# What Is Autism?

#### By Elisabeth Herschbach



## TEEN DISORDERS



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## CHAPTER ONE

## What Is Autism?

born in 1947. Just four years earlier, Austrian American psychiatrist Leo Kanner became the first to identify the condition as a distinct syndrome. In a 1943 article, the Johns Hopkins University psychiatrist described eleven young patients with unusual symptoms. The children showed "an inability to relate themselves in the ordinary way to people and situations," he wrote.<sup>4</sup> They seemed disengaged from their surroundings, absorbed in a world of their own. They moved in repetitive ways: banging their heads, spinning, rocking, flapping. Some of the children didn't speak. Others simply repeated certain words or phrases over and over. Because they appeared so withdrawn into themselves, Kanner described these children as "autistic" from the Greek word *autos*, which means "self."<sup>5</sup>

Kanner introduced autism to the medical world. It took almost another four decades, however, for the condition to be officially recognized by mainstream psychiatry. In 1980, autism

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Leo Kanner identified autism in the 1940s. His ideas eventually developed into a recognized, diagnosable condition.

was included for the first time as its own diagnostic category in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*)—considered the authoritative guide for diagnosing behavioral and mental disorders. Since then, the thinking about autism has continued to evolve. As research and clinical practice expand our understanding, health professionals continue to revise and redefine the standards for diagnosis in updated versions of the *DSM*. In 2020, the criteria used to diagnose autism were based on the fifth edition (*DSM-5*), published in 2013.

## **DEFINING AUTISM**

Autism is considered a developmental disorder because it involves delays and impairments in typical developmental skills, beginning in early childhood. It is characterized as pervasive, meaning widespread, because it affects so many different behaviors and functions, with lifelong effects. And it is classified as a syndrome, as opposed to an illness, because it is defined in terms of a cluster of signs and symptoms rather than a single, specific underlying biological process.

The *DSM-5* groups these symptoms into two main areas. The first involves problems with social communication and interaction. These can take many different forms, ranging from impaired verbal and nonverbal communication skills to difficulties interpreting social contexts and relating to others. Like Kanner's young patients, autistic children may have trouble interacting with peers or family members. They may fail to make eye contact or to respond when addressed by name. They may struggle

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to interpret body language or other social cues. John Elder Robison, who was diagnosed with autism as an adult, describes spending hours memorizing facial expressions so that he could

learn to replicate them. "I didn't even understand what looking someone in the eye meant," he writes in his autobiography, *Look Me in the Eye*. "And yet I felt ashamed, because people expected me to do it."<sup>6</sup>

"I didn't even understand what looking someone in the eye meant. And yet I felt ashamed, because people expected me to do it."<sup>6</sup>

-John Elder Robison, who was diagnosed with autism as an adult, in his autobiography, Look Me in the Eye

The second main area involves restricted, repetitive patterns of behavior, including ways of moving, speaking, thinking, and engaging with the world. For example, people with autism may have a tendency to rock back and forth, spin in circles, or flap their hands—repetitive motor movements commonly known as stimming. Children may interact with objects in unusual ways, such as lining up toys or flipping and spinning objects instead of engaging in more typical play. They may verbally repeat certain phrases over and over—a phenomenon known as echolalia. Many people with autism demonstrate rigid thinking patterns or inflexible adherence to routines, struggling with changes and transitions. Restricted interests are also common, such as the tendency to develop an intense, all-consuming interest in a narrow, very specific topic or activity.



Those with autism may sometimes try to block out the outside world. They may feel overstimulated and overwhelmed.

Equally common are sensory processing problems, which the *DSM-5* also classifies under the category of restricted, repetitive patterns of behavior. For example, many people with autism are oversensitive to certain sounds, feelings, tastes, textures, smells, or visual sensations. In her first-person account of autism, *Thinking in Pictures*, Temple Grandin describes how her sensory problems intersected with other symptoms of autism during her childhood. Overwhelmed by too many environmental stimuli, sometimes she would break down into a temper tantrum. Other times, she would retreat into herself to block out the confusion of the world around her. "I would often space out and become hypnotized. I could sit for hours on the beach watching sand dribbling through my fingers," she writes. "I went into a trance which cut me off from the sights and sounds around me. Rocking and spinning were other ways to shut out the world when I became overloaded with too much noise."<sup>7</sup>

## **AN AUTISM EPIDEMIC?**

When Temple Grandin was diagnosed with autism, the condition was considered very rare. Today, autism is considered one of the most common developmental disorders affecting children.

Current estimates of the prevalence of autism vary. According to the Centers for Disease Control and Prevention (CDC), one out of every fifty-nine children in the United States met the criteria for an autism diagnosis in 2018. The National Survey of Children's Health (NSCH) put the rate even higher, at one in forty children. That equates to some 1.5 million children nationwide.

## Gender Gap

According to the CDC, boys are four times more likely to be diagnosed with autism than girls. In 2018, the CDC estimated that approximately 1 in 37 boys had autism. For girls, the rate was 1 in 151. Some researchers speculate that this may be tied to brain differences between males and females. But others think that many girls on the spectrum are simply getting missed. "The model that we have for a classic autism diagnosis has really turned out to be a male model," clinical neuropsychologist Susan F. Epstein says.<sup>1</sup> In girls, the symptoms can manifest somewhat differently. For example, girls tend to manifest fewer repetitive behaviors and a higher level of social engagement. Because they don't fit the stereotype, their symptoms can be mistaken for something else. Page, a mother to two autistic children, says that's what happened in her daughter's case. While her son was diagnosed at sixteen months. her daughter was not diagnosed until about five years of age. "We got a lot of different random little diagnoses." she recalls. "They kept saying, 'Oh, you have a girl. It's not autism.""2

1. Quoted in Beth Arky, "Why Many Autistic Girls Are Overlooked," Child Mind Institute, n.d. www.childmind.org.

2. Quoted in Maia Szalavitz, "Autism—It's Different in Girls," Scientific American, March 1, 2016. www.scientificamerican.com.

Though the estimates differ, the consensus is that rates of autism diagnosis have risen sharply in the past few decades. In 1966, researchers estimated that roughly 1 in 2,500 American children had an autism diagnosis. By 2000, the prevalence rate had reached 1 in 150 children, according to the CDC. And by 2014, the estimate had more than doubled to a rate of 1 in 68. Between 2012 and 2014 alone, the CDC reported a 30 percent increase in prevalence. These numbers mirror trends around the alobe, where rates of autism are estimated to have risen significantly worldwide since the 1990s.

## AUTISM PREVALENCE

In 2018, the Autism and Developmental Disabilities Monitoring (ADDM) network released the results of a study on autism prevalence among eight-year-olds. It found higher rates of autism among boys compared to girls. Overall, it found that approximately one in fifty-nine children had been diagnosed with autism.



"Autism Spectrum Disorder," CDC, April 2018. nimh.nih.gov.

## Source Notes

#### Introduction: Struggling to Fit In

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2. Grandin, Thinking in Pictures, p. 17.

3. Quoted in Oliver Sacks, "An Anthropologist on Mars," *New Yorker*, December 27, 1993. www.newyorker.com.

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6. Quoted in Andrew Solomon, *Far from the Tree: Parents, Children, and the Search for Identity.* New York: Scribner, 2012, p. 233.

7. Grandin, Thinking in Pictures, p. 34.

8. Quoted in Emily Willingham, "Spike in Autism Numbers Might Reflect Rise in Awareness," *Scientific American*, April 1, 2014. www.scientificamerican.com.

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10. Solomon, Far from the Tree, p. 245.

11. Ido Kedar, "I Was Born Unable to Speak, and a Disputed Treatment Saved Me," *Wall Street Journal*, September 23, 2018. www.wsj.com.

12. Lorna Selfe, *Autism Spectrum Disorder: All That Matters.* New York: McGraw-Hill Education, 2014, p. 10.

## For Further Research

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