Dear Chairman Jones,

I am the mother of twenty year twins that have autism. They function at opposite ends of the autism spectrum. One is a junior at Boise State University. He lives on campus and plays in the marching band. The other is nonverbal and lives at home while attending high school. His name is Douglas.

The boys were born in Las Vegas. We moved to Elko when they were 10 years old. Upon moving to Elko I was stunned by the discrepancy of services compared to Las Vegas. The school district special education teachers had not even heard of Picture Exchange Communication System (PECS) or Applied Behavior Analysis (ABA).

My son, Douglas, did not access ABA until he was 14 years old. Before treatment Douglas displayed clinically significant aggression towards himself and others. Fortunately, he has made significant IQ gains from a baseline of 20-25 to 47-67 10 months later, and he demonstrated increased appropriate behaviors. He continues to improve his skills - from independently brushing his teeth to sitting in a restaurant. It is my hope that Douglas will have the necessary supports and services, so that he can live at home and run a small business in the community. His father and I are working hard to ensure that he has the skills and behaviors to keep himself out of an institutional placement.

I have served on the Governor’s Council on Developmental Disabilities and the Commission on Services for People with Disabilities. I chaired the Education subcommittee for the 2008 Autism Task Force. In 2005 I founded the Northern Nevada Autism Network to help other parents in rural Nevada access autism treatment for their child. I am currently president of the NNAN. Our mission continues to focus on reducing barriers to treatment and maximizing educational opportunities.

The following is a list of my concerns regarding living with autism in rural Nevada:

Autism Treatment Assistance Program
Services that are developed to meet the needs of children with autism in urban areas need to be flexible enough to meet the needs of children in rural Nevada. ATAP funds autism treatment. ATAP requires an autism diagnosis. In rural Nevada accessing a diagnostic evaluation is a significant barrier to treatment. If the child cannot access a diagnostic evaluation, he cannot access treatment. ATAP funds need to be flexible enough to help fund diagnostic clinics across rural Nevada.

In addition, ATAP no longer has a care manger in Elko. In December 2013 Elko only had 3 children receiving funding through ATAP. Currently, Brook Adie, ATAP Program Manager, reports that 7 Elko children are receiving treatment. I am not aware of ATAP funding in Winnemucca, Wendover or Ely. ATAP does not provide flyers to our local pediatricians, schools or service providers. My charity, NNAN, prints and distributes their brochure. Last year a pilot program between ATAP and ECSD was suggested by a provider. The pilot would have increased the skills of the teachers and provided

EXHIBIT L Health Care
Document consists of 4 pages.
Entire exhibit provided.
Meeting Date 5-07-14

treatment for the children, but because of the low numbers of ATAP funded children and lack of collaboration with the ECSD it was never developed. A local care manager could promote autism treatment to families and doctors and help coordinate providers and services to increase access to treatment in several rural communities.

Adult

The Home and Community Based Waiver funds habilitative care and SLA services. However, the habilitative programs cannot include ABA. Douglas requires ABA to learn new skills – like doing his laundry. In his earlier ABA program he demonstrated that he can learn new skills and appropriate behaviors with ABA and a 14 year precedent was set that without ABA his skills and behavior deteriorate. If Medicaid funded ABA then his habilitative plans could include ABA goals and objectives. Douglas will also require ABA to learn new skills related to employment. Job and Day Training (JDT), also needs to fund ABA, so that adults with autism that require ABA to learn can learn new job skills.

The SLA Self -Directed program was terminated in June 2013, due to lack of enrollment. The self-directed program provides flexibility to hire and train one's SLA's to best meet one's needs. The self-directed program provides increased scheduling flexibility allowing the guardians to take a much needed vacation. The self-directed program allows for greater continuity of care in regards to program oversight, employees and employee training. In addition to SLA services, a self-directed JDT program would allow for full inclusion in the community. With a self-directed JDT program adults with disabilities could develop and maintain a small business within their community. By having their own business they would not be segregated into a Community Training Center to access JDT.

Insurance

The largest employers in rural Nevada are not based in Nevada, so they do not offer an autism health insurance benefit of $3000/mo to the age of 22 years old. Robert Johnson, BCBA, reports that one gold mining company insurance only funds one hour of consult a month and no interventionist hours. State of Nevada, Hometown Health, only provides a $450/mo benefit for my son. Working families that have health insurance need to be able to fully access their health insurance benefit with ease. Furthermore, autism benefits need to extend beyond the age of 22 years old. The benefit ought to be based upon skill acquisition and behavioral improvement more so than age.

NEIS

At the April Autism Commission meeting I was at the videoconference site in Elko with Martha Schott-Bernius, Health Program Manager of NEIS. She said that since July 2013 they have diagnosed about 9 children with autism. I had been talking to Brook Adie, ATAP Program Manager, and it seemed that the numbers of children being referred to ATAP and the numbers being diagnosed at NEIS did not match up. I asked

Martha if she referred families to ATAP for ABA. She said that she is looking into it, but at this time thinks that the ABA therapy is too much for the really young children. She said that there isn't any data to support that the really young children need ABA. She said that the data supports the model they are using at NEIS. I asked if NEIS helps the families fill out the ATAP application. She said families are being told there is a 2 year waitlist and the families get discouraged and don't feel it is worth it. I stated that NEIS could help organize the records and help the families apply for ATAP. She said that they inform all the families, but some families are just not interested or are having a difficult time just dealing with the diagnosis. I agree that receiving an autism diagnosis can be earth shattering for parents. I remember receiving the diagnosis, twice. However, with the diagnosis I had hope that we could finally help our sons. I believe that families trust NEIS to guide them to services and treatment to maximize their child's potential. The Early Start Denver model demonstrated that children as young as 18 months old benefitted from 25 hours a week of ABA, when 20 hours were provided by therapists. ATAP provides funding to help families access 25 hours a week of ABA. The NEIS mission statement states, "provide services and supports to families to meet the individualized developmental needs of their child". It would seem they would be collaborating with ATAP to achieve their mission.

Pediatricians

- Screenings: The local pediatricians that I have talked to do not perform the M-CHAT in office. They refer families to the school district or NEIS for screening. I spoke with the Nursing Program Director at Great Basin College and despite that they have a pediatric rotation they do not teach the nursing students to perform the M-CHAT.
- Diagnostic Evaluations: Parents report that some pediatricians are uncomfortable providing an autism diagnosis and refer the family out of area.
- Access to healthcare: Parents have reported to me that they are not able to schedule with local pediatricians, because some are not taking any more children with autism.

Diagnostic Evaluations out of town

Oftentimes Elko families must travel four hours to Boise, Salt Lake or Reno to access a diagnostic evaluation. I have made the drive many times with Douglas. Before he began therapy, Douglas would cry and scream for hours while I was driving. He would become self abusive. He made several attempts to bite and scratch me as I was driving. The unfamiliar restrooms and stops along the way increased his rage. When we would arrive at the doctor's office I would be exhausted and Douglas would be overwhelmed. After visiting the doctor I would drive home, because it was easier then spending the night in an unfamiliar hotel. I have heard similar stories from other families. I also know families that won't even try the four hour drive. Rural Nevada children need readily available access to M-CHAT screenings and a mobile diagnostic clinic for those who have red flags identified by the screenings.

Elko County School District

Karen Branzel, ECSD Special Education Facilitator, reports 58 students with autism ages 3 through 22. She reports 9821 students in the district. This is a rate of 1 in 170 students with autism. The national average is 1 in 68. At the 1 in 68 rate, Elko should have 144 students with autism, a rate 2.5 times greater than what is reported. Children in preK attend a 3 hour class 2 to 4 days a week. An autism specialist works with the student 1 – 4 hours a week. Elko County School District has 1 – 2 autism certified special education teachers. A collaborative pilot program between ATAP and ECSD would provide training to the teachers and paraprofessionals while providing 25 hours a week of evidenced based intervention. The one to four hours a week in a segregated setting is not likely to yield significant gains.

Unlike other medical conditions, the school district plays a critical role in the improvement of children with autism. It is paramount that teachers and paraprofessionals are able to effectively implement behavior plans and IEP goals, as well as collaborate with the student's ABA provider. For the last couple of years Douglas has had unexplained bruising during the school year. At first I talked to the teacher and the problem resolved for a few months. The bruising continued, so I talked to the site administrator. I filed police reports. Last year I filed a State complaint, which determined that Douglas' IEP was being implemented. Then six months later, in September 2013 Douglas' home based SLA walked in on an incident at the school. Katheryn Liggett reported that she witnessed the teacher pushing Douglas to the floor by pressing her knees into his back five or six times. He sustained bruising from this incident. This was the last day that Douglas was in this classroom. I began talking to the Superintendent, Jeff Zander, about options. The school district is now providing transition to employment skills in the community. Douglas is once again making tremendous gains in skills acquisition. He is a much happier person at home and in the community. I relate this incident as a demonstration that all service providers that work with people with autism must be competent, lest they undo or hinder the treatment being provided.