

# INCLen Diagnostic Tool for the assessment of Autism Spectrum Disorder: A new tool in the speech-language pathologist's armoury

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## Abstract

**Objective:** INCLen Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD) is an indigenously developed tool for the assessment of Indian children with ASD. This tool has been developed by the INCLen group in India, and it is used by mental health professionals and pediatricians. This work was to demonstrate its clinical utility for speech-language pathologists (SLPs) and sensitize them to this new tool. **Materials and Methods:** Forty children between 2 and 10 years of age, with the referral diagnosis of ASD and social communication disorder (SCD) from the Department of Child and Adolescent Psychiatry, were enrolled for the study. Diagnosis was reviewed and the Childhood Autism Rating Scale was administered on all children. The children were grouped as (i) children with ASD and (ii) children with SCD, i.e., "no ASD." The INDT-ASD was then administered by an SLP, who was blind to group membership. **Results:** Thirty-nine out of forty children were correctly diagnosed by the INDT-ASD, showing high diagnostic accuracy of the tool. In addition to this, it is quick to administer, has very elaborate guidelines to observe different behaviors, a good scoring algorithm, and it is freely available in many regional languages. **Conclusion:** INDT-ASD is a simple and effective tool that can also be used regularly by SLPs and other professionals for the diagnosis of Indian children with ASD.

**Key words:** Autism spectrum disorder, INCLen Diagnostic Tool for Autism Spectrum Disorder, indigenously developed, speech language pathologist

## Introduction

Autism spectrum disorder (ASD) refers to a range of impairments in areas of social interaction and communication skills along with the presence of repetitive and restricted behaviors as its core features.

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The degree of impairment may range from mild to severe. The diverse presentation of symptoms usually makes diagnosis a challenge, especially when symptoms vary over the course of the child's development. A combination of extensive observation of the child's behaviors and a culturally relevant detailed diagnostic tool is needed to arrive at a satisfactory diagnosis. Speech-language pathologists (SLPs) play a major role in the evaluation and intervention of various communication disorders, ASD being one of them. It is indeed necessary for them to have access to good diagnostic tools.

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A number of internationally acclaimed tools have been developed over the years for the purpose of evaluation of children with ASD. While some are screening instruments, for example, Social Communication Questionnaire<sup>[1]</sup> the Pervasive Developmental Disorder Screening Test,<sup>[2]</sup> Modified Checklist for Autism in Toddlers,<sup>[3]</sup> few others are diagnostic tools, namely, Autism Diagnostic Observation Schedule (ADOS),<sup>[4]</sup> Autism Diagnostic Interview-Revised (ADI-R),<sup>[5]</sup> Childhood Autism Rating Scale (CARS-2),<sup>[6]</sup> etc. Once a screening evaluation demonstrates signs of ASD, a detailed assessment is the next step. ADOS is a widely used diagnostic tool for ASD. However, the administration of this tool necessitates administration-specific training and certification and so does the ADI-R. This tool-specific training limits its use in India by a wide range of professionals dealing with ASD. In addition, these tools require standardization in the Indian context as western norms and protocols can lead to reduced compatibility, especially caused by cultural bias that in turn affects the psychometric properties of the instrument.<sup>[7]</sup> CARS is another highly used tool to identify children with ASD<sup>[6]</sup> and determine symptom severity through quantifiable ratings based on direct observation. This tool has been validated in the Indian population,<sup>[8]</sup> and it is widely used by psychiatrists, psychologists as well as SLPs. There are a few other tools that have been developed in India, for example, (a) the Indian Scale for the Assessment of Autism (ISAA)<sup>[9]</sup> and (b) the Communication-DEALL developmental checklist (CDDC).<sup>[10]</sup> The ISAA is an instrument used largely to classify children with ASD and quantify their disability for availing benefits. The CDDC is a well-acclaimed tool for assessing baseline skills in eight developmental domains in ASD, which aids in planning intervention. Although this is not a tool for the assessment of ASD exclusively, the tool can be used by teachers and parents apart from other trained professionals dealing with children with ASD. In 2014, a new tool for the diagnosis of ASD - the INCLIN Diagnostic Tool for ASD (INDT-ASD)<sup>[11]</sup> was developed, and it was found to have good psychometric properties.<sup>[11]</sup> The tool (described in the next section) has been developed with regional issues of tool construction in mind, as opposed to an International context.

The INDT-ASD was developed by a group of developmental pediatricians and psychologists.<sup>[11]</sup> To the best of our knowledge, there are no reports of the tool being used by SLPs. Hence, the current study was taken up to understand the tool and to report the feasibility for an SLP to use it.

## Materials and Methods

### The tool

INDT-ASD is a diagnostic tool developed based on the DSM-IV<sup>[12]</sup> guidelines. It consists of two sections. The first section includes questions related to three cardinal domains - social interaction, communication, and restricted interests, and the second section relates to scoring as well as arriving at diagnostic classifications that includes autism, Asperger's disorder, Rett's disorder, childhood disintegrative disorder, and pervasive developmental disorder - not otherwise specified, Intellectual Developmental Disorder (IDD), and an Indeterminate category (which indicates that criteria are not met for any of the above disorders, or there are too many unsure responses or they could not be tested in appropriate conditions). The questions in the tool vary according to the age group of children, i.e., below 4 years of age, above 4 years of age, and above 6 years of age and are accompanied by simple, relevant, and easy-to-understand examples that make it clear for the caregivers to comprehend and relate to. The time taken for the administration of the test may range from 30 to 45 minutes. The items, based on the response given, are marked as Y (Yes), N (No), or U (Unsure). A binary form of scoring has been adopted for this tool, and a score of 1 is given if the child has a deficit in the particular area, and a score of 0 is given if the child does not have any deficits. Each domain is individually scored leading to differential diagnosis. The scoring involves a well-planned out algorithm that is described in detail in the manual.<sup>[11]</sup>

### Participants

In this cross-sectional study, a consecutive sampling method was used to recruit children. Children between the age range of 2–10 years, with a referral diagnosis of either ASD or social communication disorder (SCD) from the Department of Child and Adolescent Psychiatry (CAP), were enrolled for the study. This study sample consisted of a total of forty children (30 males and 10 females).

### Procedure

The study was taken up in a hospital, which has a large inflow of children with ASD. A detailed clinical evaluation was conducted by both the Department of CAP and Speech Pathology and Audiology. DSM-V<sup>[13]</sup> guidelines were used to arrive at a diagnosis of either ASD or SCD. CARS-2 was administered on all children to confirm ASD diagnosis. Children referred as ASD met the criteria on CARS-2. Similarly, children referred as SCD did not meet ASD criteria on CARS-2. Hence, participating children were grouped as children with

ASD (Group I: G-I) and Children with SCD, i.e., “no ASD” (Group II: G-II).

The INDT-ASD was then administered by an undergraduate intern (SA) and monitored by an SLP (SSM) who has over 4 years of experience of working with children with ASD. The first author (SA), who evaluated all children, was blind to the group membership of the child. All children were involved in a play session and observations made were then compared to the responses obtained through parental interview.

## Results

A total of forty children (30 males and 10 females) with a mean age of  $57 \pm 24.77$  months were recruited and grouped on the basis of DSM-V guidelines and the CARS-2 as (G-I) 35 children with a diagnosis of ASD and (G-II) 5 children with a diagnosis of SCD (no ASD). The descriptive details of all the forty participants have been presented in Table 1. Post hoc, it was found that children in the two groups were matched on age and gender ratio [Table 1]. All children happened to belong to the upper economic strata based on the Kuppuswamy scale.<sup>[14]</sup> All forty children were assessed on the INDT-ASD, and the scores on this tool showed that (i) only 34 children qualified to get a diagnosis of ASD and (ii) 6 children as “no ASD.” The five children who were diagnosed as SCD/no ASD by CARS were correctly identified as “no ASD” by INDT-ASD. Further, of the 35 children diagnosed as ASD based on DSM-V guidelines and CARS-2, 34 children were correctly identified as “ASD present” by INDT-ASD and one child was diagnosed as no ASD. This effectively put the diagnostic accuracy of INDT-ASD at 97.22%. The only child who was diagnosed as ASD (score of 30) by CARS-2 and diagnosed as “no ASD” by INDT-ASD was reassessed on CARS-2 by a child psychologist in the Department of CAP, who was blind to the status of the child and the study. The child received a score of 30.5. Thus, this child was misdiagnosed as “no ASD” by the INDT-ASD.

**Table 1: Descriptive details of the participants**

|                              | ASD               | No ASD            | Comparison between groups   |
|------------------------------|-------------------|-------------------|-----------------------------|
| <i>n</i>                     | 35                | 5                 | -                           |
| Males (%)                    | 27 (77.14)        | 3 (60)            | $\chi^2_{(df=1)} = 0.69$ ,  |
| Females (%)                  | 8 (22.86)         | 2 (40)            | $P = 0.407$                 |
| Age (months) (mean $\pm$ SD) | 57.66 $\pm$ 24.84 | 52.40 $\pm$ 26.54 | $t = 0.42$ ,<br>$P = 0.693$ |
| Range (months)               | 24-117            | 29-86             | -                           |

ASD: Autism spectrum disorder; SD: Standard deviation

Further, within the 34 children who were diagnosed as “ASD present” by INDT-ASD, (a) 26 (76.47%) children received a diagnosis of Autism, (b) 3 (8.82%) children “Asperger’s disorder,” and (c) 5 (14.71%) children “Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)”. No child received a diagnosis of “ASD present” with a category of Rett’s disorder or Childhood Disintegrative Disorder (CDD).

## Discussion

Diagnosis of ASD, despite the availability of various test materials, has always been a challenge. INDT-ASD is a relatively new tool and it has much strength to its credit. The test, being indigenously developed, is a useful tool for the diagnosis of Indian children with ASD without interferences of sociocultural differences. The tool has good psychometric properties which include good internal consistency, high diagnostic accuracy, high criterion validity and high-moderate convergent validity, and adequate content validity with a 4-factor construct validity for diagnosis of ASD.<sup>[11]</sup> Other positive aspects such as ease of availability (a freely available tool), ease of administration, reduced time consumption, and simple scoring make it effective in most clinical setups. It also provides a simple, yet informative manual that lists the observations that need to be made during a play session involving children with ASD. Further, it also highlights the toys that may be used based on the gender of the child, thus taking into consideration the significance of play in the assessment of ASD. The tool provides ample opportunity for parental interview as well as direct interaction with the child.

Even though the questions are varied according to age groups, the efficiency of the tool remains equally good. This efficiency over a wider age range could also facilitate early diagnosis as well as intervention of a larger group of children.<sup>[15]</sup> Each of the three domains (social interaction, communication, and restricted interests) has questions that shed light on all areas of deficits. Culturally relevant examples for social gestures such as saying “Namaste” or touching feet, pretend play like “ghar-ghar,” “teacher-student,” “chor-police,” etc., are used that are relevant to Indian children. Since the domains are individually scored, the child’s level in each area can be separately understood with ease and provide a holistic view of the child’s overall abilities. The language delay and the pragmatic deficits, which are universal to all children within the spectrum, are clearly acknowledged. Both verbal and nonverbal communication is considered, due to which clinicians can understand the communication skills of the child

regardless of the mode of communication. Weightage to the age of onset of symptoms (>3 years and below 3 years) is given, and it is crucial because in children with ASD, atypical developmental patterns may be present and these children may warrant a diagnosis of PDD-NOS. Since the tool is based on DSM-IV-TR, clear-cut criteria are given for the diagnosis of Asperger's syndrome, Rett's disorder, CDD, and PDD-NOS. It also accommodates a possible diagnosis of IDD, which may account for most of the symptoms in severe cases. This certainly takes care of overestimation of ASD population. The "indeterminate" category allows the clinician to place a child in this category when criteria are not fulfilled or when there are too many unsure responses – indicating the need for follow-up and further evaluation to arrive at a satisfactory diagnosis. Apart from English, the tool is also available in various Indian languages including Hindi, Malayalam, Odia, Konkani, Urdu, Khasi, Gujarati, and Telugu.<sup>[11]</sup>

Based on the results from the current study, it can be said, with caution, due to the limited sample size, that the tool has a high diagnostic accuracy. Blinding to group membership of the clinician administering INDT-ASD strengthens the results of this study. Of the forty children assessed on the INDT-ASD, only one child (26 months, male) received a discrepant classification (ASD on DSM-IV and CARS-2 and no ASD on INDT-ASD). The caregivers of this child claimed that the child was capable of most things, but these claims did not correspond to the observations made during the play sessions, thus making the scoring challenging (2 additional sessions were taken for this child to help make the child feel comfortable with the clinician). Furthermore, this child scored 30 (session 1) and 30.5 (session 2) on CARS-2 showing only a mild severity. It is possible that since the child is very young, CARS-2 could have produced a false-positive result and incorrectly diagnosed the child as ASD. As proposed by Lord,<sup>[16]</sup> had the score of 32 been taken as the cutoff, the child would have been diagnosed as no ASD<sup>[17]</sup> on CARS and thus concurring with the diagnosis of INDT-ASD. To add a further note with regard to this, the child's file was reviewed 7 months' post completion of the study. The CAP team had initially made a diagnosis of ASD and had mentioned on follow-ups about many improvements the child had shown with intensive early intervention. Some of the key components of the intensive program included speech-language therapy, five times a week, including both center-based as well as individual sessions, occupational therapy, increase in qualitative interaction with parents, complete cessation of screen exposure, and placement in a play school. Presentations of such children are not

uncommon in a clinical setup and hence there is ample opportunity to evaluate and document such children on INDT-ASD.

In addition, the tool was able to subgroup children within the spectrum as Asperger's and PDD-NOS. The accuracy of identifying PDD-NOS and Asperger's was analyzed post hoc by reviewing records and history. Of the five children diagnosed as PDD-NOS by INDT-ASD, only three qualified for clinical diagnosis of PDD-NOS based on DSM-IV guidelines. Further, all three children who were diagnosed as Asperger's by INDT-ASD also qualified for the diagnosis of Asperger's as per DSM-IV guidelines. The exercise of further assessing each child for autism versus Asperger's versus PDD-NOS was not taken up at the initial phase of recruitment since the institution where the current study was taken up follows the latest DSM-V guidelines and according to these guidelines, it is just one classification system of ASD. Diagnostic break up of autism, Asperger's, and PDD-NOS, etc., is not a part of DSM-V. If one wants to assess diagnostic accuracy of INDT-ASD based on autism, Asperger's, and PDD-NOS, it would require more number of children to be recruited with a better age stratification.

Since the latest version of the Diagnostic and Statistical Manual (DSM-V) has made some significant changes in the criteria for autism diagnosis,<sup>[13]</sup> the compatibility of INDT-ASD with DSM-V needs to be addressed. As rightly pointed out,<sup>[15]</sup> though the tool is able to diagnose children with severe symptoms, the reliability of the tool to diagnose children with high functioning autism and children with only some symptoms of autism could be further explored. The tool's accuracy in helping differentially diagnose severe ASD and IDD can be explored too. The INDT-ASD can be an integral part of SLPs diagnostic tool because of its cultural appropriateness, ease of administration, and scoring. Above all, it does not require a tool-specific training or certification and can be used by professionals such as pediatricians, psychologists, psychiatric social workers, and SLPs who work with ASD.

## Conclusion

The INDT-ASD is a simple and effective tool that helps in the diagnosis of ASD. The simplicity of the tool can be useful in many clinical setups including speech-language pathology. Although the classification accuracy and specificity of the tool was found to be high, it would be interesting to validate this with a larger and wider clinical sample. SLPs could explore the amount of

assistance it provides in setting baselines and goals for intervention. Since India is a country with many languages it would be helpful to translate the tool to more languages.

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### Conflicts of interest

There are no conflicts of interest.

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