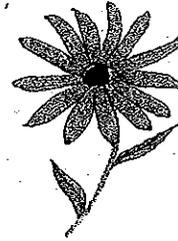


PCAD Project



Protocol for Recording Baseline Behavior Information for Persons With Down Syndrome as per the IASSID/AAMR Practice Guidelines on Assessment and Care Management

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Protocol for Recording Baseline Behavior Information for Persons With Down Syndrome as per the IASSID/AAMR Practice Guideline on Assessment and Care Management

A. Purpose:

This protocol can help agencies providing primary services and supports to adults who may be at-risk of Alzheimer's disease record optimal behavioral functioning on a selected set of behaviors. There are two parts to this protocol (Part A – administration of a behavioral assessment instrument, and Part B – video recording of behaviors).

B. Restrictions:

As the AADS data and video recordings are personal, they should be treated as part of the adult's private record (program plan) and be bound by all the confidentiality provisions resident in state law regarding protection of privileged information of persons admitted to services with the agency. No information should be disclosed or the recordings shared without proper authorization.

C. Data Collection

As per the guidelines issued by the AAMR/IASSID regarding the collection of baseline information on adults at risk of dementia, it is recommended that the behavioral scales and video record program be administered to persons with Down syndrome after age 40 (and for those already showing decline or particularly at-risk if can be administered at a younger age). They should be used with at-risk persons with other etiologies of intellectual disability after age 50.

The behavioral scales and recordings should be made available to diagnostic and assessment services for review of pre-morbid functioning and comparison against functioning at time of the diagnostic evaluation.

D. Information Collected:

Baseline information should take two forms

Part A. Administration of a standardized behavioral assessment measure of ADLs, and IADL skills (e.g., AAMR's Adaptive Behavior Scale – ABS; Assessment for Adults with Developmental Disabilities – AADS, etc.).

Standard: Scale should be administered under ideal conditions so as to capture optimal functioning and using informants with sufficient knowledge of the individual or under conditions of direct observation.

Timeframe: Administration for persons with Down syndrome should start after 40th year or earlier if there is any suspicion that the adult may be at risk for Alzheimer's disease or cognitive decline. For persons with etiologies other than Down syndrome, the assessment should start after the 50th year and then repeated every two to three years.

Protocol: Assessment is scored and kept in the Subject's record.

Using the AADS. An authorized copy of the AADS (US Version)¹ is provided as part of this protocol package. The AADS should be completed by someone who is familiar with the adult (it can be a parent, relative, or staff member). The AADS should be

completed at about the same time that the adult is enrolled in the video record program. The data from the AADS should be kept in the adult's private record and treated as confidential information. If early Alzheimer's disease is suspected in an adult with Down syndrome, the AADS should be re-administered at periodic intervals of at least every six months. If no decline is suspected, it should be re-administered on the same schedule as the video record program.

Part B. Recording of standard set of behaviors to photographically illustrate optimal physical and verbal functioning.

Rationale: Information is needed to ascertain dementia by observing decline in five broad areas: memory, general mental functioning, higher cortical functioning, skills, and personality. The behavioral examples included in this protocol illustrate general functioning in these five categories:

- *Memory* - looking for losses in retention of information from previous levels
- *General mental functioning* - looking for how the person processes information and reports facts and events
- *Higher cortical functioning* - looking for dysfunction in personal tasks involving movement or language
- *Skills* - looking for changes in living and work functions
- *Personality* - looking for changes in personal style, responding to questioning, and interacting

Standard: Video or digital photography should be employed under relaxed and ideal conditions so as to capture optimal functioning using a specific set of performance behaviors.

Timeframe: Photography should be undertaken close to the same time as the administration of standardized behavioral assessment measure. Photographs should be date-stamped or date and times otherwise logged on the film record. Begin the taping/digital recording with voice-over of date, location, and name of person being recorded –alternatively, print this information on a sheet of paper and record on the video/digital recording.

Protocol: Digital photography of the following standard behaviors:

a. Walking 10 paces.

The camera should be set to record full body (head to foot) movement. Subject is asked to walk toward camera, turn and walk away from the camera. If Subject uses cane, walker or other adaptive equipment, he or she should use it in the recording. If Subject uses a wheelchair or motorized carrier, he or she should demonstrate use of it in the recording.

Script for "Walking:"

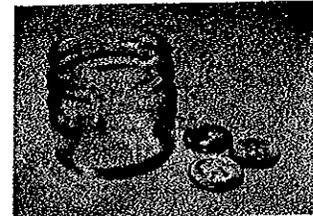
(1) The individual is positioned approximately 10 feet/paces (about 3 meters) from the camera, which is then turned on. The person is instructed to, "walk toward the camera." If the Subject has difficulty walking, he or she can be helped by the interviewer. If the person uses a walker or another walking aid,

they should use it. If a person is in a wheelchair, he or she should be asked to come toward the camera in the wheelchair. If they are unable to use the wheelchair independently, record the person being asked, but not responding for about 10 seconds. Tell the person to stop when they reach the area of the camera, so he or she doesn't walk into it.

(2) Once the person reaches the area in front of the camera ask him or her to walk back to where he or she started. If the person needs assistance, offer it.

b. Praxis task #1 (putting coins in a jar)

The camera should be set to record the person in a sitting position capturing facial expressions, conversation and other movement. Ideally a time recording should be used. Subject is asked to sit comfortably at a desk or table and is given 3 small coins (in countries with decimal currency use 10 cent pieces; in other countries use equivalent size coins – between 15 - 18 mm in diameter; in the US use dimes). He or she is then asked to pick up the coins with one hand and place each, one at a time, in the jar. He or she is then asked to pick up the coins with the other hand and place each, one at a time, in the jar. After each sequence, the interviewer removes the coins from the jar and places them on the surface of the table/desk.



Script for "Place each of the coins inside the jar:"

(1) A small (1 to 1.75 ounce glass jar; or 31g to 50g glass jar – with +/- 35 mm opening) transparent jam/honey jar is placed in front of the individual with three coins in front of the jar (3 dimes) with the request: "Place each of the coins inside the jar." It does not matter which hand the person uses first.

(2) If the Subject shifts hands during the task, he or she is to be instructed not to do so. Picking up the coins with the thumb and the fingers or sliding the coins to the edge of the table before picking them up are acceptable responses.

(3) At the end of this item the examiner says, "That's fine. Good," and empties the coins back onto the table with the jar next to the coins and proceeds to next item.

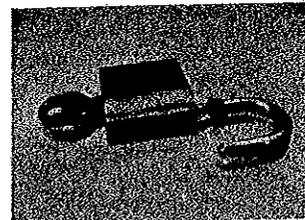
(4) The same jar is placed in front of the individual, with the same three coins place beside it. The Subject is told: "Place each of the coins inside the jar with the other hand." This a repeat of the previous item but now the person must successfully perform with the other hand.

(5) The task is terminated with verbal approval by the interviewer while the jar and coins are removed and set aside.

c. Praxis task #2 (opening and closing a key padlock)

The camera should be set to record the person in a sitting position capturing facial expressions, conversation and other movement. Ideally a time recording

should be used. Subject is asked to sit comfortably at a desk or table and is given a small padlock (approx. 30 mm x 25 mm case size with key lock) and is asked first to unlock the padlock and then to lock the padlock. *Lock should be checked for ease of use; it should not stick and should open readily when key is inserted and turned.*



Script for "Unlock the padlock:"

(1) A small padlock and key are placed side by side and the subject is asked "to unlock the padlock." The person should pick up both items, place the key in the key hole and turn it until the lock opens and the swivel becomes free. The person can be prompted to complete the procedure. When the lock is opened, take the lock and key from the person and proceed to next item.

Script for "Lock the padlock:"

(1) Hand the person the lock with the key in position and with the swivel out. The person is required to independently swivel the catch until it is over the hole of the padlock then to press down firmly until the catch snaps shut. The person can be prompted to complete the procedure.

(2) The task is terminated with verbal approval by the interviewer while the padlock and key are removed and set aside.

d. Conversation

The camera is set up to record the person in a comfortable sitting position in a chair or at a table or desk facing the interviewer. The person is asked to answer a series of questions and engage in conversation. The purpose is to record social interaction skills, select performance, and receptive and expressive language skills involving reports about self, life situation, and life activities.

1. Subject is asked the Orientation items from the MMSE²

"What day is it today?"

"What is today's date?"

"What is the month?"

"What is the year?"

"What is the season?"

"Where are we now?"

"What is the building we are in?"

"What is the town or city?"

"What is the state?"

"What is the country?"

Comment: This is not a test situation, so the Subject can be asked follow-up questions to determine extent of knowledge and communication abilities. If any of the questions are unfamiliar or confusing, use names of terms that he or she may more readily understand or with which he or she may be more familiar.

Interviewer should indicate on the recording that the question was answered correctly – for example, if the day is Thursday, and the person says it is

Saturday, the interviewer should note the correct date ("Today is Thursday, John" or a variant). This way the recording will show if the person actually responded correctly.

2. Subject is then engaged in conversation, while introducing these questions into the flow of the conversation:

Personal topics:

1. "What is your name?"
2. "Where do you live?"
3. "How old are you?"
4. "When is your birthday?"

Work and social topics:

5. "Where do you work or attend program or service? (Use whichever applies)"
6. Who are your close friends?
7. Where do they live?

How time spent topics:

8. What do you do most days?
9. What would you like to do most days?
10. What is your most favorite thing to do?
11. Where is your favorite place to go?
12. What is your favorite TV show or movie?

Personal preference topics:

13. If you could have a pet, what would it be?
14. What is your favorite food?
15. What makes you happy?
16. What plans do you have for this weekend?

Script:

(These are untimed functions, but if Subject takes excessive time to respond, probe for response. If no response is forthcoming, move onto the next item.) As the interviewer, you can alter the questions to appeal to the comprehension level of the Subject. The goal is to produce responses as part of the conversation.

E. Equipment

Any video taping or digital recording equipment can be used. If digital recording is undertaken, the files should be saved in a format easily used and accessible to IBM-compatible personal computers (or the system in use at the agency).

Notes

¹ The AADS is used with permission from the scale's developers at the University of Birmingham in the United Kingdom. This version was adapted for use in the United States by the University at Albany.

² MMSE = Mini Mental State Examination

Information Page

Comments and suggestions are welcome. Please direct them to the address shown below

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Albany, New York 12222
For information, contact dementcare@aol.com

Version 2.0b (February 2003)

Digital Recording Record

Name: _____

Date of Birth _____

Residence/Address _____

Recording #1

Date of recordings _____

- | | Dates |
|---|-------|
| <input type="checkbox"/> Behavioral scale information collected | _____ |
| <input type="checkbox"/> Recording of walking | _____ |
| <input type="checkbox"/> Recording of putting coins in a jar | _____ |
| <input type="checkbox"/> Recording of opening a pad lock | _____ |
| <input type="checkbox"/> Recording of conversation | _____ |

Recording #2

Date of recordings _____

- | | Dates |
|---|-------|
| <input type="checkbox"/> Behavioral scale information collected | _____ |
| <input type="checkbox"/> Recording of walking | _____ |
| <input type="checkbox"/> Recording of putting coins in a jar | _____ |
| <input type="checkbox"/> Recording of opening a pad lock | _____ |
| <input type="checkbox"/> Recording of conversation | _____ |

Recording #3

Date of recordings _____

- | | Dates |
|---|-------|
| <input type="checkbox"/> Behavioral scale information collected | _____ |
| <input type="checkbox"/> Recording of walking | _____ |
| <input type="checkbox"/> Recording of putting coins in a jar | _____ |
| <input type="checkbox"/> Recording of opening a pad lock | _____ |
| <input type="checkbox"/> Recording of conversation | _____ |