

## **Autism and Young Children: Painting a Picture for Nevada**

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Autism Spectrum Disorder (ASD) is a neurological disorder that can cause social, communication, and behavioral difficulties in those impacted (American Psychiatric Association, 2013). Often people with ASD experience difficulties in social situations and applying skills to new situations. Many young children with ASD show delays in developing language skills and it is estimated that 30-50 percent of people diagnosed with autism will not develop an adequate communication system (National Research Council, 2001).

Early intervention is key to increasing quality of life for children and families impacted by autism. Not only does early intervention help to improve skills, it also decreases costs associated with autism by up to 66 percent over the course of a child's life (Järbrink, 2007). As the cost of autism treatment is estimated to be between \$40,000 and \$60,000 per year, investment in early learning and behavioral intervention programs is critical (Autism Speaks, 2018).

### **Key Nevada Facts and Statistics**

- In 2017, there were 1,281 children ages 3 to 5 (before kindergarten age) receiving services in the schools for ASD and 6,373 school age children receiving services for ASD through the schools.
- From July 2018 through December 2018, NEIS and other Early Intervention providers report 117 children ages birth to 2 identified as having ASD with an average age of 30 months.
- As of November 2018, 662 children were receiving ATAP services, with 442 total children waiting at an average age of 7, with an average wait time of 360 days (ATAP, 2018).
- Nevada is experiencing waitlists for initial evaluations to diagnose autism, then once diagnosed receiving treatment for autism.
- There is a lack of fully certified teachers in the schools teaching children with ASD. As of October 2018, only 37 percent of the teachers in CCSD have been fully trained in autism.
- Currently there are 193 Board Certified Behavior Analysts (BCBAs) certified under the Behavior Analyst Certification Board in Nevada and 732 registered behavior technicians (RBTs). This is not enough to meet current needs.
- Nevada's Medicaid Reimbursement rate is 5th lowest in the nation at \$31.41.

### **Key U.S. Facts and Statistics**

- Rate of autism is estimated at 1 in 59 by the CDC and as high as 1 in 40 by the American Academy of Pediatrics.
- 30 percent of all children remain undiagnosed at 8 years of age.
- The cost of autism over a lifetime is estimated between \$1.4 million and \$2.4 million. Annually, the cost of autism services in the United States are estimated at \$236 to \$262 billion dollars (Buescher, Cidav, Knapp, & Madell, 2014).
- Notably, the cost of autism services can be cut across the lifetime by approximately two thirds with early intervention (Järbrink, 2007).
- Synergies Economic Consulting (2013) has estimated the benefit to cost ratio at 11-to-3.

### **Recent Actions in Nevada**

- School districts continue to accept Alternative Route to Licensure (ARL) teacher candidates to build capacity.
- Recently increased funding to the statewide Autism Treatment Assistance program to \$9.6 million in the 2017 fiscal year.
- Behavior Analysts will be licensed under a separate professional board in the state of Nevada.
- Insurance companies are required to cover applied behavior analysis therapies for children with ASD while they are of school age.

### **Considerations for Future Actions**

- Support parents' and families' knowledge of child development.
- Develop professionals' understanding of available services.
- Provide incentives to recruit people to the field, specifically for RBTs, BCBAAs, special education teachers, and diagnosticians such as clinical psychologists and developmental pediatricians.
- Increase Medicaid rates to be comparable across the country in order to provide more access to treatment and shorter wait times for families.
- Utilize telehealth options for those in rural communities.
- Provide funding for the Nevada Commission on Autism Spectrum Disorders (currently unfunded) to increase ability to provide guidance across the state.
- Continue to work with Pediatricians to conduct autism screeners at 18 and 24 month appointments with referrals made to early intervention services if the screener indicates a need. Discontinue the wait and see approach.

### **Implications of Maintaining Status Quo**

- Long wait times for initial diagnosis and treatment will continue.
- Not building workforce capacity across all service providers wastes time that could be spent on early intervention, risk of decreased long term outcomes, and increased long-term costs associated with autism.
- Risk losing people who are currently working in the field.

### **Introduction**

Autism Spectrum Disorder (ASD) is a neurological disorder that can cause social, communication, and behavioral difficulties in those impacted (American Psychiatric Association, 2013). As a spectrum disorder, no two individuals with autism will have the same experiences; Some people with autism will have a hard time interpreting social situations, some may have a strong adherence to routines and rituals while others may become preoccupied with parts of things. Additionally, there are behaviors and communication challenges associated with autism that make generalizing to new situations difficult. Many young children with ASD show delays

in developing language skills and it is estimated that 30 to 50 percent of people diagnosed with autism will not develop an adequate communication system (National Research Council, 2001). This can lead to an increase in behavior challenges and social isolation for the child and family.

The Community Report on Autism (2018) from the Centers for Disease Control and Prevention states that the estimate of children identified with ASD has increased from 1 in 68 in 2012 to 1 in 59 children in 2014. This estimate is based on the findings of CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. A most recent study from Kogan et al. (2018) in the *Journal of Pediatrics* notes the rates of ASD could be as high as 1 in 40 children. ASD currently affects more males than females at a rate of 4-to-1, and the prevalence is growing among all nationalities, races, and socioeconomic classes. Most children identified with ASD under the ADDM Network assessment criteria indicated developmental concerns before 3 years of age. Of most importance, the CDC (2018) also reported that early access to services can impact the developmental progress of a child, but less than 42 percent of children received an evaluation by 3 years of age. Further, CDC (2018) reported that the average age of children in the ADDM Network diagnosed with ASD was 4 years and 4 months and that 30 percent of all children remained undiagnosed at 8 years of age. Although schools can identify children as having ASD, a medical diagnosis is a requirement for health insurance coverage and access to support services (CDC). Factors such as long wait-lists, time-consuming evaluations, cost of care, and a lack of providers can result in a two-year difference between the earliest signs of ASD and mean age of diagnosis (Gordon-Lipkin, Foster, & Peacock, 2016).

Autism is considered a "hidden disability" in that children and adults with ASD do not show any physical signs of the disorder. This can lead to a lack of understanding from the community. Currently, the exact causes of ASD are unknown and there is no cure, however, there is strong evidence to indicate that there is a genetic component to ASD. We do know that early intervention for children and families and individuals with ASD can lead to significantly improved outcomes. This paper will describe the cost of treating autism, current Nevada indicators, the assessment process, funding

and return on investment, and describe who the educational providers are within the state.

### **Cost of Autism**

Currently, the cost of autism services in the United States are estimated at \$236 to \$262 billion dollars annually (Buescher, Cidav, Knapp, & Madell, 2014). Of these costs, around \$61 to \$66 billion dollars are earmarked for children while \$175 to \$196 billion dollars are targeted for adults. (Buescher et al., 2014). Across one's lifetime, the cost of autism services will be between \$1.4 and \$2.4 million dollars, depending on the level of autism. Notably, the cost of autism services can be cut across the lifetime by approximately two thirds with early intervention. (Järbrink, 2007). Synergies Economic Consulting (2013) has estimated the benefit to cost ratio at 11-to-3. Early identification and treatment of autism is not only critical for the child's future success, it also will save money in the long run.

### **Nevada Indicators**

During the 2016-2017 school year there were 8,769 three- to five-year old children receiving special education services in the state of Nevada and of these, 1,281 were diagnosed as having ASD (U.S. Department of Education, 2017). Nationally, there is a trend of an underdiagnosis of autism spectrum disorder, and Nevada falls into this category. Travers and Krezmien (2018) analyzed official count data from the IDEA Data Center from 2014 for students with autism in seven racial categories in all 50 states. When using California as a comparison group, Travers and Krezmien (2018) found that 18 states, including Nevada, significantly under-identified students from every racial group. Travers and Krezmien (2018) determined that the number and percentages of students with autism in Nevada were: American Indian or Alaska Native 40 (0.8 percent), Asian 312 (1.2 percent), Black or African American 439 (1.0 percent), Hispanic (Latino) 1,487 (0.8 percent), Hawaiian or Pacific Islander 2 (0.9 percent), Two or more races 311 (1.2 percent), and White 2,220 (1.4 percent). In a study of ASD comparing the prevalence and characteristics among 4-year old children in sites participating in the ADDM Network, female and non-Hispanic White children were more likely to receive their first comprehensive evaluation by 36 months compared with male and non-Hispanic Black children (Christensen et al., 2016).

Nevada Early Intervention Services and the Autism Treatment Assistance Program (ATAP) in reports to the Nevada Commission on Autism Spectrum Disorders on January 17, 2019 (Nevada Commission on Autism Spectrum Disorders, 2018) provided several relevant statistics:

- From July 2018 to December 2018, 117 children were diagnosed with ASD. The average age of diagnosis was 30 months. This program serves children who are birth through age 2.
- As of November 30, 2018, there were 32 new applications to the program, 662 active children, and 442 total children waiting.
- The average time a child will be on the ATAP waiting list is 360 days with wait time in the north at 213 days, rural Nevada at 260 days, and southern Nevada at 413 days.

These data do not capture all of the children with ASD in the state of Nevada, but provide an overview. Specifically, there are children who are not yet of school age who are not identified. Additionally, there may be children receiving early intervention services who are waiting to meet with a developmental pediatrician or psychologist for an ASD-specific evaluation. Having a formal diagnosis when one has ASD is critical to receiving the necessary intensity of early intervention services that are publicly funded as well as accessing services that are covered by insurance to ensure development during the critical early years.

### **Identifying and Assessing Autism**

The American Academy of Pediatrics recommends that physicians administer an autism specific screening tool at 18- and 24-months during a child's wellness checks (Johnson et. al, 2007) to catch any early indicators of autism. The pediatrician works with the family to answer a series of questions related to ASD, and if the child shows any indicators of ASD the family should be referred to an early intervention provider. The first point where the system can lose children is if a "wait and see" approach is taken; If there is even the slightest developmental concern, for autism or any other developmental delay, families should be referred to an early intervention service provider. In Nevada, the point of contact is Nevada Early Intervention Services. At the time the family makes contact, the Early Intervention Provider has 45 calendar days to complete the assessment process. However, this assessment is not required to include

an autism specific diagnostic tool. The early intervention provider will complete global assessments that examine social, communication, self-help, cognition, and motor functioning and provide services for children who meet the deficit criteria in any of these areas. This allows the early intervention agency to be in compliance with the letter of the law. Due to a lack of qualified assessment providers, once families are eligible for services, there is often a waiting time to participate in an autism specific comprehensive evaluation. The wait can be as long as eight months, and in some instances even longer, delaying access to intensive early intervention and applied behavior analysis treatment.

Insurance coverage for additional assessment varies and does not always cover qualified providers. Each insurance provider has a credentialing process which can inhibit providers from adding insurance companies. Families can choose to pursue an early assessment from out-of-network providers at an out of pocket cost ranging from \$1,600 to \$2,400. An additional issue to identification of autism can be the “wait and see” approach. Providers and families may choose to see how the child responds to basic early intervention. Using this approach could delay the intensity of intervention that is required for children to maximize the early learning years.

Autism spectrum disorder can be diagnosed by a variety of qualified professionals, e.g. a developmental psychologist, psychiatrist or pediatrician can provide a medical diagnosis of autism. In schools, a school psychologist, along with the parents, teachers, and other professionals may make an educational diagnosis of autism. The educational diagnosis of autism allows the student to receive services through schools, but does not allow children to access services that are covered by insurance companies. Early intervention providers for children ages 0-2 can sometimes be trained in administering the diagnostic tool, but are not able to make a medical diagnosis.

One of the tools utilized frequently is the Autism Diagnostic Observation Schedule (ADOS), which is considered the “gold standard” assessment protocol (Gordon-Lipkin et al., 2016). ADOS is a comprehensive multidisciplinary team approach that can require a lengthy questionnaire-based screening process before an appointment can be scheduled. Clinical testing can then proceed over multiple visits and take up to three hours (Gor-

don-Lipkin et al., 2016). While time intensive, this tool can provide additional information that can be utilized to make an autism diagnosis and requires that a diagnostician administer the tool with the child. Other tools used to diagnose ASD such as the Childhood Autism Rating Scale or the Autism Diagnostic Interview (Revised) rely more on an interview than an observation. There are benefits and disadvantages to using each tool. Children with autism may behave differently under observation so parent report is a critical component. However, over a series of sessions the assessment is conducted in a way that lessens this impact on children. Conversely, when relying on parent report, there can be over- or underreporting of symptoms. This can be combated by a skilled interviewer. No matter what additional instruments are utilized to gather information as part of the assessment process, all take additional time to complete (typically an additional one-and-a-half to three hours) as well as people qualified to administer the tools—and the autism specific tools are only one component of a complete assessment.

### **Educational Services for Children with Autism**

Once children are diagnosed with ASD, they receive educational services in a variety of ways from a variety of providers. The location and type of service children receive depends upon the age of the child, the needs of the child, and the resources available to the family. Services can be publically funded educational services, privately funded clinical services or, more often than not, a combination of public and private services. The educational services are described below:

**Services for Children ages 0-2.** Children before the age of three in the state of Nevada can receive services through an Early Intervention provider as required by Part C of the Individuals with Disabilities Education Improvement Act (IDEIA, 2004). Families must first reach out to Nevada Early Intervention Services for the initial point of contact and then can select a provider in their area. The family works with the provider to develop an Individualized Family Service Plan. Services from this plan typically take place in the natural environment, which means wherever we find children of this age (i.e., home, child care environment). Many parents receive services in the child’s home one to two times a month with additional support from providers, such as speech therapy, occupational

therapy, and possibly behavioral therapy. The focus of these services is to support the family in supporting the child. While the specialists try to work with the family's schedule, many times the services take place during the typical workday, which can be hard for families to embed in their schedule if they are working.

**Services for Children ages 3-21.** Once children reach the age of 3, if they qualify, they can receive services from the public school system through the Individuals with Disabilities Education Improvement Act (2004). These services for children ages 3-5 years typically take place on school campuses and can be in settings that are fully inclusive, with other children their age, or in settings that are self-contained, meaning only with other children with disabilities. The early childhood special education programs for children ages 3-5 are taught by a teacher with an Early Childhood Developmentally Delayed Teaching License. If the classroom is a self-contained classroom for children with autism, the teacher must have an autism teaching license. Typically, the programs range from two-and-a-half hours, four days a week to six hours a day, five days a week. When children move to the age where they are eligible to attend kindergarten, they can receive educational services in their grade level classroom, in a combination of a kindergarten classroom and a resource room, or in a self-contained classroom with some access to general education or more restrictive settings as needed. The Individualized Education Program team (i.e., teacher, parents, speech therapists, school psychologist, etc.) work together to decide the least restrictive environment for the student.

**Clinical Services.** In addition to publicly funded school programs, to make progress and gain skills, children with autism benefit from intensive behavior interventions. While these intensive behavior interventions are implemented in schools in conjunction with academic interventions, many children benefit from additional support in clinical or home settings. During this clinical intervention, children work one-on-one with an adult to develop a variety of skills as determined by the parent and the intervention team. Different researchers have arrived at varying amounts of intervention, but it is generally accepted that students need between 20-30 hours per week of intensive, intentional intervention (Lovaas, 1987; National Research Council,

2001). Although children may be present in school for this amount of time, not all of that time is spent in intensive intervention. Therefore, families rely on private agencies to increase the intensity of intervention. It is critical that intensive intervention begin as soon as the diagnosis of autism is made.

**Examples of Service Models.** Although more research has been conducted in the past years to show the effectiveness of early intervention (Green, Brennan, & Fein, 2002; Howard et al., 2014; Macdonald, Parry-Cruwys, Dupere, & Ahearn, 2014; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011), it is still not a common practice to recommend a single type of intervention for individuals with ASD due to the range of outcomes within each treatment paradigm (National Research Council, 2001; Peters-Scheffer et al., 2011). While the National Research Council (NRC) reports that early intervention was paramount to receiving the best outcome available for children with ASD, the organization merely list all possible early interventions with research support, without endorsing one intervention as being more effective than another (National Research Council, 2001). This lends to confusion as to which services children should be enrolled in. Also, many of the providers vary in intensity, cost, and age of intake—This impacts when children begin the intervention. The lack of information regarding early intervention services hinders enrollment, as well as funding, and the intense nature of the intervention. Without clear recommendations for early intervention services, there may not be successful enrollment in these services.

Both Early Intensive Behavioral Intervention (EIBI) and the Early Start Denver Model have shown promising results and outcomes for young children with ASD (Dawson et al., 2009; Dawson et al., 2012; Eldevik et al., 2009; Estes et al., 2014; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Lovaas, 1987; MacDonald, et al., 2014; Peters-Scheffer, et al., 2011; Reichow & Wolery, 2009; Rogers et al., 2012; Vismara & Rogers, 2008). Treatment may begin as early as 12 months old, with children showing increases in IQ scores, increases in adaptive behavior skills, and decreases in autism-like symptoms. Some have even shown a loss of the diagnosis of ASD, or a reduction of the level of autism (Dawson et al., 2009; Vismara & Rogers, 2008). More research is being conducted to address concerns of experimental research designs

(Reichow & Wolery, 2009), and varying hours of treatment (Eldevik et al., 2009; Peters-Scheffer et al., 2011; Reichow & Wolery, 2009). The Early Start Denver model is currently being utilized by only a few providers in Nevada (e.g., UNLV Medicine Ackerman Autism Center, 2018) with preliminary reports of good outcomes/success.

No matter which method implemented, many researchers believe if all children received early intervention, communities would see an immense reduction in individuals with ASD, in services needed for ASD, in teachers needed for ASD, and in overall supports needed for these individuals (McEachin, Smith, & Lovaas, 1993). Not only would there be a decrease in services needed, it would cost society less, as these individuals do not continue to require life-long care (Howard et al., 2014; McEachin, Smith, & Lovaas, 1993). With intensive early intervention, a majority of individuals make immense gains that impact their quality of life and independence as adults.

#### **Current Status of Qualified Providers**

Children with autism typically receive services from a variety of professionals including teachers, board certified behavior analysts (BCBAs), registered behavior technicians (RBTs), paraprofessionals, speech therapists, and occupational therapists. As with many states across the nation, there is a need for more highly qualified providers in order to reduce wait time, increase the quality of services, and improve outcomes for students with autism. More specifics about the providers will be provided below.

**Teachers in Nevada.** Aligned with a national trend, Nevada continues to experience a shortage of special education teachers, specifically in the area of autism. To provide an example of the shortage, under request for public records, Clark County School District (CCSD) provided information on the current state of self-contained autism programs. As of October 2018, there are 635 programs in CCSD, of which 232 teachers hold a standard or professional license, 251 are listed under the autism option where teachers who have a teaching license in one area teach in a classroom outside of their licensed area, 96 are Alternative Route to License (ARL) teachers and 30 are long term substitutes. This means that only 37 percent of the teachers have been fully trained in autism. Teachers in the autism option typically had a formal mentoring experience

of some kind for their initial teaching license (e.g., student teaching, teaching internships). However, teachers who complete ARL programs may have never had intensive mentoring with multiple field experiences and a full-time teacher who teaches with them for a semester. As such, the feedback given to them is by a school district assigned mentor who has multiple teachers and sites to work with as well as their building supervisor who may or may not have knowledge of best educational practices and strategies for students with ASD.

Moreover, the Individuals with Disabilities Education Improvement Act (2004) requires that all students with disabilities have access to the general education curriculum in the least restrictive environment. This means students with autism should also be attending classes with their peers in the general education classroom for at least part (if not most or all) of their school day. Unfortunately, very few teachers in general education have received any training, mentoring, or coaching on working with students with autism. As the state and the nation face a shortage of teachers, this priority has become lessened, but with recent supreme court cases such as *Andrew F. v. Douglas County* (2017), school districts may face increasing pressure for ensuring meaningful academic outcomes for students with disabilities.

**Board Certified Behavior Analysts in Nevada.** As previously mentioned, children with autism often require intensive one-on-one clinical services to make meaningful progress. These services are often provided under the direction of a Board Certified Behavior Analyst (BCBA). Currently there are 193 Board Certified Behavior Analysts certified under the Behavior Analyst Certification Board in Nevada. There are 31 BCBA-D's at the doctoral level, 144 BCBA's at the Master's level, and 18 BCaBA's at the Bachelor's level. In comparison, Arizona has 363 Behavior Analysts and 441 RBTs certified, while Utah has 383 Behavior Analysts and 926 RBTs (Behavior Analyst Certification Board, 2018). These individuals are necessary to provide services to the growing number of individuals with ASD in the state. Without a BCBA, services based in Applied Behavior Analysis (ABA) will not be covered under insurance, Autism Treatment Assistance Program (ATAP), or Medicaid funding.

**Registered Behavior Technicians (RBTs)** are the providers in Nevada who work under the supervision of the BCBA, providing the daily one-on-one services for students with autism. The RBT is a relatively new credential as the Behavior Analyst Certification Board began accepting applications for the Registered Behavior Technician (RBT) in 2014, with a requirement of 40 hours of training (BACB Newsletter, 2013). This change was needed as children with autism who are receiving applied behavior analysis services in a clinical or home setting were typically spending most of their time with a tutor (now RBT). Before 2014, no training was required of the tutors who were spending the most time in direct service with children with autism, and as such, children were often receiving services from someone with minimal knowledge and experience. Preliminary research suggests that 40 hours of training for the RBT can lead to at least a basic demonstration of procedures (Fisher et al., 2014).

Currently, there are 732 Registered Behavior Technicians in the state of Nevada that are eligible to provide direct intervention to children (Behavior Analyst Certification Board, 2018), an improvement from 354 in 2016 (Nevada Commission on Autism Spectrum Disorders, 2016). When Nevada numbers are compared to our neighboring states, Arizona has 441 RBTs while Utah has 926. Although the numbers have improved, the Nevada Commission on Autism Spectrum (2018) disorders reported to the governor in 2018 that more training programs are needed as we could double the number of RBTs and still not have enough providers.

These needs can be compounded for those in rural and underserved populations without the necessary access to BCBA's or Board-Certified Assistant Behavior Analysts (BCaBAs) to oversee training (Cihon, Cihon, & Bendient, 2016; Carr, Nosik, & DeLeon, 2017; Nevada Commission on Autism Spectrum Disorders, 2016). Currently, there are no RBTs, BCBA's, or BCaBAs in Mesquite or Laughlin (BACB, 2018). Overton, a rural town approximately 63 miles outside of Las Vegas, has three RBTs, but there are currently no BCBA's or BCaBAs. There are eight RBTs and two BCBA's in Elko, Nevada. In places where there are few people, the eligible RBT provider could be a close family friend or even RBT related. Providing services under those conditions can be a conflict of interest but may be the only option. Additionally, it is

expensive for those seeking to get the RBT credential, having to spend money to pay for the testing as well as travel to a testing site (Salt Lake City, Reno, Las Vegas). This requires time and money that is expected of the RBT candidate for a position that may pay between \$15-20 per hour.

**Related Services.** Children with Autism often require additional support from specialists, such as speech therapists, occupational therapists, and psychologists. We often refer to these providers as related service providers. There are shortages of qualified related services providers in both the private and school sector. Specifically, families are encountering waiting times for diagnostic services, speech services, occupational therapy services as well as other services. Additionally, there are very few providers who deliver mental health services for people with ASD. All of these specialists are necessary to ensure that children are identified and receive services in a timely manner.

#### **Cost and Funding for Programs**

As previously stated, the cost of providing services for people with autism can be anywhere from \$1.4 to 2.4 billion dollars annually for the United States. These costs can be reduced by up to 66 percent over the course of a person's lifetime with intensive early intervention (Järbrink, 2007). Early identification is the first step, requiring a medical and/or educational autism diagnosis. The educational diagnosis is funded in part by provisions of the Individuals with Disabilities Education Improvement Act (2004), in which states receive funding from the federal government to ensure access to education for students with disabilities. It is important to note the federal government has not fully funded this mandate since it originated in 1975. The Center for Disease Control estimates the cost of Applied Behavior Analysis Therapy to be \$40,000 to \$60,000 per year (Autism Speaks, 2018). Insurance companies are currently required to cover applied behavior analysis therapies but families are still left with the cost of co-pays and meeting insurance deductibles. To supplement these costs and attempt to provide access to treatment for those who cannot afford it, several programs are in place.

**The Autism Treatment Assistance Program (ATAP)** is a statewide funding source that was created to assist families in accessing ABA-based treatments in the state of Nevada. ATAP provides temporary assistance and funding for families that

qualify for services for children under 20 years old with an autism diagnosis (Aging and Disability Services Division, 2018). For children that do not qualify for Medicaid or private insurance, the 2015 legislature approved a budget of roughly \$4.9 million for the 2016 fiscal year to increase the current caseload to 692, and raised again in 2017 to \$9.6 million to increase the caseload to 836 cases in the 2017 fiscal year. However, the latest report shows that only 662 children were receiving ATAP services, despite the increased budget given each year, with 442 total children waiting at an average age of 7, with an average wait time of 360 days (ATAP, 2018). Of the children waiting on the list, there are 45 children from northern Nevada, 95 from rural Nevada, and 302 in southern Nevada. The average wait time is 213 days for northern Nevada, 260 days in rural Nevada, and 413 days in southern Nevada.

ATAP has also publicized upcoming changes to the funding process; Starting in January 2019, the program began providing up to \$500 a month for families rather than a \$6,000 amount that is dispersed during the first of the year. While the amount is the same, the timing of the disbursement can cause many families who have high deductible insurance programs to be forced to significantly reduce services until they meet the deductible. There was an appeal process in place for families currently receiving funding at the start of January to try to individually problem solve this issue. However, the consequences for families who are unable to pay the high deductible “upfront” could cut services for some children by as much as 75 percent. More information and study is needed on this provision as there may be a need to provide different funding options for high deductible insurance plans and other family needs.

**Medicaid.** Medicaid began providing funding for families in Nevada for ABA-based services in 2014. Currently, an estimated 30 percent of the 8,500 children with an autism diagnosis are eligible for Medicaid-based services. There are only 302 cases in which children are receiving Medicaid-based services in the fee for services program, which falls far short of the budgeted allotment for 1,879 cases in the last biennium. Barriers to Medicaid include long wait lists for providers that both diagnose and accept Medicaid (Legal Aid Center of Southern Nevada, 2018). Although providers have

petitioned for higher rates to be paid for RBT’s conducting ABA-based services, Nevada remains the fifth lowest rate out of all 50 states. The mean rate for RBT services paid by Medicaid throughout the country is \$47.85, however, Nevada falls significantly below this number, paying \$31.31 per hour worked by RBT’s, with the highest rate in the country being \$76.08 in Alaska (Autism Speaks, 2018). As of June 2017, there were 15 providers enrolled in Medicaid, with 14 of those having a wait list to access services. There are currently 35 service providers in the state of Nevada, meaning that less than half enrolled as Medicaid providers (FEAT, 2018).

### **Impact on Families**

Having a child with autism can have a huge impact on families. While parent involvement is a key component of most effective intervention programs, there are times that parents just want to be parents who love and have fun with their child. There is incredible pressure placed on families to constantly seek additional services, manage the financial burden, and then cope with extra challenges that can come with any child who experiences communication challenges. Families have to learn new educational systems beyond what most experience in school—many have to try to master insurance systems and sometimes the social security system. Additionally, families are required to complete paperwork that repeatedly asks for personal information, all of this while sometimes coping with a situation that can seem scary and uncertain. The process can lead to a feeling of isolation and, if they have had to fight for services, many feel frustrated with systems. Research has shown that mothers of children with ASD earn 35 percent less than mothers of children with another health limitation and 56 percent less than mothers of children with no health limitations (Cidav, Marcus, & Mandell, 2012). Additionally, the behavioral challenges associated with autism can lead to less time at work for parents of children with autism (Gould, 2004).

### **Current Barriers within Nevada**

As mentioned, there are numerous barriers to implementing intensive early intervention in the state. First of all, more qualified professionals are needed in all areas that provide services to students with autism. Specifically, there needs to be a mechanism to recruit people to diagnose autism, become teachers, BCBA’s, RBT’s, paraprofessionals, and speech

therapists. While there has been an increase in the number of people with the RBT credential, the requirement to make all interventionists RBT's has led to a lack in the workforce that is not growing at a rate that meets the demand. Moreover, it is not enough to recruit professionals to the field, we also must focus on retaining these professionals to help improve the quality of services provided. By working to recruit and retain more autism professionals, we reduce the amount of time people are on waitlists for services, leading to early implementation of services and better outcomes.

There have been several changes in leadership over the years which have led to difficulties in the provision of services offered by ATAP. Clinical providers have not been able to predict funding for any substantial period of time. Another funding issue is related to the Medicaid rates which are below the national average. Addressing this may help incentivize more providers to accept Medicaid payment, making services more accessible. Additionally, even after receiving a medical diagnosis and funding, families from rural areas may continue to face barriers to accessing services, such as shortages of certified individuals in their area. In summary, as stated by the Nevada Commission on Autism Spectrum Disorders (2018), all workforce goals have been hampered by "insufficient resources across personnel, materials, and time."

#### **Areas for Possible Improvement**

While much has been noted about the needs and barriers related to autism education in the state of Nevada, there is also a community of people across the state who are committed to working for the betterment of all. Building on some of the resources that are in place can continue to improve access to services. The following are recommendations that could be considered:

- Provide incentives to recruit people to the field, specifically for RBTs, BCBAs, special education teachers, and diagnosticians such as clinical psychologists and developmental pediatricians;
- Increase Medicaid rates to be comparable across the country in order to provide more access to treatment and shorter wait times for families;
- Utilize telehealth options for those in rural communities;

- Examine whether licensing fees are an impediment for BCBAs/LBAs and then adjust fees accordingly;
- Encourage interagency collaboration (including diagnostic, educational, and behavioral services) amongst public and private agencies;
- Provide funding for the Nevada Commission on Autism Spectrum Disorders to increase the ability to provide guidance across the state;
- Continue to work with Pediatricians to conduct autism screeners at 18 and 24 month appointments with referrals made to early intervention services if the screener indicates a need. Discontinue the wait and see approach;
- Increase funding for early intervention services across the state and consider additional funding for children with ASD who need intensive behavioral interventions;
- Incentivize insurance companies and providers to increase access to providers or provide more opportunity for families that have insurance to receive behavioral intervention services of choice, and reduce wait times; and
- Tap resources through development of training programs including outreach to currently enrolled high school and university students. Examine current training programs at universities across the state to see what resources are needed to increase capacity in these areas.

Early Intervention services for children with autism are not only beneficial to the child's quality of life, they also provide a return on investment that will reduce costs to society. By acting early, children with autism will need fewer resources throughout their educational career and have better outcomes as adults (Piccininni, Bisnaire, & Penner, 2017). Families will be able to be more productive in the workforce. The cost of not doing so is \$1.4-2.4 million dollars over the course of each child's lifetime. Addressing needs now is better for the interests of all stakeholders.

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