



The Housing and Community-Living Landscape for People with Developmental Disabilities in Nevada

Policy Report

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May 2024

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Report Acknowledgements



This report is supported by the Nevada Governor’s Council on Developmental Disabilities through 75% of grant funds from the Federal Department of Health and Human Services; Administration on Community Living grant #2201NVSCDD-01 and 25% matching funds appropriated by the Nevada State Legislature under NRS 232.320 administered through the State of Nevada Department of Health and Human Services for a total of an estimated \$104,380. The contents are solely the responsibility of the Guinn Center and do not necessarily represent the official views of any other associated or financial supporting agency.

The Guinn Center appreciates the support and collaboration of the NGCDD.



The Nevada Housing Coalition’s mission is “creating sustainable solutions through community awareness, capacity building, and advocacy to ensure housing options for all Nevadans.” We wish to express our gratitude to the Nevada Housing Coalition (NHC), which served as a formal consultant to this project. NHC team members supplied ongoing substantive support and expertise over the project period, which, among others, included connecting us with stakeholders and community partners that informed our understanding of best practices and needs in the housing space.



The mission of the JUSTin HOPE Foundation (JHF) is “to give hope to families and individuals with Intellectual and Developmental Disabilities by promoting inclusion and creating opportunities through education/training and family support to maximize the individual’s potential.” We wish to express our heartfelt thanks to JHF, which not only provided us with in-kind contributions and material incentives for focus group participants, but helped facilitate robust community conversations that offered the unique perspective of lived experience.

The Guinn Center is grateful to the self-advocates, support networks, and other subject matter experts who shared their experiences and expertise with us. Thank you.

The analysis found in this report is that of the Guinn Center and does not necessarily reflect the views or positions of any individual or entity that provided any form of support. All errors and omissions are our own. Views expressed by subjects and participants in this report are their own.

The Housing and Community Living Landscape for People with Developmental Disabilities in Nevada

Introduction

Since the Great Recession, housing has become increasingly difficult and more expensive to secure for all Americans and, thus, is a current and challenging issue for policymakers. Decision making has been aided by an abundance of research that has addressed many issues, including housing supply and demand, affordability, wealth building through property ownership, generational differences in access, social determinants in securing housing, risk factors and causes associated with losing housing, and supplementary assistance needed by some populations, such as seniors, veterans, and people with disabilities.

What remains underexamined is the housing and community-living needs of people with developmental disabilities (DD).¹ As one study commissioned by the California State Council on Developmental Disabilities observed, “[W]hat makes the DD community’s housing crisis unique is its seeming invisibility to the general public, policymakers, and legislative bodies. While other communities, such as veterans and the homeless population, have aggressively entered the public arena to describe and advocate for their needs, the DD community’s needs are less recognized and understood.”

This viewpoint may not wholly capture the circumstances of people with DD in Nevada, how well their interests are represented in the Legislature, or the sufficiency of advocacy efforts. However, the feeling of being invisible to the general public and the sense that the community’s needs are not adequately recognized or understood are consistent themes for people with DD who spoke to the Guinn Center about their experiences.

This evaluation of community-living needs and resources for people with DD in Nevada was commissioned by the Nevada Governor’s Council on Developmental Disabilities (NGCDD). This work is merited, particularly as the twin “crises” of housing affordability and the COVID-19 pandemic intersected with other challenges, such as the availability of supportive services and the supply of accessible housing. The hope is this report will provide a high-level overview of the housing and community support landscape for Nevadans with DD and offer some general next steps for public policy advocacy and future research.

This study was conducted over two years using a mixed-methods approach. The Guinn Center:

- Conducted twenty individual interviews with a diverse set of stakeholders (“key informant interviews”), including people with DD (self-advocates) and their support networks; caregivers;

¹ See Appendix A for definitions of “developmental disability” and “intellectual disability” as codified in Nevada and federal law.

service providers; State of Nevada representatives; and subject matter experts in both Long-Term Services and Supports (LTSS) and housing (in particular, affordable and supportive housing);

- Hosted three focus groups: (1) self-advocates (four participants); (2) support networks (five participants); and (3) service providers (six participants) – note that we prepared focus group questions and prompts in advance (see Appendix B) but kept the discussions open-ended to encourage robust conversations;
- Reviewed Nevada’s statutory provisions and administrative code related to the DD community, along with policy and procedure manuals and guidance documents, the *Medicaid Services Manual* (Chapter 2100 contains the Home- and Community-Based Services [HCBS] Waiver for People with Intellectual and Developmental Disabilities, which will be discussed further), and the State of Nevada Executive Budget for 2023-2025, among other resources (as cited and sourced);
- Evaluated relevant materials available from federal sources and other states’ websites. We randomly sampled 20 states but also looked at several additional states highlighted as leaders in housing for people with DD;
- Gathered and analyzed data from a wide variety of sources as cited throughout this report; and
- Considered existing literature on housing for people with DD, though this research is limited.

The centerpiece of this analysis is the lived experience of self-advocates and their support networks. Their insights are invaluable to deepening our understanding of housing and community-living challenges. To preserve anonymity while ensuring clarity for the reader, we may refer to someone by a pseudonym or a pronoun, which may not reflect the gender of the participant in question.

We must also mention the limitations of this report. Specifically, it is preliminary and exploratory only. Also, information from other states can be misleading, particularly as some of it is un-dated or predates a significant federal administrative change in 2023 that should positively affect community-based services for people with disabilities.² In addition, states’ terminology can be both too vague and too specific. While that seems contradictory, consider that there are only so many options to describe living arrangements, and a term one state uses may mean something different in another. At the same time, states tend to use technical language and acronyms that create barriers to understanding. Information from other states is meant only to illustrate and serve as a point of departure for future research.

Some of the data provided herein presents challenges in that it may be old (pre-pandemic) or skewed because of the unusual circumstances of the 2020-2021 COVID-19 pandemic. Thus, we advise readers to exercise caution in making any inferences. We use the most recent year of data for each metric presented, meaning there is no consistent reference year. Additionally, national data sources are often standardized, which means the definitions used may not apply precisely to Nevada. In general, the data used in this report helps to illuminate challenges and possibilities but not to draw any definitive conclusions.

² <https://acl.gov/programs/hcbs-settings-rule>

Defining Developmental Disabilities, Housing, Community Living and Supportive Services

To aid the reader in avoiding assumptions or misinterpretations, this report begins by providing a practical understanding of the terms used. Please read and use this report with the following definitions in mind.

Developmental Disability – A developmental disability (DD) occurs before age 22, during the developmental years. Most DDs persist into adulthood and remain defined as a developmental disability, regardless of a person’s age. A DD should not be confused with a developmental delay, which is a lag in reaching a developmental milestone during childhood that may be overcome with intervention and not be indicative of a lifelong condition.

The definition of DD in Nevada statute is more limited than the federal definition; it explicitly focuses on neurological impairments and implicitly on intellectual disabilities. The federal definition, which is used by the Nevada Governor’s Council on Developmental Disabilities and other Nevada programs funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, is more expansive than the Nevada definition. The federal law more explicitly includes physical and sensory disabilities. (See Appendix A for both definitions.)

For this report, the federal definition is used.

Housing – The Merriam-Webster definition is “dwellings provided for people.” We use this simple and universal definition while acknowledging that people with DD may need additional support or assistance to utilize their housing in a manner similar to someone without a disability.

Community Living – Following the passage of the Americans with Disabilities Act in 1990, the United States Supreme Court rendered its *Olmstead v. LC* decision in 1999. The court held that people with disabilities have a qualified right to receive state-funded supports and services in the community rather than in institutional settings when the following three-part test is met:

1. The person’s treatment professionals determine that community supports are appropriate;
2. The person does not object to living in the community; and
3. The provision of services in the community would be a reasonable accommodation when balanced with other similarly situated individuals with disabilities.

The *Olmstead* decision resulted in the terminology “least restrictive environment appropriate” and requires states to have a comprehensive working plan for serving qualified persons in less restrictive settings and to move waiting lists at a reasonable pace.³ The Aging and Disability Services Division recently updated its plan for compliance with the Americans with Disabilities Act and the *Olmstead* Decision. As a significant provider of services to Nevadans with DD, this plan will be beneficial in advancing ASD services to the most community-integrated setting appropriate. However, the ASD

³ <https://www.olmsteadrights.org/about-olmstead/>

plan acknowledges difficulty in fully capturing the spirit of the law without a cooperative effort that includes other state, county, city, and community-based service providers.

In any case, this report assumes “community living” is that which exists under the spirit and letter of the Americans with Disabilities Act and the Olmstead decision.

Supportive Services – Under the definition of housing, which is universal for all people, we acknowledge that people with DD may need additional support or assistance to use their housing equitably. Depending on the nature or extent of a person’s disability, they may need no help or an extensive array of supports. These supports may be provided by family, friends, nonprofit organizations, or public agencies.

People with **sensory** impairments may need visual or auditory alert systems, adaptive communication or reading devices, or orientation and mobility training. Individuals with **physical** disabilities may need accommodations such as a ramp or an accessible bathroom, or ongoing support such as Personal Assistance Services. People with **intellectual** disabilities may not have difficulty entering or navigating their housing but may need help with things like transportation, homemaking, or bill paying to enable their long-term ability to live in the community. Individuals whose disability comes with **behavioral** challenges may need more intensive support to minimize risks to themselves or others.

In any case, we define supportive services as enabling community living in the least restrictive environment appropriate and desired by the person with a developmental disability. According to the most recent data from the U.S. Census Bureau, there are approximately 450,000 Nevadans with a disability, or about 14 percent of the population.⁴

Housing for People with DD in Nevada

The availability of affordable housing is a problem in general for Nevadans. As a result of the COVID-19 pandemic, from 2020 to 2021, Nevada experienced a doubling of housing insecurity, from 12 percent to 25 percent.⁵

From December 2019 to December 2020, single-family home prices increased as much as 36.3 percent in urban areas of Nevada. Such market factors disproportionately burdened low-and-moderate-income households, further exacerbating the need for quality, affordable housing.⁶ Despite drops in average rental costs since 2022, the relative cost of housing remains high in 2024. A single-income household at the median income level must spend 46 percent of its income on rent in Reno and 43 percent in Las Vegas.⁷

⁴ <https://data.census.gov/table/ACSST1Y2022.S1810?q=Disability&g=040XX00US32>

⁵ Coughenour, C., Chien, L.C., Gakh, M. *et al.* Food and Housing Insecurity in Nevada During the COVID-19 Pandemic. *J Community Health* **49**, 296–313 (2024). <https://doi-org.unr.idm.oclc.org/10.1007/s10900-023-01284-8>

⁶ https://liedcenter.unlv.edu/wp-content/uploads/2021/01/6025_Lied-Housing-Market-Report_Dec-2020.pdf

⁷ <https://thenevadaindependent.com/article/nevadas-2024-rental-market-stabilizing-but-prices-remains-above-pre-pandemic-levels>

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In this context, Nevadans with DD and their families/caregivers compete for housing with everyone else seeking affordable options.

In addition to housing supports available to Nevadans generally, there may be programs or services to specifically assist people with DD in securing housing. One example is the Nevada State Treasurer's Achieving a Better Life Experience (ABLE) Program. The ABLE Program allows eligible Nevadans with disabilities to create a special tax-advantaged savings and investment account for personal and disability-related expenses, which may include housing.

The assets in an ABLE account, subject to certain limitations, are exempt from the means-tested Medicaid or Supplemental Security Income programs. Family members and friends can also contribute to an ABLE account.

Many people with DD may qualify for Medicaid through the state plan or a Medicaid waiver; waivers are discussed in detail later in this report. Under federal rules, Medicaid programs can pay for housing-related services that promote health and community integration, such as assistance in finding and securing housing and home modifications when individuals transition from an institution to the community. However, Medicaid cannot pay for rent or room and board. Thus, while Nevada Medicaid pays for many support services to enable community-based living for people with DD, it does not provide housing.

While recipients of Medicaid services have some discretion over their residential setting, a person's needs and the availability of support services may determine where they ultimately live.

Below is a brief overview of housing considerations for various subgroups of the DD population.

HOUSING FOR THOSE WITH SENSORY DISABILITIES

As mentioned above, people with sensory impairments may need visual or auditory alert systems, adaptive communication or reading devices, or orientation and mobility training to fully access their home environment. Recent data from the Centers for Disease Control and Prevention show that 13 percent of Americans have a vision or hearing disability; this percentage represents approximately 416,000 Nevadans. It is difficult to know how many require special accommodations in their physical dwelling, but a 2020 survey by the Nevada Housing Division found only 1,978 vision- and hearing-accessible units among rentals eligible for the federal Low-Income Housing Tax Credit. Since 1991, housing developments receiving federal assistance must have at least one unit and 2 percent of total units accessible to residents with hearing or visual impairments.⁸

HOUSING FOR THOSE WITH PHYSICAL DISABILITIES

To access and utilize their housing, individuals with physical disabilities may need accommodations such as a ramp, an accessible bathroom, or other physical adaptations. A 2023 study reports that 3.3 million Americans use a wheeled mobility device. This number represents approximately one

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<https://housing.nv.gov/uploadedFiles/housingnewnv.gov/Content/Programs/HDB/AccessibilityInNevada2020.pdf>

percent of the population and translates to approximately 32,000 Nevadans who may be wheelchair users. It is unclear how many wheelchair-accessible dwellings exist in Nevada. The above-referenced 2020 Nevada Housing Division survey found 4,187 mobility-accessible units among rentals eligible for the federal Low-Income Housing Tax Credit. Housing developments receiving federal assistance must have at least one unit and 5 percent of total units accessible to residents with mobility impairments.

HOUSING FOR THOSE WITH INTELLECTUAL DISABILITIES OR BEHAVIORAL CHALLENGES

Generally, Nevadans with intellectual disabilities, or with behavioral challenges that manifest from a DD, face challenges similar to any other resident in finding an appropriate physical dwelling. As discussed elsewhere in this report, finding and receiving appropriate *support services* in the least restrictive and appropriate setting is the central challenge for these subgroups of Nevada's DD population.

Supportive Services to Enable Community-Based Living for Nevadans with DD

Many people with DD require services or other help to lead functional lives and thrive in their communities, meaning that community-based living for people with DD exists in a system of support. Thus, community living for people with DD often must be viewed through a lens of *service delivery* rather than *physical housing infrastructure*. Depending on the type of DD a person has, the array of services and supports needed will vary, as is explored below.

SUPPORTIVE SERVICES FOR THOSE WITH SENSORY DISABILITIES

Nevadans who are blind or severely visually impaired have a variety of resources available to support them in their desire to live independently in the community. Examples of these resources include:

The Bureau of Services to the Blind and Visually Impaired (BSBVI) provides various services to eligible individuals whose vision is not correctable by general eye care. These services include vocational rehabilitation, assistance in finding a job, and job site modifications. For those unable to work, BSBVI can help with home management and daily living skills, mobility training, communications skills, low vision exams and aids, and other services. They also offer a free monthly low-vision clinic and an audiobook program.

Two State of Nevada independent living programs are available to assist people with severe visual impairments. The Older Individuals Who are Blind program through BSBVI assists with non-work-related services and devices for those over age 55. The Assistive Technology for Independent Living program through the Aging and Disability Services Division provides similar help for individuals aged 55 and under.

BlindConnect operates a residential blindness skills training program. It utilizes structured discovery teaching methods across topics, including independent living skills, cooking, cleaning, braille, long white cane travel training, and assistive technology. BlindConnect also operates Angela's House Training Center, which is co-located with the Regional Transportation

Commission's Mobility Center in Las Vegas. They also offer a peer support group and an extensive website [resource list](#).

In southern Nevada, the [Blind Center of Nevada](#) provides various life enrichment and support programs.

Nevadans who are deaf or hard of hearing also have resources available to support their independent living. Some of these resources include:

[Relay Nevada](#) (dial 711) provides a variety of free services to help Deaf and hard of hearing Nevadans use telephone communication, depending on their specific needs.

The [Nevada Interpreter/CART Registry](#) lists sign language interpreters and Communication Access Realtime Translation (CART) providers who meet minimum qualifications as required by Nevada Revised Statutes 656A. Government agencies are generally required to provide accessible communication to members of the public needing such assistance; this can include providing a qualified sign language interpreter.

The [Nevada Telecommunication Equipment Distribution Program for the Deaf, Hard of Hearing and Speech Impaired](#) provides access to telecommunication-related equipment at no cost to people with hearing disabilities. The project is funded through a small monthly surcharge on phones in the state as required by Nevada Revised Statutes 427A.797.

Nevadans with speech disabilities can also receive assistance from the resources outlined above. The available assistance includes:

[Relay Nevada](#) (dial 711) offers Speech-to-Speech (STS) telephone relay services for people who have difficulty speaking or being understood on the telephone. STS Relay involves specially trained operators familiar with the speech patterns of a wide variety of individuals who have difficulty being understood.

[Nevada Telecommunication Equipment Distribution Program for the Deaf, Hard of Hearing and Speech Impaired](#) provides access to telecommunication-related equipment at no cost to people with speech difficulties.

The [Assistive Technology for Independent Living program](#) through the Aging and Disability Services Division may be able to provide communication devices or other assistance helpful to someone with a speech disability.

Although these instances are not common, people with sensory disabilities whose condition is severe enough to place them at risk of requiring institutional care may qualify for services under Nevada's Medicaid waiver for people with physical disabilities; details about this resource are outlined in the following section on Physical Disabilities.

SUPPORTIVE SERVICES FOR THOSE WITH PHYSICAL DISABILITIES

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The DD population subgroup with the greatest difficulty finding housing appropriate for their disability may be those with mobility impairments, particularly those who use wheeled mobility devices. Individuals who do not have an accessible dwelling may be able to receive help making it accessible through the [Bureau of Vocational Rehabilitation](#) (if they are working or planning to work) or through the [Assistive Technology for Independent Living program](#).

In the 1990s and early 2000s, the Nevada Governor's Council on Developmental Disabilities partnered with Accessible Space, Inc. to develop [15 apartment buildings](#) in Nevada with approximately 330 affordable, fully accessible apartments. Some also offer on-site, 24-hour staff and assisted living services for individuals with a physical disability, traumatic brain injury, or cognitive disability.

Nevada's Home and Community-Based Services (HCBS) Medicaid Waiver for Persons with Physical Disabilities provides community-based, in-home services to enable persons with severe physical disabilities to remain in their homes and avoid placement in a long-term care facility. The provision of home and community-based services is based on the identified needs of the recipient and available funding. The physical disability waiver program is managed by the Aging and Disability Services Division (ADSD). An eligible individual must be diagnosed with a physical disability, be at risk of nursing home placement without services, and meet income guidelines. Information about available waiver services is detailed on the program's [website](#) and can include home modifications for accessibility and in-home personal assistance.

Adults with physical disabilities whose income exceeds the criteria for waiver eligibility may qualify for ADSD's [Personal Assistance Services](#) program. It offers in-home attendant care, respite for family caregivers, and case management services.

SUPPORTIVE SERVICES FOR THOSE WITH INTELLECTUAL DISABILITIES OR BEHAVIORAL CHALLENGES

People with intellectual DDs in Nevada live in many different settings, often dictated by their level of care needs. However, contrary to the Americans with Disabilities Act and the Olmstead Decision, people with intellectual DDs are sometimes compelled to live in more restrictive and institutional settings than they desire.

An example of support services at a higher level of care is the State of Nevada's 48-bed [Intermediate Care Facility](#) for Individuals with Intellectual Disabilities (ICF/IID) located at Desert Regional Center (DRC, which serves individuals with DD in the Las Vegas area and Boulder City). The ICF/IID "provides comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence." It serves those with intense support needs, is a Medicaid State Plan service, and is not considered community-based care. Nevada also funds small-group [ICF/IDD facilities](#) that are required to meet requirements similar to those of the DRC facility. Together, these small facilities provide services to more people than the DRC facility.⁹

⁹ A search of the Department of Health and Human Services (DHHS), Division of Public and Behavioral Health (DPBH) website, "Find a Health Facility," shows that Nevada [has licensed](#) several non-State entities to operate

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For other people with intellectual DDs who do not need the level of care provided by the ICF/IID, Residential Support Services may be provided on a continuum of service delivery models ranging from intermittent services up to a 24-hour Supported Living Arrangement (SLA). An SLA provides residential support for individuals requiring assistance to live in the community, and services can be provided in many settings. These SLAs often exist in what is termed a “congregate setting,” which might be viewed as somewhere between institutional and full community-based living. There are three main service formats for SLAs:

- **Intermittent SLA.** The service recipients in this program require intermittent support while living in a home or apartment by themselves, with a roommate, or with family.
- **24-Hour SLA.** The 24-hour supported living arrangements support recipients in need of maximum support services. People typically live in a home with roommates in a community neighborhood and share the support services from the provider with a maximum of four recipients per home.
- **Shared Living.** Service recipients who desire or need a family living situation may receive services from a provider who includes the service recipient in their family life and activities. This arrangement allows a maximum of two recipients per home.

The funding stream for these services is the 1915(c) Home- and Community-Based Services (HCBS) Waiver for People with Intellectual and Developmental Disabilities, which is an optional service approved by the federal Centers for Medicare and Medicaid Services under subsection (c) of Section 1915 of the Social Security Act that provides recipients with services in home- or community-based settings. It allows states to waive Medicaid regulations to target specific populations, address areas of need, and relax certain income and resource rules.

The waivers come with requirements. They must be person-centered and provide recipients “with the opportunity to remain in a community setting in lieu of institutionalization.”¹⁰ In addition, the waiver must comply with the 2023 HCBS Settings Rule, a major federal administrative change noted above. It requires that the service recipient select a residential setting from multiple options, that services optimize autonomy and independence, and that the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS. Per Nevada’s waiver – with the exception of the person’s natural family home and approved Shared Living Services – Residential Support Services must be offered in a non-provider-owned home, which is owned or leased in the service recipient’s name or on the person’s behalf (though there are certain “exceptions to the exception”).

That the waiver, as a general rule, prohibits owners’ provision of services is an important matter. There is only one independent living community for people with disabilities in Nevada: Opportunity

intermediate care facilities. Beyond the State ICF/IID, there are 54 beds across seven licensees. However, the Guinn Center was unable to obtain additional information about these entities.

¹⁰ We acknowledge that some interviewees find the language “in lieu of institutionalization” harmful and stigmatizing. While many people benefit from home- and community-based care, available because of years of advocacy work, some need facility-based care, like the State ICF/IID..

Village's residential community, Betty's Village.¹¹ It does not provide Residential Support Services, as it is not currently permitted to do so. According to a representative from Betty's Village, "the State doesn't allow you to be the owner and operator of the facility [and provide residential supports]." However, individuals who live at Betty's Village may choose to pay for supports privately if they are able, or receive them through the Medicaid waiver, if eligible. At the time of this writing, Betty's Village houses 94 residents in 70 units; its wait list is approximately 250 people, and it is raising funds for its second residential community.

Children with Autism who may present with intellectual or behavioral conditions may qualify for assistance from Nevada's Autism Treatment Assistance Program (ATAP). The ATAP is a statewide program of the Aging and Disability Services Division and provides temporary assistance and funding to pay for evidence-based treatment for children on the Autism spectrum who are under the age of 20 and diagnosed as a person with ASD by a physician, psychologist, child or adolescent psychiatrist, pediatric neurologist, or other qualified professionals.

Housing Challenges for People with DD in Nevada

System Complexity

In addition to the housing challenges that all Nevadans face, people with DD have the additional challenge of navigating a complex and fragmented system to access the support services that enable community living.

The focus groups and one-on-one interviews conducted by the Guinn Center for this report revealed that many self-advocates and their support networks want to find a home for themselves or their family members but often only find services instead of housing. Many said that, while they need services, they also are seeking a place to live. When we indicated that services and living arrangements were sometimes connected, it did not resonate. One focus group participant said, "the whole thing is just so confusing," and everyone agreed.

Another family member questioned why "Medicaid is involved." This participant stated that his family is not Medicaid-eligible and, therefore, his daughter is excluded from finding a place to live. He indicated he is not wealthy enough to afford support and rent but not poor enough for Medicaid. He was unaware of the waiver but said he would have been "suspicious" of something that asked him "to waive something." (As noted, it is program requirements that are waived; this is not an individual waiver of rights, but this is the participant's perception.)

People spoke about being overwhelmed and not knowing where to begin to find the needed services and supports. They sensed that the system is big and deeply complex, and there is no one way to find an access point or information to help them get started. They felt particularly burdened by having to share personal information and gather paperwork for eligibility determinations. The waiver process for individuals with intellectual and/or developmental disabilities often begins with contacting Developmental Services, which is part of the Nevada Department of Health and Human Services

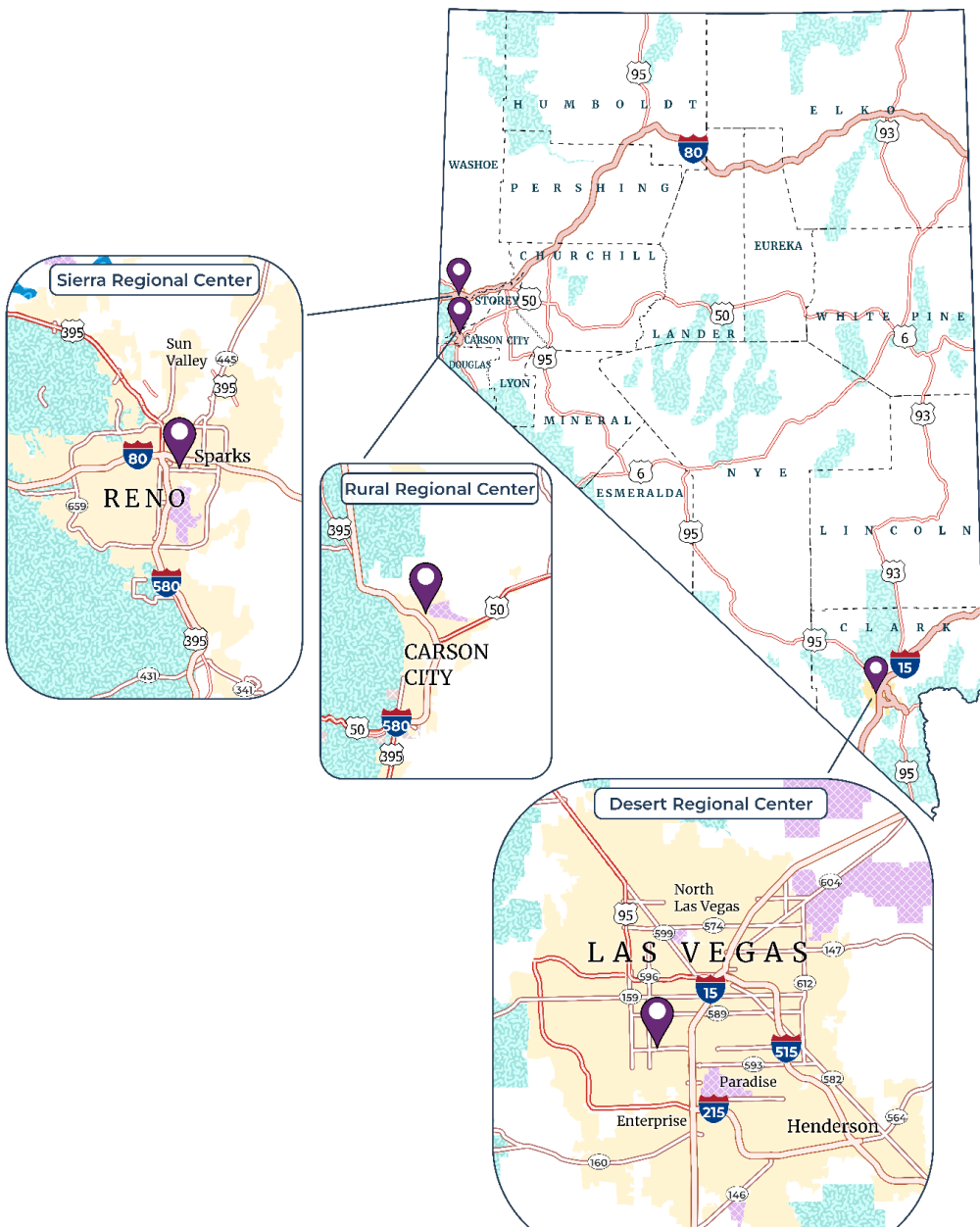
¹¹ Opportunity Village is a nonprofit organization that serves people in Las Vegas with intellectual disabilities.

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(DHHS), Aging and Disability Services Division (ADSD). Developmental Services provides many of its services through three Regional Centers. Desert Regional Center (DRC) serves metropolitan Las Vegas and Boulder City; Sierra Regional Center (SRC) serves Washoe County; and Rural Regional Center serves those living elsewhere in Nevada (see Figure 1 for a map). Often, those seeking services are directed toward the Home- and Community-Based Services (HCBS) Medicaid Waiver for People with Intellectual and Developmental Disabilities. The process unfolds, as described by a representative of ADSD in testimony before the Nevada Legislature on March 22, 2022:

Aging and Disability Services is the first touch point for someone who wants to become waiver-eligible. The social worker or the service coordinator does the intake process to make sure the individual meets the waiver criteria. That application is then sent to the Division of Welfare and Supportive Services (DWSS), DHHS, which looks at the financial eligibility to make sure the person is eligible. The final entity in the loop is DHCPS; once it gets through ADSD and DWSS, the application goes to Nevada Medicaid for final approval, as DHCPS is the administering agency.

Figure 1. Map of Regional Centers – Intake



Each person served by a regional center has an annual person-centered plan (PCP), which is developed by considering the person's needs, preferences, and desired outcomes for community living. There is also at least quarterly contact from a service coordinator. A person may receive residential services paid for with State funds or Medicaid waiver services paid for with a combination of State and federal dollars. According to the Home- and Community-Based Services (HCBS) Waiver for People with Intellectual and Developmental Disabilities, "[t]he applicant/recipient will be given the right to choose waiver services in lieu of placement in an ICF/IID. If the applicant/recipient and/or designated representative/LRI prefers placement in an ICF/IID, the service coordinator will assist the [them] in arranging for facility placement."

For people approved for Residential Support Services, ASD contracts with community service providers. Under the terms of the PCP, the service provider helps people secure a place to live and may provide staff support for the person to live in the community. As one service provider explained to the Guinn Center, this can take many forms. For example, a person may prefer to live in his or her family home and, if he or she needs only intermittent help, the service provider may offer that assistance. Service providers may also connect people with Sharing Living arrangements or 24-hour SLAs. For individuals who wish to live independently with intermittent support and who can do so under their PCP, service providers often assist with finding a residence to rent or buy.

While the process is not without its complexities for administrators and service providers, the experience is intended to be frictionless for people with DD. If a person contacts the local Regional Center, intake should follow. If determined eligible, the service coordinator should help develop a PCP and make a connection with a service provider who will ensure the requisite help is given in the preferred residential setting.

To be sure, this is a simplified view of the process and there are wait lists that can limit people's ability to receive specific services and supports. Regardless, system navigation and its perception of complexity present a challenge to people with DD and their support networks. There can be a disconnect between the process, its ecosystem of institutional actors, and the people being served. Two explanations may account for the disjuncture.

First, the process is person-centered. This means that, while some aspects are generalizable, the PCP seeks to balance several factors to help determine each person's optimal residential setting. This makes it challenging to envision the "house" at the end of the process because there is no template or self-administered assessment tool that can guarantee a preferred housing outcome.

Second, some of the material available on various program websites is technical guidance written in administrative language. It may be intended for professional audiences, such as service coordinators or service providers, but it can create a barrier to understanding for those seeking services. Nevada is similar to other states in this regard, if not an improvement on many, for which we observed an overuse of acronyms and technical language. If people seeking help are unfamiliar with terminology that may be commonplace to program administrators, like "waiver," they may find the process exhausting and overwhelming, as noted by some focus group participants. This potentially poses barriers to entry and can discourage the pursuit of services and supports.

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Mismatch of Preferences and Housing Outcomes

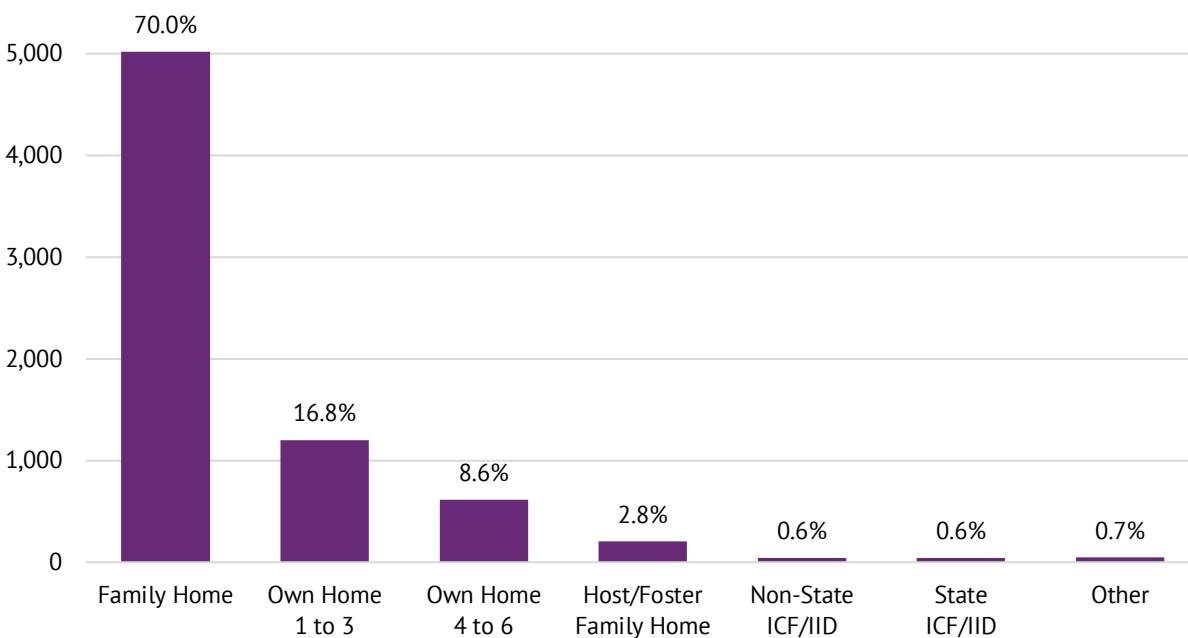
Each person’s experience with his or her developmental disability is unique. Diagnoses can be complex, and co-occurring medical conditions are not uncommon. People with DD in our focus groups stressed how important it is that this be better understood. Moreover, the perceived lack of understanding sometimes leads them into living arrangements they would not have chosen for themselves.

For many people and their support networks, a keyword is “independence.” One person with an intellectual DD described how well-equipped she is to live away from her family home. (According to the information the participant shared, she has all the tools and supports to live independently but, according to the participant, her service coordinator disagrees and will not adjust the PCP.

It is relevant to note that this landscape analysis report is not a program evaluation. We can neither establish the facts nor verify the testimony provided. We can only relay accounts of how people with DD have experienced their pursuit of community living in Nevada. It may be that the participant is unable to live away from home and their preference is an aspirational goal.

For context, Figure 2 shows where people with intellectual or developmental disabilities (I/DD) were living in Fiscal Year (FY) 2019.

Figure 2. Residential Settings Among People with I/DD in Nevada, FY 2019



Source: Residential Information Systems Project (RISP), University of Minnesota, 2022, *Long-Term Supports and Services for Individuals with Intellectual or Developmental Disabilities: Status and Trends Through Fiscal Year 2019*. Population: Recipients of Long-Term Supports and Services. Note: Definitions of settings are adjusted for alignment with Nevada’s state-specific terminology.

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In the previous section, we observed that Residential Support Services are provided in non-provider-owned homes. The [data](#) in Figure 2 otherwise defines I/DD Group Homes as “residence[s] owned, rented, or managed by the residential services provider, or the provider’s agent, to provide housing for persons with I/DD in which staff provide care, instruction, supervision, and other support for residents with I/DD.” While Nevada provides 24-hour supported living arrangements (SLA) through the Medicaid waiver, as described previously, it does not have group homes as defined above. Therefore, “Own Home” can refer to a person living alone, living with roommates, or living under a 24-hour SLA.

Roughly seven in 10 Nevadans with I/DD (70.0 percent; 5,020 individuals) live in their family homes. This agrees with available research showing this is the predominant living arrangement for people with I/DD. In [California](#), 80.0 percent of people with I/DD live with a family caregiver, and 63.0 percent of adults do so. A [study of housing for people with I/DD](#) in the Pacific Northwest shows that these numbers are 70.0 percent in southwest Washington and 61.0 percent in Oregon.

Figure 3 shows Nevada’s share of people with I/DD living with a family member exceeded the national average of 62.0 percent in FY 2019. In fact, Nevada ranks eighth highest in the nation on this metric.

Figure 3. Share of People with I/DD Living with a Family Member, by State, FY 2019



Source: Residential Information Systems Project (RISP), University of Minnesota, 2022, [Long-Term Supports and Services for Individuals with Intellectual or Developmental Disabilities: Status and Trends Through Fiscal Year 2019](#). Population: Recipients of Long-Term Supports and Services. Note.: Share is estimated.

The interpretation of this data is somewhat contested, which is to say the significance of being ranked eighth in the nation is tempered by experience. Some people view this as a “major win.” That is, the ability to live at home rather than in an institutionalized setting is the hallmark of a system-wide transformation – one that is welcome. Others, particularly those individuals whose family members benefit from a level of support that only facility-based care can provide, fear that “the ground is shifting beneath them.” Their family members require a level of support neither they nor a 24-hour SLA can provide. It is also essential to recognize that many people with I/DD experience communication challenges. As one family member noted, the inability to speak does not mean that someone has no voice, and his or her preferences, however expressed, should carry weight.

Considering the communication challenges of some people with DD, the perspectives of those who can and prefer to live at home should not be disregarded. Many people with DD can live comfortably and happily at home, sometimes with family help. However, one key informant who works closely with a demographic sub-group within the DD community stated that cultural competence requires sensitivity to the needs of some populations for which independence among people with disabilities is not a norm.

National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD) survey, which is a national effort to measure and improve the performance of public developmental disabilities agencies, shows that roughly 25 percent of Nevadans with I/DD who live in their parent’s or relative’s home want to live somewhere else. This is near the average of all states for the 2021-2022 survey period.

We do not have a clear picture of whether people with DD in Nevada are living where they would like. In our focus groups and interviews with self-advocates, we learned that some people are unhappy with their living arrangements or prefer to live away from home, which is something that seems unachievable to them. We also heard from individuals and their support networks who expressed fear their living arrangements could change at any time. Additionally, many people do not seem to like the 24-hour SLA, with opinions including insufficient levels of care (i.e., among family members of people who have benefited from facility-level care, like the State ICF); too high a level of care, particularly among those who may wish to live independently but whose disability places their needs between intermittent and maximal supports; and dislike of their living arrangements (i.e., unsafe neighborhoods, fear of roommates, etc.), though this might change with implementation of the 2023 federal HCBS Settings Rule.

The charts presented in this sub-section do not align well with our findings from the focus groups. This may be a function of having different sample groups, especially as ours, definitionally, are not representative. The key question, as raised in the California study, is: “[D]o consumers live in their current setting out of choice or because there is no alternative[?]” A program evaluation, coupled with a needs assessment, could begin to answer that question for people with DD in Nevada.

Affordability Issues

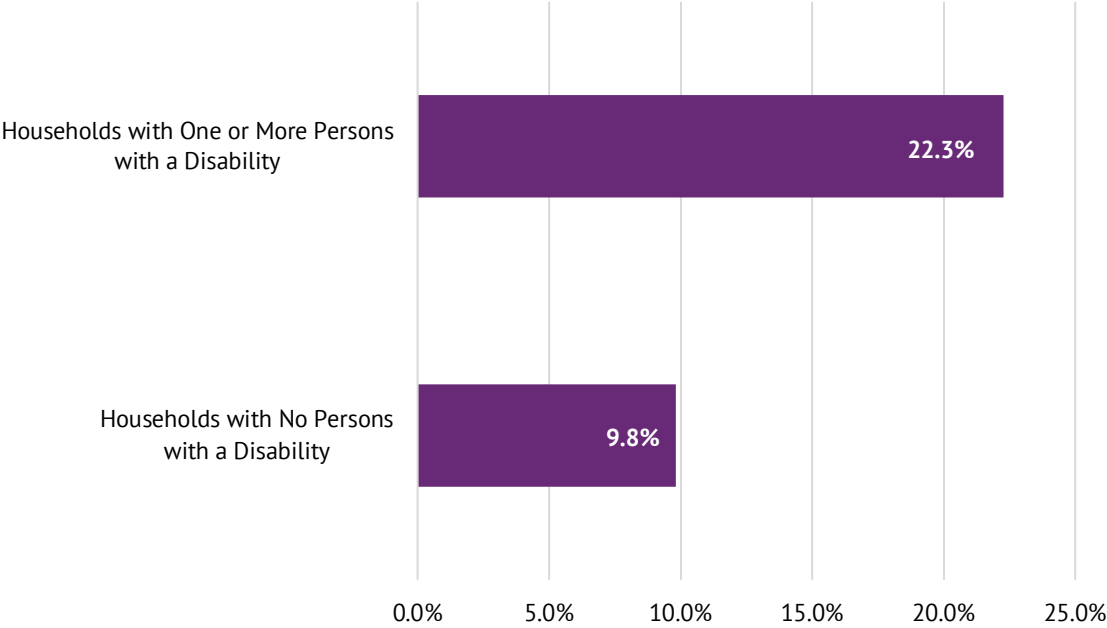
The most cited challenge by people with DD and their support networks is their inability to find affordable housing. As one person maintained, “No way. I can never live alone or even with roommates.

The rent is too high. I know I won't ever own my own home." Focus group participants echoed this sentiment, and key informants raised it without prompting. Affordability is more than a challenge for people with DD in Nevada – it is a barrier. This situation is emotionally charged and supported by various data.

We do not know how many people with DD live in poverty or what income constraints they experience. Many people with DD rely on Supplemental Security Income (SSI), "a federal program that provides monthly payments to...people who are 65 or older, as well as people of any age, including children, who are blind or have qualifying disabilities." The maximum monthly payment for a person with a disability in Nevada in 2023 was \$914. While the Social Security Administration provides data by state on SSI recipients, it does not disaggregate the data by disability diagnosis. National estimates have been modeled for those with intellectual disabilities, but state-specific data would be necessary to conduct a robust analysis.

Although it, too, provides a rough estimate, Figure 4 uses recipients of the Supplemental Nutrition Assistance Program (SNAP) as a proxy for poverty but does not account for disability type.

Figure 4. Receipt of Food Stamps/SNAP in the Past 12 Months (Households), 2022



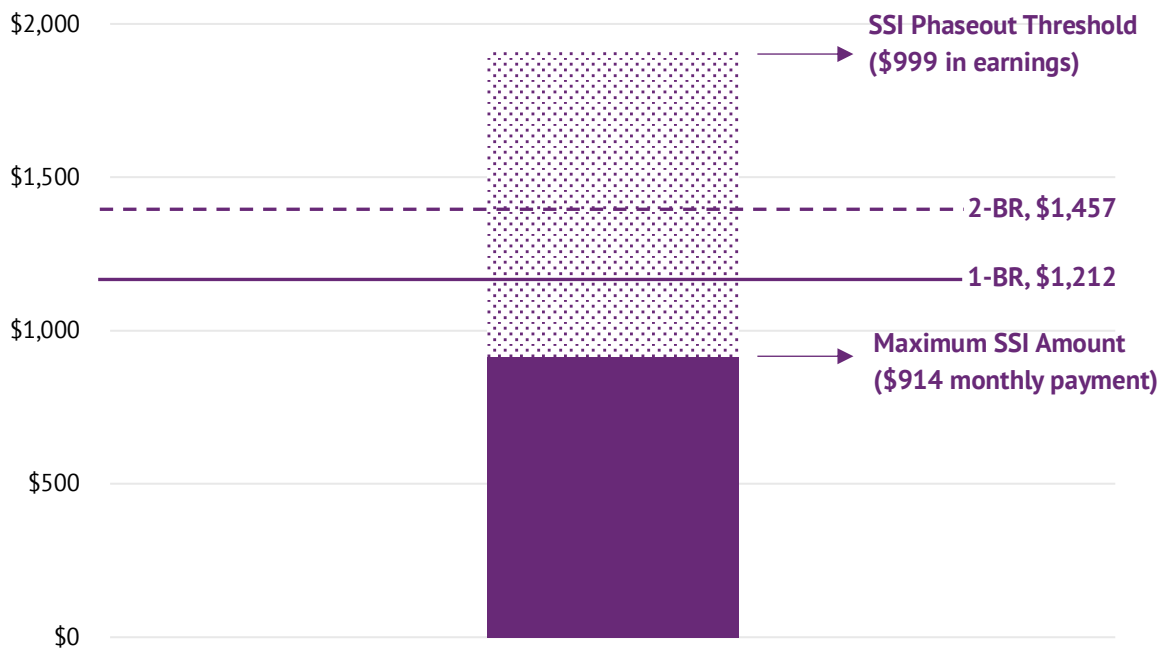
Source: U.S. Census Bureau, American Community Survey

Figure 4 illustrates the challenge for households in which one or more persons have a disability versus those that do not. For the former, nearly one in four households receives SNAP benefits (22.3 percent), while that number is 9.8 percent for households in which no person has a disability. In other words, the rate of SNAP usage more than doubles with the presence of a person with a disability. There is a correlation between poverty and disability. One analysis shows that direct costs, such as health care, medical equipment, and child care, among others, and indirect costs, including caregiver job loss or part-time employment, make the economic costs of disability difficult to manage.

The financial constraints of people with disabilities intersect with what is commonly referred to as the “housing crisis” in Nevada. The statistics are well-documented but bear repeating. The National Low Income Housing Coalition (NLIHC), which advocates for increasing low-income housing across the United States, finds 17 affordable and available homes for every 100 extremely low-income (ELI) renter households in Nevada. ELI is defined as “at or below either the federal poverty guideline or 30 [percent] of the area median income, whichever is greater.” Nevada’s ratio is the lowest in the nation. By contrast, the state with the most affordable and available homes for every 100 ELI renter households is South Dakota at 58. Moreover, the monthly rent that is affordable with an SSI monthly payment of \$914 is just \$274.

Figure 5 provides a hypothetical illustration for a person with DD wanting to rent an apartment in the Las Vegas area.

Figure 5. Receipt of Supplemental Security Income (SSI) and HUD Fair Market Rent in the Las Vegas Area, 2023: An Illustrated Example



Source: Social Security Administration, 2023, *A Guide to Supplemental Security Income (SSI) for Groups and Organizations*; and U.S. Department of Housing and Urban Development’s Office of Policy Development and Research (PD&R), HUD User, *FY 2023 Fair Market Rent Documentation System: The FY 2023 Nevada FMR Summary*

Figure 5 is premised on several assumptions and should be interpreted with caution. First, not all rents in the state are as high as those in the Las Vegas area. Among metropolitan areas, Las Vegas rents were higher than in Carson City but lower than in Reno. Las Vegas thus serves as a reasonable median, especially as there is much variation across the rural counties. Second, income is presumed to be the SSI monthly maximum for a person receiving a disability benefit in Nevada. As Figure 5 shows, among people with disabilities who earn other income, SSI phases out with \$999 in earnings,

or a total \$1,913 per month (the SSI benefit, plus monthly earnings).¹² Here, the assumption is a reliance by people with DD on SSI, which is “an important income source.” However, given the data limitations, we recognize this scenario may not be representative.

However, if the SSI affordable rent is \$274 per month, a hypothetical person in Figure 5 hoping to rent in the Las Vegas area would face housing costs that exceed what he or she could afford. Even if this person were to dedicate their entire SSI payment to rent, the monthly benefit amount of \$914 would fall short of what is needed to rent a one-bedroom apartment in Las Vegas (\$1,212), much less a two-bedroom apartment (\$1,457).¹³ Someone with additional earnings above the monthly SSI benefit might be able to afford an apartment, but that would depend on his or her financial circumstances and ability to pay other fixed monthly costs. At the SSI phaseout threshold, we would note that rent in excess of roughly \$574 per month could create a cost burden and that dollar amount is not quite half the monthly fair market rent for a one-bedroom apartment in Las Vegas.¹⁴

For people with DD, other complicating factors may interact with cost but are not apparent to people without DD. Earlier in this report, we provided an example of a person who would like to live independently but has been told this may not be possible. While she finds this frustrating, she appreciates that her desire for independence, even if supported by the State of Nevada, could create difficulties for her father, who is her primary caregiver. She has a bachelor’s degree and a job that she feels pays well and is commensurate with her abilities. Yet, her developmental disability precludes her from obtaining a Nevada driver’s license. While the person can move within her city’s transportation network, the location of potential housing would either be cost-prohibitive or unsafe. If she were to move outside the transportation corridor, she might find somewhere affordable to live, but that would mean her father would need to drive her to work and on errands. While he does so already, Her father does not have the added cost of driving to a separate location to do so, as she lives in the family home. This would create a burden beyond what seems sensible or practicable (e.g., housing costs, transportation costs, travel time, etc.), so she continues to live at home.

Although it may seem clear that affordability is a challenge for people with DD, we do not have sufficient information to establish this with certainty. According to the studies mentioned above, in the Pacific Northwest, rent increases are associated with housing risk for people with DD and, in California, “there are no housing markets...where a consumer with DD whose sole source of income is SSI can afford a safe, decent rental unit.” Although we did not conduct a county-specific analysis, this seems to be true for Nevada’s metropolitan areas.

¹² For more on SSI benefits and the phaseout threshold, see: Guinn Center, “Integrated Employment Opportunities for Individuals with Disabilities in Nevada: An Assessment,” 2021, <https://guinncenter.org/wp-content/uploads/2022/01/Guinn-Center-Integrated-Employment-2021.pdf>

¹³ This discussion centers on a person who wishes to live alone (with support in the home, as necessary). Someone who would like to live with a roommate could share the costs of a two-bedroom apartment. Assuming an equal split, rent would amount to \$728.50 per person per month, but for someone who has no earnings and receives only a monthly SSI benefit, \$728.50 would account for 79.7 percent of his or her monthly income.

¹⁴ According to the NLIHC, “[a] household is cost-burdened when it spends more than 30 [percent] of its income on rent and utilities[.]”

The question for any state is what sort of financial support it provides to assist people with DD in making rent and mortgage payments. It is difficult to obtain this information, with only Ohio providing a clear-cut example, from 2019:

If I get a waiver, can I live by myself?... A waiver does not pay for things like a place to live (rent), food, or utilities such as heat and electricity. You will need to use your own money to pay for those things. There may be programs that can help you pay part of the cost if your money is not enough. Your service and support administrator (SSA) can provide information about benefits and public programs that may help you with these costs.

Thus, this would suggest that, in Ohio, if a person with DD would like to live alone or with roommates, he or she would need to have the resources to do so or find public housing assistance, perhaps with the help of a support professional.

Nevada sometimes assists with room and board on a limited basis. The Department of Health and Human Services (DHHS), Aging and Disability Services Division (ADSD) provides guidelines to Regional Center staff in its *Policy Manual*. Policy #41-4 is titled “Residential Services Cost of Living Allocations.” It states:

The cost of housing, to include motel, apartment, and single dwelling homes, will be limited to a maximum of \$770.00 per person per month. The Housing and Urban Development (HUD) fair market value and local rental pricing will be reviewed to determine if requested rent amounts are reasonable. If the individual chooses to exceed the approved rent amount, the individual/family/guardian/provider will be solely responsible for the additional costs above the maximum amount unless otherwise approved by the Regional Center Agency Manager or designee.

(NOTE: This guidance is dated January 25, 2019. A stakeholder shared guidance for FY 2024 with the Guinn Center, but it is not publicly available. Nevertheless, we note that the major change is that the cap on the housing subsidy will be increased to current market rates based on rental availability.)

According to ADSD, in Fiscal Year 2023, nearly \$85 million in State funding was authorized for room and board assistance statewide. *However, a person must receive services from the SLA program to qualify for a room and board subsidy*, which means it depends on a person's desire for SLA services and whether a provider is available.

Aging Family Caregivers

The availability of qualified human capital considerably influences the quality of community-based support services for people with DD. However, this is not entirely a workforce development question.

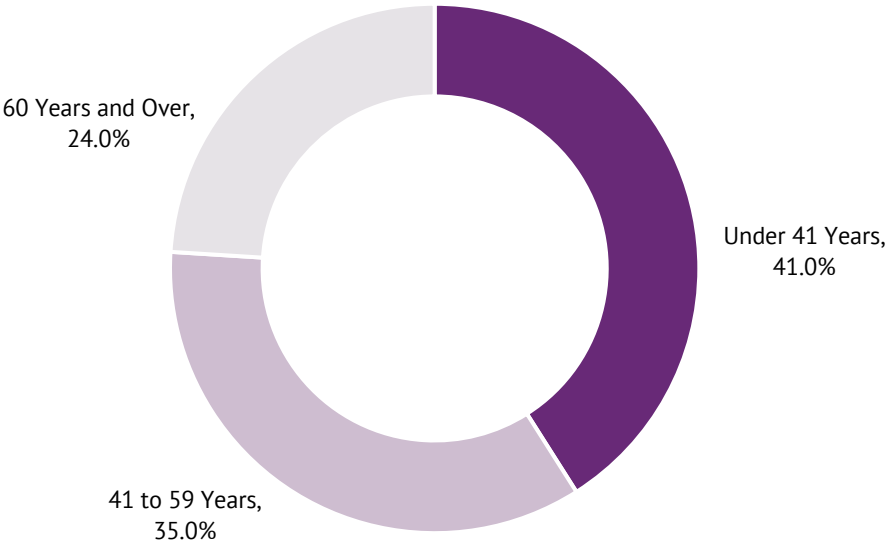
As we have shown, most Nevadans with I/DD live in their families' homes, where their parents or other relatives serve as caregivers. Anecdotally, this living arrangement seems to be less common among other DD subgroups, but it is the case for some. Many family caregivers cited fears about aging as their greatest concern. One parent stated that she is financially secure and thus able to support her adult child with DD “meaningfully and lovingly,” but she is unsure what will happen when she is no longer able or when her resources are exhausted. Despite her current financial security, she cannot save for future eventualities. Moreover, she expects her child's needs to grow as she also ages.

People in support networks describe it as a looming crisis, particularly as they have begun to age and experience their own challenges. Some cried as they shared their fears and anxieties. They asked, “Where will ‘Liam’ go when I can’t care for him?,” “What happens if there is a crisis and ‘Emma’ doesn’t know how to get help?,” “Will ‘Max’ end up experiencing homelessness?,” “What if ‘Fiona,’ who is incredibly vulnerable, can’t recognize that someone is exploiting her?,” and more thoughts along these lines. While difficult to hear, this testimony is necessary because it shines a light on unaddressed or unseen struggles.

The California survey previously discussed found that “[M]any of these parents worry about their own aging/death, but many of them have no solutions and have made no arrangements for the housing of their adult disabled child. They perform caregiving themselves and worry about the physical demands as they age.”

Figure 6 shows the distribution of caregivers by selected age cohorts for FY 2019 in Nevada.

Figure 6. Share of DD Caregivers in Nevada, by Selected Age Cohorts, FY 2019



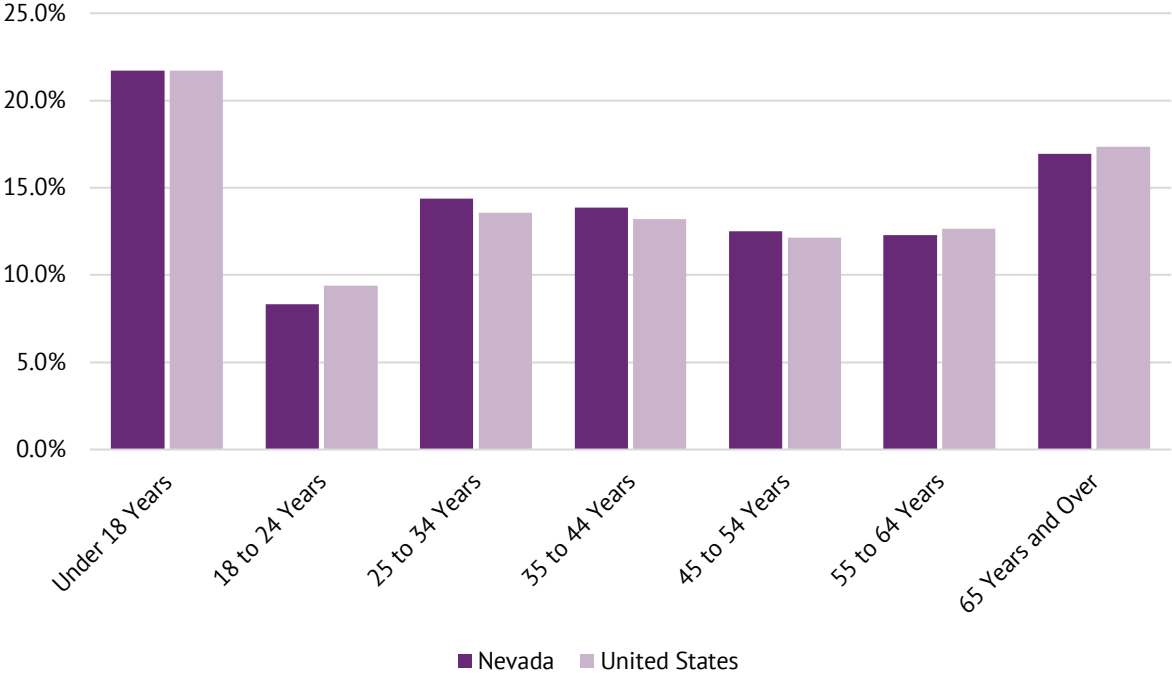
Source: Kansas University Center on Developmental Disabilities, The University of Kansas, 2022, *The State of the States in Intellectual and Developmental Disabilities (State Profiles: Nevada)*. *Note.:* Share is estimated.

The data for Nevada is consistent with the finding that DD caregivers are aging. Nearly one in four DD caregivers (24.0 percent) are 60 and over.

The Pacific Northwest study previously discussed describes the problem as part of “the national demographic trend of the aging baby boomer cohort, which creates risk for adults with I/DD who live with an older caregiver.” The comparatively large boomer cohort implies that many family caregivers will be aging into the need for care.

Figure 7 shows that age groups in Nevada currently mirror the nation's. While it does not necessarily reflect the age distribution of caregivers specifically, it shows Nevada's largest adult age group is over age 65.

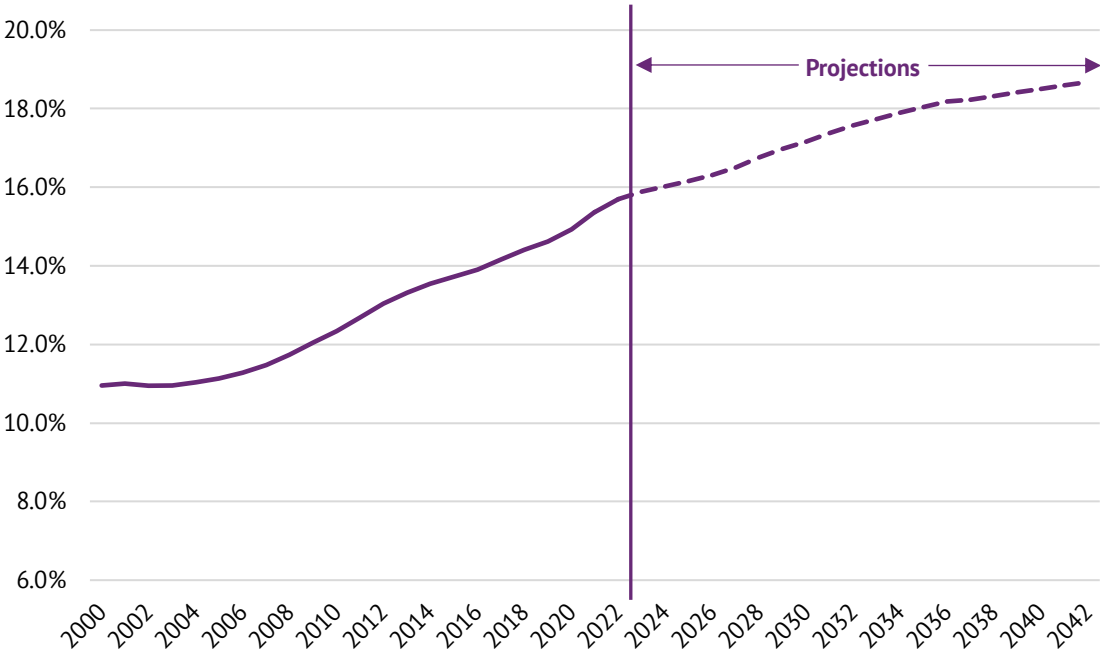
Figure 7. Population, by Age Group, for Nevada and the United States, 2022



Source: U.S. Census Bureau, American Community Survey

The Nevada State Demographer recently released population projections through 2042, as shown in Figure 8. The figure is scaled for legibility, so the 20-year projected growth in Nevada's population aged 65 years and over may seem particularly pronounced. Between 2023 and 2042, the senior population is expected to grow from 519,863 to 734,404, which is a 41.3 percent increase (i.e., an increase of 2.8 percentage points as a share of the population). The number of family caregivers within this subgroup is unknown but it appears there will be a growing number of senior caregivers for adult children with DD.

Figure 8. Share of Nevada’s Population Aged 65 Years and Over, 2000-2042



Source: Nevada Department of Taxation, Nevada State Demographer (Christopher Wright), 2023, Nevada County Age, Sex, Race, and Hispanic Origin Estimates and Projections 2000 to 2042: Estimates from 2000 to 2022 and Projections from 2023 to 2042

Shortages in the Direct Support Professionals Workforce

Not all people with DD receive help from a family caregiver. Direct support professionals (DSPs) help people with disabilities maximize community participation, including living in integrated settings. They provide caregiving and support with activities of daily living. Some are employed by service providers, though others may work independently.

Little is known about the DSP workforce, though the U.S. Department of Labor has acknowledged a nationwide shortage of workers. Part of the data challenge is that DSPs are not treated as an occupational group, as defined by the U.S. Bureau of Labor Statistics (BLS) in its Occupational Employment and Wage Statistics. Classification by BLS would deepen our understanding of the DSP workforce, as this data contains information on total employment, wages, and more. It is difficult for states to align workforce priorities with unmet needs without appropriate data.

This report previously mentioned the NCI®-IDD survey of people with I/DD. It currently is collecting survey data on DSPs, noting that “The goal of the survey and the resulting data is to help states examine workforce challenges, identify areas for further investigation, benchmark their workforce data, measure improvements made through policy or programmatic changes, and compare their state

data to those of other states and the NCI-IDD average.” Nevada did not participate in the 2021 DSP workforce survey.

Nevada’s service providers cited the DSP shortage as one of the DD community’s most challenging issues. If they are unable to provide intermittent supports or 24-hour SLA because of staffing shortages, people with DD may not receive services, even if they are eligible for Residential Support Services through the Medicaid waiver. Put bluntly, some people go without care under these conditions, particularly if there are no natural supports, such as family caregivers, to close the gaps. “Recruitment,” “retention,” “turnover,” and “attrition” were the words invoked most frequently when we discussed the DSP workforce with stakeholders. According to legislative testimony, in 2022, disability agencies’ staff turnover was 132 percent, with a vacancy rate of 22 percent.

One service provider observed, however, that legislatively approved increases to several reimbursement rates could “relieve some pressure” by allowing a more competitive wage. According to the Request for Renewal for the 1915(c) Home- and Community-Based Services (HCBS) Waiver for People with Intellectual and Developmental Disabilities (Draft, October 1, 2023), the “Nevada Legislature approved the following rate increases: T2017–Habilitation, residential, waiver–\$8.05/15-minutes (28.8 [percent] increase) T2017:UJ–Habilitation, residential, waiver, sleep–\$4.89/15-minutes (28.7 [percent] increase).”

Regardless, staffing shortages persist, affecting both HCBS and the State ICF. In testimony before the Legislative Committee on Senior Citizens, Veterans and Adults with Special Needs (March 22, 2022), a representative from ASD’s Community Based Care and Development Services, stated:

The other main issue we are experiencing at the ICF is a major staffing shortage. Developmental support technicians do the day-to-day, 24-hour services; we are currently vacant 28 jobs, which is about 25 percent of all of the techs we need to operate the actual campus. The ICF provides 24-hour services—this is a facility-based setting, as opposed to a home- and community-based setting—and there must be active treatments happening to make sure we are promoting functional skills. This includes a whole lot of different services: nursing; counseling; physical therapy; speech therapy; basically, anything a person needs to be able to be healthy and reside successfully at the ICF.



Possible Next Steps

ADDITIONAL RESEARCH

This landscape analysis has discussed various challenges in Nevada’s housing market and difficulties experienced by people with DDs in accessing community-living support services in the most integrated setting appropriate. In addition to the observations made in the Conclusion section below, additional research could also explore best practices in other states or countries to expand the availability of affordable, accessible housing. It might also identify effective strategies for maximizing the available federal Medicaid resources for Nevadans with DD and better approaches for coordinating Olmstead compliance across the State.

There is value in pursuing additional research and program evaluations related to housing and support services for Nevadans with DD. However, there may be current advocacy measures worth exploring to improve community-living outcomes for people with DD.

Many questions remain outstanding, and additional research is needed. Policy recommendations thus are premature. Nevada may benefit from a program evaluation and needs assessment. The perception from self-advocates, support networks, and caregivers is that the disability system needs substantial improvement. As this report was not designed as a program evaluation, the Guinn Center did not have access to information to determine if structural or administrative changes with the system are needed beyond the qualitative information gathered through interviews. Based on that data alone, it is recommended that additional study be undertaken to further evaluate the system and identify the severity of gaps in access to affordable housing and the availability of housing and care options that align with individual choice. Further study to review the sufficiency of existing funding and staffing for the range of community based and institutional care options, and the demand for expanded options for the full range of community based living options. Below are a list of questions that have been identified that would help to gather the additional needed information for a more robust study of housing, care, and support options for individuals in Nevada with developmental disabilities: .

- How many adult Nevadans with DD or, in the case of children, how many families are waiting to get affordable housing?
- How many Nevadans have developmental disabilities and how many are age 22 or older? Where do they live and where do they want to live? How old are their family caregivers?
- How many Nevadans with DD are being served in each available setting? What is the objective quality of each setting?
- Is funding adequate to serve the population, or are needs going unmet?
- What would adequate funding imply for people’s preferred living arrangements?
- How much do individuals’ income and assets matter in determining one’s living arrangement?
- In the wake of the pandemic health emergency, how can staffing shortages be addressed?
- What can be done to expand and support the caregiver population, both family members and direct support professionals?

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- Are people with DD, who genuinely need facility-based care, waiting in 24-hour supported living arrangements because of insufficient ICF capacity?

A robust assessment is necessary before policy interventions can be designed or implemented.

It is suggested that further research include an analysis of promising models from other states for Nevada to consider. For example, the “Florida Legislature has appropriated funding for a competitive grant program for housing developments designed and constructed to serve persons with developmental disabilities.” Other states have more closely integrated housing and supports, such as Louisiana, which established a Permanent Supportive Housing (PSH) program after Hurricanes Rita and Katrina. By 2012, PSH had provided housing for over 2,300 people with disabilities in its Gulf Coast region. Without more research, it is difficult to determine if either approach would be advantageous to Nevada.

A potential springboard in Nevada is Assembly Bill 310, enacted during the 82nd (2023) Legislative Session. It charges the Nevada Housing Division with the development and implementation of a supportive housing grant program to procure and develop supportive housing, among other provisions, for people who have a disabling behavioral or physical health condition and who experience homelessness or have been at imminent risk of homelessness or unnecessary institutionalization.

IMPROVING OLMSTEAD IN NEVADA

The Aging and Disability Services Division recently updated its plan for compliance with the Americans with Disabilities Act and the Olmstead Decision. As a significant provider of services to Nevadans with DD, this plan will help advance ASD services to the most community-integrated setting appropriate. However, the ASD plan acknowledges it is difficult to fully capture the spirit of the law without a cooperative effort that includes other state, county, city, and community-based service providers.

Perhaps the NGCDD and disability advocates can work with State policymakers to ensure all public disability service entities have a working Olmstead plan and to create an overarching statewide plan that compels and empowers these entities to work together and coordinate their resources to benefit Nevadans with disabilities.

ENSURE PEOPLE WITH DISABILITIES ARE GIVEN PRIORITY IN PUBLIC HOUSING PROGRAMS

Nevada’s implementation of general public housing programs is beyond the scope of this study. However, we recognize there may be opportunities within these programs to improve the access of Nevadans with DD to affordable and appropriate housing.

Perhaps the NGCDD and disability advocates can:

- Work with Nevada’s Public Housing Agencies that administer the federal Section 8 housing program to ensure they have exercised their option to give preference to people with disabilities. Also, ensure that the program is fully providing the required reasonable accommodations, which

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can include adjustments to policies and procedures or housing modifications to ensure full participation by people with disabilities.

- Work to expand the use and impact of the federal Section 811 supportive housing program for people with disabilities. Until federal policy was changed in the early 2010s to disallow the involvement of nonprofit organizations in housing development, this program resulted in the development of over 330 affordable, accessible housing units in Nevada. Can similar outcomes be replicated under a different model in cooperation with public entities? Could a consultant be hired to help facilitate the process?
- Determine if other housing programs are being fully leveraged to benefit people with DD. For example, the Mainstream Voucher program provides Section 8 low-income rental assistance for adults with disabilities under age 62. Is the program being fully accessed and implemented in Nevada? Additionally, when accessible housing units become available, they should first be offered to people who require these accommodations. Is this standard practice in Nevada?
- Work with Nevada's congressional delegation to determine if the State is accessing the complete array of federal housing resources available.
- Determine if there are State or local programs that could be implemented or expanded to improve the availability of affordable housing for people with DD. Could State or local resources be used to attract additional federal or private funding?

GETTING TO DATA-INFORMED DECISIONS

Housing programs generally serve the community at large. While these programs may collect some data on people with disabilities, that is not their focus. Support service programs are focused on people with disabilities, but they may not have much data related to housing.

Perhaps the NGCDD and disability advocates can initiate a coordinated effort to create a dataset specific to housing and community-based living for people with DD. Can the State's NPWR longitudinal data system be used for this purpose?

MAKING NO WRONG DOOR A REALITY

In 2015, ADSD created a [No Wrong Door Strategic Plan](#) that would make the array of disability services easier to access. Nearly a decade later, the plan has experienced implementation challenges and Nevadans still struggle to understand what supports are available and how they are accessed.

Perhaps the NGCDD and disability advocates can advocate for the implementation of this plan and for the inclusion of disability services provided by State agencies beyond ADSD and by nonprofit community agencies.

MOVING TOWARD POLICY OR FUNDING INITIATIVES

Finally, endeavoring into the opportunities above, even if they do not lead to successful outcomes, could expose gaps and opportunities in public policy or funding. By identifying such opportunities,

the NGCDD could work with the Governor's Office to propose responsive budgetary or statutory initiatives.

Conclusion

The availability of affordable housing for many Nevadans, including those with DD, is a tremendous challenge. For those with physical DDs, especially those who use a wheelchair, the greatest challenge beyond affordability tends to be finding a physically accessible dwelling. Nevadans with intellectual DDs tend to struggle with finding community-based support services to maximize their independent living.

While many people with DD receive Medicaid services through the state plan or a waiver, Medicaid is not a housing program and does not pay rent or mortgage costs. On a limited basis, the State may fund these costs for people who choose services under an SLA. Otherwise, apart from housing assistance available to all citizens, people with DD and their families are on their own to pay for housing.

There are many programs to help people with DD to maximize their independence in community-based living. Some of these are available to all people with DD, and some are targeted to different subgroups of the DD population. The data indicate that the institutionalization rate among Nevadans with DD is low. However, interviews with community members revealed a desire for greater community integration and independent living.

Access to support services can sometimes be frustrated by the complexity of program eligibility and application processes and a disconnect between programs that serve the same people. For those who receive help from family members, there is a concern their support may be lost as their family ages. There is also a critical shortage of direct support professionals to deliver services, even when funding is available.

The Guinn Center spoke with 35 people across three focus groups and 20 key informant interviews and conducted other research, including data collection and a review of government documents. The lived experiences of self-advocates, support networks, and caregivers animated this analysis. Without their forthrightness and candor, it would not have been possible to fully understand the specific challenges faced by people with DD seeking housing and support services in Nevada. Finally, subject matter experts supplied the critical information that linked disparate pieces of information and helped clarify matters needing additional inquiry.



Appendix A. Definitions of Developmental Disabilities

Pursuant to *Nevada Revised Statutes* (NRS) 435.007:

- “ 5. “Developmental disability” means autism, cerebral palsy, epilepsy or any other neurological condition diagnosed by a qualified professional that:
- (a) Is manifested before the person affected attains the age of 22 years;
 - (b) Is likely to continue indefinitely;
 - (c) Results in substantial functional limitations, as measured by a qualified professional, in three or more of the following areas of major life activity:
 - (1) Taking care of oneself;
 - (2) Understanding and use of language;
 - (3) Learning;
 - (4) Mobility;
 - (5) Self-direction; and
 - (6) Capacity for independent living; and
 - (d) Results in the person affected requiring a combination of individually planned and coordinated services, support or other assistance that is lifelong or has an extended duration.

[...]

9. “Intellectual disability” means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.”

Source: [NRS 435.007](#)

Pursuant to the *Code of Federal Regulations* 45 CFR 1325:

- “ *Developmental disability.* The term “developmental disability” means a severe, chronic disability of an individual that:
- (1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (2) Is manifested before the individual attains age 22;
 - (3) Is likely to continue indefinitely;
 - (4) Results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) Self-care;
 - (ii) Receptive and expressive language;
 - (iii) Learning;

(iv) Mobility;

(vi) Self-direction;

(vii) Capacity for independent living; and

(viii) Economic self-sufficiency.

(5) Reflects the individual's need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(6) An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in paragraphs (1) through (5) of this definition, if the individual, without services and supports, has a high probability of meeting those criteria later in life. ”

Source: 45 CFR 1325

Appendix B. Focus Group Question Prompts

Self-Advocates

1. How would you describe your home?
 - *Probe:* Do you live at home or with friends or by yourself?
2. Has it been difficult to receive services and supports (with specific respect to living arrangements)?
 - *Probe:* Please describe your experience.
3. There has been a lot of discussion about housing options for people with DD.
 - *Probe:* What is your experience in finding a place to live?
 - *Probe:* Would you say it has been easy or hard?
4. Do you think housing is easy to afford or too expensive?
5. Would you like to live independently?
 - *Probe:* For example, would you like to live in your home or with roommates?
6. Are you happy with where you live now?
 - *Probe:* If you are not happy, what would you like better? (Prompts: live in own home or apartment with roommates, live in own home or apartment alone, live in a supported living arrangement)
7. How would you make the housing system better for other people with DD?
8. If we have not covered it here, what else would you like us to know about housing for people with DD?

Support Networks

(*Note:* Along with family members, some participants may be paid or unpaid caregivers. Moderator will explain that “family member” may refer to a biological or legal family member *or* the person to whom the participant is providing care, irrespective of relationship.)

9. How would you describe your living arrangements?
 - *Probe:* Does your family member with DD live at home?
10. Have you experienced challenges in receiving services and supports for your family member with DD (with specific respect to living arrangements)?
 - *Probe:* If so, what is the nature of those challenges?

11. There has been a lot of discussion about housing options for people with DD.
 - *Probe:* What is your experience with the housing system for people with DD?
 - *Probe:* Have you encountered barriers in finding the right housing option for your family member with DD?
12. Can you speak to the extent to which you have faced affordability issues in securing housing for your family member with DD?
13. Would you like to see your family member live independently?
 - *Probe:* How would you describe the process if you have pursued an independent living arrangement?
14. Are you satisfied with your family member's living arrangement?
 - *Probe:* Do you believe your family member is satisfied with their living arrangement?
 - *Probe:* If you or your family member is not satisfied, what would you recommend for another living arrangement for your family member with DD? (Prompts: live in own home or apartment with roommates, live in own home or apartment alone, live in a supported living arrangement)
15. How would you improve the housing system for people with DD?
16. If we have not covered it here, what else would you like us to know about housing for people with DD?

Service Providers

1. Where do most of the people whom you serve live?
 - *Probe:* Are the people you serve generally satisfied with their living arrangements?
2. How does the housing system for people with DD work?
 - *Probe:* How should it work?
 - *Probe:* What would a resilient supportive housing system "look like"?
3. Is there a housing crisis for people with DD?
 - *Probe:* What is the nature of that crisis?

4. What do you believe keeps your clients (or most of the people you are serving) from living where they want to live? (Prompts: insufficient income, lack of affordable/accessible/supportive housing, too few providers)
5. What do you believe would assist people with DD in moving toward living where they want to live? (Prompts: life skills training, financial assistance, behavioral and/or mental services, more affordable housing units)
6. How would you improve the housing system for people with DD?
7. Whose ultimate responsibility is it to ensure that people with DD are living in housing of their choice?
8. How should policymakers, elected officials, the housing industry, and the DD service system balance the use of limited resources to create housing for those with the greatest need versus those desiring choice and increased integration into the community?
9. Should supportive and/or affordable housing be guaranteed under Nevada law for people with DD?
10. If we have not covered it here, what else would you like us to know about housing for people with DD?

DRAFT



About the Guinn Center

The Kenny Guinn Center for Policy Priorities is a nonprofit, nonpartisan policy center addressing key challenges faced by policymakers in Nevada. We are affiliated with the University of Nevada, Reno, with researchers and collaborative partnerships at NSHE institutions across the state.

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