



Editorial

World Autism Awareness Day: Reflections on the Indian context

This year on World Autism Awareness Day (April 2), it will be nearly 80 years since the American Child Psychiatrist Leo Kanner first applied the term infantile autism to young children with delayed and deviant language and social development, repetitive behaviours and lack of imagination¹. The following year, 1944, Austrian physician Hans Asperger described adolescent males, who were intellectually able, but had disabling abnormalities of social communication and interaction and obsessive preoccupations and coordination difficulties² now referred to as Asperger disorder. These early-onset developmental conditions recognized as persisting were referred to as pervasive developmental disorders in International Statistical Classification of Diseases and Related Health Problems (ICD) revisions 9 and 10 and Diagnostic and Statistical Manual of Mental Disorders (DSM) editions III and IV, culminating in the classification of autism spectrum disorder (ASD) in ICD-11³ and DSM-5⁴. ASD is manifest in early childhood with lifelong core features of disabling impairment in social communication and interactions together with restricted, repetitive behaviours, insistence on sameness and abnormal sensory sensitivities. This neurodevelopmental disorder has a heterogeneous, complex aetiology including genetic, neurobiological, environmental and sociocultural risk factors and associated impairments in cognitive and language abilities and mental health comorbidities such as attention-deficit hyperactivity disorder (ADHD) and anxiety. Current estimates of prevalence vary but are about one in 68 children⁵.

Despite an incomplete understanding of the global epidemiology of ASD, it is the leading neurodevelopmental disorder in children and causes lifelong disability. Understanding its heterogeneous phenomenology, risk factors and comorbidities and developing evidence-based prevention, early

intervention and age-specific treatments become an international priority. To date, most research has been done in 'Western' countries, therefore, it is timely to comment on progress and challenges presented by a widening research and service delivery gap in lower- and middle-income countries, specifically with reference to India. Patra and Kar⁶ conducted an exhaustive literature search of ASD studies in India from which we structured our reflections. Their scoping review found 159 articles indicating that significant Indian research is being conducted in tertiary medical and educational centres and registered non-government organizations. Most studies are related to children and focussed on clinical phenomenology of ASD including assessment tools, biomarkers (genetic, biochemical and neurophysiological) and evidence for behavioural, parent-based and pharmacological interventions. Some qualitative research gave voice to parent lived experiences and the sociocultural context. Studies on risk factors and epidemiology were only few. Research and service delivery gaps were identified and informed in our following comments.

Clinical phenomenology

Delayed diagnosis is a challenge internationally because the gold standard requires a tertiary multidisciplinary team. A lack of clinicians trained in this complex diagnostic process and the use of research standard instruments make it impractical for most public health delivery services. Assessment and diagnosis are also complicated by frequent comorbidities of anxiety, depression, ADHD and schizotypal symptoms, the increased risk of epilepsy and a scattered cognitive profile ranging from intellectual disability to superior abilities. Parental and sociocultural factors and the burden of care experienced by family and community also require careful consideration. Need this be the situation? Have we become too focussed on a

This editorial is published on the occasion of World Autism Awareness Day - April 2, 2022.

necessary research imperative to use a complex and not universally available assessment protocol when simpler public health population approaches might be sufficient to ensure that most children with neurodevelopmental disorders such as ASD are identified and provided with community-based interventions? The scoping review identifies two freely available Indian screening tools the INCLIN (INDT-ASD) and the Indian Scale for Assessment of Autism⁶. Other autism screening tools translated into Hindi/Bengali/Kannada are also available, and we suggest that at least one of these should be a component of the broader developmental screening programme by the Indian Child Health Screening and Early Intervention Services. This would increase the likelihood of the identification of children with developmental problems, including autism, and facilitate their receipt of local community-based services.

Interventions

International research on intervention focusses on centre-based intensive multidimensional behavioural, communication and education elements which are impractical to apply as public health measures in large populations with limited resources⁷. When young children assessed in a community setting screen positive for a neurodevelopmental delay, including autism, a local community approach to early intervention is the most feasible option for lower- and middle-income countries. There is compelling evidence that parent education and skills training augmented by local resources such as community centres, playgroups and preschools promote child development, reduce behavioural and emotional disturbance, improve communication skills and reduce parental distress with long-term positive outcomes⁸. The main elements of parenting programmes are education about the symptoms of autism, developmental delay and associated emotional and behavioural problems; strategies to improve communication and language such as use of visual prompts, picture scripts for desired social behaviours and visual timetables to structure daily activities; managing difficult behaviour and understanding why this happens and how to respond positively; teaching effective calming strategies and working collaboratively with community healthcare services and teachers. Some evidence-based programmes are available in manualized and online formats⁸ potentially allowing translation into an Indian language. Others require therapist training which reduces their public health applicability. Public

health strategy to improve the understanding, care and management of children with neurodevelopmental disorders is the most feasible and practical option until such time as specialized centre-based multimodal programmes become widely available in India⁷.

The scoping review⁶ indicated that there were no studies that considered the essential role schools play in promoting better developmental outcomes in children and youth with ASD, who require individualized learning plans and curriculum adjustment to accommodate their communication, social and cognitive challenges. These plans include the use of visual communication strategies and timetables to foster comprehension, reduce anxiety and prepare for change; channelling autistic preoccupations to engage interest and teach numeracy and literacy skills; keyboard or voice recognition software to compensate for writing disability and noise-cancelling headphones to compensate for distressing sound sensitivities^{9,10}. A simple and effective school intervention that improves long-term outcomes is a formal transition meeting and plan involving the parents, child, past and new teachers and key child health workers before the child begins in a new education setting¹¹. Transition meetings introduce the new teacher to the child and the parents and previous teacher provides information about educational/behaviour support needs and the results of previous assessments. The new teacher provides information about the school and its curriculum. There is some evidence that in India, a majority of teachers are aware of autism but have limited training in the educational management of children with developmental disorders⁶. Teacher training programmes should include education on individual learning needs and teaching strategies for children with development disorders. Regional consultation support for schoolteachers to facilitate the provision of individualized learning programmes is a cost-effective public health response¹².

Biomedical research on neurodevelopmental disorders

This is well developed in Indian tertiary institutions and contributes to international scientific endeavour⁶. Indian research institutions are well placed to collaborate with international studies which require large sample numbers. Globally, the practical translation of the burgeoning genetic, biochemical, neurophysiological and risk factor information remains elusive. A number of biological causes of ASD have been identified

although these account for only a minority of cases perhaps about 10 per cent and include comorbid intellectual disability and/or well-recognized genetic disorders such as Fragile X, Prader-Willi and Williams syndromes⁵. Traumatic and complicated perinatal experiences increase the risk of neurodevelopmental difficulties about six-fold and intrauterine infection with rubella or exposure to heavy metal poisoning are known risks⁵. ASD is also associated with an increased risk of epilepsy⁵. Therefore, education about risk factors must be included in the training of community health workers to facilitate the assessment of children with developmental delays and expedite referral to regional/child health centre clinics for more detailed assessment.

Autism spectrum disorder (ASD): The lived experience

International parent and consumer advocacy and qualitative research on lived experience is progressively informing current research and service delivery and is already a clear feature of Indian research⁶. Parent advocacy is also raising awareness of gaps in services and the need for parental involvement in every stage beginning with assessment through to the provision of support in adulthood. Parental and consumer advocacy has also facilitated a focus on issues such as cultural safety and sensitivity and improving the identification of females and adults with ASD and gaps in service provision for them.

Epidemiology

There is a paucity of population screening of young children for developmental delay and ASD in India. This fundamentally limits the collection of longitudinal information on the prevalence, gender distribution, educational, social, employment and community participation of people with neurodevelopmental problems across the lifespan. Reliable epidemiological information is vital to the planning of community services. In a country with such a large population, only a national, evidence-based public health approach will reduce the high economic, health, family and community burden of neurodevelopmental disorders including ASD.

Conclusions

India is ideally placed to be an international leader in large population research and the implementation of developmental screening of young children by

community health workers. Children who screen positive for neurodevelopmental difficulties will include those who have ASD, but what is most important is that all these children and their families will benefit from local community-based early intervention programmes and support. Continued implementation of and research on parenting/family programmes will promote adaptive child behaviour and build communication, social and play skills which in turn reduces parental stress and burden and increases community awareness and participation. We advocate this public health approach to the identification and care of people with ASD in India. The application of local, community-based screening and support programmes also provides a valuable opportunity for studies on their reach, effectiveness, adoption, implementation and maintenance¹³ and a platform for epidemiological studies.

Financial support & sponsorship: None.

Conflicts of Interest: None.

Bruce J. Tonge* & Avril Vaux Brereton

Centre for Developmental Psychiatry & Psychology,
Monash University, Melbourne, Australia

*For correspondence:
bruce.tonge@monash.edu

Received March 30, 2022

References

1. Kanner L. Autistic disturbances of affective contact. *Nervous Child* 1943; 2 : 217-50.
2. Asperger H. Autistic psychopathy of childhood. *Arch Psychiatr Nervenkr* 1944; 117 : 76-136.
3. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems (ICD-11)*, 11th ed. Geneva: WHO; 2019.
4. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*, Vol. 5. Washington, DC: APA; 2013.
5. Brereton A, Tonge B. *Autism spectrum disorders*. In: Hupp S, Jewell JD, editors. *The encyclopedia of child and adolescent development*. New Jersey: John Wiley & Sons, Inc.; 2019. p. 1-11.
6. Patra S, Kar SK. Autism spectrum disorder in India: A scoping review. *Int Rev Psychiatry* 2021; 33 : 81-112.
7. George B, Padmam MS, Nair MK, Leena ML, Russell PS. CDC Kerala 14: Early child care practices at home among children (2-6 y) with autism – A case control study. *Indian J Pediatr* 2014; 81 (Suppl 2) : S138-41.

8. Tonge BJ, Bull K, Brereton A, Wilson R. A review of evidence-based early intervention for behavioural problems in children with autism spectrum disorder: The core components of effective programs, child-focused interventions and comprehensive treatment models. *Curr Opin Psychiatry* 2014; 27 : 158-65.
9. Cafiero JM. Technology supports for individuals with autism spectrum disorders. *J Special Edu Tech* 2012; 27 : 64-76
10. Ikuta N, Iwanaga R, Tokunaga A, Nakane H, Tanaka K, Tanaka G. Effectiveness of earmuffs and noise-cancelling headphones for coping with hyper-reactivity to auditory stimuli in children with Autism Spectrum Disorder: a preliminary study. *Hong Kong J Occup Ther* 2016; 28 : 24-32.
11. Department of Education and Early Childhood Development, State Government, Victoria. *Autism Spectrum Disorder: transition learning and development statement*. Available from: <http://timeforafuture.com.au/wordpress/wp-content/uploads/2022/03/ASD-Transition-Statement.pdf>, accessed on March 20, 2022.
12. Basu D, Nagpal S, Mutiso V, Ndeti D, Lauwrens Z, Hadfield K, *et al*. Enhancing resilience and mental health of children and adolescents by integrated school-and family-based approaches, with a special focus on developing countries: A narrative review and call for action. *World Soc Psychiatry* 2020; 2 : 7-19.
13. Holtrop JS, Rabin BA, Glasgow RE. Qualitative approaches to use of the RE-AIM framework: Rationale and methods. *BMC Health Serv Res* 2018; 18 : 177.