



**Nevada Commission
On Autism Spectrum Disorders**
Addressing issues across the lifespan

December 30, 2018

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

Dear Governor Sandoval:

As chairperson of the Nevada Commission on Autism Spectrum Disorders, I am writing to update you on the activities of the Commission as required by Executive Order.

First and foremost The Commission on Autism Spectrum Disorders expresses its gratitude for your dedicated support during your time as governor and extension of the executive order that allows us to continue to operate as we head into the upcoming legislative session. Your leadership and support has led to improvements in the services provided to and lives of children, adults, and families affected by autism.

The Commission has met several times since our last report of June 2018. While in the past we have functioned with the help of five subcommittees, each focused on goals set forth in the 5 Year Strategic Plan, over the last 6 months it has continued to be difficult to reach a quorum in the majority of our subcommittees. Subcommittee chairs and members have been discouraged by the lack of response to previous efforts to move the work of the commission forward and have ceased to function. We have begun to rebuild our subcommittees with a focus on the Insurance and Funding Subcommittee, Workforce Development Subcommittee, and the Adult/Transition Service and Resources Subcommittee. All of the the members of the Commission and those who are now subcommittee members are passionate about improving the lives of children and adults in Nevada who struggle with autism. We look forward to the legislative session and expect to be actively involved in advocating for children, adults, and families affected by autism.

The Commission is currently working with legislators to put forward legislation that will move the commission into statue rather than continuing to be under executive

order. This will provide much needed stability as we continue to seek ways to improve the care of children and adults with autism and better support the families that are affected by this ever more common neurodevelopmental disorder. The commission plans to be active in this legislative session, collaborating with community groups, service providers, and families, in supporting legislation that we believe will further the goals and objectives of the commission.

The Commission has continued to maintain our relationship with the Aging and Disabilities Services Division (ADSD) and the Autism Treatment Assistance Program (ATAP). We have struggled to have a true collaborative relationship with these agencies in the development and implementation of their policies. The Commission is unable to serve in the advisory capacity it was intended to serve as we are not made aware of changes until decisions have already been made. We continue to hope to be more helpful in the decision making process in an advisory role before policies are created, modified, or implemented.

The following items continue to be the commission's top priorities as our state strives to lead the way in improving treatment of children and adults with, and assistance for, families affected by autism spectrum disorder. These are listed according to the commission's subcommittees and the 5-year strategic plan submitted by the previous commission.

Funding and Insurance

1. Continue to actively engage with self-funded insurance plans to ensure the provision of autism treatment benefits, including ABA and other evidence-based interventions.

2. Work to increase the Medicaid reimbursement rate for ABA services and streamline the billing and collecting processes.

3. Continue to work with ASDS staff to ensure that ATAP resources are used equitably and efficiently to provide timely access to ABA and other evidenced-based interventions. Such interventions include, but are not limited to speech therapy, occupational therapy, Early Start Denver Model, and DIR/Floor Time.

4. Continue to work with Federal representatives to ensure that the autism treatment provisions enacted in the ACA remain intact as Congress works through legislation related to healthcare and tax reform.

Over the course of the last 6 months, the Funding and Insurance subcommittee has been rebuilt and had met several times as they attempted to continue to address the above-mentioned priorities. Stable administrative support has been helpful and appreciated. After discussion with the Funding and Insurance Subcommittee The

Commission has planned to join with other groups in the state to present one voice in support of a BDR to increase the medicaid reimbursement rate for Registered Behavior Technicians to the national average of \$48 per hour. This change will serve to attract more providers to Nevada, increase our workforce, and ultimately decrease waiting time for ABA and increase hours of therapy to children.

Resource Development

3. Allow private ABA therapists to work collaboratively with the public schools.

While this will continue to be an goal of the commission, the Resource Development Subcommittee is currently on hold as we focus our efforts on other areas. As the commission stabilizes and moves forward into statute, we will work to rebuild this committee. We continue to believe that working with individual school districts and the Department of Education is important in the identification and, more importantly, the appropriate management of children with autism as they often spend the majority of their day in school. Coordinated services between the school districts and community providers would provide continuity of care. We continue to strongly recommend a committee be established to determine the feasibility and process of implementing this type of collaboration. This committee would include representatives from the state Department of Education, participating school districts, Medicaid, ATAP, and BCBA leaders. To date efforts to advise and engage with the Department of Education have been unsuccessful.

Workforce Development

4. We must increase the number of training programs for autism therapy providers in our state; Licensed Behavior Analysts (BCBAs), Licensed Assistant Behavior Analyst (BCaBAs), and a Registered Behavior Technician (RBTs).

The commission is currently looking to find a new chair for this subcommittee. Nevada continues to face serious shortages in these provider lines. Shortages in providers have led to long waiting times for services. Research is clear that earlier intervention leads to better outcomes in social, cognitive, and adaptive functions. One obstacle in increasing the number of providers has been attracting new providers to the field due to the low Medicaid reimbursement rate for RBTs. Another has been the cost of becoming a licensed RBT, both to the individual and the providers that have to train the RBT as the training for licensure requires 40 hours of supervised work that cannot be billed or reimbursed. This is the primary reason the commission is working with other community groups and parents to endorse legislation to increase the Medicaid RBT rate to the national average of \$48 per hour.

Another concern that may affect workforce numbers in Nevada is the implementation of a \$500 per month cap on ATAPs insurance assistance plan.

Historically, this plan has helped families who could not afford to pay the out of pocket expense of their high deductibles to still receive services prior to meeting those deductibles. Unfortunately, the \$500 amount will cover only a few hours of services per month. For comparison, Fee for Service Medicaid reported paying between \$1294.84 and \$1779.37 per patient per month during the last fiscal year. This would leave families to pay roughly \$700 to \$1200 per month until their deductible is met or leave providers to carry this financial load until the deductible is met. Neither options is sustainable and our concern is that this will lead to loss of service hours for patients and loss of providers or at the very least slow or arrest any potential growth of provider numbers. The commission is seeking to work with ATAP and ADSD to determine if there is a more effective and sustainable way to use the allotted \$6000 per year to help children and families receive the recommended number of service hours.

Other proposals previously recommended by the subcommittee included a) providing high school magnet programs and psychology classes with information and guest speakers on the field and career opportunities, and b) providing information to undergraduate students in psychology, education, and related fields on the field and career opportunities. However, the Commission lacks the resources to develop these programs and materials, disseminate them, and provide resources to schools, colleges, and universities seeking information. Collaboration with other state agencies like the Department of Education and the Department of Education, Training, and Rehabilitation is needed but efforts to reach out have as of yet been unsuccessful.

Adult/Transition Services and Resources

5. Development of programs to provide aging Nevadans with autism meaningful employment.

6. Support measures that allow adults significantly impacted by autism to receive quality services by a trained and skilled workforce

A new chair has recently been named for the Adult/Transitions Services and Resources subcommittee. We expect to report progress on these goals in the next report.

Community Education

7. Support a statewide resource website for Autism Spectrum Disorder.

The Subcommittee on Community Education has not met since the last report and there is no chair or members currently. Efforts to rebuild this subcommittee will continue after the legislative session.

Nevada's Autism Statistics and Highlights as reported to the Commission.

The most recent numbers available are included below. Changes from the previous report are provided in (parenthesis).

8,679 total number of children under age 21 with ASD in Nevada based on data from NEIS and Department of Education numbers from August 2017.

ATAP

- **662** total children served by ATAP (-21)
 - 5 are under 3 years (+1)
 - 150 are 3-5 years (-12)
 - 179 are 6-8 years (-14)
 - 160 are 9-11 years (same)
 - 162 are 12-18 years (-68)
 - 6 are older than 19 years

- 442 children on ATAP waiting list; average age 7 (-77)
- 48 new applications per month on average for ATAP (+1)
- 340 days on average a child will be on the ATAP waiting list (-78)
 - 40 children under 3 years on waiting list (-9)
 - 247 children 3-7 on waiting list (-34)

NEIS (July - November 2018)

- 97 children diagnosed with ASD (+31 from the 6 months previous)
- 30 months is the average age at which a child is diagnosed with ASD
- 172 children in the diagnostic process; including those who have started testing, have been scheduled for testing, and those who have been referred but have not yet scheduled or started testing

ABA providers from the Behavior Analyst Certification Board

BCBA/BCaBA – 195 (+83)

RBTs – 736 (+241)

Enrolled in Medicaid

95 BCBA's

6 Psychologists

6BCaBA's

560 RBT's

The Commission is proud to recognize and applaud our State Legislators for their ongoing support of programs which benefit individuals with Autism. We look forward to working with those who will continue in state service and welcoming those who will be beginning their terms of service. We appreciate the valued

support we receive from your Chief of Staff and ASDD staff members and agencies. We hope that moving forward we can continue to work in a more collaborative manner with ASDD, ATAP, and other state agencies. Nothing will be accomplished without collaboration. As mentioned above, with the help of supportive legislators, we are moving forward with legislation that we hope will make the commission permanent and provide much needed support. For now, the commission will continue to work on ways our state can lead the way in its care of individuals with ASD in the most effective and efficient manner so that all Nevadans living with Autism Spectrum Disorder will achieve optimal outcomes and reach their full potential.

With continued hope and gratitude,

A handwritten signature in black ink, enclosed in a thin black rectangular border. The signature is cursive and appears to read 'Mario J Gaspar de Alba'.

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