

THE MOSAIC MIND: UNDERSTANDING THE UNIQUE LANDSCAPE OF AUTISM

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ABSTRACT

Vast swaths of the global population, including a significant number in India are being affected by Autism spectrum disorder (ASD), an all-encompassing neurodevelopmental condition. In the face of increased recognition and diagnostic progress, India is a tough place to get help for autism due largely lack of social stigma around its diagnosis but also because many families simply cannot afford it. Even though the Rights of Persons with Disabilities Act, of 2016¹ and the National Trust Act, of 1999² have some inbuilt protection tools for people with ASD, these laws are not effectively implemented. Although initiatives have been started by the government, especially in areas such as special education, early intervention, and vocational training yet there is a huge gap between policy and practice.

Popular media through movies like 'Taare Zameen Par' played an important role in de-stigmatizing autism spectrum disorder (ASD) by educating people. The multiple faces of ASD, the comorbidities associated with it, historical views, and society's view are discussed in this article from India indicating to encourage knowing & helping those who suffer because they are different than we can ever be. The provision of treatment and social acceptance becomes highly important in promoting inclusion for those with ASD, hence a better standard of life.

Keywords: Autism Spectrum Disorder, Comorbidity, Public Health Policies, Awareness, Societal Acceptance, Early Intervention, Special Education, Vocational Training, DSM-5.

INTRODUCTION

A young child who can count down the alphabet just Lender Half & backward but yet still has to ask someone for an explanation to understand a simple joke. This dilemma is at the core of ASD, a multifaceted neurodevelopmental condition that impacts several in India.

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¹ Rights of Persons with Disabilities Act, 2016

² National Trust Act, 1999

ASD is perhaps particularly misunderstood - one in every 18 million individuals has the condition, yet its cause remains a complete mystery. Yes, that's right, this never-seen-before-in-the-land-of-Karma is not a hard-to-believe confession that you just read now; it is sad satire for us to know what goes on when autistic individuals are mistaken as lunatics - being aloof and socially isolated in their own backyard.

The neurodevelopmental disorder that is Autism Spectrum Disorder (ASD) lasts lifelong. It impacts how people synthesize information and navigate the world. People with ASD face difficulties predominantly in the domains of social interaction and communication. This can manifest as difficulty understanding nonverbal cues, trouble initiating or maintaining conversations, or a preference for routines and repetitive behaviors.³ According to the Centers for Disease Control and Prevention, ASD is a developmental disorder disability caused by differences in the brain.⁴ It is considered the third most common developmental disorder. Around 78 million people in the world are affected by ASD and the outcome and impact on the individuals and families is enormous and worse.⁵

The causes of ASD are still not clearly identified but it is believed that they come from both genetic and environmental causes. Although there is no single cause for this disorder, researchers have discovered some genes which might be related to ASD."Furthermore, other environmental conditions like parental age at conception or some health problems during pregnancy can have a part in its development. It must also be stated that ASD affects every kind of person regardless of color, background, etc."⁶

The diagnosis of ASD is complicated and requires a multifaceted evaluation from someone who knows how to diagnose these syndromes. Autism is so called a spectrum disorder because it occurs in so many different ways. Similarly, ASD is unevenly applied across those who have it. This is due to the varying combinations of strengths and challenges each person presents. Unlike a simple illness like a fever with a single treatment, ASD requires a

³ Vijay Sagar KJ. Research on autism spectrum disorders in India. *AP J Psychol Med.* 2011;12:69–72.

⁴ <https://economictimes.indiatimes.com/magazines/panache/18-million-indians-have-autism-learn-more-about-3rd-most-common-developmental-disorder-know-the-basics-of-parenting-children-with-asd/articleshow/99182225.cms?from=mdr>

⁵ https://www.researchgate.net/publication/364115924_Public_Health_Dimensions_of_Autism_Spectrum_Disorder_in_India_An_Overview

⁶ Center for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged eight years – autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveillance Summaries* (Washington, DC) 2014;63: 1–21.

personalized approach.

A full assessment conducted by a group of experts, frequently comprising a developmental pediatrician, psychologist, and speech-language pathologist, is usually required to diagnose ASD. Rather than the use of one single test for diagnosis, it is a combined judgment of parent accounts, test reports, and observations that make the concrete manifestation of ASD. There isn't a "one-size-fits-all" approach to treating ASD due to its unique character. Effective interventions are made to fit each person's different needs and abilities. For individuals with ASD, early intervention is key as it markedly enhances results. More about ASD's details, issues, and resolutions will be discussed in this piece.

HISTORY

In Greek, the term "autism" is derived from the terms "autos" which means "self" and "ismos" which means "activity," thus it carries its own truth. The term was first used by Leo Kanner in his landmark paper, 1943 to refer to children who exhibited an "extreme inability to relate to others."⁷

Indian literature first saw the term, "autism", in 1959. Unlike many underdeveloped countries, India has a rather large body of literature on autism. The first documented scientific study on autism in India was conducted in 1944 by Darjeeling-based Viennese doctor A. Ronald. Prior to the early 1980s, little was known about autism, particularly in relation to its widespread nature that affects people of all ages.⁸

In 1991, a group of parents who were brought together by a common experience founded Action for Autism (AFA). Providing assistance to people with autism was their aim. The lives of those with autism have improved over time because of a large part of AFA. When AFA successfully pushed for the inclusion of teacher training tailored to autism in the Rehabilitation Council of India (RCI) curriculum, it marked a significant turning point in 1998. As a result, the Diploma in Special Education (Autism Spectrum Disorders) was created in 2003, which was a game-changer for the support and education of people with ASD.

⁷ Feinstein A. Kanner, Leo BT. Encyclopedia of autism spectrum disorders. In: Volkmar FR, ed. Springer; 2013:1668–1669.

⁸https://www.researchgate.net/publication/364115924_Public_Health_Dimensions_of_Autism_Spectrum_Disorder_in_India_An_Overview

Beyond the Silence: My Life, the World, and Autism was the first book written and published by Tito Mukhopadhyay, a youngster with autism from Bangalore, in 2000.⁹ This publication, which combined early articles with advice from mothers, was crucial to the development of autism awareness in India. In the years since awareness of autism has increased along with research. The annual World Autism Awareness Day, which falls on April 2nd, has played a role in this advancement. An environment that is more inclusive has been fostered by improvements in healthcare brought about by heightened public awareness of autism.

India was introduced to Western psychology and psychiatry during the British colonial era. The term "child exhibiting schizophrenic behavior" first appeared in 1959, coinciding with an increase in autism research conducted in India. "In India, autism has gained widespread recognition in the fields of medicine, politics, and law after receiving consistent attention in the late 1980s and early 1990s."¹⁰

TYPES OF AUTISM

DSM Categorization of the Types of Autism

DSM-5

In the US, the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) is commonly used by clinicians who make mental disease diagnoses. It describes the specific conditions for which it sets out requirements for anxiety, depression, ADHD, and autism spectrum disorder and lists their individual needs. You know, the DSM-5 has been revised a few times to accurately represent what we now understand about our mental health disorders.

The DSM-5, released in 2013 changed the manner that clinicians diagnose autism. One diagnosis, ASD, was introduced to harmonize earlier classificatory systems which were commonly different from one another or in the case of Asperger's syndrome and PDD-NOS such as diagnoses occurred when no other classification fit. This integrated approach recognizes the pervasive nature of autism, including people at all levels of functioning. As a result, those who previously would have received an autism diagnosis according to DSM-

⁹ <http://www.rehabcouncil.nic.in/writereaddata/autism.pdf>.

¹⁰ Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social science & medicine*, 58(7), 1323-1335.

IV guidelines will likely not meet the criteria for ASD under DSM-5 regulations.

DSM-4

With the advent of DSM-4, autism has invariably been listed among pervasive developmental disorders (PDDs). The five differences within this category included PDD-NOS, Rett's disorder, autism spectrum disorders (ASD), Asperger's disorder, and childhood disintegrative disorder. According to DSM-4 classifications Asperger's disorder, PDD, and autistic disorder are special types of Autism Spectrum Disorder (ASD).

So basically there are five different types of autism and they are discussed below:

1. Asperger's Syndrome

- In earlier days, By 2013 Asperger's syndrome was officially diagnosed, but now it is categorized as Level I Autism Spectrum Disorder (ASD) in the DSM-5.
- While people with Asperger's syndrome are usually good communicators and intellectual achievers, they frequently struggle in social situations. They could exhibit repetitive and inflexible behaviors and mental patterns.
- Asperger's syndrome is commonly characterized by the following symptoms:
 - An intense focus on particular passions or interests, frequently choosing to participate in a small number of activities.
 - Having trouble reading social cues, such as body language, gestures, facial expressions, humor, and sarcasm.
 - Difficulty in controlling emotions, which can lead to tantrums, behavioral reactions, verbal outbursts, or self-harm.

2. Rett Syndrome

- 1 in 10,000 females have Rett syndrome (a type of Autism Spectrum Disorder) female cases are much rarer. It is often seen in children aged 18 to 18 months, also known as "regressive autism" when a child who is developing normally suddenly begins losing previously learned communication skills.

- Tsyndrome'srome symptoms might include:
 - Loss of movement or difficulty walking;
 - Decreased muscular tone;
 - Microcephaly, or smaller head size;
 - Speech difficulties;
 - Loss of hand function;
 - Uncontrolled hand movements.

3. Childhood Disintegrative Disorder (CDD)

- In the DSM-5, the uncommon ailment called the Childhood Disintegrative Disorder (CDD) has been included under the Autism Spectrum Disorder (ASD) group.
- After the age of three, CDD usually becomes apparent, and its delayed onset frequently causes a regression in previously learned social, verbal, and physical skills.
- The following skills may be lost in children with CDD:
 - Language and vocabulary previously taught
 - Social skills and adaptable actions
 - Toilet training abilities, if established
 - Specific motor abilities

4. Kanner's Syndrome

- Children with this syndrome sometimes referred to as classic autistic disorder, may exhibit traits of intelligence, alertness, and perceptiveness. Nonetheless, they display fundamental traits of the illness, such as:

- Difficulty connecting emotionally with people;
- Uncontrollable speech patterns;
- An intense obsession with item manipulation;
- Strong visual and rote memory abilities combined with significant learning challenges in other domains

5. Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

- Sometimes children display learning problems and behavioral issues that look similar to those of autism but they do not qualify for a specific diagnosis under ASD; such children are usually diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). This disorder was used for milder symptoms compared to other types of Autism Spectrum Disorder (ASD).
- PDD-NOS symptoms can include:
 - Atypical social conduct
 - Inconsistencies or delays in skill development in a variety of domains, including motor, visual-spatial organization, academic, cognitive, sensory, social, and behavioral Issues with communication
- PDD-NOS was previously used as a "catch-all" diagnostic for people who did not meet the DSM-IV's precise criteria for autism.

FAMOUS PERSONALITIES WITH AUTISM

Temple Grandin

Prominent authority on animal behavior, Temple Grandin is a fierce supporter of autism awareness. She has openly discussed her personal experiences with ASD, having been diagnosed with the disorder herself.

Dan Aykroyd

The well-known actor and comedian, well known for his parts in Ghostbusters and Saturday

Night Live, has been candid about his Asperger Syndrome diagnosis.

Satoshi Tajiri

Pokémon's creator, Satoshi Tajiri, is known to suffer from ASD. His strong focus and ingenuity are sometimes attributed to his illness.

Susan Boyle

After winning "Britain's Got Talent," the Scottish singer was later diagnosed with Asperger Syndrome.

Sir Isaac Newton

It is believed that Sir Isaac Newton, who is widely recognized as the founder of modern science, was autistic. He demonstrated characteristics like:

- Hardly any verbal communication;
- Extreme devotion to his work;
- demeanor that came out as either impatient or indifferent.

LEVELS OF AUTISM

The DSM-5 divides ASD into three categories based on the degree of help required for day-to-day functioning and the severity of symptoms.

ASD Level 1

Most people with Level 1 autism share certain characteristics and experiences. Compared to people with Level 3 autism, who may have minimal or no verbal communication abilities—although some Level 3 individuals can speak—they are usually able to employ more complex vocabulary in their verbal communication.

ASD Level 2

A level 2 autism diagnosis denotes a moderate need for assistance. Those with Level 2 autism may face more difficulties with social and communication skills than those with Level 1 autism, and they will need "substantial support" to navigate everyday activities.

They frequently require extra assistance and modifications in order to carry out their everyday activities.

ASD Level 3

This Levis describes as "requiring very substantial support". This means that people require a considerable amount of assistance and adaptations in numerous situations, including the household, work environments, academic establishments as well as public spaces. People with level 3 autism not only exhibit behaviors such as constant meltdowns, uncontrolled violence, and self-harm but they may also have much difficulty communicating verbally speaking for some who do better.

Apart from these categories, autism can also be categorized as high-functioning or low-functioning; however, these classifications are not as accurate and are not as frequently applied in the field of diagnosis as they formerly were.

COMORBIDITY OF AUTISM WITH OTHER DISORDERS

Autism is not alone. Together with other conditions like ADHD, epilepsy, OCD, and schizophrenia, autism frequently coexists.

Psychiatric Comorbidity is the term used to describe when a person has two or more psychiatric problems. People who have autism spectrum disorder (ASD) often exhibit this. Studies show that people with ASD in all age groups are impacted by mental comorbidity, which includes anxiety disorders, bipolar and mood disorders, and suicidal thought behavior savors. Core symptoms of ASD, like social difficulties and repeated behavior savors, might be made worse by the coexistence of other mental health disorders. People with ASD reported a lower quality of life when they had these comorbid disorders. Furthermore, it was found that among those with ASD, mental comorbidity was a risk factor for suicide.

For example, in those identified with ASD later in life, symptoms may be misinterpreted for emotional-behavioural oral problems, such as ADHD, which could postpone the diagnosis of ASD. Recent research, it is found that children with ASD who were diagnosed later than those who were diagnosed earlier demonstrated mental health and social difficulties before being diagnosed, and they also had a greater increase in behavioral problems during adolescence. This implies that symptoms of ASD in those with a delayed diagnosis may

seem less severe.

Among the prevalent conditions that often co-occur with autism are:

Autism and Epilepsy

Approximately a third of individuals afflicted by autism also suffer from epilepsy, a disorder distinguished by repeated seizures. For those with autism, seizures can further impede cognitive and developmental progress, making epilepsy a serious issue.

ADHD and Autism

ASD affects 30% to 50% of people with ADHD, making it one of the most prevalent co-occurring disorders. Persistent inattention, hyperactivity, and impulsivity are characteristics of ADHD that can coexist with symptoms of autism, including issues with regular behavior and attention.

Schizophrenia and Autism

Even though it is less prevalent, autism and schizophrenia together can be very difficult to manage. The typical onset of schizophrenia is in late adolescence or early adulthood, and symptoms include severe disturbances in thinking behavior, delusions, and hallucinations.

OCD and autism

OCD, or obsessive-compulsive disorder, frequently coexists with autism, causing people to display both the obsessive-compulsive disorder's intrusive thoughts and compulsive behaviors as well as the behavioral characteristics of autism. This may make autistic people more inflexible and reluctant to change.

Intellectual Disability and Autism

It is estimated that nearly 50% of individuals with autism are also affected by some of degree intellectual deficit. Another common co-occurring disorder is intellectual disability. It is a syndrome with a deficit in adaptive behavior, as well as threshold levels of intellectual functioning.

FINAL THOUGHTS

Autism Spectrum Disorder (ASD), a complex multi-dimensional disorder known to affect individuals globally, is becoming rampant in India. Like the rest of the world we have seen similar trends - Increasing awareness together with availability and better methods for diagnosis are fuelling growth in ASD. Nonetheless, India continues to struggle to fulfill the needs of people with autism as a result of poor awareness, an acute shortage of trained professionals, and limited access to specialized interventions

Fortunately, public health policies and guidance in India have started to systematically tackle these problems. Statutes such as the National Trust Act, 1999¹¹, and the Rights of Persons with Disabilities Act, 2016¹² provide a fundamental basis to protect the rights of individuals suffering from ASD ensuring them employment opportunities along with healthcare & educational facilities. The goal was to reduce the stigma and discrimination inherent in these laws, by demanding that those with disabilities should be mainstreamed into society.

Also, the Indian government has rolled out targeted initiatives for people with autism such as vocational training, special education programs, and early intervention services. However, legislation has still not caught up to reality and many families are struggling to find the support and services they need.

In recent times, the movie industry has done much to inform the public about autism. Cheerful means through which films such as “Taare Zameen Par”, “The Good Doctor”, “Atypical”, and so on have been important enlighteners about autism spectrum disorders & associated dysfunctions. The films highlight the challenges of ASD, faced not just by those with it but their families too... and what acceptance is really all about. Cinema has helped to eliminate taboos by addressing characters with autism in a confirmative and realistic way.

The Sixty-seventh “World Health Assembly”¹³ in May 2014 adopted a resolution entitled "Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders." More than sixty nations were in agreement with this resolution. It requests that the World Health Organization collaborate with allied organizations and Member States to create national capacities for developmental disorders, including autism spectrum disorders

¹¹ National Trust Act, 1999

¹² Rights of Persons with Disabilities Act, 2016

¹³ Global prevalence of autism: A systematic review update. Zeidan J et al. Autism Research 2022 March.

(ASD) intervention.

CONCLUSION

Despite the progress made in diagnosing and treating autism spectrum conditions in India, more work remains to be done. While public health laws and regulations provide a foundation, effective implementation is necessary for significant change. Improved awareness through education and public outreach can support this effort, helping to build a more inclusive community where individuals with autism can thrive. To ensure that every individual with ASD has the opportunity to reach their full potential and to assist the autistic community in India, adequate funding for services, research, and advocacy is crucial.

