Indian J Med Res 157, April 2023, pp 227-229
DOI: 10.4103/ijmr.ijmr_506_23

Quick Response Code:

Editorial

Autism in India: Time for a national programme

We are regularly inundated by the statistics on rising prevalence of autism. According to the latest estimates from the Centres for Disease Control and Prevention in the USA, nearly one in 36 children meet criteria for an Autism spectrum disorder (ASD) diagnosis[1]. This is in sharp contrast to less than two decades ago, when the prevalence of autism was considered to be around one in 100 children[2]. While debates rage on about factors that underlie such large increases in the American prevalence estimates, it is worth reflecting on a few key differences in the ground realities for autism in India. To this end, this editorial presents a set of perspectives on autism research and clinical services in India and emphasizes the need for a coordinated national programme.

While biochemical pathways involved in core autism symptoms are unlikely to be different between cultures, there can be notable cultural differences in who choose to get an ASD diagnosis. Notably, the majority of children with an ASD diagnosis within the USA and UK are likely to be attending mainstream schools, unlike in India[1,3,4]. This key difference might be driven by a range of sociological factors, such as the allowance of provisions for inclusion in mainstream schools in UK and Europe, as well as factors related to private/national medical insurance coverage of autism interventions. This difference in ascertainment poses a distinct set of challenges and priorities for autism in India.

Autism is defined by the behavioural phenotype, and tools to measure the phenotype are the starting point for both research and clinical work on autism. However, most standardized autism screening and diagnostic tools used most widely across the world have limited availability in Indian languages. While we have translated, adapted and validated some of these tools in Indian languages[5], other teams have developed new instruments that are designed with the target population in mind[6]. While the former approach allows for easier comparison with other studies globally, it might miss out on picking up subtle culturally specific differences as the item list is comparatively constrained. The latter approach avoids this drawback, but can create challenges for quantitative comparison with other globally used scales. In both cases, these tools are typically available for <5 of the 22 official languages of India, representing a core area of need for future work. Beyond screening and diagnostic instruments, task-based measures constitute critical components of an autism research toolkit. While some of these measures are easier to translate and adapt (*e.g.*, embedded figures task, which requires the participant to identify a simple embedded shape from within a large complex display), other measures such as those involving complex emotion recognition present greater challenges due to cultural variability[7]. A combination of self and/or caregiver-report alongside observational/task measures is ideal for more comprehensive phenotyping. Crucially, phenotyping must not remain limited to measures of behaviour and brain alone – autism is increasingly viewed as a systemic condition. Greater focus on areas that have historically been under-researched in autism, such as sleep, diet, sensory symptoms and immune function need to be included within routine phenotyping.

While considering the next steps for development, standardization or adaptation of tools to measure the autistic phenotype – we also need to consider the users of these tools. Most available tools need to be administered by a specialist mental health professional. According to the latest estimates, India has <10,000 psychiatrists, majority of whom are concentrated in big cities[8]. While the number of mental health professional continues to grow, the current gap

---

This editorial is published on the occasion of the World Autism Day - April 2, 2023

© 2023 Indian Journal of Medical Research, published by Wolters Kluwer - Medknow for Director-General, Indian Council of Medical Research

between the demand and supply cannot be met directly by the specialists alone. This gap is not relevant for phenotypic assessments alone, but also for providing psychological interventions. Parallel efforts to widen the reach of diagnostic and intervention services through involving non-specialists, similar to a stepped-care model for psychological therapies, is required in order to bridge this chasm. To this end, emerging lines of evidence suggest the feasibility of such an approach for both autism identification and intervention in an Indian contex[9,10]. Two pillars for such an approach to succeed are the availability of a suitable non-specialist workforce [*e.g.*, Accredited social health activist (*ASHA*)/*Anganwadi* workers and parents/caregivers] and the appropriate digital technology (*e.g.*, mobile applications) that can capture both self/caregiver report as well as observations/task performance.

A causal chain typically links phenotypic assessments and interventions – which presents its own set of challenges. These challenges are by no means unique to India, but are still worth considering in an effort to build a responsive and proactive national strategy for autism. Very often, a clinical diagnosis serves as a gateway for interventions and services – with some parents having to wait for years, or travelling across the country, to get a confirmed diagnosis of autism. Delays in interventions can be costly for neurodevelopmental conditions such as autism, given the importance of critical periods in brain development. Early interventions are associated with the best outcomes. As such, it is vital to develop a pipeline of routine phenotypic assessments for the key domains of development (social, motor, sensory and cognitive) – that then leads to parent/non-specialist-assisted behavioural interventions, irrespective of the clinical diagnosis. Within such a framework, if a child presents with social behavioural difficulties –he/she could be referred to a parent/non-specialist assisted programme on evidence based actionable strategies in social skills development. This child might eventually get a clinical diagnosis of Autism or Social Communication Disorder – but would have already benefited from an early intervention. There is a growing evidence base for simple behavioural interventions that parents/caregivers can be trained on, which can have a positive impact. The risks for administering these interventions to a child who may not necessarily need them are significantly lower than those of not administering them to someone who could benefit. More research on the sustainable implementation of such public health pathways that do not depend critically on a confirmed diagnosis from a specialist is of vital importance.

Taken together, India is poised at a unique global position in shaping the global agenda on autism, due to the sheer size of its population and extent of variability in genetics, diet, socio-economic conditions, and environment. This diversity, coupled with a concerted attempt to build public awareness and recognition of autism, can catalyse a move from primarily being a knowledge consumer to a producer of critical knowledge in this field. Coordinated efforts are required to address both fundamental research questions (*e.g.*, on different genetic and environmental factors that may influence the likelihood for autism), as well as more applied research on implementation pathways for effective identification of support needs and the design of appropriate interventions. Insights from such research can be helpful in large parts of the globe, since 95 per cent of children with neurodevelopmental disorders live in low and middle income countries[11]. Beyond the necessary focus on children, there is a critical need to understand and develop ways to support the growing population of autistic adults. Across the globe, research and clinical services in autism have traditionally focused more on children than on adults[12]. There is thus a critical need for further research on supporting autistic adults through the lifespan. To this end, the need of the hour is to develop a national programme on autism, to link researchers, clinicians, service providers to the autism community in India.

Importantly, such an effort can only succeed if it is informed by extensive consultation with different stakeholders, with a primary focus on end-users within the Indian autism community[13]. While the Interagency Autism Coordinating Committee in the USA (*https://iacc.hhs.gov/*) can provide an informative template to build on, it will require substantial innovations and modifications to work within an Indian context. Crucially, such a programme in India will need to partner closely with the private sector, given the important work done by some of the parent collectives and nongovernmental organizations in this space. A national programme for autism and neurodevelopmental conditions, supported by an articulated time-bound strategy, can pave the way forward for innovative multidisciplinary research and support services for autism across the country.

***Acknowledgment*:** Author (BC) was supported by the Medical Research Council UK (Ref: MR/S036423/1) and the European Research Council (Ref: 865568).

***Conflicts of Interest*:** None.

Bhismadev Chakrabarti[1,2,3]
[1]Centre for Autism, School of Psychology & Clinical Language Sciences, University of Reading, UK,
[2]India Autism Center, Kolkata 700 020, West Bengal & [3]Department of Psychology, Ashoka University, Sonipat 131 001, Haryana, India
b.chakrabarti@reading.ac.uk

Received March 17, 2023

References

1. Maenner MJ, Warren Z, Williams AR, Amoakohene E, Bakian AV, Bilder DA, *et al*. Prevalence and characteristics of autism spectrum disorder among children aged 8 years — autism and developmental disabilities monitoring network, 11 sites, United States, 2020. *MMWR Surveill Summ* 2023; *72* : 1-14.
2. Centers for Disease Control and Prevention. *Autism data visualization tool*. Available from: *https://www.cdc.gov/ncbddd/autism/data/index.html*, accessed on April 12, 2023.
3. Rudra A, Belmonte MK, Soni PK, Banerjee S, Mukerji S, Chakrabarti B. Prevalence of autism spectrum disorder and autistic symptoms in a school-based cohort of children in Kolkata, India. *Autism Res* 2017; *10* : 1597-1605.
4. Roman-Urrestarazu A, van Kessel R, Allison C, Matthews FE, Brayne C, Baron-Cohen S. Association of race/ethnicity and social disadvantage with autism prevalence in 7 million school children in England. *JAMA Pediatrics* 2021; *175* : e210054.
5. Rudra A, Banerjee S, Singhal N, Barua M, Mukerji S, Chakrabarti B. Translation and usability of autism screening and diagnostic tools for autism spectrum conditions in India. *Autism Res* 2014; *7* : 598-607.
6. Gulati S, Kaushik JS, Saini L, Sondhi V, Madaan P, Arora NK, *et al.* Development and validation of DSM-5 based diagnostic tool for children with Autism Spectrum Disorder. *PLoS One* 2019; *14* : e0213242.
7. Rudra A, Ram JR, Loucas T, Belmonte MK, Chakrabarti B. Bengali translation and characterisation of four cognitive and trait measures for autism spectrum conditions in India. *Mol Autism* 2016; *7* : 50.
8. Garg K, Kumar CN, Chandra PS. Number of psychiatrists in India: Baby steps forward, but a long way to go. *Indian J Psychiatry* 2019; *61* : 104-5.
9. Dubey I, Bishain R, Dasgupta J, Bhavnani S, Belmonte MK, Gliga T, *et al.* Using mobile health technology to assess childhood autism in low-resource community settings in India: An innovation to address the detection gap. *medRxiv* 2021. Doi: 10.1101/2021.06.24.21259235.
10. Rahman A, Divan G, Hamdani SU, Vajaratkar V, Taylor C, Leadbitter K, *et al*. Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): A randomised controlled trial. *Lancet Psychiatry* 2016; *3* : 128-36.
11. Olusanya BO, Davis AC, Wertlieb D, Boo NY, Nair MKC, Halpern R, *et al*. Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. *Lancet Global Health* 2018; *6* : e1100-21.
12. Howlin P, Magiati I. Autism spectrum disorder: Outcomes in adulthood. *Curr Opin Psychiatry* 2017; *30* : 69-76.
13. Dey I, Chakrabarty S, Nandi R, Shekhar R, Singhi S, Nayar S, *et al*. Autism community priorities in diverse low-resource settings: A country-wide scoping exercise in India. *Autism* 2023. Doi 10.1177/13623613231154067.