Addressing the Challenging Behaviors Associated with Autism

A Proven Method to Reduce Challenging Behaviors in Any Environment

By George Sues
Chief Executive Officer
The Arc of Delaware County, NY

The behavior challenges related to autism can feel daunting for family, caregivers, and community service organization professionals alike. But dwelling on challenging behaviors leads to a focus on questions such as, “What will we do when this individual displays this challenging behavior again?” The answers often lead to a culture focused on intervention and physical restraints.

Caregivers often feel that this approach is not effective, and they’re right—physical intervention to address behavior challenges can result in escalation, humiliation, and injury. But the field of community support services has relied on these traditional, reactive approaches for so long there is little belief and less conviction that positive, proactive philosophies and approaches can work.

But instead of focusing on handling negative behaviors, what if the question caregivers asked was, “What will we do to prevent this individual from behaving in this negative way again?” It’s possible to break the cycle of negative reinforcement and physical restraint, and shift to a dynamic that focuses instead on encouraging positive behaviors. At The Arc of Delaware County, the team has created a positive, restraints-free environment for people with autism and many other developmental disabilities—and helped other organizations reduce their use of restraints too, with the same step-by-step approach used internally.

This approach is based on a series of proven steps that move toward a culturally reinforced positive approach to reduce and even eliminate challenging behaviors in a way that is actionable for organizations, schools, and home care environments.

By applying these steps, other professionals and family caregivers can do the same:

1. Let Go of Preconceptions - There is a common belief that in order to prevent people from hurting themselves or others, one must physically intervene. This idea is outdated, ineffective, and can hold teams back from making the all-in personal investment that is necessary to gain real results from a positive approach.

The most effective way to dramatically see Proven on page 28.

Assessment and Treatment of Problem Behavior for Adults with ASD

By Ethan Eisdorfer, MA
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Douglass Developmental Disabilities Center at Rutgers University

As individuals with autism age out of the educational system, families are faced with a number of challenges. Maladaptive behavior, in particular, can be a significant stressor for families of adults with Autism Spectrum Disorder (ASD). While estimates of the prevalence of problem behavior vary considerably, it tends to be more common in individuals with ASD relative to other disorders. Common topographies of problem behavior include aggression, self-injurious behavior, property destruction, ritualistic behavior, disruption, and inappropriate vocalization, as a few examples. While procedures for assessment and treatment for these kinds of problem behavior are well-established in the behavioral literature, the adult population presents unique challenges for families and care providers.

Functional Assessment of Problem Behavior

Functional assessment is an important first step in the effective treatment of maladaptive behavior. Functional assessment represents a collection of procedures used to determine the environmental factors that cause and maintain maladaptive behavior. Functional assessments may include indirect assessment procedures (e.g., questionnaires and structured interviews), descriptive assessment (e.g., collecting observational data related to the antecedents and consequences of maladaptive behavior), and functional analysis (e.g., hypothesis testing and the manipulation of environmental variables).

Over the last several decades, a robust literature validating the effectiveness of functional assessment has emerged. The literature has shown that these assessment procedures are effective for identifying the function of maladaptive behavior and that treatments based on these procedures are more effective than treatments that are selected arbitrarily (Pelios, Morren, Tesch & Axelrod, 1999). While the literature validating the effectiveness of these procedures is clear, assessing the maladaptive behavior of adults with autism presents unique challenges as compared to assessment with younger populations. Some of these challenges are highlighted below.

Legislation - Perhaps one of the most significant barriers for older individuals with autism is the fact that legislation mandating the use of functional assessments only extends to individuals up to age 21. As a result, adults diagnosed with autism are not entitled to the same behavioral supports as their younger counterparts. Consequently, adults diagnosed with autism have fewer opportunities to have sound functional assessments conducted, which can lead to poorer outcomes over time.

Cost of services - Providing services for adults with autism spectrum disorders represents a substantial economic expense for families and government agencies (Cimera and Cohan, 2009; Ganz, 2006; Jarbrink, McCrone, Fombonne, Zanden, & Knapp, 2007). It has been estimated that it costs approximately $3.2 million dollars to financially support an autistic person over their lifetime (Ganz, 2006). With limited funds available, assessment and treatment practices are more likely to use less thorough models of assessment and treatment which require less time, money and other resources.

Lack of qualified staff - Another significant challenge is the lack of available trained staff with experience working with adults with ASD. Many staff members tasked with assessment and treatment plan development lack the necessary training to do so effectively (Sigafoos, Roberts, Couzens, & Caycho, 1992; Wood, Lusseli, & Harchik, 2007). This gap in the availability of well-trained professionals can lead to poorly designed assessment and treatment.

Severity of the maladaptive behavior - Another barrier to effective assessment and treatment is the severity of the behavior being treated in adults. Adults with autism see Adults on page 26.
Autism Spectrum News

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Steps to Increasing the Success of a Behavior Plan

By Lana Small, MSW  
The YAI Network

A large percentage of caregivers of children with autism will want (or need) to implement a behavior plan. When I ask a parent what he or she wants out of a behavior plan designed for his or her child the answer can usually be found among the following: “I want my child to be more compliant with requests. I want her to be less resistant to participating in tasks. I want her to develop more appropriate skills. I wish he could let me know what he wants so I don’t always have to be guessing. I want him to make better choices. I want her to give up her own desires and interests sometimes and engage in other activities.”

These are all worthy outcomes for behavior plans. For a child with autism who gets stuck in routines, responding to the requests that do not include reinforcing activities from his/her point of view, successfully communicating needs and learning skills that will help him/her be more effective in the environment are all important skills.

A successful behavior plan benefits the parent as well. A parent develops a more positive view of the child, gains confidence in parenting skills, feels more in control of the environment and achieves a healthy respect for the child and his/her abilities. A well implemented plan benefits all parties.

As the implementers of the plans, we are motivated for change with all of the benefits. But why are behavior plans so difficult to execute? Even the clearest written and detailed plan can be challenging to start, keep going and see through. The problem I have discovered – no discussion about the pre-plan preparation and overall planning.

Before a builder starts his construction, he surveys the land, develops the blueprints, looks at his budget and gets all his certifications. Before we implement a plan we also need to do some pre-planning. The writer of a behavior plan would have assessed the target behaviors, the learner’s skill set and the needs of the environment. The person who will implement the plan often does not properly assess his/her preparedness to put the plan in action. One of the things that we overlook is that a behavior plan for the child is also a behavior plan for the parent, caregiver or professional who will implement it.

Here are some important strategies to prepare for implementing a behavior plan:

1. Acknowledge that you, as the implementer, are also on a behavior plan. A behavior plan has instructions for the implementer, as well as what is expected of the child. If a schedule is to be employed to produce specific actions, the instructor must abide by the timeframe for prompting appropriate behaviors. A behavior plan depends on the implementer’s ability to produce the right behavior at the right time. The person employing the plan must be able to change his or her behavior as needed. The child is not the only one who needs to do something different.

2. Take the time to learn the basic theory on which the strategy or plan is based. The knowledge of why you perform a particular behavior at a specific time gives credibility to what you do and makes it easier. It will also help you avoid making “adjustments” to the plan without evaluating the possible outcomes.

3. Know yourself, especially your kryptonite. Remember that green crystal that could turn the man of steel into a weak, bumbling mess? Each of us has our weaknesses in areas that would prevent the implementation of a behavior plan. Plans require consistency, attention to detail, and clear and logical thinking. When would either of these be a problem in your interactions with your child? Is it when your child does a particular behavior that you find just unbearable? When you are tired? After a stressful day at work? When others are present in the environment? Knowing these weaknesses and deciding how to deal with them is important to your success.

4. Practice managing your feelings. Some of us are better at this than others. If you wear every emotion on your sleeve or in your posture, others, including your child, will read them and respond. Many parents tell me they do not pay attention to their child’s inappropriate behavior because they understand that the behavior is motivated by a need for attention. While it is true that they may not respond verbally, the contortions of their face and the stress that is obvious from their body language says, “I see you, you got my attention.” Or, by

see Success on page 35
IT TAKES BRAINS TO SOLVE AUTISM

Alex Plank never saw himself as super. More like “awesome” really. He feels that being on the autism spectrum is a gift, and he wants to share that gift with scientists so they can understand what makes his brain unique.

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This initiative is guided by:
The Effects of Cortisol on Individuals with ASD

By Jeanne D’Haem, PhD
and Irene Van Riper, EdD
William Paterson University

One Saturday, Catherine Maurice took her son and daughter, Daniel and Anne-Marie, for a walk. Anne-Marie has autism. A little black dog ran out of a driveway, yapping excitedly. Ann-Marie was afraid and began to cry. This excited the puppy then began to jump up on her. The dog was not dangerous, he just wanted to play. Anne-Marie started to run around screaming and would not respond to her mother’s efforts to reassure her. Her mother finally picked Anne-Marie up and took both of the children home. Daniel cried for about five minutes and was soon calm. Anne-Marie cried for the rest of the weekend.

This scene is described in the book, *Let Me Hear Your Voice: A Family’s triumph over Autism*. Similar situations take place every day in classrooms and homes with individuals with autism. A neurobiological perspective can help us to understand incidents like this and assist those with autism.

When an individual becomes stressed by a strange dog, for example, the body produces cortisol; a neurobiological stress hormone reflecting hypothalamic-pituitary-adrenal (HPA) axis activity. It has been termed the stress hormone because it is secreted at higher levels during a flight or fight response to stress. Small increases have positive effects. However, higher levels have been shown to impact cognitive function.

When we are highly agitated and therefore cortisol levels are high, thinking and memory are affected (Jacob and Nadel, 1985). Anne-Marie’s body was flooded with cortisol and she could not process her mother’s reassurance. It is not that she would not listen to her mother. Her brain was so chemically stressed she could not respond as she would normally. Spratt et al (2014) found significantly higher serum cortisol response in children with autism. Analysis showed significantly higher peak cortisol levels and prolonged duration of the cortisol elevation in children with autism. Daniel, who was also frightened of the puppy, was able to calm down after a little while but his sister was upset for the entire weekend.

According to the research of Corbett, et al, 2014, there may exist a spectrum of responsivity to stress. Some individuals have abnormally high levels of cortisol when faced with a stressful situation, while others have abnormally low levels (Ruttle, et al, 2011). The length of time the behavior persists is also relative to the level of cortisol. In some individuals, stress arousal heightens the level of cortisol, but this reaction begins to decrease as time elapses. This same research study explains that an individual may adapt to long-term stress with a decrease in cortisol, demonstrating under-arousal in stressful situations.

Individuals with ASD, like Anne-Marie, often have hyper-responsivity to stress (Corbett, Schupp & Lanni, 2012). Stress levels are related to factors such as age, gender, SES and context in relationship to the individual. If an individual with ASD, as in Anne-Marie’s case, is faced with an unexpected situation, the event may be experienced as quite stressful.

Once we understand what is happening, physically, to individuals with autism when they are stressed it becomes clear that having appropriate interventions in place is crucial. Walker (1995) conceptualized the “acting out cycle.” The phases of calm, agitation, out-of-control, de-escalation and...
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Applied Behavior Analysis (ABA) is a science wherein procedures, based on basic principles, are applied to important matters of everyday life in order to help individuals increase functional skills, while decreasing problematic ones (Cooper, Heron, & Heward, 2007.) Most notably, ABA has been utilized to improve the quality of life for children with developmental disabilities, specifically children who have been diagnosed with Autism Spectrum Disorder. ABA teaching strategies have been highly successful in improving functional communication skills, self-help skills and social skills. Moreover, they have been extremely successful at helping to decrease maladaptive-problematic behaviors such as physical aggression, repetitive self-stimulation, and self-injurious behaviors.

B.F. Skinner’s analysis of verbal behavior (1957) suggests that language is behavior and can be thought using behavioral procedures (e.g. reinforcement). Arguably, one of the most important skills we all first naturally learn is asking for things we want. This produces an immediate and specific response. That is, we get what we want! Many individuals with developmental disabilities have learned problematic ways to request (mand) for the things they want. These include physical aggression, self-stimulatory behavior, and self-injurious behavior. For instance, an individual may collapse on the floor, kicking and screaming when his/her favorite television show is turned off. A concerned caregiver will typically turn the television back on, console the individual or find another way to make the individual happy and calm. In this way, the caregiver has reinforced the problematic request (the mand) of the individual to restart the television show.

Research from thirty years ago suggested replacing problematic ways of requesting with more appropriate forms. This is known as Functional Communication Training (Carr & Durand, 1985) or mand training. This involves teaching individuals an appropriate alternative way to request for the things they want instead of the problematic ones. The form of the request can be utilized through vocal, signs, picture exchange system (such as PECS), or any augmentative device (vocal output systems).

In August 2014, the Services for the UnderServed in New York was awarded a federal Balanced Incentive Program Innovation Fund grant (BIP) to transfer the technology of ABA generally used with children to adults with developmental disabilities. Services for the UnderServed (SUS) is a nonprofit human services agency who serves individuals and families with a wide range of challenges; mental illness, intellectual/developmental disabilities, HIV/AIDS and veterans compound by histories of homelessness, substance abuse, poverty and unemployment.

The BIP grant is looking to transition individuals over the age of 21 in the borough of Brooklyn from institutional care.

From Crisis to Competence - ABA Used to Improve Communication Skills in Developmental Center

By Vivian Attanasio, BCBA, James O’Brien, BCBA, and Amy Bukzspan, BCBA
Services for the UnderServed Inc.

A

After the behavior technician engaged Stephen with the balloon for a few minutes, the behavior technician held the balloon. Stephen then said, “Balloon” on his own without prompting to gain access to the balloon and continue the social interaction with the behavior technician.

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Autism and Safety: It’s Unpredictable

By Jill F. Harris, PhD and Adrienne P. Robertiello
Children’s Specialized Hospital

While safety is important to everyone, it is a major concern among many people with autism spectrum disorder (ASD) as the complex communication, social, sensory and behavioral challenges associated with ASD may place people with this disorder at increased risk of injury or death. Indeed, research indicates that nearly half of children with ASD have eloped from a safe place with 26% having gone missing long enough to cause concern and be in danger of drowning or being injured by a vehicle. Yet, only half of parents of children with ASD report receiving guidance on preventing or addressing elopement behaviors (Anderson, Law, Daniels, et al., 2012). While the disorder is felt to not affect life expectancy, Danish researchers found that the ASD mortality rate may be twice as high as the general population (Mouridsen, Bronnum-Hansen, Rich, et al., 2008). Shavelle and colleagues (2001) found that accidents from insufficient supervision and drowning may contribute to elevated death rates among people with ASD. People with ASD may also experience other safety concerns such as increased risk of victimization due to bullying or harassment (Carter, 2009), sexual abuse (Sullivan & Knutson, 2000), or injury resulting from restraint or seclusion (Kutz, 2009).

Some common reasons for ASD-related emergency calls include events where the person has escaped from a caregiver, home or school; wandered to an unsafe place including attempting to enter nearby buildings; caregiver actions being misinterpreted; a person with unusual behavior being interpreted as suspicious, threatening or on drugs; rearranging store materials being interpreted as shoplifting; or when a person displays escalating behaviors and the caller is unaware of the autism (Debbaut & Legac, 2004). It should be noted that accuracy of statistics regarding safety issues and people with ASD may be in question since data recorded in emergencies may not include whether a perpetrator or victim has a disability such as ASD. Clinical use of the medical diagnostic code for wandering (V40.31) is one way to promote appropriate treatment planning and accuracy of tracking data.

Characteristics of ASD and Relationship to Safety

ASD may impact safety in a myriad of ways. Social communication deficits associated with the disorder may affect the ability of the person to effectively communicate concerns or understand verbal directions. Nonverbal communication including body language and tone may be misunderstood. For example, commands such as “stop” or “look out” may be misinterpreted, resulting in reduced response to community officials and emergency warnings. Social challenges may impact recognition of harassment or bullying and effective handling of such situations. Restricted interests and repetitive behaviors may also place a person with ASD at increased risk. For example, a person with ASD may be drawn to water or fire. The person may also consider a place or object comforting and not recognize that their “safe place” has become hazardous. Insistence on sameness may lead to meltdowns and increase in physical aggression or self-injurious behaviors during transitions between tasks or when routines are changed. Sensory issues may lead a person with ASD to be hyper-sensitive to temperature, pain, sound, light, texture, or crowds. This may result in challenging behavior as an attempt to avoid the stimuli. Hypo-sensitivity may result in seeking out stimuli as demonstrated by reduced sensation of pain, recognition of injury or ability to gauge rough from gentle touch. Co-morbid conditions that affect some people with ASD may further impact on safety. For example, cognitive impairment may affect ability to recognize safety risks and to follow directions. Motor difficulties may reduce balance and coordination, placing the person at increased risk of injury. Feeding issues may affect some people with ASD who may have difficulty remaining seated during travel. Features often associated with emergency situations such as alarms, flashing lights, crowds, and commotion may trigger increased agitation among people with ASD. First responders may misconstrue features in the home environment such as scars from self-injurious behavior, extra security on windows and doors, and less home decorations, which may or may not indicate abuse or neglect.

In order to address this major concern, it is important that people with ASD, their families, and service providers including first responders (police, fire, emergency medical technicians, paramedics), daycare, school, therapy and healthcare workers, child protection workers, and emergency shelter staff receive training to improve safety awareness in order to prepare, prevent, and more effectively intervene. With funding from Kohl’s Cares, Adrienne Robertiello, Autism Outreach Educator at Children’s Specialized Hospital, has created training curriculum and materials to address this need. Sample curriculum for the person with ASD may include but not be limited to:

• Circles of intimacy and body boundaries
• Recognizing community partners – Who can help and how to interact
• Recognizing, preventing, and responding to bullying
• How not to bully others
• What to do if I am harassed – How not to harass others
• Sexual activity, sexual expression, and protection from abuse
• Safety workers and their roles
• Sample curriculum for first responders and other service providers may include but not be limited to:
  • Overview of autism spectrum disorder
  • Personal, social, and societal aspects; Effects on daily life through the lifespan
  • Dangerous situations; Reduced fear of danger; Unpredictable responses/behaviors
  • Personal safety; Vulnerability; Challenges/adaptive methods of reporting danger/incident
  • Community and citizen safety: Water dangers; Appropriateness of communication/behaviors; Potential inability to seek help
  • Vehicular and travel safety: Personal vehicles; pupil transportation; mass transportation; traffic control devices
  • Law enforcement and criminal justice system: Minimizing confrontational encounters; Person with ASD as victim; Perpetrators with ASD; Competence and consent; Strategies to reduce incidents; Judicial system
  • Neglect, abuse, bullying, exploitation: Increased risk; Misconstrued environments and behaviors; Victims/perpetrators; Red flags; Assessment and response
  • Search and Rescue: Common challenges; Modified responses; Prevention; identification and response options (personal tracking devices, medical alerts, etc.)

While some emergency responders have adopted online training on ASD and safety, interactive workshops may be more comprehensive and effective as they provide opportunities for direct interaction and focus on specific concerns. Recommended specific strategies for first responders include:

• Ask basic closed-ended information questions.
• Avoid unnecessary touching or restraint.
• For crisis de-escalation, approach in quiet non-threatening manner, calm tone, reduce gestures and reduce touch; reduce sensory challenges; provide familiar objects; watch personal space; simplify language and be concrete; don’t insist on eye contact or verbal response; and recognize that self-stimulatory behaviors may be calming.
• During Search & Rescue, be aware of need to use forced entry due to extra locks; may be hiding in personal “safe place;” search areas with water first, and expand search parameters and don’t ignore dangerous places.
• Teach 911 dispatchers to recognize characteristics of ASD; use simple concrete

see Safety on page 41
Autism Resources at Your Fingertips!

The Autism Community Hub is the best source for resources on Autism Spectrum Disorders (ASD) for individuals and the general community.

Presented by Children’s Specialized Hospital and Kohl’s Autism Awareness, The Community Hub is the only comprehensive source providing reliable information on Autism in your community. Together, we can build stronger, more inclusive communities.

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KohlsAutismAwareness

This community service is made possible by the Kohl’s Autism Awareness program at Children’s Specialized Hospital
Awake Challenged, Punctually Challenged, and Underground Thursday Challenged

By Jennifer Kolarik, BS
Lead Career Coordinator
CIP Brevard

One of the biggest hurdles that adolescents and young adults on the ASD or LD Spectrum face is having a reversed sleep schedule where they stay awake at night (often playing video games or surfing the internet) and sleep during the day. This is especially so if students are living independently for the first time. No one is around to tell them to “go to bed.”

This impacts their work lives whether it’s volunteering, interning, or doing a paid job. Even if they make it to work on time, they may lack energy and even nod off because they are tired and/or sleep deprived.

Meet Melanie. Melanie was very bright and enthusiastic about her internship working with animals. Soon after she started her internship, her supervisor noticed that when Melanie sat down during slow times, she would close her eyes for what she thought was a moment and then fall fast asleep. It was my job to figure out how to best help her stay awake at work.

I came up with some strategies so Melanie and others like her, who were continually “awake challenged,” could do their jobs without falling asleep on the job or nodding off.

Suggested Strategies for “Awake Challenged” Students

Help your “awake challenged” students realistically decide how many hours of sleep each one will need each night and what time he/she needs to wake up by in order to get ready and “make it to work on time.” Based on that information, decide (together) on a good bedtime and get a promise (in writing if you can) that he or she will try to stick to it.

Students might ask a roommate or their roommates to support the fact that he or she will be going to bed at this time each night. Students like Melanie can also use a simple spreadsheet and record how many hours per night they sleep, as well as the time they went to bed and got up in the morning. As patterns develop you can further aid students with positive reinforcement or extra help and encouragement.

Encourage students to develop a wind-down routine. A hot drink, reading for half an hour and then turning off the light, having a hot shower or relaxing bath, or doing some gentle yoga or stretching right before bed will set the scene for a solid night’s sleep.

Ask the student to set an alarm or multiple alarms to help her/him remember when it is time to go to bed and time wake up.

Have the “awake challenged” young person bring healthy snacks and drinks to work each day and take occasional breaks so he/she can eat, hydrate, and boost energy levels. The student should not develop an overdependence on caffeine or energy drinks to keep awake. Instead encourage him/her to keep a food or energy journal to learn more about his or her daily patterns.

Most of my students have “Executive Function” challenges that impact them on the job. Ken, one of my favorite students, was severely “punctually challenged” due to “EF” issues.

Ken had his Associate’s degree and several certifications. He was very bright and had a great sense of humor. Ken often showed up at my office 15 minutes before he was supposed to be at work and let me know he didn’t have enough gas to get to his internship. It turns out he liked to drive around over the weekend and then realized his car was on empty just as he was about to leave for work on Monday morning.

To make matters worse, Ken did not carry his debit card with him and would have to go to the nearest bank to withdraw money from his checking account to put gas in his car. He knew by that point that he would be late for work. Ken would then need to contact his internship supervisor again and explain that he was going to be late.

I helped Ken by working on his organizational and planning skills. We made evening and morning checklists to address everything that needed to be done (including checking the gas tank the night before) so that he allowed time to buy gas in the morning, if he needed it. We put this in the form of a reproducible checklist that he would fill out each night.

We decided that each night he needed to: Check the car for gas, lay out work clothes, shower and shave, make a lunch, charge his cell phone, and make sure that his keys and backpack were by the front door.

It was a long slow process until Ken finally saw this routine’s value. By preparing the night before, he could identify if he needed to plan extra time in the morning to address any glitches or things that would make him late for work.

Ken is an example of a student who had the education and experience to succeed but didn’t have the “EF” skills in place to make sure he had gas or plan ahead for getting gas.

Repetition and routine turned out to be the key in helping Ken. Over time with repetition, repetition, repetition, and occasional nagging from me, this young man made wonderful strides in his punctuality.

Ken now has worked nearly full-time for the same company for a number of years.

“Underground Thursday” Challenged

What is “Underground Thursday” do you ask? It could really fall on any day of the week - but for Zach, his “underground” day would always be a Thursday. He used up so much effort and energy to get through his Monday to Wednesday work days that he would call in “sick” almost every Thursday for the rest of his time with us.

It was as predictable as the tides.

Zach and I had many one-on-one chats about this. I finally determined that Zach lacked the key skill of “perseverance” for the times when he was feeling overwhelmed.
What to Expect When Expecting a Functional Behavior Assessment

By Melissa L. Olive, PhD, BCBA-D, Patrick N. O’Leary, MA, BCBA, and Abigail V. Holt, MA, BCBA
Applied Behavioral Strategies, LLC

In 1994, the Individuals with Disabilities Education Act (IDEA) mandated the use of Functional Behavior Assessment (FBA) under certain conditions for special education students. Today, FBA is used to set the foundation for treatment of challenging behaviors in schools, homes, group homes for adults with disabilities, and even in-patient hospitals for the treatment of severe challenging behavior.

Over thirty years ago, scientists first made connections between challenging behavior and consequences associated with behaviors. For example, Horner and Budd taught communication to a participant and noted that challenging behavior decreased when communication increased (Horner & Budd, 1985). Iwata and colleagues (Iwata, et al., 1982/1994) demonstrated they could cause challenging behavior to increase or decrease simply by changing consequences to targeted behaviors. As a result of these initial investigations, researchers later began designing treatments for challenging behavior based on its function.

Specifically, the function or the payoff of the behavior is maintained by the individual gaining or avoiding consequences. See Table 1 on page 37 for a list of possible consequences and examples.

In order to determine the function of behavior or why behavior is occurring, assessors must complete a number of steps. These include indirect assessments, direct assessments, and functional analysis. We will describe each step with more detail. This paper will not focus on how to do an FBA but rather what ingredients to look for when an FBA is being completed.

Indirect Assessments

Indirect assessment, the first step in the FBA process, is designed to drive future assessment steps (O’Neill et al., 1997). Information gathered during these initial assessments help the evaluator identify specific areas that should be of further focus. These assessments do not typically involve the client themselves, but rather include interviews and record reviews about the client, her history, and potential settings and circumstances that are most problematic.

At the onset of the indirect assessment, evaluators will identify and define targeted behaviors using objective, observable, and measurable descriptions (Alberto & Troutman, 2012). Evaluators will also review related records and documents to determine how information about the client’s history...
Contributing Factors of Aggression and Self-injury in Autism

By Jenny E. La Barbera, PsyD, BCBA-D
Co-Director
NY Behavior Analysis and Psychological Services

Although self-injury and aggression are not included in the diagnostic criteria for a diagnosis of autism, they are often associated with the diagnosis (American Psychiatric Association, 2013). These symptoms are often the most problematic and concerning symptoms that caregivers face when seeking treatment for their loved ones. Best practices indicate that the first course of action is for the person to receive a thorough assessment that not only assesses specific times and activities in which the behaviors may be more severe, but the function or purpose of the behavior itself. Information from multiple respondents is typically necessary to obtain adequate information regarding the nature of the individual’s difficulties. This assessment process is called a functional behavior assessment (FBA).

Once a functional behavior assessment is conducted, the results of the assessment are then used to develop a treatment plan that is individualized and specifically addresses the method in which interventions and modifications will be implemented to assist the individual in obtaining his or her needs with a more acceptable form of behavior. A second assessment option is a functional analysis (FA), which is a type of functional behavior assessment. This type of assessment is considered to be the standard in assessing problem behaviors (Hanley, Iwata, & McCord, 2003). A functional analysis is a standardized procedure, conducted in a controlled setting, in which the presentation and removal of stimuli is systematically conducted for the purpose of identifying which stimuli results in the highest proportion of problem behaviors.

Once the stimuli can be identified the function of the problem behavior can be determined and a behavior intervention plan can be developed.

These methods are highly effective in identifying the function of an individual’s self-injurious and aggressive behaviors, however, when the results are indicative of a behavior that serves multiple functions or a sensory function, treatment options may become more complicated. In these situations, an individual’s self-injurious behaviors may initially serve the function of obtaining access to a desired object or activity, however, if the object or activity at that moment is not of the quality or quantity that the individual desires, he may resort to engaging in self-injury to obtain a reaction from another individual. Hence, self-injury serves multiple functions and although initially it was the result of a desire to obtain access to an item or activity, it may have transformed into fulfilling a desire to obtain attention.

Occurrences such as these become even more complicated when an internal drive (sensory function) is responsible for the behavior. It is often difficult to identify the motivating drive of sensory maintained behavior and offer a competing response. Confusion and doubt of initial hypotheses are common responses to behaviors such as these when behavior intervention plans do not produce the desired effect on the target behavior.

When these situations occur, there are multiple options for conducting an ongoing assessment of the individual’s needs and behaviors and examining extraneous variables that may be at play. Furthermore, additional evidenced-based treatments geared towards reducing other interfering symptoms could prove to be beneficial and should be sought out.

When an individual is engaged in what has been determined to be a sensory maintained behavior or a behavior that appears to serve multiple functions and has not been successfully addressed, it is critical to rule out other variables that are likely complicating the problem. Sleep and mood disturbances, side effects of medication, diet, and medical problems can result in physical or mental challenges.

For example, Johnson, Giannotti, and Cortesi (2009) found that 40% to 80% of children with autism spectrum disorders (ASD) experienced insomnia. Furthermore, anxiety, autism symptom severity, gastrointestinal problems, and sensory sensitivities were found to be associated with sleep disturbance in individuals with autism spectrum disorders (Hollway, Aman, & Butter, 2013).

With regard to medication, side effects of commonly prescribed medications for aggression and self-injury, such as Aripiprazole (Otsuka Pharmaceutical Co., Ltd., see Self-injury on page 43).
Managing Challenging Behavior Due to Autism During Emergencies: Advice for First Responders

By Vanessa Tucker, PhD, BCBA-D
Assistant Professor of Special Education
Pacific Lutheran University

First responders are by definition available and on call twenty-four hours a day to provide emergency services ranging from medical to safety and protection needs. In most cases these encounters are brief, intense and are paired with stressful episodes including medical emergency, fire or other life threats. These encounters must be managed well and require expert intervention on the part of first responders to quickly provide assistance. These encounters intensify when a child or adult with Autism (ASD) is involved. First responders, including police, fire and Emergency Medical Services (EMS) can benefit from guidance regarding the needs of this population.

The literature regarding this topic is sparse at best. A review indicates that first responders need more training in this topic as well as other disabilities (Good, 2011; White, 2012). A child or adult diagnosed with ASD is seven times more likely to need emergency medical services as compared with a typically developing comparison group (McDermont, Zhou & Mann 2008). Mims (2008) classifies this population as “high risk” in terms of medical and emergency care needs. The literature highlights higher risk in terms of such emergency situations as elopement, wandering (Law & Anderson, 2011) and drowning (Myers, 2012). Greater research into techniques that positively support those with ASD during emergencies is needed for training purposes and effective intervention (Kupietz, ND).

ASD is defined by social communication impairments and the presence of restricted and repetitive patterns of behavior (American Psychiatric Association, 2013) paired with atypical responses to sensory stimuli. A person with this diagnosis may react very differently to the stimulation and demands of an emergency situation. These issues set the stage for challenging behaviors. A person with ASD may have limited communication skills impacting their ability to respond to commands, provide information about their internal states or resulting in behaviors that increase risk such as running or aggression to self and others. Sensory stimuli in the form of lights and sirens may be misinterpreted by the person as threatening or aversive. The presence of strangers dressed in unfamiliar clothing with equipment that invades personal space can be a trigger for behavior. Tactile defensiveness (dislike of being touched or touching things) can create tremendous barriers to a physical exam or to the use of equipment designed to obtain vital signs.

Behaviors can create tremendous risk to all involved and should be addressed by both through prevention and response tactics. Prevention is the first line of defense followed by using strategies that meet the unique needs associated with ASD. Resources will be provided for more specific supports, training and information available for first responders and families.

Prevention Tactics

The first priority is to provide high quality training in the basic aspects of ASD to all first responders during initial ongoing training. This content needs to highlight the unique learning and behavioral needs of those with ASDs including specific tactics that can be used to quickly interpret and respond to behaviors. Training should emphasize the incredible variability of this population as well as the need for partnership with families and caregivers. Training should focus on the core impairment areas of ASDs as they pertain to the demands of an emergency situation. First responders need to understand that children and adults with ASD may not respond to commands, may struggle with the sensory aspects of the situation, will not be good reporters of symptoms, may not comply with medical examinations and might run away from supports. They also need to be prepared for aggression and to interpret this as a probable communication breakdown rather than an intentional act.

Familiarity with EMS agencies is a viable prevention tool. For example, a child with ASD may be prone to running/eloping from her home. This child may not react in a typical manner to interactions with

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Should Parents Tell Their Children They Have Asperger’s?

By Shuli Sandler, PsyD
Spectrum Services
and Michael Rosenthal, PhD
Child Mind Institute

A diagnosis of Asperger’s can be an overwhelming experience for parents and children. Some parents may feel an initial sense of relief at finally finding an answer to their child’s difficulties; at the same time, it also can foreshadow a long and trying road ahead full of therapies, academic difficulties, and social skill building. As clinicians who often evaluate and treat children with Asperger’s, one of the major questions parents frequently ask us is whether they should share the information about the diagnosis with their child. This is a complicated decision that deserves careful consideration.

Children who have been given an explanation and understanding of the label of Asperger’s may feel a sense of belonging after realizing that there are lots of children out there just like them. Rather than feeling stigmatized or defective, they may experience a sense of empowerment in having a community of like-minded children they may find at school, camp, or in various social skills groups or other treatment settings. It can offer inroads for forging connections with others who share similar challenges. Children may use their Asperger’s label as a potential cornerstone for building self-advocacy skills, and it can help facilitate a sense of control in their lives. For some, Asperger’s may be seen less as a disorder and more as a positive and fundamental part of their self-concept.

On the other hand, learning about their diagnosis can also feel oppressive. Children may feel a sense of shame or embarrassment. To some, the word Asperger’s can feel like a disease or a term describing what is “wrong with them.” We have seen children who were exposed to the word Asperger’s when they were diagnosed but avoid saying it at all costs, because of the sense of impairment it represents. In this regard, it can feel like an albatross. They may see Asperger’s as a challenge that holds them back from their potential. Disclosing the diagnosis can present other issues. For example, because children with Asperger’s often have difficulties with the subtle nuances of communication, it may be hard for them to learn when it is appropriate or inappropriate to share the information with others. Furthermore, there is misunderstanding about the diagnosis at a societal level and all too often it is framed in terms of its deficiencies rather than its differences.

We think this is an extremely important yet complicated issue, and one that needs to be dealt with carefully and sensitively to maximize the child’s adjustment to what lies ahead.

This article presents some ideas for consideration, as well as guidelines for parents struggling with this very issue to help them make the right decision for their child.

Psychiatric Versus Medical

For better or for worse, our society feels differently about psychiatric diagnoses and medical diagnoses. Interestingly, many parents feel less conflicted about the prospect of telling their child that they have a pervasive medical condition such as diabetes...
Challenging, disruptive, and potentially dangerous behaviors frequently are a concern for caregivers and family members of individuals with Autism Spectrum Disorders (ASD). In recent years, the methodology of Functional Behavior Assessment (FBA) has come to be recognized as one of the most effective means of addressing these behaviors (Carr, 1994). The technology of this approach has been developed through the efforts of practitioners working under the Positive Behavior Supports (PBS) model, building on research that has grown out of the scientific endeavors of Applied Behavior Analysis (ABA).

What this approach has come to show is that even behaviors that look the same to a casual observer (physical aggression, self-injury, destruction of objects) may actually be quite different depending on who performs the behavior, what setting it occurs in, and a variety of other conditions or circumstances. For example, self-injury exhibited by one person might be motivated by escape from a task demand, while another person might be motivated by an effort to alleviate pain or discomfort. Through systematic analysis, behavioral scientists have been able to identify circumstantial factors that help in understanding what influences the motivation and/or meaning of the behavior for the person the individual (Wacker et al., 1990).

The value of this approach is that researchers have come to recognize that effective intervention strategies need to be individualized and based on the function. This involves adapting behavior plans based on recognition of the identified needs and using that insight, first to focus on meeting those needs in order to prevent problem behavior. Once this has been accomplished, efforts are directed to teaching and supporting the development of more positive alternative behaviors that meet the same needs. In this way, behavior specialists have the opportunity to individualize the development of behavior intervention and support plans, much in the way that clinicians individualize the treatment of mental health disorders based on the feelings and past experience of the patient.

Since most individuals who engage in problem behavior either don’t know or can’t communicate why they engage in the behavior, it is necessary for support providers to assess the behavior in order to determine the function of the behavior. This is true both for individuals with strong cognitive skills, as well as those who have some degree of intellectual disability, because most of us are not very good observers of ourselves. In order to do this objectively and effectively, researchers have demonstrated that in most cases, the function of a behavior can be discovered by identifying the typical antecedents that immediately precede the behavior, and the consequences that typically follow these the behavior (Carr, 1994). The circumstances that precede the behavior are considered to serve as triggers for the behavior, while the conditions that follow the behavior have come to be understood as rewarding, or in

see Setting Events on page 39
Why Emotional Literacy Is So Important

By Jaime Fleckner Black, PsyD
Spectrum Services

Social and emotional literacy develop over time and need to be nurtured just like any other skill such as math or riding a bike. Unlike math or bike-riding, however, the teaching of emotional literacy is often overlooked. It has been referred to as the “missing piece” of education despite its profound impact on children’s well-being. Emotionally competent individuals are able to communicate effectively, empathize, problem solve, and resolve conflict. Studies have shown that kids who develop these skills are more likely to do well at work as adults, have longer-lasting marriages, and have lower rates of anxiety and depression. Studies also suggest that emotionally-literate characteristics like self-restraint, persistence, and self-awareness are better predictors of life outcomes than common academic measures. In addition, these children tend to do better in school due to their ability to work well with others, control impulses, and appropriately channel emotions.

What Is Being Done In Schools?

Many schools are embracing the research and implementing social-emotional learning (S.E.L) programs. Mark Brackett, senior research scientist at Yale University and former bullying victim, developed one such program called Ruler. Ruler’s goal is to develop children’s capacity for self-reflection and critical thinking. Students and teachers use concepts such as “mood meters” to help gauge emotions. Teachers encourage children to develop coping mechanisms, such as using self-talk or taking a walk when upset. S.E.L. has received more attention in the past few years due to concerns about bullying, violence, and suicide, but these programs are certainly not the norm at this time.

Social Skills Groups
Teach More than Manners

Certain children, particularly those with autism, Aspergers, and social phobia require more guidance and support in developing social and emotional competencies. Social skills deficits are a hallmark of these conditions and they tend to persist into adulthood due to a dearth of interpersonal experiences. How can a child learn conversation skills, conflict negotiation, and perspective taking, for example, if she has no one to practice with? The right kind of social skills group could help a child develop these kinds of skills, but not all social skills groups are created equally.

Effective groups:
• Promote skill generalization to the outside world and often take place on the playground or in other real-world locations where real-life problems tend to unfold
• Stimulate social motivation
• Reinforce appropriate social responding
• Increase the understanding of nonverbal communication

The best programs help children become better observers of themselves and others. They guide them in appropriate ways of expressing themselves. Parents of children in school groups should request specific plans and ask about generalization strategies. Parents can reinforce practiced skills at home and with play-dates.

What Parents Can Do with Children

There are also groups available for adults who struggle socially and emotionally. The goal is to increase social awareness and for members to develop a better understanding of the world around them. Social skills groups can help adults navigate the interpersonal complexities of the workplace, establish platonic and romantic relationships, and understand social norms in different situations.

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Jaime Fleckner Black, PsyD
Common Mealtime Concerns in Individuals with ASD

By Brandon Nichols, MSEd, BCBA, LBA and Michelle Myers, BA, BCaBA
The Tom Golisano Center for Autism at Springbrook

Feeding problems in children with ASD may include selective eating or “picky eaters,” rapid eating (child takes numerous bites within a short period of time), inappropriate mealtime behaviors (e.g., tantrums), and inadequate intake/food consumption. These behaviors can lead to numerous health (e.g., aspiration, choking), developmental, and social concerns for children. Feeding problems occur more frequently in children with ASD than in typically developing children (Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998). Studies have shown that 72% of children with ASD eat a “narrow” variety of foods, 31% display sensitivity to various food textures, and 53% of children with ASD have some type of nutrient deficiency related to feeding patterns (Schreck, Williams, & Smith, 2004; Field, Garland, & Williams, 2003; Cornish, 1998). Additionally feeding issues can be extremely stressful for both the child and the family. Therefore, the successful treatment of feeding problems can have significant impacts such as improved health, improved quality of life for both children and families, decreased mental health problems in families, and reduced risk of long-term eating problems (Piazza & Carroll-Hernandez, 2004).

Feeding behaviors in children with ASD may occur for numerous reasons and are specific to each individual. These include medical, sensory, and behavioral causes. If a child is having medical problems such as constipation, stomach aches, or toothaches then this may result in a child refusing to eat. Similarly, many children with ASD have difficulties with sensory processing and this can make eating certain foods a challenge (Baxter, Bellando, Pulliam, Watson, Powell, Srivorakiat, & Bing, 2014). This can include but is not limited to certain textures and colors (e.g. child only eats beige food or refuses to eat any green foods; a child may not eat crunchy or soft foods). Numerous researchers have reported that the inadvertent reinforcement of inappropriate mealtime behaviors frequently contributes to the onset and maintenance of feeding problems (Piazza et al., 2003). For example, if a caregiver removes non-preferred food items when a child refuses to eat or consumes the correct amount of food, the child may be more likely to display inappropriate behaviors during meals to avoid eating less preferred food (Bachmeyer, 2009). Similarly, if a caregiver provides access to preferred food items when a child refuses to eat less desirable food items, the child may be more likely to refuse in the future in order to gain access to the preferred foods.

Knowing the signs and symptoms of feeding issues for children with ASD can be challenging. Many caregivers are unfamiliar with common symptoms and struggle with knowing when to get help. Some of the most common signs and symptoms of feeding problems include:

- If there are weight changes (loss or gain)
- If a child only eats a limited number of food items or only certain textured food (e.g., only soft foods)
- If mealtime behaviors are causing stress
- If a child complains or shows signs of pain (e.g., constipation, tooth pain, food allergy/rash)

Even when a caregiver observes these signs or symptoms, identifying what to seeMealtime on page 45
Is the Label or the Person the Focus?

By Patricia Fratangelo
Executive Director
Opportunities and Choices in Life

People who are diagnosed with Autism are often seen first for the diagnosis that they have. Many times programs are developed by organizations that have expertise with the labeled disability. People with autism are often accepted into programs based on this diagnosis. This is not unlike many other disabling conditions, hence the many programs that are available for elders, people with developmental disabilities, people with mental health diagnosis, people with autism, the list goes on. As the saying goes, “birds of a feather flock together.”

Although these programs are not wrong or do not mean to harm, it is just the nature of the program that may not meet the needs of each person involved. When you truly begin to know a person and see them for the unique individual that they are, you may find that the predetermined program may not be the best fit.

To bring this to point, while sitting at a meeting with many Commissioners of our state, a conversation began about the need for proper assessments. Of course every department in each state feels that they are properly assessing their clientele and has the proper programs to meet their needs. But the real question is, are the assessments for a program, or are the assessments really weighing the needs of the person being assessed?

When this question was brought up, it struck a nerve. The reaction was, if we really evaluated what each person needed, they may not fit into the “silos” we have developed.

This is exactly the reason why predetermined programs do not work for all people. Could this not be the cause of why many behavioral problems then begin to rise?

Listening to each person with autism has taught us a lot about how a system can best support each individual. As with each of us, every person with autism has different aspirations, skill sets, histories, communication needs, and goals that they wish to work on and move towards. It is with taking the time to try to understand this, that one can pick up on what is sometimes referred to as authentically important in that person’s life.

I will introduce you to two men who are each diagnosed with Autism. Each of their names has been changed. Each person and their story is very different from the other. Their success is in the planning that occurred to get them what was needed, not just what was available. One of the men was previously in a situation that did not work and caused great angst. The other was asking to continue life with a normal lifestyle. The success is with each individual’s journey. The downfall would be if these men had been grouped together.

Steve Learns to Stand Up for Himself

Steve always lived a sheltered life with family who adored him and always took care of him. As Steve got a bit older and moved into being an adult, he began to struggle with standing up for what he felt was right, and at the time it was right for him. After a lot of planning, Steve moved into his own apartment with a combination of paid and unpaid support to equate a 24 hour service.

At first mom was extremely involved, helping to decorate or stopping in unexpectedly. But as Steve became more secure in his lifestyle, he began to hold a line. He would move things that mom brought in and put them where he wanted, saying it was his home. When she walked in unexpectedly, he learned to tell her to knock first and remove her shoes, as this was his home. If anyone tried to put his clothes away he would tell them No! This was important for him to do.

As Steve began to know more people at his housing complex, he began to get involved in community BBQ’s and would take his turn to host one. He would get help from his housemate and his staff to invite people to come over. If mom showed up he would make it clear that this was his party not hers.

Steve went through a tough and embarrassing experience at the State Fair over 20 years ago that left an obvious scar on him that drew negative attention and forced his family to leave. As he would drive by with staff he would say, “I want to go to the fair…I want to go…I can’t go…I can’t go…”. Year after year he would say this and every year he would say, “Maybe next year.” After about five years, Steve asked if he and the staff could go together. The staff told him yes and that they could leave whenever he wanted. The day arrived and without anxiety Steve went to the fair and had a great time. After being there for about two hours Steve said, “I need to go.” They quietly left the fair and went back to this apartment. On the way home, Steve shared the following:

“Sometimes it takes me more time…sometimes I can’t just do something the whole day. I can get filled up like a pool of water – but when the pool is full, the water just runs to the ground. When I get filled

see Focus on page 40
Positive Behavioral Interventions and Supports: An Effective Approach for Schools to Prevent and Manage Challenging Behaviors

By Christine Alter, LCSW
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Positive Behavioral Interventions and Supports (PBIS) was developed in the 1980s as a data based behavioral intervention for students with behavioral disorders (BD). Positive Behavioral Interventions and Supports (PBIS) is an evidenced based approach which incorporates behavioral and academic supports within a comprehensive framework. The PBIS philosophy gained support in the 1990s, with the reauthorization of the Individuals with Disabilities Act (IDEA) of 1997. A subsequent grant and its funded research indicated that PBIS should focus on prevention, data driven decisions, school-wide programming, and direct social skill teaching, all within a collaborative team-based approach (Sugai and Simonsen, 2012).

Positive Behavioral Interventions and Supports is a great tool to help schools prevent and manage challenging behaviors, as well as teach and reinforce school wide expected behaviors. The PBIS process emphasizes consistency and continuity and therefore would work well in addressing the needs of students on the spectrum who learn best with routine and repetition. Under the PBIS framework, schools create their own unique set of expectations which they define with explicit and concrete behaviors. Staff and students alike are taught the school specific “code of conduct” which is usually developed around a school mascot or theme. Student behavior is evaluated based upon the school’s clear expectations. For example, “Responsibility” is a common value for PBIS schools. It might be defined by arriving to school and/or class on time.

Staff is trained to use the code of conduct to acknowledge or address both appropriate and inappropriate behaviors. Schools develop clear protocol for recognizing and rewarding those students who meet school expectations. They also intervene when students are not meeting expectations. Protocol usually includes reviewing the school value and explaining how to demonstrate the value with behavior. If required, more specific skill development can be offered. More serious or repetitive violations become disciplinary matters which are handled by administration’s predetermined data-based procedure.

According to the DSM-V, Autism Spectrum Disorder (ASD) has two key characteristics; deficits in social communication and restricted or repetitive behaviors and interests. Students with ASD often experience difficulties with; social reciprocity, interpreting nonverbal social cues and developing social relationships. (www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria). PBIS focuses on both academic and social skill building. This school-wide behavioral framework clarifies expected behaviors and uses re-teaching and reinforcement to encourage development of appropriate behaviors.

PBIS schools support students with a three-tier behavioral approach. The Positive Behavioral Interventions Supports framework incorporates more intensive supports for those individuals and groups of individuals who need it. The multi-tiered approach gives schools the flexibility to handle all types of behaviors, including the more challenging ones.

Universal expectations or tier one supports set school wide guidelines for the behavior of all students. Students (and staff) are explicitly taught the expected behaviors. Interventions focus on teaching students to understand the school’s social, behavioral and academic rules. Students are held accountable to this “code of conduct”. By incorporating a PBIS approach schools are able to explicitly explain their culture. Students are better able to understand and navigate school expectations. Students who meet or exceed school expectations receive reinforcement or rewards.

Tier-two and tier-three interventions offer additional assistance to individual(s) who are exhibiting more challenging behaviors and might need extra attention or skill development to meet school requirements. Tier-two and tier-three supports help schools meet the needs of students who require... see Effective Approach on page 40

YAI International Conference
May 4-7, in New York City

By The YAI Network

Autism will be a major focus at YAI’s 2015 International Conference, Living, Loving, Working & Learning in Intellectual and Developmental Disabilities, May 4-7, in New York City.

Over 200 presenters, from as far as Australia and Alaska, will provide attendees with techniques and strategies that can be effective with children, adolescents and adults with autism and other developmental disabilities. YAI’s annual global gathering at The Hilton New York Midtown serves as a major forum for the exchange of ideas and information in the field.

“As we mark the 25th anniversary of the Americans with Disabilities Act in July, we should remember that many children with disabilities grew up under ADA and are living and working in the community today as adults,” said Matthew Sturiale, CEO of YAI. “But as our field continues to change, so has the definition of inclusion and quality of life. Children and adults on the autism spectrum, and their families deserve the same dignity, freedom of choice, and sense of belonging to a community as anyone else in society. We need to listen to the individuals we support to see what is important to them.”

Among some conference highlights are:

Living
Dr. Stephen Shore, Clinical Assistant Professor of Special Education, Adelphi University, New York (www.autismasperger.net/bio.htm), on the benefits of teaching individuals with ASD a music curriculum and how it can enhance social skills, communication, and other aspects of life.

Loving

Working
Anita Lesko, BSN, RN, MS, CRNA, of Flying High with Autism Foundation, Florida (www.bornwithaspergers.com).

see Conference on page 36
Growth Hormone Treatment Improves Social Impairments in Patients with Genetic Disorder Known to Cause Autism

By The Mount Sinai Hospital at The Mount Sinai School of Medicine

A

growth hormone can significantly improve the social impairment associated with autism spectrum disorder (ASD) in patients with a related genetic syndrome, according to a pilot study conducted at the Icahn School of Medicine at Mount Sinai and published today on PubMed, a public database of biomedical topics maintained by the National Institutes of Health (study originally published in the December 12 issue of the journal Molecular Autism).

The study results focus specifically on the use of insulin-like growth factor-1 (IGF-1) to treat Phelan-McDermid syndrome (PMS), a disorder caused by a deletion or mutation of the SHANK3 gene on chromosome 22. Along with facing developmental and language delays and motor skill deficits, most people with PMS also have autism spectrum disorder.

SHANK3 is a focus of research in the field because of its essential role in the function of synapses, the gaps between nerve cells that “decide” whether messages continue along nerve pathways as they regulate bodily processes. While Phelan-McDermid syndrome is a rare disorder, advanced genetic technology has revealed it to be a relatively common cause of ASD. “Ours is the first controlled trial of any treatment for Phelan-McDermid syndrome,” says Alexander Kolevzon, MD, Clinical Director of the Seaver Autism Center at the Icahn School of Medicine at Mount Sinai. “Because different genetic causes of ASD converge on common underlying chemical signaling pathways, the findings of this study may have implications for many forms of ASD.”

IGF-1 is a commercially available compound that promotes nerve cell survival, synaptic maturation and synaptic plasticity, the ability of synapses to strengthen or weaken over time, in response to increases or decreases in their activity. It is currently approved by the Food and Drug Administration for the treatment of short stature.

Researchers enrolled nine children aged 5-15 years who were diagnosed with Phelan-McDermid syndrome in a placebo-controlled, double-blind, cross-over design study. All participants were exposed to three months of treatment with IGF-1 and three months of placebo, in random order. Compared to placebo, the IGF-1 phase was associated with significant improvement in social withdrawal and restrictive behaviors as measured by the Aberrant Behavior Checklist and the Repetitive Behavior Scale, respectively, both standard behavior scales used to assess treatment effects in ASD.

Preclinical studies of SHANK3 deficient

see Hormone on page 27

The Changing World of OPWDD Services and Supports

By Peter Pierri

Executive Director

InterAgency Council of Developmental Disabilities Agencies, Inc.

or every parent who watches their child morph into a young adult right in front of their eyes, this transformation is filled with anticipation, uncertainty and limitless challenges. For the parent with a child on the autism spectrum these issues are magnified as they begin to explore the world of supports funded and regulated by New York State’s Office for People with Developmental Disabilities (OPWDD). Of course, many families receive some OPWDD services when their children are younger, often in the form of respite or after school programs. In fact, almost 25% of all people served by OPWDD are under the age of 22. However, by the time students reach 16 years of age, families need to begin planning for the days after graduation from school. Effective and thorough transition planning is absolutely crucial to help determine what supports the young adult will need to lead a productive and fulfilling life. Complicating this process is the current transformation of virtually every service offered by OPWDD, including day and residential supports, employment services, as well as those services offered through a self-determination approach. Some of these changes are driven by reforms of long-standing funding reimbursement formulas. However, much of OPWDD’s transformation is derived from initiatives on the part of the Federal government, whose effort is focused on ensuring that individuals with developmental disabilities are actively engaged in the full complement of available community experiences.

Employment Opportunities

Nationally, the rate of employment among individuals with developmental disabilities is extremely low and New York lags behind many other states. OPWDD submitted a plan to the Federal government focused on how they would improve this situation. The plan calls for the number of people in competitive employment to increase by at least 700 individuals annually. Competitive employment is defined as employment in an integrated setting, in the general workforce, where a person earns at least minimum wage. To achieve this goal, OPWDD is creating a new service called Pathway to Employment, which focuses on comprehensive career planning. It will provide assistance for participants to obtain or maintain competitive employment. This service is now becoming available and it engages a participant in identifying a career direction; provides instruction and training in pre-employment skills; and develops a plan for achieving competitive, integrated employment. Within 12 months, the outcome of this service is intended to be a determination of the participant’s stated career objective; a detailed career plan to guide individualized employment supports; and preparation for supported employment services and attainment of a job. Current reimbursement rates for OPWDD’s supported employment service are problematic as they are designed in such a manner that assumes a job coach will eventually fade from the job site and the individual will remain employed without on-site supports. We know that for many individuals on the autism spectrum, acquiring job skills is only part of the reason why support on the job is necessary. Often their communication deficits and/or behavioral challenges require long-term supports in order for them to retain their employment, and therefore, a job coach may be needed long-term to ensure long-term success for the individual. Fortunately, OPWDD’s proposal for revising the funding for supported employment is being designed to allow a job coach to remain in place as long as the individual needs that support.

OPWDD’s plan also calls for the closure of all sheltered workshops in 6 years, due to the fact they are segregated environments that do not afford the opportunity for typical interactive exposure with people without disabilities. New York’s sheltered workshops collectively serve almost 8,000 individuals. OPWDD anticipates 50% of these individuals will transition to some form of competitive employment within the next 6 years and OPWDD will be giving individuals, and their families, information regarding employment alternatives. Those that will not choose this path may have either medical or behavior-related issues that would create significant barriers

see OPWDD on page 30
Rumination: Past, Present, and Future

By Jennie England, MA, BCBA, and James T. Chok, PhD, BCBA-D

Melmark

Rumination is characterized by regurgitation of previously ingested food into the mouth, and re-chewing, re-swallowing or expelling that food (Chail, Camilleri, Williams, Litzinger, and Perrault, 2003). Although rumination is typically observed in infants and individuals with developmental disabilities, it does occur in adolescents, children, and adults with normal intelligence (Chail, Camilleri, Williams, Litzinger, and Perrault, 2003). It is estimated that an average of 6-10% of individuals with severe intellectual disability who are living in a residential treatment facility engage in rumination (Lang et al., 2011). There are several medical conditions/diagnoses that could result in ruminative behavior. These include gastro-esophageal reflux disease, upper gastrointestinal motility disorders (e.g., gastroparesis), and bulimia nervosa (Chail, Camilleri, Williams, Litzinger, and Perrault, 2003). The medical consequences of engaging in rumination over a prolonged period of time range from halitosis to malnutrition, dental erosion, and weight loss (Chail, Camilleri, Williams, Litzinger, and Perrault, 2003). In addition to medical complications, several social consequences of ruminative behavior have been identified. These include, but are not limited to, unkempt personal appearance and foul odor, which can result in social isolation and/or decrease in educational or vocational opportunities (Lang et al., 2011). Thus, it is important that behavioral treatments for ruminative behavior, in conjunction with medical interventions (when applicable), are evaluated.

Since Iwata et al.’s (1982/1994) seminal article on the importance of determining the function of behavior prior to treatment, the use of functional analysis has become a cornerstone assessment in the field of applied behavior analysis. Functional analysis results allow clinicians to determine what types of environmental conditions evoke challenging behavior and what consequences maintain it. Functional analyses have been conducted for behaviors such as aggression, self-injury, property destruction, and more recently food refusal and rumination. Although not within the scope of this article, the majority of functional analyses of rumination conducted have revealed that, in most cases, rumination is maintained by an automatic reinforcer (Lyons, Rue, Lusiselli, and DiGennaro, 2007; Wilder et al., 2009; Woods, Lusiselli, and Tomasson, 2013), meaning that often the reinforcer for ruminative behavior is produced by the behavior itself and is not socially mediated. However, the use of functional analysis to determine the functional reinforcer of ruminative behavior is limited and more research is needed in this area.

Several treatment options have been used to treat ruminative behavior, including punishment, differential reinforcement of alternative behavior, differential reinforcement of other behavior, the delivery of a competing item, and manipulation of meal variables. Positive punishment, which involves the presentation of an aversive stimulus following a response, and a subsequent reduction in behavior, has been effective at decreasing rumination. Sajwaj, Libet and Agra (1974) were able to eliminate rumination in an infant, by squirting unsweetened lemon juice into the infant’s mouth at the first sign of rumination. The elimination of rumination also resulted in increased weight gain, babbling, smiling, see Rumination on page 44

Jennie England, MA, BCBA
James T. Chok, PhD, BCBA-D
Understanding the Father Factor While Raising Children with ASD

Robert Naseef, PhD
Psychologist
Alternative Choices

Fathers of children with autism tend to be either very involved or withdrawn and virtually absent from interactions with professionals—with the majority seemingly uninvol ved. From this observation, many professionals assume that fathers do not wish to be involved. Is this really the case, or do men relate and need to be engaged somewhat differently?

Fathers are often poorly represented at IEP meetings, conferences, and support groups for parents of children with autism. Usually they are at home watching the children so that their partners can attend, or they are at work providing for their families. Men generally prefer to do things to help out as opposed to connecting by talking about the stresses and strains. Until relatively recently, the role of fathers in child development was largely ignored in the professional literature. While traditionally regarded as providers and protectors, fathers were not expected to be involved in day-to-day parenting, with the notable exception of discipline. In emphasizing the importance of mothers, researchers lost sight of the father in the family context. The word parent became synonymous with mother. This same trend applied to fathers of children with disabilities. Consequently, the literature specifically about fathers of children with ASD is limited; however, the broader literature can inform contemporary practice and research.

Father Involvement
Lamb (2010) found that past studies consistently reported that fathers tend to “specialize” in play, whereas mothers specialize in caretaking and nurturance. This narrow view failed to capture similarities of fathers and mothers on child development. The emerging role of fathers over the past three decades has spurred research. Increased father involvement has been demonstrated to result in improved cognitive competence, increased empathy, fewer sex-stereotyped beliefs, and better self-control.

Lamb further speculates that increased paternal involvement promotes both parents’ fulfillment. Fathers can be close to their children while mothers can also be close to their children and pursue career goals. Lamb concludes that fathers and mothers seem to influence their children in similar rather than dissimilar ways. Paternal warmth, nurturance, and closeness are associated with positive child outcomes regardless of whether the parent involved is a mother or a father.

Jones and Mosher (2013) in a nationally representative survey of over 10,000 men found that most American fathers say they are heavily involved in hands-on parenting. This results in significantly better outcomes for their children in academic success, fewer behavior problems, and healthier eating habits. Fathers living with children younger than 5 reported that 90% bathed, diapered, helped toilet or helped their children to get dressed at least several times weekly. Even more played with their children and ate meals with them frequently. Two-thirds read to them several times weekly. Ninety percent of fathers living with children ages 5 to 18 reported eating meals together several times per week and talking with them about their day. Two out of three fathers helped with homework frequently, and about half took their children to or from activities.

Father Involvement in Clinical Interventions
Men are less likely than women to seek mental health services and medical treatment across race, ethnicity, age, and parental status (Addis & Mahalik, 2003). Not surprisingly, fathers are significantly less involved in clinical interventions for their children than mothers, and fathers tend not to be included in the overwhelming majority of research on child- and family-related therapy. Nonetheless there is evidence suggesting that fathers have a positive influence on child behavior when they are included in the mental health treatment.

Research has consistently shown that men are less likely than women to admit to uncomfortable or negative feelings (Addis & Mahalik, 2003). Seeking help typically involves recognition of problems and is in direct conflict with the masculine gender roles.
Dear Jack,

When you were about a year old, we saw a bunch of doctors and specialists to try and figure out why you didn’t talk or point or look at us. And at that time, many people told us not to rush to give you a label.

“Be careful with a label, because it will be on all of his forms and medical records,” one man advised.

“It will follow him for the rest of his life,” another woman warned.

See Jack-a-boo, people don’t like labels. No one wants to be limited or boxed in or classified. They especially don’t want to be pigeon-holed, which actually has little to do with a bird and more to do with compartmentalizing people into teeny-tiny, mutually exclusive categories.

But at the tender age of 18 months, the doctor diagnosed you with autism spectrum disorder, and from that point forward, you were labeled.

Honestly? I’m glad.

Now, I’m not saying I’m glad you have autism. I’m not really sure how I feel about that. I’m just saying I’m glad we know you have autism. I’m glad for the label.

See, if you didn’t have this label, I would probably snap at you to stop jumping and rocking and flapping. I would think you were naughty and rude and disrespectful.

I might rush you whenever you try to explain something to me in your halted, robotic speech.

Every day I would feel exasperated and frustrated and angry and scared. I might even feel embarrassed or ashamed.

Maybe we would hide in the house like we did when you were a toddler, avoiding play dates and trips to the library so I didn’t have to see all the other kids who could wave bye-bye and blow kisses and play peek-a-boo.

But now, we don’t hide. We go to the movies and to church and to restaurants and roller skating. We go on vacation.

Jack, you are labeled. And every day I feel exasperated and enlightened and aware and frustrated and thrilled and angry and scared. I feel protective and vulnerable and inspired.

However, I never, ever feel embarrassed or ashamed.

(Well, I might have been a little bit embarrassed the time we went to see Maleficent and you announced, “We don’t need to BUY your candy. We have some HIDDEN IN MY MOTHER’S PURSE,” to the guy who took our tickets.)

Renouncing your label would be a fundamental rejection of who you are, like denying that you have blue eyes or long legs. If I didn’t know you had autism, I might call to you impatiently when you stop to count all the tubs of frosting in the aisle of the grocery store.

“Jack, come on. Let’s go!”

But instead, I will myself to slow down, to stop the cart next to you and help you choose the best, most perfect pink frosting for the heart-shaped Valentine’s Day cake you’ve been talking about baking for weeks and weeks.

Maybe I would wish your baking phase was over, because sometimes it wears on me. But as I become more and more acquainted with autism, I know there will just be another phase lurking right behind it—it could be something innocuous like when you used to rub soap all over the walls, but maybe it will be something dangerous and scary, like when you used to try and run behind cars to see the license plates.

With your label, I have learned to enjoy the hoof beats of horses, because I know there are zebras ahead.

If we didn’t know you had autism, Daddy and I would probably be divorced. The pressure of fitting a square boy into a round world would be way too much for us, and we would crack apart.

Oh, we still argue. You know that. We disagree on whether or not you should wait see Label on page 38

Jack proudly writing out his Valentine’s Day cards

See, if you didn’t have this label, I would probably snap at you to stop jumping and rocking and flapping.

I would think you were naughty and rude and disrespectful.

I might rush you whenever you try to explain something to me in your halted, robotic speech.

Every day I would feel exasperated and frustrated and angry and scared. I might even feel embarrassed or ashamed.

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Oh, we still argue. You know that. We disagree on whether or not you should wait see Label on page 38
Behavior as Desire for Control in Autism Spectrum Disorders

By Daniel Crofts, MA
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Genesee County Chapter NYSARC

O ccasionally we all need a gentle reminder that autism is not an abstraction floating around in the ether. Autism is real precisely because people experience it, and separate cases of autism spectrum disorders differ so markedly because their subjects are unique individuals with different personal experiences, genetic and environmental influences, etc.

For that reason, in my opinion, any exploration of behavioral issues in autism should be prefaced by a consideration of human behavior in general. Certain behavioral issues are particular to autism. This is especially true of sensory-related behaviors, and I would say that the sensory component, after consideration of possible medical concerns, should come first.

At the same time, there are as many reasons for human behavior as there are ways of being, and people on the autism spectrum are no different in that regard. That said, I want to focus on a motivation for human behavior that is perhaps not attended to as much as it might be: Control.

No one likes to lose control. Most of us – even if unconsciously – will latch onto it wherever we can, however superficial our control might be in any instance. So imagine being a child on the autism spectrum: Your sensory sensitivities are such that the world seems always to be either attacking you or preparing to do so; your understanding of social, personal and practical circumstances is different from those of the world around you as to make you feel like you are on another planet some days; and you find yourself often unable to comply with what is expected of you.

Doesn’t sound so easy, does it? In similar circumstances, who wouldn’t look for and seize whatever little control they could? Here is where behavioral concerns can come into play.

If you think about it, disruptive behavior is almost like a kind of magic. In your mind, the play of the misbehaving child a moment: With a single word, gesture, action or refusal, you can exercise a powerful influence on your environment. For a child, their attention away from whatever they were doing before in order to handle the situation you are creating, the whole mood and atmosphere of your surroundings change, and your peers might even have behaviors of their own.

Quite possibly, you may even be able to get out of unwanted situations or obtain something that you desire.

How’s That for Control?

Again, there are many kinds of behavior. For people on the autism spectrum as well as for everyone else, these tend to be repetitive and strange, or of no different interest and themselves. But there is so radically dependent on adult caregivers that his/her self-confidence and self-control will only attain healthy development to the degree that adult controls and aids see Control on page 35

Adults from page 1

often engage in challenging behavior that is considerably more intense in comparison to that of the behavior of their younger counterparts. The risk of injury may deter staff members from running sound functional assessments despite the empirical support for their use.

Concern with running traditional functional analysis - While traditional functional analysis represents the most accurate way to determine the function of the behavior, it is also the most intrusive and time-intensive assessment method. Furthermore, there is a concern that this kind of assessment involves the evocation of maladaptive behavior, which increases risk to the learner and the staff who are conducting the assessments.

Complexity of challenging behavior in adults - Intervening with challenging behavior in adult populations with autism tends to be more labor-intensive and difficult, in that it tends to be more complex.

Maladaptive behavior that has occurred over the course of many years may be controlled by many different factors and have multiple forms, which can increase the difficulty and the duration of the assessment and intervention process.

These concerns often lead to the use of less intrusive, yet less empirically sound modes of assessment. The use of less supported methods of assessment increases the likelihood of errors occurring in the assessment process, which in turn, compromises the subsequent effectiveness of interventions and worsens outcomes for the adult ASD population.

Assessment Solutions

In light of these challenges, there have been a number of less intrusive assessment variations that may be of particular use for older learners exhibiting challenging behavior. These procedural variations include: AB models of functional analysis, trial-based functional analysis and the functional analysis of precursor behavior.

AB models of functional analysis - AB models of functional analysis involve manipulating the settings or antecedents for problem behavior and observing the effect on the occurrence of the behavior. For example, a practitioner may expose a student to low levels of attention (e.g., acting distracted) or presenting difficult demands (e.g., a math worksheet) and then observe the effects on problem behavior. These manipulations may provide valuable information about what triggers and maintains problem behavior. For instance, if an individual engages in problem behavior when presented with demands, but does not engage in the absence of demands, it suggests that escape may be the function of the behavior.

Functional analysis of precursor behavior - Precursor models of assessment generally involve conducting a functional analysis for a less severe problem behavior that reliably precedes the more severe challenging behavior. For example, if inappropriate vocalizations were to occur immediately prior to aggression, conducting a functional analysis of the vocalization may yield information about the function of the aggression without actually evoking it. Precursor models of assessment have garnered empirical support for their use (e.g., Smith & Churchill, 2002) and may be particularly useful for limiting the occurrence of problem behavior during the assessment process.

Intervention Strategies for Adults with Autism Spectrum Disorders

Broadly speaking, best-practice interventions can occur at one (or more) of three points along the ABC sequence of problem behavior described above: doing something to the environment before the behavior happens, training an alternative behavior, or changing what happens after the behavior has just occurred. It bears repeating that the implementation of all of these strategies either require or are greatly enhanced by an accurate understanding of the function of the maladaptive behavior in question, which may be determined through functional assessment techniques.

The bottom line is that better assessments permit better treatments.
Understanding Aggressive and Self-injurious Behavior

By Rachel LaPiana, MSEd, BCBA
ABA Training Coordinator
QSAC

When addressing challenging behaviors, specifically when it comes to aggressive behaviors and self-injury, it’s important to understand the reasons as to why these behaviors are occurring before determining a solution. The behavior of all living organisms serves specific purposes; and the reason behavior occurs varies depending on an individual’s need in a given moment. Dependent on the circumstances, one behavior can serve multiple functions or multiple behaviors can serve one purpose.

Understanding the basic function of behavior is pertinent when dealing with the behaviors related to individuals on the autism spectrum. Research indicates that individuals with greater skill deficits often engage in higher rates of aggressive behaviors. This is likely due to inefficient communication abilities, reduced social skills and social supports, as well as a greater degree of intellectual disabilities (Sturmey, n.d.). Aggressive behaviors tend to be more prevalent during the younger years of a person’s life and appear to be directed toward familiar people and caregivers as opposed to strangers (Autism Speaks, 2012). Further, some studies suggest that self-injurious and aggressive behaviors can be a result of biological or biochemical components leading to compulsive type behaviors that are difficult to treat (Autism Speaks, 2012). However, in general, most behaviors are learned and reinforced over time.

At the very core of most human behavior is the inherent need to satisfy primary needs. The primary needs of all living beings are classified as unlearned and natural; these include hunger, thirst, sexual drive, and the ability to maintain appropriate temperature. Once basic needs are met, individuals then look to satisfy what are known as secondary needs. Secondary needs include items and activities that are learned and are comprised of things that living beings desire but do not require for survival.

In relation to human action and primary vs. secondary needs, the term reinforcement is widely used in the behavior analytic community. Reinforcement refers to the presentation or removal of a stimulus immediately following a behavior which serves to meet the needs of the individual. Reinforcement can be replaced with a more appropriate hormone from page 22

When understanding the function of any behavior, experts often look to do a functional assessment and sometimes a functional analysis to determine a cause or pattern in behavior. Maintained across all functions, aggressive behaviors toward one’s self or others serve to meet the needs of the individual. Often times, individuals with autism are unable to make requests for the things they need and want. Once identified, the function of aggressive behaviors that are emitted can be replaced with a more appropriate single medical school, the Health System has an extensive ambulatory network and a range of inpatient and outpatient services—from community-based facilities to tertiary and quaternary care.

The System includes approximately 6,600 primary and specialty care physicians, 12-minority-owned free-standing ambulatory surgery centers, over 45 ambulatory practices throughout the five boroughs of New York City, Westchester, and Long Island, as well as 31 affiliated community health centers. Physicians are affiliated with the Icahn School of Medicine at Mount Sinai, which is ranked among the top 20 medical schools both in National Institutes of Health funding and by U.S. News & World Report.

For more information, visit www.mountsinai.org, or find Mount Sinai on Facebook, Twitter and YouTube.

In relation to severe problem behavior when it comes to aggressive behaviors and self-injury, it’s important to understand the reasons as to why these behaviors are occurring before determining a solution. The behavior of all living organisms serves specific purposes; and the reason behavior occurs varies depending on an individual’s need in a given moment. Dependent on the circumstances, one behavior can serve multiple functions or multiple behaviors can serve one purpose.

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In relation to human action and primary vs. secondary needs, the term reinforcement is widely used in the behavior analytic community. Reinforcement refers to the presentation or removal of a stimulus immediately following a behavior which
reduce challenging behaviors and see positive improvement is to fully commit to bringing about a new kind of environment—the caregivers have to change before the individual with challenging behaviors will.

2) Gather Data - It’s important to start by collecting baseline data for several reasons. Having a quantitative measure of the starting point allows accurate and objective progress tracking, encourages new thinking, and demonstrates ultimate success.

The first step is to determine what the caregiver or organization wishes to measure, and how that data will be collected. Examples include: number and types of physical interventions utilized by the organization and its various departments, numbers of injuries, number of tantrums, the amount and extent of damage to property, and others as relevant. Each organization may determine what it will measure, but, measurement is critically important.

3) Assess Internal Team - This is primarily geared toward organizations, but would be relevant for any group working together to create a more positive environment for an individual with autism to reduce challenging behaviors, including families, caregiving teams, and others.

Instituting this type of change will go more or less easily depending on the expertise of the team involved, and their willingness to embrace whatever changes affect them individually. An early step in the process should be to objectively assess team expertise as well as their willingness to change or improve.

4) Define a Plan and Goal - Depending on their size and current expertise any given organization should be able to dramatically reduce their reliance on physical interventions within one to three years. A proper internal assessment will generate the information and analysis necessary to set a proper goal within a reasonable time frame.

For an organization, that goal might look like “The XYZ Organization will reduce the number of physical interventions by 80 percent within 18 months.” For a family or individual caregiver, it may be “I will work with [name] to reduce tantrums by 10 percent this month.”

Organizations should make sure that measurable goals are announced loud and clear throughout the organization.

5) Share the Plan with the Full Team - Dramatically increasing the effective use of praise and reinforcement is an essential element of a positive approach. Most people who work in this field have never worked in or experienced an environment where praise and reinforcement are used lavishly.

This presents a dilemma whereby many staff members feel they use praise and reinforcement effectively when, in fact, significant improvement is needed.

An immediate step can be taken to collect baseline data. The types and rates of reinforcement should be counted for a particular time interval. Then goals can be established and an organized effort can be initiated to dramatically increase both the types and rates of praise and reinforcement. Consider challenging staff to praise or reinforce each person they are working with once per minute for one week.

6) Increase Praise and Reinforcement - Positively meaning doing good in people and on the good times. It nourishes strong, caring and productive relationships. The most powerful tool for positivity is consistent use of praise and reinforcement. This practice frees caregivers to use their creative power to find solutions rather than manage problems.

When consistent in this practice, the benefits will quickly become evident—people respond well to praise and reinforcement when it is properly and lavishly used.

This applies to how staff training is approached in addition to direct interaction with individuals with autism.

7) Redefine Key Support Roles - This is especially important in organizations, where the roles of specialists like psychologists and behavioral specialists need to evolve from doing to teaching. Job descriptions may need to be rewritten to reflect this change. They should adopt a view of themselves as behavioral mentors to direct service, supervisory and clinical staff.

The goal of this process is to put the tools of positive practice in the hands of the people who do the work. Rather than the traditional paradigm of having a very small percentage of “behavioral specialists” on staff, the emerging new paradigm will use existing specialists to train and develop the entire workforce so that 100 percent of the team will become specialists in positive behavioral approaches.

Outside of organizational settings, caregivers should consider, who else plays a role in the individual’s life? Be sure everyone is on the same page with this new positive approach.

8) Limit the Availability of Physical Intervention - Another way to help reduce the implementation of physical intervention is

see Proven on page 42

Asperger’s from page 16

or asthma then a psychiatric one. So, why the difference? One of the big answers is stigma. Despite how far we’ve come in the field, psychiatric disorders of the mind are viewed and treated differently than those of the body. And even parents of special needs children, while likely more sensitive to the effects of the stigma, are not necessarily immune to them.

This issue is especially complicated when it comes to autism spectrum disorders. There are some in the field who don’t view Asperger’s or autism spectrum disorders as disorders at all but rather as unique ways of perceiving the world that should be embraced rather than cured. All of this makes it even harder for parents to gauge the meaning of the diagnosis and cautious about attributing a label that can be lifelong.

Parents Processing Their Own Experiences

Another important consideration is the parents’ reactions to the diagnosis. One thing to keep in mind is that our children are reflections of ourselves. More often than not, one or both parents identifies with what their child is going through because they experienced similar struggles themselves. There are times where a child’s diagnosis may also bring to light a parent’s undiagnosed condition that has been untreated or misunderstood for many years. Acknowledging their child’s disability may therefore trigger painful memories and powerful defenses for parents which, if left unattended or unresolved, can have a meaningful impact on how their child makes sense of their diagnosis. Therefore, if you are considering having this discussion with your child, we recommend first investing time into exploring your beliefs and biases about their diagnosis. Even if you hold these views close to your chest, your children may pick up on them implicitly. We are big advocates of parents scheduling meetings with a psychologist as a means of processing through their own feelings about their child’s diagnosis before sharing it with their child. These meetings can help parents clarify some of their own feelings and help them formulate a language and description that they are comfortable with in speaking with their child.

Thinking about the Child’s Age and Level of Functioning

Children are diagnosed at various different ages, across different times in their lives. They can be diagnosed as young as two or three or well into adolescence, so the discussion about when and how to talk to a child about the diagnosis will likely be impacted by the age of the child. In addition, the Asperger’s diagnosis can be given to a wide range of children with various challenges and levels of emotional maturity. Some children may be able to grasp the nature of the diagnosis at seven and eight, while for other children, it may seem too abstract, even at 16 years old. Both a child’s
Bitten by the Truth

By Alexandra Bricklin, MA, MT-BC
Parent and NSEAI Certified Special Education Advocate

Three years ago, at 4 am in the morning, my life began to unravel when my daughter sank her teeth into the fleshy part of my inner thigh. “Mommy, please help me!” she begged as she fell to her knees and grabbed my legs. Then she clamped down hard and held on tight like a pit-bull. I screamed, her teeth still embedded in my inner thigh. When the policeman approached her, she kicked him. He faced her down and handcuffed her. Two emergency responders strapped her into a gurney and shuttled off to the hospital. That morning we had seen a Cognitive Behavioral Specialist for my daughter’s nocturnal panic disorder and its resulting insomnia. This specialist had confronted her: “If you continue keeping your mommy up at night, she will get sick!” This, of course, was the trigger that set her off that night. Ever since her dog had died, she had been terrified of falling asleep. Her solution was to stay awake.

When I arrived at the ER, I learned she had bitten hospital personnel. This explained the 4-point restraints and a bleeding catheter hanging between her bare legs. She remained in 4-point restraints until evening when involuntarily admitted into acute psychiatric care.

How had my cute, beloved autistic child grown up into such an ugly dangerous adult? For 26 years I had allowed myself to be held captive by her angry outbursts, and had vehemently sought abolution. What more could I do to help this wild (adult) child acquire impulse control?

Five Days Later

The jury approved an additional two weeks of treatment but I couldn’t afford the cost to discharge her into pending 24/7 in-home supports. Within two weeks, I had two awake staff all night long, 7 nights a week. They blocked her from beating on my bedroom door. In response, she threw household objects at them and threatened to kill them.

Each night, I lay wide awake locked up in my bedroom listening to her tirades, shuddering like a victim of an air-raid. In the morning, I got up, made her breakfast and went to work, leaving her in the care of the next shift.

It was agonizingly stressful trying to adjust to the 12 different people coming and going in and out of my house day and night. My feelings of discomfort with the strange people awake all night in my living room resulted in forfeiting all urges to go downstairs for anything, not a cup of tea or a snack, not for anything. I reassured myself that all of those people were necessary to keep my daughter out of institutionalization. I honestly did appreciate them tremendously. So, why was I so miserable?

Even when her screaming out for me began to diminish and her insomnia improved, I did not. It wasn’t until she began smiling again saying, “I love you mom!” that I began to confront the source of my own pain and suffering.

At first I thought I was merely sick from the deadly antibiotic I had taken in order to prevent infection from the human bite I had sustained. “The antibiotic has a warning label: Can cause serious diarrhea. I had a stool sample taken. The lab test came back negative. Then I rationalized that it must be exhaustion and disorientation from my loss of control over my own home that was causing me to feel so ill. I was having flu-like symptoms - night sweats, chills, chronic diarrhea, stomach pain and no appetite. I was restless, irritable and couldn’t concentrate.

When I could no longer eat anything, I took myself to the emergency room with my suitcase packed. I wanted to be admitted. At least I could receive IV fluids and some rest. The ER doctor grinned. “You think you need to be admitted, huh?” he joked. He had been on duty that dreadful night. When he inquired if she was still living at home, he ordered a CT scan, pumped me intravenously with Pepcid AC and sent me home with a tranquilizer.

“Oh, so now what?” I argued with myself. And then, in the midst of my angst, a subtle but miraculous thought revealed itself: “I don’t want to live with her.”

see Truth on page 34

Building Comprehensive, ABA-Informed Services in an Adult Residential Setting

By Rishi Chelminski, BCBA, Terence G. Blackwell, BCBA, and Louis Cavaliere
Services for the UnderServed Inc.

Throughout the United States, services for school-aged children with Autism have been bolstered by IDEA (the Individuals with Disabilities Education Act). Of the services IDEA has made available, those informed by the science of applied behavior analysis (ABA) are gaining broad recognition as the most successful (Lilenfeld, 2005; Rogers & Visnara, 2008). A review of recent publications, whether it be the National Institutes of Health, the US Surgeon General, opinions of a variety of state and national departments of health, or over 50 years of scientific research, points to the fact that ABA-informed services are the foundation for effective treatment of individuals with Autism Spectrum Disorders (ASD).

At the age of 21, many people with ASD transition into systems where ABA-informed services are few and far-between, and the barriers to receiving such services are high. The needs of these individuals do not cease once they reach 21. To the contrary, a review by Happe and Charlton (2012) published in the journal Gerontologist identifies many ways in which the needs of adults diagnosed with ASD are likely to increase over the lifespan. If their needs persist, the applicability of ABA-informed services persists as well. In order to provide the highest-quality of services across the lifespan, new models of ABA-based practices need to be developed that work beyond the school setting. This task is daunting on many levels; the world of adult services exists on framework of funding and oversight that presents challenges not seen in the school setting. However, in 2011 Services for the UnderServed Inc. (SUS) committed to taking on this challenge, and many of the individuals we serve have already begun to benefit from this decision.

We were fortunate in our timing. Although ABA is often thought of as a field suited to working with children, many of its guiding principles dovetail well with recent trends in adult services. In recent years, “one size fits all” models of care have given way to an emphasis on person-centered interventions (for a review on Person-Centered Planning, see the NYS OPWDD website www.opwd.ny.gov). ABA-based services have, by their fundamental nature, always been entirely person-centered. Indeed, this is one reason why they are so readily funded in the school setting through IDEA. Practitioners who use ABA to inform their work take a functional analytic approach to treatment. This means that interventions are chosen based on direct, empirical observations of each individual’s own preferences, values, skills, and relationships with their environment (Hagopian & Boelte, 2005).

Along with the movement towards person-centered planning, there has been a concerted movement towards evidence-based, data-driven interventions. This is another area in which ABA-based services are fundamentally well-suited to provide solutions. Under an ABA-based model, treatments are not only developed based on empirical observations, but are continuously evaluated using data analysis of an individual’s behavior.

Finally, the coming climate in our field is one that recognizes interdisciplinary collaboration as an essential part of high-quality, person-centered care (World Health Organization, 2010), an idea bolstered by the implementation of initiatives such as the Affordable Care Act. Such collaboration requires a natural science-based language and set of principles that crosses disciplines. Within a medical environment, practitioners of myriad medical disciplines collaborate well with one another because they are united by the common language and principles of biology, chemistry, and physics. Much in the same way, at SUS we have found that therapists of many disciplines, direct-service professionals, and care coordinators can collaborate well when their work is unified by the language and principles of ABA.

This last idea is one which may require perhaps the most difficult cultural shift within adult service agencies. Although ABA is a science which informs practice, and therefore a potential tool for uniting many disciplines and providing comprehensive care, it is often used in isolation from other services that an individual may receive. As an agency wishing to integrate ABA into our palate of services, at SUS we have chosen to move away from the mindset of “having an ABA therapist that is available to our individuals,” and instead move toward the more comprehensive goal of “having a range of therapists available, all of whom use ABA to inform their practice.”

Creating such a comprehensive clinical environment requires long-term strategic planning. It is probably not surprising that we have chosen our Behavior Intervention Specialists to take on the role of bringing ABA-informed services to our programs. However, we also recognized early on that this project required commitment...
Commitment, it would alleviate many un-
expected, rather than typical, stress for families and
interests, while others do not engage in challenging
behaviors. For instance, during times when their family or care-
provider is not available, some children may exhibit stimula-
tion seeking behaviors, such as running or rocking. These
behaviors can be challenging for caregivers and can lead to
stress and frustration. It is important for caregivers to
understand the triggers and factors that contribute to
challenging behaviors and to develop strategies to
manage these behaviors in a positive and safe manner.

Effect of Preceding or Antecedent Physiological
Factors on Challenging Behavior

The Effect of Preceding or Antecedent Physiological Factors on Challenging Behavior

By Mindy Scheithauer, PhD, BCBA, Joanna Lomas Mevers, PhD, BCBA-D, and Nathan A. Call, PhD, BCBA-D
Marcus Autism Center
Emory University School of Medicine

Challenging behaviors (e.g., aggression, self-injury, and disruption) are prevalent among indi-
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to manage these behaviors in a positive and safe manner.
Addressing Skill Deficits in Students with High Functioning Autism as a Proactive Approach to Prevent Behavioral Challenges

By Edel McCarville, PsyD and Colleen Menard, MSED
Leviton Public Schools

Students with high functioning autism (HFA) typically display cognitive abilities in the average to above average range, and some superior range; therefore often participate in general education classes. While these students have many strengths, specific educational and behavioral approaches are often needed to address the core deficits of an autism spectrum disorder. Failing to address the specific needs of students with HFA may in turn lead to these students displaying challenging behaviors (Myles, 2005).

A proactive and multi-dimensional approach using antecedent interventions can be effective in addressing the core deficits associated with ASDs and the individual needs of students with HFA. Specifically, interventions addressing deficits in social communication, behaviors associated with having a restricted range of interests, or stereotyped patterns of behavior should be part of a student’s educational program. Further, individuals with HFA often struggle with adaptive functioning; meaning they may need support to complete certain daily activities in school. Also, it is important to note that 70% of individuals with an ASD may have one additional diagnosis, and 40% may have two additional diagnoses. Common comorbid conditions are ADHD, developmental coordination disorder, anxiety disorders and depressive disorders (American Psychiatric Association, 2013). Therefore, when educating students with ASDs, it may be necessary to consider these additional skill deficits. If core deficits are not addressed, then students are likely to experience more significant challenging behaviors. Due to the variety of components involved in educating children with HFA, a multi-leveled intervention package is often necessary. Merely addressing challenging behavior that is occurring without addressing skill deficits that exist will not teach students replacement adaptive skills that they need in order to be successful. Adaptive functioning is important because adaptive skill is closely related to functional independence and quality of life (Scahill & Lord, 2004).

Students with ASDs experience delays related to social communication, therefore specific teaching to target these deficits can help to improve school performance. Lack in skill-set may appear as lack of motivation in a student with HFA. Additionally, difficulties with cognitive flexibility are common; meaning students with HFA often have difficulty in “going with the flow.” Accepting changes or creating an alternative plan when a student’s idea does not work out the way they anticipated can lead to behavioral challenges. A modified cognitive behavioral therapy (CBT) approach is effective in helping students to restructure thoughts that lead them to becoming “stuck.” CBT approaches have been shown to significantly reduce mood disorders in children with ASDs (Bauminger, 2002). Educational staff can modify traditional CBT in order to accommodate the needs of students with HFA. Providing visual aids from page 42

Residential from page 29

from a broader array of stakeholders, from the direct service professionals up through the agency to the CEO and Board. Integrating ABA as a science that informs practice (rather than a practice that exists in isolation) means that in some way, an ABA-based solution must be offered to meet the needs and expectations of all of these stakeholders.

Towards this end, we undertook this project with the consultation of experts within the field of ABA and residential care, who have helped bring ABA-informed services to other settings. In particular, the leadership of Dr. Brian Iwata has proven essential to our progress; Dr. Iwata is among the world’s foremost researchers in the clinical application of behavior analysis. With his assistance we were able to mount a series of lectures and discussions that generated interest in ABA among our agency’s management and clinical staff. In this way, we learned what these stakeholders needed from us, and addressed their needs by developing policies and procedures that satisfied both their requirements, and the best-practices models common to the field of ABA.

These policies and procedures primed the environment within our agency for the substantial part of our ABA project: bolstering the ranks of our clinical staff with Board-Certified Behavior Analysts, and (more recently) Registered Behavioral Technicians. These clinicians have brought ABA’s functional-analytic perspective to our agency, and with it a person-centered, data-driven, highly-collaborative model of services that has already begun to produce results for the individuals we serve. We would like to close this article with an exciting example of these results.

In recent years, SUS has begun serving a large number of individuals with very complex needs. These young adults came to us from agencies specializing in the treatment of very severe self-injury and aggression, as they were deemed as having behavior “too severe” to be treated in a traditional setting. Following their transition to adult services, SUS was able to use ABA-informed services to not only manage these individuals’ behavior service plans, but also conduct a controlled reduction of the restrictive and intrusive interventions that many of them had grown accustomed to. In one house alone, we were recently able to fade away 1:1 staffing for half individuals living there, while still making progress in reducing their challenging behavior and strengthening their adaptive skills.

In much of the nation, 1:1 staffing is regarded as one of the most restrictive and intrusive services that can be prescribed to an individual. These individuals’ ABA-informed services have not only furthered their clinical progress, but have also given them new measures of independence and dignity. It is with this vision that we continue our roll-out of ABA-informed services, and look forward to seeing similar developments from our colleagues in New York State. As we face the challenge of adapting ABA from the school setting to the adult services setting, we hope to create an environment in which individuals with ASD can continue to access cutting-edge treatments after 21, and across the lifespan.

References


go to do (e.g. checking heart rate) be-
before attempting to use this on the person.
Caregivers and parents can help respond-
ers to understand what kinds of touch are
likely to be met with tactile defensiveness and
and can demonstrate effective strategies.
Carefully explain, in very simple language,
what you are doing if it involves a specific
or the use of equipment on the person’s body.
Overall fear of the unfamiliar can be ad-
dressed by allowing the child or adult to
have a favorite comfort object, to retreat (if
safe and feasible) to a familiar place or
sit with a familiar person. Emergency sit-
uations such as fires or car accidents may
require different response methods and are
beyond the scope of this particular article.
Communication difficulties can be dealt
with calling situations where it is possible
to rely on the caregiver or parent to be the
model for any
caregivers if available and following
their lead. Responders must remember that
a person with ASD may very not respond
to commands the first time and will need
time processing time as well as possible
augmentative systems. The team should dele-
gate one person to be the main communi-
cator in any situation. This person should
speak calmly and avoid the tendency to re-
peat or raise their voice or complain or
a response. Providing a few extra
seconds of wait time to process language is
critical. Use a “talk, wait, repeat” model
when asking questions or providing basic
commands. Repeating of questions or
mands should be paired with a visual, ac-
tion or model on a caregiver or other safe
person. The language should be kept as lit-
eral as possible, while avoiding the use
of humor or sarcasm, as these are often misin-
terpreted by persons with ASD. Eye contact
may be fleeting, avoid or otherwise im-
paired. Demanding eye contact may result
in less compliance and more refusals. En-
courage the person to look at the responder
by using a favorite object or other item and
bringing it to their eye level. Do not insist
on “look at me” during an examination.
The person with ASD may require
transport in a vehicle to obtain further in-
tervention. The caregivers or the vehi-
cule paired with strangers, lights and other
sensory influx may trigger stress reactions
leading to refusal behavior. Encourage the
caregiver or parent to be the model for any
actions including, for example, using the
backboard, neck brace or other immobiliz-
ing device. The action of a familiar adult
“doing it first” may change the level of
compliance with the actual person. Physi-
cal interventions may lead to increased
rassal and aggression. In these situations the
first responder should limit conversation
and verbal input to one person who speaks
calmly, literally and provides visuals when-
ever possible. Recognition of these events
as frightening and unpredictable can con-
tribute to the prevention of frustration and
impairment on the part of the first responder.

Resources
Behaviors that are emitted by individuals
with ASDs during emergencies can be un-
predictable, frightening and difficult for all
involved. There are a number of resources
available that are specifically written for
any
interested party. For example, the National
Fire Protection Association (www.nfpa.
org/disabilities) has a web page dedicated
to providing information about emergency
response issues. In 2010 this organization
produced an informative resource for special
social stories that specifically designed to address the unique
needs of children with ASD in response
to smoke alarms entitled “I Know My Fire Safety Plan” (NFPA, 2010). This book
can be personalized to the individual child and
interacts with electronic platforms. Autism Speaks (www.autismspeaks.org)
has a basic information page dedicated
to best practices in an emergency situa-
tion. Their list of “Quick Facts for EMS”
provides concise and helpful strategies
(www.autismspeaks.org/family-services/
asd-safety-project/first-responders/-
emergency-services). Training, prevention
and intervention strategies can all assist to
create a more positive experience for those
with ASDs and the first responders who
provide emergency assistance.

Summary
Training is a vital component of the first
responder’s ongoing professional devel-
oping and should include a focus on the
predictability of ASDs as well as the general
needs that encompass the definition of this
disorder. Ongoing research into best prac-
tices during emergencies is needed along
with a continued focus on training for all
providers. Emergency situations for chil-
dren and adults with ASDs require a spe-
cial focus on prevention through building
familiarity as well as intervention that con-
siders the core impairment areas.

References

American Psychiatric Association. (2013). Diagnostic and Statistical Manual of Men-

der: A fire/EMS challenge. Fire Engineer-
ing, 164 (3), 42-51.

Kupietz, K. (ND). Best practices for Au-
tism during emergencies. Retrieved from:
http://www.usfa.fema.gov/pdf/efop/
efo46708.pdf.

McDermont, S., Zhou, L. & Mann, J.
(2008). Injury treatment among children with Autism or Pervasive Develop-
mental Disorder. Journal of Autism and Develop-
dmental Disorders, 38(4), 626-633.

Mims, T. (2008). Seeing an invisible dis-
bility: Autism spectrum disorder awareness
training for firefighters in Tuscaloosa, Al-

Law, P. & Anderson, C. (2011). IAN re-
Retrieved from: http://iancommunity.org/
cs/ian_research_reports/ian_research_re-
port_elopement.

Myers, S. (2012). Review of mortality in
autism drowning. Association for Science
in Autism Treatment. Retrieved from:
http://usatonline.org/resources/articles/
mortality.htm.

National Fire Prevention Association
2010/nfpa-releases-interactive-fire-safety-
ty-storybook-for-children-with-au-
tism-spectrum-disorder Retrieved from:
www.nfpa.org.

www.paeMSC.org/assets/files/Au-
tism%20101%20for%20EMS%20Practi-
tioners.pdf

Quick Guide for Emergencies (ND).
https://www.autismspeaks.org/family-ser-
ices/asd-safety-project/first-respond-
ers/emergency-services. Retrieved from:
www.autismspeaks.org.

Stelter, L. (2013). First responders, take
code: CDC reports 1:50 children has Au-

White, B. (2012). Autism awareness for
the fire service. Minnesota Fire Chief. Jan-
uary/February, 30-32.

Aggressive from page 27

and socially acceptable behavior. For ex-
ample, if an individual is hungry and is not able
to request food items either
seeing food he or she might hit a caregiver to
alert attention in order to be given a meal or
a snack. Similarly, if a teacher asks a child
to put away a favorite toy and, in turn, the
child begins to pull at his eyelashes it is likely
that the child is not ready to put away
and will like more time to play.
At times, an individual might act aggres-
ively or demonstrate self-injurious behav-
ors as a result of being presented with a
change in the environment that is thought to
be aversive. He or she may engage in par-

ticular behavior to escape a place, person,
or task. If historically, the task is removed
or the individual is taken away from the
original environment upon demonstration of
aggression, it may be predicted that
is probable that he or she may have learned
that in order to escape or avoid something
that they “don’t like,” aggression or self-in-
jury is what is necessary in order to have the
aversive stimulus removed under a specific
circumstance. By identifying causal factors
(e.g. patterns in behavior and antecedents
and/or consequences to behavior), a clini-
cian or teacher can create a plan to teach
the individual to make requests more suitably.
Some studies suggest that aggressive or
self-injurious behavior can be an extreme
result of attention seeking motivating sys-
tems. These studies have found that chil-
dren learn to emit problem behavior in re-
sponse to low level adult attention (Carr &,
Durand, 1985). If the person has a limited
ability to communicate, he or she may not
be able to explain to a caregiver that they are
not feeling well or that something is wrong.
It can very difficult to identify as the rea-
son for particular behaviors if there are no
observable symptoms of illness. If aggres-

see Aggressive on page 40
Opinion Piece: Standardized Testing in Schools Inadequately Accommodates Special Education

By Vicki Ofmani, MEd, LDT-C
Supervisor/SLE Coordinator
The Forum School

The decision to share the diagnosis is an important part of the child’s forging of his or her unique identity. While it may take time, we believe treating your child with respect and support when sharing this information will help your child to integrate this information and empower him or her for success and self-actualization through hard work, insight, and understanding.

Over the years in diagnosing and working with children with Asperger’s and their families we have been humbled and challenged by this complex issue. As mentioned earlier, there is no singular approach because each child is unique and what will work for one child may not work for another. We hope that this article has stimulated some “food for thought” or ideas about how to empower our children by helping them get to know themselves better.

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Vicki Ofmani, MEd, LDT-C

Vicki Ofmani refers to the fact that each teacher within the school should be fully certified by the state and that they must demonstrate their knowledge of the subject they teach through specific credentials or scores on tests. Though a teacher with Special Education certification may pass subject area Praxis exams, they are not considered “highly qualified” to teach those subjects at the high school level without taking a mandated number of college credits in that specific subject area. This is discriminatory as the high school level the general education subject area teacher may teach the special education students with NO special education experience or coursework. Again, the emphasis is placed on achieving subject matter knowledge, not necessarily the unique needs of the classified student.

As many of us in the special education arena would lament, there is a gap in reasoning here. At a time where more and more of our students are identified with disabilities such as Autism Spectrum Disorder, Behavioral Disabilities, and Specific Learning Disabilities, regular education teachers are not required to be highly qualified in areas such as “applied behavioral analysis” or “best practices in differential instruction.” However, special education teachers must be highly qualified in academic areas which mean they are tested on their knowledge of the Asperger’s student’s cognitive and emotional indicators. Far be it from offering ideas of isolationism, special educators are, however, focused on the child’s social, psychological, and physiological development as a whole. Their understanding of typical and atypical child development and instructional methodologies is one of the core foundations that have kept New Jersey’s reputation as the premiere state for educational practices in force. However, theories in economics are easily accessible from the internet. Standards are necessary in education. The Common Core State Standards (CCSS) are what is expected. They are criteria, ideals, goals. They are the top rung. Academic content standards are statements about what students should know and be able to do upon finishing point of each grade level. There are simply too many. It has been the intent of the states’ consortiums to make the standards rigorous to “make” us Americans more competitive in the global market. They simply have not taken into consideration developmental markers. Our students meet these markers at a far different pace than their typically developing peers. That is explicitly why they have been classified in New Jersey for educational consideration under the law (N.J.A.C. 16A:14).

The intent is clear and admirable. The content standards are proclaimed as things that should ensure teachers that their students have the skills and knowledge they need to be successful at each stage of learning. However, the vastness of them; the complex age and developmental level should be factors when thinking about disclosing the child’s diagnosis and considering ways to share this important information.

How to Talk with Your Child

The decision to share the diagnosis is a deeply personal and heavily nuanced one; a one-size-fits-all approach does not apply. Obviously, there are lots of things to consider. Our view is that in most cases, there is tremendous value in having an open discussion with your child about the nature of his or her difficulties and sharing with them their diagnostic label may be an important part of this conversation as well. Whether this conversation is being prompted by a recent evaluation and diagnosis, or parents have chosen to disclose this information after keeping it quiet, odds are your child knows something is different about them. In general we have found that children construct all sorts of fantasies and ideas about what is wrong with them and having a candid discussion may actually dispel some of their worst fears. Below are a few suggestions to foster an open discussion with your child:

1) Highlighting strengths and weaknesses: We all have things we are good at and things we are not as good at. It’s pretty easy to come up with a list for each of us. It might be helpful for each of the family members, including parents, to speak about three things they are good at and three things that they struggle with. What is unique about the child with Asperger’s is the level of discrepancy that can exist between different areas. A 10-year-old with Asperger’s may have a reading level equivalent to a teenager in high school but math abilities of a five year old. What can be difficult for the child is the feeling of having such a large split inside of them. It can also be valuable to highlight the feeling of this dramatic chasm between the areas.

2) Using metaphors: Even though each child’s challenges are unique, there are certain characteristics that are fairly common in children diagnosed with Asperger’s. It might be helpful, again depending on the age and maturity of the child, to use metaphors to talk about some of these symptoms. For example, to explain executive functioning difficulties, we may talk about a huge pile of papers, with no folders to organize them. To explain cognitive inflexibility, we may talk about a child’s brain getting “stuck” and unable to move past something. For emotional dysregulation, we may talk about a child whose feelings feel way too big for his little body, and for social deficits, we may talk about going to visit a foreign country and feeling like we have a hard time understanding the language or culture. We have found the use of metaphors particularly valuable in highlighting what it can feel like for a child with Asperger’s dealing with these difficulties. These metaphors can also be used to explain to siblings, family members, friends or teachers when they don’t understand why these children are having a difficult time in some of these areas.

3) Role models: Many role models exist that speak openly and share their challenges. Having your child learn about different role models in pop-culture or sports with specific areas of difficulty who model perseverance, hard work, and embracing their challenges can be helpful. Thankfully we have many role models in our culture that are open about their challenges, so it might be helpful to find a role model that connects with the child’s area of interest. For example, a baseball player might have an area of difficulty for a child interested in baseball, or learning about an engineer with difficulties for a child who loves transportation, or an actor on a child’s beloved television show who has shared some challenges.

4) Respect their processing style: Children’s reactions to these talks reflect a full range of responses. Some children will have many questions and want to understand more. They may want to look up what different words mean and feel like they can’t stop talking or thinking about it. Other children will be resistant to talking to think and reflect about this information. You may want to enlist the help of mental health professionals to facilitate the healthy processing of some very complicated information. We very much believe that the understanding and synthesizing of this information is an important part of the developmental process and integral to your child’s forging of his or her unique identity. While it may take time, we believe treating your child with respect and support when sharing this information will help your child to integrate this information and empower him or her for success and self-actualization through hard work, insight, and understanding.

Asperger’s from page 28

No Child Left Behind (NCLB) covers many federal education programs. The act, in 2001, was put forth to strengthen America’s educational system by requiring States to implement accountability systems covering all students. Although NCLB covers various education programs, the requirements for testing accountability and school progress undoubtedly receive the most attention. No Child Left Behind requires each state to test each student in reading and mathematics each year in grades 3 – 8 and once during high school. In science, states must test one time in grades 3-5, 6-8, and high school.

It seems improbable that any educator would argue the point that all our students should be proficient in grade-level math and reading. It is also plausible to trust that the school system should have expectations that adequate yearly progress will be made and that it should be measurable. In order for a school to have made adequate yearly progress, it must meet its target for student reading and math aptitude each year.

No Child Left Behind also requires that all teachers be highly qualified. This term refers to the fact that each teacher within the school should be fully certified by the state and that they must demonstrate their knowledge of the subject they teach through specific credentials or scores on tests. Though a teacher with Special Education certification may pass subject area testing on page 44
would never grow up and may never stop motherly preoccupations with a child who smile as if nothing bad had happened! For each morning and serve breakfast with a mommy who would religiously wake up screamed at and even bitten. I had been a “PLEASE DO NOT DISTURB” sign on a "any more!" I heard myself blurt out loud. This was not a new revelation but I now had a new level of conviction. The power of that thought in that particular moment opened me up to a viscerally state of self-preservation. When your baby bites your breast, it is time to wean!

The Final Battle

We had moved twice before, each time had resulting in psychiatric hospitalization. This time was different. I could retreat into my apartment and lock the door. It worked for a few months. Then one day she launched a physical attack. I reached the door of my apartment, entered quickly and locked it. I warned her: “If you don’t calm down, I will call the police!” She replied in her evil cartoon voice: “HA HA HA, I will NOT allow over, they can improve the lives of those with limited communication skills. ABA/ VB should be considered best practices for teaching adults with disabilities so that they can continue to grow and change over time in the least restrictive environments.

Vivian Attanasio, BCBA, is Director of BIP, James O’Brien, BCBA, is an ABA Consultant, and Amy Bukzspan, BCBA, is a Behavior Intervention Specialist at Services for the UnderServed Inc. For more information, contact Vivian Attanasio at vattanasio@sus.org or visit www.sus.org.

References


anxious, depressed, or tired. Instead of hanging in there and getting himself to work on Thursdays, he’d give up and call in “sick.”

Zach was working toward his A.S. in Information Technology and was very bright. When he was at his internship, he did a good job. But as Woody Allen said “Eighty percent of success is showing up.” Here is how I helped Zach.

Strategies to Help “Underground Thursday Challenged” Zach

I had him turn in a copy of his internship timesheet to me every week or every two weeks so we could review his work and attendance and identify any reoccurring patterns. This allowed me to show him in black and white, that he was missing work on most Thursdays.

In addition to having Zach set multiple alarms to get up on Thursdays as an audio clue, we looked at his underlying problem of anxiety and depression and realized that Zach’s stress was being dealt with by avoidance.

He also told me that he had trouble remembering to take his medications for anxiety and depression when he was feeling anxious or depressed. We looked at this pattern as well. Having Zach verify with me that he had taken his medication daily (via a quick check-in, text, or email) also helped.

Jennifer Kolarik and CIP Brevard student Thea Judin

We set up a sleep routine (that he would track and chart) and made getting a good night’s sleep another self-help priority.

We asked his supervisor at work if Zach could start an hour later in the morning or stay an hour later in the afternoon. Zach was one of those people who just need a little extra time in the mornings. Being able to start his job a bit later (am instead of 8 am or 9 am allowed Zach to be on time and the accommodation was motivation to stop calling in sick half way through the week.

At one point we considered having Zach work a part-time job. Although I would love for every young adult to maintain a full-time job (whether volunteer, internship, or paid), I would rather see a student work part-time 20-30 hours per week and be successful than try unsuccessfully maintain a full-time job.

This article was excerpted from Chapter 5, Autism and Learning Differences (An Active Learning Teaching Toolkit); by Dr. Michael McMannon, EdD, and Francine Britton, published by Jessica Kingsley Publishers, London 2015.

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References

role which includes lack of emotional expression, control, and self-reliance. Typically men have a more active coping style than women and prefer active problem solving rather than talking about the problems. The general misconception that therapy involves merely talking about problems rather than actively solving problems tends to deter men from participating in treatment. Engaging fathers requires effort by parents and therapists alike to ascertain attitudes about the importance of involving fathers in child and family are important.

Fathers of Children with Developmental Disabilities

Prior to 2000, there was a consensus in the professional literature that mothers and fathers initially respond differently to a child with a disability. Fathers seem less emotional and focus traditionally more on long-term problems such as the financial burden. Mothers respond more openly with their emotions and are more concerned with the challenges of the daily care of the child. Consequently, fathers who are less involved in daily interaction with their children tend to have a prolonged period of denial about the disability and its implications (Seligman and Darling, 2007).

Parental roles were thus polarized, and fathers were observed to be uncomfortable with female-dominated service systems. The daytime hours of schools and agencies did not accommodate fathers’ working lives. In their discussion of fathers in early intervention and family support programs, Davis and May (1991) pointed out that fathers of children with intellectual disabilities were frequently considered as an afterthought by professionals.

Fathers of Children with Autism

Recent research literature on fathers of children with autism lacks topics that relate to paternal involvement in intervention for their child and intervention on fathers themselves. In research on mothers and fathers of preschool and school-age children with autism, Hastings et al. (2005) found that fathers reported using more avoidant coping strategies and less problem-focused coping than did mothers. The emotions of fathers are often unacknowledged or seen as secondary to the needs of the child and mother, and these findings have clear implications for clinical practice.

While mothers typically seek help from external sources, fathers are more likely to rely on the support of their partner (Bristol et al., 1998). This reason is that clinicians will best meet the needs of fathers by working toward strengthening the relationship between the parents and facilitating communication on the day to day issues. Some fathers have indeed been supported by other fathers of a child with an ASD. Clinicians can facilitate these connections where men can discuss their concerns and possibly show emotion with peers.

Until lately, there was a lack of research about the importance of involving fathers in child and family are important.

Increasing Father Involvement

Given the increased evidence of greater male parent involvement with their children, one would expect greater participation of fathers in early intervention for their children with ASD. Nonetheless, mothers continue to be the primary participants in both autism research and early intervention. This de-facto one-parent participation model ignores the growing evidence that mothers and fathers each play an early and integral role in the development of their children, perhaps particularly in their early and communicative skills (Filippin & Crais, 2011). Continuing to ignore fathers may result in missing opportunities to maximize social-communicative gains for young children with ASD.

Evidence from studies of father–child interactions with typically developing children indicates that fathers offer different language models than mothers which make important contributions to children’s language development (Clarke-Stewart, 1980). Fathers tend to use a more complex language model with their children than do mothers such as with vocabulary that is more varied. Although it is likely that this may apply to communicative development for children with ASD, there is less evidence to support this as extensive evidence, Filippin and Crais (2011) found only three single-subject experiments that specifically reported that fathers participated in parent communication training with their child with autism. An assumption seems to be that outcomes for mothers also apply to fathers. However, as discussed, fathers have different language models and may have a unique influence on communicative development of their children.

Also through play, both mothers and fathers help their children achieve higher level language and symbolic abilities, and there are qualitative and quantitative differences between paternal and maternal play with their child with ASD. In addition, fathers are more likely to engage in play that stretches beyond the physical properties of the toys (Bristol et al., 1998). As their child’s play partner, fathers have a distinctive role in supporting their child’s development through play. Research has demonstrated that interventions can improve both play and language outcomes for children with ASD, but the intervention did not record data specifically on fathers (Kasari, Paparella, Freeman, & Jahromi, 2008).

From a parental perspective, it tends to be more difficult to engage in play with a child who has less repetitive and more varied play. However, with intervention fathers may be uniquely suited to support the play development of their children with ASD.

Conclusion

By focusing primarily on mothers, researchers, and interventionists may be inadvertently placing burdens on mothers. Since fathers more commonly work more hours outside the home, employment provides a respite and may in part explain their lower levels of stress as compared to mothers. Increasing father involvement in early intervention and special education may have positive outcomes for both children and parents. Flippin and Crais (2011) conclude that fathers have unique ways of playing and social interactions, and the emotions of fathers may have a unique influence on communicative development of their children.

Flippin and Crais (2011) conclude that fathers have unique ways of playing and social interactions, and the emotions of fathers may have a unique influence on communicative development of their children. Flippin and Crais (2011) conclude that fathers have unique ways of playing and social interactions, and the emotions of fathers may have a unique influence on communicative development of their children. Flippin and Crais (2011) conclude that fathers have unique ways of playing and social interactions, and the emotions of fathers may have a unique influence on communicative development of their children. Flippin and Crais (2011) conclude that fathers have unique ways of playing and social interactions, and the emotions of fathers may have a unique influence on communicative development of their children.
may impact behaviors. For example, evaluators may review prior medical records (with appropriate consent, of course) to identify potential medical causes or influences on the behavior. In this example, evaluators may discover that the client has a history of chronic ear aches and infections. Evaluators may look to identify how these aches and infections may impact the target behavior. Prior testing results, previously attempted interventions, and recommendations of past service providers may also yield helpful information.

Evaluators should also complete an interview with relevant parties including parents, caregivers, teachers, siblings, or anyone else with consistent client contact (in some cases, even the client herself) (Alberto & Troutman, 2012). The information provided is necessarily impacted by the interviewee’s relationship with the client. Evaluators are interested in the form or topography of the behavior, the contexts where the behavior occurs, situations when the behavior never occurs, and the time of day behaviors are most likely to occur. Sleep patterns, medication, medication changes, and dietary factors may also be important types of information.

Finally, rating scales are another type of indirect assessments used to help evaluators ascertain why individuals believe behaviors are occurring. Specific rating scales, like the Motivation Assessment Scale (MAS; Durand & Crimmins, 1990) or the Questions About Behavior Function (QABF; Matson & Vollmer, 1995), provide a series of questions interviewees are asked to rate on a Likert-scale rating (e.g., 1 is less likely to 6 is most likely). These assessment settings are identified by the evaluator, this information may be used to determine how to prevent a behavior from occurring or how to decrease the likelihood of a behavior.

A final direct assessment evaluators may use is called a preference assessment. Evaluators may conduct preference assessments to assist them in identifying stimuli likely to serve as reinforcers specific to an individual student. Preference assessment may also be completed indirectly by interviewing others or by completing rating scales about reinforcers. However, research has shown that direct preference assessments yield most accurate results.

### Data Analysis

Following the completion of indirect and direct assessments, evaluators analyze all the data. The purpose of the data review is to illuminate any patterns among antecedents, behaviors, and consequences (O’Neill et al., 1997). While reviewing assessment data, evaluators seek to answer the following questions:

- Are the same antecedents occasioning behaviors?
- Are behaviors followed by similar consequences?
- Is the behavior occurring within the context of the same activity, materials, and/or people?
- Does the individual terminate the behavior following a particular consequence?

A high quality FBA will include data and graphs to depict the findings of the analysis. The results of an FBA lead to a hypothesis about why behaviors occur. Hypotheses may include any one of the 8 functions shown in Table 1 below or any combination of those functions.

<table>
<thead>
<tr>
<th>Possible Function</th>
<th>Variations</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get Something</td>
<td>Obtain Attention</td>
<td>Child hits sibling. Child receives long lecture about not hitting.</td>
</tr>
<tr>
<td></td>
<td>Obtain Objects</td>
<td>Child throws tantrum at checkout line. Child gets candy to stop tantrum.</td>
</tr>
<tr>
<td></td>
<td>Obtain Activities</td>
<td>Child has a meltdown so staff let him play on computer to self-calm.</td>
</tr>
<tr>
<td></td>
<td>Obtain Sensory</td>
<td>Child rocks back and forth and wiggles fingers. Child receives visual input.</td>
</tr>
<tr>
<td>Avoid Something</td>
<td>Escape Attention</td>
<td>Child never raises hands during class to avoid being called upon.</td>
</tr>
<tr>
<td></td>
<td>Escape Objects</td>
<td>During mealtime, child throws food and plate. Non-preferred food is removed.</td>
</tr>
<tr>
<td></td>
<td>Escape Activities</td>
<td>Child during group instruction, child hits peers, child is sent to time out.</td>
</tr>
<tr>
<td></td>
<td>Escape Sensory</td>
<td>Child has a stomach ache. Child hits self in the head and endorphins relieve the belly pain.</td>
</tr>
</tbody>
</table>

### References


recovery are widely accepted. Occasional-ly we do not know what has triggered the agitation, since there are both fast and slow triggers. A person may become upset by a loud noise, or a series of small events such as their favorite shirt not being available and the bus running late. During this pe-riod stressed individuals are unable to stay on task and may be non-compliant. Con-frontation or punishment at this stage may serve to create an additional trigger and result in an even greater adrenal cortisol secretion. During the acceleration phase, many individuals will attempt to draw others in by hitting or screaming. In peak, out-of-control periods, cortisol has impaired coping functions. Restraint is sometimes needed in order to keep the person from harming themselves or others. During the de-escalation period, students become calmer. Finally the cortisol level diminish-es and a period of subdued behavior and interactions follows.

Typical descriptions of the acting out cycle include “went crazy;” “lost it;” and “gowed nuts.” These descriptions are harm-ful because they blame the person and do not acknowledge the cortisol excitation that has made them biologically unable to access normal thinking. We would not pun-ish a person with cerebral palsy for walk-ing slowly. It is well known that peo-ple with ASD become easily over aroused and, once over-stimulated, they remain so for extended periods (Baranek, 2002). We need to stop punishing individuals with ASD, in a state of adrenal cortical arousal, for not being able to respond appropriately. It is impossible for them to do so!

Understanding that adrenal cortical excita-tion can last for hours, or even days in some individuals, is crucial when design-ing interventions. Every time Anne-Marie began to quiet down, she would re-mem-ber the dog and “go off again,” crying and ter-rified. Her mother tried reassuring her and then ignoring her behavior, but noth-ing worked.

On Monday, Catherine tried to de-drama-tize the incident by telling a social story about the dog. “The dog….made so much noise….and we all told that dog to stop.

Ann-Marie was the bravest of all! She stood there and said, ‘Go away, dog!’

Anne-Marie began to repeat, “Go away dog!” and smiled calmly. The cortisol had finally drained and she could access her neo-cortex and was able to learn a new skill (Maurice, 1993, pp. 179). Social stories, de-veloped by Carol Grey (1993), are anteced-ent prompts to prepare individuals with ASD for events that are stressful. They de-scribe situations from the person’s point of view and suggest different behaviors. Once a trigger has been identified, a story can be written to prepare the individual with a way to manage the stressful stimulus.

Nathan hated loud noises, especially fire drills. He would scream for hours after the loud warning rang. So we wrote The Fire Drill Tree (Grey, 1994) as a book that ed-geed his stress, and related a sequence of events he should follow. He read the book over and over on fire drill days and was able to keep himself calmer, refraining from screaming.

The response to a student, who is agi-tated or even in the out-of-control phase, is critical. Punishment will only increase the stress reaction. There should be con-sequences for inappropriate behavior, but no, ever during the threes of an episode is not the time to enforce them. A person in the midst of adrenal cortical excitation is not capable of learning, so response strategies need to be taught and reviewed frequently.

Breathing is an important tool in calm-ing the mind. When an individual inhales slowly, with a longer exhale, it helps the body to become calm. Individuals with ASD can be taught slow, careful breathing techniques. Directing a person to “breathe with me” is much more effective then shouting “calm down!”

Individuals have different ways to recov-er from stressful situations. When parents, teachers or caregivers are aware of indi-vidual preferences, they can offer choices. Music can be very calming. Some teachers use motor-related songs, beginning with large movements and ending with whispers and slow controlled movements. Blanket rubs, weighted vests or slow rocking can be soothing and allow the brain to quiet down. The old phrase, “take a walk and get a drink,” is often effective since the water can help to dilute the cortisol.

David became highly agitated if his bus was late or the schedule changed. Sending him to a “time-out” room, as punishment for screaming and biting, in-creased his behavior. A calm-down area was created in a private corner. David was introduced to the area first, and reminded that he could choose to listen to music, look at train schedules, or sit in the beanbag chair when he felt agitated. He found the bean-bag chair soothing and would often pull a acoustic book to highlight his solitary time, similar to Temple Grandin’s squeeze machine. He was usually able to return to his task after about 20 minutes. Eventually he learned to ask for the calm-down area.

Individuals with ASD are physiologi-cally prone to higher levels of cortical excita-tion than others. Caregivers, teachers and parents must be aware of this chemical response to stress and its longer duration. Most people know when they are getting upset and have developed strategies to help them calm down. This is even more im-portant for children and adults with autism.

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References


Setting Events from page 17

behavioral terms, reinforcing the behavior. The reinforcement occurs because the outcome of the behavior either meets a felt need, or provides some type of physical, social, or emotional pleasure or satisfaction. A cornerstone of behavior intervention involves developing an understanding of the various factors that help to explain why the problem behavior occurs. This includes the identification of: (a) the settings events, described below, (b) the antecedents, which specifically cause the behavior to occur, (c) an operationally defined problem behavior, and (d) an outcome or consequence that results from the behavior, which the person finds rewarding and motivates them to engage in the behavior again. These elements are sometimes referred to as the “four-term contingency.”

For example, an individual may be prompted to perform a task s/he does not wish to complete, and they may respond by engaging in problem behavior. When the caregivers shift their attention to managing the behavior, it may be difficult to follow through on efforts to get the person to complete the task. If the individual does not complete the task, the behavior is reinforced by the individual’s escape from the demands. Researchers have identified a variety of other functional patterns in addition to escape, which include gaining or avoiding social attention, gaining access to items or activities the individual desires, and creating patterns of sensory stimulation that are satisfying or comforting (Carr, 1994). Accurate identification of these functions often leads to individualized strategies, and when these are applied systematically, proactively, and in conjunction with a wide array of educational and other support programs, can make a tremendous impact on effectively reducing the frequency and severity of problematic behaviors, and supporting more positive behavioral alternatives. One challenge in applying these strategies with individuals who have ASDs though, is that characteristics of the ASD may serve to increase the likelihood of problem behaviors. In some cases, the occurrence of a disorder, specific disability, or psychiatric illness may be considered a setting event for the occurrence of problem behavior. This is significant because psychotropic medications have the potential to alter an individual’s response to environmental stimuli. For instance, researchers have recommended that selection of psychotropic medications include consideration of specific pharmacological treatment effects on an individual’s response to environmental stimuli maintaining both adaptive and problematic behavior (Thompson & Symons, 1999; Schall & Hackenberg, 1994). This highlights an important concern regarding the relationship between functional assessment of behavior, function based behavioral intervention, and drug treatment.

These factors highlight a variety of concerns related to the impact of what would be considered setting events, on the development and implementation of effective behavior support plans for individuals with ASD. Several examples highlight this concern. First, many individuals with ASD have an unusual need or craving for specific types of sensory stimulation. Understanding the unique pattern of sensory needs and their relationship to problematic behaviors is an important factor in developing effective intervention and support strategies. The focus on setting events provides a means of making adaptations to proactively meet sensory stimulation needs part of a support plan designed to prevent the problematic behaviors.

A related consideration is the frequent co-occurrence ASD and anxiety disorders (White et al., 2009). The experience of anxiety, its impact on adaptive functioning, and the potential justification for diagnosis of a co-occurring disorder often are overshadowed by the symptoms and problematic behaviors that accompany an ASD. Appropriate identification of anxiety, and determination of the role this plays as a predisposing factor for problematic behavior, is an important factor in developing appropriate and effective supports. Specifying feelings of anxiety as a setting event would justify the inclusion of calming activities or relaxation exercises as a precursor intervention designed to prevent the problem behavior. Recognition of an anxiety disorder as a setting event would indicate that the intervention and treatment of that disorder should be identified as a prevention strategy for those problem behaviors. This kind of assessment of behavior and development of a Functional Behavioral Assessment hypothesis afford the opportunity both to recognize and address important factors that often are neglected in developing behavior plans, along with establishing a framework that facilitates the integration of behavior intervention and support planning with clinical intervention. In addition to identifying environmental variables that precede and follow problem behavior, the functional assessment gathers information about an individual’s communication, social skills, and other aspects of adaptive functioning and circumstances. This information can be used to design interventions to teach the individual new skills effectively competing with a problem behavior. For instance, an individual may engage in disruptive behavior at school or work in order to avoid persisting on a difficult task. The functional assessment process may indicate that the individual does not know how to ask for assistance or how to complete the task. In other cases, an individual may have strong social and communication skills that are not being used in settings where problem behaviors are occurring. Information related to an individual’s social and communication skills will provide the foundation for selection and teaching of new, adaptive skills that may function to replace problem behaviors or reduce the motivation to perform them.

The clinician or behavior specialist who desires to work with individuals with ASD and who may be dually diagnosed should become familiar with the clinical literature regarding mental illnesses and their treatment. An understanding of psychiatric diagnoses and pharmacological treatments is extremely important in providing the most comprehensive and effective intervention and support. In the mental health literature, it has been noted that one of the most critical areas of support for families is information about mental illness, the impact it may have on behavior, and how these conditions can be treated. Valuable resources for obtaining such information can be found through the National Association for Dual Diagnosis, with a listing of resources on NADD’s website (www.thenadd.org). Care providers also need to know how the mental illness will likely affect the behavior of the person. In conclusion, we wish to highlight the need for consideration of the very nature of ASDs as a potential setting event for problem behavior. We encourage the creation of comprehensive functional assessments that consider both ASDs and potential anxiety disorders among persons with ASDs. Effective treatment of challenging behaviors requires thinking across various ways in which we as a field have looked at understanding problem behaviors.

References


Behavioral Health News Leadership Awards Reception

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up with too much stuff going on I get upset and cry. No one understands that just because I get upset and cry it doesn’t mean that I do not like what I am doing. Sometimes, it is just too much - too long. I still like to do things like everyone else. Sometimes everything is too much for me, the noise, the people - I become very anxious and get very upset.” That day the staff realized: We need to take the time to understand. Sometimes, people with autism cannot tell us what is not working or why. But with listening, gentle support, a deep respect, trust and meaningful relationship, different approaches may bring out wonderful experiences.

Institutionalized with No Potential Seen
When we met Mike, he was institutionalized and had been for most of his life. He was seen as severely autistic, non-communicative, with limited social skills. He had had many behavioral problems. He was destined to leave the institution because of the institution being closed, not because people there saw a brighter future for him. Once out, he moved in with his family and then began to receive support in his new home. One of his supporters felt that Mike was trapped into a web of autism and began to help him to have a voice. His supporter helped him to identify common boards and devices. This support staff was amazed at the interest and intelligence that Mike exhibited as they began to research what might work for him. Mike essentially made all the decisions, and worked to order the device. At times of day. Once it is identified that a flood of information came from Mike. He was so misunderstood before. He was a man of great strength, intelligence and aspirations for a betterlife. He was a man who had not had a bit of education who then also began to work on his GED diploma.

“I want to say this is the happiest I have felt in a long time. Also, I can’t believe that I am actually excited about the future. The actual thought of attending a university is now a living reality. A benchmark of some sort I am here today. I am very pleased at all of the progress we have made. Eats a per- sonal approach and predictability of disciplinary pro- cedures is a good fit when working on promoting appropriate behaviors for students and parents. Parental involvement and support is often crucial to the success of these supports.

PBIS focuses on student outcomes and behaviors in both the academic and social arenas. Students with ASD benefit from routine and structure. PBIS sets clearly stated rules and school-wide expectations. Consequently, the PBIS approach is helpful to promote appropriate behavior and address challenging behavior. Consistent teaching and re-teaching of expectations is an integral component of each tier of support under PBIS. The collaborative team approach and predictability of disciplinary procedures is a good fit when working on promoting appropriate behaviors for students with ASD.

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References
Wong, C., Odom, S.L., Hume, K., Cox, A. W., Fettig, A., Kucharzcyzk, S., … Schultz, T.R., (2013). It is widely accepted that students with Autism Spectrum Disorder learn best when given concrete rules and consistent reinforcement. Their stress level is also diminished when they can predict their environment (LaVoie, 2005). The school-wide and individual evaluation of these students with Autism Spectrum Disorder. The explicit nature of the PBIS framework operationalizes pro-social values so students can better understand the behavioral expectations across all settings (i.e. classroom, hallways & cafeteria). Tier-two and tier-three interventions provide the opportunity to help students understand how to address appropriate behaviors across all school settings. As you would imagine, parental involvement and support is often crucial to the success of these supports.

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anything additional professionals are faced with a treatment and intervention challenge. Often, the content is misunderstand ing the function of the undesirable or challenging behavior (Toussaint & Tiger, 2012). Professionals must discreetly observe the individual engaging in this behavior in the absence of other people, without a response from anyone and across environments and various times of day. Once it is identified that the function of the behavior is automatic, therapeutic interventions can be designed and implemented. Although such functional analyses are extremely useful for the basis of treatment development, assessments are often not possible due to the risks of harm to the individual or therapists (Borrero & Borrero, 2008).

Of all behavior that can occur, aggressive and self-injurious behaviors are by far the most dangerous and troublesome to treat. By identifying the reinforcing variables and the function of these behaviors, professionals can look to create treatment plans that will replace the harmful behavior and often functional analyses are conducted in order to ascertain that automatic reinforcement is the true function of self-injurious behavior (Toussaint & Tiger, 2012). Professionals must discreetly observe the individual engaging in this behavior in the absence of other people, without a response from anyone and across environments and various times of day. Once it is identified that the function of the behavior is automatic, therapeutic interventions can be designed and implemented. Although such functional analyses are extremely useful for the basis of treatment development, assessments are often not possible due to the risks of harm to the individual or therapists (Borrero & Borrero, 2008).

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Q SAC (Quality Services for the Autism Community) is committed to providing the most appropriate interventions to our participants as possible. As a behavior specialist and therapist, the content and evidence-based practices to improve the lives of our participants in a socially significant and safe way. For more information related to challenging behavior and/or treatment plans, please view our website at www.q sac.com or contact Rachel directly at rlaplana@q sac.com or 718-728-8476.

References


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Antecedent-based strategies - Techniques that change the environment prior to the occurrence of a behavior in order to prevent that behavior from occurring are known as antecedent-based strategies. These techniques may include providing access to preferred items/activities or breaks from task demands on a schedule independent of the occurrence of the maladaptive behavior in order to reduce an individual’s motivation to engage in problem behavior. This procedure, referred to as noncontingent reinforcement (NCR), has been shown to be effective in reducing problem behavior in individuals with autism (Vollmer, Iwata, Zarcone, Smith, & Mazaleski, 1993), and may be effectively combined with other behavioral interventions.

Antecedent-based strategies are a particularly important tool in the treatment of problem behavior in adults with ASD. As noted previously, older individuals with ASD may be capable of extremely dangerous and harmful actions as compared to the capabilities of children. As the saying goes, an ounce of prevention is worth a pound of cure. However, the use of strategies like NCR require the presence of an adequate number of well-trained staff to ensure that the schedule is followed correctly and consistently.

Consequence-based strategies - The last category of interventions are those which alter the outcomes produced by the behavior in a way that makes the behavior less likely to happen again in the future. Consequence-based strategies may include breaking the relationship between a behavior and the outcome that has previously been associated with it, known as extinction, and may also include removing something from the individual’s environment which makes the problem behavior less likely to occur in the future, referred to as punishment.

It is important to note that, in many cases, these interventions may be combined in a way that improves their effectiveness for addressing problem behavior. For example, when attempting to reduce problem behavior through the training of a new adaptive communicative request with FCT, it can be advantageous to have problem behavior contact extinction. This effectively creates a scenario where the new response “works” and the old one does not, which can increase the speed at which the desired behavioral change occurs.

When intervening with adults with ASD in particular, the risks of implementing extinction may be prohibitive. Under these circumstances, practitioners need to emphasize the use of preventative procedures and FCT to address challenging behavior. Identifying strategies for decreasing maladaptive behavior without the use of extinction represents an important area in need of research.

In conclusion, as rates of autism diagnosis continue to rise, more and more adults with ASD are in need of effective assessment and treatment procedures. Despite the fact that the majority of the related literature reflects the needs of children with autism, some helpful insights regarding working with the adult population have emerged. Assessment strategies, such as AB analyses, trial-based functional analyses (FA), and precursor FAs, represent empirically-sound assessment procedures that may limit the risks associated with challenging behavior in older populations. Relatively little research has investigated treatment issues as specific to individuals with ASD. Preventative strategies, replacement skills (FCT) and extinction all remain key components in designing effective interventions for this population. In which extinction is not a viable option, practitioners must increase emphasis on other preventative treatment components to keep people safe.

There exists a troubling gap in state of assessment and intervention for older individuals with ASD. Failure to identify viable solutions for this population can lead to poor outcomes, including more intrusive interventions, more restrictive placements, and an increased likelihood of psychotropic medication use. The assessment and treatment approaches outlined above provide an important starting point in the development of a comprehensive model of care for this rapidly growing population.

References

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language; ask simple questions to identify real danger(s); clarify understanding of instructions; pause to allow time to process information; and redirect conversation to stay on topic.

Practical interventions for families:

• To reduce drowning risk teach water safety; use locked fences/gates around any source of water; train life guards to recognize ASD; utilize safety mechanisms including alarms; notify neighbors, pool owners, and local first responders; and ensure adequate supervision during outings near water.

• For elopement challenges, use video modeling, reinforcements, and social stories to teach person to walk safely. Use special locks, personal tracking devices and security alarms. Use identification such as ASD alert card, medical alert jewelry, or iron-on garment labels; child identification kits.

• In preventing abduction and sexual exploitation, use role playing, video modeling, and practice scripts with common lures. Use social stories relating to whom to approach for help, methods of recognizing and avoiding uncomfortable and unsafe situations.

• To increase travel safety, use adaptive car seats or transport safety restraint; establish travel rules; and use social stories.

• Consider the use of service animals to help protect, calm, regulate behaviors, and prevent escape.

• Evaluate if proper use of 911 should be taught if the person does not recognize real dangers or emergencies.

Resources

Children’s Specialized Hospital has assembled a free, downloadable resource for people with ASD, caregivers, and service providers. Resources include the Autism Family Safety Handbook, “911 Means Emergency” pamphlet for individuals and first responders, emergency information forms, identification cards, and more available at www.childrens-specialized.org/KohlsAutismAwareness/safety.

Additional Resources


National Autism Association Autism Safety www.autismsafety.org

Jill F. Harris, PhD, is Director of Program Development and Adrienne Robertiello is Autism Educator at Children’s Specialized Hospital. Please visit www.childrens-specialized.org.

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supports, scripts to outline the presenting problem, and coming up with reasonable solutions to the problem can be effective tools to use when students face scenarios that seem dire and hopeless to them. For instance, presenting a visual diagram of the problem helps students think about how they may adjust and modify their behavior. When students expend their energy on small problems, they often get drained and become unmotivated to learn. Oftentimes, these small problems can lead students to feeling overwhelmed. Frequently, students with HFA will need guidance in developing solutions to these problems to prevent an extreme emotional and behavioral challenge. In this context, and for example, not receiving a perfect score on a test could be experienced as a traumatic event for a student with a rigid thought process. Frequent practice is often required to prepare students for the fact that they will be presented with problems on an ongoing basis and that these problems will vary in magnitude depending on the issue. Forgetting to bring in your homework or losing a game is a less severe problem than getting into a fight on the playground. Learning to recognize the size of the problem and the reaction that matches this problem is an important skill that students must learn. Cognitive restructuring, a skill used in a social context (Wellman, Baron-Cohen, Caswell, Gomez, Swettenham, Toye, & Lagattuta, 2002), also can be taught. Social based interventions such as modeling, reinforcement, and social stories can further improve skill development in natural settings (Gray, 2000; Matson, 2007). For example, the goal of a social story is to provide correct social information leading the student to more appropriate responses. In school, many students with HFA often experience anxiety, which affects their ability to focus, participate in social activities with peers, and in instruction. With the use of social stories and problem solving skills may lead to increased anxiety and behavioral challenges in school. Many students may appear to be noncompliant or oppositional, when in fact the behaviors they are demonstrating are more related to skill deficits. Many students with HFA experience anxiety related to specific fears which appear to be a result of conditioned learning (Koegel, Openden, & Koegel, 2004). These phobias may be successfully addressed using systematic desensitization interventions. Systematic desensitization can be done by gradually teaching students to tolerate stimuli that present as aversive to them. Many students with HFA experience difficulties with emotional recognition and regulation. Teaching correct recognition of emotions can be done using videos, books, or through video modeling. Video modeling for individuals with ASDs has shown to be effective in addressing social–communication skills, functional skills, and behavior. Additional skills learned through video modeling can be maintained over time and generalized to other settings (Bellini & Akullian, 2007). Behavior mapping is another tool that teaches students to conceptualize what behavior is exhibited and what factors may have caused them to become angry or frustrated, so it is important to listen to what they have to say. The use of Atwood’s emotional thermometer (2004), to allow the student to self-rate the level of intensity of their emotions in the moment can be helpful. What is considered to be challenging behavior can take many forms and may require different reactive approaches. Whichever approach is used, it is important to remain calm while helping the student to de-escalate. When the student is calm, this serves as an opportunity to debrief and discuss possible alternative solutions to the challenging behavior that was exhibited, and to develop a plan should the student encounter this problem again. Edel McCarville, PsyD, is a School Psychologist and Colleen Menard, MSEd, is a Speech and Language Pathologist with Special Education for Public Schools. For more information, please contact Edel at emccarville@levittownschools.com.

References


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to make it less available. In some organizations all employees are trained in the use of physical interventions. Simply adopting a policy whereby only the absolute fewest number of staff necessary in a given location are trained sends a powerful message. As does adopting a policy that only our “best” or most “experienced” employees will be so trained. This can be applied by keeping tools used for physical restraint out of easy reach, and ensuring that all participants in the process understand that physical restraint is a last resort.

9) Increase Scrutiny of Physical Interventions - It’s important to not only use positive reinforcement, but also to reduce the use of physical interventions. Taking a careful look at instances when physical intervention is used can help in this effort.

This means pausing after the situation is over and considering some key questions: What triggered the situation? What could prevent or minimize the challenging behavior in the future? Can the situation be avoided altogether? How could caregivers proactively reinforce positive behaviors to replace the challenging behavior?

In an organizational setting, scrutiny of these instances also sends a powerful message throughout the organization that these are serious goals being set. Scrutiny will be even more effective if it emphasizes a search for root causes rather than blame.

It’s important that the entire environment of the culture commit to making this change—one individual can’t effect this change alone. But when these steps are applied consistently over time, this shift should be successful in most environments—The Arc of Delaware County team has seen it time and again within the organization, as well as in other organizations that adopt this method.

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based on why the behavior occurred were attempted, but it was not until strategies to address these specific environmental antecedents were implemented that problem behavior was consistently decreased. Horner, Day, and Day (1997), identified that delaying or cancelling a planned activity (e.g., school events and outings) increased the likelihood of problem behavior, specifically during academic work, for persons with developmental delays. For both individuals, the treatment included specific components (e.g., 10 minutes access to a preferred activity or rescheduling the event on a calendar) to prevent problem behavior during days that the antecedents occurred.

In summary, when treating problem behavior, it is crucial to focus on how one can alter the consequences of problem behavior when developing interventions, but it is as important to consider antecedent events. In all of the studies discussed above, antecedents were strategically assessed, meaning that data were collected on a daily basis regarding problematic behaviors and specific antecedents. This type of assessment is crucial to determine if and how antecedent events are playing a role in an individual’s challenging behavior. Following this assessment, strategies can be planned to control the effects these variables have on problem behavior. It is important that these treatment components are used strategically before the occurrence of problem behavior. For example, if a child is found to be more likely to engage in problem behavior to get out of homework when he/she is tired, it may be beneficial to allow for a nap or decrease the amount of work on days that he/she is tired before problem behavior occurs. Reactive strategies, such as allowing a child to stop working following problem behavior and take a nap because the child is tired should be avoided, as this is likely to exacerbate the problem by teaching the child that problem behavior results in a break from work. Instead, caregivers/teachers should take data on sleep and problematic behaviors to determine if a relationship exists between them, and if it does then strategize an environment to prioritize starting homework on these days. Environment-behavior relationships are crucial in understanding challenging behaviors exhibited by individuals diagnosed with ASD, and best practice is to consider both antecedents and consequences in behavioral assessments and treatments.

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References


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2014, December) and Risperidone (Seahill, Koenig, Carroll, Pachler, 2007), can produce unwanted challenges. Two concerning side effects of Risperidone include weight gain and an increase in appetite (Seachill, et al., 2007), and these unintended results carry additional significance with a child who is already displaying aggressive behaviors. Additionally, if the function of the self-injury or aggression was to gain access to food or if food was the most reinforcing item to a child prior to the introduction of the Risperidone, the child’s difficulties could be exacerbated.

A diagnosis separate to an autism diagnosis is another possible explanation for self-injury and aggression, so, it is critical that individuals undergo a thorough evaluation and receive accurate diagnoses. Tsiouris, Mann, Patti, and Sturme (2003) found that aggression and self-injury was not an equivalent symptom of depression in individuals with intellectual disabilities. As a result, it would not be logical to assume that an individual with an intellectual disability possesses a dual diagnosis of depression due to displays of self-injury or aggression. However, it is worth considering if another underlying disorder is influencing the individual’s behaviors. It is also beneficial to receive a second opinion when there are questions or inconsistencies within a diagnosis.

Medical diagnosis in combination with autism can also exacerbate a child’s impairments. For example, seizure disorders are prevalent in individuals with autism spectrum disorders, particularly when there is a comorbid diagnosis of intellectual disability (Matson, Shoemaker, 2009), and studies have shown that children with seizure disorders display greater impairments in the areas of adaptive behaviors, personal/social abilities, communication, motor abilities, and cognitive abilities than children without seizure disorders (Matson, Neal, Hess, Mahan, & Fodstad, 2010). It is also suspected that seizure disorders impact children with ASD to a greater degree than children with other development delays (e.g., spina bifida, cerebral palsy, microcephaly, Down’s syndrome). Untreated medical diagnoses, such as seizure disorders, can offer a possible explanation for allaying in marked and conflicting hypotheses of the function of an individual’s self-injury or aggression.

Given these aforementioned circumstances, it is critical that caregivers of individuals with autism consider all possible explanations for self-injury and aggression displayed by their loved ones and that psychological and medical professionals investigate alternate explanations for an individual’s concerning behaviors and inform caregivers of any other possible explanation.

All treatment options explored should be evidenced-based in order to be confident that the treatment will produce the expected outcome and to avoid losing time in which effective treatments could be improving the individual’s life. When challenging behaviors such as self-injury and aggression are of concern, an effective course of action includes conducting an FBA and FA early on to rule out any maintaining sources of reinforcement that could be addressed and possibly avoid unnecessary intrusive interventions with potential side effects, prior to considering other factors that could be impacting the individual’s mood and behavior.

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References
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reaching for objects, and interest in social attention. Another punishment procedure that has resulted in decreased rumination was reported by Singh, Manning, and Angell (1982). Singh, Manning, and Angell (1982) prompted twins, who engaged in ruminative behavior, to brush their teeth, for 2 minutes, with a toothbrush soaked in Listerine and wipe their lips with a face cloth dipped in Listerine. Results of the procedure showed a decrease in ruminative behavior and an increase in stereotypic and appropriate behaviors. Due to the rapid decrease in rumination and the serious medical and social concerns related to chronic rumination, positive punishment with brushing was subsequently used as an alternative treatment for rumination. However, today clinicians evaluate the effectiveness of less restrictive procedures such as differential reinforcement of other behavior, the use of competing items, diet changes, and non-contingent access to stimuli prior to beginning a punishment-based procedure to decrease rumination.

Non-contingent delivery of food or drink has been shown to reduce ruminative behavior (Lyons, Rue, Luisselli, and DiGennaro, 2007). However, in order for these treatments to maintain low levels of rumination they often need to be delivered frequently, which can be impractical for caregivers and result in undesirable side effects for the client, such as weight gain. Therefore, researchers have also evaluated treatments which can be easily delivered frequently in a natural environment. Rhine and Varbo (2009) demonstrated that ruminative behavior, in a 6-year-old, by providing non-contingent access to chewing gum. Kliebert and Tiger (2011) decreased rumination, maintained by automatic reinforcement, by providing access to apple juice every 15 seconds, after lunch. These results, however, did not maintain in post-non-contingent juice sessions, which were conducted right after the 15 second access to apple juice. Similarly, Wilder et al., (2009), decreased rumination in a 37-year-old male by delivering an apple pie flavored spray every 10 seconds. The researchers used a audible tone to signal the participant of the preferred flavor which they had taught the individual to self-administer. Although both of these treatments were found to be effective, one major limitation exists to extending these treatments to a residential or school setting. The apple and flavor spray were delivered on a dense schedule, which would be difficult to implement across a school day or residential hours. However, these may be viable treatment options if individuals are taught to administer the items themselves or rumination does not occur throughout the day (Wildier et al., 2009).

Due to the limited success and cumbersome nature of these treatments described above, researchers have begun manipulating antecedent variables which may result in decreased rumination. Researchers evaluated the effects of caloric intake and supplemental feedings for individuals who engage in rumination. Antecedent manipulations have shown promising results in decreasing rumination. In 1981, Rast, Johnston, Drum, and Conrin systematically evaluated the effect that food quantity from regular portions to satiation portions. When the participants were eating satiation portions they were permitted to eat as many “potatoes, cream of wheat, unflavored gels, and apples as they wanted. The authors found that when participants were given satiation portions the duration and frequency of rumination decreased. Other researchers have reported similar results. For example, Green, Rawal, Vazin, and Winston, (1991). Thibadeau, Blew, Reedy, and Luisselli (1999) provided unlimited access to white bread for 1 hour post meal. The authors made the decision to use white bread because this was a preferred food item for participants. White bread starch content was similar to foods used in other satiation diet programs. This procedure resulted in significantly decreased levels of rumination. In follow-up observations the researchers found that these results were maintained up to 15 months after the conclusion of the study.

Future researchers and clinicians should evaluate different variables that may have similar effects. For example, food items include, food type (e.g., meat, starch, fruit), food texture (e.g., smooth versus crunchy), and food preference. For example, it is possible that an individual may be instructed to eat a preferred food in comparison to a non-preferred food to gain additional access to its reinforcing qualities (e.g., taste, texture). Although there are medical diagnoses that coincide with rumination as a symptom (e.g., gastro-esophageal reflux), there are times when no medical basis for rumination is apparent. In these cases behavioral interventions, in conjunction with medical recommendations or a primary treatment, may assist in decreasing or eliminating rumination. Early behavioral strategies emphasized the use of punishment, whereas more recent interventions have utilized reinforcement and antecedent modification. Behavior analysts have much to offer in the treatment of rumination given their adherence to ongoing data collection and the systematic exploration and analysis of variables that might influence rumination.

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References


Testing from page 33

nature of them at every developmental learning stage; the disregard for different learning abilities (heavens - let’s not dis- cuss the many Who’s of the year)? Mastery of these standards horrendous for our special students with severe emotional disturbances. Our special education stu- dents, as part of their IEP, typically have some but not all of the grade level standards in their IEP. The question begins to be asked: Why would we presume to test them on a standardized test which measures vast numbers of markers to which they have not been introduced. The CCSS do not pre- scribe curriculum, instructional practic- es, the materials or the texts teachers use to assist students through the learning process. However, our special students don’t neces- sarily (nor do they usually) make those gains within the one year as prescribed. For exam- ple, by the end of first grade students should be able “to write an opinion essay in which they introduce the topic or book name they are writing about, state an opinion, supply a reason for the opinion, and provide a sense of closure (CCSS W.1.1).” The adoption of this standard does not usurp the instruction of other standards. It does not prescript that in complete sentences or discern the difference between fact and opinion. In fact, pro- viding a focus for learning and a goal, how- ever lofty, and every level throughout our students’ education is profoundly necessary. The CCSS are not a curriculum, but they are an informative measure. Our students’ ability to live and learn independently will not be measured by the Partnership for Assessment of Readiness for College and Careers. According to the Washington Post (June 27, 2014) “In the 2014 Common Core Tests, the majority of students will be using CCSS. However, the CCSS are not the only curriculum that serves us poorly.

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do next can be difficult. Many parents and caregivers are left with the question of “What do I do now?” It is recommended that caregivers begin seeking assistance with primary care providers (Baxter et al., 2014). Primary care providers generally have the skills to help evaluate and decide the first course of treatment. The primary care provider is able to manage the problems in many situations. However, if additional assistance or expertise is needed then the primary care provider is able to make referrals to the correct specialists. These specialists may include allergists, gastroenterologists, psychologists, speech language pathologists, occupational therapists, registered dietitians, and/or behavior analysts. If extra assistance is needed then the caregivers, primary care provider, and additional specialists are able to work together to address the problem.

Not all feeding issues require expert assistance and there are situations where caregivers are able to intervene using simple strategies to correct the problem such as:

- **Create a schedule and routine:** This may include having your child eat at the same time and place. By creating a schedule the child will learn what is expected during meals.

- **Avoid eating all day:** Having food and drink available all day decreases your child’s appetite and may limit how much they want to eat during mealtimes. If you’re full, you’re not going to want to eat anymore!

- **Limit the amount of distractions during mealtimes:** Distractions take the focus off the food and may lead to the child being more focused on the activities rather than eating. Common distractions include television, video games, toys, books, phones, computers, and an excessive number of people.

- **Model healthy eating behaviors:** Children learn many new things by watching and imitating the behaviors of others. So make sure that you model the feeding behaviors you want to see.

Reward behaviors that you want to continue seeing: If the child exhibits a behavior you want him/her to repeat, reward him/her for doing this. Rewards may include social attention such as praise or high five’s, getting access to preferred food items, or favorite toys/activities.

- **Ignore challenging behavior:** When possible, do not provide extra attention to a child who is doing things that you do not want them to do. Common challenging feeding behaviors may include spitting, throwing food, or screaming. Limiting the amount of attention may reduce the enjoyment or any “fun” the child may be having by displaying these behaviors. At times, it may not be possible to ignore the behavior due to safety concerns and you may need to consult with an expert for additional advice concerning how to best manage your child’s challenging meal-time behaviors.

- **Follow the rule of 3:** When presenting food to your child it is important to present a combination of preferred and non-preferred food items. The rule of thumb is to offer 3 foods at a time and at least 1-2 of these foods should be items your child already likes. The other food should be an item your child does not like. This will expose your child to non-preferred food items and get him/her used to having these food items near him. Initially, encourage your child to try a small bit and gradually try to get them to eat a little more. Eventually, the goal is for the child to eat a good size portion of the new food.

- **Presentation of food items:** Altering the way you present new foods may increase your child’s willingness to try them. Present new foods in small bites or in fun, familiar ways that make it more likely your child will eat them.

- **It is important to note that each child is different and these strategies may not be effective for every child. Caregivers should have ongoing dialogue and support from the child’s primary care provider while implementing these basic strategies (Baxter et al., 2014). By using these “caregiver friendly” strategies, caregivers may be able to prevent the need for more specialized interventions (Bachmeyer, 2009).

While there are some simple strategies that families can implement without consultation from a specialist, there are also interventions that have been effective in reducing feeding problems but require a specialist. If your child continues to struggle with mealtimes using some of the simple strategies above, you will want to share these struggles with the primary care provider and perhaps contact a Board Certified Behavior Analyst (BCBA) with experience treating feeding challenges. It is important to highlight that these more complicated interventions should not be done without support and guidance from the appropriate specialist(s).

In summary, it is important to emphasize how challenging and stressful feeding problems can be for parents/caregivers of children with ASD. Feeding problems are often complicated with each child’s problems being unique. In many cases, even with professional guidance, the strategies listed above may result in slow progress marked by small, subtle gains (Baxter et al., 2014) or may be entirely ineffective. Feelings of frustration, sadness, or hopelessness may be overwhelming to caregivers. Thus, it is recommended that caregivers reach out for support and individualized coping techniques from family, friends, professionals, or support groups. By ensuring their own mental health, they may be better able to successfully implement feeding interventions like those above, in collaboration with a physician. Finally, it is recommended that caregivers keep the treatment team informed of the child’s progress and remember to celebrate even the smallest improvements.

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**References**


Emotional From page 18

start by describing your own thought pro-
cess. You can even say the exact opposite of
what might be obvious in an attempt
to draw your child out of silence. Exer-
cises like these can also be done while
watching television. Body language is
often more revealing than the spoken
word. Shows can even be watched with-
out sound to gauge a child’s awareness of
visual nuances. The difficulties these
children (and adults) face tend to be tied
to difficulties drawing social inferences,
not to a fundamental inability to connect.
There are many creative ways for parents
to help their children improve their social
capabilities.

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Best Practices from page 24

Step 1: Precisely define the problem be-

havior - Behaviors should be identified
and described in terms that are specific,
observable, and measurable. For example,
“mood swings” may be difficult to de-
scribe and may change over time. A be-
havior may be defined as a child saying
“no,” yelling, and flailing his/her body
onto the floor.” This is contrasted with labeling the child as
having “anger management problems,”
which is a functional term. A functional
behavior is sufficiently defined when two
observers could independently spot
it based on the definition provided.

Step 2: Measurement - The purpose of
measurement is to determine the frequen-
cy, intensity, and duration of a target
behavior. For example, “calling out” may
occur 3 times in a day or 10 times in a
45-minute class period. Tantrums may
occur more than twice a day and may last
minutes each and present with strong in-
tensity. The measurement stage provides
baseline data. After an intervention is
conducted, follow-up data can help deter-
mine whether the intervention is effective
and can be used to make adjustments to
the plan. Although data collection may
seem tedious, the rationale is the same
used by a physician prescribing medica-
tion for cholesterol – assessing initial and
follow-up levels ensures that the interven-
tion is working.

Step 3: Functional Assessment - The goal of
the functional assessment is to better un-
derstand the child’s reason for, or function of,
the specified behavior. Behavior typi-
cally occurs for a reason – gaining attention
from adults or peers; escaping or avoiding
a demand or request; gaining access to
something preferred (or tangible); and try-
ning to obtain or avoid something that is in-
ternally or automatically reinforcing (e.g.,
increasing time listening to pleasant music,
decreasing social pressure). Hypoth-
eses about functions are determined based on
the data collected about what occurs
directly before and after a child exhibits
the target behavior, and are often the key
to successful intervention. For example,
if the function of a child’s tantrum be-
havior is to gain the teacher’s attention,
then the teacher’s verbal reprimand
may be increasing the likelihood of it occurring
again. If a child’s tantrum behavior serves
the function of escaping a task, sending him
to time-out may be giving him exactly what
he wants. Thus, indentifying the function
of a child’s behavior is critical in order to
develop an effective intervention and mini-
imize the possibility of responding to the
problem behavior in ways that will actually
keep it going.

Step 4: Developing the plan - Writing a BIP
involves identifying behaviors you would
like to see more of (i.e. replacement behav-
iors) and selecting strategies to facilitate
the development of these behaviors. Replace-
ment behaviors can include specific skills,
such as practicing in New York City at
Spectrum Services (specservices.com) in
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