



**IACC Workshop:
Addressing the Housing Needs of People on the Autism Spectrum
July 2019
Meeting Summary**

Background

During the Autism CARES Act of 2014 authorization period, the IACC voted to convene a working group to address housing concerns among individuals on the autism spectrum and their families. The goal of the Working Group was to research best practices on housing, review implementation of current federal regulations, and address housing issues faced by autistic individuals, including those with more severe disabilities. The mission statement for the Working Group states:

In the autism community we face a mounting housing crisis, with a growing population of autistic adults with diverse needs lacking appropriate living situations. The goal of this working group is to examine a wide variety of housing options and service models for people with autism, and to develop strategies to achieve a broad array of supported housing options through-out all of our communities that enable autistic individuals to achieve person-centered outcomes.

The Working Group convened in 2019, beginning with a conference call in June to discuss potential activities to improve housing issues. The Working Group decided to organize a workshop in July 2019 that would address the housing needs of people on the spectrum. The workshop included advocates in the community that have established different successful housing models for individuals with autism across the spectrum. This Update will include highlights presented and discussed at the workshop.

Members of the IACC discussed the outcome of the workshop at their July 2019 full committee meeting, which was the last IACC meeting to be held under the Autism CARES Act of 2014, and decided

that the issues highlighted at the workshop will serve as an excellent base for the next iteration of the IACC to consider further activities and action related to housing for people on the autism spectrum.

Highlights from the IACC Workshop: Addressing the Housing Needs of People on the Autism Spectrum

On July 23, 2019, the Interagency Autism Coordinating Committee (IACC) Housing Working Group convened a workshop to address housing issues for people on the autism spectrum. The Working Group aimed to explore housing options and person-centered outcomes for a diverse population of people with autism spectrum disorder (ASD) across the lifespan, whose housing opportunities are often limited. Four main topics related to addressing housing issues were discussed at the workshop, with the goal of representing several diverse and innovative models of housing and housing-related services to meet the needs of people on the autism spectrum:

- Overview of Housing Issues
- Intentional Community Models
- Apartment/Dispersed Community and Service Delivery Models
- Personalized Adult Services and Housing Navigation

For each topic, there were presentations on current housing models and development efforts.

Descriptions of specific housing programs were meant to be illustrative of the range of existing models and do not represent specific endorsement by the IACC. Presentations were followed by a thorough discussion of the gaps, needs, and hopes for future research and services in that area. The workshop participants also discussed potential options for the IACC's involvement in alleviating the challenges related to housing needs for people with ASD. The discussions of each topic are summarized below.

Overview of Housing Issues

Heidi Eschenbacher, Ph.D.

Researcher, Institute on Community Integration, University of Minnesota

Desiree Kameka, M.T.S.

Director of Community Education & Advocacy, Madison House Autism Foundation

Presentation Highlights

Dr. Eschenbacher reviewed the [Residential Information Systems Project \(RISP\)](#), an ongoing initiative to study the long-term services and supports used by people with intellectual and developmental disabilities (IDD). In the United States, about 17 percent of people with IDD receive services for residential and associated supports through IDD agencies, but this estimate varies drastically across states. Most of the individuals who receive these long-term services and supports are funded by a Medicaid Alternative Care Facility (ACF) waiver or Intermediate Care Facility (ICF) waiver. In 2016, the average funding cost for a Medicaid Waiver across all age groups was just under \$44,000, and in some states, most of this funding is allocated towards community care facilities. Dr. Eschenbacher also presented data from the National Core Indicators (NCI), which includes autism-specific data. The NCI data indicates that while more than half of adults with ASD receive services in a parent's or family member's home, they would prefer to live elsewhere and that personal autonomy is a critical factor.

Ms. Kameka discussed recent trends and insights from the [Autism Housing Network \(AHN\)](#). She explained that a lack of residential supports has left many adults with ASD vulnerable to isolation, homelessness, abuse, and financial stress. AHN launched the Empowering Communities Initiative (ECI), which educates people on the autism spectrum and their families about housing and support options in their communities. The ECI surveyed 126 people with ASD in Colorado about their support needs. Individuals reported requiring one-on-one provider support, services that promote social interaction, accessible transportation, and planned community resources. However, the data also revealed that many people with ASD and their families are unaware of current options, indicating a disconnect between autistic adults, their caregivers, and the service system. Ms. Kameka pointed out that states have an obligation to meet these needs while preventing forced institutionalization and abuse. Existing efforts (such as ECI) to address these issues are promising indicators that the ASD housing crisis can be solved with ongoing stakeholder collaboration and advocacy.

Discussion of Challenges and Desired Outcomes

Workshop participants addressed the need for increased and improved data collection related to housing and ASD. There is a lack of data on housing funding, the current living situations and conditions for individuals with autism, as well as information on quality of life factors. Current data do not typically compare different housing models, leaving policymakers to regulate housing based on personal values rather than objective measures. Additionally, most of the data about homelessness

and ASD comes from the United Kingdom, indicating a need for increased attention to homelessness of individuals with ASD in the United States. The participants also expressed concern that nonverbal people with ASD may be underrepresented in the data, particularly when researchers use means of data collection that do not provide accommodations for communication barriers.

The workshop participants also discussed the concern that too few people with ASD receive supports that meet all of their needs, and it was suggested that Medicaid waivers could be revised to ensure that services are not "cherry picked." However, they note that it is important to consider that the [Housing & Community Based Services \(HCBS\) Final Rule](#) does not officially designate a comprehensive listing of needs and services, and the data may not accurately capture the scope of long-term services and supports that people with ASD actually require and receive.

Intentional Community Models

Denise Resnik

CEO and Co-Founder, DRA Collective

Krista Mason

Executive Director, Benjamin's Hope

Terry Hamlin, Ed.D.

Associate Executive Director, Center for Discovery

Lindsay Johnson

Director of Policy and Partnerships, The Kelsey

Presentation Highlights

Ms. Resnik discussed [First Place AZ](#), a specialized apartment complex in Arizona designed to foster community and independence for neurodiverse people. The program provides a curriculum of practical skills to teach residents about finance, technology, and communication. First Place AZ reports that among individuals who graduate from the facility's transition program, 94 percent are able to sustain gainful employment and 89 percent become able to thrive outside of their family home. In addition, the First Place AZ facility supports the First Place Global Leadership Institute, which collaborates with

international experts and industry leaders to address priority issues in housing and IDD. The apartment complex receives funding from philanthropy, private investors, and new markets tax credits.

Ms. Mason is a parent of a young adult with ASD, named Ben, and the co-founder of [Benjamin's Hope](#), a farmstead community in Michigan that offers care and community to 33 adults with intellectual and developmental disabilities (IDD). The organization takes a "whole-person" approach to care, helping residents to engage with the community, health and wellness, the arts, and spirituality. In addition to gardening and caring for animals, residents at Benjamin's Hope volunteer at the local museum and hospital. Medicaid funding covers about 75 percent of the program's care-related costs, which range from \$4,000 to \$8,000 depending on the resident's care needs. The remaining costs are covered by charitable giving.

Dr. Hamlin is the associate executive director at the [Center for Discovery](#), a rural continuous learning program for autistic individuals with severe, aggressive, or maladaptive behaviors in New York. At the Center, members understand that lifestyle and environment significantly impact wellbeing among people with autism. The Center collaborated with autistic self-advocate Temple Grandin to design homes that promote privacy and reduce stress, including elements such as private bathrooms, natural light, and muted color palettes. The Center for Discovery also aims to improve health and wellbeing by ensuring that residents receive an organic whole food diet, on-site medical care, regular exercise, sleep hygiene, social connectedness, and limited exposure to environmental toxins. Currently, the Center supports 1,200 individuals, including 336 who currently live in-residence. In addition to housing, the Center also houses a research institute where ASD and its co-occurring conditions are studied. The Center is collaborating with the local town and relies on significant philanthropic donations to fund new facilities.

Ms. Johnson discussed [The Kelsey](#), a residential community in the Bay Area of California that serves individuals with and without disabilities across a wide range of incomes. The program recently convened a three-part stakeholder workshop to develop actionable solutions for scaling and sustaining these residential models. Their top priorities included finding permanent funding sources for IDD housing issues and piloting inclusive communities in the Bay Area. Ms. Johnson explained that although city developers are interested in creating diverse, affordable housing, they need guidance from inclusion-minded organizations. The Kelsey model addresses three primary barriers to care: affordability, accessibility, and inclusivity. Ms. Johnson encouraged communities and disability

advocates to form partnerships to address and overcome these barriers. The Kelsey is funded through a blend of public and private funding, as well as a significant donation from the Chan Zuckerberg Initiative.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed issues related to cost of living and employment. Ms. Resnik described the efforts of First Place AZ to address some of these issues, by creating jobs for people with and without ASD. They are also including the voices of people on the autism spectrum by working with an IT firm that employs individuals with ASD.

Workshop participants expressed concern about the costs associated with supportive housing, suggesting that community organizers might consider developing models that rely on existing amenities in order to cut down on costs. Ms. Resnik mentioned that the typical cost of supports, community life, amenities, and home at First Place AZ is about \$3,800, which is not significantly more than the average cost through Medicaid at \$3,600. She said they are working with policymakers to begin to blend public and private funds based on proof points.

Apartment/Dispersed Community and Service Delivery Models

Jim Whittaker

President/CEO, The Arc Jacksonville

Maedi Tanham Carney

Founder and Executive Director, Integrated Living Opportunities

Mary Anderson

Executive Director, ABLE Inc.

Presentation Highlights

Mr. Whittaker described [The Arc Jacksonville Village](#), a residential community in Florida serving 120 individuals with IDD through a non-structured, independence-focused living program. The Village was designed with input from family members who wanted to ensure that their children have opportunities for social engagement and inclusion. Accordingly, the community offers classes, dining services, a fitness center, a movie theater, a game room, and other services. The community fosters a spirit of

independence by allowing residents to come and go without restriction, while maintaining campus safety. Mr. Whittaker explained that the Arc Jacksonville is able to offer apartments at rents substantially lower than others in the area because it receives funding support from a blend of public, private, and nonprofit partnerships—including affordable housing federal tax credits, government grants, corporate grants, and foundations.

Mr. Osborne next talked about the [Faison Residence](#), an inclusive semi-independent apartment complex and community for adults with ASD in Virginia. The program promotes autonomous living by offering support systems without continually monitoring residents. To ensure that residents remain safe and healthy, first responders and other service providers also live in the apartment complex. Although staff members offer a few supportive services, residents must demonstrate some life skills such as the ability to cook, clean, and manage their own care. The community also offers an educational program to teach valuable independent living skills, such as learning to use public transportation or ride-sharing. The Faison Residence remains committed to meeting residents' needs while promoting personal growth, stability, and autonomy. The facility accepts Medicaid Waivers, housing vouchers, private insurance, and private pay.

Ms. Tanham Carney discussed [Integrated Living Opportunities \(ILO\)](#), a non-profit organization in the Washington, DC area that helps families develop support networks to enable people with IDD to live as integrated, contributing members of the community. Each family-centered community village at ILO is called a "pod." Family members convene here twice a month to discuss their needs with a Community Builder, a staff member trained to help residents navigate the community. Before moving into the community, potential residents take a Life Process Skills assessment and receive personalized support from staff Life Coaches. The organization is working to become sustainable in the long term with continuous support from grant and foundation funding.

Ms. Anderson discussed [ABLE Inc.](#), an assisted living community dedicated to serving adults with IDD in North Dakota. The program emphasizes the importance of affordable housing options for individuals on the autism spectrum. Ms. Anderson explained that in the early days of ABLE Inc., the program only had the capabilities to provide multi-family group homes. However, they discovered that the group living structure caused problems among roommates, who often had incompatible personalities or incompatible financial means. They used these lessons learned to build a new apartment complex designed specifically for their community, using a proximity housing model rather than a scattered

housing model. Ms. Anderson said that despite these recent successes, ABLE Inc. still struggles to secure adequate resources and staffing support.

Personalized Adult Services and Housing Navigation

Gail Godwin, M.A.

Executive Director, Shared Support Maryland

Presentation Highlights

Ms. Godwin discussed her experiences as executive director of [Shared Support Maryland](#), where she provides personalized housing support to people with severe disabilities. The program currently supports 110 people, 45 of whom identify as autistic. Ms. Godwin explained that although Shared Support Maryland has no assets or real estate, the model successfully helps individuals gain control and responsibility over their own housing. The program recognizes that one of the housing issues among people with IDD is that individuals lack the resources to connect with landlords or realtors—despite an abundance of housing programs and vacant homes. In general, Shared Support Maryland aims to provide people with IDD with the same set of tools and resources that all individuals use to independently manage their own housing and community settings.

Discussion of Challenges and Desired Outcomes

The workshop participants discussed the recurring theme of housing and support costs. Some participants suggested that housing itself is a small portion of overall costs and remains similar across most housing models—the most significant increases and variations in cost are the result of individualized services, particularly for severely affected individuals who require the most significant supports. To address the costs of housing and services delivered, Ms. Godwin noted that her organization has developed prosperous relationships with funders and other organizations by holding annual fundraisers and offering for-fee state certification and training services.

The participants also discussed the topic of supporting romantic relationships among residents. Service providers explained that most community living settings have some couples (both married and unmarried) and that these relationships do not pose an issue. However, some long-term couples may face regulatory barriers to combining their funding and supports.

Summary

The workshop offered an opportunity to view several housing models at different care levels and different levels of integration into the community. Throughout the workshop, it was clearly expressed that adults with autism want autonomy and the opportunity to make their own choices about their housing. Yet, it was also discussed that there is a need for more options for autistic people with severe disability who cannot function in places requiring a higher level of independence than they can manage. Workshop participants agreed there is a need for a diverse set of options for the diverse population; the autism spectrum is heterogenous and includes people who need a high degree of supervision or care, and also includes adults who may need some support but can otherwise function independently and may be harmed by overly intrusive support.

There was an underlying theme of cost throughout the workshop. Many of the presenters described the difficulty in obtaining funding to build residences; additionally, many self-advocates and family members expressed concerns about the costs of some of the housing model options in their communities. Based on the discussion, the cost of the physical structure of a home seems relatively constant across the different models; instead, cost differences are based predominantly on the varying services and supports that are provided in the residences. However, there were many successful models that used different means of funding to support housing and services costs as well as maintain an affordable lifestyle for the tenants. While many of the models excel at providing quality housing for people with ASD, it was also noted that it may be challenging to scale these models to the capacity needed to accommodate this growing population. Future considerations should address the scalability, sustainability, and funding for replication projects.

It is important to recognize that there are many differences in state laws that may make it challenging to replicate successful models. The working group members agreed that there is a need for better understanding of the state-by-state differences. They also spoke of the challenges of housing service delivery, such as maintaining high quality direct support staff. In addition, program service providers often bundle services, which sometimes forces individuals to use their limited resources to pay for services that they don't want or need in order to get services that they do want or need.

The Working Group agreed that a top goal for addressing housing needs is to define and improve outcomes, which will help researchers understand the real-life implications of housing policy and funding mechanisms. Researchers and policymakers also need more basic information about what housing options are available across states and how these differences drive economic and quality-of-life outcomes. Currently, there is a lack of research to define what is considered to be a good outcome or what contributes to a good outcome; having this fundamental data would make it easier to affect the type of public policy changes and support new housing initiatives, including funds to build new sites and support attendance at these residences, as well as ways to increase capacity.

Importantly, it is necessary to consider the values of the ASD community in order to determine meaningful outcomes and outcome measures.

While the workshop provided a space to address many of the housing issues that are facing the autism community, there were some items that were not fully addressed. There is still a need to focus more on how these models can be scaled to meet the growing demand. Currently, there are groups of people who receive no services while they remain on waitlists to receive funding. There is also a need to expand discussions beyond adult housing to include the entire lifespan, including options for children and adolescents. Lifespan issues also include consideration for the population of people living with an older caregiver who may be left without support systems when that caregiver passes away. Additionally, there is a need to support research to understand the cost of not providing housing and the societal financial impact.

Overall, workshop participants agreed there are areas for the IACC, policymakers, and other stakeholders to improve and fill the gaps on housing issues for people with autism. The Working Group hopes that these important discussions will resume in future iterations of the IACC, in order to continue and expand these efforts.