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Review article

Bridging the gap: autism spectrum disorder in children in the United States and worldwide: a narrative review

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Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by difficulty with communication and social interactions as well as restricted or repetitive behaviors. Over the last few decades, the prevalence of ASD has increased globally, with major differences in reporting, diagnosis, and interventions between developed and developing countries. The United States (U.S.) has seen a sharp rise in diagnosed ASD cases, with a current prevalence of approximately 1 in 31 children, due to improved awareness, early screening programs, and timely intervention. The U.S. healthcare system supports early intervention services through policies such as the Individuals with Disabilities Education Act and insurance mandates for ASD coverage. However, countries in Latin America, Africa, and Asia face challenges in ASD care, including limited access, stigma, underdiagnosis, and lack of resources. The World Health Organization Caregiver Skills Training, a global initiative, and the involvement of nongovernmental organizations are gradually bridging this gap. An interprofessional approach highlighting cross-cultural research, training providers, screening tools, referral options, policy implementation, and community-based care on a global scale will help reduce disparities in ASD care among countries. Making ASD care a global public health priority could help ensure developmental and mental healthcare equity. This study compares ASD care in the U.S. to that worldwide, highlighting the importance of global collaboration for early detection, service availability, and research.

Key words: Autism spectrum disorder, Applied behavior analysis, Communication social interaction, Occupational therapy, Child

Key message

The prevalence of autism is increasing worldwide. The United States has the highest numbers, likely due to the availability of better treatment options. However, global disparities exist, especially in low-resource settings in which stigma, underdiagnosis, and limited services hinder care. A coordinated international approach emphasizing early screening, inclusive policies, and culturally sensitive support systems can bridge this gap and improve the outcomes for children with autism and their families worldwide.

Introduction

Autism spectrum disorder (ASD) is among the most prevalent neurodevelopmental disorders in children. While its management has advanced significantly in some parts of the world, especially the United States (U.S.), disparities persist globally.

Children with ASD in U.S.

According to the Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring Network report, the prevalence of ASD in the U.S. is currently approximately 1 in 31 children compared to 1 in 150 in 2000.[1)] This increased prevalence is likely related to enhanced awareness, screening and diagnostic tools, and early intervention facilities. Pediatricians routinely screen children for ASD at 18 and 24 months using ASD screening questionnaires such as the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R).[1)]

The M-CHAT-R and M-CHAT-R with Follow-up (M-CHAT-RF) consist of 20 questions each. In the M-CHAT-R, responses are recorded as yes or no, whereas in the M-CHAT-RF, they are marked as Pass or Fail. For children who receive a normal M-CHAT score of zero, the expected pattern of responses is as follows: questions 2, 5, and 12 should be answered "no," and all remaining questions

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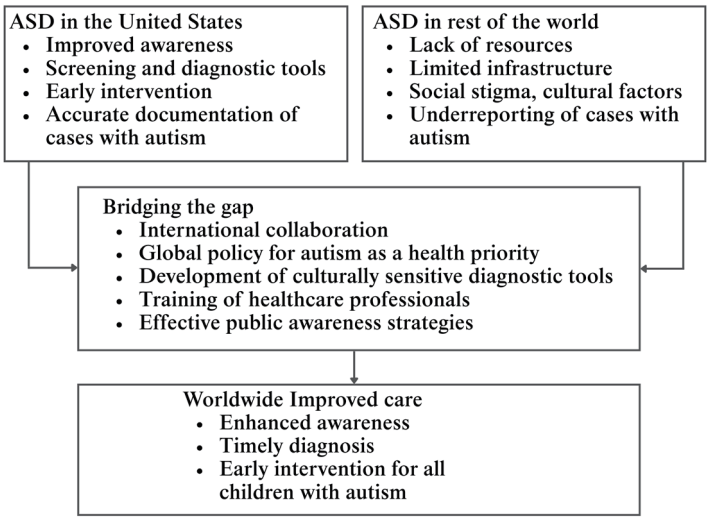

Graphical abstract. ASD, autism spectrum disorder.

should be answered "yes." Any deviation from this response pattern is considered abnormal, with each incorrect answer contributing 1 point to the total M-CHAT score. M-CHAT grading indicates patients at low, medium, or high risk.[2)]

A score of 0–2 on the M-CHAT-R indicates low risk, for which no further action is necessary. A score of 3–7 suggests moderate risk; in such cases, the M-CHAT-RF should be administered. Only the items marked as at risk on the initial M-CHAT-R are then reviewed during follow-up. If 2 or more of these items remain at risk after follow-up, the child should be referred immediately for further evaluation. Children who score 8–20 are considered at high risk and should be referred immediately for a comprehensive diagnostic assessment and early intervention services. Additionally, if there are concerns about possible signs of ASD from the pediatrician or parent, a referral should be made regardless of the child's M-CHAT score.[2)]

Children are referred to specialists for speech, vision, hearing, and ASD evaluations. Children at medium risk are re-evaluated using the M-CHAT-RF, and further management is decided based on the re-evaluation scores. All patients with speech delays begin speech therapy, and based on the confirmation of ASD, start receiving specific ASD services. Insurance coverage mandates support therapies such as applied behavior analysis (ABA) and occupational and speech therapy. However, insurance benefits for ASD services vary significantly across states and are influenced by insurance plan coverages. The National Institutes of Health provides research funding, while organizations such as Autism Speaks advocate for advanced services and support networks. These systems help with the inclusion of, acceptance of, and early intervention for children with ASD.[3)]

Public school systems are mandated to support children with ASD under the Individuals with Disabilities Education Act (IDEA).[1)] According to the IDEA, children under 3 years of age at risk of developmental delays are eligible for early intervention services. Treatment of specific symptoms, such as speech therapy for language delays, does not require the receipt of a formal ASD diagnosis. Children with ASD and other disabilities are eligible for services through the local education system starting at 3 years of age by receiving an Individualized Education Program or 504 plan and starting services before formally starting school. Parents can also ask for an evaluation by contacting their local public school system, even if the child is not yet old enough for kindergarten or not enrolled in a public school through a program called "Child Find."[4)]

Under the IDEA, children with ASD receive a range of free services in public schools, including speech and occupational therapies to support fine motor skills and sensory processing. They also receive physical therapy to address motor development and movement difficulties and behavioral interventions to address challenging behaviors and promote positive behaviors. The program also provides social skills training and assistive technology, such as tablets, to enhance the child's learning and communication. ABA develops specific skills in a systematic manner to improve the overall quality of life of children with ASD. The IDEA mandates that children with disabilities, including those with ASD, be educated alongside their nondisabled peers whenever possible to foster inclusion and social interactions.[4)]

Children with ASD worldwide

Asian, African, and Latin American countries face major obstacles to ASD care. Their exact prevalence data are not

available because of underdiagnosis related to stigma, cultural factors, limited screening tools, and a lack of management services. According to a study in 2022 by Zeidan et al.,[5] the global ASD median prevalence within and across regions is 100/10,000 (range, 1.09/10,000–436.0/ 10,000). In India, studies report a wide ASD prevalence range (0.09%–1%) depending on the population and diagnostic criteria used.[5]

In Sub-Saharan Africa, ASD remains highly stigmatized and is often misunderstood as a spiritual or behavioral issue rather than a medical condition. Limited healthcare infrastructure, scarce resources, and lacking public policy create further barriers to care.[6] Similarly, in parts of Southeast Asia and the Middle East, the diagnosis often occurs late; moreover, only few educational or therapeutic services are available. Language, cultural beliefs, and socioeconomic constraints also affect its perception and management. In low-resource areas, social stigma, shame, and cultural norms dominate, leading families to conceal their children's conditions and seek alternatives.[6]

Despite the presence of disparities between developing and developed countries, the global prevalence of ASD is increasing, likely due to the efforts of individual countries, the World Health Organization (WHO), and the involvement of nongovernmental organizations. In India, along with the M-CHAT, the Trivandrum Autism Behavioral Checklist and Social Communication Questionnaire (SCQ) are used to screen for and evaluate ASD.[7]

In 2023, Chakrabarti[8] described various factors, such as population size, diet, environmental, genetic, social, and economic, and the inclusion of children with ASD in mainstream schools in India, as components of effective ASD management as well as the need to create a national ASD program.

In South Korea, along with the M-CHAT and SCQ, the Social Responsiveness Scale and Behavior Development Screening for Toddlers are also used. Developmental screenings are performed 8 times in children aged 2 weeks to 6 years. The Korean Developmental Screening Test for Infants and Children includes 6 domains, and children older than 1 year of age are screened for additional items specific to ASD.[9] South Korea has a national program supporting patients with ASD. Children with ASD, speech delays, or intellectual disabilities can be registered with the Korea National Disability Registration System to obtain social welfare benefits.[10] South Korea is making progress in helping children with ASD. However, some target areas require more investment and development, as Kim et al.[11] studied in 2019 by comparing ASD services in Massachusetts, U.S., and Seoul, Korea.

According to the National Autistic Society, approximately 1% of the population in the United Kingdom (U.K.) has ASD. The U.K.'s National Strategy for People 2021–2026 highlights key roles such as ASD acceptance and understanding, improved educational opportunities, healthcare equality, and helping young adults become more independent and transition smoothly to adulthood. This policy covers children, young people, and adults with ASD.[12]

Based on data from the Department of Social Services, National Disability Insurance Agency, increasing Australians have ASD, with higher risk of premature deaths, unemployment, and academic difficulties, Australia has developed a national ASD strategy that includes 22 commitments highlighting services provided to, diagnostic strategies for, and health and social economic help for patients with ASD.[13]

In 2023, a study conducted in New Zealand described the current policy and plans to support patients with ASD, which highlighted its national ASD strategy to enhance educational, social, economic, and inclusion opportunities and provide future research directions.[14]

The prevalence of ASD has been steadily increasing over the last 3 decades in European countries, with estimates of 1%–2% among schoolchildren. In 2023, Mendez et al.[15] surveyed 3 European countries to examine the challenges to receiving ASD care. The study found some barriers, such as long waiting times to obtain a diagnosis, limited access to interventions, a lack of sufficient support for families, and unavailability of adequate information about ASD. These findings highlight the need to strengthen European policy to improve the quality of life of children with ASD and their families.

In 2023, Fong et al.[16] studied the needs of native and newcomer families of patients with ASD in Canada. In that study, native families preferred to receive services in rural and remote areas while preserving their cultural norms. Newcomer families prioritized quality services, including therapy and peer support. Both groups reported longer wait times similar to those of the general population. The findings emphasize the need for service structure and function to accommodate the needs of patients with ASD in underserved communities.

Efforts to minimize disparities

Despite these challenges, several global initiatives have been developed. The WHO Caregiver Skills Training program empowers parents of children with developmental disorders, including ASD, via community-based training sessions in more than 30 countries. Nongovernmental organizations and local advocacy groups are working to improve awareness and provide support, while academic

partnerships are helping to develop culturally appropriate screening tools.[17]

After receiving feedback from widespread field testing in various regions and discussions with international experts, family advocates, caregivers, and service providers, the WHO has created 5 different packages of the Caregiver Skills Training program for parents of children with disabilities, including ASD, to increase their parenting skills and confidence. The program is delivered by nurses, community-based workers, or caregivers and includes health education and social services for children and their families. The 5 Caregiver Skills Training program documents include introduction, adaptation, facilitator, participant, and home sections.[18] The program includes 9 group sessions and 3 home visits to teach caregivers how to include a child's daily activities to promote social interaction, communication, and learning. The sessions target participation, development, engagement, daily living skills, the management of challenging behaviors in children with ASD, and the development of coping strategies for caregivers.[18]

Autism Europe, an international organization, is improving the quality of life of people with ASD and their families in 40 European countries via 90 ASD organizations. Autism Europe is increasing public awareness and advocating for the rights of patients with ASD.[19]

ASD care and services differ significantly between developing and developed countries within specific regions. However, each country is making progress at both regional and national levels. For example, developed nations such as the U.K. have introduced initiatives such as the National Autism Strategy 2021–2026.[12] There are several national and international resources for ASD empowerment, including ANCA and Autism Society in Canada, Irish Society for Autism in Ireland, Autism All Stars UK, and The National Autistic Society in UK, Autism Association of Western Australia, and Autism Aspergers Advocacy in Australia. There are multicultural ASD organizations, such as Autismo Diario and online ASD communities, such as MyAutismTeam and WrongPlanet.net, that help patients with ASD.[20] (Tables 1, 2)

Future directions

ASD care must be prioritized within national health and education strategies; moreover, there is a need for extensive efforts to close this gap. Training healthcare professionals through continuous medical education programs and the integration of M-CHAT screening at the 18- and 24-month wellness visits for every child can aid the early diagnosis. Moreover, future research to understand the different presentations of ASD across countries affected by cultural factors could aid the development of tailored interventions. Thus, a global response must extend beyond diagnostics and include support and social inclusion for families. Equity in ASD care requires policy, community, and healthcare system alignments. Learning from the U.S. experience of adapting successful models to the local context and international collaboration can facilitate the sharing of ASD knowledge, resources, and management options among healthcare professionals. ASD has no geographical limitations, but its available resources are limited; therefore, addressing this gap is a moral responsibility.[1-20]

The early diagnosis of ASD can help children receive early intervention services to facilitate patient acquisition of adaptive skills, improve long-term outcomes, and improve the overall quality of life of patients and families. In 2023, Okoye et al.[21] reviewed the benefits of the early diagnosis of ASD as well as the possible risks, including

Table 1. Factors related to autism spectrum disorder, United States (U.S.) versus worldwide[1-21]

Factors	Autism spectrum disorder in U.S.	Autism spectrum disorder in the rest of the world
Prevalence	1:31	1:100
Social factors affecting ASD management	Improved awareness among families. Families themselves seek the advice Available family support services	Limited awareness Language barrier Social stigma, pressure, and cultural factors. Families try to hide the diagnosis Lack of family support
Health professionals' related factors	Trained health care professionals	Shortage of healthcare professionals
Available resources	Availability of screening tools Availability of early intervention I nsurance coverage Easily accessible applied behavior therapy, occupational therapy, and speech therapy options National Institutes of Health research funding Advocacy from other organizations ASD coverage under the Individuals with Disabilities Education Act	Limited infrastructure Lack of resources Socioeconomic constraints Inaccessibility to educational and therapeutic services World Health Organization's Caregiver Skills Training program Nongovernmental organizations involvement Absence of public policy in the developing countries, while some of the developed countries in the region have new national programs Efforts at national, regional and international levels

ASD, autism spectrum disorder.

Table 2. Summary of key published papers related to ASD[3,5,6-11,14-16,21]

Title	Year of publication	Authors	Key findings
Autism spectrum disorder: definition, epidemiology, causes, and clinical evaluation	2020	Hodges et al.[3]	The clinical evaluation of ASD begins with screening, follows referral for confirmation of diagnosis, and guides screening for comorbid conditions.
Global prevalence of autism: A systematic review update	2022	Zeidan et al.[5]	The prevalence of autism has increased over time and varies across sociodemographic groups
The global prevalence of autism spectrum disorder: A three-level meta-analysis	2023	Talantseva et al.[6]	There was an increase in autism prevalence estimates over time.
Unraveling the Spectrum: A Comprehensive Review of Autism Spectrum Disorder in India	2024	Uke et al.[7]	Timely interventions and a multidisciplinary approach are necessary for improving the lives of individuals with ASD and for dealing with the rising prevalence of ASD globally.
Autism in India: Time for a national programme	2023	Chakrabarti[8]	The article highlights the need for a coordinated national program in India.
Diagnosis and Assessment of Autism Spectrum Disorder in South Korea	2024	Kim and Yoo[9]	In South Korea, developmental screening is done 8 times in children from the age of 2 wk to 6 yr. The test includes 6 domains, and children more than 1 yr of age are screened with additional items specific to ASD
The Korea National Disability Registration System	2023	Kim et al.[10]	The Korea National Disability Registration System is a significant data resource for research on the epidemiology of disabilities.
Comparison of Services for Autism Spectrum Disorder in Massachusetts with Those in Seoul	2019	Kim et al.[11]	The limited availability of services and interventions for individuals with ASD and their families in Seoul, compared to Massachusetts, highlights key areas that require additional investment and development.
How do we get autism support right in Aotearoa New Zealand? Final Report	2023	van der Meer et al.[14]	Aotearoa New Zealand is undergoing changes in how autism support is provided, making it a crucial time to explore community perspectives on future approaches that can best promote inclusion and support for autistic individuals.
Autism care pathway in Europe	2023	Mendez et al.[15]	The article found the variability and gaps in the care pathway for autism with co-occurring epilepsy, highlighting the substantial efforts required by caregivers and underscoring the need for policy across Europe to enhance the quality of life for children with ASD.
Comparing the autism service needs and priorities of Indigenous and newcomer families in Canada: Qualitative insights	2024	Fong et al.[16]	This article highlights differences and similarities between Indigenous and newcomer families in Canada. It explores how these insights can inform the development and provision of appropriate and impactful services and supports for individuals with ASD.
Early Diagnosis of Autism Spectrum Disorder: A Review and Analysis of the Risks and Benefits	2023	Okoye et al.[21]	This review emphasizes the need for a balanced approach to early autism diagnosis, recognizing its benefits for timely intervention and improved outcomes, while underscoring the importance of accurate diagnostics, family support, societal awareness, and future directions such as biomarkers and AI-based diagnostic tools.

ASD, autism spectrum disorder; AI, artificial intelligence.

overdiagnosis or misdiagnosis. An early ASD diagnosis can cause social stigma that affects the child's interaction with their environment. Children and caregivers face the complicated process of an ASD evaluation performed by different specialists to arrive at a challenging diagnosis. That review emphasized the importance of using a logical approach, using correct tools, and including artificial intelligence to arrive at an accurate, confirmatory, and timely diagnosis of ASD.

Footnotes

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