

A large, white, stylized map of New York State is centered on the page. The map is filled with a pattern of small white dots and lines, resembling a network or data visualization. The year '2024' is written in white on an orange rectangular background that overlaps the top of the map.

2024
ROCHESTER
Neuro-Inclusive
Housing Market Analysis

A silhouette of a city skyline in shades of orange and brown, featuring various skyscrapers and a bridge, positioned at the bottom of the page.

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

Special thanks to the individuals and families in the Rochester area

who shared their experiences with us through the surveys.

We also extend our thanks to the Golisano Foundation for supporting and ensuring the completion of this report. We also thank Sen. Jeremy Cooney's office for heeding the results and helping push for accessible, affordable housing in the state of New York.

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Two decades ago, four moms came together, determined to build a future where every child—no matter their diagnosis or developmental challenges—could thrive.

What began as a small group of families seeking support has grown into AutismUp, a thriving community now serving nearly 4,000 families across the Greater Rochester Area.

Creating a supportive community has always been at the heart of our mission. We understand the isolation many families face when raising a loved one with autism or other developmental differences. AutismUp exists to provide a network of support, understanding and acceptance at every stage of their journey. Our commitment is simple: No family should ever feel alone.

Cultivating meaningful opportunities is a cornerstone of what we do. By listening to the voices of self-advocates, families, schools and providers, we continue to adapt our programs and services, filling critical gaps and creating enriching experiences that benefit every family member.

However, ensuring our loved ones have a place to call home has emerged as one of the most urgent challenges we face today. Our mission has always been to offer help for today and hope for tomorrow, but the strain on support systems, long waitlists and limited housing options makes it clear: We cannot wait for someone else to solve this crisis. As a parent-led organization, we feel the urgency in our own homes and know that many of the families we serve are desperate for stable, safe housing for their loved ones.

This initiative would not have been possible without the unwavering support of our community. To the families who shared their insights and those who contributed financially, your dedication speaks volumes about our region's resolve. We are also deeply grateful to the nonprofits, local businesses and charitable foundations—including the Golisano Foundation's encouragement and generosity—that helped us spearhead this effort. A special thank you to Senator Jeremy Cooney, whose steadfast support helped bring this initiative to life.

In this report are key insights highlighting the depth of the housing crisis we face—and the immediate need for action. They raise the critical question that keeps many of us awake at night: *What happens to our*

loved ones when we are no longer here to support and advocate for them? Rising housing costs and stagnant funding that has not kept pace with inflation paint a grim picture, underscoring that no single entity or funding source can solve this crisis. We must embrace a new, collaborative approach—one that blends resources, breaks down system silos and creates solutions that support the whole person. Our data underscores the critical need to prioritize safe and accessible housing for individuals with complex needs, many of whom are being institutionalized, sent out of state or languishing on waitlists at alarming rates.

We intend for this report and collaborative effort to serve as a catalyst for meaningful action—at both local and state levels—leading to homes and policies that reflect the dignity, inclusion and independence all individuals deserve. But we can't do this alone. We need you. We are establishing a Housing Task Force and invite you to join us. We are calling on self-advocates, families, developers, investors, providers, agencies, governmental officials and local representatives to come to the table. We need expertise in building permits, zoning laws and subsidies to create sustainable housing solutions. We also need policy-makers committed to creating, sponsoring

and supporting legislation that breaks down the barriers and bureaucratic hurdles exacerbating this crisis. Most importantly, we must ensure that the people we intend to serve—those with autism and other developmental differences—are at the heart of these discussions. Too often, their voices are left out of the conversation.

Moving forward, let's set a new expectation. Together, we can turn these findings into real, lasting change, creating a future where every person with autism or other developmental differences has access to a home that truly meets their needs. This is not just a report—it's an opportunity to be part of something bigger, something transformative.

Thank you for your partnership and support as we work toward a brighter, more inclusive future for the IDD community.

With gratitude,

Sarah Milko
CEO, Parent, Founding Member
AutismUp



Office of the County Executive
Monroe County, New York

Adam J. Bello
County Executive

November 7, 2024

Sarah Milko
Chief Executive Officer
AutismUp
50 Science Parkway
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Dear Ms. Milko:

Across Monroe County and New York State, individuals with profound autism, intellectual and developmental disabilities (A/I/DD), and behavioral and mental health needs are facing dire challenges. Many are repeatedly hospitalized, placed in nursing homes, or languish on waitlists as they struggle to secure safe, appropriate housing. The current system is failing to meet needs and is leaving families and individuals in crisis.

I want to commend AutismUp for their leadership in addressing these challenges through the Build Up ROC Housing Initiative. As a family-led organization serving over 4,000 local families, AutismUp has taken bold steps to confront the housing crisis facing individuals with A/I/DD. Their initiative is uniting policymakers, nonprofits, businesses, and families, all committed to finding viable solutions to the housing shortage.

The reality is sobering, individuals are losing jobs to care for loved ones due to inconsistent supports, some on the brink of homelessness. A growing number of families have placed their children in foster care to get access to needed services, others have sent their loved ones to far-off facilities, and some have surrendered their children in emergency rooms out of sheer desperation. Currently, 249 children are in out-of-state placements at a staggering cost of \$1,000 per person, per day; while others endure long hospital stays—averaging 243 days—because safe discharge plans are increasingly difficult to secure.

This is a statewide issue, and we must come together to break the cycle of institutionalization and inadequate housing. The Build Up ROC Housing Initiative provides a pathway forward, exploring innovative housing solutions and advocating for increased funding to stabilize living environments for those with A/I/DD.

I stand with AutismUp in supporting this critical work and encourage others to do the same. Together, we can establish a Housing Task Force, bringing together families, providers, Monroe County leaders, New York State Legislators, and health and human services organizations to create lasting change. By working together, we can transform the current policy and infrastructure to ensure that every individual with unmet complex needs has access to safe, appropriate housing and services within their community. I am proud to join AutismUp and our local leaders in taking decisive action for our most vulnerable citizens.

Sincerely,


Adam J. Bello
Monroe County Executive

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“The human toll of the housing crisis must be quantified.

Group homes don't feel like

home when individuals are

stripped of choice. Imagine

being told where you can

live and who will share your

bedroom. I have family

members living this nightmare

who worry that the placement

they waited years to secure

could close. This crisis

continues to worsen.

Action is needed now.”

— Sarah Clark
Assembly Member



EXECUTIVE SUMMARY

Focusing on the supportive housing needs and preferences of New Yorkers with intellectual and developmental disabilities, we conducted a survey with the participation of 519 residents in Rochester. The data showed that:

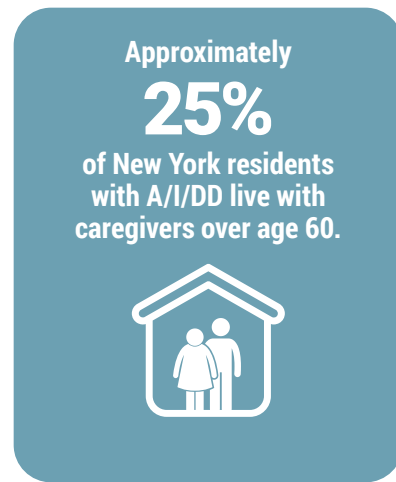
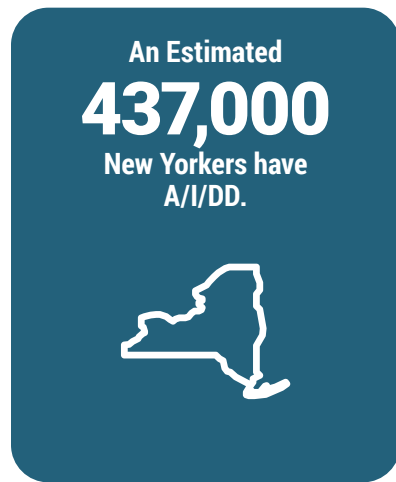
- 95% of them want to buy or rent their homes.
- 52% of survey respondents fear they would be forced to live in a group setting against their will.
- The majority face significant barriers to access affordable and supportive housing.

The clear-cut message that emerges from the data: Of over 400,000 people with **autism and/or intellectual/developmental disabilities (A/I/DD)**^{†,1}, less than a third of them are receiving long-term support services. More than 100,000 are living with parents over age 60, and most of them will outlive those parents. Also, with family caregivers aging, some may develop their own age-related disabilities or healthcare issues that may hinder them from caring for their adult dependents.

Housing is also unaffordable. According to the **National Low Income Housing Coalition**,²

[†]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.

¹This report uses person-first and identity-first language, recognizing that adults with A/I/DD 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 while recognizing that language is important and ever evolving. For more information: 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>



only 34 affordable housing units are available for every 100 extremely low-income households in New York state. Rising demand and limited housing inventory have increased housing costs, further complicating the landscape for individuals with A/I/DD. It is even more difficult to find affordable housing options that are accessible.

Due to limited housing and support options, adults with A/I/DD often live with family members out of necessity rather than choice. If adults with A/I/DD face a crisis, they have limited options and may end up in hastily made, nonpreferred residential placements to avoid homelessness. Such placements may potentially displace them from their communities into an institutional setting or other restrictive or unsuitable environment.

This crisis presents an opportunity for positive change. A century ago, it was common practice for parents to institutionalize children with disabilities. Fifty years ago, the closure of Willowbrook represented a significant turning point in this regard. While the legislation enacted since then has established a critical foundation, more work and advocacy can be done to fully include individuals with A/I/DD in every facet of the community.

The Supreme Court's *Olmstead v. L.C.* decision³ mandates states to provide support in home and community settings instead of institutions when the state's treatment professionals have

determined that community-based support is appropriate. Consequently, a pressing need persists to reimagine how adults and families in this population are supported. Proposals must focus on sustainable, long-term solutions to address their complex needs.

To offer data-driven recommendations to mitigate these potentially traumatic outcomes, the Rochester Housing Market Analysis (RHMA) explored the housing and services needs and preferences of adults with A/I/DD and/or their families/caregivers in Rochester, New York. Our goal is to expand available housing and community options. Recommendations included in this report attempt to ensure the creation of more affordable, supportive and community-integrated housing options for individuals with A/I/DD.

Data for this study was gathered through primary and secondary resources. A survey was administered in Rochester to adults with A/I/DD and their family members. The survey was sent to self-advocates, family members and various providers. Survey instructions required only one response per person with A/I/DD. Responses could be entered by an adult with A/I/DD or by a family member or caregiver/provider who would fill out the survey on behalf of the adult.

Data from the Office of People with Developmental Disabilities (OPWDD), the U.S. Department of Housing and Urban



Development (HUD), the Centers for Disease Control (CDC) and other research institutes were included as secondary sources to identify data gaps, including those in housing and services, for this population.

Key Findings

The following is a snapshot of key findings noted throughout the report:

- **Significant data gaps:** New York state does not track the number of adults with A/I/DD, making it difficult to plan housing and services. Based on prevalence data, this study estimates that approximately 64,400 individuals with A/I/DD reside in Monroe County; more than 16,000 of those individuals live with caregivers over age 60. Many individuals may face a crisis, including homelessness, if aging caregivers are no longer able to care for or house them.
- **Limited access to services:** As of June 2022, 126,925 individuals with A/I/DD received services through OPWDD. An estimated 437,000 New Yorkers have A/I/DD, but only 29% receive long-term services and supports (LTSS).

“There are no apartments for rent that I can afford, even with roommates. I worry I will have to live in my family home forever. Because OPWDD says I don’t qualify, I have no supports. Because no one is keeping track of me, I fear I could become homeless.”

— Survey respondent



- **De facto waitlists:** New York does not maintain a waitlist for those who are eligible for LTSS; however, de facto waitlists exist for services offered by OPWDD. Access is limited by inadequate funding and bureaucratic red tape. As a result, it typically takes years to receive residential placement services. Those with the highest support needs are the most difficult to place and find themselves with the longest wait times.
- **High support needs:** Only 68% of survey respondents with high support needs receive OPWDD services, highlighting the critical need for expanding such services.

- **Employment challenges:** Of respondents over age 18, 79% are not currently employed. Of those who work, only 34% earn more than \$900 a month.
- **Public benefits:** Few respondents receive public benefits outside of Medicaid. Only 49% of total respondents receive supplemental security income (SSI). Only 35% of total respondents receive support from the Supplemental Nutrition Assistance Program (SNAP), and only 24% of the total respondents receive Social Security disability insurance (SSDI).
- **Limited suitable housing:** Housing assistance through OPWDD is limited. Other subsidized or permanent, supportive housing models do not meet the specific needs of adults with A/I/DD. Many of these housing options target other vulnerable populations, including those experiencing homelessness, exiting incarceration, living with **serious mental illness**⁴ and/or domestic abuse, as well as veterans and/or seniors.

“Transportation is lacking, which makes people with IDD feel stuck at home with fewer chances to get out in the community.”

— Survey respondent

- **Housing cost burden:** OPWDD serves only 29% of individuals with A/I/DD. Consequently, some do not have access to crucial funding and resources enabling them to afford housing. With fair market rent in Rochester at \$1,050 for a one-bedroom apartment, only about 32% of respondents could afford rent with the help of family members or friends. If an individual is willing to have a roommate, 49% could afford a shared two-bedroom apartment. Even when considering the addition of family financial support, most respondents need subsidized housing or a housing choice voucher (HCV). Without housing assistance, they would be severely cost burdened.
- **Underutilized benefits:** Despite low income, few respondents live in subsidized housing units or units with rental assistance. Even fewer respondents utilize HCVs or energy assistance. Only 5% of those living in non-certified or **consumer-controlled settings** report living in a housing unit with rental assistance while 3% utilize HCVs.
- **Housing preferences:** Another key finding indicates that 84% of respondents note a preference to rent versus purchase a home, with strong preferences for physical amenities like easy-to-clean, smart-home and security features, as well as universal and sensory-friendly design. The top five preferred community amenities include proximity to grocery stores, restaurants and health clinics, as well as access to public transportation. Residents also prioritize walkable communities with access to walking and bike paths.
- **Community integration challenges:** Individuals with A/I/DD experience loneliness, with 79% reporting feeling disconnected from people outside their families due mainly to a lack of natural supports; 80% face barriers to engaging with their community, including feeling overwhelmed or the lack of transportation or activities of interest in their communities.
- **Reliance on family for transportation:** Surveys indicate that 78% of respondents rely on family members for transportation, underscoring the need for better public transit options.
- **Interest in independent living:** Finally, 69% of respondents want to live independently and 58% are interested in attending residential transition programs to help them attain this goal even if only possible through private pay.

Like anyone else, adults with A/I/DD want 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, know their neighbors, be regulars at their favorite local places of business and have a true sense of belonging. However, few affordable and supportive housing options are available to meet these needs and preferences.

Housing models for adults with A/I/DD must be adaptable to personal growth, because static approaches will not meet evolving needs. An array of options gives individuals the dignity of adjusting supports as their circumstances change.

“Our loved ones in traditional group homes don’t always feel welcome. It’s time to ditch the inhumane mindset and show respect by giving the disability community the same choices over their lives as everyone else. ‘We the People’ doesn’t really include them, so our fight for their basic human rights is the key to ending this crisis for the long term. No more band-aids.”

— Mother of a survey respondent



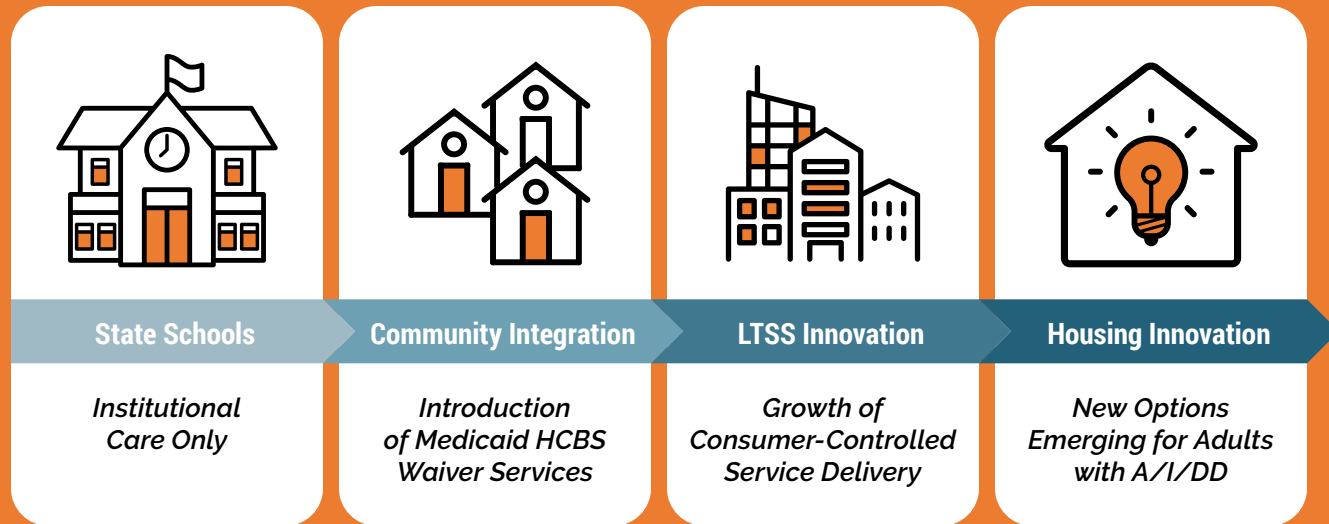
BACKGROUND

Data show that, in 2019, 7.39 million people were estimated to have been diagnosed with an intellectual and/or developmental disability (I/DD) in the United States.⁵ Approximately 19% received **Long-term services and supports (LTSS)**⁶ through state departments of developmental disabilities.⁵ Of those receiving LTSS, 973,205 were adults over age 21. Researchers and clinicians have demonstrated significant growth and positive improvements in the quality of life of individuals with A/I/DD who receive supportive services.⁷ The advent and subsequent evolution of Medicaid-funded LTSS programs is a driving force for providing access to these essential lifelong supports.^{8,9}

History & Evolution of Support Services

Medicaid home- and community-based services (HCBS) waiver programs¹⁰ are the largest LTSS funding sources for individuals with A/I/DD.¹¹ This has not always been the case. Medicaid began funding medical services for Americans in 1965.¹² At the time, a disproportionate percentage of Medicaid funding for people with disabilities was only available through institutions or nursing facilities. Unnecessary institutionalization significantly impacted children and adults with A/I/DD, who were often forced to separate from their families to live in institutions to receive services.

7.39 million people were estimated to have been diagnosed with an intellectual and/or developmental disability (I/DD) in the U.S.⁵



A notable example of such institutionalization was the Willowbrook State School on Staten Island in the state of New York. After years of public outcry and numerous lawsuits, Willowbrook closed in 1987. The horrors that occurred there reflected similar issues across the nation—overcrowding, underfunding and a failure to meet even the most basic needs of residents.¹³ The closure of Willowbrook marked a significant change in the approach to meeting the needs of individuals with developmental disabilities. Following this landmark event, legal reforms were enacted through statutes and case law. The term “Willowbrook Class” was also established to guarantee basic rights, treatment services, case management and advocacy for those affected.¹⁴

Through the Omnibus Budget Reconciliation Act of 1981, a new provision in Medicaid funding allowed individuals with A/I/DD and their families to “waive” the institutional entitlement and access services in their homes and communities.¹² In expanding Medicaid to provide services homes and communities, states had—and continue to have—considerable flexibility to structure Medicaid programs.⁹ The waivers allow states

to customize and expand coverage for those in need of long-term care.

HCBS is a federal/state partnership, with states and the federal government contributing costs through the **Centers for Medicare and Medicaid Services (CMS)**,¹⁵ matching the state’s dollars inclusive of HCBS. [The **Office of People with Developmental Disabilities (OPWDD)**¹⁶] offers Medicaid-funded HCBS waiver programs to provide LTSS in community-based settings. This is unlike **New York State Medicaid**,¹⁷ which provides healthcare for low-income adults within their communities.

Following the implementation of HCBS waivers in the 1980s, individuals with A/I/DD, their families and supporters began to advocate for more choice of and access to community-based services. On June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the **Americans with Disabilities Act (ADA)**.^{18,19} This decision provided a legal framework for the efforts of federal and state governments to integrate individuals with disabilities into their communities.

Medicaid Waiver: OPWDD in New York

The process for determining waiver eligibility requires documentation of a specific disability of **autism spectrum disorder (ASD)**,²⁰ cerebral palsy, epilepsy, **familial dysautonomia**,²¹ Prader-Willi syndrome or other neurological conditions that impair functioning.²² The person must also demonstrate that the diagnosis prohibits them from functioning independently or that, given their age, the development of functional skills related to daily living is significantly below expectations.

Some services offered by OPWDD include day habilitation, live-in caregiver, pre-vocational services, residential habilitation, respite, supported employment, community transition services, individual directed goods and services, **support brokerage**,²³ assistive technology/adaptive devices, community habilitation, environmental modifications (home accessibility), family education and training, intensive behavioral services and vehicle modification services.²⁴ The **Consumer-Directed Personal Assistance Program (CDPAP)**,²⁵ **respite care**,²⁶ residential services in **certified settings**,²⁷ long-term care health programs, **self-direction**²⁸ and other personalized care services may also be included.²⁹

In the 2024 Joint Legislative Budget Hearing testimony, OPWDD reported that almost 135,000 New Yorkers received LTSS.^{30,31} It is noteworthy that the number of people reported as receiving services varies among different sources. For example, the Residential Information Systems Project reported that the state provided LTSS to 124,427 in 2020.³⁰ This was significantly lower than the 138,862 served in pre-pandemic 2018. In its Medicaid Data Sheet, OPWDD reported that it served 117,934 people in 2018. By 2022, it had served 126,925.³² OPWDD had not previously recorded more than 127,000 served per year in its Data Book.

Whether the number of people served by OPWDD is 126,925 or 135,000, the number is still low compared to the estimated 437,000 individuals with A/I/DD who reside in the state. Due to the low number of people receiving LTSS, adults with A/I/DD in need of services may enroll in/qualify to receive healthcare services through Medicaid. However, services are not comprehensive enough to meet their daily or long-term needs.

The number of individuals with A/I/DD in New York who receive Medicaid but not LTSS is unclear. In total, 7.5 million New Yorkers are enrolled in Medicaid.³³ This number not only includes those receiving LTSS but also those enrolled due to low income. Of the total number of people enrolled in Medicaid, 57% are residents of New York City, while the rest of the state accounts for the remaining 43%. In Monroe County, approximately 215,200 people are enrolled in Medicaid.

The City of Rochester is in OPWDD Region 1.³⁴ Seventeen counties make up OPWDD’s Region 1, which is currently a combination of the Finger Lakes Region and Western New York (WNY). These counties include Allegany, Cattaraugus, Chautauqua, Chemung, Erie, Genesee, Livingston, Monroe, Niagara, Ontario, Orleans, Schuyler, Seneca, Steuben, Wayne, Wyoming and Yates. The total number of individuals served in this region was 23,661 in 2022.³⁵ The average payment per individual for LTSS in the region is \$57,533—\$157 less than the average payment in 2017. In Region 1, the average payment per individual in a supervised, certified residential setting is \$132,057.³⁵ On average,

OPWDD reported that almost 135,000 New Yorkers received LTSS.^{30,31}

care coordination was \$3,590 per individual while about 5,758 people utilized self-direction. The average cost for self-direction per setting in the region is not clear.

Implications of OPWDD Policies on Living Arrangements

OPWDD rates and average payments per setting show a bias toward certified settings, which receive more direct and indirect funding from inception.³⁶ Certified property cost reimbursement is based on prevailing market values. Certified housing is also exempt from local taxes and capital gains on property appreciation. Conversely, there is limited funding through OPWDD for **non-certified housing setting**.³⁶ The main funding comes through the Integrated Supportive

Housing (ISH) program and the OPWDD Housing Subsidy.^{37,38} Other noncertified settings have no cost subsidy and are taxed as regular homeowners.³⁶ When modifications are needed, public funding is often limited, leaving adults and/or their family members to bear the cost, sometimes due to limited funds or years-long wait times due to bureaucratic red tape.³⁹

Services for people in certified settings or **provider-controlled settings**⁴⁰ are also funded at higher rates than those in noncertified or **consumer-controlled settings**⁴⁰ with similar levels of need.³⁶ It is easier for providers to report and bill for services for people living in certified housing than for people using self-direction to live in independent housing.

People in both certified and noncertified settings face staffing shortages and may find it difficult to obtain services.⁴¹ However, staff working in certified settings are often guaranteed payment.³⁶ On the contrary, when support for a person to stay in their family home is limited, family members often must provide care without a guarantee of being paid caregivers.^{41,42} The average amount of respite per individual per year in Region 1 is \$9,155. This amounts to about \$760 per month.³² In general, family members may not be paid for providing support and may not have enough hours of in-home respite due to the low budget and high cost of maintaining quality staff.³⁶

The implicit bias for certified settings makes it difficult for adults with A/I/DD to choose where to live and receive adequate support, even if their choice is to remain in their family homes. Likewise, without adequate support for family caregivers, they may face financial, emotional and physical pressures, thereby negatively impacting their quality of life, employment and physical health.^{41,42,43}

Heightened Scrutiny Visit

In 2014, CMS released new regulations to ensure Medicaid-funded HCBS waiver programs provided person-centered support in noninstitutional settings. This required all states to submit an HCBS **statewide transition plan (STP)**⁴⁴ outlining 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. This protects individual autonomy to make choices and control the decisions in their lives, a right most people take for granted.⁴⁵

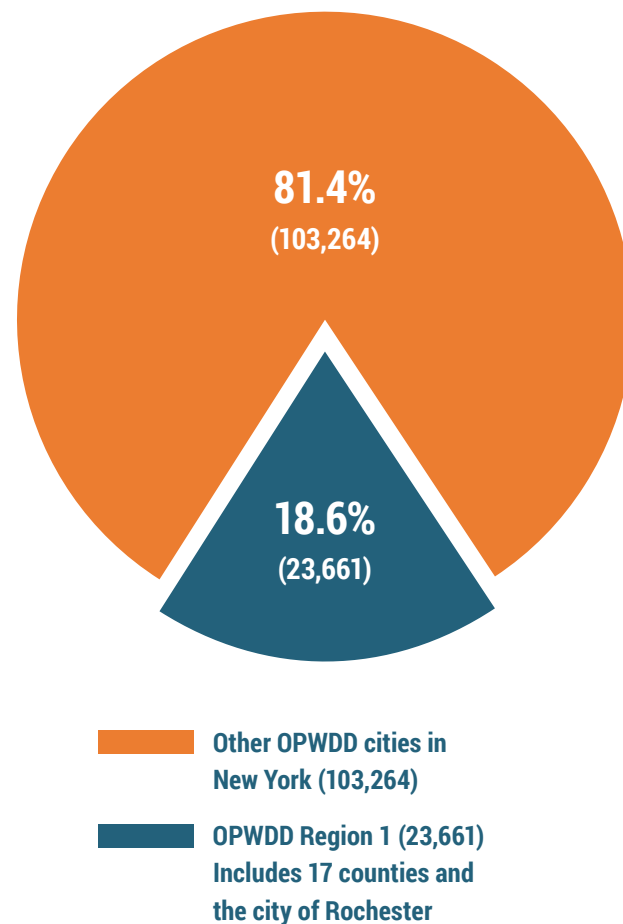
The OPWDD's toolkit for HCBS settings contains residential and day settings rules.⁴⁶ Some components of these rules are that all settings must:

- Be fully integrated into the broader community to the same degree as individuals who are not receiving HCBS.
- Be selected by the individual among options including nondisability-specific settings and an option for a private unit in a residential setting.
- Ensure individual rights of privacy and autonomy.
- Facilitate individual choice regarding services and supports and who provides them.
- Be a specific place that can be owned, rented or occupied under a legally enforceable agreement by the individual receiving services. The individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the jurisdiction's landlord/tenant law or equivalent.

- Be physically accessible.
- Offer each individual privacy in their sleeping or living unit.
- Allow individuals to have visitors of their choosing at any time.

In October 2023, CMS and the **Administration for Community Living (ACL)**⁴⁷ performed site visits⁴⁸ at residential or community locations providing HCBS identified by New York Department of Health (DOH) or stakeholders as having the qualities of an institution and requiring a **heightened scrutiny**⁴⁹ review

Received LTSS in New York



“Thousands of individuals are confined to institutional settings, a reality I personally experienced and fought to overcome. My current living situation is far from ideal; despite avoiding homelessness, I’m grappling with the pressures of an over-burdened system. It is more than just a roof over one’s head—we all deserve a sense of belonging and comfort.”

— Jensen Caraballo, Self-Advocate

to determine compliance with the HCBS settings criteria. These site visits are required to determine if the state is in compliance with CMS rules. The assessment included site visits to hospitals, congregate housing, adult care facilities and supportive housing where autonomy, independence and community integration may be less apparent.⁵⁰ These visits included sites from all agencies using HCBS in New York, including the Department of Health (DOH), OPWDD, Office of Mental Health (OMH) and Office of Addiction Services and Supports (OASAS).

The assessment concluded that the majority of individuals receiving Medicaid-funded HCBS are living in private homes, including their own, or sharing the homes of family members, friends or neighbors. Those who live in group homes or other settings were also assessed and several were identified as living in settings that were potentially institutional.

Across the state, the heightened scrutiny review found that:

1. There was no clear case management function outside of the settings where individuals receive services. There was no third-party planning, oversight and assurance of health and welfare for individuals receiving HCBS. Should a participant enrolled in the waiver program be discharged by a provider, there was no entity to assure the continuation of services through **person-centered planning**.⁵¹
2. Without a system of person-centered planning, there is no assurance that a choice of services, supports, providers or service settings is offered or that the person's preferences and goals are considered.

3. The programs overseen by the DOH are targeted to serve individuals between ages 24 and 65, focusing primarily on medical needs; these programs do not address the need for habilitation supports and individuals are not offered employment opportunities.

Across the site visits, CMS determined that the HCBS final settings rules were violated.⁵² To demonstrate compliance, the DOH submitted a **corrective action plan (CAP)**⁵³ indicating that extra time will be needed to ensure full provider compliance for integrating all people into the community.⁵⁴ This integration includes support in having full access to the community, engaging in community life and receiving services in the community. Another area in which HCBS providers needed additional support was more housing options for individuals served outside the family home, including nondisability-specific settings. More support was also needed to help optimize autonomy and independence of adults served while facilitating choices of services and supports and increasing the provider network in the state. The time for compliance was to be no later than November 2024.

The **settings rules**⁴⁹ provide a series of standards to which states operating Medicaid waivers must adhere. Though many individuals with A/I/DD may be eligible for Medicaid services based on income, many do not qualify for HCBS waivers or other Medicaid-funded LTSS due to eligibility criteria. Consequently, they may lack needed support and may not earn a living wage independently or be able to maintain housing due to cognitive impairments. Without other dedicated support staff or case managers to check in and assist when needed, the population of individuals with A/I/DD who are ineligible for Medicaid-funded LTSS are at greater risk of declining physical and mental health and could experience more negative social outcomes, including homelessness.⁵⁵

More work is needed to ensure that New Yorkers with A/I/DD have more opportunities to live in their communities and receive services. In particular, there is an increased need to expand service options to ensure more individuals with A/I/DD receive LTSS. For those already eligible for waiver services, an increased need exists for case management and person-centered planning to ensure those served have dignity, autonomy and independence to facilitate choice of services and housing. Considering these findings, the state should invest more

resources to expand LTSS and increase access to HCBS waivers to improve health and social outcomes of adults with A/I/DD.

Person-Centered Approaches

Access to healthcare was and continues to be limited for many individuals with A/I/DD.^{56,57} Multiple barriers range from provider shortages and lack of insurance coverage to stigma and inadequate care coordination or involvement of individuals



Aspects of Person-Centered Planning

with A/I/DD.⁵⁸ These challenges result in poorer health outcomes and a lower quality of life. Those who received services experienced dissatisfaction with the system.⁵⁶ Reasons for dissatisfaction included that people in need of care were not offered the opportunity to make their own healthcare decisions or collaborate in their own treatment.⁵⁹ One way to address these concerns was to shift to person-centered planning.

While varied in implementation, person-centered planning focuses language, values and actions on respecting the views of the person and their loved ones. This approach shifts from an illness and/or deficit focus to a strengths-based, person-centered one that considers the whole person and offers the opportunity to enter into a genuine partnership with the care system.⁶⁰ It involves a collaborative process between a person in need of care and everyone in the person's life whom they identify as supportive, including clinical practitioners and other mental health staff, as well as natural supporters (e.g., friends, family members, representatives from faith communities), the case manager and HCBS provider(s).

The aim of the planning process is to develop and implement an actionable plan to assist the person in achieving their unique personal goals. People can better learn about the options tailored to their needs and interests. Person-centered practices are present when people have the full benefit of community living and support designed to assist them as they work toward their desired life goals.

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. CMS requires that the state incorporate person-centered planning into the statewide transition plan.

Housing as a Social Determinant of Health

When considering the individual, it is difficult to separate a person's healthcare needs from their housing needs. Housing is a major social determinant of health.⁶¹ Grewal and colleagues (2024) found that stress about housing affordability negatively impacts mental health.⁶² People at risk of or currently experiencing homelessness had lower rates of healthcare screening and a lower likelihood of accessing preventive or primary care.⁶³ Several researchers have found correlations between housing and food insecurity, lower access to transportation and education, and housing displacement.^{61,63} Adults experiencing housing insecurity are more likely to use their limited income to fulfill basic needs (like housing) before more complex needs like seeking medical treatment before healthcare needs become urgent. This occurs even though, in the long term, healthcare costs may exceed immediate housing costs or income. As a result, adults experiencing housing insecurity are more likely to delay addressing healthcare needs until the condition requires emergency care, ultimately leading to higher morbidity and mortality rates.

It is worth noting that adults with A/I/DD are more likely to use emergency care due to various health conditions, as well as systemic, social and healthcare challenges.⁶⁴ However, utilization of emergency care could drastically increase without adequate support or housing. One study found that annual utilization of emergency departments was between 13% and 19% for youths with ASD who had HCBS waivers.⁶⁵ Among those without waivers, annual utilization of emergency departments was above 28%. Limited studies have been conducted to connect housing insecurity and the health of individuals with A/I/DD. However, Blaskowitz and colleagues (2019) noted that people living in **group homes**⁴⁰ were less likely to be hospitalized or contribute to high hospital utilization.⁶⁴ It is likely that



housing insecurity will further increase the use of emergency departments, resulting in worse health and social outcomes. In another study, Friedman (2021) found that of 251 people with I/DD, those with continuity and security in their lives and/or engaged in their communities have fewer emergency room visits and hospitalization rates regardless of diagnostic status or level of support needs/severity.⁶⁶

Finding and affording housing is difficult for individuals with A/I/DD. When they desire to move out of their family home or other living situation, they are more likely to face housing insecurity due to various physical and mental health challenges, as well as the systemic barriers explored further in this report. The Residential Information Systems Project (RISP) estimates that only 11% of the nation's 1.38 million people receiving LTSS live in their own homes.⁵ This means only 151,800 do not live with a family member and receive services in their own homes. In contrast, others receiving services live in family homes or in a variety of provider-controlled or certified settings like group homes, **host homes**⁴⁰ and **intermediate care facilities for individuals with intellectual**

disability (ICF/IID),⁶⁷ supported living or other residential settings. It is essential to develop a holistic approach to meet the housing and support needs of adults with A/I/DD.

Neuro-Inclusive Housing Framework

The Rochester Housing Market Analysis uses the **neuro-inclusive housing framework**⁶⁸ to assess the needs and preferences of individuals with A/I/DD. The neuro-inclusive housing framework comprises the consideration of the following three elements when exploring or creating residential options through person-centered planning that meets the needs of individuals with A/I/DD. These elements can be addressed through public, private and nonprofit collaborations:

- 1) **Housing:** Local planners and housing developers can use this report to become more aware of needs and preferences to plan for the inclusion of individuals with A/I/DD in existing or future developments. Housing with **sensory-friendly**⁶⁹ design, easy-to-clean features and other **cognitive accessibility**⁷⁰ features benefits residents with and without A/I/DD.
- 2) **Individualized LTSS:** LTSS providers can offer individualized services to help people in their own homes, as well as give them wider access to the community.⁷¹ This report provides insights into preferences and gaps.
- 3) **Supportive amenities:**⁴⁰ These amenities 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 tenants who are ineligible for HCBS or other LTSS to help them connect to their community and remain stably housed.

Lack of Affordability Leads to Limited Choice of Living Arrangements

According to the U.S. Department of Housing and Urban Development (HUD), over a third of U.S. households are cost burdened.⁷² HUD considers housing to be affordable if a person spends less than 30% of their income on housing. Households that spend more than 30% are considered cost burdened. This standard measure of determining housing affordability does not account for household spending costs.⁷³ Some of these costs could include food, transportation, healthcare, childcare, home insurance or HOA fees and other expenses. The Joint Center for Housing Studies of Harvard University noted that 62% of renters are cost burdened and find housing unaffordable.⁷³

Also, the cost burden is not limited to renters. Home prices nationwide have been soaring by 30% over the last four years.⁷⁴ The combination of high demand for housing and limited supply over the last decade has led to a drastic increase in home prices. Between the start of 2020 and early 2023, rent rose 23.9% while home prices rose 37.5%.⁷⁵

New York City has increased housing supply by almost 61,000 units since 2021.⁷⁶ Not every city has experienced such growth. In Rochester, more people are willing to buy homes than there are homes for sale.⁷⁷ The average home price in September 2024 was \$282,500, a 13% increase from the previous year.⁷⁸ Between 2019 and 2024, home prices in the city increased, with the median listing price per sq increasing by 42.6%.

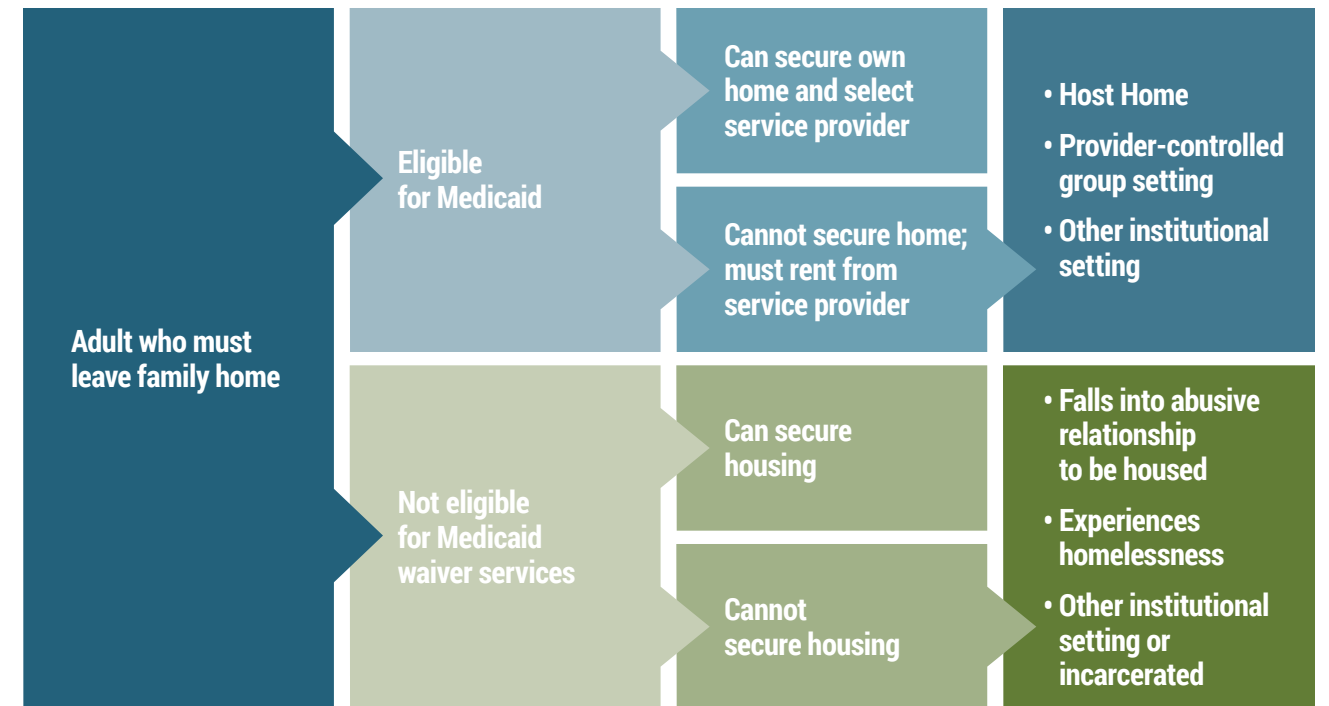
Only 34 housing units are available for every 100 households with extremely low income.⁷⁹ According to the 2023 Annual Homelessness Assessment Report, more than half the total number of people experiencing homelessness in the U.S. were in California, New York, Florida and Washington.⁸⁰ In New

York, the total number of people experiencing homelessness on a single night was 103,200. This number represents a 39.1% increase from 2022.

The **United States Interagency Council on Homelessness**⁸¹ states that one reason for the rise in homelessness is that the rise in rent outpaces the rise in wages across the nation.⁸² This phenomenon is especially true for Rochester, among the top five cities in the nation where rent growth is outpacing wage growth.⁸³ Between 2022 to 2023, median rent increased by 5.7%, outpacing the 3.2% wage increase. These increases do not include other factors like the increase in housing expenditures over the same period or food costs.

Another factor contributing to housing insecurity and cost burden is educational attainment.⁸⁴ Educational attainment can contribute to household earning potential and the ability to afford a home. In Rochester, while about 85% of the population have a high school degree or some college education, less than 30% have a bachelor's degree or higher.⁸⁵ Low educational attainment, coupled with the rise in unemployment from 3.5% in 2023 to 4.1% in 2024, has further worsened the housing affordability crisis.⁸⁶ With a median income of \$48,618, about 53% of the renter households are rent burdened.^{79,85,87} It is important to note that households with

80% of homes listed for sale in Rochester are significantly more expensive than what a household making \$50,000 or less can afford.



extremely low incomes inhabit approximately 41% of renter-occupied units in Rochester.⁸⁸

Homeowners are also cost burdened and experience housing affordability challenges.^{89,90} In April 2024, the National Association for Realtors stated that 80% of the homes listed for sale in Rochester are significantly more expensive than what a household making \$50,000 or less can afford. This severely limits housing options. Cost-burdened households are also more likely to live in substandard housing units with incomplete kitchens, plumbing, heating or air-conditioning or in overcrowded housing arrangements.⁷² These substandard housing conditions could be detrimental to health.

As rent and home prices soar, income for most adults with A/I/DD remains fixed. Most adults with A/I/DD are either unemployed or underemployed due to various socioeconomic, physical, mental health, cognitive or **executive function**⁹¹ challenges.⁹² As a result, they cannot afford housing through earned income alone. Those employed also fear that their income may disqualify them from eligibility for programs like Medicaid, **Supplemental Security Income (SSI)**,⁹³ SNAP,

etc. Recent national research indicates that approximately 30% to 40% of people experiencing homelessness have a cognitive impairment, including A/I/DD, and become homeless later in life, often due to the death of the family caregiver.⁹⁴

The flowchart above shows current housing choices for adults with A/I/DD.

It is worth noting that OPWDD has a supportive housing initiative, the Integrated Supportive Housing (ISH) program,³⁷ that couples affordable housing with supportive services. This program is called The ISH program encourages and supports the development of new housing opportunities for individuals with A/I/DD. Program support includes rental and supportive services for individuals or rental subsidies and capital funds for developers. Funding covers up to 25% of the total units available in the property. However, the success of the ISH program depends service variability, funding constraints and limited number of units. Different housing providers may offer different services. The difference in services offered may limit ISH housing options available to adults with A/I/DD. In general,

OPWDD Housing Subsidy Program Eligibility

- 1 Have or will have appropriate support services and safeguards to meet their needs in noncertified community housing as documented in their Life Plan.
- 2 Be able to live independently without receiving support services that exceed the individual's authorized service amount.
- 3 Apply annually for all eligible benefits (e.g., SSI/SSD, Section 8, food stamps) and not receive other housing subsidies.
- 4 Maintain sufficient financial resources for essentials after meeting housing costs.
- 5 Hold tenancy rights with a legally binding lease or deed that ensures equal rights and responsibilities as any other tenant without disability-specific restrictions and be legally and financially responsible for the housing unit.

the support offered in ISH housing units may not be comprehensive enough to support the complex needs of adults with A/I/DD.

It is not clear how many adults with A/I/DD live in ISH housing units.

Another supportive housing program in New York is the OPWDD Housing Subsidy Program.³⁸ This subsidy supports eligible individuals who choose to live independently in the community. Under this program, individuals control their own housing and housing-related decisions, including with whom they live. Individuals can choose to live alone, with others and/or with a live-in caregiver. Eligibility requires a person be at least age 18. See graphic at left.

Applicants for the Housing Subsidy cannot be added to an existing mortgage or deed or refinance the property to access an OPWDD Housing Subsidy. The maximum amount a person can receive under this program is \$1,250. This amount is determined by a number of factors, including number of bedrooms—not to exceed four—county of residence, individual income and offsets for utilities. Since 2013, the OPWDD Housing Subsidy Program has supported approximately 7,000 individuals to live independently.⁹⁵

The state requested proposals for more supportive housing units through the **Empire State Supportive Housing Initiative (ESSHI)**.⁹⁶ The state anticipates the development of 20,000 housing units over 15 years, with 1,400 units developed yearly. The term “units” under this program describes individuals versus housing units. The program supports those with serious mental illnesses, substance-use disorders, those experiencing chronic homelessness, those in need of housing post incarceration and individuals with A/I/DD. No capital funding is available through this program; operational funds are intended to meet the needs of these populations to maintain housing. The ability to access ESSHI



funds is based on the developer's ability to fully finance the developments. ESSHI funds can subsidize the cost of housing and supportive services by up to \$25,000 per qualified individual. Developers can secure capital funding through other public funds like the Low-Income Housing Tax Credits (LIHTC). This program also faces challenges similar to those of the ISH program, including service variability, inconsistent funding and a limited number of units.

When a crisis placement is necessary, a group home or host home is only available to those who qualify for HCBS waiver services. The ISH program and the OPWDD Housing Subsidy are only available to those eligible for OPWDD, while the ESSHI housing funds can be utilized by those eligible for Medicaid. Other state-funded housing programs, like the Section 8 **housing choice voucher (HCV)**⁴⁰ program, may be available but are difficult to navigate. These programs are also not specifically designed for adults with A/I/DD and may not encompass the level of support needed.

With rising costs of certified housing and increased demand for flexible housing options, OPWDD recognizes the need for more housing options for individuals with A/I/DD.⁹⁷ In 2022, OPWDD initiated a grant for providers to enhance Supportive Individual Residential Alternatives and Family Care. In 2023, 17 nonprofit service providers received these grants. OPWDD also initiated the Supportive Integrated Housing Pilot. Under this pilot, OPWDD allocates a portion of enhanced Federal Medical Assistance Percentage (FMAP) funding to increase access to affordable, noncertified housing for HCBS waiver participants, including those transitioning from certified settings. However, OPWDD serves less than 30% of New Yorkers with A/I/DD, for whom a wider range of funding for housing assistance is needed. These housing options should not be dependent on OPWDD eligibility because they exclude up to 70% of New Yorkers with A/I/DD who may need housing assistance and supportive housing but are not being served by OPWDD.

County	Population	Combined A/I/DD	Estimated to be living with a caregiver over age 60 (25%)
Monroe	752,035	64,374	16,093

Invisible Need

Individuals with A/I/DD have been largely excluded from the Rochester-area Community Health Needs Assessment (CHNA) conducted by the Monroe County Department of Health.⁹⁸ Their housing and healthcare needs remain largely unknown and unmet due to a lack of data.³⁸ This makes them an “invisible” population, particularly in the housing market.

Rochester is a city with urban-suburban areas with a population of 209,325, of which 29%, or about 60,000 people, live below the poverty line.^{85,99} A total of 402 housing vouchers are available from two programs: housing choice vouchers (HCV) and **non-elderly disabled (NED) vouchers**.^{100,101} These vouchers are not specifically set aside for adults with A/I/DD. Even if adults with A/I/DD can find an affordable housing unit or obtain a housing voucher, affordable housing units or units accessible with vouchers may not meet their supportive housing needs.

According to the City of Rochester **Consolidated Plan**¹⁰², the number of people living with a disability in the city has been increasing. In 2015, the estimated number of people with disabilities was 17.6% among those ages 18 to 64.¹⁰³ By 2021, this number had increased to 35.7%.⁹⁹ The city does not currently track the number of households of individuals with A/I/DD that are cost burdened. The housing needs of adults with A/I/DD are not specifically included in the city’s Consolidated Plan.

Prevalence of A/I/DD

Researchers across the nation estimate the prevalence of A/I/DD to better quantify the number of individuals living with the diagnosis in the country.^{104,105} One reason for estimating is that no census data is collected on individuals with A/I/DD. Data gaps for individuals with A/I/DD, especially those not enrolled in Medicaid, make it difficult to ascertain the number needing housing.

Based on national prevalence data, the estimates below reflect the number of individuals with A/I/DD in Monroe County. Nationally, about 8.56% of children have A/I/DD.¹⁰⁶ The prevalence of an ASD diagnosis is 3.05% of the nation’s population. According to the National Core Indicators, 25% of people with I/DD live with caregivers over age 55.^{107,108}

This estimate is crucial in determining the potential size of the population and how to meet their needs. Approximately 16,093 people living with family caregivers over age 60 are of urgent concern. As previously stated, the total number of individuals served by OPWDD in Region 1 is 23,661, representing only 37% of the estimated number of those with A/I/DD in Rochester. Rochester is just one city in Region 1. This estimate further highlights the need to expand LTSS and supportive housing for New Yorkers with A/I/DD. When family members can no longer offer due to economic circumstances, aging, health concerns or death, adult residents with A/I/DD in the city could be at risk of homelessness or other healthcare crises.

Additional Barriers Identified by Local Leaders

In addition to the cost of housing, individuals with A/I/DD face numerous barriers despite having access to housing assistance or their families’ ability to help them pay rent.



Systems for access to housing and services for adults with A/I/DD are disconnected and do not include cognitive accessibility features.¹⁰⁹ This population often has challenges with reading and writing, executive function, communication and/or social interactions. Such challenges can make navigating these complex systems necessary for access to 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. They may have difficulty understanding that they can and should apply to more than one housing authority for assistance.



A lack of stability of housing regulations and funding persists. Due to instability in regulations, there is no sustainable housing solution.^{109,110} Also, limited funding is available to develop and open new residential options for individuals with A/I/DD.¹¹¹ The waiting list for residential services continues to increase.



Adults with A/I/DD have extremely low income. They often have low educational attainment, rely on public benefits and have cognitive challenges that make full-time employment difficult.⁹² SSI and SSDI may have annual cost of living adjustments, but any increases are not enough to keep up with fluctuations in the rental market. They need access to housing that fits within a fixed-income budget to avoid eviction or loss of housing when housing costs rise rapidly due to inflation. Those employed may also need to locate housing near their employer—and finding a new employer may cause additional hardship.



Benefits cliffs exists for those employed. Benefits cliffs occur when an increase in wages results in benefits recipients surpassing the threshold for receiving benefits.¹¹² Adults with A/I/DD may be motivated to work more but fear losing benefits like Medicaid, SSI or SSDI because of increased wages. These public benefits are necessary as adults with A/I/DD may be unable to support themselves without additional help.



Lack of supportive amenities and adequate case management persist for individuals ineligible for LTSS. Individuals with A/I/DD who do not qualify for Medicaid waivers may 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 and social opportunities, conflict resolution, breaking down the steps in a task and/or creating a follow-through plan.



There is no state-funded housing navigation program for adults with A/I/DD. Some benefits of housing navigation include access to resources.¹⁰⁹ Navigators can help individuals identify and access housing programs, financial assistance and supportive services tailored to their complex needs. Secure housing can lead to improved health outcomes, reducing the risk of homelessness and associated physical and mental health issues because individuals can access healthcare more easily without the barriers of unstable living situations.¹¹³ Navigators can help individuals build social connections and reduce isolation by facilitating housing in supportive communities. The main state-funded housing navigation program is through the **emergency housing voucher (EV)** program.¹¹⁴ The EV program is for those who are homeless, at risk of homelessness, fleeing or attempting to flee, domestic violence, dating violence, sexual assault, stalking, or human trafficking, or were recently homeless or have a high risk of housing instability.



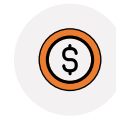
Avenues for housing navigation through OPWDD are limited.

Housing navigation services may be reimbursable through OPWDD.¹¹⁵ However, reimbursements are only possible if a person has a self-direction budget through OPWDD and bills housing navigation under the other than personal service (OTPS) category from their budget. The other way to include housing navigation services is if a person has community habilitation services and housing is included in their life plan. However, while housing navigation services are included, OTPS funding is insufficient to cover all other essential expenses. Maximum OTPS funds are \$3,000 per year. Other essential expenses that can be covered through OTPS include phone service, internet, software, utilities and personal transportation.



The OTPS budget line in self-direction is inadequate to cover future planning.

The current OTPS budget line in self-direction is overextended, leaving no funds for crucial future planning services like benefits navigation services. To better support individuals with A/I/DD, the budget line must be expanded to not only cover basic needs but also ensure resources for long-term supports and planning.



OPWDD funding does not keep up with the population's complex needs.

For example, per-member, per-month payment allocations keep up with neither the rising number of individuals with A/I/DD nor inflation, cost of living or wages of industries that compete with wages of support staff. The average Medicaid payment per individual for in 2022 was approximately \$150 less than in 2017.³⁵



Existing housing stock is often inaccessible.

For those who use wheelchairs, ADA-accessible units may be sufficient. However, individuals with A/I/DD have additional accessibility needs related to their cognitive differences. They 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**;¹¹⁶ technology to support executive function; 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 for self-regulating and/or self-stimulating functions that—without sound-insulating spaces—could disrupt neighbors and/or result in noise complaints.



Individuals with A/I/DD are at risk of being victims of predatory relationships.

Location and security features must be carefully considered because adults with A/I/DD have a significantly greater risk of being victims of assault and/or a serious violent crime than other persons with disabilities.¹¹⁷ 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.¹¹⁸

“Some of my friends might want to share an apartment with me, but even if we found one that was accessible and three of us chipped in, we wouldn't have enough money. I am working as many hours as I can but don't want to lose my benefits.”

— Self-Advocate

“ I knew this initiative would be a major undertaking—but data opens doors! With a sister on the spectrum and four kids with varying needs, I’m personally invested. While AutismUp doesn’t have immediate plans to build housing, we feel the urgency to act and reassure the 4,000+ families we serve. The next steps are crucial.”

— Heather Burroughs, Advocacy & Education Director
AutismUp



HOUSING MARKET ANALYSIS



Educational Outreach

Most individuals with A/I/DD and their families have not explored options for life beyond the family home. To ensure that respondents were aware of various options, they 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,⁴⁹ participants were able to learn about a broad range of choices. While some options presented during the learning session may not currently be available in New York, it was essential to include them so participants could express their needs and preferences—and help effect changes in the market, including housing and healthcare systems.

WEB OUTREACH
 Invitation sent to 20+ organizations



Expanded presentation and survey, plain-language presentation and survey

LEARNING
 Multiple live virtual presentations with Q&A



Recordings on website and promoted through collaboration with other organizations

WATCH PARTIES
 15+ in-person



Targeted at individuals with A/I/DD and their families

Learning sessions included live virtual training with time for a Q&A. AutismUp also hosted more than 15 watch parties bringing participants together in person to watch the recorded learning session with a subsequent live Q&A. The recording of the learning session was also posted on the AutismUp website for those unable to attend the live events. More than 20 community-based organizations were contacted to promote and facilitate this study.

Plain-language materials were created to ensure cognitive accessibility. 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, thereby facilitating data collection on the needs and preferences of individuals 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 that included examples of housing types and features. Benefits and considerations of the various elements of residential options were discussed to promote person-centered, meaningful choices. Individuals attending live sessions and watch parties could ask questions during and after the presentation.

Participants then completed the Rochester 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, consolidated and housing plans, along with 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.

Local Leaders

Local leaders were invited to participate in a three-hour Local Leaders Organizations and individuals comprised county officials, leaders in low-income housing developments and other representatives from community-based organizations and foundations. 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. Discussion and suggestions are highlighted throughout this report and in the Recommendations section. More than 60 people attended the workshop.

BUILD UP ROC

UNLOCKING POSSIBILITIES TOGETHER



Considerations and Limitations of the Process

- **Survey 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.
- **Educational presentations and videos:** Respondents watched a 45-minute presentation to help them understand options for services and housing included in the survey. The presentation introduced and explained housing and service options using visuals, verbal descriptions and videos. It also included examples of property types, service options and other supportive amenities.
- **Data outreach:** Electronic tablets were provided to encourage participation. The survey collection time was extended by one week to increase the number of responding self-advocates.

To ensure adequate data, only the expanded needs and preferences survey was emphasized. Respondents, self-advocates and

family members were given a survey guide to answer each survey question.

Lastly, local organizations that collaborated on this study worked largely with individuals already receiving OPWDD services. Because many who responded to this survey were HCBS waiver recipients, the percentage of people on waiver services may not be representative of the population in Rochester or even New York currently eligible for or receiving services.

- **Data translation:** Due to limited exposure to specific service delivery models and development types currently unavailable or underutilized in New York, demand data on preferences may shift if recommendations are implemented and choices expanded.
- **Diversity of participants:** About 80% of respondents identify as White or Caucasian, with 10% identifying as Black or African American. Other ethnicities and/or their families were underrepresented in the data.

“ I used to feel bitter that my child’s need for constant care kept me home, away from moments others take for granted. Caring for my daughter is a privilege, but the toll of strained systems and broken promises has worn me down. NYS needs to act so we can stop languishing on waitlists, feeling forgotten—or worse, like we don’t matter. No family should have to live this way.”

— Survey Respondent



DEMOGRAPHICS

Unless otherwise noted, demographic data in this section are compiled from the 2024 Rochester 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.

A total of 519 people responded to the survey. Of those respondents, 72% were family members who responded on behalf of their adult/or child dependent with A/I/DD; 17% of respondents were self-advocates, while 10% were support coordinators, non-family caregivers or service providers who responded on behalf of their clients. For this study, the term respondent is used to represent individuals with A/I/DD regardless of whether they responded by themselves or the responses were input by family members or providers/caregivers. The results will also be segmented to show how self-advocates responded.

Respondents self-identified disabilities with which they had been diagnosed: 95% of respondents self-identified as having autism or intellectual/developmental disability; 79% self-identified as having more than one disability, signaling they have one or more co-occurring physical or mental health conditions.

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 could help clarify potential barriers to independent living.

The disabilities I identify with include:	
Autism	71%
Anxiety	44%
Intellectual Disability	41%
Depression	20%
Obsessive-Compulsive Disorder (OCD)	18%
Epilepsy or Other Seizure Condition	16%
Other Developmental Disability	12%
Other Mental Health Challenges	11%
Asperger's	8%
Cerebral Palsy	7%
Other Disability Not Specified	7%
Down Syndrome	7%
Physical Disability & Use a Mobility Device	7%
Blind and/or Visual Impaired	5%
Bipolar Disorder	5%
Deaf or Hard of Hearing	3%
Traumatic Brain Injury	2%
I'd rather not disclose.	1%
Prader-Willi Syndrome	1%

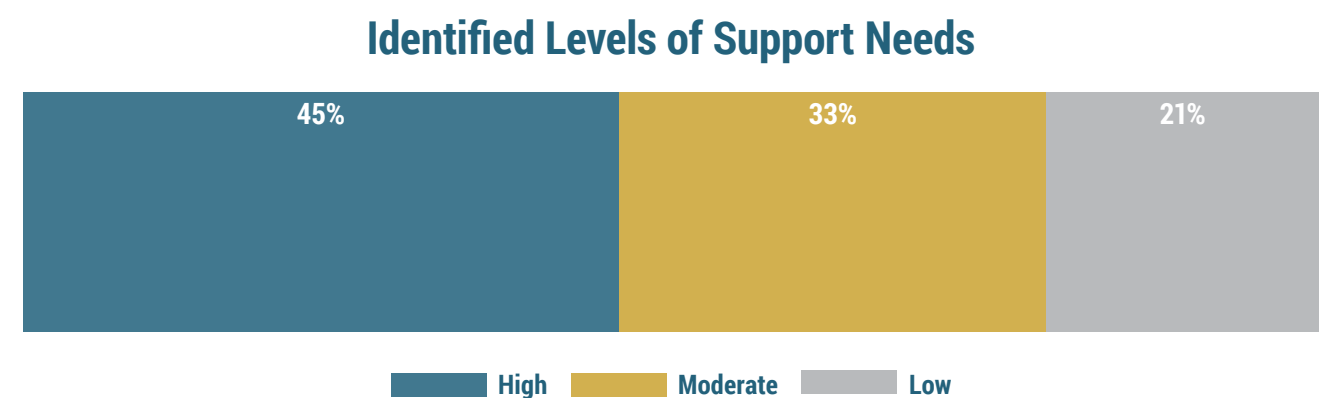
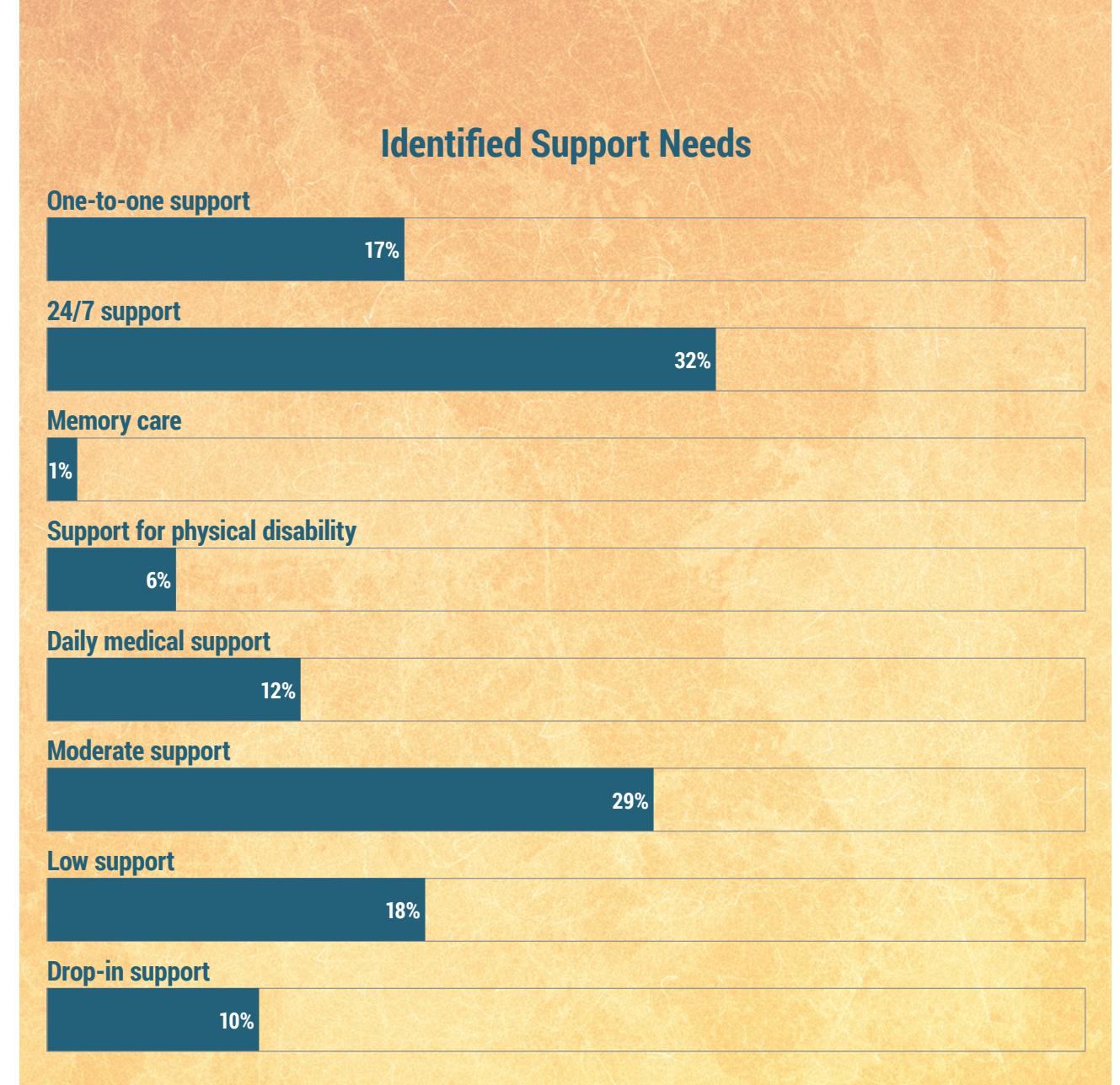
*Does not total 100% because respondents could choose more than one answer.

Survey respondents could self-select one or more disabilities with which they identify; 79% of survey respondents indicated they had multiple diagnoses, such as autism and a co-occurring ID or physical or mental health challenges, such as anxiety, depression and obsessive-compulsive disorder (OCD). Given the prevalence of co-occurring diagnoses, 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 an autism-friendly, cognitive format. Finding a provider that takes one's insurance and understands the **neurodivergent**⁴⁰ population, as well as the executive function needed for scheduling an appointment and accessing reliable transportation, is just one example of barriers to quality mental healthcare for individuals with A/I/DD.

Identified Support Needs

Respondents were asked to identify their level of support. The charts at right shows their responses.

Data on the level of support needs indicate the number of direct-support hours a person may need to live in their own home and participate in the community and/or the complexity of support. Individuals with A/I/DD have a wide range of support needs. The data was later grouped to show the number of people with high, moderate or low support needs. High support needs included individuals with 1:1 support, 24/7 support and those in need of memory care. Moderate support needs included individuals with physical disability in need of daily medical support or those who identified as having moderate support. The final group were those with low and drop-in support needs.





Support Needs⁴⁰

Moderate Support

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

One-to-One Support

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

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.

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.

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.

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.

Low Support

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

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.

Where and With Whom Respondents Live

Respondents were asked where and with whom they live. The chart below shows the distribution of responses.

A total of 76% of respondents identify as living with family caregivers; of that total, only 32% are under age 18. The majority

Age of family caregiver (of those respondents indicating they live with a family caregiver)

18-30	1%
31-45	13%
46-60	57%
61-75	25%
76+	2%
Undisclosed	3%



60%
Family home



16%
With family but at risk of inconvenience



7%
Own home alone



6%
Group home



2%
Own home with friends who choose not to provide support



1%
Own home with a non-family caregiver

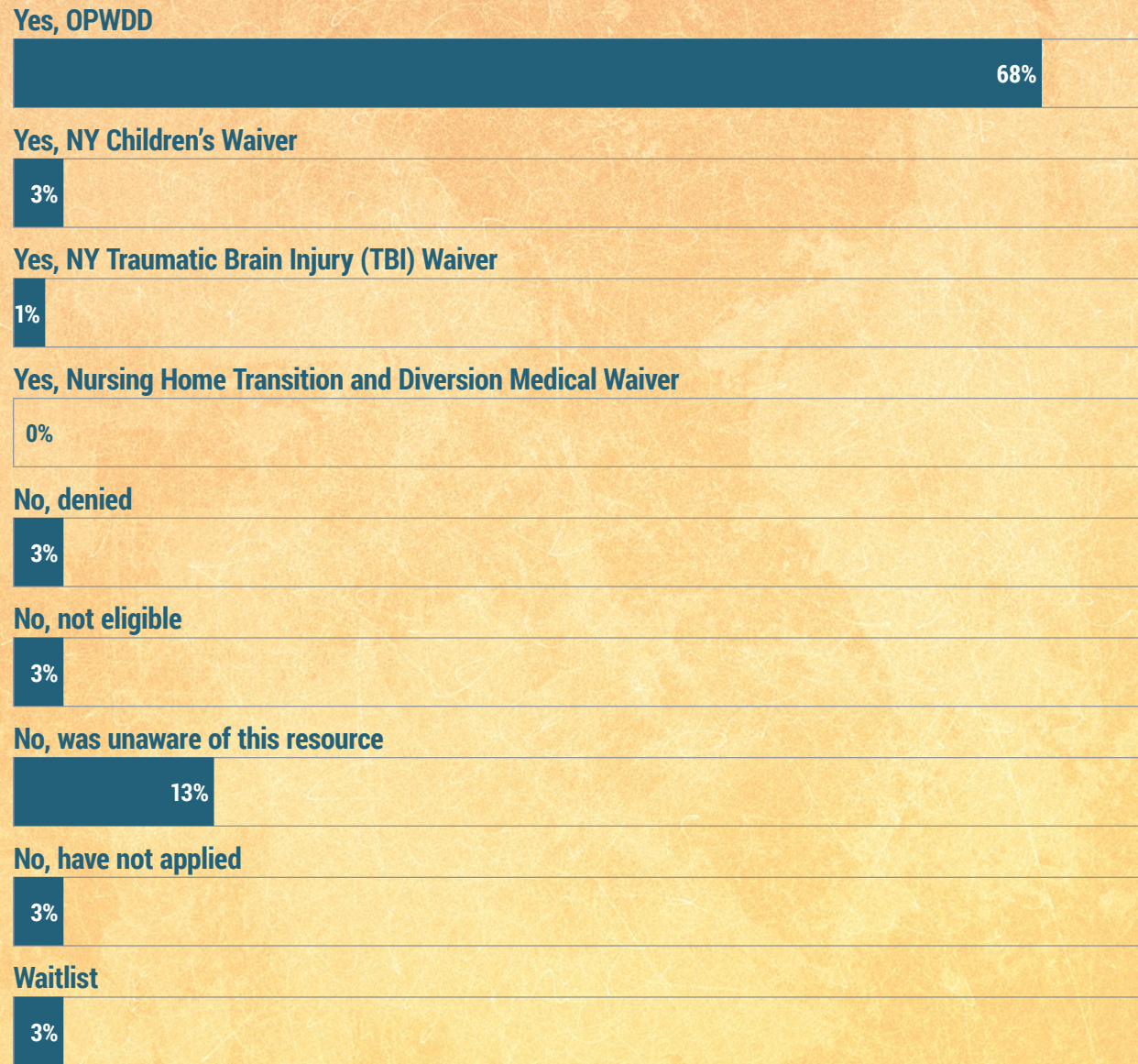


1%
In a temporary setting

Where do you currently live?

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

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



“ Even with OPWDD eligibility, we’re caught in a roller coaster of endless paperwork and disappointments. We’ve jumped through every hoop, yet we remain trapped in an underfunded system, waiting for help, wondering if it will ever come. When I can no longer hold everything together, it’s my child who will suffer. It is heartbreaking and disgraceful.” — Survey Respondent

of those living with family members are between ages 19 and 34. This data is in line with other studies showing that the majority of those with A/I/DD live with family. Among those living with family, 27% state that their family caregivers are over age 60.

Utilization of HCBS Services

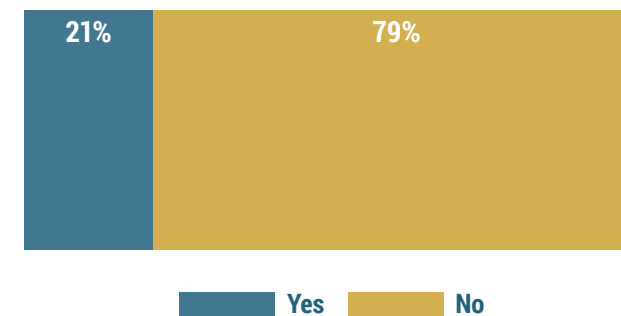
In addition to support needs, recipients were asked if they receive LTSS through HCBS waivers serving individuals with A/I/DD. There are four waiver services for New Yorkers with A/I/DD: children's waiver, nursing home transition and diversion waiver, NY Office for People with Developmental Disabilities (OPWDD) and the traumatic brain injury waiver. The main waiver service is through OPWDD; to be eligible, an individual must:

- have a diagnosis of a developmental disability
- be eligible for the intermediate care facilities for individuals with intellectual disabilities (ICF/IID) level of care.
- be Medicaid eligible.
- have chosen HCBS waiver services over institutional care.

Although a person might meet the criteria for receiving waiver services, those services are not guaranteed.¹¹⁹ The state of New York does not currently maintain a waitlist for services.¹²⁰ However, this does not mean that people are able to receive services as soon as they are determined eligible. Many services have de facto waitlists that could take months or years. For example, one article estimated that it takes eight years for individuals with A/I/DD to be placed in certified housing settings.¹²¹

The chart to the left shows the distribution of those receiving waiver services in New York.

Do you work or volunteer?



Earned Income and Government Benefits

The table below shows the respondents earned income. Respondents were asked if they work or volunteer. Those who work were given the option to select their monthly earned income.

Of the respondents over age 18, 79% are not currently unemployed. Of those who work, only 34% earn over \$900 a month, as shown in the chart below.

Monthly Earned Income of the 21% Who Work	
\$0-\$299	24%
\$300-\$600	25%
\$601-\$900	14%
\$901-\$1,200	13%
\$1,201-\$1,500	6%
\$1,501-\$2,000	5%
\$2,001+	9%
Work but do not know income	4%

According to HUD, for a household of one person, the very low and extremely low-income limits for Rochester residents are \$33,950 and \$20,400 per year, respectively.¹²² As shown below, survey respondent earned income indicates that adults with A/I/DD are extremely low income, largely falling below 30% of the **area median income (AMI)**.¹²³ With fair market rent in the city of Rochester at \$1,050 for a one-bedroom apartment and \$1,307 for a two-bedroom apartment,¹²⁴ less than 7% of total respondents would be able to pay the base monthly market rent even if all monthly income went to rent. They would be severely cost burdened and unable to afford other primary needs like food and clothing.

The use of federal Medicaid waiver dollars to fund room and board for those who use waiver-funded services is prohibited.¹²⁵ 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 Insurance (SSDI)**¹²⁶ and/or Supplemental Security Income (SSI). Using SSI or other fixed income toward housing still leaves very little for other household or primary expenses.

In 2024, the maximum SSI a recipient can receive is \$943. New York also has the New York State Supplement Program (NYSSP), which adds an additional \$87 for a maximum of \$1,030 for an individual living alone.¹²⁷ For those living with others, the New York State Supplement Program (NYSSP) maximum is \$23. If a person starts work and receives a paycheck, benefits decrease to a 2:1 ratio, as illustrated in the chart below. If an individual receives financial support to cover housing costs, their SSI benefit may be reduced by one-third.

Those with A/I/DD who are employed often work less than 20 hours per week.¹²⁸ Even when working and receiving federal assistance, housing costs for Rochester residents are out of reach for most adults

with A/I/DD. To better illustrate the housing affordability challenge, the chart below includes sample income and SSI benefits for an adult living alone based on typical jobs and weekly schedules.

Explanation of table: The column titled "Total monthly income" is calculated as the total monthly earned income from a job a person might have plus the deduction of SSI due to earned income.^{129,0} The percentage of earned income spent on housing is the amount of rent as determined by the National Low Income Housing Coalition divided by the total monthly income calculated in the second column.

Source of Income	Total Monthly Income	% of income needed to afford market rate rent of 1-bedroom (\$1,050) ¹²⁴
2024 Maximum SSI Benefit	\$1,030	102%
Average SSI adult child survivor benefits ¹³⁰	\$1,067	98%
8 hours/week at minimum wage (\$15/hr.) ¹²⁴ plus SSI	\$1,313	80%
16 hours/week as fast-food worker (\$16.90/hr.) ¹²⁴ plus SSI	\$1,613.30	65%
24 hours/week as stocker/order filler (\$18.43/hr.) ¹²⁴ plus SSI	\$1,957.18	54%

⁰ Calculations: ((Gross Monthly Wages before taxes) - \$85 (general and earned income exclusion)) divided by 2 = Countable Earned Income. SSI Federal Benefit Rate - Countable Earned Income = Reduced SSI Benefit Due to Earned Income. Reduced SSI Benefit Due to Earned Income + Gross Monthly Wages before taxes = Total Gross Monthly Budget amount.

According to this chart, individuals with A/I/DD who rely on SSI would be unable to afford rent. Even if they chose to share a two-bedroom apartment, they would still be severely cost burdened with the added potential of negative effects on their health. Likewise, if a person works as a stocker/order filler for 24 hours per week and receives SSI, the person's total monthly income would be \$1,957. The person would be cost burdened if they live alone.

Other public benefits programs are available to households with very low and extremely low incomes. These programs include **SNAP**¹³¹ for food assistance and **Home Energy Assistance Program (HEAP)**¹³² to help cover increased energy costs and housing choice vouchers, which provide permanent rental subsidies. Although they would be income qualified, few respondents utilize these benefits.

The chart at right reflects the distribution of survey respondents utilizing public benefits.

Given that the majority of the respondents have very low or extremely low incomes, more respondents could be utilizing benefits like SNAP, housing choice vouchers or **Lifeline**.¹³³

One reason for low enrollment may be that 76% of respondents live at home with family caregivers. Living with others may drive up household income, which may make a person with A/I/DD ineligible for benefits HEAP. Securing a housing choice voucher is difficult.¹³⁴ Voucher waitlists are open for regular project-based vouchers for short periods only—and waitlists are often open for less than a day. Even if an adult with A/I/DD can get on a waitlist and secure a housing choice voucher, limited availability of affordable housing units might prevent them from utilizing the vouchers.¹³⁵ Given the low income of adults with A/I/DD, most will need public benefits, housing assistance or affordable housing units.

"OPWDD doesn't think I qualify, but I don't know who else could help me. I want to have enough income and life skills to move out of my family home soon."

— Survey Respondent

Public benefits or assistance utilized by survey respondents	
Medicaid	75%
SSI	49%
SNAP (food assistance)	35%
SSDI	24%
Medicare	18%
Not currently enrolled	11%
HEAP	8%
Unit with rental assistance	5%
Lifeline	4%
Housing choice voucher	3%

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

Maximum housing cost a family member or friend is willing and able to help you cover	Nothing	\$300 or less	\$450 or less	\$600 or less	\$800 or less	\$1,100 or less	\$1,500 or less	\$2,000 or less	Unsure
		9%	42%	8%	6%	5%	6%	2%	4%

Maximum housing cost you can afford to pay	Nothing	\$300 or less	\$450 or less	\$600 or less	\$800 or less	\$1,100 or less	\$1,500 or less	\$2,000 or less	Unsure
		0%	38%	11%	13%	13%	8%	3%	0%

Potential of Family Investment in Housing Stability

Since most adults with A/I/DD do not earn enough income to afford housing costs, two subsequent questions were posed to determine whether family members or friends would be able to support respondents in affording housing. See chart above.

The first question addresses the maximum housing cost respondents could pay without additional financial help from family or friends.

Approximately 75% of respondents can pay only \$800 or less; almost 50% of respondents can pay only \$450 or less.

The second question addressed the maximum assistance families could offer to cover their loved one's monthly housing costs.

About 61% of respondents state that family members could assist with at most \$800 a month.

In sum, with fair market rent at \$1,050 for a one-bedroom, \$1,307 for a two-bedroom and \$1,580 for a 3-bedroom, only about 32% of total respondents could afford a one-bedroom apartment with help from family or friends. If an individual is willing to have a roommate,

49% could afford a shared two-bedroom, while 72% could afford a shared three-bedroom apartment.

The parameter for exclusion was set at adding the maximum rent respondents can pay

“Future planning for residential options depends on an adequate number of support professionals who are well qualified and trained to meet the varied support needs of people with A/I/DD. This will require an advocacy component to which families and self-advocates are willing to commit.”

— Survey Respondent

Maximum housing cost you can afford to pay	Maximum housing cost a family member or friend is willing and able to help you cover								
	\$300 or less	\$450 or less	\$600 or less	\$800 or less	\$1,100 or less	\$1,500 or less	\$2,000 or less	\$3,500 or less	\$3,500 or more
\$300 or less	128	10	6	6	4	3	0	1	3
\$450 or less	27	13	4	1	3	0	0	0	2
\$600 or less	34	11	10	4	3	0	0	0	2
\$800 or less	25	7	5	9	6	4	1	0	1
\$1,100 or less	15	2	5	3	8	1	0	0	0
\$1,500 or less	1	1	0	2	4	2	3	0	1
\$2,000 or less	0	0	0	0	1	0	2	0	0
\$3,500 or less	0	0	0	0	0	1	0	0	0
\$3,500 or more	0	0	0	0	0	0	0	0	4

The numbers in the chart above represent responses from a total of 519 survey respondents.

and the maximum amount of housing costs the family can cover as shown in the table above. The total could not be below \$550, the minimum needed to afford a three-bedroom apartment with roommates.

Even when considering the addition of family financial support, most respondents need subsidized housing or a housing choice voucher to afford housing. This is because family members may also have their own household costs and personal and/or healthcare or emergency expenses that could prevent them from providing consistent monthly assistance. Individuals with A/I/DD with aging parents may also be unable to receive housing assistance in the long term because parents may retire or incur additional costs due to their age-related healthcare needs, which may prevent them from supporting their loved ones financially.

“There are no group homes that can help with my respiratory needs that can take me, so I am forced to live hours away from my family in a hospital-like setting.”

— Self-Advocate

Planning for the Future

The table below shows the distribution of respondents who have done future planning.

Not all families can help their loved ones with such costs. However, given the estimated 19,500 people with A/I/DD living with caregivers over age 60 in Richland and Lexington counties combined, plans must be in place before aging family caregivers relinquish care. These plans could be in the form of a **special needs trust**¹³⁶ that could pay for housing and healthcare needs or an **Achieving a Better Life Experience (ABLE) account**¹³⁷ that might enable adult dependents to purchase a home without the additional funds affecting the person's benefits.

The survey finds that 47% of respondents have not engaged in any type of future planning. Some do not have the extra income. Consequently, adult dependents could be at risk of homelessness when and if their family members are unable to provide care.

Have you or your family done any future planning?	
Yes, I have a special needs trust.	33%
Yes, we have met with a special needs lawyer.	19%
Yes, I opened up an ABLE account.	12%
Yes, I am part of a pooled special needs trust.	3%
No	27%
No, we do not have extra income to do this.	27%

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

Challenges Faced by Those with Higher Support Needs

Individuals with high or complex needs often face systemic barriers to accessing healthcare.¹³⁸ Community healthcare or mental health systems may not be sufficiently equipped to serve those with autism and a co-occurring mental health issue. Service delivery, diagnosis and mental health support may be severely lacking as primary care providers may not be knowledgeable about the healthcare needs of individuals with A/I/DD.^{138,139}

Additionally, people with high support needs are still more likely to live in highly institutionalized environments.^{42,140,141} These settings offer little to no opportunities for self-determination, person-centered planning and/or community engagement. This may be partly due to the perception that the inclusion of people with higher or more complex needs is difficult to achieve or very costly.^{42,142} Esteban and colleagues (2017) found that individuals with I/DD and high support needs who live in institutional settings have little or no opportunities to make friends.¹⁴⁰ They also find it difficult to keep in touch with their relatives or engage in their community.

Inclusion in the community of those who require more support improves their adaptive behavior, self-determination and quality of life.¹⁴³ McCarron and colleagues (2019) and Esteban and colleagues (2024) found that people with I/DD who have high support needs benefited more from the transition to community living than their peers with a disability but less intensive needs.^{143,144} There were significant improvements in decision-making, community engagement and quality of life, as well as reduced occurrences of maladaptive behaviors. If those behaviors occurred, they were less severe.

In this study, those with high support needs self-identify by indicating their needed level of support, including 24/7 support, one-on-one support or high behavioral support needs. Of the 519 respondents, 235 have high support needs. Of those with high support needs, 79% live at home with family caregivers, similar to the total number of people in this survey who live with family.

Data showed that 75% are on waivers. This high percentage is likely due to the fact that most of the outreach was done in collaboration with organizations serving people already receiving waivers. However, despite high support needs, the remaining 25% are not receiving waivers. When respondents were asked if they work or volunteer, 91% responded no. Regarding other public benefits, only 51% of respondents with high support needs receive SSI, as shown in the chart below.

Where do you live? (High support needs)	
Family home	62%
With family but at risk of homelessness	17%
Group home	9%
Own home alone	4%
Own home with a non-family caregiver	3%
In a temporary setting	2%
Own home with friends who do/do not provide support	2%
Currently experiencing homelessness	1%
Host home	0%

"I am scared that I will have no one to help me since I need 24/7 assistance."

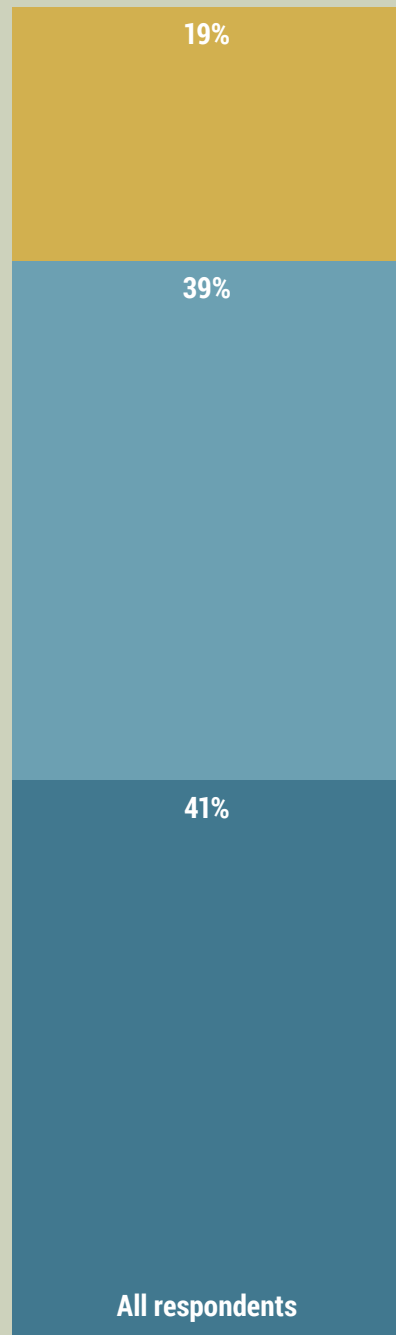
— Survey Respondent

Individuals with I/DD, especially those with more complex needs, still have limited input in making decisions regarding who will provide support and how.¹⁴² This is in addition to limited housing options for those with complex needs. More advocacy and funding are needed to increase housing options for individuals with A/I/DD with high support needs. These housing options must include adequate supportive services that prioritize person-centered planning, self-determination and community engagement.

Public benefits or assistance utilized by survey respondents	
SSI	51%
SNAP (food assistance)	36%
SSDI	26%
Not currently enrolled	7%
HEAP	7%
Lifeline	4%
Unit with rental assistance	3%
Housing choice voucher	2%

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

Do you engage in social activities in your community?



■ Yes, I enjoy activities
■ Sometimes
■ No

Community Engagement and Challenges

BARRIERS TO COMMUNITY ENGAGEMENT

The charts show whether participants engage in social activities and their barriers to engagement.

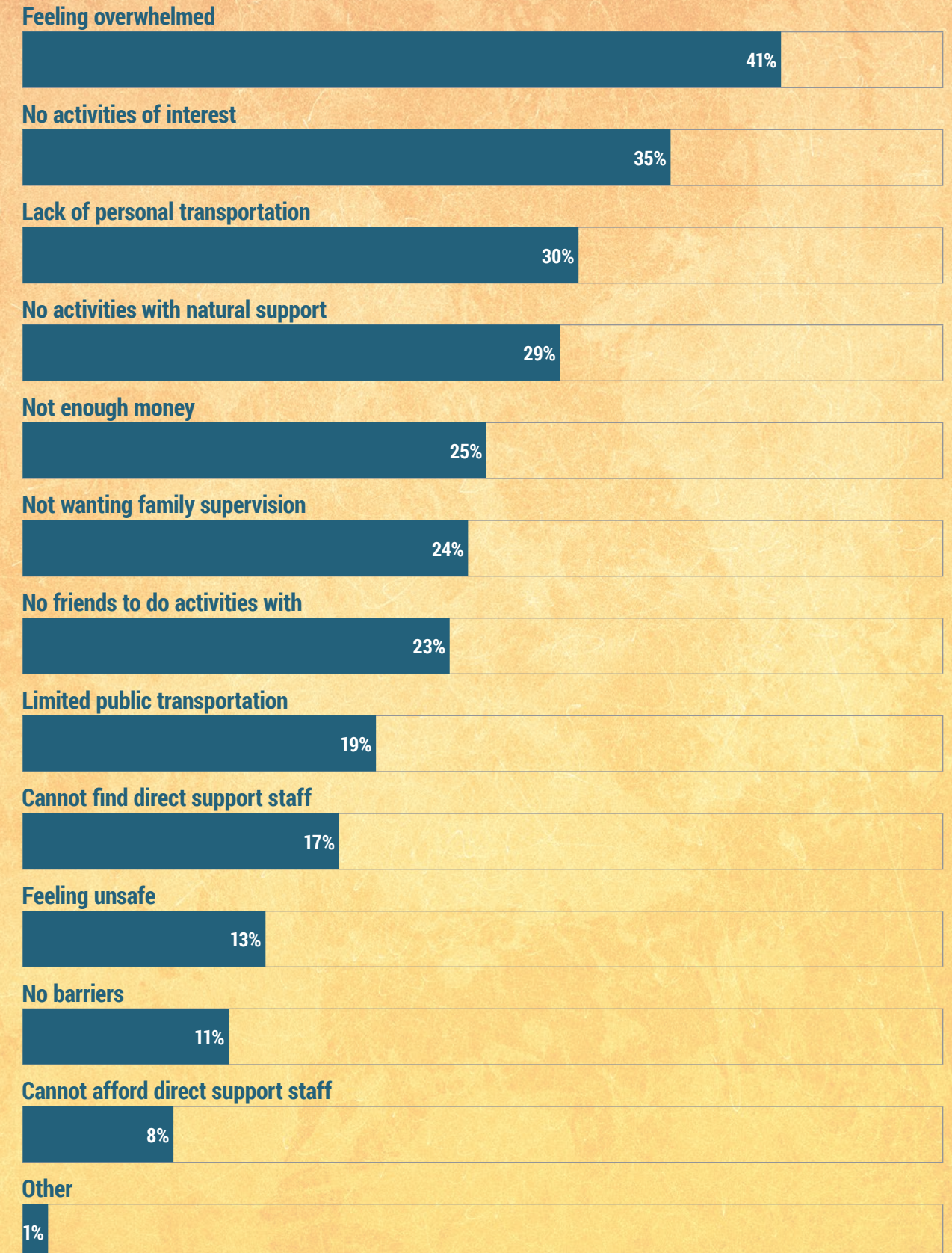
The distribution indicates 41% responded that they engage in their communities, while 39% mentioned that they do but only sometimes. Of respondents who engage to some degree, 88% said they are satisfied with their community engagement. Of total respondents, 19% expressed a lack of engagement. When asked about the barriers respondents faced in community engagement, the most prominent barrier is feeling overwhelmed.

TRANSPORTATION

Access to transportation plays a key role in people's lives, from commutes to work, school, restaurants and healthcare appointments to visiting family and friends. Lack of access to transportation has been linked to increased feelings of isolation and loneliness, diminished health, stress, obesity and other negative outcomes that can exacerbate other physical or mental health conditions.^{145,146} One study found that 3.6 million people delayed or avoided care every year due to lack of transportation, with approximately 25% of people missing appointments nationally.¹⁴⁷

Lack of transportation for those with A/I/DD also poses a unique challenge necessitating anticipating transportation-related social tasks such as asking drivers, fellow passengers, family/friends/caregivers or passersby for assistance, along with dealing with social anxiety, loud environments, late schedules and other interactions.¹⁴⁸ Negative experiences

Barriers to Community Engagement



could further impact health by influencing feelings of diminished self-efficacy and self-advocacy, as well as stress and perceived social isolation.

In the chart below, respondents were asked how they go places.

Most individuals with A/I/DD rely on friends and family to go places. Medicaid covers transportation to and from medical appointments for those who qualify for services.¹⁴⁷ State Medicaid programs can also choose to cover nonmedical, community transportation through HCBS waivers. Transportation under these waivers can be limited by geographic area and targeted disability group. The scope, enrollment and number of trips can also be

capped. OPWDD offers **non-emergency medical transportation (NEMT)** to those eligible for Medicaid.¹⁴⁹ Transportation can also be covered under OTPS. However, as stated above, the OTPS budget is limited. It is insufficient to cover the array of services a person with A/I/DD may need.

In facilitating community engagement among individuals with A/I/DD, transportation cannot be limited to medical appointments. More supportive options are needed to increase transportation access. Neuro-inclusive properties would benefit from **transit-oriented developments (TOD)**¹⁵⁰ or walkable locations. Emerging developments can use this data for site selection and in design to seek parking variances, or include sheltered

pick-up/drop-off areas. The local planning department could consider exploring **land banking**¹⁵¹ properties for future neuro-inclusive development. Transportation options to popular places in the community may be a valuable supportive amenity.

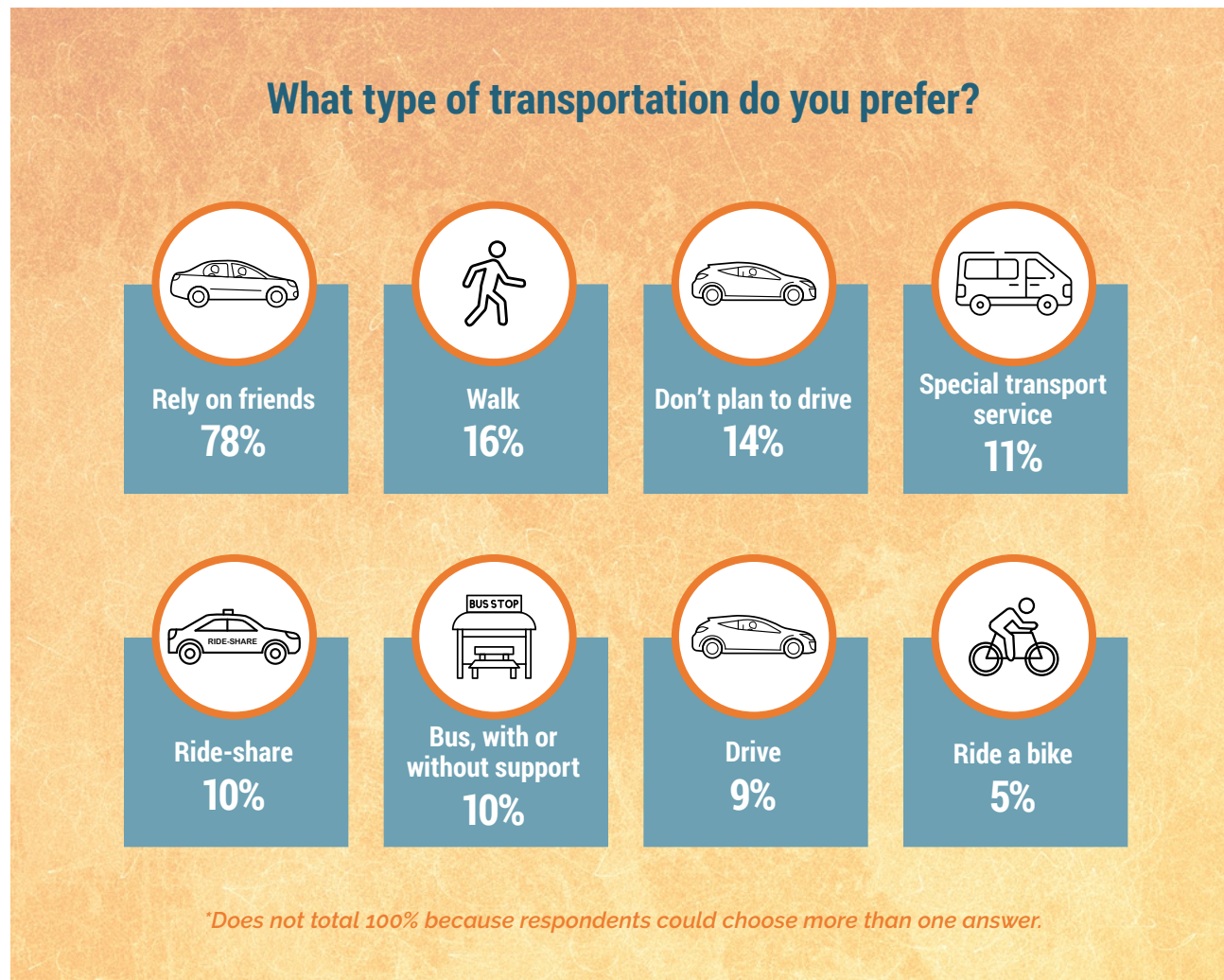
DRIVERS OF LONELINESS

The chart at right shows responses about having friends.

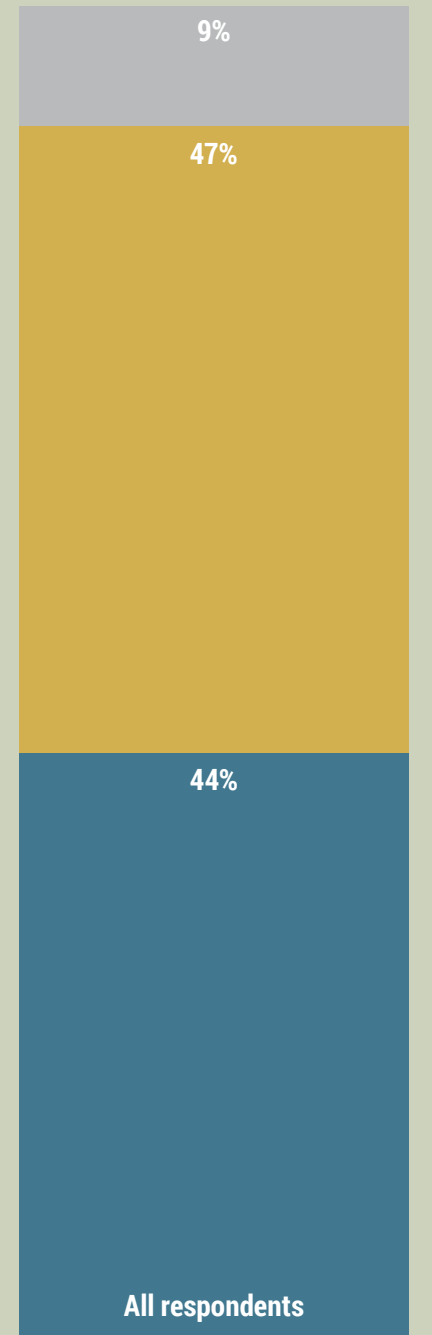
Loneliness is a major public health concern that can have a significant ripple effect on one's mental health and support system.¹⁵⁴ The U.S. Surgeon General Advisory states that lacking social connections is as dangerous as smoking up to 15 cigarettes a day. A synthesis of data across 16 independent longitudinal studies shows poor social relationships (social isolation, poor social support, loneliness) were associated with a 29% increase in the risk of heart disease and a 32% increase in the risk of stroke. Another study found that loneliness is a risk factor for worsening cognitive abilities in older adults.¹⁵⁵ In general, loneliness can increase the risk of death from all causes, including diseases.¹⁵⁵

Transportation is a major consideration in the facilitation of social interaction. Social interaction evolves from a basic human need to belong and progresses through friendships, healthcare relationships or a support system.¹⁵² A lack of social interaction can lead to social isolation or loneliness. Though no generally accepted definition of loneliness exists, one researcher defines it as "the immediate awareness of being fundamentally separated from other people."¹⁵³

Children with autism have significantly fewer reciprocal relationships or friendships than their typically developing peers.¹⁵⁶ Among autistic students included in social interactions in class and

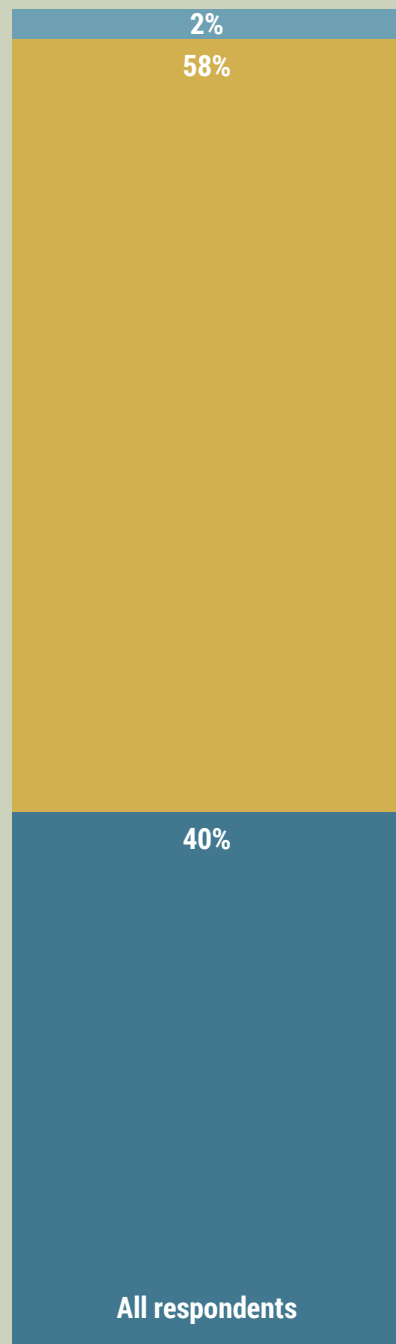


Do you have friends?



■ Yes, I have some friends.
■ No
■ Other

**Of those who have friends:
Do you hang out with them
as often as you want?**



■ Yes
■ No
■ Sometimes

activities, they are more likely to be placed in the periphery and experience more social isolation. Another study found that children who are rejected and lack friends in elementary school are more likely to be lonely in adolescence.¹⁵⁷ Loneliness has also been associated with mental health conditions and worsening physical health challenges. 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 their neurotypical peers.¹⁵⁸

This study defines loneliness as the lack of having one's social needs met through friendships. Respondents were asked if they have friends beyond family members and paid staff. Respondents were also asked to indicate if they experience loneliness and barriers to friendship. A staggering 74% of total respondents in this survey indicate they experience loneliness.

Of those responding yes, less than half often visited or hung out with their friends. See the chart at left.

“Socializing is a key component of human nature. Learning about the barriers to friendship faced by the A/I/DD community can help us develop solutions that adapt to their needs instead of asking them to change who they are.”

— Avery Mickens
 Research & Public Policy Writer
 Colonel Harland Sanders Center for Applied Research, First Place Global Leadership Institute



When respondents were asked about barriers to friendships, the top one noted was a lack of understanding by neurotypical individuals of how to be a friend to those with A/I/DD.

Without additional support, these barriers to friendship and community engagement faced by individuals with A/I/DD will continue to lead to loneliness and isolation. Creating spaces and places is critical for individuals with A/I/DD to connect within the greater community and build neurodiverse relationships. In developing housing, common areas and activities can be designed to create avenues for social interactions within the built environment (e.g., clustered mailboxes, lawn activities in open spaces, pedestrian-oriented site planning, etc.). This can also include supportive amenities to facilitate more significant social opportunities and engagement, including life skills or fitness classes and such positions as activities coordinator or community navigator.

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

People do not understand how to be a supportive friend to me.	38%
I need staff support to see my friend.	35%
I don't know where to go to meet potential friends.	34%
I experience too much anxiety to try to meet new people.	34%
Lack of transportation	31%
I do not know how to turn potential friends into long-term friendships.	30%
I have difficulty scheduling to meet with friends.	29%
I don't have money to spend on outings with friends.	24%
I accidentally do things that have hurt relationships.	18%

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

“I miss being able to see my friends during the school day. For me, living somewhere that is friendly and encourages me to be social is important.”

— Survey Respondent



Future Concerns

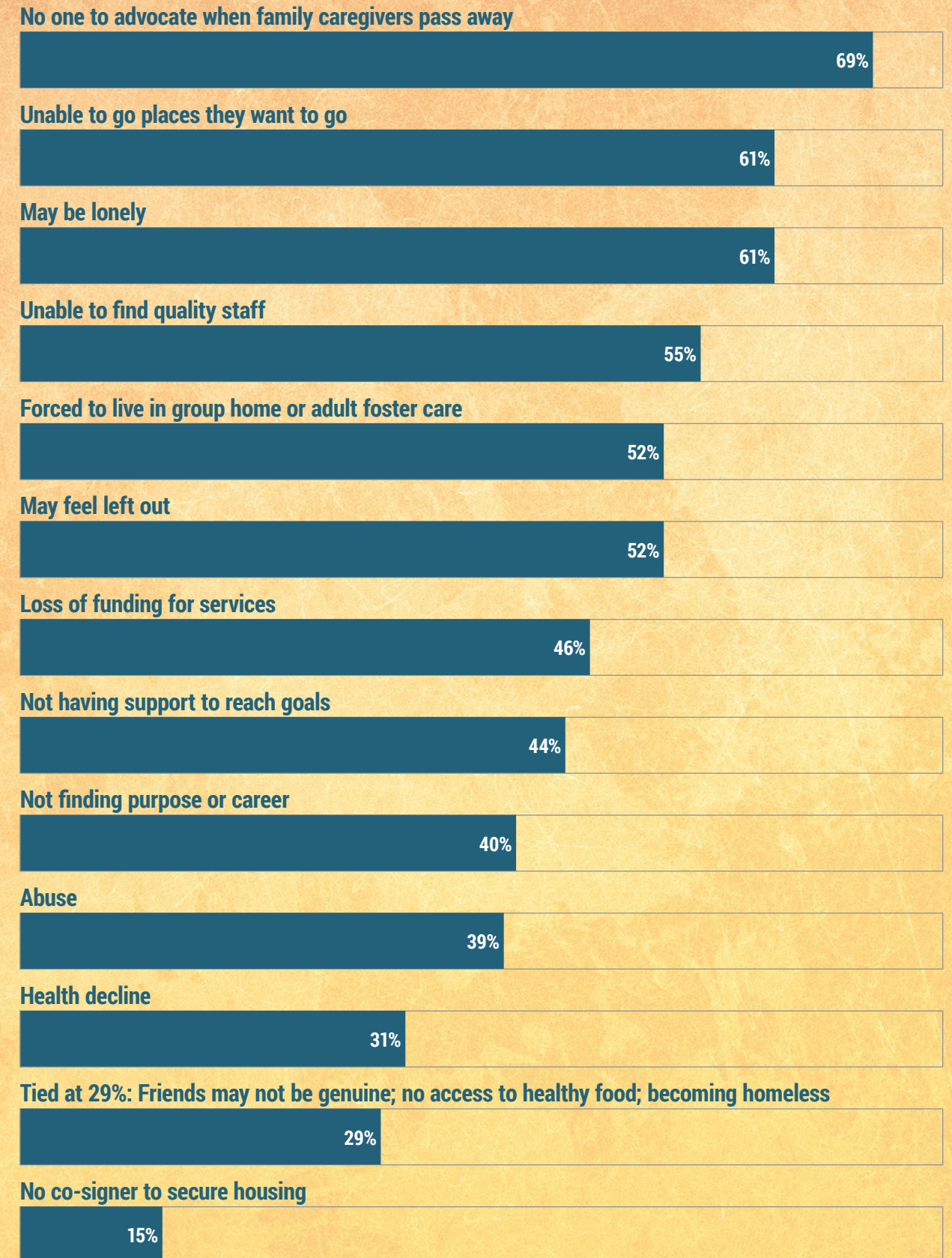
Respondents were also asked about their future concerns. See chart on next page.

In February 2024, OPWDD issued a request for proposal to announce the availability of state funds for an I/DD-specific Ombudsman program. The bid prioritized proposals or work plans to address the developmental, socio-economic, racial, ethnic and cultural needs of people with I/DD.¹⁵⁹ This program aims to assist individuals with A/I/DD in preserving their rights. The Ombudsman service will act as a resource and help advocate for individuals and families as they navigate OPWDD's programs. It will also collect and analyze data on Ombudsman program activities to identify common themes, issues and trends in service needs and use that information to support ongoing quality assurance and improvement activities.

"All of us in government, particularly in human services, must realize that this problem must be fixed—now. Our responsibility is not only to recognize peoples' sense of urgency but also to understand, embrace and share it. Our responsibility is to do everything possible to 'get to yes' when approached with time-sensitive requests."

— Survey Respondent

Future Concerns



“We went to a hotel with everything you needed under one roof. Green spaces, stores, food, social gathering places, a front desk—even someone to help coordinate transportation.

It hit me: This is what people with A/I/DD could benefit from every day! Supportive amenities are the little things that really are the big things when it comes to feeling secure after someone moves out of their family home.”

— Survey Respondent



HOUSING & SUPPORT PREFERENCES

Individuals with A/I/DD have not always had such commonplace options available. As noted earlier, the option to receive LTSS and healthcare services in the community only began in 1981. Despite the wave of deinstitutionalization over the last four decades, no equivalent effort has been made to develop supportive housing options or provide rental assistance to make housing more affordable for adults with A/I/DD.

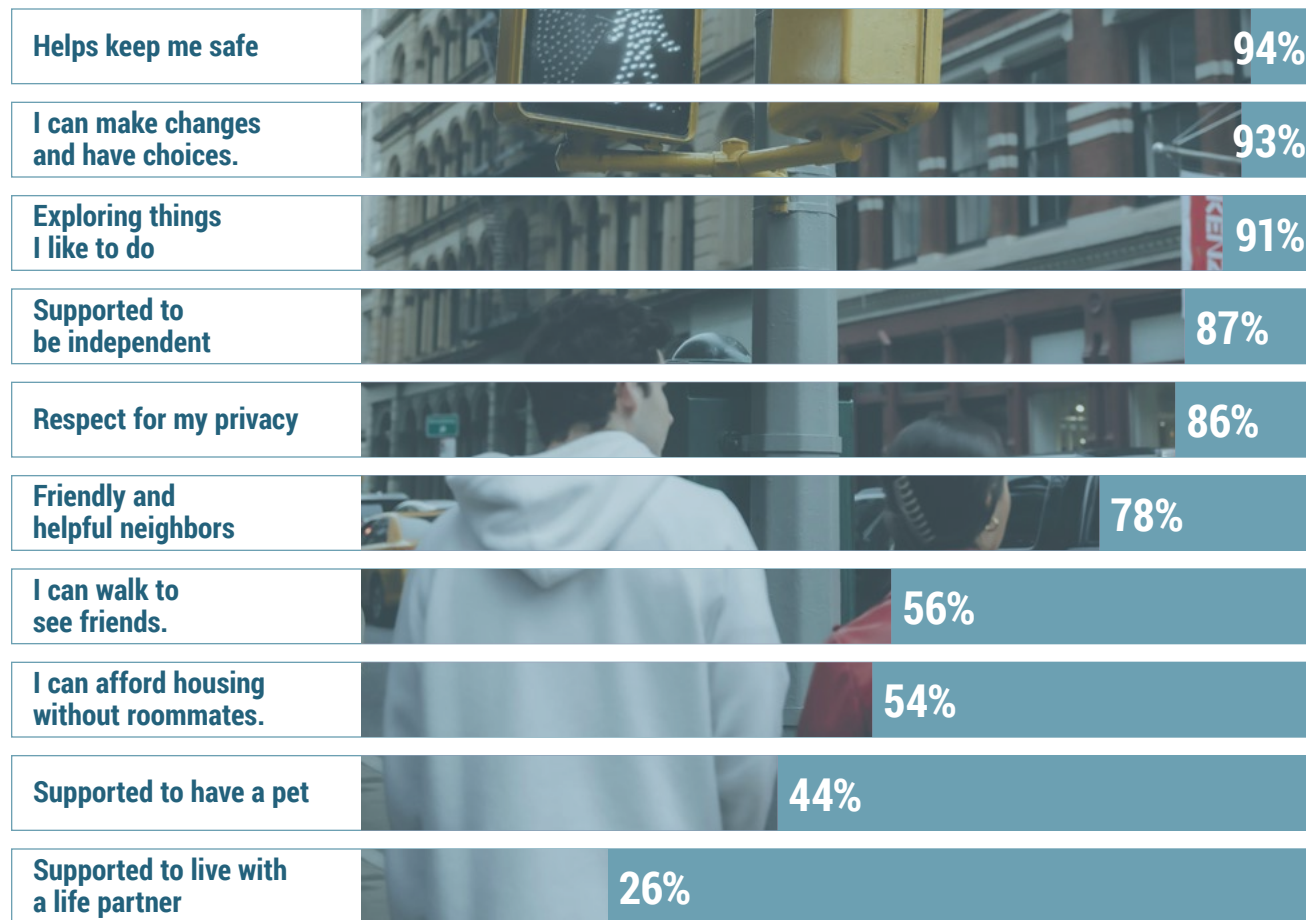
The following chart shows the hierarchy of responses when respondents were asked to identify what was important to them in a future home.

The lack of housing options also means that most adults with A/I/DD must live with family or in provider-controlled settings like group homes. Provider-controlled and some consumer-controlled options may not

“I would like to see a housing model for people on the autism spectrum that has a mix of patio homes/cottages, apartments and fully assisted living options on a campus with trees and paths and transportation and recreation.”

— Survey Respondent

What is important for your future home and supports?



Who do you want to control your housing?

Consumer-controlled: I find and control my own housing. I choose any service provider I want.	72%
Provider-controlled: I find a service provider I like and move into their housing.	17%
Hybrid	7%
Not answered	4%

include options like respect for privacy, the ability to make changes to living spaces or having a pet.

It is also important to acknowledge the resistance many neighborhoods exhibit when group homes are proposed.¹⁶⁰ Often, these homes are not welcome and there are no invitations to community events, no offers to join a backyard gathering or swim in a neighbor's pool. Living in a neighborhood does not automatically make one feel like a true "neighbor." Individuals living in these group homes and the staff who support them acutely feel this sense of exclusion. The persistent stigma surrounding group homes prevents those with A/I/DD from feeling truly embraced and valued as members of their community.

Individualized Long-Term Services & Supports

When exploring housing options available to adults with A/I/DD, it is important to distinguish among service delivery models that may impact housing.

As discussed 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; or one can select a consumer-controlled setting where they find and manage their preferred home and location before selecting their service provider and method of service delivery.

The same single-family home in a typical neighborhood or part of a **planned community**⁴⁰ could have various LTSS arrangements individualized for residents. In the following housing arrangement example, Amanda's parents bequeathed their home so she and her housemates pay rent to a special needs trust that financially manages the home. This is a consumer-controlled setting because Amanda can change her service delivery model and/or service provider as desired and stay in her home.

Examples of possible living arrangements and service delivery options:

(A) Amanda lives with two housemates who have A/I/DD; all 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**⁴⁰ arrangement.

C) Amanda lives with two housemates. One of the housemates does not have A/I/DD. Amanda and her support team hire staff

How are long-term support services (LTSS) and housing connected?



Provider-Controlled (PC)

Housing & support services are connected.

Choice of HCBS service provider determines individual's housing.



Consumer-Controlled (CC)

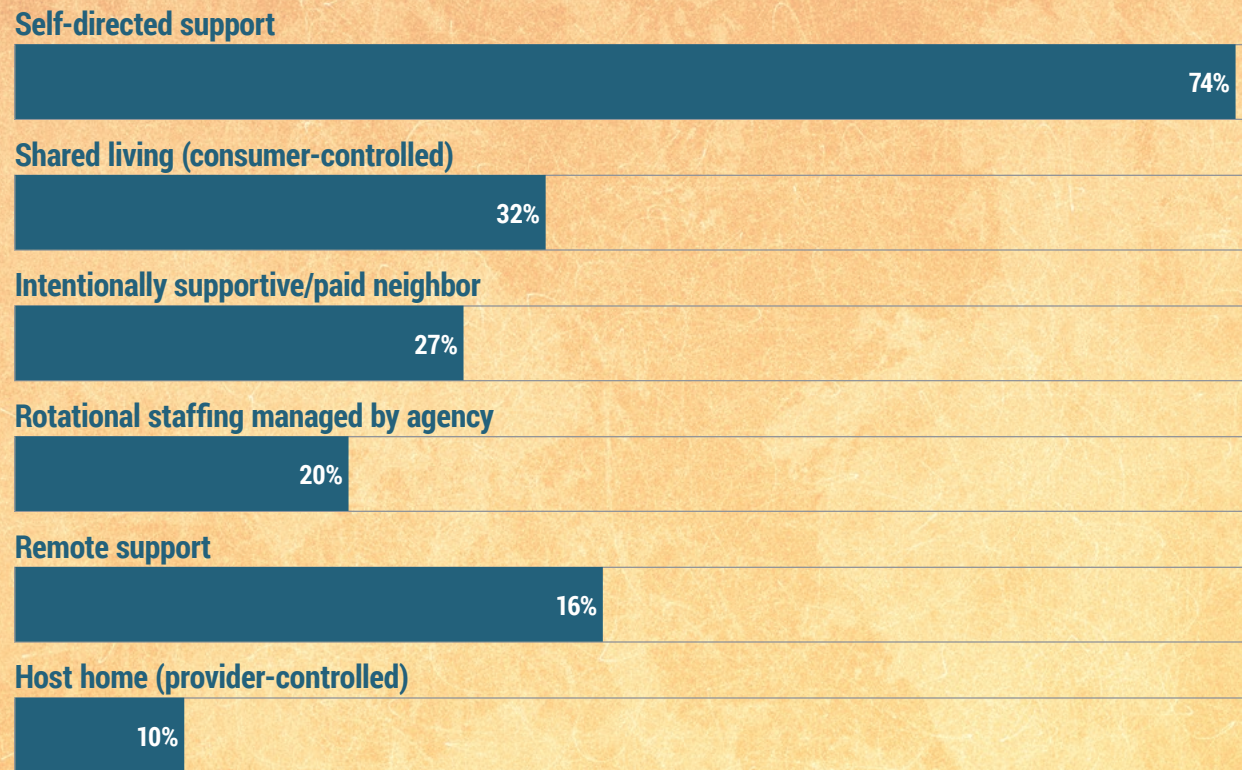
Housing & support services are not connected.

Individuals choose preferred housing and local HCBS service provider.

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**.⁴⁰

In this study, respondents were asked who they want to control their housing.

Preferred Service Delivery Model



Service Delivery Models

Respondents were also asked to select how they prefer to receive supportive services. See the chart above.

As noted above, 74% of respondents prefer **self-directed support**.⁴⁰ For this research, self-directed support is when an individual receiving LTSS is given a budget to spend on their LTSS based on their support needs. One of the funded waiver service delivery models is self-direction. Under this model, a person receiving LTSS can choose where to live, hire staff and plan support.

The state offers two types of self-direction: budget authority self-direction and agency-supported self-direction.³⁵ The main differences between the two lie in the individual's

level of control and responsibility over their services and funding. Budget authority self-direction emphasizes individual control over funding and the flexibility to choose and manage services independently. Agency-supported self-direction provides a balance of individual choice and agency support, with more oversight and assistance in managing services. Both models aim to empower individuals with disabilities but with differences in control and responsibility. Also, the state allocates more on average per individual for budget authority than agency-supported self-direction.

For this research, shared living is a housing arrangement where an individual with LTSS invites a provider to live with them in their own home. The provider could be a paid friend, paid family caregiver or staff recruited through

an agency. This is a consumer-controlled model whereby individuals with A/I/DD retain control of their housing. The consumer can request a change in service provider and not be forced to leave the home. This model is a form of noncertified setting.

It is worth acknowledging that New York is one of a few states that funds all six of these service delivery models. However, as stated above, access to these services is limited. Less than 30% of New Yorkers with A/I/DD receive services. In Monroe County, the percentage is significantly less. More advocacy is needed to expand funding for these service delivery models while increasing the self-direction budget. Increasing access to services can ensure adults with A/I/DD are sustainably housed.

74% of respondents prefer self-directed support, where an individual receiving LTSS is given a budget based on their support needs.



LTSS Delivery Model⁴⁰

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.

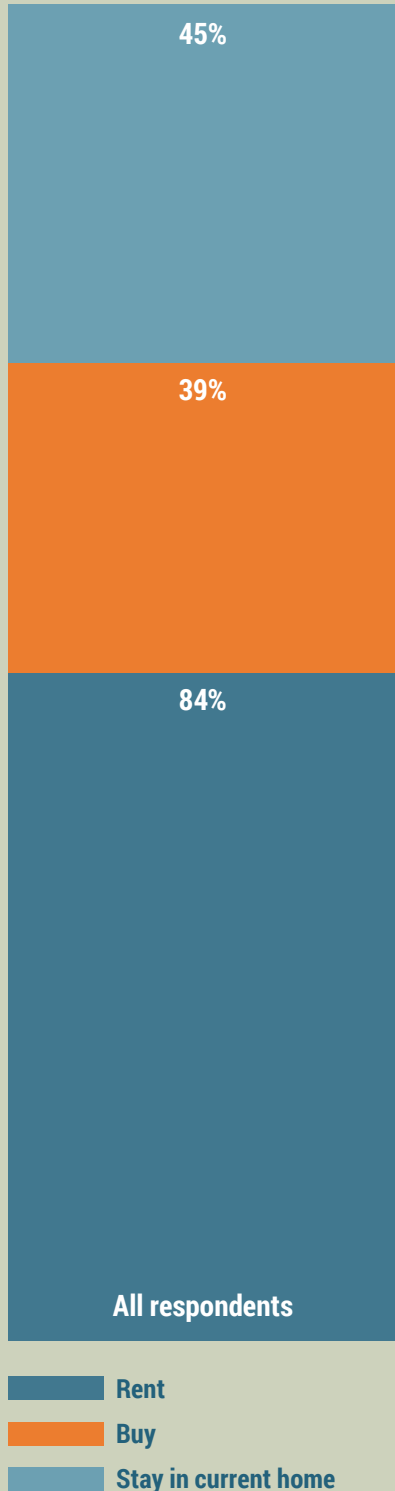
Paid Neighbor

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**.

Do you want to rent or buy in the future?



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

Renting Versus Homeownership

Most adults with A/I/DD will likely be extremely low-income over their lifetimes. At the same time, the typical rental market can be unstable for those on a fixed income. For example, landlords may or may not renew tenant leases. Continuous rent increases could also price out adults with A/I/DD. Individuals and families may view homeownership as a more stable option.

The chart at left shows responses to the survey question regarding renting or buying a home.

For the majority of the respondents, the first choice was to rent a home. In total, 95% of respondents wanted to rent or buy their own home.

Homeownership and rental subsidies for those who prefer to rent should be incorporated into plans to meet the housing needs of adults with A/I/DD. Only a small percentage of families could purchase a home without assistance on behalf of their dependent loved one. Public housing authorities can expand participation in the HCV homeownership program to assist individuals with A/I/DD attain homeownership.¹⁶² Currently, the Rochester Housing Authority has 125 participants in the HCV homeownership program. Expanding this program can help provide more permanent housing options for adults with A/I/DD who want to buy a home.

It is important to note that some who indicated they prefer to buy a home want to add an **accessory dwelling unit (ADU)**¹⁶² to a current family or friend's property. For those who prefer to remain on a property controlled by a family or friend, allowing **use-by-right**¹⁶³ ADUs for dependent family members, individuals with A/I/DD or seniors can be a viable alternative and help increase housing options. Vouchers can also be applied to renting ADUs as reasonable

"I would like to live in a community where neurotypical people want to share in the lives of people with A/I/DD."

— Survey Respondent

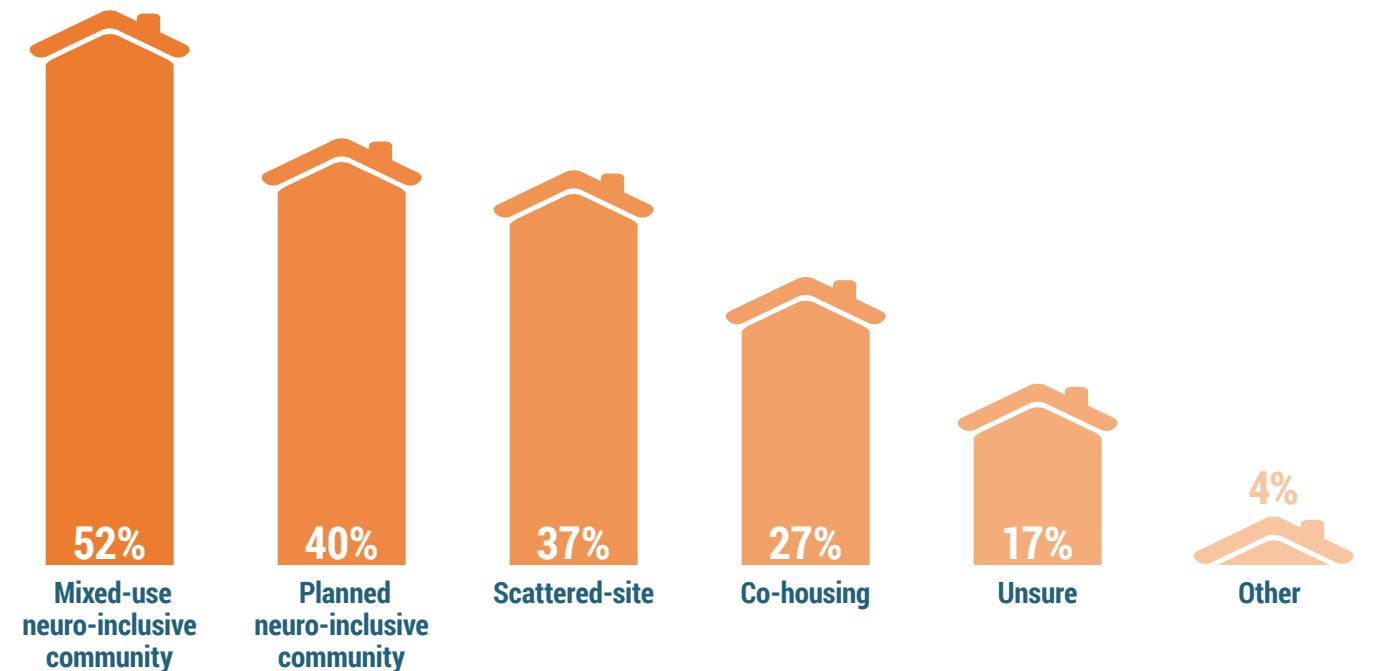
accommodation under certain circumstances. By developing tools and housing stock to meet the needs of homeowners with A/I/DD or their families, the limited resource of rental subsidies can be preserved for those who prefer a consumer-controlled rental option. Incentives should be created for landowners,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

Housing Type

Respondents were given the opportunity to learn about the benefits and considerations of various housing types. Then they were asked to select their preferred housing types. The chart below shows their responses.

Respondents indicated they prefer both **neuro-inclusive planned community**⁴⁰ and **mixed-use planned community**⁴⁰ developments. People may prefer these two options due to the availability of additional accessibility features, safety nets and supportive amenities. Neuro-inclusive planned or neuro-inclusive mixed-use planned communities are designed for the accessibility needs of individuals with A/I/DD. However, everyone, including residents without disabilities, can benefit from design features or supportive amenities that make housing more accessible to the neuro-divergent population.

What type of housing setting are you interested in?



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



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 large-scale, 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

Large-scale 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.

Unit Type

Respondents were also asked to select preferred unit types. The chart below shows their responses.

What unit type interests you?	
Apartment/condo	60%
Single-family home	57%
Single-story townhome	46%
Accessory dwelling unit (ADU) (e.g., mother-in-law house, etc.)	39%
Multi-story townhome	23%
Other	6%

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

“My ideal living arrangement is in my own apartment with agency staff checking in two or three times a week to refill meds, and take me to my appointments and outings.”

— Survey Respondent

Living Arrangements

Next, respondents were asked if they would like to share their homes. Individuals 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.⁵ This may include sharing a bedroom and a bathroom with those they did not select as roommates. Nondisabled adults often experience this type of living situation by choice in student housing during early adulthood. 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.

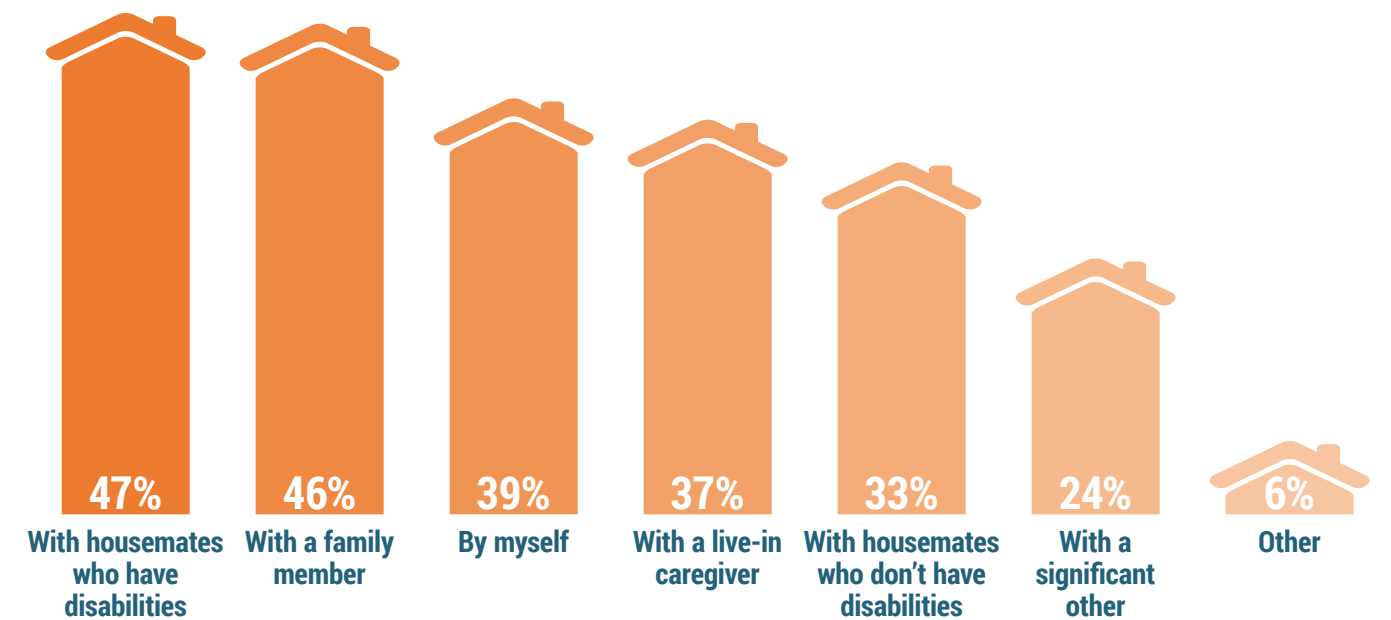
The chart below shows responses for preferred living arrangements.

As noted in the Background section of this report, most adults with A/I/DD are either unemployed or underemployed due to systemic barriers, executive function

challenges and/or other physical or mental health conditions. As a result, most adults with A/I/DD cannot afford fair market rent for a one-bedroom apartment in Rochester. However, some might be able to afford a two- or three-bedroom apartment if shared with their chosen housemates who may or may not have disabilities.

For the 47% of respondents who want to live with housemates, it is imperative to create affordable housing options that meet this need. This housing option must also recognize and respect individual choice and self-agency. When planning to meet the needs of individuals with A/I/DD who may prefer to live with a roommate, best-practice strategies include same-size bedrooms in two-plus bedroom units. Ideally, each bedroom would have its own bathroom. It is also recommended that bedrooms not share walls in consideration of privacy and sound sensitivities of individuals with A/I/DD.

Who would you want to live with?



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



Physical Amenities⁴⁰

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

In developing housing options, it is important to consider home features, structural features or physical amenities that could better support adults with A/I/DD and increase inclusivity and accessibility.¹⁶⁴ Environmental factors can facilitate or hinder inclusion in their communities and may negatively impact their health. One study found that the physical environment of young adults with Down syndrome impacted their socialization more than their social environment.¹⁶⁵

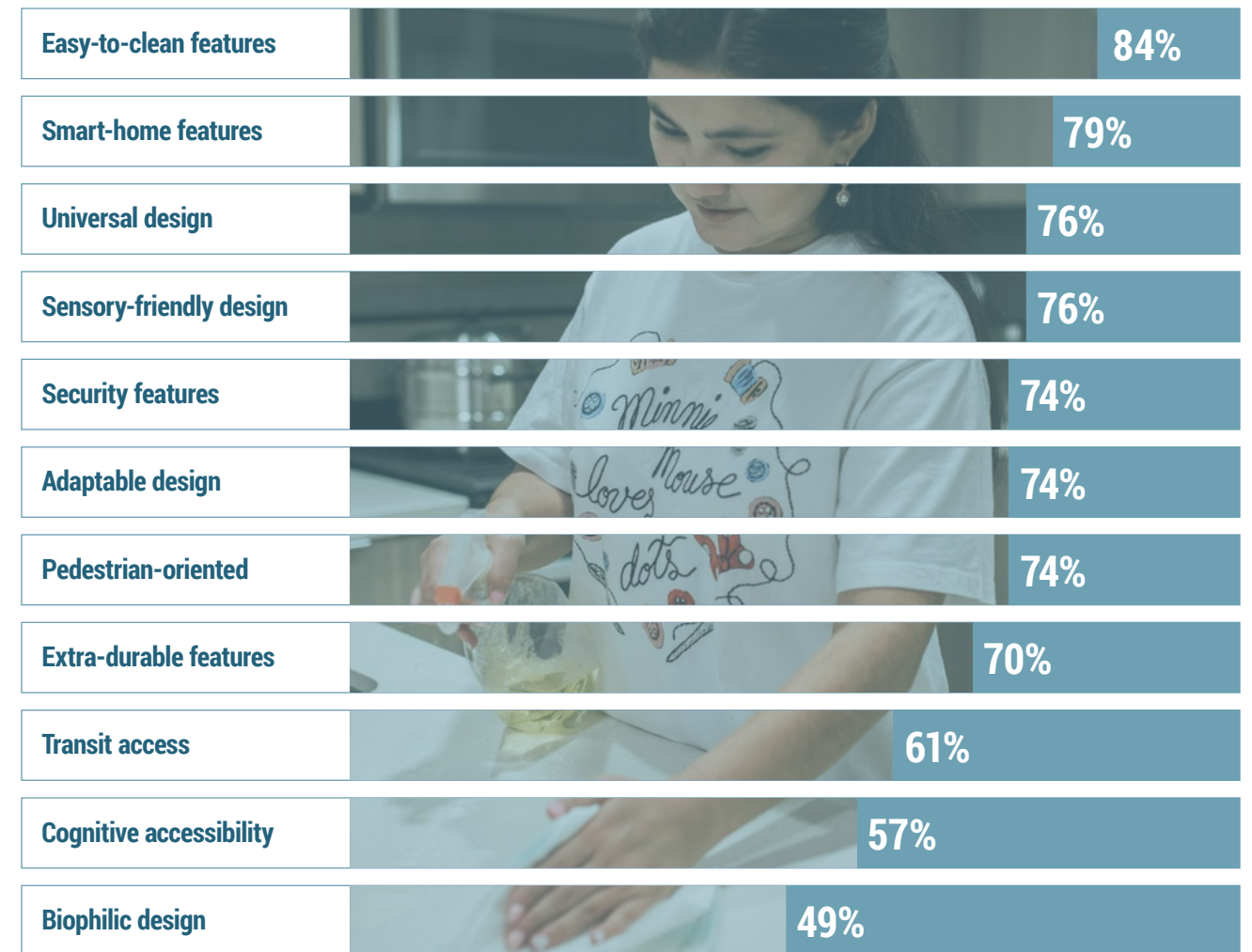
When accessibility features are considered, people often refer to the Americans with Disability Act (ADA) and the compliance measures therein for mobility devices.¹⁶⁶ However, individuals with A/I/DD may not necessarily have accessibility needs related to mobility. Their accessibility needs may have a different origin of impairment, often impacting safe social interaction, independent living skills, atypical sensory perception, etc. Therefore, in designing homes accessible to and supportive of individuals with A/I/DD, the survey also included asking respondents about those amenities. Respondents were asked to rate the importance of certain physical features in their future homes.

The percentages in the chart below are those of respondents indicating that the following physical features are important or extremely important to them when considering housing.

The data was also segmented to determine which physical amenities self-advocates considered important and very important. Their responses are on the next two pages.

Although modifications and design strategies are supportive of individuals with A/I/DD, they may also be attractive for neurotypical residents. Just like curb cuts required by the ADA make walking on sidewalks easier for those with mobility issues, they also serve

What type of physical amenities would be helpful?



as a convenience for those using a stroller or grocery cart. Everyone can benefit when housing and community spaces are designed to be more neuro-inclusive.

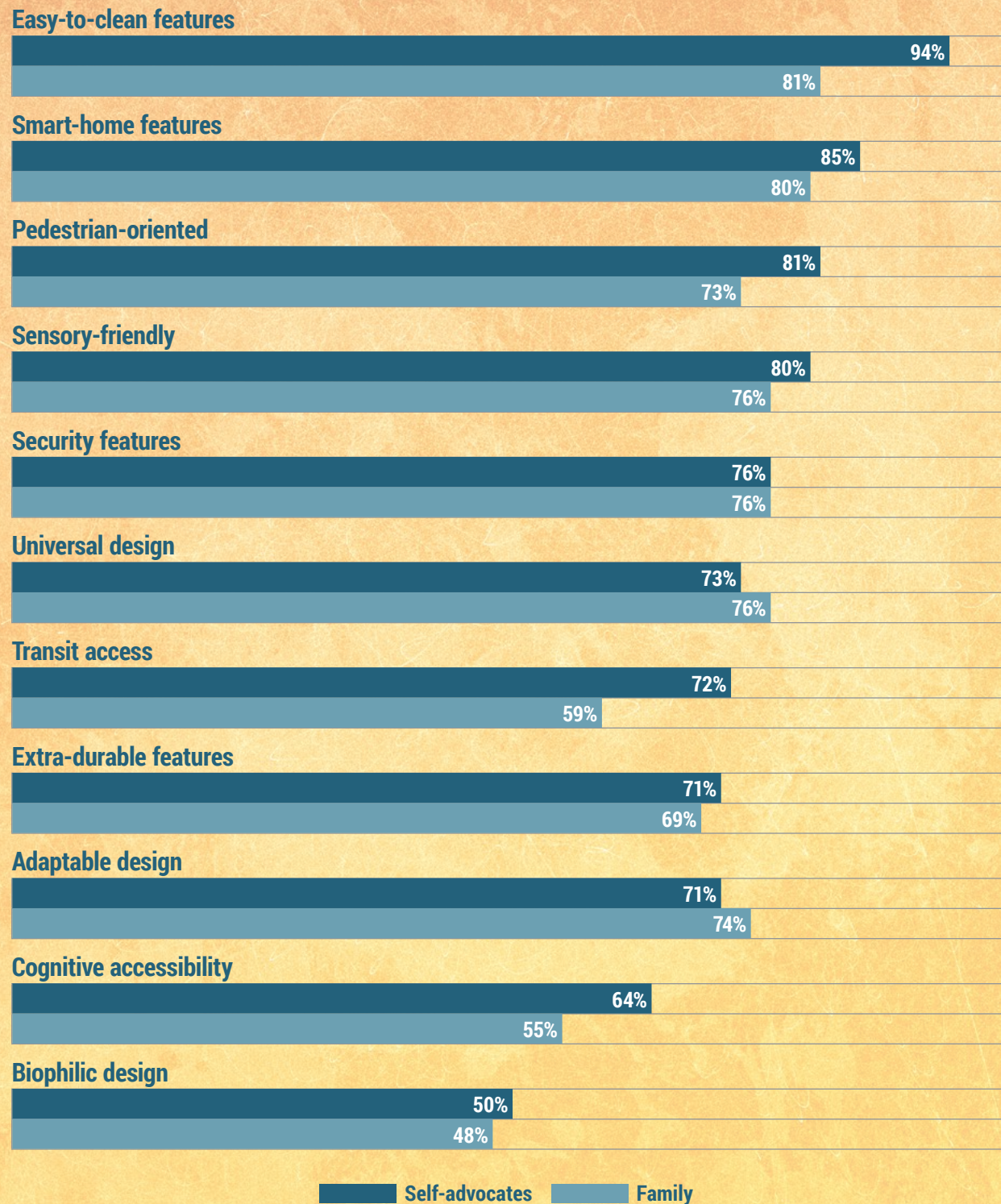
One way the state can incentivize developers to incorporate these physical amenities is through prioritization in its **Qualified**

Allocation Plan (QAP)¹⁶⁷ or the 2024 Affordable Housing Development and **HOME Investment Partnerships American Rescue Plan Program (HOME-ARP)** requests for proposal.¹⁶⁸ The QAP details the prioritizations developers use to be more competitive when applying for **low-income housing tax credits (LIHTC)**.¹⁶⁷

“All of the amenities listed in this survey sound like necessary supports for my sibling and others in the community.”

— Survey Respondent

What physical amenities are you interested in?



Under the LIHTC program, the Internal Revenue Service allocates nonrefundable tax credits to state housing finance agencies. The basic federal requirement for awarding the tax credit is that recipients must make a strong commitment to providing low-income housing.¹⁶⁹ However, state financing agencies have discretion in determining the recipients. In return for the tax credits, developers must set aside at least 20% of the units for low-income households or a minimum of 40% of the units must be affordable to households earning 60% or below of area median income. Rent for these units must be no more than 30% of qualifying income, depending on the rate chosen in the qualified allocation plan for the project.^{170,171}

The LIHTC program surpasses any other public program in creating affordable rental units.¹⁷³ LIHTC has financed approximately 50,000 housing units annually since 2010. It was estimated that LIHTC cost the government approximately \$8.4 billion in 2017. LIHTC has also been used to preserve and rehabilitate other affordable housing units for the elderly and individuals with disabilities.

By executive order, the New York State Division of Housing and Community Renewal has been designated as the State Housing Credit Agency to allocate the tax credits. Proposed priority points for development plans with set-aside units for adults with A/I/DD, supportive amenities and/or design features such as the physical amenities listed in the study can be included in the state's QAP. More points can be allotted to housing developments that include neuro-inclusive housing features and amenities, making it more likely for developers to consider neuro-inclusive development to qualify for LIHTC. This added incentive can help increase the supply of affordable and supportive housing for adults with A/I/DD.

Supportive Amenities

Respondents were also asked what supportive amenities were important in their future homes. Supportive amenities are not the same as individualized LTSS. They could be available to residents who live at a specific property and could offer additional needed support that individualized LTSS providers

“I think housing should be available in areas close to suburban shopping, with access to parks and activities—not in inaccessible, closed-off areas near expressways.”

— Survey Respondent



Supportive Amenities⁴⁰

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.

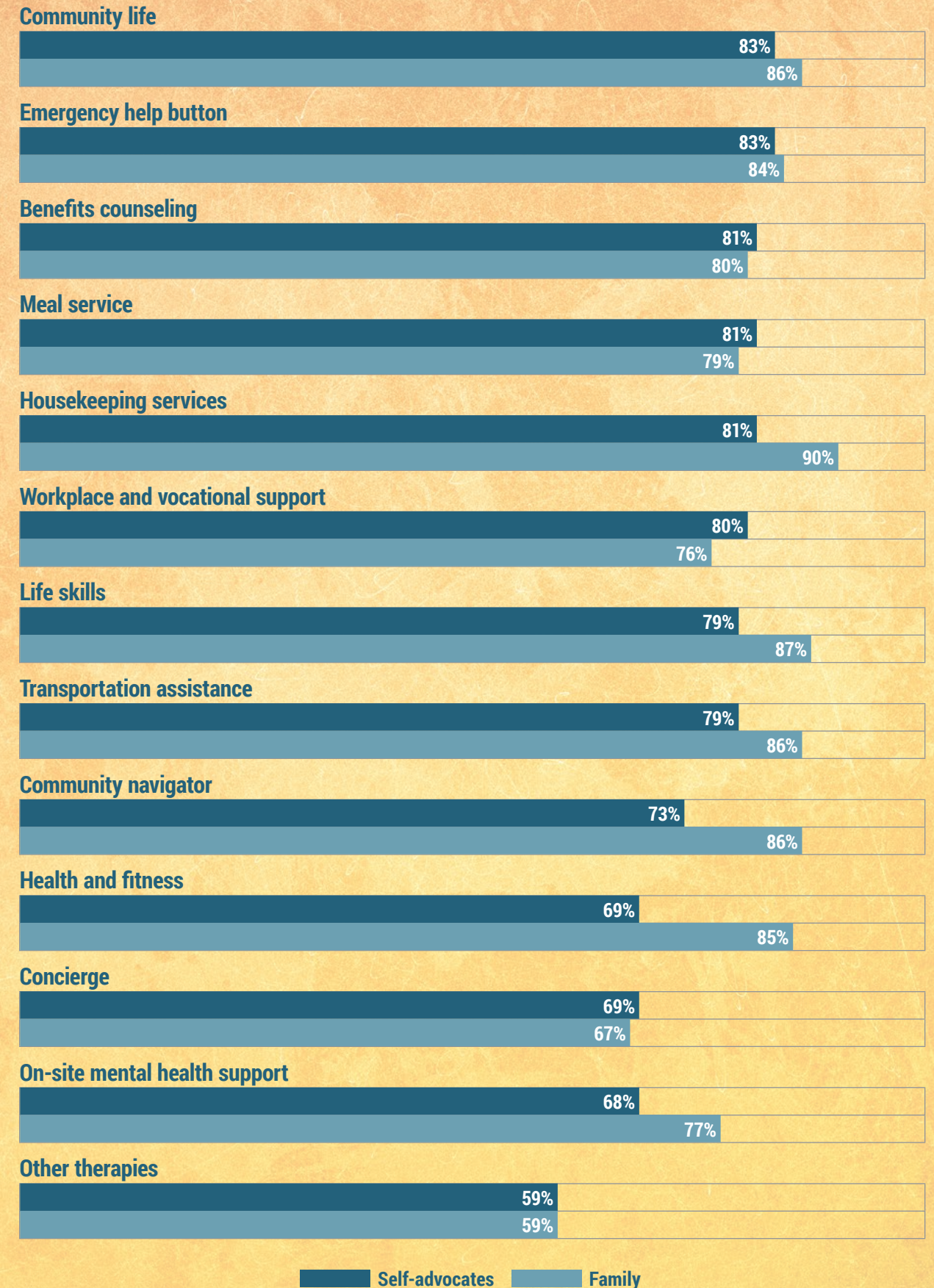
often do not include due to Medicaid funding limitations. They could also offer an alternative supportive option for individuals ineligible for waiver services who need assistance to remain housed, employed and connected to their community.

The chart on next page shows responses to questions about supportive amenities. Percentages are those of respondents who indicated that the options listed are important or extremely important.

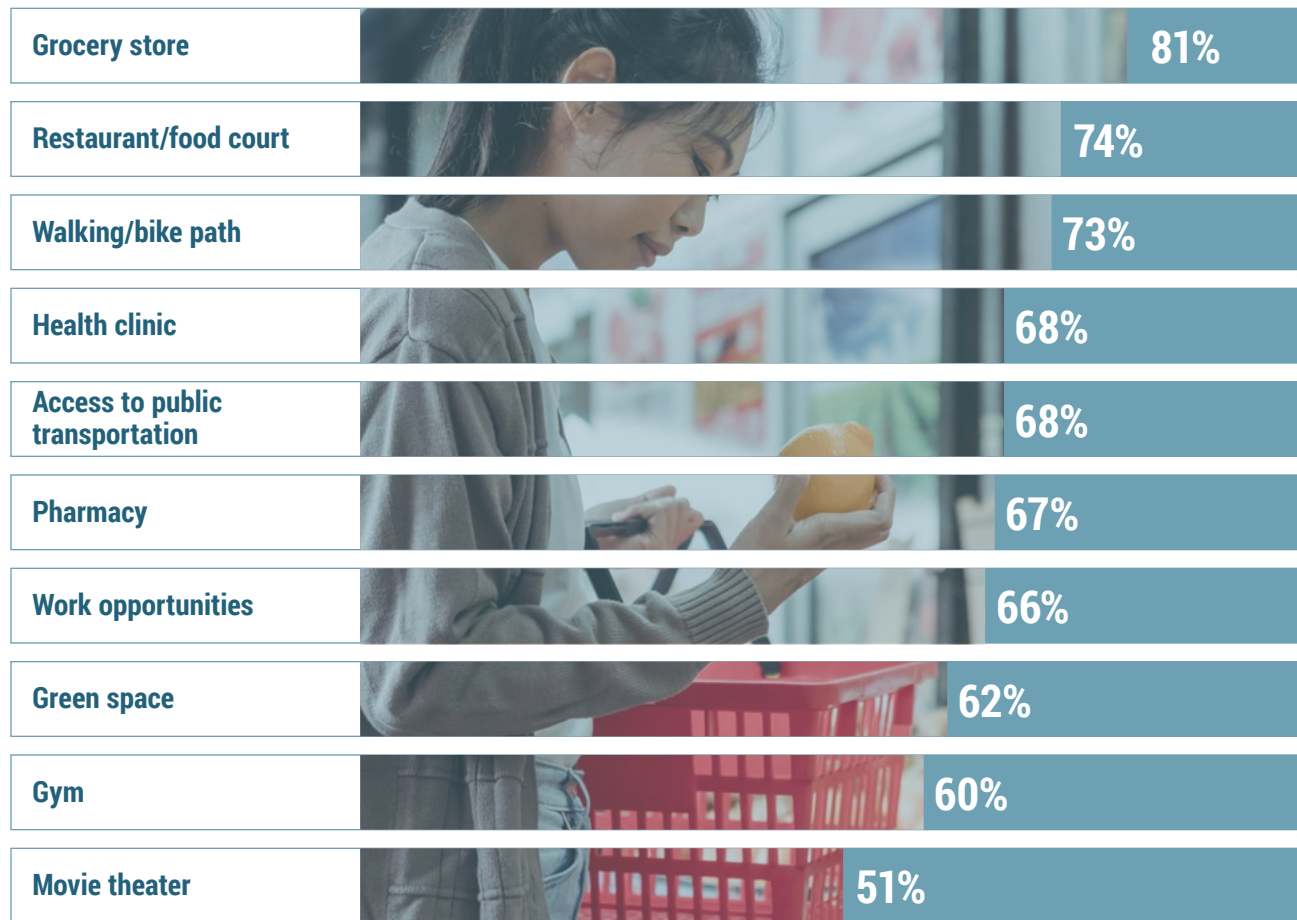
Data were also segmented to determine supportive amenities self-advocates considered important and very important. Below is how self-advocates responded..

Medicaid providers, property management or housing developers are not the only sources of supportive amenities. Local community-based organizations like AutismUp can also provide them. The city can support nonprofit organizations serving adults with A/I/DD to provide supportive amenities in affordable housing developments. Housing developers can also collaborate with community-based organizations that offer supportive amenities. Residents can decide whether to opt in.

Would these supportive property amenities help you?



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



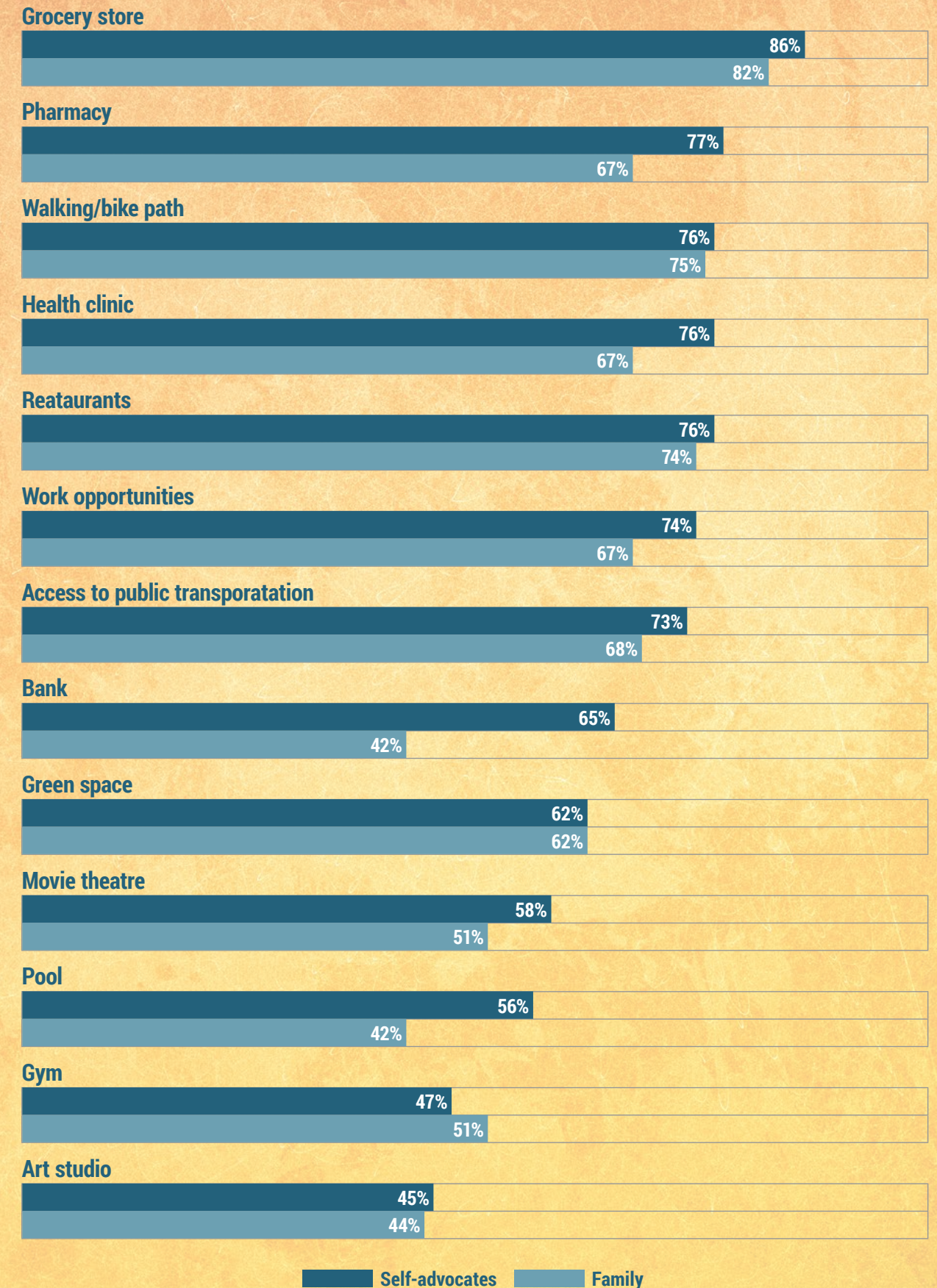
Community Amenities

Respondents were also asked about community amenities. These are features in or near the communities where they want to live. The chart above shows the responses.

Data were also segmented to determine supportive amenities self-advocates considered important and very important. Below is how self-advocates responded.

Most adults with A/I/DD do not drive, so it is imperative for housing developers and community planners to ensure adults with A/I/DD can access housing in a transit-oriented location within walking distance of community amenities. Developers in Rochester can secure land parcels through land banking or a **community land trust**⁴⁰ to develop or rehabilitate underutilized parcels of land to build transit-oriented housing developments.¹⁷³ Securing land parcels can help ensure affordable and accessible housing developments.

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



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



Community Development

In addition to community amenities, respondents were also asked what accessibility features would be helpful when engaging in their community. The chart above shows their responses.

These accessibility features could be incorporated into community events like the Rochester International Jazz Festival, Carifest Parade and Festival, Play Day on Riverway, Artist Row, community garage sales and others. Fairs or other public spaces can also incorporate these elements to increase accessibility for individuals with A/I/DD.

“It would be so great if we could purchase housing in a community planned for our needs and with like-minded people with whom to share resources.”

—Survey Respondent



TRANSITION & FUTURE OPPORTUNITIES

The final section of the survey included residential transition programs and future opportunities. Individuals with A/I/DD and their families are familiar with the term “transition.” Most families must try different strategies to assist their loved one in transitioning from childhood to adulthood.¹⁷⁴ Families employ these strategies because many individuals with A/I/DD are not given enough support by the educational system to plan for or facilitate the transition to adult care.^{175,176} Other systemic barriers, including

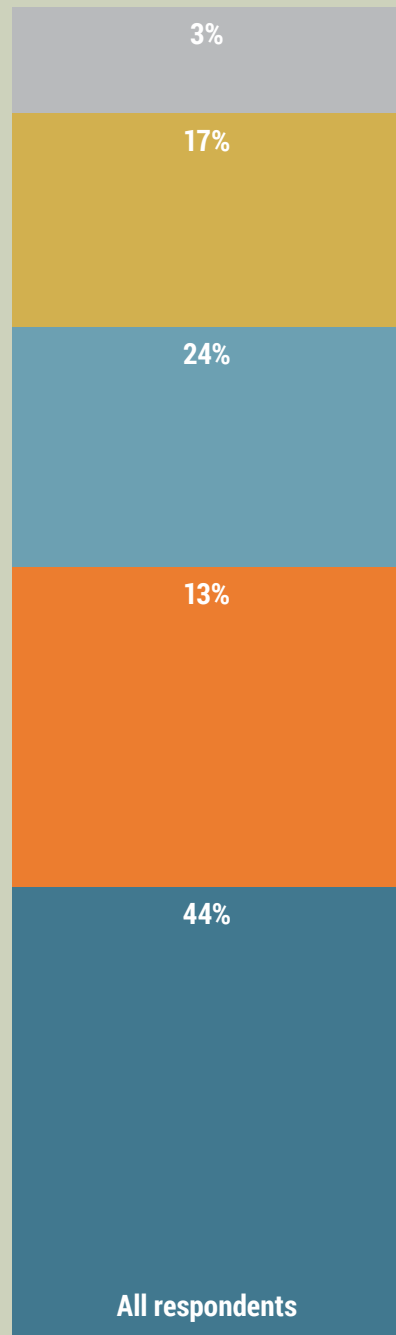
lack of knowledge by and training of service providers, lack of capacity of service providers, long waitlists, understaffing and low reimbursement for extra care, also make it difficult for youths transitioning to adulthood and adults with A/I/DD to access LTSS and healthcare.^{177,119}

For this study, the term “transition” program does not refer to healthcare but to housing and independent living. Moving from a family home is a major decision for both neurotypical

“We need good, safe housing options for people with disabilities. They need the opportunity to have full, happy lives on their own; but they may still need support to live independently.”

— Survey Respondent

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



- Yes, if assisted with cost
- Yes, even if private pay
- Unsure
- No
- Previously attended

and neurodivergent young adults and their families. However, individuals with A/I/DD may have been living in the family home for years, even decades, and change may be more challenging than for a neurotypical counterpart. Changing environments, daily routines and transportation routes, along with the stress of leaving the stability of the family home, require greater direct support for a transitional period. Consequently, those with A/I/DD may need a transition program to develop skills to live independently.

The chart at left shows the results of asking respondents about interest in or previous attendance of a residential transition program.

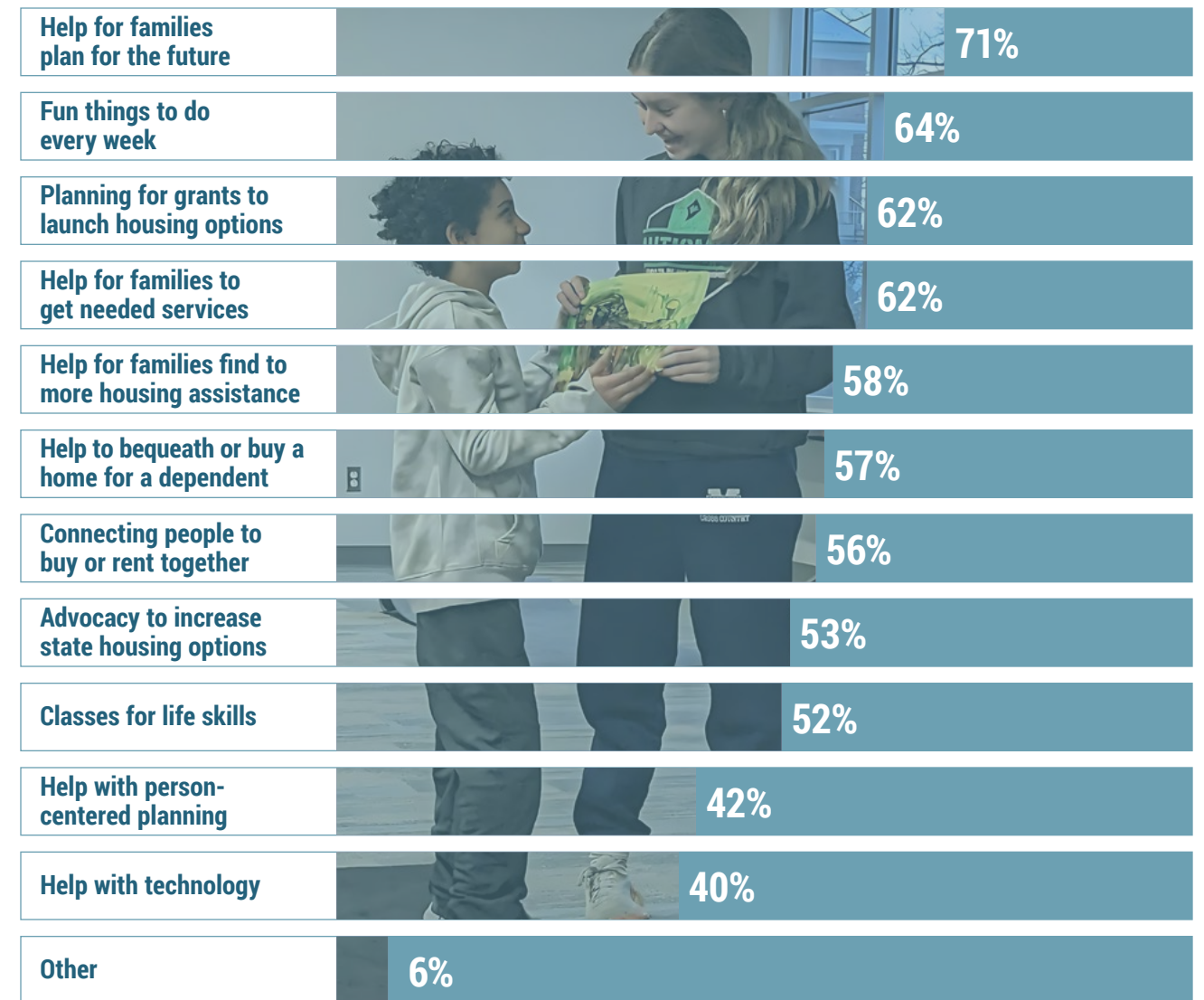
Future Opportunities

Respondents were asked about desired future opportunities; results are listed in the chart on the next page.

“For those wanting to live independently with support, it would help to have more trained providers in the areas of money management, house management, benefit specialists, etc. Maybe MCC could have certificate programs and self-directed budgets with different rate caps for different provider levels.”

— Survey Respondent

Desired future opportunities



“ Reviewing the data clarified challenges families face with self-directed housing. Advocating for a dedicated budget line to fund a ‘house manager’ role could relieve the administrative burden for many families. This role could also help ensure sustainability and parents would have peace of mind knowing that, when they’re no longer here, someone would keep the home aligned with the needs of their loved ones.”

— Amy Johnson, Owner
Spectrum Services NY



RECOMMENDATIONS

New York also has a larger percentage of people living in certified residential settings than most other states, leading to higher spending. As the population ages and new alternatives are developed, there is also an opportunity to shift the settings mix to one that includes lower per capita costs and greater average levels of integrated settings. 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 the Rochester Housing Market Analysis Local Leaders Workshop.

Acknowledge the Need for Restructuring the Current System

- **Unmet obligations:** Currently, OPWDD supports less than one-third of individuals with A/I/DD in New York state. Those who receive support report limited choices and inconsistent quality, highlighting the need for significant improvement in serving this population. More advocacy is needed to remove the inequities in service delivery while ensuring service delivery is tailored to the complex needs of individuals with A/I/DD.
- **Current legislation:** Legislation for a blue ribbon commission was introduced to address the needs of individuals with A/I/DD. However, this legislation should be expanded to include representation from families or individuals using self-direction and ensure independent review versus asking OPWDD to investigate their own practices.

Closing of Data Gaps

- **Public reporting of critical data:** Segment the OPWDD Data Book to include and identify those with A/I/DD experiencing homelessness.
- **Improvement of transition tracking:** Collect and track data on individuals with A/I/DD, especially those transitioning from youth to adulthood or out of the family home, to better allocate resources to prevent them from experiencing housing insecurity.
- **Case management enhancements:** Modify OPWDD case management tools to identify individuals with A/I/DD who have been involuntarily displaced due to the lack of affordable, accessible housing and/or are currently living in a provider-controlled setting but desire a consumer-controlled setting.
- **Tracking of family caregiver homes:** Identify adults with A/I/DD living in family caregiver homes. These families can be segmented into those who would meet eligibility criteria for OPWDD services and those who do not or would likely not meet eligibility criteria but still have supportive housing needs.
- **Understanding of racial and ethnic disparities:** Work with partner agencies to determine methods for identifying households by race and ethnicity with a child and/or dependent adult with A/I/DD living in the home and whether they are housing cost burdened (spending more than 30% of income on housing).

- **Collaboration and partnership to monitor data gap:** Request that Partners Ending Homelessness and members of the Homeless Services Network consider identifying those they serve who may have an A/I/DD to understand how many unhoused are falling through OPWDD cracks.
- **Housing voucher utilization:** Consider changing policy restrictions to categorize utilization rates by residents with A/I/DD currently receiving a housing choice voucher, **811 Project Rental Assistance**¹⁷⁸ or other permanent rental subsidy, public housing or permanent supportive housing.

Long-Term Services and Supports

- **Adequate funding for waiver services:** Increase funding and/or legislative action to ensure waiver services keep up with the complex needs of individuals with A/I/DD and that funding is appropriated to the levels of need.
- **Support for older caregivers:** 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 and to those at risk of displacement into provider-controlled or more restrictive settings than needed.
- **Case management for ineligible adults:** 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.

- **Housing navigation services as a part of OPWDD services:** Consider adding housing services available in other states for waiver recipients to explore, secure, transition to and maintain a tenancy in housing. These include pre-tenancy supports, housing stabilization services, transitional housing services and tenancy-sustaining services.¹⁷⁹
- **Expanded integrated supportive housing (ISH):** Expand funding and increase the capacity of the ISH program to house adults with A/I/DD currently living in institutional settings.
 - Evaluate the program to determine who is served and related outcomes.
 - Identify the number of adults with A/I/DD served in these programs.
- **Long-term viability:** Create a separate budget line with adequate funding for house managers of people with self-direction budgets to ensure self-directed homes are effectively set up, properly staffed and sustainable long after parents are not able to provide this support.
- **Non-medical transportation services:** People with self-direction can use their OTPS budget line for personal transportation, but the amount provided does not sufficiently cover basics (like phone and utilities) and transportation. Additional opportunities for nonmedical transportation services using Medicaid should be explored to break down this significant barrier to community engagement and potential employment.¹⁸⁰

- **Supportive amenities in housing developments:** Create a funding stream for supportive amenities that community-based organizations can provide in housing developments.
- **Awareness campaign for LTSS:** Create an awareness campaign to help individuals with A/I/DD and their families better understand and apply for LTSS and other public benefits. This can be through the ombudsman program.¹⁶⁰

Rental Subsidies and Affordable Housing Choices

- **Prioritize individuals with A/I/DD in applications for rental assistance.** In local HCV waitlist applications, prioritize low-income individuals with A/I/DD and/or those receiving OPWDD waiver services.
- **Create housing assistance programs for individuals with A/I/DD regardless of Medicaid eligibility.** Public housing authorities can create housing assistance programs meeting the housing needs of those diagnosed with A/I/DD that is not predicated on Medicare eligibility.¹⁸¹ This program can be modeled after the Housing Options for Persons with AIDS.
- **Expand HCV homeownership.** Expand the homeownership voucher program and prioritize adults with A/I/DD in applications for homeownership vouchers.

- **Fund housing navigation services regardless of Medicaid eligibility.** Develop and/or provide funding for accessible housing navigation services for adults with A/I/DD who have low income to guide them through the complex process of securing affordable housing.
- **Fund benefits navigation.** Develop and/or provide funding for accessible benefits navigation services for adults with A/I/DD who have low income, regardless of Medicaid eligibility, to guide them through the complex process of securing and maintaining public benefits.
- **Increase 811 funding applications.** Promote collaboration among OPWDD and public housing authorities 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.
- **Educate landlords to address sources of income discrimination.** To prevent unintended sources of income discrimination with HCVs, offer educational opportunities to landlords, property managers and developers to help them better understand how individuals with A/I/DD access their LTSS, what they provide as potential tenants, and their unique financial and legal arrangements.

- **Increase housing stock.** Approach the Rochester Housing Development Fund Corporation (RHDFC) and Greater Rochester Housing Partnership (GRHP) to consider redeveloping homes in their Home Rochester Program, targeting households of adults with A/I/DD.
- **Promote resources to assist in purchasing homes.** Request that the City of Rochester's Home Purchase Assistance Program Grant (HPAP) be expanded to include assistance to families who are purchasing a home for a dependent loved one with A/I/DD.

Increase Development of Neuro-Inclusive Communities

- **Implement land banking to increase housing developments for adults with A/I/DD.** Rochester Land Bank Corporation could partner with local service providers to issue request for proposals to develop properties targeting residents with A/I/DD.
- **Increase housing stock by providing incentives for developers.** Incentivize neuro-inclusive housing development or set-aside units targeting adults with A/I/DD through density bonuses, fee waivers, parking variances, etc.

- **Include individuals with A/I/DD in city development plans.** Using Rochester's 2034 Comprehensive Plan Guidebook, explore the action plans and reach out to community partners undergoing redevelopment efforts to ensure consideration of individuals with A/I/DD.
 - Prioritize individuals with A/I/DD within New York's Quality Allocation Plan to incentivize developers to create affordable neuro-inclusive housing for adults with A/I/DD.
- **Expand funding sources for housing development.** Develop a funding source and/or incentives through the Rochester Housing Stability Fund for new construction or rehabilitation that create additional units for single or two-person households incorporating universal and neuro-inclusive design elements.
- **Offer pre-development technical assistance grants:** Approach the Greater Rochester Housing Partnership to expand their predevelopment loan program using a model recently launched by the Colorado Housing and Finance Authority to offer **pre-development technical assistance grants**¹⁸² to landowners like local nonprofits, faith communities and developers to hire consultants, and/or conduct feasibility activities to create local neuro-inclusive solutions.

Local Community Development

- **Include A/I/DD in local DEI efforts.** To increase the visibility of Rochester's population of individuals with A/I/DD, include adults with A/I/DD in Celebrate City Living efforts or in local diversity, equity and inclusion efforts.
- **Incentivize businesses to employ adults with A/I/DD.** This could be done through incentivizing DEI officers and experts to train business managers to support adults with A/I/DD.
- **Include the needs of adults with A/I/DD in strategic plans.** Recognize the housing needs of those with A/I/DD living with family caregivers in future housing strategic planning documents or local comprehensive plans.
- **Combat loneliness.** Explore how to address the loneliness crisis and increase natural support systems.
- **Develop transit-oriented development and walkable communities.** Partner with community land trusts, such as Rochester's City Roots Land Trust, and/or practice land banking of properties near public transportation and/or within walking distance of grocery stores for future affordable, neuro-inclusive planned or mixed-use communities.
- **Modify zoning ordinances.** Modify zoning codes to allow the addition of an ADU or tiny home as a "use by right"¹⁶⁴ on property that will house a dependent adult with A/I/DD; offer planning grants and waive fees associated with requesting approval.

“We need to educate [our leaders] to help us remove barriers and create more viable housing options—especially for those with complex needs.”

— Survey Respondent



CONCLUSION

Every person deserves the opportunity to build a life that reflects their needs, preferences and dreams. As with the neurotypical population, individuals with A/I/DD want a home that is safe, stable and comfortable. They want a home 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. However, few affordable and supportive housing options are available to meet those needs and wants.

For individuals with A/I/DD living with aging caregivers, it is not a matter of whether they will lose their primary caregiver—it is a question of when. The loss of their primary caregiver could lead to the loss of their home,

“The systems put in place by NYS to advocate and assist those with disabilities and their families are failing and lack options, which increases trauma, homelessness and a multitude of hardships.”

— Survey Respondent

too. A crisis like this is not only traumatizing but could also lead to health decline. An adult with A/I/DD may be forced to live in a skilled nursing facility for months or years due to lack of housing.

Adults with A/I/DD who want to move out of family homes may also face difficulties due to unaffordable housing. Complex systems of obtaining social benefits like a housing choice voucher are difficult to navigate and are underutilized by this population. Housing choice vouchers are also limited and waitlists are common. Even if they were to obtain vouchers, the current housing stock is not supportive and does not include physical amenities, supportive amenities or cognitive accessibility features. Evidence-based research has shown that these housing features can help improve social outcomes.

Other factors like workforce shortages, changing demographics and a rapidly aging population, especially of adults with A/I/DD, make it imperative for policymakers to increase housing options and access to services. Greater options and innovation in LTSS and housing options, coupled with physical and supportive amenities, can help build a place in the world where individuals with A/I/DD can thrive like their neurotypical peers. Housing models for those with A/I/DD must be adaptable to personal growth; static approaches will not meet evolving needs. A continuum of options allows individuals the dignity of adjusting supports as their circumstances change.

Thanks to the First Place Global Leadership Institute and AutismUp, the Rochester Housing Market Analysis expresses the residential needs and preferences of this invisible population. Meeting their housing needs will help result in improved quality of life and health for individuals with A/I/DD. With a more supported population, average Medicaid costs could be reduced through fewer emergency room visits and emergency placements. A data-driven approach to meeting the housing needs and preferences of this population will also help prevent future displacement and homelessness.

Join us in Rochester.

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



GLOSSARY

TERM	DEFINITION	PAGE
811 Project Rental Assistance (PRA)	This program seeks to identify, stimulate and support successful and innovative state approaches to providing integrated supportive housing for people with disabilities. ¹⁷⁹	82
Accessory dwelling unit (ADU)	An ADU is a small, independent residential dwelling unit located on the same lot as a stand-alone (i.e., detached) single-family home. It may also be referred to as a casita, granny flat, accessory apartment or secondary suite. It may be a converted portion of an existing home or an addition to a new or existing home. ¹⁶³	64
Achieving a Better Life Experience (ABLE) account	ABLE accounts are tax-advantaged savings programs that allow individuals with disabilities to save and invest money without jeopardizing eligibility for public benefits. ¹³⁷	48
Administration for Community Living (ACL)	The ACL 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. ⁴⁷	19

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 services. ¹⁹	17
Area median income (AMI)	AMI is a key metric in affordable housing. It 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. ¹²³	44
Autism and/or intellectual/developmental disability (A/I/DD)	A/I/DD represents differences, usually present at birth, 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 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. ¹	9
Autism spectrum disorder (ASD)	ASD is a neurodevelopmental disorder defined by specified differences in social communication and the presence of focused interests and repetitive behaviors. ²⁰	17
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. ¹⁵	16
Certified setting	A setting that has been assessed and certified by OPWDD ensuring quality care in a quality environment. ²⁷	17
Cognitive accessibility	Cognitive accessibility refers to inclusive practices that remove barriers for individuals whose disabilities affect how they process information. ⁷⁰	23

TERM	DEFINITION	PAGE
Community land trust (CLT)	A CLT 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. ⁴⁰	74
Corrective action plan (CAP)	CAPs outline the actions and activities the state proposes to bring the agency and/or setting into compliance with the settings criteria are submitted to CMS. As a result of the 2014 HCBS settings rules, states were required to develop 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 perform heightened scrutiny visits to identify if and when state agencies and/or HCBS providers are not meeting the requirements under the settings rules. ⁵³	20
Consolidated plan	A plan designed to help state and local jurisdictions assess affordable housing and community development needs and market conditions, enabling 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. ¹⁰²	28
Consumer-controlled setting	A property where the housing provider is not connected to the LTSS (see Glossary) provider. Residents can choose and change their LTSS providers while remaining in the same housing. ⁴⁰	13
Consumer-Directed Personal Assistance Program (CDPAP)	A Medicaid program that provides services to chronically ill and/or physically disabled individuals who have a medical need for help with daily living activities. ²⁵	17
Emergency housing vouchers (EV)	Housing choice vouchers to assist individuals and families who are homeless, at-risk of homelessness, fleeing, or attempting to flee, domestic violence, dating violence, sexual assault, stalking, or human trafficking, or were recently homeless or have a high risk of housing instability. ¹¹⁴	30

TERM	DEFINITION	PAGE
Empire State Supportive Housing Initiative (ESSHI)	ESSHI provides services and operating funding for congregate supportive housing in the state of New York. ⁹⁶	26
Executive function	Higher-level cognitive skills used for control and coordination of other cognitive abilities and behaviors. Executive function 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. ⁹¹	25
Familial dysautonomia	A genetic disorder that impacts the development and survival of certain nerve cells. ²¹	17
Graded movement	Movements whereby a person uses the appropriate amount of force to complete motor skills. Individuals 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. ¹¹⁶	31
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 live in this development type through private pay or Medicaid ICF/IID (see Glossary). ⁴⁰	22
Heightened scrutiny	The process of evaluating settings that wish to receive/or are already receiving HCBS funding to ensure they meet all requirements of the HCBS Settings Rule. These requirements state that all settings that receive Medicaid HCBS funding must: provide access to the broader community, give people choice and control in their daily lives, and provide opportunities for competitive integrated employment. ⁴⁹	19
Home Energy Assistance Program (HEAP)	A federally funded program that helps income-eligible households pay for energy costs, repairs and weatherization. ¹³²	45

TERM	DEFINITION	PAGE
HOME Investment Partnerships American Rescue Plan Program (HOME-ARP)	A program designed to increase housing supply for those experiencing homelessness and other qualified populations. ¹⁶⁹	69
Host home	An LTSS (see Glossary) provider's home where an individual with LTSS lives. ⁴⁰	23
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 residence must agree to rent under the HCV program. Qualified recipients include low-income families, the elderly and individuals with disabilities. ⁴⁰	27
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. ⁶⁷	23
Land banking	Public or community-owned entities created to acquire, manage, maintain and repurpose vacant, abandoned and foreclosed properties. ¹⁵²	53
Lifeline program	Lifeline is a federally funded program designed to assist individuals with meeting their phone needs. It helps cover a portion of qualifying individuals' phone bills to help them maintain connections through their device(s). ¹³³	45
Long-term services & supports (LTSS)	A variety of support services that assist individuals with functional limitations due to various conditions and/or disabilities in their everyday life. ⁶	6
Low-income housing tax credits (LIHTC)	A federal program that encourages private investment in affordable housing. ¹⁶⁷	69

TERM	DEFINITION	PAGE
Medicaid Home- and Community -Based Services (HCBS) Waiver Program	Medicaid-funded state programs that develop and distribute waivers to meet the needs of individuals who prefer to receive long-term care in their home or community. HCBS waiver programs are required to meet a variety of criteria including: showcasing that providing waiver services will not exceed the cost of providing the same services in an institution; ensuring the protection of an individual's health and welfare; providing adequate and reasonable provider standards to meet the needs of the population served; and ensuring that services adhere to an individualized and person-centered plan of care. ¹⁰	15
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. ⁴⁰	65
National Low Income Housing Coalition (NLIHC)	A nonprofit organization established to help end America's affordable housing crisis. The NLIHC works to implement racially and socially equitable public policies that ensure those with the lowest incomes have quality homes that are accessible and affordable in communities of their choice. ²	9
Neuro-inclusive housing framework	This framework takes three specific elements into account when creating residential housing solutions that includes designing and building neuro-inclusive housing for neurodiverse individuals. 1) Housing, including affordability, renting vs. owning, property type and neuro-inclusive design elements. 2) Individualized long-term support services considering factors like in-person or remote support, Medicaid funding and various other service delivery models. 3) Supportive amenities, including planned activities, community navigators, life skills classes and assistance identifying a natural support system. ⁶⁸	23
Neuro-inclusive planned community	Small- or large-scale, planned property with multiple residential units that meet the needs of neurodiverse individuals. Community also has recreational amenities featuring commercial properties such as restaurants and shops. Property management helps maintain housing and common spaces with the goal of making life as convenient and enjoyable as possible while supporting connection and belonging. ⁴⁰	65
Neurodiverse/ Neurodivergent	Of neurological difference that includes ADHD and I/DD, autism, cerebral palsy, Down syndrome and epilepsy. ⁴⁰	38
New York State Medicaid	The state agency that provides healthcare for low-income adults with A/I/DD within their communities. This is distinct from the OPWDD, which offers Medicaid-funded HCBS waiver programs to provide LTSS in community-based settings. ¹⁷	16

TERM	DEFINITION	PAGE
Noncertified housing	Noncertified housing is simply housing controlled by the consumer. Housing includes market rate developments, affordable housing development, and rental and mortgage subsidies that are available based on economic need of an individual or a region or municipality. ³⁶	18
Non-elderly disabled (NED) vouchers	Category 1 NED vouchers enable non-elderly individuals or families to access affordable housing on the private market. Category 2 NED vouchers enable non-elderly disabled individuals currently residing in nursing homes or other healthcare institutions to transition into the community. ¹⁰⁰	28
Non-emergency medical transport (NEMT)	NEMT refers to transport services to and from scheduled medical appointments ranging from dentists to neurologists, as long as the appointment was scheduled in advance and is not an emergency service. ¹⁵⁰	52
Office for People with Developmental Disabilities (OPWDD)	New York state's OPWDD coordinates services for New Yorkers with A/I/DD, providing services from approximately 500 nonprofit and state-run service-providing agencies. About 80% of OPWDD services are provided by nonprofits; about 20% are provided by state-run services. ¹⁶	16
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. ³	10
Person-centered planning	The process of choosing and arranging needed services and supports of an adult with A/I/DD directed by the person receiving the supports. ⁵¹	20
Planned communities	A small- or large-scale, intentionally developed property with multiple residential units that also has recreational amenities. These communities can also feature commercial properties, such as restaurants and shops. Property management helps maintain housing and common spaces. The goal is to make life as convenient and enjoyable as possible. This development type is typically located in suburban settings. ⁴⁰	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 through pre-development and technical assistance grants. ¹⁸³	85
Provider-controlled setting	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. ⁴⁰	18

TERM	DEFINITION	PAGE
Qualified Allocation Plan	A document that states and some local agencies use to allocate federal Low-Income Housing Tax Credits (LIHTC). ¹⁶⁷	69
Remote support	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. ⁴⁰	61
Respite care	Respite care is when a professional comes in to relieve the primary caregiver for a specified period of time to allow them to travel, spend time with family, rest, etc. ²⁶	17
Self-directed support	Support given to an individual based on an assessment of their LTSS. They are responsible for recruiting, hiring, training, scheduling and firing support staff. Some states allow family members to be hired as support staff. ⁴⁰	62
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. The self-direction model prioritizes participant choice, control and flexibility. ²⁸	17
Sensory-friendly	Accounting for the five senses and taking into account environmental factors that contribute to and prevent sensory overload. ⁶⁹	23
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. ⁴	12
Settings Rule	A federal regulation that requires states to ensure that individuals receiving Medicaid HCBS services have access to and choice in community living, services and employment. ⁴⁹	20
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. ⁴⁰	61
Social Security Disability Income (SSDI)	Benefits paid to individuals and certain members of their family if the individual is insured: i.e., they have worked for a specific length of time and paid social security taxes. ¹²⁶	44

TERM	DEFINITION	PAGE
Special needs trust	A trust created for an individual with disability(ies) by a family member that does not impact the individual with special need'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. ¹³⁶	48
Statewide transition plan (STP)	In 2014, CMS finalized a rule establishing new requirements for the settings in which Medicaid home- and community-based services (HCBS) are delivered (CMS 2014a). Under the rule, states must develop implementation plans, known as STPs, and determine which providers meet the new requirements. ⁴⁴	19
Supplemental Nutrition Assistance Program (SNAP)	A federal program providing nutrition benefits to low-income individuals and families. ¹³¹	45
Supplemental Security Income (SSI)	Monthly benefits provided to individuals with limited income and resources who are disabled, blind or age 65 or older. ⁹³	25
Support brokerage	A service where a qualified individual (a support broker) assists individuals with their budgets to determine what services they need and help them find a suitable provider for those services. ²³	17
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. ⁴⁰	23
Transit-oriented development (TOD)	A current pilot program that provides funding to local communities to integrate land use and transportation planning with a new fixed guideway or core capacity transit capital investment. This program strives to improve public transit to address the needs of everyone and helps get people to jobs, school, healthcare, and visits with family and friends. ¹⁵¹	52
United States Interagency Council on Homelessness	The only federal agency with the sole mission of preventing and ending homelessness in the United States. ⁸¹	24
Use by right	A homeowner's right to use property and structures on their land in accordance with the zoning laws for their area. ¹⁶⁴	164

“Barriers must be broken and local agencies, as well as the state, need to respect and include parents’ concerns.”

— Survey Respondent



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