

NGCDD FFY 2017-2022

5 Year State Plan Survey Results

Overview:

The 5 Year State Plan Survey was created through Survey Monkey and directly distributed to **48** agencies including those represented by the Council as well as agencies, organizations and individuals from diverse geographic, ethnic, cultural, socio-economic, disability and personal/professional backgrounds.

Surveys were distributed and conducted via email, Facebook, in person and through focus groups throughout the state. Accessible formats and accommodations were provided as needed. The Survey consisted of 5 questions; 2 multiple choice, followed by 3 open ended questions designed to elicit a more comprehensive response to the identified choices in question 2, which were taken from the Areas of Emphasis in the DD Act. The open ended responses were then individually reviewed and categorized as shown in the following pages.

A total of **331** responses were received, with over 900 open ended questions reviewed. All responses were anonymous to allow for complete honesty.

Of Note: There is a slight disparity in the data between what individuals identified as most important to them and what was needed or seen as a barrier to getting those things. That disparity is due to the nature of the population completing the survey and the varied responses to the open ended questions. Percentages are rounded up to the nearest whole number so the total will not add up to exactly 100% and most of the open ended questions identified more than one need or barrier so those percentages will also not add up to exactly 100%.

Basic Findings:

- Individuals with disabilities were the most represented population of the survey
- The 3 most important Areas of Emphasis in the DD Act were:
 1. Access to Services
 2. Education/Training
 3. Health
- To get those things people needed the following 3 things the most
 1. A better job/employment
 2. Better transportation
 3. More/better social opportunities (friends, recreation opportunities, etc)
- The top 3 barriers to getting what they need were
 1. Lack of money (Federal/ state/agency funding, better paying job, etc.)
 2. Not knowing what resources are available or what to plan for
 3. Lack of resources/services (employment, qualified healthcare, etc.)

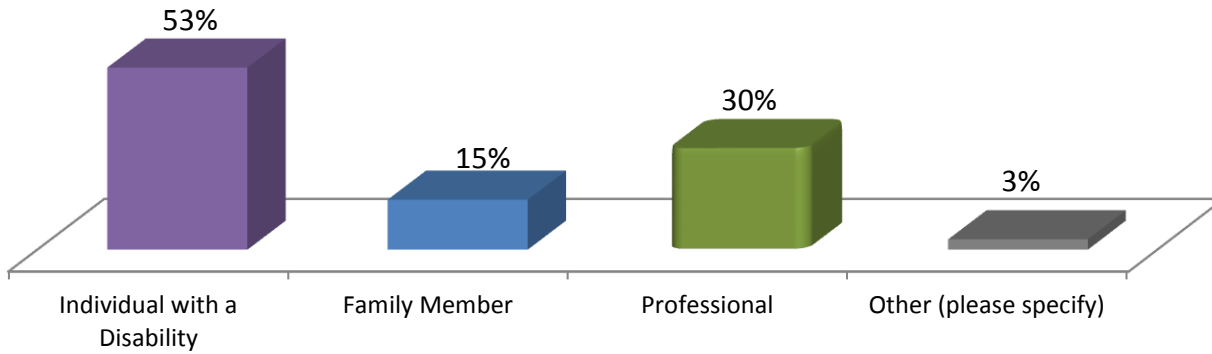
The following pages represent a more detailed breakdown of the survey and results.

Direct Reciepients:

Agency	North	South	Rural	Statewide	Method	Culturally Specific
Access to Healthcare				1	SM	
ADSD				1	SM	
Aspergers Support Group of Northern Nevada	1				SM	
Azul Blue		1			SM	1
Deaf and Hard of Hearing Advocacy Resource Center				1	SM	
Dept of Ed				1	SM	
DETR/Voc Rehab				1	SM	
Disability Awareness Coalition	1				SM	
Down Syndrome Network of Northern Nevada	1				SM	
Down Syndrome Organization of Southern Nevada		1			SM	
Early Intervention Parents, NV	1				SM	
Early intervention/Part C				1	SM	
Easter Seals NV				1	SM	
Elko Area Transit Service			1		SM	
Elko PACE event			1		In person/FG	
Family Ties of Nevada				1	SM	
Give Me A Break, Inc.		1			SM	
Grant A Gift Autism Foundation (Southern Nevada)		1			SM	
High Sierra Industries	1				SM	
JUSTin Hope Foundation	1				SM	
Maternal and Child Health Advisory Board				1	SM	
Maternal and Child Health Coalition				1	SM	
Medicaid				1	SM	
Milagros Escondidos		1			In person	1
National Federation of the Blind – Nevada				1	SM	
NCED	1				SM	
NDALC				1	SM	
Nevada Housing Division				1	SM	
Nevada Indian Commission				1	FAX SM	1
Nevada PEP				1	SM	
Nevada Relay				1	SM	
Northern Nevada Autism Network (Elko)			1		SM	
Northern Nevada Center for Independent Living	1				SM	
Northern Nevada Disability Access	1				SM	
Note-Ables	1				SM	
Opportunity Village, Las Vegas		1			In person/FG	
Partners in Policymaking Las Vegas class		1			In person/FG	
People First of Nevada (7 chapters)				1	In person/FG	
Project INPUT (Inspiring Native People to Uplift Themselves) (Mesquite)			1		SM	1
RAGE		1			SM	
Regional Centers				1	SM	
Reno Transit Authority	1				SM	
Ruby Mountain Resource Center (Elko)			1		SM	
Sierra Nevada Transportation Coalition	1				SM	
Silver State Fair Housing Division				1	SM	
Southern Nevada Center for Independent Living		1			SM	
The Continium	1				SM	
United Cerebral Palsy of Nevada				1	SM	
Totals	13	9	5	21		4

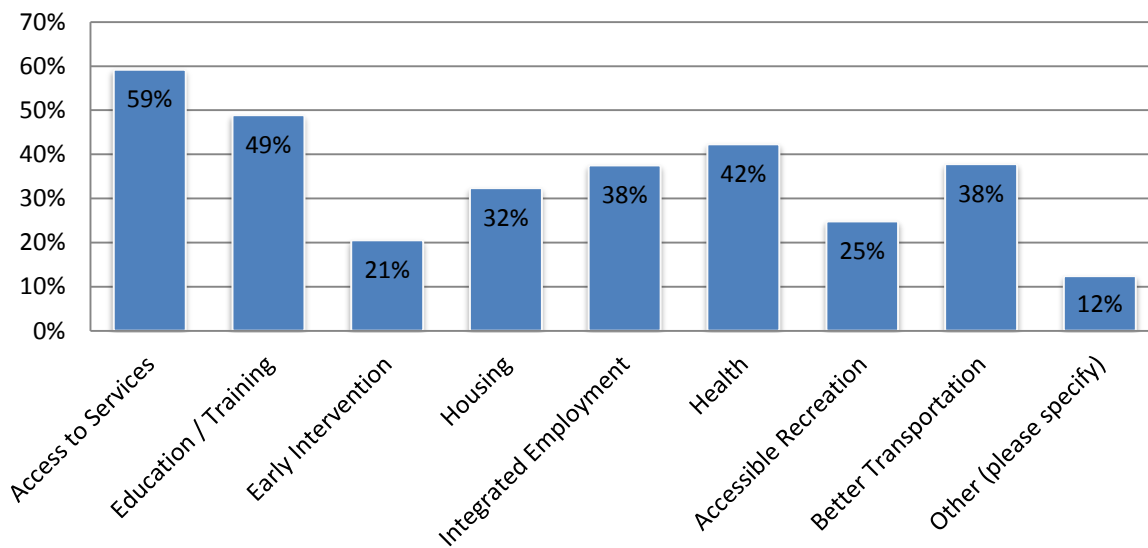
Q1 Please check the category that best describes you:

Individual with a Disability	53%
Family Member	15%
Professional	30%
Other (guardian, dual role)	3%



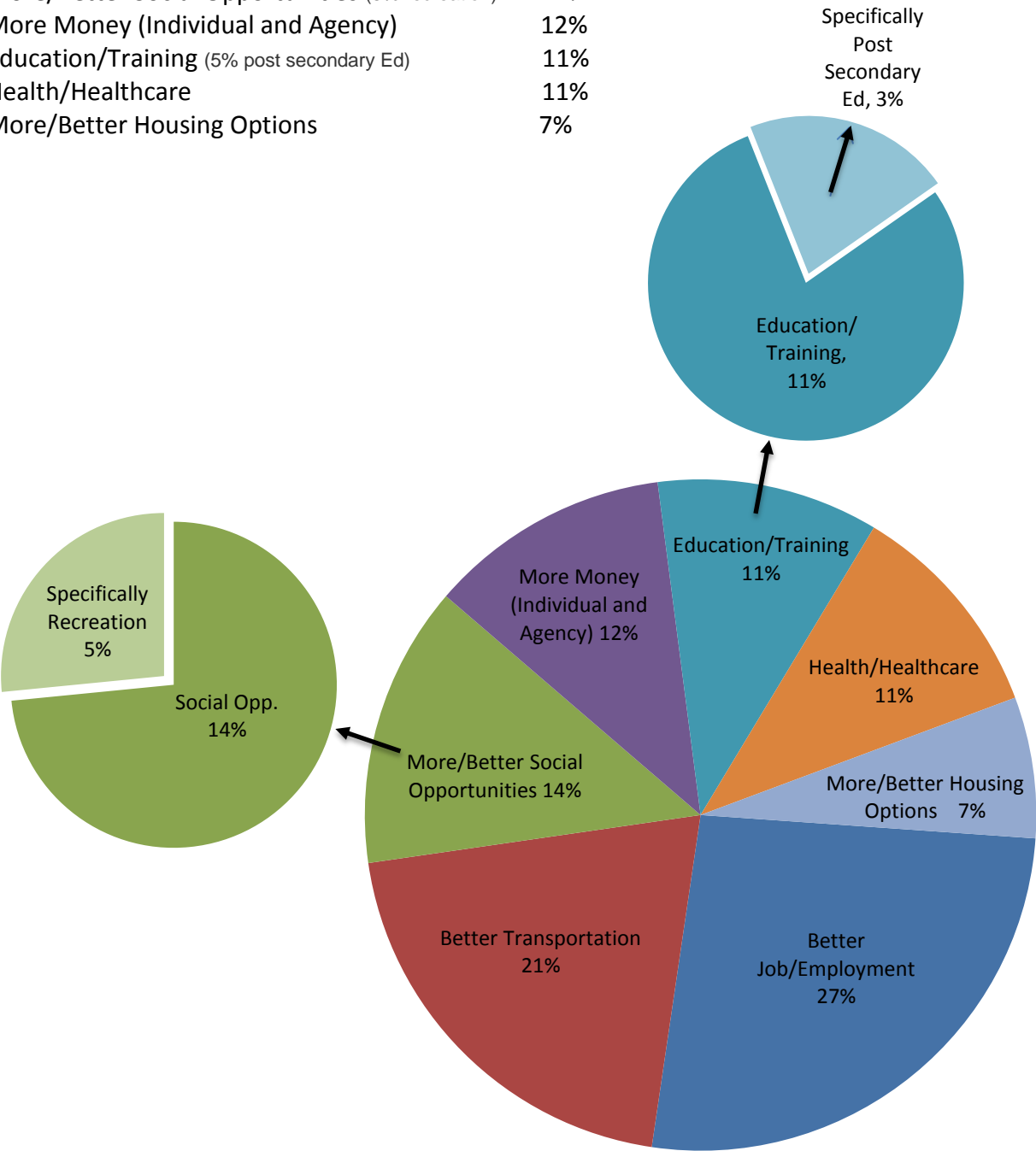
Q2 Three (3) things that are most important to you:

Access to Services	59%
Education / Training	49%
Health	42%
Better Transportation	38%
Integrated Employment	38%
Housing	32%
Accessible Recreation	25%
Early Intervention	21%
Other (Medicaid/insurance, job carving, friends, AT, sensitivity training, access to professionals in the rurals, coordination of care)	12%



Q3 What do you need to get those things?

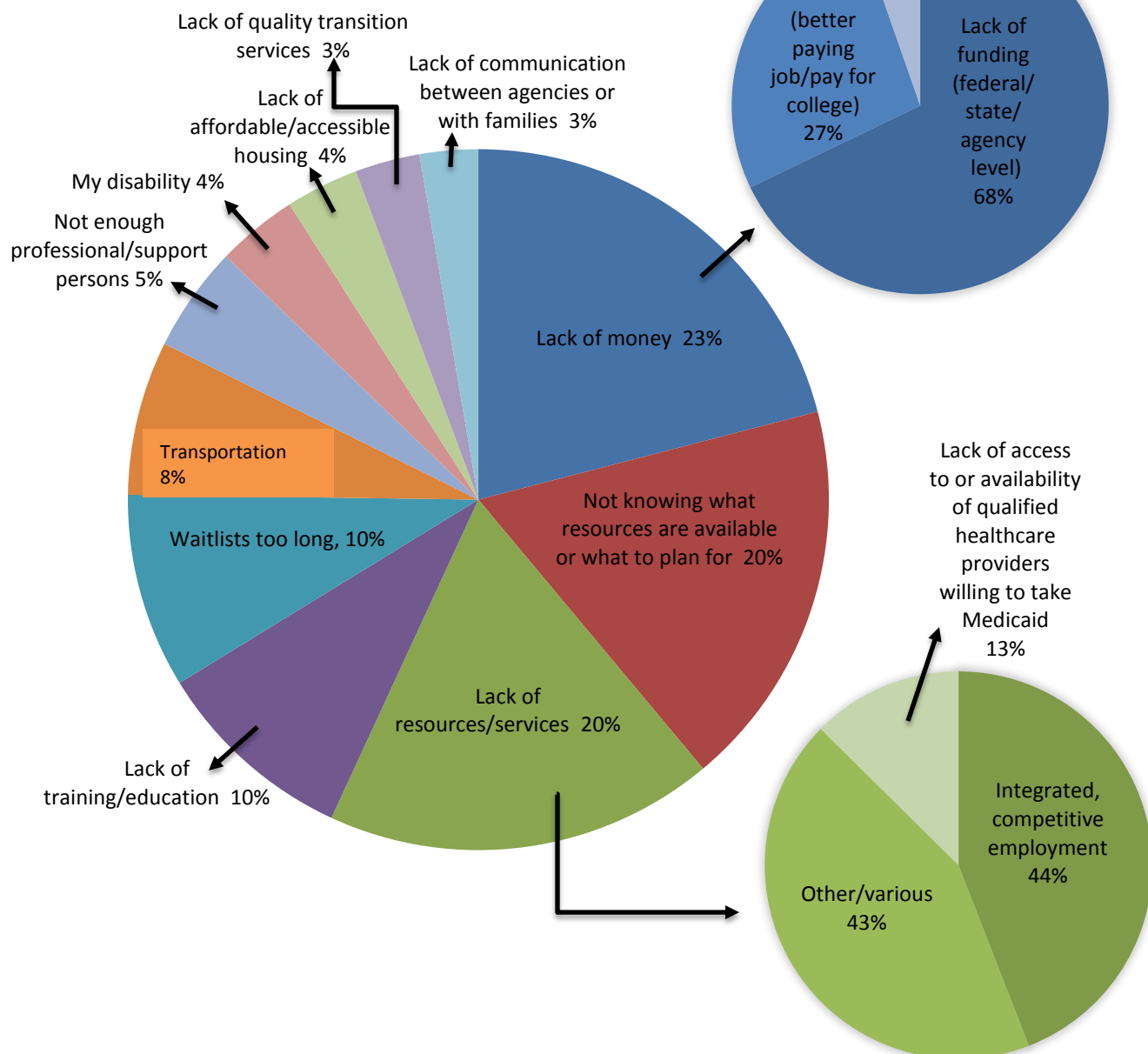
Better Job/Employment	27%
Better Transportation	21%
More/Better Social Opportunities (5% recreation)	14%
More Money (Individual and Agency)	12%
Education/Training (5% post secondary Ed)	11%
Health/Healthcare	11%
More/Better Housing Options	7%



Q4: What's stopping you/what are the barriers?

Lack of money
 Not knowing what resources are available or what to plan for
 Lack of resources/services
 Lack of training/education
 Waitlists too long
 Lack of transportation options/services
 Not enough professional/support persons
 My disability
 Lack of affordable/accessable housing
 Lack of quality transition services
 Lack of communication between agencies or with families

23%
 20%
 20%
 10%
 10%
 8%
 5%
 4%
 4%
 3%
 3%



Summary of comments:

* Indicates a re-occurring comment

Job/Employment

- *Bigger paycheck, work in the community
- Voc rehab needs a lot more help and a lot more people to provide help to the community.
- "I didn't know I could do that, but how can I do that? In school nobody told me I could do something and work at my dream job."
- Voc rehab will only help for so long but what happens when the job coach pulls out and my child needs support to keep their job? Then we have to apply all over again and wait and wait and by that time my child has been let go. I'd rather have them work somewhere where they were understood and supported and not judged and not let go to then make them feel like a failure.
- Maybe having some information sessions with various Chamber of Commerce groups throughout the state and various business groups throughout the state.
- * There aren't enough job coaches/job developers to support those that can work in the community but need support (especially support past the 90 days they usually get). This is why people end up in sheltered workshops - because there's extremely limited choices for them to go (especially in the rural areas) and not enough qualified or decent paid job coaches to convince businesses to hire people, train the people with I/DD to work there and then provide the business and the people the continued support needed for successful employment.
- I don't know about WIOA. All I've heard is bits and pieces but I haven't received a clear answer on how I'm supposed to do it. I don't have enough tools or support. I know everyone needs to go into the community for employment within 4 years but some of them just can't because of health and/or behavior issues. We get no help from the schools - so the kids come out with no tangible work skills or even a desire to work in the community.
- There is a significant gap between what I am learning and experiencing in school and what I'll need to find paying work in Clark County. There are very few opportunities, if any, for employment for someone with my level of disability, and my limited range of ability.
- The job coaches and counselors at Vocational Rehabilitation must successfully place people with autism in integrated employment, self-employment or CTC's. The process needs to be streamlined and consistent. Managers need training about how to proactively prevent misunderstandings and bullying in the workplace. They also need training about how to resolve issues that occur due to the disability or lack of communication. Young people with disabilities and their parents need to learn early in their teenage years that there are several employment and educational options - not just arts and crafts at Opportunity Village. University Student Health Services need to better support young adults with autism.
- *Better job, higher wages at Opportunity Village
- I'm currently working with DETR to try and find employment for both of my Autistic girls, and this has been very slow, and frustrating. Feel I'm having to chase them down to try and get help.
- Need help finding job training.
- Better service providers and better information outreach on the services that help get integrated employment. So many families don't even know where to look for employment without thinking of sheltered workshops.
- Since UNR has a behavior analysis program there are lots of qualified graduates but a lack of opportunities to keep them local and provide quality jobs for this very skilled group of students.
- My line of work does not recognize my disability! They do not see that it is a part of me and although I am a perfectly capable human being, my job is biased against me because I do not do it like everyone else.

Transportation

- *More bus services on evenings and weekends.
- What Transportation is a better question! Logisticare will send some bus tickets if you have any ability to walk and will reimburse mileage only after a certain number of miles.
- Bus services are inadequate, sidewalks are missing, broken, obstructed and generally unsafe, there are not enough controlled crossings, many complex traffic lights have inaccessible signals, Supplemental educational resources such as orientation and mobility training, and sign language interpretation are inadequate or missing altogether.
- Can't get to a job without transportation - adult daughter can't live on her own in the apartment and have transportation outside of her parents giving it to her if you live outside of ADA loop. Becomes a cycle that can't be broken.
- *Challenges with Paratransit including not being picked up, long waits for rides and scheduled rides being unavailable.
- *More options for transportation and sensitivity training for RTC employees.

Social/Recreation

- Need more places/activities to make friends
- *Scheduled, accessible, safe activities that I know about and can get to.
- More friends with similar disabilities
- There are very few recreation opportunities available. Most people after 18 have nothing to do because nothing is offered in the community and there is no transportation if something was available.
- Funding to support inclusion supports and services (no grants exist for inclusion).
- Recreation programming to support the 14-22 age group, kids can still go to school till a later age but there are little to no services available to provide after school/work for this age range that may not be able to stay alone.

Money

- *Basically need more of it all around.

Education/Training

- *Better education/ training to progress my knowledge of working with individuals with disabilities.
- *Families and individuals need to have more information and training regarding advocacy and rights, choices and resources.
- The scope of training needs to be broadened to be more inclusive (undocumented, LGBTQIA, language translation to reflect NV populations, etc.)
- Better training across agencies so they know what the choices are available throughout Nevada.
- Getting all of the information available to educators to give to students and families is challenging.
- Parents and individuals with disabilities are being left to figure things out on their own. Regional Centers and Vocational Rehabilitation need to be taking an active role in the IEP meeting, not just passing out brochures. Parents of teenagers with disabilities need to be familiar with services and how they will impact their family and individual. SLA and JDT services need to be self directed (sort of like PCA services through Consumer Direct), to provide flexibility as to how the hours are utilized and so that specially trained staff that has worked with the individual in one program can transition with the person to the new funding stream.
- Nevada needs help developing a workforce of Registered Behavior Technicians to provide services through Medicaid and private health insurance. 19 certificants is too few to serve the over 6500 children with autism in Nevada.
- Staff providing PCA, JDT and SLA services need to be competent in autism specific strategies to reduce

aggression and provide habilitative care. Paraprofessionals working with children with disabilities must be competent in providing evidenced based services based upon the disability. There needs to be person centered collaboration between NEIS, ATAP, school districts, Regional Centers and Vocational Rehabilitation.

- Nevada is in desperate need of upgrading program/education for children with disabilities. For Autistic kids, everything falls off after elementary. They either have to mainstream or go into CLE classroom. Neither was appropriate for my girls.
- Better oversight/training for individuals working at the Ruby Mountain Resource Center. I don't think plans of care and needs are being met or given to the coaches who work with them.
- *More education and meaningful training opportunities for professionals (more specific to EI and young children), on best practices and to help access or understand community resources. have more communication with social workers or understand their process in relation to EI programs.
- Outcomes can be improved if the individual/caretaker knows what needs to be done and is provided with training to ensure that individuals get proper and timely nutrition, education regarding short-term and long-term care, etc..
- There are very few educational programs in Nevada for any age group. It is difficult to get children the educational programs and supports needed at school and there is little advocacy to assist. As children get older, there is no funding for job coaching and placement.

Health

- * More providers, esp. in rural areas that accept Medicaid
- Doctors who are more knowledgeable of a person with a disability and their individual needs.
- Develop health promotion strategies for people w/ disabilities through training opportunities.
- *Better dental and medical coverage.
- Dental care that covers more than just routine visits.
- *More mental health services.
- *More specialized medical care for children and adults with special health care needs. For example medical geneticists who provide medical care and consultation to children and adults with conditions identified through Newborn Screening.
- Medicaid does not cover the costs for medical formula for individuals with conditions that require specialized food to ensure good health outcomes.
- Coordinated medical home to access and receive individual services and supports.
- Early Intervention: Better communication with Medical Outreach will allow doctors to give information and have children inputted into early intervention services immediately and not when they are already 2-3 years old.
- Medical providers in rural Nevada are reluctant to refer children for an autism evaluation or treatment.

Housing

- *More affordable, accessible, ADA housing, and in particular for those of low-and fixed-incomes.
- There are very little options for independent/assisted living for young adults. Only private run homes.

Waitlists

- Wait lists are outrageous!
- Long waits for specialists, slow access to EIS
- The waiting list for Early Intervention is way too long! I have heard stories of children waiting over 5 years for services. We need to invest more in staff to handle the caseload, so that the children will receive proper treatment in a timely manner.
- Have Aging and Disability services request more funding to eliminate the waiting list for Home and Community Based Services.

- There is either a waitlist for services or an income limit that does not allow families who could really benefit from the service to access.
- WAITING LISTS for people who want to remain at home - think WIN Waiver. I was told the wait list for a patient of min was 18 months. So what does he do in the meantime???? He is already living in his own home (owned outright) but needs more PCA hours than he can personally afford on his SSDI. Because he is not in a nursing home, the "money-follows-the-person" funding does not apply. This is so ridiculous I cannot even begin to express my frustration.

Transition

- *Not enough support in the schools to transition to a competitive job or inclusive postsecondary education.
- There needs to be informed choice.
- Families transitioning from Part C to Part B services would continue to benefit from education on services to connect them to resources in the community.

General Access to Services

- *Improved communication within agencies about resources, and what to plan for to disseminate to people with disabilities and their families which will help them access services.
- *Not knowing about the services, not enough opportunities in the community, and not enough community support (to help fund and develop programs). I have seen a lot of organizations try to host amazing events but never get the people to actually participate or give money which hinders any growth or development. I don't blame the organizations, I think it may just be a Reno/Northern Nevada culture.
- Need services in our family home. I would like funded supports in our home when my father travels or works or tries to enjoy a life of his own. If I am to function in the home we share as a relatively independent adult, then I should be able to contract for a qualified care provider to support me for what I need when I need it. That includes transporting me where I want to go when I want to go there, supporting me there, and helping me with daily living needs including medications.
- The deaf community may be underserved because of reimbursement for a translator. Most companies charge a 2 hour minimum for services and that is often more than what providers get paid for the patient visit.
- Better way of getting financial help to families when their child is born with a life long disability/healthcare needs. Co-pays alone can cause bankruptcy in extreme cases. The process for Medicaid assistance is long and stressful especially when you are dealing with life and death decisions on a daily basis right after the child is born.
- *Need Coordination of services. In the last year we have discovered just how UN-connected the following are: SRC and developmental services in general, State Medicaid offices offering "Medical Case Management", the PCA agencies, the Independent Living Program, Home Health Care, Outpatient and the Autism groups. How pathetic that SRC did not know that State Plan offers private duty nursing, or that Maxim does not coordinate with anyone else, or that a person with private duty nursing cannot get MEDICAL case management because they have a service coordinator at SRC (who knows NOTHING about the medical aspects of care). No wonder we can't make dollars stretch: it's too many doors, too many "programs".
- Do not allow the DD council staff to actually administer any programs such as "A Team" or Partners in Policymaking. They do not have the training, experience or understanding on how to work with adults with disabilities and their families. Help the DD council understand the problems in Early Intervention and the data.
- Recent system analysis done found: Access to services - making it easier for consumers to navigate the LTSS system as well as MORE services to be high on the needs list. We also identified the need to ensure better training across agencies so they know what the choices are available throughout Nevada.

- Information on Person Centered Planning. Could the council have information on Person Centered Planning and how that process will be implemented in Nevada? Could the information have a timeline when persons with disabilities will actual participate in the Person Centered Planning process.
- People don't know to ask about the things they don't know about.
- As a service coordinator for early intervention families I find it extremely frustrating to talk with someone at Medicaid about benefits for a family. Family ties was a very big help in getting some information.
- The physical strain of going to offices and sitting for hours before being seen was very hard for my family member, as was receiving conflicting information about what he qualified for and when he could access certain services. Being qualified as disabled but not able to have Medicare Disability health coverage for two years, and losing Medicaid due to ~\$20 over the monthly income amount allowable once the disability income started, made the first 9 months nearly life threatening to him until he could finally apply for the ACA health coverage during their open enrollment. Having someone he could have talked with who could walk him through the process and paperwork at the different agencies would have been helpful.