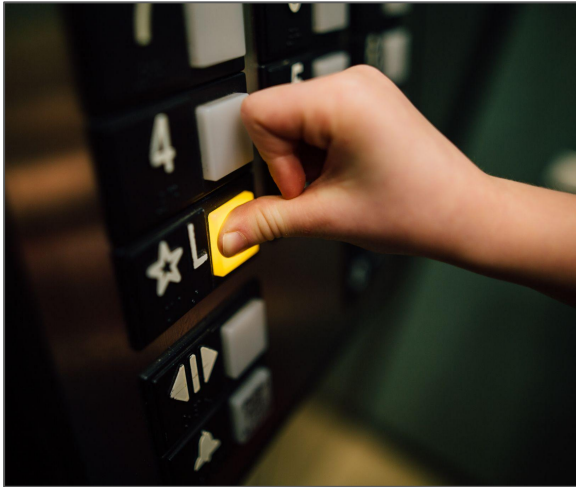


A Guide to Improving Healthcare for Persons with Special Healthcare Needs

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A 17-year-old boy with autism and intractable seizures was hospitalized for an EEG analysis, a medical procedure necessary to pinpoint the location of his seizures and aid in subsequent treatment. However, medical staff were unable to complete the diagnostic analysis on two occasions because the boy kept attempting to leave the room due to his obsession with riding elevators. Olivia Miller, a Behavior Analyst at his hospital, created a system where he could earn points for listening to his medical staff that would get him a ticket to ride the elevator at the end of his stay. It worked! He earned eight elevator rides and was able to move on to the next step of his medical care, ending his seizures!

Difficulty with medical examinations and procedures that result in delayed access to care is common among children and adults with intellectual and developmental disabilities. But they can be prevented or ameliorated by a skilled Behavior Analyst. Some common examples include:

- Dental exams and treatment cannot be delivered to children with special health needs who scream and resist. A Behavior Specialist can help children with disabilities acquire the skills necessary to remain calm.^{1,2}
- Hearing aids are only effective for children with special health needs, if they can tolerate wearing them. A Behavioral Specialist can assist children in acquiring the skills necessary to keep their prescription prostheses in place.³
- Blood draws are often needed to identify physiological markers that may contribute to illness or other forms of severe problem behavior. But blood draws cannot be obtained if the child avoids any indication that such a procedure will take place. You need a willing and active participant. A Behavior Specialist can reduce anxiety around these difficult procedures to the point where blood can be effectively drawn.⁴

In an effort to increase access to specialized care, this guide has been created to help with the implementation and integration of effective behavioral services into all healthcare settings, such as hospitals and clinics.

A Guide to Improving Healthcare for Persons with Special Healthcare Needs

In this document, we present a summary of the evidence for the efficacy of Behavior Analysts in dealing with a wide variety of common problems that persons with intellectual and developmental disabilities experience within the healthcare setting. Although our summary is brief, we provide links and references to the literature that will enable you to assess the efficacy of services for each of the problems we describe.

We address the issues involved in increasing the availability of Behavior Analysts in healthcare settings. We discuss the ethical and educational requirements for Behavior Analysts to expand their scope of practice. We also provide an analysis of the policies that govern reimbursement for Behavior Analytic Services.

These services will not become as widely available as they need to be unless Healthcare Providers and Behavior Analysts work collaboratively to persuade hospitals and clinics to make them available. Therefore, the last section of this guide provides you with steps you can take to create a local Action Circle to make these services available in your community.

The Power of Behavior Analysis

Beginning in the 1960s, scientists and clinicians began applying principles of learning to human behavior. With the goal of remediating the most challenging and problematic behavior problems, the field of Applied Behavior Analysis (ABA) took form. Since then ABA has become the most empirically supported form of intervention for a large host of behavior problems. These include the behavioral excesses and deficits commonly associated with special health needs, challenging behavior displayed by elderly people with dementia, and [organizational problems](#) common to many businesses and places of employment, to name a few.



The mountain of evidence that supports implementation of behavior analytic interventions continues to grow. However, the influx of Behavior Specialists in medical and healthcare settings is not keeping pace with the demand for their services. Nevertheless, exemplars of ABA services in healthcare settings do exist and serve as models for quality standard of care.

Preparing Children with Disabilities for Medical Exams

Many children with intellectual and developmental disabilities and autism spectrum disorder (ASD) have medical fears and phobias.⁵ These are usually demonstrated by intense emotional reactions and avoidance behavior in the medical settings. Only about half the time do providers know how to address fears and avoidance.⁶ In the absence of positive behavior support, providers often do not know what to do and utilize more restrictive medical interventions such as sedation in order to conduct an exam. Research shows that fear and avoidance can be reduced through graduated exposure to the feared situations along with positive reinforcement for fearless or approach behavior leading to the successful completion of medical examination and procedures^{1,2} such as dental exams and having blood drawn.^{4,7} For more information [click here](#).



Establishing Activities of Daily Living

Feeding Disorders. Approximately 1 in 4 children have some form of a feeding disorder. This number increases to 8 out of 10 for children with developmental disabilities.⁷ This can result in malnutrition, even to the point of requiring invasive medical procedures. Behavior Analysts have been successful in creating interventions and measuring outcomes related to increased food intake and increasing food variety that remediate the majority of eating disorders. Successful strategies include increasing positive reinforcement for accepting food and reducing reinforcement for food refusal.⁷ For more information [click here](#).

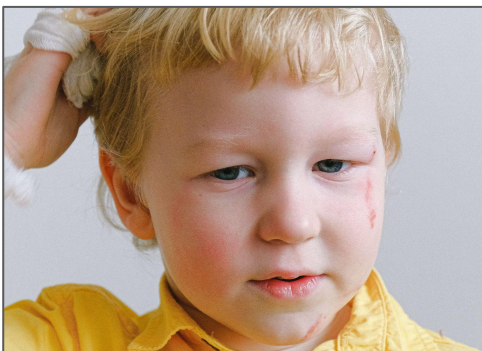
Toileting. Both children with disabilities and typically developing children, often have difficulties in developing appropriate toileting habits. Delays in developing appropriate toileting may result in stigmatization, restricted access to the community, restricted development of social relationships, and negative health issues.⁸ Behavior Analysts have developed effective procedures for teaching toileting that involve a lot of positive reinforcement for each of the steps in toileting.⁹ Examples of effective procedures can be found [here](#).

Sleep. Up to 50% of children will experience a sleep problem during childhood, with sleep issues reported as one of the most commonly discussed topics during well-child visits.^{10,11} Children with developmental disabilities are even more likely to have sleep problems, with some studies reporting 40-80% of children who have an autism spectrum disorder (ASD) and/or intellectual disability (ID) affected by sleep concerns. Additionally, up to 58% of children with mild-to-profound ID are experiencing sleep problems.¹² The effect of sleep disturbance is suggested to correlate with other highly concerning behaviors such as aggression and self-injury; however, results from a national survey of pediatric residency programs indicated that pediatricians received only about 5 hours of training on sleep concerns.¹³ Embodied in the behavior analytic literature are effective evidence-based treatment strategies for various sleep disturbances,¹² indicating a need within healthcare settings for collaboration with behaviorally-skilled practitioners. For more information [click here](#).

Self-Injury

More than half of children diagnosed with intellectual and developmental disabilities engage in self-injurious behavior (SIB).¹⁴ SIB can have significant social ramifications, impact a caregiver's quality of life, lead to permanent physical damage, and be life-threatening.¹⁵ This can lead to increased stress for the individual, their caregivers, and supporting healthcare providers. Given the frequency that children with disabilities undergo medical procedures, healthcare providers are more likely to encounter SIB and therefore experience the collateral effects.

Behavior Analysts have expertise in the implementation of intervention strategies (e.g., differential reinforcement procedures) that not only lead to significant decrease in SIB, but also increase appropriate replacement behaviors. It is important to note that ensuring the support and expertise of Behavior Analysts in behavior analytic practices is necessary for successful outcomes.¹⁶ This further illuminates the need to integrate Behavior Analytic Services into healthcare settings, like training of medical staff and family and early intervention services. For more information [click here](#).



Aggressive Social Behavior

Aggressive social behavior is perhaps the single most important risk factor for the development of antisocial behavior and related problems, including depression, academic failure, and substance use. Therefore, preventing this behavior can help to alleviate most of the behaviors of childhood and adolescence that commonly lead to involvement with the criminal justice system.



Family Interventions. There is extensive evidence from research over the last 40 years showing that children's aggressive social behavior can be prevented through family interventions.¹⁷⁻¹⁹ These programs help parents to abandon the use of punitive and coercive approaches to their children's behavior. They also help parents to develop skills in setting limits, richly reinforcing prosocial behavior, and communicating with their children in patient and caring ways.²⁰ At least 16 family interventions have been identified.²¹ The widespread availability of such programs for families would have a significant impact in reducing the number of children who develop aggressive social behavior and, subsequently, become entangled in the criminal justice system.

School Interventions. Similarly, there are tested and effective school-based programs that have proven benefit in reducing children's aggressive social behavior.^{18,20,22,23} This includes programs such as the PAX Good Behavior Game,²⁴ cooperative learning,²⁵ Positive Behavior Intervention and Support,²⁶ and the PATHS^{27,28} program, which reinforce cooperative behavior and promote self-regulation of emotional behavior.

Communication

Children with intellectual and developmental disabilities often have difficulties in communicating. They may not learn to talk, may not develop typical levels of verbal behavior, may avoid eye contact, and may avoid interacting with others. Here is a brief summary of some evidence-based approaches to increasing communication skills.

Improving joint attention for promoting verbal behavior for children with autism spectrum disorder. Explicit instruction to increase joint attention among young children with ASD contributes to the development of their verbal ability.²⁹



Early intervention on social communication outcomes for children with ASD.

A meta-analysis of these interventions showed that they significantly improved children's communication, although the effect size was only 0.36.³⁰

Augmentative and alternative communication (AAC). This involves teaching children to communicate in ways other than talking. A review of 14 studies indicated that AAC improves communication skills, including phonological awareness, vocabulary, requesting, and developing narrative skills in children aged between 6 and 10 years with mixed diagnoses.³¹



Efficacy of focused social and communication intervention practices for young children with autism spectrum disorder: A meta-analysis. Social communication interventions produce medium positive effects ($g = 0.51$; $NAP = 0.86$). Effects are stronger if parents are involved.³²

Models for Integrating ABA into Healthcare Settings

Behavior Analytic Services have been integrated into healthcare settings in at least four models:

First, some hospitals have fully integrated ABA services into their system. Perhaps the best example of this is the Kennedy Krieger Institute in Baltimore, Maryland, which is a premier hospital dedicated to improving the lives of people with developmental disabilities and disorders of the brain, spinal cord and musculoskeletal system. In the last five years, the inpatient treatment setting for severe problem behavior displayed by people with IDD reported that 85% of patients discharged had reduced their problem behaviors by at least 80%, and 88% of patients had maintained their treatment gains at follow-up. Similar programs have been established at Seattle Children's Hospital, the Marcus Autism Center, and the New England Center for Children.

Second, healthcare facilities are realizing that ABA services are just as relevant for addressing the challenging behaviors of people without IDD. For example, the Boston Children's Hospital has created a Behavior Response Team that helps treatment staff to address problems like children who aggressively resist diagnostic and treatment practices.

Third, there is increasing use of ABA services to address the challenging behaviors of people with IDD who are receiving medical care. For example, Behavior Analysts can help children follow through on complying with medical regimens, such as wearing glasses or hearing devices, exercising, or take medication.

Fourth, behavioral services are increasingly being used to assist Healthcare Providers in managing burnout, providing more compassionate care, and managing implicit bias. For example, the Performance System Technologies lab at the University of Nevada, Reno (UNR) has been working collaboratively in partnership with UNR's School of Medicine (UNR Med) to systematically integrate behavior analytic measurement and technology into its nursing, medical, and physician assistant curricula. The curriculum initiatives are focused on teaching students how to: healthfully manage stress; build resilience; communicate effectively among their healthcare team; and provide culturally humble care. For more information related to this work see: <https://med.unr.edu/diversity-inclusion/research>.

More detailed description of these models of integration can be found [here](#).

Policies Supporting the Use of Behavior Analysts in Healthcare Settings

There is widespread support for the provision of behavioral services in healthcare settings. Based on the evidence we summarized above, numerous national organizations have increasingly endorsed and adopted the reimbursement for these services and policies.

Among the organizations supporting the efficacy of these services are: the American Association on Intellectual and Developmental Disabilities; Autism Speaks; American Academy of Child and Adolescent Psychiatry; National Professional Development Center on Autism Spectrum Disorders; Organization for Autism Research; and the Association for Science in Autism Treatment. Support for ABA has also come from federal agencies such as the National Institute of Mental Health, the Centers for Disease Control, the National Institute of Child Health and Human Development, and the Office of the Surgeon General of the United States.

There is growing legal support for the provision of ABA services. Health insurance reform in all fifty states has deemed ABA services to be a health insurance benefit when medical necessity is documented.

In California, the federal requirement for mental health and behavioral health parity was interpreted to require coverage for ABA services for conditions other than autism. This interpretation was adopted thanks, in part, to advocacy by the Mental Health-Autism Insurance Project (www.mhautism.org).³³

Four states (Florida, Massachusetts, Missouri and Nevada) have passed laws indicating ABA as one of several ancillary covered benefits for individuals with Intellectual Disability and/or Down syndrome and other disabilities (Fetal Alcohol syndrome, certain physical disabilities, other). View the laws for ABA coverage for Down Syndrome at the [Massachusetts](#) and [Florida](#) websites.

To integrate ABA services into the healthcare systems or expand ABA services beyond services for IDD, one must be mindful of the [Behavior Analyst Certification Board \(BACB\) ethical guidelines](#) for developing new competencies.

If you would like to see ABA services made more available, Values to Action can help. They can assist you in creating a local Action Circle that clearly defines policies relevant to the goal of making this happen in your state and advocates for the incorporation of these services in your local hospitals and clinics. For more information on how Values to Action can be of assistance, please contact hello@valuestoaction.org.

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