



Editorial

The future of autism: Global & local achievements & challenges

In recognition of the World Autism Day, we celebrate the major contributions that India has made in the field of autism and call for continued action to address the urgent needs of children and adults with autism and their families. In this time of concern for all of us, major strides have been made in India and around the world in approaching the ever-increasing numbers of children and adults identified with autism spectrum disorder (ASD, used interchangeably with the word autism). However, there is an enormous amount of work to do. A multi-level, multi-pronged approach to work within and across systems and the development of new ones to maximize society's responsibility for all people with neurodevelopmental disorders such as autism has emerged in India. This represents the way forward globally, as championed by the World Health Organization (WHO)¹. This includes recognition of the importance of working with families in designing services that meet their needs as well as providing families with information that allows them to support their children to the best extent². It also includes provision of training and support for teachers and school staff so that children receive appropriate education. And finally, it includes recognizing that we are all adults for far more years than we are children; this is true for children with autism as well. Thus, we need to make plans for children with autism who will become adolescents and then adults, who still have the capability of learning. Changes in governmental, academic, philanthropic and non-governmental approaches, families and emerging advocates and self-advocates have come about, but more are needed.

One way to how to conceptualize such a multi-pronged approach is outlined recently by Lai *et al*³. These authors propose three 'pillars' of evidence-based care and support across the lifespan that also cross disciplines of psychiatry, neurology, paediatrics,

psychology, general medical practice, speech pathology and other related disciplines. The pillars involved (i) maximizing potential by supporting development and building skills, (ii) minimizing barriers including societal, familial and individual by increasing adaptation, and (iii) optimizing person-environment fit, which we would extend beyond workplace or school to include health system, family and societal supports, and community needs.

Let us highlight examples of different programmes that represent achievements globally, including those in India, beginning with minimizing barriers. Following the lead set by the United Nations (WHO Resolution on ASD, EB133/4, 2013)⁴, many countries have formally recognized ASDs as a disability requiring mandated services. This has typically been a multi-step process in each country, moving from creating policies for disabilities, broadly defined, and policies about the universal right to education, both with specific mentions of autism. This specific attention was important, because initially, in many countries, autism was excluded from other policies. Even then, one of the greatest limitations globally has been the distance between the stated policy and implementation of this specific recognition of autism.

In India, in 2016, autism was certified as a disability within the Right for Persons with Disabilities Act⁵. This included mandatory formation of State level medical boards. These medical boards moved carefully and relatively quickly to provide expertise for specific needs in India. Most important, indigenously designed and validated tools such as INDT-ASD (INCLIN Diagnostic Tool for Autism Spectrum Disorder) were developed^{6,7}. These tools have been shown to have excellent psychometrics in several different trials. Thus, children with autism can receive diagnoses using

¹This editorial is published on the occasion of the World Autism Awareness Day - April 2, 2020.

open-source instruments and materials developed in India, which is another barrier to services that can be addressed. However, there remain implementation challenges for parents to get certification to address the next ‘pillar’ consisting of building skills and facilitating development. Two outgrowths of early identification are particularly important: the need to support families in providing techniques and information to them about how best to interact with their children, and the need to work directly with children to help improve the skills that underlie communication and language learning. Both of these needs are urgent: work with families to support their interactions with their children begins a cascade towards learning and more positive interactions that we believe can last for years⁸. There is now considerable evidence that, though language learning continues on gradually throughout development, the greatest gains in children with autism occur early, usually before they begin formal education at six or seven years⁹. Thus, there is reason to persist in efforts to find children as early as possible and begin treatment both through parent-mediated efforts and direct teaching.

Successful early intervention programmes in India include both direct treatments such as Communication DEALL (Developmental Eclectic Approach to Language Learning)^{10,11} and parent-mediated approaches such as PASS (Parent mediated intervention for Autism Spectrum Disorders in South Asia) and PASS plus^{12,13}. These projects provided uniquely Indian approaches to working with children and families and, in the case of PASS, replicated findings of an original, manualized clinical strategy carried out in the UK. Such programmes begin the efforts we need to make to build skills in young children that then must be continued in schools and by families throughout childhood. Around the world, we need to better recognize and credit the role of schools in providing much of the skill-building received by autistic children and ensure teachers and administrators have adequate support for the very diverse needs of children who may range from minimally verbal and significantly delayed to very articulate but with learning disabilities, mental health challenges (such as anxiety or hyperactivity) and unique social needs.

The third pillar described by Lai *et al*³ is creating person-environment fits through adapting ordinary real-world environments, such as workplaces, schools and community settings so that autistic people can participate as fully as possible. Detailed multi-method

descriptions of adults with autism in India have been reported¹⁴. Private philanthropy and partnerships with local governments have developed educational programmes and supported conferences providing and learning experiences (*e.g.* Centre for Autism and other Disabilities Rehabilitation Research and Education in Thiruvananthapuram). Non-governmental organizations have served as a major impetus for change¹⁵ and been recognized by international autism experts (*e.g.* INSAR 2015 Advocate Award to Merry Barua¹⁶). A major force of advocacy for public health services for neurodevelopmental disorders and autism has been led by Patel *et al*¹⁷, an internationally recognized leader in global mental health. Similarly, the recognition of the particular ethical challenges of research in neurodevelopmental disorders and autism in lower and middle-income countries has come from India¹⁸.

Thus, the world knows more about autism because of the dedication and leadership of Indian academics, advocates and parents and authorities. We know that early intervention can make a difference^{12,13}. We now have learned that children with autism can be identified using indigenously developed standardized measures and then benefit from appropriate education^{6,7}. We know that adults with autism can participate in many activities at home and in the community when their families and communities have adequate support¹⁴, though there are consequences to the families in terms of stress and work-life balance that should be addressed. We know that research can be conducted ethically outside of Western countries¹⁸.

All of us who work and study in the field of autism know that there remain enormous challenges to ensure people with autism and their families the same opportunities for happiness, health and community participation. Out of the work of many in India, and across the world, we must make this happen.

Conflicts of Interest: None.

Catherine Lord

Semel Institute of Neuroscience
and Human Behavior, University of
California, Los Angeles,
California 90024, USA
clord@mednet.ucla.edu

Received March 30, 2020

References

1. World Health Organization. *World report on disability 2011*. Geneva: WHO; 2011.
2. Vivanti G, Kasari C, Green J, Mandell D, Maye M, Hudry K. Implementing and evaluating early intervention for children with autism: Where are the gaps and what should we do? *Autism Res* 2018; *11* : 6-23.
3. Lai MC, Anagnostou E, Wiznitzer M, Allison C, Baron-Cohen S. Evidence-based support for autistic people across the lifespan: Maximising potential, minimising barriers, and optimising the person-environment fit. *Lancet Neurol* 2020. pii: S1474-4422(20)30034-X.
4. World Health Organization. *Comprehensive and coordinated efforts for the management of autism spectrum disorders*. EB133/4; 8 April 2013. Available from: https://apps.who.int/gb/ebwha/pdf_files/EB133/B133_4-en.pdf, accessed on March 2, 2020.
5. Department of Empowerment of Persons with Disabilities. *The Rights of Persons with Disabilities (RPwD) Act, 2016*. New Delhi: Ministry of Social Justice & Empowerment, Government of India; 2016. Available from: <http://disabilityaffairs.gov.in/content/page/acts.php>, accessed on March 2, 2020.
6. Juneja M, Mishra D, Russell PS, Gulati S, Deshmukh V, Tudu P, et al. INCLen diagnostic tool for autism spectrum disorder (INDT-ASD): Development and validation. *Indian Pediatr* 2014; *51* : 359-65.
7. Vats P, Juneja M, Mishra D. Diagnostic accuracy of international epidemiology network (INCLen) diagnostic tool for autism spectrum disorder (INDT-ASD) in comparison with diagnostic and statistical manual of mental disorders-5 (DSM-5). *Indian Pediatr* 2018; *55* : 485-7.
8. Pickles A, Le Couteur A, Leadbitter K, Salomone E, Cole-Fletcher R, Tobin H, et al. Parent-mediated social communication therapy for young children with autism (PACT): Long-term follow-up of a randomised controlled trial. *Lancet* 2016; *388* : 2501-9.
9. Pickles A, Anderson DK, Lord C. Heterogeneity and plasticity in the development of language: A 17-year follow-up of children referred early for possible autism. *J Child Psychol Psychiatry* 2014; *55* : 1354-62.
10. Karanth P, Chandhok TS. Impact of early intervention on children with autism spectrum disorders as measured by inclusion and retention in mainstream schools. *Indian J Pediatr* 2013; *80* : 911-9.
11. Karanth P, Shaista S, Srikanth N. Efficacy of Communication DEALL - An indigenous early intervention program for children with autism spectrum disorders. *Indian J Pediatr* 2010; *77* : 957-62.
12. Divan G, Vajaratkar V, Cardozo P, Huzurbazar S, Verma M, Howarth E, et al. The feasibility and effectiveness of PASS plus, a lay health worker delivered comprehensive intervention for autism spectrum disorders: Pilot RCT in a rural low and middle income country setting. *Autism Res* 2019; *12* : 328-39.
13. 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.
14. Daley TC, Weisner T, Singhal N. Adults with autism in India: A mixed-method approach to make meaning of daily routines. *Soc Sci Med* 2014; *116* : 142-9.
15. Barua M, Kaushik JS, Gulati S. Legal provisions, educational services and health care across the lifespan for autism spectrum disorders in India. *Indian J Pediatr* 2017; *84* : 76-82.
16. Barua M. Lessons from Neeraj, my son with autism. *J Religion Disabil Health* 2007; *11* : 29-40.
17. Patel V, Saxena S, Lund C, Thornicroft G, Baingana F, Bolton P, et al. The Lancet Commission on global mental health and sustainable development. *Lancet* 2018; *392* : 1553-98.
18. Daley TC, Singhal N, Krishnamurthy V. Ethical considerations in conducting research on autism spectrum disorders in low and middle income countries. *J Autism Dev Disord* 2013; *43* : 2002-14.