Explore and appreciate the uniqueness of ASD

Focusing on respect, empathy and inclusion

Currently, it is estimated that, worldwide, about **1 in 100 children** has autism.[1] **An autism spectrum disorder (ASD)** diagnosis can trigger tough questions and difficult emotions. There is so much to learn, it can be hard to know where to start. Myths and misconceptions surrounding the topic of autism and ASD often cloud the path to proper diagnosis and treatment.

Whether you're living with autism, parenting a child with autism, or both, separating fact from fiction can make a world of difference in your experience. It's important to keep in mind that every child/person on the spectrum is unique and people with autism do not all think or act exactly the same.

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Defining ASD

Some people use the word "neurodiversity" to describe the diverse ways people's brains can work, which can include ASD, as well as other conditions (attention deficit hyperactivity disorder or learning disabilities).

ASD affects how a person interacts with the world. It often makes it difficult for the person to communicate with or understand other people. Having ASD may result in difficulties with socializing, communicating and behavior.

Symptoms can change over time and a person's response to therapy can vary. The intensity of the spectrum details points towards specific types, also helping dictate the appropriate treatment plan.

Severity is classified by **three levels**, indicating how much support a person requires in each of these areas:

Level 1
Requires support

Level 2
Requires substantial support

Level 3
Requires very substantial support

ASD is classified according to whether it co-exists with a language impairment or intellectual disability and by the level of severity and degree of support needed for its two core symptoms. For one to be considered on the autism "spectrum", a person may demonstrate signs and symptoms within two specific areas:

Social interaction and social communication

Children with autism have trouble relating to other people. This may include trouble reading another person's facial expressions, avoiding eye contact, not wanting to be touched or not wanting to play or interact with other people. Children with autism often take much longer than other children to learn to speak, while others never learn to speak. They also often do not use other forms of communication, like hand gestures, facial expressions and different tones of voice.

Limited interests and repetitive behaviors

People with autism tend to show intense interest in specific things. They also often repeat the same behaviors. This might include being solely focused on things that spin or shine while ignoring other things, preoccupation with a specific topic or subject, adhering to rituals and getting upset if a routine changes, reciting "scripts" from a movie, TV show, or conversation from the past, repetition of physical motions like flapping the hands, rocking, or spinning.

Debunking myths

A common misconception about people diagnosed with ASD is that it impacts their intellect. Cognitive skills of individuals with ASD are usually uneven, regardless of the general level of intelligence. Performance on tasks that require rote, mechanical, visuospatial, or perceptual processes is usually better than on tasks that require higher-order conceptual processes, reasoning, interpretation, integration, or abstraction. Other common beliefs surrounding ASD include:

✖ Autism is a disease

Autism is not an illness at all, it's just the way your brain works. ASD is a neurodevelopmental disorder, which means something about brain development and function is different from that of a "typical" child. But different doesn't mean wrong. And autistic people aren't all different in the same ways.[3]

✖ Autism is a mental illness

Health care professionals use the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) to diagnose both neurodevelopmental disorders and mental health conditions. But most mental illnesses develop later in life (ex: schizophrenia and alcohol use disorder). ASD, on the other hand, is a condition you're born with. Another distinction lies in the fact that mental illnesses have clear medical treatments available, but there is no medicine that can treat autism.[3]

✖ There is an autism epidemic

While it is true autism is becoming more common as a diagnosis, it's primarily because there is greater recognition of the disorder, increased medical expertise in the field, changes to diagnostic groupings and rules identifying more than one condition (ex: ASD and attention-deficit/hyperactivity disorder- ADHD).[3]

✖ Childhood vaccines cause autism

A past publication claiming the measles, mumps and rubella (MMR) vaccine caused autism has been disproved. There is no scientific support for the idea that vaccines cause autism.[3]

✖ Only boys can be autistic

The most recent data from the *U.S. Centers for Disease Control and Prevention* (CDC) shows that autism isn't a sex-specific condition, though boys are more likely to have ASD than girls. Their research suggests that about 4% of boys have ASD, while the number of autistic girls is lower, at 1%.[4]

Latest diagnostic criteria include five benchmarks:[2]

Criterion A: social communication deficits – (1) Deficits in social-emotional reciprocity (normal back-and-forth conversation, sharing of interests, emotions, initiating or responding to social interactions); (2) Deficits in non-verbal communicative behaviors used for social interaction (poorly integrated verbal and non-verbal communication, abnormalities in eye contact and body language, deficits in understanding and use of gestures, lack of facial expressions and non-verbal communication); and (3) Deficits in developing, maintaining and understanding relationships (difficulties adjusting behavior to suit various social contexts, in sharing imaginative play or in making friends and absence of interest in peers).

Criterion B: fixated interests and repetitive behaviors – (1) Stereotyped or repetitive motor movements, use of objects, or speech; (2) Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or non-verbal behavior; (3) Highly restricted, fixated interests that are abnormal in intensity or focus; (4) Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment.

Criterion C: symptoms existing in early childhood; however, they may not fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life.

Criterion D: symptoms impairing functioning – clinically significant impairment in social, occupational or other major areas of current functioning.

Criterion E: impairments not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

To diagnose ASD, all five criteria must be met.

Early indications

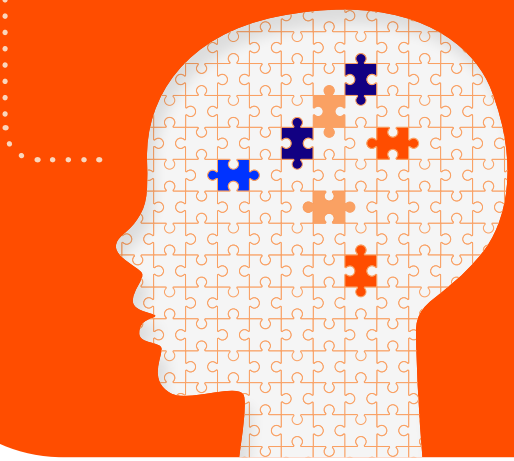
Social communication and interaction skills can be challenging for people with ASD. And people with ASD have behaviors or interests that may seem unusual. These behaviors or interests set ASD apart from conditions defined solely by social communication and interaction difficulties.

In the first two years of life, ASD commonly presents when the primary care provider notices speech/language delays. They may also notice failure to make eye contact and limited interest in socializing. Approximately 1/4 to 1/3 of children with ASD achieve early language milestones but have regression or plateau of language, communication, and/or social skills between 15 to 24 months of age.[6] The regression of skills can be gradual or sudden and may occur in the context of preexisting developmental delays or atypical development.

Lack of interest in socializing, absent or delayed speech/language skills, marked resistance to change, and restricted interests are common features for older toddlers and preschoolers. Children with less severe characteristics may initially present in kindergarten or later. They may present with behavior disturbances (disruptive behaviors, difficulty following instructions because of over-focus on preferred interests) or with symptoms of a co-existent condition such as attention deficit hyperactivity disorder or anxiety. Atypical social and language development may only become obvious after a more intense scrutiny of the child's overall development.

Examples of social communication and interaction and behavioral characteristics related to ASD can include:[5]

- Avoids or does not keep eye contact
- Does not respond to name by nine months of age
- Uses few or no gestures by 12 months of age (ex: does not wave goodbye)
- Repeats words or phrases over and over (called echolalia)
- Gets upset by minor changes and has obsessive interests
- Flaps hands, rocks body, or spins self in circles
- Has unusual reactions to the way things sound, smell, taste, look, or feel



Proactive interventions

"An ounce of prevention is worth a pound of cure."[7] When it comes to addressing ASD, it's vital to seek help if needed rather than rely on assumptions or waiting for "the right time." There are essential milestones children should achieve at appropriate stages (CDC's Developmental Milestones), and if any inconsistency or delay is observed, it is crucial to seek professional help. Professional intervention may trigger further assessment and initiate the most key step within this whole journey: receiving a proper diagnosis, the biggest and best opportunity for accessing ASD resources and services.

If your child receives a formal diagnosis of ASD, it may seem that your entire world has been turned upside down. But it sets the wheels in motion towards initiating treatment as early as possible. Early intervention for children with autism refers to the process of identifying and addressing developmental domains — including social, communication and behavioral skills. The age range for early intervention is most effective when started as early as possible, ideally before the age of three.

Early diagnosis and early intensive treatment have the potential to affect outcome, particularly with respect to behavior, functional skills and communication. Although there is no cure, early intervention can help enhance the child's social and communication skills, assist with learning appropriate behaviors, improve family dynamics and increase their potential for academic success.[8] In some instances symptoms can decrease over time and in a small minority be minimized to the extent that they no longer cause disability.

Challenges

ASD frequently co-occurs with other neurodevelopmental conditions or symptoms of neurodevelopmental conditions. Symptoms of comorbid conditions (disruptive behaviors) may be exacerbated by negative social experiences and increased awareness of differences and social difficulties (ex: isolation, marginalization, and bullying).[9]

Children with ASD may have or develop comorbid conditions, including:[10]

- Epilepsy
- Developmental and mental health comorbidities (hyperactivity, anxiety, depression, behavioral regulation)
- Sleep problems (late onset, frequent waking, restlessness), which may affect daytime function
- Gastrointestinal, feeding, and nutrition problems (constipation, restricted diet, pica—eating non-food items)

Primary care providers should monitor for both medical and mental health concerns and provide appropriate treatment or referral as indicated. When diagnostic studies are necessary, it is important to determine whether the child can participate and how to best prepare him or her for the test. Children with ASD are substantially underserved in the health care setting.[11]

Support system

Parents of children with ASD require a vast amount of support from their family and friends. Once the family understands that the scenario is projected for decades, several shifts may happen in the family dynamics – moving to other locations where access to care might be better; changing jobs; quitting activities; struggling financially; and many other hidden details that are not on the surface. Parents with kids on the spectrum are overwhelmed, and although they may try to disconnect, even for an ephemeral moment, the radar is always "on." Going to a simple play date (assuming the child is invited at any moment) can be as tricky as planning a trip around the world – it requires lots of details, and brings restlessness and concerns front and center. "How will my kid behave?", "Is it going to be OK?", "Shall I just wait in the car, just in case?"

A primary care provider is key to the care and treatment of an individual with ASD. In some instances, he/she may be the first one to raise concerns about ASD or with whom the family discusses concerns about ASD. The primary care provider may be responsible for early identification of autism spectrum disorder (ASD); routine health maintenance, preventive care and care coordination for children with ASD; and provider of support, guidance, and advocacy for families of children with ASD.

Many families require ongoing education and support to facilitate enrollment in appropriate autism therapy programs. The primary care provider can help the family to understand the essential components of the treatment program and which types of programs might be most beneficial.

Lastly, the primary care provider can assist families in understanding special education laws that pertain to children with ASD, educate families about their rights, and help them navigate the individualized education program (IEP) process. Primary care providers must know which local or national agencies and organizations provide autism interventions and/or support so that they can guide the family appropriately.

Dr. Lior Baruch, Medical Principal, International Health, Cigna Healthcare℠

A parent's journey – from one of our own

When your very first child is on its way, your dreams are bigger than the entire world. Nothing is impossible and reality is just a vision. By age one, our oldest son, born as we were entering the COVID-19 pandemic, didn't achieve specific milestones determined for normal development. By then, some comparisons start to happen, but being an overprotective parent (as anyone should be), you blind yourself with pride, and postpone any harsh and unknown move. Was it naive? Was it wrong? Was it just trying to do the best given the circumstances? We will never know but live in peace with it.

By 18 months, other milestones were not achieved, raising several red flags. It was time (a bit delayed) to seek professional help. By the age of two, following a detailed assessment, our son received a formal diagnosis of autism spectrum disorder (ASD) – non-verbal, no eye contact, no social interaction, and with very picky preferences. Food texture was a problem. Anything out of the normal routine, irrespective of the day of the week, was a problem. And complete lack of communication was a big problem.

By then, all your selfish dreams are buried six feet under, and new dreams are born, every single day. This is where you understand that love is the single and unique thing parents are supposed to give to their children. And when you think it's too much, you should rethink it, because it's never enough. That love is a pillar to provide support, to learn the unknown and educate yourself, and to seek more and more, always, towards your child's happiness and independence.

Things that have worked very well: asking for help, speech therapy (lots of it), occupational therapy (lots of it), making your child your life priority (there's no other plan), and supporting each other within our household. **Not every day is a good day, but tomorrow is always different, and it's an opportunity to make it better.** It could be another failure as a bad day, but there's always another tomorrow.

Things that have not worked well: ABA therapy. Our son was non-verbal. Behavior adjustments were not required to improve his communication skills by then. It was a positive mistake that we are proud to have made – we just tried everything possible, and with that, we have learned what worked versus what didn't. ABA therapy goals are to see an increase in positive behaviors and a decrease in negative behaviors. Children can also learn new skills and improve their social interactions. But it was not the silver bullet we expected or what we needed at the time. It doesn't mean he won't need it in the future. It was just bad timing, for his specific scenario.

Fast forward: our son just turned five. He's making lots of eye contact, especially when he wants something very much (ice cream!). He can be as silly as any other kid, and it fills our hearts with joy. He is relatively verbal and is making improvements every single day. He is extremely intelligent. He loves his dog, is very affectionate, and will not spare you from a hug if he genuinely likes you. Car racing and other joyous activities are replacing his love of dinosaurs, while book browsing and music remain a priority, as they have been since he was very young. The difference today is that he enjoys listening to storytelling and is trying to read on his own.

My selfish dream today: to have a full conversation with my son, about anything in the world, and learn about his wishes, dreams and ideas.

Treatment

Treatment for autism spectrum disorder (ASD) focuses on behavioral and educational interventions that target the core symptoms of ASD (deficits in social communication/interaction and restricted, repetitive patterns of behavior, interests and activities). Pharmacologic interventions may be used to address medical or psychiatric comorbidities or provide symptom control but do not treat the core deficits. In addition, many families seek complementary or alternative therapies.

Specific treatment programs should be individualized according to the child's functioning and needs. At the core of all treatments, the focus should include respect, empathy and inclusion. Treatment programs should be monitored to ensure appropriate response to therapy. All programs should be reviewed and modified as the child's needs change over time.

The importance of early intensive behavioral and educational interventions in improving outcomes for children with ASD is well documented. Most of the research has focused on early-preschool and school-age children.[12] There is less robust information about the efficacy of treatment programs in children younger than two years or in adolescents. No single therapy has proven to be most effective. However, certain therapies have more data to support their efficacy than others.

Applied behavior analysis, or ABA therapy, is based on the idea of rewarding certain behaviors to encourage children to repeat and increase them. Behaviors not reinforced will decrease over time and gradually disappear. ABA may help autistic people improve social interactions, learn new skills, increase positive behaviors and reduce challenging behavior.

ABA therapy has garnered significant attention and recognition for its effectiveness in treating autism spectrum disorder. In fact, studies have shown that ABA therapy has an **over 89% success rate** in treating autism spectrum disorder in children.[13] Studies show that ABA significantly affects socialization, communication and expressive language. The duration of ABA therapy can vary depending on the specific needs and progress of each individual. Research has demonstrated that, on average, 66% of children referred for ABA therapy initiate therapy and remain in services for 12 months. However, less than half (46%) continue therapy for 24 months.[14]

ABA Therapy has an

89%+ success rate in treating ASD in children

Treatment goals

ASD is a chronic condition requiring a comprehensive treatment approach. Individuals with ASD have varying degrees of impairment in social and behavioral function. Management must be individualized according to the child's age and specific needs. Management of ASD requires a multidisciplinary approach that makes use of the child's strengths to address his or her weaknesses.

Current treatments for ASD seek to reduce symptoms that interfere with daily functioning and quality of life. Treatments can be administered in education, health, community, or home settings, or a combination of settings. Individuals with ASD maturing into adulthood can make use of additional services to help improve health and daily functioning and facilitate social and community engagement.[15]

Approaches to treatment are diverse and varied. Many types of treatments are available and generally can be broken down into the following categories, although some methods involve more than one approach: behavioral, developmental, educational, social-relational, pharmacological, psychological, complementary, and alternative.[5]

The overarching goals of treatment are to maximize functioning, move the child toward independence, and improve the quality of life. Specific goals address the core deficits of ASD and seek to:[16]

- ✔ **Increase independence skills**
- ✔ **Develop self-regulation skills**
- ✔ **Improve non-verbal communication**

By setting specific, measurable, attainable, realistic/relevant and timely (SMART) goals for students with autism, educators, therapists and parents can provide targeted support and measure progress effectively. These goals highlight the importance of promoting the growth and development of students with autism.

Key areas of development for students with autism include:[16]

- **Social Skills:** Promoting social interaction such as turn-taking, sharing, making eye contact, understanding emotions, and using appropriate social greetings
- **Emotional Regulation:** Strategies for identifying and expressing emotions, self-calming techniques, and developing coping skills to navigate challenging situations
- **Independent Living Skills:** Developing skills such as personal hygiene, meal preparation, money management, time management and transportation skills

Looking ahead

It is difficult to predict outcomes for children with ASD, especially for children younger than three years. Some children will retain the diagnosis despite improvement in core symptoms while others, particularly those with milder symptoms, may no longer meet diagnostic criteria for ASD. Typically, children who no longer meet criteria for ASD demonstrate some residual social, language, and behavioral symptoms and may meet criteria for language, attentional, and/or mood disorders.

Early intervention, accurate diagnosis and appropriate treatment can help optimize results for individuals with ASD. Factors associated with positive treatment outcomes include higher cognitive abilities, movement toward peer inclusion and a reduction of ASD symptoms. For many parents/caregivers and primary care providers, the optimum goals of intervention and treatment remain focused on ensuring **respect, empathy and inclusion** for their child.

Global Health Benefits

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