Equitable access to sustainable healthcare services for children with autism

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This perspective article addresses the critical issue of equitable access to sustainable healthcare services for children with autism spectrum disorder (ASD). Despite the increasing prevalence of ASD globally, significant disparities persist in accessing appropriate healthcare services. The lack of comprehensive data on autism prevalence and incidence in many regions further exacerbates this challenge, hindering the development of targeted interventions and equitable resource allocation. This paper sheds light on barriers to equitable access, including geographical disparities, cultural stigma, communication barriers and inadequate training of healthcare providers. Strategies for achieving sustainable solutions are proposed, including the expansion of telehealth services, financial assistance programmes, competency training, community-based support programmes and investment in high-quality research. By addressing these challenges and implementing evidence-based interventions, we can work towards ensuring that all children with autism have access to the healthcare services they need for optimal development and well-being.

In recent years, the prevalence of autism spectrum disorder (ASD) has increased significantly, with estimates suggesting that approximately 1 in 36 children are diagnosed with ASD in the USA alone.[1] Despite this rise, access to sustainable healthcare services for children with autism remains a significant challenge, particularly in underserved communities.[2] Equitable access to healthcare services is a fundamental human right, yet disparities persist,[3] hindering the well-being and development of children with autism.

However, the scope of our understanding of autism prevalence and incidence is not as comprehensive as initially assumed. We must acknowledge the limitations highlighted in recent critiques of methodologies employed in global health assessments such as the Global Burden of Disease (GBD) study.[4] These critiques raise concerns about the validity and reliability of reported incidence and prevalence rates, especially in low- and middle-income countries (LMICs).[4]

Specifically, the GBD study, which often reports incidence and prevalence over large areas and across multiple years, lacks sufficient data on neurodevelopmental conditions such as autism and attention-deficit hyperactivity disorder (ADHD) in many regions. A systematic review indicates that out of worldwide countries surveyed, only 34 have conducted studies on autism prevalence or incidence.[5] Large regions, including Central Asia, significant parts of South America and most of sub-Saharan Africa, lack reliable epidemiological data on autism prevalence or incidence.[5]

Furthermore, where data do exist, studies from underrepresented countries often suffer from limitations such as small sample sizes and methodological shortcomings.[5] These studies may fail to define cases satisfactorily or replicate clinical data accurately. Despite these uncertainties, the GBD estimates do not adequately represent this issue.

This lack of comprehensive data hampers our ability to address the healthcare needs of children with autism effectively. Without accurate prevalence and incidence figures, it is challenging to develop targeted interventions and allocate resources equitably. Thus, there is an urgent need for improved methodologies and increased research efforts to ensure that all children with autism, regardless of geographical location or socioeconomic status, have access to appropriate healthcare services for autism. This perspective paper aims to delve deeper into these challenges and propose strategies for achieving sustainable solutions in healthcare access for children with autism. Sustainability refers to the long-term financial and operational viability of healthcare services. This includes ensuring that healthcare services are adaptable to changing needs, are supported by appropriate policies and evolve alongside advances in autism care.

Current challenges and proposed solutions

Barriers to equitable access

Geographical disparities and financial constraints
Rural and remote areas often lack specialised healthcare facilities and trained professionals, making it difficult for families to access essential services for their children with autism.[6] The high cost of autism-related interventions, therapies and medications place a heavy financial burden on families, particularly those without adequate insurance coverage.[7]

Cultural stigma and inadequate support systems
Cultural beliefs and societal attitudes towards autism can contribute to stigma, discrimination and

misunderstanding, leading to delayed diagnosis and limited access to appropriate services.[8] Insufficient support systems for caregivers, including respite care, counselling and educational resources, further exacerbate the challenges faced by families raising children with autism.[9]

Communication barriers

Communication difficulties pose significant challenges for individuals with autism, affecting their ability to access and utilise healthcare services effectively. Primary healthcare providers' limited knowledge and training in communicating with people with autism further compounds this issue, leading to misdiagnosis, inappropriate management and dissatisfaction with healthcare experiences.[10] Furthermore, prolonged waiting times and limited appointment durations impede effective communication and understanding between healthcare providers and individuals with autism.[10]

Time constraints and lack of training

Healthcare providers may lack specialist training in autism, facing obstacles such as limited time availability, gaps in knowledge and uncertainties regarding access to specialised services.[10] Despite recognising the importance of such training, resource constraints often prevent healthcare providers from undergoing necessary education and awareness-raising initiatives. Additionally, the lack of consistent training and awareness among healthcare professionals may result in poor communication practices towards individuals with autism, further hindering their access to quality healthcare services.[10]

Strategies for sustainable solutions

Telehealth and telemedicine

Expanding telehealth services can bridge geographical barriers by enabling families in remote areas to access specialised care and consultations from experts located elsewhere. Moreover, the use of mobile and digital technologies can enhance the accessibility of healthcare services, particularly in LMICs, where resources and infrastructure may be limited. These technologies hold promise for promoting awareness, assessing large numbers of children who require screening and diagnostic evaluation, training and supervising providers, and delivering interventions.[2]

Financial assistance programmes

Government subsidies, insurance mandates and community-based initiatives can alleviate the financial burden on families, ensuring that all children with autism have access to essential therapies and interventions. Additionally, social policy and legislation must be enacted to support the optimal rollout of sensitive health systems for young children with autism, particularly in LMICs. This includes recognising autism as a developmental disability and providing financial support for services, respite care and long-term care, in alignment with international commitments to equity and financial risk protection inherent in universal health coverage.[2]

Cultural competency training

Healthcare providers should undergo cultural competency training to better understand and address the unique needs of diverse populations, reducing stigma and improving access to care. Furthermore, interventions must be adapted to culturally diverse settings to ensure their sociocultural acceptability, relevance and physical accessibility to local stakeholders, especially parents and caregivers. The process of adaptation should entail examining possible obstacles and devising methods to overcome them, including simplifying language, adjusting delivery venues for enhanced participation and integrating cultural concepts.[2]

Community-based support programmes

Establishing community-based support programmes, including parent support groups, respite care services and educational workshops, can provide families with the resources and guidance they need to navigate the challenges of raising a child with autism.[11] Additionally, task-sharing strategies can be implemented to deliver supervised health services, including surveillance and interventions, through adequately training paraprofessionals such as teachers, nursing assistants and community health workers. This approach, integral to a stepped care model, allows for the rational redistribution of tasks among various members of a workforce team, ensuring the delivery of evidence-based interventions of adequate quality.[2]

Tiered care systems

To strengthen the service structure, we recommend evidence-based models that emphasise tiered care systems and the integration of primary care and social services for children with autism. For example, Bolton et al[12] demonstrated how such models successfully address variability in care needs across different socioeconomic settings, providing a more accessible and sustainable healthcare framework for individuals in LMICs. This evidence underpins our recommendations and highlights their effectiveness in diverse contexts.

Discussion

Equitable access to sustainable healthcare services for children with autism is vital, requiring collaborative efforts from policymakers, healthcare providers and community organisations to address systemic, service-related and psychosocial barriers. Strategies encompass policy reforms, capacity-building initiatives and community empowerment.

Tiered care systems, which stratify healthcare into levels of increasing specialisation, offer a promising model for addressing the diverse needs of children with autism across different regions. In LMICs, resource constraints often make it difficult for all patients to access specialist care. However, task-sharing approaches, where

paraprofessionals and community health workers manage less complex cases under the supervision of specialists, have proven to be effective.[2] This approach helps extend services to under-served populations by utilising trained non-specialists to deliver basic interventions. It ensures that specialists can focus on managing more severe and complex cases, optimising the use of scarce resources in LMICs.

In contrast, high-income countries (HICs) often have better infrastructure, enabling the integration of primary healthcare providers, social care services and autism-specific interventions across various levels of care. In HICs, tiered care systems allow for a more coordinated and comprehensive approach to managing autism. For instance, primary care physicians may identify early signs of autism and refer patients to specialised services, while social care providers work with families to address behavioural and social challenges. This integration ensures that children receive the right level of care at each stage of development, facilitating early interventions, timely referrals and continued support throughout childhood and adolescence.

Tiered care models are scalable and adaptable to different socioeconomic contexts, making them a cornerstone of sustainable autism care. In LMICs, the scalability of task-shifting approaches – where community health workers deliver care at a basic level – enables broader access to services despite limited resources. These systems are also adaptable, allowing for the gradual inclusion of more specialised services as resources become available. In HICs, the adaptability of tiered care allows for a flexible approach to healthcare, integrating various levels of support depending on the severity of the condition and ensuring that children can access specialised autism interventions when necessary.

Addressing the variation in needs across regions requires context-specific solutions. In LMICs, the primary challenge is the shortage of specialists, which makes task-sharing and tiered care essential. In HICs, where specialists are more readily available, the focus is often on integrating services to ensure comprehensive and ongoing support. By tailoring tiered care models to these differing regional needs, we can work towards achieving equitable access to autism care on a global scale.

Changes in diagnostic thresholds, particularly the broadening of criteria for autism in recent years, have led to a significant increase in the number of children eligible for services. This shift reflects a more inclusive understanding of autism, encompassing a wider range of behaviours and developmental patterns. However, this broadening poses unique challenges for resource-limited LMICs, where healthcare systems may not have the capacity to adapt quickly to these evolving global standards. In these regions, limited access to diagnostic tools and specialised training, together with poor awareness, can result in delayed or missed diagnoses, further exacerbating existing disparities in access to care.

Efforts to harmonise diagnostic thresholds across regions are crucial for ensuring that children with autism, regardless of where they live, receive appropriate and timely care. By standardising diagnostic criteria and improving the availability of resources globally, we can create a more equitable system where all children have the opportunity to be accurately diagnosed and provided with the necessary interventions. Harmonisation efforts involve not only aligning diagnostic practices but also ensuring that regions have the infrastructure, training and support needed to implement these changes effectively. This will help close the gap in care between high-income and resource-limited settings, promoting more consistent and fair access to autism services worldwide.

Conclusion

To ensure that children with autism receive equitable and sustainable healthcare, concerted efforts by policymakers, healthcare providers and community organisations are essential. By investing in telehealth, supporting financial assistance programmes and adopting culturally competent, tiered care systems, we can address the disparities that hinder access to care. The time to act is now – by prioritising equity, sustainability and adaptability in autism care, we can build a future where no child is left without the support they need to thrive.

Data availability

Data availability is not applicable to this article as no new data were created or analysed in this study.

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Declaration of interest

None.

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