



COMMISSION ON AUTISM SPECTRUM DISORDERS - KEY INFORMANT SUMMARY REPORT

2024

Abstract

The Commission on Autism Spectrum Disorders conducted a Key Informant Survey to gather insights from professionals, stakeholders, service providers, and service recipients.

Respondents provided input on key topics, including funding, insurance coverage, workforce development, and access to resources. Findings from the survey reveal both strengths and areas for improvement in ASD services across the state.

Key Informant Summary Report

Commission on Autism Spectrum Disorders

Introduction

Nevadans living with autism spectrum disorder (ASD) and their families, including targeted populations such as early childhood, youth, adults, and individuals residing in rural and frontier areas, face significant challenges. The following section of the report presents insights from 28 key informants, highlighting critical issues in areas such as funding, insurance, workforce development, and available resources.

Needs of Individuals Living with ASD

Key informants were asked to identify the most pressing needs and challenges faced by individuals living with ASD across Nevada.

Additionally, they were asked to evaluate the extent to which these needs are currently being addressed and to pinpoint the most significant barriers preventing access to essential services.

Availability to Intervention

- **Waitlists for providers to get ASD Diagnosis:** Many families face long waitlists for initial diagnosis, which delays access to necessary services.
- **Lack of providers for Diagnosis:** There is a shortage of providers qualified to diagnose ASD, especially in rural areas.
- **Lack of ABA therapy providers:** A significant number of families struggle to find ABA therapists, leading to limited access to this effective intervention.
- **Lack of Speech/OT Providers:** Finding speech and occupational therapists specializing in ASD can be challenging, limiting the availability of essential support services.
- **Lack of Respite Care for families, specifically in rural areas in Nevada:** Families, particularly those in rural areas, often lack access to respite care, which provides temporary relief and support.
- **In-home services:** The availability of in-home services for individuals with ASD can be limited, impacting their ability to receive support in their natural environment.

- **Specialized Daycare/Childcare for children with behavioral needs/ASD**
Diagnosis: Finding specialized daycare or childcare that can accommodate the unique needs of children with ASD is a common challenge.
- **Providers not accepting insurance:** Many providers do not accept insurance, making accessing services financially difficult for families.

Funding for Resources

- **Lack of funding and community support:** Insufficient funding for ASD services and limited community support can hinder access to resources.
- **Insurance:** Insurance benefits for ASD services can be inadequate, with limited coverage and high out-of-pocket costs.
- **Waitlists for services due to insurance companies not funding sufficiently or consistently:** Insurance companies may not provide sufficient or consistent funding for ASD services, leading to long waitlists.

Adequate Support Staff

- **Insufficient staffing and staff burnout due to lack of sick/PTO, lack of coverage for cancellations:** Understaffing and staff burnout can negatively impact the quality and consistency of support services.
- **Often inadequate support and training of RBTs due to overstretched BCBA:** RBTs may not receive adequate support and training due to the workload of BCBA.
- **Adults with autism who are receiving Home and Community Based Waiver services need access to appropriately trained HCBW staff in the home and on the job site (Job and Day Training), medication management by a nurse, and access to Applied Behavior Analysis and Board Certified Behavior Analysts' services:** There is a need for appropriately trained staff to support individuals with ASD in various settings, including homes and job training.

Additional Challenges

- **Education / services / socialization / transportation / affordable housing / 24-hour care providers:** Families face challenges in accessing free and appropriate public education (FAPE), socialization opportunities, transportation, affordable housing, and 24-hour care providers.
- **Lack of assessments from the schools, lack of access to providers for a diagnosis, lack of services in the community past the age of 21, and lack of**

providers for treatment: There are gaps in services and support for individuals with ASD, particularly after the age of 21.

- **Getting a diagnosis and obtaining services in a timely fashion:** Accessing timely diagnosis and services is a significant challenge for many families.
- **Assistance for parent/guardian/caregiver training from providers:** Families may benefit from training and support to provide increased quality care and to effectively advocate for their children with ASD.
- **Lack of access to services and understanding of the need:** There may be a lack of understanding of the need for ASD services and limited access to these resources.
- **More hours are needed for therapy and support and more prepared teachers:** There is a need for increased hours of therapy and support, as well as better-prepared teachers to meet the needs of individuals with ASD.

It is important to note that these challenges may vary depending on individual circumstances, geographic location, and available resources.

Individuals with Autism Spectrum Disorder (ASD) encounter substantial challenges in accessing essential interventions, funding, and adequate support staff. These obstacles include extended waitlists for diagnoses and services, limited availability of specialized providers, inadequate insurance coverage, and insufficient support in key areas such as respite care, in-home services, and specialized daycare. Furthermore, significant gaps exist in services and support for individuals with ASD, particularly for those over the age of 21. Collectively, these challenges impede their ability to achieve their full potential and lead fulfilling lives.

Overall, the responses indicate that current needs for individuals with ASD are not being adequately met. Many families face significant challenges in accessing necessary interventions, funding, and support.

Key areas of concern

- **Limited access to services:** Long waitlists, insufficient funding, and a shortage of providers contribute to limited access to essential services.
- **Inadequate support:** Families often lack adequate support, including respite care, in-home services, and specialized daycare.
- **Gaps in services for older individuals:** Services and support for adults with ASD are particularly limited.

- **Discrimination and lack of understanding:** Individuals with ASD may face discrimination and a lack of understanding from employers, healthcare providers, and the community.

Although some progress has been achieved, there remains a clear and pressing need to further enhance access to services, secure additional funding, and increase awareness of the unique needs of individuals with ASD.

Gaps in Service

Based on the provided responses, the top three themes related to gaps in service for individuals with ASD are:

1. Geographic Disparities:

- **Limited access outside of major cities:** Many individuals, especially those in rural areas, face difficulties in accessing services due to the concentration of providers in larger cities like Las Vegas and Reno.
- **Lack of services in specific regions:** Some areas, such as Elko County, have virtually no testing or diagnostic services available.

2. Limited Funding and Insurance Coverage:

- **Economic barriers:** Income and insurance coverage can significantly limit access to services for many families.
- **Insufficient funding:** Inadequate funding for ASD services can lead to long waitlists and limited availability.

3. Transitional Services and Support:

- **Lack of services after school:** There is a significant gap in services and support for individuals with ASD after they transition from school to adulthood.
- **Limited residential options:** Finding appropriate residential services, especially for individuals with severe autism or medical complexities, can be challenging.

Key informants were asked to identify what works and what doesn't work when seeking services; in addition, the major barriers to accessing services.

Based on their responses, the following key barriers to service access for individuals with ASD were identified:

Limited availability of providers:

- **Geographic disparities:** A lack of providers outside of major cities, especially in rural areas, limits access to services.
- **Shortage of specialists:** There may be a shortage of providers qualified to diagnose and treat ASD, particularly for older individuals.
- **Financial constraints:**
 - **Income eligibility:** Many families may not meet income criteria for government-funded services.
 - **Insurance limitations:** Insurance coverage can be inadequate, with limited benefits and high out-of-pocket costs.
- **Lack of knowledge and support:**
 - **Limited awareness of resources:** Families may not be aware of available resources or how to access them.
 - **Lack of support:** Families may struggle to find appropriate support, such as caseworkers or community providers.
- **Systemic challenges:**
 - **Long waitlists:** Families may face long waitlists for both diagnosis and services.
 - **Discrimination and bias:** Individuals with ASD may experience discrimination and bias from providers and employers.

Addressing these barriers requires a comprehensive approach that includes increasing the availability of providers, expanding funding for services, improving access to information, and fostering greater understanding and acceptance of individuals with ASD.

Based on the responses provided, several strategies have been identified as effective in supporting individuals with ASD and mitigating the challenges they face:

1. Advocacy and Policy Change:

- **Advocating for increased funding:** Efforts to increase funding for ASD services can help improve access and availability.

- **Promoting policy changes:** Advocating for policy changes, such as expanding eligibility criteria for government-funded services or improving insurance coverage, can help address financial barriers.

2. Improving Access to Services:

- **Expanding provider networks:** Increasing the number of providers, especially in rural areas, can help reduce waitlists and improve access to services.
- **Providing training and support:** Offering training and support to providers can enhance their knowledge and skills in working with individuals with ASD.
- **Developing telehealth options:** Utilizing telehealth can expand access to services, especially in rural areas.

3. Enhancing Family Support:

- **Providing information and resources:** Offering families information about currently available resources and ongoing guidance on how to access them can be helpful.
- **Connecting families with support groups:** Connecting families with support groups can provide emotional support and valuable information.
- **Offering parent training:** Providing parent training can equip families with the knowledge and skills to support their children effectively.

4. Promoting Understanding and Acceptance:

- **Raising awareness:** Increasing public awareness about ASD can help reduce stigma and discrimination.
- **Providing education and training:** Educating the community, including employers and healthcare providers, about ASD can foster greater understanding and acceptance.
- **Encouraging inclusive practices:** Promoting inclusive practices in schools, workplaces, and the community can help create a more supportive environment for individuals with ASD.

By implementing these strategies, we can take meaningful steps toward overcoming the barriers faced by individuals with ASD and fostering a more inclusive, equitable, and supportive society for all.

Affordable Care Act

Key Informants were asked to identify opportunities or concerns the Affordable Care Act (ACA) will have on ASD services/systems in Nevada.

Based on the responses, there is uncertainty and concern about the potential impact of the ACA on ASD services.

Key points:

- **Limited knowledge:** Many respondents expressed a lack of familiarity with the ACA and its specific implications for ASD services in Nevada.
- **Concerns about funding:** Some respondents expressed concerns about whether the ACA would adequately fund ASD services, particularly ABA therapy.
- **Potential barriers to access:** Some respondents identified potential barriers to accessing services, such as limited provider networks, high costs, and insurance limitations.
- **Mixed views on benefits:** While some respondents hoped the ACA would improve access to services, others expressed concerns about potential limitations and challenges.

Overall, it's clear that the impact of the ACA on ASD services in Nevada is complex and uncertain. Further analysis and information are needed to fully understand its potential effects.

Medicaid

Respondents were asked if their organization use Medicaid to fund services. Those who answered “yes” were asked to provide a brief description of the services offered and the methods of delivery. A total of eleven respondents indicated that they use Medicaid to fund their services.

Those who said "Yes":

- **School-based services:** Several respondents mentioned that their children receive services through their school's Individualized Education Program (IEP).
- **Private therapy services:** Some organizations and individuals provide private therapy services, such as ABA, speech, and occupational therapy.
- **Medicaid acceptance:** Some organizations accept Medicaid as a form of payment.

- **Advocacy and support:** Some respondents mentioned providing advocacy and support to families in finding services.

Overall, while some individuals can access services, many others face significant barriers. The availability and accessibility of ASD services vary widely depending on location, financial circumstances, and other factors.

Programs and Services Coordination

Key Informants were asked how well programs and services are coordinated across systems.

The following aspects of ASD services are going well, according to the responses:

- **Direct family peer support:** Peer support groups are providing valuable emotional support and practical advice to families.
- **Grassroots organizations:** Local nonprofit organizations are actively coordinating services and supporting families.
- **Collaboration among agencies:** Some agencies are successfully collaborating and referring clients to each other, improving access to services.
- **Effective coordination:** In certain cases, coordination among systems and agencies is working well, leading to positive outcomes for individuals with ASD.

What still needs to be done

- **Improved coordination:** There is a need for greater coordination among multidisciplinary teams and agencies to ensure seamless care for individuals with ASD.
- **Increased parent involvement:** Encouraging greater parent involvement in the coordination of services can help ensure that their child's needs are met.
- **Expanded services for older individuals:** Services and support for individuals with ASD who have "aged out" of school-based programs need to be expanded.
- **Improved access to assessments and referrals:** Schools and other agencies should ensure that children with ASD are assessed and referred to appropriate programs when necessary.
- **Increased funding and resources:** Additional funding and resources are needed to support the expansion of services and improve accessibility.

Overall, while there are some positive examples of effective practices, substantial improvements are necessary to ensure that individuals ASD receive the comprehensive support they need.

Transition

Key Informants were asked to describe where they transition their clients after completing ASD services or aging out of school-based programs.

Based on the responses, there are a few common destinations for individuals with ASD after they "age out" of school-based programs:

- **Adult-focused organizations:** Some respondents mentioned partnering with organizations that specialize in services for adults with ASD.
- **Post-employment supports:** Individuals may transition to post-employment support services through the employment network.
- **Regional Center:** The Regional Center may provide some services or referrals for individuals with ASD after they age out of school-based programs.
- **Aging & Disability Services Division:** This government agency may be able to provide some support or resources for individuals with ASD.

However, it's important to note that **many respondents expressed frustration and uncertainty about the available options** after individuals age out of school-based programs. This suggests a significant gap in services and support for this population.

Awareness

Respondents were asked how well individuals with ASD and those that care for them know about services that are available and what their organization does to educate parents about available services.

Organizations' Efforts to Inform Families about Services

Based on the responses, organizations are taking various steps to inform families about available services for individuals with ASD:

- **Providing information and referrals:** Organizations like Northern Nevada Autism Network (NNAN) and parent training centers are actively involved in providing information about resources and referring families to appropriate services.
- **Outreach and education:** Organizations are conducting outreach activities and hosting parent education events to increase awareness of available resources.

- **Collaboration with schools:** Some organizations are collaborating with schools to ensure that parents are informed about resources and support options.
- **Individualized support:** Organizations may provide individualized support to families, helping them identify and access the resources they need.

However, the responses also indicate that there is a need for **more widespread and consistent efforts** to inform families about available services. This could involve increased collaboration among organizations, greater investment in outreach programs, and improved communication with schools and other relevant agencies.

Strengths and Critical Issues

Key Informants were asked to identify areas of ongoing strengths within the various systems in Nevada that should be maintained, expanded, or leveraged in other areas.

Based on the responses, the top three themes related to strengths in supporting individuals with ASD are:

1. Specialized Services:

- **Applied Behavior Analysis therapy (ABA):** Therapy that is widely recognized as an effective intervention for individuals with ASD.
- **Specialized Clinics and Programs:** A range of clinics and programs provide tailored services for individuals with ASD, including those dedicated to early intervention, adult support, and vocational training.

2. Family Support:

- **Respite care:** Respite care programs, including self-directed respite, can provide valuable support to families.
- **Parent training and information:** Organizations that provide parent training and information can empower families to effectively support their children.

3. Government Programs:

- **Autism Treatment Assistance Program (ATAP):** provides financial assistance to families for intervention services.
- **Regional Center:** The Regional Center can offer support and resources for individuals with ASD.

- **Medicaid:** Medicaid can help cover the cost of some services for individuals with ASD (CHECK SPELL OUT).

While these strengths are notable, there remains a critical need for improvement in accessibility, affordability, and the availability of services for individuals ASD. This is particularly true for those in rural areas and for individuals who have "aged out" (up to age 22) of school-based programs.

Key Informants were asked to identify the most critical issues that Nevada needs to address to meet the needs of people living with ASD now and in the future.

Based on the provided responses, the following key themes emerged:

1. Comprehensive Support Services:

- **Transition services:** The need for comprehensive transition services to help individuals with ASD transition from school-based programs to adulthood.
- **Residential care:** The importance of quality residential care and home-based services.
- **Mental health support:** The need for mental health services for individuals with ASD who require additional support.

2. Improved Access and Affordability:

- **Financial support:** The need for financial support to help families access necessary services.
- **Accessibility:** Ensuring that services are accessible to individuals in all regions, including rural areas.

3. Education and Awareness:

- **Education on ASD:** Raising awareness and understanding of ASD among the general public, educators, and healthcare professionals.
- **Person-first language:** Promoting the use of person-first language when referring to individuals with ASD.
- **Training for professionals:** Providing training and education for professionals working with individuals with ASD.

4. Advocacy and Policy Change:

- **Full inclusion:** Advocating for full inclusion in schools, communities, and workplaces.
- **Policy changes:** Advocating for policy changes to ensure that individuals with ASD have access to necessary services and support.

5. Addressing Systemic Issues:

- **Addressing stigma:** Challenging stigma and discrimination associated with ASD.
- **Improving accessibility:** Ensuring that services are accessible to individuals with disabilities, including those with transportation or communication challenges.
- **Addressing systemic barriers:** Identifying and addressing systemic barriers that hinder access to services.

These themes underscore the urgent need for a comprehensive approach to supporting individuals with ASD, one that addresses both their unique individual needs and the systemic challenges they encounter.

Recommendations

Policy Level Changes

Key Informants were asked what policy level changes are needed to improve services for people with ASD at the local, regional, and/or state level.

Based on the responses, several policy-level changes were suggested to improve support for individuals with ASD:

1. Funding and Resource Allocation:

- **Increased funding:** There is a general call for increased funding for ASD services and programs.
- **Expanded access to resources:** Ensuring that resources are available in all areas, including rural regions.
- **Financial support for families:** Providing financial support to families, such as through the ATAP.

2. Service Delivery and Access:

- **Lifelong support:** Ensuring that individuals with ASD have access to lifelong support, rather than being limited by age restrictions.

- **Improved access to services:** Expanding access to services, including in areas like mental health, respite care, and vocational training.
- **Addressing systemic barriers:** Identifying and addressing systemic barriers that hinder access to services, such as limited provider networks and insurance limitations.

3. Healthcare and Insurance:

- **Improved insurance coverage:** Mandating better insurance coverage for ASD services, including ABA therapy.
- **Fairer reimbursement rates:** Ensuring that providers are adequately compensated for their services.

4. Education and Awareness:

- **Educating professionals:** Providing training and education for professionals working with individuals with ASD, including educators, healthcare providers, and law enforcement.
- **Promoting person-first language:** Raising awareness of the importance of using person-first language when referring to individuals with ASD.

5. Employment and Inclusion:

- **Quotas or goals for hiring:** Implementing quotas or goals for hiring individuals with disabilities.
- **Full inclusion:** Promoting full inclusion in schools, communities, and workplaces.

These recommendations highlight the need for comprehensive and systemic changes to ensure that individuals with ASD have access to the support and services they need throughout their lives.

Practical Changes

Key Informants were asked what practical changes are needed to improve services for people with ASD at the local, regional, and/or state level.

Based on the responses, several key themes emerged regarding the practical changes needed for individuals with ASD:

1. Improved Access and Affordability:

- **Increased funding:** The need for increased funding to support services and programs for individuals with ASD.
- **Expanded access to services:** Ensuring that services are accessible to individuals in all regions, including rural areas.
- **Financial assistance:** Providing financial assistance to families to help them access necessary services.

2. Education and Awareness:

- **Education for professionals:** Training professionals in various fields, including education, healthcare, and law enforcement, on ASD and how to work effectively with individuals ASD.
- **Public awareness:** Raising awareness about ASD and challenging stigma and discrimination.

3. Specialized Services:

- **Early intervention:** Ensuring access to early intervention services.
- **Transitional support:** Providing comprehensive transition services for individuals as they move from school-based programs to adulthood.
- **Specialized therapy:** Offering specialized therapies, such as ABA and speech therapy.

4. Systemic Changes:

- **Policy reforms:** Advocating for policy changes to improve access to services and support for individuals with ASD.
- **Improved coordination:** Enhancing coordination among different systems and agencies involved in providing services.
- **Addressing systemic barriers:** Identifying and addressing systemic barriers that hinder access to services, such as transportation challenges and limited housing options.

These themes emphasize the necessity of a comprehensive approach to supporting individuals with ASD, focusing on both their individual needs and the systemic challenges they encounter.

Projects/Approaches

Key Informants were asked to share other projects or approaches that is occurring successfully in another state/location that should be considered for implementation in Nevada.

Schools:

- Scenic View Academy in Provo, Utah (mentioned but location may not be ideal)
- Schools dedicated to serving children with ASD (mentioned in Arizona and California, specific locations not provided)
- Bay Area or Northern California (mentioned for special autism school transportation)

Adult Services and Housing:

- Adult housing with support – Arizona (link provided):
<https://www.autismhousingnetwork.org/community/first-place-phoenix/>
- Many states have more robust Regional Center Services than Nevada (mentioned but specific states not provided)
- Adult housing with support is missing in Nevada (mentioned as a need)
- Programs in other states that work with Lyft and Uber for transportation (mentioned but specific states not provided)
- California - parents being paid to provide caregiver services for underage children (mentioned but details not provided)
- Massachusetts and New York - offering several housing options for underage children (mentioned but details not provided)

Programs and Support:

- Employment training facilities for people with Autism (mentioned in Georgia, location may not be ideal)
- Summer camps for social skill development (mentioned as a need)
- Movie theaters with sensory days (mentioned as a need)

Policy and Legislation:

- Arkansas HCBS 1915(c) Medicaid Autism waivers (mentioned)

- Arkansas TEFRA-like program (mentioned)
- North Dakota's Autism Waiver & State Plan (link provided): <https://www.hhs.nd.gov/cfs/autism-services>
- Families on Track program (mentioned)
- FASD (Fetal Alcohol Spectrum Disorder) United Family Navigator Program (mentioned)

Other Insights

In addition to the primary themes identified, respondents provided the following additional insights:

1. Need for Improved Assessment and Diagnosis:

- **Early and accurate diagnosis:** The importance of early and accurate diagnosis to ensure timely intervention and support.
- **Improved assessment practices:** The need for school psychologists and other professionals to improve their assessment and diagnostic practices.

2. Systemic Challenges:

- **Limited access to services:** The ongoing challenge of limited access to services, particularly for individuals with complex needs.
- **Lack of understanding:** The need for increased understanding of ASD among the general public, educators, and healthcare professionals.
- **Systemic barriers:** Identifying and addressing systemic barriers that hinder access to services, such as limited housing options and transportation challenges.

3. Advocacy and Policy Change:

- **Advocacy for individuals with ASD:** The importance of advocating for the rights and needs of individuals with ASD.
- **Policy reforms:** The need for policy changes to address the specific challenges faced by individuals with ASD.
- **Prioritizing neurodiversity:** Recognizing the importance of neurodiversity and designing programs and policies that are inclusive of individuals with diverse needs.

4. Personal Experiences and Recommendations:

- **Shared experiences:** Many respondents shared personal experiences and recommendations based on their own journeys.
- **Call for action:** Several respondents emphasized the urgent need for improvements in the system and called for action to address the challenges faced by individuals with ASD.

These additional themes further underscore the complex and multifaceted challenges associated with ASD and reinforce the need for comprehensive, continuous support for individuals with ASD and their families.

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).