



MADISON
HOUSE
AUTISM
FOUNDATION



AUTISM AFTER 21

FIRST FINDINGS OF A UTAH REVIEW &
TOOLKITS FOR AUTISM INCLUSION

2023



MADISON HOUSE AUTISM FOUNDATION
AUTISM AFTER 21
UTAH PROJECT

**GENEROUS SUPPORT
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Authors' Note

This is a collaborative research study designed and executed by both an autistic and a neurotypical researcher. While it is not representative of the whole of the autistic experience, we want you to know that this neurodiversity was crucial to the development of each step of this study. Sumiko and Anna co-authored this report and in an effort to dismantle the stigma around autism, we feel it is important that this be celebrated as an example of the work that is well within the capability and talent of many people in the autistic community.

Thank you for reading this and being with us on this journey.

Anna & Sumiko

Authors

Anna Smyth, MS
Founder and Principal Consultant
Thrive Utah

Sumiko Martinez, PhD
Director, Autism After 21 Utah Project
Madison House Autism Foundation

(Complete author bios on page 37.)

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FOREWORD



In my role as Executive Director at Utah State University's Institute for Disability Research, Policy, and Practice, I am involved in myriad conversations about intellectual and developmental disabilities, including autism, throughout the state, and it has been a privilege to be involved with the AA21 Utah Project. Although there are multiple, small local efforts, there hasn't been a coordinated, statewide effort to address the housing and community inclusion needs of individuals with disabilities in Utah. This report changes that! This important report outlines the community needs of autistic adults here in Utah and provides a clear roadmap for moving forward to address the needs of Utahns with autism and other disabilities as we work towards more neuro-inclusive communities.

Approximately 20% of Utah's population qualifies as having a disability under the Americans with Disabilities Act, and one of the fastest growing subpopulations are individuals with autism. Although awareness of autism has grown over the past 20 years, many autistic people still deal with stigma and discrimination in their everyday lives. There are currently many adults with autism who are living, learning, and working within our communities, but they continue to struggle with fitting in and accessing the supports that they need to be successful.

The goal of the Autism After 21 Utah Project was to learn more about how autism-friendly and neuro-inclusive our communities are in the state of Utah and to provide information on areas for targeted investment and improvement. This report makes it clear that people with autism and other disabilities face multiple barriers to community inclusion, employment, housing, transportation, recreational opportunities, and virtually all other aspects of community life. This report provides clear documentation of these challenges and the scope of the needs facing individuals with disabilities in our state. This report also provides a framework for dialogue and collaboration as we all come together to try and address these challenges. Addressing these issues for autistic adults will help to improve the quality of life for many other people in Utah as well.

Utah has, historically, been very effective at working as a collaborative disability community. Going back to the early years of the deinstitutionalization movement in the 1970s, parents, providers, professionals, and politicians came together to create community-based programs to meet the needs of individuals with disabilities and their families. This grassroots tradition of advocacy and activism continues to form the foundation of Utah's disability community, and it is my hope that this study and the work that follows will help to build bridges and lead to collaborative solutions to Utah's housing and community living crisis.

Building inclusive communities is truly a collaborative process; it takes autistic self-advocates, individuals with other disabilities, family advocates, professionals, business leaders, religious leaders, community organizers, politicians and everyday people coming together to create a vision of a state where everyone has access to what they need to thrive. Joining together in conversation with the Autism After 21 Utah Project is one way to begin this process and to better understand how we can improve, starting with our local communities and growing outwards from there.

Sincerely,
Matt Wappett, PhD

Photo: Brent Pace - Unsplash



UTAH: THE FASTEST GROWING STATE

For ten years, Utah has been the fastest growing state in the nation.¹ Utah has a stable economy, beautiful scenery for rest and recreation, delicious food and much more. As the decade-long population boom indicates, Utah is an appealing place to live, but, are the many resources and assets here equally available to all who call it home? Are the leaders across the state committed to creating inclusive environments where diversity in its many forms can thrive amidst this rapid increase in population?

OBI-WAN'S STORY

Obi-Wan* lives in the desert, but not the remote reaches of Tatooine! Instead, he lives in the deserts of rural Utah, surrounded by beautiful scenery and open spaces. He is an autistic adult in his late 20s, flourishing in a community where he is well-known and valued, but he hasn't always felt that way.

During high school, Obi-Wan faced barriers and negative perceptions from others because of his autism. He credits his longtime teacher/mentor with helping him survive high school, succeed in college, and find his professional path.

He always wanted to work with young people, and now mentors autistic students. Autistic youth often face mental health challenges, and Obi-Wan is proud to be a sounding board for his students when they're struggling. He knows firsthand the importance of community inclusion and belonging. He says, "I was stuck in a rut. Depressed, semi-suicidal. I needed to find a way to find out. Then I learned that there was this lady offering a Tai Chi class, I enrolled in a class, found my people, and the rest is history." Now he has earned multiple belts in different martial arts disciplines and volunteers at the dojo.

Despite finding social inclusion in his community, Obi-Wan still works three jobs to make ends meet, and he worries about being able to afford living in his community as the cost of housing has skyrocketed. But for now, he is looking forward to helping autistic youth through his work and coming into his own as a martial artist.

**Each of our interview participants chose pseudonyms, and this participant opted for Obi-Wan. This is a nickname from his mentor, representing the way he has overcome adversity.*

In addition to the overall population growth, Utah has a growing autistic community. As of 2020, approximately 77,064 people in Utah are estimated to have autism. Seventy-two percent of those are nearing or in adulthood.^{2,3} As these individuals are navigating the world of employment, relationships, housing, transportation and more, our communities have the opportunity to evaluate the barriers and challenges that our autistic neighbors and community members are experiencing in their efforts to thrive as adults.

The Autism After 21 (AA21) Utah Project launched in 2021, beginning with this research study to identify the needs of autistic individuals and their families. In addition to learning about basic, current needs like shelter and care, the AA21 Utah Project is asking deeper questions: what does thriving look like and feel like for an autistic adult? In what ways can we shift and expand our community structures and perspectives to be more inclusive of neurodiversity? This research study is the first step in a multi-phase initiative to engage multi-sector stakeholders and develop communities where adults with autism can experience self-determination and thrive.

Our intent is that the data in this report be both clear and actionable. The community feedback shared in this report can **inform local and state government, businesses, and neighborhoods** as to how we move toward a more integrated and inclusive society. Our hope is that, as Utah continues to grow, it can be a great place to live and work for all of its residents.

REPORT LANGUAGE

Language is one of the most powerful mediums available to human beings. Additionally, language is never truly neutral. Acknowledging that our language calls certain meanings and implications into being, the AA21 Utah Project researchers and authors are mindful of the language used in this report.

Identity-first language



Leads with a person's diagnosis¹⁶

Examples:
autistic person
autistic adult

Many individuals prefer this description because it conveys that autism is integral to the development of the brain and cannot be separated from the person

Person-first language



Puts a person before their diagnosis¹⁷

Examples:
person with autism
adult with autism

Many people prefer this description because it emphasizes that a person's identity is multifaceted and that their diagnosis does not solely define them as a whole person

This report will use both identity-first and person-first language interchangeably. Any quotes from in-depth interviews are edited for clarity but will use the language preferred by the interviewee, so there may be some variations. For example, some people refer to themselves as “autists” or “autistics,” and you may see those terms included as well in quotes from the autism community. Project researchers chose to honor the language choices of the people who participated in this study by including their preferred descriptors exactly as stated.

The AA21 Utah Project supports those in the autistic community to continue speaking up and shaping the language that is most inclusive. The AA21 Utah Project recognizes that the currency of certain labels changes over time and that the language chosen for this report at this time may be replaced with more informed and inclusive terminology. The AA21 Utah Project supports and encourages those changes that are driven by the autistic community. There is a list of key words and their definitions at the end of this report in the appendices.



“ I know everyone’s struggling with housing for a lot of different reasons. But there are specific executive functioning tasks that go into finding a place to live.

And there’s a lot of social things like working with landlords and finding understanding roommates **that are specifically difficult for me, because I’m an autistic person.**

LEO, INTERVIEW PARTICIPANT

“ **[Autism] helps me get into my creative mind.**

You know, helps me problem-solve. I’ve thought of things in a certain way that some people say, ‘I would have never thought of it that way.’ I do things a certain way that doesn’t always make sense to others, but it makes sense to me, which is what makes me uniquely me.

So, I wouldn’t trade it for anything else.

JES, INTERVIEW PARTICIPANT

“ If I could wave a magic wand, and it would get rid of the stigma and fear around disability, I think that would do more to advance the cause of people with disabilities or neurodiverse individuals than...anything else.

I think on a very real level, people are still afraid of autism.

MATT, INTERVIEW PARTICIPANT

“ For those who aren’t aware of those invisible disabilities, I think it comes down to education, right?

How can we help people feel seen in a way that honors this population’s voice and choice?

BECKY, INTERVIEW PARTICIPANT

“ **Maybe the city or local governments could sponsor a series of seminars** and just have some speakers come in that are directed at hiring practices or **creating a diverse workforce...**

because we have some employee assistance programs that we can use for other businesses as well as city employees.

TAWNY, INTERVIEW PARTICIPANT

AUTISM IN UTAH

An Unseen Population

We want our [adult] child to be more independent, less dependent on us for some basic things. But there's only so much we can do to build all the structure for her, so we're trying to cheer from behind.

- Andrew & Lia,
interview participants

How do I maximize my strengths, and how do I work around the struggles? What do I say to other people? How do I get people to give me a fair shot in life?

- Terrence,
interview participant

It would be so awesome if there was a hotline resource that people can call when they first get diagnosed. Especially for people who get a diagnosis later on. And maybe the first step of all that would be 'Hey, let us help you get access to a diagnosis' because I wonder how many people really are like me, and slipped through the cracks?

- Ken,
interview participant

The United States faces a growing humanitarian and economic crisis involving approximately 5.5 million autistic adults. If we include their parents and two siblings, this number exceeds 30 million living with autism. There is no national comprehensive plan to help this unseen population.

When an individual with autism reaches the age of 21, federal services end abruptly, leaving families to fend for themselves. **Each year 100,000 children join the ranks of the millions of adults already on the autism spectrum.**⁴ Many will remain at home with aging parents and little hope of employment. Isolation, lack of activity, and lack of community engagement can lead to cascading physical and mental health issues as well as increasing health expenses, including high blood pressure, obesity, diabetes, and depression. Clients and families put significant investment into adolescent services and unfortunately feel like they are starting back at square one when they enter the adult arena. The substantial investment made in their schooling begins to erode. According to the "A Place in the World" report,⁵ as their caregivers age, many face homelessness or displacement from the only community they have known.

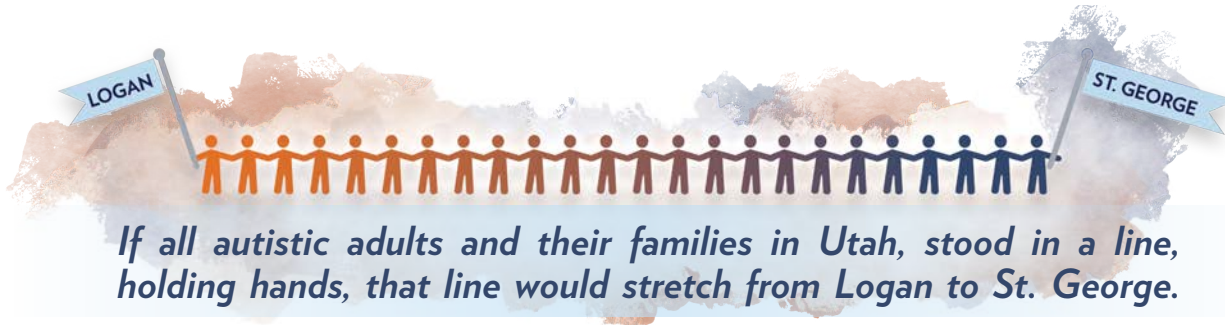
Utah is optimally suited to take the lead in developing these long-term plans by creating solutions for long-term housing, accessible healthcare, employment and community engagement. As Utah helps itself, it paves the road for other states to follow.

A Growing Concern

Utah has one of the highest rates of autism in the nation, which makes it an appropriate place to begin a national movement.⁶

This problem is too large for families to address on their own—it requires leadership, hospitable communities that are interconnected and supportive, and an understanding of the complexity of autism and its impact on citizens and the economy.





The crisis can be addressed, but only by collaboration among self-advocates, community, business, government, and healthcare leaders to produce a working lifespan plan. A diagnosis of autism overlaps with many systems of care, including social services, health, education, housing and employment. Effective solutions must work across these systems.

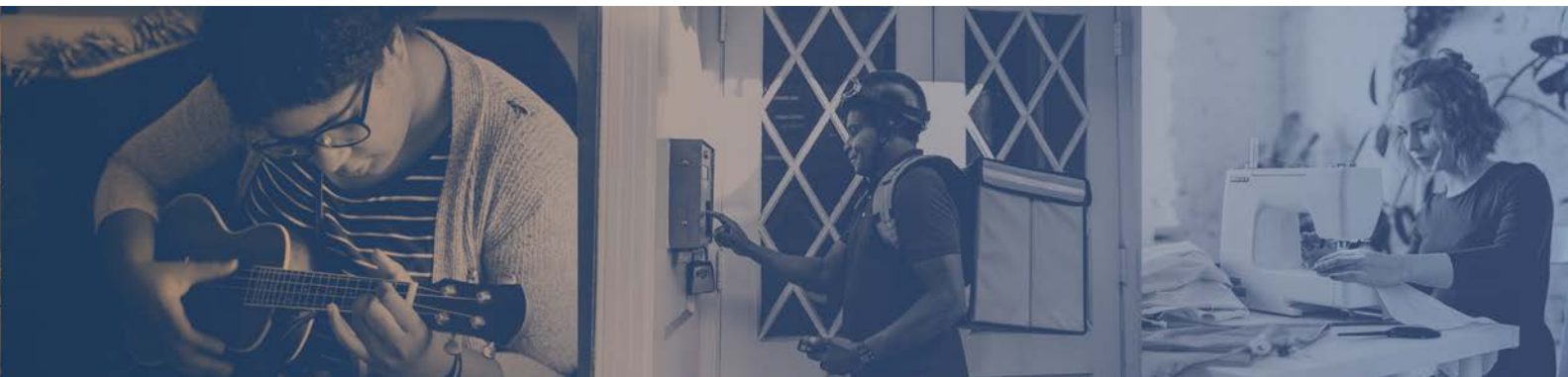
What is Autism?

According to the National Institute of Mental Health, “Autism spectrum disorder (ASD) is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. Autism can be diagnosed at any age, and is described as a ‘developmental disorder’ since symptoms generally appear in the first two years of life.”⁷ Autism itself is a relatively young condition, only recognized as a unique disorder by the Diagnostic and Statistical Manual of Mental Disorders (DSM) in the 1980s.⁸ The Center for Disease Control and Prevention estimates that 2.21% of the US adult population are on the autism spectrum.⁹ Nationwide, one in 36 eight-year-olds are diagnosed with autism, suggesting that this number will climb dramatically in the coming decade.¹⁰ Additionally, obtaining a formal diagnosis of autism can be a time-consuming and expensive process. There may be countless adults in Utah who are autistic but have never received a diagnosis. We also now know that many diagnostic tools have not been as effective at recognizing autism in girls and women, Black, Latinx, and Native American populations, and as a result, many autistic children were misdiagnosed—or missed entirely.^{11,12} In order to prepare for an unprecedented population of autistic adults, we need to focus on building autism-friendly, neuro-inclusive communities that will help all Utahns thrive throughout the lifespan.

The Interagency Autism Coordinating Committee (IACC) shows that only 2-3% of funding for autism research is for lifespan issues—one of the seven priority areas identified by the committee.¹³ The IACC’s goal for Lifespan Issues is “**All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, satisfying relationships, and meaningful access to services and supports.**”¹⁴ The Autism After 21 Utah research study is intended to support this goal of centering the needs of autistic adults and their families in Utah’s conversations about neuro-inclusive communities.

“I know even within my own family, I have cousins that are afraid of Michael. And it’s because they do not have those opportunities to engage with him, to interact with him. And so I see my community garden as a way forward. It’s a place where anyone can come and work, and see that Michael has a goal, a mission, a job, a responsibility.”

- Adrienne, community leader & parent advocate



STUDY OBJECTIVES

Guiding Research Questions

In 2022, the AA21 Utah Project launched a research study, focused on statewide data collection of the “autism-friendliness” of Utah communities. Project researchers use the phrase “autism-friendliness” to encapsulate the IACC’s Lifespan Issues goal. The researchers collected data via an electronic survey questionnaire and in-depth interviews to explore these questions:

How autism-friendly are communities in Utah?

What autism-friendly strengths and assets are in place that support full inclusion of autistic adults in Utah communities?

What are the gaps and barriers faced by autistic adults and their families?

What attitudes and expectations do community leaders and decision-makers have regarding adults with autism?

What attitudes and expectations do autistic adults and their families hold regarding adults with autism living in their local community?

How much and what kind of experiences have community leaders and decision-makers had with adults with autism and their families? Vice versa?

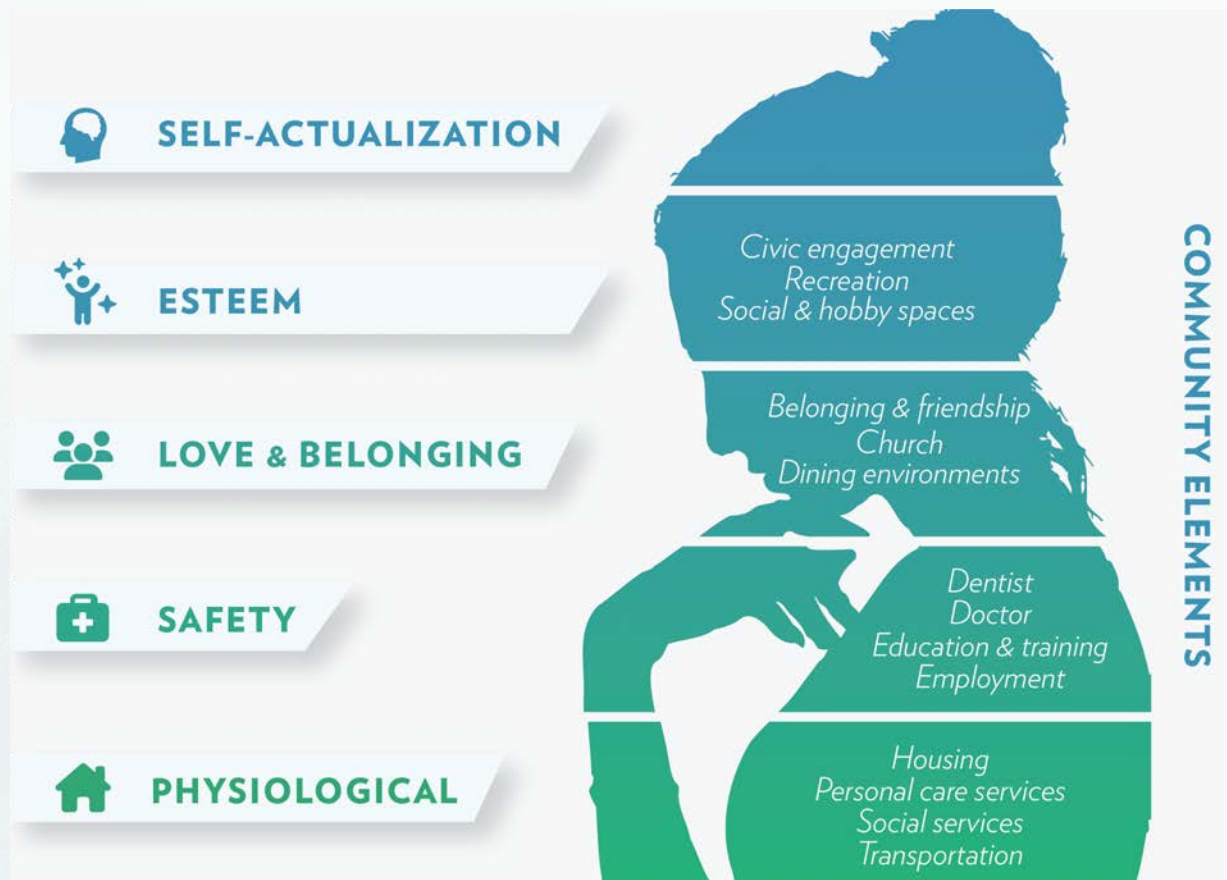
Where and how is knowledge and information about autism accessed?
By whom and how often?

These research questions, taken together, set the stage to generate an actionable set of data to serve as a baseline for future phases of the Autism After 21 Utah Project, which seeks to create more neuro-inclusive communities through evidence-driven collaborations. These collaborations may involve facilitated discussions for autistic adults and family members, community leaders, and interested volunteers; regional working groups to address local needs in various communities across the state; and information-sharing across regional working groups.



Elements of Community: A Hierarchy of Needs

Building from the Substance Abuse and Mental Health Services Administration’s Eight Dimensions of Wellness, described in the Research Methods section below, AA21 Utah study researchers developed a theoretical set of **community elements** that represent the facets of adult life which need to be well-managed and well-resourced in order for an individual to thrive. These elements map onto the levels of Abraham Maslow’s famous Hierarchy of Needs (FIG. 3.1). Maslow’s model identifies the key needs that shape an individual’s motivation and the order in which those needs must be met. For example, if we don’t have adequate shelter, our attempts at completing an education or maintaining friendships will be negatively impacted.¹⁵ The hierarchy of needs, as a model for understanding behavior, helps us shift our focus from deviance or deficiencies in an individual and instead identifies how communities can help a person thrive.



Maslow's Hierarchy levels are listed on the left, and this study's Community Elements are mapped onto the right.

FIGURE 3.1

As Leo, one of the interview participants in the AA21 Utah research study, pointed out, “Being secure in those ways [housing and employment] is a really important foundation to be able to build up these other things. It’s like Maslow’s hierarchy of needs. If you don’t have shelter, if you’re insecure with employment and your access to basic things, you’re not going to be able to find a social group, you’re not going to be able to pursue your hobbies, learn to do new things, or find your people.”

By identifying which Elements of Community are experienced as sufficient by the people with autism and their families throughout the state, as well as the gaps and barriers to inclusion for autistic adults, communities and leaders at all levels will be able to leverage the data into action to make community life more neuro-inclusive.

RESEARCH METHODS

In addition to Maslow's hierarchy, the AA21 Utah research study is grounded in one primary psychosocial framework to inform our data collection methodology: The Substance Abuse and Mental Health Services Administration's (SAMHSA) Eight Dimensions of Wellness. This theoretical model is explained below along with the key elements that support and frame the AA21 Utah research study.

The Eight Dimensions of Wellness

SAMHSA has developed a framework for whole person wellness broken down into eight dimensions (SEE FIG 4.1):¹⁸



FIGURE 4.1

These dimensions influence each other and affect an individual's overall quality of life. This model also strongly aligns with recent evidence-based models for psychological well-being from leading experts.^{19,20} While these dimensions directly pertain to the wellness of a single individual, this study extends the framework to a sociological level, suggesting that these eight dimensions can be used to identify and evaluate a thriving, neuro-inclusive community. This research is focused on two key aspects of the framework:

- The interconnected relationship between the dimensions of wellness
- The interconnected relationship of an individual's inner and outer world

Our research seeks to align data within this framework by asking questions through the lens of each of these eight dimensions. For example: what elements must be present, or what elements are specifically identified as missing or inaccessible for adults with autism? Is a community truly whole when certain segments of the population are unable to achieve wellness in these eight dimensions?

This premise is a key underpinning for the study design, and it is a focusing tool for the research team. Just as an individual person's wellness can be improved in any of the eight dimensions, the AA21 Utah research study suggests that community wellness can also be improved by boosting the level of neuro-inclusion in all domains of life.



Research Participant Criteria

In order to participate in the AA21 Utah research study, an individual had to meet the following criteria:



18 years of age or older



Utah resident



Adult with autism OR
Relative of adult with autism OR
Caregiver of adult with autism OR
Community Leader

Those who participated in the study may hold several of these roles simultaneously. For example, an individual may be a community leader as well as have a family member with autism. Or an adult with autism may have a relative, such as a sibling or child, who is also on the autism spectrum.

Data Collection Methods

The AA21 Utah research study collected quantitative data through an anonymous online survey consisting mostly of multiple choice and ranking questions. Invitations to complete the surveys were distributed to the community of autistic individuals and their families as well as community leaders through community partners (listed in the Acknowledgments section).

The qualitative data were collected via recorded in-person and Zoom interviews with adults with autism, family members, and community leaders representing all regions of the state of Utah. All individuals who participated in interviews elected a name to be used in the report. Some have chosen pseudonyms. Videos from Zoom interviews were destroyed immediately following the session, and only the audio files were retained.

Participation in both the survey and interviews was voluntary and participants could opt-out at any time during the process and had the option to skip questions both in the survey and the interview. Interviewers completed a formal training in qualitative research methodology as well as trauma-informed interviewing.

The Institutional Review Board (IRB) at the Utah Department of Health and Human Services reviewed all data collection methods, protocols, and tools for this research study to ensure project researchers upheld high ethical research standards throughout the process. The IRB approved all revisions to the study protocol, including edits to recruitment materials and translated materials. Particular attention was given to accessible language in the survey and interview questions as well as an autism-friendly protocol for conducting in-person and Zoom interviews. This protocol allowed for participants to experience a supportive environment and be at ease as much as possible while participating in the research.

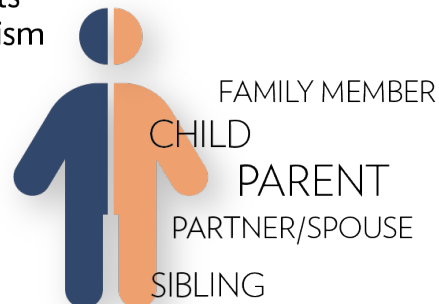


KEY FINDINGS

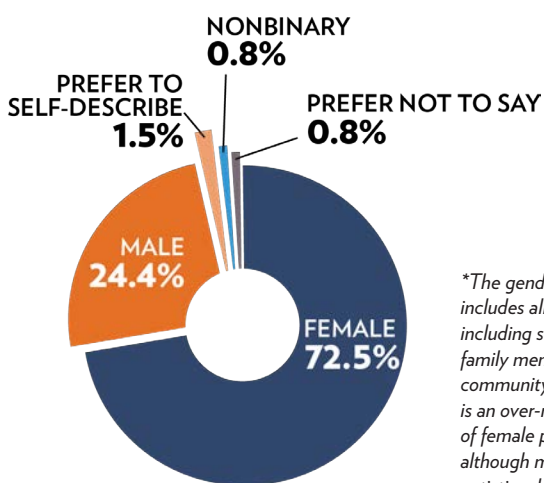
Response Demographics

There were a total of 133 survey responses after cleaning the data. Some of the survey questions were only asked of participants in a certain role such as a family member of a person with autism or a community leader. Thus, by design, not all respondents answered every question. Of these 133 responses, the demographic distribution is as follows:

HALF of respondents are adults with autism

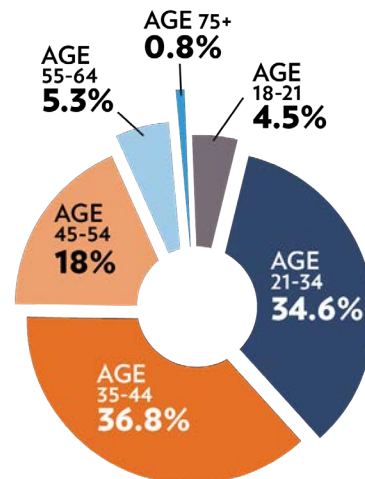


10% indicated two or more relationships with autism

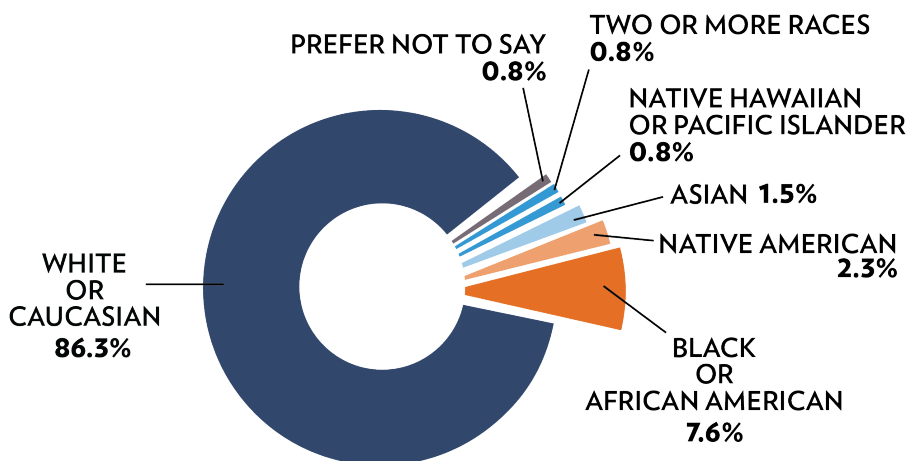


GENDER

**The gender breakdown includes all participants, including self-advocates, family members, and community leaders. There is an over-representation of female participants, although most diagnosed autistic adults are male.*

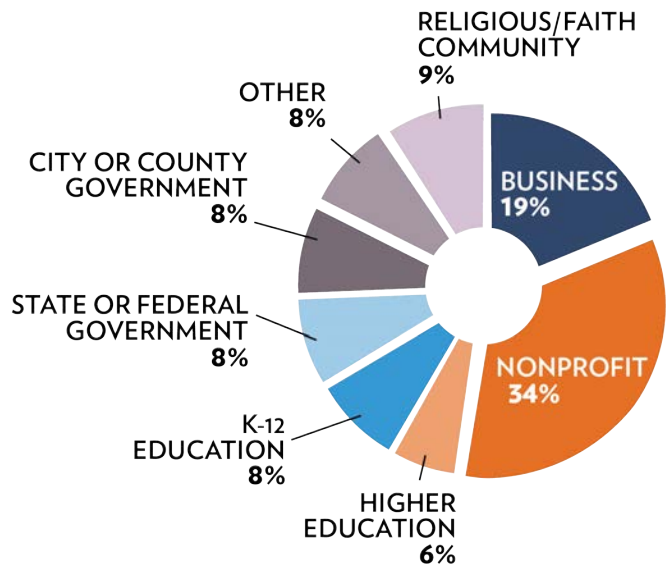
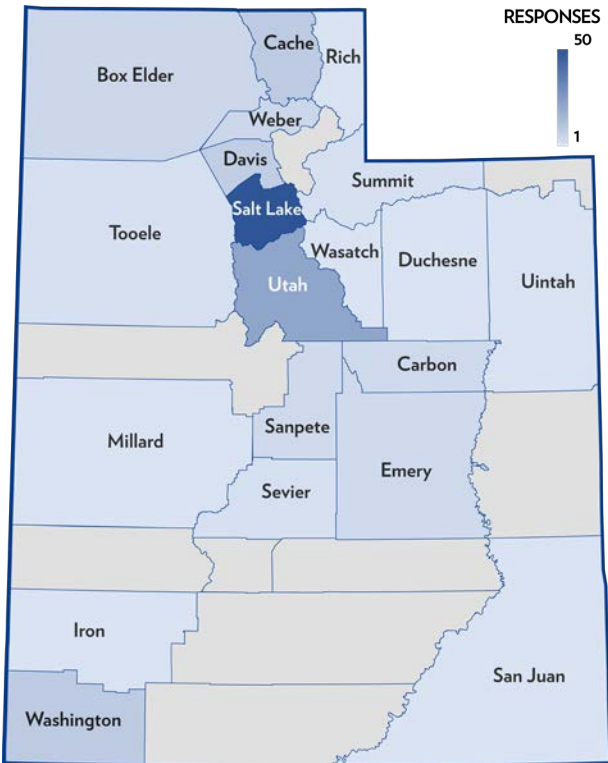
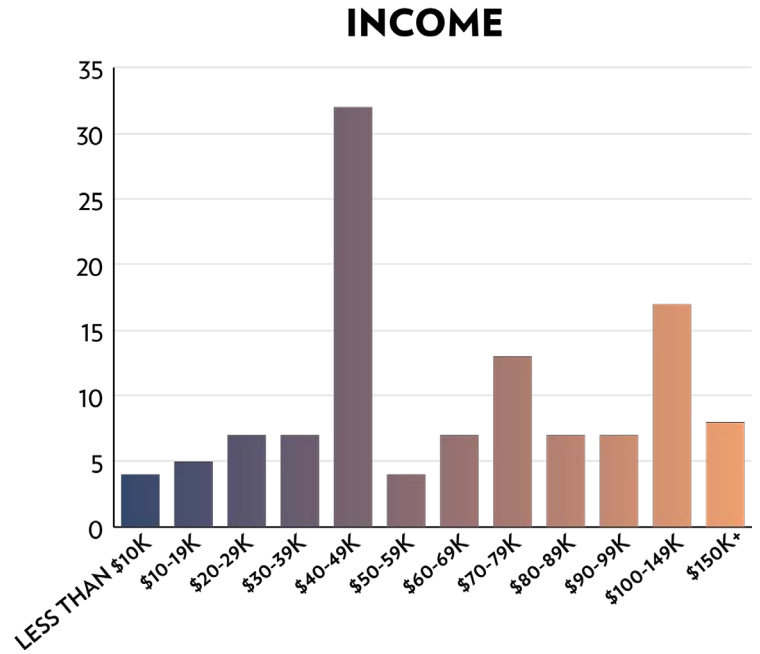
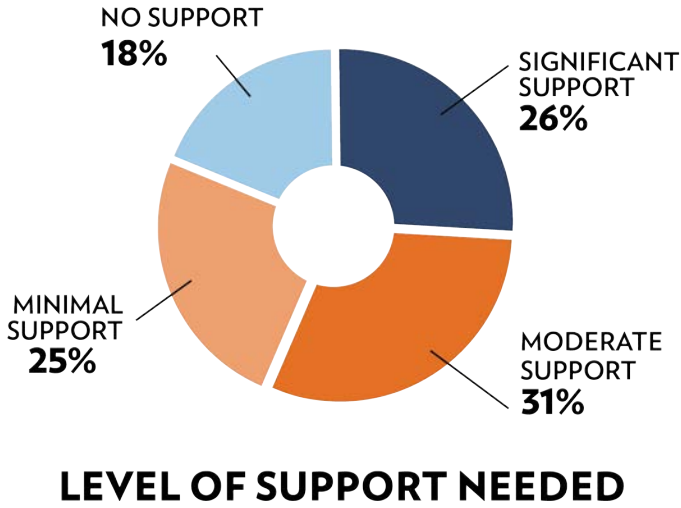


AGE



RACE





The study findings are discussed in terms of three main themes: How We Live (which includes Housing and Public Supports), How We Feel, (which includes Belonging, Friendship & Recreation) and How We Learn (which includes information searching habits and media access). The intent is for the three major themes to help focus future action along similar lines.

How We Live

As previously illustrated, thriving is a multi-faceted experience. Survey participants who identified as autistic were asked to select from a list all of the community resources that they currently need on a day to day basis. They were also asked to identify which elements they do currently have access to. Additionally, survey participants with an autistic adult relative were asked these same questions on behalf of their relative—what do they need on a day to day basis and what do they currently have access to.

The results indicated these top five needs:

- **Autism-friendly affordable housing**
- **Autism-friendly dentist**
- **Autism-friendly social services**
- **Social belonging and friendship**
- **Recreation opportunities**

Survey respondents were asked which Community Elements they had access to (SEE FIG 5.1). The elements that were reported as most accessible to respondents were social services and an autism-friendly dentist; however, two-thirds indicated that they did not have access to these. Access to the rest of the Community Elements ranked below 20%. This means that even the most accessible Community Elements are only accessible to a third of adults with autism in Utah.

Therefore the data show that the top unmet needs are housing, social belonging and friendship, and recreation opportunities. However, even though access to a dentist and social services are ranked as the top two areas of autism friendliness, the rates of access are still less than 50%, and these areas should still be heavily considered.

ELEMENTS OF COMMUNITY

Q: **WHAT DO YOU CURRENTLY NEED?**

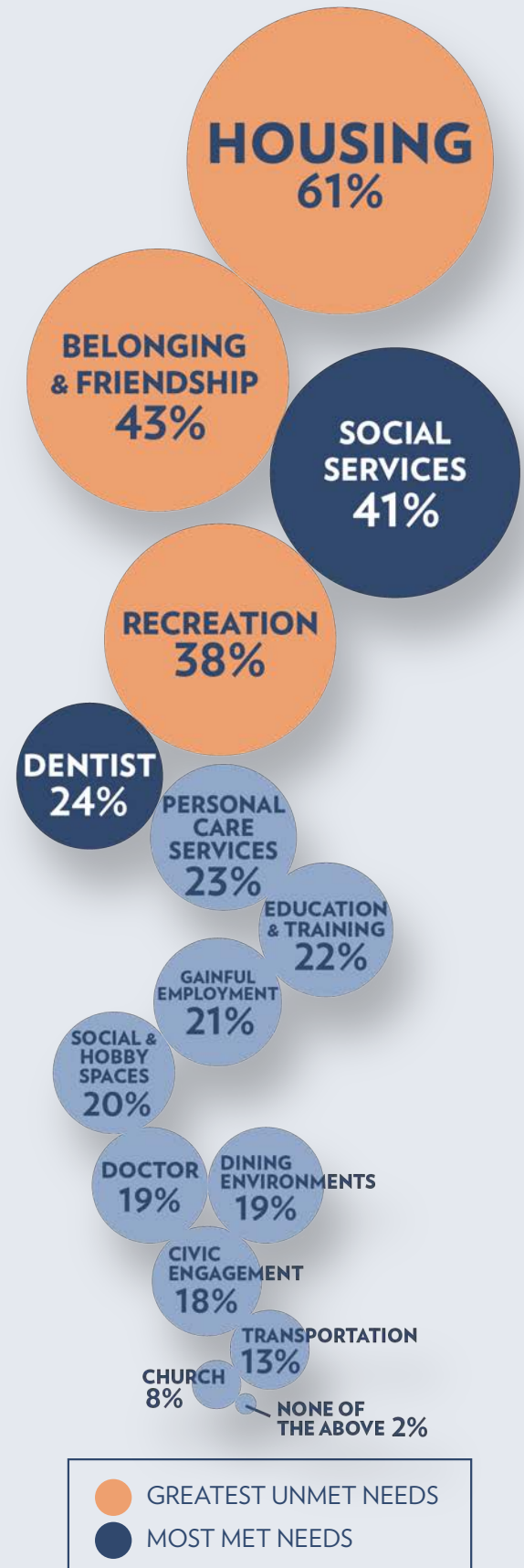


FIGURE 5.1

HOUSING

The population boom has created a housing crisis in Utah that is affecting areas both rural and urban. It is not surprising that survey responses indicated housing is too expensive. The data also showed that most respondents are currently living in single-family homes, often because they are living with family caregivers. This is in contrast to preliminary data from the 2023 Salt Lake Valley Neuro-Inclusive Housing Market Analysis showing a strong preference for apartments and condos over single family homes. Further research is necessary to more clearly understand the needs of autistic adults and their families in regions across the state.

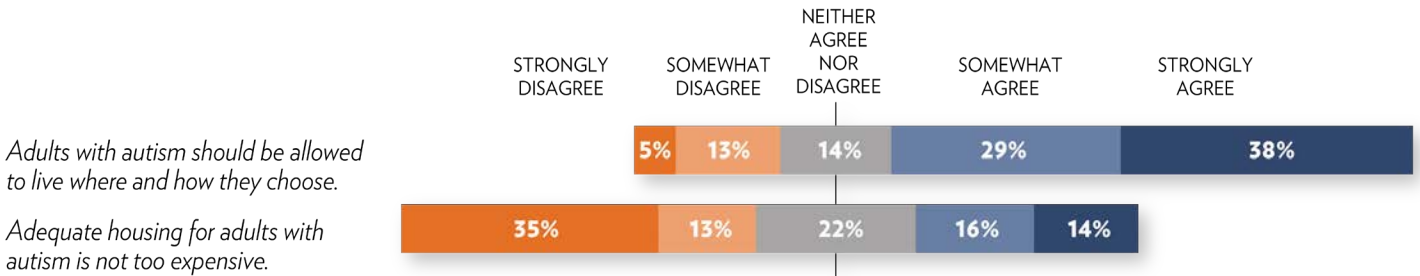


FIGURE 5.2

Housing concerns go beyond expense and availability. Families are sometimes displaced due to lack of formal supports in rural areas, or due to bullying or lack of social inclusion. One family with an autistic young adult at college and an emerging adult completing high school has experienced a split, with one parent and child moving from their hometown to a more urban area to access treatment and support after their child was bullied so severely she attempted suicide.

“Our autistic child finished the school year at a counseling center in Provo, in a day treatment for depression. She’s found connection there, she’s doing after-school stuff there. And it’s positive. But it meant that we rented an apartment in Provo. So we’re set up in two places, maintaining the cost of two households and the drives back and forth [for work]. So the financial cost, counseling, the drive, the gas - I mean, the treatment has put a strain on things, paying the rent on top of the mortgage.”

- Andrew and Lia, interview participants

“It was a real eye opener for me when I was contacted by a woman who works at a facility for older people - there was a mom who lived in the facility, and she passed away, but she had an older son. And the son, he’s autistic, he was in his 50s. So this woman reached out, saying ‘I don’t know what to do for him. He doesn’t qualify to be in this facility, but I don’t know where else he can go. And he basically has very little income.’ So I have no idea. Where do older autistic people with no parents - where do they go? That experience made me realize there’s this huge need for this demographic. It was terrifying, because I thought, that could be my son. That could be my son if something happens to me.”

- Stacy, interview participant

“My dream home? I think for me, I just would like a simple mini-house with a kitchen, a living room space, small but big enough to have three or four guests over, and one bedroom...and small, because I don’t want it to cost too much. And I also just want less to clean. It would be nice to be within a 20 minute walk to a grocery store, because I’m used to walking a considerable distance...the housing situation is hard for everyone right now. And it’s kind of to the point where you either have to be married, or you have to have someone who is just like you and needs to pair up to make it affordable.”

- Terrence, interview participant

PUBLIC SUPPORTS

Over 60% of responses indicated at least a moderate level of awareness of their local Public Housing Authority's housing resources for people with autism (FIG 5.3). However, another 20% indicated zero awareness. Data were also collected on public supports like knowledge of the local general plan and perception of first responders. Survey participants were asked whether their municipality's general plan addresses the needs of people with autism. Only 18% said yes with the remaining selecting "No," "Unsure" or "I don't know what a general plan is."

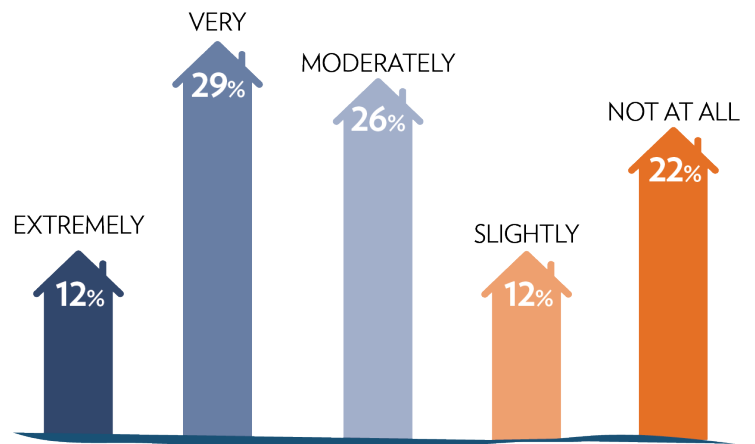


FIGURE 5.3

AWARENESS OF GENERAL PLAN

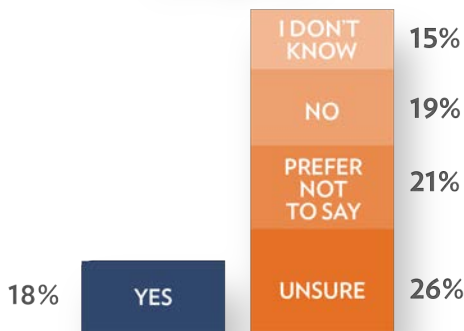
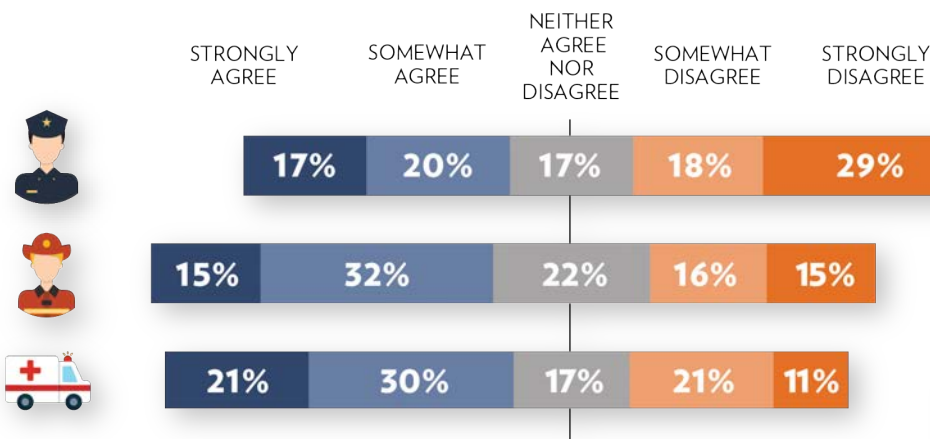


FIGURE 5.4

FAMILIARITY WITH PUBLIC HOUSING RESOURCES

How familiar are you with your local Public Housing Authority's housing resources for people with autism?

Confidence in the fire department and emergency medical services to attend appropriately to the needs of adults with autism is high, contrasting with low confidence in the police (SEE FIG 5.5). These data points, combined with the housing crisis of inadequate affordable housing options may be areas for local leaders and community members to discuss in greater detail.



"Most master plans incorporate ADA compliance, however, they often neglect sensory over-stimulation in those plans."

- Survey participant



FIGURE 5.5

TRUST IN FIRST RESPONDERS

I trust my community's first responders to appropriately attend to the needs of people with autism.



How We Feel

Survey responses from adults with autism indicate a strong sense of support from family and friends (FIG 5.6). This represents a solid emotional and social base from which adults with autism may begin to broaden their self-expression in their community of choice. This is only possible, however, if the larger community curates and designs spaces and events where autistic adults can feel regulated, safe, and included. (SEE COMMUNITY EVENT TOOLKIT, PG 29)

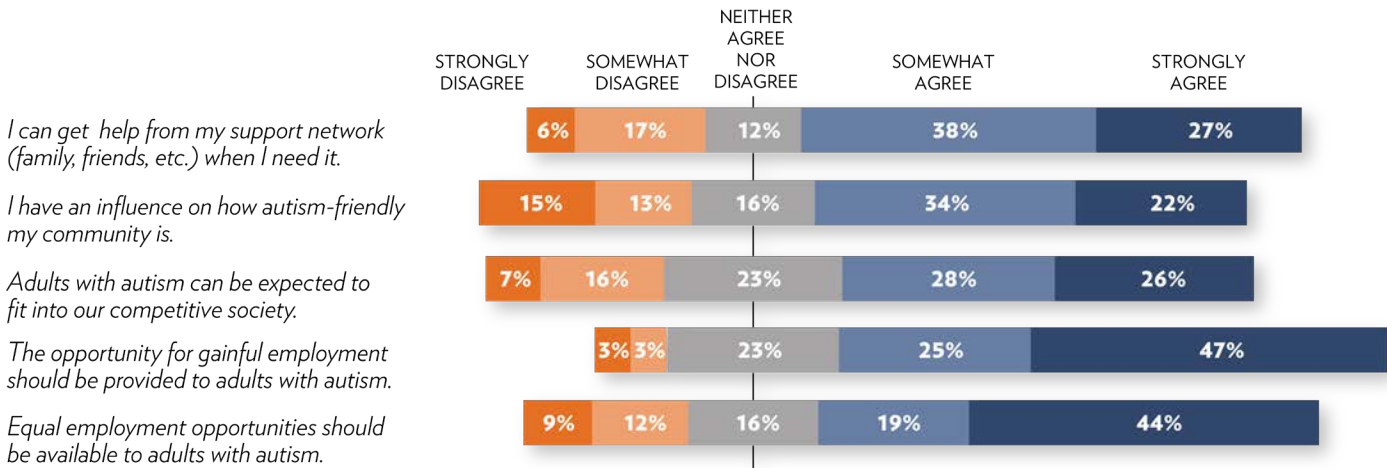


FIGURE 5.6

BELONGING, FRIENDSHIP & RECREATION

The majority of autistic adults, their families, and community leaders appear to be receptive and ready for a more integrated and inclusive way of living. Fifty-two percent of those surveyed agreed with this statement: “I have an influence over how autism-friendly my community is” and 54% agreed with the statement “Adults with autism can be expected to fit into our competitive society.” Questions related to job opportunities and housing autonomy also showed high levels of agreement (SEE FIG 5.6). The data reflect an eagerness of autistic adults and their families as well as community leaders to reach the IACC’s previously mentioned goal that **“All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, satisfying relationships, and meaningful access to services and supports.”**²¹ Moreover, the majority of survey participants feel empowered to make this a reality.

“There are some resources for people with disabilities, but I wish there were more inclusive, integrated opportunities for people with disabilities including integrated, scatter site housing and integrated employment. Too many options for people with disabilities are segregated and disability-specific.”
- Survey participant

“The local community theater openly says they want people with disabilities to audition. I feel accepted and safe at the store Gamer’s Asylum. People don’t comment much when I wear headphones in otherwise ‘inappropriate’ situations like at a restaurant.”
- Survey participant

“One of the things I’ve learned is, you need to just be bold with people. If you feel like they’re kind of degrading you, don’t be offended, just say, ‘Hey, you don’t need to talk to me like I’m a seven year old kid, okay?’ And most of the time, they’ll say, ‘Oh, sorry, I didn’t realize I was doing that.’”
- Terrence, interview participant

“I’ve only made a couple of attempts to advocate for myself by communicating to other people, ‘Hey, I have autism, and it affects my sensory experience and my social interactions in these ways.’ It did not go over very well. So I just stopped. I don’t want to bother with this, because people don’t understand. And the way they respond is just really insulting and just awful.”
- Sue, interview participant

How We Learn

Ongoing learning about the autism spectrum is a critical aspect of establishing autism-friendly communities. There is a lot of work still to be done in dispelling myths about people with autism and understanding the talents and skills that autistic individuals can contribute to a vibrant society.

According to the data, autistic adults and their families across the state are seeking out information on autism regularly and have a high level of confidence that they will find what they're looking for (FIG 5.8). Those in the autism community are keeping themselves well-informed and therefore their knowledge and their voices can be tremendous assets on state, regional and local levels as policies and plans for inclusive communities are being developed.

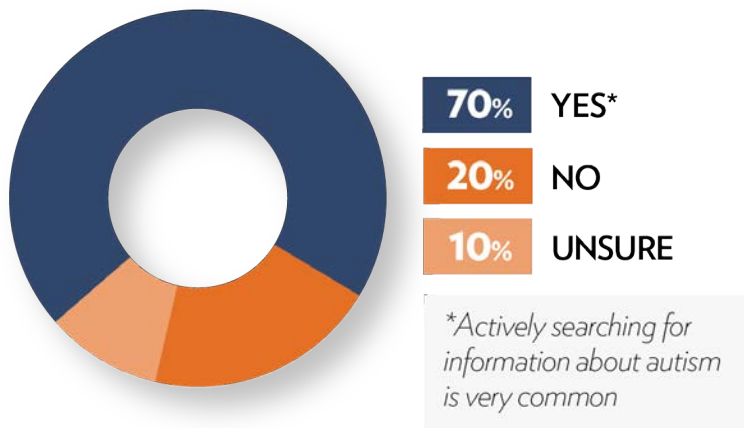


FIGURE 5.7

ACTIVE INFO SEARCH

Have you actively searched for information about autism or information featuring people with autism?



Photo: Gemma Chua-Tran - Unsplash

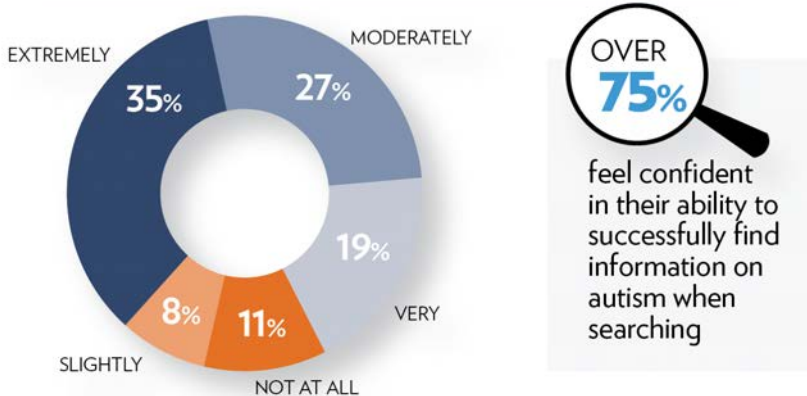


FIGURE 5.8

MEDIA CONFIDENCE LEVEL

If you needed to find information about autism or support for people with autism, how confident do you feel that you'd be able to find what you're looking for?

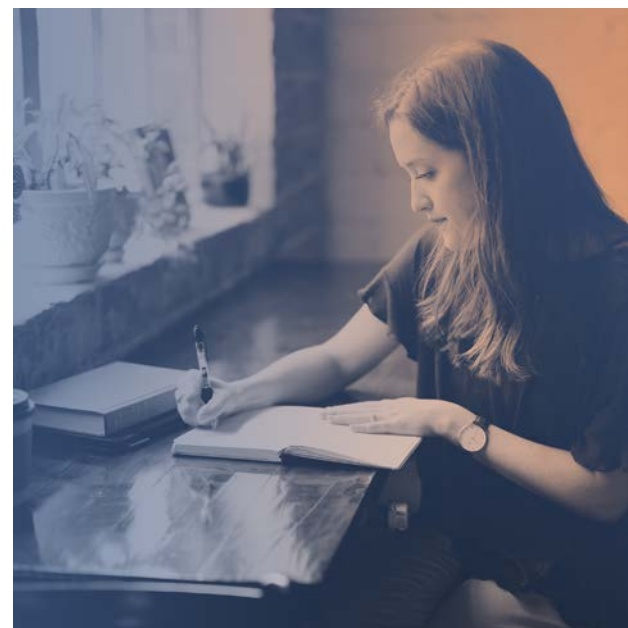
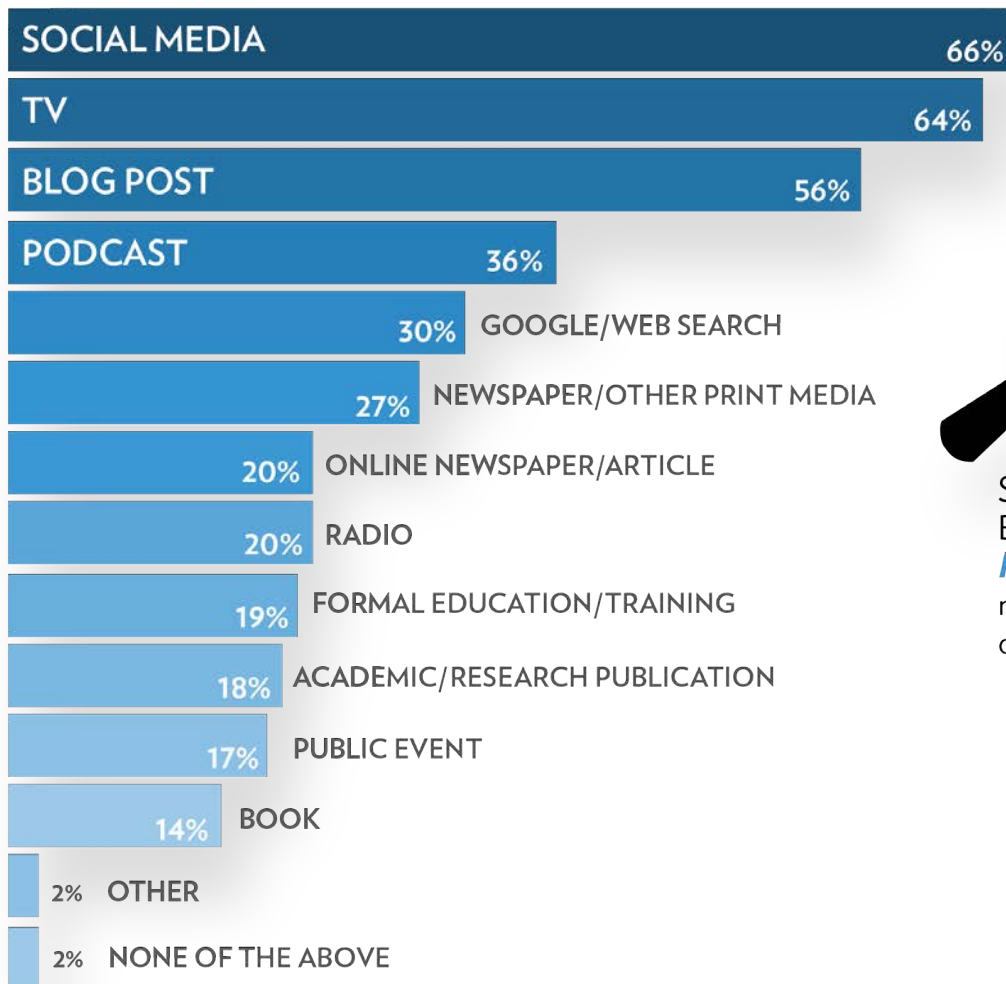


Photo: Hannah Olinger - Unsplash



SOCIAL MEDIA, TV & BLOG POSTS are the **MOST** accessed media for information on autism

*Does not total 100% because respondents could choose more than one

FIGURE 5.9

MOST COMMONLY ACCESSED MEDIA

In the last six months, which of the following media have you read or watched related to autism or featuring people with autism?

It seems that Utah’s communities are ready to connect with neighbors experiencing autism, listen deeply, and engage with useful, actionable information about autism and the autistic lived experience. Engaging in this way will begin the critical process of dismantling the deeply rooted and damaging stigmas around autism. (SEE DIALOGUE TOOLKIT, PG 31)

“Maybe the city or local governments could sponsor a series of seminars and just have some speakers come in to talk about hiring practices, or creating a [neuro]diverse workforce. I think those are things that we can do. I think we can probably do some of that with the resources that we have, because we have some employee assistance programs that we can not just use for city employees, we can use them for other businesses. And so that might be a way we could get that expertise out to those who hire.”
 - Tawny, interview participant

“We don’t need artificial harmony here. What we’re trying to do is to be productive, and how we’re helping each other learn, grow, understand, work together better. What that generally means is encouraging people to have the difficult conversations that they might feel reluctant to have.”
 - Dan, interview participant

CALL TO ACTION

Change happens when enough individuals decide that the current situation is no longer acceptable. It is our responsibility as a community and a society to ensure that everyone's needs are being met and that every person has the resources they need to thrive and contribute. This study demonstrates that while many of autistic Utahns' basic needs are being met, there are significant gaps that we as a community can address in many areas. Our goal is to create neuro-inclusive communities where thriving is the default, not the exception. In order to do this, we need to act on several different levels. This call to action is for each of us. Wherever we are in Utah, whatever roles we fulfill in our families, in our communities, our workplaces, our churches, there are things that we can start doing right now to begin making Utah better.

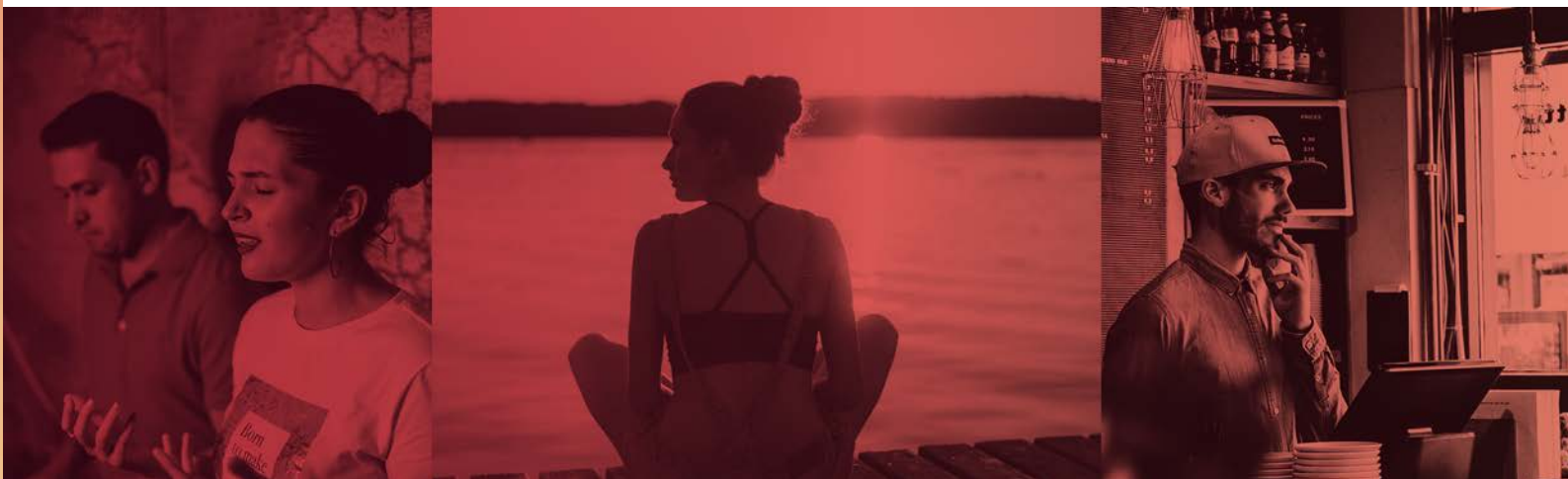
Growing our communities in more neuro-inclusive ways is not only the ethical thing to do, it enriches our state and makes it better for everyone. Our thriving economy, our vibrant cultural organizations, and our local and state governments all work best when everyone is able to participate fully.

The interrelated needs cannot be sustainably met by the efforts of the autistic adult or the autistic community alone. It involves the full community, neurodivergent and neurotypical Utahns alike, working together. Community change begins with shifting attitudes, dismantling stigma around autism and other intellectual/developmental disabilities, and deepening knowledge.

As Utah communities and leaders consider how to harness this data into creating positive change, it is helpful to identify the optimal environments and situations to begin this work. The data collected regarding frequency and location of interactions between autistic adults and community leaders indicates that most interactions are happening at community events. This demonstrates an opportunity for event planners, as well as those attending these events, to create spaces for listening and connecting (SEE COMMUNITY EVENT TOOLKIT, PG 29). Next to community events, the other two most common settings for interactions between leaders and the autistic community were work and church.

As a State

It is important to acknowledge that the state of Utah is made up of individual people, each of whom can take action in several key ways. It is our hope that the state of Utah will continue to implement policies and enact legislation to support opportunities for autistic adults and individuals with intellectual/developmental disabilities (I/DD) to thrive. We want to commend Utah for making progress in key areas, such as with the Utah Autism Initiative, a multi-sector collaborative



project overseen by the Department of Health and Human Services, and the work done by agencies such as the Utah Parent Center and the Utah Developmental Disabilities Council.

Leaders in state government, state agencies, and state boards can cultivate a philosophy of continuing personal education and improvement in regards to autism. Learning is a powerful tool for inclusion and acceptance, and if you are in a position of leadership within the state of Utah, we call on you to educate yourself about autism. We also call on you to improve existing policies, which includes removing policy barriers that prevent those in need of social safety nets from finding them. Critical to this work is deliberately seeking out and amplifying the feedback of autistic adults, engaging in deep listening to learn from those lived experiences, and thoughtfully prioritizing the solutions identified.

Likewise, we call on **state leaders** to continue to diversify governing boards, oversight committees, and all public bodies to include autistic adults with seats at the tables of power. Furthermore, we hope that in addition to increasing representation, the structures and institutional norms those boards, committees, and public bodies operate within are examined and made more neuro-inclusive to allow not just for a seat, but for full, self-determined participation.

"We have a lot of kind people, but there are very limited resources in the rural remote area that we live."

-Survey participant

We also call on **state leaders** to allocate adequate funding for individuals to be able to access social support services and housing, and to improve infrastructure and incentives so that Utahns can access those services particularly in rural and remote areas of the state.

To this end, AA21 Utah is currently conducting a series of housing market analysis studies throughout the state to help guide decision makers as they work alongside the private sector to fulfill the demand for neuro-inclusive housing. We invite state leaders to continue engaging with [Neuro-Inclusive Housing Utah](#), to read the publications, use the toolkits provided, and participate in ongoing conversations and symposia.

Finally, we call upon **state leaders** to be vocal advocates for autistic adults. Make it known that you will not tolerate ableism, that you know the inherent value and dignity of all Utahns, and that you will lend your voice to the voices of self-advocates as they seek to create a more just and accessible state.

"I would love to see actual autistic voices showcased and amplified. Seeing billboards and campaigns featuring young boys and autism moms, or conflating autism with visible and learning disabilities, makes me feel that I, an AFAB (assigned female at birth) adult, don't belong in the autistic community despite my diagnosis and support needs. Adults, girls and women, and POC are so often ignored when discussing autism, as are individuals with Level I and II support needs."

-Survey participant



As a Region

Utah's diverse regional landscapes reflect the diversity of communities in our state. Each region within Utah has unique assets to help meet the needs identified in the AA21 Utah study. It is our hope that each region of the state will step up to create more neuro-inclusive communities. **Regional and local health departments, county, city, and town governments, business leaders, nonprofit leaders, and public servants at all levels** have the opportunity to build upon their existing community assets.

"Yeah, we're having little wins here and there, but it just needs to be happening on a bigger scale. And I think it needs to be happening with the implementation of our city leaders. [...] As someone who has been frustrated over the years and scared for what my son's future looks like, I just wish I felt like there was more investment from the people who could really help push things and make a difference."

- Stacy, interview participant

We commend the many organizations already engaged in this work such as Columbus Community Center, the Autism Council of Utah, ScenicView Academy, the universities and colleges in Utah, and the many people who are often volunteering their time to step into the gap. We hope that more regional leaders will join these exemplary organizations in promoting high quality information about autism to be published and shared in the effort to continue de-stigmatizing autism. We call upon you to help educate the public on local general plans and specifically invite engagement from the local autistic community in shaping those plans and determining local priorities.

We hope that **Chambers of Commerce throughout Utah** will incentivize local businesses to create inclusive professional environments by offering professional development and learning opportunities to help maximize the available workforce through inclusive hiring and retention practices. We call on **businesses and private sector leaders** to commit to disability inclusion in diversity, equity, and inclusion initiatives.

"I run a software company, and we hire a lot of people, a lot of different backgrounds, and in some areas that we hire it tends to be more neurodiverse. It all starts from something around understanding, respect, and commitment to develop an understanding of this population. We will commit to treat people in this community with deep respect. And then we make a commitment to have workplaces that are actually accommodating. It's a little bit hard to track because 'accommodating' means different things, and we have to do the jobs that move things forward. But having a commitment means you're creatively looking for those ways."

- Dan, interview participant



Photo: Roman Kraft- Unsplash

We call on Utah’s **public safety officials and police forces** to continue educating officers about autism in an ongoing effort to ensure the safety of all members of our communities. We commend the work currently being undertaken by public safety departments throughout the state to provide a minimum of three hours of training on autism, and we call upon each **public safety group** to continue learning. We have heard heartening anecdotes about the difference this training is already making in the lives of autistic individuals and their families.

At the regional level, AA21 Utah will be holding a series of meetings for **autistic adults and community leaders** to come together to address local needs and opportunities. Our study data indicate that infrequent interactions are happening between leaders and the autistic community, and we’d like those interactions to continue to increase in frequency and depth. (SEE FIG 6.1) We invite each of you to join us in listening and building together. We hope you will also use the toolkits in this report within your spheres of influence. Regional and local changes are perhaps some of the most impactful ways to improve our communities.

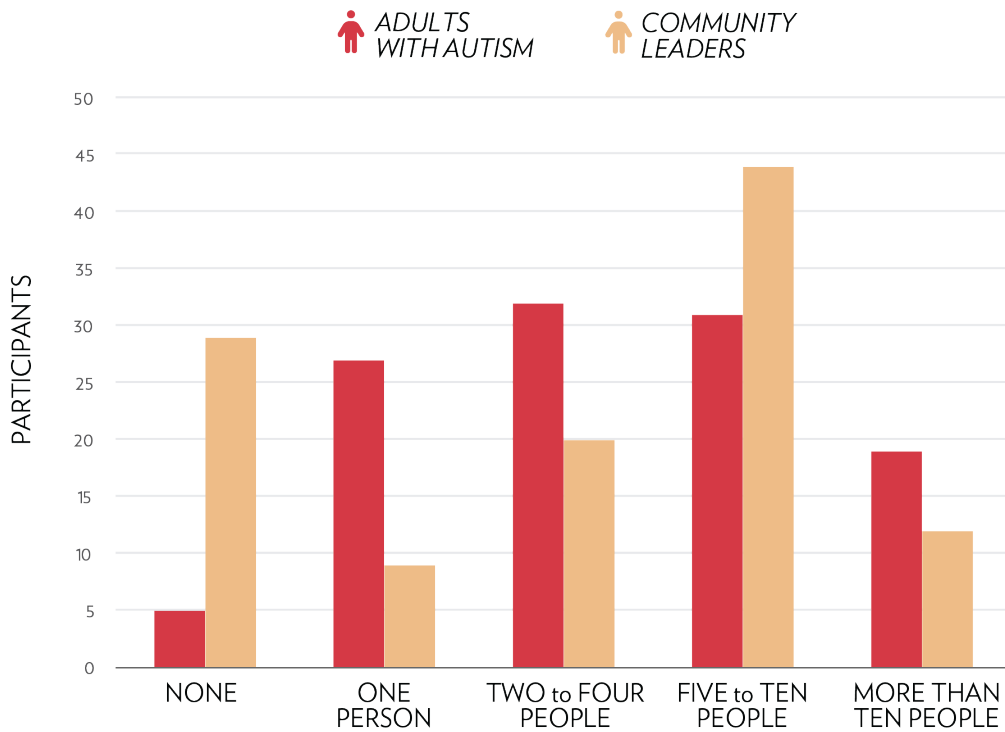


FIGURE 6.1

INTERACTIONS BETWEEN LEADERS & ADULTS WITH AUTISM

How many adults on the autism spectrum/community leaders have you interacted with in the last six months?

*“We definitely need more housing options!
And more awareness from employers about how to support autistic employees,
and what benefits autistic employees can bring to their businesses.”*

- Survey participant

As a Neighborhood

Utahns are known for our friendliness and community spirit, and that starts within our neighborhoods and local communities. Although it may seem daunting, there are so many things that **each of us** can do within our neighborhoods, congregations, and social networks to help make our communities more neuro-inclusive.

We call on **neurotypical Utahns** to engage in continuous personal education about autism, and to share what you are learning. Talk about autism acceptance, celebrate the accomplishments and talents of autistic people in your lives just as much as anyone else's, and teach the next generation principles of inclusion. These actions are needed in order to build a truly neuro-inclusive community. We hope you will use the Dialogue Toolkit to prepare for transformative conversations, and that you will join the collective voice of advocacy for our neurodivergent neighbors.

"Young adults with autism have a hard time finding social activities that are age appropriate and serve their needs as an adult as opposed to a child. Spaces like a bar or social gathering space where sports are played that have 'quiet' rooms or allow for spacing so that they don't feel crowded or rushed."

- Survey participant

"The way I like to put it is I don't want to be over-protected. I want to learn and grow with you guys. You think about the drawing about rock climbing, and there's the person on top of the mountain helping pull the guy up. I'm the rock climber; help me reach greater heights with you. But don't just protect me and care for my safety. Show me how to be well and functional and independent; show me the way."

- Terrence, interview participant

This report includes toolkits for both dialogue and events, and we hope they will be useful to you as you are working on neuro-inclusive community events. We encourage you to join in regional meetings and conversations. Recognize your individual power as a resident of Utah to promote and enhance knowledge and create local change. We call on each of you to create more opportunities for social belonging and friendship to occur in neighborhoods, at community gatherings, in churches, and within your local networks.

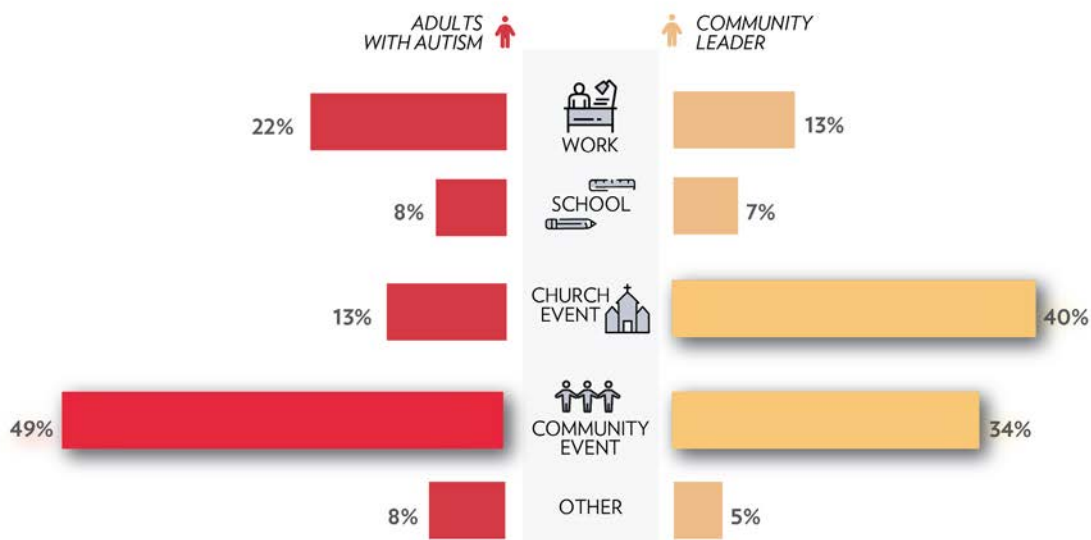


FIGURE 6.2

LOCATION OF INTERACTIONS WITH LEADERS/ADULTS WITH AUTISM

Where have you interacted with a community leader/person with autism in the last six months?

STUDY LIMITATIONS

The AA21 Utah study researchers acknowledge that, as with all research, this study is subject to certain limitations. The limited sample size means that the data in this study do not necessarily represent the experiences of the entire autistic population in Utah. They should be used as a starting point for action rather than regarded as definitive. Additionally, the demographics of the participant sample overrepresented certain races and ethnicities and underrepresented others. White respondents were overrepresented in comparison to the general population. Black respondents and Native American respondents were also overrepresented in our survey data. Latinx respondents, however, were underrepresented, as were Asian and Pacific Islander respondents. Additionally, due to the nature of the online survey, autistic adults who were in a legal guardianship were not eligible to participate. Adults with autism who do not have reciprocal or spoken language abilities were also unable to participate in the interview process. Finally, the AA21 Utah research team did not conduct statistical analyses on the data. Future research should work with community members, advocates, and Institutional Review Boards to find ethical and participatory ways to include autistic adults in guardianships in the planning and execution of research, including both surveys and interviews. In addition to enhanced accessibility measures, future research should also focus on increasing the sample size and demographic representation of study participants.



TOOLS FOR IMPLEMENTATION

These toolkits are designed to help you skillfully engage in making your community a more neuro-inclusive place to live, work, and socialize. Each toolkit includes four key topics of consideration along with several specific tasks to work on. All these toolkits are also available as individual files on the [Madison House Autism Foundation website](#).

COMMUNITY EVENTS

Design events with the needs of autistic attendees in mind

BUSINESS

Embrace the talents and support the needs of your autistic employees while also better serving your autistic customers

DIALOGUE

Create spaces of deep listening as you learn about the lived experience of adults with autism

LEADERS

Be a multiplier by using your platform for autistic voices to be heard

HOUSING

Understand this issue more clearly from the perspective of autistic adults

COMMUNITY EVENTS

TOOLKIT

This toolkit is meant to inform the design of events with the needs of autistic attendees in mind.



PLANNING COMMITTEE

CONSIDER:

How are we ensuring neurodiversity is represented on our committee?

TRY THIS:

Pay a consultant to advise you.

Recruit autistic committee members.

Solicit feedback from attendees using our Dialogue Toolkit.



USER EXPERIENCE

Does our event design create barriers for neurodivergent attendees to participate as fully as they want to?

Consider the sound level of any audio elements.

Design cognitively accessible signage using clear, descriptive, accurate words and pictures.

Consider the venue: sound, lighting, movement of crowds, etc.



SENSORY TOOLS

In what ways does our event accommodate for attendees' sensory sensitivities?

Let attendees choose a color-coded conversation badge (green = I'm ok with conversation, yellow = approach me only if we know each other, red = please don't approach me).

Include and advertise sensory and activity rooms for self-regulation and calming.

Make sensory kits available for all attendees.



DIGITAL PROMOTION

How well are we advertising any neuro-inclusive elements of our event?

On your event website, prominently feature Americans with Disabilities Act (ADA) and neuro-inclusive information.

Implement a pre-event online accessibility request and feedback form.

Create a color-coded event venue map with support areas clearly identified.



For more information, scan this code (point the phone camera at the code, then tap the link that pops up to load the website).



BUSINESS TOOLKIT

This toolkit is designed to help businesses embrace the talents & support the needs of their autistic employees.



PERFORMANCE

CONSIDER:

How does our company's performance depend on being neuro-inclusive?

TRY THIS:

Complete the National Organization on Disability [employment tracker assessment](#) to get your scorecard.

Hold listening sessions using our Dialogue Toolkit.

Tie Senior Leadership bonuses to neuro-inclusive performance metrics.



SOCIALIZING

Do we make social events necessary even if they are not essential to the functions of an employee's job?

Review your company's calendar of events and determine which can be optional.

Communicate clear expectations to all employees and ensure they feel safe not attending optional events.

Consider the goal of the event and whether it can be achieved in a different way.



SENSORY

Have we thought about the sensory elements of our workplace?

Adjust the lighting if possible (i.e. soft dim light).

Eliminate conflicting noise sources.

For in-person meetings, have fidget items available for all attendees.



ABLE ACCOUNTS

Are our benefits packages improving the financial wellness of all our employees?

Partner with [ABLEtoday](#) for a presentation or info session on Achieving a Better Life Experience (ABLE) accounts.

Include ABLE accounts as a part of your Human Resources onboarding process.

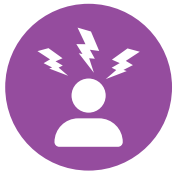
Consider a match for employees with ABLE accounts.

For more information, scan this code (point the phone camera at the code, then tap the link that pops up to load the website).



DIALOGUE TOOLKIT

This toolkit is designed to help neurotypical individuals open up spaces to hear from our autistic friends, family, and colleagues.



MANAGE FIGHT OR FLIGHT

CONSIDER:

How can I physically work with my discomfort around uncertainty that might come up in conversation?

TRY THIS:

Recognize that discomfort is very normal and is often a sign of growth.

Breathe deep into your belly to calm your nervous system.

Engage in movement during dialogue to let your body know it's not in danger. For example, take a walk during a difficult conversation.

Name it - say aloud, "I notice I am uncomfortable" as a way to accept your experience and work with it in a healthy way.



LISTEN DEEPLY

How can I practice deep listening to prepare myself for transformative conversations with autistic individuals?

Listen to understand, not to respond or advise.

Respect every person's unique lived experience.

Pause for five seconds before and after speaking. Silence can be valuable.



CHECK ASSUMPTIONS

What are my assumptions that might create barriers to a trustworthy, neuro-inclusive space?

Ask yourself, "What assumption am I making about this person or situation? Is it true? What evidence do I have?"

Assume positive intent - again and again and again.

Always assume there is a lot you can learn from every interaction.



RETHINK THE RULES

Am I expecting that my conversation partners conform to unspoken neurotypical rules of interaction?

Embrace fidgeting/movement - this can help people calm their nervous systems and self-regulate.

Eye contact can be uncomfortable. Not making eye contact might help your conversation partner focus on what you are saying.

A conversation is like a dance - sometimes you might need to pause or slow down to stay in step together!



For more information, scan this code (point the phone camera at the code, then tap the link that pops up to load the website).



LEADERSHIP TOOLKIT

This toolkit is designed to help leaders learn about the autistic experience and amplify autistic voices.



EDUCATE YOURSELF

CONSIDER:

How curious and humble am I about my understanding of autism?

TRY THIS:

Take a disability inclusion training (e.g. [EARN trainings](#)).

Commit yourself to continually learning more about inclusion.

Diversify your sources of learning to include autistic voices, neurodiverse sources, etc.

Recognize your own unconscious biases around neurodiversity and disability.



AMPLIFY VOICES

How can my position of influence be used to empower people with autism?

Use your platform to build awareness of autistic individuals' work and talents.

Pay autistic people for sharing their unique lived experiences, skills, and knowledge.

Share the microphone as often as possible.



DISMANTLE STIGMA

How committed am I to actively debunking damaging stereotypes about people with autism?

Support the autistic adults in your life as they use their unique strengths and talents regularly.

Call out/call in ableist comments, policies, etc.

Cultivate a growth mindset so you can gracefully accept and respond to feedback regarding inclusivity.



TAKE ACTION

In what ways can I more deeply listen, more wisely speak, and regularly catalyze positive change for the autistic people in my life?

Use the Dialogue Toolkit to host facilitated conversations or listening sessions.

Leverage your power as a leader to make your sphere of influence more neuro-inclusive.

Show up for neurodivergent people in your life - make bold moves to support them and help them thrive.

For more information, scan this code (point the phone camera at the code, then tap the link that pops up to load the website).



HOUSING TOOLKIT

This toolkit is an invitation to join us as we collaborate in addressing this massive, complex problem together.

Housing is the most urgent and most agreed-upon issue facing adults with autism in Utah. AA21 Utah is working to create a state where all individuals have access to neuro-inclusive, accessible, affordable housing. Here are some insights on how you can join us in this collaborative, growing movement.

Precariousness of Unmet Housing Needs

“So you know, sometimes I look at a social interaction, or I look at trying to figure out a complex problem like how to find housing, and I see a saber-toothed Tiger. It feels too big. Me and my mom had this whole conversation last night about, ‘What do I do now? How do I find housing that is affordable?’ I probably can’t afford to not have a roommate, but finding roommates who will be good and who understand my autism is so hard. The housing market is just kind of terrible right now in general. So, it kind of feels impossible, as I’m looking at my lease running out at the end of May. It’s scary.”

- Leo, interview participant

What Does Autism-Friendly Housing Look Like?

It looks like having choices so every person can find their unique place in the world.

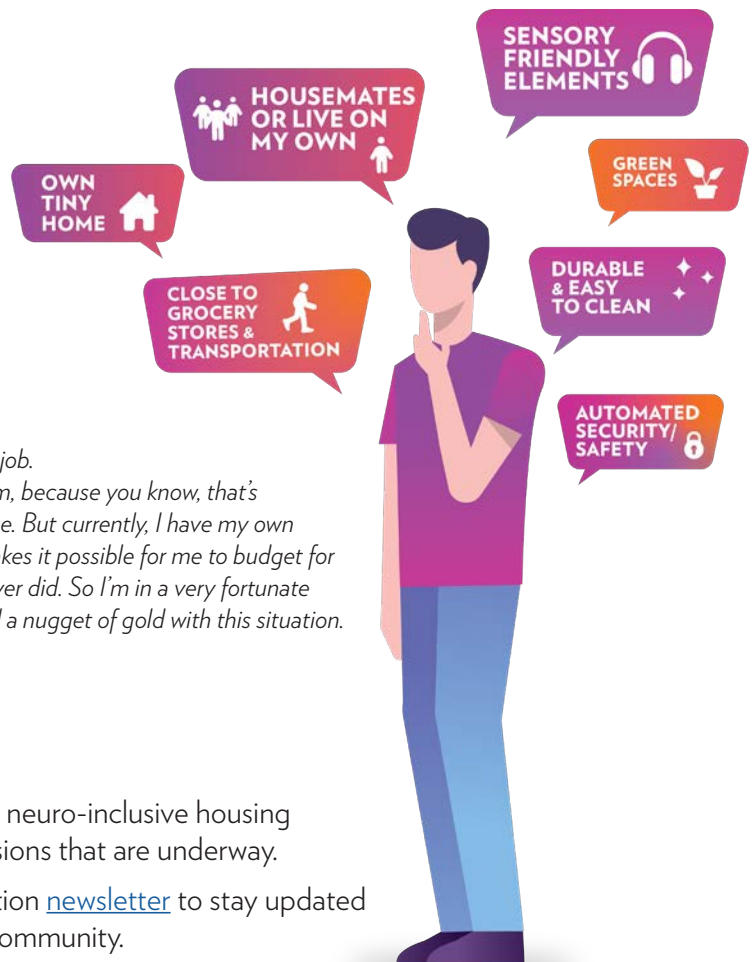
The Security of Having Housing Needs Met

So I’m very lucky now. I get provided an apartment through my job. Before, I was living with roommates, usually two or three of them, because you know, that’s how you can afford it, you have to split costs with somebody else. But currently, I have my own place with its own washer, dryer. My job pays for it all, which makes it possible for me to budget for other things in the future. I’m paying down debts faster than I ever did. So I’m in a very fortunate situation that I wish I could recommend to more people. I found a nugget of gold with this situation.

- Terrence, interview participant

How Can I Get Involved?

- Go to neuroinclusiveutah.org to learn more about neuro-inclusive housing options and the current research and strategy sessions that are underway.
- Subscribe to the Madison House Autism Foundation [newsletter](#) to stay updated on education and research opportunities in your community.
- Learn about your community’s existing general plan and local Public Housing Authority’s resources for autistic adults.



For more information, scan this code (point the phone camera at the code, then tap the link that pops up to load the website).

ACKNOWLEDGMENTS

Study Participants

Special thanks to all those who shared their experiences of autism with us through in-depth interviews and survey responses. We are deeply grateful for your willingness to participate in the effort to create a more neuro-inclusive Utah. Without you, this report would not exist.

Community Partners

This work is also made possible by the tremendous support of our Community Partners, who helped us find people interested in participating in research, as well as shared their own time and knowledge to guide this work.

Active Re-Entry	St. George Interfaith Council
Awesome Autistic Ogden	Techie for Life
Bridge21	The Heron School
Columbus Community Center	United Way of Salt Lake
Digital Respons-Ability	USU Institute for Disability, Research, Policy, and Practice
Nate's Place	Utah Autism Initiative
Neurodiverse UT	Utah Department of Health & Human Services
NextWork	Utah Developmental Disabilities Council
Salt Lake City Public Library System	Utah Office of Homeless Service
Salt Lake Interfaith Roundtable	Utah Parent Center
San Juan School District	Utah Pride Center
Sowing Seeds for Change	Utah Statewide Independent Living Council

Institutional Review Board

We are grateful for the time and expertise of the Department of Health and Human Services Institutional Review Board for the consideration and approval of this study. In particular, we want to thank Dr. Frank Rees, Bruce Larsen, Shauna Ayres, and Dr. Bruce Quaglia for their patience and recommendations.

Autism After 21 Utah Advisory Board Members

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Adrienne J. Scott-Ellis

Founder of Sowing Seeds for Change, Retired Veteran Educator & Parent Advocate

Amy Wadsworth, MS

Director of NextWork Columbus Community Center, Parent Advocate

Camille Bowen

Statewide Housing Program Specialist for Utah Department of Health and Human Services, Parent Advocate



Colin Kingsbury, MS

Program Manager of the Autism Systems Development Program, Utah Department of Health and Human Services

David Allred, PhD

Associate Provost for Innovation, Online Learning, and Faculty Development at Snow College, Parent Advocate

Emily Niehaus

Founder & CEO of The Heron School, Parent Advocate

Ian Summers, PhD

Marketing Scientist at BlueOcean, Exec. Board Member of Utah Developmental Disabilities Council, Self-Advocate

Joey Hanna

Executive Director of Utah Parent Center, Parent Advocate

Matthew Wappett, PhD

Executive Director of USU Institute for Disability Research, Practice, and Policy

Misty Higgins, MEd

Operations Officer of Nate's Place Community Center

Nathan Anderson

Senior Director of Public Affairs for Union Pacific Railroad, Parent Advocate

Stacy Bernal

Diversity, Equity, and Inclusion Manager for Utah Jazz, Founder of Awesome Autistic Ogden, Parent Advocate

Tyler Black, MS

Administrator at Utah Department of Health and Human Services

Whitney Geertsen

Founder of Neurodiverse UT, Self-Advocate

Editor

Ann Carrick, MA

Autism After 21 Utah Project Communications Manager, Madison House Autism Foundation

Dixie Barlow

Freelance Editor

Contributing Researcher

Heather Smith, MSW

Research Intern, Madison House Autism Foundation

Critical Readers

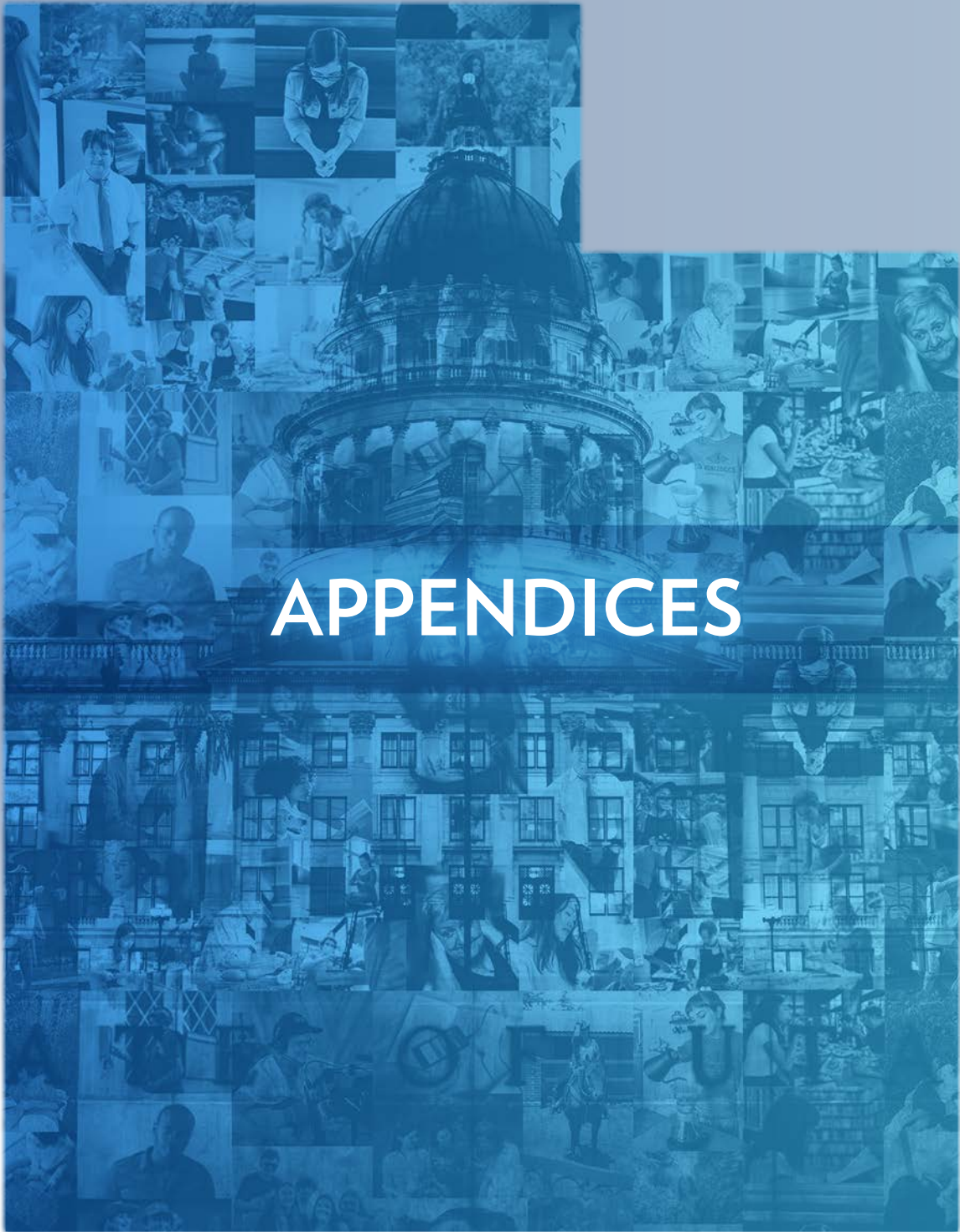
Many thanks to the critical readers for this report, including Whitney Geertsen, Dr. David Allred, Dr. Christopher Manente, Dr. Val Hemming, Dr. Gonzalo Laje, Desiree Kameka Galloway, Mary Eargle, Joey Hanna, Dr. Gregory Prince, and JaLynn Prince. It is all the better for your time and efforts!

Graphic Design

Kristen Suermann

Founder & Graphic Designer, G Cubed Design Co., LLC





APPENDICES



AUTHORS



Sumiko Martinez, PhD

Sumiko is driven by resolute belief in her value system, which can be distilled to one sentence: we each have innate power and should use it to positively impact humanity. With her optimistic stance underpinning dedication to a service-oriented career, she engages communities to effect meaningful changes. She worked in higher education for fifteen years and partnered with K-12 and college educators across Utah to increase equitable access to education. Most recently she joined Madison House Autism Foundation as Director of the Autism After 21 Utah Project, an innovative endeavor to create more neuro-inclusive communities throughout Utah.

Sumiko earned a BA in English from Westminster College and a master's degree and PhD in Communication from the University of Utah. She has been a keynote speaker and invited lecturer at conferences, fundraisers, and events and has served on nonprofit boards in her community. In 2020, she was awarded the Utah Women in Higher Education Network's Special Recognition Award for her work on emergency student financial aid.

She and her husband, Sean, live in Sandy, UT, with their hilarious twin daughters and enjoy motorcycle rides with their bikes, Ginger and Lenore.



Anna Smyth, MS

Anna was diagnosed on the autism spectrum in 2018 after suffering extreme sensory burnout during her success-filled employment at a management consulting firm. In the years since, she has charted her own path of managing her autistic needs and continuing to do the consulting and training work she deeply loves with nonprofits, companies, and government agencies. She has developed needs assessment and program evaluation analytics tools for municipalities and school districts across the state and has also designed and implemented capacity-building curricula. Accordingly, she engages with state legislators, policymakers and business leaders around health, environmental, and education issues affecting Utah's communities.

During several years working abroad as Assistant Director of International Development at a prestigious private university in Guatemala, her team curated educational forums for top policymakers, Nobel Prize winners, and government leaders from around the world. She also worked with leaders of the country's largest businesses and high net worth individuals on transforming the developing world through strategic investments in education.

Anna earned her master's degree in Community Health Promotion and Education from the University of Utah. Her graduate studies, while focused on health interventions, gave her tools like data-driven strategy and systems-thinking to apply to her work more broadly in the social sector. She is insatiably curious and highly engaged in her local community—serving on nonprofit advisory boards and grantmaking committees and founding a TEDx event in Salt Lake City, now in its eleventh year.

REFERENCE GUIDE

Authors' Note:

This reference guide is listed in two parts. The Endnotes section refers to works cited directly in the body of this report. The Complete Bibliography section refers to works the authors reviewed during the process of preparing, executing, and writing about the study as a whole, but are not necessarily cited directly in the body of the report.

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Key Terminology

Autism	A neurological and developmental condition that affects how people interact with others, communicate, learn, and behave.
General Plan	In Utah, a General Plan is a detailed document that a city or town uses to describe what it wants to become and how it will get there. A city's General Plan often gives guidance to City Councils and city staff, but it does not establish law.
Identity-first language	Language that leads with a person's diagnosis: for example, autistic person or autistic adult are both identity-first language.
Intellectual/ Developmental Disability	Anything affecting a person's ability to learn, reason, problem-solve, or perform adaptive behaviors (such as social skills).
Methodology	A systematic approach to collecting and analyzing data for a research study. Since this report uses both qualitative and quantitative data collection and analysis, it is considered a "mixed-methods" study.
Neurodivergent	A person whose neurology or brain wiring is substantially different from the norm. This word is usually used in reference to people with intellectual/developmental disabilities.
Neurodiverse	Describes as group of people that have different neurotype. For example, you could use the word "neurotypical" to refer to a group of people that includes autistic people, neurotypical people, ADHD people, etc.
Neuro-inclusive	A way of creating something that is accessible to people with neurotypical and neurodivergent brains.
Neurotypical	A term that originated in the autistic community which refers to a person with typical neurology; someone who does not have an intellectual/developmental disability.
Person-first language	Language that puts a person before their diagnosis: for example, person with autism or adult with autism.



Pseudonym	A false name chosen by a research participant to help protect their privacy and anonymity.
Qualitative data	Information that typically describes, gives nuance, or explains concepts that are not represented by numbers. Qualitative data is often collected via interviews, observation, focus groups, and other non-numerical processes.
Quantitative data	Information that is represented by numbers, such as things that can be counted, measured, or assigned a numerical value. Quantitative data is often collected via surveys, polls, questionnaires, or other numerical processes.
Self-advocate	A person who actively participates in decisions about their own life. This can look like speaking up for what someone needs, communicating needs through a means other than spoken language, choosing activities, living arrangements, employment, and interests/hobbies according to what the person finds enjoyable.
Support needs	The varied levels and types of help that an autistic person or individual with I/DD might have in order to navigate daily life. Some examples include quieter environments, lighting that is not harsh or flickering, more time to think about things and respond, 24/7 care to keep someone from eloping (running away) into harm's way, or many other things. Support needs are about accessibility in order to function, and are not extra conveniences or luxuries.
Support services	Any of a variety of forms of help that a person with autism or other I/DD might need in order to navigate daily life. Some examples include social skills training; housing equipped with special safety features; another person to help with transportation, job coaching, or other personal needs; or many other things. Some people receive financial support from the government to help pay for the support they need, but many other people do not qualify for benefits, and must choose between paying for support services themselves or going without.



For any inquiries regarding this study, please contact:
Sumiko Martinez, PhD
Director of the AA21 Utah Project
smartinez@madisonhouseautism.org



www.madisonhouseautism.org/AA21-Utah-Reports