

Understanding and Treating Co-Occurring Conditions

A Person-Centered Collaborative Approach to Achieving Best Outcomes For Autistic Individuals with Co-Occurring Conditions

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Autism Spectrum Disorder (ASD) is characterized by the presence of persistent deficits in social communication and social interaction across multiple contexts as well as restrictive, repetitive behavior, interests, or activities (American Psychiatric Association, 2013). Many individuals with ASD require some level of support for social and communication skills and to promote independence with daily tasks. Additionally, some individuals may experience behavioral excesses that interfere with learning and engagement in daily activities or pose a risk to their health and safety.

The behavioral characteristics common to ASD are also often common to, or can be complicated by, a number of developmental, medical, and psychiatric conditions. Research indicates that individuals with ASD are very likely to experience



co-occurring conditions such as developmental disabilities, epilepsy, gastro-intestinal issues, sleep disruption, feeding issues, and psychiatric disorders (Autism Speaks, 2017). Knowledge of co-occurring conditions and how they may present in

individuals with ASD can inform a more comprehensive, interdisciplinary approach to behavioral assessment and intervention that supports best outcomes for individuals served. Additionally, the consistent use of the strategies discussed within this article

may help to identify new or undiagnosed conditions that may alter the course of ongoing intervention to best meet the needs of the individual.

Assessment in the Context of Co-Occurring Conditions

Behavioral assessment is a cornerstone of quality behavior analytic work, guiding the development of effective and meaningful interventions (e.g., Carr et al., 1994; Goldiamond, 1974). Individualized and contextualized behavioral assessment selection and design can also identify behavioral patterns that are indicative of possible co-occurring conditions, prompting interdisciplinary collaboration. Likewise, well-crafted assessments can guide existing collaborations and ultimately inform intervention development beyond a purely behavior analytic lens. Regardless if there is a known co-occurring condition, behavior analysts are ethically bound to consider and assess the role of health or other variables when assessing behavior and collaborate

see Collaborative on page 8

Why So Many Autistic Individuals Have Eating Disorders

By Claire Jack, PhD
Autistic Therapist and Training Provider

Eating disorders have a devastating effect on the lives of those affected and are associated with the highest mortality rates of all mental illnesses. While they can affect anyone, there is a higher incidence of people with autism who have eating disorders compared to the general population. Studies have found that between 20 and 30 percent of people with eating disorders also have autism or display signs of the condition.¹ One study showed that women with anorexia nervosa scored significantly higher on the Autism Spectrum Quotient questionnaire than women without anorexia.²

Like many others with autism, especially women, I have faced a lifetime of disordered eating, including bingeing and purging. I was overfed by my mother from a young age and discovered that food calmed me down long before I started school. My emotional eating became extreme binge eating by the age of 8. By the time I was a teenager, I'd either be bingeing or following such restrictive eating regimes that eating has never, ever been a natural or worry-free activity.



Why Are Autistic Individuals at Such High Risk of Developing Eating Disorders?

Emotional Regulation Issues - Autism is characterized by emotional regulation issues; people with autism are more likely to experience mental health issues in general, including anxiety and depression.³ Many

people develop eating disorders as a coping mechanism for anxiety or difficulties with emotional expression and communication.

Foods that are high in fat and sugar, in particular, can stimulate neurotransmitters that make someone feel calmer. Many autistic people frequently find themselves in situations that are difficult to cope with,

and food can be a way to deal with feelings of overwhelm and anxiety. In a disordered world, food, and sometimes excessive exercise, can become a way to impose control.

Restricted Foods - Children with autism often display restrictive eating patterns which may continue into adulthood. Autistic children not only have a higher incidence of food allergies than the general population, but they may also have sensory issues around food and find particular textures or tastes unpalatable.

My client Fiona described how, from childhood into adulthood, she could not eat certain colors of food together. "Mealtimes have always been a nightmare," she said. "As a child, I used to end up having meltdowns if anything red was placed on my plate. I couldn't have the wrong textures together. I once made myself vomit after a meal because I was forced to eat it. As an adult, I have a lot of fear around food and sometimes starve myself because eating is too overwhelming."

Peer Pressure - In many cultures, there is a high degree of pressure to be slim - particularly for girls, though boys are affected

see Eating Disorders on page 27

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Table of Contents

Understanding and Treating Co-Occurring Conditions

- 1 [A Person-Centered Collaborative Approach to Achieving Best Outcomes](#)
- 1 [Why So Many Autistic Individuals Have Eating Disorders](#)
- 4 [Autism, Epilepsy, and Seizures: The Signs and Basic First Aid](#)
- 6 [Diagnosing Depression in Autistic Individuals](#)
- 7 [The Art and Science of Treating Depression in Autism](#)
- 10 [Providing Primary Behavior Health Care Services to Autistic Clients](#)
- 12 [Autism and the Gut: Co-Occurring GI Challenges & Psychosocial Factors](#)
- 13 [Understanding, Diagnosing, and Treating Catatonia in Autistic Individuals](#)
- 14 [A World Without Emotions: Alexithymia and Autism](#)
- 16 [The Big Sigh](#)
- 16 [Autism and Its Many Comorbidities: Conditions, Deficits, and Challenges](#)
- 17 [Sensory Processing Differences and Autism](#)
- 17 [A Meeting of Worlds: Multidisciplinary Teams in Autism Treatment](#)
- 18 [Evaluating and Treating Restrictive Eating in Children with Autism](#)
- 19 [Navigating Sensory Processing Disorder](#)
- 20 [Ehlers-Danlos Syndrome as a Co-Occurring Health Issue in Autism](#)
- 21 [Autism and Comorbidity: A Systematic Approach to Treatment](#)
- 22 [Consideration of Comorbidity in Intervention and Treatment Response](#)

Celebrating and Supporting Autistic Children and Adults

- 15 [An Autistic's Vision for Lasting and Successful Workplace Neurodiversity](#)
- 19 [A Beautiful Mind - See It Through My Eyes](#)
- 21 [Addressing Abuse of Children and Adults on the Autism Spectrum](#)

In the News

- 23 [EarliTec Receives FDA Clearance for EarliPoint Autism Evaluation](#)

Editorial Calendar

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Autism, Epilepsy, and Seizures: How to Recognize the Signs and Administer Basic First Aid

By The Daniel Jordan Fiddle Foundation
and the Epilepsy Foundation

The purpose of this information is to offer general information on Autism and Epilepsy and the co-condition as well as the types of seizures and basic first aid recommended by the Epilepsy Foundation. This information is taken from *Seizure Recognition and First Aid*, a publication of the Epilepsy Foundation published in 2009. One should not rely on this general information as individual cases may vary. It is recommended that one's physician should always be consulted on all information provided here as a public service.

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Could It Be Epilepsy?

Only a physician can say for certain whether or not a person has Epilepsy. Many people miss the more subtle signs of the condition and therefore also miss the opportunity for early diagnosis and treatment. The symptoms listed below are not necessarily indicators of Epilepsy, and



may be caused by some other, unrelated condition. However, if one or more of the following symptoms is present, a medical check-up is recommended:

- Periods of blackout or confused memory
- Occasional "fainting spells" in which bladder or bowel control is lost, followed by extreme fatigue
- Episodes of blank staring in children; brief periods when there's no response to questions or instructions
- Sudden falls in a child for no apparent reason
- Episodes of blinking or chewing at inappropriate times
- A convulsion, with or without fever



- Clusters of swift jerking movements in babies

Facts About Epilepsy

- Epilepsy is defined as a tendency toward recurrent seizures unprovoked by any systematic or acute neurological insults.
- A seizure is the manifestation of abnormal electrical activity in the brain.
- The highest incidence of a first seizure occurs in individuals under 20 years old.
- In 2008, the CDC reported that 2.7 million Americans have Epilepsy and that Epilepsy affects 1 in 100 adults.
- There are different types of seizures that are manifested by a variety of symptoms.

- Seizures can be diagnosed by electroencephalogram known as an "EEG" which is a recording of electrical activity in the brain.

- Medications are available to help individuals control seizures and in some cases may be reduced or discontinued as a person ages.

- Individuals with Epilepsy can lead full and productive lives with proper treatment and monitoring.

Epilepsy and Autism: The Co-Condition

- As many as one-third of individuals with Autism also have Epilepsy.
- Two peaks of onset: infancy & adolescence.
- The risk of Epilepsy is low, about 2% by 5 years and 10% by 10 years, for those with Autism who do not have intellectual and developmental disabilities or Cerebral Palsy.
- Individuals with both Autism and Epilepsy have a more challenged developmental trajectory than those with either Autism or Epilepsy alone.

see *Autism and Epilepsy* on page 24

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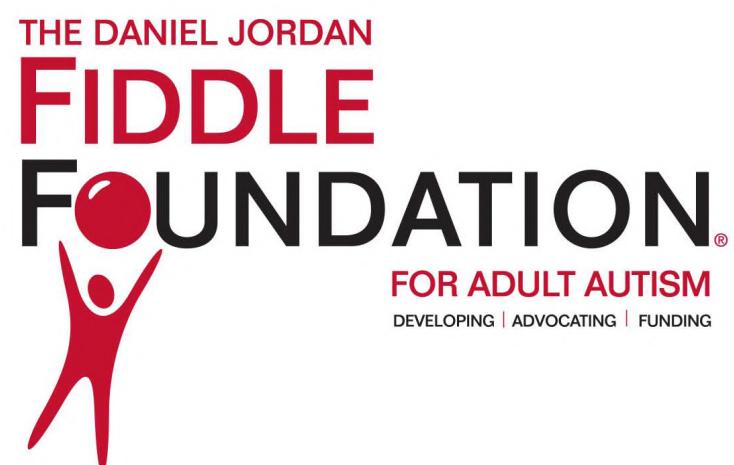
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Diagnosing Depression in Autistic Individuals

By Marina Sarris
SPARK
 Simons Foundation
 Autism Research Initiative

This article discusses topics that may be upsetting to some people. The National Suicide Prevention Lifeline provides free, confidential support 24/7 at 1 (800) 273-8255 and by [online chat](#). This is the first of two articles about depression in people with autism. Part 2 is [The Art and Science of Treating Depression in Autism](#).

As a young child with autism, Ben had trouble putting his feelings into words, except when he was angry. In one of those moments, he told his mother he didn't want to live. She took him to mental health providers while he was growing up. But they focused on treating him for anxiety, rather than depression.

Then came the COVID-19 pandemic, which disrupted college and just about everything else for Ben, who is now 20. "I had a really off day, in combination with everything else that was piling up," recalls Ben, a participant in the SPARK autism study. He made an attempt on his life. Only then did he receive a formal diagnosis of, and treatment for, major depression.

He is not alone. People who have autism are four times more likely to experience



depression during their lifetime than the general population, according to a 2019 analysis of many studies. About 40 percent of autistic adults, and 8 percent of youth, have had depression, according to that analysis.¹

Adults on the autism spectrum were five times more likely to attempt suicide than the general population, according to another large study from Kaiser Permanente Northern California. Almost half of those people who tried to take their lives had

not been diagnosed with depression before their attempt.²

Depression is one of the more serious conditions often found in people who have autism. Unfortunately, it also may be misunderstood or even missed by families, caregivers, or doctors.

Is it Depression or Autism?

The symptoms of depression may be harder to recognize in people on the spec-

trum. Sometimes that's because "high-profile problems" such as aggression and self-injury draw doctors' attention away from depression and anxiety, according to some researchers.³

Other times the signs of depression may be mistaken for autism itself. Although depression and autism are very different, some symptoms may be found in both conditions, explains Rowan University psychologist Katherine Gotham, PhD, who researches autism and depression. Those overlapping traits include sleep problems, trouble concentrating, and having an emotionless facial expression and monotone voice.^{4,6}

A lack of interest in socializing is another symptom found in both autism and depression. "If you have someone who seems to be less interested in social things," asks Gotham, "is that because they have autism, or is that because they are a person with autism who's depressed?"

And sometimes, symptoms of depression may differ from textbook examples. Rather than looking tired and sad, a depressed person who has autism may be irritable or agitated, or have emotional outbursts, according to research.^{3,5,7}

Unfortunately, there are no lab tests or scans for depression. Doctors typically rely on a patient's ability to describe his feelings. That's a heavy burden for people

see [Diagnosing on page 28](#)

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The Art and Science of Treating Depression in Autism

By Marina Sarris
SPARK
 Simons Foundation
 Autism Research Initiative

This is the second of two articles about depression in people with autism. Part 1 is [Diagnosing Depression in People with Autism](#).

Thanks to research, we know more about depression in children and adults with autism than we used to know. Scientists have studied the rates of depression, risk factors for it, and ways to diagnose it in people on the spectrum. But we know much less about how the typical treatments for depression work in them.

“We definitely do not have anything that’s a gold standard, at this point in time, in terms of treating depression in people with autism,” says Rowan University psychologist Katherine Gotham, PhD, who researches autism and depression.

Research into treating depression in autism is lagging behind efforts to describe and assess these problems, according to a 2014 article by autism researchers.¹ This is not surprising, they say, because scientists need to understand a problem before it can be treated.

Gotham and other researchers have noted the lack of rigorous research into



medicines for depression in people with autism.² As of September 2020, no one has completed and published a randomized controlled trial of antidepressants for treating depression in children and adolescents who have autism, she says. In a *randomized controlled trial*, scientists randomly assign people to different groups that receive either a drug or a sugar pill, and then compare their responses. This kind of study is considered the best way to see if a medication works well for a condition.

People who have autism are four times more likely to experience depression during their lifetime than the general population, according to a 2019 analysis. About 40 percent of autistic adults, and 8 percent of youth, have had depression.³ Depression increases the risk of suicide. Studies show that people with autism are at higher risk for suicidal thoughts, plans, or actions than the general public, although how much higher varies widely among the studies.⁴⁻⁸

Of course, that does not mean that children, teens, and adults with autism are not

being treated successfully for depression. Faced with limited data about autism and depression, doctors often rely on their clinical experience to treat depressed patients who have autism.

“Certainly, people with autism respond to the traditional treatments for depression,” says psychiatrist Robert Wisner-Carlson, MD. Wisner-Carlson is chief of the Autism and Neurodevelopmental Outpatient Program at Sheppard Pratt, a mental and behavioral health system in Towson, Maryland. He says that those treatments may include:

- **Antidepressant medicine** - Clinical experience suggests that one type, Selective Serotonin Reuptake Inhibitors or SSRIs, “are useful and generally safe” in autism, according to an article by psychiatrists at the University of North Carolina-Chapel Hill.⁹ SSRIs, which include Prozac and Zoloft, are also used to treat some anxiety disorders.
- **Counseling**
- **Cognitive behavioral therapy**, which helps someone change their distorted thoughts
- **Mindfulness therapy**, which involves breathing and relaxation techniques

see [Treating on page 36](#)

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Collaborative from page 1

with relevant professionals (Behavior Analyst Certification Board, 2020; see code 2.12).

How can assessments identify behavioral patterns indicative of a co-occurring condition? Tools and assessments that can guide this process might include a thorough review of client records, surveys completed by caregivers or others familiar with the individual, direct observations, plotting behavioral data across different variables (i.e., scatterplot), analyzing events immediately prior and following behavior, assessing preference, or systematically arranging specific conditions and observing behavior within them. These approaches can shed light on the behavior of interest and can be used to detect how co-occurring conditions relate, by providing more information with respect to the following:

1. Does the behavior occur **irrespective of context**?
2. When does the behavior occur **in relation to other variables**?
3. What does the behavior **look** like?

If the behavior of interest persists irrespective of environmental contexts or ongoing activities, our assessment and investigative work are far from over. This does, however, inform us that there is likely a variable at play that is not captured in the immediate social environment, and some aspect of engaging in the behavior may be contributing to its persistence (i.e., automatic reinforcement; Vollmer, 1994). For instance, the individual may be responding to internal stimulation and the target behavior may be alleviating discomfort or pain, prompting further medical assessment.

With information about when the behavior occurs with respect to other variables (i.e., temporal relations), correlational information might inform us that the behavior is more or less likely to occur around particular times or activities. For instance, there might be patterns surrounding particular times of day, days of week, or times of month, corresponding to biological factors such as sleep, bowel movements, meals, menstrual cycles, seizure activity, or medication. Depending on behavioral patterns that are identified, behavior analysts can then initiate collaboration with professionals specializing in that area or areas.

Identified patterns related to medication might prompt collaboration with prescribing psychiatrists, neurologists, or physicians, helping identify paradoxical effects



Sheila A. Klick, BCBA

of medication or needed adjustments to scheduled administration times (e.g., stimulants to treat attention deficit hyperactivity disorder). Ongoing assessment throughout the collaboration will help each professional bring their expertise to the table in the design, implementation, and monitoring of interventions leading to best outcomes for the individual (e.g., Bird et al., 2022).

In addition to the contexts in which behavior is observed and the relation of its occurrence to other variables, how the behavior looks or its topography can be equally insightful. Most notably, behavior directed at a specific area of the body might be indicative of pain, discomfort, or a medical condition, prompting medical examination. As an example, you might suggest an individual who engages in persistent self-scratching is assessed by a dermatologist. Similarly, if self-injury shifts to a novel topography targeting the abdomen, seeking assessment from a gastroenterologist or gynecologist might be appropriate.

The topography, or form, of behavior can also be correlated to specific diagnoses, with syndrome groups associated with specific behavioral profiles. Several examples include Down syndrome corresponding to higher social skills ratings and lower levels of challenging behavior, Prader-Willi syndrome corresponding to higher levels of behavior characterized as anxious or repetitive, and Angelman syndrome corresponding to a demonstrably happy affect, hand-clapping, and mouthing behavior (Walz & Benson, 2002). In both assessment and intervention phases, it is important to keep behavioral profiles related to co-occurring conditions or diagnoses in mind.

At times, the forms of behavior associated with specific diagnoses are repetitive, or stereotypic, in nature, similar to what is noted for Prader-Willi syndrome as mentioned above. This can also be the case for anxiety (Moore et al., 2021), vision impairment or deaf blindness (Gal & Dyck, 2009, Molloy & Rowe, 2011, Singer et al., 2021), Obsessive Compulsive Disorder (OCD; Chok & Kessler, 2014), among other conditions. Repetitive, or stereotypic, behavior can present in a variety of forms, such as body rocking, hand-flapping, or eye-pressing. Most often, such behavior persists irrespective of context or social consequences, suggesting it is at least partially maintained by automatic reinforcement (Rapp & Vollmer, 2005). Nonetheless, assessment can still prove to be beneficial as it can guide the identification of specific co-occurring



Jill M. Harper, PhD, BCBA

conditions, inform intervention design, and serve as relevant information in evaluating interventions.

Intervention Considerations in the Context of Co-Occurring Conditions

Using behavioral assessment in conjunction with information specific to co-occurring conditions can enhance the efficacy of treatment (Brodhead, 2015). At times, the presence of some conditions might contraindicate behavioral intervention that would otherwise be considered best practice. For example, toilet training procedures in the face of co-occurring gastrointestinal (GI) difficulties or the treatment of vocal perseverations in the presence of a co-occurring anxiety diagnosis require consideration of the interactional effects across diagnoses. When faced with such co-occurring conditions, behavior analysts must consider if they have the expertise to serve the client. If not, consulting with other professionals or seeking additional education might be necessary.

When addressing behavior related to co-occurring conditions, it is critical that clinicians and collaborating professionals consider the following questions throughout the intervention process:

1. Are there any **contraindications** of a function-based intervention?
2. How can interdisciplinary **collaboration** guide intervention?
3. How does the intervention take the **whole person** into account?

Designing Interdisciplinary Interventions

In the context of co-occurring conditions, medical, genetic, or otherwise, intervention is often multi-faceted and spans across disciplines (Cox, 2012). For example, when a behavior analyst is tasked with addressing frequent bowel movement accidents of a client with an ASD diagnosis and a GI condition, they should be asking “How can interdisciplinary collaboration guide intervention?” Consideration of both diagnoses prompts professionals to take the whole person into account during intervention development. A purely function-based approach is likely not the best option; given the GI condition, a treatment package involving both medication and behavior analytic procedures will likely be most effective. In this case, intervention might involve ongoing medication, as-needed laxatives, scheduled bathroom



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trips, and rewards or reinforcement for successful toileting. Assessment of both the medical components and daily patterns would inform the prescribed medication and best schedule of proactive bathroom trips. This is one of countless scenarios in which taking co-occurring conditions into account in the assessment and intervention of behavioral targets leads to best outcomes.

At times, contraindications can be addressed through direct modification of behavioral interventions. For example, when working with an individual who engages in vocal perseverations maintained by attention, a behavior analytic intervention might involve attending to the first statement while ignoring repetitive statements and providing attention for novel topics of conversation instead. However, in light of a co-occurring anxiety disorder, the initial behavior analytic approach is now contraindicated as ignoring requests will likely increase behavioral symptoms of anxiety. The intervention must be altered to account for the individual as a whole. Such changes might include neutral schedule reviews for repeated statements around upcoming events and high-quality interactions for novel topics of conversation.

Implementing Interventions with Integrity

Once the intervention is designed, implementation must include a comprehensive training plan so that all behavior-change agents (e.g., teachers, parents, therapists) understand the interaction between intervention components. That is, how each aspect of the plan works together to treat the individual as a whole. For example, an individual diagnosed with an anxiety disorder and ASD may be prescribed medication to reduce the symptoms of anxiety in general and behavioral interventions may include specific antecedent strategies to reduce the impact of certain environmental events on behavioral symptoms of anxiety such as advanced noticed for changes in schedules. Caregiver understanding of the interaction between these interventions is critical to the efficacy of implementation and thus the outcome of the intervention plan.

Although not necessary, when possible, components of a multidisciplinary intervention should be implemented systematically to allow for evaluation of the efficacy of each. For example, working in concert with prescribing professionals, such as psychiatrists or neurologists, is incredibly

see Collaborative on page 26

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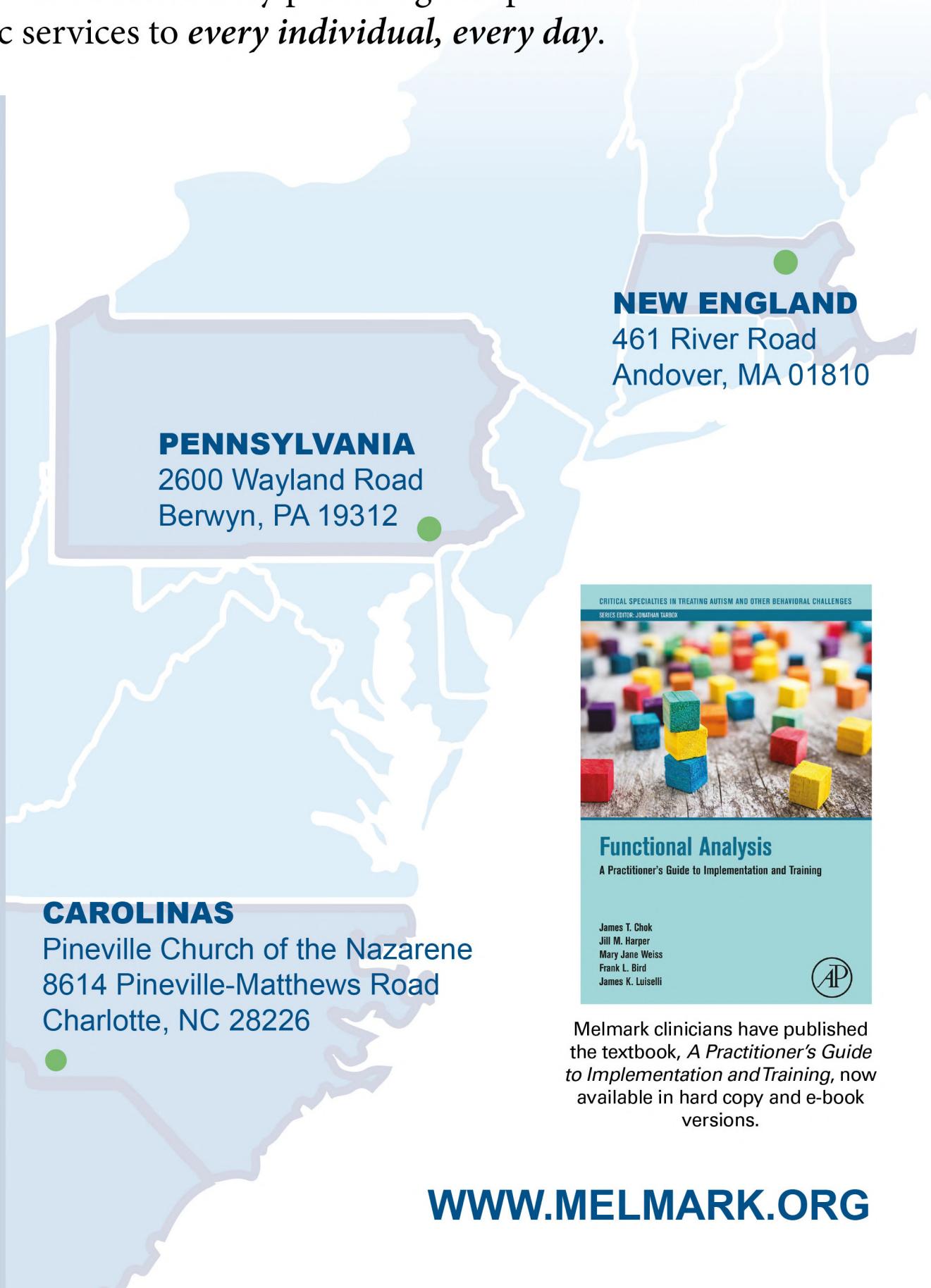
Tyler working on reading skills with Kelly Anglin, Special Education Teacher, at Melmark New England



Carrie working on her lesson plans with her teacher, Anna Eisenberger, M.Ed., at Melmark Pennsylvania



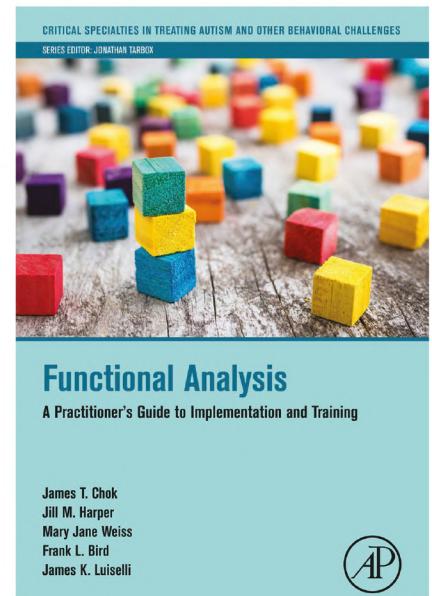
Simeon enjoying a walk with Melmark Carolinas Director of Program Administration and Clinical Services, Brad Stevenson, Ph.D., BCBA-D



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Providing Primary Behavior Health Care Services to Autistic Clients: Is This an Exception or the New Rule for ABA Organizations?

By Howard Savin, PhD
and Jeffrey Selman, PsyD, BCBA
First Children Services

It is well known, but not fully appreciated, that an ASD diagnosis triggers a tsunami of emotions within the family of the autistic individual. Many established ABA provider groups have realized that the needs of parents and siblings of ASD individuals should be tended to via an interdisciplinary treatment approach. While ABA services are frequently the intervention of choice, it is not the only treatment option. [First Children Services](#) has developed a STRIVE model for this purpose. This article will highlight the clinical pathway leading to the choice of a behavioral health care intervention for addressing the pressing emotional and behavioral needs of an ASD youth. In this instance, both child and parent were engaged in the treatment process.

Case Illustration

The following client was referred to our STRIVE Diagnostic Clinic. The child and family subsequently initiated psychological counseling with a licensed clinician. All identifying information has been changed.



Sam is a 9-year-old Caucasian male who presented with his mother for diagnostic clarification. He was referred by his pediatrician for concerns about autism spectrum disorder (ASD). Sam was previously diagnosed with Generalized Anxiety Disorder and is prescribed Zoloft, 100mg. According to his mother, Sam has a longstanding history of social difficulties. Specifically, Sam has had difficulty relating to other children

and reading social cues. He has always had a tough time making friends, taking cues from peers, making eye contact, and acting very shy in front of others. He does not often reciprocate social interactions. Though Sam has a small group of friends that he has had since kindergarten, he has had difficulty making new friends since then.

Sam often has trouble with transitions. He usually flops to the ground when there

are unexpected changes. His mother describes him as “rigid” and that he often thinks in “black and white” terms. Sensory issues are present. Sam does not like loud events (fireworks, movies, crowded cafeteria) and maintains a very restricted diet.

Sam’s evaluation included a structured ASD interview with Sam’s mother, consultation with Sam’s pediatrician, clinical observation, rating scales completed by Sam, his mother and teachers, and the administration of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). The ADOS-2 is a semi-structured, standardized autism assessment tool, and is considered the “gold standard” instrument for diagnosing autism.

The evaluation supported the diagnosis of ASD. Sam’s mother was provided feedback on the evaluation, psychoeducation about the results, and recommendations to help support Sam and his family. Evidence-based, cognitive-behavioral therapy (CBT) was recommended to address Sam’s anxiety and social skills, and parent training and counseling was also recommended for Sam’s mother. Sam’s mother was additionally provided information on school-based supports, e.g., Individualized Education Program (IEP) or Section 504 Accommodation Plan.

see *Primary Care* on [page 35](#)

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Autism and the Gut: Co-Occurring Gastrointestinal Challenges and Psychosocial Factors

Harry M. Voulgarakis, PhD
Assistant Professor of Child Study
St. Joseph's University, New York

Autism is a complex spectrum of behaviors and other distinguishing characteristics across individuals, for which our understanding continues to unfold. Alongside its well documented social and sensory related symptoms, autism also regularly co-occurs with a host of medical complications that impact sleep, eating and digestion, and brain functioning. Recent research suggests that anxiety, ODC, ADHD, sleep disorders, and a range of gastrointestinal challenges are elevated in individuals with autism spectrum disorders. National estimates of children ages 4 to 8 years old with autism found that 95% of children presented with at least one co-occurring condition/symptom (Soke et al., 2018). An earlier study which included both children and adults with autism presented similar findings, and seizures and gastrointestinal symptoms in the autism population greatly exceeded the general hospital population (Kohane et al., 2012). It is unclear if these conditions are directly related to the pathology of autism, if autism itself poses a risk for such disorders, or if the presence of autistic symptomatology simply exacerbates challenges - and such factors vary based on the individual and the condition.

Gastrointestinal (GI) dysfunction is arguably one of the most common co-occurring medical challenges associated with autism. Broad estimates for the prevalence of GI dysfunction in autism vary from 10% to as high as 85%, with some studies suggesting as high as a 95% co-occurrence. The reported problems can range from mild discomfort to more severe and chronic conditions such as constipation, severe abdominal pain, persistent diarrhea or constipation, and chronic reflux (Holinhue et al., 2018). Even though autism is a neurodevelopmental disorder that is assessed and diagnosed based solely on social and behavioral characteristics, our neurobiological and pathophysiological understanding of autism continues to un-



fold. The observed co-occurrence of gastrointestinal dysfunction alongside a range of other metabolic and immune problems in autism has led researchers to explore the brain-gut connection more thoroughly in this population. It has subsequently been hypothesized that individuals with autism present with altered gut microbiota, which is associated with gastrointestinal dysfunction, in children with a genetic predisposition for autism (Fattorusso et al., 2019). Further, there is a wide body of research to suggest altered maternal gut microbiota and factors in the uterine environment associated with altered gut microbiome in are strongly associated with the presence of autism in mouse models (Afroz et al., 2021; Kim et al., 2022), which has also been observed in human participants; factors including diet can impact the uterine environment and microbiome, linking diet-induced gut dysbiosis to neurodevelopmental disorders and thereby impacting pre- and early postnatal brain development (Gesu et al., 2021). A recent review by Krigsman and Walker (2021) further suggests that gut dysbiosis and systemic immune dysregulation may directly impact neurodevelopment, rather than autism in and of itself predisposing someone with autism to a GI disorder.

Whether the causal factors associated with the increase prevalence of gastrointestinal dysfunction in autism are biological or not, there are many reported behavioral symptoms that accompany this presentation. Atypical and complex feeding and eating related behaviors are often reported, exacerbated by the rigidity and preference for sameness that is seen in autism. Challenges that are commonly in parents of children with autism include extremely limited diets resulting in lower nutritional intake and challenging mealtime behaviors. A review by Pinto-Silva et al. (2022) also found that in addition to food selectivity and problem behaviors at meal time, sensory sensitivity, anthropometric deviations, and nutritional deficits were also commonly reported. Further, inconsistent toileting and self-care routines, paired with limited communication skills, may contribute to or exacerbate these GI challenges. Deficits in socialization and communication skills in children with autism were found to be correlated with adaptive functioning deficits in the areas of communication and daily living skills, which include eating, hygiene, and self-care (Voulgarakis et al., 2021). Other research by Chakraborty et al. (2021) found that of their sample, 93% had at least one gastrointestinal symptom

and repetitive behaviors and stereotypes were positively associated with gastrointestinal symptom severity, however, social and communication difficulties were not significantly associated.

In the case of autism spectrum disorders, gastrointestinal dysfunction as well as its other associated medical challenges presents a complex set of barriers for individuals and their families. Behavioral difficulties as well as social and communication skills make it difficult for those with autism to communicate their needs, compounded by genetic and pathophysiological dispositions to gastrointestinal challenges. Various treatments are available that have been found to alleviate GI symptoms specific to those with autism. Recent research has found that probiotic supplementation has been helpful in reducing some of the behavioral symptoms reported, however there is a less stable trend to be seen with respect to changes on the microbiome level (Davies et al., 2021). A similar review by Tan et al. (2021) supports these findings. They also discuss evidence surrounding fecal microbiota transplantation, which has gained much attention as of recently. The review indicates that there is some evidence of efficacy, however the current research available includes small sample sizes and requires more extensive research and replication. Dietary modifications and other approaches to regulate gastrointestinal information has also shown some promise. Psychosocial interventions that support communication, pain management, coping, and medical adherence are also among supports available.

It is critical for families, clinicians, educators, and providers alike to remain abreast of these developments and continue to implement strategies to mitigate these challenges. Educational programs that focus on self-help and independence are beneficial for those who have more impaired adaptive skills as they transition to adulthood. Psychosocial research supporting individuals and their families with autism and other complex medical challenges should continue, as well as biomedical research to understand the brain-gut connection among

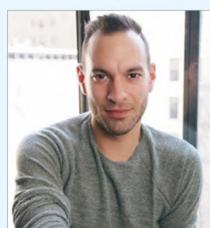
see Gastrointestinal on page 25

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Understanding, Diagnosing, and Treating Catatonia in Individuals with Autism Spectrum Disorders

By Jan M. Downey, MA, CCC-SLP, TSHH and Mary E. McDonald, PhD, BCBA, LBA
Eden II Genesis Programs

Catatonias is a distinct cluster of mood, motor, vocal and affective disorders once thought to be solely a specifier for various psychotic and mood disorders. It is now recognized in the *Diagnostic and Statistical Manual of Mental Disorders* (5th edition; *DSM-5*; American Psychiatric Association, 2013) as an associated feature of autism spectrum disorder (ASD). Unfortunately, the pervasive lack of awareness of this condition leads to misdiagnosis or a failure to diagnose the syndrome at all. Those responsible for the care of individuals with ASD who develop catatonia may erroneously assume that the individual is engaging in these behaviors “on purpose” (Shah & Wing, 2006). Increases in catatonia research in ASD have resulted in the emergence of promising treatment interventions depending on the severity level of the symptoms (Dhossche, 2014). It is critical to note that if the condition is not properly treated, it is likely to become chronic, and an exacerbation and worsening of symptoms will occur.

What Does Catatonia Look Like Among Individuals with ASD?

Catatonia in ASD is also referred to as “catatonia-like deterioration in individuals with ASD” (Dhossche, Shah & Wing, 2006) or “autistic catatonia” (DeJong, Buntton & Hare, 2014). The onset of catatonia in individuals with ASD is insidious; there is a marked and obvious deterioration in movement, vocalizations, pattern of activities, self-care and practical skills (Dhossche et al., 2006). More specifically, individuals typically exhibit slowed movement and verbalizations, slowed task initiation and completion, difficulty crossing thresholds, increased reliance on prompting, passivity and lack of motivation, Parkinsonian features such as akinesia and rigidity, day-night reversal, repetitive and ritualistic behaviors, and seemingly purposeless agitation/excitement (Shah & Wing, 2006).

Catatonia in ASD typically occurs between the ages of 15 and 20 with the average age about 18 years; however, a few cases have been reported outside the typical age range. Research conducted by various medical and psychological professionals indicates an increase in recognition of pediatric catatonia (Dhossche, 2014). A limited number of studies suggest catatonia occurs in approximately 12-18% of adolescents and young adults with ASD although many researchers believe this number may be higher (Shah, 2016).

Catatonia in ASD may present as *mild*, *moderate*, or *severe*, with symptoms fluctuating from day to day (Shah & Wing 2006). In its most severe form, the stability of the individual’s autonomic system is affected, potentially impacting heart rate, blood pressure, body temperature, digestion, metabolism (thus affecting body weight), urination and defecation (individuals become incontinent), breathing and swallowing,



Total immobility is also a possibility, with reliance on others for all previously mastered self-help skills and activities of daily living. Individuals demonstrating some verbal skills prior to the emergence of catatonia may become mute. The individual is at risk to lose a substantial amount of weight and experience dehydration due to decreased food and fluid intake. This severe presentation of catatonia-like deterioration in ASD necessitates hospitalization as the individual is at significant risk for serious medical morbidity and mortality (Shah & Wing, 2006).

Individuals with ASD who develop moderate catatonia present with limited mobility and a decrease in speech-language and communication skills, self-help skills, and activities of daily living. These individuals exhibit extreme slowness in the ability to initiate, continue and complete a task. The autonomic system may or may not be affected to some degree. The mild presentation is similar to the moderate form but presents as less severe and does not involve the autonomic system (Downey & McDonald, 2019).

Children with ASD may exhibit precursor catatonia-like behaviors years before it develops; however, these are usually reported in hindsight. The precursors include social passivity, a history of slowed movement, and slowness to initiate and respond. While the presence of these characteristics does not in and of itself predict a future comorbid diagnosis of catatonia, they are “red flags” necessitating increased observation and ongoing assessment. Because the development of catatonia is a slow deterioration of the individual’s abilities, it behooves clinicians who are knowledgeable in early signs of catatonia-like symptoms to conduct a clinical observation and screening. These early steps will help guide intervention and appropriate referrals as soon as possible to reduce the potential exacerbation of catatonic symptoms (DeJong et al., 2014). An initial assessment is critical to ascertain the degree to which the catatonia-like deterioration has interfered with the individual’s everyday life, considering the impact on areas such as speech and communication, mobility, self-help skills, activities of daily living, leisure

skills, and work or school (Downey & McDonald, 2019).

How is Catatonia Diagnosed?

Characteristics of catatonia and ASD have some overlap in symptoms, such as repetitive behaviors, reliance on prompting, and seemingly purposeless agitation, which may lead to misdiagnosis or a fail-

ure to diagnose the condition. Two key factors when making a diagnosis are the emergence of new symptoms and/or a change in the type and pattern of premorbid functioning (Ghaziuddin, Quinlan, & Ghaziuddin, 2005). For example, reliance on prompting may significantly increase while the ability to execute previously mastered tasks, such as dressing oneself or completing a meal within a reasonable amount of time, significantly decreases. Essential components of evaluation include clinical observation and the use of standardized and non-standardized assessments including the Bush Francis Catatonia Screening Instrument (BFSI, 1996), a sub-test of the Bush, Fink, Petrides, Dowling, & Francis Rating Scale (BFCRS, 1996) by medical professionals and clinicians knowledgeable in the manifestations of catatonia in ASD. The Shah and Wing (2006) “blueprint for the assessment of catatonia in ASD” may also be helpful in diagnosing the condition. The clinician must consider the entirety of the person’s history including parent, teacher and physician interviews, videos, and data. Evaluation of changes across many different areas, such as weight loss resulting from eating and/or drinking difficulties, toileting accidents, slowness and other abnormalities in motor movement, increased

see *Catatonia* on page 29



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A World Without Emotions: Alexithymia and Autism

By **Andréas RB Deolinda, BA, BSc**
Advocate for Children with Special Needs

Before we delve into defining alexithymia and autism I'd like to paint a picture in your mind. Imagine living in a world where emotions do not appear to exist - no clear indications of anger, sadness, or happiness. So much so that even categorizing these emotions does not exist - a neutral reality where everyone looks the same and talks the same. What would that world look like for you?

For people with alexithymia, this image isn't far off from their everyday experience. Individuals with this condition do have feelings but they find it difficult to recognize their own emotions or those of others. The word alexithymia is derived from the terms "lexis" which means a combination of words; "thymos" which means mood or emotion; and "a" which represents a lack of. Altogether, it is the lack of words or terms to express emotions or moods. The condition was first introduced into the field of psychiatry by Peter E. Sifneos in the early 1970s.

Some of the symptoms of alexithymia overlap with those of autism spectrum disorder (ASD); this has raised questions around whether alexithymia is a form of autism. This article will look into the similarities between the two and determine wheth-



er there's substantial evidence to agree with this statement. The understanding of the relation between autism and alexithymia could potentially help parents to better understand their child's condition and enable better intervention practice to help improve their child's emotional regulation.

What is Alexithymia?

Alexithymia is defined as the inability to recognize or identify your own emotions. Individuals who have alexithymia have in-

common the inability to either verbalize their emotions due to lack of awareness of the emotion, or possible confusion of emotional feelings.

This condition has been found to overlap with symptoms of autism spectrum disorder (ASD). Alexithymia is found to be highly prevalent in individuals on the spectrum and, over the last two decades, studies have been conducted to investigate the relationship between the two. To understand this overlap, let's look further at the symptoms of alexithymia.

What Are the Symptoms of Alexithymia?

According to Poquérusse et al. (2018), characteristics of alexithymia include:

- Difficulty identifying feelings and distinguishing between feelings and bodily sensations of emotional arousal
- Difficulty describing feelings to other people
- Reduced capacity to fantasize and to imagine
- Stimulus-bound, externally-oriented cognitive style
- Low perspective-taking as well as difficulty understanding and describing the emotions of others

The lack of emotional awareness impacts the individual's ability to understand his/her subjective emotional state; an individual finds it difficult to interpret or recognize verbal or non-verbal emotional stimuli such as facial expression or tone of voice. In turn they lack emotional regulation. In the same way, he/she may find it difficult to understand the emotions of others, leading to difficulties in social interaction.

see Alexithymia on page 31



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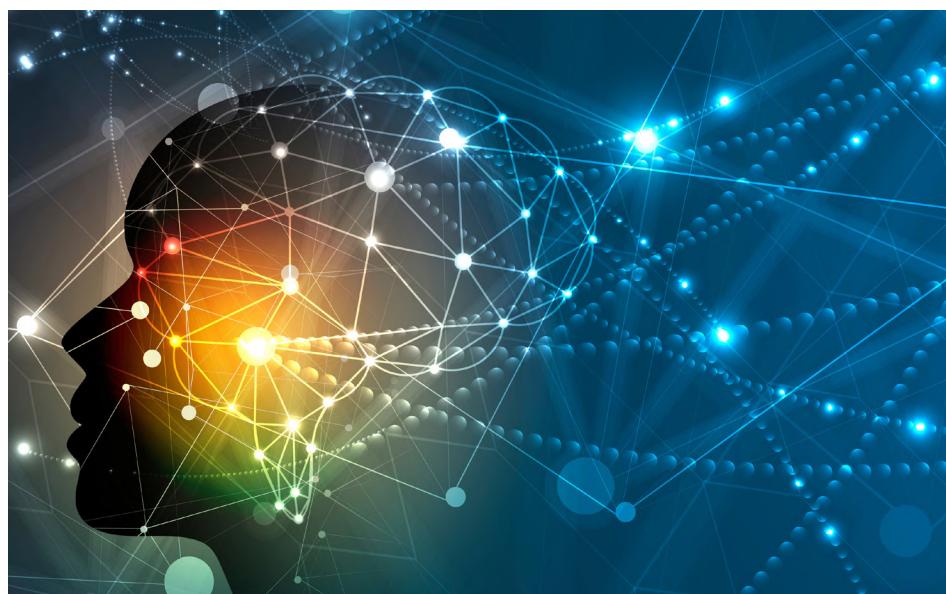
An Autistic's Vision for Lasting and Successful Workplace Neurodiversity

By Sam Farmer
Neurodiversity Community
Self-Advocate, Writer/Author,
and Public Speaker

Consider Dan Burger, a gifted and autistic computer science student at Vanderbilt University, Nashville, TN. In spite of the challenges he faced along his journey through school and into the workforce, Burger's exceptional abilities at visual problem-solving and dealing with large amounts of data ultimately won out. His invention, a data visualization platform which NASA licensed, has been used, among other applications, to analyze information gathered by the Kepler space telescope. Today, he is employed by Google.

Anderson Cooper covered Burger's story on *60 Minutes* because his is a truly unique and remarkable story. Arguably too unique. Regrettably, this kind of story is not as prevalent as it should be because some 75% of autistic adults are either unemployed or under-employed relative to their ability.

At Vanderbilt's Frist Center for Autism and Innovation, Burger experienced a supportive workplace culture which focused on his strengths rather than on his deficits. The Frist Center emphasizes inclusivity and excellence above all else. Mutual expectations center around precise, concrete,



and respectful communications, resulting in a work environment characterized by professionalism and productivity.

Not all autistic individuals in today's workforce are as fortunate, mostly because barriers to sustained employment of autistic individuals persist. Such barriers stem from fundamental misunderstandings between neurotypical and neurodivergent people which are yet to be sufficiently addressed. It is with the intent of wanting to bridge these misunderstandings and bring about more success stories like that of Burger's that I introduce my vision for

lasting and successful workplace neurodiversity. I call it the CAALE framework (pronounced like "kale," the green vegetable): **C**ollaboration; **A**ccommodation; **A**cceptance; **L**istening; **E**mpathy.

Collaboration: When a company commits to cultivating a more inclusive workplace, they sometimes implement a neurodiversity hiring program as a means to that end. Google chose to collaborate with the [Stanford Neurodiversity Project](#) to ensure the success of their [Autism Career Program](#). Likewise, with respect to [Dell's Neurodi-](#)

[versity Hiring Program](#) and the [Neurodiversity in the Workplace](#) initiative. These and other collaborative efforts illustrate the importance of companies not going it alone when it comes to bringing neurodivergent individuals into their organizations. Neurodiversity hiring programs consider not only how candidates are evaluated and hired but also the onboarding process and the training of a company's neurotypical employees as to how they can best interact and work with their neurodivergent colleagues.

Collaboration between neurotypical and neurodivergent co-workers often entails extra effort and keeping an open mind, considering the neurological, learning and thinking differences involved in this dynamic. The result is greater [interpersonal intelligence](#). Collaborative skills are strengthened when, for example, colleagues take into account each other's perspectives and unique personality attributes while working through a given problem to be solved.

Accommodation: Neurodivergent individuals face some distinctive challenges in the workplace because we are neurologically different than most - not less capable or intelligent. As such, the proper accommodations help us fulfill our true potential. A few examples: accommodate autistics dealing with increased sensory sensitivities

see Neurodiversity on page 33

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The Big Sigh

By Becca Lory Hector
Autism and Neurodiversity Researcher/
Consultant/Speaker/Author/Advocate
Evolving Skye, LLC

This is one of those days. I feel it the moment I open my eyes. I instantly loathe that I am awake. I fall into an old habit of calculating how many hours I will have to reasonably be out of my bed before I can crawl back into it without having to feign illness or apologize for not returning a text. Twelve? Maybe if I stay in bed a little longer I can make it eleven. As I close my eyes, hoping for a lessened sentence, the dogs start to rouse. I hear the shuffle of early morning stretches, yawns, and scratches that tell me I don't have long. The cat paw on my face tells me I am already late. These sounds, these sensations, this is morning and I am not a morning person.

As breakfast preparations for all species begin, I am cranky and short with canine, feline, and human alike. My morning disposition does not discriminate. The coffee grinder interrupts an effort to remind myself that not too long ago my life was quiet because it was empty and sad. I note that I am criticizing my past self even as I try to focus on the present. I push away thoughts of canceling my day and getting back into bed as I fill my cereal bowl. Gluten free cereal and almond milk. Who is this per-



Becca in her car with her dog Sir Walter Underfoot

son and why do I bother? I start out each day like this, with healthy intention but I know I will end it with chocolate. While I should be marveling at my abilities to both set intentions and not be perfect, I instead question the reason for it all.

The thought floats around my head just long enough for me to recognize the voice. I have heard it many times over the years. Deftly, it seeps into my bones through the language of my mind. I know you, depres-

sion. We've spent plenty of time together. While we go periods without talking at all, when you come back, it's like you never left. We pick up right where we left off. With thick, critical judgments and sharp, self-deprecating descriptions. I can always anticipate you dropping by after I have spent a day or so with your partner in crime, anxiety. In my exhaustion, I do not have the strength to say no to you.

The day moves forward as my energy

moves in dull spikes. I float in a dissociative nebula of thoughts and motions, trying to push through this day that will not end. I am reminded to take a break and eat something. I have no appetite. Stupid interoception. Six hours down, six more to go. I eat something. I chew but don't taste. The waste of time irritates me and so does the low blood sugar. Whatever.

A few hours later. I can focus no more. I turn off my computer and head upstairs. A dog walk is suggested. I look out the window and a tiny piece of me can actually see that it is beautiful outside. It's chilly, as early Autumn is supposed to be. I layer on a heavy hoodie and a hat. The weight and warmth instantly comfort me. I take the first deep breath I have taken all day. The cool air easily fills my lungs leaving me ever so slightly lighter, looser.

In the car, behind the safety of sunglasses, I can hear the dogs panting as they stick their noses into the wind. They too understand the importance of a lungful of cool fall air. We arrive at the place we will walk. I forget myself and grumble, driving to walk. My depression takes the tone of a curmudgeonly old man fighting change as I step onto trail.

I watch as the dogs take in each smell, each sound. Their paws never wavering as we make our way over the loose rocks that make up the trail floor. Occasionally, a rock

see Big Sigh on page 28

Autism and Its Many Comorbidities: Conditions, Deficits, and Challenges

By Karl Wittig, PE
Advisory Board Chair
Aspies for Social Success (AFSS)

There is a popular and common saying within the autism community that "when you've met one person with autism, you've met one person with autism." It becomes clear that this is true when one considers the variety of conditions which occur comorbidly with ASD. Being on the autism spectrum is only one characteristic of an individual, who may suffer from other unrelated conditions and face challenges and deficits not included in the diagnostic criteria for ASD. Some of these may have no connection to autism; there is no law against winning more than one genetic lottery - in fact, it happens all the time within the typical population as well. Others may be related, but not technically be part of the syndrome or fall under any of its diagnostic criteria. Still others can occur in connection with, or as a result of, living on the autism spectrum in the context of a typical world. We will consider a few examples and cases of all these categories, as well as some that have affected me personally.

Common Comorbid Traits That Are Not Part of ASD

One common deficit of many an autistic is poor physical coordination, to the ex-



Karl Wittig, PE

tent that it has become a stereotype. There is nevertheless something to this one, because many of us have always been poor at sports and other physical activities. When I first attended a support group shortly after my diagnosis over 20 years ago, many members told stories about how bad they were at sports, and there was much commiseration among the group. More significantly, learning to drive a car poses a significant challenge to many autistics (including myself, and an alarmingly high

number are never able to do so). Although none of the diagnostic criteria for ASD involve physical coordination or any aspect thereof, these deficits are common enough that there clearly must be some connection. A few researchers have suggested that diminished size or development of the cerebellum may provide a possible explanation.

Among those autistics who are athletic, they are much more likely to excel in an individual sport than in team sports. This should not come as a surprise, since the latter require coordination with other players in addition to having good coordination oneself. Even then, I have known at least one autistic in my local community who is a successful Special Olympian in various team sports. As for myself, I was always so bad that I had to be excused from physical education classes in later grades. Not to mention, learning to drive was also difficult for me. This is just one of many mysteries to which my autism diagnosis finally provided an explanation.

Another frequent problem that many autistics face involves gastrointestinal issues. Much has been said and written about this, and autism researchers have been looking into so called "brain-gut connections" in their attempts to explain it. Still, however, it once again does not appear in any diagnostic criteria for ASD, and the connection largely remains unknown. I learned that this is a common issue among autistics and have even lived with it for much of my life; in fact, I suffered chronic GI

pains at the age of six for which I was given an extensive battery of tests that did not lead to any conclusive results (yet another mystery explained by my ASD diagnosis). I did not fully appreciate how common this is in the autism community, however, until it came up at a support meeting that I was facilitating, when I asked the group members if they experienced GI problems. To my amazement, at least three-fourths of the people in attendance raised their hands! Once again, there must be a connection between this and the autism spectrum.

Conditions That Are Often Comorbid with ASD

There are many other conditions, largely neurodivergent and psychiatric, that often occur concurrently with ASD. Although I have no background whatsoever in neuroscience or mental health, I have both learned about and personally encountered numerous cases of such during my involvement with the autism community, particularly while attending and facilitating adult support groups.

Among the most common are conditions such as ADHD (which itself was often a misdiagnosis for ASD), OCD (which can appear similar to the repetitive behaviors of ASD), and various others. This does not surprise me, because all these conditions are neurologically based. There is so much

see Comorbidities on page 22

Sensory Processing Differences and Autism

By Paige Siper, PhD
Chief Psychologist
Seaver Autism Center for Research
and Treatment at the Icahn School
of Medicine at Mount Sinai

In 2013, the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) included for the first time sensory reactivity within the diagnostic criteria for autism. The DSM-5 describes three categories of sensory differences:

1. Sensory hyperreactivity is an overresponsiveness to sensory stimuli that may take the form of individuals covering their ears in response to sounds, squinting or avoiding the sight of certain objects, resisting the feel of certain textures, or discomfort when touched by others.
2. Sensory hyporeactivity is an underresponsiveness to sensory stimuli, which can result in significant safety concerns. For example, an individual who is hyporeactive may not respond to the sound of an alarm, the feel of pain or temperature, or the sight of a car passing by.
3. Sensory seeking is an excessive interest in sensory stimuli. Individuals who are sensory seeking may repeatedly seek out the sight, feel, or sound of certain objects.



Paige Siper, PhD, Chief Psychologist of the Seaver Autism Center for Research and Treatment at the Icahn School of Medicine at Mount Sinai, meets with a patient

Each of these examples can affect daily living and quality of life. Research suggests up to 90 percent of individuals on the autism spectrum display sensory differences compared with people who do not have autism.

A Sensory Assessment

If a child is displaying sensory hyper-

reactivities, hyporeactivities, or seeking behaviors that are affecting their daily functioning, a sensory assessment may be warranted. The goal of a sensory assessment is to identify personal sensory preferences. Everyone has sensory preferences, and by determining those preferences we can modify environments accordingly.

Over the past several years, teams at the

Seaver Autism Center for Research and Treatment at the Icahn School of Medicine at Mount Sinai developed a novel sensory assessment called the Sensory Assessment for Neurodevelopmental Disorders (SAND). The SAND combines a semi-structured, clinician-administered observation and a corresponding caregiver interview. Clinicians observe, within an exam setting, how a child responds to stimuli that prompt sensory responses, and they also interview caregivers about their child's daily experiences.

Following an assessment, parents will learn about their child's unique sensory preferences and sensitivities, and then an individualized treatment plan can be developed and implemented. Adjustments in an individual's sensory experiences can have a profound impact on adaptive behavior, social engagement, and learning.

Services at the Seaver Autism Center

The Seaver Autism Center is a multidisciplinary program with a [large research focus](#) ranging from natural history studies that track change over time to clinical trials that test new treatments. All individuals participating in research at the Center receive an autism-focused research evaluation. The Center also offers neuropsychological and psychoeducational evaluations,

[see Sensory Processing on page 36](#)

A Meeting of Worlds: Multidisciplinary Teams in Autism Treatment

By Elise Settanni, MEd, BCBA, LBS and
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Lehigh University Autism Services

As Dr. Stephen Shore said, "if you've met one individual with autism, you've met one individual with autism." Autism is a spectrum disorder with great variability in support needs from one person to the next. Given the spectrum of the disability, services and care for children with autism must be as individualized and unique as they are. Therefore, children with autism are often supported by a team of providers across various settings. Cox et al. (2012) identified the following seven support areas and the professions providing those supports for children with autism:

1. Communication needs supported by speech /language pathologists (SLP);
2. Social-emotional needs supported by psychologists or counselors;
3. Sensory-motor needs support by occupational therapists (OT) or physical therapists (PT);
4. Adaptive daily living skills supported by OT;
5. Cognition needs supported by special education professionals;



6. Behavior management needs supported by behavior specialists or behavior analysts; and
7. Biomedical needs support by physicians, nutritionists, or other medical professionals.

In school settings, multidisciplinary teams consist of any combination of the aforementioned providers. Students might receive behavior support from a behavior specialist, board certified behavior ana-

lyst (BCBA), or even school psychologist. They will be supported in academics by the special education teacher, general education teacher, and paraprofessionals. Their related service needs (e.g., speech/language needs, adaptive living skills, sensory-motor needs) are met by the SLP, OT, PT, or vision therapist. Social skills and communication needs can be met by the special education teacher, BCBA/behavior specialist, school counselor, and SLP. Additionally, if the child receives services in the home, a member from that team, typi-

cally the BCBA or behavior specialist, will collaborate with the school team to ensure consistency across environments. There is a lot of overlap across professionals in the supports they might provide for a child with autism. Depending on the needs of the child, the team can range from very small to quite large. To best serve children with a variety of support needs it is critical that providers maintain working, collaborative relationships as research suggests that collaborative teams and program planning can lead to improved student outcomes (Hunt et al., 2003).

For example, Joaquin is a third grade student with autism. He spends most of the day in the inclusive setting, working out of the general education curriculum. He has social needs, sensory needs, and communication difficulties. At school, he is supported by a team of professionals. The general education and special education teachers work closely together to adapt the curriculum and monitor Joaquin's progress within the curriculum. The special education teacher, SLP, school BCBA, and home BCBA work together to support his social skill and communication needs. The special education teacher, OT, school BCBA, and home BCBA collaborate to meet his sensory needs. The whole team meets at least annually for his IEP meeting. His home BCBA observes him at school and develops programming at home to work

[see Multidisciplinary on page 30](#)

Evaluating and Treating Restrictive Eating in Children with Autism

By Alana Telesford, PhD,
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Autism Center at the Child Mind Institute

Picky eating is common for children with autism spectrum disorder (ASD). Autistic individuals often show atypical eating patterns and have more difficulty with mealtime behaviors in comparison to their non-autistic peers (Christensen et al., 2019; Mayes & Zickgraf, 2019; Sharp et al., 2013). Parents of autistic youth commonly report struggles with their child's mealtime behaviors, ranging from extreme pickiness in accepted foods to an inability to sit at the table and independently eat without distractions (Strand, 2021; Vissoker et al., 2015). Feeding challenges have co-occurred with autism for as long as autism has been recognized in the Diagnostic and Statistical Manual (Kanner, 1943; Ritvo & Freeman, 1977) and in recent years has gained an increased understanding, which has led to improved treatment options and outcomes (Christensen et al., 2019; Mayes & Zickgraf, 2019; Sharp et al., 2013). Treating feeding challenges in autistic children is multifaceted and requires a comprehensive evaluation followed by a combination of individual therapy and caregiver training (Smith et al., 2020; Zimmer et al., 2012, Zulkifli et al., 2022).

The most common eating challenges experienced by autistic children include limited variety in accepted foods, strong preferences for certain food brands, and hypersensitivity to food textures and colors (Mayes & Zickgraf, 2019; Strand, 2021). While these are quotidian challenges for young children (Bourne et al., 2022), autistic children are more likely to develop long term rigidities around food (Strand, 2021), which can lead to nutritional inadequacies (Sharp et al., 2018) and limit a child's capacity to participate in social engagements involving food (Kuschner et al., 2017). Multifactorial aspects of a child's behavior, social cognition, and environment contribute to the development of restrictive eating patterns (Vissoker et al., 2015).

Core autism traits, including sensitivity to sensory input, proclivity for sameness and routines, and strong reactions to novelty, set the stage for autistic children to develop strong food preferences (Kuschner et al., 2017). Common social behavior during mealtimes, such as trying a new food to be polite, is less salient to an autistic child due to differences in the way they process social information. Anxiety related to novel or nonpreferred foods and associated avoidance behaviors (Kuschner et al., 2017) can easily develop, including crying, spitting, gagging, eloping from the table, and aggressive behavior.

Similarly, caregivers may try to avoid children's emotional-behavioral escalation during mealtimes, and ensure their child is getting enough calories, by accommodating their child's preferences. Caregivers often find themselves making children their own meal separate from the family meal, allowing less nutritive foods during meals, allowing the child to wander while eating, and allowing screen use

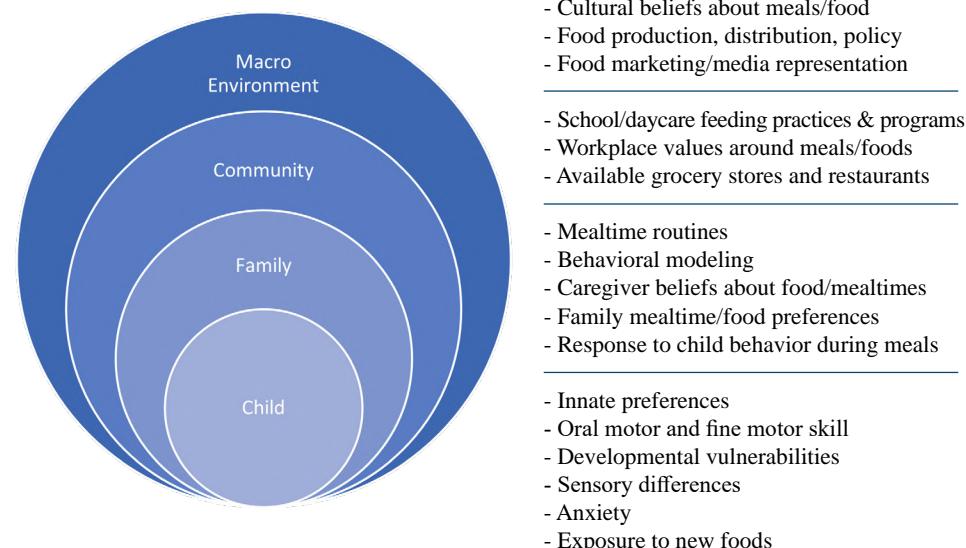


Figure 1: Multisystemic factors that influence eating and mealtime behaviors

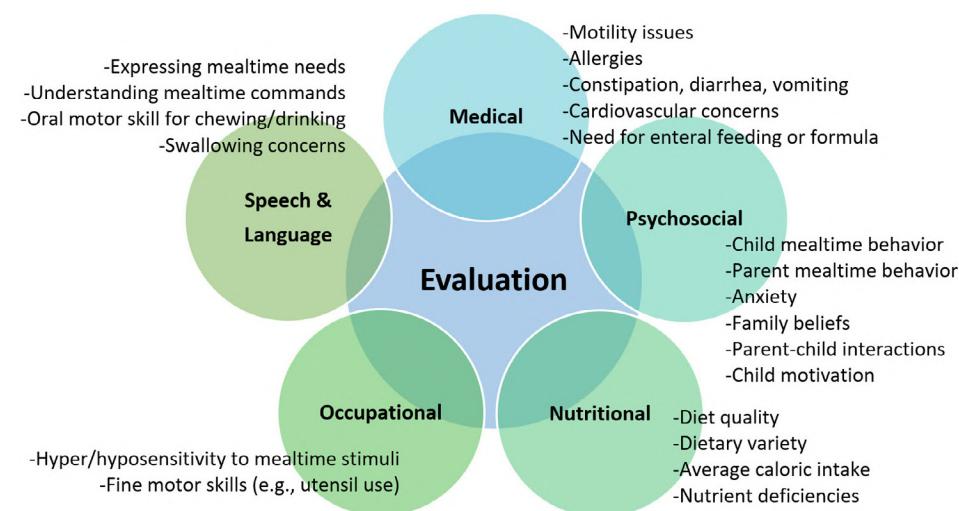


Figure 2: Multidisciplinary components of a comprehensive evaluation for restrictive eating

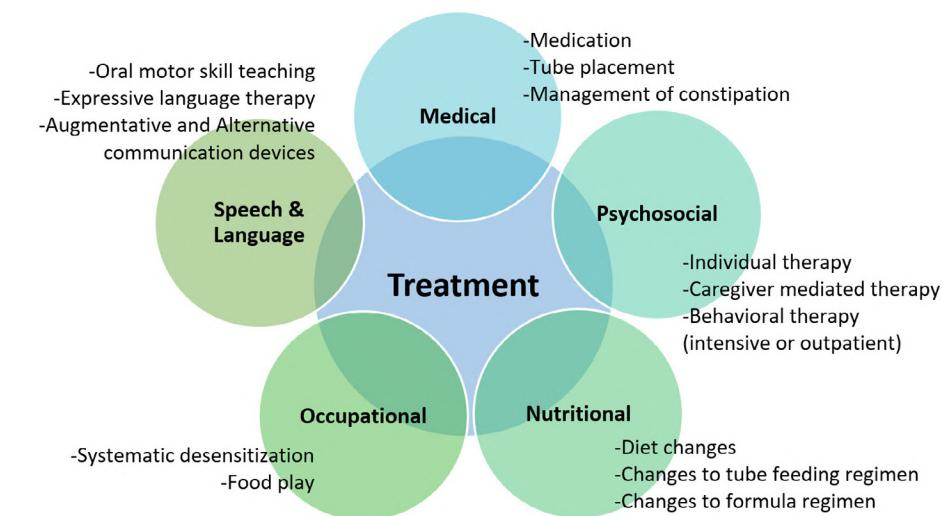


Figure 3: Multidisciplinary components of a comprehensive treatment for restrictive eating

for the duration of the meal. In the long term, this pattern of child and caregiver behaviors contributes to a more limited diet and an increase in mealtime behavior problems.

Chronic restrictive eating may reach clinical thresholds for a diagnosis of a feeding disorder requiring intervention. Avoidant Restrictive Food Intake Disorder (ARFID) is a pattern of feeding disturbances in which a child exhibits a

persistent lack of interest in food and habitually avoids nonpreferred food (American Psychiatric Association [APA], 2013). A diagnosis of ARFID requires persistent failure to meet appropriate nutritional needs and is associated with one, or more, of the following:

- Significant weight loss;
- Significant nutritional deficiency;

- Dependence on enteral feeding or nutritional supplements and/or;
- Marked inference with psychological functioning (APA, 2013).

Evaluating ARFID requires comprehensive, multidisciplinary assessment. Pediatricians and/or gastroenterologists are key in ruling out medical causes of feeding problems, such as reflux, constipation, food allergies, motility problems, or other chronic health conditions. Occupational therapists (OTs) evaluate sensory aspects of feeding, such as how children process the way foods look, smell, feel, and taste. Speech-language pathologists (SLPs) assess oral-motor skill development necessary for chewing and swallowing. Registered dietitians (RDs) survey nutritional status and develop dietary plans. Psychologists and other behavior health providers evaluate environmental, behavioral, and emotional factors affecting mealtimes (Smith et al., 2020; Zimmer et al., 2012, Zulkifli et al., 2022).

Depending on the child's age and complexity of medical, behavioral, and environmental factors, a variety of treatment options for ARFID are available. Most commonly, individual therapy with the child and coordinated training with a caregiver is indicated. Children learn the skills needed to accept new foods, while caregivers learn new strategies to support children's mealtime behavior and expand the range of foods accepted.

Behavioral treatment can be applied in intensive form, through partial or full hospitalization programs, or in a less intensive outpatient setting. In the latter, caregivers are heavily involved in sessions to ensure carryover of skills to mealtimes at home. Behavioral strategies reduce challenging behaviors and increase food acceptance in individuals with ASD (Johnson et al., 2019). Antecedent strategies can include increasing mealtime structure, establishing discriminant stimuli through visual aids, reinforcement systems (e.g., contingent token systems, noncontingent praise, differential attention), and extinction protocols (e.g., nonremoval of spoon). These techniques in combination with rewards, planned ignoring, and escape-extinction have strong empirical support (Sarcia, 2020; Williams et al., 2010).

Outpatient behavioral treatment with integrated caregiver-mediated interventions can support food flexibility by modifying caregiver responses to children's behavior. Specifically, caregivers learn to reduce accommodation behaviors and increase supportive responses to their child (Bloomfield et al., 2019; Shimshoni, Silverman, & Lebowitz, 2020). The Autism MEAL Plan (Sharp et al., 2014) and the Behavioral Parent Training Program for Feeding Problems (Johnson et al., 2015) are two group-based programs designed to teach caregivers to address feeding problems in young (under 8 years) autistic children. In both programs, caregivers are trained in basic behavioral principles (e.g., antecedents and consequences, daily schedules and mealtime routines, effective communication, stimulus

see *Restrictive Eating* on page 35

A Beautiful Mind - See It Through My Eyes

By Jozette Prescott, MA
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Liz, as she is affectionately called, has spent her 29 years living a life of resiliency - a life which given inherent challenges makes her journey that much more remarkable. During her childhood, Liz received early intervention services beginning at nine months when it was suspected that she might have a mild form of Cerebral Palsy. She excelled in preschool and was recommended for general education. However, due to Elizabeth's learning disabilities, she was transferred to special education classes.

Social awkwardness, a classic feature of autism, can be quite daunting for a person on the spectrum. As noted by Autism Speaks, many children and adults on the autism spectrum need help in learning how to act in different types of social situations. They often have the desire to interact with others but may not know how to engage friends or may be overwhelmed by the idea of new experiences ([Autism Speaks; Social Skills and Autism](#)). This was indeed true for Elizabeth who had the desire to socialize but didn't know how to socialize and thus did not know how to make friends. Her social skills were described as poor and she relied on her circle of support found in her family - her mother, father,



Elizabeth's Artwork of Her Roommates

two brothers, sister, and extended family members. She was also challenged by self-esteem issues, making experiences in her community extremely limited.

In her formative years, it became evident that Elizabeth had a unique gift for meticulous attention to detail. At the young age of 5, she began to draw. She found solace from her poor social skills in artistic expression and "canvassed" the world as seen through her eyes. Her inspiration was found through watching friends of her older brothers and sister, as well as art curation shows on Public Broadcasting Service (PBS) channel. While largely self-taught, Elizabeth's budding craft was nurtured through classes at the Brooklyn

Botanical Gardens as well as weekly art classes at her school. Elizabeth developed a specialty for making portraits in the style of realism.

Autistic Savant

Evidence has shown that not only are many children with [autism spectrum disorders \(ASD\)](#) highly intelligent, demonstrating creative and cognitive abilities that far exceed those of their non-ASD peers, but children with ASD are also better able to process details compared to other children (Drake, J. E. (2012)).

While not explicitly diagnosed as a savant, Elizabeth's intrinsic artistic abilities,

where she is able to draw completely from memory, can be likened to Savant Syndrome. Instructor Monica Walker notes in [Autism & Artistic Talent](#) that "roughly ten percent of those diagnosed with autism will have savant syndrome. These individuals will possess inherent autistic savant abilities, generally first seen during early childhood. Common abilities include extensive mathematical calculations, memorization, and artistic or musical skills. The latter group, artistic autistic savants, may play a musical instrument with perfect pitch or be able to play a piece of music in its entirety after only hearing it once. An

see A Beautiful Mind on page 23

Navigating Sensory Processing Disorder

By Claudia Rose Addeo, MS, BS
Teacher, Award-Winning Writer,
PhD Student, Neurodiverse Advocate

As someone who not only is earning their doctorate in the field of literacy education but was diagnosed at the tender age of two with pervasive developmental disorder (PDD), a category found among autism spectrum disorders (ASD) along with a list of additional sub-diagnoses, it's safe to say that not all individuals with autism have the same characteristics. Regardless of an individual's age, there are some very common sub-diagnoses linked to autism. One of those diagnoses being sensory processing disorder (SPD). The ability for an individual to take in, organize and make sense of different kinds of sensations received by the brain involves the use of sensory processing (Schoen et al., 2009). However, SPD impairs one's ability to process these different types of sensations. What most people don't realize is that rates of SPD can be as high as 90% among those with autism (Schoen et al., 2009). It doesn't take a rocket scientist to recognize how impactful SPD can be on the daily occurrences of navigating life for an individual with autism.

A very common, primary sub-type of SPD that individuals with autism possess is sensory modulation disorder (SMD), which can be described as having difficulty



regulating one's responses (i.e., duration, intensity, and/or type of response) in a flexible and adaptive manner to sensory experiences that occur in daily life (Schoen et al., 2009). Now, I must admit, over twenty years ago when I was formally diagnosed with PDD (eventually becoming inattentive ADHD, my current diagnosis), I was unaware of my own SPD until recently when I myself experienced sensory overload. Once realizing I had SPD after experiencing firsthand sensory overload, I researched the different types of SPD in order to correct-

ly identify mine so I could find a remedy that could best fit my needs. Therefore, the purpose of this article is to shed light on SPD among individuals with autism and discuss different options that will either prevent the occurrence of sensory overload or serve as an anecdote. Since discovering triggers and remedies for SPD, my life has improved drastically. For that reason, I hope this information can bring as much comfort to you as it has brought to me.

A few of the most common forms of SPD include but are not limited to the

following: visual processing, auditory processing, tactile processing, and multi-sensory processing (Proff et al., 2022). In quite a few cases, mine included, a person can possess more than one form of SPD. However, there may be some forms of SPD that are more sensitive than others. For example, I myself have visual, auditory, and tactile SPD. Amongst those three, my auditory SPD is by far the most challenging form of sensory processing. Granted, this could also be due to the fact that my initial diagnosis included an auditory processing delay, but history has shown me that whatever the reasoning is, my auditory processing skills are the most difficult for me to navigate. I know what you're thinking, "How do you know your SPD is being triggered?" I'll admit that to this very day, I'm still learning what can trigger my SPD, because life brings about new circumstances that requires us to use these different forms of sensory processing, bringing about new sensory triggers.

The first memory I can recall in going into sensory overload was on my kindergarten fieldtrip to the planetarium where they had a space show presented similarly to an IMAX movie theater with extremely amplified speakers and blasting spaceship noises throughout the entire show with different light patterns. Thankfully, my mother insisted on joining the fieldtrip and noticed how I tensed up, shook from nerves,

see Processing Disorder on page 34

Ehlers-Danlos Syndrome and Its Comorbidities As a Co-Occurring Health Issue in Autistic People

By Tara J. Marshall, BA, SLPA
and Aimee Piller, PhD, OTR/L, BCP
Piller Child Development

Ehlers-Danlos Syndrome (EDS) occurs in as many as 8% of autistic individuals with even a higher percentage that may have hypermobility spectrum disorders (HSD) (Cederlof et al., 2016, Kindgren et al., 2021). This estimate is low since EDS is more commonly diagnosed in females (Castori, 2012), who are generally undercounted in assessing characteristics of autism. There are currently 13 accepted subtypes of EDS (Miller & Grosel 2017), with genetic testing for 12 of the subtypes, but not for the estimated 90% with Hypermobility EDS (hEDS). Occupational and physical therapists (OTs and PTs) are often the first to note signs of EDS that include lax joints or low tone, both commonly noted in documentation of clients diagnosed with autism. Autistic children frequently have sensory processing differences, and EDS may compound the effects upon the sensory system, including a general hyposensitivity to proprioceptive input (feedback from muscles and joints) and vestibular issues, such as dizziness (Levine et al., 2021).

EDS and HSD include known risk factors for joint pain (Baeza-Velasco et al., 2018), subluxation (Shirley et al., 2012), full dislocation (Dabbas et al., 2008), immune system conditions (Brock et al., 2021), gastrointestinal disorders (Beckers et al., 2017), and other conditions that may cause severe pain. This may contribute to delays in communication and other skill development in young autistic individuals. Up to 89% of people with hEDS or HSD develop a Mast Cell Activation Disorder (MCAD) (Monaco et al., 2022). Symptoms related to MCADs include a lack of mental clarity that impacts learning new information, word-finding difficulty, cognitive processing issues, and difficulties regulating emotions. A person diagnosed with autism who also has MCAD may experience increased early learning difficulties, self-injurious behavior, and perceived aggression that are frequently associated with autistic individuals with high support needs (Theoharides et al., 2019).

Besides these potential diagnoses, people with EDS have a higher incidence of dysautonomia, particularly Postural Orthostatic Tachycardia Syndrome (POTS) (Mathias et al., 2021), autoimmune disorders (Celiac disease, lupus, multiple sclerosis, etc.) (Rodgers et al., 2017), Primary Immunodeficiency Disorders, such as CVID, (Brock et al., 2021), immunoglobulin deficiency disorders, and gastrointestinal dysmotility, sometimes leading to diagnoses of gastroparesis (Alomari et al., 2020). Since collagen and other connective tissue are part of the foundation of the neurological tissue, differences in the connective tissue in EDS may be why so many with EDS are also neurodivergent (Castori & Voermans 2014).

EDS, HSD, and MCAD may be difficult to diagnose, further impacting the prevalence of the disorder. Currently, ge-



netic testing is available for all 13 types of EDS except for Hypermobility EDS (hEDS) (Forghani, 2019). While initial testing for MCAD looks for high serum tryptase counts, this is only a valid test if the person has Mastocytosis or Hereditary Alpha Tryptasaemia (Wu & Lyons 2022). Research indicates that 10% of mastocytosis pediatric patients are autistic (Theoharides, 2009). Research is still in process for the prevalence of H₂T in autism, but it is widely-accepted there is an incidence of 6% of people having the mutated gene for this MCAD. Recent research, however, indicates that Mast Cell Activation Syndrome (MCAS) may have an incidence of 17% (Vacheron et al., 2021), with most people only experiencing mild symptoms, such as dermatological or gastrointestinal sensitivities. Underdiagnosis may also be due to the testing process. Testing usually includes a 24-hour urine collection. If the urine is not frozen immediately, typical room temperatures break down the histamine byproducts and the test is likely to return a false negative (Valent et al., 2020). Further, only about 16% of people with MCAS have high serum tryptase (Afrin et al., 2017). Tryptase is suspected to act much like a meat tenderizer as noted by Dr. Afrin (2016) and is thought to be related to the joint issues common in EDS, possibly even an underlying cause since mast cells break down collagen. High histamine can result in what appears to be an extreme allergic reaction however, even if IgE (Immunoglobulin E) allergy testing comes back negative (Theoharides et al., 2019). While there is no research data available at this time, anecdotally people with MCAD report that their joint hypermobility has decreased, to the extent that some have been able to return to beloved activities that place a great deal of pressure upon their joints (Hell's Bells and Mast Cells, 2022).

MCADs can present very differently in different people (Afrin et al., 2016). Mast cells initially develop in the bone marrow and are distributed by the vascular system and mature in various areas of the body. Depending upon what organ or biochemical system is affected by abnormal mast cells people can experience a very diverse

variety of symptoms, everything from GI sensitivities to food (Weinstock et al., 2021), severe allergic reactions, and unusual presentations of a variety of diseases or disorders that frequently do not respond to the usual treatment. Mast cells are found in the brain, with higher numbers in the amygdala and the cerebellum, both of which have been documented to be atypical in either form or activity in autistic individuals (Hendrikson et al., 2017).

Recognizing that EDS, HSD, and MCADs may be underdiagnosed, it should be considered when working with autistic children and adults due to its potential impact on behaviors, communication, and executive functioning. As previously noted, OTs and PTs may be the first medical professionals to recognize the signs of EDS. Due to the complexity of issues autistic children with EDS may face, occupational therapy plays a key role in improving patient outcomes. OTs have a unique ability to design interventions to address the known symptoms of these co-occurring disorders to help clients improve participation and functioning and manage their symptoms. EDS and related disorders impact more than physical and can cause difficulties in social, emotional, and mental health and well-being (Levine et al., 2021), which may be more pronounced in autistic individuals. Occupational therapists address symptoms seen in both EDS and autism including modifying the environment, training in the use of adaptive equipment to improve independence, energy conservation, and improving sleep hygiene, to name a few. Occupational therapists address physical, sensory, emotional, and social areas to help person improve overall participation and engagement in daily activities (Levine et al., 2021). Further, occupational therapy is recognized as an effective intervention in up to 70% of individuals with EDS (Song et al., 2020).

Occupational therapists should be aware of other comorbidities that may impact a person, such as pain, that the person may not be able to adequately identify or communicate. They should be trained in recognizing pediatric pain symptoms even when pain is not reported. They should also work to address motor performance to support

and protect joints and prevent subluxation. Further, OTs and other therapists need to be considerate of the impact of these disorders on executive functioning and help design interventions to support executive functioning through cognitive training and environmental supports. In addition, OTs need to be mindful of the potential GI implications that may impact feeding and eating, overall nutrition, and energy levels to participation in daily activities. OTs address the needs of the whole child to ensure symptoms are managed in a manner that promotes participation in daily activities, leading to increased participation and increased sense of well-being.

If you suspect you or someone in your care may meet the criteria for Ehlers-Danlos Syndrome, please refer to the [Beighton Criteria for Joint Hypermobility](#). If you further suspect the presence of an undiagnosed Mast Cell Activation Disorder, you can go through a checklist of common symptoms at the [Bonn Validated Mast Cell Questionnaire](#).

Tara J. Marshall, BA, SLPA, is an Autistic adult with hEDS and a suspected Mast Cell Activation Disorder working as a Speech Language Pathology Assistant. Aimee Piller, PhD, OTR/L, BCP, FAOTA, is a pediatric occupational therapist and owner of Piller Child Development, LLC who specializes in sensory processing disorders.

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see *Ehlers-Danlos* on page 26

Autism Spectrum Disorder and Comorbidity: A Systematic Approach to Treatment

By Heidi Hillman PhD, BCBA-D, LMHC
Eastern Washington University

Comorbidity refers to the presence of one or more mental or physical conditions that coincide with a primary mental or physical condition (Al-Beltagi, 2021). Research has shown that 70% of autistic children meet the criteria for one comorbid disorder and 40% meet the criteria for two or more comorbid diagnoses - ranging from skin and food allergies to headaches to mental health disorders (Isaksen et al., 2013; Mansour et al., 2017). The most common comorbid diagnoses among autistics include ADHD, mood disorders, and anxiety disorders (Mansour et al., 2017; Wilson et al., 2014).

Comorbid diagnoses can be challenging for families and therapists (Al-Beltagi, 2021; McCrimmon et al., 2014) due to the complexity of exploring and supporting multiple disorders. However, it does not have to be challenging. I encourage families and therapists to focus on the autistic rather than on separate diagnoses to gain a more descriptive picture of the behaviors.

Using a holistic approach helps for several reasons. First, the individual (child, teen, or adult) is the same person - the di-



agnosis label didn't change that. Second, a holistic approach captures the complexity of the symptomatology since one disorder can exacerbate or mask another disorder. Which leads to: What is the best way to work with autistic clients who present with comorbidities?

I designed a systematic approach when working with my autistic families. I first develop a trusting relationship, followed

by an assessment to identify the underlying cause of behaviors. The initial step in the assessment is identifying sensory overloads that may be causing the symptoms. Once sensory issues are addressed, the autistic's anxiety decreases and now we can focus on the comorbidities. However, in my experience once I remedy sensory overloads most symptoms disappear.

Trust

Effective treatment begins with feeling understood and treated with respect. When working with autistics, we may be working with both the individual and their trust issues because those who came before us destroyed the trust. Trust is earned; we are not entitled to it. To show that the relationship with us will be different, enjoy being with them, talk about their interests, and show unconditional support rather than immediately asking for behavior changes.

Assessment

When designing treatment plans for autistics with comorbid disorders, the first question we must ask is why is the autistic individual exhibiting these behaviors or symptoms? An effective strategy to answer this question is conducting an assessment, focusing on environment-behavior interactions.

The philosophy behind an assessment is that behaviors are not abnormalities; they are reasonable behavioral adaptations exhibited within the context of the environment. An assessment identifies factors leading up to the occurrence of behaviors. For example, I feel anxious when looking

see Systematic on page 37

Addressing Abuse of Children and Adults on the Autism Spectrum

By Nora Baladerian, PhD
Co-Founder and Co-Director
Disability Without Abuse Project

Parents and caregivers who work directly with individuals (children and adults) with an autism spectrum disorder diagnosis are in most cases overwhelmed with the impact and difficulties they face in accommodating to the reality they and their child face when learning of the diagnosis. I will not attempt to define autism in this brief article, and as many agree, coming to a diagnosis is complex! Those in the autism support effort learned from people with autism the best characterization I have ever heard in terms of what autism is: "When you've met one person with autism...you've met ONE PERSON with autism." Although there are some foundational similarities among those with this diagnosis, variations are plentiful.

I have worked with many individuals with autism and their families and have so far found truth in the above statement. Although we say this about those in the neurotypical population, the reality of it is striking for the autistic population. As a result, most attention in the literature and other gatherings is focused on increasing socialization, social skills, communication enhancements and options, management of emotional overloads, building social skills, and building an academic career,

Victims Without Disabilities 2012	Victims Without Disabilities 2017	Victims Without Disabilities 2019	Victims With Disabilities 2012	Victims With Disabilities 2017	Victims With Disabilities 2019
Females: 15 per 1,000	Females: 11.4 per 1,000	Females: 11.3 per 1,000	Females: 26 per 1,000	Females: 32.8 per 1,000	Females: 49.4 per 1,000
Males: 16 per 1,000	Males: 14.11 per 1,000	Males: 13.4 per 1,000	Males: 23 per 1,000	Males: 31.8 per 1,000	Males: 42.7 per 1,000
Decreased incidence annually from 2012 - 2019			Increased incidence annually from 2012 - 2019		

**Bureau of Justice Statistics: 2012 to 2019:
Comparing crime victims with and without disabilities**

among others. My life took me on a different path, in terms of my attention to the difficulties they face. My experience caused me to focus on the problem of abuse of people with autism and other developmental disabilities.

For many years, recognition of the abuse of children and adults did not specifically address those with disabilities of any kind. In more recent years, beginning efforts are being made to learn the incidence of abuse in the population, as well as responding to abuse when it happens in terms of law enforcement, medical attention, and psychological treatment for trauma.

The following is a relevant and recent report of a study of the incidence of abuse in this population:

"For American children diagnosed with autism spectrum disorders, a study found that almost 89% of study participants had experienced an incident of victimization, and 82.1% had experienced an incident within the last year. Among those victimized once within the last year, 92% experienced at least a second victimization within that same period. Implications include considering the impact of exposure to multiple forms of victimization and addressing the possibility of long term trauma (Pfeffer, 2016)."

The Bureau of Justice Statistics issues a biannual report on abuse of people with disabilities. The table above is their summary of the past three reports where trends can be identified easily.

I would say that the quote of Pfeffer's

study is the "tip of the iceberg." However, in general one can say that abuse is not a focus of inquiry or interest in the literature. Yet, I would suggest that it should be on the top of every list made to support children and adults with autism. There are many cases in which abuse is not identified as the source of the child's new difficulties, with these changes are ascribed to the disability, rather than the impact of trauma. For this reason, I developed a brief "cheat sheet" guide for physicians whose client may present with a number of new difficulties (often referred to as behaviors when in fact they are symptoms of a significant problem - trauma), to facilitate discovery of abuse that the patient (child or adult) may not be able to describe. The "cheat sheet" is called, "Dr. Chap" to encourage physicians meeting with individuals (and the caregivers/parents) with disabilities to inquire into the following:

Developmental Regression: Signs of regression such as loss of language, increased clinginess, acting as less than their developmental age and prior achievements, and needing help for previously achieved developmental milestones.

Communication: Changes in communication, particularly the onset of elective mutism, use of baby talk, stopping talking and only gesturing, for example.

see Abuse on page 33

The Prevalence of Comorbidities in Autism: Consideration of Comorbidity in Intervention and Treatment Response

By Julie Rasmuson
Director, Student Accessibility Services
York College of Pennsylvania

“If you have met one person with autism, you have met one person with autism.” In this quotation, Dr. Stephen Shore, an autistic professor of special education, refers to the unique and varied experience the autism spectrum can be for those individuals who experience it. Autism is an individualized disorder, not only because of the array and intensity of characteristics that can fall within an autism spectrum diagnosis but also due to the high prevalence and wide variety of accompanying comorbidities. “Comorbidity is the presence of one or more additional diseases or disorders that coincide with a primary disease or disorder. A comorbid condition is a second order diagnosis that has core symptoms that are distinct from the primary disorder (Al-Beltagi, 2021).” Comorbid medical and mental health conditions occur more often in individuals with autism spectrum disorder (ASD) than in the general population.

It is imperative that not only physicians, health practitioners and specialists, but also human service providers, families, and caregivers who work to support the



ASD community are aware of the prevalence of these comorbid conditions. This knowledge and understanding can be pivotal, in aspects of determining appropriate lifelong care in the facets of both medical and behavioral health. Taking comorbidities into consideration can be critical when developing individualized and appropriate interventions, preventive care, education and treatment plans, and support services. “Alarmingly, multiple studies show that people with ASD have significantly shorter lifespans not due to autism itself but to

accompanying mental and physical health conditions (Bennett, 2017).” Better management and treatment of comorbid conditions can lead to better lifelong outcomes for individuals with autism, including a longer lifespan.

Many of these comorbid disorders and conditions can last throughout a lifetime, while some are outgrown in developmental phases. Comorbidities can have a significant impact on behavior, development, and health. Many of these impacts can mirror the symptoms of the primary diagnosis

of autism. Early identification, treatment, the development of appropriate interventions, and a collaborative care approach of both autism and comorbid conditions can improve long-term outcomes. Below are the prominent comorbid conditions and discussion of the prevalence of these conditions found in conjunction with autism spectrum disorder.

Mental Health Conditions

85% of children with autism also have some form of comorbid psychiatric diagnosis, and 35% are taking at least 1 psychotropic medication as treatment (Bennett, 2022).

Individuals with ASD have a high prevalence of multiple mental health disorders such as:

- **ADHD** - 50-70% of the ASD population is affected.
- **Depression** - 26% of the ASD population is affected vs 10% of the general population.
- **Anxiety** - 30% of the ASD population is affected vs 10% of the general population.

see Treatment Response on page 32

Comorbidities from page 16

that has yet to be learned about the brain, its functions, and its disorders that it is easy to see how different conditions can overlap or be related, depending upon the structures or processes in the brain that might be involved.

Also common are learning disabilities and deficits such as dyslexia and dyscalculia. Ironically, both go against common autistic stereotypes. Dyslexia, for instance, flies in the face of the precocious and hyperlexic reader with an encyclopedic memory for facts in specialized areas of interest, whereas dyscalculia constitutes the exact opposite of an autistic persona who has a phenomenal ability with numbers and even great mathematical talent. Intellectual disability, of course, is also often comorbid with ASD. What all of these have in common is that they are considered developmental disabilities, as is ASD itself. Once again, it is easy to see how there might be some connection.

Psychiatric illnesses can also be comorbid with ASD. In my own community, I have known individuals on the autism spectrum who also suffered from bipolar disorder. I have also met those with psychotic or schizophrenic disorders. As far as anyone can tell, these conditions are separate and distinct from their ASD. Yet again, however, I must emphasize that these are strictly my own personal impressions based on limited knowledge and experience as a layperson. Thankfully, however, much research is taking place in all these areas, and we will hopefully learn more about the connections between these conditions and ASD in the not-so-distant future.

Conditions That Are the Result of Living with Autism

Some common psychiatric conditions are clearly the direct (or at least indirect) result of living with ASD and the many social, daily living, and other challenges that it creates for the individual. Challenges with daily living and deficits in basic life skills, for instance, can create tremendous anxiety for a person on the autism spectrum, and various anxiety disorders are known to be quite common in the autism community. Similarly, difficulties with socialization, making friends, finding romantic partners, and having a good relationship with others in the workplace or community can cause significant depression; once again, this is quite common in the autism community, as are the social anxiety disorders that can also result from this. Probably the most extreme condition, however, is post-traumatic stress disorder (PTSD) in autistics who have been the victims of long-term and persistent bullying or other social marginalization; this has been documented in some cases. Despite my lack of mental health background, it is easy for me, as a person on the autism spectrum, to see how these conditions can easily develop.

Unlike other comorbid conditions, those in this category have the advantage that they can be readily eliminated by addressing their root causes before they result in more severe consequences. Deficits in social skills and daily living skills, for example, can readily be identified and subsequently addressed. Also, therapeutic techniques for dealing with resulting conditions can be made more effective by

recognizing the underlying causes during treatment, while simultaneously dealing with these causes to whatever extent is possible. Conditions resulting from societal factors, such as bullying, will require changes in our communities and in society, which will not be as simple to accomplish. Nevertheless, every effort must be made to address these issues for such comorbid conditions to be finally eliminated.

Eating Disorders Comorbid with Autism

I will conclude by discussing a condition often comorbid with autism that has affected me personally, namely eating disorders. I have had severe selective eating issues which developed at the age of 2 ½ years, at which time other classic autistic traits (e.g., lining up my toys in a row) also manifested themselves - this is how I know that they are related to autism.

What distinguishes the food issues common in autistics with more familiar eating disorders like anorexia and bulimia is that, whereas the latter are typically caused by concerns related to body image, autistic issues are more likely to involve a relationship with the food itself, which presents sensory stimuli such as taste and texture. In such cases, it can be regarded as a sensory issue comparable to the auditory and visual sensitivities that are so well-known in autistics. Still, this often results in poor eating habits that can in turn lead to obesity - yet another comorbid condition not uncommon among autistics.

I have lived with this condition my entire life and was known as an extreme “picky

eater” throughout my childhood. As an adult, I often tell people that I have the eating habits of a 12-year-old, and to this day prefer the kinds of food that are typically found on a “children’s menu.” Many years ago, I was referred to by someone as “anorexic” because I was very thin at the time (I have since put on a few pounds!). In fact, the conditions that I have been living with are known as food neophobia and food aversion (again caused by my reaction to sensory stimuli).

I began to appreciate how much of an issue this was for autistics because, whenever I mentioned that I suffered from it on adult panels at conferences and workshops, someone would always approach me afterwards to discuss it because they had a child on the spectrum with exactly the same problem. A few years ago, I attended a specialized workshop about this at an autism conference. Luckily, I arrived early for the session because, after a short while, the room filled to capacity and was standing room only. I have also learned, whenever the issue is discussed, that even as everyone has their individual food preferences, the same kinds of foods repeatedly appear when different cases are presented; I jokingly refer to these as the “basic autistic food groups!”

Although there are numerous reasons for the individual differences that exist among autistics, the wide variety of comorbid conditions that they live with constitute a significant part of the diversity within our community.

Karl Wittig, PE, is Advisory Board Chair for Aspies for Social Success (AFSS). Karl may be contacted at kwittig@earthlink.net.

EarliTec Diagnostics Receives FDA 510(k) Clearance For the EarliPoint Evaluation for Autism Spectrum Disorder

By Shay Smith
Health+Commerce

The EarliPoint Evaluation is the first FDA-cleared tool to assist clinicians in diagnosing and assessing autism in children as young as 16 months old.

On June 10th, 2022, EarliTec Diagnostics, Inc. (EarliTec), a digital health company developing novel diagnostic and therapeutic products for children with autism spectrum disorder (ASD) and early childhood vulnerabilities, announced U.S. Food and Drug Administration (FDA) 510(k) clearance of the EarliPoint™ Evaluation for ASD for children ages 16-30 months. The EarliPoint Evaluation is the first objective measurement tool to assist clinicians in the diagnosis and assessment of ASD. Clinical data show the tool safely, consistently, and effectively delivers an ASD diagnosis and measures a child's level of social disability and cognitive ability.

"A child's formative years are critical, filled with rapid cognitive, social, emotional, and physical development. Sometimes differences in development are so subtle that parents and pediatricians are hesitant to act until delays become more problematic. It's important to have clear, definitive infor-

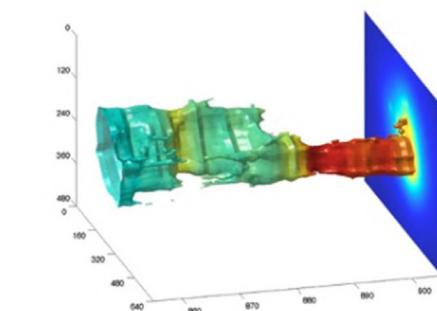


Figure 1
Attentional Funnel for Typically Developing Children

EarliPoint Attentional Funnel

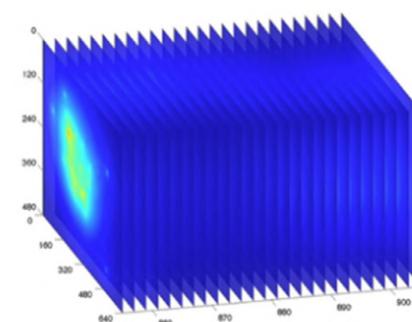


Figure 2
Moment-by-Moment Eye-Gaze Measurement

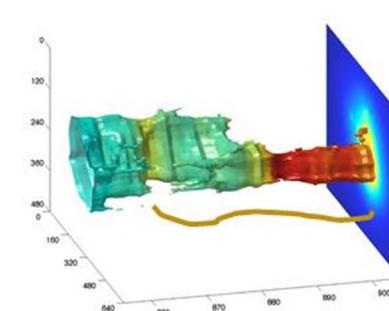


Figure 3
Deviation from Attentional Funnel

mation about these differences, so interventions can begin as soon as possible," said Dr. Christopher J. Smith, Chief Science Officer at the Southwest Autism Research and Resource Center. "We need to take full advantage of the brain's neural plasticity in the early developmental time period. EarliPoint represents a breakthrough that utilizes solid empirical data to facilitate earlier diagnosis of ASD. It literally gives years back to families that are better spent on intervention rather than waiting."

ASD is a common neuro-developmental condition that affects 1 in every 44

children, more than all childhood cancers, juvenile diabetes, and heart disease combined.¹ Many parents suspect symptoms of autism in the first 18 months of life.² However, the median age for diagnosis in the U.S. is much later, at age 4-5 years, and later still in children from minority and low-income families.³

Early intervention is one of the most important factors for improving lifetime outcomes, yet prolonged diagnostic journeys delay the possibility of treatment, said Tom Ressemann, Chief Executive Officer of EarliTec.

"EarliTec was founded to advance ASD care by developing new approaches to diagnosing, monitoring, and treating children. Better understanding the clinical progression and symptoms for individuals can result in tailored interventions to achieve the greatest gains," Ressemann said. "Today's clearance is an exciting first step, and we look forward to advancing our ongoing partnerships with clinicians who can use EarliPoint Evaluation to identify young children with autism and help children and

see [EarliPoint on page 27](#)

A Beautiful Mind from page 19

other may see a landscape or cityscape and draw it in detail without having taken art classes or entirely from memory. Research shows that one ability that features across all individuals with savant syndrome is a prodigious working memory, no matter the skill. Working memory involves the ability to hold and process an abundance of verbal and non-verbal information. It appears to be an intrinsic part of the syndrome. Research also shows that these individuals have an intense attention to detail. Researchers have not yet been able to identify why savant syndrome occurs. One of the leading theories is that left brain (logic, language) impairment or injury results in right brain (artistic, concrete thinking) compensation, as there are high occurrences of left-brain abnormal functioning among individuals diagnosed with ASDs. In other words, the right side of the brain takes over the functions of the left side. The left hemisphere often completes development later, and, as a result, is under prenatal influences that can be harmful for an extended period of time.

Currently, researchers are using CT and fMRI scans to study the artistic savant brain at work. However, more studies on the link between autism and artistic genius need to be conducted.

Researchers have set out to examine common patterns in the lives and artwork of six artistic savants who had features of "pervasive developmental disorder" including impairment in social interaction and communication as well as restricted

repetitive and stereotyped patterns of behavior, interest, and activities. Results of the study noted that, "all six demonstrated a strong preference for a single art medium and showed a restricted variation in artistic themes. None understood art theory. Some autistic features contributed to their success, including attention to visual detail, a tendency toward ritualistic compulsive repetition, the ability to focus on one topic at the expense of other interests, and intact memory and visuospatial skills. The artistic savant syndrome remains rare and mysterious in origin. Savants exhibit extraordinary visual talents along with profound linguistic and social impairment. The intense focus on and ability to remember visual detail contributes to the artistic product of the savant" (Autistic savants. [correction of artistic]. Hou C, Miller BL, Cummings JL, Goldberg M, Mychack P, Bottino V, Benson DF. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, 01 Jan 2000)

The Big Transition

Change doesn't necessarily come easy nor without a certain degree of emotional upheaval. For Elizabeth, that was especially true when she moved into residential living at [Services for the UnderServed \(S:US\)](#) in 2020 after having lived in the community with her family since infancy. As an extremely shy person, this transition could have proved challenging as adjusting and settling in takes time. However, Elizabeth bonded with her peers through art. She created precise and intriguingly

detailed portraits of her peers and offered her masterpieces as treasured gifts to her housemates.

At S:US, Elizabeth's creative talents are nurtured. Staff members work with Elizabeth to help research and expose her to various expressive opportunities by way of professional art classes and events that are of interest. However, her social awkwardness stands in the way of her being able to take advantage of some of these opportunities. Through routine work with her Psychiatrist, Counselor, Behavior Intervention Specialist, staff, and those alike, we continue to explore ways in which Elizabeth can overcome her anxieties and become more at ease in public.

Elizabeth's favorite type of art is ancient Egyptian, but she also enjoys art spanning the Roman period, influences from India, and the Native American heritage. She also draws inspiration from visits to art museums and galleries and draws on a daily basis, frequently crafting her art 3-5 times per week.

In a recent interview, when asked what she loves about art, Elizabeth shared that, "I can draw anything I want. Sometimes I look at people and draw them or sometimes I make it up in my head or look at photos on my phone or tablet." She also shared her realization that the practice of making art is therapeutic. She stated, "Art calms me down and helps me feel better when I am angry or feel sad."

Elizabeth's goal of sharing her talent more widely was realized in the selection of [her artwork at the 2022 New York Alliance For Inclusion and Innovation Virtual](#)

[Art Gallery](#) in April. The gallery showcased three of Elizabeth's pieces amongst those of other artists with developmental disabilities. The gallery curated unique pieces that captured the impact of the global pandemic on their lives, and pieces that reflected feelings around racism, racist behavior, violence, and bullying, as well as pieces on advocacy for people with disabilities in an exhibit entitled "The View from Here." Elizabeth was honored and beyond thrilled to have her drawings featured and the S:US community and is very proud of her many accomplishments. Since she has been making art for over 20 years, Elizabeth feels that drawing is her lifelong passion. She endeavors to pursue painting classes, attend art school, and dreams of selling her drawings in the future. Anyone would be privileged to own one of her pieces.

Jozette Prescott, MA, is Vice President of Residential Services at Services for the UnderServed (S:US). For more information, visit [sus.org](#).

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Autism and Epilepsy from page 4

- Individuals with Autism and severe intellectual and developmental disabilities have a risk of acquiring Epilepsy of 5% at 1 year, 15% at 5 years, and 25% at 10 years.
- Individuals with Autism and both intellectual and developmental disabilities and Cerebral Palsy have a risk of acquiring Epilepsy of 20% at 1 year, 35% at 5 years, and 65% at 10 years.
- Epilepsy persists in the majority of patients into adult life with remission in only 15% of adults with Autism and Epilepsy.
- Epilepsy and Autism may reflect the same underlying brain abnormality and there are many disorders such as Fragile X, Tuberous Sclerosis and Down Syndrome where Autism and Epilepsy may co-occur on this basis.

Types of Seizures

Seizure disorders take several forms, depending on where in the brain the malfunction takes place and how much of the total brain area is involved.

Generalized Tonic Clonic Seizure: These are the ones which most people generally think of when they hear the word “Epilepsy.” In this type of seizure, the person undergoes convulsions which usually last from two to five minutes, with complete loss of consciousness and muscle spasms.

Absence Seizure: Takes the form of a blank stare lasting only a few seconds.

Partial Seizure: Produces involuntary movements of arm or leg, distorted sensations, or a period of automatic movement in which awareness is blurred or completely absent.

Since these seizure disorders are so different in their effects, they require different kinds of action from the public. Some require no action at all. The following information describes seizures in detail and how to handle each type. Please share this important information with caregivers, first-responders, and those who work with individuals who have Autism and/or Epilepsy.

First Aid for Seizures in Special Circumstances

Although the fold-out chart inside this brochure gives information on basic first aid for a generalized tonic clonic (convulsive) seizure, there are some special circumstances in which additional steps should be taken. One should not rely on this general information as individual cases may vary, therefore a physician should always be consulted on all first aid procedures.

A Seizure in Water: If a seizure occurs in water, the person should be supported in the water with the head tilted so his face and head stay above the surface. He should be removed from the water as quickly as possible with the head in this position. Once on dry land, he should be examined and, if he is not breathing, artificial respiration should be begun at once. Anyone who

has a seizure in water should be taken to an emergency room for a careful medical checkup, even if he appears to be fully recovered afterwards. Heart or lung damage from ingestion of water is a possible hazard in such cases.

A Seizure in an Airplane: If the plane is not filled, and if the seat arms can be folded up, passengers to the left and/or right of the affected person may be reassigned to other seats, so that the person having the seizure can be helped to lie across two or more seats with head and body turned on one side. Once consciousness has fully returned, the person can be helped into a resting position in a single reclining seat. If there are no empty seats, the seat in which the person is sitting can be reclined, and, once the rigidity phase has passed, he can be turned gently while in the seat so that he is leaning towards one side. Pillows or blankets can be arranged so that the head doesn't hit unpadded areas of the plane. However, care should be taken that the angle at which the person is sitting is such that his airway stays clear and breathing is unobstructed.

A Seizure on a Bus: Ease the person across a double or triple seat. Turn him on his side, and follow the same steps as indicated above. If he wishes to do so, there is no reason why a person who has fully recovered from a seizure cannot stay on the bus until he arrives at his destination.

Is an Emergency Room Visit Needed?

An uncomplicated convulsive seizure in someone who has Epilepsy is not a medical emergency, even though it looks like one. It stops naturally after a few minutes without ill effects. The average person is able to continue about his business after a rest period, and may need only limited assistance, or no assistance at all, in getting home. However, occasionally a seizure will fail to stop naturally and as noted earlier, there are several medical conditions other than Epilepsy that can cause seizures. These include:

- diabetes
- poisoning
- brain infections
- hypoglycemia
- heat exhaustion
- high fever
- pregnancy
- head injury

When seizures are continuous or any of these conditions exist, immediate medical attention is necessary.

Avoiding Unnecessary Trips to the Emergency Room

The following are some suggestions to help people with Epilepsy avoid unnecessary trips to the emergency room and help one decide whether or not to call an ambulance. One should not rely on this general information as individual cases may vary,

therefore a physician should always be consulted in all emergencies.

No Need to Call an Ambulance:

- If medical I.D. jewelry or card says “Epilepsy,” and
- If the seizure ends in under 5 minutes, and
- If consciousness returns without further incident, and
- If there are no signs of injury, physical distress, or pregnancy.

An Ambulance Should Be Called:

- If the seizure has happened in water.
- If there's no medical I.D. and no way of knowing whether the seizure is caused by Epilepsy.
- If the person is pregnant, injured, or diabetic.
- If the seizure continues for more than five minutes.
- If a second seizure starts shortly after the first has ended.
- If consciousness does not start to return after the shaking has stopped.

If the ambulance arrives after consciousness has returned, the person should be asked whether the seizure was associated with Epilepsy and whether emergency room care is wanted.

For Law Enforcement Officers: Epilepsy And Drugs

Despite medical progress, Epilepsy cannot be cured in the same sense that an infection can be cured. However, seizures can be controlled completely or significantly reduced in most people who have the disorder. This control is achieved through regular, daily use of antiseizure drugs called anticonvulsants. Doses may have to be taken up to four times a day, and people with Epilepsy therefore usually carry medication with them. To miss a scheduled dose is to risk a seizure.

Many medications are used in the treatment of Epilepsy. More than one drug may be prescribed. Among them phenobarbital, Ativan (lorazepam), Klonopin (clonazepam), Tranxene (clorazepate), and Valium (diazepam).

If a law enforcement officer has any doubts about the legality of a person's possession of medication, the physician who prescribed the drug, or the pharmacy that dispensed it, should be contacted without delay. Depriving a person with Epilepsy of access to her medication may put her health and life at risk.

When medication is taken away, for even as little as several hours, the following may happen:

- A convulsive seizure with subsequent injury due to falling on cement floors, or in a confined area.
- A series of convulsive seizures called status epilepticus, in which the convulsions continue non-stop, or are followed

by coma or a subsequent series of seizures. These are life threatening, and the mortality risk is high unless prompt treatment at a properly equipped medical facility is available.

- Episodes of automatic behavior, known as complex partial seizures, in which the person, unaware of where he is or what his circumstances are, injures himself in unconscious efforts to escape, or is injured in struggles with law enforcement personnel. A person having this type of seizure is on automatic pilot so far as his actions are concerned. Efforts to restrain can produce a fighting reaction which he cannot control.

Types of Seizures, What to Look for, and How to Respond

Recognizing the different symptoms of seizures can help you determine the type. Read on to learn what seizures look like, what they are not, what to do, and what not to do if a seizure occurs.

Generalized Tonic Clonic Seizure (also called Grand Mal)

What It Looks Like

Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control, usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.

What It Is Not

- Heart attack
- Stroke

What To Do

- Look for medical identification.
- Protect from nearby hazards.
- Loosen ties or shirt collars.
- Protect head from injury.
- Turn on side to keep airway clear unless injury exists. Reassure as consciousness returns.
- If single seizure lasted less than 5 minutes, ask if hospital evaluation wanted.
- If multiple seizures, or if one seizure lasts longer than 5 minutes, call an ambulance.
- If person is pregnant, injured, or diabetic, call for aid at once.

What Not To Do

- Don't put anything in the mouth.
- Don't try to hold tongue. It can't be swallowed.
- Don't try to give liquids during or just after seizure.

see Autism and Epilepsy on page 25

Gastrointestinal from page 12

neurodevelopmental disorders. Finally, gastrointestinal challenges co-occur alongside a host of other medical complications that remain under-researched in autism and other neurodevelopmental disorders, and research and continue to explore the biological in medical factors that are intertwined with autism’s complex social presentation.

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Harry M. Voulgarakis, PhD

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Autism and Epilepsy from page 24

- Don’t use artificial respiration unless breathing is absent after muscle jerks subside.
- Don’t restrain.

Absence Seizure
(also called Petit Mal)

What It Looks Like

A blank stare, beginning and ending abruptly, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth, Child or adult is unaware of what’s going on during the seizure, but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.

What It Is Not

- Daydreaming
- Lack of attention
- Deliberately ignoring adult instructions

What To Do

- No first aid necessary, but if this is the first observation of a seizure, medical evaluation is recommended.

Simple Partial Seizure

What It Looks Like

Jerking may begin in one area of body, arm, leg, or face. Can’t be stopped, but patient stays awake and aware. Jerking may proceed from one area of the body to another, and sometimes spreads to become a generalized convulsive seizure.

What It Is Not

- Acting out, bizarre behavior
- Hysteria
- Mental illness
- Psychosomatic illness
- Parapsychological or mystical experience

What To Do

- No first aid necessary unless seizure becomes convulsive, then first aid as noted for a Generalized Tonic Clonic seizure.
- No immediate action needed other than reassurance and emotional support.
- Medical evaluation is recommended.

Complex Partial Seizure
(also called Psychomotor or Temporal Lobe)

What It Looks Like

Usually starts with blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or flail at restraint. Once pattern established, same set of actions usually occur with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. No memory of what happened during seizure period.

What It Is Not

- Drunkenness
- Intoxication on drugs

• Mental illness

- Disorderly conduct

What To Do

- Speak calmly and reassuringly to patient and others.
- Guide gently away from obvious hazards.
- Stay with person until completely aware of environment.
- Offer to help getting home.

What Not To Do

- Don’t grab hold unless sudden danger (such as an approaching car) threatens.
- Don’t try to restrain.
- Don’t shout.
- Don’t expect verbal instructions to be obeyed.

Atonic Seizures
(also called Drop Attacks)

What It Looks Like

A child or adult suddenly collapses and falls, After 10 seconds to a minute he recovers, regains consciousness, and can stand and walk again.

What It Is Not

- Clumsiness
- Normal childhood “stage”
- In a child, lack of good walking skills
- In an adult, drunkenness, acute illness

What To Do

- No first aid needed unless the person was hurt upon falling.
- Medical evaluation is recommended.

Myoclonic Seizures

What It Looks Like

Sudden brief, massive muscle jerks that may involve the whole body or parts of the body. May cause person to spill what they were holding or fall off a chair.

What It Is Not

- Clumsiness or poor coordination

What To Do

- No first aid needed but medical evaluation is recommended.

Infantile Spasms

What It Looks Like

These are clusters of quick, sudden movements that start between 3 months and two years. If a child is sitting up, the head will fall forward, and the arms will flex forward. If lying down, the knees will be drawn up, with arms and head flexed forward as if the baby is reaching for support.

What It Is Not

- Normal movements of the baby
- Colic

What To Do

- No first aid needed but medical evaluation is recommended.

Ehlers-Danlos from page 20

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Collaborative from page 8

beneficial when designing treatment packages that might be affected by prescribed medication (Newhouse-Oisten et al., 2017). For instance, some seizure medications also function as mood stabilizers and might influence behavioral interventions, making collaborating even more important. Behavior analysts should work with prescribing professionals to collect relevant measures throughout intervention and systematically change a single medication or behavioral component at a time while holding others constant. This type of ongoing collaboration across disciplines allows for systematic intervention evaluation, taking the whole person into account.

Monitoring: The Cycle of Intervention Design, Implementation, and Modification

The intervention process is not complete once the intervention is implemented. Rather, collaborative communication and monitoring are necessary to inform inter-

vention refinements, maintenance of intervention effects, and fading in some cases. Effective, ongoing collaboration across professionals requires using common language and understandable data (Bowman et al., 2021). Behavior analysts can contribute through measurement systems that highlight correlations between variables relevant to co-occurring diagnoses (e.g., behavioral data, bowel movements, sleep patterns). For example, interventions that target toilet training for an individual with ASD and a GI diagnosis might include data collection specific to the frequency, type, and timing of bowel movements as well as prompted and independent requests for the bathroom. To best evaluate interventions targeting perseverative speech related to an anxiety diagnosis, data collection might include the frequency of perseverative speech as it relates to the timing of both environmental events and the administration of anxiety-reducing medication. It is also important to consider the individual's engagement in their daily activities, and overall quality of life measures.

Conclusions

When it comes to assessing and treating behavior in the context of co-occurring conditions, collaboration is an essential component for achieving best outcomes for the individual. The possibility for collaboration with other fields is inherently built into some service delivery models for those with developmental disabilities, such as special education schools or behavioral units partnered with medical centers. We understand this is not the case for all behavior analysts or professionals working with individuals with ASD and co-occurring conditions. In these cases, we encourage communication across professionals to whatever extent possible by requesting individuals or caregivers seek assessment by other professionals (e.g., medical, dental, neurological), share relevant data with other service providers, and advocate for additional services relevant to co-occurring conditions when appropriate. The behavior analyst must go beyond the collection of data and ensure that the data are accessible

to all members of the interdisciplinary team and the team as a whole review the data to make collaborative, data-based decisions.

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see Collaborative on page 30

Eating Disorders from page 1

as well. For autistic girls, who may already find it hard to fit in with their peers, trying to be thin could be a way to feel “socially acceptable.”

Another client, Marianne, told me, “I was always the odd one out and I figured that this was because I was a bit fat. I thought if I lost weight, I’d be accepted by the other girls. Of course, that didn’t happen. But my obsession with fitting in led to a lifelong eating disorder.”

Obsessive Interests - Autism is characterized by intense levels of interest and focus on particular subjects and developing an unhealthy obsession with food can fit with this general autistic profile.

Jenny described how she became obsessed with calorie intake and restriction as a teenager. “I’m good with numbers anyway, and when I discovered calorie counting it became a complete obsession. I could reel off the calories in hundreds of foods. I’d obsessively count, and I started to restrict more and more. I became obsessed with eating as little as possible, and by then the eating disorder had taken complete control of me.”

Routines and Rigid Thinking - People with autism often display problems with executive function, including cognitive flexibility. This means that, while they may be fantastic at determinedly pursuing an idea or course of action, they find it hard



Claire Jack, PhD

to shift to new ways of doing things. When a person with autism is set on a particular path - such as eating in a controlled manner - they can display such determination in sticking to that path that it can trigger or intensify an eating disorder.

How is Treatment Influenced?

While research finds that adolescents with autism are as likely as neurotypicals to recover from an eating disorder,⁴ adults with autism tend to experience longer-lasting and more severe disorders.⁵

Facilities specializing in the treatment

of eating disorders should allow increased time to develop a therapeutic relationship with autistic patients. Acknowledging the sensory issues that people with autism face around foods is also important when drawing up treatment plans.

Eating disorder practitioners who are working with autistic clients could also benefit from additional training and an understanding of the types of strategies that help autistic people regulate their emotions. Considering the rituals, routines, and rigid thinking which people with autism display in other aspects of life will also help shape therapeutic interventions.

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**EarliPoint from page 23**

families get the interventions and support that are most beneficial.”

EarliTec’s technology utilizes Dynamic Quantification of Social-Visual Engagement (DQSVE), which captures a child’s moment-by-moment looking behavior that is otherwise imperceptible to the human eye. EarliTec’s EarliPoint Evaluation can assist in the early identification of ASD and provides the EarliPoint Severity Indices that correlate with the levels of social disability and verbal and non-verbal ability.

By directly measuring a child’s preferential attention to critical social information in the environment, EarliPoint provides the first objective diagnostic tool for providers. Conducted by a trained technician, the evaluation involves a child watching a series of short video scenes depicting social interactions between children. Eye-tracking technology monitors the child’s focus and responsiveness, and using patented analysis technology, these data are compared to age-expected reference metrics to determine if the child is missing key moments of social learning.

“This is a significant milestone as we continue to develop innovative technologies designed to improve the lives of children and families affected by autism,” said Sreeni Narayanan, Chief Technology Officer of EarliTec. “How we quantify moment-by-moment behavior of a child not

only provides objective measures of each child’s strengths and weaknesses today - measures that can be universally available and accessible to all families - it provides a digital health platform that can support care in the future, so that all individuals affected by autism receive timely, individualized care.”

The EarliPoint Evaluation was granted clearance based on positive results from two studies, a pivotal clinical trial and a repeatability and reproducibility study, in which more than 500 individuals were enrolled. These studies were preceded by a feasibility trial involving more than 1,000 children. The FDA 510(k) clearance represents the first regulatory milestone for the company, with plans to continue clinical research and deepen partnerships within the ASD community that will enable optimal clinical outcomes to best meet patient and caregiver needs.

EarliTec’s recently announced \$19.5 million financing, led by Bernie Marcus with participation from the Georgia Research Alliance, was used to support the FDA submission and the development of the technology created by researchers at Children’s Healthcare of Atlanta, Emory University School of Medicine and Yale University.

About Autism

Autism spectrum disorder (ASD) affects roughly 1 in 44 children, more than

all childhood cancers, juvenile diabetes and heart disease combined.¹ While many parents suspect symptoms of autism in the first 18 months of life, the median age for diagnosis in the U.S. remains four to five years of age.² Lack of access to expert clinicians and other disparities in care can further delay diagnosis. Prolonged diagnosis delays the possibility of treatment in a situation where early intervention is one of the most important factors for improving lifetime outcomes.

About EarliTec Diagnostics

EarliTec Diagnostics is a digital health company making earlier identification and treatment for ASD and related disabilities accessible to children everywhere. Developed by leading researchers at Children’s Healthcare of Atlanta, Emory University School of Medicine and Yale University, EarliTec is pioneering the development of biomarkers that help parents, providers and caregivers understand how a child is viewing the world. The company’s initial product, the EarliPoint™ Evaluation for Autism Spectrum Disorder, is the first objective measurement tool that clinicians can use to assist in the detection and assessment of ASD in children as young as 16 months of age.

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view the original article, published on June 10, 2022, at www.businesswire.com/news/home/20220610005563/en/EarliTec-Diagnostics-Receives-FDA-510-k-Clearance-for-the-EarliPoint-Evaluation-for-Autism-Spectrum-Disorder.

For more information, please call Shay Smith at (707) 971-9779 or email shay@healthandcommerce.com.

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Diagnosing from page 6

whose autism impairs their ability to communicate through words, facial expressions, and body language.

Children and teens may not be able to label their feelings as *guilt* or *worthlessness*, some of the words doctors are looking for when considering depression.⁷

Even adults who speak fluently may struggle to identify their own emotions, a condition called alexithymia,⁸ and to describe their moods to a doctor. “They may just say, ‘Oh, everything’s OK,’ when it’s really not OK,” says psychiatrist Robert Wisner-Carlson, MD. Wisner-Carlson is chief of the Autism and Neurodevelopmental Outpatient Program at Sheppard Pratt, a mental and behavioral health system in Towson, Maryland.

The Lens of Depression

When he was younger, Ben’s symptoms seemed to confuse his doctors and counselors, his mother says. For example, one time he said he did not want to live - a warning sign - but a psychologist did not think he was seriously depressed. The reason? Ben also said that he needed to meet some fellow students to finish a project that was due soon. Because of that, “they said he does not fit the profile of someone who’s depressed.”

But his desire to follow rules, a common trait of autism, or his perfectionism could also explain his concern about the project, his mother says. Because Ben earned good grades, health care providers seemed to overlook his depressed feelings, she says.

Ben says he looks at life through different lenses that may reflect having anxiety, depression, or a goal for the future. “The lens of depression is often forced upon your eyes though, because of immediate circumstances or a bunch of things piling up,” he says.

Researchers are studying ways to improve doctors’ ability to diagnose depression in people who have autism. Do the questionnaires commonly used to screen for depression work with autistic adults? In a study involving almost 900 SPARK participants, Gotham’s research team found that one such questionnaire did, in fact, work in autistic adults.⁹

When Should You Suspect Depression in Someone with Autism?

Doctors and researchers alike say it is important to look for *changes* in someone’s sleep and eating habits, in their interests, and their irritability or agitation levels. This is crucial if the person cannot describe their feelings. Doctors may rely on information from relatives or others about such changes when evaluating someone with autism.

“I think initially we were hypothesizing that depression might really look different in people with autism,” Gotham says. “What

we have found so far is that depression looks different in *some* people with autism. But it looks a lot like the depression that we know, in a lot of people on the spectrum.”

For example, one common symptom of depression is a loss of interest in things that someone used to enjoy. For people with autism, that might mean a change in their special interests. Many people on the spectrum have a passion for a favorite topic, such as video games, art, music, or nature. Depressed people might spend less time on their special interest - or dramatically more time, to the exclusion of all else, Gotham says. Or they might develop a new interest in “dark or morbid topics,” she says.

Depression Risks from Childhood through Adulthood

Who is more likely to experience depression? According to research, risks include:

- A family history of depression or bipolar disorder, which may have existed before a parent had a child with a disability^{5,10}
- Experiencing trauma, including bullying^{11,12}
- Being verbal and having at least average intelligence^{10,13-16}
- In children and teens, having anxiety or another psychiatric condition¹⁰
- Being older

People’s risk for depression rises as they move from childhood to adulthood, whether they have autism or not, Gotham says. “At each stage of life taken by itself - childhood, adolescence, and adulthood - people on the autism spectrum appear to be at a greater risk for depression compared to the general population,” she says.

One stage, the transition to adulthood, poses a particular challenge for people who have autism, with stresses that may increase the risk of depression, says Wisner-Carlson, the psychiatrist at Sheppard Pratt.

Students with autism often receive an array of services through their public schools. But when they graduate, usually between ages 18 and 21, they lose school services, such as speech therapy, social skills instruction, and psychological help. They may not qualify for help under the adult disability system, he says. Even if they do qualify, they may have to wait a long time to receive services. The sudden loss of services “can be huge jolt,” says Wisner-Carlson, like “falling off a cliff.”

Other factors can influence risk. Families of people who have autism seem more likely to have a history of depression and bipolar disorder, Wisner-Carlson says. “The genetic studies of psychiatric illness and autism show a lot of genetic markers that overlap.”

And other factors play a part, too. “Individuals with autism are probably more of-

ten victimized and bullied,” Wisner-Carlson says. Research shows that children who have autism are bullied at a higher rate than other children.¹⁷ Bullying is linked to depression in typically-developing teenagers, and one study found psychiatric effects from bullying into adulthood.^{18,19}

Some aspects of autism itself may add to depression. For example, rumination - thinking over and over again about things that upset you - is a risk factor for depression in the general population. People with autism have repetitive motions and obsessive interests, which may be related to rumination.^{20,21} Another study found a link between depression and the planning and organizational problems often experienced by people who have autism.²²

Those planning problems, in fact, can make it harder for adults on the spectrum to find a psychiatrist and make an appointment, says Wisner-Carlson. Even placing a phone call can be difficult, he says.

The risk for depression is not spread evenly across the spectrum. People who are verbal and don’t have intellectual disability are more likely to be diagnosed with depression.

Some wonder if depression appears to be more common in verbal people because it’s easier to diagnose and research them. “How do you identify trauma or depression in someone who’s nonspeaking or has very low communication skills?” asks social worker Dena Gassner, an autistic member of the SPARK Community Advisory Council. But, she warns, “The illusion is thinking those are the *only* people we’re struggling to identify.” Even verbal people may escape diagnosis, she says.

Resources

- The National Suicide Prevention Lifeline provides free, confidential support 24/7 at 1 (800) 273-8255 and by [online chat](#). It also has prevention and crisis resources, and information for professionals.
- Text HOME to 741741 in the U.S. and Canada to be connected by text message to a trained, volunteer crisis counselor at the [Crisis Text Line](#).
- [Be the One to Save a Life](#) has resources for people in crisis.
- [National Alliance on Mental Illness](#) 1 (800) 950-6264
- To locate a psychiatrist or other mental health provider, contact your doctor. You also may use this [child and adolescent psychiatrist](#) finder or [adult psychiatrist](#) finder.

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Big Sigh from page 16

gets kicked into the brush or a twig cracks under a foot or paw. The remaining leaves rustle on the trees as some float silently to ground. I can almost smell snow. I notice the world seems closer. More detailed. My depression lifts with each footfall. I can tell because my brain is taking pictures with my eyes again. When I see it all this clearly it seems so simple. This is what it is all

about. A walk. A breath. A reminder.

It is not twelve hours later that I return to where this day began, but thirteen. My hair flattens under the weight of my head as I lean back onto my pillow. My feet are safely tucked under one dog as the other takes her place next to me. Two cats take their positions as head warmers. The soft light of the tv flicks off and we turn out the light. In the almost darkness that streetlights and blinds provide, I listen. The night sounds

are different. It is a quiet symphony of breathing, adjustments, and purrs. But I am waiting for my favorite sound. A cat cleans itself and yawns. I adjust my pillow. From down by my feet, I hear it. My dog takes a deep breath which is followed by a big sigh. I love that sound. It is the sound of giving into rest. It is the sound of comfort. It is the sound that reminds I am exactly where I am supposed to be. As I close my eyes, I don’t worry about when the morn-

ing will arrive. I take in a deep breath and let out my own big sigh.

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Catatonia from page 13

prompt dependency, reduction or loss of speech, and catatonia-like excitement (occurrences of inappropriate behavior, and behavior that is not within the individual's control) (Shah & Wing, 2006).

The "lorazepam challenge test" may be used to diagnose catatonia, particularly in individuals exhibiting the more severe form (Dhossche, 2014; Sienaert, Dhossche, Vancampfort, De Hert, & Gazdag, 2014). An individual suspected of having catatonia is administered one or two milligrams of lorazepam intravenously or intramuscularly. The test should be conducted when a diagnosis of catatonia is suspected (Sharma, Jena, Sharma, & Agrawal, 2014). A positive response to the test, which is rapid resolution of all catatonic symptoms, strongly supports a diagnosis of catatonia (Sienaert et al., 2014). Similarly, zolpidem, a non-benzodiazepine, is also used to diagnose and treat catatonia when there is a lack of response to lorazepam (Sienaert et al., 2014).

Other medical conditions may play a role in the development of catatonia, including encephalitis, autoimmune diseases, biological factors, epilepsy, hormonal changes during puberty, and the use of antipsychotic medications (Dhossche, Shah, & Wing, 2006). Healthcare professionals must first rule out treatable causes when an individual with ASD demonstrates catatonia-like symptoms. When a treatable underlying medical cause cannot be identified, appropriate methods of treatment and management are imperative (Hare & Malone, 2004).

How is Catatonia in Individuals With ASD Treated?

The evidence basis supporting the treatments for catatonia in individuals with ASD is limited but growing. Researchers, including Aspy and Grossman (2016), assert that true catatonic behaviors are motiveless and without function. However, this is not to suggest that teaching strategies and prompting techniques based in the principles of applied behavior analysis (ABA) are not of some benefit to individuals afflicted with this condition. A behavioral evaluation using functional assessment (FA) method, along with an initial assessment, are recommended to ascertain to what degree the catatonia-like deterioration has interfered with the individual's everyday life and at what level (mild, moderate, or severe). Antecedent interventions, prompting strategies, and reinforcement may be effective components of treatment. For example, reinforcement can target adaptive behavior such as decreased time to complete a task or increased appropriate use of utensils when eating (Downey & McDonald, 2019). The BFCRS (1996) is a recommended tool to include as part of this evaluation to assess the severity level of the catatonia so appropriate methods and course of treatment can be implemented (Sienaert, et al., 2014).

Individuals with mild to moderate catatonia may benefit from the non-medical



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psychological approach and management principles described by Shah and Wing in 2006. The management principles provide strategies for each area potentially affected by catatonia such as incontinence, eating, drinking and swallowing, speech and communication, motor movement, and catatonia-like excitement. In addition to their "blueprint for assessment of catatonia in ASD," Shah and Wing also developed a "blueprint for the treatment of catatonia in ASD" for all severity levels (Downey & McDonald, 2019).

Pharmacological treatments for catatonia include benzodiazepines, specifically lorazepam; it is the first choice of pharmacological treatment. Zolpidem, a non-benzodiazepine, is used when there is a lack of response to lorazepam. Some individuals with ASD presenting with catatonic symptoms may require a combination of the Shah and Wing (2006) approach and lorazepam or zolpidem (Dhossche, 2014).

Bilateral Electroconvulsive therapy (ECT) may be administered to individuals demonstrating the more severe form of catatonia-like deterioration who do not respond to the psychological approach and management principles or psychopharmacological treatment (Sienaert et al., 2014). Research to date indicates more effective alleviation of catatonic symptoms when administering bilateral ECT and/or high doses of lorazepam as compared to other approaches and should be strongly considered when treating the severe form of catatonia in ASD as this severe form can be fatal. In some cases, symptoms of catatonia remain after treatment. In other cases, patients only experience partial response to treatment; that is, some symptoms are eradicated and some remain, or symptoms are somewhat alleviated, but not to baseline (pre-catatonia) levels. A systematic review of interventions by DeJong et al. (2014) found that decreased frequency of bilateral ECT and/or dosages of lorazepam following initial successful treatment often results in recurrence of some catatonic symptoms. Dhossche (2014) notes that in some cases maintenance bilateral ECT may be critical to reduce the recurrence of catatonic symptoms (Wachtel, Hermida & Dhossche, 2010).



Mary E. McDonald, PhD, BCBA, LBA

The DeJong et al. (2014) review determined the current body of research is promising but indicates caution should be exercised when making recommendations for treatment. They strongly suggest the need for more robust, controlled, high quality studies to further determine the safety and effectiveness of these treatments. Dhossche (2014) concurs that there is a need for the treatments to be gauged further as research increases but asserts that these treatments are the best recommendations available at this time, based on current clinical research to attain positive outcomes.

An increased awareness of the potential development of catatonia-like deterioration in individuals with ASD by those involved in their care and education helps ensure appropriate assessment, treatment and/or appropriate referrals at the onset of the condition. When left untreated or improperly treated, the disorder can become chronic or develop into its most severe presentation (Downey & McDonald, 2019). Knowledge gleaned by parents, medical professionals, special educators, clinicians, and all those caring for and working with individuals with ASD will decrease the likelihood that this debilitating condition will continue to remain "hidden in plain sight" (Aspy & Grossman, 2015-16).

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Multidisciplinary from page 17

on generalization of skills and provide consistency with school programming. His school BCBA observes him and meets with the home BCBA to ensure consistency with addressing behavioral needs. His OT and SLP work directly with him and provide consultation for his general education teacher, special education teacher, and home BCBA. The size of his team and overlap of professional expertise necessitates that the members are in regular communication and work together.

Individuals with autism are more likely to have co-occurring diagnoses, such as gastrointestinal problems, epilepsy, sleep disturbances, feeding challenges, attention-deficit/hyperactivity disorder, anxiety, and depression, than the general population (Al-Beltagi, 2021). Further, individuals with communication deficits may not be able to effectively communicate pain or other signs and symptoms of these conditions. These individuals may be under the care of a developmental pediatrician, specialist, or mental health counselor to receive diagnosis and treatment for these co-occurring conditions. Previously mentioned team members, including BCBA, teachers, and related service members, may be involved in collaboration with these medical professionals to assist in providing a description of challenging behaviors and symptoms, which may help to both diagnose and effectively treat a co-occurring medical condition. In addition, if medications are prescribed, the team should be aware of the dosage, duration of action, and particularly any potential side effects (Copeland & Buch, 2020). Team members can also collaborate to teach skills that facilitate medical assessment (e.g., tolerating a blood pressure reading, blood draw, or ear exam).

With multidisciplinary teams, there are bound to be differing treatment opinions that present potential areas of conflict within the team. To address navigating proposed treatments stemming from differing theoretical bases, Brodhead (2015) proposed a decision making model to aid in navigating treatment decisions using the following questions:

**Elise Settanni, MEd, BCBA, LBS**

- What is the treatment?
- Is the child's safety at risk?
- Are you familiar with the treatment? If not, familiarize yourself with it and reassess child safety.
- Is the treatment's success possible when translated into behavioral principles?
- Will the treatment negatively interfere with the child's other goals?
- Consult the Checklist for Analyzing Proposed Treatments - a checklist developed by Brodhead that evaluates treatment components within seven domains (i.e., function-based treatment, skill acquisition, social outcomes, data collection, treatment integrity, social validity, and resources).
- Are the impacts to the child sufficient to justify the possibility of compromising the professional relationship?

This decision making model can be useful for professionals who may not agree with a proposed treatment on a conceptual

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basis. Through this model, professionals can determine if and when they should question certain treatments.

Let's revisit Joaquin's situation. Suppose that he has been having difficulty attending to tasks and has been moving around a lot. The OT recommends doing "heavy work" prior to long periods of sitting and academic tasks. Initially, the special education teacher is in agreement, but the general education teacher and both BCBA's are hesitant to try the intervention. Using the decision making model above as proposed by Brodhead, the team first establishes that the intervention consists of heavy work such as pushups or jumping on the trampoline (step a). Next, they determine that the child's safety is not at risk (step b). The team takes some time to familiarize themselves further with the intervention through discussion with the OT and other resources (step c). After further review, they maintain that the child's safety is not at risk with this intervention. Through this process, the BCBA's were able to translate the intervention into behavior analytic terms (step d) and determine that the intervention aligns with an evidence based practice called antecedent exercise. At this point, the team recon-

venes and decides to move forward with the intervention without hesitation. Using Brodhead's structure for decision making, the team was able to avoid conflict and come to a decision in an effective, collaborative, and congenial way.

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Collaborative from page 26

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Alexithymia from page 14

Levels of Emotional Regulation

The three levels of emotional regulation are:

- Initiating response caused by emotions
- Inhibiting emotion triggers
- Modulating emotional responses

Our environment is the primary source of trigger for any stimuli, including emotional stimuli. How we respond to those stimuli is granted by how well we regulate these emotional inputs. Emotional regulation helps us to filter out all inputs and focus on the important ones so that it doesn't evoke fear or stress.

People with autism and alexithymia find it difficult to regulate emotions because of the difficulty in identifying them. In turn, this makes it difficult to attend to the semantic representation of those emotions because they can't identify what the emotional trigger is and how to deal with the resulting emotions when it occurs.

Is Alexithymia a Form of Autism?

As discussed, a person with alexithymia has difficulty with social interaction and social relationships, understanding the intentions and attitudes of others, difficulties with facial expression recognition, and recognizing emotional tones of speech, body movement/expression, and making decisions that take into account the point of view of others. In parallel, some individuals with autism struggle with these elements.

In both conditions, symptomatic traits include both communication difficulties and social difficulties while some autistic individuals may experience difficulties with cognitive processing of their emotions, identifying them, and describing their feelings.

Alexithymia in ASD is common in both low-functioning and high-functioning individuals, therefore difficulties with emotional recognition are exclusive of neurocognitive capacity. Another overall similarity between alexithymia and ASD is the construct of empathy where some studies have found that empathy levels seem to be low.

All these similarities point to possible co-occurrence of alexithymia with autism. However, it is not supported nor clear that alexithymia is a form of autism. It does seem to be clear though, that alexithymia can occur within the autism population.

Autism and Alexithymia: Theory of Mind

Theory of mind is a social-cognitive skill that defines the ability to think about the mental state of others as well as your own. The mental states referred to here are: emotions, feelings, beliefs, and thoughts.

According to Jean Piaget's theory of cognitive development, children's thoughts and communications are often egocentric - the child is unable to see the point of view of others and assumes others feel, think, hear, and feel the same way he/she does. With age, these egocentric traits fade and the theory of mind emerges.

The theory of mind informs our ability to understand others, make inferences of



Andréas RB Deolinda, BA, BSc

others' ways of thinking and feeling - this is especially important in order to develop social skills. Some autistic individuals and/or people with alexithymia struggle with this because of the difficulties around understanding their own emotions and those of others.

This leads to the understanding that a person with difficulties processing and defining emotions does not necessarily lack a theory of mind but rather is unable to because his/her emotional processing is altered, making it difficult to interpret his/her own mental states as well as those of others.

Can You Have Alexithymia Without Autism?

It is important to note that alexithymia is not autism, but simply a distorted emotional processing that is co-occurring among individuals with ASD. Alexithymia is a psychological construct that is defined by difficulties in emotion processing and should therefore not be considered as a diagnosis of a condition.

As we know, autism is characterized by a variety of traits. These traits differ across every individual on the spectrum - so we find that there is a wide heterogeneity of emotional competence within the autistic population. Given this, it can be implied that, although research supports that alexithymia co-occurs with autism, alexithymia can occur without an autism diagnosis, and that not every person on the spectrum has alexithymia. The two conditions can occur without the presence of the other.

Alexithymia and Other Conditions

Alexithymia studies focusing on its relationship with eating disorders have found correlation with individuals with eating disorders as compared to those in a "healthy" control group.

It is found that individuals with eating disorders have difficulties identifying and communicating their feelings. This is because individuals with difficulty in emotion processing turn to maladaptive practices as a coping mechanism; these maladaptive eating behaviors include purging, dietary restriction, and bingeing.

Nowakowski et al. (2013) states that when children are taught that emotions are negative (i.e., frightening or unacceptable), this leads to the belief that those emotions

should not be expressed. When the person feels those emotions, it leads to secondary emotions such as guilt or shame. This is then followed by maladaptive behaviors to cope with those experiences.

The study by Nowakowski et al. found that individuals with eating disorders have high levels of difficulty in identifying and describing their emotions; this is possibly due to lack of emotional regulation.

Interventions for Alexithymia

Therapies or training that teach social cues and communication etiquette are beneficial for both autism and alexithymia even in the absence of alexithymia. Here are a few tips or ideas to teach your child emotional recognition.

Visual Supports:

- Use visual images with emotions to teach your child to recognize emotional facial expressions.
- Teach your child the different types of emotions through images and practice mimicking those expressions with body language.

Cognitive Behavioral Therapy (CBT) for Emotion Recognition:

- CBT is often an effective treatment for the regulation or management of emotions. Cognitive therapy techniques aid people in identifying and evaluating inaccurate beliefs and notions centered around emotions.
- At the core of CBT to teach emotional regulation is mindfulness. Mindfulness teaches people to both identify their emotions and to explore aspects of emotions through their bodies.
- For individuals with alexithymia, there are techniques set in place that will help them effectively recognize, cope with, and coherently express emotions that may not be obvious to them and have better recollection of emotional memories.

Cognitive Reappraisal:

- Cognitive reappraisal is aimed at altering how we think to teach us an alternative, adaptive way to look at a situation. For children with alexithymia as well as autism, this technique could help them understand that a given stimulus is not necessarily designed to cause harm to them.
- By combining CBT with cognitive reappraisal, a child can learn that certain emotions whether sad, happy, or angry each serve a purpose.

Conclusion

Alexithymia is not necessarily a clinical diagnosis but rather explains a type of personality that can occur across the general population. The prevalence of alexithymia is most significant among autistic individuals. Research indicates that alexithymia and difficulties with emotional processing are closely related to depression and anxiety.

The inability to recognize one's own emotions can lead to depression because of the inability to define and understand one's internal conflicts for what they are and express or explain them to others. Therefore, a person with alexithymia and/or autism who experiences difficulties with emotional regulation or emotion recognition may experience anxiety and depression.

Some autistic children experience a variety of social skills challenges and emotional regulation that cause anxiety or aggressive behaviors. This challenge could be due to the fact that some autistic children may find it difficult to understand the world around them. In a "neurotypical world," the experience of autistic individuals isn't fully understood and so much still has to be done to raise awareness and acceptance of autism in our society.

If this is the case, the child may not necessarily have alexithymia but rather needs the necessary training and teaching to understand the world around them; as well as learn social cues so that he/she is better adapted to facing the realities of a "neurotypical" society.

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Treatment Response from page 22

- **Bipolar Disorder** - 11% of the ASD population is affected vs 2% of the general population.
- **Schizophrenia** - 7% of the ASD population is affected vs 0.5% of the general population.

ADHD, anxiety, and depression are the most diagnosed comorbidities.

Comorbid mental health conditions can be especially difficult to diagnosis since many of the symptoms can look like the core symptoms of ASD including difficulties with communication and expression, lack of engagement, inattention, lack of eye contact, repetitive behaviors, emotional regulation difficulties, or hyperactivity.

Genetic Disorders

The connection between ASD and genetic disorders takes into consideration both the prevalence of how many individuals with ASD have the related comorbid genetic disorder and how many with the related comorbid disorder have ASD to fully understand the correlation. The recommendation is that all children receiving an ASD diagnosis receive a consultation with a geneticist due to the increased rate of comorbid genetic disorders that can occur in conjunction with autism. With many genetic disorders early detection and intervention can be critical in long term outcomes. Some of the genetic disorders that are known to be associated with autism are Fragile X Syndrome (FXS), Down Syndrome, and Duchenne Muscular Dystrophy. FXS occurs at a rate of 2%-3% for all ASD cases have FXS, and about 25%-33% of FXS patients have ASD. Down Syndrome occurs at a typical rate for those with ASD and in the general population, 1/800. But the rate for those with Down Syndrome also having comorbid ASD is very high at 40%.

Other disorders that have a genetic basis occur at a higher rate as well such as various mitochondrial and metabolic disorders.

Neurological Disorders, Epilepsy, and Sensory Dysfunction

Neurological disorders are found in greater prevalence in individuals with autism than in the general population. It is more likely for ASD individuals to have macrocephaly, hydrocephalus, cerebral palsy, migraine/headaches, ADHD, autonomic nervous system dysfunction, congenital ab-



Julie Rasmuson

normalities of the nervous system.

Epilepsy occurs at a much higher rate with 30% of the ASD population having a comorbid seizure disorder, compared to 6-7% of the general population, and 60% having an abnormal electroencephalogram (EEG).

Sensory dysfunction also occurs at a high prevalence in individuals with autism. Sensory dysfunction can lead to a person having difficulty filtering sensory input making them hyper or hypo sensitive to stimuli. This inability to process sensory information can lead to challenges with learning, behavior, toileting, feeding, communication problems, self-confidence problems, and short-attention-span. Lower cognition and verbal levels correlate significantly with the age at which bowel and urine training is completed in children with autism as well and this is an important life skill for independent living.

Sleep Disorders

Between 50% to 80% of children with autism have a sleep disorder. Problems include difficulty falling asleep, frequent, and prolonged waking, or extremely early rising.

This can cause major concerns for both the individual and their family. Lack of sleep in children with autism can affect behavior, aggression, learning, anxiety, attention, mental health, communication, and the ability to engage in their everyday activities and lives.

Gastrointestinal and Feeding Disorders

Gastrointestinal (GI) disorders are common in individuals with ASD affecting 46% to 84% of the population. Common GI

symptoms found in the ASD population include food intolerance and sensitivities, nausea, vomiting, abdominal pain, flatulence, chronic constipation and/or diarrhea, gastroesophageal reflux, ulcers, colitis, inflammatory bowel disease, and/or failure to thrive.

As discussed previously many comorbid GI disorders also may have a root cause embedded in additional comorbid metabolic, dysautonomia, or dysfunction conditions.

An additional theory is that sensory concerns and rigidity surrounding feeding and diet can lead to feeding disorders causing a lack of adequate intake of fiber, fluids, and intake of a limited variety of foods. It is believed this can cause or exacerbate some of the associated GI concerns in the ASD population.

Other Increased Comorbid Disorders: Immune and Auto Immune Conditions, Cardiovascular, Allergic Disorders, Diabetes

- 25% of children with ASD have immune deficiency and dysfunction.
- Cardiovascular disease affects 37% of the ASD population vs. 23% of the general population.
- Allergic disorders are significantly more common in people with ASD from all age groups with a significant increase in all varieties of allergic disorder including asthma and atopic conditions. Allergic conditions can affect behavior and there is a correlation between the severity of allergies and the severity of autism.
- Food allergies are also increased affecting 20%-25% of ASD children, compared to 5%-8% in the general population.
- 30% of children with autism are obese, compared with 13% of the general population. This may correlate with the increase in diabetes found in 8% of the ASD population vs 4% of the general population.

Conclusion and Impacts

Our medical and mental health systems are often designed to evaluate, treat, and offer intervention for one condition at a time. The lens shift that needs to be considered is based on the extensive data that has been obtained regarding the high prevalence of comorbid conditions coinciding with autism. To provide the best care, this knowledge must be utilized to develop meaningful interventions for individuals

as a whole. Symptoms should not be overlooked or simply assumed that they are associated as a part of an individual's autism diagnosis. Other medical or mental health comorbidities that could be causing symptoms should be ruled out when determining meaningful and individualized interventions, supports, or therapies.

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Neurodiversity from page 15

by designating one or more areas of a workplace as being free of bright lights, louder sounds, talking and excessive foot traffic, and with dispersed workspaces. Allow for frequent breaks and/or daytime siestas. Make written transcripts of meetings available for those who are visual as opposed to auditory learners. Assign structured, predictable, and/or repetitive tasks to autistic employees who tend to perform these kinds of responsibilities exceptionally well. Assign individualized tasks to neurodivergent workers who may struggle in team-oriented scenarios yet thrive on their own.

An accommodation will only be as effective as the degree to which the workplace understands why it is necessary and can accept that only some will be granted the accommodation. Otherwise, resentment, jealousy, and/or intolerance may set in when an employee asks, "Why is he entitled to this but I am not?" An accommodation should be viewed as an effort to level the playing field at a diversified workplace, not as a basis for stigma.

Acceptance: Accept neurodiversity as being a natural attribute of the human population and that the workplace is better off acknowledging, accommodating, and embracing it rather than turning away from it. Accept that many of the hardships and challenges neurodivergent people face stem from societal expectations established by the neurotypical majority which therefore can be very difficult if not impossible for a neurodivergent individual to

**Sam Farmer**

meet. Accept that neurodivergent people have lots to offer the workplace (as evidenced by Dan Burger's accomplishments, for example) but only if the workplace cultivates an environment in which they are able to succeed. Accept all employees for who they are, allowing them to be their true, authentic selves without adverse consequences.

Listening: We all have personal stories to tell. Personal stories often resonate with those to whom they are genuinely conveyed. As a neurodiversity community advocate, I would love for all neurodivergent people to tell their own stories so as to raise awareness and make way for

acceptance. Furthermore, all employees, whether neurodivergent or neurotypical, have workplace needs and desires which are more likely to be honored if they are communicated. For example, to be heard, validated, and viewed as valued members of the workforce.

As important as it is for neurodivergent individuals to share what they would like their associates to know about them, it all ends up being for naught if they are not listened to. A workplace with which I would want to be associated is one at which all employees are invited to impart their personal stories, needs and desires, and at which co-workers listen to each other and take each other's words to heart.

Empathy: When an individual is able to imagine stepping into another's world, view things from her perspective and feel what she is feeling, wondrous things become possible. Empathy, when exercised at the workplace, strengthens workforce cohesion. Differences, whether neurological or otherwise, are bridged. Employees achieve greater interconnectedness. The other pillars of the CAALE framework (collaboration, accommodation, acceptance and listening) are able to take hold. A company can implement the greatest neurodiversity hiring program in existence, but unless the workplace culture cultivates at least a measure of empathy, the goals of the program cannot be fully realized.

Empathy does not require anything extraordinary. All it takes is a desire and a commitment to do what is right and what is best for the organization and its people. Knowledge of the benefits of intra-work-

place empathy can incentivize a company that aspires to greater inclusivity to help it flourish.

The CAALE framework was born from years of experience at an inclusive workplace of which I have been most fortunate to be a part as well as all that I have learned from other neurodivergent individuals who continue to tell stories about their challenges and triumphs at work and elsewhere. Dan Burger, myself, and many others are working to change the narrative around neurodiversity from one that focuses too much on stigma, marginalization and inability to one of acceptance, belonging, and acknowledgment of one's strengths and unique abilities. More success stories are waiting to happen. Perhaps the CAALE framework can help at least some of these stories come to fruition.

Sam Farmer is a neurodiversity community self-advocate, writer/author, and public speaker. Diagnosed later in life as autistic, Sam shares stories of lived experiences, ideas, and insights as to how one can achieve greater happiness and success in the face of challenge and adversity. A Long Walk Down a Winding Road - Small Steps, Challenges, & Triumphs Through an Autistic Lens is his first book. Visit sam-farmerauthor.com to learn more.

Sam would like to thank Tim Vogus for his contributions to this article. Tim Vogus is the Brownlee O. Currey, Jr. Professor of Management at the Vanderbilt University Owen Graduate School of Management and Deputy Director of the Frist Center for Autism and Innovation.

Abuse from page 21

Health: Changes in overall well-being, with the onset of new difficulties in areas such as sleep, hygiene, and eating habits.

Activity/Behavioral Changes: Change in sleep patterns (too much, too little), the need to sleep with parents or other family members, onset of self-injury, change in eating (too much/too little).

Psychological Changes: Onset of depression, anxiety, phobias, night/day terrors, hallucinations, hearing voices, fear of location of abuse (refusal to go to school, get on the bus).

I also believe that those professionals providing direct services to individuals with Autism are not provided with information about signs and symptoms of abuse, and thus a child/adult on the spectrum may go without help for quite a while, particularly those who do not know the words to describe what has happened to them or do not have a method to communicate.

Starting at the beginning, knowing that abuse is a "clear and present danger," parents and other caregivers must learn not only the signs of abuse (as they may appear in their loved one), but also how to reduce the risk of abuse in the first place and, if it occurs, what are initial emergency steps to respond (report the abuse, remove the perpetrator from the autistic person's life, and find effective and compassionate trauma therapy).

In 2012, in the absence of a national survey on abuse in the population of those with disabilities, along with the Arc of

**Nora Baladerian, PhD**

Riverside County, CA, we developed one - [you can view the report here](#). We began dissemination on May Day and closed on November 1st, accumulating 7,289 responses. The responses showed that the extent of abuse is very high in the population of those with disabilities, and little pre- and post-efforts to reduce the risk of abuse existed. Although we did not do a survey on the availability and impact of trauma therapy for those with autism, in general reports are that post-trauma healing programs are rare for those with autism.

Reducing the Risk of Abuse

When addressing such a complex problem, it is often difficult to know where

to begin. I think it is prudent for anyone/everyone caring for an individual on the spectrum to complete a "risk reduction plan." I developed this term and program to use instead of the term "prevention," as it is not possible to prevent 100% of abuse from occurring, but it is possible to reduce the risk the impact of abuse. Briefly, the following factors are essential:

- Acknowledge that abuse is not only possible but likely.
- Talk to your child/adult about what abuse is, including: physical abuse, verbal/emotional abuse, financial abuse, sexual abuse.
- Ask them to tell you right away if this has happened or happens.
- When abuse is suspected, reporting to the police is essential as the process will include a medical examination to assess for wounds and evidence (for prosecution of the perpetrator(s)).
- Taking the individual to the hospital or police station immediately is important, both to collect evidence and get help in the form of treatment of any injuries as well as trauma therapy. When doing this, the individual accompanying the abuse victim should be aware of all of the circumstances of the abuse.

In many cases, the victim does not have any language to use to describe what has happened as sexual abuse is not part of their known communication teaching. For

example, the PECS system does not offer an option to communicate abuse of any kind. Thus, having someone with the individual to participate in information gathering interviews is essential. If the individual cannot describe what happened, using anatomical drawings or dolls can facilitate the description of what happened.

Responding to and Healing the Impact of Abuse

An assault of any kind (verbal, emotional, sexual, financial) can be extremely traumatic. Often the individual feels embarrassed and ashamed (for being a victim) but also frightened, confused, and angry. Trauma treatment is recommended to begin immediately. The best therapies are those whose impact is felt during the treatment session. Some abuse survivors will wish to talk about what happened to them while others will not want to talk about it at all. Some therapies require the survivor to talk about what happened, yet this is also difficult as it may reignite the victim's traumatic experience. Working with sexual (or other) assault victims with Autism is a mix of conducting the therapy at the best pace for the survivor of abuse and facilitating their release of strong emotions such as terror, anger, self-protection, sadness, hopelessness, helplessness, depression, and self-blame among others.

It has been my experience that most sexual assault victims do not want to "tell the story" of what happened to them. Feelings of shame, embarrassment, and helplessness

see Abuse on page 34

Processing Disorder from page 19

then went into sensory overload all within the first ten seconds of the show. It was then that my mother saw my anxiety-ridden reaction to sensory overload, quickly removing me from the theater to step outside and begin the process of sensory decompression.

Another common tell-tale sign that an individual with autism is experiencing sensory overload due to their SPD can be indicated if the individual is exhibiting restricted and repetitive behaviors (RRBs), often related to increase in arousal levels (Leekam et al., 2011). A class of behaviors including high frequency, repetition in a constant manner, and strong desire for sameness in the environment are formed from RRBs (Leekam et al., 2011). Restrictedness is seen in the narrowness of focus, inflexibility and preservation in interests, activities, and insistence that aspects of the environment stay the same (Leekam et al., 2011). Repetition is shown in rhythmic motor stereotypies, repetitive speech routines, and rituals (Leekam et al., 2011). With that being said, there are some practices that can certainly help one regroup from experiencing sensory overload, awareness is key.

Though this may be easier said than done, the #1 recommendation for those who experience sensory overload is to *remove yourself from the environment* and find a quiet, calm space to regroup, allowing for cognitive processing abilities to decompress from the overload. It's vital for those who have SPD to know this is not their *fault* but rather how their brain is wired. Studies have literally shown that neurodivergent individuals, including those with autism, have atypical sensory perception in comparison to those who are neurotypical (Proff et al., 2022). Additionally, functional MRI studies have revealed that frontal brain areas play a major role in



Claudia Rose Addeo, MS, BS

sensory processing sensitivity, serving as yet another reminder that SPD is neurological and *not* optional (Schredl et al., 2022). Furthermore, sensory hyper/hypo sensitivity can be linked to both cognitive and visuo-motor control challenges among those with ASD (Brandes-Aitken et al., 2018).

When discussing different forms of SPD, it should also be noted that certain cases of sensory overload can be more mild than other cases. For example, it's common among those who have visual SPD to prefer dimmed lighting or feel discomfort by fluorescent lights. Another tool that can help address and assess which forms of SPD you have or what may trigger your SPD is by *keeping a journal*. There is something to be said for tracking different forms of processing and noticing how you react to different sensory experiences. Many do not realize a big component of SPD is experiencing high sensory processing sensitivity,

which involves increased depth of processing, awareness of subtleties, high emotional reactivity, and ease of overstimulation (Schredl et al., 2022). Therefore, it's important to be mindful of SPD, how one feels when experiencing sensory overload, and what caused this trigger when journaling.

The last piece of advice recommended to help navigate SPD is by taking note of *sensory pleasures*. Though this may not be a term you would blurt out at the dinner table, it's just as paramount when discussing SPD. If sensory overload is caused by triggers of SPD, we can also encounter forms of sensory processing that give us pleasure. For example, I love the way a hot bath feels on my body. This sensory pleasure redirects my attention, helping me regroup from sensory overload. It's recommended to have a trial-and-error period by journaling which activities give *sensory pleasure* and **not** sensory overload! Whether trying to identify sensory triggers or sensory pleasures, the most crucial component of this process is to write everything down to reflect on the information gathered about your SPD while noting the progress made overtime.

I know first-hand being neurodivergent, and having had ASD myself, can be challenging. However, I hope this information can provide you with a solid start on how to identify your own SPD while making it easier to navigate. I believe in you my gifted, neurodivergent readers!

Claudia Rose Addeo was hand-picked to receive the 2020 "Top Young Writer Award" from Autism Parenting Magazine! Claudia is currently a doctoral student, certified elementary school teacher, neurodiverse advocate, and is in the process of publishing her first children's book! Having earned a master's degree in literacy education, Claudia writes and speaks about her personal journey, sharing addi-

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Abuse from page 33

may overwhelm the victim/survivor. Therapy specialists working with individuals with autism know to “tread carefully” so as not to restimulate these emotions but treat them so the individual no longer feels them.

Treating the individual victim is essential. The therapist helps the survivor know that they can and will heal from the trauma. Many are helped when they learn they are not the only one who has been abused. Currently, many therapists are using what used to be considered “alternative healing” approaches, but are now accepted (and proven) therapeutic interventions for individuals who have been abused. In this brief article, I will only highlight two of these. The first is Thought Field Therapy TFT, the second is Eye Movement Desensitization Restructuring (EMDR). The advantage of both approaches is that results (feeling better) are fairly rapid and persist over time. Both have been tested extensively and found to be “effective,” meaning that the trauma victim feels significant relief from trauma symptoms after treatment. I have

studied and practiced Thought Field Therapy with my clients with very remarkable results. Thought Field therapy does not require the individual to talk about their abuse – a great advantage over other approaches. Most do not want to talk about it, they just want to feel better. TFT employs the energy meridian system used in acupuncture and acupressure. The patient is asked to focus on the feeling they have when recalling the abuse, usually a combination of terror/fear, confusion, physical pain/discomfort, confusion, anger, invasion, and helplessness. They are then led through a series and sequence of tapping upon themselves specifically designed to release trauma. They are then asked how bad it feels when they think about the abuse. Treatment continues until they are at a “zero” when thinking of the trauma. The advantages are that there is nothing ingested, injected, or inhaled. The shift is permanent and there is no pain and no side effects.

Healing includes not only the relief from the post-traumatic stress symptoms, but also re-building one's sense of self, place in the world, and feelings of self confidence in healing from the abuse not only

emotionally but learning that they are not alone. Many, after treatment, wish for opportunities to help others who have been victimized to not feel they are alone and to know that they can heal from the trauma.

Resources

Risk Reduction Workbook: This is a workbook that provides most of the information any caregiver (individual/family/agency) needs to design an Individual Response Plan for their loved one or client. It is individualized to the skills and needs of each person.

Survivor - This is a support book for survivors of sexual assault, detailing what is meant by “sexual assault,” supporting the individual by knowing they are “not alone” or “not at fault” and that there are hundreds upon hundreds of others who have similarly been attacked by family, acquaintances, or strangers.

VERA - This is an organization that created an online guide about sexual abuse of children and adults with disabilities and in-

cludes information on healing approaches and resources.

Thought Field Therapy - This is a psychological healing treatment effective for trauma.

EMDR - This is a psychological healing treatment for trauma.

Additional resources can be found at www.DisabilityWithoutAbuse.com, a project that supports offering information, resources, guidance for those who wish to strengthen their risk reduction plans and treatment options when abuse occurs.

Nora Baladerian, PhD, is Co-Founder and Co-Director of the Disability Without Abuse Project and the prior Founder of the Disability & Abuse Project. For more information, visit disabilitywithoutabuse.com.

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Restrictive Eating from page 18

fading, shaping new feeding behaviors, and behavior tracking), then skills are applied to mealtimes to reduce behavioral challenges and increase food acceptance.

School-aged children and adolescents with ASD and ARFID can also benefit from individual and/or family-based cognitive behavioral therapy (CBT). Burton and colleagues (2021) found a combination of evidence-based treatments, Family Based Treatment (FBT) and the Unified Protocol (UP) for ARFID, effectively reduced mealtime anxiety and increased oral intake in autistic youth with ARFID. Similarly, Kuschner and colleagues (2017) piloted The Building Up Food Flexibility and Exposure Treatment (BUFFET) program as an outpatient group intervention to help autistic children aged 8-12 think and act more flexibly around food. BUFFET draws strategies from empirically supported CBT programs for autistic youth (Facing Your Fears and Unstuck and On Target). In this approach, families are first educated about malnutrition, ARFID, and strategies to enhance youth motivation to participate in meals. Then, youth and caregivers receive training in the thought-feeling-behavior connection, cognitive reappraisal, and positive behavior supports. Finally, children, caregivers, and clinicians work together to complete mealtime exposures with novel foods; children are coached to restructure negative thoughts about food and caregivers are coached to replace maladaptive parenting behaviors.

In sum, eating is a routine daily event and the behavioral and emotional difficulties associated with ARFID can create chronic distress in youth and their families. However, evidenced-based intervention is available. When consistent treatment is provided across settings, families can learn the skills necessary to shape greater food flexibility, increased oral intake, consistent mealtime routines, and a more positive mealtime environment. The key to improving feeding, particularly in autistic youth, lies in early identification and comprehensive evaluation to create a specialized treatment program that addresses the multifaceted feeding needs of the child and family.

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Discussion

There are critical clinical choice points in comprehensively meeting the needs of ASD individuals while skills and behavioral needs must be identified and formally represented in treatment plans. Social skills groups, individual skills training, CBT counseling and parent training can be delivered by BCBA's, psychologists and other licensed clinicians as training and circumstances dictate. Given the significant client demand for services, long waiting list that impede access to care, and

**Cynthia Martin, PsyD**

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Primary Care from page 10

Sam initiated psychological counseling with a licensed clinician at our STRIVE Center. Counseling sessions are held weekly. Sam's mother participates at the conclusion of each session and attends parent counseling once per month. Sam receives CBT to address social anxiety, nervousness, worry, and social skills. Goals include emotional identification and labeling, cognitive reframing, coping skills, problem-solving, and distress tolerance. His sessions include modeling, roleplay,

rehearsal, and review of "homework" assignments. Play has been incorporated to maintain rapport and practice social skills. His mother receives psychoeducation during her sessions, training on how to help Sam generalize skills learned in therapy, and an opportunity to process her own emotional experiences raising Sam. Future appointments will include joint parent-child sessions so they can learn collaborative problem-solving techniques and improve communication in the family. Progress in the identified skill areas is being made.

the emotional needs of parents and siblings that often go unsupported, First Children's treatment model has evolved. The array of clinicians on staff expanded and an interdisciplinary treatment model was developed to comprehensively address the needs of the autistic individual and their family members. This appears to be a growing trend for providers of ASD services.

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Treating from page 7

Sometimes those treatments need to be changed for people who have autism. For example, researchers and doctors say that people with autism may be more likely to have certain side effects from SSRIs, such as impulsive or irritable behavior and trouble sleeping. That appears to be especially true in children and teens.¹⁰ Doctors may recommend starting at a low dose and slowly increasing it for these youth if necessary.^{2,11}

Other possible side effects of these drugs include suicidal thoughts and behaviors in teenagers, or a worsening of mood problems in people who have bipolar disorder.

These medications “should be prescribed cautiously in youth with ASD [autism spectrum disorder], with close monitoring,” according to an article about anxiety in the medical journal *Pediatrics*.¹¹

When evaluating depressed patients, psychiatrists consider whether they may have bipolar disorder. Bipolar disorder involves periods of depression and mania. “There’s some evidence that the incidence of bipolar disorder may be higher in people with autism. So, you also have to be looking at whether the person has periods that meet, or partially meet, the criteria for mania. Is there a family history of bipolar disorder?” Wisner-Carlson says. Bipolar depression is often treated with different medicines than those used to treat major depression.

Doctors sometimes prescribe certain antipsychotic medication, in combination with another drug, to treat severe depression in the general population, according to the National Institute of Mental Health. A study of 53 adults who were hospitalized with depression found that antipsychotics were often prescribed to the patients who had both autism and intellectual disability.¹²

Combining Treatments for Depression

Janet, who asked to be anonymous, says that she has struggled with depression since a difficult childhood. “I don’t think I’ve lived any segment of my life without depression on some level, but I cope with it usually by having structure and having a goal,” says Janet, an autistic participant in the SPARK autism study. About 10 years ago, she was diagnosed with depression

and prescribed an SSRI. But she had a serious side effect, so she can only take low doses of an antidepressant.

“I’m a big believer in you don’t take any kind of medication for depression without pairing it with talk therapy or cognitive behavioral therapy or something like that, so I’ve always done that,” she adds.

Therapies for Depression That Don’t Involve Medication

Unlike medication, there is more research into non-drug therapies for children and adults who have autism. But many of the studies are small and do not include a broad range of people on the spectrum.

In cognitive behavioral therapy, or CBT, a therapist helps a patient change unhelpful thoughts and behaviors. That can improve mood and coping. According to clinical psychologists Tony Attwood and Michelle Garnett, this therapy involves these ideas:

- Our perceptions or thoughts about events, people, and situations determine our behaviors,
- The consequences of our behavior affect how often we repeat them, and
- We can monitor and change our thoughts and behavior over time.¹³

Some researchers have examined ways to modify CBT to treat depression and anxiety in people with autism. These changes include using concrete language and images, and incorporating the patient’s special interests. Many people on the spectrum have an intense interest in a favorite topic or activity.

A small study in Australia showed that a CBT program called “think well, feel well and be well” helped to decrease symptoms of depression and stress in teenagers and young adults with mild forms of autism. In that study, participants were taught that how they look at a situation, whether as a threat or as a challenge, affects their emotions and thoughts.¹⁴ Other small studies showed that CBT held promise for treating autistic adolescents or adults with depression.¹⁵

Mindfulness Therapy and Autism

One study of autistic adults in the

Netherlands suggested that a mindfulness therapy that was adapted for autism was helpful. As part of the therapy, 20 adults were taught to pay attention to experiences “in the present moment in a nonjudgmental and accepting way.” They learned breathing exercises and how to meditate for 40 to 60 minutes daily, for six days a week. A similar group of 21 adults with autism received no therapy and served as a comparison group for the treatment group.¹⁶

The therapy group showed a drop in symptoms of depression and anxiety compared to the comparison group.

The adults in that study had intelligence scores in the average range. In fact, many of the studies of CBT and mindfulness do not include people who have intellectual disability or limited speech. For that reason, it’s not known how those therapies would work with them.

Some researchers have called for more studies of medication for depression to help people across the broad autism spectrum. “These studies should include some focus on minimally verbal individuals since they are less likely to benefit from the available psychological interventions,” according to two psychiatrists at UNC.⁹

Additional Resources

- The National Suicide Prevention Lifeline provides free, confidential support 24/7 at 1 (800) 273-8255 and by [online chat](#). The lifeline also has prevention and crisis resources, and information for professionals.
- To find a cognitive therapist in your area, see the [Academy of Cognitive and Behavioral Therapies](#).
- The [National Association for the Dually Diagnosed](#) for people with intellectual/developmental disabilities and mental health needs.

This article is based upon one that appeared on [IANcommunity.org](#) in 2016.

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Sensory Processing from page 17

individual psychotherapy for those on the autism spectrum and their siblings, parent training, and medication management. The Seaver Autism Center has a large community outreach program that offers social skills groups and training for both families and professionals. The Center has a variety of collaborations with local cultural institutions in New York City such as the American Museum of Natural History and the Guggenheim Museum.

Over the past year, the Center has made it a priority to improve care and better support individuals on the autism spectrum’s sensory needs. Our teams developed [Sensory Toolkits](#) that are now available within Mount Sinai’s pediatric emergency depart-

ments and at specialist outpatient offices. We are starting to disseminate the toolkits to other practices within and outside of the Mount Sinai Health System with the goal of improving the patient experience. Each kit has several sensory tools, as well as an information sheet that explains the intended use of each tool to satisfy sensory needs and ultimately to make each person’s experience more comfortable. Families can take the kits home with them.

The Seaver Autism Center also developed a learning module to train physicians, clinicians, and staff members within different disciplines how to best support neurodiverse patients. They are actively collecting data on both of these initiatives to ensure these new programs are serving their intended purpose. Finally, our teams

are surveying caregivers of children on the autism spectrum to determine which sensory interventions and supports have and have not worked for their child.

This article has been republished with permission from The Mount Sinai Health System. You may view the original article, published on April 8, 2022, at <https://health.mountsinai.org/blog/what-are-sensory-processing-differences-and-how-do-they-relate-to-autism/>.

Paige Siper, PhD, is a licensed clinical psychologist, Chief Psychologist of the Seaver Autism Center for Research and Treatment at the Icahn School of Medicine at Mount Sinai, and an Assistant Professor in the Department of Psychiatry. She has expertise in the diagnosis, neuropsychological assessment, and treatment of children and adults with a variety of neurodevelopmental disorders (NDDs). Dr. Siper’s research focuses on sensory processing and biomarker discovery using electrophysiological and behavioral approaches. Dr. Siper is the co-developer of the Sensory Assessment for Neurodevelopmental Disorders (SAND), which is the first clinician-administered observation and corresponding caregiver interview to quantify sensory reactivity symptoms specific to NDDs. In her role as Chief Psychologist, Dr. Siper oversees the psychological assessment process for a broad research portfolio ranging from natural history studies to clinical trials. Dr. Siper presents her work nationally and internationally and has appeared on CNN, Lifetime, CBS, and NBC.

Systematic from page 21

at people in the eye while talking with them. Through an assessment we can tease out that sustained eye contact is a precursor for my anxiety. Rather than focusing solely on behavior and increasing appropriate behaviors (looking at a person's face when talking), realize that behind every behavior is a need in disguise. I look away from a person not because I don't want to hear them, rather I look away to reduce my anxiety so I can hear them. When we meet my need rather than solely focusing on my behavior, we begin to understand the reason for my behavior. Many times, the need in disguise is a sensory sensitivity.

Sensory Processing

Environments and activities neurotypicals consider normal, autistics find painful or exhausting. The main reason is we are sensitive to sensory stimuli. Because of the sensory sensitivity, autistics live in stressful environments. Addressing sensory issues needs to be the starting point of any treatment. Why? Often behaviors we observe are a result of sensory overload.

Many autistics are in a constant state of sensory overload, which heightens their anxiety. The anxiety can then cause agitation, impulsivity, irritability, and outbursts. Not until the sensory overload is reduced do anxiety levels decrease and we begin to see more positive behaviors emerge. For example:

- Food refusal may be due to food allergies or teeth pain.
- Pulling at clothes may be due to irritating sensations.
- Crying and yelling may be due to the individual being frustrated but not able to verbalize the emotions.

**Heidi Hillman PhD, BCBA-D**

- Scratching skin may be due to a skin allergy.
- Repeating memorized movie scenes or retelling stories multiple times may be how the autistic shows joy and enthusiasm about the experience.
- Fidgeting may reduce anxious feelings while in social contexts.

It is not until we address underlying sensory issues that our treatment plan can be effective. Once the autistic's anxiety is under control, they are calmer and able to communicate and interact. So often, emphasis is placed on challenges with the social domain because that is what people see. However, it is difficult for autistics to learn new skills when they are in a constant state of anxiety or stress. Therefore, equipping autistics with strategies to prevent, or at the very least reduce, sensory overloads is a vital goal when working with comorbidities.

Naturalistic Environments

The primary goal of any treatment is promoting long-term positive outcomes. To meet that goal, skills taught must be consistently used by the autistic individual. A disadvantage of the clinic setting is that teaching is more passive; we hope the client will use the taught skills outside of the clinic. A more proactive and enjoyable way is through natural environment teaching.

The use of natural environments grew out of the recommendation from Stokes and Baer (1977) to teach skills in multiple settings. Teaching in natural environments provide authentic learning experiences and more opportunities to learn complex skills. Additionally, the focus is on the autistic's understanding of the skill, rather than memorizing steps. When a client has a practical understanding of a skill, they are more likely to utilize the skill in the future. For example, how to escape an over stimulating situation or learning how to self-regulate emotions.

One benefit of working in natural environments is that the autistic individual takes the lead in deciding which behavior to work on. Autistics value opportunities to contribute to the decision-making process regarding goals and treatment. When autistics don't have buy-in, interventions are less meaningful and ultimately less effective. Additionally, teaching within natural environments increase the chances the skills taught will maintain over time.

Using a holistic process allows us to focus on the individual when designing effective interventions. The primary focus of an assessment needs to be uncovering and addressing sensory overloads rather than merely treating symptoms. Address the sensory overloads, then address the other comorbidities. Ultimately, effective treatment occurs when autistic clients feel understood, accepted, and respected, which

paves a path to a better prognosis among autistics with comorbid diagnoses.

For more information, Heidi Hillman can be reached at hhillman@ewu.edu.

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Free Support Group for the Family Members of Adults with an Asperger/Autism Spectrum Profile

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Our mission is to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives.

For more information, visit the website www.aane.org or contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

Socialization and Life Skills Group for Adults with an Asperger/Autism Spectrum Profile

This support group, Opening Doors, is now in partnership with the Asperger/Autism Network (AANE). This group is for adults who have an Asperger or similar autism spectrum profile. Learn, socialize and receive support from others who share common experiences.

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Anna L. Nasci, OTR/L, MS, NCC, LMHC | Masako Hashimoto, MS, NCC, LMHC - OpeningDoorsWestchester@gmail.com

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