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Expert Opinion Article

Growing Up With Autism Spectrum Disorder: Understanding Labels, Advocacy, And Neurodiversity

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Abstract

This article explores the psychosocial challenges faced by individuals on the autism spectrum and their caregivers. It examines how social narratives, diagnostic labels, and advocacy efforts shape their lived experiences. Drawing on in-depth interviews with autistic self-advocates, caregivers, and practitioners, the study investigates the evolving discourse around autism, the shift from deficit-based models to neurodiversity frameworks, and the importance of inclusive practices. Findings suggest that while awareness has grown, societal stigma, ableism, and inconsistency in practitioner approaches continue to challenge autistic individuals' rights to self- definition and inclusion.

Introduction

The research began as a personal inquiry into atypical development, triggered by the diagnosis of the author’s cousin and her own childhood experience of being labeled “special.” This led to a deeper questioning of why differences are medicalised or stigmatised. Autism, often misunderstood, is not simply a disorder but a different mode of being. This article aims to capture that journey.

What is Autism and Atypical Development?

According to the WHO, Autism Spectrum Disorder (ASD) refers to impaired social communication, restricted interests, and repetitive behaviours. Despite awareness, autism remains poorly understood, often perceived as a "disease" rather than a difference in neurodevelopment. As autism diagnoses rise globally, research struggles to keep pace, particularly in countries like India where data remains sparse and support systems underdeveloped.

Research Objectives & Methodology Objectives

Explore psychosocial challenges of autistic individuals.

Trace journeys of growing up on the spectrum.

Assess awareness of autism advocacy and neurodiversity.

An exploratory qualitative design was used. Interviews with 5 key respondents (including self-advocates and caregivers) were conducted via video conferencing. Tools included a semi-structured interview guide, purposive sampling, and thematic analysis. Ethical consent and confidentiality were maintained throughout.

Theoretical Lenses

Prevalence & Causes - CDC data (2018) estimates 1 in 59 children are diagnosed with ASD. Males are four times more likely to be diagnosed than females. Early diagnosis facilitates better interventions. The cause remains elusive—hypotheses include genetic mutations, environmental toxins, or advanced parental age, but no conclusive link has been found, especially not with vaccines.

Ableism & Labelling - Ableism is ingrained in societal norms and educational systems, assuming that neurotypicality is superior. Labels like “high-functioning” or “low-functioning” reinforce stigma and marginalisation. Diagnostic terms differ between DSM, ICD, and practitioners, leading to confusion and miscommunication with families.

Neurodiversity Movement - The neurodiversity model sees autism not as a disease, but a natural variant of human cognition. It pushes against the pathologizing “medical model.” Advocates argue for the right to exist without needing to be "fixed." However, resistance remains from professionals adhering to traditional models.

Indian Context - Indian literature on autism largely focuses on causality, not lived experience. Advocacy and inclusive education are under-resourced, often led by NGOs. Research on ableism and neurodiversity in India is almost nonexistent.

The Diagnostic Journey, Role of Practitioners and Lived Experiences of Autism

For caregivers, diagnosis is a complex emotional process. Initial denial, shock, or guilt is common. One respondent described how external comments triggered a sense of “something wrong,” leading to eventual testing. In India (1980s), diagnosis was rare and information scarce, adding to confusion and helplessness.

Practitioner attitudes significantly shape parental responses. Negative framing can amplify trauma. Respondents emphasized the need for humility, continuous learning, and empathy in professionals. A dismissive or clinical tone alienates families during a vulnerable period.

1. Sensory Processing & Communication

Autistic individuals often experience hypersensitivity to light, sound, or touch. One respondent described struggling in public spaces due to noise and fluorescent lights.

Non-verbal individuals, in particular, face communication barriers that lead to frustration and aggression, often misinterpreted by others.

Therapies like the Picture Exchange Communication System (PECS) were shown to significantly improve communication and reduce isolation.

2. Peer Relationships & Social Navigation

Autistic people face challenges in social engagement, understanding non-verbal cues, and maintaining peer relationships. Misunderstandings, especially around personal space or behavior, can lead to social exclusion or even hospitalization.

Respondents noted they prefer routine, struggle with ambiguity, and often find small talk meaningless—an issue in both education and work settings.

3. Professional Barriers

Even highly capable autistic individuals face discrimination in employment. One respondent, a university professor, highlighted how social skills—rather than competence—became barriers to career advancement. Despite producing high-quality work, the lack of peer rapport hindered tenure opportunities. Having a job was seen not just as economic necessity but as a source of social structure, routine, and dignity.

4. Role of Caregivers

Caregivers experience a mix of pride, exhaustion, and uncertainty. Many described moments of helplessness due to lack of information or social stigma. However, empowerment came through research, advocacy, and online communities. Parents of verbal and non-verbal children alike emphasised the importance of acceptance over conformity.

5. Terminology and Identity Politics

The study revealed varying preferences in labels: “autistic person” vs “person with autism” vs “neurodivergent.” The choice is deeply personal and often influenced by exposure to advocacy communities. Media representations further complicate understanding, swinging between romanticising savant traits and depicting autism as tragedy.

6. Neurodiversity and Future Directions

The neurodiversity model encourages society to move from a deficit mindset to one that celebrates difference. Inclusion is not about making autistic individuals “fit in” but about creating environments that respect varied cognitive styles. Awareness, accessible education, and media responsibility are key levers for change.

Conclusion

Autism is not a disease to be cured but a difference to be understood. Labels must be used sensitively, support must be individualised, and advocacy must be centered around lived experiences. By integrating neurodiverse voices into policy, education, and healthcare, a more inclusive world becomes possible—where difference is not deficit, but diversity.

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