

THE ENIGMA OF AUTISM



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He enjoys playing alone, lost in his little world, jumping and talking to himself. He is fascinated by the spinning of the cars' wheels, but will not play with cars like other kids do. Noises bother her and so do new places and people. He likes his world to be predictable. The smallest of change in routine can throw him off and he becomes inconsolable. She is bright and can recall dates, events, and details, but she cannot hold a simple conversation with peers. He gravitates towards adults. These are some of the concerns we hear from parents. The meltdowns, the odd mannerisms, the total disregard for social connections, and the look of someone lost in a world within oneself, all these add to enigma.

So, what is Autism? Autism Spec-

trum Disorder is defined as persistent deficits in two major areas: a) social interaction and social communication and b) restricted or repetitive behaviors or interests. These deficits are typically seen within the first three years of the child's life. This might co-occur with intellectual impairment, but that is not a requirement.

The diagnostic process typically begins when concerned parents or pediatricians notice oddities. In infancy or toddler years, parents typically notice poor eye contact, failure to engage in early speech such as babbling, failure to respond to own name, unusual movements such as twirling, rocking, or flapping arms, playing with toys in peculiar ways, unusual responses to sensory input such as sensitivity to noise or appearing disengaged in activities, behaviors that lean towards self-harm such as hitting oneself or banging hands or head on objects, or difficulty with changes in routine. The umbrella that covers the range of abilities in Autism is very wide. Some

children are high functioning and able. Children who are higher in the spectrum might display good verbal skills, but might have other areas of challenges such as narrow interests or odd mannerisms. Early diagnosis is shown to have the best outcome for the child, especially when the child is provided supports through early intervention.

The Individuals with Disabilities Act (IDEA) mandates that all the states in the US provide services for infants and toddlers with disabilities and their families. Consequently, Early Intervention Services (IES) are provided in all the states. The services might include physical therapy, speech therapy, occupational therapy, and behavioral services. Once the child is in the school system, the child might be eligible to be considered for an Individualized Education Plan (IEP) or a Section 504 (or 504).

So what should parents do if they suspect their child is displaying symptoms of Autism? Make a list of the behaviors you are observing. Note the behaviors with specific



examples to support your observations. Talk to your pediatrician about your concerns. If you feel the need for a second opinion, a developmental pediatrician is recommended. Developmental pediatricians have specialized training in physical, emotional, and psychological development from infancy to young adulthood and they are familiar with the typical and atypical learning and behaviors in children. A consultation with psychologist who has experience working with children who have developmental delays is also an alternate option for a second opinion. Psychologists employ assessment tools to evaluate intellectual abilities, academic achievement, and employ clinical interview with the parents to assess the child's symptoms.

Accurate diagnosis is only the beginning. Caring for the child can be a life long journey. Consequently, self-care cannot be emphasized

enough. The emotional and physical demands of caring can lead to caregiver stress. You cannot help your child if you are struggling with the emotions of your child's diagnosis. Most parents go through a process of denial when their child is initially diagnosed. Why us? Why me? Why my child? No one in my family has this diagnosis! These are natural thoughts. These might change into anger and sadness. It is normal to grieve. Do not allow yourself and your family to go through this journey alone. Several families have already been through it and are willing to mentor. Reach out. Lean on others. Vent. Ask questions. Agencies such as the Statewide Parent Advocacy Network (SPAN) have parent mentors you can speak with.

Cultural and religious views of disability can sometimes act as a support and, at other times, a hindrance. Families' views about their child's disability is likely to impress

their choice of treatments, and their choices in how much they reach out to others for help and support. Be more aware of how your religious beliefs are affecting your perceptions of your child's disability. Process it with someone who is well-versed in your religion and accepting of differently-abled people. Jana Raksha program is a community program that provides a spiritual based shoulder for the community to lean on. Alternately, you can reach out to organizations or professionals who are familiar with the culture and it's challenges. Such resources are available through SAMHIN and SAMHAJ.

Connect locally to a parent support group. Reach out to the local school district to ask for information regarding parent support groups, look online, or research some of the resource links provided at the end of this article. An informed parent is the best advocate for their child. Advocacy groups such as Autism Speaks, POAC Autism Services, and SPAN provide information and guidance regarding early intervention and IEPs, and help parents advocate for their children. Some children and adults might also have co-occurring issues such as social anxiety, compulsive tendencies, attention deficits, tics, and depression. Consult a psychiatrist or a psychologist and consider treatment.

Autism might be enigmatic in many ways, but it is one of the widely studied disorders. There are several treatment options and treatment programs available. Moreover, many families are already on this journey and you surely do not have to walk alone.

RESOURCES

American Psychiatric Association
www.psychiatry.org
Autism Speaks - <https://www.autismspeaks.org>;
School Community Toolkit - https://www.autismspeaks.org/sites/default/files/school_community_tool_kit.pdf
Autism NJ - <http://www.autismnj.org/>
www.mynjpsychologist.com