
Autism Spectrum Disorder (ASD): the enigmatic disorder that knows no boundaries

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Abstract

Autism Spectrum Disorder (ASD) is a global health crisis that knows no borders; it does not discriminate based on nationality, ethnicity or social status. ASD is a very complex neurological condition, most commonly appearing during the first three years of life. ASD affects the way a person's brain and body works. It is not a disease and is not contagious. ASD is a lifelong developmental disability. Professionals diagnose ASD by the presence or absence of certain behaviours, characteristic symptoms and developmental delays. Early intervention therapy is the only documented way of managing ASD. So awareness of this disorder is of utmost need for early detection and subsequent early intervention.

Key Words: Autism Spectrum Disorder (ASD), Triad of Impairment, Neuro-diversity

1. Introduction

Case I: Neelam is a below average standard III student. She is very naughty and cannot stand still for more than a minute. She does not pay attention to what the teacher is saying and so misses out the instructions in class. She cannot understand mathematics. It seems that she has not grasped the basic mathematical concepts. However she has a very good memory and her teachers were surprised that she used to memorize short mathematical problems without even

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understanding them. She could not complete her homework because she did not remember what the teacher said. Her teachers were exasperated with her because nothing seems to interest Neelam for long. She could not be promoted to standard IV that year.

Case II: Ujaan is bright young software professional. He is a workaholic. His boss likes him very much because he is always serious about his work. He is highly praised by his superiors in office because of his innovative ideas. He is the asset of his organization as he can ‘think out of the box’. However Ujaan’s colleagues think of him as a nerd. Ujaan just cannot understand jokes or even sarcasm. He cannot infer anything from the facial expression or tone of voice of another speaker. Ujaan has two favourite suits which he has worn alternately for years. Though the suits are now discoloured and frayed Ujaan refuses to discard them. Friends and family have considered Ujaan as ‘unsocial.’

Case III: David is at present the vice captain of his school. He tries to instill discipline in all his fellow students. But he often tries to monitor his classmates even after class hours. His classmates often express their anger non-verbally which he cannot understand. Only when somebody clearly and verbally states his displeasure comprehension dawns on him. He just cannot understand why his batchmates do not like routines and discipline because he himself enjoys following routines. He is the topper in mathematics in his class but struggles with language papers. He cannot understand metaphors and their usage.

Case IV: For the first 6 months Tenzing appeared to be a healthy, happy boy. But his developmental milestones were delayed. He first walked when he was 1 year and 3 months. But he balanced his whole body weight on his little toes. He is still a toe walker. He did not say “ma” until he was 3 years old. Now he is 8 years and that is the only word he says clearly but rarely. He never pointed at anything. Whenever he wanted anything, he started crying. His mother had a tough time trying to guess his needs. Tenzing likes to chew strings, pencils and rubber toys even as an 8 year old. Till date he cannot eat, bathe or dress independently. He is still not fully toilet trained despite his family’s efforts.

Case V: Amir, a 4 year boy shows no interest in the class activities of his playschool. But he likes scribbling a lot. However the patterns during his scribbling are the same. To his mother

it apparently has no meaning but she thinks that it means a lot to little Amir. He wants to make friends in his playschool but somehow he cannot. He cannot join them spontaneously at play. He plays rather oddly with cars turning the wheels only. When he is excited he runs from wall to wall flapping his hands like a bird. He talks in monosyllables. When his family members could not understand what he wanted, he created tantrums. He would roll on the ground, crying and screaming. During these terrible tantrums he often threw things or tried to bite the person in front of him.

Case VI: Jitesh is an English graduate. He is soft-spoken and very shy. He used to sit in the last bench and never asked any questions in class. He was loner and did not have any friends in college. It always seemed that he used to memorize by rote because if the question was asked differently he could not frame the answer himself. When asked what is ambition was just mumble or said something vague. It always seemed that his mind was wandering somewhere. Jitesh has appeared for several interviews but never got a job. He has recently got a job of a typist in a special school for mentally challenged students.

Six seemingly separate unrelated instances. None of the six individuals remotely are similar. The level of their life skills, communication and intellectual ability may differ but they all have Autism Spectrum Disorder (ASD), an enigmatic disability. Recent study suggests, as many as 1 in 100 children have some form of ASD¹.

2. Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) happens when the brain develops differently and has trouble with an important job, making sense of the world. Every day, our brains interpret (understand) the things we see, smell, hear, taste, touch, and experience. But when someone's brain has trouble interpreting these things, it can make it hard to talk, listen, understand, play and eventually learn. Autism is a very complex neurological condition, most commonly appearing during the first three years of life. Autism affects the way a person's brain and body works. It is not a disease and is not contagious. Autism spectrum disorder (ASD) is a lifelong developmental disability.

3. Triad of Impairment

One of the most significant contributions to the clinical understanding of autism as a spectrum disorder has been that of Lorna Wing.² Wing found that there were 3 areas of impairment, forming a cluster of features that provide diagnostic criteria for the identification of autism. This cluster is referred to as the triad of impairments which are as follows.

- 1) **Impairment of Social Interaction:** The implications of this impairment is that the individual may show impaired, deviant and extremely delayed social development, especially interpersonal development. The variation may be from very cut off and aloof, to passive, active but odd or over-formal social skills. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction. Failure to develop peer relationships appropriate to developmental level. Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest).
- 2) **Impairment of Social Communication:** The individual with autism will have impaired and deviant language and communication, both verbal and non-verbal. Delay in or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime). For the individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others. Stereotyped and repetitive use of language or idiosyncratic language.
- 3) **Impairment of Social Understanding and Imagination:** Individuals will possess rigidity of thought & behavior and impoverished social imagination, ranging from inability to play imaginatively with toys or other children. They may be involved in repetitive stereotyped activities. Individuals would have difficulties in understanding abstract concepts such as feelings and emotions. Apparently inflexible adherence to specific, nonfunctional routines or rituals. Stereotyped and repetitive motor mannerisms

(e.g., hand or finger flapping or twisting, or complex whole-body movements). Persistent preoccupation with parts of objects.

Autism Spectrum Disorder (ASD) may occur alone or with accompanying disorders such as mental retardation, cerebral palsy, attention-deficit hyperactivity disorder (ADHD) or seizures.

4. Manifestation of the disorder as a spectrum disorder

Individuals with autism demonstrate certain degree of impairment that may differ widely.³ ASD manifests itself in a myriad of ways in different individuals. One person with ASD may be non verbal, intellectually challenged and almost entirely self absorbed, while another may be verbal, bright and in tune with his surroundings. It is a spectrum condition which means that individuals within the autistic spectrum differ in how severely they are impaired in each of the triad areas - some will have significant difficulties in all areas, while for others, their difficulties may appear to be quite subtle. So the symptoms of people with ASD will fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms. While all people with ASD share certain difficulties, their condition will affect them in different ways.

Most individuals with autism have unusual responses to stimuli from the environment. One or more of the senses may be oversensitive (hypersensitive) or under sensitive (hyposensitive). These include eating problems, sensitivity to sound, touch, smell or taste, fine and gross motor difficulties, attention difficulties, behaviour problems, specific language difficulties, and/or special skills.⁴ Some people with the condition may also have accompanying learning difficulties, while others are much more able, with average or above average intelligence.⁴ It may be hard for them to play, to make friends or to learn new things.

5. Prevalence of Autism Spectrum Disorder (ASD)

Autism is a global health crisis that knows no borders -- it does not discriminate based on nationality, ethnicity or social status. It's high time that the world begins to recognize the scope of this problem and acts internationally and locally to improve the lives of the growing number of individuals and families affected by this devastating disorder.⁵ Centres for Disease

Control and Prevention (CDC) with Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance reported on 28^h March 2014 now 1 in 68 children have ASD.⁶ Growth of the neuro-developmental condition of autism is indeed a phenomenon.⁷ The increase in diagnosed cases can be accounted for by increased awareness of the disorder in all its variants and the use of wider diagnostic criteria.⁸ Over the past decade and worldwide, estimates of increases between 50% to over 2000% in cases of Autistic Disorder diagnoses have been charted, studied and discussed.⁹

This makes autism the third most common developmental disorder, more common than Down's syndrome. Since autism spectrum conditions are far more common in males than in females (classic autism occurs in four males for every one female, and Asperger's syndrome occurs in nine males for every one female), this may suggest that the number of autistic traits a person has is connected to a sex-linked biological factor – genetic or hormonal, or both.¹⁰

Diagnosing autism is much more complex than the description of these particular characteristics.¹¹ Professionals diagnose autism spectrum disorders through the presence or absence of certain behaviours, characteristic symptoms and developmental delays. Diagnostic and Statistical Manual of Mental Disorders (DSM) is the manual used by clinicians and researchers to diagnose and classify mental disorders.

6. Early signs of ASD

Fundamentally, early detection is important because earlier intervention appears to drive better outcomes than later onset intervention¹². This is due to brain development which occurs through interplay between external stimulation and neurobiological processes. With early and intensive intervention, most children improve their ability to relate to others, communicate, and help themselves as they grow older. It is ironical that although ASD is congenital, signs of the disorder may be evident only to person who is experienced and aware of this enigmatic disorder. Being a spectrum disorder the signs will be different for different individual.

Parents often become concerned when their child does not like to be held or cuddled. Some children do not seem interested in playing certain common toddler games. Parents also may be confused about their child's hearing abilities. It often may seem that a child with autism does not hear, yet at other times, he or she may appear to hear a distant background noise, such as the horn of a car far away. Usually the child does not babble or point by age 1 year. There are no single words by 16 months or two-word phrases by age 2 years. The parents become more distressed when the child does not begin to talk. However sometimes, a child with autism will start to talk at the same time as other children the same age, then lose his or her language skills later on. If the child does not respond his name nor has poor eye contact it may be a red flag of ASD.

7. Later signs of ASD

ASD does not affect someone's physical appearance. Children with autism may look like other neuro-typical 'normal' kids, but if you meet them you would find they are different in some ways. The signs of whether a child has the disorder show in a pattern of behaviour which requires careful observation. Given below are some typical later signs which may be present due to the triad of impairment of ASD.

i) Difficulty with social interaction.

This includes recognizing and understanding other people's feelings and managing their own. People with an ASD may not understand the unwritten social rules which most of us pick up without thinking. For example they may stand too close to another person or start an inappropriate subject of conversation, appear to be insensitive because they have not recognized how someone else is feeling, prefer to spend time alone rather than seeking out the company of other people, not seek comfort from other people, appear to behave oddly or inappropriately, as it is not always easy for them to express feelings, emotions or needs. However some may want to interact with other people and make friends, but may be unsure how to go about this. This range of difficulties can lead to problems in the classroom and the playground. As they have difficulty in making and later sustaining friendship they may

become the school bully. But more often they are the ones who are subject to ridicule and bullying from the peer group at the educational institution/workplace.

ii) Difficulty with social communication:

This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice. Some people with an ASD may not speak, or have fairly limited speech. They will usually understand what other people say to them, but may use alternative means of communication themselves, such as sign language or visual symbols. Others will have good language skills, but may still find it hard to understand the give-and-take nature of conversations, perhaps repeating what the other person has just said (echolalia) or talking at length about their own interests.

iii) Impairment of Social Understanding and Imagination:

Individuals with ASD may have preoccupation or obsession with certain objects or subjects. Their areas of interest maybe very narrow and restricted patterns, or may be abnormal in intensity or focus. Lack of ‘pretend play’ in younger children where imagination is required. The individual may have an inflexible adherence to specific routines or rituals. They may struggle to make and maintain friendship with children of the same age, due to poor social skills, or show little interest in other children.

Many of the above characteristics may be present in the normal human population. In fact some of the characteristics maybe an asset viz. innovative thinking, eye for detail, preference for discipline and routine in isolation. But when these characteristics are so many and affect the normal functioning of an individual it will be considered as a disorder, ASD.

8. Intervention strategies

No medicine is available nor is there any prenatal screening. Early intervention therapy is the only documented way of managing ASD. Applied Behavior Analysis (ABA), Verbal Behavior Analysis (VBA), PECS (Picture Exchange Communication System), Floortime (also known as Greenspan), Social Stories and TEACCH (Treatment and Education of Autistic and

Communication Handicapped Children) program are some established methods for intervention therapy.

9. Several Theories to explain Autism Spectrum Disorder (ASD)

Since autism was first described, independently and almost simultaneously, by Leo Kanner¹³ and Hans Asperger¹⁴ (1944), many theories have been proposed to account for this enigmatic disorder¹⁵.

a) The Theory of Mind (ToM) Hypothesis of autism

In essence, this theory states that individuals with autism fail to “impute mental states to themselves and others”¹⁶ and that this deficit manifests as an inability to mentalise, or failure to take into account others’ mental states. However, it was only in the mid-80s that a theory proposed that some of the core elements of autism might arise from a primary cognitive deficit. In doing so, the theory imposed a developmental psychological perspective on research and became hugely influential for both researchers and practitioners.

b) Executive Function (EF) Theory

In contrast to the theory of mind hypothesis of autism, the Executive Function autism has been variously characterized as a deficit of EF, which is the executive function.¹⁷ This theory did not originate from neurotypical research; rather, its conception came from researchers who noted that some symptoms of autism were similar to those associated with specific brain injury. In contrast, Gillberg and Coleman¹⁸ defined EF as all those faculties needed to work in a motivated fashion, towards a goal that may not be reached instantly.

c) Weak Central Coherence (WCC) Theory

Another theory is the Weak Central Coherence Theory (WCC)^{19, 20, 21, 22, 23}. The essence of the theory is that typically developing individuals process information by extracting overall meaning or gist. Happé and Frith²⁴ suggested that autism is characterized by weak or absent drive for global coherence. Individuals with autism process things in a detail-focused or piecemeal way—processing the constituent parts, rather than the global whole.

In addition to the above theories more theories have been postulated over the years viz. complex information processing²⁵ Multiple-deficit accounts approach²⁶ and empathy²⁷. Each

of these theories is a valid description of many aspects of the autistic syndrome but each, in answering unsolved questions at one level of explanation, introduces them at another.

10. Etiology of Autism Spectrum Disorder (ASD)

The exact etiology of ASD remains largely unknown; however, literature suggests both heritable and genetic components²⁸. ASD has no single cause. Factors such as hitting a child, inability to spend adequate time, mothers working outside the home are all unrelated to the cause of ASD. The combination of this broad variation of phenotypes and a 60-90% concordance rate in identical twins²⁹ suggests a large number of genetic and environmental biasing factors³⁰. Recent research suggests genetic, neurological, immunological, and environmental contributions^{31, 32, 33}. ASD and the immune system have been linked genetically and symptomatically^{34, 35, 36}. Recent studies have shown that normal neurons in developing and adult brains express proteins of the major histocompatibility complex (MHC) class I, known for their role in the immune system^{37, 38}. ASD is a complex disorder, and most scientists who study ASD believe that there is no single cause.

11. Autism Spectrum Disorder (ASD) in India

Recent research indicates that ASD occurs in at least 1% of the human population¹. Given the population of India, this means there are a staggering number of children and families who are impacted by this disorder. ASD is expected to be on rise in India, with nearly 2 million individuals with this disability³⁹. Despite this high figure of the Autism Spectrum Disorder (ASD) in India, this disability did not find mention in the official disability statistics of India even a few years ago. In Indian Census 2001 there were only 5 categories of disability and autism to be counted as a mental disability. The scenario improved slightly during Census 2011. 8 disability Codes were provided. The new 3 Codes were: Mental Retardation, Mental Illness, 'Any Other' and Multiple Disability. So during Census 2011 Autism fell in 'Any Other' category. This was a minor achievement as Autism emerged from the shadows of mental illness and mental retardation.

Despite the large number of individuals with ASD in India the services available to tap the potential of these individuals with ASD is relatively few. Lack of supportive, autism friendly environment in educational institutes and work places cause a huge wastage of our human

resources. In a developing country like India the undiagnosed figures can be much higher than that of UK. The reason why autism is such a misunderstood and misdiagnosed condition is because it frequently falls between the cracks of mental retardation and mental illness.

However in recent times many researchers, Non Government Organisations (NGOs) and professionals in the education and medical sectors are working on autism. Sustained professional focus on autism began in the late 1980s and 1990s⁴⁰ and autism is now widely recognized in educational, medical and legal circles in India.

12. Recent Research Focus on Autism Spectrum Disorder (ASD)

Baron-Cohen and Swettenham⁴¹ proposed for the creation of subgroups in autism. They stated that autism is in fact a complex of cognitive disorders: impaired theory of mind, WCC and executive dysfunction. They argued that autistic individuals can be affected differently in these three, possibly independent, domains. Furthermore, Bishop⁴² stated that the blurred boundaries of autism are not just a consequence of the subjective and elusive nature of its symptoms. Instead it may be that ASD is actually a disorder without clear boundaries⁴³. Autism research has already moved in a neuropsychological direction: mapping cognition onto brain function^{44, 45, 46, 47, 48} Some researchers think there is as yet no single theory for autism⁴⁹.

There is little doubt that the study of autism has highlighted the complex nature of development in general and that developmental trajectories are not fated from diagnosis. Autism may, in fact, be a good example of both *equifinality* (where there is more than one developmental pathway to a given outcome) and *multifinality* (where early experiences do not necessarily result in the same outcome)¹⁵. Belmonte and Bourgeron⁴⁸ proposed that complexities found within neuronal networks within even single gene disorders may enlighten us to the many possible routes in a multiple gene disorder like autism.

13. What is it like to have Autism?

It is like if one suddenly was transported to a foreign country where one did not speak the language and had no alternative way of communicating with the people around. It would be quite difficult to comprehend the social rules of that country. To varying degrees, this is how

people with Autism experience their surroundings every day. This is why they may behave and act in ways that may appear strange or even bad, and may effectively isolate the individual from society even more. To be an individual with ASD (especially individuals who have a severe form of ASD) means being able to see yet have no vision; to hear yet not be able to listen; to feel yet not know what one is feeling; to want yet not be able to ask.

For the child with autism the disability is a lifelong challenge, both for him and his family. The first step is the family's acceptance of autism. Acceptance from the society should follow. Dustin Hoffman as Raymond, from the film *Rain Man* made an entire movie-going generation aware of autism. Recent movies like '*Barfi*' and '*My Name is Khan*' from India have depicted the lead characters with ASD. As people are becoming more aware of the neuro-diversity, present

chances of acceptance will hopefully increase. Acceptance means not asking an individual with ASD to change their behaviors or emotions that are part of their unique biology. It means appreciating that their biology is beyond their control. Acceptance means recognizing that the best way to unlock their full potential is by creating a supportive environment for their special needs. Acceptance isn't just one day or one month's program. Acceptance is a daily process of love, encouragement, hope, optimism and resiliency.

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