Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities

October 21-22, 2020
Welcome & Introductions

Developing a New Generation of Housing Options for People with Autism and Neurodiversities

Denise D. Resnik  
Founder & President/CEO

Desiree Kameka Galloway  
Director

FirstPlace

Autism Housing Network
Agenda

October 21, 2020

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Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities

The universal language to research, develop and achieve supportive housing solutions.
Welcome & Importance of Building a Marketplace of Options

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

“Housing and community options for special populations are today where the senior housing industry started 50 years ago. We still have much to do to create a marketplace of options, recognizing that, like age, diagnosis alone does not determine an individual’s home needs or preferences.”
Asking Tough Questions

Looking up and out to marketplace principles and the evolution of other sectors for answers
The First Place Global Leadership Institute Addresses 10 Priority Issues

- Quality of Life
- Isolation
- Housing Crisis
- Business Models
- Support Staff
- Public Policy
- Research
- Adult Medical Care
- Technology Platforms
- Heterogeneity
“For millions of adults with autism, ‘the next empty bed’ should not be the only option. By bridging innovation across different industries, we can create an array of neuro-inclusive housing opportunities that benefit everyone in communities across the country.”
It has been estimated that 30%–40% of homeless adults have a cognitive impairment, including people with intellectual disabilities (ID).

Innovators are creating solutions—but need to scale!

# OF ADULTS LIVING WITH FAMILY

5.4M

# OF PEOPLE LIVING WITH A FAMILY CAREGIVER OVER 60

1.3M

ANNUAL GROWTH

~15k

We have designed *A Place in the World* as the go-to source.
Leadership Advisory Board
Leadership Advisory Board
Leadership Advisory Board Members

- 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 Blackbourn, 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
- 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, 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
- Marci Muhlestein, Director, First Place Global Leadership Institute Center For Education, Training & Employment
- 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
Lead Partners

United Healthcare Community Plan

PHOENIXIDA
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.
Making the Case to Community Partners

Amy Pawlowski & Juan Salgado
Lead Partners
Health Starts at Home

Amy Pawlowski
Executive Director, Complex Care
United Healthcare Community Plan

“Helping individuals with a range of different abilities live the healthiest, happiest, most integrated lives possible drives me every day. I'm excited to be a part of advancing the healthcare delivery system to work better for everyone.”
Community Development & Opportunities for All

Juan Salgado
Chief Executive Officer
Phoenix IDA/Phoenix Community Development & Investment Corporation

“Building communities that provide housing for all members of our diverse population is part of our mission. We are pleased to provide support for such a groundbreaking study and look forward to its results.”
Federal Shortcomings & Gaps in the System

Andrea Whitsett
Director
ASU Morrison Institute for Public Policy

“We want 'A Place in the World' to inform the decision-making happening in the community and at the same time inspire future scholars who select this type of research for their career paths.”
Federal Shortcomings & Gaps in the System

Andrea Whitsett & Desiree Kameka Galloway
Our mission is to produce independent, consequential public policy research and facilitate knowledge exchange to advance solutions for Arizona and beyond. We conduct research that is informed by and in service to the community.
Alison Cook-Davis  
Associate Director for Research

Chrissie Bausch  
Analyst
“There is not just a housing gap, but a legitimate housing crisis facing adults with autism and other cognitive disabilities. Distinct policy actions—and inaction—influence how we understand and measure the adequacy of housing and services for neurodiverse adults.”
Growth of Consumer-Controlled Service Delivery

Introduction of Home and Community-Based Services (1980)

Growth of Consumer-Controlled Service Delivery

Neuro-Inclusive Housing Stock Emerging
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
September 2020

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

Pooja Paode Daniel Jordan Fiddle Foundation Public Policy Fellow
August 2020
The Daniel Jordan Fiddle Foundation Reports on Public Policy

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
September 2020

- No landmark policy focused on housing assistance for adults with autism and/or I/DD
- Disability-specific HUD initiatives provided fewer than 120,000 affordable units total, fraction of demand:
  - 80,000 NED vouchers
  - 33,000 Section 811 units
- Identifies barriers in Medicaid LTSS; eligibility, waitlists, funding caps, etc.
- Other barriers to current housing stock; inaccessibility for residents with high support needs, discrimination, tenant retention, etc.
● Identifies gaps in current data collection
● Barriers in data:
  ○ Data excludes non-LTSS recipients.
  ○ Data does not reflect functional support needs.
  ○ Lack of consistent operational terms to collect valuable market data exists.
  ○ Housing accessibility data is ADA specific, excludes I/DD-specific data points.

Better data is needed to move beyond deinstitutionalization alone and toward access to diverse, affordable residential options.
Moving Forward Together with Data

Show Demand  Drive Solutions  Analyze Outcomes  Understand Who Is Falling Through the Cracks
Poll

What is the biggest obstacle in your way?

(check all that apply)
Speaking the Same Language

Bridging Diverse Strategies for Addressing National Housing Needs

Chrissie Bausch, PhD
October 21, 2020
Why is shared language important?

- **Articulate** market supply & demand
- **Include** the full range of support needs
- **Increase** choice, supply & access
- **Enable** data collection & comparison
- **Facilitate** evidence-based solutions
- **Inspire** innovation, collaboration & investment
- **Inform** decision-makers & stakeholders
- **Prioritize** quality of life
Part 1: Developing a New Generation of Housing Options

- Background: A Growing Market
- Methods
- Nomenclature
- Housing Market Guide
- Promising Practices

Part 2: Public Policy

Part 3: Call to Action

Appendix: Worksheets

Elements of Report
Part 1: Developing a New Generation of Housing Options

➔ Background: A Growing Market
➔ Methods
➔ Nomenclature
➔ Housing Market Guide
➔ Promising Practices

Part 2: Public Policy
Part 3: Next Steps
Appendix: Worksheets

Focus of Presentation
## Development & Methods

*More Than a Decade in the Making*

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<th>Qualitative Review</th>
<th>Synthesis</th>
<th>Testing &amp; Review</th>
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<tr>
<td>Laid by <em>Opening Doors</em> (SARRC, ULI, ASU), First Place Global Leadership Institute, Autism Housing Network, Think Tanks, Leadership Advisory Board</td>
<td>Secondary sources, government programs, interviews</td>
<td>Following four guiding principles</td>
<td>Is the report accurate, clear, useful, and comprehensive?</td>
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Foundational Sources

Opening Doors
A discussion of Residential Options for Adults Living with Autism and Related Disorders, Urban Land Institute Arizona, Southwest Autism Research & Resource Center, Arizona State University (2009)

Housing & Community Worksheets
Led by Autism Housing Network and First Place Global Leadership Institute

Think Tanks
Informed discussions with Leadership Advisory Board and experts in industry, advocacy and research, 2018-19 (approximately 100 participants)
Qualitative Review

Secondary Sources
Housing, services, special populations
- 120+ reports, websites, etc. from government, advocacy, research, industry
- *Special populations*: autism, Down syndrome, intellectual and developmental disabilities (I/DD), physical disability, seniors, HIV/AIDS, veterans

In-Depth Interviews
Experts from:
- Advocacy
- Architecture/design
- Finance
- Individuals with autism
- Parents of adults with autism
- Real estate development
- Research
- Service & support provision
Synthesis: 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
Testing & Review: Leadership Advisory Board
Nomenclature Framework

Residents
- Life goals
- Support needs
- LTSS delivery model
- Funding options for LTSS
- Funding options for housing

Property Development
- Developer type
- Financial stack
- Land source & incentives
- For sale or rent

Properties
- Target market
- Relationship to LTSS
- Residential unit type
- Development type
- Lifestyle
- Private vs. shared residence
- Physical amenities
- Supportive amenities
- Payment model
- Availability

*LTSS = Long-Term Services & Supports
**Residents Nomenclature**

<table>
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<tr>
<th>Life goals</th>
<th>Support needs</th>
<th>LTSS disability model:</th>
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<tr>
<td>Learn life skills</td>
<td>No support needs</td>
<td>Agency-based rotational staffing</td>
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<td>Grow in independence</td>
<td>Deep-in support</td>
<td>Host Home</td>
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<tr>
<td>Build relationships</td>
<td>Low support</td>
<td>Intermediate Care Facilities for Individuals with Intellectual Disability (ICF-ID)</td>
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<tr>
<td>Get and maintain a job</td>
<td>Moderate support</td>
<td>Natural supports</td>
</tr>
<tr>
<td>Participate as a member of the greater community</td>
<td>Low support</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Achieve stability</td>
<td>Moderate support</td>
<td>Field neighbor</td>
</tr>
<tr>
<td>Be safe at home</td>
<td>Daily meals support</td>
<td>Remote support</td>
</tr>
<tr>
<td>Find a permanent home</td>
<td>Memory care</td>
<td>Residential transition program</td>
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<tr>
<td></td>
<td>High behavioral support</td>
<td>Self-directed support</td>
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<tr>
<td></td>
<td>One-on-one support</td>
<td>Shared Living</td>
</tr>
</tbody>
</table>

**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:**
- Section 8
- Home loan
- Homeownership Voucher Program
- Housing Choice Voucher (HCV) Program
- Mortgage
- Private pay
- Rental assistance
- Single Family Housing Programs

**Properties Nomenclature**

<table>
<thead>
<tr>
<th>Target Market</th>
<th>Property's Relationship to LTSS</th>
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<tr>
<td>Adults with autism</td>
<td>Consumer-controlled setting</td>
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<td>Adults with disabilities</td>
<td>Provider-controlled setting</td>
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<td>Adults with intellectual and developmental disabilities</td>
<td>Hybrid setting</td>
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**Residential Unit Type:**
- Tiny home
- Accessory dwelling unit (ADU)
- Apartment
- Condominium
- Manufactured home
- Single-family home
- Apartments
- Single room occupancy (SRO)
- Dormitory
- Facility-based setting

**Development Type:**
- Scattered site
- Mixed-use development
- Elderly-only community
- Group living
- Planned community
- Young adult
- 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
- Intellectual community
- Live-style/Play
- Personal preference
- Feelacency

**Physical Attributes:**
- Accessible design
- Acceptable design
- Cognitive accessibility features
- Common area space
- Easy-to-clean features
- Extensive features
- Recreational features
- Restroom amenities
- Restroom-covers
- Personal preference
- Security features
- Safety-sensitive design
- Smart home features
- Transit access
- Universal design

**Supportive Amenities:**
- Benefits counseling
- Community life
- Community navigation
- Health and fitness activities
- Housekeeping services
- Life-skills training
- Meal service
- Personal preference
- Resident assistant
- Workplace and vocational support

**Property Development Nomenclature**

<table>
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<th>Developer Type</th>
<th>Financial Stack</th>
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<td>Joint venture</td>
<td>Affordable Multifamily Housing Bonds</td>
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<td>Private developer</td>
<td>Charitable campaigns</td>
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**Land Source & Incentives:**
- Section 8
- Affordable Multifamily Housing Bonds
- 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
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.) [1][2]. 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.

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 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 waivers 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].
Physical Amenities

Physical amenities are built features of the residential unit, building and/or development that make life easier and more enjoyable for residents [3]. 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 [71]. Adaptable design includes many age-in-place features [72].

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 [72].

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 systems and more [18], [13].

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 [13].
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 soaks, 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 [72]. Universal design includes many age-in-place features [72].
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 (2a). 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 (2a).

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 and dusting 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.
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 needed
- Deep in support
- Moderate support
- Light support
- Daily medical support
- Memory care
- High behavioral support
- One-on-one support

LTSS subsidy model
- Adults with autism
- Adults with disabilities
- Adults with intellectual and developmental disabilities (ID/DD)
- Adults with high support needs
- Family
- General market
- Intergenerational
- Low-income residents
- Multigenerational
- Multifamily
- No-model 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
- Accessory home
- Single-room occupancy (SRO)
- Dormitory
- Facility-based setting

Development Type
- Assisted living
- Independent living
- Co-housing community
- Group living
- Planned community
- Student housing
- Group home
- Other residential facility for people with ID/DD
- Assisted living
- Nursing home

Lifestyle
- Active living community
- Agricultural/ranching community
- Faith-based community
- Intellectual community
- Live-work-play
- Personal preference
- Fit-for-tenancy

Properties Nomenclature

Target Market
- Adults with autism
- Adults with disabilities
- Adults with intellectual and developmental disabilities (ID/DD)
- Adults with high support needs
- Family
- General market
- Intergenerational
- Low-income residents
- Multigenerational
- Multifamily
- No-model adults
- Seniors
- Students

Private vs. Shared Residence
- Private Residence
- Shared with housemates

Physical Attributes
- Accessible design
- Adequate design
- Cognitive accessibility features
- Common area space
- Easy-to-clean features
- Entertainable features
- Recreational amenities
- Recreation amenities
- Resident-created
- Personal preference
- Security features
- Sensory-friendly design
- Smart-home features
- Transport access
- Universal design

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

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
- Grant
- Home Investment Partnerships Program (H.I.P.P) 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 loans
- Rural Rental Housing Loans (ELECTION 23)

Land Source & Incentives
- Biogas
- Community Land Trust
- Donation
- Land lease
- Place-based tax incentives
- Publicly owned property
- Purchase

Fair Sale or Rent
- Rental/lease
- Affordable rental/lease
- Homeownership
- Affordable homeownership
- Mixed model
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 ASD have access to smart home technology and other supportive 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 pool, community room and fitness center, residents have access to the Faison Center’s 50,000-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
- Late 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

Richmond, Virginia
faisoncenter.org/the-faison-residence
Property Snapshot (cont.)

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
Bergen County’s United Way
Madeline Housing Partners, LLC

Northeast New Jersey bergenunitedway.org

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.”

Through the Very Special Housing program, their partnership provides over 139 affordable housing units across 28 separate projects, including condominiums for first-time homeowners, senior citizens’ 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 Torino, 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, he felt, was not to study it, but to increase the supply of homes that people could afford. He started to do that about 15 years ago and then when it was brought to his attention the 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 Torino, “We’ve managed to flip the equation or the conversation 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 Alliedville, New Jersey received the 2010 Governor’s Excellence in Housing Award for Best Supportive Housing. A special needs housing in Ramsey was awarded the 2010 Community Housing Award from the Supportive Housing Association of New Jersey.

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 populations. According to Tom Torino, part of what makes Very Special Homes innovative is “the ability to be more flexible, to put different packages together, to pool capital across various partners to mix populations within one site or to subsidize another within a site, and to aid separate populations, but to house in a common community rooms. Our ability to mix seniors, with folks with intellectual 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.”
Thank you!

Chrissie Bausch, PhD
jcbausch@asu.edu
Poll

How will *A Place in the World* be useful to you in the short/long term?

*(check all that apply)*
Better Data, Better Policy

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

Desiree Kameka Galloway
Director
Autism Housing Network
Data to Drive the Marketplace

PROJECT-SPECIFIC DATA

LOCAL COMMUNITY DEMAND DATA
Lessons Learned:

● Ensure shared understanding of terms (*A Place in the World* as a guide with training).
● Collect only the data you need.
● Share with a small cohort to clarify confusing questions.
● Identify those at risk of being under-represented.
● Use plain language for a self-advocate survey.
● Specify “interest survey” (not an application).
A comprehensive, 32-course curriculum focusing on employment and life skills. Each semester-length course comprises 17 modules. Information learned from courses is implemented in daily life.
Outcomes are based on First Place Transition Academy program operated by the Southwest Autism Research & Resource Center (SARRC), including the Learn4Independence® curriculum.

**TRANSITION ACADEMY OUTCOMES**

- **58% of graduates had never been employed prior to enrollment.**
- **81% were employed upon graduation.**
- **42% of graduates are from out of state.**
- **84% live in their community of choice after program completion.**
- **29% of graduates tried living outside family home prior to enrollment.**
- **35% chose to live at a First Place property.**

**Transition Academy Graduate Employers**
- Arizona Animal Welfare League
- Arizona Autism Charter School
- Arizona Diamondbacks
- Arizona School Boards Association
- Arizona School for the Arts
- Knight Transportation
- Lo-Lo’s Chicken & Waffles
- Omni Biocutical Innovations
- SSP America (Warehouses)
- The Precisionists, Inc.
- TJ Maxx

**Graduate Skills**
- Achieving personal goals
- Connecting regularly with others
- Maintaining an apartment
- Preparing for a job search
- Navigating the community
- Planning & implementing based on weekly needs

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Earning Public Support

innovation sometimes necessitates a certain amount of disruption — shaking up the status quo, breaking away from the confines of public policy and hoping around and over roadblocks until we can inspire a new, more effective direction.

As one example, the relationship between SARRC and RIMPAC is a testament to the benefits — and results — of joining forces as innovative change agents in the field of autism. It hasn’t happened overnight, considering SARRC was founded 10 years ago and RIMPAC just seven years ago.

One of our shared goals of supporting individuals with autism and other neuro-differences and their families throughout their lifetimes — with the clearest for many children in education, housing, healthcare and career opportunities leading to greater independence — strengthens collaboration among the philanthropic, public, private and nonprofit sectors and its ultimate impact.

Consider that SARRC’s early intervention programs started through philanthropic funding, allowing us to develop, develop and create models and learn what works and what doesn’t. Working with our board, we are creating a school demonstrating an intensive early-intervention program in a more natural classroom environment for children with and without autism at a fraction of the cost and with better outcomes.

Founded in 2001, the Community School at SARRC was funded-through a three-year “demonstration grant” from the State of Arizona. Favorable results enabled it to work with a broader community to pass Arizona legislation allowing families to pay for the Community School program using insurance benefits. Today, the school is one of SARRC’s most successful programs, with a doubling in the number of classrooms since it opened, an expansion into its second year and a robust student body.

Looking forward, and consider that RIMPAC and SARRC continue to innovatively with a critical group of students and the new model for four years of operating the RIMPAC Transition Academy as a private pay and philanthropically supported enterprise, several participants are members of the Arizona Department of Developmental Disabilities have the opportunity to apply a portion of their Arizona Long-Term Care program support to Academy tuition. This is a positive step toward offering a more sustainable and inclusive program.

Both organizations are the result of collective perseverance and engaged inter-agency leadership, creating the social capital that helps us innovate, learn, collaborate and ultimately succeed. We are particularly grateful for the teamwork led by visionaries like the Arizona Department of Economic Security Director Michael Turner, a long-time supporter of our work who has consistently challenged us to overcome roadblocks and consider “new government can make sense of it all” through new opportunities at a fraction of the cost with better outcomes and more hopeful futures.

Despite capital facilitators connections and cooperation, helping build a framework for change for the better. Together, SARRC and RIMPAC are a powerful force for social change when innovation demonstrates meaningful, improved quality of life and economic outcomes — to the benefit of us all.

For more information about RIMPAC, visit rimpacinc.org.
"Ensure no stone goes unturned and no data point overlooked in the pursuit of exceptional results. Sound research and precise measurement have never been more important for achieving authenticity in your business, marketing and PR."
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.

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 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 individuals in 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 services providers, and the development of supportive housing 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 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 diagnostic 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, sustained and healthy dimension of housing markets in communities everywhere.
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Thank you!

We welcome your feedback and questions:
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