Nevada Governor’s Council on Developmental Disabilities (NGCDD)

5 Year State Plan Findings to Support the

2021-2026 Draft Five Year State Plan

Each State Developmental Disabilities Council is required to submit a Five-Year State Plan to the Administration on Developmental Disabilities based on a review of current needs, services and supports available in their state, taking into consideration current funding and Council capacity. The plan must outline the intended use of federal funding through the creation of Goals, Objectives and Activities. Federal law mandates that the plan address some or all the Areas of Emphasis established by Congress. The Areas of Emphasis are: Child Care, Health, Community Supports, Housing, Education and Early Intervention, Quality Assurance, Recreation, Employment and Transportation. Federal law allows Council’s to choose which Areas of Emphasis to focus on based on capacity and identified needs while also mandating certain objectives the Council must address in their plan, which are noted in the Draft Plan as DD Act Mandate. Federal law also mandates Councils submit their Draft Plan for public review and comment. Draft Plans are reviewed and approved by the full Council before they are submitted for public comment.

# **Input Overview**

Input methods were provided in multiple formats to ensure access to and for a wide array of stakeholders. COVID-19 restrictions and public safety guidelines provide challenges to gathering input, especially from advocates as we could not do in person visits, focus groups or listening sessions. In response, we replaced in person sessions with surveys, multi-method listening sessions and direct contact by phone however, as expected, input was still down.

Input methods included accessible surveys in English and Spanish using mandated DD Act Areas of Emphasis with the ability to provide open ended comments; phone calls in English and Spanish from Council staff; printable surveys in English, Spanish and plain language using icons to support visual learners; input gathered from advocates and family members during group discussions and surveys from our 2019 Self-Advocacy Conference; 2019 Statewide Transportation Summit; statewide listening sessions conducted via Zoom with the opportunity to call in using our toll-free conference call line for those with limited digital access. Closed captioning was and participants were able to write comments in the Chat section as well as provide them verbally. Council staff also identified and participated in other Statewide community forums and assisted anyone needing help completing the survey.

Information regarding our surveys and listening sessions were distributed Statewide to our extensive email list-serve, current and past Partners in Policymaking participants and through social media accounts, our Website, Council members, Service providers, advocacy groups, State Agencies, non-profit agencies and Network Partners. Contact information was provided for staff to support participants with accommodation requests.

To engage and gather input from targeted disparity, underrepresented and culturally diverse groups and regions, we conducted outreach to the Nevada Office of Minority Health and Equity and through our connections with cultural leaders and community representatives. Our Self Advocacy Coordinator is bi-lingual which has allowed increased outreach and input from Nevada’s largest cultural minority group representing the Latinx population.

# **Demographics**

## Input:

Total number of participants: 257

Survey responses: 214

Listening session participants: 41

Other (included but not limited to: in person calls, other Statewide DD Network community forums (State Nevada Resilience Advisory Committee, State Commission on the Deaf and Hard of Hearing, Statewide Independent Living Council, Special Education Advisory Committee, Interagency Coordinating Council for Early Intervention, Aktion Club), 2019 NGCDD Transportation Summit and Statewide Self Advocacy Conference, barriers identified by State Agency DD Council representatives.

Open-ended responses reviewed: 626

## Category

Family members: 114

Professionals: 71

Individuals with I/DD: 60

Other (guardian, etc.): 10

## Race/Ethnicity

Information was not collected from virtual public input sessions. Percentages rounded to nearest whole.

66% White or Caucasian, 14% Hispanic or Latino, 8% I Don’t Know or Choose Not to Answer, 7% Black or African American, 6% Asian or Asian American, 5% Two or More Races, 3% Native Hawaiian or other Pacific Islander, 1% American Indian or Alaska Native, 1% Another Race

## Rural/Urban:

Information was not collected from virtual public input sessions. Percentages rounded to nearest whole.

77% Urban (City), 23% Rural (Country)

# **Findings:**

Top Areas of Emphasis to address based on funding capacity and identified needs:

1. Employment
2. Health
3. Quality Assurance = monitoring, improving or providing education on services to prevent abuse, neglect, discrimination or interfere with basic human rights
4. Transportation
5. Housing
6. Education (school aged through college and transition services in high school)

The top barriers to accessing areas identified:

* Long wait lists/not enough services (lack of providers, lack of mental/behavioral health, youth, rural).
* Not knowing what services are available.
* Not enough or can't access coordinated health, dental, mental health, and other human and social services (not enough providers, insurance denials).
* Not enough services or support for residential/assisted living or other housing options (group homes not safe, turn around, lack of training or oversight).
* Not enough accessible and/or affordable transportation options.
* Not enough transition services into to adulthood (limited programs for adults, little transition planning or options).
* Not enough services or supports for getting and keeping a paying job (livable wages, continued supports past 90 days, respect and understanding from employers).
* Hispanic and Rural communities are most lacking in all Areas of Emphasis.

# **Summary of Comments:**

Common issues identified in open-ended comments are summarized and listed below. Many comments also address Quality Assurance.

Employment

* Long wait for employment services and supports. This hinders some participants from being able to find employment in a timely manner. They get frustrated and quit.
* Not enough job opportunities that pay a living wage.
* Lack of jobs/opportunities in the community.
* Lack of accommodations provided on the job.
* Lack of adequate job training, job coaches and long term supports on the job.
* Not enough community education about including people with I/DD & not enough relationship building. with employers. People still largely work and recreate in segregated environments or programs specifically for people with disabilities.
* Lack of employers who have expertise and/or experience working with individuals who have significant disabilities, communication issues, invisible disabilities, mental health and/or medical needs.
* Lack of job supports for individuals who have significant disabilities, communication issues, invisible disabilities, mental health and/or medical needs who want to work.

Transportation

* Number one issue for the reasons people cannot participate in activities, events, employment or leave their homes.
* ADA service areas need to be expanded (Nevada is growing and thousands don’t have access to transportation).
* Limited or no connecting routes to get to other cities.
* Limited transportation in Rural areas.
* Paratransit lengthy travel times, routes running late.
* Not cost effective (have to choose between going to the grocery store or work, can’t afford both).
* Public options not flexible enough for needs (when a ride needs to be scheduled quickly).

Education

* Not graduating with the proper education/skills needed.
* Not enough information/supports/services for students and parents.
* Not enough qualified teachers/support staff/aids.
* Not enough services before/after school/during school breaks/COVID quarantines.
* See transition comments as well.

Health: Dental, Mental and Other Human and Social Services

* Lack of providers that accept Medicaid.
* Lack of specialty providers.
* Lack of quality providers.
* Lack of social/emotional/behavioral and mental health therapy and supports for children, individuals and families.
* Lack of accessibility to dental care (not enough providers, transportation limitations, great need, limited provider knowledge of need, prevention education initiated too late and does not include care giver).
* Caseworkers don’t have enough time to provide quality, person centered coordination and care.
* Application processes for services too lengthy and difficult to understand.
* Limited services/funds to help a family care for adults with disabilities.

Housing

* Not knowing what housing options or assistance is available.
* Lack of affordable housing for range of abilities and needs.
* Limited affordable residential housing options for adults with severe disabilities/mental health/medical needs/no family or family can’t care for them.
* Limited choice for nursing care or ICF's outside of a state-run institution for adults with severe disabilities/mental health/medical needs/no family or family can’t care for them.
* Many families cannot afford personal nursing care or a traditional assisted living facilities.
* Group homes are rented/providers cannot make appropriate accommodations for wheelchairs, etc. protections favor landlords more than tenants.
* Lack of quality trained providers in group homes/understaffing/high turnover.
* Too many stipulations on rental assistance, application process too difficult.
* Residents in group homes often unable to leave the house or engage in meaningful activities due to understaffing/staff not wanting to take residents places.

Transition

* Limited or no transition services leaving high school to employment, transportation, education, recreational activities. Adults and families are left on their own.
* Confusion of how the transition services offered by the school can be provided at the same time as the transition services offered by VR.
* Communications between state agencies is cumbersome and confusing, pages of applications for each step makes it difficult to apply or understand services.
* Need for more coordination between VR and schools with Pre- Employment Transition Services.
* Parental education and life skills are huge needs in assisting with adulthood transition, especially in cases with multiple diagnosis.
* Transition supports need to take social/recreational/life skill services and needs into account.
* Limited transition supports for individuals with Autism.

Quality Assurance: Education on Services to Prevent Abuse, Neglect, Discrimination or Interfere with Basic Human Rights

* Acts of discrimination of people with disabilities in all areas above.
* The collaboration of the council with the organizations that offer protection services to people with disabilities is important.
* Some families don't have internet access, or devices are needed for work or others in school.
* I was told by a worker from DRC that everyone had to first go to a group home before being placed into an apartment. The group homes for this population are not required to be licensed by the Bureau of Health Care and Quality Compliance (BHCQC). Without this monitoring the quality of care is very careless and unsatisfactory. Quantity of people served is their biggest concern for profit, rather than quality of care to the clients.
* Providers were allowed to become the Representative Payee of their disability money and their paychecks and want to only issue a small amount of money to them each week and cannot give a report of what amount of money they have left. The group home facility and DRC need to be held more accountable for their behavior.
* Hard to understand the use of technology.

How Can We Help Self-Advocates Become Better Leaders in their Community?

Comments not already addressed above:

* Setting up trainings for advocates about state agencies and how to attain access to the services.
* Increase awareness activities Educating the community at large.
* Provide trainings that do not talk down or minimize those with developmental disabilities. Be open to advocates who do not have a vested, economic interest in maintaining the status quo.
* Making them take part in activities. NGCDD has done a great job giving each of them the chance to participate.
* The Hispanic community must be educated at the state level about their rights and the protection services available; since there are still a good number of families/individuals who don’t know what their rights are and how to protect them.
* Be more visible in our communities, feel like no one knows about services, that help is out there and how to access it.
* By holding agencies accountable for the data on their services. What is working, what is not working. Updating services more often.
* By engaging with family-run organizations more.
* Go into community and learn what the needs are and speak with the families and get the families voice in the needs and changes.
* Allow us to be part of the training process. The employer knows the job. We know the individual.
* Better self-education. Autism has so many faces and each child is different. We cannot allow everyone to be lumped together. We need the resources to be able to assist each child with where they are on the spectrum to help the adjust socially.
* Help them get out of places that don’t see their true potential and treat them less than they are.
* Help me be able to live and work like you.
* Reach out, support with ALL aspects of transition, recognize agencies that are far superior resources and fund them!
* Participate in clubs be allowed to pursue desires in high school. Help them not get lost in the crowd.
* Support local non-profits that enable advocates to service their communities, continue education, on the job training and vital social activities with peers
* Encourage, inform, and make sure you have snacks!
* Support efforts to ensure accessibility of deaf students
* Make sure that at least some of the council members look like the people that they are supposed to represent and get some new council members. Term limits.
* Advocating for use of evidenced based practice regarding child engagement and attachment with caregiver.
* Train us in cultures, disabilities, job coaching, mentoring.
* Stop letting essential services get away with not providing quality services.
* Surveys like this are a great start.
* Have partnerships with senior centers throughout Nevada
* I think the self-advocacy summit in Las Vegas last year was very informative as well as transportation in Atlantis Casino was well done with an exception of some accommodations for people with disability and people who are using walkers other than that it was a great turn out people who are professionals get to listen to people with disability and provide services that are having some gaps
* Well I think that Council is doing a great job with partners in policymaking I feel very enlightened and renew my dedication to move forward with people with disability and our rights I think that Having a coordinated partnership with other agency a.k.a. system advocacy is a wonderful way to involve and educate and empower people with disability because it’s about us with us so in regards to 88/30 anniversary I think we need to unite and be heard and be seen especially with the Upcoming session.
* Have more activities in the rural areas.
* Look into group homes taking all but $5 a week of your money.
* Get agencies to talk.
* Make group home providers accountable for adequate, trained staff instead of allowing them to open more group homes when they don't have enough staffing for the ones they are currently running. Put fines in place or remove license from care providers after QA warning are not rectified. Currently if appears they know there are no repercussions from ignoring warnings or blame it on a staff member.
* Promote State agencies partnership. Cut out gatekeepers. One ROI between state agencies. Have a Voice in our largest school districts, which are failing our youth regarding transition. Teachers do not understand or refuse to partner with parents and other state agencies in a meaningful manner. One data base for state services treatments.

Other Comments:

* In Nevada, there are a large number of adults with disabilities who have stayed at home or in group homes or assistance facilities because there simply aren’t enough resources for them in the workplace, such as training centers, nor respect to open employment sources for them in the community; we need training centers, my son was incarcerated for writing on a paper, I hit my mother hard, after 25 minutes chatting with him in his room, the police took him out in handcuffs, he, and we, didn’t know what was happening, they had him in jail for 13 hours and supposedly he would appear in court the next day. They called at 8am and they said that we had to come and pick up our son, but right now... he had his hearing a month later and they said to dismiss the case, [he was asked] to leave the room, this is not a place for him ... how does a parent fight for his rights? How, if they tell you that, if he said that he hit you, then is it domestic violence? When, however I called 911 to ask that they send paramedics and take him to the hospital because he was having a crisis... he has autism and he can say that he is the president and he will be imprisoned for that crime... we need laws to protect them. Nobody helped me, nobody knew what to do... because it was so simple, he was innocent and they made them write his statement on a sheet, they trampled on him ... he has autism, he is verbal and he was 18 years old... adulthood without laws for them can be terrible, now with the coronavirus issue, we cannot have our children locked up, but they don’t understand the masks, the laws etc. WHAT WILL PROTECT THEM? Will they go to jail for not complying with the laws that are normal for everyone? ...help us protect them, between 911, police, and hospitals, we can lose our children very easily. And this affects everything in a job, at work, living at home or group home or iWorks, if they are renting by themselves, equity for all, but adequate rules and laws must be implemented on mental health. My son was traumatized by the police on another occasion; it was the same, we called 911 asking for paramedics, and in the blink of an eye, they used a taser on him inside his room. They entered with shields and weapons and he was having a meltdown, as they see him as physically normal, because autism cannot be seen, they treat him as a criminal or because of racism [sic], he is Hispanic-American, LAWS TO PROTECT THEM
* For many Hispanic families, the role of the council within the disabled community and how they can help them is still very confusing. Programs must also be created that provide the opportunity to access services at affordable prices to Hispanic people with disabilities but who, unfortunately, are undocumented.
* Let’s continue working and learning together for a better Nevada. We appreciate your work. We are Parents to a child with autism, he’s almost an adult and we worry about that stage where we see that there is not much help.
* Make these people with disabilities feel that you care.
* Put cameras in the classrooms for special children and cameras that do work at school as well
* Peer support is priceless.
* Send this survey to families via mail as well.
* Thank you for providing this survey for the community voice to be heard.
* Respite care is a major area of need as well. I support families that have children with disabilities from birth through 26 years of age with varying disabilities, and respite care is lacking and non-existent in many areas of the state. Also, specialized and inclusive daycare settings.
* Less talk, less planning, more action!
* Research and data on women with I/DD health needs, access to services, and treatment. Information/goals pertaining to support for mothers and expecting mothers with I/DD. 2. Develop a goal geared towards serving or highlighting the I/DD LGBTQ community. 3. Increase community presence in underserved communities (Indigenous, African American, Hispanic, etc..).
* Speaking with our legislators at the next legislative session about providing businesses with work incentives for employing individuals with disabilities. Following up with Customized Employment. Advocates and get ideas about individuals owning and operating their own businesses. Creating a chapter of APSE Association of People Supporting Employment First and providing funding (grant monies) to have certified Employment Support Professionals to help individuals with disabilities to find and maintain integrated employment.
* Everyone can contribute to the economy, so jobs and sheltered workshops are needed to meet individual needs for society's success. Open mined employers are needed that are willing to continue retraining beyond the 90 days.
* Early Intervention is underfunded and needs additional resources to provide for more services to come under the state's provision of services - less community providers that only offer limited availability and access and more state employees to reduce long term consequences for individuals and families and less burden on the state long term.
* Please find a resource center for special needs adults to go to, staying at home all day is not healthy for these people!
* Yes, staff pour their life into this and doing things for others and don’t get recognition for what they do just people complaining. Also they put together programs that people want or bitch about that they need or do not have and then they do not show up to the services when provided.
* If a College Learning Experience Campus were created to those who desire and are capable why not let it be a continued public education for these adults? Let them mingle, have clubs, work, study with tutors and such and provide self esteem for these adults who have special needs. It can be done. Sincerely,
* FUND programs other than the big named one in Las Vegas (OV) and take care of ALL the residents of the community.
* There should be clearer guidelines with SSDI, Medicaid, Medicare, and DRC. It seems like everyone has a different set of funding and rules and it is not clear what is available to assist with disabled people. It is not easy to find help with this.
* I need dental insurance.
* You guys always do amazing and I have confidence you will continue to do so. You guys are awesome! Thank you!
* Nope. Thank you guys for all you do. You guys are great.
* Keep going.
* How come council members are stacked from the north and stacked with people who only represent those with friends like them. I have never seen no council members at West Academy in North Las Vegas or the black urban council. Don't we matter too? I will be moving soon to another state where they say it's better, but I don't know.
* Pre-k to 12 PUBLIC education needs to be funded and funded huge. Betsy deVos has never walked in the shoes of public schoolers. Deaf Ed needs qualified and screened teachers and support staff Who support sign language, and those people need to be paid for their expertise in ASL, deaf Ed specialization and extra Work and paperwork for Deaf+ students.
* Listen to the experts on deafness who know the best way to educate Deaf children, not the Special Ed experts but those who have expertise in deafness.
* If it’s possible it would be great to see a person with disability who is qualified to be employed with the council just saying. Thank you so much for doing this you guys are awesome have a stupendous week
* In the short term broaden communications about the COVID 19 rights of clients and guardians in regard to state mandates. Group homes are not under federal oversight and regulations as nursing homes. Since many are in this vulnerable population category and there is no definable end date, neglect becomes a more distinct possibility as time goes on.
* Promote the importance of warm hand offs, break down silos. Promote helping the participants as the number one outcome measure. Currently processes and paperwork is measured outcome for success.
* Children with autism can learn better when they have positive experiences. Keep children with autism free of abusive environments where they go to learn Stop isolating children with autism. Create an environment to be with others children.
* Please extend the help for kids with disabilities, ATAP is a very helpful instrument in helping kids with Autism.
* Our state plan must be inclusive for all people with ID/DD not just the people who are able to "voice" their opinion. I applaud your efforts to engage the entire community and hope we can continue to champion the development of broader choices and support for both adults and children.
* The advent of covid-19 has put a spotlight on these needs. Housing and medical needs, ICFs, are a major major major need area. The council should be a thought leader in this area. It should be a specific category in the five-year plan.
* Nevada Needs a Real working Department of disabilities. The Desert Regional Center and the case workers are mismanaged, are over worked, are not well trained, and fail the disabled in the Las Vegas community!!!
* Technology support for the home for our lower income families.
* I believe that giving parents a seat at the table and providing support to them helps gather firsthand feedback on the journey of raising a child with different abilities or special needs.
* We need more community services for the disabled. Also, school's need to include special needs children in daily activities
* The LIDs are always last on the list because it is expensive to support these communities per person served but at some point, it has to be their turn. They must arrive at the top. An overview of the budgets for all services as a group would be helpful - taking the big picture on things like the Autism money that was given back because services were NOT provided. 30 million dollars was a waste to silo into 1 group when that could have been used for all folks with autism - not just ABA therapy - but hearing aids, ASL, other communication therapies. With the COVID crisis impacting budgets this will be critical for the next 5 years in the developmental years of these children - thus creating a later burden on the state without these crucial supports in language development and acquisition. This is an investment in our disability community where we - the system - creates disabilities that are unnecessary. There has to be a better way of meeting the needs of the population and staying within the limitations of government. The disconnect between what the state provides and what the folks need must come from the community an then be translated into a realistic set of goals for funding those services. We know what best practices is but we don't do them. Waste of time, energy and money. Why can't we do what is best? More education is needed for parents and communities to convince them professionals are their best source of support. If the professionals aren't helping - we need different ones. Last thing - monitor how things/units/services/families are counted and measured. This is where the breakdown happens in my mind - if we count things this way - no wait lists - if we provide adequate services - we have huge wait lists. this is an accountability problem the council can definitely address. Thank you
* Consider that closing sheltered workshops will create serious problems for those that can't work outside that environment. Many will lose their SSI benefits and Medicaid if they leave that environment. Don't take a "one size fits all approach" to assisting those with disabilities.
* Increase reimbursement for attending out of state conferences, using the Community Development Fund. The amount currently doesn't even cover half of what hotel and airfare cost.
* Realize Vocation rehab. is not in tune of the needs of disability community.
* Yes, there are other things that should be considered. They are: 1. Look into the Administrative rules for Desert Regional Center (DRC) 2. Implement licensing all group home facilities by BHCQC and eliminate the so call monitoring by DRC. 3. Stop allowing group homes from becoming Representative Payees for the people they care for because it is a conflict of interest and allows fraud. Also, do not allow them to put all of their client's money into their general bank account and not have the capability of producing a ledger for each client served. 4. Improve the Home Support program administered by DRC.
* This is very helpful and encouraging.
* Consider including a physical therapist or other provider who works in EI or schools on the council.
* Outreach and grassroots advocacy efforts needed. Maybe a cross disability group tackling similar barriers or issues, such as civil rights in general.
* Your office provides a vital role in supporting the civil rights of people with developmental and intellectual disabilities and connecting with individuals and their families throughout Nevada.
* Not to forget we need siblings’ voices to be heard, they are the biggest advocates and the strongest supporters for the communities this Council is trying to speak on behalf of.
* How can we attract doctors and specialists to this state to help with the shortages?
* I invite council members to shadow professionals and families in other discipline areas to see a wider range of needs (example - a professional who typically works with adults shadowing Early Intervention professionals).
* OFF YOUR COLLECTIVE ASSES AND ON YOUR FEET. UNITEDLY.
* Thank you for all you are doing! Please acknowledge dental care in all aspects of creating and planning your next State Plan.
* Include services for childcare/supervision/recreation for school aged youth with disabilities.
* I am so glad this is an ongoing process and I appreciate all the efforts done this far to increase services for individuals with a developmental disability.
* Please do not just consider but actually build a real plan to help rural Nevada.
* I would like to see more emergency preparedness and disability.
* Many kids with disabilities are not in the public school, there needs to be more connection with PTs, OTs, EIS.
* More funding the disabled and inclusion is the goal to benefit everyone.
* Medicaid needs to work faster.
* Orientation & Mobility Services need to be covered under both private insurance and Medicaid. White cane should be covered under Medicaid as a Medical Dural Equipment; you have to buy your own white cane if you are not public school.
* Fewer Bureaucrats, more support for people in the community. We don't need more meetings or focus groups, stop spending money on muffins and lunches, and instead on supports for people within the community.
* Funding for special needs programs. Some sort of directory or resource where we can find the correct physicians, dentists, counselors. I really wish there was a way to have something like the Northern Nevada Down Syndrome Association come out here. Once a month. Have a party or something. Thanks for everything you're trying to do.
* You're doing a GREAT job!!!
* Rural issues on the forefront not as an afterthought. Needs to be a focus. And more in the south. More outreach and information to people in southern Nevada.
* Early transition from EI to school needs called out as a priority area in addition to adolescence.
* I appreciate collaborating with NGDCC. It’s staffed and empowered by a strong and smart group of women and overseen by community members who are committed to making a difference.

Nevada Governor's Council on Developmental Disabilities

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