Building Neuro-Inclusive Community, Strengthening Mental Health: The Autism After 21 Utah Project

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Cover Page Footnote

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Plain Language Summary

Research shows that strong social bonds are important for health and happiness. However, a lot of people in the U.S. are lonely. It is worse for people with disabilities. Research shows that many autistic adults do not have the social bonds they want and need. They also often face struggles with mental health, being stuck at home, and low support. There is not enough research on autistic adults and their well-being. There is also not enough autism research that includes the voices of autistic adults.

The Autism After 21 Utah study is research focused on autistic adult wellbeing. The research looks at the needs and wants of autistic adults in their local area. Topics include friendship and social belonging, housing, local inclusion, and more. One hundred thirty-three autistic adults, family members, and local leaders in Utah were involved. They filled out a survey. Twenty-four people also volunteered to be interviewed; eight of the interviewees and half of the survey-takers were autistic adults. Friendship and belonging were ranked as the second-greatest need among autistic adults. Forty-three percent said that friendship and belonging were lacking in their lives. This research shows a greater need for inclusion. This report shows some next steps for supporting autistic adults' access to friendship and belonging. Further research is needed to find the best methods for supporting inclusion for autistic adults. This study's team plans to look at ideas in the next steps of the project.

Abstract

Over two decades of research shows strong positive relationships are a consistently powerful indicator of wellbeing and resilience. However, the U.S. Surgeon General notes that loneliness and isolation is an epidemic in the U.S., and that it is exacerbated for individuals with physical and mental disabilities as well as those with isolating economic or environmental situations. A recent review shows that many autistic adults in particular face challenges in finding the connections they want and need. They also often have compounding mental health conditions, such as depression and mental illness, lower incomes, isolating home environments due to a lack of resources, and significantly higher incidence of suicide deaths compared to non-autistic adults. However, there is still very little research on autistic adults, especially research that focuses on their wellbeing and that brings in their first-hand perspective.

The current Autism After 21 Utah (AA21 Utah) study addresses these gaps and reveals some positive news about Utah's readiness to build more neuro-inclusive communities to facilitate friendship and belonging, as well as some challenges that autistic adults are currently struggling with in social relationships and finding resources. The researchers surveyed 133 autistic adults, family members, and community leaders across Utah regarding needs and barriers to greater community inclusion. Twenty-four participants also volunteered to be interviewed for more in-depth perspectives; eight of the interviewees and half of the survey respondents were self-advocates. Friendship and belonging were ranked as the second-greatest unmet need for community inclusion among autistic adults and their families. Forty-three percent of participants indicated that friendship and belonging were lacking from their lives. The AA21 Utah study advocates for a community-based approach to inclusion and suggests strategies for improving autistic adults' access to friendship and belonging. Further research is needed to determine the best methods for ensuring social belonging and friendship for autistic adults and individuals with intellectual/developmental disabilities (I/DD). The AA21 Utah study researchers plan to address these methods in upcoming phases of the project.

Introduction

Decades of research demonstrate strong, positive relationships are key indicators of wellbeing and resilience. Having healthy, trusting bonds with others is associated with many positive outcomes (Donaldson & Donaldson, 2018). Relatedly, researchers have found a sense of social belonging can positively impact achievement, physical and mental health, wellbeing, and even occupational success (Allen et al., 2021). What does this mean for autistic adults, whom society views as voluntarily disconnected from social circles? Is the stereotype of preferred social isolation accurate for this community, thereby warranting investigation into a separate classification of wellbeing for autistic individuals, or are there nuances that have been missed in research, which has historically left out voices of autistic adults themselves?

This article outlines the issue of, and research behind, loneliness and wellbeing in the autism community and provides data into various inclusion needs identified by autistic adults and their family members through the AA21 Utah Project.

Loneliness and (Dis)Connection

Loneliness is something all people experience at some point—a painful, aching emptiness. Loneliness has been variously described as "a form of subjective social isolation…a negative emotional state resulting from a gap between someone's actual and desired social relationships" (Grace et al., 2022, p. 2118); a multidimensional emotional state that can be experienced as intimate, relational, or collective loneliness (Cacioppo et al., 2015); and perhaps most poetically, "as a social pain, something comparable to physical pain, because if physical pain arises to protect us from physical dangers, loneliness would manifest itself as a way to protect us from the danger of remaining isolated" (Yanguas, et al., 2018, p. 302). More recently, the U.S. Surgeon General has deemed loneliness and isolation an epidemic, further exacerbated for individuals with physical and mental disabilities as well as those with isolating economic or environmental situations (Office of the Surgeon General, 2023). Despite the lingering stereotype of individuals on the autism spectrum preferring solitude, research has shown autistic individuals do experience loneliness, sometimes more intensely than their neurotypical peers (Grace et al., 2022). A meta-analysis investigating loneliness in autistic compared to neurotypical individuals found higher levels of loneliness in autistic samples, with a large effect size (Hymas et al., 2022). However, a recent review of literature in this area shows more research is needed for autistic adults. Research so far indicates individual mental health and autism-related challenges, and insufficient environmental inclusion and understanding from others, all contribute to loneliness in autistic adults (Grace et al., 2022).

Indeed, autistic adults are often more isolated from their communities than neurotypical adults. Some self-isolate because they feel misunderstood, excluded, or bullied (Ee et al., 2019). Some have comorbid anxiety, depression, or other challenges that inhibit community participation (Hossain et al., 2020). Additionally, many autistic adults and others with intellectual/developmental disabilities (I/DD) do not have access to inclusive housing and communities (Resnik & Kameka Galloway, 2020). These isolating factors impact not only loneliness but access to overall wellbeing.

Wellbeing in Autistic Adults

While loneliness is a significant risk factor for this population, social support, a sense of belonging, and positive relationships are all significant protective factors (Hedley & Dissanayake, 2017). They buffer the impact of traumas and challenges and can also increase wellbeing (Leader et al., 2021; Tobin et al., 2014). Research on wellbeing, particularly in the field of positive psychology, shows positive and negative experiences should sometimes be thought of as each being on their own spectrum, rather than opposing sides of a single spectrum. Reducing a negative experience does not necessarily increase positive wellbeing. Thriving is sometimes best cultivated through positive actions (Diener et al., 1985). What do these positive actions look like? One of the most effective is building positive relationships, but strong impacts can arise from creating space for positive emotions, meaning, achievement, personal growth, and more (Ryff & Keyes, 1995; Seligman, 2018). Research has shown these positive actions can be cultivated both individually and in communities (Joseph, 2015; Lomas et al., 2014).

Much research within the autism community has focused on correcting maladaptive behaviors, with less focused on whole-person wellbeing and the supports and inclusion needed for autistic adults to thrive. Among this research, there is insufficient representation from the voices of autistic adults with the data collection skewed heavily from parents and/or providers.

Despite these historical research biases, the body of research on autistic wellbeing is growing, enough now to warrant several review publications and meta-analyses. Semistructured interviews with autistic adults has shown several themes for wellbeing that are important to them, many of which align with dimensions of wellbeing found with general populations. This includes topics such as achievement and growth, a sense of support and positive relationships, good health and accommodating living arrangements, engagement with special interests, meaningful work, and more. Themes unique to autistic adults include being in an inclusive culture, viewing their autism as a strength, building more understanding between autistic and non-autistic individuals, and social acceptance of autism (Hwang et al., 2017). In a review of several articles on self-determination, a sense of autonomy was found to be related to quality of life by autistic individuals (Kim, 2019). A review of articles on social participation in autistic adults found informal social support (through support groups, social networks, and social skills groups) contributed to quality of life. Researchers also found quality of life was generally lower for autistic adults than that of neurotypical peers. One of the biggest predictors behind lower quality of life in this group revolved around social relationships and social support (Tobin et al., 2014).

The tie between social support and quality of life also shows the importance of looking at community influences on wellbeing, rather than solely internal factors. As Jansen-van Vuuren and Aldersey (2020) noted in their review of stigma and acceptance toward the I/DD community,

> …although the literature confirms that stigma is still a major barrier to acceptance and inclusion for people with IDD regardless of culture, there appears to be progress in terms of using diverse approaches to support acceptance and belonging. (p. 163)

Wilson et al. (2017) found community-supported social inclusion through volunteer event coordinators had a positive impact on wellbeing for those with intellectual disabilities. Participants reported a sense of belonging, a wider circle of friends, greater confidence, happiness, and positive lifestyle changes. In a review of wellbeing outcomes from community-level interventions and social prescribing pathways supporting autistic adults, researchers found "[s]elf-determination, employment, social support, personal development, coping, self-advocacy, and physical and emotional wellbeing are relevant indicators of quality of life for this population" and community interventions focused on recreational opportunities and social support increased a wealth of wellbeing indicators (Featherstone et al., 2022, p. e622). However, the researchers emphasized that more research is needed, particularly research "includ[ing] people with IDD in identifying and prioritizing interventions that promote belonging within their communities" (Jansen-van Vuuren & Aldersey, 2020, p. 163).

The AA21 Utah Project addresses these gaps in the literature, focusing on wellbeing concerns across the lifespan, beyond those just facing autistic youth, as well as data collection that centers the voices of autistic adults themselves, rather than representatives or caregivers.

This project also moves the dial of autistic adult wellbeing from the individual level to what communities can do to increase wellbeing for their autistic neighbors and employees, particularly from a participatory and inclusive research perspective. Overall, the study seeks to align opportunities for community participation and wellbeing with the strengths of local autistic residents/citizens while simultaneously removing barriers to inclusion through community education, engagement, and action. While this work centers and amplifies the voices of autistic adults, the efforts to create this inclusive, integrated culture can only be accomplished if neurotypical and neurodivergent individuals work together as a united force.

Theoretical Framework

Elements of Community

In the AA21 Utah study, researchers developed a framework to measure the extent to which autistic adults feel sufficient support and access within various key aspects of life. This Elements of Community framework, as it was labeled, was based on two well-established models of well-being and thriving. These two models are Abraham Maslow's Hierarchy of Needs and the Substance Abuse and Mental Health Services Administration (SAMHSA) Eight Dimensions of Wellness (Maslow, 1958; SAMHSA, 2016).

Maslow's Hierarchy of Needs was used as a foundation for the Elements of Community framework because of its strengths-based approach to wellbeing rather than the more common pathologizing lack of wellbeing via deviance, deficiencies, or in this case, disability (Table 1).

Table 1

Mapping Elements of Community to Maslow's Hierarchy of Needs

Maslow's hierarchy category	Elements of community mapping to category
Self-actualization	
Esteem	Civic engagement, volunteer opportunities Recreation Social & hobby spaces
Love & belonging	Belonging & friendship Religious/faith community Autism-friendly dining & social environments
Safety	Healthcare (autism-friendly doctor, dentist, etc.) Education & training Employment Transportation
Physiological	Affordable autism-friendly housing Autism-friendly personal care services (fitness center, hair/nail care, etc.) Affordable social services

SAMHSA's Eight Dimensions of Wellness is a psychosocial model that highlights the important reality that wellbeing extends beyond physical and emotional dimensions, and it also includes financial, occupational, social, spiritual, environmental, and intellectual aspects. Critical to this model is the acknowledgement of the interdependence of these eight dimensions, like Maslow's Hierarchy (Deckers, 2018; Martin, 2020).

SAMHSA's model was originally focused on the wellbeing of an individual, but research has been conducted by leading psychosocial experts extending the model to a sociological level, indicating that the model can be used to identify and evaluate a thriving, neuro-inclusive community (Ryff, 2014; University of Pennsylvania Positive Psychology Center, n.d). Indeed, the National Institutes of Health recommends this type of social ecological framework of health when focusing on community engagement because health is impacted by an individual's interaction with others and their environment (McCloskey et al., 2015).

Methodology

The AA21 Utah study is a mixed-methods study with survey and interview components. The study was designed and executed by both an autistic and a neurotypical researcher, and took a cue from the Interagency Autism Coordinating Committee's (IACC) Lifespan Issues 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. (Interagency Autism Coordinating Committee, 2021, p. 66)

The study assessed the autism-friendliness or neuro-inclusivity of Utah communities. Particular attention was given to cognitively accessible language in both the survey and interview questions.

The study focused on the following research questions, designed to be action-oriented and create baseline data for community interventions during the community engagement phase of the AA21 Utah Project.

- 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?

Survey Methodology

After receiving IRB approval from the Utah Department of Health and Human Services, we recruited survey participants through a network of 24 community partner organizations as well as the AA21 Utah email newsletter. To participate in the survey, respondents needed to meet the following eligibility criteria:

- An adult who self-identifies as autistic or was diagnosed with autism
    - OR the family member of an autistic adult
    - OR a community leader or decision-maker with the ability to make decisions impacting at least 50 people, who have been in their position for at least 6 months
- Not in a legal guardianship
- At least 18 years old
- Living in Utah OR with an autistic adult family member living in Utah

The survey was conducted electronically, and responses were anonymous. A total of 353 responses were received. The data were cleaned to eliminate duplicate responses, spam-bot responses, and incomplete responses, as well as responses that did not meet the eligibility criteria. After data cleaning, 133 survey responses were included in the final analysis. Responses came from 88 different ZIP codes in Utah, with the majority representing the Salt Lake Valley, an urban and suburban area within the state's most densely populated corridor.

Interview Methodology

Interview recruitment was carried out through the same network of partner organizations. Interested potential interviewees contacted the study's lead author, who screened them for eligibility based on the same criteria as above. Participants were invited to choose a pseudonym, and most opted to do so. Interviews were conducted in-person or via Zoom, depending on the participant's preferences. Twenty-four semistructured interviews ranging from 60-90 minutes were conducted (Table 2).

After the interview session, Zoom recordings were separated into audio and visual files. The video files were permanently destroyed to protect confidentiality. Audio files from the interviews were transcribed and inductively coded to identify major themes. In addition to the use of pseudonyms, all family member names and identifying details in this article have been changed to preserve anonymity.

Table 2

Interviewees' Relationship to Autism

Relationship to autism	Number of interviews conducted
Autistic self-advocates	6
Autistic self-advocate and parent of an autistic adult	1
Autistic self-advocate and child of an autistic adult	1
Parent of autistic adult	7
Parent of autistic adult and community leader	2
Sibling of an autistic adult	1
Spouse of an autistic adult	1
Community leader	5
Total Number of Interviews	24

Findings from AA21 Utah Study

Demographics of Respondents

A total of 133 survey responses were included in the analysis. Some survey questions were only asked of participants in a certain role (e.g., caregiver of a person with autism or a community leader). Thus, by design, not all respondents answered every question. Of these 133 responses, 53% identified as autistic adults (with or without a diagnosis) and 39% identified as parents of people with autism; with the remaining 8% identifying as siblings, spouses/partners, children, or extended family members. Responses represented urban, suburban, and rural areas of the state in 20 out of the state's 29 counties. Tables 3-5 give additional demographic information for survey participants.

Table 3

Gender Identification of Survey Participants

Gender identification	Percentage of survey participants
Female	72.5
Male	24.4
Nonbinary	.8
Prefer to self-describe	1.5
Prefer not to say	.8

Table 4

Age of Survey Participants

Age	Percentage of survey participants
18 - 21 years	4.5
22 - 34 years	34.6
35 - 44 years	36.8
45 - 54 years	18.0
55 - 64 years	5.3
65 - 74 years	0.0
75+ years	.8

Table 5

Race/Ethnicity of Survey Participants

Race and ethnicity	Percentage of survey participants
Asian	1.5
Black or African American	7.6
Native American	2.3
Native Hawaiian or Pacific Islander	0.8
White or Caucasian	86.3
Two or more races	0.8
Prefer not to say	0.8

Researchers also asked what level of support was needed; for the autistic adults participating, this was self-reported. For the family members participating, this was an estimate of how much support their autistic family member needed on a weekly basis (Table 6).

Table 6

Estimated Level of Support Self-Reported by Autistic Adults and Family Members

Level of support needed	Percentage of survey participants
No support needed	18.0
Minimal support needed	25.0
Moderate support needed	31.0
Significant daily support needed	26.0

Autism Friendly Community Findings

Survey participants who identified as autistic were asked to select from a list of the Community Elements they currently needed on a day-to-day basis. Additionally, survey participants with an autistic adult relative were asked the same question on behalf of their relative. The results indicated these top five needs: autism-friendly affordable housing, an autism-friendly dentist, autism-friendly social services, social belonging and friendship, and recreation opportunities.

Survey respondents were then asked which of the Community Elements they (or their relative) currently had access to. The three greatest unmet needs among the elements of community were housing (61%), belonging and friendship (43%), and autism-friendly recreation opportunities (38%). For the purposes of this article focusing on mental health for autistic adults, we will concentrate on the second unmet need: belonging and friendship.

Most autistic adults surveyed indicated they felt a strong sense of support from friends and family (Table 7). However, over a third of participants did not feel like their support network was able to help them when they were in need.

Table 7

*Responses to: "I Can Get Help From My Support Network
(Family, Friends, etc.) When I Need It"*

Response	Percentage of survey participants
Strongly agree	27
Somewhat agree	38
Neither agree nor disagree	12
Somewhat disagree	17
Strongly disagree	6

The survey asked several questions around attitudes towards community integration, and overall responses were positive. Fifty-four percent of participants agreed autistic adults can fit into our competitive society; 72% believed gainful employment opportunities should be available to adults with autism, and 63% agreed equal employment opportunities should be available to autistic adults. Finally, 56% of participants agreed they had an influence over how autism-friendly their community was. Taken together, these indicate an interest from autistic adults, their families, and community leaders to work towards a more neuro-inclusive society (Table 8).

It should be noted that although many of the respondents were positive about community integration, there were still some who strongly disagreed. Further research is needed into why people disagree about the availability of equitable employment opportunities.

Table 8

Attitudes Towards Community Integration and Equality (Percent)

Survey question	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Autistic adults can be expected to fit into our competitive society.	26	28	23	16	7
The opportunity for gainful employment should be provided to adults with autism.	47	25	23	3	3
Equal employment opportunities should be available to adults with autism.	44	19	16	12	9
I have an influence on how autism-friendly my community is.	22	34	16	13	15

Themes of Mental Health in Interview Findings

Several themes emerged from individual interviews. This article focuses on themes of mental health, which appeared in 12 out of 24 interviews, community inclusion (12 out of 24 interviews), and friendship and belonging (10 out of 24 interviews). This section aims to amplify the voices of autistic adults and their families who identify struggles with mental health, and in many cases, identify increased access to friendship and belonging and community inclusion as factors that would mitigate some of their negative mental health experiences.

Mental health was a prevalent theme, with many participants mentioning their own, or their autistic family member's, negative experiences with suicidality, depression, anxiety, and social anxiety. Additionally, many drew direct parallels between negative social experiences and mental health struggles. Many participants expressed ambivalence regarding their mental health, social expectations, and to what extent communities should/could be expected to change to be more inclusive.

Mental Health: Struggles and Negative Experiences

Participants' discussions about mental health centered largely on negative rather than positive experiences. Several interviewees mentioned the frequency with which autism co-occurs with mental health conditions: "...it's hard to talk about just autism, too…Jane [our daughter] has autism, the depression, the anxiety" (Lia and Andrew).

Other participants spoke about geographical barriers they encountered while seeking mental health treatment with a doctor who specializes in helping autistic teens and adults.

Leo: I feel like Utah in general doesn't have as many doctors as maybe some other places…. In high school, I [would] have to take the day off school to drive to psychiatrist

appointments with my mom, it would be a day trip.

At times, entire families are displaced from their communities because of the lack of mental health services in rural areas. Lia and Andrew have one college-aged child and one high-school-aged child, both of whom are autistic and identify as queer. As a result, their family has experienced alienation from their very religious community, and their children have experienced extreme bullying that has seriously impacted their mental health.

Lia: We're strongly considering moving to [a different] County and having Andrew commute [to his job in a rural county] to get Iris into a better school situation. Iris was bullied in sixth grade and had a suicide attempt.

Andrew: Yeah. And how much Iris…still struggles with depression. And so Iris's depression we feel is more about connection and if she could find connection we think her depression would be... [gestures hopelessly]. And so how much of her depression is because of her autism, which makes it so that she can't find those connections? And it's just really layered.

Other families discussed the stigma they experienced, even within their own family. Jordan and Ken (who has autism, anxiety, and depression) are a young married, mixed-neurotype couple with two small children. They live close to Jordan's parents but do not have a close relationship with them.

Jordan: [My mother] and Ken's mom both had real struggles with understanding and validating mental health issues in general.

Stigma around autism is compounded by stigma around mental health conditions such as anxiety and depression (Raymaker et al., 2020), leaving autistic adults with such conditions at even more of a disadvantage as they work to stabilize their mental health without the understanding and support of people they should be able to rely on.

Professionals are not immune from this stigmatization, either. Leo, an autistic college senior, related an incident from a creative writing class in which a college professor publicly revealed some negative stereotypical beliefs about autism while giving them feedback on a manuscript of a novel.

Leo: My main character is autistic because I like writing about people like me, I cared a lot about representation. The professor…as we were having that discussion about [how the character], she should be having more distress about this, he kind of went, *Well, we already know, there's something wrong with her* and did this with his head? (gestures to head, spinning finger around in loopy motion implying "crazy").... It genuinely baffles me still. But, you know, it was a really insensitive comment. And, you know, kind of told me that he sees that as there's something wrong with me.

Such disheartening anecdotes were not uncommon, with several participants sharing

experiences with professionals in various capacities beyond educational settings.

Autistic adults also experience microaggressions that contribute to feelings of alienation and isolation. Terrence is an autistic man in his mid-20's living in an urban area, who related this experience of being questioned over the way his non-drivers' state identification card looked.

> **Terrence**: Well, I actually have had one time where I was going to a bar and I showed my state ID, and they're like, *Why is your state ID vertical? Are you a criminal?* And I'm like, *No, I'm a non-driver. I have a disability.* And he was very apologetic very quickly, like, *Oh, I'm sorry, I didn't even know that was a thing. But you look so functional, how can you not drive?* And I'm like *Tourette's syndrome*. And it's just lack of education.

While Terrence's experience didn't result in any physical harm, it is a serious concern for many autistic people and their families, particularly for people of color. Stacy, whose son, Jacob, is in his late teens, related a fear about law enforcement personnel misinterpreting her son's behavior as threatening or criminal.

> **Stacy:** I worry that it takes things like what happened with Linden Cameron [a 13-year-old autistic boy] a couple of years ago, like seeing this very traumatic thing happen where police come out, and they end up shooting this teenager multiple times.

Similarly, Adrienne, whose son, Carter, is in his early 20's and does not use spoken language, hoped if law enforcement ever had an interaction with her son they would recall their training and think:

> So, how is the neurodiverse individual seeing certain incidents, circumstances? Take a minute, how are they perceiving this with the interaction with me [a police officer], as I'm coming with my hand on the gun and giving these commands, how intimidating that is, and how their [the autistic person] reaction is going to be. Think about that, how you're presenting yourself.

Participants expressed a preference for working with mental health professionals whose specialty was autistic patients. Terrence, who experienced anxiety and depression while serving a religious mission, related his frustration with the kind of advice he received from non-specialists.

> **Terrence**: Yeah, that would be counseling, and I hate counseling. I was okay with like, a specialist therapist, but if it's gotten to the point where if anybody comes up and says, *Think positively*, I hate that…During my mission…I was under a lot of stress, I had the worst depression of my life. And the counselors would be like, *Okay, here's a chart to think positively!*…It just upset me after a while because I was doing everything I could.

After returning from his religious mission and graduating college, he noted, "I feel like after that my anxiety was huge. And it got worse with college and resources were hard to come by. Yeah, lots of hyperventilating." However, reflecting on his in-vivo experience with the

interview, Terrence observed his own progress applying the things he learned with his autism-centric therapist: "[I] went to therapy [with an autism specialist], did some really good hard trying to get better at emotions. And I hadn't hyperventilated once [during] this whole thing so I'm very proud of myself."

Sue, a woman who was diagnosed with autism in her mid-30s, had a similar positive experience with a mental health professional. She related an experience when her very successful career in a rigorous field of work was suddenly derailed by a sensory nightmare of a workplace where her requests for accommodations were ignored. Upon being forced to quit a job she loved to preserve her mental and physical health, as well as her life itself, Sue set an appointment with a psychologist whose specialty was teens and adults on the autism spectrum.

> **Sue: …**she had this intake form and I filled it all out and it was basically like, what is your day-to-day experience? And I remember she said, *I don't even need to do a diagnosis, you have autism, it's so obvious you have autism. Everything you reported is just right on the money.* And I remember talking to her and telling her, *I want to die, I can't take any more. And this pressure, and I feel like I'm in prison all day, like there's nowhere for me to go to regulate.* And she was like, *Yes, you know what you need to do, and you do it.* And it was such an interesting experience meeting with her. Her office was amazing. She had shelves up along the ceiling…just full of Legos. And she had all of these different collections of all kinds of stuff, and this whole table full of heavy rocks and fidget toys. And she just was so – it was amazing. It was just, wow. And I just stared at the floor the whole time I talked to her. And I kept telling myself, *Wow, I don't have to feel bad about this, I can just do what feels comfortable. This is crazy, I've never been able to do this. People demand eye contact and stuff.* And so there was sort of this sense of validation and liberation that came from that a little bit.

Friendship and Belonging as Ameliorating Factors

While mental health issues posed unique problems for autistic adults and their families, there were promising indications that increasing friendship and belonging could help mitigate these issues and increase wellbeing. Many of the same interview participants who related difficulties with mental health also had found hope and improved mental wellbeing within reliable friendships and open-minded and inclusive communities.

For some participants, the influence of one or two close friends who were educated about autism and accepting of the needs of autistic adults made a tremendous difference. Sue shared some of the confidence she felt in her friendship with Cassandra, and the knowledge that she could really be herself and take care of her needs without fear of stigmatization.

> **Sue**: …my needs, they vary and they oscillate quickly. But I'm very aware of them. So it'll just be an instance of, *Hey, I just need to lay down for a second.* We're taking a walk outside, and I just need to lay down on my stomach for a second. Or, Can we just stop talking for a minute? Most people are not gonna respond very well, when they're in the

middle of a conversation: Could we just stop talking for a minute, and just sit? That would be very off-putting for most people…And she's [Cassandra] always, *Yeah, sure, that's fine…*I feel like it is because she's just really aware, like she's educated herself.

Other participants' spouse or partner acted as a key influential person who helped them manage their mental health.

Jordan: Yeah, I guess, housing, and mental health and school. So with some of the struggles with the her classes, I helped her in some cases, I was writing letters to her professors on her behalf, you know, on their, their Canvas or whatever to say, Hey, I'm having this anxiety or panic attack, can I come and do a makeup of this test or that sort of thing? And so it was all individually focused to get the help that she needed.

Ken: Oh, yeah. Like, every, every couple months, I go through a "what am I doing with my life" introspection session where I get very depressed and mopey. And then…my husband will come and give me a lecture like, *You're great. You're awesome. And you're still going to achieve your dreams,* but it is cyclical. Yeah.

Influential people who provided pathways to friendship and belonging came out of unexpected contexts as well. Leo, the college student, shared a story about a co-worker from the library who made them feel included and welcomed consistently.

Leo: I do want to briefly mention one of my co-workers…. I have severe social anxiety. And I was really, really shy when I started my job at the library…. And this co-worker kept, you know, inviting me to be part of conversations. And I would feel like, *But, can I really do that?* And so I would stay back and not do that. But she kept just, you know, gently being like, *You know, if you want to come [join in]* and made it clear that I was welcome anytime that I decided that I wanted to. So, when I did finally become comfortable enough to start opening up, I knew that I was still welcome. And that was really, really helpful. To give me the space and the time to acclimate.

In addition to influential people providing friendship and belonging, an overall sense of finding one's community in a larger sense can similarly contribute to wellbeing. Obi-Wan is a man in his late 20s who lives in a rural county in southern Utah. He found the belonging he was seeking through a martial arts class in his community.

Obi-Wan: I was basically stuck in a rut, depressed, semi-suicidal, and just basically needed to change my patterns…. Then I learned that there was this lady who was offering a Tai Chi class, I met her at one of our local gyms and the rest is history.

Obi-Wan previously struggled with finding recreation opportunities that were sensory-friendly, and often felt cut off and excluded from the community by his sensory sensitivities. The martial arts community to which he was welcomed often held classes outdoors or in rooms with natural light rather than fluorescent lights and was a good fit for his needs.

Many different types of communities can provide the friendship and belonging that people crave. This study illustrates that community is not necessarily solely a place-based construct, but rather can be found in many types of gatherings, such as a regular group gathering to play the popular role-playing game Dungeons and Dragons.

> **Jordan:** As far as some of our other community stuff…like our D&D (Dungeons & Dragons) group…. I intentionally kind of held back a lot to try and let her [Ken, Jordan's spouse] be more involved. And I felt like these are people that would really be friends with her. And the last few months, I've been able to just be like, *Hey, I'm gonna stay home with the boy because he's just too grumpy.* And she went with Gwen up there. They played and she found out that yeah, really, I *am* their friend… And so I think that's been really helpful for her to start to see like, *Oh, I really do have some friends.* And…

> **Ken:** …it takes a very long time! (laughs)

Mutual social connection was the key for community in this case. While the D&D group members were not located in the same geographical community, they came together around their interests and provided friendship, belonging, and recreation simultaneously. Ken reflected on how she runs through a mental checklist of things to do during interactions with friends, such as emotionally validating what the other person says and paying attention to facial expressions. She said:

> I feel like conversation is kind of like a pie chart. It's like, I have to make sure for example, I monitor and make sure, *Okay, I've talked about myself for this percentage of the time.* And I need to kind of keep it in this percentage, balance it with how much I talked about the other person.

This attention that Ken pays to social norms of friendship is perhaps indicative of the extra burden that many autistic adults feel they must shoulder if they want to maintain friends, and may be an area in which better understanding of and inclusion for autistic adults could lessen their cognitive load and make more authentic interactions possible.

This active cultivation of the potential for affiliation and friendship is certainly part of the journey to community-building for people—autistic or otherwise. Terrence also commented on the other side of the equation, and the work that his friends invest into their friendships as well.

> **Terrence:** Those [people] who genuinely care and want to be kind people will try to learn and figure out how to make things work. Like my friends, they don't get bothered at all that they have to pick me up to hang out. If they know I'll ride TRAX to the nearest station, it doesn't bother them. But to somebody who does, well guess what? There's plenty of people, there's plenty of fish for you out there, you can go hang out with them.

Friendship and belonging was identified as the second-highest unmet need among participants in the survey, but the interview participants offered stories of hope and resilience through friendship and community inclusion that deserve to be taken seriously. The next section

of this article is action-oriented, with specific things people in a variety of positions can do to help offer friendship and belonging to all members of our community and help to decrease the mental health burden caused by the isolation and marginalization of autistic adults.

Suggestions for the Community

To successfully create neuro-inclusive communities, residents must be committed to ongoing learning about lived autistic experiences and the autism spectrum. Many damaging myths and stereotypes persist when it comes to people with autism, and those must be dismantled to value the full humanity and contributions of autistic adults in our communities.

Participants in the AA21 Utah study regularly seek information on autism and have a high level of confidence in their ability to find the information they need. In addition to having lived experience that must be centered in community development projects, the autism community is well-informed, and their expertise can be an asset to plans for inclusive communities on state, regional, and local levels (Tables 9-11).

Table 9

Responses to: Have You Actively Searched for Information About Autism or Information Featuring People with Autism?

Response	Percentage of survey participants
Yes	70
No	20
Unsure	10

Table 10

Responses to: 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?

Response	Percentage of survey participants
Extremely	35
Very	19
Moderately	27
Slightly	8
Not at all	11

Table 11

Responses to: In the Last Six Months, Which of the Following Media Have You Read or Watched Related to Autism or Featuring People with Autism? (Choose All That Apply)

Media source	Percentage of survey participants
Social media	66
TV	64
Blog post	56
Podcast	36
Google/web search	30
Newspaper/other print media	27
Online newspaper/article	20
Radio	20
Formal education/training	19
Academic/research publication	18
Public event	17
Book	14
Other	2
None of the above	2

The data indicates that Utahns are actively seeking information about autism. We suggest community-building projects include education and awareness communications strategies capitalizing on the places where people are looking for information and amplifying the experiences of autistic adults and their families.

In addition to communications campaigns, research participants had suggestions for other ways to help communities learn more about autism and begin dismantling misunderstandings and stigma that are often additional barriers for autistic adults. Tawny, a community leader, suggested local engagement with the business community as well as civic employees to help provide awareness and education.

> **Tawny:** …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… We have some employee assistance programs that we cannot 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.

Similarly, Dan, the CEO of a prominent tech company and the father of a neurodivergent

child, noted:

> **Dan:** 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.

This openness to learning and discomfort is a positive indicator for the kinds of community change that can lead to neuro-inclusive communities. What follows are suggestions on some ways communities can practice neuro-inclusion that would lead to improved mental health for autistic individuals.

> ***Neuro-Inclusion Practices to Improve Mental Health and Wellbeing.*** Neuro-inclusion is not a panacea, but rather a set of practices and orientations examining our society's design and finding places where it can be improved to be more cognitively accessible. Some practices included in this section require coordinated government efforts on the federal or state levels; many would only require slight modifications to existing processes or community events that would be cost-neutral or require a minimal event of investment, but potentially have a significant impact.

Several of the participants spoke about the importance of belonging in the workplace, both from the perspectives of autistic adults and from the perspectives of community leaders. Jes, a trans man in his early 20s, had previous negative workplace experiences with co-workers who were intolerant of his sensory needs, but has found a job working in a machine shop where he is able to thrive.

> **Jes**: People here are really nice and understanding. It's been really nice…. Well, they're always, you know, watching out for me. You know, they can tell when I'm having a good day, a bad day. They're always checking in. They're always communicating. So, I just kind of vibe pretty well here.

Sue, the woman whose successful career was interrupted by the inflexible working conditions and culture in her previous company, points out:

> **Sue:** I was this perfect example of [someone who just] needed a handful of things…. If I could say, *I need to work from home two days a week, and I need to not have my desk in this spot, I need to have it in that spot…*then I probably could have stayed and I probably would have been a huge asset [to the company] and I would have really enjoyed it. [I could have used]...some of the gifts that I have because of the way my brain is designed.

Several of the business leaders interviewed for the AA21 Utah study indicated an openness to these very types of flexible working conditions that would have enabled talented people like Sue to continue.

> **Dan**: I would like to ask them [autistic employees or advocacy groups] for examples of

ways that we're able to support folks who are on the autism spectrum or not neurotypical in a workplace like ours, especially when…there wasn't much question, by and large, about their ability to do the job…[There is] such a range on the spectrum.

Renee, the CEO of an education-technology company, reflected on how government and businesses could create partnerships to better serve their neurodivergent customers and help them feel a stronger sense of belonging in a variety of settings.

Renee: So, then you get the government to help incentivize. An incentive in the autism community would be something like…reimburs[ing] business staff and giv[ing] extra monetary incentives for volunteering or being involved. But I see that time is another issue that businesses could do as well. And that time could be spent through training to understand those who are neurodiverse…. So that maybe there's [an incentive], *Okay, we'll pay you, we'll pay your staff to actually do this training*, instead of just relying on people's good intentions and taking a half day off to do it.

Terrence also mentioned the idea of a public/private partnership in the medical and healthcare arena that would also be very valuable in the mental health sector.

Terrence: When you're a non-driver…it can be sometimes very difficult to find medical care that accepts your insurance plan and is easily accessible by public transit…it seems like the ones that accept Medicaid are the ones that are in harder to reach areas. From a business standpoint, [it makes sense to say] *We've gotten enough demand, why add this to our list of responsibilities?* And there's no government leaders saying*, Can you be an accessible place? We'll give you an incentive if you do.*

Other participants mentioned small, inexpensive changes to existing events could have a big impact. Talking about their autistic daughter's efforts to be involved in the community, Lia and Andrew discussed the idea of sensory spaces.

Andrew: She'll go to farmers markets sometimes to just go and look around and be around people. So yeah, she'll go, and I think that she would go more often and she'd be able to stay longer if she knew there was a designated place she could go to decompress.

Including sensory spaces, sensory kits, or even signage notifying attendees that sensory accommodations are available would help neurodivergent individuals feel more seen and welcomed at community events.

Study Limitations

This study had a limited sample size of 133 survey participants and 24 interview participants. Participants were primarily concentrated in suburban/urban Salt Lake, Utah, and Davis counties, and, therefore, do not represent rural and remote experiences of autism and community inclusion sufficiently.

White, Black, and American Indian/Native American respondents were overrepresented in comparison to the general population. Latinx/Hispanic respondents were underrepresented, as were Asian and Pacific Islander respondents. Additionally, because of the nature of the online survey, autistic adults in legal guardianship were ineligible because we had no reliable mechanism to obtain consent from their legal guardians.

Adults with autism who do not use reciprocal or spoken language were also unable to participate in the interview process. Potential candidates with intellectual disabilities in addition to autism may not have been able to access the opportunity. Future research should work with community members, advocates, and Institutional Review Boards to find ethical and participatory ways to include these subgroups in the planning and execution of research. Future research should also focus on increasing the sample size and demographic representation of study participants.

Conclusion

The disability community is largely excluded from many conversations about mental health, loneliness, and wellbeing. Even in the 2023 Surgeon General's health advisory on the loneliness epidemic, people with disabilities are only mentioned four times (Office of the Surgeon General, 2023). There is little research on inclusive communities from the perspective of the autism community. This first phase of the AA21 Utah Project worked directly with autistic self-advocates and family members to assess their community-based needs and preferences for health and wellbeing. Overall, the project team found the top three reported needs that were perceived as least accessible were autism-friendly affordable housing, social belonging and friendship, and opportunities for recreation. Given that positive relationships are a core predictor of wellbeing, further collaborative or participatory scholarly research is needed (carried out in conjunction with autistic adults) into how opportunities for friendship and belonging can be cultivated and supported in communities to promote thriving and to evaluate the effectiveness of different types of interventions.

Civic leaders, nonprofits, and community members also have a crucial role in setting the scene for these interventions. The project team recommends several specific undertakings: public awareness campaigns dismantling harmful myths about the autism spectrum, developing systems to engage with the business community to educate employers and neurotypical colleagues about creating a neuro-diverse workplace, and the adoption of sensory-friendly spaces throughout the community are just a few ideas that would help to work towards a more inclusive society that benefits the mental health of autistic adults. Addressing social belonging and loneliness, as well as other dimensions of wellbeing, can provide solutions for both mental health challenges and strengths-based wellness (i.e., whole-person wellbeing). The process and data from this study will serve as a pilot for other states wanting to create more inclusive communities that support whole-person wellbeing.

The next phase of the strengths-based AA21 Utah Project is the pivot point. Working with autistic consultants, the team is implementing a grassroots engagement program with any

community that wants to become more neuro-inclusive. Communities could be as small as a religious congregation or as large as a county. The program is meant to be flexible, to encourage community, build connections, and to continue raising autistic voices while working on priorities for inclusion outlined by the autism community. The project team will be tracking output from these community engagement groups and evaluating whether they result in positive outcomes for autistic adults' inclusion in their communities.

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