## **Mobile App Diagnostic Tool For Autism Spectrum Disorder**

**Available on Google Play Store and iOS** 



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# Training module for AIIMS modified INCLEN diagnostic tool for autism spectrum disorder (INDT-ASD)

Center of Excellence & Advanced Research on Childhood Neurodevelopmental Disorders, Child Neurology Division, Department of Pediatrics, All India Institute of Medical Sciences, New Delhi



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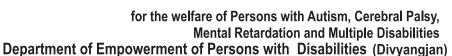
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## **AIIMS Modified INDT-ASD Tool for Autism Spectrum Disorder**

New Tool Developed By Sheffali Gulati, Jaya Shankar Kaushik, Biswaroop Chakrabarty, Lokesh Saini, Savita Sapra, N K Arora, R M Pandey, Rajesh Sagar, V K Paul, Shobha Sharma

#### How to use the tool:

Website: http://www.pedneuroaiims.org

## **Previous Tool Developed By INCLEN-NDD Project**

Investigators: NK Arora (Project Leader), MKC Nair (Principal Investigator), Jennifer Pinto-Martin (Co-PI), Donald Silberberg (Co-PI), Sheffali Gulati (Network Co-ordinator) and INCLEN Study Group

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## Training module for AIIMS modified INDT-ASD tool for Autism spectrum disorder

#### Learning objectives:

- 1. To describe the diagnostic criteria and core symptoms of autism spectrum disorder
- 2. To clinically evaluate a child with suspected autism spectrum disorder using AIIMS modified INDTASD tool

# Training module for AIIMS modified INDT-ASD tool for Autism spectrum disorder

#### Introduction

Autism is a neurodevelopmental disorder characterized by impairment in reciprocal socialization, qualitative impairment in communication along with repetitive behaviour. The two key domains of autism spectrum disorder includes deficit in social communication/ interaction and restrictive and repetitive behavior. Autism spectrum disorder is diagnosed based on DSM-5 criteria. DSM-5 diagnosis of autism spectrum disorder includes qualitative impairment of social interaction, social communication and restrictive and repetitive behaviour. It is a behavioural disorder that has multiple etiologies including genetic and environmental. It is a lifelong disorder with evolution of symptoms as the child grows with need for sustained support.

Autism spectrum disorder (ASD) is a common Neurodevelopmental disorder across the globe. All the epidemiological studies show a significantly greater number of boys than girls with autism. Male to female ratios vary from 2:1 to 3:1. Prevalence of ASD in United States as per the recent data was 1 in every 68 children\*. However, incidence of ASD was estimated at 1:54 in males and 1:252 in females\*. In a recent study by INCLEN to study the prevalence of neurodevelopmental disorders in children, prevalence of autism spectrum disorder in India was estimated at 1.4% (unpublished data). In a study by INCLEN (unpublished data) to estimate the prevalence of neurodevelopmental disorders in children, the prevalence of autism spectrum disorder in Indiawas estimated at 1.1% (range=0.7-1.7). The prevalence in rural areas was 1.1% (0.7-1.8), while in urban areas, it was estimated to be 1.2% (0.5-2.7)

\*Centers for Disease Control and Prevention, Autism and Developmental Disabilities Monitoring Network. Identified Prevalence of Autism Spectrum Disorders. 2012. [Internet]. 2015. Available from: http://www.cdc.gov/ncbddd/autism/data.html.

#### Diagnosis of autism spectrum disorder

Diagnostic and statistical manual of mental disorder (DSM) provides a common language for clinician, researchers, insurers, and families. As per DSM-IV classification, following criteria needs to fulfill to label a child as autism: qualitative impairment in social interaction (2 out of 4 item), qualitative impairments in communication (1 out of 4 items) and restricted repetitive and stereotyped patterns of behaviour, interests and activities (1 out of 4 items). A child would be considered autistic when 6 out of 12 criteria were fulfilled. DSM has launched its fifth revision wherein there is transition from autism and pervasive developmental disorder to autism spectrum disorder (DSM-5). DSM-5 clubs the three core domains into two core domains with social communication and interaction into one domain and restrictive, repetitive behaviour or interest being the other domain. Additionally, sensory symptoms were included in the latter domain.

As per DSM-5 revision, following criteria needs to be fulfilled to label a child as autism spectrum disorder:

- A. Persistent deficits in social communication and social interaction (3 out of 3 items)
- B. Restricted, repetitive patterns of behavior, interests or activities (2 out of 4 items)
- C. Symptoms must be present in the early developmental period (essential)
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning (essential)
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay (essential).

#### INCLEN diagnostic tool for autism spectrum disorder (INDT-ASD tool)

INDT-ASD tool for diagnosis of autism was diagnosis of autism by primary care physician to reach a diagnosis of autism. The tool was developed by team of 49 national and international experts. The experts include pediatrician, pediatric neurologist, epidemiologist, clinical psychologist, special educator. The team developed an appropriateness criteria and the tool was developed over 2 day workshop. The tool has two sections: Section A has 29 symptoms/items and Section B has 12 questions pertaining to response based on section A. It takes 45-60 minute to administer the tool. The tool has combination of parental response and observation. The tool was initially developed in English and then forward and backward translated to Hindi and English.

Diagnostic performance of INDT ASD tool are as follows: Diagnostic accuracy [AUC=0.97 (0.93, 0.99); P<0.001], Sensitivity 98%, specificity 95%, PPV 91%, NPV 99%\*. Concordance rate between the INDT-ASD and expert diagnosis for 'ASD group' was 82.52% [Cohen's  $\kappa$ =0.89; 95% CI (0.82, 0.97); P=0.001]. The convergent validity with CARS (r = 0.73, P= 0.001). Merits of INDT-ASD include high diagnostic accuracy, adequate content validity, good internal consistency, high criterion validity, high to moderate convergent validity and easy to administer. Few of major concerns especially in light of revision of DSM-IV to DSM-5 it needs upgradation. Moreover, the present tool lacks severity scoring for grading the severity of autism. In the light of revision of DSM-IV to DSM-5, the present tool needs upgradation

\*Juneja M, Mishra D, Russell PSS, Gulati S, Deshmukh V, Tudu P, et al. INCLEN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD): development and validation. Indian Pediatr. 2014 May; 51(5):359–65.

#### Why move from DSM-IV to DSM-5

- 1. DSM-5 provides a single umbrella diagnosis for disorders including autism, asperger syndrome, rett syndrome, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) as autism spectrum disorder.
- 2. Symptoms of autism spectrum disorder are specific (NOT pervasive) to impairment in social interaction and communication with presence of restrictive, repetitive behaviour.
- 3. There are concerns of validity of category labelled as pervasive developmental disorder-not otherwise specified (PDD-NOS) and Childhood disintegrative disorder (CDD)
- 4. There are concerns of PDD-NOS being labelled as mild developmental disorder and Asperger as 'odd' behaviour. Moreover, overuse of PDD-NOS leads to diagnostic confusion and may contribute to epidemic of autism
- 5. Symptoms of autism spectrum disorder are not salient among children with Rett syndrome. Moreover, Rett syndrome is a recognized genetic syndrome that can have symptoms of autism spectrum disorder.
- 6. Developmental regression in autism spectrum disorder has a wide range in timing and nature of loss of skills, hence precise existence of childhood disintegrative disorder has been challenged by many author worldwide.
- 7. Literature has suggested that there is a considerable overlap between high functioning autism and Asperger syndrome questioning the need for separate category for the latter.

#### Clinical consensus criteria (CCC) for Autism spectrum disorder as per DSM-5\*

- 1. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:
- a. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction
- b. Deficits in nonverbal communicative behaviours used for social interaction; ranging from poorly integrated verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
- c. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behaviour to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people
- 2. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
  - a. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).

- b. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
- e. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
- d. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).
- 3. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
- 4. Symptoms together limit and impair social, occupational and other areas of daily functioning.
- 5. These disturbances are not better explained by intellectual disability or global developmental delay.

<sup>\*</sup>American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

#### Merits of DSM-5 over DSM-IV

There is large number of merits of DSM-5 diagnosis of autism spectrum disorder over previous DSM-IV.

- 1. It includes a single umbrella diagnosis for all ASD and dilution of ambiguous terms like pervasive developmental disorder and its subtypes like PDD-NOS.
- 2. It ensures appropriate services and insurance coverage to those who did not benefit earlier: Asperger, PDD-NOS. This has a major implication among countries where medical insurance exists for providing autism services. All children previously diagnosed as autism, PDD-NOS, Asperger (DSM-IV) will continue to obtain the medical benefits.
- 3. One of the major advantages of DSM-5 is that it allows co morbidities like ID, ADHD, Genetic disease (Rett, Fragile X, Tuberous sclerosis). Hence under DSM-5 it is possible to have diagnosis like ASD with ADHD, ASD with ID and ASD with Fragile X. In addition, DSM-5 separates children with isolated communication problems into social communication disorder (SCD) rather than PDD-NOS.

#### Symptoms of autism spectrum disorder

#### A. Deficits in social emotional reciprocity

- a. There may be lack of joint attention in the form of inability to share his/her interest by pointing to parents the object of intrest like a dog/cat/flower/train
- b. There may be lack of initiation of conversation to talk about his interests or achievements
- c. There may be lack of sharing of his/her emotions, happiness or distress with parents
- d. There may be lack of initiation of conversation or lack of adding significant content for the conversation to continue.
- e. Child may prefer to play alone and not mix up with other children
- f. There may be an impairment of involvement in rule based games

#### B. Deficit in non verbal communicative behaviour

- a. Poor integration of verbal behaviour and non verbal behaviour
- b. They may have poor eye contact
- c. There may be impairment in use of appropriate gestures during social interaction
- d. There may be total lack of facial expression while interacting with parents or strangers

#### C. Deficits in developing, maintaining and understanding of relationship

- a. They may not enjoy the company of other children
- b. There may be lack of friends with whom he/she can chat, share or play together
- c. They may play with children of younger or older age group
- d. There may be lack of imaginative play

#### D. Stereotyped, repetitive motor movement or speech

a. Child may repeat certain words or phrases regardless of the meaning that he/she has heard

- b. Child may repeat few words or phrases he/she heard in television regardless of meaning or context
- c. He/she may have pronoun reversal with replacement of "I for me" and "me for you"
- d. He/she may speak out of context or irrelevantly
- e. Child may show excitement by flapping his hands, wring his hands, rocking, spinning or making some unusual finger or hand wringing
- E. Insistence on routines: child unreasonably insist on doing things in a particular way and/or become upset if there is any change in the daily routine
- F. Highly fixed or restricted interest: Child may prefer to play with a particular part of a toy/object rather than the whole toy/object
- **G.** Sensory symptoms:
  - a. Child may show indifference or excessive reaction to pain
  - b. He/she may show abnormal interest in feeling the textures
  - c. He/she may show abnormal reaction to sounds by covering their ears
  - d. He/she may have excessive smelling or touching of object in unsual manner
  - e. He/she may have fascination with lights or moving objects

#### Co morbidities of autism spectrum disorder

Co morbidities of autism spectrum disorder includes epilepsy and a wide range of psychiatric disorders, behavioural problems, sleep related problems. Table depicts the list of comorbid conditions that are common among children with autism spectrum disorder.

#### Co-morbid conditions of autism spectrum disorder

Broad category	Co morbid condition
Psychiatric	Anxiety (43-84%) Depression (2-30%) Obsessive compulsive disorder (37%) Oppositional defiant disorder (7%) Behavioural problems
Behavioural	Disruptive Irritable Aggressive behaviour (8-32%) Self injurious behaviour (34%)
Sensory disturbances	Tactile (80-90%) Auditory sensitivity (5-47%)
Neurological	Seizures and epilepsy (5-49%) Tics (8-10%)
Gastrointestinal	GERD (8-59%) Constipation (8-59%)
Sleep disturbances	Sleep disruptions (52-73%)

#### Early diagnosis of autism

Symptoms of autism are known to appear as early as infancy and in first 2 years of life. Hence, identifying the child at early age is essential for early intervention of autism. Average age at diagnosis of autism is 3 years. Hence there is a long delay between parent's initial concerns and eventual diagnosis. Moreover, there is lack of sensitive tools to identify the symptoms at such early age and there is a natural variability in the nature and timing of early signs of autism. Early diagnosis of autism often gives answer to parents concerned about their child's atypical development and leads to transition from unfocused worry to mobilized efforts to learn about the disorder. This ensures that it allows the most appropriate treatment to be selected and delivered.

Symptoms of autism in infants include decreased imitation, decreased social responses: responses to their name, looking at other people, social smiles, fewer appropriate facial expressions, increased sensory and stereotypic behaviours and decreased nonverbal communication and gestures. Symptoms in toddlers include typical play for developmental level but little or no pretend play, history of normal or near normal motor development and lack of expected language, social, and gestural development for nonverbal developmental level.

As per American Academy of Neurology (AAN), autism spectrum disorder was suspected when one of following features is present:

- No babbling or pointing or other gesture by 12 months;
- No single words by 16 months
- No 2-word spontaneous (not echolalic) phrases by 24 months
- Loss of language or social skills at any age.

#### Differential diagnosis

- 1. Social (pragmatic) communication disorder (SCD): children with marked deficit in social communication but whose symptoms otherwise do not meet the criteria for autism spectrum disorder must be considered for SCD
- 2. Intellectual disability (ID): It is essential to differentiate intellectual disability from autism spectrum disorder (ASD) although both can co exist and the current DSM-5 gives the liberty to label "ASD with ID"
- 3. Landau Kleffner syndrome: children with autism spectrum disorder with later age at onset of regression must always be considered for a possibility of landau-kleffner syndrome. A sleep electroencephalogram could help in identifying this rare potentially treatable epileptic encephalopathy of childhood.
- 4. Undiagnosed hearing impairment may often masquerade symptom of pretending to be deaf making a suspicion of autism spectrum disorder. However, children with isolated hearing impairment often have good non verbal communication and absence of restrictive, repetitive movement or speech.

### Diagnostic criteria:

Consensus Clinical Criteria (CCC): Autism Spectrum Disorder (ASD) is defined as group of developmental disorders characterized by persistent deficit in social communication and interaction across multiple contexts along with presence of restricted, repetitive pattern of behaviour, interest, or activities. The criteria for diagnosis is based on best currently available evidence and / or consensus among national and international experts, using minimal investigations to serve the needs of resource-constrained settings.

#### **Instructions for Evaluation**

- 1. In evaluating a child, clinicians rely on questionnaires and direct observation (both structured and unstructured settings) to arrive at a diagnosis
- 2. In the current program, DSM-5 criteria are used for the diagnosis of autistic spectrum disorders
- 3. For the ease of application, a part of DSM-5 criteria have been converted into a questionnaire. This consists of questions to elicit responses in two relevant categories:
  - a. Persistent deficit in social communication and interaction across multiple contexts
  - b. Presence of restricted, repetitive pattern of behaviour, interest, or activities
- 4. This symptom cluster of two domains is associated with onset at early developmental age with resultant impairment in daily activities.

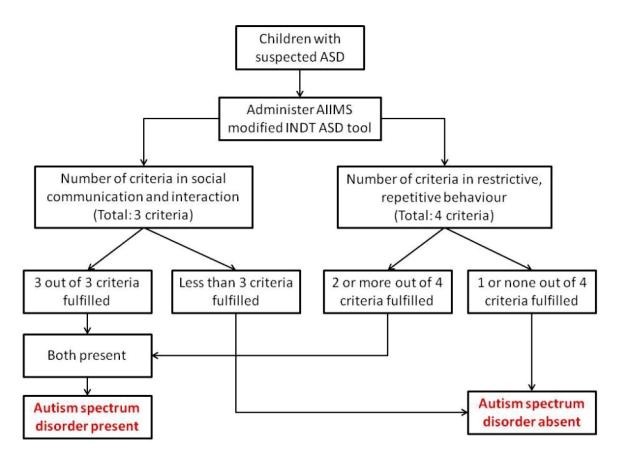
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  - b. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
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## Figure depicting the analysis of AIIMS modified INDT ASD tool



### AIIMS Modified INDT-ASD Diagnostic Tool for Autism Spectrum Disorder

#### **Tool interpretation:**

AIIMS Modified INDT ASD tool for autism spectrum disorder is based on DSM 5. The tool has

S.No	Item	Function	Number of	Interpretation
			questions	
1	Section A1a	Social emotional reciprocity	8 questions	Mandatory item
	Section A1b	Non verbal communication	4 questions	Mandatory item
	Sections A1c	Relationships	3 questions	Mandatory item
2	Section A2a	Stereotyped movement or speech	7 questions	At least 2 items out of 4
	Section A2b	Routines	1 question	items from
	Section A2c	Fixed interests	1 question	A2a to A2d
	Section A2D	Sensory symptoms	4 questions	

Footnote\*: At least 1 question in each item must be marked in shaded or circled response to consider that item to be present

#### **Final interpretation:**

To diagnose as autism spectrum disorder (ASD: Present) (Section B: Question 1 to 4)

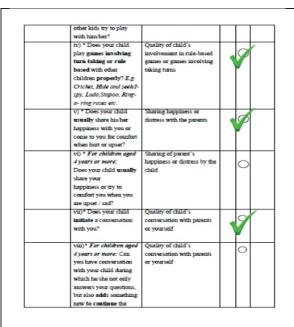
- 1. All sections A1a, A1b, A1c must be fulfilled
- 2. Atleast 2 out of 4 items from section A2a, A2b, A2c, A2d must be present
- 3. Onset must be in early developmental period
- 4. These symptoms must have resulted in impaired functioning

#### Example 1:

3 year boy brought with complaints of poor eye contact and delayed speech. He was born of non consanguineous marriage, first in birth order. His neonatal period was eventful, was born by normal delivery with birth weight of 3.2 Kg, cried immediately at birth and was discharged the next day. He subsequently attained age appropriate motor milestones but his speech was delayed. Parents have often observed him to be "in his own world", often not responding to commands when called. He often reacts by excessive jumping and spinning when he gets excited. Mother has noticed that when offered a toy he does not play with it, rather spins its wheels and throws it away. He likes playing with toffee wrappers and threads. A pediatrician suspected autism spectrum disorder and referred the case for evaluation.

Let us apply the AIIMS modified INDT ASD tool to see whether he fulfills the criteria for diagnosis of autism.

#### Tool Analysis Section A1a AIIMS Modified INDT-ASD Diagnostic Evaluation for ASD Question (i) On asking the parents does i) \* For children aged Observe how the child the child ever point to bring his less than 4 years: draws attention toward a Social Does/did your child ever toy/object of interest; Look emotional reciprocity point with his/her index for coordinated pointing attention, mother replied "no". You also finger to bring your attention to show the things that interest observe that when you ask the child to him/her? E.g. kite, plane flying in the sky, point to an object he does not point. \* cowldog on the road etc For children aged 4 years or more: Does shows that we give importance to what your child usually bring things to show you on his/her own parents report. Hence we mark as "no". he/she has made painted or new toy/gift? Circle shows that "no" is considered a ii) \* For children aged 4 years or more, and feature of autism. Hence section A1a is are able to speak: Does your child talk to you about things he'she likes fulfilled as even one question being or has achieved without being asked about them? iii) \* Does your child Quality of play activity in a positive will be considered an autistic group of children or with usually prefer to play alone and gets iblings irritated/moves away feature. when his/her sibs or Question (ii): Not applicable (age<4 years) Question (iii): Ask parents about his solitary play. Here answer of "yes" is autistic response.



Answers to question IV, V, VII are autistic response, whereas question VI and VIII are not applicable. Any ways we already have more than one response being in circle (autistic) against section A1a. Hence, we consider Section A1a is fulfilled.

	conversation?		
Section A1b Non verbal communication	<ol> <li>*For children aged less than 4 years:</li> <li>Does your child usually enjoy being taken in the lap or hugged? For children aged 4 years or more: When your child was a baby/toddler, did he'she enjoy being taken in the lap or hugged?</li> </ol>	In children below 4 years age: Response to being touched and cuddled by parent: enjoys/tolerates/squirms/ stiffens/ gets upset/ Indifferent	·
	ii) Does your child usually make eye contact with you or other people? E.g. While playing, asking for things, talking to you.	* Quality of eye contact	Ø
	iii) * Does your child usually use various gestures appropriately during social interactions?  E.g. Namaste, Salaam, waving by-bye, hollo, touching feet etc. (At least sometimes spontaneously) (use appropriate example as required)	Use of these gestures in response to your greeting and while departing	•
	iv) Does your child usually show appropriate facial expressions according	*Appropriateness of facial expressions while interacting with parents, with you (stranger), while	V

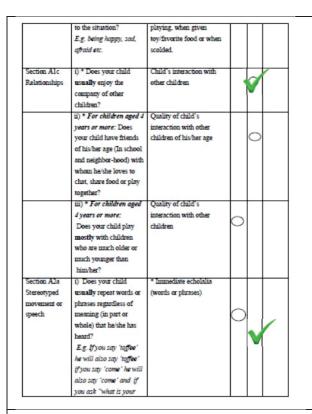
#### Section A1b

Question (i) Mother replied that "my child enjoys being taken in the lap".

Hence the response would be marked "yes".

Question (ii): Mother replied that "my child maintains a good eye contact". However, you observed that eye contact was very poor. See asterix\*. Here observation will take precedence. Hence final response would be marked "no" which is autistic. Hence Section A1b is fulfilled.

Question (iii) and (iv) were marked as per the parental response and observation.



#### Section A1c

Question (i): Mother replied "No he does not enjoys the company of other children and he prefers to play alone and does not mix with other children".

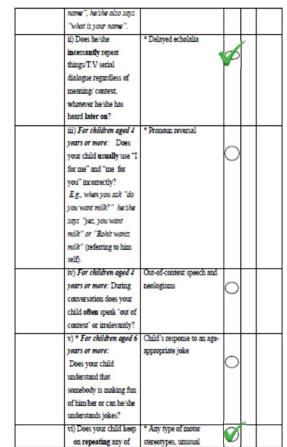
Hence answer will be marked "no".

Answer of "no" is a circled response.

Hence the section A1c is fulfilled.

Question (ii): Not applicable

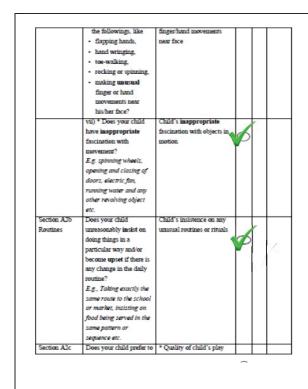
Question (iii): Not applicable



#### Section A2a

Question (i): mother replied "no" "he does not repeat the words". Nor did you observe immediate echolalia on observation. Hence response is "no"

Question (ii): Mother replied no to delayed echolalia. But you observed that he was using same words which you were conversing with parents few minutes ago without any context. Hence delayed echolalia was present. See asterix\*. Here observation will take precedence. Hence final response would be marked "no" which is autistic. Hence Section A2a is fulfilled.

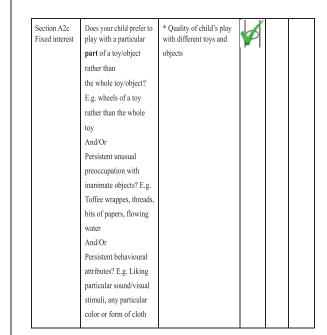


Question (vi): Mother replied "yes, he jumps and rocks by showing excitement". You also observed that he had hand flapping movement. Hence we mark as "yes". Circle shows that "yes" is considered a feature of autism. Hence section A2a is fulfilled.

Similarly, question vii was marked.

Section A2b

Mother replied that "no, my child does not have any fixed routines". Hence section A2b is not fulfilled.



Section A2c

Mother replied "no my child does not enjoy playing with toys, he loves its wheels". Hence we mark a response of "yes". Response of "yes" makes the section A2c fulfill the criteria.

Section A2d

Mother replied "no" to all sensory symptoms and nor did you observe any of abnormal sensory symptoms. Hence section A2d is not fulfilled.

. No. of criteria fulfilled in Al of the section A (Social Interaction a	nd communication)
0: Two or less	
1: Three	_ 1
2. No. of criteria fulfilled in A2 of the section A (restrictive and repe	titive)
0: Nil or one	1
1: Two or more	
3. Is there onset at early development?	
0: No	1
1: Yes	<u> </u>
4. Is there an impaired functioning?	
0: No	_ 1
1: Yes	
5. Interpretation of questionnaire (1 to 4)	
0: No ASD (If response to any of 1-4 is "0")	
1: ASD present (If response to 1-4 is "1")	
6. Total number of criteria fulfilled in A1 and A2 together	
0: Four or less	1
1: five or more	
7. Summary assessment of ASD	
0: No ASD (Response to 5 and 6 is "0")	
1: ASD (Response to 5 and 6 is "1" and 8 is "0")	1
8. Can these symptoms be solely explained by Intellectual Disability	?
0: No 1: Yes	0
9. Additional note and observation during the interview	
We observed delayed echolalia which was der	nied by mother
Name of the Assessor Signature of the Assessor	Date of assessment
Dr X	02.02.16

#### **Section B**

- 1. Number of criteria is 3 out of 3 as Section A1a, A1b, A1c all were fulfilled
- 2. Number of criteria in A2 is 2 out 4 as A2a, A2c were fulfilled.
- 3. Yes there is onset at early development (he is 3 years)
- 4. Yes, It has resulted in impaired functioning
- 5. Hence ASD is present as 3 out 3 in section A1 and atleast 2 out 4 in section A2 are fulfilled
- 6. Total number of criteria is 5 out of 7
- 7. Summary assessment: ASD present
- 8. No, these symptoms cannot be explained by Intellectual disability.
- 9. Additional comments: We observed delayed echolalia which was denied by mother.

## Example 2:

2 year boy brought with complaints of delayed speech and poor response to sound. He was born of non consanguineous marriage, third in birth order. He was born by normal delivery with birth weight of 3.2 Kg, cried immediately at birth, developed jaundice on day 2 of life requiring exchange transfusion, remained admitted for 10 days in NICU and then was discharged the next day. He subsequently was late in attainment of all milestones. He currently does not speak and respond to any amount of calling. A pediatrician suspected autism spectrum disorder and referred the case for evaluation.

Let us apply the AIIMS modified INDT ASD tool to see whether he fulfills the criteria for diagnosis of autism.

## Section A: AIIMS modified INDT ASD tool for autism spectrum disorder

Section A	Questions	Response	Number of response	Analysis
	Questions	response	in circle	7 11141 y 515
			(autistic symptom)	
Ala	Question i	Yes		Section A1a fulfills
	Question ii			
	Question iii	No		
	Question iv	No	Yes	
	Question v	Yes		
	Question vi			
	Question vii	Yes		
	Question			
	viii			
A1b	Question i	Yes		Section A1b does
	Question ii	Yes		not fulfill
	Question iii	Yes		
	Question iv	Yes		
Alc	Question i	Yes		Section A1c does
	Question ii			not fulfill
	Question iii			
A2a	Question i	No		Section A2a does
	Question ii	No		not fulfill
	Question iii			
	Question iv			
	Question v			
	Question vi	No		
	Question vii	No		
A2b	Question i	No		Section A2b does
				not fulfill
A2c	Question i	No		Section A2c does
				not fulfill
A2d	Question i	No		Section A2d does
	Question ii	No		not fulfill
	Question iii	No		
	Question iv	No		

## Section B AIIMS modified INDT ASD tool for autism spectrum disorder

Section B	Response	Analysis
Question 1	0	Only one out of three in
Question 2	0	section A1 and none in
Question 3	1	section A2 out of four
Question 4	1	fulfilled. Hence child does
Question 5	0	not have ASD.
Question 6	0	Final diagnosis: No autism
Question 7	0	spectrum disorder
Question 8	1	

## Example 3:

10 year old boy brought with complaints of inability to understand commands and delayed speech with difficulty in comprehending commands. He was born of non consanguineous marriage, third in birth order. He was born by normal delivery with birth weight of 3.2 Kg but did not cry at birth. He developed neonatal seizures and was subsequently admitted in NICU for 15 days. All his milestones were delayed with sitting achieved at 3 years, walking by 4.5 years. His present concerns are poor speech, into his own world, does not understand most of commands. A pediatrician suspected autism spectrum disorder and referred the case for evaluation. Let us apply the AIIMS modified INDT ASD tool to see whether he fulfills the criteria for diagnosis of autism.

## Section A: AIIMS modified INDT ASD tool for autism spectrum disorder

Section A	Questions	Response	Number of response in circle (autistic symptom)	Analysis
A1a	Question i	Yes		Section A1a fulfills
	Question ii	Yes		
	Question iii	Yes		
	Question iv	No	Yes	
	Question v	Yes		
	Question vi	Yes		
	Question vii	Yes		
	Question viii	No	Yes	
A1b	Question i	Yes		Section A1b fulfill
	Question ii	Yes		
	Question iii	No	Yes	
	Question iv	Yes		
A1c	Question i	Yes		Section A1c does
	Question ii	Yes		not fulfill
	Question iii	No		
A2a	Question i	No		Section A2a does
	Question ii	No		not fulfill
	Question iii	No		
	Question iv	No		
	Question v	No		
	Question vi	No		
	Question vii	No		
A2b	Question i	No		Section A2b does not fulfill
A2c	Question i	No		Section A2c does not fulfill
A2d	Question i	No		Section A2d does
	Question ii	No		not fulfill
	Question iii	No		
	Question iv	No		

## Section B AIIMS modified INDT ASD tool for autism spectrum disorder

Section B	Response	Analysis
Question 1	0	Only two out of three in
Question 2	0	section A1 and none in
Question 3	1	section A2 out of four
Question 4	1	fulfilled. Hence child does
Question 5	0	not have ASD.
Question 6	0	Final diagnosis: No autism
Question 7	0	spectrum disorder
Question 8	1	

## **Schemes of The National Trust**

## Disha – Early Intervention & School Readiness

#### **Scheme Description**

- Day care facility for children with NT disabilities in the age group of 0-10 years for at least 4-6 hours per day for a batch size 20
- Training and counseling to children and the parents to enable mainstreaming of children
- · Professional services by special educators, therapists and counselors
- · Availability of optional transport facility
- · Continuous evaluation of children and mapping of development chart
- · Assistance and guidance for admission to schools
- · KPIs monitored shall be PwD strength, LIG:Non LIG ratio, PwD development, PwD mainstreaming, Parent Counselling

Set-up	1,55,000	Immediately after enrolment
Sustenance	4,500 per Differential PwD per month	Monthly for 3 months (min. PwD is 20% of batch size, i.e. 4)
Monthly Recurring	4,500 per eligible PwD per month (+1000 Transport allowance)	Monthly on 1:1 ratio for LIG:Non LIG and All BPL

## Vikaas - Day Care

- Day care facility for PwD above 10 years of age for at least 6 hours in a day (between 8 am 6 pm) for a batch size 30
- Training and counseling to PwDs in the age group of 10+ years for enhancing interpersonal and vocational skills, besides mainstreaming
- Professional services by special educators, therapists and counselors
- · Availability of optional transport facility
- Enable family members to fulfill other responsibilities
- · Provision for setting up Work Centers
- · KPIs monitored shall be PwD strength, LIG:Non LIG ratio, PwD development, Gainful employment of PwD

Set-up	1,95,000	Immediately after enrolment
Sustenance	3,850 per Differential PwD per month	Monthly for 3 months (min. PwD is 20% of batch size, i.e. 6)
Monthly Recurring	3,850 per eligible PwD per month (+1000 Transport allowance)	Monthly on 1:1 ratio for LIG:Non LIG and All BPL
Work Centre	Rs. 25,000 to Rs. 1,00,000/-	Case to case basis

## **Samarth – Respite Care Residential Scheme**

#### Scheme Description·

- · Residential facilities including meals for orphans/abandoned, families in crises, destitute, BPL and LIG PwDs in all age groups for a batch size 30.
- · Provision to shift an adult resident to GHARAUNDA if stay in Samarth exceeds 5 years and PwD is an adult
- · Professional services by special educators, therapists and counsellors for age-specific vocational and pre-vocational activities
- RO should own the location or its should be on a lease of minimum 5 years with renewable clause
- · KPIs monitored shall be PwD strength, LIG:Non LIG ratio, PwD registration with Niramaya scheme, PwD development, Gainful employment of PwD, Inclusion events organized

Set-up	2,90,000	Immediately after enrolment
Sustenance	7,000 per Differential PwD per month	Monthly for 3 months (min. PwD is 20% of batch size, i.e. 6)
Monthly Recurring	7,000 per eligible PwD per month	Monthly on 1:1 ratio for LIG:Non LIG and All BPL
Work Centre	Rs. 25,000 to Rs. 1,00,000/-	Case to case basis

## **GHARAUNDA – Group Home for Adults**

- Residential facilities including meals and all other facilities for life long stay of adult PwDs (>18 years of age) for a batch size 20.
- · Professional services by special educators, therapists and counsellors for age-specific vocational and pre-vocational activities
- RO should own the location or its should be on a lease of minimum 10 years with renewable clause
- · Provision of crisis fund per Gharaunda Centre to be maintained with the National Trust INR 10,00,000/-
- · KPIs monitored shall be PwD strength, LIG:Non LIG ratio, PwD registration with Niramaya scheme, PwD development, Gainful employment of PwD, Inclusion events organized

Set-up	2,90,000	Immediately after enrolment
Monthly Recurring	10,000 per eligible PwD per month	Monthly on 1:1 ratio for LIG:Non LIG and All BPL
Crisis Fund	10,00,000/-	On need basis
Work Centre	Rs. 25,000 to Rs. 1,00,000/-	Case to case basis

## Niramaya – Health Insurance

#### **Scheme Description**

- · Health Insurance for PwDs under NT Act
- · Full premium to be paid by the National Trust
- · Benefits include surgery, hospitalization, OPD, medicines, dentistry, medical tests, therapies etc. up to Rs.1 Lakh
- No requirement of health check-up or age proof
- · No bar for government or private hospitals/practitioners
- · Enrollment on monthly basis through Registered Organizations (RO)
- · Facilitation through 34 regional claim centers
- · Annual enrolment fee for BPL Rs. 250/-, Non BPL Rs. 500/- and PwD with Legal Guardian (Other than natural parents) FREE.
- · KPIs monitored shall be: turnaround time for the application, Niramaya status report

Health Insurance 1,00,000 per PwD per year As and when PwD will claim
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## **Gyan Prabha – Education Support**

- Encourage PwDs to pursue vocational training/higher education/professional courses
- · Wide range of courses like medical, engineering, law, management and regular graduation and post graduation covered
- · No age or income limit for eligibility
- · Recurring fixed amount for the specified courses covering course fees, transportation, books, OPEs (max 10%) etc. on presenting proofs except OPE
- Funding shall be provided for maximum duration of course or till when course is completed by PwD as applicable
- · KPIs monitored shall be: turnaround time for the application, Gyan Prabha status report

Sustenance	5,200 per PwD per month	Depending on course structure:
Graduation/ Post Graduation	2,000 per PwD per month	Monthly, semester wise, trimester wise or annually.
Vocational Course	1,600 per PwD per month	Wise of dimiddify.
Transportation allowance (for any course)	20,000/- per PwD per annum or actuals, whichever is less	

## Sahyogi – Care Associate Training

#### **Scheme Description**·

- Creating a pool of skilled care associates through theoretical and on-the-job training to support PwDs and their families
- · Two types of courses Primary (3 months), Advanced (6 months) having both theory and internship
- · Parents and guardians are also eligible to apply for the courses. However, they shall not be involved in internship period of course
- Meeting(s) for placement amongst families, institutions and trained care associates on a quarterly basis
- · KPIs monitored shall be trainee strength, trainee attendance, internship opportunities, placement, RO visit status report

Set up Cost	1,00,000/- for both primary and advanced	On time on acceptance of proposal
Trainee Cost	Primary – 4,200 per trainee per batch Advanced – 8,000 per trainee per batch	On completion of training
Trainee Stipend	Primary – upto 5,000 per trainee per batch Advanced – upto 10,000 per trainee per batch *Stipend for all, including parents/ guardians of PwD	On completion of training

## **Prerna – Marketing Assistance**

- · Funding for participation in fairs and/or exhibitions at district, state, regional and national level
- · NT to sponsor up to four events in a financial year
- Minimum participation of 51% PwDs in production of saleable items/articles
- · An incentive of 10% for RO on sales turnover verified by Office of DC/DM/LLC/Social Welfare
- NT shall also reimburse the expenses that ROs incurred in designing and publishing brochures marketing the products prepared by PwDs
- · KPIs monitored shall be: Event participation and Growth rate of PwD supported

Support for participation in events	National Level – INR 30,000/- Regional Level (participation of min 5 states) - INR 25,000/- State Level - INR 20,000/- District Level - INR	50% on approval of event proposal 50% on completion of event
Incentive on Sales Turnover	10,000/- 10% of total sales	Annually
Reimbursement for brochures	10,000 per RO per year	Annually

#### Sambhay – Aids and Assistive Devices

#### **Scheme Description**

- · Additional centres to be set up in cities of India with population of more than 5 million (as per 2011 Census)
- · Demonstration of aids, assistive devices, software & an accessible model of Kitchen, Living Room & Bathroom etc. for enabling and empowering the PwDs
- · Management coordinator at these Sambhav centres shall be deployed by NT
- · ROs to provide one demonstrator/facilitator and one maintenance staff
- · Sambhav centre can procure new aids/ assistive devices and same shall be reimbursed by NT within maximum limit allowed
- · KPIs monitored shall be: increased no. of visitors, organizing visits to the centre (for ROs, educational institute and Medical institute)

Set up Cost	10,00,000/- (Stage I – 5,00,000 and Stage II – 5,00,000)	Stage I – on approval of application Stage II – On completion of setup period
Monthly Recurring Cost	40,000/- per month	To be paid bi-annually
Reimbursement for new devices	On actuals with maximum limit of INR 3,20,000/- per annum	Annually

## **Badhte Kadam – Awareness & Community**

- · Awareness generation for general public and community stakeholders through various activities for example exhibition, rallies, workshops, media outreach etc.
- · Innovative/special proposals to be sanctioned separately
- · Create platforms for collaborative initiatives between govt. officials, medical fraternity, legal professionals & educational institutes for the betterment of PwDs
- · Outreach activities in areas where NT is under represented
- · Maximize benefits of NT schemes
- · KPIs monitored shall be: activities completed, enabling changes in society and gathering feedback

Distributing Handouts, posters etc. at Educational/ financial/ medical institutes	20,000/-	Workshops with govt officials, legal/ medical/ bank/educational professionals	17,000/-
Sessions with voluntary organizations like CRY or MAD	15,000/-	Social inclusion event like cricket match	16,000/-
Organize Roadshows	13,000/- per day	Sessions in schools/ colleges/ other educational institute	8,000/-

