



CHATZLESTON Neuro-Inclusive Housing Market

Analysis





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*Glossary terms noted in bold



When you think about life-changing events that forever shape who we are, you may think about the birth of a child, your wedding, getting your dream job or other such events.

Seldom does the thought of having a child with a disability enter your mind, but it happens more frequently than one could ever imagine. A staggering one in 36 children will be diagnosed with autism spectrum disorder—and the statistics continue to astound us.

Once a parent receives the news that their child has a permanent, lifelong disability, they cannot help but start to project into the future. For many families, the unknown haunts them every year as their child reaches their next birthday and the same troubling question persists:. What will happen to them when I am no longer here?

At SOS Care, that question has resonated throughout our organization's core for over two decades. SOS Care's ideal response to this question was to create a place where people with disabilities could live together in a loving, nurturing and symbiotic community; a place where they genuinely want to be together. As a result, a seed was planted. Programs were created and customized so that individuals throughout their lifespan could acquire the skills necessary to live independently but with some support in place. Everything from

ABA therapy to pre- employment transition services, social skills training, summer camps, and vocational training opportunities, including employment coaching and respite programs, were designed to move toward the end goal. We always knew the missing link was housing. No one else was attempting to tackle this monstrous project. We knew we had to try.

Visits were made to other states to meet with advocates and providers tackling the housing issue for those with disabilities. Self-advocates, friends and families shared their vision with SOS Care, a concept was formulated and a dream began to grow. Land was purchased and the dream of providing affordable housing to individuals with autism and/or intellectual/developmental disabilities (I/DD) was born.

Homelessness in our community and state is an ever-growing problem. Our organization's mission is to answer the call for help when individuals or families face the challenges of autism and/or I/DD. Our vision is to provide the resources needed for independent living for all individuals in South Carolina with autism and/or I/DD. Achieving this, they would no longer be in danger of becoming homeless.

This dream is now a reality in South Carolina. It's called Oak Tree Farm, a labor of love for those who need it most. Parents can rest easy knowing there IS a place for their loved ones. Once this project is



complete, the challenge is not over; there will always be a desperate need for housing for those with autism and/or I/DD. Our team continues to push one building block at a time, one project at a time. The alternative is too daunting to imagine. That is our driving force and motivation. It is an arduous project with numerous stumbling blocks—sometimes too tedious to comprehend—but not impossible.

We are proud of where we started and how far we have come. We remain unstoppable and unrelenting. We can say that we left our mark on this community, that change has occurred through this hard work and that many families will sleep easier at night knowing their loved one is safe and living their best life. While significant progress has been made, there is still much work to do, which is why the Charleston Housing Market Analysis and others like it are so important. The data collected will be instrumental in effecting change in South Carolina and across the country.

Thanks to all who have collaborated with us and made this dream a reality to ensure a more inclusive future for all with autism and/or I/DD and those who love them!

Yours in partnership,

Sarah Pope

Saran Pope CEO of SOS Care. Inc.

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"I believe every community

is responsible for its elderly,

disabled and children.

SOS Care is taking action

to provide critical services

to those most vulnerable in

our community. I fully support

and applaud their efforts."

Angela R. Childers
 Chief Executive Officer, Charleston County
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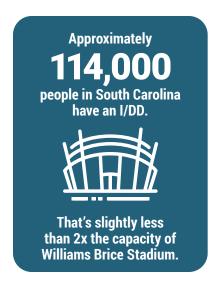
or the past 40 years, the movement to deinstitutionalize adults with a diagnosis of autism¹ and/or intellectual/developmental disabilities (A/I/DD),2 has led states to provide support to help adults with A/I/DD remain in the community and live in the family home with their parents as their natural supports/caregivers. This has led to greater visibility, community engagement and higher quality of life for neurodiverse families and adults with A/I/DD. Yet, 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. Many individuals with A/I/DD do not prefer to or cannot live in their family home but face a scarcity of other options.

Due to limited housing and support options, adults with A/I/DD often live with family members, whether or not that is their first

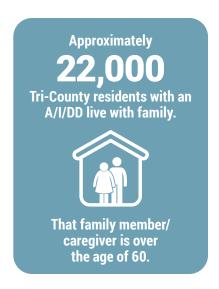
choice, until a crisis forces a hasty placement or homelessness—potentially displacing them counties away from their home and community into an institutional setting or other unsuitable environment.

In order to offer data-driven recommendations to mitigate these potentially traumatic outcomes, the Charleston Housing Market Analysis (CHMA) explored the needs and preferences of adults with A/I/DD and/or their families/caregivers in the South Carolina Tri-County Region. The three counties are Charleston, Dorchester and Berkeley.

The Joint Center for Housing Studies of Harvard University (2023)³ estimated that between 2010 and 2021, home prices increased most rapidly in the southern parts of the country, most notably in cities including Greensboro, NC, Columbia, SC and Charleston, SC. Charleston experienced an 8% annual







increase in home prices. The number of homes sold in the state at or below \$100,000 has also steadily decreased by almost 14% yearly. 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 Charleston, 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.

According to the South Carolina Interagency Council on Homelessness, in 2021, there were only 46 **affordable housing** units for every 100 extremely low-income households.⁵ Additionally, over 50% of the state's renters and 25% of homeowners were cost burdened. With the increasing demand for and low inventory of housing, costs continue to rise steadily.

Using Centers for Disease Control and Prevention (CDC) prevalence rates, not actual incidence, an estimated 22,223 individuals with A/I/DD live with caregivers over age 60 in the Tri-County area, a matter of urgent concern. They are at higher risk of losing their home and primary caregiver when their family member can no longer support them due to death, aging, health concerns and other economic circumstances.

As federally mandated by the Supreme Court **Olmstead v. L.C.** Decision (Olmstead), states must provide support in home and community settings instead of in institutions when the state's treatment professionals have determined that community-based support is appropriate. However, due to the lack of services and affordable, accessible housing, some adults with A/I/DD are at risk of undue displacement, institutionalization or homelessness. Funding sources to develop supportive housing or offer rental subsidies to persons with disabilities are acutely lacking and not A/I/DD specific.

This lack of data on the current housing needs of adults with A/I/DD, the aging of their caregivers and the goal of expanding housing and community options targeting the identified residential demand are the impetus for the CHMA. It provides critical missing data to catalyze a movement to develop the housing and community options so greatly needed for adults with A/I/DD across the Tri-County area.

Key Findings

The following is a snapshot of Key Findings that will be explained throughout the report:

- Significant data gaps exist because the number of adults with A/I/DD in South Carolina is unknown. This includes those experiencing homelessness. A/I/DD is also unsegmented in 211 assistance calls or the South Carolina Homeless Management Information System (SCHMIS).
- Most South Carolina residents with A/I/DD cannot earn a housing wage and the majority (53%) are not receiving Long-Term Services & Supports (LTSS).
- Current subsidized housing models or permanent supportive housing offer neither the accommodations nor the safety net adults with A/I/DD need to obtain and maintain housing. Affordable housing models often target people experiencing chronic homelessness, those with serious mental illness, domestic abuse, veterans or seniors.
- South Carolina relies on provider-controlled settings and does not have HCBS funding pathways for preferred service delivery models identified in the survey data in one's own home, a consumer-controlled setting, which may be more cost-effective and less restrictive.
- Survey results reveal that 62% of respondents are concerned they will be forced to live in a group home or adult host home (provider- controlled settings), 50% are concerned they will be abused and 38% fear they may become homeless.

- Adults with A/I/DD encounter more challenges connecting with individuals outside their biological family. Sixty-nine percent report loneliness and 44% have faced discrimination due to disability.
- Ninety-three percent of respondents experience barriers to engaging with their community; lack of transportation is the top reported barrier, followed by feeling overwhelmed or over-stimulated and not having enough money.
- Some families can assist in lifespan costs if offered guidance and opportunities to invest in housing stability for their loved ones.

"Individuals with disabilities

have the same desires to

live in a safe and stable

home and community as

their neurotypical peers;

however, the avenue in which

they pursue these dreams

requires significant support

and cooperation of agencies,

extended families and the

community to help them

realize these dreams."

Mollie LautRetired, Horry County School District

"This is an overwhelming

topic and you offered a way

to understand and digest

a lot of the many facets

needed to make an

informed decision about

future housing and planning

for the future."

Respondent
 Charleston Housing Market Analysis Survey



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

History & Evolution of Support Services

Medicaid began funding medical services for people with A/I/DD in 1965. An individual had to go to a special facility serving people with A/I/DD or an institutional setting to access services. As a result, people who needed services often had to make the difficult decision of being separated from their family,

friends and communities to receive benefits. In 1981, a new provision in Medicaid funding allowed people with A/I/DD and their families to access services in their homes and communities. The home and community-based services (HCBS) authority "waives" the requirement to be institutionalized and allows people with A/I/DD to access Medicaid-funded services at home or assistance in engaging with the greater community.

HCBS 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. The **South Carolina Department of Health and Human Services Community Long-Term Care** offers Medicaid-funded HCBS waiver programs targeting adults with A/I/DD who qualify for services.



State Schools

Institutional Care Only



Community Integration

Introduction of Medicaid HCBS Waiver Services



LTSS Innovation

Growth of Consumer-Controlled Service Delivery



Housing Innovation

New Options Emerging for Adults with A/I/DD

Following the implementation of HCBS waivers in the 1980s, individuals with A/I/DD, their families and supporters began to advocate for more choice and access to 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 (ADA).⁷ 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.

In 2014, CMS released new regulations to ensure Medicaid-funded HCBS waiver programs provided person-centered support in non-institutional settings. This required all states to submit an HCBS **Statewide Transition Plan (STP)** that outlined how the state would ensure compliance with the new HCBS settings rules. Under the HCBS settings rules, people receiving services must have full access to the benefits of community living and should receive services in their preferred home and community. It protects individuals' autonomy to make choices and control the decisions in their lives, a right most people take for granted.⁸

In January 2023, CMS and the Administration for Community Living (ACL) performed several site visits at residential or community locations that provide HCBS services identified by the South Carolina Department of Disabilities and Special Needs (DDSN) or stakeholders as having the qualities of an institution and required a heightened scrutiny review to determine compliance with the HCBS settings criteria. In response to the site visit report and review of the South Carolina STP, it was identified that workforce issues impacted the state's ability to demonstrate compliance with the settings rule.

To demonstrate compliance, the South Carolina Medicaid agency, Healthy Connections, submitted a Corrective Action Plan (CAP) indicating that extra time will be needed to ensure full provider compliance for integrating all people into the community. This integration includes being supported in having full access to their community, engaging in community life and receiving services in the community. Another area in which HCBS service providers needed additional support was more housing options for individuals being served outside of the family home, including non-disability-specific settings. Healthy Connections also indicated

the need for additional time to comply with setting rules that help optimize autonomy and independence for adults served while facilitating choices of services and supports and increasing the provider network in the state.

During spring and summer 2023, the DDSN held listening sessions as part of a strategic plan. These listening sessions sought to identify how people receiving—or waiting to receive—services described a "good life" and what kind of life/experiences they wanted. In August, the South Carolina DDSN issued "The Journey to Help South Carolinians with Disabilities to Live Their Best Lives," As a result of the findings from the listening sessions, The DDSN identified seven goals and actions.

Though many individuals with A/I/DD may be eligible for Medicaid support based on income, many do not qualify for HCBS waivers or LTSS due to other eligibility criteria. Consequently, they fall through the cracks if they cannot earn a living wage independently or maintain housing due to cognitive impairments without the assistance of vocational rehabilitation or other dedicated support staff or case managers to check in and offer help when needed.

Today, the goal should not be simply to place people into programs but to build a personcentered ecosystem of support offering choices for individuals with A/I/DD whose needs may change over time.

Person-Centered Approaches

Person-centered approaches, while varied in implementation, are based on the premise of person-centered thinking, planning and practices. Person-centered thinking focuses language, values and actions on 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

7 Goals & Actions for Living a Good Life

- 1 Enhance navigation and support.
- 2 Expand person-centered services and supports.
- 3 Strengthen provider capacity, proficiency and quality.
- 4 Advance system-wide governance.
- **5** Foster relationships.
- 6 Transform the system through technology and ongoing quality.
- 7 Establish regional centers as hubs of specialized care.

choose. It is a way to learn about the options and interests that promote quality of life and identify the support (paid and unpaid) needed to achieve it. Person-centered practices are present when people have the full benefit of community living and support designed to assist people as they work toward their desired life goals.

Like a web instead of a brick wall, elements of life may change or need adjustment.

Person-centered planning helps adults with A/I/DD navigate life changes. This takes planning around a person's needs and preferences, not just selecting the "right" program. Due to relentless efforts by families and advocates, coupled with access to needed LTSS, individuals with A/I/DD across the country can now live in their own home, engage in their communities and function in everyday life. Whether it is about helping organize their daily schedule, assistance getting ready in the morning, support preparing meals, job coaching or maintaining

their home, LTSS provided by existing community-based organizations are necessary and must be funded because family caregivers generally do not outlive their loved ones with A/I/DD.

Neuro-Inclusive Housing Framework

Finding and affording housing is typically out of reach when an individual with A/I/DD desires to move out of their family home or



Aspects of Person-Centered Planning

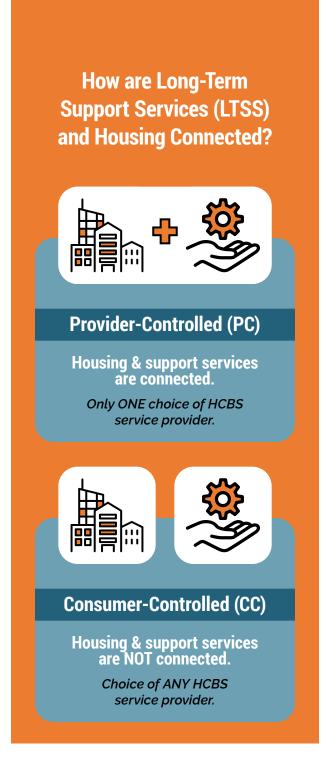
other living situation and intensifies in a crisis. It is essential to develop a holistic approach to housing to meet the support needs of adults with A/I/DD.

This Housing Market Analysis uses the neuro-inclusive housing framework to assess the needs and preferences of adults with A/I/DD. The neuro-inclusive housing framework is comprised of the following three elements to consider when exploring or creating residential options targeting adults with A/I/DD. These elements can be addressed through public, private and nonprofit collaborations:

- 1) Cognitively accessible and sensory-friendly housing in walkable, safe locations benefits 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 adults with A/I/DD in existing or future developments.
- 2) Long-Term Services & Supports (LTSS) that can be provided by the existing network of more than 45 providers in the Tri-County area can offer the individualized services needed to help people in their own homes, as well as access to the community. This report provides insights into preferences and what gaps to fill.
- 3) Supportive amenities are necessary to provide property-specific support to address isolation and foster greater community integration, promote social well-being, build natural support systems or facilitate employment and/or life skill classes. Supportive amenities may be essential for those ineligible.

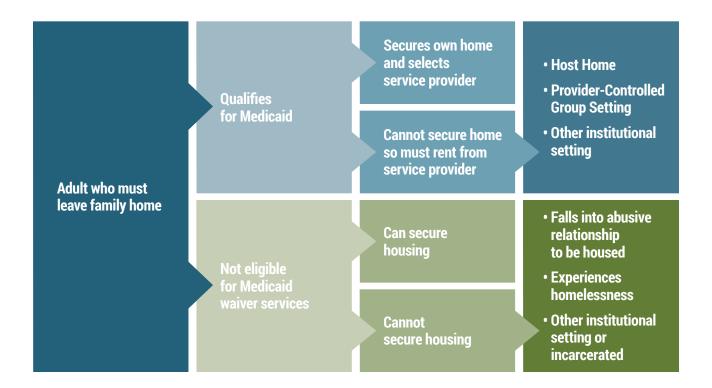
Lack of Affordability Leads to Limited Choice of Living Arrangements

The Joint Center for Housing Studies of Harvard University estimates that nationally, 62% of renters do not have enough income to



afford a comfortable standard of living after they pay rent. As a result, large numbers of households face housing insecurity and the burden of rising costs. This is acutely felt by adults with A/I/DD, who often have fixed incomes or earn low wages.

The ability of adults with A/I/DD to earn a living wage may be limited due to their neurodevelopmental disability.¹³ Only 42% of survey respondents indicate they are



employed. Most adults with A/I/DD are either unemployed or underemployed due to various socioeconomic or physical, mental health, cognitive or **executive functioning** challenges.¹⁴ Adults with A/I/DD are unable to afford housing through earned income alone. For those who are employed, there is also the fear that their income may disqualify them from being eligible for services through Medicaid. Approximately 22,944 adults with A/I/DD in the state receive Medicaid-funded LTSS.¹⁵ Only about 5,000 adults with A/I/DD receive HCBS-funded services outside the family home in any setting across South Carolina.¹⁶

Healthy Connections offers Home Again, a program targeted explicitly at individuals who have been in a skilled nursing facility or hospital, or otherwise institutionalized for 60 consecutive days or more and need an intermediate or skilled level of care.¹⁷ This approach means that adults with A/I/DD risk institutionalization in order to access housing assistance.

When a move is desired or needed, finding accessible, affordable housing and/or roommates who can share housing costs is difficult. Furthermore, the selected services included in current South Carolina HCBS waivers targeting adults with A/I/DD may not meet their support needs in consumer-controlled settings or their own home unless they only require a few hours of daily support. Lack of housing options and/or access to enough support services often leads people with A/I/DD to be placed with minimal choice in a group home or adult host home or remain in the family home because they cannot afford housing in their community.

"I would like to get help in understanding how to apply and access SSI, SSDI, Medicaid, Medicaid Waivers, Medicare. I cannot figure it out and have become paralyzed from confusion."

- Respondent, Charleston Housing Market Analysis Survey

County	Adult population	2.2% autism in adulthood ¹³	1.65% intellectual disability	6.06% developmental disability (not autism or ID)	Combined A/I/DD	Estimated to be living with caregiver over age 60 (27%)
Charleston	419,279	9,224	6,918	25,408	41,550	11,219
Dorchester	166,133	3,655	2,741	10,068	16,464	4.445
Berkeley	245,117	5,393	4.044	14,854	24,291	6,559
Total	830,529	18,272	13,703	50,330	82,305	22,223

When a crisis placement is necessary, a group home or adult host home is often only available to those who qualify for HCBS waiver services through DDSN. Other state-funded supports may be available but would not be A/I/DD specific. Such supports should be assessed for the cognitive accessibility of adults with A/I/DD who are not eligible for HCBS services and who may be at high risk of homelessness. According to the South Carolina Interagency Council on Homelessness, the number of people over age 50 experiencing homelessness in the state increased by 18% between 2020 and 2021.5 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 the death of the family caregiver.18

Invisible Need

The fast-growing Tri-County Region represented in the CHMA accounts for almost half of the state's population and represents urban and suburban areas. The area also presents housing challenges similar to other major metropolitan areas. Only 42 affordable units per 100 are available to extremely low-income renter households in South Carolina. Additionally, these affordable housing do not often consider the needs of adults living with A/I/DD living with aging family caregivers.

Not all housing or **consolidated plans** include persons with disabilities as a segmented need, and no mention is made of people with developmental disabilities. As of 2023, there are no **mainstream housing choice vouchers** or **non-elderly disabled (NED) vouchers** targeted specifically at people with A/I/DD.²¹

Prevalence of A/I/DD

Data gaps for individuals with A/I/DD, especially those not enrolled in Medicaid, make it extremely difficult to ascertain the number of people needing housing. Census data is not collected on the number of people with A/I/DD. Therefore, estimates reflect existing data sets where those with A/I/DD are segmented in a given area. Nationally, about 2.2% of the U.S. adult population is on the autism spectrum, 1.65% of children have an intellectual disability and the prevalence of children diagnosed with a developmental delay other than autism spectrum disorder or intellectual disability is 4.55%.^{22,23}

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.¹⁵

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

Discrimination due to disability	44%
Bulling that led to missing school, employment or other social events	23%
Mate-crime (a "friend" who misused or exploited a relationship with you)	7%
Discrimination due to race or ethnicity	5%
Domestic violence or emotional abuse from a family member	5%
Abuse or exploitation from a professional serving people with A/I/DD	5%
Discrimination due to religion	4%
Domestic violence or emotional abuse from a romantic partner	4%

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

Of urgent concern are the approximately 82,305 individuals with A/I/DD in the Tri-County area at high risk of losing their home and primary caregiver when their family member can no longer support them due to death, aging health concerns and other economic circumstances.

Additional Barriers

In addition to the cost of housing, people with A/I/DD face numerous barriers even if they have access to housing assistance or their families can afford to help them pay rent.



The systems to access housing and services are disconnected and can be cognitively inaccessible to people with A/I/DD. Adults with A/I/DD often have challenges 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. They may also lack 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. They need access to housing that fits within a fixed income budget in order to avoid eviction or loss of housing when housing costs rapidly rise due to inflation.



Lack of supportive amenities and adequate case management persist for those ineligible for LTSS. Individuals with A/I/DD who do not qualify for Medicaid waivers need supportive amenities or regular assistance from case managers to maintain housing, public benefits, connections within the greater community and potential employment. These include identifying and submitting required documents for continued benefits, social opportunities, conflict resolution, breaking down the steps in a task and/or creating a follow-through plan.



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 engage in repetitive physical and/or verbal behaviors which serve self-regulating and/or self-stimulating functions that—without sound-insulating spaces—could disrupt neighbors and/or result in noise complaints.



People with A/I/DD are 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 simple assault and/or a serious violent crime than other persons with disabilities.24 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.25 In a study conducted on mate crime, 100% of respondents ages 16-25 with autism report they cannot distinguish between someone who is a friend and someone who is abusive.26



Discrimination based on disability is the highest reported form of housing discrimination.²⁷ Despite progress in the rights and inclusion of persons with disabilities, it is not uncommon for landlords to reject their rent applications. Likely due to ill-perceived financial, criminal or cognitive differences of adults with A/I/DD, the greatest number of Fair Housing Act complaints across multiple agencies are due to discrimination against disability.²⁸

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

SOS Care market leaders, advisors and sponsors have invested significant time, energy and resources to understand the needs and preferences of adults with A/I/DD and/or their families in Charleston and the Tri-County area.

The CHMA demonstrates the data and actionable direction for developing tools and changing systems that can ignite a new wave of housing options across South Carolina so every person with A/I/DD can find their place in the world.

58% of respondents had

experienced discrimination,

abuse or exploitation.

"As you know, future planning

for special needs people

is a moving target. We always

need to work together to

try to find more funding

sources to appropriately

meet each person's needs."

Respondent
 Charleston Housing Market Analysis Survey



Educate neurodiverse community Assess needs and preferences Approach housing industry with consumer data

Increase housing stock that meets local needs

Educational Outreach

ost individuals with A/I/DD and their families have not had the opportunity to explore their options for life beyond the family home. Respondents were required to participate in a learning session informing them of the benefits and considerations of various elements of residential choices. Using the nomenclature from A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities,

participants were able to learn about the broad range of choices. While some options presented during the learning session may not currently be available in South Carolina, it was essential to include them so participants could express their needs and preferences and help effect changes in the market and system.

Learning sessions included live, virtual training with time for questions and answers. SOS Care also hosted three "watch parties" to bring participants together in person to watch the



Invitation sent to 70+ organizations (Summer 2023)



Expanded presentation and survey, plain-language presentation and survey

LEARNING

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



Recordings on website and promoted through collaboration with other organizations

WATCH PARTIES

Three in-person watch parties targeting self-advocates (June, July 2023)



Targeting individuals with A/I/DD and their families

recorded learning session with subsequent live Q&A. The recording of the learning session was also posted on the SOS Care website for those unable to attend the live events. More than 70 community-based organizations were contacted as part of the process for promoting and facilitating the CHMA.

Plain-language materials were created to ensure a more cognitively accessible format. These materials included a recorded, live learning session in **plain language**, a visual guide to help participants track their preferences during the learning session and a plain-language survey.

Participants made a significant time commitment and demonstrated a willingness to learn about multiple approaches to residential options, enabling data collection on the needs and preferences of adults with A/I/DD and their families. During the 30- to 75-minute sessions, each option was introduced and explained using visuals, verbal descriptions and videos (where available). Benefits and considerations of the various elements of residential possibilities were discussed to promote person-centered, meaningful choices. Individuals attending live sessions and watch parties could ask additional questions during and after the presentation.

Once participants completed the learning session, they were requested to complete the Charleston Housing Market Analysis Needs & Preferences Survey. This included questions regarding demographics, barriers to community engagement, support needs, housing preferences and utilization of public benefits. Comprehensive plans, consolidated plans, housing plans and any previous housing analysis from typical housing market needs were reviewed by researchers from the First Place Global Leadership Institute.

After the surveys closed, data were analyzed and presented at the Local Leaders Workshop.

"Our work must continue to

fully include people with

disabilities. This requires their

personal input, their choices

and their communities

supporting a safe place they

can call their home."

Julia Barrett-Martinelli
 Executive Director, Accessibility

"People with disabilities should have a voice in where they live, work, and contribute to their community. The 1999 Olmstead ruling found that the unjustified institutionalization of people is a form of discrimination under the ADA and that states must protect the rights to community integration for people with disabilities.

To uphold these rights, states need to invest in infrastructure like housing, transportation and competitive work opportunities."

- Beth Franco, Disability Rights South Carolina

Local Leaders

Local leaders were invited to participate in a three-hour Local Leaders Workshop. Participating organizations and individuals comprised county officials, bankers, leaders in low-income housing developments, real estate developers, land-use experts and other representatives from community-based organizations and foundations. Self-advocates and family leaders were also essential contributors. The presentation allowed stakeholders to review the data and identify potential recommendations for future action. Initial

data analysis indicated the variety of and demand for residential needs and preferences. Local leaders were eager to discuss potential solutions and address barriers. Details of their discussion and suggestions are highlighted throughout this report and in the Recommendations section.

Considerations and Limitations of the Process

- Training materials: To provide more accessible training materials, the plain-language surveys did not include all questions from the full survey, limiting some of the demographic and preference data collected.
- Data preferences: Due to limited exposure to specific service delivery models and development types currently unavailable or underutilized in South Carolina, demand data on preferences may shift if recommendations are implemented and choices are expanded.
- Diversity of participants: Black or African American individuals and/or their families were underrepresented in the data, with a slight over representation of members of the Hispanic population.



"Loneliness is far more than just a bad feeling—it harms both individual and societal health. It is associated with a greater risk of cardiovascular disease, dementia, stroke, depression, anxiety and premature death. The mortality impact of being socially disconnected is similar to that caused by smoking up to 15 cigarettes a day and even greater than [the impact] associated with obesity and physical inactivity."

⁻ Dr. Vivek H. Murthy, 19th and 21st U.S. Surgeon General



Unless otherwise noted, demographic data in this section is compiled from the 2023 Charleston Housing Market Analysis Needs & Preferences Survey. It provides demographic information for respondents with A/I/DD and/or their families. The following section details future preferences for housing, services and community engagement.

The DDSN process for waiver eligibility requires documentation of a specific disability within seven categories: high-risk infant, intellectual disability, other related disability to intellectual disability, autism, head injury, spinal cord injury and related disability. It is important to note that a person's diagnosis does not dictate the type of housing, supportive amenities or service delivery model they may need or prefer. However, diagnostic information is helpful in understanding possible barriers to independent living, breadth of diversity and potential funding sources. Survey respondents could self-select one or more disabilities with which they identify.

Compliance with the ADA for accessibility by those with physical disabilities who may use a wheelchair or other mobility device represents a small population with A/I/DD surveyed (8%). Design and accommodations targeting adults with A/I/DD may be safety related due to sudden falls from seizures (19%), alternative emergency communication methods due to intellectual, vision or hearing impairments (66%) and often autistic adults (68%) need accommodations related to sensory differences involving lighting, sound and other effects. The Preferences section of this report offers more detail on specific design and physical amenities.

The disabilities I identify with include:		
Autism	63%	
Intellectual Disability	58%	
Anxiety	39%	
Depression	20%	
Epilepsy or Other Seizure Condition	15%	
Obsessive compulsive disorder (OCD)	14%	
Asperger's	12%	
Other Developmental Disability	12%	
Down Syndrome	9%	
Other Disability Not Specified	9%	
Cerebral Palsy	8%	
Other Mental Health Challenges	6%	
Physical Disability & Use a Mobility Device	6%	
Deaf or Hard of Hearing	6%	
Blind and/or Visual Impaired	3%	
Bipolar Disorder	2%	
I'd rather not disclose	1%	
Traumatic Brain Injury	1%	
Prader-Willi Syndrome	1%	

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

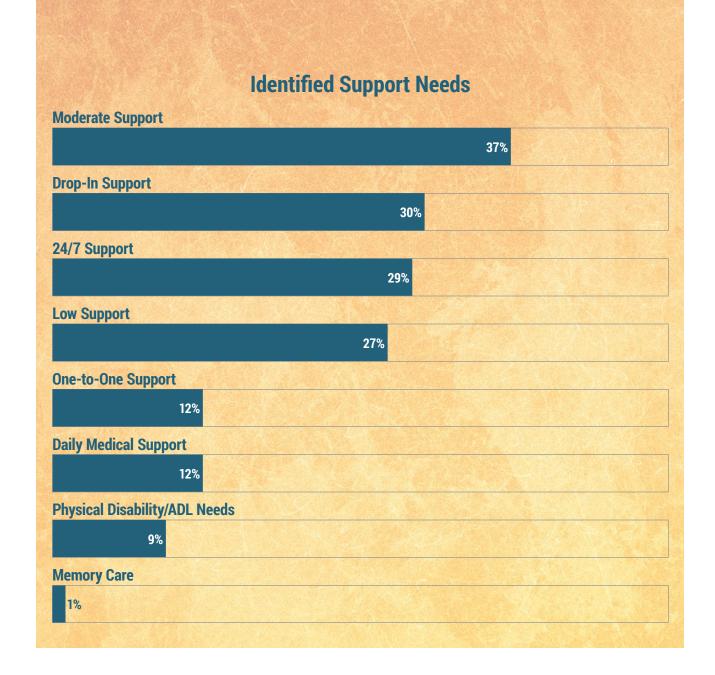
The analysis also reveals a high rate of co-occurring mental health challenges such as anxiety, depression and obsessive-compulsive disorder (OCD). Emerging supportive housing opportunities may include building relationships with mental health providers for on- and off-site mental health support, therapeutic interventions and counseling, and/or life coaching in a cognitively autismfriendly format. Finding a provider that takes one's insurance and understands the **neurodivergent** population, as well as the executive functioning needed for scheduling an appointment and accessing reliable transportation, are just some examples of barriers to quality mental healthcare for people with A/I/DD.

Identified Support Needs

The data on the level of support needs indicate of the number of hours a person may need for direct support to live in their own home and to participate in the community. People with A/I/DD have a wide range of support needs not otherwise captured in existing South Carolina data sets. This is critical as adults with A/I/DD are often displaced into provider-controlled settings when affordable, accessible housing cannot be secured. Placement may be in a more restrictive environment, providing more staff supervision than needed, resulting in the potential for a significant fiscal impact on taxpayers.

Ten percent of survey respondents report being denied or ineligible for waiver services, while 30% are unaware these services exist. The root cause of this 40% gap needs more exploration in South Carolina as caregiving families continue to age. Some adults with A/I/DD who may only have drop-in or low-support needs may not have access to or financing for these services.

Some adults with A/I/DD may have been out of school before the **Individuals with**



Disabilities Education Act (IDEA) and/or ADA were fully implemented. In that case, there may be no documentation from their childhood to offer as documentation of disability. This could result in barrier to accessing LTSS for some of the older population of adults with A/I/DD with drop-in or low-support needs and high risk of homelessness. This is particularly true if they are unable to access services and cannot earn a living wage or manage day-to-day needs without family support due to executive function impairments.

Equally important are the needs of 12% of individuals who have more profound autism or other I/DDs who require one-to-one support needs. The only residential option for an adult

with A/I/DD with high-support needs in South Carolina is a four- or three-bed provider-controlled group home, as service and reimbursement limitations restrict a person with high-support needs from living in their own home or consumer-controlled setting.

Limits on the daily rate or maximum fee a provider can bill to Medicaid to support the individual also restrict a person with one-to-one support needs from choosing residential options outside of an institutional setting. The maximum daily rate from the DDSN for a three-bedroom high management group home is \$442.78 or \$18.42 an hour.²⁹ This rate is inadequate for a provider agency to organize and maintain





Support Needs³⁰

Moderate Support

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

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.

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.

Low Support

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

One-to-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 Needs

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.



staffing to provide the level of quality support and oversight needed for individuals with one-to-one support needs. Thus, there is no waiver-funded residential solution in South Carolina that would meet the direct support needs of someone requiring one-to-one direct support. Even with the possibility of an intermediate care facility for individuals with intellectual disabilities (ICF/IID), it is difficult to find a provider "empty bed," even for a crisis placement. Individuals with A/I/DD have spent several days in hospitals due to the scarcity of options.

Although representing a smaller subset of the data, those who need memory care are important to recognize as having growing support needs due to the propensity of older adults with autism and Down syndrome to develop early-onset dementia and Alzheimer's.^{31,32}

To adequately measure disparities, it is important that future research, data collection and/or modification to policy and funding rates segment the population based on the level of support needed. It is recommended that segmentation be based on whether an individual with A/I/DD owns or rents a home outside of the family home versus whether they live with a family member.

Utilization of HCBS Services

As discussed in the Background section of this report, the purpose of a Medicaid waiver authorization is to assist people with A/I/DD to live in the community as any other member of society needing support and services versus in an institutional setting. As with all states, applicants must qualify for the program.

South Carolina offers two waivers targeting adults with A/I/DD through DDSN: the intellectual disability/related disabilities (ID/RD) and community supports (CS) waivers. Eligible applicants must:

- Have an intellectual or related disability
- Be able to receive Medicaid or already have Medicaid
- Require a level of care that would be provided in an ICF/IID, institutional care facility or nursing facility
- Choose to receive the services by signing a Freedom of Choice form³³
- · Have needs the waiver can meet
- Receive a service every 30 days to keep the waiver³⁴

Are you (or a loved one) receiving services through a medicaid waiver? Yes, Intellectual Disability and Related Disabilities (ID/RD) Waiver through DDSN 33% **Yes, Community Long-Term Care (CLTC)** Yes, Community Support (CS) Waiver through DDSN No, denied 5% No, not eligible 4% No, have not applied 13% No, was unaware of this resource 29%

"Many people don't apply
because of the seven- to
15-year waitlist.... Other
groups would find this
discriminatory. But people
with disabilities aren't always
able to advocate for what
they need. Sadly, the practice
continues year after year."

- Sarah Pope, CEO, SOS Care

Although a person might meet the criteria for receiving waiver services, the person is not guaranteed those services. Due to high demand, those who may be eligible are often placed on waiver waitlists. As of 2021, more people were waiting for services than those served.35 Of the 24,192 people on waiver waitlists in the state, 24,038 have I/DD. It is worth noting that the number of people on waitlists in the state increased by 113% between 2018 and 2021. However, workforce shortages limit the state's capacity to serve more people. From 2019 to 2021, the number of people receiving LTSS increased by approximately 1,000 annually. Another key contributor to the long waitlist is the lack of funding to expand the network of providers in South Carolina.36

"Our daughter has applied for Medicaid waivers and is on the

waitlist. My wife and I are over 60, work full time and have health

problems. We are scared that at some point we will not be able

to financially support our daughter's needs."

- Respondent, Charleston Housing Market Analysis Survey

Forty-three percent of survey respondents are on the ID/RD or CS waiver. South Carolina senior residents with physical abilities (but not A/I/DD) with support needs can also seek services from the SCDHHS Community Long Term Care (CLTC). Four percent of respondents indicate they receive services from CLTC.

Even more concerning is that 30% of respondents do not know that waiver resources are available to provide families and individuals with respite, day programming, supported employment or other LTSS to keep them living in their family home or prepare them for the transition to a different home. South Carolina may have a data gap of 43% of adults with A/I/DD who are invisible in existing datasets due to either not knowing about the waiver program or not applying. This indicates that much greater awareness is needed to ensure neurodiverse families are informed about the assistance DDSN and other agencies provide.

South Carolina HCBS Waiver(s): The table on page 32 includes data for the number of individuals enrolled in each of the HCBS waivers as of 2021. Additionally, there are 24,038 individuals on waitlists.

Income and Government Benefits

As shown to the right, survey respondents' earned income indicates that adults with A/I/DD are extremely low-income, largely falling below 30% **Area Median Income (AMI)** in the Tri-County area.

Currently, the use of federal Medicaid waiver dollars to fund room and board for those who use waiver-funded services is prohibited. Recipients of waiver-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 most 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.

In 2024, the maximum amount of SSI a recipient will be able to receive is \$943. If the person starts work and receives a paycheck, benefits will decrease at a 2:1 ratio, as illustrated in the chart on page 33. If an individual receives financial support to

Earned Income		
\$0-\$300	26%	
\$301–\$600	10%	
\$601–\$900	6%	
\$901–\$1,200	3%	
\$1,201-\$1,500	2%	
\$1,500+	5 %	

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

Waiver name	Target population served	# on waivers	Administering agency
Community Long Term Care (CLTC)	All ages with various disabilities, including A/I/DD	20,394	South Carolina Healthy Connections Medicaid
Intellectual Disability/ Related Disabilities Waiver (ID/RD)	All ages with A/I/DD PDD/NOS in children served separately	8,350 365 (PDD/NOS)	South Carolina Continuum of Care
Community Supports Waiver including Head or Spinal Cord Injuries (HASCI)	Require the care that an ICF/IID would provide	963 703 (Head/Spinal)	South Carolina Department of Disabilities and Special Needs
Community Supports Waiver	PWD eligible for Medicaid Require the care that an ICF/IID would provide	_	South Carolina Department of Disabilities and Special Needs

cover their housing cost, their SSI benefit will be reduced by one-third.³⁷ Some states offer a state supplement to their SSI recipients; however, South Carolina does not.³⁸

The CHMA survey shows that 42% of respondents are employed. Those with A/I/DD who are employed often work less than 20 hours per week.³⁹ Even when working and receiving federal assistance, housing costs for

Public benefits or assistance utilized by survey respondents	
Medicaid	60%
SSI	37%
SSDI	23%
Medicare	19%
SNAP (food assistance)	9%
Housing Choice Voucher	2%
LIHEAP	1%

Charleston residents are out of reach for most adults with A/I/DD. Though South Carolina seeks a legislative **Employment First** Initiative, it is not expected to result in housing wages earned by adults with A/I/DD.⁴⁰

To better illustrate the housing affordability challenge, the chart on page 33 includes sample income and SSI benefits of adults with A/I/DD based on typical jobs and weekly schedules.

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 national level; nowhere in the U.S. can someone who relies in whole or part on SSI afford rent.⁴¹

Other public benefits programs are available to households with very low- and extremely low-income incomes. These programs include the Supplemental Nutrition Assistance Program (SNAP) for food assistance, Low Income Home Energy Assistance Program (LIHEAP) to help cover increased energy costs and Housing Choice Vouchers, which provide permanent rental subsidies. People with A/I/DD underutilize these programs.

Income of public benefits plus earned income ⁴²	Total monthly income (earned income + deduction of SSI due to earned income) ⁴³	% of income needed to afford market rate rent of 1-bedroom in the Tri-County area (\$1,357)	% of income needed to share a market rate rent of 2-bedroom in the Tri-County area (\$767)
2024 Maximum SSI benefit	\$943	144%	84%
Avg. SSDI adult child survivor benefit ⁴⁴	\$1067	127%	72%
8 hours/week at minimum wage (\$7.25/hr) plus SSI	\$232 + \$869.50 = \$1,101.50	123%	70%
16 hrs/week as a fast food worker (\$11.46/hr) plus SSI	\$733.44 + \$618.78 = \$1,352.22	100%	57%
24 hrs/week working as a stocker/order filler (\$14.97/hr) plus SSI	\$1,437.12 + \$266.94 = \$1,704.06	94%	53%

Although they would be income qualified, few adults with A/I/DD in the Tri-County area currently utilize these public benefits. Research is needed to understand why adults with A/I/DD are not accessing these assistance programs despite their eligibility.

According to the National Low Income Housing Coalition, the fair market rent for a one-bedroom and two-bedroom is \$1,357 and \$1,533, respectively.45 No mainstream or NED housing vouchers are available to help subsidize housing costs for adults with disabilities in the Tri-County area.46 Although people with A/I/DD can apply for a housing choice voucher, securing it is challenging.47 It is worth noting that there are NED and mainstream vouchers available through public housing authorities in other counties in the state; however, it is not clear whether all the vouchers available in the state are portable. There are a total of 915 mainstream and NED vouchers combined in the state. Even if vouchers are portable, the process is lengthy and may exclude people with A/I/DD.48

Additionally, even when voucher waitlists are open for regular project-based vouchers, they are only available for very short periods. The very short application period may not allow enough time for adults with A/I/DD to apply. For example, the Housing Authority for the City of Charleston announced it would accept preliminary applications online for project-based housing vouchers for 17 units.49 The application period for one-bedroom units began at noon on Nov 15, 2023, and was stipulated to end either when units were filled or at 3 p.m. the same day. This shows that there is a limited supply of vouchers and available units to rent with housing choice vouchers.50 Most adults with A/I/DD need public benefits and housing assistance or affordable units to prevent displacement or homelessness if no other arrangements have been made with other family members when a crisis occurs.

Potential of Family Investment in Housing Stability

Survey respondents were asked to share their current income, public benefits and anticipated special needs trust or family investment in their future. As the chart indicates, most survey respondents would need or anticipate monthly rental costs of \$600 to \$800 to ensure housing stability. Although most adults with A/I/DD are not earning income to support market-rate housing costs, when considering sharing a two-bedroom unit with financial support from family or other non-public sources, most survey respondents could afford market-rate housing with a roommate. Almost a third also report anticipating the ability to afford market-rate housing. However, even when considering the addition of family financial support, most respondents need subsidized housing or a housing voucher to afford housing in the Tri-County area.

When asked to consider adding family assistance to help cover housing costs, essential variances exist related to socio-economic status. Of those surveyed, approximately 45% have created some form of special needs trust. This financial device protects against the financial exploitation of adults with A/I/DD. It provides a vehicle for families to assist their loved ones financially without putting means-tested public benefits at risk. Although

No mainstream or NED

housing vouchers are

available to help subsidize

housing costs for adults

with disabilities in the

Tri-County area.44

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

Cost including: rent/mortgage, utilities, upkeep, etc.		
\$0-\$300	9%	
\$301-\$450	8%	
\$451-\$600	24%	
\$601-\$800	27%	
\$801–\$1,100	13%	
\$1,101-\$1,500	9%	
\$1,501-\$2,000	5%	
\$2,001–\$3,500	4%	
\$3,501+	2%	

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

not a disqualifying factor, if an SSI recipient is assisted by a family or a special needs trust, their SSI will be reduced by a third. Special needs trusts are an essential tool for those whose families may be able to offer an inheritance or a **bequeathed home**. Only about 27% of self-advocates note having a special needs trust.

The Charleston Homeownership Initiative⁵¹ (HI) is a key component of the Charleston redevelopment plan. The HI provides affordable housing to low- and moderate-income families, assists with revitalization efforts and is a catalyst for capacity for nonprofit organizations. It is unlikely that adults with A/I/DD and/or their families are aware of or can navigate this process. An **Achieving a Better Life Experience (ABLE) account**

and/or special needs trust might enable these families and individuals to save for a home purchase, but it is important that the program not require an "owner-occupier" and that the home can be held in a special needs trust due to the vulnerability of some adults with A/I/DD.

Planning for the Future

Not all families are able to assist their loved ones with housing costs. The survey indicates that nearly half of those who responded have not done family planning. Some families cannot afford a financial planner, legal fees or upfront costs. Those who have not done financial planning may be at imminent risk of becoming homeless if they lose their primary caregiver or in situations where their benefactor is either unable or unwilling to provide care.

Using special needs trust funds and other financial tools such as PalmettoABLE⁵² accounts is crucial for individuals with A/I/DD to plan for housing stability. Market-rate developers need to understand the demand and respond with more inclusive housing.

Most adults with A/I/DD rely on their parents to help fill gaps in support or identify if they may be at risk of abuse or neglect. However, data reveals that the majority of adults with A/I/DD lack a natural support system, including someone who is active in their life but not paid to support them. Most adults with A/I/DD will outlive their parents; thus, there is

According to HUD, a person is rent-burdened if they spend more than 30% of their their income on housing.

Have you or your family done any future planning?	
Yes, I have a special needs trust.	45%
Yes, we have met with a special needs lawyer.	19%
Yes, I opened up an ABLE account.	24%
Yes, I am part of a Pooled special needs trust.	1%
No	30%

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

16%

No. we do not have extra

income to do this.

an urgent need to help plan and develop the relationships needed to build natural support systems.

A/I/DD-specific housing or lifespan navigation services are not available in South Carolina. Yet, aging caregivers may need assistance to plan for the transition of their loved one from the family home to another setting due to the disconnect among housing, LTSS and public benefit systems. Other states offer various housing services in waiver options.⁵³

Without planning or a robust natural support system, individuals and their families may wait until a crisis occurs to act. This is not only traumatic for all parties, but it also disrupts the routine and stability of the family home during the transition and efforts to find the right fit if the first solution does not work. Offering housing and lifespan navigators could prevent placement in a group home; more costly institutional settings such as a psychiatric facility, ICF/IID or skilled nursing home; homelessness or an extended stay in an emergency room.

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

Mother	70%
Father	57 %
Neurotypical sibling	44%
Aunts/uncles	21%
Cousins	15%
Close family friends	14%
Grandparents	11%
Stepfather	9%
Sibling with A/I/DD	6%
Stepmother	5%
None	1%

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

Transportation

Respondents indicate relying heavily (81%) on friends and family for transportation. Only 12% of respondents drive and 7% use the public bus system. Neuro-inclusive properties would benefit from transit-oriented or walkable locations. Emerging developments can use this data in their design to seek parking variances or include a sheltered pickup/drop-off area. Transportation options to popular places in the community may be a valuable supportive amenity, considering South Carolina, unlike other states, does not offer transportation as a waiver-funded service.

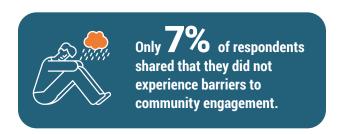
More research is needed to provide additional insights to help foster solutions and remove this persistent barrier to community engagement.

Future Concerns

When asked about the future, individuals and families are concerned about what will happen when they can no longer rely on family caregivers for housing or support. The leading concern is that they or their loved one will be lonely (63%) or unable to go where they want or need to go (62%). Sixty-two percent of all respondents worry they will be forced to live in a group home or adult host home. Fifty-six percent are concerned they will be unable to find quality staff and 55% are worried they or their loved ones will be left out.

Among self-advocates who completed the survey, respondents indicate their top five concerns include being forced to live in a group home or adult host home (65%), feeling neglected (59%), being unable to get to places they want or need to go (56%), becoming lonely (53%) and fearing they will become homeless (53%).

Most of these concerns can be addressed by community development efforts that recognize people with A/I/DD as part of diversity, equity and inclusion strategies. Adults with A/I/DD must be considered in community and city plans by those seeking state or federal grant opportunities or reviewing local applications for proposed home developments. This report offers valuable insights into the unique needs and preferences of adults with A/I/DD and should be cited for purposes of future community planning.

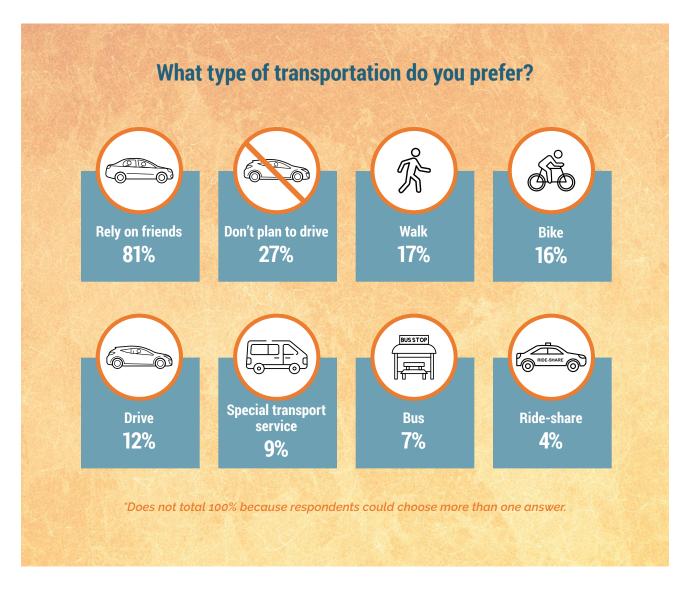


Barriers to Community Engagement

Lack of transportation prevents over 63% of respondents from accessing their community. The II/RD and CS waivers provide funding for "private vehicle modification" but do not include discrete non-medical transportation services. Public transportation may be too overwhelming, expensive, inaccessible or unavailable where individuals live. On September 28, 2023, CMS issued a guidance letter to all state Medicaid directors regarding the current and new Medicaid transportation policy. The new policy includes new flexibilities providing transportation to HCBS recipients and enabling them to access community services, activities and resources

when other options are unavailable. States may, at their discretion, provide non-medical transportation services separately under a section 1915(c) waiver, a section 1915(i) **State Plan Amendment (SPA)**, a section 1915(j) SPA, a section 1915(k) SPA or a demonstration project under section 1115 of the Act.⁵⁴ More research is needed to provide additional insight that can help foster solutions and remove the most prevalent barrier to community engagement.

The following top five barriers can be mitigated by developing spaces and places for neurodiverse relationship building. Community integration and a feeling of belonging do not just happen when people with or without disabilities exist in a geographic location.



TOP 5

Family concerns for the future



Concerned they may be lonely

2

Unable to go places they want to go



Forced to live in group home or adult foster care



Not finding quality staff

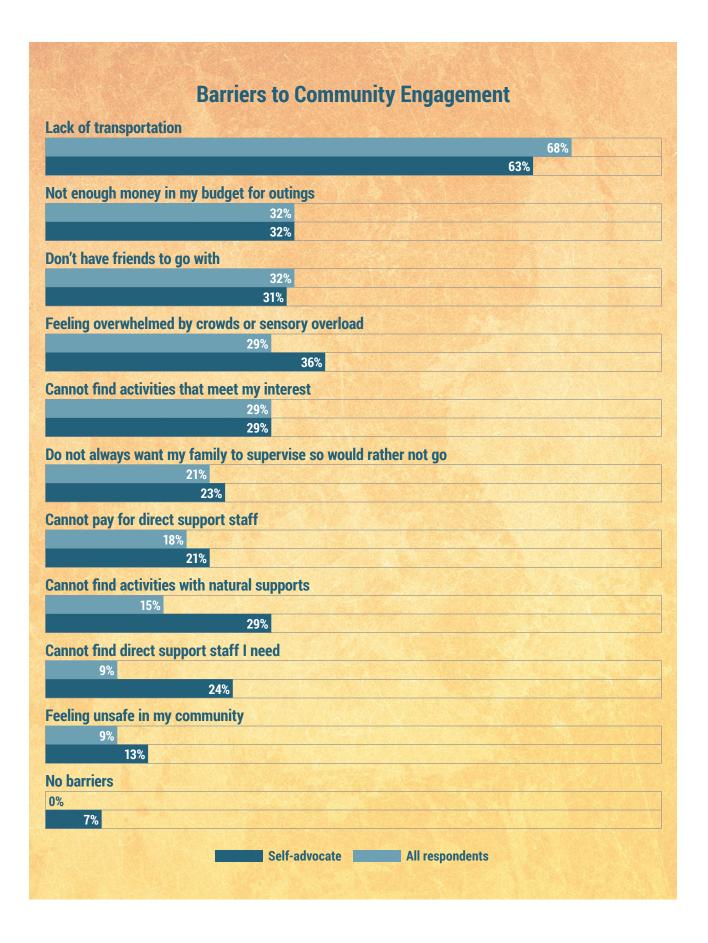


Concerned they will be left out

Intentional community building requires input and feedback from self-advocates and family advocates who understand the needs and preferred relationship-building activities to create more inclusive environments. Local advocacy organizations and service providers like SOS Care are exemplary collaborators and sources for making local events or public spaces more accessible. For example, to address the second most significant barrier of feeling overwhelmed, a local event may offer sensoryfriendly elements during a designated time period by lowering music volume, dimming lights and requesting that vendors not reach out unless approached.

If you experience loneliness, what are your barriers to friendship?

to menusing:	
I do not know how to turn potential friends into long-term friendships.	45%
I don't know where to go to meet potential friends.	42%
People do not understand how to be a supportive friend to me.	41%
I experience too much anxiety to try to meet new people.	26%
I need staff support to see my friends.	26%
I have difficulty scheduling to meet with friends.	22%
I accidentally do things that have hurt relationships.	21%
I don't have money to spend on outings with friends.	18%
I see my friends as much as I want.	11%



TOP 5

Self-advocate concerns for the future



Forced to live in group home or adult foster care

2

Concerned with being left out



Unable to go places they want to go



Concerned with being lonely



Concerned with being becoming homeless

Loneliness

Loneliness is a major public health concern for all Americans that can have a significant ripple effect on one's mental health and support system. Adults with A/I/DD often experience cognitive or social impairments due to their disability, making forming and maintaining social connections more difficult than for **neurotypical** people. Significantly, 69% of survey respondents indicate they or their family members with A/I/DD experience loneliness. The chart on page 38 shows the barriers to friendship faced by all respondents of the survey.

Data isolated to show responses from self-advocates only indicate they experience loneliness and do not know where to find friends; 64% are unaware of how to turn potential friends into long-term friendships; 55% percent report feeling socially anxious; and 46% feel that people do not understand how to be a supportive friend to them.

Without additional support, challenges faced by adults with A/I/DD (such as social anxiety, challenges exploring and scheduling social opportunities, and maintaining social ties) will continue to lead to loneliness and isolation. Creating spaces and places for neurotypical and adults with A/I/DD to connect within the greater community and build neurodiverse relationships is critical. Planned and mixed-use communities can be designed for soft social interactions within the built environment (e.g., clustered mailboxes, lawn games in open spaces, pedestrian-oriented site planning, etc.) and can include supportive amenities to facilitate more significant social opportunities and engagement, such as an activities coordinator, life skills or fitness classes, or community navigator.



Unless otherwise noted, the preferences data in this section are compiled from the 2023 Charleston Housing Market Analysis Needs & Preferences Survey. The data provides information from respondents with A/I/DD or their families about their future preferences for housing, services and community engagement. The following section offers data-driven recommendations to meet demand.

Adults with A/I/DD and their families have similar desires as neurotypical tenants: safety, respect for privacy, desirable location, good neighbors and the freedom to make decisions. As the data from this section reveals, specific design features and supportive amenities that respondents rank as highly rated features should be considered when local communities and the state respond to the need.

100% of self-advocates

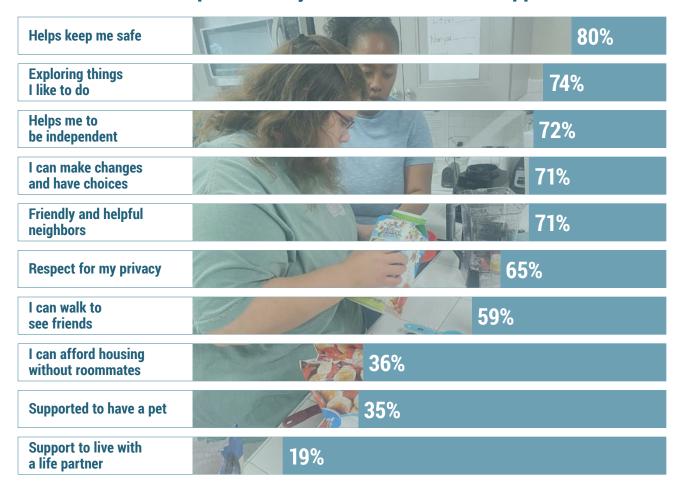
reported they don't know

where to meet friends.

Individualized Long-Term Services & Supports

As described by the Neuro-Inclusive Housing Framework included in the Background section of this report, housing and LTSS providers may or may not be connected. One can live in a provider-controlled setting where the service provider secures and maintains housing for those they serve. Alternatively, one can select a consumer-controlled setting where they find and manage their preferred home and location before selecting their service provider and service delivery method.

What is important for your future home and supports?

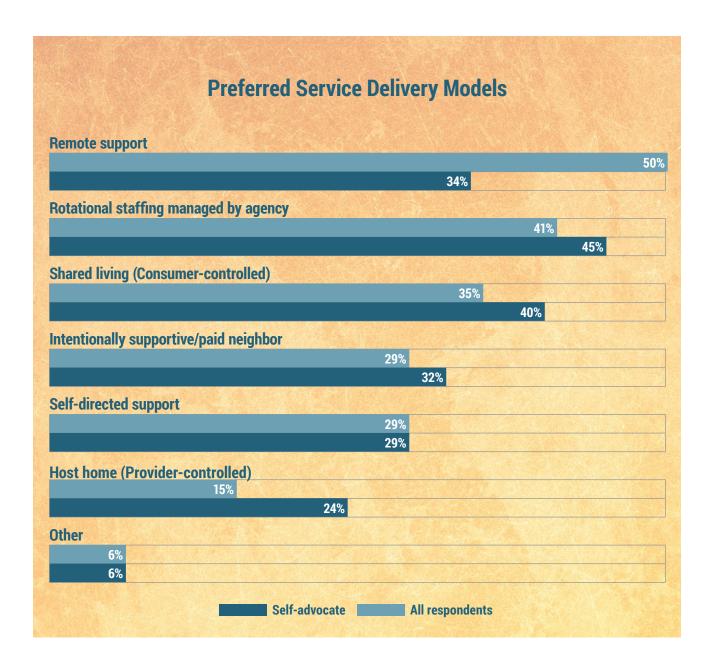


The same single-family home in a typical neighborhood or part of a planned community could have various LTSS arrangements individualized for residents. In this housing arrangement example, Amanda's parents bequeathed their home.

Who do you want to your housing	
Consumer-controlled: I find and control my own housing. I choose any service provider I want.	53%
Provider-controlled: I find a service provider I like and move into their housing.	47%

Examples of possible living arrangements and service delivery options:

- (A) Amanda 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.
- B) Amanda lives with her caregiver and the caregiver's child in a **shared living** arrangement.
- C) Amanda lives with two housemates. One of the housemates does not have A/I/DD. Amanda and her support team hire her staff through **self-direction**, and her neurotypical roommate might be paid to assist as needed. The third housemate uses a different LTSS agency that provides **remote support**.



It is important to note that in South Carolina, not all adults with A/I/DD can live in a consumer-controlled setting and access needed residential services in their own homes. If an adult with A/I/DD has moderate support needs, their only choice is a provider-controlled setting due to a lack of service delivery models and associated funding in South Carolina. Other states have more choices, enabling adults with moderate- to high-support needs to access the services they need in a home they own or rent.

Consumer-controlled and provider-controlled settings are in somewhat equal demand after being informed of the considerations and benefits of various service delivery models. Housing Market Analyses completed in other communities show a much higher demand for consumer-controlled settings. The difference in preference in Tri-County area may be due to lack of exposure, as South Carolina relies heavily on provider-controlled **residential** habilitation settings. Fewer than 700 adults with A/I/DD who receive HCBS live in a consumer-controlled setting.⁵⁶ More insights are needed to understand this variation for the Tri-County region.

Rotational staffing managed by an agency is the most preferred form of service delivery in South Carolina.

The second most preferred form of service delivery is shared living in a consumer-controlled setting. The least desired service delivery model is the host-home in a provider-controlled setting. Host homes remain an essential service delivery option as it is the preferred option of 24% of respondents.

When isolating self-advocate responses, the highest-ranked preferred service is technology and remote support (50%). Self-advocate preferences are followed by rotational staffing (41%) and shared living (35%), with 29% preferring self-direction and 29% preferring a paid or intentionally supportive neighbor.

There are significant discrepancies between what individual respondents prefer and what is currently available through HCBS waivers in South Carolina:

Shared living is ranked as the second most desirable service delivery option (40%) and third most preferred among self-advocates (35%). However, it is unavailable as a waiverfunded service in South Carolina. Although, similar to a host home arrangement since a service provider lives with the service recipient, a shared living arrangement is consumer-controlled. It gives the resident with A/I/DD at least equal control over the home. The consumer can request a change in service provider and not be forced to leave the home. Under the current host home model (Community Training Home I Model, or CTH I), the resident with A/I/DD must move if the service provider no longer wants to provide services to the service recipient.

Self-advocates preferred remote support, which is unavailable as a waiver-funded service in South Carolina. The ID/RD and CS waivers offer to fund "assistive technology and appliances" used to increase or improve the functional capabilities of a person, thereby

resulting in a decrease or avoidance of the need for other waiver services. The waiver also offers a Personal Emergency Response System (PERS), an electronic device that enables a person at high risk of institutionalization to get help in an emergency. Although important ways to use technology, these options do not provide the ongoing monitoring needed for remote support. Remote support/monitoring uses technology to provide real-time assistance by direct support professionals 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.57 For examples of how South Carolina can offer remote support in its waiver, refer to the 17 Technology First states offering state- and waiver-funded models that include remote support/monitoring.58



NFlyte is an app created by Stacey Ledbetter, CEO, Founder, to support individuals with

autism and intellectual disabilities and their families as they navigate the path toward independence. NFlyte is an all-in-one platform for practical life skills. Parents and caregivers can upload reminders and important documents, and their child can check off completed to-dos and have a visual list of tasks needed to function as an independent adult. Families can be connected with their adult children and track progress while empowering them to manage their day-to-day tasks. NFlyte offers shared & customizable visual schedules, grocery lists, a community cookbook, document storage, in-app messaging, a mood tracker and a success scorecard. NFlyte truly supports independence for peace of mind.

A paid or intentionally supportive neighbor is unavailable as a waiver-funded service delivery model in South Carolina, yet desired by 32% of respondents. The New York Office of Persons with Developmental Disabilities (OPWDD) offers a waiver-funded model through its self-direction program.⁵⁹

Only 29% of respondents indicate they would like to self-direct their LTSS. Other Market Analyses, co-developed by First Place Global Leadership Institute, show much higher demand for self-directed support. This may be due to limited exposure and lack of awareness, as South Carolina has capped self-directed hours to 28 hours per week. Therefore, if a person needs more than four hours of daily support, they cannot use self-direction to remain stably housed and supported as a service delivery model. More insights should be sought to understand this variation for the Charleston Tri-County area.

Remote support, shared living, self-direction and a **paid neighbor** can all help alleviate the direct support workforce challenges that service providers continue to face, as described in the 2023 report, *Opportunities for South Carolina to Strengthen Home and Community-Based Services for People with Disabilities*.⁶¹

Shared living is ranked as

the second most

service delivery option (40%)

and third most preferred

among self-advocates (35%).

However, it is unavailable

as a waiver-funded

service in South Carolina.



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

Data show that adults with A/I/DD and their families seek diverse financial commitments to secure housing. Thirty-seven percent of all respondents want to buy a home. Of the respondents, 60% want to rent from a service provider, and 11% want to remain in the family home while 10% want to add an accessory dwelling units (ADU) to their property.

The typical rental market can be unstable for those on a fixed income, and landlords of the typical housing stock may or may not renew tenants' leases. Individuals and families may view renting from a provider or homeownership as a more stable option.

Do you want to rent or buy your future home?		
Rent a room in a provider-controlled setting.	60%	
Rent my own home, but need rental assistance to afford housing.	27%	
Prefer to buy a home, but unsure if I or my family can afford it.	25%	
Buy a home together with others.	20%	
Rent my own home.	18%	
Buy a home.	16%	
Remain in current family home and family will move out.	11%	
Add an accessory dwelling unit to my family property.	10%	

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

Most adults with A/I/DD will likely be extremely low-income over their lifetimes. A financial argument exists to help individuals or their families purchase instead of using a rental subsidy such as **housing choice vouchers (HCV)** over decades. Homeownership should be 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.

Only a small percentage of families could purchase a home for their dependent loved one without assistance. Public housing authorities can offer the HCV homeownership voucher to assist individuals to attain homeownership.⁶²

Helping individuals and families purchase a home may provide additional, naturally occurring affordable housing if the person desires to rent a room to a caregiver or roommate 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 a property controlled by a family or friend, the friend's property—allowing use-by-right ADU for dependent family members or individuals with A/I/DD or seniors—can be a viable alternative and help increase housing options. Vouchers can also be applied to renting an ADU from a relative as a reasonable accommodation under certain circumstances.

By developing tools and housing stock targeting homeowners with A/I/DD or their families, the limited resource of rental subsidies can be preserved for those who prefer a consumer-controlled rental option. Incentives should be created for landowners, developers and families to drive the development of attainable homeownership and rental options.

HCV Cost Over 30 Years in the Tri-County Area

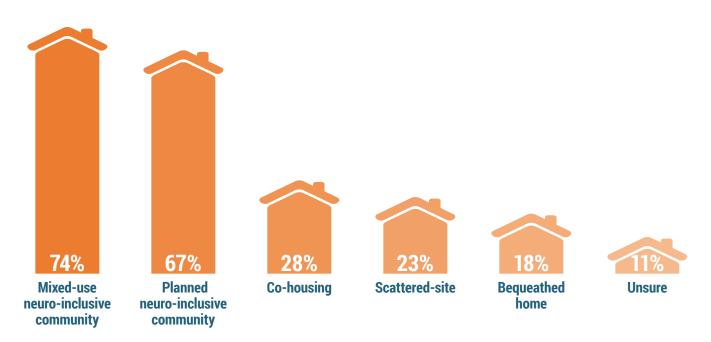
Public housing authority name	Avg. monthly rental subsidy ⁶³	For 30 years	For 30 years, with projected inflation ⁶⁴
Housing Authority of the City of Charleston	\$839.41	\$302,187	\$487,063
Charleston County Housing and Redevelopment Authority	\$817.42	\$294,271	\$474.303
Housing Authority of North Charleston	\$857.22	\$308,599	\$497.397

Housing Type & Physical Amenities

After learning about the benefits and considerations of various development types, it is clear that participants prefer neuroinclusive **mixed-use planned community** development types. This may be due to

additional accessibility features, safety nets and supportive amenities that are unavailable in scattered-site housing. Neuro-inclusive planned or neuro-inclusive mixed-use planned communities are designed for the accessibility needs of adults with A/I/DD. However, these communities can benefit everyone.

What type of housing setting are you interested in?





Bequeathed Home

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

Scattered-Site Housing

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

Planned Community

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

Mixed-Use Community

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

Cohousing

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

Twenty-eight percent of respondents prefer a **cohousing** solution, typically a homeownership model where people design, fund and manage their neighborhood. Twenty-three percent prefer a setting in the typical housing stock, with 18% wanting to bequeath their family home to a loved one with A/I/DD.

As South Carolina reviews and executes its HCBS STP, this information sheds light on diverse needs and preferences in the development of living options, including the desire to have neuroinclusive planned and mixed-use communities that, when thoughtfully designed, can foster integration into the greater community and enhance overall social well-being and mental health.

Unit Type

Respondent data shows significant diversity in the preferred unit type. Just as the neurotypical population has a variety of preferences, adults with A/I/DD and their families also have diverse preferences. There is no one-size-fits-all approach to meeting housing demand for people with A/I/DD.

What unit type are you interested in?		
Apartment/condo	73 %	
Townhome	58%	
Small cottage home or patio home	52 %	
Single-family home	45%	
Accessory dwelling unit (ADU) (e.g., mother-in-law house, etc.)	28%	

If an adult with A/I/DD has moderate support needs, their only choice is a provider-controlled setting due to a lack of service delivery models and associated funding in South Carolina.

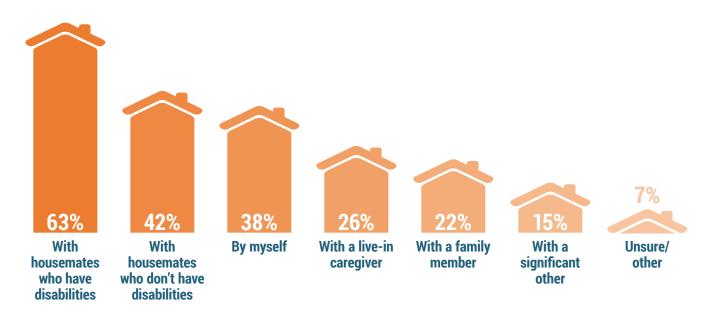
Preferred Living Arrangements

Sharing one's home is an intimate experience. In the past and even today, people with A/I/DD are often expected to live with multiple unrelated individuals with disabilities in a group setting to access services or afford housing. This may include sharing a bedroom and a bathroom with those they did not select as roommates. Non-disabled adults often experience this type of living situation during early adulthood in dormitories or student housing; thus, sharing a bedroom or a bathroom should not be expected of adults with A/I/DD unless it is with a significant other or someone they choose.

When asked about living arrangements, most respondents prefer having a housemate. Thirty-eight percent prefer a single unit with no roommates. Twenty-six percent seek to share their home with a caregiver. If shared living becomes possible in South Carolina, this may increase as this service delivery model was highly preferred.

When planning to meet the needs of people with A/I/DD who may prefer to live with a roommate, best-practice strategies include same-size bedrooms in two-plus-bedroom units, each bedroom having its own bathroom and, ideally, bedrooms not sharing walls in consideration of privacy and sound sensitivities.

How many housemates would you want to live with?





Easy-to-Clean Features

The building and/or residential unit includes features that make cleaning and maintenance easier.

Smart-Home Features

The residential unit and/or building includes devices, appliances and other technologies that can be customized to enhance residents' comfort, safety and independence.

Pedestrian-Oriented

The building and/or development is located 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...

Extra-Durable Features

The building and/or residential unit includes extra-durable features, such as graffiti-resistant paints, floor drains and sealed surfaces (for water play), solid-wood furniture without sharp corners and more.

Sensory-Friendly

Sensory-friendly spaces take into account environmental factors that contribute to sensory overload, accounting for all five senses.

Universal Design

The residential unit and/or building includes design features that most people can use regardless of age, agility or ability. It seeks to optimize accessibility and continues to evolve with advancements, including enabling technologies.

Physical Amenities & Design Preferences

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. Survey data shows that most respondents select the physical amenities presented as "important" or "very important."

The "Top 5" features that meet the preferred accessibility needs of adults with A/I/DD include easy-to-clean and extra durable features valued for easier maintenance and longevity. Smarthome features ranked second and may consist of reminders if an oven is left on or a door is open. The third ranking included pedestrian-oriented human-centered mobility design to make walking around one's community safer for those who do not drive or are challenged by depth perception, which can make it difficult to crossroads safely. 65 As safety was ranked highest in what people wanted from their housing and support system, it is unsurprising that security features were included in the Top 5. They may include a secured entry, video doorbell system and/ or having a trusted person help them decide if it is safe to open the door to someone they do not recognize due to face blindness.

Most of these modifications and design strategies may also be attractive to neurotypical residents. Just like a curb cut required by the ADA makes walking on sidewalks easier for those with mobility issues, it also serves as a convenience for those using a stroller or grocery cart. When housing and community spaces are designed to be more neuro-inclusive, everyone can benefit.

What type of physical amenities would be helpful?

Easy-to-clean features	91%
Smart-home features	87%
Pedestrian-oriented	86%
Security features	83%
Extra-durable features	81%
Sensory-friendly design	73%
Universal design	70%
Adaptable design	68%
Transit access	67%
Biophilic design	61%
Cognitive accessibility	60%





Community Navigator

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

Life-Skills Training

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

Community Life

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

Resident Assistant

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

Meal Service

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

Benefits Counseling

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

Supportive Amenities

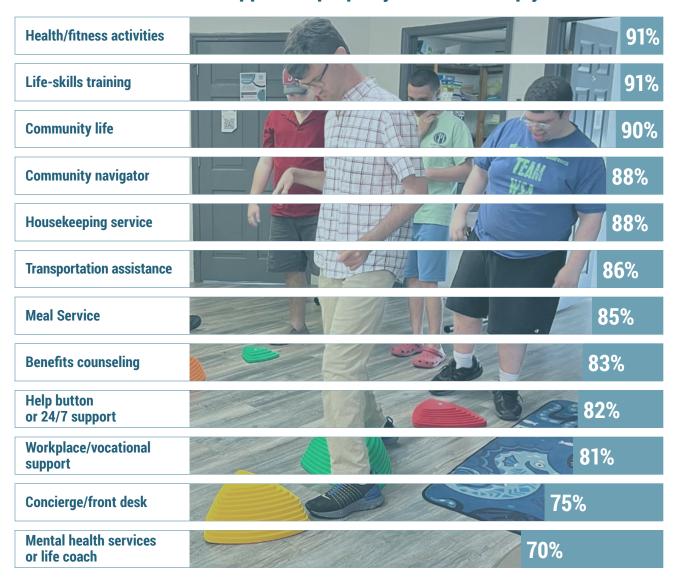
Supportive amenities are not the same as individualized LTSS. Supportive amenities are available to all residents who live at a specific property; they offer additional needed support that individualized LTSS providers often do not include. They also offer an alternative supportive housing option for individuals ineligible for waiver services who need assistance to remain housed, employed and connected to their community.

Supportive amenities can be provided by local community-based organizations like SOS Care and need not be provided by the housing developer or property management company. Housing developers can collaborate or partner with community-based organizations that offer supportive amenities. These amenities should be voluntary.

Most of the supportive amenities shared are desired by the majority of respondents. Health and fitness activities, life skills classes, and someone to plan and facilitate fun social activities are the highest-ranking amenities and reflect a desire for more group social opportunities. The next highest preferred supportive amenity is a community navigator or person to help connect residents to opportunities in the greater community. Housekeeping, transportation and meal service rounded out the preferred supportive amenities, which could act as accommodations for those with executive functioning challenges in whereby such assistance can help them focus on employment stability, maintaining relationships, other life skills, and mental health.

Federal Medicaid HCBS compliance guidance documents provided to assist state agencies in ascertaining if a residential setting may meet the basic characteristics of a Medicaid HCBS (as required by regulation) refer to a common dining area and access to prepared meals as potential institutional red flags.⁶⁶ It is essential

Would these supportive property amenities help you?



for South Carolina to consider the need to create social opportunities and support how future neuro-inclusive mixed-use developments can include a common food court area or voluntary meal service for residents.

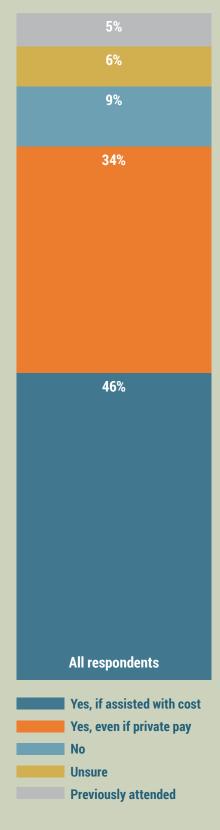
At this time, South Carolina lacks a funding stream or mechanism for providing supportive amenities in existing or emerging multi-family developments.

"I want to see my new home a few times before I move in.

I like to see things beforehand so it can help me transition."

- Self-Advocate Respondent, Charleston Housing Market Analysis Survey

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



Transitioning from the Family Home

The figure to the left shows responses from respondents when asked about their interest in attending a residential transition program.

Moving from a family home is a big decision for neurotypical and neurodivergent young adults and their families. Adults with A/I/DD may have been living in the family home for years, even 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 require greater direct support for a transitional period.

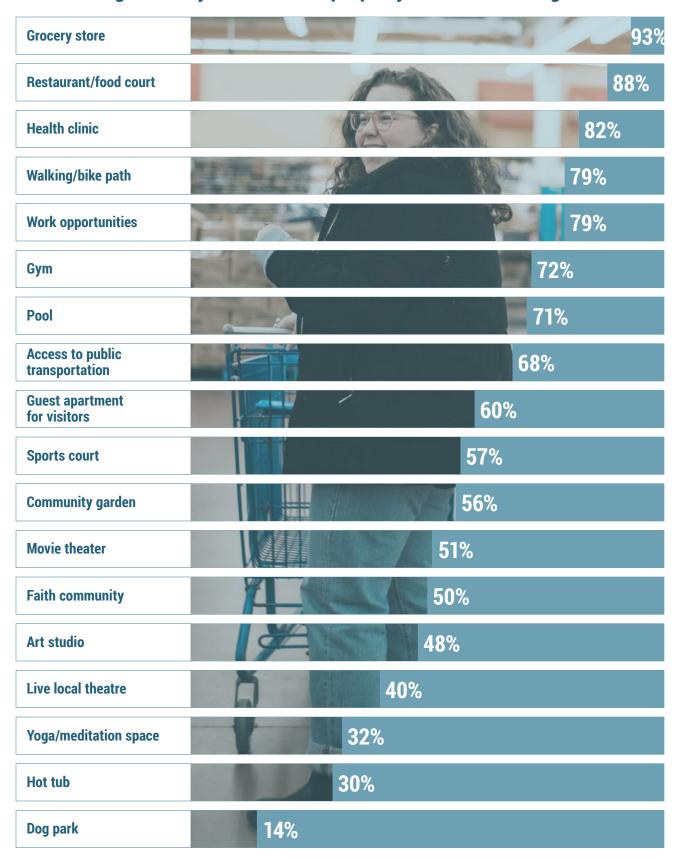
Eighty percent of survey respondents indicate the desirability of a post-secondary transition program offering intensive life skills training as a bridge to independent living. Six percent would need assistance to cover the cost. Private pay, post-secondary residential transition programs exist nationwide with successful outcomes in increased employment rates, decreased need for in-person support staff and increased ability to self-advocate and navigate the community safely.

South Carolina has no funding stream or mechanism for post-secondary residential transition programs.

Community Development

With 88% 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 can access housing in a location that is walkable to needed community amenities. Through land banking or a community land trust, parcels can be secured in ideal locations for neuroinclusive mixed-use or planned communities, ensuring that affordable, accessible housing is not located in a food desert or isolated forming to residents who do not drive.

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



Survey respondents indicate that food access within walking distance of the property is a top-ranked need. 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, purchasing groceries, meal preparation, inviting others to join in a meal, eating a meal alone and/ or 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 when living on a limited budget. These features can support the creation of community, provide increased social opportunities to decrease feelings of loneliness and increase a sense of belonging. Eating a meal with others is a powerful way to build relationships.

The survey also includes elements to 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 make the Tri-County area more neuro-inclusive.

Community Accessibility & Accommodations

The chart on page 57 shows the responses from respondents asked to rate the importance of these accessibility features and accommodations:

These accessibility features could be incorporated into the Holiday Festival of Lights, Flowertown Festival, Coastal Carolina Fair, and places like Joseph Riley Riverdogs Baseball Stadium or other community events and activities. Not only do they increase accessibility for neurodiverse families and self-advocates, but they are also of value to neurotypical participants.

Location

When asked about location in the Tri-County area, Charleston County was ranked highest preference, followed by Berkeley and Dorchester, as shown in the table below.

These responses could be due to the familiarity of locations where respondents currently live. Charleston is also more urban than the other counties in the Tri-County area and thus more walkable for those who do not drive or use public transportation. Due to density, it may have more employment opportunities, community amenities and access to services. In contrast, Dorchester County is more suburban and residents likely have less access to job opportunities, transportation and service providers. Residents who live in less populated or smaller towns may feel more connected to and safe in their community with fewer people and may have fewer challenges building a natural support system. It is worth noting that Dorchester County has developed an allabilities park/playground and strengthened its therapeutic programs.

Data obtained through the CHMA should not limit opportunities for future sites. The need remains for increasing housing and economic opportunities in all areas.

Which of the following areas would you prefer to live?		
Charleston County	48%	
Berkeley County	28%	
Dorchester County	24%	

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

Knowing what to expect when going somewhere	72%
Person/space to go to if I feel scared/confused	64%
Sensory-friendly environments	62%
Extra time/space to interact at my own pace	60%
Knowing who will be present ahead of time	56%
Visual-based cues	51%
Pedestrian-oriented design	50%
Quiet, low sensory space to decompress at an event	49%
Color-coded wayfinding	38%
Wheelchair/mobility device accessibility	24%



TOP 5

Desired future opportunities



Planning for grants to launch housing options



Fun things to do every week



Help families get needed services



Help families find more housing assistance

Classes for life skills

Opportunities Needed

When asked about future opportunities, most respondents request planning grants to launch housing solutions, more fun things to do, assistance finding housing and accessing services, and life skill classes.

The Colorado Housing and Finance Authority developed a unique technical assistance grant program in response to its Housing Market Analysis. Landowners can apply twice a year for the program that provides recipients with a consultant team, including a neuro-inclusive housing expert, an architect and a financial development consultant. This team includes community engagement, checks for the feasibility of the property, and develops architectural renderings and a proforma for the potential property. This program provides funding and expertise for landowners to explore using their property for neuro-inclusive housing.⁶⁷

"Some individuals

with a disability

will need full-time care.

Please include that

in future planning."

Parent Respondent, Charleston
 Housing Market Analysis Survey



The following recommendations for developing a Housing and Community Roadmap are derived from focus group feedback and data analysis by First Place Global Leadership Institute researchers and Charleston Housing Market Analysis local leaders.

Closing of Data Gaps

- Segment the South Carolina Homeless Management Information System (SCHMIS) or point-in-time data to identify adults with A/I/DD experiencing homelessness.
- Develop a housing and lifespan navigation program to target individuals with A/I/DD and their families, better connecting people to available resources while collecting data and guiding them to plan for the transition out of the family home before falling into crisis.

- Modify DDSN 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 desiring a consumer-controlled setting.
- Identify adults with A/I/DD living in family caregivers' homes. These families can be segmented into those who would meet eligibility criteria for DDSN services and those who do not or would likely not meet eligibility criteria yet have supportive housing needs.
- Work with partner agencies to determine methods to identify households by race and ethnicity with a child or adult dependent with A/I/DD living in the home and whether they are burdened due to housing costs (spending more than 30% of income on housing).

 Consider a change of policy restrictions that would allow for the categorization of utilization rates by residents with A/I/DD currently receiving a housing choice voucher, 811 Project Rental Assistance, or other permanent rental subsidy, public housing or 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 feasible.
- Expand awareness of the homeownership HCV, ensuring it is also accessible to non-"owner-occupiers" and marketed to adults with A/I/DD and their families.
- Identify local Community Development Financial Institutions and/or the SC State Housing Finance and Development Authority's interest in developing 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 families to invest in housing for their dependent, low-income family members with A/I/DD.
- Develop a guide, model neuro-inclusive plans and other tools for neurodiverse families to add an ADU to their property.

- Increase awareness of demand for housing targeting adults with A/I/DD and their families with the Home Builders Association of South Carolina. More homes are needed to qualify at the price point for the HCV homeownership voucher, helping adults with A/I/DD and their families attain homeownership.
- 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 DDSN waiver services in local HCV waitlist applications.
- Decrease trauma and support smoother transitions from the family home by ensuring policy for housing assistance programs does not first require the experience of homelessness or institutionalization for access to assistance.
- Expand the existing collaboration among DDSN, Public Housing Authorities and the Charleston Department of Housing and Community Development to apply for additional 811 funding and other housing subsidies to increase access 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 Services & Supports, what they provide 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 South Carolina Qualified 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 South Carolina Housing Trust Fund and the South Carolina Community Loan Fund.
- Develop a funding source and/or incentives for new construction or rehabilitation that create additional units for single or two-person households incorporating universal and neuro-inclusive design elements. This could be implemented via a community land trust or by modifying 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 nonprofits, faith communities, local planning departments, and developers to hire consultants and/or conduct feasibility activities to create local neuro-inclusive solutions.

"For most adults with A/I/DD, the definition of community is often limited to immediate family members and/or paid staff. This is because adults with A/I/DD are tasked with socializing, living and engaging, which may include complex rules, contracts, leases or social standards. However, we can support the executive functioning, cognition and/or sensory needs of a person with A/I/DD and give them enough grace to make mistakes and learn, while creating neuro-inclusive communities."

 Toyosi Adesoye, Research Coordinator & Data Analyst, Global Leadership Institute

Long-Term Services & Supports

- Increase funding and/or legislative action to make waiver services available to all adults with A/I/DD living with a caregiver over age 60 or at risk of displacement into providercontrolled or more restrictive settings than needed.
- Identify a pathway to prevent homelessness of adults with A/I/DD deemed ineligible for LTSS but in need of case management and scheduled drop-in support.
- Consider adding housing services available in other states for waiver recipients to explore, secure, transition and maintain tenancy in housing. These include pre-tenancy supports, housing stabilization services, transitional housing services, tenancy sustaining services, etc. 68, 69
- Add or modify waiver services to expand service delivery models in demand in South Carolina are already available in other states, including shared living, remote support and paid neighbors.
- Add non-medical transportation services using Medicaid to break down this significant barrier to community engagement and potential employment.
- Remove the 28-hour cap for self-directed service for adults with A/I/DD of any level of support needed to self-direct their LTSS.
- Create a funding stream for supportive amenities that community-based organizations can provide in housing developments.
- Create an awareness campaign to help individuals with A/I/DD and their families understand and apply for LTSS and other public benefits.
- Ensure transition planning during adolescence to address needed post-high school supports.

Local Community Development

- Include adults with A/I/DD in local diversity, equity and inclusion efforts to increase the visibility of Charleston'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.
- Explore how to address the loneliness crisis and increase natural support systems.
- Practice land banking of properties within walking distance of grocery stores for future affordable, mixed-use, neuro-inclusive planned 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 ADU or tiny home as a "use by right" on property that will house a dependent adult with A/I/DD; offer planning grants and waive fees associated with requesting approval.



A 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 and know their neighbors, be regulars at their favorite local places of business and have a true sense of belonging.

There are not enough residential options to meet surging demand. For the A/I/DD population, it is not a matter of whether people with A/I/DD will lose their existing home and primary caregiver; it is a question of when. Workforce shortages, changing demographics and a rapidly aging population mean the Tri-County area needs increased access to housing, greater options, and innovation in LTSS and supportive amenities. Without planning, many people with A/I/DD will be forced into crisis placements in emergency

rooms, nursing facilities, psychiatric hospitals and institutional settings—or could face incarceration and even homelessness. These consequences are traumatic for individuals and their families—and expensive for the state.

The following are just some of the pressing, systemic challenges facing the Tri-County area and South Carolina collectively:

- The specific number of adults with A/I/DD is unknown. Major data gaps persist in understanding the needs of those living in aging family caregivers' homes.
- The current housing stock is largely financially, physically and cognitively inaccessible.
 Data demonstrates high demand for neuro-inclusive mixed-use and planned communities; thus, incentives and funding streams are needed to equip developers and local communities with the tools to respond.

For the A/I/DD population
as a whole, it is largely not`
a matter of if they will lose
their existing home and
primary caregiver, it is a
question of when.

- Public Housing Authorities serving the Tri-County area do not offer mainstream housing vouchers or non-elderly disabled vouchers for adults with disabilities.
- •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, LTSS and other public benefits.
- Services funded within the DDSN waiver programs do not include 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 or adding an ADU 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 22,000 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 LTSS, an urgent gathering of local leaders and elected officials is needed to develop a roadmap for supportive housing solutions to prevent the displacement of and risk of homelessness for adults with A/I/DD in the Tri-County area.⁷¹

Thanks to the research teams at the First Place Global Leadership Institute and SOS Care, Charleston and the greater Tri-County area, market data expresses the residential needs and preferences of this invisible population. Meeting their housing needs will result in improved quality of life and health, and a more stable population. With a more supported population, average Medicaid costs could be reduced through fewer emergency room visits, emergency placements and even homelessness.

The cost of doing nothing will be exorbitant. Immediate action is needed to enable more effective and sustainable planning for individuals with A/I/DD and their families, and to help every Tri-County resident find a home—and their place in the world.

Join us in Charleston by reaching out to housing@soscaresc.org.

For more information and to view other A Place in the World® Housing Market Analyses, visit www.firstplaceaz.org/leadership-institute/housing-market-analyses



TERM	DEFINITION	PAGE
811 Project Rental Assistance (PRA)	The Section 811 Project Rental Assistance (PRA) program seeks to identify, stimulate and support successful and innovative state approaches to providing integrated supportive housing for people with disabilities. ⁷²	62
Accessory dwelling unit (ADU)	An accessory dwelling unit (ADU) is a small, independent residential dwelling unit located on the same lot as a stand-alone (i.e., detached) single-family home ("Accessory", 2022). It may also be referred to as a casita, granny flat, accessory apartment or secondary suite ("Accessory", 2022). It may be a converted portion of existing home or addition to a new or existing home. ⁷³	48
Achieving a Better Life Experience (ABLE) account	Tax-advantaged savings programs that allow individuals with disabilities to save and invest money without jeopardizing eligibility for public benefits. 74	36
Administration for Community Living (ACL)	The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose and with the ability to participate fully in their communities. ⁷⁵	14
Affordable housing	Generally defined as housing in which the occupant is paying no more than 30% of gross income for housing costs, including utilities. ⁷⁶	10

TERM	DEFINITION	PAGE
Americans with Disabilities Act (ADA)	An act of Congress enacted in March 2010 prohibiting discrimination against people with disabilities in various areas, including employment, transportation, public accommodations, communication and access to state and local government programs and service. ⁷⁷	14
Area median income (AMI)	Area median income, or AMI, is a key metric in affordable housing. AMI is the midpoint of a specific area's income distribution and is calculated on an annual basis by the Department of Housing and Urban Development (HUD). HUD refers to the figure as median family income, or MFI, based on a four-person household. ⁷⁸	33
Autism and/ or intellectual/ developmental disability (A/I/DD)	IDDs are differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems. Intellectual disability starts any time before a child turns 18 and is	9
	characterized by differences with both: Intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and	
	Adaptive behavior, which includes everyday social and life skills.	
	The term "developmental disabilities" is a broader category of often lifelong challenges that can be intellectual, physical, or both.	
	"IDD" is the term often used to describe situations in which intellectual disability and other disabilities are present. ⁷⁹	
Bequeathed home	A home left through a will or as a gift to someone else. Careful planning is needed for a loved one with a disability. ⁸⁰	36
Centers for Medicare and Medicaid Services (CMS)	CMS is the federal agency that provides health coverage to more than 160 million individuals through Medicare, Medicaid, the Children's Health Insurance Program and the Health Insurance Marketplace. CMS works in partnership with the entire healthcare community to improve quality, equity and outcomes in the healthcare system. ⁸¹	13
Cognitively accessible	Cognitive accessibility refers to inclusive practices that remove barriers for people whose disabilities affect how they process information. ⁸²	17
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 own homes. ⁸³	50

TERM	DEFINITION	PAGE
Community land trust	A community land trust (CLTs) is a nonprofit organization 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. CLTs develop rural and urban agriculture projects, commercial spaces to serve local communities, and affordable rental and cooperative housing projects to conserve land or urban green spaces. The goal is to create permanently affordable homes providing successful homeownership opportunities for generations of lower-income families. ⁸⁴	56
Community Training Home I Model (CTH I)	In the Community Training Home-I Model, personalized care, supervision and individualized training are provided in accordance with a service plan to a maximum of two individuals living in a support provider's home where they essentially become one of the family. Support providers are qualified and trained private citizens. ⁸⁵	46
Corrective action plan (CAP)	As a result of the 2014 HCBS settings rules, states were required to develop state transition plans addressing how the state would comply with the Olmstead decision and meet the requirements of the new HCBS settings rules. CMS and ACL have visited states to visit settings to perform heightened scrutiny visits and as a result identified when state agencies and/or HCBS providers are not meeting the requirements under the settings rules. Corrective action plans (CAP) which outline the actions and activities that the state proposes to take to bring the agency and/or setting into compliance with the settings criteria are submitted to CMS. ⁸⁶	14
Consolidated plan	A plan designed to help state and local jurisdictions assess their affordable housing and community development needs and market conditions. It enables data-driven, place-based investment decisions. This plan is comprised of annual action plans that provide a summary of the actions and activities, along with federal and non-federal resources that will be used each year to address the needs and goals specified in the plan. ⁸⁷	19
Consumer- controlled setting	A property where the housing provider is not connected to the LTSS provider. Residents can choose and change their LTSS providers while remaining in the same housing. ³⁰	11
Employment First	Employment First is a national systems-change initiative centered on the premise that all individuals, including those with the most significant disabilities, are capable of full participation in competitive integrated employment (CIE) and community life. Under this approach, publicly financed systems are urged to align policies, regulatory guidance and reimbursement structures to commit to CIE as the priority with respect to the use of publicly financed day and employment services for youth and adults with significant disabilities. ⁸⁸	34

TERM	DEFINITION	PAGE
Executive functioning	Higher-level cognitive skills used for control and coordination of other cognitive abilities and behaviors. Executive functioning is 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. 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.	18
Face blindness or prosopagnosia	A neurological disorder characterized by the inability to recognize faces.90	52
Freedom of Choice form	The Freedom of Choice form must be signed with "home and community-based services" selected prior to waiver enrollment. The presence of this completed and signed form ensures that the waiver case manager has explained the services available through the waiver and provided sufficient detail about both ICF/IID (see "I" in glossary) and waiver services to enable an informed choice. ⁹¹	31
Graded movement	Movements whereby a person uses the appropriate amount of force to complete motor skills. People with A/I/DD may use too much or too little force when performing actions such as opening a door, flushing a toilet, stepping down, etc. ⁹²	21
Group home	A provider-controlled setting where two to six unrelated persons with disabilities share a home and are supported in their daily living activities. Residents can pay to live in this development type via private pay or Medicaid ICF/IID. ³⁰	11
High management	High management (intensive support residential habilitation) is delivered through the Community Training Home II (CTH II) model, which is shared by up to three individuals with a brain injury, spinal cord injury or similar disability or those who have a diagnosis of intellectual disability and display extremely challenging behaviors. ⁹³	29
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. ⁹⁴	13
Host home	An LTSS provider's home where an individual with LTSS lives. ³⁰	11
Housing choice voucher (HCV)	Voucher program allowing qualified individuals or families to pay 30% of their income toward rent at a location of their choosing and paying the remainder of rent costs. The property owner of the chosen living place must agree to rent under the program. Qualified individuals include low-income families, the elderly and individuals with disabilities. ³⁰	48
Housing or lifespan navigation services	Services offering assistance in understanding residential choices, applying for housing assistance, tenant stabilization, and guiding elements needed for financial and legal planning beyond living with parents. May or may not be available as a waiver-funded service (state dependent). 95	37

TERM	DEFINITION	PAGE
Human-centered mobility design	User-centric transport systems with highly intuitive elements, from ticketing to wayfinding. Human-centered mobility design must be efficient, cost-effective and accessible to the widest population in order to support a growing and vibrant city. The system should be mode agnostic whereby passengers can switch between walking or cycling, or taking a bus, tram or car for optimum flexibility but also inherently resilient if there is failure of one mode or maintenance is required. Ticketing systems and real-time information should enable seamless end-to-end journeys across all modes. ⁹⁶	52
Individuals with Disabilities Education Act (IDEA)	The Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. Congress enacted the Education for All Handicapped Children Act (Public Law 94-142), also known as the EHA, in 1975 to support states and localities in protecting the rights of, meeting the individual needs of, and improving results for infants, toddlers, children, and youth with disabilities and their families. This landmark law's name changed to the Individuals with Disabilities Education Act, or IDEA, in a 1990 reauthorization. The law was last reauthorized in 2004 with periodic new or revised regulations to address the implementation and interpretation of the IDEA. ⁹⁷	29
Intermediate care facilities 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. 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. This program serves over 100,000 individuals with intellectual and other disabilities and related conditions. 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.	31
Land bank	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. ⁹⁹	56
Long-term services & supports (LTSS)	A variety of services that assist individuals with functional limitations due to various conditions and/or disabilities in their everyday life. 100	11
Low Income Home Energy Assistance Program (LIHEAP)	This federal program provides home energy assistance to eligible low-income households to help them meet their home heating and/or cooling needs. ¹⁰¹	34
Mainstream housing choice voucher	A voucher that assists non-elderly individuals with disabilities. These vouchers operate under the same rules as other housing vouchers. 101	19
Means-tested	Limited eligibility to individuals and families whose incomes and/or assets fall below a predetermined threshold (means test). ¹⁰³	36

TERM	DEFINITION	PAGE
Mixed-use planned community	Large-scale residential development of various uses with robust, curated amenities providing residents with the experience of living in a self-contained town. Amenities can include parks, playgrounds, swimming pools, tennis courts, golf courses and more.	49
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 featuring 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. ³⁰	49
Neurodiverse/ Neurodivergent	Of neurological difference including autism, Down syndrome, cerebral palsy, epilepsy, ADHD and I/DD.30	9
Neurotypical	Not affected with a developmental disorder, particularly autism spectrum disorder; exhibiting or characteristic of typical neurological development. ¹⁰⁵	42
NFlyte	An all-in-one life skills app for autistic adults needing independent living support that enables families, caregivers and support programs to provide remote help. ¹⁰⁶	46
Non-elderly disabled (NED) vouchers	Vouchers allowing non-elderly disabled individuals to access affordable housing. Category 1 NED vouchers allow non-elderly individuals or families to access affordable housing on the private market. Category 2 NED vouchers allow non-elderly disabled individuals currently residing in nursing homes or other healthcare institutions to transition into the community. ¹⁰⁷	19
Olmstead v. L.C.	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 state transition plans and HCBS settings rule). ¹⁰⁸	8
Owner-occupier	A person who owns the dwelling in which they live. ¹⁰⁹	37
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. ³⁰ Also referred to as a resident assistant.	47
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. ¹¹⁰	15
Plain language	A clear, concise and straightforward way of communicating that allows a broad audience to understand information the first time they read/hear it. ¹⁰⁶	24
Planned communities	A small- or large-scale, intentionally developed property with multiple residential units that also has recreational amenities. They sometimes also feature commercial properties, such as restaurants and shops. Property management helps maintain housing and common spaces. The intent is to make life as convenient and enjoyable as possible. This development type is typically located in suburban settings. ³⁰	56

TERM	DEFINITION	PAGE
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 the community dedicated to assisting people experiencing homelessness. ¹¹¹	61
Pre-development technical assistance grant	These grants help catalyze small-scale affordable housing developments by providing access to affordable housing consultants and pre-development grant assistance. Potential small-scale projects, of 30 units or less may apply for affordable housing planning and development technical assistance (TA) services and pre-development grants to further their work. ¹¹²	63
Private vehicle modification	This service offers modifications to a privately owned vehicle used to transport the waiver participant, along with any equipment needed by the participant to make the vehicle accessible. ¹¹³	39
Provider- controlled settings	Property where the housing provider is both property manager and LTSS provider. Residents cannot change their LTSS provider in a provider-controlled setting without moving to a different home. ³⁰	11
Public housing authorities	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). ¹¹⁴	35
Remote support/ monitoring	The use of technology to provide real-time assistance by a direct support provider from a remote location. 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. ¹¹⁵	44
Residential habilitation	Residential habilitation services include the care, skills training and supervision provided to individuals in a home or community-based setting. The degree and type of care, supervision, skills training and support is based on the plan and the person's needs. Services include assistance with acquisition, retention or improvement in skills related to activities of daily living, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. ¹¹⁶	45
Rotational staffing	The selection by an individual needing LTSS of an agency to recruit, hire, train, schedule and fire support staff for them.30	46
Scattered-site housing	A property (residential unit or development) located within the general housing fabric of a community. It is not part of a housing development that serves a specific residential market. In affordable housing circles, scattered-site housing also refers to affordable housing dispersed throughout the community. ³⁰	49
Self-directed support	A budget given to an individual needing LTSS 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. ³⁰	43

TERM	DEFINITION	PAGE
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. When a person practices self-direction, they decide how, when and from whom their services and supports will be delivered. As a model, self-direction prioritizes participant choice, control and flexibility. ¹¹⁷	44
Sensory-friendly	Sensory-friendly spaces that, accounting for the five senses, take into account environmental factors that contribute to and prevent sensory overload. ¹¹⁸	15
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. ¹¹⁹	17
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. Because private homes are consumer-controlled settings, the individual can ask their LTSS provider to move. ³⁰	44
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 specific length of time and paid social security taxes. ¹²⁰	33
Soft social interactions	Surface-level behaviors that reveal a list of latent variables related to personality, social and communication skills, interpersonal skills, leadership skills, decision making, etc. ¹²¹	42
South Carolina Department of Disabilities and Special Needs (DDSN)	DDSN strives to serve all South Carolinians eligible for services and ensure that services meet high established standards. Populations served by DDSN include individuals with intellectual disabilities, related disabilities, autism spectrum disorder, traumatic brain injury, traumatic spinal cord injury, and similar disabilities (disabilities affecting the brain or spinal cord not associated with the process of a progressive degenerative illness or disease, dementia or a neurological disorder related to aging). ¹²²	14
South Carolina Homeless Management Information System (SCHMIS)	An internet-based client data management system that helps coordinate shelter and services for unhoused individuals and those struggling with a housing crisis. ¹²³	11
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. It is often used after the family member's passing to pay for services that improve/maintain the surviving person's quality of life. ¹²⁴	36
State plan amendment (SPA)	When a state is planning changes to its program policies or operational approaches, it sends state plan amendments (SPAs) to the CMS for review and approval. States also submit SPAs to request permissible program changes, make corrections or update their Medicaid or CHIP state plan. ¹²⁵	39

TERM	DEFINITION	PAGE
Statewide transition plans (STP)	In 2014, CMS finalized a rule establishing new requirements for the settings in which Medicaid home- and community-based services (HCBS) are delivered. Under the rule, states must develop implementation plans, known as statewide transition plans, and determine which providers meet the new requirements.	14
Supplemental Nutrition Assistance Program (SNAP)	A federal program providing nutrition benefits to low-income individuals and families. ¹²⁶	34
Supplemental Security Income (SSI)	Monthly benefits provided to individuals with limited income and resources who are disabled, blind or age 65 or older. ¹²⁷	33
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. ³⁰	17
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." 128	46
Wayfinding	A system of signs, colors and other design elements to help people navigate their environment. ¹²⁹	21

"This is great information and it gave me a lot to think about.

It is an overwhelming topic and you offered a way to understand and digest a lot of the many facets needed for making an informed decision about future housing and planning."

Parent Respondent, Charleston Housing Market Analysis Survey



- This report uses both person-first and identity-first language, recognizing that autistic individuals and/or those with a diagnosis of intellectual and/or developmental disabilities may prefer one or the other. Our goal is to respectfully share the perspectives of the individuals and/or their families who participated in this report and recognize that language is important and ever evolving. For more information, see National Institutes of Health (2023). Writing respectfully: Person-first and identity-first language. U.S. Department of Health & Human Services. https://www.nih.gov/about-nih/what-we-do/science-health-public-trust/perspectives/writing-respectfully-person-first-identity-first-language
- For this report, the term adults with autism and/or intellectual/developmental disabilities (A/I/DD) refers to those with a diagnosis of an autism spectrum disorder (ASD), intellectual disabilities (ID) and/or developmental disabilities (DD). Where data and/or a study is specific to those with only ASD, only ID, only DD or I/DD in general, the specific terms are used.
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