

Nevada Governor’s Council on Developmental Disabilities

Federal Fiscal Year (FFY) 2024 Annual Report

The Nevada Governor’s Council on Developmental Disabilities (NGCDD) is a federally funded, self-governing organization authorized in the Federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and established under Nevada Revised Statutes (NRS) 232.320, housed within the Nevada Department of Health and Human Services (NV-DHHS). The NGCDD serves as an independent educator to the Governor and Legislature on public policy issues. Our Federal charge in DD Act is identifying the most pressing needs of people with intellectual and 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.

In the FFY 2024, the Council spent approximately \$900,000 in grants, contracts, and state funds, and currently has 5 staff and 1 intern.

Staff Names and Titles:

- Executive Director: Catherine Nielsen, MPA
- Executive Assistant: Rebecca Ortiz
- Projects Manager: Marisol Rivas
- Self-Advocacy Coordinator: Ellen Marquez
- Public Health Liaison: Kimberly Palma-Ortega
- Intern: Alysa Marquez

This annual report for the FFY 2024 year outlines the goals and objectives set forth and achieved by the Council Staff and Council Members toward our 2021-2026 5-Year State Plan between the dates of October 1, 2023, and September 30, 2024. All goals and objectives were met or exceeded, and progress has been made overall on the 5-year state plan outcomes and outputs.

We have increased the number of federal and state funded projects and increased activities and visibility in all areas of the State. We continue to work collaboratively with our DD Act Partners (the Nevada Center for Excellence in Disabilities and the Nevada Disability Advocacy and Law Center), as well as the state agencies and organizations that serve individuals with developmental disabilities across the state.

Council Members:

Individuals with I/DD:

- *Maxmillian Lowe, Vice Chair*
- *Stacy Alaribe*
- *Gabriel Tejada*
- *Brynlin Thornley*
- *Vacancy (awaiting Governor appointment)*
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Parents, Family Members, or Guardians of Individuals with I/DD who are unable to advocate for themselves:

- *Christine Riggi, Chair*
- *Kathleen Kingston (also representative of individual who previously or currently resides in an institution)*
- *Stacy Carlston*
- *Arthur Reitz*
- *Melissa Bart-Plange*
- *Anna Marie Binder*

Representative of Special Education: Individuals with Disabilities Education Act (IDEA):

- *Ashley Price, Office of Inclusive Education, Department of Education*

Representative of Vocational Rehabilitation Act of 1973

- *Vivian Turner, Office of Vocational Rehabilitation, Department of Employment, Training, and Rehabilitation*

Representative of Aging: Older Americans Act of 1965 (OAA)

- *Vacant, Aging and Disability Services Division, Department of Health and Human Services*

Representative of Maternal and Child Health Program: Title V of Social Security Act (SSA)

- *Vickie Ives, Child, Family and Community Wellness, Department of Health and Human Services*

Representative of Medicaid: Title XIX of Social Security Act (SSA)

- *Ellen Frias-Wilcox, Division of Health Care Financing and Policy, Department of Health and Human Services*

Representative of Protection and Advocacy Agency (P&A)

- *Kate Osti, Nevada Disability Advocacy and Law Center*

Representative of University Center for Excellence on Developmental Disabilities (UCEDD)

- *Randall Owen, Nevada Center for Excellence in Disabilities, University of Nevada, Reno*

Representative of a Local or non-governmental agency concerned with services for people with developmental disabilities.

- *Lisa Bonie, Northern Nevada Center for Independent Living*

Representative of Private, non-profit group concerned with services for people with developmental disabilities.

- *Taylor Chaney, The Garden Foundation, Las Vegas, Nevada*

NGCDD Performance on Goals for FFY 2024

Input gathered from individuals with I/DD, families, professionals, and state services led to the selection of the goals and objectives of our 5-Year State Plan.

The top Federal Areas of Emphasis based on identified needs and funding capacity include:

- Employment
- Health
- Quality Assurance = monitoring, improving, or providing education on services to prevent abuse, neglect, discrimination or interfere with basic human rights
- Transportation
- Housing
- Education (school age through college and transition services in high school)

The top barriers to accessing the areas of emphasis include:

- Long wait lists/not enough services.
- Not knowing what services are available.
- Not enough or cannot access coordinated health, dental, mental health, and other human and social services.
- Not enough services or support for residential/assisted living or other housing options.
- Not enough accessible and/or affordable transportation options.
- Not enough transition services into adulthood.
- Not enough services or supports for getting and keeping a paying job.
- Hispanic and Rural communities are most lacking in all Areas of Emphasis.

The key activities for this plan include:

- Serving as an independent educator to the Governor and Legislature on public policy issues that impact people with I/DD.
- Gathering input on the services available and barriers faced by people with I/DD to create a 5-Year State Plan that addresses the most important issues identified based on funding, capacity, and Federal “Areas of Emphasis” outlined in the DD Act.
- Advocacy, capacity building, and systems change activities to improve self-determination, independence, productivity, integration, and inclusion in all areas of community life for people with I/DD.
- Funding innovative projects that test best practices or look at new approaches to inform policies and practices that lead to greater independence and self-sufficiency for people with I/DD.
- Supporting people with I/DD and their families to be full and equal participants in decisions that affect their lives.

In response to the results of the needs assessment and the requirements of the DD Act, a detailed plan of action for the NGCDD was developed as part of the 5-year proposal. The goals were designed to improve the lives of Nevadans with developmental disabilities and their families. Additional periodic information can be found in the quarterly project performance report at each quarterly Council Meeting. The complete plan and progress on each of the goals and objectives are included annual periodic performance report for FFY 2023.

Goal 1: The NGCDD will work towards ensuring that individuals with I/DD and/or family members of individuals with I/DD will be able to make more informed decisions about their lives by improving access to information on services, supports, and rights.

- For the 2022-2023 (FFY 23) year, a total of 211 individuals with I/DD, 236 family members of those with I/DD, and 218 professionals in the disability community were served. This goal was substantially exceeded.
- The Council expanded their Zoom video-conferencing package to include the ability to host language translation. During the NGCDD Lunch and Learn series and the Partners in Policymaking class, attendees needed language translation into Spanish. By use of this feature and interpreters, seamless language translation was provided during the requested *Lunch and Learns*, and all NGCDD PIP classes. This allowed the Council to reduce the barriers to accessing technology for students with language translation needs.
- The Council continued circulating the anti-bullying publication featuring stories and advice from Self-Advocates, Family Members, Teachers, and Professionals around the State on how to combat the issue of bullying in the State of Nevada. Copies of this publication have been sent statewide electronically and is now available in English and Spanish. The Council often works to raise awareness about developmental disabilities within the community. This anti-bullying campaign continues to help reduce stigmas and discrimination, fostering a more inclusive society. As public attitudes shift, we've ultimately seen a reduction in bullying overall.
- The Council added an accessibility feature known as the Recite Me Toolbar to our website. This toolbar allows for individuals with accessibility needs to utilize different features to increase their access to information on our website. The features include selection of font size, font types, color themes, language translation written and spoken verbally into 60+ language, and more. The data of site users is provided below.
 - 279 various pages were viewed on the Council website while utilizing the accessibility ReciteMe Toolbar. With over 101 unique users, individuals utilizing accessibility tools increased from years past.

- Top accessibility features used include: Screen reader, translation into languages other than English, utilizing a change in style or font, and using reader aids such as a ruler, magnifier, or dictionary.
- By utilizing the features with the ReciteMe toolbar, an increase in access to information was noted by the increase in site users over the past 2 years the toolbar has been active. While the use of the toolbar alone does not make a website accessible, it does allow for site users to access the information in additional formats making their experience on our website easier and simpler.
- **Council Staff and Members participate on various Councils, Committees, Coalitions and Boards. These include but are not limited to:**
 - Commission for Persons who are Deaf and/or Hard of Hearing
 - The Nevada Resilience Advisory Committee
 - The Special Education Advisory Committee (SEAC)
 - Commission for Services for Persons with Disabilities (CSPD)
 - The Diversity, Equity, and Inclusion Advisory Group for the Department of Health and Human Services – State of Nevada
 - Carson Agency Action Network
 - Aktion Club of the Carson Valley
 - Assistive Technology (AT) Council
 - Nevada Center for Excellence in Disabilities – Consumer Advisory Committee
 - The Nevada Disability Advocacy and Law Center (NDALC) – Protection and Advocacy for Individuals with Mental Illness (PAIMI) Council and the NDALC Board.
 - Interagency Coordinating Council and the Family Resources Sub-Committee
 - National Association for Councils on Developmental Disabilities Council (NACDD)
 - The President’s Committee for Person’s with Intellectual Disabilities
 - Nevada Human Rights Committee
 - Blind Children’s Foundation Board
 - Rare Disease Council
- The Council continued to disseminate community health binders aimed at providing resources to increase public education, awareness, access to services and supports, and information on their rights. By improving access and reducing barriers to receiving and organizing this information, this project increased the ability of individuals with I/DD, their families, and other community members to make informed decisions about their lives.

- The Council held a series of Lunch and Learn webinars throughout the year on various topics. All attendees reported an increase in their knowledge on the various topics. The topics include:
 - Diploma Options in Nevada
 - Phase Out of 14c in Nevada and Coordinating Services
 - Internet Safety
 - Resources and Services provided by the Bureau of Vocational Rehabilitation
 - Resources for Special Education Teachers
 - Federal Disability Laws and Advocacy
 - Aging and Disability Services for People with Disabilities in Nevada
 - Coordination of Benefits
 - Emergency Preparedness
 - Transition Options and Resources
 - Employment and Internship Options through Vocational Rehab
 - Legislature and NELIS
 - IEP Options, Resources, and Using Chat GBT to Support your IEPs
 - Meaningful Community Participation
 - Pre-ETS and Employment Services



(Photo is of DD Council Staff at a local resource fair.)

- Council Staff and Members hosted and attended various events in the community including:
 - Mark Wellman Adventure Day
 - Autism Awareness Fair
 - Carson City Health Fair
 - Disability Awareness Day
 - Down Syndrome Network of Northern Nevada Buddy Walk
 - Down Syndrome Organization of Southern Nevada Buddy Walk
 - Mesquite Annual Health Fair
 - Be a Hero Fun Run and Family Resources Fair



(Photo is of DD Council Staff with Senator Catherine Cortez Masto)

- Council Staff and Members attended various conferences and trainings across the country aimed at advancing education, awareness, networking, and resources, which will allow individuals with I/DD to be able to make more informed decisions about their lives by improving access to and quality of already available information on services, supports and rights. These conferences included:
 - Disability Policy Seminar – Washington, D.C. – 4 Staff and 1 Community Member attended this event.
 - Association of People Supporting Employment First – Charlotte, North Carolina – 3 Staff Members attended this event.
 - National Association for Councils on Developmental Disabilities – Washington, DC – 5 Staff Members, 1 intern, and 2 Council Members attended this event.

- The Council provided educational materials to the public who were able to make more informed decisions about their lives by improving access to information on services, supports, and rights. These educational materials included information on:
 - Alternative Diploma Guidance for the State of Nevada
 - Transition through a lifespan
 - Reducing Bullying in the Community Guidance
 - Preparing for an Emergency
 - Medical Information Cards
 - Middle School and High School Transition
 - 504 and the IEP Process
 - Mental Health Resources for Youth in Nevada





An emergency preparedness guide for individuals with disabilities to help keep you informed, healthy, safe and connected.

- The Council provided full interpretation/accommodations into requested formats (ASL, Spanish, and large print) reducing barriers to access technology and digital information for all Council sponsored events and meetings. The Council also provides Braille information on all staff’s business cards. In addition, the Council has purchased a Braille printer, received full training, and has opened up this printer for use by all State agencies. This will allow the Council to expand access for individuals with visual impairments and use Braille as their primary language. In the 2023 Legislative Session, State Agencies were mandated to create a language access plan. By expanding use to the Braille printer, agencies will be able to ensure that access to information in Braille is available and ready for users of the Braille language.
- The Council Hired a Public Health Liaison, overseeing emerging need across the state birth to death. Working alongside the Access and Functional Needs, Diversity, Equity, and Inclusion specialist for the Division of Emergency Management, the PHL provided training and education to the Emergency Management personnel and local Emergency Managers across Nevada. Training included but was not limited to:
 - G-197, the Integration of Access and Functional Needs into Emergency Management
 - The Nevada Emergency Managers Access and Functional Needs Integration Guide
- Due to the unique collaboration of both the Council and the Division of Emergency Management, the Public Health Liaison has been identified to be activated during various public health emergencies and events across the State of Nevada. The PHL also co-created the Nevada AFN Disaster Coalition

Workgroup that receives weekly briefings with updates that may be relevant locally, statewide, and nationally. This collaboration has been instrumental for sharing of resources and to navigate preparedness efforts before, during, and after a disaster.

Goal 2: The NGCDD Staff and Members ensured individuals with I/DD will have the information, education, and training necessary to participate in local and state advocacy and policy making activities.

- For the 2023-2024 (FFY 24) year, over 246 individuals with I/DD, 89 family members of those with I/DD, and 44 professionals in the disability community were served. This goal was substantially exceeded.



- For FFY 24, the NGCDD provided 3 individuals with I/DD and 9 family members of those with I/DD, the Partners in Policymaking curriculum. In total, each student is expected to complete 128 hours of curriculum. In total 1 individual with I/DD and 5 family members of those with I/DD successfully completed the entire course curriculum and graduated the course. Graduation took place for the NGCDD PIP Class of 2024 at the Silver State Self-Advocacy Conference in Reno, NV on August 6, 2024. In total 23 agencies presented to the class on the various areas of required content.

Important topics covered include:

- History and Future of Disabilities: People First Language
- Quality and Inclusive Education
- Person Centered Planning, Self Determination, and Informed Choice
- Supported Decision Making
- Housing
- Government: Local, State and Federal Policy, Legislation and Process
- Parliamentary Procedure and Serving on Boards
- Community Organizing and Advocacy

○ Family Support and Supported Living

○ Accessibility and Assistive Technology

- Educational materials on transition out of middle/high school were provided to students with I/DD and family members at various public education events. This included information about transition across a lifespan and information on mental health crisis for youth in Nevada. The Council continued to advertise for the series of videos for the Youth Empowering Students (Y.E.S.) Program designed to provide students in middle and high school with information on transition options available to them. Topics information is provided on includes:
 - Rights and Services Available
 - Post-Secondary Education
 - Diploma Options
 - Employment Options
 - Supported Decision Making and Guardianship



- The Council hosted the Silver State Self-Advocacy Conference 2024 in Reno, Nevada at the Grand Sierra Resort, on August 6th and 7th. An estimated total of 57 individuals with I/DD, 32 family members of those with I/DD, 44 professionals in the disability community, and 7 “other” participated in this event. The Council provided funding that covered 55 hotel rooms and 32 roundtrip flights for self-advocates and family members in the I/DD community. During the conference, the Council hosted speakers from across the country on various topics surrounding the disability community. A total of 28 breakout sessions and 5 general sessions took place. Those topics included (but were not limited to):
 - Leadership
 - Sexual Education
 - Community Services/Supports
 - Policymaking
 - Community Safety
 - Early Intervention, IEPs, School Supports
 - Advocacy
 - Independent Living
 - Crime Victims/Resources
 - Mental Health
 - Voting Rights

- The Consumer Leadership Development Fund (CLDF) was established to make funds available to help offset the costs for self-advocates and/or parents/family/guardians of children/adult children with developmental disabilities to participate in conferences, workshops, and other training opportunities, that will increase their knowledge of disability issues and increase their skills as advocates. Funds were provided to support a total of 11 individuals with I/DD and 7 family members of individuals with I/DD to attend events across the country. These events included:

- The Down Syndrome Congress
- The Arc National Conference
- Disability Policy Seminar
- National Association of Councils on Developmental Disabilities Annual Conference
- Aktion Club Annual Conference
- Chromosome 18 Registry and Research Conference
- Hands and Voices 20th Annual Conference
- Angelman Syndrome Family Conference



(Photo of DD Council Staff and CLDF Recipient Steven Cohen at the Capitol in Washington, D.C.)

- The Developmental Disabilities and Bill of Rights Act requires Developmental Disabilities Councils to provide support to Self-Advocacy Organizations statewide. Support was provided to several Self-Advocacy Organizations in the form of funding for registration and non-profit status, resources, information to sustain independence, and funding to provide support to attend events and conferences that will increase their knowledge of disability issues and increase their skills as advocates. Funds were provided to support a total of 175 individuals with I/DD and 45 family members of individuals with I/DD. The following events and agencies were provided with support:

- The Down Syndrome Organization of Southern Nevada
- The Aktion Club of the Carson Valley
- The Aktion Club of Reno/Sparks
- People First of Winnemucca
- People First of Las Vegas

○ People First of Reno/Sparks

○ The Arc of Nevada

Goal 3: The NGCDD Staff and Members worked towards developing and strengthening systems that improve quality services and access to quality services and supports for individuals with I/DD and their families.

- For the 2023-2024 (FFY 24) year, a total of 192 individuals with I/DD, 45 family members of those with I/DD, and 49 professionals in the disability community were served. This goal was substantially exceeded.

For 2023-2024, the NGCDD provided funds to the community for three objectives.

- For the Council's transportation objective, the Council hosted in partnership with the Nevada Center for Excellence in Disabilities (NCED), the State UCED, two iCanBike camps. These two camps were held in Las Vegas, NV, and Reno, NV. The total number of participants at both camps were 45 individuals with disabilities and 82 volunteers. The total amount of funding used for these camps was approximately \$30,000. The outcomes of these camps include a significant number of individuals with I/DD are now able to ride their bicycles independently, expanding transportation options for this individual across their lifespan.
- For the Council's employment objective, Best Buddies was granted \$50,000 to train individuals with I/DD, as well as employers, on the importance of creating and following best practices, benefits of hiring individuals with I/DD, and educating individuals and their families on inclusive practices currently proving to be successful in the I/DD community. Best Buddies has successfully trained 52 individuals with I/DD and a total of 12 employers, in a total of 10 training sessions. People with I/DD and employers in Nevada have reported an increase in employment options available to them and in information/access to integrated and competitive wage jobs. Additionally, individuals with I/DD have reported feeling empowered to seek meaningful employment opportunities.
- For the Council's transition objective, GiGi's Playhouse Las Vegas was granted \$40,000. This objective was to increase access to quality services and support to individuals with I/DD transitioning into or currently in adulthood. GiGi's provided several training opportunities throughout the year, including rights, advocacy, employment, post-secondary options, work-based learning opportunities, health and fitness, money management, customer service skills, team building, mental and physical health/wellness, social skills, communication, and confidence building. A total of 51 individuals with I/DD reported having an increase in advocacy for themselves and/or others, and that the information helped better how to express their needs and wants. In total, over 680 hours of direct services were provided. All participants were also provided with and viewed the YES video, noted under Goal 2.

For the remaining objectives, projects were completed in-house. This included:

- For additional work on the Council’s transition objective, information was continuously provided on transition over a lifespan. An estimated total of 75 Life Stages Tool Guides in English and 35 in Spanish were distributed over the year to various organizations and at all community events supported by the Council. Organizations included: Douglas County School District, the Aktion Club of the Carson Valley, AZULBLUE, the Down Syndrome Organization of Southern Nevada, GiGi’s Playhouse of Las Vegas, Nevada Disability Advocacy and Law Center, the Nevada Center for Excellence in Disabilities, Down Syndrome Network of Northern Nevada, the JUSTin Hope Foundation, and more. 100% of surveys returned stated their advocacy skills and/or knowledge increased, and they would recommend the Tool Guide to someone else.
- Information printed by the Nevada Department of Education on guidance for Alternative Diplomas in Nevada, was provided at all Council events hosted and attended. Approximately 50 copies of the Alternative Diploma Guidance was provided to family members and teachers within the I/DD community.
- Council Staff participated in Statewide Town Halls in order to gain further information on data on the current needs across the State of Nevada. These Town Halls will continue through the FFY 25, and information gathered will be produced in a Town Hall Report. This report will be utilized to put together the next 5-Year State Plan to begin October 1, 2026.
 - The Council also put out a Community Survey to gather input from the community on the input of Council activities. The information below is a recap of the information in that survey:
 - **Survey respondents:** 50% were individuals with disabilities, 33.33% were family members of individuals with disabilities, 16.67% were professionals, 16.67% were both a family member and an individual with disabilities, and 25% were professionals and a person with a disability and/or a family member of an individual with disabilities.
 - When asked if they felt the work the Council has done has helped individuals with developmental disabilities and/or family members be better advocates for themselves or others, 83.33% responded with yes.

- When asked if they believe the work the Council has done has helped individuals with developmental disabilities and/or their family members be more informed about decisions that affect their lives, 83.33% responded yes.
- When asked if they believe the work the Council has done has helped individuals with developmental disabilities and/or family members have more control in the decisions that affect their lives, 75% responded yes.
- When asked if they believe the work the Council has done has led to increased awareness and education about individuals with developmental disabilities, 83.33% responded yes.
- When asked if they believe the work the Council has done has benefitted the lives of individuals with developmental disabilities and/or family members, and if they believe that the work the Council has done has had a positive impact on the disability community in Nevada, 83.33% responded yes.