Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Strategic Plan

2015 - 2020

Letter from the Chair

To Governor Sandoval, Legislators, Policymakers and Nevadans:

The Centers for Disease Control National Health Statistics Reports estimates that 1 in 50 children has Autism Spectrum Disorder (ASD). In 2013, Nevada's Department of Education had identified more than 6,200 students with ASD ages 3-21 attending school.

To understand the whole story, one needs also to know this prevalence rate has increased every year. There was a 119.4 percent increase in ASD diagnoses from 2000 to 2010 according to the CDC. Left untreated, the estimated lifetime cost of supports for these children is $3.2 million, with 80 percent of that cost in adult services. The United States vocational rehabilitation (VR) system reports the number of individuals with ASD it serves has increased 121 percent, while another study found that adults with autism were among the most costly to serve. Yet another study suggested the current service system may be inadequate to accommodate the needs of youths with ASD who do not have intellectual disabilities during the transition to adulthood.

These grim statistics prove the urgent need for action. The good news is that the adverse financial impact to Nevada, and more importantly, the direct negative impact to Nevadans affected by ASD can be substantially reduced with the delivery of comprehensive treatment and services. The vision of the Nevada Commission on Autism Spectrum Disorders supports this philosophy. It states: *All Nevadans living with Autism Spectrum Disorder will achieve optimal outcomes to reach their full potential.*

Research has shown children who receive early intense intervention using Applied Behavior Analysis (ABA), need less supports as adults and as many as 47% of these children go on to lead independent lives. Conversely, left untreated, 90 percent will lead a life of dependency on supports and services that may not be available. The opportunity to be one of the 47% has not been a reality for most Nevadans with ASD as access to evidence-based treatment continues to be limited. Nevada must remedy this fact and now prepare to provide supports and services for those untreated youths transitioning into adulthood.

Utilizing the 2008 Nevada Autism Task Force Action Plan as a starting point this five-year strategic plan clarifies and brings focus to key recommendations aimed at addressing the unmet needs of Nevadans with ASD across their lifespan. The implementation of these recommendations provides the opportunity for our state and local governments, public service agencies, educational institutions, and the private sector to collaborate to change lives and ensure fiscal responsibility to Nevada's taxpayers.

I want to express my gratitude to Governor Sandoval, Legislators and the Division of Aging and Disability Services for their ongoing support. I want to acknowledge the contribution of practitioners including those from Nevada Universities, Autism Speaks and the Marcus Center for Autism who provided increased knowledge by sharing their expertise. I also want to recognize the countless key stakeholders from across the state who worked together to deliver this five-year strategic plan to guide Nevada in our vision.

I encourage our community, Legislators and Policymakers to work together to address this crisis. The time for action is now.

With Hope,

Jan M. Crandy

Acknowledgements

This strategic plan is a result of the combined efforts of the Nevada Commission on Autism Spectrum Disorders, the Governor, the Division of Aging and Disability Services, and countless key stakeholders from across the state working together to ensure all Nevadans living with Autism Spectrum Disorder are valued, supported and actively engaged in their communities.

Governor Brian Sandoval directed the Nevada State Legislature in the reauthorization of the Commission on Autism Spectrum Disorders (CASD) which was tasked with developing the plan contained herein.

The Division of Aging and Disability Services provided organizational leadership and staff support to the Nevada Commission on Autism Spectrum Disorders.

Hundreds of key stakeholders, including consumers, providers, advocates and family members of individuals with autism contributed to this plan by completing surveys, participating in key informant interviews and attending steering committee and subcommittee meetings.

The combined commitment of time and ideas from each of these groups is sincerely acknowledged and appreciated.

Strategic Planning Steering Committee

Keri Altig, CASD Commissioner

Jan Crandy, CASD Commissioner, Chair

Shannon Crozier, CASD Commissioner

Jane Gruner, Aging and Disability Services Division

Mary Liveratti, CASD Commissioner

Mark Olson, CASD Adults & Aging Subcommittee Chair

Julie Ostrovsky, CASD Youth & Transition Subcommittee Chair

Michele Tombari, CASD Early Childhood Subcommittee Chair

Korri Ward, CASD Commissioner & CASD Rural Services Subcommittee Chair

Social Entrepreneurs, Inc., a company dedicated to improving the lives of people by helping organizations realize their potential, provided support in the development of this plan.

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Executive Summary

Prevalence rates of individuals with an Autism Spectrum Disorder (ASD) have increased significantly over the last 30 years. According to the Center for Disease Control, between 2000 and 2010, the prevalence of autism in U.S. children increased by 119%, making it the fastest growing developmental disorder in the United States (Investigators, 2014). Current estimates indicate that as many as 1 in every 50 children suffer from the condition (Stephen J. Blumberg, et al., 2013).

Because of the dramatic increase in the incidence of ASD, service systems throughout Nevada for people with ASD have been unable to respond to the current need. Delayed identification and treatment, insufficient access to comprehensive care, and the deficiency of a qualified and sufficient workforce is preventing individuals with ASD from achieving optimal outcomes. Proactive steps must be taken to improve systems and services. Recognizing this reality, the Nevada Commission on Autism Spectrum Disorders embarked upon a strategic planning process to explore and confirm the most pressing needs of Nevadan's with ASD across the lifespan and to establish a five-year plan to guide the Commission in responding to those needs.

The Strategic Plan contained herein is the result of months of research, outreach and analysis. Throughout the process, seven critical issues were identified as requiring action.

> "The prevalence of autism has increased dramatically over the last decade. We know early diagnosis and treatment can promote independence and reduce the need for services as an adult. Now is the time for a serious look at addressing this issue."
>
> ~ Ben Kieckhefer
> Director of Communications and Business Development
> McDonald Carano Wilson LLP

Critical Issues

Funding: More financial resources are needed to adequately fund the system serving individuals with ASD throughout Nevada.

Services: There currently is not enough service capacity or the delivery of evidence-based treatment to appropriately respond to individuals living with ASD throughout the lifespan.

Workforce: There is an insufficient supply of qualified service providers throughout Nevada to serve people living with ASD.

Screening & Diagnosis: Access to treatment and services are delayed because of insufficient screening and diagnostic practices in Nevada.

Knowledge: People do not know what resources are available or how to access them. Additionally, there is not enough public awareness of ASD to support individuals within community settings.

Schools: Schools do not consistently provide the necessary supports, interventions, accommodations, or transitions to students nor do they provide sufficient training of administrators, faculty and staff.

Systems: Systems are not coordinated or proactive in their approach to serve individuals with ASD throughout the lifespan.

Following the identification of critical issues, goals and objectives were developed to guide efforts over the next 5 years.

Strategic Plan Goals and Objectives

Goal #1: Maximize public and private funding sources to support the full scope of services needed for all Nevadans with ASD.

Objective 1.1: Secure state and federal funding, grants and other resources to ensure adequate service delivery.

Objective 1.2: Expand access to health insurance benefits for ASD services.

Objective 1.3: Expand Medicaid Coverage for ASD services throughout the lifespan.

Objective 1.4: Establish a self-directed care option for Individuals in Nevada.

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Goal #2: Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective 2.1: Promote and legislatively advocate for the adoption of policies and funding which deliver comprehensive services for young children to ensure optimal outcomes.

Objective 2.2: Promote and legislatively advocate for policies and funding which ensure effective education, supports, and transition implementation for school aged children.

Objective 2.3: Promote and legislatively advocate for policies and funding which deliver self-directed, person-centered services for adults.

Objective 2.4: Promote and legislatively advocate for policies and funding which adequately meet the needs of individuals with ASD living in rural and frontier areas of the state.

Objective 2.5: Expand and integrate data systems among all State departments and stakeholders to track diagnosis, treatment, services, and outcomes for individuals living with ASD to improve coordination of care, and to disseminate information.

Goal #3: Expand the number and quality of professionals providing services to individuals with ASD.

Objective 3.1: Establish a sufficient pool of credentialed Registered Behavior Technicians (RBT).

Objective 3.2: Develop a recruitment and retention plan for a skilled and sufficient ASD workforce throughout the state.

Objective 3.3: Establish training options for primary and secondary ASD service providers.

Objective 3.4: Collaborate with ADSD to support its Web-based directory / marketplace for ASD providers.

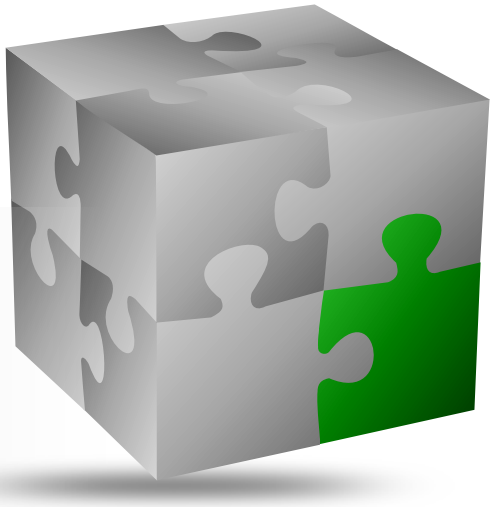
Goal #4: Promote a well-informed, empowered and supportive Nevada population around the issue of ASD.

Objective 4.1: Establish a statewide education and outreach campaign regarding ASD.

Objective 4.2: Develop a navigational network to support families in accessing information, services, and a peer network for support.

Nevada must focus on the goals and objectives contained in this plan to adequately respond to the needs and challenges of individuals and families affected by ASD. The sooner treatment begins in the life of a person with ASD, the better the outcomes.

The Commission is the entity best positioned to lead this charge, and for those reasons should be supported in its existence beyond the current sunset date of June, 2015.



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Background and Introduction

Commission on Autism Spectrum Disorders

The Nevada Commission on Autism Spectrum Disorders (herein referred to as "Commission") was established through Executive Order in 2008 by Governor Jim Gibbons, and amended by Governor Brian Sandoval in 2011. It is structured to include a composition of five members, appointed by the Governor, which includes representation from the school system, an expert in behavioral analysis, a member of the general public, and two parents of children with an Autism Spectrum Disorder.

The work of the Commission is an extension of an effort that was started in 2007 when Governor Gibbons established the Nevada Autism Task Force. The task force was comprised of 14 individuals that met for a year to study and make recommendations regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in the state. The result of their efforts is contained in the 2008 Report of the Nevada Autism Task Force: An Action Plan For Nevada's Legislators and Policy Makers. This final product of the workgroup contained 146 specific recommendations regarding the appropriate response to autism in the state of Nevada. The primary task of the Commission is to "continue the work of the Task Force by developing strategies to implement, to the extent possible, the recommendations made by the Task Force."

Since its establishment in 2008, the Commission and its established Subcommittees have worked to make progress in implementing the recommendations of the Task Force. Some legislative accomplishments include:

- Passage of AB 162, which requires insurance policies to offer an option of coverage for the screening, diagnosis, and treatment of Autism Spectrum Disorders for individuals under 18 or up to 22 years old if enrolled in high school.
- Passage of SB 359, which requires employees and contractors of Early Intervention (EI) to perform screenings for autism at the age levels and frequency recommended by the American Academy of Pediatrics. This bill laid the foundation for best practices when serving an individual with ASD. It also established a training and education component for individuals in the school systems and in EI that work with children and families facing autism.
- Passage of AB 316 & AB 345, which established the Autism Treatment Assistance Program (ATAP) within the Aging and Disability Services Division (ADSD) as Nevada's Autism Program, placing them in Nevada Statute. The legislation requires the establishment of statewide standards, and the data collection and annual reporting of the number of individuals with Autism Spectrum Disorder (ASD) as well as services rendered.

While grateful for progress made, tremendous gaps in services and supports still remain. The prevalence of ASD and the number of Nevada residents impacted continues to rise at a rate surpassing the availability of supports and services needed. There is a critical need to develop a comprehensive statewide approach to deliver treatment, services, and necessary supports across the lifespan. Recognizing this reality, the Commission 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.

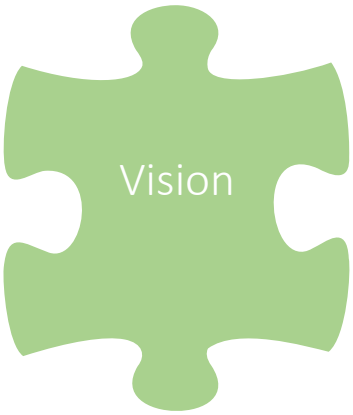
Organization of the Plan

The plan is comprised of the following seven sections.

Executive Summary	This section summarizes the key information from all of the other sections of the strategic plan into an executive summary. It provides a high level overview of the mission of the Commission, the major issues and goals of the plan, and key strategies to realize those goals.
Background and Introduction	This section provides background information about the commission and the purpose of the plan. It provides context and historical perspective leading up to the development of the strategic plan.
Strategic Orientation	This section presents the vision, mission and guiding principles held by the Commission. This framework is what is used as the "looking glass" through which all decisions related to the Commission are made.
Methods	This section presents the methods and the approach to the strategic planning process through each phase of development.
Situational Analysis	This section of the report describes the current reality of individuals with ASD in each stage of life for residents throughout Nevada. It explores the most pressing needs facing the population, as well as strengths and weaknesses of the service system.
Goals and Objectives	This section lists the goals of the Commission over the 2015-2020 timeframe. It also provides specific objectives that will be pursued and the benchmarks to measure success or the need to modify their approach.
Updating the Plan	This section describes how the Commission will measure and report on its success and lessons learned. Specific milestones for assessing progress are described and the frequency for reporting and discussing results.

Strategic Orientation

The Commission functions within the framework of the following vision, mission and guiding principles.



All Nevadans living with Autism Spectrum Disorder will achieve optimal outcomes to reach their full potential.

*The Nevada Commission on Autism Spectrum Disorders mission is to provide **leadership**, **oversight** and **legislative advocacy** in support of Nevadans living with Autism Spectrum Disorders.*

Community Support: Nevada's communities will increase safety, acceptance and accessibility while being responsive to the needs of individuals with ASD and their families.

Equal Access: Nevadans deserve equal access to comprehensive services across their lifespan so that they achieve optimal outcomes and a better quality of life for themselves and their families.

Empowerment: Nevadans should be empowered to make informed decisions and take an active role in their outcomes through education on programs, services, advocacy, and evidenced-based treatments.

Early Intervention: Nevadans found to be at risk for ASD deserve to start treatment and receive services at the earliest possible age.

Self-determination: All Nevadans with ASD have the right to self-determination and to choose their own home, community, employment, social and recreational activities, caregivers, direct support professionals and goals, with the support of family and friends.

Applied Behavioral Analysis: Applied Behavior Analysis (ABA) is a fundamental component of comprehensive services and should be implemented as recommended by the Behavior Analyst Certification Board Guidelines.

Workforce: A sufficient, statewide, competent workforce is crucial to support optimal outcomes and quality of life for individuals with ASD.

Evidence-based Practices: Professionals should utilize evidence-based practices with fidelity and regularly monitor the effectiveness of treatment to promote better outcomes for the individual, family and Nevada's communities.

System of Care: The system of care must be comprehensive, responsive to the needs of individuals and families living with ASD, and include program evaluation, outcome data and applied research to ensure that the most effective treatment models and screening tools are utilized in Nevada.

Person-centered Framework: Primary and secondary providers should deliver a coordinated, comprehensive and standardized system of care that embraces a person-centered framework throughout their lifespan.

Methods

To develop this strategic plan, a three-phased approach was used to include: Phase I – Data Collection and Assessment; Phase II – Identification of Critical Issues; and Phase II – Establishment of the Strategic Plan. The three phases took place between July 2014 and December 2014.

Phase I – Data Collection and Assessment

The initial phase of the project involved development of the Strategic Planning Steering Committee which would serve to support and oversee the strategic planning process. The group included all members of the Commission on Autism Spectrum Disorders as well as the Chair of each Commission Subcommittee and a leadership representative from the Aging and Disability Services Division (ADSD). The Steering Committee was responsible for clarifying planning questions, identifying critical issues, and developing strategic goals and objectives.

During the first two meetings with the Steering Committee, a research plan and outreach approach were approved, which established the framework for initial data collection. The data collected was meant to confirm the key needs of individuals living with autism, and to explore what areas within the existing system should be expanded, changed, discontinued or legislated to better meet current and future needs of these individuals. There were four data collection methods used to solicit stakeholder feedback. Each is described more fully below.

Key Informant Interviews

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

Subcommittee Focus Group Discussions

Between September and October 2014 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.

Consumer Surveys

Surveys were issued to consumers, family members, care providers, and advocates to solicit input regarding the strengths and weaknesses of the current system as well as their suggested solutions for any identified deficiencies. Surveys were distributed through the Steering Committee, offering respondents the option of completing the tool either on-line through Survey Monkey, or in hard copy form. A total of 399 surveys were collected from consumers across the state over a period of 31 days (August 22 – September 22, 2014).

Provider Surveys

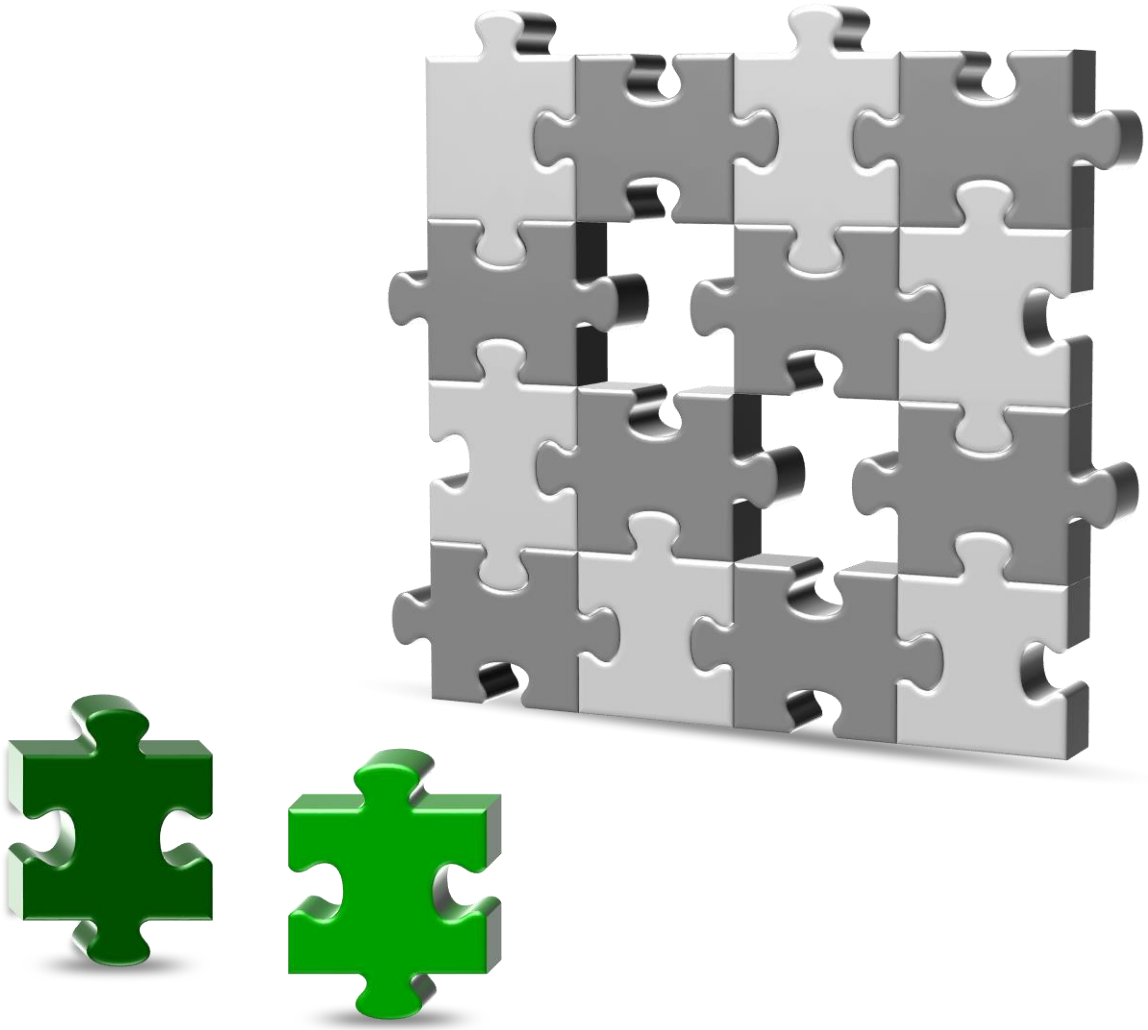
Provider surveys were issued to organizations that provide direct services to individuals living with ASD throughout the lifespan. Surveys were distributed through the Steering Committee, requiring organizations to complete the survey on-line through Survey Monkey. A total of 77 surveys were collected from ASD providers across the state over a period of 24 days (August 28 – September 20, 2014).

Phase II – Identification of Key Needs and Critical Issues

Input received through data collection efforts was analyzed to identify the key needs and most critical issues of individuals living with autism. These results were reviewed during an in-person Steering Committee meeting. Critical issues that were identified were prioritized by the Steering Committee and served as the foundation for the establishment of the strategic goals contained in the plan.

Phase III – Establishing the Strategic Plan

The Steering Committee held three working meetings October through December to complete the strategic plan document, building specific goals, objectives and actions to be taken over the next five years. The plan was finalized at the last of these meetings in December.



Situational Analysis

The following situational analysis was completed under the direction of the Steering Committee. Autism Spectrum Disorder definitions were taken from industry leaders, while prevalence data was taken from national statistics and applied to the Nevada population. This information was combined with key informant interviews, subcommittee focus group discussions, consumer surveys and provider surveys as a mechanism to identify the strengths, challenges and issues that the Commission on Autism Spectrum Disorders should consider for strategic plan action. The results of this analysis were used by the Steering Committee to prioritize critical issues and to guide the development of corresponding strategic plan goals and objectives.

Definition of Autism Spectrum Disorder

Autism Spectrum Disorders, as defined by the National Institute of Health (NIH) is "a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior."[1] The National Institute of Mental Health (NIMH) declares that the symptoms associated with ASD can cause clinically significant impairment in social, occupational, or other important areas of functioning and that these symptoms vary in their severity by each individual.[2]

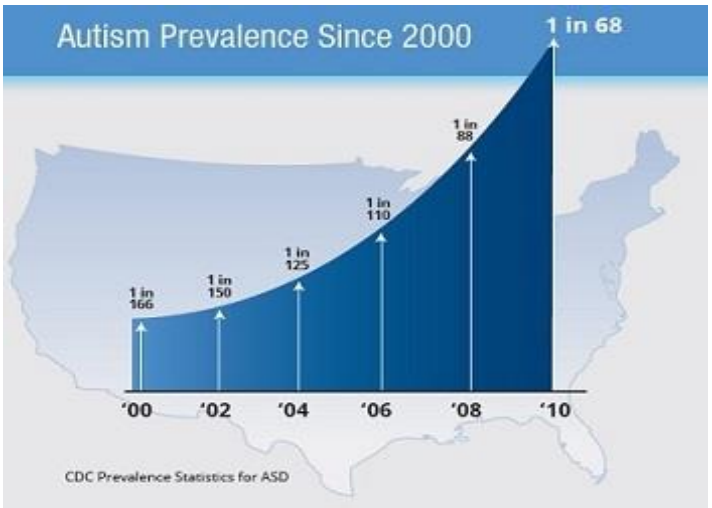
Autism Spectrum Disorders, as defined by the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV), include Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder.

"My son has a unique way of looking at the world. Being that he has no way to verbally communicate I am locked out of his thoughts as he seems to be locked out of mine. He finds joy in the smallest of things; you can see it in his face. Be it from falling pieces of paper that he has ripped up into small bits or the sensation of running or clapping his hands."

~ Consumer Survey Respondent

Prevalence of the Issue

The first diagnosis of autism occurred in 1943. Since then, the prevalence rates of individuals identified with an Autism Spectrum Disorder (ASD) have increased significantly, especially over the past thirty years. Consequently, ASD is the fastest growing developmental disorder in the United States.



The most recent Center for Disease Control (CDC) estimates identify that 1 in 68 children have an Autism Spectrum Disorder (1.47% of the population), representing a 30% increase from previous estimates reported in 2012 of 1

[1] Downloaded on November 20, 2014 from: http://www.ninds.nih.gov/disorders/autism/detail_autism.htm

[2] Downloaded on October 27, 2014 from: http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml

in 88. The prevalence of parent-reported Autism Spectrum Disorders in school-aged children is reported to be as high as 1 in 50 according to the CDC National Health Statistics Reports (2.00% of the population). There are not any studies that recognize prevalence of ASD in older populations. Because of this reality, it is difficult to know the exact number of individuals in Nevada who are living with ASD. The school age classification prevalence rates offer some guidance, while statistics collected through Nevada school districts provides additional perspective. During the 2013-2014 school year, 6,217 children (out of a total student population of 437,149 (Bureau, 2014)) were classified with autism or ASD, accounting for approximately 1.42% of the student population.

The chart below identifies the number of students by county identified with ASD, and the age at which the condition was reported.

District	Students with ASD	Student Age at Reporting																			
		2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Carson City	47			5	4	3	1	2	5	6	4	1	2	1	2	6	4	1			
Churchill	32			2	1	4	2	3	1	1	1	1	2	5	2	1	1	3	1	1	
Clark	4934	3	294	344	382	460	418	399	392	349	364	292	286	252	189	175	128	98	53	37	19
Douglas	60			2	2	7	1	1	3	7	4	3	5	7	4	4	3	5	1	1	
Elko	59		4	2	4	3	3	8	1	4	3	2	4	2	7	2	5	3			2
Esmeralda	0																				
Eureka	0																				
Humboldt	46		2	2	1	2	4	2	6	3	4	4	2		2	5	2	2	3		
Lander	9						2		1			1	2	2			1				
Lincoln	5					1				1		1			1	1					
Lyon	118		1	3	3	13	11	9	11	12	9	13	4	6	6	2	7	5		1	2
Mineral	8		1			1		1	1			2		1	1						
Nye	46				2	4	2	1	10	4	2	5	3	3	2	4		2	2		
Pershing	7				1	2		1	1	1		1									
Storey	2				1								1								
Washoe	637		10	8	27	51	56	48	52	54	68	48	38	51	47	31	28	9	4	6	1
White Pine	8				1			1	1	1	1	1		1			1				
Charter	199				1	5	6	13	16	13	15	32	26	21	15	20	13	3			
Nevada - Total	**6217**	**3**	**312**	**368**	**430**	**556**	**506**	**489**	**501**	**456**	**475**	**407**	**375**	**352**	**274**	**251**	**193**	**131**	**64**	**46**	**24**

"An estimated 709 kids with ASD will be graduating from high school between 2015- 2020. An additional 1,883 will exit between 2021- 2025. The majority of these young adults will need some level of lifelong supports as it is unlikely that they received treatment at levels to produce optimal outcomes as access was very limited to that age group when they were under the age of 8".

~ Commission Member

Systems Description

There are a variety of different systems in the state of Nevada that provide services to individuals living with ASD. Services throughout the state differ based on target population, geographic region and funding source. As a result, there are often different challenges for persons seeking assistance based on services available and where individuals try to access those services.

The system relies upon a variety of providers to include 1) primary providers, 2) secondary providers, and 3) linkage, advocacy, and coordination efforts. The following section summarizes each category. In addition, the strengths and weaknesses of the system are explored.

Service Providers

Primary Providers

Primary providers of ASD services in Nevada include state operated programs such as Nevada Early Intervention Services (NEIS), the Autism Treatment Assistance Program (ATAP), and the Regional Center Programs, all of which are managed within the Aging and Disability Services Division. Additionally, some individuals with ASD are provided mental health services through the Division of Public and Behavioral Health (DPBH) as well as the Division of Child and Family Services (DCFS). Adults living with ASD may receive services through the Bureau of Vocational Rehabilitation (Voc Rehab) within the Department of Employment, Training and Rehabilitation.

Other primary providers of ASD services include school districts, non-profit and community-based organizations and private practitioners.

Nevada Early Intervention Services (NEIS)

Early Intervention services are provided to children from **birth to age 3** based on eligibility criteria or biological risk. Services provided directly or indirectly may include: screening and evaluation, special instruction, service coordination, psychological, occupational therapy, physical therapy, speech-language pathology, audiology, vision, family training and counseling, nutrition, social work, nursing, health (if necessary to enable a child to participate in other EIS), medical (for diagnostic or evaluation only), assistive technology, and transportation. Services are provided at no cost to the family.

Autism Treatment Assistance Program (ATAP)

Autism Treatment Assistance Program (ATAP) was created to assist parents and caregivers with the expensive cost of providing Autism-specific treatments to their child with ASD. Services are provided to children **under the age of 19** with a diagnosis of ASD. ATAP provides a monthly allotment to pay for on-going treatment development, supervision and a limited amount of weekly intervention hours based upon a child's individual treatment plan. ATAP is structured to be one of many supports provided to families, and not a solitary source for comprehensive care and treatment.

Developmental Services / Regional Centers

Developmental Services works with consumers, their families and community based providers to provide services and specialized programs for children and adults with intellectual disabilities and related conditions to enhance quality of life, promote independence through personal choice, and facilitate integration into their local communities.

Currently, Developmental Services operates three Regional Centers statewide. Desert Regional Center in Clark County and Southern Nevada, Sierra Regional Center in Washoe County and Rural Regional Center in Carson City and Rural Nevada. The agencies provide person-directed planning so that people can make choices about their lives, live in the least restrictive manner possible and live productively as part of the community. Services purchased or provided include: service coordination, family supports, residential supports, jobs and day training, clinical services, and quality assurance.

Division of Public and Behavioral Health (DPBH)

DPBH provides inpatient and outpatient behavioral health services to adults in Washoe, Clark, and select rural communities throughout Nevada. It also provides behavioral health services to children and adolescents in rural health clinics throughout Nevada.

Division of Children and Family Services (DCFS)

DCFS provides behavioral health services to children and adolescents in Washoe and Clark County.

Bureau of Vocational Rehabilitation (Voc Rehab)

Voc Rehab employs counselors around the state, including JobConnect, a statewide network that connects businesses with employees. While Voc Rehab has no ASD-specific programs, it supports these individuals as a member of the disabled community. The Bureau of Vocational Rehab offers a range of employment services including assessments of job-related skills, assistance with job searches, job placement and retention, collaboration with employers and agencies, transportation services, career counseling and guidance, and post-employment services.

Vocational rehabilitation services are available to high school students with disabilities that serve as a barrier to employment. Students do not need to be enrolled in special education services; if necessary, a separate evaluation may be conducted to determine eligibility for VR services. Students can be referred to vocational rehabilitation or apply directly.

School Districts

Special Education services are provided to children with disabilities (ASD included) through their local school district. A multidisciplinary team is tasked with establishing an Individualized Education Plan (IEP) which determines the supports that will be provided. School-based supports vary based on school district policy and resources, and are most deficient in the rural parts of the state.

Non-profit and Community-Based Organizations

A number of non-profit and community-based organizations provide services to individuals with ASD which include tutoring, day programs, recreation and leisure activities, support groups, respite care, pre-vocational programs, housing and supportive living arrangements, just to name a few. These services

are limited throughout the state and tend to be nonexistent in the rural and frontier areas. The quality of care and capacity of each organization varies.

Private Practitioners

Private behavioral analysts, interventionists, therapists and diagnostic providers are concentrated primarily in Washoe and Clark Counties. Access to these services often depends upon school system authorizations, Medicaid enrollment and health insurance approvals, and availability of providers.

Secondary Providers

Beyond the primary providers, there are also demands placed on a number of other systems throughout Nevada that respond to persons with ASD. Secondary providers, such as emergency responders, hospital emergency rooms, law enforcement, primary care practitioners, residential support staff, and social services centers often come into contact with individuals with ASD. While many do not see themselves as providers of ASD services and are not fully equipped to address the complex needs of these individuals, they are part of a continuum of services providing access to care.

Linkage, Advocacy and Coordination Efforts

Nevada has a number of collaboratives, organizations, and workgroups that operate regionally and statewide that seek to address systems improvement for consumers accessing autism specific and supportive services. These entities establish linkages, provide advocacy and promote coordination critical to an effective continuum of care.

Commission on Autism Spectrum Disorders (CASD)

The Nevada Commission on Autism Spectrum Disorders was established in November 2008 through Executive Order by Governor Gibbons, and is tasked with implementing the recommendations of the 2008 Report of the Nevada Autism Task Force: An Action Plan For Nevada's Legislators and Policy Makers. The Commission provides bi-annual reports to the Governor, providing an update regarding progress as well as a list of recommended actions to be taken by the legislature to better support the needs of individuals living with ASD in Nevada.

Autism Coalition of Nevada (ACON)

The Autism Coalition of Nevada is an advocacy organization, whose mission is to support legislation for appropriations which fund screening, diagnosis and treatment clinics for people with Autism. As a coalition, they:

- Provide a forum for ASD groups throughout the state to meet with each other,
- Combine resources to develop and implement autism awareness and advocacy,
- Provide information to and between agencies and other interested groups regarding conferences, seminars, meetings and other events, and
- Provide a communication network throughout the state to assist persons seeking information and referral.

Families for Effective Autism Treatment (FEAT)

Families for Effective Autism Treatment, Inc. is a non-profit organization of parents and professionals, designed to help families with children who have received the diagnosis of ASD. FEAT offers a support

network where families can meet each other and discuss issues surrounding autism and treatment options.

Grant a Gift Autism Foundation

Grant a Gift acts as a Community Safety net by navigating families living with autism through the complex systems of care and funding in Nevada. GGAF also empowers families to become self-advocates through education in policy and transition planning through the life-span.

Nevada Autism

Established in 2003 under the name RAIN (Reno Autism Information Network), Nevada Autism was Nevada's first non-profit established to help families with autism access services, answer questions, solve problems and provide support.

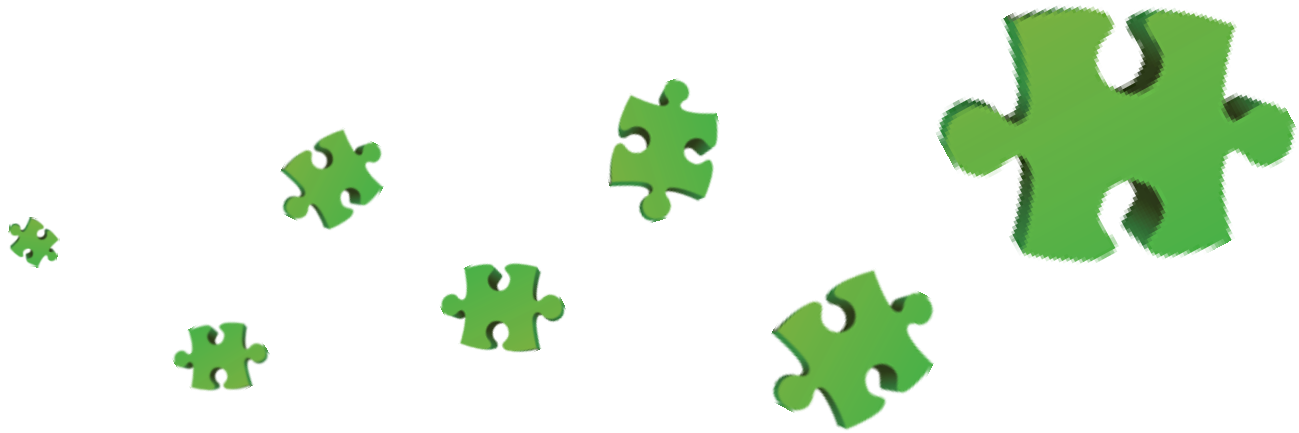
Nevada PEP

PEP services are about empowering families to be life-long advocates for their children through education and skill building. PEP recognizes that parents are experts on their children; and must learn about disabilities, intervention needs, and how to develop a support system to meet those needs.

Northern Nevada Autism Network (NNAN)

NNAN is a volunteer operated non-profit advocacy organization established to help families in Elko County affected by autism. The goal of NNAN is to increase autism awareness and access to treatment. NNAN is comprised of a diverse group of parents helping other parents, and dedicated to easing families' uncertainties as they navigate through the world of autism.

This complex system of primary and secondary service providers, supported by state and local coordination and advocacy efforts, serve a growing population of people being diagnosed with and recognized as having ASD. While the service population has grown, the availability of qualified staff and resources is insufficient to meet the demand. The following section describes the strengths and weaknesses of the service system as described by key stakeholders.



System Strengths and Weaknesses

Nevada has a complex network of service providers that support individuals living with ASD. An assessment was conducted to explore what challenges exist within the system and to identify opportunities to leverage existing strengths. The following section provides a description of system strengths and weaknesses as identified by stakeholder outreach activities which included key informant interviews with community partners, surveys to consumers and providers, and focus group discussions during Commission Subcommittee meetings with members and participants. The summary report for each of the outreach methods conducted can be found in the appendix of this plan.

System Strengths

Key Informants and Subcommittee Focus Group discussions described "pockets of excellence" where services and systems are functioning well, and offer an opportunity for the state to expand on successful efforts. These are detailed below.

University-Based Autism Programs: Both the University of Nevada, Reno and the University of Nevada, Las Vegas host 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.

Aging and Disability Services Division (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.

> *"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."*
>
> ~ Key Informant

Autism Treatment Assistance Program (ATAP):
The ATAP program was identified as a significant strength for individuals living with autism, as a state sponsored program providing assistance to fund treatment 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: Stakeholders 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.

> *"We have an amazing advocacy community in Nevada among community-based organizations and parent alike."*
>
> ~ Key Informant

Size and Configuration of State Staff/Systems: Stakeholders recognized that the configuration of state programs allowed easy access to state staff and leadership as well as provided for an agile and flexible approach to services.

Commission on Autism Spectrum Disorders Advocacy: Stakeholders, specifically key informants and 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.

Other strengths identified by Key Informants and Subcommittee Focus Group discussions included the Lovaas Treatment Center, the Vocational Opportunities for Inclusive Career Education (VOICE) program in Washoe County, the Governor's efforts at establishing the Task Force on Integrated Employment, the Technical Assistance Center on Social Emotional Intelligence (TACSEI) program, and the continuation of increased funding during each legislative session.

System Weaknesses

Stakeholders identified a number of weaknesses that need to be addressed to strengthen the system.

Service Sufficiency: All stakeholder groups identified a lack of sufficient services to meet the needs of individuals living with ASD across the lifespan and throughout Nevada, with an emphasis found in the more rural parts of the state.

Financial Supports: All stakeholder groups identified the need for additional financial supports necessary to address the various needs of individuals living with ASD. While stakeholders recognized the gains made through the ATAP program, they indicated that the amount of funding is still insufficient as wait-lists are significant and individuals receiving services are not getting research levels of care. Significant criticism was levied against insurance products that either deny service claims or erect barriers to prevent access.

Workforce Sufficiency: Nevada does not have a sufficient network of services/providers to adequately respond to the growing number of individuals with ASD across the lifespan. This results in a long wait for services, and puts some people in a position to either having to settle for services that are not high quality, or to not pursue services at all.

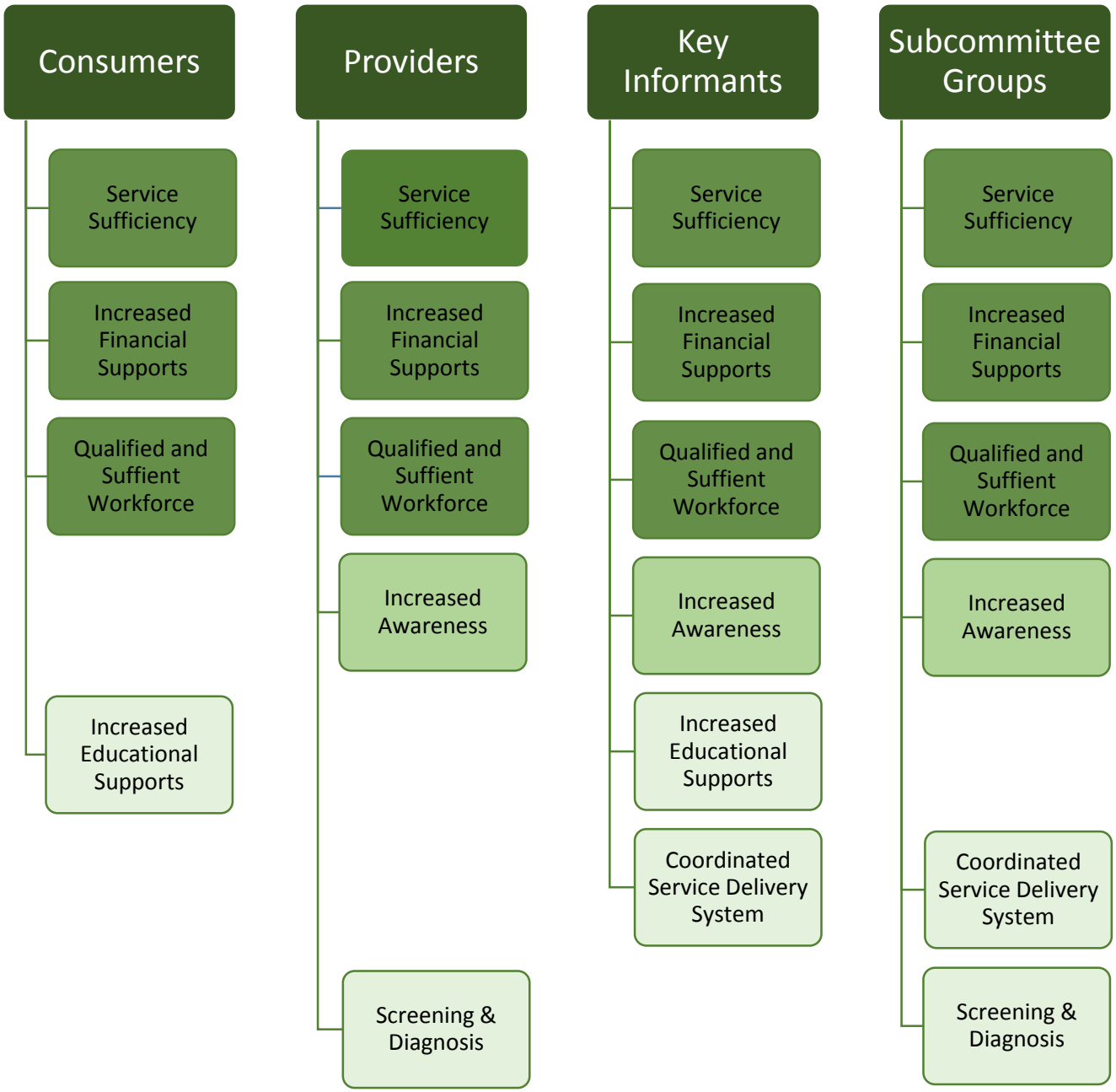
Service Coordination: Stakeholders describe a system that is fractured, and siloed in its approach to serve individuals. Additionally, transitional supports are insufficient or initiated too late. While stakeholders described the current situation as being "better than it used to be," they still described the need for additional service coordination efforts.

> *"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."*
>
> ~ Key Informant

Key Needs

A number of consistently identified needs emerged from the analysis of all outreach conducted. Some needs were cross-cutting and applied to the overall population of people living with ASD in Nevada. Other needs were specific to targeted populations such as early childhood, youth, adults, and those living in rural and frontier areas of Nevada.

The chart below identifies the needs that were ranked as most significant for individuals across the lifespan according to stakeholder groups.

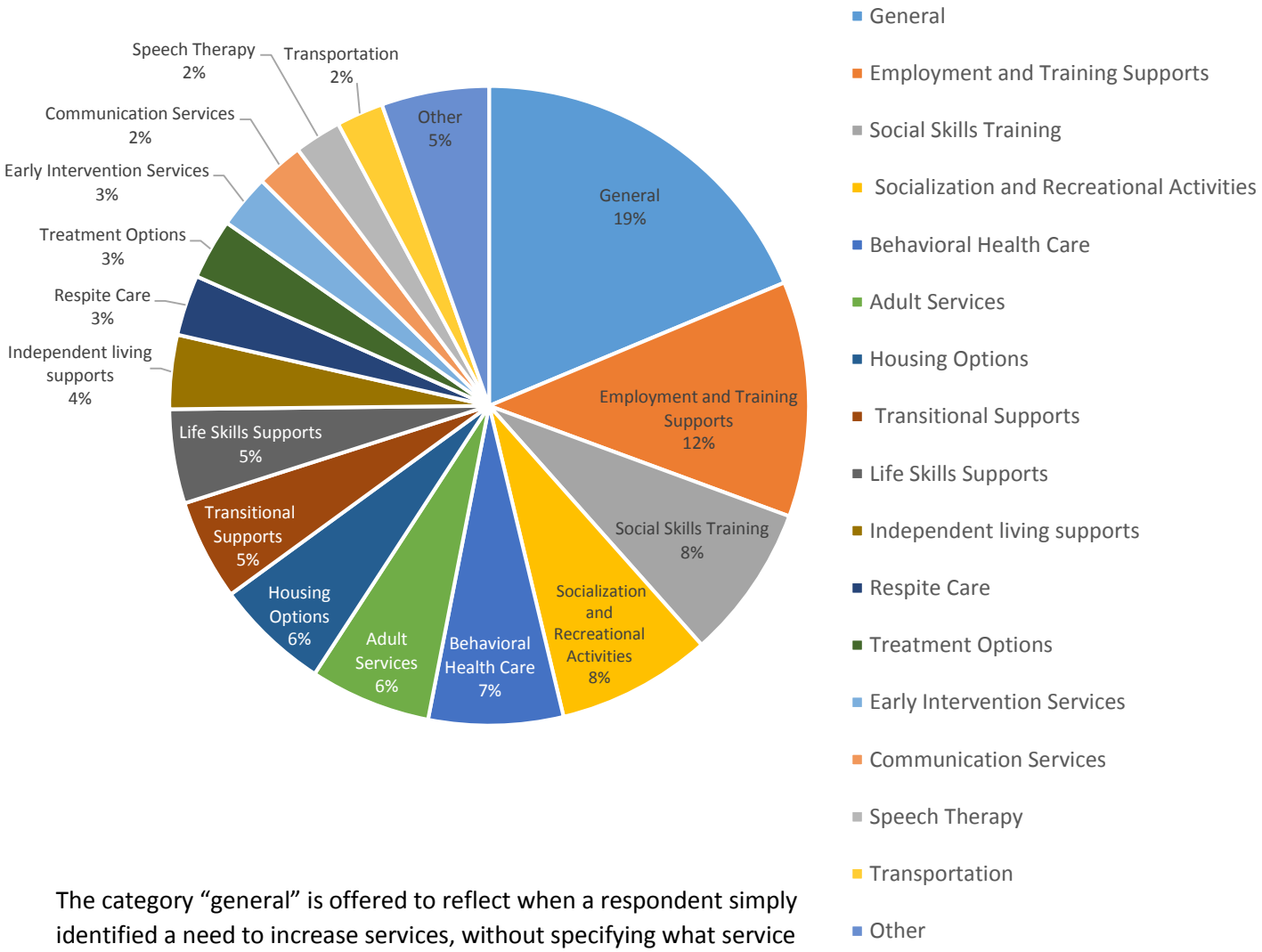


There were three needs identified by all stakeholder groups (key informants, subcommittee groups, consumers and providers); those were the need for more services and programs, the need for additional financial resources/support, and the need for an increased workforce. Three stakeholder groups identified the need for increased awareness. Areas of need that were identified by at least two of the four stakeholder groups included increased educational supports, increased coordination across service delivery systems, and the need for screening and diagnosis services.

Service Sufficiency

Individuals living with ASD require sufficient services to meet the variety of needs that present themselves across the lifespan. Services such as applied behavior analysis, therapy (physical, occupational, and speech), behavioral and physical health care, and assistive technologies were just some of the services identified by stakeholders as insufficient. There was widespread agreement 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***.

Respondents to the consumer survey identified the following services most needed for themselves.

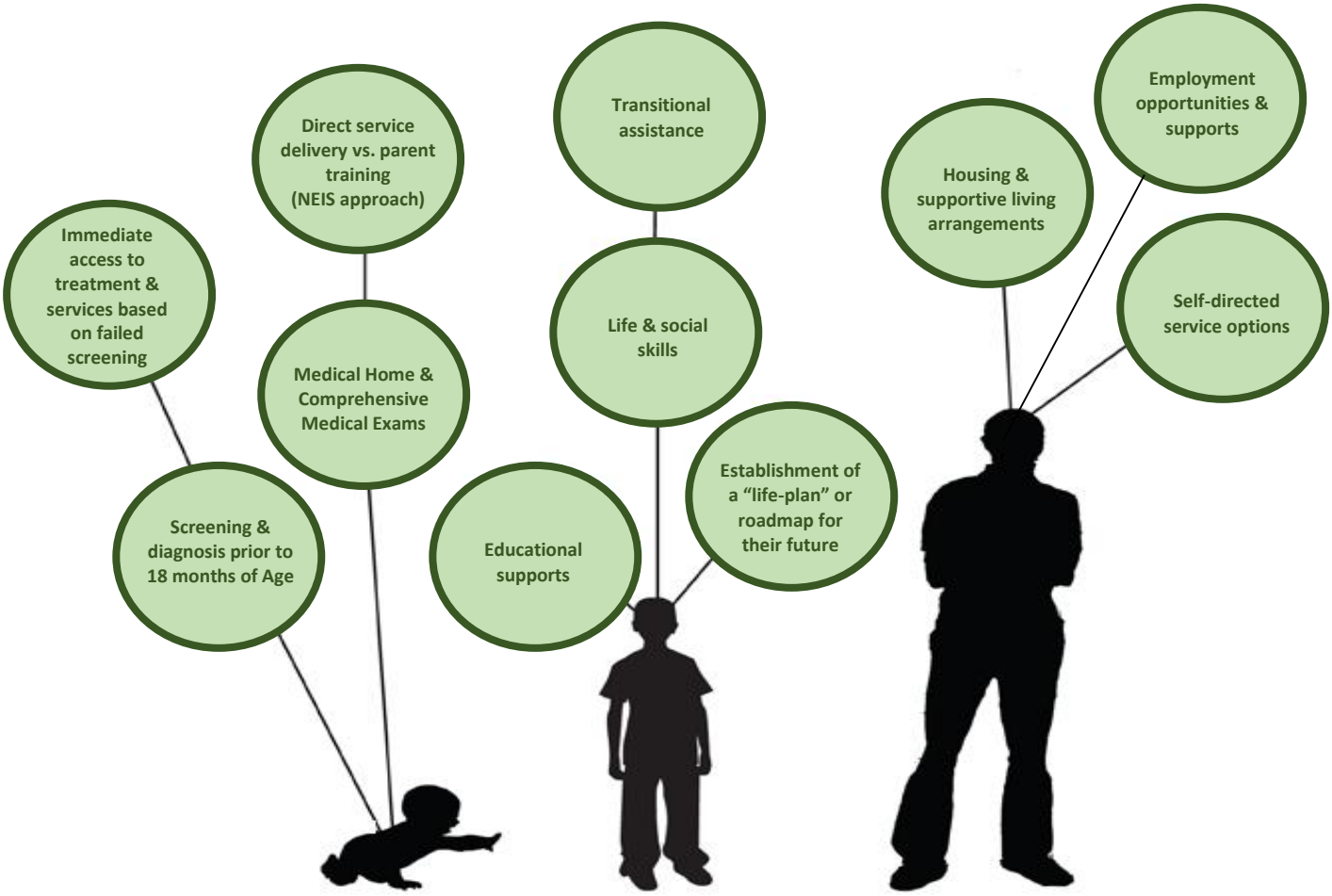


The category "general" is offered to reflect when a respondent simply identified a need to increase services, without specifying what service in particular was needed.

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

Service Needs that Were Particular to each Subpopulation

The following graphic demonstrates 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 Adults 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 the needs 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."*

Increased Financial Supports

All stakeholders identified the need to develop increased financial resources to support the affordability of services. Issues noted included:

- 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 in place which sometimes require individuals to pay for services up front and then wait for reimbursement. This is often not feasible for individuals and families with limited financial resources.
- 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.

Qualified and Sufficient Workforce

All stakeholder groups identified the need for a qualified and sufficient workforce to assist and support individuals living with ASD throughout the lifespan. Data collected identified the need for primary providers as well as secondary providers that are skilled and knowledgeable about ASD and the best approach to providing services to this specialized population. In addition, there was widespread recognition of 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.

Increased Awareness

Stakeholders recognized 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. 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."

Increased Educational Supports

Stakeholder groups identified the need for sufficient and consistent support provided through school districts, and a need to coordinate services between school systems and other providers. Stakeholders identified that schools are not currently 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.

Coordinated Service Delivery System

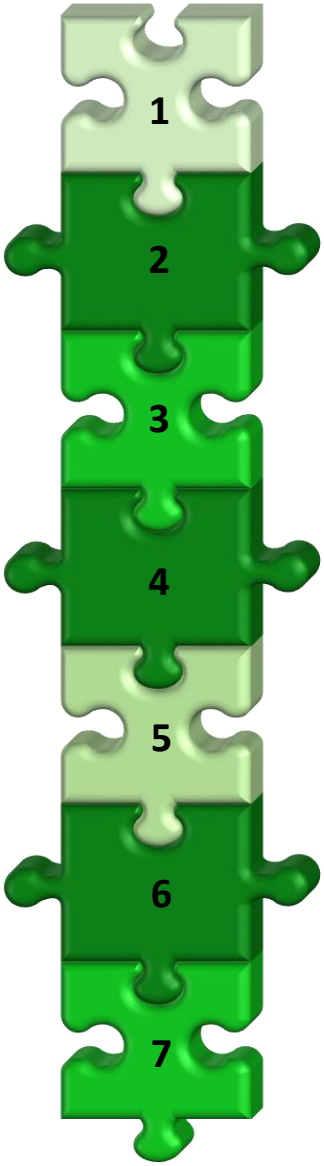
Individuals on the spectrum may require services from a variety of different systems, concurrently over the course of their lifetime. There is a need to have these various systems work in conjunction with one another to provide coordinated, and seamless person-centered care. Various applications, eligibility 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 reactive and siloed in its implementation efforts.

Screening & Diagnosis

Multiple stakeholder groups acknowledged 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 diagnose as early as possible, with a preference for use of the evidence-based tools and 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.

Critical Issues

The key needs identified in the situational analysis as critical for action were confirmed and prioritized by the Commission Steering Committee as follows:



Funding: More financial resources are needed to adequately fund the system serving individuals with ASD throughout Nevada.

Services: There currently is not enough service capacity or the delivery of evidence-based treatment to appropriately respond to individuals living with ASD throughout the lifespan.

Workforce: There is an insufficient supply of qualified service providers throughout Nevada to serve people living with ASD.

Screening & Diagnosis: Access to treatment and services are delayed because of insufficient screening and diagnostic practices in Nevada.

Knowledge: People do not know what resources are available or how to access them. Additionally, there is not enough public awareness of ASD to support individuals within community settings.

Schools: Schools do not consistently provide the necessary supports, interventions, accommodations, or transitions to students nor do they provide sufficient training of administrators, faculty and staff.

Systems: Systems are not coordinated or proactive in their approach to serve individuals with ASD throughout the lifespan.

Framework for Action

Goals and Objectives

The following goals and objectives were developed to address the most critical issues currently facing Nevadans living with ASD throughout the lifespan. This framework is intended to guide the actions of the Commission from January 2015 through December 2019.

Goal #1: Maximize public and private funding sources to support the full scope of services needed for all Nevadans with ASD.

Objective 1.1: Secure state and federal funding, grants and other resources to ensure adequate service delivery.

Objective 1.2: Expand access to health insurance benefits for ASD services.

Objective 1.3: Expand Medicaid Coverage for ASD services throughout the lifespan.

Objective 1.4: Establish a self-directed care option for Individuals in Nevada.

Goal #2: Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective 2.1: Promote and legislatively advocate for the adoption of policies and funding which deliver comprehensive services for young children to ensure optimal outcomes.

Objective 2.2: Promote and legislatively advocate for policies and funding which ensure effective education, supports, and transition implementation for school aged children.

Objective 2.3: Promote and legislatively advocate for policies and funding which deliver self-directed, person-centered services for adults.

Objective 2.4: Promote and legislatively advocate for policies and funding which adequately meet the needs of individuals with ASD living in rural and frontier areas of the state.

Objective 2.5: Expand and integrate data systems among all State departments and stakeholders to track diagnosis, treatment, services, and outcomes for individuals living with ASD to improve coordination of care, and to disseminate information.

Goal #3: Expand the number and quality of professionals providing services to individuals with ASD.

Objective 3.1: Establish a sufficient pool of credentialed Registered Behavior Technicians (RBT).

Objective 3.2: Develop a recruitment and retention plan for a skilled and sufficient ASD workforce throughout the state.

Objective 3.3: Establish training options for primary and secondary ASD service providers.

Objective 3.4: Collaborate with ADSD to support its Web-based directory / marketplace for ASD providers.

Goal #4: Promote a well-informed, empowered and supportive Nevada population around the issue of ASD.

Objective 4.1: Establish a statewide education and outreach campaign regarding ASD.

Objective 4.2: Develop a navigational network to support families in accessing information, services, and a peer network for support.

Implementation Plan

The following table highlights the goals, objectives, timing, milestones and benchmarks for strategic plan action. This table will be used as a management tool to track and communicate the progress being made by the Commission.

Goal I. Maximize public and private funding sources to support the full scope of services needed for all Nevadans with ASD.				
Objective	**Strategies**	**Timeline for Completion**	**Partners in Action / Responsible Parties**	**Benchmarks for Measuring Success**
Objective 1.1: **Secure state and federal funding, grants and other resources to ensure adequate service delivery.**	1.1.1 Advocate and provide legislative testimony to support funding for services that support individuals with ASD.	2015-2019	**CASD Resource Development Subcommittee**, ADSD, DETR	• Maintenance of and/or increase to state and federal funding allocations for NEIS, ATAP, Regional Centers, and DETR.
	1.1.2 Provide letters of support to statewide agencies and non-profit organizations in their pursuit of additional funding opportunities.	2015-2019	**CASD Resource Development Subcommittee**	• Commission response to all requests for support.
Objective 1.2: **Expand access to health insurance benefits for ASD services.**	1.2.1 Identify and engage organizations that utilize self-funded insurance plans to increase ASD coverage.	2015-2019	**CASD Resource Development Subcommittee**	• Number of Self-Funded Organizations that develop ASD benefits within their insurance option. (1 Organization per year)
	1.2.2 Advocate with the Nevada Division of Insurance and/or the legislature to establish a directive which aligns health insurance products with the Affordable Care Act.	2017	**CASD Resource Development Subcommittee**, Insurance Commissioner	• Directive establishing health insurance parity with ACA.
	1.2.3 Ensure legally mandated ASD health insurance benefits are delivered, tracked and enforced.	2019	**CASD Resource Development Subcommittee**, Insurance Commissioner, Attorney General	• Establishment of a compliance officer within the Attorney General's Office or the Insurance Commissioner's office.

Goal I. Maximize public and private funding sources to support the full scope of services needed for all Nevadans with ASD.

Objective	Strategies	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success
Objective 1.3: **Expand Medicaid Coverage for ASD services throughout the lifespan.**	1.3.1 Advocate for Medicaid coverage which supports ASD screening, diagnosis, and treatment.	2015	**CASD Resource Development Subcommittee**, DHCFP	• Establishment of a State Plan Amendment which establishes: • Adequate reimbursement rates • Appropriate levels of coverage • Expanded coverage for adults.
	1.3.2 Identify and ensure that Medicaid reimbursement rates are sufficient to support access to services.	2015	**CASD Resource Development Subcommittee**, DHCFP	• Children with ASD diagnosis who are receiving Medicaid coverage are receiving ABA treatment.
	1.3.3 Expand Medicaid coverage for ASD services through adulthood (age 21 or 26).	2019	**CASD Resource Development Subcommittee**, DHCFP	
Objective 1.4: **Establish a self-directed care option for Individuals in Nevada.**	1.4.1 Advocate for legislation that enacts a person-centered self-directed care option and supports it with sufficient funding.	2018	**CASD Resource Development Subcommittee**, ADSD, DHCFP	• Establishment of a Self-Directed Home and Community Based Waiver option for Nevadans.
	1.4.2 Collaborate with ADSD, DHCFP, other public agencies and private providers to educate and train all Nevadans with ASD and their families on person-centered planning.	2019	**CASD Resource Development Subcommittee**, ADSD, DHCFP, DETR	

Goal II. Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective	Strategies	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success
Objective 2.1: **Promote and legislatively advocate for the adoption of policies and funding which deliver comprehensive services for young children to ensure optimal outcomes.**	2.1.1 Advocate for immediate eligibility of and connection to comprehensive treatment and services for children based upon a failed ASD screening.	2015	**CASD Early Childhood Subcommittee**	• Policy that supports presumptive eligibility for services based on failed screen within NEIS, ATAP.
	2.1.2 Collaborate with statewide partners to establish systematic screenings for ASD. • Nevada Early Intervention Services (NEIS) • Early Education/QRIS System • Tribal Agencies • State Health Department • Child Protective Services • UNLV and UNR Centers for ASD • Touro University	2017	**CASD Early Childhood Subcommittee,** ADSD, Tribes, DPBH, Universities	• Establishment of organizational policies that support systematic ASD screenings.
	2.1.3 Compile and adopt service standards for children age 0-6, living with ASD. Standards may cover issues such as: • Screening & Diagnosis • Immediate Access to Care • Evidence-based Treatment • School Based Services • Family Supports	2016 2019	**CASD Early Childhood Subcommittee,** ADSD, Universities	• Publication of Nevada ASD service standards document (inclusive of the needs of children age 0-6 with ASD). • Data indicates that children age 0-6 with ASD are receiving comprehensive services.

Goal II. Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective	Strategies	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success
Objective 2.1 (Cont.): **Promote and legislatively advocate for the adoption of policies and funding which deliver comprehensive services for young children to insure optimal outcomes.**	2.1.4 Advocate for public policies and funding allocations that support service standard implementation.	2017-2019	**CASD Early Childhood Subcommittee**	• Establishment of policies that support service standard implementation. • Development of funding mechanism to support service standard implementation.
	2.1.5 Establish and advocate for funding to support pilot programs for ASD screening utilizing the most scientifically advanced screening tools and/procedures.	2019	**CASD Early Childhood Subcommittee**	• Pilot programs launched in at least four locations.

Objective 2.2:
 	
Promote and legislatively advocate for policies and funding which ensure effective education, supports, and transition implementation for school aged children.
	2.2.1 Compile and adopt service standards for children age 7-21, living with ASD. Standards may cover issues such as:
	• Screening & Diagnosis
	• Evidence-based Treatment
	• School Based Services
	  • Individual Education Plan Development
	  • Coordination of Care
	  • ASD Treatments (including ABA), Services & Supports
	  • Assistive Technology Resources
	  • Annual Transition Supports
	• Life & Social Skill Development
	• Transitional Supports
	• Higher Education & Employment Assistance
	• Family Supports
		2016	**CASD Youth and Transitions Subcommittee,** ADSD, DETR, Universities	• Publication of Nevada ASD service standards document (inclusive of the needs of children age 7-21 with ASD).

Goal II. Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective	Strategies	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success
Objective 2.2 (Cont.): **Promote and legislatively advocate for policies and funding which ensure effective education, supports, and transition implementation for school aged children.**	2.2.2 Advocate for public policies and funding allocations that support service standard implementation.	2017-2019	**CASD Youth and Transitions Subcommittee**	• Establishment of policies that support service standard implementation • Development of funding mechanism to support service standard implementation.
	2.2.3 Establish and advocate for funding to support piloting cutting-edge high school transitional programs.	2018	**CASD Youth and Transitions Subcommittee,** High School(s)	• Pilot program launched in at least four high school campus.
	2.2.4 Advocate with the Nevada Department of Education (NDE) to ensure that school districts serving children with ASD coordinate services with other community based providers.	2018	**CASD Youth and Transitions Subcommittee,** NDE	• NDE Policy that requires coordination of care by school districts serving children with ASD.
Objective 2.3: **Promote and legislatively advocate for policies and funding which deliver self-directed, person-centered services for adults.**	2.3.1 Collaborate with the Governor's Task Force on Integrated Employment to advocate for and ensure that the employment needs and choices of Nevadan's with ASD, are identified, understood and addressed.	2015	**CASD Adults and Aging Subcommittee,** Governor's Task Force on Integrated Employment	• Presentations made to Governor's Tasks force on Integrated Employment regarding needs of individuals with ASD. • Governor's Task Force Plan addresses needs of individuals with ASD.

Goal II. Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective	Strategies	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success

Objective 2.3 (Cont.):
 	
Promote and legislatively advocate for policies and funding which deliver self-directed, person-centered services for adults.
	2.3.2 Promote entrepreneurial enterprise and business creation opportunities for Nevadans with ASD to:
	• Governor's Office of Economic Development
	• Local and state agencies
	• Private for-profit and non-profit entities
		2015-2019
		
		2019
			CASD Adults and Aging Subcommittee, Office of Economic Development	• Presentations made to:
				  • Governor's Office of Economic Development (annually)
				  • Public Agencies (4 annually)
				  • Private Entities (4 annually)
				• Development of a $500,000 fund to support entrepreneurial enterprise efforts for people with ASD.

	2.3.3 Collaborate with ADSD, DHCFP, Commission on Services for Persons with Disabilities, providers and recipients to establish policies and systems which enable Nevadan's with disabilities, including ASD, to self-select their own residential setting.	2015	**CASD Adults and Aging Subcommittee,** ADSD, DHCFP, CSPD	• Completion of a web-based marketplace for housing options available to individuals with disabilities.
	2.3.4 Compile and adopt service standards for adults over the age of 21, living with ASD. Standards may cover issues such as: • Eligibility for Services • Treatment • Higher Education & Employment Assistance • Housing Options and Supports • Family Supports	2016	**CASD Adults and Aging Subcommittee,** ADSD, DETR, Housing Division, Universities	• Publication of Nevada ASD service standards document (inclusive of the needs of adults with ASD).

Goal II. Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective	Strategies	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success
Objective 2.3 (Cont.): **Promote and legislatively advocate for policies and funding which deliver self-directed, person-centered services for adults.**	2.3.5 Advocate for public policies and funding allocations that support service standard implementation.	2017-2019	**CASD Adults and Aging Subcommittee**	• Establishment of policies that support service standard implementation • Development of funding mechanism to support service standard implementation.
Objective 2.4: **Promote and legislatively advocate for policies and funding which adequately meet the needs of individuals with ASD living in rural and frontier areas of the state.**	2.4.1 Research, identify, and advocate for alternative approaches to providing ASD services in rural communities.	2016	**CASD Rural Populations Subcommittee**	• Nevada ASD rural services approach recommendations.
	2.4.2 Advocate for rural parity in ASD services provided through school districts.	2017	**CASD Rural Populations Subcommittee,** NDE	• NDE Policy that requires all school districts throughout the state offer equal access to ASD supports.
	2.4.3 Advocate with NEIS and ATAP for funding to support travel expenses for families when accessing services unavailable in local community.	2019	**CASD Rural Populations Subcommittee,** ADSD	• Approval of policies and funding allocations to support travel expenses for families accessing care through NEIS and ATAP.
	2.4.4 Coordinate with state service providers to utilize mobile clinics and tele-medicine for treatment, services and supports.	2019	**CASD Rural Populations Subcommittee,** DPBH	• Implementation of mobile clinics in 5 rural communities across the state.

Goal II. Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.

Objective	Strategies	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success
Objective 2.5: **Expand and integrate data systems among all State departments and stakeholders to track diagnosis, treatment, services, and outcomes for individuals living with ASD to improve coordination of care, and to disseminate information.**	2.5.1 Identify data elements within each ASD service system that best measure issues such as: • Number of individuals needing services • Number of individuals screened and diagnosed • Time between failed screen and access to service • Number of individuals accessing services • Type of service and levels provided • Number of individuals and time on waitlists • Cost per eligible • Number of professional trained • Outcomes associated with service delivery • Longitudinal Outcomes	2018	**CASD Data Subcommittee,** ADSD, NDE, DETR	• Expanded Data Collection Protocol for ASD services.
	2.5.2 Develop a feasible methodology for the collection of these data elements across services systems.	2019	**CASD Data Subcommittee**	• Implementation of integrated data collection processes and ability to analyze data across ASD service systems.
	2.5.3 Compile and analyze data on an annual basis.	2019	**CASD Data Subcommittee**	• Annual Report of Services Provided to Nevadans with ASD.

Goal III: Expand the number and quality of professionals providing services to individuals with ASD.				
Objective	**Strategies**	**Timeline for Completion**	**Partners in Action / Responsible Parties**	**Benchmarks for Measuring Success**
Objective 3.1: **Establish a sufficient pool of credentialed Registered Behavior Technicians (RBT).**	3.1.1 Collaborate to track and fund RBT trainings statewide.	2015	**CASD Workforce Development Subcommittee,** DETR, CCSD, UNR, UNLV	• 80% of ATAP Interventionists credentialed as RBT's.
Objective 3.2: **Develop a recruitment and retention plan for a skilled and sufficient ASD workforce throughout the state.**	3.2.1 Coordinate with the Department of Employment, Training, and Rehabilitation to conduct an assessment of the workforce supporting individuals with ASD to identify the current and projected need.	2016	**CASD Workforce Development Subcommittee,** DETR, CCSD, UNR, UNLV	• Workforce Assessment Report
	3.2.2 Identify infrastructure needs (to include University programs) to support developing specific workforce skills and abilities.	2017		
	3.2.3 Develop and implement a recruitment and retention plan.	2017		• Workforce Recruitment and Retention Plan
		2018		• UNLV has an accredited BCBA and BCaBA program.
		2019		• ABA is an established career path within one high school magnet program in Clark County School District

Goal III: Expand the number and quality of professionals providing services to individuals with ASD.				
Objective	**Strategies**	**Timeline for Completion**	**Partners in Action / Responsible Parties**	**Benchmarks for Measuring Success**
Objective 3.3: **Establish training options for primary and secondary ASD service providers.**	3.3.1 Develop a training approach that incorporates online learning toolkits, training workshops, statewide conference participation and peer supported networks for individuals in the field.	2015	**CASD Workforce Development Subcommittee,** DETR, ADSD, Universities	• Establishment and/or collection of Training toolkits for: • Law Enforcement Officers • Medical Professionals • School Staff • Peer Support Networks
	3.3.2 Compile content and advocate for resources necessary to implement the training approach.	2016-2019		• Exhibit and or provide a Presentation around ASD Issues at one professional conference per year.
	3.3.3 Develop content and resources necessary to implement the training approach.	2017		• Online Training available through ADSD Website
Objective 3.4: **Establish a Web-based directory/marketplace for ASD providers.**	3.4.1 Collaborate with ADSD to support the launch of its web-based directory/marketplace.	2015	**CASD Workforce Development Subcommittee,** ADSD, DETR, Universities	• Launch of web-based marketplace.
	3.4.2 Outreach to ASD providers for inclusion into the directory/marketplace.	2016		• All ASD licensed providers will be included in directory within 3 months of the website launch. • 10% increase in the amount of unlicensed providers included in directory after 1 year of website functionality.
	3.4.3 Develop a consumer driven rating system for ASD providers on the web-based directory.	2017		• Launch of consumer driven rating system.

Goal IV: Promote a well-informed, empowered and supportive Nevada population around the issue of ASD.

Objective	Strategy	Timeline for Completion	Partners in Action / Responsible Parties	Benchmarks for Measuring Success
Objective 4.1: **Establish a statewide education and outreach campaign regarding ASD.**	4.1.1 Coordinate with the Division of Public and Behavioral Health to establish and implement a statewide community education campaign. • Develop outreach materials for billboards, posters, and flyers specifically for rural Nevada.	2015	**CASD**, DPBH, ADSD, collaboration with non-profits and parents	• Launch of Outreach Campaign
	4.1.2 Redevelop the 100 Day Toolkit to incorporate a 365 day timeframe, to support parents and individuals in Nevada who have been diagnosed with ASD.	2016		• Completion of 365 Day Toolkit, ready for distribution
Objective 4.2: **Develop a navigational network to support families in accessing information, services, and a peer network for support.**	4.2.1 Development of a parents driven peer support network statewide that provides information, education, support and advocacy. 4.2.2 Development of a website that supports access to information, resources and connection to peer support network.	2018	**CASD**, DPBH, ADSD, collaboration with non-profits and parents	• Peer Support Network Launched • Navigational Network Website Launched

Timeline

2015

Maintenance of and/or increase to state and federal funding.

One self-funded insurance plan org to increase ASD coverage.

Establishment of Adequate Medicaid Reimbursements.

Ensure Medicaid coverage support for ASD screening, diagnosis, and treatment.

Presumptive Eligibility established for NEIS & ATAP.

Work with the Governor's Task force on Integrated Employment.

Nine Entrepreneurial enterprise presentations completed.

Web-based marketplace for housing options completed.

ASD Training toolkits established/compiled.

RBT Training conducted statewide.

Launch Web-based marketplace for ASD Providers

Launch Outreach Campaign

2016

Maintenance of and/or increase to state and federal funding.

One self-funded insurance plan org to increase ASD coverage.

Publication of Nevada ASD service standards document.

Nine Entrepreneurial enterprise presentations completed.

Nevada ASD rural services approach recommendations.

ASD Workforce Assessment Report.

ASD Provider Outreach for inclusion in ADSD Provider marketplace website.

Professional Conference Participation

Redevelop 100 Day Toolkit

2017

Maintenance of and/or increase to state and federal funding.

One self-funded insurance plan org to increase ASD coverage

Alignmnet of health insurance products with ACA.

Statewide Partners establish Systemic ASD Screenings.

Nine Entrepreneurial enterprise presentations completed.

NDE Policy requiring statewide parity for ASD supports.

Workforce Recruitment and Retention Plan.

Online Training available through ADSD Website.

Professional Conference Participation

Consumer driven rating system on ADSD Provider marketplace website.

Policies and funding to support service standard implementation

2018

Maintenance of and/or increase to state and federal funding.

One self-funded insurance plan org to increase ASD coverage.

Legislative enacted self-directed care option.

High school transitional pilot programs launched in at least four locations.

NDE Policy that requires coordination of care by school districts for children with ASD.

Nine Entrepreneurial enterprise presentations completed.

Expanded Data Collection Protocol for ASD services.

Professional Conference Participation

UNLV has an accredited BCBA and BCaBA program.

Peer Support & Navigational Network Website Launched.

Policies and funding to support service standard implementation

2019

Maintenance of and/or increase to state and federal funding.

One self-funded insurance plan org to increase ASD coverage.

ASD health insurance benefits monitoring established.

Expand Medicaid coverage for services through adulthood.

Conduct person-centered planning training.

ASD screening pilot programs launched in at least four locations.

$500,000 fund to support entrepreneurial enterprise efforts.

NEIS & ATAP reimburse families for travel to access services.

Mobile clinics in five rural communities.

ABA career path established at one CCSD magnet program.

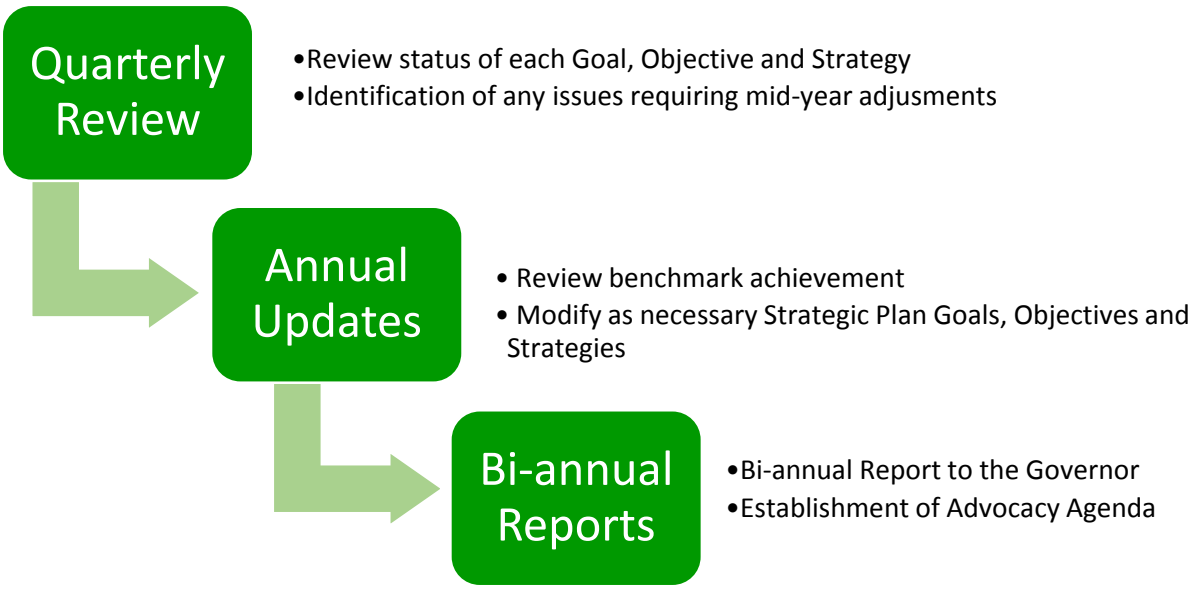
Professional Conference Participation

Annual Report of ASD Services.

Policies and funding to support service standard implementation

Plan Updates

This plan will be used as a tool by the Commission, with progress reviewed quarterly and updates established annually. Quarterly review will occur during regularly scheduled Commission meetings, where issues can be identified and action established if needed. Annual updates will drive efforts related to bi-annual reports to the Governor as well as the advocacy agenda of the Commission.



Appendices

Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Key Informant Summary Report

ACKNOWLEDGEMENTS

The Nevada Commission on Autism Spectrum Disorders 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 Nevada, Inc.
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	University of Nevada, Reno Center for Excellence in Disabilities
Casey Lynn Hayden, M.A., BCaBA, LaBA	The Lovaas Center for Behavior Intervention
Janice John	Nevada Department of Employment, Training and Rehabilitation, Bureau of Vocational Rehabilitation
Cheryl Jung	Advocate
Robin Kincaid	Nevada PEP
Julie Kotchevar, M.A.	Nevada Aging and Disability Services Division
Ron Leaf, Ph.D.	Autism Partnership
Kenneth R. MacAleese, Ph.D., BCBA-D, LBA	Advanced Child Behavior Solutions
Jon Sasser	Washoe Legal Services
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.

Introduction and Background

The Nevada Commission on Autism Spectrum Disorders (herein referred to as "Commission") has embarked upon a strategic planning process to explore and confirm the most pressing needs of individuals with Autism Spectrum Disorder (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 stakeholders to confirm the needs of individuals living with ASD, 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 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. Companion documents summarize other outreach efforts.

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 years.

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 Social Entrepreneurs, Inc. (SEI) by the Commission and each of the Commission Subcommittees. SEI sent an email 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. These 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 are grouped by major themes. Text found following the puzzle bullet point ( ) represents quotes taken directly from interviewees.

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.

Service Sufficiency:

A majority of key informants identified a lack of sufficient services to meet the needs of individuals living with ASD throughout Nevada. Lack of sufficient services was identified for all subpopulations throughout Nevada, although there was an emphasis placed on 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 Autism Treatment Assistance Program (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.
- Nevada Early Intervention Services (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 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.

ABA Treatment

- There are very few families that are being provided Applied Behavioral Analysis (ABA) services [through NEIS]. The ones that are getting services, they are not getting it at the required intensity.
- Access to ABA services are being met at a minimal level.
- A vast minority [of people with ASD] are getting [high quality, intensive ABA] treatment.
- Lack of ABA services is one of the biggest gaps in services throughout the state.

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 an IEP structure.
- There are 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 State Plan 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 are 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 aware 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 individuals to help them understand what is available.
- Those that know (about the services), know it really well. Those that don't, become pawns in the system. They are reliant upon people to tell them, and if those people 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.
- [Meeting the] Licensing requirements [for Certified Autistic Behavioral Interventionists (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.

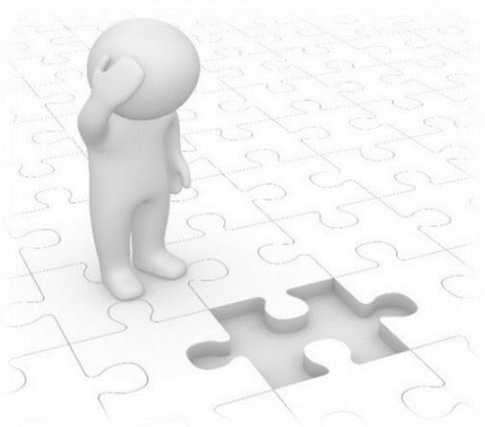
Service Coordination

Being that individuals with ASD often receive services through multiple systems and providers throughout their lifespan, it was important to understand how often 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.

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.

While multiple interviewees described the current situation as being "better than it used to be," they still described the need for additional service coordination efforts.

- Systems are very fragmented. Families are very concerned that they have to fill out yet 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 between 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) within 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 Universities throughout Nevada, as well as the benefits of 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 University programs helps 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 Disorders 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 Technical Assistance Center for Social Emotional Intelligence (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 and partnerships (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 providers 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 direct services, supports and treatment to individuals with ASD throughout the lifespan.
- Equip secondary 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.

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?

Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Consumer Survey Summary Report

ACKNOWLEDGEMENTS

The Nevada Commission on Autism Spectrum Disorders Strategic Planning Steering Committee would like to thank all of the individuals that took the time to complete the consumer survey, providing information for this Commission to further understand the needs of people living with Autism Spectrum Disorder in Nevada. The Commission would also like to extend its appreciation for the network of service providers that distributed the survey to consumers throughout the state.

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

Introduction and Background

The Nevada Commission on Autism Spectrum Disorders (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 service 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 surveys completed by consumers of ASD services and the family members that care for them. Companion documents summarize other outreach efforts.

Purpose

Consumer surveys were issued to consumers, family members, care providers, and advocates to solicit input regarding the strengths and weaknesses of the current system as well as their suggested solutions for any identified deficiencies.

This report synthesizes the results of the survey. 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 five year period of time.

Methodology

The Committee approved a total of 15 questions posed in the survey tool which can be found in the appendix. Consumer surveys were distributed through the Committee, offering respondents the option of completing the tool either on-line through Survey Monkey, or in hard copy form and sent back to SEI for data entry and analysis.

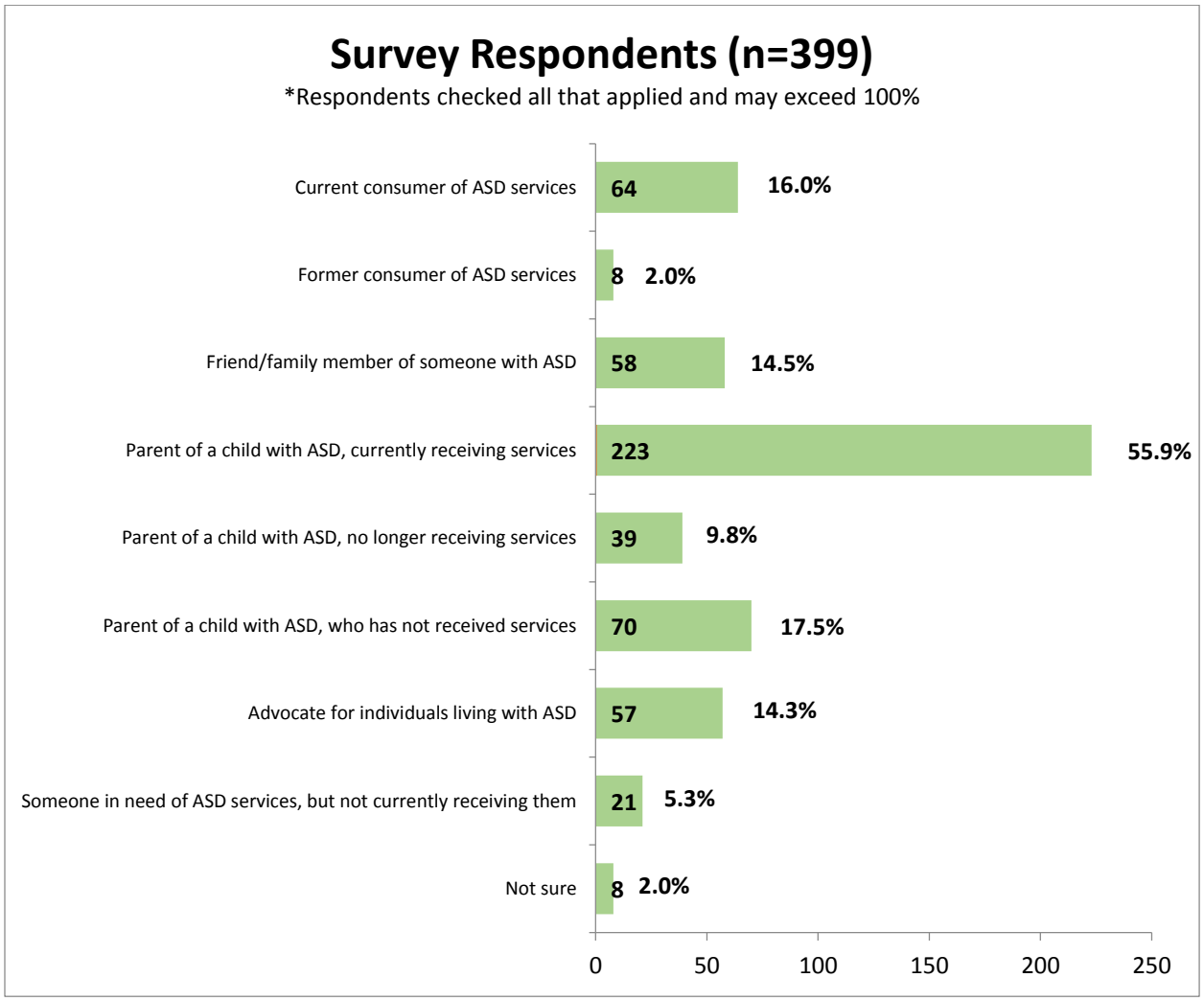
Surveys were collected over a period of 31 days (August 22 – September 22, 2014). A total of 399 surveys were completed by consumers from across the state. [The number of responses varies for each question as not all respondents answered every question on the survey. The number of respondents for each question, represented as the 'n' value, is listed in the title of each graph.]

Survey Respondents Profile

Affiliation

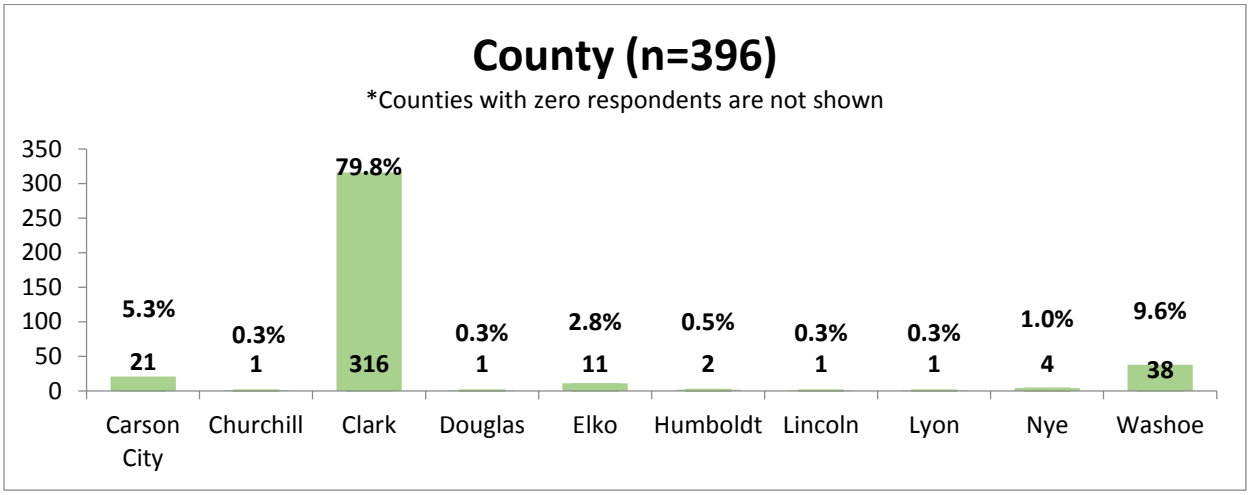
The survey tool asked respondents to identify a category that best described their profile/affiliation. The figure below demonstrates that over half (223 of 399 or 55.9%) of the respondents were parents of a child who is currently receiving services. Twenty-one (5.3%) respondents were in need of ASD services, but not currently receiving them, and 70 respondents (17.5%) were parents of a child with ASD who have not received services.

Of the total 399 surveys, 322 (80.7%) were completed on behalf of someone with ASD, who was unable to complete it independently.



Geographical Representation

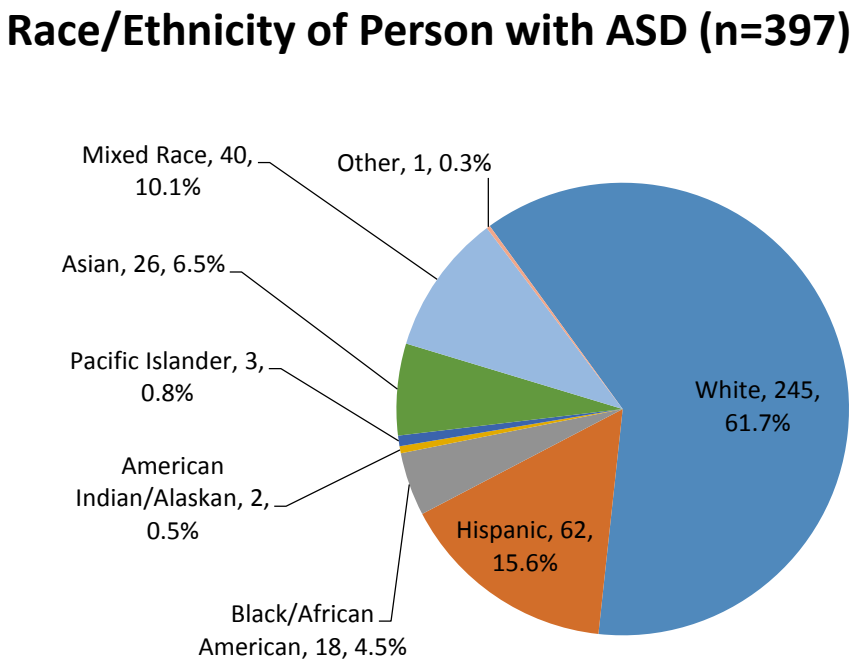
Respondents were asked to identify the county that they live in. The majority of respondents live in Clark County, (316 of 396 or 79.8%). Forty-two respondents (10.8%) live in rural Nevada while 38 (9.6%) live in Washoe County.



Demographic profile

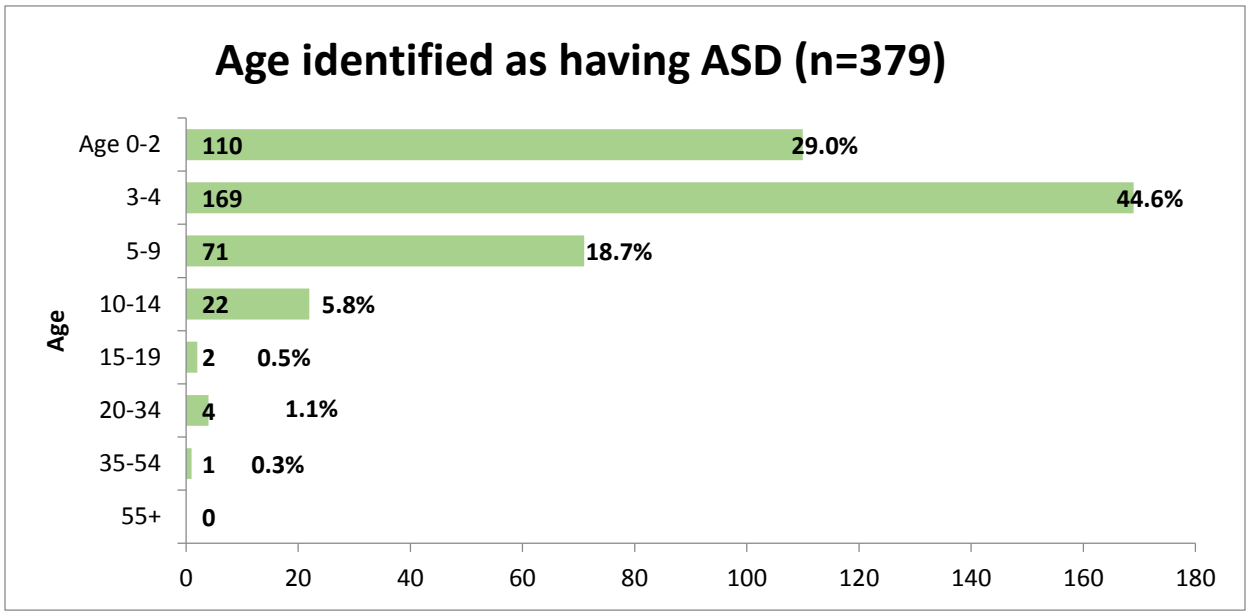
Respondents were asked to identify their race/ethnicity. Survey respondents were mostly White with 245 out of 397 respondents (61.7%). The next largest group was Hispanic (62 or 15.6%).

Race

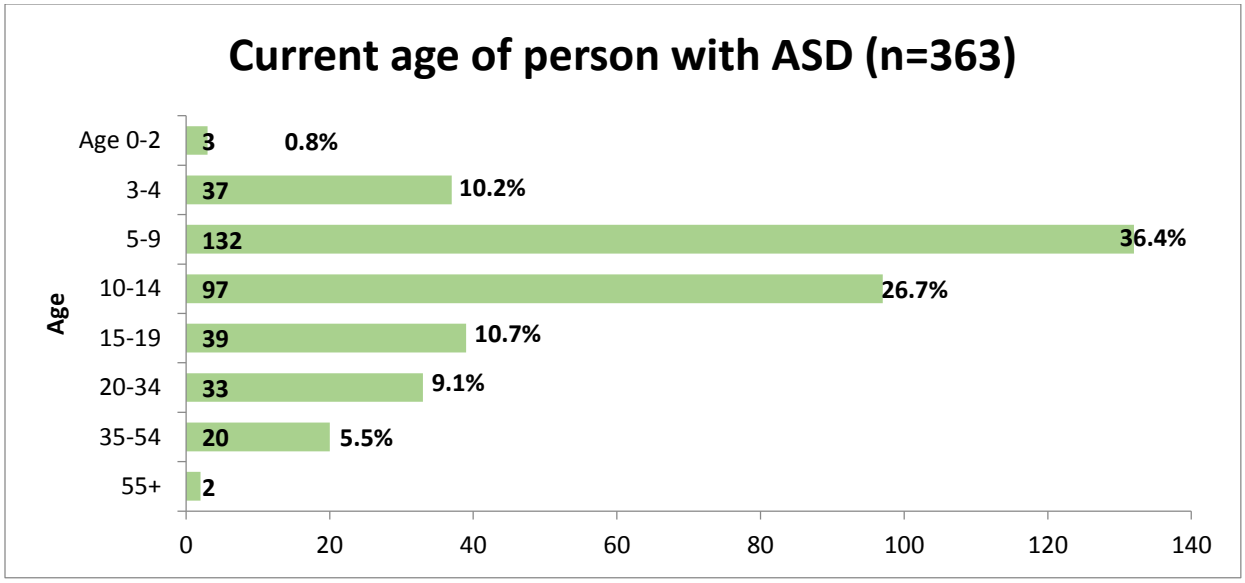


Age

Respondents were asked to identify at which age they (as the person with ASD) or the person they care for (with ASD) were identified as having an Autism Spectrum Disorder. Most individuals were identified as having ASD between the ages of 0 and 4 (179 of 379 or 73.6%) while 100 (26.4%) were identified as having ASD after the age of 5. No respondents were identified with ASD after the age of 55.



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



It should be noted that the survey tool asked this question in two different ways, and likely created confusion for respondents. For this reason, it is suggested that the finding of this question, in particular, should be reviewed with caution.

Findings

A number of consistently identified themes emerged from the consumer survey analysis. In addition to cross-cutting themes that apply to the overall needs of individuals living with ASD in Nevada, there are also themes that are specific to targeted populations such as early childhood, youth, adults, and those living in rural and frontier areas of Nevada.

Most significant concerns

Respondents were asked to identify their three greatest worries for themselves (as someone living with ASD) or for the person they know living with ASD. The three issues that were most often cited by respondents (n=390) were:

30%

Worry that individuals with ASD would be unable to live independently, or on their own.

of respondents…

22%

Worry that conditions render them vulnerable and at risk for being taken advantage of, bullied, or hurt.

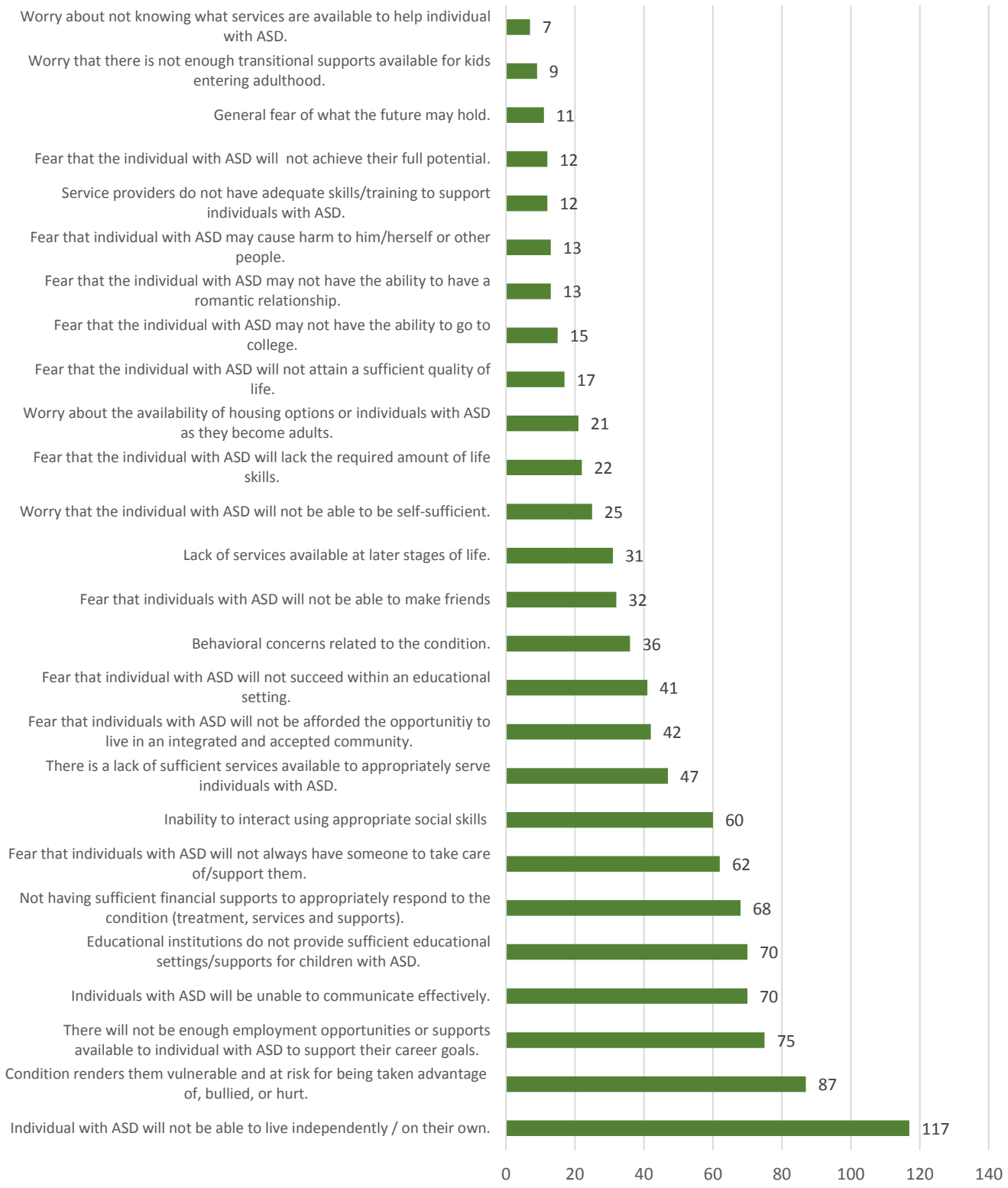
of respondents…

19%

Worry that there will not be enough employment opportunities or supports available to individuals with ASD to support their career goals.

of respondents…

A more comprehensive account of the concerns identified are provided in the table found on the following page.



Other concerns listed that had less than a 1% (6 respondents) response rate included issues such as long waiting lists, access to recreational opportunities, and lack of self-determination service options.

Most pressing needs

Respondents were asked to identify the most pressing needs that they (as someone living with ASD) or that the person they know living with ASD has. The three needs that were most often cited by respondents (n=379) were:

31%

Need an increase in educational supports.

of respondents…

27%

Need financial support.

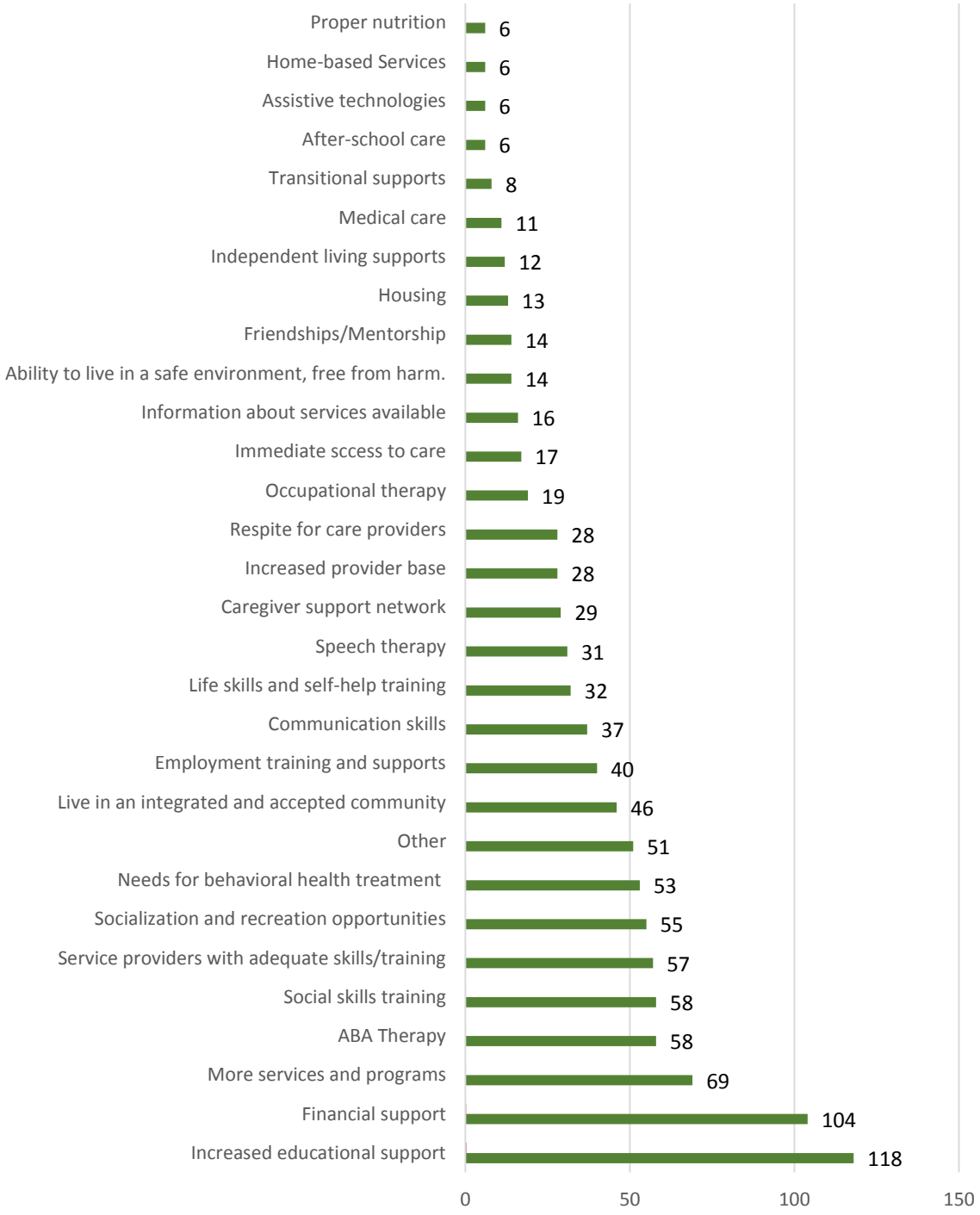
of respondents…

18%

Need more services and programs.

of respondents…

A more comprehensive account of the needs identified are provided in the table below.



Other needs listed that had less than a 1% (6 respondents) response rate included transportation, support to attend college, early intervention, physical therapy, increased understanding, self-determination, assisted living facilities, Board Certified Behavioral Analyst (BCBA) support, evidence-based treatment, parent education, and bilingual services.

What is Working Well

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

Respondents (n=359) cited most often the following:

21% *ABA therapy*

of respondents cited…

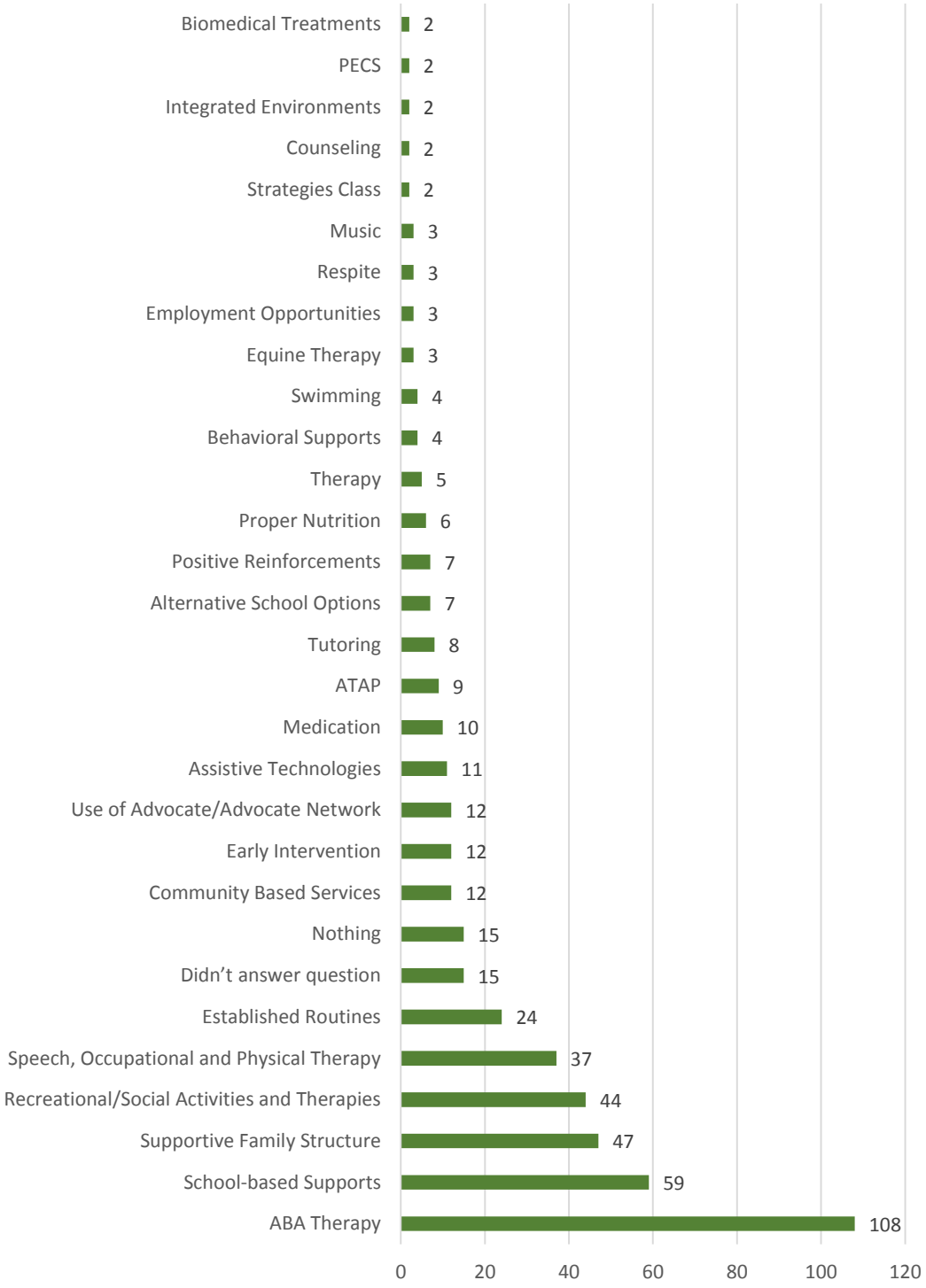
11% *School-based supports*

of respondents cited…

9% *Supportive family structure*

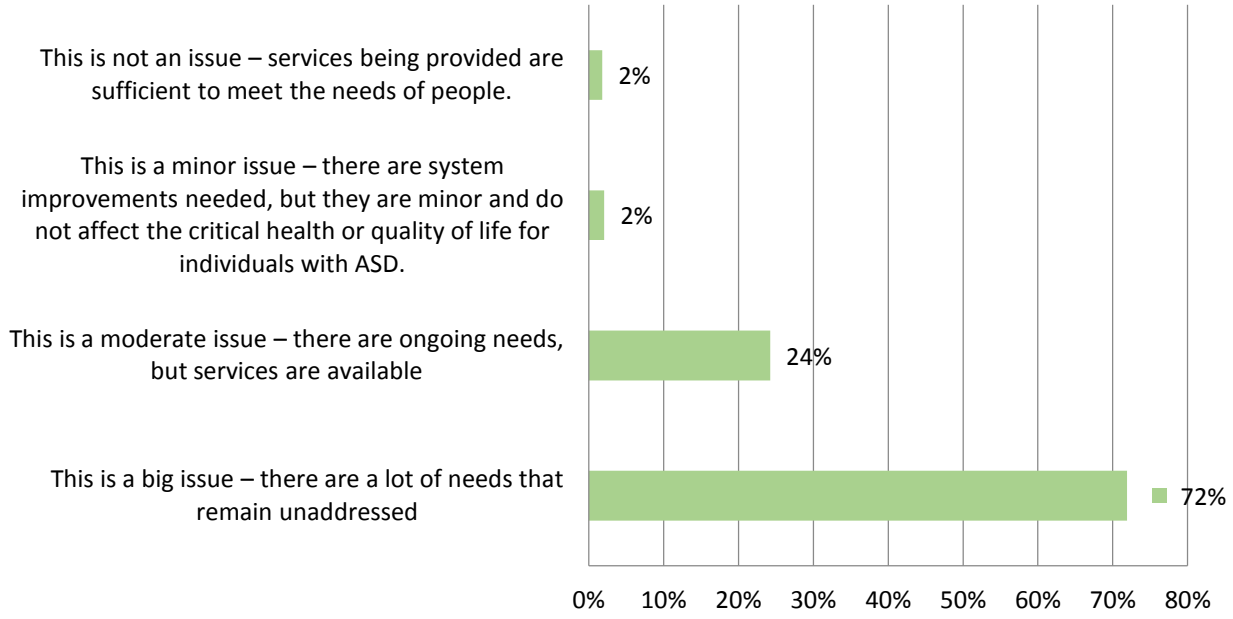
of respondents cited…

A more comprehensive account of what respondents cited as working well is provided in the table below.



Access to Care

Respondents were asked to indicate how significant of an issue it is to access care in their communities. As the chart below demonstrates, more than 70% of the respondents (n=279) indicated that there are a lot of needs that remain unaddressed, while 24% indicate that there are ongoing needs but that services are available.



The following chart demonstrates the access to care issue broken down by county of residence.

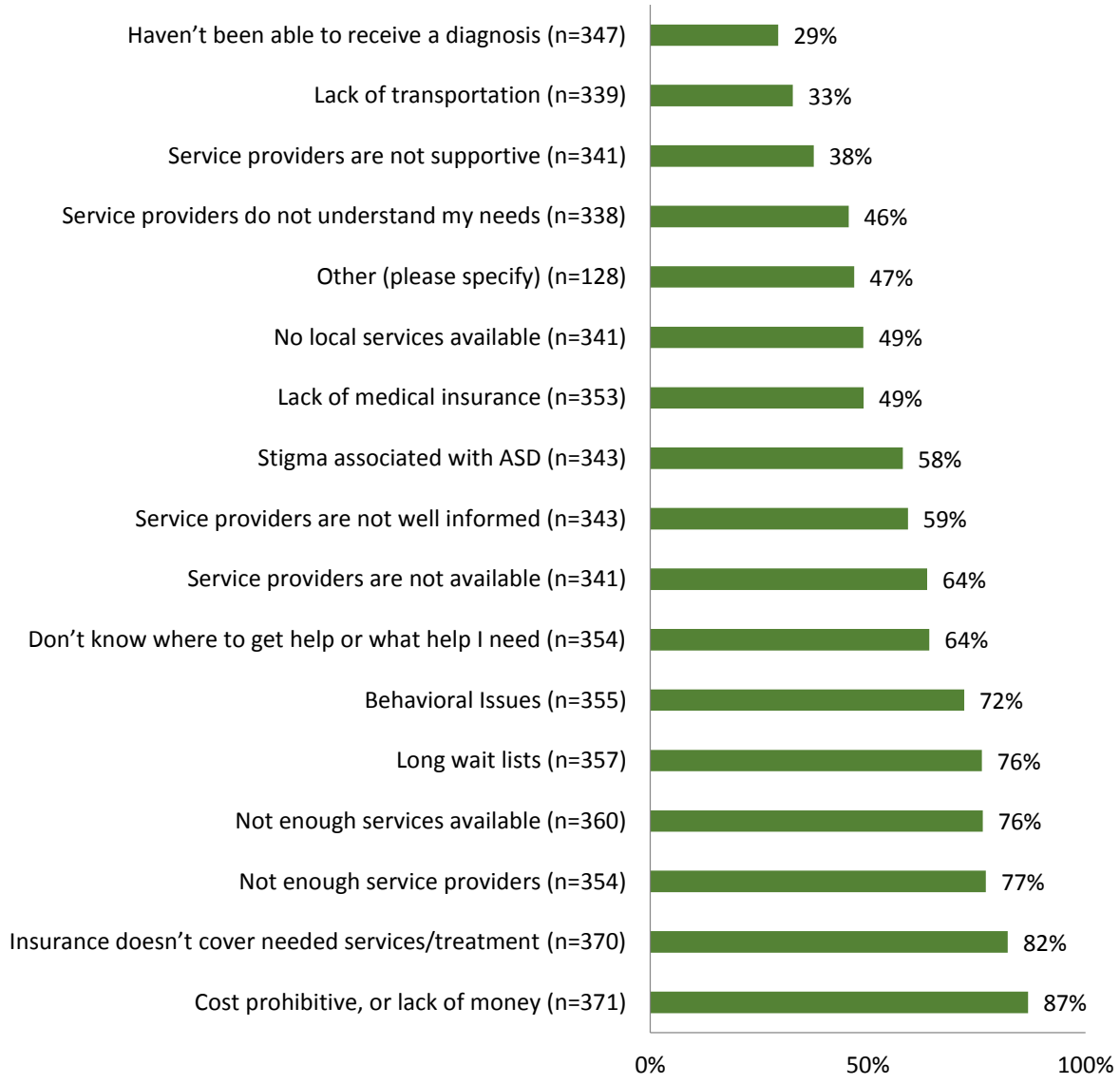
County	n	Big issue	Moderate issue	Minor issue	Not an issue
Carson City	20	60.0%	30.0%	5.0%	5.0%
Churchill	1	0.0%	100.0%	0.0%	0.0%
Clark	310	74.2%	22.6%	1.9%	1.3%
Douglas	1	100.0%	0.0%	0.0%	0.0%
Elko	9	77.8%	11.1%	0.0%	11.1%
Humboldt	2	100.0%	0.0%	0.0%	0.0%
Lincoln	1	100.0%	0.0%	0.0%	0.0%
Lyon	1	100.0%	0.0%	0.0%	0.0%
Nye	4	100.0%	0.0%	0.0%	0.0%
Washoe	37	54.1%	40.5%	2.7%	2.7%

*Counties with no respondents were not listed.

More than half of respondents in each county (except Churchill) believed that there are a lot of needs that remain unaddressed, and as such it was a big issue. Those who believed services were a big issue ranged from 54.1% to 100.0% (with the exception of Churchill). One respondent lived in Churchill County and believed services were a moderate issue.

Barriers to Services

Respondents were asked to identify, among a list of issues, those they believed were barriers to services. The most significant barrier to services was the lack of money, with 87% of respondents indicating it as a barrier to services. Insurance coverage, not enough services available, not enough service providers, long wait lists, and behavioral issues were also among the top barriers identified. The table below identified the percentage of respondents (n=390) that indicated affirmatively that the specific issue was a barrier to services.



Other responses included socializations, lack of coordinated referrals, school district acceptance of children with ASD, and childcare.

Respondents were asked to identify the extent to which each issue listed was a barrier to services. The table below indicates the responses ranging from a big problem to an isolated problem. The number of respondents for this question is different than the one on the previous page, as respondents may have answered that the issue was a problem without ranking the severity of the issue.

Issue	n	Big problem	Medium problem	Little problem	Isolated problem
Cost prohibitive, or lack of money	306	77.5%	18.6%	3.3%	0.7%
Insurance doesn't cover needed services/treatment	294	83.3%	12.2%	3.1%	1.4%
Not enough services available	269	69.5%	25.3%	4.8%	0.4%
Not enough service providers	257	68.5%	25.7%	5.4%	0.4%
Long wait lists	267	71.2%	20.6%	6.7%	1.5%
Behavioral Issues	258	53.5%	31.4%	11.6%	3.5%
Don't know where to get help or what help I need	228	54.8%	31.1%	11.8%	2.2%
Service providers are not available	212	63.2%	32.1%	4.2%	0.5%
Stigma associated with ASD	197	48.2%	32.5%	16.8%	2.5%
Service providers are not well informed	203	51.7%	29.1%	16.3%	3.0%
Lack of medical insurance	179	69.3%	17.9%	7.8%	5.0%
No local services available	178	71.9%	21.9%	5.6%	0.6%
Service providers do not understand my needs	152	44.7%	33.6%	17.1%	4.6%
Service providers are not supportive	133	46.6%	27.1%	20.3%	6.0%
Lack of transportation	129	30.2%	37.2%	24.8%	7.8%
Haven't been able to receive a diagnosis	116	42.2%	31.0%	13.8%	12.9%
Other (please specify)	62	88.7%	3.2%	3.2%	4.8%

Most issues explored as barriers were identified as big problems, the largest of which proportionately was that insurance doesn't cover the needed services/treatments (83.3%). The second largest barrier identified most often as a big problem was that the service was cost prohibitive, or that there was a lack of money to secure the service (77.5%).

Responses captured within the "other" category included socialization skills, lack of coordinated referrals, school district acceptance of children with autism, and childcare.

Critical Issues

Respondents were asked to identify what the Commission should focus their efforts on to address the needs of people living with ASD. Respondents cited most often the following critical issues:

63%

Increase services

of respondents cited…

27%

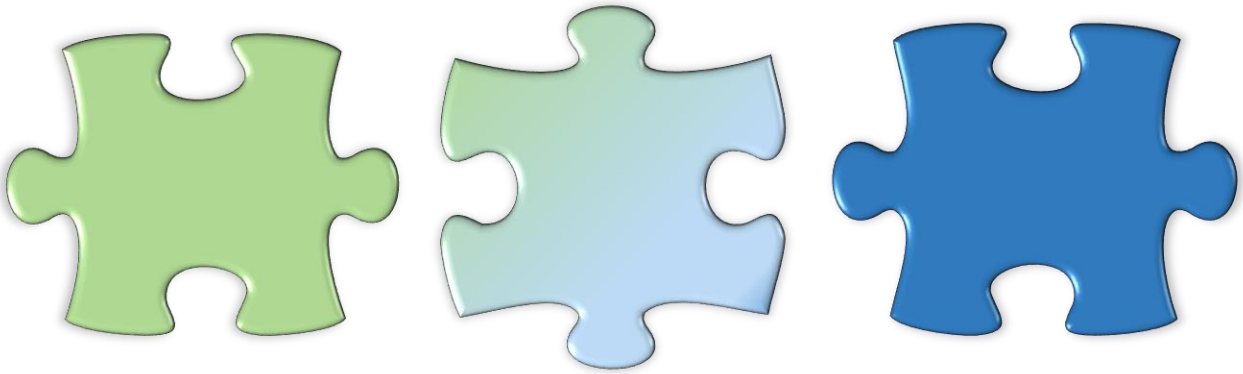
Increase educational supports

of respondents cited…

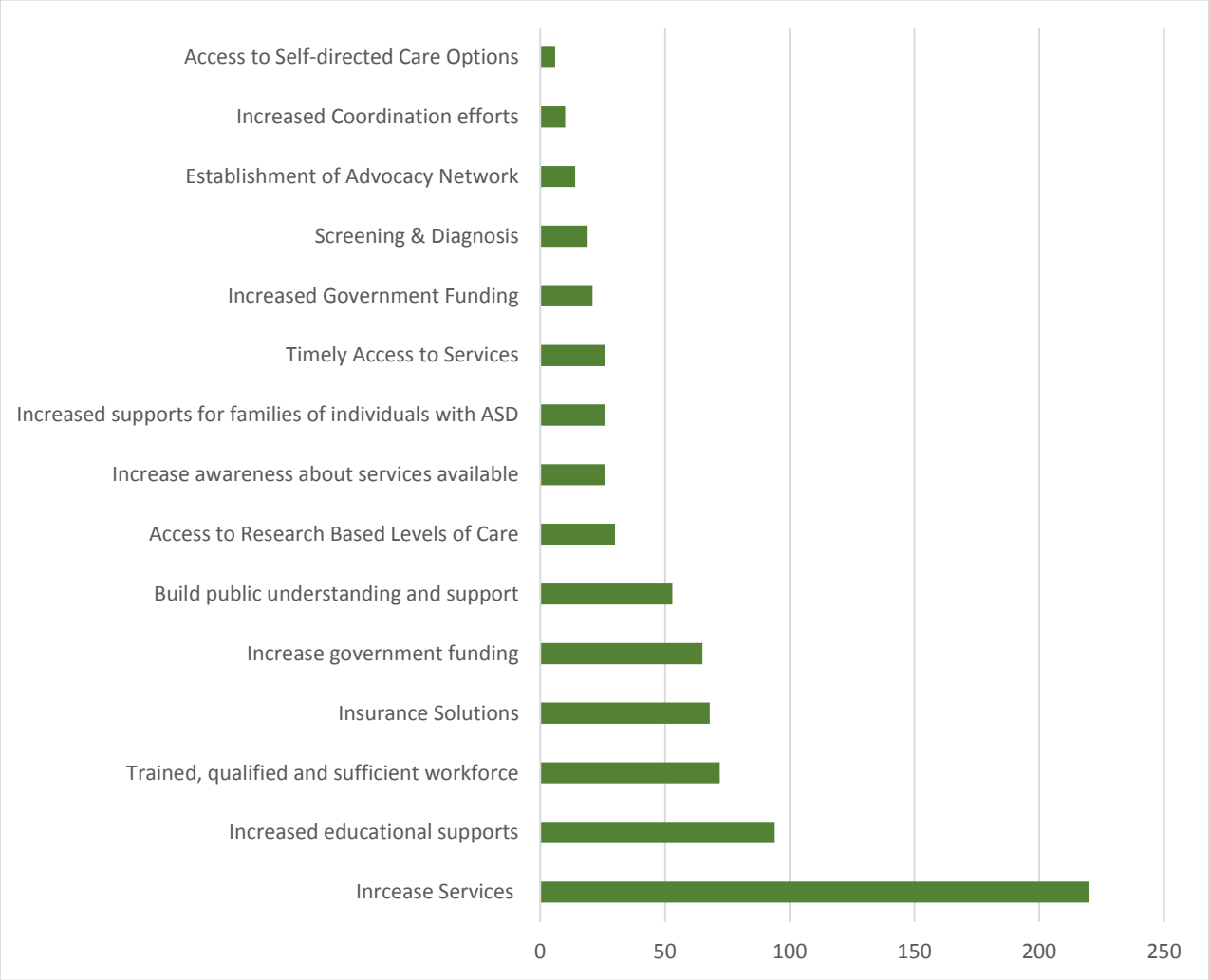
21%

Development of a trained, qualified and sufficient workforce

of respondents cited…

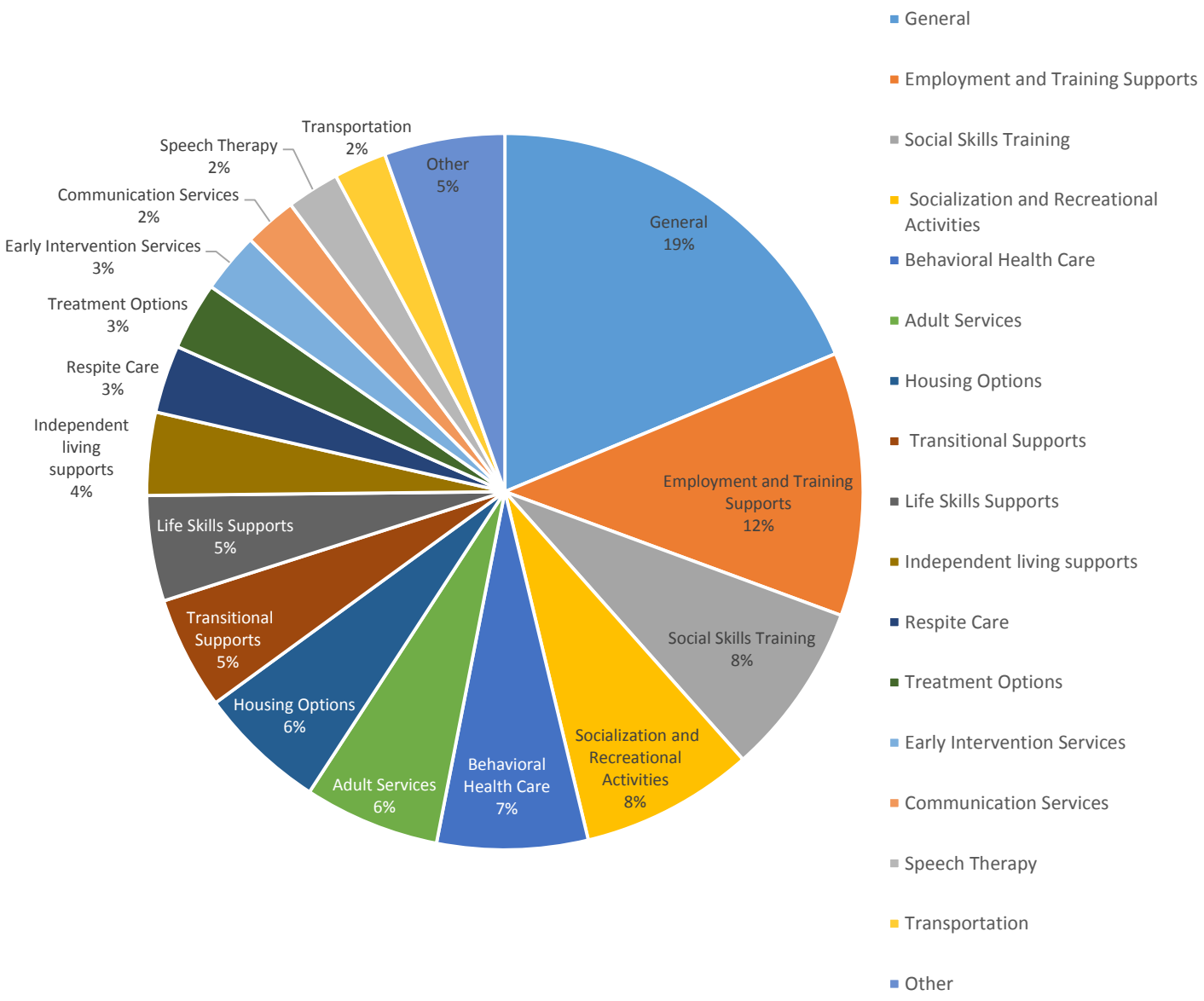


A more comprehensive account of critical issues is provided in the table below.



Other critical issues listed included access to bilingual services, access to assistive technologies, entitlement to services based on diagnosis, increased support for families of individuals living with ASD, and integration opportunities.

Since the most significant critical issue identified was an increase in services, the pie chart below details which services were identified as needing to be increased. The pie chart represents a total of 750 responses, as respondents could have offered more than one suggestion in their answer.



The category "general" is offered to reflect when a respondent simply identified a need to increase services, without specifying what service in particular was needed.

Personal Experiences

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

"Living with a child with ASD has been difficult. When my child would bang his head into walls, jump out of moving cars, telling us how he will kill us, yelling, screaming, taking a medication that was supposed to help with these behaviors and then having a side effect to the medications the doctors put him on, then going to many doctors to help your child and then they tell you, (It looks like this is the best we will get) Battling with the medical insurance to have them cover him, so they think it is far to increase our premiums by 55% because he is unstable. Then taking him out of state because those specialists were supposed to be more knowledgeable. The terrible expense of taking care of a child/adult with ASD is very difficult on the family. All the therapy they need. Horse therapy, social therapy, physical therapy, speech therapy. He can't be left alone; family and other friends don't like to socialize with you because you're so consumed with your child. Not enough respite services to cover for a couple of date nights so you can save your marriage that is hanging on a thread because your child needs so much attention and help. Fighting with the schools to help with services, trying to get him financial services to pay for the other expenses because you can't work as much, and the list goes on. All this being said, I love my son and want the best for him and I will do what I need to, to help him have a life he deserves."

"At this moment we are struggling with school, he has been placed on regular classes, I agree at one point because I was told he was a grade level, not on his 5th grade he has been coming home with 5th grade level homework and is constantly struggling to finish his work. As much as we explain he still is not on that same level. It broke my heart the 4th day of the 2014-2015 school year he asked "Mom is there homework in paradise?' At first I did not understand his question so asked, what do you mean? He said "Is there homework in heaven? My heart broke; this was when I understood how much my son was struggling in class that he did not even wanted to be here. Please help!!!"

"We first tried to get him diagnosed with Early Intervention, but they said he was fine. When Child Find diagnosed him, he went to a school shortly thereafter. The second day of school, he came [home] and told us, "I am ____ ____." He had never told us his last name before. Since then, he has learned to communicate much better, including expressing feelings, explaining what he is pretending, and tells us some of his favorites (favorite color, favorite TV show, etc.). Some favorites are still a mystery to us."

"Our child was told he is nonverbal and will probably not be able to talk. We always thought his grunting sounds and strange noises were all we were ever going to hear. Our hearts were broken knowing we would probably never hear his first words and at the time the only sound he liked to make was the "moooooo" sound from a cow. To us that was heaven. When we finally got ATAP services and settled on our provider LOVAAS, they gave us HOPE that he will be able to talk and they were going to prove it! Granted we had such admiration for them that they believed that so much but being told countless times that he wasn't going to talk, we just took it as they were just being nice. Mind you, this was in February. 7 months later, OUR SON IS TALKING!!! We never would have dreamed this was a possibility! Its amazing hearing him FORM SENTENCES and just saying the little things that matter such as mommy, daddy, sissy and I love you!! Without these services and him being diagnosed at such an early age, I really hate to think of what could have been if we were to have listened to his first doctor that told us NOTHING IS WRONG WITH HIM, HE'S A BOY, HE'LL GROW OUT OF IT! Lucky for us, as his parents, we decided to get a second opinion. I understand doctors are humans too and they will get it wrong along the way, but if they are more informed about autism then it just being "another problem" we might get somewhere."

"A child 16 years old lives with his single mother. His behaviors escalated and he is very aggressive and violent towards his mother. He was hospitalized when 911 was called, and he remains in the ER at the hospital in four point restraints and heavily sedated. This is not the treatment this child needs. Every RTC locally has declined serving him because his communication is at a level where he is unable to participate verbally in group therapy. We have begged RTC's out of state to work with him (which is shameful to begin with, why do we have to ship our kids out of state?) It's time for Nevada to have a children's stabilization unit locally, for behavior therapist to work with a child to stabilize them and assist family members with training, so they can return home or to a children's supported living arrangement. This is not a unique situation; this is happening several times a year."

Conclusion

Consumer Surveys provided useful insight for the Strategic Planning Steering Committee to consider as they finalize the 2015-2020 Strategic Plan. The most important issue that was identified through survey responses, including open-ended questions, was the need for additional resources to support improved outreach, increased services, and a larger and more qualified workforce. Targets for resource development included both government funding as well as insurance product solutions.

Next Steps

The information provided by the consumers of ASD services 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.

Consumer Survey

English Tool

We are collecting information from individuals across the state living with Autism Spectrum Disorder (consumers, family members, care providers, and advocates) to help the state understand what kind of services are needed to support Nevada residents with Autism Spectrum Disorder (ASD). We are also trying to identify what prevents people who need assistance from getting the help they require. All responses will remain anonymous.

If you would like to take this survey online, please go to: https://www.surveymonkey.com/s/NV-ASD

You can complete the survey by:

1. Completing it online at the link provided.
2. Completing the survey in the interactive PDF provided, saving it and emailing it to: lwatson@socialent.com
3. Completing the survey in hard copy and mailing it to:

Social Entrepreneurs, Inc. Attn: Lisa Watson
6548 South McCarran Blvd., Suite B
Reno, NV 89509

RESPONDENT PROFILE QUESTIONS

Please answer the following questions to help us understand who you are representing as you complete this survey.

1. Which of the following best describes you?
(check all that apply)

- ☐ Current consumer of ASD services
- ☐ Former consumer of ASD services
- ☐ Friend/family member of someone with ASD
- ☐ Parent of a child with ASD, currently receiving services
- ☐ Parent of a child with ASD, no longer receiving services
- ☐ Parent of a child with ASD, who has not received services
- ☐ Advocate for individuals living with ASD
- ☐ Someone in need of ASD services but not currently receiving them
- ☐ Not sure

2. At what age were you or the person that you care for identified as having an Autism Spectrum Disorder?

_____

3. What age are you (as the person with ASD) or the person that you care for with ASD currently?

_____

4. Please check the box below if you are completing this survey on behalf of someone with ASD who is unable to complete it independently.

☐ I am completing this survey on behalf of someone with ASD who is unable to complete it independently.

Please answer the following questions, as they relate to yourself, or the person with ASD if you are completing it on their behalf.

5. What is your gender?

☐ Male ☐ Female

6. What is your age?

- ☐ 0-12
- ☐ 13-17
- ☐ 18-20
- ☐ 21-24
- ☐ 25-44
- ☐ 45-64
- ☐ 65-74
- ☐ 75+

7. What is your race/ethnicity?

- ☐ White
- ☐ Hispanic
- ☐ Black/African American
- ☐ American Indian/Alaskan
- ☐ Pacific Islander
- ☐ Asian
- ☐ Mixed Race
- ☐ Other

8. What County do you live in?

- ☐ Carson City
- ☐ Churchill
- ☐ Clark
- ☐ Douglas
- ☐ Elko
- ☐ Esmeralda
- ☐ Eureka
- ☐ Humboldt
- ☐ Lander
- ☐ Lincoln
- ☐ Lyon
- ☐ Mineral
- ☐ Nye
- ☐ Pershing
- ☐ Storey
- ☐ Washoe
- ☐ White Pine

SURVEY QUESTIONS

9. Can you please share with us what your 3 greatest worries are for yourself (as someone living with ASD) or for the person you know living with ASD? These may be things you are worried about now or things you are worried about for the future.
a.
b.
c.
10. We are trying to understand the greatest needs of people who are living with ASD in Nevada. Can you please provide us with the 3 most pressing needs that you or the person you know with ASD has?
a.
b.
c.
11. Can you please tell us what is working well for you (as someone living with ASD), or for the person you know living with ASD?

12. There are a number of reasons that people may not receive the assistance they need. We want to understand why people who need services may not be able to access care. Please indicate which of the following you believe prevents you or other people from accessing services, treatments and/or supports; and then select severity of the issue.

Barriers to Services	Is this an issue?		If you answered yes, please indicate to what extent you believe this issue prevents you/others from accessing care.			
	No	Yes	Big Problem	Medium Problem	Little Problem	Isolated Issue
No local services available						
Lack of transportation						
Lack of medical insurance						
Haven't been able to receive a diagnosis						
Insurance doesn't cover needed services/treatment						
Cost prohibitive, or lack of money						
Long wait lists						
Not enough services available						
Not enough service providers						
Don't know where to get help or what help I need						
Behavioral Issues						
Stigma associated with ASD						
Service providers are not available						
Service providers are not well informed						
Service providers are not supportive						
Service providers do not understand my needs						
Other (please describe):						

SURVEY QUESTIONS

13. How significant of an issue is services to individuals with ASD in your community?

- ☐ This is a big issue – there are a lot of needs that remain unaddressed
- ☐ This is a moderate issue – there are ongoing needs, but services are available
- ☐ This is a minor issue – there are system improvements needed, but they are minor and do not affect the critical health or quality of life for individuals with ASD.
- ☐ This is not an issue – services being provided are sufficient to meet the needs of people.

14. What do you think we should focus on to address the needs of people with ASD? Please list them in order of importance.

Most important issue to address for people with ASD:

Second most important issue to address for people with ASD:

Third most important issue to address for people with ASD:

15. It is important for us to understand unique family experiences of individuals who live with ASD. Please provide us with an experience that you have had as someone with ASD, or as someone who cares for someone with ASD that will help us describe living with ASD in Nevada. (500 word maximum)

Thank you for taking the time to complete this survey. Your input is valuable and appreciated!

Spanish Tool

Estamos recabando información en todo el estado de personas que viven con el Trastorno del Espectro Autista (personas diagnosticadas con dicho trastorno, sus familiares, cuidadores, y defensores) para ayudar al estado a entender qué tipo de servicios se necesitan para apoyar a los residentes de Nevada con el Trastorno del Espectro Autista (TEA; siglas en inglés ASD). También estamos tratando de identificar lo que impide a las personas que necesitan ayuda obtener dicha ayuda.

Todas las respuestas serán anónimas. Si a usted le gustaría responder esta encuesta en línea, por favor visite: https://www.surveymonkey.com/s/NV-ASD-Spanish

Usted puede llenar la encuesta:

1. En línea (internet) a través del enlace (link) proporcionado.
2. En el PDF interactivo proporcionado, y luego guarda la encuesta en la computadora y la envía por correo electrónico a: lwatson@socialent.com
3. En una copia impresa y luego la envía por correo

Social Entrepreneurs, Inc. Attn: Lisa Watson
6548 South McCarran Blvd., Suite B
Reno, NV 89509

PREGUNTAS SOBRE EL PERFIL DE LOS ENCUESTADOS

Por favor conteste las siguientes preguntas para ayudarnos a entender a qué grupo está usted representando al completar esta encuesta.

1. ¿Cuál de las siguientes opciones lo describen mejor? (marque todas las que sean aplicables)

- ☐ Consumidor actual de los servicios de ASD
- ☐ Ex consumidor de servicios ASD
- ☐ Amigo / miembro de familia de una persona con ASD
- ☐ Padre (o madre) de un niño con ASD, que actualmente recibe servicios
- ☐ Padre (o madre) de un niño con ASD, que ya no recibe servicios
- ☐ Padre (o madre) de un niño con ASD, que no ha recibido servicios
- ☐ Defensor de personas que viven con ASD
- ☐ Alguien que necesita de los servicios de ASD pero que no los está recibiendo
- ☐ No está seguro

2. ¿A qué edad usted o la persona que usted cuida fue identificada con un trastorno del espectro autista?

_____

3. ¿Qué edad tiene usted actualmente (como la persona con ASD) o qué edad tiene la persona con ASD que usted cuida?

_____

4. Por favor marque la casilla que aparece a continuación si usted está llenando esta encuesta en nombre de una persona con ASD que no puede completarla de forma independiente:

- ☐ Estoy completando esta encuesta en nombre de una persona con ASD que no puede completarla de forma independiente.

Por favor conteste las siguientes preguntas, que se refieren a usted mismo o a la persona con ASD en caso esté llenando esta encuesta en su nombre.

5. ¿Cuál es su sexo?

☐ Masculino ☐ Femenino

6. ¿Cuál es su edad?

☐ 0-12	☐ 21-24	☐ 65-74
☐ 13-17	☐ 25-44	☐ 75 +
☐ 18-20	☐ 45-64	

7. ¿Cuál es su raza / etnia?

- ☐ Blanco
- ☐ Hispano
- ☐ Negro / afroamericano
- ☐ Indio Americano / de Alaska
- ☐ Isleño del Pacífico
- ☐ Asiático
- ☐ Mestizo,
- ☐ Otros

8. ¿En qué condado vive usted?

☐ Carson City	☐ Eureka	☐ Nye
☐ Churchill	☐ Humboldt	☐ Pershing
☐ Clark	☐ Lander	☐ Storey
☐ Douglas	☐ Lincoln	☐ Washoe
☐ Elko	☐ Lyon	☐ White Pine
☐ Esmeralda	☐ Mineral	

PREGUNTAS DE LA ENCUESTA

9. ¿Puede por favor compartir con nosotros sus 3 principales preocupaciones por usted mismo (como alguien que vive con ASD) o por la persona que usted conoce y que vive con ASD? Estas pueden ser cosas que le preocupan acerca de la actualidad o cosas que le preocupan acerca del futuro.
d.
e.
f.
10. Estamos tratando de entender las principales necesidades de las personas que viven con ASD en Nevada. ¿Puede por favor indicarnos las 3 necesidades más urgentes que tiene usted o la persona que usted conoce y que vive con ASD?
d.
e.
f.
11. ¿Puede por favor decirnos qué es lo que está funcionando bien para usted (como alguien que vive con ASD), o para la persona que usted conoce y que vive con ASD?

12. Hay una serie de razones por las que la gente puede no estar recibiendo la asistencia que necesita. Queremos entender qué es lo que impide a las personas que necesitan servicios acceder a la atención. Por favor, indique cuál de las siguientes razones cree usted que le impide a usted u otras personas acceder a los servicios, tratamientos y / o apoyo; y luego señale la gravedad del tema.

Barreras para acceder a los servicios	¿Es este un problema?		Si su respuesta es sí, por favor indique en qué medida cree que este problema le impide a usted o a otros acceder a la atención.			
	No	Sí	Problema grande	Problema mediano	Problema pequeño	Asunto aislado
Ausencia de servicios disponibles en mi localidad						
Falta de transporte						
Falta de seguro médico						
No he podido recibir un diagnóstico						
El seguro no cubre los servicios o tratamientos necesitados						
Costo prohibitivo, or falta de dinero						
Larga lista de espera						
Los servicios disponibles no son suficientes						
Los proveedores de servicios no son suficientes						
No sé dónde recibir ayuda o qué tipo de ayuda necesito						
Problemas de comportamiento						
Estigma asociado con el ASD						
Los proveedores de servicios no están disponibles						
Los proveedores de servicios no están bien informados						
Los proveedores de servicios no brindan apoyo						
Los proveedores de servicios no entienden mis necesidades						
Otras (por favor, describae):						

PREGUNTAS DE LA ENCUESTA

13. ¿Qué tan importante es en tu comunidad el tema de los servicios para individuos con ASD?

- ☐ Es un gran problema - hay una gran cantidad de necesidades desatendidas
- ☐ Es un problema moderado - hay necesidades presentes, pero los servicios están disponibles
- ☐ Es un tema de menor importancia - hay necesidad en mejoras del sistema, pero son menores y no afectan a los estados de saludos críticos o a la calidad de vida de las personas con ASD.
- ☐ No es un problema - los servicios que se proporcionan son suficientes para satisfacer las necesidades de las personas.

14. ¿En qué cree usted que deberíamos centrarnos para hacer frente a las necesidades de las personas con ASD? Por favor, enumérelas por orden de importancia.

Tema más importante para hacer frente a las necesidades de personas con ASD:

Segundo tema más importante:

Tercer tema más importante:

15. Es importante para nosotros conocer las experiencias familiares únicas de las personas que viven con ASD. Por favor, proporcione una experiencia que usted haya tenido como alguien diagnosticado con ASD, o como alguien que cuida de una persona con ASD; que pueda ayudarnos a describir la vida con ASD en Nevada. (500 palabras como máximo)

17. **Gracias por darse el tiempo para completar esta encuesta. ¡Su aporte es valioso y apreciado!**

Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Subpopulation Summary Report

ACKNOWLEDGEMENTS

The Nevada Commission on Autism Spectrum Disorders 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, facilitated the subcommittee focus group discussions and prepared this summary report.

Introduction and Background

The Nevada Commission on Autism Spectrum Disorders (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 service 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 meeting participants. This report is a summary of the information collected through focus groups held with each subcommittee representing specific subpopulations of individuals living with ASD throughout Nevada. Companion documents summarize other outreach efforts.

Purpose

Focus groups were held with each of the Commission Subcommittees: Early Childhood, Youth and Transition, Adults and Aging, and Rural Populations. The purpose of these focus group 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 focus group participants.

Methodology

Subcommittees were established by the Commission to explore the full range of issues and solutions to specific segment populations. This exploration was meant to inform the Commission throughout the course of their strategic planning process. Subcommittees met on numerous occasions to review research, interview national leaders, hear relevant presentations, and to discuss issues particular to their population focus. Subcommittees then scheduled a meeting to act as a focus group to document issues of particular importance and recommend priorities and strategies for future action.

Focus groups were held with Subcommittee and community members who chose to participate in the open and publicly posted meetings which occurred according to the following schedule:

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 24, 2014	1:00 – 4:00 pm
Rural Populations	Nevada Youth Training Center 100 Youth Center Rd., Elko	October 1, 2014	10:00 am– 12:00 pm

Each focus group began with a brief description of the Commission on Autism Spectrum Disorders, the strategic planning process, and an explanation of how the information collected during the focus group discussion was relevant to planning efforts. Each group discussed issues affecting their particular population and recommended actions 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.

Focus Group Discussion Participants

The following identifies all of the individuals that participated in the subcommittee focus group discussions on the dates specified in the table on the prior page:

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 Cavenaugh (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 Richard (Member)	Andrew Devitt	Jan Crandy	Ralph Sacrison
Shannon Crozier (Member)	Denise Robinson	Megan Crandy	*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.*
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 focus group identified the most important issues related to their specific subpopulation. In analyzing the whole collection of subcommittee focus 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 focus group 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 evidence-based tools, 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 discussions, there was a significant amount of conversation 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 as insufficient by the groups. There was widespread agreement 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 gaps in services for individuals with ASD, while significant 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 individuals with ASD 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[3] as well as secondary providers[4] that are 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 of 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."

COORDINATED SERVICE DELIVERY SYSTEM

Individuals on the spectrum may require services from a variety of different systems, concurrently 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 reactive and siloed 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, ADVOCACY 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."

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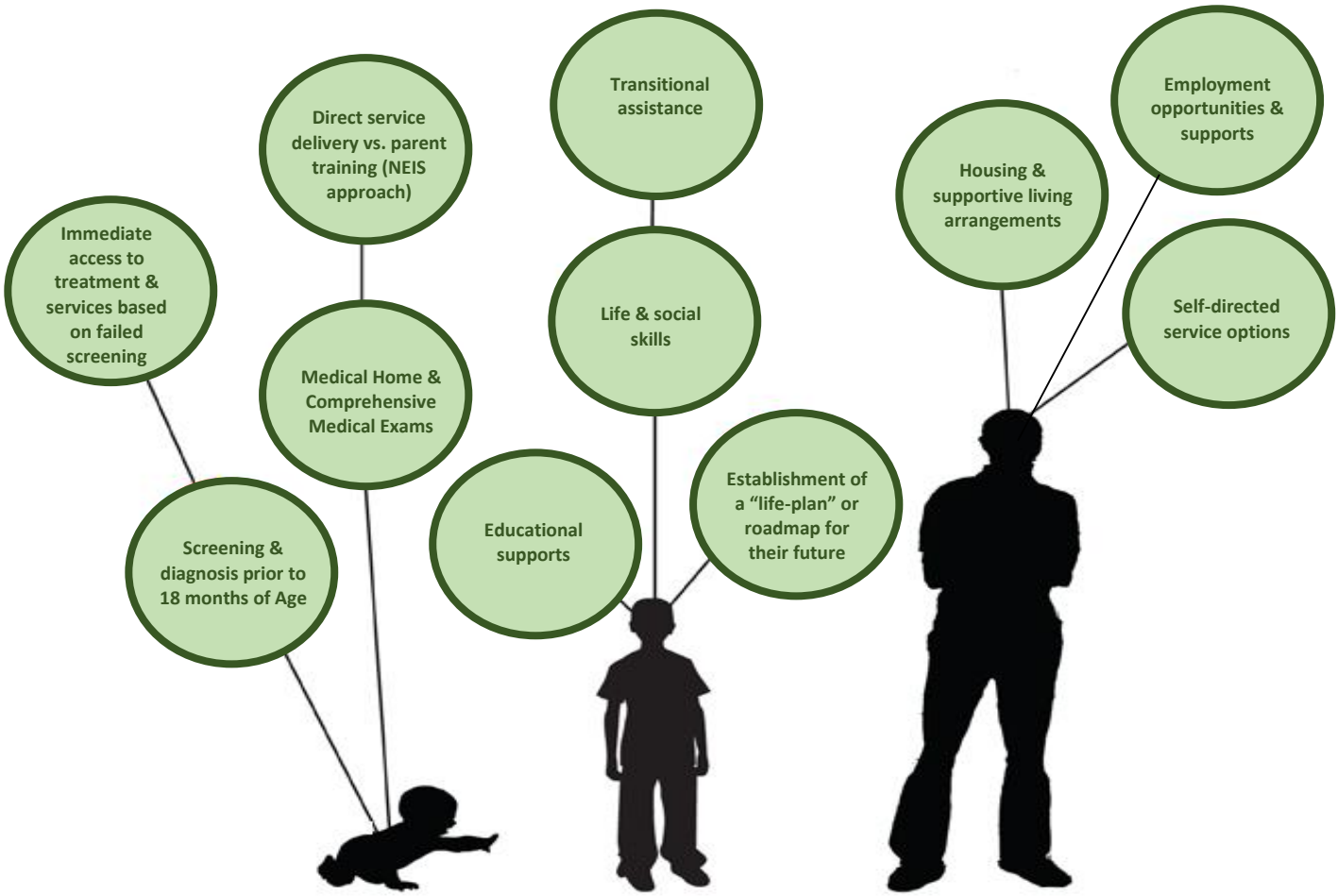
[3] **Primary Providers:** Provide services directly related to the ASD diagnosis, such as ABA, Occupational, Speech, and Physical Therapists, Residential Support Staff, Personal Care Attendants, and Behavioral Interventionists.

[4] **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.

Needs that Were Particular to Each Subpopulation

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



EARLY CHILDHOOD

Screening & diagnosis prior to 18 months of age: The earlier a child is identified as having a spectrum disorder, the better their chances for receiving the care needed to produce long-term benefits.

Immediate access to services based on failed screening: Children need access to services immediately upon a failed screen, and should not have to wait for a diagnosis or other eligibility barriers.

Medical home[5] and comprehensive medical exams: A medical home and access to comprehensive medical exams, while beneficial for all children, is critical to children with ASD due to the complexity of their needs.

Direct service delivery vs. parent training (NEIS approach): Children with ASD require direct service delivery to support optimal growth and development. While parent training is complimentary to such efforts, it should not be the primary approach to servicing this population.

[5] **Medical Home:** A model in which medical care is delivered by a trained physician that is known to the patient in an accessible, continuous, comprehensive, family-centered, coordinated, compassionate, culturally effective way.

YOUTH

Educational supports: Youth with ASD need support to achieve their academic potential. This includes qualified and trained teachers and aides as well as an administration that recognizes and honors the needs of these children. Additionally, children with ASD need supportive services such as home-based ABA services that complement their educational setting, as well as IEP accommodations.

Life & social skills: Youth with ASD need ASD specific skill development in the interconnected areas of life and social skills, as their condition renders this an area of particular difficulty.

Transitional assistance: Transitions between different stages of life can be particularly difficult for youth with ASD. Transitional assistance such as moving from grade to grade, school to school, and from school to community are needed.

Establishment of a "life plan" or roadmap for the future: Typical youth often have a plan for their life as adults, as well as an intended path to achieve such plan. Youth with ASD are often left without this roadmap, robbing them of adequate preparation for adulthood.

ADULTS

Housing and supportive living arrangements: Adults with ASD need to have housing options that fit their unique needs and supports community integration within the community of their choosing.

Employment opportunities & supports: Employment is critical to self-sufficiency, and as such individuals with ASD require job opportunities that are aligned to their personal interests, employers that are willing to hire them, and supports (such as a job coach) that support their long-term success.

Self-directed Service Options: Each individual with ASD is unique, and as such should be afforded the person-centered option of identifying the supports and services that are best suited to meet their needs.

There were needs that were consistently identified by both the Youth and Transition Subcommittee as well as the Adults 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:
- 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 focus 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 narrative presents the 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, diagnositic resources are so over-extended, that individuals may have to wait over a year to aquire 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 screening or diagnosis.
- **Immediate Access to Treatment and Services:** Children with a failed screening are not provided immediate access to intensive, evidence-based care. This is a problem, as early intervention provides the most significant chance for positive outcomes related to a spectrum disorder.
- **Family Support Services:** Families of children with ASD are not provided the necessary 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

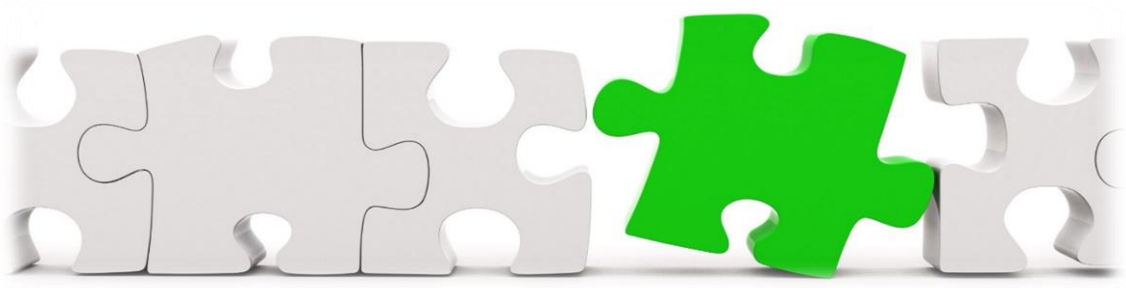
- **School Based Supports:** Schools are not structured to fully support individuals with ASD. They do not have sufficient funding to provide the necessary supports, interventions, accomodations, transitions, or ASD specific training of administrators, faculty and staff.
- **Transitional Assistance:** Youth 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, services, and support options provided to the adults and aging populations, as most ASD specific services end at the time an individual turns 22.
- **Employment Opportunities and Supports:** Adults with ASD have specialized employment needs and job supports that are not currently being provided. They need employment opportunities that fit their unique interests. Additionally, they 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 even more 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 are reluctant 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 Disorders 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 the 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 screening and/or diagnosis. This network should assist individuals, families, and professionals 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 early and consistent screening 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, throughout the lifespan, 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 (e.g., 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, services and supports, 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 were 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.

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?

Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Provider Survey Summary Report

ACKNOWLEDGEMENTS

The Nevada Commission on Autism Spectrum Disorder Strategic Planning Steering Committee would like to thank all of the individuals that took the time to complete the provider survey, providing information for this commission to further understand the needs of people living with autism spectrum disorder in Nevada.

The Nevada Commission for Autism Spectrum Disorders Steering Committee Members conducted all aspects of the Provider Survey and developed this report independently.

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 surveys completed by consumers of ASD services and the family members that care for them.

Purpose

Provider surveys were issued to a variety of providers that serve individuals with ASD, in an effort to solicit input regarding the strengths and weaknesses of the current system as well as their suggested solutions for any identified deficiencies.

This report synthesizes the results of the survey. 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

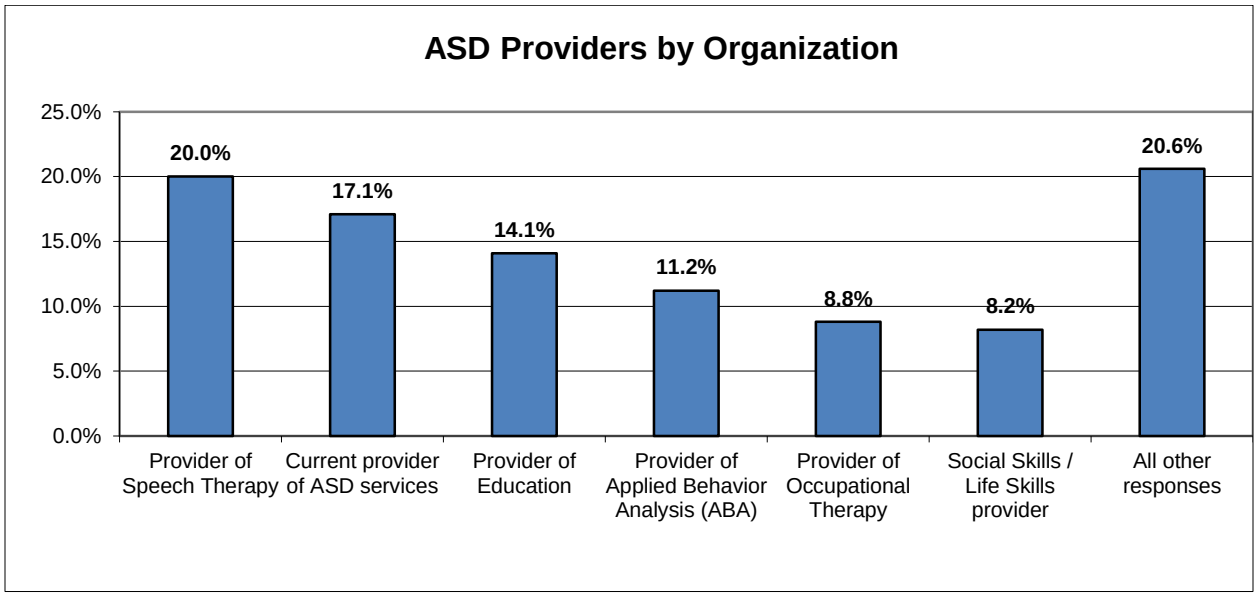
Two members of the Committee established the questions making up the provider survey. Provider surveys were distributed through the Committee, asking respondents to answer the questions on-line through the use of Survey Monkey.

Surveys were collected over a period of 27 days (August 26 – September 22, 2014). A total of 77 surveys were collected from providers across the state.

Survey Respondents Profile

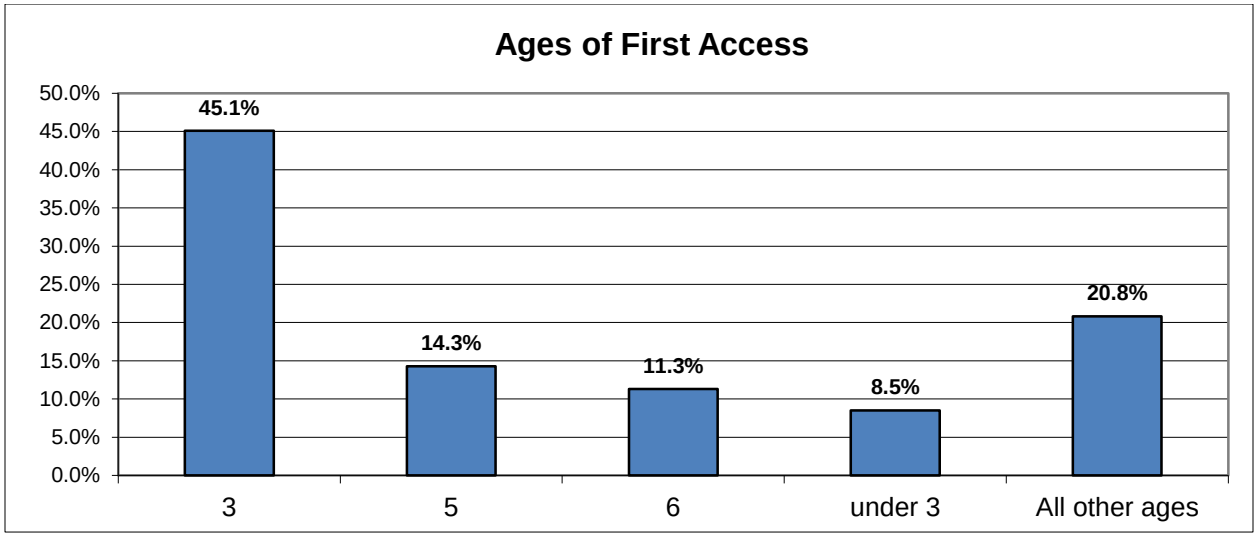
Affiliation

There were a total of 77 surveys collected from providers across the state. The survey tool asked respondents to identify a category that best described their organization. 18 categories were available for selection to represent provider types. Respondents were not representative of all 18 categories and zero surveys were received for at least five provider types. Speech Therapists represented 34 of the 77 respondents. Respondents did not include all state agencies or school districts.



Demographic profile of Individuals Served

Respondents were asked to identify the age of the clients they serve with Autism Spectrum Disorder. 39.5% indicated they serve individuals with ASD beginning at 3 years old through Adulthood. The average age of first access was 3 years old as indicated by 45.1% of respondents.

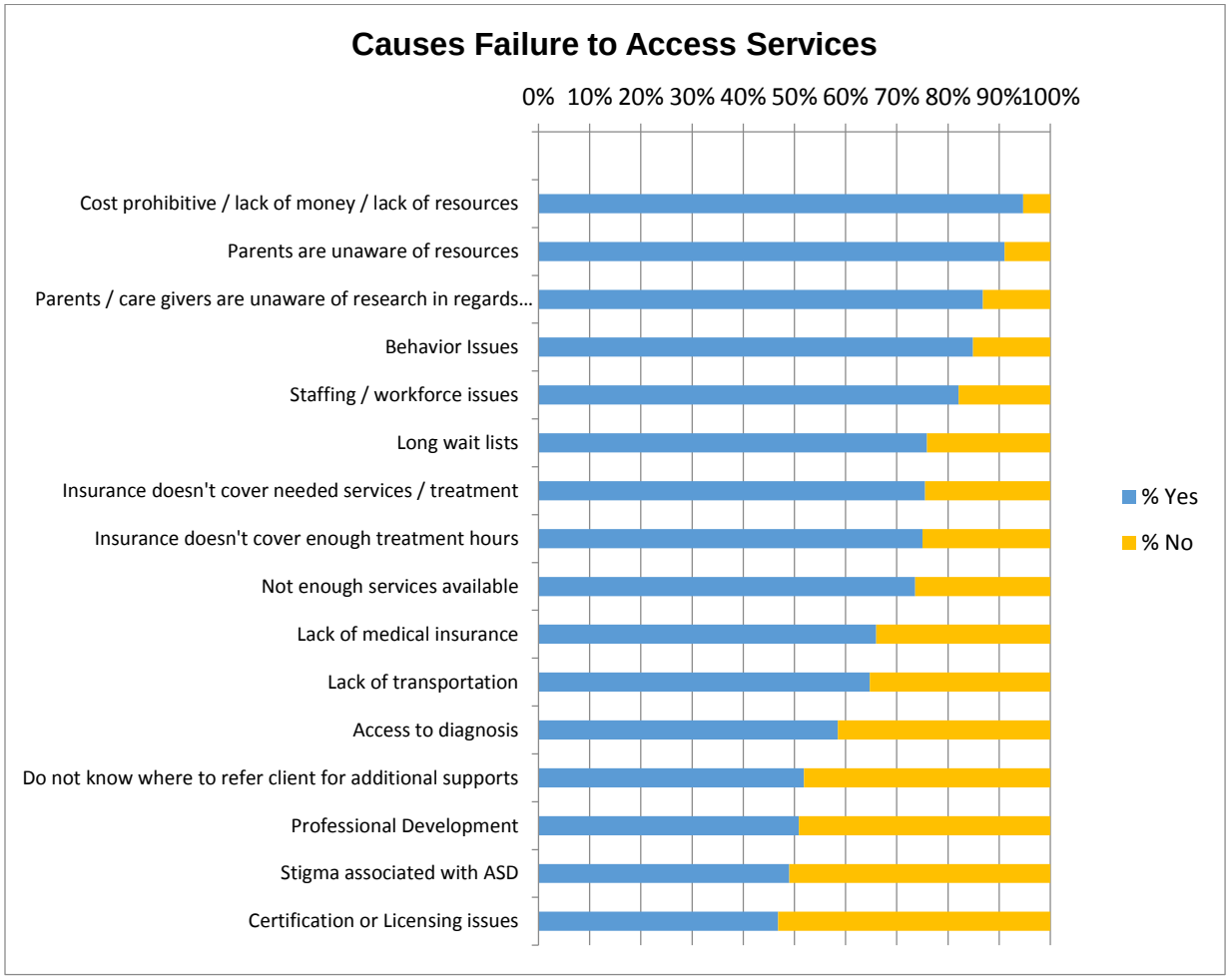


Survey Analysis

Provider Surveys offered information for the Strategic Planning Steering Committee to consider as they finalize the 2015-2020 Strategic Plan. Survey analysis provided a limited view due to the small sample size. Future recommendations should include the development of a robust provider survey with required participation to gain a true picture of services in Nevada for individuals with ASD and their families.

Core problem

Survey respondents were asked to indicate reasons people with ASD may not receive the assistance they need. Lack of funding was revealed as the number one issue with 94.7 % of providers acknowledging this reason. Two other top reasons why assistance is not received are because parents are unaware of resources 91.1%, and parents/caregivers are unaware of research in regards to ASD 86.8%. Besides insurance issues, which are covered in the next section, the other top reasons people with ASD do not receive the services they need are, behavior issues 84.9%, staffing / workforce issues 82.1%, long wait lists 75.9 %, not enough services available 73.6%, lack of transportation 64.7%, and access to diagnosis 58.5%.



While the survey did not produce a mandate for any one of a number of significant problems, the responses, both open ended and specific, identified common themes. These included lack of funding,

need for a variety of additional services, need for sufficient, trained, and certified staff, and insurance complications. It is not possible to conclude from the survey which of these needs should dominate our focus, except that they all can be distilled into the bottom line issue, which is a lack of funding.

"Equitable service delivery. There is a big disparity in services offered and received for those educated parents and individuals for their children and those from low income or minority families." -- Provider

One provider suggested that we let the market make the determination and the service deficiencies will be resolved by the willingness to pay. That approach highlights a critical issue. Families with money are in a much better position than those without. Unfortunately, the majority of children suffering from ASD are not fortunate enough to have families capable of funding the needed resources. The facts are that the level of expense involved is beyond the reach of even the middle class income levels. The same is true even if the insurance problems can be resolved because 20% of Nevadans are uninsured and reimbursements are limited to $36,000, an amount insufficient to cover robust therapy and family support.

It is estimated to cost at least $17,000 more per year to care for a child with ASD compared to a child without ASD. Costs include health care, education, ASD-related therapy, family-coordinated services, and caregiver time. For a child with more severe ASD, costs per year increase to over $21,000. In addition to medical costs, intensive behavioral interventions for children with ASD cost $40,000 to $60,000 per child per year. – CDC

In the search for improvement it is necessary to face reality. Sufficient funding will not be available in the foreseeable future, either from government sources or the economy, to resolve many (if any) of the problems cited. With that in mind, is it better to focus on improving the scope and quality of services available to those who can afford them or on services the State is able to provide for the less fortunate? Fundamentally, the majority of services provided by the State are available through the school system, and that, in itself, is a problem because it excludes important issues, such as intense levels of treatment delivered early in life and the adult population. These will be addresses in the third finding below.

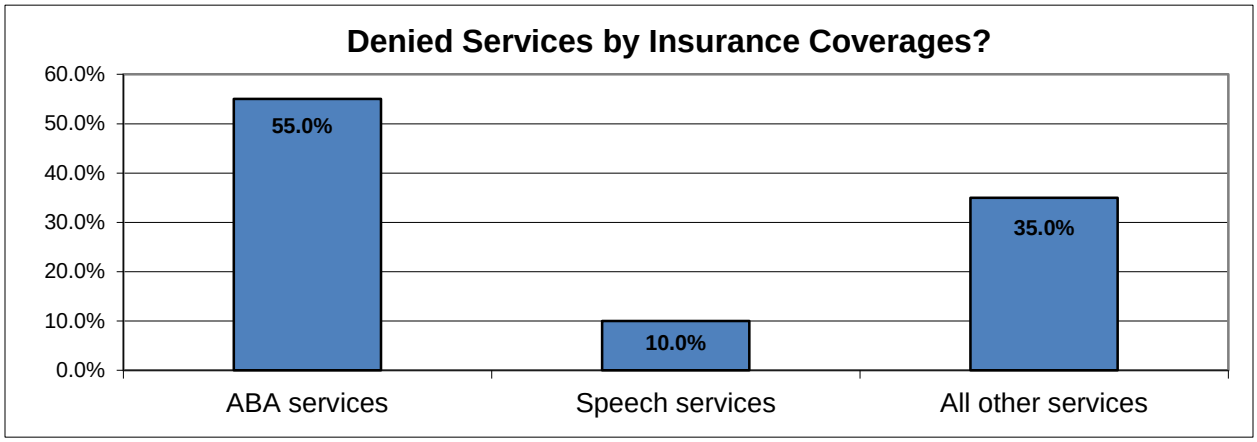
The bottom line appears to be how to manage the funding constraints to produce the best outcomes.

Insurance

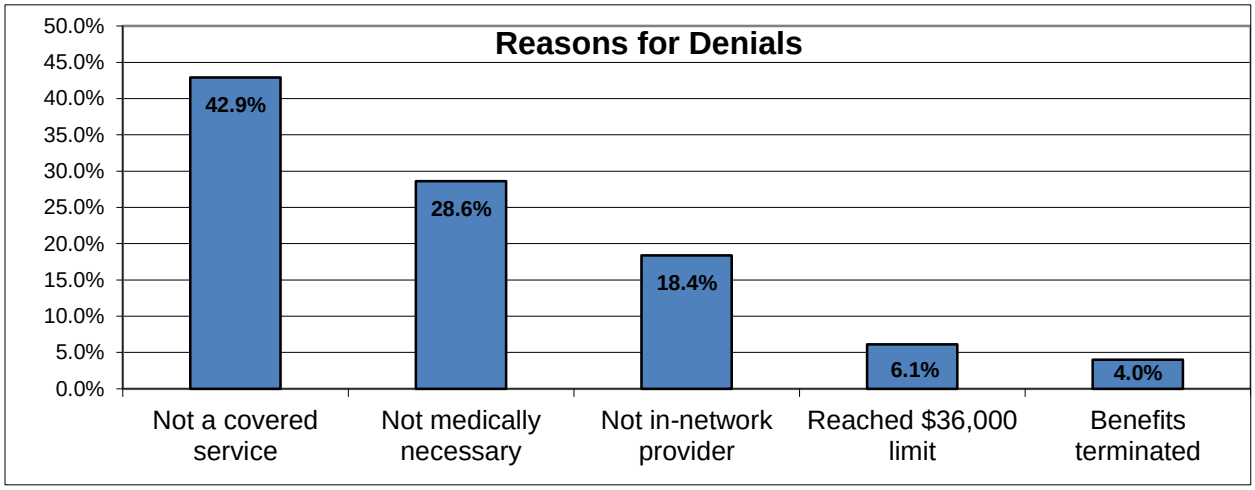
Insurance coverage for Autism Spectrum Disorders remains a significant issue, even after the passage of AB 162. When providers were asked "reasons why people may not receive the assistance they need," issues with insurance were also highly indicated as the cause. 75.5% of providers stated insurance doesn't cover needed services/treatment, 75.0% specified insurance doesn't cover enough treatment hours, and 66.0% indicated a lack of medical insurance altogether.

ABA providers indicated issues with Nevada's certification process for behavior interventionists as a barrier to providing treatment. The requirement is costly and takes too long resulting in an insufficient workforce to meet the treatment needs of Nevada's insured children. This issue will become more significant as national requirements and insurance companies operating in multiple states will recognize and likely require the BACB Registered Behavior Technician (RBT), providers in Nevada may be forced to have their staff meet both requirements. Tricare insurance has already put the RBT requirement in place effective December 2015. Additional concerns cited by ABA providers included: Low rates, lack of coverage under self-funded plans, lack of standardized CPT billing codes, insufficient funding to support recommended levels of treatment and authorization/payment response time.

100% of providers indicated receiving denials for ABA, speech therapy, or other services from insurance companies.



The survey also revealed the major reasons why claims were denied. 42.9% of providers surveyed indicated insurance companies had denied claims saying they were billing for services not covered by the policy. 28.6 % said their claims were denied as not medically necessary.



There does seem to be a real disconnect as to the services covered. The survey listed ABA as most commonly denied, then Speech Therapy, Assessments, Social skills group, diagnosis, family training, occupational therapy, the number of hours requested, case management and appropriate supervision hours. In other words, everything. However, many of these services are in fact covered, at least in part,

by many insurance policies. The disconnect may be coding, communication or stubbornness on the part of the insurance company, but it is obvious that the providers need help.

To assess provider knowledge of resources available to help resolve insurance issues, providers were asked, "When an issue with insurance coverage presents do you refer the individual or family to the Nevada Office for Consumer Health Assistance (GovCHA)?" By far the largest number of respondents, 70.9%, said they were not even aware of this resource.

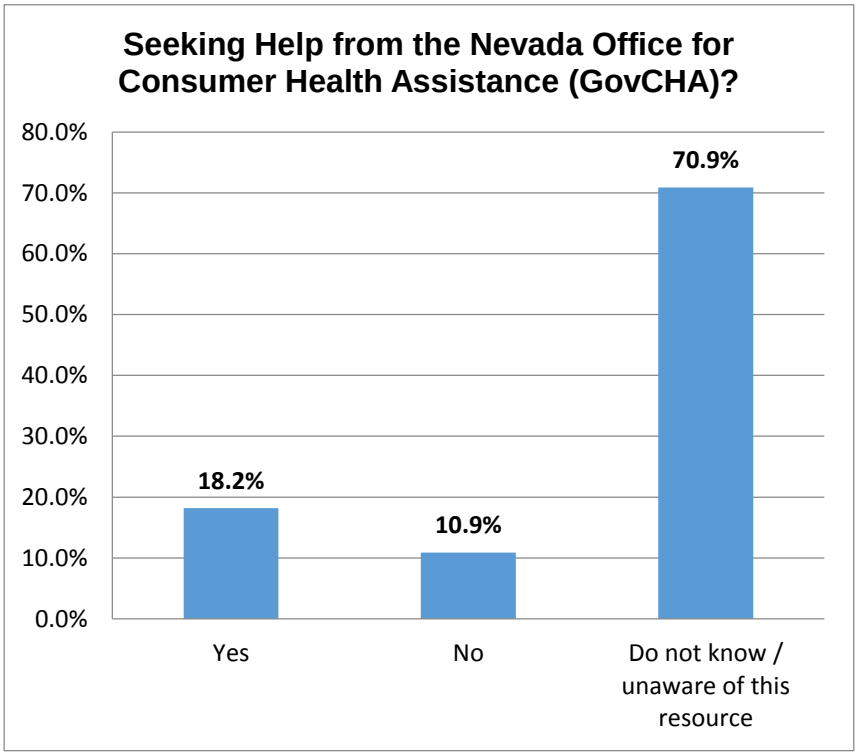
The three most significant insurance problems identified in the survey were that companies are difficult to deal with, they do not cover some or all services, and payment is too frequently very late in arriving.

Simply communicating with insurance companies can be very frustrating. Response time is slow, representatives are not knowledgeable or are deliberately obtuse, providers are often given "the run around", and coding is difficult. Providers also experience problems with credentialing.

"Have a state governing body that enforces insurance coverage for denials."

- Suggested by a provider

The state has certain authorities and influence over the insurance industry so it is possible that many of these problems can be resolved. Providers need to be made aware of Nevada Office for Consumer Health Assistance (GovCha) and utilize this office to aid in solving insurance related issues. Training could also benefit ASD providers, who have demonstrated inexperience in regards to insurance billing practices.



Special issues

There are several special issues that should be raised for consideration:

- Early intervention. There are excellent studies indicating that early intervention utilizing applied behavior analysis (ABA) models (Early Intensive Behavior Intervention, EIBI) provide optimal outcomes. This issue was addressed by several providers but primarily because enough services are not available, early diagnosis is uncommon or hard to obtain, there is a concentrated

upfront cost (research indicates it is offset in the long run), and EIBI is not available through Nevada Early Intervention Services (NEIS) or Nevada's school system. Children who have failed an autism screen do not have access to treatment prior to receiving a diagnosis. Limited resources and provider wait times often cause a known child with ASD to wait for coverage of treatment due to the lack of an official diagnosis. It is possible that focusing on this area may provide the best use of scarce resources in the long run and be the most beneficial if lack of availability to middle and lower class income level is resolved.

- A number of providers addressed the lack of specialized services to those children with more difficult symptoms. This appears more common in the rural areas and cost prohibitive to the lower income levels. Statewide access to services should be equitable.

- Transition. One of the more common problems identified was the transition to adult life. There is a real problem of insufficient training in life and occupation skills. Young adults do not know how to live on their own and their employability is compromised by a lack of specific skills. Comments were also made as to educating the business environment as the potential of this population. However, we must be practical. If we do not give them the necessary skills they will not be employable. The onus here generally is on the school districts where students with special needs are often left behind.

"The children on the ASD spectrum age into adolescents, then adults. This tidal wave of children need supports to assure their transition is supported and smooth, and with the increase in CDC numbers, more children will require assistance. It has been clearly established in the national and international literature that people with ASD can make a meaningful contribution to a work setting, the exact same as persons without disabilities. It simply requires more (person-centered) effort from teachers, parents, counselors, and businesses. It also requires some outside-the-box, innovative thinking and flexibility. My specific recommendation is provide financial support for programs that train, teach, and transition individuals to work in the community, in integrated settings, where they can earn a respectable wage and not be dependent on the system. Those with ASD should NOT be in a segregated setting, they should be included like everyone else."

- *Provider*

- Better diagnosis services. Many providers lamented the inability to secure effective diagnosis services, both for insurance purposes and for early intervention. Perhaps better communication with the medical community and early childhood education system would be a productive focus.

- Rural area. This survey was conducted primarily with providers from Washoe and some of the more rural counties. It is probable that the availability of services in these areas and the focus of the school systems are different than in the large metropolitan area surrounding Las Vegas. Certainly, Las Vegas has a broader range of services available that would be difficult or

impossible to find in less densely populated areas. Therefore, when focusing on long term plan of action, the rural areas will have different needs and since this survey did not incorporate the metropolitan experience a similar survey of that area would beneficial.

- Low income or minority families. This has been addressed and perhaps suffices to say, the most used and accessible resource currently available to these families is Medicaid, which currently does not provide coverage for ABA. And the public schools, which needs an influx of funding to support additional staffing, training and implementation of programs specific for children with ASD.

- School districts limitations. Teacher turnover was cited as a concern, ability to maintain trained staff and the limited number of specific programs to serve students with ASD.

- Funding to support ongoing staff development across all professionals serving individuals with ASD.

- Parent/caregiver and individual with ASD's need for education and training to become informed decision makers and support informed choice.

- A need for uniform data collection on outcomes and implementation of standards across systems.

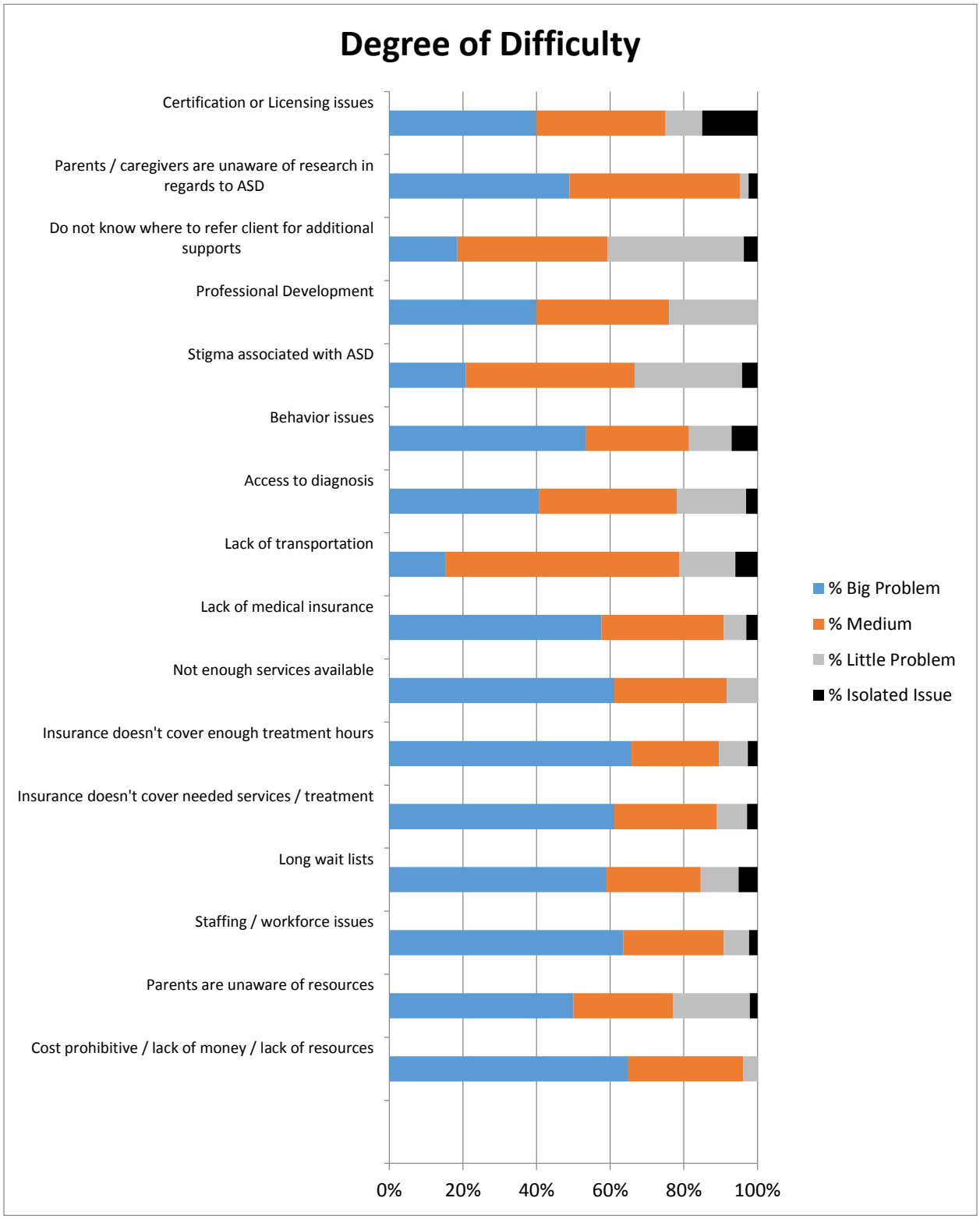
Cost Benefit Analysis

As stated in the introduction, the purpose of this strategic planning process is 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. This survey identifies a wide spectrum of pressing needs and it is obvious that money will be a primary constraint as well as the core deficiency. However, included in the overall five year plan the commission might want to focus on one of the special issues raised by the survey based on which might provide the best cost benefit to our ASD families given probable funding levels. For example, Nevada could establish itself as the premier state for early intervention; or with the best school programs for supporting those with ASD; or implementing a successful public school program for transition to adulthood. Unfortunately it is unlikely that all of these can be done during the same five year span. Perhaps finding the greatest benefit to the largest number of children would be the best approach. But perhaps not, research currently indicates establishing and providing evidence-based treatment early and intensively provides the most benefit in the long run.

Next Steps

The information offered by providers of ASD services 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.

Reasons People May Not Receive the Assistance They Need



Selected Comments from Providers

- In the school districts in Nevada, I have come across untrained, unsupervised, uncredentialed individuals developing behavior plans and training staff on how to treat individuals in need of behavioral support. This is disastrous for the client, and is occurring across multiple schools and multiple counties. A "Behavior Specialist" that is not credentialed or supervised by a credentialed Behavior Analyst has no right to implement treatment and put plans into place.

- Due to teacher turnover, the training needs in the school district are constant and ongoing. Due to funding the resources are already stretched. Providing families with more of the resources they need after school would increase their success in school. Funding education and especially special education to a point where we could have adequate personnel with incentives to stay in these programs, as well as paraprofessionals that were paid more than a poverty wage so we can access more highly qualified individuals, would make a huge difference. Addressing all of this would increase the ability to have more productive home/school partnerships.

- There is a single mom in the area who cares for a severely disabled 26 year old daughter. The daughter has autism among a multitude of other issues. She is very violent and rages against her mother. She bites and hits her mother and threatens to kill her younger brother. This mother has to go to Reno (4 hours away) to get treatment for her daughter. The daughter is able to participate in a day training program, which provides her mother some respite. The daughter has been suspended from the public transit bus due to poor behavior. She regularly upsets the drivers and the other passengers with her stories of abuse, threats of murder (specifically to the younger brother) and threats of suicide. The mother is exhausted and feels like there is no way out. She isn't looking to have someone take her daughter, but some relief would be nice. The daughter is too violent for a group home and the mother says there aren't facility centers for people with these disabilities. I asked her what will happen when she is too old to care for her daughter or if she dies before her daughter. She will do her best to leave her daughter with a family member, but who is going to want to take her? This does not answer the question, but it shows what a real person trying to care for her child is facing. I would think specialized facilities or respite caregivers would be an excellent way to improve the outcomes of these individuals, but it would probably be cost prohibitive to the families.

What is Working Well:

- Within our district we have created many specialized classrooms for all children on the spectrum. We have access to several skilled professionals as a resource, and we have attempted to meet the needs of these students and provide ongoing training for interested teachers.

- Extensive training provided to teachers and service providers who work with students presenting with autism; provide consultation services for school-based teams relative to special education evaluations involving suspicion of autism; increasing emphasis on data collection (e.g., hand-held data collection devices) for determining student progress.
- I work for Washoe County School District and our special education department has a sub-department that supports staff working with students who have a diagnosis of Autism. If problems arise I have trained support staff that I can contact.

- As a provider, we are successfully getting individuals on the spectrum to work in the community and earn at least minimum wage. They make a meaningful contribution, pay taxes, and enjoy their work. Also we have extensive collaboration with Vocational Rehabilitation and DHHS-Developmental Services (SRC). Agencies are working together to better serve folks with ASD. We can still do better though.

Suggestions

- Evaluate and improve university programs for teachers
- Allocate resources to attract and retain talented teachers
- Site administration accountability for the quality of programs for kids with ASD
- Utilize the talent of knowledgeable professionals that already exist in the district and community and compensate them for delivering quality training
- Address the actual core issues that impact schools and not continuously repeat the same mistakes and recycle the same issues without any consistent framework/benchmarks for progress 6. Invest in curriculum and materials that are engaging for students with ASD - especially interactive technology
- Focus on 21st century skills in the educational planning for students with ASD!!! (Which includes communication)
- Address the gross inequities between resources allocated to a few demanding people (usually white and educated) and those for families with less understanding of their rights and the means needed to seek better interventions and proper education for their children (often minority families)
- Career opportunities for interventionists should be nourished to help remedy Low rates of pay and limited working hours that result in the career being unattractive and not competitive with other career opportunities. Mechanisms to recruit, educate and train interventionist should be in place at both community college and university levels in Las Vegas. Insurance coverage should include the research-based dosage of both therapy hours and supervision hours.
- Rural Areas of Las Vegas needs specific plans to provide proper treatment to families in these communities and funding. The quality and distilling CEU for individuals qualified to provide Autism diagnosis. I believe there are a lot of false positives and a disregard to other diagnoses such as other social and communication disorders, Global Delays, mental health, poor environmental enrichment and so forth.
- More training in communication devices for those that don't talk.
- Availability of options and capacity to serve adults with autism related to affordable and appropriate housing, and appropriate employment.

- I would provide them services that they need while accepting advice from their families. I would work on making responsible costs for these services and I would be sure that they know about them plus this would include a complete breakdown of all the costs of the services involved so that necessary services can be provided and unnecessary services can be eliminated. They are as different as you and I. The one size fits all theory does not work. They need the opportunities to try everything and find out what works best and what is in their budget. This is what needs to be done with insurance and insurance needs to help with this ever growing population. We all have to help and stop worrying about the cost and our ability to help. We can help them and they are very awesome to have here with us.

Provider Survey

We are collecting information from providers across the state serving individuals with Autism Spectrum Disorder to help the state understand what kind of services/treatments/supports are needed to support Nevada residents with Autism Spectrum Disorder (ASD) across the lifespan. We are also trying to identify what prevents people who need assistance from getting the help they require. We are hoping you will share information on all the barriers that limit the clients you currently serve from accessing the services you provide or what is currently causing a wait list. All responses will remain anonymous.

To complete this survey online, please go to: https://www.surveymonkey.com/s/ASD-Providers

Deadline for survey submission is: **Friday, September 19th, 2014.**

ORGANIZATIONAL PROFILE QUESTIONS

Please answer the following questions to help us understand the organization you are representing as you complete this survey.

16. Which of the following best describes your organization?

(check all that apply)

- ☐ Current provider of ASD services
- ☐ Current provider with a State Agency
- ☐ Provider of Applied Behavior Analysis (ABA)
- ☐ Provider of Speech Therapy
- ☐ Provider of Occupational Therapy
- ☐ Provider of Education
- ☐ Provider of Funding/Resources
- ☐ Job Coach/Job Developer provider
- ☐ Provider for Basic Skills Training
- ☐ Provider for Respite
- ☐ Social Skills/Life Skills provider
- ☐ Psychologist
- ☐ Provider of alternative therapies
- ☐ Provider of Medical Treatment
- ☐ Provider of Transportation
- ☐ Provider of Housing and/or Residential Services
- ☐ Personal Care Attendant
- ☐ Other _____

17. What County is your organization based in?

- ☐ Carson City
- ☐ Churchill
- ☐ Clark
- ☐ Douglas
- ☐ Elko
- ☐ Esmeralda
- ☐ Eureka
- ☐ Humboldt
- ☐ White Pine
- ☐ Lincoln
- ☐ Lyon
- ☐ Mineral
- ☐ Nye
- ☐ Pershing
- ☐ Storey
- ☐ Washoe

18. What Counties do you serve?

- ☐ Carson City
- ☐ Churchill
- ☐ Clark
- ☐ Douglas
- ☐ Elko
- ☐ Esmeralda
- ☐ Eureka
- ☐ Humboldt
- ☐ White Pine
- ☐ Lincoln
- ☐ Lyon
- ☐ Mineral
- ☐ Nye
- ☐ Pershing
- ☐ Storey
- ☐ Washoe

19. What age of clients do you serve with an Autism Spectrum Disorder?

_____

20. What is the average age when your clients first access treatment/services/supports within your organization?

_____

21. How are your clients or families paying for the services you provide? (check all that apply)

- ☐ Self-Funded
- ☐ Regional Center
- ☐ Insurance
- ☐ Other _____
- ☐ ATAP
- ☐ School District
- ☐ Medicaid

22. How many clients with ASD do you or your organization currently serve?

_____

23. How many are currently on your wait list?

_____

24. Number of staff within your organization?

- ☐ 1-5
- ☐ 11-19
- ☐ 26-50
- ☐ 6-10
- ☐ 20-25
- ☐ 51+

SURVEY QUESTIONS

25. How does your organization address professional development?
26. What quality control measures do you or does your organization have in place?
27. Do you track and /or report outcomes?
28. What information do you provide your clients about resources and choices available in their community?
29. Have you attempted to contract or enroll with at least one private insurance company in order to provide autism services covered under AB162? ☐ Yes ☐ No
30. What are the 3 biggest issues you find when working with private insurance companies?
a.
b.
c.
31. What services have been denied by insurance coverage?
32. What was the reason(s) for denial? ☐ Not medically necessary ☐ Benefits terminated ☐ Not a covered service ☐ Not in-network provider ☐ Reached $36,000 limit ☐ Other _____
33. When an issue with insurance coverage presents do you refer the individual or family to the Nevada Office for Consumer Health Assistance (GovCHA)? ☐ Yes ☐ No ☐ Do not know/unaware of this resource
34. Can you please tell us what is working well for you as a provider in Nevada.
35. When serving transitioning youth or adults with ASD, how do you support self-determination and choice?
36. We are trying to understand the greatest needs of individuals who are living with ASD in Nevada. Can you please provide us with the 3 most pressing needs you observe for the individuals you serve?
a.
b.
c.

37. There are a number of reasons why people may not receive the assistance they need. Please indicate which of the following you believe prevents your clients or families from accessing services, treatments and/or supports and the severity of the issue.

Barriers to Services	Is this an issue?		If you answered yes, please indicate to what extent you believe this issue prevents you/others from accessing care.			
	No	Yes	Big Problem	Medium Problem	Little Problem	Isolated Issue
Lack of medical insurance						
Lack of transportation						
Insurance doesn't cover enough treatment hours						
Access to a diagnosis						
Insurance doesn't cover needed services/treatment						
Cost prohibitive, or lack of money, or lack of resources						
Long wait lists						
Not enough services available						
Staffing/workforce issues						
Parents are unaware of resources						
Behavioral Issues						
Stigma associated with ASD						
Professional Development						
Do not know where to refer client for additional supports						
Parents/caregivers are unaware of research in regards to ASD						
Certification or Licensing issues						

38. How do you educate the families and clients you serve on evidence-based treatment and research?

39. What do you think Nevada's priorities should be if we are going to achieve the greatest outcomes for individuals with ASD and their families? Please list them in order of importance.

Most important issue to address for people with ASD:

Second most important issue to address for people with ASD:

Third most important issue to address for people with ASD:

40. Please use this space to add any specific recommendations for improving the outcomes of individuals with ASD in Nevada?

Thank you for taking the time to complete this survey. Your input is valuable and appreciated!

Nevada's Historical Commitment to Autism Spectrum Disorders

1997

- Clark County School District began funding ABA home programs.

2002

- Nevada Provider Rates Task Force Strategic Plan includes findings for Services for Individuals with Autism

2004

- Nevada Early Childhood Autism Task Force develops recommendations for Early Intervention Services.

2007

- AB 629 passed, creating Nevada Autism Task Force and appropriating $2M in general funds for Autism Services. Funding supports pilot to serve children across the spectrum.

2008

- Nevada Autism Task Force delivers Action Plan for Nevada's Legislators and Policymakers with 146 recommendations, 11 for immediate action. Governor establishes Nevada Commission on ASD.

2009

- Legislature approved additional $3.2 million for autism services, bringing the total to $5.2 million. Continues funding for autism self-directed programs for a total of 121 children.
    - AB162 passed, Nevada becomes the 11th state to enact *autism* insurance reform on May 29, 2009. Applies to small and large group health plans, and State worker Health Plan, governed by state law. Individual plans will have to offer an optional rider for autism coverage. To read the bill and view its complete history go to: http://www.leg.state.nv.us/75th2009/reports/history.cfm?ID=345

    - AB359 passed, the bill requires all children being evaluated at Nevada Early Intervention or its community partners for services be screened for Autism according to the American Pediatrics Association recommendations. Requires Nevada Early Intervention to notify parents immediately if their child is found to be at risk of autism and refer child for a diagnosis and treatment. ·Requires the staff, who serve children with Autism within the Nevada Early Intervention or its contractors to provide parents with accurate information on autism and evidence-based treatments.· Lays out a foundation of skills paraprofessionals should acquire to work with students with autism. Requires school district staff to refer to the 2008 Autism Task Force document when designing programs

for students with autism. You can read the bill and its history by going to: http://www.leg.state.nv.us/75th2009/reports/history.cfm?ID=709 .

2011

- AB 345 passed establishing Autism Treatment Assistance Program (ATAP) as primary treatment program – funds transferred from MHDS self-directed autism program.
  - FY 12 ATAP slots = 134
  - FY 13 ATAP slots = 137
  - 174 additional children served through MHDS program

  - AB316 passed, requires a statewide standard for measuring outcomes and assessing and evaluating persons with Autism Spectrum Disorders through the age of 21 years for the purposes of receiving services. Requires the Division to designate, as part of the statewide standard, a protocol for determining whether a person is a person with Autism Spectrum Disorder. Requires the Division to collect certain information relating to persons with Autism Spectrum Disorders and to document the services provided to and the progress of those persons. **Surveillance Improvements -** Requires the Department of Education, the Health Division and the Department of Employment, Training and Rehabilitation to report to the Aging and Disability Services Division information relating to persons with Autism Spectrum Disorders. You can read the bill and its history by going to: http://legiscan.com/NV/text/AB316/2011

2013

- Autism Treatment Assistance Program received $11.7M over the biennium through general fund and tobacco settlement dollars
  - FY 14 slots = 307
  - FY 15 slots = 572

2014

- Interim Finance Committee funded $113,000 to support Nevada Commission on Autism Spectrum Disorders and the Development of 5-year Strategic Plan to address the needs of Individuals with ASD across the Lifespan. Work begins on the plan July 2014, with the goal of completion of December 2014.

- The Legislative Committee on Health Care voted to support the following and address during the 2015 Legislative Session:

  Draft a Letter to the DHHS encouraging the Department to:

  1. Develop mechanisms to provide readily available access to the Modified Checklist for Autism in Toddler screenings that assess risk for Autism Spectrum Disorder in rural Nevada and a mobile diagnostic clinic for those who have red flags identified by the screenings. In rural Nevada, accessing a diagnostic evaluation is a significant barrier to treatment. \

2. Allow Autism Treatment Assistance Program (ATAP) funds to be used to support diagnostic clinics across rural Nevada, if it is determined to be feasible and appropriate. (Recommendation Nos. 18a and 18b proposed by Korri Ward, B.S., Founder and President, Northern Nevada Autism Network)

3. Encourage coordination between ATAP, Nevada Early Intervention Services, and rural school districts with the intent of promoting autism diagnoses, treatment, and helping coordinate providers and services to increase access to treatment and services in rural communities.

4. Require Nevada Medicaid to cover Applied Behavior Analysis (ABA) services as soon as possible by:

   i. Seeking clarification from Centers for Medicare and Medicaid Services regarding whether ABA can be included in the Nevada Medicaid State Plan via a plan amendment;

   ii. Preparing and submitting such an amendment;

   iii. Initiating the process of certifying providers of ABA services and establishing rates;

   iv. Providing ABA services to Early Periodic Screening Diagnosis, and Treatment children;

   v. Making the necessary request to shift available funding during this biennium to cover these services; and

   vi. Developing a budget for the next biennium that includes sufficient funding for Medicaid coverage of ABA and to eliminate the ATAP waiting list.

Revise the following provisions of NRS related to autism services and insurance coverage:

1. Remove the requirement that autism behavior interventionists be certified by the Board of Psychological Examiners. Instead, autism behavior interventionists will continue to work under the supervision of a licensed and Board Certified Behavior Analyst or a Board Certified Assistant Behavior Analyst but without their own certification. *Until 2017, at which time the National Registered Behavior Technician (RBT) will be required.*

2. Remove the requirement that an autism behavior interventionist be certified as a condition to insurance coverage for autism spectrum disorders. *Until 2017, at which time the National Registered Behavior Technician (RBT) will be required.*

3. Remove the statutory limitation of $36,000 per year for applied behavior analysis treatment for consistency with the Affordable Care Act.

Glossary of Terms

Applied Behavior Analysis ("ABA")
An evidence- based treatment for individuals with autism that utilizes positive reinforcement to encourage positive behavior while at the same time reducing interfering behaviors. ABA can also help children and adults with autism learn new skills.

Autism Spectrum Disorder
A developmental disability significantly impacting verbal and nonverbal communication and social interaction. Autism Spectrum Disorders, as defined by the DSM-IV, include Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder.

Board Certified Behavior Analyst ("BCBA")
A credentialed professional who has specific training and expertise in the analysis and treatment of behaviors.

Frontier Areas – Frontier areas are sparsely populated rural areas that are isolated from population centers and services. Frontier is defined as places having a population density of six or fewer people per square mile.

Medical Home
A model in which medical care is delivered by a trained physician that is known to the patient in an accessible, continuous, comprehensive, family-centered, coordinated, compassionate, culturally effective way.

Person-centered Practice
Person-centered practice is defined as treatment and care that places the person at the center of their own care and considers first and foremost the needs of the person receiving the care. It is also known as person-centered care, patient-centered care and client-centered care. Person-centered practice is treating persons/patients/clients, as they want to be treated.[6]

Primary Providers
Provide services directed related to the ASD diagnosis, such as ABA, Occupational, Speech, and Physical Therapists, Residential Support Staff, Personal Care Attendants, and Behavioral Interventionists.

Respite Care
Temporary help provided by a professional to caregivers to allow them a break in caring for a family member with an illness or a disability.

Rural Area
U.S. Census defines rural as: Territory, population and housing units not classified as urban. "Rural" classification cuts across other hierarchies and can be in metropolitan or non-metropolitan areas.

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[6] Definition adapted from retrieval on November 19, 2014 from: http://www.health.vic.gov.au/older/toolkit/02PersonCentredPractice/docs/Guide%20to%20implentating%20Person%20centred%20practice.pdf

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.

Self-Determination
A characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions and to be goal-oriented and self-directing.[7]

System of Care
The system of care model is an organizational philosophy and framework that involves collaboration across agencies, families, and youth for the purpose of improving services and access and expanding the array of coordinated community-based, culturally and linguistically competent services and supports.[8]

Transition Planning
Helping an individual with disabilities move from the school setting into adult services. Areas to be considered include: post-secondary education options, housing, employment, public benefits, recreation and social interests.

[7] Retrieved on November 19, 2014 from: http://www.ngsd.org/everyone/what-self-determination
[8] Retrieved on November 11, 2013 from: http://www.tapartnership.org/SOC/SOCvalues.php

Research Resources

The Commission Chair, with input from other individuals developed this list of research resources that is useful in understanding autism.

What is Autism?
http://www.autismspeaks.org/what-autism

Medicaid & Autism: 8 Things You Should Know
http://www.autismspeaks.org/blog/2014/12/05/medicaid-autism-8-things-you-should-know?utm_medium=text-link&utm_content=Medicaid & Autism: 8 Things You Should Know

Significant Studies and Findings

Autism Therapy Produces Greatest Gains When Started Before Age 2
Treatment, based on the principles of Applied Behavior Analysis (ABA), provided 20 to 30 hours of one-on-one therapy each week. The children were between 1 and 3 years old at the time they began therapy. After one year of intervention, testing showed gains in social and communication skills across all age groups.
http://www.autismspeaks.org/science/science-news/study-autism-therapy-produces-greatest-gains-when-started-age-2

http://www.sciencedirect.com/science/article/pii/S0891422214003898

Optimal Outcomes in individuals with a history of autism.
Although possible deficits in more subtle aspects of social interaction or cognition are not ruled out, the results substantiate the possibility of Optimal Outcomes from autism spectrum disorders and demonstrate an overall level of functioning within normal limits.
http://onlinelibrary.wiley.com/doi/10.1111/jcpp.12037/abstract;jsessionid=0A330EBA4E2D1734F8374042FE0A4354.f01t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false

The Realities of Autism: Changing the nature of autism for children tomorrow
http://iacc.hhs.gov/events/2014/slides_ami_klin_011414.pdf

Using participant data to extend the evidence base for intensive behavioral intervention for children with autism
http://www.ncbi.nlm.nih.gov/pubmed/20687823

Young adults with autism less likely than any other disability group to be employed or enrolled in higher education
35 percent of young adults (ages 19-23) with autism have not had a job or received postgraduate education after leaving high school.
http://pediatrics.aappublications.org/content/129/6/1042

Cost of Autism
A study in 2006 by the Harvard School of Public Health estimated that it costs $3.2 million to take care of an individual with autism over the lifetime. Adult care and lost productivity are the biggest sources of that amount.
http://archive.sph.harvard.edu/press-releases/2006-releases/press04252006.htmlhttp://archpedi.jamanetwork.com/article.aspx?articleid=570087

Implications of childhood autism for parental employment and earnings.
Adding to the severe financial strain, families with children diagnosed with ASD also earn **28% less overall** compared to families whose children do not have health limitations, according to a recent report in the journal Pediatrics. For mothers, the disparity is even starker, with earnings that are 56% less than those of mothers of children with no physical or mental limitations.
http://www.ncbi.nlm.nih.gov/pubmed/22430453

Cost of lifelong care can be reduced by 2/3 with early diagnosis and intervention.
Autism Society estimate based on Government Accounting Office Report on Autism, 2006

Study Demonstrating Cost-Effectiveness, includes references to additional related studies
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585334/

It costs more than $8,600 extra per year to educate a student with autism. (Lavelle et al., 2014)

Behavioral Approaches to Managing Severe Problem Behaviors in Children with Autism Spectrum and Related Developmental Disorders: A Descriptive Analysis
This review covers 101 outcome studies published since 1995 that used behavioral techniques to address severe aggression, self-injury, and property destruction, in children between 6 and 18 years of age.
http://www.sciencedirect.com/science/article/pii/S1056499313000837

Increasing Student Success Through Instruction in Self-Determination
http://www.apa.org/research/action/success.aspx

The Importance of Family Involvement for Promoting Self-Determination in Adolescents with Autism and Other Developmental Disabilities
http://foa.sagepub.com/content/14/1/36.short

Outcomes for People with Autism
http://www.researchautism.net/autism/other-aspects-of-autism/outcomes-for-people-on-the-autism-spectrum
Outcomes in adults with autism spectrum disorders: a historical perspective
http://aut.sagepub.com/content/17/1/103.abstract

Brief Report: Quantifying the Impact of Autism Coverage on Private Insurance Premiums
http://link.springer.com/article/10.1007/s10803-009-0701-z

Autism Spectrum Disorders and Health Care Expenditures The Effects of Co-Occurring Conditions
http://www.cdc.gov/ncbddd/autism/features/autism-keyfindings2012.html

Data and Statistics
http://www.cdc.gov/ncbddd/autism/data.html

BACB Guidelines for Health Plan Coverage of Applied Behavior Analysis Treatment for Autism Spectrum Disorder
http://www.bacb.com/Downloadfiles/ABA_Guidelines_for_ASD.pdf

Notable States Addressing Autism

Pennsylvania Bureau of Autism Services
http://www.dhs.state.pa.us/dhsorganization/officeofdevelopmentalprograms/bureauofautismservices/index.htm

Bureau of Autism Services Virtual Training & Resource Center
http://bastraining.tiu11.org/

The largest and most comprehensive survey of individuals with ASD to date.
http://www.paautism.org/resources/AllResources/ResourceDetails/tabid/142/language/en-US/Default.aspx?itemid=280

Ohio Center for Autism and Low Incidence
http://www.ocali.org/

Autism Internet Modules
Online high-quality information and professional development. AIM modules are available at no cost. Certificate and credit options are available for a fee.
http://www.autisminternetmodules.org/

New Jersey Office of Autism
http://www.state.nj.us/humanservices/ddd/home/ooa.html

Massachusetts Autism Commission
http://www.mass.gov/eohhs/gov/commissions-and-initiatives/autism/the-massachusetts-autism-commission-final-report.html

National Resources

American Academy of Pediatrics – Autism
http://www.aap.org/en-us/search/Pages/results.aspx?k=autism

Association for Science in Autism Treatment
info@asatonline.org
http://www.asatonline.org

Autism National Committee (AUTCOM)
http://www.autcom.org

Autism Research Institute (ARI)
director@autism.com
http://www.autismresearchinstitute.com
Tel: 866-366-3361

Autism Society
http://www.autism-society.org/

Autism Speaks, Inc.
contactus@autismspeaks.org
http://www.autismspeaks.org

Autistic Self Advocacy Network ASAN
http://autisticadvocacy.org

Behavior Analyst Certification Board
http://www.bacb.com/
Tel: 212-252-8584 (888) 288-4762

U.S. Department of Health & Human Services
IACC Interagency Autism Coordinating Committee
http://iacc.hhs.gov/about/index.shtml

MAAP Services for Autism, Asperger Syndrome, and PDD
info@aspergersyndrome.org
http://www.aspergersyndrome.org/
Tel: 219-662-1311
Fax: 219-662-1315

SafeMinds
http://www.safeminds.org/
Tel: 404-934-0777

Plan Contributors

Development of the plan contained herein would not have been possible without the contribution of the following individuals who participated at some level in the strategic planning process.

Brook Adie
Annette Aloiau
Keri Altig
Jacqueline Barr
Barbara Buckley, Esq.
Nicole Ann Cavenagh, Ph.D.
Steven Cohen
Dosheen Cook
Jan Crandy
Megan Crandy
Shannon Crozier, Ph.D., BCBA-D
Jennifer Davidson
Andrew Devitt
Vanessa Fessenden
Mario J. Gaspar de Alba M.D., FAAP
Ryan Giles
Sarina Grant
Jane Gruner
Scott W. Harrington, Ph.D., BCBA-D
Casey Lynn Hayden, M.A. BCaBA, LaBA
Marisa Hendron, M.A.
Janice John
Mel Johnson
Robert Johnson
Cheryl Jung
Nicole Kalkowski
Thomas Kapp
Adryon Ketcham, M.A., BCBA, LBA
Robin Kincaid
Kathleen Kingston
Vanessa Knotts
Julie Kotchevar, M.A.
Ron Leaf, Ph.D.
Mary Liveratti
Kenneth R. MacAleese, Ph.D., BCBA-D, LBA
Charles Marriott, M.Ed., BCBA, LBA
Maria Martin
Kristin Merwin
Molly Michelman
Don Millen
Mark Olson
Johnette Oman
Julie Ostrovsky
Stephanie Patton
Renee Portnell
Dee Raymond
Carol Reitz
Toni Richard
Denise Robinson
Sylvia Ruiz
Ralph Sacrison
Jon Sasser
Jon Paul Saunders, B.A. BCaBA, LaBA
Erin Snell
Valerie Soto
Jennifer Stapel-Wax, Psy.D.
Michele Tombari
Dan Unumb, Esq.
Lorri Shealy Unumb, Esq.
Barbara Vanlandingham
David Vanlandingham
Debra C. Vigil, Ph.D., CCC-SLP
Korri Ward
Judy White
Robin Williams

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