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

Executive Summary

Community Information Now
Prepared for the Kronkosky Charitable Foundation
June 2018
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. 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. The Foundation-contracted 2016 Autism Prevalence Assessment\(^1\) used national estimates of prevalence by sex and race/ethnicity to model prevalence estimates by age group across the lifespan, but the size and characteristics of this population are much less clear than for children who are likely to be identified and diagnosed in early childhood or school systems. 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 needs and those of their families and caregivers, 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 have been formally assessed or diagnosed with ASD. “Adults with ASD/IDD” is used as shorthand throughout this report.

Data Sources and Methods

Because of the dearth of both local data and a national evidence base on adults with ASD, the assessment was split into two phases. Phase 1 gathered and analyzed information that would define the scope and approach to Phase 2. Through a series of meetings and site visits with key service providers, adults with ASD/IDD, and families and caregivers of adults with ASD/IDD, CI:Now explored what was and was not possible to know about local population characteristics, service needs and system capacity, policies and practices, and priorities.

Phase 2 employed a quantitative approach to attempt to answer a number of questions about the size and needs of the local population of adults with ASD/IDD, the costs associated with ASD/IDD, current service system capacity to meet the needs of adults with ASD/IDD, and unmet need. The full version of the Final Report includes a detailed methodology and user cautions for each area of analysis at the end of each section. Table numbering from the full report is retained to facilitate cross-reference.

Results of Note

Estimated Number of Adults with ASD and ASD-Attributable Costs

No U.S. local, state, or national prevalence rates for adults with ASD are available. The only robust and generalizable adult population ASD prevalence figures, developed using a community (rather than clinical) sample, surveys, and validated assessment tools, are from England. 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 ASD prevalence rates, the adult prevalence rates estimated in this report were modeled using child prevalence rates. The numbers in parentheses in the table below represent the range of the estimate, or confidence interval.

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

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>2018</td>
<td>337 (321-348)</td>
<td>21,618 (20,091-23,005)</td>
<td>1,790 (1,679-1,877)</td>
<td>559 (534-582)</td>
</tr>
<tr>
<td>2030</td>
<td>402 (385-419)</td>
<td>26,858 (24,885-28,679)</td>
<td>2,601 (2,438-2,731)</td>
<td>773 (737-806)</td>
</tr>
<tr>
<td>2050</td>
<td>426 (405-443)</td>
<td>35,975 (33,140-38,653)</td>
<td>4,032 (3,775-4,252)</td>
<td>1,150 (1,093-1,203)</td>
</tr>
</tbody>
</table>

*The small populations of Bandera and Kendall County do not allow modeling by race/ethnicity by sex.

To estimate ASD-attributable costs by county, CI:Now adjusted the most recently-available U.S. ASD-attributable cost figures for inflation. The inflation-adjusted cost, which includes accommodation (housing), employment support, direct medical, direct non-medical, and loss of productivity, was then applied to the estimated population of adults with ASD. The costs associated with ASD are considerably higher when IDD is also present. Because no cost figures were available for education, family expenses, or benefits, the resulting cost figures are almost certainly underestimates. Tables D.2 and D.3 summarize estimated annual and lifespan ASD-attributable costs by county and presence of IDD.

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

<table>
<thead>
<tr>
<th></th>
<th>Bandera</th>
<th>Kendall</th>
<th>Comal</th>
<th>Bexar</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated number of adults with ASD</td>
<td>337</td>
<td>559</td>
<td>1,790</td>
<td>21,618</td>
<td>24,304</td>
</tr>
<tr>
<td>With IDa</td>
<td>$13.3M</td>
<td>$22.0M</td>
<td>$70.6M</td>
<td>$852.6M</td>
<td>$958.5M</td>
</tr>
<tr>
<td>Without IDa</td>
<td>$11.4M</td>
<td>$18.9M</td>
<td>$60.5M</td>
<td>$731.0M</td>
<td>$821.9M</td>
</tr>
</tbody>
</table>

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

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Table D.3. Estimated Aggregate Lifespan Cost\(^b\) in Billions for Adults with ASD by Geography, 2017

<table>
<thead>
<tr>
<th></th>
<th>Bandera</th>
<th>Kendall</th>
<th>Comal</th>
<th>Bexar</th>
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<tr>
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<td>559</td>
<td>1,790</td>
<td>21,618</td>
<td>24,304</td>
</tr>
<tr>
<td>With ID(^a)</td>
<td>$0.4B</td>
<td>$0.6B</td>
<td>$2.0B</td>
<td>$23.6B</td>
<td>$26.6B</td>
</tr>
<tr>
<td>Without ID(^a)</td>
<td>$0.3B</td>
<td>$0.5B</td>
<td>$1.7B</td>
<td>$20.8B</td>
<td>$23.3B</td>
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</tbody>
</table>

\(^a\) 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.

Characteristics of Adults with a Documented Diagnosis of ASD

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. The Alamo Area Council of Governments Intellectual and Developmental Disability Services (AACOG IDDS) department, formerly known as the Alamo Local Authority (ALA), provided a fully de-identified dataset consisting of demographic and other key characteristics of 2,762 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.

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.

State eligibility rules require that ID must be listed as the primary diagnosis for anyone for whom a diagnosis of ID has been confirmed, and the information system in which this dataset is maintained does not allow query of secondary diagnoses. Therefore one cannot query diagnosis information to identify all individuals with ASD with or without ID. (If 20% of adults with ID are assumed to have co-occurring ASD, the total number of adults with ASD in the dataset is estimated to total 1,817; see Table B.10.)

The dataset contains a total of 408 individuals with primary diagnosis of Autistic Disorder. Of these, nearly half are younger than 18 years old. Of those 18 and older, 79% are between the ages of 18 and 29, and only 1.4% are 65 or older. Eighty-six percent are male. Of those for whom living arrangements are documented, virtually all live in the care of relatives. Information on educational attainment is unrecorded for close to half of those individuals 25 and older, but of those, only 4% continued their education beyond high school. Adaptive behavior level is unrecorded for a third of individuals, but of the remainder, 85% are documented as mild or moderate.

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. 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.

Estimated Population Not in Care

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. An estimated 19,801 (range 18,274-21,188) Bexar County adults with ASD (with or without ID) are not receiving service coordination through AACOG IDDS (Table B.10).

Provider-Reported Service Capacity

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. 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 responses paint a picture of a high degree of specialization in both services and client characteristics. For example, 28% of responding providers reported that 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 (Table E.5). Nearly a third reported that fewer than 10% of their adult clients with ASD also have IDD, but a quarter reported that 100% of adult clients with ASD also have IDD (Table E.6). 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.

The service most commonly offered was adult day care, often called “dayhab”, offered by about half of respondents (Table E.8). A substantial proportion offered supported housing (33%), supported employment (33%), respite care (27%), and vocational services (27%). Several types of assistance are rarely offered, even within programs specifically for adults with ASD. Fewer than half of 16 responding providers report that 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 (Table E.9). The most common type of requirement reported relates to client diagnosis, IQ, and level of functioning (Table E.10).
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 (Table E.11). 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, as might be expected given the variation in service offerings and client characteristics. The staff turnover rate per year ranged from 0% to 80%, with a median turnover rate of 23% (Table E.13). 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.

### 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. The full version of the Final Report includes a lengthier narrative on these challenges, but following is a brief summary.

First, 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.

Second, beyond the total number itself, we have even less information about the characteristics of the total local adult population with ASD. 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 who:

- are older and perhaps have never received a formal diagnosis; these adults likely have spent their entire lives at home in the care of family members.
- may have received a formal diagnosis along the way but have a moderate functional level. 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.
- have a mental illness or substance abuse issues but do not exhibit behaviors that would lead to interaction with the criminal justice system.
- 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.
- 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

First, 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 as a whole apply to the care of 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. Further, 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. Over and over in Phase 1, providers spoke with a sense of urgency not just about challenges, but about what is possible. Among those middle-aged and older adults who were not brought into the service system as a child, a substantial proportion have been living at home, loved and cared for by family but not learning any daily living skills. 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.
Acknowledgements

CI:Now wishes to thank Ingrid Petty and Maria Carreon from the Kronkosky Charitable Foundation for their active partnership, their patience, and their continual willingness to connect CI:Now with local ASD/IDD subject matter experts, key service providers, and any information sources they came across. Many thanks go also to Cara Magrane, the Executive Director of Autism Lifeline Links (ALL) and one of those subject matter experts. All three pushed forward with a collaborative and practical approach in the face of many unknowns.

CI:Now also extends thanks to the many staff of the organizations who gave generously of their time to help with this assessment. In total, over 20 staff of key organizations participated in the Phase 1 meetings, including staff from 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. Many of these staff have decades of local on-the-ground experience and knowledge that cannot be found in quantitative datasets, peer-reviewed literature, or anywhere else.

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.

Leadership and staff of the Alamo Area Council of Governments Intellectual and Developmental Disability Services department donated many hours of their time both in Phase 1 meetings and in the query, de-identification, and interpretation of the administrative data used in Phase 2. CI:Now is grateful for their willingness to work through the necessary privacy and security controls to enable this assessment to include aggregate information from a critical local dataset on services for adults with ASD/IDD. Special thanks go to Jacob Ulczynski, Director of IDD Services, for his help interpreting that data and reviewing the related content in this assessment.

Finally, CI:Now extends its greatest thanks to the adults with ASD and the families of adults of ASD who gave freely of their time, knowledge, and experience in Phase 1. Their insight made this often-challenging assessment stronger, as did their relentlessly matter-of-fact and positive determination to meet whatever comes their way and find the best path forward.