

NACC UNIFORM DATA SET

DOWN SYNDROME MODULE



Neuropsychological Battery

UDS Version 3.0, March 2015

DS Module Version 3.0, October 2020

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Down Syndrome Module video recording procedures

- It is recommended that all neuropsychological testing sessions be video recorded for reliability purposes. If you are video recording, please ensure that you are obtaining appropriate consents from your participants per your local IRB requirements.
- Recordings should be set up to capture the test materials and workspace (preferably from an overhead angle). Study staff should ensure that testing is conducted in a private, quiet space to ensure that both the participant(s) and examiner can be easily heard.
- Study staff should turn on the camera as soon as s/he enters the room and should continue recording throughout the encounter. Stopping and starting the recording often creates separate files on the camera or computer hard drive. If the recording is stopped and started for any reason, study staff should ensure that all files are retrieved at the end of the session.

Down Syndrome Module neuropsychological testing schedule

Instrument name	Administered by	Approx. length
Down Syndrome Mental Status Examination (with ShoeBox)	Psychologist	25 min
Cued Recall Task	Psychologist	10 min

Instructions for Down Syndrome Mental Status Examination (DSMSE)

WITH SHOEBOX MEMORY TEST

ADMINISTRATION

- Follow the instructions and script as written on the DSME test sheet.
- On **Introduction (I), Item A**, the examiner should introduce himself/herself by first and last name. On **Introduction (I), Item B**, the examiner should introduce himself/herself by first name only (i.e., modeling the answer expected from the participant). Note: The examiner should not include titles (e.g., “Dr.”), as this may affect the participant’s ability to answer **Item IIF**.
- On **Orientation (II), Items D and F**, the examiner should give three multiple-choice responses if the participant cannot answer the question. The correct answer should be the second of the three choices.
- On **Verbal Repetition (III)**, the examiner should speak more slowly than in a conversation but not too slowly.
- On **Verbal Comprehension (V), Items D, K, and L**, when making the request “Give me ...,” the examiner must not offer his/her hand to receive the object before the participant has moved the object toward the examiner.
- On **Immediate Memory (VI)**, the examiner should complete Trial 1 with all three objects before repeating the entire procedure. This is the only trial that is scored. Subsequent trials (up to three total) are completed to ensure that the participant learns the location of the objects for the delayed memory task.

SCORING

- Follow the scoring instructions as written on the DSMSE test sheet.
- For **Orientation (II), Item F**, examples of acceptable responses include doctor, psychologist, counselor, teacher, social worker, researcher, and scientist.
- For **Verbal Repetition (III)**, two methods will be used to score responses on this item. The first method is that prescribed on the test sheet (i.e., 1 point for each completely correct response, with the single exception that for the response “I bought cookies at the store,” the participant will be given credit if she/he substitutes “in” for “at”). The second method provides alternate scoring that allows partial credit for partial completion of a response. Rather than only 1 point for a completely stated response, the participant receives 1 point for each correctly stated word and may receive a score from 1 to 9, depending on the length of

the response. Articles receive no credit, and if articles are omitted, no credit is deducted. No substitutions are permitted. With this method the highest possible score for this item is 30.

Note: The DSMSE will be reported as two sets of scores — one set of scores obtained by scoring this section according to the method described above and a second set of scores obtained by the method described on the test sheet. Each set of scores will consist of scores for each of the six cognitive domains and a total score.

- For **Verbal Comprehension (V)**, in items **A, B, and C**, no credit is deducted for picking up the object. On **Item E**, no credit is deducted for carrying the key over to the ball or, on **Item F**, for carrying the truck over to the key. On **Item I**, no credit is deducted for putting the key in the truck. All other responses must be made exactly as requested. For example, for “Put the key next to the ball,” credit is not given for putting the ball next to the key, even though by doing so the participant gets the key next to the ball.
- For **Immediate Memory for Location (VI)** and **Delayed Memory for Location (IX)**, credit is given if the participant locates the object either verbally or nonverbally (e.g., by pointing).
- For **Naming (VII)**, if the participant had made an incorrect response or no response to sleeve, but then responds to cuff with “sleeve,” give credit for the previously incorrect response, but give no credit for cuff. Give credit for identifying collar as “neckline.”

Subject ID _____ Date ____ / ____ / ____ Examiner's initials ____

Down Syndrome Mental Status Examination (DSMSE) WITH SHOEBOX MEMORY TEST

SOURCE: Haxby, J. V. (1989). Neuropsychological evaluation of adults with Down's syndrome: patterns of selective impairment in non-demented old adults. *Journal of Intellectual Disability Research*, 33(3), 193–210.
<https://doi.org/10.1111/j.1365-2788.1989.tb01467.x>. Reproduced with permission.

Checklist of items needed:

- Stopwatch
- Ball
- Key
- Yellow truck
- Opaque box
- For Item VIII, Naming: Examiner must be wearing garments with a collar, sleeve, and cuff
- Pencil
- 20 1-inch cubes

Shoebox Memory Test items:

- Opaque box with lid
- Bar of soap
- Cup
- Glue
- Sponge
- Watch
- Fork
- Doll
- Tire

I. INTRODUCTION

Introduce yourself by name and ask:

A. _____ (2) ***“What is your name?”***

Score: 1 point for correct first name and 1 point for correct last name.

If the participant offers only first or last name, ask for the other. Repeat this question and all other questions as often as necessary.

“My name is ...” and have participant repeat it.

Participant's response: _____

II.A. SHOEBOX MEMORY TEST (Aylward & Burt)

General instructions: Verbal instructions and allowable follow-up prompts are indicated in bold. Record all gestures and responses. For object naming, give credit only for recognizable responses (i.e., so for soap). For recall give credit for name and appropriate gestures or nonverbal vocalization, if they specify object.

Immediate Memory — Three items:

- soap
- cup
- ring

“What is this called?”

PROMPTS: ***“This is a ...”*** Provide correct name for each object not named and have them repeat it. Place the three objects on the table in front of the participant.

“Put the ___ in the box.” Check objects correctly placed in box. Place the objects in the box if the person does not. Put the lid on the box.

“What is in the box?”

PROMPTS: ***“There’s a ...”*** ***“What else is in the box?”*** or ***“and a ...”***

If participant does not recall all objects, discontinue Immediate Memory.

Immediate Memory — Six items:

- soap
- cup
- ring
- glue
- sponge
- watch

Take each item out of the box and place in front of participant. Show the person each NEW object and ask:

“What is this called?” Prompt as above. Provide correct name for each object not named and have them repeat it.

“Put the in the box.” Check objects correctly placed in the box. Place the objects in the box if the person does not. Put the lid on the box.

“What is in the box?”

PROMPTS: ***“There’s a ?”*** ***“What else is in the box?”*** or ***“and a ...?”***

If participant does not recall all six objects, discontinue Immediate Memory.

Immediate Memory — Nine items:

- soap
- cup
- ring
- glue
- sponge
- watch
- fork
- doll
- tire

Take each item out of the box and place in front of participant. Then, show the person each NEW object and ask: ***“What is this called?”*** Prompt as above. Provide correct name for each object not named and have them repeat it.

“Put the ___ in the box.” Check objects correctly placed in box. Place the objects in the box if the person does not. Put the lid on the box.

“What is in the box?”

PROMPTS: ***“There’s a …?” “What else is in the box?” or “and a …?”***

III. ORIENTATION

A. _____ (2) ***“How old are you?”***

Score: 2 points for correct answer, 1 point if within 5 years.

B. _____ (3) ***“What is your birthday?”***

Score: 1 point each for correct month, date, and year.

C. _____ (2) ***“What season is it?”***

Score: 2 points for correct answer if multiple choice is not given, 1 point if it is.

If participant cannot say, ask, ***“Is it summer, fall, winter, or spring?”***

D. _____ (2) ***“What day of the week is it?”***

Score: 2 points for correct answer if multiple choice is not given, 1 point if it is.

Ask as a multiple choice question if participant cannot state day of the week spontaneously.

E. _____ (1) ***“What is my name?”***

Score: 1 point for correct name

F. _____ (2) ***“What kind of work do I do?”***

Score: 2 points for correct answer if multiple choice is not given, 1 point if it is.

Accept anything that is close to correct, e.g. teacher. If correct answer is not given, ask, ***“Am I a waiter, a doctor, or a policeman?”*** (Substitute correct profession for doctor if necessary, and say policewoman if female.)

IV. VERBAL REPETITION

“Say exactly what I say.”

Score as correct if all words are in the correct order and recognizable, despite articulation errors. Record response verbatim. (Give no credit if item is repeated.) Score: 1 point per item.

Discontinue after three consecutive failures.

- F. _____ (8) **Ball** _____
 House _____
 Apple juice _____
 Come with me. _____
 The cat ran home. _____
 I bought cookies at the store.

 There is a vegetable garden in the backyard.

 The car broke down before we even left the city limits.

SCORE: Method 1: _____
 Method 2: _____

V. A. SHOE BOX MEMORY TEST: Delayed Memory

“What is in the box?”

TIME ELAPSED:

PROMPTS: ***“There’s a ?”*** ***“What else is in the box?”*** or ***“and a ?”***

Proportion Saving: SAVE: Delayed Memory Recall / Highest Immediate Memory

VI. A. NAMING FOR THE IDENTITY OF 3 OBJECTS (ball, key truck)

Show the participant each object and ask, ***“What is this called?”***

If no response is given, ask, ***“This is a ... ?”*** Record all gestures and responses using phonetic alphabet. Provide correct name for each object not named by participant and have participant repeat it.

“Where is the key?”

“Where is the ball?”

Repeat this procedure up to three times or until participant correctly indicates location of all three objects.

- A. _____ (3) TRIAL: Truck Key Ball
1. _____ _____ _____
2. _____ _____ _____
3. _____ _____ _____

Score: 1 point for either naming or pointing to location. Give credit only for first trial.

VIII. NAMING

- A. _____ (8) Scoring: 1 point each if utterance is recognizable (e.g., /bo/ for elbow or /sli/ for sleeve). Record response using phonetic alphabet.

_____ watch

_____ pencil

_____ finger

_____ elbow

_____ shirt

_____ collar

_____ sleeve

_____ cuff

IX. VISUOSPATIAL CONSTRUCTION

- A. _____ (3) **Item 1 — Stacking blocks:**

Put a block on the table in front of the participant and hand the participant another block.

Say, ***“Put this on top of this one here.”***

After participant has stacked first block, give him or her another block and indicate that he or she should put that on top of the other two. Then give the participant a fourth block.

Score: 1 point for each block stacked by participant.

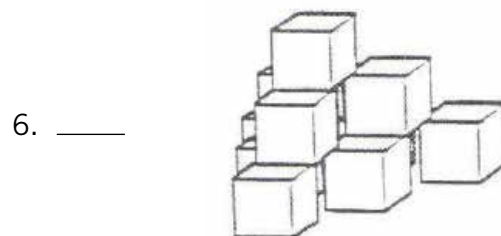
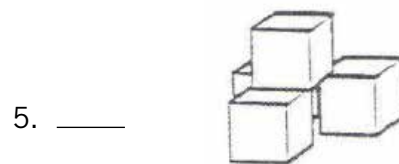
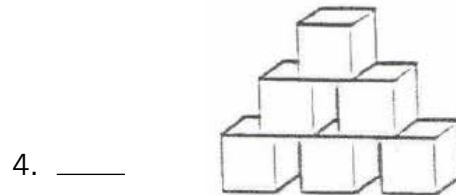
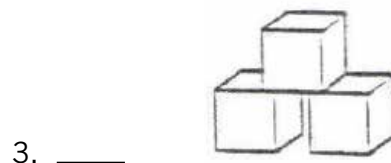
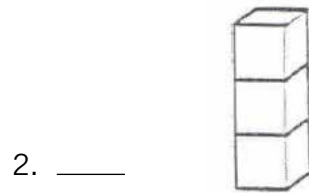
B. _____ (5) **Items 2–6 — Constructing 3-D patterns to model:**

Give participant the correct number of blocks for each design. Construct design in front of participant and indicate that he or she should make one just like it.

Score: 1 point for each design. (Give half credit on designs 3-6 if participant doesn't leave gaps in between blocks and correct participant's construction.)

Time limit: 1 minute per design.

Discontinue after two consecutive failures.



X. DELAYED MEMORY FOR LOCATION

A. _____ (3) Score: 1 point for each location correctly indicated.

_____ ***“Where is the truck?”***

_____ ***“Where is the key?”***

_____ ***“Where is the ball?”***

XI. APRAXIA

Score: 1 point for each item (ideomotor apraxia)

A. _____ (2) **Intransitive:**

_____ ***“Show me how you wave goodbye.”***

_____ ***“Show me how you salute.”***

B. _____ (2) **Transitive:**

If participant fails either transitive item, give him/her object and say,
“Show me how you use this.” Give half credit if correct.

_____ ***“Show me how you throw a ball.”***

_____ ***“Show me how you lock a door with a key.”***

DSMSE SCORING: If any question is not assessed, enter the appropriate not assessed code (i.e, 8, 88, or 88.8) for the item and total sub-score. If any total sub-score is 8=Not assessed, enter reason code, 995–998, for the DSMSE Total Score.

		TOTALS (Score 1)	TOTALS (Score 2)				
Personal information IA+IIIA+IIIB	1a1. ____ (0 – 7; 8=Not assessed)	1b2. ____ (0 – 11; 88=Not assessed)	1b3. ____ (0 – 11; 88=Not assessed)				
Season/day IIIC+IIID	1b1. ____ (0 – 4; 8=Not assessed)	(1a1 + 1b1)	(1a1 + 1b1)				
Shoebox Memory							
Object IIA	<table border="1"> <tr> <td>Immediate</td> <td>Delay</td> </tr> <tr> <td>1c1. ____ (0 – 9; 88=Not assessed)</td> <td>VA 1c2. ____ (0 – 9; 88=Not assessed)</td> </tr> </table>	Immediate	Delay	1c1. ____ (0 – 9; 88=Not assessed)	VA 1c2. ____ (0 – 9; 88=Not assessed)	1c3. ____ (0 – 18; 88=Not assessed) (1c1 + 1c2)	1c4. ____ (0 – 18; 88=Not assessed) (1c1 + 1c2)
Immediate	Delay						
1c1. ____ (0 – 9; 88=Not assessed)	VA 1c2. ____ (0 – 9; 88=Not assessed)						
Memory							
Place VIIA	<table border="1"> <tr> <td>Immediate</td> <td>Delay</td> </tr> <tr> <td>1d1. ____ (0 – 3; 8=Not assessed)</td> <td>XA 1d2. ____ (0 – 3; 8=Not assessed)</td> </tr> </table>	Immediate	Delay	1d1. ____ (0 – 3; 8=Not assessed)	XA 1d2. ____ (0 – 3; 8=Not assessed)	1d3. ____ (0 – 6; 8=Not assessed) (1d1 + 1d2)	1d4. ____ (0 – 6; 8=Not assessed) (1d1 + 1d2)
Immediate	Delay						
1d1. ____ (0 – 3; 8=Not assessed)	XA 1d2. ____ (0 – 3; 8=Not assessed)						
Apraxia							
Intransitive XIA	1e1. ____ (0 – 2; 8=Not assessed)	1e3. ____ (0 – 4; 8=Not assessed)	1e4. ____ (0 – 4; 8=Not assessed)				
Transitive XIB	1e2. ____ (0 – 2; 8=Not assessed)	(1e1 + 1e2)	(1e1 + 1e2)				
Language							
Naming VIA+VIIIA	1f1. ____ (0 – 11; 88=Not assessed)	Language Score 1 1f5. ____ . ____ (0.0 – 31; 88.8=Not assessed) (1f1 + 1f2 + 1f4)	Language Score 2 1f6. ____ . ____ (0.0 – 53; 88.8=Not assessed) (1f1 + 1f3 + 1f4)				
Repetitions IVA (Method 1)	1f2. ____ (0 – 8; 88=Not assessed)						
Repetitions IVA (Method 2)	1f3. ____ (0 – 30; 88=Not assessed)						
Comprehension VIB	1f4. ____ . ____ (0.0 – 12; 88.8=Not assessed)						
Visuospatial							
IXA+IXB	1g1. ____ (0 – 8; 88=Not assessed)	1g2. ____ (0 – 8; 88=Not assessed)	1g3. ____ (0 – 8; 88=Not assessed)				
Knowledge of the Examiner							
IIIE+IIIF	1h1. ____ (0 – 3; 8=Not assessed)	1h2. ____ (0 – 3; 8=Not assessed)	1h3. ____ (0 – 3; 8=Not assessed)				
DSMSE TOTAL SCORE:		TOTAL SCORE 1:	TOTAL SCORE 2:				
		1j1. ____ . ____ (0.0 – 81; 995 – 998)	1j2. ____ . ____ (0.0 – 103; 995 – 998)				

Instructions for Cued Recall Task

MATERIALS

Three cards with black-and-white pictures

Cards: Items and cues

Note: Alternate Versions 1 and 2 over the test cycles

Version 1 (Set A)		Version 2 (Set B)	
ITEM	CUE TO BE GIVEN	ITEM	CUE TO BE GIVEN
CARD 1		CARD 1	
grapes	A piece of fruit	cake	Something to eat
helicopter	Something that flies	iron	Something that gets hot
candle	Something that gives light	star	Something in the sky
screwdriver	A tool	tree	Something in the garden
CARD 2		CARD 2	
hat	Something to wear	tie	Something to wear
lips	Part of the face	hand	A part of the body
scissors	Something to cut things with	top	A toy
rabbit	An animal	squirrel	An animal
CARD 3		CARD 3	
TV	A piece of furniture	dresser	Belongs in the bedroom
pot	Belongs in the kitchen	pitcher	Belongs on the table
guitar	A musical instrument	barn	Something that belongs on a farm
bike	Something with wheels	swing	Something to ride on

ADMINISTRATION

TRAINING TRIALS

- Present Card 1 and ask the participant to point to and name each item (e.g., “grapes”) when its category cue is given verbally by the examiner (e.g., “a piece of fruit”).
- After all four items on that card are named correctly, turn the card over and ask participants for immediate free recall of those four items.
- Record the number of items which were correctly recalled (e.g., 3, meaning that the participant recalled three out of four items).

- If the participant fails to recall all four items, turn the card face up and ask the participant to point to and name the items again.
- Turn the card face down and ask the participant again for free recall.
- This is repeated three times with each card or until all four items are recalled.

Note: Continue to the test trials even if the participant does not recall all four items on one or more cards.

Note: If the participant makes a reasonable sign for an item (and the sign is distinct from any other sign used for any other item), this can be accepted as a response.

TEST TRIALS

- Ask the participant to recall all 12 items (free recall).
- Write down the order of recall in the **Free Recall** column.
- Record the intrusions that the participant makes (in column labeled Intrusions to FR).
- After sufficient time and encouragement to allow maximum free recall, ask for the cued recall. Present participants with the category labels for items not retrieved by free recall.
- Check off the items that were recalled with the cue in the column labeled **Cued Recall**.
- If a participant fails to retrieve the item with a cue, remind the participant of the missed item.
- Record the intrusions that the participant makes (in the column labeled **Intrusions to CR**).

SCORING

TRAINING TRIALS

Record the number of items correctly recalled for:

- Card 1 (Trials 1–3)
- Card 2 (Trials 1–3)
- Card 3 (Trials 1–3)

TEST TRIALS

For each trial, record the total number of:

- Items that were correctly recalled without cueing (free recall)
- Intrusions to free recall
- Items that were correctly recalled after the cue was presented (cued recall)
- Intrusions to cued recall

Cued Recall Task

SOURCE: Devenny, D. A., Zimmerli, E. J., Kittler, P., & Krinsky-McHale, S. J. (2002). Cued recall in early-stage dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research*, 46(6), 472–483. <https://doi.org/10.1046/j.1365-2788.2002.00417.x>. Reproduced with permission.

Cued Recall Task — Set A Learning Phase

	Trial 1	Trial 2	Trial 3
Card 1			
Card 2			
Card 3			

Cued Recall Task — Set A

Test Phase

Category	Trial 1				Trial 2				Trial 3			
	Free recall	Intrusions to FR	Cued recall	Intrusions to CR	Free recall	Intrusions to FR	Cued recall	Intrusions to CR	Free recall	Intrusions to FR	Cued recall	Intrusions to CR
Card 1												
Fruit (grapes)												
Flies (helicopter)												
Gives light (candle)												
Tool (screwdriver)												
Card 2												
Wear (hat)												
Face (lips)												
Cut (scissors)												
Animal (rabbit)												
Card 3												
Furniture (TV)												
Kitchen (pot)												
Instrument (guitar)												
Has wheels (bike)												
TOTALS												

Cued Recall Task — Set B

Learning Phase

	Trial 1	Trial 2	Trial 3
Card 1			
Card 2			
Card 3			

Subject ID _____ Date ____ / ____ / _____ Examiner's initials _____

Cued Recall Task — Set B

Test Phase

Category	Trial 1				Trial 2				Trial 3			
	Free recall	Intrusions to FR	Cued recall	Intrusions to CR	Free recall	Intrusions to FR	Cued recall	Intrusions to CR	Free recall	Intrusions to FR	Cued recall	Intrusions to CR
Card 1												
Eat (cake)												
Hot (iron)												
In the sky (star)												
Garden (tree)												
Card 2												
Wear (tie)												
Body (hand)												
Toy (top)												
Animal (squirrel)												
Card 3												
Bedroom (dresser)												
Table (pitcher)												
Farm (barn)												
Ride (swing)												
TOTALS												