation
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# Contents



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# Introduction

The Kronkosky Charitable Foundation has made a significant investment in addressing autism spectrum disorders (ASD) among area youth, convening and staffing a collective impact initiative and contracting for a quantitative assessment. That *Autism Prevalence Assessment*, conducted by Capital Healthcare Planning, focused on the eight-county San Antonio CBSA (core-based statistical area, which includes the Foundation's four-county service area) and built on the September 2015 and December 2015 ASD research briefs by the Foundation. Both the assessment and the collective impact initiative also built on the Foundation's experience and relationships from prior grantmaking in the area of ASD services.

While work is well underway to increase local service capacity and better coordinate services for children with ASD, similar efforts are needed to support and improve quality of life and independence among adults with ASD. Especially among middle-aged and older adults, a formal assessment might never have been conducted and a diagnosis never established. That lack of a formal diagnosis makes it much more difficult to build adequate service capacity for this population and for individuals to qualify for those diagnosis-based services that do exist.

The Foundation contracted Community Information Now (CI:Now) to learn more about area adults with ASD – diagnosed or not – and about their characteristics and needs, particularly in the areas of housing, skills for independent living, behavior supports, opportunities for social interaction and engagement, education, and employment. At the recommendation of the Foundation's partner service providers, the scope of the assessment was expanded to include adults with intellectual and developmental disabilities (IDD) because a large proportion of adults with ASD have IDD and because older adults are much more likely never to have been formally assessed or diagnosed with ASD. "Adults with ASD/IDD" is used as shorthand throughout this report.

Because of the dearth of both local data and a national evidence base on adults with ASD, that work was split into a two-phase approach. An exploratory and qualitative Phase 1 gathered information to define the scope and approach to Phase 2. Phase 2 focused much more heavily on quantitative data, mining several administrative datasets and conducting a survey of local providers' capacity to serve adults with ASD/IDD. Because they were so different, the Phase 1 and Phase 2 approaches, methods, and results are presented separately, followed by a single **Summary and Implications** section for the entire study.

To our knowledge, this assessment is the first of its kind in the United States. Several states have integrated and analyzed administrative data to determine the characteristics and utilization patterns of children and adults with ASD receiving state-funded services. A handful of states have launched statewide surveys to explore the needs of people with ASD and their families who are already engaged with the service system.[1] And 16 states, of course, have participated at some point in the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network.[2] Local community assessments of ASD are common in the United Kingdom, although they vary in scope and depth. No other U.S. community that we are aware of, though, has undertaken an in-depth assessment of adults with ASD or published detailed modeled estimates of the local adult population with ASD.

[1] See, for example, the Pennsylvania Autism Census and the Oklahoma Autism Needs Assessment Survey

[2] Centers for Disease Control and Prevention. (2018). Autism and Developmental Disabilities Monitoring (ADDM) Network. Retrieved from https://www.cdc.gov/ncbddd/autism/addm.html

In a 2011 article titled "Autism Hidden in Plain Sight," the *Los Angeles Times* shined a bright light on the human and societal consequences of undiagnosed autism in Los Angeles adults:

> *"What happened to all the people who never got diagnosed? Where are they? …evidence suggests the vast majority are not segregated from society — they are hiding in plain sight.*
>
> *"… If modern estimates of autism rates apply to past generations, about 2 million U.S. adults have various forms of it — and society has long absorbed the emotional and financial toll, mostly without realizing it."*[3]

Our community does not know how many undiagnosed adults with ASD are "hidden in plain sight" in family homes and neighborhoods, or how many are homeless or institutionalized in hospitals, jails, or shelters. The Kronkosky Charitable Foundation and Community Information Now hope that this assessment is useful first step in finding those answers. Those answers, in turn, lay the foundation for connecting our adults with ASD and their families with community and with services and resources to support them in realizing the full possibility of their lives.

[3] Zarembo, A. (2011, December 16). Autism hidden in plain sight. Los Angeles Times. Retrieved from http://www.latimes.com/local/autism/la-me-autism-day-four-html-htmlstory.html

# Phase 1

## Approach

Phase 1 was initially intended to employ a combination of meetings and semi-structured interviews, focus groups, and self-administered online surveys. Exploratory and qualitative in nature, the intent was much like a feasibility study: to begin to paint a picture of what was and was not possible to know about local population characteristics, service needs and system capacity, policies and practices, and priorities. The work began as expected with informal meetings with several key service providers. It became clear very early on what the critical issues were and what would be feasible to learn in Phase 2. Thus the Phase 1 plan was scaled back significantly as those early conversations progressed, and those Phase 1 learnings directly informed the Phase 2 analysis plan.

In the end, Phase 1 consisted of meetings between CI:Now and over 20 staff of key adult ASD/IDD service providers, including The Arc of San Antonio, the Alamo Local Authority, Autism Treatment Center, the Center for Health Care Services Dual Diagnosis Program, Education Service Center Region 20, Mission Road Developmental Center, and Reaching Maximum Independence, Inc. Also, one family discussion group was attended by four adults with ASD/IDD and approximately 20 parents and other caregivers of adults with ASD/IDD.

Meetings were 90 minutes to two hours in length and held between January and May 2017. With the exception of the Adults and Families discussion group, the meetings were not attended by anyone from the Foundation or any other third party. Especially among service providers, the meeting participants were generally aware of the child *Autism Prevalence Assessment* and Autism Lifeline Links. They were supportive of this assessment and eager to help.

The meetings were quite informal, with participants briefed on the purpose of the assessment overall, and this phase in particular, and encouraged to share whatever they thought was relevant and useful. However, the following questions were used to guide discussion and ensure that all issue areas of highest interest to the Kronkosky Charitable Foundation were covered.

- What kinds of services do you offer for adults with ASD/IDD?
- What issues are faced by the adults you serve and their families/caregivers in these areas?
  - Housing
  - Health
  - Social engagement
  - Skills for independent living
  - Education and vocational training
  - Employment
- What are the major gaps and weaknesses in our local service system for adults with ASD/IDD and their families? Is there anything that works exceptionally well?
- What policy barriers – either laws or organizational policies – do you see getting in the way of your better serving adults with ASD/IDD, or in the way of our being a community where adults with ASD/IDD can thrive?
- What staffing issues do you face?

- What financial barriers do you see getting in the way of your better serving adults with ASD/IDD, or in the way of our being a community where adults with ASD/IDD can thrive?
- If services to meet all local needs were funded and money were not an issue, how easy or hard would it be for you to significantly scale up your service capacity?
- What data or other information would help you in your work?
- If we were going to try to quantify the number and characteristics of adults with ASD/IDD, what ideas do you have about how we might do that?
- If we were going to try to outreach to adults with ASD/IDD and their caregivers, what ideas do you have about how we might do that?

CI:Now's team member took extensive notes during each meeting; conversations were not tape-recorded. CI:Now subsequently conducted a qualitative analysis of the content of those notes, looking for key issues and common themes across meetings. The information provided here reflects participants' contributions directly and without filter or revision to the greatest extent possible. No statements were fact-checked or augmented with additional information from sources outside the conversations.

The remainder of this report discusses those issues and themes, as well as their implications for the much more quantitative Phase 2 of the assessment. The information gathered is grouped into topics, but significant overlap and intersection exist among topics.

## Key Issues and Common Themes

Following are key issues and questions that emerged from those conversations. The word "participant" is used throughout this section to indicate a person who participated in one or more of those conversations. A participant may thus be an agency or program administrator, a direct service provider, an adult with ASD/IDD, or a family member or paid caregiver of an adult with ASD/IDD.

### Overall Functioning and Daily Living Skills

Participants report tremendous variation in what individual adults with ASD/IDD need, what life skills they currently have, and what level of functioning they're capable of with appropriate supports. It is impossible to know a person's strengths and needs without a thorough individualized assessment. Although opinion differed somewhat among participants, most indicated that to the degree it serves anyone's needs well, the current system best meets the needs of the group of adults with ASD/IDD who have a middle level of functioning; those with lower and higher levels of function and daily living skills are less well-served.

- Lower-functioning adults with ASD/IDD may have behavioral and physical issues that many service providers are reluctant to take on, such as assisting with toileting and maintaining safety in cases of profound disability or illness. Risk of elopement (running away) or hurting themselves or others were cited as eligibility exclusion criteria common to many programs.

- Higher-functioning adults with ASD/IDD especially need better access to education and job training, social and recreational opportunities, independent and semi-independent housing opportunities with appropriate supports, and appropriately-supported employment. Some participants noted that the Intermediate Care Facilities (ICF) program has available capacity, but that that level of service is too intensive and restrictive for higher-functioning people.

Many participants spoke of a long local history of families choosing to keep adults with ASD/IDD living at home. The typical older adult with ASD/IDD left formal schooling early in life and was subsequently exposed to little or no life skills training, as parents/caregivers see "doing for" the adult with ASD/IDD as an expression of love, care, and family loyalty. This choice is often reinforced by fears about perceived lack of safety in dayhab programs and especially in group homes, discussed further in the **Supportive Housing** section.

Most participants reported that ongoing, lifelong, individually-tailored life skills training is critical to maximizing the well-being and independence of adults with ASD/IDD at all levels of functioning, and critical to family and caregiver quality of life as well. Life skills can be taught in a variety of settings, including a day program and at home. Participants reported that not only is life skills training needed so that adults with ASD/IDD can continue acquiring new skills, but also to help counteract the regression that commonly occurs when the adult leaves school.

A few participants suggested a role here for "transition schools." Several participants spoke of home-based life skills training as a potential entry point to engaging adults with ASD/IDD and their aging caregivers in cases where the adult has been at home his or her entire life and the caregiver is suspicious of the safety of dayhab programs and group homes. Life skills training and other service provision and coordination should be grounded in ongoing, lifelong individual assessment.

Almost to a one, participants spoke of "the wait list": the Intermediate Care Facilities (ICF) program is capped and the Home and Community-based Services (HCS) program has a waitlist reported to be as many as 15 years long. Interstate moves, including military, mean starting over at the bottom of the list. Participants reported schools and early intervention providers being key to encouraging families to register their child with ASD/IDD on the interest list at a young age in anticipation of service needs when the child must leave school.

Participants reported that not all families register their child timely, though, for a variety of reasons. For adults approximately 30 and older, who may never have been diagnosed at all, they and their families may first hear of the wait list during a time of crisis, like the adult with ASD/IDD experiencing a worsening of symptoms, or a health crisis on the part of the family caregiver, and only at that point does the 15-year clock start.

Few participants had any idea what happens to undocumented adults with ASD/IDD and their families. Undocumented adults and their families do not have access to most of the benefits on which adults with ASD/IDD rely. One participant theorized that nonprofits intentionally do not ask about citizenship or legal residency status, but few participants reported working with this population.

## Connection to Others

Connection to others and engagement in the world around them were consistently reported as critical to well-being. The best ways to connect with others and with the community, however, vary greatly by individual functioning and preference. Participants consistently reported that determining and supporting these "best ways" is difficult in perhaps any circumstances, but especially within the constraints set by policy and funding requirements. The greatest gap is connection and socialization opportunities for high-functioning adults with ASD, whose world is often confined to just work and home.

Nearly all participants reported that depending on the adult with ASD/IDD and the program, day activity or "dayhab" programs may play many critical roles, including but not limited to life skills training, socialization opportunities, and caregiver respite. To be successful, dayhab settings, programming, and staffing must be tailored to the individual abilities and needs of the adult with ASD/IDD, which can be very expensive and logistically challenging if the client population is varied. Behavioral support appears to be an important component of both day and residential programs, but not all programs have behavioral support providers on staff.

Many participants also spoke of the inherent tension between "community integration" (CI) requirements and the issues of self-determination, safety, and community tolerance. CI requirements do not take into account what adults with ASD/IDD actually want to do with their day, or what activities are safe for them given their level of functioning and medical needs.

Many participants were anxious about impending increased state CI requirements for dayhab. Participants feared that expanded requirements without commensurate increases in funding would likely result in heavy reliance on a narrow set of low- and no-cost options for group outings, potentially straining the patience and goodwill of the owners and patrons of those businesses. Several participants felt that an ongoing disconnect between Texas Department of Aging and Disability Services (DADS) and service providers was especially evident in the new CI requirements. For example, some participants reported that DADS staff were handing down policy developed in isolation and without communication or consultation with front line service providers.

## Physical and Mental/Behavioral Health and Self-Care

Participants reported adults with ASD/IDD being vulnerable to largely the same array and severity of physical and behavioral illnesses as adults without ASD/IDD – diabetes, obesity, cardiovascular disease, cancer – with some important exceptions. Some participants reported that adults with ASD are more vulnerable than adults without ASD to having brittle bones and breaks, and to developing dementia as they age.

Adults with ASD/IDD were also reported to be at increased risk of crime and victimization due to non-assertive behavior and because of a high but misguided trust in strangers. Disruptive behaviors may lead to criminal justice involvement, and depending on cognitive ability and mental health issues, the adult with ASD/IDD may not understand what is happening or why. Higher-functioning adults with ASD but not IDD were reported to be relatively more vulnerable to substance abuse than were lower-functioning adults with ASD and those with IDD.

Most participants talked about adults with ASD/IDD having varying degrees of decreased self-care ability, including the ability to communicate pain and illness. Several participants spoke of psychotropic medication being used to control difficult behaviors, sometimes to the point of a person with a high functional potential being "buried" in a nearly unresponsive state through intentional or unintentional overmedication.

Some participants spoke of sedatives being the treatment of first and last resort for adults brought to the emergency room by their families in a state of severe distress and with disruptive behavior. ER staff, poorly equipped to address the situation appropriately, sedate the adult with ASD and send them home.

It appears that a small number of primary care physicians and specialists, including psychiatrists, have established ASD/IDD-friendly practices and are relied upon heavily by non-healthcare providers. However, psychiatrists are in short supply in general, as are primary care providers, geriatricians, and other specialists in many areas. Access to appropriate and quality care is further complicated if the provider is not trained or not willing to provide care to an adult with ASD/IDD. Some participants spoke of the need for better referral resources for these kinds of services.

## Supportive Housing

An inadequate supply and variety of affordable supportive housing options emerged repeatedly as a major problem. The highest-functioning adults with ASD/IDD may be living independently, semi-independently with on-site support, or with family. The lowest-functioning are at home, in state schools, and in nursing facilities. Those in between may be living with family or in group homes. Some participants spoke of the risk of homelessness, particularly for those aging out of Child Protective Services eligibility, for males, and for those whose sole remaining family caregiver is an older adult who is frail or ill.

Group homes are a critical component of the housing "system" for adults with ASD/IDD, but unfortunately appear to be viewed by the public as dangerous and to be avoided. Other participants spoke of the very uneven quality of both supervision and physical conditions among different group homes. Several participants talked about group homes being unfairly stigmatized, and of confusion among code compliance officers and the general public about the differences between group homes and boarding homes. One reported problem is that no good way exists to ensure that people who are highly trusting and childlike are housed with similar peers rather than with adults with criminal backgrounds and predatory behaviors. An HCS provider cannot refuse an eligible client who's a poor fit for a group home opening.

Some participants spoke of adults with ASD/IDD doing very well in good adult foster homes, with reduced anxiety and higher quality of life. Some adults with ASD/IDD are reported to be able to successfully discontinue psychotropic medications and reduce toileting issues. Good adult foster homes, though, are reported to be in very short supply. Foster care with any family but the adult's own family is considered very hard to scale, and any adult foster care introduces the need for training, ongoing support, and oversight.

Many participants spoke of a need for residential services with health care appropriate to the aging adult's functional level and physical and mental health, including dementia. Some participants noted that assisted living facilities are typically grossly unequipped to care appropriately for the older adult

with ASD/IDD, and that residential services for adults with ASD/IDD are typically equally unequipped to handle major medical issues.

Some participants noted that semi-independent living slots are going unused because there is currently no way to "add on" minimal supportive services. Many higher-functioning adults with ASD are capable of living semi-independently but need someone to help them plan and get started on their day each day. That assistance could be an in-person home visitor or even a "tele-support" model via videoconference. One participant suggested that local nonprofits need to increase efforts to apply for tax credits for affordable housing for adults with ASD/IDD.

## Postsecondary Education

Postsecondary education, in the form of either formal college or vocational certificate programs, did not appear to be high on the priority worry list of most participants. Interestingly, it was discussed most in the Adults and Families discussion group, where participants referred to programs in Austin that support adults with ASD/IDD enrolling in and staying in college. One participating agency spoke of their computer coding training program.

As is the case with employment, inappropriately low expectations on the part of both service providers and families might factor into adults with ASD/IDD not pursuing – or not even considering – college. Although participants did not mention it, San Antonio's overall low rate of college enrollment and graduation may also play a part.

## Employment and Workforce Training

Many participants reported insufficient employment opportunities, job training, and employment supports for adults with ASD/IDD. One participant noted that there has been no apparent increase in employment since ADA was passed, which is unexpected and makes little sense. Participants reported slow implementation of the Achieving a Better Life Experience (ABLE) Act of 2013, which enabled tax-advantaged savings accounts for people with disabilities that can be used for qualified disability expenses like housing, transportation, and education.

Given the policy environment, many participants talked of employer policies being key to successful employment, including some that might seem exploitative at first glance. Having a 401(k) or more than $2,000 in assets triggers loss of eligibility for state funding. Absent changes in eligibility rules, then, allowing an employed adult with ASD *not* to have a retirement account, to have limited work hours, and perhaps even to make a lower wage, may be necessary if the adult with ASD/IDD wants to work without losing benefits. Many participants spoke of the Arc of Texas Master Pooled Trust, generally referred to as simply "the Arc Trust," which helps adults with ASD/IDD establish financial security without losing benefits.

Several participants spoke of families' inappropriately low expectations of adults with ASD/IDD and fears for their well-being and safety as barriers to job training and employment. Participants spoke of schools frequently on the role of setting higher expectations when the person with ASD/IDD is a child. But particularly for adults aged approximately 30 and older, who may never have been formally diagnosed and may not have ever engaged in services, no external force is present to help adults with ASD/IDD and their families think about and work toward maximum independence.

With training and appropriate supports, which may be intensive, employment is possible for many adults with ASD/IDD, not just the highest-functioning. Some training programs and job opportunities participants mentioned included computer coding, janitorial services, and kitchen staff.

## Caregiver Workforce Issues

Employee recruitment and retention were reported as serious problems by most participants, who reported that it is very difficult to find people willing to do direct care. The shortage is severe enough that it would limit local capacity to serve more adults with ASD/IDD even if additional funding became available. Nursing, assisted living, and other fields compete for people with a similar entry-level skill set but can offer significantly higher wages. Most participants noted that they cannot recruit simply for a skill set; they're looking for a "certain kind of person" who can provide direct care with love and respect without quickly burning out.

One participating agency spoke of having good success recruiting among local refugee immigrants who are willing to do the hard work of direct care, sometimes as a stepping stone in a longer career path. Some participants reported having much better success recruiting and retaining older people and people of color than millennials and non-Hispanic whites. One participant spoke of it being easier to retain staff who provide services in the home rather than in a residential setting.

Several participants spoke of a looming staffing crisis, as existing staff are largely aging "baby boomer" women. These staff have decades of experience and high levels of passion and personal commitment but are closing in on retirement age and cannot be retained indefinitely.

Turnover was reported to be a problem as well, with one participant referring to an industry turnover rate of about 55% nationwide. Participants reported that turnover costs were very high and had negative impacts not just on the agency's financial health, but also on the quality of life of the adult with ASD/IDD.

Some participants spoke of a need for translation services to assist the increasing number of immigrants, often refugees, who speak neither English nor Spanish. These adults and families are, overall, the least equipped to navigate the complicated service system.

Participants reported that staff, especially direct care staff, need intensive supports, including training and frequent debriefs. Certification programs exist, and certification is seen as valuable in theory. But participants reported that they already can't pay competitive wages and could not pay the needed wage differential for certified staff. In lieu of certification, participants reported relying on a patchwork of training programs, often developed and operated in-house.

## Information Needs and Data Sources

Nearly all participants spoke of the value of the Capital Healthcare Planning *Autism Prevalence Assessment* on children with ASD and were pleased to hear that more information would become available about area adults with ASD/IDD. Better data about these adults, their living situation, level of functioning, and specific needs would be valuable for service provider planning, local service coordination efforts, resource development, and advocacy.

Following is a list of specific information needs and potential data sources that emerged from the conversations.

- Need to quantify the population of adults with ASD or IDD, but an overall count won't help at all. Need a much more granular breakdown by functional level and type and degree of need, with projections if possible
- Need thorough individualized assessment of functional level, life skills, physical and mental health status
- Need to know the needs of the family as well, since parents and other family members have grief and burnout issues and may have ASD and/or IDD as well
- Need to better understand the needs and situation of older parents/caregivers of adults with ASD/IDD
- Case studies showing long-term impact would be helpful. "What could have turned out differently?"
- Would be helpful to know what percent are employed
- Would be helpful to know age of caregiver
- Would be helpful to know living situation
- How many are we serving, how many are we not serving, and what is the cost of both?
- School districts would have records for adults with ASD up to about age 28
- The San Antonio Policy Department and county jail might have records from criminal justice encounters with adults with ASD/IDD

# Phase 2

## Approach

The design of Phase 2 was directly informed by the Phase 1 conversations about what is known about area adults with ASD/IDD, what would be helpful to know, and what data sources are available. Before beginning Phase 2 it was clear that not all the questions raised in Phase 1 could be answered completely – or in some cases, at all – using the available data. However, the Phase 2 analysis was intended to lay a solid foundation for planning, advocacy, and further analysis of the characteristics, needs, and opportunities of the area population of adults with ASD/IDD and the systems that serve them.

This section outlines the goals of Phase 2, with specific analysis objectives and data sources for each. The information to be gathered falls in the two broad categories of **Population and Costs** and **Service System and Workforce**. The detailed methodology for each analysis objective is presented in the next section alongside the key points and summary data tables.

## Population and Costs

### A. Estimated and projected population of adults with ASD/IDD

*Purpose:* Estimate as closely as possible the true current and projected size and characteristics of the local adult population with ASD/IDD

*Description:* Estimate the size and characteristics of the local population of adults with intellectual and developmental disabilities (IDD) in general and with autism spectrum disorder (ASD) specifically, whether or not those individuals have ever been formally diagnosed with ASD or have ever engaged with the local system of care. Estimates of adult and childhood prevalence will be used to develop population projections for the years 2030 and 2050. Where possible, estimates will be disaggregated on the following characteristics:

- disorder (ASD, other IDD)
- demographics (age group, sex, race/ethnicity)
- functional level
- co-occurring physical or behavioral illness or disability

*Data Sources:* National and state population prevalence studies, local child population prevalence estimates, HASA health information exchange, Blue Cross Blue Shield and Medicaid claims datasets through UT School of Public Health

### B. Identified population characteristics

*Purpose:* Describe the current situation and needs of the population engaged with the health care system or AACOG IDDS (including “interest list”)

*Description:* Analyze the characteristics of the “identified” population, defined as having a formal diagnosis of ASD/IDD or a family-/self-reported diagnosis documented in the health care system or AACOG IDDS system of care. Depending on data source, characteristics available include:

- diagnosed disorder (ASD, other IDD)
- co-occurring physical or behavioral illness or disability
- demographics (age group, sex, race/ethnicity)
- living and caregiver situation
- functional level
- needs

*Data Sources:* Alamo Local Authority and THHS Interest List, HASA health information exchange, Blue Cross Blue Shield and Medicaid claims datasets through UT School of Public Health

### C. Estimated population not in services

*Purpose:* Estimate the size and characteristics of the population not receiving needed services

*Description:* Quantify and describe to the degree possible the population in care and the total population needing care.

*Data Sources:* Alamo Local Authority, population estimates calculated in 1.A. above

### D. Estimated costs

*Purpose:* Estimate local lifetime costs and other costs if available (e.g., health care) to inform local planning, case-making, and resource allocation

*Description:* Use lifetime and service-specific cost estimates from literature and state and local administrative datasets to estimate local costs

*Data Sources:* Cost literature, THHSC/AACOG IDDS, UTSPH claims datasets

## Service System and Workforce

### E. Current capacity

*Purpose:* Determine the current capacity of the local service system and opportunities for improvement in key service areas:

- Dayhab
- Respite (overnight, weekend)
- Supported housing (semi-independent living, group homes, assisted living for older w/ medical needs)
- Supported employment
- Healthcare (primary care, psychiatry, other behavioral health)

*Description:* Build on existing datasets/efforts to quantify local capacity for the above categories of services, as well as collect ideas for system improvement

- **Healthcare workforce analysis.** Analyze provider-to-population ratio for selected healthcare provider types.

- **Provider survey.** Work with stakeholders to develop and test an online survey to allow providers to easily and securely report detailed information about service capacity, similar to the information captured by the ALL Community Engagement Committee's Stakeholder Questions spreadsheet, along with cleaning and analysis of that response data. Will include an opportunity to share ideas about barriers and opportunities, possibly including a section framed using appreciative inquiry. (KCF and ALL staff will assist with survey outreach and reminders.)

*Data Sources:* Local providers, Texas Medical Board, TDSHS Health Professions Council

## F. Estimates of unmet need

*Purpose:* Estimate the size and characteristics of the gap between service need and service capacity in the key areas noted in 2.A. above.

*Description:* Quantify and describe to the degree possible the mismatch between need and capacity for each key service type.

*Data Sources:* Alamo Local Authority "interest list," population estimates calculated in 1.A. above, and service capacity data from 2.A. above

# Results

Each of the analysis objectives described above utilized different data sources and different analysis methods. To prevent confusion, this section of the report presents the key points and detailed methods of each analysis separately.

## Population and Costs

### A. Estimated and projected population of adults with ASD/IDD

#### Key Points

- CI:Now modeled estimates and projections of the local number of adults (18 and older) with ASD by applying CDC's most recent (2014) Autism and Developmental Disabilities Monitoring Network (ADDM) national prevalence rates for eight-year-olds[4] (Table A.1) to the populations of Bandera, Bexar, Comal, and Kendall Counties as projected by the Texas Demographic Center[5] (TDC) for 2018, 2030, and 2050 using the 1.0 migration scenario[6] (Tables A.5 through A.16).
- Table A.3 compares the estimates generated by the different methods, with the recommended estimates bolded. Because the CDC ADDM prevalence rates have a confidence interval, or range of probable values, each estimate provided here has a range as well, presented in parentheses after the estimate.
    - Bandera and Kendall Counties are overwhelmingly non-Hispanic white. Although the prevalence gap by race/ethnicity as measured by the CDC ADDM appears to be narrowing over time, non-Hispanic whites still have a markedly higher ASD prevalence than other racial/ethnic groups. Thus the estimates calculated using race/ethnicity were slightly higher than that calculated using only sex, although at two to three percent variance, the differences are tiny. The population numbers were too small to model estimates using race/ethnicity by sex.
    - The estimates calculated for Comal County and Bexar County using race/ethnicity by sex were lower than those calculated using only sex or only race/ethnicity. Similar to Bandera and Kendall Counties, the lowest estimate for Comal County varied from the highest estimate by only two percent. In Bexar County, however, the variance was 10%. Bexar County's adult population is only 28% non-Hispanic white, as compared to 81%, 77%, and 73% in Bandera, Kendall, Comal Counties, respectively. Because the CDC ADDM's ASD prevalence rate is about 23% higher for non-Hispanic whites than for Hispanics (Table A.1), which make up 59% of Bexar County's adult population, the different racial/ethnic distribution in Bexar County has a strong effect on the variety of the estimates depending on method.

[4] Christensen, D.L., Baio, J., Van Naarden Braun, K, et al. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. *MMWR Surveillance Summaries*, Vol. 65, No. 3.

[5] Texas Demographic Center, Population projections for 2017 by county, race/ethnicity, and age group. Downloaded 11/7/2017 from http://txsdc.utsa.edu/Data/TPEPP/Projections/

[6] Per the TDC website, the 1.0 scenario "assumes population change due to migration at a rate equal to the 2000-2010 migration rate and also reflects changes due to natural increase (births and deaths)."

  - Using the same modeling methods and assumptions with TDC population projections for 2030 and 2050, the number of people with ASD was projected for each of those years by county (Table A.3). Detailed estimates and projections by county follow (Tables A.5 through A.16).

- The estimation method, key assumptions, and the likely effects on the estimates if any of those assumptions are incorrect are described below in *Methods.* The estimated and projected numbers of adults with ASD by county are as follows:
  - Using CDC prevalence by race/ethnicity (Table A.1), the total number of adults with ASD in Bandera County is estimated at **337 (estimate range 321 to 348)** (Table A.5), growing to a projected **402 (385-419)** by 2030 (Table A.6) and **426 (405-443)** by 2050 (Table A.7).
  - Using CDC prevalence by race/ethnicity (Table A.1), the total number of adults with ASD in Kendall County is estimated at **559 (534-582)** (Table A.8), growing to a projected **773 (737-806)** by 2030 (Table A.9) and **1,150 (1,093-1,203)** by 2050 (Table A.10).
  - Using CDC prevalence by race/ethnicity by sex (Table A.2), the total number of adults with ASD in Comal County is estimated at **1,790 (1,619-1,877)** (Table A.11), growing to a projected **2,601 (2,438-2,731)** by 2030 (Table A.12) and **4,032 (3,775-4,252)** by 2050 (Table A.13).
  - Using CDC prevalence by race/ethnicity by sex (Table A.2), the total number of adults with ASD in Bexar County is estimated at **21,618 (20,091-23,005)** (Table A.14), growing to a projected **26,585 (24,885-28,679)** by 2030 (Table A.15) and **35,975 (33,140-38,653)** by 2050 (Table A.16).

- These estimates far exceed those published by Capital Healthcare Planning (CHP) in 2016 for four primary reasons.
  - First, the estimated prevalence of ASD has grown steadily over the years, with the published CDC ADDM estimates growing from one in 88 in 2010 to one in 68 in 2012 and one in 59[7] in 2016, a 49% increase over 2010. Thus prevalence rates CI:Now employed in 2018 are significantly higher than the best estimates available in 2016 and earlier.
  - Second, the gap in estimated prevalence between white males and other demographic groups is closing over time; from 2014 to 2016 the CDC ADDM estimated prevalence for Hispanics and females increased 39% and 25%, respectively, as compared to an increase of 11% for non-Hispanic whites and 13% for males. Because the San Antonio area's population is predominantly Hispanic and roughly half female, the narrowing of that gap has a tremendous effect on the resulting estimated population with ASD.
  - Third, CHP used Claritas population projections while CI:Now used Texas Demographic Center (TDC) population projections based on the 1.0 migration scenario, which should more accurately reflect the area's very rapid growth since the 2010 Census.
  - Finally, CHP applied a global or base prevalence rate, adjusted for the area's demographic mix, to each county's total population. CI:Now's approach to factoring in the local demographic mix was to apply race/ethnicity- and sex-specific rates to county population subgroups, disaggregated by race/ethnicity, sex, and age group. The total county estimate of population with ASD is the sum of the population estimates in each of those subgroups.

[7] Centers for Disease Control and Prevention. (2018). Autism and Developmental Disabilities Monitoring (ADDM) Network. Retrieved from https://www.cdc.gov/ncbddd/autism/addm.html

## Estimation Methods

- No U.S. local, state, or national prevalence rates for adults with autism spectrum disorder (ASD) are available. The only robust adult population ASD prevalence figures, developed using a community sample, surveys, and validated assessment tools, are from England.[8] That study found no meaningful differences between adult and child prevalence rates. As it is the only community study of adults, and as it found no difference between adult and child prevalence rates, the adult prevalence rates estimated in this report were modeled using child prevalence rates.
    - The study did see a slight decline in prevalence in older adult age groups, but the differences among age groups were not statistically significant. CI:Now believes this pattern may be explained by the male-to-female ratio that decreases with increasing age, as on the whole, women live longer than men in the U.K. and U.S., and ASD prevalence is much lower among females than among males.
- The national prevalence rates CI:Now used are the most recent available from the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring Network (ADDM), just released on April 27, 2018, and are for eight-year-olds. The ADDM surveillance system relies on a combination of health and education datasets in 11 sites across the country. These new prevalence rates – overall 1 in 59 children, or about 1.7% – are higher than those previously assessed by ADDM and in wide use now, including by Autism Speaks and other advocacy groups.
- The four approaches to modeling estimates using the CDC rates are:
    - *Total population alone.* Apply the CDC's overall prevalence rate (1 in 59, or 1.68%) to the county-level total populations. This approach is not appropriate because ASD prevalence differs dramatically by sex, with ASD much more common among males than females overall, particularly among those with ASD but not intellectual disability (ID). This approach also fails to account for differences by race/ethnicity. ASD is most common among non-Hispanic whites and least common among Hispanics.
    - *Sex alone*. Apply the prevalence rates for males and females to county-level male and female population totals. This approach accounts for the sex differences in ASD prevalence but likely overstates ASD prevalence in areas with a large Hispanic population, and the four counties in the Kronkosky target area differ dramatically in racial/ethnic makeup. Because there are only two sexes in each county, this approach does not run into the problem of "small cell sizes" in the highly rural counties (Bandera and Kendall) where the total population is small.
    - *Race/ethnicity alone*. This approach accounts for prevalence differences by race/ethnicity, but does not explicitly account for differences by sex. It does run into the "small cell sizes" problem because the non-Hispanic black and "other" non-white, non-Hispanic populations are tiny, together composing less than 3% of the population in both Bandera and Kendall Counties. This approach is the best possible for Bandera and Kendall Counties.
    - *Race/ethnicity by sex*. This approach accounts for prevalence differences by both sex and by race/ethnicity and so is the preferred approach. This method is only feasible for Bexar and Comal Counties, however, with their much larger total populations.

[8] Brugha, T.S., McManus, S., Bankart, J., et al. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. Archives of General Psychiatry, Vol. 68, No. 5.

## Critical Assumptions

This approach relies on five critical assumptions, shown in order of decreasing effect on the estimates:

1. *That the true ASD prevalence is roughly the same for eight-year-olds and for adults of all ages*, which would mean that the increase in diagnosed ASD over the past half-century is primarily due to increased awareness and screening, changes in diagnostic criteria, and improved access to diagnosis, not to a true increase in the frequency of the condition. This assumption underpins this entire analysis, and if it is incorrect, these estimates are of no value.

   Available data does indicate among a small proportion of children diagnosed with ASD – typically those with Asperger, a higher IQ and functional level, and without ID – symptoms decrease over time, with some children no longer qualifying for diagnosis by adolescence.[9] Assuming that improvement occurs among 10% or fewer of diagnosed eight-year-olds, the impact on the total estimate is negligible. This scenario is one that it has a profound impact for an individual child and his or her family, but very little impact on a population-level estimate.

2. *That apparent differences in ASD prevalence by sex and by race/ethnicity are real* and not an artifact of differences in symptom presentation, diagnostic criteria, access to diagnostic services, or even in systemic and implicit biases (e.g., attribution of challenging behaviors to "attitude" rather than illness among African-Americans, particularly boys)[10]. Varying degrees of evidence exist in support of all of these factors, though, and the differences in CDC ADDM prevalence by race/ethnicity appear to be narrowing substantially over time. (The gap between males and females has narrowed much less substantially.) Thus it is very possible that the true differences in prevalence by race/ethnicity, and less so by sex, are less dramatic than what current CDC data indicates.

3. *That the sex prevalence ratio – the male-female difference in ASD prevalence – is more or less consistent across all racial/ethnic groups*. CI:Now used that assumption to calculate sex-specific prevalence rates for each racial/ethnic group (Table A.2). No available evidence indicates this is an unsafe assumption, but if it is in fact wrong, the effect on the estimates could be quite sizable, particularly for Bexar County where Hispanics make up an estimated 59% of the adult population.

4. *That the CDC's non-Hispanic Asian/Pacific Islander ASD prevalence rate is appropriate to apply to the full "Other race/ethnicity" population* in each county (see Table A.1), which is composed of several racial/ethnic groups. This prevalence (1.35%) is quite low and is applied to a very small proportion of the population – 5% in Bexar County and 2% in the other three counties. If this assumption is wrong, the effect on the total population estimate of adults with ASD is extremely minimal, but the effect on the estimate for that particular racial/ethnic group could be significant.

5. *That the Texas Demographic Center's county-level population projections for 2018, 2030, and 2050 are accurate and that the 1.0 migration scenario recommended by the Texas State Demographer is appropriate*. These projections are well-regarded and in common use, but the effect of inaccuracies or invalid assumptions in TDC's projections would introduce error into these estimates of adults with ASD, particularly for the rural counties and smaller racial/ethnic populations.

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[9] See for example Suh, J., Orinstein, A., Barton, M. et al. (2016). *Journal of Autism and Developmental Disorders*. Vol. 46:3505. Retrieved from https://doi.org/10.1007/s10803-016-2868-4

[10] See for example U.S. General Accounting Office. (2018). *K-12 education: Discipline disparities for black students, boys, and students with disabilities*. Washington, DC. Retrieved from https://www.gao.gov/assets/700/690828.pdf

## Summary Tables

**Table A.1. CDC ADDM Prevalence Rates per 1,000 Population for Eight-Year-Olds, 2014**

| | | Prevalence per 1,000 (95% CI*) | Prevalence |
|---|---|---|---|
| **Total** | | 16.8 (16.4-17.3) | 1 in 59 |
| **Sex** | Male | 26.6 (25.8-27.4) | 1 in 38 |
| | Female | 6.6 (6.2-7.0) | 1 in 152 |
| **Race/ Ethnicity** | White, non-Hispanic | 17.2 (16.5-17.8) | 1 in 58 |
| | Black, non-Hispanic | 16.0 (15.1-16.9) | 1 in 63 |
| | Hispanic | 14.0 (13.1-14.9) | 1 in 71 |
| | Asian/Pacific Islander (API), non-Hispanic | 13.5 (11.8-15.4) | 1 in 74 |

*CI = 95% confidence interval, or the range in which we can be 95% certain the true number lies
Source: Baio, J., Christensen, D.L., Maenner, M.J., Daniels, J., et al. (2018). Prevalence of autism spectrum disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *MMWR Surveillance Summaries*, Vol. 67, No. 6.

**Table A.2. CDC ADDM Prevalence Rates for Eight-Year-Olds, 2014, With Sex Prevalence Ratio Applied to All Race/Ethnicity Groups**

| | Estimate and 95% Confidence Interval | | |
|---|---|---|---|
| | Total | Males | Females |
| Total pop | 16.8 (16.4-17.3)[1] | 26.6 (25.8-27.4) [1] | 6.6 (6.2-7) [1] |
| White, non-Hispanic | 17.2 (16.5-17.8) [1] | 27.2 (26.0-28.2) [2] | 6.8 (6.2-7.2) [2] |
| Black, non-Hispanic | 16.0 (15.1-16.9) [1] | 25.3 (23.8-26.78) [2] | 6.3 (5.7-6.8) [2] |
| Hispanic | 14.0 (13.1-14.9) [1] | 22.2 (20.6-23.6) [2] | 5.5 (5.0-6.0) [2] |
| API, non-Hispanic | 13.5 (11.8-15.4) [1] | 21.4 (18.6-24.4) [2] | 5.3 (4.5-6.2) [2] |

Source: [1] Baio et al.; [2] Calculated by CI:Now

**Table A.3. Comparison of Estimated Number of Adults with ASD by Estimation Method**

| | Bandera | Kendall | Comal | Bexar |
|---|---|---|---|---|
| Modeled using only sex | 332 (322-344) | 545 (525-565) | 1,834 (1,769-1,903) | 24,141 (23,264-25,019) |
| Modeled using only race/ethnicity | 337 (321-348) | 559 (534-582) | 1,836 (1,749-1,915) | 22,132 (20,830-23,406) |
| Modeled using race/ethnicity by sex | | | 1,790 (1,679-1,877) | 21,618 (20,091-23,005) |
| Best estimate | 337 (321-348) | 559 (534-582) | 1,790 (1,679-1,877) | 21,618 (20,091-23,005) |
| Overall prevalence | 1 in 60 | 1 in 61 | 1 in 63 | 1 in 68 |

**Table A.4. Summary of Estimated and Projected Number of Adults with ASD by County and Year**

| | | Estimated | Projected | |
|---|---|---|---|---|
| **County** | **Modeling Method*** | **2018** | **2030** | **2050** |
| Bandera | By race/ethnicity only | 337 (321-348) | 402 (385-419) | 426 (405-443) |
| Bexar | By race/ethnicity by sex | 21,618 (20,091-23,005) | 26,858 (24,885-28,679) | 35,975 (33,140-38,653) |
| Comal | By race/ethnicity by sex | 1,790 (1,679-1,877) | 2,601 (2,438-2,731) | 4,032 (3,775-4,252) |
| Kendall | By race/ethnicity only | 559 (534-582) | 773 (737-806) | 1,150 (1,093-1,203) |

*See Table A.2

**Table A.5. Estimated Number of Adults with ASD by Age Group and Race/Ethnicity in Bandera County in 2018**

| TDC Population Projections: Bandera County, 2018, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other** | **Total** |
| 18-29 | 1,780 | 22 | 767 | 70 | **2,639** |
| 30-44 | 2,041 | 11 | 665 | 51 | **2,768** |
| 45-64 | 6,779 | 23 | 1,278 | 142 | **8,222** |
| 65+ | 5,802 | 17 | 700 | 114 | **6,633** |
| **Total** | **16,402** | **73** | **3,410** | **377** | **20,262** |
| **Number of Adults Estimated to Have ASD** | | | | | |
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other*** | **Total** |
| 18-29 | 31 (29-32) | 0 (0-0) | 11 (10-11) | 1 (1-1) | **43 (40-44)** |
| 30-44 | 35 (34-36) | 0 (0-0) | 9 (9-10) | 1 (1-1) | **45 (44-47)** |
| 45-64 | 117 (112-121) | 0 (0-0) | 18 (17-19) | 2 (2-2) | **137 (131-142)** |
| 65+ | 100 (96-103) | 0 (0-0) | 10 (9-10) | 2 (1-2) | **112 (106-115)** |
| **Total** | **283 (271-292)** | **0 (0-0)** | **48 (45-50)** | **6 (5-6)** | **337 (321-348)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.6. Projected Number of Adults with ASD by Age Group and Race/Ethnicity in Bandera County in 2030**

| TDC Population Projections: Bandera County, 2030, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other** | **Total** |
| 18-29 | 1,546 | 17 | 1,158 | 59 | **2,780** |
| 30-44 | 2,251 | 24 | 1,186 | 95 | **3,556** |
| 45-64 | 5,264 | 16 | 1,437 | 89 | **6,806** |
| 65+ | 9,791 | 31 | 1,387 | 155 | **11,364** |
| **Total** | **18,852** | **88** | **5,168** | **398** | **24,506** |
| **Number of Adults Projected to Have ASD in 2030** | | | | | |
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other*** | **Total** |
| 18-29 | 27 (26-28) | 0 (0-0) | 16 (15-17) | 1 (1-1) | **44 (42-46)** |
| 30-44 | 39 (37-40) | 0 (0-0) | 17 (16-18) | 1 (1-1) | **57 (54-59)** |
| 45-64 | 91 (87-94) | 0 (0-0) | 20 (19-21) | 1 (1-1) | **112 (107-116)** |
| 65+ | 168 (162-174) | 0 (0-1) | 19 (18-21) | 2 (2-2) | **189 (182-198)** |
| **Total** | **325 (312-336)** | **0 (0-1)** | **72 (68-77)** | **5 (5-5)** | **402 (385-419)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.7. Projected Number of Adults with ASD by Age Group and Race/Ethnicity Bandera County in 2050**

| TDC Population Projections: Bandera County, 2050, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other** | **Total** |
| 18-29 | 1,631 | 17 | 1,877 | 93 | **3,618** |
| 30-44 | 2,067 | 8 | 1,948 | 72 | **4,095** |
| 45-64 | 4,803 | 26 | 2,824 | 202 | **7,855** |
| 65+ | 8,784 | 20 | 2,041 | 101 | **10,946** |
| **Total** | **17,285** | **71** | **8,690** | **468** | **26,514** |
| **Number of Adults Projected to Have ASD in 2050** | | | | | |
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other*** | **Total** |
| 18-29 | 28 (27-29) | 0 (0-0) | 26 (25-28) | 1 (1-1) | **55 (53-58)** |
| 30-44 | 36 (34-37) | 0 (0-0) | 27 (26-29) | 1 (1-1) | **64 (61-67)** |
| 45-64 | 83 (79-85) | 0 (0-0) | 40 (37-42) | 3 (2-3) | **126 (118-130)** |
| 65+ | 151 (145-156) | 0 (0-0) | 29 (27-30) | 1 (1-2) | **181 (173-188)** |
| **Total** | **298 (285-307)** | **0 (0-0)** | **122 (115-129)** | **6 (5-7)** | **426 (405-443)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.8. Estimated Number of Adults with ASD by Age Group and Race/Ethnicity Kendall County in 2018**

| TDC Population Projections: Kendall County, 2018, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other** | **Total** |
| 18-29 | 3,530 | 34 | 1,944 | 203 | **5,711** |
| 30-44 | 3,981 | 17 | 1,813 | 90 | **5,901** |
| 45-64 | 10,520 | 38 | 2,293 | 290 | **13,141** |
| 65+ | 8,153 | 37 | 857 | 152 | **9,199** |
| **Total** | **26,184** | **126** | **6,907** | **735** | **33,952** |
| **Number of Adults Estimated to Have ASD** | | | | | |
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other*** | **Total** |
| 18-29 | 61 (58-63) | 1 (1-1) | 27 (25-29) | 3 (2-3) | **92 (86-96)** |
| 30-44 | 68 (66-71) | 0 (0-0) | 25 (24-27) | 1 (1-1) | **94 (91-99)** |
| 45-64 | 181 (174-187) | 1 (1-1) | 32 (30-34) | 4 (3-4) | **218 (208-226)** |
| 65+ | 140 (135-145) | 1 (1-1) | 12 (11-13) | 2 (2-2) | **155 (149-161)** |
| **Total** | **450 (433-466)** | **3 (3-3)** | **96 (90-103)** | **10 (8-10)** | **559 (534-582)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.9. Projected Number of Adults with ASD by Age Group and Race/Ethnicity in Kendall County in 2030**

| TDC Population Projections: Bandera County, 2030, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other** | **Total** |
| 18-29 | 3,993 | 17 | 2,765 | 246 | **7,021** |
| 30-44 | 5,253 | 39 | 3,179 | 278 | **8,749** |
| 45-64 | 10,914 | 23 | 3,533 | 315 | **14,785** |
| 65+ | 14,505 | 69 | 1,966 | 247 | **16,787** |
| **Total** | **34,665** | **148** | **11,443** | **1,086** | **47,342** |
| **Number of Adults Projected to Have ASD in 2030** | | | | | |
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other*** | **Total** |
| 18-29 | 69 (66-71) | 0 (0-0) | 39 (36-41) | 3 (3-4) | **111 (105-116)** |
| 30-44 | 90 (87-94) | 1 (1-1) | 45 (42-47) | 4 (3-4) | **140 (133-146)** |
| 45-64 | 188 (180-194) | 0 (0-0) | 49 (46-53) | 4 (4-5) | **241 (230-252)** |
| 65+ | 249 (239-258) | 1 (1-1) | 28 (26-29) | 3 (3-4) | **281 (269-292)** |
| **Total** | **596 (572-617)** | **2 (2-2)** | **161 (150-170)** | **14 (13-17)** | **773 (737-806)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.10. Projected Number of Adults with ASD by Age Group and Race/Ethnicity in Kendall County in 2050**

| TDC Population Projections: Bandera County, 2050, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other** | **Total** |
| 18-29 | 5,193 | 22 | 5,222 | 863 | **11,300** |
| 30-44 | 6,364 | 17 | 5,467 | 468 | **12,316** |
| 45-64 | 14,793 | 36 | 7,572 | 1,013 | **23,414** |
| 65+ | 19,595 | 34 | 4,719 | 371 | **24,719** |
| **Total** | **45,945** | **109** | **22,980** | **2,715** | **71,749** |
| **Number of Adults Projected to Have ASD in 2050** | | | | | |
| **Age Group** | **Anglo** | **Black** | **Hispanic** | **Other*** | **Total** |
| 18-29 | 89 (86-92) | 0 (0-0) | 73 (68-78) | 12 (10-13) | **174 (164-183)** |
| 30-44 | 109 (105-113) | 0 (0-0) | 77 (72-81) | 6 (6-7) | **192 (183-201)** |
| 45-64 | 254 (244-263) | 1 (1-1) | 106 (99-113) | 14 (12-16) | **375 (356-393)** |
| 65+ | 337 (323-349) | 1 (1-1) | 66 (62-70) | 5 (4-6) | **409 (390-426)** |
| **Total** | **789 (758-817)** | **2 (2-2)** | **322 (301-342)** | **37 (32-42)** | **1,150 (1,093-1,203)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.11. Estimated Number of Adults with ASD by Age Group, Sex, and Race/Ethnicity in Comal County in 2018**

| TDC Population Projections: Comal County, 2018, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 5,175 | 6,871 | 16,307 | 11,680 | **40,033** |
| Anglo Female | 4,859 | 7,400 | 16,929 | 12,546 | **41,734** |
| Black Male | 206 | 183 | 469 | 183 | **1,041** |
| Black Female | 154 | 143 | 432 | 163 | **892** |
| Hispanic Male | 3,597 | 3,189 | 3,916 | 1,637 | **12,339** |
| Hispanic Female | 3,393 | 3,336 | 4,458 | 2,083 | **13,270** |
| Other Male | 324 | 328 | 450 | 222 | **1,324** |
| Other Female | 289 | 398 | 653 | 302 | **1,642** |
| **Grand Total** | **17,997** | **21,848** | **43,614** | **28,816** | **112,275** |
| **Number of Comal County Adults Estimated to Have ASD** | | | | | |
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 141 (134-146) | 187 (178-194) | 444 (423-460) | 318 (303-329) | **1,090 (1,038-1,129)** |
| Anglo Female | 33 (30-35) | 50 (46-53) | 114 (106-122) | 85 (78-90) | **282 (260-300)** |
| Black Male | 5 (5-6) | 5 (4-5) | 12 (11-13) | 5 (4-5) | **27 (24-29)** |
| Black Female | 1 (1-1) | 1 (1-1) | 3 (2-3) | 1 (1-1) | **6 (5-6)** |
| Hispanic Male | 80 (74-85) | 71 (66-75) | 87 (81-92) | 36 (34-39) | **274 (255-291)** |
| Hispanic Female | 19 (17-20) | 18 (17-20) | 25 (22-27) | 11 (10-13) | **73 (66-80)** |
| Other Male* | 7 (6-8) | 7 (6-8) | 10 (8-11) | 5 (4-5) | **29 (24-32)** |
| Other Female* | 2 (1-2) | 2 (2-2) | 3 (3-4) | 2 (1-2) | **9 (7-10)** |
| **Grand Total** | **288 (268-303)** | **341 (320-358)** | **698 (656-732)** | **463 (435-484)** | **1,790 (1,679-1,877)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.12. Projected Number of Adults with ASD by Age Group, Sex, and Race/Ethnicity in Comal County in 2030**

| TDC Population Projections: Comal County, 2030, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 6,059 | 8,446 | 19,241 | 22,574 | **56,320** |
| Anglo Female | 5,850 | 8,637 | 19,374 | 23,311 | **57,172** |
| Black Male | 208 | 324 | 565 | 428 | **1,525** |
| Black Female | 212 | 252 | 476 | 493 | **1,433** |
| Hispanic Male | 5,628 | 5,335 | 5,306 | 3,555 | **19,824** |
| Hispanic Female | 4,903 | 5,343 | 6,292 | 4,481 | **21,019** |
| Other Male | 734 | 691 | 877 | 495 | **2,797** |
| Other Female | 629 | 606 | 1,181 | 697 | **3,113** |
| Grand Total | 24,223 | 29,634 | 53,312 | 56,034 | **163,203** |
| **Number of Comal County Adults Projected to Have ASD in 2030** | | | | | |
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 165 (157-171) | 230 (219-238) | 524 (499-542) | 615 (586-636) | **1,534 (1,461-1,587)** |
| Anglo Female | 40 (36-42) | 58 (54-62) | 131 (121-140) | 158 (145-168) | **387 (356-412)** |
| Black Male | 5 (5-6) | 8 (8-9) | 14 (13-15) | 11 (10-11) | **38 (36-41)** |
| Black Female | 1 (1-1) | 2 (1-2) | 3 (3-3) | 3 (3-3) | **9 (8-9)** |
| Hispanic Male | 125 (116-133) | 118 (110-126) | 118 (109-125) | 79 (73-84) | **440 (408-468)** |
| Hispanic Female | 27 (24-30) | 29 (26-32) | 35 (31-38) | 25 (22-27) | **116 (103-127)** |
| Other Male* | 16 (14-18) | 15 (13-17) | 19 (16-21) | 11 (9-12) | **61 (52-68)** |
| Other Female* | 3 (3-4) | 3 (3-4) | 6 (5-7) | 4 (3-4) | **16 (14-19)** |
| **Grand Total** | **382 (356-405)** | **463 (434-490)** | **850 (797-891)** | **906 (851-945)** | **2,601 (2,438-2,731)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.13. Projected Number of Adults with ASD by Age Group, Sex, and Race/Ethnicity in Comal County in 2050**

| TDC Population Projections: Comal County, 2050, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 7,467 | 10,582 | 25,649 | 37,057 | **80,755** |
| Anglo Female | 7,122 | 10,780 | 24,255 | 33,736 | **75,893** |
| Black Male | 399 | 377 | 916 | 748 | **2,440** |
| Black Female | 349 | 406 | 689 | 756 | **2,200** |
| Hispanic Male | 10,204 | 9,497 | 11,072 | 6,933 | **37,706** |
| Hispanic Female | 8,742 | 8,803 | 11,587 | 9,298 | **38,430** |
| Other Male | 1,231 | 2,086 | 2,924 | 1,200 | **7,441** |
| Other Female | 1,053 | 1,743 | 2,545 | 1,659 | **7,000** |
| **Grand Total** | **36,567** | **44,274** | **79,637** | **91,387** | **251,865** |
| **Number of Comal County Adults Projected to Have ASD in 2050** | | | | | |
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 203 (194-211) | 288 (275-298) | 699 (666-723) | 1,009 (962-1,045) | **2,199 (2,097-2,277)** |
| Anglo Female | 48 (44-51) | 73 (67-78) | 164 (151-175) | 228 (210-243) | **513 (472-547)** |
| Black Male | 10 (9-11) | 10 (9-10) | 23 (22-25) | 19 (18-20) | **62 (58-66)** |
| Black Female | 2 (2-2) | 3 (2-3) | 4 (4-5) | 5 (4-5) | **14 (12-15)** |
| Hispanic Male | 226 (210-241) | 211 (196-224) | 245 (228-261) | 154 (143-164) | **836 (777-890)** |
| Hispanic Female | 48 (43-53) | 48 (44-53) | 64 (57-70) | 51 (46-56) | **211 (190-232)** |
| Other Male* | 26 (23-30) | 45 (39-51) | 63 (54-71) | 26 (22-29) | **160 (138-181)** |
| Other Female* | 6 (5-7) | 9 (8-11) | 13 (11-16) | 9 (7-10) | **37 (31-44)** |
| **Grand Total** | **569 (530-606)** | **687 (640-728)** | **1,275 (1,193-1,346)** | **1,501 (1,412-1,572)** | **4,032 (3,775-4,252)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.14. Estimated Number of Adults with ASD by Age Group, Sex, and Race/Ethnicity in Bexar County in 2018**

| TDC Population Projections: Bexar County, 2018, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 44,137 | 52,007 | 69,590 | 44,782 | **210,516** |
| Anglo Female | 37,350 | 48,481 | 70,464 | 52,878 | **209,173** |
| Black Male | 13,929 | 14,022 | 17,744 | 6,650 | **52,345** |
| Black Female | 12,729 | 13,138 | 17,501 | 8,450 | **51,818** |
| Hispanic Male | 121,857 | 123,965 | 126,680 | 50,481 | **422,983** |
| Hispanic Female | 115,667 | 128,605 | 138,151 | 67,972 | **450,395** |
| Other Male | 11,177 | 12,688 | 8,600 | 2,801 | **35,266** |
| Other Female | 10,396 | 13,779 | 11,338 | 4,688 | **40,201** |
| **Grand Total** | **367,242** | **406,685** | **460,068** | **238,702** | **1,472,697** |
| **Number of Bexar County Adults Estimated to Have ASD** | | | | | |
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 1,202 (1,146-1,244) | 1,416 (1,350-1,466) | 1,895 (1,806-1,962) | 1,220 (1,162-1,262) | **5,733 (5,464-5,934)** |
| Anglo Female | 252 (233-269) | 328 (302-349) | 476 (440-508) | 357 (330-381) | **1,413 (1,305-1,507)** |
| Black Male | 353 (331-373) | 355 (333-375) | 450 (422-475) | 168 (158-178) | **1,326 (1,244-1,401)** |
| Black Female | 80 (73-87) | 83 (75-90) | 110 (100-120) | 53 (48-58) | **326 (296-355)** |
| Hispanic Male | 2701 (2511-2876) | 2,748 (2,555-2,925) | 2808 (2611-2990) | 1,119 (1,040-1,191) | **9,376 (8,717-9,982)** |
| Hispanic Female | 636 (573-697) | 707 (637-775) | 760 (684-833) | 374 (337-410) | **2,477 (2,231-2,715)** |
| Other Male* | 239 (207-273) | 271 (236-309) | 184 (160-210) | 60 (52-68) | **754 (655-860)** |
| Other Female* | 55 (46-65) | 73 (61-86) | 60 (51-71) | 25 (21-29) | **213 (179-251)** |
| **Grand Total** | **5,518 (5,120-5,884)** | **5,981 (5,549-6,375)** | **6,743 (6,274-7,169)** | **3,376 (3,148-3,577)** | **21,618 (20,091-23,005)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.15. Projected Number of Adults with ASD by Age Group, Sex, and Race/Ethnicity in Bexar County in 2030**

| TDC Population Projections: Bexar County, 2030, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| | 18-29 | 30-44 | 45-64 | 65+ | Total |
| Anglo Male | 38,602 | 54,064 | 57,812 | 55,265 | **205,743** |
| Anglo Female | 32,770 | 45,679 | 54,116 | 61,078 | **193,643** |
| Black Male | 14,262 | 18,010 | 20,236 | 12,546 | **65,054** |
| Black Female | 12,962 | 15,743 | 18,082 | 14,035 | **60,822** |
| Hispanic Male | 149,334 | 169,853 | 165,241 | 95,820 | **580,248** |
| Hispanic Female | 137,539 | 163,177 | 177,889 | 117,522 | **596,127** |
| Other Male | 18,604 | 24,709 | 17,155 | 5,267 | **65,735** |
| Other Female | 16,709 | 24,420 | 21,152 | 7,762 | **70,043** |
| **Grand Total** | **420,782** | **515,655** | **531,683** | **369,295** | **1,837,415** |
| **Number of Bexar County Adults Projected to Have ASD in 2030** | | | | | |
| | 18-29 | 30-44 | 45-64 | 65+ | Total |
| Anglo Male | 1,051 (1,002-1,088) | 1,472 (1,403-1,524) | 1,574 (1,501-1,630) | 1505 (1435-1558) | **5,602 (5,341-5,800)** |
| Anglo Female | 221 (204-236) | 309 (285-329) | 366 (338-390) | 413 (381-440) | **1,309 (1,208-1,395)** |
| Black Male | 361 (339-382) | 456 (428-482) | 513 (481-542) | 318 (298-336) | **1,648 (1,546-1,742)** |
| Black Female | 81 (74-89) | 99 (90-108) | 114 (103-124) | 88 (80-96) | **382 (347-417)** |
| Hispanic Male | 3,310 (3,078-3,524) | 3,765 (3,500-4,008) | 3,663 (3,405-3,899) | 2124 (1975-2261) | **12,862 (11,958-13,692)** |
| Hispanic Female | 756 (681-829) | 897 (808-984) | 978 (881-1,072) | 646 (582-709) | **3,277 (2,952-3,594)** |
| Other Male* | 398 (345-454) | 528 (459-603) | 367 (318-418) | 113 (98-128) | **1,406 (1,220-1,603)** |
| Other Female* | 89 (75-104) | 130 (109-152) | 112 (94-132) | 41 (35-48) | **372 (313-436)** |
| **Grand Total** | **6,267 (5,798-6,706)** | **7,656 (7,082-8,190)** | **7,687 (7,121-8,207)** | **5,248 (4,884-5,576)** | **26,858 (24,885-28,679)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

**Table A.16. Projected Number of Adults with ASD by Age Group, Sex, and Race/Ethnicity in Bexar County in 2050**

| TDC Population Projections: Bexar County, 2050, 1.0 Migration Scenario | | | | | |
|---|---|---|---|---|---|
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 37,061 | 48,532 | 55,300 | 48,515 | **189,408** |
| Anglo Female | 31,604 | 40,454 | 44,600 | 44,318 | **160,976** |
| Black Male | 16,976 | 20,063 | 27,574 | 17,721 | **82,334** |
| Black Female | 15,300 | 17,223 | 21,214 | 16,370 | **70,107** |
| Hispanic Male | 183,765 | 215,034 | 258,861 | 170,252 | **827,912** |
| Hispanic Female | 166,908 | 191,011 | 245,795 | 194,832 | **798,546** |
| Other Male | 41,661 | 61,177 | 50,548 | 13,819 | **167,205** |
| Other Female | 36,501 | 56,699 | 56,085 | 17,587 | **166,872** |
| **Grand Total** | **529,776** | **650,193** | **759,977** | **523,414** | **2,463,360** |
| **Number of Bexar County Adults Projected to Have ASD in 2050** | | | | | |
| | **18-29** | **30-44** | **45-64** | **65+** | **Total** |
| Anglo Male | 1,009 (962-1,045) | 1,322 (1,260-1,368) | 1,506 (1,435-1,559) | 1,321 (1,259-1,368) | **5,158 (4,916-5,340)** |
| Anglo Female | 214 (197-228) | 273 (252-291) | 301 (278-321) | 299 (276-319) | **1,087 (1,003-1,159)** |
| Black Male | 430 (403-454) | 508 (477-537) | 699 (655-738) | 449 (421-474) | **2,086 (1,956-2,203)** |
| Black Female | 96 (87-105) | 108 (98-118) | 133 (121-145) | 103 (93-112) | **440 (399-480)** |
| Hispanic Male | 4,073 (3,787-4,337) | 4,767 (4,432-5,075) | 5,738 (5,335-6,109) | 3,774 (3,509-4,018) | **18,352 (17,063-19,539)** |
| Hispanic Female | 918 (827-1,006) | 1,051 (946-1,152) | 1,352 (1,217-1,482) | 1,072 (965-1,175) | **4,393 (3,955-4,815)** |
| Other Male* | 891 (773-1,016) | 1,308 (1,136-1,492) | 1,080 (938-1,233) | 295 (257-337) | **3,574 (3,104-4,078)** |
| Other Female* | 194 (163-227) | 301 (253-353) | 297 (250-349) | 93 (78-110) | **885 (744-1,039)** |
| **Grand Total** | **7,825 (7,199-8,418)** | **9,638 (8,854-10,386)** | **11,106 (10,229-11,936)** | **7,406 (6,858-7,913)** | **35,975 (33,140-38,653)** |

*Assumes non-Hispanic Asian/Pacific Islander prevalence rate for this entire racial/ethnic group

## B. Identified population characteristics

### Key Points

- Table B.1 summarizes the most common diagnosis groups for the total population who at some point in a 12-year period received service coordination (i.e., case management) through the Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) department, formerly known as the Alamo Local Authority (ALA).
    - AACOG IDDS, part of a network of 39 local IDD Authorities in Texas, serves eligible adults and children with intellectual disabilities, developmental disabilities, and related conditions and their families in Bexar County.[11] The data was queried by AACOG IDDS and key fields provided to CI:Now as a fully de-identified dataset.
- Tables B.2 through B.8 include *only* the subset of that population with a primary diagnosis of Autistic Disorder. Eligibility rules require that intellectual disability (ID), if present, must be listed as the primary diagnosis. Thus individuals with a primary diagnosis of ID may also have an ASD diagnosis, but individuals with a primary diagnosis of ASD can be assumed not to have a co-occurring ID diagnosis.
    - This subset does not include the population with both ASD and ID. Because only the primary diagnosis can be queried electronically, identification of individuals with both ASD and IDD would require a manual records search, the cost of which was prohibitively expensive for this assessment.
    - The records include only the population with a primary diagnosis of Autistic Disorder who actually received services during the time period. This dataset is different from the "interest list", which is essentially a waitlist for state-funded services. The interest list consists of children and adults who have not necessarily received an individualized assessment to confirm or exclude a diagnosis of Autistic Disorder. As of April 2017, the Texas Home Living program interest totaled 4,389 Bexar County individuals and the Home and Community Based Services interest list totaled 5,767 Bexar County individuals. Both interest lists are managed by AACOG IDDS. The Medical waiver program interest list, which is not managed by AACOG IDDS, totaled 8,958 people. There is overlap among the three interest lists, as a single person may be on more than one interest list. Once registered on the interest list, the wait to enroll in services can be as long as 15 years.
- **It is important to note that these characteristics cannot safely be generalized to the entire population of adults with ASD**, as certain characteristics may make people systematically more or less likely to engage in services.
    - No **primary diagnosis** was documented for 31% of AACOG IDDS records (Table B.1). Among the remaining records, about 40% overall had a primary diagnosis of intellectual or developmental disability (IDD). At 46% of records, IDD was more common among males than among females (33%). Mood disorders were the primary diagnosis for 50% of females and 30% of males. Schizophrenic disorders, somewhat more common among males than females, were the primary diagnosis for 19% overall.

[11] *AACOG Intellectual and Developmental Disability Services*. Retrieved from http://www.aacog.com/66/Intellectual-Developmental-Disability-Se.

- The **age** distribution of the total population (all ages) recorded in the AACOG IDDS administrative dataset is presented by sex (Table B.2) and by race/ethnicity (Table B.3). Only 12% of total records are for adults 30 and older.
- Although **race/ethnicity** is unknown for 12% of records (Table B.3), the racial/ethnic composition of the remaining records (all ages) is similar to Bexar County's general population. However, per the CDC ADDM child prevalence estimates (Table A.1) we would expect to see a white (non-Hispanic)-to-Hispanic ratio of about 1.5 to one. Instead, we see a markedly different white (non-Hispanic)-to-Hispanic ratio of 0.5 to one. Looking only at the small number of AACOG IDDS records for adults 18 and older, the white (non-Hispanic)-to-Hispanic ratio is 0.7 to one (Table B.4).
- The **ratio of males to females** of all ages in the dataset is 5.5 to one (Tables B.1. and B.2), exceeding the CDC ADDM male-to-female prevalence ratio of 4.5 to one (Table A.1). Looking only at the small number of AACOG IDDS records for adults 18 and older, the male-to-female ratio is even higher at 6.1 to one (Table B.5).
- **Educational attainment** for adults 25 and older is unrecorded for nearly half of the records in the AACOG IDDS dataset (Table B.6). Among the remaining records, only about 4% continued their education beyond high school, as compared to nearly six in 10 adults 25 and older in Bexar County's general population.
- **Living arrangements** are unknown for 11% of records in the AACOG IDDS dataset (Table B.7). Of the remaining records, virtually all lived in the care of family or relatives. A handful lived alone or in group quarters.
- The level of **adaptive behavior** is not recorded for more than a third of records in the AACOG IDDS dataset (Table B.8). Of the remaining records, about four in 10 showed mild or no behavior impairment. About half showed a moderate behavior impairment, with the remaining approximately 10% showing severe or profound impairment.
- State eligibility rules require that ID must be listed as the primary diagnosis for anyone for whom a diagnosis of ID has been confirmed. The information system in which this dataset is maintained does not allow query of secondary diagnoses. CI:Now applied estimates of the prevalence of ASD among people with ID to the total number of AACOG IDDS adults with ID in an attempt to estimate the total number of adults with ASD in the dataset, as well as the prevalence of ID among AACOG IDDS adults with ASD.
    - The estimated prevalence of ASD among people with ID ranges from 4% to 40%, with a mean of 20%.[12] Applying those three prevalence estimates to the total number of AACOG IDDS adults with an ID diagnosis (Table B.9) yields an estimated number of adults with both ID and ASD that ranges from 276 to 2,762.
    - Adding to those figures the 436 AACOG IDDS adults who are known to have ASD without ID yields estimates of total AACOG IDDS with ASD (with or without ID) ranging from 712 to 3,198 (Table B.10).
    - The resulting percentage of estimated total AACOG IDDS adults with ASD who have co-occurring ID ranges from 38% to 86% (Table B.10).

[12] Matson, J.L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, *30 (2009)*, 1107–1114.

- Looking at teaching, psychiatry, rehabilitation, acute care, skilled nursing, pediatric, and long term facility **hospital discharges** among Bexar County adults 18 and older, excluding military and Veterans Administration (VA) facilities, ASD/IDD was a documented diagnosis for only 189 records.
    - Table B.11 breaks down these 189 visits, which cannot be assumed to represent 189 unduplicated people, by sex, race and ethnicity, and age. Table B.12 shows the primary diagnoses for these 189 visits. Mental disorders were heavily represented among primary diagnoses, while intellectual disability and non-specific "emotional state" diagnoses were common among secondary and tertiary diagnoses.
    - The hospital discharges with a recorded ASD diagnosis have a dramatically different **age distribution** from that of the full dataset of all Bexar County discharges with any diagnosis (Table B.13, Figure B.1). As a percent of total visits, the 18 to 29 age group among discharges with an ASD/IDD diagnosis is three times as large as what we see for the total set of discharges, while the 65-and-older age group is only about one-tenth of that for total discharges. Again, these are discharges rather than individual people; 100 discharges might represent 100 people with one visit each or one person with 100 visits.
- CI:Now also queried the Texas Outpatient Public Use Data File, finding only 207 visits (Table B.14). This dataset contains only surgical and radiological procedures performed at teaching, psychiatry, rehabilitation, acute care, skilled nursing, pediatric, and long term facility non-military/VA hospitals and ambulatory surgery centers, not preventive or primary care visits.
- Individualized assessment and diagnosis of ASD are unlikely to be performed in the emergency department or general inpatient setting, and coding practices are driven by payer requirements and federal regulations. However, systematically asking the family/caregiver whether the patient exhibiting aggressive or distressed behavior has ever been diagnosed with ASD, and documenting that response as structured data, would likely identify hospital utilization for issues that could be better handled in a less-expensive and better-equipped crisis care or hospital diversion setting.

## Methods

- CI:Now used multiple administrative data sources to explore the characteristics of the local population of adults with ASD who are engaged with the ASD service system or with the general health care system. Listed below are the sources and organizations that CI:Now used in this report and reached out for data access:
    - De-identified administrative data provided by the the Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) department, formerly known as the Alamo Local Authority (ALA). The AACOG IDDS dataset consists of demographic and other key characteristics of unduplicated persons with IDD, residing in Bexar County, who received service coordination (i.e., case management) through AACOG IDDS between May 2007 and January of 2018. The data was queried by AACOG IDDS and key fields provided to CI:Now as a fully de-identified dataset. Because the dataset spans multiple years, it should not be considered a current snapshot.
        - Available information abstracted from the record, where available includes: 1) demographic characteristics; 2) educational attainment; 3) adaptive behavior scores; 4) living arrangements; and 5) other diagnosis or medical conditions.
    - Hospital inpatient data from the 2016 Texas Hospital Inpatient Discharge Public Use Data File (TXIPUDF). The 2016 TXIPUDF contains de-identified patient level discharge data from 706 Texas

hospitals. The dataset does not capture military or Veterans Administration (VA) hospitals, but does include a variety of other types, including general and teaching hospitals, psychiatric hospitals, acute care facilities, and rehabilitation, skilled nursing, and long-term care facilities.

- At CI:Now's request, Healthcare Access San Antonio (HASA), the local health information exchange (HIE), also queried its inpatient and emergency department dataset. CI:Now found both sources had a similar and very small number of records of adults with a documented ASD diagnosis. Because the number of hospital records was so small in both of these datasets, the plan to query a 2012 Medicaid claims dataset was abandoned. Only the TXIPUDF results are detailed in this report.

- Hospital outpatient procedure data from Texas hospitals and ambulatory surgery centers from the 2016 Texas Outpatient Surgical and Radiological Procedure Public Use Data File, which again excludes military and VA hospitals.
- With regard to both the inpatient and outpatient procedure datasets, the records included in this report are those that 1) belong to an adult (aged 18 and older); 2) are Bexar County residents; and 3) had an ASD related diagnosis code in the principal or any of the secondary diagnoses:
  - ICD-9-CM code of 299.00, or
  - ICD-10-CM codes of F84.0, F84.1, F84.5, F84.8 and F84.9

- Results in the tables below show the number and percent distribution of the total ASD population identified by each source by demographic, educational, or health-related characteristic.
- Three additional secondary data strategies are in development, but data will not be available in time for the release of this report. Should either approach yield meaningful results, that analysis will be published as an addendum or second edition to this report.
  - A request has been made to the Texas Health and Human Services Commission for aggregate characteristics of adults with ASD, with and without IDD, who are enrolled in Medicaid or SSI.
  - A request has been made to HASA to query for other variables that might capture adults with ASD absent an ASD diagnosis code:
    - Prescription of a new-generation (atypical) antipsychotic absent a documented diagnosis of schizophrenia, a mood disorder, or bipolar disorder. Atypical antipsychotics (e.g., risperidone, aripiprazole) are commonly prescribed for management of behavioral symptoms in people with ASD[13], but are also commonly prescribed for management of symptoms of serious mental illness.
    - A procedure code for conscious sedation in the emergency department setting in the presence of unstructured text keywords that might describe a "meltdown" or behavioral episode involving aggression or self-injurious behavior. Emergency departments are often a source of care of last resort in this situation, and sedation is typically the only solution – however poor or temporary – that can be offered in that setting.

[13] See for example Chavez, B. (2012). The role of second generation antipsychotics in autism disorder. *Mental Health Clinician*, September 2012, Vol. 2, No. 3.

## Summary Tables

**Table B.1. Most Common Primary Diagnosis Groups* among AACOG IDDS Adults 18 and Older**

| Primary Diagnosis | Male | | Female | | Unknown | | Total | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| **Intellectual and Developmental Disabilities** | | | | | | | | |
| Mild intellectual disabilities | 1,495 | 5.5% | 1,067 | 3.9% | 10 | 0.0% | 2,572 | 9.4% |
| Other specified intellectual disabilities | 2,397 | 8.8% | 1,644 | 6.0% | 9 | 0.0% | 4,050 | 14.8% |
| Unspecified intellectual disabilities | 154 | 0.6% | 127 | 0.5% | 3 | 0.0% | 284 | 1.0% |
| Pervasive developmental disorder* (includes autistic disorder, Asperger's, and autism-like behaviors) | 360 | 1.3% | 75 | 0.3% | 1 | 0.0% | 436 | 1.6% |
| **Personality Disorders** | | | | | | | | |
| Schizophrenic disorders | 2,092 | 7.6% | 1,351 | 4.9% | 0 | 0.0% | 3,443 | 12.6% |
| **Mood Disorders** | | | | | | | | |
| Episodic mood disorders | 2,635 | 9.6% | 4,188 | 15.3% | 1 | 0.0% | 6,824 | 24.9% |
| Depressive disorder, not elsewhere classified | 172 | 0.6% | 171 | 0.6% | 1 | 0.0% | 344 | 1.3% |
| Anxiety, dissociative and somatoform disorders | 91 | 0.3% | 106 | 0.4% | 0 | 0.0% | 197 | 0.7% |
| **Other and Unknown** | | | | | | | | |
| Other nonorganic psychoses | 169 | 0.6% | 93 | 0.3% | | 0.0% | 262 | 1.0% |
| Observation and evaluation for suspected conditions not found | 114 | 0.4% | 57 | 0.2% | 1 | 0.0% | 172 | 0.6% |
| Unknown | 4,321 | 15.8% | 4,092 | 15.0% | 374 | 1.4% | 8,787 | 32.1% |
| **Grand Total** | **14,000** | **51.1%** | **12,971** | **47.4%** | **400** | **1.5%** | **27,371** | **100.0%** |

*Eligibility rules require that intellectual disability (ID), if present, must be listed as the primary diagnosis. Thus individuals with a primary diagnosis of ID may also have an ASD diagnosis, but individuals with a primary diagnosis of ASD can be assumed not to have a co-occurring ID diagnosis.

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.2. Age by Sex, All Ages, AACOG IDDS Individuals with a Primary Diagnosis of Autistic Disorder**

| Age | Male | | Female | | Unknown | | Total | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| Under 18 | 156 | 38.2% | 32 | 7.8% | 1 | 0.2% | 189 | 46.3% |
| 18-29 | 148 | 36.3% | 24 | 5.9% | 0 | 0.0% | 172 | 42.2% |
| 30-44 | 28 | 6.9% | 5 | 1.2% | 0 | 0.0% | 33 | 8.1% |
| 45-64 | 9 | 2.2% | 2 | 0.5% | 0 | 0.0% | 11 | 2.7% |
| 65+ | 3 | 0.7% | 0 | 0.0% | 0 | 0.0% | 3 | 0.7% |
| **Grand Total** | **344** | **84.3%** | **63** | **15.4%** | **1** | **0.2%** | **408** | **100%** |

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.3. Race/Ethnicity by Sex, All Ages, AACOG IDDS Individuals with a Primary Diagnosis of Autistic Disorder**

| Race/ Ethnicity | Male | | Female | | Unknown | | Total | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| Hispanic | 180 | 44.1% | 25 | 6.1% | 1 | 0.2% | 206 | 50.5% |
| White | 91 | 22.3% | 16 | 3.9% | 0 | 0.0% | 107 | 26.2% |
| Black | 26 | 6.4% | 2 | 0.5% | 0 | 0.0% | 28 | 6.9% |
| Other | 13 | 3.2% | 4 | 1.0% | 0 | 0.0% | 17 | 4.2% |
| Unknown | 34 | 8.3% | 16 | 3.9% | 0 | 0.0% | 50 | 12.3% |
| **Grand Total** | **344** | **84.3%** | **63** | **15.4%** | **1** | **0.2%** | **408** | **100%** |

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.4. Race/Ethnicity by Age, All Ages, AACOG IDDS Individuals with a Primary Diagnosis of Autistic Disorder**

| Race/ Ethnicity | Age Group | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | < 18 | | 18-29 | | 30-44 | | 45-64 | | 65+ | | Total | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Hispanic | 110 | 27.0% | 81 | 19.9% | 13 | 3.2% | 2 | 0.5% | 0 | 0.0% | 206 | 50.5% |
| White | 40 | 9.8% | 48 | 11.8% | 12 | 2.9% | 6 | 1.5% | 1 | 0.2% | 107 | 26.2% |
| Black | 7 | 1.7% | 15 | 3.7% | 5 | 1.2% | 1 | 0.2% | 0 | 0.0% | 28 | 6.9% |
| Other | 6 | 1.5% | 10 | 2.5% | 0 | 0.0% | 1 | 0.2% | 0 | 0.0% | 17 | 4.2% |
| Unknown | 26 | 6.4% | 18 | 4.4% | 3 | 0.7% | 1 | 0.2% | 2 | 0.5% | 50 | 12.3% |
| Total | 189 | 46.3% | 172 | 42.2% | 33 | 8.1% | 11 | 2.7% | 3 | 0.7% | 408 | 100.0% |

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.5. Race/Ethnicity by Sex, AACOG IDDS Adults 18 and Older with a Primary Diagnosis of Autistic Disorder**

| Race/Ethnicity | Male | | Female | | Total | |
|---|---|---|---|---|---|---|
| | n | % | n | % | n | % |
| Hispanic | 83 | 37.9% | 13 | 5.9% | 96 | 43.8% |
| White | 60 | 27.4% | 7 | 3.2% | 67 | 30.6% |
| Black | 19 | 8.7% | 2 | 0.9% | 21 | 9.6% |
| Other | 9 | 4.1% | 2 | 0.9% | 11 | 5.0% |
| Unknown | 17 | 7.8% | 7 | 3.2% | 24 | 11.0% |
| **Grand Total** | **188** | **85.8%** | **31** | **14.2%** | **219** | **100.0%** |

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.6. Educational Attainment by Sex, AACOG IDDS Adults 25 and Older with a Primary Diagnosis of Autistic Disorder**

| Educational Attainment | Male | | Female | | Total | |
|---|---|---|---|---|---|---|
| | n | % | n | % | n | % |
| < 9th Grade | 1 | 1.0% | 0 | 0.0% | 1 | 1.0% |
| 9th to 12th Grade | 13 | 13.0% | 1 | 1.0% | 14 | 14.0% |
| HS Graduate/GED | 30 | 30.0% | 8 | 8.0% | 38 | 38.0% |
| Some College | 0 | 0.0% | 1 | 1.0% | 1 | 1.0% |
| Bachelor's Degree | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Graduate Degree | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Other | 1 | 1.0% | 0 | 0.0% | 1 | 1.0% |
| None | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Unknown | 37 | 37.0% | 8 | 8.0% | 45 | 45.0% |
| **Grand Total** | **82** | **82.0%** | **18** | **18.0%** | **100** | **100.0%** |

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.7. Living Arrangements by Sex, AACOG IDDS Adults 18 and Older with a Primary Diagnosis of Autistic Disorder**

| Living Arrangement | Male | | Female | | Total | |
|---|---|---|---|---|---|---|
| | n | % | n | % | n | % |
| **Community Setting** | | | | | | |
| Care of Family or Relative | 152 | 69.4% | 29 | 13.2% | 181 | 82.6% |
| Living Alone in Own Home | 2 | 0.9% | 0 | 0.0% | 2 | 0.9% |
| **Group Quarters or Institutional Setting** | | | | | | |
| Intermediate Care Facilities, Institution for Mental Disease | 1 | 0.5% | 0 | 0.0% | 1 | 0.5% |
| HCS Client | 2 | 0.9% | 0 | 0.0% | 2 | 0.9% |
| Other Group Quarters | 4 | 1.8% | 0 | 0.0% | 4 | 1.8% |
| **Other and Unknown** | | | | | | |
| None of Above | 5 | 2.3% | 1 | 0.5% | 6 | 2.7% |
| Unknown | 22 | 10.0% | 1 | 0.5% | 23 | 10.5% |
| **Grand Total** | **188** | **85.8%** | **31** | **14.2%** | **219** | **100%** |

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.8. Adaptive Behavior, AACOG IDDS Adults 18 and Older with a Primary Diagnosis of Autistic Disorder**

| Adaptive Behavior | Male | | Female | | Total | |
|---|---|---|---|---|---|---|
| | n | % | n | % | n | % |
| 0 = No Behavior Impairment | 6 | 2.7% | 1 | 0.5% | 7 | 3.2% |
| 1 = Mild | 42 | 19.2% | 9 | 4.1% | 51 | 23.3% |
| 2 = Moderate | 58 | 26.5% | 11 | 5.0% | 69 | 31.5% |
| 3 = Severe | 9 | 4.1% | 3 | 1.4% | 12 | 5.5% |
| 4 = Profound | 1 | 0.5% | 1 | 0.5% | 2 | 0.9% |
| Unknown | 72 | 32.9% | 6 | 2.7% | 78 | 35.6% |
| **Grand Total** | **188** | **85.8%** | **31** | **14.2%** | **219** | **100%** |

Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

**Table B.9. AACOG IDDS Adults 18 and Older with ID Who Are Estimated to Have Co-occurring ASD**

| | | Number of ALA Adults with ID estimated also to have ASD, by estimated co-occurrence rate* | | |
|---|---|---|---|---|
| | n | Low (4%)[b] | Mean (20%) [b] | High (40%) [b] |
| Adults with a primary diagnosis of Intellectual Disability (ID) (all ID diagnosis groups) | 6,906[a] | 276 | 1,381 | 2,762 |

*The estimated "co-occurrence rates" shown are the lowest, mean, and highest estimated percentages of people with ID who also have ASD, as cited by Matson and Shoemaker (2009).

Sources: [a] Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

[b]Matson, J.L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, *30 (2009)*, 1107–1114.

**Table B.10. Estimated Total AACOG IDDS Adults 18 and Older Estimated to Have ASD, With and Without ID**

| | Number of AACOG IDDS Adults with ID estimated also to have ASD, by estimated co-occurrence rate* | | |
|---|---|---|---|
| | Low (4%)[b] | Mean (20%) [b] | High (40%) [b] |
| AACOG IDDS adults known to have ASD without ID | 436[a] | 436[a] | 436[a] |
| AACOG IDDS adults known to have ID who are estimated* to have co-occurring ASD | 276 | 1,381 | 2,762 |
| Total estimated AACOG IDDS adults with ASD, with or without ID | 712 | 1,817 | 3,198 |
| Estimated percentage of total AACOG IDDS adults with ASD who have co-occurring ID | 39% | 76% | 86% |

*The estimated "co-occurrence rates" shown are the lowest, mean, and highest estimated percentages of people with ID who also have ASD, as cited by Matson and Shoemaker (2009); see Table B.9. above.

Sources: [a] Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) administrative data, May 2007 to January 2018. Alamo Area Council of Governments, Bexar County, Texas.

[b]Matson, J.L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, *30 (2009)*, 1107–1114.

**Table B.11. Demographics of Hospital Inpatient Discharges with a Diagnosis of ASD* among Bexar County Adults 18 and Older, 2016**

| | Number of Visits | Percent of Visits |
|---|---|---|
| Presence of IDD | | |
| IDD diagnosis also recorded | 53 | 28.0% |
| No IDD diagnosis recorded | 136 | 72.0% |
| Sex | | |
| Male | 114 | 60.3% |
| Female | 52 | 27.5% |
| Unknown/Missing | 23 | 12.2% |
| Race | | |
| Asian | 1 | 0.5% |
| Black | 4 | 2.1% |
| White | 149 | 78.8% |
| Other | 35 | 18.5% |
| Ethnicity | | |
| Hispanic | 66 | 34.9% |
| Non-Hispanic | 123 | 65.1% |
| Unknown/Missing | 0 | 0.0% |
| Race/Ethnicity (Calculated) | | |
| Asian | 1 | 0.5% |
| Black | 4 | 2.1% |
| White | 114 | 60.3% |
| Other | 4 | 2.1% |
| Hispanic | 66 | 34.9% |
| Age | | |
| 18-29 | 101 | 53.4% |
| 30-44 | 52 | 27.5% |
| 45-64 | 31 | 16.4% |
| 65+ | 5 | 2.6% |
| **Total Inpatient Visits by Adults with ASD/IDD*** | **189** | **100%** |

*ASD is defined as having an ICD-10 diagnosis code of F84.0, F84.1, F84.5, F84.8 and F84.9 in the principal diagnosis field or any of the 24 secondary diagnosis fields. IDD is defined as having an ICD-10 diagnosis code of F70-F73, F78-F79 in the principal diagnosis field or any of the 24 secondary diagnosis fields.

Source: Texas Hospital Inpatient Discharge Public Use Data File, 2016. Texas Department of State Health Services, Center for Health Statistics, Austin, Texas.

**Table B.12. Most Common Diagnoses for Hospital Inpatient Discharges with a Diagnosis of ASD* with or without IDD among Bexar County Adults 18 and Older, 2016**

| | Number of Discharges | Percent of Discharges** |
|---|---|---|
| Most Common Principal Diagnoses | | |
| Bipolar disorder | 35 | 19% |
| Schizophrenia | 15 | 8% |
| Schizoaffective disorders | 14 | 7% |
| Other sepsis | 11 | 6% |
| Major depressive disorder, single episode | 7 | 4% |
| Pneumonitis due to solids and liquids | 7 | 4% |
| Most Common Secondary Diagnoses | | |
| Pervasive developmental disorders | 56 | 30% |
| Symptoms and signs involving emotional state | 30 | 16% |
| Respiratory failure, not elsewhere classified | 8 | 4% |
| Heart failure | 5 | 3% |
| Pneumonitis due to solids and liquids | 5 | 3% |
| Most Common Tertiary Diagnoses | | |
| Pervasive developmental disorders | 51 | 27% |
| Attention-deficit hyperactivity disorders | 8 | 4% |
| Symptoms and signs involving emotional state | 7 | 4% |
| Other anxiety disorders | 6 | 3% |
| **Total Discharges of Adults with ASD/IDD*** | **218** | **100%** |

*ASD is defined as having an ICD-10 diagnosis code of F84.0, F84.1, F84.5, F84.8 and F84.9 in the principal diagnosis field or any of the 24 secondary diagnosis fields. IDD is defined as having an ICD-10 diagnosis code of F70-F73, F78-F79 in the principal diagnosis field or any of the 24 secondary diagnosis fields.

**Percentages do not add to 100% because only the most frequently-occurring diagnoses are shown here.

Source: Texas Hospital Inpatient Discharge Public Use Data File, 2016. Texas Department of State Health Services, Center for Health Statistics, Austin, Texas.

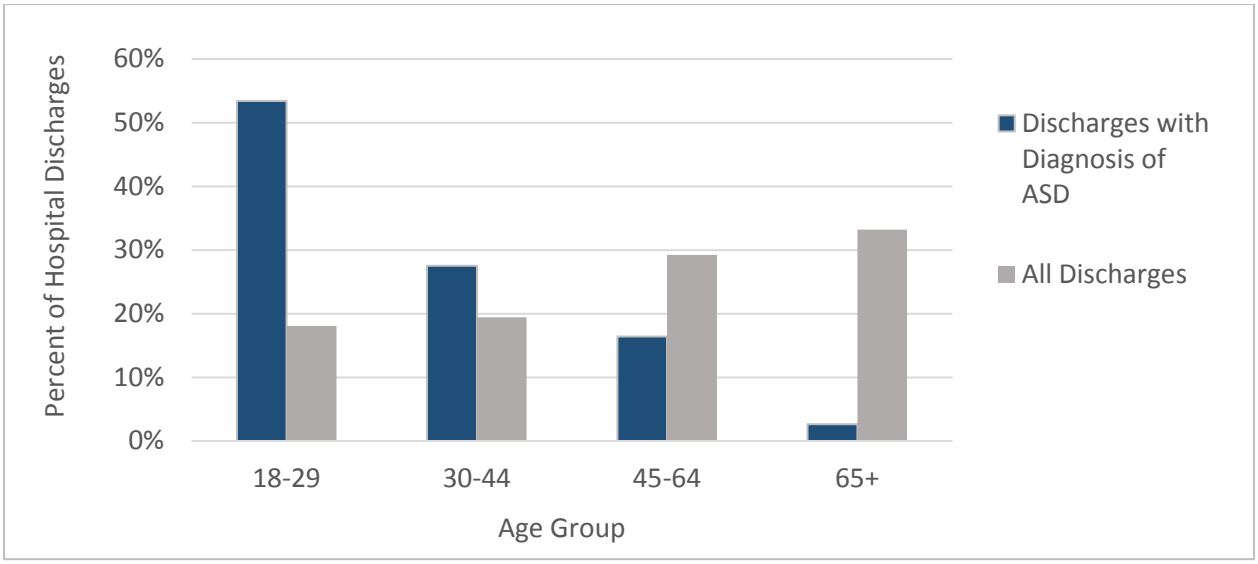
**Table B.13. Age Distribution of Hospital Inpatient Discharges of Bexar County Adults 18 and Older with Any Diagnosis vs. with a Diagnosis of ASD* with or without IDD*, 2016**

| Age Group | Discharges with ASD/IDD Diagnosis | | All Discharges | |
|---|---|---|---|---|
| | n | % | n | % |
| 18-29 | 101 | 53% | 29,770 | 18% |
| 30-44 | 52 | 28% | 32,053 | 19% |
| 45-64 | 31 | 16% | 48,204 | 29% |
| 65 and older | 5 | 3% | 54,741 | 33% |
| Total Discharges | 189 | 100% | 164,768 | 100% |

*ASD is defined as having an ICD-10 diagnosis code of F84.0, F84.1, F84.5, F84.8 and F84.9 in the principal diagnosis field or any of the 24 secondary diagnosis fields. IDD is defined as having an ICD-10 diagnosis code of F70-F73, F78-F79 in the principal diagnosis field or any of the 24 secondary diagnosis fields.

Source: Texas Hospital Inpatient Discharge Public Use Data File, 2016. Texas Department of State Health Services, Center for Health Statistics, Austin, Texas.

**Figure B.1. Age Distribution of Hospital Inpatient Discharges of Bexar County Adults 18 and Older with Any Diagnosis vs. with a Diagnosis of ASD*, 2016**




*ASD is defined as having an ICD-10 diagnosis code of F84.0, F84.1, F84.5, F84.8 and F84.9 in the principal diagnosis field or any of the 24 secondary diagnosis fields. IDD is defined as having an ICD-10 diagnosis code of F70-F73, F78-F79 in the principal diagnosis field or any of the 24 secondary diagnosis fields.

Source: Texas Hospital Inpatient Discharge Public Use Data File, 2016. Texas Department of State Health Services, Center for Health Statistics, Austin, Texas.

**Table B.14. Demographics of Outpatient Discharges by Bexar County Adults 18 and Older with ASD*, 2016**

| | Number of Visits | Percent of Visits |
|---|---|---|
| **Presence of Co-occurring IDD** | | |
| IDD diagnosis also recorded | 26 | 12% |
| No IDD diagnosis recorded | 181 | 88% |
| **Sex** | | |
| Male | 153 | 74% |
| Female | 52 | 25% |
| Unknown/Missing | 2 | 1.0% |
| **Race** | | |
| Asian | 1 | <1% |
| Black | 11 | 5% |
| White | 147 | 71% |
| Other | 48 | 23% |
| **Ethnicity** | | |
| Hispanic | 91 | 44% |
| Non-Hispanic | 116 | 56% |
| **Race/Ethnicity (Calculated)** | | |
| Asian | 1 | <1% |
| Black | 10 | 5% |
| White | 95 | 46% |
| Other | 10 | 5% |
| **Age** | | |
| 18-29 | 147 | 71% |
| 30-44 | 37 | 18% |
| 45-64 | 23 | 11% |
| 65+ | 0 | 0% |
| **Total Outpatient Visits by Adults with ASD/IDD*** | **207** | **100%** |

*ASD is defined as having an ICD-10 diagnosis code of F84.0, F84.1, F84.5, F84.8 and F84.9 in the principal diagnosis field or any of the 24 secondary diagnosis fields. IDD is defined as having an ICD-10 diagnosis code of F70-F73, F78-F79 in the principal diagnosis field or any of the 24 secondary diagnosis fields.

Source: Texas Outpatients Surgical and Radiological Procedure Public Use Data File, 2016. Texas Department of State Health Services, Center for Health Statistics, Austin, Texas.

## C. Estimated population not in services

### Key Points

- The Phase 2 analysis plan called for the calculation of estimated size and characteristics of the population of Bexar County adults with ASD/IDD not receiving needed services. This estimate proved to be impossible to calculate, as no central data source exists for all ASD/IDD service providers.
- The only possible calculation is the gap between the estimated number of Bexar County adults with ASD/IDD (Table A.4 and A.14) in 2017 and the estimated number of adults with ASD (with or without ID; see Table B.10) receiving service coordination through AACOG IDDS as of April 2017.

### Methods

- The number of adults with ASD (with or without ID) receiving service coordination through AACOG IDDS between April 2017 was estimated as shown in Table B.10 and described in the methodology for that section.
- That estimate was subtracted from the estimated number of Bexar County adults with ASD in 2017 (see Tables A.4 and A.14 and accompanying assumptions and methodology).
- One caution to note is that adults with ASD who are paying for ASD services entirely out of their own pockets rather than through state-funded programs will not be in service coordination through AACOG IDDS. The number of people in this situation is unknown.

### Summary Tables

**Table C.1. Estimated Number of Bexar County Adults with ASD [a] not Receiving Service Coordination through AACOG IDDS [b], 2017**

| | Estimate and Confidence Interval |
|---|---|
| Estimated number of Bexar County adults with ASD in 2017[a] | 21,618 (20,091-23,005) |
| Estimated number of Bexar County adults with ASD (with or without ID) receiving service coordination through AACOG IDDS as of April 2017 [b] | 1,817 |
| Estimated number of Bexar County adults with ASD (with or without ID) not receiving service coordination through AACOG IDDS as of April 2017 | 19,801 (18,274-21,188) |

[a] See Tables A.4 and A.14, as well as accompanying estimate methodology

[b] See Table B.10 for estimate details and assumptions. This estimate does not include any individuals who are on the interest list and not receiving service coordination because of insufficient state program funding.
Source: Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) aggregate report, April 2017. Alamo Area Council of Governments, Bexar County, Texas.

# D. Estimated costs

## Key Points

- The most recent estimates of costs associated with ASD in the United States are 2011 figures published in 2014 by Buescher et al.,[14] (Table D.1) for adults with and without intellectual disability (ID). Except for those categories for which cost is unknown – education, family expenses, and benefits – these figures represent *all costs attributable to ASD*, not just families' out-of-pocket costs. These costs do not, however, capture every cost for an adult with ASD; for example, health costs for conditions not considered related to ASD are not included. And again, estimates of some cost categories are not available, likely resulting in an underestimate of ASD-attributable annual and lifetime costs.
- CI:Now adjusted Buescher et al.'s numbers for inflation to yield dollar-equivalent numbers for 2017. The 2017 total annual ASD-attributable cost **is $98,594 for an adult with both ASD and ID** as compared to **$56,360 for an adult with ASD but without ID**.
- To estimate ASD-attributable costs by county, CI:Now applied the 2017 inflation-adjusted figures to the estimated population of adults with ASD presented in Section A. Because the costs associated with ASD are considerably higher when ID is also present, CI:Now applied the commonly-accepted assumption that 40% of ASD population has ID[15] to the CI:Now estimates of population of adults with ASD.
- Table D.2 compares the estimated *annual* aggregated ASD-attributable costs for adults with ASD by county, by presence of intellectual disability. **The 2017 aggregate annual estimated ASD-attributable costs for adults with ASD and ID in the four-county Kronkosky Charitable Foundation area are $958.5 million compared to $821.9 million for adults without ID.**
- Table D.3 estimates the *lifespan* aggregate ASD-attributable costs attributable to ASD for adults with ASD by county. For this calculation "lifespan" is the period from birth to age 67[16], the average life expectancy used by Buescher et al. **For the four-county Kronkosky Charitable Foundation area, the adult lifespan aggregate ASD-attributable cost is $26.6 billion for adults with both ASD and ID and $23.3 billion for adults with ASD but not ID.**
- Tables D.4 through D.7 show detailed annual and lifespan costs by race/ethnicity and presence of ID for Bandera and Kendall Counties. Tables D.8 through D.11 show detailed annual and lifespan costs by presence of ID and race/ethnicity and sex for Bexar and Comal Counties.

[14] Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA pediatrics, 168(8), 721-728.
[15] Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA pediatrics, 168(8), 721-728.
[16] Shavelle, R.M., & Strauss, D. (1998.) Comparative mortality of persons with autism in California, 1980-1996. .Journal of Insurance Medicine, Vol. 30(4):220-225.

## Methods

- To evaluate and estimate the costs associated with autism spectrum disorder (ASD), CI:Now conducted a systematic literature review of articles published between January 2007 and December 2017 to understand factors that contribute to the cost of ASD among the adult population with ASD. Studies based outside the United States were excluded from the analysis.
- Cost estimates selected included those that 1) provided the most recent estimates associated with ASD in the United States; 2) are widely cited; and 3) aligned with numbers and sources used by the CDC.
    - Annual aggregate costs and lifespan ASD-attributable costs include accommodation (housing) costs, employment support costs, direct medical costs, direct non-medical costs, and loss of productivity costs combined. The medical costs category includes inpatient, outpatient, emergency physician, other health professional, home health care, pharmacy, and out-of-pocket costs. Non-medical costs include special education, childcare, day care, travel to medical appointments, home care modifications, and overnight and other respite. Productivity loss includes the opportunity costs due to lost or disrupted employment.
    - Because most recent estimates of costs associated with ASD in the United States are 2011 figures, CI:Now adjusted those numbers for inflation using the Bureau of Labor Statistics' Consumer Price Index Inflation Calculator to yield equivalent numbers for 2017.
- To estimate local population costs by county, CI:Now applied the 2017 inflation-adjusted figures to the estimated population of adults with ASD presented in Section 1. Because the costs associated with ASD vary by presence of ID, CI:Now applied the commonly-accepted 40:60 ratio (an assumption that 40% of ASD population has ID and 60% does not)[8] to the CI:Now estimates of population of adults with ASD.
    - The 40:60 ratio is based on multiple surveys conducted among the ASD population in the UK. As reported by Buescher et al. (2014) [8] 40% to 60% of people with ASD also have an intellectual disability affecting the overall treatment, care, and support costs of individuals.

## Summary Tables

**Table D.1. Mean Annual U.S. Cost per Adult (18 years of age and older) with ASD by ID**

| Category | With Intellectual Disability (ID) | Without ID[a] |
|---|---|---|
| **Mean U.S. Costs per Year in 2011 Dollars** | | |
| Accommodation | $36,161 | $18,080 |
| Employment Support | $705 | $352 |
| Services: medical | $27,159 | $13,580 |
| Services: nonmedical | $11,387 | $5,693 |
| Productivity loss for individual with ASD | $10,718 | $10,718 |
| Productivity loss for parents | $1,896 | $1,896 |
| Education | Unknown | Unknown |
| Family Expenses | Unknown | Unknown |
| Benefits | Unknown | Unknown |
| **Total costs in 2011 dollars** | **$88,026** | **$50,319** |
| **Total costs adjusted to 2017 dollars** | **$98,594** | **$56,360** |

Source: Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA pediatrics, 168(8), 721-728.

**Table D.2. Estimated Aggregate Annual Costs in Millions for Adults with ASD by Geography, 2017**

| | Bandera | Kendall | Comal | Bexar | Total |
|---|---|---|---|---|---|
| Estimated number of adults with ASD | 337 | 559 | 1,790 | 21,618 | 24,304 |
| With ID[a] | $13.3M | $22.0M | $70.6M | $852.6M | $958.5M |
| Without ID[a] | $11.4M | $18.9M | $60.5M | $731.0M | $821.9M |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population. Cost adjusted for inflation.

**Table D.3. Estimated Aggregate Lifespan Costs[b] in Billions for Adults with ASD by Geography, 2017**

| | Bandera | Kendall | Comal | Bexar | Total |
|---|---|---|---|---|---|
| Estimated number of adults with ASD | 337 | 559 | 1,790 | 21,618 | 24,304 |
| With ID[a] | $0.4B | $0.6B | $2.0B | $23.6B | $26.6B |
| Without ID[a] | $0.3B | $0.5B | $1.7B | $20.8B | $23.3B |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population. Cost adjusted for inflation.

[b] Cost adjusted for inflation. Original source author assumes life expectancy to age 67[17]

[17] Shavelle, R.M., & Strauss, D. (1998.) Comparative mortality of persons with autism in California, 1980-1996. Journal of Insurance Medicine, Vol. 30(4):220-225.

**Table D.4. Estimated Aggregate Annual Costs in Millions for Adults with ASD by Race/Ethnicity by Intellectual Disability, Bandera County**

| | Anglo | Black | Hispanic | Other | Total |
|---|---|---|---|---|---|
| Estimated number of adults with ASD | 283 | 0 | 48 | 6 | 337 |
| With ID[a] | $11.2M | $0.0M | $1.9M | $0.2M | $13.3M |
| Without ID[a] | $9.6M | $0.0M | $1.6M | $0.2M | $11.4M |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population. Cost adjusted for inflation.

**Table D.5. Estimated Aggregate Lifespan Costs[b] in Millions for Adults with ASD by Race/Ethnicity by Intellectual Disability, Bandera County**

| | Anglo | Black | Hispanic | Other | Total |
|---|---|---|---|---|---|
| Estimated number of adults with ASD | 283 | 0 | 48 | 6 | 337 |
| With ID[a] | $309.2M | $0.0M | $52.4M | $6.6M | $368.2M |
| Without ID[a] | $271.8M | $0.0M | $46.1M | $5.8M | $323.7M |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population. Cost adjusted for inflation.

[b] Original source author assumes life expectancy to age 67.

**Table D.6. Estimated Aggregate Annual Costs in Millions for Adults with ASD by Race/Ethnicity by Intellectual Disability, Kendall County**

| | Anglo | Black | Hispanic | Other | Total |
|---|---|---|---|---|---|
| Estimated number of adults with ASD | 450 | 3 | 96 | 10 | 559 |
| With ID[a] | $17.7M | $0.1M | $3.8M | $0.4M | $22.0M |
| Without ID[a] | $15.2M | $0.1M | $3.2M | $0.3M | $18.9M |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population. Cost adjusted for inflation.

**Table D.7. Estimated Aggregate Lifespan Costs[b] for Adults in Millions with ASD by Race/Ethnicity by Intellectual Disability, Kendall County**

| | Anglo | Black | Hispanic | Other | Total |
|---|---|---|---|---|---|
| Estimated number of adults with ASD | 450 | 3 | 96 | 10 | 559 |
| With ID[a] | $491.7M | $3.3M | $104.9M | $10.9M | $610.7M |
| Without ID[a] | $432.2M | $2.9M | $92.2M | $9.6M | $536.9M |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population.

[b] Cost adjusted for inflation. Original source author assumes life expectancy to age 67.

**Table D.8. Estimated Aggregate Annual Costs in Millions for Adults with ASD by Race/Ethnicity and Sex and by Intellectual Disability, Comal County**

| | Estimated Number of Adults with ASD | With ID[a] | Without ID[a] |
|---|---|---|---|
| Anglo Male | 1,090 | $43.0M | $36.9M |
| Anglo Female | 282 | $11.1M | $9.5M |
| Black Male | 27 | $1.1M | $0.9M |
| Black Female | 6 | $0.2M | $0.2M |
| Hispanic Male | 274 | $10.8M | $9.3M |
| Hispanic Female | 73 | $2.9M | $2.5M |
| Other Male* | 29 | $1.1M | $1.0M |
| Other Female* | 9 | $0.4M | $0.3M |
| **Grand Total** | **1,790** | **$70.6M** | **$60.5M** |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population. Cost adjusted for inflation.

**Table D.9. Estimated Aggregate Lifespan Costs[b] in Millions (M) or Billions (B) for Adults with ASD by Race/Ethnicity and Sex and by Intellectual Disability, Comal County**

| | Estimated Number of Adults with ASD | With ID[a] | Without ID[a] |
|---|---|---|---|
| Anglo Male | 1,090 | $1.2B | $1.0B |
| Anglo Female | 282 | $308.1M | $270.9M |
| Black Male | 27 | $29.5M | $25.9M |
| Black Female | 6 | $6.6M | $5.8M |
| Hispanic Male | 274 | $299.4M | $263.2M |
| Hispanic Female | 73 | $79.8M | $70.1M |
| Other Male* | 29 | $31.7M | $27.9M |
| Other Female* | 9 | $9.8M | $8.6M |
| **Grand Total** | **1,790** | **$2.0B** | **$1.7B** |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population.

[b] Cost adjusted for inflation. Original source author assumes life expectancy to age 67.

**Table D.10. Estimated Aggregate Annual Costs in Millions for Adults with ASD by Race/Ethnicity and Sex and by Intellectual Disability, Bexar County**

| | Estimated Number of Adults with ASD | With ID[a] | Without ID[a] |
|---|---|---|---|
| Anglo Male | 5,733 | $226.1M | $193.9M |
| Anglo Female | 1,413 | $55.7M | $47.8M |
| Black Male | 1,326 | $52.3M | $44.8M |
| Black Female | 326 | $12.9M | $11.0M |
| Hispanic Male | 9,376 | $369.8M | $317.1M |
| Hispanic Female | 2,477 | $97.7M | $83.8M |
| Other Male* | 754 | $29.7M | $25.5M |
| Other Female* | 213 | $8.4M | $7.2M |
| **Grand Total** | **21,618** | **$852.6M** | **$731.0M** |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population. Cost adjusted for inflation.

**Table D.11. Estimated Aggregate Lifespan Costs[b] in Billions for Adults with ASD by Race/Ethnicity and Sex and by Intellectual Disability, Bexar County**

| | Estimated Number of Adults with ASD | With ID[a] | Without ID[a] |
|---|---|---|---|
| Anglo Male | 5,733 | $6.3B | $5.5B |
| Anglo Female | 1,413 | $1.5B | $1.4B |
| Black Male | 1,326 | $1.4B | $1.3B |
| Black Female | 326 | $0.4B | $0.3B |
| Hispanic Male | 9,376 | $10.2B | $9.0B |
| Hispanic Female | 2,477 | $2.7B | $2.4B |
| Other Male* | 754 | $0.8B | $0.7B |
| Other Female* | 213 | $0.2B | $0.2B |
| **Grand Total** | **21,618** | **$23.6B** | **$20.8B** |

[a] Assumes a 40% prevalence of intellectual disability (ID) among the ASD population.

[b] Cost adjusted for inflation. Original source author assumes life expectancy to age 67.

# Service System and Workforce

## E. Current Capacity: Available Workforce

### Key Points

- Tables E.1 and E.2 show the number of establishments (businesses) for several types of direct care establishments, with average number of total employees per establishment displayed to provide a sense of the size of the business. (The number of direct care employees specifically is not available.)
    - Because adults with ASD/IDD are likely a small proportion of the total number of people who need direct care services, the total number of persons with an independent living difficulty is used as a proxy measure for need, but it is likely an underestimate (see Methods).
    - Across all direct care establishment types in Bexar County, the ratio of persons with an independent living difficulty is 155.2 per establishment. In Comal County, the ratio is 151.4.
- Health care provider shortages are typically calculated using total population, so Table E.3 follows this convention, painting a very different picture of workforce relative to demand. The number of total people per provider in Bexar County is 1,180:1 for primary care providers, 9,387:1 for psychiatrists, and 2,338:1 for psychologists. The ratios are worse for Comal and Bandera Counties.
- Table E.4 shows the ratio of population per provider for key direct care occupational employment types, again using total population. The geography for these measures is the San Antonio-New Braunfels Metropolitan Statistical Area (MSA), the smallest geography for which the data is available. The MSA is an eight-county area including Atascosa, Bandera, Bexar, Comal, Guadalupe, Kendall, Medina, and Wilson. The resulting number of people per provider is 106:1 for personal care aides, 659:1 for home health aides, and 2,243:1 for psychiatric aides.

### Methods

- CI:Now used multiple approaches to estimating demand.
    - The American Community Survey estimates the percent of people who report having one of several types of disability: vision, hearing, ambulatory, self-care, and independent living.[18] Unfortunately, there is no way to determine the combined number of people who have an independent living difficulty and/or a self-care disability. As there is likely substantial overlap between these two categories, the two population numbers cannot be added together to give a total unduplicated number of people with at least one of the two disability types. In both Bexar and Comal Counties, the percent of people with an independent living disability is about twice as high as the percent of people with a self-care disability, so CI:Now chose the population with an independent living disability.
    - Health care provider workforce analyses typically use total population as the denominator, so that convention was followed for primary care providers, psychiatrists, psychologists, and several types of direct care aide.

[18] U.S. Census Bureau. (2017). How Disability Data are Collected from The American Community Survey. Retrieved from https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html

- Workforce numbers are drawn from the U.S. Bureau of Labor Statistics and the Texas Department of State Health Services. The available Bureau of Labor Statistics data on direct care establishments and employees does not differentiate between employee function. Thus the employee total includes all employees per establishment, not just those employees who provide direct care services. For this reason no ratio of population per direct care worker could be calculated for direct care establishments.
- All population estimates are drawn from the U.S. Census Bureau American Community Survey, using five-year rather than one-year estimates to minimize the margin of error associated with the estimate.

## Summary Tables

**Table E.1. Direct Care Establishments by Type, Bexar Co.**

| | Number of Establishments[a] | Average Total Employees per Establishment* |
|---|---|---|
| Home Health Care Services | 210 | 79.2 |
| Nursing Care Facilities | 92 | 77.0 |
| Continuing Care, Assisted Living Facilities | 88 | 48.7 |
| (Day) Services for Elderly/Disabled | 155 | 55.0 |
| **Total** | **545** | **67.0** |
| Estimated Persons with an Independent Living Disability[b] | 84,565 | |
| Estimated Persons with an Independent Living Disability per Establishment | 155.2 | |

*Includes all employees, not solely direct care employees

**The U.S. Census Bureau defines an independent living disability as follows: "Because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping."[19]

Source: [a]Bureau of Labor Statistics, 2016; and [b]U.S. Census American Community Survey 2016 5-year estimates, Table S1810, Bexar Co.

**Table E.2. Direct Care Establishments by Type, Comal Co.**

| | Number of Establishments[a] | Average Total Employees per Establishment* |
|---|---|---|
| Home Health Care Services | 14 | 49.6 |
| Nursing Care Facilities | 9 | 113.0 |
| Continuing Care, Assisted Living Facilities | 8 | 63.8 |
| (Day) Services for Elderly/Disabled | 7 | 27.0 |
| **Total** | **38** | **63.4** |
| Estimated Persons with an Independent Living Disability[b] | 5,754 | |
| Estimated Persons with an Independent Living Disability per Establishment | 151.4 | |

*Includes all employees, not solely direct care employees

**The U.S. Census Bureau defines an independent living disability as follows: "Because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping."[20]

Source: [a]Bureau of Labor Statistics, 2016; and [b]U.S. Census American Community Survey 2016 5-year estimates, Table S1810, Comal Co.

[19] U.S. Census Bureau. (2017). How Disability Data are Collected from The American Community Survey. Retrieved from https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html

[20] U.S. Census Bureau. (2017). How Disability Data are Collected from The American Community Survey. Retrieved from https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html

**Table E.3. Estimated Total Population per Provider for Selected Health Care Provider Types**

| | | Primary Care Physicians | Psychiatrists | Psychologists |
|---|---|---|---|---|
| **Bandera** | Number of providers[a] | 4 | 0 | 6 |
| | Total population[b] | 21,015 | 21,015 | 21,015 |
| | Population per provider | 5,253.8 | - | 3,502.5 |
| **Bexar** | Number of providers[a] | 1575 | 198 | 795 |
| | Total population[b] | 1,858,699 | 1,858,699 | 1,858,699 |
| | Population per provider | 1,180.1 | 9,387.4 | 2,338.0 |
| **Comal** | Number of providers[a] | 98 | 9 | 43 |
| | Total population[b] | 124,234 | 124,234 | 124,234 |
| | Population per provider | 1,267.7 | 13,803.8 | 2,889.2 |
| **Kendall** | Number of providers[a] | 38 | 6 | 17 |
| | Total population[b] | 39,010 | 39,010 | 39,010 |
| | Population per provider | 1,026.6 | 6,501.7 | 2,294.7 |

*Note that a provider may be practicing only part-time.

Source: [a]Texas Department of State Health Services, 2016; and [b]U.S. Census American Community Survey 2016 5-year estimates, Table B01003, for Bandera, Bexar, Comal, and Kendall Counties.

**Table E.4. Estimated Population per Worker by Occupational Employment, San Antonio MSA**

| Occupation* | Workers[a] | Total Population[b] | Population per Worker |
|---|---|---|---|
| Personal Care Aide (SOC 31-1122) | 22,030 | 2,332,345 | 105.9 |
| Home Health Aide (SOC 31-1121) | 3,540 | 2,332,345 | 658.9 |
| Psychiatric Aide (SOC 31-1133) | 1,040 | 2,332,345 | 2,242.6 |

Source: [a]Bureau of Labor Statistics, 2016; and [b]U.S. Census American Community Survey 2016 5-year estimates, Table B01003, San Antonio-New Braunfels, TX MSA.

* A description of each occupation is available from https://www.bls.gov/soc/2018/major_groups.htm#31-0000

## Provider-Reported Service Capacity

### Key Points

- Table E.5 shows what percent of providers' adult clients have an ASD diagnosis, and what percent of those adults with ASD also have IDD. For the largest group, 28% of responding providers, adults with ASD make up fewer than 10% of their adult client population. For another 28% of responding providers, 61% or more of their adult clients have an ASD diagnosis.
- Data about co-occurring IDD were missing for two providers. Of the remaining 16 providers, nearly a third reported that fewer than 10% of their adult clients with ASD also have IDD. For a quarter of responding providers, 100% of adult clients with ASD also have IDD.
- Providers reported widely varying levels of functioning among their adult clients with ASD (Table E.6). The pattern of a minimum of 0% and maximum of 95% to 100% at every functional level indicates that the functional levels vary tremendously *among* providers' client populations, but not necessarily within the client population of a single provider.
- About two-thirds of 18 responding providers allow for and record a comorbid physical or mental health diagnosis (Table E.7).
- Table E.8 summarizes the percent of 15 responding providers who offer each of several key service types. The service most commonly offered, by about half of respondents, was adult day care, often called "dayhab." A substantial proportion offered supported housing (33%), supported employment (33%), respite care (27%), and vocational services (27%).
- Table.E.9 explores some types of assistance that are often not available, even within programs specifically for adults with ASD. Fewer than half of 16 responding providers report that they offer services to adults with ASD who exhibit aggressive or explosive behavior. A larger proportion (63%) assist adult clients with toileting and activities of daily living. Only about a third offer assistance with transportation.
- Providers were queried about client eligibility criteria. The most common type of requirement reported relates to client diagnosis, IQ, and level of functioning (Table E.10).
- Providers were asked about their cost of care per client and fees assessed to clients (Table E.11). Two providers offering day or evening activity services reported a cost of care of $0 or another amount lower than the fee assessed; they may have been reporting *net* cost of care after contract reimbursement or client fee. To minimize confusion, these two providers were excluded from the analysis, leaving 12 respondents who provide very different types of services. The minimum, median, and maximum costs of care across the 12 respondents were $50, $1,000, and $80,000, respectively. The minimum, median, and maximum fees assessed per client across the 12 respondents were $0, $0, and $900, respectively. The calculated gap for each provider between the cost of care and the fee assessed per client ranged from $50 to $79,400, with a substantial median gap of $600 per client.
- Providers reported accepting a variety of contracts arrangements including Medicaid Waiver, private insurance, and Texas Department of Family and Protective Services (clients in state custody) (Table E.12). Virtually all providers reported accepting private pay arrangements.

- The ratio of adult clients with ASD to staff varied widely across respondents (Table E.13), as might be expected given the variation in service offerings and client characteristics. The ratio varied from one adult client per staff member (1:1) to 40 adult clients per staff member (40:1), with a median of six clients per staff member (6:1). The staff turnover rate per year ranged from 0% to 80%, with a median turnover rate of 23%.
- All but one (92%) of 13 responding providers reported providing services during weekday hours, with opening times ranging from 7 a.m. to 9 a.m. and closing times from 3:30 p.m. to 5:30 p.m. Several respondents reporting offering evening (23%) or weekend (31%) hours, with one provider reporting operating 24 hours a day, seven days a week.
- Providers were asked about the type of training their direct care staff have. On-the-job training was the preparation most commonly reported, by 10 (77%) of 13 respondents. Nine reported that direct care staff have a high school diploma or equivalent. A total of five reported that their direct care staff had an associate's degree or were a Certified Nurse Assistant (CNA)/Licensed Vocational Nurse (LVN). Nearly a third reported that staff had received training not leading to a certificate, with only two respondents reporting training leading to a certificate.
- Two-thirds of 13 respondents reporting have no behavioral health providers at all on staff. Of the other four respondents, behavioral health staffing ranged from 0.5 FTE to 5.0 FTE.

## Methods

- An online provider service capacity survey about local services for adults with autism spectrum disorder and other intellectual and developmental disabilities (ASD/IDD) was distributed by the Kronkosky Charitable Foundation to a large number of organizations that might likely provide services to adults with ASD/IDD, including some community partners of Autism Lifeline Links. The survey was developed by the Kronkosky Charitable Foundation, Autism Lifeline Links, and CI:Now.
- Providers who agreed to participate were presented with a series of questions covering topics such as service capacity, cost of care, client to staff ratio, level of functioning of the clients served, and types of assistance provided. Respondents were also asked to offer any ideas and suggestions for improvement of local service capacity or coordination.
- The survey was available to Bexar County providers from January 10, 2018 to March 13, 2018.
- A total of 21 providers participated in the survey. Three of those served only children; those respondents are not included in this analysis. Of the remaining 18 respondents, five did not answer all questions. The number of respondents to each question is noted in the data table for that question.
- For the question about client-to-staff ratio, four respondents reversed the ratio and reported number of staff members per client. The directionality of these responses was reversed before analysis.

## Summary Tables

**Table E.5. Number of Respondent Bexar County Providers by Diagnosis of Adult Client Population**

| | Providers | |
|---|---|---|
| | n | % |
| **Percent of Adult Clients Who Have an ASD Diagnosis** | | |
| ≤ 10% | 5 | 28% |
| 11% - 20% | 3 | 17% |
| 21% - 40% | 3 | 17% |
| 41% - 60% | 2 | 11% |
| 61% - 80% | 3 | 17% |
| 80% - 100% | 2 | 11% |
| **Total Respondents** | **18** | **100%** |
| **Percent of Adult Clients with ASD Who Also Have IDD** | | |
| ≤ 10% | 5 | 31% |
| 11% - 20% | 2 | 13% |
| 21% - 40% | 3 | 19% |
| 41% - 50% | 2 | 13% |
| 51% - less than 100% | 0 | 0% |
| 100% | 4 | 25% |
| **Total Respondents** | **16** | **100%** |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.6. Percentage of Adults (18 and older) with ASD Served by Functioning Status**

| Client Functional Status | % of Adult Clients with ASD by Functional Status Level | | |
|---|---|---|---|
| | Minimum Reported Across All Providers | Median Reported Across All Providers | Maximum Reported Across All Providers |
| High | 0% | 20% | 100% |
| Moderate | 0% | 40% | 100% |
| Low | 0% | 10% | 95% |
| **Total Respondents = 17** | | | |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.7. Number of Respondent Bexar County Providers Providers by Whether a Comorbid Physical or Mental Health Diagnosis is Provided and Recorded**

| Response | n | % |
|---|---|---|
| Yes | 11 | 65% |
| No | 6 | 35% |
| **Total Respondents** | **17** | **100%** |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.8. Number of Respondent Bexar County Providers by Type of Service Provided**

| Service Type | n | % |
|---|---|---|
| Adult Day Care | 8 | 53% |
| Medical Care | 2 | 13% |
| Respite Care | 4 | 27% |
| Supported Housing | 5 | 33% |
| Supported Employment | 5 | 33% |
| Vocational Services | 4 | 27% |
| Therapy | 2 | 13% |
| Other: Parent/Host Companion Provider, Attendant and Habilitation, Social Skills | 3 | 20% |
| **Total Respondents** | **15** | * |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018
* Percentages do not sum to 100% because a single provider may offer multiple service types

**Table E.9. Number of Respondent Bexar County Providers by Type of Assistance Available**

| Response | n | % |
|---|---|---|
| Services available for adults with aggressive or explosive behavior | 7 | 44% |
| Assist adults in toileting and activities of daily living | 10 | 63% |
| Provide transportation services* | 5 | 31% |
| **Total Respondents** | **16** | **100%** |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

* Respondents reported using VIAtrans Paratransit, Alamo Regional Transit, company-owned transportation, and a waiver program or general revenue funded transportation service

**Table E.10. Types and Frequency of Eligibility Criteria**

**Service Area.** A total of 3 providers listed having service area eligibility requirements such as:

- Belong to counties of service

**Financial.** A total of 5 providers listed having financial requirements such as:

- Home Community Services
- Medicaid eligible or sliding scale fee based on % of federal poverty level
- Families must be able to pay out of pocket
- Clinic offers low income reduced rates

**Diagnosis.** A total of 10 providers listed having a diagnosis requirement such as:

- Must have IDD or related condition diagnosis for the Medicaid programs (ICF and HCS)
- ASD diagnosis prior to age 22
- IQ and ABL determine which services may be available
- Adults must be independent eating and toileting
- IDD, significantly impaired in ADL's social skills
- ASD high/medium functioning
- Employable and ability to function mostly independently

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.11. Cost of Care per Client and Fee Assessed to Client**

| | Minimum | Median | Maximum |
|---|---|---|---|
| Cost of Care (n=12) | $50 | $1,000 | $80,000 |
| Fee (n=12) | $0 | $0 | $900 |
| Cost of Care Exceeds Fee by (n=12) | $50 | $600 | $79,400 |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.12. Number of Respondent Bexar County Providers Accepting Contracts by Funding Source**

| Funding Source of Contracts Accepted | Number of Providers |
|---|---|
| Medicaid Waiver | 9 |
| Texas Department of Family and Protective Services | 2 |
| Insurance | 3 |
| Private Pay | 13 |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018
*Other funding sources include fundraising, grants and private donations; Medicaid and Medicaid Star Plus; DARS/TWC; and "funding from AACOG and other service groups"

**Table E.13. Adult Client-to-Staff Ratio and Turnover Rate**

| | Minimum | Median | Maximum |
|---|---|---|---|
| Ratio of adult clients to staff (n=14) | 1:1 | 6:1 | 40:1 |
| Staff turnover rate (n=14) | 0% | 23% | 80% |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.14. Number of Respondent Bexar County Providers by Hours of Operation**

| Hours of Operation | n | % |
|---|---|---|
| Weekday (closes by 5:30 p.m.) | 12 | 92% |
| Evening | 3 | 23% |
| Weekends | 4 | 31% |
| 24/7 | 1 | 8% |
| **Total Respondents** | **13** | **100%** |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.15. Number of Respondent Bexar County Providers by Type of Direct Care Staff Preparation**

| Type of Direct Care Staff Preparation | n | % |
|---|---|---|
| On the job training | 10 | 77% |
| High school diploma/GED | 9 | 69% |
| Associate's degree | 3 | 23% |
| Certified Nurse Assistant (CNA)/Licensed Vocational Nurse (LVN) | 2 | 15% |
| Training leading to certificate | 2 | 15% |
| Training NOT leading to certificate | 4 | 31% |
| **Total Respondents** | **13** | **100%** |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

**Table E.16. Number of Respondent Bexar County Providers by Full-Time Equivalent (FTE) Behavioral Health Providers on Staff**

| Behavioral Health FTE on Staff | n | % |
|---|---|---|
| 0.0 | 9 | 69% |
| 0.5 to 1.0 | 2 | 15% |
| 4.0 to 5.0 | 2 | 15% |
| **Total Respondents** | **13** | 100% |

Source: Kronkosky Charitable Foundation, Survey of Provider Capacity to Serve Adults with ASD/IDD, 2018

## F. Estimates of unmet need

### Key Points

- The Phase 2 analysis plan called for the calculation of estimated size and characteristics of the gap between service needs and service capacity. This estimate proved to be impossible to calculate, as we were unable to responsibly estimate what number of adults with ASD need each of the key service types like day habilitation, supported housing, respite care, supported employment, and vocational services. Some patterns and themes do emerge from the data; these are discussed in Implications and Potential Next Steps.

# Summary and Implications

## Assessment Challenges and Limitations

This assessment has been challenged throughout by the severe shortage of even good estimates of the size and characteristics of the overall local population of adults with ASD, with or without IDD.

- There are no state or even U.S. estimates of ASD prevalence among adults over 30, and the few prevalence studies for young adults have yielded estimates that clearly cannot safely be applied to our local adult population. But those studies that do exist find prevalence rates not significantly different from those among older children and younger teens.
- The end result is that the CDC ADDM prevalence figures for eight-year-olds emerged as the least-worst hook we could find to hang our hat on methodologically. On the positive side, the CDC ADDM prevalence rates are disaggregated by sex and race/ethnicity, a critical factor in generating estimates for our heavily Hispanic population and the heavily female older population.

Beyond the total number itself, we have even less information about the characteristics of the total local adult population with ASD.

- We know a good bit about the people we are serving through state-funded programs, particularly those under the age of about 30 who were more likely to have been diagnosed as children or teenagers and more likely to have entered the system early. We likely also know more about those adults with ASD/IDD who are either very high-functioning and can navigate the system with a degree of success, or who have families or caregivers who are able to do so.
- We know next to nothing about those adults with ASD/IDD who are not engaged in state-funded programs. This large and varied group includes adults with ASD of all functional levels who are older and perhaps have never received a formal diagnosis; we suspect that a large proportion of these have spent their entire lives at home in the care of family members who are unaware that services are available, cannot access services, or are afraid to entrust their loved one to a service provider.
    - It includes those adults who may have received an ASD diagnosis along the way but have a moderate functional level that lets them fall through a wide crack between services targeted to the very high-functioning and services targeted to the very low-functioning. Their symptoms are never or rarely severe or publicly disruptive enough to force their engagement in care through the mental health or criminal justice systems. They are well enough that they and their families are able to get by, usually, in most ways.
    - It also likely includes those who have a mental illness or substance abuse issues but do not exhibit behaviors that would lead to interaction with the criminal justice system. It likely includes those adults with ASD/IDD who are not stably housed, whether or not they are living on the streets, and through preference or barriers have not engaged with the homeless services continuum of care. Finally, it likely includes those older adults with ASD/IDD who have been diagnosed, perhaps inaccurately, as having age-related dementia.

# Key Findings

Over the course of Phase 2, the assessment aim shifted from "find the answers" to "leave no stone unturned while looking for the answers." While not completely unexpected, that was not the outcome that either the Kronkosky Charitable Foundation or CI:Now hoped for. Taking the qualitative information from Phase 1 and the Phase 2 quantitative provider survey data together, though, several patterns do emerge clearly.

## ASD-Focused Service Capacity and Unmet Need

- The current service environment is less a system than a spotty patchwork of specialized organizations that offer very different types of services, and those services, the staffing, and the physical plant are often specialized to serve people with a specific profile of diagnosis, IQ, and functional level. That specialization may be driven by the service provider or, more likely, by the policy environment and the requirements and quirks of each different state-funded program.
- Assuming that sufficient capacity were available, the services that an adult with ASD/IDD and his/her family need – and would engage – are incredibly specific to that adult's individual level of functioning, ability to perform daily activities of living, potential functional capacity, individual preference, and family attitudes and preference. Complicating the picture, all of these factors can be expected to change over the course of the adult's lifetime. A single thorough individualized assessment conducted when the person with ASD is a teenager or young adult will not yield a care plan that is appropriate when the person is 35, 55, or 75 years old.
- No matter how strong the quality of existing programs, however, funding constraints mean that it is clearly impossible for current capacity to provide any meaningful level of service to more than about 8% to 9% of the nearly 22,000 adults estimated to have ASD in Bexar County alone. Even if we assume that the estimates are *double* the actual number of adults with ASD, thousands of adults with ASD and their families are currently unable to access the services they need.
- The situation is more dire in the other three more rural counties studied, as nearly 1,500 adults with ASD are estimated to live in Comal County alone, with another 700-plus in Bandera and Kendall Counties. As Comal County grows in population and infrastructure, services may be sprouting in the more urban New Braunfels area. Families caring for adults with ASD in rural Comal County and in Bandera and Kendall County, however, are largely faced with moving to Bexar County for services or going it alone.
- Unless effective measures are put in place now to prepare, tremendous population growth throughout the region combined with rapid growth in the older population together point to a situation that will rapidly grow worse. Bexar County's population is estimated to grow from 1.4 million in 2017 to 1.8 million in 2030 and 2.5 million in 2050. The number of Bexar County adults with ASD is projected to grow almost as fast, from an estimated 21,618 in 2017 to 26,858 in 2030 and 35,975 in 2050, two-thirds higher than the 2017 estimate. If the ASD prevalence rate among Hispanics is in reality more similar to that of non-Hispanic whites than the CDC ADDM has found to date, Bexar County's population of adults with ASD is higher than currently estimated, and it will grow more rapidly than currently estimated.

## Broader System Issues Affecting Adults with ASD

Several service system challenges faced by the region affect adults with ASD/IDD as well.

- The size of the direct care workforce already falls short of need in Bexar and surrounding counties. Quantifying that shortfall is complicated by the fact that we do not know what proportion of the total population needs direct care. Age and disability figures are available, of course, but many disabilities do not call for direct care, and age is increasingly divorced from functional level and need for direct care.
    - As the population grows and ages, however, we can expect that the number of people who need direct care will grow as well. Without intentional effort, the direct care workforce will not grow in parallel.
    - Beyond basic availability of a direct care provider, it is clear that many conditions call for the worker to have specialized training and ongoing support on the job. ASD is just one of these conditions. And as much as any older adult, older adults with ASD are vulnerable to other conditions like dementia and Alzheimer's and illnesses and disabilities requiring specialized medical care in a facility and/or in the home.
- Bexar County's housing stock is growing less affordable over time. The community already shouldered an inadequate stock of housing affordable for lower-income people, and in recent years fewer units in the middle price range are being built. The result is rents and sale prices that are rising faster than wages or housing subsidies. A significant number of adults with ASD could live independently, some needing daily support and some needing no support. But in addition to the cost of any supportive services required, the cost of the housing itself becomes an issue, particularly if the adult is underemployed or unemployed.
- Medicaid appears to be the thread holding much of the system together for adults with ASD who qualify. However, those who do not qualify face the same health care and medication affordability challenges that the rest of the adult population does. We can expect that situation to become more acute for older adults with ASD whose health care and medication needs are greater than when they were younger.

## ASD and Older Adults

The intersection of ASD and older age remains unclear.

- Care is likely provided by family in the home for the overwhelming majority of non-institutionalized older adults with ASD, and one or both of their parents are the sole caregivers. These parent caregivers are aging and at some point will be unable to manage the level of care required. If ASD has been with us to more or less the same degree for many decades now, as the prevalence estimates calculated here assume, these older adults with ASD who suddenly find themselves without their longtime caregiver are getting along somehow, and we are not facing a new impending crisis. Perhaps another family member steps in and assumes responsibility for their care, or perhaps they find themselves in a nursing home or other institutional setting. If many adults with ASD remain in an institutional health care setting long-term without being discharged, the very low number of discharges in the inpatient data would not be surprising.
- A more poignant possibility is that perhaps many adults with ASD do not outlive their parent caregivers. ASD is much more common among males, and males on the whole have a shorter life

expectancy than females. Life expectancy is also shorter on average among people living in chronic poverty. Bexar County's overall population has a high rate of poverty, and chronic poverty is a more likely outcome for a family who experiences decades of lost wages for both the adult with ASD/IDD and the caregiver, whether or not they face high costs of care. Finally, the rate of behavioral health risks may be higher, and the rate of protective and self-care behaviors lower, for adults with ASD than for the adult population overall.

## Bright Spots

The picture is by no means entirely bleak. Awareness of ASD has increased dramatically over the past decade. Though there is a long way to go, children with ASD are less isolated and more included than previous generations of people with ASD. The presence of coding clubs, social groups, inclusionary activities, and even mainstream television programing is drawing attention to differently-abled people with special needs and ASD. The families of children with ASD are active, vocal and proud of their child, coining the slogan, "My sibling/child rocks the spectrum." This awareness, advocacy, and pride will likely continue to result in more welcoming communities and improved systems or care and services for people with ASD.

But we need not and should not simply wait for that future to arrive. Over and over in Phase 1, providers spoke with a sense of urgency not just about challenges, but about what is *possible* – right now, starting where people are. Among those middle-aged and older adults who did not connect with the service system as a child, a substantial proportion have been living at home, loved and cared for by family. Perhaps they have been at home all day, every day, for decades, without significant interventions to support learning new skills. A tremendous gap exists between their current functional level and their potential functional level, and that gap represents possibility.

No matter where they or their caregivers start, chances are that they could move much closer to their maximum potential. Doing so, though, is likely predicated on their connecting with others who can both support and push them, changing their attitudes and beliefs about what is possible, helping them set goals for their own growth and journey, and providing services and supports that assist them in reaching those goals.

# Moving Forward

While this assessment stops short of specific policy or program recommendations, it's clear that the region would benefit from work moving forward in several different "lanes" in parallel. Following are three potential lanes of work that emerged from this assessment.

- *Developing good data to inform decisions and actions*. No data currently exists to accurately quantify the size, characteristics, needs, or strengths of the general area population of adults with ASD/IDD. In addition to making the best use we can of administrative data on client characteristics and service utilization, the San Antonio region must incubate new data sources to inform planning and progress measurement for the total population of adults with ASD/IDD, including those not currently in care. In addition, both the state and localities would benefit from integration of Texas state-level administrative datasets related to ASD/IDD and the sharing of aggregate local information from that integrated data system or data warehouse. Pennsylvania may serve as a model for that work. Finally, seemingly unrelated organizations or departments within a single organization may find it valuable to collaborate on data collection and information sharing. As just

one example, AACOG's Intellectual and Developmental Disability Services (AACOG IDDS) department might work with the Alamo and Bexar Area Agencies on Aging, supported by and housed with AACOG, to identify older people with a disabled adult child for whose care they are partly or solely responsible.

- *Addressing the policy and finance environment*. While stakeholders at all levels – local, state, and national – may not agree on what changes should be made, it's clear that the current policy and finance environment creates many challenges and constraints that will hinder the work of building local capacity to serve adults with ASD/IDD. Information from both Phase 1 and Phase 2 points to the likelihood that only so much of the problem can be solved without policy change. Following are some examples offered by service providers in Phase 1 conversations.
    - Increased funding for and flexibility in publicly-funded programs to house and care for adults with ASD/IDD would be of great help. Unlike many other service sectors like affordable housing and health care for the low-income and uninsured, the bottleneck is much less at the level of the service provider's capacity than the number of available slots in programs like the Home and Community-based Services (HCS) program and the Intermediate Care Facilities (ICF) program. Funded programs like HCS and CLASS are highly specific, often narrow in services offered and in client eligibility, and have the capacity to address the needs of only a small fraction of the population with ASD/IDD. A wait of up to 15 years to secure one of those slots surely cannot be considered accessible or effective, perhaps especially here in the San Antonio region, to which many families move through company relocations or military permanent change of station orders. Because wait lists are state-specific, a move to Texas from another state puts a family back at the bottom of the list.
    - Highly-structured programs may not address the specific needs of every individual with ASD/IDD. Semi-independent living slots may go unfilled because generally high-functioning adults with ASD need minor additional support that is not provided, such as an hour or less of individualized assistance with planning each day.
    - Public and organizational policies may conflict to the detriment of the adult with ASD/IDD. For example, legislated policy tremendously limits the income and assets allowed for a disabled person to remain eligible for publicly-funding programs like Medicaid and Supplemental Security Income (SSI). At the same time, employers who are readily willing to hire adults with ASD/IDD often have inflexible rules about minimum allowed work hours, minimum pay requirements, and employer contributions to retirement accounts, and each of these can endanger the employee's eligibility. Pooled special needs trusts can provide a workaround, but workarounds may not scale well.
- *Making the best use of what we have now*. In the absence of good data, supportive policy, or adequate funding, we can still work together to maximize the outputs and outcomes from the inputs and assets we have locally. Many participants in this assessment – service providers, adults with ASD, and families of adults with ASD/IDD – offered ideas in this vein. Among others, these ideas included how adults with ASD might be able to support each other, how families might support each other, how providers might find and connect with adults with ASD/IDD not currently engaged in services, how existing services might be better coordinated, how we might build the direct caregiver workforce, and how minimal investments in one area might leverage great returns in another.

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Twenty-one organizations participated in the Phase 2 provider capacity survey. Most of them slogged through completion of the survey, giving their best effort at providing accurate information about widely-varying operations via a standardized format that did not allow much flexibility.

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