

"Understanding Autism in Goa, India: A Holistic Exploration of Psychosocial Experiences, Community Engagement, and Institutional Support"

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Abstract

This article thoroughly explores Autism Spectrum Disorder (ASD) in Goa, India, utilizing a multifaceted approach. It examines psychosocial experiences through case studies, incorporating perspectives from families and teachers. The study reviews literature on language impairments, developmental profiles, and advanced brain imaging for ASD diagnosis. Cultural and socioeconomic factors impacting autism perception are analyzed, emphasizing community roles in awareness and support. The assessment of ASD services acknowledges progress but notes challenges like limited access and professional shortages. The government's role in policy formulation and NGO contributions are explored, urging collaborative efforts for inclusive environments and advocating for ongoing awareness to ensure dignified integration for individuals with ASD in Goa.

I. Introduction

A. Brief overview of autism :

Autism, also known as Autism Spectrum Disorder (ASD), is a complex and multifaceted neurodevelopmental condition that impacts an individual's social interaction, communication, and behaviour. It is characterized by a wide spectrum of symptoms and severity levels, which is why it's referred to as a "spectrum" disorder. Autism typically manifests in early childhood, and its symptoms can vary greatly from person to person. Autism is a childhood disorder that disrupts the typical progression of social, communicative, and cognitive development. Autism is categorized as a psychological disorder that primarily manifests in early childhood, with a diagnosis generally excluding cases emerging after the third year of life. In contrast, other serious psychological conditions in childhood, like attention deficit disorder, anxiety, and depression, tend to appear later, even though there might be early signs. The early onset of autism makes it distinct from predetermined systematic disturbances. Autism is further characterized by its diversity in symptoms and developmental paths. Given this diversity and the presence of milder symptoms in both relatives of those with autism and the general population, autism is often described as a syndrome. A significant variation among individuals with autism lies in the co-occurrence or absence of mental retardation (as noted by Sigman et al., 2006).¹

¹ Sigman, M., Spencer, J.S. & Wang, T.A. (2006). Autism from developmental and neuropsychological perspectives. *Annual Reviews of Clinical Psychology*, 2, 327 -55

Autism spectrum disorder (ASD) is a complex developmental disorder that affects communication and behaviour. Children with ASD may have difficulty with social interaction, communication, and repetitive behaviour's.

Autism spectrum disorders encompass three primary diagnoses: autistic disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). In this context, "autism" refers to this collective group of diagnoses. It's important to note that there is currently no biologically definitive test for diagnosing autism. Instead, diagnosis relies on behavioral criteria, which include the presence of specific impairments in three fundamental domains: social interaction, communication, and repetitive or stereotypical behaviour (as described by Newschaffer et al., 2006).²

B. LITERATURE REVIEWS

In their study conducted in 2004, Chan, Cheung, Leung, and Cheung focused on assessing the verbal expression and comprehension skills of 46 Chinese children with autism, aged between five and six. The findings revealed that a significant majority, specifically 63% of the children with autism, exhibited language impairments. More precisely, 42% displayed impairments in both their verbal expression and comprehension abilities, while 21% showed limitations in their expressive language skills.³

Bernabei and Camaioni (2001) provided a detailed developmental profile of a child with autism throughout the initial three years of life. This profile was constructed by synthesizing clinical data gathered from various sources, including home videos spanning from birth to 3 years and cognitive and communicative assessments at 24, 34, and 38 months.

The analysis of the home videos demonstrated a notable progression in the child's development up to the first year of life. However, a concerning shift occurred between the 12th and 18th months when certain previously acquired skills began to regress. During this period, a decline in social interaction, communication, and language abilities became evident. In the subsequent developmental phase, spanning from 18 to 38 months, the child's communicative and linguistic skills remained relatively stable, but there was a continued decrease in social interactive behaviors.⁴

In 2018, Anibal Sólón Heinsfeld and colleagues conducted a study involving the analysis of brain imaging data from individuals with Autism Spectrum Disorder (ASD) using the worldwide multi-site database called ABIDE. ASD is characterized by repetitive behaviors and social difficulties, and it affects one in every 68 children in the United States, according to the Centers for Disease Control and Prevention.

² Newschaffer, C. J., Croen, L.A., Daniels, J., Giarely, E. & Grether, J. K. (2006). The epidemiology of autism spectrum disorders. *Annual Reviews of Public Health*, 28, 20-53

³ Chan, A. S., Cheung, J., Leung, W. W. M., Cheung, R. & Cheung, M. (2004). Verbal expression and comprehension deficits in young children with autism. *Focus on Autism and Other Developmental Disabilities*, 20, 117-125

⁴ Bernabei, P., & Camaioni, L. (2001). Developmental profile and regression, *Autism*, 5, 287-297

The study specifically focused on functional brain imaging data to investigate patterns of functional connectivity. The aim was to identify objective markers that could be used to classify individuals with ASD, and to examine the neural patterns that emerged as a result of this classification. Notably, the researchers achieved a diagnostic accuracy rate for ASD that was 70% higher than the previously established state-of-the-art methods when compared to control individuals in the dataset.⁵

In 2019, Bipin Nair and his research team introduced an automated cognitive approach aimed at classifying Autism Spectrum Disorders (ASDs) based on brain MRI data. MRI imaging is a highly effective method for scrutinizing structural changes in the brains of individuals with ASD. Their study aimed to predict the underlying neurotransmitter patterns responsible for ASD, which could facilitate the precise localization of the areas of the brain associated with autism.

Their methodology involved employing Principal Component Analysis (PCA) to extract relevant features from the MRI images, and they used the Naive Bayesian technique for feature classification. The process begins by extracting features from the MRI images and categorizing them into two labels. The following steps were implemented: Initial noise reduction was conducted through pre-processing, involving the application of median and unsharp masking. Subsequently, the pre-processed images were subjected to segmentation to extract key features, with the application of the Otsu segmentation method.⁶

Research on the psychosocial aspects of Autism Spectrum Disorder (ASD) is expanding, but there is a notable gap in understanding the psychosocial experiences of autistic children in Goa, India. This case study-oriented research seeks to investigate the psychosocial encounters of autistic children in Goa by considering the viewpoints of the children, their families, and their teachers. The paper will encompass three distinct participant groups: autistic children, their families, and their teachers. Recruitment for the research will be carried out through diverse channels, including educational institutions, healthcare givers, and non-profit organizations.

This paper is expected to provide insights into the psychosocial experiences of autistic children in Goa from the perspectives of the children themselves, their families, and their teachers. These insights will be used to develop recommendations for improving the lives of autistic children and their families in Goa.

C. Methodology

There is a growing body of research on the psychosocial aspects of ASD. However, there is limited research on the psychosocial experiences of autistic children especially in Goa, India. This case study-based research approach aims to explore the psychosocial experiences of autistic children in Goa from the perspectives of their families, and their teachers.

⁵ Anibal Solon Heinsfeld, Alexandre Rosa Franco, R, Cameron Craddo, Augusto Buchweitz & Felipe Meneguzzi 2018, ‘_Identification of autism spectrum disorder using deep learning and the ABIDE dataset’, Elsevier, *NeuroImage: Clinical* vol. 17, pp. 16–23.

⁶ Bipin Nair, BJ, Shobha Rani, N, Saikrishna, S & Adith, C 2019, ‘_Experiment to Classify Autism through Brain MRI Analysis’, *International Journal of Recent Technology and Engineering (IJRTE)*, vol. 8, no.154.

This research will adopt a case study-based approach. Case study research is a qualitative research method that involves an in-depth investigation of a small number of cases. This approach is well-suited for exploring complex phenomena such as the psychosocial experiences of autistic children.

The research will involve autistic children's families, and their teachers. Participants will be recruited from a variety of sources, including schools, hospitals, and non-profit organizations working among Autistic children.

Data will be collected through semi-structured interviews with participants. The interviews will be transcribed and analysed using thematic analysis. Thematic analysis is a qualitative data analysis method that involves identifying and analysing patterns in the data.

D. Significance of studying autism in Goa, India:

Studying autism in Goa, India holds profound significance on multiple fronts. Firstly, it contributes to a broader understanding of how autism manifests in diverse cultural and socioeconomic contexts. Each region may have unique cultural beliefs, practices, and resources that influence the experience of individuals with autism and their families. By examining autism in Goa, we gain insights into how these factors impact the diagnosis, treatment, and acceptance of individuals with autism.

Secondly, investigating autism in Goa sheds light on the challenges faced by a region with specific healthcare infrastructure, educational systems, and governmental policies. It provides an opportunity to assess the adequacy of existing services, identify gaps in support, and suggest improvements tailored to the needs of the local population.

Furthermore, this research can serve as a catalyst for raising awareness and reducing the stigma surrounding autism in Goa. A deeper understanding of autism can lead to greater empathy, acceptance, and inclusion within the Goan community, ultimately improving the quality of life for individuals on the autism spectrum and their families.

Further, the study of autism in Goa is not only a matter of scientific inquiry but also a crucial step towards creating a more inclusive and supportive environment for individuals with autism. It has the potential to enhance the lives of those affected by autism in Goa while contributing to our global knowledge of this complex condition.

Purpose of the article

The purpose of this article is multifaceted:

Education and Awareness: This article seeks to educate readers about autism in the unique context of Goa, India. Autism, often misunderstood or stigmatized, is a complex condition that manifests differently in each individual. By providing a thorough overview of the condition and its prevalence in Goa, we aim to enhance public knowledge and dispel misconceptions. We want readers to grasp the significance of understanding autism's nuances in this specific region, as it can shape the lives of many Goan families and their loved ones.

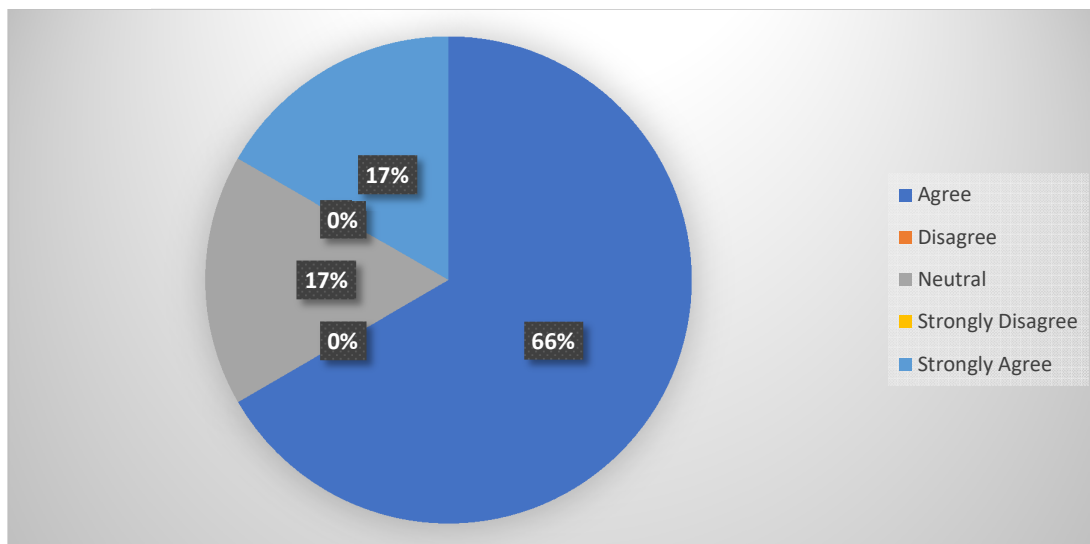
Advocacy for Improved Support: Through this article, we aspire to be advocates for change. By highlighting the existing services and support systems, as well as acknowledging the challenges faced in Goa, we hope to drive home the need for improvement. It is our intent to encourage the government, non-profit organizations, and local communities to work collaboratively to enhance the resources available for individuals with autism. We believe that every person with autism deserves the opportunity to lead a fulfilling life with the support they require.

Fostering Research and Collaboration: Our article calls for the promotion of research and collaboration in the field of autism. Understanding autism is an ongoing endeavor, and we encourage researchers, professionals, and organizations to work together to further our knowledge and develop targeted interventions. We hope this article serves as a catalyst for partnerships and initiatives that advance our understanding of autism in Goa and contribute to global efforts to support individuals on the autism spectrum.

Promoting Empathy and Inclusion: Ultimately, our core objective is to promote empathy and inclusion. We envision a society in Goa, India, and the world over, where individuals with autism are accepted, valued, and included in all aspects of life. By informing, inspiring, and advocating for change, we aim to contribute to the creation of a more compassionate and understanding community that empowers individuals with autism to thrive and contribute to society.

F. psychosocial problems faced by parents of autistic children

Emotional Stress and Coping Mechanisms



Note: It is hard to establish effective communication and rapport with autistic children.

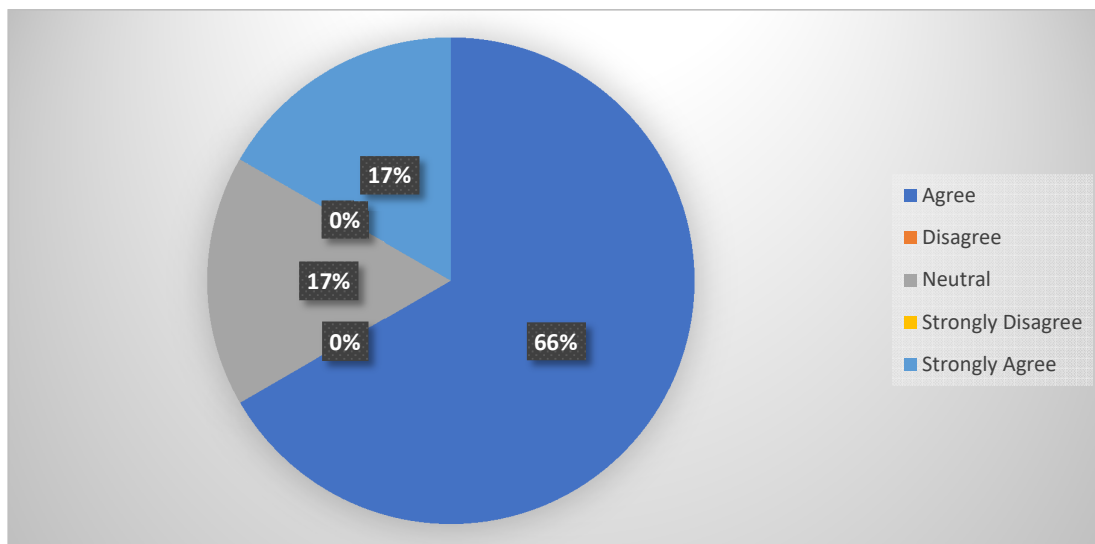
Raising a child with autism presents parents with a myriad of emotional challenges. The daily demands of caring for a child with unique needs, managing meltdowns, and addressing communication difficulties can lead to significant emotional stress. Parents often experience a sense of helplessness as they witness their child's struggles. This stress can take a toll on their mental well-being, leading to anxiety and even depression. Coping mechanisms become

crucial for parents to navigate these emotional hurdles. They often find solace in support groups where they can connect with other parents facing similar challenges. Additionally, seeking therapy or counselling can provide a safe space for parents to express their feelings and learn effective coping strategies, ultimately helping them to better support their child.

Financial Strain and Its Implications The financial strain on parents of autistic children cannot be understated. The costs associated with autism, including specialized therapies, educational support, and medical care, can quickly add up. Parents may face the dilemma of allocating significant portions of their income to meet their child's needs, which can lead to financial stress and uncertainty about the future. These financial pressures can hinder parents from pursuing personal goals or saving for their child's long-term well-being. The weight of these financial burdens can also take a toll on their mental health, compounding the challenges they already face. Consequently, financial planning and access to resources are essential to mitigate this psychosocial issue.

Marital Strain and Social Isolation The unique demands of caring for an autistic child can strain marital relationships. The stress, differences in parenting approaches, and disagreements about treatment and therapy options can lead to conflicts between partners. Parents often find themselves navigating these challenges while trying to maintain a united front for their child's well-being. Social isolation is another pervasive issue, as parents may need to limit their social interactions due to their child's needs or the unpredictability of meltdowns. This can lead to feelings of loneliness and exclusion, which can further impact their mental health. Building a strong support system, both within the marriage and through connections with other parents and caregivers, is crucial to address these psychosocial problems and provide a more holistic environment for the child.

Mental Exhaustion



Note: Working with autistic children can be emotionally taxing, and I often feel stressed or burnt out.

During our research it was found that around 66% of the respondents agreed to the fact that it was mentally and emotionally straining to deal with the various needs of the autistic children.

Psychological and emotional burnout, characterized by prolonged mental and emotional exhaustion due to persistent stress and overwhelming demands, often occurs in caregiving roles, impacting individuals facing chronic and excessive pressures. This state includes persistent fatigue, both physically and emotionally, leading to challenges in daily tasks and a sense of depletion even after sufficient rest. Cynicism and detachment manifest as a negative outlook towards work and relationships, accompanied by emotional distancing from responsibilities. Reduced cognitive abilities and job performance decline contribute to difficulty concentrating and decision-making. Despite achievements, a diminished sense of satisfaction prevails, fostering increased irritability and heightened emotional reactions. Physical symptoms like headaches and disrupted sleep patterns further compound the burnout experience. Isolation and a reduced ability to empathize result, along with a sense of helplessness in the face of challenges. Burnout stems from factors such as excessive workload, lack of control, unclear expectations, and insufficient support. Early recognition and proactive strategies, including seeking support and practicing self-care, are crucial to effectively prevent or address burnout.

I. Cultural and Socioeconomic Factors

A. Cultural attitudes and beliefs in Goa towards autism

- **Limited Awareness and Misunderstanding:** In many parts of Goa, there is still limited awareness and understanding of autism. Some individuals may be unfamiliar with the condition and its characteristics, resulting in misconceptions and misunderstandings about autism. **Stigma and Social Isolation:** Similar to many other cultures, there is a level of stigma associated with autism in Goa. People with autism and their families may experience social isolation and discrimination due to prevalent misconceptions about the condition.
- **Traditional Beliefs and Healing Practices:** Traditional and cultural beliefs play a significant role in shaping attitudes toward autism. In some cases, autism may be attributed to supernatural or spiritual causes, leading to the use of traditional healing practices and rituals as a response.
- **Limited Access to Services:** Access to autism-related services, such as specialized education, therapy, and support, may be limited in certain areas of Goa. This lack of accessibility can place additional burdens on families seeking appropriate care for their children with autism.
- **Evolving Perceptions in Urban Areas:** In urban areas of Goa and among more educated populations, attitudes toward autism appear to be evolving. Increased exposure to information, awareness campaigns, and access to resources like the Internet and media are contributing to more positive and informed perspectives regarding autism.
- **Support Groups and Advocacy Efforts:** In recent years, there has been a growing effort to establish support groups and advocacy organizations for individuals with autism and

their families in Goa. These groups play a crucial role in raising awareness, providing support, and advocating for better services and greater acceptance.

- **Promoting Inclusion:** There is a growing recognition of the importance of inclusion in schools and other community settings in Goa. Inclusive education and awareness campaigns are actively working to promote acceptance and understanding of individuals with autism, striving for a more inclusive society.

It's essential to acknowledge that attitudes and beliefs about autism can vary widely within any culture or region and may evolve over time as awareness and understanding grow. The level of awareness, access to services, and acceptance of individuals with autism may differ from one part of Goa to another. Additionally, the experiences of individuals with autism and their families depend on various factors, including their socioeconomic status, education, and access to resources.

J. The role of the community in supporting individuals with autism

The community plays a pivotal role in supporting individuals with autism, contributing significantly to their well-being and overall quality of life. Here are key aspects of the community's role in providing support:

1. **Raising Awareness and Education:** The community should prioritize awareness and education about autism. Understanding the characteristics, challenges, and the diverse nature of the autism spectrum is essential. This knowledge helps reduce stereotypes and misconceptions, fostering empathy and inclusion.
2. **Creating Inclusive Environments:** Inclusive communities strive to create environments where individuals with autism can participate fully. This inclusivity should extend to schools, workplaces, recreational facilities, and public spaces, ensuring that their needs are accommodated.
3. **Building Support Networks:** Support networks are crucial for individuals with autism and their families. Local organizations, support groups, and online communities offer resources, information, and emotional support, helping individuals and their families navigate the challenges they may face.
4. **Advocacy Efforts:** The community can advocate for the rights and needs of individuals with autism. Effective advocacy can lead to changes in policies, laws, and public attitudes that benefit the autism community and ensure their inclusion and equality.
5. **Ensuring Access to Services:** Communities must ensure that essential services, such as healthcare, educational support, and therapeutic services, are accessible. Collaboration with local agencies is vital to improve the availability and quality of these services.

6. Promoting Job Opportunities: Encouraging businesses to create job opportunities for individuals with autism is crucial. Programs and initiatives that promote inclusive employment help individuals with autism become active and valued members of the workforce.

7. Supporting Inclusive Education: Schools in the community should prioritize inclusive education. This involves implementing tailored teaching strategies, support services, and creating a welcoming environment for students with autism.

8. Inclusive Recreation and Activities: Community centers and recreational facilities should provide programs that are inclusive and adapted to the needs of individuals with autism. These opportunities foster social interaction, engagement, and a sense of belonging.

9. Cultivating Respect and Acceptance: Fostering an environment of respect and acceptance within the community is paramount. It's essential that individuals with autism feel valued and understood, with their unique strengths appreciated and celebrated.

10. Emergency Preparedness: Communities can plan for the unique needs of individuals with autism during emergencies, ensuring they have the necessary supports and accommodations in place, especially during natural disasters or evacuations.

11. Public Awareness Campaigns: Organizing awareness campaigns and events can help the community better understand and accept autism. These initiatives serve to reduce stigma, increase empathy, and create a more inclusive and understanding environment.

12. Community Policing and First Responders: Local law enforcement and first responders should receive training on how to interact with individuals with autism, especially during emergency situations, to ensure their safety, well-being, and understanding of their unique needs.

Autism Spectrum Disorders (ASD) Services in Goa

Autism Spectrum Disorder (ASD) services in Goa have made progress in meeting the unique needs of individuals on the spectrum and their families through early intervention programs, special education schools, and various therapies. Psychiatric and medical services, along with parent training and support groups, contribute to the comprehensive support system. Government initiatives and private clinics play roles in building the infrastructure, including respite care services.

However, challenges persist, such as limited access to specialized services, a shortage of trained professionals, and varying quality of special education. Raising public awareness is crucial to combat misconceptions and stigma, ensuring social inclusion. The financial burden on families, inadequate support for parents and caregivers, and coordination among service providers are additional challenges, including long waiting times and difficulties in transitioning into adulthood for individuals with autism.

Addressing these gaps requires collaborative efforts, including awareness campaigns, expanded professional training, improved service accessibility and quality, and advocacy for comprehensive government policies and funding. The focus should be on creating a more inclusive and supportive environment in Goa for individuals with ASD, empowering them to realize their full potential.

G. The role of government and non-profit organizations

Government's Role:

The government of Goa plays a pivotal role in overseeing and facilitating Autism Spectrum Disorder (ASD) services in the state. Their involvement extends to formulating crucial policies and regulations, providing a legal framework for autism services, and allocating financial resources to support interventions for individuals with ASD. Adequate funding is emphasized to ensure accessibility to a broad spectrum of interventions, addressing early diagnosis and specialized therapies for individuals across socio-economic backgrounds.

In education, government initiatives focus on promoting inclusive practices, particularly through funding and overseeing special education programs that cater to the unique needs of children with ASD. Additionally, government agencies provide healthcare facilities offering diagnostic services, medical care, and therapeutic support, contributing to the overall well-being of individuals with autism. In essence, the government's indispensable role in Goa spans from policy formulation to resource allocation and educational support, laying the foundation for comprehensive ASD services.

Role of Non-Profit Organizations:

Non-profit organizations in Goa play a crucial role in complementing and enhancing Autism Spectrum Disorder (ASD) services. Acting as a bridge between the government, healthcare providers, and the autism community, these organizations fill gaps and offer specific services not readily available through official channels. Their key contributions include raising public awareness, reducing autism stigma, and fostering a more inclusive and understanding society.

Beyond awareness, non-profits directly support individuals with ASD and their families by providing therapy programs, respite care, and training sessions. Support groups organized by these organizations create a sense of community, enabling individuals and families to connect, share experiences, and access valuable information and emotional support.

Moreover, non-profits engage in advocacy efforts to influence policy changes and secure additional resources for ASD services. This collaborative approach with government agencies, healthcare professionals, and educators ensures that policies remain up-to-date, responsive to evolving needs, and adequately funded. Overall, the dedicated work of non-profit

organizations is invaluable in promoting the welfare and inclusion of individuals with autism within the Goan community.

k. Conclusion

There is an urgent need to plan residences and centers to support autistic individuals transitioning into adulthood in India. Current educational systems inadequately address the needs of autistic children, leading to challenges in mainstream and special education settings. While some autistic children can thrive with proper support, they often face barriers such as inflexibility and academic pressure.

Access to special schools is limited, as they may lack expertise in handling the unique challenges of autism. Advocacy is essential for special schools to invest in training and techniques to bridge the gap in care and education for autistic children and their families.

Notably, autism is not officially recognized as a separate disability in the Persons with Disabilities Act of 1995. However, advocacy efforts, notably led by AFA, have resulted in the inclusion of autism in the National Trust Bill of 1999. This legislative milestone marks the first recognition of autism as a distinct condition in India, allowing individuals with autism to receive specific benefits under this act.

However, to get access to a majority of benefits, a disability certificate is required, and currently there is no disability certificate being issued just for autism. Those who want to avail of any schemes do opt to take the disability certificate for Autism with MR (Mental Retardation). read more about Legislation and Policy.⁷

The autism movement in India has seen significant advancements over the past two decades, with earlier diagnoses, increased service availability, and growing awareness. However, collaborative efforts are essential to ensure individuals with autism can achieve their full potential and lead dignified lives. Advocacy from parents, siblings, relatives, and professionals is crucial for addressing the rights of this marginalized group.

In India, understanding autism requires considering societal attitudes toward disabilities, marked by historical stigma, shame, and misconceptions. These negative perceptions, prevalent globally, contribute to the distinctive behaviors associated with autism. Historically, families concealed children with autism due to stigma, perpetuating ignorance and superstition. Fortunately, there has been a positive shift in recent years, with reduced stigma and increased acceptance.

⁷ <http://www.autism-india.org/autism-india.php>

References

1. Amaral, D., Geschwind, D., & Dawson, G. (2011). *Autism spectrum disorders*. Oxford University Press.
2. *Autism*. (n.d.). Autism - India. <https://www.autism-india.org/autism-india.php>
3. Casanova, M. F., El-Baz, A. S., & Suri, J. S. (2013). *Imaging the brain in autism*. Springer Science & Business Media.
4. Dewey, D., & Tupper, D. E. (2004). *Developmental motor disorders: A Neuropsychological perspective*. Guilford Press.
5. Kautish, S., & Dhiman, G. (2021). *Artificial intelligence for accurate analysis and detection of autism spectrum disorder*. IGI Global.
6. Schwartz, R. G. (2010). *Handbook of child language disorders*. Psychology Press.
7. Silleresi, S. (2023). *Developmental profiles in autism spectrum disorder: Theoretical and methodological implications*. John Benjamins Publishing Company.