



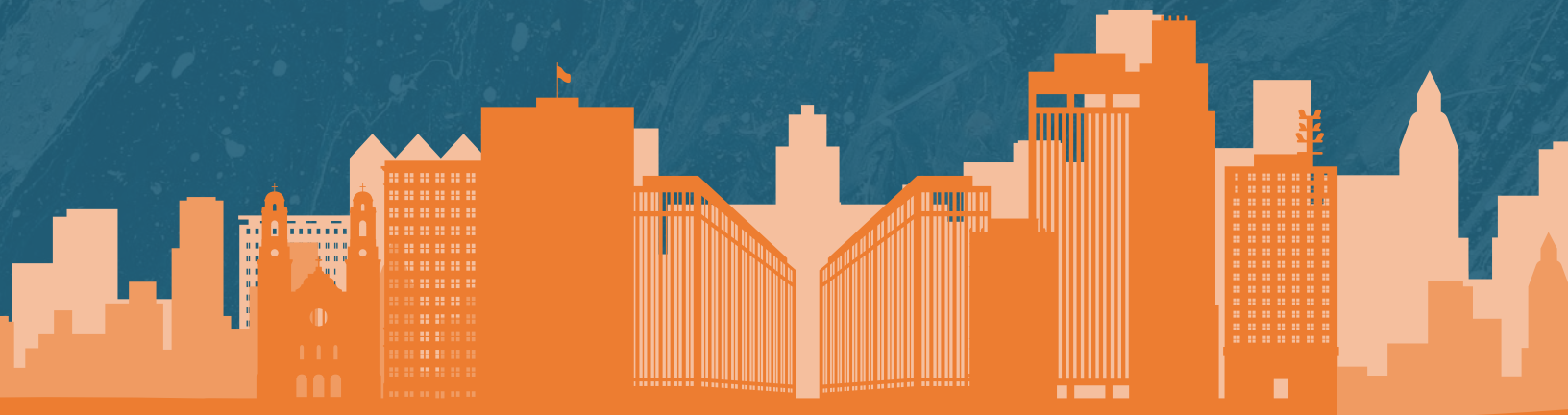
**Autism  
Action  
Partnership**



**2023**

**OMAHA**

**Neuro-Inclusive  
Housing Market  
Analysis**



**Data Driving a Place in the World for Autistic Adults and  
Others with Intellectual/Developmental Disabilities**

*The Omaha Housing Market Analysis builds on the housing needs and assessments identified in the 2021 Housing Affordability in the Omaha and Council Bluffs Area report sponsored by Front Porch Investments. The Omaha Housing Market Analysis focuses in particular on the housing needs of adults with autism and/or other intellectual/developmental disabilities.*

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***Autism Action Partnership (AAP) was founded in 2008 with the goal of addressing the unmet needs of the Nebraska autism community. Since its inception, our programming has expanded and evolved in direct response to the needs of those we serve.***

Through direct service, community education, workforce development and strategic partnerships, AAP has made a significant contribution to countless lives. While much has been accomplished, the unmet needs of the autism community may be greater and more diverse than ever.

Communities worldwide, including ours, are experiencing a growing need to support autistic adults. In 2015, AAP developed and launched a workforce development program (now called Prosper Workforce Services), as a first step toward serving adult members of the autism community. As the program grew, we became increasingly aware of the barriers outside the workplace that were directly impacting employment success. This realization inspired our pursuit of further programming and support. With guidance from First Place AZ and utilization of its Learn4Independence® curriculum, AAP launched an independent living program (Prosper Academy) in 2022. Academy students are growing and learning—and providing additional valuable insights regarding the needs of autistic adults in our community.

These programs and experiences were the driving force behind AAP's desire to address

the housing needs of those we serve. However, having the desire does not mean we have the expertise! Therefore, the opportunity to pursue a neuro-inclusive housing market analysis with trusted partners with the requisite expertise was serendipitous. This project provides critical and targeted information for how best to address the housing needs in Omaha and can/will be used by anyone seeking to do so.

We hope this is beginning of conversations and action that move the needle further in addressing the needs and preferences expressed by those in our community now—actions/initiatives that will improve outcomes well into the future.

As is true with much of AAP's success over 15 years, we could not have done this alone. In addition to our friends and partners at First Place AZ, Madison House Autism Foundation

and Make Waves Foundation, we owe thanks to many. Funding for this project also came from the generous support of Front Porch Investments. The survey responses came from incredibly busy parents, caregivers and self-advocates who shared their valuable time and unique insights. Representatives from numerous sectors offered their expertise as local leaders and/or critical readers to help ensure the report was comprehensive and accurately represented the views of diverse stakeholders.

On behalf of Autism Action Partnership, I offer my sincere thanks!

Yours in partnership,

Justin Dougherty  
President & CEO, Autism Action Partnership

“ A housing crisis is facing the A/I/DD community. This is not a ‘them’ issue—it is an ‘us’ opportunity. Creating neuroinclusive housing options will strengthen our community for ALL members.”

— Justin Dougherty  
President & CEO, Autism Action Partnership



## EXECUTIVE SUMMARY

For the past 40 years, the movement to deinstitutionalize adults with a diagnosis of **autism<sup>1</sup> and/or intellectual/developmental disabilities (A/I/DD)**,<sup>2,3,4</sup> has led states to provide support to help adults with A/I/DD remain in the community and live in the family home with their parents as their **natural supports<sup>5</sup>/caregivers<sup>6</sup>**. This has resulted in greater visibility, community engagement and higher quality of life for **neurodiverse<sup>7</sup>** families and adults with A/I/DD. Yet, every state across the nation is now at a critical point in history where these family caregivers are becoming seniors and may be experiencing age-related disabilities themselves. Many individuals with A/I/DD do not prefer to or cannot live in their family home but face a scarcity of alternatives.


Due to limited housing and support options, adults with A/I/DD often live with family members, even if not their preference, until

a crisis forces a hasty placement, potentially displacing them counties away from their home and community and into an institutional setting or other unsuitable environment that may include homelessness.

To offer data-driven recommendations and mitigate these undesirable and traumatic outcomes, the Omaha Housing Market Analysis (OHMA) explored the needs and preferences of adults with A/I/DD and/or their families/caregivers in Omaha.


According to the State of the States in Intellectual & Developmental Disabilities, about 46,000 people with A/I/DD live in Nebraska but only about 5,000 receive **long-term services and supports (LTSS)**.<sup>8,9</sup> Additionally, despite promising practices, most people with A/I/DD live without the support they need. As the rate of diagnosis increases, along with the rate of youth and adults with

At least  
**46,000**  
people in Nebraska  
have an I/DD.




That's more than 2.5x the  
capacity of Chi Health Arena.

An estimated  
**71%**  
live with their family,  
but their family is aging.



Senior caregivers often experience  
age-related disabilities themselves.

Approximately  
**24%**  
live with a caregiver  
over age 60.



They need housing and  
support systems in place.

A/I/DD, demand is rising for resources that help people with A/I/DD obtain housing that is affordable, accessible and supported.

Research into **social determinants of health** demonstrates higher healthcare costs when individuals are in unstable housing, lack access to LTSS and/or experience loneliness. Adults with A/I/DD encounter more challenges connecting with individuals outside their biological family. This lack of connection is exacerbated by their lower educational attainment and/or unemployment or under-employment. A holistic approach to addressing these barriers is required, which can lead our community to better outcomes.

As federally mandated by the Supreme Court *Olmstead v. L.C. Decision (Olmstead<sup>10</sup>)*, states must provide support in home and community settings versus institutions when the state's treatment professionals have determined that community-based support is appropriate. However, due to the lack of services and appropriate housing, some adults with A/I/DD are at risk of undue displacement, institutionalization or even homelessness. Funding sources to develop supportive housing or offer rental subsidies to persons with disabilities are lacking and not A/I/DD specific.

Lack of data on the current housing needs of adults with A/I/DD, the aging of their caregivers and the goal of expanding housing and community options targeting the identified residential demand are the impetus for the OHMA. This analysis is providing critical data, enabling us to catalyze a movement for developing greatly needed housing and community options for adults with A/I/DD in Omaha.

## Key Findings

*The following represents a snapshot of what is explained throughout this report:*

- Significant data gaps exist because the exact number of adults with A/I/DD who need **affordable housing<sup>11</sup>** and/or LTSS in Omaha is unknown. This includes those experiencing homelessness.
- Most Omaha residents with A/I/DD do not earn a housing wage. The majority are not receiving LTSS, with over 2,300 on the waitlist for services in Nebraska.<sup>12</sup> Among survey respondents, almost 60% have no earned income and about 77% do not receive LTSS.
- Current subsidized housing models or permanent supportive housing offer neither the accommodations nor the safety net adults with A/I/DD need to obtain and maintain housing. Affordable housing models often target people experiencing chronic homelessness and/or domestic abuse, as well as those with **serious mental illness<sup>13</sup>**, including veterans or seniors.
- In Douglas County, only 11% of the rental units are subsidized, despite about 66% of rental households being severely rent burdened.<sup>14,15</sup> Of the survey respondents, only one utilized a housing choice voucher.
- Survey results indicate that adults with A/I/DD who would otherwise qualify for services based on income are not utilizing public benefits. Of the survey respondents, only 23% received SSI, 15% were on waivers and 13% received SSDI.
- About 10,820 adults with A/I/DD in the Omaha area live with caregivers over age 60.

- Adults with A/I/DD experience more significant social and systemic barriers to obtaining and maintaining housing as a result of impairments due to their cognitive and/or **executive functioning<sup>16</sup>** challenges.
- Eighty percent of survey respondents report experiencing loneliness, mainly due to feeling overwhelmed and lacking public or personal transportation.
- Most survey respondents prefer **mixed-use planned communities<sup>7</sup>** and/or **neuro-inclusive planned communities<sup>7</sup>** over existing, **scattered-site housing<sup>7</sup>** stock.
- The majority of survey respondents desire to invest in housing stability through homeownership, yet limited guidance and tools make this difficult.
- Seventy-nine percent of survey respondents prefer a **consumer-controlled<sup>7</sup>** home. Yet, these preferred service delivery models, such as **shared living<sup>7</sup>** and self-directed services, are inaccessible due to a lack of housing options.
- The majority of survey respondents indicated that various **supportive amenities<sup>7</sup>** and/or a post-secondary transition program are needed. Yet, Nebraska does not have a funding stream for these types of supportive programs.

Research into social  
determinants of health  
demonstrates higher healthcare  
costs when individuals are  
in unstable housing.

“ A growing number of communities across the country are elevating housing and housing affordability as core civic priorities because a growing body of research shows how quality housing positively impacts people’s health and well-being.”

— Front Porch Housing Assessment Report



## BACKGROUND

Future planning is critical for an understanding of the past and current landscape individuals with A/I/DD and their families must navigate to prepare for life beyond the family home. The following content provides the necessary background information and local perspective on the current state of housing and services targeting adults with A/I/DD in Nebraska.

### History & Evolution of Support Services

Medicaid was established and began funding medical services for people with low incomes in 1965. An individual with A/I/DD had to go to a special facility or reside in an institutional setting to access services. To receive benefits, people who needed services often had to make the difficult decision of

being separated from their family, friends and communities. In 1981, a new provision allowed seniors, people with disabilities and their families to access services in their homes and communities.<sup>3</sup> This **home- and community-based services (HCBS)**<sup>17</sup> program “waives” the requirement to be institutionalized and allows people with A/I/DD to access Medicaid-funded services at home or assists them in engaging with the greater community.

The program is a federal and state partnership, with states contributing costs and the federal government, through the **Centers for Medicare & Medicaid Services (CMS)**,<sup>18</sup> matching state dollars inclusive of HCBS.

Medicaid-funded HCBS is the largest funder of LTSS for adults with A/I/DD. Following the implementation of Medicaid HCBS waivers,



individuals with A/I/DD, their families and supporters began advocating for more integration of community-based services. On June 22, 1999, the U. S. Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constituted discrimination in violation of Title II of the **Americans with Disabilities Act (ADA)**.<sup>19</sup> This decision provided a legal framework for the efforts of the federal and state governments to integrate individuals with disabilities into the communities where they live.

Though individuals with A/I/DD may be eligible for healthcare funded by Medicaid based on income, many do not qualify for Medicaid-funded HCBS that would cover the cost of LTSS due to other eligibility criteria. They fall through the cracks if they cannot earn a living wage and maintain their housing independently without the assistance of support staff or case managers.

Today, the goal is not to place people into programs but to build an ecosystem of support and services with inclusive approaches to housing, habilitation and employment—to name a few—centered around adults with A/I/DD.

The Medicaid program is known as the **Nebraska Medical Assistance Program**.<sup>20</sup> The **Medicaid and Long-Term Care (MLTC)**<sup>21</sup> plan oversees the Nebraska Medicaid program, HCBS and the **State Unit on Aging**.<sup>22</sup> HCBS waivers are the primary ways people with A/I/DD receive LTSS. Four main HCBS waivers exist for Nebraskans who qualify for Medicaid services:<sup>23</sup> **Aged and Disabled (AD) Waiver**,<sup>24</sup> **Comprehensive Developmental Disabilities Waiver**,<sup>25</sup> and **Traumatic Brain Injury (TBI) Waiver**.<sup>26</sup>

These waivers offer services such as adult day programs, assistive technology and short-term behavioral intervention programs; they also offer community integration programs such as independent life skills and others like respite for family caregivers.

There are three main service types offered through the waivers.<sup>9</sup> The first service type is residential services to support individuals with A/I/DD to live in the community. The other type are day services and employment services. Day services are non-residential services that support individuals to improve skills such as daily living skills. Employment services supports individuals to obtain and maintain employment. The state allows for

other services, which can provide various support such as transportation, respite services for family caregivers, and other emergency or technical services.

To receive services through the waivers, applicants who qualify can choose between two provider options. The first option is to select from a list of **developmental disabilities (DD) agency providers**.<sup>27</sup> This is usually a provider enrolled as a Medicaid provider and certified through the **Department of Health and Human Services (DHHS)**. The provider is responsible for all staffing providing care to eligible applicants. The second option is the **DD independent provider**.<sup>27</sup> An independent provider enrolled as a Medicaid provider is directly hired by the Medicaid beneficiary. The beneficiary is then responsible for hiring, training, supervising and/or, if appropriate, firing the provider. The option of **self-direction**<sup>28</sup> to choose providers is a sound example of **person-centered planning**<sup>29</sup> championed by many disability-rights advocates.

According to Tanis (2023)<sup>4</sup>, in 2019, 5,100 people were enrolled in LTSS in Nebraska. The Kaiser Family Foundation noted that in the same period, nearly 3,000 people were on waitlists for HCBS waivers across the state.<sup>30</sup> All those on the waiver waitlists are people with A/I/DD. In 2019, Disability Rights Nebraska (2019) noted that people spend an average of seven years on waitlists for waiver programs.<sup>31</sup> the majority of those on waitlists range between age 10 and 30. By 2021, the number of people with A/I/DD receiving LTSS decreased to 4,821.

One reason for the long waitlist is that the state spends fewer resources on services for

those with developmental disabilities. Total IDD spending in the state in 2021 was about \$449.1 million.<sup>4</sup> Nebraska IDD spending is less than the IDD spending in neighboring Kansas, and less than half of the IDD spending in Colorado, Iowa and Missouri, respectively. In fact, Nebraska ranks 39th nationally in IDD spending when compared as a percentage of personal income.

Of the three main types of service offered in the state, Nebraska spends the most on residential services.<sup>9</sup> About 65% of the total cost for providing services in the state was spent on residential services. In 2018, of almost 4,100 people in the state receiving residential services with LTSS, 41% received those services in a **consumer-controlled setting**, while 59% received them in a **provider-controlled setting**. On average, it costs the state three times as much on a per-service basis in provider-controlled settings than in consumer-controlled settings. This is not to suggest that the state should completely shift from provider-controlled to consumer-controlled, because an in-home residence may not be the appropriate setting for every individual with A/I/DD. However, should adults with A/I/DD choose to live in their own homes or in consumer controlled-settings, market options should be available to meet their needs.

### Person-Centered Approaches

In supporting adults with A/I/DD, service allocation should be responsive to the support needs of individuals. This is the foundation of the person-centered approach. This approach emphasizes person-centered thinking, planning and practices focusing

**Of almost 4,100 people in the state receiving residential services with LTSS, 41% received those services in a consumer-controlled setting, while 59% received them in a provider-controlled setting.**



on language, values and actions regarding respecting the views of the person and their loved ones. It emphasizes quality of life, well-being and informed choice. Person-centered planning is directed by the person with helpers they choose. It is a way to learn about a person's preferences and interests while identifying needed supports (paid and unpaid). Person-centered practices are present when people have the full benefit of community living and support designed to assist them as they work toward their desired life goals.

Like a web instead of a brick wall, elements of their life may change or need adjustment; but person-centered planning helps prevent them from faltering through life changes. This takes planning around a person's needs and preferences, not just selecting the "right program." Due to the relentless pursuit of advocates and their families, more individuals with A/I/DD can live in their own or a family member's home and receive the services they need to function in everyday life. This may involve helping to organize a daily schedule, getting ready in the morning, supporting

meal prep, job coaching or maintaining a home. These long-term support services are provided to eligible, waiver-enrolled individuals by existing community-based organizations across the state.

In 2020, the state began incorporating the Nebraska Person-Centered Planning Initiative.<sup>32</sup> This involved implementing and developing training and support for **Charting the LifeCourse (CtLC)** framework developed by the University of Missouri-Kansas City.<sup>33</sup> The kickoff for switching to the framework was held on March 9, 2022. Since then, DHHS has hosted monthly webinars and discussions with experts to support and train people to use the framework.

### Neuro-Inclusive Housing Framework

Public, private, nonprofit and philanthropic partners can develop scaled solutions using the following neuro-inclusive housing framework. The following three areas need support from policymakers and funding sources for Omaha organizations and businesses to develop supportive housing solutions for this population:

- **Housing:** Local planners and housing developers can use the OHMA to become more aware and plan for the intentional inclusion of this population in existing and future developments by building cognitively **sensory-friendly**<sup>34</sup> homes with **cognitive accessibility**<sup>35</sup> in walkable, safe locations benefiting residents with and without A/I/DD.
- **Long-term services and supports (LTSS):** A network of 71 providers in the area offers individualized services to help people in their homes access the community.<sup>36</sup> This report provides insights into what gaps need to be filled and future preferred service delivery models.

### How are Long-Term Support Services (LTSS) and Housing Connected?



#### Provider-Controlled (PC)

Housing & support services are connected.

*Only ONE choice of HCBS service provider.*



#### Consumer-Controlled (CC)

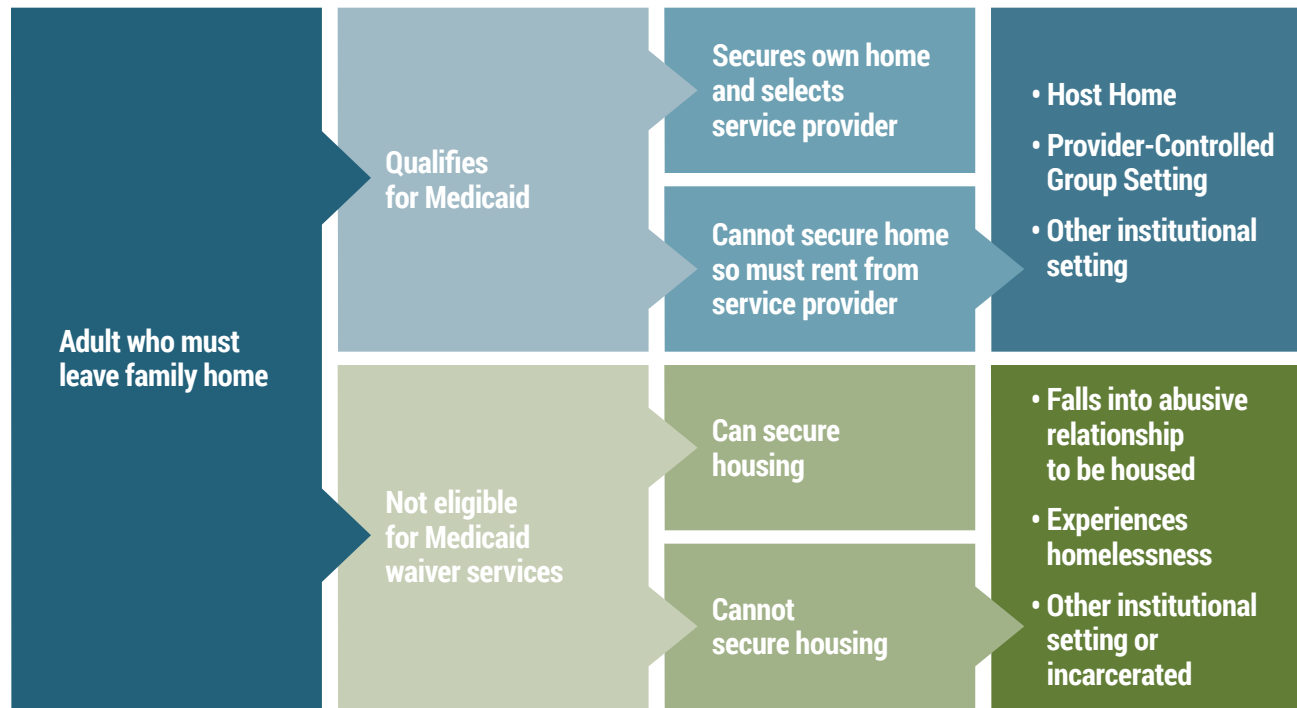
Housing & support services are NOT connected.

*Choice of ANY HCBS service provider.*

- **Supportive amenities:** Community-based organizations can provide property-specific supports to address isolation, foster greater community integration, promote social well-being, build natural support systems and facilitate employment and/or life skill classes. Supportive amenities are essential to help those ineligible for LTSS to connect to their community, maintain stability and thrive.



**Aspects of Person-Centered Planning**



### Lack of Affordability Leads to Limited Choice of Living Arrangements

Finding and affording housing is nearly always out of reach when an individual with A/I/DD is ready to move out of their family home or other living situation. The ability of adults with A/I/DD to earn a living wage in Omaha may be limited due to possible co-occurring mental or physical health or executive functioning challenges.<sup>37</sup>

Executive functioning broadly regulates goal-directed, future-oriented, high-order cognitive processes. This can affect various processes like planning, adaptive behavior, response inhibition and working memory. In adults with **autism spectrum disorders (ASD)**, challenges with executive functioning have been associated with reduced adaptive functioning challenges and co-occurring depression and anxiety.<sup>38,39</sup> Adults with A/I/DD may atypically engage socially and may self-injure when feeling overwhelmed. They may also have difficulty communicating their needs or understanding social cues. These challenges make finding and keeping a job or an apartment difficult when an adult

with A/I/DD lacks adequate support. Other studies have found that executive functioning challenges are more significantly experienced in people diagnosed with autism.<sup>40,41</sup>

Most adults with A/I/DD are either unemployed or underemployed due to these challenges.<sup>42,43</sup> Consequently, they would be unable to afford housing. For adults with A/I/DD who are employed, they also fear that their income may disqualify them from being eligible to receive services through Medicaid. This loss of service may mean loss of support to keep a job, maintain an apartment or take care of themselves, including making medical appointments.

The **National Low Income Housing Coalition**<sup>44</sup> estimates that a person must work 58 hours at minimum wage to afford a one-bedroom apartment in Nebraska.<sup>45</sup> In Omaha, the fair market rent for a two-bedroom unit is \$1,083. To afford a two-bedroom apartment at fair market rent, a person would need to make \$43,320 a year, which means a person would need to gross \$3,610 a month. Even at that income level, the person would still be considered rent burdened. The Department of Housing and Urban Development considers a

Area	Housing strategy or consolidated plan	PHA or other prioritized efforts targeting people with disabilities	Identifying people with A/I/DD specifically as a need	PHA waitlist status	Current number of vouchers targeting people with disabilities
Omaha	City Consolidated Plan	Yes	No	Six months to 24 months	120 mainstream vouchers, with 97 currently utilized
Omaha	PHA Annual Report	Yes, grouped under persons with disabilities	No	—	—

person to be rent burdened if they spend more than 30% of their income on housing costs.<sup>46</sup>

As a result of these challenges, most adults with A/I/DD often remain in their family homes little to no housing options available to them.<sup>47,48,49</sup> Additionally, 24% of adults with A/I/DD live with caregivers over 60, while 35% have caregivers between ages 41 and 59. For Nebraskans with IDD receiving LTSS, the majority live in **group homes**<sup>7</sup> or adult **host homes**<sup>7</sup> with fewer than six people.<sup>4</sup> Without creative and innovative solutions, those with aging caregivers may be at risk of homelessness or being placed in a more restrictive setting.

When a crisis placement is necessary, a group or adult host home is only available to those qualifying for Medicaid LTSS. Those not eligible for these services are currently at high risk of homelessness. Data obtained from the state's **point-in-time** count for homelessness show there was a 16% increase in the number of people experiencing homelessness in Nebraska between 2021 and 2022.<sup>50</sup> Recent national research indicates that approximately 30–40% of people experiencing homelessness have a cognitive impairment, including A/I/DD, and become homeless later in life, most often due to the death of the family caregiver.<sup>51</sup>

### Invisible Need

The Omaha Housing Market Analysis covers the Omaha area. This fast-growing area accounts for almost half a million residents, and is experiencing a deficit of affordable and supportive housing challenges similar to other major metropolitan areas.<sup>52</sup> Nebraska has only 38 affordable rental homes per 100 extremely low-income renter households.<sup>53</sup> In Omaha, one in four households is rent burdened.<sup>54</sup> This means they pay more than a third of their income on housing. However, these estimates do not precisely segment the housing burden on adults with A/I/DD, or those with A/I/DD living with aging family caregivers. The **Nebraska Supportive Housing Plan** notes there must be an adequate supply of supportive housing options, independent living options or rental subsidies for adults to obtain housing.<sup>55</sup>

The table above offers a snapshot of the necessity for understanding and action inclusive of the needs of people with A/I/DD as articulated in local municipal housing or **consolidated plans**<sup>56</sup> and local **public housing authorities (PHA)**.<sup>57</sup>

None of the housing or consolidated plans includes persons with A/I/DD as a segmented need. Though the city of Omaha identified people with disabilities in the 2023 Consolidated Annual Performance and

Public Housing	Housing Choice Vouchers		Mainstream HCV		HCV% for PWD
	Total	Leased Up	Total	Leased Up	
Omaha Housing Authority	4,942	83%	120	81%	2%
Bellevue Housing Authority	333	94%	13	92%	6%
Douglas County Housing Authority	1,070	95%	282	83%	26%

Evaluation Report, people with A/I/DD were not recognized as a population with supportive housing needs.<sup>58</sup>

As of 2023, there were 415 **Mainstream Housing Choice Vouchers**<sup>59</sup> and no **Non-Elderly Disabled (NED) vouchers**<sup>60</sup> targeted for people with disabilities in the OMHA area (not A/I/DD specifically).<sup>61</sup>

Not all housing vouchers are being used despite the need for people to be able to access rental subsidies. In 2021, the U.S. Department of Housing and Urban Development (HUD) Office of Inspector General (OIG) reported that 62% of PHAs had voucher-utilization rates of less than 95% (standard performance). Compared to **housing choice vouchers (HCV)** targeting all low-income renters, the voucher utilization rate targeting people with disabilities was lower for Omahan Mainstream voucher holders. Underutilization is reportedly due to factors outside of HUD's control, including insufficient landlord interest or participation, lack of availability of affordable housing and housing costs increasing faster than the PHA's budget. The HUD OIG recommended developing a plan to optimize leasing to increase the number of families assisted and reduce unused vouchers.<sup>62</sup>

The Joint Center for Housing Studies of Harvard University estimated that nationally, 62% of renters do not have enough income to afford a comfortable standard of living after paying their rent.<sup>63</sup> Consequently, large numbers of people face housing insecurity and the burden of rising costs. This is acutely felt by adults with A/I/DD, who often have fixed incomes and/or earn low wages. A lack of housing options prevents the neurodiverse population from moving beyond their family home.

In line with the OMHA and the Harvard Housing study, the Nebraska Developmental Disabilities Council Report showed that many parents who were family caregivers and independent providers noted the waitlists for housing vouchers were too long.<sup>64</sup> There is a need to reduce housing waitlists. The study reported the limited availability of safe, affordable and supportive housing options. Even when housing units were affordable, they were often substandard units or the units were located in less-than-favorable neighborhoods. Some parents also noted that while there are affordable housing options in rural communities, there were no residential programs and few providers to serve the needs of their adult child with A/I/DD.

Location (city) <sup>69</sup>	Adult population <sup>69</sup>	2.2% autistic adults <sup>70</sup>	1.65% intellectual disability	6.06% developmental disability (not autism or ID)	Combined A/I/DD	Estimated to be living with caregiver over age 60 (24%) <sup>71</sup>
Omaha	364,835	8,026	6,020	22,109	36,155	8,677
Bellevue	47,639	1,048	786	2,887	4,721	1,133
Papillion	17,988	396	297	1,090	1,783	428
La Vista	12,678	279	209	768	1,256	301
Gretna	6,631	146	109	402	657	158
Ralston	5,133	113	85	311	509	122
<b>Total</b>	<b>454,904</b>	<b>10,008</b>	<b>7,506</b>	<b>27,567</b>	<b>45,081</b>	<b>10,819</b>

### Prevalence of A/I/DD

Census data is not collected on the number of people with A/I/DD. Therefore, estimates must reflect existing data sets for segmenting this population in each area. The Centers for Disease Control estimates that one in four adults has a disability.<sup>65</sup> Nationally, about 2.2% of the U.S. adult population is on the autism spectrum, 1.65% of children have an intellectual disability, and the prevalence of children diagnosed with a developmental delay other than autism spectrum disorder or intellectual disability is 6.06%.<sup>65,66</sup>

According to the National Low Income Housing Coalition, Nebraska has a housing shortage of 40,621 units.<sup>67</sup> Douglas County

has only 9,725 federally subsidized affordable housing units out of 86,335 occupied units.<sup>6,68</sup> This means only about 11% of the rental units in the country have any form of federal assistance. From the estimates of incomplete data sets, and considering the population of low-income adults with A/I/DD currently living with family caregivers, this statistically invisible population could nearly double the current housing deficit.

Of urgent concern are the approximately 10,820 individuals with A/I/DD in the Omaha metro area at high risk of losing their homes and primary caregivers. This may occur when their family member can no longer support them due to aging health concerns, changing economic circumstances or death.

**The Joint Center for Housing Studies of Harvard University estimated that nationally, 62% do not have enough income to afford a comfortable standard of living after paying their rent.<sup>32</sup>**

## Additional Barriers

In addition to the cost of housing, people with A/I/DD face numerous barriers even if they have access to housing assistance or their families can afford to help them pay rent.



**The systems to access housing and services are disconnected and can be cognitively inaccessible for people with A/I/DD.** Adults with A/I/DD often have challenges with reading and writing, executive functioning, communication, and/or social interactions. Such challenges can make navigating the complex and often disconnected systems required to access housing, services, and other public benefits more daunting. They may also lack experience with or knowledge of documentation and system requirements to access various types of assistance.



**Most adults with A/I/DD are on a fixed, extremely low income.** They often have low educational attainment, rely on public benefits and have cognitive challenges that make full-time employment difficult. They need access to housing that fits within a fixed income budget to avoid eviction or loss of housing when costs rise rapidly due to inflation.



**Lack of supportive amenities and adequate case management persist for those ineligible for LTSS.** Individuals with A/I/DD who do not qualify for Medicaid waivers need supportive amenities or regular assistance from case managers to maintain housing, public benefits, connections within the greater community and potential employment. These include identifying and submitting required documents for continued benefits, social opportunities, conflict resolution, breaking down the steps in a task and/or creating a follow-through plan.



**The existing housing stock is often inaccessible.** Individuals may need **wayfinding**<sup>72</sup> signage or icon cues instead of text only; sensory-responsive features such as natural and low-voltage versus fluorescent lighting; extra-durable fixtures for challenges with **graded movement**<sup>73</sup> technology to support executive functioning; or a lift for transfers that may not be weight bearing without modifications to structural support. Some adults with A/I/DD may also engage in repetitive physical and/or verbal behaviors which serve self-regulating and/or self-stimulating functions that—without sound-insulating spaces—could disrupt neighbors and/or result in noise complaints.



**People with A/I/DD are at risk of being victims of predatory relationships.** Location and security features must be carefully considered, as adults with A/I/DD have a significantly greater risk of being victims of simple assault and/or a serious violent crime than other persons with disabilities.<sup>74</sup> Data show that 66.5% of those on the autism spectrum and 62.5% of those with I/DD report being survivors of physical, emotional or sexual abuse.<sup>75</sup> In a study conducted on mate crime, 100% of respondents ages 16–25 with autism report they cannot distinguish between someone who is a friend and someone who is abusive.<sup>76</sup>



**Discrimination based on disability is the highest reported form of housing discrimination.**<sup>48</sup> Despite progress in the rights and inclusion of persons with disabilities, it is not uncommon for landlords to reject their rent applications. Likely due to ill-perceived financial, criminal or cognitive differences of adults with A/I/DD, the greatest number of Fair Housing Act complaints across multiple agencies are due to discrimination against disability.<sup>77</sup>

AAP, their advisors and sponsors have invested significant time, energy and resources to understand the needs and preferences of adults with A/I/DD and/or their families in Omaha. The OHMA demonstrates the data and actionable direction for developing tools and changing systems to ignite a new wave of housing options across Nebraska so every person with A/I/DD can find their place in the world. This marketplace of options must meet the needs of urban, suburban, and rural Nebraskans and their heterogeneous support needs.

“There are several critical areas of need, including long waitlists for services; the “services cliff” experienced after high school; workforce shortages; services for older adults; and racial, ethnic and geographic disparities in access to quality autism services and care.”

— Interagency Autism Coordinating Committee (IACC)

“One of the most critical components of this project is that it is led by the voices of the A/I/DD community.”

— Michaela Ahrens,  
Senior Director of Programs, Autism Action Partnership



# HOUSING MARKET ANALYSIS



Most individuals with A/I/DD and their families have not had the opportunity to explore their options for life beyond the family home. Respondents were required to participate in a learning session informing them of the benefits and considerations of various elements of residential choices. Using the nomenclature from *A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities*,<sup>7</sup> participants were able to learn about the broad range of choices. While some options

presented during the learning session may not currently be available in Omaha, it was essential to include them so participants could express their needs and preferences to help effect system and market changes.

## Educational Outreach

Learning sessions included live virtual training with time for questions and answers. AAP also hosted three “watch parties” to bring

What Are the Financial Options for Housing?

## Rent Your Home

Medicaid pays for housing only in institutional settings: Intermediate care facility (ICF), nursing home, etc.

- Fair market rent
- Rental assistance: fair market rent plus housing choice voucher
- Rental assistance: subsidized housing unit
- Rent room in a provider-controlled setting

## Neuro-Inclusive Housing Framework

- Individual Residential Services: your chosen provider
- Housing: bricks & mortar
- Supportive Amenities: "safety net" or "secret sauce"

### How Can People with I/DD Access LTSS?

#### LTSS Delivery Model: Agency-Based Rotational Staffing

**Benefits:**

- Agency recruits, trains and schedules staff for your needs.
- Lots of people to share stories, interests and relationships
- If someone calls in sick, the agency can replace from their pool of people.

**Considerations:**

- Too many new people can be overwhelming.
- Less involvement in selection and scheduling of staff

## Supportive Amenities

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

## Omaha Statistics on Residential Options

Omaha has only 120 housing vouchers targeted for people with any disability.

To afford a 1-bedroom apartment	68/wk Hours needed at minimum wage	\$31,760/yr Annual salary needed to afford a 1-bedroom apartment
To afford a 2-bedroom rental home	83/wk Hours needed at minimum wage	\$18.73/hr Hourly wage needed to afford a 2-bedroom rental home

participants together in person to watch the recorded learning session with subsequent live Q&A. The recording of the learning session was also posted on the Autism Action Partnership website for those unable to attend the live events. More than 85 community-based organizations were contacted as part of the process of promoting and facilitating the OHMA.

Plain-language materials were created to ensure a format with cognitive accessibility. These materials included a recorded, live learning session in **plain language**,<sup>7,78</sup> a visual guide to help participants track their preferences during the learning session and a plain-language survey. Additionally, AAP translated the materials into Spanish and held a Spanish language focus group with 22 families participating.

Participants made a significant time commitment and demonstrated a willingness to learn about multiple approaches to residential options, enabling data collection on the needs and preferences of adults with A/I/DD and their families. During the 30- to 75-minute sessions, each option was introduced and explained using visuals, verbal descriptions and videos (where available).

Participants made a significant time commitment and demonstrated a willingness to learn about multiple approaches to residential options, enabling data collection on the needs and preferences of adults with A/I/DD and their families.

**148**  
Respondents

**16%**  
Self-Advocates

**22**  
Spanish-Language Respondents

Benefits and considerations of the various elements of residential possibilities were discussed to promote person-centered, meaningful choices. Individuals attending live sessions and watch parties could ask questions during and after the presentation.

Once participants completed the learning session, they were requested to complete the Omaha Housing Market Analysis Needs & Preferences Survey. This included questions regarding demographics, barriers to community engagement, support needs, housing preferences and utilization of public benefits. First Place Global Leadership Institute researchers reviewed comprehensive and consolidated plans, as well as any previous housing analysis from typical housing market needs.

After the surveys closed, data were analyzed and presented at the Local Leaders Workshop.

### Local Leaders

Local leaders were invited to participate in a three-hour Local Leaders Workshop. Participating organizations and individuals comprised of county officials, bankers, leaders in low-income housing developments, real estate developers, land-use experts and other representatives from community-based organizations and foundations. Self-advocates

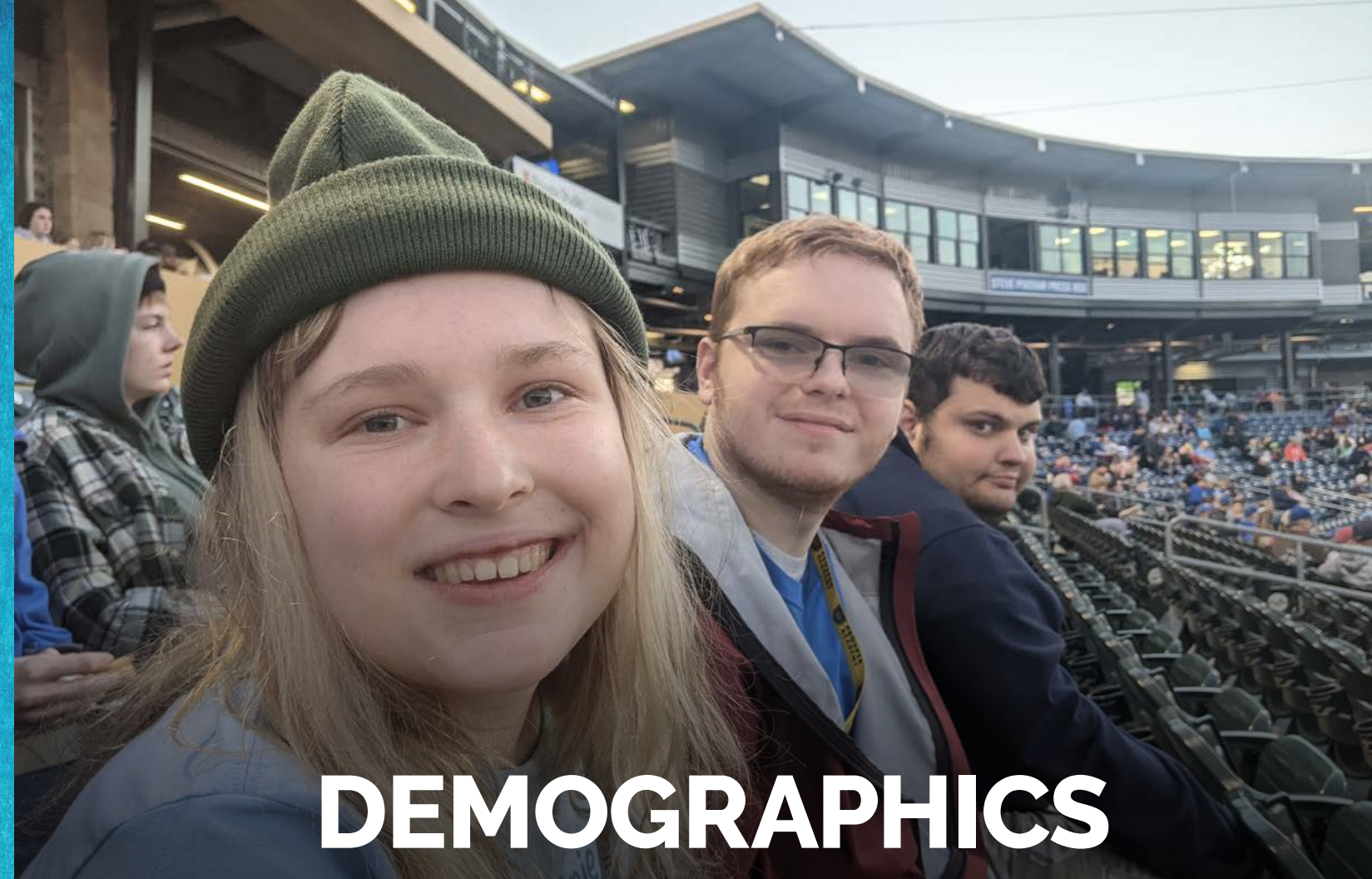
and family leaders were also essential contributors. The presentation allowed stakeholders to review the data and identify potential recommendations for future action. Initial data analysis indicated the variety of and demand for residential needs and preferences. Local leaders were eager to discuss potential solutions and address barriers. Details of their discussion and suggestions are highlighted throughout this report and in the Recommendations section.

### Considerations and Limitations of the Process

- **Training materials:** To provide more accessible training materials, the plain-language surveys did not include questions as extensive as the full survey, limiting some of the demographic and preference data collected.
- **Data outreach:** Data reflects a large respondent base with an autism diagnosis. This is likely due to the primary outreach of Autism Action Partnership constituents. More outreach to the greater A/I/DD community may be considered for future studies or housing initiatives.
- **Data translation:** Translation of materials was offered to Spanish-speaking participants who participated in a focus group. Yet, comments at the end of the survey indicated they would have liked to have the video recording translated, which may have resulted in more Spanish-speaking participants. Only one self-advocate is represented in the Spanish-speaking survey respondents; therefore, we cannot provide further analysis of Spanish-speaking self-advocates.
- **Diversity of participants:** While targeted outreach was conducted by AAP, Black or African American individuals and/or their families are underrepresented in the data—most respondents are white, with 15% identifying as Hispanic.

“ I truly believe Omaha is the city for this type of project, with so many ideal locations for a pedestrian-oriented housing development for the I/DD, neuro-diverse population. I look forward to the final analysis of the survey.”

— Respondent  
Omaha Housing Market Analysis Survey



## DEMOGRAPHICS

*Unless otherwise noted, demographic data in this section are compiled from the 2023 Omaha Housing Market Analysis Needs & Preferences Survey. It provides demographic information for respondents with A/I/DD and/or their families. The following section details future preferences for housing, services and community engagement.*

Disability housing is often characterized as compliant with the ADA, designed to ensure accessibility by those with physical disabilities who may use a wheelchair or other mobility device. Yet, when considering housing targeting adults with A/I/DD, the need for roll-in showers, floating sinks and extra-wide doorways represents only a small segment of the population of adults with A/I/DD.

In general, diagnosis should not label or drive a specific housing development. Just as being a senior doesn't limit the diversity of housing and support preferences of the aging community, adults with A/I/DD have different needs and preferences; thus, a one-size-fits-all solution is not suitable. Yet,

diagnostic information is helpful in understanding the possible barriers to independent living that can be overcome through design, service delivery and supportive amenities. For example, data reflects a high rate of co-occurring mental health challenges such as anxiety, depression, obsessive-compulsive disorder (OCD) and other mental health challenges. Emerging supportive housing opportunities may consider building relationships with mental health providers that can provide on- and off-site mental health support and/or life coaching in a format ensuring cognitive accessibility. Finding a provider that takes Medicaid, as well as understands the neurodivergent population's challenges in scheduling an appointment and accessing

The disabilities I identify with include:	
Autism	84%
Anxiety	54%
Intellectual disability	29%
Depression	24%
Asperger's	20%
Other mental health challenges	16%
Obsessive compulsive disorder (OCD)	14%
Other developmental disability	13%
Other disability not specified	10%
Epilepsy or other seizure condition	8%
Physical disability & use a mobility device	5%
Deaf or hard of hearing	5%
Down syndrome	4%
Cerebral palsy	3%
Bipolar disorder	3%
Blind and/or visually impaired	2%
Traumatic brain injury	1%
Prader-Willi syndrome	0%
I'd rather not disclose.	0%

\*Does not total 100% because respondents could choose more than one answer.

reliable transportation are all barriers to equitable mental healthcare for adults with A/I/DD.

With 84% of respondents identifying as representative of the autistic population, preference data on design and supportive amenities reflected in this study are likely influenced by the need for accommodations based on differences in executive function, sensory regulation, and/or social and relational support needs.

This diagnostic information should not replace the important community engagement efforts that should be undertaken in future housing or community development.

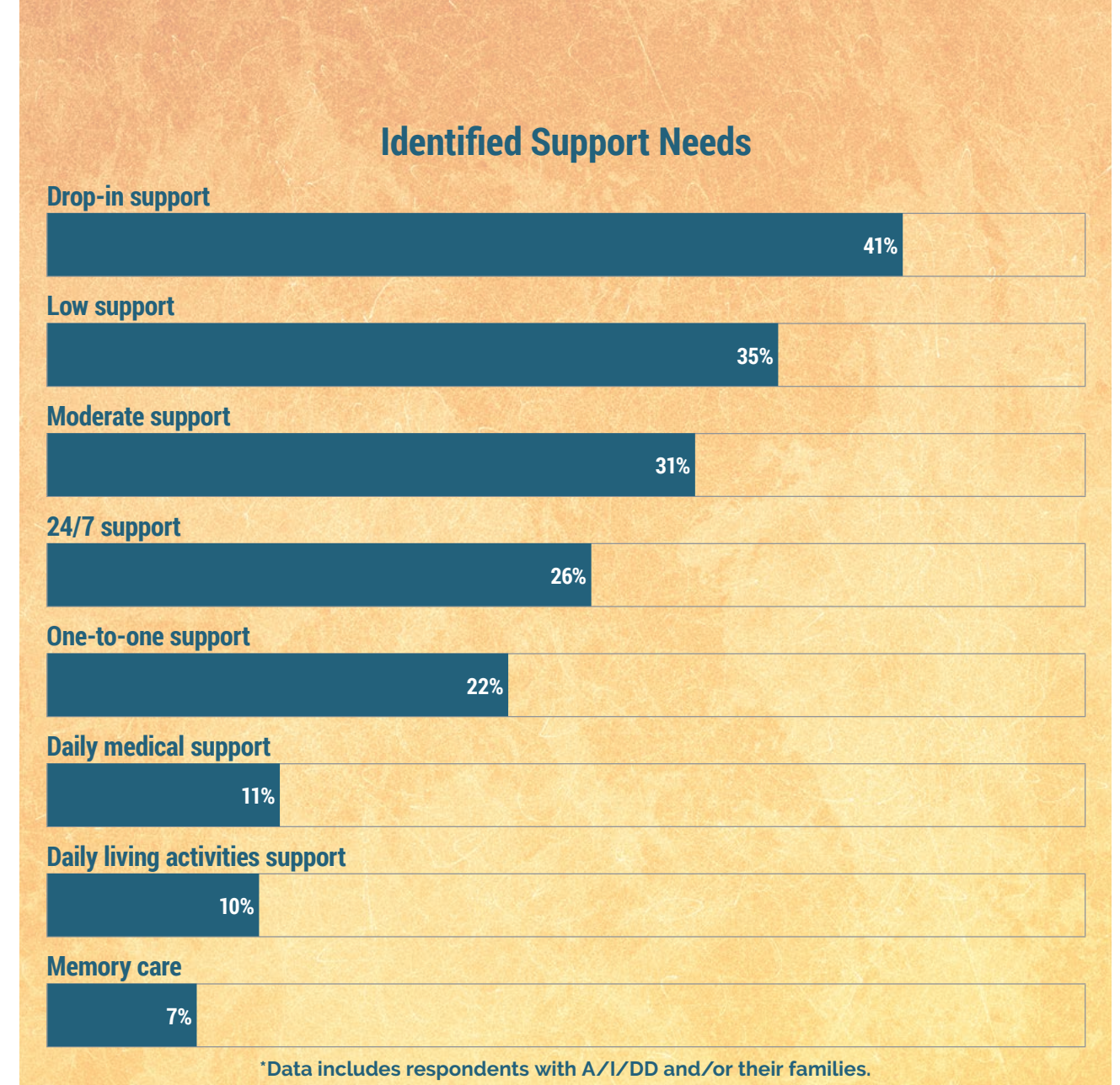
### Identified Support Needs

People with A/I/DD have a wide range of support needs. Data on the level of support needs paint a picture of the paid staff support a person may need to stay stably housed, complete activities of daily living and engage in the greater community.

The purpose of HCBS waiver services is to assist people with A/I/DD to live in the community with support and services like any other member of society. Applicants for HCBS waiver services must be determined eligible by the state Department of Developmental Disabilities (DDD). Eligibility requirements include:

- **Documentation of developmental disability**
- **Need to qualify as needing the level of support** in an **intermediate care facility for individuals with intellectual disabilities (ICF/IID)**<sup>79</sup>
- **Meeting income eligibility** for Medicaid<sup>80</sup>

Those with drop-in or low-support needs represent the largest segment of the data collected by the 2023 Omaha Housing Market



Analysis Needs & Preferences Survey (41% and 35%, respectively). Due to only needing intermittent support, maybe even just a few days a week, those with drop-in or low support needs are at risk of being determined ineligible for services funded by DDD. Eleven percent of survey respondents report being denied or ineligible for waiver services. This inability to access LTSS places the population with drop-in or low support needs at high risk of displacement and homelessness if, due to executive functioning impairments, they cannot earn a living wage or are unable to manage day-to-day needs without support.

The **National Core Indicators® -Intellectual and Developmental Disabilities (NCI-IDD)**<sup>81</sup>

tracks data for adults with A/I/DD receiving HCBS services across most states. The waiver recipients in NE 2021 NCI-IDD reported that most waiver recipients in Nebraska (54%) receive 24-hour, on-site support and only 12% receive less than daily support.<sup>82</sup> More research is needed to determine if those with low and drop-in support needs are eligible and receiving services in the least restrictive setting or if there is a larger proportion of adults with A/I/DD who are living in settings designed for those with higher support needs due to lack of affordable, accessible housing.

Equally important are the needs of individuals who have more profound autism or other I/DD





## Support Needs<sup>7</sup>

### Moderate Support

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

### One-to-One Support

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

### Drop-In Support

The individual requires a Direct Support Professional (DSP) to check in with them every few days or as requested; the individual is self-sufficient the majority of the time.

### Daily Medical Support

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

### 24/7 Support

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

### Physical Disability/ADL Needs

Due to a physical disability, the individual may use a wheelchair or mobility device and requires additional DSP assistance with transfers and other activities of daily living.

### Low Support

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

### Memory Care

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

and are in need of one-to-one or non-shared staff support. Twenty-two percent of survey respondents indicated they or their loved ones would need higher levels of support.

DDD recognizes five funding tiers related to the level of support needs, including one-to-one or non-shared staff support:<sup>83</sup>

- **Basic Tier** is for a participant who needs limited support and personal attention.
- **Intermediate Tier** is for a participant who needs full-time support but typically does not need staff assistance during overnight hours.
- **High Tier** is for a participant who needs full-time services and support with staff available on-site and overnight.
- **Advanced Tier** is for a participant who needs full-time services and support with a sole, non-shared staff required to provide direct support on-site and overnight.
- **Behavioral Risk Tier** is for a participant with intense behavioral needs who requires full-time services, support and supervision with a non-shared staff on-site and overnight.

Although representing a smaller subset of the data, it is important to consider those who need memory care and recognize that this is a growing segment of aging and older adults with autism and Down syndrome who develop early-onset dementia and Alzheimer's.<sup>84</sup> DDD and advocates must assess whether services included in current HCBS waivers can meet these current and future needs.

More research or data collection should segment the population based on level of support needs to identify disparities and whether an individual with A/I/DD owns/rents a home outside of the family home or lives with a family member. This will improve data collection, articulation of demand and pressing issues.

### Utilization of HCBS Services

The following chart shows the Medicaid waiver status of respondents.

Nebraska offers two HCBS waivers targeting adults with A/I/DD:

- **Developmental Disabilities Adult Day (DDAD) waiver<sup>85</sup>** offers services focused

## Are you (or a loved one) receiving services through a Medicaid waiver?

Yes, Comprehensive Developmental Disabilities Waiver through Nebraska DHHS

6%

Yes, HCBS Waiver for Aged Adults and Children with Disabilities through Nebraska DHHS

6%

Yes, Developmental Disabilities Adult Day Waiver Service through Nebraska DHHS

4%

Yes, received a waiver but not sure which

4%

On waitlist for a waiver

21%

No, have not applied

18%

No, not eligible

9%

No, denied

2%

No, was unaware of this resource

27%

\*Data includes respondents with A/I/DD and/or their families.

on daytime community integration and inclusion, including job support or teaching skills for future employment.

- **Comprehensive Developmental Disabilities (CDD)** waiver offers services for daytime community integration and residential support.

Twenty percent of all respondents are receiving an HCBS waiver. Only the CDD waiver offers residential support for those who can no longer live with family caregivers, represented by only 6% of the survey respondents.

It is alarming that 27% of survey respondents are unaware of HCBS waiver services and 18% have not applied. Not only does this put individuals with A/I/DD at risk of falling into crisis when family caregivers can no longer

It is important to note that waitlists for HCBS services have been eliminated in 13 states.<sup>53</sup> With significant advocacy efforts and more funding, the waitlist can be reduced significantly or even eliminated in Nebraska.<sup>54</sup>

provide support or housing, but it also reflects significant data gaps in the number of adults with A/I/DD who may need waiver services in the future. This indicates that expansive awareness must be raised to ensure neuro-diverse families are aware of the assistance DDD provides and to stress the importance of applying before support is needed.

Twenty-one percent of survey respondents report being on the waitlist for services. When segmenting for Spanish-speaking respondents only, 55% are on the waitlist. DDD reported that as of January 1, 2023, there were 2,304 individuals on the Developmental Disabilities registry list, down 647 individuals from January 1, 2022 when there were 2,951 individuals on the registry.<sup>12</sup>

It is important to note that waitlists for HCBS services have been eliminated in 13 states.<sup>86</sup> States have broad flexibility in how they organize their systems of care to best comport with each state's context and administrative functions. States with long waitlists have utilized a variety of methods to reduce the number of individuals waiting for services. Some states use additional appropriations to draw down federal match dollars by creating new "support" waivers. These support waivers do not offer the same comprehensive or individualized services as other waivers and/or provide non-residential services. States have also reduced waitlists by screening people on waitlists for eligibility, and/or ensuring that the list is current and up-to-date. By screening for at least one waiver eligibility, Ohio reduced the waitlist by nearly 70,000, as those who

remained on the list were deemed eligible for service.

Nebraska currently screens people on waitlists for eligibility.<sup>9</sup> However, the state does not have support waivers. With significant advocacy efforts and more funding, the waitlist can be reduced significantly or even eliminated in Nebraska.

## Earned Income and Government Benefits

The chart below shows the distribution of respondents' earned income.

As survey respondents and the NCI-IDD report indicate, the population of adults with A/I/DD largely falls below 30% of the

Earned Income	
\$0-\$300	59%
\$301-\$600	12%
\$601-\$900	9%
\$901-\$1,200	6%
\$1,201-\$1,500	2%
\$1,500+	9%

\*Does not total 100% because respondents could choose more than one answer.

**area median income (AMI)**<sup>87</sup> in Omaha. Forty-one percent of survey respondents indicate they earn income, with most earning less than \$1,500 monthly. In 2019, NCI-IDD reported that only 32% of waiver recipients were working, averaging 33 hours per month at an average of \$9.54 an hour and earning approximately \$315 a month. Although they would qualify for services based on income, only a small percentage of adults with A/I/DD are utilizing public benefits.

**Utilizing Public Benefits**—The chart below shows the utilization of public benefits among respondents.

Federal law prohibits federal Medicaid waiver dollars from being utilized to fund room and board. Recipients of waiver-funded services must pay for their housing, even in **provider-controlled settings** such as group homes or adult host homes. This is typically paid for using earned income,

Public benefits or assistance utilized by survey respondents	
Medicaid	44%
SSI	23%
Waivers	15%
SDSI	13%
Medicare	8%
SNAP (food assistance)	7%
LIHEAP	1%
Lifeline (phone/internet bill)	1%
Housing with rental assistance	1%
Housing choice voucher	< 1%

**Social Security Disability Income (SSDI)**<sup>88</sup> and/or **Supplemental Security Income (SSI)**,<sup>89</sup> leaving very little for other expenses such as clothing, recreational and/or leisure spending. It is surprising that only 23% of all respondents report receiving SSI while only 13% of all respondents report receiving SSDI.

Even if all public benefits are utilized, there is an extreme income disparity between housing costs and combined state and federal assistance designed to help those with A/I/DD unable to earn a living wage to pay for living expenses. In 2024, the maximum recipients of SSI will be able to receive is \$943, and if the person becomes employed, benefits will decrease at a 2:1 ratio as income is earned.<sup>90</sup>

Even when receiving federal assistance and competitively employed, for most adults with A/I/DD find that housing costs in Omaha are out of reach. To better illustrate the housing affordability challenge, the figure below includes sample income and SSI benefits based on typical jobs and weekly schedules for adults with A/I/DD.

Other public benefits and safety net programs, such as the **Supplemental Nutrition Assistance Program (SNAP)**<sup>91</sup> for food assistance, **Low Income Home Energy Assistance Program (LIHEAP)**<sup>92</sup> to help cover home heating and/or cooling needs and housing choice vouchers that provide permanent rental subsidies are all underutilized by this population. More research is needed to understand why adults with A/I/DD are not accessing these assistance programs despite being financially eligible.

**According to HUD, a person is rent-burdened if they spend more than 30% of their income on housing.**

Income of public benefits plus earned income	Total monthly income (earned income + deduction of SSI due to earned income)	% of income needed to afford market rate rent of 1-bedroom in the Omaha area (\$888) <sup>46</sup>	% of income needed to share a market rate rent of 2-bedroom in the Omaha area (\$542) <sup>46</sup>
2024 maximum SSI benefit <sup>93</sup>	\$943	94%	57%
Avg. SSDI adult child survivor benefit	\$1067	83%	51%
8 hours/week at minimum wage <sup>93</sup> (\$12/hr.) plus SSI	\$384 + \$793.50 = \$1,177.50	75%	46%
16 hrs/week as a fast food worker (\$13.07/hr.) <sup>46</sup> plus SSI	\$836.48 + \$567.26 = \$1,403.74	63%	39%
24 hrs/week working as a stocker/order filler (\$14.97/hr.) <sup>46</sup> plus SSI	\$1,496.64 + \$237.18 = \$1,733.82	51%	31%

### Potential of Family Investment in Housing Stability

Survey respondents were asked to share what they believed they would need for total budgeted housing costs inclusive of their current income, public benefits and any anticipated **special needs trust (SNT)**<sup>94</sup> or family investment in their future. As the chart above indicates, most survey respondents need or anticipate needing support to cover monthly rental costs of \$450 to \$1,100 to ensure housing stability.

The 2023 **Omaha Housing Affordability Action Plan**<sup>95</sup> estimates that over 7,000 rental units will need to be priced below \$1,000 a month for households making less than \$50,000. Over 11,000 for-sale units will also need to be priced below \$250,000<sup>96</sup> Yet, these estimates do not take into consideration the demand of adults with A/I/DD currently living in family caregivers' home.

Although most adults with A/I/DD are not earning income to support market-rate housing costs, most survey respondents

could afford such housing with a roommate if they received financial support from family or other non-public sources. Almost a third also report anticipating the ability to afford a one-bedroom, market-rate unit. However, even when considering the addition of family financial support, many respondents will need subsidized housing or a housing voucher to afford housing in Omaha.

When asked to consider adding family assistance to help cover housing costs, essential variances exist related to socio-economic status. Of those surveyed, approximately 21% have some form of a special needs trust. This financial tool protects against the financial exploitation of adults with A/I/DD, providing a vehicle for families to assist their loved ones financially without putting **means-tested**<sup>97</sup> public benefits at risk. Although not a disqualifying factor, if an SSI recipient is assisted by a family or a special needs trust, their SSI will be reduced by a third. Special needs trusts are an essential tool for those whose families may be able to offer an inheritance or a **bequeathed home**.<sup>98</sup>

Creating an SNT is essential in future planning; however, it only addresses the legal aspect—one of the four key planning issues. Different types of SNTs serve specific purposes. The other three key issues of future planning are government benefits, budget/financial projections and lifestyle planning.

### Planning for the Future

The chart below shows the percentage of respondents engaged in future planning.

Sixty-one percent of all survey respondents have yet to do any future financial planning or report difficulty due to the absence of resources to fund an SNT for their loved one. Regarding Spanish-speaking respondents, not one had done any future financial planning. Most of the Spanish-speaking respondents indicated that they did not have extra income to do future planning. Consequently, those who did not or could not plan will need housing assistance or very affordable units to prevent displacement or homelessness if no other arrangements have been made with other family members if a crisis occurs.

Presently, most adults with A/I/DD can rely on family caregivers to help fill gaps in support or help them identify if they may be at risk of abuse or neglect by others. Yet, survey data reveals that the majority of adults with A/I/DD have a limited natural support system: those who are active in an individual's life and not paid to support them. Most adults with A/I/DD will outlive their parents, underscoring the urgent need to help plan and develop the relationships needed to build natural support systems. Natural supports can help people develop a sense of belonging in their communities; they can also be critical in helping identify and prevent situations that can lead to neglect, abuse or mate crime.

Further impacting the ability to plan, Nebraska does not offer A/I/DD-specific **navigation services** available to other populations, such as veterans, seniors or those experiencing homelessness. Yet, because the housing, LTSS and public benefit systems are disconnected, individuals and their caregivers may need assistance navigating different program options to plan for the transition of their loved one from the family home into another setting. Other states provide various housing services in their waiver options.<sup>99</sup>

Without planning, adults with A/I/DD may fall into crisis, which could be traumatic. Offering **housing and lifespan navigators**<sup>100</sup>

Have you or your family done any future planning?	
No	41%
No, we do not have extra income to do this.	31%
Yes, I opened an ABLE account.	21%
Yes, I have a special needs trust.	21%
Yes, we have met with a special needs lawyer.	8%
Yes, I'm part of a pooled special needs trust.	0%

\*Does not total 100% because respondents could choose more than one answer.

could prevent placement in a group home, a more expensive institutional setting such as a psychiatric facility, ICF/IID, skilled nursing facility, an emergency room or the experience of homelessness.

### Barriers to Community Engagement

All self-advocate survey respondents indicate they experience barriers to community. Of family respondents, only 3% shared that they do not experience barriers to community engagement.

Self-advocates and families both share the same top five barriers, yet a higher proportion of self-advocate respondents indicate experiencing barriers. Feeling overwhelmed by crowds is the greatest barrier to community engagement, reported by 74% of self-advocates. Other barriers include 65% reporting not having enough money in their budget to engage in community activities and 57% having limited access to public transportation. Furthermore, 48% reported not having friends to hang out with; 48% also lack personal transportation, while 35% report feeling unsafe in the community and unable to find activities.

Most of these reported barriers can be addressed by raising awareness of neurodiversity in the community and intentionally creating spaces and places to help facilitate social interaction.

Whether in public locations, such as recreational centers, or intentionally addressed in the design of future community assets, community integration and a feeling of belonging does not happen spontaneously when people with and without disabilities coexist in a geographic location. It requires intentional community-building that engages participants and enlists feedback to understand the needs, preferences and desired relationship-building activities that create more neuro-inclusive environments.

# TOP 5

## Self-advocate concerns for community engagement

- 

1 Feeling overwhelmed by crowds
- 

2 Not enough money in my budget
- 

3 Limited public transportation
- 


4 Lack of personal transportation
- 

5 Do not have friends who want to attend activities

# TOP 5


## Family concerns for community engagement

**1**  **Lack of personal transportation**

**2**  **Do not have friends who want to attend activities**

**3**  **Limited public transportation**

**4**  **Feeling overwhelmed by crowds**

**5**  **Not enough money in my budget**

For example, in April 2022, AAP hosted a month-long Common Senses Festival in Omaha that helped advance community members' understanding of autism and highlight best practices for inclusion in venues and services. The festival combined numerous installations, events and activities to highlight how all members of a community benefit from inclusive practices. With over 5,500 attendees, the success of the Common Senses Festival also served as a catalyst for the creation of COMPASS, AAP's inclusion training program.

### Transportation

Lack of public and personal transportation options also ranked in the top five barriers for both self-advocate and family respondents. This is unsurprising because only 18% of survey respondents drive. Survey respondents indicate relying primarily on friends and family for transportation. Only 23% respondents use the public bus system. One explanation for this could be that public transportation may be too overwhelming, inaccessible or may not be available where individuals live. Ride-sharing apps are used



*Autism Action Partnership's COMPASS program provides comprehensive services to businesses, organizations and community groups seeking to become more inclusive of autistic and neurodivergent individuals. COMPASS offers training, technical assistance and consultation services customized to the needs and goals of each customer. Autism Action Partnership publicly acknowledges COMPASS partners who demonstrate an ongoing commitment to transforming and maintaining inclusive environments for individuals of all abilities.*

**"We need to know what services are available and how to get them. It has been hard doing everything on my own to support my son. I wish there was a coordinator who would help with all the processes and forms and help guide me. Supportive housing would be amazing and it needs to happen soon!"**

— Respondent, Omaha Housing Market Analysis Survey

by 14% of respondents. For those individuals enrolled in one of the five HCBS waivers available in Nebraska, non-medical transportation in the community is included as a service on their person-centered plan.<sup>101</sup> The transportation service provides rides to access community services, activities and resources when other options are unavailable. However, only 3% of respondents use this option. Since only 5,000 people are receiving LTSS services, transportation is likely needed by those not receiving services through waivers.

Neuro-inclusive properties would benefit from transit-oriented or walkable locations. Emerging developments can use this data in their design to seek parking variances or include a sheltered pick-up/drop-off area. More research is needed to better understand solutions to this persistent barrier of community engagement in Omaha.

### Drivers of Loneliness

The chart below shows the responses when asked about factors contributing to loneliness:

Significantly, 80% of survey respondents indicate they or their family members with A/I/DD experience loneliness as their most significant concern for the future. Loneliness is a major public health concern and has a significant ripple effect on one's mental health and support system. Forty-nine percent of respondents noted that one of the barriers

#### If you experience loneliness, what are your barriers to friendship?

I do not know how to turn potential friends into long-term friendships.	<b>49%</b>
People do not understand how to be a supportive friend to me.	<b>49%</b>
I don't know where to go to meet potential friends.	<b>46%</b>
I experience too much anxiety to try to meet new people.	<b>41%</b>
I do not have transportation to see friends.	<b>34%</b>
I accidentally do things that have hurt relationships.	<b>32%</b>
I have difficulty scheduling to meet with friends.	<b>25%</b>
I don't have money to spend on outings with friends.	<b>21%</b>
I need staff support to see my friends.	<b>19%</b>
I see my friends as much as I want.	<b>11%</b>

*\*Does not total 100% because respondents could choose more than one answer.*

**“We are called to build a movement to mend the social fabric of our nation. It will take all of us—individuals and families, schools and workplaces, healthcare and public health systems, technology companies, governments, faith organizations and communities working together to destigmatize loneliness and change our cultural and policy response. It will require reimagining the structures, policies and programs that shape a community to best support the development of healthy relationships.”**

— Dr. Vivek H. Murthy, 19th and 21st Surgeon General of the U.S.

to friendship is that the **neurotypical**<sup>102</sup> world needs to understand how to better engage with the neurodivergent population. Equally, 49% report they do not know how to turn potential friends into long-term relationships. The top two barriers to friendship underscore the need for reciprocal efforts from neurotypical and neurodivergent community members. Like barriers already identified in accessing the community, social anxiety, not knowing where to go to meet friends and lack of transportation are additional reasons why adults with A/I/DD report feeling lonely.

Community developers could use the data described in the next section on preferences to enhance accessibility through relationship-building with community-based organizations like AAP that serve adults with A/I/DD. Thoughtful housing design can also assist in breaking down barriers to community and isolation. Examples include being pedestrian-oriented, offering spaces for **soft social interactions**<sup>103</sup> (shared mailboxes, community checkerboards, sensory trails, etc.) and partnering with community-based organizations to offer more supportive amenities that facilitate greater social opportunities and engagement.

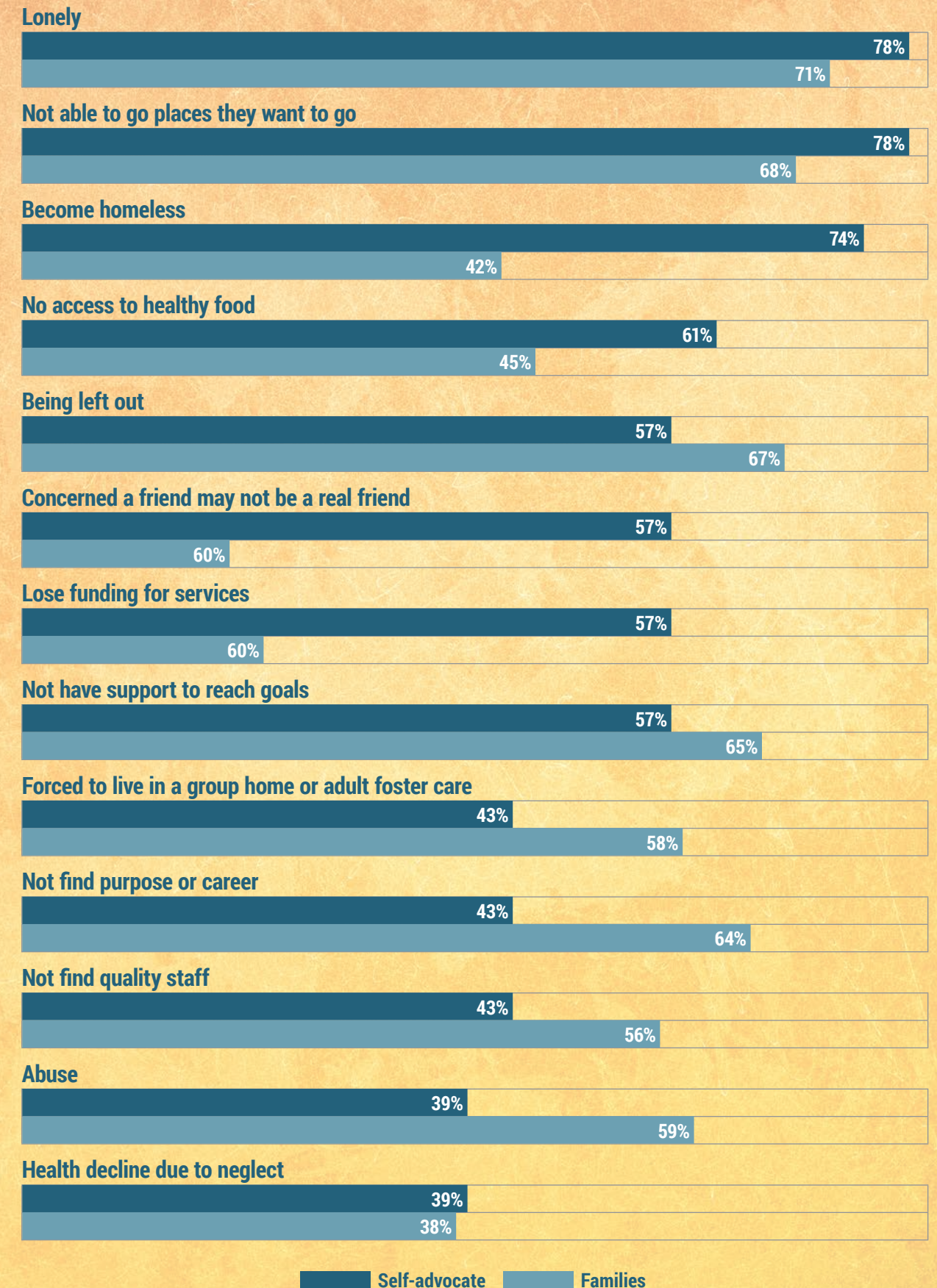
### Future Concerns

The following charts show input of survey respondents asked about their future concerns ranked from the most to the least concerns. The second chart is ranked from most to least concerns faced by self-advocates.

When asked about the future, both individuals and families have grave concerns about what will happen when they can no longer rely on family caregivers for housing or support. Segmenting the data revealed significant differences in future concerns among self-advocates who can speak for themselves and other respondents who may be representing a loved one with A/I/DD.

Among Spanish-speaking respondents, the top three concerns are abuse (91%), loneliness (86%) and being forced to live in a group home or adult foster care (82%). More work is needed to understand the disparities and cultural differences in order to address the significant percentages of concern facing the Spanish-speaking population in Omaha.

### Future Concerns



# TOP 5

## Self-advocate concerns for the future

1



Concerned with being lonely

2



Unable to go places they want to go

3



Not have support to reach goals

4



Concerned they will be left out

5



Not find purpose or career

The top two concerns of loneliness and transportation are shared by self-advocates and other respondents. Yet, when looking at the next top three biggest concerns, there are differences when segmenting respondent data:

### Top 3 concerns of self-advocates include:

- 78% worry about becoming lonely and not being able to go places,
- 74% were concerned about becoming homeless.
- Other concerns include being unable to access healthy food and not having support to reach goals.

### Top 3 concerns of family members and other respondents include:

- 72% concerned about loneliness,
- 68% not being able to go places,
- 67% concerned about being left out.

**“We need to know interim options until a house option is available. I currently have to provide all transportation [home to work is not on a bus line] and must manage everything for my autistic son. I have no one to help if I need to travel or want a break. What’s out there for us now?”**

— Respondent, Omaha Housing Market Analysis Survey



*Preferences data in this section are compiled from the 2023 Omaha Market Analysis Needs & Preferences Survey unless otherwise noted. The data provides information from respondents with A/I/DD and/or their families about their needs and preferences for housing, services and community engagement in the future. The next section offers details about data-driven recommendations to meet demand.*

Adults with A/I/DD and their families have similar desires to those of neurotypical tenants: safety, respect for privacy and good neighbors. They also value other unique aspects, including flexibility and choice, assistance in becoming more independent and connecting with areas of interest or other meaningful activities. The following data on

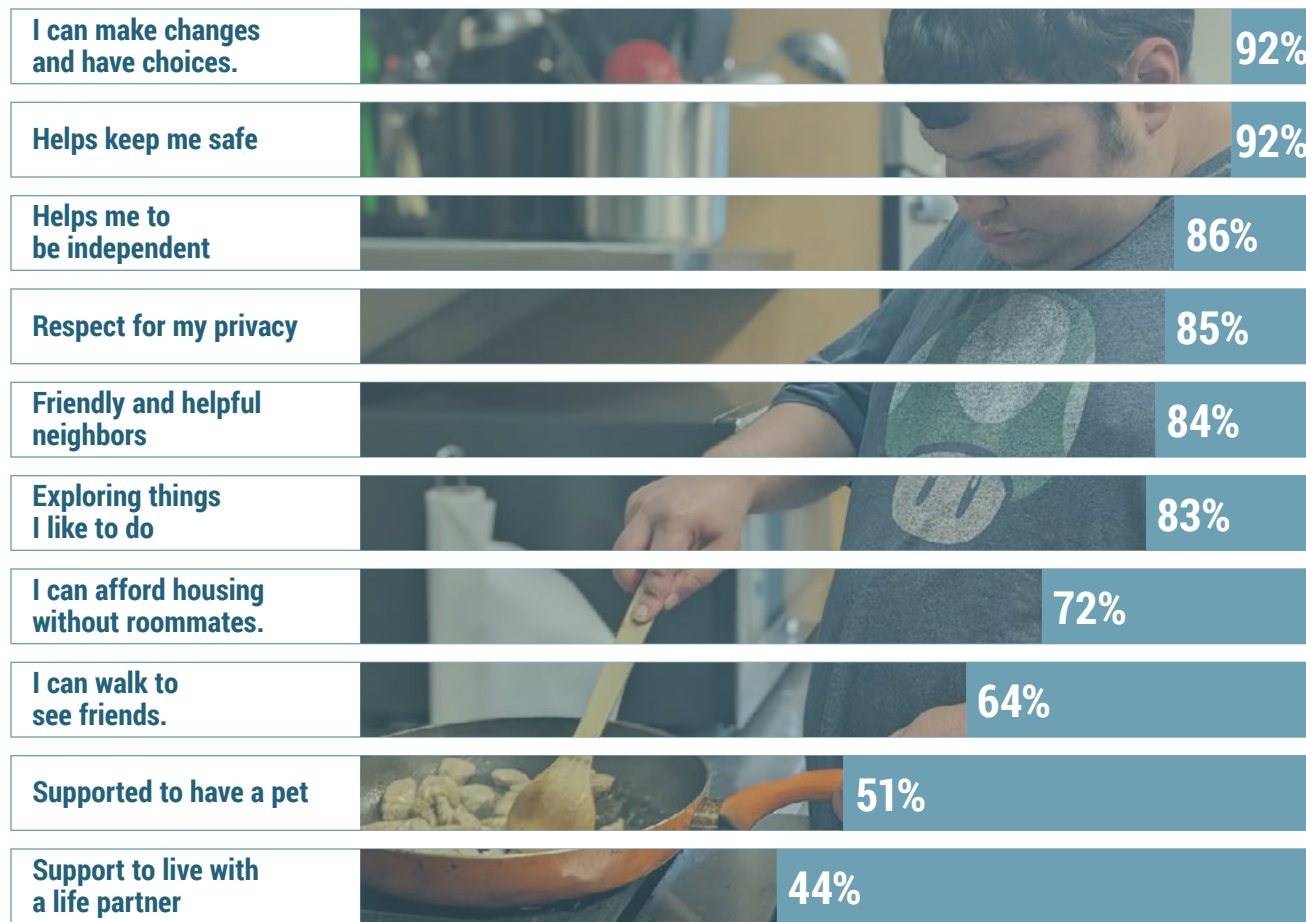
preferences include elements of the built environment and the ecosystem of support needed to help adults with A/I/DD thrive.

### Individualized Long-Term Services & Supports

As described by the Neuro-Inclusive Housing Framework included in the Background section of this report, housing and LTSS providers may or may not be connected. One can live in a provider-controlled setting where the service provider secures and maintains housing for those they serve. Alternatively, one can select a consumer-controlled setting where they find

**79% of self-advocates prefer to find and control their own housing.**

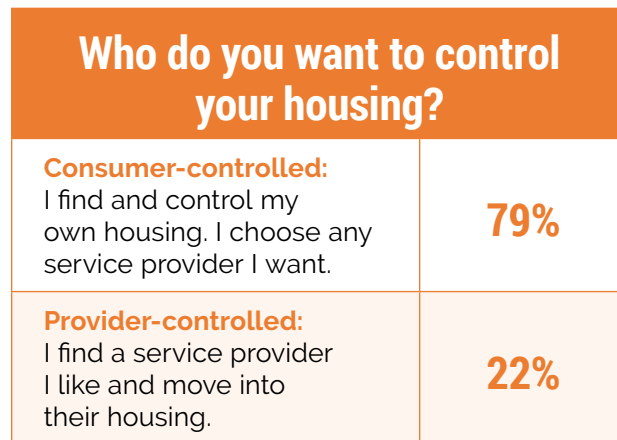
## What is important for your future home and supports?



\*Data includes respondents with A/I/DD and/or their families.

and manage their preferred home (for rent or for sale) before selecting their service provider and LTSS service delivery method..

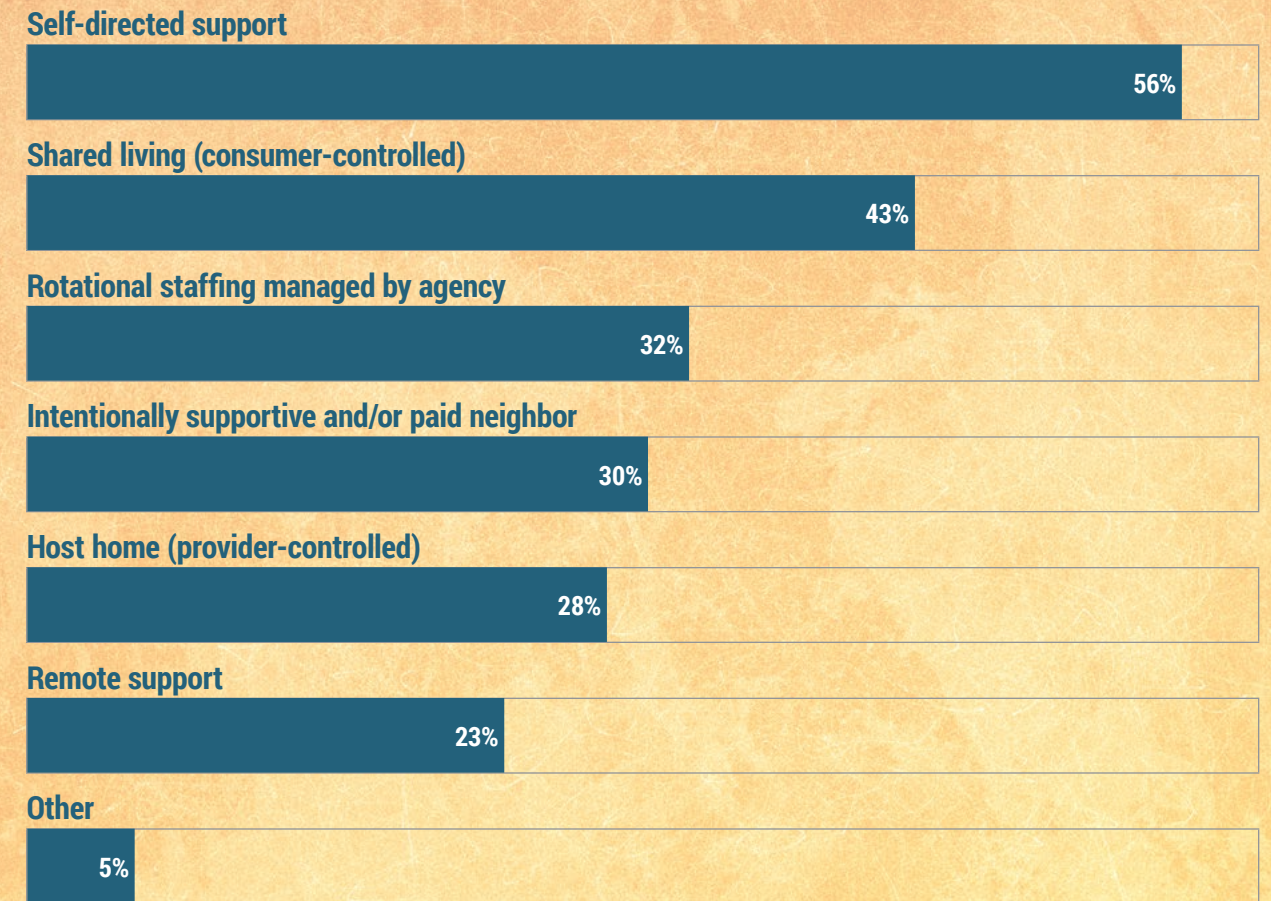
The figure below shows responses to the question of control of housing.



In a provider-controlled setting, one's service provider is responsible for maintaining and managing the home. If they no longer like and seek to change their service provider, a resident must move. One of the benefits of selecting a provider-controlled setting is that it may simplify the decision-making process regarding housing and support services. Most survey respondents prefer a consumer-controlled setting, offering more choice and control over their service provider, service delivery system and future.

For example, in a consumer-controlled setting, the same single-family home scattered in a typical neighborhood or part of a **planned community**<sup>7</sup> could have various LTSS arrangements individualized for residents. For example: Mason's parents purchased a home and placed it into a SNT.

## Preferred Service Delivery Models



\*Data includes respondents with A/I/DD and/or their families.

The following are possible living arrangements and service delivery options that Mason can change overtime or as needed:

(A) Mason lives with two housemates who have A/I/DD and choose to hire the same service provider who schedules rotating staff to meet their individual and collective needs.

(B) Mason lives with his caregiver and the caregiver's child in a shared living arrangement.

(C) Mason lives with two housemates. One housemate does not have A/I/DD. Mason and his support team hire his support staff through self-direction; his neurotypical roommate might also be paid to assist as needed. The third housemate uses a different LTSS agency providing remote support.

## Service Delivery Models

The chart above shows respondents' preferred service delivery models.

After learning of the considerations and benefits of various service delivery models, self-direction (56%), shared living (42%) and agency-based **rotational staffing**<sup>7</sup> (32%) are rated as the top three most preferred service delivery models. Fortunately, Nebraska HCBS waivers offers each of these service delivery options with at least four different funding levels. While the infrastructure of the DDD service system should be able to accommodate these top preferences, once out of the family home, implementation of self-direction and shared living require access to consumer-controlled, affordable, accessible





## LTSS Delivery Model<sup>7</sup>

### Self-Directed Support

An individual who needs LTSS is given a budget to spend on their LTSS based on an assessment of their support needs. They are responsible for recruiting, hiring, training, scheduling and firing support staff. Some states allow family members to be hired as support staff.

### Rotational Staffing

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

### Shared Living

An individual with LTSS needs invites a person or family member(s) to live in their home to provide LTSS. Because private homes are consumer-controlled settings, the individual can ask their LTSS provider to move.

### Host Home

An individual with LTSS needs lives in the home of their LTSS provider. As a provider-controlled setting, the LTSS provider (host) can ask the individual to move.

### Paid Neighbor

A person who lives on the same property (but not in the same home) as an individual with LTSS needs, who can offer LTSS on a scheduled or on-call basis. This is also referred to as a resident assistant.

### Remote Support/Monitoring

When possible, an individual may have their LTSS needs met via remote service, using technologies such as video conferencing, smart-home devices and other **enabling technology**.

housing that is currently out of reach for those with A/I/DD.

Lack of access to consumer-controlled housing options was recognized as a major obstacle in Goal 2 of the **2019 Nebraska Olmstead Strategic Plan**.<sup>104</sup> Nebraskans with disabilities will have access to safe, affordable, accessible housing in the communities in which they choose to live.<sup>105</sup> Under the requirements outlined in Nebraska Statute §81- 6122, this plan was evaluated in 2021.<sup>106</sup> Evaluation of progress toward the plan's goals showed little state fiscal or policy advancement in increasing access to consumer-controlled housing opportunities.

Without greater access to consumer-controlled housing options, self-direction and shared living are not possible residential options for Omahans with A/I/DD. Although not as highly preferred by survey respondents, both a **paid neighbor**<sup>7</sup> (30%) and remote support (23%) are desired yet have no current funding mechanism in Nebraska. The New York Office of Persons with Developmental Disabilities (OPWDD) offers a waiver-funded paid neighbor model through the state's self-direction program.<sup>107</sup> Nebraska DDD could explore incorporating this service delivery model into its existing self-direction program.

All DDD-administered waivers offer to fund assistive technology and/or a **personal emergency response system (PERS)**,<sup>108</sup> an electronic device that enables a person to press a button and get help in an emergency. Although important ways to use technology, these options do not provide the ongoing monitoring needed for remote support. **Remote support/monitoring**<sup>109</sup> uses technology to provide real-time assistance by direct support professionals from a remote location. This service often reduces the number of in-person direct support providers needed by an individual while enabling safety, privacy and independent task completion.<sup>105,110</sup> For examples of how Nebraska can offer remote support in its waivers, refer to the 17

**“Technical Assistance Collaborative's assessment, reinforced by consistent stakeholder feedback, is that there has been little progress toward increasing access to safe, affordable, accessible housing for individuals with disabilities... The lack of adequate housing options contributes to individuals with disabilities experiencing extended stays in institutions and congregate care settings when they could live successfully in community-integrated settings.”**

— Nebraska Olmstead Plan Evaluation Report on Progress with Plan Implementation, June 2020 to December 2021

**Technology First States**<sup>111</sup> offering state- and waiver-funded models that include remote support/monitoring.

### Renting Versus Homeownership

Survey respondents seek bequeathed, for-rent and for-sale opportunities to secure housing.

It is not surprising that homeownership in various forms—buying a separate home, purchasing with others, adding **accessory dwelling units (ADU)**<sup>110</sup>—is preferred by most respondents since the rental market is unstable for those on a fixed income. Families may also be concerned that, without their support or home as a safety net, their loved ones could be evicted, displaced or experience homelessness due to the lack of viable alternatives. Unlike other populations that may have the capacity to earn housing wages in the future, individuals with A/I/DD may not be able to earn a living wage due to limitations in their skill set or cognitive abilities. Currently, the required housing wage for a one-bedroom unit is full-time employment with at least \$17.08 per hour, which is not accessible to most adults with A/I/DD.<sup>46</sup>

### Do you want to rent or buy your future home?

Rent a room in a provider-controlled setting.	<b>39%</b>
Rent my own home, but need rental assistance to afford housing.	<b>31%</b>
Prefer to buy a home, but unsure if I or my family can afford it.	<b>31%</b>
Buy a home.	<b>31%</b>
Add an accessory dwelling unit to my family property.	<b>28%</b>
Rent my own home.	<b>21%</b>
Buy a home together with others.	<b>17%</b>
Remain in current family home and family will move out.	<b>11%</b>
Other	<b>5%</b>

*\*Does not total 100% because respondents could choose more than one answer.*



Majority of adults with A/I/DD will likely be extremely low income over their lifetimes, there is a financial argument to help individuals and/or their families purchase a home versus using a rental subsidy over decades. Without assistance, only a small percentage of families would be able to purchase a home for their dependent loved one. Mortgage assistance or homeownership programs may provide additional affordable housing options for adults with A/I/DD.

Fortunately, the **Omaha Housing Authority** offers a **Bridges to Homeownership program** that allows qualified individuals and families participating in the HCV rental subsidy program to use their vouchers to buy a home and receive monthly assistance in meeting homeownership expenses.<sup>112</sup> The renter must locate housing and secure their own mortgage. Mortgage products developed to help **owner-occupied**,<sup>113</sup> low-income households may need to be modified to allow the purchase of a property for a low-income dependent with A/I/DD.

Nebraska offers a property tax relief program called the **homestead exemption**<sup>114</sup> with an eligibility category specific to adults with developmental disabilities.<sup>115</sup> Fortunately, this includes not just owner-occupiers but also beneficiaries of homes held in a trust. Some potential challenges to this program include:

- Although the property tax exemption is 100% if the occupier's income is below \$34,600.99, the maximum assessed value on the homestead must be \$110,000 or 225% of the average assessed value of a single-family residential property in the county, whichever is greater. This may limit the location of or accessibility to a home to accommodate a shared living arrangement due to such low maximum thresholds for the assessed value.
- A certificate of disability must be signed by the deputy director of the Division of Developmental Disabilities. It is unclear whether the deputy director would sign if the individual has not applied or may not be eligible for services through DDD.<sup>116</sup>

For those who prefer to remain on a family member's or friend's property, allowing use-by-right ADUs for dependent family members or individuals with A/I/DD or seniors could help increase housing options for this population and others.

Homeownership, in addition to rental subsidies for those who prefer to rent, should be incorporated into plans to meet the housing needs of adults with A/I/DD. Developing tools and housing stock targeting homeowners with A/I/DD or their families can help ensure housing stability. The limited resource of HCVs or subsidized units can also be preserved for those who prefer a rental option. The state could work toward creating incentives for landowners, developers and families to make homeownership more attainable while also creating options that qualify for the homestead exemption.

### Housing Type & Physical Amenities

The chart to the left shows the preferred type of housing development by respondents.

After learning about the benefits and considerations of various development types, it was clear that participants preferred **mixed-use planned communities** and **neuro-inclusive planned communities**. This may be due to additional accessibility features, safety nets and supportive amenities these options may provide that are unavailable in scattered-site housing. A mixed-use planned or neuro-inclusive planned community is designed for the accessibility needs of adults with A/I/DD but can benefit everyone.

When segmenting only Spanish-speaking respondents, 68% prefer to bequeath the family home—nearly three times as often as primarily English-speaking respondents. More research should be done to understand this difference and how to make this option more accessible, since none of the

#### Bequeathed Home

The home in which a neurodiverse family currently resides is maintained as the primary residence for the adult family member/s with A/I/DD when other family members pass away or move out.

#### Scattered-Site Housing

A residential unit located within the general housing fabric of a community. It is not part of a housing development that serves a specific residential market. In affordable housing circles, scattered-site housing also refers to affordable housing dispersed throughout the community.

#### Planned Community

Small- or large-scale, planned property with multiple residential units and amenities that meets the targeted demand of neurodiverse tenants. Property management helps maintain housing and common spaces with the intent of making life as convenient and enjoyable as possible while supporting connection and belonging.

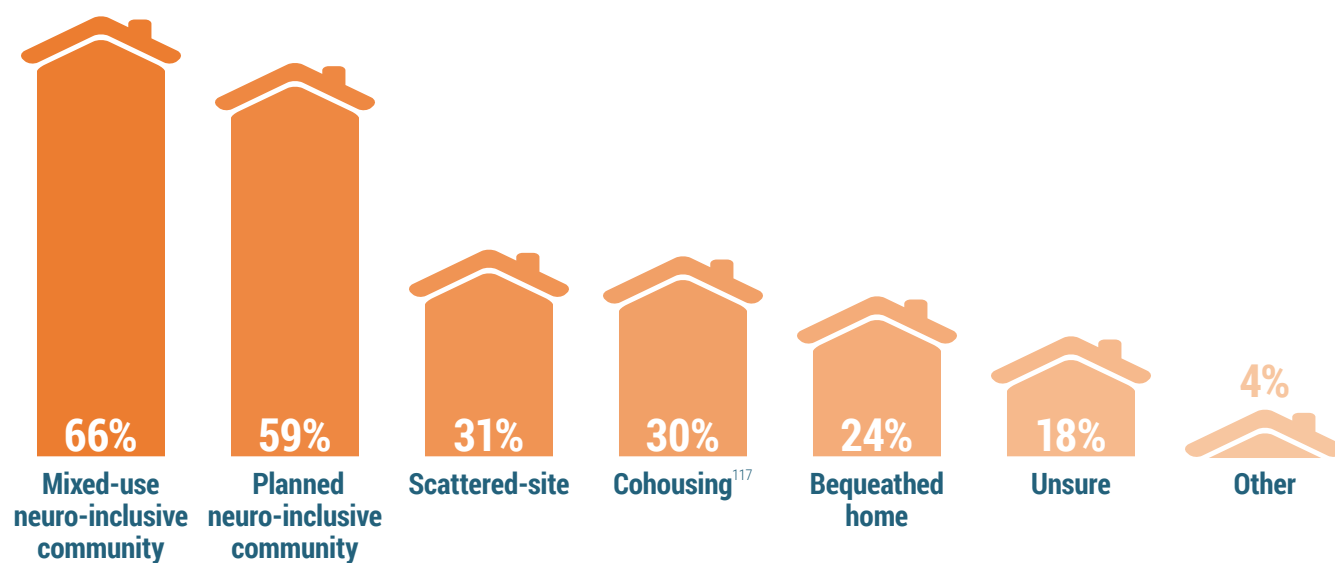
#### Mixed-Use Community

Large-scale residential development of commercial, public and private uses with robust, curated amenities to give residents the experience of living in a self-contained community. Amenities are open to the public and may provide additional community engagement or employment opportunities.

#### Cohousing

A neighborhood or apartment/condominium created by its residents. Cohousing communities typically feature private residential units, a large community center or common house with amenities and pedestrian-oriented design. The property is designed and managed by residents. Many host weekly common meals and events prepared/organized by residents.

### What type of housing setting are you interested in?



*\*Does not total 100% because respondents could choose more than one answer.*

**In the past and even today, people with A/I/DD with access to housing must choose whether to live with multiple, unrelated individuals with disabilities in a provider-controlled group setting, remain in the family home or risk experiencing homelessness.**

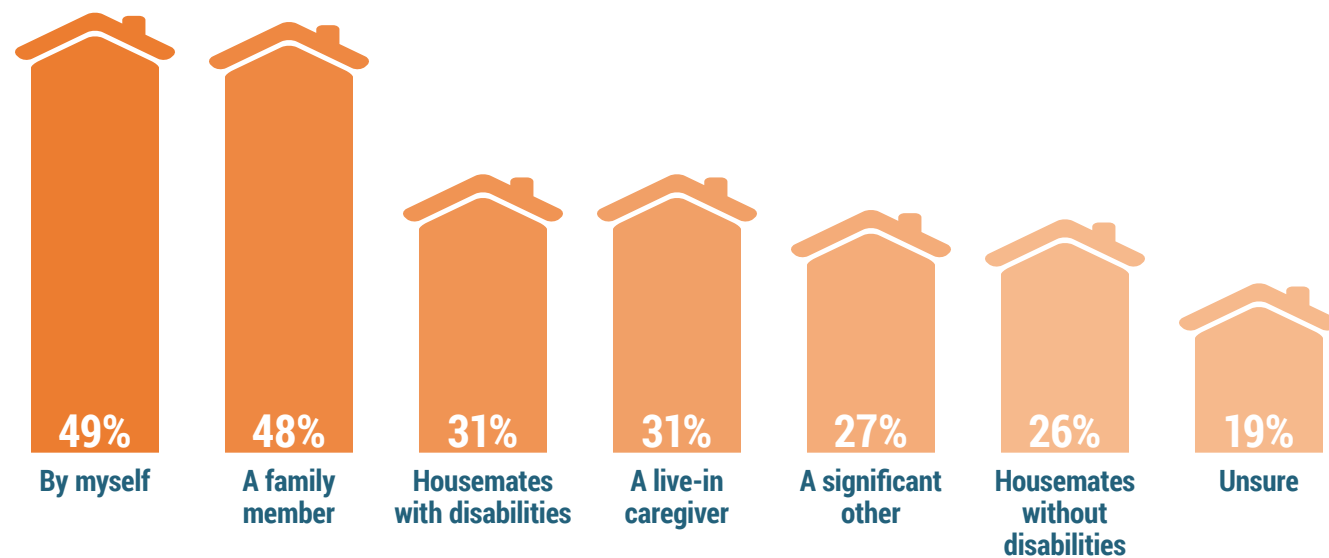
Spanish-speaking respondents indicate they have done any future planning. Translation of information was indicated in open-ended survey responses as a need and, in this case, can help open the door to much needed planning.

As states review and execute their HCBS state transition plans,<sup>118</sup> the OHMA sheds light on diverse preferences in development types, including mixed-use planned and neuro-inclusive planned communities. Such communities are designed to foster integration and improve social outcomes for adults with A/I/DD.

### Unit Type

Respondent data show significant diversity in the preferred unit type. Just as the neuro-typical population has a variety of preferences, adults with A/I/DD and their families also have diverse interests. There is no one-size-fits-all approach to meeting housing demand for people with A/I/DD, yet data show that single-level buildings or those with elevators are preferred. This is likely due to safety features for those presenting with co-occurring conditions such as epilepsy, along with the desire to age in place and not be forced to move if mobility needs changes.

### Who would you like to live with?



*\*Does not total 100% because respondents could choose more than one answer.*

### Living Arrangements

The chart to the left shows the preferred living arrangements by respondents.

Sharing one's home is an intimate experience. When asked about living arrangements, most respondents desire to live in a single unit without roommates. However, in the past and even today, people with A/I/DD with access to housing must choose whether to live with multiple, unrelated individuals with disabilities in a provider-controlled group setting, remain in the family home or risk experiencing homelessness. Non-disabled adults often experience this type of congregate living arrangement during early adulthood in dormitories or student housing.

Living with a family member is the second most preferred option (48%), followed by living with a caregiver or other disabled housemates (31%). It is important to recognize that 27% expect to be in a committed relationship and able to live with their significant other.

These details are important for developers as they plan properties that meet the needs of adults with A/I/DD. For those who may prefer to live with a roommate or caregiver, best-practice strategies include same-size bedrooms in two-plus-bedroom units with each bedroom having a bathroom and, ideally, bedrooms not sharing walls in consideration of privacy and sound sensitivities.

### Physical Amenities & Design Preferences

The following charts show the physical amenities respondents prefer. The segmented chart is ranked from most preferred among self-advocates to least preferred. The second chart includes respondents with A/I/DD and/or their families and is ranked from most to least preferred.



### Physical Amenities<sup>7</sup>

#### Easy-to-Clean Features

The building and/or residential unit includes features that make cleaning and maintenance easier.

#### Smart-Home Features

The residential unit and/or building includes devices, appliances and other technologies that can be customized to enhance residents' comfort, safety and independence.

#### Pedestrian-Oriented

The building and/or development is located in a walkable neighborhood with intentional limits on vehicle traffic. Walkable neighborhoods can be safer for residents (adults and children) who may not recognize street crossings..

#### Extra-Durable Features

The building and/or residential unit includes extra-durable features, such as graffiti-resistant paints, floor drains and sealed surfaces (for water play), solid-wood furniture without sharp corners and more.

#### Sensory-Friendly

Sensory-friendly spaces take into account environmental factors that contribute to sensory overload, accounting for all five senses.

#### Universal Design

The residential unit and/or building includes design features that most people can use regardless of age, agility or ability. It seeks to optimize accessibility and continues to evolve with advancements, including enabling technologies.

# TOP 5

## Physical amenities most important to self-advocates

**1**  **Adaptable design**

**2**  **Transit access**

**3**  **Sensory-friendly features**

**4**  **Extra-durable features**

**5**  **Biophilic design**

Many adults with A/I/DD do not have accessibility needs related to mobility devices and ADA compliance. Their accessibility needs have a different origin of impairment, often impacting safe social interactions, independent living skills, atypical sensory perception, etc. Almost all the neuro-inclusive design features presented are valued by more than 65% of respondents.

When combining all survey respondents, the top five valued physical amenities are easy-to-clean, sensory-friendly, extra-durable, smart-home features and pedestrian-oriented locations. These features are valued for being ease of maintenance and durability; sensory-friendly considerations may include additional soundproofing, neutral color palettes, dimmable lighting, etc.; pedestrian-oriented site planning makes walking around one's community safer for those challenged to understand vehicular danger or who have difficulty crossing streets; and smart-home features like reminders if an oven is left on or a door is left open. These modifications and design strategies preferred by respondents may also be attractive to neurotypical residents.

When segmenting for self-advocates, their top five are adaptable design (83%), transit access (83%), sensory-friendly features (78%), extra-durable features (74%) and biophilic design (74%). Spanish-speaking respondents value additional security and cognitive accessibility features (such as wayfinding colors, icons instead of text, pictorial instruction, etc.

**Almost all of the neuro-inclusive design features presented are valued by more than 65% of respondents.**

## What type of physical amenities would be helpful?



\*Data includes respondents with A/I/DD and/or their families.





## Supportive Amenities<sup>7</sup>

### Community Navigator

A front desk and/or designated person in the building who can help residents connect with the community or problem solve.

### Life-Skills Training

Independent living classes such as cooking, budgeting, time management, etc.

### Community Life

Planned social activities or organized weekly gatherings based on resident interests.

### Resident Assistant

A front desk and/or designated person in the building who can help residents connect with the community or problem solve.

### Meal Service

Option to purchase prepared meals from an on-site restaurant, café, dining hall or meal plan.

### Benefits Counseling

Assistance in understanding and navigating government programs and/or privately funded savings programs without legal/financial advice or case management.

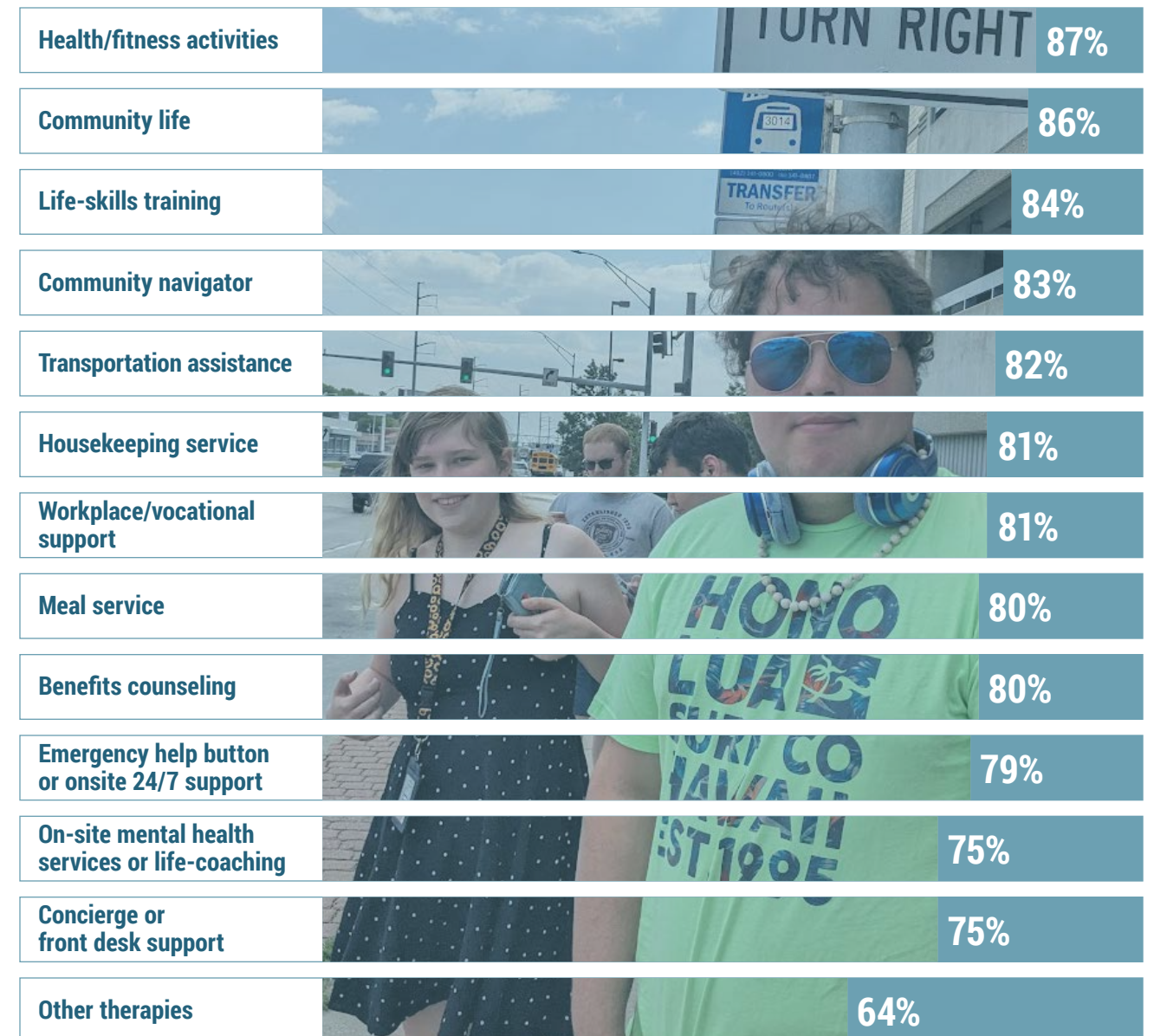
## Supportive Amenities

Supportive amenities are not individualized, LTSS. They are available to all residents who live at a specific property and offer additional support that individualized LTSS providers often do not offer. They also create an alternative supportive housing option for individuals ineligible for an HCBS waiver who need supportive housing to remain housed, employed and connected to their community. Supportive amenities do not need to be provided by the housing developer or property management company, who can partner with community-based organizations to provide such on-site services. Following the evidence-based best practice of the **Housing First**<sup>119</sup> homeless assistance approach, supportive amenities should be voluntary.

Although specific supportive amenities are ranked higher than others, it is noteworthy that supportive amenities within housing options are highly desired. When segmenting the various populations, there are slight differences in preferences. The top three preferences for family respondents include valuing community life (91%), benefits counseling (89%) and life skills classes (89%). The top three valued supportive amenities for Spanish-speaking respondents include life skills classes, workforce or vocational support, an emergency help button or 24/7 staff on-site. Self-advocates prefer housekeeping (83%) and health and fitness classes (83%), followed by valuing a voluntary meal service (74%), community navigator and on-site mental health services.

Among self-advocates, meal service may have been ranked higher because of the high executive functioning load required in meal preparation. Other executive functioning loads required in meal service may include meal planning, budgeting, transportation to/from a grocery store, maneuvering the sensory challenges of a grocery store, meal preparation, inviting others to join in a meal,

## Would these supportive property amenities help you?



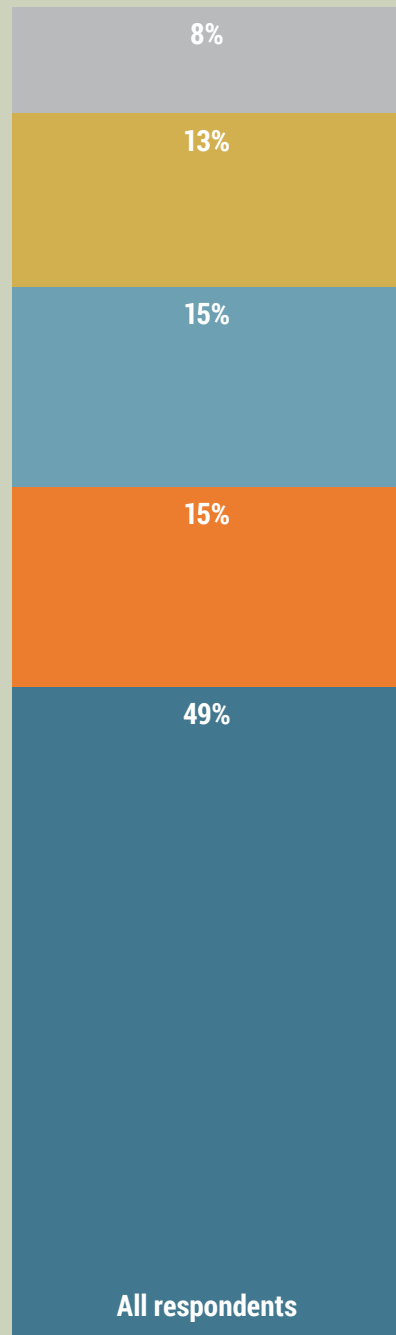
\*Data includes respondents with A/I/DD and/or their families.

or eating a meal alone and cleaning up. Access to a meal plan and a common dining area may alleviate some of this responsibility, which is more difficult when living on a limited budget or without access to a car. These options, which can support the creation of a

community, provide social opportunities to decrease feelings of loneliness and increase a sense of belonging. Eating a meal with others is a powerful way to build relationships.

**Self-advocates prefer housekeeping (83%) and health and fitness classes (83%), followed by valuing a voluntary meal service (74%).**

## Would you be interested in a residential transition program to help bridge the gap between the family home and independent living?



- Yes, if assisted with cost
- Yes, even if private pay
- No
- Unsure
- Previously attended

Federal Medicaid HCBS compliance guidance documents are provided to assist state agencies in ascertaining if a residential setting may meet the basic characteristics of a Medicaid HCBS. The HCBS settings rule identifies settings presumed to have institutional qualities and therefore do not meet HCBS funding requirements. These are known as settings that isolate.<sup>120</sup> For example, guidance documents refer to a common dining area and access to prepared meals as a potential red flag, because it might be construed as an institution.<sup>121</sup> It is important that Nebraska consider the need to create social opportunities and identify how future developments might include a common area and/or voluntary meal service for residents and meet their executive functioning challenges while promoting social interactions.

The Omaha Housing Authority currently has a senior and disabled services coordinator who provides supportive and referral services, as well as fosters relationships between community partners and residents to facilitate social activities and other opportunities for engagement and outreach. More exploration is needed to understand if this program is accessible and applies to adults with A/I/DD.<sup>122</sup>

### Transitioning from the Family Home

The bar chart shows respondents' preferences for a residential transition program.

Moving from a family home setting is a big decision for neurotypical and neurodivergent young adults. Adults with A/I/DD may have been living in the family home for decades longer and change may be more challenging than for a neurotypical counterpart. Changing environments, daily routines and transportation routes, as well as the stress of leaving the stability of the family home, require greater direct support for a transitional period. This is where a post-secondary transition program

can be valuable to those who want more intensive life skills training.

The majority of survey respondents indicate the desirability of a post-secondary transition program offering intensive life skills training serving as a bridge to independent living. Despite the significant proven advances of AAP's Prosper Academy, especially in just one year, Nebraska lacks a clear public funding stream for post-secondary residential



#### AAP Program Spotlight: Prosper Academy Autism Action Partnership offers a

*two-year post-secondary program to promote independent living, self-sufficiency and social skills for young adults with autism. Students live and experience campus life as a resident of John Paul II Newman Center and classroom instruction using Learn4Independence®, a licensed curriculum used in similar transition programs across the country. The current Prosper Academy cohort includes the following outcomes:*

*(1) After more than 170 hours of support riding the bus, 100% of participants can ride independently.*

*(2) After 43 hours of nutrition and cooking support, 100% of participants are able to prepare meals.*

*(3) About 94% of Prosper Academy's parents and other supportive adults (PASAs) attend non-required information sessions.*

[autismaction.org/prosperity/academy](http://autismaction.org/prosperity/academy)

transition program tuition to make it financially accessible to most adults with A/I/DD needing assistance covering costs.

### Community Development

The following page shows respondents' preferred community amenities.

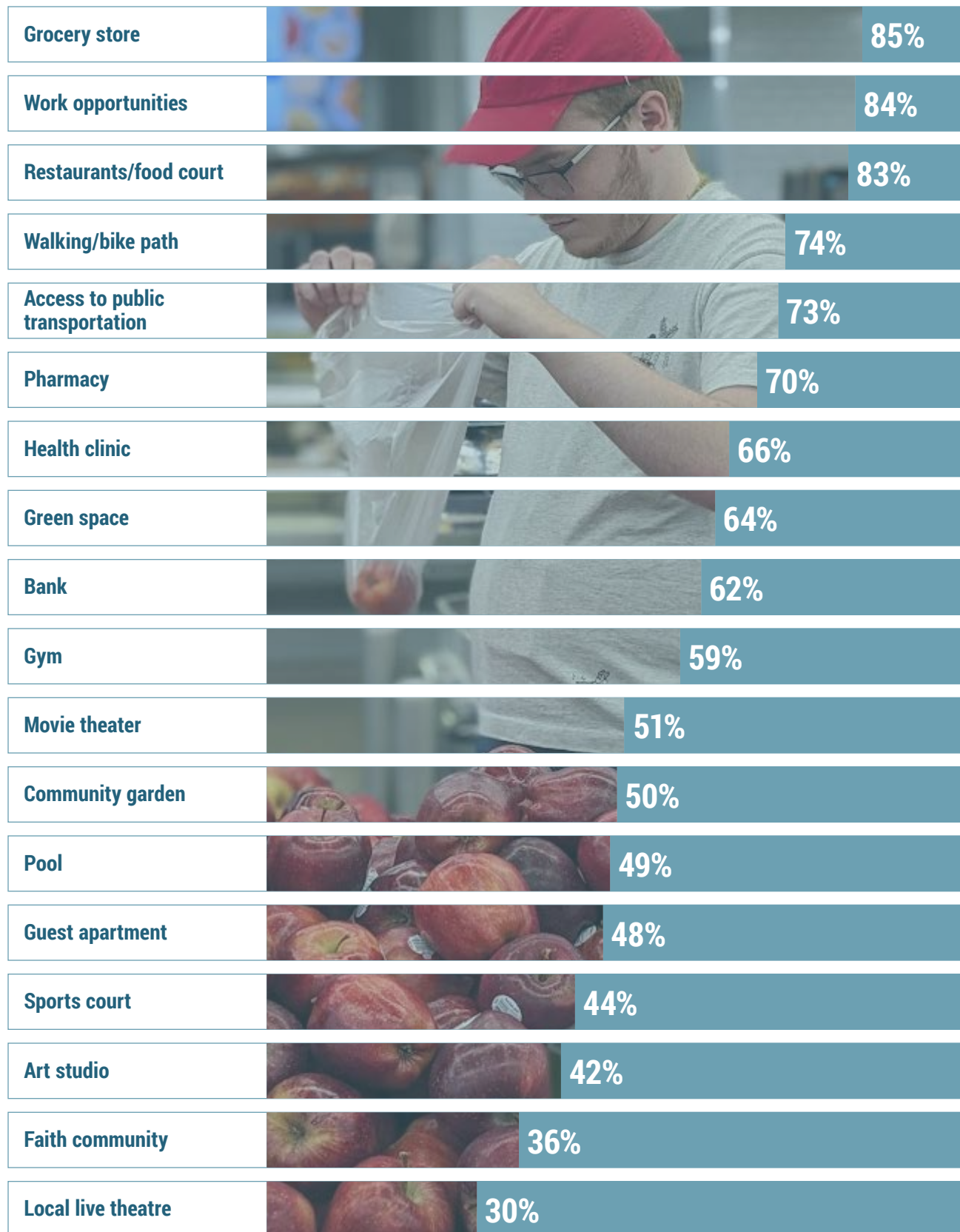
While housing is an important element of community development, local planners and businesses can also use this data to continue making Omaha more neuro-inclusive.

With 88% of all respondents reporting that they do not drive, planners and community development professionals at the local level play an integral part in ensuring that adults with A/I/DD can access housing in a walkable location close to public transportation. Survey respondents also indicate the importance of food access within walking distance of the property and workplaces that offer accommodations. Most respondents also indicate the importance of access to a pharmacy or health clinic, a walking or bike path, a gym and green space.

When comparing the data of this study with the public engagement sessions held for the development of the Omaha Housing Affordability Action Plan, the top desired amenities are virtually the same: grocery store, public transit, cycling and pedestrian trails, parks and entertainment.<sup>123</sup>

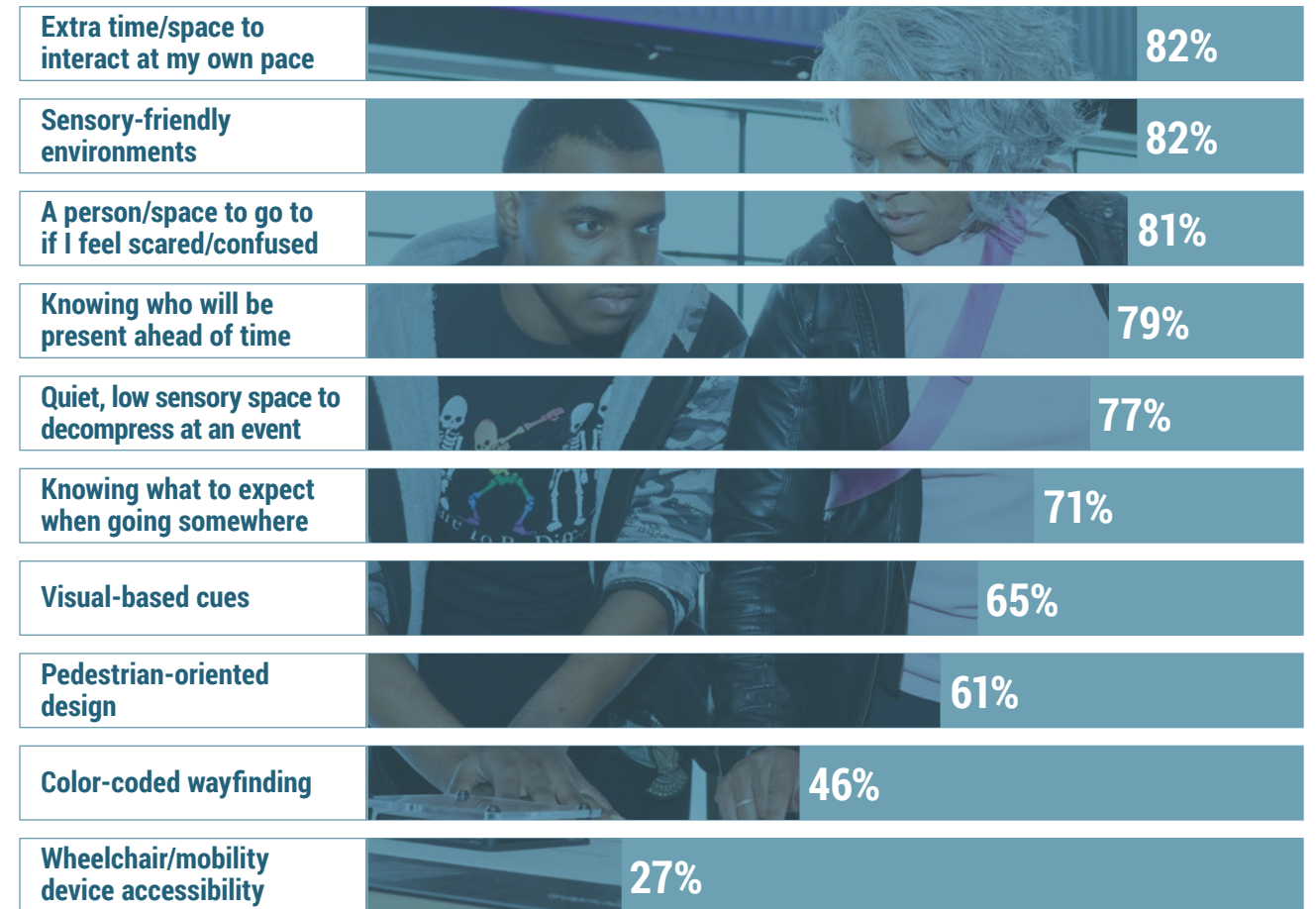
With the limited commodity of land, local planners and community developers should consider **land banking**<sup>124</sup> and/or utilizing a **community land trust**<sup>125</sup> to secure parcels that would be ideal locations for mixed-use planned or neuro-inclusive planned communities. Securing this type of property is critical to ensuring that affordable, accessible housing is not located in a food desert or isolating for residents who cannot drive.

## What things would you like on the property or within walking distance?



\*Data includes respondents with A/I/DD and/or their families.

## How important are these elements in making community events and spaces more accessible for you?



\*Data includes respondents with A/I/DD and/or their families.



The previous page shows respondents' preferred accessibility features.

The survey also included elements that would make Omaha events and the local community more accessible to the neurodiverse population. These elements could be incorporated into local festivals and markets, the State Fair, public comment sessions at City Hall or other community activities.

For example, a store or library may consider sensory-friendly hours where lights are

dimmed, music is set at a low volume or turned off, and staff do not approach others for assistance unless it is requested. A local event could offer a designated space to use or person to contact when participants feel overwhelmed or need a break in a quiet, low-sensory input environment. A map and/or **social story** can be written and placed on the website describing what to expect when people arrive, who and how many people may be present, what sights/smells/sounds they may encounter, etc.<sup>126</sup>

AAP has been hosting sensory-friendly events for the autism community since its inception in 2008. These events are held at local venues like museums, theaters, ballparks, etc. to allow families to experience the same enrichment opportunities as other families but in a manner more conducive to their needs. Over the years, AAP has begun working with many of these venues and partners to help advance their inclusive practices year-round—not just during special events. For example, AAP funded the creation of a sensory-friendly software application for the Omaha Henry Doorly Zoo and Aquarium (OHDZA) that all families can use to increase their enjoyment. The Omaha Zoo 4 All app includes a map with sensory information, a social story, accessibility information and updated information regarding each exhibit. OHDZA also has 10 sensory kits provided by AAP for guests if they become overwhelmed while visiting. Notably, these efforts have not negatively impacted the experience of neurotypical zoo visitors. Families with children or adults with autism regularly share that this has given them an additional activity for them to share with their neurotypical family members and friends.

Planning for the inclusion of adults with A/I/DD not only increases accessibility for neurodiverse families and self-advocates but also is of value to neurotypical residents of Omaha.

The figure to the left shows the distribution of where respondents want to live.

When asked about location, responses indicate diverse representation across the Omaha region, with Midtown and West Omaha areas being of highest preference. This could be due to familiarity with respondents' locations or perceived access to service providers or community amenities. Statistically, the development of additional residential options targeting adults with A/I/DD would be in high demand in any of these geographic areas.

When asked what opportunities are needed in the future, most respondents request life skills classes, assistance accessing services and planning for the future, planning grants to launch housing solutions, more fun things to do and help finding housing assistance.

Minnesota offers two robust Medicaid-funded examples of a Housing and Lifespan navigation program targeting adults with A/I/DD: Housing Stabilization Services and Housing Access Services. These programs include financial assistance and navigators for those on an HCBS waiver and those who do not yet have or are ineligible for an HCBS waiver.<sup>127</sup>

The Colorado Housing and Finance Authority developed a unique technical assistance grant program in response to the Denver Housing Market Analysis.<sup>128</sup> The program provides funding and expertise to landowners to explore using their property for neuro-inclusive housing. Landowners can apply twice a year for a grant that provides a consultant team, including a neuro-inclusive housing expert, an architect and a financial development consultant. The team offers community engagement, checks for the feasibility of the property, develops architectural renderings and a pro forma for the potential property.

Which of the following areas would you prefer to live?	
Midtown	51%
West Omaha	47%
Papillion/La Vista/Ralston	39%
Millard	31%
Downtown	30%
Southwest Omaha	29%
Elkhorn	27%
South Omaha	24%
Northwest Omaha	23%
Gretna	23%
Bellevue	23%
Bennington	18%
North Omaha	9%
Other	7%

# TOP 5

## Desired future opportunities

- 
**Classes for life skills**
- 
**Help for families to plan for the future**
- 
**Help families get needed services**
- 
**Planning for grants to launch housing options**
- 
**Fun things to do every week**



“ I went undiagnosed with autism for over 30 years, but I was able to get both of my kids diagnosed at younger ages, so they’ve been able to have treatment. Nebraska specifically is not set up to help or handle people with our kind of disability—and it scares me.”

— Respondent  
Omaha Housing Market Analysis Survey



## RECOMMENDATIONS

The following recommendations can guide the development of a Housing and Community Roadmap for Omaha. They are derived from data analysis by First Place Global Leadership Institute researchers, feedback from the Local Leaders Workshop and critical readers of the Omaha Housing Market Analysis. Recommendations based on a crosswalk of the Omaha Housing Affordability Action Plan are also included, since only 5% of its public engagement participants had a disability.<sup>124</sup>

### Closing of Data Gaps

- Segment the **Homeless Management Information System (HMIS)**<sup>129</sup> or point-in-time<sup>130</sup> data to identify adults with A/I/DD experiencing homelessness.

- Develop a housing and lifespan navigation program to target individuals with A/I/DD and their families, better-connecting people to available resources while collecting data and guiding them to plan for the transition out of the family home before falling into crisis.

>> Identify adults with A/I/DD living in family caregivers’ homes—segmented by those who need supportive housing and do and do not meet eligibility criteria for DDD services.

>> Determine methods and work with partner agencies to identify households by race and ethnicity with a child or adult dependent with A/I/DD and determine whether they are cost burdened (spending more than 30% of their income on housing).

- Identify adults with A/I/DD enrolled in Medicaid-funded health plans whom DDD may not identify.
- Modify DDD case management tools to identify individuals with A/I/DD involuntarily displaced due to the lack of affordable, accessible housing and/or currently living in a provider-controlled setting but who desire a consumer-controlled setting.
- Categorize utilization rates by residents with A/I/DD currently receiving a Housing Choice Voucher, **811 Project Rental Assistance (811 PRA)**<sup>131</sup> or other permanent rental subsidy and distinguish utilization rates of residents with A/I/DD currently living in public housing or in Permanent Supportive Housing.
- Identify a pathway to prevent homelessness of adults with A/I/DD deemed ineligible for an HCBS waiver or other LTSS but who are in need of case management and scheduled drop-in support.
- Consider adding housing services available in other states for waiver recipients to explore, secure, transition and maintain tenancy in housing. These include pre-tenancy supports, housing stabilization services, transitional housing services, tenancy sustaining services, etc.<sup>67, 68</sup>
- Add or modify waiver services to expand service delivery models, including remote support and paid neighbors in demand in Omaha, which are already available in other states.

## Long-Term Services and Supports

- Create an awareness campaign to help individuals with A/I/DD and their families understand and apply for LTSS and other public benefits.
- Increase funding and/or prompt legislative action to make HCBS waiver services available to adults with A/I/DD living with a caregiver over age 60 or at risk of displacement into provider-controlled or more restrictive than necessary settings.
- Appropriate funding to provide services for eligible individuals with developmental disabilities on waitlists for waiver programs, thereby eliminating the waitlist.
- Create a monitoring system to ensure that the state keeps up with the demand for services and moves people from the waitlist faster to prevent a years-long wait for services.
- Create a funding stream for supportive amenities that community-based organizations can provide to residents within housing developments.
- Create a funding stream for post-secondary transition programs to become available for those who cannot afford to private pay.

## Increase in Homeownership

- Develop a homeownership guide, including essential details from the Homestead Tax Exemption and Bridges to Homeownership program, to help individuals with A/I/DD and their families understand how to invest in stable housing when possible.
- Modify the ADU zoning codes following the suggestions of the Omaha Housing Affordability Action Plan and include the development of a guide, offer model neuro-inclusive and universal design plans, and other needed tools for neurodiverse families to add an ADU to their property.

**“Nearly 30,000 housing units are needed in the city by 2030, with affordable units representing 60% of that need. The purpose of this Housing Affordability Action Plan is to outline strategies so all residents of Omaha have a choice of housing type and location, regardless of income.”**

### — Omaha Housing Affordability Action Plan

- Explore needed modifications to the Bridges to Homeownership program, ensuring accessibility to non-owner-occupiers who may need to use an SNT or other trust to protect and manage the asset due to their disability.
- Identify the interest of the Nebraska Investment & Finance Authority, a local community bank or other Community Development Financial Institutions to develop a mortgage product for families to invest in housing stability for their low-income, dependent adult with A/I/DD.
- Increase awareness of the demand for housing targeting adults with A/I/DD and their families through the Metro Omaha Builders Association and Nebraska State Home Builders Association.
- Increase awareness of local **community land trusts** of the demand for housing targeting adults with A/I/DD and their families.
- Decrease trauma and support smoother transitions from the family home by ensuring policy requirements for housing assistance programs do not first require the experience of homelessness or institutionalization for access to assistance.
- Plan to respond to federal HUD **Notice of Funding Availability (NOFA)** for additional 811 PRA funding, mainstream and NED voucher funding, as well as other housing subsidies to increase use by adults with A/I/DD.
- To prevent unintended discrimination, offer educational opportunities to landlords, property managers and developers so they can better understand how people with A/I/DD access their LTSS, what they offer as potential tenants, and their unique financial and legal arrangements.
- Develop incentives for landlords to offer leases to tenants with A/I/DD.
- Provide training and produce plain-language materials for adults with A/I/DD to understand tenant rights. Model materials can be found on The Kelsey Plain-Language Leasing website.<sup>132</sup>
- Prioritize low-income people with A/I/DD and/or those receiving DDD services in Housing Choice Voucher (HCV) waitlist applications.

## Rental Subsidies

## Increase Development of Neuro-Inclusive Mixed-Use and Planned Communities

- Prioritize housing targeting adults with A/I/DD within the **Qualified Allocation Plan (QAP)**<sup>133</sup> to incentivize developers to create integrated neuro-inclusive housing.
- Earmark funds for neuro-inclusive housing and/or efforts targeting adults with A/I/DD within the Nebraska Affordable Housing Trust Fund (NAHTF).
- Consider prioritizing Omaha's Section 108 Loan Guarantee Program applicants that intend to include set-aside units for adults with A/I/DD.
- Develop a funding source or incentives for new construction or rehabilitation that creates additional units for single or two-person households incorporating universal and neuro-inclusive design elements. The Omaha Housing Affordability Action Plan suggests doing this via community housing bonds, affordable housing fees and/or the General Fund.<sup>134</sup>
- Using a model recently launched by the Colorado Housing and Finance Authority, offer **pre-development technical assistance grants**<sup>135</sup> to landowners such as local nonprofits, faith communities, local planning departments and developers to hire consultants and/or conduct feasibility activities to create local neuro-inclusive solutions.

## Local Community Development

- Explore how to address the loneliness crisis and increase natural support systems.
- Include adults with A/I/DD in local diversity, equity and inclusion efforts to increase the visibility of Omaha's neurodiverse population.
- Include recognition of the housing needs of people with A/I/DD living with family caregivers in future City of Omaha biannual Affordable Housing Report and subsequent Omaha Housing Affordability Action Plans.
- Expand support for local housing and lifespan navigation programs to target individuals with A/I/DD and their families, better connecting people to available resources while guiding them to plan for the transition out of the family home before falling into crisis.
- Practice **land banking** of properties within walking distance of grocery stores for future affordable housing or mixed-use and/or neuro-inclusive planned communities.
- Modify zoning codes to allow for adding an ADU or tiny home as a "use by right" on a property that will house a dependent adult; offer planning grants and waive fees associated with requesting approval.
- Expedite projects using **tax increment financing**<sup>136</sup> if partnered with a community-based organization that serves adults with A/I/DD and offers set-aside units for planned development



# CONCLUSION

Similar to the neurotypical population, adults with A/I/DD seek a home that is safe, stable and comfortable where they can be themselves and be proud to bring friends and family. They want to access daily neighborhood conveniences, meet and know their neighbors, be regulars at their favorite local places of business and experience a true sense of belonging.

There are not enough residential options to meet surging demand. For the A/I/DD population, it is not a matter of *whether* people with A/I/DD will lose their existing home and primary caregiver; it is a question of *when*. Workforce shortages, changing demographics and a rapidly aging population mean that Omaha needs increased access to housing. Additionally, greater options and innovation in LTSS and supportive amenities will keep people from losing the supportive services they need to thrive. Without planning, many

people with A/I/DD will be forced into crisis placements in emergency rooms, nursing facilities, psychiatric hospitals and institutional settings—or could face incarceration and even homelessness. These consequences are traumatic for individuals and their families—and expensive for the state.

***The following are some of the pressing, systemic challenges facing Omaha and Nebraska collectively:***

- The specific number of adults with A/I/DD is unknown. Major data gaps persist in understanding the needs of those living in aging family caregivers' homes.
- The Nebraska HCBS waivers are acutely underfunded. Efforts should immediately commence to eliminate the waitlist and provide waivers to adults with A/I/DD living with senior family caregivers.

For the A/I/DD population as a whole, it is largely not a matter of if they will lose their existing home and primary caregiver, it is a question of when.

- The current housing stock is largely financially, physically and cognitively inaccessible. Data demonstrate high demand for mixed-use and neuro-inclusive planned communities; thus, incentives and funding streams are needed to equip developers and local communities with the tools to respond.
- Data on the need for affordable housing do not capture the needs of those living in aging family caregivers' homes.
- As of 2023, fewer than 10,000 of the 54,000 severely rent-burdened households are receiving some form of rental subsidy; there are only 605 mainstream and NED vouchers targeting people with disabilities.
- No financial tool for housing developers exists that meets the needs of supportive housing targeting adults with A/I/DD.
- No housing navigation program, such as those used by seniors and veterans, is available to help adults with A/I/DD and their families work through the complex and disconnected systems of housing assistance, LTSS and other public benefits.

- No incentives or mortgage products are available for neurodiverse families to assist their loved ones in purchasing a home that can be held in a trust, thereby protecting the asset from those who would exploit or take advantage of a vulnerable adult with A/I/DD.

An estimated 10,820 adults with A/I/DD in Omaha live with a caregiver over age 60 (based on incidence and prevalence data). With many of these individuals predicted to be without formal long-term supports and services, an urgent gathering of local leaders and elected officials is needed to develop a roadmap for supportive housing solutions to prevent the displacement of and risk of homelessness for these adults with A/I/DD.<sup>137</sup>

Thanks to the efforts of the research team at the First Place Global Leadership Institute, Omaha market leaders, advisors and sponsors, Omaha now has market data on the needs and preferences of residential demand of this persistently invisible population. Meeting their housing needs will result in a healthier and more stable population, which has the potential to reduce Medicaid costs, increase quality of life and enable more effective and successful longer-term planning for individuals and their families to help prevent disruptive emergency placements and even homelessness.

The cost of doing nothing will be exorbitant. Immediate action is needed to help every resident find a home—and their place in the world.

Join us by reaching out to [info@autismaction.org](mailto:info@autismaction.org).



# GLOSSARY

TERM	DEFINITION	PAGE
<b>2019 Nebraska Olmstead Strategic Plan</b>	In the Supreme Court decision <i>Olmstead v LC</i> , the court stated that public entities should develop “a comprehensive, effective working plan for placing qualified persons with...disabilities in less restrictive settings.” The plan must reflect an analysis of the extent to which the public entity is providing services in the most integrated setting and must contain concrete and reliable commitments to expand integrated opportunities. Further the Nebraska legislature requires the Department of Health and Human Services to provide continuing analysis of the progress of the strategic plan by 2021 and every three years thereafter. <sup>104</sup>	46
<b>811 Project Rental Assistance (811 PRA)</b>	The Section 811 Project Rental Assistance (PRA) program seeks to identify, stimulate and support successful and innovative state approaches to providing integrated supportive housing for people with disabilities. <sup>131</sup>	64
<b>Accessory dwelling unit (ADU)</b>	An accessory dwelling unit (ADU) is a smaller, independent residential dwelling unit located on the same lot as a stand-alone (i.e., detached) single-family home. They may also be referred to as casitas, granny flats, accessory apartments or secondary suites. They may be converted portions of existing homes or additions to new or existing homes. <sup>110</sup>	47
<b>Affordable housing</b>	Generally defined as housing in which the occupant is paying no more than 30% of gross income for housing costs, including utilities. <sup>11</sup>	9

TERM	DEFINITION	PAGE
<b>Aged and disabled (AD) waiver</b>	The AD waiver provides services for people over age 65 and people ages 0–64 with disabilities. Waiver services are intended to help people live safely in their own homes instead of in a nursing home. <sup>24</sup>	12
<b>Americans with Disabilities Act (ADA)</b>	A 1990 act of Congress prohibiting discrimination against people with disabilities in various areas, including employment, transportation, public accommodations, communications and access to state and local government programs and services. <sup>19</sup>	12
<b>Area median income (AMI)</b>	Area median income—often referred to as AMI—is a key metric in affordable housing. AMI is defined as the midpoint of a specific area's income distribution and is calculated on an annual basis by the Department of Housing and Urban Development (HUD). HUD refers to the figure as median family income, or MFI, based on a four-person household. <sup>87</sup>	34
<b>Autism and/or intellectual/developmental disabilities (A/I/DD)</b>	<p>IDDs are differences typically present at birth that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems.</p> <p>Intellectual disability starts any time before a child turns 18 and is characterized by differences with both intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and adaptive behavior, which includes everyday social and life skills.</p> <p>The term "developmental disabilities" is a broader category of often lifelong challenges that can be intellectual, physical, or both.</p> <p>"IDD" is the term often used to describe situations in which intellectual disability and other disabilities are present.<sup>4</sup></p>	7
<b>Bequeathed home</b>	The asset of a home left to someone through a will or as a gift. Careful planning is needed for a loved one with a disability. <sup>98</sup>	35
<b>Bridges to Homeownership program</b>	This program allows housing choice voucher (HCV) recipients to use their voucher to buy a home and receive monthly assistance in covering homeowner expenses. <sup>112</sup>	48
<b>Centers for Medicare &amp; Medicaid Services (CMS)</b>	CMS is the federal agency that provides health coverage to more than 160 million through Medicare, Medicaid, the Children's Health Insurance Program and the Health Insurance Marketplace. CMS works in partnership with the entire healthcare community to improve quality, equity and outcomes in the healthcare system. <sup>18</sup>	11
<b>Charting the LifeCourse (CtLC) framework</b>	The CtLC 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 how they want to live. <sup>33</sup>	15
<b>Cognitive accessibility</b>	Refers to inclusive practices that remove barriers for people whose disabilities affect how they process information. <sup>35</sup>	15

TERM	DEFINITION	PAGE
<b>Cohousing</b>	An intentionally planned housing community created by its residents. Cohousing communities typically feature private residential units (single-family homes, townhouses, etc.), a large community center or common house with amenities and pedestrian-oriented design. The property is designed and managed by residents. Many host weekly common meals and events prepared/organized by residents. Residents typically own their own homes. <sup>117</sup>	48
<b>Community land trust</b>	A community land trust (CLT) is a nonprofit organization governed by a board of CLT residents, community residents and public representatives who provide lasting community assets and shared equity homeownership opportunities for families and communities (Grounded Solutions Network, 2023). CLTs develop rural and urban agriculture projects, commercial spaces to serve local communities, and affordable rental and cooperative housing projects that conserve land or urban green spaces (Grounded Solutions Network, 2023). The goal is to create permanently affordable homes providing successful homeownership opportunities for generations of lower-income families. <sup>125</sup>	65
<b>Comprehensive developmental disabilities (CDD) waiver</b>	The CDD waiver provides services to help people of all ages who have developmental disabilities. These services are intended to maximize independence as participants live, work and socialize in their communities.	12
<b>Consolidated plan</b>	A plan designed to help state and local jurisdictions assess their affordable housing and community development needs and market conditions (HUD Exchange, 2023). It enables data-driven, place-based investment decisions (HUD Exchange, 2023). This plan is comprised of annual action plans that provide a summary of the actions and activities, along with federal and non-federal resources that will be used each year to address the needs and goals specified in the plan. <sup>56</sup>	17
<b>Consumer-controlled setting</b>	A property where the housing provider is not connected to the LTSS provider (Resnik & Kameka Galloway, 2020). Residents can choose and change their LTSS providers while remaining in the same housing. <sup>7</sup>	13
<b>Developmental disabilities adult day (DDAD) waiver</b>	DDAD Waiver services help people ages 21 and over who have developmental disabilities. Services maximize participants' independence to work in their communities. There is a focus on competitive, integrated employment. <sup>85</sup>	31
<b>Developmental Disabilities (DD) agency provider</b>	A DHHS certified company enrolled by Medicaid to provide developmental disabilities services (Nebraska Department of Health and Human Services). This provider is responsible for hiring and supervising staff and/or contractors, and completing other administrative work for DD services. <sup>85</sup>	13
<b>Developmental Disabilities (DD) independent provider</b>	An independent provider is a person enrolled as a Medicaid provider and employed by the eligible adult over age 19. The enrolled individual is responsible for hiring, training, scheduling, supervising, and dismissing their independent provider. The enrolled individual will also support the independent provider to develop and run rehabilitative programs. <sup>27</sup>	13

TERM	DEFINITION	PAGE
<b>Executive functioning</b>	Higher-level cognitive skills used for control and coordination of other cognitive abilities and behaviors. Executive function is broken down into organizational and regulatory abilities. Organizational abilities include attention, planning, sequencing, problem-solving, working memory, cognitive flexibility, abstract thinking, rule acquisition and the selection of relevant sensory information. Regulatory abilities include initiation of action, self-control, emotional regulation, monitoring of internal and external stimuli, initiating and inhibiting context-specific behavior, moral reasoning and decision-making. <sup>16</sup>	9
<b>Graded movement</b>	Movements whereby a person uses the appropriate amount of force to complete motor skills. People with A/I/DD may use too much or too little force when performing actions such as opening a door, flushing a toilet, stepping down, etc. <sup>73</sup>	20
<b>Group home</b>	A provider-controlled setting where two to six unrelated persons with disabilities share a home and are supported in their daily living activities. Residents can pay to live in this development type via private pay or Medicaid ICF/IID. <sup>7</sup>	17
<b>Home- and community-based services (HCBS)</b>	Services that help with daily activities while allowing individuals to stay in their own homes or live with their families, thereby reducing the need for institutional care. <sup>17</sup>	11
<b>Homeless Management Information System (HMIS)</b>	A local information technology system used to collect data on housing to help advise organizations and agencies on the housing and services needs of individuals and families experiencing and/or at risk of homelessness. <sup>129</sup>	63
<b>Homestead exemption</b>	The Nebraska homestead exemption program is a property tax relief program for six categories of homeowners: <ol style="list-style-type: none"> <li>1. Persons over age 65</li> <li>2. Veterans totally disabled by a non-service-connected accident or illness</li> <li>3. Qualified disabled individuals</li> <li>4. Qualified totally disabled veterans and their surviving spouses</li> <li>5. Veterans whose home was substantially contributed to by the U.S. Department of Veterans Affairs (VA) and their surviving spouses</li> <li>6. Individuals with a developmental disability</li> </ol> Income limits and homestead value requirements are in place for categories 1, 2, 3 and 6. Income limits are on a sliding scale. There are no income limits and homestead value requirements for categories 4 and 5. <sup>114</sup>	48
<b>Host home</b>	An LTSS provider's home where an individual with LTSS lives. <sup>7</sup>	17
<b>Housing choice voucher (HCV)</b>	Voucher program allowing qualified individuals or families to pay 30% of their income toward rent at a location of their choosing and paying the remainder of rent costs. The property owner of the chosen living place must agree to rent under the program. Qualified individuals include low-income families, the elderly and individuals with disabilities. <sup>7</sup>	18

TERM	DEFINITION	PAGE
<b>Housing First Model</b>	A homeless assistance approach that prioritizes permanent housing, allowing for individuals to pursue personal goals and improve their quality of life in ways that would not be possible while experiencing homelessness. <sup>119</sup>	54
<b>Housing or lifespan navigation services</b>	Services offering assistance in understanding residential choices, applying for housing assistance, tenant stabilization, and guiding elements needed for financial and legal planning beyond living with parents. May or may not be available as a waiver-funded service (state dependent). <sup>100</sup>	36
<b>Intermediate care facilities for individuals with intellectual disabilities (ICF/IID)</b>	An optional Medicaid benefit created by the Social Security Act (SSA) to fund "institutions" (4 or more beds) for individuals with intellectual disabilities. The SSA specifies that such institutions must provide "active treatment" as defined by the Secretary. Currently, all 50 States have at least one ICF/IID facility. This program serves over 100,000 individuals with intellectual and other disabilities and related conditions. Many are non-ambulatory and/or have seizure disorders, behavior problems, mental illness, visual or hearing impairments, or a combination thereof. All must qualify for Medicaid assistance. <sup>79</sup>	28
<b>Land banking</b>	Public authorities or nonprofit organizations created to acquire, hold, manage and sometimes redevelop properties to return them to productive use to meet community goals, including increasing the supply of affordable housing or stabilizing property values. <sup>124</sup>	66
<b>Long-term services and supports (LTSS)</b>	A variety of services that assist individuals with functional limitations due to various conditions and/or disabilities in their everyday life. <sup>8</sup>	7
<b>Low Income Home Energy Assistance Program (LIHEAP)</b>	This federal program provides home energy assistance to eligible low-income households to help them meet their home heating and/or cooling needs. <sup>92</sup>	34
<b>Mainstream housing choice voucher</b>	A voucher that assists non-elderly individuals with disabilities. These vouchers operate under the same rules as other housing vouchers. <sup>59</sup>	18
<b>Medicaid and Long-Term Care (MLTC)</b>	Medicaid and Long-Term Care (MLTC) oversees the Nebraska Medicaid program, home- and community-based services (HCBS), and the State Unit on Aging. Medicaid provides healthcare services to low-income families, seniors and individuals with disabilities. HCBS are available to those who qualify for Medicaid waivers, including the elderly, adults and children with disabilities, and infants and toddlers with special needs. <sup>21</sup>	12
<b>Means-tested</b>	Limited eligibility to individuals and families whose incomes and/or assets fall below a predetermined threshold (means test). <sup>97</sup>	35
<b>Mixed-use planned communities</b>	Large-scale residential development of various uses with robust, curated amenities providing residents with the experience of living in a self-contained town. Amenities can include parks, playgrounds, swimming pools, tennis courts, golf courses and more. <sup>7</sup>	

TERM	DEFINITION	PAGE
<b>Natural supports</b>	Natural supports are unpaid relationships (for example, friends, family, neighbors, community members) who support people with intellectual and developmental disabilities (IDD) in their communities and natural environments. Natural supports can improve individuals' relationships and community integration. <sup>5</sup>	7
<b>National Core Indicators-Intellectual and Developmental Disabilities (NCI-IDD)</b>	A national initiative to measure and improve the performance of public developmental disabilities agencies. <sup>81</sup>	29
<b>National Low Income Housing Coalition</b>	An organization dedicated to accomplishing racially and socially equitable public policy that ensures everyone, especially those with the lowest incomes, has quality homes that are accessible and affordable in communities of their choice. <sup>44</sup>	16
<b>Nebraska Medical Assistance Program</b>	The Nebraska Medicaid Assistance program provides healthcare services to low-income families, seniors and individuals with disabilities. <sup>20</sup>	12
<b>Nebraska Supportive Housing Plan</b>	A strategic plan developed to work with DHHS and related state agencies to promote and prioritize supportive housing for Nebraskans living with and recovering from serious behavioral health conditions. <sup>55</sup>	17
<b>Neuro-inclusive planned community</b>	Small- or large-scale, planned property with multiple residential units that meets the needs of neurodiverse individuals; also has recreational amenities featuring commercial properties such as restaurants and shops. Property management helps maintain housing and common spaces with the intent of making life as convenient and enjoyable as possible while supporting connection and belonging. <sup>7</sup>	49
<b>Neurodiverse/ neurodivergent</b>	Of neurological difference, including autism, Down syndrome, cerebral palsy, epilepsy, ADHD and I/DD. <sup>7</sup>	7
<b>Neurotypical</b>	Not affected by a developmental disorder, particularly autism spectrum disorder; exhibiting or characteristic of typical neurological development. <sup>102</sup>	40
<b>Non-elderly disabled (NED) voucher</b>	A voucher allowing non-elderly disabled individuals to access affordable housing. Category 1 NED vouchers allow non-elderly individuals or families to access affordable housing on the private market. Category 2 NED vouchers allow non-elderly disabled individuals currently residing in nursing homes or other healthcare institutions to transition into the community. <sup>60</sup>	18
<b>Omaha Housing Affordability Action Plan</b>	The City of Omaha publishes a biannual Affordable Housing Report. With the passage of LB 866 by the Nebraska Legislature in 2020, cities of the metropolitan, primary and first class must submit a report to the Urban Affairs Committee of the Legislature detailing its efforts to address the availability of and incentives for affordable housing through its zoning codes, ordinances and regulations. <sup>95</sup>	35

TERM	DEFINITION	PAGE
<b>Omaha Housing Authority</b>	The public housing authority that oversees the city of Omaha and its housing activities.	48
<b>Olmstead v. L.C.</b>	This 1999 U.S. Supreme Court decision determined that states cannot make institutionalization a condition for publicly funded health coverage unless it is clinically mandated. (See also state transition plans and HCBS settings rule). <sup>10</sup>	8
<b>Owner-occupier</b>	A person who owns the dwelling in which they live. <sup>113</sup>	48
<b>Paid neighbor</b>	A person who lives on the same property (but not in the same home) as an individual with LTSS needs who can offer LTSS on a scheduled or on-call basis. Also referred to as a resident assistant. <sup>7</sup>	46
<b>Person-centered planning</b>	A process of choosing and arranging needed services and supports of an adult with A/I/DD directed by the person receiving the supports. <sup>29</sup>	13
<b>Personal emergency response system (PERS)</b>	Devices designed for individuals with mobility limitations to call for help in emergency situations. <sup>108</sup>	46
<b>Plain language</b>	A clear, concise and straightforward way of communicating that allows a broad audience to understand information the first time they read/hear it. <sup>78</sup>	24
<b>Planned community</b>	A small- or large-scale, intentionally developed property with multiple residential units that also has recreational amenities. They sometimes also feature commercial properties, such as restaurants and shops. Property management helps maintain housing and common spaces. The intent is to make life as convenient and enjoyable as possible. This development type is typically located in suburban settings. <sup>7</sup>	44
<b>Point-in-time (PIT)</b>	A continuum of care (CoC) is required to conduct a point-in-time (PIT) count of people experiencing homelessness at least every other year. CoCs are also required to conduct an annual housing inventory count (HIC) documenting residential resources in the community dedicated to assisting people experiencing homelessness. <sup>130</sup>	17
<b>Pre-development technical assistance grant</b>	This type of grant helps catalyze small-scale affordable housing developments by providing access to affordable housing consultants and pre-development grant assistance. Potential small-scale projects, of 30 units or less may apply for affordable housing planning and development technical assistance (TA) services and pre-development grants to further their work. <sup>135</sup>	66
<b>Public housing authorities (PHA)</b>	A state, county, municipality or other government entity or agency of entities authorized to engage in the development or operation of low-income housing under the U.S. Housing Act (1973). <sup>57</sup>	17

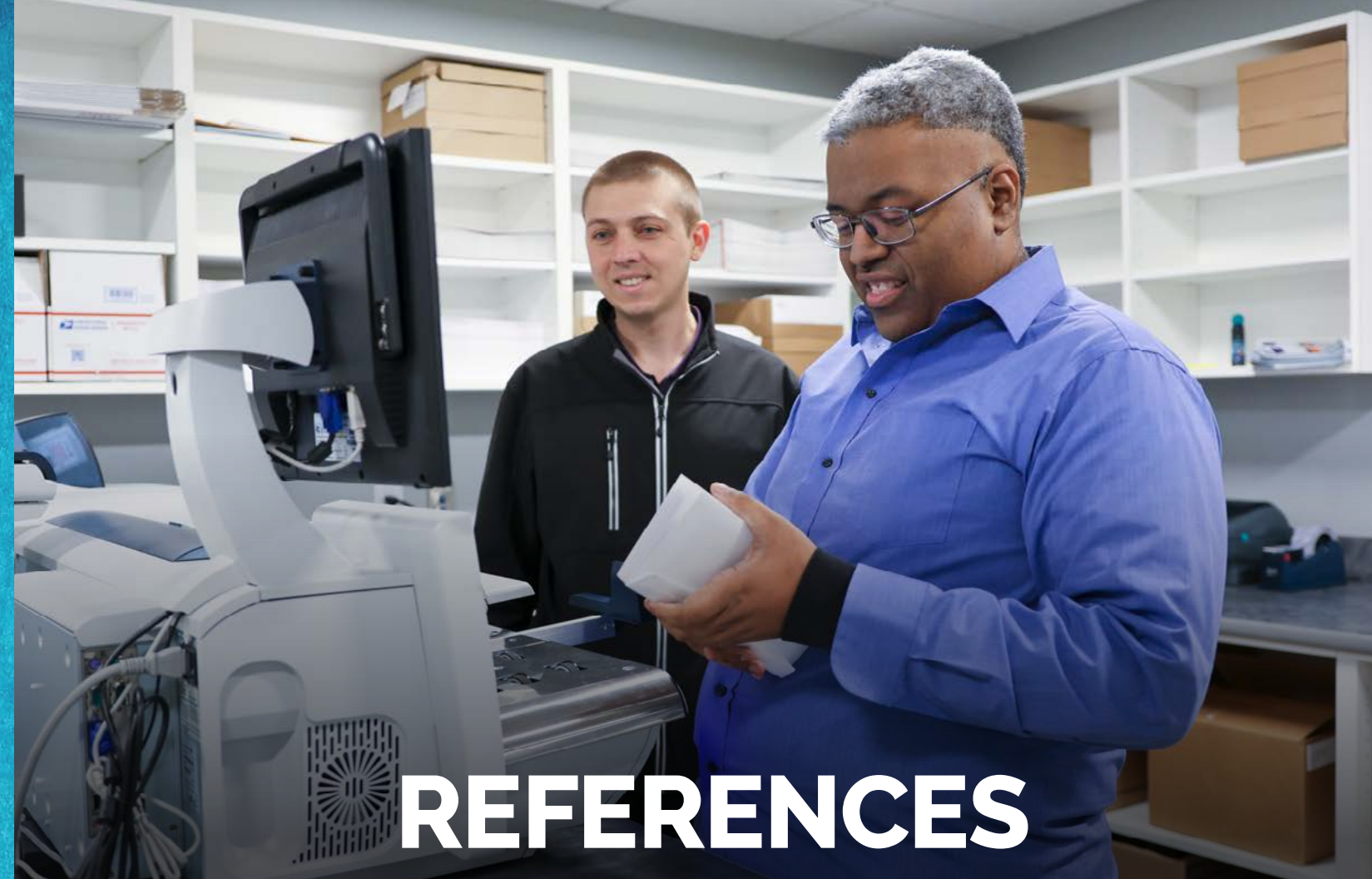
TERM	DEFINITION	PAGE
<b>Qualified allocation plan</b>	The federal Low Income Housing Tax Credit program requires each state agency that allocates tax credits, generally called a housing finance agency, to have a qualified allocation plan (QAP). The QAP sets out the state's eligibility priorities and criteria for awarding federal tax credits to housing properties. In some states, the QAP also sets threshold criteria for noncompetitive 4% tax credits and any state low-income housing tax credits. <sup>133</sup>	66
<b>Remote support/monitoring</b>	The use of technology to provide real-time assistance by a direct support provider from a remote location. This service often reduces the number of housekeeping or homemaker personal care services needed by an individual while enabling safety, privacy and independent task completion. <sup>109</sup>	46
<b>Rotational staffing</b>	The selection by an individual needing LTSS of an agency to recruit, hire, train, schedule and fire support staff for them. <sup>7</sup>	45
<b>Scattered-site housing</b>	A property (residential unit or development) located within the general housing fabric of a community. It is not part of a housing development that serves a specific residential market. In affordable housing circles, scattered-site housing also refers to affordable housing dispersed throughout the community. <sup>7</sup>	9
<b>Self-directed support</b>	A budget given to an individual needing LTSS to spend on their LTSS based on an assessment of their support needs. They are responsible for recruiting, hiring, training, scheduling and firing support staff. Some states allow family members to be hired as support staff. <sup>7</sup>	46
<b>Self-direction</b>	A model of long-term care service delivery that helps people of all ages, with all types of disabilities, maintain their independence at home. When a person practices self-direction, they decide how, when and from whom their services and supports will be delivered. As a model, self-direction prioritizes participant choice, control and flexibility. <sup>28</sup>	13
<b>Sensory-friendly</b>	Sensory-friendly spaces that, accounting for the five senses, take into account environmental factors contributing to and preventing sensory overload. <sup>34</sup>	15
<b>Serious mental illness</b>	A mental, behavioral or emotional disorder resulting in serious functional impairment that substantially interferes with or limits one or more major life activity. <sup>13</sup>	9
<b>Shared living</b>	A living situation where an individual with LTSS needs invites a person or family member(s) to live in their home to provide LTSS. Because private homes are consumer-controlled settings, the individual can ask their LTSS provider to move. <sup>7</sup>	9
<b>Social Security Disability Income (SSDI)</b>	SSDI pays benefits to individuals and certain members of their family if the individual is insured, meaning they have worked for a specific length of time and paid social security taxes. <sup>89</sup>	34
<b>Soft social interactions</b>	Surface-level behaviors that reveal a list of latent variables related to personality, social and communication skills, interpersonal skills, leadership skills, decision making, etc. <sup>103</sup>	40

TERM	DEFINITION	PAGE
<b>Special needs trust (SNT)</b>	A trust that can be created for an individual with disability(ies) by a family member that does not impact the individual's financial qualification for government programs. It is often used after the family member's passing to pay for services that improve/maintain the surviving person's quality of life. <sup>94</sup>	35
<b>State Unit on Aging</b>	The Nebraska State Unit on Aging is a subdivision of the Medicaid and Long-Term Care Division of the Nebraska Department of Health and Human Services. The unit oversees funding to help Nebraskans stay in their homes. These funding sources include the Older Americans Act, the Nebraska Community Aging Services Act and the Aging & Disability Resource Center Act. <sup>22</sup>	12
<b>State transition plans (STP)</b>	In 2014, CMS finalized a rule establishing new requirements for the settings in which Medicaid home- and community-based services (HCBS) are delivered (CMS 2014a). Under the rule, states must develop implementation plans, known as statewide transition plans, and determine which providers meet the new requirements. <sup>118</sup>	50
<b>Supplemental Nutrition Assistance Program (SNAP)</b>	A federal program providing nutrition benefits to low-income individuals and families. <sup>91</sup>	34
<b>Supplemental Security Income (SSI)</b>	Monthly benefits provided to individuals with limited income and resources who are disabled, blind or age 65 or older. <sup>89</sup>	34
<b>Supportive amenities</b>	Supports and features offered by a property that make life easier and/or more enjoyable for those living there. Such services include community life activities, housekeeping and meal services, etc. <sup>7</sup>	9
<b>Tax increment financing</b>	A value capture revenue tool that uses taxes on future gains in real estate values to pay for new infrastructure improvements. <sup>136</sup>	66
<b>Technology First States</b>	States that apply a "framework for systems change where technology is considered first in the discussion of support options available to individuals and families through person-centered approaches to promote meaningful participation, social inclusion, self-determination and quality of life." <sup>111</sup>	47
<b>Traumatic brain injury (TBI) waiver</b>	The Medicaid HCBS TBI waiver currently offers specialized assisted living services for people with traumatic brain injury. <sup>26</sup>	12
<b>Wayfinding</b>	A system of signs, colors and other design elements to help people navigate their environment. <sup>72</sup>	20



“ AAP leverages our network of trusted partners to ensure as many Omahans as possible had the opportunity to participate in this study.”

— Autism Action Partnership



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