



FUELING HOUSING AND COMMUNITY OPTIONS FOR ADULTS WITH AUTISM AND OTHER NEURODIVERSITIES



The universal language for a guiding narrative to research,
develop and achieve supportive housing solutions.

Publishers

Denise D. Resnik, Founder & President/CEO, First Place AZ
Desiree Kameka Galloway, Director, Autism Housing Network, Madison House Autism Foundation
The Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy at The Watts College of Public Service and Community Solutions

Research Team

Andrea Whitsett, Director, Morrison Institute for Public Policy, Watts College of Public Service and Community Solutions, Arizona State University
Alison Cook-Davis, Ph.D., Associate Director for Research, Morrison Institute for Public Policy, Watts College of Public Service and Community Solutions, Arizona State University
Chrissie Bausch, Ph.D., Research Analyst, Morrison Institute for Public Policy, Watts College of Public Service and Community Solutions, Arizona State University
Pooja Paode, Daniel Jordan Fiddle Foundation Adult Autism Public Policy Fellow, Fiddle Center for Public Policy at the First Place Global Leadership Institute; Graduate Research Assistant, Morrison Institute for Public Policy, Watts College of Public Service and Community Solutions, Arizona State University
Hye Rin Yoon, Graduate Research Assistant, Morrison Institute for Public Policy, Watts College of Public Service and Community Solutions, Arizona State University
Audrey Cleaver, Graduate Research Assistant, Morrison Institute for Public Policy, Watts College of Public Service and Community Solutions, Arizona State University
Alex Tam, Student Intern, Morrison Institute for Public Policy, Watts College of Public Service and Community Solutions, Arizona State University

Independent Reviewers

Christopher Banks, President/CEO, Autism Society of America
Brian Be, Self-Advocacy Coordinator, LEND graduate
Darren Larson, Self-Direction Advocate
Del Lausa, Senior Program Manager, Downtown Emergency Service Center (DESC) Housing Program
Martha Roherty, Executive Director, National Association of States United for Aging and Disabilities (NASUAD)
Stephen Shore, PhD, Professor, Adelphi University
Marlene Sotelo, BCBA-D, MT-BC, COO, Els for Autism Foundation
Julie Truong, B. Arch., Architectural Designer, Creative, Spectrum Fusion
Steve Vetrano, APEX Board Member; Chief Executive Officer, Avondale House
Linda Walder, Founder and Executive Director, The Daniel Jordan Fiddle Foundation
Andy Warren, Founder, Career Gap Year; Former President, Maracay Homes
Peter Wolff, Principal, Katerra

Production Team

Jonathan Adamson, Resident Filmmaker/Videographer, Madison House Autism Foundation
Mary Ann Bashaw, Communication Specialist, First Place AZ
Alyssa Land, Digital Marketing and Creative Coordinator, First Place AZ
Sydnee Schwartz, Social Media Specialist, First Place AZ
Michelle McGinty, President, DRA Collective
Rachael Myer Curley, Account Director, DRA Collective

Recommended Citations

Part 1: Developing a New Generation of Housing Options
Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). *A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities*. Phoenix, AZ: First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy at the Watts College of Public Service and Community Solutions.

Part 2: Speaking the Same Language

Paode, P. (2020). *Housing for Adults with Autism and/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs*. In D. D. Resnik & D. Kameka Galloway (Eds.), *A Place in the World: Fueling Housing and Community Options for Adults with Autism and other Neurodiversities* (pp. 143-173). First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy at the Watts College of Public Service and Community Solutions.

Part 3: Call to Action

Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). *A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities*. Phoenix, AZ: First Place AZ; Madison House Autism Foundation.

Editors

Denise D. Resnik, Founder & President/CEO, First Place AZ
Desiree Kameka Galloway, Director, Autism Housing Network, Madison House Autism Foundation

Leadership Advisory Board

Michael Alessandri, Executive Director, University of Miami Center for Autism & Related Disabilities
Joe Battaglia, Executive Director, UBS Financial Global Family Office Americas
Peter Bell, President & CEO, Ascendigo Autism Services
Joe Blackburn, President & CEO, Everest Holdings
George Braddock, Director, Creative Housing Solutions
David Brown, CEO, Valley Leadership
Catherine Camp Boyle, President, Autism Housing Pathways, Inc.
David Brown, CEO, Valley Leadership
Catherine Camp Boyle, President, Autism Housing Pathways, Inc.
Scott Copeland, Principal, RST Development, LLC
Shelly Dival, Building designer, Enabling Spaces
Mike Duffy, Senior Associate / Project Design Architect, RSP Architects
Karen Fluharty, Founder, Parents With A Plan
Charlie Hammerman, President and CEO, The Disability Opportunity Fund
Anna Hundley, Executive Director, Autism Treatment Center - Texas (ATC)
Desiree Kameka Galloway, Director of Autism Housing Network, Madison House Autism Foundation
Amy Lutz, Secretary, National Council on Severe Autism
Christopher Manente, Executive Director, Rutgers Center for Adult Autism Services
Dean Mon, First Vice Chairman 2019, National Association of Home Builders
Marcy Muhlestein, Global Leadership Institute Director, Center For Education, Training, And Employment, First Place
JaLynn Prince, Founder & President, Madison House Autism Foundation
Christopher Ptomey, Executive Director, ULI Terwilliger Center for Housing
Denise Resnik, Founder & President/CEO, First Place AZ
Christopher Smith, Vice President & Director of Research, SARRC
Michael Storz, President, Chapel Haven, Inc
Tom Toronto, President, Bergen County’s United Way
Mike Trailor, Chief Strategy Officer, Native American Connections
Jim Whittaker, President/CEO, The Arc Village

This seminal work would not be possible without the generous support of UnitedHealthcare Community Plan, the Phoenix IDA, the Arizona Community Foundation and Bill and Alyssa Sunderland, all leaders recognizing the value of housing as a major social determinant of health and the need for a common language to inform, improve and launch a marketplace of innovative housing solutions.

Through a broad and more robust generation of options, individuals can better match their needs and interests with homes, natural supports and long-term support services while informing outcomes demonstrating what works, what needs to work better and how supportive public policy can help align all sectors.



Please refer to aplaceintheworld.org for version 1.0 of *A Place in the World* published on October 21, 2020, as well as future versions. Thanks to our independent reviewers and other greatly valued feedback along the way, we will make revisions as we continue to learn—together—how best to fuel a new wave of housing and community options.



FUELING HOUSING AND COMMUNITY OPTIONS FOR ADULTS WITH AUTISM AND OTHER NEURODIVERSITIES

Passage of the Americans with Disabilities Act (ADA) 30 years ago empowered tremendous societal advances. With better access to early intervention and educational support, people with disabilities are increasingly included and valued, adding diversity to schools, workplaces and communities.

For this new decade and in those to follow, we must do more to integrate a significant underrepresented, underserved and underestimated segment of the population of people with disabilities: individuals with autism and other intellectual and developmental disabilities (I/DD).

This new “inclusion generation” of neurodiverse children transitioning to adulthood is the first to benefit from the billions of dollars invested in research, early identification and intervention, as well as improved educational supports resulting from the Individuals with Disabilities Education Act (IDEA) era. Together with prior generations, most are overwhelmingly supported in nearly every area of adult life by family members and aging caregivers. Public planning and economic availability for current and future housing, community engagement and long-term support service needs are tenuous, putting ever-increasing numbers at risk of displacement from their communities into the “next empty bed” or even homelessness.



Photo: The Arc Jacksonville Village

Just as housing and support options for seniors have diversified and expanded over the past 50 years, individuals with autism and other I/DD should also be able to access a variety of choices to meet their broad spectrum of support needs and diverse lifestyle preferences.

A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities focuses on the data and tools needed to create more places for those in search of homes and a sense of community belonging— everywhere.

Inspired by the vision of ensuring housing and community options are as bountiful for people with autism and other neurodiversities as they are for everyone else, this report is informed by a cross section of pioneering leaders within the disability community, as well as expertise in real estate, community development and public policy.

Named after the 2016 PBS NewsHour series featuring Greater Phoenix as “the most autism-friendly city in the world,” *A Place in the World* is the sister study to the groundbreaking 2009 report, *Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders*, the first-ever study to focus on the housing challenges of adults with autism and other neurodiversities.

Arizona State University Watts College of Public Service and Community Solutions and its Morrison Institute for Public Policy, the First Place Global Leadership Institute and its Daniel Jordan Fiddle Foundation Center for Public Policy, Autism Housing Network and sector leaders from across the U.S. and around the globe have united to take a critical step toward advancing a marketplace of options while recognizing the historic disconnect among prospective residents and their families, service providers, housing developers and policy officials struggling to address demand based on vastly different experiences and points of reference. (Refer to page 2 for a roster of Leadership Advisory Board Members.)

A Place in the World sets forth the foundational nomenclature for housing and service delivery models that define market segments, inform best practices and guiding principles, and help drive crucial partnerships that address pressing needs.

This study aims to serve as the definitive, foundational resource for the housing industry, scholars, direct service providers, policymakers, researchers and other stakeholders through:



A UNIVERSAL LANGUAGE

indispensable for innovation, expansion of and investment in supportive housing developments throughout the U.S. and beyond.



SEGMENTATION

leading to a meaningful collection of baseline and outcome data empowering the tracking and sharing of impact and economic realities, whether sourced through public or private payers.



VALUABLE CONNECTIONS

between housing developers and technology providers with a better grasp of the needs and nuances of the market segments and who are responding with solutions with a range of price points.



NOMENCLATURE

used as a tool in the facilitation of major policy advancements based on data-driven outcomes versus ideology alone, positioning this real estate segment within a solid, varied portfolio of a community's residential offerings.

Private, public, nonprofit or philanthropic leaders and fellow pioneers have produced *A Place in the World* in a manner that transcends all sectors, using descriptive language defining features, amenities, locations, price points and economic realities in terms understood by consumers, developers, providers and funders. By aligning housing, long-term support services and community supports expressed in terms better understood by those poised to deliver, we can more effectively fuel a dynamic marketplace of options.

We have designed A Place in the World as the go-to source for realizing, researching and replicating housing solutions:

REALIZING

Individuals and their families can use the nomenclature to understand the range of residential options available in language that works across states, as well as articulate their preferences in their person-centered plan.

RESEARCHING

Policymakers and researchers can collect more precise data on demand, distinct segments in more diverse settings, and corresponding and meaningful outcomes extending beyond a diagnosis.

REPLICATING

This bridge-building nomenclature brings consumers together with the housing industry recognizing both the demand and valued ingredient of inclusivity for healthy, thriving housing markets, to the benefit of everyone. The nomenclature can also be used for community preference surveys to give planners and developers added insights into constituents' needs, property characteristics, target markets and attainable, responsive financial structures.

We encourage you to use this resource to inform your decisions and broaden your marketplace perspectives on housing and community options for the neurodiverse population.

Advancing a new wave of residential and community development is not something any of us can do alone. But we can get it done together, marking this point in history as the time we ignited a more hopeful generation of options so that individuals with autism and other I/DD and their families can recognize that a diagnosis need not stand in the way of friends, jobs, supportive communities and homes of their own.

As always, stronger together in our collective quest to change the world,

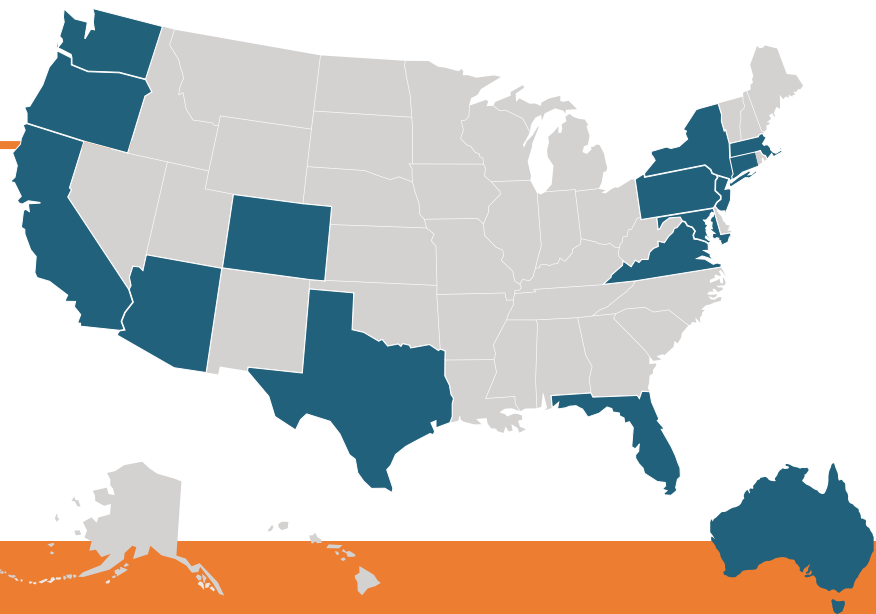


Denise D. Resnik
Founder & President/CEO
First Place® AZ
firstplaceaz.org



Desiree Kameka Galloway
Director
Autism Housing Network
autismhousingnetwork.org

Leadership Advisory Board



The Leadership Advisory Board (LAB) is composed of international thought leaders who are defining—and defying—barriers as they continue to explore various models to increase access to supportive housing across the country and around the world. As industry professionals, LAB members were selected based on their backgrounds in real estate, support services and/or community development; representation of all sectors—public, private, nonprofit, philanthropic; and geographic diversity with interests in urban, suburban and rural settings. They participated in A Place in the World think tanks and served as sources for ASU's Morrison Institute for Public Policy, the project navigator for research and data collection, as well as assistance with report development. Several LAB members and various independent reviewers also served as critical readers of the report.

At Morrison Institute for Public Policy, a research center within Arizona State University's Watts College of Public Service and Community Solutions, we combine academic rigor with the goal of informing real community change.

That is why we were eager to collaborate with First Place AZ, the Autism Housing Network and The Daniel Jordan Fiddle Foundation. *A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities* is a shining example of rigorous research informed by and in service to the community.

Morrison Institute collected and synthesized viewpoints and data to improve our understanding of residential options for adults with autism and other neurodiversities. This body of research—with input from members of the Leadership Advisory Board representing public, private, nonprofit and philanthropic sectors—provides information, tools and examples that housing developers, families and individuals can use to expand the number and range of residential options.

Like many Morrison Institute projects, this was a team effort. Dr. Chrissie Bausch was the lead author. She had outstanding support from our staff and leadership, particularly Dr. Alison Cook-Davis, Dr. Melissa Kovacs and senior analyst Erica Quintana, as well as student research assistants Audrey Cleaver, Pooja Paode, Alex Tam and Hye Rin Yoon. We are grateful to Denise Resnik, Desiree Kameka Galloway and their teams at the First Place Leadership Institute and the Autism Housing Network for their collaboration and leadership, as well as to the interview participants, representatives of the featured properties, Leadership Advisory Board members and critical readers for their considerable input. This work would not have been possible without the generous sponsorship of UnitedHealthcare Community Plan, Phoenix Industrial Development Authority, the Arizona Community Foundation and Bill and Alyssa Sunderland.

We hope this report promotes dialogue, facilitates further research and helps aid the development of more housing solutions. We are proud to be part of this important effort to help individuals with autism and other neurodiversities find their place in the world.



Andrea Whitsett
Director
Morrison Institute for Public Policy
morrisoninstitute.asu.edu



Table of Contents

Introduction: Expanding Residential Options for Adults with Autism and Other Neurodiversities

14

Part 1: Developing a New Generation of Housing Options

By Morrison Institute for Public Policy, First Place AZ & Madison House Autism Foundation

Background	16	Housing Market Guide	76
16	Adults with Neurodiversities: A Growing Market for Housing and Services	78	First Place–Phoenix
22	Methods	82	29 Palms
		86	Noah Homes — Memory Care Homes
		90	Yellow House — Ascendigo Autism Services
		94	Chapel Haven Schleifer Center
		98	The Arc Jacksonville Village
		102	CASS Housing
		106	Crescent Commons
		110	Our Home — Cathedral Park
		114	Marbridge
		118	Faison Residence
Nomenclature	24	Promising Practices	122
28 Residents		124	First Place AZ
28	Life Goals	130	The Arc Jacksonville
30	Support Needs	136	Bergen County's United Way/ Madeline Housing Partners, LLC
32	LTSS Delivery Model		
34	Funding Options for LTSS		
36	Funding Options for Housing		
38 Properties			
38	Target Market		
42	Property's Relationship to LTSS		
44	Residential Unit Type		
48	Development Type		
52	Lifestyle		
54	Private vs. Shared Residence		
56	Physical Amenities		
60	Supportive Amenities		
62	Payment Model		
64	Availability		
66	Property Development		
66 Development Type			
68	Financial Stack		
72	Land Sources & Incentives		
74	For Sale or Rent		

Part 2: Public Policy

By Pooja Paode, Daniel Jordan Fiddle Foundation Adult Autism Public Policy Fellow

Executive Summary	144
Housing for Adults with Autism and/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs	148
149	Abstract
150	Introduction
154	Methods
154	Evolution of Housing and Relevant Service Delivery Policy
155	Current Federal Programs Increasing Access to Housing
162	Summary and Limitations of Key Programs
172	Conclusion
Better Data Make Better Policy: Defining Unmet Housing Needs of Adults with Autism and Other Neurodiversities	174
175	Abstract
175	Introduction
178	Background
181	Method
183	Results
187	Discussion
192	Conclusion
Part 3: Call to Action	
By Denise D. Resnik and Desiree Kameka Galloway	
Next Steps for Fueling the Marketplace	194
References	198
198	Part 1: Developing a New Generation of Housing Options
208	Part 2.1: Public Policy
216	Part 2.2: Public Policy
Appendices	221
223	Residents Worksheet
224	Properties Worksheet
227	Property Development Worksheet
229	Nomenclature At-a-Glance

List of Acronyms

ABLE	Achieving a Better Life Experience account
ADA	Americans with Disabilities Act
ADU	Accessory Dwelling Unit
AMI	Area Median Income
ASD	Autism Spectrum Disorder
CDBG	Community Development Block Grant
CDFI	Community Development Financial Institutions
DSP	Direct Support Professional
HCBS	Home and Community-Based Services
HCV	Housing Choice Voucher
HOME	Home Investment Partnerships Program
HTF	Housing Trust Fund
HUD	U.S. Department of Housing and Urban Development
ICF/ID	Intermediate Care Facilities for Individuals with Intellectual Disabilities
I/DD	Intellectual and Developmental Disabilities
LIHTC	Low-Income Housing Tax Credit
LLC	Limited Liability Company
LTSS	Long-Term Services and Supports
NMTC	New Markets Tax Credit
SNT	Special Needs Trust
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income

Introduction:

Expanding residential options for adults with autism and other neurodiversities

Like everyone, people with autism and other neurological differences seek to lead full lives with relationships, pursuits, community and choices. Housing plays an instrumental role. However, many adults with neurological differences struggle just to find information about housing that meets their preferences and support needs [1], [2], let alone housing itself. Even when they find housing aligned with their interests, it is too often financially unattainable [3] or it is already fully occupied [2], [4], [5].

The fact that waitlists are typical for properties serving adults with autism and other neurological differences is revealing about the extent of unmet housing demand. Millions of Americans have autism, intellectual and developmental disability (I/DD) and/or other neurodiversities (hereafter “adults with neurodiversities”) [6], [7]. The lack of appropriate and affordable residential options requires many to live with parents or other relatives; some even experience institutionalization, homelessness or incarceration [3], [8], [9].

More can be done to meet the housing demand of adults with neurodiversities and provide options that reflect the range of preferences and support needs of these citizens. We refer to the multiple ways that housing and support services can be aligned as residential options. The supply and diversity of residential options have improved in recent years, thanks to efforts and collaborations among private firms, philanthropic organizations, advocates, service providers, policymakers, individuals and families (e.g., [10]–[13]).

The goal of *A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities* is to inspire and inform more collaboration, innovation and action that will expand residential options for adults with autism, other neurodiversities, as well as for other special populations. It provides information, tools and examples that everyone—from developers to individuals and their families—can use to continue to grow the number and diversity of choices for housing and services.

A Place in the World includes a summary of research findings by Pooja Paode, the 2019-20 **Daniel Jordan Fiddle Foundation Fellow in Public Policy**. Paode examined current federal housing assistance programs for adults with I/DD and assessed the extent to which they provide adequate assistance to meet housing demand among this population [14]. In a second paper, she illustrated how existing data are insufficient for describing residential needs of adults with autism and/or I/DD, and identifies data needed to articulate housing demand for this growing population [15].

The sections that follow provide tools and helpful examples for addressing these types of challenges:



1. **Nomenclature**, or shared language for describing residential options in ways relevant to the preferences and needs of adults with neurodiversities. Thematically organized with clear definitions, the nomenclature can help developers and service providers understand the range of residential preferences and needs among adults with neurodiversities and articulate where they fit into this marketplace; assist individuals and their families in identifying the housing and service options that are best for them; and enable data collection and analysis that provides a clearer picture of supply and demand for housing and services. Importantly, it can facilitate the development of evidence-based solutions for residential options.
2. **Housing Market Guide** illustrating the nomenclature with a range of real properties serving individuals with neurodiversities in creative ways.
3. **Promising Practices** featuring developers that have implemented innovative housing development strategies for adults with neurodiversities and other special populations.
4. **Worksheets** enabling stakeholders to apply the nomenclature to their own housing, project and/or community.

Expanding residential options for adults with autism and other neurodiversities will require communication, collaboration, creativity and commitment across sectors and stakeholders. *A Place in the World* is a resource for housing providers, service providers, policymakers, investors, researchers, advocates and others seeking to ensure that individuals with autism and other neurological differences find their place in the world.



Photo: First Place AZ, Good Eye! Media

Part 1: Developing a New Generation of Housing Options

By Morrison Institute for Public Policy, First Place AZ & Madison House Autism Foundation

Adults with Neurodiversities:

A growing market for housing and services

A diversity of neurological differences

Autism spectrum disorder (ASD) is a developmental disorder typically diagnosed in early childhood. People with autism often experience difficulties in three main areas: social interaction, social communication and/or social imagination. Many people with autism avoid eye contact and lack interest in faces. Many also experience heightened sensory sensitivity. Their cognitive abilities and skills range from gifted to severely challenged. Some, but not all, require support for activities of daily living, such as personal care, meal preparation or transportation [16].

Autism is one of many neurological conditions. Other examples include attention deficit hyperactivity disorder (ADHD), cerebral palsy, Down syndrome, dyslexia and epilepsy.

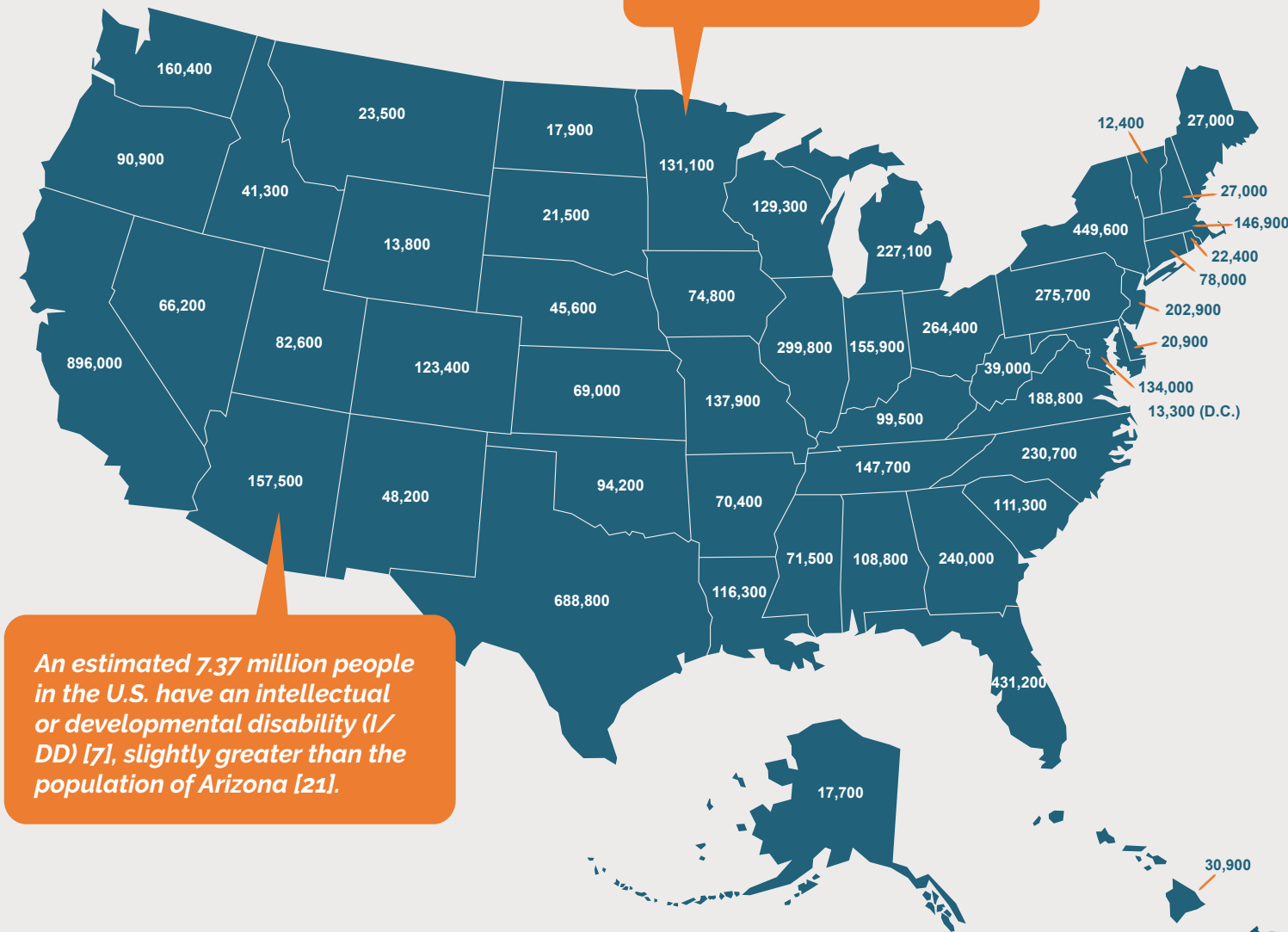
Some people with neurological differences have an intellectual or developmental disability (I/DD). Developmental disabilities include chronic conditions that can be cognitive and/or physical and appear before age 22. They include impairments in physical, learning, language or behavior areas [17]. Intellectual disabilities are cognitive and typically appear by age 18. They include limits to a person's ability to learn and function in daily life [18]. An estimated 33% of children with autism also have an intellectual disability [19].

Neurodiversity is a term used to capture the broad range of conditions and support needs associated with neurological differences, including those with and without I/DD [20].

Millions of Americans have autism and/or Intellectual and Developmental Disabilities (I/DD).

The number of adults with neurodiversities is unknown. This data represents only people with I/DD eligible for Medicaid LTSS. A national prevalence study would likely significantly increase the total number in each state who would benefit from supportive housing options.

Number of Individuals with I/DD by State, 2016 [7].



The population of adults with autism and/or Intellectual Disabilities (I/DD) is growing.

The proportion of children diagnosed with autism has increased from 1 in 150 to 1 in 54 between 2000 and 2016 [22].

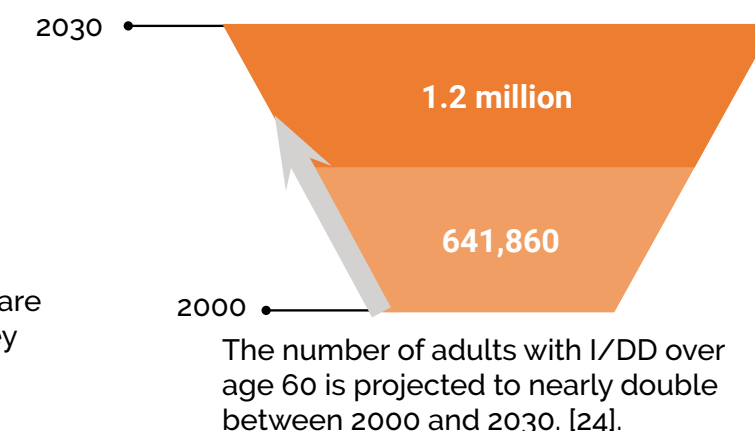
Approximately 50,000 young people with autism exit high school each year [23].

These young people will need housing and services over the course of their lifespan. Thanks to medical advances and improved living conditions, people with I/DD are living longer, with a life expectancy similar to that of the general population [24].

Many adults with I/DD will outlive their caregivers.

In 2017, 1.3 million people with I/DD lived with a caregiver who is over age 60 [27].

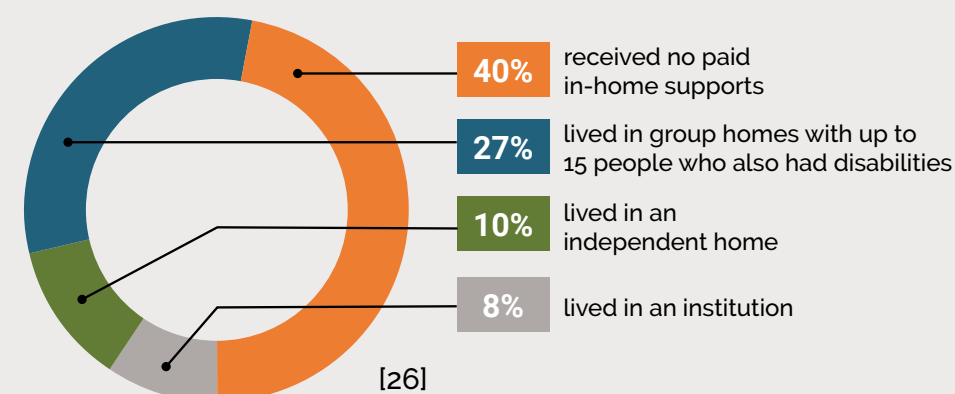
Many parents and caregivers of adults with I/DD are worried about what will happen to the person they support when they can no longer do so [16], [28].



About 75% of adults with I/DD live with family members...

...and the majority do not receive formal services or supports [25]. Family members often serve as unpaid primary caregivers for their adult loved ones with I/DD [2]. Only 17% of adults with I/DD receive Medicaid funding for Long-Term Support Services [7].

The situation is similar among adults with autism. One study found that 49% lived in the home of a parent or relative, of whom:



People with disabilities (including I/DD) experience poverty at twice the rate...

...of people who do not have disabilities [29]. This is tied to the fact that people with disabilities achieve lower rates of education, employment and financial independence, and have more basic needs, such as home health care, medications and assistive technologies [30]. People with autism face these challenges as well [26].

To pay for housing and other basic expenses, many people with disabilities depend on government programs, such as Supplemental Security Income (SSI) and rental assistance programs from the U.S. Department of Housing and Urban Development (HUD).

Even with these programs, it can be extremely challenging to cover housing costs.

In 2016

SSI program participation was

4.8 million

adults with disabilities under the age of 65. [3]

Average annual income of a single person receiving SSI payments was

\$9,156

22% below the federal poverty level for a single person and equivalent to 99% of the national average rent for a studio apartment [3].

Median annual income for households that receive rental assistance from HUD's three primary programs is

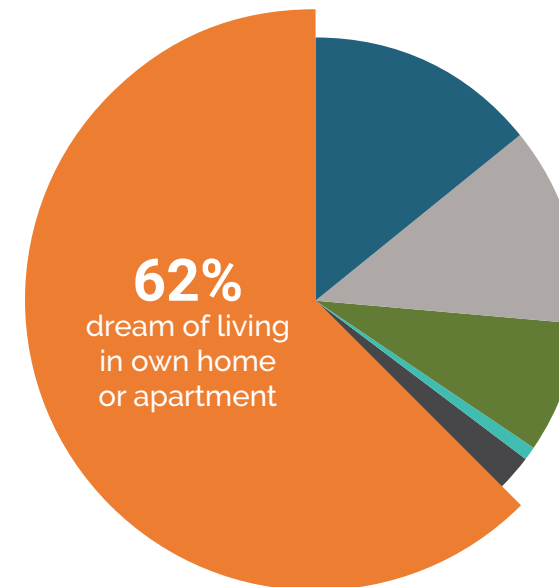
\$13,500

[30] approximately 25% below the federal poverty level for an average-sized household [31].



Photo: First Place® AZ, Good Eye Media

People with I/DD are interested in a variety of residential options.



In a national survey by The Arc [2], people with I/DD and family members of people with I/DD identified a variety of dream homes:

- 14% Supervised group home or apartment
- 12% Home of a family member
- 8% Planned community or campus where only people with I/DD live
- 1% Host home
- 2% Other

More research is needed to further understand preferences for housing and services [15].

For example, among those who select each of these housing options, what are their support needs? How many are young adults, middle aged or seniors? What are their lifestyle and service delivery preferences? Which physical amenities and supportive amenities do they associate with each type of housing? Which funding options are available to them? This and other information would help developers, service providers, advocates and their collaborators more effectively meet housing demand.



Methods

A Place in the World builds on the foundation laid by the 2009 report *Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders* [16], which identified best practices for built environments for individuals with autism.

Following the publication of *Opening Doors*, the Autism Housing Network conducted more than 100 site visits across the U.S. to determine the range and scope of existing residential options for individuals with I/DD. Based on these visits, it developed housing and community worksheets of core categories and concepts for person-centered residential options [32]. First Place AZ and the Autism Housing Network convened a Leadership Advisory Board (LAB) and two think tanks over 2018-19 with participation from more than 100 experts to discuss goals and additional concepts needed to develop a shared nomenclature from the worksheets, and, ultimately, the *A Place in the World* report. The goals of the report were established as follows:

- Inclusive of diverse support needs
- Compatible with federal definitions and programs
- Intuitively usable for stakeholders
- Goal-oriented to improve the supply, quality and choice of person-centered residential options for individuals with neurodiversities and/or I/DD

Morrison Institute for Public Policy at Arizona State University was brought on in fall 2019 to complete the next step of synthesizing relevant concepts from the general housing market, federal programs for housing and services, and housing for special populations that included individuals with I/DD, HIV-AIDS and/or physical disabilities, as well as seniors and veterans. This entailed the following:

Expert Interviews

Semi-structured interviews were conducted with 14 experts from various perspectives in industry, policy, research and disability advocacy, including family members of people with autism, I/DD and other neurodiversities, and a self-advocate with autism. These conversations informed concerns, information gaps, goals and strategies related to housing and services from key perspectives. The interviews were also essential sources for the Housing Market Guide and Promising Practices sections of the report.

Literature Review

Secondary sources on housing, services and related federal programs were reviewed. These included articles, reports and websites from industry, government, research centers, nonprofit organizations and advocacy groups. Sources were recommended by interviewees and LAB members, as well as identified via Google searches. Over 120 sources were reviewed. Key terms, concepts and/or definitions related to housing and services were identified from each source and catalogued in a spreadsheet.

Synthesis

The results of the literature review were then synthesized into the nomenclature, following the four guiding principles that emerged from think tank discussions. Select categories from the nomenclature were tested in April 2020 by participants in the *A Place in the World* webinar. Feedback from this webinar was used to revise the nomenclature for clarity and usability.

Critical Review

In summer 2020, LAB members reviewed the report for clarity, accuracy and relevance in reference to the diverse stakeholders the report aims to reach. Their feedback is incorporated in the final report.



Nomenclature

A shared system of terms, or nomenclature, that describes existing and emerging residential options for people with neurodiversities can be instrumental to building the collaborations, policies, research and actual housing needed to meet the population's needs. Speaking the same language can facilitate communication around market supply and demand, opportunities in real estate and financing, gaps in information and policy, and innovation in design.

In service to this goal, we propose the *A Place in the World* nomenclature as a framework and system of terms for articulating residential developments and preferences. This nomenclature follows four guiding principles:

4 GUIDING PRINCIPLES

- **INCLUSIVE**
Inclusive of all support needs
- **COMPATIBLE**
Compatible with federal definitions and programs
- **INTUITIVE**
Intuitive usability for all stakeholders
- **GOAL-ORIENTED**
Goal-oriented to improve the supply, quality and choice of person-centered residential options for all individuals with neurodiversities and/or I/DD so they may lead enriching lives



Photo: Autism Housing Network

This descriptive tool was developed to recognize that the residential choices available to people with neurodiversities are largely shaped by government funding for housing and services, which varies by state.

While it does not cover state-level policies, the nomenclature provides a general framework where state and local funding sources and programs may be inserted and/or compared. Similarly, the details of design and construction were beyond the scope of this effort, as was the decision process that individuals and their families may undertake when making choices for housing and services. Helpful sources at this level of detail exist (e.g., [1], [16], [33]); still, there are many unanswered questions about residential development for the neurodiverse housing market. It is our hope that the *A Place in the World* nomenclature will provide a foundation of shared language that can facilitate more discussions, reports, toolkits and creative solutions within and among stakeholders.

Throughout the nomenclature, the terms “neurodiverse” and “neurodiversity” are used to refer to individuals across the broad range of conditions and support needs associated with neurological differences, including those with and without intellectual and developmental disabilities (I/DD).

For details of how the nomenclature was developed, see the Methods section (page 22).

The nomenclature is organized into three sections, each representing a key element of residential development: residents, properties and property development (Table 1). Each section contains categories and terms that help articulate the section’s focal element for the neurodiverse housing market. Within categories, terms are listed alphabetically or, if applicable, by order of increasing scale or intensity. Though the sections are distinct in the nomenclature, they are thoroughly interrelated.

For example, a housing development for neurodiverse adults (residents) will likely feature amenities that appeal to that market and will adopt a payment model that aligns with the affordability goals and amenities offered at that site (property). The developers may have accessed land or applied financial resources available only for housing development for adults with disabilities and/or low-income residents (property development). Thus, whether you are a developer, a person with neurodiversity, a family member, a financier, policymaker, service provider, property manager, researcher or other stakeholder, all three sections of the nomenclature are relevant to you.

Table 1. Nomenclature framework

Residents	Properties
Life goals Support needs LTSS delivery model* Funding options for LTSS* Funding options for housing	Target market Relationship to LTSS* Residential unit type Development type Lifestyle Private vs. shared residence Physical amenities Supportive amenities Payment model Availability
Property Development	
Developer type Financial stack Land source & incentives For sale or rent	

*LTSS refers to Long-Term Services and Supports.

Defining the Link Between Housing and Services

The types and frequency of support needed and the preferred service delivery model vary with each adult with autism and/or I/DD. Defining the ways housing and services intersect in the community is important to contextualize housing policy for this population. Today, two terms generally define how residential settings interface with LTSS delivery:

- **Consumer-Controlled Settings:** Properties where the housing provider is not inextricably linked to residents’ LTSS provider(s), enabling residents to choose their preferred provider(s). Different from provider-controlled settings, residents may change their support service provider without changing where they live.
- **Provider-Controlled Settings:** Properties where the housing provider is both property manager and LTSS provider. In such residential settings, residents are unable to change their LTSS provider without moving to a different home.

Residents

This section includes categories and terms that describe individuals with neurodiversities and intellectual and developmental disabilities (I/DD) in ways relevant to residential choices. Housing providers and LTSS (Long-Term Services and Supports) providers can use this section to better understand and serve current and prospective residents and/or care recipients. Individuals and their families can use this section to articulate their life goals, support needs and funding options and align these with options for housing, LTSS and other supports.

Life Goals

Residential choices can be instrumental in achieving certain life goals. This category lists some common housing-related goals of individuals with neurodiversities, but there are many more possibilities. When looking at housing options, individuals and their families can consider whether the lifestyle, supportive amenities, physical amenities, etc. align with their goals. If applicable, they can also consider whether/how an LTSS provider and LTSS delivery model align with their goals. Listed in order of inward- to outward-facing goals.

Learn life skills

The individual aims to learn, practice and eventually master skills that they need or want in order to participate in everyday life. Examples include grocery shopping, taking public transit, cooking, financial management and social skills.

Grow in independence

The individual aims to learn and practice self-sufficiency in activities of daily living and to depend less on in-person support.

Build relationships

The individual aims to learn skills and have opportunities to meet new people and maintain relationships.

Get and maintain a job

The individual aims to secure and retain employment.

Participate as a member of the greater community

The individual aims to be integrated into the social fabric of the greater community to the degree the individual desires through hobbies, volunteering, civic engagement, recreational activities, etc.

Achieve stability

The individual aims to find a home and communities that provide them with a daily sense of comfort, belonging and safety, from which they can engage positively in daily life.

Be safe at home

The individual aims to have access to support(s) needed for specific impairments (visual notifications of gas leaks, anti-scald devices, etc.), challenging behavior (self-injurious behavior, pica, etc.) and difficult decision making (predatory relationships, etc.).

Find a permanent home

The individual aims to find a home where an individual can live comfortably, with the support(s) they need, for the remainder of their life. This is often an important consideration while planning for when parents, family members or other providers of natural supports are no longer able to provide the level of care an individual needs due to advanced age or death.

Support Needs

Support needs refers to the level of individualized LTSS for activities of daily living that an individual with a disability needs for personal wellness and community integration. Support needs are characterized by both the frequency of care and the nature of care needed (behavioral, medical, etc.) [32]. When identifying their support needs, individuals and their families should consider their needs on a typical day and their worst day. They can align their support needs with the LTSS delivery model and provider that best suits them. When looking at housing options, individuals and their families can consider whether a property, including the supportive and physical amenities, works with their support needs. Direct Support Professional (DSP) refers to the provider of individualized support for the person with an intellectual or developmental disability (I/DD) and/or other disability. The following are listed by increasing level of support.



Photo: First Place® AZ, Good Eye Media

No support needs

Not all neurodiverse individuals need long-term services and supports for activities of daily living.

Drop-in support

The individual needs a DSP to check in with them every few days or as requested; the individual is self-sufficient the majority of the time.

Low support

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

Moderate support

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

24/7 support

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

Daily medical support

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

Memory care

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

High behavioral support

The individual needs specialized support(s) to mediate severe challenging behavior, significant adaptive skill deficits and medical/behavioral issues to participate safely in home and community life. Examples of severe challenging behavior include aggression, self-injury, pica, elopement and property destruction.

One-on-one support

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

LTSS Delivery Model

This category includes common methods for delivering Long-Term Services and Supports (LTSS) to individuals with intellectual and developmental disabilities (I/DD) [32]. LTSS is individualized support for activities of daily living, such as meal preparation, hygiene, recreation and more. Individuals and their families can fund LTSS delivery with Medicaid or private pay; access and eligibility varies by state (see “Funding Options for LTSS” below). Individuals and their families can match their support needs and funding options for LTSS with the LTSS delivery model that best suits their needs. The following are listed in alphabetical order.

Agency-based rotational staffing

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

Host home

An individual with LTSS needs lives in the home of their LTSS service provider. As a provider-controlled setting, the LTSS provider (host) can ask the individual to move. This is also referred to as adult foster care or the family teaching model [34], [35].

Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID)

This optional Medicaid benefit provides comprehensive, individualized health care and rehabilitation services to individuals in need of active treatment services. ICF/IDs are provider-controlled settings that provide both housing and LTSS to residents [36].

Natural supports

Services and supports are provided by person(s) such as family, friends, neighbors and/or community members for no financial payment. Natural supports may be reciprocal, where supports, services and/or non-financial benefits (such as cookies and/or friendship) are exchanged instead money.

Not applicable

Not all neurodiverse individuals need LTSS for activities of daily living and therefore do not need LTSS delivery.

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

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.

Residential transition program

An individual who needs LTSS may participate in a one- to five-year residential program that teaches greater autonomy in activities of daily living and life skills for maintaining relationships and employment. The goal of the program is for the individual to rely less on LTSS in the future. It is also referred to as a post-secondary transitional program.

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.

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 [37].

Funding Options for LTSS

Funding options for Long-Term Services and Supports (LTSS) include the various financial resources individuals with intellectual and developmental disabilities (I/DD) and/or other disabilities may use to pay for services and supports. This category lists some common options, but other options may be available at the state or local level. Individuals and their families can match their funding options with those accepted by the LTSS provider of their choice (in consumer-controlled settings) or of their residential provider (in provider-controlled settings). The following are listed in alphabetical order.



Photo: rupixen.com - Unsplash

Medicaid Home and Community-Based Services (HCBS) waiver

These Medicaid-funded waivers finance recipients' LTSS in non-institutional settings. HCBS waivers are administered by state governments. Each state offers different HCBS waivers (by various names) and state-specific plans that cover different LTSS delivery models [38]. Check which HCBS waivers are available by state here: [medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html](https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html)

Medicaid Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID)

This optional Medicaid benefit provides comprehensive, individualized health care and rehabilitation services to individuals in need of active treatment services. ICF/IDs are provider-controlled settings that provide both housing and LTSS to residents. ICF/ID waivers are administered by state governments [36].

Medicare

The federal health insurance program for people 65 or older, people with disabilities and people with end-stage renal disease. Different parts of Medicare cover the costs of hospital stays (including skilled nursing facilities, hospice care and some home health care); doctors' services, outpatient care, medical supplies and preventive services; and prescription drugs [39].

Not applicable

Not all neurodiverse individuals need LTSS for activities of daily living and therefore do not need funding to pay for LTSS.

Private pay

The individual has private financial resources from their personal income, family support, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Achieving a Better Life Experience (ABLE) account and/or Special Needs Trust (SNT) to finance their LTSS need [40]–[43].

Funding Options for Housing

Funding options for housing include the various financial resources that an individual may use to pay for their housing [32]. Some common sources are listed here, but other options may be available at the state or local level. Individuals and their families can match their funding options with those accepted by the housing option(s) where they would like to live. The following are listed in alphabetical order.

Bequest

A home that a family member or friend has given or bequeathed to an individual by naming them in their will. Ownership is transferred upon the death of the giver.

Down payment assistance

Grants or low-interest loans that reduce the amount a recipient must save for the down payment on a home. State, county and city governments across the U.S. offer these programs. Some offer specialized programs for people with disabilities.

Home loan

A sum of money that an individual borrows from a financial institution or bank to assist with the purchase of a home. The amount borrowed, or loan principal, must be repaid, often with interest (the cost of borrowing money).

Homeownership Voucher Program

This program is part of the HUD Housing Choice Voucher (HCV) program. It allows families to use their HCV voucher to buy a home and receive monthly assistance to cover homeownership expenses. Participants must be first-time homebuyers, meet specific income and employment requirements (not required of elderly and disabled participants), complete a pre-assistance homeownership and counseling program, and meet any additional eligibility requirements set by the local Public Housing Agency (PHA) administering the program [44].

Housing Choice Voucher (HCV) Program

This program is part of the U.S. Department of Housing and Urban Development (HUD) Section 8 program. It assists very low-income families, the elderly and people with disabilities to afford decent housing in the private market. Vouchers are administered by local public housing agencies. Voucher recipients are responsible for finding suitable housing where the owner agrees to rent under the program. Recipients pay 30% of their monthly adjusted gross income for rent and utilities, and the voucher subsidizes the balance [45].

Mortgage

A legal agreement between a lender (bank, creditor) and a property holder, in which the lender loans money to the property holder with interest in exchange for taking title of the property, under the condition that the conveyance of title becomes void when the debt is repaid. If an adult with a disability does not have sufficient income to qualify for a mortgage, mortgage lender Fannie Mae will consider their parent or legal guardian the owner/occupant [46].

Private pay

The individual has private financial resources from their personal income, family support, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Achieving a Better Life Experience (ABLE) account and/or Special Needs Trust (SNT) to finance their housing costs [40]–[43].

Rental assistance

Emergency assistance grants to help individuals pay rent and utilities. Across the U.S., nonprofit organizations and local and state governments offer this assistance. It is often a special, one-time grant.

Single Family Housing Programs

The U.S. Department of Agriculture (USDA) offers programs to income-eligible families and individuals to build, repair or own a safe, affordable home in rural areas. The programs include low-interest, fixed-rate homeownership loans, as well as loans and grants for home repairs, including modernization, accessible design and energy efficiency. Elderly and very low-income homeowners are eligible for these programs. Competitive grants are available to nonprofit, self-help housing organizations, as well as federally recognized tribes, to enable families to build their own homes. These programs are administered by USDA Rural Development [47].

Properties

This section consists of categories and terms that describe residential properties in ways relevant to individuals with neurodiversities. Developers and housing providers can use this section to develop their properties in ways that serve neurodiverse individuals, as well as to market their properties. Prospective residents and their families can use this section to better understand the range of housing options available and narrow down the options that best suit them.

Target Market

This category describes the different types of residents that a property or development might primarily aim to serve through design, physical amenities and supportive amenities. Some properties do not target any specific residential market [32]. When looking at housing options, individuals and their families can consider if a property's target market aligns with their preferences, support needs and social interests. The following are listed in alphabetical order.

Adults with autism

The property caters to adults on the autism spectrum. The property might feature sensory-friendly design, relaxation spaces, life-skills training and security features [16], [33].

Adults with disabilities

The property caters to, and/or reserves residential units for, adults with any medically determinable physical or mental impairment that results in a person's inability to engage in any substantial gainful activity. This includes physical disabilities, sensory disabilities (such as visual or hearing impairment) and I/DD [48]. For example, properties that receive funds from certain housing programs (such as the HUD Section 811 program) agree to reserve a certain percentage of units for people with disabilities.

Adults with intellectual and developmental disabilities (I/DD)

The property caters to adults who have a lifelong intellectual or developmental disability that affects cognitive functioning (ability to learn, reason, problem solve, etc.), adaptive behavior (such as everyday life skills and social skills) and/or physical impairments. Examples of I/DD include cerebral palsy, Down syndrome, Fragile X syndrome, traumatic brain injury and autism. A property catering to residents with I/DD might feature planned activities, universal design, smart-home features and security features [49].

Adults with high support needs

The property caters to individuals with high support needs who require at least 24/7 supervision and/or care from health professionals. For example, individuals with high support needs may require respiratory care or therapeutic care, or may exhibit physical aggression. These properties may include amenities like extra-durable features, built-in lifts and extra storage space for durable medical equipment.

Families

The property caters to families, often with children. It may offer amenities, such as play areas, parks, on-site childcare and close proximity to schools.

General market

The property caters to the general public; it does not have a target market.

Intergenerational

The property intentionally houses younger and older residents who are not related to each other. The property may feature adaptable and/or universal design features so residents may age in place. Such properties are sometimes intentional communities where residents provide natural and/or paid supports to each other and socialize together. For example, there are intergenerational housing programs that place students with seniors or seniors with families with children [50].

Low-income residents

The property offers affordable or subsidized housing to individuals or families with an annual gross income of 80% (low-income) and/or 50% (very low-income) of the area median income where they would like to live [51].

Multigenerational

The property is designed so that multiple generations of a family can live together or in close proximity [52]. For example, the property may include an accessory dwelling unit where grandparents or adult children live, and/or feature universal or adaptable design.

Neurodiverse adults

The property caters to adults across the range of neurological differences, including autism, Down syndrome, cerebral palsy, epilepsy, attention deficit hyperactivity disorder (ADHD) and I/DD, as well as to neurotypical adults [20], [32]. Residents may provide natural supports or be intentional about developing neurodiverse relationships. All residents may enjoy features that include sensory-friendly design and smart-home features, and various supportive amenities, such as cooking classes and community life.

Seniors

The property caters to adults age 55 and older. The property may offer amenities like landscaping, housekeeping service, planned activities, dining, universal design and age-in-place features.

Students

The property caters to students enrolled in an educational program. Examples include a dormitory or student housing complex. The property may offer amenities, such as student-life programs, study rooms, dining halls and bike-share programs.

Property’s Relationship to LTSS

The terms in this category specify the relationship between the property (residential unit or housing development) and individualized Long-Term Services and Supports (LTSS). Housing providers can use these terms to indicate whether residents would use a third-party LTSS provider or if the property itself is the on-site LTSS provider. Individuals and their families can seek housing where the property’s relationship to LTSS aligns with their own LTSS needs and choices. These terms are especially relevant to LTSS funded by Medicaid [32].

Consumer-controlled setting

Properties where the housing provider is not inherently connected to residents’ LTSS provider(s). Each resident chooses their LTSS provider(s). Residents may change their service provider and stay in their home. For example, a private home (apartment, single-family home, etc.) is a consumer-controlled setting where one or more residents can choose their LTSS provider and change providers if needed. In some consumer-controlled settings such as a planned community for individuals with disabilities, the housing provider may also be an LTSS provider; but residents still have the option of choosing or changing to a different LTSS provider while staying in the same home. Some residents of the property may not receive LTSS because they have no support needs.

Provider-controlled setting

Properties 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. Examples include host homes, most group homes, ICF-IDs, etc.

Hybrid setting

In some cases, a property may include both consumer-controlled and provider-controlled settings. For example, a provider-controlled group home within a planned community would make the planned community a hybrid setting.

Residential Unit Type

This category describes the many types of homes available, with reference to their physical design, size and sales model. Housing providers can use this category to specify the type(s) of housing they have to offer to prospective residents. Individuals and their families can consider which of these options they would consider most comfortable according to their lifestyle, support needs and finances. The following are listed in order from smallest to largest residential space/setting.

Tiny home

A small independent residential unit that is under 400 square feet in size. Tiny homes aim to enable simpler living in a more efficient, sustainable and affordable space. They may be designed and/or built by the owner or built from a tiny house kit. A tiny home is not built on a permanent foundation; it may be a mobile unit with wheels (technically making it a recreational vehicle). They may be purchased or rented/leased [52], [53].

Accessory dwelling unit (ADU)

A small, independent residential unit (such as a studio or one-bedroom apartment) built on a permanent foundation on the same lot as a single-family home. It may be attached or unattached to the primary home. ADUs are owned by the homeowner of the lot on which they are located and can be rented/leased. They are also referred to as accessory apartments, secondary suites and guesthouses [54].

Apartment

A private residence that is rented/leased by one or more residents (tenants), often in a building (multiplex, complex) containing at least several other similar units owned by a single landlord. Apartments vary in size from micro-units (less than 400 square feet) to three-bedroom units and sometimes larger.

Townhouse

A single-family residential unit that shares a wall with another townhouse (forming a duplex, triplex or fourplex, for example) and often has at least two floors [55]. They are typically owned but can also be rented/leased.



Condominium

A private residence owned by an individual, typically in a building or complex with at least several other units, each owned by different individual homeowners. They vary in size from micro-units (less than 400 square feet) to three-bedroom units and sometimes larger. “Condos” share common areas like yards, swimming pools, garages and/or gyms with other unit owners, which are maintained through fees to a homeowners association or board of elected condominium owners [55].

Manufactured home

A factory-built home that is assembled on site on a rectangular chassis versus a permanent foundation. They come in a range of floor plans and can be placed on a foundation, on a lot or in a home park. Manufactured homes are typically owned; if the manufactured home is in a home park, the homeowner pays rent on the lot. Manufactured homes can also be rented/leased [56].

Single-family home

A private residence built on a single lot that does not share walls with any other residential or commercial property. Single-family homes generally come with a private front and backyard, offering more privacy and space than other housing options [55]. They can be purchased or rented/leased by an individual or group.

Adaptable home

A residential unit that can be adapted to meet diverse and changing needs of the household. It may feature movable walls, multifunctional furniture and/or entrances at various parts of the home. An example of an adaptable living space is a single-family home that can easily be transformed into a duplex [52].

Single room occupancy (SRO)

A residential unit designed for occupancy by a single individual, often within a larger residential building such as a dormitory, group living or facility-based setting. In addition to sleeping and closet space, an SRO may include a bathroom, food preparation area and/or sitting area. They are typically rented/leased [57].

Dormitory

A building that provides residential quarters for several people, often but not always students. The residential unit may be one of many small furnished bedrooms that each sleep one to three people, or a large furnished bedroom where multiple people sleep, typically with a shared bathroom. The building may be a mixed-use development where residents have access to physical amenities (shared kitchen, fitness room, study rooms, etc.) and supportive amenities (community life, meal service, etc.). “Dorms” can be either consumer- or provider-controlled settings.

Facility-based setting

A room or suite of rooms in a provider-controlled facility that offers medical and/or behavioral care. The residential unit may be a furnished bedroom or suite (private or shared) with a private bathroom with access to common areas and a common dining area. They typically do not have access to a kitchen.

Development Type

This category describes types of real estate developments that include residential units [32]. Housing providers can use this category to specify the type of development of which their housing is a part. When considering potential housing options, individuals and their families should consider how the development type might impact their lifestyle, community integration, LTSS delivery and life goals. The following are listed by increasing involvement of property management in residents' lifestyle, housing and services.



Scattered site

A property (residential unit or development) that is located within the general housing fabric of a community. It is not part of a housing development that serves a specific residential market [58]. In affordable housing circles, "scattered-site housing" also refers to affordable housing that is dispersed throughout the community [59].

Mixed-use development

A real estate development that blends residential, commercial, cultural, institutional and/or (if appropriate) industrial uses. This development type is typically located in urban settings and allows for greater density. It reduces distances between destinations and can promote pedestrian- and bicycle-friendly environments [60].

Cohousing community

An intentionally planned housing community created by its residents. Cohousing communities typically feature private residential units (single-family homes, townhouses, etc.), a large community center or common house with amenities and pedestrian-oriented design. The property is designed and managed by residents. Many host weekly common meals and events prepared/organized by residents. Residents typically own their homes [61].

Group living

A residential development with furnished living units that each have three to four private bedrooms (some with en-suite bathrooms and closet space) and shared kitchen, dining and living spaces for group activities. Some also include hotel-like services, organized social events and recreational amenities [52]. This is also referred to as co-living [62].

Planned community

A small- or large-scale, intentionally planned property with multiple residential units (such as apartments, condominiums and/or single-family homes) that also has recreational amenities (such as parks, tennis courts, golf courses and trails). They sometimes also feature commercial properties, such as restaurants and shops. Property management helps maintain housing and common spaces. The intent is to make life as convenient and enjoyable as possible. A planned community may offer physical and supportive amenities that cater to neurodiverse residents. They are typically consumer-controlled settings, as most are not LTSS providers. This development type is usually located in suburban settings [63].

Student housing

A type of residential development intentionally designed for students, often of institutions of higher education (universities, colleges). Student housing is typically a dormitory or apartment community. This development type is unique in that it typically rents on a per-bed basis; is fully furnished; offers roommate-matching services; offers leases that align with the academic calendar; and provides student-oriented amenities (student-life programs, study rooms, dining halls, bike-share programs, etc.). The property may be managed by an institution of higher learning or by a private company. Residents can pay rent with private financial resources and/or scholarships.

Group home

A provider-controlled setting where two to six unrelated persons with disabilities share a home and are supported in their activities of daily living. Residents can pay to live in this development type via private pay or Medicaid ICF/ID.

Other residential facility for people with I/DD

Typically a provider-controlled setting that serves six or more residents with an intellectual or developmental disability (I/DD) who have at least 24/7 support needs. Other residential facilities are intended for long-term residency (versus short-term respite). They may be state operated, privately operated and/or an ICF-ID [64].

Assisted living

Typically a provider-controlled residential community where 25 or more residents live in a private room or apartment, share common areas and receive assistance with various activities of daily living, including meals, personal care, medications, laundry, etc. depending on their level of support needs. Some also offer social and recreational activities [65].

Nursing home

Typically a licensed private facility that offers a range of health and personal care services with a greater focus on medical care. Services may include nursing care, rehabilitation services, 24-hour supervision, meals and assistance with daily activities. Some people stay for a short time, but others live in nursing homes on a permanent basis due to ongoing physical or cognitive conditions. Nursing homes are provider-controlled settings that provide both housing and LTSS to residents. They are also referred to as skilled nursing facilities [65].

Lifestyle

Some residential communities and developments, particularly planned communities, cater to particular lifestyle interests through the physical and supportive amenities they offer or their proximity to other amenities [32]. There are many possible lifestyles to which a property may cater. Housing providers can use this category to communicate with prospective residents about the culture and community of their property. When considering potential housing options, individuals and families may consider how their own lifestyle fits with that community, if applicable. The following are listed in alphabetical order.



Photo: Marbridge

Active-living community

The property or community offers programmed activities for residents in addition to physical and supportive amenities. Activities might include swimming, fitness classes, dancing, crafting, continuing education, walking trails and more. Property management helps maintain housing and common spaces. Active living communities were originally developed as independent, maintenance-free living for adults 55 and older, but many active-living communities are not age restricted [66].

Agricultural/ranching community

The property or community centers on agricultural activities, such as animal care, gardening or growing crops and processing raw materials. They may also offer vocational training programs. They may be located in rural, suburban or urban settings.

Faith-based community

The property or community centers on religious faith. It may encourage specific religious affiliation and/or incorporate spiritual rituals and practices into daily life.

Intentional community

The property or community centers on shared social values and/or interests. They often feature common areas and aim for a high level of social cohesion and interaction. In communities where some or most residents have an intellectual or developmental disability (I/DD) and/or other disability, there may be an emphasis on natural support among neighbors and peer advocacy [67].

Live-Work-Play

Typically mixed-use developments in which residents can live close to restaurants, shops, entertainment and their place of work. The concept is that the neighborhood provides for most residents' needs within walking distance, allowing for more social interaction with neighbors, as well as pedestrian- and/or bicycle-oriented transit [68].

Personal preference

The lifestyle at the home or property is determined by the individual resident's own interests.

Pet-friendly

The property or community explicitly welcomes pets. It may offer pet-focused amenities, such as pet-friendly landscaping or on-site pet stations and groomers [69].

Private vs. Shared Residence

Some residential units are private residences for an individual or family, while others are shared with housemates (not to be confused with shared physical amenities at a property, such as tennis courts, game room, etc. that all residents of a property or development can use). When considering housing options, individuals and their families should consider whether they would prefer living alone or with a housemate, based on their preferences, support needs and financial options. The following are listed in alphabetical order.

Private residence

The residential unit (apartment, accessory dwelling unit, etc.) is set up for an individual person or family.

Shared with housemate(s)

The residential unit is set up to be shared by two or more unrelated people. Housemates may have some private space (such as their own bedrooms and closets) but share the kitchen, living room and/or bathroom. This can be a socially and/or financially beneficial arrangement for some.



Photo: The Arc Jacksonville

Physical Amenities

Physical amenities are built features of the residential unit, building and/or development that make life easier and more enjoyable for residents [32]. This category includes some common physical amenities but is not a comprehensive list. Housing providers can use this category to communicate with prospective residents about the built features they would enjoy there. When looking for housing, individuals and their families can align their goals, interests, lifestyle and LTSS needs with the physical amenities available at potential housing options. Physical amenities are also referred to as hard infrastructure or environmental supports. The following are listed in alphabetical order.



Accessible design

The residential unit and/or building meets the requirements of state and local codes and regulations for accessible housing. While specific standards vary by location, examples include wide doors, sufficient clear floor space for wheelchairs, grab bars in bathrooms, no-step entrances and many others. This is also referred to as ADA-compliant design. (ADA refers to the Americans with Disabilities Act) [70].

Adaptable design

The residential unit includes design features that are easily adjusted, added or removed to adapt to an individual resident's needs or preferences. Adaptable design may include elements of universal and accessible design but allows for the possibility of concealing or removing them unless/until needed. If/when they are needed, the changes can be made with unskilled labor and without structural or finished material changes. Examples include built-in wide doors, knee spaces, control and switch locations, grab-bar reinforcements and more [70]. Adaptable design includes many age-in-place features [71].

Cognitive accessibility features

The building includes signage with simple visual indicators (illustrations, icons), as well as text to indicate different space functions or directions around the building.

Common area space

The building or development offers communal areas for different types of interactions outside of individual residential units. Examples include multipurpose rooms, sitting areas, a community kitchen and more [52].

Easy-to-clean features

The building and/or residential unit includes features that make cleaning and maintenance easier. These may include floor drains, waterproof bathroom(s), elevated cabinets, washable paint, toilets with concealed cisterns and push-panel flush system, and more [16], [33].

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 [33].

Recreational amenities

The building or development offers shared recreational amenities, such as a swimming pool, sports court(s), garden, game room, fitness room (gym), art studio, computer room, walking/biking trails and more.

Relaxation amenities

The building or development offers space to unwind. For example, it may include a room with soothing sounds, hammock swings, body socks, large beanbags and/or a light projector. It may have a designated studio for guided meditation, yoga and more.

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.

Personal preference

The physical amenities in the home or property are determined by the individual resident's own preferences and needs.

Security features

The residential unit, building and/or development offers security features, such as keycard access, concierge service, security cameras or gated access.

Sensory-friendly design

The residential unit and/or building is designed with low-sensory-input strategies that reduce noise, visual clutter and climate variation. It typically features natural light, nonfluorescent (no-flicker) lighting, neutral colors and nooks in common spaces.

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. Examples include smart thermostats, motion detector lights, automatic stove shut-off, voice- and smart-device-activated locks, lights, blinds and other smart devices. Also referred to as enabling technology [72], [73].

Transit access

The building and/or development is conveniently located near public transit, such as bus or light rail.

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. Examples include lever door handles, low-height light switches, adjustable countertops and more [70]. Universal design includes many age-in-place features [71].



Photo: CoHousing Solutions

Supportive Amenities

Supportive amenities are supports or features voluntarily provided by a property, typically via paid staff, that make life easier and/or more enjoyable for residents. Supportive amenities are part of the property and benefit all residents; they are not individualized LTSS. The cost of supportive amenities may be covered in rent, tuition or out-of-pocket fees [32]. This category includes some common supportive amenities but is not a comprehensive list. Housing providers can use this category to communicate with prospective residents about the supportive features they would enjoy there. When looking for housing, individuals and their families can align their goals, interests, lifestyle and LTSS needs with the supportive amenities offered by potential housing options. Supportive amenities are also referred to as soft infrastructure or built-in supportive amenities. The following are listed in alphabetical order.

Benefits counseling

The property has staff who assist residents and their families in navigating government programs, as well as privately funded savings programs. The staff may help them understand how employment and other life decisions will impact their benefits, but they do not offer legal or financial advice, or case management [74].

Community life

The property coordinates hobby groups or planned social activities, such as movie nights, sports events, dances, game nights, etc. These may be organized by residents or a staff member/activity coordinator.

Community navigator

The property has on-site staff who facilitate community integration, answer questions and provide other types of helpful assistance. Also referred to as a concierge.

Health and fitness activities

The property offers on-site activities that promote fitness, wellness and health: swimming, hiking, Zumba, yoga, weight training, etc.

Housekeeping service

The property has hired or contracted staff who regularly help residents with light cleaning and upkeep of their home, including vacuuming, cleaning the bathroom and kitchen, making beds and changing linens.

Life-skills training

The property has staff and/or courses that help residents learn and practice daily activities for independence, such as transit navigation, cooking, financial management, social skills and more.

Meal service

The property offers the option to purchase prepared meals from an on-site restaurant, café, dining hall or meal plan. Residents may eat in their own residential unit or in a communal dining space with other residents and staff.

Personal preference

The supportive amenities at the home or property are determined by the individual resident's own preferences and needs.

Resident assistant

The property has designated staff who live on-site and are available to assist other residents with minor and major emergencies during working and nonworking hours. Residents may reach their resident assistant on-site or remotely via technology, such as intercom and/or phone.

Workplace and vocational support

The property has staff who assist residents in exploring, preparing for and/or retaining employment, volunteer positions, and/or vocational and educational opportunities.

Payment Model

There are multiple ways an individual can financially acquire housing [32]. This section highlights some common approaches. Housing providers can use this category to communicate with prospective residents about how the property is financially structured, how it accepts payment and what is included with payment. When looking at housing options, individuals and their families can match a property's payment model and accepted funding sources with available funding options. The following are listed by degree of resident ownership, from rental/lease to individual ownership.

Rental/lease

The resident(s) of the residential unit pay rent to the housing provider (landlord), typically on a monthly basis, in exchange for occupying the unit. A lease is a legal agreement that typically lasts 12 months, while a rental agreement typically lasts 30 days.

Affordable rental/lease

The resident(s) of the residential unit pay no more than 30% of their monthly adjusted gross income for rent and utilities. Where affordable housing is not available on the general market, individuals and families with low incomes (earning less than 50% of the Area Median Income, or AMI) may receive government support (such as HUD Housing Choice Vouchers) to subsidize the cost of rent and utilities [45], [51]. Eligibility may vary by property and program.

Tuition-based

The resident(s) pay a single combined fee for rent, LTSS, utilities and/or amenities to their housing provider (landlord), typically on a monthly basis. The resident can use private financial resources (earned income, family support, etc.) and/or vouchers, waivers and other kinds of assistance to pay tuition, depending on the housing and program provider.

Cooperative ownership

A group of people own or control a residential unit (such as a single-family home) or housing development (such as a multiplex) and related community facilities on a democratic basis. Individual residents do not directly own the real estate. Instead, the cooperative housing corporation owns the real estate and residents buy shares or a membership. This comes with the exclusive right to vote in the corporation's affairs and to live in a specific unit as long as the resident complies with the cooperative's rules and regulations. Cooperatives can be market rate or limited equity, the latter of which helps maintain affordability. There are also leasing cooperatives, in which an outside investor (typically a nonprofit corporation created for this purpose) owns the real estate. The legal entity of the cooperative could be a cooperative corporation, a limited liability company (LLC), nonprofit mutual benefit corporation or other type of entity [75].

Subsidized homeownership

An income-eligible individual or couple purchases the residential unit (single-family house, townhouse, etc.) with assistance from a government program (such as down payment assistance, HUD Homeownership Vouchers) or nonprofit organization (such as a community land trust). A portion of the cost of the home is covered (by a monthly homeownership subsidy or silent second mortgage, for example), and the homeowner is responsible for the balance. In cases where the home is subsidized by a nonprofit organization, if/when the homeowner sells the home, the homeowner may receive a proportion of the equity accrued in the home during their ownership; the remaining equity stays with the nonprofit organization so that the home may be sold to another income-qualified buyer at a subsidized rate. Eligibility varies by program and property; typically, the home buyer(s) will have an annual gross income of 80% (low income) or 50% (very low income) of the Area Median Income (AMI) [76], [77].

Group ownership

A group of people purchase, build and/or renovate a residential unit (such as a single-family home) or housing development (such as a triplex, complex). Each partner owns a percentage of the asset or of the legal entity that owns the asset. If the partners form a legal entity that owns the asset, it could be a limited liability company (LLC), nonprofit mutual benefit corporation or other type of legal entity.

Individual ownership

An individual (or couple) purchases the residential unit (single-family home, condominium, etc.). They may finance this large purchase with private financial resources, down payment assistance, a home loan and/or mortgage. The asset (home) could also be held in a special needs trust if the owner is at risk of financial mismanagement or exploitation.

Availability

Properties designed for people with disabilities are in varying stages of development; existing options are limited [32]. This category includes terms that indicate the availability of a residential unit or property based on the stage of development and level of occupancy. Housing providers can use this category to communicate with prospective residents. Individuals and their families can plan their housing decisions around the availability of the housing options where they want to live. The following are listed by stage of development and occupancy.

Planning stages

The property development is in the process of being organized and coordinated by the developer; it is not yet available to prospective residents.

Pre-development

The property will be available to prospective residents within two years.

Pre-sales/leasing

Units in the property are being sold or leased before they are ready for residents to move in.

Available

The property is fully developed and has openings for prospective residents.

Waitlist

The property is fully developed and occupied. Prospective residents must wait for an opening. They may be put on a waitlist or mailing list to be notified that they may apply to fill the vacancy.



Photo: First Place® AZ, Good Eye! Media



Property Development

This section includes categories and terms that describe details of developing a property for the neurodiverse housing market. Developers of all types can use this section to explore, plan, build and market housing properties that serve the neurodiverse market.

Developer Type

Different types of developers are involved in developing housing, supports and/or services. They may have different objectives and resources to complete their projects. This category defines the different types of developers. The following are listed in alphabetical order.

Joint venture

A business arrangement between two or more parties who agree to pool their resources to develop a real estate project.

Nonprofit developer

The property developer is a nonprofit organization. It has tax-exempt status—501(c)(3) or 509(a)—because it furthers a social cause and provides a public benefit. Examples include community land trusts.

Private developer

The property developer is an individual, privately held or public company or corporation.

Financial Stack

The financial stack includes the various financial resources that a developer may use to finance a housing development. This category includes financial sources commonly used to develop housing for individuals with disabilities and individuals who earn a low income. Other financial resources may be available depending on the target market and location of the property. The following are listed in alphabetical order.

Affordable Multifamily Housing Bonds

The Public Finance Authority (PFA) offers this program fueled by tax-exempt bonds to finance low-income multifamily and senior housing developments. For-profit and nonprofit developers are eligible to receive this low-interest financing if they agree to set aside a minimum of 20% of units for individuals earning no more than 50% of the Area Median Income (AMI) [78].

Capital campaign

An organized drive to accumulate substantial funds to finance an organization's major functions or projects, such as a new building or repair project. Also referred to as a capital development campaign [79].

Charitable campaign

A fundraising event intended to raise money, visibility and support for a nonprofit organization or charitable cause.

Community Development Block Grant (CDBG) Programs

These programs from the U.S. Department of Housing and Urban Development (HUD) provide annual formula grants to state, county and municipal governments to provide decent housing and suitable living environments. Local governments administer the program [80], [81].

Community Development Financial Institutions (CDFI) Fund

This fund from the U.S. Department of the Treasury offers tailored resources and programs to invest federal funds alongside private capital to support economically disadvantaged communities. Banks, credit unions, venture capital providers and more can be local CDFIs. They aim to foster economic opportunity and revitalize neighborhoods [82].

Grants

A financial award from a grantor (government agency, corporation, trust, foundation, etc.) given to an eligible grantee for a specific purpose. Some grants are conditional: They may be used only for certain purposes, may maintain specific standards and/or may require a proportional contribution from the grantee [79], [83].

Home Investment Partnerships Program (HOME) Program

This program from the U.S. Department of Housing and Urban Development (HUD) provides formula grants to states and local governments to build, buy, and/or rehabilitate affordable housing for rent or homeownership, or to provide direct rental assistance to people with low incomes. Recipients often collaborate with local nonprofit groups to achieve eligible activities. Local governments administer the program [84], [85].

Housing Finance Agencies

State-level agencies that offer a wide range of support and assistance to individuals, families and organizations to provide affordable housing to those who need it. Specific programs vary by state; many offer disability-specific programs [86].

Housing Trust Fund (HTF)

This fund from the U.S. Department of Housing and Urban Development (HUD) allocates formula grants to state governments for the production or preservation of affordable housing. State-level agencies distribute the funds. Separately, some states have a state-level housing trust fund supported by state funds [87].

Impact investment

A sum of money that a developer borrows from a lender (individual investor, financial institution, nonprofit organization, etc.) at zero or low (less than 2%) interest to fund a project that has multiple rates of return including social, personal, environmental and/or financial impacts across the broader community. Affordable housing is an example of such a project. Impact investments allow developers to deploy capital that may not be available to them otherwise (for example, from traditional lenders) and leverage other capital (such as grants, loans) as additional financing to bring projects to scale and achieve greater impact [88].

Low-Income Housing Tax Credit (LIHTC)

This U.S. Internal Revenue Service (IRS) program provides tax credit units to developers to build new affordable housing. The LIHTC program offers a 4% tax credit and a 9% tax credit; each has a different award process, benefits and financing structure. It is distributed by state-level tax credit agencies. Funding priorities are guided by a state Qualified Allocation Plan, which in some states prioritizes people with intellectual and developmental disabilities (I/DD) [89].

Multi-family housing programs

The U.S. Department of Agriculture (USDA) offers programs that finance affordable multifamily rental housing in rural areas that target low-income, elderly and disabled individuals and their families, as well as domestic farm laborers. These programs guarantee loans to develop new affordable rental housing, restructure loans for existing housing, offer grants for home repairs and rehabilitation, and provide rent subsidies for low-income tenants [90].

New Markets Tax Credit (NMTC) Program

This program from the U.S. Department of Treasury is a place-based gap financing tool that aims to create jobs and address unmet needs in low-income communities. The NMTC program incentivizes private investors to invest in eligible community development organizations by offering a 39% credit against federal taxes, spread out over seven years. This program is administered by local Community Development Entities (CDEs), which can be a non-profit loan fund, community development organization or private financial institution [91].

Philanthropic gifts

A contribution to a nonprofit agency to support its operation and/or a specific project, including a housing development.

Private capital

Any private investment in the equity or debt securities of real estate or other real assets.

Private sector loan

A sum of money that a developer borrows from a financial institution (such as a bank) to fund large capital expenses and/or operational costs. The amount borrowed, or loan principal, must be repaid with interest (the cost of borrowing money). Most commercial loans are backed by collateral.

Rural Rental Housing Loans (Section 515)

The U.S. Department of Agriculture (USDA) offers 30-year loans at 1% interest to provide affordable housing to very low-, low- and moderate-income families, people with disabilities and people who are elderly in rural communities. Loans may be used to purchase land or buildings, construct or renovate buildings, or provide necessary facilities (such as waste disposal systems and/or water systems). The loans are administered by the USDA's Rural Development Housing Service and Community Facilities Programs Office. Eligible applicants include individuals, for-profit corporations, nonprofit organizations, limited equity cooperatives, Native American tribes, public agencies and partnerships in targeted communities [92], [93].

Section 811 Supportive Housing for Persons with Disabilities Program

This program from the U.S. Department of Housing and Urban Development (HUD) offers two options for nonprofit organizations to provide supportive housing for low-income individuals with disabilities [94].

- Capital Advance**

The Section 811 program includes Capital Advance funding to develop permanent supportive rental housing for very low-income adults (18+) with disabilities. Projects must be either integrated (no more than 25% of residential units are designated for people with disabilities) or be a group home with 100% of units designated for people with disabilities. This program also provides Project Rental Assistance Contracts (PRAC): rental subsidies to maintain affordability of the housing for 40 years. Nonprofit organizations (with 501(c)(3) tax exemption) are eligible [95].

- Project Rental Assistance**

Under this Section 811 program, state housing agencies can receive project rental assistance if they have partnered with state agencies for health and human services and Medicaid to ensure the housing is targeting the population most in need of deeply affordable housing. It only includes funds for rental assistance; it does not provide funds for construction or rehabilitation [96].

Land Sources & Incentives

Land or property for housing development may come from a variety of sources. This category identifies possible sources, as well as incentive programs that encourage development in specific geographic areas, which can help lower land costs. The following are listed in alphabetical order.

Bequest

The developer receives the property for site development via bequeathal: a donor, supporter or partner names the developer in their will as the owner of the property, to be given at the time of the donor’s death.

Community Land Trust

The homeowner leases land from a Community Land Trust—a nonprofit, community-based organization with a mission to provide affordable housing in perpetuity. The Trust owns the land and leases it to the people who live in the homes built on that land. To provide affordable housing for future homeowners, the lease includes a resale formula that balances the interests of present homeowners with the long-term goals of the Trust [76].

Donation

The developer receives the property for site development via charitable donation.

Land Lease

The developer leases a piece of land from a landowner. The lease is typically long term (50-100 years), where the developer can make improvements, such as constructing commercial buildings, government buildings and/or residential units. Depending on the terms of the lease, the developer (tenant) may pay expenses on the property, such as taxes, insurance, maintenance and repairs. At the end of the lease, the landowner may have the rights to the building(s) transferred to them; allow the developer to remove the improvements; or allow the developer to purchase the improvements. Also referred to as a ground lease [97].

Place-based tax incentives

The developer accesses land located in a geographic area that is designated as economically distressed, difficult to develop, or a qualified census tract and therefore eligible for state and/or federal place-based tax incentives. Examples include the New Markets Tax Credit Program, Opportunity Zones, Neighborhood Stabilization Program (NSP), and others. These programs can help reduce land costs and other development costs [98], [99].

Publicly owned property

The developer accesses land or buildings owned by the state, county or municipal government to develop affordable housing. Generally, a government will identify surplus and/or underutilized assets that could be repurposed for housing and makes it available to developers at no cost, at a discount or at fair market value. The developer is typically expected to create and maintain the affordability of the housing [100], [101].

Purchase

The developer purchases the property for site development.

For Sale or Rent

Some properties are developed for residents to own, while others are developed for residents to rent/lease. Some properties have an explicit goal of long-term affordability. The chosen model has important implications for the design, financing and management of the property. Developers can align the sale/rent model of a given property with one or more payment models. (See page 62.)

Rental/lease

The housing development is designed to be rented/leased to residents (tenants).

Affordable rental/lease

The housing development is designed to be rented/leased to income-qualified residents (tenants) at a rate of 30% or less of the Area Median Income (AMI). The development may therefore be eligible to receive funding designated for affordable housing (such as the IRS Low-Income Housing Tax Credit Program, HUD HOME Program, etc.) and/or accept funds from housing subsidy programs such as the HUD Housing Choice Vouchers program.

Homeownership

The housing development is designed to be sold to the resident(s) who will live there.

Affordable homeownership

The housing development is designed to be sold at a subsidized rate to the income-qualified resident(s) who will live there. This may be achieved in partnership with a government program, community land trust or other nonprofit organization that covers a portion of the market cost of the home so that it is accessible to low-income or first-time homebuyers.

Mixed model

The housing development includes units for rent/lease, for homeownership, and/or at market and affordable rates.



Photo: First Place® AZ, Stephen G. Dreiseszun/Viewpoint Photographers



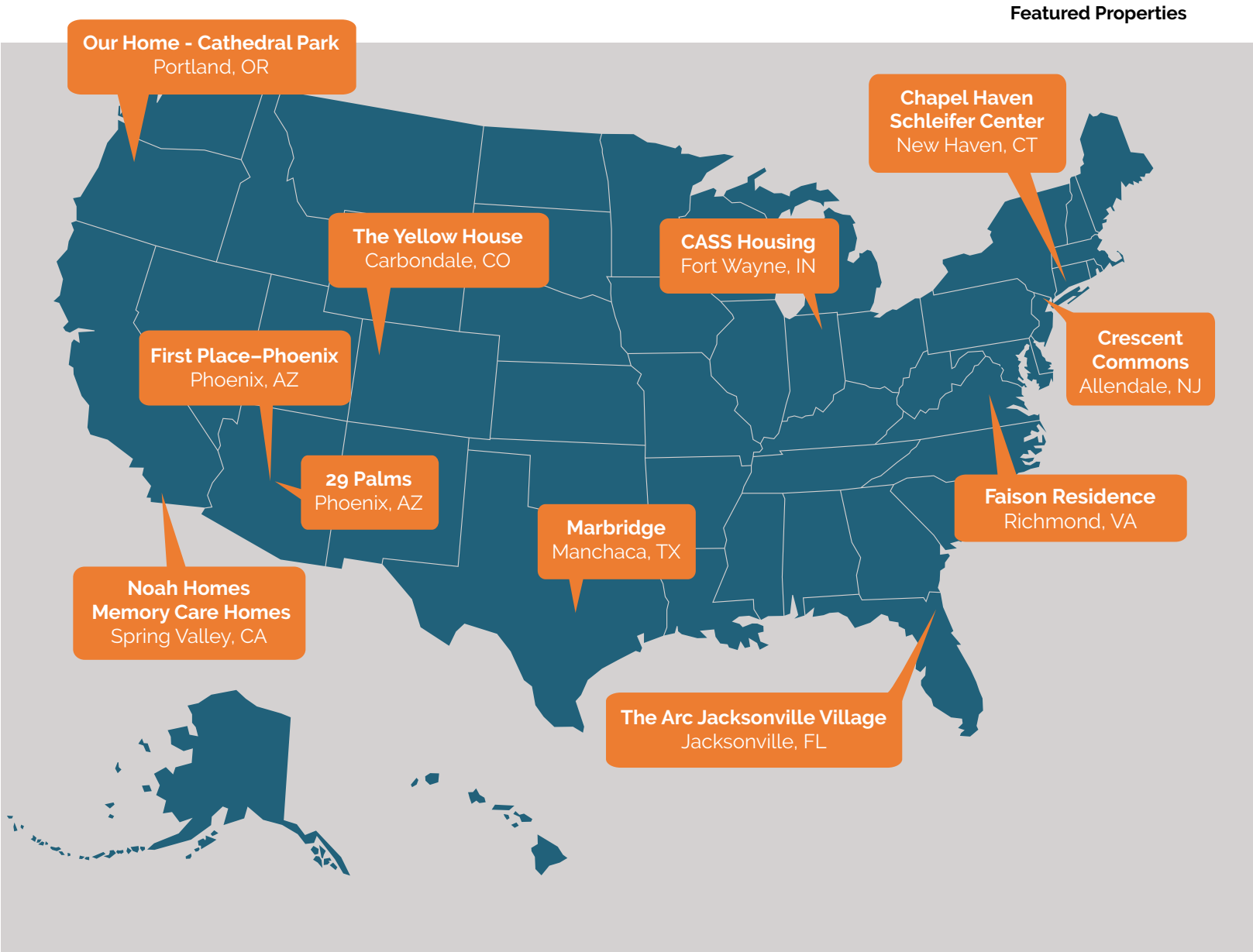
Housing Market Guide

For adults with autism, intellectual and developmental disabilities (I/DD) and other neurodiversities to make meaningful choices about housing and services, they need a range of options that reflect a diversity of preferences, goals, support needs and price points.

Property Selection

This Housing Market Guide is a collection of diverse properties serving a broad range of residents with neurodiversities across the U.S. Properties were selected¹ to illustrate the application of the proposed nomenclature and represent a variety of:

- Individuals (residents) and their support needs
- Long-Term Services and Supports (LTSS) delivery
- Residential units and housing developments
- Physical and supportive amenities
- Lifestyles
- Affordability
- Funding options



The properties are listed alphabetically by state. The guide provides a snapshot of each property, recognizing that each has evolved over time and will continue to adapt to meet the needs of current and future residents. Contact each property for up-to-date information on availability, pricing and other details.

This guide not only highlights a range of residential options; it can also serve as a source of information and inspiration for individuals and families searching for the housing and service-delivery options best suited to their needs, as well as for developers, advocates and decision-makers who can broaden the number and range of options in communities across the country.

For a more comprehensive roster of innovative housing solutions across the U.S., visit autismhousingnetwork.org/housing.

¹Inclusion in this guide does not constitute an endorsement.

First Place–Phoenix Snapshot

First Place–Phoenix, the first property of developer First Place AZ, offers 55 private apartments, along with active living and life-skills training for neurodiverse residents in a consumer-controlled setting. This intentional community and mixed-use development is also home to the First Place Transition Academy (a two-year program that helps neurodiverse adults build crucial skills for independent living and career-readiness) and the First Place Leadership Institute (a multidisciplinary, hands-on training center for professionals, educators, support staff and medical personnel, as well as a site for research and advancements in public policy). Thoughtful building design includes sensory-friendly and accessible qualities, relaxation and recreation spaces, transit access and security features.

First Place provides various supportive amenities, including community life and health and fitness activities. In partnership with leading educational institutions, the First Place doctoral and postdoctoral fellowship for autism research supports scholars working in applied research, assessment and intervention, family support, service coordination, community integration, community development and public policy. As residents, fellows enjoy the benefits of a First Place home—a living, learning laboratory and an enriching life experience. First Place–Phoenix is a supportive, inclusive community where residents can make friends, have fun, live independently—and have a place of their own to call home.

Residents & Services

Target Market

- Adults with autism
- Neurodiverse adults

Resident Support Needs

- No support needs
- Drop-in support
- Low support
- Moderate support

Property Relationship to LTSS

- Consumer-controlled setting

LTSS Delivery Model

- Agency-based rotational staffing
- Residential transition program
- Self-directed support

Funding Options for LTSS

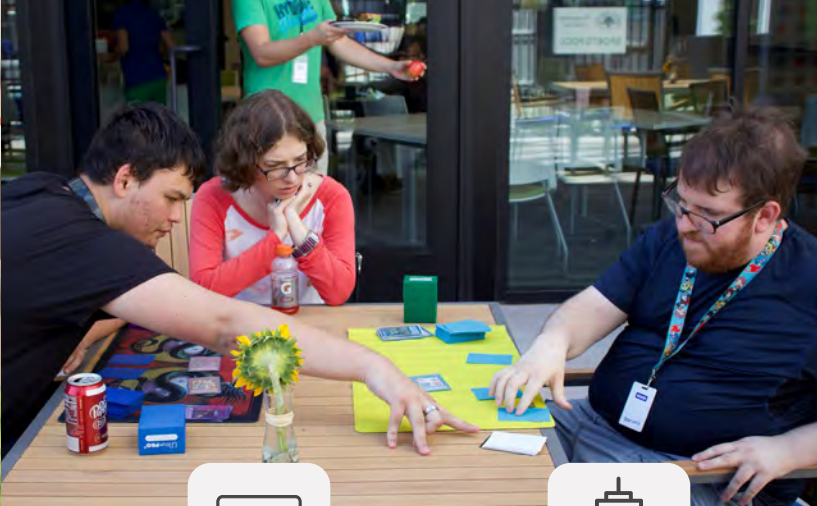
- Private pay
- Medicaid HCBS waiver

First Place–Phoenix

Phoenix, Arizona

firstplaceaz.org

For more information, see p. 124 of the Promising Practices section.



Residential Unit Type

Apartments (55 Units)



Development Type

Mixed-use development



Lifestyle

Intentional community
Active-living community



Private vs. Shared Residence

Private Residence

Physical Amenities

- **Sensory-friendly design** (non-fluorescent lighting, natural light, non-toxic low VOC materials)
- **Accessible design** (ADA-compliant units)
- **Cognitive accessibility features** (color palettes and signage, including visual symbols and Braille for multiuse functions and way-finding)
- **Security features** (keycard access, concierge)
- **Smart home technology**
- **Relaxation space** (Zen room)
- **Common area space** (culinary teaching kitchen, multipurpose room)
- **Recreation space** (organic garden, swimming pool, patio, barbecue, fitness and game rooms, Lego and reading lounges)
- **Transit access**

Supportive Amenities

- **Life-skills training** (transportation navigation, meal planning and instruction, social integration)
- **Workplace & vocational support** (support developing career-readiness skills, such as arriving on time, packing a lunch, dressing appropriately)
- **Community life** (daily social activities and events, such as Social Saturdays, special guests, dances; local outings)
- **Health & fitness activities** (meditation, yoga, Zumba, sports, pool activities)

Payment Model

- **Rental/lease for housing**
- **Tuition-based program** for residential Transition Academy program

29 Palms Snapshot

The intentional community of 29 Palms is an apartment property for adults with autism who have graduated from the First Place Transition Academy and seniors (55+) who do not have autism. Senior residents (who live in 15 of the 21 units) and Academy graduates (who live in the remaining six units) demonstrate the spirit of community through natural supports (e.g., residents with autism helping seniors with heavy items or offering technology assistance with cellphones, apps, computers; seniors helping residents with autism with cooking or problem solving when "life happens"). The renovated property includes sensory-friendly design, adaptable features, smart home technology and convenient access to public transit. The project is a collaboration between the Foundation for Senior Living and First Place AZ.

The developers have a second similarly configured property underway called Spectrum Courtyard Apartments (scheduled for December 2020 completion and leasing in January 2021). Both properties have been made possible by grants from the Arizona Department of Housing and other donors. Spectrum Courtyard and 29 Palms serve as home for Transition Academy graduates, but anyone who meets income qualifications can lease an apartment (per Fair Housing). Both properties demonstrate second places or next places for neurodiverse adults.

Residents & Services

Target Market

- Adults with autism
- Neurodiverse adults
- Seniors (55+)

Resident Support Needs

- Drop-in support
- Low support
- Moderate support

Property Relationship to LTSS

- Consumer-controlled setting

LTSS Delivery Model

- Natural supports
- Self-directed support

Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver



29 Palms

Phoenix, Arizona

PBS NewsHour Special: youtu.be/BT1GWb2BoRE



Residential Unit Type

Apartments
(21 Units)



Development Type

Planned community



Lifestyle

Intentional community
Active-living community



Private vs. Shared Residence

Private Residence
Shared with housemate

Physical Amenities

- Common area space
- Sensory-friendly design
- Adaptable design (age-in-place)
- Smart home technology
- Security features
- Pedestrian-oriented
- Transit access

Supportive Amenities

- Community Life
- Resident assistant
- Workplace and vocational support

Payment Model

- Affordable rental/lease

Noah Homes Snapshot

Individuals with I/DD are living longer than ever before [24], [102], but may need age-related memory care for dementia and Alzheimer's disease as early as their forties [103], [104]. In 2016, Noah Homes developed two 5,000-square-foot memory care homes for up to 20 people with I/DD, the first of their kind in the U.S. The memory care homes have a staff-to-resident ratio of 1-to-2, state-of-the-art technology, and opportunities to participate in groundbreaking techniques to fight Alzheimer's, dementia and other age-related challenges.

The property includes on-site offices for partners engaged in research into age-related disease. Living costs are affordable through a combination of Social Security Income funding, supplemental funding from the California Department of Developmental Services and Noah Homes' own fundraising. Residents are not responsible for any additional costs. Residents can enjoy a sense of community, as the two homes are located in a planned community where many residents with I/DD have lived for decades.

Residents & Services

Target Market

- Adults with intellectual and developmental disabilities and dementia and/or Alzheimer's disease

Resident Support Needs

- 24/7 support
- Memory care
- High behavioral support

Property Relationship to LTSS

- Provider-controlled setting

LTSS Delivery Model

- Agency-based rotational staffing

Funding Options for LTSS

- Medicaid HCBS waiver

Noah Homes Memory Care Homes

Spring Valley, California
noahhomes.org/memorycare



Residential Unit Type

Other residential facility



Development Type

Planned community



Lifestyle

Intentional community
Active-living community
Faith-based community



Private vs. Shared Residence

Private Residence

Physical Amenities

- Common area spaces (community center, patios)
- Relaxation spaces (garden, orchard)
- Recreation spaces
- Security features
- Cognitive accessibility features
- Easy-to-clean features
- Extra-durable features
- Accessible design

Supportive Amenities

- Community Life

Payment Model

- Tuition-based (negotiated rate)

Photo: Noah Homes

Photo: Noah Homes

Yellow House Snapshot

The Yellow House is a single-family home located in the rural community of Carbondale, Colorado near Aspen in the Rocky Mountains. A family purchased an existing home for their young adult son with autism and renovated it in 2014 to meet his sensory and behavioral needs. Property management, residential support and day services are provided by Ascendigo Autism Services.

The Yellow House is located in a quiet residential neighborhood that is walkable to recreational amenities (parks, recreation center, bike and hiking trails) and to Main Street with restaurants, shops, creative spaces, a movie theater, public transportation and other small-town amenities. The house has three bedrooms, each with its own full bath, and design features for sensory comfort, safety, independence, privacy and ease of maintenance. An accessory dwelling unit (ADU) is rented to an Ascendigo employee who provides on-call backup and property oversight. The landscaped yard has swings, vegetable gardens, a pond, spa and patio. The original residents were three adults with autism whose families shared equal operational control through a cooperative-ownership LLC. Currently, one person resides there, but the goal is to have up to three residents living and thriving in the house together.

The current occupant and his family hired Ascendigo to provide agency-based, rotational staffing to meet his support needs. These services include case management, behavior therapy, program coordination to access sports (skiing, lake sports, hiking, biking, climbing, riding, etc.), continuing education, social opportunities and employment supports. Ascendigo provides direct-support professionals for overnight care and serves as the property manager. This nonprofit service provider offers similar services to other adults with autism in the community who live in their own homes, family homes or rental units. The level of service varies by client, with some receiving only drop-in support (such as life coaching) or vocational services, and others needing day services and back-up residential supports.

Residents & Services

Target Market

- Adults with autism

Resident Support Needs

- 24/7 support
- High behavioral support

Property Relationship to LTSS

- Consumer-controlled setting

LTSS Delivery Model

- Agency-based rotational staffing
- Paid neighbor

Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver

Yellow House Ascendigo Autism Services

Carbondale, Colorado
ascendigo.org



Residential Unit Type

Single-family home
Accessory dwelling unit (ADU)



Development Type

Scattered site



Lifestyle

Live-work-play
Pet-friendly



Private vs. Shared Residence

Private Residence (current)
Shared with housemates (past/future)

Physical Amenities

- Relaxation amenities (sensory room)
- Pedestrian-oriented
- Transit access
- Security features
- Smart home technology
- Cognitive accessibility features
- Easy-to-clean features
- Extra-durable features
- Sensory-friendly design
- Accessible design (ground floor)
- Personal preference

Supportive Amenities

- Personal preference
- Resident assistant

Payment Model

- Cooperative ownership (LLC)

Chapel Haven Schleifer Center Snapshot

Chapel Haven Schleifer Center offers student-housing apartments for young adults enrolled in the Center's unique transitional programs designed for those with intellectual and developmental disabilities and other neurodiversities. Programs include the REACH program for adults with developmental disabilities and autism, and the Asperger Syndrome Adult Transition (ASAT) program for adults with social communication disorders. Each program has a unique set of supportive amenities. Chapel Haven recently added the Schleifer Adult Independent Living (SAIL) campus, an intergenerational apartment complex for program graduates who want or need lifelong support. SAIL enables residents to comfortably age in place in a non-institutional setting. This \$45 million campus was built with universal design and, more specifically, sensory issues in mind. Chapel Haven also has a campus in Tucson, Arizona called Chapel Haven West, which offers a program for adults with social communication disorders.

Residents & Services

Target Market

- Neurodiverse young adults
- Adults with autism
- Adults with intellectual and developmental disabilities (including executive functioning, social communication)
- Intergenerational

Resident Support Needs

- Drop-in support
- Low support
- Moderate support
- 24/7 support

Property Relationship to LTSS

- Provider-controlled setting

LTSS Delivery Model

- Paid neighbor
- Residential transition program

Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver
- Approved private special education high school

**Chapel Haven
Schleifer Center**

New Haven, Connecticut
chapelhaven.org

Photo: Chapel Haven Schleifer Center



Physical Amenities

- **Transit access** (major bus lines; walking distance to businesses, universities, houses of faith)
- **Sensory-friendly design** (non-fluorescent lighting, natural light, non-toxic low VOC materials)
- **Accessible design** (ADA-compliant units)
- **Universal design**
- **Cognitive accessibility features** (each floor coded in differing color palettes to ease way-finding; signage includes visual symbols and Braille)
- **Security features** (all students have fobs to apartment and buildings; video surveillance; overnight awake staff (REACH) administrators on call)
- **Relaxation space** (student lounges on each floor; balcony space with comfortable seating encourages socialization)
- **Common area space** (teaching apartment, culinary teaching kitchen, outreach center for dances, karaoke)
- **Recreation space** (patio, barbecue, paid memberships to nearby JCC for swimming, basketball, rock climbing, etc.; fitness and game rooms, fitness center, yoga space, activity lounges)

Supportive Amenities

(Varies by program)

- **Life-skills training** (curriculum taught in apartment setting; includes managing a monthly budget, meal planning and preparation, mobility training and apartment maintenance)
- **Functional academics** (10 core subject areas taught by certified educators)
- **Curriculum-based assessment for each student** (monitoring progress every six months, benchmarked for progress in independent living)
- **Social communicative competency** (woven into all aspects of our curriculum by speech-language pathologists trained in pragmatics)
- **Community life** (includes hourly help by Chapel Haven counselors; weekend recreation program; structured day programming)
- **Resident assistant**
- **Workplace and vocational support** (includes extensive job placement assessment through the CareerAbility program; internship experiences, job sampling, supported and independent job placement; ongoing job retention services)
- **Housekeeping service** (includes life skills specialists who provide coaching and monitor apartment maintenance)
- **Benefits counseling** (assistance for families seeking application for social security and other government entitlements)
- **Meal service** (healthy meals on order; cooking instruction; guidance from full-time wellness coordinators)

Payment Model

- **Tuition-based**



Residential Unit Type

Apartments



Development Type

Student housing
Mixed-use development



Lifestyle

Intentional community



Private vs. Shared Residence

Private residence
(50% of units)
Shared with housemate
(50% of units)

The Arc Jacksonville Village Snapshot

The Arc Jacksonville Village is one of the first consumer-controlled planned communities for adults with I/DD in the U.S. Developed by the nonprofit The Arc Jacksonville, it offers affordable apartments with accessible design, smart home technology, and multiple recreation spaces and common areas. Residents have the opportunity to live independently in an inclusive and supportive residential community with peer-to-peer support. They enjoy robust on-site and off-site recreation options with walkable access to the broader community and public transit.

Residents & Services

Target Market

- Individuals with intellectual and developmental disabilities
- Low-income residents

Resident Support Needs

- Drop-in support

Property Relationship to LTSS

- Consumer-controlled setting

LTSS Delivery Model

- Agency-based rotational staffing
- Remote support
- Self-directed support
- Paid neighbor

Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver

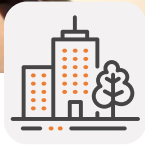
The Arc Jacksonville Village

Jacksonville, Florida
arcjacksonville.org/the-village
For more information, see p. 130 of the Promising Practices section.



Residential Unit Type

Apartments



Development Type

Planned community



Lifestyle

Intentional community
Live-work-play



Private vs. Shared Residence

Private residence (65 units)
Shared with housemate (32 units)

Physical Amenities

- **Accessible design** (ADA-compliant units; wheelchair-accessible units)
- **Common area spaces** (community center with dining room, great room, activity room, meeting rooms)
- **Recreation space** (game room, theater room, computer room, swimming pool, hot tub, picnic area, basketball court, garden, fitness center)
- **Smart home technology** (units equipped with emergency on-call system)
- **Security features** (gated community, on-site overnight security)

Supportive Amenities

- **Community life** (on-site and off-site recreation options and activities)
- **Resident assistants** (live-in, on-site staff)
- **Life-skills training** (supported-living coaching)
- **Meal service** (*dining hall optional*)
- **Village vehicles shuttle service**

Payment Model

- **Rental/lease**
- **Affordable rental/lease**

CASS Housing Snapshot

CASS Housing is a nonprofit developer that provides consumer-controlled, customizable, affordable housing with onsite supports for residents with neurodiversities and I/DD. Each property consists of a single-family home with three accessory dwelling units (ADUs) or single room occupancy (SRO) units (depending on zoning in the local jurisdiction), a common space and communal kitchen. A neurotypical steward (resident assistant) lives in the house (with their family as applicable) and adults with neurodiversities and/or I/DD live in the ADUs. Each ADU is a private residence with its own bedroom, bathroom and kitchenette. Residents choose their preferred LTSS providers. The steward checks in with residents once a day and cultivates community life through weekly shared meals and monthly outings. All CASS Housing properties currently offer an independent living model. In the next five years, the plan is to develop a planned community offering family living and family-plus models for adults with additional support needs. This expansion has been facilitated by impact investments, including from a CASS Housing resident and several residents' families.

Residents & Services

Target Market

- Neurodiverse residents
- Adults with intellectual and developmental disabilities

Resident Support Needs

- No service needs
- Low support
- Drop-in support

Property Relationship to LTSS

- Consumer-controlled setting

LTSS Delivery Model

- Agency-based rotational staffing
- Paid neighbor
- Remote support
- Self-directed support

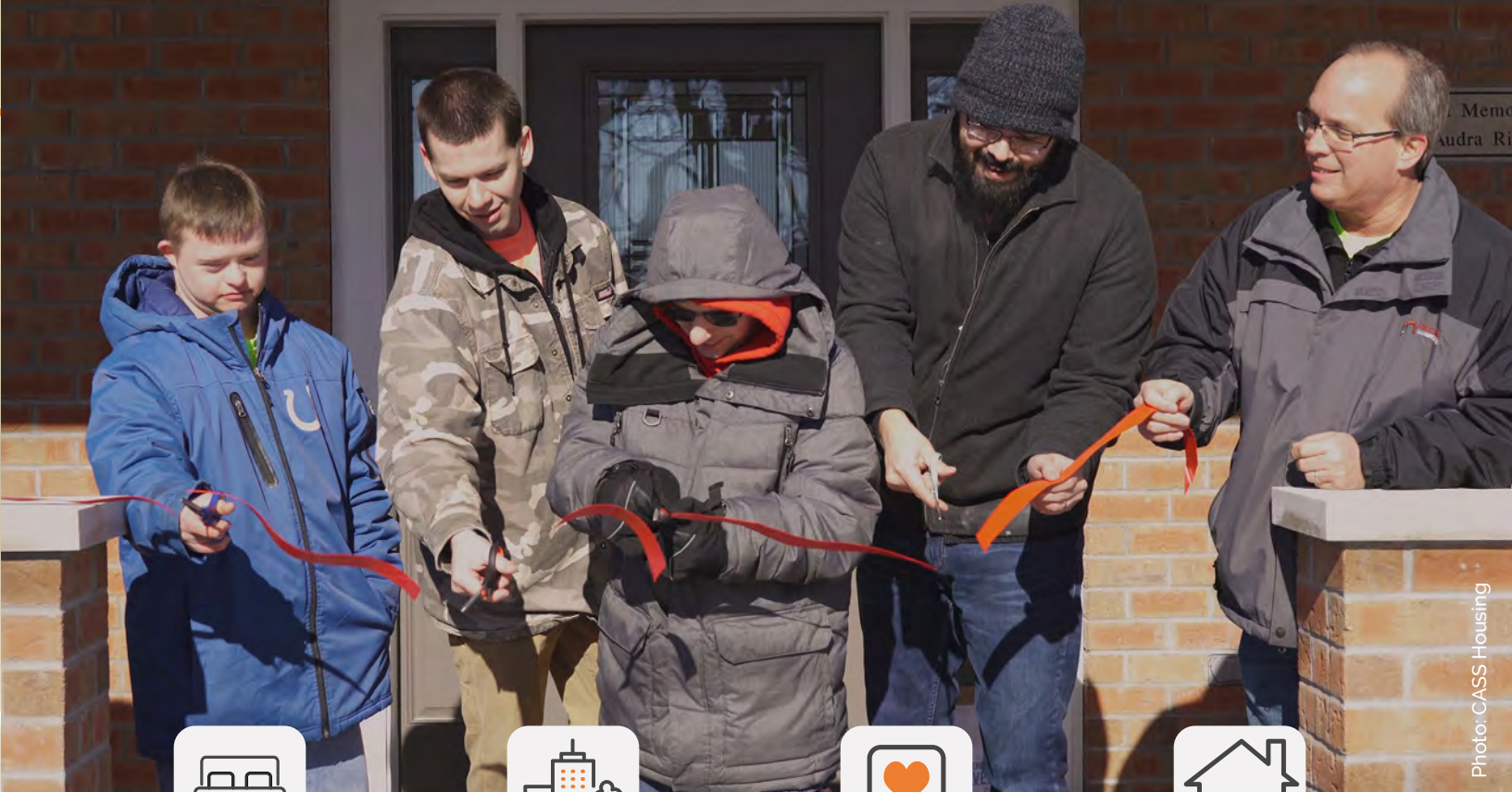
Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver



CASS Housing

Fort Wayne, Indiana
casshousing.org



Residential Unit Type

Single-family home
+3 accessory dwelling
units or single room
occupancy units



Development Type

Scattered site
Planned community
(in the future)



Lifestyle

Intentional community



Private vs. Shared Residence

Private Residence

Physical Amenities

- Common area space
- Smart home technology
- Security features
- Easy-to-clean features
- Extra-durable features
- Accessible design
- Adaptable design
- Personal preference

Supportive Amenities

- Resident assistant (steward)
- Community life
- Community navigator
- Life-skills training
- Benefits counseling
- Personal preference

Payment Model

- Affordable rental/lease
- Rental/lease

Crescent Commons Snapshot

Crescent Commons is an affordable residential complex of the nonprofit developer Bergen County's United Way/Madeline Housing Partners LLC. The complex has 17 affordable-lease apartments, six homeownership townhouses and a three-bedroom licensed group home. In this hybrid setting, LTSS in the group home is provider controlled, while LTSS in the apartments and townhouses is consumer controlled. The property is a short walk from downtown Allendale, Crestwood Lake and public transit (train and bus). Residents currently include families and neurodiverse adults.

Residents & Services

Target Market

- Neurodiverse adults
- Low-income residents
- Families

Resident Support Needs

- No service needs
- Drop-in support
- Low support
- Moderate support
- 24/7 support

Property Relationship to LTSS

- Hybrid setting

LTSS Delivery Model

- Agency-based rotational staffing
- Self-directed support
- Residential transition program

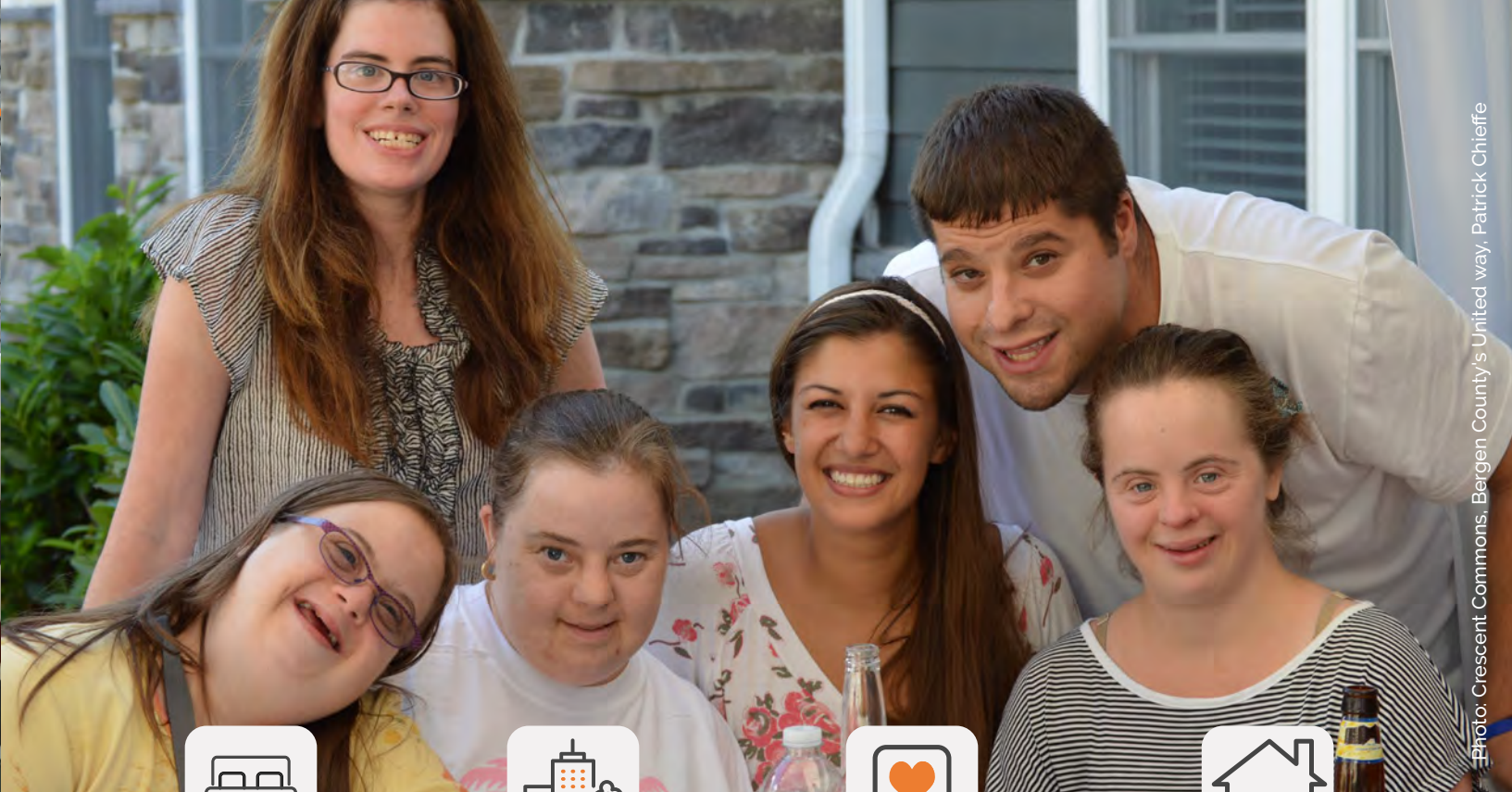
Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver

Crescent Commons

Allendale, New Jersey
bergenunitedway.org

For more information, see p. 136 of the Promising Practices section.



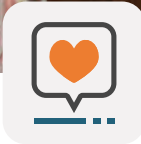
Residential Unit Type

Apartments (17 units)
Townhouses (6 units)
Single-family home
(3-bedroom group home)



Development Type

Scattered site
Group home



Lifestyle

Personal preference



Private vs. Shared Residence

Private residence
(apartments & townhouses)
Shared with housemates
(group home)

Physical Amenities

- **Common area space** (community room)
- **Transit access**

Supportive Amenities

- **Benefits counseling** (housing service coordinator)

Payment Model

- **Affordable rental/lease** (apartments & group home)
- **Individual ownership** (townhouses)

Our Home - Cathedral Park Snapshot

Our Home – Cathedral Park (OHCP) is a cohousing-inspired community developed by the nonprofit Our Home, Inclusive Community Collaborative for people with diverse abilities, ages and income levels. With an anticipated completion date of 2022, OHCP will offer studio, one-, two- and three-bedroom condominiums architecturally designed to promote community connection and interaction, as well as the privacy of individual homeownership. The property offers both conventional market-rate ownership and subsidized units for qualified individuals. People who experience disability will live in 20-25% of the 28 units as homeowners or tenants. OHCP emphasizes community connection, belonging, cooperative decision-making, sharing, respect, diversity, reciprocity based on individual strengths and interests, and more. Its location offers convenient access to urban amenities, nature, public transit and Portland's Cathedral Park.

Residents & Services

Target Market

- Adults with disabilities
- Adults with intellectual and developmental disabilities
- Neurodiverse adults
- Low-income residents
- Families
- Seniors
- Intergenerational

Resident Support Needs

- Varies by person

Property Relationship to LTSS

- Consumer-controlled setting

LTSS Delivery Model

- Agency-based rotational staffing
- Natural supports
- Paid neighbor
- Remote support
- Self-directed support
- Shared living

Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver

Our Home
Cathedral Park

Portland, Oregon
ourhomecathedralpark.com



Residential Unit Type

Condominiums
(28 units)



Development Type

Cohousing community



Lifestyle

Intentional community
Active-living community
Pet-friendly
Live-work-play
Personal preference



Private vs. Shared Residence

Private residence
Shared with housemate(s)

Physical Amenities

- **Common area space** (common kitchen, laundry, outdoor gathering spaces, small & large indoor gathering spaces, dog-washing station, bike room, covered parking)
- **Relaxation amenities**
- **Pedestrian-oriented**
- **Transit access**
- **Security features**
- **Smart home technology (individualized)**
- **Easy-to-clean features**
- **Universal design**
- **Accessible design**
- **Adaptable design**
- **Personal preference**

Supportive Amenities

- **Community life** (meal sharing, educational opportunities)
- **Health and fitness opportunities**
- **Personal preference**

Payment Model

- **Individual ownership**
- **Group ownership**
- **Subsidized ownership**
- **Rental/lease**

Marbridge Snapshot

The Marbridge campus offers a variety of residential options for adults with I/DD in a provider-controlled setting. Residents can maintain their preferred activities and friendships as their support needs change with age. The Village at Marbridge emphasizes independent and semi-independent living in a shared single-family home. Each cottage in the Village has three two-bedroom suites, a living area, kitchen, dining area and laundry room. Instructors provide training and oversight for independent living skills like shopping and cooking.

The Ranch at Marbridge offers assisted living. Residents can live in a private bedroom in one of The Ranch's four lodges or in a shared room in a dorm setting. There are several communal areas, including living rooms, dining rooms and an enrichment center. Staff help with activities of daily living and are available around the clock. The Villa at Marbridge offers 24-hour skilled nursing care in spacious shared bedrooms. This faith-based community offers community life, activities on and off campus, health and fitness activities, relaxation spaces and more.

Residents & Services

Target Market

- Adults with intellectual and developmental disabilities
- Neurodiverse residents
- Adults with profound medical needs

Resident Support Needs

- Drop-in support
- Low support
- Moderate support
- 24/7 support
- Daily medical support

Property Relationship to LTSS

- Provider-controlled setting

LTSS Delivery Model

- Agency-based rotational staffing (24-hour awake staff)

Funding Options for LTSS

- Private pay
- Dual Eligible Medicare–Medicaid (skilled nursing facility)

The Marbridge logo consists of the word "Marbridge" in a white, sans-serif font, centered within an orange rectangular background.

Manhaca, Texas
marbridge.org



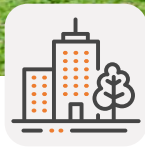
Photo: Marbridge

Photo: Marbridge



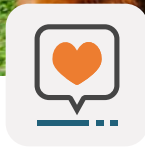
Residential Unit Type

Single-family home
(15 cottages at The Village;
4 lodges at The Ranch)
Dormitory (The Ranch)
Facility-based setting
(nursing home at The Villa)



Development Type

Planned community
Assisted living
Nursing home



Lifestyle

Faith-based community
Live-work-play
Intentional community
Active-living community



Private vs. Shared Residence

Shared with housemates (single- and double-occupancy bedrooms)

Physical Amenities

- **Common area space** (living rooms, kitchens, laundry rooms, recreation room at The Village. Living rooms, TV rooms, enrichment center at The Ranch)
- **Recreational spaces** (swimming pool, athletic facility, wellness center, equestrian center, fishing pond, horticultural/sustainable garden center)
- **Relaxation spaces** (multisensory integration room, enrichment/ community centers, swings, outside seating/gathering areas)
- **Pedestrian-oriented**
- **Sensory-friendly design**
- **Accessible design**
- **Adaptable design**
- **Chapel**

Supportive Amenities

- **Community life** (independent and supervised outings into the Greater Austin community and beyond; formal and informal activities on campus)
- **Life-skills training** (157+ training classes, including cooking, money management, social skills, public transportation and more held during the week with 20 instructors)
- **Meal service** (room & board included in tuition)
- **Health and fitness activities** (12 Special Olympics sporting opportunities, yoga, cardio training, bocce, etc.)
- **Housekeeping service**
- **Life-skills training**
- **Workplace and vocational support** (employment available on campus & in the community)
- **Benefits counseling**
- **Resident assistant**
- **Full-time nursing staff**
- **Full-time licensed nurse practitioner & medical doctor**
- **Occupational therapy**
- **Physical therapy**
- **Speech therapy**

Payment Model

- **Tuition-based**

Faison Residence Snapshot

The Faison Residence is an apartment community where a third of the units are rented to adults with autism and other developmental disabilities who are generally independent but need occasional assistance and supervision. The remaining units are rented to the general public. The property was developed by the Faison Center—a school for children and adults with autism—that wanted graduates to have more options for housing and services.

As a hybrid setting for LTSS delivery, residents with autism and I/DD have access to smart home technology and other supportive in-home services in a provider-controlled setting while they transition from home-based services to more independent adulthood. The remaining units are consumer controlled. Neighbors look out for each other at this intentional and active-living community. The retail space of this mixed-use development is home to a health clinic, sandwich shop and salon, with security systems throughout the building. In addition to the on-site patio, community room and fitness center, residents have access to the Faison Center's 10,000-square-foot, state-of-the-art community center for physical activity and entertainment.

Residents & Services

Target Market

- Adults with autism
- Neurodiverse adults
- Adults with intellectual and developmental disabilities
- General market

Resident Support Needs

- No service needs
- Drop-in support
- Low support
- Moderate support
- 24/7 support

Property Relationship to LTSS

- Hybrid setting

LTSS Delivery Model

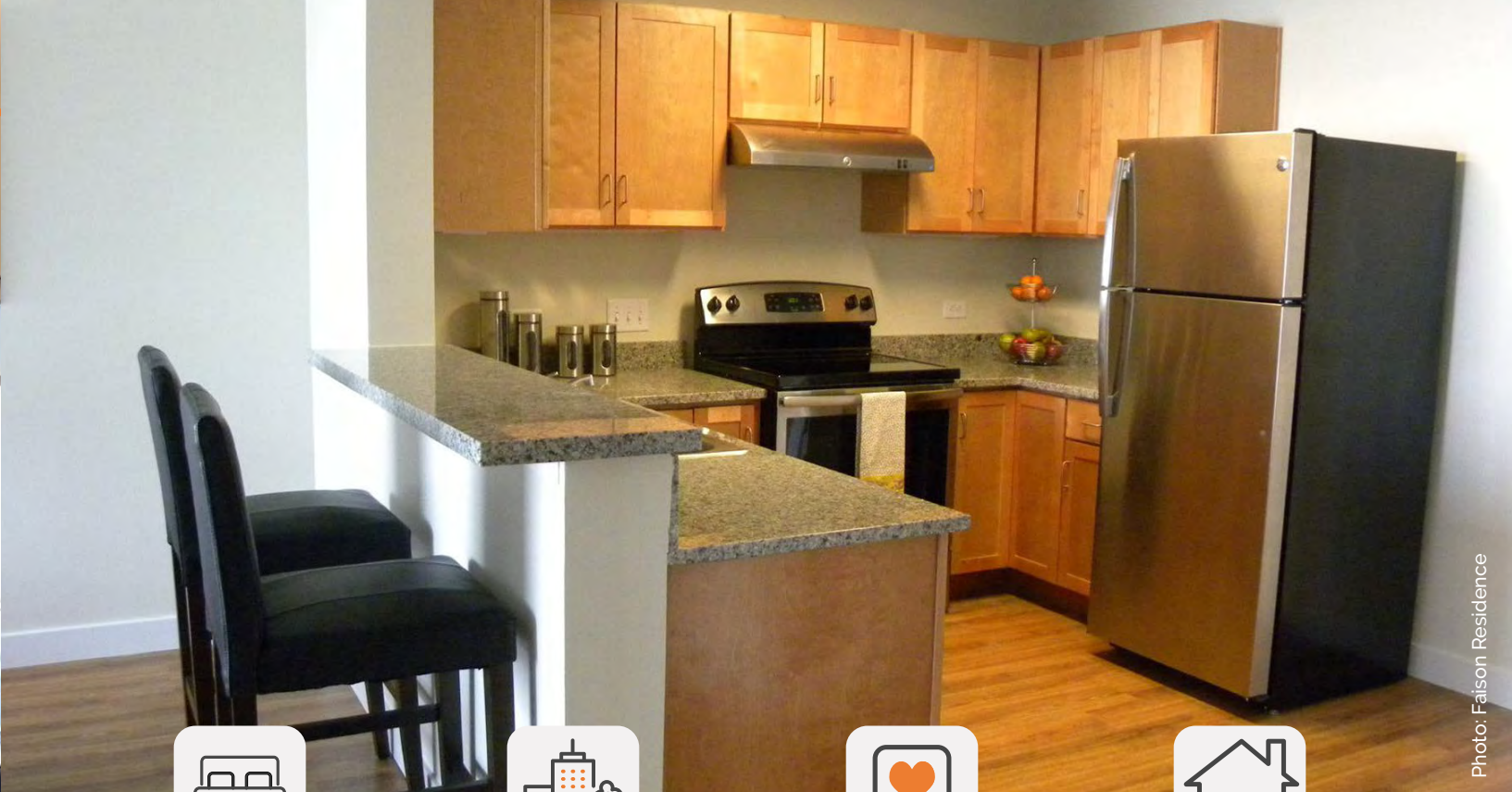
- Agency-based rotational staffing
- Paid neighbor
- Remote support

Funding Options for LTSS

- Private pay
- Medicaid HCBS waiver

Faison Residence

Richmond, Virginia
faisoncenter.org/the-faison-residence



Residential Unit Type

Apartments
(45 units)



Development Type

Mixed-use
development



Lifestyle

Active-living community
Intentional community



Private vs. Shared Residence

Private residence
Shared with
housemate(s)

Physical Amenities

- **Common area spaces** (community room, patio)
- **Smart home technology**
- **Security features**
- **Recreational amenities** (fitness room, community center)
- **Transit access**

Supportive Amenities

- **Community life**
- **Resident assistant**
- **Life-skills training**
- **Workplace and vocational support**
- **Community navigator**

Payment Model

- **Rental/lease**
- **Affordable rental/lease**

Promising Practices

Person-centered options for housing and support services have expanded as a result of the pioneering work of nonprofit and private developers. By working across public, private, nonprofit and philanthropic sectors, and with creative financing and good design, developers are illustrating how a collaborative sector approach can increase the housing supply for special populations and meet the demands of neurodiverse populations while building better, stronger, more inclusive communities, and pushing the imagination of what is possible, practical and sustainable.

This chapter highlights three innovative housing development models from across the U.S., drawing from in-depth interviews with leaders from each development organization. In Arizona, First Place AZ models how to incorporate insights from the general housing market, well-researched design and integration of supportive amenities, physical amenities and community life into building comfortable homes in a supportive, neuroinclusive environment. In Florida, The Arc Jacksonville demonstrates how the visions of people with intellectual and developmental disabilities can be expressed through an independent living, deeply affordable planned community. In New Jersey, Bergen County's United Way/Madeline Housing Partners, LLC illustrates how to leverage favorable policy, creative financing and attractive design to expand quality affordable housing in an inflated real estate and rental market. The application of the *A Place in the World* Nomenclature is further illustrated in this chapter, with bold text denoting terms from the nomenclature.

These developers share a commitment to quality housing that contributes to the independence, spirit of community and quality of life of residents with diverse needs and abilities.

They demonstrate how nonprofit and private-sector developers can use policy, research and engagement with prospective residents and a variety of funding sources to stimulate a new generation of successful person-centered housing and support services. They illustrate what can be accomplished through collaboration, creativity and unstoppable persistence.



The promising practices of these development models shed light on what has worked to respond to the needs and preferences of the neurodiverse housing market. They offer several takeaways:

Supportive state & local policies

such as tax credits dedicated to housing for adults with I/DD or regulations that encourage affordable housing development can help increase the supply of and access to quality residential options for adults with neurodiversities.

Collaborations

among developers, property managers and/or service providers, for example, can allow organizations to lend their strengths without fundamentally changing their operations or identities.

Affordability

does not have to mean compromising on beautiful design and amenities or relying on traditional federal funding sources.

Design features

such as natural light, lever door handles, durable materials or community spaces can be incorporated to make a residential development more adaptable for special populations and appealing to the general market.

Thinking beyond the four walls

of a building—about how residents live both in and outside of the home—can improve quality of life and community connection.



Photo: First Place® AZ, Good Eye! Media

First Place AZ

Phoenix, Arizona
firstplaceaz.org

See page 78 of the
Housing Market Guide.

of Units

55

Capacity

75

people with autism and
other neurodiversities

First Place AZ is a 501(c)(3) nonprofit charitable organization founded in 2012. Its mission is to "set the standard for developing communities that integrate adults with autism and other neurodiversities into the fabric of society through housing, healthcare, education, employment, supportive systems and culture" [105].

Its first property, First Place–Phoenix (First Place), is a consumer-controlled apartment property and intentional community of neurodiverse residents in Phoenix, Arizona. Opened in July 2018, the mixed-use building includes 55 private apartments (one-, two- and four-bedroom suites), as well as recreation spaces, relaxation spaces and common area (connector) spaces. Located in the heart of Phoenix, First Place offers convenient access to transit, jobs, lifelong education, restaurants, retail and recreation. It is a new residential prototype designed to empower each resident to grow in independence and self-sufficiency within the First Place environment and greater Phoenix community.



Photo: First Place® AZ, Good Eye! Media

Thinking beyond four walls.

First Place approaches housing for special populations with insights from the general market. *"Historically, the bar has sadly been kept low in terms of expectation for what people consider to be appropriate housing for individuals with special needs, which is why we haven't seen a lot of innovation. At First Place, we often look up and out to the general market to inform our questions about what people want, need and deserve as valued members of our communities. With that mindset, we're testing and developing solutions for how more people with autism and other differences are better integrated into First Place and other market-driven and affordable housing properties, expanding choice and opportunities for community integration."*

— Denise D. Resnik, Founder & President/CEO of First Place AZ

The property features three primary uses: First Place Apartments for residents; First Place Transition Academy for students; and First Place Leadership Institute for training, data collection, research and public policy advancements. First Place collaborates with the Southwest Autism Research & Resource Center (SARRC) and GateWay Community College to offer its Transition Academy, a two-year, post-secondary education program focused on building crucial life skills for independent living and career readiness.

According to First Place AZ Founder, President and CEO Denise D. Resnik, location, design and community connections are among the essential ingredients of First Place. "Sound principles for residential real estate include good location, property design responsive to the needs and interests of those served and integration within the greater area—whether its urban, suburban or rural. What's special about First Place is how the property lives and breathes to build community and those all-important connections among and between neighbors, staff and the broader urban community.

Residents are attracted to First Place because they're looking for friends, a job, a home of their own and the chance to learn how to live more independently."



What was the development process?

First Place AZ leveraged multiple funding streams, including **New Markets Tax Credits**, a **private sector loan** and charitable contributions from more than 100 donors to develop the real estate. A comprehensive **capital campaign** with support from foundations and donors of all sizes also funded start-up operations and program development.

After purchasing the land in midtown Phoenix in 2014 that would become the site of First Place–Phoenix, First Place retained RSP Architects, a firm that had already demonstrated its understanding and appreciation for the target market through their work leading the design of SARRC's Campus for Exceptional Children ten years prior. The thoughtful building design of First Place–Phoenix was the culmination of two decades of research, travel, focus groups and design charrettes. A core resource was the 2009 report *Opening Doors*, a collaboration among SARRC, the Urban Land Institute and Arizona State University that identified guidelines and best practices for built environments that meet the needs of individuals with autism [16].

“While the primary uses are essential, it is these spaces in between that bring out its true beauty and specialness.”

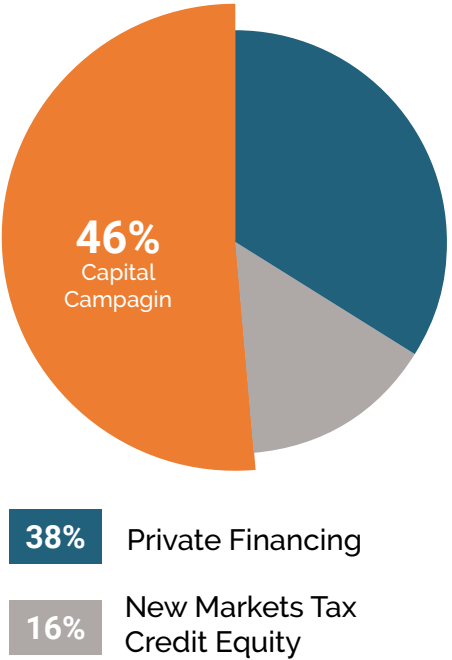
A source of design inspiration also came from the Japanese art form of kintsugi pottery. As First Place lead architect, Mike Duffy, explained, “We felt it was essential to have a lot of supported spaces where people could get outside of their units, interact with each other, meet for a game night on floor three, and play cards on floor four in one of the activity zones... We developed this concept taking inspiration from kintsugi pottery, the Japanese art form in which broken pieces of pottery are repaired using resins made from precious metals such as gold or silver. It's this elegant and beautiful metaphor that directed our design for First Place, in that the resin holds it all together. Our task as designers was to create supportive spaces that not only satisfied the base program but also supported these important places for the community of First Place to learn, to grow, to thrive and to succeed. While the primary uses are essential, it is these spaces in between that bring out its true beauty and specialness.”

First Place AZ Property Development

-  **Developer type**
Nonprofit developer
-  **Financial stack**
 - Charitable campaigns
 - New Markets Tax Credits
 - Philanthropic gifts
 - Private sector loan
-  **Land source**
Purchased land
-  **For sale or rent?**
Rental/lease

First Place to Build an Adult Life: Funding Sources

Funding sources used to develop First Place AZ



Development costs.

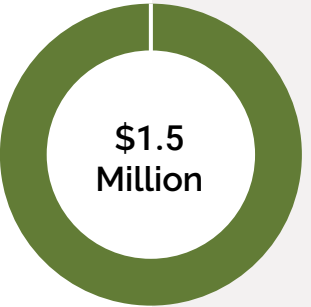
Total development cost



Construction cost



Land cost



Other property and transition program start-up expenses





Photo: First Place® AZ, RSP Architects

Lessons learned.

Persistence and flexibility were important ingredients for making First Place–Phoenix a reality. One example is the location and land source. As Resnik explained, “Prior to our current location, we fell in and out of love with many others, at one time believing that the 40 acres someone offered to donate was going to be the perfect site for our planned community. Well, that was about 20 years ago, and we quickly learned that we were not prepared to build an entire community, including the streets, sewers and ecosystem of support. Since we had been developing a supportive, connected Phoenix community for years, we turned to a midtown location where we could leverage the assets of the urban area and be closer to where other people wanted to live.”

Duffy shared insights on designing homes for special populations: “Designing for autism is just good design. It’s not that different from any of our other design processes. We just need to add in a few more layers. The vast majority of everyone we talked to in either focus groups or design charrettes typically had some very intimate, close connection to autism. Several were also on the spectrum. We were talking to the experts and it was really important we get this right.”

“Designing for autism is just good design. It’s not that different from any of our other design processes. We just need to add in a few more layers.”

Policy matters.

Through collaboration with Arizona policy makers, the First Place Transition Academy has become more affordable. Starting from its launch in 2015, First Place AZ and SARRC tracked the Transition Academy’s efficacy by gathering evaluative data. With that data as evidence, they worked with Arizona policymakers to build a funding crosswalk, allowing Transition Academy participants to braid together public funds to support enrollment. As of mid-2019, members of the Arizona Department of Economic Security’s Division of Developmental Disabilities (DDD) who are eligible to receive Arizona Long-Term Care System (ALTCS) services from SARRC can reduce out-of-pocket program costs by approximately 50%. For qualified members, private pay covers rent and amenities, while DDD and ALTCS provide funding for long-term care services.

Who lives at First Place?

First Place was designed for adults with autism and other neurodiversities (such as Down syndrome, traumatic brain injury). It is also open to neurotypical adults. It is not a medical home and is not for those who need intensive support or with self-injurious or violent behaviors. Current residents come from across the U.S.

How do residents receive support?

First Place is a **consumer-controlled setting**, where residents receive support from staff and have the ability to access LTSS as needed from their preferred third-party service provider(s) funded through **Medicaid HCBS waivers** and/or **private pay**.

First Place provides multiple **physical amenities** to help residents enjoy the comfort of their homes without challenging distractions. For example, the **sensory-friendly design** includes natural light, nonfluorescent lighting and nontoxic materials with low volatile organic compounds—features that benefit everyone. **Cognitive accessibility features** include color palettes and signage that promote way finding, reminding residents of their location and helping guide them to where they want to go next.

Supportive amenities at First Place are diverse. The property strives to create a sense of community and facilitate friendships by offering daily activities from Mindful Monday and Wellness Wednesday to Finally Friday and Social Saturday. The community offers an app called LifeLoop for residents to register maintenance requests and sign up for recreational activities and outings, several of which are led by fellow residents who are members of the Council of Resident Engagement (CORE).

How do residents pay?

Residents pay the **tuition-based** costs with private financial resources (private pay). Individuals who are qualified through the Arizona Dept. of Economic Security DDD and ALTCS can apply for public funding to help cover cost of enrollment in the Transition Academy and pay for rent and amenities with private pay.



Photo: The Arc Jacksonville

The Arc Jacksonville

Jacksonville, Florida
arcjacksonville.org/the-village

See page 98 of the Housing Market Guide.

of Units
97

Capacity
121
residents

The Arc Jacksonville is a nonprofit 501(c)(3) organization that began in 1965 as a grassroots movement to champion the inclusion of persons with unique abilities. It has been advocating for and serving individuals and families ever since.

Its residential development, The Arc Jacksonville Village, is one of the first **consumer-controlled planned communities** for adults with intellectual and developmental disabilities (I/DD) in the U.S. Opened in May 2016 in Jacksonville, Florida, it offers 97 affordable one- and two-bedroom rental **apartments** for 121 residents.



Photo: The Arc Jacksonville

As an intentional community catering to individuals interested in a live-work-play lifestyle, the Village supports peer-to-peer connection and walkable access to the broader community and public transit. Many of the Village's residents have participated in The Arc Jacksonville On Campus Transition at the University of North Florida, which provides vital services and supports to assist students in successfully transitioning into adulthood and life in the community. About two-thirds of residents are employed full or part time in the broader community.

As President/CEO of the Arc Jacksonville Jim Whittaker explained,

"The whole concept was actually driven by families and individuals receiving services who had an interest in living in such a community."

Our agency had acquired a large parcel of property and it happened to be located in a thriving area of Jacksonville surrounded by all kinds of amenities and other housing."

Thinking beyond four walls.





"What started to surface during focus group conversations was: Wouldn't it be really cool if we could develop a community that focused more on independent, semi-independent living in an apartment sort of setting where individuals would control their own space, make choices, and also have staff supports when needed and have unlimited access to the Jacksonville community?"

– Jim Whittaker, President/CEO of The Arc Jacksonville

What was the development process?

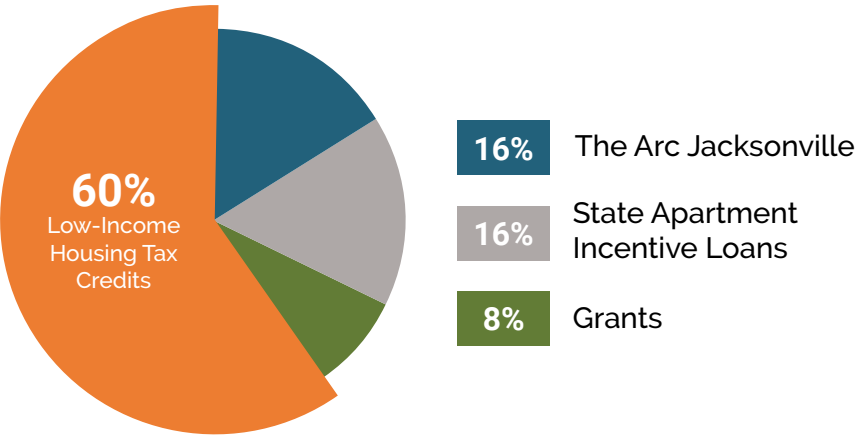
The Arc Jacksonville acquired a large parcel in a thriving area of Jacksonville through a cost-free, long-term land lease from the state of Florida. It leveraged **Low-Income Housing Tax Credits** (see Nomenclature, page 70), State Apartment Incentive Loans (SHIP Funds) and a Developmental Disabilities Grant to finance development and construction of the Village. Funds from a local capital campaign helped build out additional property amenities and establish an endowment.

The Arc Jacksonville Village Property Development

- **Developer type**
Nonprofit developer
- **Financial stack**
 - Capital campaign
 - Grant (Developmental Disabilities Grant)
 - Low-Income Housing Tax Credits
 - State Apartment Incentive Loans (SHIP Funds)
- **Land source**
Land lease
- **For sale or rent?**
Rental/lease

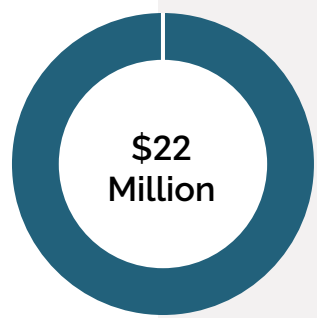
It Takes a Village: Funding Sources

Funding sources used to develop The Arc Jacksonville Village [106]

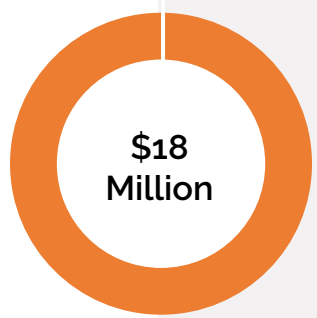


Development costs.

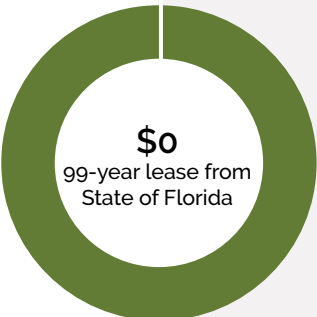
Total development cost



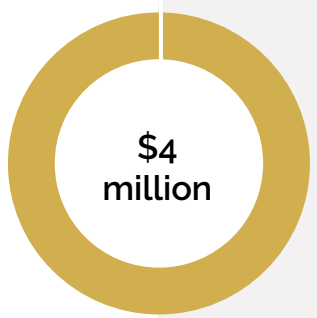
Construction cost



Land cost



Other development and start-up expenses



Lessons learned.

Residents of The Village seem most content when they have their own private living space. "If I were to do this again, I would build all one-bedrooms... Most of our resident issues are roommate related. The way The Village is designed, your best friend can live right next door to you, or across the way, without having to share space. I just think personal space is huge." – Jim Whittaker, President/CEO of The Arc Jacksonville

Policy matters.

The decision at the Florida Housing Finance Corporation to open a dedicated application stream for housing for individuals with intellectual and developmental disabilities (I/DD) has been instrumental for expanding residential choices in Florida. Said Whittaker, "Kudos to our state... The agency that deals with Affordable Housing Tax Credit was very receptive, after many meetings and conversations regarding how individuals with I/DD were left out of the housing equation, a decision was made a few years later to seek proposals for an I/DD development using Affordable Housing Tax Credits. Florida has now funded five communities with two new projects in various stages of development, ours being the first."

"Florida has now funded five communities with two new projects in various stages of development, ours being the first."

Photo: The Arc Jacksonville



Photos: The Arc Jacksonville



Who lives at the Village?

The Village caters to **adults with intellectual and developmental disabilities (I/DD)** with **drop-in support needs**. At present, Whittaker estimates that 20% of residents have autism. The vast majority of residents are from Florida, with roughly 10% from out of state.

How do residents receive support?

The Village is a consumer-controlled setting. Residents are required to have **self-directed support services** funded through **private pay** or **Medicaid HCBS waivers** (administered by Florida's Agency for Persons with Disabilities). Private-pay residents can receive Long-Term Services and Supports (LTSS) directly from the Village staff. For those whose service needs are funded through Medicaid waivers, The Arc serves only as a landlord; the resident picks their service provider from the broader community.

The Arc Jacksonville Village offers a variety of **physical amenities** and **supportive amenities** to residents. For example, each apartment has an intercom that can be used to request immediate help from on-site support staff in the event of an emergency. The Village also hosts AmeriCorps volunteers, both neurotypical and neurodiverse, to provide additional in-person support to residents. For residents with autism, this might mean encouraging them to participate in social activities or helping keep family members looped in.

As a gated community in a suburban center, the Village offers a balance of safety net, independence, and community. "The majority of families were interested in a community, which offered security and safety, opportunities for social engagement, community employment, recreation, affordability, services and staff supports, dining options and access to the broader community without restrictions. Each resident has a gate access code, in addition to family members and providers... Our gates are open during the daylight hours and they close at dark," said Whittaker.

In addition to The Village's interconnection with the Jacksonville community, residents provide community and support for each other. As Whittaker emphasized, "The Village offers [residents] that ability to hang out with who they want to; you know, to have friendships, to do things in small groups, to go off-site and explore the community."

How do residents pay?

Thanks to **Affordable Housing Tax Credits**, rent at the Village is half to one-third the rate of similar market-rate housing in Jacksonville. Residents pay rent with Housing Choice Vouchers and/or private pay (e.g., third-party benefits, earned income, family support)



Bergen County's United Way/ Madeline Housing Partners, LLC

Northeast New Jersey
bergenunitedway.org

See page 107 of the
Housing Market Guide.

Crescent Commons

17

affordable-lease
apartments

6

homeownership
townhouses

1

3-bedroom licenced
group home

Capacity

41

residents

Bergen County's United Way/Madeline Housing Partners, LLC is a housing development partnership that offers affordable, creative housing solutions for community members with the highest support needs across northern New Jersey. The two nonprofit organizations Bergen County's United Way and Madeline Corporation formed their partnership in 2004 with the mission to "build quality homes that empower individuals and families to live independently and thrive in the communities of their choice" [107]. Through the Very Special Homes program, their partnership provides over 317 affordable housing units across 28 separate projects, including **condominiums** for first-time homebuyers, senior (55+) communities and licensed **group homes**, among other types of housing. With more projects in development, the number of quality affordable housing units it offers continues to grow.

Tom Toronto, President of Bergen County's United Way, explained that in the expensive housing market of Northeast New Jersey, "Affordable housing, or the lack thereof, is the biggest issue... The only way to address that, we felt, was not to study it, but to increase the supply of homes that people could afford. We started to do that about 15 years ago and then when it was brought to our attention the



Thinking beyond four walls.

A key strategy of Bergen County's United Way/Madeline Housing Partners, LLC is creatively combining financial resources for housing for different special populations. According to Toronto, part of what makes Very Special Homes innovative is "the ability to be more flexible, to put different packages together, capital stacks together, to mix populations within one site or to subdivide within a site and build for separate populations, but to have a common community room... Our ability to mix seniors with folks with intellectual developmental disabilities, to build with veterans, with families, and to mix populations and to do that successfully has also, I think, broadened the horizons and the understanding of what affordable housing could actually be."

depth of the problem of lack of housing for folks with intellectual and developmental disabilities, we began to produce supportive housing."

To date, Bergen County's United Way/Madeline Housing Partners, LLC has secured more than \$30 million through collaborations with municipalities, counties and New Jersey state entities to fund their projects. Their record of successful partnerships with local and state government has produced more collaborations over time. Said Toronto, "We've managed to flip the equation or the convention around affordable housing in the state of New Jersey by building really attractive housing for residents drawn from the local community. So that's put us in demand for the municipality because we have a kind of ready-made solution to a pretty knotty issue."

This housing partnership has been honored for its designs. Orchards Commons Special Needs Housing development in Allendale, New Jersey received the 2010 Governor's Excellence in Housing Award for Best Supportive Housing. Airmount Woods Special Needs Housing in Ramsey and Dina's Dwelling in New Brunswick have each earned the Innovation in Supportive Housing Award from the Supportive Housing Association of New Jersey.

Bergen County's United Way/Madeline Housing Partners, LLC
Property Development



Developer type
Nonprofit developer



- Financial stack**
- Bergen County's United Way capital
 - CDBG Program
 - Federal Home Loan Bank
 - Grants
 - HOME Program
 - Housing First Capital Fund
 - Municipal Housing Trust Fund
 - New Jersey Division of Developmental Disabilities
 - New Jersey Housing Mortgage and Finance Agency
 - Partner capital
 - Philanthropic gifts
 - Private sector loans
 - Shelter Support Funding



Land source
Varies by property:

- Donation
- Purchased land

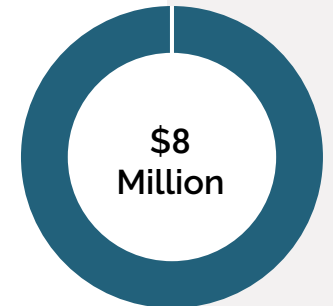


For sale or rent?
Varies by property:

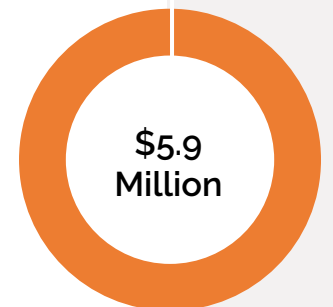
- Affordable rental/lease
- Rental/lease
- Homeownership

Development costs for Crescent Commons.

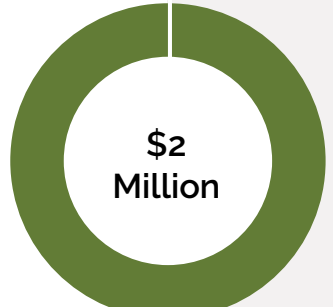
Total development cost



Construction cost



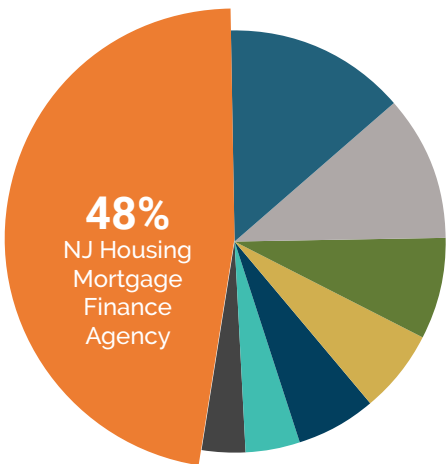
Land cost



Other development and start-up expenses



A Very Special Homes property: Crescent Commons in Allendale, NJ



- 14% Borough of Allendale Housing Trust Fund
- 11% Bergen County United Way
- 8% 6 Homeownership sales
- 6% NJ State HOME
- 6% Bergen County HOME
- 4% Federal Home Loan Bank
- 3% DDD Capital Fund

Lessons learned.

Supportive housing can be attractive housing. "People have an image of public housing, and it's high-rise, substandard materials, not well-built, not attractive. So the fact that we have built architecturally attractive, beautiful buildings that look like market-rate housing with materials that market-rate developers use has changed attitudes...[though] sometimes that increases our own capital into a job, to build it to the standard we want and what the population deserves." – Tom Toronto, President, Bergen County's United Way

Partnerships matter.

Quality housing for special populations often requires collaboration across partners with different skills and expertise. With Very Special Homes, Bergen County's United Way contributes financing and development expertise. Madeline Corporation contributes development expertise and property management. Their group homes are staffed by state-approved service providers. Working together has improved their ability to provide affordable residential options to special populations in their community.

Residents include individuals with I/DD, families, seniors, veterans, survivors of domestic violence and individuals who have experienced homelessness.

Policy matters.

When Bergen County's United Way/Madeline Housing Partners, LLC first started Very Special Homes, it benefited from leadership at the state level, including the Governor's Office and the New Jersey Housing Mortgage Finance Agency. "The governor at that time created something called the Special Needs Housing Trust Fund. What it implies is more supportive housing, and we took great advantage of that," said Toronto.

New Jersey's regulatory environment also encourages affordable housing development. Municipalities are constitutionally obligated to establish a realistic opportunity for the provision of affordable housing for low- and moderate-income households. Most municipalities meet this obligation via their land-use and zoning powers [108]. Collaborations like those with Bergen County's United Way/Madeline Housing Partners, LLC are another way municipalities can meet these obligations.

Who lives in Very Special Homes?

Residents of Very Special Homes include **individuals with intellectual and developmental disabilities, families, seniors, veterans, survivors of domestic violence and individuals who have experienced homelessness.**

How do residents receive support?

With the exception of its group homes, all Very Special Homes properties are **consumer-controlled settings**, where each resident chooses his or her own service provider(s) according to their support needs (though not all residents have support needs). Service providers enter into a formal Memorandum of Agreement with Bergen County's United Way/Madeline Housing Partners to ensure they will provide appropriate services to the resident. Residents pay for LTSS with **Medicaid HCBS waivers** (administered by the New Jersey Division of Developmental Disabilities) and/or **private pay**.

Physical and supportive amenities vary across Very Special Homes properties. Each property has a community room (**common area space**) where residents can meet and organize activities; tenants are encouraged to arrange social gatherings and events. Bergen County's United Way and Madeline Corporation host periodic meetings with residents to share news and updates, and hear from residents about issues or concerns at the property. All tenants receive support from a Housing Service Coordinator (**benefits counseling**) who assists with tenant eligibility, assessing service needs and connecting tenants to support resources.

How do residents pay?

Rents are based on U.S. Department of Housing and Urban Development annual guidelines for affordability. Tenants who receive state or federal rental assistance are responsible for paying 30% of their gross income for monthly rent.



Part 2: Public Policy

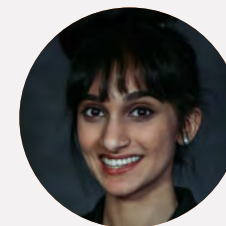


The purpose of public policy is inherent in the words themselves: the goal for a definitive, guiding course or method of action of, relating to or affecting all people in a community or nation.

Dedicated, knowledgeable and collaborative forces converging for a common purpose can change public policy—and lives—for the better. A Place in the World is the product of such a convergence.

A Place in the World is an unprecedented collaboration among a wide array of partners from the private, nonprofit, philanthropic and public sectors that includes Arizona State University Watts College of Public Service and Community Solutions and its Morrison Institute for Public Policy, the First Place Global Leadership Institute and its Daniel Jordan Fiddle Foundation Center for Public Policy, Autism Housing Network, and pioneering leaders from across the U.S. and around the globe.

Since 2002, the South Carolina-based Daniel Jordan Fiddle Foundation has blazed trails to develop, fund and advocate for programs and public policy related to all aspects of adult life for those with autism, including job training, residential living, the arts, recreation, health and wellness, and socialization.



Pooja Paode, Arizona State University graduate student, Morrison Institute research assistant and inaugural Daniel Jordan Fiddle Foundation Public Policy Fellow, commenced the fellowship in August 2019 with the goal of producing two seminal, public policy white papers. Both included in this report, the first addresses extensive, persistent shortcomings of federal programs and the second demonstrates how better data make better policy. These works track with Paode's studies in policy and data gaps influencing housing and support services for adults with autism and other intellectual/developmental disabilities. Paode holds two master's degrees from ASU: public policy and the science of health care delivery. Her bachelor's degree is in neurobiology, physiology and behavior.

Disclaimer: Information included here is provided for guidance and support purposes only and by virtue of inclusion in these documents is not endorsed by Arizona State University (ASU) Watts College of Public Service and Community Solutions, ASU Morrison Institute for Public Policy, and lead partners and sponsors of A Place in the World: .

Executive Summary

Pooja Paode, Daniel Jordan Fiddle Foundation Adult Autism Public Policy Fellow; Daniel Jordan Fiddle Center for Public Policy at the First Place Global Leadership Institute

Housing for Adults with Autism and/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs

This policy review outlines the historical evolution of federal policies that influence housing and LTSS for adults with autism and/or I/DD, summarizes key federal programs intended to provide access to consumer-controlled housing options for people with disabilities, and summarizes barriers to accessing these programs. The paper reveals significant gaps in federal housing support for adults with autism and/or I/DD across the lifespan, resulting in a fragmented and underfunded patchwork of housing assistance.

Key Takeaways

To date, there has been no landmark policy focused on housing assistance for adults with autism and/or I/DD, and no policies resulting in significantly increased access to affordable housing for this population.

Medicaid Home and Community-Based Services (HCBS) Waivers are the primary resource for LTSS targeting adults with autism and/or I/DD. This program is prohibited from covering the cost of room and board and provides residential LTSS funding to only a fraction of adults who need services to live in a home of their own. In addition:

- Many adults with autism are not eligible for HCBS waiver services. There is considerable variation in Medicaid eligibility across states and eligibility is often limited to those with an intellectual disability and/or extremely low-incomes.
- Waivers rarely cover costs associated with finding or maintaining housing. HCBS waivers in less than a quarter of states help adults access housing, typically by funding housing stabilization services and accessibility modifications. In these states, adults with autism and/or I/DD are rarely a target or priority population to receive housing stabilization services.
- Funding restrictions limit services available—even to eligible individuals. State cost-control policies, limitations of available service benefits and competition among multiple populations for Medicaid services limit coverage for adults with autism and/or I/DD.

The Department of Housing and Urban Development (HUD) addresses demand-side housing affordability for people with disabilities through Non-Elderly Disabled (NED) Housing Choice Vouchers (HCVs), Section 811 Capital Advance funding and Section 811 Project Rental Assistance funding. These programs target people with disabilities in aggregate without considering the unique needs of people with autism and/or I/DD. In addition:

- NED vouchers and Section 811 units reach a small fraction of demand. Approximately 80,000 NED vouchers and 33,000 Section 811 units are utilized nationally. However, it is unclear how many adults with autism and/or I/DD utilize NED vouchers or live in Section 811 units because utilization data are only publicly available for the aggregate population of adults with disabilities. Ineligibility for Medicaid LTSS may directly and indirectly decrease access to housing.
- There is considerable competition for vouchers and demand for affordable housing units. Demand for vouchers consistently exceeds supply; most adults with autism and/or I/DD are seeking the same housing vouchers and project-based affordable housing units as the other 11 million extremely low-income households that cannot afford rent.
- Individuals with vouchers may be unable to use them. Adults may experience barriers, such as housing discrimination and a lack of residential options suitable for the varying support needs of this population.

Affordability is just one barrier to housing stability. A lack of diverse housing options—especially residential options that accommodate individuals with higher support needs or more severe autism, rental market barriers, and other funding and regulatory barriers—also prevent access to housing for adults with autism and/or I/DD.

Better Data Make Better Policy: Defining Unmet Housing Needs of Adults with Autism and Other Neurodiversities

Data play an essential role in shaping conversations around policy gaps and potential solutions. This summary of the larger white paper illustrates how existing data are insufficient for understanding the residential needs of adults with autism and/or I/DD, inhibiting policy solutions that can help people access the housing and support services they need to thrive. It summarizes the data available (based on regularly collected national surveillance surveys, administrative data sets and state data sets), identifies additional data needed to articulate demand, and considers opportunities for future research and policy change.

Key Takeaways

- Data needed to calculate total unmet housing demand include:

Demand	Met Demand	Unmet Demand
Number of adults in each population segment and demographic characteristic, their housing preferences and support needs	Number of adults able to access housing that meets their needs and preferences	Housing stock needed to match housing and support needs and preferences
- In general, available data do not enable researchers or decision makers to measure and respond to the housing needs of a diverse population of adults with autism and/or I/DD.
- Inadequate data disaggregation and inconsistent data collection (through a lack of consistent operational terms) across states make linking relevant data between multiple sources challenging. This precludes an analysis of real housing supply and demand for adults with autism and/or I/DD.
- Housing accessibility data is typically considered in the context of the experiences of adults with physical disabilities. However, the experiences, housing preferences and support needs of adults with cognitive impairments are effectively invisible. Data delineate the population based on broad diagnoses such as autism or I/DD (as opposed to functional and support needs) or measure housing needs for people with disabilities in aggregate.
- Data focused on current recipients of LTSS obscure the diversity of housing needs of the population of adults with autism and/or I/DD. No data is available to describe housing-related experiences of those not receiving services or not recognized by their state developmental disability agency.
- The lack of data prevents housing for this population from becoming a policy priority. Better data are needed to move beyond deinstitutionalization alone and more toward access to diverse and affordable residential options.

Policy Opportunities

Data shape policy and policy shapes data. The following housing-related data recommendations will help elevate housing for adults with autism and/or I/DD as a policy priority.

- Facilitate data linkage between existing data sets. At the federal level, national surveillance and administrative data sets should use foundational terms and outcome measures representative of the diverse housing needs of this population. Across these population data sets, data collected linked to adults with autism and/or I/DD should describe individuals and family sociodemographic characteristics. Measures can be added to existing data sets to enable data linkage and support decision-making.
- Collect better data on available housing relevant to adults with autism and/or I/DD. For example, the following data about housing stock can enable decision-makers to evaluate the housing supply for adults with autism and/or I/DD: affordability, relationship to LTSS (consumer- versus provider-controlled), available physical and supportive residential amenities, residential unit type (private versus shared), lifestyle accommodations, cost to residents and funding options.

To address the need for appropriate housing and avoid consequences such as unnecessary institutionalization, homelessness or displacement from one's community, advocates, funders and policymakers must:

- Elevate housing as a priority in policy and legislative conversations related to both housing and LTSS for adults with autism and/or I/DD.
- Clarify and communicate the specific federal and state policy barriers and funding gaps that limit access to housing and LTSS.
- Support researchers collecting and analyzing data about housing accessibility, including housing preferences and support needs, for this population.
- Identify and address the most pressing barriers that prevent individuals from accessing residential options that best align with their preferences and support needs.

The lack of housing assistance and LTSS for people with autism and/or I/DD is at odds with the right to choose one's home and community codified in legislation, such as the Developmental Disabilities Assistance and Bill of Rights Act, Americans with Disabilities Act, and supported by the Supreme Court Olmstead decision. As family caregivers continue to age without swift and significant changes to the status quo, and given gaps in housing policy and LTSS programs, the nation is on an inevitable trajectory of persistently adverse outcomes.



Photo: CoHousing Solutions

Housing for Adults with Autism and/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs

Pooja Paode
Daniel Jordan Fiddle Foundation Adult Autism Public Policy Fellow; Daniel Jordan Fiddle Center for Public Policy at the First Place Global Leadership Institute

Technical Assistance provided by Desiree Kameka Galloway
Director of the Autism Housing Network, Madison House Autism Foundation

Abstract

Housing options for adults with autism and/or intellectual and developmental disabilities (I/DD) are closely tied to how federal policies around both Long-Term Support Services (LTSS) and housing have evolved since the 1970s.

This paper outlines the historical evolution of these policies, summarizes key federal programs within Medicaid and HUD that are intended to provide access to consumer-controlled housing options for people with disabilities, and lists barriers to accessing these programs. Medicaid has made increasing access to community-based services a policy priority through federal and state Home and Community-Based Services (HCBS) waivers; however, it is restricted from funding room and board. Although all 50 states have HCBS waivers approved specifically for individuals with I/DD, only a few states target housing-related service funds to help this population access housing. HUD programs have increasingly shifted to address the needs of adults with disabilities, but these federal programs do not provide adequate assistance to meet housing demand. This review establishes significant gaps in federal housing support for adults with autism and/or I/DD across the lifespan that result in a fragmented and underfunded patchwork of housing assistance. To address the need for appropriate housing and avoid consequences like unnecessary institutionalization, homelessness or displacement from one's community, housing must be brought to the forefront of policy and legislative conversations regarding adults with autism and/or I/DD.

Introduction

Approaches to residential options for adults with autism and others with intellectual and/or developmental disabilities (I/DD) have shifted significantly over time (Perl, 2016). In general, federal policies have shifted away from funding only institutional care to upholding principles of the independent living movement that aim to give individuals more choices for where and how Long-Term Support Services (LTSS) are delivered. The most significant policy shift, made in 1981 to decrease Medicaid expenditures and provide services in the community, was the authorization of Medicaid Home and Community-Based Services (HCBS) waivers. This funding for services delivered in community-based settings enabled adults with autism and/or I/DD to live and be supported in their family home and other residential settings (Centers for Medicare & Medicaid Services, 2020; Lakin et al., 2003).

Adults with autism and/or I/DD are significantly limited by access to affordable housing and LTSS for their support needs. Advocacy groups continue to identify considerable gaps in the residential options available to adults with autism and/or I/DD who already face a relatively high housing cost burden due to lower incomes and higher support needs (American Association on Intellectual and Developmental Disabilities et al., 2019; Albrecht & Brown, 2014; IACC, 2019; Schaak et al., 2017).

The benefits of consumer-controlled housing include:



Despite these benefits, historically there has been a persistent lack of housing options to meet the diverse needs of this population, in part because housing is often overlooked in relevant legislative and policy conversations (California State Council on Developmental Disabilities, 2018).

Today, more than
5.4 million

individuals with I/DD are known to live in the home of a family caregiver (Tanis et al., 2020).

Almost 25%

or 1.3 million individuals—live in the home of a family caregiver over the age of 60.

From a longitudinal perspective,

~60%

of those individuals live with a caregiver over the age of 41, suggesting there will be a large population of people living with an elderly caregiver in the next few decades (Tanis et al., 2017).

In addition,

50,000

people with autism are aging out of high school every year (Roux et al., 2017).

Little of this urgently approaching demand is met by existing housing options. Over the last decade, only 100,000 people (approximately 3% of the total with I/DD) have been able to access residential options beyond their family home. Little data is collected on the residential options actually available or accessible to or preferred by adults with autism and/or I/DD. The lack of access to residential options is concerning given the growing population of these adults and their aging caregivers (Residential Information Systems Project, 2020; Roux et al., 2015). It is reported that 30% to 40% of individuals experiencing homelessness have a cognitive impairment, including traumatic brain injury, learning difficulties, intellectual disabilities, autism spectrum disorder and attention deficit hyperactivity disorder. Loss of family caregiver is reported to be the main cause of becoming homeless. (Brown M, McCann E., 2020).

There are also disparities—some linked to living arrangements—in housing and LTSS access within the population of adults with autism and/or I/DD. Individuals living in group or residential housing facilities are more likely to receive comprehensive services than individuals living independently or within a family home (Schott, Nonnemacher & Shea, 2020). Comparing state Medicaid HCBS service recipients with I/DD, individuals with autism diagnoses are more likely to live in a family member's home and 42% less likely to live in their own home, agency apartments or other living arrangements outside the family home (Hewitt et al., 2017). As a result, adults with autism may experience worse health and social outcomes (Roux et al., 2017).

Caregivers who currently provide both housing and support for their loved one are especially concerned about the future when they are no longer able to take care of their family member. In one study, over half of parents of adults with developmental disabilities worry about their children's future living arrangements, the meeting of their support needs and their future quality of life (Easter Seals, 2008). These concerns are exacerbated by existing systemic barriers to housing and LTSS access, such as a shortage of direct care workers and underfunded state service systems (Graham, 2017). Absent a coherent policy agenda that addresses these gaps, some fear deleterious consequences for this population (Lutz, 2016).

A future where adults with autism and/or I/DD can choose from a variety of residential options and access support services calls for a comprehensive policy agenda that prioritizes 1) the development of appropriate housing and increased housing assistance; 2) access to LTSS for those who need it; and 3) a system that helps individuals access LTSS in the residential setting of their choice. These choices should include consumer-controlled and provider-controlled settings (currently the predominant housing model).

Defining the Link Between Housing and Services

The types and frequency of support needed and the preferred service delivery model vary with each adult with autism and/or I/DD. Defining the ways housing and services intersect in the community is important to contextualize housing policy for this population. Today, two terms generally define how residential settings interface with LTSS delivery:

- **Consumer-Controlled Settings:** Properties where the housing provider is not inextricably linked to residents' LTSS provider(s), enabling residents to choose their preferred provider(s). Different from provider-controlled settings, residents may change their support service provider without changing where they live.
- **Provider-Controlled Settings:** Properties where the housing provider is both property manager and LTSS provider. In such residential settings, residents are unable to change their LTSS provider without moving to a different home.

This paper focuses specifically on access to consumer-controlled residential settings, in part because adults with autism and/or I/DD who prefer this option require assistance to afford housing. In addition, housing shortages and affordability challenges especially limit access to consumer-controlled residential options. Without housing assistance, the individual must choose between a provider-controlled setting or homelessness. Addressing housing for those who can and prefer to live in consumer-controlled settings plays an important role in preventing unnecessary placement in provider-controlled living arrangements that may be too restrictive to adults with lower support needs while appropriate for others.

Although not in the scope of this policy review, ensuring access to provider-controlled settings such as group homes, host homes or intermediate care facilities (ICF-ID) for those who prefer those settings and service delivery models is an equally important policy goal requiring further exploration. These residential settings should be considered part of the portfolio of options and housing policy conversations for adults with autism and/or I/DD.

Developing a sustainable, person-centered system will require considerable shifts in policy and practice. Examining the evolution of existing policy mechanisms governing housing (particularly consumer-controlled settings) for adults with autism and/or I/DD can help identify gaps and inform potential policy solutions.

This policy brief summarizes federal housing policy aimed at increasing access to housing assistance for adults with autism and/or I/DD, including:

1. **Legislation, regulations and court decisions** that have impacted housing access
2. **Existing federal programs** that provide housing assistance for this population (with an emphasis on housing assistance for consumer-controlled settings)
3. **Barriers** to accessing housing through existing programs

Methods

To understand the evolution of policy related to residential options for adults with autism and/or I/DD, secondary sources related to federal policy on disability and housing such as academic literature and federal reports were reviewed to identify key policy events, policy insights and barriers to access. Applicable federal housing programs were identified, as well as eligibility criteria and utilization for this focal population. Housing subsidy policies were limited to those that subsidize housing demand by lowering housing costs for individuals with autism and/or I/DD, either by giving individuals assistance to afford market rent or subsidizing developers to reduce rental costs. The scope of policies and programs was limited to federal policies (including legislation, court decisions, programs and agency guidance) that aimed to help people live in the community; increase the use of community-based LTSS; and increase access to housing for adults with autism and/or I/DD through housing assistance services, housing voucher assistance, direct cash assistance and funding subsidies for the development of housing.

Evolution of Housing and Relevant Service Delivery Policy

Table 1 chronologically lists and summarizes federal legislation, regulations, court cases and programs that set parameters around LTSS and housing for individuals with disabilities (Conrad, 2020; MACPAC, 2020; Perl, 2016; Smith et al., 2000; Turnbull et al., 2007; U.S. Department of Housing and Urban Development, 2020; U.S. Department of Justice, 2020). The majority of policies listed are designed to apply to and serve the broader population of people with disabilities. Policies that specifically impact adults with autism and/or I/DD are indicated in the table.

The evolution of these policies reflects the efforts of countless self-advocates, neurodiverse families and friends who have called for programs to help individuals thrive in the community. In addition to establishing programs to increase the availability of residential options, critical protections that articulate their civil rights of self-determination and equal opportunity (Developmental Disabilities Assistance and Bill of Rights Act), publicly funded services in community-based settings (Olmstead v. L.C.) and protections from housing discrimination (Kushner, 1989) were codified for adults with autism and/or I/DD.

Current Federal Programs Increasing Access to Housing

Three federal agencies fund programs that help adults with autism and/or I/DD live in a home of their own through individually accessed subsidies:

- **The Department of Health and Human Services (HHS) Centers for Medicare and Medicaid Services** provides funding for Long-Term Support Services (LTSS), including some forms of housing-related assistance (room and board excluded).
- **The Department of Housing and Urban Development (HUD)** provides rental subsidies and assistance to purchase housing, as well as capital to housing developers to make housing more affordable or attainable.
- **Social Security Administration (SSA)** provides a cash benefit to assist with living expenses, including housing or LTSS costs.

These programs and their corresponding funding allocations are administered differently across states. Federal funding from HHS and HUD is typically managed at the state or local level, while payments from the SSA are provided directly to eligible individuals by the federal government. As a result, who is eligible and the kind of housing assistance for which they are eligible varies significantly by state. Figure 1 summarizes federal programs through which adults with autism and/or IDD may receive assistance to live in a home of their own (if eligible). To date, there has been no landmark policy focused on the issue of housing for adults with autism and/or I/DD, and no policies resulting in significantly increased access to affordable, appropriate housing for this population.

The following section provides an overview of key Medicaid and HUD programs, including the extent to which adults with autism and I/DD are eligible to receive assistance, the type of assistance available, how many people participate in each program (utilization) and barriers to access. Barriers are exacerbated by documented limitations of SSA funding levels, which are not enough to afford fair market rent in any housing market in the U.S. (Martone, 2020).

Table 1.



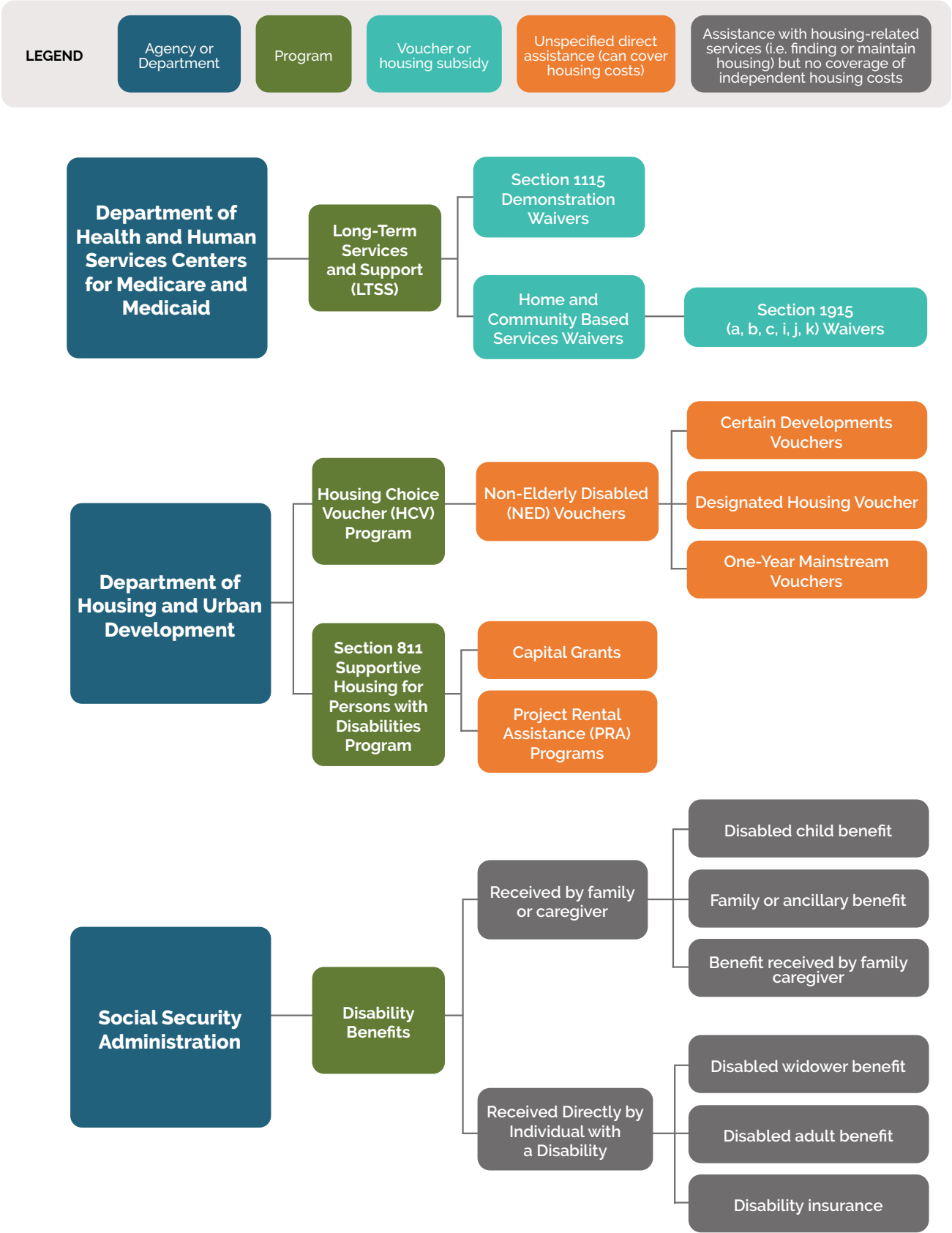
Table 1. (Continued)





Federal Programs Providing Housing Assistance to Adults with Autism and/or I/DD

Figure 1.



Summary and Limitations of Key Programs

Medicaid HCBS Waivers

Home and Community-Based Services (HCBS) waivers are intended to finance recipients' long-term services and supports (LTSS) in community-based (non-institutional) settings. HCBS funding specifically covers services but not housing costs. In general, Medicaid HCBS programs aim to increase access to community-based services for individuals living in, or at risk of, unnecessary placement in institutional settings. HCBS programs have expanded over time to cover a variety of support services through various service delivery models. State trends suggest LTSS delivery systems are increasingly collaborating with housing resources and broadening enrollment to serve people with I/DD (Ensslin & Kruse, 2016). Medicaid ultimately plays a limited role in housing assistance, as waiver funding is prohibited from covering room and board.

Manatt Health's (2020) inventory of state HCBS investments in supportive housing benefits summarizes the extent to which Medicaid Section 1915 Home and Community-Based Waivers and Section 1115 Demonstrations cover housing-related costs (such as housing counseling, tenancy services or adaptations) for a subset of states in the U.S. (n=12). Kaiser Family Foundation (2019) provided further information about Medicaid eligibility and current waitlists.

Eligibility varies and waivers covering housing services target broad populations.

In general, access to LTSS available in consumer-controlled settings varies by state, as each state Medicaid authority determines service availability and funding allocation. As it follows, HCBS eligibility criteria are determined on a state-by-state basis. State eligibility criteria are only consistent in that individuals must be considered eligible by a state's requirements for services in an institutional setting (Centers for Medicare & Medicaid, 2020).

Manatt Health (2020) found that in fewer than half of the states in their sample (n=5), LTSS waivers were designed to increase access to consumer-controlled residential options for adults with autism, intellectual disability, developmental disability or needing support for some activity of daily living. Only half (n=2) of the states that provide direct assistance for one-time housing costs specifically assist individuals with autism and/or I/DD who may be eligible based on support needed for activities of daily living (Manatt Health, 2020). Beyond the states reviewed in Manatt Health's brief, 12 additional states have waivers that fund housing-related services to transition out of institutions and/or home modifications specifically for adults with autism and/or I/DD (Centers for Medicare & Medicaid, 2020).

Currently, only extremely low-income individuals are eligible for HCBS waiver services. Data from Kaiser Family Foundation (2020) demonstrate that adults with disabilities are required to have, on average, a median annual income limit of \$9,000 to be eligible for services across all 50 states. States typically must provide Medicaid to Social Security beneficiaries (74% FPL) and may extend eligibility for HCBS waiver recipients with I/DD up to 100% FPL or 300% of Social Security Income (SSI) levels (Kaiser Family Foundation, 2020).

Waivers rarely cover costs associated with housing.

Manatt Health (2020) found that of the 12 states reviewed, nine fund housing stabilization services, including services to help individuals find and maintain housing. Half (n=6) of the states fund home or environmental accessibility modifications. Less frequently, state waivers supported one-time transitional services (n=1), housing counseling (n=1) and housing consultation (n=1). As per federal regulation, no waivers provide direct assistance for room and board. Waivers in four of the states reviewed allow individuals to receive direct cash assistance for one-time or nonrecurring housing costs, including security deposits, utility assistance and other start-up costs.

Limitations

When adults with autism and/or I/DD are the target population for a waiver, they are typically eligible only if they require an institutional (or intermediate) level of care (Manatt Health, 2020). There is a broad population of adults with autism and/or I/DD who are not eligible based on these criteria but who still need supports, services and housing assistance to live in the community. In addition, there is a significant gap between the maximum annual income limit to be eligible for LTSS (100% FPL, or \$12,760; 300% SSI, or \$28,190) and the livable wage needed to afford housing (Aurand et al., 2017). This may further restrict the already limited earning potential of those who rely on Medicaid and SSI supports. A recent report from the National Low Income Housing Coalition (2020) reinforces that even before the recent coronavirus pandemic, housing costs outpaced what those receiving SSI could afford.

Many adults with autism and/or I/DD are not eligible for an HCBS waiver.

Medicaid funding restrictions limit the services available—even to those eligible.

State Medicaid funding allocated toward LTSS may vary depending on the state's expansion status (as per the Affordable Care Act) and the design of HCBS waiver services. States may place caps on both the number of individuals served and the funding allowed per individual. These caps may disproportionately impact adults with higher support needs. Specifically, adults preferring to live in a consumer-controlled residential setting are unable to do so if waiver funding is capped at a level below what they need to fulfill their support needs.

Access to services also prevents HCBS-eligible individuals from living in settings other than their family home. In 2018, almost 590,000 individuals with I/DD alone were on a waiting list for Medicaid HCBS waiver services (Kaiser Family Foundation, 2020). The most recent evidence available suggests state cost control policies, including limitations on financial eligibility criteria and available service benefits, further increase the number of persons on Medicaid HCBS waiting lists (Ng, Stone, & Harrington, 2015).

Because Medicaid HCBS dollars cannot be used to cover direct housing costs such as room and board outside of institutional settings, state-administered Medicaid programs can only cover costs of an individual's housing transition, sustaining an individual's tenancy and state-level housing collaborative services (Medication and CHIP Payment and Access Commission, 2018; Scotti & Cruz, 2020).

Although Medicaid dollars cannot be used to pay for housing costs, state Medicaid programs have increasingly begun to collaborate with other public or private entities to increase funding for housing (Kleinman et al., 2017). These collaborations are still limited by a shortage of affordable housing, a lack of supportive services in the community and difficulties securing stable funding streams to assist residents paying rent.

HUD Programs Targeting People with Disabilities

The Department of Housing and Urban Development (HUD) addresses housing affordability and accessibility through a variety of programs by increasing the supply of affordable housing through subsidies to housing developers, financial assistance to homebuyers and rental subsidies that decrease housing costs.

HUD programs address supply- and demand-side housing access for adults with disabilities, but currently do not offer any programs specifically targeting the housing needs of adults with autism and or I/DD. Section 8 Housing Choice Vouchers (HCVs) are the primary federal program designated to help low-income households and other special populations access market-rate housing through the provision of vouchers that lower the cost of housing by subsidizing rent (Perl, 2016). However, the ability to pay for housing is just one mediator of housing access for adults with autism and I/DD (Grey et al., 2015).

Multiple HUD programs seek to increase the supply of affordable housing for low-income households. However, Section 811 Project Rental Assistance (PRA) is the only HUD program specifically aimed at producing affordable, accessible supportive housing to non-elderly, low-income individuals with disabilities (The Arc, 2020; Perl, 2016; Sloane, 2019). Other supply-side funding programs not specific to housing for people with disabilities include Community Development Block Grants (CDBG), Low-Income Housing Tax Credits (LIHTC), the HOME Investment Partnerships Program (HOME) and the National Housing Trust Fund (NHTF). There are no HUD programs specifically targeting people with autism or I/DD despite their unique risk of becoming unnecessarily institutionalized, displaced from their community or homeless.

Eligibility for Non-Elderly Disabled (NED) Vouchers

A subset of the Housing Choice Voucher program (for which low-income adults with autism and/or I/DD may also apply), NED vouchers include the following voucher categories: NED Category 1 and Category 2, Designated Housing, Certain Developments, One-Year Mainstream Housing Opportunities for Persons with Disabilities and the Project Access Pilot Program. NED vouchers are allocated for all people with disabilities (Table 2). Historically, no HUD programs have specifically addressed residential options for adults with autism and/or I/DD.

Table 2. HUD Housing Choice Vouchers Available to Non-Elderly Adults with Disabilities

NED Voucher	Function
NED Category 1	Enable non-elderly persons or families with disabilities to access affordable housing on the private market.
NED Category 2	Enable non-elderly persons with disabilities currently residing in nursing homes or other healthcare institutions to transition into the community.
Project Access Pilot	Provide vouchers to selected Public Housing Authorities (PHAs) that partner with state Medicaid agencies to assist non-elderly disabled persons transition from nursing homes and other institutions into the community.
Designated Housing	Enable non-elderly disabled families who would have been eligible for a public housing unit if it had not been restricted to elderly families only through an approved Designated Housing Plan to receive rental assistance.
Certain Developments	Enable non-elderly families who do not currently receive housing assistance in certain developments where owners establish preferences for, or restrict occupancy to, elderly families to obtain affordable housing.
One-Year Mainstream	Enable non-elderly disabled families on the PHA's waiting list to receive a voucher.

NED Voucher Use

At this time, 55,000 NED vouchers are allocated specifically for all non-elderly persons with disabilities. Between 1997 to 2009, 397 Public Housing Agencies distributed 948 vouchers for NED Category 2 and 54,019 vouchers for all other NED programs. Since 2018, additional vouchers have been authorized; funding appropriated for FY18 was estimated to serve an additional 27,000 households through NED vouchers (Center on Budget and Policy Priorities, 2017; Department of Housing and Urban Development, 2020; Technical Assistance Collaborative, 2020).

Section 811 Capital Advance and Project Rental Assistance Funding

Section 811 historically funded housing development through interest-free capital advances and operating subsidies to developers. In the past decade, the program has expanded to provide project rental assistance (PRA) to state housing agencies.

Since 1992, the combination of these two HUD programs designed to increase affordable, accessible housing to people with disabilities in general has provided only approximately 85,000 households of persons with disabilities have been able to access affordable housing. In general, it is unclear how many adults with autism and/or I/DD utilize NED vouchers or live in Section 811-funded projects because utilization data are only publicly available for the broad population of adults with disabilities.

The Capital Advance program serves approximately

28,000

households, including an adult with disabilities across 2,390 properties.

To date, over

\$200 Million

in Section 811 PRA funds have been awarded to a total of 27 state housing agencies across the U.S.

Grantees are working to develop over

5,000

permanent supportive housing units for people with disabilities.

Since 2015, approximately

2,300

households have moved into these units (HUD Exchange, 2020).

Limitations

HUD housing programs that target people with disabilities are initiated and managed at the state or local level, leading to significant variation in housing supply and accessibility across the nation. However, few states specifically focus on housing for adults with autism and/or I/DD (McCormick, Schwartz & Passerini, 2019). Adults and their families experience multiple barriers to voucher use and access to affordable housing units (Bailey, 2020; Center on Budget and Policy Priorities, 2019b; Coughlin et al., 2017; Freeman, 2012; Hoffman, Kehn, & Lipson, 2017; Irvin et al., 2013). Neither NED Housing Choice Vouchers nor Section 811, as currently funded, can meet the demand of the nearly 1.3 million adults with autism and/or I/DD who currently live with family caregivers over the age of 60. This does not account for younger adults, including the 50,000 young adults with autism transitioning out of high school annually.

Vouchers and Section 811 PRA units reach just a fraction of those needing housing.

Currently, NED vouchers make up 23% of all Housing Choice Vouchers (Center on Budget and Policy Priorities, 2019). It stands to reason that an even smaller fraction of vouchers ends up allocated to adults with autism and/or I/DD. Therefore, it is unlikely that this program is able to meet the unmet needs of adults with autism and I/DD wanting to live in a consumer-controlled setting.

The success of NED vouchers (and similar housing programs) also may depend on what subset of adults with autism and/or I/DD are targeted at the state level. Specifically, vouchers have the largest impact when they target communities with “low transition rates” out of institutions (Hoffman, Kehn, & Lipson, 2017). States that target individuals currently living in institutional settings for NED vouchers may unintentionally be biased against individuals living at home with aging caregivers and at eventual risk of homelessness. This aligns with HUD voucher utilization data reporting that 86,100 adults with disabilities have been homeless for long or repeated periods of time (Center on Budget and Policy Priorities, 2019). In addition, a large proportion of individuals with autism and/or I/DD do not receive state services that would make them candidates to be targeted for NED voucher assistance. For example, only 17% of the total population of individuals with I/DD in the U.S. have access to residential LTSS (Residential Information Systems Project, 2020).

Considerable competition for vouchers and demand for affordable housing units

Most adults with autism and/or I/DD are seeking the same housing vouchers and project-based affordable housing units as other low-income households. In general, states struggle to provide enough housing for vulnerable populations competing for limited state and federal resources. Because demand for vouchers consistently exceeds supply, they are allocated through a queueing system that effectively rations access to vouchers. In this system, only a fraction of the eligible households receives vouchers due to short application periods, wait-list selection processes, and barriers to completing all of the steps required to complete their application (Moore, 2016). Due to shortages, programs serving specific populations may negotiate preferential treatment to receive priority access to vouchers (Coughlin et al., 2017). However, there are also limitations in how priority populations are defined. For example, some state housing voucher programs may prioritize people experiencing homelessness but exclude those residing in institutions or living with aging family caregivers. (McCormick, Schwartz & Passerini, 2019). These individuals may ultimately be at risk for homelessness or must remain in an institutional setting, violating their rights under the Olmstead Decision.

Individuals with vouchers may be unable to use them.

Individuals who have a housing voucher may face barriers to using it. Barriers include unwillingness of some landlords to accept vouchers (sometimes due to reluctance to rent to people with disabilities), discontinuation of a voucher program and difficulty accessing available funds for home modifications (Brooks & Updety, 2020; Coughlin et al., 2017). Other discrimination may happen on the basis of source of income (the source being a voucher). In fact, the majority of discrimination complaints pursuant to the Fair Housing Act are on the basis of disability (Freeman, 2012; National Fair Housing Alliance, 2019).

Affordability as one of many barriers to housing stability

It is important to note that housing affordability is just one of numerous market barriers to finding a place to live faced by adults with autism and/or I/DD.

A lack of diverse housing options

In addition to overall funding shortages, people with autism and/or I/DD have a diverse range of support needs, preferences and limitations. Individuals with more severe autism, for example, may experience additional behavioral challenges that impact which living arrangements work for them. This can even result in eviction in response to property damage or the inability to follow property rules (such as quiet hours) intended for neurotypical populations (Jewett, 2017; Lutz, 2016). Housing policy for adults with autism and/or I/DD will need to increase access to non-institutional residential settings that are both affordable and appropriate—meaning they meet the diverse needs and preferences of the entire population.

Barriers in navigating the housing market

Navigation of options in the market also present access barriers to individuals with autism and/or I/DD. Challenges have been documented at each step of the rental process—when attempting to locate and learn about units during the application process and even while moving in and living at a rental property (Hammel, 2017). Affordable housing policy for this population, largely representing extremely low incomes due to earning-capacity limits, has been mostly limited to rental programs and not ownership.

Funding and regulatory barriers

Current market-rate housing options also have limited disability-accessibility features. Decision-makers know little about the state of cognitive accessibility features (especially important to adults with autism and/or I/DD) in the U.S. housing stock due to a lack of data (Bo'sher et al., 2015). Furthermore, renters with autism and/or I/DD may or may not be able to invest in making their home more accessible due to cost or landlord restrictions.

Shortages in public funding, affordable housing and LTSS are a constant challenge. A recent committee convened by the National Academies (2018) notes that housing providers are working in a siloed and fragmented policy environment marked by inadequate and unreliable funding streams, as well as misaligned incentives further discussed by Wachino (2015) as the “wrong pockets” problem. They document both market and regulatory barriers that inflate housing costs through restrictive zoning and land-use ordinances. A lack of consistent local accountability around affordable housing means there is not always the political will required to push this conversation forward (National Academies of Sciences, Engineering, and Medicine, 2018).

Conclusion

Federal programs are seriously limited in their scope and capacity to provide necessary housing assistance to adults with autism and/or I/DD. Although self-advocates and their families have persistently expressed critical needs and fears about future living arrangements, no policies have meaningfully addressed housing accessibility and affordability for adults with autism and/or I/DD.

This review of policy and programs that address housing for this population illuminates major gaps and a shortage of affordable, accessible housing that preclude most adults from living and being supported in their own home.

Existing housing resources for people with autism and/or I/DD are fragmented, poorly coordinated and in high demand (National Academies of Sciences, Engineering, and Medicine, 2018). Despite the best intentions to support community-based living (articulated by a number of federal laws codifying independent and supported living rights), the U.S. has never truly prioritized the policy goal of ensuring access to both housing and LTSS by the population of adults with autism and/or I/DD.

Policy aimed to support community living for this population first focused on cost reduction and deinstitutionalization with the delivery of community-based services. This focus on service delivery is reflected in the availability of success metrics that describe where services are delivered, the cost of services and the number of individuals served, as opposed to broader metrics that describe the life experiences and outcomes of adults with autism and/or I/DD. While Medicaid is restricted from providing direct housing assistance, HUD programs do not currently provide adequate support to meet the housing needs of this population. Limitations of HCBS and HUD housing assistance are further exacerbated by existing market barriers.

The need for housing and LTSS currently outpaces available funds and programmatic reach. A large population of adults with autism and I/DD will most likely outlive their family caregivers who currently shoulder the burden of insufficient housing and LTSS options available to support their loved ones. Without adequate access to consumer-controlled housing options, some individuals with autism and/or I/DD are at risk of placement into provider-controlled or institutional settings, which may be unnecessarily restrictive.

Time is limited for millions of adults with autism and/or I/DD who are living with aging caregivers, as well as for those transitioning to adulthood annually. If the current shortage of housing accessible to adults with autism and/or I/DD persists, especially in the face of a growing population, individuals will be at considerable risk of homelessness or unnecessary placement in Medicaid-funded, provider-controlled settings or institutions. These and other outcomes are at odds with the right to choice codified in legislation such as the Developmental Disabilities Assistance and Bill of Rights Act, Americans with Disabilities Act and supported by the Supreme Court's Olmstead decision.

In order for people with autism and/or I/DD to live and be fully supported in the community, it will be necessary to explore policy levers to increase the availability of residential options that reflect the diversity of this population. Many individuals and families fear a world in which a lack of residential options ultimately forces displacement of people from their communities. This displacement will impact not only quality of life and health outcomes of adults with autism and I/DD, but also communities across the country that can benefit from neurodiverse citizens who have the opportunity to live in a home of their own.

Better Data Make Better Policy: Defining Unmet Housing Needs of Adults with Autism and Other Neurodiversities

Pooja Paode

Daniel Jordan Fiddle Center for Public Policy at the First Place Global Leadership Institute

Abstract

Access to appropriate housing and services is a growing concern for adults with autism and/or intellectual and developmental disabilities (I/DD).

Data limitations preclude the ability to accurately quantify or delineate housing demand for this population. Without data sets that characterize housing needs and evaluate outcomes associated with different residential options, it is difficult to address the substantial housing challenges facing this population. This paper illustrates how existing data are insufficient for describing residential needs of adults with autism and/or I/DD; summarizes available data; and identifies data needed to articulate housing demand for the growing and diverse population. The paper argues that current data limitations inhibit the development of policy solutions that can help people access the housing and support services they need to thrive. Opportunities for future data collection, research and policy priorities are considered.

Introduction

Housing challenges for adults with cognitive and developmental disabilities

Through its influence on domestic life, health and safety, housing is an important social determinant of health that has long been established as essential to individual and community well-being. Almost 70 years after the passage of the Housing Act of 1949, the U.S. is still grappling with a severe affordable housing crisis (Schwartz, 2014 p. 2). Nearly one-third of American households are currently cost-burdened, paying more than 30% of their income for housing. Adults with cognitive impairments, including adults with autism and those with other intellectual and developmental disabilities (adults with autism and/or I/DD) bear an even greater housing cost burden due to limited income and support needs (Emerson, Graham, & Hatton, 2006). These support needs may require more complex housing accommodations that can be more costly than existing affordable and market-rate housing options (Brand & Gheerawo, 2010; Grey et al., 2015). Insufficient housing access magnifies existing challenges faced by adults with autism and/or I/DD, including financial burdens, mental health challenges due to isolation or loneliness, and caregiver stress (Grossman & Webb, 2016; Shivers, SonnierNetto, & Lee, 2019; Williamson & Perkins, 2014). Without access to housing that is accessible and affordable, autistic adults and others with I/DD are at high risk of homelessness or displacement from their community into the “next empty bed.”

Access to appropriate residential options—defined as housing that is safe, affordable, connected to community with access to needed supports and services—is a growing concern for adults with autism and/or I/DD (Bigby & Fyffe, 2009; Grey et al., 2015; Lutz, 2015; White, 2015). Support needs range from infrequent drop-in support to higher support needs requiring 24-7 daily support staff. As it follows, individuals also have a variety of needs and preferences related to housing, service delivery and lifestyle (Thompson et al., 2009). Due to eligibility or service access barriers, many are either ineligible for or not currently accessing long-term support services (Residential Information Systems Project, 2020). As a result, little data is available to describe their experiences, limiting the characterization and mitigation of informally recognized gaps and hindering solutions that can be effectively addressed by public, private, philanthropic and nonprofit sectors.

Residential options available to adults with autism

An emerging market of diverse housing options has begun to address unmet housing demand (Autism Housing Network, 2020; Roux et al., 2017). However, publicly funded programs do not come close to fully meeting the high volume of unmet housing needs among adults with autism and/or I/DD (Dawkins & Miller, 2017; Hammerman & Bennett, 2010; Prince, Kameka, & Prince, 2016; Roux et al. 2016). Existing federal and state programs also do not adequately support the development of residential options to accommodate the diversity of needs and preferences within this population (Wiesel, 2011).

The evolution of policy surrounding both housing and long-term support services (LTSS) over the past 50 years has resulted in an underfunded patchwork of federal and state-level systems inadequately equipped to serve the needs of adults with autism and/or I/DD across the lifespan (California SCDD, 2018). Existing programs for housing and LTSS—through the Centers for Medicare and Medicaid, the Department of Housing and Urban Development (HUD) and state developmental disability agencies—serve just a fraction of the population in settings outside of family homes (Wachino, 2017; Residential Information Systems Project, 2020).

The importance of data in shaping housing policy

The absence of coherent policy surrounding the housing needs of adults with autism and/or I/DD has left stakeholders with limited data to describe housing needs (Hammerman & Bennett, 2010). It is therefore impossible to accurately quantify or delineate housing demand among adults with autism and/or I/DD (Bonardi et al., 2019; Haverkamp et al., 2019; Anderson et al., 2019). Without data to accurately characterize their housing needs and evaluate outcomes associated with different residential options, it will be difficult to address the substantial housing challenges faced by this population.

Recognizing that data play an essential role in shaping conversations around policy gaps and potential solutions, this paper illustrates how existing data are insufficient for describing residential needs of adults with autism and/or I/DD, inhibiting policy solutions that can help people access the housing and support services they need to thrive. It summarizes the data available, identifies additional data needed to articulate demand, and considers opportunities for future research and policy change.

Background

A recent report from the Autism and Developmental Disabilities Monitoring Network (2020) estimates there are about 5.5 million adults with autism in the U.S., about 50% of which also have an intellectual disability (Matson and Shoemaker, 2009; Roux et al., 2017). The University of Minnesota's Residential Information Systems Project (2020) estimates about 7.37 million individuals living with I/DD. Due to improve diagnostic testing, this is a young population. The population of adults with autism and/or I/DD is growing steadily. Every year, 50,000 individuals with autism graduate from high school (Roux et al., 2016). In addition, of the 20% with I/DD known to state agencies, 39% with I/DD are below the age of 21 (Residential Information Systems Project, 2020). The majority of adults with I/DD live in their family home. Currently only 2% of individuals with I/DD receiving LTSS currently live in their own home and not a provider-controlled or institutional setting (Residential Information Systems Project, 2020).

The importance of housing for adults with autism and/or I/DD

Adults with autism and/or I/DD are diverse with equally diverse housing needs and preferences. While the importance of housing is not unique to adults with autism and/or I/DD, this vulnerable and at-risk population warrants policy and research attention. In general, adults with disabilities are socioeconomically more burdened than adults without disabilities, significantly limiting their ability to cover housing costs (Emerson, Graham, & Hatton, 2006).

Despite decades of investment in early identification, intervention and education, the lack of public investment in the development of residential options can lead to poor outcomes for individuals and their communities (Roux et al., 2015; Roux et al., 2017). Housing accessibility is especially concerning for individuals with I/DD. If they cannot find or afford housing, they become at risk of homelessness, institutionalization and displacement from their communities (Health and Human Services, 2010; Batten, 1992).

Importantly, this population is often aggregated into the larger population of adults with disabilities, although the housing accessibility challenges they experience are very different (Mansell & Beadle-Brown, et al., 2009). Accessible housing standards are often interpreted in relationship to individuals with physical disabilities, as opposed to through the lens of those with cognitive or sensory impairments. Primary data and secondary studies about the housing demand often presented data in aggregate or only for specific segments of the broader population of adults with autism and/or I/DD Subpopulations also vary in their housing preferences, support needs, and their eligibility for government programs—differences that

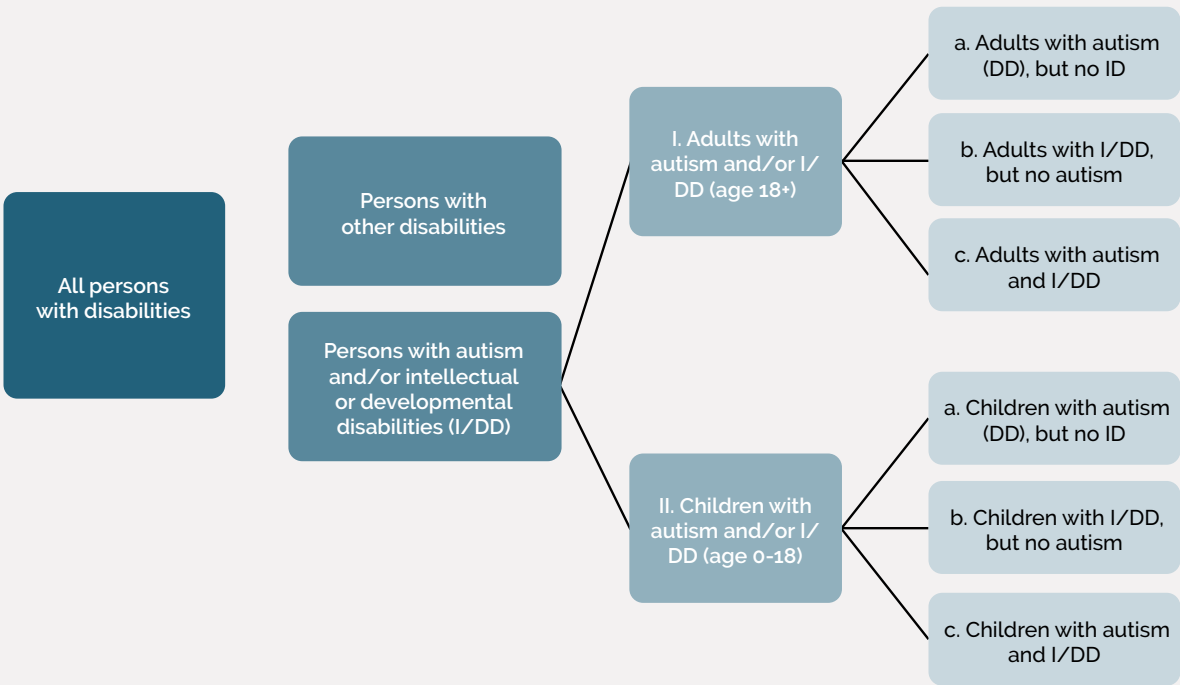


Figure 1.

are not distinguished in available data. Figure 1 highlights the major diagnosis-based segments of the population for which specific data are currently available, including adults with autism only, adults with I/DD but no autism, and adults with both autism and I/DD. These population segments, which report on diagnosis and sometimes functional limitations, are not described in terms of level of support needs, which would be necessary to measure the adequacy of housing and services.

Adults have limited access to housing choices, requiring them to live with aging parents and family members until they are no longer able to do so. Many adults are outliving these adult caregivers for the first time (Grey et al., 2015). The burden of caregiving and housing falls mostly on family members. According to Residential Information Systems Project (2020), 17% of all individuals with I/DD received residential long-term support services, meaning 83% do not receive residential services and are largely supported by family members. Of those who receive residential support, the majority still live in their family home and only 7% of the population of people with I/DD (about 515,000) have access to the residential supports and live outside of the family home. Furthermore, 871,000 (12%) of all individuals with I/DD live with caregivers over the age of 60, a number projected to increase.

Due to eligibility or service-access barriers, most are not currently accessing government services (Residential Information Systems Project, 2020). As a result, little data is available to describe their experiences, limiting the characterization and mitigation of informally recognized gaps and hindering solutions that can be effectively addressed by public, private, philanthropic and nonprofit sectors.

Federal programs for housing and services

Federal programs designed to cover housing and service needs have evolved significantly since the 1970s. Activists recognized individuals with disabilities as contributing members of the community, which helped shift the conversation about how housing policy impacts this population. This led to a gradual shift from an institutional approach, where Medicaid paid for support services within institutional settings (covering both housing and support services) for adults with I/DD, to a more person-centered, community-based approach (National Council on Disabilities, 2016).

Following the shift to person-centered and community-based living for adults with I/DD, Medicaid authorized the Home and Community-Based Settings (HCBS) waiver, which allows individuals to access residential options outside of institutions (National Council on Disabilities, 2016). By providing services in community-based settings, the HCBS waiver authority enabled community-based living in provider-controlled housing settings and one's own home, as well as self-directing services. It does not, however, pay for room and board in these community-based settings because Medicaid is prohibited from doing so. In effect, while this enabled people to move out of institutions and have their LTSS costs covered, it did nothing to ensure they would have access to adequate housing.

In addition to Medicaid, the Department of Housing and Urban Development, through its Housing Choice Voucher program, Section 811 Supportive Housing for Persons with Disabilities Program and National Housing Trust Fund funds the development of subsidized housing and offers permanent rental subsidies to help people afford housing. Adults with I/DD are eligible for a subset of Housing Choice Voucher, the Non-Elderly Disabled Voucher program, which broadly supports the overall population of adults with disabilities (Department of Housing and Urban Development, 2020).

Method

To summarize the limitations of available data for characterizing unmet housing needs for adults with autism and/or I/DD, data points needed to define and characterize unmet housing needs were identified based on secondary sources and input from subject matter experts (Figure 2). These data—although not exhaustive—would ideally enable stakeholders to calculate unmet housing demand for different segments of the broader population of adults with autism and/or I/DD and also help identify socioeconomic disparities.

Figure 2. Data Needed to Calculate Total Unmet Housing Demand

DEMAND	Number of adults in each population segment and demographic characteristic, as well as: <ul style="list-style-type: none">• Their housing needs and preferences• Their support needs and preferences
- MET DEMAND	Number of adults able to access housing that meets support needs and preferences
= UNMET DEMAND	Housing stock needed to match housing and support needs and preferences

Inclusion criteria

Data pertaining to adults with autism and/or I/DD from publicly available original datasets produced by government agencies, research institutions and nonprofit organizations were identified. Only data collected regularly (e.g., quarterly, annually, every 10 years) were included.

Broad data categories were adapted from categories of prevalence studies identified by Anderson and colleagues (2019). They include national surveillance surveys, administrative data and compilations of state datasets. National surveillance surveys include U.S. population-based surveys, which are recurring nationally representative surveys that use “consistent sampling, data collection and management practices across locations and over time” (Anderson et al., 2019). Administrative data are regularly collected by federal agencies in order to monitor,

reimburse or regulate funded services (Ward, 2013). Some data sources widely referenced to understand housing and service use among adults with I/DD were not specifically included because they draw or compile data from sources already included in the analysis. For example, the Residential Information Systems Project (RISP) at the University of Minnesota and National Autism Indicators Report curated by the A. J. Drexel Autism Institute draw from these sources and play an important role in making these data publicly available. In addition, more specific data about housing needs and preferences are collected sporadically through point in time surveys but were not included in this analysis because they are not collected regularly.

Analysis

Codebooks and/or data dictionaries for each data set were then compared against a framework of ideal data needed to define unmet need. Analysis also included summaries drawn from existing studies on the limitations of state and federal datasets for the purpose of population surveillance (Havercamp et al., 2019, Bonardi et al., 2019, Anderson et al., 2019). Gaps and limitations were identified by review of major topics or subtopics in survey codebooks, summarizing relevant academic literature and comparing the ideal framework described in Figure 2 to available data.

Results

Summary of selected surveys and datasets

Table 1 summarizes datasets included in the analysis. In general, only a few data sources capture longitudinal data. Table 3 summarizes federal data sources and the extent to which they enable decision makers to characterize and respond to housing and LTSS demand for adults with autism and/or I/DD. These are based on the data needed to calculate unmet demand for residential options described in Figure 2.

Table 1. Existing Surveys and Datasets Regularly Reporting on Adults with Autism and/or I/DD

National Surveillance Surveys	Administrative Data	State Data
<ul style="list-style-type: none">American Community Survey (ACS)Current Population Survey (CPS) Survey of Income and Program Participation (SIPP)National Core Indicators (NCI) Adult Consumer Survey (ACS)National Health Information Survey (NHIS)American Housing Survey (AHS)	<ul style="list-style-type: none">Medicaid Current Beneficiary SurveyMedicaid Home and Community-Based Services (HCBS) Program SurveySocial Security National Beneficiary Survey (NBS)Housing Choice Voucher Utilization	<ul style="list-style-type: none">State of the States in Intellectual and Developmental Disabilities (SOS)State-specific data (Bonardi et al., 2019)

Analysis of available data describing unmet housing needs

Table 3 summarizes federal data sources and the extent to which they enable decision makers to characterize and respond to housing and LTSS demand for adults with autism and/or I/DD. Current data were evaluated based on the following broad dimensions: disaggregation; representation of the U.S. population; inclusion of data on current arrangements, needs and preferences; and inclusion of data about housing and services. These categories include the minimum data needed to understand unmet housing needs but are not exhaustive.

Table 3.

Legend			Category of Data		
Data not collected or available	Data partially collected or partially available (not across all data points specified or across all surveys)	Data collected and available	National Surveillance Surveys	Administrative Data	State Data
Are data disaggregated for meaningful segmentation?					
Relevant diagnoses (autism and/or I/DD) and functional limitations					
Support needs (type and frequency)					
Children and adults					
Are data representative of the U.S. population?					
Collected comprehensively across U.S. states and territories					
Include individual, family and family caregiver characteristics (e.g., age, race, ethnicity, income and other social determinants of health)					
Include individuals receiving public, private and/or no services					
Do data capture current arrangements, support needs and housing preferences?					
Current housing arrangement (e.g., in own home, in family home with family caregiver, in planned community)					
Current service utilization					
Individual residential preferences (e.g., property type, amenities)					
Individual support needs (type and frequency)					
Service delivery model (consumer- or provider-controlled)					
Are data about available housing and services for adults with autism and/or I/DD collected?					
Types of residential settings available (developed and in development)					
Types of supportive amenities for adults with autism and/or I/DD available					
Consumer- or provider-controlled service delivery					
Accessibility (including cost and local availability)					
Expenditures related to housing and services (individual, state and federal)					

In general, national surveillance surveys provide the greatest level of disaggregation and opportunity to collect data representative of the broader U.S. population of adults with autism and/or I/DD. With the exception of the American Housing Survey, which enables the linkage of data on housing accessibility (primarily physical accessibility) with data on the prevalence of cognitive disabilities and functional challenges with activities of daily living, national surveillance surveys do not collect data regarding housing and support needs or preferences. Administrative datasets provide data for service recipients (such as those receiving LTSS services or HUD vouchers) across the entire U.S. They include recipient service utilization well disaggregated by age but do not collect data related to housing and support needs or preferences. State data include considerable data about service utilization, some about living arrangements and costs (a dimension not included in Table 3) but do not include data related to housing and support needs or preferences. In addition, operational definitions describing the population of adults with autism and/or I/DD and available services vary significantly across states (Bonardi et al., 2019).

Disaggregation

National surveillance surveys vary in how they disaggregate data for different segments of the population. No surveillance surveys differentiate between whether individuals receive public, private or no services (13-15). While some collect data on broad diagnoses (autism, intellectual disability or developmental disability) and functional needs, they do not collect data related to the varying support needs, which are more important to understanding unmet housing and support needs than diagnosis data alone.

Administrative datasets consistently differentiate between children and adults by collecting age data but rarely report data related to diagnosis or level of support needs. State-level data vary considerably in how they disaggregate segments of the population based on support needs. For example, when state datasets disaggregate by diagnosis or support needs, it is difficult to compare data across states based on different operational definitions for segments served. This echoes other analyses that find state data are not collected based on consistent operational definitions or common terminology across states (Bonardi et al., 2019). When states do disaggregate data by living arrangement, data is typically only disaggregated for LTSS recipients or other state service recipients (SOS).

Representation

Although national surveillance surveys collect some sociodemographic data such as race, ethnicity and income, administrative datasets and state datasets do not typically differentiate between these sociodemographic characteristics. The surveys that collect these characteristics collect little data related to housing and

support needs. Some of the surveys that do disaggregate data (for children versus adults, by diagnosis or by functional need) are not generalizable to the entire population of the U.S. For example, while the National Core Indicators ACS survey differentiates between children and adults, it does not include data across all states and territories.

The most specific data available—describing current living arrangements, service usage and government expenditures—are administrative data collected for Medicaid LTSS recipients. These data, although collected regularly, are not representative of the broader population of adults with autism and/or I/DD.

Housing arrangements, needs and preferences

Federal and state datasets do not collect data about service delivery preferences. No datasets currently track any characteristics of residential options necessary for adults with autism and/or I/DD. While the American Housing Survey collects housing stock and accessibility data, data are limited to the specific needs of individuals with physical disabilities. Only administrative datasets are available to describe current housing arrangements and service usage but are limited to federal and state service recipients. No data regarding individual housing needs, individual support needs or preferred service delivery models are collected across any of the datasets. As a result, there is little to no available data describing residential options that meet various housing and support needs collected consistently or for a diverse, representative cross section of adults.

Available housing and services

National surveillance surveys, administrative datasets and state datasets do not collect data about housing or services for adults with autism and or I/DD. No data are collected on characteristics of the housing stock needed for adults with autism and/or I/DD, including the property type, available supportive amenities, what service delivery models are available for different residential options or their cost. State and federal service expenditure data collected through administrative and state datasets are the only exception to this rule.

Discussion

Data gaps identified

Data limitations stand in the way of sufficiently quantifying or qualifying the housing and support needs of a growing population of adults with autism and/or I/DD. Furthermore, although they are the most specific data available to describe the population, the data available from administrative data sets bias measurement of current housing arrangements and potential housing needs through the experiences of service recipients. Available data do not reflect the diversity of adults with autism and/or I/DD in the U.S. through inadequate data disaggregation and inconsistent collection across states. Finally, no data are collected regarding this population's current housing arrangements, housing preferences and support needs.

Current and future implications

There are current and future implications of this data void—not only for adults with autism and/or I/DD, but the community as a whole.

Linking data between multiple sources is challenging, preventing decision-makers from making a comprehensive housing needs assessment.

Data are not sufficiently disaggregated by age, support needs or other meaningful segments of the population. This makes it difficult to define housing needs for the diverse range of adults with autism and/or I/DD. As a result, decision-makers do not have the data to understand the population's housing needs, let alone the differences in housing demand of meaningful segments of this population.

In addition, it is not possible to link data on housing (and how different residential options suit different support needs) to data on adult support needs, because this data does not exist. The lack of data available to describe how different residential options may impact quality of life outcomes also precludes an analysis of real housing supply and demand for adults with autism and/or I/DD. Data biased toward broad diagnoses such as autism or I/DD are not as actionable as data describing the prevalence and variety of specific support needs.

The unique lived experience and resulting housing and support needs of adults with cognitive impairments are effectively invisible.

The cognitive and functional impairments of adults with autism and/or I/DD—for which most data are collected—impact their housing and support needs and lived experiences in a variety of ways. However, current data sources may consider all individuals with disabilities in aggregate or only include meaningful data for individuals with physical disabilities. For example, data about housing accessibility are only available for accessibility related to physical disabilities. This has already prevented policymakers from studying whether the U.S. housing stock adequately meets the needs of those with cognitive disabilities, particularly adults with autism and/or I/DD.

Disaggregation and the use of consistent operational definitions are needed to align state data. However, states do not collect data on adults with autism and/or I/DD using consistent operational definitions. In addition, some states consider people with disability in aggregate and may lump adults with I/DD especially under the umbrella of adults with disabilities. Data on the number of adults with autism who are ineligible for long-term support services yet need support and are at risk of falling through the cracks into homelessness can help identify solutions for those with autism who experience chronic homelessness. Other states report and consider the unmet housing needs of adults with disabilities in tandem with other populations that experience severe housing cost burdens, such as adults with HIV/AIDS and aging adults (McCormick, Schwarz & Passerini, 2019).

Data largely focused on current recipients of LTSS obscure the housing needs of the population as a whole.

Data for those who are not service recipients or recognized by their state developmental disability agency are simply not collected, omitting the experiences of those who do not access services due to barriers such as waitlists, eligibility criteria, documentation and cultural barriers. Medicaid LTSS utilization data provides the most specific data related to adults with autism and/or I/DD. However, many individuals do not receive services.

The University of Minnesota’s Residential Information Systems Project (2020) reported that only 17% of individuals with I/DD received LTSS, while only 20% of individuals were “known to or served by” state I/DD agencies. Data currently excludes the experiences of most adults with autism and/or I/DD, including but not limited to 850,000 (known) adults living with aging caregivers and individuals with autism not connected to state programs or not eligible for Medicaid funding. According to the Colorado Autism and Developmental Disabilities Monitoring Project (2020), 32% percent of adults with autism and significant support needs were not accessing LTSS.

The State of the States, which aims to quantify state and nationwide progress regarding the provision of services and supports for adults with I/DD, relies on data from state agencies primarily (Braddock, 2019). This resource is a relatively comprehensive and reputable source of data for stakeholders but only captures the experiences and costs associated with a fraction of the population of adults with autism and/or I/DD utilizing Medicaid LTSS. Individuals ineligible for or unable to access services still experience considerable socioeconomic challenges, require support services and have unmet housing needs. Although their experiences are not captured in the datasets reviewed, this does not change the fact that they need to be accounted for in policy conversations related both to housing and those about adults with autism and/or I/DD.

The lack of data sets makes the problem invisible to decision-makers.

Adults with autism and/or I/DD, their families and advocates clearly recognize there are not enough residential options to meet the needs of this population. It is well established that many caregivers fear what will happen to their children with autism and/or I/DD once they are unable to care for them. Many adults with current and impending housing needs are not clearly or explicitly accounted for in existing data. As data for individuals not receiving services are excluded, their short- and long-term housing needs are excluded from broader discussions about housing.

Importantly, decision-makers do not have the data available to describe the living arrangements and impending housing needs of individuals both receiving and not receiving state services. Ultimately, the lack of data collected related to the availability and potential shortfall of residential options makes the nature of the problem impossible to define accurately. It also means that housing for this population is largely overlooked in policy and legislative discussions related to both housing and adults with autism and/or I/DD.

Better data are needed to move beyond deinstitutionalization and toward access to appropriate and affordable residential options.

Housing, as a source of stability and a social determinant of health, should be a crucial piece of the policy agenda to support adults with autism and/or I/DD. Federal policy priorities focused on deinstitutionalization instead of overall housing access result in the collection of very little housing-related data, even for service recipients. LTSS data are reported for federal programs that prioritize community-based service delivery and transitioning individuals out of institutions (deinstitutionalization) as opposed to transitioning the broader population into different types of residential options. Since Medicaid, the federal program providing the most services specific to adults with autism and/or I/DD, is prohibited from funding room and board, housing is overlooked in policy conversations.

The policy goal of deinstitutionalization currently applies to the approximately 73,855 people living in intermediate care facilities, or 1% of the population of adults with I/DD (Residential Information Systems Project, 2020). Deinstitutionalization accomplishes an important, but very small, fraction of the broader goal of increasing access to appropriate housing and support services. Prioritizing deinstitutionalization alone will not ensure that adults with autism and/or I/DD will have long-term access to the appropriate housing and support services needed to thrive in the community.

Data shape policy and policy shapes data collection. To prioritize and ultimately fund the collection of better data, housing should be integrated into policy discussions for adults with autism and/or I/DD, which currently focus on support services and primarily consider housing mostly in the context of deinstitutionalization. Simultaneously collecting better data regarding access to appropriate residential options will result in more meaningful quality of life indicators for adults with autism and/or I/DD.

Opportunities to improve data availability

To define housing policy problems and potential solutions, adequate data are required to drive discussion, distinguish the various market segments (based on support needs, income, etc.) and align stakeholder interests. Collecting data is costly. While it may not be totally feasible to operationalize the collection of the comprehensive data needed to describe the unmet housing needs of adults with autism and/or I/DD, measures can be added to existing data sets enabling data linkage and support decision making.

At the federal level, national surveillance and administrative data sets should use foundational terms and outcome measures representative of the diverse housing needs of adults with autism and/or I/DD. Across these population datasets, data collected linked to adults with autism and/or I/DD should describe individuals and family sociodemographic characteristics (e.g., age, race/ethnicity, income), diagnosis and functional needs, support needs, current living arrangements, housing preferences, accessibility of the U.S. housing stock for adults with cognitive disabilities, eligibility for LTSS, and eligibility for state or local housing support.

The following data points on housing stock (both in terms of what housing is available and what is needed) would enable decision makers to evaluate the supply of housing stock for adults with autism and/or I/DD: affordability, relationship to long-term services and supports (consumer- versus provider-controlled), available residential physical and supportive amenities, the residential unit type (private versus shared residence), lifestyle accommodations, cost to residents and funding options.

Federal and state programs helping adults with autism and/or I/DD to access services and housing that enables them to live in the community and policy leaders entrusted with their implementation should be empowered to make decisions based on comprehensive data. To evaluate the extent to which housing-focused policies and programs impact the individuals they are intended to reach, researchers can then evaluate the following dimensions of state and federal programs: current living arrangements and service utilization of adults with autism and/or I/DD, program eligibility criteria, the number of adults with autism and/or I/DD needing services and access to housing, barriers to accessing programs or appropriate housing in general, and the number of individuals served, on program waitlists or not served but needing services. Much of these data are already collected but not adequately linked to the population's housing needs (Arc, 2019).

Having these data will allow us to more accurately inform policy conversations focused on adults with autism and/or I/DD. They will also enable researchers to ask more relevant questions about housing access and enable decision-makers to respond. For example, who is falling through the cracks and why? What are the most pressing barriers that prevent individuals from accessing residential options that align best with their support needs? What state and federal policy and funding gaps limit access to housing and LTSS? And, ultimately, how can we improve access to diverse, appropriate and affordable residential options for adults with autism and/or I/DD throughout their lifespan?

Conclusion

Housing needs for adults with autism and/or I/DD are overlooked in both disability and housing policy conversations. The data currently available are not disaggregated by meaningful population segments but primarily by individuals accessing state disability services that rarely include data on housing availability, housing needs and preferences for adults with autism and/or I/DD. This limits the extent to which housing needs are reported and precludes this demand from being met by stakeholders in public, private, nonprofit and philanthropic sectors. This paper begins to explore limitations of existing data, identifies opportunities to improve data collection and contextualizes data as a part of a broader goal: to ensure access to housing and services needed by adults with autism and/or I/DD is fully supported in the community.

To fuel a diverse and appropriate supply of residential options for adults with autism and/or I/DD, decision-makers require a comprehensive understanding of housing demand and the extent to which this need is currently met. Without data sets that define the spectrum of demand for housing, stakeholders will be poorly equipped to advocate and develop the necessary residential options. Shifts in policy and the prioritization of the right data can and will inform a marketplace of affordable and accessible residential options for a growing population of adults with autism and/or I/DD.

Part 3: Call to Action

By Denise D. Resnik and Desiree Kameka Galloway

Next Steps for Fueling the Marketplace

“The next empty bed,” or homelessness, should not be the only choice for adults with autism, intellectual/developmental disabilities (I/DD) or other neurodiversities.

According to a 2020 systematic review of studies on intellectual disability and homelessness in the Journal of Applied Research in Intellectual Disabilities, the loss of a family caregiver was a main determinant of people with an intellectual disability becoming homeless.

Following billions invested in early diagnosis, intervention and education, it is imperative we respond with urgency to ensure individuals are supported, housed and able to contribute to their communities. More than one million U.S. adults with I/DD live with a caregiver over age 60 and are at extreme risk of homelessness or displacement from their communities due to a lack of housing and community-based LTSS. There is no time to lose.

Our collective and immediate action can influence the development of spaces and places for neuro-inclusive housing. Person-centered planning can only be realized through a person-centered system. Policy and technology fueled by passionate pioneers has the power to influence local housing development and access to essential supports.

Consider what you can do and what we can do together. Here are nine recommendations for moving the needle forward:



1. Lead by example by speaking the same language.

- Benefit from the universal language detailed in *A Place in the World* enabling you to express your needs, preferences or properties in terms broadly understood. The market must have knowledge of what people want in order to respond.
- Apply the nomenclature and this body of work to your property, industry, interests and passionate pursuits. Neuro-inclusive recognition in all industries is needed for greater inclusion overall.
- Develop technologies to maximize opportunities to match people with properties and community resources.



2. Gather market intel.

- Require that all U.S. state Medicaid and IDD Agency directors collaborate with other governmental and nongovernmental stakeholders to submit a plan for how they will meet demand based on property development type, service delivery preferences and support needs to prevent crisis placements of people with autism and I/DD in inadequate, unsuitable settings.
- Ensure all local comprehensive planning and statewide housing plans include people with I/DD due to being high risk for homelessness, community displacement or forced institutionalization.
- Prepare a safety net for the loss of the family caregiver. Conduct local market analyses to understand the neurodiverse community and its preferences for a variety of supportive housing options, especially high-risk populations such as those living with aging caregivers over 60, caregivers with health challenges or terminal disease/disorders, or currently living in an abusive relationship. The Autism Housing Network's Empowering Communities Initiative offers an example: <https://www.autismhousingnetwork.org/wp-content/uploads/2020/04/Housing-Community-Development-Report-PDF.pdf>



3. Mine the assets in your community, industry and state.

- Produce whole-person, whole-community approaches by adopting principles from the national Home Matters® movement; learn more about the first statewide Home Matters to Arizona initiative. Community building starts locally and organically.
- Request planning grants for and the feasibility of supportive housing development to bring together collaborators and conduct required pre-development activities on potential sites.
- Develop campaigns for under-utilized properties that can be developed into supportive housing. This includes incentives, planning grants and capacity-building initiatives for local faith-based congregations, universities, community colleges, vacant land or remnant lots, etc.
- Engage and encourage students in various programs in local colleges and universities to apply their professional knowledge and skills to address challenges faced by people with autism and other I/DD.



4. Engage policy leaders.

- Call a meeting, write a letter, tell your story. Unless the policymaker has a family member with autism or I/DD, they are likely unaware of the existing housing and LTSS crisis. See website for a link to names of U.S. representatives.*
- Involve policy officials early in your endeavors so they better understand opportunities for alignment and more supportive policies that can pave the way on local, state and national levels.
- Encourage state and local jurisdictions to remove zoning or land-use barriers and expedite approval to develop supportive housing on property owned or controlled by organizations guided by social missions.



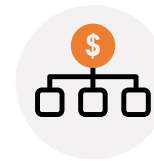
5. Collaborate on data collection.

- Demonstrate what's working and what needs to work better for diverse individuals and properties. Update segmentation of data currently being collected—including government-funded Developmental Disabilities Projects of National Significance—to include service delivery models, level of support needs and property development type to enable the alignment of data points and collection platforms.
- Seek government and private innovation funding to research, create and measure the impact of innovative models of supportive housing—including supportive and physical amenities—and prevent displacement or homelessness of at-risk populations with autism and I/DD.
- Revise the census on homeless and incarcerated populations to facilitate data collection so we can better understand the gravity of the number of adults with autism, I/DD or other neurodiversity who are falling through the cracks due to lack of housing or LTSS. Close the gaps through updates to Medicaid and HUD eligibility criteria.



6. Expand programs to address this uniquely at-risk population.

- Provide Non-Elderly Disabled (NED) Housing Choice Vouchers to all people with autism and I/DD who qualify based on their income.
- Make Medicaid HCBS waivers an entitlement so that every person who needs LTSS can receive services in the home of their choice.
- Leverage the success of the Low Income Housing Tax Credit (LIHTC) model and develop a Supportive Housing Tax Credit program to help fund the rapid development of supportive housing for people with disabilities.
- Alter current affordable housing financing sources and structures in response to demand, which may include prioritizing a percentage of Housing Trust Funds to focus on increasing access to housing for at-risk populations with autism or other I/DD.



7. Introduce new financing structures and instruments.

- Revise the IRS tax code incentivizing (1) donations to nonprofits that provide housing, LTSS or community-based services to people with autism or I/DD; and (2) private investment or bequeathment of housing for individual families in positions to save for and invest in future homeownership for a dependent loved one.
- Create private real estate funds yielding multiple rates of return, including social impact.
- Provide regulatory exceptions and incentivize innovation of public-private-philanthropic-nonprofit partnerships that infuse the marketplace with needed tools for developing deeply affordable, sustainable supportive housing that includes cost-saving technology.



8. Build industry infrastructure and safeguards.

- Set forth industry competency standards and protocols for supportive housing that include property management, skilled supportive amenity providers, and integrative housing and healthcare programs.
- Invest in the recruitment, retention and development of career paths for a robust direct support workforce of skilled, person-centered thinkers.
- Increase the capacity, retention and accountability of case managers as person-centered planning facilitators and implementers.
- Fortify strong systems of accountability for identifying and preventing abuse, neglect or exploitation of neurodiverse populations.



9. Create new, user-friendly resources.

- Develop a new source to help families and friends understand how to bequeath or purchase a home for a loved one with I/DD that protects them from financial exploitation, provides an adequate plan for sustainability and increases the housing stock available for others in need.
- Prioritize outreach and tools for senior family caregivers and their loved ones in non digital formats for transition planning to prevent traumatic crisis placements or homelessness.
- Develop a coalition of professionals who can provide technical assistance to emerging neuro-inclusive developments.

Let us mark this point in history as the time we ignited a more hopeful generation of options for individuals with autism and other I/DD and their families. Regardless of level of support needs—from low to very high—a diagnosis need not stand in the way of homes, friends, jobs and supportive communities. By working together and bridging innovation across different locations and sectors, we can create an array of neuro-inclusive housing opportunities and fuel a new wave of residential options that become a permanent, valued and healthy dimension of housing markets in communities everywhere.

*U.S. House of Representatives: <http://www.house.gov>; U.S. Senate: <http://www.senate.gov>. You can also get the phone number for your member of Congress using the U.S. Capitol Switchboard: 202224-3121. The White House website also has a form where you can send the president a message: <http://www.whitehouse.gov/>.

Part 1 References

- [1] Autism Speaks, "Housing and Residential Supports Tool Kit," 2011. [Online]. Available: [https://www.autismspeaks.org/sites/default/files/2018-08/Housing Tool Kit.pdf](https://www.autismspeaks.org/sites/default/files/2018-08/Housing%20Tool%20Kit.pdf).
- [2] C. Friedman, "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," Washington, D.C., 2019. [Online]. Available: <https://futureplanning.thearc.org/pages/learn/where-to-start/deciding-where-to-live/housing>.
- [3] G. Schaak, L. Sloane, F. Arienti, and A. Zovistoski, "Priced Out: The Housing Crisis for People with Disabilities," Boston, MA, 2017. [Online]. Available: <http://www.tacinc.org/media/59493/priced-out-in-2016.pdf>.
- [4] M. Connery, "Disability Housing: What's happening? What's challenging? What's needed?," Cambridge, MA, 2016. [Online]. Available: https://www.jchs.harvard.edu/sites/default/files/connery_disabilityhousing_april2016_v2.pdf.
- [5] A. S. F. Lutz, "Who Decides Where Autistic Adults Live?," The Atlantic, 2015. <https://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/> (accessed Aug. 14, 2020).
- [6] P. M. Dietz, C. E. Rose, D. McArthur, and M. Maenner, "National and State Estimates of Adults with Autism Spectrum Disorder," J. Autism Dev. Disord., 2020, doi: 10.1007/s10803-020-04494-4.
- [7] 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.
- [8] A. L. Goehner, "A Generation of Autism, Coming of Age," The New York Times, 2011. <https://www.panaacea.org/wp-content/uploads/2016/03/When-Children-With-Autism-Become-Adults-New-York-Times.pdf> (accessed Aug. 14, 2020).
- [9] D. Kameka, "Housing Community Development For Residents with Intellectual/Developmental Disabilities," Gaithersburg, MD, 2020.
- [10] T. Bahrapour, "These moms are building a forever home for their adult autistic children," The Washington Post, 2019. <https://www.washingtonpost.com/lifestyle/2019/01/29/faced-with-few-options-these-moms-are-building-home-their-adult-autistic-children/> (accessed Jul. 24, 2020).
- [11] M. H. Breslow, "Housing for Adults with Autism: A Growing Crisis," Autism Spectrum News, 2019. <https://autismspectrumnews.org/housing-for-adults-with-autism-a-growing-crisis/> (accessed Jul. 24, 2020).
- [12] C. Reagor, "New Phoenix apartments open for adults with autism," The Arizona Republic, 2018. <https://www.azcentral.com/story/money/real-estate/catherine-reagor/2018/09/30/phoenix-apartments-called-first-place-adults-autism-opens/1421650002/> (accessed Jul. 24, 2020).
- [13] D. D. Resnik, "Aging and Assimilating into the Community: Building Supports for Mid and Later Life with Autism," in Autism Spectrum Disorder in Mid and Later Life, S. D. Wright, Ed. Philadelphia, PA: Jessica Kingsley Publishers, 2016, pp. 264–277.
- [14] P. Paode, Housing for Adults with Autism and/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs. In D. D. Resnik & D. Kameka Galloway (Eds.), A Place in the World: Fueling Housing and Community Options for Adults with Autism and other Neurodiversities (pp. 143–173). First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy at the Watts College of Public Service and Community Solutions, 2020.
- [15] P. Paode, "Better Data Make Better Policy: Defining Unmet Housing Needs of Adults with Autism and Other Neurodiversities," 2020.
- [16] S. Ahrentzen et al., "Opening Doors: A Discussion of Residential Options for Adults Living With Autism And Related Disorders," 2009. [Online]. Available: https://www.firstplaceaz.org/wp-content/uploads/openingdoors_print_042610_001.pdf.
- [17] Centers for Disease Control and Prevention, "Facts About Developmental Disabilities," 2019. <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html#:~:text=Developmental disabilities are a group,1> (accessed Jul. 29, 2020).
- [18] Centers for Disease Control and Prevention, "Facts About Intellectual Disability," 2019. <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts-about-intellectual-disability.html> (accessed Jul. 29, 2020).
- [19] Centers for Disease Control and Prevention, "Autism and Developmental Disabilities Monitoring (ADDM) Network," 2020. <https://www.cdc.gov/ncbddd/autism/addm.html> (accessed Jul. 29, 2020).
- [20] A. Bailin, "Clearing Up Some Misconceptions about Neurodiversity," Scientific American, 2019. <https://blogs.scientificamerican.com/observations/clearing-up-some-misconceptions-about-neurodiversity/> (accessed Jun. 15, 2020).

[21] United States Census Bureau, "2019 National and State Population Estimates," 2019. <https://www.census.gov/newsroom/press-kits/2019/national-state-estimates.html> (accessed Jul. 29, 2020).

[22] Centers for Disease Control and Prevention, "Data & Statistics on Autism Spectrum Disorder," 2020. <https://www.cdc.gov/ncbddd/autism/data.html> (accessed Jul. 29, 2020).

[23] A. M. Roux, P. T. Shattuck, J. E. Rast, J. A. Rava, and K. A. Anderson, "National Autism Indicators Report: Transition into Young Adulthood," Philadelphia, PA, 2015. [Online]. Available: <https://iacc.hhs.gov/publications/general/2015/natl-autism-indicators-report-july-2015.pdf>.

[24] T. Heller, "People with Intellectual and Developmental Disabilities Growing Old: An Overview," Minneapolis, MN, 2010. [Online]. Available: <https://ici.umn.edu/products/impact/231/231.pdf>.

[25] D. L. Braddock, R. E. Hemp, M. C. Rizzolo, E. S. Tanis, J. Wu, and L. Haffer, The State of the States in Intellectual and Developmental Disabilities, 10th ed. Washington, D.C.: American Association on Intellectual and Developmental Disabilities, 2015.

[26] A. M. Roux, J. E. Rast, K. A. Anderson, and P. T. Shattuck, "National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood," Philadelphia, PA, 2017. [Online]. Available: <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Developmental-Disability-Services-and-Outcomes-in-Adulthood/>.

[27] D. L. Braddock, R. E. Hemp, E. S. Tanis, J. Wu, and L. Haffer, The State of the States in Intellectual and Developmental Disabilities, 11th ed. Washington, D.C.: American Association on Intellectual and Developmental Disabilities, 2017.

[28] L. Anderson, S. A. Larson, A. Wuorio, and K. C. Lakin, "Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (FINDS)," Washington, D.C., 2011. [Online]. Available: www.aaid.org/content_100.cfm?navID=21.

[29] P. She and G. A. Livermore, "Long-term poverty and disability among working-age adults," J. Disabil. Policy Stud., vol. 19, no. 4, pp. 244–256, 2009, doi: 10.1177/1044207308314954.

[30] National Council on Disability, "National Disability Policy: A Progress Report," Washington, D.C., 2017. [Online]. Available: [https://ncd.gov/sites/default/files/NCD_A Progress Report_508.pdf](https://ncd.gov/sites/default/files/NCD_A%20Progress%20Report_508.pdf).

[31] U.S. Department of Health and Human Services, "Annual Update of the HHS Poverty Guidelines," Washington, D.C., 2016. [Online]. Available: <https://www.federalregister.gov/documents/2016/01/25/2016-01450/annual-update-of-the-hhs-poverty-guidelines>.

[32] First Place - Phoenix and Autism Housing Network, "Housing and Community Worksheet: A Discussion of Nomenclature & Segmentation Fueling Marketplace Options for Neurodiverse Populations," Phoenix, AZ, 2019.

[33] G. Braddock and J. Rowell, "MAKING HOMES THAT WORK : A Resource Guide for Families Living with Autism Spectrum Disorder + Co-occurring Behaviors," 2011. [Online]. Available: https://iacc.hhs.gov/meetings/iacc-meetings/2011/services-workshop/september15/homes_that_work_091511.pdf.

[34] Morrison Institute for Public Policy and Arizona Developmental Disabilities Planning Council, "If You Build It, They Will Come," Phoenix, AZ, 2012. [Online]. Available: [https://addpc.az.gov/sites/default/files/media/IfYouBuildItTheyWillCome_REV2 ADDPC_Housing_Options_0.pdf](https://addpc.az.gov/sites/default/files/media/IfYouBuildItTheyWillCome_REV2_ADDPC_Housing_Options_0.pdf).

[35] H. Robinson, "A Guide for Making Housing Decisions- Housing Option for Older Adults," Washington, D.C. [Online]. Available: <https://www.n4a.org/files/HousingOptions.pdf>.

[36] Centers for Medicare & Medicaid Services, "Intermediate Care Facilities for Individuals with Intellectual Disabilities." <https://www.medicare.gov/medicaid/long-term-services-supports/institutional-long-term-care/intermediate-care-facilities-individuals-intellectual-disability/index.html> (accessed May 29, 2020).

[37] R. E. Cooper, "Shared Living: A New Take On An Old Idea," Arizona Developmental Disabilities Planning Council, 2013. https://addpc.az.gov/sites/default/files/media/NEWaddpc_sharedliving_brief_5.14.13.pdf (accessed Sep. 05, 2020).

[38] Centers for Medicare & Medicaid Services, "Home & Community Based Services 1915(c)." <https://www.medicare.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html> (accessed May 29, 2020).

[39] Medicare.gov, "What's Medicare?" <https://www.medicare.gov/what-medicare-covers/your-medicare-coverage-choices/whats-medicare> (accessed Jun. 26, 2020).

[40] Social Security Administration, "Supplemental Security Income (SSI) Benefits." <https://www.ssa.gov/benefits/ssi/> (accessed May 28, 2020).

[41] Social Security Administration, "Disability Benefits." <https://www.ssa.gov/benefits/disability/> (accessed Aug. 17, 2020).

[42] IRS.gov, "ABLE Accounts - Tax Benefit for People with Disabilities," 2020. <https://www.irs.gov/government-entities/federal-state-local-governments/able-accounts-tax-benefit-for-people-with-disabilities#:~:text=The Achieving a Better Life,pay for qualified disability expenses.> (accessed Aug. 17, 2020).

[43] R. Clarfeld, "Special Needs Trusts: What They Do And How They Work," Forbes.com, 2018. <https://www.forbes.com/sites/robclarfeld/2018/12/17/special-needs-trusts-what-they-do-and-how-they-work/#551e3f215dc7> (accessed Aug. 17, 2020).

[44] U.S. Department of Housing and Urban Development, "Homeownership Vouchers." https://www.hud.gov/program_offices/public_indian_housing/programs/hcv/homeownership (accessed Jun. 26, 2020).

[45] U.S. Department of Housing and Urban Development, "Housing Choice Vouchers Fact Sheet." https://www.hud.gov/program_offices/public_indian_housing/programs/hcv/about/fact_sheet (accessed May 28, 2020).

[46] Fannie Mae, "B2-1.1-01, Occupancy Types (05/01/2019)," 2020. <https://selling-guide.fanniemae.com/Selling-Guide/Origination-thru-Closing/Subpart-B2-Eligibility/Chapter-B2-1-Mortgage-Eligibility/Section-B2-1-1-Occupancy-Types/1032995641/B2-1-1-01-Occupancy-Types-05-01-2019.htm> (accessed Sep. 04, 2020).

[47] U.S. Department of Agriculture Rural Development, "Single Family Housing Programs." <https://www.rd.usda.gov/programs-services/all-programs/single-family-housing-programs> (accessed Aug. 17, 2020).

[48] Social Security Administration, "Disability Evaluation Under Social Security." <https://www.ssa.gov/disability/professionals/bluebook/general-info.htm#:~:text=The law defines disability as,not less than 12 months.> (accessed Aug. 17, 2020).

[49] National Institute of Child Health and Human Development, "Intellectual and Developmental Disabilities (IDDs): Condition Information," 2016. <https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default> (accessed May 28, 2020).

[50] Housing Opportunities & Maintenance for the Elderly (HOME), "Intergenerational Housing," 2019. <https://www.homeseniors.org/services-in-the-community/intergenerational-housing> (accessed Jun. 15, 2020).

[51] HUD's Office of Policy Development and Research, "Income Limits," 2020. <https://www.huduser.gov/portal/datasets/il.html> (accessed Sep. 05, 2020).

[52] C. Broikos and M. Stanton, "Making Room: Housing for a Changing America," Washington, D.C., 2019. [Online]. Available: <https://www.aarp.org/content/dam/aarp/livable-communities/livable-documents/documents-2019/making-room-web-singles-010819.pdf>.

[53] The Tiny Life, "What is the Tiny House Movement?," 2020. <https://thetinylife.com/what-is-the-tiny-house-movement/> (accessed May 29, 2020).

[54] American Planning Association, "Accessory Dwelling Units," 2020. <https://www.planning.org/knowledgebase/accessorydwellings/> (accessed Aug. 17, 2020).

[55] Redfin, "Different Residential Building Types," 2020. <https://www.redfin.com/resources/difference-between-building-types> (accessed May 29, 2020).

[56] A. Colley, "What is a Manufactured Home? The Next Step Beyond Mobile Homes," Realtor.com, 2019. <https://www.realtor.com/advice/buy/what-is-a-manufactured-home/> (accessed Aug. 17, 2020).

[57] U.S. Department of Housing and Urban Development (HUD), "Understanding SRO," 2001. [Online]. Available: <https://files.hudexchange.info/resources/documents/Understanding-SRO.pdf>.

[58] K. Albrecht and L. Brown, "Research Brief: Evidence for Integrated Housing," 2014. [Online]. Available: https://d1wqtxts1xzle7.cloudfront.net/49456581/Housing-Brief.pdf?1475949463=&response-content-disposition=inline%3B+filename%3DRResearch_Brief_Evidence_for_Integrated_H.pdf&Expires=1592414623&Signature=IRrVXBetuz-3nFEF6jEzXHfxC~Y~Hg~iZ0Kbcw5cLL~g~H6a~E3BoU.

[59] J. Hogan, "Scattered-Site Housing: Characteristics and Consequences," Washington, D.C., 1996. [Online]. Available: https://www.huduser.gov/portal/publications/pdf/Scattered_site_housing.pdf.

[60] American Planning Association, "Mixed Use Development," 2013. <https://web.archive.org/web/20130207034351/https://www.planning.org/nationalcenters/health/mixedusedevelopment.htm> (accessed May 29, 2020).

[61] The Cohousing Association of the United States, "CohoUS an association," 2020. <https://www.cohousing.org/> (accessed Aug. 27, 2020).

[62] Coliving.com, "What is coliving?," 2020. <https://coliving.com/what-is-coliving> (accessed Jun. 15, 2020).

[63] A. Velez, "What Is a Planned Community? A Place With Perks, From Zip Lines to Velodromes," reator.com, 2017. <https://www.realtor.com/advice/buy/what-is-a-planned-community/> (accessed May 29, 2020).

[64] Residential Information Systems Project (RISP), "Residential Information Systems Project (RISP) Annual Data Collection Operational Definitions: Working Draft Updated February 2013," Minneapolis, MN, 2013. [Online]. Available: https://risp.umn.edu/media/download/cms/media/risp/resource_materials/RISP_Operational_Definitions_February_2013.pdf.

[65] National Institute on Aging, "Residential Facilities, Assisted Living, and Nursing Homes," 2017. <https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes> (accessed May 28, 2020).

[66] L. Logan, "Active Adult Communities: What are they?," Seniorhomes.com, 2020. <https://www.seniorhomes.com/active-adult-communities/> (accessed Sep. 05, 2020).

[67] Foundation for Intentional Community, "Policies," 2019. <https://www.ic.org/policies/> (accessed May 29, 2020).

[68] Idea Associates, "Benefits of a Live-Work-Play Community," 2011. <https://www.ideaassociates.com/2011/09/29/live-work-play-community/> (accessed May 29, 2020).

[69] Avalon Communities, "Pet friendly," 2020. <https://www.avaloncommunities.com/pet-friendly> (accessed May 29, 2020).

[70] NC State University Center for Universal Design, "Definitions: Accessible, Adaptable, and Universal Design," Raleigh, NC, 2006. [Online]. Available: https://projects.ncsu.edu/ncsu/design/cud/pubs_p/docs/Fact Sheet 6.pdf.

[71] Age in Place, "What is Aging in Place?," 2020. <https://ageinplace.com/aging-in-place-basics/what-is-aging-in-place/> (accessed May 28, 2020).

[72] SimplyHome, "Top 5 Ways Enabling Technology Reaches Beyond Remote Monitoring," simply-home.com, 2019. <https://www.simply-home.com/blog-overview/top-5-ways-enabling-technology-reaches-beyond-remote-monitoring?rq=remote support> (accessed Sep. 05, 2020).

[73] B. Turner, "DIDD's Enabling Technology Program," TN Department of Intellectual and Developmental Disabilities, 2020. <https://www.tn.gov/didd/for-consumers/enabling-technology.html> (accessed Sep. 05, 2020).

[74] Colorado Association of People Supporting Employment First, "A Benefits Counseling Guide," 2019. [Online]. Available: <https://apse.org/wp-content/uploads/2014/01/Benefits-Counseling-Guide-.pdf>.

[75] National Association of Housing Cooperatives, "Buying into a Housing Cooperative," 2013. <https://coophousing.org/resources/owning-a-cooperative/buying-into-a-housing-cooperative/> (accessed May 29, 2020).

[76] R. Greenstein and Y. Sungu-Eryilmaz, "Community Land Trusts," Land Lines, 2005. <https://www.lincolnst.edu/publications/articles/community-land-trusts> (accessed May 29, 2020).

[77] U.S. Department of Housing and Urban Development Office of Policy Development and Research, "Paths to Homeownership for Low-Income and Minority Households," 2012. <https://www.huduser.gov/portal/periodicals/em/fall12/highlight1.html> (accessed Jun. 26, 2020).

[78] Public Finance Authority, "Affordable Multifamily Housing Bonds." <https://www.pfauthority.org/finance-programs/affordable-multifamily-housing-bonds/> (accessed May 29, 2020).

[79] Council on Foundations, "Glossary of Philanthropic Terms," 2020. <https://www.cof.org/content/glossary-philanthropic-terms> (accessed May 29, 2020).

[80] U.S. Department of Housing and Urban Development, "Community Development," 2020. https://www.hud.gov/program_offices/comm_planning/communitydevelopment (accessed Sep. 05, 2020).

[81] U.S. Department of Housing and Urban Development, "CDBG: Community Development Block Grant Programs." <https://www.hudexchange.info/programs/cdbg/> (accessed May 29, 2020).

[82] U.S. Department of the Treasury CDFI Fund, "What are CDFIs?," Washington, D.C. [Online]. Available: https://www.cdfifund.gov/Documents/CDFI_infographic_v08A.pdf.

[83] Business Dictionary, "Grant (definition)," WebFinance Inc., 2020. <http://www.businessdictionary.com/definition/grant.html> (accessed May 29, 2020).

[84] U.S. Department of Housing and Urban Development, "HOME Overview," 2013. <https://www.hudexchange.info/programs/home/home-overview/> (accessed May 29, 2020).

[85] HUD.gov, "HOME Investment Partnerships Program." https://www.hud.gov/program_offices/comm_planning/affordablehousing/programs/home/ (accessed Sep. 05, 2020).

[86] National Council of State Housing Agencies, "About NCSHA," 2020. <https://www.ncsha.org/about-us/> (accessed May 29, 2020).

- [87] U.S. Department of Housing and Urban Development, "Housing Trust Fund." <https://www.hud.gov/hudprograms/housing-trust> (accessed May 29, 2020).
- [88] J. Chen, "Impact Investing," 2019. <https://www.investopedia.com/terms/i/impact-investing.asp> (accessed Aug. 17, 2020).
- [89] C. P. Scally, A. Gold, and N. DuBois, "The Low-Income Housing Tax Credit," Washington, D.C., 2018. [Online]. Available: https://www.urban.org/sites/default/files/publication/98758/lithc_how_it_works_and_who_it_serves_final_2.pdf.
- [90] U.S. Department of Agriculture, "Multi-Family Housing Programs."
- [91] The New Markets Tax Credit Coalition, "About the NMTC," 2020. <https://nmtccoalition.org/progress-report-2019/about-the-nmtc/> (accessed May 29, 2020).
- [92] National Rural Housing Coalition, "Section 515 Rural Rental Housing Loans," 2011. <https://ruralhousingcoalition.org/section-515-rural-rental-housing-loans/> (accessed May 29, 2020).
- [93] The Housing Assistance Council, "USDA Rural Rental Housing Loans (Section 515)," 2011. <http://www.ruralhome.org/storage/documents/rd515rental.pdf> (accessed Sep. 05, 2020).
- [94] U.S. Department of Housing and Urban Development, "SECTION 811 SUPPORTIVE HOUSING FOR PERSONS WITH DISABILITIES," 2016. https://www.hud.gov/program_offices/housing/mfh/progdesc/disab811#:~:text=Through the Section 811 Supportive,low-income adults with disabilities. (accessed Aug. 14, 2020).
- [95] U.S. Department of Housing and Urban Development, "FY 2019 Section 811 Supportive Housing for Persons with Disabilities (Capital Advance)," 2020. https://www.hud.gov/program_offices/spm/gmomgmt/grantsinfo/fundingopps/fy2019_section811_capadvance (accessed May 29, 2020).
- [96] U.S. Department of Housing and Urban Development, "Section 811 Supportive Housing for Persons with Disabilities." https://www.hud.gov/program_offices/housing/mfh/progdesc/disab811 (accessed May 29, 2020).
- [97] A. Johnson, "What is a Ground Lease?," SFGATE, 2019. <https://homeguides.sfgate.com/ground-lease-1793.html> (accessed Jun. 15, 2020).
- [98] U.S. Department of Housing and Urban Development, "Place-Based Tax Incentives for Community Development," 2019. <https://www.huduser.gov/portal/periodicals/em/SpringSummer19/highlight1.html> (accessed May 29, 2020).
- [99] U.S. Department of Housing and Urban Development, "NSP Basics." <https://www.hudexchange.info/programs/nsp/nsp-eligibility-requirements/> (accessed May 29, 2020).
- [100] Local Housing Solutions, "Use of publicly owned property for affordable housing." <https://www.localhousingsolutions.org/act/housing-policy-library/use-of-publicly-owned-property-for-affordable-housing-overview/use-of-publicly-owned-property-for-affordable-housing/> (accessed May 29, 2020).
- [101] California Department of Housing and Community Development, "Public Lands for Affordable Housing Development," 2020. <https://www.hcd.ca.gov/community-development/public-lands-for-affordable-housing-development.shtml> (accessed May 29, 2020).
- [102] A. M. W. Coppus, "People with Intellectual Disability: What do we know about Adulthood and Life Expectancy?," *Developmental Disabilities Research Reviews*, vol. 18, no. 1. John Wiley and Sons Inc., pp. 6–16, 2013, doi: 10.1002/ddrr.1123.
- [103] R. E. Nieuwenhuis-Mark, "Diagnosing Alzheimer's dementia in Down syndrome: Problems and possible solutions," *Research in Developmental Disabilities*, vol. 30, no. 5. pp. 827–838, Sep. 2009, doi: 10.1016/j.ridd.2009.01.010.
- [104] Z. R. Lucock, R. A. Sharp, and R. S. P. Jones, "Behavior-Analytic Approaches to Working with People with Intellectual and Developmental Disabilities who Develop Dementia: a Review of the Literature," *Behav. Anal. Pract.*, vol. 12, no. 1, pp. 255–264, Mar. 2019, doi: 10.1007/s40617-018-0270-8.
- [105] First Place AZ, "Vision, Mission & Goals," 2020. <https://www.firstplaceaz.org/about/vision-goals/> (accessed Sep. 03, 2020).
- [106] J. Whittaker, "Home and Community-Based Services and Long-Term Services and Supports: New Initiatives, Expanded Options [Panel presentation].," 2019, [Online]. Available: [https://accses.org/CMS/Resources/dropbox/2019 winter summit/jimwhittaker2019wintersummit.pdf](https://accses.org/CMS/Resources/dropbox/2019%20winter%20summit/jimwhittaker2019wintersummit.pdf).
- [107] Bergen County's United Way, "History & Mission," 2018. <https://bergenunitedway.org/our-mission/> (accessed Sep. 03, 2020).
- [108] State of New Jersey Department of Community Affairs, "About the Council," 2020. <https://www.state.nj.us/dca/affiliates/coah/about/> (accessed Sep. 03, 2020).

Part 2.1 References

- A** Administration for Community Living. (2019, March). Consumer Choice and Control. <https://acl.gov/programs/consumer-control>
- Administration for Community Living. (2020) History of the DD Act. Retrieved August 5, 2020 from <https://acl.gov/about-acl/history-dd-act>
- Albrecht, K., & Brown, L. (2014). Research Brief: Evidence for Integrated Housing. Autistic Self Advocacy Network. 4 pp. www.autisticadvocacy.org
- American Association on Intellectual and Developmental Disabilities (AAIDD), American Network of Community Options and Resources (ANCOR), Autism Society of America (ASA), National Association of Councils on Developmental Disabilities (NACDD), The Arc, United Cerebral Palsy (UCP). (2019). Public Policy Agenda for the 116th Congress 2019-2020. Accessed July 24, 2020 from <https://www.autism-society.org/wp-content/uploads/2019/03/DigitalCopy.pdf>
- Aurand, A., Emmanuel, D., Yentel, D., Errico, E., & Pang, M. (2017). Out of Reach 2017: The High Cost of Housing. National Low Income Housing Coalition.
- B** Bailey, P. (2020). Housing and Health Partners Can Work Together to Close the Housing Affordability Gap. Center on Budget and Policy Priorities. <https://www.cbpp.org/research/health/medicaid-can-partner-with-housing-providers-and-others-to-address-enrollees-social>
- Bo'sher, L., Chan, S., Ellen, I. G., Karfunkel, B., & Liao, H. L. (2015). Accessibility of America's Housing Stock: Analysis of the 2011 American Housing Survey (AHS). Available at SSRN 3055191.
- Brooks, M., Uprety, A. (2012, March 25). How Fair Housing Helps People with Intellectual and Developmental Disabilities Live Independently. Equal Rights Center. <https://equalrightscenter.org/housing-intellectual-developmental-disabilities/>
- Brown M, McCann E. (2020). Homelessness and people with intellectual disabilities: A systematic review of the international research evidence. J. Appl. Res. Intellect. Disabil; 00:1–12. <https://doi.org/10.1111/jar.12815>
- C** California State Council on Developmental Disabilities. (2018, December). Expanding Housing Opportunities for People with Intellectual and Developmental Disabilities. <https://scdd.ca.gov/wp-content/uploads/sites/33/2018/12/statewide-strategic-framework-for-expanding-housing-opportunities-for-people-with-intellectual-and-developmental-disabilities-10.16.pdf>
- Center on Budget and Policy Priorities. (2017, October 11). 2017 Housing Choice Voucher Program Factsheets. <https://www.cbpp.org/research/2017-housing-choice-voucher-program-factsheets-sources-and-methodology>
- Center on Budget and Policy Priorities. (2019a, March 4). Agencies Generally Use All Available Voucher Funding to Help Families. <https://www.cbpp.org/research/housing/agencies-generally-use-all-available-voucher-funding-to-help-families-afford>
- Center on Budget and Policy Priorities. (2019b, May 31). Housing Vouchers Work: Huge Demand, Insufficient Funding for Housing. <https://www.cbpp.org/blog/housing-vouchers-work-huge-demand-insufficient-funding-for-housing-vouchers-means-long-waits>
- Centers for Medicare & Medicaid Services. (2007). Money Follows the Person Rebalancing Demonstration. https://www.cms.gov/Regulations-and-Guidance/Legislation/DeficitReductionAct/downloads/MFP_FactSheet.pdf
- Centers for Medicare & Medicaid Services. (2020). State Waivers List. <https://www.medicare.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>
- Colello, K. J. (2017). Medicaid Financial Eligibility for Long-Term Services and Supports. Congressional Research Service.
- Conrad, J. A. (2020). On intellectual and developmental disabilities in the United States: A historical perspective. Journal of Intellectual Disabilities, 24(1), 85-101.
- Coughlin, R., Ward, J., Denny-Brown, N., Hagen, B., Maurer, K., Morris, E., & Perez, B. (2017). Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2016. Cambridge, MA: Mathematica Policy Research.
- Crossley, M. (2018). Bundling Justice: Medicaid's Support for Housing. The Journal of Law, Medicine & Ethics, 46(3), 595-601.

- D** Dawkins, C., & Miller, M. (2017). The Characteristics and Unmet Housing Program Needs of Disabled HUD-Assisted Households. *Housing Policy Debate*, 27(4), 499-518.
- Department of Housing and Urban Development (HUD). Housing Discrimination Under the Fair Housing Act. (2020). Retrieved July 26, 2020 from https://www.hud.gov/program_offices/fair_housing_equal_opp/fair_housing_act_overview
- E** Easter Seals. (2008). Living with Disabilities Study Key Findings. Retrieved from https://www.easterseals.com/shared-components/document-library/key_findings_living_with_disabilities_study_low_res.pdf
- Ensslin, B., & Kruse, A. (2016). State Trends in the Delivery of Medicaid Long-Term Services and Supports. Center for health care strategies, INC., Brief.
- F** Federal Legislative Milestones in Medicaid and CHIP. (2020, June 4). Medicaid and CHIP Payment and Access Commission (MACPAC). Accessed August 4, 2020 from [https://www.macpac.gov/federal-legislative-milestones-in-medicaid-and-chip/#:%7E:text=Social%20Security%20Amendments%20of%201971,%E2%80%9D%20\(ICF%20DMRs\)](https://www.macpac.gov/federal-legislative-milestones-in-medicaid-and-chip/#:%7E:text=Social%20Security%20Amendments%20of%201971,%E2%80%9D%20(ICF%20DMRs))
- Freeman, L. (2011). The Impact of Source of Income Laws on Voucher Utilization and Locational Outcomes. Washington D.C.: U.S. Department of Housing and Urban Development Office of Policy Development and Research.
- G** Graham, J. (2017, May 9). Severe Shortage of Direct Care Workers Triggering Crisis. Kaiser Health News. <https://www.disabilityscoop.com/2017/05/09/severe-shortage-care-crisis/23679/>
- Grey, J. M., Griffith, G. M., Totsika, V., & Hastings, R. P. (2015). Families' Experiences of Seeking OutOfHome Accommodation for Their Adult Child with an Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 12(1), 47-57.
- H** Hammel, J. (2017). Rental Housing Discrimination on the Basis of Mental Disabilities: Results of Pilot Testing. Government Printing Office.
- Hewitt, A. S., Stancliffe, R. J., Hall-Lande, J., Nord, D., Pettingell, S. L., Hamre, K., & Hallas-Muchow, L. (2017). Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States. *Research in Autism Spectrum Disorders*, 34, 1-9.
- Hoffman, D., Kehn, M. E., & Lipson, D. J. (2017). The Missing Link: Examining the Impact of Housing Vouchers and Community-Based Services and Supports on Transitions from Nursing Facilities to the Community. *Journal of Disability Policy Studies*, 27(4), 243-251. <https://doi.org/10.1177/1044207317694847>
- https://reports.nlihc.org/sites/default/files/or/OOR_2020_Mini-Book.pdf
- HUD Exchange. (2020). Section 811 Project Rental Assistance Program: Successfully Supporting Independent Living for People with Disabilities. <https://www.hudexchange.info/resource/6032/section-811-pra-successfully-supporting-independent-living/>
- I** Irvin, C., Denny-Brown, N., Kehn, M., Lester, R., Lipson, D., Lim, W., . . . Stone, E. (2013). Money Follows the Person 2012 Annual Evaluation Report. Princeton, NJ: Mathematica Policy Research. Retrieved from <https://www.mathematicapr.com/our-publications-and-findings/publications/money-follows-the-person-2012-annual-evaluation-report>
- J** Jewett, C. (2017, November 30). Nowhere to Go: Young People with Severe Autism Languish in Hospitals. Kaiser Health News. <https://khn.org/news/for-thousands-of-autistic-teens-hospital-ers-serve-as-home/>
- Jones, N. L. (2007). Section 504 of the Rehabilitation Act of 1973: Prohibiting Discrimination Against Individuals with Disabilities in Programs or Activities Receiving Federal Assistance. Congressional Research Service.
- K** Kaiser Family Foundation. (2011, October 2). Impact of the Medicaid Fiscal Relief Provisions in the American Recovery and Reinvestment Act (ARRA). Accessed August 1, 2020 from <https://www.kff.org/medicaid/issue-brief/impact-of-the-medicaid-fiscal-relief-provisions/>
- Kaiser Family Foundation. (2019, June 28). Medicaid Eligibility for Long-Term Care Through the Special Income Rule. <https://www.kff.org/other/state-indicator/medicaid-eligibility-for-long-term-care-through-the-special-income-rule/?currentTimeframe=0&sortModel=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D>
- Kaiser Family Foundation. (2020, February 27). Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers. <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D>
- Kaiser Family Foundation. (2020, February 4). Key State Policy Choices About Medicaid Home and Community-Based Services. Appendix Table 7: State Financial Eligibility Criteria for Medicaid HCBS Waivers by Target Population, FY 2018 <https://www.kff.org/report-section/key-state-policy-choices-about-medicaid-home-and-community-based-services-appendix-tables/>
- Kathleen Moore, M. (2016). Lists and Lotteries: Rationing in the Housing Choice Voucher Program. *Housing Policy Debate*, 26(3), 474-487.
- Kleinman, R., Kehn, M., Wishon Siegwarth, A., & Brown, J. (2017). State Strategies for Coordinating Medicaid and Housing Services. *Psychiatric Rehabilitation Journal*, 40(2), 225-232.
- Kushner, J. A. (1989). Fair Housing Amendments Act of 1988: The Second Generation of Fair Housing. *Vand. L. Rev.*, 42, 1049.

- L** Lakin, K. C., Prouty, R., Polister, B., & Coucouvanis, K. (2003). Trends & milestones: Twenty Years of Growth in Medicaid Home and Community Based Services, Recipients, and Costs: June 1982 to June 2002. *Mental retardation*, 41(5), 394-397.
- Lipson, D., Hoffman, D., & Kehn, M. (2013). Findings from the Evaluation of the Non-Elderly Disabled (NED) Housing Choice Voucher Program (No. f2e4a658bce84a8db4aee7daddaef775). Mathematica Policy Research.
- Lutz, A. S. (2015, May 27). Who Decides Where Autistic Adults Live? The Atlantic. <https://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/>
- M** Manatt Health. (2020, January). State Investments in Supportive Housing: An Inventory of State Efforts. https://www.shvs.org/wp-content/uploads/2020/01/Supportive-Housing-Chart_Final.pdf
- Martone, K. (2020). Olmstead Implementation. Technical Assistance Collaborative. https://nlihc.org/sites/default/files/AG-2020/6-05_Olmstead-Implementation.pdf
- McCormick, L., Schwartz, A., & Passerini, C. (2019). Housing for People with Disabilities: A Review of State Olmstead and HUD Consolidated Plans. *Journal of Planning Education and Research*, 0739456X19844567.
- Medication and CHIP Payment and Access Commission. (2018). Medicaid's Role in Housing. <https://www.macpac.gov/wp-content/uploads/2018/10/Medicaid%E2%80%99s-Role-in-Housing.pdf>
- N** National Academies of Sciences, Engineering, and Medicine. (2017). Developing Affordable and Accessible Community-Based Housing for Vulnerable Adults: Proceedings of a Workshop. National Academies Press.
- National Academies of Sciences, Engineering, and Medicine. (2018). Program and Policy Barriers to Permanent Supportive Housing. Permanent Supportive Housing: Evaluating the Evidence for Improving Health Outcomes Among People Experiencing Chronic Homelessness. National Academies Press (US).
- National Fair Housing Alliance. 2019 Fair Housing Trends Report. (2019, November 1). <https://nationalfairhousing.org/2019-fair-housing-trends-report/>
- National Institute of Health Interagency Autism Coordinating Committee (NIH IACC). (2019). Housing Workgroup. <https://iacc.hhs.gov/meetings/working-group-meetings/2019/housing/workshop/july23/>
- National Low Income Housing Coalition. (2020). Out of Reach: The High Cost of Housing.
- Ng, T., Stone, J., & Harrington, C. (2015). Medicaid Home and Community-Based Services: How Consumer Access Is Restricted by State Policies. *Journal of aging & social policy*, 27(1), 21-46.
- O** O'Shaughnessy, C. (2014). Money Follows the Person (MFP) Rebalancing Demonstration: A Work in Progress.
- Oliver S, Gosden-Kaye EZ, Winkler D, Douglas JM. The outcomes of individualized housing for people with disability and complex needs: a scoping review [published online ahead of print, 2020 Jul 9]. *Disabil Rehabil*. 2020;1-15. doi:10.1080/09638288.2020.1785023
- P** Perl, L. (2016). Section 811 and other HUD housing programs for persons with disabilities. Congressional Research Service.
- R** Residential Information Systems Project (2020). Living Arrangements: Long-Term Supports and Services (LTSS) Recipients by Setting Type and Year. Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from <https://risp.umn.edu>
- Rosenbaum, S. (2016). Using the Courts to Shape Medicaid Policy: Olmstead v. L. C. by Zimring and Its Community Integration Legacy. *Journal of health politics, policy and law*, 41(4), 585-597.
- Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Anderson, Kristy A. National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2017.
- Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.
- Rowland, D., Lyons, B., & Edwards, J. (1988). Medicaid: Health Care for the Poor in the Reagan Era. *Annual review of public health*, 9(1), 427-450.
- S** Schaak, G., Sloane, L., Arienti, F., & Zovistoski, A. (2017). Priced Out: The Housing Crisis for People with Disabilities. Boston, MA: Technical Assistance Collaborative. Retrieved May 31, 2018 from <http://www.tacinc.org/media/59493/priced-out-in-2016.pdf>
- Schott, W., Nonnemacher, S. & Shea, L. Service Use and Unmet Needs Among Adults with Autism Awaiting Home- and Community-Based Medicaid Services. *Journal of Autism Developmental Disorders* (2020). <https://doi.org/10.1007/s10803-020-04593-2>
- Scotti, S., Cruz, N. (2020, May). Connecting Health and Housing Through Medicaid. National Council of State Legislatures. <https://www.ncsl.org/research/health/connecting-health-and-housing-through-medicaid.aspx>

Self-Directed Services. (2020). Centers for Medicare & Medicaid Services. <https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html>

Sloane, L. (2019). Mainstream and Non-Elderly Disabled (NED) Vouchers. National Low Income Housing Coalition 2020 Advocates' Guide. [https://nlihc.org/sites/default/files/AG-2020/4-06_Mainstream-and-Non-Elderly-Disabled-\(NED\)-Vouchers.pdf](https://nlihc.org/sites/default/files/AG-2020/4-06_Mainstream-and-Non-Elderly-Disabled-(NED)-Vouchers.pdf)

Smith, G., O'Keeffe, J., Carpenter, L., Doty, P., Burnwell, B., Mollica, R., & Williams, L. (2000). Understanding Medicaid Home and Community Services: A Primer.

Svahn, J. A. (1981). Omnibus Reconciliation Act of 1981: Legislative History and Summary of OASDI and Medicare provisions. Soc. Sec. Bull., 44, 3.

T Tanis, E.S., Lulinski, A. & Wu, J., Braddock, D. & Hemp, R. (2020). The State of the States in Intellectual and Developmental Disabilities, Department of Psychiatry, University of Colorado. United States Profile. Retrieved October 8, 2020 <https://stateofthestates.org/wp-content/uploads/2020/05/UnitedStates.pdf>

Technical Assistance Collaborative. (2014). Housing Choice Vouchers Targeted to Non-Elderly Persons with Disabilities – Another Tool to Help End Homelessness. <http://www.tacinc.org/media/49145/NED%20for%20Homeless.pdf>

Technical Assistance Collaborative. (2020). Database of Vouchers for People with Disabilities. <http://www.tacinc.org/knowledge-resources/vouchers-database/>

Turnbull III, H. R., Stowe, M. J., Turnbull, A. P., & Schrandt, M. S. (2007). Public Policy and Developmental Disabilities. Handbook of developmental disabilities.

U U.S. Department of Housing and Urban Development (HUD). (2020). Housing Choice Voucher (HCV) Data Dashboard. https://www.hud.gov/program_offices/public_indian_housing/programs/hcv/dashboard

U.S. Department of Housing and Urban Development (HUD). Key HUD Statutes. (2020). Retrieved July 26, 2020 from <https://www.hud.gov/hudprograms/keystatutes>

U.S. Department of Justice. A Guide to Disability Rights Laws. (2020). Retrieved August 5, 2020 from <https://www.ada.gov/cguide.htm>

U.S. Equal Employment Opportunity Commission. The Rehabilitation Act of 1973. (2020). Retrieved August 5, 2020 from <https://www.eeoc.gov/statutes/rehabilitation-act-1973>

W Wachino V. Coverage of Housing-Related Activities and Services for Individuals with Disabilities. Center for Medicaid & CHIP Services (CMCS) Informational Bulletin. Baltimore, MD: Centers for Medicare & Medicaid Services, U.S. Department of Health and Human Services; 2015. <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-06-26-2015.pdf>.

Part 2.2 References

- A** Anderson, L. L., Larson, S. A., MapellLentz, S., & Hall-Lande, J. (2019). A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000. *Intellectual and Developmental Disabilities*, 57(5), 421-438.
- Autism and Developmental Disabilities Monitoring Network (ADDM). (2020). Community Report on Autism. Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/autism/addm-community-report/documents/addm-community-report-2020-h.pdf>.
- Autism Housing Network. (2020). Housing Directory. Retrieved August 4, 2020 from <https://www.autismhousingnetwork.org/housing/>.
- B** Bigby, C., & Fyffe, C. (2009). Position statement on housing and support for people with severe or profound intellectual disability. *Journal of Intellectual and Developmental Disability*, 34(1), 96-100.
- Bo'sher, L. (2015). Accessibility of America's Housing Stock : Analysis of the 2011 American Housing Survey (AHS) . Washington, D.C: U.S. Department of Housing and Urban Development, Office of Policy Development and Research.
- Bonardi, A., Lauer, E., Lulinski, A., Fay, M. L., Morris, A., Nygren, M. A., & Krahn, G. (2019). Unlocking the Potential of State Level Data: Opportunities to Monitor Health and Related Outcomes in People with Intellectual and Developmental Disabilities. *Intellectual and Developmental Disabilities*, 57(5), 390-404.
- Braddock, D.L., Hemp, R.E., Tanis, E.S., Wu, J. & Haffer, L. (2017). *The State of the States in Intellectual and Developmental Disabilities: 2017*. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities, Department of Psychiatry.
- Burke, M. M., Lulinski, A., Jones, J., & Gallus, K. (2018). A Review of Supports and Services for Adults with Intellectual and Developmental Disabilities (IDD) and Their Families in the United States: Past and Present Contexts Impacting Future Research, Practice and Policy. *International review of research in developmental disabilities* (Vol. 54, pp. 137-176). Academic Press.
- C** Carlson, S., Keith-Jennings, B., Chaudry, R. (2017) SNAP Provides Needed Food Assistance to Millions of People with Disabilities, Center on Budget and Policy Priorities, June 14, 2017. <https://www.cbpp.org/research/food-assistance/snap-provides-needed-food-assistance-to-millions-of-people-with>
- D** Dawkins, C., & Miller, M. (2017). The Characteristics and Unmet Housing Program Needs of Disabled HUD-Assisted Households. *Housing Policy Debate*, 27(4), 499-518.
- Disability Data Digest 2018. Medisked/Arc. www.inarf.org/uploads/2/5/1/7/25171275/august-2018-disability-data-digest-medisked.pdf.
- E** Emerson, E., Graham, H., & Hatton, C. (2006). The Measurement of Poverty and Socioeconomic Position in Research Involving People with Intellectual Disability. *International review of research in mental retardation*, 32, 77-108.
- G** Grey, J. M., Griffith, G. M., Totsika, V., & Hastings, R. P. (2015). Families' Experiences of Seeking OutofHome Accommodation for Their Adult Child with an Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 12(1), 47-57.
- Grossman, B. R., & Webb, C. E. (2016). Family Support in Late Life: A Review of the Literature on Aging, Disability, and Family Caregiving. *Journal of Family Social Work*, 19(4), 348-395.
- Grossman, B. R., & Webb, C. E. (2016). Family Support in Late Life: A Review of the Literature on Aging, Disability, and Family Caregiving. *Journal of Family Social Work*, 19(4), 348-395.
- H** H. L. (2017). Health and Healthcare Access among Adults with Autism Spectrum Disorder and Intellectual Disability 2015 - 2016. Waltham, MA: The Lurie Institute for Disability Policy - Brandeis University. Retrieved May 31, 2020, from http://lurie.brandeis.edu/pdfs/FINAL_HealthcareAccessASDandIDD_LurieDataBrief_20180109.pdf.
- Havercamp, S. M., Krahn, G. L., Larson, S. A., Fujiura, G., Goode, T. D., Kornblau, B. L., & National Health Surveillance for IDD Workgroup. (2019). Identifying People with Intellectual and Developmental Disabilities in National Population Surveys. *Intellectual and Developmental Disabilities*, 57(5), 376-389.

- L** Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Lerner, J. G., & Pollack, D. (2015). Where Have All the Developmental Centers Gone? The Federal Push for Community-Based Services for People with Intellectual and Developmental Disabilities. *Cap. UL Rev.*, 43, 751.
- Lutz, A. S. (2015, May 27). Who Decides Where Autistic Adults Live? The Atlantic. <https://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/>.
- M** Mansell, J., & Beadle-Brown, J. (2009). Dispersed or Clustered Housing for Adults with Intellectual Disability: A Systematic Review. *Journal of intellectual and developmental disability*, 34(4), 313-323.
- Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in developmental disabilities*, 30(6), 1107-1114.
- McCormick, L., Schwartz, A., & Passerini, C. (2019). Housing for People with Disabilities: A Review of State Olmstead and HUD Consolidated Plans. *Journal of Planning Education and Research*, 0739456X19844567.
- R** Residential Information Systems Project (2020). Living Arrangements: Long-Term Supports and Services (LTSS) Recipients by Setting Type and Year. Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>.
- Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Anderson, Kristy A. National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2017.
- Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.
- S** Schaak, G., Sloane, L., Arienti, F., & Zovistoski, A. (2017). Priced Out: The Housing Crisis for People with Disabilities. Boston, MA: Technical Assistance Collaborative. Retrieved May 31, 2018, from <http://www.tacinc.org/media/59493/priced-out-in-2016.pdf>
- Schwartz, A. F. (2014). *Housing policy in the United States*. Routledge.
- Sergeant, L., Dewsbury, G., & Johnstone, S. (2007). Supporting People with Complex Behavioural Difficulties and Autistic Spectrum Disorder in a Community Setting: An Inclusive Approach. *Housing, care and support*, 10(1), 23.
- Shivers, C. M., SonnierNetto, L., & Lee, G. K. (2019). Needs and Experiences of Family Caregivers of Individuals with Autism Spectrum Disorders Across the Lifespan. *Journal of Policy and Practice in Intellectual Disabilities*, 16(1), 21-29.
- Smith, S. K., Rayer, S., Smith, E., Wang, Z., & Zeng, Y. (2012). Population Aging, Disability and Housing Accessibility: Implications for Sub-National Areas in the United States. *Housing Studies*, 27(2), 252-266.
- T** Thompson, J. R., Bradley, V. J., Buntinx, W. H., Schalock, R. L., Shogren, K. A., Snell, M. E., ... & Gomez, S. C. (2009). Conceptualizing Supports and the Support Needs of People with Intellectual Disability. *Intellectual and developmental disabilities*, 47(2), 135-146.
- W** Wachino, V. Coverage of Housing-Related Activities and Services for Individuals with Disabilities. Center for Medicaid & CHIP Services (CMCS) Informational Bulletin. Baltimore, MD: Centers for Medicare & Medicaid Services, U.S. Department of Health and Human Services; 2015. <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-06-26-2015.pdf>.
- Ward, M. M. (2013). Estimating Disease Prevalence and Incidence Using Administrative Data: Some Assembly Required. *Journal of Rheumatology*, 40(8), 1241-1243. doi:10.3899/jrheum.130675.
- White, G. B. (2015, December 16). Nowhere to Go: The Housing Crisis Facing Americans with Disabilities. Retrieved August 04, 2020, from <https://www.theatlantic.com/business/archive/2015/12/renting-with-a-disability/420555/>.
- Wiesel, I. (2011). Allocating Homes for People with Intellectual Disability: Needs, Mix and Choice. *Social Policy & Administration*, 45(3), 280-298.
- Williamson, H. J., & Perkins, E. A. (2014). Family Caregivers of Adults with Intellectual and Developmental Disabilities: Outcomes Associated with U.S. Services and Supports. *Mental Retardation*, 52(2), 147-159.



Worksheets

If you are a developer, financier, advocate, policymaker, family member and/or individual with a neurodiversity, use the following worksheets with the nomenclature to dream, brainstorm, plan and take action!

A challenge related to housing and services for adults with neurodiversities is finding the right language to describe residential options and communicate individual preferences.

These worksheets are tools for exploring, designing and communicating about residential options. There is a worksheet for each section of the nomenclature: residents, properties and property development.

Each box is a category from the nomenclature. Fill in the blank spaces with terms from the nomenclature to describe yourself (if you are a resident) and/or residents (if you are a housing provider), your current home or property, and/or your dream home or property. For many categories, you may find that more than one term applies.

You may only want to complete one or two of the three worksheets.

Start wherever you wish—and go as far as you like!

Residents Worksheet

Housing developers and financiers: How would you characterize the people who live (or will live) at your development? Bridge this information with the Properties Worksheet to align property characteristics with the goals, interests and needs of the residents you serve.

Advocates and policymakers: Who are the members of your community with housing and service needs? What are their goals and funding options? Bridge this information with the Properties Worksheet to identify met and unmet housing needs.

Individuals and families: How would you describe yourself (or your loved one) to a housing provider, case manager or advocate to make sure your housing, services and supports best serve you and your goals, interests and needs? Bridge this information with the Properties Worksheet to help identify your ideal home and/or residential community.

Life Goals

Support Needs

LTSS Delivery Model

Funding Options for LTSS

Funding Options for Housing

Properties Worksheet

Housing developers: How would you characterize your current housing project? How would you develop housing for adults with neurodiversities and/or I/DD? How are you seeking input from the people—current and future residents—you intend to serve when making decisions about these property characteristics?

Advocates and policymakers: How would you describe the residential options available in your community? How would you add to or adapt existing options to meet the goals, preferences, housing needs and service needs of community members with neurodiversities and/or I/DD?

Individuals and families: How would you describe your ideal home and/or residential community?

Residents and Services*

Support Needs

LTSS Delivery Model

Target Market

Funding Options for LTSS

Funding Options for Housing

Property Characteristics

Residential Unit Type

Development Type

Lifestyle

Physical Amenities

Supportive Amenities

Property's Relationship to LTSS

Payment Model

Private vs. Shared Residence

Availability

*Sections in orange may have already been identified in Resident Worksheet on page 195.

Property Development Worksheet

Housing developers: What ingredients did you (or would you) leverage to develop a housing project for adults with neurodiversities?

Advocates and policymakers: What ingredients for property development are available in your community? How would you add to or adapt existing ingredients to help meet the goals, preferences, housing needs and service needs of community members with neurodiversities and/or I/DD?

Individuals and families: How would you leverage resources for property development to provide more residential options in your community?

<div>Developer Type</div>	<div>Financial Stack</div>
<div>Land Source & Incentives</div>	
<div>For Sale or Rent</div>	

Residents Nomenclature

Life goals

- Learn life skills
- Grow in independence
- Build relationships
- Get and maintain a job
- Participate as a member of the greater community
- Achieve stability
- Be safe at home
- Find a permanent home

Support needs

- No support needs
- Drop-in support
- Low support
- Moderate support
- 24/7 support
- Daily medical support
- Memory care
- High behavioral support
- One-on-one support

LTSS delivery model*

- Agency-based rotational staffing
- Host home
- Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID)
- Natural supports
- Not applicable
- Paid neighbor
- Remote support
- Residential transition program
- Self-directed support
- Shared living

Funding options for LTSS*

- Medicaid Home and Community-Based Services (HCBS) waiver
- Medicaid Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID)
- Medicare
- Not applicable
- Private pay

Funding options for housing

- Bequest
- Down payment assistance
- Home loan
- Homeownership Voucher Program
- Housing Choice Voucher (HCV) Program
- Mortgage
- Private pay
- Rental assistance
- Single Family Housing Programs

*LTSS refers to Long-Term Services and Supports.

Properties Nomenclature

Target Market

- Adults with autism
- Adults with disabilities
- Adults with intellectual and developmental disabilities (I/DD)
- Adults with high support needs
- Families
- General market
- Intergenerational
- Low-income residents
- Multigenerational
- Neurodiverse adults
- Seniors
- Students

Property's Relationship to LTSS

- Consumer-controlled setting
- Provider-controlled setting
- Hybrid setting

Residential Unit Type

- Tiny home
- Accessory dwelling unit (ADU)
- Apartment
- Townhouse
- Condominium
- Manufactured home
- Single-family home
- Adaptable home
- Single room occupancy (SRO)
- Dormitory
- Facility-based setting

Development Type

- Scattered site
- Mixed-use development
- Cohousing community
- Group living
- Planned community
- Student housing
- Group home
- Other residential facility for people with I/DD
- Assisted living
- Nursing home

Lifestyle

- Active-living community
- Agricultural/ranching community
- Faith-based community
- Intentional community
- Live-Work-Play
- Personal preference
- Pet-friendly

Private vs. Shared Residence

- Private Residence
- Shared with housemate(s)

Physical Amenities

- Accessible design
- Adaptable design
- Cognitive accessibility features
- Common area space
- Easy-to-clean features
- Extra-durable features
- Recreational amenities
- Relaxation amenities
- Pedestrian-oriented
- Personal preference
- Security features
- Sensory-friendly design
- Smart-home features
- Transit access
- Universal design

Supportive Amenities

- Benefits counseling
- Community life
- Community navigator
- Health and fitness activities
- Housekeeping service
- Life-skills training
- Meal service
- Personal preference
- Resident assistant
- Workplace and vocational support

Payment Model

- Rental/lease
- Affordable rental/lease
- Tuition-based
- Cooperative ownership
- Subsidized homeownership
- Group ownership
- Individual ownership

Availability

- Planning stages
- Pre-development
- Pre-sales/leasing
- Available
- Waitlist

Property Development Nomenclature

Developer Type

- Joint venture
- Nonprofit developer
- Private developer

Financial Stack

- Affordable Multifamily Housing Bonds
- Capital campaign
- Charitable campaign
- Community Development Block Grant (CDBG) Programs
- Community Development Financial Institutions (CDFI) Fund
- Grants
- Home Investment Partnerships Program (HOME) Program
- Housing Finance Agencies
- Housing Trust Fund (HTF)
- Impact investment
- Low-Income Housing Tax Credit (LIHTC)
- Multi-Family Housing Programs
- New Markets Tax Credit (NMTC) Program
- Philanthropic gifts
- Private capital
- Private sector loan
- Rural Rental Housing Loans (Section 515)
- Section 811 Supportive Housing for Persons with Disabilities Program
 - Capital Advance
 - Project Rental Assistance

Land Source & Incentives

- Bequest
- Community Land Trust
- Donation
- Land Lease
- Place-based tax incentives
- Publicly owned property
- Purchase

For Sale or Rent

- Rental/lease
- Affordable rental/lease
- Homeownership
- Affordable homeownership
- Mixed model



aplaceintheworld.org