

COMMISSION ON AUTISM SPECTRUM DISORDERS - CONSUMER SURVEY SUMMARY Report

2024

Abstract

The Commission on Autism Spectrum Disorders conducted a Consumer Survey to gather insights from individuals with ASD receiving services across Nevada. Respondents were asked to self-identify workforce stability, service accessibility, and infrastructure of support for individuals with autism and their families

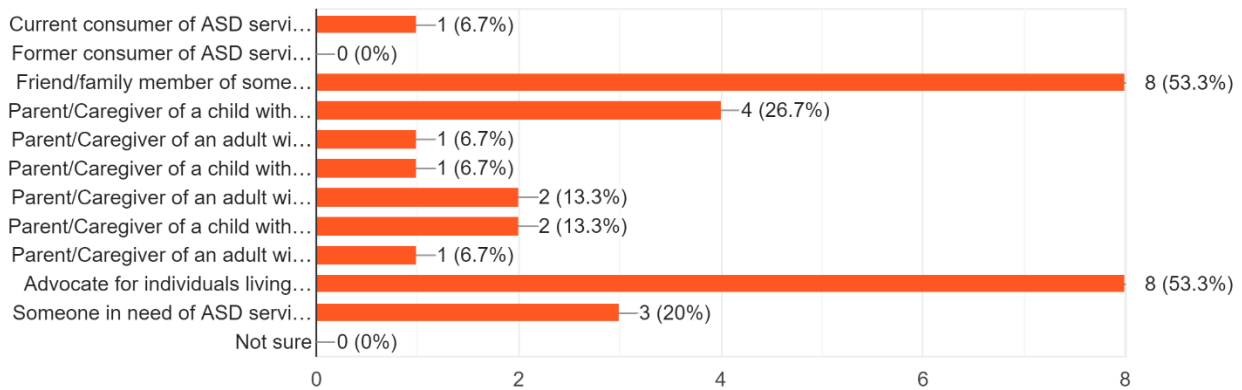
CONSUMER SURVEY SUMMARY OF RESULTS

Affiliation

The survey tool asked respondents to identify a category that best described their profile/affiliation. Of the total 15 surveys, 9 (60%) were completed on behalf of someone with ASD, who was unable to complete it independently.

Consumer Survey – 15 Respondents (n=15)

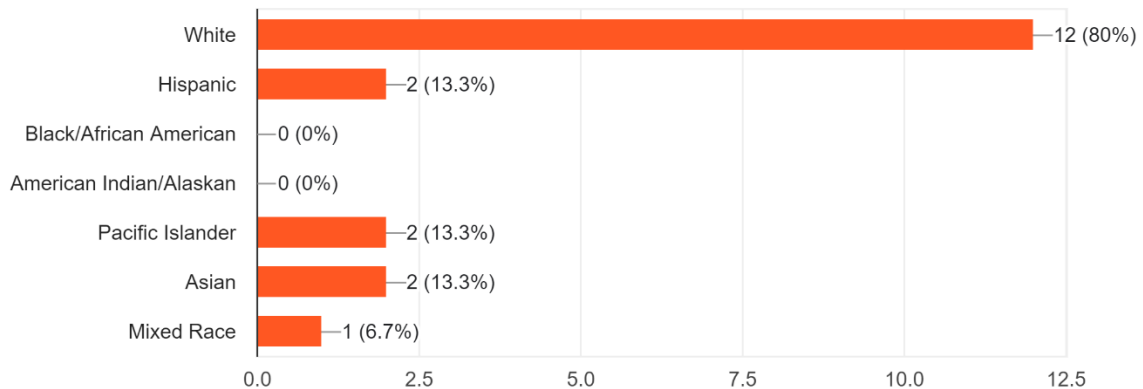
*Respondents checked all that applied and may exceed 100%



Demographic Profile

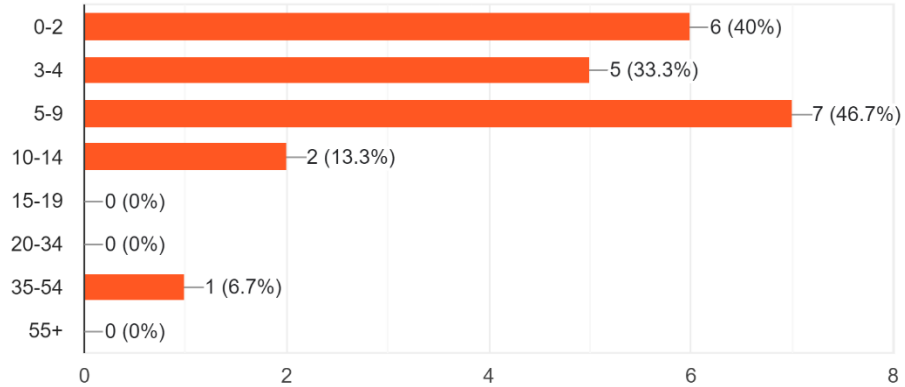
Race/Ethnicity

Respondents were asked to identify their race/ethnicity. Survey respondents were mostly White with 12 out of 15 (80%) respondents.

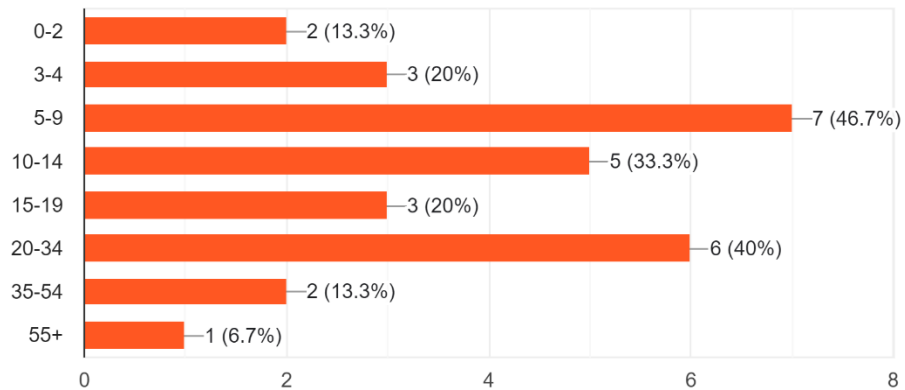


Age

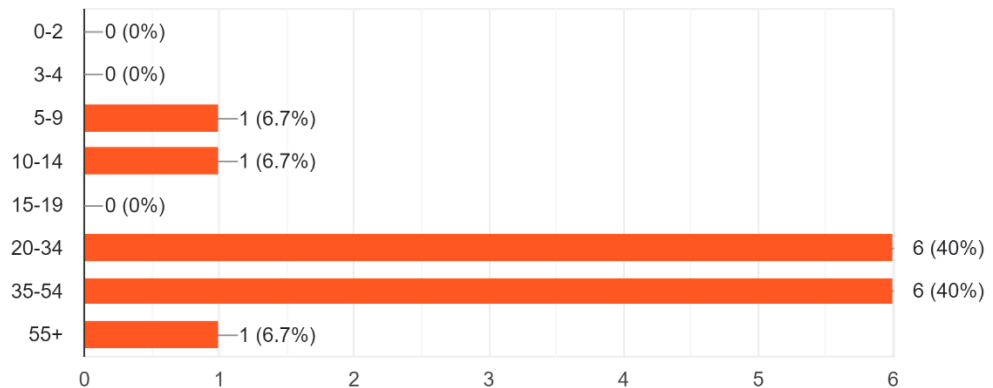
Respondents were asked to identify at which age they (as the person with ASD) or the person they care for (with ASD) were identified as having an Autism Spectrum Disorder.



Respondents were also asked to identify their current age, as the person with ASD (or the person they care for with ASD)

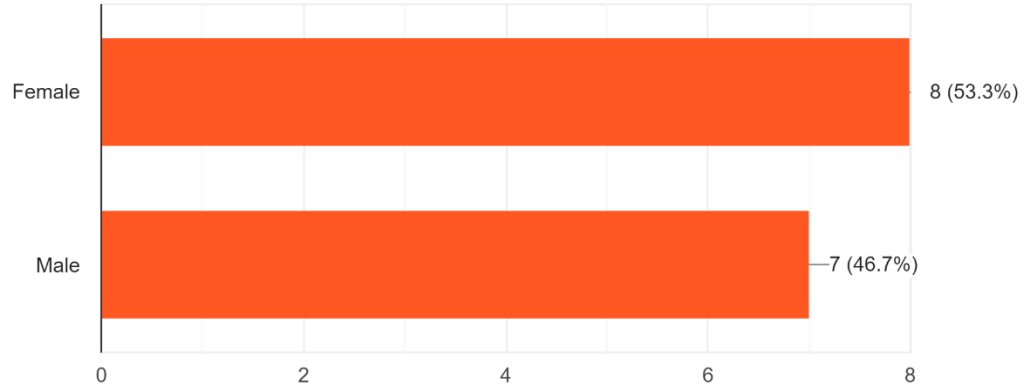


Respondents were asked for their age.



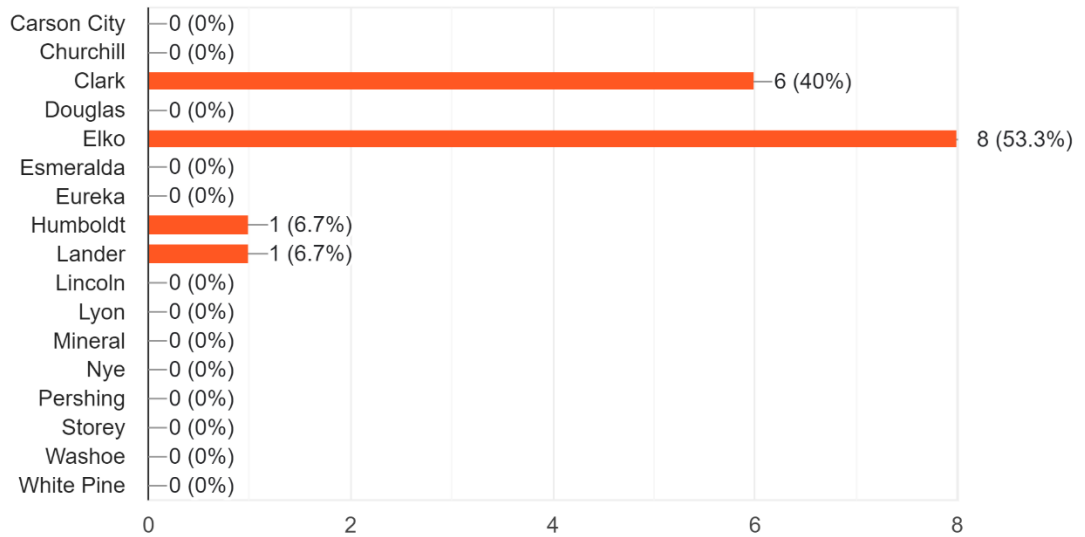
Gender

Respondents were asked to identify their assigned gender at birth as they relate to themselves, or the person with ASD if they are completing it on their behalf.



Geographical Representation

Respondents were asked to identify the county that they live in. The majority of respondents live in Elko County, (8 of 15 or 53.3%).



Findings

Most significant concerns

Respondents were asked to identify their three greatest worries for themselves (as someone living with ASD) or for the person they know living with ASD.

The top three recurring themes seem to be:

1. **Future Care and Support:**

- Many responses express anxiety about what will happen when parents or caregivers are no longer able to provide support. This includes worries about institutionalization, lack of adequate care, and the overall uncertainty of adult services for individuals with autism.

2. **Access to Quality Services:**

- Respondents highlight concerns regarding the availability and quality of services, particularly for transitioning into adulthood. This includes worries about access to therapy, job opportunities, and adequate staff support, as well as the inadequacy of resources in rural areas.

3. **Healthcare and Daily Care Needs:**

- There are significant worries about medical care being minimized and the daily care needs of individuals not being met. This encompasses concerns about understanding medical issues, allergies, and the overall provision of care that meets individual needs.

These themes illustrate the pressing need for improved support systems, resource availability, and comprehensive care strategies for individuals with autism, particularly as they transition into adulthood.

Direct responses:

- I worry that I may have to live in an institution, because I have limited service hours. I worry that doctors minimize my medical issues. I worry that HCBW staff will not understand me or my needs and will push me beyond my limits or ignore me during their shift.
- education, access to sports, access to therapies
- Out living my mother and who will provide adequate care
- Healthcare Daily care understand of the needs and allergies

- My brother/clients won't have job opportunities for lack of transitioning resources, My clients receiving services later in life and missing out on full amount of services and resources misdirecting the heirachy of importances for the needs a clients has (going to child fine instead of full time aba)
- access to quality services, ability to get staff credentialed in timely manner, transition services for young adults
- What happens to me when my parents are gone
- there won't be assistance in the workforce to better help them get situated. 2) they will get lost in adulthood without the proper services or help to better get them prepared 3) wish there was services to help them maneuver dating and all of the rural area were better equipped in general! Rural areas are not equipped with anything
- What happens to me when my parents are no longer here
- Will they have the care they need now and in the future. Will the costs of care be affordable to families needing it. Will there be enough respite staff to give caregivers a break.
- I am worried for their services and opportunities as an adult. Currently, there are lots of resources for children and adults with autism but once they become an adult, the resources are no longer available.
- Success in school, getting a job and services after graduation
- Learning how to deal with it going through life and being discriminated against.
- Safety in school, not being able to receive services fast enough, being bullied in school for being different
- Child's safety in school, not being able to express her feelings or if someone hurt her, not given the opportunities to excel

Most Pressing Needs

Respondents were asked to identify the most pressing needs that they (as someone living with ASD) or that the person they know living with ASD has.

The top three needs identified are:

1. Consistent and Well-Trained Staff:

- There is a strong demand for reliable and well-compensated staff across various support roles (RRC, HCBW, JDT) who are trained in effective communication tools and positive reinforcement techniques. This includes a

need for specialized training related to autism services and individual care plans.

2. Access to Quality Services and Resources:

- Respondents express a critical need for access to quality services, particularly Applied Behavior Analysis (ABA), educational support, and healthcare resources that are equipped to cater to individuals with autism. This includes a desire for more immediate services rather than long waitlists and improved collaboration among service agencies.

3. Transportation and Housing Support:

- There is a significant need for adequate housing options, supportive care, and transportation services, especially in rural areas where such resources are lacking. Ensuring individuals can access necessary programs and activities is essential for their integration and overall well-being.

These needs highlight the importance of improving workforce stability, service accessibility, and infrastructure to better support individuals with autism and their families.

Direct responses:

- Care, housing, transportation
- work programs to help them get started effectively in the workforce, 2) transportation is non-existent in the rural areas in general, 3) any activities in general is non-existent in the rural areas that helps the disabled to socialize with the community
- Transportations, home help, help for my aging parents
- Program supports, staffing, and medical needs met.
- Adult services
- Quality ABA in rural communities
- Receiving services in school, more activities for children with sensory issues, insurance
- Programs that cater to kids with ASD, funding to help pay for services, classes to help parents, teachers, caregivers how to tend to kids with ASD

What is Working Well

Respondents were asked to identify what was currently working well for them as someone living with ASD, or for the person they know living with ASD.

The top three things that work well are:

1. In-Home Supports and ABA Therapy:

- Many respondents noted that in-home supports, particularly through organizations like the Neighbor Network of Northern Nevada (N4), have been beneficial. ABA therapy was specifically highlighted for its positive impact, helping individuals learn important skills such as communication and daily routines.

2. Advocacy and Community Resources:

- Advocacy efforts, such as those from organizations like FEAT, and community resources that provide financial assistance (like ATAP) are working well. These resources help families navigate complex systems and access necessary support, enhancing awareness and understanding of autism within the community.

3. Therapies and Social Engagement:

- Speech and occupational therapies, as well as frequent social activities like playdates, are recognized as effective in helping individuals develop communication skills and engage socially. The involvement of caring parents and aides who treat individuals with respect and empathy also contributes positively to their development.

These elements highlight the importance of supportive environments, effective therapies, and advocacy in enhancing the quality of life for individuals with autism.

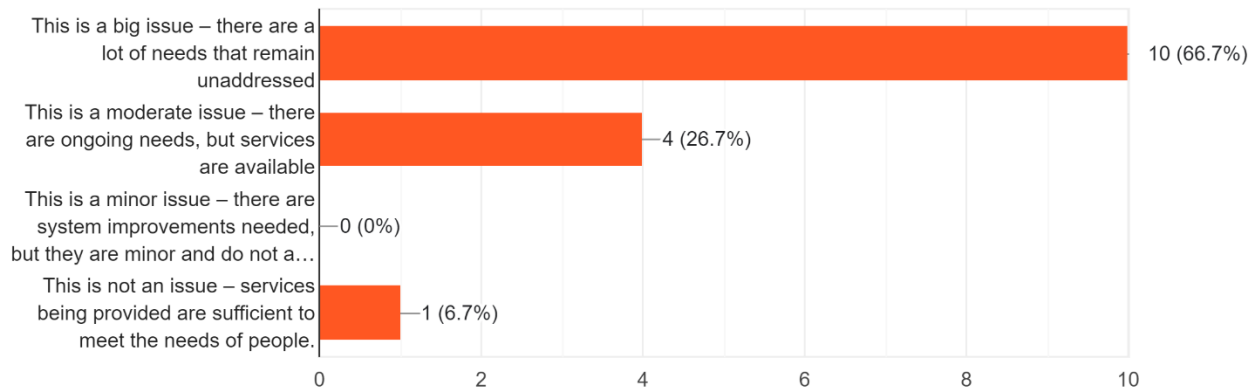
Direct responses:

- Living with family
- Neighbor Network of Northern Nevada (N4) has been able to provide me the same staff for several months. Yet, there is no one to come before 8:30 am or stay after 6pm. I have to rely on my parents (who are getting old) to keep me safe, cook meals and help me. In the past I received ABA and this greatly improved my life. I learned to use a schedule board, communicate with voice output, do leisure things, wait and tolerate things I didn't like. One thing that is working is that N4 does pay for current staff to train new staff.
- Advocacy and FEAT
- In home supports

- What is working is parents and aids are aware. Currently treating him like a person they care about, insurance is helpful because of the many needs that show up. People that are nonverbal are more difficult to access the healthcare needs. The needs are multiple for those with disabilities. ASD is far more serious than the general public is aware.
- Having prior knowledge working in a self-contained classroom and my BCBA I have been able to help navigate my client's and brother through the processes providing them knowledge and holding to expectations.
- atap for financial assistance, nevada aba facebook as a crowd sourcing of knowledge
- I have to travel out of area or state to get better assistance or any assistance.
- Getting medical appointments, friendly staff, some State support for expenses.
- ABA therapy
- ABA services
- keeping him active, talking with him through difficulties he faces throughout the day, being patient.
- Speech therapy, occupational therapy
- Speech therapy, occupational therapy, frequent play dates

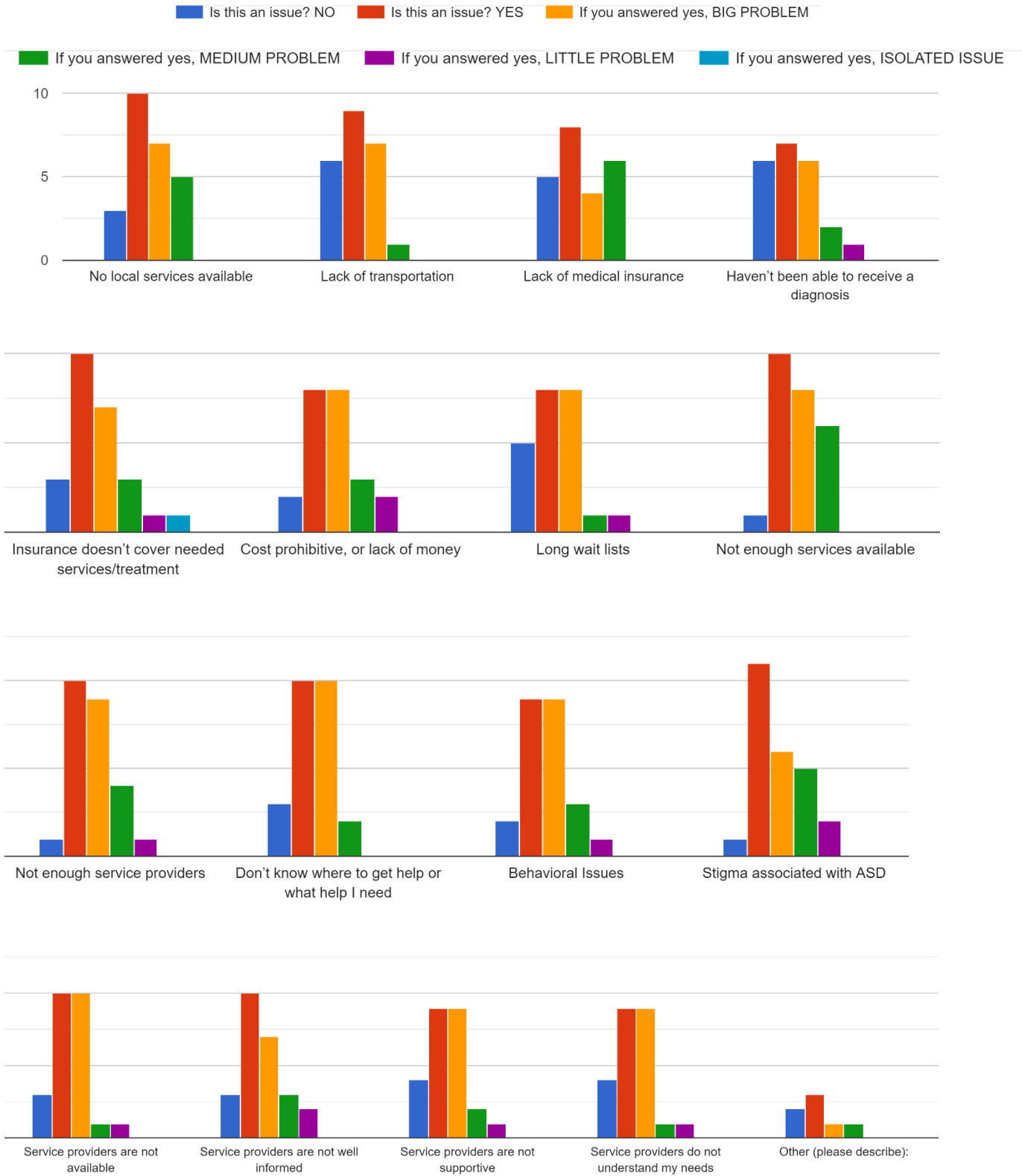
Access to Care

Respondents were asked to indicate how significant of an issue it is to access care in their communities.



Barriers to Service

Respondents were asked to rate, among a list of issues, those they believed were barriers to services. The following chart indicates the range in severity to Barriers to Service they believe that prevents themselves or other people from accessing services, treatments and/or supports.



Critical Issues

Respondents were asked to identify what the Commission should focus their efforts on to address the needs of people living with ASD.

The most significant theme from the responses is **the pressing need for comprehensive, well-funded, and accessible support services for individuals with autism and their families**. This theme includes several interrelated issues:

1. Training and Retention of Staff:

- There is a clear emphasis on the necessity for HCBW and RRC staff to receive ongoing training, particularly in ABA, to effectively support individuals with autism. Additionally, competitive compensation is crucial for retaining trained staff, which is essential for maintaining quality care.

2. Early Diagnosis and Intervention:

- Respondents highlight the importance of early diagnosis (18 months to 3 years) and access to ABA therapy and other therapies in schools. There is concern over the lack of services available for early intervention, which can significantly impact long-term outcomes.

3. Comprehensive Care and Support Systems:

- The need for 24/7 care options, respite services, and sufficient support for families is frequently mentioned. Families express the unsustainability of relying on them for care, highlighting a need for more flexible and accessible care solutions beyond group homes.

4. Resource Accessibility and Navigation:

- There is a desire for better access to resources, including guidance on navigating the diagnostic process and understanding available services. Creating a timeline for services and understanding how to access them at different life stages is critical.

5. Rural Access and Public Understanding:

- Respondents emphasize the lack of services in rural areas and the need for increased community understanding of autism. This includes addressing issues such as bullying and the importance of social communication and interaction opportunities.

6. Funding and Financial Support:

- Financial barriers are a significant concern, with calls for improved funding for services, insurance coverage, and support for families managing the costs associated with care and therapies.

Overall, these issues underline the necessity for a coordinated approach to service provision that addresses the diverse needs of individuals with autism and their families, ensuring accessibility, quality, and sustainability of care.

Personal Experiences

The Commission sought to further their understanding of the unique family experiences of individuals who live with ASD in Nevada, and asked respondents to provide a testimonial as a conclusion to the survey tool. The following excerpts are offered for consideration.

I have autism, intellectual delay, generalized seizure disorder, and cerebral palsy. I use a voice output device and gestures to communicate. Sometimes, I can't sleep for days. Othertimes, I can only sleep for days. Well trained HCBW staff work hard to make my days fun. We go to stores, the park, and to restaurants. I order my own food and talk to the clerks at the stores. With the help of staff, I do my own laundry, clean my kitchen and mop my floors. I love to play shooting the can games, air hockey and Wii fit. I love to swim. I just saw the Beatles Love show in Vegas for my birthday and I thought it was fantastic. I want to travel to more shows. My success in the community is dependent upon well trained HCBW staff, my parents training staff and filling in when there is no staff, ABA when I was younger to give me skills and tolerance, and a home of my own (or an apartment attached to my parent's house).

my son changed school 7x due to difficulty eith collaboration between the school and ABA

Lack of empathy and compassion within the community based on autistic meltdowns due to sensory issues and lack of community support and understanding

Person becoming over stimulated by lights in a store or something else and starts screaming. Child gets so frustrated he/she starts to disrobe in Public. The runners, run won't cooperate and get in the car, or run away in a store. The thing that helped the most is when someone said, how can I help to the care taker or friend. People just don't know, what to do best to ask.

My brother was diagnosed with ASD at 2 years old in 2009 when I was a teenager. His diagnosis changed the trajectory of my life. I have not only received my Bachelors in Special Education and my Master's in Intellectual Disabilities and Autism. I worked in the

school district for 5 years as a self-contained teacher and behavior specialist. Then moved into the private sector working in home and in clinic as a BCBA. I have seen many injustices done to my brother and my clients through the CCSD system, such as being kept in self-contained and not given a chance in resource or general education due to funding, teacher's not providing adequate data to suffice remaining in self-contained, para-professional not being trained appropriately in the ASD field nor being paid to stay once trained. I have sat with many clients that know nothing about the IEP process or what is taking place due to not being provided any information and just ran through the meeting to get it done. I have seen clients and my own mother given a diagnosis and told good luck out there and not fully preparing them for the road ahead when having a child with Autism. I believe being a parent with no road map is hard enough, including a diagnosis of Autism is a whole different journey and the parents need better supports and advocacy to help them navigate all the different components of their new life (school, community and home). Parents are being left behind to just google what they can and are being misled in various directions instead of getting the direct resources they need. I think we have a lot of opportunities to grow in as a state to better represent and help those on the spectrum. (Just to throw it out there, I would like to hear about opportunities in how to assist in that as well... I don't want to just state the problems, but would love to assist in a solution as well)

Medicaid didn't cover necessary medical procedure

I don't have friends

It is a challenge to find staff willing to give guardians a long-term break such as a weekend away.

This is not my personal story to share but rather someone that I advocate for. Recently, this child who is 5 years old unlocked the preventative strategies in his apartment and left in the middle of the night. He was found in town at the local gas station and the authorities were notified. His mother is a single mother and did not hear him leave and thought that with the extra locks in the house that this would have prevented him from escaping. The authorities were not well informed about autism and were reluctant to give the child back to his mother. This was scary and traumatizing for his family and the lack of understanding from community members was concerning because they didn't understand how to communicate with the child or the best steps to help the family with this experience.

My son could not focus in class and would constantly wander the classroom or hallways. Thinking this was a game he would run from any teacher trying to get him to refocus. One time he ran out of the school trying to escape a teacher and laughed at her the entire time.

when they finally caught up to him and brought him back to the school he immediately apologized but couldn't tell us why he did it.

Movie day- easy outing, sparked her interest and in return- happier attitude more willing to do hw and chores. Rewards and outings help in getting her To do chores and have a happier attitude over all

My daughter has sensory issues, so it's nice when certain places host events where they cater just to kids who are on the spectrum or have sensory issues. You don't feel judged, everyone understands what you are going through.

Autism Commission Members

<i>Korri Ward (Chair)</i>	Parent of a child with ASD who resides in a county with a population of <100,000.
<i>Corey Nguyen (Chair)</i>	Member who is a behavior analyst.
<i>Anna Marie-Binder</i>	Representative of the public at large.
<i>Amy Walch</i>	Parent of a person with an ASD who is over 12 years of age.
<i>Amy Coyne</i>	Representative of school districts in this State (Clark County).
<i>Nicole Muhoberac</i>	Parent of a child with autism who is under 5 years of age.
<i>Linda Tran</i>	Representative of school districts in this State (Washoe County).