

# State of Nevada Intellectual and Developmental Disabilities Community Town Hall Report 2024/2025



## **Nevada Governor's Council on Developmental Disabilities**

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# INTRODUCTION

## **Executive Summary**

The Nevada Governor’s Council on Developmental Disabilities (NGCDD) is a federally funded, self-governing organization within the State of Nevada. NGCDD’s Federal charge in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is identifying the most pressing needs of people with intellectual/developmental disabilities (I/DD) in Nevada and developing innovative and cost-effective ways to advance advocacy through policy, capacity building and systems change activities to promote equal opportunity, self-determination, and community inclusion. The community identified their most pressing needs and presented ideas on addressing the barriers. The information obtained in this report is a collection of information gathered at town halls held across the state and using the NGCDD’s Five-Year State Plan Survey and will be used to build the next Five-Year State Plan for the NGCDD.

## **Council Mission**

The NGCDD engages in advocacy, system’s change, and capacity building activities for people with developmental disabilities and their families to promote equal opportunity, self-determination, and community inclusion.

## **Council State Plan**

The next version of the NGCDD’s Five-Year State Plan will be based on the areas of emphasis identified in the DD Act and will address the needs in the State of Nevada from Oct. 1, 2026, to Sept. 30, 2031.

## **Looking Ahead**

The next Five-Year State Plan will work to address the known needs and gaps within the State of Nevada for individuals with I/DD. With the help of the citizens in the State of Nevada, the NGCDD can identify these gaps and needs and build plan to address them in unison with the community it impacts. NGCDD’s goal is to never speak for anyone, but to support everyone’s desire to communicate their needs in their own ways.

# 2024/2025 STATEWIDE TOWN HALLS

In 2024 and 2025, the NGCDD held a series of Town Halls across the State, both in person and virtually. A total of 191 people attended these meetings, including 35 individuals with I/DD, 89 family members of individuals with I/DD, and 67 professionals who work within the I/DD community.

## **Major Takeaways from the Town Halls include:**

- Major lack of services in the rural communities, creating barriers to almost every aspect of life.
- Lack of accessible transportation creates a barrier to accessing services in the community, obtaining employment, and attending school.
- While services may be available, there are concerns about location of services, knowledge of services available, and rights to access services.
- There is limited knowledge shared and/or known by protected parties about both Federal and State laws.
- The current status of the State budget for all disability-related programs brings a large amount of concern to the community.
- There are little to no recreational opportunities in the state that expand throughout a lifespan.
- There are little to no opportunities to provide a “meaningful day” to individuals with little or no vocational goals.
- The lack of a deaf school and deaf resource center has left those who are deaf and hard of hearing with little resources.

# MAJOR THEMES FROM TOWN HALLS

## May 6, 2024 – Fallon, NV

- Due to the location and the distance to the closest urban city many services are unavailable.
- Many providers that come to Fallon, quickly leave the area due to lack of available services and difficulty in receiving reimbursement from insurance providers and the State of Nevada.
- Employment services and options are scarce, leaving many residents with volunteering as their only option. Available employment options often include those requiring the ability to do physical labor on farms or in seasonal positions.
- Transportation services are also scarce leaving many resident reliant on each other or having significant delays in their ability to reach needed services. Public transportation services are only available from 7 a.m. to 5 p.m. with a cost of \$2/one way. Since many residents are low income, public transportation is not affordable.
- Vocational rehabilitation lacks the ability to retain job coaches and developers.
- Providers for specialty services such as therapy services, audiology services, and pediatricians are rarely available and quickly leave the area. Additionally, with one hospital and few providers, time to see providers or receive care is also extended.
- Many families are multi-generational homes or live on tribal lands, creating a variety of barriers to receiving services and trusting the community to provide.
- Due to a limited number of providers, residents needing specialty care are required to travel to Reno or Carson City. However, due to transportation difficulties, this also creates additional barriers to receiving care.
- There are very few social or recreational opportunities for individuals with I/DD, and most are community run and funded.

## Aug. 19, 2024 – Reno, NV

- Many providers and programs (both state and private) are unaware of what services and programs are available, and what each program does/does not do.

- Lack of understanding of limitations within Nevada law exist at both the provider and the recipient level.
- State programs lack accountability when they are unable to meet the program requirements.
- There are no services for deaf and hard of hearing (D/HH) residents. Students who are D/HH are not receiving sufficient services in schools. There is a significant lack of interpreters available for students and there are little to no D/HH individuals in positions of leadership.
- Waitlists to receive services are also heavily present. Several attendees noted regional centers refusing to provide required and necessary services. Multiple families expressed having been told that regional centers are out of funding, even at the start of the new budget cycle.

## **Aug. 22, 2024 – Carson City, NV**

- Services are available but are not widely known about or are not available state-wide.
- There is lack of options available for adults without vocational goals, or those in the gap between the end of their employment and their ability to obtain Medicare or SSI.
- There are few services available, and many residents are required to travel to Reno to receive services.
- Transportation services are limited, yet expanding, and public transportation services are limited to 6:30 a.m. to 7:30 p.m., Monday-Friday, and 8:30 a.m. to 4:30 p.m. on Saturdays. However, coordinated transportation from Carson City to the surrounding areas is scarce and limits options for receiving services in nearby towns. Additionally, very few ride share providers work in this location and are not a viable solution.
- Providers report a delay in receiving payment for services creating a gap in their ability to provide services, noting their inability to pay staff and keep lights on during several months of the year.

## **Sept. 16, 2024 – Pahrump, NV**

- Due to the rural nature of this community, many of the needs are met through the community members, community service organizations, or the Nye Communities Coalition, a local community service agency.
- Schools lack accountability to the services provided to students with disabilities. Additionally, due to the limited availability of services, there is no consistency provided to the students to build proper success. There are no services that specifically support the needs of students who are D/HH, blind or visually impaired, or with severe/profound autism, resulting in outsourcing of services to fill these needs. This often occurs through tele-health services contracted through Clark County School District. Many students are on a consult basis for these services, rather than receiving hands-on direct service. The school district lacks knowledge on providing transition services in coordination with vocational rehabilitation.
- The community lacks an understanding of how to serve the disability community.
- The local hospital does not have specialty care, and many cases requiring additional support are transferred to Las Vegas.
- There is limited transportation throughout the town but also coordinated transportation to other areas of the State, including those needing to obtain basic care and support needs in Las Vegas.

## **Sept. 17, 2024 – Mesquite, NV**

- Although it is located in Clark County, Mesquite is more than an hour outside of Las Vegas. Due to the unique nature of this county, residents qualify for Clark County services but lack the ability to access them due to their location. Providers are limited on the amount of time they can travel from Las Vegas to Mesquite to provide the services. Additionally, there are virtually zero D/HH services in Mesquite.
- There are very few accessible or affordable housing options available.

- Due to the rural nature of the town, many families' only options are to travel to Las Vegas to receive services. Unfortunately, many families do not have access to reliable transportation to do so. There are staff that can travel to assess but the waitlist is long.
- There are only two elementary schools, one middle school, and one high school. The schools here are the core of much of the town's activities.
- There are very few providers including primary care, therapy providers, and specialists. Those who have come into the town to provide services have expressed difficulties with the State's reimbursement process and noted this as a primary reason for stopping services in this area. The amount of funding reimbursed was less than the cost of transportation to/from and the cost to provide the services.
- There is little to no mental healthcare available. There is a suicide crisis occurring as well, with a lack of available mobile outreach crisis services.
- Many residents are forced to travel to Utah to receive a majority of their needed services.

## **Sept. 18, 2024 – Las Vegas, NV**

- Clark County School District (CCSD) was the main topic of concern during this town hall. The lack of accountability for lack of services provided was an overwhelming number of instances discussed.
  - Transition is not discussed or added to most IEPs within the district, which means transition out of high school is delayed or with significant barriers.
  - Bullying is a major problem in the CCSD, and most parents expressed having encountered at least one instance of bullying for their child with an I/DD.
  - There are few services available for students who are D/HH.
- Rental requirements are making availability of homes scarce including the amount needed to secure the home (first/last month's rent, security deposits, application fees) and rental requirements (credit score, employment history, rental history, and lease length requirements).



## **Sept. 23, 2024 – Elko, NV**

- Due to the rural location of this city, there is limited transportation services available. The residents expressed they would benefit from iCanBike being hosted in their town in order to assist in training individuals with I/DD how to ride a bike for transportation. Most of this area is accessible by bike and thus would assist in lack of transportation options.
- Elko is growing and services are not equipped to handle the expansion.
- There is a lack of audible signaling devices and truncated domes at intersections for individuals with visual impairments.
- There is a lack of education and job training opportunities using assistive technology.
- There is a lack of education on guardianship and supported decision-making. Several members of the community expressed experiences where supported decision-making agreements were challenged.
- Many residents are needing assistance with social security including applying for services and understanding the requirements. The need to provide information and training to this community on benefits was discussed at length.
- Services dogs are needed by several residents but due to their location, they're having difficulties obtaining them.
- Multiple families expressed having been told that Rural Regional Centers are out of funding, even at the start of the new budget cycle.
- Community members also expressed the need to training providers on various aspects of providing services to individuals with I/DD including medication management.

## **Oct. 3, 2024 – Virtual Town Hall**

- Many families would like advocacy surrounding paid family caregivers.
- Families also expressed concerns about struggles they've had with supported decision making and agreements being honored in the State of Nevada. Several providers have providing difficulties to individuals trying to use their agreement and the authenticity of the agreement being questioned.

- Families would like universal changing tables available in public spaces statewide. The difficulties expressed from lack of dignity to safety and hygiene, as well as privacy concerns were all noted.
- There are few afterschool care programs for children with disabilities statewide. Additionally, childcare for individuals with I/DD is scarce.
- Due to the lack of coordinated transportation options that connect most of the state, many families leave the State of Nevada to neighbor states (California, Utah, Arizona) to receive necessary services.
- Mental healthcare is lacking statewide, and the availability of services is scarce particularly for those that serve the I/DD community.
- Cameras in the classroom were discussed heavily as parents are expressing more instances of suspect mistreatment, as well as a lack of services or support being provided.
- There are long wait times for Applied Behavioral Analysis (ABA) therapy services and very few providers able and willing to provide the services.
- Education services for all students with I/DD across the state were expressed as a measure of concern. There was particular mention of the lack of services for students who are D/HH, those who are blind or have other visual impairments, and those with profound levels of need.
- The State of Nevada does not have sufficient services and support for individuals who are D/HH. There are no deaf schools and no deaf resource centers. There is a significant gap in interpreter services from the number of qualified and available interpreters to funding and support for providing interpreter services in the community. Additionally, there is a lack of understanding by providers, community members, legislators, service organizations, and the State as a whole of the needs of the D/HH community.

## **Dec.18, 2024 – Virtual Town Hall**

- Significant concern was raised about the status of funding for regional center services statewide. The funding requested for this fiscal year was based on a rate study from 2021 that significantly underestimated the number of individuals that need services.

This funding concern has created a hold on most regional center services for new clients and many currently used services for existing clients. These services include the funding provided for room and board, one-time costs, respite, purchase of services, self-directed family support services, the family preservation program, supported living arrangements, jobs and day training services, and other services traditionally covered by the regional center funding. All new applicants are being added to waitlists to better understand the number of individuals needing support.

- ADSD stated that new services are being added if there is an emergent need which will result in homelessness, institutionalization, loss of housing placement, etc. if services are not received. However, many individuals are expressing this is not the case and they are being turned away for all services regardless of the imminent danger of emergent need.
- Many families would like advocacy surrounding paid family caregivers.

## **Jan. 16, 2025 – Virtual Town Hall**

- Several families expressed concerns over the rural areas of the state (particularly Elko County) having a vast difference in the services being provided between schools. Some schools are supportive of their students with I/DDs and others hinder their progress.
- There is a major lack of inclusive opportunities in the community particularly as it addresses recreational and social needs. Some families are advocating for a one-stop-shop that would allow for all needs to be met on an as needed basis.
- Other families expressed meeting the needs of finding resources through an online platform, but this is only available in Washoe County at this time.
- There were increased concerns about the individuals receiving regional center services that are at risk of needing to move in the coming months. Several families expressed receiving mixed messages about the true cause of this deficit.
- Attendees expressed concerns over the Governor's comments about the use of rainy-day funds for state deficits.

- Attendees expressed the need for a flexible and viable solutions to meet the needs of the community, suggesting the incorporation of existing organizations and the creation of meaningful days program to impact the need greatly.
- Several community members expressed concerns about treatment for the I/DD community by law enforcement officers and first responders. While there was an NRS passed to support the requirement for this training, attendees expressed that they have seen little to no positive improvement after the implementation. Additionally, they expressed the required training is outdated, contains inappropriate language, and does not provide sufficient information about how to interact with an individual with an I/DD.
- Many families expressed concern about being able to connect with the Regional Center case workers. They expressed that many instances of communication go unanswered and that there is little to no movement on the cases they assist with. The participants discussed the need for better communication and understanding between service providers and the community.

# STATEWIDE TOP AREAS OF EMPHASIS

The areas of emphasis are outlined in the DD Act as early childhood intervention, education, employment, health, housing, quality assurance (monitoring, improving, or providing education on services to prevent abuse, neglect, discrimination or interfere with basic human rights), recreation/social, and transportation. The Council released a survey in May 2024 at the start of the Statewide Town Halls and closed the survey at the completion of the Town Halls. Total survey respondents include: 66 individuals with I/DD, 217 family members, 174 professionals, and 10 “other”. The survey was available in English, Spanish, and American Sign Language. The most pressing needs identified from the survey are as follows:

- Employment
- Health
- Education
- Recreation/Social
- Housing
- Quality Assurance – Monitoring, improving or providing education on services to prevent abuse, neglect, discrimination or interfere with basic human rights.

**Additionally, the survey provides an option for “other” that is not listed in the current areas of emphasis. The responses under “other” are listed as a summary below:**

- Coordination of Services
- Services for Individuals with Profound Disabilities
- Availability of State Funded Services
- Food Services
- Mental and Behavioral Health Support
- Services for Adults with I/DD with specific focus on the aging population
- Services for Adults 60+ who do not qualify for Medicare or Social Security
- Emergency Preparedness and Safety
- Adult Programs
- Independent Living Support and Services

# STATEWIDE TOP BARRIERS

**Survey respondents were asked to identify the top barriers to addressing the major areas of emphasis. The following are listed in descending order.**

- Long wait list for services.
- Not enough school services or supports.
- Not enough or cannot access social or recreational activities.
- Not enough or cannot access coordinated health, dental, mental health, and other human and social services
- Not enough or cannot access community housing or supports.
- Not enough transition services from school into to adulthood.
- Not enough services or supports for getting and keeping a paying job.
- Not enough accessible and/or affordable transportation options.
- Not enough early intervention services/supports.
- Not enough services or supports for adults who choose not to work.
- Other (see below)
- Accessibility and/or technology issues

**Additionally, the survey provides an option for “other” that is not listed in the current barriers. The responses under “other” are listed as a summary below:**

- Not enough trained special education teachers.
- Lack of a paid family caregiver law creates a barrier to low-income families.
- School classrooms are too crowded to provide efficient services.
- Few programs to support profound Autism and similar I/DDs.
- Lack of D/HH services including schools and a resource center.
- Elimination of Sub-Minimum wage has left some individuals with limited options.
- Gap in providers referring children for early intervention services, and lack of providers to provide early intervention services.
- Lack of options or services for adults with I/DD.
- Lack of support for children and adults with I/DD to remain home. Many families struggle to afford care in the home and are provided as institutional living as an acceptable alternative.
- Large caseloads on available workers increases wait times.
- Lack of available and skilled providers in rural and frontier Nevada.
- Lack of services for individuals who are blind or visually impaired.
- Both Washoe County School District and Clark County School District were specifically mentioned as causes for lack of success of students with I/DD.
- Lack of Emergency Preparedness training and end of life support.

# STATEWIDE RECOMMENDATIONS

## **Recommendation #1**

Increase education to individuals with disabilities, family members, and professionals including all staff, providers, and agencies that serve the I/DD community on rights, services, and options available to individuals with I/DD.

## **Recommendation #2**

Increase access to all services in the rural portions of the State of Nevada including availability of coordinated transportation of services, additional reimbursement to providers for specialty services including mobile therapy services, and funding to support new providers and programs in rural communities.

## **Recommendation #3**

Increase meaningful day services and available options for adults with I/DD including those with no vocational goals or who have aged out of employment opportunities.

## **Recommendation #4**

Increase access to all D/HH services including the addition of deaf resource centers and deaf schools in Northern, Southern, and the rural areas of the State. Additionally, advocate for the expansion of interpreter services and expansion of American Sign Language programs for foreign language credit in schools.

## **Recommendation #5**

Eliminate wait lists for services statewide by increasing funding, support, and availability of needed services for individuals with I/DD across the lifespan.

## **Recommendation #6**

Implement changes to statutes and policies pertaining to transition from youth to adulthood for individuals with I/DD, including changes related to accountability and failure to address transition needs starting at the age of 14.

## **Recommendation #7**

Increase funding to services including wages for providers and reimbursement of needed services to family caregivers.

### **Recommendation #8**

Increase access to mental health services for individuals with I/DD statewide, particularly in rural areas. Expand mobile crisis services and mental health outreach programs to address the suicide crisis and provide support for individuals with severe and profound disabilities.

### **Recommendation #9**

Enhance law enforcement and first responder training on how to interact with individuals with I/DD. Update the required training curriculum to ensure it is relevant, person-centered, and inclusive of best practices.

### **Recommendation #10**

Expand housing options and rental assistance programs for individuals with disabilities. Address barriers such as rental deposit requirements, credit score restrictions, and the overall lack of accessible housing options statewide.

### **Recommendation #11**

Improve regional center accountability by implementing oversight measures to ensure services are provided in a timely manner, funding is appropriately allocated, and communication between caseworkers and families is improved.

### **Recommendation #12**

Increase education and support for guardianship alternatives, including supported decision-making agreements, and ensure these agreements are honored by providers, agencies, and state programs.

### **Recommendation #13**

Advocate for the creation of universal changing tables in public spaces statewide to promote dignity, accessibility, and hygiene for individuals with disabilities and their families.

### **Recommendation #14**

Expand inclusive recreational and social opportunities for individuals with I/DD across all regions, including one-stop-shop resource centers and community-based programs that provide both social engagement and service coordination.