

Behavioral characteristics and rights of Children with Autism Spectrum Disorders

Hameeda Begum Safavi

Abstract

Developmental challenges, as well as a host of social, behavioural, and physical issues, are all part of autism spectrum disorder (ASD). ASD patients often have abnormal behaviours and interests, as well as odd learning and attention methods, as well as impaired verbal and nonverbal communication skills. People with autism frequently suffer from medical conditions such as asthma, digestive problems, recurrent viral infections, and seizures, in addition to these behavioural symptoms. Autism was long considered a rare disease, but it is now one of the most common developmental disorders. An actual increase in mass cannot be ruled out, given the increased prevalence of advanced parental age at conception and perinatal risk factors such as preterm and high-risk infant survival.

Keywords: Autism, developmental challenges, behavioural issues

Introduction

Children with disabilities are among society's most marginalized and disenfranchised populations. Due to continuous prejudice in opposing views and a lack of applicable regulations and legislation, they are effectively denied their rights to healthcare, education, and even survival.

UNICEF's mission is to make the world a better place "where every child has the opportunity to grow up healthy, safe, and educated so that they can achieve their full potential." Every day, we strive to make this goal a reality. We help the most vulnerable children wherever and whenever they need us, no matter who they are or where they were born."

UNICEF's work has a renewed and intensified focus on equity to identify and address the core causes of inequality so that all children, particularly those most disadvantaged in society, can achieve their rights.

According to UN Enable, approximately 650 million people, or 10% of the world's population, live with disabilities. Abuse is especially prevalent among disabled women and girls. According to the findings of the UNICEF survey, 30 per cent of street children are disabled. Children with disabilities have a death rate of up to 80% in some countries with high IMR rates. In this way, autism is one sort

of impairment. One out of every 59 children has autistic or autism spectrum disorder (ASD), and its prevalence has been progressively increasing over the previous decade. Boys are four times more likely than girls to have autism. Autism cannot be cured, but early intervention, diagnosis, and treatment can significantly enhance the lives of those who have it. Autistic children require rigorous therapy as well as unique educational programmes. Adults with autism confront additional difficulties. The legislation protects autistic people of all ages.

Autism spectrum disorder (ASD) causes developmental disabilities and numerous social, behavioural and physical challenges. Individuals with ASD often display unusual behaviours and interests, unique ways of learning and paying attention, and impaired verbal and non-verbal communication skills. In addition to these behavioural symptoms, individuals with autism will often have physical ailments such as asthma, digestive disorders, persistent viral infections and epilepsy.

Autism has become more prevalent in India, as it has in the Western world, over the years. Autism was once believed to be a rare disorder, but it is now considered one of the more common developmental disabilities. The increase in prevalence is primarily due to increased professional awareness. Case definition changes, early discovery, and

diagnostic case substitution could all play a role. However, given the increased prevalence of advanced parental age at conception and perinatal risk factors such as prematurity and high-risk infant survival over the years, an actual increase in bulk cannot be ruled out.

The prevalence of ASD (previously known as PDD) was 1 in 125 in children aged 3-6 years and 1 in 85 in children aged 6-9 years in the INCLEN research. 0.90 per cent of the population lived in rural areas, 0.6 per cent in mountainous areas, 1.01 per cent in urban areas, 0.1 per cent in tribal areas, and 0.61 per cent in coastal areas.

Even though there has been a vast increase in the number of cases being detected, most people with autism in India, especially adults, remain undiagnosed and do not receive the services they need.

HISTORICAL PERSPECTIVE

When A. Ronald, a Viennese paediatrician in Darjeeling, presented an overview of the symptoms, aetiology, types, and treatment of 'difficult children,' autism was first described in India in 1943. A "difficult child," according to him, was not significantly behind the average child, was trainable, but had aberrations or deviations in the areas of sensitivity, inclination, and volition. Although Ronald's essay did not utilize the term "autism," some of the symptoms he described were similar to Kanner's descriptions of autistic children. There were published case reports and studies on Autism from India starting in the early 1960s. However, their numbers were substantially smaller than those described in the western literature at the time.

Until 1980, only a few centres and a few individual professionals diagnosed children with autism, and general medical knowledge was lacking. It was also discovered that many patients with autism had received their diagnosis from outside the country. By the early 1980s, more professionals were aware of the condition's existence. Still, most believed it was a rare disorder challenging to diagnose and treat and associated with poor outcomes.

By the late 1990s, a few autism-specific organizations and schools had sprung around the country as doctors and parents of children

with autism sought to promote community awareness of the disorder.

In many areas, including diagnosis, treatment choices, parental participation, pre-vocational and vocational possibilities, human resource development, legislation, and research, autism awareness has increased considerably in India over the last two decades.

What exactly is Speak Up?

Autism Europe, the F.M. Regina Association, CIRENEO, The National Autistic Society, Autismo Burgos, Alpha Foundation, and Progetti Sociali collaborated on SPEAK UP (System for the Protection and Empowerment of Autistic Children as Victims or Unintentional Perpetrators), a European project.

SPEAK UP aims to increase current knowledge and understanding of safeguarding children and young people with autism on a European level, both as victims of abuse and as perpetrators of abuse and violence against others. This project entails the creation of this handbook and another one aimed at preventing or reducing rage and aggression in children with autism. The result of an information resource and a programme to avoid the risk of maltreatment for children and young people with autism.

Because this is a reference for professionals throughout Europe, there is no discussion of the legal frameworks that govern this field of employment, which vary by nation. On the other hand, the guide should be used in conjunction with existing legislation and practises in the individual countries.

What exactly is autism?

- Autism is a developmental disability that lasts the rest of a person's life. How a person perceives and understands their environment is a spectrum disorder because it affects people differently. All autistic people, however, struggle with social communication, interaction, and social imagination. Many autistic people are also hypersensitive to sounds and smell.

Social Communiqué:

Some persons with autism do not speak at all or only speak in a limited way. Others have high language abilities but have difficulty with communication components, such as taking

turns or constantly talking about their particular passion while failing to recognize that the other person may not be interested.

- People with autism have problems recognizing facial emotions and body language since nonverbal communication is difficult. They may also believe that people mean exactly what they say, such as "pounding your head against a brick wall." As a result, sarcasm and humour may be challenging to grasp. Some autistic persons will repeat statements or phrases they've heard, or they may repeat what you just said to them. This is referred to as 'echolalia.' The lines or words may have originated from anyone: a family member, a teacher, a television commercial, or their favourite show.

Interaction with others:

Children with autism have trouble identifying and understanding the feelings and emotions of others, which is referred to as 'Theory of Mind' deficits. Some children with autism may come across as cold and uncaring, as well as odd. They may appear to be unable to empathize. They may also be unable to express or even comprehend their emotions, and they may act in ways that others without autism do not, such as laughing at tragic events.

They may not know the unspoken rules that persons without autism know. They may approach someone too closely or say wrong things about the situation. Many people with autism desire connections and relationships, but they may come to them unusually or inappropriately because they struggle with social contact. Theory of Mind is expected to originate in early childhood and be a lifelong ability¹. The Theory of Mind is persistently impaired in people with autism, including those with Asperger syndrome.

They may prefer to be alone rather than seek out the company of others. Some autistic children might not appear to be exceptionally loving, while others seem to be too affectionate - but on the whole, autistic children are caring. But only on their terms, that is, when they choose to be loving rather than when their parents want them to be loving.

Sensory Problems

- Our seven senses are our seven senses (proprioception): sight, sound, taste, smell,

balance (vestibular), and bodily awareness are our seven senses (proprioception). Many autistic people have sensitivities to one or more of their senses, and they can be either over- or under-sensitive. This can significantly impact both the autistic person and their family. Sensory sensitivity can manifest itself in the following ways in children with autism:

- Throwing and catching can be difficult due to a lack of depth awareness.
- Background noise is brutal to drown out, resulting in poor concentration.
- Touch, even light touch, can be uncomfortable for them.
- They may be adamant about wearing certain textiles because others are too painful or uncomfortable for them, or they may despise wearing clothes altogether.
- They may only consume very bland foods or have a specific colour or texture. Some people may be underweight as a result of a low-calorie diet.
- They may lack the ability to gauge personal space and approach individuals too closely. Investigation. Some will seek sensory stimulation by self-harming, while others may have spare bedrooms or sleep on the floor due to sensory difficulties.

INVESTIGATION. SOCIAL UNDERSTANDING VS INTELLECT

- It can't be assumed that children with autism have the same level of social knowledge as people without autism. Many autistic children with ordinary or above-average intellect still fail to grasp others' intentions and predict their actions' implications. This is due to their troubles with the theory of mind and has nothing to do with their IQ. This means that confident children and young people with autism may place themselves in dangerous circumstances and be ignorant of the danger regardless of their IQ level.

- Many young people with autism want to 'fit in' and be accepted, so they will try to disguise their difficulties and present an image that they believe others want to see or anticipate from them instead. Again, if they misread what they think is required of them, or if others assume they understand everything stated or asked of them, they are in embarrassing situations.

- **What Autism is Not**

Even though autism is not a cognitive disability or a mental illness, children with autism face several learning and mental health issues.

A learning deficit affects around 55% of people with autism², and mental health concerns affect 66% of infants and adolescents with autism³.

Many autistic people, on the other hand, do not have a learning disability or a mental health problem and hence lie between the two services.

Even if they do not fit the criteria for learning disability or mental health services, their families may have unmet and sometimes undiagnosed needs. This might make families feel lonely and as if they are on their own without professional assistance. Specialists must examine the requirements of children and teenagers with autism with a thorough grasp of autism and how it affects the kid. It's also critical that these agencies collaborate to provide the most outstanding possible care for autistic children and teenagers.

- **Safeguarding Autistic Children and Adolescents**

Autism affects people's capacity to understand and report potential indications of abuse to varying degrees because they have trouble with social communication and social engagement. Regardless of IQ, if a person's social awareness is damaged in any manner, it will indeed alter how they process and understand specific circumstances.

Children with autism are particularly vulnerable to maltreatment due to their inability to read other people and understand and interpret their intentions.

The belief that a child with autism with an average or above-average IQ will be less vulnerable due to a better comprehension of what is going on puts children with autism at even greater risk.

Autism's very nature can put people at risk. High levels of tension and anxiety, self-injurious conduct, a desire to be alone, behaviour that might be viewed as confronting to others, and a dislike of physical touch, are all prevalent. This necessitates a delicate balancing between what is caused by autism and how it manifests differently in each individual and a possible symptom of abuse.

Some parents may believe that accepting their children for who they are can withdraw from society. Is that a case of neglect? To cope with an uncertain world, many persons with autism require structure and routine in their lives. Some parents may let this take over and rule their children's life.

Numerous therapies and interventions claim to cure autism. Some of these techniques may appear to be abusive in and of themselves. Some parents explore these therapies and interventions out of desperation. Since the claims for some of these therapies and interventions are unclear, it can be difficult for parents to know what to believe when seeking additional information about the various treatments and interventions.

Sensory cues might influence the behaviour of a youngster. Seeking sensory stimulation can lead to self-destructive conduct.

Children with autism often exhibit challenging behaviour, exposing them to ineffective, inappropriate, or violent treatment.

Children with autism frequently share situations with other children who may demonstrate abrasive behaviour

Detecting Potential Signs of Abuse in Autistic Children

It's critical not to assume that all indications and indicators are related to the child's autism or that all are related to the child's mistreatment.

Designated persons and safety specialists acquire the best results when evaluating both possibilities and thoroughly investigating them.

It is critical for people dealing with autistic children to have high-quality, precise information obtained and analyzed regularly so that changes may be noticed and updated. To guarantee a uniform approach while addressing data protection standards, information about the kid should be sourced and shared with anyone who comes into touch with them.

This will aid in recognizing how autism impacts them, as well as the 'normal' characteristics that the youngster exhibits and any minor alterations in behaviour. However, there could be other reasons for these changes, and every possibility should be investigated. It's also critical that information on the child is

transmitted when they move through different stages of their lives, such as from primary to secondary school and from child to adult services.

Sleep troubles are pretty frequent in children and young people with autism, and parents of children with autism, like any parent with a child who won't sleep, will try various methods to tackle the problem. Many parents of babies and little children, whether they have autism or not, maybe concerned. However, this can be more difficult for some parents of autistic children. The child may have developed a routine; it's what they're used to, and they're hesitant to give it up. This may be something that the parents urgently try to persuade the child to give up. Still, as the child grows older and more prominent, it may seem less suitable to continue, but parents may be afraid of what professionals will think or whether they will find something sinister in it.

Because of their sensory issues, many children with autism find wearing clothes extremely painful. For this reason, their parents may have allowed them to remove their garments when they enter the house at a young age. This is perfectly okay when the child is young, but as the youngster grows older, it may be frowned upon. Parents may be apprehensive about how they will be evaluated if they seek assistance to manage this, similar to how they could be judged if they share a bed with their child.

Are there signs of abuse or self-harm?

Self-harming behaviour serves a purpose for everyone who engages in it. Changing and breaking that habit is difficult for anyone. It is critical to understand why the person is acting this way and its purpose. It's also crucial to be on the lookout for changes in that behaviour and identify the possible causes of those changes.

It is critical not to assume that the child's concerns are solely related to their autism, as in all of these cases. All of these issues are real and common among autistic children, but they could also be symptoms of abuse. Knowledge of the child, thorough data recording, and questioning early warning signs of concern are all required.

Aetiology of Autism

- There is no known cause of Autism Spectrum Disorder, but studies suggest that genetic and environmental factors may play a role. Pre- and perinatal events such as pregnancy disorders, labour complications, foetal distress, low birth weight, and premature birth have been studied and linked to ASD. These risk factors are prevalent in India and have a significant impact on children's developmental outcomes. A population-based cohort study that used a questionnaire to identify prenatal, perinatal, and neonatal risk factors for Autism Spectrum Disorder discovered advanced maternal age, foetal distress, and gestational respiratory infections as risk factors for ASD. Labor complications, pre-term birth, neonatal jaundice, delayed birth cry, and birth asphyxia were perinatal and neonatal risk factors for ASD.

PRESENTATION IN CLINICAL TERMS

The clinical spectrum of autism in Indian children is consistent with that of other cultures, with the core features being relatively universal.

A descriptive study conducted in a hospital setting that primarily included moderate to severely affected cases described the most common presenting complaints as delayed development, speech delay, and "losing oneself in one's world." Other symptoms included a lack of eye contact, impaired joint attention, a lack of interest in or inappropriate toys, and difficulty with toilet training. There was a deficiency in imaginative and pretended play. Aside from behavioural issues such as hyperactivity, aggression, self-injury, pica, excessive mouthing of objects, and seizures were also significant concerns. Hand flapping and rocking were two common motor stereotypies observed. Overreaction to the sound of a pressure cooker whistle or a mixer-grinder was an often-reported sensory symptom.

A lack of response to name, no meaningful speech, a lack of social interest in other children, no index finger pointing, a lack of joint attention, an inability to follow verbal commands, a lack of pretends play, unusual play, and poor eye contact were all clinical characteristics in children younger than two years old. To mention a few, children with ASD were seen to engage in repetitive stereotypical

behaviours such as rocking, hand flapping, hand staring, spinning, and toe walking. Spinning utensils, mouthing or licking toys, slamming objects, and lining and stacking them were all examples of non-functional item use. More than a quarter of the youngsters participated in self-harming behaviours such as hitting themselves, headbanging, or severe scratching that resulted in blood.

Regression is ordinary in autistic children, though the prevalence is unknown. According to studies, most parents report regression between the ages of 12 and 24 months. Language regression, particularly in the expressive language sector, usually occurs between 18 and 24 months. Apart from language, regression is generally slow and subtle, and it can occur in other domains such as social skills and cognition.

Thus, even though most of the characteristics seem similar, the diversity of culture and socioeconomic status in India may impact symptom expression and recognition. Commonly, children, especially girls and young women, are expected not to make direct eye contact with men, elders or strangers, speak only when spoken to and not indulge in social chitchat. Tone of voice may vary across regions, with some dialects being expressed in a loud or 'warrior-like' tone even during normal conversation. Plenty of local colloquial is used in villages and rural areas, which may be difficult to understand. In most Indian languages, the second and third-person pronoun (you, and he/she/they, respectively) can differ depending on the addressee's age and familiarity with the speaker.

Similarly relationships are explicitly named depending on the relation to the particular person. For example, the father's sister is 'bua', and the mother's sister is 'music'. Gestures for greeting also differ across age and religion. Thus, in some societies, people are greeted with either folded hands (Namaste) or touching the feet of elders as a mark of respect; in others, 'salaam' is the primary mode of greeting. Contact gestures for greeting like hugging or shaking hands may not be acceptable. These subtleties of Indian culture are difficult to grasp and complicate the therapy.

While enquiring about and assessing play, it is seen that many children from lower socioeconomic backgrounds don't have access

to conventional toys and are often seen to play with sand, mud, bricks and household utensils. These children, especially girls, are also burdened with household responsibilities and don't have time or the opportunity to play with peers. Many families from lower socioeconomic strata and some with too much emphasis on academics are neither aware of their child's play nor interested in encouraging it. In children from higher socioeconomic groups, excessive use of smartphones and gadgets may manifest with rote use of westernized English, which may be taken as a positive attribute by the parents

Aside from that, greater solitary play and social isolation linked with gadget use both hide and contribute to social issues. With less demands to obey societal standards and greater secondary social interaction and peer group exposure, the dissolution of the conventional joint family system also leads to shifting symptomatology. However, it has also resulted in women breaking down customary barriers.

The cutoff at which all these normal variations in behaviour converge into deviant cannot be defined easily, and this may impact the screening and diagnostic processes and influence the prevalence rates of autism and broader autism phenotypes across regions

SCREENING TOOLS FOR ASD IN INDIAN CHILDREN

Screening is crucial for identifying children at risk for ASD and facilitating early behavioural and educational interventions to improve outcomes. The Indian Academy of Pediatrics has recently issued guidelines for screening for ASD at 18 months and 24 months of age, using ASD specific screening tools.

Internationally standardized and validated tools for autism screening that are used in India include Modified Checklist for Autism in Toddlers (M-CHAT), Autism Spectrum Quotient (ASQ), Social Communication Questionnaire (SCQ), Social Responsiveness Scale (SRS), Autism Behavior Checklist (ABC) and Social Communication Disorder Checklist (SCDC). SCQ, SCDC and ASQ have been translated into Hindi and Bengali. The translated instruments were found to show similar properties to the original agencies, and the results showed that these tools could be used for screening purposes in the sub-

continent. However, the devices were validated on a small population. Further studies need to be done on a more significant subset of children before being used in epidemiological studies. Around 4% of children with Asperger Syndrome (DSM- IV criteria) did not meet the cutoff scores on these tools.

M-CHAT has been translated into many Indian languages, and Hindi, Bangla, Kannada and Tamil versions are available on the website. M-CHAT has been regularly used in clinical and epidemiological studies for screening toddlers, and the prevalence rate of toddlers at-risk for ASD was consistent with large scale screening studies in other countries. However, in most epidemiological studies conducted, the second stage diagnostic assessment was not done. A descriptive hospital-based study found that all screen-positive CHAT children were found to fulfil DSM criteria for autism. Conversely, in a retrospective study, all toddlers with autism were found to have failed M-CHAT.

There have been no published studies using Social Communication Questionnaire in the general population from the Indian Subcontinent. In a clinic-based sample of 30 children with ADHD, 28% children were SCQ screen-positive. In an unpublished study, 106 children with epilepsy were screened using SCQ, and 8 of 9 screen positive children fulfilled DSM-IV criteria. However, most parents perceived difficulties in understanding some of the items in the questionnaire, so that SCQ may be too technical from parents' perspective.

A study conducted to estimate sibling risk used the Social Responsiveness Scale (SRS) to screen siblings aged four and more, followed by diagnostic assessment using DSM-IV. All siblings who screened positive in SRS fulfilled the diagnostic criteria for autism.

The autism behaviour checklist (ABC) has potential utility for evaluating children with ASD in resource-poor settings, as it is available free of cost. The sensitivity of ABC in diagnosing autism in Indian children was assessed in a developmental clinic. Using the suggested initially cutoff score of 67, the checklist was found to have a sensitivity of 78%. When a lower cutoff of 45 was used, the sensitivity increased by 98%.

Even though many screening tools are widely used in India, most people cannot understand the original English versions. Many of these tools have been translated into local languages, but their psychometric properties have not been thoroughly examined. Screening tools for older children and adults, such as the SCQ and SRS, are expensive and inappropriate in resource-limited settings. Furthermore, before they can be used for population-based screening, the tool must be culturally adapted and modified following local socio-cultural and linguistic norms.

Indigenous Tools Developed in India :

Two tools have been developed in India to overcome the limitations of internationally available tools, standardize diagnosis, and thus facilitate early intervention for children with autism. These tools are the INCLIN Diagnostic Tool for Autism Spectrum Disorder and the Indian Scale for Autism (ISAA) assessment. These tools are completely free to use.

LEGAL PROVISIONS FOR PEOPLE WITH ASD:

The Act on the Rights of Persons with Disabilities (RPWD) of 2016:

Autism Spectrum Disorder (ASD) is now a disability under the Rights of Persons with Disabilities (RPWD) Act of 2016. The RPWD Act recognizes the equality of individuals with disabilities and outlaws disability discrimination, whether direct or indirect. The Government of India has developed rules for assessing disability and certifying them. Following certification, children with ASD are eligible for special privileges such as inclusive education, scholarships, free transportation on state buses, railway concessions, self-employment loans, and financial aid for further education.

Article 7 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) of 2006 – Disabled Children

1. States Parties must take all necessary steps to guarantee that disabled children have the same admittance to all human rights and fundamental freedoms as children who are not disabled..

2. The child's best interests must take precedence in all acts concerning children with impairments.

3. States Parties must ensure that children with disabilities have an equal right to freely express their opinions on all issues that affect them, that their opinions are given appropriate weight based on their age and maturity, and that they receive disability and age-appropriate assistance in exercising that right.

Article 24 – Education

1. The United Nations Charter affirms the right of individuals with disabilities to an education, with the goal of ensuring that this right is achieved without discrimination and on an equal footing.

States Parties must offer a comprehensive education system at all levels to ensure the full development of human potential as well as a sense of dignity and self-worth.

2. In countries that have ratified the Convention on the Rights of Persons with Disabilities, the UN Charter guarantees the right of people with disabilities to free and compulsory primary and secondary education (ROC). States Parties are expected to ensure that persons with disabilities are not excluded from the general education system based on disability and that children with disabilities have equal access to an inclusive, high-quality, and accessible primary or secondary education as other children in their communities.

3. States Parties must provide opportunities for people with disabilities to learn life skills and social development skills to participate fully and equally in education and as members of the community.

States Parties shall adopt reasonable steps to this aim, such as facilitating the learning of Braille, alternative script, augmentative and alternative modes, means, and formats of communication, orientation and mobility skills, and offering peer support and mentoring.

Facilitating sign language acquisition and promoting the linguistic identity of the deaf people. Providing education for blind, deaf, or deaf and blind persons, especially children, in the most appropriate languages, modes, and ways of communication for the individual, as

well as in situations that promote academic and social growth..

4. States Parties shall make reasonable efforts to hire qualified sign language and Braille teachers, including teachers with disabilities, and train professionals and employees working at all levels of education to help ensure the implementation of this right. This training includes disability awareness and the use of appropriate augmentative and alternative modes, means, and formats of communication, educational strategies, and materials to assist people with disabilities.

5 The UN Charter should ensure that people with disabilities have equal access to Everyone else receives basic tertiary education, vocational courses, adult education, and lifelong learning.

States Parties must offer adequate accommodations in schools and higher education institutions for people with disabilities.

Conclusion

Our understanding of autism spectrum disorder has changed over time. Sixty years ago, the condition was simply an unidentified developmental delay grouped with intellectual disabilities. Today, it is recognized as a significant neurologically based disorder, an important public health issue, and a research topic. Researchers have struggled for years to find a cause for the disorder, with little success.

Despite this difficulty, research is moving in increasingly sophisticated directions. Numerous treatments have been developed to assist children with autism spectrum disorder in maximizing their potential to learn and become socially fluent, regardless of the severity of their impairments. A piece of legislation like this is a godsend for children with disabilities. These Acts cover a wide range of issues concerning children's rights with disabilities. It also directs the government to carry out its duties with zeal and develop schemes and programmes for the benefit of children.