Nevada Commission On Autism Spectrum Disorders

Addressing issues across the lifespan

May 7, 2014

Good morning, Senator Jones and committee members. For the record, I am Jan Crandy, chair of the Nevada Commission on Autism Spectrum Disorders, a public member of the Federal Interagency Autism Coordinating Committee, and a care manager for Nevada's Autism Treatment Assistance Program (ATAP).

The Centers for Disease Control (CDC) released new prevalence rates last month for autism which now indicate about 1 in 68 school age children are on the spectrum.

The Nevada Commission on Autism Spectrum disorders believes the upsurge of people with Autism Spectrum Disorders (ASD) will impact access for all disabilities, increase expenses, stretch provider capacity, increase waitlists, and threaten the long-term viability of all state programs.

In Nevada, there continues to be gaps in coverage and capacity to address the needs of individuals across the lifespan and spectrum of ASD. Some of those gaps, I hope to address today are:

- Medicaid's lack of coverage for evidence-based treatment specific to Autism (ABA)
- Insurance barriers
- Insufficient workforce and staffing issues to support children with insurance coverage
- Lag between initial concerns, identification (failed screen and diagnosis) and access to research levels of evidence based treatment
- Sustainability.

During the December 2013 Commission meeting, members voted to support the development of a five-year strategic plan to address the needs of individuals with ASD across the lifespan. Commission members are holding workshops with experts, advocates, and others to develop the plan in 2014.

Relevant Nevada statistics reported to the Commission:

- 5,145 school age children identified with ASD by Nevada School Districts
  - Approximately 100 children are receiving ABA in home programs funded by CCSD
- 546 children on ATAP wait list and pending wait list status (referral list)
- 247 children currently receiving treatment from ATAP
- 65 – Number of children receiving Autism specific funding through the Regional Centers
- Approximately ½ of children served by ATAP are covered by Medicaid
- NEIS indicates 155 children have been diagnosed with Autism this year, 291 in the previous year.
- NEIS is currently serving 40 children with autism
- 563 three-year olds with Autism in Clark County School District
- 71 three-year olds and under currently on ATAP wait List
- 11 three-year olds are currently active with ATAP

Nevada's ability to meet the needs of individuals with Autism requires cost effective choices, and utilizing all available resources.

Agencies and programs which currently provide treatment, services or supports include the Autism Treatment Assistant Program, Nevada Regional Centers, School Districts, and Nevada Early Intervention with their Community Partners.

Autism Treatment Assistance Program (ATAP)

The rate at which ATAP is currently picking up waitlist children is on target to meet the needs of 50% of the wait list. However, due to the cost per child, the program is picking up older children faster than the group of children under the age of 6 with a ratio of approximately 5:15.

Funding older children has a significant impact to the younger children who are left waiting. Research shows optimal outcomes happen when children start treatment prior to 46 months. By allowing them to wait, we are defining a future of life-long supports. The current path we are on will lead to astronomical costs in adult care.

There needs to be a significant investment and increase made to support children under the age of six. Nevada must ensure treatment starts as soon as a child is diagnosed and provide research levels of intensity that is comprehensive and delivered with fidelity.

Sustainability of the program to support the increased number of all children with ASD requires all funding sources be tapped, including insurance and Medicaid. The state Medicaid plan needs to provide at a minimum, coverage for ABA.

NEIS

Advances in screening and diagnosis tools now provide the theoretical capability to identify 95% of children with ASD before the age of 24 months. Median age of diagnosis in US is 4.6 years old.

The Commission was pleased to recognize improvements made by Nevada Early Intervention (EI) to provide diagnosis at an earlier age, as a result of AB316 and AB345. EI established protocols to meet the requirements. However, the number of children receiving research levels of evidence-based treatment for the age group 2-3 year olds has not improved as indicated by the number of children for that age group served by the state Autism Treatment Assistance Program (ATAP). Data provided by EI indicates the majority of the children with ASD served by EI and their Community Partners receive 5 or less hours of direct treatment per week. The data also demonstrated inconsistent levels across programs.

A referral system has been established to track referrals to ATAP as required by regulation. **(NRS 427A.880: Referral to Autism Treatment Assistance Program.** For an infant or toddler with a disability who has autism spectrum disorder and is eligible for early intervention services, the Division shall refer the infant or toddler to the Autism Treatment Assistance Program established by NRS 427A.875 and coordinate with the Program to develop a plan of treatment for the infant or toddler pursuant to that section.)

In my personal experience, history has shown Nevada Early Intervention's unwillingness to support a specific model, treatment, or any policy to address research levels of intensity for children with autism. I understand it is a funding issue, and will require a change in the way they

provide services. Staff continues to indicate there is not research to support treatment for this age group, which is just not true. I have included exhibits to show studies which include children as young as 18 months. (Exhibit 1 – Table C-1. Studies that examined the Effectiveness of Intensive Behavioral Intervention)

> Children who are under 3 years of age with an ASD diagnosis have better outcomes when they receive 25-30 hours/week, and it is not uncommon for children in this age group to receive 30 hours of treatment or more as they approach 3 years of age. Children who present characteristics of ASD at age 36 months will continue to require ongoing treatment. *(Exhibit 6, Behavior Analyst Certification Board (BACB) developed "Guidelines for Health Coverage of Applied Behavior Analysis Treatment for Autism Spectrum Disorders." page 15)*

Without early intervention, the symptoms of autism can worsen, resulting in more costly treatment over the course of a lifetime. The Autism Society estimates that the lifetime cost of caring for an individual with autism ranges from $3.5-$5 million.
(Autism Society, this figure includes insurance costs and non-covered expenses, Medicaid waivers, educational spending, housing, transportation, employment, related therapeutic services and parental productivity loss.)

With effective treatment, the lifetime costs can be reduced by 65% (Jarbrink & Knapp, 2001)

I included two exhibits to support cost/benefit. (Exhibits 2 – Funding Autism Treatment is Cost Effective and 3 – Table 16: Intervention Specific Analyses Cost/Benefit)

Medicaid coverage could help offset the cost for Nevada Early Intervention Services. For children with ASD, Early and Periodic Screening, Diagnostic and Treatment (EPSDT) is one of the most important of the mandated benefits. Under the EPSDT provision, a child's pediatrician may screen and diagnose, then prescribe a range of medically necessary treatments pursuant to diagnosis. EPSDT has been an important source of coverage for Medicaid-eligible children once a diagnosis of ASD is established, although it is statutorily limited to a certain set of benefits that does not include Home and Community Based Services (HCBS).

Clark County School District (CCSD)

CCSD is the only school district in Nevada currently providing in-home ABA treatment in addition to the school day. Approximately 100 children currently receive this benefit. CCSD has indicated it will fade this option out by 2015.

Regional Centers

Regional Centers currently provide case management and assistance to families to address specific autism treatment to 65 children under the age of 11.

Respite, Family Preservation, Supports are among some of the services available for children not receiving autism treatment.

Insurance Barriers

- Nevada's state Medicaid plan does not include coverage for ABA.

Centers for Medicare & Medicaid Services (CMS)

State plans, waivers, and other programs designed specifically for persons with ASD are necessary for life-long services and supports. Many states have identified the need for Medicaid services that provide coverage for both children and adults with ASD. Some states have HCBS waivers for persons with a diagnosis of a developmental disability and/or mental illness; as noted, however, services under these waivers are often not sufficient for persons with ASD. Interviewees reported that in order to meet the growing demand for care to children, youth, and adults with ASD, state Medicaid agencies must create autism-specific programs.

Adding coverage of ABA treatment would provide Nevada with federal funds.

A number of states have autism specific waivers. I have included two exhibits (Exhibit 4 – Appendix E: Medicaid 1915© ASD Specific Waivers and Exhibit 5 – Autism Spectrum Disorders (ASD): State of the State of Services and Supports for People with ASD).

Private Insurance Barriers

- **Shortage of certified behavior interventionists (CABIs)**
- **Limited in-network providers**
- **$36,000 cap does not provide Intensive ABA**

When Nevada passed AB162, requirements were put in place for those professionals who would be allowed to bill insurance. At the time, Nevada was the only state to implement licensing and certification requirements, because a national certification was already in place.

AB162 made the requirement that nationally certified Board Certified Behavior Analysts (BCBA) and Board Certified Assistant Behavior Analysts (BCaBA) become licensed in Nevada and the paraprofessionals called behavior interventionists working under their supervision and licenses become certified. Nevada is still the only state to require behavior interventionists to be certified.

To provide an education on the delivery of ABA and the on-going supervision and training of behavior interventionists, I have included in my exhibits the Behavior Analyst Certification Board (BACB) "Guidelines for Health Coverage of Applied Behavior Analysis Treatment for Autism Spectrum Disorders." These professionals are the specialists recognized nationwide to treat autism. This document defines treatment dosage; it also outlines the tiered service delivery model. This service model allows for a cost-effective delivery of treatment, utilizing paraprofessionals to deliver the bulk of the treatment hours. (Exhibit 6)

One child's team typically consists of a supervising BCBA or BCaBA and 2-4 CABIs to implement the recommended weekly treatment hours.

Nevada has a total of 91 Board Certified Behavior Analysts, 331 ATAP interventionists, however of those permitted to bill insurance there are only 37 Licensed Board Certified Behavior Analysts, 13 Licensed Board Certified Assistant Behavior Analyst, and 85 Certified Behavior Interventionists (CABIs),

The Nevada Board of Psychological Examiners regulates the licensing and certification.

85 CABIs full time at 40 hours a week are only capable of providing a total of 3,400 hours per week. Reports indicate insurance is providing 14 hours a week or less of treatment, the average is far less. If insurance companies are providing 14 hours a week per client, insurance **would only be able to serve 242 children statewide with the current available workforce.**

ATAP currently utilizes behavior interventionists and does not require the certification, the staff are trained and supervised by the same BCBA and BCaBA professionals and receive an hourly rate significantly lower than what insurance is reimbursing. To date, ATAP has trained 560 interventionists.

- Cited issues with behavior interventionist becoming certified are the fees of up to $500.

Issues delaying the start of treatment for insurance covered children:

- The timeframe it takes to get a behavior interventionist certified. Some providers have indicated as long as 6 months for the process to be completed. Shortest is 90 days.
- Tests only occur three times a year and are not offered in Northern Nevada, Southern Nevada and Rural Nevada (Elko) each time. CABIs are offered a temporary certification while waiting to take the test, some insurance companies will not accept the temporary.
- Insurance also require their own credentialing after the certification has been submitted
- Limited in-network providers who deliver intensive behavior intervention

Public record indicates the Division of Insurance, GovCha, and the Board of Health have all received complaints about barriers to accessing insurance coverage.

The current situation: In-network provider Southwest Autism currently reports a wait list to serve children with insurance coverage which is currently up to 10 months or more. For example, a child with HPN insurance received authorization and began waiting for services in December 2013 and is being told treatment cannot start until after September, 2014 (10 months) due to staffing issues.

I believe the certification requirement for behavior interventionists is a major problem, and not necessary, as these paraprofessionals work under the license of the BCBA, much like a paralegal works under the license of an attorney. **A registry supporting background checks would be an good solution. It would allow utilization of the full available workforce to support children with insurance coverage and it would likely decrease the cost of weekly treatment hours**.

I hope my testimony has explained the Nevada Commission on Autism Spectrum Disorders views and provided:

- Justification for Medicaid coverage; Justification to address insurance barriers; An urgency to start treatment early and Support for ATAP

Our hope is that policymakers will consider this information in their decision making so that all children in Nevada have sufficient access to evidence-based interventions.

Thank you and with hope,
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