







Data Driving a Place in the World for Autistic Adults and Others with Intellectual/Developmental Disabilities



Special thanks to native Utahn JaLynn Prince, Founder & President of Madison House Autism Foundation, mother of an autistic 33-year-old son and visionary of the Autism After 21 Utah Project, of which this housing assessment is an important part.

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The spirit of Utah is uniquely shaped by commitment to family, genuine care for our neighbor and boundless potential for the future. These elements bolster our belief that Utah can and will pave the way for a more inclusive future for every adult with autism and/or intellectual/developmental disabilities (A/I/DD) and the families who love them.

In Utah, one in 40 children is on the autism spectrum. When those children become adults, many face an uncertain future that too often includes isolation, unemployment or underemployment. When aging caregivers die, these challenges are often compounded by sudden displacement from the only community they have ever known. At Madison House Autism Foundation (MHAF), we believe the greatest key to ensuring a different future for these individuals and their families is to support every community's effort to become as inclusive as possible.

Like most Utahns, we believe that the smartest way to invest in a better future is to root those recommendations in data. In May 2021, MHAF launched the first phase of

a statewide community needs assessment study. Our goal was to gather feedback from autistic adults, their families and community leaders on what it would take for Utah's communities to become truly neuro-inclusive.

The first round of data in this study (published in Autism After 21 Utah: First Findings of a Utah Review & Toolkits for Autism Inclusion) confirmed that the number one concern for autistic adults in Utah is housing—surpassing all others by a long shot. With that data in hand, MHAF immediately launched the first of a series of housing market analysis studies to understand what autistic individuals and their families need and want for future residential and support options to effect positive change in the housing market for autistic adults and individuals with I/DD.

We are excited to release the first report in this housing series and are confident that this data will lead to real, actionable items, diverse housing solutions and regulatory improvements in Utah. Our regional strategy workshops with housing and service leaders are a testament to the positive engagement and interest we have seen in this community to date.

None of this would have been possible without the visionary support of the Larry H. & Gail Miller Family Foundation, the Union Pacific Community Ties Grant, the Brent & Bonnie Jean Beesley Foundation, the Williamsen Family Foundation and a



coalition of exceptional partners: Columbus Community Center, the Autism Housing Network, First Place Global Leadership Institute, Neurodiverse Utah, Neuro-Inclusive Housing Solutions, the Utah Department of Health and Human Services, the Utah Parent Center, Utah State University's Institute for Disability Research, Policy & Practice, Valley Behavioral Health and the Adult Ability Center of Lifetime Learning. I offer my heartfelt gratitude to each and every one of these organizations and to the remarkable self-advocates, family advocates and professionals involved in this project for their time and efforts.

Looking ahead, I am excited to continue collaborating with my fellow Utahns, utilizing this data to shape policy, funding opportunities, cultural norms and built environments for more neuro-inclusive housing. I invite anyone to join our coalition at neuroinclusiveutah.org and push for greater access to the fundamental human need for housing. All autistic adults and others with intellectual/developmental disabilities in Utah deserve the same opportunities and to live with self-determination and dignity.

Yours in partnership,

Sumiko Martinez

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

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Without immediate and

urgent action, Utah risks

catastrophic trauma to

thousands of families,

as well as local ecosystems,

if the housing and support

needs of the A/I/DD

population remain invisible

and unmet.

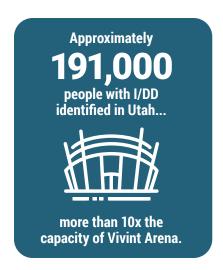


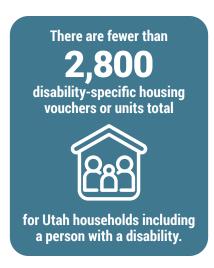
or the past 40 years since the movement to deinstitutionalize this population, families in Utah have been encouraged to care for their loved ones with autism and/ or intellectual/developmental disabilities (A/I/DD)\* in the family home. This has led to greater visibility and higher quality of life for many neurodiverse families, but every state across the nation is now at a critical point in history where these family caregivers are becoming seniors and may be experiencing age-related disabilities themselves. There are also many individuals with A/I/DD who do not prefer to or cannot live in their family home but who face a scarcity of other options. Despite the promising practices, the majority of Utah residents with A/I/DD are living in the family home through adulthood without the support they need to transition. Due to limited housing and support options, this population often lives with family members until a crisis forces a hasty placement or homelessness—

potentially displacing them counties away from their home and community into an environment that may not work for them.

At least 191,000 adults with A/I/DD are identified and call Utah home. Of those, approximately 32,000 are living with a caregiver over the age of 60. A total of 6,348 children or adults with A/I/DD had access to long-term support services (LTSS) in 2022 to help them in their home and in the community across the state of Utah. Only 151 new service recipients were taken off of the waiting list in 2022. This growth rate does not meet the current need and will not meet the impending demand.

The University of Utah Kem C. Gardner Policy Institute reported in April 2023 that "housing instability and homelessness threaten the economic well-being of at least 40,000 **extremely low-income** renter households







in Utah."<sup>3</sup> It reports that the 2023 General Legislative Session passed six housing-related bills and was the most productive session for housing assistance in recent history. They estimate that 18% of Salt Lake County renters, approximately 22,000 households, are very low or extremely low income. Yet, adults with A/I/DD remain statistically invisible in this number due to being housed with family caregivers and unsegmented in the Utah Homeless Management Information System (UHMIS).

Unfortunately, many Utahns with A/I/DD cannot earn a living wage and/or need the assistance of support staff or case managers to either maintain or increase their household and/or employment status. Consequently, without access to these supports or housing, this population is at high risk of potentially traumatic experiences due to displacement and/or homelessness unless they are intentionally considered and included.4 Funding sources to develop supportive housing or offer rental subsidies to persons with disabilities are woefully lacking and are not A/I/DD-specific. Section 811 Supportive Housing for People with Disabilities offers a total of 173 units in 8 properties across Utah, and only 2,041 housing vouchers (rental subsidies) are specifically designated for households including a person with any disability.5.6

As federally mandated by the **Supreme Court** Olmstead Decision, Utah is responsible for providing community-based services and housing options to prevent the institutionalization of adults with A/I/DD.7 Not only is this a moral imperative, it is more fiscally responsible for Utah tax payers. Without access to affordable housing, adults with A/I/DD are left with the choice of homelessness or living in a provider-controlled group home or host home (adult foster care). Medicaid costs to live in a consumer-controlled setting. one's own home, are often significantly less than in a Medicaid-funded, providercontrolled setting or homelessness. A 2021 report estimates homelessness costs \$42,000 to \$104,000 a year per person in a similar size metropolitan area of the West.8 In Utah, the average cost of a group home is \$104,984 per person, per year and a host home is \$82,756 per person, per year.2 A person with low support needs could be served in their own home for less than half the Medicaid costs at an average of \$31,835-\$35,033 a year.2 A person with drop-in support needs could be housed and offered supportive amenities for far less.

The lack of data on current residential needs and preferences, the aging of both individuals with A/I/DD and their caregivers, and the goal of expanding the housing and community options for adults with A/I/DD are the impetus for the Salt Lake Valley Neuro-Inclusive Housing Market Analysis.

#### **Snapshot of Key Findings:**

- The housing needs of adults with A/I/DD are not specified or included in local housing assessments, consolidated plans, or public housing authorities' (PHA) annual reports.
- Approximately 15,000 individuals with A/I/DD in the Salt Lake Valley are at high risk of losing their home and primary caregiver when their family member can no longer support them due to death, their own aging and health concerns, and other economic circumstances.<sup>1,9,10,11</sup>
- Waitlists continue to limit access to essential long-term support services (LTSS) needed to live outside the family home, and current service delivery models do not match preferences identified in this analysis.<sup>12</sup>
- Supportive amenities are highly desired, but there is no funding source for communitybased organizations to offer them.
- Post-secondary transition programs are in demand and exist in Utah, but are only available to private-pay families due to lack of public funding options.
- Individuals and families seek homeownership options, but guidance and tools are needed to help them invest in long-term housing stability and supports. This may include bequeathed homes, the addition of an accessory dwelling unit (ADU) or unit purchase from existing housing stock.
- Neuro-inclusive housing is in demand, but only 35% of families can afford market-rate housing costs. There is not a funding mechanism for affordable, neuro-inclusive housing development.
- Neurodivergent adults are disproportionately experiencing homelessness.

Research into **social determinants of health** (**SDOH**) demonstrates that health care costs are higher when individuals are in unstable housing, lack access to long-term support services, and/or experience loneliness. Adults with A/I/DD are at increased health risks due to additional challenges connecting with individuals outside of their biological family, lower educational attainment, and/or being un- or under-employed.<sup>13</sup> A holistic approach is required to address these barriers to stable housing and optimal health care.

The heart of the state of Utah is firmly grounded in family health and prosperity. Without immediate and urgent action, Utah risks catastrophic trauma to thousands of families, as well as local ecosystems, if the needs of the A/I/DD population remain invisible and unmet.

This Housing Market Analysis demonstrates the data and actionable direction for launching a new wave of housing options so that every person with A/I/DD can find their place in the world.

"Like Maslow's hierarchy

of needs, if you don't have

shelter or are insecure with

employment and access

to basic things, you won't

be able to find a social

group, pursue your

hobbies or learn

new things."

Leo, Autism After 21 Utah
 Project Self-Advocate
 Interview Participant



"Landlords play an important role

in the community and the housing

choice voucher (HCV) program.

**HUD** data indicates the number of

landlords accepting vouchers has

decreased over the past decade

while demand has increased.

More landlords must be educated

about the HCV program and needed

accommodations to help

individuals with disabilities

access decent, safer housing."

Camille Bowen, Statewide Housing Program Specialist
 Utah Department of Health and Human Services



standing of the past and current landscape individuals with A/I/DD and their families must navigate to prepare for life beyond the family home. The following content provides the necessary background information and local perspective on the current state of housing and services targeting adults with A/I/DD in Utah.

# **History & Evolution** of Support Services

Medicaid began funding medical services for people with A/I/DD in 1965. Although an important step forward, an individual could only access needed services and medical support at a special facility or reside in an institutional setting. This separated them from their family, friends, and neighborhoods. In 1981, a new Medicaid provision

created a program allowing people with A/I/DD and their families to access services in their home and community.14 This homeand community-based services (HCBS) program "waives" the requirement for institutionalization and allows people with A/I/DD to access Medicaid-funded long-term support services (LTSS) in their own home or a provider-controlled setting, and/or assists them in engaging with the greater community while living in the family home. The program is a federal and state partnership, with states contributing costs and the federal government, through the Center for Medicare and Medicaid Services (CMS), matching a percentage of the state's dollars. In Utah, the current federal contribution of nearly \$286 million comprises 70% of Utah's LTSS budget, with the state contributing just over \$100 million, or 30%.1

Over time, individuals with A/I/DD, their families and supporters continued to advocate



**State Schools** 

Institutional Care Only



**Community Integration** 

Introduction of Medicaid HCBS Waiver Services



LTSS Innovation

Growth of Consumer-Controlled Service Delivery



**Housing Innovation** 

New Options Emerging for Adults with A/I/DD

for more choice of, and control over, where they live, work, and learn, with a strong preference for community-based services. On June 22, 1999, the U.S. Supreme Court held in Olmstead v. L.C. that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act (ADA). This decision provided a legal framework for the efforts of the federal and state governments to integrate individuals with disabilities into the communities in which they live. As mandated by the Olmstead decision, the Utah Department of Health and Human Services. Division of Services for People with Disabilities (DSPD) offers 11 different waiver options, as well as a Medicaid State Plan to serve adults with A/I/DD, adults with physical disabilities, adults with traumatic brain injury, and the elderly directly in the community instead of an institutional setting.15

Due to the relentless efforts of advocates and their families, currently more than 6,000 individuals with A/I/DD receive the services they need to function in everyday life.<sup>12</sup> Whether it is assistance with organizing their daily schedule, getting ready in the morning, preparing meals, job coaching, or maintaining their home, these long-term support services are provided by existing community-based

organizations across Utah as long as an individual is deemed eligible and can access a waiver. While many adults with A/I/DD qualify for Medicaid based on income and physical and/or mental health needs, some do not qualify for long-term support services. They fall through the cracks into homelessness if they cannot earn a living wage without the assistance of support staff or case managers.

Today, Medicaid waivers aim to build an ecosystem of support centered around offering choices for individuals whose needs may change over time.

#### **Person-Centered Approaches**

While varied by specific methods, person-centered approaches build a support system around each unique individual. Like a web instead of a brick wall, elements of their life may change or need adjustment; thus person-centered planning is multifaceted and helps prevent them from faltering through normal and/or more significant life changes. This takes intentional planning around a person's needs and preferences, not just selecting the "right program."

Person-centered thinking focuses on language, values and actions by respecting the views of the person. It emphasizes quality of life, well-being, and informed choice. Person-centered planning is directed by the person with helpers they choose. It is a way to learn about choices and interests, as well as identify supports (paid and unpaid) needed to achieve a more independent, self-determined life. Person-centered practices are present when people have the full benefit of community living and supports designed to assist them as they work toward their desired life goals.

#### Neuro-Inclusive Housing Framework

Using the following neuro-inclusive housing framework, public, private, nonprofit, and philanthropic partners can come together and develop scalable solutions. The following three areas need support from policymakers and funding sources in order for organizations and businesses in Utah to develop more supportive housing solutions for this population:



**Aspects of Person-Centered Planning** 



Housing: Cognitively accessible and sensory-friendly housing in, safe locations that benefit residents with and without A/I/DD. Local planners and housing developers can use this report to become more aware and plan for the intentional inclusion of this population in existing and future developments.

Long-term support services: A network of over 125 approved providers already serves adults with A/I/DD in Salt Lake County, offering individualized services to help people in their homes and to access the community. This report offers insights into what gaps need to be filled and future preferred service delivery models.

Supportive amenities: these propertyspecific supports can be provided by community-based organizations to address isolation and foster greater community integration, promote social well-being and building of natural support systems, or facilitate employment and/or life skill classes. Supportive amenities are essential for those ineligible for long-term support services to help tenants connect to their community and remain stably housed.

#### Lack of Affordability Leads to Limited Choice of Living Arrangements

Finding and affording housing is nearly always out of reach when an individual with A/I/DD desires to move out of their family home or other living situation and typically intensifies into a crisis. The ability of adults with A/I/DD to earn a living wage in Salt Lake Valley may be limited due to their neurodevelopmental disability. The National Low Income Housing Coalition estimates that to afford a one-bedroom apartment in Salt Lake City and/or County, a person would need to work full time earning \$24.19 an hour or work 133 hours a week at minimum wage. 17 If sharing rent in a two-bedroom unit, a person would still need to work full time earning at least \$14.46 an hour or work 80 hours at minimum wage. Currently, the DSPD reports that only 21% of adults with any disability are employed

in the community, working an average of 10.5 hours a week pre-pandemic.<sup>18,19</sup>

When a move is needed, finding appropriate housing or roommates who can afford housing is difficult. This population is often displaced with minimal choice in a provider-controlled vacancy, such as a group home or host home, if housing cannot be identified. For someone who does not need 24/7 residential support, this comes at an enormous cost to the public through Medicaid funding. A placement in a residential group home averages \$104,984 a year or \$82,756 in a host home. Nearly 2,800 adults with A/I/DD receiving waiver services live and pay rent to their service provider in a provider-controlled setting that may or may not be their preferred residential choice and may offer a higher level of supervision than needed due to a lack of affordable housing.20

The Center on Budget and Policy Priorities reports that across Utah, there are only 700 supportive housing units targeted for seniors and people with disabilities in general.<sup>21</sup> There is no data to ascertain how many of these supportive, affordable units include a resident with A/I/DD.

Utah's disability-specific rental assistance programs for low-income Utahns with disabilities offer a total of 2,041 households housing vouchers, only 682 serving Salt Lake Valley residents with disabilities.<sup>22</sup> It is unknown how many heads of household receiving rental assistance in Utah are adults with A/I/DD. Three rental assistance programs offer subsidies to help non-elderly people with disabilities afford rent. These programs do not collect data on how many participants have A/I/DD:

- Mainstream Housing Choice Vouchers (HCV)
- Non-Elderly Disabled (NED) Vouchers
- Section 811 Project Rental Assistance

# What happens when family caregivers can no longer provide housing support?

Without access to affordable, accessible housing, people with A/I/DD experience:



# Displacement

into "the next empty bed" of a provider-controlled setting

**OR** 



# **Homelessness**

This costs taxpayers more than providing the subsidies needed for someone to live in a consumer-controlled setting—their own home.



\$8,749/mo Group Home



\$6,896/mo Host Home



\$**791-3,494**/mo

Housing Subsidy & Supported Living\*

\*for someone with drop-in or low support needs

Looking specifically at PHA resources targeting Salt Lake City and Salt Lake County, there is not enough rental assistance targeting adults with disabilities to meet the need. These targeted rental assistance programs are underutilized and do not meet the standard

# **HCV Details of Salt Lake Valley's Public Housing Authorities**<sup>24</sup>

Public housing authority name	Total HCV, % leased up	# of NED and/or mainstream HCV, % leased up	HCV% for PWD	Waitlist status
County of Salt Lake (Housing Connect)	2,946, 90.5% leased up	286, 85.7% leased up	9.7%	Opened June 1 with a centralized system with SLC PHA
Housing Authority of Salt Lake City	3,170, 88.5% leased up	496, 62.9% leased up	15.6%	Opened June 1

performance of utilization rates—95% as set by the HUD Office of Inspector General.<sup>23</sup> Of great concern is the disparity that disability-specific vouchers have lower utilization rates when compared to non-disability-specific vouchers. During the Salt Lake Valley Local Leaders Workshop, underutilization was reported to be due to insufficient landlord interest or participation, lack of availability of appropriate and accessible housing units, and housing costs increasing at a rate faster than the PHA's budget. PHA's must work to create a plan to educate landlords and optimize leasing to increase the number of adults with A/I/DD assisted, thereby reducing the number of unused vouchers.

Adults with A/I/DD often have fixed incomes and/or low wages from employment. A lack of affordable housing options prevents the neurodivergent population from moving beyond their family home. When an adult with A/I/DD loses their last aging family caregiver and/or a crisis placement is needed, the safety net of a group home or adult host home care is only available to those who qualify for a Medicaid waiver or an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). Those not eligible for these Medicaid services are currently at high risk of homelessness due to the lack of rental assistance and supportive housing options. According to the Utah Homeless Management Information System (UHMIS), in 2022 over 6,300 unsheltered individuals were newly experiencing homelessness in the Salt Lake area.25 UHMIS does not have data on the

population of adults with A/I/DD, let alone if they are homeless due to being ineligible for waiver services. Recent national research indicates that approximately 30-40% of people experiencing homelessness have a cognitive impairment, including A/I/DD, and become homeless later in life, most often due to death of the family caregiver.<sup>4</sup>

#### **Invisible Need**

The Salt Lake Valley Neuro-Inclusive Housing Market Analysis covers Salt Lake City and Salt Lake County and includes the review of housing assessments, consolidated plans and PHA's Annual Plans to assess whether adults with A/I/DD are considered and prioritized in these various aspects of planning. None of these plans for Salt Lake City or Salt Lake County included mention of persons with A/I/DD as a segmented need; consequently, planning is likely not occurring nor being prioritized to meet the needs of adults with A/I/DD.

The 2023-2027 Housing Element of the Salt Lake City General Plan to guide Salt Lake City's efforts in meeting the housing needs of its residents does not include those with A/I/DD in the demand data.<sup>26</sup> Although the plan aims to increase physical accessibility of housing options, many adults with A/I/DD who do not need these physical accommodations would benefit instead from supportive amenities and cognitive design accommodations.

40% of respondents had zero

or low knowledge about

their local public housing

authority's housing resources

for people with disabilities

despite 61% of respondents

identifying neuro-inclusive

housing as

their primary

unmet need.

Sumiko Martinez
 Director of the
 Autism After 21
 Utah Project



Salt Lake County's Comprehensive Plan and subsequent Annual Plans describe that there is a priority for "Special Needs" populations, yet this includes chronically homeless, the elderly, and in general persons with disabilities. In the 2023-2024 Annual Action Plan, Salt Lake County Housing and Community Developments' HOME Rental Housing program has committed to help finance the development and construction of approximately 408 rental units. Of the 408 rental units, 18 units will be designated HOME-assisted units to serve those with "special needs." <sup>27</sup>

The stated prioritization is an important step forward, yet in comparison to the demand of these diverse "special needs" populations, the practice of prioritization does not seem substantial.

Although Utah does not collect data on the number of Utahns who have A/I/DD, it is possible to estimate how many adults with A/I/DD may live in a specific geographic area with a need for housing, long-term support services, and/or supportive amenities using existing datasets and prevalence rates.

The DSPD has identified nearly 4,000 people with intellectual disabilities or other related disabilities who have applied to receive

**Secures own home Host home** and selects service Providerprovider Qualifies for **Controlled Group** Medicaid Setting Cannot secure a home so must rent from Other institutional service provider settina Adult who must leave Falls into abusive family home Can secure relationship to be housing housed Not eligible for Experiences **Medicaid waiver** homelessness services **Cannot secure** Other institutional housing settings or incarcerated

services in Salt Lake County.<sup>28</sup> Major data gaps exist for individuals with A/I/DD who have not applied for DSPD services or who are ineligible, resulting in a grossly incomplete estimate excluding many adults with A/I/DD. 35% of survey respondents indicated they are not using DSPD services.

#### The Centers for Disease Control (CDC)

reports that 1 in 4 adults in Utah has a disability that functionally impacts them. The data are segmented in the areas of cognition (13%), mobility (9%), independent living (7%), hearing loss (6%), vision (3%) and/or self-care (2%).29 Adults with A/I/DD do not fit into only one of these areas, and their support needs and accommodations due to disability usually overlap. Adults with A/I/DD as 25% of Utah's population would be an overestimation, but such an assumption would be helpful for local communities to consider the diverse needs of their residents with various disabilities. Using this functional dataset and Census data for 2022, of the approximately 890,000 adults living in Salt Lake County, at least 62,000 have a disability that impacts their ability to live independently as defined by the CDC: serious difficulty doing errands alone, such as visiting a doctor's office." 9 Still, this dataset does not provide information on the number of adults with A/I/DD who often have higher support needs and fewer opportunities to make a living wage than someone who may not have an A/I/DD but uses a wheelchair or is visually impaired.

# cDC prevalence rates and Census data sets can be better tools in estimating the number of adults with A/I/DD in a geographic area. The CDC estimates that 2.2% of the U.S. adult population is on the autism spectrum,

1.65% of children have an intellectual disability, and the prevalence of children diagnosed with a developmental delay other than autism spectrum disorder or intellectual disability is 6.06%. The University of Kansas 2022 State of the States in Developmental Disabilities estimates that 17% people with A/I/DD live with a family caregiver over age 60, placing them at immediate risk of displacement or homelessness when their aging caregiver passes away.

From estimates of incomplete data sets, and considering the population of low-income adults with A/I/DD currently living with family caregivers, this statistically invisible population could quadruple the University of Utah's estimated deficit of 17,000 affordable housing units for extremely low-income residents in Salt Lake County.<sup>3</sup> Of urgent concern are approximately 15,000 individuals with A/I/DD in Salt Lake County at high risk of losing their home and primary caregiver when their family member can no longer support them due to aging and health concerns, death and other economic circumstances.

Local communities must do what is necessary to identify this statistically invisible population of adults with A/I/DD. Across Utah, the needs of adults with A/I/DD and their aging caregiving family members must not be excluded from local housing assessments, consolidated plans or public housing authorities' annual reports considering the high risk of displacement and/or homelessness.

Salt Lake County adult population	2.2% autism in adulthood <sup>30</sup>	1.65% intellectual disability <sup>31</sup>	6.06% developmental disability (not autism or ID)	Combined A/I/DD	Estimated to be living with caregiver over age 60 (17%)
888,506	19,547	14,660	53,843	88,050	14,969

#### **Additional Barriers**

In addition to the cost of housing, this population faces numerous barriers even if they have access to housing assistance or their family can afford to help them pay rent.

The systems to access housing and services are disconnected and can be cognitively inaccessible to people with A/I/DD. Adults with A/I/DD often have challenges in areas such as reading and writing, executive functioning, communication, and/or social interactions. Such challenges can make navigating the complex and often disconnected systems required to access housing, services, and other public benefits more daunting. They may also lack experience with or knowledge of documentation and system requirements to access various types of assistance.

Many adults with A/I/DD are on a fixed, extremely low income. They often have low educational attainment, cognitive challenges preventing full-time employment, and/or rely on public benefits. This necessitates budgeting on a fixed-income that does not increase with inflation or rising housing costs.

Lack of supportive amenities and case management prevail for those ineligible for long-term support services funded by Medicaid waivers. Individuals with A/I/DD who do not qualify for waiverfunded services need supportive amenities and assistance with case management. This includes breaking down the steps in a task: i.e., identifying required documents, completing applications, creating a follow-through plan.

The shortage of direct support professionals (DSPs) is currently causing displacement and can prevent people from moving out or remaining in a home of their own. Direct support professionals (DSPs) in Utah receive low wages and report feeling burned out and exhausted due to this critical workforce shortage. In a 2022 report, 50% of clients represented have reportedly

been unable to access funded services and 18% of waiver recipients have reportedly relocated to access services.<sup>38</sup> This shortage causes individuals and families to fear that they or their loved one would be suddenly displaced due to gaps in support services.

The existing housing stock lacks accommodating features desired by adults with A/I/DD and their families. Individuals may need wayfinding signage or icon cues in addition to text; sensory-responsive features such as natural and low-voltage versus fluorescent lighting; extra-durable fixtures for challenges with graded movement; technology to support executive functioning; or a lift for transfers that may not be weight bearing without modifications to structural support. Some adults with A/I/DD may also have vocal tics, or use scripting or repetitive behaviors that—without soundinsulating spaces—could lead to disruption for neighbors and/or noise complaints.

This population is at risk for predatory relationships. Location and security features must be carefully considered, as adults with A/I/DD have a significantly greater risk of being victims of assault and other violent crime than other persons with disabilities.<sup>30</sup> Data show that 66.5% of those on the autism spectrum and 62.5% of those with I/DD report being survivors of physical, emotional, or sexual abuse.<sup>31</sup> In a study conducted on mate crime, 100% of respondents ages 16-25 with autism reported they cannot distinguish between someone who is a friend or someone who is abusive.<sup>32</sup>

Discrimination based on disability is the highest reported form of housing discrimination.<sup>33</sup> Despite progress in the rights and inclusion of persons with disabilities, it is not uncommon for landlords to reject their rent applications. Likely due to misperception regarding financial, criminal, or cognitive differences of adults with A/I/DD, the greatest number of Fair Housing discrimination complaints across multiple agencies is due to disability.<sup>34</sup>

Have you or a person with A/I/DD in your current household ever experienced any of the following?				
Bullying that led to missing school, employment or other social events	38%			
Discrimination due to gender identity and/or sexual orientation	21%			
Discrimination due to disability	19%			
Mate-crime (a "friend" who misused or exploited a relationship with you)	19%			
Abuse or exploitation from a professional serving people with A/I/DD	15%			
Discrimination due to religion	11%			
Domestic violence or emotional abuse from a romantic partner	11%			
Financial abuse from a family member or caregiver	10%			
Discrimination due to race or ethnicity	8%			
Abuse or exploitation from an acquaintance or community member	5%			
Domestic violence or emotional abuse from a family member	5%			

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

Without immediate action, the "invisible" housing crisis currently faced by adults with A/I/DD and their families risks becoming a full-blown emergency with widespread, lasting consequences.

Madison House Autism Foundation, partners of Neuro-Inclusive Housing Utah, local leaders, and fiscal sponsors have invested significant time, energy, and resources in the process to better understand the needs and preferences of Salt Lake Valley's neurodiverse population. This Salt Lake Valley Neuro-Inclusive Housing Market Analysis aims to offer data-driven insights for actionable solutions listed in the Recommendations section.

78% of respondents had

experienced discrimination,

abuse or exploitation.



Educate neurodiverse community

Assess needs and preferences Approach housing industry with consumer data

Increase housing stock that meets local demand

### Salt Lake Valley's Neuro-Inclusive Housing Market Analysis Process

ost individuals with A/I/DD and their families have not had the opportunity to explore their options for life beyond the family home. To provide meaningful feedback, participants of the Salt Lake Valley Housing Market Analysis were required to participate in a learning session informing them of the benefits and considerations of various elements of residential choices. Using the nomenclature from A Place in the World:

Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities, participants were able to learn about the broad range of choices.<sup>13</sup> While some of the options presented during the training session may not currently be available in Utah, it was important to include them so participants could express their needs and preferences to help stimulate market and systems change.

#### **Website Outreach**

Invitation sent to 35+ organizations (January 2023)



Expanded presentation & survey, plain-language presentation & survey

### **Learning Session**

Two live virtual presentations with Q&A (February 2023)



Recordings on website and promoted through collaboration with other organizations

# **Focus Groups**

Two in-person focus groups targeting self-advocates (April 2023)



Targeting neurodivergent youth experiencing homelessness (Thank you, VOA!)

## **Learning Session Outreach**

The learning sessions included a live, online presentation with subsequent Q&A. The learning session was recorded and posted on Neuro-Inclusive Housing Utah's website (neuroinclusiveutah.org) for those unable to attend the live event. More than 35 community-based organizations were contacted to assist in promoting and facilitating the learning sessions and follow-up surveys. Plain-language materials were created to ensure a more cognitively accessible format. These materials included a pre-recorded, live presentation in plain-language—a visual guide to support participants in tracking their preferences during the presentation-and a plain-language survey. In order to collect feedback from neurodivergent youth experiencing or who had recently experienced homelessness, an in-person focus group was held at the Volunteers of America, Utah Youth Resource Center in Salt Lake City.

During the 60- to 90-minute sessions, the presenter introduced and explained each survey element using visuals, verbal descriptions, and videos where available. The presenter discussed the benefits and considerations of each element to promote person-centered, meaningful choice. Individuals attending live sessions had the opportunity to ask questions during and after the presentation.

Participants made a

significant time commitment

and demonstrated a

willingness to learn about

multiple approaches to

residential options, enabling

the collection of credible

data on the needs and

preferences of adults with

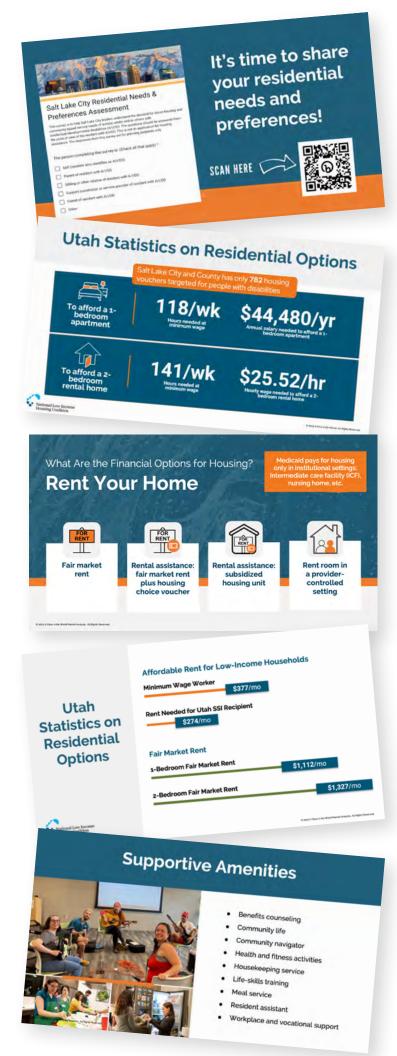
A/I/DD and their families.

Once a participant completed the learning session, they were asked to complete the Salt Lake Valley Housing Market Analysis Needs & Preferences survey. This included questions regarding demographics, barriers to community engagement, support needs and preferences, housing preferences, and utilization of public benefits.

Neuro-Inclusive Housing Utah is currently working with leaders in the Spanish-speaking community to determine how to provide learning sessions and collect data in the most culturally appropriate and accessible way.

#### **Local Leaders Workshop**

Local leaders were invited to Columbus Community Center's Hub of Opportunity to participate in the process and provide feedback on the collected data. Organizations and individuals who participated were leaders in housing, healthcare, and disability and human services from city, state, and community-based organizations. Self-advocates and family leaders were also essential contributors. Local leaders assisted with identification of existing data and outreach to potential stakeholders. They also participated in a workshop to review the survey data and identify potential recommendations for future action. Data and initial analysis indicated the diversity of and demand for various residential options. Local leaders were eager to discuss potential solutions and address barriers. Details of their suggestions and discussion are highlighted throughout this report and in the Recommendations section.





#### Considerations and Limitations of the Process

- Survey materials: To provide more accessible survey materials, the plain-language surveys did not include questions as extensive as the full survey, limiting some of the demographic and preference data collected.
- Service providers: Due to outreach to service providers who support adults with A/I/DD in their own home, a higher percentage of adults living outside the family home are represented in the data than what would be reflected generally in the neurodivergent population.
- Inequity due to support needs: Family members who are caregivers to individuals with one-to-one, high behavioral or medical support needs shared that many of the options presented that they believed were preferred by their loved one are not currently available in Utah.

Utah is currently working
with leaders in the Spanishspeaking community to
determine how to provide
learning sessions and
collect data in the most
culturally appropriate

and accessible way.







- Focus groups: Due to limited identification of adults with A/I/DD currently experiencing homelessness, the in-person focus group was comprised of those under age 22 who self-identified as neurodivergent and were receiving services at the VOA Youth Center.
- Survey language: Surveys were available in English only; a more inclusive Spanishlanguage study is in the planning stages.
- Survey participation: Participation required a significant time commitment, including attending a learning session or watching a recording prior to completing the survey. This may have discouraged potential participation in the study.
- Diversity of participants: Participants in the study included a notable demographic over representation of Black/African Americans and an underrepresentation of White Americans. Survey participants from Asian and Latina/Hispanic backgrounds were slightly overrepresented.

"Every person is deserving

of certain things, like a

safe place to live. To look

at someone whose brain

is wired differently and say,

'Oh, you're just not trying

hard enough,' is really

messed up."

Neurodivergent youth experiencing homelessness



The following section was written by Kristy Chambers, a local leader with years of experience serving the unhoused, reflecting of her participation in the focus group conducted by Neuro-Inclusive Housing Solutions targeting neurodivergent youth experiencing homelessness.

Homelessness and its many complexities impact countless people, including youth on the autism spectrum. Based on a British survey, 12% of the homeless population is estimated to have strong signs of autistic traits compared to just under 2% of the general population.<sup>35</sup> Contributing factors to this population's elevated risk of homelessness include insufficient awareness of autism in local government homeless services and inadequate data collection to identify needs. In addition, a recent international review of

studies concluded that approximately 30–40% of people experiencing homelessness have a cognitive impairment, including intellectual/developmental disabilities, and become homeless later in life, most often due to death of the family caregiver.<sup>4</sup>

On April 10, 2023, a focus group of six individuals self-disclosing as neurodivergent was conducted at Salt Lake City's downtown Volunteers of America Youth Center. The purpose of this meeting was to hear from those with lived experiences to understand housing preferences as well as determine potential measures to prevent homelessness. The group included racially diverse participants between ages 15 and 22. Several participants identified as part of the LGBTQ community. Two participants mentioned they had children. Questions asked were (1) What would you like to have in your dream home? (2) What would you not want in your home/community?

(3) What could have prevented you from experiencing homelessness? (4) Other related needs. Participants were also asked to rank their preferences in housing design and support services through a visual voting method.

The overarching themes of many of the responses were safety and security in housing and a strong desire to feel cared for and valued. Explanations of housing preferences included:

- Not feeling confined to a small space or trapped, with a preference for large windows
- One-bedroom versus a studio apartment to address executive functioning needs and task organization
- Pedestrian-oriented design to offer space when they "don't want to go out in public but need somewhere outside" or a quiet, private place to retreat outside their home
- Additional soundproofing in walls to drown out external sounds to which they are highly sensitive
- Easy-to-clean features to make maintaining their home more manageable
- Location close to public transportation to get to and from employment opportunities or within walking distance from an employer

"We must dismantle the

stigma of homeless =

drug addiction = bad person

and homeless = bad mom."

#### - Focus group self-advocate participant

Many mentioned experiencing unsanitary, unsecured and noisy living conditions with landlords violating tenant rights. The need for accommodations and resources to understand tenants' legal rights was stated in several instances.

Due to limiting eligibility criteria, the participants in the focus group would likely be deemed ineligible for long-term support services through a home- and community-based service (HCBS) waiver. Supportive amenities and/or a postsecondary transition program to teach life skills are essential to help keep this population from falling back through the cracks to homelessness. The top-ranking service needs included a dedicated navigator to assist in understanding all available social services, money management and an onsite mental health counselor. Several participants noted that youth need special assistance to keep them from being exploited or "dragged into bad things" as well as to secure shelter for themselves and prioritize services for those trying to stabilize.



Many were unfamiliar with how to access needed services and, in all instances, felt discriminated against in employment situations when they could not provide a home address or disclosed they were homeless. Knowledge of available housing and support resources, including transition support before aging out of foster care and job placement with willing employers, were the primary homeless-prevention measures mentioned. There was also a strong focus on finding a neurodivergent and/or LGBTQ-friendly therapist who takes Medicaid.

#### Conclusion

By engaging with youth with lived experience, we can better understand the measures that can prevent the tragedy of homelessness for this young population. Stable housing provides safety and allows individuals to connect with resources, participate in the community through employment and better manage comprehensive health needs. For autistic youth, an inclusive environment with housing and the necessary supports tailored to their specific needs would allow many in this disenfranchised population to thrive and become contributing members of our community.

Recommendations for next steps to address prevention and remediation of homelessness of this population can be found in the Recommendations section.



Kristy Chambers serves as CEO of Columbus Community Center and is the former CEO of Fourth Street Clinic in Salt Lake City.

She has dedicated the last 20 years of her career to the nonprofit, social services sector, developing new programs and overseeing large building projects, including the Fourth Street Clinic dental program for individuals experiencing homelessness and the NextWork adult autism program for independent living housed at the Hub of Opportunity affordable housing apartment complex. Kristy graduated from UCLA with a Bachelor of Arts in Economics with a Business Emphasis, has a master's degree in business taxation from the Washington School of Law and is currently pursuing a Master of Public Policy from the University of Utah.



"It was a real eye opener for me

when I was contacted by a

woman who works at a facility

for older people about a resident

mom who passed away and had

an autistic son in his 50s. 'I don't

know what to do for him,' she said...

It was terrifying because I thought

that could be my son..."

- Stacy, Autism After 21 Utah Project interview participant



Demographic data within this section is compiled from the 2023 Salt Lake Valley Neuro-Inclusive Housing Analysis Needs & Preferences Survey unless otherwise noted. It provides demographic information for respondents with A/I/DD and/or their families. The next section goes into detail about future needs and preferences for housing, services, and community engagement.

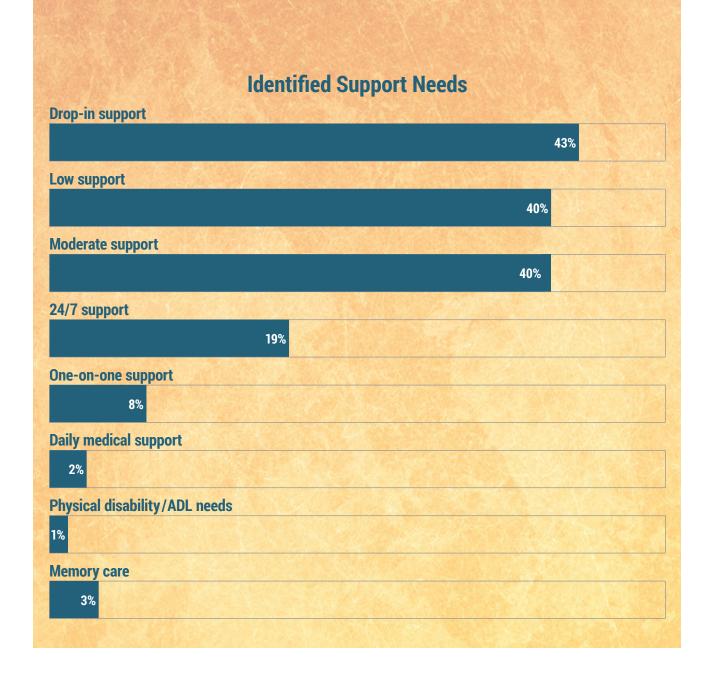
### **Diversity of Respondents**

A person's diagnosis does not dictate the type of housing, supportive amenities, or service delivery model they may need or prefer. However, diagnostic information is helpful in understanding possible barriers to independent living and breadth of diversity, along with potential funding sources. Compliance with the Americans with Disabilities Act (ADA) is required by law in

granting accessibility to those with physical disabilities who may use a wheelchair or other mobility device but who represent a small segment of the population of people with A/I/DD.

Diagnostic information in this analysis can inform design and accommodations, which may be safety related when targeting certain populations due to sudden falls from seizures; alternative emergency communication methods due to vision, hearing, or cognitive impairments; and sensory differences due to vision, hearing, or cognitive impairments, and sensory differences due to autism or processing disorders involving lighting, sound, and other materials.

The analysis also reports a high rate of co-occurring mental health challenges, such as anxiety, depression, and OCD. Emerging supportive housing opportunities may



consider building relationships with mental health providers that can provide on- and off-site mental health support, therapeutic interventions and counseling, and/or life coaching in a cognitively accessible and autism-friendly format. The focus group of unhoused, neurodivergent youth also underscored the desire for the identification of LGBTQIA+-friendly service providers. Finding a provider that takes one's insurance and understands the challenges of the neurodivergent population in scheduling an appointment and accessing reliable transportation—all barriers to mental healthcare—necessitates further exploration.

Wide range of support: People with A/I/DD have a wide range of support needs not otherwise captured in existing Utah data sets. The data on level of support needs outlines the number of hours a person may need for direct support. Support needs are not static: Some days an individual may have more or fewer support needs. This data only reflects those who participated in the Salt Lake Valley Housing Analysis Needs & Preferences Survey; it does not represent overall levels of support needed for the entire A/I/DD population, constituting a major data gap in Utah.





# Support Needs<sup>13</sup>

# **Drop-In Support**

The individual requires a Direct Support Professional (DSP) to check in with them every few days or as requested; the individual is self-sufficient the majority of the time.

# **Low Support**

The individual requires a DSP to support them with a few daily tasks but can be self-sufficient most of the day.

# **Moderate Support**

The individual requires a DSP periodically throughout the day but can be self-sufficient for several hours at a time.

# 24/7 Support

The individual has access to a DSP at all times, but the DSP may be shared with others; they are not the only person receiving support from the DSP the majority of the time.

# **One-on-One Support**

The individual requires the full attention and in-person support of at least one DSP at all times.

# **Daily Medical Support**

The individual requires the attention of a medically trained/certified provider to safely complete daily routine care, such as assistance with eating, breathing (including durable medical equipment), etc.

# **Physical Disability ADL**

Due to a physical disability, the individual may use a wheelchair or mobility device and requires additional DSP assistance with transfers and other activities of daily living.

# **Memory Care**

Due to symptoms of dementia or Alzheimer's disease, the individual requires a safe environment with additional structure and support to navigate throughout the day.



Drop-in or low support: Those with drop-in or low support needs represent the largest segment of the data collected and are also the most likely to be invisible or found ineligible for waiver services funded by Medicaid. 30% of survey respondents report having been denied or deemed ineligible. This inability to access long-term support services places the population with drop-in support needs at high risk of displacement and homelessness if they cannot earn a living wage or are unable to manage day-to-day needs without support due to executive functioning impairments.

Moderate support: Those with moderate support needs, the second largest reported level of support needed, would likely be eligible for waiver services. However, if they cannot access affordable housing, they may have no choice but to be placed in a provider-controlled setting such as a host or group home that caters to those with 24/7 support needs, at a higher cost to taxpayers.

One-on-one support: Equally important but often unmet are the service needs of individuals who have high levels of support with challenging behaviors. It is often difficult to find consistent providers in the I/DD or behavioral health system that can support those who need one-to-one and/or behavioral

support needed to live outside of the family home and participate in the community.

*Memory care:* Although representing a smaller subset of the data, those who need memory care are important to consider as a growing support need due to the propensity of older adults with autism and Down syndrome to develop early-onset dementia and Alzheimer's.<sup>36</sup>

Future research or data collection should always segment the population based on level of support needs to measure any disparities. To improve data collection and articulation of this issue, it is recommended that data be segmented based on whether an individual with A/I/DD owns/rents a home outside of the family home versus lives with a family member.

25% of self-advocate

respondents indicated they

were currently homeless

or at imminent risk of

homelessness.

The disabilities I identify with include:		
Autism	56%	
Anxiety	29%	
Depression	21%	
Asperger's	13%	
Intellectual disability	12%	
Bipolar disorder	10%	
Obsessive-compulsive disorder (OCD)	6%	
Other mental health challenges	6%	
Physical disability and use mobility device/s	5%	
Epilepsy or other condition causing seizures	4%	
Other developmental disability	3%	
Other disability not specified	3%	
Traumatic brain injury	2%	
Cerebral palsy	2%	
Deaf or hard of hearing	2%	
Down syndrome	2%	

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

I identify as:		
White or Caucasian	50%	
Black or African American	21%	
Hispanic or Latino	16%	
English as a second language	10%	
Asian	5%	
LGBTQ+	3%	
Native Hawaiian or other Pacific Islander	1%	
American Indian or Alaska Native	.6%	

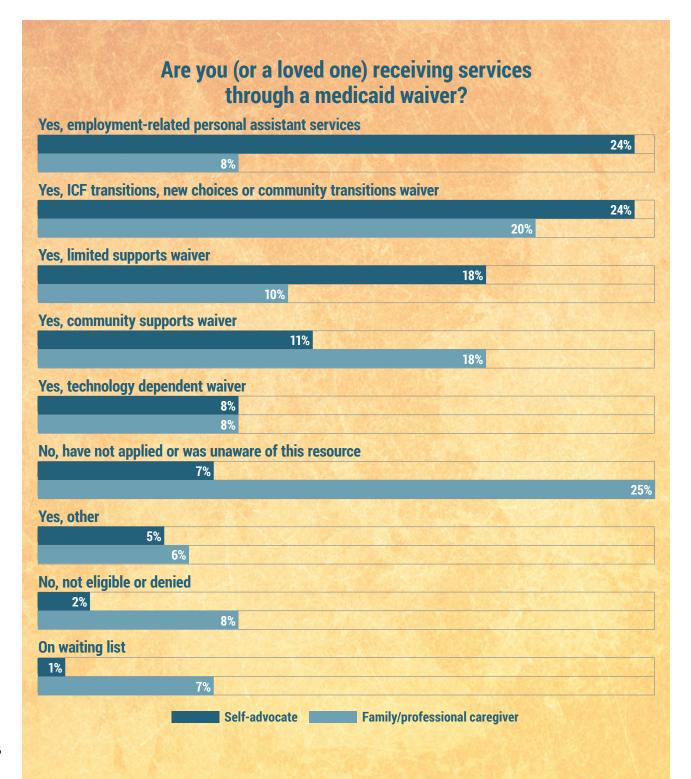
\*Does not total 100% because respondents could choose more than one answer.

Age of individuals with A/I/DD represented		
0-13	1%	
14–18	8%	
19-21	31%	
22-34	50%	
34-49	8%	
50-65	.6%	
65+	.6%	
I prefer not to share.	.6%	

### Waiver Utilization to Access Services

Long-term support services funded by a Medicaid HCBS waiver exist to assist people with A/I/DD to live in the community as any other member of society but with needed supports and services. As with all states, applicants must meet state-specific eligibility criteria and be financially eligible for Medicaid.

They often require the level of support needed for placement in an Intermediate Care Facility (ICF) or other institutional setting. It is noteworthy that 65% of respondents indicated they are receiving long-term support services through a Utah waiver. Of the 11 waivers Utah offers, the Salt Lake Valley Neuro-Inclusive Housing Analysis respondents targeting the A/I/DD population reported predominantly using seven of these waivers.



## 35% of respondents report not receiving long-term support services, making them invisible in state data.

Waiver name	Target population served	Administering agency
Community Supports Waiver	I/DD diagnosis (or related condition) resulting in functional impairment in three or more areas of major life activity. Onset of condition before age 18 for intellectual disability (or before age 22 for other related conditions) but can apply at any age.	DSPD: dspd.utah.gov/ medicaid-waivers
New Choices Waiver Program	Person with a disability who is not eligible for placement in a Medicaid-certified Intermediate Care Facility (ICF).	Utah Department of Health: medicaid.utah.gov
Limited Supports Waiver (LSW)	I/DD diagnosis (or related condition) resulting in functional impairment in three or more areas of major life activity. Onset of condition before age 18 for intellectual disability (or before age 22 for other related conditions) but can apply at any age. Self-Administered Services (SAS) model possible.	DSPD: dspd.utah.gov/medicaid-waivers  Targets participants with low support needs who are on the current waitlist for DSPD services. This waiver has an annual
Employment-	Person with a disability (as established by the	service spending cap of \$20,834. Utah Department of
Related Personal Assistant Services (EPAS)	Social Security Administration or State Medical Review Board) currently employed in an integrated community setting making at least minimum wage working a minimum of 40 hours per month or self-employed and needs personal assistance to maintain employment. Is currently receiving Utah Medicaid. (May be paying a spend down or Medicaid Work Incentive premium)	Health: medicaid.utah.gov
Technology Dependent Waiver	Must meet admission criteria for nursing facility (NF) care. Must have at least one caregiver trained and available to provide skilled nursing and/or rehabilitation services at least five days per week and be dependent on one or more of the following: mechanical ventilator; tracheostomy-based respiratory support; continuous or bi-level positive airway pressure support (C-PAP or Bi-PAP); or intravenous administration of nutritional substances or medications through a central line.	Utah Department of Health: medicaid.utah.gov
Community Transitions Waiver	I/DD diagnosis who has had at least a 12-month stay in any Medicaid-certified ICF located in Utah.	DSPD: dspd.utah.gov/ medicaid-waivers/
ICF Transition Program	I/DD diagnosis who lives in any Medicaid-certified ICF located in Utah.	Utah Department of Health: medicaid.utah.gov

"It's disheartening to see how frequently the service needs of individuals with high-support requirements and challenging behaviors go unmet. Adequate service provision plays a crucial role in enabling these individuals to live fulfilling lives within their communities. The difficulty in finding consistent providers highlights the pressing need for increased funding and support in the I/DD and behavioral health systems. It's important to ensure that everyone has the opportunity to access the one-to-one and behavioral support they require to actively participate in the community."

 Julie Winn, Vice President at Valley Behavioral Health Waivers used by survey respondents: Three of the waivers (ICF Transition, Community Transition, and New Choices waiver) are not accessible to new waiver applicants unless they have lived in an institutional setting such as an ICF, nursing facility, licensed assisted living, or other Utah-licensed medical institution.<sup>37</sup> These are important tools for adults with A/I/DD who no longer want to live in an institutional setting and seek a community-based residential option. These three waivers have been consolidated in the bar graph and represent high utilization among self-advocates who were able to transition to a community-based setting.

For those wishing to directly transition from the family home into their own home or a provider-controlled, community-based setting. Utah offers two waivers designed to specifically target the needs of adults with I/DD who want to be supported to live outside of the family home (Community Supports Waiver and Limited Supports Waiver). The DSPD Demographic Dashboard shares that a total of 2,060 Salt Lake County residents are receiving services funded by the Community Supports Waiver with another 28 Salt Lake County residents receiving services funded by the Limited Supports Waiver.<sup>28</sup> Of the survey respondents, 46% indicated currently utilizing one of these waiver options. DSPD reports that 1,544 individuals with A/I/DD are eligible and waiting for services in Salt Lake County. 22 Respondents also utilized waivers that do not target the A/I/DD population. This occurs when waiver recipients may prefer the services or service delivery model offered in other waivers.

In 2022, DSPD reported that a total of 151 people across the state were removed from the waiting list to receive waiver services.<sup>2</sup> Access to waiver services is the initial step for many to consider leaving the family home and living in their own home or other provider-controlled setting. When tracking the number of waiver recipients who lived in a community-based setting from 2009-19, the State of the

Income of public benefits plus earned income in a few of Utah's largest occupations <sup>17</sup>	Total monthly income (earned income + deduction of SSI due to earned income) <sup>39, 40, 41</sup>	% of income needed to afford market rate rent of 1-bedroom in Salt Lake Valley (\$1,112)	Monthly housing costs considered affordable <sup>42</sup>
2023 Maximum SSI benefit	\$914	122%	\$274
Avg. SSDI adult child survivor benefit <sup>51</sup>	\$980	113%	\$294
SWI program average: 14 hrs/week (\$8.38/hr) plus SSI	\$469.28 + \$721.86 = \$1,191.14	93%	\$357
16 hrs/week working as a cashier (\$12.15/hr) plus SSI	\$777.60 + \$567.70 = \$1,345.30	83%	\$404
24 hrs/week working as a teacher's assistant (\$14.78/hr) plus SSI	\$1,418.88 + \$247.06 = \$1,665.94	67%	\$500
40 hrs/week working as an inventory stocker (\$15.26/hr)	\$2,441.60 (SSI no longer available due to earned income)	46%	\$732

States in Developmental Disabilities reported an average additional 68 people per year who moved out of their family home into a supervised residential setting. This rate of access to essential waivers services will not meet the impending demand when Utah can no longer rely on aging family caregivers who may soon become unable to provide a home and support for their loved one.

Furthermore, even when waiver services are being accessed, Utah is experiencing a severe direct support professional (DSP) shortage and DSP burnout. According to a 2022 DSPD report:

- 85% of support coordinators report programs being understaffed, making waiver recipients vulnerable to neglect.
- 50% of clients represented have reportedly been unable to access services for which they have received funding. 18% of the clients have reportedly relocated to access services.
- 3% of clients represented (75) have been discharged from residential settings, including two discharged into homelessness.<sup>38</sup>

Utah must prioritize and exponentially increase access to stable, long-term support services to prevent displacement or homelessness of the nearly 15,000 adults with A/I/DD living with senior family caregivers in Salt Lake Valley.

Public benefits or assistance utilized by survey respondents	
Lifeline (phone and internet assistance)	3%
SNAP (food assistance)	13%
HEAT Program (energy assistance)	12%
Housing Choice Voucher	3%

#### **Income & Government Benefits**

As of today, Medicaid waivers are prohibited from funding room and board. Recipients of waiver services must pay for their housing, even in provider-controlled settings such as group homes or adult host homes. Housing is typically paid for using the majority of waiver recipients Social Security Disability Income (SSDI) and/or Supplemental Security Income (SSI), leaving little for other expenses such as clothing, medical needs, recreational spending, and/or leisure spending.

In 2023, the maximum a recipient of SSI can receive is \$914; if the person starts to work, benefits will decrease at a 2:1 ratio as income is earned. If an individual receives financial support from family to cover their housing cost, their SSI benefit is reduced by one third.39 Some states offer a supplement to SSI recipients. Utah does not offer a supplement to its nearly 28,000 SSI recipients with a disability. 40 Although employment is often desired and sought by the A/I/DD population, only 23% of survey respondents were employed. DSPD offers a short-term program called Supported Work Independence (SWI) to adults with A/I/DD waiting for waiver services to "obtain and maintain competitive employment in an integrated setting, earning at least minimum wage."37 In 2022, DSPD reported that 244 adults were served, and 54% obtained employment at an average hourly rate of \$8.38 working 14 hours per week.<sup>18</sup> Even when employed and receiving federal assistance, housing costs for Salt Lake Valley residents are out of reach for most adults with A/I/DD.

Only 5% of survey respondents reported that they earn, or their loved one earns, an income of over \$1,500 a month and thus would need to spend over 70% of their income to afford rent even if they also received SSI. This extreme income disparity between housing costs and federal assistance—designed to help those unable to earn a living wage to pay for life expenses—should be addressed at the federal level. Nowhere in the U.S. can someone who lives off of SSI afford rent.<sup>44</sup>

Despite likely being eligible based on low-incomes, other public benefits and safety net programs are all under-utilized by this population. More research is needed to understand why adults with A/I/DD are not accessing these assistance programs despite being financially eligible.

"DSPD is usually not able to offer services immediately after a person is determined eligible. Disability services are dependent on funding allocations from the Utah State Legislature each year. Currently, thousands of eligible Utahns are waiting for services."

Utah Department of Human Services
 Guide to Eligibility and Services<sup>37</sup>

#### **Financial Support from Family**

Although adults with A/I/DD may be extremely low income and unable to earn a housing wage, the survey indicated that some families are able to assist their loved one financially. Of those surveyed, approximately 42% have created a special needs trust or are part of a pooled special needs trust. This is a financial device that protects against financial exploitation of people with A/I/DD, as well as provides a vehicle for families to financially assist their loved one without putting meanstested public benefits at risk. For those whose families may be able to offer an inheritance or a bequeathed home, it is an essential tool. When asked to consider the addition of family assistance to help cover housing costs, there is a clear variance related to socioeconomic status. Over 36% could assist their loved one to afford a one-bedroom market rate rent in the Salt Lake Valley area. When considering a two-bedroom unit with a friend or caregiver, nearly 51% could afford to split the cost of rent.

Have you or your family done any future planning?	
Yes, I have a special needs trust.	31%
No	33%
No, we do not have extra income to do this.	21%
Yes, I am part of a Pooled special needs trust.	10%
Yes, I opened up an ABLE account.	7%
Yes, we have met with a special needs lawyer.	7%

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

## When I no longer live with my family, my total housing costs per month must be:

Cost including: rent/mortgage, utilities, upkeep, etc.		
\$0-\$300	15%	
\$301-\$450	15%	
\$451–\$600	19%	
\$601–\$800	7%	
\$801–\$1,000	7%	
\$1,001-\$1,200	9%	
\$1,201-\$1,500	5%	
\$1,501-\$2,000	6%	
\$2,001–\$3,500	10%	
\$3,500+	5%	

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

It is important to remember that over half of respondents have not done any future planning or may financially be unable to afford legal fees or have the extra income to fund a special needs trust for their loved one. Therefore, a large population of adults with A/I/DD will need access to public benefits and housing assistance or deeply affordable units to prevent displacement or homelessness when a crisis occurs.

## **TOP 5**

Family concerns for the future



Not finding quality staff



Concerned they may be lonely



Undesirable housing due to unaffordability



Concerned they may be abused



Concerned with limited, unhealthy food options

#### **Future Concerns**

Although daunting, adults with A/I/DD and their loved ones must discuss the reality that parents will likely not outlive their children. Planning for the future and addressing concerns directly will allow Utah families to use their time and resources most effectively to prepare for the day when one parent or both parents will no longer be present as a safety net.

When segmenting data from self-advocate respondents and family/professional caregiver respondents, differences exist in their top concerns; yet abuse and loneliness are cited in the top five of both.

One of the most important aspects of future planning is building a natural support system: people who are unpaid in one's life and can be an unbiased source of support, friendship, problem solving, and/or a safety net. Natural supports can protect and/or identify abuse, neglect, or isolation and offer additional and unbiased support beyond paid caregivers. When asked about the depth of natural supports, less than 4% report having more than three close friends, less than 8% have at least one close friend, and 21% indicate a sibling or cousin as part of their ongoing natural support system; 92% of respondents do not have at least one close friend.

Creating a special needs trust (SNT) is essential to future planning. However, it only addresses one of the four key planning issues: legal. Different types of SNTs serve specific purposes. The other three key issues of planning are government benefits, budget financial projections, and lifestyle planning.

# People who will likely be present and active in the future as a natural support system include:

Mother	71%
Father	66%
Neurotypical sibling	13%
Stepfather	11%
Stepmother	10%
At least 1 close friend	8%
Grandparents	<b>7</b> %
Sibling with A/I/DD	6%
Aunts/uncles	4%
Cousins	4%
More than 3 close friends	3%

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

The lack of a natural support system puts adults with A/I/DD at risk of abuse, neglect and/or unmet needs. Sobering data indicate the need for greater awareness and opportunities to help adults with A/I/DD build friendships and their natural support system prior to the loss of their parents. It must also be underscored that natural support systems should not be relied upon too heavily for direct caregiving instead of the use of waiverfunded long-term support services or other public benefit systems.

## TOP 5

Self-advocate concerns for the future



Loss of funding for services

2

Limited transportation options



Victim of mate-crime



Concerned with being lonely



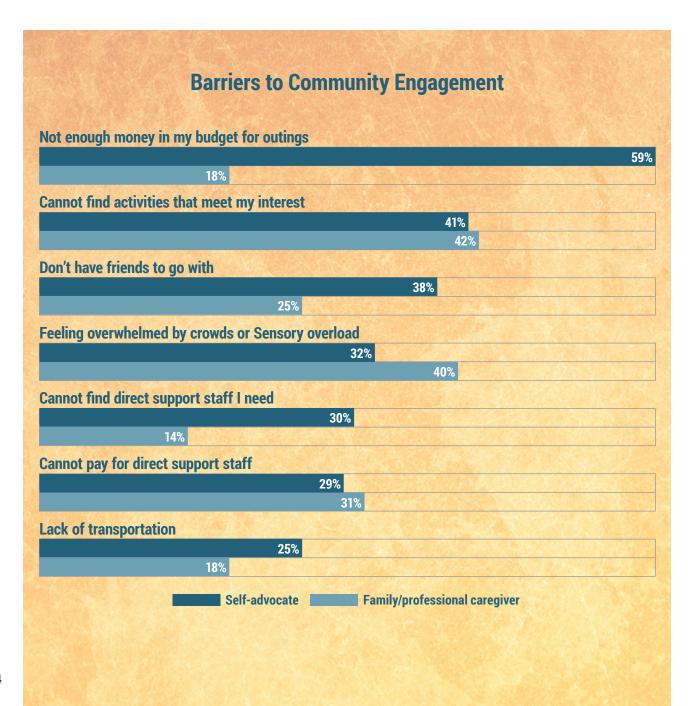
Concerned with being abused

## Barriers to Community Engagement

Despite progress in enforcement of ADA compliance in community buildings and facilities, the top barriers adults with A/I/DD face for community engagement are not related to ramps or use of braille as accommodations. For respondents, their biggest barriers to participating in community life include not having enough money in their budget, not having friends/staff to participate with, being unable to find activities that meet their interests, and experiencing sensory overload.

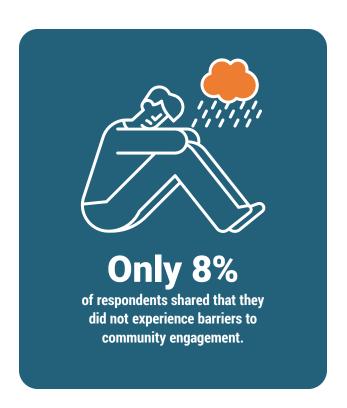
## It is significant that 91% of survey respondents indicated that they or their family members with A/I/DD experience loneliness.

Loneliness is a major public health concern and has a significant ripple effect on one's mental health and support system. In May 2023, the U. S. Surgeon General Dr. Vivek Murthy released a new Surgeon General Advisory calling attention to the public health crisis of loneliness, isolation, and lack of connection in our country. The physical health consequences are equivalent to smoking 15 cigarettes a day, 29% increased risk of heart disease, 32% increased risk of stroke,



If you experience loneliness, what are your barriers to friendship?		
People do not understand how to be a supportive friend to me.	35%	
I experience too much anxiety to try to meet new people.	34%	
I do not know how to turn potential friends into long-term friendships.	28%	
I don't know where to go to meet potential friends.	28%	
I don't have money to spend on outings with friends.	27%	
I have difficulty scheduling to meet with friends.	24%	
I accidentally do things that have hurt relationships.	21%	
I have lack of transportation to see friends.	15%	
I see my friends as much as I want.	9%	
I need staff support to see my friends.	7%	

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



50% increased risk of developing dementia for older adults, and more than 60% increased risk of premature death.<sup>46</sup>

Already experiencing physical and mental health disparities, decreasing loneliness in this population can have significant effects. Noted in the data and needing addressing is that the greatest barrier adults with A/I/DD face when developing and maintaining relationships involves the need for the **neurotypical** population to better understand how to engage with the neurodivergent population.

"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."

These barriers can be mitigated by developing more neuro-inclusive spaces for relationship building. Planned and mixed-use residential communities can develop a built environment designed for soft social interactions with supportive amenities to facilitate greater social opportunities and engagement. Whether in public spaces, such as recreational centers, or addressed in intentional design in future community assets, community integration and a feeling of belonging do not happen spontaneously when people with and without disabilities coexist in a geographic location. It requires intentional community-building and practice that seeks continuous feedback from self-advocates, family members as well as the broader community to understand the needs and preferred relationship-building activities to create more neuro-inclusive environments.



 Self-advocate respondent, Autism After 21 Utah Project



"We have financial resources and a townhouse for use, but we are unable to move forward due to the inability to find staff, helpful neighbors or other support people to utilize the bricks and mortar."

Salt Lake Valley Housing Market Analysis participant



Preferences data in this section are compiled from the 2023 Salt Lake Valley Neuro-Inclusive Housing Needs & Preferences Survey unless otherwise noted. The data provide information from respondents with A/I/DD and/or their families about their future needs and preferences for housing, services, and community engagement. The next section offers details about data-driven recommendations to meet demand.

## Individualized Long-Term Support Services

As noted in the Neuro-Inclusive Housing Framework in the Introduction, an individual's housing, service delivery model, and service provider no longer need to be inextricably connected. In this example, Olivia's parents bequeathed their home so she could choose her preferred housemates. They would all

pay rent to a special needs trust in which the house is held for her protection.

### Possible living arrangements and service delivery options Olivia may choose:





(A) Olivia lives with two housemates who have A/I/DD and they choose to hire the same service-providing agency that schedules rotating staff to meet their collective needs.



(B) Olivia lives with a caregiver and the caregiver's child in a shared living arrangement.



(C) Olivia lives with two housemates. One housemate does not have A/I/DD. Olivia and her support team hire support staff through self-direction,



#### **Self-Directed Support**

An individual who needs LTSS is given a budget to spend on their LTSS based on an assessment of their support needs. They are responsible for recruiting, hiring, training, scheduling and firing support staff. Some states allow family members to be hired as support staff.

#### **Rotational Staffing**

An individual who needs LTSS selects an agency that provides LTSS to recruit, hire, train, schedule and fire support staff for them.

#### **Shared Living**

An individual with LTSS needs invites a person or family member(s) to live in their home to provide LTSS. Because private homes are consumer-controlled settings, the individual can ask their LTSS provider to move.

#### **Host Home**

An individual with LTSS needs lives in the home of their LTSS provider. As a provider-controlled setting, the LTSS provider (host) can ask the individual to move.

#### **Paid Neighbor**

A person who lives on the same property (but not in the same home) as an individual with LTSS needs, who can offer LTSS on a scheduled or on-call basis. This is also referred to as a resident assistant.

#### **Remote Support/Monitoring**

When possible, an individual may have their LTSS needs met via remote service, using technologies such as video conferencing, smart-home devices and other **enabling technology**.

which sometimes includes her neurotypical roommate. Her third housemate uses a different agency providing remote support.

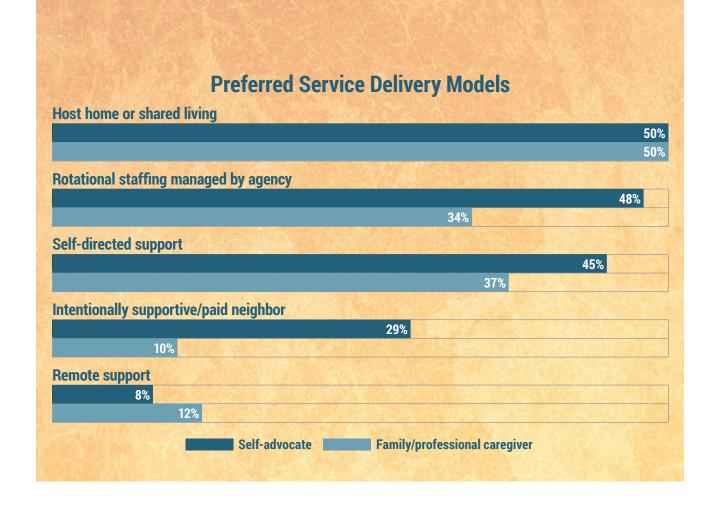
After being informed of the considerations and benefits of various service delivery models, both self-advocates and neurotypical respondents indicated their preferred service delivery models.

### Preferred Service Delivery Models

In the expanded survey, it is worth noting that shared living (a consumer-controlled, live-in caregiver option) ranked three times higher than Host Home arrangements. This was not segmented in the plain-language materials or survey. In the plain-language survey, we asked participants "Who do you want to control your housing?" The majority of respondents desired a provider-controlled setting. This may be due to the added responsibilities or stress of maintaining a household and/or ensuring they have access to a service provider, as loss of services was one of self-advocates' greatest fears.

Agency-based rotational staffing is currently the most utilized service delivery model in Utah and was also ranked desirable by 50% of survey respondents. Self-directed support was ranked third most preferred, also at 50%. In Utah, this service delivery model is called self-administered services (SAS).

Who do you want to control your housing?	
Provider-controlled: I find a service provider I like and move into their housing.	<b>72</b> %
Consumer-controlled: I find and control my own housing. I choose any service provider I want.	28%



There are several discrepancies between other service delivery options preferred by survey respondents and what is predominantly used and potentially available in the future in Utah:

- Although having a live-in caregiver is indicated as the most preferred service delivery model (shared living or host home) by 59% of respondents, this service delivery model is least utilized as an out-of-family home service delivery model in Utah.
- The Limited Supports Waiver has an annual total spending cap of \$20,834 and thus likely not appropriate as an out-of-family home waiver option for those who have moderate, 24/7, or 1:1 support needs, which is nearly 65% of survey respondents.
- It is unclear if SAS is being used for adults with A/I/DD who have 1:1 or 24/7 support needs.

 An intentionally supportive/paid neighbor service delivery model was indicated as desirable by 26% of respondents and a majority of self-advocates. However it is unavailable as a waiver-funded service in Utah. New York Office of Persons with Developmental Disabilities (OPWDD) offers a waiver-funded, paid neighbor model through the state's equivalent of DSPD.<sup>47</sup>

Although rated the least desirable, 11% of respondents indicated a preference for remote support that is also unavailable as a waiver-funded service in Utah. Seventeen states have become **Technology First states** and offer state or waiver-funded models that include remote support/monitoring. Remote support/monitoring is defined as the use of technology to provide real-time assistance by a direct support professional from a remote location. This service often reduces the number of in-person personal care services needed by an individual while enabling safety, privacy, and independent task completion.

Do you want to rent or buy your future home?		
Remain in current family home and family will move out	30%	
Rent my own home, but need rental assistance to afford housing	29%	
Rent my own home	20%	
Rent a room in a provider-controlled setting	20%	
Buy a home	20%	
Prefer to buy a home, but need assistance to afford to finance it	10%	
Buy a home together with others	8%	
Add an accessory dwelling unit to my family property	7%	

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

CMS is reviewing flexibilities one state at a time in consideration of remote and virtual supports—temporarily approved during the COVID-19 public health emergency—becoming permanent. States request that the most efficacious become ongoing support options; these include commercially available and, in most cases, affordable options like Ring doorbells, Alexa, real-time/two-way and interactive video to help with cooking, sensors and wayfinders.<sup>49</sup>

#### Renting Versus Homeownership

Home ownership is a highly preferred option indicated by survey respondents, especially since the rental market can be unstable for those on a fixed income. Families are also concerned that their loved ones could be evicted without access to another home as a safety net, be displaced, or experience homelessness due to a lack of alternatives.

Most housing assistance programs are focused on subsidized units or use of a housing voucher. Home-buying assistance is often restricted to "owner-occupiers," preventing adults with A/I/DD who may need the protection of a special needs trust to protect their asset or preventing parents from using these important tools to invest in stable housing for their dependent loved one.

As the majority of adults with A/I/DD will likely be extremely low income over their lifetimes, there is a financial argument for helping individuals and/or their families purchase a home instead of using a rental subsidy over decades.

By developing tools and housing stock targeting homeowners with A/I/DD or their family, housing stability can be insured and the limited resource of housing choice vouchers or subsidized units can be preserved for those who cannot buy or prefer a rental option in the typical housing stock. Incentives should be created for landowners, developers, and families to drive the development of attainable home-ownership options.

Without assistance, only a small percentage of families would be able to purchase a home for their dependent loved one. This opportunity may provide additional, naturally occurring affordable housing if the person desires to rent a room to someone else in the purchased home. Mortgage products developed to help owner-occupied, low-income households

РНА	Average monthly rental subsidy <sup>50</sup>	For 30 years	For 30 years with projected inflation <sup>51</sup>
City of Salt Lake	\$840.89	\$302,720	\$487.921
Salt Lake County	\$889.70	\$320,292	\$516,243

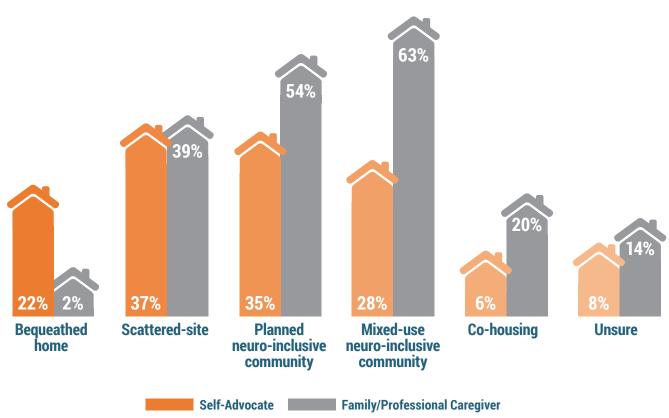
may need to be modified to allow for the purchase of a property for a low-income dependent with A/I/DD. For those who prefer to remain on a family or friend's property, allowing use-by-right accessory dwelling units (ADU) for dependent family members, individuals with A/I/DD, or seniors could help increase housing options for this population, as well as others.

Homeownership should be an option incorporated into plans to meet the housing needs of adults with A/I/DD, in addition to rental subsidies for those who prefer to rent.

#### **Housing & Development Type**

After learning about the benefits and considerations of various development types, it was clear that Utah residents desire diverse development and housing types.

#### What type of housing setting are you interested in?



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



#### Development Type<sup>13</sup>

#### **Bequeathed Home**

The home in which a neurodiverse family currently resides is maintained as the primary residence for the adult family member/s with A/I/DD when other family members pass away or move out.

#### **Scattered-Site Housing**

A residential unit located within the general housing fabric of a community. It is not part of a housing development that serves a specific residential market. In affordable housing circles, scattered-site housing also refers to affordable housing dispersed throughout the community.

#### **Planned Community**

Small- or largescale, planned property with multiple residential units and amenities that meets the targeted demand of neurodiverse tenants. Property management helps maintain housing and common spaces with the intent of making life as convenient and enjoyable as possible while supporting connection and belonging.

#### **Mixed-Use Community**

Largescale residential development of commercial, public and private uses with robust, curated amenities to give residents the experience of living in a self-contained community. Amenities are open to the public and may provide additional community engagement or employment opportunities.

#### **Cohousing**

A neighborhood or apartment/condominium created by its residents. Cohousing communities typically feature private residential units, a large community center or common house with amenities and pedestrian-oriented design. The property is designed and managed by residents. Many host weekly common meals and events prepared/organized by residents.

What unit type are you interested in?		
Apartment/condo	<b>54</b> %	
Small cottage home or patio home	40%	
Townhome	25%	
Accessory dwelling unit (ADU) (e.g., mother-in-law house, etc.)	23%	
Single-family home	12%	

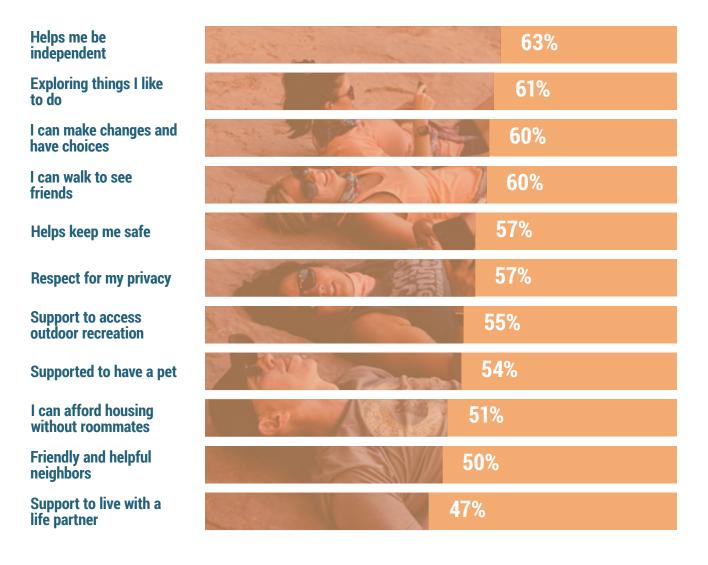
\*Does not total 100% because respondents could choose more than one answer.

Using existing housing stock, bequeathing a family home and adding an ADU, as well as helping to identify accessible scattered-site housing, should be explored. In Massachusetts, a local community passed a use-by-right bylaw to add an ADU to a family property for a dependent loved one. This bylaw removes the barrier of having to invest time and money into an application that may or may not be approved by local government. This effort is now headed to the state level as a bill, giving individuals and families another option for investing in housing stability while adding more affordable units to existing neighborhoods. More research is needed to understand why self-advocates highly ranked the desire for their families to bequeath their home while family caregiver respondents ranked this option the lowest of all options.

Neuro-inclusive planned communities and neuro-inclusive, mixed-use planned communities were the highest ranked development types preferred by survey participants. This may be due to the additional accessibility features, safety net, and supportive amenities these options provide that are unavailable in scattered-site housing. A neuro-inclusive planned or neuro-inclusive, mixed-use planned community is designed for the accessibility needs of adults with

A/I/DD but could benefit anyone who chooses to live in a neurodiverse community, regardless of whether they have a disability. The Autism Housing Network website at autismhousingnetwork.org provides examples of neuro-inclusive planned communities and neuro-inclusive mixed-use planned communities using a variety of housing types, including townhomes, small cottage homes, and single-family homes with attached ADU.

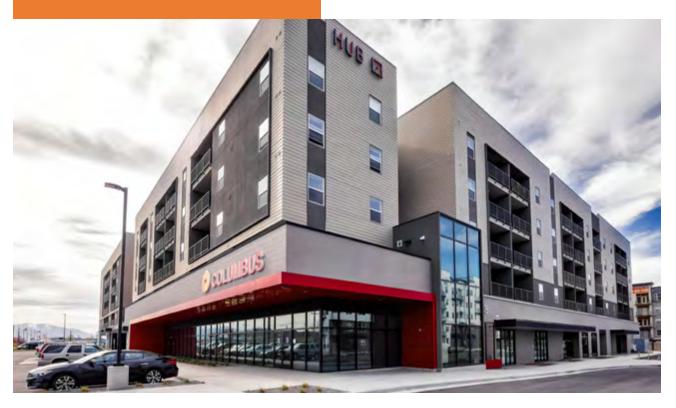
#### What is important for your future home and supports?



## Salt Lake City's Hub of Opportunity

The Hub of Opportunity in Salt Lake City is an example of a neuroinclusive. mixed-use community. pedestrian-oriented, The 157-unit apartment building offers full transit access and incorporates affordable and market-rate 1-3 bedroom units. A full range of amenities includes a communal space and kitchen, sensory room, gaming room, computer lab and two workout centers, as well as a library, large walkable courtyard including community gardens, children's play center, outdoor movie theater, BBQ grill and fire pits, and hammock park. On-site retail and commercial space includes a STEM Education Center, Auticon, a coffee shop, barber shop and English/Spanish learning Center. The Hub is also home to the NextWork Academy, a post-secondary transition program for neurodivergent adults, and the Columbus Community Center.

As states review and execute their HCBS Statewide Transition Plan (STP). this information sheds light on the diverse preferences of living options, including neuro-inclusive, mixed-use, and planned communities. Residents of the model examples included in the Salt Lake Valley Neuro-Inclusive Housing Market Analysis Learning Session are able to create their own schedule, select their preferred service provider and service delivery model, as well as come and go as desired. These options are not only wanted, but when thoughtfully designed can foster integration into the greater community with the potential to enhance overall social well-being and mental health.



#### **Physical Amenities**

Many adults with A/I/DD do not have accessibility needs related to mobility devices and ADA compliance. Their accessibility needs have a different origin of impairment, often impacting safe social interaction, independent living skills, atypical sensory perception, etc.

Features that meet the preferred accessibility needs of adults with A/I/DD include age-in-place adaptability so residents do not have to move if their mobility changes.

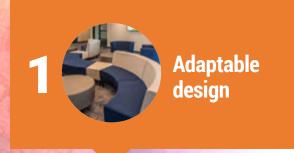
Smart-home features include reminders if an oven is left on or a door is open, remote temperature control, and door-locking capabilities. Mate-crime and bullying necessitate the incorporation of security features such as keycard access for easy entry or a video doorbell system to have a trusted person help them decide if it's safe to open the door to someone they do not recognize due to face blindness. Pedestrian-oriented also means human-centered mobility design that makes walking around one's community safer for those who do not drive or are

#### What type of physical amenities would be helpful?



## TOP 5

Requested design features and physical amenities











challenged by depth perception, making it difficult to cross roads.<sup>53</sup> Extra-durable and easy-to-clean features are valued for easier maintenance and longevity of fixtures. These are all examples of modifications and design strategies that were preferred by respondents and may also be attractive to neurotypical residents.

Stakeholders with A/I/DD have made it clear that access to neuro-inclusive mental health practitioners is difficult. A 2019 Utah-based longitudinal study of suicide in autistic people concluded that autistic youth were twice as likely to be at risk for suicide and that autistic females died from suicide three times more often than their neurotypical peers.<sup>54</sup> With a higher co-occurrence of depression, anxiety, and other mental health challenges, a mental health clinic that caters to the neurodivergent population would be a groundbreaking model for more innovative mental health services.

A place to eat meals with others was ranked in the top 5 preferences for opportunities within walking distance or on a potential residential property. This may be due to the high executive functioning load required of single residents for solitary efforts including but not limited to: meal planning, budgeting, transportation to/from a grocery store, maneuvering the sensory challenges of a grocery store, meal preparation, eating a meal alone and cleaning up. Planning group meals or potlucks with access to a common dining area may help alleviate added responsibility and isolation. A common dining space can also help in the creation of community, provide increased social opportunities to decrease feelings of loneliness and increase a sense of belonging. Eating a meal with others is a powerful, enduring way to build relationships.

Federal Medicaid HCBS compliance guidance documents—provided to assist state agencies to ascertain if a residential setting may meet the basic characteristics of a Medicaid HCBS, as required by regulation—make reference to

#### What things would you like on the property or within walking distance?

Access to public transportation	64%
Mental health clinic	63%
Movie room or theater	63%
Park or green space	62%
Restaurant/food court	62%
Walking/bike path	<b>59</b> %
<b>Grocery store</b>	58%
Hangout to watch movies	58%
Coworking space	58%
Places to eat meals with others	57%
Guest apartment for visitors	57%
Health clinic	57%
Gaming/computer room	56%
Hot tub	56%
Sensory room	54%
Gym	54%
Work opportunities	53%
Faith community	53%
Art studio	<b>52</b> %
Community garden	51%

## TOP 5

Desired amenities within walking distance or on property

Access to public transportation



Mental health clinic



Movie room or theater



Park or green space



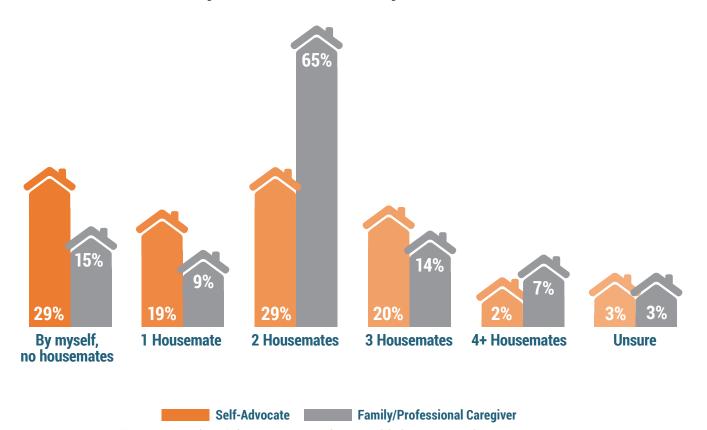
Restaurant/ food court a common dining area and access to prepared meals as a potential institutional red flag.<sup>55</sup> There may be additional licensing and survey requirements for these amenities that may add to administration and/or budgetary costs. It is important that Utah takes into account the need to create social opportunities and support how future developments can include a common area and/or voluntary meal service for residents.

## Roommates & Living Arrangements

Sharing one's home is an intimate experience. In the past, people with A/I/DD were often expected to live in a group home with multiple, unrelated individuals with disabilities in order to access services or afford housing. With extremely limited options, most were/are unable to choose housemates. Neurotypical adults often experience this type of living situation only during early adulthood in dormitories or student housing. When asked about living arrangements, self-advocates were most interested in single units or threebedroom units. Responses from individuals who do not have A/I/DD indicated a strong preference for two housemates or a threebedroom unit. Data reflected that more than 3 housemates was significantly less desirable. It is worth noting that long-term roommate matching can be a challenge and intentional communication with a liaison or mediator may be needed to resolve conflict with roommates.

Unrelated persons living together may still be evaluated as a household in various public assistance programs. Therefore, if using public assistance, it may be imperative to consider the income of housemates in order to avoid being bumped out of financial eligibility due to household income exceeding the various income threshold limits. For 2023, the federal poverty level for a one person household was \$14,580; for a two person household is \$19.720; and for a three person household is \$24,860.

#### How many housemates would you want to live with?



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

#### **Supportive Amenities**

Supportive amenities are not individualized, long-term support services. Supportive amenities are available to all residents who live at a specific property; they offer additional needed support that individualized long-term support service providers often do not offer. They also offer an alternative supportive housing option for individuals ineligible for waiver services who need supportive housing in order to remain housed, employed, and connected to their community. Supportive amenities can be provided by local community-based organizations and need not be provided by the housing developer or property management company. Housing developers can choose to partner with community-based organizations that can provide supportive amenities. These amenities should be voluntary to anyone living in their residences. Although certain supportive amenities were ranked higher than others, it is important to note that, overall, supportive amenities within housing options were highly desired overall.

"I'm considered high functioning yet under-/unemployed.

I don't qualify for services and my parents had to move to

Utah with me. When they're gone, then what?"

 Self advocate respondent, Salt Lake Valley Housing Market Analysis survey

#### Would these supportive property amenities help you?

Community navigator	64%
Life-skills training	63%
Community life	61%
Resident assistant	60%
Workplace/vocational support	60%
Housekeeping service	58%
Meal service	58%
Health/fitness activities	55%
Benefits counseling	53%
Transportation assistance	50%



#### Supportive Amenities<sup>13</sup>

#### **Community Navigator**

A front desk and/or designated person in the building who can help residents connect with the community or problem solve.

#### **Life-Skills Training**

Independent living classes such as cooking, budgeting, time management, etc.

#### **Community Life**

Planned social activities or organized weekly gatherings based on resident interests.

#### **Resident Assistant**

A front desk and/or designated person in the building who can help residents connect with the community or problem solve.

#### **Meal Service**

Option to purchase prepared meals from an on-site restaurant, café, dining hall or meal plan.

#### **Benefits Counseling**

Assistance in understanding and navigating government programs and/or privately funded savings programs without legal/financial advice or case management.

## Would any of these extras be helpful in your home? (plain-language responses)

Classes to help me stay healthy	53%
A front desk where I can ask questions or get help	51%
Classes that help me become more independent	51%
Fun things that someone else plans. I can choose to join or skip	32%
Someone to help me clean	25%
A therapist to talk to about hard things in life	23%
Someone to help me find a job	23%
Someone to help me connect with people or places	14%
Someone to help me manage my money	13%
Emergency help button in my home	6%
Affordable, already cooked meals	2%

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

"Utah waivers still exclude a

large portion of the autistic

community... [Eligibility] is

currently decided by abled/

neurotypical people and misses

the scope of dynamic disability."

- Whitney Lee, Founder and Director, Neurodiverse Utah

## TOP 5

Requested supportive amenities



Community navigator



Life-skills training



Community



Resident assistant



Workplace & vocational support



#### **Location & Transportation**

When asked about location, respondents indicated both urban downtown and suburban Salt Lake Valley as nearly equal preferences, even when segmented by self-advocate and family/professional caregiver. Nearly a quarter of respondents preferred living outside of Salt Lake Valley. Feedback from stakeholders indicates that individuals and families may relocate to Salt Lake Valley or other areas of Utah for better access to services. According to a 2022 DSPD report, 18% of clients have reportedly relocated to access services.<sup>38</sup>

Of interest are the 14% of family caregivers who indicated they would be willing to relocate to another state to find a residential solution. Not only could this displace an individual and their natural support systems developed over years, but the economic value of the family unit could also be at risk. Utah has the 15th highest waiting list in the country and 17 states report no waiting list.<sup>58</sup>

## Which of the following areas would you prefer to live?

Suburban Salt Lake City	48%
Downtown Salt Lake City	43%
Outside Salt Lake City but in Utah	24%
In a different state outside Utah	14%

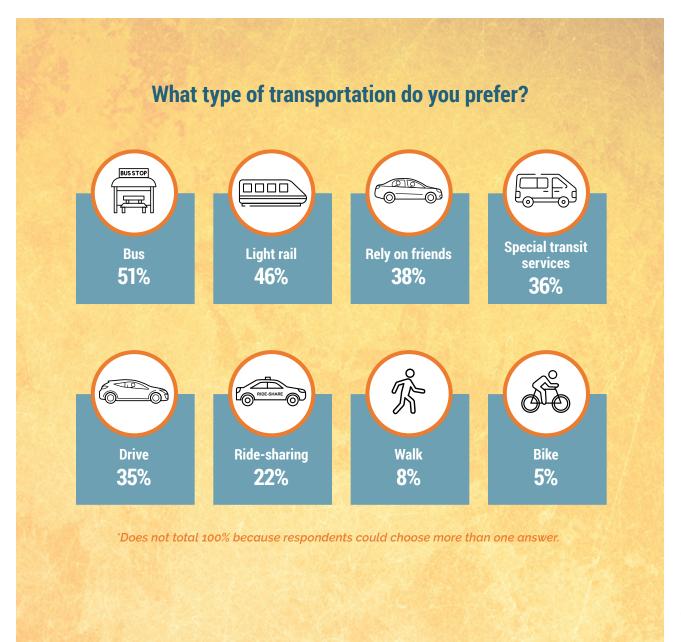
\*Does not total 100% because respondents could choose more than one answer.

"[Residential choice] is an issue that really needs to be addressed in our state."

 Salt Lake Valley Housing Market Analysis family caregiver survey respondent Respondents indicated using a wide variety of transportation options. As only 35% of respondents drive, neuro-inclusive properties do not need as much parking and would benefit from transit-oriented or walkable locations. The inability to get to where they need to go was one of the top five concerns of self-advocates. Additional transportation options to popular locations in the community may be a valuable supportive amenity considering that public transportation may be too overwhelming. expensive, or inaccessible for some adults with A/I/DD. More research is needed to provide additional insights that can help foster solutions and remove this persistent barrier to community engagement.

#### **Transitioning from Family Home**

Moving from a family home setting can be daunting for both neurotypical and neuro-divergent young adults. Adults with A/I/DD may have been living in the family home for decades longer than—and change may be more challenging for—a neurotypical counterpart. Changing environments, daily routines, transportation routes, and the stress of leaving the stability of the family home require greater direct support during such a significant transition. Residential post-secondary transition programs operate across the country, as well as in Utah. Programs typically range from two to four years where adults



# Would you be interested in a residential transition program to help bridge the gap between the family home and independent living?

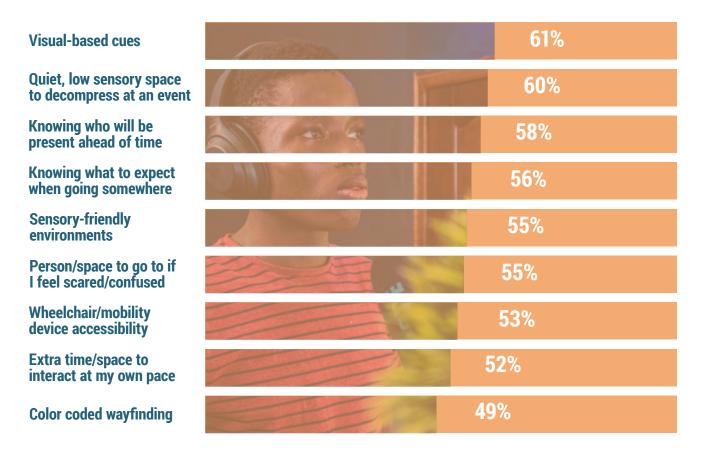


with A/I/DD live outside of the family home and receive intensive life skills training while also doing job exploration and internships or attending college. The goal is for attendees to leave the program needing fewer long-term support services and be well established in navigating and participating in the greater community. Data indicate that 74% of self-advocates and 66% of family/professional caregivers desire a residential post-secondary transition program as a bridge to independent living.

In Utah, this type of programming is only offered by private-pay providers since there is no waiver service to cover the cost. More research is needed into existing Utah programs to understand the potential cost-savings of Medicaid long-term support services or effects on homelessness due to participation in the program.

Columbus Community Center's NextWork Academy is one such transition program in Salt Lake Valley, currently graduating their first cohort of participants after a three-year program of life skills courses and living full-time in training apartments. Initial outcomes for participants have been positive, indicating increased independence and comfort in every single one of the 13 skill areas assessed, such as social skills, self direction, and community use. Even more significantly, 85% of participants who are graduating from NextWork Academy have been able to gain the skills needed to move out of the training apartments at The Hub and into their own apartments in the community. Transition programs can equip individuals with A/I/DD with the tools needed for independent living, but the high cost is still prohibitive for many families. Increased funding or support is needed to make transition programs available to all socioeconomic groups, rather than only those who can afford to pay the full cost out-of-pocket.

## How important are these elements in making community events and spaces more accessible for you?



As caregivers continue to age, they will need assistance to plan for the transition of their loved one from the family home into another setting. Waiting until a crisis is not only traumatic for all involved, but it removes the routine and stability of the family home and the chance to find the optimum fit. There is limited support available through DSPD or the Utah Independent Living Center due to lack of funding.

Offering robust and well-funded housing and lifespan navigators could assist families in understanding their housing and support options, including their ability to invest in housing stability for their loved one, thereby potentially avoiding placement in an unwanted setting, as well as more expensive institutional settings such as a psychiatric facility, state ICF, skilled nursing home, emergency room—or ultimately homelessness.

# TOP 5 Desired future opportunities

1

Connect people to buy or rent together

2

Help families bequeath or buy a home for a dependent



Help families plan for the future



Help families get needed services

5

Help families find more housing assistance

#### **Community Development**

With 65% of respondents reporting that they do not drive, local planners and community development professionals play an integral part in ensuring that adults with A/I/DD are able to access housing in a location with walkability and/or close proximity to public transportation. With land a limited commodity, land banking and/or utilizing a community land trust to secure properties as ideal locations for neuro-inclusive, mixed-use, or planned communities is critical to ensuring that affordable, accessible housing is not located in a food desert or does not isolate residents who cannot drive.

The survey also included elements making spaces more accessible to the neurodiverse population. Housing is one element of community development. Local planners and businesses can use this data to continue making Salt Lake Valley more neuro-inclusive.

These elements could be incorporated into local festivals and markets, Utah Utes football games and other sporting events, the Utah State Fair, public comment sessions at a City Hall, or other community activities. Not only does this increase accessibility for neurodiverse families and self-advocates, but it is also of value to neurotypical participants.

The Autism After 21 report offers a Community Events Toolkit with some considerations to help make events more neuro-inclusive. From ensuring neurodivergent representation on the event planning committee, to creating sensory-friendly areas, this toolkit has ideas to get you started and make sure that everyone in the community has access to gatherings that are a part of public life.



#### **Community Events Toolkit**

	Consider	Try this
Planning Committee	How are we ensuring neurodiversity is represented on our committee?	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?	Share Americans with Disabilities Act (ADA).  Implement a pre-event online accessibility request and feedback form.  Create a color-coded event venue map with support areas clearly identified.

"Housing SLC: 2023-2027"

envisions a more affordable

city for everyone and prioritizes

individuals and households

who face the greatest

risk of housing insecurity,

displacement and

homelessness."

— Housing SLC: A Five-Year Housing Plan<sup>59</sup>



Salt Lake City and Salt Lake County have compiled extensive and detailed plans to address housing needs throughout the valley; however, the data in this report demonstrate that adults with A/I/DD are largely invisible in current efforts. Based on the Implementation Plan in Housing SLC: 2023-2027, autistic adults and individuals with I/DD can be included in multiple places and their housing needs addressed.<sup>59</sup>

For example, the plan proposes early steps, such as forming a workgroup and conducting data collection for annual reporting. We recommend simple adjustments, such as recruiting A/I/DD representation to the workgroup and specifically seeking data from adults with A/I/DD and neurodiverse households.

Appendix A includes a comprehensive table of suggestions based on the strategies in place from the Housing SLC: 2023-2027 Implementation Plan. Incorporating neurodiversity into existing plans can help address housing needs and prevent those living with senior caregivers from experiencing displacement or homelessness.

The following are additional recommendations derived from Local Leaders Workshop feedback and analysis by Neuro-Inclusive Housing Solutions.

### **Closing Data Gaps**

- Segment the homeless management information system (HMIS) or point-in-time (PIT) data to identify adults with A/I/DD experiencing homelessness.
- Modify DSPD case management tools to identify individuals with A/I/DD living in a provider-controlled setting but desiring a consumer-controlled setting who have been involuntarily displaced due to the lack of affordable, accessible housing.
- Identify adults with A/I/DD living in family caregivers' homes. Segment by those who would meet eligibility criteria for waiver services and those who do not or would likely not meet eligibility criteria yet have supportive housing needs.
- Determine methods and work with partner agencies to identify households by race and ethnicity who have a child or adult dependent with A/I/DD living in the home.
   Determine whether they are cost burdened due to housing costs (spending more than 30% of income on housing).
- Categorize utilization rates by residents with A/I/DD currently receiving a Housing Choice Voucher, 811 Project Rental Assistance or other permanent rental subsidy; distinguish utilization rates of residents with A/I/DD currently living in public housing or in Permanent Supportive Housing.
- The Utah Independent Living Center offers navigation services to people with disabilities to help them understand and apply for affordable housing, housing vouchers, SNAP, etc. They are underfunded to meet the needs of the A/I/DD community and can be a key source for additional data collection.

### **Increase in Homeownership**

- Develop a homeownership guide to help individuals with A/I/DD and their families understand how to invest in stable housing when financially possible.
- Develop a guide, model neuro-inclusive plans, and other needed tools for neurodiverse families to add an ADU to their property.
- Identify the interest of local Community Development Financial Institutions and/or the Utah Housing Corporation to develop a mortgage product for families to invest in housing stability for their low-income, dependent adult with A/I/DD.
- Develop a tax incentive for Utah families who can invest in housing for their dependent, low-income family members with A/I/DD.
- Increase awareness of demand for housing targeting adults with A/I/DD and their families with the Salt Lake Home Builders Association.
- Increase local community land trusts' awareness of the demand for housing targeting adults with A/I/DD and their families.

#### **Rental Subsidies**

- Develop an A/I/DD-specific rental subsidy program or other Housing First approaches that streamline housing to those with A/I/DD without preconditions that offer supportive services or case management.
- Increase funding for the Community-Based Housing Allowance program, a state-funded program for adults currently served by a DSPD waiver.
- Prioritize low-income adults with A/I/DD and/or those receiving DSPD services in Housing Choice Voucher (HCV) waitlist applications.
- Decrease trauma while supporting smoother transitions from the family home by ensuring policy requirements for housing assistance programs do not first require homelessness or institutionalization as prerequisites for access to assistance.
- To prevent unintended discrimination, offer educational opportunities to landlords, property managers, and developers to help them better understand how people with A/I/DD access their long-term support services, what they offer as potential tenants, and their unique financial and legal arrangements.
- Develop incentives for landlords to offer leases to tenants with A/I/DD.
- Develop training and plain-language materials for adults with A/I/DD to understand their tenant rights.

# Increase Development of Neuro-Inclusive Mixed-Use & Planned Communities

- Prioritize adults with A/I/DD within the Utah Quality Allocation Plan to incentivize developers to create integrated, neuro-inclusive housing.
- Earmark funds for neuro-inclusive housing and/or efforts targeting adults with A/I/DD within the Olene Walker Housing Loan Fund, Salt Lake County Housing Trust Fund, and/ or Salt Lake City Housing Trust Fund.
- Develop a funding source or incentives for new construction or rehabilitation that creates additional units incorporating universal and neuro-inclusive design elements. This could be activated via a community land trust or a modification to existing funding mechanisms.
- Using a model recently launched by the Colorado Housing and Finance Authority, offer Pre-Development Technical Assistance grants to land owners, such as local nonprofit faith communities, local planning departments, and developers, to hire consultants and/or conduct feasibility activities to explore creation of more local neuroinclusive solutions.<sup>60</sup>

### **Long-Term Support Services**

- Increase funding and/or legislative action to make waiver services available to all adults with A/I/DD living with a caregiver over the age of 60 or at risk of displacement into more expensive and restrictive settings than needed.
- Identify a pathway to prevent homelessness of adults with A/I/DD deemed ineligible for long-term support services but in need of case management and drop-in support.
- Create a funding stream for supportive amenities that can be provided by community-based organizations in existing or planned housing developments.
- Consider adding the full range of housing services available in other states for Utah waiver recipients. These include pre-tenancy supports, housing stabilization services, transitional housing services, tenancy sustaining services, etc.<sup>61</sup>

- Ensure Self-Administered Services is available as a service delivery model for all adults with A/I/DD regardless of level of support needs.
- Consider increasing the funding cap on the Limited Supports Waiver to meet the needs of adults with moderate support needs.
- Explore other states' use of remote/virtual support and/or a paid neighbor program to expand Utah's service delivery models.<sup>62</sup>
- Explore how to address the loneliness crisis and increase natural support systems.
- Better understand the barriers to, and gaps in, accessing mental health support.



### **Local Community Development**

- Include adults with A/I/DD in local Diversity, Equity, and Inclusion efforts to increase the visibility of Salt lake Valley's neurodivergent population.
- Include recognition of the housing needs of adults with A/I/DD living with family caregivers in future housing strategic planning documents or local comprehensive plans.
- Expand support for local housing and lifespan navigation programs, such as DSPD Housing or local Centers for Independent Living, to target individuals with A/I/DD and their families. This support better connects people to available resources while guiding them to plan for the transition out of the family home before falling into crisis.
- Practice land banking of properties within walking distance of grocery stores for future affordable housing or mixed-use, neuroinclusive planned communities.

- Offer a property tax waiver for low-income residents with A/I/DD who live in a bequeathed home.
- Modify zoning codes to allow for the addition of an accessory dwelling unit (ADU) or tiny home as a "use by right" on the property to house a dependent adult. Offer planning grants and waive fees associated with requesting approval.
- Partner with local community-based organizations to provide resources for services in accessible places (school bathrooms or where people congregate) in an accessible format.
- Encourage developers to include a set-aside of units for adults with A/I/DD in emerging multi-family developments.
- Use the Autism After 21 Utah Project report and toolkit to make publicly sponsored events more neuro-inclusive.



"For the A/I/DD population

as a whole, it is not a

question of if they will lose

their existing home and

primary caregiver, it is

a question of when."

— Desiree Kameka Galloway, Director of Autism Housing Network



Just like the neurotypical population, adults with A/I/DD seek a safe, stable, and comfortable home where they can be themselves and proud to welcome friends and family. They want to access daily neighborhood conveniences, meet people in the neighborhood, patronize their favorite places of business and feel a true sense of belonging.

Current residential options are inadequate and simply do not and cannot meet surging demand. For the A/I/DD population as a whole, it is largely not a matter of if they will lose their existing home and primary caregiver, it is a question of when. Workforce shortages, changing demographics, and a rapidly aging population mean Salt Lake Valley needs increased access to housing, services, supportive amenities, and technology to support innovation. Without planning, many members of this population will be forced into crisis placements in provider-controlled

settings, emergency rooms, nursing facilities, psychiatric hospitals, or institutional settings. They could also face homelessness or incarceration. These consequences are traumatic for individuals and their families, and they are expensive for the citizens and state of Utah.

The following are pressing, systemic challenges facing Salt Lake Valley's ability to meet the needs of its neurodiverse population:

- Lack of housing for adults with A/I/DD results in significantly increased Medicaid expenditures due to placement in providercontrolled settings or a state of homelessness.
- Current housing stock is largely inaccessible: financially, physically, and cognitively.
- No financial tool for housing developers exists that meets the needs of supportive housing targeting adults with A/I/DD.

The cost of doing nothing
will be exorbitant. Immediate
action is vital to help every
Salt Lake Valley resident find
a home and their place in
the world.

- Data on, and plans for, local housing demand do not capture the needs of adults with A/I/DD living in aging family caregivers' homes.
- Despite surging demand, no guides, incentives, or mortgage products are available for neurodiverse families to invest in stable housing for their loved one.
- Waitlists to access services persist amid a DSP workforce crisis adding to the inability of service providers to meet demand.
- This population currently lacks the natural support systems that can help thwart abuse, neglect, or isolation/loneliness when their aging parents or caregivers are no longer present.

In Salt Lake Valley, estimates indicate 15,000 adults with A/I/DD are living with a caregiver over age 60 (based on incidence and prevalence data), with many of these individuals predicted to be without formal long-term services systems. A gathering of local leaders and elected officials is urgently needed to develop a roadmap for supportive housing solutions to help prevent the displacement of and risk of homelessness for adults with A/I/DD in Salt Lake Valley.

Thanks to the efforts of the research team and participants of the Salt Lake Valley Neuro-Inclusive Housing Market Analysis, Salt Lake Valley now has market data on the needs and preferences of residential demand for this invisible population. Meeting their housing needs will result in a healthier and more stable population. This has the potential to reduce Medicaid costs, increase quality of life, and enable more effective and successful long-term planning for individuals and their families to help prevent disruptive, emergency placements and even homelessness. The cost of doing nothing will be exorbitant. Immediate action is vital to help every Salt Lake Valley resident find a home and their place in the world.

Join us in this endeavor by signing up for action alert email updates at neuroinclusiveutah.org or by reaching out to SMartinez@MadisonHouseAutism.org.



TERM	DEFINITION	
Accessory dwelling units (ADU)  An accessory dwelling unit (ADU) is a smaller, independent residential dwelling unit located on the same lot as a stand-alone (i.e., detached) single-family home. Also be referred to as casitas, granny flats, accessory apartments or secondary suites. May be converted portions of existing homes or additions to new or existing homes.		9
Affordable housing	deriversally defined as medicing in inner the codapant is paying in many	
Americans with Disabilities Act (ADA)  A 1990 act of Congress prohibiting discrimination against people with disabilities in various areas including employment, transportation, public accommodations, communications and access to state and local government programs and services.		12
Autism and/ or intellectual and/or developmental disability(ies) (A/I/DD)  A diagnosis of autism, Down syndrome, cerebral palsy, fragile X syndrome etc. A/I/DD impacts one's cognitive ability to perform activities of daily living unassisted.		7
Bequeathed home The asset of a home left through a will or as a gift to someone else. Careful planning is needed for a loved one with a disability.		9

TERM	DEFINITION	
Community land trust	Community land trusts (CLTs) are nonprofit organizations governed by a board of CLT residents, community residents and public representatives who provide lasting community assets and shared equity homeownership opportunities for families and communities. The goal is to create homes that remain permanently affordable, thereby providing successful homeownership opportunities for generations of lower-income families.	
Consolidated plan		
Consumer- controlled setting	Property where the housing provider is not connected to the LTSS provider. Residents can choose and change their LTSS providers while remaining in the same housing.	
Direct support professional (DSP)	Someone who works directly with people with A/I/DD. DSPs aim to assist people in realizing their full potential. They help people become integrated and engaged in their community.	
<b>Enabling technology</b> Various types of technological devices used to support a person with disabilities in living as independently as possible. This can include sensors, mobile applications, remote support systems and other smart devices to help individuals navigate jobs and their community, exercise more control over their environment, and provide remote support and reminders when necessary.		50
Executive function		
Extremely low income	The FY 2014 Consolidated Appropriations Act changed the definition of extremely low-income to be the greater of 30/50ths (60 percent) of the Section 8 very low-income limit or the poverty guideline as established by the Department of Health and Human Services (HHS), provided that this amount is not greater than the Section 8 50% very low-income limit. Consequently, the extremely low income limits may equal the very low (50%) income limits. Income Limit areas are based on FY 2023 Fair Market Rent (FMR) areas.	
Face blindness or prosopagnosia	A neurological disorder characterized by the inability to recognize faces.	57

TERM	DEFINITION		
Graded movement	Movements whereby a person uses the appropriate amount of force to complete motor skills. People with A/I/DD may use too much or too little force when performing actions such as opening a door, flushing a toilet, stepping down, etc.		
HCBS Statewide Transition Plan (STP)			
Home- and community- based services (HCBS)	settings. HCBS waivers are administered by state governments. Each state offers different HCBS waivers (by various names) and state-specific plans		
Homeless management information system (HMIS)  A local information technology system used to collect client-level data and data on the provision of housing and services to homeless individuals and families and persons at risk of homelessness. Each Continuum of Care (CoC) is responsible for selecting an HMIS software solution that complies with HUD's data collection, management and reporting standards.		75	
Host home (adult foster care)  Where an individual with LTSS needs lives in the home of their LTSS provider.		8	
Housing and lifespan navigators	nd lifespan for housing assistance, tenant stabilization, and guiding elements needed		
Housing assessments			
Housing choice vouchers (HCV)  Vouchers allowing qualified individuals or families to pay 30% of their income toward rent at a location of their choosing with the remainder of rent costs paid through the HCV program. The property owner of the chosen living place must agree to rent under the program (Resnik & Kameka Galloway, 2020). Qualified individuals include low-income families, the elderly and individuals with disabilities.		15	
Human-centered mobility design  User-centric transport systems with highly intuitive elements, from ticketing to wayfinding. Mobility design must be efficient, cost-effective and accessible to the widest population in order to support a growing and vibrant city. The system should be mode agnostic—whereby passengers can switch between walking or cycling, or taking a bus, tram or car for optimum flexibility—but also inherently resilient if there is failure of one mode or maintenance is required. Ticketing systems and real-time information should enable seamless end-to-end journeys across all modes		57	

TERM	DEFINITION			
Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/	An optional Medicaid benefit created by the Social Security Act (SSA) to fund "institutions" (4 or more beds) for individuals with intellectual disabilities. The SSA specifies that such institutions must provide "active treatment" as defined by the Secretary. Currently, all 50 States have at least one ICF/IID facility. All must qualify for Medicaid assistance.			
Land banking	Public authorities or nonprofit organizations created to acquire, hold, manage and sometimes redevelop properties in order to return them to productive use to meet community goals, including increasing the supply of affordable housing or stabilizing property values.			
Long-term support services (LTSS)	A variety of services that assist individuals with functional limitations due to various conditions and/or disabilities in their everyday life.			
Means-tested	Limiting eligibility to individuals and families whose incomes and/or assets fall below a predetermined threshold (means test).	41		
Medicaid state plan  An agreement between a state and the federal government describing how that state administers its Medicaid and Children's Health Insurance Programs, or CHIP. It assures that a state will abide by federal rules and may claim federal matching funds for its program activities. The state plan establishes what groups of individuals are to be covered, services to be provided, provider methodologies to be reimbursed and the administrative activities underway in the state.		12		
Natural supports	,			
Neuro-inclusive planned community  Small- or large-scale planned property with multiple residential units that meets the needs of neurodiverse individuals; also has recreational amenities that can feature commercial properties such as restaurants and shops. Property management helps maintain housing and common space with the intent of making life as convenient and enjoyable as possible whil supporting connection and belonging.		55		
Neurodivergent	Of neurological difference including autism, Down syndrome, cerebral palsy, epilepsy, ADHD and I/DD.	9		
Neurodiverse  To intentionally reflect the diversity of neurological differences in a group which includes both neurotypical and neurodivergent representation		7		
Neurotypical Of typical neurological pattern and development.		46		
Non-elderly disabled (NED) vouchers vouchers  Vouchers allowing non-elderly disabled individuals to access affordable housing. Category 1 NED vouchers allow non-elderly individuals or families to access affordable housing on the private market. Category 2 NED vouchers allow non-elderly disabled individuals currently residing in nursing homes or other healthcare institutions to transition into the community.		15		

TERM	DEFINITION	PAGE
Paid neighbor	A person who lives on the same property (but not in the same home) as an individual with LTSS needs who can offer LTSS on a scheduled or on-call basis. Also referred to as a resident assistant.	51
Person-centered planning A process of choosing and arranging needed services and supports of an adult with A/I/DD directed by the person receiving the supports.		12
Plain-language	A clear, straightforward way of communicating that allows a broad audience to understand information the first time they read/hear it.	22
Planned communities  A small- or large-scale, intentionally developed property with multiple residential units that also has recreational amenities. They sometimes also feature commercial properties, such as restaurants and shops. Property management helps maintain housing and common spaces. The intent is to make life as convenient and enjoyable as possible. This development type is usually located in suburban settings.		49
Point-in-time (PIT)  Continuums of care (CoC) are required to conduct a point-in-time (PIT)  count of people experiencing homelessness at least every other year.  CoC are also required to conduct an annual housing inventory count (HIC) documenting residential resources in their community dedicated to assisting people experiencing homelessness.		75
Pooled special needs trusts are run by nonprofit organizations set up to expertly and efficiently administer a master special needs trust on behalf or individual beneficiaries with disabilities. Assets are combined and invested together; funds are spent on beneficiaries in proportion to their share of the total amount.		41
Provider- controlled group home or setting  Property where the LTSS provider is both the landlord and sole LTSS provider. Residents cannot change their LTSS provider in a provider- controlled setting without moving to a different home.		8
Public housing authorities (PHA)		
Section 811 Project Rental Assistance	Also known as housing choice vouchers, this program allows individuals to pay 30%-40% of their income to rent and utilities while the remaining cost of both is covered.	15
Self-administered services (SAS)  A service delivery model that offers an alternative to receiving services from a provider-based agency by allowing the person, or their representative (often a family member) to become the employer. SAS services are provided in the home of the person or in their community. It is the responsibility of the employer to choose, hire, train, schedule, and supervise qualified Employees to provide services to the person and ensure SAS rules are followed.		51
Social determinants of health (SDOH)  The conditions in which people are born, live, learn, work, play, worship and age that impact health, functioning and quality of life outcomes. This is split into five domains: economic stability, education access and quality healthcare access and quality, neighborhood and built environment, and social and community context.		9

TERM	ERM DEFINITION			
Social Security Disability Income (SSDI)	<b>Disability</b> individual is "insured," meaning they have worked for a sufficient length of			
Soft social interactions				
Special needs trust				
Supplemental Security Income (SSI)	Monthly benefits provided to individuals with limited income and resources who are disabled, blind, or age 65 or older.	40		
Supportive amenities				
Supreme Court Olmstead Decision (Olmstead v. L.C. that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.		12		
Technology First states				
Utah Department of Health and Human Services, Division of Services for People with Disabilities (DSPD)  Part of the Utah government agency with a mission to promote opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provide supports for people with disabilities to lead opportunities and provides		14		
Utah Homeless Management Information System (UHMIS)  Utah's local information technology system used to collect client-level data and data on the provision of housing and services to homeless individuals and families, as well as persons at risk of homelessness. Each Continuum of Care (CoC) is responsible for selecting an HMIS software solution that complies with HUD's data collection, management and reporting standards.		8		



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# **APPENDIX**

## Recommendations for Housing SLC: 2023-2027 Implementation Plan<sup>59</sup>

## **Strategy C**

Demonstrate investment in the rehabilitation of existing uninhabitable housing stock into moderate income housing

#### **Current Action Item**

Increase funding for acquisition, rehabilitation, and development of affordable housing.

#### 2023 Goal

Convene working group to research options of increasing funding for affordable housing and develop recommendations.

#### Recommendation

Include a professional in the A/I/DD community who understands housing development and can assist with funding sources and/or strategies targeting adults with disabilities.

#### **Current Action Item**

Incentivize the purchase and conversion of hotels, motels, and other buildings to deed-restricted deeply affordable and transitional housing.

#### 2024 Goal

Develop incentive and funding strategy, work with partners to determine priority sites.

#### Recommendation

To unlock an incentive, prioritize inclusion of set-aside units for adults with A/I/DD at risk of displacement or homelessness.

#### **Current Action Item**

Adopt an adaptive reuse ordinance to facilitate the conversion of historic buildings into housing.

#### 2025 Goal

Monitor response to ordinance adoption through annual reporting on number of properties using ordinance, number of units created, etc. (ongoing)

#### Recommendation

Include data collection of adults with A/I/DD or neurodiverse households in annual reporting.

## **Strategy E** Create or allow for, and reduce regulations related to, internal or detached accessory dwelling units in residential zones

#### **Current Action Item**

Adopt revised accessory dwelling unit (ADU) ordinance to make the development of ADUs easier and more widespread throughout the city.

#### 2023 Goal

 Receive feedback from Planning Commission, City Council, and public on proposed ordinance.

#### Recommendation

Consider adding a "use by right" clause to proposed ADU ordinance to make it easier for families to add an ADU for a dependent family member (elderly, A/I/DD, or other disability).

#### **Current Action Item**

Make it easier to build tiny homes as a form of deeply affordable/ transitional housing through zoning, funding, and streamlined plan and design review.

#### 2023 Goal

Support legislation to adopt ICC/MBI building standards for modular construction in the 2024 general legislative session.

#### Recommendation

Include A/I/DD professionals or their feedback in the proposed workgroup to ensure that at least some of the pre-approved ADU plans are both cognitively and physically accessible.

#### **Current Action Item**

Monitor response to ordinance adoption through annual reporting on number of ADUs created. (ongoing)

#### 2025 Goal

Monitor response to ordinance adoption through annual reporting on number of properties using ordinance, number of units created, etc. (ongoing)

#### Recommendation

Include the number of units used for people with A/I/DD or other disabilities in monitoring and collecting data for deed-restricted ADUs.

## Strategy J Implement zoning incentives for moderate income units in new developments

#### **Current Action Item**

Adopt and implement the Affordable Housing Incentives Ordinance.

#### 2023 Goal

Work with Planning Commission, City Council, and public on Affordable Housing Incentives Ordinance.

#### Recommendation

Prioritize neuro-inclusive housing or set-aside units for adults with A/I/DD in the Affordable Housing Incentives Ordinance draft.

## **Strategy K**

Preserve existing and new moderate income housing and subsidized units by utilizing a landlord incentive program, providing for deed-restricted units through a grant program, or, notwithstanding Section 10-9a-535, establishing a housing loss mitigation fund

#### **Current Action Item**

Support projects that allow tenants to build wealth and/ or gain equity in their building based on tenure.

#### **2023 Goal**

Convene working group to research best practices for tenant wealth and equity building programs.

#### Recommendation

Include representation from the A/I/DD community in the proposed workgroup for the inclusion of units for adults with A/I/DD in a tenant wealth- and equity-building program.

#### **Current Action Item**

Support projects that allow tenants to build wealth and/ or gain equity in their building based on tenure.

#### **2024 Goal**

Develop pilot program or partnership.

#### Recommendation

Include a community-based partner for the inclusion of units for adults with A/I/DD in the pilot program or partnership.

#### **Current Action Item**

Adopt an adaptive reuse ordinance to facilitate the conversion of historic buildings into housing.

#### 2027 Goal

Monitor impact of housing developments through annual reporting on number of individuals served, number of individuals transitioned from homelessness to housing, etc.

#### Recommendation

Identify and monitor the impact of neurodivergent residents of the permanent affordable housing properties funded.

### Strategy L Reduce, waive, or eliminate impact fees related to moderate income housing

#### **Ongoing**

Continue to reduce and waive impact fees on eligible projects as allowed by Salt Lake City Code Chapter 18.98

#### **Current Strategy**

Continue to reduce and waive impact fees on eligible affordable housing developments when such waivers and reductions are applied for (ongoing)

#### Recommendation

Identify if neuro-inclusive properties can be added as an "eligible project" in Salt Lake City Code Chapter 18.98 for reduction or waiving of impact fees.

## **Strategy M** Demonstrate creation of, or participation in, a community land trust program for moderate income housing

#### **Current Action Item**

Continue to manage and expand **City's Community Land Trust (CLT)** program.

#### 2023 Goal

Convene working group to develop City's CLT strategy, including identifying priority sites for acquisition and potential funding sources.

#### Recommendation

Include representation from the A/I/DD community in Salt Lake City's CLT workgroup.

#### **Current Action Item**

Explore the feasibility of issuing home equity conversion mortgages to existing homeowners in return for a deed restriction, possibly through the City's Homebuyer Program.

#### 2023 Goal

Convene working group to research best practices and potential opportunities for a program and to develop program framework.

#### Recommendation

Include A/I/DD representation for feedback on the potential program or Salt Lake City's Homebuyer Program to meet the needs of bequeathing a family home to a dependent with A/I/DD.

#### **Current Action Item**

**Work with community development** partners to acquire priority properties for permanently affordable housing.

#### 2023 Goal

Initiate conversations with community development partners and establish shared goals and priorities.

#### Recommendation

Include developers of existing neuro-inclusive properties in conversations about acquiring properties within walking distance of needed amenities or programs targeting adults with A/I/DD.

#### **Current Action Item**

Work with community development partners to acquire priority properties for permanently affordable housing.

#### **2026 Goal**

First property acquired by the **City/Redevelopment Agency** or through a partnership with community development partner(s).

#### Recommendation

Target landowners who may be sensitive or passionate about the needs of adults with A/I/DD in the Salt Lake City CLT program and the possibility of its use for developing neuro-inclusive housing.

## **Strategy 0** Apply for or partner with an entity that applies for state or federal funds or tax incentives to promote the construction of moderate income housing

#### **Current Action Item**

Continue to partner with entities that apply for state and/or federal funds to preserve and create low to moderate income housing through annual funding opportunities.

#### **Ongoing Goal**

Continue offering annual funding and partnership opportunities through the Housing Stability division. (ongoing)

#### Recommendation

Request Housing Stability Division review of existing opportunities and offer incentives or prioritize funding to increase housing units targeting adults with A/I/DD.

## Strategy P

Demonstrate utilization of a moderate income housing set aside from a community reinvestment agency, redevelopment agency, or community development and renewal agency to create or subsidize moderate income housing

#### **Current Action Item**

Continue to release housing funds through Redevelopment Agency of Salt Lake City (RDA) Notices of Funding Availability (NOFA) for development or acquisition of moderate income housing.

#### **Ongoing Goal**

Continue to release annual Notices of Funding Availability based on affordable housing set-aside funding from project area budgets, prioritizing funding for projects based on RDA board guidance.

#### Recommendation

Explore prioritizing funding for neuro-inclusive housing in the Redevelopment Agency of Salt Lake City (RDA) board guidance.

#### **Current Action Item**

Utilize Inland Port Housing Funds and other housing set-aside funds to expand affordable housing options, including tenant equity opportunities throughout the city.

#### 2023 Goal

Convene working group to research best practices for tenant wealth and equity- building opportunities and begin developing possible programs and guidelines.

#### Recommendation

Include A/I/DD representation in the workgroup proposed for the inclusion of units for adults with A/I/DD in tenant wealth- and equity-building opportunities.

#### **Current Action Item**

Develop a financing program for low-income homeowner accessory dwelling unit (ADU) construction.

#### 2023 Goal

Convene working group to research best practices, engage potential partners, and develop framework for an ADU financing program.

#### Recommendation

Consult with Special Needs Planners to ensure the ADU Financing Program can be utilized by adults with A/I/DD and their families when the adult must protect the asset in trust.

## Strategy W

Create or allow for, and reduce regulations related to, multifamily residential dwellings compatible in scale and form with detached single-family residential dwellings and located in walkable communities within residential or mixed-use zones

#### **Current Action Item**

Adopt and implement Affordable Housing Incentives Ordinance.

#### 2023 Goal

Work with Planning Commission, City Council, and public on Affordable Housing Incentives Ordinance.

#### Recommendation

Prioritize neuro-inclusive housing or set-aside units for adults with A/I/DD in the Affordable Housing Incentives Ordinance draft.

## Strategy X

Demonstrate implementation of any other program or strategy to address the housing needs of residents of the municipality who earn less than 80% of the area median income, including the dedication of a local funding source to moderate income housing or the adoption of a land use ordinance that requires 10% or more of new residential development in a residential zone be dedicated to moderate income housing

#### **Current Action Item**

Expand workforce, artist, and essential worker housing, up to 125% AMI, so that these populations can live in the city in which they serve.

#### 2024 Goal

Develop framework, partnerships, and potential funding sources.

#### Recommendation

Explore partnership and potential funding sources with the Utah Division of Services for People with Disabilities and other A/I/DD service providers in consideration of the direct support professional workforce in crisis due to low wages and lack of staff in specific geographic areas.

#### **Current Action Item**

Establish a Community/Tenant
Opportunity to Purchase Policy at the
city level to include technical assistance,
funding, and other services and resources
offering the opportunity to purchase
before the property goes to market.

#### 2024 Goal

Convene a working group of internal staff, community partners, and residents to research best practices and develop a policy framework.

#### Recommendation

Include A/I/DD stakeholders and prioritize neuro-inclusive housing or set-aside units for adults with A/I/DD in the draft Community/ Tenant Opportunity to Purchase policy.

#### **Current Action Item**

Host regular tenant education events.

#### 2023 Goal

Convene partners and host first events; develop schedule.

#### Recommendation

Include plain-language tenant education events for cognitively accessible outreach to the A/I/DD community through Neuro-Inclusive Housing Initiative partners.

## **Strategy X (Continued)**

#### **Current Action Item**

Support community and grassroots organizations that provide displacement assistance, tenant organizing, tenant mutual aid, legal services, and other resources/efforts that help tenants.

#### 2024 Goal

Develop program to support grassroots organizations and develop parameters.

#### Recommendation

Explore the navigation and direct support needs of the grassroots A/I/DD community in developing funding opportunities or programs to meet the needs of the neurodivergent community.

#### **Current Action Item**

Develop a tenant advocate pilot program to help tenants understand their legal obligations and rights, inspect units, and connect with other resources.

#### 2024 Goal

Convene a working group of internal staff, community partners, and residents to research best practices and develop a program framework.

#### Recommendation

Include representation from the A/I/DD community for the development of the tenant advocate pilot program to include feedback on outreach and cognitive accessibility strategies.

#### **Current Action Item**

Support community and grassroots organizations that provide displacement assistance, tenant organizing, tenant mutual aid, legal services and other resources/efforts that help tenants.

#### 2024 Goal

Develop program to support grassroots organizations and develop parameters.

#### Recommendation

Review existing neuro-inclusive housing opportunities to explore how to increase funding awareness and innovation in service delivery targeting adults with A/I/DD.

#### **Current Action Item**

Improve and expand tenant resources, access to legal services, and landlord training to better meet the level of need and protect tenant rights.

#### 2023 Goal

Make changes to the Landlord Tenant Initiative to better meet needs of tenants while continuing to serve and educate landlords.

#### Recommendation

Work with DSPD on the Landlord Tenant Initiative to include education on the needs of adults with A/I/DD as tenants.

#### **Current Action Item**

Define indicators to track displacement and develop systems to track progress to better know where and how the city's anti-displacement policies and actions are working.

#### 2023 Goal

Refine list of displacement indicators to track and report.

#### Recommendation

Explore how to collect data on the displacement of adults with A/I/DD (including into a providercontrolled setting due to lack of affordable housing) when refining the list of displacement indicators.

## **Strategy X (Continued)**

#### **Current Action Item**

Convene a Regional
Anti-Displacement Coalition to
provide an ongoing platform for
cross-agency/cross-sector discussion
and collaboration on responding to
emerging issues and challenges.

#### 2023 Goal

Convene Anti-Displacement Coalition and establish regular meeting schedule.

#### Recommendation

Include representation from DSPD and others in the A/I/DD community in the Anti-Displacement Coalition.

#### **Current Action Item**

Continue supporting and expand funding for homeless street outreach programs that connect individuals experiencing homelessness with critical resources and housing.

#### 2023 Goal

Monitor metrics associated with street outreach programs, including number of residents served and connected with shelter and housing resources, etc.

#### Recommendation

Include metrics for data collection of street outreach programs to identify adults with A/I/DD experiencing homelessness.

#### **Current Action Item**

Convene a physical accessibility working group of internal and external stakeholders.

#### 2023 Goal

Convene a working group of internal and external stakeholders and establish regular meeting schedule.

#### Recommendation

Include representation from A/I/DD stakeholders in the physical accessibility working group to also include cognitive accessibility needs and preferences.

#### **Current Action Item**

Create a public-facing rental database that includes information on accessibility, rent amounts, unit conditions, etc.

#### 2024 Goal

Design and launch database.

#### Recommendation

Ensure the public-facing rental database is cognitively accessible and meets ADA guidelines. Plugins such as AccessiBe are great for increasing accessibility for the neurodivergent population.

#### **Current Action Item**

Continue supporting and expand funding for homeless street outreach programs that connect individuals experiencing homelessness with critical resources and housing.

#### **Ongoing Goal**

Based on metrics, increase funding for street outreach programs.

#### Recommendation

Include data collection of utilization and impact on adults with A/I/DD in monitoring and annual reporting.



