

The Case for Positive Behavior Supports in Nevada
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With more than 7% of all children displaying serious emotional and behavior problems and up to 15% of individuals with intellectual disabilities engaging in aberrant behavior, the need for behavior support services in Nevada and across the nation is high. Behavior problems interfere with an individual's ability to learn, be self-sufficient, hold a job, have relationships and be an active member of the community. Not only do challenging behaviors impact the individual's quality of life, but family members and care providers of individuals with challenging behavior report higher levels of stress, anxiety and depression, thereby reducing the quality of life for all involved. A family member or care provider's inability to effectively address the challenging behaviors often result in a high use of state resources, and in Nevada, out-of-home and out-of-state placements are increasing. There is a growing body of evidence that documents both the need for behavior support services and the effectiveness of Positive Behavior Support practices in reducing challenging behaviors, preventing the future occurrence of challenging behaviors, increasing independence, and increasing quality of life for the individual and their social support system. In the state of Nevada, where disability-specific support services have long waitlists and are often perceived as inaccessible, the Positive Behavior Support-Nevada project is a key resource for families and providers in need. The following report is broken down into two sections: (1) need and (2) evidence, with subsections for national and statewide data.

THE NEED FOR BEHAVIOR SUPPORT SERVICES

National need:

- According to the National Health Statistics Report published in 2012, **7.4% of all children aged 4-17 have serious overall difficulties with regard to emotional and behavioral problems.** The report states that the prevalence of emotional and behavioral problems are highest in the population of children with diagnosed disabilities and if not already diagnosed, these behavioral problems put the individual at high risk for receiving a diagnosis of developmental or learning disability.
- **“The prevention or reduction of early aggressive and disruptive behavior has important educational and mental health implications.** Disruptive behavior problems contribute to loss of instruction time in the classroom, frustration for children and families, and considerable societal burden associated with antisocial acts, including delinquency and harm to others, making them a significant public health burden. Research indicates that both school and family factors contribute to behavior problems in children,” (Reinke, Splett, Robeson, & Offutt, 2009).
- “People with intellectual disabilities seem to be vulnerable for developing behavior problems. **Studies have reported that 7–15% of individuals with “administrative” intellectual disability (that is, individuals with intellectual disability who receive services from the authorities) have severe behavior problems.** Severe behavior problems among people with intellectual disability are often termed “challenging behavior” and aggression towards others, temper tantrums, screaming or shouting, and self-injury are examples of behaviors that may be challenging to relate to for family,

support staff and others. Such behaviors may be excessively controlled by people in the environment and may result in social isolation and restricted opportunities for taking part in ordinary social and societal activities, and it may be very difficult to establish a dignified life situation for people with severe behavior problems,” (Myrbakk & von Tetzchner, 2008).

- “Challenging behaviors such as tantrums, self-injury, and aggression are highly prevalent among children with autism spectrum and other developmental disorders (e.g., Einfeld & Tonge, 1996; Emerson et al., 2001). Serious forms of these behaviors (including those that cause harm to the person and others) are estimated to be present in 10% to 15% of this population (Lowe et al., 2007)... **Problem behaviors interfere with efforts to help these individuals live more independently by disrupting educational and vocational efforts as well as home life** (Fox, Vaughn, Wyatt, & Dunlap, 2002). In addition, there is a growing body of research demonstrating that when children with developmental disorders engage in problem behaviors, their parents are also likely to report more stress and related psychological symptoms such as anxiety and depression (Hastings, 2002; Hastings & Johnson, 2001; Lecavalier, Leone, & Wiltz, 2006; Seltzer et al., 2010).” (see Durand, V.M., Hieneman, M, Clarke, S, Wang, M & Rinaldi, M.L., 2012).
- **“Kids with disabilities represent three-quarters [75%] of children physically restrained and 58 percent of those placed in seclusion or some other form of involuntary confinement at school,** the Education Department said. Such children are also more than twice as likely to receive an out-of-school suspension. What’s more, federal officials found that children served under the Individuals with Disabilities Education Act account for a quarter of all students who are arrested and referred to law enforcement by schools. Meanwhile, kids with disabilities represent just 12 percent of the nation’s students,” (Diament, 2014).

Nevada’s Need:

- According to a Las Vegas Review-Journal article from March, 2014, **357 children with autism are on a waitlist** for help from the state’s Autism Treatment Assistance Program (ATAP). (see Appendix A)
- According to a Las Vegas Review-Journal article from March, 2014, **the ATAP service receives 16 new requests for services each month and only 2 individuals graduate each month,** making the waitlist exponentially longer over time. (see Appendix A)
- According to a report published in 2013 by the Substance Abuse and Mental Health Services Administration (SAMHSA), **of the adults receiving Medicaid Coverage in Nevada, 27.7% qualify for serious mental illness (the highest national percentage),** 34.5% qualify for serious psychological distress and 23% qualify for substance use disorder.
- An interview with Dr. Elaine Brown, Chief Psychologist for the State of Nevada’s Developmental Services, resulted in discussions of the current system wherein children with disabilities and challenging behaviors are referred primarily to psychiatrists and put on medications or sent out of state for behavior supports. **Dr. Brown says, “I would like to see the behavior services come to the forefront of what we need to provide to both our families and adults.”**
- Nevada’s Report of the Commission on Services for Persons with Disabilities explains that, **“There is an interrelationship between the services of positive behavioral**

supports, respite, and independent living. All help reduces the care demands on caregivers who are supporting someone with disabilities or special care needs. However, a caregiver might not be able to access respite; for example, if a behavioral challenge makes it difficult to provide care...any relief [respite] to a caregiver will not be achieved if an individual's Independent Living goal to work is prevented by a behavioral issue that isn't addressed first." (see Appendix B)

THE EVIDENCE THAT POSITIVE BEHAVIOR SUPPORT HAS A SIGNIFICANT IMPACT

National Evidence for Positive Behavior Support:

- **Almost every state in the nation has a PBS Project**
- **Positive Behavior Support interventions in the home and community have shown to significantly reduce problem behavior, increase independence and have maintained effects at follow-up visits** (e.g., Durand, Hieneman, Clarke, Wang & Rinaldi, 2012; Greenwald, Seniuk & Williams, 2014; Lucyshyn, Albin, Horner, Maan, Maan & Wadsworth, 2007)
- There is a nation-wide movement towards incorporating Positive Behavior Supports and Mental Health initiatives. We expect to see more data being generated on the **benefits of prevention of challenging behavior and reduced prevalence of mental health disorder diagnoses** in children. With regard to School-wide PBS and the *Interconnected Systems Framework for School Mental Health*, the, "programs and services reflect a "shared agenda" with strong collaborations moving to partnerships among families, schools, and mental health and other community systems," (Barrett, Eber & Weist, 2012).

Evidence for the PBS-Nevada Project:

- **The PBS-Nevada project supported 197 focus individuals in FY13 and has a goal of supporting at least 170 focus individuals throughout the state in FY14**
- There is an **ongoing request list for PBS services**, with the list being longest in the rural areas of the state, where other support services are limited
- Each focus individual is triaged into a service level that best fits their behavioral needs:
 - Focused Needs Workshops (Level 1) = Potty Pros; Functional Communication Training; Picky Eaters; Routines and Transitions
 - Significant Needs Workshop (Level 2) = Breaking the Cycle of Defiance
 - Pervasive Needs Workshops (Level 3) = Addressing Challenging Behavior; Prevent, Teach, Reinforce
- In FY14, our service delivery model was modified to include 2.5 hours of workshop time and 1 hour of in-home consultation support for each unit of service. In FY14, during Quarters 1&2, our outcome data are:
 - **Level 1 (1 unit of service) – 97% (35/36 individuals) demonstrated sustainability with reduced problem behavior, increased independence and increased quality of life**

- **Level 2 (3 units of service) – 80% (4/5 individuals) demonstrated sustainability with reduced problem behavior, increased independence and increased quality of life**
- **Level 3 (5 units of service) – 79% (15/19 individuals) demonstrated sustainability with reduced problem behavior, increased independence and increased quality of life**
- We anticipate that these outcome data numbers for FY14 will increase as more individuals are assessed and more data are collected.
- Kaci Fleetwood, the parent of a child with a disability, explains her experience with PBS-Nevada, saying that, “With trainings and in-home consultation, we were able to improve our quality of life for ourselves, and not just our son.” She also discusses her struggle with obtaining services in the state, explaining that PBS-Nevada is a necessary program for families because it is a team approach, providing consistency across environments, and is accessible to all families. **“We’ve been incredibly frustrated with how hard it is to get services for our son because there’s red tape everywhere. It’s like you have to apply for Medicaid to get denied by Medicaid to then apply for Katie Beckett...it is just nonsense! With PBS-Nevada, you can go directly to them and then the next time there is a training you can go, without anyone telling you that you have to qualify based on income. The accessibility is huge!”**
- **PBS-Nevada Case Example: In Quarter 1 of FY14, one of our stories of success comes from the family of a 4-year-old boy diagnosed with autism (and on Nevada’s waitlist for ATAP services) as well as a severe medical condition resulting in profound developmental delays. When this boy began with PBS-Nevada, he had no functional form of communication, could not go out into public places without having major meltdowns, was not toilet trained, and was unable to complete any simple demands or self-help skills. Through the course of completing a series of our workshops, including behavioral assessments and team intervention planning, as well as receiving in home consultation with our PBS staff, the parents of the boy were able to teach him to use an iPad communication program to effectively communicate his wants and needs, go out into the community and have a meal with his parents and older sister in a restaurant, and use the toilet independently. The family is thrilled at their son’s significant increase in skills and quality of life, as well as their own quality of life, having been taught how to best support their son, helping him to gain skills and independence while significantly reducing his challenging behaviors. Additionally, as a result of PBS-Nevada services and the significant decrease in behavior problems, the intrusive medical interventions historically used are currently being re-examined and discussion of completely removing the medical interventions have begun.**
- In the Las Vegas Review Journal news article from March, 2014 (see Appendix A), a mother of an 8-year old boy diagnosed with autism was interviewed about her son’s challenges, stating that her primary concerns were his inability to toilet himself and communicate effectively. **With a 97% success rate for this fiscal year, if the boy were enrolled in PBS-Nevada’s Potty Pros and Functional Communication workshops, the family would obtain critical information and support while on the ATAP waitlist and possibly have reduced needs for intensive services.**

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Appendix A

LAS VEGAS REVIEW-JOURNAL

Parents of autistic children decry state's long wait list for services

Posted: March 2, 2014

By YESENIA AMARO

Olivia Espinoza repeatedly called out to her 8-year-old son, who paced the living room floor like a sentry on patrol.

He wouldn't make eye contact and stayed fixated on his footsteps as the adults around him spoke of the challenges of raising an autistic child.

Irma Alvarado's autistic son, 9-year-old Rojelio, tugged at a red necktie while the discussion unfolded.

The third mother at the informal gathering on Thursday said her severely autistic child's need for treatment and services is going unmet.

"It's a huge desperation," Maria Sosa said in Spanish of her 8-year-old son Jose's situation. "Sometimes you don't even know what to do anymore."

Their sons are among 357 children on a wait list for help from the state's Autism Treatment Assistance Program, which offers therapy to improve communication and behavior.

Autism spectrum disorders are a group of developmental disabilities that can cause significant social, communication and behavioral challenges, according to the Centers for Disease Control and Prevention.

Early treatment for autism is crucial, the mothers said. But the average time it takes to obtain services for children put on the wait list in January is 275 days, said Tina Gerber-Winn, deputy administrator for the state's Aging and Disability Services Division.

The wait list backlog began when the program started in 2009, Gerber-Winn said last week. The program gets referrals from multiple sources, including families, schools and health care providers.

"It has slowly grown since people have become more aware," she said.

At the end of January, the state's autism treatment assistance program was serving 199 children, from those younger than a year up to 19. The state-funded program is closing an average of two cases per month because each case varies in therapy length. The average monthly cost per case in January was \$1,233, but officials said that average changes, depending on how much therapy participants need.

However, the program receives an average of 16 new requests for services a month, Gerber-Winn said.

Once in the program, a target is set for a child's improvement. A behavior analyst decides when the target has been met and closes a case, which sometimes can take years.

"We only have the ability to service so many cases," said Gerber-Winn, adding that she understands families are upset because they've been waiting so long for services.

Jose Sosa was identified as autistic when he was 3 years old and has received little treatment. He got six months of speech therapy soon after he was diagnosed, his mother said. He still uses diapers and can't speak in complete sentences.

Maria Sosa submitted the first application to the state's autism program about three years ago but was later told her paperwork couldn't be found in the system. It's been a year since she submitted a second application, and her son has still not made it to the front of the line.

"He is not functional," Maria Sosa said of Jose on Thursday night as she and the other mothers gathered at an east valley home to drink coffee and watch their children play. "He needs a lot of help. I know that all the children (on the wait list) need help, but my son really needs it."

Jose needs to be watched at all times. He also won't stay still and doesn't recognize danger.

"If there's fire in front of him, he'll go up and grab it," Sosa said.

She hopes state officials will heed her call for help before it's too late for the therapy to make a difference for her son.

Children on the wait list are in desperate need of services but are languishing, said Barbara Buckley, executive director of the Legal Aid Center of Southern Nevada.

"It makes no sense," she said last week. "We see the therapy makes a difference in their lives. ... For them to sit on the waiting list when you know it can change their lives, it's just a travesty."

The issue is one of the highest priorities for the Legal Aid Center, Buckley said. She has been in communication with Mike Willden, director of the Nevada Department of Health and Human Services, to see what can be done to speed up the process. They also plan to contact state lawmakers.

Lawsuits in Florida and Ohio directed the states to pay for applied behavior analysis treatment for autistic children under their Medicaid programs, Buckley said. Last fall, a federal appeals court upheld the order for Florida to offer the treatment under Medicaid.

"That's an angle that we are looking at," she said.

The Legal Aid Center's goal is for children to receive services as soon as possible. The center will keep all of its options open, including litigation if necessary, Buckley said.

The Legal Aid Center became aware of the issue because it represents an autistic foster child who needed treatment.

“Because the cost of behavioral plans vary, it is necessary to balance the addition of new children to the program with the agency’s budgeted authority,” Gerber-Winn said.

For fiscal 2014, the program has a budget of \$4.1 million. That increases to \$7.7 million for fiscal 2015. Those budgets include \$2.6 million added to help decrease the number of children on the wait list, Gerber-Winn said.

The additional funding will allow the program to increase services to 307 children by June and to 572 by June 2015, Gerber-Winn said. The program also has added seven new positions.

The funding “will allow the program to serve 50 percent of the current waiting list,” she said.

But mothers say time is passing and their children are losing their windows of opportunity.

“It’s not fair that our children are not getting the help,” said Olivia Espinoza, who leads a support group, Azul Blue, and has an autistic 8-year-old, Matthew Villalobos, who doesn’t speak and still uses a diaper. “My son is in the same situation. It’s sad not to have a solution.”

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Appendix B

From: Nevada's Report of the Commission of Services to Persons with Disabilities (2012)

Findings Related to Positive Behavior Support Services

Problem behavior is a primary factor causing families and social service programs to move people to more restrictive service environments. The challenge of delivering any service is multiplied in the face of difficult behaviors; in the absence of specialized training, service delivery can become nearly impossible.

Positive behavior support (PBS) strategies are considered effective when interventions result in increases in an individual's success and personal satisfaction, and the enhancement of positive social interactions across work, academic, recreational, and community settings. Valued outcomes include increases in quality of life as defined by an individual's unique preferences and needs and positive lifestyle changes that increase social belonging.

Internationally, positive behavior support training has been recognized as an effective, science-based approach for addressing a wide array of challenging behavior problems that impede progress toward personal goals and lifestyle gains. Many states have active positive behavior support training programs in many agency and school settings. An ever-expanding number of successful outcomes in Nevada and elsewhere demonstrate the impact that positive behavior support can have for families and service providers trying to provide a service while overcoming problem behaviors.

Positive behavior support (PBS) offers behavioral expertise and trains family members, care providers and educators to develop and carry out realistic and viable support plans. Building PBS capacity in our service systems is vital. *In fact*, Nevada statutes require developmental services and child and family services (NRS 433.5506), mental health and medical facilities (NRS 449.782), and public and private schools (NRS 388.5285 and NRS 394.372) to employ positive behavior supports before moving a service recipient to a more restrictive setting.

In Nevada, and in an ever-growing number of sites in other states, positive behavior support is being adopted in programs serving autism spectrum disorders and developmental disabilities in children and adults, early childhood, emotional and behavioral disorders, traumatic brain injury, mental health and child welfare. Building sustainable positive behavior support is not just a matter of training, but of a commitment by school districts and service agencies to implementing and sustaining the PBS procedures, and to learning to use PBS as the way to deliver behavior support within existing resources and funding.

Nine PBS providers responded to the Commission's survey and their responses yielded the following insights:

- 80% of respondents reported a decrease in their budgets since 2008; the average decrease was 46%.
- 80% indicated funding is "fair" or "poor."

- Among those who offered waiting list data, the average waiting list was 28 people and the average wait time for services was 7.5 months.
- The average person receives 23 hours of PBS support and training; funding comes from the State and Federal government funds, individual donations and collaboration with other agencies.
- The primary challenges noted by providers are a need for greater technical assistance, and the lack of funding for more intense training and follow-up with families.