



# Realizing the Promise of Olmstead

A community-based housing study and policy recommendations  
for Georgians with intellectual and developmental disabilities and  
their caregivers

MAY 2023

## Acknowledgements

Support for this report was provided by the Georgia Council on Developmental Disabilities. The views expressed here do not necessarily reflect the views of the Council.

There are many people who made this project possible and gave their time and knowledge to ensure the research and recommendations capture the true needs and preferences of Georgians with IDD and their caregivers. In particular, we would like to thank:

Jordan Hall  
Derek Heard  
Teresa Heard  
Jessica Mathis  
Gaylon Tootle\*

### The project leadership group:

Beate Sass  
Tim Sass  
Claire Dees  
Vimal Isaac  
Joanna Jackson

\* Gaylon passed away at the beginning of the project. His presence and passion are deeply missed by all that knew him.

### Key informants:

Whitney Fuchs  
Desiree Kameka Galloway  
Marisol Risner Sivley  
David Whittenton  
Stacey Ramirez  
Pam Blanton

### Research assistants:

Jessica Franks  
Komal Alam

Several of the survey questions were adapted from "There's No Place Like Home: A National Study of How People with Intellectual and/or Developmental Disabilities and Their Families Choose Where to Live," by Carli Freedman, PhD. Thank you to Dr. Friedman and The Arc for allowing us to adapt their survey questions for our use.

## Disclaimers

This report does not endorse or oppose any specific housing type for Georgians with IDD. References to specific organizations and projects are not endorsements.

A PUBLICATION BY

 **GEORGIANS FOR A  
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THE VOICE FOR GEORGIA HEALTH CARE CONSUMERS

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# Introduction

**For Georgians with intellectual and developmental disabilities (IDD), housing is an issue of health & well-being, independence, civil rights, & finances. Unfortunately for many, housing that meets their health needs and individual preferences is difficult to find. As a result, their health suffers and they face consequences like reduced independence and unaffordable health care bills.**

Historically, most children and adults with IDD in the United States were unjustly forced to live in institutional settings. However, a 1999 Supreme Court case known as the “Olmstead decision” determined that the mass institutionalization of people with disabilities was unjustified segregation and violates Title II of the Americans with Disabilities Act.<sup>1</sup> The Court ruled that in order to keep people with disabilities out of institutional settings, public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated (taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity).

Since the Olmstead decision, thousands of Georgians with IDD have been released from institutional care to live in community-based settings. The change has been largely positive, but with little policy or systems supports to ensure adequate, affordable, accessible housing and support services, deinstitutionalization has fallen short of its potential. Many people with IDD have either chosen or are forced to live with their parents, many of whom are baby boomers and are increasingly struggling to care for their adult children. Those who want to live on their own struggle to find housing that meets all their needs—such as proximity to family, access to transportation, affordability, and availability of support services.

While people with IDD, family members, advocates, and service providers agree that there are far too many barriers to housing for people with IDD, limited data is available to describe the prevalence or severity of issues they face. Available data rarely differentiates between people with IDD and people with other kinds of disabilities and state-specific data is uncommon.

To address these shortfalls, Georgians for a Healthy Future, with funding from the Georgia Council on Developmental Disabilities (GCDD) and with guidance from the project leadership group, conducted a survey of Georgians with IDD and caregivers of people with IDD to better understand their current housing status, needs, and preferences. We deepened this research by convening focus groups of survey respondents to clarify and contextualize the survey findings. The final research component included

1. Olmstead v. L.C. (98-536) 527 U.S. 581 (1999) [https://www.law.cornell.edu/supct/html/98-536\\_ZS.html](https://www.law.cornell.edu/supct/html/98-536_ZS.html)

key informant interviews and an environmental policy scan to compile existing data about housing for people with developmental disabilities, examine current housing and independent living services and supports in Georgia, and review best practices and policies of other states.

This report describes our research findings about the housing issues faced by Georgians with IDD and their families, as well as promising policies and programs undertaken in other states to address this issue. We additionally recommend actionable state policy and systems changes that we believe will improve housing and housing supports for all Georgians, particularly those with IDD.

# Background

## DEFINITION

**Intellectual and developmental disabilities (IDD)** are differences in a person's brain and other body systems that are usually present at birth but can start any time before a child turns 18. These differences uniquely affect the trajectory of a person's physical, intellectual, and/or emotional development. IDD is characterized by differences in intellectual functioning, such as the ability to learn, reason, and problem solve, and differences in adaptive behavior, including everyday social and life skills.<sup>2</sup> Individuals with IDD may also experience physical differences, such as hearing, vision, and mobility impairments. Examples of IDDs are autism spectrum disorder, down syndrome, cerebral palsy, and fragile x syndrome.

## PREVALENCE

The prevalence rate for IDD in America is estimated to be about 2.2%. This means that an estimated 7.37 million Americans and 240,000 Georgians live with an IDD.<sup>3</sup> This number is estimated using U.S. census data and the estimated prevalence of IDD within the population. It is important to note that accurately capturing the number of people living with IDD is extremely difficult, if not impossible, due to the varying levels and measures of IDD.

## POVERTY AND HOUSING AFFORDABILITY AMONG PEOPLE WITH IDD

People with IDD often live on fixed incomes and are among the poorest Americans.<sup>4</sup> Most people with IDD live on Social Security and Supplemental Security Income benefits, which are often far lower than typical rents. This disparity between income and real costs frequently prices people with IDD out of rental markets across the country, including in Georgia.

Data from Technical Assistance Collaborative (TAC) housing affordability analysis found that in 2022, a Georgian with a disability received Supplemental Security Income (SSI) benefits of \$841 per month (about 17.3% of the statewide median income). At that income level, a person with a disability would have to spend 112% of their monthly income to rent a one-bedroom apartment. Within Georgia's federally defined housing market areas, the cost ranged from 70% of SSI payments in the Stewart County housing market area to a high of 163% of SSI payments in the Atlanta-Sandy Springs-Roswell housing market area.<sup>5</sup> When Georgians with IDD can find affordable & accessible places to live, the availability of support services to accommodate independent living can be a limiting factor.

2. National Institutes of Health (2021). About Intellectual and Developmental Disabilities (IDDs). <https://www.nichd.nih.gov/health/topics/idds/conditioninfo>

3. S. A. Larson et al., "In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2016," Minneapolis, MN, 2018. [Online]. Available: [https://ici-s.umn.edu/files/4pQ7Pt7HxF/risp2016\\_web.pdf](https://ici-s.umn.edu/files/4pQ7Pt7HxF/risp2016_web.pdf).

4. *Statement on Housing and IDD*, n.d. American Association on Intellectual and Developmental Disabilities <https://www.aidd.org/news-policy/policy/position-statements/housing>

5. Technical Assistance Collaborative (2022). *Priced Out: The Housing Crisis for People with Disabilities* <https://www.tacinc.org/resources/priced-out/>

When housing availability, affordability, & accessibility, or the availability of support services fall short for people with DD, the risk of institutionalization & homelessness increases. An estimated 17% of homeless individuals in Georgia have a disability, outpacing the prevalence of disability among Georgians overall (12.6%). Of the Georgians with a disability who are experiencing homelessness, more than two-thirds are unsheltered, meaning that they are sleeping outside or in similarly unsafe places.<sup>6</sup> Even if an individual with IDD is able to avoid institutionalization or homelessness, many find themselves “cost-burdened” by their housing – i.e. paying so much for rent that they are unable to afford basic necessities or are forced to live in inadequate conditions. This can further exacerbate their health conditions, reduce their ability to work or go to school, or negatively impact other parts of their lives.

## WAIVERS

For people with IDD to realize their right to live full lives in the communities of their choosing, as intended by the Olmstead decision, they must have access to **long-term support services (LTSS)**. LTSS can include nursing facility care, adult daycare programs, home health aide services, personal care services, transportation, and supported employment. LTSS can be provided and paid for by Medicaid for people whose disability is severe enough to meet Medicaid qualifications.

Among the people with IDD who qualify for Medicaid, many are served through Medicaid 1915(c) **Home and Community-Based Services (HCBS)** waivers.<sup>7</sup> Georgia has two such waivers specifically for people with IDD called the New Options Waiver (NOW) and the Comprehensive Supports Waiver Program (COMP). The two waivers differ in the levels of support they provide. Still, both serve the goal of allowing Georgians with IDD to avoid institutionalization and live in the least-restrictive setting possible. Over 13,000 Georgians are currently enrolled in NOW and COMP waiver services. An additional 7,155 Georgians are on the waiting list.<sup>8</sup> Without these services, living outside of an institution is not an option for many.

Post-Olmstead, states rebalanced their LTSS away from institutionalization (like nursing facility care) and moved toward full community integration and individualized supports. Central to tailoring LTSS to the individual needs of recipients is the ability of people with IDD or family members of someone with IDD to self-direct eligible waiver services, including housing (also known as participant direction). Self-directed services mean that the individual or their family has decision-making authority over certain services and takes direct responsibility for managing their services with the assistance of a system of available supports. For example, individuals on self-directed waivers hire their own direct support professionals (DSP) or their legal representative does.

6. U.S. Department of Housing and Urban Development (2020). *The 2020 Annual Homeless Assessment Report (AHAR) to Congress* (p. 66, 87). <https://www.google.com/url?q=https://www.huduser.gov/portal/sites/default/files/pdf/2020-AHAR-Part-1.pdf&sa=D&source=docs&ust=1680896554736812&usg=AOvVawzn9AQIA2jhOdMU27jTuXz>

7. Centers for Medicare and Medicaid Services (2019). "Value-Based Payment for Home and Community-Based Services: Intellectual and Developmental Disability Systems." [www.medicaid.gov/state-resource-center/innovation-accelerator-program/iap-downloads/program-areas/iap-hcbs-ltss-factsheet.pdf](http://www.medicaid.gov/state-resource-center/innovation-accelerator-program/iap-downloads/program-areas/iap-hcbs-ltss-factsheet.pdf)

8. Department of Behavioral Health and Developmental Disabilities (2022). *Final Report of the Senate Study Committee on People with Intellectual and Developmental Disabilities and Waiver Plan Access (SR770)*. [https://www.senate.ga.gov/committees/Documents/Transparency/In-HighSchoolAtheletics\\_FinalReport.pdf](https://www.senate.ga.gov/committees/Documents/Transparency/In-HighSchoolAtheletics_FinalReport.pdf)

Self-direction is only available to waiver recipients who live in their own private residence or the home of a family member. With the move towards self-direction, more and more Georgians with IDD are remaining at home with their families, with parents or other family members sharing caregiving responsibilities alongside paid caregivers. While the ability to remain with their family has helped deinstitutionalization by allowing people with IDD to live in the community, it also means that parents must consider how they will transition their family member out of their home when the adult child with IDD no longer wishes to live with them or the family is no longer able to care for them.

#### **TYPES OF HOUSING AND LIVING SITUATIONS FOR GEORGIANS WITH IDD**

The types of housing available to a person with IDD vary depending on their daily support needs, ability to live independently, availability of unpaid or paid caregivers, access to waiver services, financial situation, and many more variables. Some Georgians with IDD can live in their preferred housing situation, while others are forced into a living situation due to a lack of appropriate housing, funding, and/or support services. The table on page 9 describes the various housing and living situations for Georgians with IDD. This report does not endorse or oppose any housing type.

#### **FEDERAL AND STATE HOUSING FUNDING MECHANISMS**

To understand the possible solutions to increase access to affordable, accessible housing for people with disabilities, including IDD, it is helpful to understand the available government housing funding sources. The table on page 10 lays out federal and state housing funding mechanisms that individuals with disabilities, including IDD, can use to pay for housing directly or that incentivize affordable housing developers to build housing stock that will meet the needs of people with disabilities.

**In the U.S., about 1 in 3 households using Section 8 housing vouchers are headed by a non-elderly person with a disability.**



# Types of Housing Available to Georgians with IDD

HOUSING TYPE	DESCRIPTION
<b>Independent Living</b>	Independent living options allow individuals with developmental disabilities to live on their own, either in their own homes or apartments, with minimal support. This may include support from family members or friends, as well as community resources such as transportation and employment services.
<b>Separate Living Arrangements at Home</b>	In this arrangement, an individual with IDD has a separate suite, accessory dwelling unit, or living arrangements with family. Georgians can use self-directed Medicaid waivers to pay for LTSS that allow them to stay at home.
<b>Shared Living Arrangements</b>	Shared Living/Shared Housing Arrangements allow an adult with IDD to live with individuals they are not related to (i.e. a roommate) in an independent setting (like a house or apartment). Paid caregivers can help with daily activities such as meals, transportation, and personal care. One of the benefits of these shared arrangements is that individuals can get the caregiving support they need in a positive social environment.
<b>Host Homes</b>	In a host home arrangement, an unrelated family is reimbursed for their time and for opening their home to an individual with IDD. Host homes must be licensed by state and/or approved by Medicaid and may have costs covered by Medicaid.
<b>Community Living Arrangements (CLAs)</b>	CLAs are small, community-based homes where individuals with IDD live together and receive support from trained staff members. Georgians living in CLAs have their residential services paid for in part by the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD). CLAs must be licensed by DCH.
<b>Group Homes</b>	Group homes are larger than CLAs and typically house four to eight individuals with IDD. Staff members help with daily living tasks and help residents participate in community activities. Group homes may be either state-funded or private pay. In Georgia, health care licensing by DCH is required for all group homes.
<b>Personal Care Homes (PCHs)</b>	PCHs provide rooms, food service, and certain personal services for two or more adults with disabilities not related to the owner or administrator by blood or marriage. They must be licensed by DCH. This designation includes assisted living facilities.
<b>Assisted Living Facilities</b>	Assisted living facilities are a type of PCH that provides additional services such as medication administration and support with activities of daily living.
<b>Private Choice Communities</b>	Private choice communities are larger than group homes and often found in rural settings. They frequently consist of separate cottages or larger homes with or without full time staff assigned to serve as a “house mother/father”. Almost always private pay due to Medicaid rules.

# Federal and State Housing Funding Mechanisms

PROGRAM	DESCRIPTION
<b>HUD Section 8 Housing Choice Vouchers</b>	A tenant-based rental assistance program funded by the U.S. Department of Housing and Urban Development (HUD) and administered by the Georgia Department of Community Affairs (DCA). The program helps extremely low and low-income individuals and families rent units in the private market. In the U.S., about 1 in 3 households using section 8 vouchers are headed by a non-elderly person with a disability.
<b>Georgia Housing Voucher Program (GHVP)</b>	The GHVP is administered by the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD). The program is a state-funded PSH program that helps eligible individuals obtain safe and affordable housing. It supports housing stability and integration into the community. To be eligible, a person must have a diagnosis of Serious and Persistent Mental Illness (SPMI) and meet other specific criteria. The program focuses on chronically homeless individuals and those transitioning from state psychiatric institutions, which may include people with IDD. In addition to rental support, voucher recipients are eligible for bridge funding that covers security deposits and moving expenses. GHVP was established in response to a legal settlement tied to Olmstead enforcement.
<b>Georgia HUD 811 Project Rental Assistance</b>	A <b>Permanent Supportive Housing (PSH)</b> program funded by HUD and administered by DCA. PSH is a housing intervention that combines affordable housing with voluntary support services, often with the goal of ending chronic homelessness. The HUD 811 program offers rental assistance and supportive services for people between the ages of 18 and 61 with long-term disabilities who may have difficulty living successfully in the community and may become homeless or institutionalized without support. Housing supports are tailored to the individual and may include reminders to pay rent, help to arrange medical appointments, and other services. The HUD 811 program is a project-based voucher, meaning the voucher is linked to the property, rather than the tenant. If the tenant moves to a different property that is not covered by the HUD 811 program, they lose the housing assistance.
<b>Georgia Home Access Program</b>	A program administered by the Brain and Spinal Injury Trust Fund Commission that is administered by the Department of Community Affairs (DCA) in partnership with Statewide Independent Living Council (SILC). The Home Access Program provides grant awards of up to \$10,000 to modify owner-occupied homes for an individual with a disability. The goal of the program is to allow people with disabilities to reside in their homes and avoid unnecessary entry into nursing homes or institutionalization. The program also helps those in nursing homes transition back into their own homes.

PROGRAM	DESCRIPTION
<b>Georgia Housing and Finance Authority Permanent</b>	<p>The GHFA PSH provides permanent housing in connection with supportive services to people with a disability who are experiencing homelessness. The program provides rental assistance through HUD, which is accompanied by a range of supportive services funded by other programs, such as those offered by local non-profits. The GHFA PSH is designed to serve a population that has traditionally been hard to reach- homeless persons with disabilities such as (but not limited to) Serious Mental illness (SMI), chronic substance abuse, and/or AIDS-related conditions. Funding for the program is awarded competitively to housing authorities, local nonprofits, or other entities through HUD's annual Continuum of Care process.</p>
<b>Low-Income Housing Tax Credit (LIHTC)</b>	<p>The LIHTC is an indirect federal subsidy that helps investors and developers build and manage affordable housing. States allocate LIHTCs to affordable housing developments through a competitive process, based on the state's Quality Allocation Plan (QAP). The QAP allows states to determine which populations and building considerations they want to prioritize for affordable housing. LIHTCs can be set aside for people with disabilities and some states direct a specific portion of their LIHTCs to people with developmental disabilities.</p>
<b>National Housing Trust Fund (NHTF)</b>	<p>THE NHTF is administered by HUD and allocates grants directly to states to build, preserve, and rehabilitate housing for people with the lowest incomes. By law, 90% of the NHTF dollars must be used for the production, preservation, and operation of affordable rental housing, and at least 75% of the money must serve extremely low-income (ELI) households earning no more than 30% of the Area Median Income (AMI). Most states target their NHTF resources to people experiencing homelessness, people with disabilities, elderly people, or other special needs populations.</p>

# Results: Online Survey

GHF, with guidance from the leadership advisory group, began our study with two online surveys: one for people with IDD and another for caregivers of people with IDD. The surveys assessed current housing and living situations, current housing accessibility and supports, housing preferences, and transition supports and preferences. We received valid survey responses from 1,684 people including 1,217 people with IDD and 467 caregivers.

## Survey Results for People with IDD

### DEMOGRAPHICS OF RESPONDENTS WITH IDD

TOTAL RESPONDENTS WITH IDD (N) = 1217

	CATEGORIES	RESPONSE	PERCENT*
<b>Gender</b>	Man	628	51.6%
	Woman	487	40%
	Genderqueer	72	6%
	Nonbinary	16	1.3%
	Other or Prefer Not to Answer	14	1.15%
<b>Race/Ethnicity</b>	White or Caucasian	654	53.7%
	Black or African American	245	20.1%
	Hispanic or Latino	121	9.94%
	American Indian or Alaska Native	174	14.3%
	Asian	51	4.19%
	Native Hawaiian or other Pacific Islander	80	6.57%
<b>Age Range</b>	18 to 24	251	21%
	25 to 34	516	42%
	35 to 44	320	26%
	45 to 54	89	7%
	55 to 64	23	2%
	65 to 74	5	.4%
<b>County of residence</b>	Rural	585	48%
	Urban	632	52%

\* All percentages are rounded to the nearest whole number and may not add up to 100%.

Survey responses were collected from 117 counties in Georgia, meaning 74% of Georgia's counties are represented in the survey results. Unsurprisingly, the largest number of responses came from Fulton County (13.85%). However, Polk, Elbert, Crawford, and Greene counties had disproportionately high responses compared to their population sizes. These four counties represent less than 1% (0.88%) of Georgia's population but comprised almost a quarter of the survey responses (22.52%).

Slightly over half of the respondents with IDD identified as male (including transgender men) (51.6%), followed by women (including transgender women) (40%), genderqueer (6%), non-binary (1.3%), and other or prefer not to answer (1.15%).

Respondents largely identified as white/Caucasian (53.7%) or black/African American (20.1%). Additional races and ethnicities represented included American Indian or Alaskan Native (14.3%), Hispanic/Latino (9.94%), Native Hawaiian or Pacific Islander (6.57%), and Asian (4.19%).

Survey respondents also tended to skew younger, with almost two-thirds (63%) under the age of 35.

People with IDD were also asked about the government benefits they received (if any). Almost all respondents (96.14%) reported receiving at least one government benefit, with Medicaid coverage (46.18%) and Social Security Disability Insurance (SSDI) (44.37%) being the most widely used benefits. Additionally, slightly under half of the respondents (44.8%) received either a NOW or COMP waiver for home and community-based services, meaning Medicaid pays for services that enable these individuals to live in the community rather than in an institution or medical setting.

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## CURRENT HOUSING STATUS

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Most respondents with IDD reported living in a community-based setting (70%) as opposed to a group home or institutional/medical setting. Most lived in either an apartment /condominium (28.3%), a single-family house/townhouse (24%), or a multi-family home/duplex (17.5%). Those that did not live in a community-based setting lived in a group/host home (16.6%), an institutional or medical setting (including intermediate care facilities for IDD (ICF-IDD) and nursing homes) (8%). A small percentage reported living in a school dormitory (4.76%). The high number of respondents living in community-based settings reflects the major shift from housing for people with IDD in institutions following the 1999 Olmstead decision.

Fifty-one (51) people with IDD reported that they were currently experiencing homelessness. While this number does not represent a large portion of respondents (4.2%), it is higher than the proportion of Georgians experiencing homelessness in the general population (1.77%).<sup>9</sup>

Over half of the respondents (54.5%) lived with family members, and 44% of respondents lived either on their own or with roommates (non-family). Interestingly, only about a quarter (26.6%) of people with IDD reported living in a situation where they do not pay a mortgage or rent. Slightly less than half (46.6%) of people with IDD reported renting their homes, which closely aligns with the number that lived independently or with roommates. About 16% (15.8%), did report owning their own home, which may mean some people with IDD live with family members but own the house they live in. Fifty-one (51) people with IDD reported that they were currently experiencing homelessness. While this number does not represent a large portion of respondents (4.2%), it is higher than the proportion of Georgians experiencing homelessness in the general population (1.77%).<sup>9</sup>

Respondents with IDD mostly felt that their income allowed them to afford the home they needed (66.3%). However, about a quarter (27.4%) said their income did not allow them to afford the home they needed.

“Because I have a job in addition to government benefits, most of my finances come from my own income, which is good and stable.”

— Person with IDD

“Because my income is small, the government benefits can only cover my basic living expenses.”

— Person with IDD

“The two incomes add up to cover the cost of housing, but living becomes a problem.”

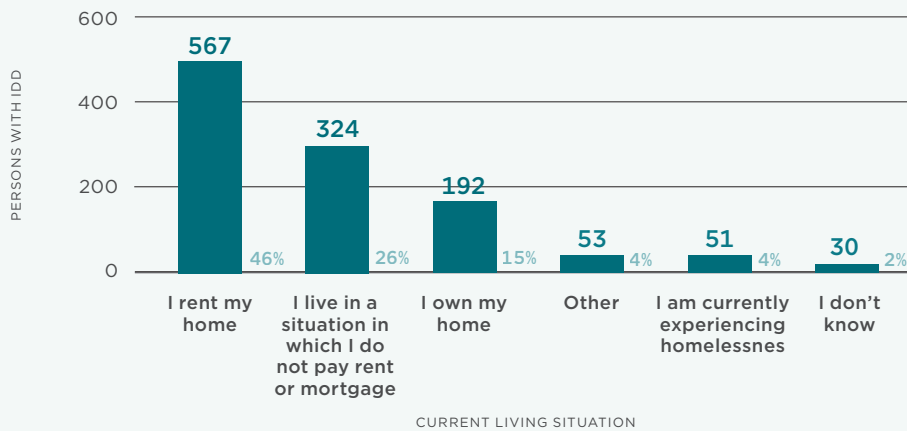
— Person with IDD

9. United States Interagency Council on Homelessness (2020), *Georgia Homelessness Statistics*. <https://www.usich.gov/homelessness-statistics/ga/>

Most respondents reported moving three or fewer times in the past five years (88%). Of those respondents that moved three or fewer times, 21.4% had not moved at all in the past 5 years, 27.1% moved once, and 39.3% moved two to three times. The most common reason for having to move in the past five years was that their home became physically inaccessible to them. The cost of rent and transportation were also common reasons for moving.

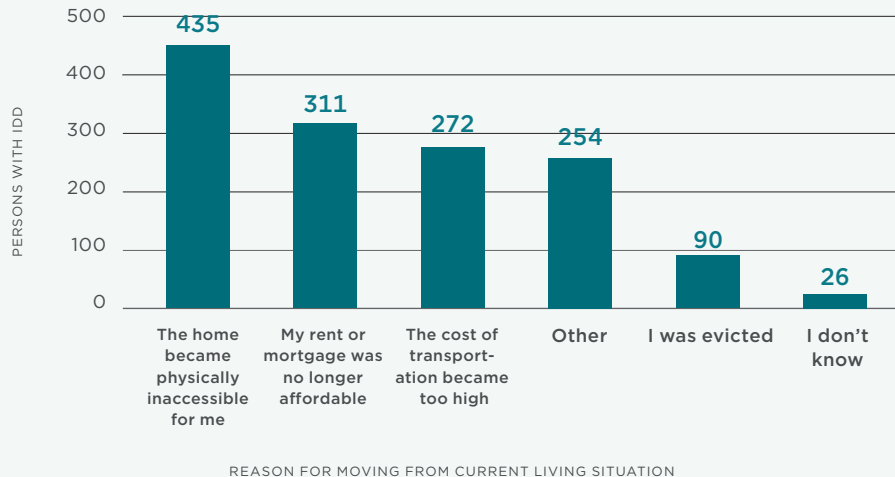
### CURRENT LIVING SITUATION AMONG SURVEY RESPONDENTS WITH IDD

Number of respondents (n = 1217)



### PERSONS WITH IDD BY REASONS FOR MOVING FROM CURRENT LIVING SITUATION

Respondents were allowed to select more than one reason. (n = 1388)



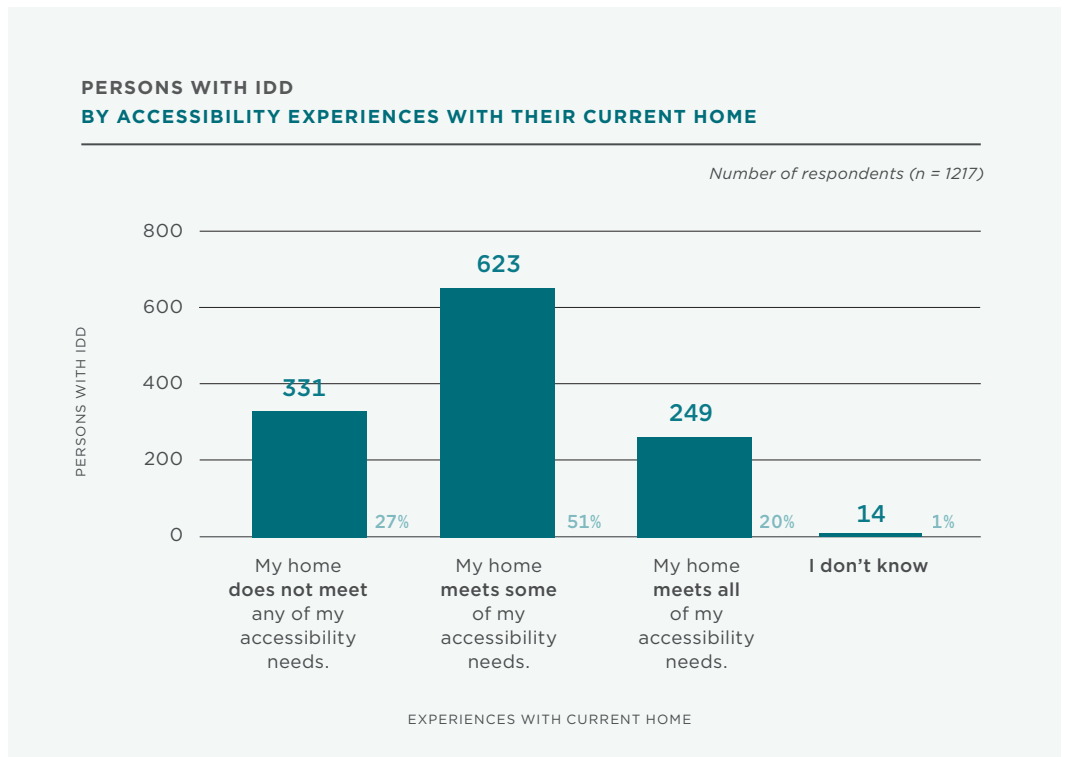
“Because of my physical difficulties, I need to find a place where I can move easily.”

— Person with IDD

## HOUSING ACCESSIBILITY

For this study, we defined home accessibility as the ability of their living situation to allow them to go about their daily routine without being segregated or isolated from society. Examples of good home accessibility include having an accessible route into and through (no steps or split levels) the unit, wide hallways and common areas without physical impediments, and access to public transportation. Examples of poor accessibility include entryways with steps, kitchens with islands, and housing that is far from accessible transportation.

When asked to describe the accessibility of their living situation, half of people with IDD (51.2%) felt that their home met some of their accessibility needs. Concerningly, about a quarter (27%) of people with IDD reported that their home did not meet any of their accessibility needs, meaning their home design likely segregated and isolated them from their community in ways that someone without IDD would not have been. Only one-fifth of respondents (20.5%) said their home met all their accessibility needs. Only one-fifth of respondents (20.5%) said their home met all their accessibility needs.





People with IDD were also asked how much their home design allows them to enter, exit, and move around their homes comfortably. About half (49%) reported that the design of their home somewhat limited their mobility, and 13% said that their home severely limited their mobility. Over a third of respondents reported that their home design either very (19.4%) or somewhat (16.5%) enabled their mobility.

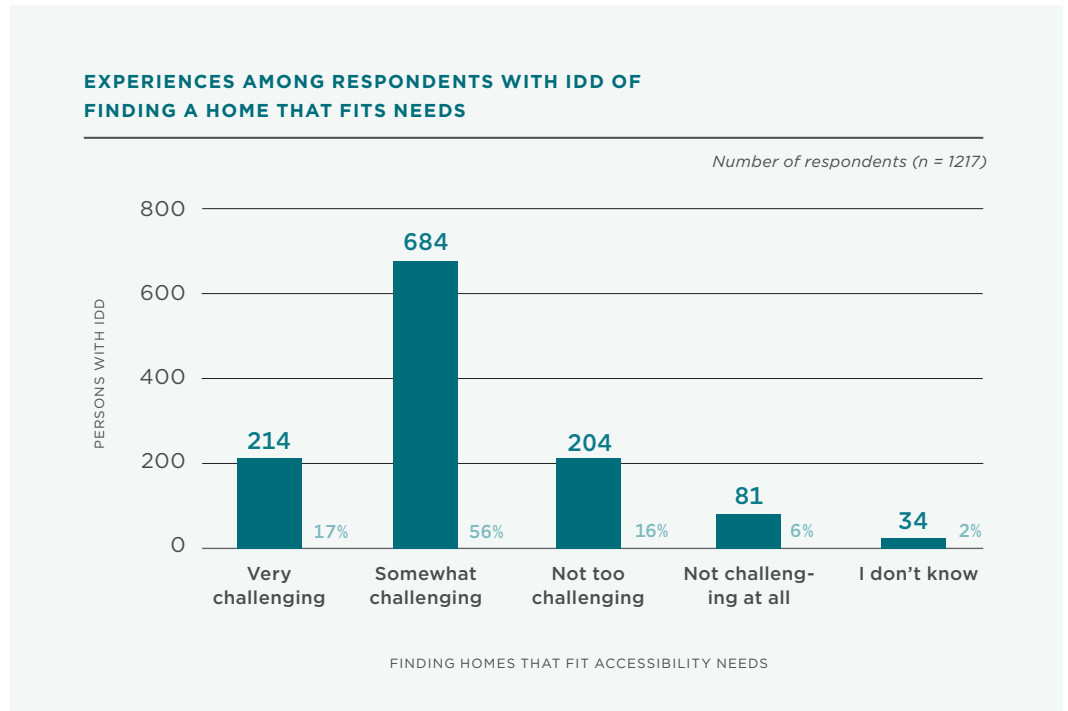
Over half (56.4%) were either somewhat or very concerned that they would have to move somewhere else because their home was not accessible to them. At the same time, 40% of respondents were either not too concerned or not concerned at all about having to move due to inaccessibility.

Most respondents with IDD (56%) reported that it was somewhat challenging to find a home that fit their needs. The fewest respondents (17.6%) reported that it was very difficult to find a home that fit their needs, and less than a quarter (23.4%) said that it was either not too challenging or not challenging at all to find a home that fit their needs.

“I am a person who is not convenient to move, so it is required that the place where I live should have independent access for the disabled and independent space for my daily life. For example, the bathroom and bedroom should be designed for people, so I feel that it is difficult to find such a place.”

— Person with IDD

## INDEPENDENCE



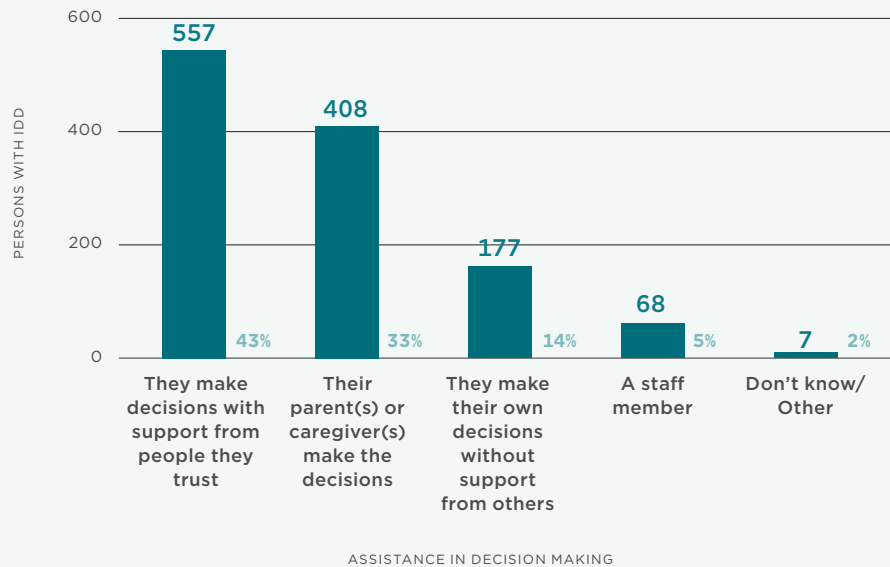
Survey respondents generally reported needing a relatively low level of support from caregivers during the day. About half (49.4%) reported needing three or fewer hours of support per day or only needing support on an on-call basis. A small percentage of people with IDD (11.3%) reported needing between 7 to 23 hours of support per day or round-the-clock support (7.6%).

When making choices about their living situations, almost half of respondents with IDD reported making decisions with support from people they trust (46%). A third of respondents (33.5%) said that their parent(s) or caregiver(s) make the decisions about their living situation, and a small portion (14.5%) said that they make their own decisions about their living situation without support from others.

Because of the limited amount of data available about people with IDD, it is difficult to know how the reported levels of independence and support among survey respondents align with Georgia's broader IDD population.

## LEVELS OF ASSISTANCE IN DECISION-MAKING AMONG RESPONDENTS WITH IDD

Number of respondents (n = 1217)



## PREFERENCES AND CHOICES

When asked about the most important physical characteristics of their home, most people with IDD (46%) responded that the house being in good condition was most important. Having their own bathroom (43%) and bedroom (40%) also ranked highly. One in three (31%) reported that the physical accessibility of the home was most important. Fewer (20%) reported that having their own place, in general, and the area in which the home was located (11%) were most important.

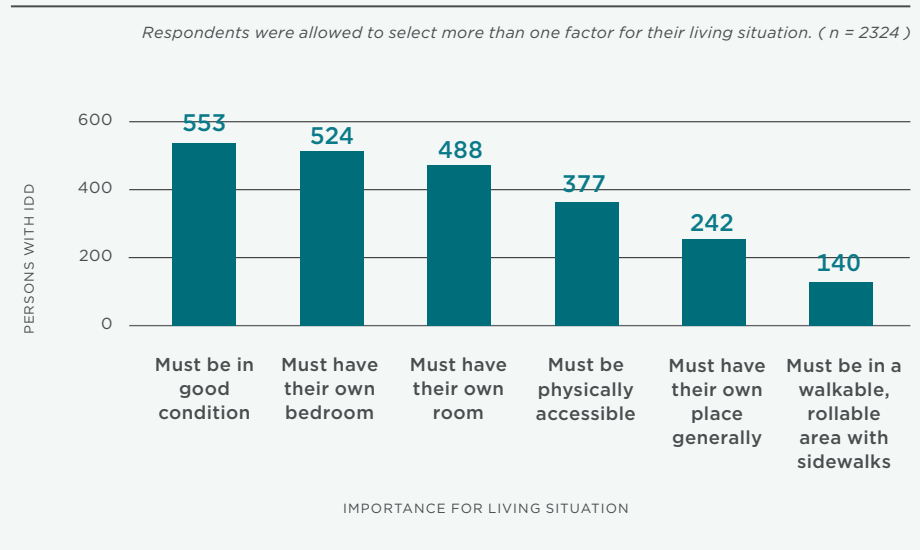
**“I have certain requirements for the infrastructure of the living environment, but I don’t think it is difficult because it is a normal requirement of an adult. Who wants to live in a place where there are no facilities around, and it’s a long way from work?”**

— Person with IDD

“In my dream house, I hope to have a convenient bathroom and a separate workshop. I want my house to be my own. I can have comfort and privacy. And there’s a little balcony where I can plant some flowers. The most important thing is that I can afford it.”

— Person with IDD

### MOST IMPORTANT PHYSICAL CHARACTERISTICS OF HOME AMONG RESPONDENTS WITH IDD



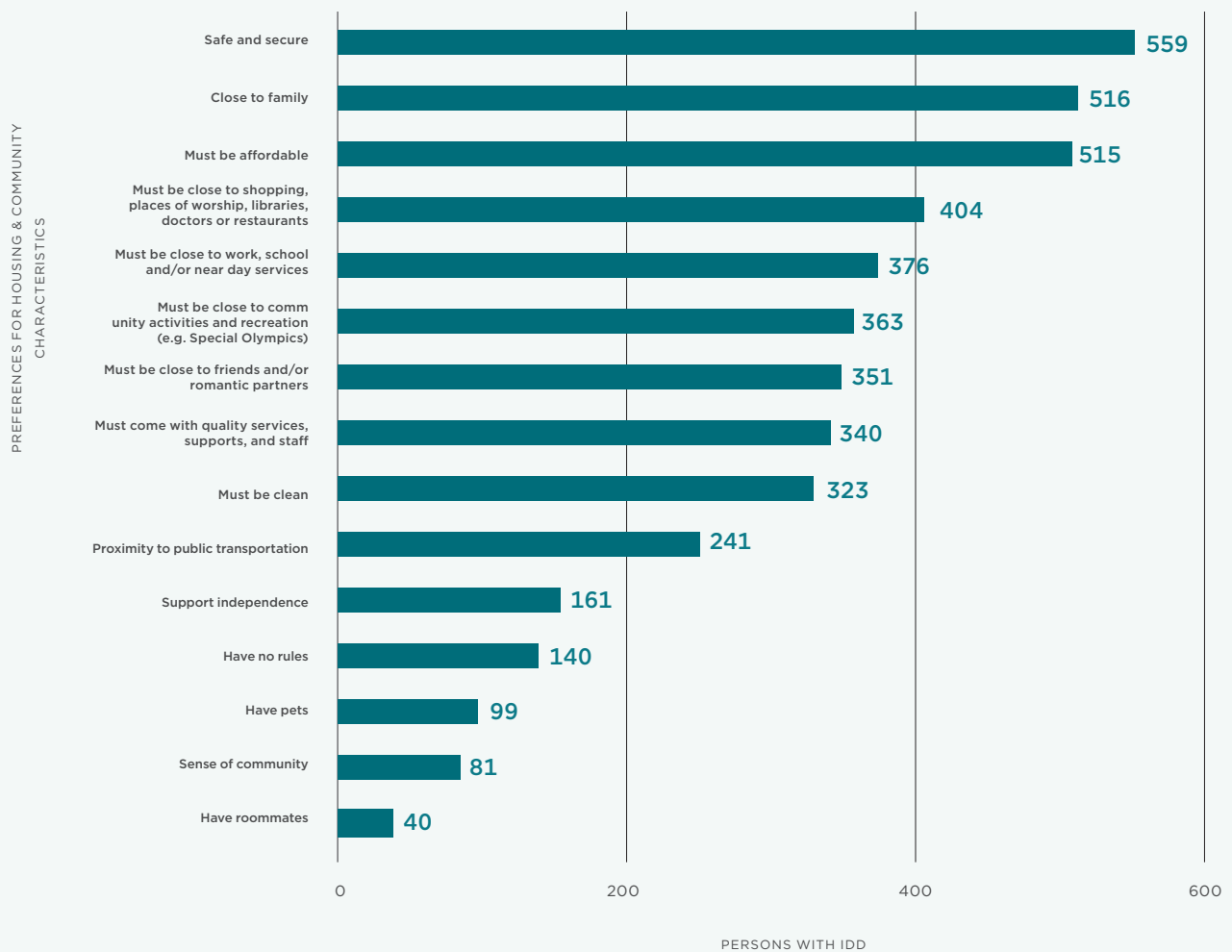
People with IDD were also asked about the most important features of the living situation and community. Most responded that safety (46%), proximity to family (42.4%), and affordability (42.3%) were important to them. Fewer responded that being able to have pets, feeling a sense of community, and having roommates were important. The complete list of responses and their importance can be seen in the next figure.

“For me, proximity to traffic and workplace is a must for me to find a house, which provides security for my life.”

— Person with IDD

## PREFERENCES FOR HOUSING OR COMMUNITY CHARACTERISTICS AMONG RESPONDENTS WITH IDD

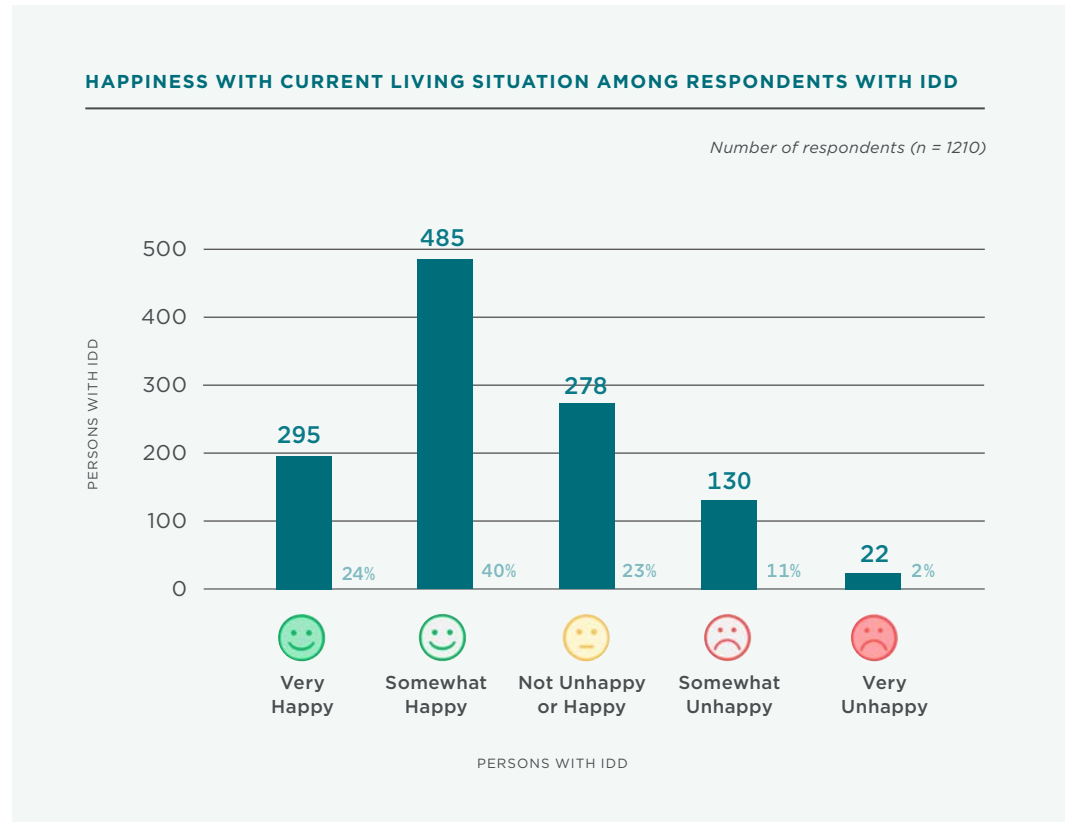
Respondents were allowed to select more than one reason. (n = 4509)



“My current job is close to home, and I will lose it if I move.”

— Person with IDD

Many participants reported being either somewhat or very happy with their current living situation (64%). A smaller proportion (22.8%) felt neutral about their living situation (neither happy nor unhappy). One out of eight (12.5%) reported that they were somewhat or very unhappy with their living situation.



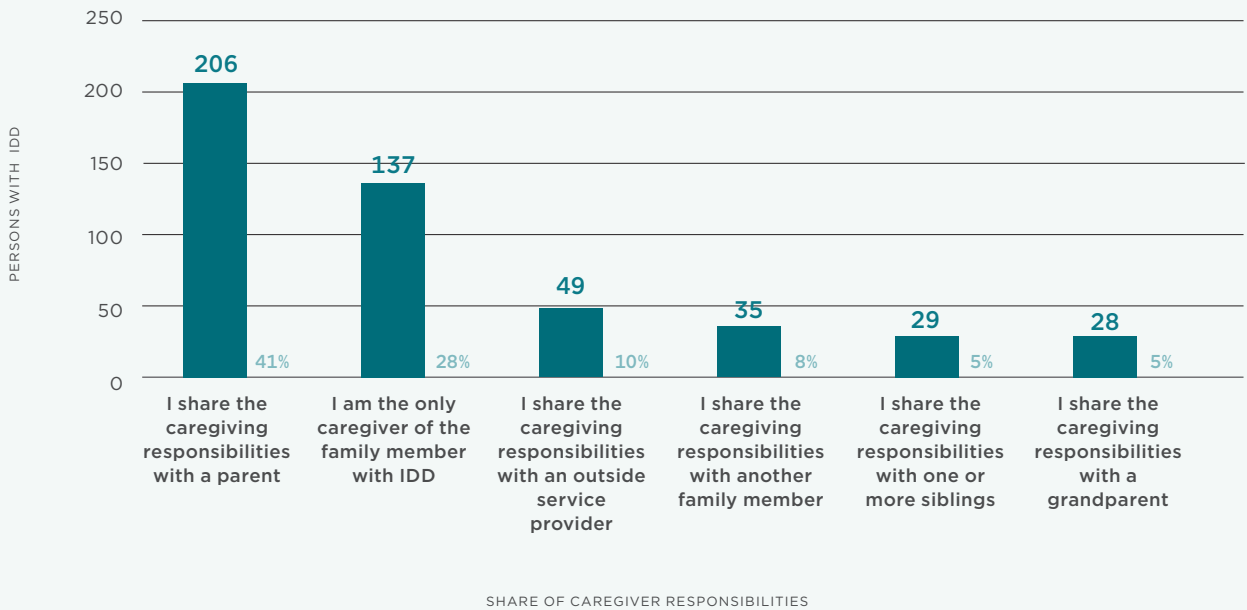
# Results for Caregivers

## CAREGIVING ARRANGEMENT

When asked about their caregiving arrangements, most caregivers reported sharing responsibilities with another person, including a parent, paid direct service professional (DSP), sibling, or grandparent. However, almost one in three caregiver respondents (29.3%) reported being the only caregiver for the person with IDD.

### CAREGIVERS BY SHARE OF RESPONSIBILITIES FOR CARE OF PERSONS WITH IDD

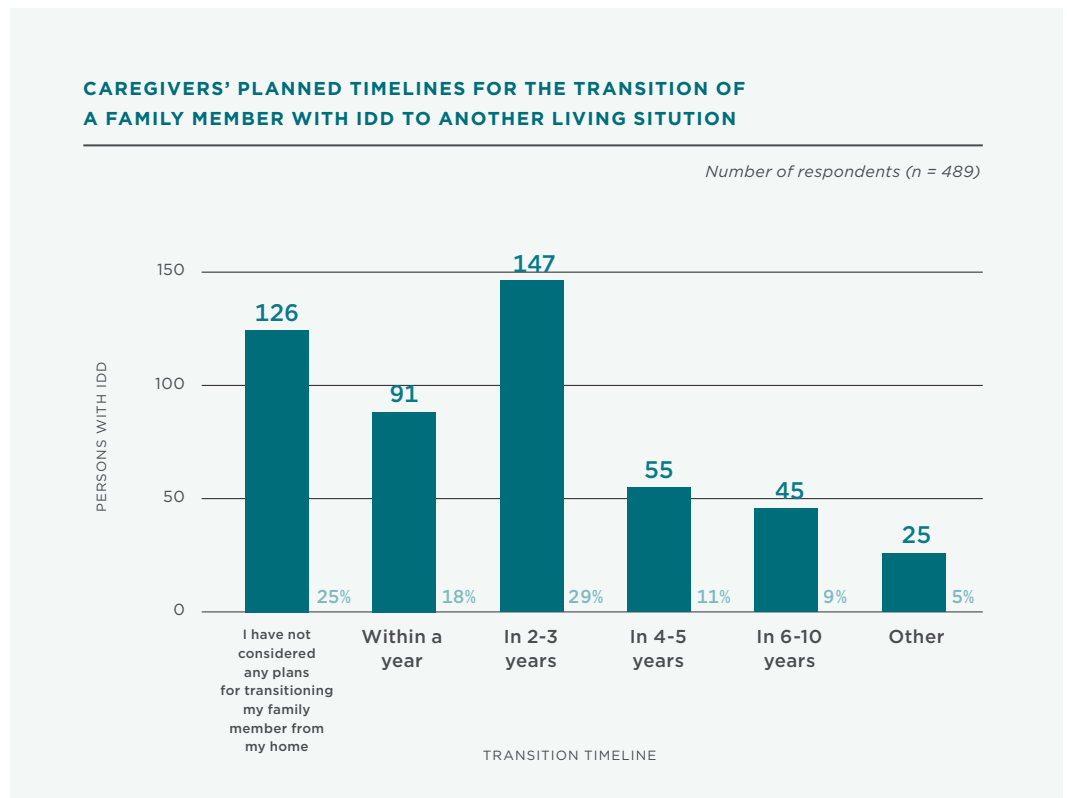
Number of respondents (n = 507)



Most caregivers also reported that the person with IDD for whom they cared currently lived in their home at the time of the survey (86%).

## TRANSITION PLANS

Caregivers were asked if they had considered plans to transition the person they're caring for to another living situation and, if so, how soon the transition might happen. A quarter (25.3%) of the caregivers reported that they had not considered any transition plans. The highest proportion (30%) said they were considering a transition to a new living situation in 2-3 years. Some caregivers reported planning to transition within a year (18.3%), and fewer reported a longer timeline of 4-5 (12%) or 6-10 years (9.5%).



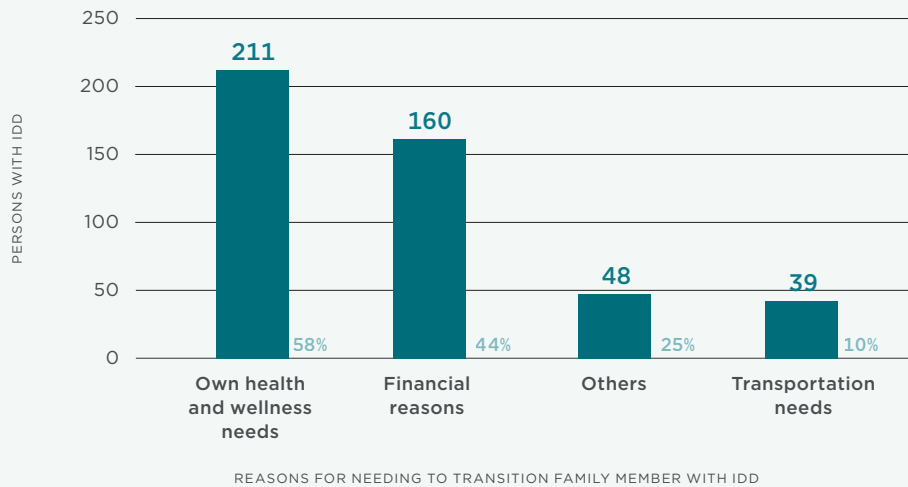
Most caregivers (84%) reported they were concerned that the family member with IDD they care for would need to move out of their home because they could no longer care for them. Of the caregivers concerned about having to transition their family member out of their home, the plurality (48%) were very concerned versus only somewhat concerned. A smaller number of caregivers (16%) reported that they were either not too concerned or not concerned at all about no longer being able to care for their family member with IDD.

Caregivers cited their health and wellness needs as the biggest reason for transitioning the family member with IDD to a different living situation. Financial concerns were also a significant consideration for caregivers.



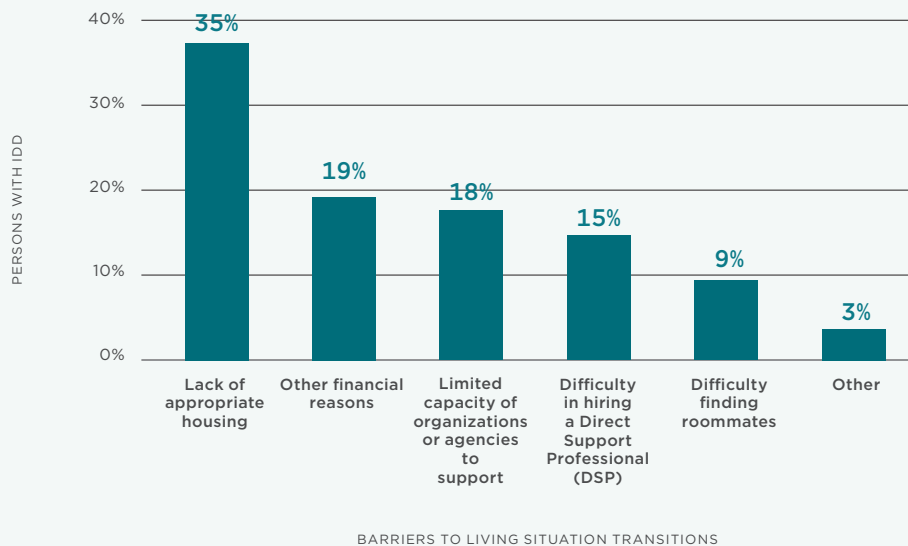
### REASONS GIVEN BY CAREGIVERS ABOUT THE NEED TO MOVE FAMILY MEMBER WITH IDD

Number of respondents (n = 364)



Caregivers cited a lack of appropriate housing as the most significant barrier to transitioning a family member with IDD that they care for to a different living situation. Unspecified financial reasons, the limited capacity of organizations and agencies to provide support, and difficulty hiring a DSP were also ranked as meaningful barriers to transition.

### BARRIERS TO LIVING SITUATION TRANSITIONS AS REPORTED BY CAREGIVERS OF PEOPLE WITH IDD



When asked to consider supports that would be most helpful for moving their family member to a new living situation, the availability of both appropriate and affordable housing were reported as the most beneficial. Caregivers also ranked support from organizations or agencies and ease in hiring DSPs highly.

“I want my child to be in a safe, supportive environment that helps him feel like he is a part of a community and is a person in his own right. I want a place that will help him thrive, [not] just exist till he dies.”

— Caregiver

“There are not many options for my daughter. It is so sad and the caregivers are paid a wage that makes it impossible to live, so even if we can find a residential program, I am not sure the caregivers will be available at the pay rate at this time.”

— Caregiver

In a testament to the diversity of housing preferences, caregivers did not demonstrate a majority preference for the living arrangements of their family members. Twenty-eight percent (28.4%) reported that their family member with IDD living with them was their preference, and another 25% selected owning their residence. Smaller proportions of caregiver respondents reported a preference for the person they care for to live in a group home setting (14.3%) or independently in a community of others with disabilities (14%).

“He requires constant supervision, and I want to know he’s cared for and lived the way I would do for him.”

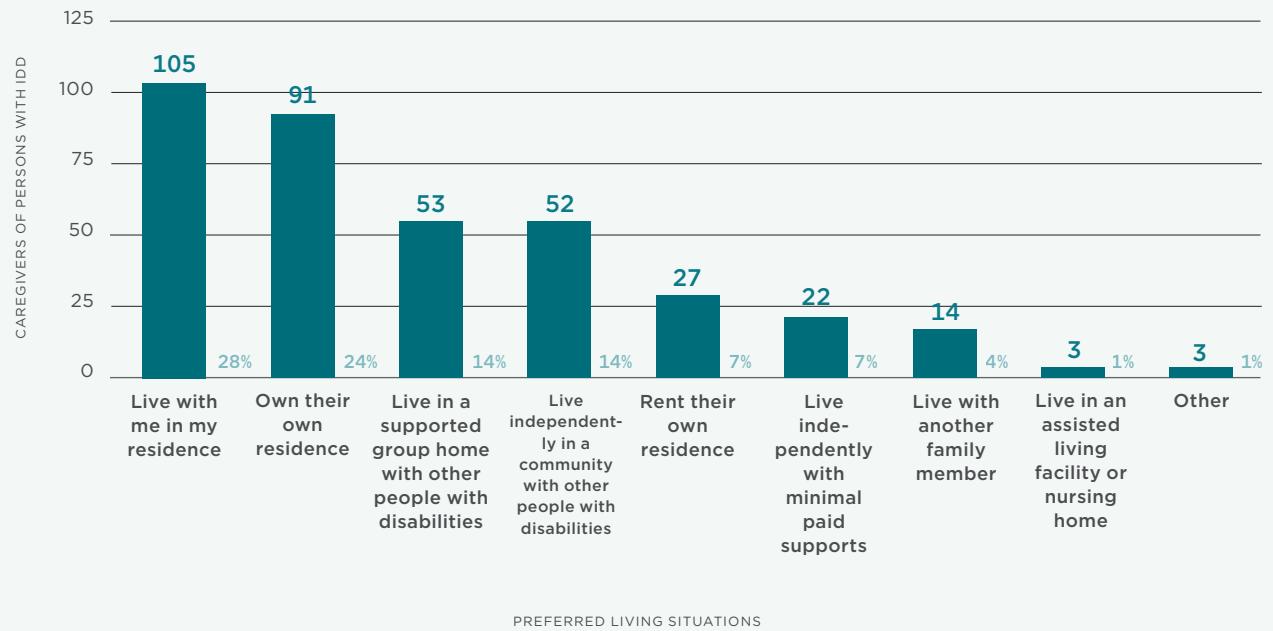
— Caregiver

“I would prefer my son to live in his own home and get services provided in his home and community.”

— Caregiver

## CAREGIVER PREFERENCES FOR THE LIVING SITUATION OF THE PERSON WITH IDD FOR WHOM THEY CARE

Number of respondents (n = 370)



# Results: Focus Groups

The second part of the study involved focus groups with survey participants. GHF conducted four focus groups, two with residents from “metro” areas of the state and two with residents from “non-metro” areas. The goal of the focus groups was to better understand and contextualize the quantitative survey results. The focus groups were initially designed to include people with IDD and caregivers. However, after extensive recruitment efforts, none of the survey participants with IDD were interested in or felt comfortable participating in the focus groups. Thus, the findings in this section reflect only the experiences and perspectives of caregivers.

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## THEMES FROM FOCUS GROUPS WITH CAREGIVERS OF PEOPLE WITH IDD

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### For people with developmental disabilities who want to live independently in the community. Options are minimal.

Caregivers for people with IDD indicated that the type of housing that would meet the needs of the person for whom they provide care is complex and impossible to find. While individual needs differed, most caregivers indicated that something akin to an apartment complex, where the person with disabilities could live with roommates and have some supervision or support on site for activities and daily tasks, would be ideal but is not generally available.

“Eventually we’re expecting him to go to a group home, but there’s not a lot of options for it and care is not as individualized as we need it to be.” — *Parent from non-metro focus group*

“As rent goes up for the individuals, it affects the amount of money they have for food. As their money goes up, their food stamps go down. Every month, I’m having to go out of pocket to pay for an individual’s rent as she doesn’t have enough money provided by the state to cover her expenses.” — *Caregiver from metro focus group*

“I’m finding that either you’ve got to be more independent than he is, or it’s cost prohibitive because he is on Social Security, and he does have the NOW waiver, but we just can’t find anything that he could afford without my husband and I contributing to it.” — *Parent from non-metro focus group*

“In trying to find my daughter housing, there’s a lot of laws in place that you can’t house more than four people with a disability in one place, they can’t have the same disability, the house can’t be on the same street as another house that houses people with disabilities and much more. How do we address those laws and build something appropriate?”

— *Parent from non-metro focus group*

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**In many cases, people with disabilities cannot live up to their potential or as independently as they would like because the accommodations, supports, and staff needed to facilitate this are not readily available or affordable, even with waivers.**

Day programs tied to group homes may be too elementary (coloring or elementary school worksheets, when the person has completed Algebra 1, for example) or may not be what the person wants to do with their days (go to a different program, work, etc.). Additionally, trained personnel to support activities of daily living are challenging to find, particularly given the low wages paid to caregivers.

“Without a waiver, you’re taking up a space for a child with a waiver that can come to these programs every day, whereas having to self-pay is expensive and can only do it a couple times a week and therefore not reaping the full benefits.” — *Caregiver non-metro focus group*

“Even with respite care funded by the state, nothing is available. Just because it is provided doesn’t mean we can actually use it. If it is provided, the care is 100 miles away from where we need it.” — *Parent from non-metro focus group*

“The day program that he had to attend was too low functioning, and they had him doing mass sheets that were like for a second grader... he needs more age-appropriate activities.” — *Parent from non-metro focus group*

“In terms of getting the resources she needs, a lot of the day centers are set up like babysitters and not anything to move individuals towards independent living which are preventing her from being able to move into group homes and gain independence. Now I’m being recommended to put my daughter in a nursing home.” — *Parent from non-metro focus group*

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**Aging parents caring for adult children with developmental disabilities struggle to find appropriate accommodations for their children as they age and consider their current situations unsustainable.**

Parents caring for their adult children with IDD are concerned about what will happen as they age and cannot provide the level of care and support their child needs. Many caregivers know their children will outlive them, or they will be unable to care for their adult children as they age and don't know what they will do. Caregivers are overwhelmed and exhausted.

“Not as young as I used to be [...] need to start finding other opportunities for my child to take care of them, but there's no clear direction in finding help.” — *Parent from metro focus group*

“Once you get into a facility or home, you have to consider managing personnel, hiring personnel, managing food stamps, managing all the elements that go into the care of an individual... Who will do that when we're gone? There's no model for that right now [...] to give continuity of care.” — *Parent from metro focus group*

“I wish there was more of a legal route in Georgia that we could actually claim in the courts but I do not have guardianship over him. We have a power of attorney, and practice supportive decision-making. But I do worry for the day when I'm not here and who will step into that position that will help him think through those supportive decisions, making choices about himself.” — *Parent from metro focus group*

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**Access to appropriate transportation is critical for people with developmental disabilities to live independently in the community.**

People with IDD need access to good public transit or a transportation service designed to accommodate the needs of people with disabilities to live independently in the community. Sometimes the programs that best fit the person's developmental level and individual goals are not available near appropriate housing options, which makes transportation an integral part of the equation.

“Being in a community that's walkable is important because public transportation isn't always available or highly reliable, especially those that go along a route to employment opportunities.”

— *Parent from metro focus group*

“We would love to move and be empty nesters but my son’s day program is here and there’s no transportation available for him in the area. He is not functioning enough to use a MARTA situation, so I feel like we’re trapped in the home we’re in.” – *Parent from metro focus group*

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**Finding good care (workforce) is extremely difficult and can negatively impact the ability of people with disabilities to live independently in the community, even if housing itself is available.**

Caregivers discussed challenges in finding someone to hire to assist their family member with IDD. Caregiving work can be stressful and emotionally demanding and pays meager wages. Family members have resorted to piecing together care, for example, by hiring someone privately to take their adult son or daughter to an activity or doing much of the work themselves, leading to exhaustion and burnout.

Caregivers also pointed out some of the unique challenges of people with developmental disabilities, including difficulty keeping up with personal hygiene, behavioral and emotional outbursts, and a lack of awareness of surroundings - especially as it relates to personal safety and security. These challenges mean that DSPs are essential for their family member to live independently. They described an inability to find an appropriate person to hire for this work or that the supports needed for a home or apartment with roommates were not available to the extent required.

“There’s a need to find care that’s more than a babysitter but not as intensive as an RN, but it’s difficult to establish and pay for.”

– *Caregiver from metro focus group*

“For an apartment kind of situation that some of us are thinking, you would have to have other roommates in order to pay the staff because one person’s waiver isn’t enough for full staff funding.”

– *Parent from metro focus group*

“Even if you have the golden ticket waiver, you can’t find support staff. You know and you’re paying support staff \$12 an hour to be frankly at our home. You could be kicked, you could be spit on, you could be yelled at, you could be managing seizures, a variety of tasks where you could make better money elsewhere, so that’s a big problem.”

– *Parent from metro focus group*

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### **It is difficult to find out about the limited existing housing options**

Several caregivers expressed a desire for better information about what is available. For example, they described the need for a dashboard or directory that is truly up-to-date and has information about housing options for people with disabilities. Participants appreciated the opportunity to learn from each other, and some were trying to develop their own housing communities because what they needed for the person in their care did not exist in any meaningful way. Caregivers also expressed frustration about waiting lists and limited housing and support services, even with the waivers.

“Lack of resources and organization out there to find up-to-date information on group homes or what is available out there. Leaves an unbelievable amount of responsibility on us as parents to work through muddy waters to find out what to do.” — *Parent from metro focus group*

“The waiting lists are so out of control, 5 to 10 years long... These programs would help with [subsidizing] the individual’s housing, but even if you get on the waiting list, you still need additional support to get the appropriate housing these individuals need.” — *Parent from metro focus group*



# Discussions

Most people with IDD reported living with family members. For some people with IDD and their caregivers, this was their preferred living situation. However, many people with IDD want to live independently in a situation that allows them to have the supports they need while being close to family, transportation, employment, and community supports. Many caregivers also reported that they either wanted their family member with IDD to live outside of their home or that the individual would eventually need to live outside of their home due to the caregiver's age or health status.

Despite these preferences, most people with IDD and their caregivers reported finding appropriate and affordable housing was difficult. Many people with IDD said that their living situation only met some of their accessibility and mobility needs and that finding a home that met all their needs was either somewhat or very challenging. People with IDD had trouble finding a home that fits both their budget and their accessibility needs.

Almost half of the caregivers indicated that they plan to transition the person with IDD to another housing situation in the next 12 months to 3 years but encounter many barriers to finding an appropriate living situation with which they and the person with IDD would feel comfortable. Caregivers found that the type of housing their family member needed either did not exist, was too far away, was too expensive, or lacked the appropriate physical, social, and community supports. Caregivers also reported feeling lost while trying to find suitable housing and exhausted from the additive demands of the housing search and day-to-day caregiving for their loved one with IDD.

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## IMPLICATIONS

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The current housing landscape is not working well for people with IDD and their caregivers. Many caregivers and people with IDD find themselves in situations that do not meet their needs or preferences because affordable and accessible housing and living situations are largely unavailable.

# Key Informant Interviews and State Policy Scan

The research project concluded by interviewing policy experts and looking at other states' successes to understand what opportunities may exist to address the gaps identified in the survey and focus group results.

## CONTRIBUTING FACTORS

According to the experts we spoke with, the lack of appropriate housing for people with IDD is being driven by several factors. These include a nationwide shortage of affordable housing in general, and a lack of housing built to meet the needs of people with IDD.<sup>10</sup> Difficulties navigating the process of finding housing, a workforce shortage of direct support professionals, and many other systemic problems have deepened the problem.<sup>11,12</sup>

These issues are not just problems for people with IDD but for all Georgians with disabilities, according to Georgia-based experts that we interviewed. The needs of Georgians with IDD vary significantly from person to person, and may range from physical accessibility to hygiene support to socialization needs. Thus, addressing the housing concerns of Georgians with IDD helps to address the housing concerns of all Georgians with disabilities.

## EXAMPLES FROM OTHER STATES

Several states have taken innovative approaches to address their own lack of affordable, accessible housing for people with IDD. The experts that we interviewed pointed to these as models that may hold lessons for Georgia.

10. Source: key informant interviews

11. Laws, C (2019). *The Direct Support Professional Workforce Crisis: Challenges, State Approaches, and Opportunities for Georgia*. [https://gcd.org/images/public\\_policy/2020/White\\_Paper\\_on\\_the\\_DSP\\_Crisis\\_CBL\\_10042019.pdf](https://gcd.org/images/public_policy/2020/White_Paper_on_the_DSP_Crisis_CBL_10042019.pdf)

12. American Network of Community Options and Resources (2022). *New Research Finds Direct Care Workforce Crisis Having Detrimental Impact on Access to Community Disability Services*. [https://www.google.com/url?q=https://www.ancor.org/wp-content/uploads/2022/10/The-State-of-Americas-Direct-Support-Workforce-Crisis-2022.pdf&sa=D&source=docs&ust=1684695066792566&usq=AOvVawO2\\_tYRPMKpaaP-mvxbTqNJZ](https://www.google.com/url?q=https://www.ancor.org/wp-content/uploads/2022/10/The-State-of-Americas-Direct-Support-Workforce-Crisis-2022.pdf&sa=D&source=docs&ust=1684695066792566&usq=AOvVawO2_tYRPMKpaaP-mvxbTqNJZ)

**EXAMPLES OF SOLUTIONS TO ADDRESS HOUSING NEEDS  
OF PEOPLE WITH IDD FROM OTHER STATES**

STATE	DESCRIPTION
<b>Florida</b>	The Florida Housing Finance Corporation (FHFC) has specifically directed 5% of the state’s Low Income Housing Tax Credit allocation authority to housing that supports people with a disability, including IDD. By dedicating a specific portion of their LIHTC to housing for people with disabilities, the state has expanded capital funding resources to create housing that is explicitly inclusive of people with disabilities, including IDD. The FHFC supplements the LIHTC commitment with grants for various housing models to serve people with IDD.,
<b>Arizona</b>	The Home Matters Arizona Fund uses a mix of public, private, and philanthropic funding to build affordable housing to serve Medicaid-eligible individuals. The fund prioritizes housing that is located near healthy food retailers, employment centers, active transportation facilities and public transit, schools, childcare, senior centers, medical facilities, public libraries, parks, community centers, and places of worship. One source of income for the fund comes from the state’s Medicaid Care Management Organizations (CMOs), who are required to direct 6% of their medical loss-ratio (MLR) to community needs. Arizona uses this funding from the CMOs to pay into the housing fund.
<b>Arizona</b>	The Housing and Health Options (H2O) program operates through an 1115 Medicaid waiver designed to address health-related social needs (i.e. social determinants of health). The H2O program combines housing and support services to allow people to remain stably housed, including people with IDD. The waiver also helps pay for community and transitional housing for Medicaid recipients in the state, including those with IDD.
<b>Minnesota</b>	Minnesota has two housing navigation programs designed to prevent and end homelessness for people with disabilities, including IDD. The Housing Stabilization Services (HSS) program uses Medicaid funding to help people with disabilities, including IDD and mental health needs, find and keep housing. The program assists eligible individuals with searching and applying for appropriate housing, creating a budget, finding funding for deposits and

STATE	DESCRIPTION
<b>Minnesota</b> <i>continued</i>	<p>moving costs, providing transitional services for people with waivers, understanding and applying for disability services, and more. The HSS program is only available to individuals on Medicaid who are eligible for HCBS.</p> <p>The Housing Access Services (HAS) program is similar to HSS, but it serves any adult with a disability, even if they do not have an HCBS waiver. The HAS program can also pay for security deposits, mover costs, or some basic furniture/household goods once the person has found housing.</p>
<b>New York</b>	<p>New York's Office for People with Developmental Disabilities operates a housing subsidy program for people with IDD that are on self-directed waivers and living outside of their family home. Unlike Housing Choice Vouchers, which are based on a percentage of the person's income, the housing stipend is a flat rate for everyone. The cost of the stipend is paid for through state Medicaid funding.</p>
<b>Colorado</b>	<p>The Colorado Housing and Finance Authority (CHFA) offers funding for pre-developmental technical assistance grants for developers interested in building housing that is inclusive of people with disabilities, including IDD. The funding helps non-profits and developers hire consultants and conduct feasibility studies to build inclusive housing. The technical assistance can include community engagement, market studies, site identification and site feasibility, financial modeling, real estate planning, and more.</p>

# Recommendations

The findings from our research have broad implications. Many recommendations for housing policy and practice at the federal, state, and local levels could be made. While all levels of policy solutions should be examined for opportunities to improve and expand housing for people with IDD, we limited our recommendations to those at the state level.

The recommendations below reflect the themes and findings of our research, as well as results and best practices identified in existing research and policy making. These suggestions are meant to improve system navigation, community infrastructure, affordability, and housing availability immediately and over the long term for people with IDD and their caregivers.

Our recommendations are presented in order of the capacity and resources required for implementation, beginning with the easiest.

## **1. Convene a standing working group of relevant state agencies, Georgians with IDD, and caregivers to address the housing needs of Georgians with IDD.**

Experts we spoke to during the project repeatedly identified the siloing and isolation of the IDD community as a significant barrier to addressing the lack of affordable and accessible housing for the population.

To break down these siloes, we recommend the creation of a multi-agency working group charged with promoting a policy-making environment in which the needs and considerations of Georgians with IDD and their caregivers are considered in all conversations regarding housing, especially affordable housing for people with disabilities.

The group should consist of all the state agencies that play a role in housing for Georgians with disabilities, including those with IDD. These agencies include the Department of Community Health (DCH), the Department of Behavioral Health and Developmental Disabilities (DBHDD), the Department of Community Affairs (DCA), and the Georgia Council on Developmental Disabilities (GCDD). An equal number of representatives who are Georgians with IDD and their caregivers should additionally sit on the working group.

We recommend that the working group be tasked with the following activities:

- Examine available housing funding sources that can be directed (or better directed) to housing for people with disabilities, including those with IDD.
- Review existing policies for housing for people with disabilities, including IDD, to identify redundancies, opportunities to streamline, and potential innovations to make it easier for people with IDD to find living situations that meet their needs.
- Apply for additional funding through the HUD 811 program and other housing subsidies.
- Explore funding, policies, and practices that will support and empower caregivers who are transitioning their family member with IDD to a new living situation, and support caregivers whose family member remains in their home.
- Understand new or emerging housing finance and policy opportunities from the federal government or other sources and how they might apply in Georgia.

The working group should be required to submit an annual report to the legislature and Governor that includes a summary of their work over the year and recommendations for legislative and executive actions to support housing accessibility and availability for Georgians with IDD.

## 2. Increase wages for direct support professionals (DSPs)

DSPs are paid caregivers that provide support to people with IDD. DSPs help with many essential tasks, including personal hygiene, cooking, cleaning, transportation, navigating social interactions, monitoring and redirecting behavior, and much more. DSPs are critical to helping people with IDD live as independently as possible, no matter what type of housing they are in. DSPs are employed by families or LTSS providers.

Individuals on self-directed waivers have flexibility in how much they pay DSPs since they can make hiring decisions independently. However, those DSPs that work in provider settings are subject to the state's Medicaid reimbursement rate. Currently, DSPs make \$10.63 an hour and often must work multiple jobs to make ends meet. Such a low wage makes it very difficult for providers to hire and retain DSPs, making it even more difficult to serve people with IDD. Increasing wages for DSPs was also a final recommendation of the Senate Study Committee on People with Intellectual and Developmental Disabilities and Waiver Plan Access (SR 770)<sup>13</sup> that met in 2022.

13. Final Report of the Senate Study Committee on People with Intellectual and Developmental Disabilities and Waiver Plan Access (SR 770) (2022). <https://www.senate.ga.gov/committees/Documents/IDDFinalReport12.14.22.pdf>

### 3. Invest in supports that empower parents who want to transition their family member with IDD to a new living situation.

Parents and caregivers need immediate support and tools to transition their adult family members with IDD into their own homes (if that is the family member's preference). Caregivers and people with IDD reported a desire for independent living in our survey but lacked the tools and resources to do so. An investment from the state in transition-related tools and assistance could help quickly relieve the burden on caregivers.

The state of Washington funded an organization called Partners4Housing, which helps families navigate benefits and supports available to people with IDD, especially those that help families create shared living arrangements. Partners4Housing supports parents with the process of transitioning their adult child with IDD into independent living situations through three activities:

1. A consultation to understand the housing needs and preferences, and potential supports needed for the adult child to live independently, based on responses from an in-depth questionnaire. If the family is interested in finding compatible roommates, and the consult determines that the individual is a good fit, the family is invited to join the invite-only roommate matching pool. The roommate matching pool helps families find potentially compatible roommates for shared living arrangements.
2. An online Benefits and Housing Review (BAHR). The BAHR identifies which benefits and housing supports individuals may be eligible for. Following the review, Partners4Housing staff coach families through the application processes for available benefits, including SSI, Section 8 housing vouchers, and food benefits, and help them maximize those benefits. They also help people who are employed maintain their Medicaid benefits.<sup>14</sup>
3. Family coaching to create shared living arrangements, including hiring DSPs or other caregivers.

Washington has funded Partners4Housing to provide consultations and benefits reviews to 50% of adults with IDD in the state currently living with their parents. To help them reach these families, Partners4Housing works with local nonprofits to help families complete the review if necessary. Nonprofit partners also help bridge gaps to communities of color and other historically marginalized communities to ensure equitable access to this service.

14. Medicaid beneficiaries that receive Supplemental Security Income (SSI) benefits are subject to income and asset limits. Both limits are quite low (meaning they cannot have many assets or work at "a substantial gainful level"). These requirements mean that if an individual with SSI benefits has a job that provides an income above a certain level, they risk losing their Medicaid.

Georgia could also similarly fund Partners4Housing and help parents get the support they need to transition their adult child with IDD into a shared living arrangement.<sup>15</sup> Alternatively, the state could allow Georgians to use NOW and COMP waiver funds for a housing and benefits assessment through Partners4Housing. Either option could provide much-needed support and resources to parents of adult children with IDD. If Georgia were to pursue a program like this, the state would need to provide sufficient funding to enable enough participation to create a robust database for finding roommates and creating shared living solutions.

#### **4. Pass legislation to require the Georgia Department of Community Affairs to set aside 10% of the Low-Income Housing Tax Credit for housing for people with disabilities, including IDD.**

The Low-Income Housing Tax Credit (LIHTC) is one of the most powerful tools for producing and preserving affordable rental housing. Through the LIHTC program, private for-profit and nonprofit organizations receive a dollar-for-dollar reduction in their federal taxes in return for financing the rehabilitation or construction of low and very low-income rental units. States control their LIHTC programs, with oversight and guidance from the federal government.

A state's LIHTC allotment is meant to be competitively allocated to entities. States allocate their LIHTC awards through the annual development of a Quality Allocation Plan (QAP), which allows them to prioritize specific housing features and populations. The LIHTC application process is highly competitive, with many more project funding requests than can be awarded. Thus, developers have strong incentives to propose projects that match or closely fit the QAP to make their funding requests as competitive as possible. In this way, the state's QAP can shape the type and location of housing built.

LIHTC projects often include a mix of income levels and population groups, including people with disabilities. This integration and diversity can create more inclusive communities where people with disabilities can live, work, and interact with their peers and neighbors without fear of being stigmatized or marginalized.

Georgia's current QAP lists integrated housing opportunities for persons with disabilities, including IDD, as a state priority. Specifically, DCA prioritizes housing for people with disabilities that is close to community resources, provides opportunities for residents to live independently and interact with non-disabled people, allows a choice of roommates and service providers, and is provided in the least restrictive setting possible.

15. Georgians for a Healthy Future has no affiliation or financial interest in Partners4Housing. This recommendation is based on our research which suggests the organization is unique in offering these services across the country.



Historically, DCA has focused housing credit resources on congregate housing developments. However, in its 2023 QAP the department states that it will not fund any new construction of congregate housing and will instead focus on integrated housing developments.<sup>16</sup> While this change and DCA's stated priorities for people with disabilities are positive steps, DCA does not set aside a minimum or specific allocation towards integrated disability housing. By defining what portion of Georgia's LIHTC allotment will be allocated to housing projects that include individuals with disabilities, including those with IDD, the state would incentivize developers and accelerate the creation of more accessible, affordable housing.

### **5. Apply for an 1115 Health-Related Social Needs (HRSN) Medicaid waiver from the Centers for Medicare and Medicaid Services (CMS) to address housing needs for Medicaid recipients with a disability.**

Section 1115 waivers allow states to “waive” certain Medicaid requirements to enable them to create innovative programs that aim to improve health outcomes for Medicaid recipients. In 2021, CMS encouraged states to use 1115 waivers in new ways to address the “health-related social needs” of Medicaid members. Health-related social needs (HRSN) are needs that cannot be met by health care services but impact a person's health and may drive-up health care costs, like a healthy diet. HRSN waivers can cover multiple non-health factors (like medically tailored meals and linkages to other state and federal benefit programs) or focus on one critical determinant, such as housing.

Using an 1115 Medicaid waiver to address housing needs for Georgia Medicaid recipients would allow the state to invest Medicaid funds into affordable and accessible housing in ways it currently cannot and in ways that ultimately result in health care cost savings. For example, Georgia could invest in outreach, transitional housing, and tenancy support services (such as case management to navigate the HUD Housing Choice Voucher process) for Georgians with disabilities at risk of institutionalization, including those with IDD.<sup>17</sup>

### **6. Establish and fund a technical assistance program to help developers and community partners match their business objectives with opportunities and incentives to build affordable, accessible housing for people with disabilities, including people with IDD.**

Experts interviewed for this project reported that affordable housing developers need to become more familiar with how to build housing that fits the needs of individuals with IDD. The lack of knowledge among developers contributes to the exclusion of the needs of people with IDD within affordable housing.

16. Georgia Department of Community Affairs, State of Georgia 2023 Qualified Allocation Plan [https://www.dca.ga.gov/sites/default/files/2023\\_georgia\\_qualified\\_allocation\\_plan\\_boardapproved.pdf](https://www.dca.ga.gov/sites/default/files/2023_georgia_qualified_allocation_plan_boardapproved.pdf)

17. HRSN waivers are different from HCBS because they are intended to address population-level health and apply to the entire state's Medicaid program. HCBS waivers, on the other hand, are given directly to an individual to cover a variety of supports and services.

To address this gap, we recommend that Georgia create a technical assistance program for housing developers and community stakeholders to promote the development of innovative housing that is inclusive of people with disabilities, including IDD.

A technical assistance (TA) program can pair developers with inclusive housing experts to help developers understand how to build disability-inclusive housing and how to “stack” multiple funding streams or incentives to pay for these developments. Specific services offered by experts and consultants through a TA program could include conducting feasibility studies or zoning reviews, assistance with grant and loan applications, guidance to establish public/private partnerships, training on best practices in disability-inclusive development, and navigating LIHTC applications.

Paired with building incentives for affordable housing that fits the needs of Georgians with disabilities, including IDD, the TA program would encourage and empower affordable housing developers to build inclusive housing for Georgians with disabilities, including IDD, by increasing their financial incentives and lowering practical barriers.

## **7. Require new state-funded housing to comply with universal design standards to ensure accessibility for individuals with disabilities.**

A pivotal step to mitigating the housing crisis for Americans with disabilities, including IDD, is to ensure that homes are physically accessible to as many people as possible. One way to make living areas accessible to everyone is through universal design.

Universal design is an approach that aims to create “products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.”<sup>18</sup> Individuals with disabilities may be unable to afford a home that meets their needs if essential accessibility design elements are missing, such as grab bars in the bathroom or ramps at entrances, and are costly to add. By implementing universal design requirements across all new housing developments, the state would promote inclusivity of residency for individuals of all abilities without additional modifications. Requiring housing to be built using universal design standards would not only make housing more accessible for people with disabilities, including IDD. It would also benefit seniors, parents using strollers for their children, and other groups with accessibility considerations. It could additionally produce savings for the state by lessening the need for post-build adaptations and assistive technologies paid for by the state.

New York City recently approved a bill that requires developers to incorporate universal design into all rental developments which host more than 40 units and receive city funds.<sup>19</sup> The state could enact similar requirements and ensure that individuals with disabilities won’t have to rely on landlords or personally pay for adaptations to accommodate their needs (in addition to rent and mortgage costs).

18. National Low-Income Housing Coalition (2022). *Expanding Access to Housing for People with Disabilities through Universal Design* <https://hfront.org/2022/12/13/expanding-access-to-housing-for-people-with-disabilities-through-universal-design/>

19. New York Law School Center for New York City Law (2023). *Council Approves Bill to Incorporate Universal Design Features in City-Funded Housing Developments*. <https://www.citylandnyc.org/council-approves-bill-to-incorporate-universal-design-features-in-city-funded-housing-developments/>

# Conclusion

Georgians with IDD and their caregivers are struggling to afford housing and living situations that fully meet their needs and preferences. The gap between currently available housing and what is needed puts Georgians with IDD at risk of poorer health, reduced independence and freedom, and financial stress.

To solve the IDD housing crisis, state leaders, advocates, and families will need to work together to reshape Georgia's housing and supports landscape. Our state will need to align current programs, invest in a well-paid workforce of direct support professionals, dedicate new resources, and reimagine policies to meet the needs of Georgians with disabilities, including those with IDD.

Falling short will mean that Georgians with IDD will continue to be left behind, without the full promise and benefits of the Olmstead decision.



50 Hurt Plaza SE, Suite 806  
Atlanta, GA 30303

TEL 404 567 5016

FAX 404 935 9885

EMAIL [info@healthyfuturega.org](mailto:info@healthyfuturega.org)

[healthyfuturega.org](http://healthyfuturega.org)