

EXPLAINED

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The scene is the neighbourhood park. A group of 2- or 3-year-old children are playing together, with their mothers watching. One toddler, Arun, is off to the side. He is looking up at the trees, squinting at the light. His mother calls several times but he does not respond. He doesn't seem interested in the other children or their toys. He holds a little car tightly in his hand. Sometimes he says a few words, but they have no connection to what the other children are talking about. Arun's mother has been worried but her family has reassured her that boys speak late.

Parents' concerns about children like Arun are often dismissed by family members and professionals who don't know the early signs of autism. Early identification is important because it leads to early intervention that can change the life of a child with autism.

Autism is a neurodevelopmental condition, not a disease. This means there is a difference in how the brains of autistic children are wired, which becomes evident as the child develops. Autism is not uncommon: recent statistics from the U.S. show a prevalence of 1 in 44, while our own Indian data suggests 1 in 100.

The diagnosis of autism is often made by a paediatrician or a psychiatrist with experience in seeing children with autism. We don't fully understand the causes of autism but clearly there is a strong genetic component. If there is one child with autism in the family, there is an increased chance of the sibling being on the autism spectrum as well.

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Autism is characterised by differences in three key areas. The first two are communication and social interaction, which often go together. Children with autism may struggle to communicate with others who are not like them. For example, children with autism may not use pointing, gestures or words to communicate, and instead may pull their parents towards what they need. They may use words out of context and sometimes repeat words.

The difference in how autistic children interact socially becomes evident when we watch them play. Games that require turn taking, like hide and seek, are often not intuitive for them. Little Arun in the park plays with cars by himself, just rolling them back and forth for hours. He can also do a 50-piece puzzle in a few minutes. Most children begin pretend play, like pretending to

feed a doll, between one and two years of age. But Arun, like many other autistic children, prefers blocks, puzzles or mechanical toys over pretend play.

The other main feature that characterises children with autism is that they have a focused area of interest or a repetitive activity they enjoy. For example, a child may focus on cars, aeroplanes or dinosaurs to the exclusion of all other activities or topics. When playing with toys or objects, they may choose to line them up or stack them instead of playing a pretend game with them. They may also have physically repetitive movements of the body like hand flapping or spinning, particularly when they are excited or anxious.

We now know that autism occurs as a spectrum: every child is different and every child looks different as they grow older. The ratio of boys to girls is believed to be 4:1 but people are now questioning this because girls with autism are probably underdiagnosed.

Kanika, a 12-year-old girl in class VI, is doing well academically but is very quiet in class. She often does not understand the gossip her classmates share, or the jokes that the other girls make, but pretends to laugh and be interested. Her passion is a manga comic character that she draws repetitively and skillfully. She is intensely anxious in social settings. Kanika has the same social and communication challenges as well as the single-minded interest in one topic that characterises autism, but she is unlikely to get a diagnosis.

Her differences are not 'typical' of what is described as autism in boys. A skilled professional can identify Kanika's autism and support her, and her family, through her challenges at school and home.

Like all of us, children with autism have strengths. They are often visual learners, good with puzzles, blocks, visual memory, and visual problem-solving, like the use of technology and visual games like chess. They have a strong sense of justice and honesty, which often means they have a harder time understanding some social rules and norms. Contrary to popular belief, three-fourths of autistic individuals have normal intelligence.

Since autism is not a disease, it is not helpful to speak of a cure. Supporting children with autism involves educating them and people in their environment. There are several scientifically proven techniques and programs to teach children with autism. Many of the programs involve coaching parents and teachers on how to connect and communicate with their child.

For example, Arun's family can be taught to observe him, note what he is interested in (cars and puzzles), and use this as an opportunity to engage with him. Getting professional guidance to teach a child with autism is not always easy. It is important to explore who is available as a resource in each community. Some communities may have occupational therapists and speech therapists who are familiar with working with children with autism. In others, it may be a teacher, a special educator or an experienced parent who is a resource person.

While it is important for the child to learn to communicate and connect, it is equally important for family members, teachers, doctors, and other children to try to understand the autistic individual. Children with autism have the same right to play, learn, and fully participate in the community as all children.

A lot of our understanding of autism today comes from autistic self-advocates: children and adults with autism who have spoken about their own experiences, and even researched the subject. Most of their difficult experiences have been related not to their autism but the lack of awareness, understanding, and empathy from others. If we want autistic children to fully achieve their potential, we need to have a common understanding: that we have all kinds of minds in the

world and every one of them belongs here.

Vibha Krishnamurthy is a developmental paediatrician and the founder of Ummeed Child Development Centre in Mumbai. She has been working with children with disabilities and their families for 25 years.

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