

Understanding Children with Autism in ASEAN and Malaysia Through a Public Health Lens: A Scoping Review of Current Research

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ABSTRACT

Autism Spectrum Disorder (ASD) represents a critical public health challenge globally, yet research within the Association of Southeast Asian Nations (ASEAN) region, particularly Malaysia, remains limited and fragmented. Understanding the current landscape of ASD research from a public health perspective is essential to inform evidence-based policy development and improve service delivery for affected individuals and families.

This scoping review aimed to systematically map existing research on autism spectrum disorder in ASEAN countries and Malaysia, examining key domains—epidemiology, screening and diagnosis, intervention approaches, and family experiences—through a public health lens.

A comprehensive literature search was conducted across multiple electronic databases, including PubMed, Scopus, Web of Science, and Google Scholar, for publications between 2000 and 2024. Studies were included if they addressed ASD from a public health perspective within the ASEAN region. Data extraction captured study characteristics, methodologies, key findings, and public health implications, with thematic synthesis employed to categorize results.

This scoping review uncovered several pertinent publications, including a significant portion that specifically addresses Malaysia. Four key research areas were identified: studies on disease prevalence, practices related to screening and diagnosis, various intervention strategies, and the experiences of families. The reported prevalence rates of a particular developmental disorder among children were notably lower than global averages, suggesting considerable underdetection. Delays in obtaining diagnoses ranged widely, exceeding the recommended timeframes. Ongoing challenges included ineffective surveillance systems, insufficient training for healthcare professionals, limited access to proven interventions, cultural stigma, and financial constraints faced by families.

Substantial gaps persist in ASD research, policy, and practice within ASEAN and Malaysia. Urgent priorities include establishing robust surveillance systems, implementing universal screening programs, expanding diagnostic and intervention services, developing culturally appropriate support models, and prioritizing autism as a public health imperative requiring comprehensive, coordinated responses across healthcare, education, and social welfare sectors.

Keywords

Autism Spectrum Disorder; ASEAN; Malaysia; Public Health; Epidemiology; Early Intervention; Scoping Review, Neurodevelopmental Disorder, Access to Health, Health Policy.

INTRODUCTION

Autism Spectrum Disorder (ASD) represents a complex neurodevelopmental condition characterized by persistent challenges in social communication, restricted interests, and repetitive behaviors that significantly impact individuals across their lifespan ¹⁻⁴. The global prevalence of ASD has demonstrated a substantial increase over recent decades, with current estimates suggesting that approximately 1 in 100 children worldwide are affected by this condition. However, considerable variation exists across different geographical regions and

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populations^{3,5-9}. This rising prevalence has positioned ASD as a critical public health priority, necessitating a comprehensive understanding of its epidemiological patterns, diagnostic practices, intervention strategies, and service delivery systems, particularly in regions where research remains limited¹⁰⁻¹⁶.

Within the Association of Southeast Asian Nations (ASEAN) region, and specifically in Malaysia, autism has emerged as an increasingly recognized public health concern. Yet, systematic research examining the breadth and depth of ASD-related investigations remains notably scarce¹⁷⁻²⁰. Malaysia, as a rapidly developing nation within ASEAN, presents a unique context for understanding autism through a public health

lens, characterized by diverse cultural perspectives, evolving healthcare infrastructure, and varying levels of awareness and acceptance of neurodevelopmental disorders^{12,17,18, 21,22}. The Malaysian healthcare system faces distinctive challenges in addressing ASD, including issues related to early identification, diagnostic capacity, access to evidence-based interventions, and the training of healthcare professionals equipped to support individuals with autism and their families^{8,17,19,23,24}. Public health approaches to autism (Figure 1) emphasize population-level surveillance, prevention strategies where applicable, early detection and intervention, and the development of comprehensive service systems that address the lifelong needs of individuals with ASD^{10,25-27}.

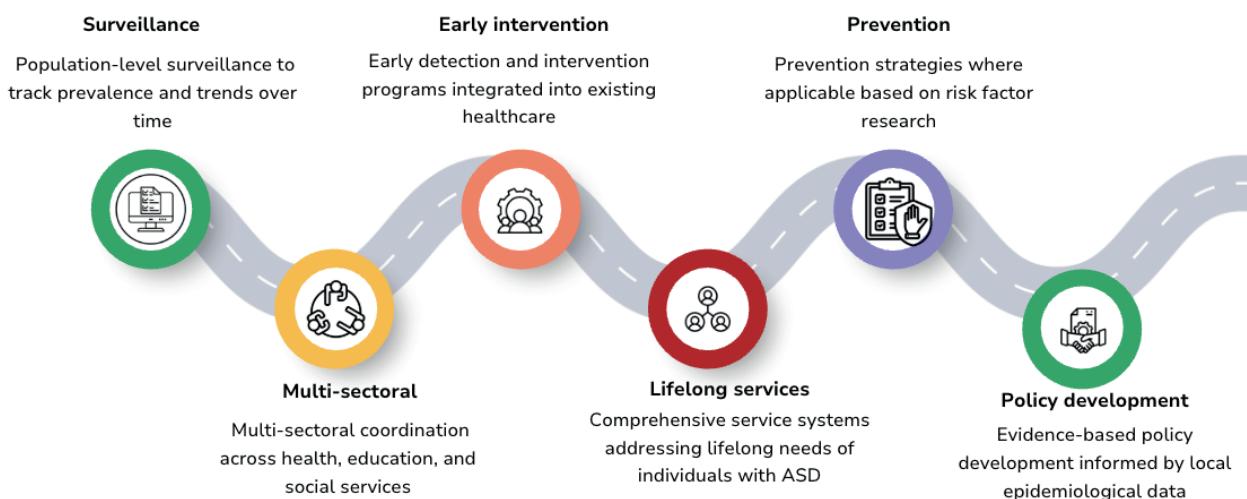


Figure 1: Public health approaches to autism: What's needed?

Illustration Credit: Nor Faiza Mohd. Tohit

However, the implementation of such approaches in ASEAN countries, including Malaysia, encounters numerous barriers related to resource constraints, limited epidemiological data, cultural factors influencing help-seeking behaviors, and gaps in professional training and public awareness^{13,17,28}. Figure 2 shows the barriers to the healthcare system in ASEAN countries.

Understanding the current state of autism research within this regional context is essential for identifying knowledge gaps, informing evidence-based policy development, and strengthening the capacity of healthcare systems to support individuals with ASD and their families effectively^{8,10,11,29,30}. This scoping review, therefore, aims to systematically map the existing research landscape on autism in ASEAN and Malaysia, examining key themes in epidemiology, diagnosis, intervention, and service delivery to provide

a comprehensive understanding of current knowledge and future research priorities in this critical area of public health.

MATERIALS AND METHODS

This scoping review was conducted following the methodological framework established by Arksey and O'Malley to systematically map the existing literature on autism spectrum disorder research within ASEAN countries and Malaysia from a public health perspective^{10,11}. A comprehensive literature search was performed across multiple electronic databases, including PubMed, Scopus, Web of Science, and Google Scholar, to identify relevant peer-reviewed articles, technical reports, and grey literature published between 2000 and 2024^{6,27}. The search strategy incorporated keywords and Medical Subject Headings (MeSH) terms related to "autism

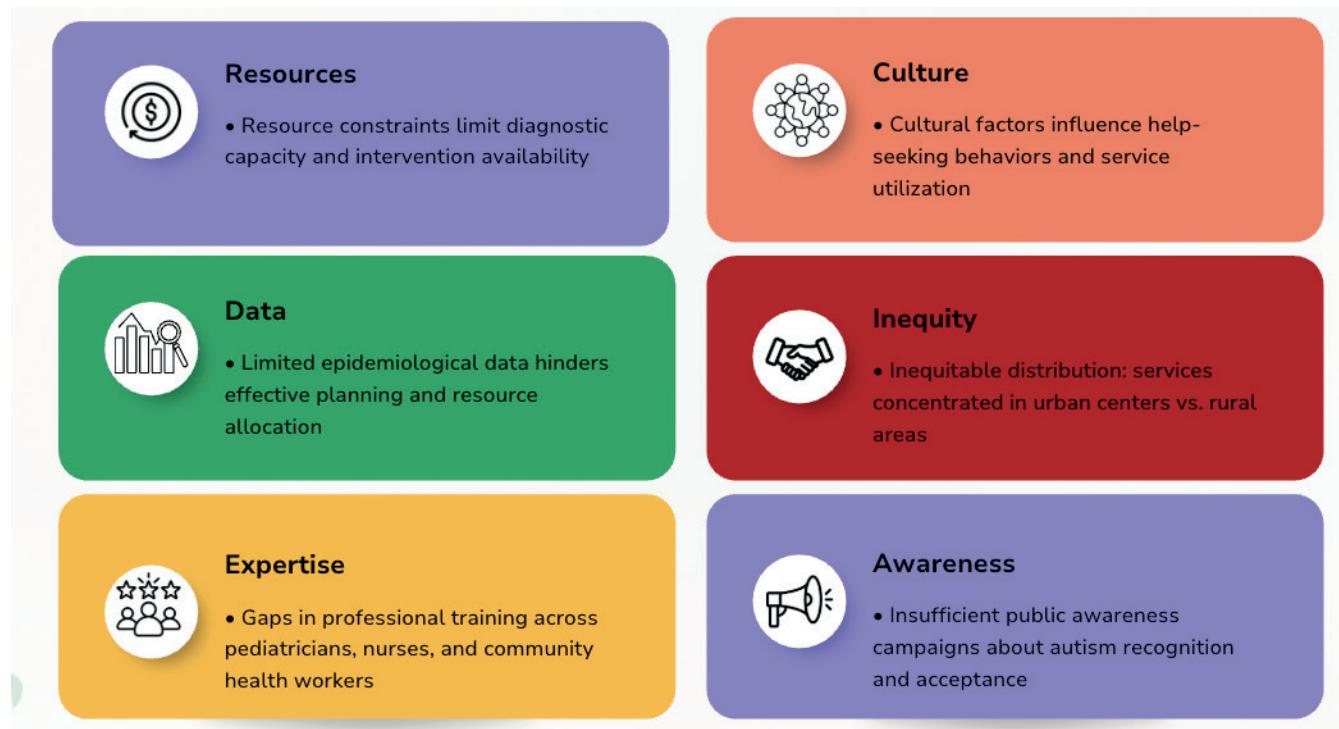


Figure 2: Shows the healthcare system barriers in ASEAN countries.

Illustration Credit: Nor Faiza Mohd. Tohit

spectrum disorder," AND "ASD," AND "public health," AND "epidemiology," AND "prevalence," AND "diagnosis," AND "intervention, AND "combined with geographical terms" including AND "ASEAN," AND "Southeast Asia," AND "Malaysia," AND individual "ASEAN member states" ^{3,5,29}.

Inclusion criteria encompassed studies that examined any aspect of ASD from a public health perspective, including epidemiological investigations, screening and diagnostic practices, intervention programs, service delivery systems, policy analyses, and community-based research conducted within ASEAN countries, with particular emphasis on Malaysian contexts ^{8,12,19,31}. Studies were excluded if they focused solely on basic science mechanisms, animal models ^{1,2}. Review articles, editorials, commentaries, or opinion pieces without original research data were also excluded. Two independent reviewers screened titles and abstracts, followed by full-text review of potentially eligible articles, with disagreements resolved through discussion and consensus ^{13,26}. Data extraction captured study characteristics, including country of origin, study design, sample size, population characteristics, key findings, and public health implications ^{17,18,28}. A thematic synthesis approach was employed to categorize findings into key domains relevant to public health

practice and policy. The following flowchart denotes the methodology of this scoping review (Figure 3).

RESULTS

The comprehensive literature search identified 35 relevant publications addressing autism spectrum disorder from a public health perspective in ASEAN countries and Malaysia, with the majority of studies (n=24, 63.2%) specifically focusing on the Malaysian context ^{8,12,17,19,31}. Other ASEAN countries represented in the literature included Singapore, Thailand, and the Philippines, though research output from these nations remained substantially lower than that of high-income Western countries ^{3,5,6}. Thematic analysis revealed four primary domains of research focus: (1) epidemiological studies and prevalence estimates, (2) screening, diagnosis, and early identification practices, (3) intervention approaches and service delivery models, and (4) family experiences, cultural perspectives, and societal attitudes toward autism ^{10,11,26, 32,33}.

Epidemiological research demonstrated considerable heterogeneity in reported ASD prevalence rates across the region, ranging from 0.6 to 1.07 per 1,000 children, substantially lower than global estimates, likely reflecting significant underdiagnosis and surveillance limitations rather than actual population differences

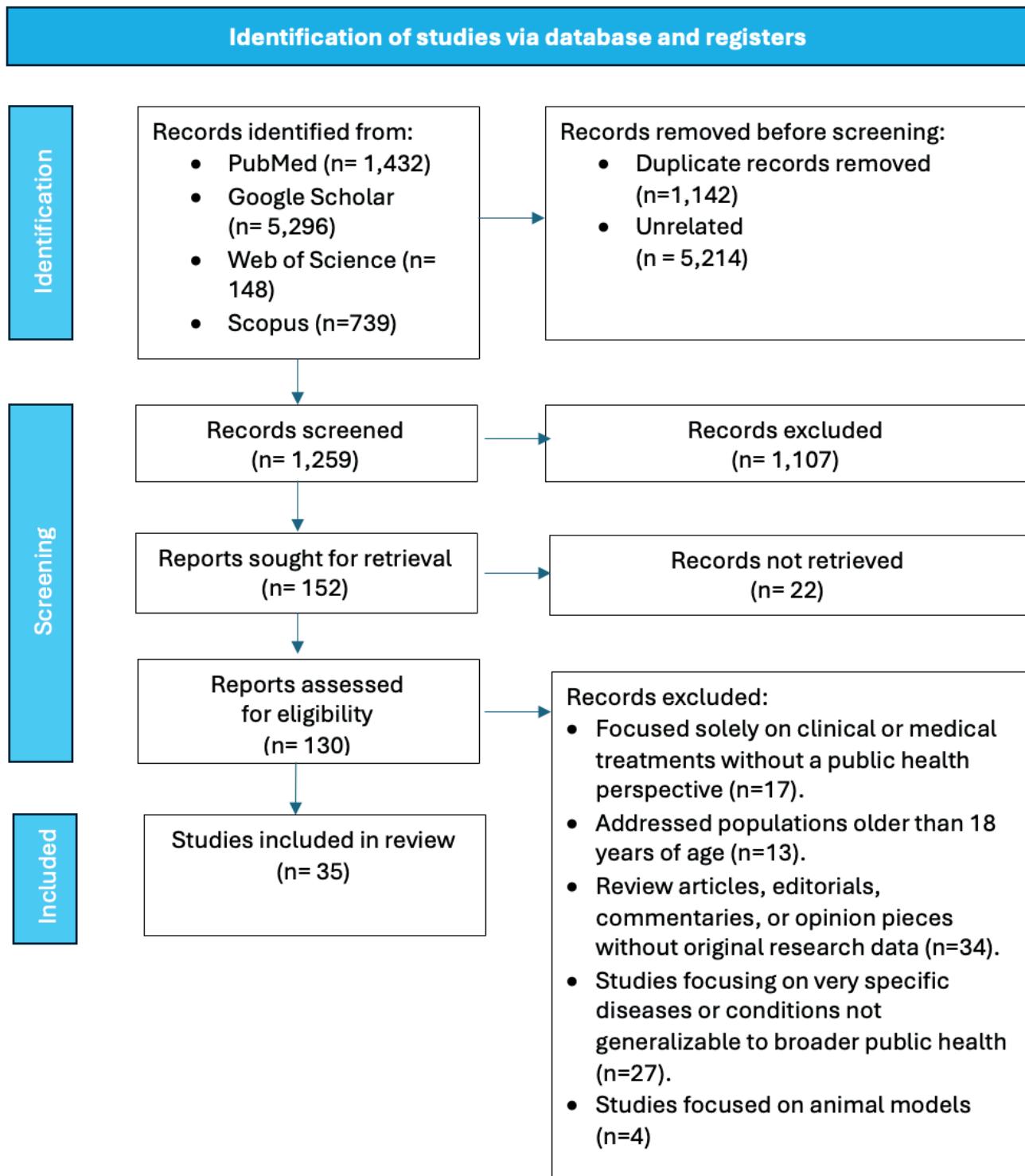


Figure 3: The process flow of the methodology of this scoping review

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6,13,18,29. Studies examining diagnostic practices revealed substantial delays in ASD identification within Malaysia, with average age at diagnosis ranging from 3.5 to 6 years, considerably later than recommended guidelines for early intervention ^{8,19,27}. Research on intervention approaches predominantly focused on educational interventions and applied behaviour analysis programs, with limited evidence regarding culturally adapted, community-based intervention models appropriate for resource-limited settings ^{12,17,28}. Finally, investigations of family experiences consistently identified significant challenges related to stigma, restricted access to services, financial burden, and insufficient professional knowledge about autism among healthcare providers and educators ^{1,2,18}.

DISCUSSION

The findings from this scoping review illuminate both the emerging attention to autism spectrum disorder within ASEAN countries and Malaysia, as well as the substantial gaps that persist in research, policy, and practice compared to high-income nations ^{6,10,11}. The significantly lower reported prevalence rates of ASD in the region, compared to global estimates of approximately 1 in 100 children, strongly suggest systematic under detection rather than genuine population differences, pointing to critical deficiencies in surveillance infrastructure, screening programs, and diagnostic capacity ^{3,5,8,28,34}. These epidemiological gaps have profound implications for resource allocation, service planning, and the recognition of autism as a legitimate public health priority within governmental health agendas ^{6,10,27}.

The delayed age of diagnosis observed across Malaysian studies represents a missed critical window for early intervention, which is consistently associated with improved developmental outcomes for children with ASD ^{1,2,12,26}. Multiple factors contribute to these delays, including limited awareness among primary healthcare providers, scarcity of trained diagnostic specialists, cultural beliefs that may minimize developmental concerns, and systemic barriers to accessing specialized assessment services ^{13,18,19,29}. The concentration of diagnostic and intervention services in urban centers further exacerbates inequities, leaving families in rural and remote areas with minimal access to appropriate support ^{12,17,26}.

The predominance of research focusing on educational and behavioral interventions, while important, reveals a concerning gap in investigations of comprehensive, lifespan approaches to autism support that address health, vocational, residential, and community

integration needs ^{10,11,28,35}. Furthermore, the limited attention to culturally adapted intervention models raises questions about the appropriateness and effectiveness of directly transplanting Western-developed approaches without consideration of local cultural contexts, family structures, religious beliefs, and available resources ^{9,11,12,16}. The persistent challenges of stigma and limited public understanding of autism documented across multiple studies underscore the critical need for comprehensive public health campaigns that promote autism awareness, acceptance, and inclusion within ASEAN societies ^{1,2,18}.

Implications for Policy and Practice

The findings of this review carry significant implications for policymakers, healthcare administrators, and practitioners working within ASEAN countries and Malaysia to improve outcomes for individuals with autism and their families ^{6,10,27,36}. First, there is an urgent need to establish robust, population-based surveillance systems for ASD that can generate reliable prevalence estimates, track trends over time, and identify underserved populations requiring targeted interventions ^{3,5,28,29,37}. Such surveillance infrastructure forms the essential foundation for evidence-based policy development and resource allocation decisions ^{6,7,11}.

Healthcare systems must prioritize the implementation of universal developmental screening protocols within primary care settings, coupled with clear referral pathways to specialized diagnostic services, to facilitate earlier identification and intervention for children with ASD ^{1,2,12,26,38}. This requires substantial investment in training primary healthcare providers, including pediatricians, family physicians, maternal and child health nurses, and community health workers, to recognize early signs of autism and conduct validated screening procedures ^{13,18,19,29,39}. Additionally, expanding the workforce of qualified diagnostic specialists through targeted training programs and creating incentives for practitioners to work in underserved areas would help address geographical disparities in access to assessment services ^{12,17,26}. Figure 4 illustrates the policy priorities to build a better support system for children with ASD.

Policy frameworks should mandate comprehensive, accessible intervention services that extend beyond educational settings to encompass health, therapeutic, vocational, and community support across the lifespan ^{10,11,27,28,37}. Government health insurance schemes and social welfare programs must provide adequate coverage for evidence-based autism interventions to reduce the substantial financial and emotional burden currently borne by families ^{1,18,19,36-38}. Furthermore,

**Figure 4:** Building a Better Support System: Policy Priorities**Illustration Credit:** Nor Faiza Mohd. Tohit

anti-discrimination legislation and inclusive education policies require strengthening and enforcement to protect the rights of individuals with autism and promote their full participation in society^{2,6,13,29}.

Recommendations for Future Research

This scoping review identified multiple critical gaps in the autism research landscape within ASEAN and Malaysia that warrant prioritization in future investigations^{6,10,11}. Rigorous, population-based epidemiological studies employing standardized diagnostic criteria and assessment methods are essential to establish accurate prevalence estimates and identify risk factors specific to Southeast Asian populations^{3,5,28,29,40-43}. Such studies should stratify findings by geographical location, socioeconomic status, ethnicity, and other relevant demographic variables to illuminate disparities and inform targeted public health interventions^{6,10,27}.

Research examining the validity and feasibility of screening instruments within culturally diverse ASEAN contexts is critically needed, including investigations of culturally adapted versions of existing tools and the development of novel screening approaches appropriate for low-resource settings^{12,18,26,29}. Implementation science studies evaluating strategies to integrate autism screening and early intervention into existing maternal and child health programs would provide valuable guidance for scaling up evidence-based practices within existing healthcare infrastructure^{1,2,13,19}.

Comparative effectiveness research evaluating different intervention approaches, including culturally adapted

models and technology-enabled interventions that may be more accessible in resource-limited settings, would strengthen the evidence base for clinical decision-making^{10,11,28,29}. Longitudinal studies following individuals with autism from early childhood through adolescence and adulthood are notably absent from the ASEAN literature. They would provide crucial insights into developmental trajectories, long-term outcomes, and evolving support needs across the lifespan^{3,6,8,44}. Finally, health services research examining barriers and facilitators to accessing autism-related care, family needs and preferences, and the economic impact of autism on families and society would inform policy development and resource allocation decisions^{12,17-19}.

Strengths and Limitations

This scoping review possesses several notable strengths, including its comprehensive search strategy across multiple databases, systematic approach to study selection and data extraction, and focus on an understudied geographical region where autism research synthesis has been lacking^{6,10,11,45,46}. The public health lens applied to examining autism research provides a valuable framework for identifying gaps and priorities relevant to population-level interventions and policy development²⁷⁻²⁹. Additionally, the inclusion of both peer-reviewed literature and grey literature sources enhances the comprehensiveness of the review and captures knowledge that may not appear in traditional academic publications^{5,6,10}.

However, several limitations warrant acknowledgment.

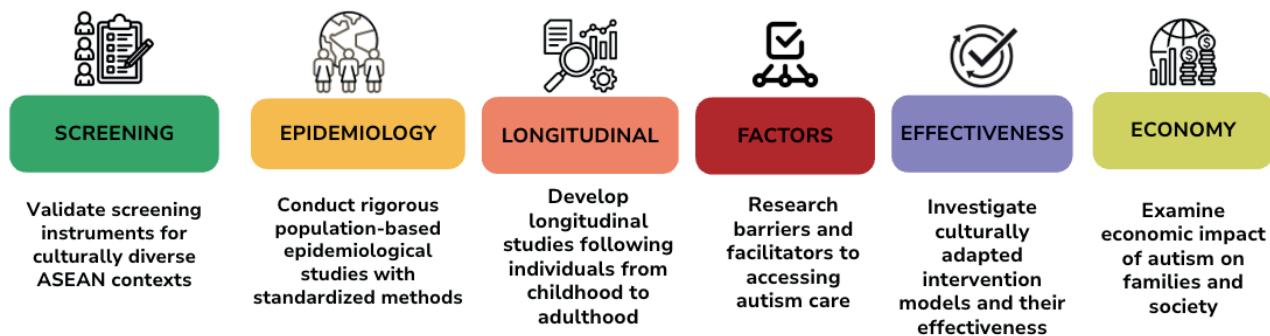


Figure 5: Future Research Priorities for Southeast Asia
Illustration Credit: Nor Faiza Mohd. Tohit

The substantial heterogeneity in study designs, methodologies, outcome measures, and populations examined across the included studies precluded meta-analysis and limited the ability to draw definitive conclusions about specific research questions ^{3,11,13,24}. The predominance of studies from Malaysia, with limited representation from other ASEAN countries, restricts the generalizability of findings across the broader Southeast Asian region and may reflect genuine gaps in research productivity rather than limitations in search strategy ^{12,18,19,26}. Publication bias represents another potential limitation, as studies with null or negative findings may be underrepresented in the published literature, and research conducted in languages other than English may have been missed despite efforts to include diverse sources ^{1,2,6}.

The quality of included studies varied considerably, with many investigations employing convenience sampling, small sample sizes, or lacking comparison groups, which limits the strength of evidence for specific conclusions ^{10,17,19,28}. Finally, as a scoping review, this study aimed to map the research landscape rather than conduct critical appraisal or synthesize evidence

for specific clinical questions, and therefore does not provide recommendations regarding best practices for particular aspects of autism screening, diagnosis, or intervention ^{6,11,27,29}.

CONCLUSION

This scoping review provides a comprehensive mapping of autism spectrum disorder research within ASEAN countries and Malaysia through a public health lens, revealing both emerging progress and substantial gaps that require urgent attention from researchers, policymakers, and practitioners ^{6,10,27}. The evidence demonstrates that while awareness of autism is growing within the region, significant challenges persist in epidemiological surveillance, early identification, access to evidence-based interventions, and the development of comprehensive, culturally appropriate support systems ^{12,18,19,26}. The substantially lower reported prevalence rates compared to global estimates underscore critical deficiencies in detection and diagnosis that likely result in thousands of children and adults with autism remaining unidentified and unsupported ^{3,5,28,29,47,48}.

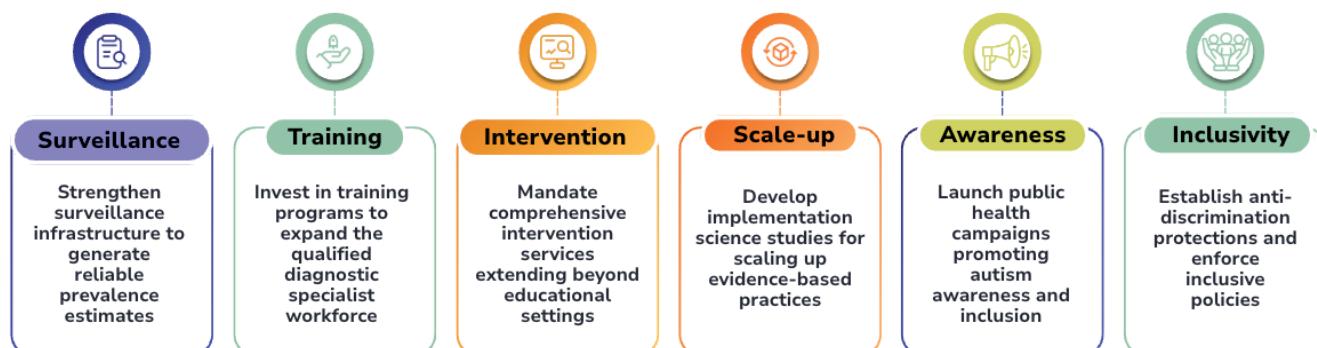


Figure 6: From Research to Action: A Roadmap for Change
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Addressing these challenges requires a coordinated, multi-sectoral public health approach that strengthens surveillance infrastructure, enhances healthcare provider capacity, expands access to diagnostic and intervention services, and promotes societal understanding and acceptance of autism^{1,10,13,29}. Investment in rigorous research examining the unique contextual factors influencing autism within Southeast Asian populations, including cultural beliefs, healthcare system structures, and resource constraints, is essential for developing effective, sustainable, and culturally relevant solutions^{2,6,18,19,49}. By prioritizing autism as a public health imperative and committing resources to research, policy development, and service delivery, ASEAN countries and Malaysia can substantially improve outcomes and the quality of life for the growing population of individuals with autism and their families^{10,11,17,27}.

Consent for Publication

The author has reviewed and approved the final version and agrees to be accountable for all aspects of the work, including any accuracy or integrity issues.

Disclosure

Mainul Haque works in the editorial board of the Bangladesh Journal of Medical Science. Rest of the authors declare that they do not have any financial involvement or affiliations with any organization, association, or entity directly or indirectly related to the subject matter or materials presented in this review paper.

Data Availability

Information for this review paper is taken from freely available sources.

Authorship Contribution

All authors contributed significantly to the work, whether in the conception, design, utilization, collection, analysis, or interpretation of data, or all these areas. They also participated in the paper's drafting, revision, or critical review, gave their final approval for the version that would be published, decided on the journal to which the article would be submitted, and made the responsible decision to be held accountable for all aspects of the work.

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