

# Commission on Autism Spectrum Disorder

## Strategic Planning

### Research Approach

The following research approach has been identified and will be used to develop and inform the Commission on Autism Spectrum Disorder’s 2015-2020 Strategic Plan. Existing federal and state data sources will be researched in an effort to construct a profile of the population living with autism spectrum disorder throughout the state of Nevada. Consumer surveys will be issued to confirm the most pressing needs of the population living with ASD, while Commission subcommittees will be engaged to further gather perspectives relevant to each of the following subpopulations; early childhood, youth, adults and aging populations, and individuals living in the most rural areas of the state. Key informant interviews will be used to identify system strengths and weaknesses. All outreach conducted will gather recommendations regarding priorities and strategies for future action.

Need	Key Questions	Data Source	Considerations
Prevalence of ASD	How many people in Nevada are living with ASD?	<ul style="list-style-type: none"> <li>• CASD 2013 Report to the Governor</li> <li>• State / Office of Ed Data (Jane)</li> <li>• National Statistics (Jan)</li> <li>• Bar Chart used for Legislative Presentation (Jan)</li> </ul>	<ul style="list-style-type: none"> <li>• National Prevalence Rates</li> <li>• Statistics regarding Identification of individuals living with ASD by various systems serving ASD populations.</li> <li>• Work with Mark to develop a chart that identifies gaps in care.</li> <li>• In report, there needs to be a description of the challenges associated with identifying the number of people living with ASD.</li> </ul>

Need	Key Questions	Data Source	Considerations
<p><b>ASD Resources Available</b></p>	<p>What kind of ASD services are available in the state? (by region: North, South, Rural). How do people enter the system to receive services? How are they referred into the system?</p>	<ul style="list-style-type: none"> <li>• <b>ASD: State of the States of Services and Supports for People with ASD</b></li> <li>• <b>ATAP Overview Handout</b></li> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Public/Private Services Graphic (Mark)</b></li> <li>• <b>Partnership Graphic (Mark)</b></li> </ul>	<p>Consider establishing a systems flow-chart identifying systems encountered throughout the lifespan.</p>
<p><b>Subpopulations of People Served by ASD System:</b></p> <ul style="list-style-type: none"> <li>- Early Childhood</li> <li>- Youth</li> <li>- Adults &amp; Aging Populations</li> <li>- Individuals in Rural Communities</li> </ul>	<p>What are the most pressing needs of people with ASD? Who needs services and does not receive them? What are the consequences of people needing services and not receiving them (to themselves as well as to the larger community)? Other issues that may be explored within each subpopulation:</p> <ul style="list-style-type: none"> <li>• <i>How does provider capacity impact particular subpopulations?</i></li> <li>• <i>What kind of transitional supports exist for individuals throughout the lifespan?</i></li> <li>• <i>What gains have been made regarding coverage of care?</i></li> <li>• <i>Are people receiving timely access to care?</i></li> </ul>	<ul style="list-style-type: none"> <li>• <b>2008 Autism Task Force Report</b></li> <li>• <b>CASD 2010-2014 Report to the Governor (Jane)</b></li> <li>• <b>2014 ADSD Integration Plan Report</b></li> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Consumer Survey</b></li> <li>• <b>Subcommittee Discussion</b></li> <li>• <b>Community Living Subcommittee Report 2011</b></li> <li>• <b>Education Subcommittee Report 2011</b></li> <li>• <b>Employment Subcommittee Report 2011</b></li> <li>• <b>Early Intervention Subcommittee Report 2011</b></li> <li>• <b>Higher Education Subcommittee Report 2011</b></li> <li>• <b>Nevada's Commitment to Autism Document</b></li> <li>• <b>Autism Commission Slide Show 2-2014</b></li> </ul>	<p><b>Early Childhood:</b> Explore issues pertaining to screening and diagnosis, Early Intervention, school system supports and training of teachers/aids, and parental voice in process.</p> <p><b>Youth:</b> Explore issues pertaining to screening and diagnosis, transition assistance, HS graduation rates, and skill development in the following areas: personal management, employment readiness and higher education access/assistance.</p> <p><b>Adults &amp; Aging:</b> Explore issues pertaining to later-life identification, HCBS Issues (housing, employment, community engagement) and self-determination across functioning levels.</p> <p><b>Rural Communities:</b> Explore barriers to care specifically due to geographical limitations.</p>

Need	Key Questions	Data Source	Considerations
<b>Barriers to Accessing Services</b>	<i>What are the major barriers to accessing services (lack of available providers, cultural competency deficiencies amongst providers, lack of resources to support acquisition of services, insurance approval of services needed, lack of transportation, lack of personal management skills associated with condition, etc.)?</i>	<ul style="list-style-type: none"> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Consumer Survey</b></li> <li>• <b>Subcommittee Discussion</b></li> </ul>	<i>Consider cross-cutting concerns as well as concerns that are specific to a subpopulation or region in the state.</i>
<b>Insurance Coverage</b>	<i>What gains have been made regarding coverage of care? What issues continue to exist that should be addressed?</i>	<ul style="list-style-type: none"> <li>• <b>AB162</b></li> <li>• <b>Nevada's Commitment to Autism Document</b></li> <li>• <b>CASD 2010-2014 Report to the Governor</b></li> </ul>	<i>Consider NV statutes related to Medicaid, and insurance provider coverage of ASD as well as the impacts of the Affordable Care Act.</i>
<b>Screening &amp; Diagnosis</b>	<i>What gains have been made regarding screening and diagnosis of people with ASD since 2008? What issues continue to exist that should be addressed?</i>	<ul style="list-style-type: none"> <li>• <b>CASD 2010-2014 Report to the Governor</b></li> </ul>	<i>Considerations should include the requirement to screen according to APA Standards.</i>
<b>Time Between need and Service Delivery</b>	<i>What is the typical time it takes to access services? Is there a delay? Is it dependent upon service access point, population being served, etc.?</i>	<ul style="list-style-type: none"> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Consumer Survey</b></li> <li>• <b>Subcommittee Discussion</b></li> </ul>	

Need	Key Questions	Data Source	Considerations
Community Awareness regarding ASD Services Available	<p><i>Does the public know that services are available? How does the public become aware of services? Are there any public outreach campaigns? Trainings provided to first responders/identifiers regarding services available?</i></p>	<ul style="list-style-type: none"> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Consumer Survey</b></li> <li>• <b>Subcommittee Discussion</b></li> </ul>	
ASD Service Provider Network Capacity	<p><i>What is the current capacity of the provider network based on service population? Are there efforts to increase network capacity in areas that have an identified need? Are the capacity issues more pronounced in any particular service area?</i></p>	<ul style="list-style-type: none"> <li>• <b>Key Informant Interviews</b></li> <li>• <b>2014 ADSD Integration Plan Report</b></li> <li>• <b>Nevada Rural and Frontier Data Book</b></li> </ul>	<p><i>Consider the impact of the requirement that autism behavior interventionists be certified by the Board of Psychological Examiners.</i></p> <p><i>Consider the unique challenge for rural areas.</i></p>
Cultural Competency of ASD Service Providers	<p><i>What is the current capacity to serve people in their home language? Is there any particular areas within the ASD system of care where this is a particular challenge?</i></p>	<ul style="list-style-type: none"> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Consumer Survey</b></li> <li>• <b>Subcommittee Discussion</b></li> </ul>	<p><i>Significant disparities persist in access to health care for children and families from cultural and linguistic minorities-- a condition that is manifested in late diagnosis of ASD for children and adults from these minorities, delaying critical treatment and intervention that could mitigate developmental lags.<sup>1</sup></i></p>

<sup>1</sup> Mandell DS, Wiggins LD, Arnstein Carpenter L, Daniels J, DiGiuseppi C, Durkin MS, Giarelli E, Morrier MJ, Nicholas JS, Pinto-Martin JA, Shattuck PT, Thomas KC, Yeargin-Allsopp M, and Kirby RS. (2009). Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders. *American Journal of Public Health*, 99(3): 493-498

Need	Key Questions	Data Source	Considerations
<b>ASD System Strengths</b>	<p><i>What are some strengths of the current service delivery system? What opportunities exist to leverage these strengths?</i></p>	<ul style="list-style-type: none"> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Consumer Survey</b></li> <li>• <b>Subcommittee Discussion</b></li> <li>• <b>Nevada’s Commitment to Autism Document</b></li> <li>• <b>AB 162</b></li> <li>• <b>AB316</b></li> <li>• <b>AB345</b></li> <li>• <b>AB359</b></li> <li>• <b>AB162</b></li> <li>• <b>NRS 391.343, 391.378</b></li> </ul>	<p><i>Consider planning and assessment of service needs and responsiveness to those needs, quality improvement systems including the use of data systems and measurement of outcomes, coordination of care between complimentary state departments serving ASD populations, cohesion/fragmentation of system, use of evidence based practices, promotion of and funding for services/supports, leadership for advancement of issues, legislative action, and flexibility/rigidity in approach to serve.</i></p>
<b>ASD System Failures</b>	<p><i>Where are there systems failures? What kind of policies and practices behave as barrier to effective and/or adequate service delivery? What are some recommended strategies to these flaws?</i></p>		
<b>Evidence Based Practices</b>	<p><i>What evidence based practices are being used within the current system? To what extent is NV implementing evidence based practices? What opportunities exist to expand evidence based practices?</i></p>	<ul style="list-style-type: none"> <li>• <b>2008 Autism Task Force Report</b></li> <li>• <b>The National Autism Center’s National Standards Report</b></li> <li>• <b>Key Informant Interviews</b></li> <li>• <b>Subcommittee Discussion</b></li> </ul>	<p><i>Consider impacts of coverage of ABA</i></p>