

A Narrative Review of Autism Spectrum Disorder in the Indian Context

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Abstract

Autism is called “spectrum” disorder because there is a wide variation in the type and the severity of symptoms that people experience. India has a vast population, diverse cultures, and multiple languages, making it crucial to understand the unique challenges faced by individuals with autism spectrum disorder in the Indian context. This narrative review explores the current state of knowledge about autism spectrum disorder in the Indian context. Databases such as PubMed, Google Scholar, Sage journals, and other sources were searched with relevant terms for preparing this review. All published literature till January 2023 was studied and those which met the inclusion criteria were included. The resources included were original research articles, review articles, web pages, and book chapters addressing the purpose of the paper. Forty-eight such studies which met the inclusion criteria were included in the study. Results showed that the prevalence of autism varied across different studies in India. The study found advanced paternal age, fetal distress, gestational respiratory infections, labor complications, preterm birth, neonatal jaundice, delayed birth cry, birth asphyxia, late initiation of breastfeeding, neonatal seizures, use of maternal hormonal intervention, and consanguinity as some of the identified risk factors of autism spectrum disorder. Parents and families of children with autism have to go through a complex negative experience, both in the family and the community. This negative experience is further compounded by the lack of awareness and access to appropriate professional help and resources. It can be concluded that there is an urgent need for services that help parents cope with the stress of parenting a child with autism.

Keywords

Autism spectrum disorder, autism, risk factors, challenges, research, India

Introduction

Autism spectrum disorder (ASD) refers to “a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively.”¹ ASD is a neurodevelopment condition that continues to exist through childhood and adulthood. Most of the disorders are discovered during the first 5 years of life. Patients with ASD often suffer from other medical conditions such as epilepsy, depression, anxiety, or attention deficit hyperactivity disorder. Individuals with ASDs have a wide range of intellectual functioning, ranging from high intelligence to substantial intellectual impairment.²

The present narrative review article discusses the following aspects of research done on ASD in India: beginning of research on autism in India, screening of ASD in India, its prevalence, its risk factors, challenges faced by

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parents and family of a child with ASD, and legal provisions for education and employment of an individual with autism.

Methods

Databases such as PubMed, Google Scholar, Sage journals, Wiley Online Library, and other sources were searched with relevant terms (such as “autism spectrum disorder in India,” “children with autism spectrum disorder,” “families with children with autism,” and “parents of children with autism spectrum disorder”) for preparing this review. All published literature till January 2023 was studied and studies which met the inclusion criteria were included. The resources could include original research articles, review articles, book chapters, and web pages addressing the purpose of the paper. The resources were subjected to the following inclusion criteria:

1. It must be published in English.
2. It must include content on autism research, beginning of research on autism in India, its screening, prevalence, risk factors, challenges for the family and legal provisions for education, and employment of individuals with autism in the Indian context.

During this search, 48 such studies were found which met the inclusion criteria.

Beginning of Research on Autism in India

The term “autism” is derived from the Greek words “*autos*” (self) and “*ismos*” (action) and was coined by Leo Kanner in his remarkable paper in 1943³ to characterize children with an “extreme inability to relate to others.”

Some early theorists believed that autism is caused by emotionally detached parenting (often referred to “refrigerator mothers”)⁴; however, this idea was long ago rejected. The diagnosis of ASD is made based on behavioral observation in 2 main categories: social communication and interaction, and restricted and repetitive behavior. Currently, there is no genetic, chemical, or neurological test for ASD. There is now a lot of evidence that ASD is primarily a neurobiological disorder, that is, the characteristic social, communicative, and repetitive behaviors observed to diagnose the disorder are the developmental consequences of the brain.⁵ However, there is no clear agreed-upon cause of autism till now. Consequently, treatment methods also vary substantially. Thus, from the inception of the disorder in 1943 to the currently used Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), there is now much more information available related to ASD.

However, the knowledge of Western psychiatry and psychology first emerged in India with the British colonialism.⁶ “Child showing schizophrenic behavior” first appeared in 1959⁷ and research on autism increased significantly since

then.⁶ Autism was given sustained professional attention in the late 1980s and 1990s,⁸ and now it is widely recognized in medical, political, and legal contexts in India.^{6,9}

Screening of Autism in India

The diagnosis of ASD in India is primarily based on the DSM-5 criteria, which is used globally. The assessment process involves the use of standardized tools and techniques for evaluating the child’s behavior, developmental milestones, and social communication skills.

Several screening tools for autism are commonly used in India. Some of the most widely used screening tools include:

INCLEN-INDT (Indian Network for Developmental and Behavioral Pediatrics—Indian Diagnostic Tool for ASD): It is specifically designed for use in India. It is a comprehensive assessment tool that evaluates a child’s developmental, behavioral, and social skills to determine if they meet the criteria for ASD. It is a culturally appropriate tool that takes into account the diverse population of India and has been shown to have good sensitivity and specificity for detecting ASD.¹⁰

Childhood Autism Screening Instrument: It is a screening tool that is used to identify children who may be at risk of ASD. It is a parent-completed questionnaire that assesses a child’s communication, social interaction, and play skills. It is a quick and easy-to-administer tool with good sensitivity and specificity for detecting ASD in young children.¹¹

Modified Checklist for Autism in Toddlers (M-CHAT) and M-CHAT Follow-up Interview: It is used to assess the risk of ASD in children aged 16 to 30 months. The M-CHAT is a 23-item questionnaire that is completed by parents or caregivers. If an individual receives a positive score on the screening test, they have a follow-up interview before deciding whether they need a referral.¹²

Childhood Autism Rating Scale (CARS): It is used to assess the severity of ASD in children. The CARS is a 15-item questionnaire that is completed by a trained professional. It is done by rating the child’s behavior, characteristics, and abilities against the expected developmental growth of a typical child.¹³

Social Communication Questionnaire (SCQ): It is used to assess the risk of ASD in children aged 4 years and older. The SCQ is a 40-item questionnaire which is also completed by parents/caregivers.¹⁴

Autism Diagnostic Observation Schedule (ADOS): This is a screening tool that is used to assess the presence and severity of ASD in children and adults. The ADOS offers a method of establishing a benchmark of measurement by identifying the

shared characteristics found in individuals with autism. This involves evaluating the person's behavior and communication skills across different social situations. By using this tool, caregivers and experts can determine where an individual falls on the autism spectrum and what interventions would be beneficial to help them receive appropriate assistance.¹⁵

Indian Scale for Assessment of Autism (ISAA): This is a screening tool that has been developed specifically for use in India. The ISAA is a comprehensive assessment tool that includes both observational and interview-based components. It consists of 40 items which are divided under 6 domains: social relationship and reciprocity, emotional responsiveness; speech—language and communication, behavior patterns, sensory aspects, and cognitive component.¹⁶

The diagnosis of ASD in India is challenging due to the lack of awareness and understanding of the disorder among the general population. Additionally, there is a lack of resources, lack of trained professionals, and language and cultural barriers, which hinders the screening and diagnosis process.¹⁷

Prevalence

The main reason behind the emerging interest in ASD is its growing prevalence. According to the World Health Organization 2019 factsheet, 1 in every 100 children worldwide is diagnosed with ASD.¹⁸ This estimate, however, is an average figure, and reported prevalence differs substantially across studies. Some well-controlled studies have reported figures that are much higher figures.² The prevalence of ASD in many low- and middle-income countries is still unknown. Epidemiological studies conducted over the past 50 years have shown that the prevalence of ASD is increasing globally. There are many possible explanations for this apparent increase, including improved awareness, expansion of diagnostic criteria, better diagnostic tools, and improved reporting².

In India, in order to estimate the prevalence of ASD, many community and school-based surveys were carried out. The first ever community-based assessment of the prevalence of neurodevelopmental disorders in children in India, and probably in the whole of the developing world assessing the children for vision and hearing problems, epilepsy, and neuromotor conditions such as cerebral palsy, speech problems, autism, and intellectual disability was conducted by Arora et al. They diagnosed 44 children with autism, using a free test called the INDT-ASD. The study revealed that about 1 in 100 children in India under age 10 has autism, and nearly 1 in 8 has at least one neurodevelopmental condition.¹⁹

Raina et al²⁰ also conducted a study to estimate the prevalence of ASDs in the selected areas (tribal, rural, and urban) of a northern state of India, Himachal Pradesh. They carried out the study in 2 phases: phase 1 included the screening of all the children in the age group of 1–10 years, with the help of ISAA; phase 2 involved the clinical evaluation of children

who were suspected of autism on screening. They screened a total of 11,000 children in the age group of 1–10 years. The prevalence rate was found to be 0.9/1000.

Another study²¹ was carried out to estimate the prevalence of autism in a selected population of school children in Kolkata, India. Parents/caregivers and teachers filled out the Social and Communication Disorders Checklist (SCDC). Children who met the cutoff on parent-reported SCDC were followed up with the SCQ. SCQ-positive children were administered the ADOS. The weighted prevalence estimate of positive scores (for broader autism spectrum + ASD + autism) was 0.23% (0.07–0.46%). However, since nearly 20% of children in this state are known to be out of the school system, the reported ASD prevalence estimate is likely to underrepresent the true prevalence.

Risk Factors

The risk factors of ASD are still debatable and cannot be attributed to any single factor. Some genetic factors, perinatal complications, family history of autism, higher parental age at the time of conception, intra-uterine exposure to medications, consanguinity, and a few more are believed to be the risk factors for ASD.^{22–25} Many studies were conducted in India to validate whether these are really the risk factors as well as to identify other factors that can be risk factors for ASD. Mamidala et al conducted a retrospective case-cohort study in India. This study was the first in India to examine the factors that contribute to ASD. The researchers analyzed children under the age of 10 with ASD and compared them to an equal number of control subjects. They looked at various pre-, peri-, and neonatal factors and evaluated a total of 25 different factors in the study. The findings showed that certain factors were associated with ASD. During the prenatal period, advanced maternal age, fetal distress, and gestational respiratory infections were found to be linked to ASD, with a measure called the odds ratio of 1.8. In the perinatal and neonatal periods, complications during labor, premature birth, neonatal jaundice, delayed birth cry, and birth asphyxia were also associated with ASD, with odds ratios greater than 1.5. The study was significant because it sheds light on the specific risk factors for ASD in the Indian population. It provided valuable information about the impact of pre-, peri-, and neonatal factors on ASD, which was previously unknown in this ethnically and socially diverse country.²²

Mamidala et al explored maternal hormonal interventions as a risk factor for ASD by directly interviewing the parents with the help of trained staff. It was found that maternal hormonal intervention was a significant risk factor for ASD with an odds ratio of 2.24.²⁴

Consanguinity is the risk factor for many disorders; however, it is not known whether it increases the risk for ASD or not. To find out this, Mamidala et al studied a large population of India and concluded that consanguinity increases the risk for ASD with an odds ratio of 3.22.²³

Saranya Ravi et al screened children aged 16–30 months for ASD and to find the association between maternal, birth, and postnatal risk factors of ASD. These children attended the pediatric outpatient department of JIPMER, Puducherry, from June to August 2014. They used Modified Checklist for Autism in Toddlers-Revised. The study found that 33 (9.4%) children were screened positive for ASD. The mean age was found to be 21 months. High mean paternal age at birth, need for resuscitation at birth, NICU stay more than 12 hours, late initiation of breastfeeding, and neonatal seizures were found to be associated risk factors of ASD.²⁵

Hence, advanced paternal age, fetal distress, gestational respiratory infections, labor complications, preterm birth, neonatal jaundice, delayed birth cry, birth asphyxia, late initiation of breastfeeding, neonatal seizures, use of maternal hormonal intervention, and consanguinity were some of the identified risk factors of autism found in the studies.

Challenges Faced by Parents and Family of Child with Autism

ASD has an intense lifelong effect on the child with autism as well as his/her family. The impact of communication, social interaction, and behavior deficits not only affects the child's interaction with his/her family but also affects the relationship between the family and the community. ASD can have a significant impact on family dynamics, causing caregiver overburden, and depression among other family members of children with autism.²⁶ Thus, the impact of the disability impacts every member of the family.

To describe the experiences of families raising a child with ASD in Goa, India, Divan et al conducted a study aimed to understand their unmet needs. The authors found that raising a child with ASD can be very challenging for families as they try to balance competing commitments, which can result in them initially withdrawing from social interactions. Second, the impact is a complex negative experience resulting in ostracism and discriminatory behavior from the wider community. Third, parents actively deal with these challenges by using different strategies and seeking support from friends, family, and healthcare professionals. Fourth, professionals in the healthcare, education, and religious fields often lack awareness about the specific needs of families with individuals who have ASD. This lack of awareness puts a significant emotional and financial burden on families. Lastly, due to these experiences, several unmet needs can be identified for supporting isolated families and providing access to comprehensive services for ASD based on scientific evidence.²⁶

Parents of a child with autism are particularly vulnerable to chronic stress and trauma. They are at a higher risk for depression, social isolation, and marital discord.²⁷ They undergo periods of disbelief, deep sadness, depression, helplessness, and feelings of inadequacy, shock, and guilt. They face difficulty in accepting a diagnosis of ASD or accepting

that their child might have a disability. Hence, there is a prolonged period of denial and self-blame for what had happened to their child.²⁸ Parents raising a child with autism face a new challenge every day. In some cases, helping their child sleep and waking them up is a tough ordeal. There is a lot of crying and sometimes they are inconsolable.²⁷ Parents undergo significant stress in teaching their child communication skills, basic life skills, finding the right school and type of education for their child, dealing with challenging behavior, guarding their children from danger, helping them to maintain friendship or a relationship, protecting their children from exclusion or bullying, and preparing their children for their adult life. They too suffer coping with other people's attitudes, ignorance, and prejudice. The lack of knowledge and awareness about autism among friends and family makes it even more difficult for the parents. Such complex interaction between personal struggle and negative societal response leaves parents feeling worried, upset, apprehensive, and sometimes embarrassed. Parents find it difficult and are hesitant to talk with friends about their child's behavior and disability.²⁸ Lack of information on resources to obtain a diagnosis of ASD²⁷ and the financially draining cost of treatment are extremely exhausting to parents and caregivers of children with ASD. Parents and caregivers were not aware of the ASD symptoms until their child was given the diagnosis of ASD. A facility-based cross-sectional study at Bhubaneswar conducted by Mahapatra et al revealed that the majority of the parents did notice deficits in social interaction and behavior among their children. However, the parents were not aware of ASD until their children were diagnosed with ASD by the child psychiatrists. Lack of awareness, limited access to services, and stress contributed to the delay in ASD diagnosis.¹⁷

Perumal et al²⁹ examined how parents' quality of life differed between 3 groups: parents of children with autism, parents of children with physical disabilities, and parents of typically developing children (control group). They discovered that when compared to parents in the other 2 groups, parents of children with ASD experienced significant difficulties in all 4 areas of life assessed by WHOQOL-BREF (i.e., physical, psychological, social, and environmental). Although little differences were observed in the physical and psychological domains, significant differences were found in the social and environmental domains in the physically disabled group and the normal group. Das et al³⁰ and Tripathi³¹ found definite stress among the parents of children with autism. Personal time constraints were seen in the majority of parents, which adversely affected their professional lives.³⁰

Mothers and fathers cope differently with the challenges faced while dealing with their child with autism. Fathers report more difficulties with their child's autistic behavior and generally have less participation in parenting, and they cope up with the stress by working away from home.³² Bhullar compared the experiences of parents of 2 adolescents with ASD differing in gender, including their daily routines

at school and at home, challenging behavior, social support, and future plans for their children. Parents of the 2 adolescents with ASD were interviewed with open-ended questions related to their child and their personal experiences. Both parents shared similarities in their experiences, such as having limited support from sources outside their families and holding hopes for their children's future that emphasized the importance of a "normal" life. However, differences were observed when it came to how the parents described their children's symptoms. Specifically, the father of the female adolescent with ASD reported more negative experiences with both his child and his spouse, along with a lack of social support. As a result, he expressed greater dissatisfaction on the satisfaction with life scale compared to the mother of the male adolescent with ASD.³²

Minhas A et al found that the mother is often solely responsible for taking care of the child with autism, which causes them to experience a lot of stress. The lack of understanding about autism among family members and health-care providers results in a delay in recognizing the condition and providing the right support and treatment for individuals with autism. The stigma and discrimination regarding autism adversely affects children with autism and their families. Professional services for ASD management are rare, concentrated in urban areas, and inaccessible to the majority of affected children.³³ Singh et al found that the majority of the mothers in their study suffered from clinical depression due to the burden associated with parenting their child with ASD. The study also concluded that social support alleviates the burden and depression associated with parenting a child with ASD.³⁴

Siblings of children with autism also suffer emotional and psychological stress. They might feel embarrassed about growing up alongside a sibling who has behavioral challenges. While they may have a deep love for their sibling, they might feel resentful at times because of the extra care and time their parents are devoting to their autistic sibling. Studies conducted indicate that the siblings of children with autism have to make a variety of adjustments and cope up with many difficulties that impact their relationships with their autistic sibling.³⁵ Rana and Mishra³⁶ also found that normal siblings of children with chronic neurological disorders (who did not have any neurological disorders themselves) had significantly impaired quality of life compared to control children without an affected sibling. Additionally, they also discovered that the majority of siblings were unaware of their sibling's impairment.

However, now many organizations such as Action for Autism in Delhi, Center for Autism Therapy, Counseling and Help in Bhubaneswar, Communication DEALL, Assisted Living for Autistic Adults in Bengaluru, Ummeed in Mumbai, and many more are working in India for spreading awareness on autism, providing rehabilitation services for children with autism as well as offering support to individuals with ASD and their families through counseling and guidance.³⁷

Legal Provisions for Education and Employment of Individuals with Autism Spectrum Disorder

The government of India has taken several initiatives to provide education for children with special needs, including those with autism. The Sarva Shiksha Abhiyan program aims to provide inclusive education to all children, including those with disabilities. For this, the Samagra Shiksha component provides support for various student-oriented activities to benefit children with special needs. These activities include identifying and assessing children with special needs, providing aids, appliances, and corrective surgeries, developing accessible learning materials such as Braille books and large print books, offering therapeutic services, conducting training for special educators and general teachers on curriculum adaptation, creating awareness about the needs of children with special needs, implementing the Right to Education Act for children with special needs, and providing resource support to schools in the form of financial assistance for hiring special educators. These initiatives aim to ensure inclusive education, remove barriers to learning, and enhance the overall educational experience for children with special needs. Under this, the National Council of Educational Research and Training (NCERT) has developed "Barkha: A Reading Series for 'All'" as an inclusive learning material for early reading. It follows the principles of Universal Design for Learning and includes tactile features, high-resolution visuals, and accessible text. A digital version of the series has also been created, allowing flexibility and accessibility for children. Additionally, the department has produced a Teacher's Handbook for including children with autism in mainstream classrooms, providing interventions, strategies, and curricular suggestions for inclusive education.³⁸

Apart from this, Inclusive Education for Disabled at Secondary Stage is a centrally sponsored scheme that supports the educational needs of children with disabilities, including autism, in secondary schools. It provides financial assistance for various interventions such as aids and appliances, support services, and inclusive education.³⁹

The University Grants Commission has implemented provisions under the Higher Education for Persons with Special Needs initiative. These provisions include the establishment of equal opportunity cells in universities, making infrastructure accessible, providing financial support for assistive devices, offering special examination facilities, conducting sensitization and training programs, offering scholarships and financial assistance, adapting the curriculum, and providing support for students with disabilities. These measures aim to promote inclusive higher education, ensuring equal opportunities and support for students with disabilities throughout their academic journey.⁴⁰

The National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID) is a premier institute dedicated to providing training, research, and education for persons with intellectual disabilities, including autism. It offers

various programs and services for children with autism and their families.⁴¹

The government also emphasizes skill development and vocational training for children with autism to enhance their employability and independence. Initiatives such as the National Skill Development Corporation⁴² and Skill India⁴³ provide vocational training opportunities for individuals with disabilities.

The Companies Act, 2013, mandates that certain companies allocate a portion of their profits toward corporate social responsibility activities.⁴⁴ Many companies have taken initiatives to promote inclusive employment by hiring individuals with disabilities, including autism. These initiatives focus on creating inclusive work environments and providing reasonable accommodations.⁴⁵

The government has reserved a percentage of job vacancies in government departments and public sector undertakings for persons with disabilities. This reservation includes individuals with autism, ensuring opportunities for employment in the public sector.⁴⁶

Initiatives such as the National Handicapped Finance and Development Corporation provide financial assistance, training, and support for starting businesses or self-employment ventures.⁴⁷

Additionally, many private organizations, nongovernmental organizations (NGOs), and community-based initiatives are also playing a significant role in promoting education and employment for individuals with special needs, including autism.

However, challenges and gaps still exist in the effective implementation and access to these opportunities.

Discussion

This article provides a brief overview of the current state of autism research in India, its screening, its prevalence, risk factors, and challenges faced by parents and families of children with autism and legal provisions for education and employment of individuals with autism. A majority of the studies found that parents and families of children with autism have to go through a lot of difficulties to provide rehabilitation to their children.^{17,26,30–32,34–36,48} Parents of children with autism need to be informed and trained so that they can become competent caregivers. Additionally, it is important to provide suitable counseling to families of children with autism to address their own feelings of grief and helplessness. It is crucial to offer support services that can help parents develop effective strategies to manage the challenges and pressures that come with raising a child with autism. Many people, including parents and teachers, are not familiar with the signs and symptoms of ASD, which delays the screening and diagnosis process. Also, there is a stigma attached to mental health issues in India, which discourages parents from seeking help for their child if they suspect they have ASD. Some

parents are also reluctant to disclose their child's condition due to fear of discrimination or social ostracism. These low awareness levels and high levels of stigmatization make the situation even worse for individuals with autism and their families. People with autism and their families require positive support from society and deserve to be respected as unique individuals and human beings. In countries like India, where awareness about autism is still growing and services for autism are limited, it is crucial to set up effective services to deal with the problems related to the autistic individual, their family, and society as a whole. Also till now, the majority of the progress made is primarily led by NGO initiatives, which are mostly parent-driven and receive very limited support from the government. Although the government has introduced provisions for the education and employment of disabled individuals, the implementation and awareness among those in need remain insufficient. Additionally, there is currently a lack of government initiatives specifically targeting autism in India. Hence, there is also a need for framing effective policies as well as implementing them; the collaboration between the government and NGOs is necessary.

Authors Contribution

Manushi Srivastava conceived the presented idea, revised the manuscript, and supervised the study. Pradyumn Srivastava provided relevant literature, revised the manuscript, and added contents to the manuscript. Arun Kumar Dubey also provided relevant literature and revised the manuscript. Priya Srivastava organized the literature, drafted the manuscript, and did the write-up. All authors discussed the results and contributed to the final manuscript.

Declaration of Conflicting Interests

All the authors declare that they have no competing interests. The authors alone are responsible for writing the manuscript.

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