

Focus on Issues and Solutions in Autism Spectrum Disorders (ASD)

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Introduction

Autism Spectrum Disorders (ASD) research and services for addressing affected individuals' needs are in their infancy in many regions around the globe, especially in those designated as *low income*. A prominent issue, note researchers,¹ is trying to establish national ASD prevalence, expounding on the experience in Iran, an *upper middle income* economic entity with noted resource disparities between its provinces.² Establishing accurate prevalence is stymied by various factors: ASD is stigmatized and consequently under-reported by parents who may keep their affected children at home rather than send them to special education settings, diagnosis is based mostly on parental reports with rare verification by ASD specialists as trained professionals and services are not readily available or accessible, and since education and treatment for ASD children and youth are financed privately, it is more available in the more affluent provinces.

To combat these factors, the authors¹ promote empowering parents by developing greater awareness, and providing training for home-based treatment to fill the gap created by economic circumstances. They highlight the need for establishing local identification norms and treatments that are culturally sensitive to their unique setting since in Iran, as in other regions, culture drives beliefs and attitudes of parents toward ASD and dictates the treatments they may choose.³ The author believes that cross-cultural research would help service providers and policymakers understand differences in defining, accepting, and appreciating ASD individual and cultural diversities in modern times, and thus promote the well-being of children and their families.

Difficulties in establishing accurate prevalence data exist in other regions as well. Researchers clarify⁴ the factors underlying this problem in the sub-Saharan region. The lack of appropriate validated tools for ASD identification in low and middle economy regions in sub-Saharan countries is a major obstacle to development of ASD research and its management. Consequently, sub-Saharan countries rely on translation of tools developed in Western affluent countries. While these may be effective in that part of the world, they are culturally inappropriate in this region, they note. Moreover, with meager financial resources, the copyright cost of their translations and adaptations are prohibitive. Another noted barrier is the lack of awareness of ASD, and scarce resources especially in rural areas. All these contribute to inaccurate reported low prevalence of ASD in the region. This situation is understandable as for the past decades, public health in this region, by necessity, was focused on reducing life threatening diseases in their populations. Ironically, with the successful reduction in infant and child mortality, there is a substantial increase of youth populations with high needs, adding to the enormous public health burden.

The persistent considerably low reported ASD prevalence statistics was instrumental in perpetuating the myth that ASD is a prominent disease in Western affluent countries and is rarely seen in their part of the world. However, this is negated by emigration of families with ASD children from African regions to northern Western countries, note the researchers. Actually, in an editorial,⁵ authors question the low ASD prevalence reported in "third world" countries, and imply that it is most probably under reported. This has implications for delay of timely diagnosis and treatment, with serious negative outcomes for children with ASD, and the accompanying impact on their families. The authors urge the need for more research effort on the prevalence, and possible management of this disorder and its complex needs in these regions.

The problem in identifying ASD prevalence is extended to South Asia, a region that is home to more than 20% of the world's population, and where ASD prevalence remains largely obscure.⁶ Although the region includes eight countries, prevalence studies were conducted in only three lower middle income countries: Bangladesh, India, and Sri-Lanka.² The researchers' systematic review yielded data based on three studies from Bangladesh, two from India, and a single study from Sri Lanka. Bangladesh with data from rural and urban communities reported prevalence was 0.02, 0.84, and 0.15% respectively, in India, rural, urban, and tribal prevalence data yielded 0.02 to 0.23%, and one study with toddlers from Sri Lanka, indicated 1.07% prevalence. The authors noted a disparity between urban and rural data, and attributed it to the health care system structure, and growing parental awareness and identification capacity in urban areas, while rural areas are more tied to cultural traditional modes of coping with health issues. A lack of awareness and skills in ASD diagnosis among health professionals contributed to missed diagnosis as well. The authors emphasize that although the prevalence data are not generalizable to the entire South Asian region, it is useful in as much as it alerts government and non-government agencies in the region to the gap in evidence, a serious issue in the face of the growing prevalence of ASD across the globe. These data are needed to facilitate choices of culturally appropriate and cost effective tools and strategies to answer the complex needs of the population with ASD in the vast region.

The studies on difficulties establishing prevalence in developing countries highlight the lack of low-cost instruments that can be easily applied in various regions for identifying ASD high risk children. They point out the need for cross-cultural studies that can determine suitability of instruments to their particular cultures. Researchers agree that there is a need in developing tools for easy access and suitability to examine risk of ASD across cultures. A study for identifying key ASD indicators across disparate cultures and economies was recently initiated.⁷ It examined a promising brief screening tool, Autism Spectrum Quotient (AQ)-Child (for children aged 4–9) in identifying ASD predictive symptoms in the UK and Japan, both Organization for Economic Co-operation and Development (OECD) high income countries, and India with a lower middle economy.² It successfully identified ASD markers common in the three cultures as well as those that are unique to each of the respective cultures. The researchers state the results support the view of universality of ASD traits, while acknowledging that some traits are linked to culturally specific differences. They conclude that these findings can facilitate the development of a “brief global screening tool for ASD” in future efforts.

A caveat is needed here in referring globally to *Western affluent countries* in management of individuals with ASD, as it may obscure their geographical pockets of archaic attitudes to ASD, and obvious inadequate integration efforts of these individuals into their social milieu. A case in point is France, an OECD high income country,² noted to lag decades in ASD management in their country. Detailed descriptions of these are delineated in an article in *Spectrum*,⁸ an online publication of Autism research news. A study conducted on inclusion of children and youth with ASD in regular public schools,⁹ notes that “increasingly” they are included but selectively: children and adolescents with more severe adaptive and cognitive deficits were “less likely” to attend school, those with sensory processing problems were only partially included, while those with anxiety tended to be included. In all, this points to the recency of the attitude of inclusion. In fact, attesting to the lag in management of children and youth with ASD is a French study.¹⁰ It unveiled the fact that most individuals with ASD are victimized by peers at school on a regular basis. The noted ASD odd behaviours and poor social interaction skills, make them exceptionally vulnerable to victimization acts, notes the author. The mental health consequences of these experiences is a significant rise in anxiety, with numbers opting not to attend school, a disheartening fact indeed. These point to lack of adequate integration efforts into public schools, and obvious neglect in preparing neurotypical students for acceptance of their neuroatypical peers. Obviously, much needs to be done to achieve a profound change in the French population in general so to help them transform their children by modeling empathetic and tolerant attitudes with matching behaviours, and thereby increasing the quality of life of ASD children and their families.

To conclude, the need for continued research efforts in gathering accurate prevalence data in the noted regions is obvious so to facilitate early identification of children with high risk for ASD, and provide them with quality interventions based on their immediate needs while waiting for confirmation of their diagnosis, as there is no time to waste.⁵ What is needed around the globe is determining the quality of interventions and the most effective intensity for their application. As researchers state, “Improving the quality of intervention provided in early childhood may be one way to increase the likelihood that long term life-satisfaction is attainable for all autistic people. (p.3)¹¹” In the Western regions, pediatricians tend to be the first contact in directing families with ASD children to services. Their habitual

recommended interventions, note researchers,¹² may no longer be valid in the face of changing evidence. For instance, in lieu of the typical recommendation of 25–40 hours per week of treatment intensity, strong evidence supports treatment intensity of 1–5 hours per week as sufficient in achieving noted improvements in behaviour, social and communication skills of children, and more. In addition, there is strong evidence in support of developmental interventions with learning goals guided by developmental sequences, and provided in natural settings through interaction with caregivers. These are considerably less disruptive to families than the highly structured provider-led treatments which are habitually recommended by pediatricians. Researchers¹³ point out that while studies continue to focus on biological underpinnings of ASD, the affected individuals immediate needs are not addressed sufficiently. What is needed, they state, is to prioritize studies that can affect immediate improvements in the lives of people with autism and their families.

The following summaries of the contributed articles in this thematic issue, *Focus on Issues and Solutions in ASD*, are replete with advances in approaches and interventions that may inform stakeholders. The ultimate goal is to facilitate addressing the complex needs of individuals with ASD and their families. Some articles focus on use of technology in treatment, others highlight memory issues with inherent difficulties that require detection and treatment. One compares the development of Theory of Mind (ToM) in two disorders of individuals with language deficits, while another explores the possible language profiles in children with ASD. While family difficulties in feeding their children with ASD is the focus in one article, facilitating transitioning of youth out of secondary education is highlighted in the other. Clearly, the articles address a considerable range of topics and age ranges.

In their review article *Telepractice and technology in treating Autism*, Petinu, Christopoulou, and Drosos¹⁴ (Cyprus) acknowledge the call for timely adaptation to Covid related circumstances by providing long distance interventions using technology-based platforms. Telepractice is proving to be a cost-efficient approach in assessment and interventions across populations and age spans, and across geographical locations while supporting inclusion of family and caregivers as facilitators in the intervention efforts. In this systematic review (Denmark) Skjoldborg, Bender, and Jensen de López¹⁵ evaluate the efficacy of employing virtual reality interventions for the improvement of life skills in individuals with ASD. Findings indicate that it has some potential for Head Mounted Display VR interventions in the improvement of life skills in individuals aged 4 to 22 years, however, there is a need for methodologically stronger study designs to fully realize its capacity for intervention with this population.

Developing concept of time and temporal cognition is a formidable task for children with Autism spectrum and Attention disorders. Temporal competence, including clock reading, is crucial in mathematics acquisition and sciences, while underlying all societal activities. In the review article with three cases, *Detecting time concept competence in children on the Autism Spectrum, and Attention Disorders*, Hus (Canada)¹⁶ provides evidence for the effectiveness of a set of tools in identifying temporal competence deficits in ASD and ADHD children and suggests approaches and interventions for their remediation. Westby (USA),¹⁷ in the review article *Autobiographical Memory and Personal Narratives in ASD*, emphasizes that individuals with ASD have deficits in autobiographical memory (AM) that affect their interactions with others, development of self-identity, and ability to self-regulate, yet AM is not routinely assessed and deficits are not typically a focus of intervention. The article addresses the nature of AM deficits in these individuals, and offers strategies for assessment and intervention.

In their original research article, Schwartz and Segal (Israel)¹⁸ report on a comparative study that evaluated ToM skills in Hebrew speaking preschool children with ASD, Developmental Language Disorders, and in typically developing peers. The results suggest that children with ASD have a fundamental difficulty in ToM that is independent of their language abilities, a finding that expands knowledge of the influence of language difficulties on ToM abilities. The review article by Vogindroukas et al (Greece and Bulgaria)¹⁹ *Language and speech characteristics in Autism* examines the diversity of speech and language profiles in individuals with ASD. The findings suggest structuring language profiles in ASD into four categories, expounded on in the article, to better understand their therapeutic needs.

A review article by Adams (South Africa),²⁰ *Feeding and swallowing issues in ASD* explores feeding difficulties that are prevalent in children with ASD and their impact on their nutrition, growth, and development. Currently, there is limited research on feeding difficulties in children with ASD. The article highlights the issues inherent in determining appropriate assessment strategies and management of these children, and their impact on family efforts, economics, and emotional costs in feeding attempts. Finally, Johnson and Kristofik's²¹ original research (USA) *Rehabilitation services for young adults with*

ASD, highlights the tremendous responsibility left to educators in transitioning students with ASD from high school to either college or the workforce successfully. Their investigation recommends adult mentorship to maximize positive outcomes in transitioning efforts, and better preparations for their students' next stage in life. They suggest that sharing positive outcomes with ASD advocacy groups may further support transitioning efforts and maximize outcomes.

In summarizing, the varied themes found in the contributed articles are a testament to the complexity of issues and the solutions that accompany populations with ASD with varied ages. Some of the suggested assessments and interventions offered in these articles may meet some of the needs of individuals with ASD, and some may even be generalizable to all regions of the globe, but others would require modification to meet the needs of specific cultures. The take home message of this editorial is: persisting with research that can answer their needs now, developing more effective tools and treatment with changing evidence, and propelling research onward in underdeveloped regions to reduce the number of children and youth with ASD whose futures are affected because of paucity of resources in their regions.

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