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ASSESSMENT FOR ADULTS WITH DEVELOPMENTAL DISABILITIES (A.A.D.S.) QUESTIONNAIRE'

This assessment is used in these two publications and focuses on behavioural change in people with Down syndrome who develop dementia.

Adams, D., Oliver, C., Kalsy S., Peters, S., Broquard, M., Basra T., Konstandinidi, E. W. and McQuillan, S. (2008). Behavioural characteristics associated with dementia assessment referrals in adults with Down syndrome. *Journal of Intellectual Disability Research*, **52**, 358-368. (DOI: 10.1111/j.1365-2788.2007.01036.x)

Adams, D. and Oliver, C. (2010). The relationship between acquired impairments of executive function and behaviour change in adults with Down syndrome. *Journal of Intellectual Disability Research*, **54**, 393-405. doi: 10.1111/j.1365-2788.2010.01271.x

Adults with Down's Syndrome (A.D.S.) Research Project
at
School of Psychology, University of Birmingham

**MANUAL FOR THE 'ASSESSMENT FOR ADULTS WITH DEVELOPMENTAL
DISABILITIES (A.A.D.S.) QUESTIONNAIRE'**

Summary

The A.A.D.S. is an informant-based questionnaire for use with adults with developmental/learning disabilities, as they become older. It specifically describes the dementia-related behaviours that may be experienced by individuals, by asking informants to rate operationally defined observable behaviours, on the basis of frequency of occurrence, care management and quality of life effects on the individual concerned. The questionnaire has two sub-scales that assess the presence of behavioural excesses (11 items) and behavioural deficits (17 items) commonly associated with dementia.

Background to measure development

The goal of measure development was to develop a scale composed of well-anchored, homogeneously scaled items that could be easily administered without extensive training to provide a standardised method of evaluating a wide range of behaviours seen in persons with learning disabilities presenting with varying degrees of dementia. Behavioural and psychological signs and symptoms of dementia are integral elements of the disease process (APA 1994, Deimling & Bass 1986, Molloy et al 1996, WHO 1992). There are many ways in which these can be grouped, for example by function e.g. sleep disorders, by altered behaviours e.g. wandering or by psychopathological symptom clusters e.g. depressive syndrome. Another method of grouping would be behavioural excesses and deficits.

The questionnaire reflects a range of behavioural excesses and behavioural deficits, reflective of the behavioural disturbances of dementia (APA 1994, Aylward et al 1997, Moss & Patel 1997, Rabins 1996, WHO 1992). A literature review and the clinical experience of the project team indicated that the items were relevant for study. The absence of measures to assess behavioural deficits and excesses in assessing for dementia in people with learning disabilities as they age has been acknowledged (Oliver 1999). Furthermore, the lack of rating scales and surveys for frequency, management difficulty and severity of behaviours which challenge had already been identified (Harris et al 1994).

The study evaluated the psychometric properties of the measure, to determine the overall number of items rated as present for individual, the frequency with which specific behavioural changes were reported as occurring and to assess inter-rater reliability. Several issues relating to the validity of the scale have been addressed.

Description of the measure

The A.A.D.S. contains twenty-eight items with a response format consisting of a seven point Likert type rating scale. The questionnaire has two sub-scales that assess the presence of behavioural excesses (11 items) and behavioural deficits (17 items) commonly associated with dementia. The *Frequency* of each item in the preceding two weeks is rated on the scale ('more than once an hour/continually' to 'once during the past two weeks'). If an item is endorsed, a rating is then made on the scale to appraise *Management Difficulty* ('no difficulty' to 'extremely severe difficulty') and the *Effect* of the behaviour on the person ('no effect' to 'extremely severe effect'). Six scores are thus obtained and the maximum possible score for *Frequency*, *Management Difficulty* and *Effect* for *Deficits* is 102 for each and *Frequency*, *Management Difficulty* and *Effect* for *Excesses* is 66 for each. Additionally, the number of excesses and deficits can be calculated by counting the number of items endorsed. Overleaf are examples of items taken from each of the sub-scales with operationalised scoring criteria.

Validity and reliability

To strengthen the face validity of the A.A.D.S., items were based on definitions of behavioural excesses and deficits outlined by DSM-IV, on protocols developed by an international working party on the assessment of dementia in adults with learning disabilities and on observable behaviours related to such definitions (APA 1994, Aylward et al 1997).

The internal consistency and validity of the A.A.D.S. was tested on a sample of 68 adults with Down's Syndrome. A proportion of this larger sample (N = 49) were involved in an exploration of reliability of the A.A.D.S.. All of the participants were verbal or partly-verbal and proportion of male to female was 29 males to 20 female, aged between 31 and 65 years (mean = 46.51, SD = 9.42).

Mean scores on the A.A.D.S. for the reliability sample were 9.19 (range 0-36, SD 9.86) for *Frequency of Excesses*, 5.10 (range 0-20, SD 5.84) for *Management of Excesses* and 3.82 (range 0-22, SD 4.88) for *Effect of Excesses*. For the *Deficits* sub-scale, the mean scores were 13.45 (range 0-80, SD 16.19) for *Frequency of Deficits*, 7.12 (range 0-46, SD 9.83) for *Management of Deficits* and 5.33 (range 0-53, SD 8.74) for *Effect of Deficits*.

To assess inter-rater reliability, two carers for 49 participants completed the A.A.D.S. Intra-class correlation coefficients for *Frequency*, *Management Difficulty* and *Effect* for *Excesses* were .81, .76 and .59 respectively. Corresponding indices for *Deficits* were .80, .83 and .76. The intra-class correlation coefficients for the number of *Deficits* and *Excesses* were .80 and .86 respectively.

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Moss, S. & Patel, P. (1997) Dementia in older people with intellectual disability: symptoms of physical and mental illness and levels of adaptive behaviour. *Journal of Intellectual Disability Research*, 41, 60-69.

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Rabins, P. V. (1996) Behavioural disturbances of dementia: practical and conceptual issues. *International Psychogeriatrics*, 8(3), 281- 285.

World Health Organisation (1992). *The ICD-10 classification of mental and behavioural disorders*. Geneva, Switzerland: World Health Organisation.

How often

Rate how often the behaviour has occurred during the past two weeks

(See instructions on front page)

- 0 = Has not occurred in the past two weeks
- 1 = Once in the past two weeks
- 2 = 2 – 3 times in the past two weeks
- 3 = More than 2-3 times in the past two weeks
- 4 = Once a day
- 5 = More than once a day
- 6 = Once an hour / all of the time

Management difficulty

Rate how much of a management difficulty the behaviour was

(See instructions on front page)

- 0 = No difficulty
- 1 = Very little difficulty
- 2 = Mild Difficulty
- 3 = Moderate difficulty
- 4 = Mod-severe difficulty
- 5 = Severe difficulty
- 6 = Extremely severe difficulty

Effect

Rate the effect of the behaviour upon the person

(See instructions on front page)

- 0 = No effect
- 1 = Very little effect
- 2 = Mild effect
- 3 = Moderate effect
- 4 = Mod-severe effect
- 5 = Severe effect
- 6 = Extremely severe effect

Example of a behavioural excess

1. Was restless

Paced up and down, was unable to sit still, fidgeted.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

Example of a behavioural deficit

28. Had a fall

Fell over or tripped up (e.g. tripped up a kerb, **fell on the stairs**).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

This questionnaire is for adults with developmental disabilities. It is about the kind of behaviours and difficulties that may be faced by people as they become older and by those who care for them. It needs to be completed by someone who knows the person well and who has supported them during the past two weeks, e.g. parent, keyworker or other main carer.

Name of carer: _____

Date:

Name of the person I care for: _____

My relationship to this person: _____

INSTRUCTIONS

1. How often did the behaviour occur?

- Read carefully the following list of behaviours. For each behaviour decide how often it has occurred in the past two weeks.
- Please rate all the behaviours the person has displayed, even if they have always been present.
- Please rate how often the behaviour has occurred by circling the number that best applies:

0= Has not occurred in the past two weeks

1= Once in the past two weeks

2= 2 – 3 times in the past two weeks

3= More than 2-3 times during the past two weeks

4= Once a day

5= More than once a day

6= Once an hour / all of the time

- If the behaviour has not occurred, or the question does not apply circle 0 and go onto the next question.

2. How difficult was the behaviour to manage ?

- Next think about how difficult the behaviour was to manage. Please rate how much of a difficulty the behaviour was by selecting the number that best applies. Some examples have been given as a general guide. (If more than one category applies select the highest number).

0= **No difficulty**: [e.g. required no response from carer; did not need supervision or physical support.]

1= **Very little difficulty**: [e.g. required occasional verbal / physical prompting, brief verbal response required; needed occasional supervision/ physical support.]

2= **Mild difficulty**: [e.g. required some verbal / physical prompting, short verbal response / minor physical action was required (e.g. redirection, touch); minor/brief change to environment (e.g. object/person moved); needed some supervision / physical support.]

3= **Moderate difficulty**: [e.g. required more than some verbal / physical prompting, moderate verbal response / physical action was required (e.g. blocking, brief hold); temporary change to the environment (e.g. objects/person(s) removed from the area); needed quite a lot supervision / physical support.]

4= **Mod-severe difficulty**: [e.g. required frequent verbal / physical prompting, person needed to be physically held for more than a moment; semi-permanent changes to environment required (i.e lasting more than a day), needed a lot supervision / physical support.]

5= **Severe difficulty**: [e.g. required continual verbal / physical prompting, person needed to be physically held for a prolonged period of time; required continual supervision / physical support, permanent changes to environment required.]

6= **Extremely severe difficulty**: [e.g. carer could not manage the behaviour; placement was threatened, required intervention from outside agency(e.g. health professional, hospital, fast response team)]

3. What effect did the behaviour have ?

- Finally think about the effect the behaviour had upon the person and their quality of life. Quality of life includes areas such as: health, relationships, choices, leisure, activities at home and in the community, physical and social environment. Please rate how much of an effect the behaviour had by selecting the number that best applies. Some examples have been given as a general guide. (If more than one category applies select the highest number).

0= **No effect**: [e.g. no effect upon health, relationships, choices or activities; no distress experienced by the individual.]

1= **Very little effect**: [e.g. short disruption in an activity; friendships occasionally disrupted; occasionally did not interact with others ; few choices were made by the carer; very little distress experienced by individual; very little effect upon general health; very slight injury (e.g. reddening of skin).]

2= **Mild effect**: [e.g. missed out on an activity in or outside the home; friendships some times disrupted; sometimes did not interact with others; some choices were made by the carer; mild distress experienced by the individual; mild effect upon general health; mild injury (e.g. bruise).]

3= **Moderate effect**: [e.g. missed out on a days activity in or outside the home, friendships quite often disrupted, quite often did not interact with others; more than some choices were made by carer; moderate effect upon general health; moderate injury (e.g. basic first aid was required); moderate distress experienced by individual.]

4= **Mod-severe effect**: [e.g. missed out on activities for two or more days in or outside the home, friendships disrupted most of the time; most of the time did not interact with others, most choices were made by the carer; mod – severe effect on general health (e.g. needed to be seen by a Doctor); mod-severe distress experienced by individual.]

5= **Severe effect**: [e.g. missed out on a weeks activities in or outside the home; friendships disrupted almost all the time; almost all the time did not interact with others, almost all choices were made by the carer; needed to attend hospital/casualty department; severe distress experienced by the individual.]

6= **Extremely severe**: [e.g. missed out on all activities in or outside the home; did not interact with others; friendships disrupted all of the time; all choices were made by the carer; needed hospital admission; extremely severe distress experienced by individual.]

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How often

Rate how often the behaviour has occurred during the past two weeks
(See instructions on front page)

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(See instructions on front page)

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Effect

Rate the effect of the behaviour upon the person
(See instructions on front page)

- 0 = No effect
- 1 = Very little effect
- 2 = Mild effect
- 3 = Moderate effect
- 4 = Mod-severe effect
- 5 = Severe effect
- 6 = Extremely severe effect

1. Was restless

Paced up and down, was unable to sit still, fidgeted.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

2. Wandered during the night

Wandered without a clear purpose around the house at night.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

3. Wandered during the day

Wandered without a clear purpose around house, garden or building.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

4. Was vocally disruptive

Was vocal for no apparent reason, (e.g. moaned, shouted, screamed, called out).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

5. Took something belonging to someone else

Took money or objects, went through other people's possessions (e.g. bags/coats/bedrooms).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

6. Cried or became tearful

Became tearful for no apparent reason.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

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7. Was uncooperative

Was unwilling to carry out or be supported with a daily task (e.g. bathing, dressing, brushing teeth), or comply with carer requests (e.g. refused to go to bed, to eat or drink).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

8. Was aggressive towards others verbally/ through gestures

Expressed aggression towards others verbally or by using signs/gestures, (e.g. shouted, name called, threatened, swore).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

9. Was aggressive towards others physically

Attempted to/was actually physically aggressive towards another person (e.g. kicked, hit, spat, scratched, bit, pushed, grabbed).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

10. Displayed sexually inappropriate behaviour

Made an inappropriate sexual advance/gesture, made sexual references, non-accidentally exposed self.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

11. Said or gestured the same thing repeatedly

Repeatedly communicated the same thing using signs/symbols or speech, although an appropriate response had been given (e.g. repeated a statement, question, request, demand)

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

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12. Was Inactive

Was not engaged in any activity, was unoccupied (e.g. sat and did nothing, stared in to space or at the wall).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

13. Found it difficult to remember words, signs or symbols

Experienced difficulty remembering words, signs or symbols (e.g. names of familiar people, objects, places).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

14. Showed no interest in a usual activity

Was not interested in an activity, was difficult to engage, did not want to do anything.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

15. Withdrew from communicating

Did not want to communicate, (e.g. did not speak / respond to a familiar person, did not reply to a question, used the least amount of words / gestures).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

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16. Was confused about the time of day

Mixed up night with day (e.g. put night-clothes on in the day, wanted their breakfast at night).

0 1 2 3 4 5 6

17. Was confused about the day, season, year

Got mixed up with the days, seasons or years, (e.g. believed it to be summer in the winter).

0 1 2 3 4 5 6

18. Was confused about themselves and others

Did not recognise themselves or other familiar people.

0 1 2 3 4 5 6

19. Was confused about where they were

Forgot where they were, thought they were somewhere else.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

Continued on next page

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20. Lost their sense of direction

Got lost in familiar surroundings (e.g. got lost on their way to the shops, could not find their bedroom).

0 1 2 3 4 5 6

21. Behaved as though they were living in the past

E.g. asked for someone who had died many years ago (parent, friend), tried to perform a past routine (leaving the house to go somewhere they no longer attend).

0 1 2 3 4 5 6

22. Had a toileting accident

Defecated / urinated inappropriately (e.g. forgot to use the toilet or did use not incontinence aids correctly). If the person has lost the control over their bowel or bladder and is supported to wear incontinent aids score as 0)

0 1 2 3 4 5 6

23. Experienced difficulty eating/drinking

Appeared to have difficulty co-ordinating eating and drinking actions (e.g. putting food/drink to mouth, using cutlery). Found it hard to swallow, choked.

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

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- 5 = Severe effect
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24. Got muddled / mixed up when carrying out an everyday task or activity

Such as: dressing, washing, cooking, cleaning; (e.g. put clothes on back to front /wrong way around, forgot how to lay the table, put things away in the wrong place).

0 1 2 3 4 5 6

25. Experienced difficulty concentrating

Became easily distracted, found it hard to concentrate on a task.

0 1 2 3 4 5 6

26. Was not alert

Slept a lot during the day, appeared drowsy, dozed at an inappropriate time (e.g. while eating or on the toilet).

0 1 2 3 4 5 6

27. Appeared physically slowed down

Appeared slow to complete an activity (e.g. dressing, washing, eating).

0 1 2 3 4 5 6

28. Had a fall

Fell over or tripped up (e.g. tripped up a kerb, fell on the stairs).

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

0 1 2 3 4 5 6

You have now finished

Thank you for your time

SPECIMEN COPY

Scoring Instructions

This questionnaire is made up of 28 items, each item describes a behaviour. Items 1 – 11 describe behavioural excesses and items 12 – 28 describe behavioural deficits. The questionnaire also assesses three areas, a) how frequently the behaviour occurs, b) how difficult the behaviour is to manage and c) the effect the behaviour has upon the individual. This gives rise to six scores:

1. Frequency of excesses
2. Management difficulty of excesses
5. Effect of excesses
2. Frequency of deficits
4. Management difficulty of deficits
6. Effect of deficits

1. To find the **frequency** score for *excesses*, add up the numbers circled in the column “how often” for items 1 to 11 (pg. 1 + 2)
2. To find the **frequency** score for *deficits*, add up the numbers circled in the column “how often” for items 12 to 28 (pg. 3, 4,5 and 6)
3. To find the **management** score for *excesses*, add up the numbers circled in the column “management difficulty” for items 1 to 11 (pg. 1 and 2).
4. To find the **management** score for *excesses*, add up the numbers circled in the column “management difficulty” for items 12 to 28 (pg. 3, 4,5 and 6)
5. To find the **effect** score for *excesses*, add up the numbers circled in the column “effect” for items 1 to 11 (pg. 1 and 2).
6. To find the **effect** score for *deficits*, add up the numbers circled in the column “effect” for items 12 to 28 (pg. 3, 4,5 and 6).

| SCORES | Frequency | Management Difficulty | Effect |
|----------------------------------|--|---|-------------------------------------|
| Excesses Items 1 - 11 | Frequency of excesses (pg. 1+2) | Management difficulty of excesses (pg. 1+2) | Effect of excesses (pg. 1+2) |
| Deficits Items 12 - 28 | Frequency of deficits (pg. 3+4+5+6) | Management difficulty of deficits (pg. 3+4+5+ 6) | Effect of deficits (pg. 3+4+5+6) |

