

Culturally adapted assessment tool for Autism Spectrum Disorder and its clinical significance

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SUMMARY

Diagnosing of Autism Spectrum Disorder (ASD) using tools developed in the West is challenging in the Indian setting due to a huge diversity in sociocultural and economic backgrounds. Culturally adapted tools, such as the International Clinical Epidemiology Network (INCLIN) Diagnostic Tool for Autism Spectrum Disorder, have been developed in several Indian languages, yet, they do not accommodate all verbal abilities and education backgrounds. To address this disparity, we developed a home-based, audiovisual game app (Autest) suitable for ASD risk assessment in Indian children under 10 years of age. The game has five modules for each age group with specific peer interaction and play skill assessments. Each module follows a story from the Panchatantra, a popular Indian story series for children. Gameplay and behavior are tracked to assess risk. The effectiveness of Autest was rated by 30 psychologists with respect to current tools. Ratings suggested that the tool is effective and can reduce social inhibition and facilitate assessment due to the lack of a language barrier using emojis, cultural appropriateness, ease of administration, and simple scoring. This tool is particularly useful for minimally verbal, at-risk children. Further usage and development of Autest can improve risk assessment and early intervention measures for children with ASD in India.

INTRODUCTION

Children with Autism Spectrum Disorder (ASD) struggle with social interactions, with verbal and non-verbal communication, and with restricted or repetitive behaviors (1). Estimates drawn from previous studies suggest that India could have more than 2 million people with ASD (2). Raina, *et al.* reported a prevalence rate of 0.9 cases per 1000 individuals (3). A 2018 study reported a prevalence rate of 1 in 100 for children under the age of 10 in India (4).

Diagnostic measures developed in the Western world, such as Childhood Autism Rating Scale (CARS), Gilliam Autism Rating Scale (GARS), Autism Diagnostic Observation Schedule (ADOS), and the Autism Diagnostic Interview Revised (ADI-R), pose challenges in the diverse sociocultural

Indian setting (5). Issues with interpretation, translation, or cultural understanding of behaviors may contribute to false positive results in traditional diagnostic tools (5). Furthermore, differences in language and cultural markers may contribute to poor diagnoses. Several studies have highlighted cross-cultural differences in autistic traits which must be addressed during diagnosis (6-7).

Various psychometric scales have been developed that are currently used for ASD diagnosis. Each of these methods involve observing the child's behavior and supplementing that information with parent's feedback. Furthermore, tests adapted to be effective in a specific cultural setting, such as India, have also been developed. Two widely used scales developed in India are the Indian scale for Assessment of ASD (ISAA) and the International Clinical Epidemiology Network (INCLIN) Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD) (8-9).

The testing times for the ISAA are around 20–30 minutes. The assessment is carried out using an assessment kit comprised of daily life objects such as a toy car, ball (different sizes), mirror, handbell, etc. (8). The ISAA is a 40-item scale split up into six domains: social relationship and reciprocity, emotional responsiveness, speech (language and communication), behavior patterns, sensory aspects, and cognitive component (8). For scoring, each of the 40 items are rated in 5 categories. These are quantified by providing percentages to indicate frequency, degree, and intensity of behavioral characteristics observed. The range in which the final score lies is used to determine the degree of ASD (8). However, this current tool is not child-friendly and lacks a visual component and a cohesive storyline.

INDT-ASD is a diagnostic tool developed based on the fourth edition of the Diagnostic and Statistical Manual (DSM), consisting of two sections (9). The first section includes questions related to three cardinal domains: social interaction, communication, and restricted interests. The second section relates to scoring as well as arriving at diagnostic classifications that include Autism, Asperger's disorder, Rett's disorder, Childhood Disintegrative disorder, Pervasive Developmental disorder, Intellectual Developmental Disorder (IDD), and an indeterminate category (which indicates that criteria are not met for any of the above disorders or that there are too many unsure responses, or they could not be tested under appropriate conditions) (9). The questions in the

1 tool vary according to the age group of the subject (below
2 4 years of age, above 4 years of age, and above 6 years of
3 age) and are accompanied by simple, relevant, and easy-
4 to-understand examples to increase comprehension for the
5 caregivers. The time taken for the administration of the test
6 may range from 30–45 minutes (9). However, it does not
7 include newer diagnostic criteria for ASD introduced in DSM-
8 5, such as sensitivity testing, which have been addressed
9 with Autest.

10 Recent attempts have been made to introduce
11 computerized forms of ASD testing, often through mobile
12 applications (10). These tests have come into being with the
13 aim of creating more accessible, reliable, and effective forms of
14 ASD screening. This method acknowledges that professional
15 administration is not scalable and that the children need to
16 be observed in their natural environments (such as schools,
17 homes, communities, etc.). Autism and Beyond is one such
18 popular application that a caregiver can utilize (11).

19 There is an acute need to develop newer means of
20 assessing ASD risk owing to inconsistencies across
21 socioeconomic and cultural backgrounds in the Western
22 world and the Indian setting (5-7). In the current study, we
23 have developed one such culturally relevant risk assessment
24 tool for ASD in the form of a computerized application
25 based on DSM-5 guidelines, which will help to perform
26 psychometric evaluations and identify children who show
27 signs of developmental delays. Autest is a visual, child-
28 friendly game app based on the Panchatantra that utilizes
29 various psychological markers for autism risk assessment.

30 We hypothesized that Autest would be clinically significant,
31 which we would test through experimental interviews of
32 professionals. We predicted that the professionals would
33 deem Autest clinically viable due to the ease of administration,
34 absence of language barrier, child-friendliness, and cultural
35 relevance. As a pre-diagnostic tool, Autest would be the first
36 step for individuals to seek more evaluation and treatment
37 based on risk score.

38 RESULTS

39 We developed a culturally adapted risk assessment tool
40 for ASD. The game format is more engaging and culturally
41 relevant than currently available diagnostic tests. The child
42
43
44

45 **Table 1. Professionals' responses to question 7-12.**

Question	Response (n = 30)
46 7. In your tests how involved are parents/caretakers in the process? (1 = Not at all, 10 = Very involved)	3.967 ± 0.850
47 8. Do you think adding a "parental questions section" can be useful 48 for our app?	26 out of 30 said yes
49 9. If so, up to what percentage of responses should come from them (say criteria like lack of social smile, speech history etc.)?	37% (± 8.3%)
50 10. (a) As our proposed test has a storyline and can be independently 51 taken, do you think diagnosis would be quicker? 52 (b) Would our app help prevent social inhibition?	(a) 14 out of 30 said yes (b) 26 out of 30 said yes
53 11. How effective do you think our app can be to detect early signs of 54 autism? (1 = Not at all, 10 = Extremely effective)	6.834 ± 0.780
55 12. Lastly, on a scale of 1-10 how willing would you be to try our app?	7.8 ± 0.805



Figure 1. Sample game scene from the Autest app. The app utilizes bright colors and animations accompanied by music to generate an interactive audiovisual experience for the test-taker.

has to complete interactive tasks to pass levels and proceed through the game. As the child is engaged throughout the process and is not interviewed by someone they have not known beforehand, social inhibition is reduced, and testing is more reliable. The use of pictures, animations, emojis, and music removes a language barrier and thus, Autest can ideally be administered in most parts of India. A sample game scene (**Figure 1**) has been provided in this paper.

To understand the validity of Autest, we remotely interviewed 30 professionals, in two groups of 15 each, about the effectiveness of our diagnostic method. The questionnaire consisted of comparative questions in six elements of ASD diagnosis based on the ISAA: social relationship and reciprocity, emotional responsiveness, speech (language and communication), behavior patterns, sensory aspects, and cognitive component. The first group filled out a written questionnaire and the second group was interviewed through a telephonic conversation. Both male and female professionals were interviewed with a mean age of 42, ranging from 28 to 60. Eight of them specialized in autism diagnosis in children. They rated the effectiveness of our tool with respect to currently used diagnostic methods in India.

The mean ratings (**Figure 2**) for each domain suggested that the tool was effective. Specifically, our tool was determined to be most effective for Behavior Patterns and Emotional Responsiveness, and least effective for Social Relationship and Reciprocity. The responses to the descriptive answers

Table 2. Results of one-way ANOVA.

Domain	F-value	p-value*
Social Relationship and Reciprocity	0.215	0.646
Emotional Responsiveness	0.091	0.765
Speech - Language and Communication	0.160	0.692
Behavior Patterns	0.261	0.614
Sensory Aspects	0.040	0.843
Cognitive Component	0.254	0.618

*p < 0.05 considered statistically significant

Table 3. Scoring rubric for Autest (the numbers in brackets represent the score assigned).

Criteria	Low range	Normal range	High range	Very high range	Maximum score
Average response delay ^a	< 0.5 sec (0)	0.5 - 1.5 sec (10)	1.5 - 4 sec (20)	> 4 sec (30)	30
Emojis ^b	9 - 10 (0)	7 - 8 (5)	4 - 6 (10)	< 4 (15)	15
Repetitive/unwanted clicks ^c	< 25 (0)	25-30 (5)	31 - 40 (10)	> 40 (15)	15
Observer questionnaire	0 - 10	10 - 20	20 - 30	30 - 40	40
Total					100

^aaverage reaction time for humans is 0.25 sec to visual stimulus. Response time is reaction time and time taken to make a choice.
^btotal 10 emoji checks, each with 3 options.
^ctotal 25-30 clicks are required to finish the game.

have been summarized in **Table 1**. A one-way ANOVA revealed that there was no significant difference between both randomly selected groups' ratings of Autest, as shown in **Table 2**. The scoring rubric used for Autest has been detailed in **Table 3**. The taxonomy in **Table 4** was adapted from the ISAA. Risk assessment can be followed by follow-up or referrals for at-risk individuals, thereby improving future diagnosis for quicker intervention.

DISCUSSION

Early diagnosis is recommended for effective intervention therapy for autistic children and their families. Often, particularly in rural areas, it becomes difficult to identify developmental delays by conducting screening tests due to lack of resources in primary and secondary care settings (12). The purpose of the game is to aid developmental-behavioral pediatricians and other medical professionals in evaluating ASD at an early age, particularly among at-risk youth. This, in turn, will lead to early intervention measures such as

Table 4. Risk-assessment rubric for Autest.

Autest Score Range	Risk Level	Corresponding ISAA diagnosis
0-20	Low risk	Normal
21-40	Moderate risk	Mild autism
41-70	High risk	Moderate autism
71-100	Very high risk	Severe autism

comprehensive diagnostic evaluation, improving the user's quality of life and integrating them into mainstream society.

As the test can be independently administered at home without prior experience, the child will be more cooperative and comfortable (13). The game is also suitable for pre-verbal and minimally verbal autistic children, who are difficult to diagnose (14). It is also the first autism risk assessment tool in India based on DSM-5 guidelines.

The 30 psychologists interviewed rated Autest in two groups of 15 each. After playing the game, the first group filled out the questionnaire by hand, whereas the second group was interviewed via telephone. Despite different modes of answering, both groups rated Autest as clinically significant across all six domains with no significant difference between the telephone group and written questionnaire group, as revealed by one-way ANOVA (**Table 2**). However, there might have been selection bias while recruiting professionals for the survey, and to address this, we will conduct a larger survey in the future.

Despite being clinically significant, Autest has certain limitations. Implementing Autest for diagnosing visually and/or hearing-impaired children could be challenging. Furthermore,

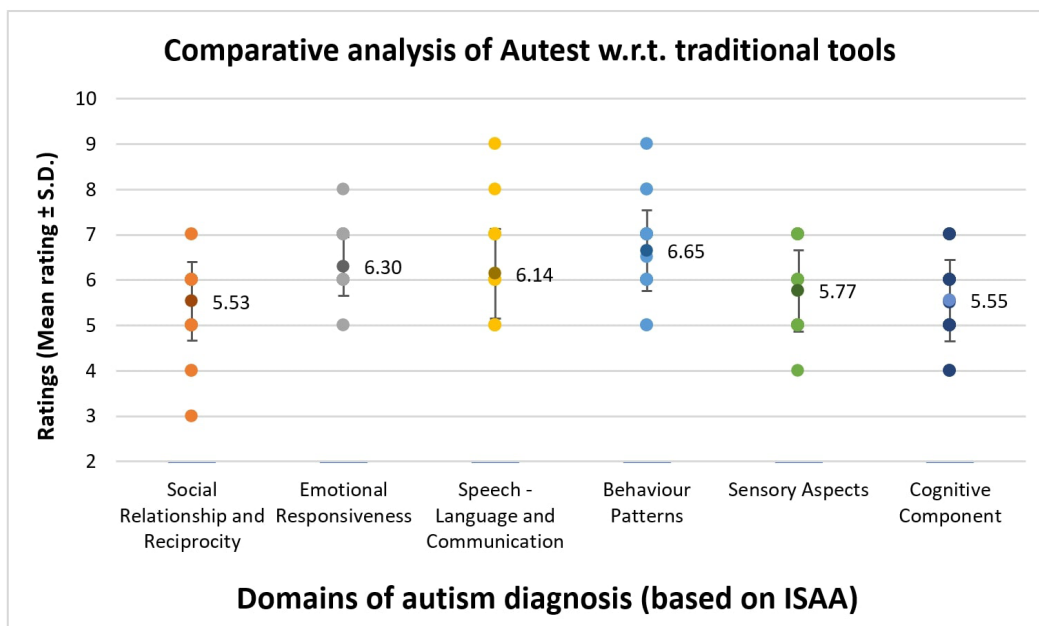


Figure 2. Scatter plot representing questionnaire responses of professionals. Lighter dots represent each individual rating, whereas the darker dot represents the mean value in each domain. Data is presented as mean ± S.D., n = 30.

1 interpreting the app and answering the observer questionnaire
2 requires a certain degree of training, which may be limited
3 in rural areas. Lastly, to use Autest, one needs access to a
4 mobile phone, tablet, or computer with sufficient capabilities
5 in terms of memory, graphics, etc. An internet connection is
6 also initially required to download the app. Moreover, several
7 studies have shown that the prevalence rate of ASD within
8 India is highest in rural areas (15-17), which could make the
9 implementation of Autest challenging (15).

10 The current study can be expanded on in the future by
11 conducting beta-tests of our game app. Additionally, expanding
12 our study to include more feedback from other related health
13 workers involved in the ASD diagnosis process, such as
14 social workers or pediatricians, can make our diagnostic tool
15 more effective. In the future, we hope to improve upon the
16 identified limitations. Additionally, we hope to expand our
17 diagnostic tool by including levels, age-based modules, and
18 a wider range of storylines to choose from. Finally, we plan
19 on partnering with healthcare professionals, especially those
20 involved with ASD patient care, to make Autest accessible
21 throughout the country in conjunction with existing culturally
22 relevant tools such as the INDT-ASD (18).

23 MATERIAL AND METHODS

24 As mentioned before, the ISAA consists of 40 test
25 questions, divided into six domains. To develop the Autest
26 application, the core idea was to integrate each of these test
27 factors with an existing story line and quantify the responses
28 by tracking interactions with the game in conjunction with the
29 observer questionnaire.

30 Choosing the storyline

31 The Panchatantra is a popular story series for children in
32 India. It contains the most widely known stories in the world
33 (19). It is an abridged version of an ancient Indian collection of
34 interrelated animal fables. We chose Panchatantra due to its
35 simplicity, abundance of social hierarchies and relationships,
36 and emotion-rich plots. Moreover, our target demographic has
37 a high likelihood of previous exposure to the Panchatantra.
38 This familiarity helps initiate the diagnostic process, and the
39 subject is more likely to be cooperative (20). Other similar
40 texts such as the Mahabharata have religious connotations
41 or affiliations.

42 We chose the story, "The Gaining of Friends" from *Mitra*
43 *labha*, the first book of the texts, due to ample number of
44 social characters and its wide coverage of the emotional
45 spectrum (19-20). The story is suitable for young children
46 of different backgrounds. *Mitra bheda*, the second book of
47 Panchatantra, has graphic elements, violence, and animal
48 abuse, which is not suitable for a diagnostic tool and therefore
49 was not considered (20). The average number of characters
50 in other stories in the *Mitra labha* is six, whereas the number
51 of characters in the selected story is nine, offering more
52 opportunities for integrating social indicators in the domains
53 of Social Relationships and Reciprocity (20).

Converting the story into game scenes

We converted the plotline into suitable scenes for our app. The story was divided into nine individual scenes based on the plot development and introduction of new characters. The story was shortened without loss of the original meaning or intention. The chosen story, "The Gaining of Friends", had two main scenes. The first takes place with the birds and the hunter, and the second takes place between the rats and the birds (20). The second scene was deleted to reduce the number of characters and character-specific monologues, in turn helping reduce complexity of the storyline. However, throughout this abridging process, we ensured sufficient characters and potential cues to help with appropriate risk assessment. The story was modified to make it playable as well as easily understandable for our target age group. Playing the game is estimated to take 20 minutes on average based on the administration of the professionals' questionnaire.

Developing the app

Unity was used to develop the final game app (21). We used the Indian Scale for Assessment of ASD as the reference diagnostic tool for our app (8). Essentially, the game will present the player a range of "situations", which are semi-structured tasks designed to "press" for communication and social interaction. These are situations with pre-determined behavioral and emotional reactions, such as social smiles or exhibition of empathy. Keeping in mind the gradual development of children, the game has five modules, increasing in complexity to account for social and language development.

Observer questionnaire (OQ)

Several parts of the game can lead to certain behavioral responses in the test-taker. To account for these in the assessment, we developed an observer questionnaire, available in English and Hindi. Usually, the observer would be the parent or legal guardian of the child present during gameplay in a natural setting.

The questionnaire comprises questions that quantify when the test-taker smiles, looks away, is aloof, mimics game sounds, produces infantile squeals or unusual noises, is hyperactive and aggressive, and is sensitive to change in color contrast and sudden sounds while playing. Each question has five options which are scored in the end.

Game design

The game has a choose-your-own-adventure setting. Throughout the game, we display emotion checkers, which are pop-ups with three emojis to check for emotional reactions to events in our game (**Figure 3**). One of the emojis depicts the appropriate emotion, another emoji depicts a contrasting emotion, and the third one either depicts a neutral or unrelated emotion. For example, if the appropriate emotion is 'happy', the other emotions depicted using emojis can be 'sad' and 'angry'.

Game scoring

The test-taker receives a total score out of 100, with 40 possible points from the observer questionnaire (OQ) and 60 from gameplay data (Table 3). A lower score on Autest indicates a lower risk of ASD. We kept this ratio after calculating from professionals' interviews that on average, 40% is most widely accepted parental/observer involvement in ASD diagnosis. In the game, we track delay of response after every instruction, emojis selected in the emoji checker, and repetitive or unwanted clicks. The total score is compared with the norms to calculate risk assessment (Table 4).

Social relationship and reciprocity

To comprehensively test for social responses, the game uses emojis and music. This makes the tool suitable for children from various socioeconomic and educational backgrounds (22-23). Poor eye contact, lack of social smile, and aloof nature is checked using the OQ. Throughout the game, the characters maintain eye contact and smile at the player. Turn-taking is addressed by a particular section of the game which requires the player to wait for their turn. The number of clicks is also tracked and accounted for in the assessment.

Emotional responsiveness

Inappropriate emotional response is checked for using emojis. At crucial points in the game, a pop-up with three emojis appear. One of the emojis is relevant to the situation. The choice of the child is recorded. Fear of danger is checked using two choices provided in the game. Choice A is visually dangerous and choice B is visually appealing and safe.

Speech (language and communication)

Several instances of the game have the character pointing at certain objects. Where the child clicks during this point is tracked to determine whether they have difficulty in using non-verbal language to communicate. The game has a repetitive audio track for certain actions. If the right emoji is chosen, "Nice!" is played. If the wrong emoji is chosen, "Oh no!" is played. Echolalic speech (repetition of speech) is checked using the OQ. Similarly, infantile squeals or unusual noises and jargon/meaningless words while playing the game are checked using the OQ.

Behavior patterns

Hyperactivity, aggressive behavior, and temper tantrums while playing are evaluated using the emoji checker and as part of the OQ.

Sensory sensitivity

In 2013, sensory reactivity or interest was added as a symptom of ASD in the fifth edition of the DSM (15). In Autest, we evaluate sensitivity to visual and auditory stimuli. Different levels of the game have different color contrast schemes. Behavioral responses to this change are quantified using the

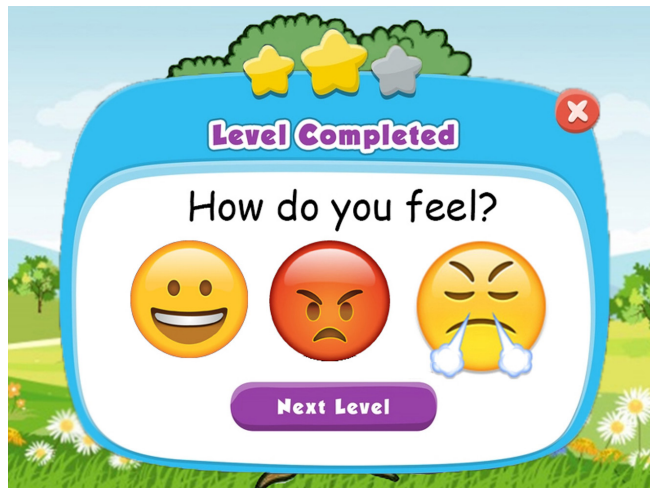


Figure 3. Emoji checker used throughout the app to check for Emotional Responsiveness.

observer questionnaire to determine if the child insists on sameness. A sudden auditory track is introduced at various points in the game. Behavioral responses to these sounds are quantified using emoji responses and the OQ.

Cognitive component

Inconsistent attention and concentration are checked for using response frequency and time. In particular, delays in following game instructions are tracked. Checking for unusual memory or savant ability was not within the ambit of our game.

Professionals' questionnaire

The *Economic Times* reports that in 2018, there were 898 psychologists in India (24). We interviewed a representative sample of two groups of 15 each (total of 30), who were chosen randomly and contacted via contact details provided online. We contacted professionals from different locations within India. A questionnaire consisting of 12 questions was developed. Instead of descriptive answers, we used a numerical rating scale of 1 to 10 wherever possible, so that it was easier to compare the data between the two groups. The questions were written in a concise manner so that it was easier for the psychologists to follow and answer. Additionally, we followed the guidelines of questionnaire design as suggested by Boparai *et al.* (25).

The first group, consisting only of psychologists, filled out the questionnaire by hand after testing Autest. The second group, which was more diverse - consisting of social workers, pediatricians, and psychologists - were interviewed via telephone. The questionnaire was read aloud, and their responses were noted accordingly.

The questions asked participants to rate Autest with respect to current diagnostic tools for each of the six domains of autism diagnosis. Furthermore, they were asked about the level of parental involvement in their tools, to determine the score to be assigned to the observer questionnaire for

1 Autest. They were asked if they think Autest would reduce
2 social inhibition and provide quicker diagnosis based on the
3 presence of a storyline. Lastly, they were asked how effective
4 they think our app is and how willing they were to try it in a
5 clinical setting.

6 The answers were either in a yes/no format or a numerical
7 value ranging between one and ten. The psychologists
8 were sent the app and instructed to test in an undisturbed
9 environment. A post-survey was conducted after they
10 responded that they finished the game—the first group was
11 sent the questionnaire, and the second group was interviewed
12 via telephone. The responses were compiled, mean values of
13 responses for each domain were calculated (**Figure 2**), and
14 a one-way ANOVA (**Table 2**) was conducted to determine
15 statistical significance between questionnaire methods to test
16 if there was a statistically significant difference between the
17 two questionnaire methods.

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