



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

June 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.

The Commission has met several times since our last report of December 2017. 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 been 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. While all of the members of the Commission and many of its subcommittee members remain passionate about improving the lives of children and adults in Nevada who struggle with autism, others have begun to feel it impossible to move forward on any points in the strategic plan given the current structure of the commission and the barriers we have faced over the last year.

The Commission has worked to maintain our relationship with the Aging and Disabilities Services Division (ADSD) and the Autism Treatment Assistance Program (ATAP). Many of the barriers we have faced have been due to the multiple leadership changes at ADSD, active efforts from a former head of the division which prevented us from meeting during the last legislative session, and a lack of cooperation and transparency in these agencies and their policies. We continue to hope that the most recent changes in ADSD and ATAP and the direction each is headed will allow the commission to be more effective in the future. The current situation and structure of the commission has left it ineffective and caused many who had volunteered in the past to lose hope of actually making any progress on our stated goals and objectives.

The following items continue to be the commission's top priorities as our state strives to lead the way in improving treatment of children 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 process.

3. Continue to work with ASDS staff to ensure that ATAP resources are used equitably to provide access to other evidenced-based interventions in addition to ABA. 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 attempted to continue to address the above-mentioned priorities; however, little has been accomplished since the submission of last report in December 2017. Such lack of accomplishment has not been due to a lack of effort. Frequent shifts in administrative support from ADSD coupled with open meeting law constraints (specifically quorum requirements) resulted in the cancellation of several Funding and Insurance meetings, including a meeting that involved an internationally renowned expert on DIR/Floortime. Currently, the subcommittee finds itself without enough members to meet Commission bylaw requirements. Although the current members are attempting to recruit additional participants, the subcommittee has been unable to meet since early May 2018.

A recent review of minutes revealed that the Commission on Services for People with Disabilities (CSPD) is also highly interested in many of the same priorities as the Funding and Insurance Subcommittee. In fact, two of the subcommittee's priority areas (evidence-based interventions and Medicaid reimbursement rates) were covered at length during the CSPD's November 30, 2017, meeting. Given this subcommittee's difficulty in recruiting members and maintaining forward momentum, it may be strategically beneficial to combine the efforts of this subcommittee with those of the CSPD, as the CSPD appears to have the infrastructure necessary to support continued work in these critical areas.

Resource Development

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

The commission has not had success reaching out to the individual school districts or Department of Education. We continue to strongly recommend a committee be established to determine the feasibility and process of implementation that would be needed and include representatives from the state Department of Education, participating school districts, Medicaid, ATAP, and BCBA leaders. Efforts to advise and engage with the Department of Education have been unsuccessful. A letter outlining this recommendation was sent in the fall of 2016. The Resource Development Subcommittee has attempted several times to meet with the State of Nevada Special Education Department director regarding BCBA's in the public schools. The subcommittee was able to contact Mr. Jensen but could not procure a meeting time and date. This has halted their progress toward one of the commission's strategic plan goal. We request the governor's office advocate with the Nevada Department of Education (NDE) to make this meeting happen and ensure that school districts serving children with ASD coordinate services with the community-based providers for continuity of care.

The subcommittee has also discussed possible ways to collaborate with statewide partners to establish systematic screenings for ASD and concerns regarding adopting service standards for individuals with ASD from birth to 21. We would like to see a more cohesive and efficient system for individuals and families struggling with autism, so they are not waiting so long for evidence-based services and qualified staff.

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).

This is more critical now than ever as ADSD and ATAP have announced their plan to transition children who have been identified with Medicaid coverage from their current, non-Medicaid participating provider to an in-network provider by March 1, 2018. A non-Medicaid participating provider is a provider whose staff are not all certified Registered Behavioral Technicians (RBTs). Previous efforts to require interventionists to become certified RBTs has led to a loss of workforce in this already underserved area. ATAP and ADSD have asked BCBAs from the provider who serve the identified children to enroll their National Provider Identification number under the ATAP group and ATAP will bill Medicaid under an approved Prior Authorization and reimburse the provider. At a recent meeting, some providers stated this would not be an option for them. A second option was provided in which providers would explain to parents that they must find an in-network Medicaid provider to obtain services. ATAP case managers have offered to assist the parents in finding a new provider to ensure as little disruption as possible to the child. We believe significant disruption is not only likely but inevitable. ATAP has also

proposed a third option for families who wish to stay with their current provider, as an out of network non-Medicaid provider. Under this option their insurance assistance plan will be maximized at \$500 per month. This plan is an option for families who have insurance coverage but wish to go out of network. 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.

Options for coordinated efforts to develop a more robust workforce of BCBA's, BCaBA's, and RBTs are extremely limited for the subcommittee without funding to support recruitment or develop training programs. Proposals 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 funds to develop these materials, disseminate them, and provide resources to schools, colleges, and universities seeking information.

Additionally, the subcommittee recommended building an ABA Nevada website to help connect families with providers, assist providers with recruitment, and be a central resource for information about ABA, certification, and opportunities across Nevada. While a web developer was identified who would volunteer to build and maintain the site, all activities had to be halted during the temporary suspension of the Commission in 2017 for several months resulted in the loss of that volunteered resource. Although this initiative was eventually approved by the Commission, the web developer was no longer available, and the opportunity was lost.

A common frustration among subcommittee members was that despite having specific strategies for meeting goals and objectives, each strategy was hampered by the same barriers of insufficient resources across personnel, materials, and time. The specific tasks to assist in workforce growth have been identified and are ready to implement when resources are available. Coordination with the Department of Education, the Nevada System of Higher Education, and the Department of Education, Training, and Rehabilitation would be beneficial to maximize efficiency and efficacy.

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

The Adult/Transitions Services and Resources subcommittee has not met since the last report, due to a lack of quorum and the loss of the subcommittee chair. As with

other subcommittees, members have lost interest due to the lack of any progress in this critical area.

Community Education

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

The Subcommittee on Community Education has been at a standstill since December. The reason being is that we have no means to put together the appropriate website the state of Nevada and its families affected by autism need due to the lack of funding. A member of the Workforce development subcommittee had volunteered to put a website together for the state at no cost because he believed the project would be beneficial to families struggling to find information on services and autism in general. Due to the many obstacles faced with how to associate this with the state and ATAP, the project became too cumbersome and he needed to focus on his own business.

The Community Education Subcommittee is in need of funding so that the website can come to fruition. I truly believe that this website will be an anchor for the business, educational, and non-profit organizations to reach out to our Autism community to help them find the resources they need to help their children and families. Without the funding to execute this website it will not come on-line.

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 [+525]. Updated data will not be available until August of 2018.

ATAP

- **683** total children served by ATAP [-39]
 - 4 are under 3 years (-6)
 - 162 are 3-5 years (-18)
 - 193 are 6-8 years (-16)
 - 160 are 9-11 years (-1)
 - 230 are 12-18 years (+68)
 - 6 are older than 19 years

- 519 children on ATAP waiting list; average age 7 [-56]
- 47 new applications per month on average for ATAP
- 418 days on average a child will be on the ATAP waiting list [+56]
 - 49 children under 3 years on waiting list (-4)
 - 281 children 3-7 on waiting list (-26)

NEIS (January - June 2018)

- 66 children diagnosed with ASD

- 29 months is the average age at which a child is diagnosed with ASD

ABA providers

- 27 enrolled with Medicaid
- 17 non-Medicaid

BCBA – 101 (+26)

BCaBA– 11 (+6)

RBTs – 491(116 getting certified) (+72)

The Commission is proud to recognize and applaud our State Legislators for their ongoing support of programs which benefit individuals with Autism. We appreciate the valued support we receive from your Chief of Staff and ADSD staff members and agencies. We hope that moving forward we can continue to work in a more collaborative manner with ADSD, ATAP, and other state agencies. Nothing will be accomplished without collaboration. The commission has discussed the possibility of joining the

in an attempt to more effectively move forward our goals and objectives. We believe this will allow for more legislative influence, increase support, and reduce redundancy of effort. We are also concerned that the executive order under which we function will expire at the end of this year and look forward to working with Governor Sandoval to renew the executive order for the commission during the fourth quarter of 2018. We are also seeking a sponsor to move forward legislation that would 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,



Mario J Gaspar de Alba, M.D., Chair
(702) 702-998-9505
Mario.gaspardelba@unlv.edu

Commission Members:

Sarah Dean
Julie Ostrovsky
Gwynne Partos
Korri Ward