

Addressing Psychiatric and Medical Conditions Associated with Autism

Understanding the Relationship Between Autism, OCD, and Repetitive Behaviors

By Philip Smith, PhD
The Boggs Center on Developmental Disabilities at Rutgers Robert Wood Johnson Medical School

One of the long-standing challenges in supporting individuals with Autism Spectrum Disorders (ASD) is the high rate of repetitive behavior they demonstrate. In addition to these individuals demonstrating high rates of repetitive behavior, many caregivers and support providers find it difficult to reduce the frequency or severity of impact these behaviors have on adaptive functioning and participation in community-based programs and activities. Part of this difficulty could potentially be related to complications that derive from the fact that repetitive behavior also is a central symptom of Obsessive Compulsive Disorder (OCD) and a variety of other neurodevelopmental disorders. This might be resulting in many treatment and support teams being confused about the nature of the repetitive behavior, and as a result, fail-



ing to use the most appropriate strategies to address those concerns. Our focus for this article will be to provide an outline of these initial concerns and offer some general insights into better understanding the relationship between ASD and OCD.

Unfortunately, in many applied settings, practitioners and caregivers often refer to the repetitive behavior of individuals with ASD as “that is just their OCD.” This is problematic since it reflects a misunderstanding of the nature of OCD and its

relationship to ASD. Both are disorders which have diagnostic criteria and appropriate treatment and/or support strategies. Sometimes, repetitive behavior may be the result of another neurodevelopmental disability, such as Intellectual Disability. In many cases these behaviors reflect the impact of ASD and have nothing to do with OCD, while for other individuals the behavior may result from OCD and have nothing to do with ASD. Finally, for some individuals, ASD and OCD may co-occur, and some instances of repetitive behavior may be due to one disorder while other instances behaviors are caused by the other disorder. It is also possible that some behaviors may be impacted by the interaction of these disorders, but that discussion goes beyond the scope of this article.

The best current understanding of the repetitive behaviors that are seen in ASD and OCD, is that they typically occur for different reasons and call for differing treatment approaches. For example, many environmental accommodations for youth with

see Behaviors on page 21

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Comprehensive Programming to Support Children with Developmental Disabilities and Significant Medical Conditions in a School Setting

By Ellen D'Amato, PhD,
Carla Johnson, MS, BCBA,
and Howard Savin, PhD
First Children Services

Supporting children with autism or other developmental disabilities and significant co-occurring medical conditions presents substantial challenges to teachers, parents and all involved caretakers. This article presents an overview of the interdisciplinary model and a representative case study illustrative of operations at the First Children School which is an Approved Private School in New Jersey. This hybrid service setting contains components of special education and medical home care.

First Children School, located in Fanwood, New Jersey, is accredited by the National Commission for the Accreditation of Special Education Services (NCASES). The school serves 90 children in grades pre-k through high school with autism and other developmental disabilities. The school provides educational and therapeutic services, per their respective IEPs, to children from 25 sending districts located in seven New Jersey counties. First Children, formerly the school program of Children's Specialized Hospital, has a long history of providing co-



Ellen D'Amato, PhD

ordinated educational services to children with challenging developmental, medical and rehabilitative needs. The school benefited from the expertise and resources of the hospital's medical, therapeutic and rehabilitative staff including neurodevelopmental pediatricians, psychiatrists, orthotists, dietitians, and physiatrists. In 2009, the school acquired a new owner and became First Children. The school continued its collaboration with the hospital through ongoing Neurodevelopmental and



Carla Johnson, MS, BCBA

Physiatry Clinics. In addition to its staff of nurses, special education teachers, occupational therapists, physical therapists, speech pathologists, psychologist and social worker, First Children expanded its staff to meet the complex needs of its growing program for children with multiple disabilities. As a result, teachers of the deaf, Board Certified Behavior Analysts, behavior therapists as well as a teacher of the visually impaired and a consulting audiologist were added to the interdisciplin-



Howard Savin, PhD

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see Programming on page 24

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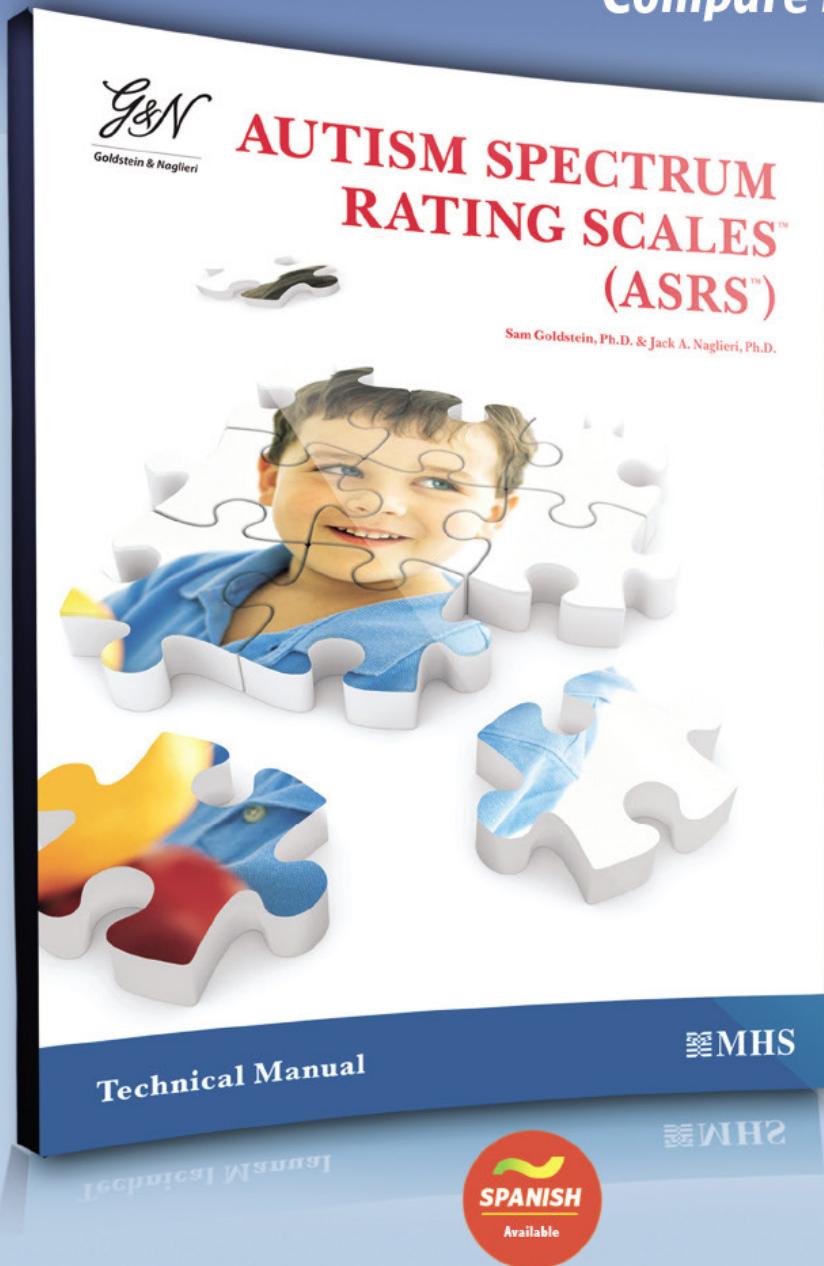
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Co-Occurring Conditions in Mild Autism Spectrum Disorder: Integrated Treatment Approaches

By Elizabeth Roberts, PsyD
National Director, Clinical Support Services
College Internship Program

Co-occurring mental health conditions are the rule rather than the exception in autism spectrum disorder (ASD). A full 70% of individuals with ASD have one co-occurring condition; 40% have two or more (Simonoff et al, 2008). Living with autism is a journey, and in talking to families, I often rely on a travel metaphor in describing ASD as “carrying suitcases.” This word picture helps families understand that ASD is the central condition, in dynamic interplay with others, and sets the stage for an integrated, multi-pronged approach to intervention.

Estimating the prevalence of the most common, co-occurring conditions in adults with mild ASD is complicated by the heterogeneity of both ASD the condition and ASD research methodology. The majority of ASD research has historically focused on children, males, and more severely affected individuals such that subgroups of adults, females, and individuals with milder forms of ASD are still much less understood. With that caveat in mind, research (Cassidy et al., 2014, Croen et al., 2015, Hofvander et al., 2009, Leitner, 2014, Leyfer et al., 2006,



Elizabeth Roberts, PsyD, works with young adults with autism and other learning differences at the College Internship Program (CIP)

Muris et al., 1998, Simonoff et al., 2008; van Steensel et al., 2011) has identified the following prevalence rates for the most commonly occurring disorders:

- Anxiety Disorders including OCD, 40-80%
- Attention Deficit Hyperactivity Disorder (ADHD), 37-85%

- Depression, 26%
- Mood disorder, 52%
- Suicidality, 66%

Other conditions or problematic behaviors that co-occur less frequently (Cacola, Miller, & Williamson, 2017, Croen et al., 2015, De Vries et al., 2010, Haruvi-Lamdan et al.,

2017, Hofvander et al., 2009, MacMullin et al., 2016) but require consideration when treating adults with mild ASD include:

- Psychosis
- Schizophrenia
- Gender dysphoria
- Trauma
- Excessive electronic gaming
- Substance use disorder (SUD)
- Learning disabilities
- Developmental Coordination Disorder (DCD)

Each of these conditions represent important and complicated topics with emerging bodies of research. A particularly important and neglected area of study is the relationship between trauma and ASD, as individuals with ASD are vulnerable to experiencing higher rates of social rejection, bullying, abuse, and conflict across development. Excessive gaming is not recognized as a disorder in the DSM 5 but will be in the next edition of the ICD. A new review of what is known about ASD and SUD indicates that these conditions co-occur more often than has been believed (Palmer & Kunreuther, 2018). Like other individuals with anxiety, individuals with ASD may be particularly at risk for cannabis dependence (Hill et al., 2017).

see *Integrated on page 22*

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Treating Patients with Autism Spectrum Disorders: What Clinical and Moral Breakthroughs in Medical Education Can Accomplish

By John Kappenberg, EdD
Director of Mentoring
and Professional Development
New York Institute of Technology
College of Osteopathic Medicine

“The arc of the moral universe is long,” said a young Martin Luther King, Jr. (quoting a nineteenth-century preacher), “but it bends toward justice” (King, 1956). He knew that the struggle for civil rights would last, not for years, but for generations. It took twenty years to expand civil rights protection to children with disabilities (Education of All Handicapped Children Act, 1975), and another fifteen to include all adults (Americans with Disabilities Act, 1990).

But the “moral universe” doesn’t bend simply by passing laws. Hearts need to change and that begins with education. During the 1990s and early 2000s, hundreds of books, films, TV dramas, and professional conferences appeared, the public learned that autism was a spectrum of disorders (ASD), and that persons “on the spectrum” carry unique insights and abilities, rather than a label of “dysfunction.”



John Kappenberg, EdD

Schools in most states required educators to learn how to teach students on the spectrum (New York State United Teachers, 2017), and today a growing number of police departments are beginning to train their officers in autism awareness (Koh, 2017). Coming “late to the table,” albeit finally, the medical profession is beginning to prepare health care professionals to treat

their ASD patients more appropriately, effectively, and fairly.

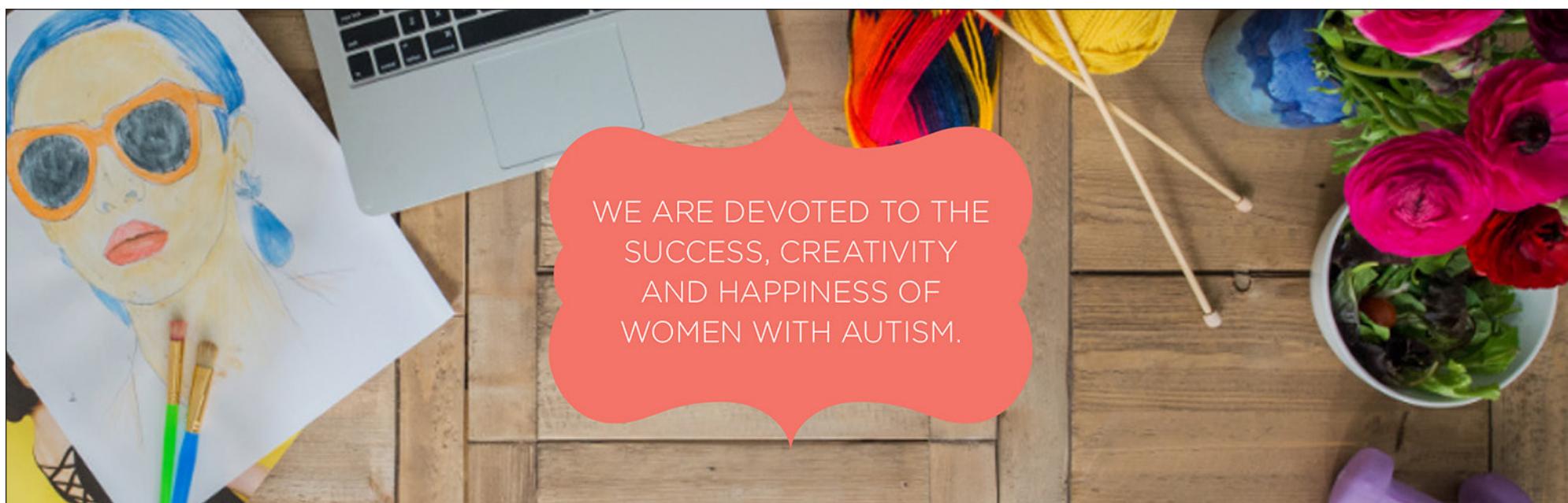
Starting in 2002, the Surgeon General published a series of reports showing that people with disabilities routinely received sub-par treatment from physicians, and recommended training health-care providers as a goal for the nation (U.S. Department of Health and Human Services, 2002). The reports made a critical distinction: Treating disability itself is not the issue. What is lacking is an understanding of how to interact with patients who live with disability; to understand their individual needs and potential; to treat basic medical needs in light of a patient’s unique disability. Does the doctor recognize that a patient on the autism spectrum is likely to be hyper-sensitive to things like florescent lighting in an examination room, or to the cacophony of voices in a crowded medical facility? Is the physician prepared to make accommodations that will support a patient with these needs?

Following the Surgeon General’s reports, health care policy-makers realized that a nation-wide program to educate practicing physicians would be extremely difficult to mandate. On the other hand, a focus on medical education would be

far more easily organized, controlled, and likely to produce lasting effects (American Medical Association, 2017). Even so, only a handful of America’s 175 accredited medical schools (AAMC, 2018; AACOM, 2018) have introduced disabilities training for their students (Long-Bellil, 2007; Conill, 2008; Graham, 2009; Davidson, 2016). For example, Linda Long-Bellil *et al.* (2011) reported on seven schools that use “standardized patients,” or actors trained to impersonate patients, as surrogates for patients with autism and other disabilities. Rick Rader, the physician who developed one of these early initiatives at the University of Tennessee College of Medicine Chattanooga, described the intent of its standardized patient program:

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see *Treating* on page 18



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Obesity and Related Issues in Individuals with ASD: The Scope of the Problem and Potential Solutions

By Mary Jane Weiss, PhD, BCBA-D
and Frank Bird, MEd, LABA, BCBA
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Obesity is a major problem around the world and in the United States for individuals with and without disabilities. The World Health Organization (2011) identified childhood obesity as one of the most serious public health risks in this century (Alwan, 2011). Obesity rates in the United States have risen over the decades and now statistics show that almost 50% of the citizens are overweight, with an astounding third of the adults in this country labeled obese (Ogden, Carroll, Kit, & Flegal, 2014). The American Heart Association (AHA; 2010) found that there are more overweight and obese adults than healthy ones. Statistics show that adolescents who are overweight will remain so going into adulthood (Barlow & Dietz, 1998).

The statistics on the prevalence of obesity in individuals with autism spectrum disorder (ASD) are mixed. Some researchers have concluded that individuals with ASD are no more at risk than the non-disabled community (Kummer, et al., 2016), while other data suggest that obesity rates are higher in people with autism, but the prevalence of individu-



Mary Jane Weiss, PhD, BCBA-D

als being diagnosed as overweight falls within the level of the general population (Zheng, et al., 2017). Ho, Eaves, and Peabody (1997) found that as the severity of autism increased, so too did the incidence of obesity. The problem in ASD is as least as serious as it is in the typically developing population and continues to be a serious one for which intensive interventions are needed.



Frank Bird, MEd, LABA, BCBA

Causes of Obesity

There are both biological and environmental explanations for this critical health problem. Much of the evidence to suggest a genetic cause has come from a number of studies on twins (e.g., Hebebrand & Hinney, 2008). However, regardless of the extent to which the genetic interpretation satisfactorily explains this problem, there

are clearly a significant number of environmental variables that surely increase the likelihood of a person becoming overweight or obese. The major environmental determinants consist of unhealthy eating and a lack of physical exercise representative of a sedentary lifestyle (e.g., Brown, et al., 2009). These two variables seem to be part of a larger, overarching hypothesis concerning lifestyle changes of our culture. Some researchers propose that an increase in two-parent working households, an increase in time spent on computers and smart phones, and more limited opportunities for physical activities, have shifted our society to a more passive one, with a resulting increase in weight (Cha, et al., 2015).

Comorbid Conditions Associated with Weight Problems

The consequences of this problem cannot be overstated or minimized. There is a significant literature base that confirms that being overweight or obese increases one's chances of developing a host of medical and psychosocial problems, such as sleep apnea (e.g., Su, 2015), diabetes (e.g., Wang, et al., 2016), high blood pressure (e.g., Kroppa, et al., 2016), orthopedic difficulties (e.g., Hoffmann, Stucker, & Rupprecht, 2016),

see *Obesity on page 20*

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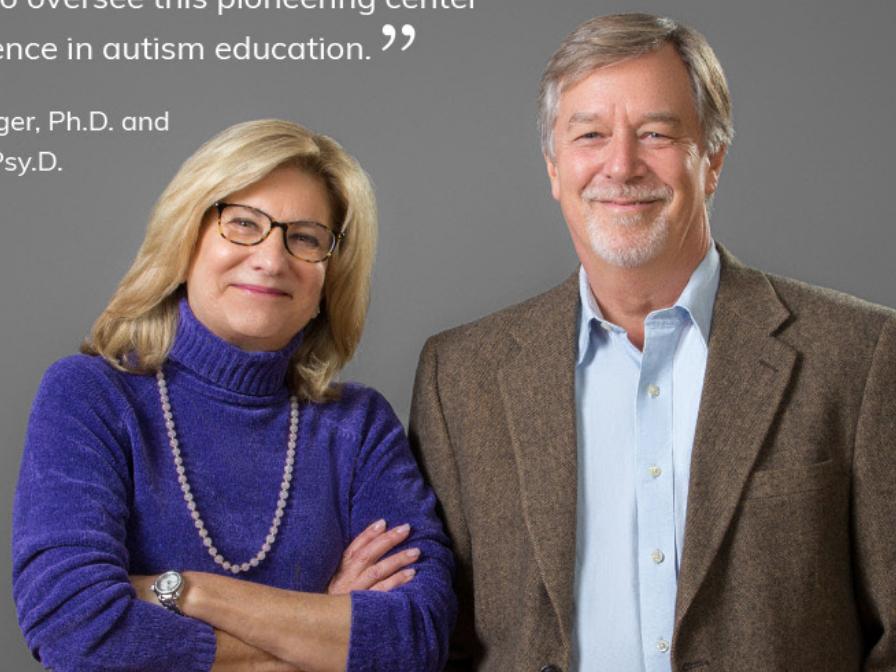
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Michael Gilberg, Self-Advocate and Special Education Attorney, Joins Autism Spectrum News Editorial Board

By Staff Writer
Autism Spectrum News

Mental Health News Education, Inc. (MHNE), publisher of *Autism Spectrum News*, is proud to announce that Michael Gilberg, Esq., Special Education Attorney, has become the newest member of the ASN Editorial Board.

David Minot, Associate Director of MHNE and Publisher of *Autism Spectrum News* stated, "I am thrilled to have Michael join the ASN Editorial Board, representing the self-advocate community. Michael brings an important perspective and helps fill a void as both a lawyer and self-advocate, and I look forward to working with him to bring more of a focus to the self-advocate community."

Michael Gilberg has years of both Special Education and Disability Rights Law and Advocacy Experience. Attorney Gilberg also has his own personal experience as someone on the Autism Spectrum. Michael received his J.D. from [Pace University School of Law](#) in 2007 after receiving both his BA and MPA, also from Pace University.

Attorney Gilberg holds numerous Professional Affiliations and Leadership Roles including:



Michael Gilberg, Esq

- [Council of Parent Attorneys and Advocates \(COPAA\)](#) – Board Member
- [National Association of Attorneys with Disabilities \(NAAD\)](#) – Board Member
- [New York State Bar Association](#) Committee on People with Disabilities
- Westchester County Autism Advisory Committee – Member

- [Autistic Self Advocacy Network](#)
- [Disability Rights Bar Association](#)
- [Westchester County Bar Association](#)

Michael's passion and strength is inspiring, especially given the difficulties he had to ensure growing up without a diagnosis in a failed system. Rightly so, he is proud to tell his story of overcoming incredible odds to become a leader and voice for families and individuals on the spectrum.

Michael's Story

"Many people have asked what motivated me to become a special education attorney. Many parents of children with disabilities who are already attorneys become special education attorneys through the process of advocating for their children. My journey to becoming a special education attorney is much more personal. I came to the field to fight for children with disabilities so that no child would have to go through what I did growing up.

Growing up I was not properly diagnosed with Asperger's Syndrome until I was 18 years old. Looking back, I know I did not get proper educational services and did not get the education I was entitled to. If my parents had known what I know now

things might have been different. Unlike many children who gave up on their lives, I worked harder and pushed ahead and got here through my own determination and hard work.

I spent my entire educational career prior to college in special education, despite not ever being given the proper identification and diagnosis. A turning point in my journey occurred when I was in the 6th grade. The school social worker at the time told my parents that I was never going to graduate High School and they should "throw me away" and forget about me since I had no future. Meanwhile I had one friend at that time, who the same social worker said was well adjusted and ready to return to mainstream public school.

Unfortunately, the social worker had betrayed my friend's trust by repeating something told to him in a private counseling session to the whole class in a group session, despite his request that it be kept private. He shared with me his feelings of betrayal by the social worker and never trusted adults after that with his private feelings. My friend did go back to mainstream public school, and because he now was keeping his feelings even more inside, he never shared with anyone the demons consuming him. The day before his

see [Gilberg on page 24](#)

This is what success looks like...



This is what an adult living with autism looks like!

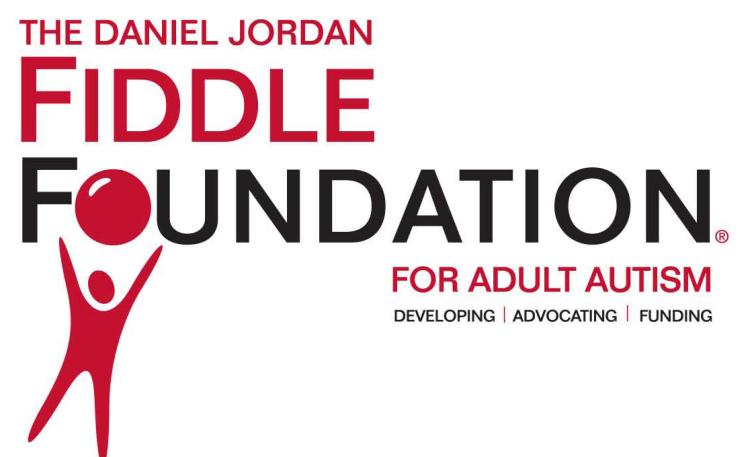
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Helping Children with Autism Fall Asleep and Stay Asleep Without Medication

By Rebecca Schulman, PsyD, BCBA-D
Behavior Therapy Associates

Sleep is an essential restorative process for every child's body and brain. Sleep has been shown to promote growth of one's muscles, bones, and skin, help protect the heart, combat germs, sickness, and injuries, and impact one's weight. Further, research has shown that sleep helps individuals remember what they learn, increases children's attention span and concentration, and boosts learning, including children's ability to solve problems and think of new ideas (Souders et al., 2009).

Unfortunately, many children experience sleep problems, which affect their functioning academically, socially, and behaviorally. In fact, 10-50% of typically developing young children and 50-80% of youth with developmental disabilities have sleep problems (Abel, Kim, Kellerman, & Brodhead, 2017; Jin, Hanley, & Beaulieu, 2013). Children with autism spectrum disorder are at a higher risk for sleep problems and have been identified as one of the highest priority populations for sleep research (Souders et al., 2009; Abel et al., 2017). The underlying cause of sleep impairments may include behavioral factors, medical factors, biological factors, or an interaction of multiple factors (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008).



Rebecca Schulman, PsyD, BCBA-D

Sleep problems not only cause frustration and discord among caregivers, but are also associated with higher levels of severe daytime problem behavior (e.g., tantrums, aggression, and self-injury), stereotypy, and noncompliance (Abel et al., 2017; Goldman et al., 2011; Jin et al., 2013; Krakowiak et al., 2008). Sleep problems may also interfere with learning, attention span, emotion regulation, and social interactions (Goldman et al., 2011; Souders et al., 2009). Additionally, persistent sleep

problems in childhood are associated with childhood and adult obesity, adolescent behavioral and emotional problems, anxiety in adulthood, and sleep problems through adulthood (Jin et al., 2013).

However, the good news is that sleep problems can be considered a skill deficit and most children can learn to be better sleepers with the use of behavior therapy. To date, there is no FDA approval for any pediatric sleep medication, there is no medication labeled for pediatric insomnia, and research does not show evidence of consistent efficacy for pharmacological interventions. Although medication may help children fall asleep quicker, it often leads to a greater amount of night awakenings. Therefore, behavior therapy is a more effective, long-term solution for sleep problems.

The first step to addressing sleep problems is assessing the specific sleep difficulties experienced by a child and identifying goals for the child's sleep. "Good sleep" is often characterized by falling asleep quickly, staying asleep throughout the night, waking up without much trouble each morning, and not feeling drowsy during the day. Common sleep problems in children with autism include delayed sleep onset, which can include sleep-interfering behavior (e.g., crying, calling out, playing, stereotypy, talking to oneself, etc.), night or early awakenings, short sleep duration, and phase shifts (i.e., sleeping at wrong

times, thus conflicting with daily routines) (Jin et al., 2013; Krakowiak, et al., 2008). Children's sleep problems are typically assessed using an open-ended interview and sleep questionnaires to identify the personal factors influencing sleep problems. This information is then combined with general information about common factors that influence good sleep and sleep problems in order to develop treatments in collaboration with parents based on the controlling variables. A child's sleep behavior may be affected by the value of sleep for that individual at any given time, environmental cues, and the degree to which behaviors other than sleeping are reinforced at night.

Individualized and comprehensive treatment consists of five steps: 1) Develop an ideal sleep schedule, 2) Create a structured nighttime routine, 3) Optimize bedroom conditions, 4) Develop regular sleep dependencies, and 5) Address sleep interfering behavior (Abel et al., 2017; Jin et al., 2013). When creating a sleep schedule, it is essential to consider age-appropriate sleep amounts and recent sleep history. It is important that parents do not try to put their children to bed too early, as this can increase the likelihood of nighttime routine noncompliance, sleep onset delays, and sleep-interfering behavior. During the initial stages of sleep treatment, parents should put their children to bed approximately

see Sleep on page 26

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ADVOCACY FOR AUTISM



A Parent's Plea for Reform of School Safety and Mental Health Programming

By Laura J. Albee, MA, BCBA, LMSW

With an estimated 17.1 million children and adolescents presenting with or having received treatment for a psychiatric disorder including Autism Spectrum Disorder (ASD), Attention Deficit Hyper Activity Disorder (ADHD), and Anxiety, school systems across the nation are being thrust into the front line of defense for early detection and treatment (Child Mind Institute, 2016). Sadly, catastrophes drive reform.

Having lost a colleague in the massacre at Sandy Hook Elementary School, I was hopeful that our local, state, and federal governments would mutually agree to programs and policies that promoted student safety and behavioral health services for those impacted by individuals grappling with mental illnesses.

After listening to our politicians and media personalities vigorously sharing their perspective on how to address gun violence and behavioral health, I'd like to offer insight as a Board-Certified Behavior Analyst, Licensed Master Social Worker, and a parent well acquainted with our cur-



Laura Albee at the end zone of the Holy Cross football field, where her son Hunter's teammates and classmates planted a tree in his memory

rent mental health system.

In 2008 our son Hunter was diagnosed with Tourette syndrome. Tourette like ASD is a life-long neuropsychiatric disorder sim-

ilarly characterized by a variety of impairments impacting social reciprocity, impulse control, and repetitive and stereotypic behaviors (Hyman & Levy, 2013; Gougeon, 2013; Greiert, 2016). Coupled with Obsessive Compulsive Disorder (OCD) and ADHD combined conditions, Tourette presents as a kaleidoscope of symptomologies impacting both body and mind and their battle for control, resulting in disruptive, aberrant, and perplexing behaviors.

Watching Hunter descend into mental illness was excruciating. Our perfect little boy became riddled with complex motor and verbal tics which made him a social pariah. Friendships faded, and acceptance of his condition became a chronic fight. I was astonished by how many educators struggled to accommodate and encourage his social, emotional, and academic well-being. School administrators and parents viewed our son as a behavior problem which discouraged friendships and community involvement. He was shunned by his Boy Scout troop, baseball teams, and church groups.

The ebbs and flows of mental illness is a lifelong struggle. In his lifetime, Hunter experienced seven involuntary hospitalizations, was prescribed a myriad of psycho-

tropic and antipsychotics, and even attended a therapeutic school. Hunter once asked, "Why did this happen to me, Mom?" Not knowing what to say I offered, "Sometimes things happen to those who will do extraordinary things."

Sadly, most treatment programs service the immediacy of the problem only, offering temporary fixes to stabilize the youngster until their next psychiatric episode. If a family is fortunate to have wealth, or assistance through agencies such as the Department of Children and Families (DCF), the Department of Developmental Services (DDS), or, in some instances, the Department of Mental Health and Addiction Services (DMHAS), they may reap the benefits of comprehensive services. Any shortage – in money, beds, or professionals – send parents on frightening odysseys of insufficient psychiatric services, weak supports, and provisional care as they try to sustain their child's health and happiness.

Once children near adulthood, they become part of a more pandemic problem. Agencies such as DCF pay little attention to youth transitioning out of their agency.

see Reform on page 25

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Advancing Behavioral Health Strategies as Individuals Approach Adulthood

By Carl E. Clark II
President and CEO
Devereux Advanced Behavioral Health

Individuals connected to the behavioral healthcare system are well aware that autism does not magically disappear on a teenager's 18th birthday. Yet, the challenges facing people diagnosed with autism spectrum disorders (ASD) shift considerably as they make the transition to adulthood. Expectations change and consistent patterns are disrupted. Crucial social skills developed and practiced in school and at home must be applied in new settings, and independent living skills assume heightened importance as core requirements of daily life.

Altering the routine of an individual with autism, at any age, can present complications. For adolescents, this issue is compounded as critical behavioral health services end - or are considerably reduced - as students leave the school environment. Specifically, during their last year of high school, youth with autism were less likely to receive 12 out of 15 behavioral health supports - such as speech language therapy, in-home/in-classroom aide and occupational/life skills - versus younger high school students (Taylor, Henninger, 2015).

Disruptions in autism services create considerable challenges for families as well. Stopping points in treatment and



Carl E. Clark II

funding require parents to navigate through complex systems and time-consuming processes to secure additional levels of support for their child while, at the same time, guiding the child through stressful transitions without a familiar or much-needed support structure.

Approximately 500,000 individuals with ASD will age into adulthood in the next 10 years (Roux, Shattuck, Rast, Anderson, 2017). Given that autism is the fastest-growing developmental disorder in the U.S., understanding how this transition

impacts an individual's treatment and quality of life, and finding innovative ways to better serve them, is becoming increasingly critical. However, reports show that just 1 percent of autism research funding is associated with adulthood and aging (Interagency Autism Coordinating Committee, 2017).

Advancing the Role of Behavioral Health

Clearly, there are gaps in the system. Youth with autism are half as likely to receive healthcare transition services as youth with other special healthcare needs (e.g., individuals with chronic, physical, developmental, behavioral or emotional conditions who also need health and related services beyond what is generally required). In addition, adolescents with autism, along with other conditions, face an even greater risk of lack of services (Cheak-Zamora, Yang, Farmer, Clark, 2013).

We must eliminate these service gaps and help families create structured, effective and long-term vision plans so youth can easily obtain the next level of care they need to thrive. To do this, we have an obligation - as an industry and a country - to advance the role of behavioral health to the same standards of physical health.

Focusing on the Whole Person

Devereux Advanced Behavioral Health is addressing this need as part of its vision

for the future, which includes reinventing the client experience - from episodic to whole-person, whole-life evidence-based - to improve outcomes.

This holistic approach calls for the same standards of treatment for physical healthcare to be applied to individuals with emotional, behavioral and cognitive differences. By integrating behavioral health into the clinical, operational and financial frameworks of primary and specialty medical care, we not only will better serve the individuals in our care, but we will be one step closer to eliminating the stigma facing those with behavioral health challenges.

The quest to reintegrate physical and behavioral healthcare requires families and providers to be in lockstep when it comes to establishing long-term strategies for individuals with autism - at every life stage. Families can best position their child for success when they have a partner who possesses a deep understanding of available resources, community and transitional supports, and funding streams, as well as insight into an individual's unique strengths and needs. This partnership begins with early diagnosis to facilitate effective interventions and treatment, and charts a course for the child to lead a positive and productive life.

see Advancing on page 26

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Treating from page 8

[individuals], but also to care about them (Rader, 1995, p. 38).

Taken as a whole, the goals of these early programs were “(1) To increase [medical] students’ comfort with patients who have multiple disabilities; (2) To develop students’ skills in communicating with nonverbal patients; and (3) To help students dissociate patients’ disabilities from their capacity to be good sources of information and partners in the care process” (Long-Bellil, 2011, p. 1165).

This last point may be the most crucial. It has the potential to open an entirely new paradigm for approaching *all* patients, not just those with developmental disabilities. In his classic study, *An Anthropologist on Mars* (1995), the neurologist Oliver Sacks described this new perspective on patients:

Nature’s imagination . . . is richer than ours. . . [disabilities] can play a paradoxical role, by bringing out latent powers, developments, evolutions, forms of life that might never be seen, or even be imaginable, in their absence. It is the paradox of disease, in this sense, [that is] its “creative” potential (p. xvi).

As medical schools prepare a new generation of doctors to treat patients with disabilities, they are transforming the way future physicians will care for *all* their patients. By improving medical care for some, they will eventually improve healthcare for everyone.

In April, 2017, the American Medical Association’s Reference Committee issued a resolution calling for all “medical schools to develop and implement curricu-

lum on the care and treatment of people with developmental disabilities” (American Medical Association, 2017). On Long Island, this is happening at the New York Institute of Technology College of Osteopathic Medicine (NYITCOM). In November, 2017, it collaborated with the Interagency Council of Long Island, and the Long Island Technical Assistance Team (RTAT) to present a full-day workshop that introduced more than 300 medical students and faculty to the field of healthcare for people with disabilities. This will become a template for future curricula focused on fulfilling the AMA mandate.

To support new curricula, medical schools will need to employ a new generation of teaching resources that will specifically focus on training healthcare students to interact with developmentally disabled patients. An example of this new genre comes from Anita Lesko who, at the age of fifty, received a diagnosis of autism spectrum disorder. As a highly successful Certified Registered Nurse Anesthetist (CRNA), she decided to expand her career from medical professional to passionate ASD advocate. After decades working with doctors and patients, she knew what the medical profession needed: A primer on autism, aimed directly at healthcare providers, and written by someone who lived in both worlds. Nothing like this was available. Her book, *The Complete Guide to Autism Healthcare: Advice for Medical Professionals and People on the Spectrum* (Lesko, 2017), was the outcome. In a field that has produced hundreds of outstanding publications, this one stands as the first of its kind.

It is a call to her colleagues to learn a new approach to patients, one tailored specifically toward people with autism. “Diabetes, cardiovascular issues, and pulmonary diseases,” she writes, “are all part of what’s taught to health care providers. So too must be autism” (p. 134).

The 22 chapters cover the full complement of medical services: office examinations, emergency room visits, surgery, anesthesia. Each one includes dozens of small changes that, taken together, would produce a radical new way of delivering care to ASD patients. For example, Lesko has designed a physician’s “Autism Care Questionnaire” to be used as part of a standard inpatient admissions protocol.

One of her most telling comments brings Oliver Sacks’ grand vision down to the physician’s examination room: “quite surely the rest of your patients would appreciate the same details [that ASD patients should receive] (p. 103) . . . the other non-autistic patients will surely enjoy the spa-like ambience of an ASD environment” (p. 122). The changes Lesko calls for would lead to dramatic improvement, not just for people on the spectrum, but in doctor-patient relationships for everyone. It’s classic example of win-win synergy.

It also shows that the moral universe can, indeed, bend toward justice.

John Kappenberg, Ed.D., is Associate Professor and Director of Mentoring and Professional Development at NYIT College of Osteopathic Medicine (NYITCOM) and consultant for educational leadership and video production. During his fifty-year career in education he has been Assistant

*Superintendent for the Sewanhaka Central High School District, Director of School Leadership at New York Institute of Technology, and Chair of Medical Education at NYITCOM. He is co-author, with Dolores Burton, Ed.D., of *The Complete Guide to RTI: An Implementation Toolkit and Mathematics, the Common Core, and RTI: An Integrated Approach to Teaching in Today’s Classrooms.**

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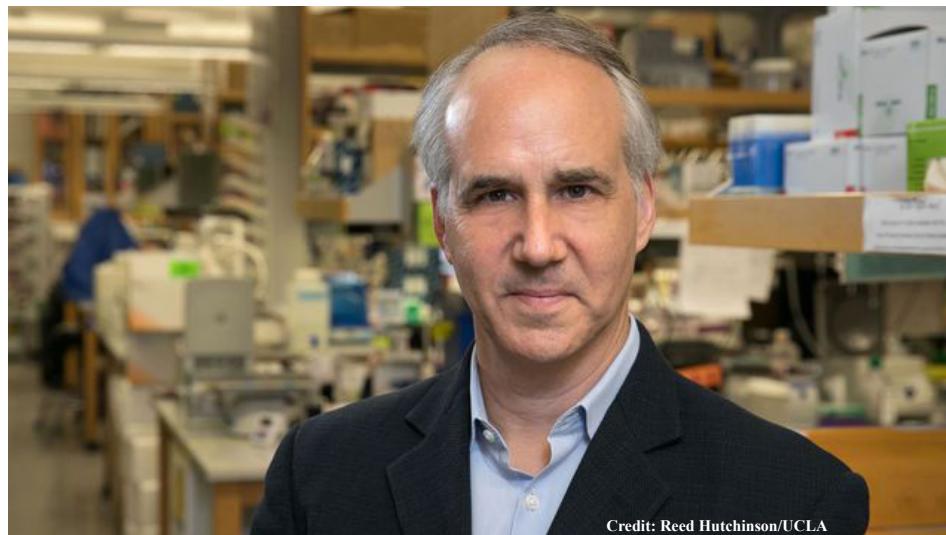
Suspect Molecules Overlap in Autism, Schizophrenia and Bipolar Disorder

By Leigh Hopper
Senior Public Information Officer
UCLA Health/David Geffen
School of Medicine

Most medical disorders have well-defined physical characteristics seen in tissues, organs and bodily fluids. Psychiatric disorders, in contrast, are not defined by such pathology, but rather by behavior.

A UCLA-led study, published in Science, has found that autism, schizophrenia and bipolar disorder share some physical characteristics — and important differences — at the molecular level, specifically, patterns of gene expression in the brain. Gene expression is the process by which instructions in DNA are converted into a product, such as a protein.

“These findings provide a molecular, pathological signature of these disorders, which is a large step forward,” said senior author Daniel Geschwind, a distinguished professor of neurology, psychiatry and human genetics and director of the UCLA Center for Autism Research and Treatment.



Credit: Reed Hutchinson/UCLA

Senior author Daniel Geschwind called the results showing a molecular, pathological signature of disorders such as autism and bipolar disorder “a large step forward”

“The major challenge now is to understand how these changes arose.”

Researchers know that certain variations in genetic material put people at risk for psychiatric disorders, but DNA alone

doesn't tell the whole story. Every cell in the body contains the same DNA; RNA molecules, on the other hand, play a role in gene expression in different parts of the body, by “reading” the instructions con-

tained within DNA.

Geschwind and the study's lead author, Michael Gandal, reasoned that taking a close look at the RNA in human brain tissue would provide a molecular profile of these psychiatric disorders. Gandal is an assistant professor of psychiatry and biobehavioral sciences at UCLA.

Researchers analyzed the RNA in 700 tissue samples from the brains of deceased subjects who had autism, schizophrenia, bipolar disorder, major depressive disorder or alcohol abuse disorder, comparing them to samples from brains without psychiatric disorders.

The molecular pathology showed significant overlap between distinct disorders, such as autism and schizophrenia, but also specificity, with major depression showing molecular changes not seen in the other disorders.

“We show that these molecular changes in the brain are connected to underlying genetic causes, but we don't yet understand the mechanisms by which these genetic factors would lead to these changes,” Geschwind said. “So, although now we

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Obesity from page 10

cardiovascular disease (e.g., Friedmann, et al., 2012), and victimization by bullies (e.g., Bacchini, et al., 2015).

Targeted Interventions with ASD

Although the causes of obesity consist of both genetic and environmental determinants, the only possibility of intervention currently is environmental. Treatment involves medical, educational, psychological, and behavioral approaches. Medical interventions include medication and surgery. Through education, at-risk individuals are taught about the importance of healthy eating, exercise, and how to make healthy choices in both areas. Psychotherapy and counseling are useful for individuals who are obese or overweight and who need emotional support in dealing with this problem.

Fundamentally, however, the problem with obesity is one of behavior change – the individual, no matter the extent of the genetic restraints, must make significant changes in behavior. From a behavior analytic perspective, weight management is framed as a problem of behavior. In this view, having a positive impact on improving peoples' lives consists of a focus on both antecedent and consequence intervention. In a behavioral framework, unhealthy eating and a lack of exercise are considered operant behaviors that are reinforced and maintained. So, another significant approach to managing and preventing obesity is in the form of assessing the maintaining (i.e., motivating) consequences for this problem and then developing function-based treatments to teach the individual better choices and better behavior. Interventions fall within two categories – antecedent interventions and consequence strategies. Both are necessary to fully treat this serious problem.

Published research clearly shows a preponderance of data that support the benefits of physical exercise on individuals with autism. For example, Pitetti, Rendoff, and Beets (2006) showed that vigorous exercise could reduce the Body Mass Index (BMI) in ten individuals with autism through a regiment of various physical education activities, such as tennis, cycling, and basketball. Lochbaum and Crews (2003) implemented weight training and aerobic activities with high-functioning individuals with autism. Results showed that not only did these individuals participate, but they were able to increase the amount of weights used and improve cardiovascular functioning. Todd and Reid (2006) investigated to what extent self-monitoring, verbal prompts, and positive reinforcement would increase physical activity in adolescent males with autism. The activities consisted of jogging, walking, and/or snowshoeing. The findings showed that over a six-month period, there was a clear increase in the amount of physical activity of these young men. Lang, et al. (2010) reviewed the extant literature on the topic of exercise by individuals with autism and concluded that not only are there existing procedures that have been shown to effectively increase physical activity, but there is often decreases in stereotype, aggression, off-task behavior, and elopement. Thus, the importance of physical activity

extends beyond weight management and improving overall health – it is an important repertoire that has generalized effects.

Another approach for managing weight is through healthy eating, focusing on types of food and quantity. There is extensive literature showing that individuals with autism frequently have serious issues with food and eating, such as poor nutrition, idiosyncratic eating habits, and food restriction (e.g., Cornish, 1998; Schmitt, Heiss, & Campbell, 2008). Any medical explanation must be explored and, if discovered, treated. But in other cases, food refusal, eating improperly, and choosing unhealthy foods are viewed as problem behaviors that need to be changed. The behavioral research identifies several procedures that have been shown to decrease eating difficulties and improve food choice and consumption. For example, Riordan, Iwata, Wohl, and Finney (1980) worked with children with developmental disabilities who exhibited food refusal. Using preferred foods as positive reinforcers, as well as extinction of the refusal response, resulted in increased consumption and a decrease in the amount of food expelled. Volkert, Vaz, Piazza, Frese, and Barnett (2011) worked with children who packed food in their mouths and refused to swallow. The technique of the “flipped spoon” (depositing food directly onto the tongue) resulted in a decrease of the target behavior. Tang, Piazza, Dolezal, and Stein (2011) implemented a comprehensive treatment package to remedy significant food refusal for two children diagnosed with autism. These children had serious medical concerns, such as constipation, encopresis, anemia, hypoalbuminemia, and hypoproteinemia. The researchers developed model multicomponent treatment plans including positive reinforcement for eating, mini-meals, shorter mealtime durations, fewer behavioral requirements, and a multidisciplinary team approach. Results showed less food refusal, more eating, the eating of a wider variety of food, and improved physiological markers. In sum, research has shown that there are effective procedures that can be implemented to decrease inappropriate eating patterns and increase the consumption of healthier foods, both of which improve the physical health of the individual.

Clinical Suggestions

Obesity is a significant problem in the United States and individuals with autism are susceptible to it. Clinicians serving these individuals must be sensitive to and be able to detect this issue in clients served, and must be knowledgeable about effective ways to intervene. Specifically, clinicians should strive to:

- Collaborate with other professionals, such as medical personnel, nutritionists, and psychologists, so a multidisciplinary approach can be implemented;
- Develop systematic programs to increase physical activity. Behavioral procedures, such as rules, schedules, and positive consequences should be considered. Shaping procedures can be used to increase tolerance of exercise if necessary. Use preference assessments to identify activities that the individual

might prefer doing;

- Establish physical exercise as a regular curriculum thread; and
- Carefully assess eating habits to determine if any overeating, food selectivity issues, or food restriction issues are noted. If so, employ various antecedent and consequent procedures gleaned from the literature to improve these habits and establish healthy eating patterns.

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ASD seek to find ways to make the repetitive behavior less stigmatizing or less disruptive, even though the repetition is not eliminated. This may include teaching a youth to follow a visual schedule, which actually involves substituting a repetitive behavior that is adaptive and may reduce anxiety or uncertainty, for one that is maladaptive and potentially disruptive. In contrast, the treatment goal for patients with OCD is to teach them to identify and eliminate obsessive thoughts and to completely block compulsive or repetitive behaviors. Failure to take the correct approach could be one reason that caregivers and support providers have had trouble addressing specific patterns of repetitive behavior for the individuals they are supporting. This makes differential diagnosis and/or diagnosis of co-occurring disorders an especially important process.

In order to understand this challenge, we need to begin with the recognition that some degree of repetitive behavior is normal and adaptive. In other words, not all repetitive behavior is pathological. Repetition of behavior is seen in a variety of everyday circumstances, including: childhood rituals associated with magical beliefs and fears, things people do in under-stimulating environments, greeting rituals, and a variety of behaviors associated with social situations such as club activities, establishing dominance or preparing for recurring events, as well as daily routines or habits. In many cases, these behaviors serve a valuable adaptive purpose. This highlights the need to determine how much, and what

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type of repetition in behavior should be recognized as pathological. Establishing a systematic basis for these decisions is the purpose of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association, 2013).

Along with a continuum of normal through pathological repetitive behavior, it also should be noted that repetitive behavior is commonly observed in individuals with a number of other psychiatric disorders including the Schizophrenia spectrum and a number of anxiety disorders. Within the neurodevelopmental disorders chapter, elevated rates of repetitive behavior are observed in a variety of Intellectual and Developmental Disabilities, not just ASD (Bodfish, et al, 2000). Research has shown,

however, that a higher percentage of individuals with ASD demonstrate problematic patterns of repetitive behavior, and that these repetitive behaviors show a wider variety of pattern and motivation, based on behavioral analysis (Bodfish, et al, 2000).

At this point it makes sense to consider a brief overview of the diagnostic criteria for the disorders we are considering. ASD symptoms are broken down into two categories: persistent deficits in social communication and social interaction across multiple contexts, and restricted, repetitive patterns of behavior, interests, or activities, which is the focal point of this discussion. Examples of these include: stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases), insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route every day).

While we don't know the exact cause(s) of ASD, it is recognized as a neurodevelopmental disorder, and the general understanding of many of the repetitive behaviors attributed to ASD is that they are the result of some type of neurological irregularity. Many of these behaviors are interpreted as attempts to cope with sensory factors, and others may relate to cognitive difficulties secondary to those neurological factors. A variety of explanations have been suggested, including: attempts to compensate for hyposensitivity or hypersensitivity to sensory stimuli, regulating the nervous system

and its response to these stimuli, and/or attempting to provide increased understanding of cause and effect relationships or anticipating what is likely to happen next. Using repetitive behavior in this way might be compared to the reasons people fidget when they are bored or repeating something to oneself in order to remember it. The difference is that the repetition reaches a level that undermines adaptive functioning or disrupts the environment in which the individual is living. This may be further complicated by social difficulties noted in the other symptom category. Looking at repetitive behaviors that occur within the framework of ASD would suggest that providing or teaching more adaptive patterns of repetitive behavior would be a reasonable treatment or support response to the repetitive behaviors that derive from such neurological exaggerations that required increased levels of repetitive behavior, combined with difficulty judging the social acceptability of these behaviors.

In contrast, the DSM5 (American Psychiatric Association, 2013) (American Psychiatric Association, 2013) defines OCD as the presence of obsessions, compulsions, or both. Obsessions are described as a combination of recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and cause marked anxiety and distress, along with attempts to suppress or ignore such thoughts, impulses, or images or to neutralize them with some other thought or action. Compulsions are defined as repetitive

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Individuals with ASD suffer from a range of learning disabilities but limitations in reading comprehension and compositional writing are the most common; the majority of students with ASD suffer with poor handwriting related to DCD.

Medical and neurologic conditions that co-occur with ASD (Canitano & Vivanti, 2007, Cohen et al., 2014, Croen et al., 2015, Fombonne, 2003) include:

- Tic disorders
- Seizure disorder
- Sleep, eating, and elimination disorders
- Obesity

Thus, careful diagnostic assessment is crucially important at the initial stage of treatment. This leads to a sophisticated case formulation that accounts for the inter-related nature of ASD, co-occurring conditions, and behavior embedded in the biopsychosocial context.

Case Example

P.R. was a 21-year old young woman with average intellectual ability and language, enrolled in a young adult transition program. Previously diagnosed with ASD, ADHD, learning disabilities, and dysgraphia she had been treated with stimulant medication in the past. Over the previous six months, she had been re-started on a new stimulant to treat ADHD. She was not doing well. An already limited food repertoire had become further restricted, resulting in alarming weight loss. She was gaming several hours a day and her sleep-wake cycle was compromised. She had recently failed the one college course in which she had enrolled. Her social isolation had increased. Self-care and hygiene were poor. At a family meeting, she bore a hollow-eyed, haunted look. A staff clinician offered his interpretation that her behavior represented a wish to die. He affirmed that the team cared deeply for her. This decisive communication prompted her to disclose a daily, grinding experience of profound dread and hopelessness. Her mother began to weep and disclosed her own history of intractable depression. The team was then able to generate a set of interventions around now more clearly identified challenges. These included closer collaboration with the treating psychiatrist around the management of ADHD and depression and avoidance of appetite suppression, regular family sessions, psychoeducation concerning the interplay of ASD, depression, ADHD, sleep, nutrition, and excessive gaming, increased staffing to support nutrition, ADLs, and academics, and a behavior management program to support alterations in her relationship to gaming.

Lumping, Untangling, and Other Quandaries

The DSM 5 makes it easier to avoid the pitfall of lumping symptoms under the ASD umbrella. While this may result in what may feel like a staggering laundry list of “problems” families ultimately feel relieved at this “divide and conquer” approach. At the same time the strands that have been untangled then need to be re-woven. Over-zealous untangling can also lead to getting lost in the desire in therapist or client to find an exact one-to-one correspondence between

a given behavior and a particular condition and so it is important for the process to remain focused on behavior change. Finally, it is crucial to appreciate the impact of the ASD symptomatology itself (including social and communication limitations) on the client’s experience of daily life, his insight and self-awareness, and capacity to receive help. The skilled clinician understands this and develops a comprehensive solution-based treatment plan.

Integrated Treatment

Individual Therapy - Successful treatment for ASD reinforces a client’s process of self-acceptance, self-determination, and self-advocacy. Intervention needs to be client-centered, engage the client’s sense of humor, and characterized by patience and careful management of the potential for misunderstanding due to cognitive inflexibility and limitations in social communication and theory of mind. Initial steps involve establishing a working relationship around client-identified goals. The next phase of treatment involves careful but non-intrusive diagnosis of co-occurring conditions and patient, appropriate psychoeducation. Clients are supported to positively frame their diagnoses as a means of understanding and accepting one’s whole self and a vehicle for getting help and joining communities.

Cognitive-behavior therapy (CBT) is the cornerstone of integrated treatment in mild ASD. Expertly described by Valerie Gaus (2007) and others, CBT is an established, evidence-based practice for the treatment of two of the most common co-occurring disorders in ASD—anxiety and depression. ADHD is best treated with well-researched CBT-based approaches developed for adults with ADHD (Ramsay & Rostain, 2015, Solanto, 2013), with modifications to manage ASD-related limitations in cognitive flexibility and pragmatic language. Integrated harm reduction therapy (IHRT), a treatment for substance use disorders (SUDs) that emerged in the 90s (Marlatt & Tapert, 1998), uses a CBT framework but draws on motivational interviewing (MI) and psychodynamic principles to support behavior change. While there is currently no research concerning IHRT for individuals with ASD and SUD, this may prove to be a promising approach in individual therapy.

Family Involvement - When treating adults with ASD clinicians may rely on standard clinical judgment around confidentiality and defer contacting family. However, adults with mild ASD are often dependent on others in many ways and tend to require a different approach. Presenting problems revolving around dysregulation (tantrums), lack of initiative, perseveration, or other behaviors occurring within a system are best supported with family involvement. While remaining fully client-centered and organized around the client’s goals, family sessions and psychoeducation are often essential to supporting behavior change.

Collateral Therapies - Individuals with mild ASD usually require additional therapies. In addition to interventions that support social learning such as group social skills training, clients may benefit from:

- Vocational coaching
- Occupational or physical therapy

- Speech & language therapy
- Behavioral coaching in natural environments
- Neurodiverse couples therapy
- Sex education

Psychopharmacology - The majority of clients with mild ASD benefit from referral to a psychiatrist to assist with diagnosis and treatment options for co-occurring conditions. Because many have been misdiagnosed or received inadequate psychoeducation, adults with ASD and often their family members are often unaware that medication sometimes helps. Past history of failed or iatrogenic medication treatment or experienced trauma in schools or healthcare settings are additional factors in this wariness. These need to be considered when making and managing referrals to treating physicians.

It Takes a Village

When young adults or adults with mild autism enter treatment, clinicians are advised to commit extra lead time to carefully evaluate for co-occurring disorders. This builds confidence and trust in the therapeutic relationship and generates a sophisticated case formulation and treatment plan. Often this involves collaborating with family members and other professionals in interesting and creative ways.

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behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) in response to an obsession or according to rules that must be applied rigidly. These behaviors or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviors or mental acts either are not connected in a way that could realistically neutralize or prevent whatever they are meant to address, or they are clearly excessive.

Some common examples of OCD symptoms include obsessions such as:

- Contamination
- Safety
- Doubting one's memory or perception
- Scrupulosity (need to do the right thing, fear of committing a transgression, often religious)
- Need for order or symmetry
- Unwanted, intrusive sexual/aggressive thought

And compulsions such as:

- Cleaning/washing
- Checking (e.g., locks, stove, iron, safety of children)
- Counting/repeating actions a certain number of times
- Arranging objects
- Touching/tapping objects
- Confessing/seeking reassurance
- List making

In previous versions of the diagnostic manual, OCD was classified as an anxiety disorder, since the anxiety generated by obsessive thoughts, and efforts to alleviate anxiety through compulsive behaviors, was considered the primary clinical dynamic that generated this disordered pattern of behavior. In DSM5, OCD was reclassified as part of a chapter on repetitive behavior disorders, which includes conditions such as Hoarding Disorder and Excoriation (skin picking) Disorder, and Trichotillomania (hair pulling) (American Psychiatric Association, 2013). While the change in grouping does not appear to be based on evidence that anxiety is not a central mechanism in OCD, the shift highlights a variety of significant challenges and questions related to making reliable diagnoses that will facilitate effective treatment.

These involve the challenge of making an appropriate differential diagnosis, assessment of co-occurring disorders, diagnostic over-shadowing of appropriate diagnoses, and a variety of other concerns. This focus on similarities in behavioral features, such as driven, repetitive behaviors instead of underlying emotional dynamics prompted this change. The shift in organization of diagnostic categories highlights the documented concerns related to the tendency for disorders to run in families. Based on this, it is important for clinicians to be reminded to look for a family history of the other anxiety disorders and OCD in family members when evaluating patients diagnosed with an ASD (Delorme et al, 2007).

Since excessive anxiety is considered one of the central underlying problems in OCD, the recommended and research supported treatments include: cognitive behavioral therapy to help patients identify and dispute inappropriate/obsessive thoughts, along with behavioral coaching and supports to prevent engaging in compulsive behaviors. These interventions often are coordinated with the use of anti-anxiety medications, to reduce the level of anxiety a patient experiences, to manageable levels, while the other treatment processes are implemented. In limited research, these treatment techniques also have been shown to be effective for patients with co-occurring ASD and OCD (Lemkuhl, 2007).

In order to provide the most appropriate treatment and supports, it is necessary to make an accurate diagnosis. This is complicated by several factors. First, since both disorders include repetitive behavior symptoms, it is necessary to make distinctions between those behaviors. This is complicated by the fact that similar behaviors may be caused by one disorder or the other. To make a distinction, clinicians need to look at other factors, including apparent motivation and relationship to thoughts, other behaviors, and life events. Evaluating thought patterns and the presence or absence of obsessive thoughts in individuals with ASD can be complicated by the fact that the other major symptom category in ASD includes deficits in social communication. These can range from individuals who are nonverbal to those who use a wide variety of language but apply it in an idiosyncratic manner. In addition to communication problems, many theorists have discussed both children and adults with autism have impairments in "theory of mind," which can make it difficult for them to understand that other people think differently than they do. Along with other complex information processing, such

as verbal information processing, central coherence, and executive functioning difficulties, it may be difficult for even verbal individuals with autism to describe their mental states, mental experiences, and even daily life experiences.

Along with these challenges, there are a variety of factors that can assist clinicians in making a differential diagnosis regarding repetitive behavior. First, as noted above, the diagnostic criteria for OCD indicate that compulsive thoughts cause distress and/or anxiety, and that repetitive behavior is an attempt to rid oneself of these repetitive thoughts or prevent a feared disaster. In contrast, many individuals with ASD find their repetitive behavior pleasurable or comforting rather than distressing. This can become a complex pattern of behavior though, as sometimes people with ASD over-stimulate themselves if they engage in a repetitive behavior for too long or may engage in agitated or explosive behaviors if the repetitive behavior is interrupted after they have been doing it for an extended period of time. Other factors that need to be taken into consideration include: the fact that in autism compulsions are more likely to be automatic and unconscious, while OCD compulsive behavior is generally brought on by obsessions. For example: an autism patient might constantly flap his hand back and forth in the air, seemingly without realizing that he is doing it, while an OCD patient might deliberately wash his hands exactly 24 times each day. In addition, ASD is strongly linked to genetic components, while OCD is more likely to be a response to life experiences. A case in point is that sometimes, Post-traumatic stress disorder can cause a patient to develop OCD as a way to deal with stress and anxiety, while ASD is usually present from birth, or identified in early childhood.

These are just several examples of the complex array of issues that need to be addressed in order to make a valid differential diagnosis or diagnosis of co-occurring disorders. The overlapping pattern of behaviors described above, combined with these challenges highlights the importance of several goals that should be pursued, both in the effort to optimize treatment and support for individuals who may struggle with repetitive behavior that may not have responded to prior treatment, along with needs to pursue more in-depth research regarding the relationship between ASD and OCD. First, it is important for the field to establish more clinicians who are familiar with the differential diagnostic challenges noted above, along with the variety of more detailed questions and concerns that

go into making the best possible clinical decisions for the individual patient. Along with this need, the large number of patients who present with these needs, and the difficulty finding successful treatment and support plans, indicate a need to develop additional clinical and diagnostic strategies and tools. Finally, a number of theorists have argued that part of the difficulty making accurate diagnoses and developing successful treatment plans may be related to questions about whether the current diagnostic scheme adequately explains the nature of these repetitive behaviors, and the relationship between those patterns that have historically been identified as either ASD or OCD. Potential solutions that have been suggested include the possibility that there may be an additional relationship between these disorders, such as an autistic subtype of OCD (Bejerot, 2007).

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interdisciplinary team is identified as well as the types and frequencies of recommended services. Team members then connect on an ongoing basis both informally and during team meetings. Depending on the needs of the child, teams may include a nurse, behavior analyst, occupational therapist, physical therapist, speech pathologist, psychologist, social worker, teacher of the deaf or teacher of the visually impaired as well as the special education teacher.

Coordination of care is essential to meet the needs of children with a dual diagnosis. Knowledge of each child's diagnosis by respective team members is key. All specialty areas including education, medical, behavioral/ABA, speech, occupational, and physical therapies must understand their targeted impact on each child with a dual diagnosis. For example, autism with hearing loss might shift the focus of communication by incorporating sign language into all therapeutic and behavioral interventions. Ongoing training and meetings for the interdisciplinary team is key for coordinating services to ensure all areas of need are being addressed.

Case Study

John is an 8-year-old boy diagnosed with autism, macrocephaly, unilateral hearing loss, and global developmental delay. He also frequently suffers from gastrointestinal issues. For the past 5 years, John has attended First Children where he receives occupational, physical, speech, and ABA therapies. John also receives services from a teacher of the deaf and is closely followed by the school nurse. He is currently in a classroom that utilizes the principles of Applied Behavior Analysis (ABA) throughout the school day. John's current goals include increasing receptive and expressive language, matching, identifying name, numbers, letters, colors, shapes, and familiar people, and waiting for instructions and preferred items. The teacher of

the deaf currently signs in the classroom for John during group activities which has increased his ability to attend, reduced maladaptive behaviors, and increased his overall participation. Prior to First Children, John was unable to understand or utilize sign language to communicate. He is now able to recognize 100 signs receptively and will independently utilize 25 signs expressively due to the coordination of care across all of John's teachers and therapists. It was found that a larger sized classroom was not conducive for John's needs. He is currently in a physically smaller classroom with six classmates and there has been a significant reduction in problem behaviors.

John has low muscle tone and prefers to not sit or stand on his own. He previously received co-treat sessions with the occupational and physical therapist once a week to address his global motor and sensory needs. Currently his occupational and physical therapy sessions are individual to address more specific therapeutic goals for each specialty. Since his enrollment at First Children, John has utilized various adaptive seating systems that allowed for safe transportation and physical support while in the classroom and therapies. Within the past year, John is now able to walk in the hallways independently due to a decrease in unsafe behaviors. Reduction of flopping, elopement and aggression in the hallway was addressed by coordinating interventions with all teachers and therapists working with him.

John has chronic gastrointestinal issues and engages in frequent rumination. These issues are closely monitored by the school nurse. In consultation with the team, the behavior analyst introduced chewing gum as an alternative behavior for the rumination. John's bowel issues peaked in 2016-2017. In coordination with the family and gastroenterologist, the nurse created a bowel plan which significantly reduced the behaviors and frequency of the gastrointestinal/bowel distress. This plan was implemented across all environments. The school nurse communicates and coordinates care with

the gastroenterologist and audiologist on a regular basis.

John also receives ABA therapy throughout the school day in his classroom and individually 4 times per week with a behavior technician. He has a history of elopement and this has successfully been addressed via ABA programming and generalized across teachers and therapists. John has also shown progress in his ability to attend and scan during work tasks. John has made gains in academic goals which are presented in a discrete trial format. This method is utilized in and out of the classroom environment in a variety of therapeutic settings. He now does well with transitions and responds positively to reinforcement.

Specifically, John has demonstrated an increase in both expressive and receptive language skills. The school behavior analyst has worked closely with John's family in addressing behaviors, reinforcement strategies, and signing that can be done in the home. Since the increase in John's communication, there has been a noticeable improvement in his ability to interact with others and also participate in social exchanges with his teachers and peers.

Creation, connection and communication are key components of an effective delivery system for children with developmental disabilities and medical conditions. A child's educational, medical, behavioral and therapeutic needs provide the framework for the identification of appropriate team members. Composition of these interdisciplinary teams may vary depending on the current as well as changing needs of the child. As illustrated in our case study, a core team, including a special education teacher and speech pathologist, occupational and physical therapists, was supported by a school nurse, social worker, behavior analyst/behavior therapist, psychologist and teacher of the deaf. Parents continue as critical members of the team as well. The ability to draw from a staff of professionals with diverse clinical backgrounds provides the depth of expertise and experience that is required when providing a comprehensive

educational program for this population.

Opportunities for team members to connect occur in many ways. Formal as well as informal team meetings are scheduled daily and as needed. Co-treatments, where two professionals provide intervention together, have been effective in sharing strategies, appropriate positions and/or techniques. Parent connections are critical as well for support and home carry-over. Parents are welcome to observe or participate in all therapy sessions. The school psychologist and social worker are available to facilitate access to community resources to help address ongoing challenges. An integrated system of total communication, established by our speech pathologists, teachers of the deaf and behavior team, assists all children in accessing and connecting with their environment. Connection with physicians and clinicians outside of the school is facilitated by our nursing staff who maintain a close relationship with our families.

Consistent communication is critical. In-service programs and trainings are provided so staff from different backgrounds and disciplines can understand not only the role but also the terminology associated with other disciplines. Medical information is shared and explained at neurodevelopmental and psychiatry clinics which are scheduled on a regular basis. Staff have ongoing opportunities to share updated information gained from their own experiences and backgrounds. All the above maximizes collaboration which is essential for effective intervention.

Ellen D'Amato, PhD, is School Psychologist and Carla Johnson, MS, BCBA, is Senior Clinical Director of Behavioral Health Treatment Services at the First Children School. Howard Savin, PhD, is Chief Clinical Officer of First Children Services.

For further information about the First Children school program or other programs offered by First Children Services please contact Dr. Howard Savin at hsavin@firstchildrenservices.com or visit www.firstchildrenservices.com.

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16th birthday (which was 4 days after I turned 16) he committed suicide, leaving his mother to find his body. Because of the social worker he never told anyone about what was haunting him. I always say this event was a turning point in my life and almost 25 years later this event still has had a great impact on who I am and who I have

become. I always say the system failed me but failed him worse. Unfortunately, when I Googled the social worker to tell him how he was wrong about me, but had failed my friend even worse, I found his obituary. He had passed away in 2011.

As an adult I proved the social worker wrong by not only graduating high school but college, graduate school, and law school and then becoming an attorney, I

realized I had something to give back so no other child would go through what both my friend and I had. I knew I had to make a difference, so children like I was would know they had a future, and children like him would know there were people they could go to and that they did not need to feel hopeless.

My life experience of having been where your child is drives my desire every day to

fight for justice for children with disabilities and their families. I made something of myself, but sadly, many end up like my friend."

For more information about Michael Gilberg, Esq., please visit www.michaelgilbergesq.com. To see the full listing of the Autism Spectrum News Editorial Board, visit www.mhnews-autism.org/editorial_board.htm.

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have some understanding of causes, and this new work shows the consequences, we now have to understand the mechanisms by which this comes about, so as to develop the ability to change these outcomes."

In addition to Geschwind and Gandal, the

study's authors are Jillian Haney, Neelroop Parikshak, Virpi Leppa, Gokul Ramaswami, Chris Hartl and Steve Horvath, all of UCLA; Andrew Schork, Vivek Appadurai, Alfonso Buil and Thomas Werge, all of the Institute of Biological Psychiatry, Mental Health Services Copenhagen in Denmark; Chunyu Liu of the University of Illinois at

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Reform from page 16

Without the due diligence of an adept case worker, and in some cases, litigious parents or guardians, a fragile child will merely exist. On their 18th birthday or in some cases their 21st they are deemed no longer eligible for services under DCF. As a social worker, I have heard parents plead for their son or daughter to remain eligible especially because those on state assistance are better provided for than those with Blue Cross Blue Shield or private insurance. I can't tell you how many times insurers denied our son extended hospital stays and medication despite his medical history. It is an exception for insurers to extend a hospital stay, especially once acute safety concerns stabilize.

Depression

Every day I see the world glide by in perfect harmony

I see laughter, but I feel pain

The sadness hits like a bullet going through the skin hitting your heart

I creep up the stairs sniffing sadness and sorrow

The paintings stare back at me showing me I'm ugly

The world is pain

I taste tears pouring down my face like a water fall

I look in the mirror and see my face

I hear the glass shatter as, "bang"

Pain flows

The rage and sorrow won't leave me alone

It stalks me everywhere I lurk

I feel the pain and agony in my heart

I sniff the air

I smell nothing but a 17 year-old boy alone, with nothing, not even hope

Hunter wrote this poem shortly after his discharge from an acute inpatient psychiatric unit. He was 14 years old. Despite numerous appeals to our insurance provider and his treaters, Hunter was released without a concrete post hospitalization plan. Within weeks Hunter was readmitted. His plummeting self-stigma extinguished all hope that he would ever find peace. Upon discharge he vowed he would never seek treatment or medication again.

When a child has a long-term psychiatric illness, the likelihood of repeated hospitalizations will only intensify without adequate outpatient psychiatric services to match their needs. Would you deny insulin to a diabetic or chemotherapy to a cancer patient? No. Why then do we ignore brain health?

Realizing we were fighting an uphill battle, we opted for home-bound tutoring and counseling services. Hunter responded beautifully. Once stable, he participated in Outward Bound and later enrolled at parochial high school where he became a three-sport athlete and honor student. Hunter aspired to become an astronomer, and dreamed of the Mars space program. He won awards in World History, English, and Geometry.

In spite of his successes he struggled to disclose his battle with mental illness. Every night he fought for his sanity, often caught up in OCD rituals that would turn into brief psychotic episodes. We became experts at hanging pictures on walls to cover the many holes from his fists of rage. We

never became angry, although we were exhausted. He was incredibly remorseful and ashamed. I would often cry, and ask myself what I did wrong during this lifetime? My husband and I would share with one another how we wished we could change places with him, so that he could be well.

On November 16, 2015, my son took his life. He was 17. We discovered Hunter lying on our bed with a bag of Skittles, and his faithful dog Buddy by his side. Although he left no note, I learned from his sister and friends how Hunter feared being the only conservative on a college campus; being away from his father whom he so dearly loved; and injuring if not accidentally killing someone as a result of a psychotic break, "The last thing I want to do is injure or kill someone. That would kill me. What a waste of a life that would be."

It is estimated that Schizophrenia costs the United States \$63 billion annually, with \$23 billion in excess direct health care costs, including \$7 billion in outpatient services, \$5 billion in medication, \$2.9 billion in inpatient treatment, and \$8.0 billion in long-term care (NAMI). Of those that go untreated, approximately 44% receive federal disability payments due to serious mental illness (NAMI). Much of the stagnation associated with universal healthcare systems stems from policymaker's inability to identify the scope, magnitude, and financial ramifications associated with the problem. Thus, "it may be necessary to incur immediate psychological costs to achieve more important but more distant goals" (as cited in Mechanic et al. 2014, p. 40).

School districts are caught in an impossible situation with the meteoric rise in pediatric and adolescent psychiatric presentations. Due to budget constraints from a local and state level, more and more children impacted by behavioral health concerns are often denied eligibility for special education and related services. Many students are not identified simply because they are working at grade level, or because there is a shortage of services due to increased demand. One reason: cost. On average, the annual expenditures to educate a neurotypical child in public school using the combined efforts of federal, state and local government is estimated to be \$12,296 per year, (U.S. Department of Education, 2015). These expenditures include \$11,001 per student for the operation of schools; \$931 for capital outlay including property and building alterations and contracting; and \$355 for interest on school debt (U.S. Department of Education, 2015).

Since its initial enactment, the federal law under the Individuals with Disabilities Education Act (IDEA) is committed to pay 40% of the average cost per student for every special education student. With public schools serving more than six million disabled learners, local school districts now receive only 20% of the 40% specified by law (NEA, 2015). Compounded by the increase need for psychiatric services, this shortfall has created a burden on local school districts to provide an equal opportunity, free and appropriate public education regardless of disability (NEA, 2015). For those parents fighting for services and even outplacement based on their child's psychiatric profile: their pursuit is often denied. The average cost of having to outplace a student in the state of Connecticut can range from \$30,000 to \$100,000 plus annually. Even if it is deemed medically and psychiatrically necessary to place a child residentially, public school districts,

DCF, DMHAS, and DDS will challenge the claim often resulting in a due process hearing to determine the justification for placement and who bares fiscal responsibility.

My husband and I spent roughly three quarters of a million dollars in order to help Hunter including attorney fees, residential treatment, psychiatric services, and medication not covered by insurance. Like many, we appealed for help only to have our hopes dashed. After Hunter's death I approached our local politicians and service providers to bring cases like my son's forward. My pleas fell on deaf ears.

I remain cautiously optimistic that our local, state, and federal governments will reform school safety and mental health programming. Many school districts are trying to address the rise in behavioral health presentations by creating specialized therapeutic programming within their districts. However, programs like these must be endorsed and financially supported at a state and local level. Moreover, they require highly trained clinicians, behavior analysts, and special education teachers with the expertise and stamina necessary for working with this complex profile.

Behavioral health is a national tsunami surging into every community, family, race, creed, and gender. Schools, healthcare organizations, and related community groups should serve as conduits for promoting brain-health and wellness. With increased awareness and assistance, we may reduce suicidal ideation and completion. We may encourage best practices for life-long wellness. Mostly, we may offer hope to the afflicted that life can and will get better.

Laura Albee, MA, BCBA, LCSW, is a Board-Certified Behavior Analyst and Licensed Master Social Worker. To contact the author, please email albeell@southernct.edu.

The viewpoints expressed in this article do not reflect the opinion of the Autism Spectrum News Editorial Board or the Publisher, Mental Health News Education, Inc. "Advocacy for Autism" articles are intended as a means for self-advocates, family members and others impacted by Autism Spectrum Disorder to share their stories.

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Transitioning from School to Work

An example of Devereux's efforts to collaborate with families and help youth prepare for adulthood can be found at the organization's Center for Autism Research and Education Services (CARES) center in Downingtown, PA.

CARES provides elementary educational services for youth with autism, beginning at age five, as well as transitional high school educational services for adolescents. Services are based on applied behavior analysis instructional strategies and focus on critical skills needed for independence and a high quality of life. The school's instructional program also includes frequent (several times per week) community-based instruction (e.g., recreation, wellness activities, employment training) to cultivate greater independence in community settings.

Between the ages of 12 to 14, students and families begin working with school staff to create a person-centered plan in preparation for adult life. An important part of that plan may be working in the community. In these cases, CARES' community-based employment training sites give students the opportunity to learn job skills, while promoting the development of

communication, appropriate work behavior and social skills.

The Importance of Community Integration

Services that strive to integrate individuals with autism into their communities - through community-based living services and employment training programs - are also imperative for the transition to adulthood.

For instance, Devereux Pennsylvania's Community Adult Autism Partnership Program (CAAPP) provides adults with autism, and other disabilities, instruction and support across community, home and work environments to help them become productive and personally fulfilled members of their communities.

The success of this program can be seen in individuals like "Robert," a former CARES student turned CAAPP participant. After Robert entered CARES, his family began exploring adult program options. During school, Robert participated in a variety of employment training opportunities, including fulfilling book requests at a library and computer data entry at a senior center. A systematic, structured and individualized approach guided Robert and his family toward a smooth transition from school into a community-based adult program. Today, he continues to successfully volunteer in community settings and attends a facility-based

program during the week.

Looking Ahead

At every age, and at every point on the spectrum, individuals living with autism need innovative and thoughtful services to help them achieve productive, healthy and socially connected lives.

As Devereux continues to advance the provision of care across the lifespan and work toward its vision of whole-person health, this evolution includes compassionate and effective treatment for those who need our support, robust partnerships with families, and reshaping public perceptions about individuals with behavioral health differences.

Ultimately, taking this approach will help adolescents with autism - on the cusp of adulthood - discover their unique and wonderful gifts, so they can be shared with the world.

Carl E. Clark II is the President and CEO of Devereux Advanced Behavioral Health.

Devereux Advanced Behavioral Health is one of the nation's largest nonprofit organizations providing services, insight and leadership in the evolving field of behavioral healthcare. The organization is a recognized partner for families, schools and communities, serving many of our coun-

try's most vulnerable populations in the areas of autism, intellectual/developmental disabilities, specialty mental health, and child welfare. For more information visit www.devereux.org.

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one hour later than when they typically fall asleep to ensure that they are sufficiently tired when going into bed. If the child falls asleep within 15 minutes, the child's bedtime should be moved 15 minutes earlier the following night. This progression should continue until the desired bedtime is achieved (Abel et al., 2017; Piazza & Fisher, 1991). As part of a child's bedtime routine, activities should progress from more active to more passive (e.g., bath time should be earlier in the routine, so as not to alter the descent of the child's core body temperature, while reading books should be later in the routine). Further, ambient light should get progressively dimmer to assist with the release of endogenous melatonin (Jin et al., 2013).

Additionally, there are several environmental conditions that can assist a child in falling asleep, including cooler temperature, indirect lighting only, white noise, and ensuring that preferred toys/activities are not visible (Abel et al., 2017; Jin et al., 2013). It is also crucial to help children develop sleep dependencies

on things that are routinely and easily present throughout the night. Therefore, it is essential that children do not become dependent on their caregivers or other items/activities to fall asleep that would not be present in the middle of the night so that they are more likely to successfully fall asleep on their own. There must also be a clear discrepancy between what is available during the day versus at night to ensure good sleep.

In order to address nighttime noncompliance, parents should begin the bedtime routine just prior to their child's natural sleep phase, as well as promote compliance during the day. Additionally, children may be given the opportunity to earn additional reinforcement for compliance (e.g., compliance results in getting to stay up longer, reading a longer book or more books, having an extra snack, additional stickers or tokens, etc.). Finally, it is helpful to assess the specific function, or purpose, of the interfering behavior (e.g., access to attention or preferred items, escape/avoidance of the dark or the bedroom) and then create interventions based on the specific function of the behavior (Jin et al., 2013).

Addressing children's sleep problems may seem daunting. However, sleep difficulties typically persist without treatment. A thorough assessment and consistent use of behavioral strategies can greatly improve children with autism's ability to fall asleep and stay asleep. Isn't it time that everyone got a good night's sleep and experience its benefits?

For more information, contact Dr. Schulman at rschulman@behaviortherapypress.com.

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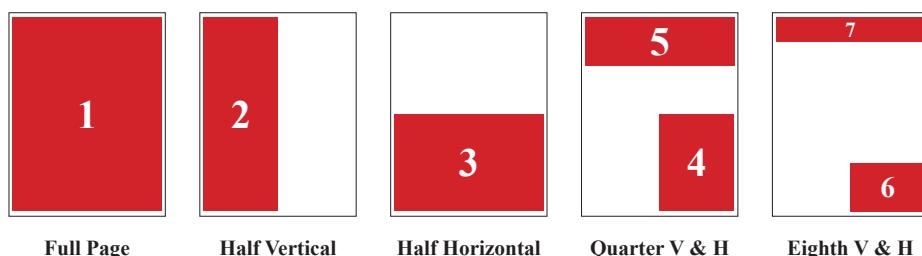
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Deadline Calendar & Ad Size Specifications

Deadline Dates

- Summer 2018 Issue - June 1, 2018
- Fall 2018 Issue - September 6, 2018
- Winter 2019 Issue - December 4, 2018
- Spring 2019 Issue - March 1, 2019



Ad Sizes - In Inches

	<u>Width</u>	<u>Height</u>
Full Page (1)	10.4	12.8
Half Vertical (2)	5.1	12.8
Half Horizontal (3)	10.4	6.4
Quarter Vertical (4)	5.1	6.4
Quarter Horizontal (5)	10.4	3.1
Eighth Vertical (6)	5.1	3.1
Eighth Horizontal (7)	10.4	1.5
Business Card (not shown)	5.1	1.5

Some see obstacles. We see outcomes.

Beacon Health Options administers Autism Spectrum Disorder services and benefits on behalf of employers, Medicaid programs, and our health plan partners under a coordinated model of care.

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