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GLOBAL LEADERSHIP INSTITUTE

A Place in the World

2022

Greater Phoenix HOUSING MARKET ANALYSIS

Data Driving A Place in the World for Autistic Adults and Others with Neurodiversities

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Publishers

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This seminal work would not be possible without the generous support of the Make Waves Family Foundation, Bank of America, Stardust Foundation and Dominium.

These community leaders recognize the need for future planning, funding and advancements in public policy, as well as the pressing importance of addressing the current and growing shortage of housing options—and access to supports that adults with autism and/or other intellectual/developmental disabilities want and need to thrive.

Version 1.1 published February 2023. Please refer to firstplaceaz.org/phx-housing-analysis *for the most current version. We thank our independent reviewers and others for their greatly valued feedback along the way. We will make revisions as we continue to learn—together—how best to fuel a new wave of housing and community options.*

"For three decades, our dreams for fueling a new generation of housing and community options have lived in dozens of three-ring binders, hundreds of computers files and countless hearts and minds. Today, we are working with indefatigable leaders from the public, private, charitable and nonprofit sectors to address the current housing crisis. This is our moment to stand for and with the underrepresented, underserved and underestimated through data, proof points and solutions—and together build more housing and community options for those living with autism and/or intellectual/developmental disabilities."

– Denise D. Resnik, CEO
First Place Global Leadership Institute

Photo: Daniele-Levis-Pelusi - Unsplash

Table of Contents

Executive Summary 6

Introduction 10

11 History & Evolution of Support Services
12 Person-Centered Approaches
13 Lack of Affordability Leads to Limited Choice of Living Arrangement
15 Invisible Need
19 Additional Barriers

Greater Phoenix Housing Market Analysis Process 22

23 Educational Outreach
25 Local Leaders
25 Considerations and Limitations of Process

Demographics 26

26 Disabilities Represented
28 Identified Support Needs
32 Income & Government Benefits
34 Planning for the Future
36 Concerns for the Future
38 Barriers to Community Engagement

Preferences 42

44 Individualized Long-Term Support Services
46 Renting Versus Homeownership
48 Living Arrangements
54 Supportive Amenities
56 Transitioning from Family Home
56 Community Development
59 Preferred Locations

Recommendations 61

62 Closing Data Gaps
62 Increase in Homeownership
63 Rental Subsidies
63 Increase in Development of Neuro-Inclusive Mixed-Use and Planned Communities
64 Long-Term Support Services Through ALTCS-DD
64 Local Community Development

Conclusion 65

Glossary* 68

References 77

*Glossary terms noted in bold.

2022

GREATER PHOENIX

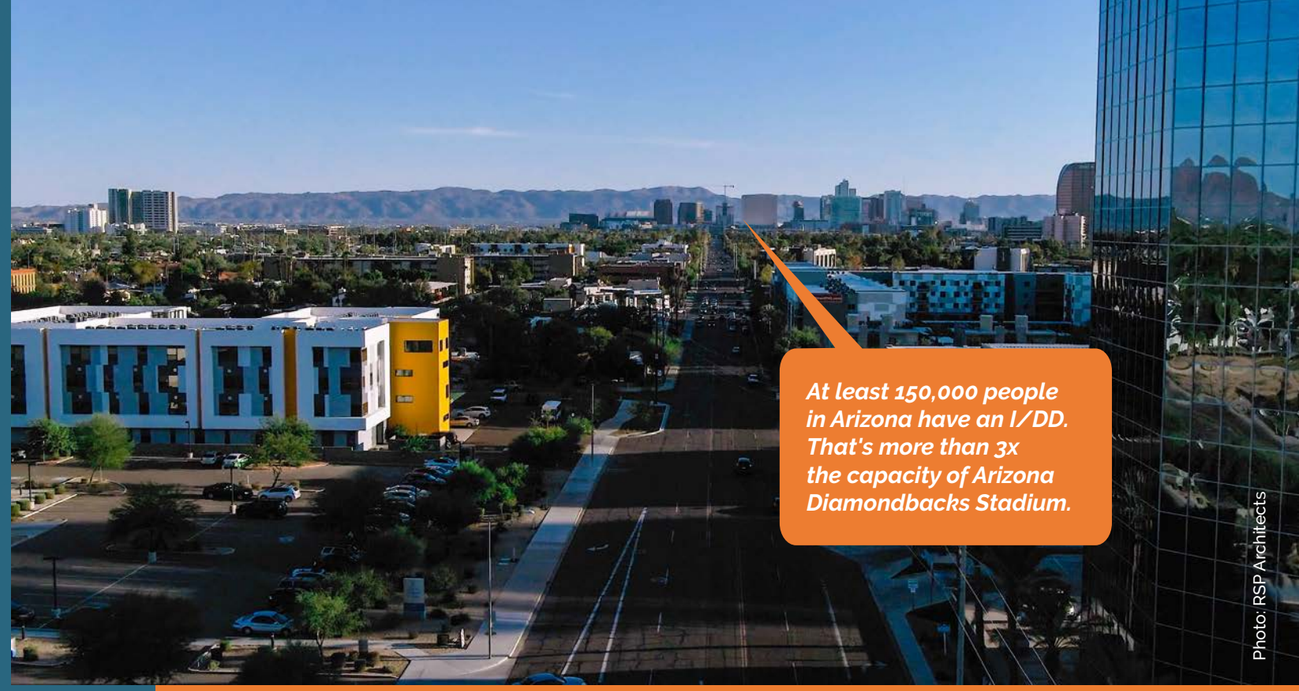
HOUSING MARKET ANALYSIS

EXECUTIVE SUMMARY

Named "the most autism-friendly city in the world," Phoenix is already a beacon of inclusion and belonging for the nation [1]. For autistic adults and others with intellectual and/or developmental disabilities, Arizona is known for providing innovative **long-term services and supports (LTSS)**, creative employment opportunities and several nationally recognized housing solutions that chose to pilot their models in the greater Phoenix area [2].

For the past 40 years since the movement to deinstitutionalize this population, families in Arizona have been supported to help their loved one remain in the family home and avoid being separated from their community in order to receive services. 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. Without housing options, this population may live with family members, whether they choose to or not, until a crisis forces a rushed placement or homelessness—potentially counties away from their home and community.

Despite the promising practices, few Arizona residents with **autism and/or intellectual/developmental disabilities (A/I/DD)** are living outside the family home with the support they need. From the data derived from **Arizona Long Term Care System (ALTCS)**, this represents about 5,000 adults with A/I/DD. Research into **social determinants of health (SDOH)** demonstrates that healthcare costs are higher when individuals are in unstable housing, lack access to LTSS and/or experience loneliness. Due to lack of post-secondary options and/or unemployment or underemployment, adults with A/I/DD have limited access to social capital and more challenges connecting with individuals outside of their family.



A holistic approach is required to address these barriers to stable housing, community connections and optimal health outcomes.

Of urgent concern are the approximately 63,000 individuals with A/I/DD in the Greater Phoenix area 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. This is particularly alarming for autistic adults who do not qualify for ALTCS.

According to the **Arizona Department of Housing**, the state needs an estimated 270,000 new units to meet overall demand [3]. Home prices in Arizona have risen 54.2% over the past two years, while the median income in Arizona has increased just 5% since 2019 [4,5]. Meanwhile, rents in the Phoenix area jumped 30% in 2021, outpricing most low-income residents [6]. Economic growth continues to spur new residents to relocate to these areas; however, growth continues to outpace housing development. As with many other low-income adults in the Phoenix area, adults with A/I/DD also need access to housing they can afford in a safe location accessible to their needs, yet they remain statistically invisible due to being housed with family caregivers.

This lack of data on the current housing needs, 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 Greater Phoenix Housing Market Analysis (GPHMA).

The GPHMA determined that adults with A/I/DD have greater barriers and challenges to accessing housing and need more support than the neurotypical population.

- The majority are extremely low income and do not qualify for A/I/DD-specific navigation services that help individuals and families access public benefits.
- Fifty percent of GPHMA respondents reported being concerned they will be forced to live in a group home or a **host home** (also known as **adult foster care**); 39% reported being concerned that they or their loved one would experience homelessness.
- The neurotypical housing stock is not designed to be **cognitively accessible**, **pedestrian oriented**, or to include **enabling technology** that may allow this population to live more independently in their own home.
- Current housing assistance programs and subsidies for the development of **affordable housing** do not recognize this population as a targeted need despite their higher risk of homelessness or institutionalization when parents pass away.
- Due to the cognitive and social aspects of their disability, this population is at higher risk of abuse, exploitation and discrimination; 55% of respondents indicated they have already experienced one of these potentially traumatic interactions.
- Families who invest in the stability of housing for their loved one, and possibly provide additional units for naturally occurring affordable housing units, do not have the guidance, tax incentives or financial tools to do so efficiently.
- Supportive amenities and preferred service delivery models are not yet funded as options for this population despite being available to other populations of people with disabilities, such as those with physical disabilities or mental health challenges.

The GPHMA research team at the First Place Global Leadership Institute, Arizona market leaders, and advisors and sponsors contributed to the Recommendation section of this report, which offers specific and practical policy and funding opportunities to help develop the tools needed for more neuro-inclusive housing stock and community development.

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

Housing

Cognitively accessible and sensory friendly housing in walkable, safe locations 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 specific inclusion of this population in existing and future developments.

Long-Term Support Services

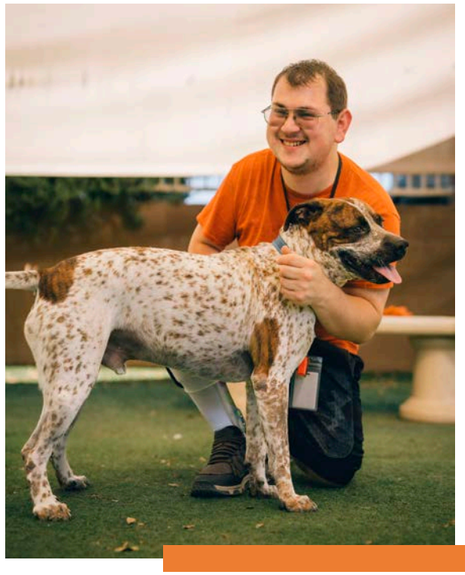
A network of Arizona providers that offers individualized services already exists to help people in their home and to access the community. This report offers insights into preferred service delivery models and existing gaps.

Supportive Amenities

These property-specific 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.

Continuing as a national leader, the greater Phoenix area now has market data to help guide the development of a roadmap to ensure this population is no longer at risk of being displaced from their community or experiencing homelessness. This first Greater Phoenix Housing Market Analysis report seeks to serve as a catalyst for action and model for other metropolitan areas across the nation to plan the places and spaces for every adult with A/I/DD to find their own place in the world.

Join us by reaching out to info@firstplaceaz.org.



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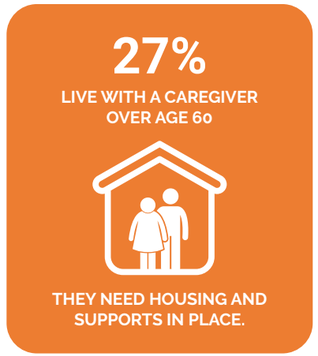
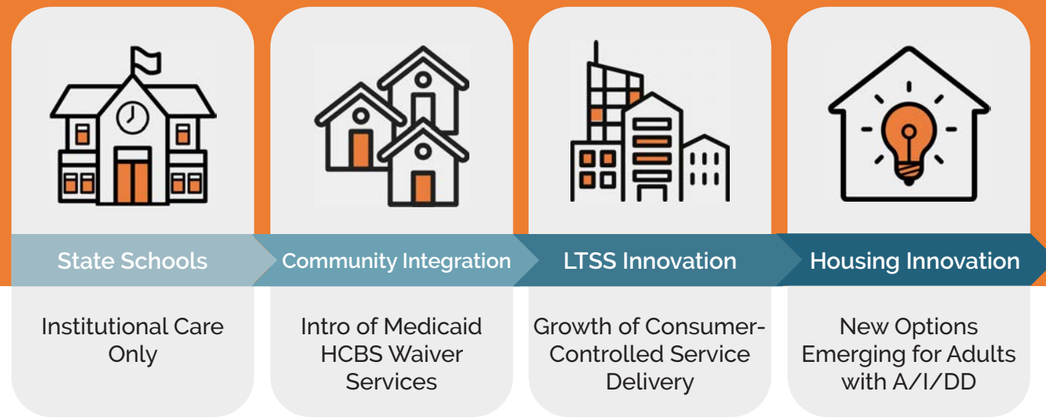
INTRODUCTION

What's exciting about this report is that those community connections-based interventions are also wins for local economies, government tax bases, and the overall well-being and vibrancy of a community. Solve where and how someone lives, and you solve so much more.

– Dave Brown, Board Member of Home Matters to Arizona and CEO of Valley Leadership

People with A/I/DD have been segregated from society by being housed in large institutions. Families had few other choices due to the lack of community services and were often told by professionals that institutionalization was the best thing for their loved ones. These settings were often understaffed, overcrowded and underfunded. In some facilities, there was litigation due to neglect, abuse and mistreatment. The Willowbrook State Developmental Center became a hallmark case "serving as an impetus for accelerating the pace of community placements, expanding community services..." [7]. Without the development of additional housing solutions, Arizona and other states across the country risk re-institutionalizing people with A/I/DD in hospitals, prisons and nursing facilities. It is critical to acknowledge how and why individuals with A/I/DD and their families changed history—and continue to empower them to advocate for a better future.





History & Evolution of Support Services

Medicaid began funding medical services for people with A/I/DD in 1965. Although an important step forward, to access these services an individual had to go to a special facility or reside in an institutional setting. This would separate them from their family, friends and neighborhood to access needed services and medical support. In 1981, a new provision allowed for the development of Medicaid funding that allowed people with A/I/DD and their families to access services in their home and community [8]. This **Home and Community-Based Services (HCBS)** program "waives" the requirement to be institutionalized and allows for people with A/I/DD to access Medicaid-funded services at home or assist them to engage with the greater community.

The program is a federal and state partnership, with states contributing costs and the federal government, through the Centers for Medicare and Medicaid Services (CMS), matching the state's dollars inclusive of HCBS. In Arizona, the Medicaid program is known as the **Arizona Health Care Cost Containment System (AHCCCS)**. Arizona's system for offering HCBS services for people who qualify is called the Arizona Long Term Care System (ALTCS). Arizona was the last state to implement a traditional Medicaid program, establishing AHCCCS in October 1982. Arizona's Medicaid program, including ALTCS, has operated since its creation under a Section **1115 Demonstration Waiver** that allows the state to use **capitated managed care** [9]. Through its unique program design, in addition to HCBS, ALTCS also provides physical and behavioral health services.

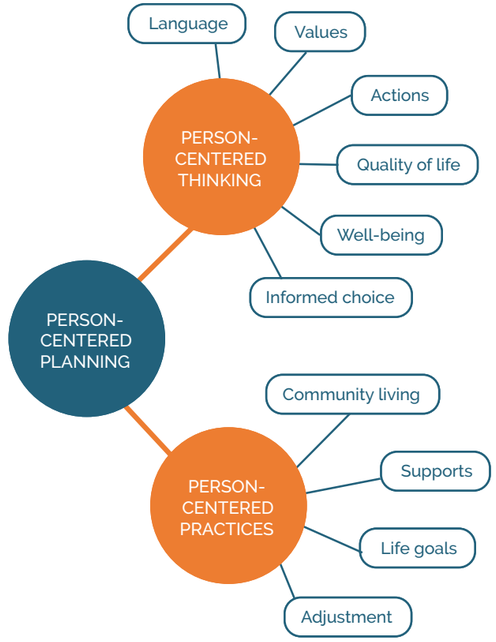
Over time, individuals with A/I/DD, their families, and supporters continued to advocate for more choice and control of where they live, work, and learn with a strong preference for community-based services. On June 22, 1999, the United States Supreme Court held in **Olmstead v. L.C.** that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. 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. While many adults with A/I/DD qualify for AHCCCS physical and behavioral health support based on income, many do not qualify for ALTCS and therefore cannot currently use the ongoing bridges for housing services.

Today, the goal is not to place people into programs but to build an ecosystem of support centered around offering choices for individuals whose needs may change over time.

Person-Centered Approaches

Person-centered approaches, while varied by specific methods, are based on the premise of person-centered thinking, planning and person-centered practices. Person-centered thinking focuses language, values and actions toward respecting the views of the person and their loved ones. 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 the choices and interests that make up a good life and identify supports (paid and unpaid) needed to achieve it. Person-centered practices are present when people have the full benefit of community living and supports designed to assist people as they work toward their desired life goals.

Like a web instead of a brick wall, elements of their life may change or need adjustment, but person-centered planning helps prevent them from faltering through life changes. This takes intentional planning around the needs and preferences of a person, not just selecting the "right program." Due to the relentless pursuit of advocates and their families, more individuals with A/I/DD can live in their own home or a family member's home and receive the services they need to function in everyday life. Whether



it's help organizing their daily schedule, assistance getting ready in the morning, support preparing meals, job coaching or maintaining their home, these are all long-term support services provided by existing community-based organizations across Arizona for those eligible for the Arizona Long Term Care System-Developmental Disabilities (ALTCS-DD) Program.

Lack of Affordability Leads to Limited Choice of Living Arrangement

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 intensifies in a crisis. The ability of adults with A/I/DD to earn a living wage in the Greater Phoenix area may be limited due to their neurodevelopmental disability. The National Low Income Housing Coalition estimates that to live in the Phoenix metropolitan area in 2022, a person would need to earn $43,640 annually to afford a one-bedroom apartment or work 66 hours a week at minimum wage [10]. Currently, only 24.9% of adults with any disability are employed in Maricopa County [11]

Provider-Controlled (PC)

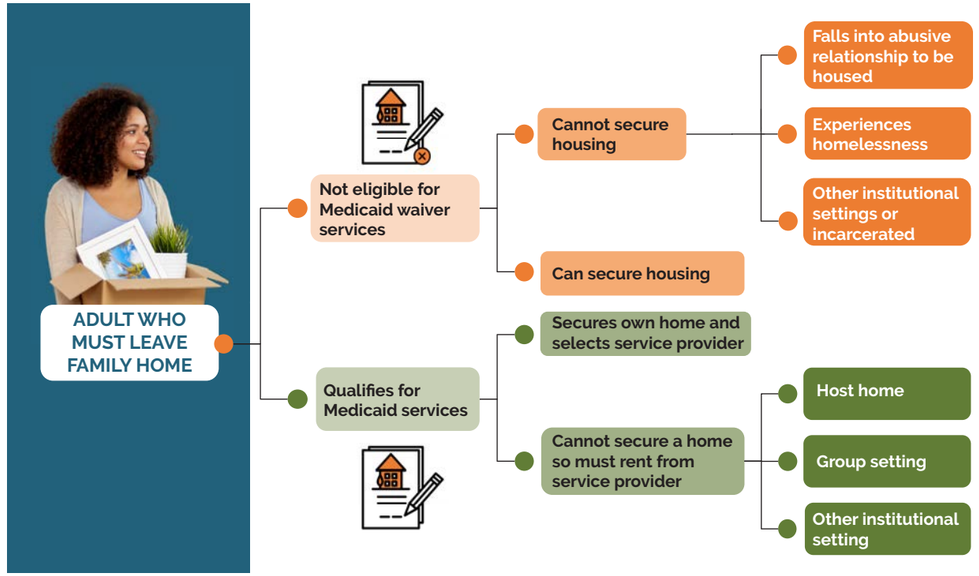
Housing & support services are connected.

Only one choice of HCBS service provider

Consumer-Controlled (CC)

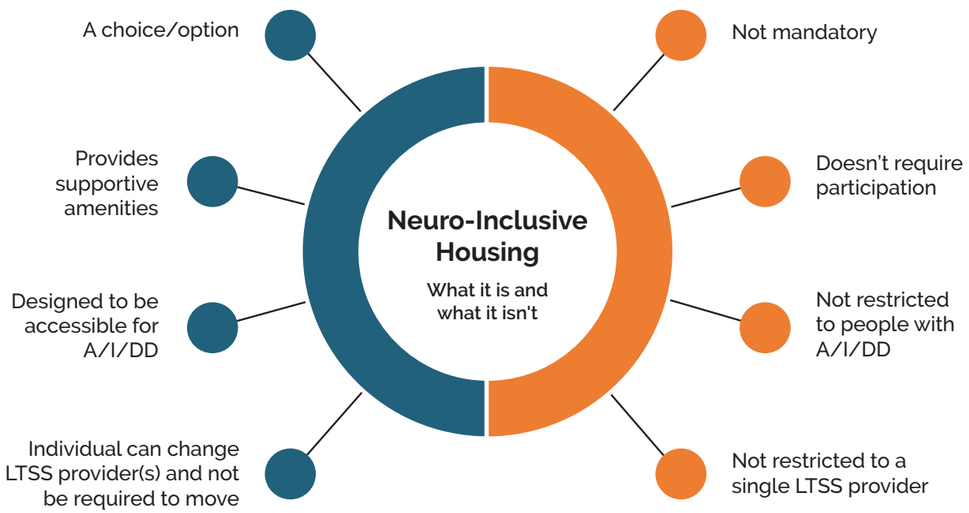
Housing & support services are NOT connected.

Choice of any HCBS service provider



When a move is desired or needed, finding housing or roommates who can afford housing is difficult without support, and this population is often placed with minimal choice in a group home vacancy or host home or remain in the family home because they cannot afford housing in their community. Approximately 4,873 adults with A/I/DD are served by ALTCS-DD live and pay rent to their service provider in a **provider-controlled setting** that may not be their preferred choice [12]. Although creative and innovative solutions may be possible, the lack of knowledge, financing and flexible policy needed prevents scaling and replication.

When a crisis placement is needed, the safety net of a group home or host home care is only available to those who qualify for Medicaid long-term support services from ALTCS. Those not eligible for these services are currently at high risk of homelessness. According to Central Arizona Shelter Services (CASS), the number of unsheltered individuals experiencing homelessness in Maricopa County has increased by 34% since 2020, with 50% of those individuals over age 50. 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 [13].



Invisible Need

The Greater Phoenix Housing Market Analysis covers major cities within the Greater Phoenix metro area and includes Phoenix, Mesa, Tempe, Scottsdale, Glendale and Surprise (in order of population size). These fast-growing cities account for almost half of the state's population and represent urban and suburban areas. Ranked as the fastest-growing county in the U.S., Maricopa County presents with housing challenges similar to other major metropolitan areas [14]. Only 26 affordable rental homes are available per 100 extremely low-income renter households in Arizona [15]. Yet, adults with A/I/DD who are living with aging family caregivers are not considered in these estimates.

The following table offers a snapshot of the need for understanding and action inclusive of needs of people with A/I/DD as articulated in local municipal housing or **consolidated plans** or local **public housing authorities (PHA)**:

Area	Housing strategy or consolidated plan	PHA or other prioritized efforts targeting people with disabilities	Identify people with A/I/DD specifically as a need	PHA waitlist status	Number of vouchers targeting people with disabilities currently [16,17]
Phoenix	Housing Phoenix Plan	Yes Estimate of 9,000 units needed for persons with disabilities	No	Closed	191 but only 166 leased/in use [18]
Mesa	City of Mesa Consolidated Plan	Yes, persons with disabilities segmented in data	Yes, within "non-homeless special needs"	Closed with 4,000+ waiting	287 but only 201 leased/in use
Glendale	Annual Action Plan	Yes, prioritized for HCV and named as targeted need in plan	No	Closed	0
Scottsdale	Consolidated Plan	Yes, prioritized for HCV and identified in segmentation	No	Closed with 2,200+ waiting	0
Tempe	Tempe's Affordable Housing Strategy	No	No	Closed with 3,000+ waiting	64 but only 39 leased/in use
Surprise*	Surprise Consolidated Plan and Assessment of Assessment of Fair Housing	Yes	Yes, named as targeted need in plan	Closed	0

* The Housing Authority of Maricopa County develops and sustains affordable housing programs throughout Maricopa HAMC's jurisdiction DOES NOT include Phoenix, Glendale, Scottsdale, Tempe, Chandler, and a majority of Mesa.

Not all housing or consolidated plans included persons with disabilities as a segmented need, and only Mesa and Surprise made specific mention of people with developmental disabilities. As of August 2022, in all of Arizona there were only 850 **Mainstream Housing Choice Vouchers** and 175 **Non-Elderly Disabled (NED) vouchers** targeted for people with disabilities (not A/I/DD specifically) [16].

For housing assistance specifically targeting adults with A/I/DD in Arizona, the Division of Developmental Disabilities has funding for fewer than 200 ALTCS-DD-enrolled individuals through **Section 811 Project Rental Assistance** and/or housing vouchers, and a waitlist of over 200 individuals [19].

In 2021 the HUD Office of Inspector General reported that 62% of public housing agencies (PHAs) had voucher-utilization rates of less than 95% (standard performance). Underutilization was reported to be due to factors outside of HUD's control, including insufficient landlord interest or participation, lack of availability of affordable housing and housing costs increasing at a rate faster than the PHA's budget. The HUD OIG recommended developing a plan to optimize leasing to increase the number of families assisted and thereby reduce the number of unused vouchers [20].

"Mesa became the first-ever Autism Certified City because we knew it was not just the right thing to do, but it also made great business sense. Our certified partners in Mesa know that the neurodiverse population not only fill various open positions, but are an asset to creating an inclusive, different-thinking staff. These individuals need to be able to find supportive, affordable housing as they enter the workforce and contribute to the community."

– Marc Garcia, CEO, Visit Mesa

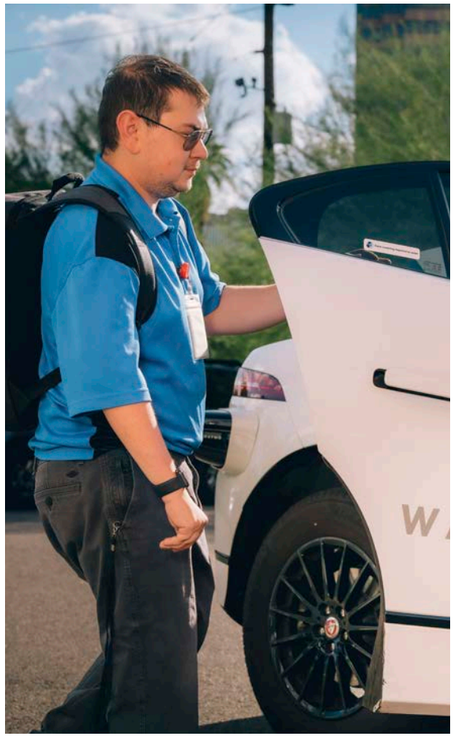


Photo: Waymo; Jedidiah Woods - jedidiah.life

Census data is not collected on the number of people who have A/I/DD. Therefore, estimates must reflect existing data sets where this population is segmented in a given area. The Center for Disease Control estimates 5.9% of Arizona residents have a disability that impacts their ability to live independently [21]. Consequently, of the seven million people living in the Greater Phoenix area, approximately 413,000 have a disability that impacts their ability to live independently. The CDC estimates that 2.2% of the U.S. adult population is on the autism spectrum, 1.14% 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 4.55% [22], [23]. The University of Kansas 2022 State of the States in Developmental Disabilities estimates that 27% people with I/DD live with a family caregiver over age 60 in Arizona [24].

The **Arizona Department of Economic Security's Division of Developmental Disabilities** has identified at least 20,000 adults with A/I/DD who receive services through ALTCS-DD. AHCCCS reports that for individuals diagnosed with autism, 42% are served by AHCCCS Complete Care (ACC) health plans; no definitive data exist for other individuals with A/I/DD served by ACC health plans. Data gaps for individuals with A/I/DD, especially for those who are not enrolled in ALTCS make it extremely difficult to ascertain the number of people who need housing, support now and in the future, and the associated gap analysis needed for planning.

From the 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 nearly double the current deficit of 97,562 needed affordable housing units for all extremely low-income residents in Greater Phoenix [15].

Location and population	Autistic adults (2.2%) [25]	Intellectual disability (1.14%) [23]	Developmental disability (Not autism or I/DD) (4.55%)	Combined A/I/DD	Estimated to be living with caregiver over age 60 (27%)
Phoenix 1,625,000	35,750	18,525	73,938	128,213	34,618
Mesa 509,475	11,208	5,808	23,181	40,197	10,853
Glendale 249,630	5,492	2,846	11,358	19,696	5,318
Scottsdale 242,753	5,341	2,767	11,045	19,153	5,171
Tempe 184,118	4,051	2,099	8,377	14,527	3,922
Surprise 149,191	3,282	1,701	6,788	11,771	3,178
Greater Phoenix Total 2,960,167	65,124	33,746	134,687	233,557	63,060

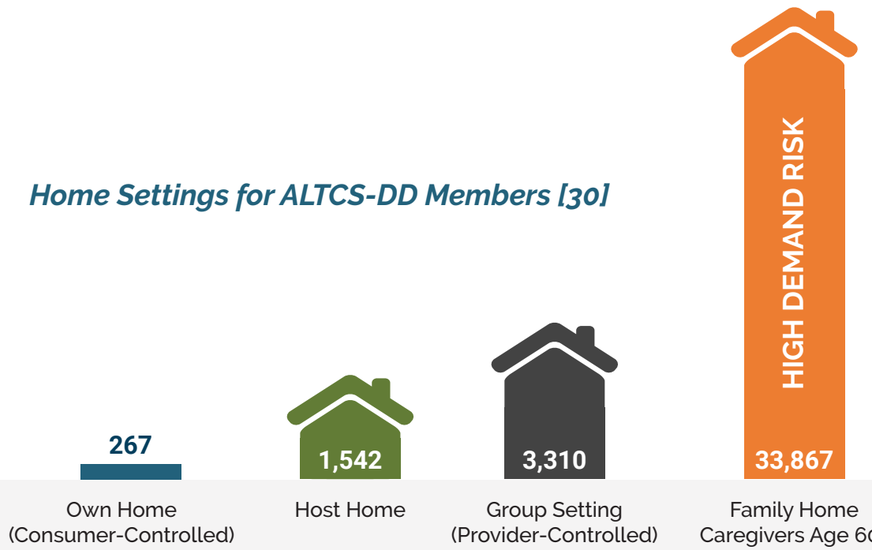
Of urgent concern are the approximately 63,060 individuals with A/I/DD in the Greater Phoenix area at high risk of losing their home and primary caregiver when their family member can no longer support them due to death, their own aging and health concerns, and other economic circumstances. Currently the UMN Institute for Community Integration Residential Information Systems Project reports that of the 20,000 adults served by ALTCS-DD, 276 adults with I/DD live in their own home, with another 4,853 living in a provider-controlled setting [26]. In order to meet the impending demand of those served and not served by ALTCS-DD, Arizona must exponentially increase access to affordable housing solutions in response to the needs and desires of Arizonans with A/I/DD and their families.

"The influx of new residents compounds the problem of low housing inventory because the county lacks approximately 150,000 rental units across all types (luxury, affordable, and subsidized)."

– ASU Experience of Housing Insecurity in Maricopa County [27]

The Joint Center for Housing Studies of Harvard University estimated that nationally 62% of renters do not have enough income to afford a comfortable standard of living after they pay their rent [28]. As a result, large numbers of Arizonans face housing insecurity and the burden of rising costs. This is acutely felt by adults with a diagnosis of autism and/or intellectual/developmental disabilities (A/I/DD). Adults with A/I/DD often have fixed incomes and/or low wages from employment. A lack of housing options prevents the neurodiverse population from moving beyond their family home.

Home Settings for ALTCS-DD Members [30]



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 for people with A/I/DD.
Adults with A/I/DD often have challenges with 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. Additionally, they may not have experience with or knowledge of documentation and system requirements to access various types of assistance.

Adults with A/I/DD are on a fixed, extremely low income.
They often have low educational attainment, rely on public benefits and have cognitive challenges that make full-time employment difficult. Therefore, they must budget on fixed-income that does not increase with inflation or rising housing costs.

Lack of supportive amenities and case management for those ineligible for ALTCS-DD.
Individuals with A/I/DD and who do not qualify for ALTCS-DD need **supportive amenities** and assistance with case management activities. These include breaking down the steps in a task: e.g., identifying required documents, completing applications and creating a plan for follow-through.

The existing housing stock is often inaccessible.
Individuals may need wayfinding signage or icon cues instead of text only; 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 sound-insulating spaces—could lead to the disruption of neighbors and/or noise complaints.

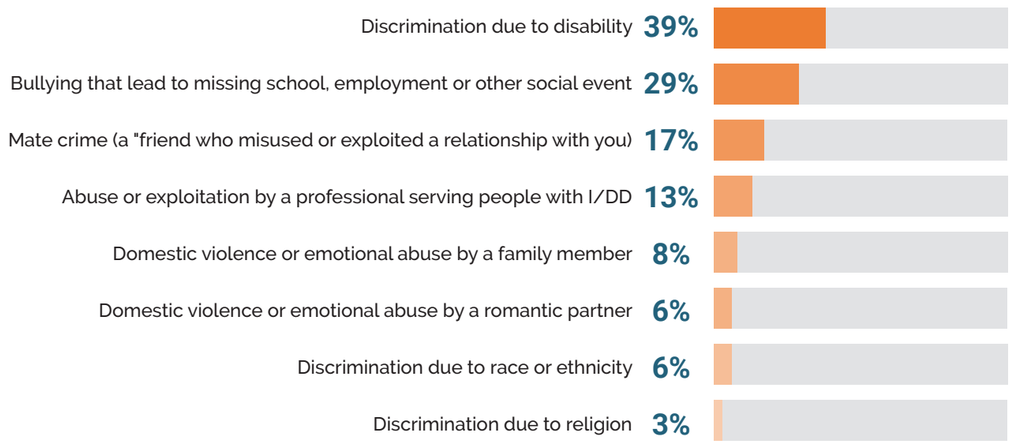
This population is at risk of being victims of predatory relationships.

Location and security features must be carefully considered, as adults with A/I/DD have a significantly greater risk of being victims of both simple assault and a serious violent crime than other persons with disabilities [29]. 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 [30]. 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 [31].

Discrimination based on disability is the highest reported form of housing discrimination [32].

Despite progress in the rights and inclusion of persons with disabilities, it is common for landlords to reject their rent applications. Likely due to ill-perceived 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 [33].

Have you or a person with I/DD in your current household ever experienced any of the following?*



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

61% report experience of discrimination, bullying leading to self-isolation, mate-crime, abuse or domestic violence.

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.

First Place AZ, market leaders, advisors and sponsors have invested significant time, energy and resources in the process to understand the needs and preferences of Phoenix's neurodiverse population.

The Greater Phoenix Housing Market Analysis demonstrates the data and actionable direction for developing tools and the necessary systems change to launch a new wave of housing options across Arizona so every person with A/I/DD can find their place in the world.

Photo: First Place® AZ, Good Eye! Media

GREATER PHOENIX HOUSING MARKET ANALYSIS PROCESS

Educate neurodiverse community

Assess preferences and support needs

Approach housing industry with consumer data

Increase housing stock to meet local demand

Most 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 GPHMA were required to participate in educational training 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. While some of the options presented during the training session may not currently be available in Arizona, they were important to include so participants could express their needs and preferences to help stimulate market and systems change.

Educational Outreach

The educational sessions included live, online training, as well as in-person with subsequent Q&As. The online training was also recorded and posted on the GPHMA website for 42 days for those unable to attend the live events. More than 80 community-based organizations were contacted as part of the process of promoting and facilitating the market study. Plain-language materials were created to ensure a more cognitively accessible format. These materials included a pre-recorded, live training in plain-language—a visual guide to help participants track their preferences during the training—and a plain-language survey. In order to collect feedback from the Spanish-speaking community, all materials were adapted and translated for a live, in-person focus group.

During the 60- to 90-minute sessions, each option was introduced and explained using visuals, verbal descriptions and videos where available. Both benefits and considerations were discussed to promote person-centered, meaningful choice. Individuals attending live sessions had the opportunity to ask additional questions during and after the presentation.

Website (invitation sent to 80+ organizations)
Summer 2022

- Expanded presentation & survey
- Plain-language presentation & survey

Two Live Virtual Presentations with Q&A
August 2022

- Expanded presentation & survey
- Plain-language presentation & survey
- Recordings made available on website

Two In-Person Focus Groups
August, September 2022

- Individuals with A/I/DD
- In collaboration with Grupo de Apoyo para Niños Especiales (GANE) and Ideal Care – Spanish presentation and survey

Participants made a significant time commitment and demonstrated a willingness to learn about multiple approaches to residential options, enabling the collection of data on the needs and preferences of adults with A/I/DD and their families.

Once a participant completed the educational training, they were requested to complete the GPHMA survey. This included questions regarding demographics, barriers to community engagement, support needs and preferences, as well as housing preferences and utilization of public benefits.

Materials & Tools

Local Leaders

Local leaders and market advisors were invited to participate in the process. Organizations and individuals who participated represent leaders in housing, healthcare, disability and human services from city, state and community-based organizations. Self-advocates and family leaders were also essential contributors. These two groups assisted with identification of existing data, as well as outreach to potential stakeholders, and participated in a presentation to review the survey data and identify potential recommendations for future action. A review of the comprehensive plans, consolidated plans, housing plans and any previous housing analysis from the typical housing market needs were reviewed by researchers from the First Place Global Leadership Institute.

After the surveys closed, data was analyzed and presented to the local leaders. Data and initial analysis indicated the diversity of and demand for residential needs and preferences. 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.

165
Respondents

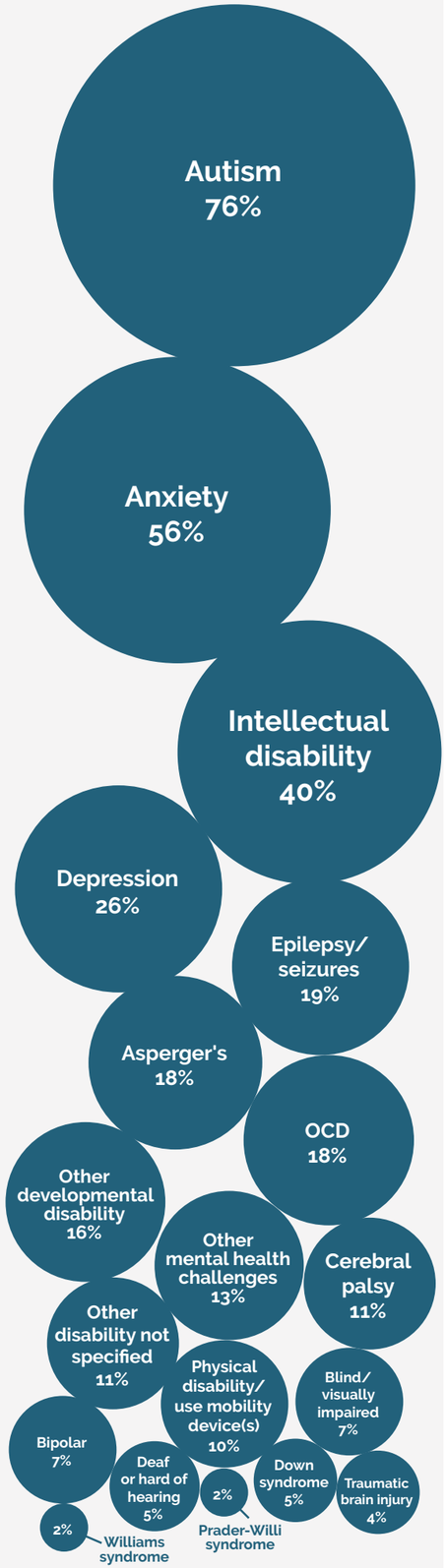
24%
Self-Advocates

HOLA!

20
Spanish-Speaking Respondents

Considerations and Limitations of Process

- To provide more accessible training materials, the plain-language surveys did not include questions as extensive as the full survey, limiting some of the demographic and preference data collected.
- A focus group targeting the Spanish-speaking community was only offered in-person, as recommended by collaborators Grupo de Apoyo Para Niños Especiales (GANE), Raising Special Kids and IDEAL Care; therefore, more responses may have been collected if a recording was available over a longer period of time—although, as reported by Spanish-speaking participants, this is a sensitive subject and online translation is not always sufficient to ensure understanding.
- Family members who are caregivers to individuals with more profound autism or high behavioral or medical support needs shared that many of the options presented, and they believed were preferred by their loved one, are not currently available in Arizona.



DEMOGRAPHICS

The demographic data within this section is compiled from the 2022 Greater Phoenix Housing Market 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 the preferences for housing, services and community engagement in the future.

Disabilities Represented

A person's diagnosis does not dictate the type of housing, supportive amenities or service delivery model they may need or prefer. Diagnostic information is, however, helpful in understanding possible barriers to independent living, breadth of diversity, along with potential funding sources. Diagnostic information in this analysis informs generally the 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 or hearing impairments and autism with sensory differences involving lighting, sound and other materials. Compliance with the **Americans with Disabilities Act (ADA)** for accessibility of those with physical disabilities who may use a wheelchair or other mobility device is required by law, but represents a small segment of the population of people with A/I/DD.

Not surprisingly, a high representation of individuals on the autism spectrum are represented in the data, likely due to the strong support First Place AZ offers to those on the autism spectrum who may not be reflected or present in other Arizona long-term support services datasets or outreach efforts due to ALTCS-DD ineligibility for having low or drop-in support needs.

"I need more purpose in my life. And I don't want to live in a group home...

...It is difficult to communicate exactly how it makes me feel to be placed with non-verbal TBI or people with epilepsy who are severely affected just because those are also my diagnoses. I have a bachelor's degree in Fine Arts from ASU and would like to be able to market the art I produced but don't know how to do that. Therefore, I have stopped painting."

The analysis reports a high rate of co-occurring mental health challenges such as anxiety, depression and obsessive-compulsive disorder (OCD). Emerging supportive housing opportunities may consider building relationships with behavioral health providers that can provide on- and off-site mental health support, therapeutic interventions and counseling, and/or life coaching in a cognitively and autism-friendly format. Finding a provider that takes one's insurance and understands the neurodivergent population, scheduling an appointment and accessing reliable transportation are all barriers to mental healthcare.

Identified Support Needs

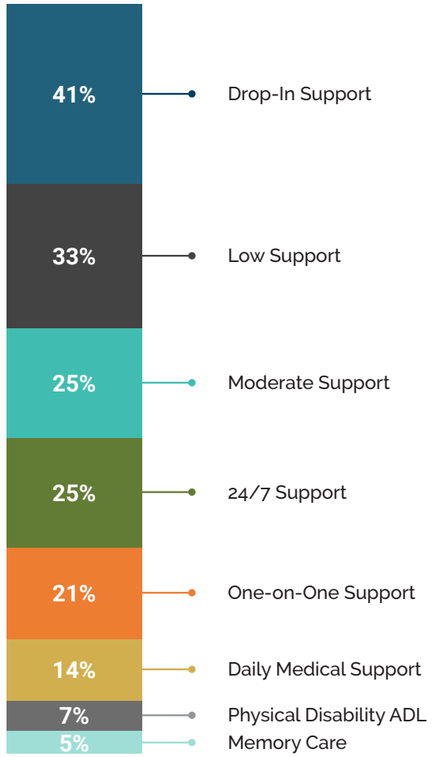
People with A/I/DD have a wide range of support needs not otherwise captured in existing Arizona data sets. The data on level of support needs paints a picture of the number of hours a person may need for direct support.

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 services funded by ALTCS-DD. 22% of survey respondents report being already denied or 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.

Equally important are the needs of individuals who have more profound autism or other I/DD 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-on-one and/or behavioral support to live independently and participate in the community.

> *"CASS is seeing more individuals who have a learning or intellectual/developmental disability becoming homeless and...facing tremendous barriers to get back into housing. We must do more to build more housing for them, as well as ensure they remain housed so they never enter the system in the first place."*
>
> *– Lisa Glow, CEO, Central Arizona Shelter Services (CASS)*

How would you describe your support needs?*



Although representing a smaller subset of the data, those who need memory-care are important to consider and recognize 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 [34].

Future research or data collection should always segment the population based on level of support needs to measure any disparities. 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 living with a family member to improve data collection and articulation of this issue.

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

Photo: First Place® AZ, Good Eye! Media

Support Needs [56]

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.

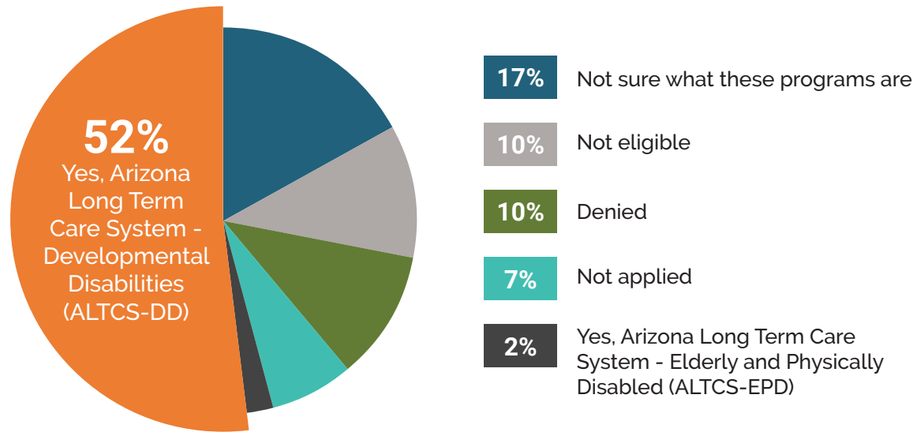
Memory Care
Due to symptoms of dementia or Alzheimer's disease, the individual requires a safe environment with additional structure and support to navigate throughout the day.

“The eligible ALTCS customer will have a functional and/or medical condition resulting in such a degree of impairment as to interfere substantially with the capacity to remain in the community, and results in long-term limitation of capacity for self-care.”

– ALTCS-DD Preadmission Screening Manual for the Developmentally Disabled [35]

Photo: Daniele-Levis-Pelusi - Unsplash

Are you (or your loved one) receiving services through a Medicaid waiver?*



As with all states, to become ALTCS-DD members, applicants must qualify as needing the level of support in an ICF/IDD and meet income eligibility.

When data was segmented for self-advocate respondents only, 43% indicated they were unaware of ALTCS.

The purpose of the HCBS waiver long-term support services is to assist people with A/I/DD to live in the community with supports and services as would any other member of society. Just over half of respondents indicated they are receiving services through ALTCS-DD or ALTCS-EPD. 10% indicated they would not be eligible and an additional 10% were denied after applying.

Additionally, 17% did not know that ALTCS resources were available to provide families and individuals with respite, day programming, supported employment or long-term support services to either keep them living in their family home or prepare them for the transition to a different home setting. This indicates that expansive awareness raising is needed to ensure that neurodiverse families are aware of the assistance ALTCS provides.

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

Income & Government Benefits

As of today, it is prohibited that federal HCBS Medicaid dollars are utilized to fund room and board for those who use ALTCS funded services. Recipients of ALTCS-DD funded services must pay for their housing, even in provider-controlled settings such as group homes or host homes. This is typically paid for using up to 70% of their **Social Security Disability Income (SSDI)** and/or **Supplemental Security Income (SSI)**, leaving very little for other expenses such as clothing, recreational and/or leisure spending. However, the Arizona Division of Developmental Disabilities has been successful in receiving state appropriations from the legislature to help offset some of the costs of room and board.

In 2023, the maximum recipients of SSI can receive is $914, and if the person starts to work, benefits will decrease at a 2:1 ratio as income is earned. If an individual receives financial support to cover their housing cost, then their SSI benefit will be reduced by one third [36]. Some states choose to offer a state supplement to their state SSI recipients, but Arizona does not offer this to their nearly 115,000 SSI recipients [37]. Although employment is often desired and sought by the A/I/DD population, only 36% of survey respondents were employed. This is higher than the reported state average (pre-COVID) of 16% who are in the ALTCS-DD system [38]. Even when employed and receiving federal assistance, housing costs for Greater Phoenix are out of reach for most adults with A/I/DD.

*Monthly income and benefits**

- 43% SSI
- 40% Medicaid (healthcare)
- 27% SSDI
- 25% Medicare
- 16% SNAP
- 16% Earn less than $300
- 14% Earn $601-900
- 9% Earn $901-1,200
- 8% Earn $301-600
- 6% Earn over $1,500
- 4% Earn $1,201-1,500
- 3% Housing Choice Voucher
- .7% LIHEAP

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

None of the respondents earns a housing wage in Greater Phoenix.

Photo: The Arc Jacksonville

Income	Total monthly income [39] (includes deduction of SSI due to earned income if applicable)	% of income needed to afford market rate rent of 1br in Greater Phoenix ($1,091)	Monthly housing costs considered affordable [40]
2023 Maximum SSI benefit	$914	120%	$274
Avg. SSDI adult child survivor benefit [41]	$980	111%	$294
8 hrs a week minimum wage ($13.85/hr) + SSI	$443.20 + $734.90 = $1,178.10	92%	$353
16 hrs a week teacher's assistant ($14.82/hr) + SSI	$948.48 + $482.26 = $1,430.74	76%	$429
24 hrs a week fast food worker ($14.75/hr) + SSI	$1,416 + $248.50 = $1,664.50	66%	$499
40 hrs a week inventory stocker ($15.27/hr)	$2,443.20 (SSI no longer available due to earned income)	45%	$733

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 as nowhere in the U.S. can someone who lives off SSI afford rent. [42]

Other public benefits and safety net programs, such as SNAP for food assistance, LIHEAP to help cover increased energy costs in summer and Housing Choice Vouchers which provide permanent rental subsidies 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.

AHCCCS received permission to begin an AHCCCS **Housing and Health Opportunities (H2O)** demonstration waiver in 2023. This will allow AHCCCS to use a permanent supportive housing model [43] as a cost-effective strategy for addressing and improving health outcomes for persons at risk or experiencing homelessness, with certain conditions. For individuals with A/I/DD this may include: those with **serious mental illness** or in need of behavioral health and/or substance use treatment, individuals determined high risk or high cost based on service utilization or health history, individuals with repeated avoidable emergency department visits or crisis utilization, individuals with chronic health conditions and/or comorbid conditions, individuals at high risk of experiencing homeless upon release from an institutional setting, young adults ages 18 through 24 who have aged out of the foster care system and/or individuals in the ALTCS who are medically able to reside in their own home and require affordable housing in order to transition from an institutional setting.

Planning for the Future

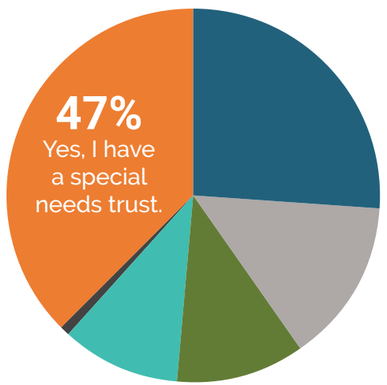
Although individuals with A/I/DD may be extremely low income and unable to earn a housing wage, the survey indicates that some families may be able to assist their loved one with housing costs. Of those surveyed, approximately 38% have created a **special needs trust**. This is a financial device that 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 **means-tested** public benefits at risk.* For those whose families may be able to offer 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 clearly a variance related to socioeconomic status. Nearly 30% could assist their loved one to afford market rate rent in the greater Phoenix area.

When I no longer live with family, my total housing costs per month (rent, mortgage, utilities, upkeep, etc.) must be:

- 17% $300 or less
- 12% $450 or less
- 18% $600 or less
- 15% $800 or less
- 13% $1,100 or less
- 12% $1,500 or less
- 9% $2,000 or less
- 4% $3,500 or less
- 1% $3,500+

* Although it doesn't disqualify an individual from SSI, if an SSI recipient is assisted by family or a SNT with the cost of housing, their SSI will be reduced by a third.

*Has your family done any future planning?**



- 33% No
- 18% No, we don't have extra income to do this.
- 14% Yes, we have met with a special needs lawyer.
- 13% Yes, I opened an ABLE account.
- 1% Yes, I'm part of a pooled special needs trust.

Over 50% of respondents have not done any future financial planning or are financially unable to afford legal fees or have the extra income to fund a special needs trust for their loved one. Therefore, they will need housing assistance or deeply affordable units to prevent displacement or homelessness if no other arrangements have been made with other family members when a crisis occurs. No A/I/DD-specific housing navigation services are available, yet aging caregivers may 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 parties, but it also removes the routine and stability of the family home and chance to find a good fit if the first solution does not work. Offering **housing and lifespan navigators** could prevent placement in a group home, a more expensive institutional setting such as a psychiatric facility, state ICF, a skilled nursing home, an emergency room or homeless.

"The effects of the income disparity between housing costs and federal assistance for adults with A/I/DD have been spelled out well in this analysis. It is important not only to address the economic effects of the housing issues, but also the psychological effects on the person if they are not living in an environment that is safe, caring and motivates them to perform at their highest potential."

– Bart Stevens, Special Needs Planning

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

Concerns for the Future*

When asked about the future, both individuals and families have grave concerns about what will happen when they can no longer rely on family caregivers for housing or support.

- **75%** I may be lonely.
- **64%** I will not be able to go places I want to go.
- **55%** I may be forced to live in a group home or adult foster care.
- **54%** I may be abused.
- **53%** I will not find quality staff.
- **49%** I will lose funding for services.
- **48%** I will not be able to access healthy food.
- **47%** A friend may be a real friend.
- **44%** I will not find purpose or have a career.
- **44%** I will not be supported to reach my goals.
- **43%** My health will decline due to neglect.
- **36%** I will become homeless.
- **24%** Other

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

"I will feel lost without my mom and dad, and no one will understand me. I have lots of fears, especially of the dark."

"Getting involved in dangerous situations and not knowing what to do."

"I am concerned to have not found a supportive environment before my parents pass away and the fear of becoming a ward of the state."

"My biggest fear for my brother [redacted] is that someone will hurt him, again. He was abused by a caretaker [redacted] and now we only trust family to help care for him. My dad is 75 and then it's only my other brother and I."

"Concerned I will not have a safe person"

"I am concerned I will not have the care I need and be part of a community that I can feel I belong to."

It is noteworthy that Spanish-speaking respondents indicated significantly higher concerns related to the possibility of loneliness (95%), being forced to move to a group or host home not of their choice (85%) or abuse (80%).

Creating a Special Needs Trust (SNT) is essential in future planning; however, it only addresses one of the four key issues: legal. There are different types of SNTs that serve specific purposes. The other three key issues of planning are government benefits, budget/financial projections and lifestyle planning.

Barriers to Community Engagement

Only about 10% of respondents shared that they did not experience barriers to community engagement.

Despite having a robust public transit system, lack of transportation is cited as the greatest barrier for people with A/I/DD. The Greater Phoenix community is an expansive suburban area where travel by public transit, while improving due to recent infrastructure investments, continues to be a car-centric community. Public transportation may be too overwhelming, expensive, inaccessible or may not be available where individuals are currently living. More research is needed to provide additional insight that can help foster solutions and remove the greatest barrier to community engagement.

The next top five barriers identified can be mitigated by developing spaces and places for neurodiverse relationship building. Whether that be in public spaces such as recreational centers or intentionally addressed in the design of future community assets, community integration and a feeling of belonging does not just happen when people with and without disabilities exist in a geographic location. It requires intentional community-building that seeks feedback from self-advocates to better understand their needs and preferences, as well as relationship-building activities to create more neuro-inclusive communities.

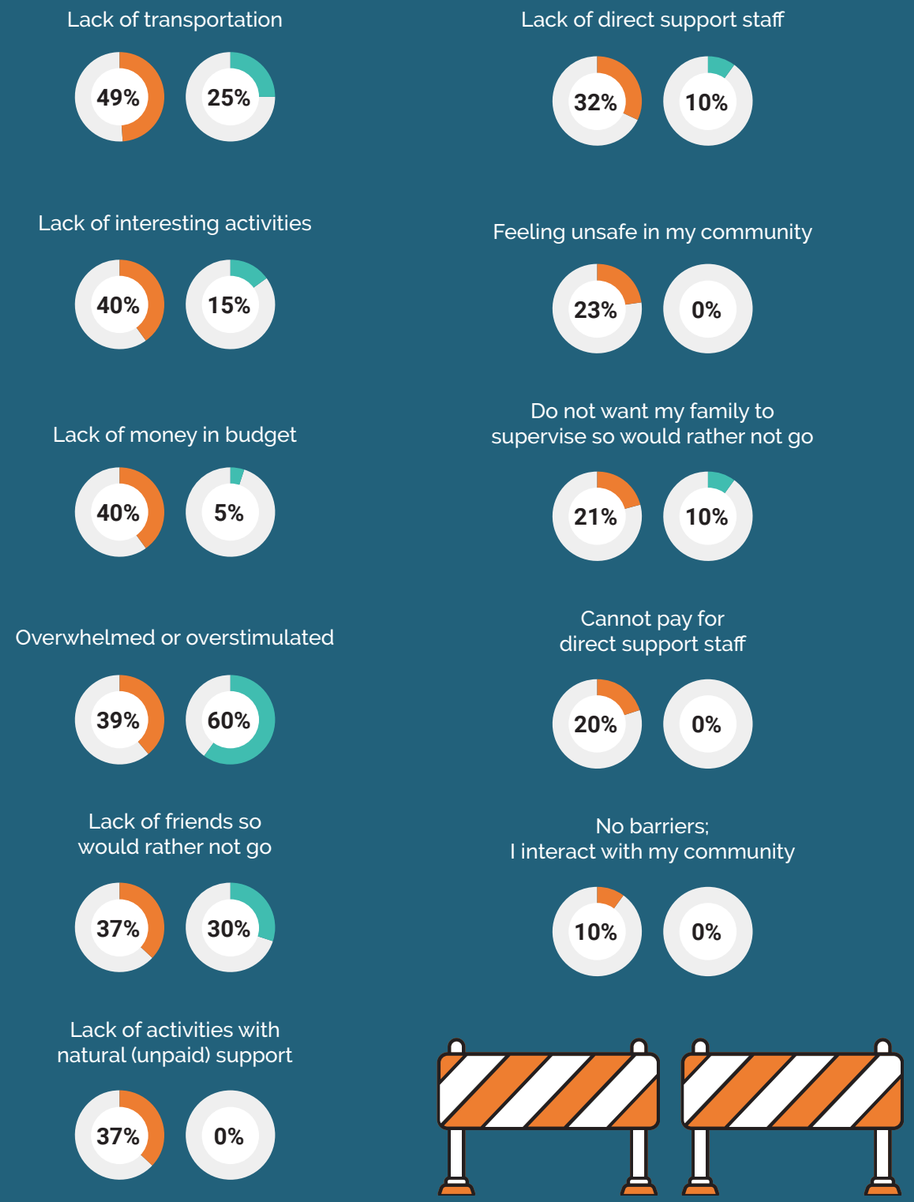
There were some notable differences between the English-speaking and Spanish-speaking participants' responses. For example, Spanish-speaking respondents indicated a strong connection to family and the prospect of various family members/ generations as future caregivers. Unlike English speakers, who reported transportation as their greatest barrier to community connection. Spanish speakers reported increased overstimulation and a lack of access to non-family friendships. Spanish speakers also indicated a higher rate of bequeathing of a family home or the potential to add an ADU to the family property. They also had higher preferences for live-in caregivers and agency-based rotational staffing.

"It was an honor to share our input. Though there are sometimes preset views on Hispanic/ Latino adults' living expectations, the First Place model made us reconsider our own views. It surpassed our expectations."

– Gabriela S. Orozco, Assistant Executive Director, Ideal Care

What are the barriers to doing the things you want to do?

English (145) Spanish (20)



Of significance is that 87% of survey respondents indicated 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. As noted in the data, this population's cognitive and/or social impairments may be exacerbated by the lack of accommodations. Planned and mixed-use communities can develop a built environment designed for soft social interactions with supportive amenities to facilitate greater social opportunities and engagement. Although named the "most autism-friendly city," nearly 40% of respondents still felt as if a barrier to developing and maintaining relationships was the neurotypical world needing to understand how to better engage with the neurodivergent population.

87%
of respondents report experiencing loneliness...

Top 5 reasons reported as barriers to friendship:

- **46%** don't know how to turn potential friends into long-term friendships.
- **45%** don't know where to go to meet potential friends.
- **39%** feel like other people don't understand how to be a supportive friend.
- **34%** report too much anxiety to try and meet new people.
- **32%** have difficulty scheduling to meet with friends.

"Social connection is not simply the absence of loneliness. Connection, experienced as support, attachment or love has a power that has not been studied sufficiently. Ethnographers have tried to track this in other societies where there are cultural norms for connection that are critical for well-being, norms that we lack in America's individualistic culture."

– Thomas R. Insel, MD, Former Director of the National Institute of Mental Health and author of Healing: Our Path from Mental Illness to Mental Health

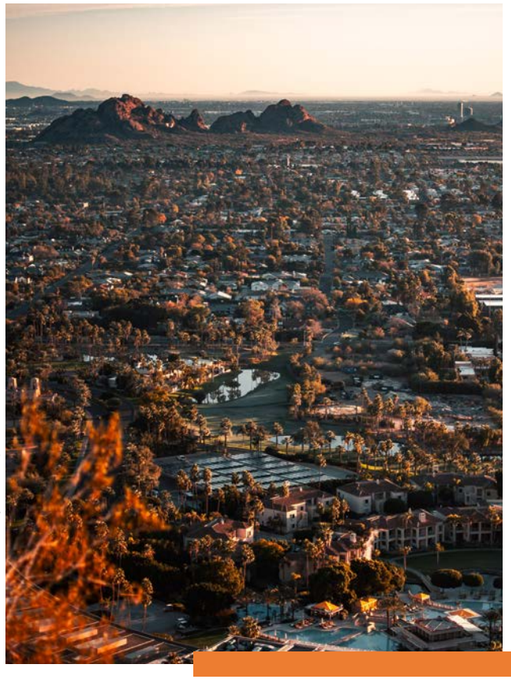


Photo: Colin Lloyd, Unsplash

PREFERENCES

The preferences data in this section are compiled from surveys administered in the 2022 Greater Phoenix Housing Market Analysis Needs & Preferences Survey unless otherwise noted. The data provide information from respondents with A/I/DD and/or their families about their needs and preferences for housing, services and community engagement in the future. The next section offers details about data-driven recommendations to meet demand.

Adults with A/I/DD and their families have similar desires as neurotypical tenants: safety, respect for privacy and the freedom to make their own decisions. There are also additional highly rated features that include intentional connection to areas of interest or assistance in becoming more independent.

Top 5 future home and support preferences

1 Helps keep me safe

Photo: First Place® AZ, Good Eye! Media

2 Respect for privacy

3 Ability to make changes & choices

4 Finding things I like to do

5 Helps me be independent

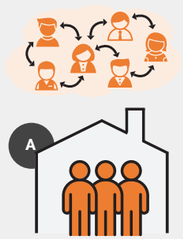
Individualized Long-Term Support Services

Housing, service delivery models and an individual's service provider no longer need to be inextricably connected. For example, the same single-family home scattered in a typical neighborhood or part of a planned community could have various LTSS arrangements individualized for residents.

After being informed of the considerations and benefits of various service delivery models, both self-advocates and neurotypical respondents indicated **self-direction** as their preferred service delivery model. In 2019, ALTCS-DD stopped expansion of the Independent Provider Program (IPP), the service delivery model which allowed individuals with developmental disabilities or their families to select and hire supporters for attendant care, homemaker, respite and/or habilitation services [44]. While Arizona residents with developmental disabilities, seniors or physical disabilities may all use an Agency with Choice model, which offers the ability to hire, fire and train workers, but is supported through a provider agency, the fully self-directed model for attendant care is only available to Arizona residents with physical disabilities, seniors, veterans and those with mental illness [45]. There is a discrepancy between what individual respondents preferred and what is available in Arizona currently.

"Almost every parent I've communicated with wants their adult son/daughter to have a high quality of life with staff that provides continuity of care, skilled/supportive care and support of their interest/activities. Families need future planning with a third-party that can bridge DDD services with appropriate residential care. The parents I associate with do not want referrals to group homes or host homes."

Felix's parents bequeathed their home, so he and his housemates pay rent to a special needs trust in which the house is now held. Possible living arrangements include:



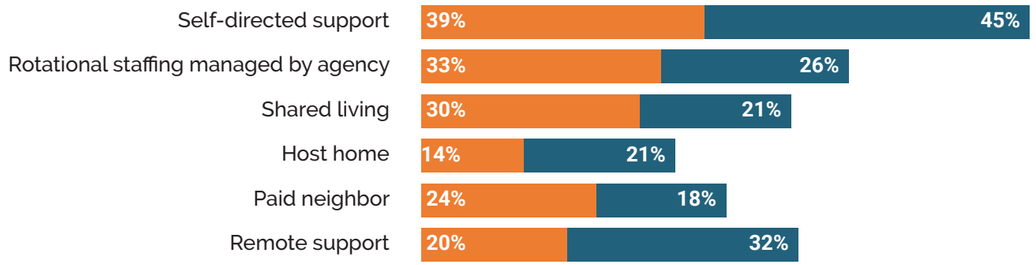
Felix lives with two housemates who have A/I/DD and choose to hire the same service provider who schedules rotating staff to meet their individual and collective needs.

Felix lives with his caregiver and the caregiver's child in a shared living arrangement.

Felix lives with two housemates. One housemate does not have A/I/DD. Felix and his support team hire his support staff through self-direction, which sometimes includes his neurotypical roommate. His third housemate uses a different agency providing remote support.

A host home arrangement is the second highest form of service delivery used in Arizona, yet survey respondents rated it as their least preferred option overall [26]. Although not as preferred as **rotational staffing** or **shared living**, having a **paid neighbor** or using remote support as a service delivery model was also indicated as a preference. New York Office of Persons with Developmental Disabilities (OPWDD) offers a waiver-funded paid neighbor model through the state's equivalent of ALTCS-DD [46]. Seventeen states have become **Technology First states** and offer example state and waiver-funded models that include **remote support/monitoring** [47]. 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 [48]. CMS is reviewing flexibilities one state at a time for the consideration of remote and virtual supports temporarily approved during the COVID public health emergency to become permanent as states request those most efficacious to become ongoing support options, such as Ring doorbells, Alexa, sensors, wayfinders and real-time/two-way interactive video to help with cooking and other life skills.

*Preferred living arrangements**



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

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.

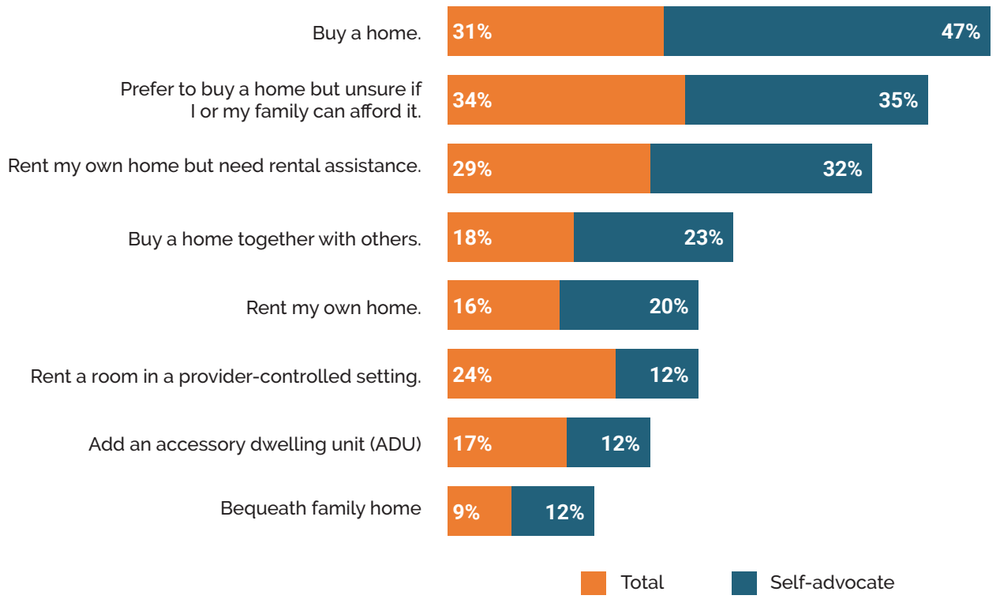
Remote Support/Monitoring
When possible, an individual may have their LTSS needs met via remote service, using technologies such as video conferencing, smart-home devices and other enabling technology.

Renting Versus Homeownership

Homeownership was a highly preferred option indicated by survey respondents. This is not surprising, as the rental market can be unstable for those on a fixed income. Families are also concerned that their loved ones may be evicted without their support or home as a safety net, or could be displaced or experience homelessness due to lack of available alternatives and without housing navigation assistance. Unlike other populations that may have the capacity to earn housing wages in the future, individuals with neurodevelopmental disabilities may not be able to earn a living wage due to limitations in their skill set or abilities; the current required housing wage in the Greater Phoenix area is at least $20.98 per hour [10].

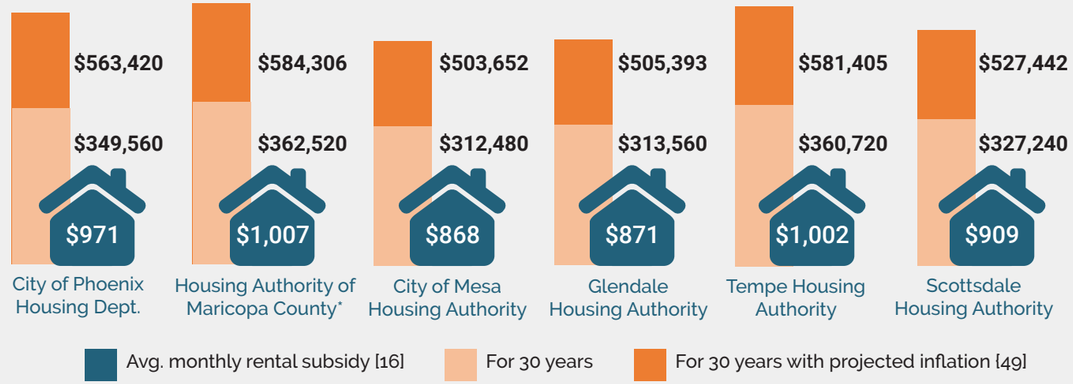
"Our biggest fear is if something happens to me, she will have no place to fall back to. We are caught in the middle where we do not make enough to save and make a plan and we make too much for her to get any assistance."

Do you want to buy or rent your future home?*



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

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



*The Housing Authority of Maricopa County is Surprise's housing authority.

"We are open to buying a side-by-side townhouse [duplex] where parents live on one side and our 21-year-old young adult learns to live independently next door with support services and in a planned community. A retirement community that also houses special need adults is a possibility."

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 can be preserved for those who prefer a rental option in the typical housing stock. Incentives should be created for landowners, developers and families to drive the development of attainable homeownership 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 for someone else in the purchased home. Mortgage products developed to help owner-occupied, low-income households may need to be modified to allow the purchase of a property for a low-income dependent with A/I/DD. For those who prefer to remain on family or a friend's property, allowing use-by-right **accessory dwelling units (ADU)** for dependent family members or individuals with A/I/DD or seniors could help increase housing options for this population, as well as others.

Living Arrangements

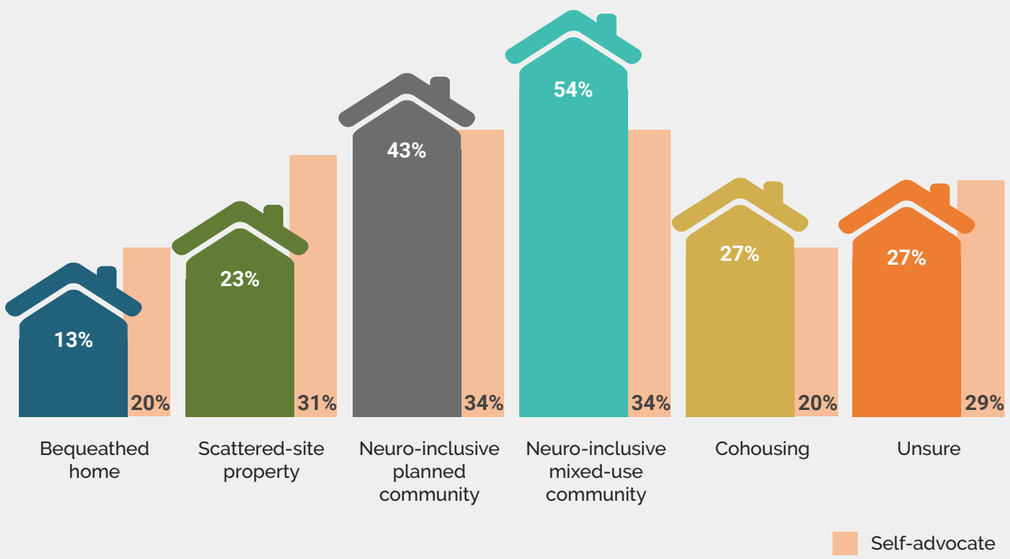
After learning about the benefits and considerations of various development times, it was clear that **neuro-inclusive planned communities** and neuro-inclusive, **mixed-use planned communities** were development types significantly preferred by participants. This may be due to the additional accessibility features, safety net and supportive amenities these options may provide that are unavailable in scattered-site housing. Arizona is home to multiple planned communities, some exclusive to individuals over age 55 (Sun City, Green Valley and PebbleCreek), while many others are inclusive of all ages and target a specific lifestyle (Verrado, Estrella and Eastmark). A neuro-inclusive planned or neuro-inclusive mixed-use planned community designs for the accessibility needs of adults with A/I/DD but could benefit anyone who chooses to live in a neurodiverse community.

When segmenting only self-advocate responses, there were some differences in preferred development types. Neuro-inclusive, mixed-use planned community was still the most preferred option, but both neuro-inclusive planned communities and **scattered-site** options were close behind. A higher percentage assumed they would stay in the family home and parents would move out of the bequeathed home. Indicated by the high number of respondents who were still unsure, a more robust educational training with video examples and diverse feedback from other self-advocates would likely be of value.

"We need leaders to acknowledge the housing crisis facing over 60,000 Arizona adults with A/I/DD living with a caregiver over age 60. Nonprofit homebuilders need more financial assistance to build sensory-accessible homes for this underserved population. Adults with A/I/DD should also be able to use housing vouchers to help them qualify for homeownership, as well as supportive services that help them live more independently."

– Michael Trailor, President & CEO of Trellis

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



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

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 [56].

Scattered-site property
A property (residential unit or development) that is located within the general housing fabric of a community. It is not part of a housing development that serves a specific residential market. In housing circles, "scattered-site housing" also refers to housing that is affordable and dispersed throughout the community [56].

Neuro-inclusive planned community
A small or large scale, planned property with multiple residential units that meet the needs of all individuals, also has recreational amenities. They sometimes feature commercial properties, such as restaurants and shops. Property management helps maintain home and common spaces. The intent is to make life as convenient and enjoyable as possible and to support connections and belonging [56].

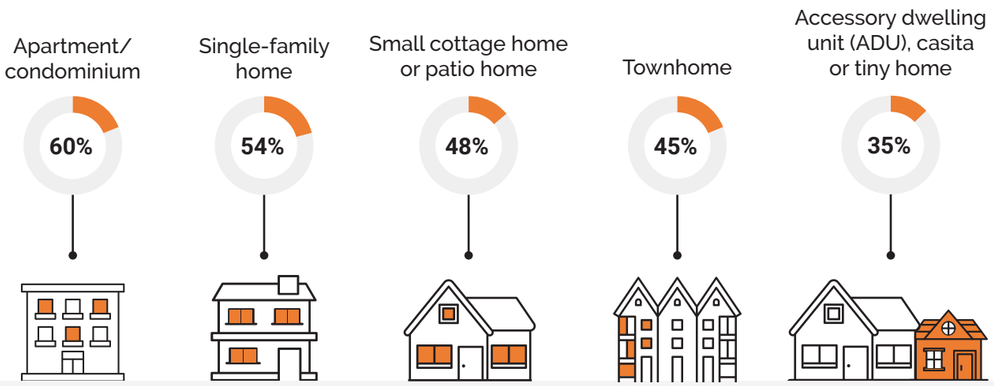
Mixed-use community
A real estate development that blends residential, commercial, cultural, institutional and/or (if appropriate) industrial uses. This development type is typically located in urban settings and allows for greater density. It reduces distances between destinations and can promote pedestrian- and bicycle-friendly environments [56].

Cohousing
An intentionally planned housing community created by its residents. Cohousing communities typically feature private residential units (single-family homes, townhouses, etc.), 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. Residents typically own their homes [56].

As states review and execute their **Home and Community-Based Services State Transition Plans**, information from this analysis sheds light on diverse preferences in living options and the desire for neuro-inclusive planned communities. When thoughtfully designed, these communities can foster integration into the greater community and may enhance overall social well-being and mental health. Residents from the model examples included in the educational training can create their own schedule, select their preferred service provider and service delivery model, as well as come and go as desired.

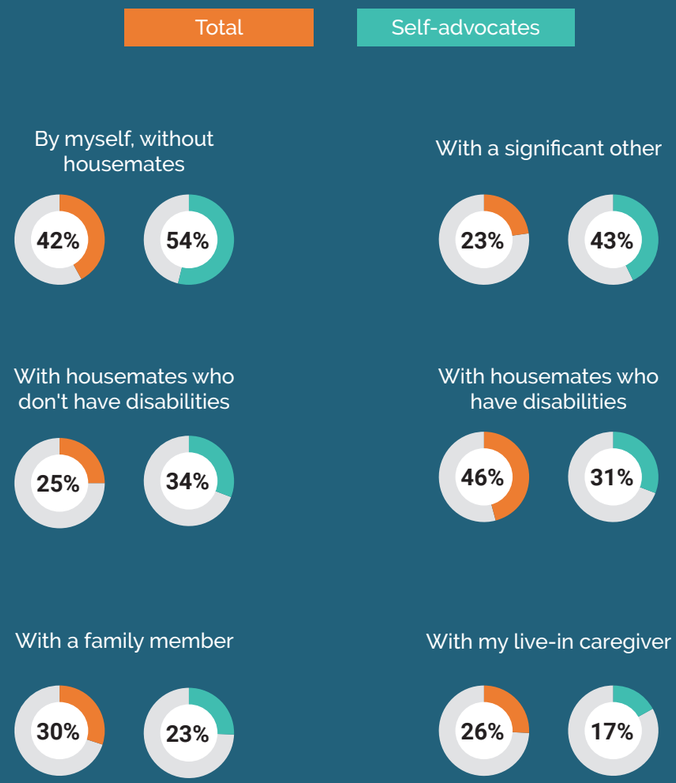
Sharing one's home is an intimate experience. In the past, people with A/I/DD were often expected to live with multiple, unrelated individuals with disabilities in a group setting in order to access services or afford housing. Non-disabled adults often experience this type of living situation only during early adulthood in dormitories or student housing. When asked about living arrangements, self-advocates were most interested in either living with a significant other or alone in a single unit. The third-highest-rated preference for self-advocates was to live with a housemate of their choosing who does not have a disability. When including responses from individuals who do not have A/I/DD, living alone or with another housemate of their choosing who has a disability was the prioritized preference. Although one of the predominant models of service delivery in Arizona, living with a caregiver was not in the top three preferences for living arrangements.

*What type of housing are you interested in?**



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

*What living arrangements would you prefer?**



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

What type of physical amenities would be helpful?

1. **Smart-home features**

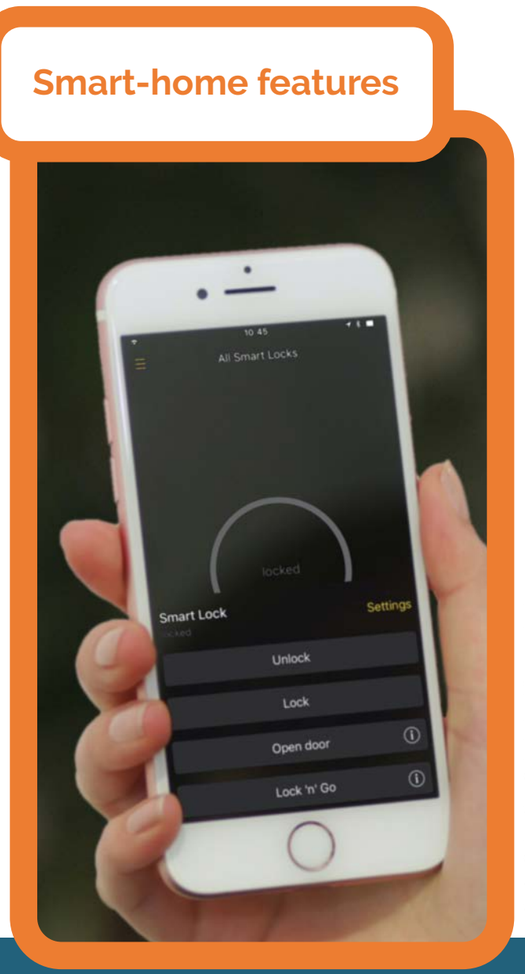


Photo: Sebastian Scholz (Nuki), Unsplash

2. Easy-to-clean features

3. Pedestrian-oriented

4. Security features

5. Extra-durable features

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 smart-home features like reminders if an oven is left on or a door is open, 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**. **Human-centered mobility design** encompasses all methods of travel, from departure to arrival. **Pedestrian-oriented** design makes walking around one's community safer for those who do not drive or are challenged by depth perception, which makes it difficult to cross streets [50]. 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.

"Apartment-type living that has the sensory privacy of a single-family home."

Supportive Amenities

Although certain supportive amenities were ranked higher than others, it is important to note that, overall, supportive amenities within housing options were highly desired.

Supportive amenities are not individualized, long-term support services. Supportive amenities are available to all residents who live at a specific property and offer additional needed support that individualized long-term support service providers often do not offer. They also offer an alternative supportive housing option for ALTCS-DD ineligible individuals that 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 to anyone living in their residences. Following the evidence-based best practice of the **Housing First model**, supportive amenities should be voluntary.

"UnitedHealthcare Community Plan of Arizona has identified areas to make the health system work better for adults with intellectual and developmental disabilities and providers caring for them; for example, improving collaboration between and among different systems to ensure that those with the most complex needs receiving high-quality supports and services. With such support, we may influence healthier outcomes and reduce housing instability..."

– Amy Pawlowski, Executive Director, Complex Care, UnitedHealthcare Community Plan

Top 5 desired supportive amenities

1. Health and fitness activities

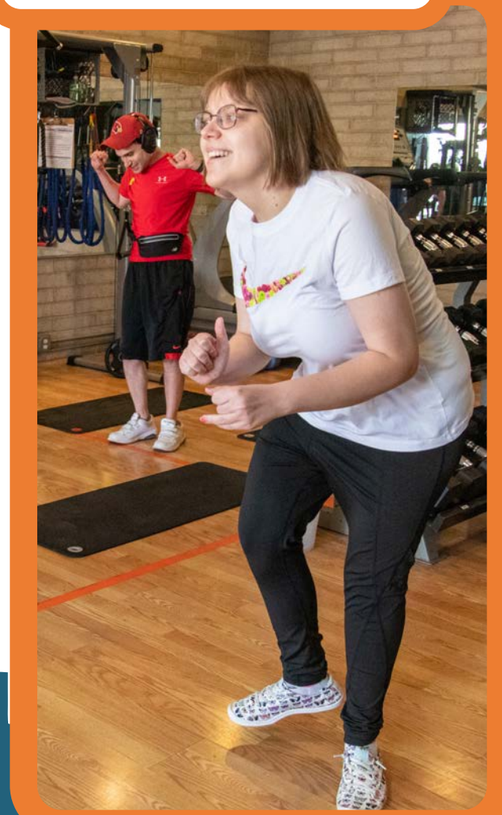


Photo: First Place® AZ, Good Eye! Media

2. Community life
3. Community navigator
4. Life-skills training
5. Meal service

Transitioning from Family Home

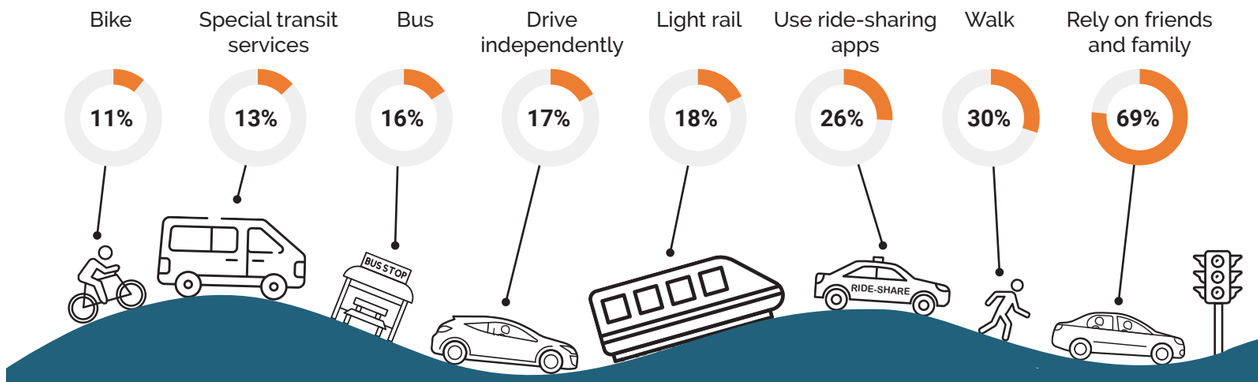
Moving from a family home setting is a big leap for both neurotypical and neurodivergent young adults. Adults with A/I/DD may have been living in the family home for decades longer and change may be more challenging than for a neurotypical counterpart. Changing environments, daily routines, transportation routes and the stress of leaving the stability of the family home requires greater direct support for a transitional period. Over half of survey respondents indicated the desirability of a post-secondary transition program offering intensive life skills training to act as a bridge to independent living. The majority would need assistance to cover the cost. In collaboration with the Southwest Autism Research & Resource Center (SARRC), First Place AZ, operates a clinical-based, residential transition program. The First Place Transition Academy utilizes the Learn4Independence® curriculum offering a model post-secondary transition program whereby outcomes have proven its effectiveness and the cost of the clinical component of the program can now be supplemented by health plans, including those funded using Medicaid dollars. A sample of the most recent data indicate that 94% of graduates navigate public and private transportation, 85% independently manage the care of their home and 70% are employed.

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

- **45%** Yes, but only if there is assistance covering the cost.
- **16%** No
- **15%** Unsure
- **14%** I have already attended a transition program.
- **10%** Yes, even if it is private pay.

Community Development

With 81% of respondents reporting they do not drive, planners and community development professionals at the local level play an integral part in ensuring that adults with A/I/DD are able to access housing in a location that is walkable and close to public transportation. Survey respondents indicated that food access within walking distance of the property was a critical need. With land a limited commodity, **land banking** and/or utilizing a **community land trust** to secure parcels of property that would be 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 isolating to residents who cannot drive.



Access to restaurants, a meal service and a place to eat meals with others ranked very high in survey questions addressing preferences in opportunities within walking distance of or on a potential residential property. This may be due to the high executive functioning load required in meal preparation, including but not limited to meal planning, budgeting, transportation to/from a grocery store, maneuvering the sensory challenges of a grocery store, meal preparation, inviting others to join in a meal, eating a meal alone and cleaning up. Access to a meal plan and a common dining area may alleviate some of this responsibility, which is more difficult without access to a car and/or living on a limited budget. These options can support a sense of community and provide social opportunities, decrease feelings of loneliness and increase a sense of belonging. Eating a meal with others is a powerful 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 a common dining area and access to prepared meals as a potential institutional red flag [51]. There may be additional licensing and survey requirements for these amenities that may add to administration and/or budgetary costs. It is important that Arizona considers the need to create social opportunities and support how future developments can include a common area and/or voluntary meal service that could be available to residents. The addition of prepared meals during the pandemic and its inclusion in the updated 1115 Demonstration Waiver indicate Arizona's willingness to respond and adjust to the needs of its health plan members.

Top community amenities on the property or within walking distance*

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

Top 5 desired accessibility amenities

1. Knowing what to expect when going out

Photo: First Place® AZ, Good Eye! Media

2. A person or place to go to when I'm scared/confused
3. Extra time and space to interact at my own pace
4. Knowing who will be present ahead of time
5. Sensory-friendly environments

The survey also included elements that would make spaces and places more accessible to the neurodiverse population. Housing is one element of community development. Local planners and businesses can use this data to continue making Greater Phoenix more neuro-inclusive. The top five accessibility features for making space more accessible to this population included knowing what to expect ahead of time, as well as having extra time or space to process, a point person to assist if needed and a sensory-friendly environment. These are elements that could be incorporated into local festivals and markets, the 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.

If we treated all our patients the way we should be treating patients with autism and intellectual and developmental disabilities—like using plain language, offering visible navigation tools, following up after appointments and allowing for more time—then ALL our patients would do better."

– Caroline Kim Kupfer, MD, Dignity Health; First Place Virginia G. Piper Health Spot Internist

Preferred Locations

When asked about location, areas of highest preference included North and Central Phoenix and Scottsdale. This could be due to the familiarity of locations where respondents currently live. This data should not limit opportunities for future sites, as it only reflects input from those who are part of this market study and therefore shouldn't represent the only areas where people want to live. Of significant interest should be the 18% of families who would be willing to relocate to another state to find a residential solution for their loved one. 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 lost. In addition, moving may not be possible due to other state waiting lists for those eligible for LTSS. Over 481,000 individuals across the country are on such lists, Arizona and California are the exception [52].

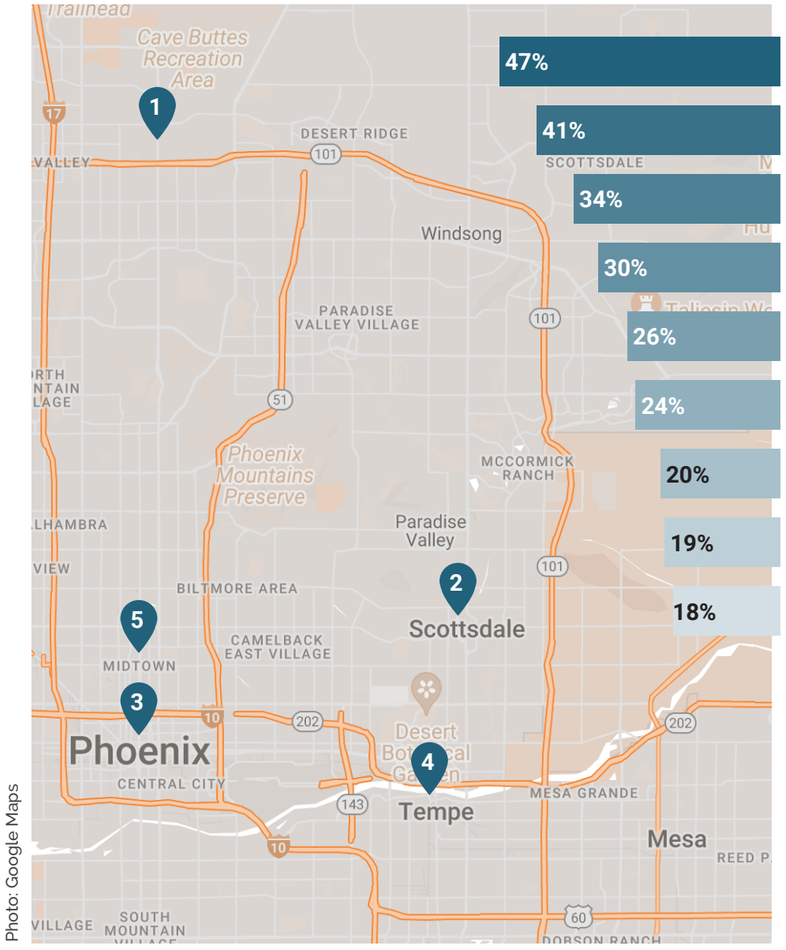


Photo: Google Maps

Top 5 desired opportunities

1. Fun things to do every week

Photo: First Place® AZ, Good Eye! Media

2. Planning grants to launch housing options

3. More help to find housing assistance

4. Help getting needed services

5. Help for families to plan for the future

When asked what opportunities are needed in the future, the majority of respondents requested more fun things to do, planning grants to launch housing solutions, and assistance in future planning, finding housing and accessing services.

Photo: Colin Lloyd, Unsplash

"Please continue to have virtual conferences and surveys like this. I feel that the more these that happen, the more people will be interested to see who we are, what we're doing, and what we hope to do to ensure that EVERYONE with disabilities has a safe, secure, and above all else, AFFORDABLE place to live on their own."

– Self-Advocate & GPHMA Local Leader Participant

RECOMMENDATIONS

The following recommendations for the development of a Housing and Community Roadmap are derived from focus group feedback and data analysis by First Place Global Leadership Institute researchers, local leaders and Greater Phoenix Housing Market Analysis advisors.

Closing Data Gaps

- Segment the **Homeless Management Information System (HMIS)** or **point-in-time** data to identify adults with A/I/DD experiencing homelessness.
- Modify ALTCS-DD case management tools to identify individuals with A/I/DD involuntarily displaced due to the lack of affordable, accessible housing and/or currently living in a provider-controlled setting but who desire a consumer-controlled setting.
- Identify adults with A/I/DD living in family caregivers' homes. Segment by those who would meet eligibility criteria for ALTCS-DD services and those who do not or would likely not meet eligibility criteria yet have supportive housing needs.
- Identify adults with A/I/DD enrolled in AHCCCS programs but not in ALTCS-DD.
- 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 and 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, and distinguish utilization rates of residents with A/I/DD currently living in public housing or in Permanent Supportive Housing.

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.
- Identify interest of local Community Development Financial Institutions and/or the Arizona Housing and Finance Authority 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 Arizona 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 Arizona Home Builders Association.
- Increase awareness of community land trusts of the demand for housing targeting adults with A/I/DD and their families.

Rental Subsidies

- Prioritize low-income people with A/I/DD and/or those receiving ALTCS-DD services in Housing Choice Voucher (HCV) waitlist applications.
- Decrease trauma and support smoother transitions from the family home by ensuring policy requirements for housing assistance programs do not require first the experience of homelessness or institutionalization for access to assistance.
- Expand the existing collaboration between the Arizona Department of Housing and ALTCS-DD to apply for additional 811 funding, as well as other housing subsidies to increase use by adults with A/I/DD at risk of displacement or homelessness.
- To prevent unintended discrimination, offer educational opportunities to landlords, property managers and developers so they can 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.

Increase in Development of Neuro-Inclusive Mixed-Use and Planned Communities

- Prioritize adults with A/I/DD within the Arizona 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 Arizona Housing Trust Fund.
- Develop a funding source or incentives for new construction or rehabilitation that creates additional units for single or two-person households incorporating universal and neuro-inclusive design elements. This could be activated via a community land trust or a modification to other existing funding mechanisms.
- Using a model recently launched by the Colorado Housing and Finance Authority, offer Pre-development Technical Assistance grants to landowners such as local not-for-profit, faith communities, local planning departments and developers to hire consultants and/or conduct feasibility activities to create local neuro-inclusive solutions.

Long-Term Support Services Through ALTCS-DD

- Explore other states' use of remote/virtual support and increase Arizona's ability to pay for new service delivery models, e.g., paid neighbors, peer-to-peer support.
- Consider adding housing services available in other states for Arizona waiver recipients. These include pre-tenancy supports, housing stabilization services, transitional housing services, tenancy sustaining services, etc. [53].*
- 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.
- Add Self-Directed Attendant Care as a service delivery model available for adults with A/I/DD as it is for the Arizona Long Care System-Elderly and Physically Disabled (ALTCS-EPD) program.

Local Community Development

- Include adults with A/I/DD in local Diversity, Equity and Inclusion efforts to increase visibility of Greater Phoenix's neurodiverse population.
- Include recognition of the housing needs of people 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 to target individuals with A/I/DD and their families, better connecting 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, neuro-inclusive planned communities.
- Develop or prioritize a local Housing Trust Fund targeting housing assistance, gap financing or funding for neuro-inclusive planned or mixed-use housing communities.
- Offer a property tax waiver for low-income residents with A/I/DD who live in a bequeathed home outside of the family home.
- Modify zoning codes to allow for the addition of an accessory dwelling unit (ADU) or tiny home as a "use by right" on property that will house a dependent adult; offer planning grants and waive fees associated with requesting approval.

*A few such services have been approved in I/DD waivers, such as in Pennsylvania's Consolidated I/DD waiver.

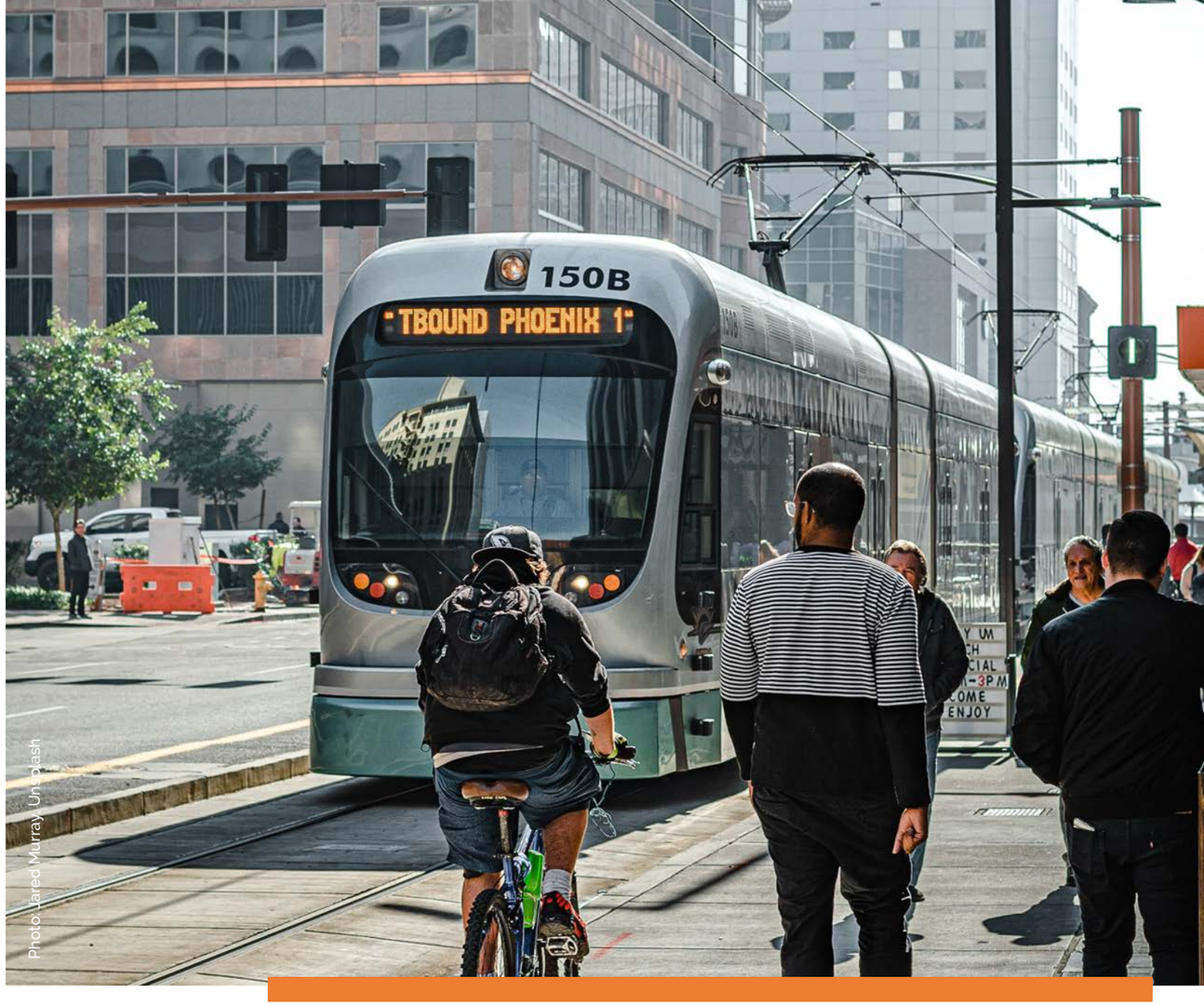


Photo shared Murray Unsplash

CONCLUSION

Home to more than seven million people, Arizona is the second-fastest-growing state in the U.S. [54]. As in other cities across the country, the cost of homes in the Greater Phoenix area has risen significantly, outpacing wage and growth levels. As with the neurotypical population, adults with A/I/DD seek a home that is safe, stable and comfortable, where they can be themselves and be proud to bring friends and family. They want to access daily neighborhood conveniences, meet people in the neighborhood, be a regular at their favorite places of business and have a true sense of belonging.

There are simply not enough residential options to meet surging demand. For the overall A/I/DD population, it is not a question of if this population will lose their existing home and primary caregiver, it is a question of when.

Workforce shortages, changing demographics and a rapidly aging population mean Arizona needs increased access to housing, as well as technology to support innovation. Without planning, many members of this population will be forced into crisis placements in emergency rooms, nursing facilities, psychiatric hospitals, institutional settings—or could face homelessness or incarceration. These consequences are both traumatic for individuals and their families and expensive for the state of Arizona.

The following are some of the pressing, systemic challenges facing Greater Phoenix and Arizona collectively:

- The specific number of Arizona adults with A/I/DD is unknown.
- Data on the need for affordable housing do not capture the needs of those living in aging family caregivers' homes.
- Data collection is not segmented by those living in a home they rent/own or those living in a home rented/owned by a family member or caregiver.
- Current housing stock is largely inaccessible: financially, physically and cognitively.
- The percentage of adults with A/I/DD ineligible for services funded by ALTCS-DD and at greater risk of homelessness is unknown.
- The size of the homeless population living with an A/I/DD is unknown, though homeless service providers are reporting increased numbers served.
- As of November 2022, the Division of Developmental Disabilities has funding for fewer than 200 ALTCS-DD-enrolled individuals across Arizona through Section 811 Project Rental Assistance and/or Housing Vouchers [19].
- Statewide, there are only 850 mainstream housing vouchers and 175 NED vouchers targeting adults with disabilities, and their utilization by those with A/I/DD is unknown.
- No financial tool for housing developers exists that meets the needs of supportive housing targeting adults with A/I/DD.
- No housing navigation program, such as those used by seniors or veterans, is available to help adults with A/I/DD and their families work through the complex and disconnected systems of housing assistance, long-term support services and other public benefits.
- No ALTCS-DD funding is offered for many of the service delivery models preferred by survey respondents.
- No incentives or mortgage products are available for neurodiverse families to assist their loved ones in purchasing a home that can be held in a trust to protect the asset from those who would exploit or take advantage of an adult with A/I/DD.

With an estimated 63,060 adults with A/I/DD living with a caregiver over age 60 (based on incidence and prevalence data) and with many of these individuals predicted to be without formal long-term services systems, an urgent gathering of local leaders and elected officials is needed to develop a roadmap for supportive housing solutions to thwart the displacement of and risk of homelessness for adults with A/I/DD in Arizona [24].

With an estimated 63,060 adults with A/I/DD living with a caregiver over age 60 (based on incidence and prevalence data) and with many of these individuals predicted to be without formal long-term services systems, an urgent gathering of local leaders and elected officials is needed to develop a roadmap for supportive housing solutions to thwart the displacement of and risk of homelessness for adults with A/I/DD in Arizona [24].

Thanks to the efforts of the research team at the First Place Global Leadership Institute, Arizona market leaders, and advisors and sponsors, Greater Phoenix now has market data on the needs and preferences of residential demand of this invisible population. Meeting their housing needs will result in a happier, healthier and more stable population, which has the potential to reduce Medicaid costs, increase quality of life, and enable more effective and successful longer-term planning for individuals and their families to help prevent disruptive, emergency placements and even homelessness

The cost of doing nothing will be exorbitant. Action is needed now to help every Greater Phoenix resident find a home—and their place in the world.

Join us by reaching out to info@firstplaceaz.org.

GLOSSARY

#	**1115 Demonstration Waiver**	Section 1115 of the Social Security Act gives the Secretary of Health and Human Services authority to approve experimental, pilot or demonstration projects determined by the Secretary to be likely to assist in promoting the objectives of the Medicaid program ("About Section", n.d.). The 1115 Waiver refers to section 1115 of the Social Security Act (SSA). States must comply with Title XIX (Medicaid) and Title XXI (Children's Health Insurance Program) of the SSA ("About Section", n.d.). Currently, 44 states have 1115 demonstration waivers in addition to their standard Medicaid program ("Statewide", n.d.). Since Arizona began providing Medicaid on October 1, 1982, AHCCCS has been exempt from specific provisions of the SSA, pursuant to an 1115 Research and Demonstration Waiver ("Statewide", n.d.). Arizona's 1115 Waiver includes the following: provisions in the SSA and corresponding regulations from which AHCCCS is exempt; Special Terms and Conditions (STCs) that AHCCCS must fulfill; and approved federal budget amounts ("About Section", n.d.). [55]	57
	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. [56]	29
A	**Accessory dwelling units**	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 ("Accessory", 2022). They may also be referred to as casitas, granny flats, accessory apartments or secondary suites ("Accessory", 2022). They may be converted portions of existing homes or additions to new or existing homes ("Accessory", 2022). [57]	47
	Adult foster care (see host home)	Where an individual with LTSS needs lives in the home of their LTSS provider (Resnik & Kameka Galloway, 2020). [56]	8
	Affordable housing	Generally defined as housing in which the occupant is paying no more than 30% of gross income for housing costs, including utilities (U.S. Department of Housing and Urban Development (HUD), 2011). [40]	8
	Americans with Disabilities Act (ADA)	An 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 (U.S. Department of Labor, n.d.). [58]	26
	Arizona Department of Economic Security (DES)	A state agency that provides protective services and assistance to children, adults and families in Arizona (State of Arizona Research Library, n.d.) [59]	17
	Arizona Department of Housing (ADOH)	A state agency established to provide housing and community revitalization to benefit the people of Arizona (Arizona Department of Housing, n.d.). [60]	7
	Arizona Health Care Cost Containment System (AHCCCS)	Arizona's Medicaid agency that provides healthcare programs to Arizona residents.	11
	Arizona Long Term Care System-Developmental Disabilities (ALTCS-DD) Program	Special services offered by ALTCS to individuals with I/DD who require ongoing intermediate care facility-level services (AHCCCS, n.d.). [61]	12
	Arizona Long Term Care System (ALTCS)	Arizona's health insurance for individuals who are elderly, have disabilities, and/or require nursing facility-level care (Arizona Health Care Cost Containment System (AHCCCS), n.d.). [61]	*6*
	Autism and/or intellectual and/or developmental disability(ies) (A/I/DD)	...a diagnosis of Down syndrome, cerebral palsy, fragile X syndrome, autism, etc. A/I/DD impacts one's intellectual ability to perform activities of daily living unassisted. [62]	6
B	**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. [63]	34
C	**Capitated managed care**	A payment methodology that enables state Medicaid plans to pay managed care organizations for risk-based managed care services through fixed, periodic payments for a defined package of benefits Medicaid and CHIP Payment and Access Commission (MACPAC), 2023). These capitation payments are typically made on a per-member, per-month (PMPM) basis (MACPAC, 2023). Managed care organizations negotiate with providers for services to their enrollees, either on a fee-for-service (FFS) basis or through arrangements under which they pay providers a fixed periodic amount for services (MACPAC, 2023). [64]	11
	Cognitively accessible	The building includes signage with simple visual indicators (illustrations, icons), design compositions that support positive pattern and color recognition, as well as text to indicate different space functions or directions around the building. [56]	8

	Cohousing	An intentionally planned housing community created by its residents. Cohousing communities typically feature private residential units (single-family homes, townhouses, etc.), 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. Residents typically own their homes [56].	49
	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 (Grounded Solutions Network, 2023). CLTs develop rural and urban agriculture projects, commercial spaces to serve local communities, and affordable rental and cooperative housing projects that conserve land or urban green spaces (Grounded Solutions Network, 2023). The goal is to create homes that remain permanently affordable, thereby providing successful homeownership opportunities for generations of lower-income families (Grounded Solutions Network, 2023). [65]	56
	Consolidated plans	A plan designed to help state and local jurisdictions assess their affordable housing and community development needs and market conditions (HUD Exchange, 2023). These plans enable data-driven, place-based investment decisions (HUD Exchange, 2023). This plan is comprised of annual actions plans that provide a summary of the actions and activities and the federal and non-federal resources that will be used each year to address the needs and goals specified in the plan (HUD Exchange, 2023) [66].	15
D	**Daily medical support**	The individual needs 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. [56]	29
	Division of Developmental Disabilities (DDD)	An Arizona government division that provides supports and services based on need, state and/or federal guidelines, eligibility and funding availability (DES, 2022). [67]	17
	Drop-in support	The individual needs a DSP to check in with them every few days or as requested; the individual is self-sufficient the majority of the time. [56]	29
E	**Enabling technology**	Various types of technological devices used to support a person with disabilities in living as independently as possible (Tennessee Department of Intellectual & Developmental Disabilities (TNDIDD), n.d.). This can include sensors, mobile applications, remote support systems and other smart devices to help individuals navigate jobs and their community, have more control over their environment, and provide remote support and reminders when necessary (TNDIDD, n.d.) [68].	8
	Executive functioning	The higher-level cognitive skills used for control and coordination of other cognitive abilities and behaviors (Weill Institute for Neurosciences, 2023). It can be broken down into organizational and regulatory abilities. Organizational abilities include attention, planning, sequencing, problem-solving, working memory, cognitive flexibility, abstract thinking, rule acquisition and the selection of relevant sensory information (Weill Institute for Neurosciences, 2023). Regulatory abilities include initiation of action, self-control, emotional regulation, monitoring of internal and external stimuli, initiating and inhibiting context-specific behavior, moral reasoning and decision-making (Weill Institute for Neurosciences, 2023). [69]	19
F	**Face blindness or prosopagnosia**	A neurological disorder characterized by the inability to recognize faces.	53
G	**Graded movement**	Movements whereby a person uses the appropriate amount of force to complete motor skills (Your Therapy Source (YTS), 2019). People with A/I/D/D may use too much or too little force when performing actions such as opening a door, flushing a toilet, stepping down, etc. (YTS, 2019). [70]	19
H	**Home and Community-Based Services (HCBS)**	Services that help with daily activities while allowing individuals to stay in their own homes or live with their families, thereby reducing the need for institutional care (Department of Economic Security, 2022). [71]	11
	Home and Community-Based Services State Transition Plans (STP)	Plan developed by states to comply with the HCBS settings rule established in response to the Olmstead decision ("Statewide", n.d.). Plans are submitted to the Centers for Medicare & Medicaid Services for review and approval ("Statewide", n.d.). March 17, 2023 is the deadline for full state compliance with the HCBS settings regulation, effective March 17, 2014 ("Statewide", n.d.). [72]	50
	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 (Department of Housing and Urban Development (HUD), 2022). Each Continuum of Care (CoC) is responsible for selecting an HMIS software solution that complies with HUD's data collection, management and reporting standards (HUD, 2022). [73]	62
	Host home (see adult foster care)	Where an individual with LTSS needs lives in the home of their LTSS provider (Resnik & Kameka Galloway, 2020). [56]	8
	Housing and Health Opportunities (H2O)	A newly approved (October 2022) program intended to enhance and expand housing services and interventions for AHCCCS members who are homeless or at risk of being homeless (Arizona Housing Cost Care Containment System (AHCCCS), 2022). The goal is to increase positive health and well-being outcomes for target populations, reduce cost of care and reduce homelessness by providing housing as a part of healthcare (AHCCCS, 2022). [43]	33

	Housing and lifespan navigators	Individuals who offer assistance understanding residential choices, applying for housing assistance and tenant stabilization, and guiding elements needed for financial and legal planning beyond life with parents present. May or may not be available as a waiver-funded service (state-dependent) [53]	35
	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 (Resnik & Kameka Galloway, 2020). 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 (Resnik & Kameka Galloway, 2020). [56]	47
	Housing First model	Housing First is a homeless assistance approach that prioritizes providing permanent housing to people experiencing homelessness, thus ending their homelessness and serving as a platform from which they can pursue personal goals and improve their quality of life ("Housing", 2022). [74]	54
	Human-centered mobility design	User-centric transport systems with highly intuitive elements, from ticketing to wayfinding highly (Mitchell et al., 2017). Mobility design must be efficient, cost-effective and accessible to the widest population in order to support a growing and vibrant city (Mitchell et al., 2017). 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 (Mitchell et al., 2017). Ticketing systems and real-time information should enable seamless end-to-end journeys across all modes (Mitchell et al., 2017). [50]	53
I	**Intermediate care facility for individuals with intellectual disabilities (ICF/IID)**	An optional Medicaid benefit created by the Social Security Act (SSA) to fund "institutions" (4 or more beds) for individuals with intellectual disabilities (U.S. Centers for Medicare & Medicaid Services (CMS), n.d.). 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 (CMS, n.d.). This program serves over 100,000 individuals with intellectual and other disabilities and related conditions (CMS, n.d.). Many are non-ambulatory and/or have seizure disorders, behavior problems, mental illness, visual or hearing impairments, or a combination thereof. All must qualify for Medicaid assistance (CMS, n.d.). [75]	31
L	**Land banking**	Public authorities or nonprofit organizations created to acquire, hold, manage and sometimes redevelop properties to return them to productive use to meet community goals, including increasing the supply of affordable housing or stabilizing property values. [76]	56
	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 (Thach & Wiener, 2018). (See also ALTCS-DD) [77]	6
	Low support	The individual needs a DSP to support them with a few tasks each day but can be self-sufficient for most of the day. [56]	29
M	**Mainstream Housing Choice Vouchers**	Vouchers that assist non-elderly individuals with disabilities (U.S. Department of Housing and Urban Development (HUD), 2020). These vouchers operate under the same rules as other housing vouchers (HUD, 2020). [78]	16
	Means-tested	Limiting eligibility to individuals and families whose incomes and or assets fall below a predetermined threshold (means test). [79]	34
	Memory care	Due to symptoms of dementia or Alzheimer's disease, the individual needs a safe environment, with extra structure and support to navigate the day. [56]	29
	Mixed-use planned communities	Large-scale residential development of various uses with robust, curated amenities that aim to give residents the experience of living in a self-contained town (Truelove, 2022). Amenities can include parks, playgrounds, swimming pools, tennis courts, golf courses and more. [80]	48, 49, 56
	Moderate support	The individual needs a DSP periodically throughout each day but can be self-sufficient for several hours at a time. [56]	29
N	**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 also feature commercial properties such as restaurants and shops. 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. (Resnik & Kameka Galloway, 2020) [56]	48
	Non-Elderly Disabled (NED) vouchers	A state, county, municipality or other government entity or agency of entities authorized to engage in the development or operation of low-income housing under the U.S. Housing Act (1973) (Law Insider, n.d.). [81]	16
O	**One-on-one support**	The individual needs the full attention and in-person support of at least one DSP at all times. [56]	29
	Olmstead Plan	This 1999 U.S. Supreme Court decision determined that states cannot make institutionalization a condition for publicly funded health coverage unless it is clinically mandated. (See also HCBS state transition plans and HCBS settings rule) [68]	11
P	**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 (Resnik & Kameka Galloway, 2020). Also referred to as a resident assistant. [56]	45

	Pedestrian-oriented	The building and/or development is in a walkable neighborhood with intentional limits on vehicle traffic. Walkable neighborhoods can be safer for residents (adults and children) who may not recognize street crossings. [56]	8
	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 (Administration for Community Living (ACL), 2021). [82]	12
	Physical Disability ADL	Due to a physical disability, the individual may use a wheelchair or mobility device and need additional DSP assistance with transfers and other activities of daily living.	29
	Planned communities	A small- or large-scale, intentionally planned property with multiple residential units (such as apartments, condominiums and/or single-family homes) that also has recreational amenities (such as parks, tennis courts, golf courses and trails). 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. A planned community may offer physical and supportive amenities that cater to neurodiverse residents. They are typically consumer-controlled settings, as most are not LTSS providers. This development type is usually located in suburban settings. [56]	48
	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 ("Point-in-time", 2022). [83]	62
	Provider-controlled setting	Property where the housing provider is both property manager and LTSS provider (Resnik & Kameka Galloway, 2020). Residents cannot change their LTSS provider in a provider-controlled setting without moving to a different home (Resnik & Kameka Galloway, 2020). [56]	14, 32
	Public housing authorities (PHA)	A state, county, municipality or other government entity or agency of entities authorized to engage in the development or operation of low-income housing under the U.S. Housing Act (1973) (Law Insider, n.d.). [84]	15
R	**Remote support/ monitoring**	The use of technology to provide real-time assistance by a direct support professional from a remote location (Centers for Medicare & Medicaid Services (CMS), 2021). This service often reduces the number of housekeeping or homemaker personal care services needed by an individual while enabling safety, privacy and independent task completion (CMS, 2021). [85]	45
	Rotational staffing	The act of an individual needing LTSS selecting an agency that provides LTSS to recruit, hire, train, schedule and fire support staff for them (Resnik & Kameka Galloway, 2020). In Arizona, this is known as the Independent Provider Program. [56]	45
S	**Scattered-site**	A property (residential unit or development) located within the general housing fabric of a community (Resnik & Kameka Galloway, 2020). It is not part of a housing development that serves a specific residential market (Resnik & Kameka Galloway, 2020). In affordable housing circles, scattered-site housing also refers to affordable housing dispersed throughout the community (Resnik & Kameka Galloway, 2020). [56]	48
	Section 811 Project Rental Assistance	This program allows individuals to pay 30% of their income to rent and utilities while the remaining cost of both is covered (Arizona Department of Housing (ADOS), 2022). This program applies to households where at least one family member has a developmental disability, is between age 18–61 and is receiving community-based long-term care services through DES (ADOS, 2022). [86]	16
	Self-directed support	A budget given to an individual needing LTSS to spend on their LTSS based on an assessment of their support needs (Resnik & Kameka Galloway, 2020). They are responsible for recruiting, hiring, training, scheduling and firing support staff. Some states allow family members to be hired as support staff (Resnik & Kameka Galloway, 2020). [56]	45
	Self-direction	A model of long-term care service delivery that helps people of all ages, with all types of disabilities, maintain their independence at home ("What is", 2021). When a person self-directs, they decide how, when and from whom their services and supports will be delivered ("What is", 2021). As a model, self-direction prioritizes participant choice, control and flexibility ("What is", 2021). [87]	44
	Serious mental illness	A mental, behavioral or emotional disorder resulting in serious functional impairment that substantially interferes with or limits one or more major life activity (National Institute of Mental Health (NIMH), 2022). [88]	33
	Shared living	A living situation where an individual with LTSS needs invites a person or family member(s) to live in their home to provide LTSS (Resnik & Kameka Galloway, 2020). Because private homes are consumer-controlled settings, the individual can ask their LTSS provider to move (Resnik & Kameka Galloway, 2020). [56]	45
	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 (Office of Disease Prevention and Health Promotion, 2020). [89]	6

	Social Security Disability Income (SSDI)	SSDI pays benefits to individuals and certain members of their family if the individual is "insured," meaning they have worked for a sufficient length of time and paid social security taxes (Social Security Administration (SSA), n.d.). [90]	32
	Special needs trust	A trust that can be created for an individual with disability(ies) by a family member that does not impact the individual's financial qualification for government programs (Lin, 2022). It is often used after the family member's passing to pay for services that improve/maintain the person's quality of life (Lin, 2022). [91]	34
	Supplemental Security Income (SSI)	Monthly benefits provided to individuals with limited income and resources who are disabled, blind, or age 65 or older (Social Security Administration (SSA), 2022). [92]	32
	Supportive amenities	Supports and features offered by a property that make life easier and/or more enjoyable for those living there. Such services include community life activities, housekeeping and meal services, etc. [56]	8, 19
T	**Technology First states**	States that apply a "framework for systems change where technology is considered first in the discussion of support options available to individuals and families through person-centered approaches to promote meaningful participation, social inclusion, self-determination and quality of life" (Tanis, 2019) [93]	45

REFERENCES

[1]	PBS NewsHour. (2016). *How Phoenix became the most autism-friendly city in the world*. PBS. www.pbs.org/newshour/show/phoenix-became-autism-friendly-city-world
[2]	The Precisionists, 29 Palms, First Place AZ, Spectrum Courtyard, Treasure House, and Luna Azul
[3]	Fernand, M. (2022). *America's rental housing 2022*. Joint Center for Housing Studies of Harvard University. www.jchs.harvard.edu/sites/default/files/reports/files/Harvard_JCHS_Americas_Rental_Housing_2022.pdf
[4]	Santarelli, M. (2022). *AZ housing market: Prices and forecast 2022 & 2023*. Norada Real Estate Investments. www.noradarealestate.com/blog/arizona-housing-market-forecast/#:~:text=According%20to%20real%20estate%20data
[5]	Winters, M. (2022). *The 10 U.S. states where income has risen the fastest since 2019*. CNBC. www.cnbc.com/2022/10/08/us-states-where-income-has-risen-the-fastest-since-2019.html#:~:text=Arizona%3A%205%2
[6]	Apartment List Research Team. (2022). *Apartment list national rent report*. Apartment List. www.apartmentlist.com/research/national-rent-data
[7]	Disability Justice. (2014). *The closing of Willowbrook	Disability Justice*. disabilityjustice.org/the-closing-of-willowbrook
[8]	Duckett, M., Guy, M. R." w/ "Duckett, M. & Guy, M. R. (2000). Home and community-based services waivers. *Health Care Financing Review, 22*(1): 123–25. www.ncbi.nlm.nih.gov/pmc/articles/PMC4194688
[9]	Arizona Health Care Cost Containment System. (2022). *A brief history of AHCCCS highlights*. www.azahcccs.gov/AHCCCS/Downloads/ABriefHistoryOfAHCCCS.pdf
[10]	National Low Income Housing Coalition. (2022). *Out of reach: Arizona*. nlihc.org/oor/state/az
[11]	Arizona Developmental Disabilities Planning Council. (2019). *Disability data for Arizona	ADDPC*. AZ.gov. addpc.az.gov/disability-data-arizona
[12]	Division of Developmental Disabilities. (2021). *Family support annual report*. Arizona Department of Economic Security. des.az.gov/sites/default/files/media/Family_Support_Annual_Report_2021.pdf?time=1667237690629

[13]	Brown, M. & McCann, E. (2020). Homelessness and people with intellectual disabilities: A systematic review of the international research evidence. *Journal of Applied Research in Intellectual Disabilities, 34*(2). https://doi.org/10.1111/jar.12815
[14]	Robustelli, T., Panfil & Y., Oran, K., Navalkha, C., Yelverton, E. (2020). *Displaced in America: Mapping housing loss across the United States*. New America. www.newamerica.org/future-land-housing/reports/displaced-america/housing-loss-in-maricopa-county-arizona
[15]	National Low Income Housing Coalition. (2022). *The gap report: Arizona*. nlihc.org/gap/state/az
[16]	Office of Public & Indian Housing. (2022). *Housing choice voucher program dashboard*. U.S. Department of Housing and Urban Development. app.powerbigov.us/view?r=eyJrIjoiM2Y2OTQ2MTAtODVkNC00Ym M2LThhOWEtZWY4MGU5YWFmZDFmIiwidCI6IjYxNTUyNGM1LTIyZ TktNGJjZC1hODkzLTExODBhNTNmYzdiMiJ9
[17]	Reagor, C. & Qin, A., Boehm, J. (2022). *Getting a housing choice voucher in the Phoenix area can take years. Finding a place to live can be tougher*. AZ Central. https://www.azcentral.com/in-depth/money/real-estate/2022/08/15/why-its-so-hard-use-housing-choice-voucher-phoenix-area/10092282002
[18]	Finkel, M., Khadduri, J., Main, V., Pistilli, L., Solari, C., Winkel, K. & Michelle, W. (2003). *Costs and utilization in the Housing Choice Voucher program*. U.S. Department of Housing and Urban Development. https://www.huduser.gov/Publications/PDF/utilization.pdf
[19]	Arizona Department of Economic Security. (2022). *Member housing opportunities*. des.az.gov/services/disabilities/developmental-disabilities/individuals-and-families/supports-and-services/housing
[20]	White, K. S. (2021). *HUD remains challenged to serve the maximum number of eligible families due to decreasing utilization in the Housing Choice Voucher program. 2021-CH-001*. U.S. Department of Housing and Urban Development. https://www.hudoig.gov/sites/default/files/2021-09/2021-CH-0001.pdf
[21]	Disability and Health Branch. (2022). *Disability & health U.S. state profile data: Arizona*. Centers for Disease Control and Prevention. www.cdc.gov/ncbddd/disabilityandhealth/impacts/arizona.html
[22]	Centers for Disease Control and Prevention. (2022). *CDC releases first estimates of the number of adults living with ASD*. www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html
[23]	Zablotsky, B., Black, L. I. & Blumberg, S., J. (2017). *Estimated prevalence of children with diagnosed developmental disabilities in the United States, 2014-2016*. National Center for Health Statistics. https://www.cdc.gov/nchs/data/databriefs/db291.pdf
[24]	University of Kansas Center for Developmental Disabilities | Life Span Institute. (2019). *State profiles - State of the states in intellectual and developmental disabilities*. State of the States in Intellectual and Developmental Disabilities Project. stateofthestates.org/state-profiles
[25]	Centers for Disease Control and Prevention. (2020). *CDC releases first estimates of the number of adults living with ASD*. www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html
[26]	Residential Information Systems Project. (2021). *Long-term supports and services (LTSS) recipients by setting type and year*. University of Minnesota. https://risp.umn.edu/viz/living-arrangements/ltss-recipientss-by-setting-type-and-year
[27]	Kurtz, L., Tziganuk, A., Cook-Davis, A. & Quintana, E. (2022). "You feel like a failure": Experiences of housing insecurity in Maricopa County. *Morrison Institute for Public Policy.* https://morrisoninstitute.asu.edu/sites/default/files/experiences_of_housing_insecurity_in_maricopa_county.pdf
[28]	Airgood-Obrycki, W., Hermann, A. & Wedeen, S. (2021). *The rent eats first: Rental housing unaffordability in the US*. Joint Center for Housing Studies of Harvard University. https://www.jchs.harvard.edu/research-areas/working-papers/rent-eats-first-rental-housing-unaffordability-us
[29]	Child, B., Oschwald, M., Curry, M. A., Hughes, R. B. & Powers, L. E. (2011). Understanding the experience of crime victims with disabilities and deaf victims. *Journal of Policy Practice, 10*(4): 247-267. https://doi.org/10.1080/15588742.2011.605829
[30]	Baladerian, N. J., Coleman, T. F. & Stream, J. (2013). *Abuse of people with disabilities victims and their families speak out: A report on the 2012 national survey on abuse of people with disabilities*. Spectrum Institute Disability and Abuse Project. https://tomcoleman.us/publications/2013-survey-report.pdf
[31]	Autism Together. (2015). *Mate crime reporting*. https://www.autismtogether.co.uk/mate-crime
[32]	Hammel, J., Smith, J., Scovill, S., Campbell, R. & Duan, R. (2017). *Rental housing discrimination on the basis of mental disabilities: Results of pilot testing.* U.S. Department of Housing and Urban Development Office of Policy Development and Research. https://www.huduser.gov/portal/sites/default/files/pdf/MentalDisabilities-FinalPaper.pdf
[33]	Office of Fair Housing and Equal Opportunity. (2020). *State of fair housing annual report to congress FY2020.* U.S. Department of Housing and Urban Development. www.hud.gov/sites/dfiles/FHEO/documents/FHEO-Annual-Report-FY2020.pdf

[34]	Vivanti, G., Tao, S., Lyall, K., Robins, D. L., Shea, L. L. (2021). *The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder.* Autism Research, *14*(10): 2189-2199. https://doi.org/10.1002/aur.2590
[35]	Arizona Health Cost Care Cost Containment System. (2020). *Arizona long term care system appendix 10 B: Preadmission screening manual for developmentally disabled*. https://azahcccs.gov/Resources/guidesmanualspolicies/eligibilitypolicy/eligibilitypolicymanual/Policy/Chapter_1000_Pre-admission_Screening/DDManualAppendix10B.pdf
[36]	U.S. Social Security Administration. (2022). *Understanding supplemental security income living arrangements—2022 edition*. https://www.ssa.gov/ssi/text-living-ussi.htm
[37]	Office of Retirement and Disability Policy. (2022). *Annual statistical supplement: Supplemental security income*. U.S. Social Security Administration. https://www.ssa.gov/policy/docs/statcomps/supplement/2022/7b.html
[38]	National Core Indicators. (2022). *NCI Charts (2017-18)*. Human Services Research Institute (HSRI) and The National Association of State Directors and Developmental Disabilities Services. http://legacy.nationalcoreindicators.org/charts/?i=12&st=AZ
[39]	Calculations: [(Gross Monthly Wages before taxes) - $85 (general and earned income exclusion)] divided by 2 = Countable Earned Income. SSI Federal Benefit Rate - Countable Earned Income = Reduced SSI Benefit Due to Earned Income, Reduced SSI Benefit Due to Earned Income + Gross Monthly Wages before taxes = Total Gross Monthly Budget amount.
[40]	U.S. Department of Housing and Urban Development. (2011). *Glossary of terms to affordable housing*. https://archives.hud.gov/local/nv/goodstories/2006-04-06glos.cfm
[41]	U.S. Social Security Administration Research, Statistics & Policy Analysis. (2022). *Monthly Statistical Snapshot, June 2020*. www.ssa.gov/policy/docs/quickfacts/stat_snapshot
[42]	Nguyen, J. & Fitzgerald, D. (2022). *Priced out: The housing crisis for people with disabilities.* Technical Assistance Collaborative. www.tacinc.org/resources/priced-out
[43]	Arizona Health Care Cost Containment System. (2022). *AHCCCS Housing and Health Opportunities (H2O) Demonstration*. www.azahcccs.gov/Resources/Federal/HousingWaiverRequest.html
[44]	Arizona Department of Economic Security. (2022). *Division of developmental disabilities policy manuals*. Arizona Department of Economic Security. des.az.gov/sites/default/files/media/DDD_Complete_Set_of_all_Policy_Manuals_110922.pdf?time=1668393368798
[45]	Applied Self-Direction. (2021). *National inventory of self-direction programs*. www.appliedselfdirection.com/self-direction-programs
[46]	New York Office for People with Developmental Disabilities. (2022). *Self-direction guidance for providers*. opwdd.ny.gov/system/files/documents/2022/03/sd_guidance-final_march2022.pdf
[47]	Division of Long Term Services and Supports Disabled and Elderly Health Programs Group. (2021). *Beyond the pandemic: How technology influences and ensures an integrated life in the community part 2 Division of Long Term Services and Supports Disabled and Elderly Health Programs Group Center for Medicaid and CHIP Services.* Center for Medicaid and CHIP Services. www.medicaid.gov/medicaid/home-community-based-services/downloads/hcbs_ta_tech_web_part2_final_07272021.pdf
[48]	Wagner, J. B., Tassé, M. J., & Ornan, G. (2022). Implementation of remote support services: Pre-COVID-19. *Journal of Policy and Practice in Intellectual Disabilities, 19*(4): 340-349. https://doi.org/10.1111/jppi.12420
[49]	Official Data Foundation / Alioth LLC. (2022). *Rent Price Inflation, 1913-2021.* Rent Price Inflation since 1913. www.in2013dollars.com/Rent-of-primary-residence/price-inflation
[50]	Mitchell, D., Claris, S. & Edge, D. (2017). Human-centered mobility: A new approach to designing and improving our urban transport infrastructure. *Collection of Engineering, 2*. https://www.scipedia.com/public/Mitchell_et_al_2016a#
[51]	Center for Medicaid and CHIP Services. (n.d.). *Exploratory questions to assist states in assessment of residential settings*. Center for Medicaid and CHIP Services. www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/exploratory-questions-re-settings-characteristics.pdf
[52]	Kaiser Family Foundation. (2022). *Medicaid HCBS waiver waiting list enrollment, by target population and whether states screen for eligibility.* www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22
[53]	Manatt Health. (2020). State Health & Value Strategies. www.shvs.org/wp-content/uploads/2020/01/Supportive-Housing-Chart_Final.pdf
[54]	World Population Review. (2022). *Fastest growing states 2022*. https://worldpopulationreview.com/state-rankings/fastest-growing-states
[55]	About Section 1115 Demonstrations. (n.d.). Medicaid.gov. https://www.medicaid.gov/medicaid/section-1115-demonstrations/about-section-1115-demonstrations/index.html

[56]	Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). *A place in the world: Fueling housing and community options for adults with autism and other neurodiversities*. Phoenix, AZ: First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy at the Watts College of Public Service and Community Solutions
[57]	Accessory dwelling units. (2022). *American Planning Association*. https://www.planning.org/knowledgebase/accessorydwellings
[58]	U.S. Department of Labor. (n.d.). *Americans with Disabilities Act*. https://www.dol.gov/general/topic/disability/ada
[59]	State of Arizona Research Library. (n.d.). Arizona Department of Economic Security. *Official Website of the State of Arizona*. https://azlibrary.gov/sla/agency_histories/arizona-department-economic-security-des
[60]	Arizona Department of Housing. (n.d.). *Welcome*. Official Website of the State of Arizona. https://housing.az.gov
[61]	Arizona Health Care Cost Containment System. (n.d.). *ALTCS: Health insurance for individuals who require nursing home level of support*. https://www.azahcccs.gov/Members/GetCovered/Categories/nursinghome.html
[62]	National Institutes of Health. (2021). *About intellectual and developmental disabilities*. U.S. Department of Health and Human Services. https://www.nichd.nih.gov/health/topics/idds/conditioninfo#f1
[63]	Wandry, C. (2022). *Will bequeathing a home or an asset to a loved one with a disability affect their benefits?* Autism Housing Network. https://www.autismhousingnetwork.org/will-bequeathing-a-home-or-an-asset-to-a-loved-one-with-a-disability-affect-their-benefits
[64]	Medicaid and CHIP Payment and Access Commission. (2023). *Medicaid managed care payment*. https://www.macpac.gov/subtopic/medicaid-managed-care-payment
[65]	Grounded Solutions Network. (2023). *Community land trusts*. https://groundedsolutions.org/strengthening-neighborhoods/community-land-trusts
[66]	HUD Exchange. (2023). Consolidated plan. U.S. Department of Housing and Urban Development. https://www.hudexchange.info/programs/consolidated-plan
[67]	U.S. Department of Economic Security. (2022). Available DDD services & supports. AZ.gov. https://des.az.gov/services/disabilities/developmental-disabilities/individuals-and-families/supports-and-services
[68]	Tennessee Department of Intellectual & Developmental Disabilities. (n.d.). DIDD's Enabling Technology Program. TN.gov. https://www.tn.gov/didd/for-consumers/enabling-technology.html
[69]	Weill Institute for Neurosciences. (2023). Executive functions. University of California San Francisco. https://memory.ucsf.edu/symptoms/executive-functions
[70]	Your Therapy Source. (2019). *What is graded movement and how you can help*. https://www.yourtherapysource.com/blog1/2019/10/31/6-tips-to-help-children-grade-movements
[71]	U.S. Department of Economic Security. (2022). *Home and community based services*. AZ.gov. https://des.az.gov/services/older-adults/home-community-based-services
[72]	Statewide Transition Plans. (n.d.). Medicaid.gov. https://www.medicaid.gov/medicaid/home-community-based-services/statewide-transition-plans/index.html
[73]	U.S. Department of Housing and Urban Development. (2022). *Homeless management information system*. HUD Exchange. https://www.hudexchange.info/programs/hmis
[74]	Housing First. (2022). *National Alliance to End Homelessness*. https://endhomelessness.org/resource/housing-first
[75]	U.S. Centers for Medicare & Medicaid Services. (n.d.). *Intermediate care facilities for individuals with intellectual disabilities (ICFs/IID)*. CMS.gov. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/ICFIID
[76]	Local Housing Solutions. (2022). *Land banks*. https://localhousingsolutions.org/housing-policy-library/land-banks
[77]	Thach, N. & Wiener, J. (2018). *An overview of long-term services and supports and Medicaid: Final report*. RTI International. https://aspe.hhs.gov/reports/overview-long-term-services-supports-medicaid-final-report-0
[78]	U.S. Department of Housing and Urban Development. (2020). Mainstream vouchers. https://www.hud.gov/program_offices/public_indian_housing/programs/hcv/mainstream
[79]	Institute for Research on Poverty. (2022). *Means-tested programs*. University of Wisconsin-Madison. https://www.irp.wisc.edu/research/economic-support/means-tested-programs
[80]	Truelove, M. (2022). *What is a master-planned community?* Bankrate. https://www.bankrate.com/real-estate/what-is-a-master-planned-community/#:~:text=Master%2Dplanned%20communities%20are%20large,courts%2C%20golf%20courses%20and%20more

[81]	U.S. Department of Housing and Urban Development. (n.d.). Non-elderly disabled (NED) vouchers. https://www.hud.gov/program_offices/public_indian_housing/programs/hcv/ned
[82]	Administration for Community Living. (2021). *Person-centered planning*. U.S. Department of Health and Human Services. https://acl.gov/programs/consumer-control/person-centered-planning
[83]	U.S. Department of Housing and Urban Development. (2022). *Point-in-time count*. https://www.hud.gov/program_offices/comm_planning/coc/pit-count
[84]	Law Insider. (n.d.) Public Housing Authority Definition. https://www.lawinsider.com/dictionary/public-housing-authority
[85]	Centers for Medicare & Medicaid Services. (2021). *Beyond the pandemic: How technology influences and ensures an integrated life in the community part 1.* Medicaid.gov. https://www.medicaid.gov/sites/default/files/2021-05/hcbs_ta_tech_web_part1_final_05272021.pdf
[86]	Arizona Department of Housing. (2022). *Section 811 project rental assistance program notice of funding availability*. https://housing.az.gov/sites/default/files/documents/files/PRA-NOFA-2022.pdf
[87]	What is self-direction? (2021). *Applied Self-Direction*. https://www.appliedselfdirection.com/what-self-direction#:~:text=Self%2Ddirection%20is%20a%20model,and%20supports%20will%20be%20delivered
[88]	National Institute of Mental Health. (2022). *Mental Illness*. National Institutes of Health. https://www.nimh.nih.gov/health/statistics/mental-illness
[89]	Office of Disease Prevention and Health Promotion. (2020). *Social Determinants of Health*. U.S. Department of Health and Human Services. https://health.gov/healthypeople/priority-areas/social-determinants-health
[90]	Social Security Administration. (n.d.). *Benefits for people with disabilities.* Social Security. https://www.ssa.gov/disability
[91]	Lin, J. (2022). *Special needs trusts—the basics*. NOLO. https://www.nolo.com/legal-encyclopedia/special-needs-trusts-30315.html
[92]	Social Security Administration. (2022). *Understanding Supplemental Security Income (SSI) overview—2022 edition*. Social Security. https://www.ssa.gov/ssi/text-over-ussi.htm
[93]	Tanis, E.S. (2021). *Advancing technology solutions for people with I/DD in Colorado*. The American Network of Community Options and Resources. https://stateofthestates.org/wp-content/uploads/2022/09/ANCOR-Tech-Report-7.1.21.pdf

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