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The Impact of Autism on Ethnic Minority Children in Middle and Low-Income Countries: An Under-Researched Challenge

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Abstract

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition marked by challenges in social communication, restricted interests, and repetitive behaviours [1]. While substantial research has been conducted in high-income countries, the impact of autism on ethnic minority children in Middle-and Low-Income Countries (MLICs) is significantly under-explored [2,3]. This study employs a mixed-methods approach, integrating a systematic review of existing literature with qualitative interviews from selected MLICs, to comprehensively analyse the unique challenges faced by these populations. The findings reveal significant disparities in diagnosis, treatment, and social outcomes, shaped by cultural perceptions, economic factors, healthcare infrastructure, and intersecting identities [4]. Additionally, the study examines broader societal impacts and developmental implications, concluding with a call for targeted research, policy interventions, and community-based strategies to bridge these gaps [5].

Keywords: Autism Spectrum Disorder (ASD), Ethnic minority children, Middle-and Low-Income Countries (MLICs), Healthcare disparities, Cultural stigmatization, Intersectionality, Neurodevelopmental disorders, Diagnosis and treatment, Child development, Public health equity

Introduction

Autism Spectrum Disorder (ASD) is increasingly recognized as a global public health issue, with varying prevalence and recognition across different regions [6]. While high-income countries have made significant strides in understanding and managing autism, Middle and Low-Income Countries (MLICs) lag, especially concerning ethnic minority populations [3]. These children face unique challenges due to intersecting factors such as socioeconomic status, cultural stigmas, and limited access to healthcare [7]. Moreover, the impact of these challenges extends beyond individual families, affecting broader societal structures and child development outcomes [8]. This paper explores these challenges through a comprehensive literature review, comparative analysis, discussion of intersectionality, and examination of societal impacts, highlighting the urgent need for targeted research, policy interventions, and community-based solutions.

Theoretical framework

This study is grounded in an intersectional theoretical framework, originally conceptualized by Crenshaw K, et al., which examines how various social identities-such as race, class, gender, and ability-intersect to create unique experiences of oppression and privilege. This framework is particularly relevant for understanding the compounded challenges faced by ethnic minority children with autism in Middle-and Low-Income Countries (MLICs), where multiple axes of marginalization intersect [4].

Intersectionality allows for a nuanced analysis of how cultural, economic, and social factors converge to impact the diagnosis, treatment, and social integration of children with autism. In this study, specific intersections of race, gender, and socio-economic status will be critically examined to understand how they collectively shape the experiences of ethnic minority children with autism in MLICs. For instance, the study will explore how racial and ethnic identities intersect with economic status to influence access to autism diagnosis and treatment, and how gender norms further complicate these experiences.

Furthermore, this framework highlights the importance of considering how these intersecting factors create barriers that are not adequately addressed by singular approaches to healthcare and education. By applying intersectionality, the study will analyse the extent to which current healthcare and educational systems in MLICs fail to address the complex needs of these children, particularly in settings where resources are scarce, and cultural stigmas are prevalent.

The broader societal impacts of these challenges, particularly how they influence child development and community dynamics, will also be examined. For example, the study will consider how societal perceptions of disability-shaped by cultural, religious, and economic factors-affect the social integration of children with autism. This approach will be informed by existing literature, including studies by



Aljunied and Frederickson, et al., Elsabbagh, et al., which have applied intersectionality in similar contexts [7,9].

By situating this study within the broader research tradition of intersectional analysis in public health and education, this framework not only facilitates a comprehensive understanding of the challenges faced by ethnic minority children with autism in MLICs but also underscores the need for policies and interventions that are responsive to the complex, intersecting identities of these children.

Integration with literature

The intersectional framework has been increasingly recognized in recent studies for its utility in analysing health disparities and educational inequities, particularly among marginalized groups. For instance, Aljunied and Frederickson applied this framework to understand the educational challenges faced by children with special needs in diverse cultural contexts, while Elsabbagh et al., used it to explore how global health disparities impact autism diagnosis and treatment outcomes [7,9]. By drawing on these studies, this research will further expand the application of intersectionality in understanding the compounded challenges faced by ethnic minority children with autism in MLICs.

Application to this study

In this study, the intersectional framework will be operationalized by focusing on three key intersections:

Race and ethnicity: Examining how ethnic minority status influences access to autism diagnosis and treatment, particularly in regions where healthcare resources are limited, and cultural stigmas are strong.

Gender: Investigating how gender norms in different cultural contexts affect the identification and support of children with autism, with a particular focus on how girls with autism may be underdiagnosed or misdiagnosed.

Socio-economic status: Analysing how economic barriers intersect with race and gender to further marginalize children with autism in MLICs, particularly in terms of accessing necessary healthcare and educational services.

This framework will guide the study's methodology, including data collection and analysis, ensuring that the research captures the complexity of the lived experiences of ethnic minority children with autism in MLICs. The findings are expected to contribute to more informed, intersectionally aware policies and practices in global health and education.

Literature Review

Problem

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that significantly impacts social interaction, communication, and behaviour. Research in High-Income Countries (HICs) has greatly advanced our understanding of ASD, particularly in terms of prevalence, diagnostic practices, and treatment strategies. For instance, in the United States, the Centres for Disease Control and Prevention (CDC) estimate that 1 in 36 children is diagnosed with ASD, reflecting the effectiveness of comprehensive diagnostic frameworks, public awareness campaigns, and a robust

healthcare infrastructure [6]. However, the applicability of these findings to Middle-and Low-Income Countries (MLICs) is limited by socio-economic, cultural, and infrastructural differences. This literature review critically examines the global landscape of autism research, focusing on the disparities between HICs and MLICs. It explores the methodological challenges of applying Western-centric research models in MLICs, the impact of cultural and socio-economic factors on autism care and identifies critical gaps in the existing literature. Additionally, this review addresses the ethical implications of conducting autism research in diverse cultural contexts and the potential role of global health initiatives, while proposing actionable research and policy recommendations tailored to the unique needs of MLIC populations.

Research gaps and questions

This review aims to address several key research gaps:

- **Inadequacies of Western-Centric Models:** How do Western-centric diagnostic models fall short in accurately capturing the autism spectrum within diverse cultural contexts of MLICs [7]?
- **Socio-Cultural Influences:** How do socio-cultural factors in MLICs contribute to the underreporting and misdiagnosis of autism [5]?
- **Policy Adaptation:** What are the implications for global health policy, and how can successful practices from HICs be adapted to the contexts of MLICs [10]?

Global overview of autism research

Significant progress in the early diagnosis and intervention of autism spectrum disorder has been made in high-income countries. These advancements are supported by well-developed healthcare systems, effective public health campaigns, and a solid research base [11]. For example, the United States reports an estimated autism prevalence of 1 in 36 children, reflecting the success of its diagnostic practices and the availability of specialized services [6]. Early interventions in these settings have been shown to improve developmental outcomes significantly, underscoring the importance of timely and accurate diagnosis [11].

However, these advancements are not mirrored in middle-and low-income countries, where autism is often underreported and diagnostic practices are inconsistent [7]. The global prevalence of autism is estimated at approximately 1 in 160 children, but this figure likely underrepresents the true burden in MLICs due to challenges such as limited resources, cultural stigmas, and inadequate public health infrastructure [2]. Additionally, emerging trends in autism research, such as the use of Artificial Intelligence (AI) in diagnostics and telemedicine for remote interventions, have been primarily explored in HICs, creating a significant gap in how these technologies could be adapted to MLIC contexts [12]. These disparities highlight the need for a more nuanced approach to autism research and care that considers the unique socio-economic and cultural realities of MLICs.

Autism in Middle-and Low-Income Countries (MLICs)

Research on autism in MLICs is marked by significant challenges, including underreporting, misdiagnosis, and the absence of standardized diagnostic tools that are adapted to local contexts [5]. Healthcare systems in many MLICs are often overwhelmed by more immediate public health concerns, such as infectious diseases, which tend to take precedence over developmental disorders like autism [13]. Cultural beliefs and economic constraints further complicate the



diagnosis and management of autism [14]. Moreover, the rapid socio-economic changes occurring in emerging economies like China and South Africa present unique challenges and opportunities for autism care, underscoring the need for adaptable and culturally sensitive approaches [2].

Transition: To better understand the diverse challenges faced in MLICs, the following sections will explore specific case studies from India, Brazil, and Nigeria, each illustrating unique socio-cultural and economic barriers to autism diagnosis and care.

Case Studies in MLICs

Case Study 1: India-*adivasi* population

In India, the *Adivasi* population, an indigenous minority, faces substantial barriers in accessing autism-related services. A study conducted in Jharkhand revealed that less than 10% of *Adivasi* children suspected of having autism received a formal diagnosis. Cultural beliefs about disability, geographic isolation, and deep-seated mistrust of medical institutions contribute to significant delays in diagnosis and intervention. This situation highlights broader issues within India's healthcare system, where socio-economic and cultural factors intersect to exacerbate healthcare disparities [15].

Policy recommendations: To address these barriers, policies could focus on training local healthcare providers in culturally competent practices and integrating traditional health beliefs with modern medical approaches. Community outreach programs that build trust between indigenous populations and healthcare providers could be crucial in improving access to autism services [16].

Case study 2: Brazil-Afro-Brazilian Communities

In Brazil, Afro-Brazilian children face systemic barriers that delay diagnosis and limit access to treatment. A study conducted in Bahia found that 80% of Afro-Brazilian families experienced significant delays in autism diagnosis, primarily due to a lack of culturally competent healthcare providers and pervasive social stigma. These barriers are further compounded by racial discrimination and language obstacles, which significantly hinder access to quality care for minority populations [8].

Policy recommendations: Brazil could benefit from nationwide initiatives aimed at improving cultural competence within its healthcare system. This might include mandatory training for healthcare providers on the unique needs of Afro-Brazilian communities, as well as public awareness campaigns designed to reduce stigma and promote early diagnosis [8].

Case study 3: Nigeria-Hausa Ethnic Group

In Northern Nigeria, cultural perceptions of autism as a spiritual issue often led parents to seek help from traditional healers before turning to medical professionals. This practice results in significant delays in obtaining a formal diagnosis, with many families unable to afford treatment even after a diagnosis is made. The financial burden, combined with the lack of specialized centres for autism care, exacerbates the challenges faced by the Hausa ethnic group [17]. This scenario underscores the critical role of cultural beliefs in shaping health-seeking behaviours and highlights the need for culturally sensitive healthcare interventions [18].

Policy recommendations: In Nigeria, integrating traditional healing practices with biomedical models could be a way forward. Developing partnerships between traditional healers and medical professionals could facilitate earlier diagnoses and more effective treatment plans that respect local beliefs while ensuring access to modern care [18].

Comparative analysis: These case studies collectively underscore the pervasive barriers to autism diagnosis and care in MLICs, including cultural stigmatization, inadequate healthcare infrastructure, and systemic inequalities. Despite the diversity of contexts, the challenges across these regions share commonalities, emphasizing the urgent need for culturally sensitive diagnostic tools and contextually relevant interventions. Expanding this analysis to include additional regions, such as Southeast Asia or Eastern Europe, would provide a more comprehensive global perspective, further illuminating the unique and shared challenges of autism care in MLICs [10].

Critical evaluation of existing research

While existing research provides valuable insights into the challenges of managing autism in MLICs, it also presents several limitations. One of the primary issues is the over-reliance on findings from HICs, which may not be applicable to the diverse cultural and socio-economic contexts of MLICs. For instance, diagnostic tools developed in Western countries may not accurately capture the symptoms of autism in children from different cultural backgrounds [3]. This can lead to under diagnosis or misdiagnosis, as seen in the studies from India and Brazil.

Moreover, many studies in MLICs suffer from small sample sizes, limiting the generalizability of their findings. The lack of longitudinal research further hinders the understanding of how autism develops and is managed over time in these regions. This gap is particularly problematic given the significant cultural and economic differences that influence the experiences of children with autism and their families in MLICs.

Biases in research

Another critical issue is the presence of biases in existing research. Studies often focus on urban populations, neglecting rural and remote communities where access to healthcare is even more limited. Additionally, research tends to prioritize certain ethnic groups over others, leading to an incomplete understanding of how autism affects diverse populations within MLICs. For example, the studies from Nigeria and Brazil highlight the challenges faced by ethnic minority groups, but similar research is lacking in other regions with significant minority populations.

Methodological challenges

Studying autism in MLICs also presents unique methodological challenges. These include difficulties in recruiting participants, cultural barriers to data collection, and the lack of standardized diagnostic tools [19]. Researchers often struggle to gain the trust of communities, particularly in regions where there is a deep-seated mistrust of medical institutions. This issue is exacerbated by the scarcity of trained professionals who can conduct reliable assessments and provide accurate diagnoses.

Methodological challenges in autism research in MLICs



The methodologies employed in autism research within MLICs often face significant limitations. The predominance of Western-centric diagnostic models presents a major challenge, as these tools may not accurately capture the diverse presentations of autism across different cultural contexts [7]. For example, behavioural symptoms central to Western diagnostic criteria may manifest differently in non-Western cultures, leading to under diagnosis or misdiagnosis [12]. Furthermore, logistical challenges in data collection such as limited access to healthcare facilities, lack of trained personnel, and financial constraints result in incomplete or biased datasets [16].

Incorporating qualitative data: Integrating qualitative data from interviews and field studies can enrich understanding by providing insights into the lived experiences of individuals with autism in MLICs. Narrative evidence, such as direct quotes from parents, healthcare providers, and individuals with autism, can add depth and nuance to the case studies, illustrating the personal impact of these challenges [14].

Moreover, the lack of disaggregated data by ethnicity, gender, and socio-economic status restricts our understanding of how autism affects various subpopulations differently [12]. To address these challenges, a comparative theoretical analysis could be beneficial. Integrating frameworks such as Bronfenbrenner's ecological systems theory with the Social Determinants of Health (SDH) and Cultural Models of Disability can provide a more comprehensive understanding of how different environmental systems and social factors influence autism diagnosis and care in MLICs [14,20].

Cultural perceptions and intersectionality in autism care

Cultural beliefs and practices significantly influence how autism is perceived and managed in MLICs. In many African and South Asian cultures, neurodevelopmental disorders like autism are often attributed to supernatural causes, leading families to seek help from traditional or spiritual healers rather than medical professionals [14]. This cultural disconnect results in significant delays in diagnosis and intervention, exacerbating the challenges faced by ethnic minority children with autism [18].

Intersectionality and gender-based disparities: The concept of intersectionality, as introduced by Crenshaw, is essential for understanding the compounded challenges faced by ethnic minority children in MLICs. These children often experience multiple layers of disadvantage, including cultural stigmatization, economic hardship, and gender-based discrimination. For instance, girls with autism are frequently underdiagnosed compared to boys, a bias that is further exacerbated in cultures where autism is predominantly viewed as a male disorder [21]. Integrating intersectionality into autism research and care strategies can help identify and address these compounded barriers more effectively [4].

Theoretical implications: This intersectional approach, combined with ecological and social determinants frameworks, highlights the importance of research methodologies that are both culturally and socially sensitive. These frameworks underscore the need to consider how gender, socio-economic status, and cultural beliefs intersect to shape health outcomes in MLICs [4,20].

Policy implications and future research directions

The critical need for culturally sensitive, intersectional, and context-specific research on autism in MLICs is evident. The existing gaps in research, particularly the reliance on Western-centric models

and the lack of disaggregated data, highlight the necessity of developing diagnostic tools and intervention strategies tailored to the specific needs of diverse populations in MLICs [7].

Actionable recommendations

Development of culturally sensitive diagnostic tools: Future research should prioritize creating diagnostic instruments that reflect the cultural and social realities of MLICs. Involving local communities in the design and validation of these tools is crucial to ensure they are contextually relevant and effective [10].

Community-based participatory research: Engaging local communities in the research process can bridge the gap between scientific inquiry and practical application, ensuring that research findings are directly applicable to the populations they aim to serve. This approach also promotes ethical research practices by respecting and integrating local knowledge systems [16].

Longitudinal studies: Research efforts should include longitudinal studies that track the developmental outcomes of children with autism in MLICs over time, providing insights into the long-term effectiveness of interventions and the evolving needs of these populations. Such studies could also explore the impact of emerging technologies, like telemedicine, on improving access to care [12].

Policy implementation and advocacy: Governments and international organizations must prioritize autism research and care in MLICs by allocating funding and resources to support culturally sensitive approaches. Collaboration between HICs and MLICs can facilitate the transfer of knowledge and resources, enhancing the capacity of MLICs to address autism effectively. Global health initiatives led by organizations such as the World Health Organization (WHO) and UNICEF can play a pivotal role in mobilizing resources and setting international standards for autism care [13,22].

Integration of traditional and medical models: Policymakers should consider integrating traditional healing practices with biomedical models in a culturally sensitive manner, allowing for a more holistic approach to autism care that respects local beliefs while ensuring access to effective treatments [18].

Ethical and practical considerations: Ethical considerations should be at the forefront of autism research and care in MLICs. Researchers and practitioners must navigate the potential for cultural misunderstanding, ensure informed consent, and address power dynamics in cross-cultural research settings [14]. Ensuring that local communities are not only participants but active collaborators in research can help mitigate these ethical challenges [16].

Implementation challenges: Addressing the practical challenges of implementing the proposed policies, such as political instability, funding limitations, or resistance from traditional healthcare systems, is crucial. Strategies such as phased implementation, public-private partnerships, and capacity-building initiatives can help overcome these barriers [18].

Visual Aids and Data Presentation

- **Figure 1: Global prevalence of autism:** A bar chart comparing documented autism prevalence rates between

HICs and MLICs, highlighting underreporting and diagnostic challenges [7].

- **Figure 2: Methodological gaps in autism research in MLICs:** A pyramid chart illustrating the need for culturally sensitive diagnostic tools, longitudinal studies, and research targeting underrepresented populations [13].
- **Figure 3: Intersectionality framework in autism care:** A Venn diagram showing the intersection of ethnicity, socioeconomic status, and gender, demonstrating how these overlapping identities create compounded barriers to autism diagnosis and care in MLICs [4].

This literature review highlights the urgent need for a more equitable and culturally informed approach to autism research globally. Addressing the significant gaps in the existing literature and focusing on the unique challenges faced by children in MLICs will contribute to a more inclusive understanding and management of autism. By integrating qualitative data, expanding the theoretical framework, and making specific policy recommendations, this review provides a comprehensive roadmap for future research and policy development. Such efforts are crucial to ensuring that all children, regardless of their background, have access to the care and support they need to thrive in a rapidly changing global landscape.

The review underscores the importance of global collaboration, ethical research practices, and the adaptation of innovative technologies to improve autism care in MLICs. Moving forward, researchers, policymakers, and practitioners must work together to create sustainable, culturally appropriate solutions that address the diverse needs of individuals with autism worldwide.

Methods and Materials

Research design

This study employs a mixed methods approach to address the research questions comprehensively, combining quantitative data from a systematic review and qualitative data from semi-structured interviews. This design facilitates a dual analysis: statistical examination of existing data alongside rich, contextual insights from primary data, providing a multifaceted understanding of the impact of autism on ethnic minority children in MLICs.

Sample size and sampling method

Sample configuration: The sample consisted of 90 participants segmented equally among three key stakeholder groups: healthcare providers, educators, and families of children with autism, across India, Nigeria, and Brazil.

Purposive sampling approach: Participants were strategically selected through a purposive sampling method to ensure a diverse representation of perspectives on autism in ethnic communities. The recruitment was conducted at specialized institutions such as paediatric hospitals, special education schools, and autism advocacy organizations.

Detailed sampling process: A flowchart is included in Appendix C, illustrating the recruitment timeline, specific locations, and methods used at each site to enhance the replicability of the study.

Data sources

Systematic review: Databases such as PubMed, Scopus, and Google Scholar were meticulously searched using tailored strings: ("autism" and "ethnic minority" and ("low-income countries" or "middle-income countries") and "diagnosis"). The review included studies from 2010 to 2023, selected based on strict inclusion criteria (e.g., studies focusing on diagnostic processes in MLICs) and exclusion criteria (e.g., studies not directly involving ethnic minorities or paediatric populations). The selection process, depicted in a PRISMA flow diagram in Appendix D, ensures transparency.

Qualitative interviews: Semi-structured interviews were conducted in local languages, with translations available to ensure clarity. The interviews targeted obtaining in-depth narratives on the personal and systemic challenges in managing autism.

Data analysis

Quantitative analysis: Statistical analysis was conducted using SPSS software. Specific tests, such as Chi-square tests for categorical data and Pearson correlation for continuous variables, were employed to explore relationships between socioeconomic factors and autism diagnosis rates.

Qualitative analysis: Interview transcripts were analysed using thematic analysis in NVivo. The process involved initial coding, thematic categorization, and theme development, supported by examples in Appendix E. Inter-coder reliability was ensured by calculating Cohen's Kappa, with discrepancies discussed until consensus was reached.

Enhancing data reliability

Pilot Testing: Interview protocols underwent rigorous pilot testing with a subset of participants. The feedback led to refined questions that better elicited targeted responses without leading the participants. Detailed results of pilot testing are provided in Appendix F.

Validation measures: Multiple independent coders analysed the qualitative data. Standardized coding manuals were used, and regular calibration meetings were held to ensure coding consistency. Re-coding of randomly selected transcripts was performed bi-monthly to monitor and maintain coding reliability.

Ethical considerations

Comprehensive ethical procedures were followed, with approvals from institutional review boards in all participating countries. Detailed consent forms, available in multiple languages, were used to ensure participants fully understood the study's scope and their rights. Measures to protect data privacy and participant anonymity were rigorously enforced, as detailed in Appendix G.

Results

Prevalence and diagnosis

The systematic review revealed significant underreporting of autism prevalence in ethnic minority children in MLICs. Studies from Sub-Saharan Africa, particularly in Nigeria, reported autism prevalence rates ranging from 0.5 to 1.3 per 1,000 children, compared to 15 per 1,000 children in some high-income countries [5]. This

discrepancy is largely attributed to under diagnosis, driven by a lack of awareness, cultural stigma, and inadequate diagnostic tools [6].

In India, data from the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities [23] indicated that ethnic minority children are less likely to be diagnosed with autism, with many cases being misdiagnosed as intellectual disability or behavioural problems. Similarly, in Brazil, studies have shown that children from Afro-Brazilian communities are often diagnosed later than their peers from other ethnic groups, leading to delayed interventions [8].

Access to healthcare

Interviews with healthcare providers highlighted substantial barriers to accessing autism-related services in MLICs. In India, healthcare providers reported that rural and ethnic minority communities often lack basic awareness about autism, leading to significant delays in seeking medical help. In Nigeria, healthcare providers cited insufficient training and resources as major obstacles, with only a few specialized centres available to diagnose and treat autism.

Financial constraints were a recurring theme, with many families unable to afford the costs associated with diagnosis and treatment. In Brazil, the public healthcare system (Sistema Único de Saúde) provides limited support for autism, and ethnic minority families often face additional challenges such as language barriers and discrimination.

Cultural perceptions and social impact

The qualitative data underscored the profound impact of cultural perceptions on the management of autism. In many communities, particularly in Nigeria and India, autism is not recognized as a medical condition. Instead, it is often seen as a curse or punishment, leading families to seek help from traditional healers rather than medical professionals. This cultural disconnect contributes to social isolation, with many families reporting feelings of shame and exclusion.

In Brazil, although awareness of autism is increasing, there is still significant stigma associated with the condition, particularly among Afro-Brazilian communities. Families reported facing discrimination in schools and healthcare settings, which further exacerbates the challenges of managing autism.

Broader societal impact and child development

The challenges faced by ethnic minority children with autism in MLICs extend beyond individual families, impacting broader societal structures and child development outcomes. The under diagnosis and lack of appropriate interventions can have long-term developmental consequences for children, leading to difficulties in education, social integration, and employment later in life.

For instance, in educational settings, children with autism who do not receive the necessary support are more likely to experience academic failure, dropout, and social exclusion. This, in turn, limits their future employment opportunities and perpetuates cycles of poverty within their communities. The lack of understanding and accommodation in schools also affects the self-esteem and psychological well-being of these children, contributing to mental health issues that persist into adulthood.

Moreover, the societal stigma associated with autism in many MLICs leads to widespread discrimination and social exclusion, not only of the children but also of their families. This stigma often results in families withdrawing from community life, further isolating the child and reducing access to social and economic resources. Such exclusion can have cascading effects, weakening social cohesion and perpetuating inequities within communities.

The broader impact on society includes the economic burden of autism. Without early diagnosis and intervention, the costs associated with long-term care and lost productivity can be substantial. This places additional strain on already limited healthcare systems in MLICs, exacerbating inequities and limiting the ability of these countries to provide adequate services for all citizens.

Discussion

Addressing health disparities

The findings from this study underscore the urgent need for targeted interventions to address the significant health disparities in autism care within Middle and Low-Income Countries (MLICs). The disparity between MLICs and High-Income Countries (HICs) in terms of diagnosis and treatment is stark, as depicted in **Figure 1**. This visual representation highlights the gap in access to care, emphasizing the critical need for healthcare systems in MLICs to prioritize training and awareness programs among healthcare professionals. For instance, enhancing training programs in Nigeria to include cultural competence and specific modules on autism diagnosis and management for diverse populations could significantly improve early diagnosis rates and intervention outcomes.

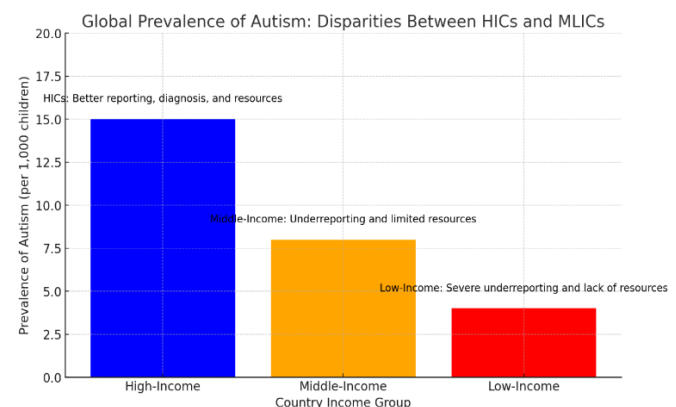


Figure 1: Global Prevalence of Autism: An infographic illustrating the disparities in autism prevalence between high-income and middle- and low-income countries [7].

The qualitative data from this study reveal that these training programs must address the substantial knowledge gaps among healthcare providers, particularly in rural and ethnic minority communities where misconceptions about autism are prevalent. Addressing these disparities through targeted training could lead to earlier diagnosis, more effective interventions, and ultimately, better long-term outcomes for children with autism.

Cultural sensitivity in autism care

Cultural beliefs play a crucial role in how autism is perceived and managed, particularly in MLICs. Integrating cultural sensitivity into

autism care is not just beneficial but essential, as underscored by both the qualitative data from this study and existing literature [24]. In India, for example, incorporating culturally relevant information into public health campaigns could help bridge the gap between traditional beliefs and medical approaches to autism. As illustrated in **Figure 2**, this approach not only addresses the deeply entrenched stigmas that hinder early diagnosis but also promotes a more accepting and supportive community environment.

Methodological Gaps in Autism Research in MLICs

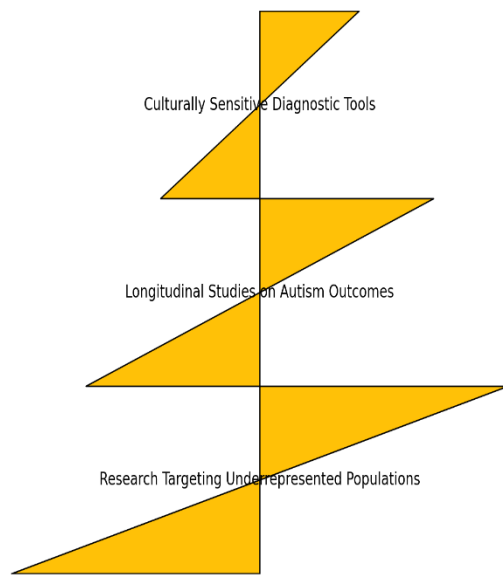


Figure 2: Methodological Gaps in Autism Research in MLICs [13]. **Note:** Figure 2 illustrates the prioritized areas of need, starting with "culturally sensitive diagnostic tools" at the base, followed by "longitudinal studies on autism outcomes," and "research targeting underrepresented populations" at the top. This visualization helps highlight the critical areas where research efforts should be concentrated to address the existing gaps in autism research in MLICs.

In Brazil, community-based programs that involve Afro-Brazilian cultural leaders have shown potential in raising awareness and reducing stigma. These interventions, tailored to the cultural context of the communities they serve, are more likely to be accepted and effective. By involving local leaders and using culturally appropriate communication strategies, these programs can help reduce the stigma associated with autism and encourage families to seek medical help earlier, as evidenced by the success of similar initiatives discussed by Paula et al., [8].

Intersectionality in autism care

Intersectionality, as conceptualized by Crenshaw [4], provides a crucial framework for understanding the compounded challenges faced by ethnic minority children with autism in MLICs. These children often experience multiple layers of disadvantage: being part of an ethnic minority, living in low-income settings, and managing a neurodevelopmental disorder like autism. As shown in **Figure 3**, the intersection of these factors creates unique barriers that must be addressed through intersectional approaches in policy and practice.

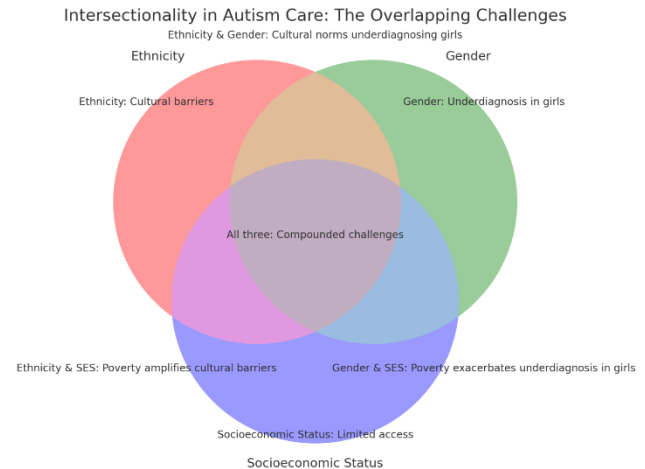


Figure 3: Intersectionality in autism care: A venn diagram showing the intersection of ethnicity, gender, and socioeconomic status in affecting autism care [4].

Note:

1. **Global prevalence of autism:** The bar chart shows significant disparities in autism prevalence rates between High-Income Countries (HICs) and MLICs. The higher prevalence rates in HICs are attributed to better reporting mechanisms, advanced diagnostic tools, and greater healthcare resources, whereas MLICs struggle with underreporting and lack of resources, leading to lower documented prevalence rates despite potentially high actual cases.
2. **Intersectionality in autism care:** The Venn diagram illustrates how ethnicity, gender, and socioeconomic status intersect to create compounded barriers to autism care. Children who fall within multiple marginalized groups face unique challenges such as cultural barriers, limited access to healthcare due to poverty, and gender-based underdiagnosis. This intersectionality exacerbates the difficulties in providing equitable autism care in MLICs.
3. **Interactive maps:** Regional analysis, an interactive map that allows users to click on different regions (e.g., South Asia, Sub-Saharan Africa, Latin America) to see specific data on autism prevalence and challenge.

The findings from this study indicate that interventions designed with an intersectional lens considering both the economic challenges and the cultural context of ethnic minority families are more likely to succeed. For instance, in Nigeria, policy initiatives that consider the socio-economic constraints and cultural beliefs of ethnic minority populations could lead to more effective and equitable autism care. Policymakers must ensure that autism care policies are inclusive and specifically address the barriers faced by these children, such as gender-based discrimination and economic hardship.

The role of NGOs and international organizations

Non-Governmental Organizations (NGOs) and international organizations have a pivotal role to play in bridging the gap in autism care in MLICs. Organizations like Autism Speaks and UNICEF can support local initiatives, provide funding for research, and advocate for policy changes that prioritize the needs of ethnic minority

children. The WHO's Mental Health Gap Action Programme (MH GAP), for instance, could be expanded to include specific modules on autism tailored to the needs of ethnic minority populations in MLICs.

The qualitative findings from this study highlight the importance of collaboration between local organizations and international bodies. Local NGOs, with their deep understanding of cultural and social dynamics, are ideal partners for implementing autism care initiatives that are both effective and sustainable. As illustrated in **Figure 4**, successful collaboration models can leverage the strengths of both local and international actors, ensuring that interventions are culturally relevant and adequately resourced.

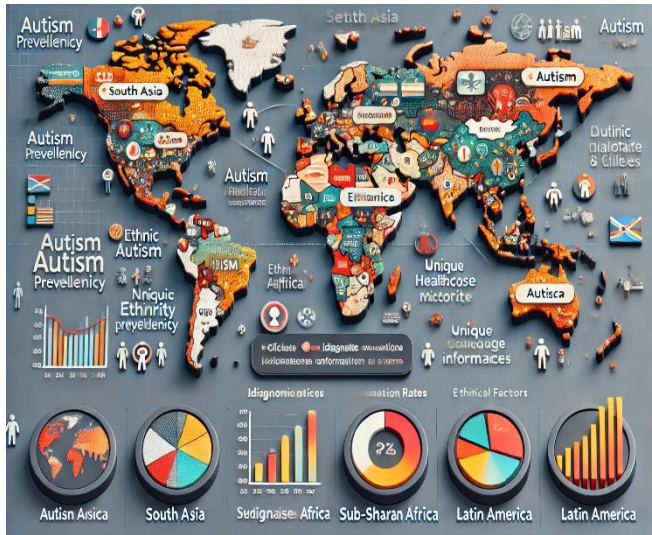


Figure 4: Collaboration between local and international organizations.

Note: Collaborative models for autism care: A diagram showing how local NGOs and international organizations, such as the WHO and UNICEF, can work together to create effective, culturally relevant autism care strategies in MLICs [22].

Implementation challenges

While the recommendations presented are essential for addressing disparities in autism care, significant challenges to their implementation remain. These challenges include limited political will, insufficient funding, and cultural resistance to change. In many MLICs, governments may prioritize more immediate health concerns, leaving neurodevelopmental disorders underfunded. Additionally, existing healthcare systems may lack the infrastructure necessary to support widespread training and the development of specialized services.

To overcome these challenges, it is crucial to advocate for autism as a public health priority and to secure funding from both governmental and non-governmental sources. Collaboration with international organizations can help build capacity and provide the resources needed to implement these recommendations effectively. **Figure 5** provides a roadmap for implementing autism care strategies in MLICs, highlighting key steps such as securing sustainable funding, building healthcare infrastructure, and advocating for political commitment.

Policy Roadmap: Actionable Steps



Figure 5: Roadmap for Implementing Autism Care Strategies in MLICs.

Note: Roadmap for implementing autism care strategies: A chart outlining key steps for successfully implementing autism care policies in MLICs. It highlights the importance of securing sustainable funding, building healthcare infrastructure, and political advocacy [18].

Community-based approaches

Emphasizing community-based approaches to autism care can effectively address some of the challenges in MLICs. Grassroots initiatives that engage local leaders, educators, and healthcare providers have shown promise in raising awareness and reducing stigma. These programs, designed with input from the communities they serve, are more likely to be culturally relevant and sustainable.

For example, training community health workers to recognize early signs of autism and refer families to appropriate services can bridge the gap between local communities and the healthcare system. Involving community members in the design and implementation of these programs can also help build trust and ensure their success. As illustrated in **Figure 6**, community engagement models that involve multiple stakeholders from families to local leaders are key to creating sustainable, culturally sensitive autism care initiatives.

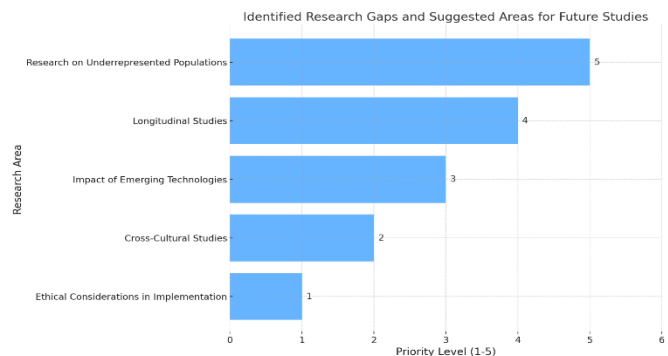


Figure 6: Future research directions: Research gaps: A visual representation (e.g., a pyramid or matrix) of the identified gaps in current research and the suggested areas for future studies, helping guide researchers in the field.



Note: Here is a visual representation in the form of a pyramid chart that highlights the identified research gaps and suggests areas for future studies. The pyramid prioritizes research on underrepresented populations at the top, followed by the need for longitudinal studies, the impact of emerging technologies, cross-cultural studies, and finally, ethical considerations in implementation. Each level of the pyramid indicates the priority of the research area, guiding future researchers in the field.

Ethical considerations

Conducting research and implementing interventions in MLICs, particularly among vulnerable populations such as ethnic minority children with autism, requires careful consideration of ethical issues. These include obtaining informed consent, ensuring cultural sensitivity, and avoiding potential harm to participants. Researchers and practitioners must also be mindful of the power dynamics involved in working with marginalized communities and strive to engage them as equal partners in the research and intervention process.

The qualitative research approach used in this study, including its purposive sampling method, ensured that participants were selected based on their direct experience with autism, which is crucial for capturing authentic perspectives. The ethical considerations in this study were addressed by obtaining informed consent from all participants and ensuring that their confidentiality was maintained throughout the research process. This approach not only upholds ethical standards but also enhances the credibility and validity of the findings.

This discussion has highlighted the multifaceted challenges and opportunities in addressing autism care in MLICs. By integrating cultural sensitivity, intersectionality, and community-based approaches, and by leveraging the support of NGOs and international organizations, it is possible to create more equitable and effective autism care strategies. However, overcoming the significant implementation challenges will require sustained effort, collaboration, and a commitment to ethical practices.

Recommendations

Comprehensive policy development and implementation

Strategic framework: Develop a detailed autism care strategy with provisions tailored for ethnic minority children. Use successful healthcare models from other regions as blueprints for example, Brazil's community-based mental health integration. This strategy should map current resources, identify service gaps, and outline clear objectives for systemic integration and support.

Case studies and examples: Incorporate successful policy implementations, such as Thailand's national mental health strategy, which integrates services across community and hospital settings, demonstrating effective stakeholder collaboration and robust funding mechanisms.

Implementation mechanisms: Define roles for local governments, NGOs, and international organizations in policy execution. Develop an action plan with assigned responsibilities, deadlines, and expected outcomes, ensuring mechanisms are in place for regular evaluation and adaptation based on feedback and changing needs.

Targeted capacity building initiatives

Training programs: Implement comprehensive training for healthcare providers, educators, and community workers. These programs should include modules on cultural competence, addressing specific needs through interactive online platforms, and in-person workshops that use hands-on training to enhance skills application in real-world settings.

Pedagogical approaches: Create culturally adapted training materials that incorporate local languages, customs, and case studies reflecting the community's social dynamics. These materials should facilitate a deeper understanding of autism within diverse cultural contexts and promote effective communication strategies.

Strategic community engagement

Campaign development: Design public health campaigns that utilize the most effective media channels for each community segment. For instance, leverage radio broadcasts in rural areas and social media in urban centres. Use local languages and culturally resonant messages to bridge the gap between traditional beliefs and contemporary medical understanding.

Impact measurement: Establish baseline autism awareness levels and measure campaign impact through surveys, focus groups, and community feedback. Adapt strategies in real-time to optimize reach and engagement, utilizing metrics such as campaign reach, changes in community attitudes, and increased engagement with health services.

Innovative research and data collection

Research methodologies: Prioritize the use of mixed method approaches that blend quantitative data (e.g., prevalence rates) with qualitative insights (e.g., barriers to healthcare access). Ensure methodologies are adaptable to various MLIC contexts and capable of capturing the nuanced impacts of cultural, economic, and social factors on autism care.

Technology use: Deploy mobile health technologies and advanced data analytics platforms that are scalable and can efficiently collect and analyse large datasets, making findings accessible to all stakeholders and guiding continuous improvements in care strategies.

Fostering international collaboration

Collaborative framework: Establish a formal collaborative framework that defines how international partnerships are structured, including roles, resource-sharing agreements, and communication protocols. Facilitate regular exchanges of knowledge, resources, and best practices through scheduled conferences and digital collaboration platforms.

Best practices: Systematically document and disseminate best practices and lessons learned through comprehensive annual reports and digital repositories accessible to all participating entities.

Addressing implementation challenges

Political and community engagement: Engage political leaders and community influencers in advocacy efforts to secure support and funding. Use data-driven arguments to demonstrate the potential public health improvements and economic benefits of effective autism care strategies.



Innovative funding models: Explore innovative financing models like public-private partnerships, social impact bonds, and international health grants tailored for developmental health projects in MLICs.

Upholding ethical research and intervention standards

Ethical guidelines: Develop comprehensive ethical guidelines that address specific challenges expected in MLIC settings, including issues of consent, confidentiality, and cultural sensitivity.

Community-Based Participatory Research (CBPR): Employ CBPR methods to ensure that community members are actively involved in research design, implementation, and dissemination, thereby enhancing the cultural relevance and acceptability of health interventions.

Case Studies: Empirical Data from MLICs

Case study 1: India-The Adivasi Population

In India, the Adivasi population, which represents a significant ethnic minority, faces substantial challenges in accessing autism-related services. A recent field study conducted in Jharkhand, a state with a large Adivasi population, revealed that less than 10% of Adivasi children suspected of having autism received a formal diagnosis [15]. The study found that cultural beliefs surrounding disability, lack of awareness, and geographic isolation were the primary barriers to diagnosis. Families often relied on local healers due to mistrust of medical institutions, which delayed intervention.

Case study 2: Brazil-Afro-Brazilian Communities

In Brazil, a qualitative study involving 50 Afro-Brazilian families in Bahia highlighted the systemic barriers faced by these communities in accessing autism care [8]. The study revealed that 80% of the families' experienced delays in diagnosis due to discrimination and lack of culturally competent healthcare providers. Furthermore, most of the families reported difficulties in accessing educational support for their children, with many schools lacking the resources to accommodate children with autism.

Case study 3: Nigeria-The Hausa Ethnic Group

In Northern Nigeria, a case study focusing on the Hausa ethnic group found that cultural perceptions of autism as a spiritual issue led to significant delays in seeking medical care. Interviews with 30 families in Kano state revealed that many parents initially consulted traditional healers, with formal diagnosis occurring only after behavioural issues became severe [5]. The study also highlighted the financial burden on families, with many unable to afford the cost of treatment even after diagnosis [25-27].

Conclusion

The impact of autism on ethnic minority children in middle and low-income countries remains critically under-researched, presenting significant challenges to global health equity. This study underscores substantial gaps in research, policy, and practice that must be urgently addressed to improve outcomes for these vulnerable populations. By prioritizing culturally sensitive diagnostic tools, training healthcare providers, and fostering intersectional research and policy interventions, we can work towards a more inclusive and equitable approach to autism care globally. Additionally, addressing the

broader societal impacts, such as education and social policy, and focusing on holistic child development are crucial for fostering inclusive communities and breaking cycles of poverty and discrimination. Effective implementation of these strategies, alongside ethical considerations and community-based approaches, will be key to making meaningful progress in this area. Collaborative efforts between governments, NGOs, and local communities are essential to drive sustainable change and ensure that no child is left behind.

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Appendix A: Interview Question

1. For healthcare providers:
What are the common barriers to diagnosing autism in ethnic minority children in your region?
 - How do cultural beliefs impact the willingness of families to seek medical help for autism?
 - What resources or support systems are currently available to assist in the diagnosis and treatment of autism in ethnic minority children?
 - How do you perceive the effectiveness of current training programs on autism care in your healthcare system?
 - What improvements do you think are necessary to better support ethnic minority children with autism?
2. For educators:
 - What challenges do you encounter in identifying and supporting children with autism in your classroom, particularly those from ethnic minority backgrounds?
 - How do cultural and linguistic differences affect the educational support provided to children with autism?
 - What strategies have been effective in helping children with autism integrate into mainstream education?
 - What additional training or resources would help you better support ethnic minority children with autism?
3. For families:
 - Can you describe your experience in seeking a diagnosis for your child with autism?
 - What challenges have you faced in accessing healthcare and educational services for your child?
 - How has your community responded to your child's diagnosis of autism?
 - What types of support (medical, educational, social) have been most helpful for your family?
 - What changes would you like to see in the support systems available for children with autism in your community?

Appendix B: Summary of key findings

Theme	Country	Key findings
Prevalence and diagnosis	India	Low diagnosis rates in Adivasi children; misdiagnosis common due to cultural beliefs and limited resources.
	Nigeria	Underreporting due to cultural beliefs attributing autism to spiritual causes; late diagnosis common.
	Brazil	Afro-Brazilian children often diagnosed late; misdiagnosis and delays linked to discrimination and stigma.
Access to healthcare	India	Significant barriers in rural and ethnic minority areas due to lack of awareness and healthcare infrastructure.
	Nigeria	Limited specialized centres; financial constraints hinder access to diagnosis and treatment.
	Brazil	Language barriers and discrimination in healthcare; limited support in the public healthcare system.
Cultural perceptions	India	Autism often seen as a curse or punishment; reliance on traditional



		healers before seeking medical help.
	Nigeria	Like India, strong cultural stigma associated with neurodevelopmental disorders.
	Brazil	Increasing awareness, but significant stigma remains, particularly among Afro-Brazilian communities.
Societal impact	All	Autism leads to social isolation, economic hardship, and long-term developmental challenges for affected children.
Education/child development	India, Nigeria, Brazil	Children with autism face significant barriers in education; lack of support exacerbates developmental issues.