

**Adults with Down’s Syndrome (A.D.S) Project
(University of Birmingham and South Birmingham NHS
Primary Care Trust)**

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

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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).

A study by Kalsy et al. (2002) 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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