



Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

Commissioners

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December 31, 2014

The Honorable Governor Brian Sandoval
State Capitol
101 N. Carson Street
Carson City, Nevada 89701

Dear Governor Sandoval:

I am writing this letter to provide an Executive Summary of our 2014 Annual Report as required by Executive Order. 2014 represented a very productive year for the Nevada Commission on Autism Spectrum Disorders.

The Commission and a designated Steering Committee representing four sub-committees with the following areas of focus: children 0-6 years of age, youths ages 7 -21, adults and rural communities concluded the development of a 5-year Strategic Plan in December. The task included contributions from Nevada stakeholders and practitioners including those from Nevada Universities, Autism Speaks and the Marcus Center for Autism who provided increased knowledge by sharing their expertise. This plan will guide Nevada in our vision and represent the Commission's deliverable for this year's annual report.

The Strategic Plan is the result of months of research, outreach and analysis. Throughout the process, **seven critical issues** were identified as requiring action to improve the lives of Nevadans with Autism Spectrum Disorders (ASD):

1. More financial resources are needed to adequately fund the system serving individuals with ASD throughout Nevada.
2. 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.
3. Insufficient supply of qualified service providers throughout Nevada to serve people living with ASD.
4. Access to treatment and services are delayed because of insufficient screening and diagnostic practices in Nevada.
5. People do not know what resources are available or how to access them. Additionally, there is not enough public awareness of ASD.
6. 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.
7. Systems are not coordinated or proactive in their approach to serve individuals with ASD throughout the lifespan.



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The urgency to address these issues is supported by the growing prevalence rate. In 1975, Autism affected 1 in 5,000 children; today the prevalence rate is 1 in 50 children.

The Commission's Strategic Plan identified the following goals:

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

2015: Ensure Medicaid begins coverage for ABA; Address insurance barriers; Advocate for Maintenance of and/or increase to state and federal funding.

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

2015: Policy in place which delivers immediate access to treatment and services based on failed autism screening

Goal 3: Expand the number and quality of professionals providing services

2015: Track and Fund statewide Registered Behavior Technician training

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

Major points:

- Statewide parity in the availability of ASD specific services is critical and warrants immediate action.
- All Nevadans with ASD need access to comprehensive services which include recommended levels of applied behavior analysis (ABA) and appropriate supports through periods of transition.
- Respondents who participated in the Consumer Survey agreed timely access to community-based service options at necessary service intervals to appropriately support individuals throughout the lifespan were insufficient at this time. (page 20 includes a graph to highlight needed services)
- Children need to be identified prior to age 3 and begin treatment to achieve optimal outcomes. Direct service delivery versus parent training (NEIS approach) is a barrier.
- Insurance barriers continue to limit access to recommended levels of treatment.
- Rates and credentialing process is not conducive to meeting or maintaining sufficient workforce to serve insured individuals with ASD.

The objectives for each goal may be reviewed on page 24-25. The Implementation Plan begins on page 26 of the plan which includes benchmarks for measuring success.

Nevada's Autism Statistics and Highlights reported to the Commission:

- 6,217 Students identified with ASD ages 3-21 attending Nevada school (DOE, 2013 for age and county breakdown see pg 12 of plan)
 - a. 315 three year olds (DOE, 2013)
 - b. Clark County School District (CCSD) indicates an 11% increase since 2013 (10/2014)



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- c. CCSD now utilizes 390 autism specific classrooms
- d. Washoe School District indicates a 17% increase since 2013 (10/2014)

- 401 Children being served by the Autism Treatment Assistance Program (ATAP, 11/2014)

- 529 Children on ATAP's wait list (CLEO, 11/2014)
 - a. 249 average number of days waiting on the ATAP wait list
 - b. 49 new applicants to ATAP averaged monthly across the last 6 months
 - c. The children currently receiving autism funding from regional centers are aging out of their program. The Regional Center is now providing respite to children receiving ATAP.

- 40 Children with ASD being served by NEIS (9/2014)
 - a. Nevada Early Intervention (NEIS) indicates the average age at which a child is identified with ASD has gone down to 28 months. They have made a commitment to administer the ADOS (diagnostic tool) before children transition at 36 months.
 - b. The Commission was informed children identified with ASD and receiving services through NEIS will have access to the Early Start Denver Model once staff is trained. Once a child has a diagnosis, the child will be assigned to a Board Certified Behavior Analyst (BCBA) and they'll get an actual behavior plan and a more intensive in-home therapy.

- The Commission voted to endorse and recognize the *National Behavior Analyst Certification Board's (BCAB) Guidelines for Healthcare Plan Coverage of Applied Behavior Analysis (ABA) Treatment of ASD* as Nevada's standard for the delivery of ABA.
 - ABA has been demonstrated to ameliorate the symptoms of ASD when delivered early and intensively.
 - ABA has been demonstrated to be effective in significantly reducing self-injurious, aggressive, self-stimulatory and wandering behavior across the lifespan.
 - ABA has been demonstrated to be effective in building new skills for individuals with ASD across the lifespan.

- The Division of Health Care Financing and Policy, Nevada Medicaid is creating the coverage for ABA under the authority of Early and Periodic Screening, Diagnostic and Treatment (EPSDT) and indicated it will be effective October 2015. The state plan amendment will enable eligible children with ASD through the age of 21 to have access to medical necessary ABA.
 - Representatives from the Commission have participated in all public workshops and on-going discussions to aid in this process.



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- The Commission recognized and appreciated the agencies' budget requests to further address the Autism Treatment Assistance Program's (ATAP) wait list. Funding 1,290 children by June 2017 would make a significant difference. The Commission acknowledges the program is an assistance program and therefore does not fully fund what is medically necessary or levels recommended by the BCAB. The Commission continues to support this program and believes the outcomes will justify continued funding.

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. While 90% of the untreated, will lead a life of dependency. 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.

The Commission is grateful for your continued support in addressing the needs of Nevadans with ASD and their families. I hope this provides you with an update and further justification to fund treatment and services which support individuals with ASD in Nevada. Improving outcomes is critical to each individual and to our taxpayers. If you have additional questions my contact information is (702) 595-2067 or comservjan@cox.net.

With Hope,

Jan M. Crandy, chair