



**Nevada Commission
On Autism Spectrum Disorders**

Addressing issues across the lifespan

Key Informant Summary Report



ACKNOWLEDGEMENTS

The Nevada Commission on Autism Spectrum Disorder Strategic Planning Steering Committee would like to thank and acknowledge the key informants that provided their valuable time and perspective by participating in interviews. Their input will be used to help craft the focus and action of the Commission for years to come.

Key Informant	Organization
Barbara Buckley, Esq.	Legal Aid Center of Southern NV, Inc.
Jon Sasser	Washoe Legal Services
Mario J. Gaspar de Alba M.D., FAAP	University of Nevada School of Medicine: Developmental-Behavioral Pediatrics
Ryan Giles	Chrysalis Homes
Scott W. Harrington, Ph.D., BCBA-D	UNR -NV Center for Excellence in Disabilities
Casey Lynn Hayden, M.A. BCaBA, LaBA	The Lovaas Center for Behavior Intervention
Janice John	DETR/Voc Rehab
Cheryl Jung	Advocate
Robin Kincaid	Nevada PEP
Julie Kotchevar	ADSD
Ron Leaf	Autism Partnership
Kenneth R. MacAleese, Ph.D., BCBA-D, LBA	Advanced Child Behavior Solutions
Robin Williams	Regional Center



Social Entrepreneurs, Inc., a company dedicated to improving the lives of people by helping organizations realize their potential, conducted the key informant interviews and prepared this summary report.

TABLE OF CONTENTS

Introduction and Background	1
Purpose	1
Methodology.....	1
Findings	2
Needs of Individuals Living with ASD	2
Service Sufficiency.....	2
Financial Supports.....	4
Awareness.....	6
Sufficient Workforce	7
Service Coordination.....	8
System Strengths	9
Autism Treatment Assistance Program (ATAP)	9
University-Based Autism Programs.....	9
Size and Configuration of State Staff/Systems	9
Recommendations	10
Increase Access	10
Increase Awareness	10
Increase Availability	10
Conclusion.....	11
Next Steps	11
Appendices.....	12
Key Informant Interview Questions.....	12

INTRODUCTION AND BACKGROUND

The Nevada Commission on Autism Spectrum Disorder (herein referred to as “Commission”) has embarked upon a strategic planning process to explore and confirm the most pressing needs of individuals with ASD across the lifespan and to establish a five-year plan to guide the Commission in responding to those needs.

As part of this process, the Commission developed a Strategic Planning Steering Committee (herein referred to as “Committee”) made up of each of the members of the Commission as well as the chair of each of the Commission subcommittees which are; the Early Childhood Subcommittee, the Youth & Transition Subcommittee, the Adults & Aging Subcommittee, and the Rural Subcommittee.

This Committee recognized the need to engage a variety of key stakeholders to confirm the needs of individuals living with autism, and to explore what areas within the existing system need to be expanded, changed, discontinued or legislated to better meet current and future needs of these individuals. The Committee identified key stakeholders as consumers and their caregivers, ASD services providers, and individuals with intimate knowledge of each of the target populations represented by the Commission subcommittees. Input was gathered by conducting key informant interviews with community partners, distributing surveys to consumers and providers, and facilitating focused discussions during subcommittee meetings with members and participants. This report is a summary of the key informant interviews that were conducted.

PURPOSE

Key informant interviews were conducted as a mechanism to gather insight on the strengths and challenges related to the existing system(s) for individuals with ASD. This report synthesizes key informants’ impressions, experiences and opinions. It will be used by the Committee in association with a variety of other data sets (both quantitative and qualitative) to finalize the focus of Commission efforts over the next 5 year period of time.

METHODOLOGY

Between September 8th and October 5th, 2014, 13 interviews were conducted with individuals identified by the Commission and each of the Commission Subcommittees as having specialized knowledge about the systems that provide services to Nevadans living with ASD throughout the lifespan.

An initial contact list was provided to SEI by the Commission and each of the Commission Subcommittees. SEI sent an email request to the individuals on the list requesting their participation and scheduled the interviews directly. Once a date and time were finalized with the key informant, a confirmation email was sent with a copy of the questions in advance. The interview questions used were developed in consultation with SEI and approved by the Committee and can be found in the appendix of this report.

All interviews were completed by Lisa Watson, SEI consultant. Each interview lasted between 30 and 90 minutes. While notes were taken during each interview, all interview participants were assured that no response would be attributed to a specific key informant. The information extrapolated from the interviews has been aggregated and summarized for the purpose of this report.

FINDINGS

The following section of the report identifies the perception of critical issues facing Nevadans living with ASD, as well as those that are specific to targeted populations such as early childhood, youth, adults, and those living in rural and frontier areas. Insights shared by interviewees is grouped by major themes.

NEEDS OF INDIVIDUALS LIVING WITH ASD

Key informants were asked to describe the most significant needs or challenges facing individuals living with ASD throughout Nevada. In addition they were asked to assess the extent to which those needs are currently being met and to identify the greatest barriers to accessing services.

The following represent major themes that were identified by multiple interview participants.

SERVICE SUFFICIENCY: A majority of key informants identified a lack of sufficient services to meet the needs of individuals living with ASD throughout Nevada. This was described for all subpopulations throughout Nevada, although there was an emphasis provided in relationship to the more rural parts of the state.

-  Lack of services is the most significant concern. There are so many families to serve and not enough resources to do so.
 -  We have not met the minimum level of care for people. We don't even have a basic infrastructure in any area of the state.
 -  Rural areas do not get even the most basic of services.
 -  We have nearly 5,000 kids identified by school districts as having ASD, but only 300 on the ATAP service roles. There appears to be a big gap between the number of people identified and those being served.
- Screening & Diagnosis*
-  It could take a kid up to 8 months to get an appointment for diagnostic services.
 -  We are not identifying kids until right before they age out of early intervention services, so they go into the backlog of ATAP waitlists and are not able to access services as soon as they should.
 -  NEIS was not screening kids early enough to get them into treatment.
 -  There is no place for adolescents to get diagnostic care.
- Early Intervention*
-  There are very few families who are receiving services from Nevada Early Intervention Services (NEIS). The ones that are getting services, are not getting it at the required intensity.
 -  NEIS has not done a good job at providing intensive interventions. We need to continue to work at diagnosing kids earlier, and then get them into intensive levels of care.
 -  Less than half of the kids that come to us come prior to the age of 6. If they came to us earlier (under 5), we could ensure that they would not need to transition to other services. They would be relatively undistinguishable from their peers.

School Based Services & Supports

- ❁ School systems do not have the appropriate levels of staff to support the needs of kids living with ASD. The staff they do have do not have the information to appropriately serve these kids.
- ❁ There is insufficient information, advocacy or services provided to kids through school districts. Kids are forced to prove they deserve a fair and equitable education.
- ❁ Some schools started to provide service to kids with ASD at the required intensity, but it became expensive so they scaled back. They are now providing some services, but it is not evidence-based. It is not done at an effective level and will not produce long-term benefits. It is putting a Band-Aid on the issue.
- ❁ Sometimes when we transition kids to school systems, the school “undoes the gains made.” They are not really well set up to support kids with ASD.
- ❁ We rely on school districts to provide services to kids with ASD, and it is probably an unrealistic expectation.
- ❁ Folks in education only strive to follow minimal standards of care, especially in IEP structure.
- ❁ There is approximately 4,900 kids with ASD in the Clark County School System, but only 70 of them are receiving home-based services.

Transitional Supports

- ❁ Families really struggle when their child turns 9, as ABA supports are only provided through that age. When kids are transitioned out of these services, they are not offered a different kind or level of service.
- ❁ There are not a whole lot of services available for transitional aged youth. There are less and less services available to kids as they age.
- ❁ When kids age out of the system (age 21) they have no place to go. If the issue isn’t addressed, these kids will be simply turned over to their families.
- ❁ We need to focus on providing kids with vocational skills and life skills much earlier.

Job Training & Employment Supports

- ❁ We don’t do a very good job at individualizing our approach to job training with teenagers. If we did, it would help them succeed in the work world.
- ❁ Vocational Rehab (Voc Rehab) serves a minimal amount of people. The jobs that they are getting are low-wage, part-time work. We need to find more meaningful living wage opportunities for our adults.
- ❁ We need to create more opportunities for integrated employment. Integrated opportunities are insufficient in Nevada.
- ❁ Research shows that exposure to work through community based experiences increases long-term outcomes for individuals with ASD.
- ❁ There are multiple levels of employment supports needed for this population. We need staff in state programs that understand the needs of this population. We need the community to step up and support job placement opportunities, and we need job coaches that can work with both the individual and the employer to ensure success.

Family Supports

- ❁ We need to honor families as a source of support for people living with ASD. We need to factor families into our care model early and often.
- ❁ Families are really struggling. Funding for respite care is minimal.
- ❁ We are just as concerned about parents taking care of themselves, positioning them to care for their families in the long-term.
- ❁ When we are fixated on just the therapeutic needs of the child, we lost the opportunity to address the comprehensive needs of the family.

Other service needs that were identified by key stakeholders included assistive technology supports, speech and language therapy, behavioral healthcare, transitional supports, housing, daily living/adaptive skill development, and person-centered planning.

In addition to the lack of service array as described above, a consistent theme throughout interviews was the shallow scope of services. There was wide-spread recognition that evidence-based treatment and appropriate levels of care was insufficient to meet the complex needs of individuals. The result of this dynamic, as described by multiple key informants, was the lack of long-term outcomes associated with treatment.

FINANCIAL SUPPORTS: Key informants identified the need for financial supports necessary to address the various needs of individuals living with ASD. Multiple key informants recognized the gains made through the ATAP program, but indicate that the amount of funding is still insufficient as wait-lists are significant. Significant criticism was levied against insurance products that either deny service claims or erect barriers to prevent access. The Affordable Care Act and changes being made to the Medicaid Waiver were identified as two opportunities that should be tracked and leveraged to support additional services in the future.

- ❁ Money is the biggest barrier to getting things done. Appropriate services are expensive.
- ❁ We need to maximize the amount of funding available to provide sufficient services. We need to ensure coverage through Medicaid, private insurance, and state funded programs (ATAP). We need to go in that order to maximize service availability.
- ❁ Needs are not being met sufficiently. Insurance and government funding is beginning to address the needs, but it is not enough. We don't have it all put together enough, especially through Medicaid.
- ❁ Reimbursement rates provided by both insurance companies and Medicaid are not enough to cover costs.

State Funding

- ❁ ATAP has really filled a huge void.
- ❁ ATAP wait lists are significant. We have parents that come to us and we check their status every month. While ATAP has really ramped up its efforts, it is not enough.
- ❁ ATAP is working, in terms of getting people something, but it is not working optimally.

Federal Funding

- ❁ The federal government’s agreement to cover ASD services is a game changer.
- ❁ We need the Medicaid issue to be dealt with so we can move on to the private insurance issues.
- ❁ Mental health parity under the Affordable Care Act may allow us to expand services to adults with ASD.

Insurance Products

- ❁ ATAP has a significant waiting list. When we began to explore the issue, we found many kids being served by ATAP that had private insurance. That is when we started looking at why insurance wasn’t covering ASD services.
- ❁ There are so many insurance companies that continue to deny coverage.
- ❁ Insurance coverage is very limited. Very few get covered for evidence-based levels of services.
- ❁ There are a lot of ASD providers in the state that do not know how to navigate insurance systems to gain access to care for their clients.
- ❁ Co-pays make accessing services difficult for our clients that have insurance.
- ❁ Kids age out of insurance coverage at age 22. Insurance mandate does not provide coverage.



AWARENESS: Key Informants were asked to describe how well individuals know what services are available and how to access them. While some interviewees felt they were not positioned to answer this question, and others acknowledged the reality that as a provider, the families they come into contact with are already informed, a majority of folks described a deficiency in the amount of information that is known or shared with individuals needing services.

Consumer Awareness

- ❁ I don't think people know about services available. People with limited resources, or who are monolingual Spanish speakers don't have access to information or know how to acquire it when the need presents itself.
- ❁ Parents are poorly educated about services available. I bet they know more about complimentary services (fad interventions) than core service delivery.
- ❁ Parents have to be persistent. These services do not just fall into your lap. Families are required to do case management and service coordination for their own child/needs. Not all families can do that because of skills, resources, or time.
- ❁ Many times, families are not that ABA home-based services are available. They are told about the services by other family members.
- ❁ I don't think people know about services as much as they could. Sometimes we need to look at how we outreach effectively. Instead of inundating them with pamphlets, people need another individual to help them understand what is available.
- ❁ Those that know (about services), know it really well. Those that don't, become pawns in the system. They are reliant upon people to tell them, and if they are uninformed or misinformed, then they are delayed in accessing care.
- ❁ We need to get better at helping parents understand how to access our services and to transition between programs easier.

Provider Awareness and Information Distribution

- ❁ Providers don't even have the necessary information to support families.
- ❁ Schools do not actively seek out information regarding community resources. There may be a fear that if informed, parents may seek out additional services that schools have difficulty providing because of cost.
- ❁ Parents go through multiple systems (NEIS, school systems, medical community) and do not get information about what their kids need or what they can get.
- ❁ I have had teachers tell me that they were told that they could not tell parents about other services available, as it would identify what they were not doing correctly.
- ❁ Providers, including pediatricians often don't know what is available.

In addition to the awareness of consumers and providers, key informants also described the need to educate the general public, to include employers and key stakeholders to build support and acceptance for individuals living with ASD.

SUFFICIENT WORKFORCE: Nevada does not have a sufficient network of services/providers to adequately respond to the growing number of individuals with ASD. This results in a long-wait for services, and puts some people in a position to settle for services that are not high quality.

*Workforce
Development*

- ❁ We have not been able to grow the professional community to keep up with the demand. There are not enough professionals to go around. This is extremely amplified in the rural communities.
- ❁ People in the rural areas are really struggling with a provider shortage.
- ❁ We need to build the provider base as more and more kids are needing the care/being diagnosed.
- ❁ Finding providers is very difficult. We are hearing more and more from families that they cannot find the right provider to meet the needs of their family based on fit or quality considerations.
- ❁ We need to expand the provider base, so that when families get a diagnosis, they have sufficient options to choose a provider that fits their needs.
- ❁ Rural areas do not typically attract professionals, leaving folks with little choice related to who will serve them.
- ❁ I have long wait-lists because I cannot keep up with the demand.

*Training &
Certifications*

- ❁ We need a new system for training providers. For private providers (accepting reimbursement through private insurance), the licensure requirement is not reasonable, and has established a deprivation of providers.
- ❁ Licensing requirements (CABI's) is an onerous process. We have only been able to get 100 certified throughout the state. ATAP has a lower-level certification, which has increased the amount of providers available. We should focus our efforts on training folks, but not make the process so time intensive and expensive as it currently is.
- ❁ Certification is really important, as it maintains a certain quality of providers who are knowledgeable, and follow evidence-based practices.
- ❁ Nevada is the only state that has this CABI certification requirement, in large part because of insurance requirements. It is a hard balancing act, as we need to provide quality and protection to the consumer as well as access.
- ❁ I think people deserve high quality services. In Nevada, how we have implemented the regulatory process is expensive and ineffective at ensuring quality. We need sensible regulation that ensures quality and supports access.
- ❁ A little amount of certification can be more damaging than beneficial, as it gives folks a false sense of "quality." We have set up a system that we wouldn't establish for doctors or pilots. ABA interventionists are providing life altering services. Lives are being compromised because we don't have adequate quality assurances.

Incentivizing Longevity in Field

- ❁ We are not sufficiently paying providers enough to incentivize longevity.
- ❁ The funding available to support staffing programs makes it hard to find quality staff. We are hiring people in circumstances where this may be their first job (because of the pay rate). This impacts the turn-over rate in the field and the quality of care we can provide.
- ❁ For Nevada’s most vulnerable population, we need to take a hard look at how much we are paying folks to provide critical care services.

SERVICE COORDINATION

Being that individuals with ASD often receive services through multiple system and providers throughout their lifespan, it was important to understand how well services were provided in a coordinated and consistent fashion. To understand this, key informants were asked to share their opinions about how well coordination occurs across systems.

While multiple interviewees described the current situation as being “better than it used to be” they still described the need for additional efforts in this area.

The system is reactive - which means we are behind the curve already. If we became pro-active, we could reach these kids earlier and achieve better outcomes.

- ❁ Systems are very fragmented. Families are very concerned that they have to fill out another application, and be screened and deemed eligible multiple times. It would be nice if Medicaid and the Regional Centers could establish a streamlined application process. It would also be nice if NEIS files could be shared with other state programs so families would not have to continually spin their wheels.
- ❁ Service coordination is pretty poor from cradle to grave. It is a nightmare for parents. Different providers don’t work together, and many have different opinions. Parents have to work with multiple providers across many disciplines. Parents either have to take on service coordination themselves, or they back off and nothing gets done for their kids. At some point, parents may just give up, especially as these kids become adults.
- ❁ Regional Centers implement services based on a different interpretation of the federal waiver.
- ❁ The school system is not collaborating with any community providers. Community providers will sometimes give the school information, but there is not any collaboration between entities.
- ❁ There is not a lot of coordination across systems. There is a lack of coordination across school systems and providers. It is almost as though they battle.
- ❁ We need to firm up our coordination between NEIS and ATAP. We can collaborate better.

Many key informants identified the hope of future gains in the area of service coordination with the integration of Developmental Services and Nevada Early Intervention Services into the Aging and Disability Services Division (ADSD) in the Department of Health and Human Services (DHHS).

- ❁ It is better than it used to be. ADSD is working on a single point of entry. We have purchased a data system that will help us link our systems. This is going to take time and lots of money, but we are moving in that direction.

- Until last year, we were all in different divisions. We have since merged and are under a single umbrella. We have really focused our efforts on streamlining our process.
- While there are some problems at every level of transition, there seems to be some progress being made.

SYSTEM STRENGTHS

Key Informants were asked to describe strengths of the services system in an effort to identify what should be maintained, expanded, or leveraged for continued progress in service to individuals with ASD. While there was no overwhelming acknowledgement of any particular system or approach, there were multiple references to the Autism Treatment Assistance Program (ATAP), Autism focused programs at University's throughout Nevada, as well as the benefits provided by the size and configuration of state staff.

AUTISM TREATMENT ASSISTANCE PROGRAM (ATAP)

- The ATAP program is a program we could look at expanding. It has a very accountable structure.
- We should build off of the ATAP model of care.
- ATAP provides a state funded program, which is not required or offered by some other states.

UNIVERSITY-BASED AUTISM PROGRAMS

- In Nevada, we have two Universities that have a training program for ABA services. UNR is the best training program in the country for training ASD behavioral analysts.
- The UNR U-CAN Program had an autism summit that brought different groups together to look at how to assess kids from multiple perspectives.
- Some of the information that comes out of the University programs help people access care.
- The Touro program is very good.

SIZE AND CONFIGURATION OF STATE STAFF/SYSTEMS

- We are small enough to know and have access to everyone in the state. With this dynamic, we can be agile and have an opportunity to get things done.
- There is a simplicity in how the system operates at the state level that makes it easy for us as providers to bill, etc. We are not wrapped up in all the justification that is required by other states.
- State leadership is very accessible.
- The Commission on Autism Spectrum Disorder has provided great leadership.
- There is some strong leadership at ADSD.

Other strengths mentioned included the Lovaas Treatment Center, the VOICE program in Washoe County, the Governor's efforts at establishing the Task Force on Integrated Employment, the TACSEI program, continuation of increased funding during each legislative session and the non-profit and community based programs that provide advocacy and support to parents of children with autism.



RECOMMENDATIONS

The following recommendations were established based on the key informant interviews and are intended to support the efforts of the steering committee as it finalizes the focus of the Commission over the next 5 year.

INCREASE ACCESS

Recommendation #1: Advocate for Insurance Solutions

- Establish insurance coverage mandates for ASD services throughout the lifespan.
- Establish a comprehensive plan to provide ABA services through Medicaid.

Recommendation #2: Increase Funding to support:

- Increased service capacity through state sponsored programs (NEIS, ATAP, Voc Rehab, and Regional Centers).
- Provision of evidence-based levels of care
- Sufficient access to services in rural parts of the state
- Decreased wait times for services

Recommendation #3: Coordinate with School Systems to strengthen:

- Response to serve kids with ASD
- Coordination with other care providers
- Access to evidence-based levels of care

INCREASE AWARENESS

Recommendation #4: Establish an Outreach and Education Campaign designed to:

- Inform consumers about available services and how to navigate various service systems and insurance products.
- Equip community partners with information about how to appropriately connect people to care.
- Educate the general public and key stakeholders in an effort to creating a supportive and accepting community.

INCREASE AVAILABILITY

Recommendation #5: Invest in Workforce Development incorporating the following components:

- Recruit, train, and Incentivize longevity in the field for professionals that provide treatment to individuals with ASD throughout the lifespan.
- Equip existing community providers to appropriately respond to the needs of individuals with ASD through their typical practice.
- Develop certification standards that balance quality with access.

CONCLUSION

NEXT STEPS

The information provided by key informants should be utilized in conjunction with the other data to include the 2008 Nevada Autism Task Force Report, provider survey data, key informant interviews and subpopulation specific information as solicited through focused discussions. These combined should equip the Strategic Planning Steering Committee with the information needed to develop a thoughtful, and responsive strategic plan for their future.

APPENDICES

KEY INFORMANT INTERVIEW QUESTIONS

1. What communities and/or constituent groups related to individuals with ASD do you feel you can represent the best?
2. In those communities and constituent groups, what are the most significant needs or challenges facing people who need/use services?
3. To what extent are those needs currently being met?
4. What are the biggest gaps in services? Are there any gaps that are particularly pronounced based on region?
5. What works and what doesn't when seeking services? What are the major barriers to accessing services for people with ASD?
6. What opportunities or concerns do you think the Affordable Care Act will have on ASD services/systems in Nevada?
7. Does your organization use Medicaid to fund services? If the answer is yes, can you give me a brief description of what and how you provide those services?
8. How well are programs and services coordinated across systems?
9. Where do you transition clients to after they have received ASD services from your agency and have aged out?
10. How well do individuals with ASD and those that care for them know about services that are available? What does your organization do to educate parents to services available?
11. What are areas of ongoing strengths within the various systems that serve individuals with ASD in Nevada that should be maintained, expanded or leveraged in other areas?
12. What are the most critical issues that Nevada needs to address to meet the needs of people living with ASD now and in the future?
13. What policy level changes are needed to improve services for people with ASD at the local, regional, and/or state level?
14. What practical changes are needed to improve services for people with ASD at the local, regional, and/or state level?
15. Are you aware of a project or approach that is occurring successfully in another state/location that should be considered for implementation in Nevada?
16. Are there any other insights you would like to share at this time?