

Neuro-developmental Disabilities Among Children in India: An INCLIN Study

<p>7. Did your child have these symptoms before three years? क्या आपका बच्चे के यह लक्षण तीन साल की उम्र से पहले शुरू हुए थे ? <input type="checkbox"/></p> <p>0:No 1:Yes/Do not know/ Not sure</p>
<p>8. Does the child fulfill <u>all</u> the following criteria for diagnosis of Rett's Disorder?</p> <ul style="list-style-type: none"> ● Female Child ● Loss of purposeful hand skills between 5-30 months age and development of stereotyped hand wringing, hand washing or hand to mouthing movements ● Loss of social engagement early in course during 9-29 months (although often social interaction develops later) ● Severely impaired expressive and receptive language development with severe psychomotor retardation <input type="checkbox"/> <p>0: No 1: Yes</p>
<p>9. Does the child fulfill <u>all</u> the following criteria for diagnosis of Childhood Disintegrative Disorder?</p> <ul style="list-style-type: none"> ● Normal development till 2 years age, by the presence of age appropriate verbal and nonverbal communication, social relationships, play and adaptive behavior ● After 2 years of age, loss of previously acquired milestones (before age 10 years) in 2 or more of the following areas (Tick (✓) the areas in which milestones are lost) <ul style="list-style-type: none"> - Expressive/receptive language - Social skills/Adaptive behavior - Bowel or bladder control - Play skills - Motor skills ● Abnormalities of functioning in at least two of the following areas: <ul style="list-style-type: none"> - Qualitative impairment in social interaction - Qualitative impairment in communication - Restricted, repetitive and stereotyped patterns of behavior <input type="checkbox"/> <p>1: No 1: Yes</p>
<p>10. There is no clinically significant delay in any of the following?</p> <ul style="list-style-type: none"> ● Language development (single words used by age 2 years, communicative phrase used by age 3 years (अपनी उम्र के हिसाब से बोलना शुरू किया था (दो साल तक शब्द बोलना और तीन साल तक दो या तीन शब्द के वाक्य बोलना। ● Cognitive Development OR Development of age-appropriate self-help skills मानसिक विकास या अपनी देखभाल करने की क्षमता ● Adaptive behavior (Other than in social interaction) <input type="checkbox"/> <p>0:No 1: Yes</p>
<p>11. Summary assessment of ASD</p> <p>0: No ASD (Response to 4 is "0")</p> <p>1: Autism (Response to ALL of 1 to 7 is "1" and 8,9 is "0") <input type="checkbox"/></p> <p>2: Asperger's Disorder (Response to 4 is "1", 6D is "1" and 10 is "1")</p> <p>3: PDD-NOS (Response to 4 is "1" and either 5 or 7 or both is "0")</p> <p>4: Rett's Disorder (Response to 4 is "1" and 8 is "1")</p> <p>5: CDD (Response to 4 is "1" and 9 is "1")</p> <p>9: Indeterminate (Criteria not fulfilled, too many unsure responses, could not be tested in appropriate condition)</p>

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12. Can these symptoms be solely explained by Intellectual Disability?		
0: No 1: Yes <input type="checkbox"/>		
If yes, refer to TAG review		
13. Additional note and observation during the interview		
Name of the Assessor	Signature of the Assessor	Date of assessment

**AIIMS Modified INDT-ASD Diagnostic Evaluation
for Autism Spectrum Disorder**

AIIMS Modified INDT-ASD Diagnostic Evaluation for ASD

Section	Ask	Observe	Yes	No	Unsure
A1a Social emotional reciprocity	<p>i) * For children aged less than 4 years: Does/did your child ever point with his/her index finger to bring your attention to show the things that interest him/her? <i>E.g. kite, plane flying in the sky, cow/dog on the road etc.</i></p> <p>For children aged 4 years or more: Does your child usually bring things to show you on his/her own he/she has made painted or new toy/gift?</p>	Observe how the child draws attention toward a toy/object of interest; Look for coordinated pointing		<input type="radio"/>	
	<p>ii) * For children aged 4 years or more, and are able to speak : Does your child talk to you about things he/she likes or has achieved without being asked about them?</p>			<input type="radio"/>	
	<p>iii) * Does your child usually prefer to play alone and gets irritated/moves away when his/her sibs or</p>	Quality of play activity in a group of children or with siblings	<input type="radio"/>		

	other kids try to play with him/her?				
	iv) * Does your child play games involving turn taking or rule based with other children properly ? <i>E.g. Cricket, Hide and seek/I-spy, Ludo, Stapoo, Ring a- ring roses etc.</i>	Quality of child's involvement in rule-based games or games involving taking turns		<input type="radio"/>	
	v) * Does your child usually share his/her happiness with you or come to you for comfort when hurt or upset?	Sharing happiness or distress with the parents		<input type="radio"/>	
	vi) * For children aged 4 years or more: Does your child usually share your happiness or try to comfort you when you are upset / sad?	Sharing of parent's happiness or distress by the child		<input type="radio"/>	
	vii) * Does your child initiate a conversation with you?	Quality of child's conversation with parents or yourself		<input type="radio"/>	
	viii)* For children aged 4 years or more: Can you have conversation with your child during which he/she not only answers your questions, but also adds something new to continue the	Quality of child's conversation with parents or yourself		<input type="radio"/>	

	conversation?				
Section A1b Non verbal communication	i) *For children aged less than 4 years: 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?	In children below 4 years age: Response to being touched and cuddled by parent: enjoys/tolerates/squirms/ stiffens/ gets upset/ Indifferent		<input type="radio"/>	
	ii) Does your child usually make eye contact with you or other people? <i>E.g. While playing, asking for things, talking to you.</i>	* Quality of eye contact		<input type="radio"/>	
	iii) * Does your child usually use various gestures appropriately during social interactions? <i>E.g. Namaste, Salaam, waving bye-bye, hello, touching feet etc. (At least sometimes spontaneously) (use appropriate example as required)</i>	Use of these gestures in response to your greeting and while departing		<input type="radio"/>	
	iv) Does your child usually show appropriate facial expressions according	*Appropriateness of facial expressions while interacting with parents, with you (stranger), while		<input type="radio"/>	

	to the situation? <i>E.g. being happy, sad, afraid etc.</i>	playing, when given toy/favorite food or when scolded.			
Section A1c Relationships	i) * Does your child usually enjoy the company of other children?	Child's interaction with other children		<input type="radio"/>	
	ii) * <i>For children aged 4 years or more:</i> Does your child have friends of his/her age (In school and neighborhood) with whom he/she loves to chat, share food or play together?	Quality of child's interaction with other children of his/her age		<input type="radio"/>	
	iii) * <i>For children aged 4 years or more:</i> Does your child play mostly with children who are much older or much younger than him/her?	Quality of child's interaction with other children	<input type="radio"/>		
Section A2a Stereotyped movement or speech	i) Does your child usually repeat words or phrases regardless of meaning (in part or whole) that he/she has heard? <i>E.g. If you say 'toffee' he will also say 'toffee' if you say 'come' he will also say 'come' and if you ask "what is your</i>	* Immediate echolalia (words or phrases)	<input type="radio"/>		

	<i>name". he/she also says "what is your name".</i>				
	ii) Does he/she incessantly repeat things/T.V serial dialogue regardless of meaning/ context, whatever he/she has heard later on ?	* Delayed echolalia	<input type="radio"/>		
	iii) <i>For children aged 4 years or more:</i> Does your child usually use "I for me" and "me for you" incorrectly? <i>E.g., when you ask "do you want milk?" he/she says "yes, you want milk" or "Rohit wants milk" (referring to him self).</i>	* Pronoun reversal	<input type="radio"/>		
	iv) <i>For children aged 4 years or more:</i> During conversation does your child often speak 'out of context' or irrelevantly?	Out-of-context speech and neologisms	<input type="radio"/>		
	v) * <i>For children aged 6 years or more:</i> Does your child understand that somebody is making fun of him/her or can he/she understands jokes?	Child's response to an age appropriate joke	<input type="radio"/>		
	vi) Does your child keep on repeating any of	* Any type of motor stereotypes, unusual	<input type="radio"/>		

	<p>the followings, like</p> <ul style="list-style-type: none"> ● flapping hands, ● hand wringing, ● toe-walking, ● rocking or spinning, ● making unusual finger or hand movements near his/her face? 	finger/hand movements near face			
	<p>vii) * Does your child have inappropriate fascination with movement? <i>E.g. spinning wheels, opening and closing of doors, electric fan, running water and any other revolving object etc.</i></p>	Child's inappropriate fascination with objects in motion	<input type="radio"/>		
Section A2b Routines	<p>Does your child unreasonably insist on doing things in a particular way and/or become upset if there is any change in the daily routine? <i>E.g., Taking exactly the same route to the school or market, insisting on food being served in the same pattern or sequence etc.</i></p>	Child's insistence on any unusual routines or rituals	<input type="radio"/>		

Section A2c Fixed interest	Does your child prefer to play with a particular part of a toy/object rather than the whole toy/object? E.g. wheels of a toy rather than the whole toy And/Or Persistent unusual preoccupation with inanimate objects? E.g. Toffee wrappes, threads, bits of papers, flowing water And/Or Persistent behavioural attributes? E.g. Liking particular sound/visual stimuli, any particular color or form of cloth	* Quality of child's play with different toys and objects	<input type="radio"/>		
Section A2d Sensory symptoms	i) Is your child indifferent to pain or temperature?	Apparent indifference to pain or temperature	<input type="radio"/>		
	ii) Does your child show excess reaction to specific sound or texture	Getting irritated with certain specific sounds or texture of certain clothes	<input type="radio"/>		
	iii) Does your child have excessive smelling?	Excessive smelling of hands or arms	<input type="radio"/>		
	iv) Does your child have excessive touching of objects?	Excessive touching objects in the room	<input type="radio"/>		

SECTION B Complete this section (1-2) based on responses from section A

1. No. of criteria fulfilled in A1 of the section A (Social Interaction and communication)		
0: Two or less		<input type="checkbox"/>
1: Three		<input type="checkbox"/>
2. No. of criteria fulfilled in A2 of the section A (restrictive and repetitive)		
0: Nil or one		<input type="checkbox"/>
1: Two or more		<input type="checkbox"/>
3. Is there onset at early development?		
0: No		<input type="checkbox"/>
1: Yes		<input type="checkbox"/>
4. Is there an impaired functioning?		
0: No		<input type="checkbox"/>
1: Yes		<input type="checkbox"/>
5. Interpretation of questionnaire (1 to 4)		
0: No ASD (If response to any of 1-4 is "0")		<input type="checkbox"/>
1: ASD present (If response to 1-4 is "1")		<input type="checkbox"/>
6. Total number of criteria fulfilled in A1 and A2 together		
0: Four or less		<input type="checkbox"/>
1: Fives or more		<input type="checkbox"/>
7. Summary assessment of ASD		
0: No ASD (Response to 5 and 6 is "0")		<input type="checkbox"/>
1: ASD (Response to 5 and 6 is "1" and 8 is "0")		<input type="checkbox"/>
8. Can these symptoms be solely explained by Intellectual Disability?		
0: No		<input type="checkbox"/>
1: Yes		<input type="checkbox"/>
9. Additional note and observation during the interview		
Name of the Assessor	Signature of the Assessor	Date of assessment



APPENDIX- XII

INDIAN SCALE FOR ASSESSMENT OF AUTISM

Name of the child: Gender: Date:

D.O.B: Age: Examiner:

Directions:

Below are given 40 statements which are divided under six domains, please tick (✓) mark the appropriate rating for each item of the scale by observing the child and by interviewing the parents in order to assess Autism

Items	Rarely Upto 20% Score 1	Sometimes 21 – 40 % Score 2	Frequently 41 – 60% Score 3	Mostly 61- 80 % Score 4	Always 81-100% Score 5
I. SOCIAL RELATIONSHIP AND RECIPROCTY					
1	Has poor eye contact				
2	Lacks social smile				
3	Remains aloof				
4	Does not reach out to others				
5	Unable to relate to people				
6	Unable to respond to social/ environmental cues				
7	Engages in solitary and repetitive play activities				
8	Unable to take turns in social interaction				
9	Does not maintain peer relationships				
II. EMOTIONAL RESPONSIVENESS					
10	Shows inappropriate emotional response				
11	Shows exaggerated emotions				
12	Engages in self-stimulating emotions				
13	Lacks fear of danger				
14	Excited or agitated for no apparent reason				
III. SPEECH-LANGUAGE AND COMMUNICATION					
15	Acquired speech and lost it				
16	Has difficulty in using non-verbal language or gestures to communicate				
17	Engages in stereotyped and repetitive use of language				
18	Engages in echolalic speech				
19	Produces infantile squeals/ unusual noises				
20	Unable to initiate or sustain conversation with others				

	Items	Rarely Upto 20% Score 1	Sometimes 21 – 40 % Score 2	Frequently 41 – 60% Score 3	Mostly 61- 80 % Score 4	Always 81-100% Score 5
21	Uses jargon or meaningless words					
22	Uses pronoun reversals					
23	Unable to grasp pragmatics of communication (real meaning)					
IV. BEHAVIOUR PATTERNS						
24	Engages in stereotyped and repetitive motor mannerisms					
25	Shows attachment to inanimate objects					
26	Shows hyperactivity/ restlessness					
27	Exhibits aggressive behavior					
28	Throws temper tantrums					
29	Engages in self-injurious behavior					
30	Insists on sameness					
V. SENSORY ASPECTS						
31	Unusually sensitive to sensory stimuli					
32	Stares into space for long periods of time					
33	Has difficulty in tracking objects					
34	Has unusual vision					
35	Insensitive to pain					
36	Responds to objects/people unusually by smelling, touching or tasting					
VI. COGNITIVE COMPONENT						
37	Inconsistent attention and concentration					
38	Shows delay in responding					
39	Has unusual memory of some kind					
40	Has 'savant' ability					

Classification	No autism <70	Mild autism 70-106	Moderate autism 107-153	Severe autism >153
Total score				

APPENDIX- XIII

IDEAS

(INDIAN DISABILITY AND ASSESSMENT SCALE) A scale for measuring and quantifying disability in mental disorders

The Persons with disability act 1995 includes mental illness as disability. The persons with mental illness are eligible to avail all the benefits under the persons with disability act 1995. The disabled people need disability certificate showing more than 40% disability from the competent authority to avail the benefits. The disability act covers seven disabilities

1. Blind
2. Low vision
3. Deaf and Dumb
4. Leprosy cured
5. Mentally retarded
6. Orthopedic handicap
7. Mental illness

The assessment tools have already been existed for the visually impaired, hearing impaired and orthopedic handicap and persons with mental retardation. These people are certified by the authentic body and become eligible by having disability certificates to avail the benefits under the PWD Act 1995. But there was no assessment tools for the certification of mentally ill people and yet these people are not availed any benefits even as disabled. Looking that perspective and to justify these people rehabilitation committee of Indian Psychiatric Society has developed the assessment tool for disability certification in 2002. This tool is known as Indian Disability Evaluation and Assessment Scale in short IDEAS. This IDEA has opened new horizon for mentally ill people. This committee has developed clear guideline to make use of it very easy.

General Guidelines:

Ø IDEAS are suited best for the purpose of measuring and certifying Disability.

Ø It is therefore a brief and simple instrument, which can be used, even in busy clinical settings.

Ø Some training is required in the use of IDEAS.

Ø This is to be used only on out patients and those living in the community. Not appropriate for in-patients.

Ø Rating should be done only based on interviews of the Primary Care Givers. Case records and patients interviews can be used to supplement information.

Ø Only in rare instances when no primary care giver is available should be the rating is based only on patient interview. This should then be documented.

ØThe gender specification “he” has been used for convenience and refers to both genders.

ØProbe questions help to guide one through the interview and to help identify dysfunction in one or more activities. Diagnostic Categories:

Patients with only the following diagnosis as per ICD or DSM criteria are eligible for disability benefits:

ØSchizophrenia

ØBipolar Disorder

ØDementia

ØObsessive Compulsive Disorder

Duration of illness: the total duration of illness should be least two years. For the purpose of scoring, the number of months the patients was symptomatic in the last two years (MI 2Y – months of illness in the last two years) should be determined.

Who does the assessment?

Only the Psychiatrist can do diagnosis and certification. Trained social workers, psychologist, or occupational therapists can do administration of **IDEAS**

Frequency of Re-certification

Psychiatric Disability will be reassessed every two years and re-certified. The feasibility of doing this in the rural areas will however have to be examined.

Items:

- I. Self care : Includes taking care of body hygiene, grooming, health including bathing, toileting, eating and taking care of one’s health.
- II. Interpersonal Activities (Social Relationship) : Includes initiating and maintaining interactions with others in a contextual and socially appropriate manner.
- III. Communication and Understanding : Includes communication and conversation with others by producing and comprehending spoken/ written/ nonverbal messages.
- IV. Work: Three areas are Employment/ House work/ Education measures any one aspect.

1. Performing in Work/ Job : Performing in work / employment (paid) employment /self employment family concern or otherwise. Measures ability to perform tasks at employment completely and efficiently and in proper time. Includes seeking employment.
2. Performing in Housework: Maintaining household including cooking, caring for other people at home, taking care of belongings etc. Measures ability to take responsibility for and perform household tasks completely and efficiently and in proper time.
3. Performing in school/ college: measures performance in education related tasks.

Scores for Each Item:

0 – No Disability

1 – Mild Disability

2 – Moderate Disability

3 – Severe Disability

4 – Profound Disability

Total Score (range 0-20)

Add scores of the 4 items and obtain total score

MI 2y months of illness in the last two years. Interview with informant and case notes if available should be used to determine for how many months in the last two years the patients exhibited symptoms(range 1-4)

MI 2 Years < 6 months: score to be added is 1

7-12 months: add 2

13-18 months : add 3

> 18 months : add 4

Global Disability

Total disability score + MI 2Y score = Global Disability Score (range 120)

Percentage:

For the purpose of welfare benefits, 40% will be cut off point. The scores above 40% have been categorized as Moderate, Severe, and profound based on the Global disability score. This grading will be used to measures change overtime

Score of 0- No disability = 0%

1-7 – Mild Disability = <40%

8 and above = > 40%

(8-13 moderate disability; 14-19 Severe Disability; 20 Profound Disability)

Source and Courtesy:<http://www.bpaindia.org/ENApril-June06.htm>

APPENDIX- XIV

Rater: _____ date: _____ patient: _____

Scale for the assessment and rating of ataxia (SARA)

<p>1) Gait Proband is asked (1) to walk at a safe distance parallel to a wall including a half-turn (turn around to face the opposite direction of gait) and (2) to walk in tandem (heels to toes) without support.</p> <p>0 Normal, no difficulties in walking, turning and walking tandem (up to one misstep allowed)</p> <p>1 Slight difficulties, only visible when walking 10 consecutive steps in tandem</p> <p>2 Clearly abnormal, tandem walking >10 steps not possible</p> <p>3 Considerable staggering, difficulties in half-turn, but without support</p> <p>4 Marked staggering, intermittent support of the wall required</p> <p>5 Severe staggering, permanent support of one stick or light support by one arm required</p> <p>6 Walking > 10 m only with strong support (two special sticks or stroller or accompanying person)</p> <p>7 Walking < 10 m only with strong support (two special sticks or stroller or accompanying person)</p> <p>8 Unable to walk, even supported</p>	<p>2) Stance Proband is asked to stand (1) in natural position, (2) with feet together in parallel (big toes touching each other) and (3) in tandem (both feet on one line, no space between heel and toe). Proband does not wear shoes, eyes are open. For each condition, three trials are allowed. Best trial is rated.</p> <p>0 Normal, able to stand in tandem for > 10 s</p> <p>1 Able to stand with feet together without sway, but not in tandem for > 10s</p> <p>2 Able to stand with feet together for > 10 s, but only with sway</p> <p>3 Able to stand for > 10 s without support in natural position, but not with feet together</p> <p>4 Able to stand for >10 s in natural position only with intermittent support</p> <p>5 Able to stand >10 s in natural position only with constant support of one arm</p> <p>6 Unable to stand for >10 s even with constant support of one arm</p>
Score	Score

3) Sitting Proband is asked to sit on an examination bed without support of feet, eyes open and arms outstretched to the front. Normal, no difficulties sitting >10 sec Slight difficulties, intermittent sway Constant sway, but able to sit > 10 s without support Able to sit for > 10 s only with intermittent support Unable to sit for >10 s without continuous support		4) Speech disturbance Speech is assessed during normal conversation. Normal Suggestion of speech disturbance Impaired speech, but easy to understand Occasional words difficult to understand Many words difficult to understand Only single words understandable Speech unintelligible / anarthria	
Score		Score	

1

Rater: _____ date: _____ patient: _____

5) Finger chase Rated separately for each side Proband sits comfortably. If necessary, support of feet and trunk is allowed. Examiner sits in front of proband and performs 5 consecutive sudden and fast pointing movements in unpredictable directions in a frontal plane, at about 50 % of proband's reach. Movements have an amplitude of 30 cm and a frequency of 1 movement every 2 s. Proband is asked to follow the movements with his index finger, as fast and precisely as possible. Average performance of last 3 movements is rated. No dysmetria Dysmetria, under/ overshooting target <5 cm Dysmetria, under/ overshooting target < 15 cm Dysmetria, under/ overshooting target > 15 cm Unable to perform 5 pointing movements			6) Nose-finger test Rated separately for each side Proband sits comfortably. If necessary, support of feet and trunk is allowed. Proband is asked to point repeatedly with his index finger from his nose to examiner's finger which is in front of the proband at about 90 % of proband's reach. Movements are performed at moderate speed. Average performance of movements is rated according to the amplitude of the kinetic tremor. No tremor Tremor with an amplitude < 2 cm Tremor with an amplitude < 5 cm Tremor with an amplitude > 5 cm Unable to perform 5 pointing movements		
Score	Right	Left	Score	Right	Left
mean of both sides (R+L)/2			mean of both sides (R+L)/2		

<p>7) Fast alternating hand movements Rated separately for each side Proband sits comfortably. If necessary, support of feet and trunk is allowed. Proband is asked to perform 10 cycles of repetitive alternation of pro- and supinations of the hand on his/her thigh as fast and as precise as possible. Movement is demonstrated by examiner at a speed of approx. 10 cycles within 7 s. Exact times for movement execution have to be taken.</p> <p>0 Normal, no irregularities (performs <10s) 1 Slightly irregular (performs <10s) 2 Clearly irregular, single movements difficult to distinguish or relevant interruptions, but performs <10s 3 Very irregular, single movements difficult to distinguish or relevant interruptions, performs >10s 4 Unable to complete 10 cycles</p>			<p>8) Heel-shin slide Rated separately for each side Proband lies on examination bed, without sight of his legs. Proband is asked to lift one leg, point with the heel to the opposite knee, slide down along the shin to the ankle, and lay the leg back on the examination bed. The task is performed 3 times. Slide-down movements should be performed within 1 s. If proband slides down without contact to shin in all three trials, rate 4.</p> <p>Normal Slightly abnormal, contact to shin maintained 2 Clearly abnormal, goes off shin up to 3 times during 3 cycles 3 Severely abnormal, goes off shin 4 or more times during 3 cycles 4 Unable to perform the task</p>		
Score	Right	Left	Score	Right	Left
mean of both sides (R+L)/2			mean of both sides (R+L) / 2		

APPENDIX- XV

Stage	Hoehn and Yahr Scale	Modified Hoehn and Yahr Scale
1	Unilateral involvement only usually with minimal or no functional disability	Unilateral involvement only
1.5	-	Unilateral and axial involvement
2	Bilateral or midline involvement without impairment of balance	Bilateral involvement without impairment of balance
2.5	-	Mild bilateral disease with recovery on pull test
3	Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent	Mild to moderate bilateral disease; some postural instability; physically independent
4	Severely disabling disease; still able to walk or stand unassisted	Severe disability; still able to walk or stand unassisted
5	Confinement to bed or wheelchair unless aided	Wheelchair bound or bedridden unless aided

APPENDIX- XVI

ALS Functional Rating Scale Revised (ALS-FRS-R)

Date:.....Name patient:.....Date
of Birth:..... Patient's
number.....Right-/left-
handed

Item 1: SPEECH

- 4 Normal speech process
3 Detectable speech disturbance
2 Intelligible with repeating
1 Speech combined with non-vocal communication
0 Loss of useful speech

Item 2: SALIVATION

- 4 Normal
3 Slight but definite excess of saliva in mouth; may have nighttime drooling
2 Moderately excessive saliva; may have minimal drooling (during the day)
1 Marked excess of saliva with some drooling
0 Marked drooling; requires constant tissue or handkerchief

Item 3: SWALLOWING

- 4 Normal eating habits
3 Early eating problems – occasional choking
2 Dietary consistency changes
1 Needs supplement tube feeding
0 NPO (exclusively parenteral or enteral feeding)

Item 4: HANDWRITING

- 4 Normal
3 Slow or sloppy; all words are legible
2 Not all words are legible
1 Able to grip pen, but unable to write
0 Unable to grip pen

Item 5a: CUTTING FOOD AND HANDLING UTENSILS

Patients without gastrostomy Use 5b if >50% is through g-tube

- 4 Normal
3 Somewhat slow and clumsy, but no help needed
2 Can cut most foods (>50%), although slow and clumsy; some help needed
1 Food must be cut by someone, but can still feed slowly
0 Needs to be fed

Item 5b: CUTTING FOOD AND HANDLING UTENSILS

Patients with gastrostomy 5b option is used if the patient has a gastrostomy and only if it is the primary method (more than 50%) of eating .

- 4 Normal
3 Clumsy, but able to perform all manipulations independently
2 Some help needed with closures and fasteners

- 1 Provides minimal assistance to caregiver
 0 Unable to perform any aspect of task

ALS Functional Rating Scale Revised (ALS-FRS-R). Version: May 2015

Item 6: DRESSING AND HYGIENE

- 4 Normal function
 3 Independent and complete self-care with effort or decreased efficiency
 2 Intermittent assistance or substitute methods
 1 Needs attendant for self-care
 0 Total dependence

Item 7: TURNING IN BED AND ADJUSTING BED CLOTHES

- 4 Normal function
 3 Somewhat slow and clumsy, but no help needed
 2 Can turn alone, or adjust sheets, but with great difficulty
 1 Can initiate, but not turn or adjust sheets alone
 0 Helpless

Item 8: WALKING

- 4 Normal
 3 Early ambulation difficulties
 2 Walks with assistance
 1 Non-ambulatory functional movement
 0 No purposeful leg movement

Item 9: CLIMBING STAIRS

- 4 Normal
 3 Slow
 2 Mild unsteadiness or fatigue
 1 Needs assistance
 0 Cannot do

Item 10: DYSPNEA

- 4 None
 3 Occurs when walking
 2 Occurs with one or more of the following: eating, bathing, dressing (ADL)
 1 Occurs at rest: difficulty breathing when either sitting or lying
 0 Significant difficulty: considering using mechanical respiratory support

Item 11: ORTHOPNEA

- 4 None
 3 Some difficulty sleeping at night due to shortness of breath, does not routinely use more than two pillows
 2 Needs extra pillows in order to sleep (more than two)
 1 Can only sleep sitting up
 0 Unable to sleep without mechanical assistance

Item 12: RESPIRATORY INSUFFICIENCY

- 4 None
 3 Intermittent use of BiPAP
 2 Continuous use of BiPAP during the night
 1 Continuous use of BiPAP during day & night
 0 Invasive mechanical ventilation by intubation or tracheostomy

Interviewer's

name.....

.....

ALS Functional Rating Scale Revised (ALS-FRS-R), Version: May 2015

APPENDIX- XVII

The New York Heart Association (NYHA) Functional Classification is a system used to classify extent of disease for patients with heart disease.

How to complete the NYHA Functional Classification

1. Nurses and physicians may complete the NYHA Functional Classification.
2. Review NYHA Functional Classification form.
3. Review medical record to assess presence and extent of cardiac disease, signs and symptoms.
4. During assessment, observe the patient's subtle dependencies and interactions within the existing support networks.
5. Interview patient and/or family to obtain information regarding symptom occurrence, functionality and comfort level using questions below.

Questions that may be useful in assessing patients include

1. Are there any limitations of physical activity? How much? What activities are limited?
2. Is there any discomfort at rest?
3. Does physical activity cause any symptoms such as fatigue, palpitation, dyspnea, or anginal pain?

4. How much activity is required to cause symptoms? Normal activity for age, less than ordinary activity, minimal activity, no activity at all

NYHA Classification - The Stages of Heart Failure:

Class I - No symptoms and no limitation in ordinary physical activity, e.g. shortness of breath when walking, climbing stairs etc.

Class II - Mild symptoms (mild shortness of breath and/or angina) and slight limitation during ordinary activity.

Class III - Marked limitation in activity due to symptoms, even during less-than-ordinary activity, e.g. walking short distances (20100 m). Comfortable only at rest.

Class IV - Severe limitations. Experiences symptoms even while at rest. Mostly bedbound patients.

APPENDIX- XVIII

CTP calculation

- Encephalopathy: None = 1 point, Grade 1 and 2 = 2 points, Grade 3 and 4 = 3 points
- Ascites: None = 1 point, slight = 2 points, moderate = 3 points
- Bilirubin: under 2 mg/ml = 1 point, 2 to 3 mg/ml = 2 points, over 3 mg/ml = 3 points
- Albumin: greater than 3.5mg/ml = 1 point, 2.8 to 3.5mg/ml = 2 points, less than 2.8mg/ml = 3 points
- Prothrombin Time* (sec prolonged): less than 4 sec = 1 point, 4 to 6 sec = 2 points, over 6 sec = 3 points

*Frequently INR will be used as a substitute for PT, with INR under 1.7 = 1 point, INR 1.7 to 2.2 = 2 points, INR above 2.2 = 3 points

The severity of cirrhosis:

- Child-Pugh A: 5 to 6 points
- Child-Pugh B: 7 to 9 points
- Child-Pugh C: 10 to 15 points
-

APPENDIX- XIX

EGFR calculator

Glomerular filtration rate (GFR) is the best overall index of kidney function. Normal GFR varies according to age, sex, and body size, and declines with age. The National Kidney Foundation recommends using the CKD-EPI Creatinine Equation (2021) to estimate GFR.

https://www.kidney.org/professionals/kdoqi/gfr_calculator

The formula required standardized assays for creatinine. Cystatin value is more specific but egfr calculation will be based on creatinine in present guidelines.

For person less than 18 years , a pediatricgfr calculator is to be used

https://www.kidney.org/professionals/kdoqi/gfr_calculatorPed

- If values for cystatin C and/or BUN are not entered, the calculator will generate GFR estimates using the creatinine-based “Bedside Schwartz” equation only (currently considered the best method for estimating GFR in children).

APPENDIX- XX

Pain Disability Questionnaire (PDQ)

The Pain Disability Questionnaire (PDQ) is a psychometric evaluation measure of functional status in patients with chronic pain. It co-relates with physical and psychological human function (pain intensity, depression) and work disability.

The pain Disability Questionnaire is a measure of functional status and focuses on disability, function, and psychosocial variables. This tool has excellent psychometric properties and consistently demonstrates strong correlations to various physical and psychosocial measures.

Pain Disability Questionnaire (PDQ) is determined by independent ratings, on a 10-point scale (from 0 =poor relevance to 10 = excellent relevance) (table I).

Then the total points calculated in Table I are converted to disability percentages as shown in Table II. Both tables are provided.

Table I: Pain Disability Questionnaire (PDQ)

Table I: Pain Disability Questionnaire (PDQ)					
	PDQ questions	Score options depending on limitation of activities.			Patient PDQ actual points
1	Does your pain interfere with your normal work inside and outside home?	0 (work normally)	1-9	10 (Unable to work at all)	
2	Does your pain interfere with personal care (such as washing, dressing)	0 (Take care of myself completely)	1-9	10 (need help with all my personal care)	
3	Does your pain interfere with your traveling?	0 (travel anywhere I like)	1-9	10 (only travel to see doctors)	

4	Does your pain affect your ability to sit or stand?	0 (no problems)	1-9	10 (Cannot sit/stand at all)	
5	Does your pain affect your ability to lift overhead, grasp objects, or reach for things	0 (no problems)	1-9	10 (Cannot do at all)	
6	Does your pain affect your ability to lift objects off the floor, bend, stoop or squat	0 (no problems)	1-9	10 (Cannot do at all)	
7	Does your pain affect your ability to walk or run	0 (No problems)	1-9	10 (Cannot walk)	
8	Has your income declined since your pain began?	0 (No decline)	1-9	10 (Lost all income)	
9	Do you have to take pain medication everyday to control your pain?	0 (No medication needed)	1-9	10 (On pain medication throughout the day)	
10	Does your pain force you to see doctors much more than before your pain began?	0 (Never see doctors)	1-9	10 (See doctors weekly)	
11	Does your pain interfere with your ability to see the people who are important to you as much as you would like?	0 (No problem)	1-9	10 (Never see them)	
12	Does your pain interfere with recreational activities or hobbies that are important to you?	0 (No interference)	1-9	10 (total interference)	
13	Do you need the help of your family and friends to complete everyday tasks (including home and work) because of your pain?	0 (Never need help)	1-9	10 (Need help all the time)	
14	Do you now feel more depressed, tense, or anxious than before your pain began?	0 (No depression/tension)	1-9	10 (Severe depression/anxiety)	
15	Are there emotional problems caused by your pain that interfere with your family, social, and or work activities?	0 (No problems)	1-9	10 (severe problems)	

	Total PDQ score	
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If patient gets 5 or more points in any domain, they will need documentation with supporting documents records. Supporting documentation-Doctor's prescription for pain medicine or hospital admission records, or +/-school or work absenteeism records etc. Imaging if available.

Points total of PDQ

No pain = 0-10

Mild pain = 11-70

Moderate pain = 71-100

Severe pain = 101-130

Extreme pain = 131-15

The conversion of Pain disability questionnaire score to disability grading is given in Table II below.

Table II			
Conversion of Pain disability questionnaire points to the disability score			
	See the total points arrived from the questionnaire. See the related disability score for the patient PDQ point range. Only one pain disability score is given table to each patient, as per the below conversion table.	Patient PDQ Points from table I	Disability score assignment to be added for patients
	No or minimal pain score = 0 to 10		0
	Mild pain = 11-70		2
	Moderate pain = 71-100		3
	Severe pain = 101-130		5
	Extreme pain =131-150		8

Sub-committees for Review of Guidelines for Purpose of Assessing the Extent of Specified Disability in a person included under the Rights of Persons with Disabilities Act, 2016 (49 of 2016)

Under the esteemed guidance of Dr. Atul Goel, DGHS, following members worked for the revising of Assessment Guidelines for Disability-

- I. For Overall Chairperson for All the Sub- Committee: Dr. Sunita Mondal, Dir & Prof, Dept. of Physiology, LHMC & Associated Hospital
- II. For Overall Member Secretary for All the Sub- Committee: Dr. Rupali Roy, Assistant Director General, Dte.GHS
- III. Members from Dte.GHS: Dr. Anita Bali Vohra, Deputy Director General, Dte.GHS

Following sub-committees were constituted to revise the Assessment Guidelines for Disability-

1. Sub-Committee on Mental Illness

S No	Composition	Committee Designation
1	Prof. Pankaj Verma HoD, Psychiatry, SJH, Delhi	Chairperson
2	Dr. Mina Chandra HoD, Psychiatry, ABVIMS & RMLH	Member
3	Dr. Smita Despande Ex Psychiatrist RMLH, Advisor	Member
4	Dr. Manushree Gupta Associate Prof. SJH, Delhi	Member
5	Ms. Pragati Pandey Asst. Prof. NIMHR	Member
6	Dr. Rohit Verma Asst. Prof. Department of Psychiatry, AIIMS, Delhi	Member Secretary

2. Sub-Committee on Locomotor Disability

S No	Composition	Committee Designation
1	Dr Sanjay Wadhwa Prof. & HoD, Dept. of PMR, AIIMS	Chairperson
2	Dr. Ritu Mazumdar HoD PMR, LHMC & KSCH	Member
3	Dr. B.D. Athani Ex Spl. DGHS, Advisor,	Member
4	Dr. Satish Kumar HoD Orthopedic, Dr. RMLH	Member
5	Dr. Shishir Chandan Prof. Neurology, SJH,	Member
6	Dr. Desh Deepak Consultant Respiratory Medicine	Member
7	Dr. Ajay Raj	Member

	Prof. Cardiology, Dr. RMLH	
8	Dr. Sameek Bhattacharya Burn & Plastic, Dr RML Hospital	Member
9	Shri T.D Dhariyal Former Deputy Chief Commissioner, GoI and State Commissioner for PwD, Delhi	Member
10	Director SVNIRTAR, Cuttack	Member
11	Dr, Suman Badhal Prof, PMR SJH,	Member Secretary

3. Sub-Committee on Visual Impairment

SL.No.	Composition	Committee Designation
1	Dr. Ritu Arora Dir. Prof. Ophthalmology Dean, Maulana Azad Medical College, New Delhi	Chairperson
2	Dr. Sarita Beri HoD Ophthalmology, LHMC & Asso. Hospital	Co-Chairperson
3	Dr. Radhika Tandon Prof. Ophthalmology, AIIMS	Member
4	Dr. Rajiv Garg Ex DGHS, Adviser	Member
5	Director NIEPVD, Uttarakhand	Member
6	Dr Anuj Mehta Prof, Dept of Ophthalmology, Safdarjung Hospital	Member Secretary

4. Sub-Committee on Hearing Impairment

S. No.	Composition	Committee Designation
1	Dr. Arunbha Chakravrti Director & Prof, Dept. of ENT, LHMC	Chairperson
2	Dr. Isha Preet Tuli Prof. ENT, VMMC & SJH	Member
3	Director AYJNISHD, Mumbai	Member
4	Mr. Parbhakar Upadhyay Audio Metrician, Dept. of ENT, LHMC	Member Secretary

5. Sub-Committee on Developmental Disorder

S. No.	Composition	Committee Designation
1	Dr. Dr. Sheffali Gulati Prof. Child Neurology Division, Department of	Chairperson

	Pediatrics, AIIMS, Delhi	
2	Dr. Mina Chandra HoD, Psychiatry, ABVIMS & RMLH	Member
3	Dr. Paul Russell Professor & lead Consultant, CMC Vellore, Tamilnadu	Member
4	Dr. Sharmila B. Mukharjee Prof. Dept. of Pediatric, LHMC, Delhi	Member
5	Director, NIEPID, Secunderabad, Telangana	Member
6	Dr. Madhuri Kulkarni Ex Head Dept. of Pediatrics, L.M.M. Medical College, Maharashtra	Member
7	Dr. Vishal Sondhi Prof. Department of Pediatrics, AFMC, Pune	Member Secretary

6. Sub-Committee on Blood Disorder

S. No.	Composition	Committee Designation
1	Dr. Tulika Seth Prof. Dept. of Hematology, AIIMS, Delhi	Chairperson
2	Dr. Dipty Jain Ex HoD, Dept of Pediatrics, GMC, Nagpur	Member
3	Dr. Cecil Ross Prof. of Medicine and Hematology, St. Johns Medical College Hospital, Bangalore	Member
4	Dr. Prantar Chakraborty Consultant, Clinical Haematology, Vivekananda Institute of Medical Sciences	Member
5	Shri TD Dhariyal Former Deputy Chief Commissioner, GoI and State Commissioner for PwD, Delhi	Member
6	Dr. Ritika Sud Prof. Medicine LHMC, New Delhi	Member
7	Ms. Shobha Tuli President Thalassemic Federation of India, New Delhi	Member
8	Shri Gautam Dongre Secretary, National Alliance of Sickle Cell Disease NASCO	Member
9	Smt. Vinita Srivastava Advisor, Tribal Health, Ministry of Tribal Affairs	Special Invitee
10	Dr. Amitabh Singh Associate Professor, Pediatrics AIIMS, New Delhi	Member Secretary

7. Sub-Committee for Chronic Neurological Disorder

S. No	Composition	Committee Designation
1	Dr. Sheffali Gulati Prof. Child Neurology Division, Dept. of Pediatric, AIIMS, Delhi	Chairperson
2	Dr. Padma Srivastava HoD, Neurology, AIIMS, Delhi	Member
3	Dr. Mina Chandra HoD, Psychiatry, Dr. RML Hospital	Member
4	Dr. Gagandeep Singh Prof & HoD, Neurology, Dayanand Medical College & Hospital, Ludhiana	Member
5	Dr. Shishir K. Chandan Sr. CMO Safdarjung Hospital, Delhi	Member
6	Dr. Anand Principal Consultant & Prof. Dr. RML Hospital	Member
7	Dr. Satish V. Khadilkar Dean, Medical Faculty, Bombay Hospital, Institute of Medical Science	Member
8	Col. Dr. Aparjita Gupta MD, Pediatric Neurology, Advance Centre for Pediatrics, Army Hospital (R&R)	Member Secretary

8. Sub-committee for Multiple Disorder

S. No.	Composition	Committee Designation
1	Dr. Mina Chandra HoD Psychiatry ABVIMS & RMLH, Delhi	Chairperson
2	Dr. Sheffali Gulati Prof, Child Neurology Division, Department of Pediatrics, AIIMS, Delhi	Member
3	Dr. Ajay Gupta Prof, Dept of Physical Medicine and Rehabilitation, SJH	Member
4	Dr. B.D. Athani Ex Spl. DGHS, Advisor	Member
5	Dr. Satria Beri HoD Ophthalmology, LHMC & Asso. Hospital	Member
6	Dr. Gautam Bir Singh	Member

	Dir. Prof. ENT, LHMC	
7	Dr. Alok Sud Director Prof. Dept. of Orthopedics, LHMC	Member
8	Shri Shishir Chandan Prof., Neurology, SJH	Member
9	Director, NIEPMD, Chennai, Tamil Nadu	Member
10	Director, NIEPVD, Uttarakhand	Member
11	Dr. Suvarna Alladi HoD, Dept. of Neurology, NIMHANS, Bangalore	Member
12	Dr. Sharmila B. Mukherjee Prof. Dept of Pediatric, LHMC	Member Secretary