



**Nevada Commission
On Autism Spectrum Disorders**

Addressing issues across the lifespan

Subpopulations Summary Report



ACKNOWLEDGEMENTS

The Nevada Commission on Autism Spectrum Disorder Strategic Planning Steering Committee would like to thank each of the Commission Subcommittees and the community members who so graciously shared their time, thoughts and recommendations with us, making up the contents of the report contained herein.



Social Entrepreneurs, Inc., a company dedicated to improving the lives of people by helping organizations realize their potential, collected the staff surveys and prepared this summary report.

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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 information collected through discussions with each subcommittee representing specific subpopulations of individuals living with ASD throughout Nevada.

PURPOSE

Discussions were held with each of the Commission Subcommittees; Early Childhood, Youth and Transition, Adult and Aging, and Rural Populations. The purpose of these discussions was to gather perspectives and recommendations regarding priorities and strategies relevant to each subpopulation with specific emphasis on the following:

- Issues of particular importance for each subpopulation, to include the greatest needs and gaps in services.
- Recommended priorities and strategies for future action.

This report presents in total the impressions, experiences and opinions of the group participants.

METHODOLOGY

Subcommittee Discussions were held with Subcommittee and community members who chose to participate in the open and publicly posted meeting on the following schedule and at the specified locations:

Subcommittee	Location	Date	Time
Adults & Aging	Nevada Early Intervention Services 3811 W. Charleston #112, Las Vegas	September 19, 2014	12:00 – 3:00 pm
Youth & Transition	Public and Behavioral Health HCQC 4220 S. Maryland Parkway, Las Vegas	September 23, 2014	12:00 – 3:00 pm
Early Childhood	Public and Behavioral Health HCQC 4220 S. Maryland Parkway, Las Vegas	September 19, 2014	1:00 – 4:00 pm
Rural Populations	Great Basin College 1500 College Parkway, Elko	September 19, 2014	10:00 am– 12:00 pm

Each focus group began with a brief description of the Commission on Autism Spectrum Disorder, the strategic planning process, and an explanation of how the information collected during the subcommittee group discussion was relevant to planning efforts. Each group discussed issues affecting their particular population and recommended action through a dynamic exchange of ideas amongst the participants.

LIMITATIONS

While each subcommittee had quorum to hold the meetings, and public to participate in each discussion, there were some populations that were either underrepresented or their needs were not voiced throughout the course of this process. These populations include children age 6-12, and older adults. Alternative forms of data collection, such as consumer surveys should be used to identify the most pressing needs, concerns and gaps in services for these populations.



SUBCOMMITTEE AND GROUP DISCUSSION PARTICIPANTS

The following identifies all of the individuals that participated in the subcommittee discussions:

Early Childhood Subcommittee	Youth & Transitions Subcommittee	Adults & Aging Subcommittee	Rural Populations Subcommittee
Michele Tombari (Chair)	Julie Ostrovsky (Chair)	Mark Olson (Chair)	Korri Ward (Chair)
Nicole Cavanaugh (Member)	Maria Martin (Member)	Steven Cohen (Member)	Sylvia Ruiz (Member)
Nicole Kalkowski (Member)	Molly Michelman (Member)	Korri Ward (Member)	Vanessa Knotts (Member)
Debra Vigil (Member)	Scott Harrington (Member)	Vanessa Fessenden (Member)	Robert Johnson (Member)
JonPaul Saunders (Member)	Erin Snell	Renee Portnell (Member)	Jan Crandy,
Toni Richards (Member)	Andrew Devitt	Jan Crandy	Ralph Sakerson
Shannon Crozier (Member)	Denise Robinson	Megan Crandy	<i>The Rural Subcommittee hosted a community focus group with representation from the communities of Elko, Winnemucca, and Pahrump. The perspective of those focus group participants were woven into the results of this report.</i>
Johnette Oman	Dee Raymond	Mel Johnson	
Adryon Ketcham	Jacqueline Barr	Kathleen Kingston	
Thomas Kapp	Jan Crandy	Annette Aloiau	
Robin Kincaid			
Ken MacAleese			
Robert Johnson			
Jan Crandy			
Jennifer Davidson			
Charles Marriott			



RESULTS

Each subcommittee identified the most important issues related to their specific subpopulation. In analyzing the whole collection of subcommittee group discussions, a number of cross-cutting themes emerged that apply to the overall efforts of the Commission.

The following section of the report summarizes the cross-cutting themes, as well as the specific concerns of each subpopulation identified throughout the subcommittee discussions.

NEEDS

CROSS-CUTTING NEEDS IDENTIFIED

Groups were asked to identify the needs of their particular service population. The discussion was inclusive to explore needs that were being met as well as those that were not in an effort to generate an overall understanding of individuals living with autism across Nevada and throughout the lifespan. Five needs were identified by all groups to include the need for 1) screening and diagnosis, 2) sufficient services, 3) a qualified and sufficient workforce, 4) a seamless service delivery system, and 5) access to information and education about the system and how it operates. Each of these needs are explored further below.

SCREENING & DIAGNOSIS

Each group described the need to identify individuals living with ASD throughout the lifespan with appropriate screening and diagnostic resources. While the early childhood group described the need to screen and diagnosis as early as possible, with a preference for use of the American Academy of Pediatrics guidelines, the other groups insisted on the need to establish routine periodic checks to identify individuals who may have been over-looked, have had their condition or needs change over time, or those that have been inappropriately diagnosed with an alternative or co-occurring condition.

“We need doctors that are knowledgeable and informed about ASD so that they can accurately screen and refer families, as well as discuss treatment options.”

SERVICE SUFFICIENCY

In all group discussion, there was a significant amount of discussion surrounding the need for service sufficiency to appropriately meet the needs of individuals living with ASD and their caregivers. Services such as applied behavior analysis, therapy (occupational, speech, and physical), physical and behavioral health care, and assistive technologies were just some of the services mentioned by the groups. There was widespread discussion around the need for **timely** access to **community-based** service **options** at necessary **service intervals** to appropriately **support** individuals living with ASD **throughout the lifespan**.

Information collected during group discussions revealed that services for individuals with ASD, while insufficient throughout the lifespan, became more pronounced as individuals aged. Additionally, the more rural areas of the state were home to the least amount of service options, requiring many to travel far distances or choose to forgo treatment and risk loss of potential.

“In the rural areas, we have to contend with the fact that the services we need either don’t exist or there is no local office to provide those services.”

QUALIFIED AND SUFFICIENT WORKFORCE

All groups identified the need for a qualified and sufficient workforce to assist and support individuals living with ASD throughout the lifespan. Discussions included the need for primary providers as well as secondary providers that were skilled and knowledgeable about ASD and the best approach to providing services to this specialized population. In addition, there was widespread recognition across group participants for the need to develop a sufficient and consistent workforce throughout the state to ensure timely access to care, and an array of service provider choices.

“People with ASD need to have access to a qualified and consistent workforce who provide supportive services to them. Turn-over in the field is significant because of the low wages and insufficient training provided. This is very disruptive to our population.”

Primary Providers: Provide services directed related to the ASD diagnosis, such as ABA, Occupational, Speech, and Physical Therapists as well as Behavioral Interventionists.

Secondary Providers: Individuals that provide care to the general public but that require specialized understanding of individuals with ASD to provide sufficient services. These individuals include law enforcement, teachers, and medical providers to name a few.

COORDINATED SERVICE DELIVERY SYSTEM

Individuals on the spectrum may require services from a variety of different systems, concurrently and/or over the course of their lifetime. There is a need to have these various systems work in conjunction with one another to provide coordinated, and seamless person-centered care. Various applications, eligibility requirements, and benefits criteria behave as barriers and place the families in a position of having to become experts in a system that is largely responsive and silo’ d in its implementation efforts.

“Families need continuity of care that comes with case management (that spans a lifetime), transitional supports into other systems, and coordination between service providers.”

“Coordination is non-existent in the rural parts of Nevada.”

INFORMATION AND EDUCATION

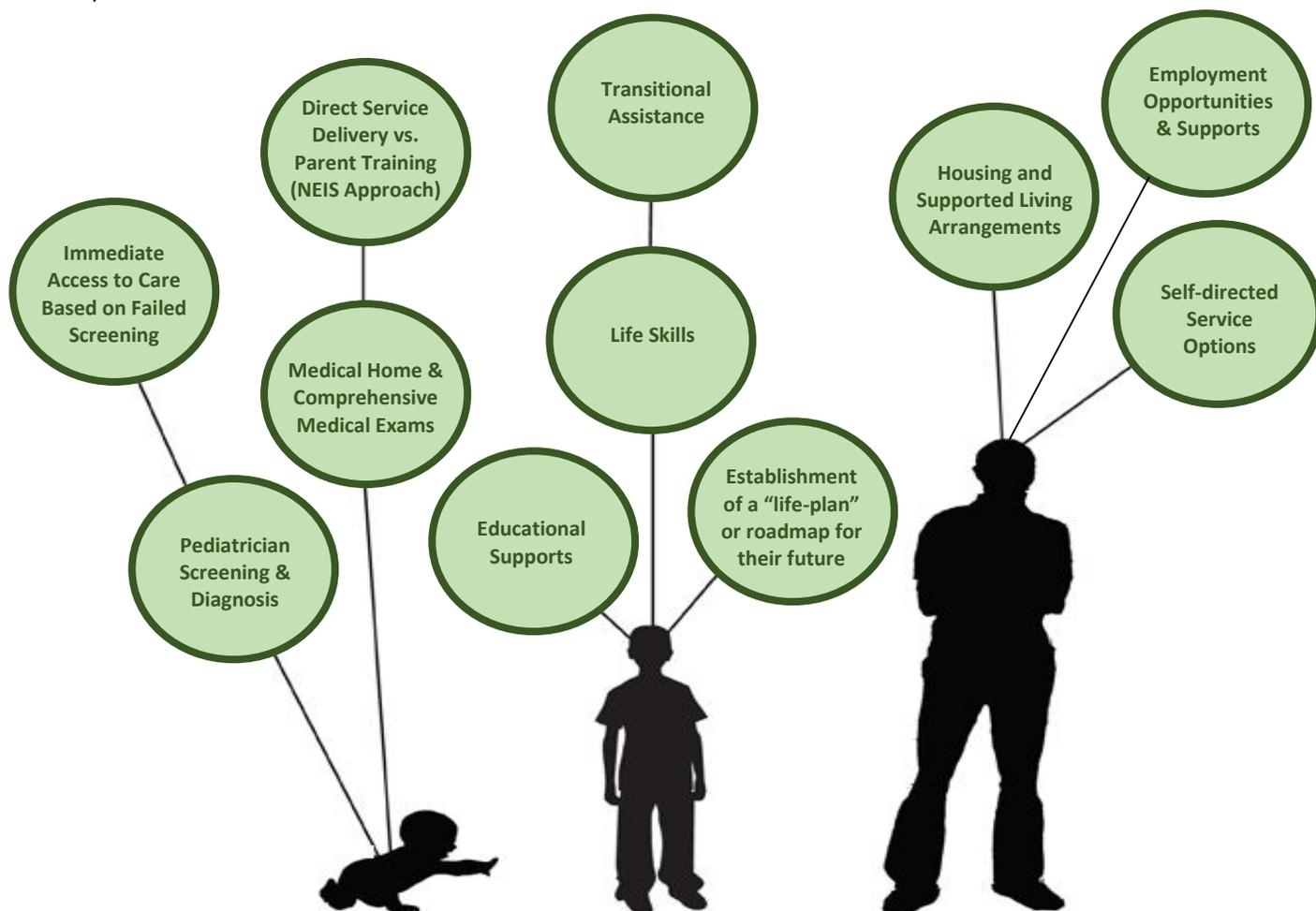
All group discussions addressed the need for an informed and educated public as well as information related to the services available for individuals with ASD and how to navigate the systems providing those services. In all groups, there was a consistent theme of families having to “fight” to understand what they are entitled to, and how to access appropriate care.

“We need people to understand what ASD is and what it is not. We need a public that is educated. We also need to educate individuals and families about where they can go to for help.”

“It would be nice to have a single place to get information, find out how to access services and how to navigate the service systems and insurance/benefits available.”

NEEDS THAT WERE PARTICULAR TO EACH SUBPOPULATION

The following graphic is meant to demonstrate the needs particular to individuals throughout their lifespan.



There were needs that were consistently identified by both the Youth and Transition Subcommittee as well as the Adult and Aging Subcommittee discussions, but not expressed as a concern for the early childhood community. These needs included:

- Recreational opportunities
- Transportation supports
- Assistance in accessing higher education; and
- Protection & safety skills.

The rural populations echoed all of which was identified by each of the other three subpopulations, emphasizing the exacerbating nature of each issue based on the lack of professional resources in the rural parts of the state.

“The most significant need for individuals living with ASD is a supportive family network. People in rural Nevada often have to choose between having access to the support offered by family or access to care. When families have to move to access care, it is detrimental to the entire family structure as well as the individual living with autism.”

Following the identification of the various needs of individuals living with ASD throughout the lifespan, Subcommittee groups were asked to describe how these needs were being met in an effort to identify both the gaps as well as the strengths of the current system.

GAPS IN SERVICES

CROSS-CUTTING GAPS IN SERVICES IDENTIFIED

Gaps in services were explored by all groups relative to the needs that were identified. Concerns voiced by all groups focused on service access, affordability, and availability. Each of these gaps are explored further below.

ACCESS

- **Lack of knowledge** regarding services available or how to navigate the service system.
- **Long wait lists** for services. Some individuals “age out” of the system prior to service implementation. Others may be “bumped” due to fluctuating needs or crisis circumstances.
- **Rigid eligibility requirements**, which are dependent upon circumstances such as a person’s age, functional level, or acquisition of a diagnosis instead of their need for support.
- **Language barriers** prevent individuals from accessing care in their home language.
- **Proximity to services and providers** was especially significant in the rural parts of the state but also served as gaps in urban areas due to a lack of transportation options available to individuals with ASD.

AFFORDABILITY

- **Insufficient Insurance Coverage** was a common barrier to accessing care. All groups cited the difficulty in navigating health insurance systems (both public and private products) for coverage of ASD services. In many cases, even when insurance coverage provided some level of care, it was not sufficient to meet the needs of individuals with ASD and/or the co-payments were outside of what individuals/families can afford to pay.
- **Reimbursement Systems** are sometimes in place which require individuals to pay for services up front and wait for reimbursement. This is often not feasible for individuals/families.
- **Competing Financial Priorities** may hinder access to care, as some individuals/families do not have the luxury of taking time off of work to attend scheduled treatments.

AVAILABILITY

- **Lack of a sufficient workforce** to keep pace with the growing demand for ASD services has created a significant gap in care.
- **Insufficient service depth and breadth** to account for the comprehensive needs of individuals on the spectrum over the life span.
- **Discontinuation of Self-directed care options** has meant that many individuals are not receiving the kind of care most suited to fit their needs. This is especially true in the rural parts of the state that suffer from a significant shortage of providers. Self-directed care provided a care option that has since been eliminated.

GAPS IN SERVICES THAT WERE PARTICULAR TO EACH SUBPOPULATION

The following table demonstrates gaps in services that were particular to each of the subpopulations.

Early Childhood

- **Screening and Diagnosis:** Screenings are not being conducted consistently amongst professionals. Furthermore, diagnostic resources are so over-extended, that individuals may have to wait over a year to acquire an appointment for a diagnostic assessment.
- **Direct Service Delivery:** NEIS supports a parent training model as opposed to a direct service approach to care, which is not often appropriate for children with a failed ASD screen or diagnosis.
- **Immediate Access to Care:** Children with a failed screening should be provided immediate access to intensive, evidence based care as early intervention provides the most significant chance for positive outcomes related to a spectrum disorder.
- **Family Support Services:** Families of children with ASD require support to sustain the long-term care efforts they provide for their children. Services such as counseling, and respite are needed in greater supply.

Youth & Transition

- **School Based Supports:** Schools are not structured to fully support individuals with ASD. They do not have sufficient funding to provide the necessary supports, interventions, or ASD specific training of administrators, faculty and staff.
- **Transitional Assistance:** Kids are not receiving transitional supports such as life-skills, planning for their future, or vocational training at the appropriate time to ensure they are as prepared as possible for the transition into adulthood.
- **Social Skills Services and Programs:** There is a lack of social skills training opportunities for kids with Autism, as well as a dearth of recreational opportunities.

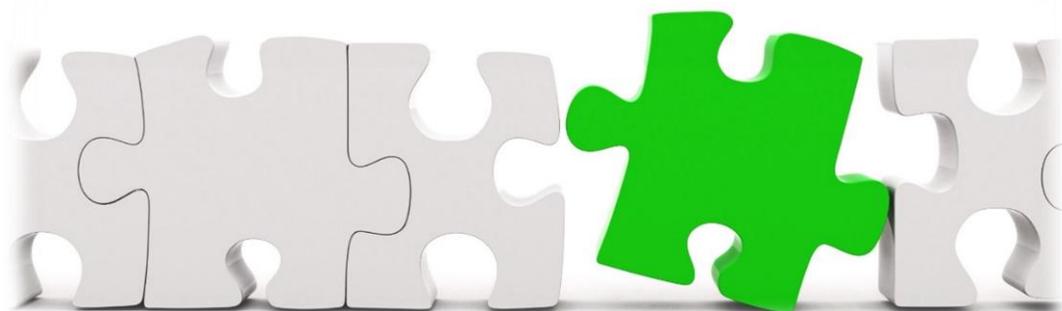


Adults & Aging

- **Insufficient Treatment Options:** There are not enough treatment options provided to the adults and aging populations, as most ASD specific services end at the time an individual turns 21.
- **Employment Opportunities and Supports:** Adults with ASD need employment opportunities that fit their unique needs and often require the assistance of a dedicated job coach and acceptance from prospective employers.
- **Housing Options:** There is not enough access to all varieties of housing options for the adult populations such as independent housing, group and residential homes. This is most pronounced for the most needy and challenged population of individuals living with ASD.

Rural

- **Lack of Providers:** There is not a significant enough service population to warrant a local provider base in many rural communities. This leaves rural areas dependent upon providers to travel from far distances to provide care, which is often not financially feasible.
- **School Based Supports:** Schools in rural areas refuse to collaborate with other state agencies in serving kids on the spectrum. There is a belief that schools do not adequately inform families about the services and supports that they are eligible for because the school is not equipped to provide those services.
- **Lack of Technology:** Telemedicine is not available in many rural areas due to the lack of internet connectivity.
- **Lack of Community Education Campaigns:** Rural areas often are not host to large scale community education campaigns (billboards, corporate campaigns, or local talk shows dedicated to issues such as ASD).



AREAS OF ONGOING STRENGTH

Each group described “pockets of excellence” where services and systems are functioning well, and offer an opportunity for the state to expand successful efforts. These are detailed below.

- University-Based Autism Programs:** Both the University of Nevada, Reno and the University of Nevada, Las Vegas are host to Autism Programs which serve to educate service providers, conduct research, and provide community based services to individuals on the spectrum. Both of these institutions were identified as a source of cutting-edge efforts for the state.
- ADSD Integration Efforts:** In the 2013 Nevada Legislature, a bill was passed that transfers Nevada’s Early Intervention Services (NEIS), previously within the Health Division, and Developmental Services (DS), previously within Mental Health and Developmental Services, into the Aging and Disability Services Division (ADSD). This was identified as an opportunity to develop a more streamlined approach to individuals with ASD as they will now be served by the same umbrella agency.
- Autism Treatment Assistance Program (ATAP):** The ATAP program was identified as a significant strength for individuals living with autism, as a state sponsored program that offers services to this population. The program was identified as offering flexible services to meet the needs of its service population. It was identified as a model for expansion of services throughout the state.
- Strong Network of Family Support Organizations:** Most of the groups recognized the benefits offered by a variety of organizations that support families and individuals living with autism. These organizations provide services, support, and advocacy that is considered invaluable to the population.
- Commission on Autism Spectrum Disorder Advocacy:** The subcommittee groups recognized the efforts of the Commission, and identified that it has been extremely effective at advocating with the legislature to make significant progress in expanding services, establishing insurance solutions, and developing state level data collection efforts to continue to monitor the efforts of service provision.



RECOMMENDATIONS

Subcommittee group discussions culminated in the establishment of following recommendations intended to provide focused input as to what goals and objectives the Commission should establish to guide future action.

ACCESS

INCREASE PUBLIC AWARENESS AND ACCESS TO INFORMATION

Launch a comprehensive statewide outreach campaign to educate parents, the public, legislators and providers about ASD. Done correctly, this would provide education, dispel myths, provide information about resources and benefits available to families, as well as outcomes associated with appropriate levels of treatment.

DEVELOPMENT OF A NAVIGATIONAL NETWORK

Develop a network in which individuals and families can access information and advocacy supports immediately upon a failed screen and/or diagnosis. This network should assist parents by providing information about **what** to do, **where** to go for help, and **how** to navigate the public service system as well as insurance products. The approach to establishing a navigation network should include multiple methods, one of which should be technology to increase reach and create efficiencies in information distribution.

ESTABLISH CONSISTENT SCREENING EXPECTATIONS & DIAGNOSTIC RESOURCES

Establish a framework for consistent screening individuals for autism spectrum disorder throughout the lifespan, leaning on research and aligned to efforts that are underway with the Affordable Care Act (ACA) and Medicaid. Additionally, focus efforts on increasing the timely accessibility of diagnostic resources.

AFFORDABILITY

ADVOCATE FOR INSURANCE SOLUTIONS

Advocate to require insurance products (both public and private) cover any and all services that are deemed “medically necessary.” Additional considerations include:

- Establish a legislative mandate that insurance companies provide mandated coverage of benefits that follow Behavior Analyst Certification Board (BACB) guidelines.
- Expand Medicaid benefits to all kids with ASD, regardless of family income (making it more of an entitlement).
- Elimination of annual benefits cap.

AVAILABILITY

INVEST IN WORKFORCE DEVELOPMENT

Work with the state to develop a plan **and** funding mechanism to recruit, train, and maintain an adequate workforce to support the needs of individuals with ASD. This system should also build in supports for training across disciplines to better equip professionals to respond to the needs of individuals with ASD (school districts, law enforcement, medical communities, criminal justice, etc.).

INCREASE STATE FUNDING TO SUPPORT ADDITIONAL SERVICE OPTIONS

Increase state funding allocations to enhance services to individuals with ASD, with a specific emphasis on the following for each service population:

- Early Childhood: research-based levels of care, direct service delivery through NEIS, and respite services,
- Youth & Transition: school-based supports, life skills training and recreational opportunities
- Adults & Aging: treatment, housing and employment supports,
- Rural Populations: self-directed care options.

CONCLUSION

All four subpopulations, Early Childhood, Youth and Transition, Adult and Aging, and Rural Populations, had similar themes with specific variations based on their individual circumstances. The most important issues identified through subcommittee discussions was the need to increase access, affordability and availability of services throughout the state, with a specific emphasis on the rural areas.

NEXT STEPS

The information provided by the subcommittee group discussion sessions should be utilized in conjunction with the other data to include the 2008 Nevada Autism Task Force Report, provider survey data, consumer survey data, and key informant interviews. 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

GROUP DISCUSSION QUESTIONS

The following questions were used as a guide to help generate discussion:

1. For each particular subcommittee population, what are the most significant needs or challenges facing people who need/use services?
2. To what extent are those needs currently being met?
3. What are the biggest gaps in services? Are there any gaps that are particularly pronounced based on region?
4. How well are programs and services coordinated across systems?
5. 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?
6. 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?
7. What progress has been made since the 2008 Autism Task Force Report was produced?
8. What policy level changes are still needed to improve services for people with ASD at the local, regional, and/or state level?
9. What practical changes are needed to improve services for people with ASD at the local, regional, and/or state level?
10. Are there any other insights you would like to share at this time?