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## **AUTISM AND HEALTH: A SPECIAL REPORT BY AUTISM SPEAKS**

Advances in Understanding and Treating the Health  
Conditions that Frequently Accompany Autism

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 **AUTISM SPEAKS®** 2017

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**The following information is solely for educational purposes. It should not be construed as medical advice nor a substitute for medical care. Please consult a physician for personalized guidance about care and treatment.**

*Editor's note: Whenever possible, the scientific citations in this report link to open-access, full-text articles.*

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# INTRODUCTION

Autism is a spectrum disorder – meaning it has many forms that affect people in a variety of ways and in varying degrees. Each person’s experience with autism presents unique challenges, as well as strengths, which define the type of support needed to lead a fulfilling life.

The facts and figures on the following pages help us better understand the complex and diverse effects of autism on people living with the condition, their families and our nation as a whole.

In particular, this year’s special report dives deeply into the latest research on the physical and mental health conditions that frequently accompany autism.

We now know, beyond doubt, that for many people, autism is a whole-body disorder. (Bolton 2009, Croen 2015) Its frequent co-morbidities include seizures, gastrointestinal disorders, sleep disturbances, eating and feeding challenges, attention deficit and hyperactivity disorder (ADHD), anxiety, depression, schizophrenia and bipolar disorder.

These issues can extend across the life span. They also contribute to an alarming rate of premature death among those with autism. Of the studies examining this troubling issue, the most recent found the average life span of someone with autism to be *half* that of the general population – an average of 36 versus 72 years. (Guan 2017)

Autism itself is not a cause of premature mortality. Rather, research suggests that it relates to many of the medical and mental health conditions in this report, most of which are treatable and some – such as obesity, depression and anxiety – potentially preventable with greater understanding and support.

**Autism itself is not a cause of premature mortality. Rather, it relates to many of the medical and mental health conditions in this report – most of which are treatable and/or preventable.**



Today, genetic research is delving into the biological causes of autism-associated health conditions. This is part of a new avenue of autism research aimed at identifying the many biological subtypes of autism and developing personalized treatments and supports.

Meanwhile, specialists at leading autism care centers are working with patients and their families to improve the health and quality of life of all those with autism by developing and disseminating evaluation and treatment guidelines for healthcare providers. (Perrin 2012, Warfield 2016) This effort also includes autism-specific medical education and teleconferencing programs to share expertise. (Mazurek 2017)

These programs have helped produce a sea change in autism awareness and treatment capabilities among the pediatricians, family physicians and other non-specialists who provide the bulk of healthcare to the nation’s estimated 3 million people on the autism spectrum.

The purpose of this special report is to summarize the latest understanding of autism’s commonly associated physical and mental health conditions, including how best to identify, treat and in some cases prevent them to improve overall health and quality of life.

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## AUTISM AND EPILEPSY (seizure disorder)

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**Epilepsy affects a fifth to a third (20 to 33 percent) of people who have autism, compared to an estimated 1 to 2 percent of the general population.**

Epilepsy, or seizure disorder, was the first medical condition clearly connected to autism. (Gubbay 1970) This association provided early evidence that autism is a neurodevelopmental (affecting brain development) condition and helped put to rest false theories relating autism to emotionally cold parenting.

Overall, epilepsy affects a fifth to a third (20 to 33 percent) of people who have autism, compared to an estimated 1 to 2 percent of the general population. (Spence 2009) The autism-epilepsy overlap appears to be most common among people who also have intellectual disability. (Amiet 2008) Intellectual disability – defined as an IQ score below 70 along with challenges in everyday function – affects an estimated 32 percent of those who have autism. (Christensen 2016)

Identifying and effectively treating epilepsy in those with autism is critically important, given the potential for brain damage and death from uncontrolled seizures. In a 2012 review of 21 studies, researchers found that epilepsy was the reported cause of death for 7 to 30 percent people with autism. (Woolfenden 2012) In addition, a review of studies on children with autism, epilepsy and sleep disorders suggests a vicious cycle – with uncontrolled seizures affecting sleep and disrupted sleep increasing seizures. (Malow 2004)



**A review of 21 studies found epilepsy to be the cause of death in 7 to 30 percent of people affected by autism.**

While the association between epilepsy and autism is well known, diagnosis can be challenging because seizures are not always outwardly evident, and many people with autism have difficulty recognizing and communicating their symptoms.

### RECOGNIZING EPILEPSY IN SOMEONE WITH AUTISM

Seizures can begin at any age, though research has identified two peaks in onset among children with autism – in the preschool years and again in adolescence. (Rossi 2000)

*Characteristic symptoms include:*

- Unexplained staring spells
- Stiffening of muscles
- Involuntary jerking of limbs



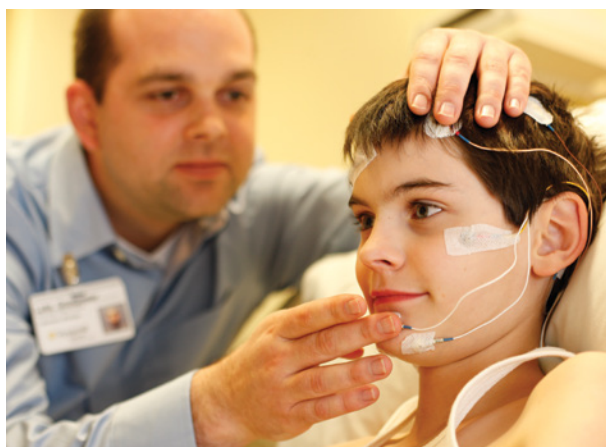
**Other less-specific symptoms can include:**

- Sleepiness or sleep disturbances
- Marked and unexplained irritability or aggressiveness
- Regression in normal development

Like autism, epilepsy is a spectrum disorder. Severity varies widely. In addition, experts now distinguish seizures by where they begin in the brain – important because it affects the choice of seizure medication, the potential benefit of epilepsy surgery, outlook and possible causes. (Fisher 2017)

## **DIAGNOSING AND TREATING EPILEPSY IN THOSE AFFECTED BY AUTISM**

Suspicion of seizures warrants prompt evaluation by a neurologist, who may order an electroencephalogram (EEG), a noninvasive process that involves placing electrodes on the head to monitor activity in the brain. By analyzing EEG patterns, the neurologist can identify seizures and other altered brain activity of concern. Often patients who have autism need EEG protocols that address their sensory and communication challenges. (Katz 2015) (See resource section for more information on autism-friendly EEG procedures.)



Treating epilepsy in patients who have autism follows the same principles as treatment of epilepsy in others. Typically, the physician selects an anti-epileptic drug based on several considerations such as the type and severity of seizures and their associated EEG patterns.

Though anti-epileptic drugs do not cure epilepsy, in most cases they can prevent or minimize seizures. After starting a medication, the neurologist works with the patient and/or his family to monitor effectiveness and side effects. Common side effects include mild fatigue, abdominal discomfort or dizziness. To minimize side effects, the doctor may start medications at a low dose and slowly increase it. Dosage adjustments are common to find an optimal dose and maintain good control of seizures over time.

Epilepsy drugs eliminate seizures in around two-thirds of patients. More difficult-to-control seizures sometimes respond to combinations of two or more medications. When medications fail to control seizures, physicians and families can discuss other options. These include *vagus nerve stimulation*, a technique that prevents seizures by sending pulses of electrical energy to the brain through a device that acts like a “pacemaker” for the brain. Another option is the surgical removal of seizure-producing areas of the brain. (Morris 1999)

## **RESEARCH ON EPILEPSY AND AUTISM**

Recent research suggests that certain gene mutations, or changes in DNA, increase the occurrence of both epilepsy and autism. The best understood of these genes cause rare syndromes whose symptoms frequently include both conditions. These syndromes include tuberous sclerosis and fragile X syndrome and cortical dysplasia-focal epilepsy. (Garcia-Nonell 2008, Huang 2015, Poot 2015) Further research holds the potential to personalize and improve treatment by more-specifically targeting a patient’s affected brain networks.

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# AUTISM AND GASTROINTESTINAL DISORDERS

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## **Children with autism are nearly eight times more likely to suffer from one or more chronic GI problems than are typically developing children.**

Gastrointestinal (GI) disorders rank among the most common medical conditions associated with autism.

(Nikolov 2009)

In 2014, researchers with the MIND Institute (University of California, Davis) documented that children with autism were nearly eight times more likely to suffer from one or more chronic GI problems than were other children. (Chaidez 2014) These GI issues included frequent abdominal pain, gaseousness, diarrhea, constipation and painful stooling. This study also linked chronic GI issues with increased severity of autism's behavioral symptoms – including repetitive behaviors, social withdrawal, hyperactivity and irritability. The association between GI issues and these autism symptoms may be particularly strong among nonverbal persons who have difficulty communicating pain and distress, they concluded.

## **AUTISM AND THE MICROBIOME**

Since the late 1990s, researchers have been adding to the evidence that unhealthy changes in the intestinal tract's normal community of digestive bacteria (the microbiome) drive both behavioral and GI problems in some people on the autism spectrum. The first reported person to make this gut-brain connection was the mother of a child with autism, Ellen Bolte, who saw a parallel between her son's symptoms and infant botulism. (Bolte 1998)

Ms. Bolte's ideas inspired the research of Sydney Finegold, an infectious disease specialist at the University of California, Los Angeles. Dr. Finegold and others showed that spikes in toxin-producing bacteria in the intestines could directly affect the brain via the vagus nerve that runs between the digestive tract and the brain. (Finegold 2002)



## **RECOGNIZING AND TREATING GI DISORDERS IN THOSE WITH AUTISM**

In 2010, the journal *Pediatrics* published the first guidelines to help healthcare providers recognize and treat GI problems in children with autism. (Buie 2012) The guidelines emphasize that a thorough evaluation for GI distress is particularly important in children who show an otherwise unexplained spike in behavioral problems. They include such specific issues as the following:

**Chronic constipation:** Between 2006 and 2010, a national survey conducted by the U.S. Centers for Disease Control (CDC) found that children with autism were more than 3.5 times more likely to suffer chronic constipation or diarrhea than were typically developing children. (Schieve 2012)

Constipation refers to difficulty emptying the bowels and usually involves hard stools. Periodic constipation is normal, but chronic constipation (lasting two weeks or more) can involve considerable daily pain and lead to a number of medical complications. These include rectal fissures, hemorrhoids and prolapse of the rectum and/or lower intestines. In addition, the pain associated with passing hard stools can lead to an aversion to toileting that compounds the problem.

Difficulty communicating pain and distress makes recognizing GI distress difficult among many who have autism – particularly the nonverbal and minimally verbal and those with intellectual disability. Telltale behaviors can include arching the back, pressing the belly and gritting teeth. GI pain can also prompt spikes in self-soothing repetitive behaviors as well as irritability, aggression, self-injury and other challenging behavioral issues.

**Common contributors to chronic constipation in patients who have autism include:**

- Diets that provide insufficient fiber, which some research suggests are particularly common with gluten-free diets as well as highly restricted diets associated with sensory aversions. (Miranda 2014, Graf-Myles 2013)
- Behavioral medications including risperidone. (De Hert 2011)
- Sensory and/or behavioral issues that interfere with regular toileting. (Dalrymple 1992)

Less common but potentially more serious contributors can include anatomic, neurological or metabolic problems and abnormal gut motility (a sluggish intestinal tract).

Often, the best treatment plan involves a combination of behavioral and medical interventions. Behavioral management includes dietary changes such as increasing fiber, eliminating constipating foods and managing toileting behaviors, which might include teaching a child to sit on the toilet after meals. Medications may include soluble fiber and/or laxatives such as mineral oil, magnesium hydroxide or sorbitol. (For more information, see the resources section of this report.)

**Chronic diarrhea:** As with constipation, periodic bouts of diarrhea are normal, but chronic diarrhea (two weeks or more) can affect health and quality of life. Evaluation includes investigating and addressing potential medical causes such as intestinal infection, immune dysfunction, inflammatory bowel diseases (Crohn’s or ulcerative colitis), irritable bowel

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## Exploring Autism’s Gut-Brain Connection

Several major research studies are currently enrolling children with autism and chronic GI stress, to increase understanding of autism’s gut-brain connection.

(AS grants 9718, 9455 and 8093; NCT02903030)

Researchers at Baylor University recently reported early results from one of these studies – profiling the intestinal bacteria of children with GI problems, around half of whom had autism. (Luna 2017) In the children with autism, the investigators found unusually high levels of several kinds of toxin-producing *Clostridia* bacteria that did not appear in the children who did not have autism. In addition, they found that episodes of pain in the children with autism correlated with spikes in both *Clostridia* and several inflammatory molecules (cytokines) in the intestinal lining. This, in turn, corresponded with an imbalance in the brain-signaling molecule (neurotransmitter) serotonin. In this way, the study outlined a biochemical chain of events from the children’s intestinal bacteria to brain circuits highly sensitive to serotonin.

In line with these findings, researchers at Ohio State University are enrolling children with autism in a clinical trial to evaluate whether a well-studied probiotic (a “good,” or health-promoting bacterium) can relieve anxiety and improve quality of life in children who have autism. (NCT02903030)

These first clinical trials extend from the promising results of studies with mice bred to display autism-like symptoms such as social avoidance and repetitive behaviors.

(Hsiao 2013, Critchfield 2011, Breece 2013)

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syndrome, celiac disease (gluten intolerance), food allergies, lactose intolerance or excessive consumption of certain foods or drinks.

Though it may seem counterintuitive, diarrhea in people with autism often results from severe constipation. This occurs when hard, stuck stools cause a backup of watery contents. Eventually, the watery contents spill around the hard stool to cause sudden diarrhea.

Treatment depends on the cause. For instance, dietary changes can ease diarrhea due to excessive juice, food allergies, lactose intolerance or celiac disease. Other times, medications or (rarely) surgery are warranted.

### **Gastroesophageal reflux disease (GERD):**

GERD results when the muscle between the stomach and esophagus (food pipe) is lax. This allows partially digested food and liquid mixed with stomach acid to move up out of the stomach. GERD can cause ulceration of the esophagus and predispose a person to esophageal cancer. The condition warrants medical evaluation and possibly a referral to a specialist.

In evaluating for GERD, healthcare professionals often look for throat discomfort and/or feelings of “heartburn,” though children sometimes experience GERD pain in atypical ways.

Importantly, nonverbal or minimally verbal people can have difficulty communicating pain and discomfort. Signs of GERD pain in a nonverbal or minimally verbal person can include an increase in repetitive and self-injurious behaviors such as head banging, as well as challenging behaviors. Other telltale behaviors can include unusual body postures, straining the neck, pushing out the jaw or tapping the throat. It can help to note if the behaviors are triggered or made worse when the person lies down (a position that worsens reflux). Additional signs can include hoarseness, chronic sore throat, cough or heartburn, dental erosions, food refusal or disturbed sleep.

Helpful behavioral modifications include elevating the head during sleep, avoiding food near bedtime, eating smaller meals and avoiding foods that tend to trigger symptoms. GERD-easing medications include antacids, histamine-2 blockers and proton-pump inhibitors. Severe and chronic GERD warrants specialized tests to identify acid levels and tissue damage in the esophagus.

### **CASEIN- AND GLUTEN-FREE DIETS**

Many parents of children who have autism report that behavior improves when their children eat a diet free of the proteins gluten and casein. (Pillsbury 2016) Gluten is found primarily in wheat, barley and rye; casein, in milk products.





A review of published studies found little evidence that a casein- and gluten-free diet reduces autism symptoms. (Mulloy 2010) Subsequently, researchers with the University of Rochester Medical Center conducted a clinical trial that switched children with autism between a diet that included gluten and casein and a diet free of them – using look-alike, taste-alike foods. (Hyman 2016) Neither the participating children, their parents nor the researchers knew who was getting which food when, until after the two segments of the study were completed. Analysis of daily diaries showed no significant change in the children's behavior. However, the researchers say it's possible that a small subset of people with autism do benefit from a gluten- and casein-free diet – a subset too small to pick up with modestly sized clinical studies.

## PROBIOTICS

Probiotics are so-called “good,” or healthful, bacteria, traditionally found in cultured food products such as yogurt and kefir in the European tradition and kombucha and kimchi in Asia.

The study of probiotics for autism is in its early stages, with a small handful of human studies now underway, as described in the sidebar on page 5. Much of this research is based on the promising results of studies with mice bred to display autism-like symptoms such as social avoidance and repetitive behaviors. (Hsiao 2013, Critchfield 2011, Breece 2013)



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# AUTISM AND DISRUPTED SLEEP

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**Over half of children with autism – and possibly as many as four in five – have one or more chronic sleep problems.**

Many people affected by autism suffer from sleep disturbances. Most studies have focused on children. These studies consistently found that over half of children with autism – and possibly as many as four in five – have one or more chronic sleep problems. (Cortesi 2010, Krakowiak 2008) These problems include difficulty falling asleep, frequent and prolonged waking during the night and extremely early rising.

Sleep issues in those who have autism go hand in hand with daytime behavioral challenges, including spikes in repetitive behaviors, communication difficulties, hyperactivity, irritability, aggression and inattention – all of which can interfere with learning and decrease overall quality of life. (Mazurek 2016)

**Sleep issues in those who have autism go hand in hand with daytime behavioral challenges that interfere with learning and decrease overall quality of life.**

Anecdotally, many parents of “poor sleepers” with autism report not being able to sleep themselves for fear that their children will leave their rooms or even their homes in the night. Wandering from safety, or “elopement,” is a common and life-threatening problem affecting nearly half of children with autism older than age 4. (Anderson 2012) Along these lines, a 2006 study found “significant” levels of chronic stress in 90 percent of parents of “problem sleepers” with autism, compared to 65 percent of parents of “non-problem sleepers” with autism. (Doo 2006)

**Genetic studies show that people with autism are twice as likely to have mutations in genes that regulate the body’s sleep-wake cycle (circadian rhythm).**

## WHAT CAUSES AUTISM-RELATED SLEEP PROBLEMS?

Research suggests that the causes of disrupted sleep in people with autism go beyond the poor “sleep hygiene” habits that cause poor sleep in the general population. (Johnson 2008) Studies have identified a number of potentially biological causes, which likely vary – and sometimes overlap – in different people. For example:

- Genetic studies show that people with autism are twice as likely as other people to have mutations in genes that regulate the body’s sleep-wake cycle (circadian rhythm). (Yang 2015)
- Up to a third of people with autism also have epilepsy, or seizure disorder. Seizures and sleep can worsen each other – undetected nighttime seizures disrupting sleep brain patterns and insufficient sleep worsening seizure control. (Accardo 2015)
- Studies suggest that 11 to 40 percent of children and teens with autism struggle with one or more anxiety disorders. (Vasa 2016, White 2009) Anxiety can interfere with the ability to fall asleep and stay asleep. It can also set up a worsening cycle with insufficient sleep worsening the anxiety and depression.
- One study suggests that, in addition to spending less time asleep, children with autism spend relatively less time in the rapid eye movement (REM) stage of sleep than do other children. On average, the children

with autism spent around 15 percent of their sleep time in REM versus 23 percent for the other children. (Buckley 2010) Associated with dreaming, REM appears to play a particularly important role in learning, memory and brain development. The finding has prompted scientists to look more broadly at autism-related changes in the neurotransmitters (brain-signaling molecules) that help control sleep.

- Some studies have suggested that the brains of people with autism produce lower levels of melatonin, the so-called sleep hormone. (Nir 1995, Kulman 2000, Tordjman 2005, Melke 2008) However, a recent study found little difference in melatonin levels between children who had autism when compared to those who did not. The finding, the investigators concluded, suggests that autism-related sleep difficulties are not solely driven by biological differences. (Goldman 2017)



## FOSTERING BETTER SLEEP

Neurologist and sleep specialist Beth Malow, of Vanderbilt University Medical Center, has pioneered research-based clinical guidelines for evaluating and addressing sleep disturbances in children with autism, (Malow 2012) as well as programs designed to teach parents strategies for improving the sleep of children with autism. (Malow 2014) *(See sidebar and the resource section of this report for more on the practical application of Dr. Malow's work.)*

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## A Model Program for Improving Sleep in Children with Autism

Neurologist and autism sleep specialist Beth Malow, at Vanderbilt University, has developed a model parent-education program that teaches autism-specific sleep guidelines in community classes led by behavioral therapists. Such community programs are crucial, Dr. Malow says, given the long waiting lists that are typical for seeing a specialist in autism sleep issues – if a family has access to one.

In the workshops, parents learn about daily habits that promote sleep, including the importance of daytime exercise and outdoor time that segues into a calming evening routine that limits screen time before bed. In addition, parents learn how to create visual schedules to help establish regular bedtime routines and to use other strategies to help children get back to sleep after waking in the night. The benefits of the program for children included increased sleep time as well as decreased daytime anxiety, inattention and challenging behaviors. The parents also reported decreased stress and improved quality of life for the entire family. (Malow 2014) See the resource section of this report to access the free parent guidebooks used in these classes.

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# AUTISM AND FEEDING/EATING ISSUES

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**Leo Kanner, the doctor credited with identifying autism in the 1940s, included feeding problems as a defining feature.**

A recent review of diagnostic records found that an estimated 70 percent of children on the autism spectrum have feeding and/or eating problems; 36 percent of these had problems classified as “severe.” (Romero 2016)

Eating and feeding challenges have long been reported by both caregivers and researchers. Leo Kanner, the doctor credited with first describing autism in the 1940s, included feeding problems as a defining feature.

(Kanner 1943)

A helpful point on the terminology: The term **feeding disorder** describes problems with eating enough or the right type of food. Among children with autism, this often involves eating only a few types of foods, eating only certain textures or colors of food, and/or disruptive mealtime behavior. These issues have many causes, including sensory aversions, anxiety (e.g. after an incidence of choking, gagging or vomiting) and rigidity (aversion to change). Many children with autism also have motor issues that involve difficulty with chewing and swallowing. Still others have digestion problems such as slow stomach emptying.

By contrast, the term **eating disorder** refers to conditions such as anorexia and bulimia, which relate to problems with body image and fear of weight gain. Some research suggests an overlap between anorexia and autism in some young women. (Wentz 2005)

**Chronic overeating** is a common issue among both children and adults on the autism spectrum. Some people with autism have poor sensitivity to internal cues such as feeling full. Autism-related aversions to strong flavors, textures and smells can lead to overconsumption of high-calorie, low-nutrient foods. In addition, increased appetite is a common and serious side effect of the only FDA-approved medicines for autism-associated challenging behavior (agitation) – risperidone (Risperdal) and aripiprazole (Abilify). (Maayan 2011, Scahill 2016) The result is a high incidence of obesity – often combined with nutritional deficiencies – in both children and adults on the autism spectrum. (Shmaya 2015, Croen 2015, Hill 2015)

**Pica**, the dangerous habit of eating nonfood items, is another feeding disorder long associated with autism. Anecdotally, pica appears to be concentrated among those whose autism is complicated by intellectual disability. It can include swallowing sharp objects such as nails, broken glass and pins, as well as poisonous substances such as paint chips and swimming pool chlorine tablets. (Call 2015) Pica can place tremendous stress on caregivers by demanding their constant vigilance.





## GUIDANCE ON RESTRICTED EATING

By some estimates, highly selective “picky” eating affects around 75 percent of children on the spectrum. (Emond 2010, Beighley 2013, Castro 2016)

Some studies suggest that “selective eaters” with autism are more likely than are other children to be underweight and have one or more nutrient deficiencies. (Zimmer 2012, Mari-Bauset 2015) Other research suggests that restricted eaters with autism tend to have similar growth rates as other children, despite lower consumption of key nutrients such as vitamins C and D. (Emond 2010)

Many autism specialty clinics employ a team approach to help children with feeding problems. These teams typically include a pediatrician, dietician and one or more therapists (occupational, behavioral and/or speech). The team meets with the child and parents to discuss concerns and the family’s eating routines. Team members watch the child eat and screen for underlying medical and motor issues. They will assess the child’s diet and nutrition, often with food diaries sent home with the parents.

The team then develops a personalized therapy plan. During visits, one or more therapists will work with the child on improving feeding skills and/or gradually broadening food choices and tolerance. The therapist also teaches parents strategies to use at home, while monitoring progress. Pill swallowing can be included among the skills taught in this manner.

## OVEREATING AND OBESITY

In 2015, researchers with Oregon Health & Science University found that the tendency for unhealthy weight gain starts surprisingly early in life for children affected by autism. Of the 5,053 children with autism in the study, nearly a third (32 percent) of 2 to 5 year olds were overweight, compared to less than a quarter (23 percent) of 2- to 5-year-olds in the general population. Sixteen percent of 2- to 5-year-olds with autism were medically obese, compared to 10 percent of 2- to 5-year-olds in the general population. The investigators found that the likelihood of being overweight or obese increased with the number of psychoactive behavioral medicines a child or teen was taking. Some of these children were taking as many as five. (Hill 2015)

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## When to Seek Help for Restricted Eating

Many parents seek guidance on when “picky eating” crosses the line into a feeding disorder that warrants professional help. Children who meet two or more of the following criteria for a feeding disorder warrant a medical referral to a feeding specialist for evaluation and treatment, according to pediatric psychologist Kimberly Brown, director the Pediatric Feeding Disorders Program at the University of Rochester Kirch Developmental Services Center.

- Avoids entire food groups such as vegetables, protein or fruit.
  - Eats only a specific brand of a favorite food or only foods of a particular shape or color.
  - Exhibits extreme anxiety when pressed to eat certain foods; may gag, vomit or act out with highly disruptive mealtime behavior.
  - Must bring desired foods when going out or has to eat at home beforehand.
  - Doesn’t respond to rewards or seeing other people eating something. Shows no interest in foods outside narrow preferences.
  - When evaluated by a professional, shows motor challenges involving chewing and/or related feeding skills.
  - At risk for nutritional deficiencies as assessed by a nutritionist or dietician.
-

Stemming weight gain – particularly weight gain related to behavioral medications – is a major concern for specialists in autism healthcare. (Coury 2014) First-line solutions include dietary and behavioral approaches such as healthier food choices, reducing portion size and increasing daily exercise. Sometimes this involves removing high-calorie foods from the home entirely or locking refrigerators and pantries. Family activities such as walking and riding bicycles can help reverse unwanted weight gain, and many parents find that increased physical activity has the added benefit of reducing their child’s problem behaviors.

Behavioral therapists experienced with autism can help families use autism-friendly communication tools and daily schedules to help curb overeating while increasing nutrition and exercise. (Ward 2015)

Despite an absence of hard numbers, studies suggest that, as a group, children and teens with autism engage in less physical activity than typically developing children. (Rimmer 2007, Rimmer 2008) Social difficulties appear to reduce involvement in team and competitive sports.

However, many people with autism enjoy more-solitary physical activity such as running, bicycling and swimming. (Potvin 2013) In addition, research suggests that parents’ physical activity is the single strongest influence on physical activity levels among children with special needs, including those with autism. (Yazdani 2013)

At the same time, food restriction and increased exercise can prove particularly difficult for some people who have autism. When behavioral strategies fail, many parents find themselves in the difficult position of choosing between their child’s physical health and a behavioral medicine that improves their child’s ability to function on a daily basis. Given the long-term health consequences of obesity, we urgently need more research aimed at solutions to this complex issue.

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Study	Participants affected by autism	% Over-weight	% Obese
Whiteley 2004	50 UK children, ages 2-12	42.0	10.0
Curtin 2005	140 US children and teens, ages 3-18	35.7	19.0
Xiong 2009	429 Chinese children, ages 2-11	33.6	18.4
Chen 2010	46,707 US children and teens, ages 10-17	--	23.4
Curtin 2010	102,353 US children, ages 3-17	--	30.4
Rimmer 2010	461 US adolescents, ages 12-18	42.5	24.6
Evans 2012	53 US children, ages 3-11	--	17.0
Hyman 2012	362 US children, ages 2-11	--	8.3
Memari 2012	113 Iranian children and teens, ages 7-14	40.7	27.4
Egan 2013	273 US preschoolers, ages 2-5	33.0	17.6
Zuckerman 2014	376 Oregon children and teens, ages 2-18	35.1	17.0
Phillips 2014	93 US adolescents, ages 12-17	52.7	31.8
Broder-Fingert 2014	2,976 US children, teens and young adults, ages 2-20	37.5	23.8

**Table 1: Excessive weight and obesity in children and teens with autism**

Studies consistently find high rates of excessive weight and obesity in children and teens with autism, though they have varied in the percentage of those affected. Table adapted from Hill 2015 *Pediatrics*.

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## RECOGNIZING AND TREATING PICA IN AUTISM

While most non-food items pass through the digestive tract without harm, even a single instance of pica can prove deadly as a result of choking, poisoning, infection or gastrointestinal perforation. (Decker 1993, Williams 2012) Other pica-related health risks include broken teeth and other dental problems, constipation, bowel obstruction and chronic lead poisoning.

Fortunately, research also suggests that pica can be decreased with behavioral therapy, once possible medical causes have been ruled out by a physician. (Call 2015) Medical causes can include nutritional deficiencies in iron or zinc and/or infection with intestinal parasites. Generally, people with pica also need evaluation for possible lead poisoning.



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### Behavioral Treatment for Pica in Autism

In 2015, researchers at Atlanta's Marcus Autism Center published the successful results of a behavioral therapy program they'd developed to reduce pica in children with developmental disabilities, including autism. (Call 2015) The program consists of 10-minute sessions in which the therapist works with a child in the presence of tempting inedible objects. A combination of three strategies proved particularly effective. They included:

- Rewarding the child with a small food treat for discarding or putting away the inedible object.
- Consistently redirecting the child's attention from the inedible object to a favorite activity.
- Shadowing the child to block attempts at eating inappropriate objects.

The blocking technique, while effective in the short term, didn't have the lasting effect on curbing pica seen with the first two strategies.

The children varied widely in how many sessions it took to curb their pica – from 3 to 87.

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# AUTISM AND MENTAL HEALTH

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Epidemiological studies suggest that between 54 and 70 percent of people with autism also have one or more other mental health conditions.

(Simonoff 2008, Hofvander 2009, Croen 2015, Romero 2016)

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## In order of estimated prevalence, these include:

**Attention deficit and hyperactivity disorder (ADHD)** affects an estimated 30 to 61 percent of people with autism. (Goldstein 2004, Lee 2006, Gadow 2006, Romero 2016)

**Anxiety disorders** affect an estimated 11 to 42 percent of people with autism. (Vasa 2016, White 2009, Croen 2015, Romero 2016)

**Depression** affects an estimated 7 percent of children and 26 percent of adults with autism. (Greenlee 2016, Croen 2015)

**Schizophrenia** affects an estimated 4 to 35 percent of adults with autism. (Chisolm 2015)

**Bipolar disorder** affects between 6 and 27 percent of people with autism. (Munesue 2008, Rosenberg 2011, Vannucchi 2014, Guinchat 2015, Croen 2015)

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Like autism, ADHD, schizophrenia and bipolar disorder are neurodevelopmental conditions that appear to have roots in early brain development. (Munesue 2008, Sikora 2012, Rapoport 2012) Among people with autism, anxiety and depression may stem, at least in part, from autism-related impairments that increase daily stress and social isolation and decrease overall quality of life. (Vasa 2016, Greenlee 2016)

Untreated mental health conditions can profoundly worsen autism's behavioral challenges. But because of overlapping symptoms, they can be particularly difficult to identify in someone who has autism. (Levy 2010, Sikora 2012, Miodovnik 2015) The social withdrawal associated with depression or schizophrenia, for example, can be difficult to distinguish from autism-related social impairments. In addition, many people with autism have difficulty identifying and expressing emotions and other internal feelings.

In recent years, autism specialists have developed guidelines for diagnosing and treating some of the most common mental health conditions affecting children, teens and adults who have autism. The following sections provide an overview of the latest understanding.

## AUTISM AND ADHD

Over the last decade, studies have suggested that between 30 and 61 percent of people with autism also have symptoms of ADHD. (Goldstein 2004, Lee 2006, Gadow 2006, Romero 2016) By contrast, the CDC estimates that ADHD affects 6 to 7 percent of the general population. (Perou 2013)



## **Between 30 and 61 percent of children with autism also have symptoms of ADHD, which affects just 6 to 7 percent of the general population.**

In addition, geneticists have discovered that many of the same gene variations that increase autism risk also increase risk for ADHD. (Lionel 2011)

Symptoms of ADHD include a persistent pattern of inattention, hyperactivity and/or impulsivity that interferes with daily life, social development and learning. People with ADHD often fail to pay close attention to details and make careless mistakes at school or work. Often, they don't appear to listen when spoken to, have trouble organizing tasks and fail to follow through on instructions and assignments, especially those that require sustained attention. (DSM-5 2013)

In 2012, researchers looked more deeply at autism and ADHD symptoms among more than 3,000 patients, ages 2 to 18, seen at centers in the Autism Speaks Autism Treatment Network. (Sikora 2012) They found multiple symptoms of ADHD symptoms in more than half these children and teens with autism. Further evaluation showed that the combination of ADHD and autism symptoms resulted in significantly worse daily function, health and overall quality of life. Yet few of these children (11 percent) were receiving treatment for their ADHD before they came to an ATN center for care.

Among the challenges – up until 2013 – were the diagnostic guidelines of the American Psychiatric Association. These guidelines specified that someone could be diagnosed with either autism or ADHD, but not both. (DSM-IV 2004) In 2013, the association changed its guidelines to allow diagnosis of both conditions in one person. (DSM-5 2013) Nonetheless, research continues to find that diagnosis of either one of these disorders tends to significantly delay the diagnosis and treatment of the other. (Miodovnik 2015) Distinguishing autism and ADHD may remain particularly challenging because both conditions involve impaired social development and challenges with attention, learning and communication.

In 2012, the journal *Pediatrics* published the first guidelines on the evaluation of ADHD in children and teens who have autism, together with detailed guidance on selecting and evaluating the best ADHD medication for those patients. (Mahajan 2012) This included information on evaluating the benefits and side effects of ADHD medications and their dosages in consultation with the family. The guidelines emphasize that decisions about using such medications are highly personal and should involve the individual and/or parents in a meaningful evaluation of goals and values.

## **AUTISM AND ANXIETY**

Studies suggest that between 11 and 42 percent of people with autism struggle with one or more anxiety disorders. (Vasa 2016, White 2009, Croen 2015, Romero 2016) By contrast, the CDC estimates that anxiety disorders affect 3 percent of children and 15 percent of adults in the general population. (Perou 2013, Kessler 2009) These disorders include separation anxiety, panic disorder and phobias (extreme fear of certain noises, places and so on).

### **Studies suggest that between 11 and 42 percent of people with autism struggle with one or more anxiety disorders.**

Social anxiety – or extreme fear of new people, crowds and social situations – is especially common among those who have autism. For many children on the spectrum, anxiety increases in adolescence. (Bellini 2006) While adults with autism continue to be understudied, case reports suggest that anxiety often remains high throughout life. (Gillott 2007, Moss 2015)

Even in the absence of a full-fledged anxiety disorder, many people with autism have difficulty controlling anxiety once something triggers it. For many, anxiety is wrapped around autism symptoms such as difficulty navigating social situations and extreme sensory sensitivities to loud noises, lights, tastes and smells. This can produce “anticipatory anxiety” when simply anticipating or otherwise thinking about an anxiety trigger produces extreme anxiety.

Yet another broad source of anxiety in those with autism involves the need for routine or sameness. This can produce anxiety in the face of changes in schedule or familiar people – for example, a new teacher, aide or even store clerk.

To date, most research on anxiety in autism has focused on children and adults who are verbal and have normal to high intelligence. Experts agree on the need for more studies involving the one-third of people with autism who are non-verbal or minimally verbal and/or have intellectual disability.

## RECOGNIZING AND TREATING ANXIETY IN AUTISM

In 2016, the journal *Pediatrics* published the first guidelines for recognizing and treating anxiety in people affected by autism. (Vasa 2016) Because many people with autism have trouble assessing and expressing how they feel, behavior often provides the best clues to underlying anxiety. Anxiety can trigger strong internal sensations of tension that include a racing heart, muscle tightness and stomachache. In someone with autism, these feelings can prompt an increase in self-soothing, repetitive behaviors (flapping, rocking, spinning, etc.) and/or destructive or self-harming behaviors (shredding clothing, head banging, etc.). Similarly, anxiety can be the underlying cause of new resistance to what had been an enjoyed activity (a trip to the beach, a birthday party, school, etc.).

The guidelines call for personalizing treatment to the developmental level of the patient, including language level and intellectual ability. They also cite the effectiveness of an autism-tailored version of cognitive-behavioral therapy.

(Wood 2009, Drahotka 2011, Wood 2015)

In general, cognitive-behavioral techniques include challenging negative thoughts with logic, role-playing, modeling courageous behavior and gradual exposure to feared situations. Gradual exposure can start with merely looking at a related picture. The autism-adapted version of this approach includes the use of visual aids that tap into the strongly visual style of learning shared by many people with autism. It also incorporates special interests to encourage participation. For example, the therapist may use a favorite cartoon character to model coping skills. She might intersperse conversations about a person’s special interest throughout the treatment session.



“My anxiety can be so profound because of the fear of social expectations, sensory violations and unexpected changes.

These are all so unbearable that I can feel frozen and unable to move forward.

A simple request of me can sometimes be the core trigger of a meltdown.”

- Sondra Williams

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Some people with autism respond strongly to the logical aspect of cognitive behavioral therapy. In clinical trials, cognitive behavioral therapy has proven particularly effective among people on the spectrum who are verbal and have normal to high intelligence. (Wood 2009, Wood 2015, Hepburn 2016) Building on this work, researchers are further modifying the approach to help those with intellectual disability and/or little to no verbal language. (Danial 2013)

## MEDICATIONS FOR ANXIETY IN PEOPLE WITH AUTISM

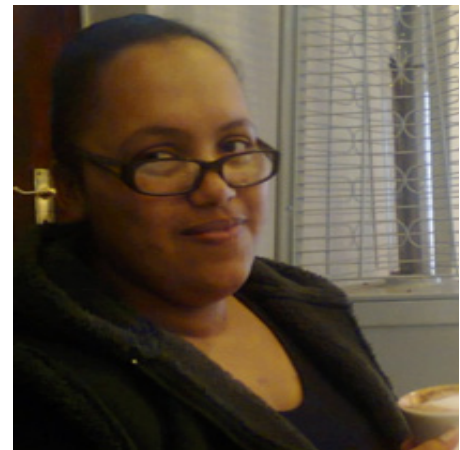
Sometimes, counseling and behavioral therapy aren't sufficient to relieve severe anxiety. In these cases, the patient and/or family may want to consult an appropriate specialist about adding an anti-anxiety medication to the treatment program. No medication has FDA-approval specifically for the treatment of anxiety in children with autism. Autism specialists commonly prescribe drugs approved to treat anxiety disorders in the general population. These include selective serotonin reuptake inhibitors (SSRIs) such as Prozac and Zoloft. However, some studies suggest that anti-anxiety medications are less effective, overall, in those with autism than with other groups. (Williams 2010) It may be that the underlying cause of autism-associated anxiety differs from that of anxiety in the general population.

## AUTISM AND DEPRESSION

Depression affects an estimated 7 percent of children and 26 percent of adults with autism. (Greenlee 2016, Croen 2015) This compares to 2 percent of children and close to 7 percent of adults in the general U.S. population. (Perou 2013, NIMH 2015) A recent report in the journal *Pediatrics* found that the rate of depression among children with autism rose dramatically with age, from just under 5 percent in grade-schoolers to just over 20 percent in teenagers. (Greenlee 2016) It likewise rose with intellectual ability (IQ), as well as the presence of one or more of the medical conditions that commonly accompany autism – particularly seizures and gastrointestinal issues.

That depression rates rise with age and intellectual ability suggests a painful awareness of autism's social challenges and isolation, the researchers propose. That the rates increase with associated medical conditions may demonstrate their profound effect on quality of life.

The authors called on healthcare professionals to consider screening for depression as a *routine* part of care for teens and adults who have autism – particularly those with normal to high IQ and those with additional medical issues.



"I suffer from anxiety and depression, so for a long time my 'strangeness' was attributed to these conditions. Since my diagnosis, I feel more in control now. I am in charge of my life and destiny. I feel that even though autism has its challenges, I have been more blessed than anything else."

- G.W.

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## RECOGNIZING DEPRESSION IN THOSE WITH AUTISM

Signs and symptoms of depression include chronic feelings of sadness, hopelessness, worthlessness, emptiness and/or irritability. Also common: social isolation, moving or talking slowly, feeling restless, and having trouble sitting still or concentrating. At its most serious, depression can include frequent thoughts about death and/or suicide.

But recognizing depression in people who have autism can present special challenges. (Gotham 2015) Having a “flat,” or unemotional, facial expression, for example, is a common trait of both autism and depression. So, too, is irritability and social isolation. As a result, it can be difficult seeing beyond a person’s autism to the underlying depression. In addition, many people on the autism spectrum have difficulty identifying and expressing how they feel. For these reasons, autism specialists have been developing and testing revised methods for diagnosing depression among children and teens on the autism spectrum. (Sterling 2015)

### Depression, Autism and Suicide

In 2012, researchers at Penn State College of Medicine reported the disturbing finding that 14 percent of children with autism age 16 or younger “sometimes” or “very often” contemplated or attempted suicide – a rate 28 times higher than for similarly aged children with typical development. (Mayes 2013) This increase in suicidal tendencies became significant after age 10, with signs of depression being the strongest predictor. Neither autism severity nor IQ altered the frequency. The authors urged healthcare providers to screen all children with autism for suicidal thoughts or attempts, in addition to raising awareness of the issue with parents.

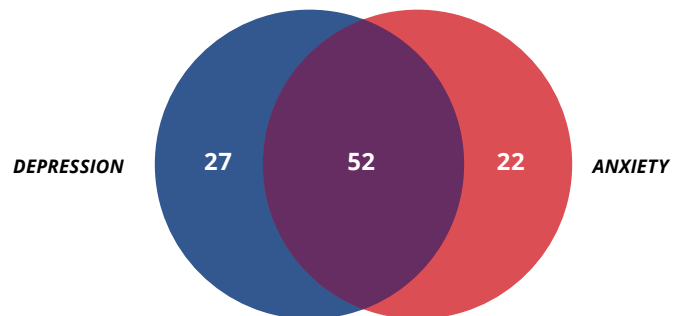


Figure 1: Autism, depression and anxiety

In 2016, Dutch psychologists found significant overlap in psychiatric issues among 101 young, middle-aged and older adults with autism. As shown in the diagram above, just over half experienced symptoms of both depression and anxiety disorder. Figure adapted from [Lever 2016](#) *J Autism Dev Disord*.

### Treating Depression in Those Affected by Autism

Cognitive-behavioral therapy has shown promise for treating depression in teens and adults who have autism. (Kuroda 2013) This work builds on a much larger body of research using an autism-modified version of cognitive behavioral therapy for extreme and chronic anxiety. (See “Anxiety and Autism” section above.)

There are no FDA-approved medications specifically for depression in patients who have autism, so psychiatrists typically prescribe those used in the general population. More research may be warranted given a 2011 study suggesting that patients with autism are more likely to experience antidepressant side effects. (Boyd 2011) The most common of these include sleepiness, agitation, increased irritability, restless leg syndrome and gastrointestinal problems.



## AUTISM AND SCHIZOPHRENIA

In the 1960s, psychiatrists referred to autism as a subtype of childhood schizophrenia. (DSM II 1968) By the 1990s, the field had made a clear distinction between the two conditions. (Rapoport 2009) Yet they share many biological similarities. Both appear to have roots in prenatal brain development. They share similar prenatal risk factors including maternal inflammation and infection as well as advanced parental age at the time of conception. (Patterson 2009, Menon 2011, Insel 2010) Research has also identified many common genetic risk factors. In other words, many of the same gene changes known to increase autism risk also increase the risk of schizophrenia. (Guilmatre 2009, McCarthy 2014)

In terms of symptoms, autism and schizophrenia both involve impairments in processing language and understanding other people's thoughts and feelings. Clear differences include schizophrenia's hallmark psychosis, which often involves hallucinations. In addition, autism's core symptoms typically emerge between ages 1 and 3 years; schizophrenia's in early adulthood.

Anecdotally, many clinicians have reported identifying autism at high rates in adults already diagnosed with schizophrenia and vice versa. However, investigations looking at how commonly these two conditions occur together vary widely in their findings. (Chisolm 2015) Taken together, the studies found schizophrenia in 4 to 35 percent of adults who have autism and found autism in 4 to 60 percent of those who have schizophrenia. By contrast, schizophrenia affects an estimated 1.1 percent of the general population, and autism affects an estimated 1.5 percent. (NIMH/Regier 1993, Baio 2014)

The authors of the above studies urge greater screening for autism among adults already diagnosed with schizophrenia as well as monitoring for schizophrenia symptoms in teens and adults diagnosed with autism.

Study	Participants	Co-occurrence
	<i>Schizophrenia diagnosed in those who have autism</i>	
Stahlberg 2004	129 adults with autism	14.8 percent
Billstedt 2005	120 adults with autism	7 percent
Mouridsen 2008(1)	89 adults diagnosed with "atypical autism"	34.8 percent
Mouridsen 2008(2)	118 adults previously diagnosed with "infantile autism"	6.6 percent
Eaves 2008	48 young adults with autism	0 percent
Hofvander 2009	122 adults with autism and normal intelligence	12 percent
Joshi 2010	217 children and teens with autism	20 percent
Bakken 2010	62 adults with autism and intellectual disability	25.1 percent
Lugnegard 2011	54 young adults with Asperger syndrome	3.7 percent
	<i>Autism diagnosed in those who have schizophrenia</i>	
Sporn 2004	75 children with childhood-onset schizophrenia	3.9 percent
Solomon 2011	16 people with a first episode of psychosis	19 percent
Hallerback 2012	46 adults with schizophrenic psychotic disorders	50 to 60 percent
Waris 2013	18 adolescents with early onset schizophrenia	44 percent
Davidson 2014	197 adults receiving early intervention for psychosis	3.6 percent

**Table 2: Autism and schizophrenia: How often do they occur together?**

Studies have varied widely in estimating how often autism occurs in those diagnosed with schizophrenia and how often schizophrenia occurs in those diagnosed with autism. Table adapted from [Chisolm 2015](#), *Neurosci Biobehav Rvw*.

## **AUTISM AND BIPOLAR DISORDER**

Bipolar disorder is a mood disorder once known as “manic depression.” People with bipolar disorder tend to alternate between a frenzied state known as mania and episodes of depression. While some people experience only the manic episodes, most alternate between these two states and can show extreme irritability.

Research shows that children and adults with autism are at increased risk for bipolar disorder. (Munesue 2008, Rosenberg 2011, Vannucchi 2014, Guinchat 2015) However, studies vary widely in estimating the prevalence of bipolar disorder among people with autism, ranging from 6 to 27 percent. By comparison, bipolar disorder affects around 4 percent of the general population. (Kessler 1994)

Some leading experts propose that bipolar disorder may be over-diagnosed in those who have autism, due to overlapping symptoms such as hyperactivity, irritability and disturbed sleep. (Witwer 2014) They caution mental health providers to tease apart the symptoms of true bipolar disorder from those of autism by looking at when the symptoms appeared and how long they lasted. For example, a child with autism may be consistently high-energy and socially intrusive through childhood. As such, her tendency to talk to strangers and make inappropriate comments are likely a consistent part of her autism, not symptoms of a manic mood swing.

### **Treatment of bipolar disorder in autism**

Some of the medications used to treat bipolar disorder can be problematic and even dangerous in someone who has difficulty recognizing and expressing feelings – as is common with autism. Lithium, for example, can in rare cases produce life-threatening toxicity. The warning signs include increasing thirst and shakiness. Anti-seizure, mood-stabilizing medications such as valproic acid may be a safer treatment for those with autism. (Witwer 2014) In addition, the antipsychotics risperidone and aripiprazole are both FDA-approved to treat irritability in children with autism, though both tend to produce significant weight gain and diabetes risk.

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## AUTISM AND PREMATURE DEATH

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**As a group, people who have autism are more than twice as likely to die prematurely. For some subgroups, the risk can be up to 10 times that of the general population.**

Among the most disheartening results of autism research is the persistent finding of premature mortality. There is an evidence base of more than 15 years of small studies suggesting premature mortality rates to be two to ten times higher than normal among various groups with autism. (Isager 1999, Mouridsen 2008, Gillberg 2010, Pickett 2011, Bilder 2013) Two new, large studies provide compelling evidence that, as a group, people with autism die younger – as much as 36 years younger – than those in the general population. (Hirvikoski 2016, Guan 2017)

This research also makes clear that autism alone is not driving the premature mortality. Rather, leading causes of death include many of the medical and mental health conditions described in this report – further highlighting the urgent need to recognize and address them.

The most recent study involved the analysis of more than 32 million U.S. death certificates, including those of 1,367 people with autism who died between 1999 and 2014. (Guan 2017) This study found that the average lifespan of someone with autism was half that of the general population – an average of 36 versus 72 years.

Accidental injury was the leading cause of death, at a rate three times higher than in the general population. Further analysis revealed that children with autism were 160 times more likely to drown than were children across the general population.

These serious findings bolster those of the other large study, out of Sweden. (Hirvikoski 2016) The investigators used Sweden's extensive national medical registry from 1997 through 2009 to compare age and cause of death among 27,000 people with autism to those of more than 2.5 million people unaffected by autism. The average age of death for people with autism was 54 years, compared to 70 years for those without autism.

Suicide and epilepsy ranked behind only birth defects as the most common causes of death, with rates eight times higher than the Swedish national average. However, the rate of premature death for those who had autism was higher across nearly all causes – including diseases of the circulatory, respiratory and digestive systems, as well as mental health and behavioral disorders. While overall premature mortality generally increased with intellectual disability, the suicide rate was significantly higher among those with normal to high intelligence. The researchers concluded that larger studies are needed to tease apart the contribution of intellectual disability from that of other autism-related issues.

**Suicide and epilepsy ranked behind only birth defects as the most common causes of death, with rates eight times higher than the national average.**

Attention must now shift to addressing the preventable and treatable issues and conditions that drive these disturbing statistics.

# RESOURCES

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## **Autism and epilepsy**

- \* *Having an Electroencephalogram (EEG): A Guide for Parents*
- \* *Having an Electroencephalogram (EEG): A Guide for Providers*
- \* What's happening to me: Understanding epilepsy and seizures: a visual story for children with autism
- \* What's happening to my friend: Understanding epilepsy and seizures: a visual story for the friends of children with autism
- \* Febrile seizures, epilepsy and autism: Your questions answered
- \* Study provides insights into autism and epilepsy
- \* Can hemp oil reduce seizures related to autism?

## **Autism and GI disorders**

- \* Autism Speaks office hours with Dr. Buie.  
A series of video interviews and follow-up Q&A's with autism-GI specialist Timothy Buie
- \* *The ATN/AIR-P Guide for Managing Constipation in Children: A Tool Kit for Parents*
- \* *Autism and Toilet Training: A Parent's Guide*

## **Autism and Disordered Sleep**

- \* *Strategies to Improve Sleep in Children with Autism Spectrum Disorder: A Parent's Guide*
- \* *Sleep Strategies for Teens with Autism Spectrum Disorder: A Guide for Parents*
- \* *Melatonin and Sleep Problems in ASD: A Guide for Parents*
- \* *The Sleep Tool Kit Quick Tips*
- \* Screen time versus sleep time in boys with autism
- \* Exploring the links between autism, sleep and behavior
- \* Q&A with the authors of *Solving Sleep Problems in Children with Autism*

## **Autism and restricted eating**

- \* *Exploring Feeding Behavior in Autism: A parent's guide*
- \* A model program for autism-related feeding disorders
- \* Seven ways to help a picky eater with autism
- \* Encouraging picky eaters with autism to try new foods
- \* Autism and mealtime: A therapist's top ten tips for success
- \* Autism & eating challenges: You are not alone!
- \* When medical issues complicate autism's eating challenges
- \* Will eating-disorder program help with autism-related food aversions?

## **Autism and overeating/obesity:**

- \* How can we stem weight gain related to behavioral medications for autism?
- \* Autism and weight gain: How to stop teen's progression from chubby to obese
- \* Autism and obesity: When exercise and healthy diet aren't enough
- \* Sports, exercise and the benefits of physical activity for individuals with autism

## **Autism and pica**

- \* *Pica and Autism: A Guide for Parents*
- \* *Pica and Autism: A Guide for Professionals*
- \* The pica-autism connection: Help and perspective
- \* Autism dilemma: Why is this teen chewing on clothes and swallowing objects?

## **Autism and ADHD**

- \* *Autism: Should my child take medicine for challenging behavior? An ATN/AIR-P tool kit*
- \* *Autism and Medication: Safe and Careful Use An ATN/AIR-P tool kit*
- \* ADHD symptoms checklist

## **Autism and anxiety**

- \* Recognizing anxiety in children and teens with autism
- \* Treating anxiety in children and teens with autism
- \* What behavioral therapies can help someone with autism and severe anxiety?
- \* Can exercise reduce anxiety in children with autism?
- \* Research yields tips for easing anxiety in nonverbal kids with autism
- \* Autism and anxiety: Parents seek help for extreme reaction to loud noise
- \* Easing separation anxiety in a 4-year-old with autism
- \* Brain imaging produces new insights into the autism-anxiety connection

## **Autism and depression**

- \* Understanding the complexity of depression in kids & teens with autism
- \* What's the connection between autism and depression?

## **Autism and premature mortality**

- \* Autism Speaks Wandering Resources
- \* Autism Speaks Swimming and Water Safety Scholarship Fund

*Clinical photos courtesy of the Autism Speaks Autism Treatment Network, Vanderbilt University Medical Center and Lurie Center for Autism.*



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**AUTISM AND HEALTH:  
A SPECIAL REPORT BY AUTISM SPEAKS**

Advances in Understanding and Treating the Health  
Conditions that Frequently Accompany Autism

 **AUTISM SPEAKS®** 2017

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**SUPPLEMENT:**

**What We Know about Autism  
In Facts and Figures 2017**

# What is autism?

## There is no one autism.

Autism, or autism spectrum disorder (ASD), refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication. We now know that there is not one autism but many subtypes, caused by a combination of genetic and environmental influences, and many accompanied by medical issues such as GI disorders, seizures, anxiety disorders and sleep disturbances.

autism affects an estimated **1 in 68** CHILDREN in the U.S.

**Autism is a lifelong condition.**



Boys are nearly **5x** more likely than girls to have autism.



On average, it costs around **\$60,000** a year to care for someone with autism.

The majority of these costs are in special education and lost parental income.

The cost of autism across a lifetime averages

**\$1.4 M to \$2.4 M**

with costs increasing with intellectual disability.



autism affects more than **70 Million** people worldwide

Nearly **1/2** of those with autism wander or bolt from **safety**



In 2015 researchers estimated the annual national cost for

caring for Americans with autism

to be **\$268 billion, rising to \$461 billion**

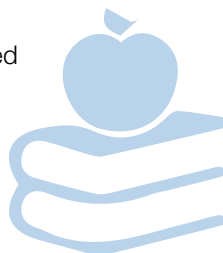
by 2025 in the absence of more-effective interventions and lifelong supports.

around **1/3** of people with autism are nonverbal

an estimated **50,000** teens

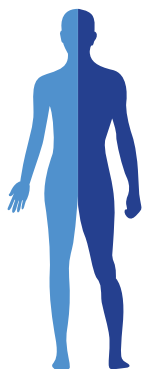
age out of **school-based**

autism services each year



only **1%** of autism research funding

went to the study of **life span issues**



autism can affect **the whole body**

drowning remains the leading **cause of** death for children with autism

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## PREVALENCE

autism affects **1 in 68** CHILDREN in the U.S.

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According to the Centers for Disease Control and Prevention (CDC), autism's prevalence in the U.S. increased from 1 in 150 in 2002 to 1 in 68 (1 in 42 boys and 1 in 189 girls) in 2010 and 2012.<sup>1</sup> The CDC attributes the increase largely to improvements in screening and diagnosis. Some studies indicate an even greater increase in prevalence over the last 20 years. As such, it remains unclear whether autism is truly increasing, and if so, by how much. This is why funding research to better understand autism is so important.

- A direct-screening study funded by Autism Speaks in South Korea found 1 in 38 school children affected by autism, most of them previously undiagnosed.<sup>2</sup> Similar direct-screening studies are now taking place in the United States to improve understanding of autism's true prevalence
- Autism affects all ethnic and socioeconomic groups.<sup>3,4</sup>
- Minority groups tend to be diagnosed later and less often.<sup>3,4</sup>

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## CAUSES

research indicates that **genetics ARE involved**

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Research indicates that genetics are involved in the vast majority of cases. At the same time, researchers are identifying non-genetic – or “environmental” – influences that can further increase risk, in those who are genetically predisposed to autism.<sup>5</sup> Understanding the risk factors that make a person more likely to develop autism will help us learn more about its biological causes.

- Children born to older parents are at a higher risk for having autism.<sup>6</sup>
- Parents who have a child with ASD have a 2 to 18 percent chance of having a second child who is also affected.<sup>7-12</sup>
- Studies have shown that among identical twins, if one child has autism, the other will be affected about 36 to 95 percent of the time. In non-identical twins, if one child has autism, then the other is affected about 31 percent of the time. This suggests that autism often results from a combination of genetic and other influences during prenatal development.<sup>7-10</sup>
- Over the last two decades, extensive research has asked whether there is any link between childhood vaccinations and autism. The results of this research are clear: Vaccines do not cause autism.<sup>13-17</sup>

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## SCREENING & DIAGNOSIS

autism can **generally be diagnosed** around age **2**

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In most cases, autism can be diagnosed around age 2 with a thorough behavioral assessment. However, the average age of diagnosis in the U.S. remains around 4 years of age.<sup>18</sup> Because earlier intervention can improve outcomes, Autism Speaks and the American Academy of Pediatrics urge universal screening for autism and other developmental disorders at 18 and 24 months, as a standard part of well-child checkups.

- Research suggests that early screening and close monitoring for autism is appropriate for children considered at high risk for the condition. This includes children born into families that already have a child diagnosed with autism, as well as children who experienced birth complications such as oxygen deprivation during labor and maternal pre-eclampsia during pregnancy.<sup>19</sup>
- Young children don't need a diagnosis of autism to begin receiving federally mandated services for related developmental issues such as speech delay and other communication and behavioral difficulties.

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## INTERVENTION & SUPPORT

early intervention **improves outcomes**

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Research has made clear that high-quality early intervention can improve learning, communication and social skills, as well as underlying brain development. It may also reduce the need for educational and behavioral support in grade school and beyond.<sup>20</sup>

- Currently, applied behavior analysis (ABA) and therapies based on its principles are the most researched and commonly used behavioral interventions for autism.<sup>21</sup>
- Many children affected by autism also benefit from other interventions such as speech and occupational therapy.<sup>22</sup>
- Far from rare, developmental regression, or loss of skills, such as language and social interests, affects around 1 in 5 children who will go on to be diagnosed with autism and typically occurs between ages 1 and 3.<sup>23</sup>

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## ASSOCIATED CHALLENGES

estimated **1/3** of people with autism are nonverbal

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An estimated one-third of people with autism are nonverbal, though many can communicate nonverbally to some degree, sometimes with the help of visual supports and/or assisted-communication devices.<sup>24</sup>

- Nearly a third of children with autism (32 percent) also have intellectual disability (IQ of 70 or less) with significant challenges in daily function). Another 24 percent score in the borderline range on measures of intellectual ability (IQ 71-85).<sup>25</sup>
- Nearly half of those with autism wander or bolt from safety.<sup>26</sup>
- Nearly two-thirds of children with autism between the ages of 6 and 15 have been bullied.<sup>27</sup>
- Nearly 28 percent of 8-year-olds with ASD have self-injurious behaviors. Head banging, arm biting and skin scratching are among the most common.<sup>28</sup>
- Drowning remains a leading cause of death for children with autism and accounts for approximately 90 percent of deaths associated with wandering or bolting by those age 14 and younger.<sup>29</sup>

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## ASSOCIATED MEDICAL & MENTAL HEALTH CONDITIONS

autism can affect **the whole body**

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Autism can affect the whole body.<sup>30</sup> Seizures, disturbed sleep and painful gastrointestinal disorders are some of the medical conditions commonly associated with autism. Autism is also frequently accompanied by mental health conditions including anxiety, depression, and attention deficit and hyperactivity disorder (ADHD).

- ADHD affects an estimated 30 to 61 percent of children with autism.<sup>31-34</sup>
- Research suggest that more than half of children with autism – and possibly as many as four in five – have one or more chronic sleep problems.<sup>35-37</sup>
- Anxiety disorders affect an estimated 11 to 40 percent of children and teens on the autism spectrum.<sup>38-40</sup>
- Children with autism are nearly eight times more likely to suffer from one or more chronic GI problems than are other children.<sup>41</sup> As many as one-third of people with autism have epilepsy (seizure disorder).<sup>42</sup>
- Studies suggest that schizophrenia affects between 4 and 35 percent of adults with autism. By contrast, schizophrenia affects an estimated 1.1 percent of the general population.<sup>43</sup>



- Autism-associated health problems extend across the life span – from young children to senior citizens.
- Nearly a third (32 percent) of 2 to 5 year olds with autism are overweight and 16 percent are obese. By contrast, less than a quarter (23 percent) of 2 to 5 year olds in the general population are overweight and only 10 percent are medically obese.<sup>44</sup>
- Research shows that the likelihood of being overweight or obese increases with the number of behavioral medicines a child is taking.<sup>44</sup>
- Significant weight gain is a common side effect of behavior-calming medications such as risperidone and aripiprazole, the only FDA-approved medications for autism-associated agitation and irritability.<sup>44</sup>

## DEMANDS ON CAREGIVERS & FAMILIES

autism costs an estimated  
**\$60,000** a year

On average, autism costs an estimated \$60,000 a year through childhood, with the bulk of the costs in special services and lost wages related to increased demands on one or both parents. Costs increase with the occurrence of intellectual disability.<sup>45</sup>

- Mothers of children with ASD, who tend to serve as the child's case manager and advocate, are less likely to work outside the home. On average, they work fewer hours per week and earn 56 percent less than mothers of children with no health limitations and 35 percent less than mothers of children with other disabilities or disorders.<sup>46</sup>

## AUTISM IN ADULTHOOD

an estimated **50,000** teens age out of school-based autism services each year

Over the next decade, an estimated 500,000 teens (50,000 each year) will enter adulthood and age out of school-based autism services.<sup>47</sup>

- Teens with autism receive healthcare transition services half as often as those with other special healthcare needs. Young people whose autism is coupled with associated medical problems are even less likely to receive transition support.<sup>48</sup>
- Many young adults with autism do not receive any healthcare for years after they stop seeing a pediatrician.<sup>48</sup>

- More than half of young adults with autism remain unemployed and unenrolled in higher education in the two years after high school. This is a lower rate than that of young adults in other disability categories, including learning disabilities, intellectual disability or speech-language impairment.<sup>49</sup>
- Of the nearly 18,000 people with autism who used state-funded vocational rehabilitation programs in 2014, only 60 percent left the program with a job. Of these, 80 percent worked part-time at a median weekly rate of \$160, putting them well below the poverty level.<sup>50</sup>
- Nearly half of 25-year-olds with autism have never held a paying job.<sup>49</sup>
- Research demonstrates that job activities that encourage independence reduce autism symptoms and increase daily living skills.<sup>51</sup>
- The cost of caring for an adult with autism averaged more than \$26,500 in the 2012-2013 fiscal year, largely for services such as community support, employment support, day care programs, supportive housing and/or in-home respite care.<sup>52</sup>

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## ECONOMIC COSTS

autism's economic **cost in the U.S.**

was estimated at **\$268 Billion** in 2015

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A recent study estimated the cost of caring for Americans with autism had reached \$268 billion in 2015 and would rise to \$461 billion by 2025 in the absence of more-effective interventions and support across the life span.<sup>53</sup>

- The majority of autism's costs in the U.S. are for adult services – an estimated \$175 to \$196 billion a year, compared to \$61 to \$66 billion a year for children.<sup>45</sup>
- Average medical costs for children and adolescents with ASD exceeded those for children without autism by \$4,110 to \$6,200 per year. On average, medical expenditures for children and adolescents with ASD were 4.1 to 6.2 times greater than for those without autism. Differences in median expenditures ranged from \$2,240 to \$3,360 per year with median expenditures 8.4 to 9.5 times greater.<sup>54</sup>
- In 2005, the average annual medical costs for Medicaid-enrolled children with ASD were \$10,709 per child, around six times higher than costs for children without ASD (\$1,812).<sup>55</sup>
- A 2014 study on the economic costs of autism in the United States and the United Kingdom found ASD to be the fourth most expensive medical condition across the two countries, beyond only trauma, cancer and cardiovascular disease.<sup>45</sup>
- Passage of the 2014 Achieving a Better Life Experience (ABLE) Act allows tax-preferred savings accounts for people with disabilities, including autism, to be established by states.
- Passage of autism insurance legislation in 45 states is providing access to medical treatment and therapies.<sup>56</sup>

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## RESEARCH FUNDING

only **1%** of autism research funding  
was spent on **life span issues**

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While autism affects an estimated 2 million people in the U.S.<sup>25,57,58</sup> across their life spans, research funding remains significantly lower than that for many less-prevalent disorders and disabilities.

- In 2017, The National Institutes of Health estimates that federal funding for autism research will total \$216 million, as it did in 2016. This is up from \$192 million in 2012. This contrasts with an estimated \$753 million for dementia research in 2016 and 2017 and \$832 million in 2016 and 2017 for brain injury (acquired cognitive impairment).<sup>59</sup>
- In 2012, only 1 percent of autism research funding went to studying life span issues such as supports to improve success in employment and community integration.<sup>60</sup>

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