Empowering
Communities
Initiative

HOUSING & COMMUNITY DEVELOPMENT

FOR RESIDENTS WITH INTELLECTUAL/ DEVELOPMENTAL DISABILITIES






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April 2020

MADISON HOUSE AUTISM FOUNDATION

AUTISM HOUSING NETWORK

Developmental Pathways

Autism Housing Network

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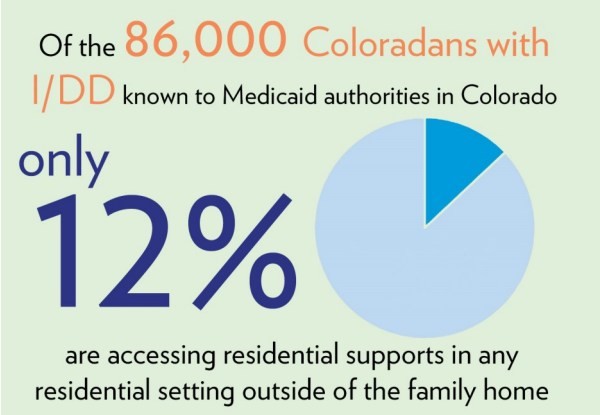
EXECUTIVE SUMMARY

86,000 Coloradans have an intellectual and/or developmental disability (I/DD) and want to be active community members. If all residents with I/DD went to watch a Broncos game, they would overflow Mile High Stadium, yet they are often not discussed as a part of the diversity within the population who may need affordable housing and extra support to be included in everyday activities in communities across Colorado. It was only a few decades ago that people with I/DD were, more often than not, hidden behind closed doors, not allowed to go to school, and banned from having a typical life. Fortunately, this attitude has largely changed, yet systemic barriers to opportunities for meaningful community inclusion are still prominent.



Although a friend, family member or neighbor with I/DD may not be intentionally hidden away and excluded, the experience of isolation and loneliness for themselves and their families is not uncommon. Most adults with I/DD live with their parents well into adulthood, watching their siblings leave the nest. With only 12% able to access housing and the support they need to move out of their family home, the question of "What happens when Mom/Dad dies?" can only be pushed aside for so long as caregivers are aging. More than 12,000 caregivers are now over the age of 60. The urgent need for affordable, cognitively-accessible housing in addition to funding for diverse options of long-term services and supports cannot be understated.

Self-advocates and families recognize a major effort is needed to prevent their loved ones with I/DD from being displaced from their community of support, forcefully institutionalized, or rendered homeless. Many went to Developmental Pathways for answers and support. Developmental Pathways helped connect advocates to develop a Housing Task Force in order to move forward with robust efforts. It is this Housing Task Force of stakeholders with the support of Developmental Pathways that engaged the Empowering Communities Initiative (ECI) to identify and provide direction of what type of housing, service delivery models and community support was needed. Results of the *ECI Residential Needs & Preferences Survey* showed that community members:

- Have a wide range of support needs. Those falling through the cracks of support include individuals with high behavioral or medical support needs and on the other end of the spectrum, those who have such low support needs they are being deemed ineligible for services.
- Favor housing to be disconnected from their service provider, allowing them to change providers without leaving their home.
- Desire to not only rely on the rental market, but would prefer home-ownership options.
- Prefer property types of an intentionally neuro-inclusive culture within the greater community such as cohousing or a planned community with built-in supports.
- Have limited natural support systems are limited and the greatest barrier to community engagement and friendship was reported as lack of social skills to maintain relationships, followed by transportation, and lastly difficulty scheduling and feeling overwhelmed by crowds or overstimulated.
- Are unsure of their preferences, even after a 3-hour training, thus more storytelling and continued education is needed.

Taking the results to local industry leadership and the professional community, the following key points in the ability of the community to meet the demand described by the *ECI Residential Needs & Preferences Survey* should be recognized:

- Affordable housing is out of reach. Individuals with I/DD are forced to remain in their family home or into a placement in a provider-controlled setting.
- Service providers want to provide person-centered support, but are limited by funding restrictions and regulations of a non-person-centered system.
- Not all desired service delivery options are currently available in Colorado.
- Stakeholders feel their choices are being limited by biased, neurotypical standards and not what the person with I/DD actually wants or needs.
- Local city planners and the housing industry are predominantly unaware of the housing needs of residents with I/DD, thus creating barriers to unique housing solutions.

This report includes initiatives to continue educating stakeholders on lifespan options and engage in advocacy efforts as well as recommendations to exponentially increase the available housing stock accessible to people with I/DD, increase access to more diverse long-term services and supports, and increase opportunities to foster neurodiverse relationships and other life skills.

These recommendations are attainable, but will require intentional outreach and partnerships as well as leadership at the state and local level to work together. If nothing is done, our communities will lose valuable neurodiversity and residents with I/DD will suffer tremendous trauma at a much higher taxpayers' expense. Fortunately, Colorado is a state of innovation and problem solvers who want to make a difference. It will be imperative that barriers to innovation are removed and incentives put in place in order to meet the demand as quickly as possible. Local organizations and groups of families who are already convening should combine efforts with the Housing Task Force. Working together, a better future is possible.

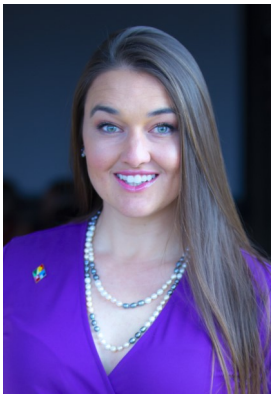
INTRODUCTION

Developmental Pathways has earned a well-deserved reputation for its work with families to find and create the best possible community support system for their loved ones with intellectual/developmental disabilities (I/DD). In recognition of their work, Developmental Pathways recently received a grant to support community educational initiatives related to housing and lifespan support needs. Developmental Pathways, prompted by a group of volunteer Housing Task Force members, sought consultant support to present best practices in the field of supportive housing, develop a community assessment tool as well as provide recommendations based on the current data and analysis.

Madison House Autism Foundation has developed a unique solution integrating technology and personal involvement to connect people with ideas to address the growing crisis, the Autism Housing Network (AHN). It is the first online platform for sharing housing solutions intentionally designed to support adults with autism and other I/DDs. Connecting and sharing stories from leaders in the field, the AHN provides the largest online housing and resource databases while promoting best practices and ideas in supportive housing across the country. It is the only online presence that brings housing resources and innovators from across the country together in one place, empowering local groups to launch and pilot innovative solutions with public, private, philanthropic and not-for-profit partners. It allows parents, adults with I/DDs, and communities to take the future into their own hands.

Through the AHN Empowering Communities Initiative, disability-housing experts share the results of years of research and on-site work with partners across the country, empowering local groups to successfully develop their own person-centered solutions, community by community.

After presenting to the Housing Task Force members, the Director of the Autism Housing Network, Desiree Kameka, was commissioned by Developmental Pathways to facilitate an Empowering Communities Initiative which included providing training, a needs assessment survey, analysis and recommendation. This proactive effort by stakeholders and Developmental Pathways should be applauded. Not only did they seek to understand options, but they invested in the education and assessment of their constituents. Our hope is that the Housing Task Force, service provider agencies, the housing industry and other local organizations use the data collected, analyzed and suggestions for next steps provided in this report to guide community development, so neurodiverse residents of Douglas County, Arapahoe County and the City of Aurora can find a home in their community with the support needed to thrive.



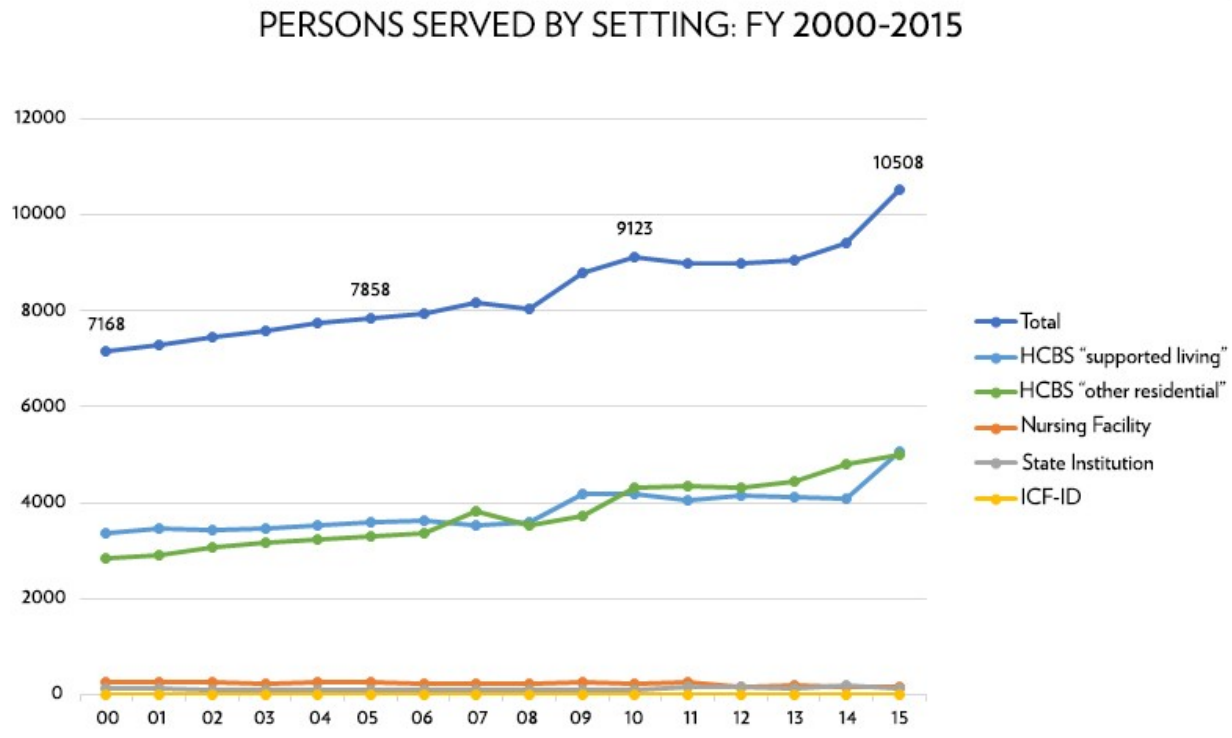
Desiree Kameka is the Director of the Autism Housing Network for the Madison House Autism Foundation (MHAF). For the last decade, Ms. Kameka's work for MHAF has focused on researching housing issues, advocating on issues of autism in adulthood, and presenting at local to international gatherings. After visiting over 100 residential opportunities and social enterprises across the USA, she developed and currently spearheads three MHAF housing initiatives: 1) Autism Housing Network; 2) Coalition for Community Choice, bringing together thousands of stakeholders and self-advocates to inform policymakers of policy barriers and opportunities; 3) Empowering Communities Initiative, providing education, consultations and visioning workshops for grassroots organizing of local housing solutions. Her passion is empowering autistic adults and parents to create a future that is exciting and life affirming.

A recognized disability housing expert and keynote speaker, Ms. Kameka is cited in media outlets such as *The Atlantic*, *Rolling Stone Magazine*, NPR, Psychology Today and ABC News. She has been invited to speak on several panels including: the United Nations World Autism Awareness Day, UBS Global Autism Innovation Roundtable, Great Minds Coming Together on Autism International Conference, and the National Institute of Health (NIH) as a participant of the Interagency Autism Coordinating Committee Housing Workgroup.

BACKGROUND: Why is this important?

In every community in our nation, individuals with intellectual and developmental disabilities (I/DD) and their families are in the midst of a housing and support crisis. Families see the challenge that lies ahead, "What happens when a parent passes away?" can only be pushed aside for so long. Due to a severe lack of appropriate housing options, many Coloradans are forced to stay in their family home for decades, deepening dependence on others. When the family caregiver can no longer support them due to their own aging challenges or death, residents with I/DD are often moved to the 'next empty bed,' which may be overly restrictive and expensive to taxpayers. Not only does this limit the dignity of autonomy in adulthood, it stresses the family unit financially, emotionally and physically. This need is growing exponentially for the following reasons:

1. Nearly 86,000 adults with I/DD are known to Colorado Medicaid authorities to need long-term services and supports, but many more remain unaccounted for either because families have never contacted the state for help, they are ineligible to receive services, or they remain un/mis-diagnosed.
2. The need for housing and long-term services and supports far exceeds the ability of governments to respond. More than 12,000 adults with I/DD live with a caregiver over the age of 60, but residential support is currently available to approximately 10,500 state-wide. Even worse, growth in community-based residential placements over the past decade averages merely an additional 265 people a year. This growth rate will certainly not be able to meet the imminent demand when aging caregivers can no longer support their loved ones with I/DD and may need support themselves.
3. A major disconnect in meeting the demand for supportive housing arises from the fact that the housing industry does not realize neuro-inclusive housing is in demand and that adults living with family caregivers are not counted as part of the larger population at risk of homelessness or institutionalization.



Source: University of Colorado State of the States

FAQ

Who are people who have intellectual/developmental disabilities (I/DD)?

People with I/DD include a wide range of individuals who have been diagnosed with autism, Down Syndrome, Cerebral Palsy, Williams Syndrome, etc. or have another cognitive disability due to chromosomal differences or traumatic brain injury as a child.

Most people with I/DD do not want to simply be defined by their diagnosis. They want to be known for their interests as artists, adventurers, athletes and for their contributions to their community as volunteers, employees or as good friends. Due to their disability, they may need help with these activities of daily living. This may be in the form of assistive technology or in-person support to help them get dressed and ready for the day, assistance with scheduling, relying on others for transportation, or having a person to help them navigate the complexities of a job or community.

Why do we need more housing for people with I/DD if they can live in group homes and host homes?

Just because someone has an I/DD does not mean they automatically get free housing and support. Waitlists are long and finding available opportunities can be difficult in a climate of very few options. Additionally, although group homes and host homes are preferred options for some people, they are not the best fit for everyone with I/DD. Group homes and host homes are considered "provider-controlled" settings, which means the service provider who supports them is also their landlord. If they no longer like their service provider or their service provider can no longer support their needs, they must move and are forced to find a new home.

Others with I/DD prefer to have more control and stability over their home. Fortunately, people with I/DD can also access needed services in a home they own or rent from any landlord. They can choose their preferred service provider from all the local options, but also change them when needed or desired without moving from their home. This is called a "consumer-controlled" setting because their services and their housing are disconnected.

As this report will show, the majority of people with I/DD and their families want to live in housing they control and is disconnected from a service provider, yet the housing stock that is accessible and affordable is extremely limited.

Why should the housing industry be concerned?

There are approximately 127 million households in the United States of America. The CDC estimates that 17% of children have a developmental disability. Thus, creating housing that meets the adaptive needs of people with I/DD is more than simply a niche market.

Not only do accessible features appeal to families who have children or adult loved ones with I/DD, these modifications help people of all ages and abilities. Curb cuts were created for accessibility of people who use wheelchairs, but they also help parents with strollers, those skating down the sidewalk, or others with a knee injury or difficulty with steps. "Neuro-inclusive modifications" may include increasing natural light and sound-proofing for those with sensory sensitivity, discrete drains in bathrooms which make clean-ups easier and decrease the risk of accidental flooding, studs for adaptive equipment in certain parts of the house which help for aging-in-place of all family members, and built in suites with separate entrances which appeal to the growing multi-generational households.

Creating a model "inclusive home" would set developers apart and be a huge draw for at least 17% of the market!

What type of services can people with I/DD access to make sure they can live in their own home?

Long-term services and supports are delivered through service providers and staff who are largely paid by Medicaid. In Colorado, people with I/DD most often access services through a "Waiver." This Home and Community-Based Services (HCBS) Waiver "waives" one's entitlement to institutional care in order to have access to services in one's home and community. Colorado has several waivers for residents to choose from which offer a different selection of services. The intent for a variety of waivers is to make sure the diverse service needs of Colorado residents are being met while maintaining appropriate oversight and financial management locally from Community Centered Boards (CCBs) and ultimately from the state authority, the Colorado Department of Healthcare Policy & Finance (HCPF).

Services for someone who no longer lives with family is decided upon between the person with I/DD, their case manager and anyone who is chosen to be part of their "Person-Centered Plan." These services may include homemaking services (helping keep their home clean), direct support providers when needed who help make sure they have meals prepared and are physically cared for, supportive employment which helps them at work, assistive technology or funding to make sure all aspects of their home are accessible, as well as transportation to work, volunteering, medical appointments, a day program or meeting with friends.

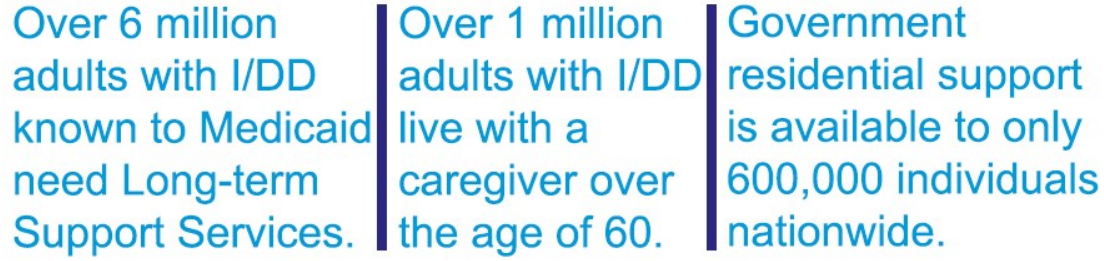
Children and adults with I/DD can contact their Community Centered Board to be assigned an Intake Case Manager who will then do an assessment of the person's support needs and goals, and ideally, an Enrollment Case Manager will be able to connect that person with the "waiver" that would provide the funding for services to best meet their needs. A Colorado resident can choose to be served by any of the CCBs, but often are served by the one that is located in their home geography. Developmental Pathways is the Community Center Board (CCB) for people who live in Douglas County, Arapahoe County and the City of Aurora. Developmental Pathways is one of 20 CCBs in Colorado and funded the Empowering Communities Initiative to understand the needs and preferences of their local constituents to better plan for support in the future. Other CCBs may or may not conduct their own needs assessment process. You can contact Developmental Pathways directly to "Get Started."

Feel free to also access the 3-hour presentation that Desiree Kameka, Project Leader of the Autism Housing Network, gave in early 2019 as part of the ECI process which offers a more in-depth overview of residential options: Video and Slides.

Why should community leaders be concerned?

Community residents are needlessly being displaced for lack of appropriate housing and long-term supports. Not only does this create an enormous disruption in their life, the community loses the valuable assets of residents with I/DD. The meticulous bagger at the grocery store with autism and a bright smile, the young woman with cerebral palsy who faithfully attends worship service and prays with few words but great passion, the older gentleman with cerebral palsy who always waves and remembers the names of all the dogs in the neighborhood, etc. bring unmeasurable value.

Housing is a powerful social determinant of health and lack of housing for people with I/DD has even greater impact as it leads to displacement from one's community of support. If only looking at financial reasons, this displacement due to lack of housing options wastes enormous financial investment of special education, vocational rehabilitation, and Medicaid that has built an entire individualized support system to help the individual participate in their specific community. Being forced to leave their community, they lose what natural support system they have built, become isolated, depressed and other health issues quickly follow.



UNDERSTANDING THE LOCAL DEMAND

Douglas County, Arapahoe County, City of Aurora

Empowering Communities Initiative Process in Partnership with Developmental Pathways

It is very difficult to accurately measure preferences when discussing residential options as many people have different understandings of what is possible. It is important to clarify the different models and nomenclature regarding property types, service delivery and other privately funded support options as the terms are not standardized. What one person thinks of a "host home" may be completely different than what the next person may consider. Therefore, it was imperative to educate stakeholders in order to achieve the most meaningful results. The following describes the process of the Empowering Communities Initiative (ECI) stakeholder trainings:

A. Four presentations on the various benefits and considerations of different funding frameworks, property types and service delivery models were offered from March 2019-April 2019 on different days and times: one in Douglas County, one in Arapahoe County and two in Aurora. These presentations were advertised digitally by Developmental Pathways as well as through flyers. Approximately 300 stakeholders attended these presentations in-person. Respite was offered at one of the presentations. The presentation was also video recorded and slides shared digitally. The presentation and Q&A lasted approximately three hours. Thus, the individuals who attended or watched the presentation were committed to becoming well informed before participating in our extensive survey.

B. After the presentation, stakeholders were asked to complete the *Residential Needs & Preferences Survey*. Hardcopies were printed for those who preferred not to fill out the survey on their phone or a laptop. The survey took approximately 10 minutes to complete. Survey results of over 100 respondents will be described in the next section.

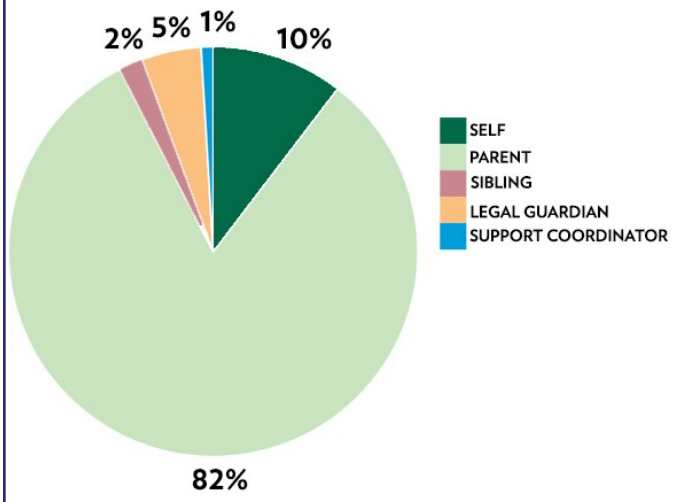
C. In May 2019, two Local Leader Workshops for service providers and community leaders were hosted to share some of the preliminary results of the surveys. These included residential service providers, disability rights activists, housing developers, architects, teachers, case managers and other leaders from local not-for-profits. An overview of state-specific statistics on supply and demand as well as results from the *Residential Needs & Preferences Survey* were shared and discussed. The workshop participants then participated in an activity to identify 1) strengths, 2) barriers, and 3) opportunities to meet the demand of the data presented. The discussion will be reflected in the next section.

This ECI report was drafted after hearing the questions of in-person presentations, analyzing the data from the survey and other sources, and facilitating the workshop

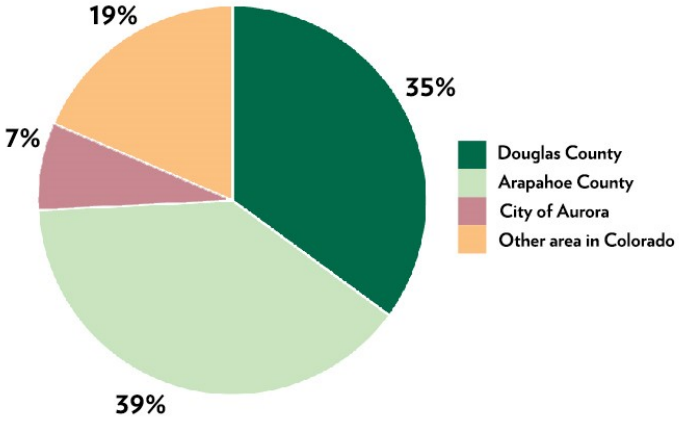
ECI SURVEY RESULTS & ANALYSIS

After committing to and participating in the 3 hour training, there were 106 surveys filled out by individuals with I/DD and/or their family members. Those who participated lived across Colorado, despite being promoted and hosted by Developmental Pathways who serve constituents primarily in Douglas County, Arapahoe County and the City of Aurora. Some drove over an hour to attend and access the information.

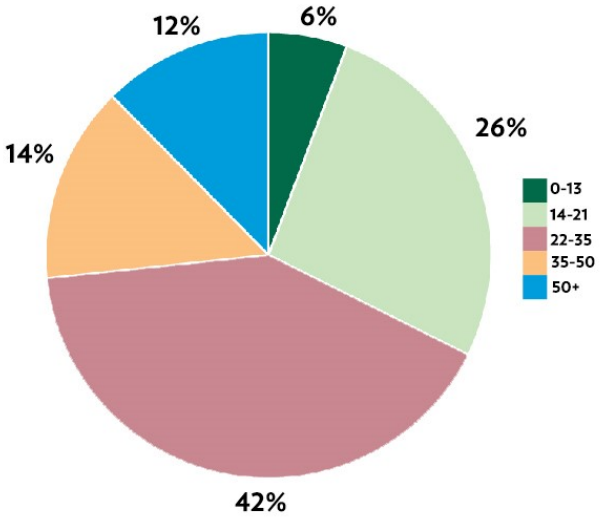
Person Completing Survey (Relationship to Resident with I/DD



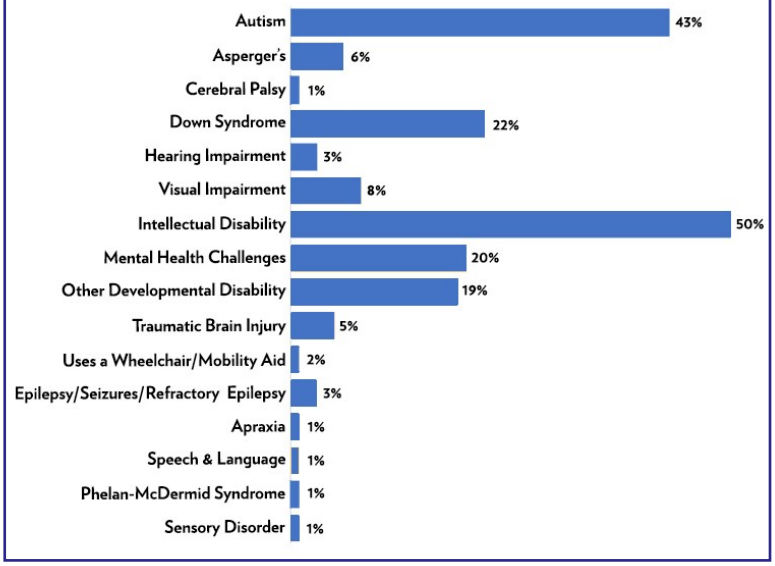
Current Location



Age of Individual with I/DD



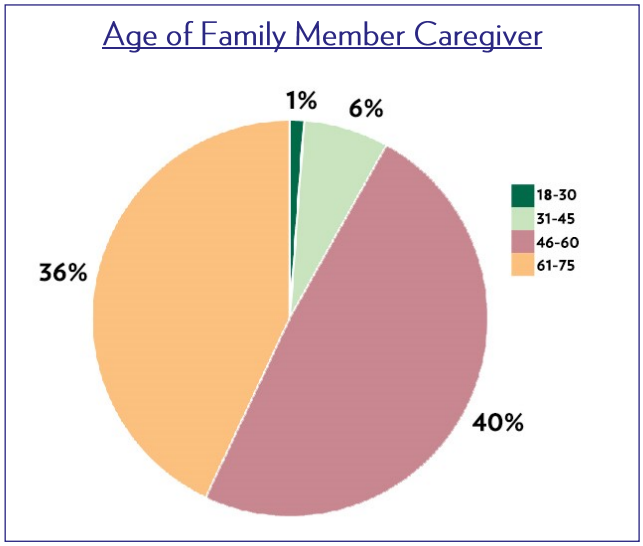
Type of Disability



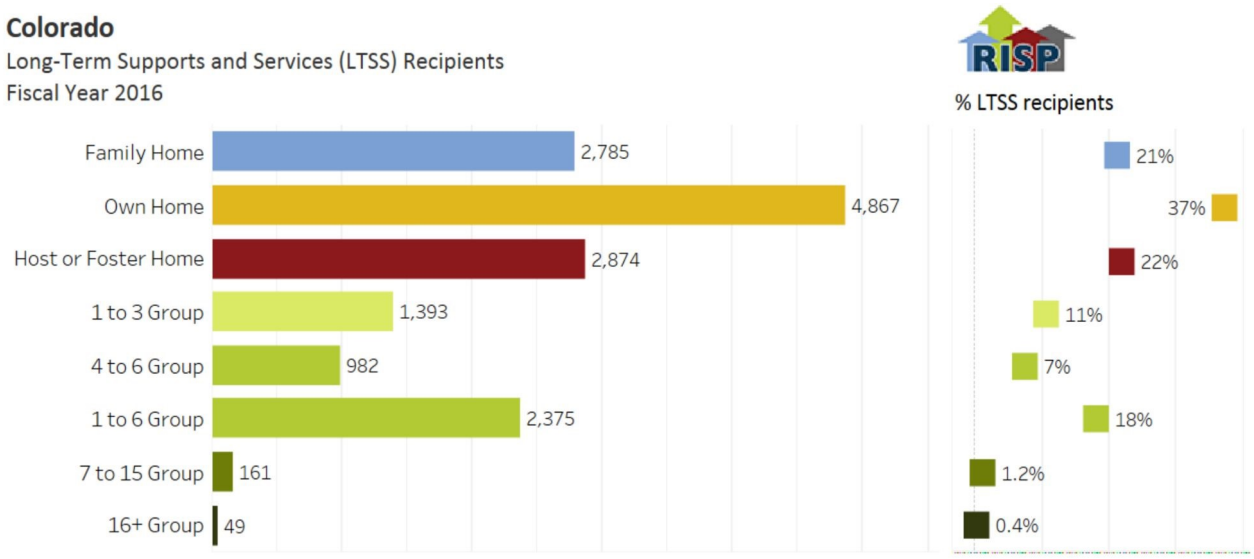
WHERE DO CO RESIDENTS WITH I/DD LIVE?

Data from the University of Colorado's *State of the States in Developmental Disabilities (SOS)* indicates that nearly 86,000 Coloradans with I/DD are known to Medicaid authorities in Colorado. Of those who participated in the ECI programming, only 62% are currently receiving any services or support from Medicaid. Thus a gap of 38% of respondents with I/DD or their family members who participated in the ECI were likely not counted in the SOS data for Colorado. This is important to recognize when developing strategies state-wide to meet the demand.

The SOS study reports that approximately 62,000 Coloradans with I/DD live with a family caregiver, with 20% of that total or approximately 12,400 living with a caregiver over the age of 60. **Of participants surveyed in the ECI process, 36% are currently living with a family caregiver over the age of 60.** As caregivers age, they will also be in need of support and no longer able to provide a home and be the primary caregiver to their loved one with I/DD. Supporting families with respite and in-home direct care is important and imperative for the well-being of the family unit, yet it should not be relied upon as the only choice for adulthood as adults with I/DD may outlive their parents and should have the opportunity to continue to grow as autonomous adults by leaving the nest when they feel ready.



The SOS study indicates that only 12%, or approximately 10,500 individuals, are accessing residential supports in any residential setting outside of the family home. According to the UM Institute on Community Integration Residential Information Systems Project (RISP), of those who receive residential support services, 42% live in a provider-controlled setting, 37% live in their "own home" or a consumer-controlled setting, and 21% are receiving residential supports while living with a family caregiver.



The number of Long-Term Supports and Services Recipients is for the IDD Agency in the state. There may be people with IDD who are served in other state agencies, such as resdients of Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). Group settings (1-6. 7-15, and 16+) include ICF/IID, group homes, and other congregate settings.

PREFERENCES IN SERVICE DELIVERY

As the growth in residential supports is considered, it is imperative that Colorado plans for the service delivery models that residents prefer. Over 50% of respondents indicated that 24/7 supervision and support would be necessary with half of those needing 1:1 support to be able to participate in the community and live outside of the family home. Notably, over 32% of respondents simply need someone to check on them once a day or every few days and do not necessarily need scheduled staff throughout the day.

32% Need daily on-site support to check in

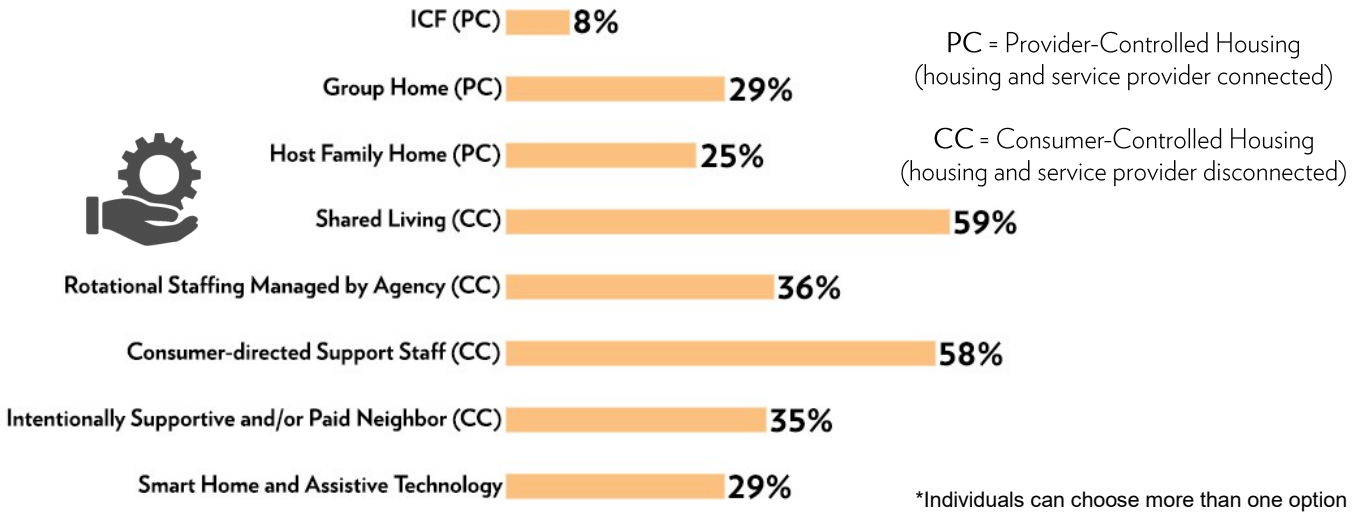
26% Need scheduled support staff

Once educated and asked about service delivery models in general, the majority of respondents valued the separation of one's housing from their service provider, thus preferring a consumer-controlled setting. Shared living was the service delivery model with the greatest indication of preference, with consumer-directed supports as a close second. It is of concern that individuals with I/DD who need access to 24/7 or 1:1 support do not have an option for consumer-directed support, which was the second most preferred choice in service delivery options. Through presentations and follow-up questions, it is clear that stakeholders are unsure of the major differences in these waiver options.

25% Need 24-hr direct support

22% Need 1:1 Support

Survey Responses for Preferred Service Delivery Models



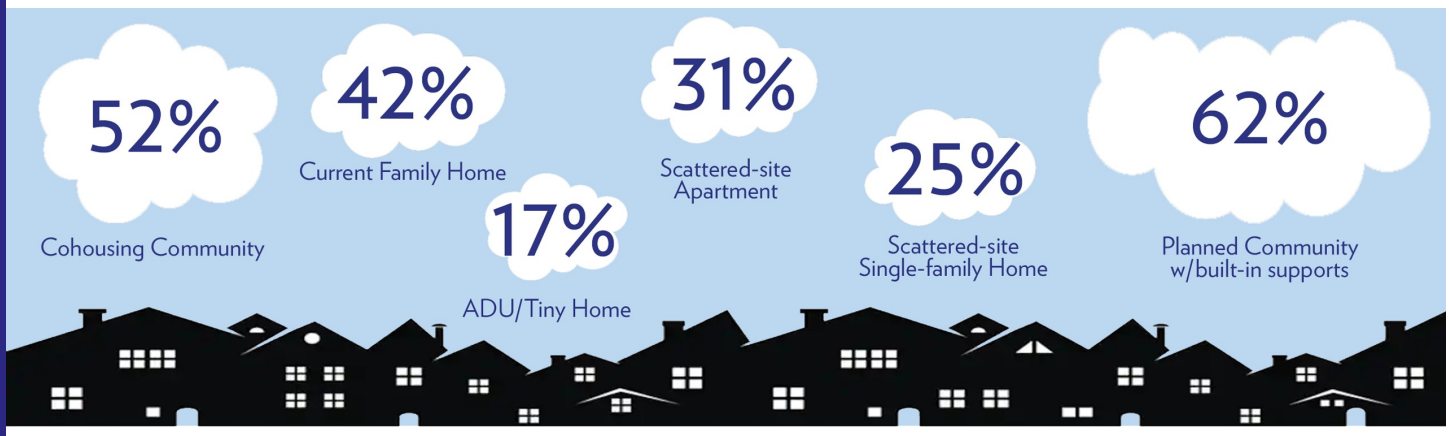
Through Community Centered Boards, residents with I/DD have two waiver choices that include supports for different residential settings:

1. Home and Community-Based Services Waiver for Persons with Developmental Disabilities waiver (DD waiver)
2. Supported Living Services waiver (SLS waiver)

*For other type of waivers intended for those without I/DD, but may work better for some situations, Single Entry Point Agencies offer the Elderly, Blind, Disabled Waiver and the Brain Injury Waiver.

HOUSING PREFERENCES

PREFERRED PROPERTY TYPE



Colorado residents with I/DD have diverse preferences in where and what type of housing they would like to live once they no longer want or can live with a parent/s or other family caregiver. The following are short descriptions of some of the property types presented at the trainings:

CURRENT FAMILY HOME — This describes a scenario when one's parent or support "leaves the nest" and the individual stays in the home. This may be a great option for those who have spent resources in modifications of the home to be more accessible. It may also be a great option for those who have created strong connections with their current neighborhood.

ACCESSORY DWELLING UNIT OR TINY HOME — This is a more affordable option that can be added to the property of one's family or supportive/paid neighbor, yet still provides the privacy of having one's own home.

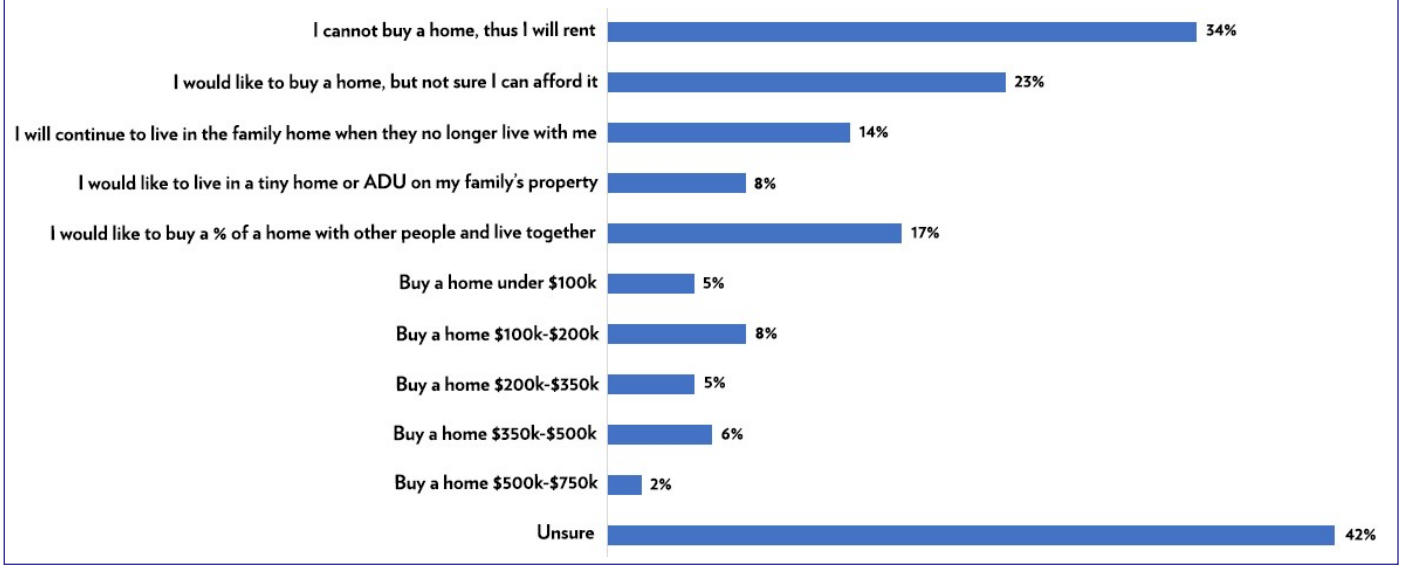
SCATTERED-SITE — Describes a typical apartment, townhome or single-family home. This home is "scattered" in a typical neighborhood and has no intentional cognitively-accessible design strategies or amenities.

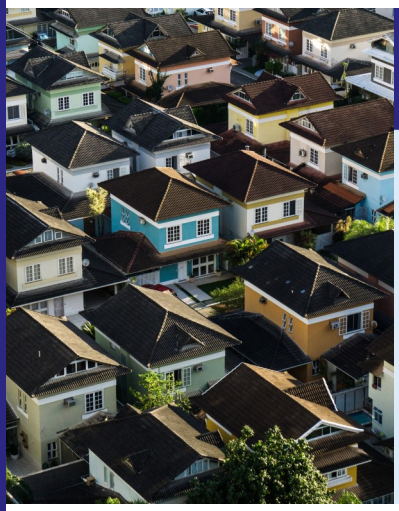
COHOUSING OR INTENTIONALLY-BUILT NEIGHBORHOOD — Describes a multi-generational neighborhood that was created collaboratively with future residents having a shared vision and purpose. Residents rent or own their own homes in the community, and do not share personal finances. They choose to live in proximity to others in order to more casually share quality time and support one another.

PLANNED COMMUNITY WITH BUILT-IN SUPPORTS — Individuals with or without intellectual/developmental disabilities may rent or own units, but the property was developed with the neurodiverse population in mind. It may intentionally incorporate both physical and cognitively-accessible design elements as well as common spaces or amenities desired by future residents with I/DD. Additionally, the property may offer soft supports not otherwise covered by Medicaid as described later in this report.

Nearly all housing assistance for people with disabilities is geared towards permanent rent subsidies (Housing Choice Vouchers) or units that are rent-restricted. These programs are vital to make rent more affordable. Yet, respondents to the *ECI Residential Needs & Preferences Survey* indicate that home ownership is certainly a desired option as well. A strong fiscal argument can be made to open more doors to homeownership for people with I/DD and their families. For example, if a person with I/DD was able to access a Housing Choice Voucher that equaled approximately $700 a month for subsidized rent, in the span of 20 years, without considering inflation or major housing market swings, rent subsidies would have paid $168,000 to a landlord. Housing choices should include opportunities for asset development through home ownership that could provide more housing security and stability than relying strictly on rent subsidies and affordable units in rental properties that expire.

Are Respondents Planning to Own Their Future Home?





HOME & COMMUNITY

Highest Ranked Preferences for Housing & Support

86%
Want to live in a SUBURBAN setting

30% would like an urban setting
28% prefer a semi-rural setting
8% would like a rural setting

52%
Want a cohousing community or intentionally-built neighborhood

62%
Want a planned community with built-in supports

59% Want consumer-controlled shared living

58% Want consumer-directed support

TOP 3 BUILT-IN FEATURES DESIRED IN FUTURE HOME

- Single-level, for aging in place
- Easy clean features
- Smart home equipped

TOP BUILT-IN SERVICES DESIRED IN FUTURE HOME

- Access to affordable transportation
- Housekeeping services
- Access to shared dining
- Emergency help intercom

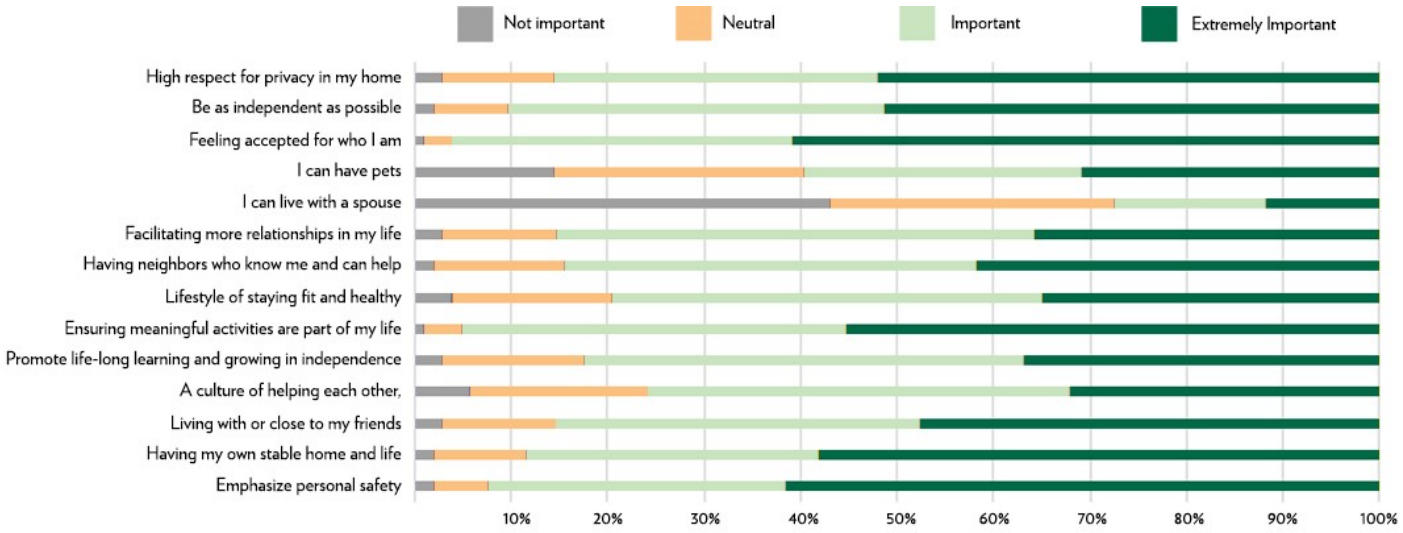
COMMUNITY SPACES DESIRED WITHIN WALKING DISTANCE

Theatre room
Dog park
Community Building
Grocery Store
Restaurants
Gym
Pool
Walking Path

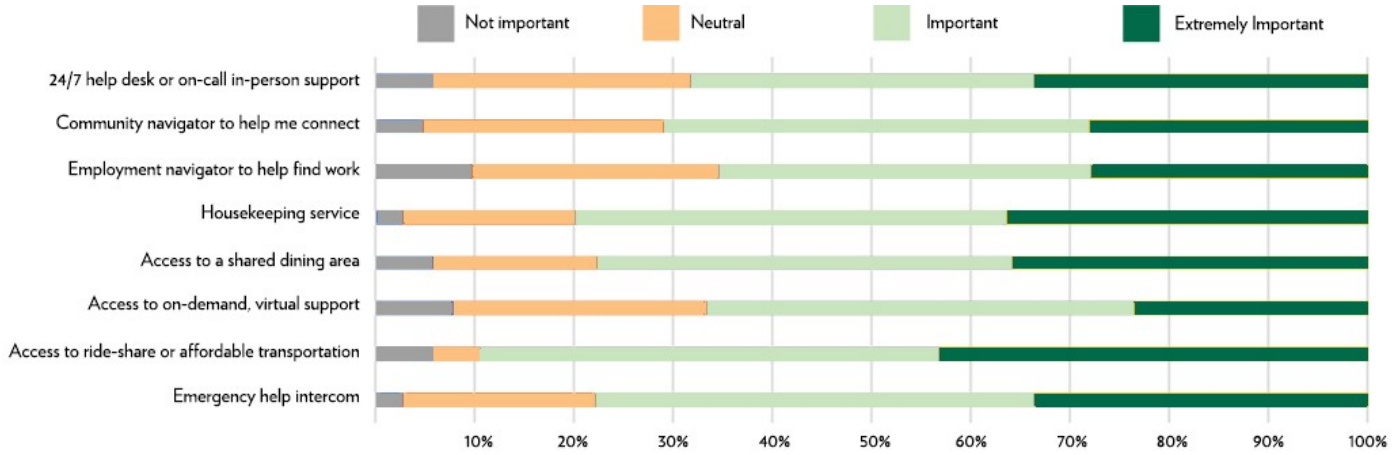
The Top 5 Desired Values for Future Residential Opportunity Ranked as Important or Very Important:

Considering the high demand of planned communities, the following are some design elements that can make housing more accessible to people with I/DD. Housing designs that incorporate the needs of I/DDs and built-in supports could be a great strategy to house those who may not qualify for an HCBS waiver, but could live independently if there was a safety net of assistance as needed.

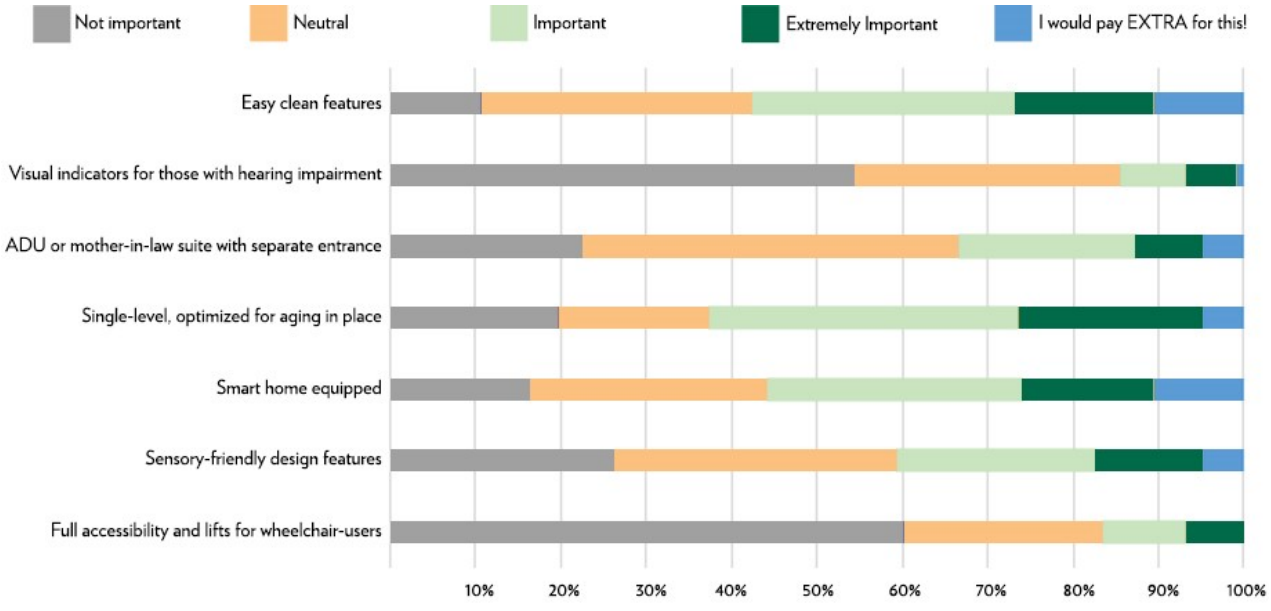
Future Residential Supports?



Without considering costs, what type of built-in services would you like in a future home?

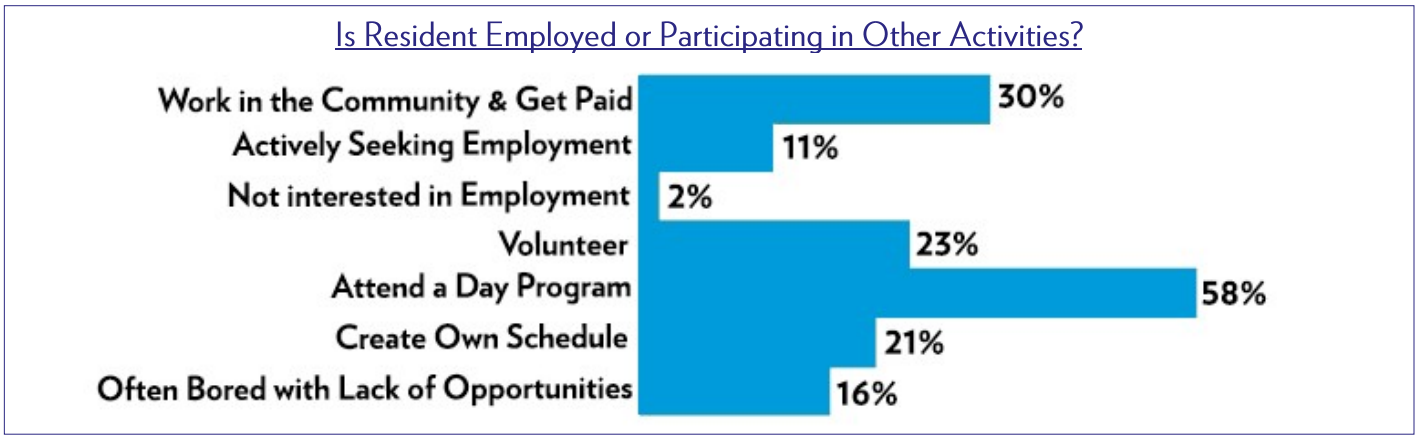


What type of built-in features would you like in a future home?

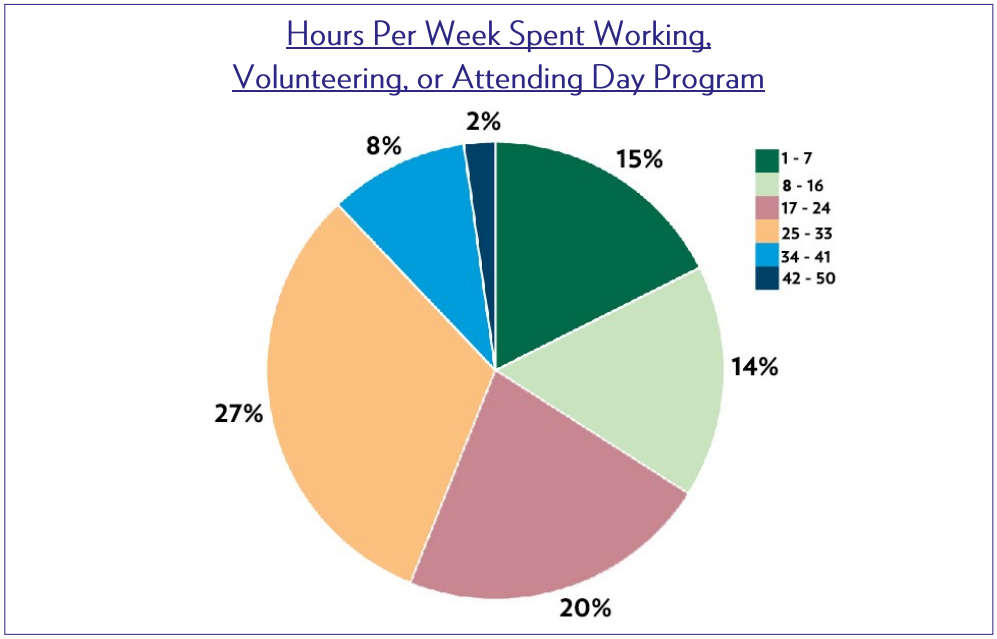


COMMUNITY ENGAGEMENT

It should be the expectation that people are able to spend time in a variety of places and spaces in their community. When looking at how residents with I/DD spend their time, most attend a day program at some point during the week, over half give back to their community through employment or volunteerism, many enjoy creating their own schedule with the things they like to do and 16% say they are “often bored.”



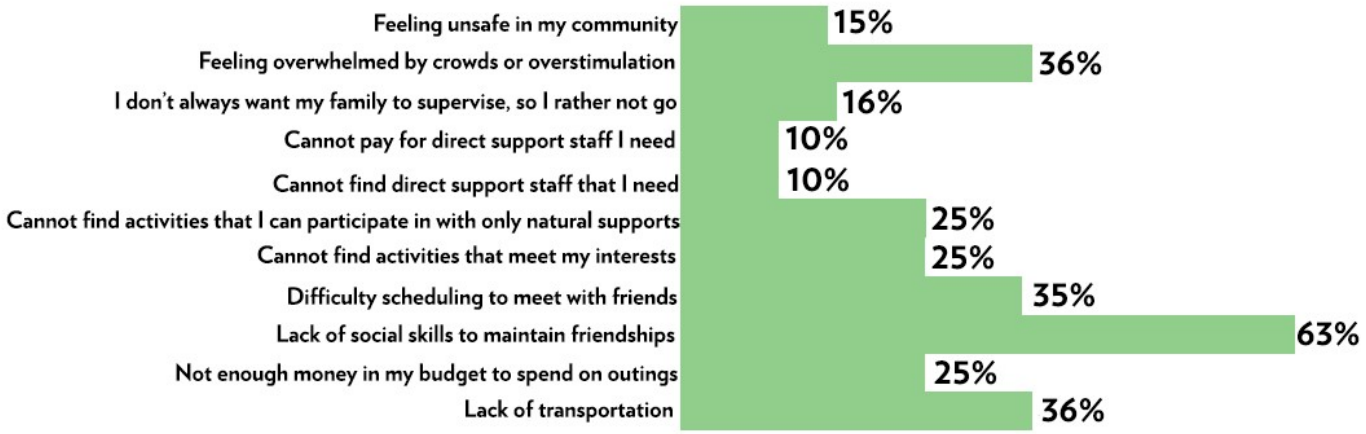
In comparison to the typical 40-hour work week, the survey asked respondents to share the total amount of hours spent at a day program, working or volunteering in the community. Only 10% spent more than 34 hours a week participating in a combination of those activities, most spent from 8-33 hours, and 15% spent less than 7 combined hours a week participating in a day program, work or volunteering. One can assume residents with I/DD spend more time at home than the majority of the neurotypical population who work full-time. Because of this, their home environment has an even greater influence on their well-being.



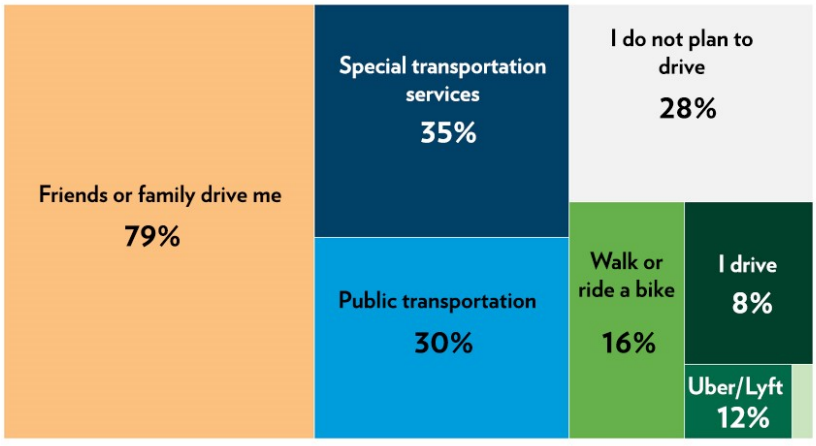
A major goal of the disability rights movement is ensuring that people with disabilities are able to access and participate in all aspects of community life. Thus, it is important to identify what barriers residents with I/DD are currently experiencing. The majority of respondents, 69%, indicated that 'lack of social skills to maintain friendship' was a barrier to community engagement. This was nearly double the next two most indicated barriers, lack of transportation and feeling overwhelmed by crowds/overstimulation, which tied at 38%. A close fourth was difficulty scheduling with friends.

For too long, people with disabilities have been expected to adapt to their environment, even when their impairment makes it impossible. A person with autism may not be able to gain the social skills needed to maintain friendships, not because of a lack of trying, but due to the very nature of their impairment and disability. Thus, being able to adapt and build environments that remove barriers to community engagement is critical. These indicated barriers may also shed light on why planned communities and intentionally neurodiverse cohousing communities were ranked as the top two property type preferences.

What are the barriers to friendship and access to the community?

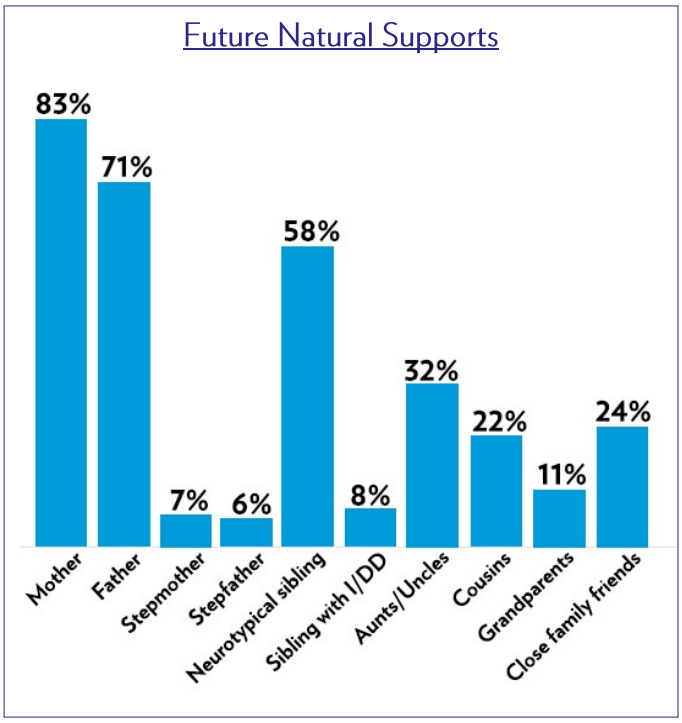


Type of Transportation Used



NATURAL SUPPORTS

As residents with I/DD age, the need for a "natural support system," those in their lives who are not paid to be present, cannot be understated. Sources for natural supports can include family, an old high school friend, Best Buddy, a neighbor who shares an interest in bird watching, a particular member of one's faith community, a Special Olympics coach or volunteer, or a manager at the coffee shop where one works. Identified natural support persons will know them well enough to be able to tell if their family or friend is not well or if something in life may be harming them.



Most often and as reflected in respondent results, those who are closest to residents with I/DD are their family members, and very specifically, their parents. Neurotypical siblings account for 58% of one's future support system and about 1 in 4 will have a cousin or close friend available. This must be improved.

The Disability and Abuse Project estimates that 62.5% of people with I/DD have been victims of abuse. Training for people with I/DD to be able to recognize and share they may be victims of abuse is a great strategy, yet many residents with I/DD may not have the capacity to communicate they are being hurt by someone through verbal affirmation. It often takes someone in their natural support system to recognize a major shift in behavior or mood to take the initiative and investigate if this change may be due to a health issue causing pain or if the person may be at risk of abuse.

Increasing one's natural support system is also imperative for maintaining and enhancing one's quality of life. Neurotypical friends and family may have more access to social and financial capital than the persons with I/DD. Thus when a need arises or is identified, one's natural support system can be activated to help them find what they may be missing instead of relying on their service provider or case manager who is often overwhelmed with the day-to-day activities. Whether it be a friend who takes someone to their favorite restaurant once a month, a new hiking buddy, a confidant to discuss current love interests, or assistance acquiring one's dream pet, having that unpaid and familiar support team is essential for maintaining quality of life and community connection.

MEETING THE DEMAND

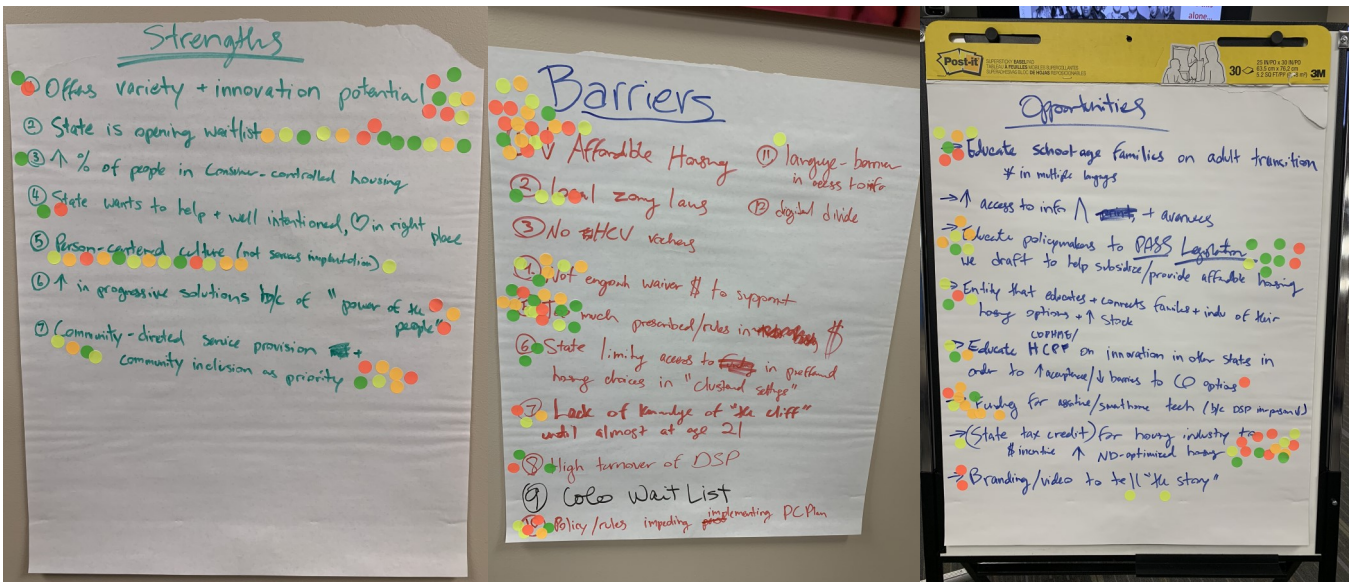
Defining and understanding the demand is the first step to creating a better future for neurodiverse Coloradans. It was important that local leaders were presented with the demand data collected from individuals and families to face the challenges and identify the barriers that will make meeting this demand difficult. Colorado is not alone as every state faces the challenges described in this section. Yet, there are ways in which the state and local communities can move forward to address these challenges.

Gathering Local Leaders to Identify Challenges in Meeting Demand:

Education and data collection are just the first two phases of the Empowering Communities Initiative. Next, a Local Leader Workshop is conducted to explore how the service providers, the housing industry and other local leaders could meet the demand and preferences of their stakeholders.

A diverse group of community leaders including residential service providers, disability rights activists, housing developers, architects, teachers, case managers and other leaders from local not-for-profits participated in two Local Leader Workshops. They were presented the data from the *Residential Needs & Preferences Survey* followed by a Q&A session.

The participants of the Local Leader Workshop were asked what they saw as Strengths, Barriers, and Opportunities to meet the demand. During an open discussion and making an initial list within each of these categories, participants were then given 4 dots to prioritize what they felt were most important to focus on in each category. They could put all the dots in one section, or spread them out. The following are the results of this activity as well as further details from the discussions:



STRENGTHS

4	Family caregiving model
7	Increase in progressive housing & employment solutions because of "power of the people"
2	Adequate funding once eligible
16	Community-based service provision and inclusion as priority
12	Increased use of consumer-controlled housing and service delivery
13	State is opening waitlists
10	Offers variety and innovation potential
2	State wants to help and is well-intentioned with heart in the right place
14	Person-centered culture (not service implementation)

Strength: Person-Centered Thinking and Inclusion are prominent values of service providers

It is clear after speaking with community member participants and professionals that many Colorado service providers place high value on person-centered thinking and inclusion. This is an important cultural value shift for a successful "system" transformation.

Strength: Systems are equipped and already deliver services largely in the greater community and consumer-controlled settings

Unlike other states, a large portion of residential services delivered are already occurring in one's "own home," thus disconnected from a service provider as desired. This does not mean individuals can access services in consumer-controlled setting on all waivers. Thus, it would be important for the state to review their waiver offerings and ensure residential supports can be accessed in the setting of one's choice with the appropriate service delivery models according to demand.

Strength: Innovation is already happening in Colorado

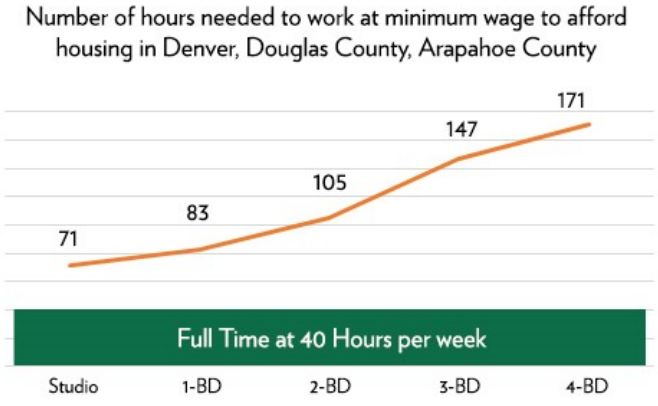
Some examples of innovation in Colorado include: *BrewAbility*, a brewery created to maximize independence for neurodiverse employees and *Tall Tales & Schweiger Ranch*, a partnership of a community-based organization and historic ranch to create a supportive project locally. Exploration and pushing the limits continue to lead Coloradans to do innovative things. It is important that policy and funding streams do not create barriers.

BARRIERS

	Disconnect between providers and Colorado lifestyle
8	Lack of available waivers for residential supports
21	Lack of affordable housing/vouchers
5	Access to help for people with high support needs
6	Complicated waiver system & process with inconsistencies & lack of an-
11	Neurotypical standards for inclusion disconnects with values of the neuro-diverse population and is limiting options
4	Local zoning laws
22	Policy & rules impeding funding and implementation
3	Lack of knowledge of "the cliff" until almost age 21
3	High turnover of direct support providers
1	Language barrier to access information
0	Digital divide

Barrier: Affordable housing is inaccessible, financially and physically, leading to displacement from one's community into more restrictive and expensive residential settings

Survey results indicated that more people preferred to live in a consumer-controlled setting, which offers them the most flexibility and control of their housing stability as they can change their provider and stay in their home. Just like everyone else, people with I/DD pay for housing with income they earn or help from family. Thus, affordability is the biggest challenge.



Source: National Low Income Housing Coalition

Housing is considered "affordable" when 30% of one's income is used for housing.

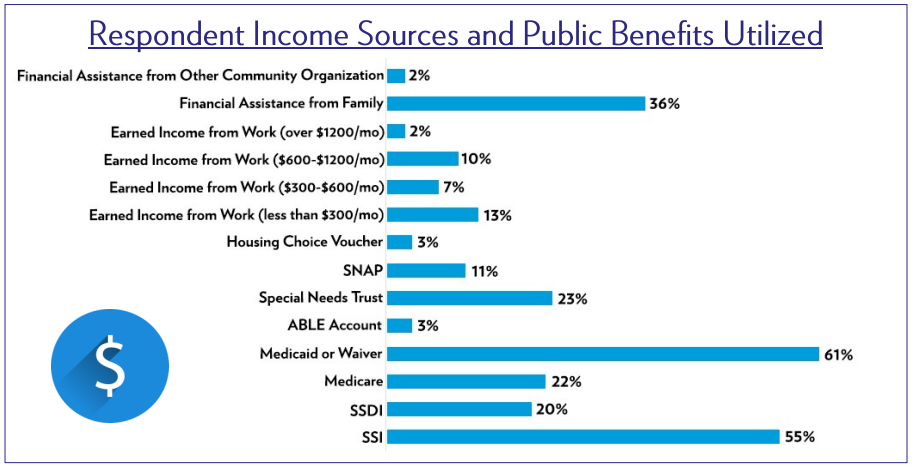
Affordable housing is a national crisis and Colorado has the 10th highest housing wage needed in the country. People with I/DD are able to access nominal support through some help from family and the government to help pay for housing costs:

- Many people with I/DD receive Supplemental Security Income (SSI). At maximum, it would be $783 a month plus a $25 CO supplement, but they could use it to help pay rent.
- Some people with I/DD receive Social Security Disability Insurance (SSDI) based on their own or their parents' contributions to Social Security in the past.
- Few have been able to access a Housing Choice Voucher, in which the landlord would have to agree to be paid from two sources: the person with I/DD who would pay 30% of their total income and the public housing authority who would cover the balance for rent.

The following graph shows various sources of income from survey respondents and how it relates to accessing housing at Fair Market Rent. A one-bedroom average rent in this area is $1,204 per month. If accessing SSI benefits, it is important to note that for every $2 earned over $65, the individual has to pay $1 back to Social Security.

INCOME SOURCE	TOTAL INCOME AVAILABLE TOWARDS RENT	% OF INCOME NEEDED TO PAY AVERAGE RENT OF 1 BEDROOM APARTMENT: $1,204	COST OF RENT NEEDED TO BE "AFFORDABLE"
Maximum SSI (56% of respondents)	**$808/month** (the $25 state supplement plus the $771 basic federal benefit)	**149%** for 1-BD	**$242.40**
SSI + earned income of $300/month (~1 day a week of work)	**$991/month** (includes mandatory deduction of SSI due to earned income)	**121%** for 1-BD	**$297.30**
SSI + earned income of $1,000/month (part-time, minimum wage)	**$1341/month** (includes mandatory deduction of SSI due to earned income)	**90%** for 1-BD	**$402.30**

Source of Rental Data: National Low Income Housing Coalition



If an individual is able to access a waiver, yet cannot find housing that they can afford or is accessible to their needs, they will be forced to live in a provider-controlled setting. This most often means "the next empty bed," which may be in a different county if a provider is unavailable locally. ***When this occurs, the investment is lost in both time and funding in developing one's natural support system, their job, their preferred day program, their preferred healthcare practitioners and their entire life routine upended which can cause trauma leading to crisis intervention.*** Without access to housing, one's life may be more restricted due to living in a provider-controlled setting at a higher cost than if supported in their own home.

Barrier: Bias that affordable housing development must have a 25% density restriction on people with I/DD

Participants in the Local Leaders Workshop reported that using capital for building affordable housing limits the density of persons with I/DD receiving Medicaid services to 25% of total units in projects seeking funding through Low Income Housing Tax Credits (LIHTC).

The 25% density limit is a federal regulation for a very specific program called Section 811 administered by the Administration for Housing and Urban Development that was created to encourage more affordable housing in integrated settings. This restriction does not apply to other affordable housing development capital administered by the Colorado Housing and Finance Authority like Low Income Housing Tax Credits (LIHTC).

LIHTC is a major source of capital for developing affordable housing units. Other states have used LIHTC funding to develop housing targeted to meet the needs of individuals with I/DD. For example, the Dave Wright Apartment Building in Heidelberg, PA sets aside 50% of the 42 units for adults on the autism spectrum. In several cities across Florida, supportive housing communities have been developed with 80% of the units reserved for people with I/DD. As the survey results indicate a high demand for planned communities with built-in supports in conjunction with the need for more affordable and accessible housing, it is important that industry leaders are clear that only Section 811 has a 25% restriction, yet other sources of affordable housing funding do not have this limitation.

Barrier: Inaccessibility of Preferred Service Delivery Options

Again to emphasize the urgency: *Almost 86,000 Colorado residents are known by Medicaid authorities. Only 12% are able to access residential supports to move out of their family home.* Data shows that growth of out-of-home residential supports has expanded by an average of only 223 residents every year for the past 15 years. It is important to note that several of the preferred service delivery options are not easily accessible in Colorado:

- Intermediate Care Facility (ICF-ID) was preferred by 9 respondents, yet Colorado has not sought to expand ICF-ID opportunities. According to the University of Colorado, since 1998 the total number of Colorado residents statewide with I/DD who live in an ICF-ID setting has ranged from 16-25. This follows the national trend towards Home and Community-Based Services, but should not be presumed to be on the decline due to disinterest in the model.
- 35% of respondents said one of their service delivery preferences would be an intentionally supportive and/or paid neighbor, yet Colorado does not have a formal waiver service to provide a stipend to a neighbor for being on-call.
- It is unclear whether the DD waiver would be flexible enough for the host home funding (provider-controlled setting) to be used for a shared living arrangement (consumer-controlled).
- Individuals with I/DD who need 24/7 or 1:1 support do not have the option for consumer-directed services through the DD waiver which is the only CCB option for those who need at least 24/7 support.
- Inability to access appropriate residential services due to waiting lists are also keeping adults with I/DD in their family home longer than desired.

It is important to note that there is a distinction between Host Family Home as a provider-controlled setting and Shared Living where the person with the disability is in control of their home and can invite a person to be a live-in caregiver. According to the RISP data, Host Family Homes are currently the second most utilized service delivery and home model in Colorado. It would be insightful to see if and what percentage of those placements are currently and/or could be a Shared Living arrangement if housing was secured through the family of the resident with I/DD.

Barrier: Many people with I/DD are not qualifying for services, and are not being counted as at-risk for homelessness or incarceration

According to the latest report from the UM Residential Information Systems Project (RISP), there are residential services in any setting other than one's family home for 1 of every 196 Coloradans. Currently, the CDC reports that 1 in 6 children have a developmental disability.

Just as not all children with a developmental disability will qualify for an Individualized Education Plan (IEP), Colorado residents with a developmental disability who may need residential supports to live outside of their family home may not qualify. For example, 1 in 59 children are diagnosed on the autism spectrum (the most prominent developmental disability), but many adults with autism will not qualify for residential supports if they do not have an intellectual disability and/or are deemed "too high functioning," yet many do not have the executive functioning skills needed to live successfully on their own without access to assistance or services.

Colorado residents who are not eligible for the residential support they need are forced to live with family caregivers. Again, these family caregivers will likely not outlive their adult son or daughter. Individuals with I/DD are not being counted as at-risk of homelessness due to living in their family home, yet they are at high-risk of homelessness as their family will not be able to support them throughout their lifetime. They are at high-risk of homelessness because employment for people with I/DD to make a living wage and afford rent is out of reach and they need some support to live independently yet cannot qualify for Medicaid LTSS.

Barrier: Local City Planning Does Not Typically Consider the Unique Current Circumstances of People with I/DD

During the period of rapid deinstitutionalization, many local communities developed zoning restrictions to ensure group homes would be scattered throughout the community and group homes would be protected from forced segregation and clustering due to NIMBY (Not In My Back Yard) backlash from existing neighbors. Additionally, it also prevented service providers from simply securing housing in large clusters and continue using institutional service delivery models. Some of these zoning restrictions would include group homes that cannot be placed next to one another or require a minimum of 1,000 feet between residential facilities. These restrictions were important at one time, but are now creating challenges for those desiring to create consumer-controlled opportunities in proximity to one another.

Local zoning that was created with only the nuclear family or neurotypical resident in mind can also pose some challenges to innovative housing solutions. Local zoning may have restrictions on the number of unrelated people who can reside at a residence. This may make it difficult for families to come together and purchase a percentage of a home that may exceed the local zoning code. Local zoning codes can also make it difficult or impossible for families to invest and create an attached or detached accessory dwelling unit (ADU) or tiny home on their private property. Additionally, for multi-family planned communities, parking requirements that assume all residents drive and have at least one vehicle may limit development opportunities.

Barrier: Local leaders and families feel the state is limiting residential choices of people with I/DD by restricting access to waiver funding

Even if an individual or their family can secure housing, without access to residential long-term support services, individuals with I/DD cannot move out of their family home. The state has the authority to increase waiver or ICF funding and enforce more restrictive policy than what is required by the federal government. They hear the loudest voices, which does not necessarily reflect the majority of individuals with I/DD and their family as most are busy simply trying to get through each day. This is why it is imperative that a diverse range of advocates continue to share their challenges and preferences for their future.

Additionally, pushback of certain residential choices could stem from an important policy change at the federal level that Colorado had to respond to through a Colorado State Transition Plan. The federal regulations for HCBS waivers were updated in January 2014 and are largely outcome-oriented to ensure this funding is not being used for institutional settings. In March 2014, official guidance from Medicaid specified that certain types of settings (farmsteads, disability-specific communities, etc.) "tend to isolate" and therefore may be institutional. Colorado may have shared this information or interpreted this guidance too strictly, assuming settings that are not scattered-site are unwanted and unfundable.

Fortunately, advocates across the country came together to tell Medicaid they were causing harm and unnecessarily restricting choices based solely on physical characteristics, not the outcomes of residents living in the setting nor considering the preferences of people with I/DD. They received an enormous amount of pushback from stakeholders across the country who felt this guidance was misleading and stigmatizing of the residential preferences of people with I/DD. Madison House Autism Foundation flew in self-advocates from different states to tell the top leaders of our country that intentional communities should not be assumed to be isolating and restrictive. See the presentation here.

Due to advocacy and educating Medicaid on how they may be unintentionally causing harm and restricting choices of people with I/DD, federal Medicaid officials superseded this stigmatizing guidance with updated guidance in March 2019 that is outcome-oriented and supports the variety of residential preferences. It will be important for Colorado advocates to share data from the ECI process with HCPF to give evidence that a wide range of property types and service delivery models are essential to meet the diverse needs and preferences of stakeholders with I/DD.

OPPORTUNITIES

11	Entity or summit that educates and connects individuals and families on lifespan support and how to increase housing stock
4	Increase communication between consumers and policymakers so policy & funding reflect preferences
2	Shifting mindset & process to person-centered, not system-oriented
1	Expand variety of lifespan options for ALL people with I/DD
9	Awareness branding or video to tell “the story” and tie to a funding solution or campaign
8	Educating the non-disability world about needs of people with I/DD as target market
6	Educate school-age families on adult transition in multiple languages
14	Educate policymakers to PASS legislation we draft to help subsidize & provide affordable housing
4	Educate HCPF on innovation in other states in order to increase acceptance and decrease barriers to more Colorado options
9	Funding for assistive and smart home technology to supplement in-person direct support
15	Financial incentives to housing industry to increase neurodiverse-optimized housing

The Local Leaders Workshop provided great insight and feedback on what is working, where barriers exist and potential next steps. In the next section, the Opportunities identified in the Local Leader Workshop will be covered and expanded upon to offer a roadmap of suggestions to help increase options and decrease barriers to a life full of purpose and community connection.

POSSIBLE NEXT STEPS FOR THE FUTURE:

The squeaky wheel gets fixed. This Empowering Communities Initiative is just the first step to community development for Housing Task Force stakeholders. The following are suggestions from survey respondents as well as best practices from other communities who are actively developing more innovative housing solutions and effectively advocating with and alongside community members with I/DD.

A. NEXT STEPS TO DEVELOP INITIATIVES FOR LIFESPAN PLANNING, SKILL DEVELOPMENT AND EFFECTIVE ADVOCACY:

a) Increase awareness among families of children with I/DD that housing is a vital component to life stability. When a child is referred to Developmental Pathways, their family could be educated on how to prepare for the lifelong needs of their loved one. This may include teaching them about an ABLE Account and the tax benefits of saving for lifespan needs, a suggested list of life skills goals that can be adapted for inclusion in an Individualized Education Plan (IEP), or even stories of adults with similar support needs to act as role models. Parents should not assume nor set expectations that their child will live with their family decades into adulthood, but instead, that they will be active members of their community and will need their own place to call home.

b) Continue to educate adults with I/DD and their families about residential options. Even after a three hour training, a large percentage of respondents were still “unsure” of what their preferences would be for property types or service delivery options for the future. Highlighting success stories of individuals transitioning to different types of “home” options may help constituents further understand their options. Additional and ongoing training tied to person-centered planning offerings may be another avenue to help educate about lifespan offerings for different lifestyles and support needs. Stakeholders must know what they want before they can best advocate for their needs.

c) It is a strong recommendation that the Developmental Pathways Housing Task Force continue and leaders of various organizations develop core values and a plan to work together towards advocacy efforts in order to speak with “one voice” to policymakers and local leadership. When policymakers or local leaders hear conflicting messages, it often results in stalled efforts.

d) Respondents of the survey indicated that it would be helpful if a database was available to connect potential roommates with I/DD, host families and supportive neurotypical roommates for shared living arrangements. This initiative could also help educate and raise awareness of the opportunity for neurotypical residents to be host homes and/or supportive roommates in shared living arrangements.

e) Understanding options and filling out all of the necessary paperwork within the disconnected "system" is extremely difficult. A very clear majority of survey respondents wanted more opportunities to learn how to navigate housing assistance (73%), Medicaid LTSS (64%), and additional financial and legal life planning options. There is clear demand for a housing and lifespan resource center for residents with I/DD to get help. Though autism-specific in name, Autism Housing Pathways in Massachusetts is one of the best grassroots efforts to educate and facilitate navigation of resources. Unfortunately, a local Center for Independent Living is not present in Douglas County, Arapahoe County, nor the City of Aurora, but would be a great, federally-funded opportunity to explore.

Due to historic reliance on provider-controlled settings, constituents with I/DD are often not thought of as needing affordable, accessible housing. Thus, the housing industry, local government, and even Public Housing Authorities are largely unaware of the magnitude of the need for affordable, accessible housing of residents with I/DD. The following are suggestions for potential next steps to increase housing options for the future:

B. NEXT STEPS TO INCREASE HOUSING OPTIONS IN LOCAL COMMUNITIES:

a) Advocate to Colorado Housing & Finance Authority (CHFA) that individuals with I/DD are an at-risk population and incentives for the development of more affordable housing that includes accessibility for both physical and cognitive impairments is needed.

- Ask if they would consider an I/DD specific homeownership class for individuals and families to understand how they can access help to buy their own home.
- Each year, CHFA must publish a Quality Allocation Plan that describes how Low Income Tax Credits, a major source of capital to develop affordable housing, will be allocated. Accessibility features for potential residents with I/DD could be listed as criteria or a specific population that applicants could intentionally include to earn extra incentive points.
- Additionally, a percentage of total LIHTC or other affordable housing subsidies or capital could be set aside to specifically address the needs of this population every funding round.
- A loan program could be developed that offers matching funds or low interest loans to families who want to invest in an ADU or tiny home on their property for a dependent adult child or aging parent.

b) Advocate to ensure that residents with I/DD are recognized as a specific Extremely Low Income (ELI) at-risk population at the local Public Housing Authority (PHA).

- Each PHA is required to establish an Annual Plan that describes the PHA's approach to meeting local housing needs among low and very low-income people. Ensure each PHA has identified residents with I/DD, both living with aging family caregivers and those who are forced to live in a provider-controlled setting or institution, within their plan and prioritized where applicable.
- PHA's can create prioritization or "preferences" of persons with I/DD within waitlists for Housing Choice Vouchers.
- Housing discrimination complaints due to disability to the Office of Fair Housing and Equal Opportunity (FHEO) outnumbers all other discrimination complaints. Thus, educating and providing landlords who participate in PHA-run programs about potential renters with I/DD could help mitigate disability-related stigma and complaints from both sides.

c) The Colorado Department of Local Affairs (DOLA) is an important entity to educate on the housing needs of residents with I/DD. DOLA is a resource for local governments across the state for training and technical assistance, and is also responsible for several funding sources related to local community development increasing affordable housing stock.

d) Local planning and zoning commissions should be educated about the housing needs of their neurodiverse citizens as zoning variances and future development must be approved by them to proceed. A few opportunities that could help ensure additional housing options include:

- Request that future development includes an accessibility plan.
- Request if future proposed development would be willing to work with a local community organization to set aside supportive housing units for people with I/DD.
- Offer greater support for variances in zoning, parking or land use when the project intentionally includes or serves people with I/DD.
- Consider adding 'use by right' in residential zoning districts for addition of accessory dwelling units for property owner dependent adult with disability or elderly family member.

Deinstitutionalization began in 1980 with the emergence of the development of Home and Community Based Service (HCBS) waivers. More individuals are being served in the community than ever before; yet, there has been an over-reliance on family caregivers who are now aging and may soon be unable to provide a home and support their loved one with I/DD. It is imperative that Colorado, along with all of the other states in our nation, address this urgent crisis to prevent the trauma associated with emergency placements and waste of fiscal resources when placements must occur in nursing facilities, hospitals or other overly-restrictive settings due to lack of options and proper planning. The following are suggestions for potential next steps to increase access to long-term services and supports (LTSS) for the future:

C. NEXT STEPS TO INCREASE ACCESS TO LONG-TERM SERVICES & SUPPORTS (LTSS):

a) State and Local Level: A census of adults with I/DD who will need LTSS at some point in their future is needed in order to properly plan and prevent forced institutionalization and homelessness. This census should include level of support needed to live independently, preferred service delivery, if they meet eligibility requirements, and what barriers were identified to access the support needed if they have contacted Medicaid in the past.

b) State and Local Level: Explore how the use of technology can assist in delivering LTSS and what system changes would need to be altered to include technology-based LTSS in Colorado.

- Several states are now moving towards "Technology-First" as a strategy to assist more people with I/DD to live as independently as possible. Tennessee has launched a video series, Enabling Technology Model Homes, and a Summit to help share how assistive technology can impact the lives of their stakeholders with I/DD.
- The Assistive Technology Act (AT Act of 2004) provides federal funding for assistive technology device demonstrations, equipment loans, reutilization and financing. The Assistive Technology Program of Colorado is hosted by the University of Colorado Center for Inclusive Design and Engineering (CIDE).
- Advocates can request more emphasis and outreach be placed on areas of 'Community Living.'
- Additionally, as the program is housed at the CIDE, it would be a great opportunity to share and request more research and training in the area of out-of-the-box technology (Alexa, Google Home, Nest, etc.) used as assistive technology to increase independent living for those with I/DD.

c) State and Local-Level: General, local and "selective" taxes can be directed specifically to help fund LTSS for people with I/DD. Colorado has one of the lowest general state tax rates in the country at 2.9% and local jurisdictions have the ability to add local tax rates as well. For example, Douglas County has a local tax rate of 1% on top of the state 2.9%. It is projected that $350 million will be generated in 2019. Douglas County has a Developmental Disabilities fund by which a projected $6.4 million dollars in 2019 is set-aside from the projected local taxes. The amount set-aside for the Developmental Disabilities fund in future years from local taxes could increase or decrease. Additional "selective" taxes on items such as alcohol, tobacco, etc. could also be imposed and directed to fund LTSS for people with I/DD.

d) State-Level: Increase flexibility of existing HCBS waivers to meet the needs and preferences of stakeholders. The Colorado Department of Health Care Policy & Financing has the ability to add additional services and/or service delivery models to existing HCBS waivers. The state can also discontinue or add HCBS waivers as the state deems necessary to meet the needs of its constituents. They can even apply for a 1115 Demonstration Waiver to explore other types of LTSS models that may not be possible through existing HCBS models. Advocates can organize and request changes to HCBS waivers to better meet their needs.

e) State-Level: States report how much money they spent on Medicaid services for eligible participants and the federal government "matches" those costs without limit. In other words, the more the state spends to care for their residents, the more money they will get from Medicaid. If the state put more money into LTSS for persons with I/DD, the federal government would match their additional contribution. The state has the ability to increase matched funding to meet the demand of their residents.

Communities miss out when individuals with I/DD are unintentionally excluded in everyday life. People with I/DD must work harder to develop relationships outside of their family and engage with the greater community as most do not drive, have limited employment hours, have difficulty maintaining relationships due to disability-related impairments, and experience more social anxiety in new or crowded places. Often, if a neurotypical local resident does not have a family member with I/DD, they are unaware of these social barriers and may not have the opportunity to develop relationships with neurodiverse neighbors. With 17% of children having a developmental disability, it is imperative that the strengths and struggles of this population become more well known in their community. Additionally, awareness and education among key local leaders about their neurodiverse residents is also crucial as they drive the economic and community development of municipalities.

D) NEXT STEPS TO INCREASE ACCESS TO COMMUNITY SUPPORT & ENGAGEMENT:

a) A local community awareness campaign focused on increasing inclusion and awareness of the value neurodiversity brings to a community may decrease isolation and unintentional exclusion.

- The Housing Task Force and partners could develop awareness materials for how to combat isolation targeted to those who may not have a family connection to residents with I/DD.
- The Housing Task Force and partners could coordinate the participation in local events such as festivals, farmers markets, etc. to set up tables with awareness materials, make sure the event is accessible, and even suggest sensory-friendly times for visitors who may be extra sensitive to noises and crowds.
- Another example is coordinating and identifying local businesses who have opted into training for their staff to become more aware of neurodiversity in their community. For example, Mesa, AZ went through an accreditation process to become an official autism certified city.
- Pictures speak louder than words and videos are an important tool to include in a campaign. Don't forget to include an "ask" while you have the attention of the viewer.

b) All elected officials should understand the needs and impact of their constituents with I/DD and their families. They are likely unaware that 17% of their residents have I/DD and that their family and friends extend their voting impact to key issues. It is important they are connected to local self-advocates and families who can act as advisors on major community development decisions.

c) The local planning and development commission should be made aware of the housing and support crisis of their residents. As they are one of the key players in the approval of permitting, zoning variances, approval of new development, etc. they should be sensitive to the needs of their constituents with I/DD and their families. For example:

- Greater consideration of permit requests when the business intends to actively recruit and employ people with I/DD.
- Consider 'use by right' zoning variance for the addition of accessory dwelling units or tiny homes for the use of a residence by a dependent with I/DD or elderly family member.
- Allow greater parking variances for housing intentionally designed for people with I/DD as most do not drive their own vehicle.
- Ensure spaces and places in the community are both physically accessible as well as cognitively accessible and sensory-friendly

d) The Madison House Autism Foundation began a movement to declare April 21st as *Autism After 21 Day* or *Ability After 21 Day* across the country. The purpose of the event is to request a local elected official to make the declaration, thus establishing not only awareness but a relationship. An event targeted to leaders and local businesses is often held in celebration of the day. The event highlights self-advocate talent and/or accomplishments and describes the continued challenges adults with I/DD face. It concludes with a simple request to be more intentionally inclusive of neurodiverse community members.

e) Share this Empowering Communities Initiative report and request to meet with the local Home Builders Association, Realtors Association, Rotary Club, Womens Club, Kiwanis Club, etc. to help raise awareness of the need for more housing, employment, volunteer and day activities for community members with I/DD.

f) Tied for the second most requested opportunity is the expansion of life-skill classes and more affordable planned activities. Developmental Pathways does a great job of sharing local opportunities with their constituents through social media and newsletters, but most of these opportunities cost money. Survey results indicate that for 25% of respondents extra money to do things is a barrier to participation, 16% are “often bored with lack of opportunities,” and 71% of survey respondents want more affordable planned activities and independent life skill classes. This is a great opportunity to develop a collaborative initiative to connect with community businesses, events, faith communities and recreational organizations for more intentional outreach. This would result in a calendar or weekly digest of opportunities where effort has been undertaken to prepare an intentionally affordable and supportive environment or activity. A full-time community connector or small staff could be funded to provide this intentional outreach and coordination through collaboration of service providers, small monthly membership fees or grants. The following are examples of requests to existing community social capital:

- Ask local gyms or recreation centers if they would consider a discounted rate for persons with I/DD or foster a co-training program to match neurotypical members alongside adults with I/DD who need a bit of support to use gym equipment successfully.
- Ask the CSU Extension Office if the Master Gardeners would be willing to offer monthly tours of the experimental orchard or a workshop on potting and caring for a plant.
- Ask local faith communities if they would like to host a game night in their fellowship hall to develop more community connections with residents with I/DD.
- Ask a grocery store or local nutritionist if they would sponsor and host a cooking class for healthy food preparation.
- Ask the local festival if they would consider adding a quiet recharge area or having a sensory-friendly time period to accommodate those where large crowds, unsolicited soliciting, loud noises, strong smells or blinking lights are subdued.

CONCLUSION

It is important that policymakers use evidence-based data and not rely on the theories of a few to create a system that offers a wide range of residential options and service delivery models for the diverse population of people with I/DD. Families and individuals with higher support needs are forgotten as they are unseen and unheard due to not being able to find the time nor the energy to advocate in-person. Equally invisible are those who are not in the system due to being "too high functioning," thus not eligible by current standards or those who live in households where asking for government support is either dismissed or perceived as too risky. Although a modest sample size, the data collected from the *Residential Needs & Preferences Survey* offers important evidence to help direct how the Housing Task Force can partner with stakeholders to create the future options stakeholders need and prefer.

In conclusion, the following are aspects of community development that must be addressed to ensure a future full of opportunity for residents with I/DD:

1. An increase in affordable, neuro-inclusive housing stock is desperately needed; barriers to development must be removed and incentives created to meet demand.
2. Individuals with I/DD and their families want to be able to invest in a home for their future stability; support should be put in place to help make this happen.
3. Barriers of service provider ability to offer individualized long-term services and supports must be removed and diverse service delivery models fully funded; a person-centered plan is useless if the system cannot deliver flexible reimbursement for person-centered supports.
4. Many are still "unsure" as to what they may or may not prefer in a long-term support system, thus continued education and storytelling are needed.
5. Intentional spaces and opportunities are needed to foster neurodiverse friendships and community connections beyond family members for increasing access to meaningful community inclusion and the development of circles of natural support.

Without immediate attention towards bridging gaps of lifespan support and housing for individuals with I/DD, there will be a continued traumatic displacement of persons with I/DD in more restrictive, expensive and inappropriate "next empty beds." Not only does this hurt society's wallet, but it impacts the societal heart from the loss of their presence and contribution as valuable community members. May this report prompt community awareness into action to ensure valuable residents with I/DD can continue to find their place and be part of their community.

"We worry as we age as my son needs physical assistance that requires bending, lifting, etc. We want him to have a safe place where he can have interactions as he is a social person. He could use help learning living skills. We can't use all our waiver money now and are having difficulty finding providers for waiver rates."

"My son is 17. I plan on finding a day program for him with opportunities to work, learn, and socialize. He wants opportunities to meet other people, make friendships, build life skills, and find a girlfriend. I am excited to see new communities pop up that provide people with disabilities with the opportunity to pursue their dreams in a safe, supportive environment."

"My child just turned 17 and I am trying to be proactive in learning about options to make decisions that will serve him well in adulthood."

"We would like the ability to visit different types of living options to visually see and experience how they work to help make the right decisions."

"Looking for apartments purchased and set up in the community for those with I/DD that can live independently with some supports."