

Autism Screening in India: Many a Chasm to Bridge

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Autism is a relatively new entrant into the arena of neurodevelopmental disorders. Though the earliest formal diagnosis was suggested by the Swiss psychiatrist Paul Eugen Bleulerback in 1911, it was only later in the 40s that the American psychiatrist Leo Kanner (1943) and the German pediatrician Hans Asperger (1944) presented their findings, to set the ball rolling. Interestingly, literature from India appeared in the same year by an Austrian Pediatrician, A Ranold working in Darjeeling [1]. Since then, both the disorder and the relevant research has been progressing at a prolific rate.

Today, Autism Spectrum Disorder (ASD) is a major neurobehavioral problem of global concern. As of 2020 CDC reports, 1 in 36 children in USA come under the spectrum [2] and autism occurs across all racial, ethnic and socioeconomic groups. The estimated prevalence in India is 1.12 (0.74-1.68) per 100 children aged 2-9 years [3], i.e., 1 in every 68 children is affected with autism. With our huge child population, the total numbers contribute to a major portion of the global prevalence. Hence, we bear a grave responsibility to detect and treat these children across the country.

Early signs of autism are often picked up by parents between 6-18 months of age and typical symptoms are evident by 2-3 years. Early detection and early intervention has definite positive developmental and behavioral outcome. Studies have shown that early interventions not only limit deterioration, but may also lead to such functional improvement that some children evolve out of the autistic traits [4]. Unfortunately, we encounter a detection gap, wherein either the diagnosis occurs late or is missed totally, leading to a tragic loss of the golden opportunity. The reasons are multiple, including dearth of trained professionals and para-professionals, non-availability of screening tools and programs, parental denial and lack of awareness.

Ideally, all children should be screened by 3 years of age. The American Academy of Pediatrics (AAP)

recommends screening for ASD at both 18- and 24-month well visits [4]. Indian Academy of Pediatrics (IAP) advocates universal ASD screening at 18 and 24/30 months for which M-CHAT-R/F, Trivandrum Autism Behavioral Checklist (TABC), and Social Communication Questionnaire (SCQ) are recommended [5].

Numerous screening tools are in use today, both internationally and nationally [6]. Some of the well-known international tools include:

- Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT R/F) : for 18-30 months; 20 item questionnaire
- Developmental Behavior Checklist: Early Screen (DBC-ES): for 18-48 months; Developmental Behavior Checklist: Autism Screening Algorithm (DBC-ASA): 4-18 years; Autism Behavior Checklist for 3-14 years
- Pictorial Autism Assessment Schedule (PAAS)
- Three Item Direct Observation Screen (TIDOS)
- Social Communication Questionnaire (SCQ) (Lifetime and Current versions): 40-item questions, in a parent-report format, based on the Autism Diagnostic Interview (ADIR) validated for 4+ years. SCQ Lifetime can be used below 4 years. This has not been translated, adapted or validated for Indian settings.

Of these, only the M-CHAT R/F is in use in India. It has been translated into multiple Indian languages, Although, none have of these versions have been adapted to Indian cultural norms or validated till date. The present research published in this issue of Indian Pediatrics [7] is a commendable step forward in this regard. There are quite a few Indian tools in vogue, which meet our needs but may not be standardized for global research. The ones best known include:

- The Indian Autism Screening Questionnaire (IASQ), derived from the Indian Scale for Assessment of

Autism (ISAA) is a 10-item questionnaire with yes/no answers which is meant for children aged 3-18 years [8]

- INCLIN Diagnostic Tool for ASD (INDT-ASD)
- Trivandrum Autism Behavior Checklist (TABC), a tool in Malayalam and English, developed and validated at Child Development Centre (CDC), Kerala, and has a 80% sensitivity and 91.1% specificity for children aged 2-6 years.
- RBSK–Autism Specific Questionnaire (RBSK-ASQ) has 3 ‘yes/no’ questions for each age-group of 15-18 months and 18-24 months [10].

All of these are designed for use in the general population by minimally trained workers. The TABC has been tried out in the Integrated Child Development Services (ICDS) Scheme centres by Anganwadi workers successfully. To ensure screening of all children across the country through front-line workers, a simple, easy to administer, validated tool of high sensitivity, specificity and convergent validity, written in a local language and customized to our social and cultural norms is essential. For a pan-India reach out autism screening needs to be incorporated in the ground level health assessment of small children by field level workers (ASHA and Anganwadi workers), who, in turn, need to be trained appropriately to use the tools. Various isolated projects have shown promising results with screening programs conducted by para-professionals. Another approach is screening at the pediatrician’s clinic, which has been initiated by IAP through its flagship program on Early Childhood Development training of all its members, which also includes autism screening with M-CHAT at 18 and 24 months.

For a parity in screening across the country, a set of validated tools may be considered. M-CHAT is useful till 30 months of age, for older children TABC or Indian Autism Screening Questionnaire (ISAQ) may be useful. Such a program, with proper documentation, can produce an extremely valuable dataset for the world to utilize. India

with its huge number of children with neurobehavioral disorders growing up in diverse situations of culture, customs and socio-economic conditions poses as a unique repository of resources for us to explore, for the benefit of children across the globe. If we can build a solid mechanism for public awareness and early identification of autism and document the same, we can be instrumental in catalyzing a global movement in the field.

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