



Finally HOME NJ Symposium Summary Report

Values
into action

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Finally HOME NJ

Housing Symposium Summary Report

Introduction

The United States has a long history of prioritizing housing as an inherent component of the 'American Dream.' Franklin Roosevelt in his State of the Union Address in 1944, declared that the U.S. had a Second Bill of Rights, including the right to a decent home. In 1948, the United States signed the Universal Declaration of Human Rights (UDHR), recognizing adequate housing as a component of the human right to an adequate standard of living.

The U.S. Supreme Court's landmark Olmstead decision in 1999 found the segregation of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA).

Since 1999, the Home and Community Based Services (HCBS) for people with disabilities has expanded to every state in the country. The Final Settings Rule compelled government and service providers to focus on the separation of housing from services, to enable greater choice and control on the part of the service participants. As a result, many people have moved to or been able to receive their services in their own home, in communities throughout the United States.

As with any social movement, there continues to be struggles for people with disabilities: those with complex support needs and those who rely solely on their public funding; to find and sustain safe affordable housing of their own choosing.

As this project concludes, we thank the New Jersey Council on Developmental Disabilities (NJCDD) for funding this important work and providing feedback and guidance throughout the project's term.

We also acknowledge the New Jersey community members who identify as having an intellectual and/or developmental disability or autism, specifically those with significant

communication, behavioral and medical support needs who remain marginalized and underrepresented even though current policies and practices directly impact them. The advocates with lived disability expertise who did participate in this project did so courageously. They represented and amplified the voices of those most impacted by said policies and practices that persist in their default toward segregated and congregate options for those with the most significant support needs.

We dedicate this report to them.

The Report's Intent

The goal of this report is twofold: First, to fulfill a critical requirement of the grant that summarizes the work completed over the course of the year. Second, to showcase the achievements of this project and to highlight the contributions of the many voices that supported this project.

We sought to bring the lessons and the perspectives gained from project participants to the Finally Home NJ project. We attempted to include all stakeholders in ways that were authentic, helpful, and respectful. We largely succeeded thanks to our partners, including people with disabilities, their families, and professional allies.

Below are the specific details as promised in our submission's response to the request for proposal by the New Jersey Council on Developmental Disabilities that resulted in this grant award for Values Into Action PA. "The Finally Home Housing Symposium Summary includes data collected from the project, curated resources, community scans, scenario-based planning solutions, examples of people renting and/or owning their own home and using HCBS services and recommendations for further planning and actions related to this."



What We Learned

The project focused on housing options for individuals with disabilities who, as they age, require support for complex medical and behavioral needs, preferably those they choose and control. Several key findings emerged:

1. Limited Accessibility: Many existing housing options are not adequately designed or equipped to meet the diverse needs of people with disabilities who have complex medical and behavioral support needs. This lack of accessibility poses significant challenges as they age and potentially will need additional specialized services. Lack of reliable transportation to access medical appointments and places in one's community were shared by the project's participants as a significant concern.

2. Lack of Suitable Housing Models: Some stakeholders believe there is a scarcity of housing models specifically tailored to accommodate the unique requirements of this demographic. Stakeholders expressed traditional housing options can lack the necessary support services and modifications essential for promoting independence and quality of life. People with complex medical and behavioral support needs are referred to living in nursing homes, regardless of their age, in order to receive the services they

need. Families who were engaged with this project requested more “intentional housing” settings be developed in New Jersey.

Some interested family members who engaged with this Project reported seeking supports and services that they believe do not currently exist in the HCBS (Home and Community Based Services) Waiver and expressed the need for a different structure. Some have sought Developmental Center placement to ensure the wellbeing of their family members given the complexity of their support needs.

3. Importance of Integrated Services: Findings underscored the critical importance of people having their support services integrated with their housing. Access to comprehensive medical care, behavioral support services, personal assistance, and community engagement programs were reported as being vital for meeting the multifaceted needs of people with disabilities.

Many people reported wanting to live independently or in their family homes with support. This was particularly evident in the Spanish-speaking Listening Session where all 17 family members in attendance reported having asked their loved ones with disabilities what their preference was for their living arrangement. The response from this Listening Session was overwhelmingly to live independently with support.

4. Need for Person-Centered Approaches: The project highlighted the significance of adopting person-centered approaches and to tailor housing solutions to individual preferences, abilities, and aspirations as this fosters a sense of autonomy, dignity, and well-being among people with disabilities.

5. Policy and Funding Challenges: Addressing the housing needs of individuals with disabilities who have complex medical and behavioral support needs requires coordinated efforts from policymakers, service providers, and funding agencies. Project participants reported the lack of sufficient funding, fragmented service delivery systems, and regulatory barriers present significant obstacles to achieving inclusive and accessible housing solutions. Additionally, the cost of housing is a national crisis that

particularly impacts people with disabilities who are more likely to experience discrimination whether it is economic (housing vouchers, credit scores, unemployment) or based on their disability. These challenges present added barriers to accessing housing for people with disabilities.

The findings underscore the urgent need for innovative housing approaches, integrated support services, and policy reforms to ensure that aging people with disabilities have access to appropriate supports and accommodations to live and thrive in their own homes and communities.



Summary of Information from Listening Sessions, the Community Survey, and Learning Sessions

Before beginning this project, we recognized the complexity of the topics of housing and supports for aging members of the I/DD community. Because of this, we knew our project needed to have a strong fact and reality-based foundation from which we could adequately address community needs and interests. An integral part of that foundation is data. It can be easy to forget that data is not just numbers. Rather, they represent

hundreds of lived experiences that encompass the good, the bad, and the complicated realities of navigating housing with complex medical and/or behavioral needs while aging.

This section serves to summarize the lessons we learned through the data. It also illustrates how we transformed the data we were given into action, creating Learning Sessions based on the most frequent and severe needs people expressed over the course of the project.

For a deeper look into the data this project acquired and the story it tells, you can [check out our presentation on the topic here](#).

Collection Methodologies

As part of the project, our team conducted two initiatives through which we collected insight and feedback from community stakeholders. First, the NJ Barriers/Challenges with Housing Survey was created with assistance from our project partner, the Community Living Education Project (CLEP) and was disseminated by Values Into Action and our grant partners.

This survey targeted three stakeholder groups: Self-Advocates, Family Members, and Professionals. It included a combination of demographic, quantitative, and qualitative questions designed to provide us with an understanding of the experiences and challenges people face when navigating housing themselves, their family members or in partnership with people accepting their support. Over the course of approximately 7 months, over 250 responses were gathered from anonymous community stakeholders. Because of the high number of responses, we were able to make informed decisions that enabled the inclusion of content and materials that aligned with the stated needs of the stakeholders who provided feedback.

Second, we had promised to host three (3) Listening Sessions in our formal proposal. In response to the community's request for their increased participation, we held a series of seven (7) Listening Sessions. These were created to provide dedicated time for stakeholders to share their stories and perspectives on the challenges and barriers that occur when navigating housing for themselves or others with complex medical,

behavioral, and/or aging needs. Sessions were held for four target audiences: people with lived experience, family members, professionals, and people from marginalized communities. For the latter of these, a session was held in partnership with the Black I/DD Consortium, and another session was held specifically for people whose primary language is Spanish. Overall, 126 people attended the Listening Sessions and provided invaluable insight and stories that helped us shape the trajectory of the project and meet the needs of our community to the best of our ability.

Themes and Trends from the Listening Sessions and Surveys

Several core themes were found through analysis of the information collected from the Listening Sessions and Survey. These themes center around common barriers people face when considering their housing options. Some are systemic in nature, some sociocultural, and some psychosocial. By analyzing the themes, we were able to identify the most apparent barriers and challenges the stakeholders who participated in this project experienced. Below is an outline of those themes.

Because our grant was designed specifically to assess the housing needs of people with complex medical and behavioral needs, we paid particular attention to the information from people who identified acuties on their NJ Comprehensive Assessment Tool (NJCAT) tiers.

Please note that any time an asterisk is denoted in front of a theme, it represents a topic that was especially concerning to self-advocates and/or family members who identified/experience acuties.

We have included quotes from respondents to remind us that each of these datapoints is associated with real people living with the realities of these barriers and challenges.

***Aging Caregivers:** This was the most frequently reported concern from family members. In written responses, they conveyed significant concern about the future of their loved one after they are gone. This was most notably communicated by those whose loved ones are living either in the family home or in their own home with support.

These families reported navigating both their own aging needs and those of their loved ones. From their perspective, they understand the current system to be the family – most often the parents – as the primary caregivers, planners, property and care managers, support systems, and ‘emergency intervention’ for their family member. To them, this means there is no formal safety net or system of support that can or will continue this work if, and when something happens to the family members.

A Self-Advocate shared their thoughts related to this concern: *“I’m currently still living in my family home. But with my parents’ aging, how long can they be expected to be my primary source of care? Going to a nursing home with a geriatric population is not an appropriate option. Myself & others like me need appropriate options for us.”*

Here is quote from a Family Member who shared their concern: *“We are aging and it is becoming increasingly difficult to take care of his needs on days that he doesn’t have staff or days that staff cancel. We are exhausted.”*

***Navigating Systems and Program Requirements:** Before families can access services or plan how to support their loved ones with living in their housing of choice, they reported they must first know how to navigate the systems through which they access resources and know how to use the technology needed to access the information. For aging caregivers, they reported that this is an additional barrier for which there is limited to no support. Moreover, documentation for program requirements is often not written in an accessible way. Respondents reported feeling the unnecessary complexity of the programs that are supposed to provide support nullifies some of the good these programs can do.

Below are direct quotes from Self-Advocates who shared their thoughts related to this concern:

“ONCE PLACED HOW GET HELPS WHEN SOMETHING COME UP? WHY STATE PROGRAMS NO SAME IN ENTIRE STATE - I BE ASK RESOURCE FOR STATE PROGRAM QUESTIONS AND TOLD MY COUNTY NO HAVE CONTRACT THEN WHY IT BE CALLS A STATE PROGRAM. LACK INTEGRITY DIRECT HINDERS OUR QUALITY LIFE FUNCTION DEMINISH OUR HEALTH.”

“New Jersey is supposed to help people who qualify if u can’t get help if u r home bound and don’t have enough money to get a computer all must be done on cell phone the board of social services is supposed to help those who can’t they plain flat out and boldly say to u no we will not come out no matter what ur condition is and if u tell them ur phone message center claims u do for quilfied individuals the social services gets mad at u and threatens to throw or remove u from program that was scary and intimidating so i gave up.”

Financial and Housing Access Barriers: Many financial barriers were prominently mentioned by all groups surveyed and throughout the Listening Sessions.

First, there is a lack of affordable housing in New Jersey (and nationally) for everyone. This has worsened over the last several years. Also, landlords may not accept housing vouchers, sometimes illegally. We learned during this project that the issue has become so severe that the New Jersey Attorney General has announced increased enforcement actions against landlords and property management companies across the state for source-of-income discrimination (Office of the Attorney General, 2023).

Second, respondents reported struggling to make ends meet with their funding allotment through the Division of Developmental Disabilities (DDD) waiver, when paying for housing and for their supports and services. More specifically, respondents communicated that the waiver amounts have not caught up with inflation over the past several years. In their experience it is nearly impossible to receive the same level of support and stable housing they may have received in the past. This concern was especially relevant among those who reported acuities on their NJ Comprehensive Assessment Tool tier.

Similar trends were noted for Section 8 / U.S. Department of Housing and Urban Development (HUD) housing voucher allowances. The cost of rent today exceeds the amount typically allocated for a voucher, and as such, the availability and wait times associated with receiving one can be for extended periods of time for some applicants. Respondents communicated high levels of frustration that they are consistently told this resource is available to them when that is not their experience. Some also communicated anger that they believe the system effectively puts them in limbo by not

allowing them to get jobs or find other means of financial support while they await a voucher because this would make them no longer qualify for the voucher.

Below are direct quotes from two Self-Advocates who shared their thoughts related to this concern:

“The [cost of living] in NJ is out of range for people w/disabilities. We are discriminated against, home vouchers and people using them are stigmatized, not allowed to live in certain communities, relegated to living in more urban areas where crime rates are much higher, police activity runs 24/7, housing is crumbling and there are more non-English speaking residents.”

“The amount of the housing vouchers need to cover more people who are working. Having a full time job isn't enough for the high cost of rent.”

***Staffing and Support:** Not having enough staff to provide adequate support in their housing of choice was a barrier communicated by all categories of respondents. This was especially relevant with those who have medical acuties identified on their NJCAT Tier, with the need for staff with appropriate experience and skills. This reflects a state and nationwide issue that impacts millions of people. One of the factors the respondents believe as contributing to this issue is the wage limitations for Direct Support Professionals (DSPs) and Self-Directed Employees (SDEs). Some family respondents reported that their loved one's medical support needs require staff with medical expertise. They expressed that it is near impossible to find medically, or behaviorally trained staff support at the current wage level used in New Jersey's Self-Direction system. There was also frustration on the part of some respondents in that their understanding is Direct Support Professional Agencies' compensation rates were higher for people with acuties, yet the DSPs employed by said agencies do not receive increased compensation for supporting people with acuties. These respondents also noted they believe the money paid to said DSP Agencies from the DDD budget did not reflect the services of high-level experienced support staff.

Another issue respondents communicated is the need for unpaid support networks. These are typically built through social connections such as friends, family, or community members. However, when family members are the primary caretakers for someone with complex medical or behavioral needs, there is little to no time available to take care of themselves, much less to go and make the social connections needed to build unpaid support systems. This issue presents a barrier for these respondents, and its impact is compounded by the staffing shortages discussed above.

A Self-Advocate shared their thoughts related to this concern: *“The biggest barrier I have with my living situation is having additional staff for when my primary staff calls out most state funding you can only have one staff and the other issue is everything is by the hour for a billable rate so it’s hard to calculate for staff or a different support that you don’t need all the time or not a certain time every day.”*

A Professional shared their thoughts related to this concern: *“The most common concern that I have heard that prevents people from living independently is having staff support and the lack of resource knowledge and information available.”*

Challenges Unique to Marginalized Communities: The topics listed below are in line with trends observed at the national level and represent the realities of the respondents living with intersecting marginalized identities. These are the most prevalent challenges and themes described by community members with marginalized identities who responded to the Survey and/or participated in the Listening Sessions.

- **Housing Access**
 - Renters typically face more barriers to making modifications to properties to make them more accessible. Racial disparities in home ownership rates mean that black, indigenous and other people of color (BIPOC) across the state have less freedom to make necessary modifications to make their homes. According to Census data from 2022, Black and Latino homeownership in New Jersey is below 50% in over two-thirds of the state’s counties (Jung, 2024).

- In addition to the challenges associated with navigating housing with complex medical and/or behavioral needs, the respondents noted BIPOC must also overcome barriers that are unique to racial minorities and that despite legal protections, discrimination in accessing housing is still an issue for them today.
 - Respondents reported their experiences in the difference in quality of housing in regions with predominantly non-white populations is significant. Public transportation, social services, and access to other community resources and supports is also limited in these regions, from their perspective.
- **Language Barriers**
 - The default language for almost all federal, state, and local government organizations and agencies is English. It has only been in recent years that a push has been made to translate important forms and documentation for accessing funding and resources into Spanish. This has led to significant disparities in families whose primary language is not English being able to access resources. This is a barrier that has impacted many families whose primary language is not English from accessing what they need. Respondents were concerned given New Jersey's population is comprised of a large number of immigrant and asylum-seeking families.
 - For some respondents, trainings and workshop are typically only offered in English, and translation services are difficult to access or not integrated into webinars (e.g. use of Wordly app in Zoom calls). Families are then left to figure things out for themselves or hope that someone they know can translate for them.
- **First Responder Treatment and Behavior Perception**
 - Respondents who are non-white living in predominantly white areas communicated that they experience more concern that their neighbors will discriminate against them or interpret their loved one behavior as "violent," and label them a danger to the community, an increased threat of eviction, or call law enforcement unnecessarily.

- BIPOC respondents shared significant concerns with the way law enforcement and first responders react to a non-white person with I/DD in times of crisis. In addition to the racial discrimination from first responders that has been nationally decried over the past several years, they described how a person having a disability – especially one that influences the way they communicate – creates additional risk to their safety. They shared many instances of increased use of restraints and deadly force, or times where help was not provided when it was needed.
- BIPOC respondents reported experiencing issues with clinical or support staff interpreting their loved one's behaviors as more aggressive and violent than a similar behavior would be interpreted for someone who is white. This is concerning because certain programs and group/congregate housing situations can evict or bar a person from participating if they have a history of aggressive behavior.

Challenges with Collecting Information/Information Collected

As is common with projects of this nature, we experienced some challenges throughout the collection of information and perspectives of the stakeholder groups. We recognize this impacts the representation of the information solicited, which in turn affected the development of the Learning Sessions, although the grant proposal accepted aligned with the tenants of the Home and Community Based Services Settings Rule. While the outputs of the Finally Home NJ Project may not be acknowledged by some stakeholders, the lessons highlighted are important to note as future projects are funded, and system advocacy efforts regarding housing are considered. Below are descriptions of the challenges we encountered.

Low Response Rate: Reaching people with lived disability experience themselves as challenging given the continuing indirect nature of the connection. There was only one response from a person living in either a Group Home or Supported Living. The lack of representation for this group made it difficult to understand their unique needs and challenges from their own perspectives. The lack of insight was detrimental to the project and made it so their voices could not be heard in the way others were.

Lack of Diverse Representation: Despite our strong outreach campaign for the survey, there was low response rates from non-White and non-Black community members. While we received a robust response from Self-Advocates who lived with their family members and who identified as White (50%) and Black (29%), there was limited responses from Hispanic, Asian, or Otherwise identifying people.

Efforts to Ensure Full Representation of Perspectives: There was a small group of stakeholders who participated and expressed concern that the project was not designed to consider their preferred solutions for those who family members have significant support needs. The Project Team continued to work with this group of stakeholders to include their perspectives at the same time as ensuring they understood the focus of the project was to consider alternatives to current housing opportunities available to those using Home and Community Based Services. The Project Team sought to listen to and express respect for their preferences while not undermining the choices they considered most appropriate for their family members, and while seeking to implement the grant activities with integrity to the goals of the project.

Lessons Learned from Learning Sessions

Given the significance of the inputs from stakeholders, we appreciated the contributions of the Finally Home NJ Project Advisory Workgroup and the Project Partner Organizations. While this project was not designed to change the DDD system or to address every individual housing concern, it was intended to amplify the voices of the DDD stakeholders as a first step in addressing the varied needs of the people with significant communication/behavioral, medical and aging needs as they impact their housing opportunities. It was challenging to include DDD representatives as intended given the climate of the discourse occurring between a group of stakeholders and DDD leadership regarding the implementation of the Centers for Medicare and Medicaid's Home and Community Based Services Final/Settings Rule. It was hoped a dialogue more inclusive of people with living disability expertise, and their Support Coordinators and Supports Brokers (if being utilized) would have occurred as proposed; however, the forums held provided opportunity for information to be shared other stakeholders who

otherwise may not have had opportunities to learn about housing resources and planning tools.

As New Jersey is a member of the national Supporting Families Community of Practice, the Charting the LifeCourse (CtLC) framework tools was selected as the planning tool to be used alongside the Learning Sessions' agendas. In this way the participants were able to not just learn information but be able to practically apply the learning in real time using the Charting the LifeCourse Framework. Below are descriptions of each Learning Session and how the CtLC tools were integrated.

Using CtLC to Plan for Housing in New Jersey: People with disabilities, family members, and professionals were invited to learn how Charting the LifeCourse Framework can be used when considering housing options. The CtLC Ambassadors who facilitated the session presented the tools and provided examples of how people can use specific tools or the entire framework, no matter the circumstance or situation, to consider aspirations and preferences as well as their needs when planning for their housing.

A Key to a Successful Move - Community Connections: The facilitators, direct service agency leaders, shared their experiences supporting people with significant support needs to live safely in their own, or their family's home. They emphasized the importance of having a support system that included family, friends, neighbors as well as paid staffing supports. The Life Trajectory Exploring tool was shared and participants were encouraged to use it during the session as they considered the information presented.

Tenant Rights and the I/DD Community: NJ Community Health Law Project, a grant partner, shared casework experiences and resources for tenant rights and defending against eviction. Because threat of eviction was noted as a recurring and significant concern in the Listening Sessions and in the survey, this scenario was used in the CtLC workshop portion of the session. The Integrated Supports Split Star tool was used to explore supports and resources available or needed to prevent potential eviction.

Overcoming Legal Challenges - Home Health Aid Appeals: The NJ Community Health Law Project colleagues presented case examples and the process of appealing denials of home health aide coverage and provided resources for navigating the process. The Life Domain Vision Tool was used to show how people can plan their vision of a good life and identify the resources and supports needed.

Highlighting Concerns of Marginalized Communities: Presenters with living expertise and experience shared the unique challenges faced by people with marginalized identities. Discussion focused on how members of our community experience racial inequality in housing and service provision, including the systemic barriers that worsen the marginalization of the Spanish-speaking population. Examples of how people are overcoming obstacles were shared. The CtLC was presented as a resource to participants to note the barriers and considerations for how to overcome them, including identifying community resources and services that may be available for them to address them.

Advocacy and Systems Change: The Associate Director at The Boggs Center, a grant partner, facilitated this session and shared current federal, state, and local resources and processes for advocating for system changes related to affordable and accessible housing for people with I/DD. Discussion focused on the important contributions personal voices and stories can make in the legislative process and can create potential for positive change. A demonstration of the Life Trajectory Planning tool showed how one can share their story with elected officials and use it to illustrate potential solutions and desired policy outcomes.

Housing Options: Finding and Financing: This session was facilitated by a representative of the Supportive Housing Association, subject matter experts, who shared a wide range of information related to finding and financing a wide array of housing options, and available funding sources. The Life Trajectory Family Perspective tool and Integrated Supports Star tool were shared to demonstrate how to begin envisioning and then planning for finding one's home.

Re-Envisioning Hope: A family member who is also a professional with extensive expertise in supporting people with disabilities with complex support needs in their own

homes and communities, discussed real-life examples of navigating barriers to make their housing preferences a reality. A Self-Advocate shared how they navigated the system to find their own home and organize and sustain the supports needed for them to live safely. The Life Trajectory Planning tool was shared to highlight the importance of person-centered thinking and planning and to encourage adaptations through the many life transitions especially when considering housing of one's own.



Examples of People Living in Homes of Their Own Choosing with Services They Choose and Control

A person/s with significant medical complexities and support needs

DB and DB, twin sisters, had been supported by a provider agency to live together for 6 years before DB died of cancer in 2021. Both were diagnosed with intellectual disabilities, and both had significant mental and physical health support needs. They had lived for many years with their mother, who also had an intellectual disability. While

both twins reported having an active and involved family who offered support in the past, family members have not been actively involved in the last five years.

Both sisters were assessed to need continuous supervision and support given the medical complexities and emerging mental health support needs, which included sleep apnea, diabetes, hypertension and hyperlipidemia. With assistance, guidance, and support with decision making, the sisters chose an apartment in a development close to their family, shopping centers, and their day support agency.

They signed their lease even though the residential service agency was to pay the rent, utilities, and other occupancy costs on their behalf (with them paying the agency room and board stipend). This is the most important aspect of Home and Community-Based Service—the separation of housing from service provision. This allowed the sisters to choose a different service provider if they became dissatisfied with their current agency, while not having to move from the home they chose for themselves.

DB and DB, with guidance and support, interviewed and selected the staff who worked with them, and they were also able to deselect them. This authority enabled the sisters to take responsibility for working with people they felt comfortable with in pursuit of their goals and they learned to alert others when they were concerned with what staff were doing, or not doing on their behalf.

They were supported to understand the helpfulness of smart home technology. Included in all discussions and planning with vendors, the sisters were able to use Echo Show with Alexa from Amazon in their home to offer medication reminders. Through vendors, they had bed shakers installed to alert them if they had a seizure or toileting accident overnight, and they had additional smoke detectors that would alert an on-call system who would contact 9-1-1 and the agency's on-call system. Their stove had a heat sensor to let them know if someone had left a pilot light on and to turn it off. They also had access to a ring doorbell that would alert them when someone arrived at their home when they were without staff support. Both ladies had cellular phones to call or video chat with agency personnel as needed.

A person with significant psychiatric support needs

LD experiences intellectual and developmental disabilities and multiple concurrent psychiatric disorders. Throughout their life, LD communicated through behavior that was harmful to themselves and others. Despite being labeled as 'too dangerous to live in their own home', LD's family decided to use the limited financial resources made available to support LD to continue to live in their home.

They encountered one of the biggest barriers: finding and maintaining staff. LD and their family worked with their Support Coordinator creatively to find staff, eventually finding people in their neighborhood who were hired and are still working for LD, providing the 2:1 staffing support they need, 24 hours a day.

Their Support Coordinator also helped them re-evaluate their budget, and together they manage it on-going to ensure LD can maintain the staffing supports they need long-term. LD continues to live happily with their family, using Home and Community Based Services as intended, in their own home, supported by people they know and who care about them.

A person with a strong and active personal network

CM is a self-advocate who lives with Cerebral Palsy. He continues to experience significant health complications and has had dual leg amputations. CM hires family members to support them.

A recent challenge involved them having to move from his home quickly post-amputation given the need for accessibility.

Working closely with their Support Coordinator, housing was found, and planning considered CM's on-going supports to maintain their physical health, as well as the new diagnosis, and the accommodations necessary for them to be safe and secure in their new home.

CM and his team focus on the training and support of the staff as well as flexibility in scheduling so that CM can be assisted as needed with his health and social appointments.

A person with limited or no personal network

KB is a self-advocate who has complex and significant support needs including use of a tracheostomy tube (trach), a wheelchair, has limited use of their hands, and a diagnosis of Werdnig-Hoffmann Disease.

They previously lived in an intentional living community but were not happy with the situation. KB was hospitalized frequently and as a result could not maintain their staffing support. Their family was not supportive, and KB recounts the time they were 'kicked out' of their family's home during a medical crisis. After providers refused to support them given the significance of their medical complexities, KB decided to self-direct their services and worked with their Support Coordinator to develop their support plan, find housing, and then recruit and hire staff.

KB uses a Section 8 voucher to rent their condominium. They currently employ 6 staff and have 4 backup staff who work together with KB effectively. KB trains staff in all their physical health needs including how to assist them with the trach.

A person using limited waiver funding

JC is a young adult who lives with Downs Syndrome and corresponding developmental and health challenges. She lives with her mother who is terminally ill. JC has waiver funding that is limited so they work closely with their Support Coordinator to manage their budget.

JC schedules her staff, so they are available to help her understand her dietary needs and plan and prepare meals, guide her in managing the home including cleaning, shopping, doing errands and supporting her mother.

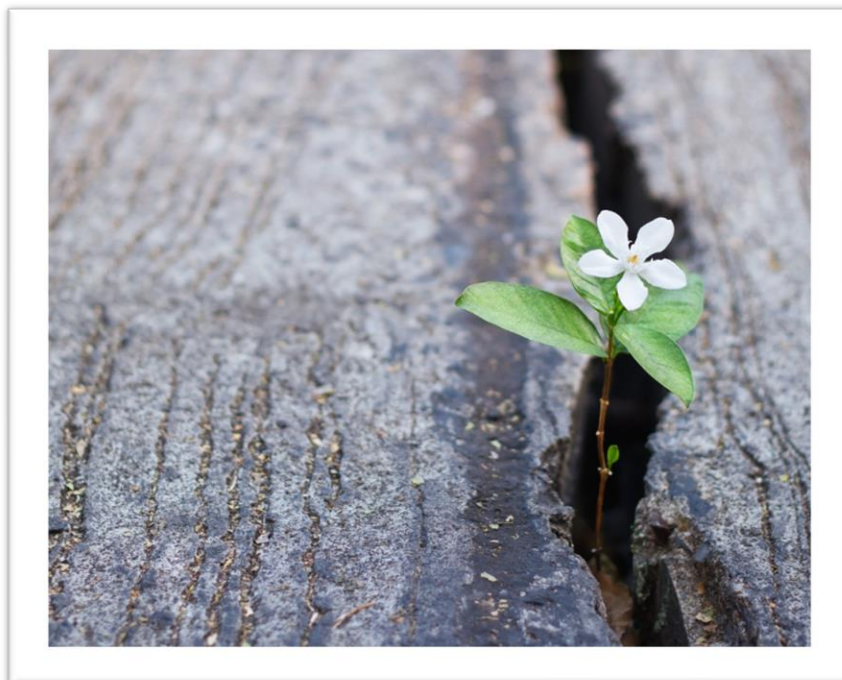
Through the pandemic, JC began using remote technology such as the Alexa to communicate with emergency personnel when her mother was in distress and to alert staff if she needed help when they were not working. Home accommodations were arranged with her health insurance company, and the use of Goods and Services service to purchase items from a local durable medical equipment company.

A person using the Community Care Program

CL is 31-years old male who lives with his parents. He communicates through his behavior, which has impacted his ability to live safely over the past 10 years. CL and his family along with their Support Coordinator and provider agency, work together to find creative ways to best support them when at home and in the community. CL is enrolled in the Community Care Program that provides significant funding. He employs 3 Self-Directed Employees and uses 2 of them when out in their community to help them and others stay safe.

CL recently participated in an intensive outpatient program that focused on understanding CL and structuring his environment and routine. CL and his team effectively advocated the needs through clear and respectful communication with DDD who in turn approved the funding to be used for this resource.

CL and his team collaborated on the desired outcome and committed to working within their roles to ensure all actions were directed toward it. CL is now communicating his preferences and needs effectively and is enjoying activities in his community. He is safe at home and can be understood without resorting to dangerous behaviors. While there are no needed accommodations for the home, the family and staff attend to the predictability of a routine and a structured and consistent approach to supporting CL. The goal is for CL to live with his parents for the long term, and his publicly funded resources will be thoughtfully used to support this aspiration.



Recommendations

Navigating the Home and Community Based Services (HCBS) is challenging and requires stakeholders to work together collaboratively to honor the aspirations, preferences and meet the needs of people with disabilities. When exploring housing options, the process can be even more complex for people with disabilities who want to choose where and with whom they live. Those making the decision to control their own housing need a committed team of people who will intentionally and thoughtfully keep the person at the center of all considerations while thinking, planning, and designing the support system that includes a home of the person's choosing.

As a result of the Finally Home Project, it became clear that the overarching theme was the NJ DDD system, like many other public systems, is complicated and complex, for all stakeholders. The project afforded the opportunity to hear and to amplify the concerns of the marginalized communities the system seeks to reach. The engagement of these community leaders and stakeholders demonstrated their commitment to shaping the

future of the Home and Community Based Services (HCBS) Waiver in NJ, specifically housing related supports and services that promote health and community integration.

Below are the recommendations that will hopefully influence a paradigm shift to support systems change to empower people and their families in their quest for suitable housing solutions within their communities. These recommendations aim to equip the system, as well as people who utilize services in the system, with suggestions as to how to improve the services and accessibility of services when planning for their housing, specifically those with complex medical and behavioral support needs and who are aging.

- 1) Ensure people with living disability experience and expertise are included in all system events and opportunities, just as family members and professionals are prioritized, invited and represented. This may mean allowing for increased resources for accommodation to ensure appropriate technology, support, accessibility and flexibility in communications and methodologies. The system should expect that people themselves, in addition to enjoying the engagement of their family members, will participate in ways that are meaningful to them, and for a frequency and duration that meets their preferences and needs. Their voices must not just be included, they must be amplified and considered first and foremost.
- 2) Include family members not only as representatives of their loved ones with disabilities but also as important and necessary stakeholder group themselves. The pressure put on families to not only know, but to communicate their disabled family members' aspirations, preferences, and needs is a monumental task. To do so repeatedly over time may create undue hardship, unrealistic expectations and produce ineffective outcomes.
- 3) Offer additional forums for people and their families to better understand the current financial and regulatory framework the state and provider systems are mandated to work within. Advocating for system change takes time, and practices must align with existing policies and regulations to maintain the public funding that enables services and supports, now.

- 4) Advocate that the state system adopts, or at the very least considers prioritizing the best practices evidenced by the NJ Council on Developmental Disabilities grant funded projects. Specifically, the Housing Navigator role, while technically available to people and their families, is not readily utilized as there is no current mechanism to pay for those supports. The NJ Division of Developmental Disabilities should enable people access to all roles available to advance the Home and Community Based Services, as originally intended and expressed in the Settings Rule.
- 5) Highlight housing as a topic does not exist in a vacuum outside of the person's support system, consider funding demonstration projects that allow for people, their families, circles and other freely chosen allies to use their public funding to: develop a housing plan integrated with their support plan; use community and system resources to locate and obtain housing of their own choosing; use supports to identify who, if anyone, they would like to live with, and then to design or redesign their staffing support system to align with new living arrangements. Finally, allow for the use of public funding to access smart home technology, remote support and home modifications not otherwise covered so that the significance of the person's support needs is no longer an obstacle to them authentically choosing where and with whom they will live.
- 6) Include the Charting the LifeCourse Tools for both short-, mid- and long-term planning, emphasizing a key component of the framework being change and transition. Decisions made today for the benefit of the person and family's current needs may not be the ones necessary for longer term sustainability. Providers must work to build trust in their expertise and commitment so that people and families trust this type of planning is natural, and that change is inevitable and expected. The pressure to make decisions now that are binding therefrom can create anxiousness and a scarcity mentality that does not promote trust, collaboration, resilience and ultimately better outcomes.
- 7) Investing in and prioritizing competent facilitation of candid and respectful discussions, learning events, feedback forums and policy briefings even when

there is significant disagreement among stakeholders should be welcomed and embraced.

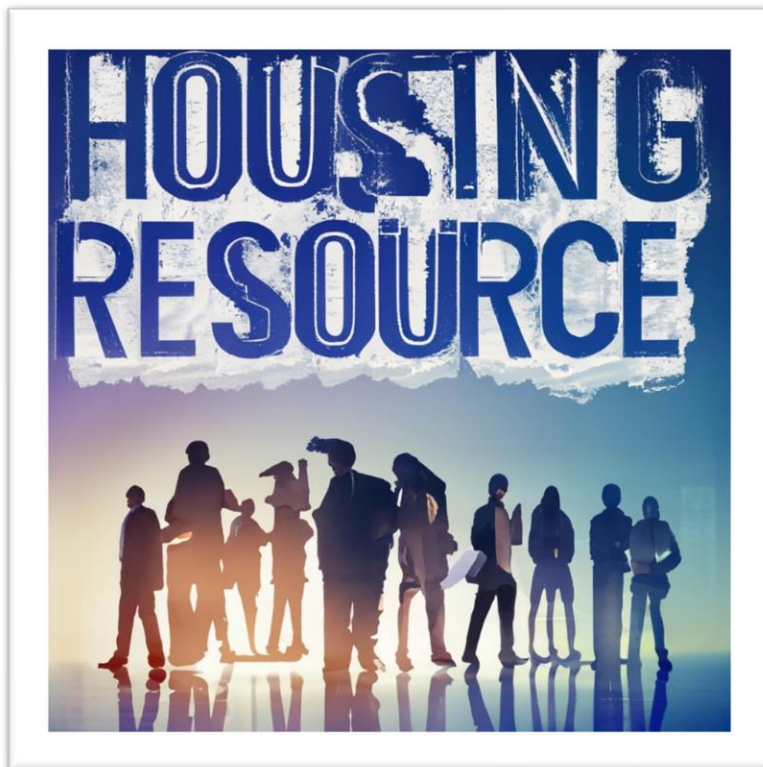
- 8) Remain open to the experiences of others in other geographic locations. There is much to learn, and much to be shared about lived experiences, new knowledge, skill development, implications of technology, etc.
- 9) Advocate for systems change that will enable school aged youth and their families to learn about disability services and the system while they are in the school transition phase by funding the Support Brokerage and Support Coordination services from birth. This would ensure time for people to learn and familiarize themselves with the services available to them as well as enable access to supportive services at an early age.
- 10) Begin collecting data regarding the Subsidized Housing Connection: state funds provided for rental (first and last month and security), furniture and other start up household items. In this way, the aspirations, preferences, needs and challenges can be better anticipated, and adaptations made accordingly.
- 11) Explore a hybrid model of Support Coordination that can more effectively navigate options other than residential services. This role would be more facilitative so as more effectively translate people's aspirations and preferences as well as incorporate their support needs into a plan that can authentically consider the services available through the current NJ DDD HCBS, and invite providers (both agency-managed, and self-directed) to support the person in realizing their outcomes.

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Housing Information and Resources

Below is a list of curated resources that were identified and shared by the Project Team. Each resource has a clickable link to take you to the website where you can explore resources and information.

Finding Housing

Housing and Community Development Network of New Jersey – Resources

A list of housing resources listed by topic. Includes housing for each county, guides for affordable housing, and other important information.

[Website Link: Housing and Community Development Network of New Jersey - Resources](#)

NJ Department of Human Services/ Division of Disability Services Housing Resources for People with Disabilities

This page contains a list of places through which you may find housing.

[Website Link: NJ DHS Housing Resources for People with Disabilities](#)

New Jersey Housing Resource Center

Online searchable registry of affordable and accessible housing units throughout New Jersey.

[Website Link: New Jersey Housing Resource Center](#)

NJ Supportive Housing Association- Housing Navigators

List of those in NJ who have completed SHA's Housing Navigator training.

[Website Link: NJ Supportive Housing Association- Housing Navigators](#)

Community Access Unlimited

Housing Programs and Options in NJ.

[Website Link: Community Access Unlimited](#)

Housing Programs within the Department of Human Services (DHS)

Housing to suit the needs of DHS consumers can include housing options for people with developmental disabilities or mental health issues, housing opportunities for the blind and visually impaired, supportive housing in the addiction recovery process, or emergency housing resources.

[Website Link: Housing Programs within the Department of Human Services \(DHS\)](#)

I Choose Home

A federal program with two main goals: move people out of nursing homes and developmental centers back into the community; and re-invest Medicaid dollars saved back into home and community-based services to grow the system.

[Website Link: I Choose Home](#)

Project Freedom

Project Freedom is a 501(c)(3) non-profit organization that develops and operates barrier-free housing to enable individuals with disabilities to live independently.

[Website Link: Project Freedom](#)

Open Low Income Housing Waiting List in New Jersey

Find applications for 62 open low-income apartment waiting lists in New Jersey. Get the information needed to apply for HUD rental housing that can't be found anywhere else.

[Website Link: Open Low Income Housing Waiting List in New Jersey](#)

Supportive Housing Connection

The Supportive Housing Connection is a partnership between the New Jersey Department of Community Affairs (DCA) and the New Jersey Department of Human Services (DHS), formed to administer DHS rental subsidies to individuals served by DHS.

[Website Link: Supportive Housing Connection](#)

Housing and Services

Administration for Community Living Housing and Services

The Housing and Services Resource Center was created to serve people working in organizations and systems that provide housing, homelessness, health, independent living, and other supportive services that help people live successfully and stably in the community. This site offers information and tools for developing cross-sector partnerships, fostering community collaboration, and using innovative strategies.

[Website Link: Administration for Community Living Housing and Services](#)

[Website Link: Administration for Community Living Identifying and Building Partnerships with Your Local Housing Sector Video Series](#)

NJ Division of Developmental Disabilities Housing Assistance

The Division of Developmental Disabilities believes that community living is the cornerstone of an independent, integrated life for people with intellectual and developmental disabilities. In support of this, the Division funds rental subsidies for individuals living in provider-managed settings, as well as those renting from private landlords.

[Website Link: DDD Housing Assistance](#)

The Division of Developmental Disabilities Housing Subsidy Program Webinar

The Community Living Education Project hosts Courtney Davey, Supervisor, Division of Developmental Disabilities Housing Subsidy Unit, as she presents: “The Division of Developmental Disabilities Housing Subsidy Program”

[Website Link: Housing Subsidy Program Recording](#)

Planning for Housing

Charting the LifeCourse Framework

The Charting the LifeCourse framework was developed by families to help individuals with disabilities and families at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.

[Website Link: Charting the LifeCourse Framework](#)

Helen Sanderson Associates

Learning and resources that create opportunities for planning with people to live a life that reflects what really matters to them.

[Website Link: Helen Sanderson Associates](#)

Funding Housing

NJ Housing and Mortgage Finance Agency

Information about low-income housing tax credits, down payment assistance programs, housing resource centers and more.

[Website Link: NJ Housing and Mortgage Finance Agency](#)

New Jersey Division of Developmental Disabilities Rental Subsidy Agreement

Overview of DDD's rental subsidy details.

[Website Link: Rental Subsidy Agreement](#)

NJ Published Rent Standards (updated 1.2024)

List of funding limits per county for housing rentals.

[Website Link: NJ Rent Standards](#)

Research & Housing Guides**Residential Information Systems Project (RISP) Annual Survey of State Developmental Disabilities Agencies (RISP)**

RISP collects and reports on national and state level data on the history of institutionalization, deinstitutionalization, and the development of community based LTSS for people with IDD in the 50 states and the District of Columbia.

[Website link: Residential Information Systems Project \(RISP\) Annual Survey of State Developmental Disabilities Agencies \(RISP\).](#)

Podcast: Housing for People with Developmental Disabilities

What happens to housing for those with developmental disabilities when their caregivers can no longer take care of them?

[Website Link: Housing for People with Developmental Disabilities](#)

Supportive Housing Association of NJ Housing Guide

Journey to housing with supports for people and families

[Website Link: Supportive Housing Association of NJ Housing Guide](#)

Values Into Action PA Housing Toolkit

Diana T. Myers and Associates, Inc. (DMA) and Values Into Action created the Finally Home Housing Toolkit as a user-friendly resource providing housing information and

tools for advocates, Housing Service Providers, Supports Coordinators, Supports Brokers, family members and other interested parties to support people with disabilities in securing the housing of their choice.

[Website Link: Values Into Action PA Housing Toolkit](#)

Housing and Community Resources

The division provides a wide range of services addressing needs in Housing Assistance, Housing Production, Community Development, Neighborhood Revitalization and Improvement, Energy Assistance and Community Services.

[Website link: Housing and Community Resources](#)

Campaign for Affordable, Accessible Housing

Community Vision's report examines the problems people with disabilities face when trying to find a home.

[Website Link: "Access Denied" Report](#)

Complex Needs Resources

The Link Center

The Link Center works to improve support available to children and adults with intellectual and developmental disabilities (I/DD), brain injuries, and other cognitive disabilities with co-occurring mental health conditions. The Link Center provides training and technical assistance and advances systems change that will increase access to effective services and supports for people with co-occurring conditions.

[Website Link: The Link Center](#)

NJ Centers for Independent Living

Centers for Independent Living, many of them funded through the Division of Vocational Rehabilitation Services, in the Department of Labor & Workforce Development, are community-based, consumer-driven organizations that provide information and referral, peer counseling, skills training, advocacy and a variety of services based on individual needs.

[Website Link: NJ Centers for Independent Living](#)

Communication First

Reduces barriers for non-traditional communicators, ensuring access to robust expressive communication tools, supports, and accommodations in all life and community settings.

[Website Link: Communication First](#)

Legal Resources

Community Health Law Project

Community Health Law Project provides housing advocacy (habitability and landlord-tenant issues) for people with disabilities.

[Website Link: Community Health Law Project](#)

Disability Rights New Jersey- Supported Decision Making

Supportive decision making allows individuals with intellectual and developmental disabilities (I/DD) to make choices about their own lives with support from a team of people.

[Website Link: DRNJ Supported Decision Making](#)

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