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Autism Spectrum Disorder: The Indian Perspective

Dr. Simran Kaur Batra, *Assistant Professor, Department of Psychology, DAV College, Chandigarh*
simranbatra.dav@gmail.com

***Abstract*:** Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by persistent challenges in social communication, restricted interests, and repetitive behaviors. While its global conceptualization has evolved from narrow medical definitions to a more inclusive neurodiversity framework, the Indian trajectory has been shaped by delayed diagnostic recognition, cultural interpretations, and uneven access to services. This paper traces the evolution of autism in India, from its first clinical reports in the 1960s to contemporary advocacy and representation in media. It examines early diagnostic invisibility, fragmented research, and the role of myths, spiritual attributions, and collectivist norms in shaping public perceptions. It also discusses traditional healing systems, the emergence of advocacy movements, shifts toward self-representation, and the portrayal of autism in Indian popular culture. Drawing on sociocultural, historical, and policy perspectives, the paper argues for indigenous, intersectional, and neurodiversity-affirming approaches that reflect India's diverse realities and move beyond deficit-based frameworks toward inclusive support and representation.

Keywords: *Autism Spectrum Disorder, Cultural Perceptions, Early Diagnosis, Advocacy, Traditional Healing Systems, Intersectional Inclusion.*

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition marked by persistent challenges in social communication, restricted interests, and repetitive behaviors (American Psychiatric Association [APA], 2013). While once viewed through narrow medical lenses, autism

is now understood as a spectrum encompassing diverse expressions of neurodevelopmental variance. The global evolution of autism, from Kanner's (1943) early conceptualization of "infantile autism" to the dimensional, inclusive framework of the DSM-5, has seen shifts in diagnostic clarity, public discourse, and research priorities (Volkmar & McPartland, 2013). The global prevalence of ASD has risen significantly, with estimates suggesting approximately 1 in 100 children worldwide are on the spectrum (World Health Organization [WHO], 2023b). These figures, however, must be interpreted within the context of increasing awareness, better diagnostic tools, and evolving sociocultural lenses. In this paper, we examine how the evolution of autism intersects with Indian contexts—historical, cultural, legal, and contemporary—and argue for a more indigenous, inclusive, and neurodiversity-informed framework moving forward.

1.1 Autism in India

First Diagnoses and Early Visibility

In India, the recognition of autism as a distinct neurodevelopmental condition lagged significantly behind Western psychiatric discourse. The first reported case of autism in India was documented in the 1960s by child psychiatrists working in tertiary care hospitals, but it remained an isolated clinical observation rather than a widely acknowledged category (Daley & Sigman, 2002). Throughout the 1970s and 1980s, the term "autism" was largely absent from diagnostic practice and mental health literature in India. Instead, children exhibiting core features of autism—such as social withdrawal, lack of verbal communication, and stereotyped behaviors—were frequently misdiagnosed with intellectual disability, childhood schizophrenia, or behavioral issues attributed to dysfunctional parenting or attachment problems (Desai et al., 2012).

One major barrier to early visibility was the lack of trained pediatric neurologists, child psychologists, and developmental pediatricians, especially outside urban centers (Srinath et al., 2005). The absence of indigenous diagnostic criteria also meant that Western-based frameworks like the Diagnostic and Statistical Manual for Mental Disorders (DSM) or International Classification of Diseases (ICD) were inconsistently applied, often without cultural contextualization. This led to a pattern of "under-diagnosis" or "late diagnosis," where children were either labeled incorrectly or not diagnosed at all until adolescence or later. In fact, a 2002 study found that many Indian clinicians were unsure about the clinical boundaries between autism, PDD-NOS, and intellectual disabilities (Daley & Sigman, 2002).

Public awareness during this time was almost negligible. Mainstream media, school systems, and even medical curricula made little to no mention of autism. Parents often attributed their child's developmental differences to idiosyncrasies, delayed milestones, or lack of discipline, resulting in delayed consultations with professionals (Ravindran & Myers, 2011). In some cases, the problem was only recognized when children failed to adapt to school environments or began to show escalating behavioral issues.

It was only in the 1990s and early 2000s that autism gained national attention, thanks in part to pioneering efforts by Indian advocacy organizations such as Action for Autism (AFA), established in 1991. AFA played a pivotal role in public education, professional training, and the introduction of diagnostic and early intervention models tailored to Indian contexts (Purkayastha, 2020). The establishment of India's first autism-specific school (Open Door) and publications such as Autism Network magazine also helped in shaping public and clinical discourse.

However, even today, many diagnoses occur late, often after the age of five, and access remains unequal across regions and socioeconomic strata. This underscores the lasting impact of historical invisibility and the continued need for early screening, especially in non-English-speaking and rural communities.

Early Indian Research and Conceptual Ambiguity

The foundational research on autism in India remained limited and fragmented until the late 1990s, largely due to the condition's delayed diagnostic visibility and minimal presence in clinical training. Early studies were predominantly descriptive case reports, lacking large sample sizes, epidemiological rigor, or culturally sensitive. methodologies. Much of this early work was heavily reliant on Western diagnostic frameworks such as the DSM-III and DSM-IV or ICD-10, which were adopted without adequate cultural adaptation or validation (Daley, 2003b).

A major issue was the lack of consensus among Indian mental health professionals regarding the diagnostic boundaries of autism. In a seminal study, Daley and Sigman (2002) found that psychiatrists, psychologists, and pediatricians in India often had divergent conceptualizations of autism, some viewing it as a subtype of intellectual disability, others confusing it with schizophrenia or attention disorders. This diagnostic inconsistency not only delayed interventions but also contributed to inappropriate educational placements and stigmatizing labels for children with autism.

Another limitation of early research was its urban bias. Most published studies were conducted in metropolitan centers like Delhi, Mumbai, or Bangalore, where access to mental health professionals and developmental pediatricians was more readily available. This urban-centric lens created a skewed understanding of autism that excluded rural populations, linguistic minorities, and non-English-speaking families—many of whom experience autism within vastly different sociocultural contexts (Desai et al., 2012).

Moreover, standardized instruments such as the Childhood Autism Rating Scale (CARS) or Autism Diagnostic Observation Schedule (ADOS) are often translated but not normed for Indian populations, limiting their reliability and ecological validity. Recent calls by Indian researchers emphasize the urgent need for indigenous, psychometrically robust tools that reflect the diversity of Indian children's behavior, language, and social interaction patterns.

Thus, while India's autism research landscape is expanding, it continues to be constrained by methodological, infrastructural, and cultural challenges. Addressing these gaps is essential for producing more inclusive and representative knowledge systems that support early identification, tailored interventions, and evidence-based policymaking.

Myths, Misconceptions, and Spiritual Attributions

The Indian sociocultural landscape is deeply intertwined with religious and spiritual beliefs, which often shape perceptions of illness and disability. In the case of autism, this has led to widespread myths and misconceptions, particularly in communities with limited exposure to clinical mental health frameworks. Behaviors such as lack of eye contact, hand-flapping, echolalia, or social withdrawal are often interpreted not as symptoms of a neurodevelopmental condition but as signs of spiritual disturbance or karmic punishment (Daley, 2004; Desai et al., 2012).

In many cases, caregivers are told that the child's condition is the result of past-life sins or divine retribution, particularly aimed at the mother. This maternal blame sometimes even from within the extended family—can cause immense psychological distress and hinder help-seeking behavior (Ravindran & Myers, 2011). Rituals such as jhad-phoonk (spirit cleansing), visits to babas (spiritual healers), or tantric interventions are often employed before medical consultation is even considered.

Research by Mandal (2015) on rural Bihar and West Bengal found that families commonly perceived autism as a "phase," "possession," or even as "God's child"—a romanticized view that, while appearing benign, often delayed therapeutic intervention. These interpretations sometimes

lead to fatalism, where parents may not pursue structured education or rehabilitation due to the belief that the condition is unchangeable or divinely ordained.

Cultural Interpretations and Social Norms

Indian sociocultural frameworks are collectivist and deeply hierarchical, emphasizing conformity, obedience, and academic performance—values that may directly conflict with the behavioral profiles of individuals with autism (Karanth & Chandhok, 2013). In such a context, a child who does not respond to greetings, interrupts adult speech, or engages in repetitive self-stimulatory behaviors may be seen as rude, spoiled, or defiant rather than developmentally different.

Furthermore, gender norms in India compound the problem: girls are more likely to be undiagnosed or misdiagnosed due to societal expectations of passivity, shyness, and caregiving behaviors. Girls may be seen as merely "quiet" or "introverted," with underlying social-communication deficits often missed (Begeer et al., 2012). The lack of visibility for female with autism in both clinical and cultural domains remains a significant gap.

Autism also challenges Indian parental aspirations centered on scholastic achievement, marriageability, and "normalcy." As such, families may experience "cultural mourning"—grieving not only the diagnosis but also the perceived loss of future expectations for the child (Daley, 2002). This can result in concealment, social withdrawal, or institutionalization, especially among middle-class urban households keen on preserving social status.

Traditional Healing Systems

India's long-standing traditional medical systems—such as Ayurveda, Siddha, Unani, and homeopathy, continue to play an important role in the management of autism. Many families view these systems as holistic and natural alternatives to pharmacological or behavioral therapies. Treatments may include herbal regimens, panchakarma therapies, dietary modifications, and meditation-based practices (Masooda et al., 2023).

However, there is growing concern that over-reliance on such treatments—especially when administered by unregulated practitioners—can delay access to evidence-based care. Misguided claims of "curing" autism through detoxification, prayer, or heavy-metal chelation (without oversight) raise significant ethical and medical red flags (Rao & Sreenivas, 2015). Therefore, while some integrative approaches may have adjunctive benefits (e.g., yoga for sensory regulation),

mainstreaming them without robust scientific validation risks reinforcing pseudoscientific narratives.

Nonetheless, recent interdisciplinary work has suggested that bridging biomedical and traditional frameworks through culturally competent dialogue—may help reduce stigma and enhance community acceptance.

1.2 Contemporary Shifts in Autism Understanding in India

Rise of Autism Advocacy and Self-Representation

Over the past two decades, India's autism advocacy landscape has undergone a significant transformation. Organizations such as Action for Autism (AFA), founded in 1991 in Delhi, were among the first to provide structured support, diagnosis, education, and awareness programs for individuals with autism and their families. AFA played a pivotal role in introducing autism into public discourse, organizing national conferences, and lobbying for legal recognition under disability rights frameworks (Daley, 2004).

One of the most notable shifts in this advocacy movement is the growing inclusion of adults with autism in leadership and decision-making roles within these organizations. This change reflects a broader global trend toward neurodiversity, which challenges the pathologizing, deficit-based views of autism and instead promotes acceptance of neurological differences as part of human diversity (Kapp et al., 2013).

Simultaneously, there has been an ongoing debate around the use of person-first language ("person with autism") versus identity-first language ("autistic person") in India. While person-first language has traditionally been emphasized in professional settings, many self-advocates are now asserting a preference for identity-first language, arguing that autism is an integral part of their identity rather than a separable impairment. This linguistic shift marks a critical reorientation in public narratives—from viewing autism as a disorder to be treated or cured, to recognizing it as a difference to be understood and supported.

Social media platforms, webinars, and community storytelling events—often spearheaded by younger, urban neurodivergent individuals—have also contributed to grassroots-level sensitization. These platforms allow individuals to reclaim their narratives, educate the public, and build solidarity. However, advocacy efforts still face structural barriers, including urban concentration, underrepresentation of rural voices, and the need for intersectional inclusion of gender, caste, and class identities within the neurodiversity movement (Verma, 2021).

1.3 Autism in Pop Culture and Media

The representation of autism in Indian popular media has seen a gradual shift over the past two decades, reflecting broader societal changes in awareness and discourse. While early portrayals were virtually nonexistent or deeply misinformed, the landscape began to change in the mid-2000s with the release of films that challenged normative understandings of child development and neurodiversity.

One of the most pivotal moments was the release of Taare Zameen Par (2007), a commercially successful and critically acclaimed Bollywood film directed by Aamir Khan. Although the film focused on dyslexia, it catalyzed national conversations about neurodivergence, inclusive education, and parental pressure. Many viewers—unfamiliar with psychological diagnoses—began to use the term "autism" interchangeably with learning difficulties, inadvertently conflating distinct neurodevelopmental conditions. This confusion, while problematic, also opened doors for broader awareness and inquiry into atypical childhood development.

Subsequent portrayals of autism in Indian cinema and television have varied in their accuracy and sensitivity. Films like My Name is Khan (2010), starring Shah Rukh Khan, featured a protagonist with Asperger's Syndrome, though the film received mixed reactions from the autism community. While praised for depicting a character with social and communication differences, the portrayal leaned heavily on dramatic tropes, positioning autism as a plot device rather than a nuanced condition. Critics argued that the film romanticized savant traits and failed to represent the diversity within the autism spectrum.

Regional cinema has also contributed to representation. The Malayalam film Swathanthryam Ardharathriyil (2018) and the Tamil film Haridas (2013) explored neurodivergent characters, often from the perspective of caregivers. In these portrayals, autism was frequently framed within family melodrama, emphasizing parental guilt, social stigma, or the search for a "cure"—themes that reflect common real-life narratives but risk reinforcing the deficit model of disability.

The advent of digital streaming platforms and short documentaries has somewhat diversified portrayals. Independent films and YouTube documentaries, such as The Reason I Jump – India Chapter and Autism: A Mother's Story, produced by Indian NGOs and educational content creators, have highlighted the lived experiences of individuals and their families. These digital

narratives often emphasize acceptance over cure, and voice over voiceover, giving space for self-representation.

However, despite growing visibility, stereotyping and sensationalism persist. Media narratives often fall into familiar tropes: the "tragic burden," the "innocent savant," or the "miraculous recovery." Rarely do they showcase the heterogeneity of the spectrum, the voices of non-speaking autistic individuals, or the challenges faced in adulthood, employment, romantic relationships, and independence (Purkayastha, 2020; Roy & Menon, 2022). Furthermore, females with autism are nearly invisible, reflecting both gender bias in diagnosis and media production.

Social media has begun to fill this representational gap, but Indian mainstream media continues to lack consultation with autistic individuals or specialists during production. As a result, well-meaning films may still perpetuate ableist narratives under the guise of inspiration or awareness. Scholars argue for a paradigm shift from "awareness-building" to neurodiversity-affirming storytelling, which portrays autistic people not as problems to be fixed but as individuals with agency, preferences, and rights (Kapp, 2020).

2. Conclusion

Rooted in a sociocultural fabric rich with spiritual beliefs, familial expectations, and communal norms, autism has often been misread, misrepresented, or simply misunderstood. For years, silence and stigma dominated the discourse, where maternal blame, karmic attributions, and ritualistic remedies filled the vacuum left by a lack of clinical awareness and systemic support.

Yet, amid these shadows, there has been light. The rise of grassroots organizations, the persistence of caregivers, and the emergence of autistic voices themselves have gradually begun to reshape public understanding. From the corridors of special education centres in urban India to the digital platforms where neurodivergent youth share their stories, a quieter revolution is taking place; one that centres dignity, choice, and acceptance over correction, cure, or conformity.

Still, this journey remains unfinished. It calls for nuanced, intersectional frameworks that include rural realities, gendered experiences, caste-based marginalizations, and linguistic diversity. It calls for media representations that move beyond the trope of the tragic genius, and for public health systems that listen more deeply and intervene more compassionately.

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