MINUTES OF THE SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Eightieth Session March 13, 2019

The Senate Committee on Health and Human Services was called to order by Chair Julia Ratti at 4:07 p.m. on Wednesday, March 13, 2019, in Room 2149 of the Legislative Building, Carson City, Nevada. The meeting was videoconferenced to Room 4412 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Exhibit A is the Agenda. Exhibit B is the Attendance Roster. All exhibits are available and on file in the Research Library of the Legislative Counsel Bureau.

COMMITTEE MEMBERS PRESENT:

Senator Julia Ratti, Chair Senator Joyce Woodhouse Senator Joseph P. Hardy Senator Scott Hammond

COMMITTEE MEMBERS ABSENT:

Senator Pat Spearman, Vice Chair (Excused)

GUEST LEGISLATORS PRESENT:

Senator Marilyn Dondero Loop, Senatorial District No. 8 Senator James Ohrenschall, Senatorial District No. 21

STAFF MEMBERS PRESENT:

Megan Comlossy, Policy Analyst Michelle Hamilton, Committee Secretary

OTHERS PRESENT:

Bailey Bortolin, Legal Aid Center of Southern Nevada
Julie Ostrovsky, Member, Nevada Commission on Autism Spectrum Disorders
Ken MacAleese Ph.D., Advanced Child Behavior Solutions, LLC
Lynda Tache, Member/Parent, Nevada Commission on Autism Spectrum
Disorders

Erik Lovaas, the Lovaas Center

Linda Hua

Gwynne Partos, Nevada Commission on Autism Spectrum Disorders

Conner Cain, Touro University

Michelle Scott-Lewing, President, Autism Coalition of Nevada

Misty Shoffner, Behavior Analyst, Applied Behavioral Analysis Institute

Kelly Venci Gonzalez, Legal Aid Center of Southern Nevada

Marc Tedoff, Ph.D., Applied Behavioral Analysis Institute

Kerri Milyko, Ph.D., the Learning Consultants

Megan Szeto, the Learning Consultants

Jon Paul Saunders, the Lovaas Center

Lenise Kryk, the Lovaas Center

Rocky Cooper, Legislative Auditor, Audit Division, Legislative Counsel Bureau

Cori More, Ph.D., Assistant Professor, Special Education, University of Nevada, Las Vegas

Robert Taylor

Terri Janison, President, Grant a Gift Autism Foundation

Mario Gaspar de Alba, M.D., Chair, Nevada Commission on Autism Spectrum Disorders

Steven Cohen

Janice John, Deputy Administrator, Rehabilitation Division, Department of Employment, Training and Rehabilitation

Desirae Wingerter, Programs Services Manager, Grant a Gift Autism Foundation William Horne, Clark County School District

Suzanne Bierman, Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services

Dena Schmidt, Administrator, Aging and Disability Services Division, Department of Health and Human Services

Gwen Dwiggins, Ph.D, Accelerated Learning Clinic

CHAIR RATTI:

We will open the hearing for <u>Senate Bill (S.B.) 174</u>.

SENATE BILL 174: Makes various changes relating to services provided to persons with autism spectrum disorders. (BDR S-680)

JAMES OHRENSCHALL (Senatorial District No. 21):

Applied behavior analysis (ABA) is an evidence-based treatment commonly provided to children with autism spectrum disorders (ASD). This treatment helps

recipients improve social interactions, learn new skills and engage in positive behaviors. Research shows that intensive, long-term ABA therapy can result in better outcomes for many children, and improve intellectual functioning, language development, daily living skills and social functioning. For many children with autism, this means between 25-40 hours of ABA therapy every week for at least several years.

In Nevada, registered behavior technicians (RBTs) account for the vast majority of professionals who provide ABA therapy. The RBTs are required to work under the supervision of a licensed psychologist, licensed behavior analyst (LBA) or licensed assistant behavior analyst. Despite the growing number of RBTs, Nevada families continue to face challenges accessing ABA services.

One challenge for families of children with autism is the limited number of hours in a week during which school-age children are available to receive RBT services. There are other demands on a child's time, such as school and the even more limited number of out-of-school hours. Nevada simply does not have enough RBTs to meet the demand for services.

In addition to this issue, children who have health insurance coverage through Medicaid face another hurdle to access ABA services due to the State's extremely low RBT reimbursement rate. Senate Bill 174 aims to address this problem by increasing the reimbursement rate for RBTs to attract additional people to the profession to serve children with autism.

Specifically, section 1 of the bill requires the Department of Health and Human Services (DHHS) to submit a request to the federal government to amend the Medicaid State Plan, to increase the fee-for-service reimbursement rate for RBTs to at least \$48 per hour.

If the federal government approves the Medicaid State Plan amendment, the Autism Treatment Assistance Program (ATAP) within the Aging and Disability Services Division (ADSD) would be required to reimburse RBTs at an equal or greater rate beginning January 1, 2020, or whenever the amendment is approved if after that date.

These changes would not only make the RBT profession more attractive, they would also make Medicaid's reimbursement rates more competitive with private health insurance.

In section 2 of the bill is a requirement for the Legislative Auditor to conduct an audit during the 2019-2021 biennium of the State's Medicaid Program, including Medicaid managed care programs, ATAP, and any other evidence based programs or services DHHS provides for children with ASD. The audit must include, but is not limited to: an analysis of the capacity of people who provide these services and wait times to receive them; identification and assessment of factors that inhibit access to and delivery of such services; and an analysis of associated revenues and expenditures, as well as any unspent funds that have been appropriated for these services since July 1, 2015.

In conclusion, I have had parents tell me the night and day results that ABA therapy has made for their children. We have made a difference in the lives of the kids in Nevada, but there are still a lot of kids in need of this therapy.

BAILEY BORTOLIN (Legal Aid Center of Southern Nevada):

I have laid out a seven page thorough history and argument (Exhibit C) detailing why this bill is important. Today I will touch on some of the highlights. There are two types of insurance for children with autism; one would be Medicaid and the other is ATAP, which is the State assistance program that bridges the gap between private insurance and the needs of a family. The Governor included a budget enhancement to ATAP to eliminate the waitlist for ATAP. Unfortunately, this does not cover the children with Medicaid, which is a large population. My written testimony covers both types of insurance; however, I will focus primarily on Medicaid.

In June of 2014, the Centers for Medicare and Medicaid Services (CMS) issued a directive to states that required states to offer ABA services through the mandatory Early and Periodic Screening, Diagnostic, and Treatment program.

As a result, Governor Sandoval requested, and the 2015 Legislature appropriated, roughly \$14.2 million for fiscal year (FY) 2016 and \$28.4 million for FY 2017. This amount includes State and federal funds. The money would have provided ABA therapy to 1,879 Medicaid eligible children beginning January 1, 2016. The estimate was based on an assumption that 30 percent of the 6,000 children reported by the State Board of Education who had autism would be eligible for Medicaid. Today that 6,000 number has grown to about 8,500 children.

Most of that money appropriated by the 2015 Legislature went unspent on ABA. For the biennium some \$2.3 million of the appropriated \$42 million was spent on fee-for-service Medicaid. The caseload was 186 kids in June of 2017, and the Division of Health Care Financing and Policy (DHCFP) provided no information regarding Medicaid children served by managed care organizations. We know children remain on waitlists and children went unserved. This was not a case that the money could not be utilized to serve kids; there were plenty of children who went without services. That budget appropriation did not seem to fix the problem. This is why we are back here today.

There is a shortage of professionals qualified to administer the required tests that lead to an autism diagnosis for children on Medicaid. This breakdown in assessments has led to a specialized court in Clark County in the Juvenile Justice Program, just for children with a suspected diagnosis of autism, who are being charged with petitions of juvenile delinquency. This really illustrates the need to get services to these children. They need medical assessments to be served by Medicaid, otherwise they are served by the juvenile justice system.

I will highlight why a performance audit is needed in Exhibit C. The bottom line is far too many Nevada children with autism are not being served in a timely manner despite available funding. The delay and lack of services greatly diminish their quality of life over the years and increase expenses for the children's parents and the Nevada taxpayers. The cost for these delays in providing intensive service to younger children is covered in the written testimony from Dan Unumb, of the Autism Legal Resource Center (Exhibit D), and from Ken MacAleese of the Advanced Child Behavior Solutions, LLC written testimony (Exhibit E) and the supplemental report (Exhibit F).

While we applaud the effort of the agencies and acknowledge progress, we have a long way to go. The \$42 million Medicaid projected cost of ABA services for the 2017 biennium was built on serving a projected 1,879 children through FY 2018. Medicaid is only serving 553 children; of those 416 are in fee-for-service and 137 are in managed care. There is also evidence that these children are being underserved.

The ATAP is an important component. While we hope the Governor's budget enhancement eliminates the waitlist, this program has received budget enhancements in the past that have not served the number of children at the level we expected.

In the 2017 biennium, ATAP was budgeted to serve 836 children, plus an additional 290 kids covered by a budget reserve. As of December 2018, ATAP is only serving 648 children and has a waiting list of 442 children, with an average wait time of 1 year. The wait time in southern Nevada is 413 days and 213 days in northern Nevada.

Of the 648 children on ATAP, 277 are identified as Medicaid recipients. One of the first things the auditors should check is whether there is a double count of these children who Medicaid counts as serving.

It is now estimated that 1 in 59 children are born with autism by the Centers for Disease Control and Prevention and it is the younger children who can best be helped. A legislative audit would identify barriers to serving the children and establish a corrective action plan to address them. You can read on page 5 of Exhibit C a list of possible identified barriers.

The other part of <u>S.B. 174</u> is the RBT rate increase to \$48 per hour. At the time the RBT rate was adopted at \$31.31, providers identified it as a barrier to serving children on Medicaid and ATAP. Since there is a limited number of RBTs, providers chose to serve children covered by higher paying private insurance. For example, Tri-Care pays \$52 per hour.

At the time the rate was adopted, ADSD stated it would study the utilization data to determine whether the rate was a barrier. Four years have passed and that has not been done.

The Committee will hear from providers, why they feel this rate is inadequate and why they cannot operate at that rate. You will also see written testimony by providers who are taking Medicaid cases, but feel this rate is not sustainable and are threatening to leave the market. Daniel Unumb, President of the Autism Legal Resource Center, has submitted a chart of the Medicaid Reimbursement Rates by State (Exhibit G). This charts shows that of the 34 states from which we could obtain data, Nevada is on the bottom tier.

Nevada is competing with neighboring states. Nevada's rates are considerably lower than all of the surrounding states except Utah. New Mexico, California, Oregon and Washington all pay substantially higher rates between \$44 and \$55. The requested \$48 per hour is a reimbursement rate equivalent to the

median of the 34 states. Providers in Utah said they feel their rate is a barrier as well and 95 percent of Utah's waitlist are Medicaid recipients.

Medicaid recipients continue to struggle to find providers who accept Medicaid or ATAP. In order to increase our rate, Nevada would need to propose a Medicaid State Plan Amendment to CMS using a cost-based rate methodology. The surrounding states with higher rates have received approval.

In conclusion, despite funding the State continues to fall short in serving children with autism. A legislative audit can determine what the barriers are to effective services and propose a corrective action plan to address them.

It is obvious that the low RBT rate is a barrier. The ADSD should have no problem putting forth the justification to the federal government for an increase as Nevada's neighboring states have done. This increase during the biennium will require a fiscal note. Any increased expense will be well worth it in terms of savings to families and the State.

JULIE OSTROVSKY (Member, Nevada Commission on Autism Spectrum Disorders): I am one of five members of the Nevada Commission on Autism. I am here to testify (<u>Exhibit H</u>) in support of <u>S.B. 174</u>. In closing, we voted unanimously to support the RBT rate increase.

CHAIR RATTI:

Is there anyone in support of S.B. 174?

KEN MACALESE PH.D. (Advanced Child Behavior Solutions, LLC):

I am a doctoral level Board Certified Behavior Analyst (BCBA) and LBA in Nevada. I am here representing myself and my company to testify, <u>Exhibit E</u> in support of <u>S.B. 174</u>. I have submitted a 13-page report, <u>Exhibit F</u>, provided by the DHCFP, which details the direct and indirect costs of autism.

LYNDA TACHE (Member/Parent, Nevada Commission on Autism Spectrum Disorders):

I am the parent of a 17-year-old with autism. I am here to testify (<u>Exhibit I</u>) in support of S.B. 174.

ERIK LÖVAAS (the Lovaas Center):

I want to go back in time and discuss the landmark study from the 1987, Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children. I want to highlight two groups, an experimental group and a control group. The experimental group received 40 hours per week of 1 to 1 treatment for children ages 4 and younger. The outcome of this 40 hour per week group was 9 of the 19 children mainstreamed into regular education classes without assistance. They maintained their treatment gains into adulthood, contributed to the economy and their quality of life was improved. Eight children were placed in language delay classes and two remained in autism classes. The control group had 10 hours per week of 1 to 1 treatment for children age 4. In the control group, 8 children were placed in language delay classes and 11 in autism classes. No one from this group achieved best outcomes. This highlights treatment intensity is important for children with autism.

I wanted to find the most current RBT data and looked in the *Medicaid Services Manual* provider type 85. From July, August and September of 2018, 604 RBTs were enrolled, approximately one-third, 210 enrolled RBTs billed 1 to 1 using codes 0364T and 0365T. Those 210 RBTs billed approximately 7.28 hours per week each of 1 to 1, with the total number of hours for the third quarter of 2018 being 19,867 hours of 1 to 1.

A total of 19,867 hours may sound like a lot, but if you divide 19,867 by 40 hours per week, the recommended number of hours a child needs, and 13, the number of weeks in a quarter, you get 38 children served. If we go with 25 hours per week, an accepted standard, 61 children in Nevada would have access to Medicaid services.

We have a deficit in RBT availability through Medicaid. I support the increase to \$48 per hour, but would even consider incentivizing that rate with an additional \$10 per hour.

LINDA HUA:

I want to share my personal story with ATAP and ABA therapy. My child has been fortunate enough to receive this therapy since the age of four. The ATAP funding has impacted our lives. We are a single income family, but not by choice. I had to stop working to help with my child's therapy. Without ATAP, we would not have been able to afford the life-changing therapy for our

daughter. When our daughter was first diagnosed with autism, she was completely nonverbal. Through ATAP, a team of therapists and tutors were formed that pushed our nonverbal daughter to speak. She has gained tremendous skills, knowledge, speech and a better quality of life.

GWYNNE PARTOS (Nevada Commission on Autism Spectrum Disorders): I am also a parent of a teenager with ASD. I will read my testimony (<u>Exhibit J</u>) in support of S.B. 174.

CONNER CAIN (Touro University):

I am here representing Touro University in support of <u>S.B. 174</u>. Touro University has a Center for Autism and Developmental Disabilities. It averages about 500 patient visits per month. Nevada continues to need more RBTs. We believe raising this reimbursement rate will create greater access.

MICHELLE SCOTT-LEWING (President, Autism Coalition of Nevada)

I am also a mom of two children with autism ages 17 and 18. I want to talk about early intervention. I can attest my two children were both nonverbal, delayed speech and walking, and in diapers until the age of five. Due to early intervention and ABA therapy, they are high functioning. My son is driving a car and started his own business. My daughter has become an entertainer. All proceeds she earns entertaining go to autism. I say this to let the Committee know the potential is there, but children have to get early intervention.

We were originally from Florida. The rate in Florida is higher and they do not have the issues experienced in Nevada. The retention and the outcomes are better in Florida than here. As a resident of Nevada, I want to see that here. Nevada is ranked number 50.

MISTY SHOFFNER (Behavior Analyst, Applied Behavior Analysis Institute):

I have been in the ABA field for the past five years. Prior to that, I worked in the psychology field. I want to compare the ABA field to the psychology field. One to one psychological services pay more, often require less training, less risk, less work and less data than those performing one to one services in the ABA field. The ABA field makes between 35 and 50 percent less than the psychology field. Nevada is really lacking options in the behavioral field. Our most severe cases are referred out of the State. From working in this field I have noticed a crisis developing.

I have chosen to work with teens. It is discouraging to work with teens who have not had prior ABA services or access to them. These individuals lack any method of functional communication. These cases go understaffed and these children are not getting any younger. These people will become adults and they cannot speak and they will be in your neighborhood. Are we going to fund this crisis by raising the pay rate for RBTs or are we going to fund it by building bigger correctional institutions?

Kelly Venci Gonzalez (Legal Aid Center of Southern Nevada):

I am the team Chief of the Education Advocacy Program at the Legal Aid Center of Southern Nevada. I primarily work with kids who did not get ABA therapy. Our kids are all Medicaid eligible from families of modest means. We work with them through Autism Court, the only court in the country that works specifically with kids who are suspected of having autism or have an autism diagnosis. The court is Diversion Alternatives for Autistic Youth. These kids are usually about 14 or 15 and have gotten in trouble with the law.

MARC TEDOFF PH.D. (Applied Behavior Analysis Institute):

I am the owner of the Applied Behavior Analysis Institute. We currently provide ABA therapy to 41 children funded by Medicaid. I am here to testify (<u>Exhibit K</u>) on the challenges we face with the current RBT reimbursement rate and why we are in support of S.B. 174.

KERRI MILYKO PH.D. (the Learning Consultants):

I am a BCBA at the doctorate level and a LBA. I am here representing the Learning Consultants. Today I want to review the required and indirect cost of running a compliant and ethical behavioral services agency (<u>Exhibit L</u>). We are in support of S.B. 174.

MEGAN SZETO (the Learning Consultants):

I am a BCBA and a LBA in Nevada. This afternoon I want to elaborate what it is like to work every day as an RBT (<u>Exhibit M</u>) and why I support the reimbursement rate increase in S.B. 174.

JON PAUL SAUNDERS (the Lovaas Center):

I am a BCBA and part-time graduate instructor at the University of Nevada, Las Vegas (UNLV). I teach ABA to future behavior analysts and teachers. I started in this field a little over 20 years ago, when my little sister Megan Crandy was diagnosed with autism. Currently, Nevada has ATAP, the insurance mandate to

cover ABA and Medicaid coverage. The RBT rate increase is just one more thing Nevada needs to get passed.

I work for the largest provider in Nevada and we have not enrolled as a Medicaid provider, because we cannot afford it. We want to serve more kids, but we do not want to risk the other clients we are currently serving. If this rate was raised, we will enroll as a Medicaid provider and help that population.

LENISE KRYK (the Lovaas Center):

I am in support of <u>S.B. 174</u>. The Lovaas Center has taken the 40 hour RBT training, in-house. A lot of RBT courses are online, but we want to give RBTs the practice and experience of working with children. The cost of our training is \$120 to \$130 depending on class-size, which is more than an online course. I recently read an article stating there is a 30 percent annual turnover rate in the ABA field. If you consider the cost of training and the turnover, the current reimbursement rate is inadequate. The requirement for RBT certification is great, but it does not help if there are not have enough RBTs to provide the service.

We have lost some of our families who had to transition to Medicaid providers. Now they want to know when we may become a Medicaid provider, because they want to come back. They tell us the Medicaid providers they had to go to have not been able to provide them adequate service. They can only do assessments. We would like to become a Medicaid provider, but cannot do so based on the current reimbursement rate.

CHAIR RATTI:

Hearing no opposition, is there anyone in neutral?

ROCKY COOPER (Legislative Auditor, Audit Division, Legislative Counsel Bureau): I am neutral on S.B. 174, because the Audit Division is nonpartisan. As indicated in the fiscal note, there is no direct fiscal impact to the Audit Division. The Audit Division is here to serve the Legislature. Most of our audits are approved by the Legislative Commission. We prepare a two year audit plan that goes to the Legislative Commission and it was approved August 2018. We welcome all audits approved by the Legislature during session. If approved, this audit would take priority over other audits on the two year audit plan. The only delay would be the completion of another audit in the plan. Approval would not replace or eliminate any other audit that has been approved by the Legislative Commission.

CHAIR RATTI:

Would this specific audit be in the rotation or is this a new request because it is narrowly focused on this specific topic?

Mr. Cooper:

This would be a new audit. It would essentially go to the top of our list.

CORI MORE, Ph.D. (Assistant Professor, Special Education, University of Nevada, Las Vegas):

I wanted to add a few key figures that have not been stated. The average cost of autism treatment, loss of wages for parents, provider costs and the cost to society over a lifetime, can be \$1.5 to \$2.5 million per child. We know these costs can be reduced by up to 66 percent. Every \$3 invested in early intervention saves \$11 to society. I receive several phone calls per week from parents looking for services they are not able to get. We know the delay in receiving treatment is a costly delay in outcome.

ROBERT TAYLOR:

I have been a RBT for two years. Last summer, I quit my job because I made more money driving for Uber and Lyft. I recently went back to work as a RBT in November. It was November in Las Vegas and Uber and Lyft were slow.

I was scheduled for three sessions a day. In the morning I drove to my first session and worked 8:00 a.m. to 11:00 a.m., then I drove 30 minutes to the next house and that session started at 12:00 p.m. to 3:00 p.m., then I drove 45 minutes to the last session that started at 4:00 p.m. to 7:00 p.m. I told them this had to change. I needed my sessions closer together, because I was spending a lot of money on fuel. I feel bad, because I went to school to do this and the families liked me. In the four months since my return, I could see the positive impact I had on the children. When I leave these jobs I feel like I am leaving a family.

Ms. Bortolin:

I would like to address the fiscal note. The fiscal note includes federal funds. The way it is written, it would require federal approval before it would go into effect.

In conclusion, you have heard a lot about the need to increase the RBT reimbursement rate. This is a clear "identified" barrier, but we have many other

barriers when you talk to the families. There are many barriers such as why it takes so long for an assessment, why children are in the juvenile delinquency system or why they have been told they can only have fee-for-service Medicaid. The barriers were brought up at every Interim Health Care Committee meeting. We keep saying there is a problem getting children with autism access to services. The performance audit will allow us to come back with answers instead of questions.

CHAIR RATTI:

We are going to close the hearing for $\underline{S.B. 174}$ and open the hearing for $\underline{S.B. 202}$.

SENATE BILL 202: Revises provisions relating to persons with disabilities. (BDR 38-685)

SENATOR MARILYN DONDERO LOOP (Senatorial District No. 8):

According to the United States Centers for Disease Control and Prevention, 1 in 59 children were diagnosed with an ASD in 2018. Most children are diagnosed after four years of age, though autism can be diagnosed much earlier. Research shows that early intervention can significantly improve a child's development. In fact, identifying autism early and providing appropriate services is a child's best opportunity for health development and positive outcomes throughout life.

Being diagnosed with autism or having a child who is diagnosed with autism is often challenging for both the child and the family. While progress has been made in Nevada to assist families of children with autism, we still have much to do. On the positive side, in 2016 the Ackerman Center for Autism was established at the UNLV School of Medicine. The Ackerman Center provides an example of how services can be integrated and developed around the need of children and their families. Established through a partnership between the Grant a Gift Autism Foundation and the UNLV School of Medicine, it provides a "medical home" for Nevadans with autism from infancy to young adulthood, offering multispecialty diagnostic, treatment and intervention services in one outpatient setting. In 2017-2018, the Ackerman Center served more than 4,000 children, two-thirds of who were from low-income households.

To obtain many State and local services, children and their families must go through numerous evaluations to determine whether a child has autism and, if

so, the types of services the child is eligible to receive. This may include evaluations for services from ATAP, Medicaid and/or the school system. This can be a time-consuming and arduous process, but it does not have to be so difficult.

<u>Senate Bill 202</u> aims to better serve children with autism in Nevada by improving coordination and efficiency of evaluations by State and local agencies to diagnose ASD. The goal of this bill is to make life a little easier for families trying to ensure their children receive the services they need to achieve their maximum potential.

Sections 1, 5 and 8 of the bill require the State Board of Education, ATAP and the DHCFP, which administers Medicaid, to coordinate so that to the extent practicable, a pupil is only required to receive one evaluation to determine his or her eligibility for applicable services or programs for individuals with ASD offered by these entities.

Enabling and requiring these agencies to coordinate evaluations is the correct solution. Doing so improves efficiency and reduces the amount of time children and families must spend on activities that could and should be coordinated already.

Section 2 of the bill requires ATAP, DHCFP and the Nevada Department of Education (NDE) to compile and submit a report every six months regarding barriers to services for children with autism and their families, data concerning effectiveness, usage and accessibility of these services and any other issues recommended for inclusion by the Nevada Autism Task Force. The report must be submitted to the Governor, the Legislative Counsel Bureau, the Nevada Autism Task Force and the Nevada Commission on Services for Persons with Disabilities.

Section 9 of the bill requires the NDE to provide to DHCFP and ATAP, with the consent of the pupil's parent or guardian, the name of each pupil who has ASD, the school in which the pupil is enrolled and contact information for the child's parent or guardian.

Sections 1 and 5 of the bill require DHCFP and ATAP to conduct outreach to these parents and guardians to determine whether the child is eligible for and may benefit from available services.

Section 7 of the bill addresses a related, but slightly different issue. According to Autism Speaks, more than half of young adults with autism are unemployed and unenrolled in higher education in the two years following high school—a lower rate than young adults with different types of disabilities. Research shows that job activities encourage independence, reduce autism symptoms and enhance daily living skills. To assist individuals with a disability in gaining employment, Nevada law currently requires an appointing authority who has a position available to make whenever possible, a temporary limited appointment of a certified person with a disability for up to 700 hours. This provision is important for individuals with disabilities, including those with autism. This section simply requires, when a person with a disability is appointed to a temporary job he or she is qualified to do, the appointing authority must provide the person with a monthly performance evaluation and indicate whether the appointing authority anticipates appointing the person to a permanent position.

I believe you will hear from at least one individual this afternoon who would have benefitted from this provision and inspired this statutory change.

Throughout my career as an educator and a school librarian, I have had the opportunity to work with children with autism. I know that we can do much more to support these children in Nevada, and the earlier we can provide them with the services they need, the better off they and all of us will be.

SENATOR HARDY:

Does S.B. 202 have a fiscal note of \$67 million?

SENATOR DONDERO LOOP:

Yes, that is a fiscal note, but we are going to address it.

TERRI JANISON (President, Grant a Gift Autism Foundation):

I am the President and CEO of the Grant a Gift Autism Foundation (GGAF) in Las Vegas, Nevada. I have submitted testimony (Exhibit N) detailing the unique partnership between GGAF and the UNLV School of Medicine. We expect this model will become the standard for autism diagnosis, treatment and research.

MARIO GASPAR DE ALBA, M.D. (Chair, Nevada Commission on Autism Spectrum Disorders):

I am a Developmental-Behavioral Pediatrician and the Chair of the Nevada Commission on Autism Spectrum Disorders. Nevada does not have enough

specialists or providers, which creates a waitlist for assessments and services. In addition, passing <u>S.B. 202</u> will help streamline the eligibility assessments for patients and families. My written testimony (<u>Exhibit O</u>) discusses why I am in support of S.B. 202.

CHAIR RATTI:

I have some questions about the appointing agency outlined in section 7.

STEVEN COHEN:

I am looking at <u>S.B. 202</u> as well as the Rehabilitation Division's version of this very same section of <u>S.B. 50</u>. The appointing authority, as an example, would be Medicaid or any agency that has a position available.

SENATE BILL 50: Revises provisions governing the temporary limited appointment of persons with disabilities by state agencies. (BDR 23-230)

CHAIR RATTI:

Who are we appointing and what are we appointing them to do?

SENATOR DONDERO LOOP:

There is a program called the 700-Hour Program. As in Mr. Cohen's case, he did the entire 700-Hour Program before he was told he would not be hired. Senate Bill 202 puts in place a person who would work side-by-side so to speak, with the person hired throughout the 700-Hour Program.

CHAIR RATTI:

We will hear testimony in support.

DR. GASPAR DE ALBA:

I would like to clarify something. Within <u>S.B. 202</u>, it replaces the "Nevada Autism Task Force" with the "Nevada Commission on Autism Spectrum Disorders".

JANICE JOHN (Deputy Administrator, Rehabilitation Division, Department of Employment, Training and Rehabilitation):

Assembly Bill No. 192 of the 79th Session was approved and enacted. It allowed the Rehabilitation Division to certify certain individuals with disabilities to be placed on the 700-Hour list. We certify the list and work with the individuals. Once they are deemed to have the skills, abilities and knowledge to

qualify for certain State positions, then we present a letter to the Division of Human Resource Management, which certifies the 700-Hour list.

This law mandated that individuals on the 700-Hour list be considered first by the appointing authority. If they were on the list and eligible, the appointing authority had to hire the person from the 700-Hour list. Senate Bill 50 seeks a language change from a "must hire" to "can hire" from the 700-Hour list. The intent of A.B. No. 192 of the 79th Session was that agencies would consider individuals with disabilities, not that they must hire them.

When someone is working 700 hours for an agency they are considered a State employee for that period of time and they are on probation during that time. They are eligible for a three-month evaluation. I do not know if the three-month evaluation is a mandate or optional. It is not optional to skip seven and eleven-month evaluations. The idea of someone getting an evaluation every month is perhaps an option an agency could consider.

CHAIR RATTI:

<u>Senate Bill 202</u> states if you are hired from the 700-Hour list, before you get hired from the list or after you get hired from the list you get a monthly evaluation. Are the monthly evaluations before or after?

Ms. John:

I believe the evaluations are during the 700-hour period of time. When they are hired, they will be given an evaluation each month. The 700 hours goes toward the one-year evaluation.

DESIRAE WINGERTER (Programs Services Manager, Grant a Gift Autism Foundation):

I am an Assistant BCBA. I am in support of <u>S.B. 202</u>, but propose a friendly amendment to address the age discrepancy between ATAP, Clark County School District and Medicaid outlined in my testimony, (<u>Exhibit P</u>), over adult eligibility for various support services.

MR. COHEN:

The one clarification I want to make is I made it through the entire 700-Hour Program and was transitioned to permanent probation. I was released from State service January 2, which was one month before I would have attained full-time status.

WILLIAM HORNE (Clark County School District):

I am here today representing Clark County School District. We are in support of <u>S.B. 202</u>; however, on the Nevada Electronic Legislative Information System (NELIS) there is a fiscal note of \$80,000 for FY 2019-2020 and 2020-2021, for a total of \$160,000. We are going to remove that fiscal note. It was originally thought there would be a need for additional staff and that will not be necessary. I spoke with Senator Dondero Loop and we are in the process of removing the fiscal note.

Ms. Bortolin:

I want to speak briefly for the assessment coordination between schools and health care. As a lawyer in Autism Court, we see children who have been identified as having autism in order to be redirected to the Autism Court; however, they lack the assessment necessary to get medical services. We are able to redirect children through the legal system, but we are not able to get them connected with the doctors and providers needed to get the treatment that will change their lives. We often see the schools have identified them as having autism, but the school assessment is not accepted by the doctors. In other instances, they are Medicaid eligible, but Medicaid was not made aware the child is labeled as a child with autism. We would like to see when one authority has recognized the child needs help, we can reach out to other sectors and connect that child with help.

Finding an autism assessment spot in court is difficult. For example, in July we will schedule a court day for October and we are excited to have an assessment spot available. The first child will come in and need an assessment. The next child will come in and need the assessment even more because they are closer to age 18. We will cancel the first child's appointment. We then get a third child needing an assessment, or they will be diverted to an adult court. We have to cancel the assessment for the second child. By the end of the day one child has received an assessment that was scheduled months out. We know that all three children in this courtroom have autism, or they would not be there. We want to increase those services and the communication to make sure these children are being assessed as early as possible.

Ms. Scott-Lewing:

I am the President of the Autism Coalition of Nevada. I did not mention earlier that it is a volunteer job. For the past 28 years, I have worked as a regulatory affairs officer for a medical device company. I work in pediatric ear, nose and

throat, and neurosurgery. This gives me a bird's-eye view of the comorbidities of autism, which are medical. Today, we have talked mainly about the therapeutic aspects of autism. Another critical component of autism is the medical comorbidities, such as seizure disorder and gastrointestinal issues. All of these issues lend themselves to the overall health of these individuals. This is why it is critical to have an autism diagnosis as soon as possible. This would give them access to all of the resources Medicaid could offer them.

CHAIR RATTI:

Seeing no one in opposition, is there anyone who wants to testify in neutral?

Dr. More:

One of the biggest confusions that parents face when looking at an autism diagnosis is the difference between the school diagnosis and the medical diagnosis. They may use similar tools. The school diagnosis is made by the individualized education team, or the multi-disciplinary team, who writes the individualized education plan. This diagnosis typically involves a school psychologist, a speech therapist, special education teacher and the parents. The medical diagnosis is done by someone in the medical field such as a clinical psychologist and/or a developmental pediatrician. This bill provides an opportunity to remove some of those barriers between the two different systems.

SUZANNE BIERMAN (Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services):

We are testifying in neutral. Our concern is federal regulations that require services reimbursable through Medicaid have a clinical diagnosis and meet medical necessity requirements in order for us to claim the federal matching funds. This is why the clinical diagnosis is critical for the medical reimbursement.

CHAIR RATTI:

I know this is a policy Committee, but we had earlier questions with regard to the fiscal note. We know Clark County is going to remove the fiscal note by local governments, but there is still a \$14 million first year and \$33 million second year fiscal note from the ADSD. As I understand it, there is a coordination of the evaluation and this leads to more children diagnosed with autism and this is what leads to the higher cost to provide those services. Is that correct?

SENATOR DONDERO LOOP:

Yes, that is my understanding. While I recognized this is a large fiscal note, I heard a couple entities are reviewing the fiscal note, much in the way Clark County did. At this time, I would rather not speak for them on this issue.

DENA SCHMIDT (Administrator, Aging and Disability Services Division, Department of Health and Human Services):

Medicaid has a medical necessity requirement and ATAP, which is a State funded program accepts both the educational and the medical assessment. The fiscal note associated with <u>S.B. 202</u> is due to the outreach requirement. It is anticipated the outreach will increase our caseload dramatically.

CHAIR RATTI:

As I understand it there is a waiting list for ATAP, but the Governor's Budget has an enhancement to address that waiting list. Does this fiscal note take into consideration the enhancement in the Governor's Budget?

Ms. Schmidt:

That is correct.

CHAIR RATTI:

This fiscal note does not reflect the proposed rate increase that we heard in S.B. 174, is that correct?

Ms. Schmidt:

That is correct.

CHAIR RATTI:

Do you have any closing remarks?

SENATOR DONDERO LOOP:

There are children who are waiting and they cannot get Medicaid, because they have not been diagnosed. I know several families, my sister-in-law is one of them, who had to leave the State to get services for her children. It makes me sad to know we have people in need, and we just cannot seem to move fast enough.

CHAIR RATTI:

We will open the hearing for S.B. 216.

SENATE BILL 216: Revises provisions relating to autism spectrum disorders. (BDR 38-33)

SENATOR OHRENSCHALL:

I am here to present <u>S.B. 216</u>. Assembly Bill No. 629 of the 74th Legislative Session appropriated funding to create the Nevada Autism Task Force. The Nevada Autism Task Force was responsible for studying the growing incidence of autism and ways to improve the delivery and coordination of autism services in the State and for making recommendations to the Governor and the Legislature. The Nevada Autism Task Force was required to complete its review by August 1, 2008. However, on November 19, 2008, Governor Jim Gibbons issued an Executive Order creating the Nevada Commission on Autism Spectrum Disorders to continue the work of the Nevada Autism Task Force. The work of the Commission was further extended through Executive Orders issued by Governor Brian Sandoval in 2011, 2015 and 2018.

In sections 5 and 6 of <u>S.B. 216</u>, it would permanently establish the Nevada Commission on Autism Spectrum Disorders in the *Nevada Revised Statutes* (NRS). The Commission will continue to be located within the ADSD and they are responsible for providing administrative support.

Section 5 outlines the Commission's membership and limits membership to a three-year term with the option of reappointment.

Section 6 requires the Commission to meet eight times each year at the call of the Governor, the Chair or a majority of membership.

The duties of the Commission would include: advising and making recommendations to the Governor regarding the needs of people with ASD and their families and the availability, delivery and coordination of services for these individuals in Nevada; reviewing available data concerning individuals with autism, such as the ages of people served by public programs for people with autism; waiting lists for such programs and the outcomes of services provided by public agencies; and submitting a report to the Governor.

In an effort to ensure the Commission has necessary data, sections 1 and 7 require the DHCFP, that administers Medicaid, and ADSD that administers ATAP, provide the Commission with specific information regarding the services these agencies provide to individuals with autism.

Section 9 of <u>S.B. 216</u> eliminates an existing requirement that the assessment ADSD is required to prescribe by regulation for measuring outcomes and assessing and evaluating people with autism up to 21 years of age who receive services through the State or local government, must be standardized.

Section 10 replaces existing references to the Nevada Autism Task Force with references to the newly created Nevada Commission on Autism Spectrum Disorders. It also requires "the treatment plan" ATAP develops for a young person with autism, ensures he or she will receive appropriate services from another entity after reaching 20 years of age. This section is crucial to ensuring continuity of care for children and young adults with autism who inevitably become adults with autism.

In 2007, as a freshman Assemblyman, I was appointed to the Interim Task Force. While serving on the Interim Task Force, I met Ralph Toddre and Jan Crandy. They pitched the idea to the Interim Task Force of a bill that would require children with autism get services through their health insurance, and they detailed the fact that most insurance policies in Nevada excluded ABA therapy for children. In 2009, I was able to introduce such a bill and it did pass.

SENATOR HAMMOND:

I have some questions about the language in sections 9 and 10.

DR. GASPAR DE ALBA:

The language is stricken because of the tool requirement. The diagnostic guidelines by the American Academy of Pediatrics do not require a tool be used. They require an evaluation with specific parts, but no specific tool to determine if a child meets eligibility by that specific diagnosis by the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition, DSM-5 standards.

SENATOR HAMMOND:

Section 9 refers to a standardized tool and section 10 is a standardized assessment and that is perfectly fine?

DR. GASPAR DE ALBA: Yes, that is correct.

Ms. Partos:

I am a member of the Nevada Commission on Autism Spectrum Disorders and we serve on a voluntary basis; however, I do not believe we would be able to continue without the administrative support.

Autism is a complex disorder. There is a saying if you meet one person with autism, you have met one person with autism. It is not just the people with autism who need the treatment. Autism impacts the families and the communities as well. There is a real need for the Nevada Commission on Autism, because of the complexity of autism.

Ms. Ostrovsky:

I have a 21-year-old son with autism and that is why I started working with the Commission and working in the autism community. I will read my testimony (Exhibit O) outlining the need for a permanent Commission proposed by S.B. 216 and the reason we are hearing so many autism bills this Session.

DR. GASPAR DE ALBA:

I am the Chair of the Commission. Passing <u>S.B. 216</u> will allow the Commission to continue its work permanently and not rely on executive orders. The Commission serves an important role in collecting and reviewing information and data related to autism and autism services. We also receive information from families relative to the current barriers they face in attempting to find diagnosis and treatment services for their children. The Commission compiles that information highlighting recommendations and information that might improve the availability, coordination and delivery of services to families affected by autism and provides it to the Governor and his staff.

The Commission uses that data to help improve and shape new and existing policy, including several of the bills introduced this Legislative Session. Senate Bill 216 improves the coordination and the flow of information between State agencies and brings that information under the Commission for review, allowing the identification of unnecessary redundancies, areas of need and insufficiency and services and programs that are demonstrating appropriate and expected improvements.

Without the Commission, the State's autism programs and service delivery are at risk of creating silos rather than collaboration. The Governor and Legislators will lose important autism information in our State. The voice, concerns and participation of autism families will certainly decrease. Without the Commission, we risk losing a group of professionals and family members deeply invested in the autism community.

CHAIR RATTI:

Seeing no opposition, is there anyone neutral?

Dr. More:

Nevada takes autism seriously. Nevada was one of the first states to require licenses for BCBAs and the Commission takes autism seriously. As an educator, the Commission is a great tool and source of valuable information.

GWEN DWIGGINS, Ph.D. (Accelerated Learning Clinic):

I am a BCBA at the doctoral level. I teetered on being opposed versus neutral. I have concerns in regard to the wording in this bill. While Dr. Gaspar de Alba did some clarifications about a standardized assessment, some of the other wording makes me nervous. These are the same concerns (Exhibit R) I had for S.B. 174. I do not want individuals who are not qualified to be giving assessments. I think we have to be careful about the wording. Behavior analysts are not qualified to give a diagnosis of autism; it goes outside of their scope of practice. I see the Commission will be prescribing the regulations of what this standard assessment would look like and I look at the individuals who are nominated to this Commission and I do not necessarily see an individual who is qualified to make those standards.

A behavior analyst without a psychological background should not be making decisions about assessments. A school district individual, unless they are a school psychologist, should not be making decisions about those assessments. A parent should not be making recommendations about what those assessments are. I support streamlining assessments and making them accessible. I know that is a barrier. I would offer suggestions to reword how it is written.

DR. GASPAR DE ALBA:

I would like to address the concern about a standardized assessment. The Commission will create a subcommittee. That subcommittee can be staffed by

those who are qualified to determine what a standardized assessment would look like, taking into account best practices provided both on the psychological, as well as the medical side.

CHAIR RATTI:

I will leave it up to Senator Ohrenschall to determine if there needs to be more clarification in <u>S.B. 216</u>.

SENATOR OHRENSCHALL:

I will reach out to the speaker and determine if there is a desire to fine tune the language.

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CHAIR RATTI: Seeing no further business, I adjourn the hearing at 6:28 p.m.				
	RESPECTFULLY SUBMITTED:			
	Michelle Hamilton, Committee Secretary			
APPROVED BY:				
Senator Julia Ratti, Chair	_			
DATE:	_			

EXHIBIT SUMMARY						
Bill	Exhibit / # of pages		Witness / Entity	Description		
	Α	1		Agenda		
	В	8		Attendance Roster		
S.B. 174	С	7	Bailey Bortolin / Legal Aid Center of Southern Nevada	Written Testimony		
S.B. 174	D	2	Daniel Unumb / Autism Legal Resource Center	Written Testimony		
S.B. 174	Е	1	Ken MacAleese / Advanced Child Behavior Solutions, LLC	Written Testimony		
S.B. 174	F	13	Ken MacAleese / Advanced Child Behavior Solutions, LLC	Report		
S.B. 174	G	1	Daniel Unumb / Autism Legal Resource Center	Chart		
S.B. 174	Н	1	Julie Ostovsky / Nevada Commission on Autism Spectrum Disorders	Written Testimony		
S.B. 174	I	2	Lynda Tache / Nevada Commission on Autism Spectrum Disorders	Written Testimony		
S.B. 174	J	1	Gwynne Partos / Nevada Commission on Autism Spectrum Disorders	Written Testimony		
S.B. 174	K	1	Marc Tedoff / Applied Behavior Analysis Institute	Written Testimony		
S.B. 174	L	1	Kerry Milyko / the Learning Consultants	Written Testimony		
S.B. 174	М	2	Megan Szeto / the Learning Consultants	Written Testimony		
S.B. 202	N	2	Terri Janison / Grant a Gift Autism Foundation	Written Testimony		

S.B. 202	0	2	Mario Gaspar de Alba / Nevada Commission on Autism Spectrum Disorders	Written Testimony
S.B. 202	Р	1	Desirae Wingerter / Grant a Gift Autism Foundation	Written Testimony
S.B. 216	Q	1	Julie Ostrovsky / Nevada Commission on Autism Spectrum Disorders	Written Testimony
S.B. 174	R	2	Gwen Dwiggins / Accelerated Learning Clinic	Written Testimony