



Socioeconomic challenges and support mechanisms for families of individuals with autism spectrum disorder In India

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Abstract

Autism Spectrum Disorder (ASD) appears with comparable frequency worldwide, spanning different social, ethnic, and geographical settings. Nevertheless, the presence and quality of resources and services dedicated to ASD are noticeably limited in developing countries, including India. Compounding this issue, the encounters of individuals with ASD are profoundly influenced by sociocultural elements. Interestingly, a significant proportion of research on ASD has predominantly originated in economically advanced countries.

The objective of this study was to delve into the ways in which social, cultural, political, and economic factors impact the experiences of individuals with ASD and their families within the context of India. To attain this objective, interviews were held with seventeen parents of children with ASD, accompanied by structured observations conducted within several ASD-related organizations located in Jaipur and New Delhi. The findings of this study underscored the substantial role played by socioeconomic and cultural factors in shaping the experiences related to ASD.

Within India, there exists a scarcity of suitable ASD-related resources, and they remain even less accessible to those who are most in need. Furthermore, stigma and a lack of awareness act as additional barriers, impeding the quality and availability of necessary treatments and interventions. Despite the endeavours of numerous non-governmental organizations to tackle these challenges, their initiatives are constrained by inadequate support and funding from the government.

Keywords: Autism, socio-cultural factors, spectrum

Introduction

Autism spectrum disorder

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder marked by difficulties in social interaction and communication, as well as the appearance of restricted and repetitive activities. ASD is characterized by a wide range of symptoms and severity levels that impact individuals differently. It is frequently diagnosed in childhood and can have a substantial influence on a person's daily functioning, relationships, and overall quality of life.

ASD is characterized by challenges in social interaction, communication, and behaviour. Symptoms of ASD encompass avoiding eye contact, difficulties in interpreting nonverbal cues, engaging in repetitive activities, and relying on established routines.

Roughly a quarter of individuals with ASD are nonverbal,

according to Autism Speaks. About 60% of those with ASD exhibit some form of cognitive impairment, while others with the condition demonstrate a normal or even above-average IQ, as highlighted by Autism Expresses. Early signs of ASD commonly emerge during childhood. It's relatively unusual for a child with ASD to initially appear to be developing typically in the early years, only to experience regression later on. As indicated by its name, ASD exists on a spectrum, resulting in considerable variation in symptoms and severity from person to person.

Although the exact aetiology of ASD is unknown, it is most likely caused by a combination of environmental, biological, and genetic factors. Notably, there is little evidence to support claims that ASD is caused by bad parenting or childhood immunisations. Unfortunately, despite their lack of evidence, these falsehoods have permeated public discourse and ASD beliefs. ASD is a chronic illness that

currently has no cure.

Nonetheless, effective management and support can be achieved through a range of seven distinct behaviour and communication interventions, encompassing Applied Behavioural Analysis (ABA), occupational therapy, and speech therapy. Initiating intervention at an early stage, preferably before the age of three, is of paramount importance to empower individuals with ASD to lead lives that are rich in significance and social integration.

Numerous research studies have provided figures ranging from one in 150 to one in 68 people having some kind of ASD (National Trust; CDC). Boys are nearly five times more likely than girls to be diagnosed with ASD. ASD tends to be very stable across social and ethnic groupings, as well as geographical locations (Feinstein, 2011; CDC; National Trust) ^[17].

While the reported cases of ASD have surged, the precise degree to which the actual prevalence of the disorder has undergone change remains uncertain. This upswing in reported cases could be ascribed to several factors, including a broader classification of ASD, increased public awareness of the disorder, and enhanced diagnostic capabilities (CDC). Regardless of the underlying causes, one inescapable reality is the need for increased allocation of resources to meet the needs of individuals with ASD as the number of diagnosed cases continues to climb.

Disability as a Social Problem

Just like any other disorder, ASD comes with its unique set of difficulties and limitations. However, the effects of socioeconomic factors play a vital role in shaping the encounters of individuals and families dealing with ASD. Furthermore, given that ASD directly impacts behaviors and social interactions, the way society interprets and responds to this condition carries significant weight. In her work titled "Fieldwork on Another Planet," sociologist Chloe Silverman delves into the societal shaping of autism, highlighting the importance of understanding ASD within the context of the society it emerges from (Silverman, 2008) ^[28].

Moreover, considering disability as a societal challenge, it follows that the remedies should encompass, to some extent, social dimensions. Consequently, the research opted to examine ASD within the framework of disability as a concern that extends to the broader society.

Overview of ASD in an Indian Context: Policy, Culture, and Society

Over 2 million people are thought to have ASD in India alone. However, assessing the true prevalence of the ailment is difficult due to frequent misdiagnosis and underreporting. "It is now widely accepted that autism knows no geographical or social boundaries," said Adam Feinstein, an autism researcher and the father of an autistic child. The majority of the world's rates are almost same. "What is undeniably true is that cultural attitudes toward autism vary dramatically in developing countries, where the disorder was not recognized until the early 1990s in some cases" (Feinstein, 2011, n.p.) ^[17].

Individuals with ASD in India, akin to their counterparts in economically disadvantaged nations, encounter a unique array of challenges alongside the impairments

conventionally associated with their condition. The official recognition of ASD in India didn't transpire until 1999, marking a notable turning point. It's worth noting that ASD was broadly categorized as mental retardation within the framework of the Persons with Disabilities Act. This initial classification has significantly influenced the prevailing understanding of ASD in the country.

Consider Bangalore, where a recent development involves the adoption of a policy aimed at increasing funding for ASD and expanding disability benefits to individuals with ASD (Kurup, 2012) ^[21]. Nonetheless, such forward-thinking efforts are more likely to materialize at the state level than at the national level.

While ASD disregards geographical and socioeconomic distinctions, a substantial chunk of research dedicated to ASD has primarily unfolded in Western countries. Although certain inquiries have unfolded in developing nations, notably India, with the intention of understanding the viewpoints of individuals with ASD or their families, such endeavors are infrequent and often skim the surface of the intricate impact that social, economic, and cultural dynamics wield on ASD experiences. Hence, the central objective of this study was to bridge a significant knowledge void pertaining to the encounters of individuals with ASD and their families within the specific context of India.

This study was fundamentally centered on comprehending the impact of social, cultural, and economic factors on the lived experiences of individuals with ASD and their families in Rajasthan. This encompassed exploring subsidiary themes and secondary research questions. These subsidiary themes encompassed investigating how a parent's socioeconomic status influences the quality of their child's treatment, the overall accessibility of services connected to ASD, and the consequences of factors like stigma and inadequate awareness about ASD on the lives of those directly affected. The primary aim was to assess how Indian society's perceptions and reactions towards ASD influence the availability and caliber of relevant services and resources. Moreover, the study endeavored to pinpoint the social, political, cultural, and economic obstacles that might hinder the effective utilization of these services.

Materials and Methods

In order to investigate the aforementioned inquiry, a series of semi-structured interviews were administered to seventeen parents who had children diagnosed with ASD. The age spectrum of the children covered early childhood to the mid-twenties. Interestingly, a significant proportion of the interviewed parents also held roles as special educators, advocates, and volunteers. To uphold confidentiality, certain names have been altered to safeguard the identity of the participants.

Engaging with individuals with ASD directly was not possible within the scope of this study due to ethical and logistical concerns. As a result, the research will focus on gathering carer perspectives and investigating the role of socioeconomic variables in influencing their encounters and problems. The appendix contains a basic set of interview questions. The study also included semi-structured observations of several ASD-related projects and establishments. The execution of all interviews and observations received support and collaboration from two

organizations: Approach Autism based in Jaipur and the DISHA Foundation.

Unfortunately, due to the time constraints of this study, a complete comparison analysis including other locations or institutions could not be done. Furthermore, while investigating the views of persons and families affected by ASD who live in rural locations, as well as their unique challenges, would have undoubtedly given useful insights, this route could not be pursued due to a variety of obstacles. Given the wide range of experiences encountered by individuals and families dealing with ASD in India, the findings of this study may not be universally relevant beyond the unique context studied below.

A summary of the findings

This study discovered that social, cultural, and economic factors alter the lives of people with ASD and their families, influencing their access to appropriate diagnosis, treatment, and intervention. Limited resources impede support for both children and adults with ASD, which is exacerbated by socioeconomic constraints in families. Inadequate awareness further impedes comprehension and intervention. Despite the efforts of NGOs and individuals, progress is hampered by a lack of information, societal shame, and insufficient government involvement.

Results and Discussion

Availability of ASD-Related Services and Resources

Many people with ASD can lead successful lives and integrate into their communities if they have adequate resources and societal support. Early intervention is critical to achieving this potential (CDC, Autism Action). Strong support networks and education for parents managing the additional obligations of raising a kid with ASD are also essential (Bashir, 2014)^[7]. However, in many cases, parents face enormous hurdles in obtaining diagnosis, treatment, education, and crucial support networks, owing to a lack of necessary resources in many parts of India.

When inquired about government policies or interventions supporting individuals with ASD, one father responded with a laugh, stating "there are none." A recent bill was introduced to rectify the shortcomings of the problematic Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995. This proposed bill aims to enhance funding and resources for individuals with disabilities, including ASD. However, it faces significant challenges, notably the absence of plans to expand special needs schools; instead, it seeks to integrate these students into an education system unprepared to cater to their requirements. As of now, the bill is pending approval. In essence, the dearth of governmental initiatives has compelled NGOs and other independent entities to fill the void and address the needs of individuals and families affected by ASD.

Established in 1991, AFA has emerged as the predominant support system for families and individuals grappling with ASD across India (Feinstein, 2011)^[17]. This non-governmental organization (NGO) stands at the forefront, providing an array of vital services and invaluable resources encompassing diagnostics, specialized education, vocational training, and support tailored for parents. In response to the scarcity of ASD-focused services in Rajasthan, Garima and

Anurag initiated Approach Autism. According to their website, "the lack of Autism specific centres in Jaipur, combined with the desire of a group of parents to do their best and make a difference in the lives of children on the autism spectrum, led to the formation of Approach Autism." Following unsuccessful attempts to obtain a diagnosis for her child in India, a mother resorted to seeking diagnosis in the United Kingdom, where her child was eventually diagnosed with autism. Divya, another mother, shared her experience that it took over two years from the initial realization that something was amiss with their son to the eventual diagnosis (In-depth Interview).

Despite the potential for academic success with adequate assistance, educational resources tailored for children with ASD remain scarce. In most instances, both government and private mainstream schools lack the requisite structure and staffing to effectively address the requirements of children with ASD.

Even though public school districts are required by law to provide a just and appropriate education to children with autism, educational programmes often fall short of meeting the needs of school-aged individuals with autism. Furthermore, for young people with autism, these provisions are frequently lacking (Bashir, Bashir, Lone, & Ahmad, 2014)^[7].

Sangita, a mother, voiced her concern that several institutions can be "intimidating or abusive" (Personal Interview). Numerous parents expressed a preference for enrolling their children in schools specifically designed for ASD, citing the better alignment of staff expertise with the unique requirements of children with ASD. The unwavering determination displayed by parents, who go to extraordinary extents to cater to their children's needs, is undeniably commendable. However, this resolute commitment also sheds light on a broader systemic shortfall in providing even the most fundamental resources to individuals and families.

Socioeconomic Status and the Accessibility of ASD-Related Services and Resources

Beyond the evident shortage of accessibility, a multitude of socioeconomic factors erect hurdles that impede individuals and families touched by ASD from engaging with or reaching ASD-oriented services and resources. Public funding from the government for those dealing with ASD, whether individuals, families, or organizations, is practically absent. Consequently, therapies and interventions, frequently entailing substantial expenses, must be privately funded. Health insurance coverage falls considerably short of meeting these demands. Furthermore, specialized educational services are inadequate in bridging this gap (2014, p.66).

The majority of parents who participated in this study were residents of urban areas with financial stability. They possessed English language proficiency and had attained varying levels of higher education, ranging from college degrees to post-graduate and professional qualifications. However, it's crucial to acknowledge that these privileges aren't universally shared among all individuals and families affected by ASD. While ASD itself doesn't differentiate based on financial status, the ability to access ASD-related services and resources is certainly shaped by social and economic factors. Right from the moment of diagnosis, the

potential to receive appropriate ASD-related support is closely tied to having adequate financial means and socio-cultural advantages.

A striking illustration of the economic burden posed by raising a child with ASD was recounted by Ashni, a mother who chose to remain in an abusive marriage against her family's advice, solely due to her husband's stable employment, ensuring her son's well-being (In-person Interview). Not all families possess the means to travel abroad for an accurate diagnosis, nor do all parents have the resources, be it time or finances, to pursue special education certification. Every child in these circumstances necessitates appropriate care and support, irrespective of their parents' financial capacity to advocate on their behalf.

Although the study was carried out in the United States rather than India, it revealed compelling statistical evidence that children with ASD residing in rural environments received their diagnoses at later stages of life compared to their urban counterparts (Mandell, 2005) ^[23]. This trend was linked to the scarcity of suitable resources in underserved rural regions.

ASD awareness

Prior to their children being diagnosed with ASD, not a single one of the seventeen parents interviewed for this study had been acquainted with the disorder, let alone comprehended its nature and implications. Another parent shared how his daughter was overfed by his wife and her family as a response to her ASD, highlighting their lack of understanding and uncertainty about how to address the condition. Further parents expressed that despite their earnest attempts to educate themselves about ASD, a scarcity of easily accessible information had impeded their ability to fully grasp the intricacies of the disorder.

Many parents expressed thankfulness for the love and acceptance their children received from family, friends, and communities, despite the fact that it was often based on a misunderstanding of what ASD entails, especially in the early years. A prevalent sentiment among many was that ASD could be treated or that it constituted a temporary phase that children would naturally overcome (Personal Interviews). While societies readily embraced and cared for children with ASD, achieving a comprehensive understanding was a gradual process, with the responsibility of raising awareness primarily resting on parents rather than the broader society.

Reva, a mother, recounted her experience of approaching the staff at a McDonald's in Jaipur to request their participation in an autism awareness event. According to her, similar to many others, the staff had limited knowledge about ASD. However, after receiving information about the condition and the challenges faced by individuals and families dealing with ASD, they expressed a willingness to contribute and support the cause.

Certainly, the role of popular media in heightening public awareness of ASD cannot be ignored. Indian movies such as "Barfi" (2012) and "My Name is Khan" (2010) have prominently featured characters with ASD, contributing to a broader understanding of the condition. Although some films may not portray ASD or disabilities accurately or sensitively, the positive representation of individuals with ASD holds significant value. Television has also played a

pivotal part in fostering awareness about ASD. For example, the television show "Aap ki Antara" set aside three-minute pieces at the end of each episode to showcase children with ASD and their families discussing their experiences.

ASD stigma, myths and misconceptions

The significant stigma associated with ASD is inextricably linked to the condition's lack of awareness. Stigma, as defined by Erving Goffman in his seminal work "Notes on the Management of a Spoiled Identity," is a process that leads to social marginalisation, transforming an individual from a whole and accepted person to one who is contaminated or devalued (1963, p. 3). This depiction is consistent with how ASD is perceived in India, where individuals and their families frequently struggle with being labelled as "different" and hence ignored by society. Kavita, one mother, emphasised that in the views of much of Indian society, there is a clear distinction between "normal" and "abnormal," with little acknowledgement for those like her 17-year-old daughter, who has ASD (Personal Interview).

The prevalent stigma surrounding ASD frequently has a negative impact on the treatment process, causing parents to be hesitant to seek early intervention or treatment at all. While accepting that a kid may have a disability and having an ASD diagnosis is a huge step, dealing with the related stigma, severity, and lifetime nature of the illness is another significant obstacle. A couple, Reva and Sudeep, admitted that they were "constantly in denial" about their son Saksham's condition, preferring to believe that he was simply a "late bloomer" (Personal Interview).

In instances where society neglects a marginalized community, such as its failure to fully accept or support individuals with ASD, the responsibility often falls upon that community and their allies to draw strength from their collective unity and individual resilience.

Nurturing hope for individuals living with Asd and their supporters

Addressing the pressing issues confronting individuals and families impacted by ASD requires immediate and broad societal and governmental engagement. The presence of accomplished and flourishing members of the ASD community emphasises the importance of such initiatives. (From the National Trust) Tito Rajarshi Mukhopadhyay, a poet who overcame significant societal restrictions, is one noteworthy example. He credits his achievements to his mother's unwavering commitment to his education. Mukhopadhyay's narrative, "Beyond the Silence, My Life, The World, and Autism," unveils his personal journey and the obstacles he encountered while navigating life with ASD in India. He has learned to appreciate the fundamental importance of his unique worldview, remarking, "Why shouldn't the often-overlooked aspects of this world, dismissed by neurotypicals, be keenly, even fiercely, observed?" Poetry, perhaps, best portrays the acute focus of autistic participation." 2010 (Savarese). Tito's achievements are a striking testament to the reality that people with ASD may use their condition to their advantage if given the correct opportunities and support.

Apart from Anvita, who aspired for her son's success in Special Olympics skating, the aspirations of most parents for their children with ASD were notably more down-to-

earth compared to achieving international literary recognition (Personal Interview). Their aspirations centered around their children's capacity to lead independent lives and manage their own well-being. They longed for their children to experience a sense of safety, security, and ease within their own bodies and minds.

Conclusion

Living with ASD is challenging irrespective of one's sociocultural or economic context, impacting both individuals and their families. Nevertheless, with appropriate care and support, many individuals with ASD can flourish. Additionally, families with autistic children can derive significant advantages from enhanced support networks and access to educational opportunities. The complications connected with ASD are exacerbated throughout India, and particularly in specific regions, due to a variety of sociocultural variables. Despite the critical need of early therapy and intervention, obtaining the essential assistance for their children can be difficult even for financially affluent, urban-dwelling, highly educated, and socially influential families. However, the situation becomes even more difficult for families with financial insecurity, lower educational levels, social fragility, or rural residency. Parents who lack familiarity with ASD face greater challenges in understanding and embracing their child's diagnosis, leading to a reduced likelihood of seeking suitable assistance or support. Stigma, which stems in part from a lack of awareness, has a negative impact on the interactions of people with ASD and their families, as well as on parents' motivation to seek treatment for their children.

In the face of insufficient governmental backing or acknowledgment, non-governmental organizations (NGOs) have emerged as the driving catalysts in endeavours to diminish stigma and enhance awareness. These organizations concurrently furnish resources, services, and support that would otherwise be out of reach or exceedingly limited for those who are most in need. Among these entities, AFA stands out as the pioneer and foremost advocate for ASD in the nation. Despite financial difficulties, the NGO strives to keep its operations running. Garima and Anurag are optimistic that with enough support and financing, they would be able to continue their mission of assisting individuals with ASD and their families throughout Rajasthan.

Individuals with ASD and their allies have regularly expressed displeasure with a society and government that fail to understand and accept their unique perspectives and methods of engaging with the world. The long-standing issue of unfulfilled core needs is about to change. However, rather than being primarily borne by those directly afflicted, the responsibility for initiating change should be shared by all.

Limitations

Several limitations affected the scope of this study. Ethically and logistically, engaging individuals with ASD in interviews proved unfeasible, preventing valuable insights from their unique perspectives from being included. While some participating parents held roles as special educators, volunteers, and advocates, the study did not systematically

explore viewpoints from additional stakeholders, such as psychologists or paediatricians. Instead, the study concentrated on capturing caregivers' perspectives regarding the challenges encountered by them and their children.

It's important to acknowledge that the group of parents interviewed in this study does not encompass all parents of children with ASD in India. Additionally, their perspectives may not accurately reflect the unique characteristics of the specific regions where the study took place.

Moreover, given that the majority of NGOs are situated in urban areas, conducting fieldwork in rural regions was unfeasible. It is anticipated that the encounters of individuals with ASD and their families in rural settings would substantially contrast with those in urban areas like Jaipur or New Delhi. While this study did engage with various NGOs, limitations in time prevented an exhaustive comparative analysis. Thus, any observations made regarding distinctions among the studied NGOs should be regarded as superficial.

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