

Commissioners

Mario J. Gaspar de Alba Gwynne Partos Sarah Dean Julie Ostrovsky Korri Ward

December 9, 2016

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 June 2016. We continue to function with the help of five subcommittees, each focused on goals set forth in the 5 Year Strategic Plan. All the members of the Commission and its subcommittees are passionate about improving the lives of children and adults in Nevada who struggle with autism. As we enter the 2017 legislative session, the Commission has determined that the following items are the Commission's top 7 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. Work to increase the Medicaid reimbursement rate for ABA services.

We ask that a review be made of the Nevada Medicaid reimbursement rate for ABA therapy. We believe our state should have a rate closer to that paid by Tricare and neighboring states. If we do not provide a competitive rate, we can expect our shortage of direct service providers, BCBAs and RBTs, to continue, much to the detriment of children and families living with autism spectrum disorder in Nevada.

2. Continue increasing financial support and funding of programs that serve individuals and families living with autism spectrum disorder.

We urge you to maintain the increasing funding that has been proposed for autism related programs and services. Funding which does not keep pace with the increasing number of

children diagnosed with autism in our state, especially in the area of early diagnostic and intervention services, will lead to later diagnosis, fewer services, poorer quality of life outcomes and even greater expenses for our state in the future as children who are not treated early will require a higher level of care and experience less independence as they age.

Resource Development

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

We recommend that private ABA providers be allowed to work with their patients in the school districts. This will benefit the patient/student as continuity of care will improve and the therapists will be a valuable resource for the special education teachers and service providers in the school district. We ask that a committee be established to determine the feasibility and process of implementation would be needed and include representatives from the state Department of Education, participating school districts, Medicaid, ATAP, and BCBA leaders. A letter outlining this recommendation has been sent under separate cover.

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).

There is a critical need to increase ABA providers who are on the front line of autism spectrum disorder therapy. The need for increasing the behavior analyst workforce in Nevada is well established. Long waits, insufficient capacity, and lack of availability across all parts of the state continue to be major challenges facing Nevadans living with ASD. Insurance carriers in Nevada, including Medicaid, will only provide funding for ABA therapy when a BCBA, BCaBA, and an RBT provide it. While there is insufficient capacity at each of these levels, the deficit at the BCaBA level is particularly acute. As of November 29, 2016 there are only 8 BCaBAs registered in Nevada. The assistant level behavior analyst is a critical piece of the workforce pyramid. When a doctoral or master's level BCBA has an assistant, they are able to scale up their practice and serve more individuals with ASD with greater efficiency. Currently only UNR has an approved program for BCaBAs and Touro and UNLV are both working to become approved training programs. Support from the state is needed to expand capacity at this bachelor level of training and would generate trained professionals who could easily integrate into the existing provider system to rapidly increase service levels. BCaBAs can participate in the supervision of RBTs, the direct service of ABA therapy, assessment, program development, and client management. Effective state-level support for this aspect of workforce development could include financial assistance or incentives for individuals to pursue this education (e.g., scholarships, graduate assistantships, etc.), financial assistance and incentives to universities and colleges within NSHE to develop these courses, and funding for the creation of an online BCaBA course sequence to improve access to education at this level. Additionally, encouragement and support for NSHE institutions to embed ABA training into their related fields coursework, such as health and human services or applied psychology, would

promote broader dissemination of information on ABA and ASD which can assist with recruitment into targeted coursework and training for BCaBAs or RBTs.

The Registered Behavior Technician, supervised by a BCBA or BCaBA is the front line, direct service therapist providing daily, on-going support and instruction to an individual with ASD. As of November 29, 2016 there are 354 RBTs registered in Nevada. The NV Department of Education (2016) reports an identified ASD population of almost 8000 aged 3 to 21, based on special education service eligibility data. If every child received just 10 hours of therapy per week, far below the research recommended dosage hours for children with ASD, that would require 70,000 therapy hours. If each RBT works 40 hours per week (which most do not), then that provides a maximum of 14,160 hours of therapy. In reality, Nevada could double or triple its number of RBTs and still not have sufficient capacity. The RBT is an entry level position. Applicants must be 18 years of age, have a high school diploma or GED certificate, and they must pass a background check. This is a pre-bachelor level position and often aimed at those who do not pursue education at academic, postsecondary institutions. It is critical that training to become an RBT be easily accessible to those in all communities. State support for increasing the RBT workforce could include financial support to develop and house an RBT training program that qualifies for DETR funding so that those eligible for education and training funds have the option to work in this rapidly expanding field where there is tremendous opportunity for employment and a clear vertical career path for those who discover a passion for ABA. Developing systems within DETR, high school career counseling programs, and other employment support agencies that raise awareness of this field and provide information on how to become trained and learn more about ABA therapy will help bridge the gap between employers and potential RBTs.

Adult/Transition Services and Resources

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

Nevada is faced with an increasing number of persons diagnosed with Autism Spectrum Disorder. As Nevadans with ASD in high school and college prepare for the workforce, integrated, community-based employment with wages at or above minimum wage becomes the obtainable goal. Segregated workshops violate the S.C.'s 1999 Olmstead decision, and leave Nevada vulnerable to federal intervention. National examples of innovative programs and projects that diversify the workforce with well qualified, passionate, and reliable job seekers continue to be published. Nevada has made some contributions (i.e., Customized Employment, Pathways to Independence, etc.) to this growing literature. In 2010, Nevada held the Employment Policy Summit, a springboard for change. We urge you to invest in the expanding number of Nevada's young adults with ASD that can and will make a meaningful contribution to our economy. Workforce development for those with ASD is an investment in human capital, our expanding economy, and a solid commitment to a diverse workforce. The Adult/Transition Services and Resources subcommittee is currently working to craft autism specific employment resource recommendations.

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

Nevadans with autism over the age of 21 are significantly impacted by the lack of an ample workforce trained to provide the essential supports which enable them to live productive lives in their community or with their families. In order to be integrated in the greater community, some adults with autism will require the services of a Board Certified Behavior Analyst to develop habilitative treatment and behavior plans. Neither private health insurance nor Medicaid fund consultations with a BCBA when the client is 22 years old or older. These adults may receive services through the Home and Community Based Waiver and the HCBW does allow for BCBA consultations, however the billable rate for adults is significantly less than the billing rate for children. Please support BCBAs being funded at a rate that is comparable with the BCBA Medicaid Rate for children. The providers of Home and Community Based Waiver services are challenged with maintaining a workforce that is skilled and capable of implementing behavioral and habilitative plans for adults severely impacted by autism. Provide quality services by a trained and skilled workforce for adults significantly impacted by autism will allow them to more successfully integrate into the greater community. A letter outlining this recommendation has been sent previously under separate cover.

Community Education

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

The commission recommends that a website be designed and maintained at the state level which will keep a list of available autism resources. Financial support for the maintenance of the website to keep it up-to-date will be needed through annual budget funding. Ideally this website could be housed under the state's Autism Treatment Assistance Program. The purpose of this website is twofold; to simplify the process for families to find much needed and evidence based services for their children with autism and provide a way for the state to monitor the number and type of autism service providers working in our state. We believe this will help to decrease the time between diagnosis and provision of services/therapy and help state leaders know where there are gaps in services and where to focus future efforts to improve autism services. The commission's subcommittee on Community Education has worked out a budget proposal and would be pleased to present that for consideration as appropriate and is committed to working with the state on this important endeavor.

Nevada's Autism Statistics and Highlights as reported to the Commission for fiscal year 2016; where possible more recent numbers are provided: [changes from June 2016 report]

8,154 total number of children under age 21 with ASD in Nevada based on data from NEIS and Department of Education numbers from August 2016 [+820]

Medicaid:

- **45** children enrolled in Medicaid and Checkup receiving ABA services through fee-for-service (44) and managed care models (1)
- \$197,610.86 quarterly costs related to ABA services provided to fee-for-service recipients

ATAP

- **677** total children served by ATAP [+20]
 - o 12 are under 3 years
 - o 183 are 3-5 years
 - o 196 are 6-8 years
 - o 155 are 9-11 years
 - o 146 are 12-18 years
- 584 children on ATAP waiting list; average age 7 [+3]
- 52 new applications per month on average for ATAP
- 266 days on average a child will be on the ATAP waiting list [-26]
 - o 52 children under 3 years on waiting list
 - o 313 children 3-7 on waiting list

NEIS

- 247 children with ASD served by NEIS [+13]
- 37 additional children diagnosed with ASD between June and September 2016
- 30.6 months is the average age at which a child is diagnosed with ASD in NEIS

The Commission is proud to recognize and applaud our State for its ongoing support of 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 work in a more collaborative manner. It is our hope that legislation passed in the upcoming legislative session will continue to be in the best interest of Nevada children and families living with autism spectrum disorder. The commission and its subcommittees 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 to reach their full potential.

If you have additional questions, my contact information is (702) 998-9505 or Mario.gaspardelba@unlv.edu.

With continued hope and gratitude,

Mario J Gaspar de Alba, M.D., Chair