BEHAVIOURAL AND EMOTIONAL PROBLEMS IN ADULTS WITH INTELLECTUAL DISABILITY: THE DEVELOPMENTAL BEHAVIOUR CHECKLIST FOR ADULTS

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DECLARATION

The research for this thesis was conducted by the author in the Monash University School of Psychology, Psychiatry and Psychological Medicine, between July 1999 and December, 2002. The work is original, and to the best of the candidate's knowledge, contains no material which has been accepted for the awarding of any other degree or diploma in any university or institution, nor does it contain any material previously published or written by another person except where due reference is made in the text. Ethics approval was gained from The Department of Human Services Ethics Committee (Application Numbers: 44/99, 75/00, 40/01) and Monash University Standing Committee on Ethics in Research Involving Humans (Application Numbers: 99/340, 2001/293) (see Appendix A.).

[redacted]

Caroline Mohr

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'If I have seen further it is by standing on the shoulders of Giants'
Isaac Newton in: Letter to Robert Hooke, February 5, 1675

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ABSTRACT

People with an intellectual disability (ID[1]) experience mental ill health more frequently than members of the general community. Unfortunately these mental health disorders often go undetected and untreated in this population.

Rating scales and checklists commonly used to assist in the diagnosis of mental illness and treatment monitoring are often not suitable for use with people with an ID. Instruments developed in recent years have some practical, theoretical or psychometric limitations in this special population.

This project aimed, in four studies, to develop a new checklist for use with adults with an ID by redeveloping an existing checklist used for young people, the Developmental Behaviour Checklist (DBC) [Einfeld, 1992 #222]. The DBC is a comprehensive rating scale of the emotional and behavioural difficulties experienced by children and adolescents with ID, completed by primary carers (DBC-P) and teachers (DBC-T). Studies using the DBC-P have confirmed that it is a reliable and valid instrument, and a cut-off score has been determined to indicate the likely presence of a psychiatric disorder.

Study 1 examined the clinic files of adults with ID assessed for behavioural and emotional disturbance to ascertain a comprehensive range of descriptions of disturbance, which were then discussed with experts. This process led to the addition of 12 new items to the DBC-P and the removal of one item, to form the Developmental Behaviour Checklist for Adults (DBC-A).

In Study 2 the ability of paid carers to reliably complete the DBC-A was assessed. Inter-rater agreement was acceptable (ICC= .48, 95% CI .24 - .66). Test-retest reliability

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[1] See Appendix B for a full glossary of abbreviations.

correlations were high (ICC= .75, 95% CI .55 - .86), however the mean scores of Time 1 and Time 2 were significantly different (*t*(33) = 3.88, p = .000 Sig. (2-tailed)), with a trend to lower ratings at Time 2. Concurrent validity was investigated by comparing the DBC-A total scores with total scores on another similar checklist, the Aberrant Behavior Checklist (ABC). The results indicate a moderate positive relationship between results on the two checklists.

Two additional assessments of concurrent validity were investigated in Study 3. Total scores on the DBC-A were compared to total scores on the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) Checklist. Again a moderate positive relationship between the two checklists was found, and clinicians' ratings of the presence and severity of psychopathology were also found to correlate with total DBC-A scores. A Receiver Operating Characteristics analysis indicated that a total cut-off score of 60 indicated with adequate sensitivity and specificity, the likely presence of a psychiatric disorder and the need for further specialist assessment.

In Study 4 the ability of family members of adults with an ID to reliably complete the DBC-A was assessed. Inter-rater agreement was acceptable with a strong positive relationship found between ratings made by two family members (ICC= .72, 95% CI .48 - .86). Test-retest reliability was also acceptable when family members (mostly mothers) completed the DBC-A twice. There was a strong positive correlation (ICC= .84, 95% CI .75 - .91) and no significant difference between scores at Time 1 and Time 2 (*t* (51) = .25, p = .81 Sig. (2-tailed)).

Data from Studies 2, 3 & 4 was used in the principal components analysis. An exploratory factor analysis was performed and after promax rotation a six-factor solution was selected. Similarities and differences of this factor solution, when compared to the child and adolescent version, were described.

In summary the four studies described here developed an existing checklist used with young people into a valid and reliable carer-completed checklist of the emotions and behaviour of adults with an ID. This new Developmental Behaviour Checklist for Adults, has acceptable psychometric properties, identifies those at risk of having a psychiatric disorder and has factorial validity.

The DBC-A has a potentially useful role to play in the assessment and management of mental health problems in adults with ID. It is also likely to be a useful research tool, for example, in service planning and epidemiological studies of psychopathology and studies of behavioural phenotypes in people with specific disorders associated with ID in adulthood.

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INTRODUCTION

There is a variable response to the mental health needs of adults with an ID in comparable countries (Jacobson, 1999; Marcos, Gil, & Vasquez, 1986; van Minnen, Hoelsgens, & Hoogduin, 1994). Few population centres have specialist mental health in ID services outside the UK, and indeed some service providers debate the need to establish them (Lennox & Chaplin, 1996; Marcos et al., 1986). Except in the UK (Day, 1999), very little teaching is undertaken in courses that train the next generation of mental health clinicians to help them provide the services that are needed (Lennox & Chaplin, 1995).

The prevalence of mental illness in adults with an ID remains imprecisely measured, although almost every study of recent times suggests that it is greater than that found in the general population (e.g. Maughan, Collishaw, & Pickles, 1999; Rymill, 2001; Simpson, 1998). Neither has the developmental trajectory of mental health problems from childhood to adulthood in people with ID been sufficiently researched and understood (Tonge & Einfeld, 2000).

People with an ID and untreated psychiatric disorders lead unnecessarily difficult and probably unhappy lives. Their carers and family members experience ongoing stress and anxiety about working and living with them, in situations that are often fraught with distress, injury and additional financial burden (Hatton, 1999; Tonge, 1999).

Carers seek help from various professionals and may receive conflicting and incompatible explanations for the cause and optimal treatment of 'challenging' behaviour. The same behaviour can be described by different professionals as challenging, maladaptive or a symptom of a mental illness, and professionals often decry the treatment suggestions of other clinicians leaving all those involved confused and often angry.

In the area of diagnosis even an experienced clinician may not be sure how much weight to give to existing diagnostic frameworks and criteria when arriving at a diagnosis for a person with an ID (Moss, 1999). When a mental health disorder is diagnosed, limited treatment, compared to that available in the general community, can be offered and may be restricted to a prescribed medication (Hollins, 1997).

In a specific health service in Victoria for adults with ID it is not uncommon for the clinicians to diagnose and treat a depressive disorder in a person with ID whose unhappiness had gone undetected for years (Burbidge, 2002). Frustratingly, their patient may have already been the subject of several behavioural programs to try and change 'challenging' behaviour.

The research reported in this thesis aimed to develop a reliable and valid carer-completed checklist of psychopathology in adults with ID. What does such research have to offer a person with ID and mental illness who is so beset with difficulties? This question can be answered from several perspectives.

In a health setting characterised by scarce resources, few services and few clinicians with expertise, it is important that those people who most need assistance are the ones who receive it. A screening instrument with an appropriate cut-off point for psychiatric caseness, with known sensitivity and specificity would help ensure that those individuals most likely to have a mental health problem receive these limited services.

In this area of specialty in mental healthcare arriving at a sound diagnosis is difficult and the information provided by a reliable and valid assessment tool might also assist the process of clinical assessment, diagnosis and management.

Communication is often limited in people with ID. Therefore a carer-completed checklist provides carers with the opportunity to convey their valuable information in a structured manner.

The comprehensive mental health assessment of a person with an ID can be time consuming. The use of a comprehensive rating scale can help make the best use of clinical time.

Repeated use of a comprehensive rating scale provides accessible information about how emotional and behavioural difficulties may change over time as part of maturation and the natural history of a disorder, or in response to treatment or environmental change.

There are conflicting results of studies into the prevalence of mental health disorder in people with ID, and the development of these disorders over time is not well understood. Therefore the development of a checklist of emotional and behavioural problems that can be used with children and adults with ID of all ages would be an asset.

In the following chapters the current literature will be reviewed in relation to the prevalence and diagnosis of mental health problems in people with ID. Existing psychopathology checklists and rating scales will be reviewed and from these an instrument developed in Australia 10 years ago, the Developmental Behaviour Checklist (DBC) (Einfeld & Tonge, 1992), was selected to form the basis of a new checklist. This psychometrically sound checklist had already performed well in epidemiological studies of children and adolescents with ID, and investigations into behavioural phenotypes and specific mental health disorders and had the potential to assist in the identification of mental health disorders in people of all ages with ID (Einfeld & Tonge, 2002).

It was hoped that extending the utility of the DBC into the field of adult mental health care and research might make a contribution to improving the mental health care of people with an ID.

CHAPTER 2

PSYCHOPATHOLOGY AND INTELLECTUAL DISABILITY IN ADULTHOOD

In this chapter the main terms will be defined and an historical perspective on psychopathology in ID will be given. Difficulties in arriving at reliable and valid diagnoses will be discussed, especially in relation to research investigating the population prevalence of psychopathology in ID.

2.1 DEFINITIONS

2.1.1 INTELLECTUAL DISABILITY

Intellectual Disability is not a universally accepted term to describe deficits in cognitive functioning and adaptive behaviour[2] occurring in the developmental period, but it is the term that will be used in this thesis. In fact there is no universally adopted term. Other terms in current usage are mental retardation (the term preferred in America), mental deficiency, mental impairment and learning disability (as it is used in the UK). Intellectual disability is the term used throughout Australia. Efforts by the association of the Australian Society for the Study of Intellectual Disability (ASSID) have led to acceptance by all government departments and non-government service organisations of the term intellectual disability.

Mental Retardation, a synonymous term with Intellectual Disability, is used in DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organization,

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[2] Throughout this thesis Australian spelling will be used except when referring to a published work, e.g. The Aberrant Behavior Checklist (Aman & Singh, 1985).

1992). The DSM-IV definition is:

> Criterion A: Significant subaverage intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test (with a mean of 100 and a standard deviation of 15).
>
> Criterion B: Concurrent deficits in adaptive behaviour in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
>
> Criterion C: The onset is before age 18 years (American Psychiatric Association, 1994, p. 46).

The DSM-IV sub-classification by IQ level into mild, moderate, severe and profound intellectual disability also appears in ICD-10, however ICD-10 gives a more definite delineation for research purposes, in contrast to clinical purposes where flexibility is more desirable. For example in DSM-IV the IQ range for mild intellectual disability is 50-55 to 70, whereas in ICD-10 it is 50-69.

Criterion B is not used in the studies reported in this thesis. Borthwick (1988) and Einfeld and Tonge (1992) discuss the issue of using Criterion B in studies of psychopathology in people with intellectual disabilities, and conclude that this criteria should not be used, because excluding individuals without deficits in adaptive behaviour from studies could elevate the prevalence of emotional and behavioural disorders found in this population.

However, as Einfeld and Tonge (1992) suggest "the effect of excluding Criteria B may be more apparent than real" (p. xi), as most people without deficits in adaptive functioning have an IQ in the upper mild ID range, a group that are often under represented in epidemiological samples used in prevalence surveys and rating scale studies. Some adults with mild ID may not have deficits in adaptive functioning, however they still experience emotional and behavioural difficulties.

Measures of adaptive functioning are also less psychometrically rigorous than tests of cognitive functioning (Aman & Schroeder, 1990). Whilst reliance on IQ score as the sole criterion for case ascertainment violates the accepted definition of intellectual disability which includes deficits in adaptive functioning, it is the only standardised method of case finding which can be relied upon to produce comparable results across studies (Aman & Schroeder, 1990).

Developmental Disability is a related but different term, defined by the presence of functional limitations in three or more areas of major life activity (e.g., self-care, receptive and expressive language, learning, mobility, capacity for independent living) originating before the age of 22 and likely to continue indefinitely (Larson et al., 2001). Pervasive Developmental disorders and cerebral palsy are examples of developmental disabilities.

2.1.2 MENTAL DISORDER

DSM-IV (American Psychiatric Association, 1994) defines mental disorder as "a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or disability (e.g., impairment in one or more important functioning area) or with significant increased risk of suffering, death, pain or disability" (p. xxi). Examples of a mental disorder as defined here are Schizophrenia and Bipolar Affective Disorder. Although 'Intellectual Disability' is part of the psychiatric classification system, it is not a mental illness (Deb, Matthews, Holt, & Bouras, 2001a).

Psychiatry is primarily concerned with the treatment of mental disorders that adversely affect an individual's mental health and ability to function and maintain an acceptable quality of life (Holland, 1999). The practice of psychiatry has made rapid progress following the development of agreed diagnostic criteria for specific mental disorders, as described in the American Psychiatric Association Diagnostic and Statistical Manual, 4th Edition (DSM-IV)(American Psychiatric Association, 1994) and the International Classification of Diseases, 10th Edition (ICD-10) (World Health Organization, 1992).

DSM-IV and ICD-10 have been designed primarily for use with people of normal intelligence, and the clinical features which must be present to confirm a diagnosis of mental disorder may be difficult to detect in a person with an intellectual disability, particularly when language skills are absent (Sovner, 1986). This does not mean that the principles inherent in the use of diagnostic criteria do not apply. The concept that psychiatric disorders form discrete syndromes with characteristic emotional features and specific behaviours is equally relevant to individuals with intellectual disabilities (Sovner & Hurley, 1986).

2.1.3 PSYCHOPATHOLOGY

The Australian Concise Oxford Dictionary (Moore, 1997) defines psychopathology as "a mentally or behaviourally disordered state" (p. 1085), however there is considerable debate in the psychological literature about the definition of psychopathology (Bergner, 1997). Bergner (1997) states that this lack of clarity and agreement about a definition has hampered efforts to study and treat psychopathology.

The definition used in this thesis of psychopathology in relation to adults with intellectual disability is:

Behaviours and emotions which are abnormal by virtue of their qualitative or quantitative deviancy and cannot be explained on the basis of intellectual disability alone, cause significant distress to the person, carers or the community, as well as significant added impairment. (Einfeld & Tonge, 1992, p. xii).

This definition was used by Einfeld and Tonge (1992) in the studies of children and adolescents with intellectual disability led to the development of the Developmental Behaviour Checklist (Einfeld & Tonge, 1992). They adapted it from Reid (1978) who derived it from the work of Graham and Rutter (1970).

2.1.4 DUAL DIAGNOSIS

Dual Diagnosis is a term adopted initially by American clinicians and researchers to refer to a group of individuals who have two co-morbid conditions, one of them being a psychiatric disorder. The term arose out of a need to make administrative distinctions because funding came from different sources (Russell, 1997). Confusingly this term is now used to refer to two groups of people with co-morbidity, firstly psychiatric disorder and intellectual disability, and secondly psychiatric disorder and substance abuse disorders. Both groups present psychiatric services with diagnostic and treatment challenges.

In some states in Australia, such as Victoria, the term Dual Disability, which refers to the co-existence of intellectual disability and a psychiatric disorder, has been adopted. As the presence of a psychiatric disorder does not necessarily equate with the long-term acquisition of any additional disability, this term will not be used here.

2.1.5 CHALLENGING BEHAVIOUR

Some behaviour of people with an intellectual disability has come to be routinely described as 'challenging' in Australian ID service systems. This term was first defined and used by Emerson, Toogood and Mansell (1987) in the United Kingdom.

Severely challenging behaviour refers to behaviour of such intensity frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities. (Emerson et al., 1987, p.166).

'Challenging behaviour' is not a clinical diagnosis and will not be used here to describe the behaviour exhibited by people with an intellectual disability. In a study cited in Russell (1997) by Allen and Kerr (1994) no significant differences were found between those people with an intellectual disability referred to two separate services, one providing treatment for challenging behaviour and the other treatment for psychiatric disorders.

2.2 PREVALENCE OF INTELLECTUAL DISABILITY IN ADULTHOOD

Approximately three percent of the population have an IQ less than 70 points, that is, have an IQ equal to or less than minus two standard deviations below the mean (Baroff, 1982). Eighty-five percent of people with an intellectual disability fall into the mild range, 10% in the moderate range, 3-4% into the severe range and 1-2% in the profound range (American Psychiatric Association, 1994). Knowledge of the prevalence of intellectual disability allows fair and equitable decision making regarding policy planning, resource allocation and service provision (Larson et al., 2001).

Study of the exact prevalence of ID in children is a difficult task however it is probably even more difficult with adults. In a recent study Larson, Lakin, Anderson, Kwak, Lee, and Anderson (2001) sought to determine the prevalence of both ID and developmental disability in the non-institutional population of the United States for the years 1994/1995 using mainly face-to-face interviews in a very large randomly selected household survey. They found a prevalence of 5.2 per 1000 adults with intellectual disability, of which 3.2 also had a developmental disability. The rates for children aged 6-17 years were much higher; 20.3 per thousand had an ID, of which 8.1 per thousand also had a DD. This finding is consistent with the assertion that rates of ascertainment of ID are not stable with respect to age (Larson et al., 2001), for two main reasons; 1. mortality increases with age, and 2. free of the intellectual demands and assessment of schooling, adults, particularly those with mild ID, tend to merge with the general population and no longer attract a label of intellectual disability. When figures from congregate care settings were added to the total community population rate of 14.9 per thousand for all people with ID and/or DD, it rose to 15.8 per thousand.

In another recent study in the UK, Morgan, Ahmed and Kerr (2000) used a health and social services record linkages approach to identify all people with intellectual disability in a health district. Prevalence rates were 4.1 (males) and 3.2 (females) per 1000, slightly higher in the city and lower in the rural areas. They state "our figures were comparable with those recorded across a wide range of Western Europe and North America populations" (Morgan et al., 2000, p.39), a claim supported by the review of studies conducted by McLaren and Bryson (1987). In common with other studies, the authors also state that those with a mild intellectual disability were probably underrepresented.

A comprehensive review of the prevalence of ID in Australia estimates levels of 4-5/1000 based on all age groups of people with an intellectual disability known to all agencies (Wen, 1997). This is a figure close to the Larson (2001) study which used the more direct method of population survey to ascertain prevalence.

2.3 HISTORICAL PERSPECTIVE OF MENTAL HEALTH IN THE LIVES OF PEOPLE WITH AN INTELLECTUAL DISABILITY

Distinctions have been drawn between mental illness and intellectual disability for centuries (Reid, 1989). In France in the fourteenth century a distinction was made in law between the 'idiot' and the 'lunatic' in the Statute de Praerogative Regis. This statute was concerned mainly with the disposition of property, and gave better protection to the rights of the 'lunatic' who was presumed to be curable, than to the 'idiot' whose prognosis was considered hopeless and whose property and other assets could be taken over by the crown (Shapiro, 1979). Separate criteria for the examination of people suspected of 'idiocy' and 'lunacy' were established by courts (Neugebauer, 1989). Examinations conducted for the assessment of idiocy were concerned with "orientation, memory, intellect and judgement" (Neugebauer, 1989, p. 570), and in lunacy hearings the evidence gathered was mostly about "disturbed behaviour and ideation..[as well as being]..evaluated for intellectual defects" (Neugebauer, 1989, p. 570). John Locke wrote in 1690, cited in Doll (1962) "Herein seems to lie the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, but idiots make very few if any propositions and reason scarce at all" (Doll, 1962, p. 23).

Descriptions of the co-occurrence of ID and mental health disorder appeared in the medical literature in the nineteenth century (Shapiro, 1979). Doctors working with people with intellectual disability began to write about their observations of disturbed behaviour in their patients which they characterised in psychiatric terms. For example, Wells wrote in 1845 (cited in Reid, 1989) about mania and suicidal behaviour in 'cretins', people whose cognitive functioning had been lowered by a goitre condition. In 1866 Seguin, (cited in Reid, 1989) divided "psychoses in idiot children" (p. 364) into 'hyperkinetic' and 'hypokinetic' subgroups. In 1888 Hurd published a paper in America titled ' Imbecility with Insanity' identifying cases of mania, melancholia, and delusional disorders (Hurd, 1888). Making what Reid (1989) was to later call "very perceptive clinical observations" (p. 364), Berkley (1915) (cited in Reid, 1989) wrote that in his view "the moron was more susceptible to psychosis than the individual of normal intelligence" (p.364). Gordon

(1918) (cited in Reid, 1989) made detailed observations of cases of manic depressive psychosis in people with an intellectual disability. His comments that their delusions lacked depth and elaboration, and in manic states they lacked a quickness of comprehension, wit or humour, are consistent with contemporary comments (Sovner & Pary, 1993).

Views on the susceptibility of people with ID to mental health disorders varied (Wright, 1982). Myerson and Boyle (1941) (cited in Wright, 1982) thought they were no more likely to have a mental illness, whilst Pollock (1945) (cited in Wright, 1982) thought that with increasing intelligence there was a diminishing incidence of mental disease. Difficulties in diagnosis were acknowledged (Heaton-Ward, 1977), however an experienced psychiatrist, Penrose (1938), working and publishing in Britain in the 1960s claimed that "the problems of separating the effects of low intelligence from those of mental illness were not insoluble" (Heaton-Ward, 1977, p. 525).

Reid (1989) comments that by the 1960s "surveys were beginning to suggest a very significant relationship between mental retardation and mental illness" (Reid, 1989, p. 365), and that since then there have been major advances in research and practice, including the proliferation of books and conferences. The National Association for the Dually Diagnosed (NADD) was established in America in the early 1980s, and Sovner and Hurley (1982) began their small but influential publication, first called 'Psychiatric Aspects of Mental Retardation Newsletter' in 1982.

2.4 RECENTLY CONDUCTED PREVALENCE STUDIES OF PSYCHOPATHOLOGY IN THE ADULT ID POPULATION

Although many claims have been made over the past thirty years that adults with an intellectual disability experience higher rates of mental illness than members of the general community, the evidence to support this contention is weak (Deb et al., 2001a). Results between studies cannot be directly compared for the following reasons:

There are different ways to report prevalence, e.g., point prevalence or lifetime prevalence. Often studies fail to report which timeframe they used, and results cannot be compared.

The assessment of behaviour disorder and mental disorder have been hopelessly confused in many studies, only occasionally being assessed and/or reported separately.

Researchers have studied both children and adults in various residential settings with all degrees of intellectual disability, often without reporting rates for groups separately. For example, the rates for adults in an institution in the 1990s cannot be compared to rates for children, any groups in the community, or even to adults in institutions in the 1960s because of changes in service philosophy.

Studies of community samples have often been administratively derived and not representative of the population of people with an ID as a whole. The results from studies of people referred to specialist services are the least generalisable results of all. Even the best studies struggle to include many people with a mild intellectual disability many of whom are 'submerged' in the general community (Einfeld & Tonge, 1996).

The definitions of a 'mental disorder', 'a psychiatric problem' or an 'intellectual disability' change across time and from study to study, again rendering comparisons meaningless.

Different methods of assessment are used, e.g., psychiatric interview by specialist psychiatrist, a checklist or rating scale completed by a carer, or review of clinic files.

Periodically reviews of prevalence studies are published, and come to different conclusions, although similar studies may be included in each review.

Wright (1982) reviewed the studies conducted in the UK prior to 1980, starting with the landmark clinical and genetic study of 1280 people with an ID by Penrose in 1938 (Penrose, 1938). Recognising the differences between, and flaws in, most studies, she concluded that her work confirmed the studies by Heaton-Ward (1977), that rates of mental disorder in the population of people with an intellectual disability was probably similar to rates in the general population (Office of Population Censuses and Surveys, 1974).

Singh, Sood, Sonenklar, and Ellis (1991) reviewed studies estimating the prevalence of mental illness in individuals with intellectual disability conducted in the 1970s and 1980s (e.g., the work of Rutter and his colleagues, (1970), Matson and Frame (1986), Heaton-Ward (1977), Jacobson (1982) and Reiss (1982)). They concluded that:

1. 8 – 10 % of individuals with intellectual disability who reside in institutions have a severe mental disorder requiring treatment.
2. About 50% of institutionalised people with ID are likely to have at least one identifiable psychiatric disorder.
3. 20 – 30% of children with ID residing in institutions had a mental disorder.
4. 20 – 35% of children with ID living in the community have a diagnosable mental disorder, compared to only 14 – 18% of children in the general population.
5. Reliable data on the prevalence of mental illness in adults with ID living in the community was not currently available (Singh et al., 1991, p. 422).

Summarised on Table 1 are the studies on the prevalence of psychopathology in adults with an ID reported from 1990 to 2001. What do these latest studies indicate? Again methodological difficulties abound, and the interpretation of the findings depends heavily on which definition of Mental Disorder is used.

Table 1. Prevalence studies of psychiatric disorder in populations with intellectual disability from 1990 to 2001

Authors/Year	Sample	Study method and measures	Findings	Comparison
Borthwick-Duffy & Eyman (1990)	78,603 clients receiving services from California Dept of Developmental Disability Services in 1986, 0-86 years.	Client Development Evaluation Report, with sections on behaviour difficulties, and psychiatric disorder if diagnosed by a qualified professional.	Dual diagnosis = 10% of total. Mild ID 54.3%, Moderate ID 25.7%, Severe ID 11.5%, Profound ID 8.5%.	
Reiss (1990)	205 adults participating in community day programmes randomly selected from enrollment records.	Reiss Screen for Maladaptive Behavior completed by teacher who knew person well.	80 (39%) tested positive for dual diagnosis, 86.7% confirmed on clinical assessment 6-12 months later.	
Ballinger, Ballinger, Reid & McQueen (1991)	100 adults (16+) randomly selected from 168 (from Dundee) in a mental handicap hospital.	Psychiatrist interviews using modified Standardised Clinical Interview Schedule (SCIS) ICD-9 diagnosis.	59 patients rated as pathological on SCIS. 80 patients had at least one psychiatric diagnosis.	
Collacott, Cooper & McGrother (1992)	371 (98%) people with Down syndrome (DS) of population in the Leicestershire Health Authority with DS, plus 371 matched controls without DS, 12% hospital group, others in community.	Examination of clinical records. 51% of DS had had a psychiatric examination, 68.5% of controls.	25.9% of DS had psychiatric diagnosis, 37.8% of controls. Depression = 11.3% DS, 4.3% controls; Schiz/Paranoid state = 1.6% DS, 5.4% controls.	
Rojahn, Borthwick-Duffy & Jacobson (1993)	All ID individuals registered in New York (91% adult) and California (51% adult).	California (as for study above) New York – Developmental Disabilities Information Survey (DDIS) recording behaviour problems and psychiatric diagnoses.	Psychiatric diagnosis 3.9% (California) and 5.4% (NY).	

Table 1. Prevalence studies of psychiatric disorder in populations with intellectual disability from 1990 to 2001

Authors/Year	Sample	Study method and measures	Findings	Comparison
Meins (1993)	798 people with ID (older than 19years) in and around Hamburg.	Children's Depression Inventory (CDI) plus psychiatric examination of high and low scorers within 13 days.	Prevalence range for depression from 3% to 9% across residential settings, about 4% for group homes, 9% for a psychiatric clinic, 4.8% overall.	Compared to rates in general population.
Crews, Bonaventura & Rowe (1994)	1,273 individuals with ID in State Training Centre, aged 10-80 years, mostly severe and profound ID.	Case records containing DSM diagnosis made by psychiatrist, psychologist or physician.	Point prevalence of psychiatric disorder = 15.55%, higher rates for those with mild ID and males; 8.88% affective disorder.	Compared to general population point prevalence of 12.6% for psychiatric diagnosis and 5.1% for affective disorder.
Haveman, Maaskant, Van Schrojenstein Lantman, Urlings & Kessels (1994)	1580 people with ID, stratified sample from 83 group homes and 24 institutions, mostly adults.	Medical 60 item checklist completed by persons GP, Gerontological Questionnaire (GQ), ratings of challenging behaviour completed by nursing staff, psychiatric disorder reported by GP.	23-29% across age groups of adult population had a diagnosed mental disorder reported by GP. Affective disorder 6.3%, Psychosis 2.6%, Neurotic disorder 4.1%, Personality disorder 5.8%.	Mild ID DS group only reported to have low rate of psychosis and no other psychiatric disorder. Severe ID DS group had low rate of disorder compared to non-DS group.
Cooper (1997)	134 people with ID, 65-94 years, compared to a representative sample of younger people with ID (20-64 years) n=73.	Medical assessment, Disability Assessment Schedule, Present Psychiatric State – Learning Disabilities (PPS-LD) a semi-structured subject & informant interview, modified ICD-10 diagnostic criteria.	68% of older group found to have a psychiatric disorder, and 48% of younger group. Schizophrenia 3% in both groups. Depression 6% in older, 4.1% in younger. Anxiety disorder 9% in older, 5.5% in younger.	

Table 1. Prevalence studies of psychiatric disorder in populations with intellectual disability from 1990 to 2001

Authors/Year	Sample	Study method and measures	Findings	Comparison
Simpson (1998)	25% random sample of register of adults with an ID using health and social services, n = 93.	PAS-ADD Interview, main carer as informant, diagnosis using ICD-10 Diagnostic Criteria for Research and DSM-IV diagnoses.	One-month prevalence of DSM-IV Axis 1 disorders was 25.8%. 2 delirium, 3 functional psychoses, 3 depression, 1 mixed affective disorder, 11 anxiety disorders, 4 hypersomnia.	General population, one month prevalence, 16%.
Maughan, Collishaw & Pickles (1999)	National Child Development Study. 100 mild ID, 7205 non-ID comparison group.	Malaise Inventory, 24-item self-completion scale, read to subjects if necessary.	29.7% men high Malaise score, 51.1% of women high Malaise score.	9.0% men with high Malaise score, 15.9% women with high Malaise score.
Morgan, Ahmed & Kerr (2000)	Study of the mainly adult population of South Glamorgan Health Authority, ID identified by inclusion on social services register with ID identified or included on data base for services from the learning disability specialty, divided into institutional group, ex-institutional group and community group.	Patients record linkage techniques. Success of study depends of the likelihood of relevant patients coming into contact with services, and the accuracy and thoroughness of coding.	Psychiatric contact Ex-institutional = 42.1% Institutional = 11.3% Community = 15.6% Overall 16.5% coded for contact with psychiatric services. Contact figures described as 'proxy' prevalence data.	Non-learning disabled comparison group for medical admissions but not for admission rates for psychiatric disorder.
Richards, Maughan, Hardy, Hall, Strydom & Wadsworth (2001)	Total 1946 British birth cohort, 41 with mild ID, 2119 controls.	Present State Examination at 36 years Psychiatric Symptom Frequency Scale at 43 years. School teachers behavioural ratings at age 15.	More likely to have a behaviour disorder at school. Four fold increase in risk of affective disorder in mid-life, not accounted for by social and material disadvantage or by medical disorder.	Control group.

Table 1. Prevalence studies of psychiatric disorder in populations with intellectual disability from 1990 to 2001

Authors/Year	Sample	Study method and measures	Findings	Comparison
Deb, Thomas & Bright (2001)	120 adults randomly selected from all 246 people with ID in a region, 101 available for an interview. All subjects resided in the community. Ages from 16 to 64 years.	101 adults and their carers interviewed by trained psychiatrist. 90/101 completed Mini PAS-ADD, 20 selected for caseness. 19/20 interviewed with carers by second psychiatrist, blind to initial diagnosis, with full PAS-ADD interview. Remaining 11 assessed on the DASH-II.	Mini PAS-ADD = 20 (22.2%) of cohort diagnosed PAS-ADD/ICD-10 = 13 (14.4%) .of cohort diagnosed.	General population = 16%.
Victoria, Australia, Prevalence survey, (1996)	Clients receiving case management from Intellectual Disability Services in Victoria.	Case managers surveyed to report on the number of clients who 1. Were formally diagnosed with a psychiatric disorder, and 2. In the opinion of the case manager did have a psychiatric disorder.	10.8% of clients with formal diagnosis additional 7% in the opinion of case manager.	
Rymill (2000)	Adults and children in South Australia with an ID receiving services from government or non-government service providers.	Survey of workers, seven criteria for the presence of a psychiatric disorder, with any 3 out of 7 indicating presence of disorder.	16.2% of adults identified as having a psychiatric disorder.	

The study by Borthwick-Duffy and Eyman (1990) fails to elaborate on what a 'Dual Diagnosis' is, except to say that a person in this group had been seen by a mental health professional and may have received a DSM diagnosis. Ten percent of their large statewide administrative sample fell into this category. This study also contains flawed conclusions about the relative risk of a person with a mild ID being at risk of having a psychiatric disorder.

In a paper by Reiss (1990) some additional computations suggest that 31% of the total sample of 205 were diagnosed with a mental health problem, as opposed to the 39% identified by the Reiss Screen of Maladaptive Behavior (RSMB), and the rates for Personality Disorder were very high. Only 11.7% of the cohort had a psychiatric disorder recorded on their case notes. There was no reported agreement on what constitutes a psychiatric disorder. In another small prevalence study of a community group (n=180) Sturmey, Burcham and Shaw (1996) report a similar finding (49%) using the RSMB as a screening tool.

Ballinger, Ballinger, Reid and McQueen's (1991) study of 100 adults in a Scottish institution was rigorous in the use of psychiatric interviews and ICD-9 diagnostic criteria. However their claim that 80 people out of 100 had at least one psychiatric diagnosis is weakened when the number of people with a diagnosis of autism, conduct disorder, Attention Deficient Hyperactivity Disorder (ADHD), personality disorder and sexual difficulty is removed, leaving a total of 21/100.

The study by Collacott, Cooper and McGrother (1992) of people with Down syndrome (DS) and matched controls, examined clinical records to find that 51% of the DS group, and 68.5% of the matched controls had had a psychiatric assessment, with 26% of the DS group, and 38% of controls receiving a diagnosis. However if autism, conduct disorder and dementia are removed from the subgroups, only 15% of the DS group, and

14% of the matched controls remain.

Rojahn, Borthwick-Duffy and Jacobson (1993) reported an enormous analysis using data from California (N=89,000, 91% adult) and New York (N= 45,000, 51% adult) intellectual and developmental disability service registers. Within the adult component of the cohort, in New York the majority (59%) of diagnoses were made up of Attention Deficit Hyperactivity Disorder (ADHD), conduct disorder and Pervasive Developmental Disorder (PDD), whilst in the Californian adult cohort these disorders comprise less than a quarter of the group, with schizophrenia making up nearly one half of the total. The magnitude of these diagnostic differences make comparisons meaningless, and indicates that the overall prevalence rates quoted are unlikely to be accurate.

Meins (1993) reports the first prevalence study of depressive disorders, in an unrepresentative sample of 798 adults with ID living in and around Hamburg. The sample included a mix of subjects living in group homes, institutions and a psychiatric hospital. Meins elected to use the Children's Depression Inventory (CDI) (Kovacs, 1985, cited in Meins, 1993) as an initial screening instrument, followed by a 'psychiatric examination' (not elaborated) he conducted of both low and high CDI scoring subjects, who were diagnosed according to modified DSM-III-R criteria. Unfortunately, these findings are compromised because they relied on the diagnostic opinion of one clinician who was not blind to the CDI score of each subject examined.

Crews, Bonaventura ands Rowe (1994) studied the case records of an institutionalised group containing very few people with a mild ID (3%), and over 80% with a severe or profound intellectual disability. Institutional groups should contain disproportionately large numbers of people with mental health problems. The finding by Crews (1994) that the point prevalence rate of a psychiatric disorder was close to that found in the general population might be accounted for by the difficulty that clinicians have in diagnosing psychiatric disorders in people with severe and profound intellectual disabilities.

Haveman, Maaskant, Van Schrojenstein, Lantman, Urlings and Kessels (1994) investigated the mental health status of a stratified sample of adults with an intellectual disability living in group homes and institutions in the Netherlands. Psychiatric disorders were reported by the general practitioners, specialists in working with people with ID. Psychiatric assessments performed by these GPs were not conducted in a standardised way. This component of study design is problematic, and makes the study conclusions difficult to interpret.

Cooper's (1997) study has many advantages over other studies. All elderly people registered for Learning Disability services, and a random sample of younger people from the same area, were all individually assessed using well-described instruments, and where standard diagnostic criteria were modified, the modifications were outlined. The overall results of prevalence of psychiatric disorder in both groups is high (older group, 68%; younger group 48%), however when dementia, possible dementia, Rett Syndrome, alcoholism, autism and behaviour disorder are removed from the overall totals, the prevalence rates are almost the same for both groups at approximately 20%.

Simpson (1998) reports the results of a small but methodologically strong study conducted in North-West England. The sample of adults with ID was randomly selected from the register of adults with ID using health and social services. Ninety-three adults and their carers were interviewed by a psychiatrist specialising in ID psychiatry, using a structured interview schedule (the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) (Moss, Prosser, Ibbotson, & Goldberg, 1996)). The interview record was examined to ascribe DSM-IV diagnoses, and 24 individuals received a diagnosis (2 delirium, 3 psychoses, 3 depression, 1 mixed affective disorder, 11 anxiety disorder, and 4 hypersomnia). The one-month period prevalence of an Axis 1 disorder was therefore 25.8% (Simpson, 1998), considerably higher than the prevalence rate for the general population of 16% (Jenkins et al., 1997), "but the sample size is too small to make statistical comparisons" (Simpson, 1998, p. 41).

Maughan, Collishaw and Pickles (1999) report data on a population study of people with a mild intellectual disability from the National Child Development Study, which was a prospective study of all children in Britain born in one week in 1958. This study is valuable because few studies of adults with an ID include people with mild intellectual disability because they often blend into the general population after leaving school. Unfortunately the measure used to assess mental health status (The Malaise Inventory, Rutter et al., 1970) is not a widely used instrument and reported only on affective symptoms. Nonetheless, the results of a 4 to 5 times higher rate of affective disorder in the ID group, are striking. These authors also compare the results with the bulk of the cohort, and attempt to determine what factors may have influenced the findings.

A study by Morgan, Ahmed and Kerr (2000) produced an overall prevalence of 16.5%, a much higher finding for an ex-institutional group (42.1%), and a lower rate for a presently institutionalised group (11.3%) and those in the community (15.6%). However their argument that contact with a psychiatric service statistic can be 'translated' into 'proxy' prevalence data cannot be justified.

Richards, Maughan, Hardy, Hall, Strydom, and Wadsworth (2001) report findings from another British cohort, the Medical Research Council's National Survey of Health and Development 1946 birth cohort. Again these findings inform the limited information available on the lives and circumstances of people with a mild intellectual disability, although the numbers are even smaller than the Maughan et al.(1999) survey. The measures used across this cohort were not validated for use with people with an intellectual disability. However for people with mild ID this may be less of a concern, and they were interview, not self-report, measures. Their findings seem to confirm the earlier reports of Maughan (1999) on prevalence, but they did not agree that early disadvantage was a predictor of poorer mental health.

In a recent methodologically sound study Deb, Thomas, and Bright (2001b) interviewed 101 people with an ID (from a random sample of 120), known to services in a region of Wales, and their carers, using instruments with known psychometric properties developed for use with the ID population. The screening tool (Mini PAS-ADD, (Prosser et al., 1998)) identified 22% as psychiatrically disordered. The follow-up interview by a psychiatrist blind to the screening result confirmed a diagnosis in 14.4%, a lower rate than the 16% point prevalence rate quoted for the general population, although the rates of schizophrenia and phobic disorder were much higher.

Only two attempts at estimating prevalence in adults with ID in Australia could be located. Although it is not explicitly stated in either study, it is likely that most of the clients identified by these surveys lived in the community, because almost all people with an ID in Australia now live in community based accommodation.

Firstly, in Victoria a survey of Intellectual Disability Services case managers was undertaken by the Disability Services Branch of the State Department of Human Services. The survey asked case workers to identify from 1776 clients with ID being provided with case management at that time, those clients who were either formally diagnosed with a psychiatric disorder, or who 'informally' appeared, in the opinion of the case worker, to have a psychiatric disorder. Ninety-five percent of clients were aged over 15 years. The questionnaires were returned by 64% of workers, who identified 10.8% of clients with a formal diagnosis, and 7% as possibly having one. Nearly half of the clients with an informal diagnosis had had a formal diagnosis in the past.

Secondly, a small Dual Disability Service (Rymill, 2001) in South Australia surveyed staff in government and non-government services for adults and children with an intellectual disability. The survey questionnaire contained seven 'indicators' that a person might have a mental illness, ranging from 1: Departure from the person's usual pattern and/or level of functioning, to 4: Clusters of symptoms which fit standard diagnostic criteria, to 7: Past or current treatment from a mental health service or private psychiatrist. Any three out of the seven criteria were taken to indicate that the person had a psychiatric disorder. The overall prevalence rate of psychiatric disorder for adults was 16.2% (A. Rymill, personal communication, June 2002).

One further publication sheds some light on adult prevalence in the Australian context. The original epidemiologically derived representative sample of children and adolescents with an ID established by Einfeld and Tonge in 1991, in the foundation research that established the Developmental Behaviour Checklist – Primary Carer version (DBC-P), has been restudied at 3-4 yearly intervals. The subjects (80% of the original group) were reassessed at Time 2 in 1995/96 when nearly half were aged 17 – 24 years. The 1991 study identified that about 40% of the cohort rated over the well-defined DBC-P cut-off score for psychiatric caseness. The 1995 study, whilst demonstrating that the mental health of 14% of the sample had either improved or deteriorated, showed that the overall rate had essentially remained the same (Tonge & Einfeld, 2000). This ongoing study does not rely on worker report or opinion, uses an epidemiological representative sample of people with ID and a checklist with demonstrated reliability and validity, surveys participants wherever they live, and its participation rate at Time 2 was high (80%).

2.5 SUMMARY AND CRITIQUE OF PREVALENCE STUDIES

There are several different types of prevalence studied in relation to disease (Kaplan & Sadock, 1988). Point prevalence is the number of people who have a disorder at a specific time. Period prevalence is the number of people who have a disorder during a specified period of time (longer than one day). Lifetime prevalence is a measure of the number of people who have had a particular disorder in their lifetime and treated prevalence is the number of people being treated for a particular disorder in a defined geographic area (Kaplan & Sadock, 1988). The studies summarised on Table 1 include examples of all these different kinds of measures of prevalence, although authors often neglect to explicitly state the form of prevalence measure employed.

Some studies summarised in Table 1 provide a clear definition of the type of disorder or illness under investigation, many do not. The terms 'mental disorder', 'psychopathology', 'mental illness', and 'psychiatric disorder' are not synonymous, which makes comparing results across studies difficult. The term 'behaviour disorder' is included in some studies, and not in others, and is rarely defined.

A few studies report the findings of an investigation into comparatively small groups of people with an intellectual disability, and some employ unrepresentative samples. The population of people with mild intellectual disability is comprehensively underrepresented in most studies, although 85% of all people with an ID have a mild ID.

Methods of investigation are varied; some are more likely to produce an accurate finding than other methods and results using one method of investigation can not be compared with studies employing another. Studies of case records or the opinions of case managers are very unlikely to yield a believable result. The results of studies employing good screening instruments are likely to be a reliable guide, but conducting confirmatory follow-up assessments by specialists depends on the local availability of trained personnel.

When diagnostic criteria are applied they are often not described if they deviate from the standard criteria, and the two standard diagnostic systems, DSM-IV and ICD-10, are not identical. A potential leap forward in conducting more accurate prevalence studies are the first tentative steps taken towards devising psychiatric diagnostic criteria for people with intellectual disability, the DC-LD (Royal College of Psychiatrists, 2001).

It may be inadvisable to attempt a summary of such methodologically diverse and often problematic studies. Nonetheless, overall it seems that if a study is assessing adults with an ID for general 'psychopathology' then between 30 and 40% will be found. This will include disorders such as ADHD, conduct disorders, personality disorders, pervasive developmental disorders, sexual disorders and dementias. If researchers assess using a narrower definition of 'mental illness' then approximately 20% of adults with an ID will be identified. The rates for schizophrenia and affective disorder seem to be higher than for the general population, and in some sub-populations, significantly higher. This conclusion is similar to that contained in a recent report from the Mental Health Special Interest Group of IASSID (Holland & Jacobson, 2001)

An important point about the findings of prevalence studies is made in a recent report of a Swedish study (Gustafsson & Sonnander, 2002), conducted into the psychometric properties of the Reiss Screen for Maladaptive Behavior (RSMB). Gustafsson and Sonnander (2002) found that "one third of the sample scored positive (indicating mental health problems) on the RSMB" (p. 227), and included data on the psychopharmacological treatment subjects were receiving. The authors conclude, "it cannot be ruled out that the ongoing psychopharmacological treatment could have influenced the results" (Gustafsson & Sonnander, 2002, p. 227), as the majority of the sample were on medication such as neuroleptics, antidepressants, and sedatives. This is a reminder that studies of prevalence rarely, if ever, report on the medication regimes of subjects. However prescribed medication will be likely to have a significant effect on the results of surveys of the prevalence of disturbed behaviour and symptoms of mental illness in such a frequently medicated group as adults with an ID (Linaker, 1990). Gustafsson and Sonnander (2002) suggest that future research screening for the presence of mental health problems should be conducted in untreated groups of people with an ID, although this may be difficult to achieve.

Finally, some prevalence rates will never be known. For example, the lifetime prevalence of schizophrenia in people with a profound intellectual disability is undeterminable, because of an inability to describe psychotic symptoms. Therefore any study of the lifetime prevalence of psychiatric disorder in all adults with an ID will give a more or less accurate estimate.

Only well-funded studies of larger representative samples, which employ specific diagnostic criteria, applied in individual assessments conducted by trained personnel will ultimately provide more accurate estimates of the prevalence of psychopathology than those currently available.

2.6 ISSUES THAT COMPLICATE OR INFLUENCE THE PROCESS OF ASSESSMENT AND DIAGNOSIS

As outlined in the preceding section on prevalence of mental health disorder in adults with an intellectual disability, a more accurate study of prevalence remains to be conducted in a community where the factors that ensure sound psychiatric diagnosis have been addressed, as far as that is possible. Accurate diagnosis can only be made by a clinician who is trained to recognise the specific factors relevant to the presentation of psychiatric disorder in people with an intellectual disability.

2.6.1 DIAGNOSTIC AND BEHAVIOURAL OVERSHADOWING

The fact that labels create a mind-set that influences subsequent perception has long been established (Langer & Abelson, 1974). Recognition of psychopathology in people with an intellectual disability may be frequently missed because of diagnostic overshadowing of the signs and symptoms of ID (Borthwick-Duffy, 1994). This is a judgmental bias hypothesised to be a function of the saliency of the ID label found in some clinical settings whereby ID is emphasised and psychopathology under-emphasised. This results in an underdiagnosis or misdiagnosis of psychopathology and hence inadequate delivery of mental health services (Alford & Locke, 1984; Reiss & Szyszko, 1983; Spengler, Strohmer, & Prout, 1990).

Analogue studies, where participants are health care professionals reading short clinical vignettes and making judgements about diagnoses, have demonstrated the diagnostic overshadowing occurs in both clinicians who are experienced in working with people with an intellectual disability and also in those without prior experience (Reiss, 1982; Reiss & Szyszko, 1983). However, diagnostic overshadowing has not been demonstrated in unpublished studies which have used other investigative procedures, such as the use of more descriptive case material (Reidy, 1987, cited in (Jopp & Keys, 2001)) or the opportunity to ask for more information (Levitan, 1983, cited in (Jopp & Keys, 2001)). No studies have been undertaken on the phenomenon of diagnostic overshadowing in actual clinical settings (Jopp & Keys, 2001).

Behavioral overshadowing is hypothesised to be a related but slightly different phenomenon, whereby a clinician assumes that because a person has an ID, all the disturbed behaviour displayed by them is the result of faulty learning in maladaptive environments (Lowry, 1997).

2.6.2 LEVEL OF INTELLECTUAL DISABILITY AND COMMUNICATION DEFICITS

Tuinier and Verhoeven (1993) claim that it is well known that " established diagnostic systems...become increasingly unreliable as the severity of a patient's mental retardation increases....[and] the expression of psychopathology may take on very different forms in individuals with severe intellectual handicaps" (p. 17). This difficulty with established diagnostic systems is further discussed in Chapter 3.

A person with a mild intellectual disability and reasonable communication skills will be most likely to be able to participate in a largely unmodified mental health assessment conducted by a clinician without special training in mental health care for adults with an intellectual disability. They will present with very similar signs and symptoms of mental illnesses as their non-disabled same age peers (Menolascino, Gilson, & Levitas, 1986).

However with increasing levels of ID, inevitably accompanied by less adequate communication abilities, the person being assessed struggles to understand questions about inner experiences and thoughts and emotions. Their clinical presentation, whilst obviously disturbed, may not allow a confident diagnosis of a mental health disorder (Silka & Hauser, 1997). As Sovner and Hurley (1989) claim " it is virtually impossible to diagnose psychotic disorders in patients with moderate to greater handicaps" (p.12).

In mood disorders it is the vegetative symptoms such as appetite and sleep disturbance and behavioural changes such as activity levels, that remain consistently accessible across the disability range when the person's communicative and cognitive abilities are too poor to allow them to express feelings of sadness, hopelessness or guilt (Sovner & Lowry, 1990).

The use of a popular assessment instrument in psychiatry, the Mini Mental State (MMS), developed by Folstein, Folstein and McHugh (1975), has been explored with people with an ID by Myers (1987). They hypothesised that the greater the degree of intellectual disability, the greater would be a persons impairment on the MMS, and the less relevant or useful the test would become when used as a cognitive screening test. The results show that the MMS can be used with confidence with people with a mild intellectual disability to screen for a range of conditions that lower cognitive functioning. They concluded "that it takes a severe developmental impairment (IQ less than 55) to depress the MMS score in the absence of delirium or dementia" (Myers, 1987, p. 88).

2.6.3 FOUR PATHOPLASTIC FACTORS

Sovner and Hurley (1986) describe four pathoplastic factors, or non-specific effects, which impact on the diagnostic process. The four factors are: Intellectual distortion, Psychosocial masking, Cognitive disintegration and Baseline exaggeration. Sovner and Hurley (1986) suggest that the more severe the intellectual disability the greater the potential influence of the factors will be.

2.6.3.1 Intellectual distortion

Intellectual distortion refers to the diminished ability to think abstractly and communicate intelligibly displayed to varying degrees by most people with an intellectual disability, which limit the person's ability to describe their own behaviour and feelings and therefore to report on experiences which are consistent with a specific psychiatric disorder. Sovner and Hurley (1986) concur with other authors (e.g. Reid, 1972) that with clients with an IQ below 50 who typically lack the communication skills necessary to describe hallucinations and delusions it is especially difficult to diagnose psychotic illnesses.

2.6.3.2 Psychosocial masking

Psychosocial masking refers to the relative lack of imagination or sophistication in symptom presentation found in people with an intellectual disability. This is said to result from their less typical real world experience and more concrete thought processes (Menolascino, Ruedrich, & Wilson, 1985). For example, a person with ID may not present with typical manic grandiosity. Instead they may appear to believe they have skills above their developmental level, e.g., can drive a car, rather than the grandiosity of omnipotent delusions seen in people of normal intellect.

2.6.3.3 Cognitive disintegration

Many stressors can cause deterioration in intellectual functioning and a clinically significant behavioral regression in a person with an ID, especially in those who have organic deficits and concrete coping mechanisms. This is a similar process to that found in the elderly, sometimes referred to a pseudodementia. As stressors overload cognitive functioning and produce breakdowns in reality testing, the person with an ID may present with the signs and symptoms of a brief reactive psychosis. To complicate the picture the stressor may be a psychiatric illness, such as an affective disorder, that in a person in the general community would not necessarily present with psychotic features.

2.6.3.4 Baseline exaggeration

In the absence of any mental illness a person with an intellectual disability will show behavioural signs of cognitive and psychosocial deficits. For them the signs and symptoms of a psychiatric disorder may be a combination of new behaviours and an increase in the severity, frequency or duration of pre-existing disturbed behaviour. This exacerbation is diagnostically relevant but can be overlooked in a mental health consultation. In the case of mania for example, the person with an ID may present with an increase in the level of pre-existing distractibility and poor judgement.

2.6.4 DOMINANT DOGMA

Information about mental health in general is not evenly distributed in the community. Many people trained to care for people with an intellectual disability have not undertaken any studies in mental health, and may hold outdated or unsupportable beliefs and prejudices about mental illness. In the 1970s it was not unusual for people otherwise uninformed about mental illness to hold the view that mental illness was a myth, following the popularisation of the ideas of Thomas Szasz (1960). Today a few people still express extreme views about psychiatric disorder and psychoactive medication (Lowry, 1997) believing the former to be a myth and the latter a means of controlling less powerful people. If the family members and other carers of people with an ID hold these views they may be very reluctant to allow a psychiatric consultation to occur, and they may be unhappy with treatment recommendations if they involve medication suggestions. If this philosophy dominates a support agency it can form an effective barrier against the person with an ID receiving mental health services (Lowry, 1997).

2.6.5 MEDICATION EFFECTS

Many psycho-active medications, but particularly anti-psychotic drugs have been prescribed without a diagnostic rationale to people with an ID, often for many years without review, to lower the rate of disturbed behaviour. Occasionally and serendipitously a person whose disturbed behaviour was caused by an often undiagnosed psychotic illness was appropriately treated. However the rate of psychotic illness in adults with an ID is much lower than the rate of prescription of anti-psychotic drugs, which means that the drug effect is one of non-specific central nervous system suppression and sedation (Sovner & Pary, 1993).

Anti-psychotic medications have many unwanted side effects, which people with an ID may find impossible to verbally describe, but suffer from nonetheless. Extrapyramidal side effects can mask therapeutic drug effects or even exacerbate the problem being treated

(Sovner & Hurley, 1987). For example, akathisia is a relatively common extrapyramidal side effect of neuroleptic (anti-psychotic) medication. It is characterised by a subjective sense of restlessness, and maybe accompanied by a variety of behavioural manifestations that range from fidgeting and irritability, to an inability to sit still, sleep disturbance, hyperactivity, and extreme agitation (Gross, Hull, Lytton, Hill, & Piersel, 1993). There is a danger that the prescribing doctor may misdiagnose this side effect as an indication that the person has not responded to drug therapy and increase the anti-psychotic dose accordingly (Sovner & Hurley, 1987).

Anti-psychotic drugs also have the propensity to mask or distort the signs and symptoms of psychiatric disorders, especially those related to mood disorders, such as sleep difficulties, decreased appetite and psychomotor agitation (Sovner & Hurley, 1984). Sovner and Lowry (1990) describe two adults with ID and rapid cycling bipolar disorder. The diagnosis of the mood disorder could not be made until the administration of an anti-psychotic medication was curtailed.

2.6.6 EPISODIC PRESENTATION

The signs and symptoms of mental illness can come and go in an unpredictable or episodic way, and if a person is assessed when they are asymptomatic the presence of a psychiatric disorder is likely to go undetected. Whether the scope of the investigation is a prevalence study in a population or the diagnostic assessment of an individual, the use of assessment tools that only ask carers to report on behaviour occurring in the last few weeks or months will underreport psychiatric disorder, especially bipolar, unipolar or seasonal mood disorders, the symptoms of which wax and wane (Lowry, 1997). This highlights the utility of keeping mood and behaviour records over more substantial time periods.

2.6.7 MEDICAL CONDITIONS

Recent research has made it clear that people with an ID have considerable primary health needs (Beange, 1996; Beange & Bauman, 1991; Lennox & Kerr, 1997; Rubin & Crocker, 1989; Ziring et al., 1988) that are present in childhood (Ackland & Wade, 1995) and only increase with age (Asberg, 1989; Ashman & Suttie, 1996). Howells' study in the UK of 151 adults with intellectual disability attending a day centre reported a large number of unknown or unmanaged medical conditions, despite rates of GP annual attendance which were similar to the general population average (Howells, 1986). In a population wide survey of adults with ID conducted in New South Wales by Beange, McElduff and Baker (1995), only respiratory and coronary heart diseases were reported at lower rates than the general population, a result which was presumed to be a consequence of lower levels of smoking and alcohol intake (Beange et al., 1995).

For any person, regardless of their developmental level of functioning, medical illness may cause distress, which may manifest as disturbed behaviour. Disturbed behaviour may also be the only way a person with an ID has to communicate distressing and painful symptoms (Kastner, Friedman, O'Brien, & Pond, 1990). Deficits in communication skills are one of the most frequent and disabling handicaps observed in people with severe and profound intellectual disability (Kiernan, 1983).

Therefore an important issue in the assessment of disturbed behaviour in people with an ID is determining whether physical illness is a contributing factor, or indeed the sole cause. Several studies have demonstrated an improvement in, or recovery from, the disturbed behaviour of people with an ID following the identification and treatment of medical conditions. Gunsett, Mulick, Fernald and Martin (1989) reported that 10 out of 56 people with a severe or profound intellectual disability referred to a behavioural psychologist were found to be suffering from a range of medical conditions. When treated for these conditions 8 of the subjects displayed fewer disturbed behaviours or returned to their 'normal' state (Gunsett et al., 1989). Peine, Darvish, Adams, Blalelock, Jensen and Osborne (1995) conducted a similarly small study with ten older people with an intellectual disability and found that of the 26 medical interventions performed, 19 (73%) were followed by a decrease in disturbed behaviour. Following seven medical interventions (27%) the disturbed behaviour either stayed the same or in one case worsened (Peine et al., 1995).

Undetected high rates of pain and other unpleasant sensations, such as nausea, are likely to occur in people with a more severe intellectual disability as they have high rates of undetected medical conditions, poor or absent verbal communication skills and behavioural limitations and idiosyncrasies that may mask the expression of pain (McGrath, Rosmus, Canfield, Campbell, & Hennigar, 1998). In a study of children and young people with absent or limited speech and severe and profound levels of intellectual disability, McGrath, Rosmus, Canfield, Campbell and Hennigar (1998) surveyed caregivers via a semi-structured interview about pain related behaviour. They developed a checklist of all the behaviours carers reported to be responses to pain. Crying, changes in sleep pattern, restlessness and loss of appetite were some of the disturbed behaviours included in the checklist that could be mistaken for evidence that a person has a psychiatric disorder.

Any assessment of disturbed behaviour in a person with an ID, especially a person with limited communicative ability, that neglects to include an assessment of physical health, risks making a fundamental error in mistaking instances of medically caused disturbed behaviour for a psychiatric disorder.

Chronic medical conditions which affect the brain, such as epilepsy and cerebral palsy, are more prevalent in people with an intellectual disability, and also contribute to poorer mental health outcomes (Peine et al., 1995).

2.6.8 FAMILY HISTORY

Advances in psychiatric research in the past four decades have allowed clinicians to appreciate even more acutely the contribution made by genetic inheritance to an individuals mental health. However, for a person an ID, the availability of information on family history of psychiatric disorder may be sparse, missing or inaccurate. The patient with an ID is unlikely to be a reliable informant, their family members may not be available for interview, and their files may not contain the relevant information. The result is that important information related to differential diagnostic decisions is often not available and this increases the degree of difficulty of the diagnostic task and the likelihood of misdiagnosis (Menolascino et al., 1986). However the availability of increasingly discriminating laboratory analysis of chromosomes and genetic abnormalities will improve this situation (Einfeld & Aman, 1995).

2.6.9 CLINICAL INTERVIEW

The clinical interview is the primary tool used by mental health clinicians for collecting diagnostic information (Sovner & Hurley, 1986). A person of normal intellect can provide a wealth of information relevant to a diagnostic formulation as they answer questions asked by the clinician related to their present experiences and past functioning. However a person with an intellectual disability, even a mild ID, may find it difficult if not impossible to engage with this interview process. They may have communication limitations, attentional difficulties, an inadequate memory for past events and a very concrete understanding of concepts related to mental health functioning, for example, the question 'Do you hear voices?' maybe taken literally (Sovner, 1986). Clinicians may not be aware that in order to collect valid and reliable information they need to interview a range of carers, consult any past records and arrange for new data to be collected about relevant behaviour, as well as observing the person with ID.

2.6.10 IMPRECISE DIAGNOSTIC, ASSESSMENT AND SCREENING TOOLS

Checklists and rating scales are used to aid the diagnostic process, to screen for the presence of disorder, and to monitor response to treatment interventions. Checklists and rating scales, either adapted from general use or developed for specific use with people with an ID who have disturbed behaviour may not be reliable or valid. This will be discussed in detail in Chapter 3. However to give two brief example, the Reiss Screen for Maladaptive Behavior (RSMB) (Reiss, 1988) which assesses a broad spectrum of psychopathology, contains no items related to mania. Therefore it could not be used as a screening tool for bipolar disorder. A study conducted by Rojahn, Warren & Ohringer (1994) which compared results from the depression subscales of the RSMB, the Self-Report Depression Questionnaire and a standard psychiatric interview reported low levels of convergent validity.

The present situation in relation to checklists and rating scales used with adults with an ID to screen for the presence of, or to diagnose, mental health disorders, will be described in detail in Chapter 3.

CHAPTER 3

RATING SCALES AND CHECKLISTS OF EMOTIONAL AND BEHAVIOURAL DISTURBANCE IN ADULTS WITH AN INTELLECTUAL DISABILITY

This chapter will provide an overview of the carer-completed rating scales and checklists available at present to assess or quantify the disturbed behaviour of people with an intellectual disability that may be related to aspects of their mental health. Following excellent reviews by Aman (1991) and Hurley and colleagues (Hurley et al., 1998), only the more recent work will be discussed in depth.

3.1 WHAT IS THE NEED FOR RATING SCALES?

Rating scales used to assess the disturbed behaviour of people with an ID are needed for the same reasons they are considered useful in a comprehensive assessment of disturbed behaviour in a person with an average or greater level of intellectual functioning. Rating scales and checklists are used to screen for the presence of psychiatric disorder in general or a particular one, as an aid to diagnosis, or to monitor the course of symptoms or the presence of adverse effects (Deb, Matthews, Holt, & Bouras, 2001).

1. Rating scales and checklists enable the clinician, the person being assessed and the lay or professional people who know the person being assessed well, to indicate the presence of relevant indicators of health or illness and provide a measure of severity of signs and symptoms exhibited by the person, during a defined time period, relevant to the purpose of the assessment. Rating scales achieve this in a more objective way than clinicians whose judgements are subject to the presence of cognitive distortions, which have been described by Achenbach (1985), Dawes,

Faust and Meehl (1989) and Einfeld and Tonge (1992).

2. The results of a rating scale or checklist, usually presented in numerical form, contribute to the comprehensiveness of the diagnostic process, and enable ongoing monitoring by repeated completion which contributes to a more reliable assessment of the effectiveness or otherwise of interventions or changes attributable to the passage of time. Hurley et al. (1998) state that "There is a general consensus that rating scales are one of the most economical, clinically relevant, and useful tools available to the clinician in assessing treatment effects" (p. 92).
3. Rating scales contribute to the efforts of the research community by assisting in 'like being compared with like'. Using rating scales and checklists with proven acceptable standards of reliability and validity makes a substantial contribution to the advancement of the knowledge base in mental health research.
4. Mental health research and assessment is particularly susceptible to the charge of subjectivity compared to other research and treatment areas in science and particularly medicine. Few laboratory tests and investigations, such as CT scan, blood test, DNA analysis, have yet to make a great deal of impact on current understanding of many aspects of mental health care, and most psychiatric conditions are still defined clinically by their syndromes and clinical features (Moss, 1995). For example there are no tests or scans that reliably show that a person has schizophrenia, depression or mania (Kroese, Dewhurst, & Holmes, 2001). Measurement error in clinical assessment can be reduced through training, especially in interviewing skills, and the accumulation of clinical experience (Streiner & Norman, 1995). The work done over decades on the development of diagnostic criteria improve the situation somewhat but still leave much room for individual clinician judgement in their interpretation and application (Einfeld & Tonge, 1992).

As Einfeld and Tonge (1992) state:

5. whether a [diagnostic] criterion is present or absent remains a matter of clinician opinion…[and further more]…while two clinicians may agree that the child is anxious, they may not agree as to whether the child's anxiety is 'excessive or unrealistic' as required by the diagnostic criteria for Overanxious Disorder (p. xv).

6. The use of a suitable rating scale or checklist allows the clinician or researcher to compare an individual result with standardised norms from a comparable peer group.

3.2 CAN RATINGS SCALES AND CHECKLISTS DEVELOPED FOR USE WITH THE GENERAL POPULATION BE USED WITH PEOPLE WITH AN INTELLECTUAL DISABILITY?

A few rating scales and checklists developed for use with the general population have been used with people with an ID. Examples include The Zung Self-rating Anxiety Scale (SAS) (Zung, 1971), The Draw-A-Person Questionnaire (DAPQ), (Machover, 1949), the Minnesota Multiphasic Personality Inventory (MMPI) in its shorter form, the MMPI-168 (Overall & Gomez-Mont, 1974), and the Diagnostic Interview for Children and Adolescents (DICA) (Reich, Herjanic, Welner, & Gandhy, 1982).

The SAS (Zung, 1971) was adapted by Lindsay and Michie (1988) and used in an exploratory study of 29 adults with mild and moderate intellectual disability. The changes made to the original format were extensive and included presenting the SAS to the subjects in an oral form (because few subjects were able to read), rephrasing and/or rewording items to make them more understandable, adding supplementary questions, varying the standard presentation, introducing random presentation, and trialling different response sets, such as introducing a simplified yes/no response option. Subjects appeared to be unable to use a response set which required a graded response to the presence of anxiety symptoms in a meaningful way, and even the simplified wording of items needed additional modification (unelaborated) for some individuals.

Brown (1994) discusses the general issue of using projective testing instruments with people with an intellectual disability and claims that preliminary work indicates that the Draw-A-Person Questionnaire (Machover, 1949) can be used with people who have a mild to 'high' moderate degree of intellectual disability, although the normative sample did not include this group. Inconsistently he states that people with an IQ greater than 60 can present valid test responses, which would exclude people with a moderate degree of intellectual disability. After the person being assessed draws a male and a female figure they answer 26 written questions about their drawings, or have these questions read to them if required, and use a five point scale to rate their answers. Some subjects needed additional explanations in order to be able to understand the five point rating scale. Individual interpretation relies on studying raw scores within six scales or reviewing T-scores provided in a manual.

McDaniel (1997) used the MMPI-168, a short form of the Minnesota Multiphasic Personality Inventory (Overall & Gomez-Mont, 1974), as a screening instrument for psychiatric disorder with 63 people with mild and moderate degrees of intellectual disability, of whom 51 had a psychiatric diagnosis. Modifications were made to the presentation of items (they were read to the subjects), "simpler variations of the theme expressed by the item were provided if necessary" (McDaniel & Compton, 1997, p. 486), yes/no was used instead of true/false and 5 additional items were added. McDaniel and Compton assert that "alterations of the terminology were accomplished without destroying the underlying meaning of the question" (McDaniel & Compton, 1997, p. 486), but give no examples, and identifies this 'new' scale as the MMPI-168 (L). Subjects were divided into two groups based on diagnosis (schizophrenic or organic mental disorder) and a third group without a psychiatric diagnosis designated the 'control' group. Repeated administrations of the MMPI-168 (L) were undertaken across months, to 53 of the original cohort. Study participants who had been discharged, transferred, were ill or had 'psychotically decompensated' were not re-evaluated. Results showed some significant differences between groups on the scores of some scales, and adequate test-retest correlations on most scales.

In a study comparing three different instruments and a psychiatrist's evaluation to assess depression in adults with a mild intellectual disability (Rojahn, Warren, & Ohringer, 1994) many of the potential 250 subjects were excluded because they had sensory deficits, an organic brain disorder, autism, schizophrenia, poor verbal skills or were taking psychotropic medication. Eighty people remained, but of these only 38 could be matched to a control subject, and due to time limitations only 16 were evaluated using the Diagnostic Interview for Children and Adolescents (DICA) (Reich et al., 1982). Rojahn and Warren (1994) selected the DICA, a standardised 24 question research questionnaire developed for use with 6 to 12 year old children without intellectual disability, as one of the instruments because it had been used in a previous study involving psychiatric patients. Rojahn and Warren (1994) state that they found "no meaningful agreement whatsoever between the methods" (p. 310) and importantly the psychiatrists evaluations were very different to the DICA results. The authors conclude that in research studies multiple screening tools should be used, and in clinical practice even experienced psychiatrists seem to be prone to 'diagnostic overshadowing' as in this study an experienced psychiatrist was reluctant to diagnose a depressive disorder when the "relatively objective information" (Rojahn et al., 1994, p. 312) gathered in the DICA clearly gave this diagnosis.

What can be concluded from studies such as these? Firstly, some researchers have reported making extensive changes to standardised instruments in order to be able to use them with people with an ID. These changes have been made to the content, the format and the presentation of items. Secondly, most studies have not had sufficient resources to be able to conduct re-validation and reliability studies using the modified instruments (Deb et al., 2001). These studies need to be undertaken before modified rating scales and checklists can be used with confidence. In one study that attempted this task the validity results were disappointing.

Finally, if modified or unmodified tools are used it appears that this is an option so far only explored for people with a mild intellectual disability. Even then the items must often be read out loud, which is a different presentation format that needs to be investigated to discover what impact this change has on the results obtained. For people with a moderate or greater degree of intellectual disability specially developed carer-completed instruments are probably required, as no studies could be located that attempted to modify 'standard' instruments for this group.

3.3 ARE RATINGS SCALES AND CHECKLISTS NEEDED IN THE ASSESSMENT OF DISTURBED BEHAVIOUR OF ADULTS WITH AN INTELLECTUAL DISABILITY?

Rating scales and checklists are especially helpful in assessing the disturbed behaviours and emotions of people with ID because:

1. Many people with an intellectual disability have difficulties with verbal communication and the understanding of complex concepts related to an assessment of their behaviour and emotions. Instruments that can be used by people who know them well, such as family members, and staff members in accommodation settings, enable valuable information to be contributed to an assessment.
2. Carer-completed checklists may also prompt carers to report on emotional or

behavioural problems in people with ID that the carer may not have spontaneously reported. Comprehensive checklists would be especially useful in this respect.

3. Many people with a mild ID may be able to use a self-report measure, however it may need to be shorter, easier to read and/ or understand if the person with an intellectual disability is going to be able to use it to give their own responses. These instruments could be adapted from those devised for the general population, as described above, or especially developed for this group.

4. Many people with moderate ID, and all those with severe and profound intellectual disabilities can not use self-report rating scales or checklists. For them the greatest need is for instruments that can be completed by professionals and lay people who know them well to report on predominately behavioural and observable events.

3.4 HOW SHOULD THESE SPECIAL RATING SCALES AND CHECKLISTS BE DEVISED?

Holland and Koot (1998), in their paper reporting on the inaugural meeting of the Mental Health Special Interest Research Group (SIRG) of the International Association for the Scientific Study of Intellectual Disability (IASSID) held in Cambridge in 1998 " propose that a clear distinction needs to be drawn between instruments" (Holland & Koot, 1998, p. 507). The important distinction they discuss which is relevant here is the one between instruments to "identify the nature and extent of problem behaviours, and which are essentially descriptive in nature" (p. 507) and those that "investigate, at least partially, aetiology (e.g. a particular pattern of behaviours, or evidence of loss of function). The latter group includes psychiatric assessments" (Holland & Koot, 1998, p. 507).

This distinction between instruments referred to by Holland and Koot (1998) assumes practical importance when the question of how to devise rating scales and checklists is addressed (Holland & Koot, 1998). Instruments that delineate and quantify disturbed behaviour whilst remaining free of attachment to a theoretical framework or assumptions about causality are most likely to be developed using what Einfeld and Tonge (1992) describe as 'bottom up' methodology. The second type referred to by Holland and Koots (1998), especially those which purport to aid in determining or screening for a particular psychiatric diagnosis, are developed using 'top down' methods (Tonge & Einfeld, 1992).

The sequence of steps taken to devise a rating scale or checklist using 'top down' methodology begins with the identification of the diagnostic framework from which item selection will be derived. Most commonly in mental health assessments that framework will be either DSM-IV (American Psychiatric Association, 1994) or ICD-10 (World Health Organization, 1992). However there has been a great deal of debate in the literature addressing the mental health needs of adults with an ID concerning the application of these diagnostic frameworks to all adults across the range of intellectual disability, from mild to profound. Einfeld and Tonge (1992) claimed that there was "substantial lack of agreement that the standard diagnostic and classification systems provide the most useful account of the behavioural and emotional problems of children with IQ below the mild range of mental retardation" (p. xxii). This lack of agreement about diagnostic systems remains unchanged 10 years later.

In measurement theory DSM and ICD are cited as examples of the Categorical model, as opposed to the Dimensional model (Streiner & Norman, 1995). It is Kendell's (1975) view, discussed in Einfeld and Tonge's (1992) original studies, that some disturbed behaviours of people with an ID may be most usefully described in dimensional terms and others as categories.

In almost all categories of disorder in these diagnostic systems very little consideration is paid to the presentation of mental illness phenomena in adults with an ID, although it has been widely assumed for nearly twenty years that they experience the entire spectrum of psychiatric disorder.

The solution to this problem may be to devise a separate diagnostic framework specifically for adults with an ID, or to modify existing categories of disorder to take account of the differences due to intellectual disability. The DC-LD (Diagnostic criteria for use with adults with learning disabilities/mental retardation) (Royal College of Psychiatrists, 2001) is one example of a new set of diagnostic categories based on the ICD framework with criteria recently proposed by panels of experts.

Based on the assumption that the existing diagnostic framework probably applies to all (Sovner & Hurley, 1990), Sovner and Hurley (1990) modified the criteria of existing DSM categories of affective disorder to try to take into account the different presentations of mental illness in people with an ID.

At present there is no research evidence to suggest which of these approaches will prove to be most useful. Instruments most applicable for use with adults with an ID developed using 'top down' methodology would need to be based on new or modified categories and criteria. Instruments developed in this way, such as the Psychiatric Assessment Schedule for-Adults with Developmental Disability (Moss et al., 1998), the Diagnostic Assessment for the Severely Handicapped-II (Matson, 1995), the Reiss Screen for Maladaptive Behavior (Reiss, 1988) and the Psychopathology Inventory for Mentally Retarded Adults (Matson, 1988), have used the standard DSM or ICD criteria devised for the general population, often 'reworded' in behavioural terms.

The alternative methodology has been called the 'bottom up' or descriptive-empirical approach (Achenbach, 1998; Einfeld & Tonge, 1992). Rating scales and checklists developed in this way are more likely to be examples of measurement instruments containing elements of the dimensional model (Streiner & Norman, 1995). This approach was adopted by Einfeld and Tonge (1992) in the development of the Developmental Behaviour Checklist (DBC) because "it allows one to commence with fewer assumptions regarding the relation between mental retardation, behaviour problems and psychiatric disorders, or their classification" (p. xxii).

Empirically based assessment 'works from the bottom or ground up' (Achenbach, 1998). A large pool of items describing, for example, emotional and behavioural problems, are collated, and then through a series of studies which refine wording, relevance, reliability, validity and factor structure, an instrument is produced which can confidently be used in clinical and research settings. By making no assumptions about why particular problems occur, or occur together, the rating scale or checklist devised using this method contributes to the accumulation of clinical expertise and research data in a way that allows discoveries to be made about the ways a population or an individual may be influenced by the greatest and most diverse range of factors (Einfeld & Tonge, 1992).

Both methods of developing rating scales and checklists have validity and, although differently sourced, have a contribution to make to the accumulation of knowledge. In different populations and for different purposes both may be used separately or together, and when combined with other assessment methods, such as the clinical interview and direct observation, the most comprehensive data is obtained on which to base treatment decisions or service planning strategies.

3.5 WHAT ARE THE BEST AVAILABLE INSTRUMENTS THAT MEASURE EMOTIONAL AND BEHAVIOURAL DISTURBANCE IN PEOPLE WITH AN ID DEVELOPED SO FAR?

The awareness that checklists and rating scales for assessing psychopathology are needed for use with people with an ID did not arise when such instruments began to be developed for the general population in the 1960s and 1970s. Only since the mid-1980s have researchers been developing specialised instruments for the assessment of psychopathology in people with an intellectual disability (Hurley et al., 1998). A few instruments appeared slightly earlier, for example, the AAMD Adaptive Behaviour Scales (Nihira, Foster, Shellhaas & Leland, 1974) and the Handicap, Behaviour and Skills (HBS) Schedule, a clinical interview of informants (carers of people with an intellectual disability) that covered some aspects of disturbed behaviour (Wing, 1980).

Many rating scales and checklists that purport to measure emotional and behavioural disturbance in people with an ID have been developed since then. In this review only the instruments developed for use with adults who have an ID that can be completed by carers will be considered (see Appendix C). This review will focus on the best of these instruments which were selected on the basis of the following criteria:

1. The notion of 'widely used' or 'well researched', as an indicator of robustness or acceptance by the field was used as a selection criterion. Scales that have briefly appeared in the literature, such as the Behaviour Disturbance Scale (Leuder, Fraser, & Jeeves, 1984), and the Strohmer-Prout Behavior Rating Scale (Strohmer & Prout, 1989), have not undergone the depth of study required to compare them to other instruments, and will not be considered.

2. Only those instruments that cover the broad range of behaviour and emotional disturbance will be reviewed, and not those that concentrate on a specific disorder, such as autism or depression.
3. Another selection criterion was those checklists and rating scales that were regarded as 'promising' in Aman's (1991) review of psychopathology in ID checklists. Aman (1991) found at the time of this review that there were few rating scales and checklists that were either sound or promising. An update of the research on those instruments he nominated will be presented.

Therefore the following review will be limited to the best available checklists and rating scales, determined by the above selection criteria. The checklists were chosen for detailed review because they met one or more of the above criteria summarised in Table 2.

Table 2. Selection criteria for inclusion in review section and the checklists selected

Selection criteria	Instruments
Widely used	PIMRA[1], RSMB[2], ABC[3] PAS-ADD[5].
Broad ranging	PIMRA, RSMB, DASH[4], ABC, PAS-ADD.
Aman recommended for screening purposes	RSMB.
Aman recommended for broad dimensions of behaviour	ABC.
Aman recommended (reluctantly) for classical categorical diagnoses	PIMRA, DASH.
Final selection	PIMRA, RSMB, DASH, ABC, PAS-ADD.

[1]PIMRA = Psychopathology Inventory for Mentally Retarded Adults, [2]RSMB = Reiss Screen for Maladaptive Behavior, [3]ABC = Aberrant Behavior Checklist, [4]DASH = Diagnostic Assessment for Severely Handicapped, [5]PAS-ADD = Psychiatric Assessment Schedule for Adults with Developmental Disability.

3.5.1 THE PSYCHOPATHOLOGY INSTRUMENT FOR MENTALLY RETARDED ADULTS (PIMRA)

The Psychopathology Instrument for Mentally Retarded Adults (PIMRA) is a structured interview presented in a rating scale format, and referred to in the literature as a carer-completed checklist (Aman, 1991). It was first described in papers by Matson, Senatore and Kazdin (1983; 1984; 1985), and this work is summarised in the PIMRA Manual (Matson, 1988). There are two versions of the PIMRA, one to be completed by carers (PIMRA-I), the Informant version, the other, the Self-Report version, to be completed with the person (adolescent or adult) with the intellectual disability, if this is possible, given their level of understanding and ability to communicate. The interviewer should be "a mental health professional who is familiar with the basic concepts of psychopathology" (Matson, 1988, p. 1).

Table 3. Psychopathology Inventory for Mentally Retarded Adults (PIMRA) – Informant version

	Reliability			Validity		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Senatore et al. 1985	Total scale .83 Split half .65					
Aman et al. 1986	Subscale range .45 - .73 M = .64	Total scores .65 Subscale range -.15 - .56		5 factors		
Davidson 1988						RSMB and PIMRA Total scores r = .83
Matson et al. 1988	Total scale .83 Split half .88	Total .91 Subscale range .48 – 1.0		3 factors	Higher ratings for those with file psychiatric diagnosis	Beck Depression Inventory r =.4, Zung SAS r = .39
Watson et al. 1988	Total scale .64			4 factors		
Iverson & Fox 1989			% agreement M = 80% Subscale range r = .4 - .77 $p<.001$			
Linnaker 1991				9 factors		
Sturmey & Ley 1990	Total scale .84 Subscales .04 - .69					PIMRA subscales and ABC subscales median correlation = .4, between total PIMRA & ABC scores = .73

Table 3. Psychopathology Inventory for Mentally Retarded Adults (PIMRA) – Informant version

STUDIES	**Reliability**			**Validity**		
	Internal consistency	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
van Minnen et al. 1994	Total scale .9 Spilt half .93 Subscale range .48 - .77 M = .62	Subscale kappas .40 - .70 p<.001				
Linaker & Helle 1994					Identifies people with schizophrenia with one item removed.	
Sturmey & Bertman 1994	Total scale .69 Subscale range -.1 - .7					
Swiezy et al. 1995					PIMRA schizophrenia subscale and DSM-III-R based checklist r = .43 PIMRA affective disorder subscale and DSM-II-R based checklist r = .58	
McDaniel et al. 1999						PIMRA & RSMB Total scores = significant Subscales = variable

The PIMRA was developed to "help plan psychologically-oriented, mental health treatment", "evaluate the effects of mental health treatments", "diagnose psychopathological conditions" and "provide a list of psychiatric symptoms that can be used in training seminars of psychiatric aspects of mental retardation" (Matson, 1988, p. 1). The 58 items were drawn from the major categories of DSM-III, and organised into eight subscales: Schizophrenia, Affective Disorder, Psychosexual Disorder, Adjustment Disorder, Anxiety Disorder, Somatoform Disorder, Personality Disorder and Inappropriate Adjustment. On each subscale Matson (1988) recommended that four items should be scored positively for a positive diagnosis, but also stated that the 'four-item rule is flexible and may be modified by experienced mental health professionals in accordance with the rules of DSM-III' (Matson, 1988, p. 3). Each item is scored either 'yes' or 'no', and 75% of the scale needs to be completed for a valid result to be obtained. No time frame for the presence of behaviours referred to by items is suggested.

Substantial research has been conducted on the statistical properties of the PIMRA. The internal consistency of the whole instrument is satisfactory (Senatore et al., 1985; van Minnen, Savelsberg, & Hoogduin, 1994), but lower and variable for the individual subscales (Aman, Watson, Singh, Turbott, & Wilsher, 1986; Linaker & Helle, 1994; Sturmey & Bertman, 1994; Sturmey & Ley, 1990; van Minnen et al., 1994; Watson, Aman, & Singh, 1988). Item-total comparisons have also varied with a few items failing to correlate with whole scale or subscale scores (Aman et al., 1986; Senatore et al., 1985; Sturmey & Ley, 1990; Watson et al., 1988). The original test-retest reliability levels were adequate (Senatore et al., 1985) but in a subsequent study they were generally inadequate (Watson et al., 1988).

Several reports address inter-rater reliability. High percentage agreement (between two raters) figures are quoted in one study of 19 subjects (Iverson & Fox, 1989), and another study of 60 subjects used the same method of computing inter-rater reliability and also reported high levels of agreement (Swiezy, Matson, Kirkpatrick-Sanchez, & Williams, 1995). However this method of reporting reliability was criticised by Aman (1991). In the study into a Dutch version of the PIMRA (van Minnen et al., 1994) there were significant correlations (from .40 to .77, p <.001) between raters on subscale scores, but on the total scale and three of the subscales the first informant rated significantly higher than the second rater. In a small subset (n=15) of a study population Linaker (1991) analysed single item inter-rater reliability using kappa (.64) and percentage agreement (85.7%). Finally, two studies have examined agreement between the informant and self report versions. One found a low mean correlation across subscales of .19 (Watson et al., 1988), and the other (van Minnen et al., 1994) a significant correlation between total scores on both versions, and significant correlations on most subscales. Interestingly the subjects themselves scored significantly higher on the self report version.

Validity studies have also produced mixed and conflicting results. Aman (1991) questioned the validity of the method of item derivation (from DSM),

> it cannot be assumed with confidence that [psychiatric] conditions appearing in the general population necessarily occur across the range of mental retardation....even if we accept that such conditions do occur irrespective of level of mental retardation, we have no evidence thus far that they would be expressed symptomatically in the same way (p. 100).

The early work on factor structure (Aman et al., 1986; Matson et al., 1984; Watson et al., 1988) suggested between two and four factors, with very little overlap with the PIMRA subscale scoring system, except on the Anxiety Disorder scale (Watson et al., 1988). A later study in Norway on the informant version of the PIMRA in an institutional population of adults with mainly severe intellectual disability (Linaker, 1991), described nine factors, some of which resembled earlier factors. Each of the nine factors were spread across two or more subscales, except for Factor Two which only related to the Psychosexual Disorder subscale. Linaker (1991) discusses in detail the possible relationship between the factor findings and the DSM-III diagnostic system. Without reaching firm conclusions, he highlighted the differences between an hierarchic diagnostic system, like DSM-III, where some 'items' are given more weight than others, and the statistical assumptions of a factor analysis, primarily that all items are equally important.

Criterion group validity was addressed by Senatore, Matson and Kazdin (1985) in a study demonstrating that subjects with documented diagnosed psychopathology had significantly higher total scores on the PIMRA than subjects without, and van Minnen, Savelsberg and Hoogduin (1994) also found that both forms of the PIMRA could significantly distinguish between people with and without diagnosed psychopathology. They also reported a significant correlation between RSMB and PIMRA-I (Informant version) total scores, and mainly significant correlations between subscales on both instruments. Another measure of criterion group validity was studied by Swiezy, Matson, Kirkpatrick-Sanchez, and Williams (1995), who used ratings of subject response to medication. They found that although scores on relevant PIMRA subscales were negatively correlated with drug responsiveness, as predicted, the correlations failed to reach significance. In the same study Swiezy et al. (1995) were satisfied that the PIMRA-I schizophrenia and depression subscales are valid after using them with 65 adults with mild to moderate intellectual disability. They compared the PIMRA results to an assessment interview by a psychologist using " a set of items derived from the schizophrenia and depression sections of the DSM-III-R" (Swiezy et al., 1995, p. 77). This seems hardly surprising with both assessments 'derived' from DSM criteria. However, Linaker and Helle (1994) in a study using the PIMRA with psychiatric patients without ID found that it correctly identified 71% as having schizophrenia or not, but that its accuracy varied greatly depending on what form the illness took (disorganised, paranoid or schizoaffective) and concluded that the PIMRA could be used with other measures in research settings but definitely not as the sole basis for diagnosis in clinical settings. In fact, they concluded there was currently no measure that could be used in this way (Linaker & Helle, 1994).

Evidence of concurrent validity comes from a range of studies. Davidson (1988), working with an earlier version of the RSMB (The Checklist of Emotional Problems with Mentally Retarded Adults, CHEMRA), found a high correspondence between total scores on the PIMRA and the RSMB. Sturmey and Ley (1990) used the PIMRA and the ABC in a small study and demonstrated moderate to strong correlations between total scores and many of the subscales. Sturmey and Bertman (1994) reported the same general findings between the PIMRA and the RSMB, a result duplicated by van Minnen, Savelsberg and Hoogduin (1994) in Holland.

Some years later McDaniel, Turner, and Johns (1999), studying a small sample of people with a mild or moderate intellectual disability residing in a facility, administered the PIMRA-I and the RSMB twelve months apart to assess the robustness of, and relationship between, the two scales in the area of personality disturbance. A lower (than the Sturmey and Bertman (1994) finding), but still significant correlation was found between total scores on both checklists and some support in the subscale relationships for the concurrent validity of both scales and persistence across time of personality difficulties

3.5.2 ABERRANT BEHAVIOR CHECKLIST (ABC)

In 1985 Aman, Singh, Stewart and Field (1985) wrote that although "There are numerous rating instruments available for assessing…maladaptive behaviour of mentally retarded persons…we have found these unsuited to our own research, which involves the assessment of psychotropic drugs" (p. 485). Difficulties with existing scales are described; they were thought to be insensitive to change, and too long for repeated use.

Table 4. Aberrant Behavior Checklist (ABC)

	Reliability			**Validity**		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Aman et al. 1985	Subscale range .86 - .9	Subscale range .96 - .99	M correlation .63 across subscales and raters	5 factor structure		Group differences in the expected direction. ABS subscale correlations significant Correlations significant with behaviour disorder
Newton & Sturmey 1988				Confirmed the stability of the factor structure in a British sample		
Sturmey & Ley 1990						PIMRA subscales and ABC subscales median correlation = .4, between total PIMRA & ABC scores = .73
Bihm & Poindexter 1991	Subscale range .84 - .93					
Sturmey & Bertman 1994						PIMRA total scores. 6 p<.001. ABC total scores .5 p<.01. Subscales: Not with PIMRA schizophrenia scale ABC – variable, highest for Irritability

Table 4. Aberrant Behavior Checklist (ABC)

	Reliability			Validity		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Aman et al. 1995	Subscale range .84 - .94			Confirmed factor structure in adults living in group homes.		
Ono 1996	Subscale range .85 - .90	Subscale correlations range .84 - .90 p<.001	Subscale correlations range .58 - .78 p<.001	Confirmed factor structure		
Paclowskyj et al. 1997	Total scale .94 Subscale range .78 - .93					DASH-II total scores correlation = .75, p<.001. subscale range variable
Walsh & Shenouda 1999						Correlations between total RSMB score and ABC subscales range from .16 (Stereotypy) to .67 (Irritability.

However the most pressing difficulty was with content, as existing scales attempted to assess behaviour across the full spectrum of ID and therefore contained many "irrelevant items" (Aman et al., 1985, p. 485) for people with severe and profound ID, the group in which the authors most needed to study drug treatment effects. An interesting finding in relation to item content came from a subsequent study (Rojahn & Helsel, 1991) using the ABC with children, some with borderline and mild ID, and did so, the authors claim, without apparent loss to the scales integrity.

The ABC (see Appendix D) was developed according to the following principles: 1. Factorially derived, 2. Composed of simple concrete descriptive items, 3. Brief, suitable for repeated use, but long enough for acceptable reliability, 4. Acceptable psychometric properties. During the first stage of development, 125 items were derived from records in case notes and inspection of other popular rating scales used with people with ID. Raters completed checklists on 418 people with moderate or greater levels of ID, excluding people who were non-ambulatory or blind, as it was thought that they would be unable to perform many of the behaviours. However, a later study (Newton & Sturmey, 1988) included a substantial proportion of people who could not walk. Each item was rated on a four-point scale with '0' indicating no problem and '3' a severe problem. In stage two, items rated for less than 10% of the sample were dropped from the checklist, leaving 100 items, and following a factor analysis only 76 of these were retained. Following a further study a five factor solution which produced dimensions that did not seem to overlap with 58 items was adopted as the final scale (Aman et al., 1985). The scale is accompanied by a glossary of item descriptions (Aman et al., 1986) which raters are asked to study prior to completing the checklist.

Interestingly, approximately one quarter of the 1591 subjects in the establishment studies on the ABC in New Zealand and America were under the age of 20 years.

Normative data is supplied in the manual for people of different ages (from 5 to 51+ years) and levels of intellectual disability (Aman et al., 1986).

Internal consistency has been investigated in numerous studies, with consistently high mean alpha levels reported (Aman, Burrow, & Wolford, 1995; Aman & Singh, 1985; Bihm & Poindexter, 1991; Newton & Sturmey, 1988; Ono, 1996; Pacalawskyji, Matson, Bamburg, & Baglio, 1997; Rojahn & Helsel, 1991; Sturmey & Bertman, 1994). Test-retest reliability appears to lie in the .70s (Aman, 1991) after later studies discounted the initially much higher findings (Aman & Singh, 1985). "Acceptable, but not high levels" (Aman, 1991, p. 37) of inter-rater reliability (r = .50 to low .60) have come from several studies (Aman & Singh, 1985; Ono, 1996; Rojahn & Helsel, 1991).

The validity of the ABC is well established. The factor structure has been confirmed in different countries (Newton & Sturmey, 1988; Ono, 1996), in different residential settings (Aman et al., 1995) and with children (Rojahn & Helsel, 1991). Criterion group validity has been addressed in the following studies: groups previously found to have lower levels of behavioural disturbance, such as Down syndrome, (Aman, Richmond, Bell, & Kissel, 1987) received significantly lower scores on the ABC, and subjects taking most psychoactive medications (Aman et al., 1995; Aman et al., 1987) or with a diagnosis of schizophrenia (Aman et al., 1987) received higher scores.

Concurrent validity "has been determined by moderate relationships in the expected direction with adaptive behaviour, maladaptive scales and direct observations" (Aman, 1991, p. 38). Since 1991 and specifically in relation to other measures reviewed here, Sturmey and Bertman (1994) found a significant correlation between RSMB and ABC total scores and some subscale scores (Sturmey & Bertman, 1994), although this finding was not supported in a study by Walsh and Shenouda (1999), perhaps because of sample differences (Walsh & Shenouda, 1999). In a study comparing scores from the ABC and

DASH-II, Pacalawskyji, Matson, Bamburg and Baglio (1997), found "a relatively high degree of overall concurrent validity" (p. 293), and many significant subscale correlations between the two scales. This finding raises many interesting points of comparison between these essentially differently derived checklist, and they conclude that "when used together for clinical purposes [the two scales] should complement each other nicely" (Pacalawskyji et al., 1997, p. 296).

There is a version of the ABC, Aberrant Behavior Checklist – Community (ABC-C) (Marshburn & Aman, 1992), available for use in community settings, as the wording of items in the original version reflected its development in institutional settings.

3.5.3 THE REISS SCREEN FOR MALADAPTIVE BEHAVIOR (RSMB)

In the manual for the Reiss Screen for Maladaptive Behavior, (RSMB) Reiss wrote "The RSMB was developed to facilitate the identification of dually diagnosed people" (Reiss, 1988, p.7), with severe, moderate or mild intellectual disability, older than 12 years, and in response to a need for an instrument that assessed psychiatric disorders such as depression, psychosis and paranoia. The RSMB was the second rating scale of this type to be developed and the first to provide normative data (Havercamp & Reiss, 1997). The RSMB consists of an alphabetical list of psychiatric symptoms, with a brief accompanying definition e.g., Paranoia – excessive mistrust and suspicion of others. It can be completed by carers with no training in the area of psychiatric symptoms, e.g., carers in residential units, special education teachers, or work supervisors. Two or more independent raters per subject are recommended (Reiss, 1988). Parents and family members as raters were not included in the foundation studies of the RSMB, although parents have been included as raters in other studies using the RSMB (e.g. Walsh & Shenouda, 1999).

Table 5. Reiss Screen for Maladaptive Behavior (RSMB)

	Reliability			Validity		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Reiss 1988	Total scale .84 Subscale range .54 - .85			8 factors derived from factor analysis	'any psychopathology' from files	
Sturmey & Bertman 1994	Total scale .8 Subscale range .4 - .7				Significant correlations *with psychiatrist* diagnosis, and the presence of a Behaviour Therapy program.	PIMRA total scores .6 p<.001 ABC total scores .5 p<.01 Subscales Not with PIMRA schizophrenia scale ABC - variable
Rojahn et al 1994						Low concurrent validity between RSMB and two other measures of depression
van Minnen et al. 1995	Total scale .92 Subscale range .46 - .87		Total scale .81 Subscale range .5 - .84		RSMB scores significantly higher for subjects with diagnosed psychopathology	

Table 5. Reiss Screen for Maladaptive Behavior (RSMB)

	Reliability			Validity		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Sturmey et al. 1995		Total .75 Subscale range .5 - .7	Total scale .67 Subscale range .5 - .8			
Sturmey et al. 1996				1 or 3 factor structure recommended		
Havercamp 1997				8 subscales confirmed as factor structure in confirmatory factor analysis		
Gustafsson & Sonnander 2002	Total scale .9		Total scale .6	7 factors similar to original factors confirmed	Significant chance corrected agreement with psychiatric ratings	

The 1988 test manual for the RSMB (Reiss, 1988) reported data on 1456 people, and contains normative data for children and adults (aged 12-70 years), with all levels of ID. The 38 items are scored 0 = no problem, 1 = problem, and 2 = major problem. Perhaps confusingly, the manual asks raters to assume that if a person with an ID is being treated with medication for a symptom, hallucinations for example, then hallucinations are a problem for this person and the rater should include them in the ratings, even if the hallucinations are controlled by treatment.

Only 26 items contribute to the eight subscales: Aggressive Behaviour, Autism, Psychosis, Paranoia, Depression (B) (behavioural signs), Depression (P) (physical signs), Dependent Personality Disorder, Avoidant Disorder. This eight-factor structure was confirmed in a later study by Havercamp and Reiss (1997) of 448 adolescents and adults with ID.

The manual contains data on studies that assessed inter-rater and internal reliability, concurrent validity, normative scale scores and suggested cut-off scores for psychiatric caseness. Aman (1991) stated "its psychometric properties have been well researched" (p.105), and found that internal consistencies were generally adequate, and inter-rater reliabilities "generally very acceptable" (Aman, 1991, p. 105). Validity studies had established that "validity is good insofar as the instrument is used for the identification of any psychopathology" (Aman, 1991, p. 105) and as the RSMB manual (Reiss, 1988) stated the RSMB's principle role was to establish the need for further mental health evaluation, the lack of validity data on subscales may be less important (Aman, 1991). Aman (1991) expressed concern about the small standardisation sample, the seemingly arbitrary choice of cut-off scores, and the presence of diagnostic subscales that he felt some users would attempt to use for diagnostic purposes even though the RSMB was not designed to be used in this way.

Sturmey has co-authored four papers investigating aspects of the statistical properties of the RSMB published in the 1990s. The first examined the validity of the Reiss Screen (Sturmey & Bertman, 1994) by correlating scores on the RSMB, the PIMRA and the ABC. "Modest to good concurrent validity" (Sturmey & Bertman, 1994, p. 203) was demonstrated, although some apparently homologous scales e.g., the schizophrenia subscale on the RSMB and PIMRA, did not correlate significantly.

The RSMB was further investigated in 1995 (Sturmey, Burcham, & Perkins, 1995) in a study of test-retest reliability (which had not been studied previously), inter-rater reliability and internal consistency, and concluded that the RSMB "appeared to have moderate to good psychometric robustness" (Sturmey et al., 1995, p. 195).

Three exploratory factor analysis studies by Sturmey, Jamieson, Burcham, Shaw and Bertman (1996) did not appear to support the eight clinical subscales described by Reiss in 1988 and later supported by his confirmatory factor analytic study with Havercamp, (1997). Sturmey et al. (1996) suggested a one or three-factor solution, and concluded, "there may be no strong justification at this time for the multiple scales based on factor analysis" (Sturmey et al., 1996, p. 290). Reiss (1997) responded critically to the publication of the factor analytic studies by Sturmey et al. (1996) claiming that there were a "number of serious problems [with] experimental design, methodology, data analysis, data computation, interpretation and reporting" (Reiss, 1997, p. 353). Reiss (1997) concludes that future studies on the RSMB investigating factor structure should employ confirmatory factor analytic techniques on large samples of 300 or more people from a diverse population, very different to the small and homogeneous samples used by Sturmey et al. (1996).

Rojahn, Warren and Ohringer (1994) investigated depression using the RSMB and two other measures of depression in a small sample of adults with a mild and moderate intellectual disability and found that there was very low convergent validity between the scales which purported to measure the same construct.

The most recent study to explore the psychometric properties of the RSMB (in translation) was conducted in Sweden by Gustafsson and Sonnander (2002) in a sample of 134, "representative of the administratively defined Swedish group of people with ID" (Gustafsson & Sonnander, 2002, p. 221). Cronbach's alpha coefficient of the total score was .90, and inter-rater agreement on total scores between two raters was r = .60.
A principal components analysis provided seven components with eigenvalues greater than 1, accounting for 67% of the total variance which could be interpreted in terms of the same clinical categories reported by Reiss (1988). Criterion validity was assessed in a small subsample (n=21) assessed by psychiatrists. The RSMB and psychiatric ratings agreed in 81% of cases, with significant chance-corrected agreement. More than one third of the total sample obtained an RSMB score indicating the possible presence of a psychiatric disorder, a similar result to other studies (Reiss, 1990).

3.5.6 DIAGNOSTIC ASSESSMENT FOR THE SEVERELY HANDICAPPED (DASH AND DASH-II)

The Diagnostic Assessment for the Severely Handicapped (DASH) Scale was first described by Matson, Gardner, Coe, and Sovner (1991b). The items were derived from DSM-II-R criteria, "previous studies of the population…and other instruments" (Matson et al., 1991b, p. 404). The 84 items were developed using two principles: "(a) appropriateness for subjects with intellectual and adaptive behaviour abilities in the severe and profound levels of mental retardation; and (b) comprehensibility to informants without formal training in psychiatric assessment " (Matson et al., 1991b, p. 405). However it is difficult to imagine a person with a severe or profound intellectual disability describing to an observer's satisfaction some of the resulting items (Ross & Oliver, 2003). For example, in Subscale 2, Mood disorder – depression, "Complains about lack of things to amuse self or do", and in Subscale 5, Schizophrenia, "sees things that are imaginary, experiences touch or other sensations on her/his skin that are imaginary" (Matson, 1995, p. 406).

The 84 items are grouped into 13 clinical scales: 1. Anxiety, 2. Mood disorder – depression, 3. Mood disorder –mania, 4. Autism, 5. Schizophrenia, 6. Stereotypies, 7. Self-injurious behaviours, 8. Elimination disorders, 9. Eating disorders, 10. Sleep disorders, 11. Sexual disorders, 12. Organic syndromes, 13. Impulse control and miscellaneous problems. Of the 84 items, one item, "Is restless and agitated", appears on three subscales, and eleven other items appear twice. For subscales 1-5 endorsement of more than half of the subscales items is used as a diagnostic index. For subscales 6-13 endorsement of at least one subscale item with a severity of 1 or 2 is used as a diagnostic index.

The resulting scale is described as multidimensional, assessing severity, frequency and duration of individual items, with each dimension rated on three levels, scored 0, 1, or 2, during the past two weeks. Aman (1991) expressed some concerns about " the appropriateness of the actual numeric scales within the DASH for rating some symptoms" (p. 78) and stated that the rating options may not prove to be "sensitive to subject differences" (Aman, 1991, p. 78). Ratings were obtained through interviews with a direct care worker who had known the subject for one month or more. Data were collected on 506 people with severe (32%) and profound (62%) ID. Inter-rater reliability was assessed from two ratings, made within three hours, on 29 residents, and was calculated using the percentage agreement formula, and was reported to be generally high, with the exception of a few items related to irritability and frustration.

Table 6. Diagnostic Assessment for the Severely Handicapped (DASH)

	Reliability			Validity		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Matson et al. 1991	Subscale range .2 - .8 (4 subscales below .5)			Items derived from DSM-III-R criteria, 6 factors		
Sevin et al. 1995		% agreement .84 for severity .84 for duration .91 for severity.	% agreement .95 for severity, .85 for duration, .86 for frequency. Low intraclass correlations for anxiety, schizophrenia and sexual disorder subscales.			
Matson & Smiroldo 1997	Mania subscale .79				Mania subscale scores correlated significantly with diagnosis of mania independently made by a psychiatric clinician	
Matson, Smiroldo, Hamilton & Baglio 1997					Only behavioural symptoms of anxiety correlated with diagnosis of anxiety	
Matson, Kiely & Bamburg 1997					Higher DASH-II stereotypy subscores significantly correlated with lower adaptive behaviour	

Table 6. Diagnostic Assessment for the Severely Handicapped (DASH)

	Reliability			**Validity**		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Paclawskyj et al. 1997	Total scale .86 Subscale ranges .28 - .84					ABC total scores with total DASH-II scores .75
Matson et al. 1998	Autism/ PDD subscale .68					Childhood Autism Rating Scale and DASH-II Autism/PDD subscale r = .69 p<.0001
Matson et al. 1999					Mixed results when depression subscale compared to independent diagnosis.	
Bamburg 2001					DASH-II Schizophrenia subscale identified people with ID and schizophrenia who had verbal skills.	

Two crucial subscales, Schizophrenia and Depression, demonstrated low internal consistency, and very few subjects were identified as depressed or anxious by the DASH, raising the question of whether the instrument could measure these important and frequently occurring conditions accurately in this population (Matson et al., 1991b).

In a separate paper a factor analysis of the data on the same sample is presented (Matson, Coe, Gardner, & Sovner, 1991a). Frequency (less than 1%) and inter-rater reliability (less than 60%) criteria eliminated seven items from the factor analysis which yielded six factors accounting for 39% of the variance. Fifteen items occurring in 10% plus of the sample failed to "load cleanly [and were] eliminated as complex variables" (Matson et al., 1991a, p. 556). This is an interesting analysis and discussion of the interface between the 13 diagnostic categories and six behavioural dimensions in the DASH. Matson et al. (1991a) concluded that "coherent taxonomies or psychiatric problems among individuals with profound and severe mental retardation might be derived from a combination of factor analytic and clinically derived scales" (Matson et al., 1991a, p. 557).

Reliability statistics are reported on the DASH in a paper by Sevin, Matson, Williams, and Kirkpatrick-Sanchez (1995). Informants (employed carers) rated the behaviour of 658 adults with severe and profound intellectual disability. Mean percent agreement figures are given for frequency, duration and severity dimensions of each item. Inter-rater agreement was greater than .85 between raters, and greater than .84 when informants ratings were repeated two weeks later. Intraclass correlations were above .5 for most scores, but below .5 for the anxiety, schizophrenia and sexual disorders subscales. The authors concluded that "reliability is demonstrated to some degree in this study" (Sevin et al., 1995, p. 94).

Between 1991 and 1997 the DASH was altered and was subsequently referred to as

DASH-II. The changes made were wording alterations to nine items e.g. ‘Hits or pinches other people’, became, ‘Hits, kicks or pinches other people’; ‘Speech is harder to understand’, was augmented with the phrase, ‘than it used to be’. Subsequent studies were conducted on the modified version (R. Laud, personal communication, October 2002).

Six papers have reported the results of validity studies of various subscales of DASH-II. Matson and Smiroldo (1997) selected 22 people with severe or profound ID with a DSM-IV diagnosis of bipolar disorder (based on a psychiatrist or psychologists ‘blind’ diagnostic opinion based on observation, case record review and a DSM-IV checklist), or no Axis 1 disorder (matched control subjects), to examine the internal consistency and validity of the Mania subscale. The Mania subscale of the DASH-II had an internal consistency of alpha = .79 and item total correlations ranged from .42 to .76. DASH-II correctly identified 90.9% individuals with independently diagnosed mania, and rejected 100% of control subjects. The one person with a bipolar disorder not identified by the DASH-II had not exhibited symptoms in the two weeks during which DASH-II evaluations were made. Individual items on the Mania subscale and total subscale scores were significantly correlated with DSM-IV diagnosis.

Matson, Smiroldo, and Hastings (1998) compared scores on the Autism/Pervasive Developmental Disorder (PDD) Subscale on the DASH-II to the Childhood Autism Rating Scale (CARS) and DSM-IV diagnostic criteria. Fifty-one adult subjects with severe or profound ID, with a diagnosis of autism (n=15) or without (n=36), were selected for this study. Internal consistency of the Autism/PDD subscale was described as ‘acceptable’ (alpha = .68), and this subscale successfully identified all subjects with autism, as did the CARS. There was a significant correlation between CARS and DASH-II scores (r=.69, p< .0001), and the total subscale score was significantly correlated with DSM-IV diagnosis (r= .87, p< .0001).

Highlighting the controversial issues of identification and diagnosis of schizophrenia in individuals with severe and profound diagnosis, Bamburg, Cherry, Matson, and Penn (2001) sought to establish the validity of the DASH-II Schizophrenia subscale. Three groups of subjects (each with N = 20) with severe or profound ID were identified: Group1. A psychiatric diagnosis of schizophrenia and elevated schizophrenia subscale scores on DASH-II, Group 2. Elevated schizophrenia subscale scores, but no psychiatric diagnosis, and, Group 3. No elevated subscale scores and no psychiatric diagnosis. An examination of subscale scores and the pattern of item endorsement suggested that the schizophrenia subscale correctly identified those subjects with schizophrenia who were verbal, but that elevations on this subscale for non-verbal subjects could be related to a range of other conditions. The authors conclude that the DASH-II "is a reasonable screening tool" for schizophrenia, but "should not be the sole instrument used for diagnosis" (Bamburg et al., 2001, p. 329).

Matson, Smiroldo, Hamilton and Baglio (1997c) investigated anxiety disorders in people with severe and profound ID using the anxiety subscale of the DASH-II. From a sample of 289, 33 individuals scoring above the cut-off score on the anxiety subscale were selected, and a separate group of 36 with no elevations on DASH-II subscales for comparison. DASH-II ratings were compared to DSM-IV diagnoses made by a psychiatrist or a psychologist blind to group allocation. All subjects with an anxiety diagnosis scored above the cut-off score, and nobody in the comparison group received a diagnosis. However, only 7 of the 33 high anxiety-scoring individuals received a diagnosis of an anxiety disorder from a clinician, prompting the researchers to look more closely at the DSM-IV criteria. The low level of agreement was attributed to the difficulty in establishing a DSM-IV diagnosis in a non-verbal person. The authors highlight the range of other disorders that may present with signs and symptoms identical to those behavioural criteria for anxiety disorders, and stress that in people with severe and profound ID an anxiety disorder diagnosis must come from multiple sources of assessment data, carefully accumulated over time, and "will rely heavily on the clinician's judgement" (Matson et al., 1997c, p. 43).

Two papers were published in 1997 by Matson and associated researchers (Matson et al., 1997a; Matson, Kiely, & Bamburg, 1997b) investigating two of the DASH-II subscales, Stereotypy and Self-injury. The first paper reports results from two studies in a population of people with a severe or profound ID (Matson et al., 1997a). In the first, the items in the Stereotypy and Self-injury subscales were compared to DSM-IV criteria in four groups: Group 1 (N = 45) scored above the cut-off score on Self-injury, Group 2 (N = 19) scored above the cut-off on Self-injury, Group 3 (n=38) scored above the cut-off on both, and Group 4 (N = 41) did not score above the cut-off on any subscales. Independent assessments were made of each subject by a psychiatrist or psychologist using DSM-IV criteria. Whilst the overall classification rate (DASH-II predicts DSM-IV diagnosis) was 83%, and no false negatives were noted, the rate for the Stereotypy group was only 32% of subjects later identified as having a movement disorder according to the applied DSM-IV criteria.

In the second study (Matson et al., 1997b) the numbers of people with severe and profound ID were much larger and the groups differently constructed: Group 1(N = 293) contained subjects who scored above the cut-off on the Stereotypies subscale and below the cut-off on the Self-injury subscale, Group 2 (N = 416) scored below the cut-off on the Stereoptypies subscale and above the cut-off on the Self-injury subscale, Group 3 (N = 122) included people who scored above the cut-off on both subscales, Group 4 (N = 356) scored below the cut-off score on all subscales. The main analysis was an inspection of the DASH-II items to investigate commonalities and differences between the groups.

Although the groups had "fairly consistent demographic data" (Matson et al., 1997a, p.462), when the four different groups were examined more closely differences were discovered. For example Group 3 contained the most subjects with profound ID and a range of comorbid conditions, such as autism and eating disorders.

Also published in 1997 was a study by Matson, Kiely and Bamburg (1997b) which examined the effect of the presence of stereotypic behaviour, (high scores on the DASH-II Stereoptypies subscale) on adaptive behaviour measured by the Vineland Adaptive Behavior Scales (Nihira, Foster, Shellhaas, & Leland, 1975). They compared the relationship between stereotypy and adaptive behaviour in two groups of people with severe and profound intellectual disability; Group 1 scored above the cut-off on the Stereotypies subscale and Group 2 did not. There was a significant difference between the groups, with Group 1 performing less adaptive behaviour, but the demographic variables for each group was not reported making it difficult to draw conclusions.

Finally, a study by Matson et al. (1999), investigated the validity of the Depression subscale of the DASH-II, by comparing high and low scorers with diagnoses made using DSM-IV criteria. In the group diagnosed by a clinician, 73% had elevated DASH-II Depression subscale scores, and the items most likely to be identified were those most readily observed in non-verbal individuals, pertaining to sleep patterns and activity levels. Of the four depressed group members without elevations on the DASH-II Depression subscale, three could be explained away be virtue of an atypical presentation, effective antidepressant treatment or presence of a bipolar disorder.

3.5.7 PSYCHIATRIC ASSESSMENT SCHEDULE FOR ADULTS WITH DEVELOPMENTAL DISABILITY (PAS-ADD) CHECKLIST

The most recently developed instrument in this group is the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) Checklist (Moss et al., 1998) "a screening instrument specifically designed to help staff recognise mental health problems in people with ID... and to make informed referral decisions" (Moss et al., 1998, p.173). The 29 items, worded in everyday language, are derived from the PAS-ADD interview (Moss & Patel, 1993) (a semi-structured clinical interview designed for people with an intellectual disability, based on the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) (World Health Organization, 1994) which produces ICD-10 diagnoses). The items are scored on a four-point scale: 1. Has not happened in past four weeks, 2. Has happened but has not been a problem for the person, 3. Has been a problem for the person, 4. Has been a serious problem for the person. The scoring algorithm suggests three possible categories of disorder, Affective or neurotic, Organic condition and Psychotic disorder (see Appendix E). Raters (family members or paid carers) are asked to consider a time frame of the 'past four weeks' (Moss & Patel, 1993). Cut-off scores are given to identify those with a possible mental health disorder (for each category of disorder) but how they were arrived at is not clear.

Most psychometric data on the PAS-ADD Checklist comes from a 1998 publication (Moss et al., 1998) reporting the results from two studies. Internal consistency of the checklist varied considering which configuration of items was used, and how many items appeared in each subscale. Moss states "Alpha's over .6 are considered acceptable" (Moss et al., 1998, p. 178), and the internal consistency of the total score and two of the threshold scales are higher than .6. The lowest was the psychosis subscale at .51.

Factor analysis was performed on 201 checklists and generated eight factors accounting for 65% of the variance. Moss et al.(1998) claim that “the majority of the factors…are readily interpretable in psychiatric terms.” (Moss et al., 1998, p. 177). There were two factors relating to depression which the authors felt were related to intellectual level.

Table 7. Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) Checklist

	Reliability			**Validity**		
STUDIES	**Internal consistency**	**Test-retest**	**Inter-rater**	**Factor structure**	**Criterion group**	**Concurrent**
Moss et al. 1998	Total scale .87		Total scale .79	8 factors interpretable in psychiatric terms	PAS-ADD identified 26% with no psychiatric condition (false positive), 56% with mild problems, and 92% with severe psychiatric disorder.	
	Subscales:		Subscales:			
	Affective .84		Affective .76			
	Organic .63		Organic .55			
	Psychotic .51		Psychotic .60			
			Agreement on identification of 'at risk' individuals by two raters .54 kappa.			
Simpson et al. 1998	Total scale .87				Correlation with PAS-ADD score and severity of psychiatric disorder r = .54	

Inter-rater reliability was measured in a study of 66 people with an intellectual disability from hospital and community accommodation employing pairs raters who were most often a staff person and a family member (Moss et al., 1998). Correlations were computed for all subscales (r = .76, .55, .60), the total score (r = .79) and the four scales derived from factor analysis (r = .55 to .70). The highest level of agreement was on the identification of at-risk individuals, those who scored over the threshold on one of the subscales. Moss (1998) report that 79% of 'at risk' decisions were in agreement, however chance corrected agreement indicated a moderate level of agreement (kappa = .54, 95% CI .34 - .75).

The subjects for the validity study came from a psychiatric practice for people with an ID who were selected to cover a broad range of conditions and degrees of severity of disorder. Paid carers and family members completed PAS-ADD checklists blind to data compiled by the psychiatrist about diagnosis and severity. The likelihood of the checklist identifying at-risk individuals rose with the severity rating they received from the psychiatrist, and depended on the disorder being one of those covered by the PAS-ADD. The PAS-ADD results identified 26% of subjects with no disorder, 56% with a mild disorder, and 92% with a severe disorder. The two individuals with severe disturbance not detected by the checklist both had a bipolar disorder and it is stated that they may not have been displaying symptoms at the time of checklist completion (Moss et al., 1998).

A study also reported at a conference in 1998 sheds some additional light on the psychometric properties of the PAS-ADD Checklist (Simpson, Creed, & Moss, 1998). In a study of 93 adults with ID the PAS-ADD Interview was used as the 'gold standard', to undertake Receiver Operating Characteristics analysis and calculate the best cut-off score on the PAS-ADD Checklist. Internal consistency was good (Cronbach's alpha .87) and four scoring methods were examined. The best agreement with the PAS-ADD Interview was obtained when any symptom reported was allocated a '1', and totaled to form an overall score, disregarding the scoring algorithm and threshold sores on the three subscales outlined by Moss (1998). Simpson (1998) conclude, "The PAS-ADD Checklist is acceptable to carers and gives satisfactory screening performance with a simple scoring method." (Simpson et al., 1998, p. 42), however this is not the scoring system recommended by the original authors.

3.6 IS THERE A NEED FOR ANOTHER INSTRUMENT TO ASSESS EMOTIONAL AND BEHAVIOURAL DISTURBANCE IN ADULTS WITH ID?

Clinicians and researchers looking for a comprehensive carer-completed checklist with sound psychometric properties to assist in the process of assessing psychopathology in adults with an ID will find that the five instruments reviewed here all have something to offer. However, they also have limitations of several possible kinds: psychometric, theoretical or practical.

Aman (1991) stated that there are "recurring problems with [all the] available instruments" (Aman, 1991, p. 178). In summary he stated that:

1. The sensitivity (the probability that a person who has a psychiatric or behavioural disorder will be classified) and specificity (the probability that a person without a psychiatric or behavioural condition will be classified by the instrument as not having a disorder) of checklists and rating scales are largely unknown.
2. For most scales the diagnostic accuracy is essentially untested. This is partly because at lower IQ levels the very expression of psychopathology may change in ways not yet understood, and even in the mild range of intellectual disability clinical presentation will vary. The lack of a 'gold standard' in diagnosis must be

surmounted, which would result in the development of valid diagnostic criteria for people with an intellectual disability equivalent to DSM-IV or ICD-10.

3. Standardisation is mostly inadequate, with scales being developed and then tested on very small groups of people, or on larger numbers but from a narrow cohort, such as an institutional population. Standardisation studies must take into account age, gender, level of IQ and residential setting at least. Funding to support large-scale standardisation trials is very difficult to attract.

These concerns have only been addressed to some extent in more recent studies.

Hurley et al. (1998) writing in another seminal publication, 'Psychotropic medications and developmental disabilities: The international consensus handbook', state that although "rating scales are one of the most economical, clinically relevant and useful tools available to help clinicians..there is no consensus in the field about which one (i.e. rating scale) is best..[and there] is a need to develop new instruments" (Hurley et al., 1998, p. 92).

The PIMRA and DASH-II, although described as carer-completed checklists, also suggest in their manuals that a 'trained' interviewer administer them (Matson, 1988; Matson et al., 1991b). This poses an obvious and substantial resourcing cost in terms of time and money to have the checklists completed.

The DASH-II has limited data available on test-retest and inter-rater reliability and concurrent validity, and some very variable data on criterion group validity. The application of standard psychiatric diagnostic criteria to adults with severe and profound levels of ID is not supported at this time by experienced researchers (Aman, 1991; Tonge et al., 1996). Indeed the DASH-II author's own studies in depression (Matson et al., 1999), schizophrenia (Bamburg et al., 2001) and anxiety (Matson et al., 1997c) assessment identify difficulties in using the DASH-II to assist in identification and diagnosis with non-verbal subjects.

There is debate and disagreement about the factor structure of the RSMB, even though it is the only checklist to have been studied using the techniques of confirmatory factor analysis, and concurrent validity data are sparse and variable.

The PAS-ADD is the most recently developed checklist, and whilst it has an interesting lineage, being one of three assessment instruments developed from the Schedules for Clinical Assessment in Neuropsychiatry, there is disagreement between two studies about how to compute and apply cut-off scores for caseness, and there are no studies of concurrent validity or test-retest reliability.

And finally, there is variable information and little data about whether these checklists can be used with children, young people and/or adults with an ID. The RSMB manual (Reiss, 1988) states it was developed for people over the age of 12 years, however in the foundation studies (Reiss, 1988) there were comparatively few younger subjects (less than 20 years) included, and in subsequent psychometric studies, none. The DASH, PIMRA and PAS-ADD were developed for adults, and their use with children or adolescents has not been reported.

Only the authors of the ABC included children younger than twelve years in the establishing studies, and a few subsequent studies of the ABC have been reported on children and adolescents with ID (Marshburn & Aman, 1992; Ono, 1996; Rojahn & Helsel, 1991). The study by Rojahn and Helsel (1991) in children with ID and a psychiatric disorder confirmed the ABC factor structure, and found the subscales clinically relevant and internal consistency of the subscales satisfactory.

Overall the psychometric properties of the ABC have been well studied and found to be satisfactory. However the ABC contains items describing observable and behavioural phenomena (exceptions are: Mood changes rapidly; Depressed mood; Irritable) and there are many emotional and experiential aspects of psychopathology not covered in the 58 items.

The clearest rationale for the development of a new carer-completed rating scale for adults would be to have available a more comprehensive instrument than the ABC, free of a doubtfully valid diagnostic framework, especially for people with greater degrees of ID, for use in clinical and research settings, that provided continuity of assessment from childhood through adulthood. This would enable groups of people with an ID of all ages to be studied, especially longitudinally, and clinical assessments could be repeated on individuals as they grew up and became older, and provide the ability to make direct comparisons between their results from year to year, for many years.

However the development of such a checklist would also need to take into account the changing nature and features of psychopathology from childhood through adulthood. For example, children rarely get dementia (American Psychiatric Association, 1994) and when they do get clinically depressed they are less likely than adults to be lethargic, sleep too much or have delusions, and other symptoms are more common, for example, somatic complaints, irritability and social withdrawal (American Psychiatric Association, 1994).

The Developmental Behaviour Checklist (DBC) (Einfeld & Tonge, 1992) is a comprehensive, carer-completed, rating scale specifically developed to assess psychopathology in children and adolescents with ID. The DBC and its psychometric properties will be described in the following chapter and its potential for redevelopment for use with adults with ID will be explored.

CHAPTER 4

THE DEVELOPMENTAL BEHAVIOUR CHECKLIST (DBC)

This chapter describes the development and psychometric properties of the Developmental Behaviour Checklist for children and adolescents (versions for parents and teachers) and how it is an appropriate choice for further development into a suitable instrument for use with adults with ID. The contribution the DBC has made in studies of behavioural phenotypes of a range of disorders which cause intellectual disability (e.g. Fragile X) or which are frequently associated with ID (e.g. autism) and the psychopathology in children with ID is described. The development of an adult version of the DBC would enable follow-up studies into adult life.

4.1 ESTABLISHING STUDIES

Tonge and Einfeld (2001) have described the substantial burden of disease born by children and adolescents with intellectual disability and their carers as a consequence of the high rates of emotional and behavioural disturbance. It was their view, (supported by a comprehensive review of available instruments (Aman, 1991)), that a new checklist was needed to adequately address clinical and epidemiological challenges, and led to their work in establishing the Developmental Behaviour Checklist (DBC-P, Primary carer version) (see Appendix F).

Einfeld and Tonge (1992) described a number of properties considered desirable in a standardised instrument for assessing the behavioural and emotional disturbance in children and adolescents. They believed it was imperative to have an instrument that contained items that specifically describe the child's disturbed behaviour and emotions, that could be reliably completed by lay rater and covered a broad range of psychopathology, especially in young people with moderate and severe degrees of intellectual disability, but was also applicable to those with a mild intellectual disability (Einfeld & Tonge, 1995).

4.2 METHODOLOGY

Einfeld and Tonge (1992) adopted the descriptive-empirical approach described in Chapter 2, noting that in the general child psychopathology field this approach had led to the development of widely used instruments, such as the Child Behavior Checklist (CBCL) by Achenbach and Eldebrock (1983), and did not preclude the later subgroupings of items that may be found to correlate with diagnoses in DSM or ICD (Einfeld & Tonge, 1995).

The DBC-P items were derived from 664 clinic files of children and adolescents with intellectual disability from the Grosvenor Assessment Clinic, in Sydney, Australia.

Einfeld and Tonge (1992) determined which of these descriptions were symptoms of emotional and behaviour disorder according to a definition modified by Reid, Ballinger and Heather (1978), itself adapted from Graham and Rutter (1970):

> Where behaviour and emotions are abnormal by virtue of the qualitative or quantitative deviance, and cannot be explained on the basis of developmental delay alone and cause significant distress to the child, carers or the community, as well as significant added impairment, then these behaviours and emotions are regarded as disordered. (Einfeld & Tonge, 1992, p. xii)

They also included a few other symptoms of clinical interest e.g. delusions, thought disorder, and hallucinations, producing 105 behavioural descriptions, which were further refined by eliminating those with low inter-rater agreement in 200 files independently rated by two experienced psychologists. Ninety-six (96) items remained. These were rewritten in lay terms so that the checklist could be used by anybody who had completed a primary school education and knows the child well.

The structure of the DBC was adapted with permission from the CBCL (Achenbach & Edelbrock, 1983). Each item is scored on a 3-point scale: not true as far as you know (0), sometimes or somewhat true (1), or often true or very true (2). The instruction 'Please describe' was added to some items to achieve adequate inter-rater agreement, and a time frame of the previous six months was suggested for identifying and rating items of concern. Items were ordered alphabetically in order to present them in a random fashion and at the end of the checklist two additional items were added, but not for scoring purposes, to assess the overall level of disturbance and provide an opportunity for the rater to add any other behaviors or emotions of concern to them. On the instructional front sheet extra information was requested about the child's physical or sensory deficits and special abilities. Two versions of the DBC were constructed, the Primary carer (DBC-P) and Teacher versions (DBC-T). Items related to sleep were removed from the Teacher version (Einfeld & Tonge, 1992).

4.3 RELIABILITY AND VALIDITY STUDIES

The results of the main reliability and validity studies conducted by Einfeld and Tonge are summarised in Table 8.

Table 8. Reliability and validity data for DBC-P and DBC-T (Einfeld & Tonge, 2002)

Study	N		
Test-Retest Reliability			
Parent-Parent	63	ICC = .83	99% CI = .69-.90
Teacher-Teacher	16	ICC = .73	99% CI = .16-.95
Inter-rater Reliability			
Parent-Parent	42	ICC = .80	99% CI = .59-.90
Teachers-Aides	110	ICC = .60	99% CI = .42-.74
Nurse-Nurse	32	ICC = .83	99% CI = .68-.92
Clinician-Parent agreement			
- item meaning	70	97%	
Internal consistency	1093	$\alpha = .941$	
Criterion Group Validity	70	$t = 7.783$	$p < .001$
Concurrent Validity			
DBC/ ABS	40	r = .86	$p < .001$
Concurrent Validity			
DBC/ SIB	40	r = .70	$p < .001$
Concurrent Validity			
Clinicians ratings/ DBC	70	r = .81	$p < .001$
Readability of the DBC	Flesch Grade Level[a] = 7.3		
Receiver Operating Characteristics	Area under the ROC curve = 92%		
Optimal cut-off score for caseness	TBPS = 46, Sensitivity = 80%, Specificity = 88%.		

ICC = Intraclass correlation; CI = Confidence intervals; r = Pearson correlation; *t* = Paired samples *t*-test; α Crronbach's alpha; CI = Confidence Interval; ABS = AAMD Adaptive Behavior Scales Maladaptive Behavior Section (Nihira, Foster, Shellhaas, & Leland, 1975); SIB = Scales of Independent Behaviour Problem Behavior Section (Bruininks, Woodcock, Weatherman, & Hill, 1984). [a] U.S grade school level.

4.4 FACTOR STUDIES

Factorial validity for the parent and teacher versions was established via Principal Components Analysis, using data from a study of 1093 children and adolescents with an intellectual disability. The factors derived were rotated using the Varimax option and the first six factors were retained on the basis of a scree plot.

Table 9. Original factor structure and characteristics of subscales (Einfeld & Tonge, 1992)

Subscale	% of Variance	Internal consistency	Parent Agreement		Teachers/Aides Agreement	
		(Cronbach's α)	ICC	99%CI	ICC	99%CI
Disruptive	15.6	.91	.78	.56 - .90	.68	.47 - .81
Self-Absorbed	6.2	.86	.79	.58 - .90	.74	.60 - .81
Communication Disturbance	3.6	.81	.75	.50 - .88	.62	.42 - .76
Anxiety	3.0	.76	.80	.61 - .90	.66	.49 - .78
Autistic Relating	2.6	.73	.78	.56 - .90	.48	.28 - .65
Antisocial	2.3	.67	.79	.60 - .90	.30	.05 - .50

A subsequent study completed by Dekker, Nunn, Einfeld, Tonge & Koot (2002a) reassessed the factor structure in a large (1536) cross-cultural sample, by combining the Australian sample with a Dutch group of children and adolescents with ID. Principal components analysis, using NOVAX (Waller, 1994), a stand-alone factor analysis program for ordinal polytomous data, produced five subscales, "providing the best overall summary of the dimensionality of the DBC" (Dekker et al., 2002a, p. 60), by combining the Disruptive and Antisocial subscales into one. The factor structure for the parent and teacher versions was similar but not identical, however the same factor structure was retained for both versions to facilitate comparisons between them in practice. Some item reordering also occurred with the re-analysis.

Table 10. Pearson Product Moment correlations[a] between corresponding original and revised DBC-P and DBC-T subscale scores (Dekker et al., 2002a, p. 606)

Revised DBC scales		Original DBC scales		DBC-P	DBC-T
1.	Disruptive/Antisocial	1.	Disruptive	.97	.97
		2.	Antisocial	.66	.53
2.	Self-Absorbed	3.	Self-Absorbed	.96	.96
3.	Communication Disturbance	4.	Communication Disturbance	.81	.82
4.	Anxiety	5.	Anxiety	.91	.89
5.	Social Relating	6.	Social Relating	.92	.92

[a] all $p < .05$

Additional psychometric properties of the DBC were also assessed by Dekker, Nunn & Koot (2002b). Good test-retest reliability was shown for both the parent and teacher versions, and moderate inter-parent agreement and high one-year stability was found for the subscale scores. The DBC subscales showed good criterion group validity, as indicated by significant mean differences between referred and non-referred children, and between children with and without corresponding DSM-IV diagnoses.

4.5 STUDIES OF BEHAVIOURAL PHENOTYPES

Many studies have been conducted using the Developmental Behaviour Checklist to explore the characteristics of behavioural phenotypes in genetic disorders in children and adolescents. The value of a carer completed psychometrically sound checklist is exemplified in the number of studies that have been done using the DBC-P.

The DBC has been used in studies of Fragile X (Einfeld, Tonge, & Florio, 1994;

Steinhausen et al., 2002), Prader-Willi syndrome (Einfeld, Smith, Durvasula, Florio, & Tonge, 1999; Steinhausen et al., 2002), Williams syndrome (Einfeld et al., 2001), Autism and Aspergers syndrome (Tonge, Brereton, Gray, & Einfeld, 1999), sleep disorder and epilepsy in children with tuberous sclerosis (Hunt & Stores, 1994), hyperactivity (Kenway, 1994) depression in adults with severe and profound intellectual disability (Evans, Cotton, Einfeld, & Florio, 1999) and the risk of injury (Sherrard, Tonge, & Ozanne-Smith, 2002).

Einfeld and Tonge (1996) have also made a contribution to epidemiological research into the prevalence of psychopathology in young people with ID using carer report on the Developmental Behaviour Checklist. Their previous studies had established a cut-off score for psychiatric caseness on the DBC. When used in a large epidemiological derived population study, scores on the DBC demonstrated that 40% of those aged between 4 and 18 years could be classified as having severe emotional and behavioural disorder or as being psychiatrically disordered (Einfeld & Tonge, 1996).

The DBC has been carefully translated using the back translation method into 17 languages other than English, e.g., German, Dutch, Spanish, French, Hindi, Italian. It has been used in studies in many other countries including South Africa, England, Holland and Germany.

In summary, the DBC for children and adolescents, devised in the early 1990s, has flourished in the research community, and results from studies which have employed it have made a significant contribution to knowledge in the area of emotional and behavioural assessment and care of young people with an intellectual disability in Australia and overseas. It is a reliable and valid instrument, with confirmed factors of clinical and research utility. It also has unexplored potential and will probably be used in studies for years to come. An obvious direction for further development of the DBC in research and clinical settings is to investigate its use with adults with an intellectual disability. There are many clinical, research and service provision advantages of having available a similar instrument that can be used with people as they get older.

4.6 THE DEVELOPMENT OF THE DBC FOR USE WITH ADULTS

Conducting longitudinal research is an important way of extending knowledge and understanding of the developmental course of psychopathology and creating effective treatments. Studies of treatments and interventions for behavioural and emotional problems in children and adolescence need long-term outcome studies to determine the effectiveness and durability of positive results achieved. These results allow the determination of the cost-effectiveness of various interventions, and their ongoing impact on the lives of people as they grow and age. This important longitudinal research can be hindered by a lack of suitable instruments that have comparable results.

Ideally to follow the course of specific problems and syndromes from childhood, through adolescence to adulthood, similar assessments procedures and instruments are needed. However, instruments suitable for use by the carers of young children contain items that are unsuitable for older children and adults, the wording of other items maybe unsuitable, and difficulties that are specific to the circumstances of adults may require additional items to be identified and inserted. These changes require a revalidation of the instrument with each new age group studied.

The descriptive empirical approach to checklist development allows for the identification of patterns of problems that might characterise certain age groups or developmental levels. Because this approach works from the 'bottom up' (Achenbach, 1997) studies may reveal syndromes that are not captured by predetermined diagnostic categories of the type found in DSM for example. Childhood disorders may continue into adulthood creating a new category of disturbance, change into a disorder resembling an existing adult disorder, or evolve into a new disorder as a result of earlier patterns of dysfunction. By using similar standardised scales to assess representative samples of individuals at intervals across the years, the predictors and patterns of emotional and behavioural disturbance most likely to impair future development and lead to adult disorders can be identified. It may also be the case that some difficulties are identified as specifically occurring during the developmental transition from childhood to adulthood or are now specifically a problem in adult life.

In response to request for an adult version of the DBC, the DBC-P was modified with a few changes in the wording of items, such as, the word 'workshop' to replace 'school', and the addition of several supplementary questions about forensic issues. These changes were made in 1997 by the authors and colleagues (B. J. Tonge, personal communication, July 1998). No formal studies were conducted on this adapted instrument.

In a file study conducted at the Centre for Developmental Disability Health Victoria (CDDHV) in 1998 (later described in Chapter 5, Study 1), using this modified form of the DBC-P, it emerged that there were a significant number of behaviours and emotional difficulties described in CDDHV files that could not be matched against DBC items. This finding suggested the design of the larger series of studies described here, in order to have available a version of the Developmental Behaviour Checklist that could reliably and validly be used with adults with an ID.

In order to achieve this aim a series of studies was designed, outlined in Table 11. Strategic planning enabled collaboration with two research projects (Pica and Living Well) conducted at CDDHV over a two year period. As mentioned above, the early part of Study 1 was begun within a project also conducted at CDDHV, The GAP MAP Project, funded by the Department of Human Services, Victoria, and the data has been used here with their permission.

The overall aim of these studies was to redevelop the DBC-P for use with adults with ID.

The specific questions to be answered were:

1. Are there existing DBC-P items which are inappropriate in a checklist for adults?
2. Are there items in the DBC-P which would be more appropriate in a checklist for adults if their wording was altered?
3. Are new items required in order to comprehensively describe the disturbed behaviours and emotions of adults with ID?
4. Can paid carers reliably complete this checklist?
5. Can family carers reliably complete this checklist?
6. Can it be shown to have acceptable levels of construct, concurrent and criterion group validity?
7. What is the factor structure of the new instrument for adults and how does it compare to the factor structure of the DBC-P?

Table 11. The studies conducted to assess the reliability and validity of the DBC-A.

	Study 1 File Study	Study 2 Pica Study	Study 3 Clinic Study	Study 4 Living Well Study
Reliability – files, paid and family carer inter rater and test retest	✓	✓		✓
Content validity	✓			
Construct validity				
A. Internal consistency		✓	✓	✓
B. Principal components analysis		✓	✓	✓
Concurrent validity				
A. Clinician - DBC-A scores			✓	
B. DBC-A - other instruments				
Aberrant Behavior Checklist		✓		
PAS-ADD Checklist			✓	
Criterion group validity			✓	

CHAPTER 5

STUDY 1

5.1 OVERALL AIM

The overall aim of Study 1 was to modify DBC-P items and to select new items for the proposed DBC-A. To achieve this the following steps were undertaken:

1. Determine whether any existing DBC-P items were not suitable for inclusion in an adult version of the checklist and if any DBC-P items needed to be reworded.
2. Select from descriptions of behavioural and emotional disturbance in the clinic files of adults with an ID new items for possible inclusion in the adult DBC.
3. Consult with Professors Einfeld and Tonge to review the proposed item content of the DBC for adults (DBC-A).
4. Determine inter-rater agreement and test-retest reliability when two clinicians independently used the draft DBC-A version to rate the behaviour of adults with an ID as described on clinic files.
5. Determine item validity by consulting with experts in the field of health care for adults with an ID and by comparing DBC-A items with the items in the Aberrant Behavior Checklist.
6. Confirm maintenance of readability from DBC-P to DBC-A.

5.2 METHOD

The adaptation and selection of items for the adult version of the DBC employed the same process of checklist construction used by Einfeld and Tonge (1992). They were guided by a definition of disturbed behaviour and emotion adapted from Reid (1978), who derived it from Graham and Rutter (1970) to determine which descriptions of behaviour and emotional disturbance would be used to develop items for the DBC-P.

> Where behaviours and emotions are abnormal by virtue of their qualitative or quantitative deviancy and cannot be explained on the basis of developmental delay alone, and cause significant distress to the person, carers or the community, as well as significant added impairment, then they will be regarded as disordered (Einfeld & Tonge, 1992, p.xii).

Excluded from the descriptions of disordered behaviour were:

1. Behaviours explicable solely on the grounds of developmental delay, e.g. cannot speak
2. Behaviours attributable solely to physical disorder e.g. convulsions
3. Non-specific broad descriptions, e.g. maladaptive behaviour
4. Ill defined terms, e.g. psychotic.

The Centre for Developmental Disability Health Victoria (CDDHV) is a joint initiative of Monash University and The University of Melbourne, funded by Human Services, a Victorian State Government department. Clinical staff at the CDDHV provide a health service for adults with intellectual and developmental disabilities throughout the state of Victoria. The patient assessment record is semi structured and includes a section enquiring about emotional and behavioural problems. The files were reviewed by CDDHV clinical staff as part of an ongoing audit process. No client identifying information was recorded as part of this review to protect confidentiality.

After the initial clinical consultation, client information is entered into the centre database under the heading of behavioural or psychiatric disturbance if these difficulties were identified in the consultation. The client files containing information about behavioural and psychiatric problems were identified from the database, and of these, 605 contained usable information recorded by CDDHV staff from their observations during appointments and in reports regarding emotional and behavioural problems (if available) from parents, teachers, Intellectual Disability Service workers, psychologists and psychiatrists, and other health specialists. No standardised rating scales or checklists were consistently or frequently used by CDDHV staff, but they were all experienced in the assessment of emotional and behavioural problems.

The descriptions of behavioural and emotional disturbance recorded in the 605 files were extracted and synonymous terms were reduced to a single term. For example, all the disordered behaviour and emotions described as related to phobias and fears of many different things and situations (crowds, escalators, shopping centres, stairs, automatic doors, heights) were subsumed under the one item, "Fears particular things or situations". Descriptions were matched with DBC-P items if possible. DBC-P items for which few direct matches were found and additional unmatchable behavioural descriptions were listed.

Existing DBC-P items were also scrutinised for any wording changes required to ensure comprehension or acceptability in the adult version.

Based on this preparatory work and in consultation with Professors Einfeld and Tonge a draft version of a DBC-A was compiled.

Three services providing either specialist health and behavioural support to adults with an ID or generic mental health services were approached to participate in a specialist consultation process. Staff from each service available on the day of the consultation completed a draft DBC-A, rating the behaviour of an adult with an ID they had worked with, and then participated in a discussion where they were asked to identify disordered behaviours and emotions that they had identified in their work with adults with an ID that they could not identify in the draft DBC-A.

Three groups of staff completed a draft DBC-A and discussed the items.

5.2.1 AGED CARE PSYCHIATRY

Members of a Community Aged Care Psychiatry team made themselves available for this consultation. The team consists of community psychiatric nurses, psychologists, medical officer, consultant psychiatrist, occupational therapist and social worker. Five team members were able to complete a DBC-A for a recent patient with an ID.

5.2.2 FORENSIC SERVICES FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

Members of the Statewide Forensic Service specialising in working with people with an ID made themselves available for this consultation. The team consists of psychologists, nurses and psycho-educational trainers, nine people in all. Each completed a DBC-A for a recent client with disturbed behaviour.

5.2.3 SPECIALIST STAFF AT THE CENTRE FOR DEVELOPMENTAL DISABILITY HEALTH VICTORIA

Six staff members from the CDDHV were available on the day, comprising three GPs specialising in health care for people with ID, two mental retardation nurses with experience in caring for people with ID and a human relations counsellor. Each completed a DBC-A for an adult they knew with an ID and disturbed behaviour.

One hundred (100) files were randomly selected from the CDDHV database from the group of adults who had been referred to the Centre in the previous 24 months for assessment of disturbed behaviour and/or a psychiatric problem.

Two experienced clinical practitioners, a clinical psychologist and a mental retardation nurse, both familiar with the DBC-P, independently rated the presence or absence of items in the 100 files on the newly drafted DBC-A.

They also rated 10 of these files independently again within two weeks.

The method is summarised in Table 12.

Table 12. Summary of method of item selection and modification for preparation of the DBC-A.

Select files coded for behavioural problems/psychiatric illness

Eliminate those without specific description of disturbed behaviour

Extract descriptions of behaviours and emotion of concern from remaining files

Reduce synonymous terms to single terms

Determine which behaviour meets definition of disturbance

Inspect existing items re: appropriate wording

Compare potential adult items to existing DBC-P items

Add new items, remove any DBC-P items inappropriate to adults, change wording of DBC-P items as required

Adjust items by lumping or splitting

Convert to lay language

Consultation with DBC-P authors

Consultations with expert clinicians

Clinicians ratings of files to assess inter-rater agreement and test-retest agreement

Further refine item wording.

5.3 RESULTS

Distribution of the IQ levels of this sample and comparison with the total population of people with an ID is provided in Table 2. The group of 605 adults from the CDDHV database is a sample of convenience and not a representative sample (see Table 13).

Table 13. Distribution of IQ level of clinic sample compared to the population of adults with an ID

Level of disability	Number of people	% of total sample	% in ID population [a]
Developmentally Disabled I.Q.>70	43	7.2	N/A
Mild	172	28.4	85
Moderate	119	19.8	10
Severe	54	8.9	3.5
Profound	4	.6	1.5
Unknown	212	35.1	N/A
TOTAL	605	100	100

[a] Source of criteria DSM-IV (American Psychiatric Association, 1994, p. 41)

On one important dimension (IQ distribution) a significant short fall is in the size of the group of adults with a mild intellectual disability (28.4% v. 85%). The CDDHV database contained information about level of disability, however about one third of the sample had not been coded for level of disability. Twenty-four adults had a developmental disability (with an IQ over 70), but they were included because they were diagnosed with Pervasive Developmental Disorder (PDD), and therefore the descriptions of disordered behaviour and emotions contained on their files is relevant to the development of a checklist that will be used with adults who have PDD, both with and without ID. People with autism, even with a normal IQ, often have significantly impaired adaptive behaviour.

Only six DBC-P items were rarely found (in less than three) in the adult files (Table 14).

Table 14. Six DBC-P items rarely found in adult files

Confuses the use of pronouns
Likes to hold or play with an unusual object
Overly interested in looking at, listening to or dismantling mechanical things.
Prefers the company of adults or younger children. Doesn't mix with own age group
Resists being cuddled, touched or held
Smells, tastes, or licks objects.

These six items from the DBC-P were only rarely identified in the adult files. When they were mentioned it was more by way of describing the person and their personal characteristics rather than describing behaviour for which the referring person was seeking assistance. Most of these items probably describe the longstanding behaviour of adults with PDD.

Two groups of behavioural descriptions that could not be matched with DBC-P items were identified. One group contained descriptions found in more than four files (Table 15).

Table 15. Eleven descriptions unmatched by DBC-P items found in more than four files

Has become more confused or forgetful
Loss of self-care skills
Substance abuse, cigarettes, alcohol, caffeine, other drugs
Increase in appetite
Has become more withdrawn
Panics. Sweats, flushes, trembles
Spits
Not communicating as much as usual
Makes gloomy statements
Bizarre speech
Loss of enjoyment or interest in usual activities.

Of these eleven items that could not be matched with items in the DBC-P, some describe key diagnostic criteria of several major psychiatric disorders, such as depression or dementia. Therefore they needed to be considered for inclusion in an adult version of the DBC which should comprehensively describe psychopathology in adults with an intellectual disability. However, each item might describe features of more than one psychiatric disorder, e.g. 'loss of self-care skills' could be related to an affective, psychotic or organic disorder. Others, such as 'Spits' for example, were included because they were frequently mentioned.

In consultation with Professors Einfeld and Tonge item wording was refined; for example, the item referring to substance abuse was split into two items: 1. Problems with cigarettes, alcohol or caffeine, and, 2. Problems with the illegal use of drugs. The second group of unmatchable items described the behaviour of only one person in the sample (Table 16).

Table 16. Descriptions of four disordered behaviours found on only one file

Attempted kidnapping
Booked birthday cake three years in advance
Rolling in the mud
Farts on purpose.

These four items found on only one file describe disturbed behaviours that were concerning to carers. Only two of these behaviours (attempted kidnapping and rolling in the mud) are potentially harmful to the person or their carers or members of the community, or caused significant distress or impairment. Because they were only reported once and are of doubtful relevance to the assessment of psychopathology they were not included in the DBC-A.

The following deletion, changes and additions were made to the DBC-P in consultation with Professors Einfeld and Tonge.

5.3.1 DELETION OF ONE DBC-P ITEM

5.3.1.2 Doesn't mix with his/her age group: Prefers to mix with older or younger people.

This item was omitted. Adults with ID may have little choice regarding the age of the people they spend time with but if they do have a preference and can make choices it is not regarded as 'disordered', unless they are sexually interested in young children, in which case their behaviour would be captured by another item relevant to sexual behaviour.

5.3.2 CHANGES TO DBC-P ITEMS *(ITALICS)*

5.3.2.1 Doesn't respond to others feelings, e.g. shows no response if *a close friend* or family member is crying.

This item was altered to reflect the fact that some adults with an intellectual disability do not have a great deal of contact with family members, and in adulthood may have been able to form other close relationships.

5.3.2.2 Excessively distressed if separated from *a* familiar person.

The 'a' was added for grammatical purposes, as an aid to comprehension.

5.3.2.3 Fears particular things or situation, e.g. the dark (or), insects or *crowds*.

'Crowds" was added because in the file review going out and about in crowded places was the most commonly reported source of fearful behaviour. The word 'or' was relocated.

5.3.2.4 Hits, bites *or injures* self.

The words 'or injures' were added to be more inclusive of the many ways an adult can injure themselves, e.g. pulling out hair, cutting with knife, bruising against walls.

5.3.2.5 Kicks, hits *or injures* others.

The words 'or injures' were added to reflect the multiple ways it is possible for an adult to injure another person, for example, adults with ID had injured others by scratching, squeezing or grabbing them.

5.3.2.6 Masturbates, or exposes self, in public

Two commas were added to this item, as an aid to comprehension. The item always intended that it was only masturbation or undressing <u>in public</u> that should be considered, but without the commas was perhaps open to some misinterpretation. The need to make this change was highlighted by several referrals to the CDDHV by carers who requested that a doctor prescribe medication for the sole purpose of preventing the adult (always a male) with an ID who they looked after, from masturbating at all.

5.3.2.7 Resists being cuddled touched or held *by close friends or family*

The words 'by close friends or family' were added because adults with an ID may have been encouraged or taught to resist being cuddled, touched or held by acquaintances or strangers in order to offer them some protection from sexual abuse.

5.3.2.8 Sleeps too much *or overly drowsy*

The phrase 'or overly drowsy' was added to this item to include the behaviour of many adults who were described in the files by their carers or observed by the doctor to be drowsy, so drowsy that it interfered with normal activities of daily life.

5.3.2.9 Talks about *or attempts* suicide

The words 'or attempts' were added to this item in order to include the behaviour of adults who have tried to kill themselves.

5.3.7 CHANGES TO THE ORDER OF PRONOUNS

Throughout the DBC-P pronouns are used in some items e.g. he/she, his/hers. The order in which the male and female pronouns are used is alternated in the DBC version for adults.

5.4 ADDITIONS TO DBC-P ITEMS

The new items for the DBC-A are shown in alphabetical order on Table 17.

Table 17. New items for the DBC-A

Bizarre speech, please describe
Has become confused or forgetful
Has become more withdrawn
Increase in appetite
Loss of enjoyment or interest in usual activities
Loss of self-care skills
Makes gloomy statements
Not communicating as much as usual
Panics. Sweats, flushes, trembles
Problems with cigarettes, alcohol, caffeine
Problems with the illegal use of drugs
Spits.

5.5 CONTENT VALIDITY

5.5.1 SPECIALIST CONSULTATIONS

The Aged Care Psychiatry staff commonly selected the following new items:

31. Has become more confused or forgetful.
32. Has become more withdrawn.
50. Loss of enjoyment or interest in usual activities.
51. Loss of self-care skills.
57. Not communicating as much as usual.

The Aged Care Psychiatry staff raised no behaviours of concern that were not included in the DBC-A.

The staff from the specialist forensic service selected the following new items:

32. Has become more withdrawn.
50. Loss of enjoyment and interest in usual activities.
51. Loss of self-care skills.
52. Makes gloomy statements.
57. Not communicating as much as usual.
67. Problems with cigarettes, alcohol and caffeine.
68. Problems with the illegal use of drugs.

Behaviours thought not to be covered by the DBC-A were:

1. Cruelty to animals.
2. Stalking/loitering around schools and playgrounds.
3. A range of sexual behaviour not necessarily involving another person e.g. fetishes, cross-dressing, with animals, with items.

The consultation with staff from the specialist health service commonly selected the following new items:

9. Bizarre speech.

50. Loss of enjoyment and interest in usual activities.

51. Loss of self-care skills.

82. Spits.

Two staff members mentioned 'polydipsia', and one mentioned 'spies and stalks staff'. Various types of sexual behaviour were also mentioned.

5.5.2 COMPARISON WITH ABERRANT BEHAVIOR CHECKLIST ITEMS

Another way of validating items in the DBC-A was to compare them to the items in a similar checklist, the Aberrant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985) whose items were derived using similar methodology (see Chapter 3). Only one ABC item (Disrupts group activities) in the 58 item ABC is not covered in the 106 item DBC-A (See Appendix G). The item 'Disrupts group activities' is not appropriate to include in the DBC-A, because only some settings for adults conduct group activities, e.g work and training environments.

5.6 CLINICIANS RATINGS OF FILES

The two clinicians (CM & AP) rating 100 files independently on the presence of DBC-A items, achieved an average inter-rater item-by-item agreement on items of .69 on the DBC-P, and .72 on the DBC-A.

On the 10 files rated again two weeks later, CM achieved test-retest agreement on the DBC-A Total Behaviour Problem Score of .76 and AP .69.

This compares favourably with the DBC-P studies where average inter-rater item-by-item agreement was .68 and test-retest reliability was .72.

Total item agreement was computed using DAG_STAT (Mackinnon, 2000). Cohen's kappa was 0.85 ($p < 0.000$), indicating very high agreement.

5.7 FURTHER REFINEMENT OF ITEM WORDING

A final change in one item was made during Study 3. The meaning of Item 21. 'Easily led by others', was clarified by modification so that it read 'Easily led *into trouble* by others'. This was done following confusion expressed by one parent, whose adult child was very easy to physically direct to complete self-care tasks, and was, in her opinion, 'easily led by others', which she described as a very positive attribute, as it made caring for her adult child much easier.

5.8 READABILITY OF THE DBC-A

The readability of new and changed items was determined by computing the Flesch Grade Level using Microsoft Word (see Table 18).

Table 18. Readability statistic for DBC-P and DBC-A

	DBC-P[b]	DBC-A
Flesch Grade Level[a]	7.3	6.4

[a] U.S. grade school level. [b] Einfeld & Tonge (1992, p. 65)

This finding compares favourably with the same statistic computed for DBC-P, demonstrating that changes and additions to the DBC-P have not produced a new checklist that is more difficult for carers with a primary level of education to read, understand and complete.

5.9 DISCUSSION

5.9.1 SUMMARY OF FINDINGS

The aims of Study 1 were achieved and in summary the findings were:

1. One DBC-P item was found not to be relevant for an adult version of the checklist, and changes were made to the wording of nine DBC-P items so that they were appropriate and acceptable for an adult version. Where pronouns appeared in items the male and female forms were alternated.
2. Twelve news items were added to the DBC-P to construct the DBC-A (see Appendix H)
3. Consultations with Professors Einfeld and Tonge assisted with the selection of items and item wording changes.
4. Two clinicians independently rated the presence of DBC-A items in 100 clinic files and achieved acceptable levels of inter-rater item by item agreement, test-retest agreement and total item agreement.
5. Consultations with experts in the health and disability fields assisted in confirming new item validity, and a comparison with items from a similar checklist, the ABC, also indicated many points of similarity in item content, although the DBC-A is more comprehensive.
6. Readability of the DBC-A is comparable with that of the DBC-P, confirming that carers with a primary level of education will be able to read and understand the items in the DBC-A.

5.9.2 RATIONALE FOR METHODOLOGY

The DBC-P is a rich repository of items describing the disturbed behaviours and emotions of children and adolescents with an intellectual disability described in language suitable for carers to use. A priority of this project in developing an instrument that could be used by the carers of adults who have an ID was to replicate this degree of comprehensiveness.

Only a descriptive/empirical approach to the selection of items produces a wealth of items observed and described by people who live and work with and care for adults with an ID.

In modifying the DBC-P it was therefore imperative to use very similar methodology. Consultation with the original authors was also helpful.

5.9.3 PROCESS

As Einfeld and Tonge (1992) have described in the DBC-P manual 'It was reasoned that any emotional or behaviour problem which was not described in 664 young persons regarded as behaviourally disturbed was not likely to be important' (Einfeld & Tonge, 1992, p. 6). Similarly the extraction of descriptions of behavioural and emotional disturbance from 605 files in this study can claim to have also been comprehensive. However when reading files one recognises that information may have been summarised and synthesised to some extent, and often shorthand terms e.g. 'agitated' were used. This may result in some loss of information, which is probably countered by using many files.

Five out of the six DBC-P items infrequently found in adult files listed in Table 14 were included in the DBC-A because of their particular clinical utility in the assessment of psychopathology in adults with an ID. This is consistent with the approach taken by Einfeld and Tonge when they selected the items for the DBC-P. Despite including the findings on emotional and behavioural disturbance from 664 child and adolescent clinical files Einfeld and Tonge (1992) found that "a few symptoms of particular clinical interest were not present" (p. 7). The items of particular clinical interest they added to the DBC-P described the symptoms of psychotic illness: hallucinations, delusions and thought disorder. Other instrument developers, e.g. Aman & Singh, authors of the ABC, excluded items occurring in less than 10% of their sample, even though they may have a valuable role to play in clinical assessment.

5.9.4 LIMITATIONS

The CDDHV database contained incomplete information about the results of formal IQ testing of the adults described in their files. However the CDDHV clinicians are very experienced practitioners who would have recorded any impressions they had about the ability level of their patients if this was not consistent with the patient having an ID. In addition almost every patient was registered with the state department providing services to people with an ID whose standard practice is to assess the intellectual ability of client to determine their eligibility for services before agreeing to provide a service.

The people described in the 605 clinic files are not representative of the general population of people with an ID, for example on IQ distribution, but this is not a limitation for this study. The aim of comprehensively describing the disturbed behaviour and emotions of adults with an ID was achieved because of the large number of files included and the range of ability levels represented.

The specialist consultations suggested the addition of items related to stalking and sexual behaviour. However it was decided not to add them to the DBC-A. These items had not emerged during the close reading of 605 files. In subsequent studies (Chapters 6-8) another 579 DBC-As were completed and no carers added items on stalking or sexual behaviour in the space provided at the end of the checklist. Therefore it was decided not to add these extra items.

It is interesting that using a similar methodology to the DBC-P most items were retained as relevant to adults and only a further twelve items needed to be added to obtain a comprehensive psychopathology checklist for adults with ID. Therefore it is likely that the DBC-A can be used subsequent to the earlier use of the DBC-P to track psychopathology in adulthood, and investigate developmental aspects of psychopathology.

CHAPTER 6

STUDY 2

6.1 OVERALL AIM

The aims of Study 2 were firstly to investigate the reliability of the DBC-A when completed by residential care workers, and secondly to assess the validity of the DBC-A in relation to another instrument also rated by care workers.

To achieve this the following steps were undertaken:

1. Estimate the level of inter-rater reliability achieved by pairs of residential care workers completing the DBC-A on an individual resident within two weeks.
2. Estimate the level of test-retest agreement achieved by residential care workers completing two DBC-As on an individual resident.
3. Assess concurrent validity of the DBC-A by comparing total scores on the Aberrant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985) to total scores on the DBC-A completed at the same time for each resident by a residential care worker.

6.2 METHOD

This study was conducted as part of a larger study (Pica Study) by the Centre for Developmental Disability Health Victoria (CDDHV) on two groups of residents of a residential institution. One group of residents was identified by staff survey as frequently performing pica behaviour, and the control group was matched on age, sex and level of dependency in order to investigate personal, medical and psychological variables associated with pica behaviour. Pica is the persistent eating of non-nutritive substances (American Psychiatric Association, 1994). Although 75 residents were identified as frequently performing pica behaviour, consent from the family members for inclusion in the study of pica behaviour was only obtained for 37 of these residents. The total cohort therefore consisted of 37 residents with pica and 40 matched control residents.

A residential care worker who knew each resident well, accompanied him or her to the on-site Medical Centre for a two-hour session of medical review and checklist completion. For each resident the ABC (Aman et al., 1985) and DBC-A were completed by the residential care worker. Correlations between total ABC and DBC-A scores were computed.

Staff in the residential unit setting completed inter-rater and test-retest DBC-As as follows.

Immediately after the completion of the DBC-A within the Pica Study an attempt was made to locate additional staff members who knew each resident well and request that they independently complete another DBC-A.

Within two weeks of the first DBC-A being completed, an attempt was also made to locate the original raters and ask them to complete another DBC-A for the resident who they accompanied to the Pica Study medical evaluations.

6.3 MEASURES

6.3.1 DEVELOPMENTAL BEHAVIOUR CHECKLIST FOR ADULTS (DBC-A)

The Developmental Behaviour Checklist for Adults (DBC-A) developed by the author was used. It is a 106-item checklist, constructed by modifying some items in the DBC-P for children and adolescents (Einfeld & Tonge, 1992) and augmenting it with twelve additional items which describe the disturbed behaviour of adults with an ID (see Study 1).

6.3.2 ABERRANT BEHAVIOR CHECKLIST (ABC)

The Aberrant Behavior Checklist (ABC) (Aman et al., 1985) is a 58 item checklist of aberrant behaviours developed for use with adults who have intellectual disability (see Chapter 3 for a detailed description).

6.4 DATA ANALYSIS

The Intraclass Correlation Coefficient (ICC) and paired-samples *t*-tests were used to analyse the test-retest reliability data. Streiner and Norman (1995) state that there "has been considerable debate in the literature regarding the most appropriate choice of the reliability coefficient" (p. 114). Some standard texts on psychometrics recommend estimating reliability with an Intraclass Correlation Coefficient (Nunnally & Bernstein, 1994), and this is the measure used by Einfeld and Tonge (1992). It is generally referred to as a more conservative measure as it "takes account of the absolute as well as relative difference between the scores of two raters" (Einfeld & Tonge, 1992, p. 12). It would also be an advantage to use the ICC here so that results between these studies and the DBC-P establishing studies conducted by Einfeld and Tonge can be directly compared. However in test-retest reliability studies it is also illuminating to assess the absolute and relative difference between mean scores separately. The absolute difference was assessed using the paired-samples *t*-test statistic.

Intraclass Correlation Coefficients were also used to estimate the strength of the relationship between the Total Behaviour Problem Score (TBPS) on the DBC-A achieved by two raters independently.

Concurrent validity was measured using Pearson Product Moment Correlations to estimate the strength of the relationship between scores on the DBC-A and the ABC.

Computations were done using SPSS Version 10.0 for Windows (SPSS, 1999).

6.5 RESULTS

6.5.1 PARTICIPANTS

The characteristics of the Pica Study resident group and the participants of the test-retest and inter-rater agreement studies are described in Table 19.

The majority of the residents studied (63.6%) had a severe or profound ID. This reflects the nature of the residents in the facility and the finding that pica behaviour is more prevalent in people with a more severe ID (Ali, 2001). Subjects were mostly males (79.2%) aged 30 or older, which reflects the male to female ratio of the institution and the ageing of its population.

An attempt was made to include all the participants in the Pica Study in the inter-rater and test-retest studies. However, a monthly staff rostering change made at the residential centre during the Pica Study meant that all participants could not be included. When the staff who attended the medical appointments, and other potential raters who knew the residents well were being sought for the test-retest and inter-rater agreement studies, some staff had left work to go on a leave break, others had moved to work the night shift, and others had changed their work location and were now working with residents they were less familiar with.

Table 19. Characteristics of the participants of the Pica Study sample (N = 77) and the participants of the test-retest (N = 34) and inter-rater (N = 53) agreement studies.

		Total cohort N (%)	Test-retest N (%)	Inter-rater N (%)
People with ID		77 (100)	34 (100)	53 (100)
Level of disability	Unknown[1]	24 (31)	15 (44)	13 (25)
	Moderate	4 (5)	1 (3)	2 (4)
	Severe	33 (43)	12 (35)	23 (43)
	Profound	16 (21)	6 (18)	15 (28)
Gender	Male	61 (79)	32 (94)	48 (91)
	Female	16 (21)	2 (6)	5 (9)
Age (years)	Range	30 – 67	30 – 63	33 – 67
	Mean	43.27	40.13	44.56

[1] The level of disability was not formally recorded, but levels of dependency assessed in the study indicated that these residents also had at least a moderate, or more severe ID.

6.5.2 TEST-RETEST AGREEMENT

Because of shift and roster changes only 34 of the original raters who completed the first DBC-A in the Pica Study could be located to complete another DBC-A.

Table 20. Intraclass correlation coefficient and paired-sample *t*-test for test-retest reliability (N = 34)

	N	Mean	Std. Dev.	ICC	95% CI	*t*	df	Sig. (2-tailed)
DBC-A 1 Pica Study	34	48.7	22.3	.75	.55 - .86	3.9	33	.000
DCB-A 2 Test-retest	34	40.3	18.4					

The relationship between the TBPS on DBC-A 1 and DBC-A 2 was investigated using Intraclass Correlation Coefficient. There was a strong positive correlation between the two scores (ICC = .75, n = 34, 95% CI .55 - .86) indicating high levels of test-retest reliability.

A paired-samples *t*-test was conducted to ascertain whether there was a significant difference between scores on DBC-A 1 and DBC-A 2. There was a significant difference between the two scores from rating Time 1 (M = 48.7, SD = 22.3) to rating Time 2 (M = 40.3, SD = 18.4), *t*(52) = 3.9, p = .000, less than .05.

6.5.3 INTER-RATER AGREEMENT

Fifty-three additional residential care workers, who knew one of the 77 residents in the Pica Study well, were located within a two-week period, and completed a DBC-A checklist.

Table 21. Intraclass correlation coefficient for inter-rater agreement (N = 53)

	N	Mean	Std. Dev.	ICC	95% CI
DBC-A 1 Pica Study	53	49.6	23.9	.48	.24 - .66
DCB-A 2 Inter- rater Study	53	43.7	22.1		

The relationship between the TBPS on DBC-A 1 and DBC-A 2 was investigated using Intraclass Correlation Coefficient. There was a moderate positive correlation between the two scores (ICC = .48, n = 53, 95% CI .24 - .66).

6.5.4 CONCURRENT VALIDITY

The relationship between TBPSs on the ABC (Aman et al., 1985) and the DBC-A was investigated using Pearson Product Moment correlation coefficient. There was a moderate positive correlation between the two variables ($r = .63$, $n = 77$, $p < 0.001$), with high scores on the ABC associated with high scores on the DBC-A.

6.6 SUMMARY OF FINDINGS

The aims of Study 2 were achieved.

1. In the inter-rater agreement study there was a moderate positive correlation between the TBPS on the DBC-A completed independently by two care workers.
2. In the test-retest study there was a strong positive correlation between the TBPS on the DBC-A completed by the same rater within two weeks, and there was a significant difference between the two scores from rating Time 1 to rating Time 2.
3. Concurrent validity was demonstrated with the ABC (Aman et al., 1985).

6.7 DISCUSSION

6.7.1 INTER-RATER AGREEMENT

The results of the inter-rater agreement study indicate that two independent raters were able to achieve acceptable, if modest, levels of agreement. There may be several reasons for this modest result that are unrelated to the checklist under study.

In a large residential facility where many care workers are employed and many residents (20+) live in each unit, the opportunities for individual staff to become well acquainted with the details of each resident's circumstances and changes in these circumstances may be limited. Although staff were asked to confirm if they knew the resident well whose behaviour they were asked to rate, (i.e. for six months or longer), in reality they may not have learnt a great deal about some of the residents in their care.

Staff who work in community residential units with only 4 or 5 residents per house are much more likely to gain a uniform knowledge of the behaviour and changes in behaviour of each and every resident. It would be an advantage to repeat an inter-rater study in this type of residential setting, especially as this is becoming the more usual living environment for people with an ID in Australia accommodated within the service system.

There were also setting and motivational differences to be considered. The first DBC-A was completed by care staff in the institution's medical centre as part of the pica behaviour evaluation. Time was especially set aside for the evaluation, and the environment allowed staff to concentrate on the task at hand. The presence of senior medical staff from CDDHV may have also facilitated their assistance. The second DBC-A was completed in an office, tearoom or empty dining room of the residential unit. Care staff were asked by a student researcher to take time out of their busy day while still in the working environment, and they may have been easily distracted by staff and resident activities.

In this study over 20 residents who were rated on the DBC-A in the Pica Study could not be included in the inter-rater agreement study because another care worker who knew them well could not be located. Roster changes made in the facility at the time of the study meant that many staff moved to other buildings, or work areas, changed to work on the night shift or commenced leave.

6.7.2 TEST-RETEST AGREEMENT

The result of the test-retest agreement study indicates that residential care workers were able to achieve excellent levels of agreement when completing the DBC-A twice. However their ratings on the second DBC-A were significantly lower than the mean TBPS on the first DBC-A they completed.

Several factors may have contributed to this finding, which is known as 'the test-retest attenuation effect' (Achenbach, 1997, p. 80). Achenbach states that "Consistent with previous findings on many measures of problems the scores tend to decline from the first to the second assessment" (Achenbach, 1997, p. 80). Again setting and motivational differences may apply as described in the inter-rater results. Perhaps when rating resident behaviour on a DBC-A in the residential unit environment, carers were eager to complete the task as quickly as possible and may have overlooked relevant items in their haste to do so, or found it hard to concentrate when distracted by the activities of others.

The test-retest study with residential care workers who participated in the Pica Study suffered even more than the inter-rater study from the shift change that occurred in the facility at the time of the study. Over half of the original raters could not be found because they had either changed work area, gone on leave or were working on night shift. More conclusive results might be drawn from a study involving more care workers as participants.

6.7.3 CONCURRENT VALIDITY

Concurrent validity is supported by the moderate positive correlation between TBPS on the DBC-A and the ABC.

As discussed in Study 1 (Item selection), almost all of the 58 items in the Aberrant Behavior Checklist (Aman et al., 1985) appear in a similarly worded fashion in the DBC-A (see Appendix F), so it is not surprising that a strong positive relationship was found between the total scores on both checklists. By looking at the items it can be seen that the ABC contains mainly observable behavioural variables, while the DBC-A also includes items concerning emotions and feelings, essentially private events, about which observers can only try to make informed comment. Both approaches to assessment in ID have merit and utility, however the DBC-A, by including more behavioural items and items asking carers to think about emotional expression, may have more to contribute to an assessment of psychopathology.

In summary the aims of Study 2 were achieved. The DBC-A developed in Study 1 can be reliably completed by paid carers of adults with ID who live in a large residential facility and the DBC-A is a valid measure of behavioural and emotional disturbance.

CHAPTER 7

STUDY 3

7.1 OVERALL AIM

The overall aim of Study 3 was to determine clinical case cut-off scores of the DBC-A and its validity as a clinical assessment tool.

This aim was achieved by:

1. Assessing concurrent validity by:
    a) comparing total scores on the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) Checklist (Moss et al., 1998) to total scores on the DBC-A completed by carers, and,
    b) comparing total scores on the 6-point psychopathology scale to DBC-A TBPS.
2. Estimating the level of inter-rater agreement between two independent raters on ratings of the presence and severity of psychopathology.
3. Investigating criterion group validity by assessing the capacity of the DBC-A to differentiate between ratings of subjects as psychiatric 'cases' or 'non-cases'.
4. Calculating the optimal cut-off score for psychiatric caseness on the DBC-A.

7.2 METHOD

Participants were adults with an intellectual disability referred to university based general practice and psychiatric clinics specialising in health care for people with an ID between January 1 2001 and August 31 2001. The clinics were conducted by a psychiatrist and three GPs, specialising in health care for people with ID from the Centre for Developmental Disability Health Victoria (CDDHV). Presence of an ID was determined by reference to the person's status as a person assessed by ID service providers as an 'eligible person', and level of ID was determined by referring to the results of formal assessment results recorded on the CDDHV file or from carer report. Each patient was accompanied by one or more carers who knew him or her well to the appointment for an initial assessment of a health problem, or a review appointment.

A letter describing the study to potential participants was sent to them when they were contacted by the CDDHV with an appointment time. A cut-off slip at the bottom of the letter could be sent back to the CDDHV if the person receiving the appointment did not want to know any more about the study. If this slip was not returned the person with an ID and their carers were met by the researcher in the waiting area of the clinic and invited to read an information document (the Plain Language Statement). This document (see Appendix I) described all aspects of the study in plain language and any questions participants or carers had were answered. Three people (one person with an ID and two carers), out of seventy-three, who read the information document declined to be involved. Once verbal consent was obtained a printed consent form was signed by the participant or a carer or guardian on their behalf, by the researcher and by a third person who witnessed the participant or carer/guardian signature. The carer/guardian then completed the questionnaires and proceeded with the patient into the interview room for their appointment with the clinician accompanied by the researcher.

The CDDHV clinician conducted their usual assessment. In general the doctor addressed comments and questions where possible to the person with an ID, usually gaining further detailed information from the family members and/or other carers. Sometimes a physical examination of the patient was conducted, and if/when this happened the researcher stayed behind a screened off area out of sight or left the consulting room if there was no screen in place. The doctors never used formal checklists or rating scales. Further medical tests and investigations were explained and organised as required, and a date made for a review appointment if necessary.

At the end of the consultation the clinician and the researcher independently rated on a six-point scale the presence and severity of the persons' psychopathology (described below), as ascertained during the session. The clinician was then informed of the results from both the checklists. PAS-ADD and DBC-A results were placed on the participant's CDDHV clinical file unless the participant, carer or guardian had requested that this not be done.

7.3 MEASURE

7.3.1 CLINICIAN COMPLETED MEASURE - RATINGS OF PSYCHOPATHOLOGY

Ratings of the presence and severity of psychopathology were made using Graham and Rutter's (1970) definition of psychopathology used by Einfeld and Tonge (1992):

> Where behaviours and emotions are abnormal by virtue of their qualitative or quantitative deviancy and cannot be explained on the basis of developmental delay alone, and cause significant distress to the person, carers or the community, as well as significant added impairment, then they will be regarded as disordered (p. xii).

'Deviance' describes the extent of the abnormality of the behaviour; 'distress' is rated as it impacts on the person with an ID and their carers; 'impairment' in adaptive functioning is considered if it is judged to be present beyond that resulting from the level of the ID.

Deviance, distress and impairment were rated on a 3 point scale, where 0 = not present, 1 = somewhat, and 2 = substantial, giving a potential score for each participant from 0 to 6 (see Table 22).

Table 22. Scoring grid for assessment of psychopathology by researcher and clinicians

	None 0	Somewhat 1	Substantial 2	
Deviance				
Distress				
Impairment				
				/6

Four clinicians employed by CDDHV were involved in this study. Clinician 1 is a consultant psychiatrist and the other three are general practitioners. All clinicians specialise in health care for people with an ID.

7.3.2 CARER COMPLETED MEASURES

The carers completed the following checklists:

7.3.2.1 The Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) Checklist

The Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) checklist (Moss et al., 1998) is a 29- item scale, with items worded in lay language, each rated on a four-point scale (see Appendix E, and Chapter 3 for a more detailed description).

7.3.2.2 Developmental Behaviour Checklist for Adults (DBC-A)

The Developmental Behaviour Checklist for Adults (DBC-A) developed by the author was used. It is a 106-item checklist, constructed by modifying some items in the DBC-P for children and adolescents (Einfeld & Tonge, 1992) and augmenting it with twelve additional items which describe the disturbed behaviour of adults with an ID (see Study 1).

7.4 STATISTICAL ANALYSIS

Concurrent validity data in Study 3 were analysed with Pearson Product Moment Correlations. Inter-rater agreement data on the psychopathology ratings by clinicians was analysed with Intraclass Correlation Coefficients. Criterion group validity data was analysed using an independent samples *t* test and an effect size statistic (Eta squared). Receiver Operating Characteristics analysis was used to determine the optimum DBC-A total score for psychiatric caseness. Computations were done using SPSS (SPSS, 1999) and DAG_STAT (Mackinnon, 2000).

7.5 RESULTS

7.5.1 PARTICIPANTS

Characteristics of the people with ID in Study 3 are described in Tables 23 and 24.

Table 23. Gender, level of ID and age of the people with ID in Study 3 (N = 70)

		Frequency	Percent
People with ID		70	100
Gender	Male	45	64
	Female	25	36
ID level	Mild	28	40
	Moderate	27	39
	Severe	14	20
	Profound	1	1
Age (years)	18-25	21	30
	26-35	20	29
	36-45	12	16
	46-55	10	14
	56-65	5	7
	66+	2	3

More people with ID were male (64%) than female (36%). Seventy-nine percent of participants had a mild or moderate degree of intellectual disability, twenty percent had a severe intellectual disability and only one participant (1%) had a profound intellectual disability. Half the participants were young adults (younger than 35 years = 59%), and ten percent (10%) were in the older age range (+55years).

Table 24. Type of accommodation of people with ID and carer who completed the DBC-A in Study 3 (N = 70)

		Frequency	Percent
People with ID		70	100
Accommodation	Community Residential Unit	39	56
	Home with family	20	29
	Institution	4	5
	Hostel	3	4
	Independent with assistance	2	3
	Nursing home	2	3
Carer who completed the DBC-A	Residential care staff	42	60
	Parent	17	24
	Other relative	4	6
	Other	7	10

Most people with an ID in Study 3 lived in a Community Residential Unit (56%) or in the family home (29%). Only six percent (6%) lived in an institution. A residential care worker (60%) or a parent (24%) most frequently completed the DBC-A and PAS-ADD.

7.5.2 CONCURRENT VALIDITY

7.5.2.1 DBC-A and PAS-ADD Checklist

The relationship between total scores on the DBC-A and PAS-ADD Checklist was investigated using Pearson Product Moment correlation coefficient. There was a strong positive correlation between the two variables ($r = .612$, $n = 70$, $p < 0.01$), with high total scores on the DBC-A associated with high total scores on the PAS-ADD.

7.5.2.2 DBC-A TBPS and ratings of psychopathology on the 6-point scale

Total scores on the 6-point rating scale of the presence and severity of psychopathology made by CM were correlated with Total Behaviour Problem Scores on the DBC-A. There was a strong positive correlation between the two variables ($r = .524$, $n = 70$, $p<.000$), with high total scores on the DBC-A associated with higher ratings made by CM on the 6-point psychopathology scale.

7.5.3 THE LEVEL OF INTER-RATER AGREEMENT ON RATINGS OF PSYCHOPATHOLOGY MADE BY CLINICIANS

The strength of the relationship between ratings on the 6-point psychopathology rating scale made independently by the clinicians and CM was estimated by Intraclass Correlation Coefficients (ICC). Table 25 shows the ICC of each clinician's ratings with CM. The highest ICC was found between the ratings of Clinician 1 and CM (.82) and the lowest between Clinician 2 and CM (.74). The weighted mean ICC was .80.

Table 25. Intraclass Correlation Coefficients (ICC) of clinicians psychopathology ratings with CM ratings, and weighted mean ICC

	N	ICC with CM	95% CI
Clinician 1 Psychiatrist	37	.82	.66 - .90
Clinician 2 GP	5	.74	-.05 - .97
Clinician 3 GP	13	.77	.42 - .92
Clinician 4 GP	15	.81	.54 - .93
Total	70		
Weighted mean ICC		.80	

7.5.4 AGREEMENT ON PSYCHIATRIC CASENESS

Agreement on psychiatric caseness was estimated by Cohen's kappa for each clinician with CM (see Table 26).

Table 26. Agreement on psychiatric caseness

		CMs ratings of caseness		
		Yes	No	Total
Other clinician ratings of caseness	Yes	37	2	31
	No	3	28	39
	Total	30	40	70

Table 27. Agreement on psychiatric caseness between CM and clinicians

	N	Cohens kappa	95% CI
Clinician 1 Psychiatrist	37	.83**	.63 – 1.0
Clinician 2 GP	5	1.0	1.0 – 1.0
Clinician 3 GP	13	.69*	.30 - 1.0
Clinician 4 GP	15	1.0	1.0 – 1.0
Total N	70		

*substantial agreement **almost perfect agreement (Mackinnon, 2000)

Agreement on psychiatric caseness between individual clinicians and CM was very high. Between individual clinicians and CM the highest levels of agreement were found with Clinician 2 (with a very small patient group), and Clinician 4, followed by Clinician 1 and finally Clinician 3.

7.5.5 CRITERION GROUP VALIDITY

To assess the capacity of the DBC-A to differentiate between psychiatric non-cases and cases (criterion group validity), the 70 cases described above were divided into two groups. Group 1 received ratings by CM of 0, 1, 2 or 3 (non-cases), and Group 2 received ratings by CM of 4, 5, or 6 (cases), on the 6-point psychopathology rating scale. Mean psychopathology ratings were 1.8 for Group 1, and 5.3 for Group 2.

An independent-samples *t* test was conducted to compare the DBC-A scores between the two groups (cases and non-cases). The results are shown in Table 28.

Table 28. Independent samples *t* test on mean DBC-A TBPS between two groups

	N	Mean DBC-A TPBC	SD	*t*	df	p
Group 1 Non-cases	32	52.9	16.0	4.48	69	.000
Group 2 Cases	38	74.8	24.6			

There was a significant difference ($t(69) = 4.48$ ($p < .000$) between the DBC-A scores of Group 1, Non-cases (M= 52.9, SD= 16.0) and Group 2, Cases (M= 74.8, SD = 24.6).

Effect size statistics provide an indication of the magnitude of the difference between groups (Cohen, 1988). The most commonly used effect size statistic is eta squared (Cohen, 1988). The formula for eta squared is:

$$\text{Eta squared } (\eta 2) = \frac{t2}{t2 + (N1+N2-2)}$$

The magnitude of the difference between the DBC-A TBPS of Group 1 and Group 2 was large, as indicated by $\eta 2 = .22$.

7.5.6 CALCULATING THE OPTIMAL CUT-OFF SCORE FOR PSYCHIATRIC CASENESS

In order to estimate the optimal cut-off DBC-A TBPS for psychiatric caseness, a Receiver Operating Characteristics (ROC) analysis was performed on the data from the 70 cases (Tables 1 and 2) seen in the clinical setting described in the previous section.

ROC analysis, originally developed for use in electronic fields, has been employed in psychiatric research for the past fifteen years to assess the overall performance of instruments used in assessment and diagnosis (Fombonne, 1991). The most efficient test or scale is the one with the greatest ability to discriminate between cases and non-cases, and to do this with the greatest sensitivity and specificity. Sensitivity is the proportion of 'true positives' or real cases that are correctly identified or selected by an instrument, and specificity is the proportion of 'true negatives' or non-cases that are also identified (Altman & Bland, 1994a). In the practical use of an instrument, where only the total score on a scale is known, it is also desirable to know the probability that the test will make a correct identification (Altman & Bland, 1994b).

The ROC curve is obtained by plotting on a graph the true positive rate, the percentage of cases scoring above the threshold or cut-off point, on the vertical axis, and the false positive rate, the percentage of non-cases scoring above the threshold or cut-off score, on the horizontal axis (Fombonne, 1991). The most commonly accepted indicator of accuracy in ROC analysis is the 'Area Under the Curve' (AUC) (Fombonne, 1991), which will vary from .5 to 1.0 (the AUC of the perfect instrument).

The optimal DBC-P Total Behaviour Problem cut-off score of 46 for psychiatric caseness was derived using ROC analysis, and was determined using the Likelihood Ratio (LR) method (Fombonne, 1991). The AUC for the DBC-P is 92%, which "suggests that the DBC-P has very good specificity and sensitivity characteristics for distinguishing definite psychiatric caseness" (Einfeld & Tonge, 1992, p. 27).

7.5.7 RESULTS OF ROC ANALYSIS

The ROC curve is shown in Figure 1. The AUC is estimated to be .77 (95% CI .65 - .88) (see Table 10). The optimal cut-off point for maximising specificity and sensitivity, and thereby minimising the false positive and false negative rate, is a DBC-A TBPS of 60. The full range of DBC-A scores for levels of sensitivity and specificity are in Appendix J.

Figure 1. Receiver Operating Characteristics (ROC) curve for DBC-A

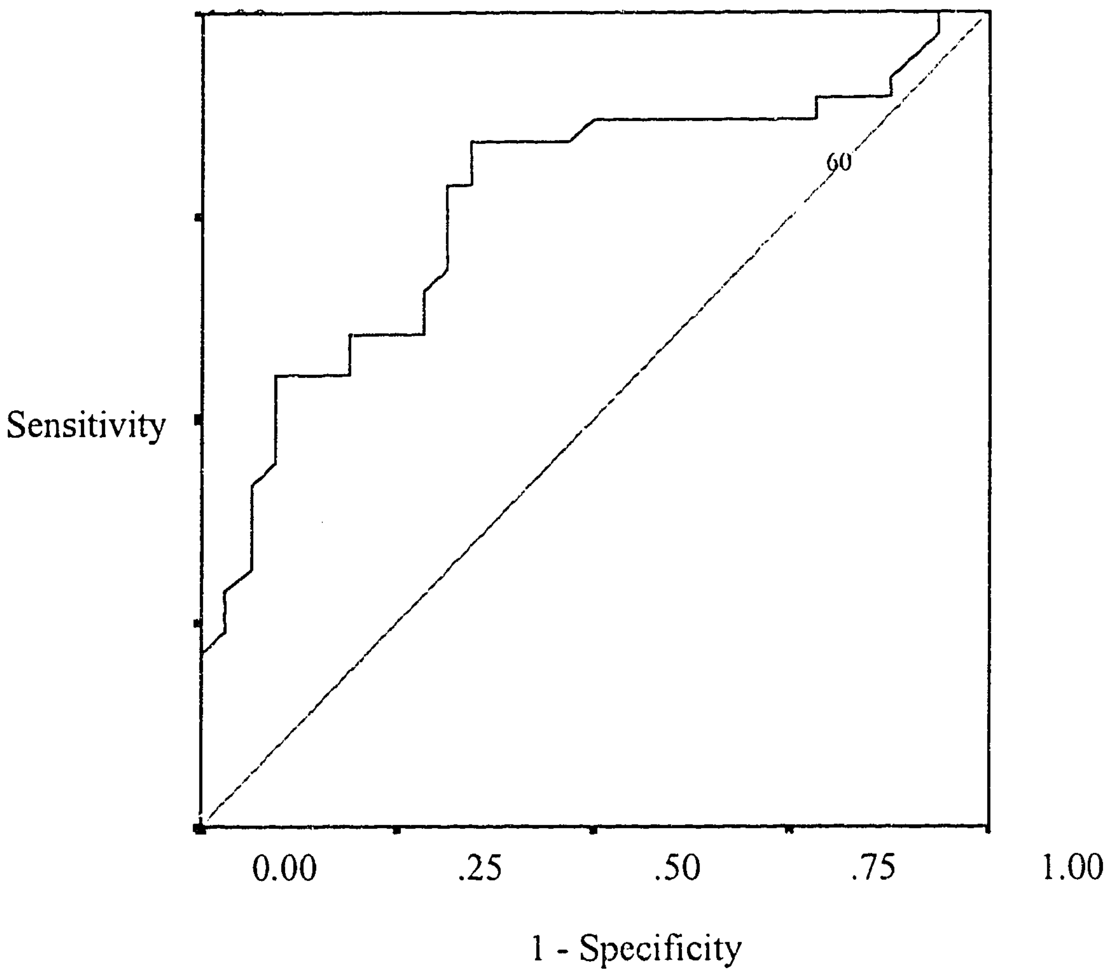


Table 29. Area under the curve statistics for the ROC analysis

			Asymptotic 95% Confidence Interval	
Area	Std Error	Asymptotic Sig.	Lower Bound	Upper Bound
.77	.058	.000	.65	.88

However in different situations a different cut-off score may be selected. For example, when using the DBC-A for screening purposes it may be desirable to eliminate false negatives, so that all the people with ID who might have a mental health problem could receive a more detailed assessment. For screening purposes the cut-off point selected would therefore be a DBC-A TBPS of 31. The false positive rate would be high (94%) but no cases of disorder would be missed (see Table 30).

This situation is unlikely to occur because resources for comprehensive mental health assessments of adults with intellectual disability are scarce, and many people would be seen unnecessarily for further assessment which would be wasteful. To select only those definite cases of disorder for further evaluation (eliminating any false positive cases) the cut-off point appropriate for this task would be a DBC-A TBPS of 96. In this scenario a large percentage (79%) of people with a psychiatric disorder would go undetected.

Table 30. Critical DBC-A values for levels of specificity and sensitivity

Critical DBC-A value	Specificity	Sensitivity
31	.06	100
60	.69	.79
96	100	.21

When a cut-off point of 60 is selected and evaluated against caseness decisions made by CM (4+ on the six-point rating scale of psychopathology) the statistics in Table 31 were computed.

Table 31. Statistics calculated around a cut-off point of DBC-A TBPS 60

Statistic	Estimate	95% CI
Predictive value of positive test	0.75	.59 - .87
Predictive value of negative test	0.70	.51 - .85

7.6 SUMMARY OF STUDY 3 RESULTS

The aims of Study 3 were achieved.

1. Concurrent validity of the DBC-A with the PAS-ADD Checklist and with ratings of the presence and severity of psychopathology (for 3 out of 5 raters) was confirmed.
2. Strong inter-rater reliability was demonstrated between four clinicians and researcher (CM) ratings on the 6-point psychopathology rating scale.
3. The capacity of the DBC-A to differentiate between psychiatric caseness and non-caseness in adults with an ID has been established.
4. The optimal DBC-A total cut-off score for psychiatric caseness was established with acceptable levels of sensitivity and specificity for screening purposes.

7.7 DISCUSSION OF STUDY 3

7.7.1 CONCURRENT VALIDITY

7.7.1.1 DBC-A and PAS-ADD Checklist

Seventy carers completed the DBC-A and the PAS-ADD checklists. The strong positive correlation between the checklists suggests they are both measuring a related construct, which is an interesting finding considering that although they both purport to measure behavioural and emotional disturbance, they have been constructed for the purpose using different methodology, and are dissimilar in important ways. The DBC-A items have been selected using 'bottom-up' methods of item derivation, and the PAS-ADD items were derived using 'top down' methodology from an existing psychiatric diagnostic framework (Moss et al., 1998). The DBC-A, with 106 items, is approximately three times larger than the 29 item PAS-ADD, and the rating of severity options differ, with 3 points on the DBC-A and four points on the PAS-ADD. However, closer inspection reveals substantial item commonality. Only one PAS-ADD item 'Suspicious, un-trusting, behaving as if someone is trying to harm them or is talking about them' is not in the DBC-A.

7.7.1.2 Ratings of psychopathology and DBC-A scores

A practical difficulty experienced in this study which may have affected the clinician ratings and carer-completed DBC-A checklists scores, and hence the findings in relation to concurrent validity, was a varying timeframe. Clinicians at CDDHV were either seeing a patient for the first time, or for a review appointment some weeks or months since the previous appointment. Carers were advised to complete both checklists taking into account the situation for the past six months if they were attending an initial assessment appointment, or in the case of a review appointment, the situation since they were last at the clinic. This advice, given verbally, was often at odds with the instructions printed on the DBC-A ('rate situation in the past 6 months').

Ratings made by CM and the clinicians on the 6-point psychopathology rating scale were also varied, from the past 6 months in the case of a first assessment or since the last appointment. Although for each patient carers and clinicians were asked to make ratings using the same time intervals, it is possible that ratings were made using differing timeframes, resulting in different values being assigned to different items.

7.7.2 CLINICIAN RATINGS

Valid use of a checklist to screen for the presence of psychiatric disorder requires that a reliable measure of psychopathology is employed in studies seeking to establish validity. In this study clinicians and researcher were trained to independently rate the presence and severity of psychopathology on the six-point scale at the end of each clinical consultation.

The correlations between their ratings was high (weight mean ICC = .80) and they agreed on psychiatric caseness in 65/70 cases (93%). This is a slightly higher rate of agreement than was achieved in the comparable study of the DBC-P (85%) (Einfeld & Tonge, 1992).

In many of the studies of checklist validity reviewed in Chapter 3 (see Table 1) the presence of psychopathology was either obtained from the files of people with ID (e.g. Matson, 1988; Reiss, 1988), or was a judgement made by a single clinician (e.g. Matson & Smiroldo, 1997; Matson, Smiroldo, Hamilton, & Baglio, 1997; Simpson, Creed, & Moss, 1998; Sturmey & Bertman, 1994; van Minnen, Savelsberg, & Hoogduin, 1995). No reliability checks are possible in these circumstances. Even when ratings of psychopathology and psychiatric diagnoses are made by more than one person (e.g. Bamburg, Cherry, Matson, & Penn, 2001) levels of agreement are not reported.

7.7.3 CRITERION GROUP VALIDITY

The six-point rating scale of psychopathology is a reliable measure of the presence and severity of psychopathology. This has been demonstrated in this study and others (e.g. Einfeld & Tonge, 1992; Graham & Rutter, 1970). To investigate criterion group validity in Study 3 the 70 cases were divided into two groups, non-cases and cases, based on the their total score on the six-point rating scale, and a significant difference between the mean DBC-A TBPSs of each group was demonstrated. Although other similar checklists, such as, PIMRA, RSMB, DASH-II, claim utility as screening measures for identifying individuals at risk of having a psychiatric disorder, the data used in studies came from files or the judgement of an individual clinician. Claims of levels of criterion group validity are considerable weakened when untested measures are used to support reported findings.

7.7.4 ROC RESULTS

The AUC finding for the DBC-A of 77% is lower than the 92% AUC of the DBC-P (Einfeld & Tonge, 1992) but still acceptable for screening purposes. Two explanations may account for this difference:

7.7.4.1 Less reliable inter-rater ratings made by paid carers

One reason for this lower finding might be that 70% of the DBC-As in Study 3 were completed by paid carers (some from large residential settings, e.g. institution, hostel, nursing home), and only 30% were completed by family members.

A ROC analysis uses two measures, which in this study were ratings of caseness (with high inter-rater reliability) and carer-completed DBC-A scores. Lower levels of inter-rater reliability were found in Study 2 (with paid carers from a large residential service) compared to the higher inter-rater reliability findings in Study 4 (with family members). All the DBC-Ps in the Einfeld and Tonge (1992) ROC analysis study were completed by parents of the children and adolescents who attended the clinics in which the study was conducted (B. J. Tonge, personal communication, December 2002). This difference has implications for the ROC analysis. A higher AUC finding for the DBC-A may be calculated from a further study conducted with adults with ID and carers who are family members or paid carers who are more reliable checklist completers.

7.7.4.2 Factors occurring in an individual consultation.

In order to understand further the individual instances when the DBC-A and clinicians ratings of caseness did not agree, all instances of disagreement in the 70 cases were reviewed.

7.7.4.2.1 DBC-A suggests caseness, but clinicians' ratings do not.

Both these cases were review appointments, and two possible reasons for the discrepancy emerged:

1. A timeframe problem. In one case the clinician reviewed changes over the last few months because she knew the GP of the person with an ID had made medications changes that had improved behaviour in the past few months. However the carer completed the DBC-A in reference to the situation in the last six months, as instructed, because it was six months since they last attended the clinic.
2. Lack of information conveyed in the appointment. In one case a previous clinic appointment had been for detailed assessment. At this appointment the clinician, now more familiar with the behavioural and emotional problems being experienced by the person with an ID, did not explore these difficulties in detail. This lack of information presented in the clinical session made ratings of psychopathology low, although the DBC-A score was high because the carer completed the DBC-A in reference to the last six months (since they were last at the clinic) as requested.

7.7.4.2.2 Clinicians indicate caseness, but DBC-A does not.

Two possible reasons for discrepancy were supported by the case review:

1. Cyclic mood disorders prompted the carer to use rating '1' (somewhat or sometimes true for the person) on the DBC-A, because emotional and behavioural problems waxed and waned, although they were intermittently severe, and therefore produced a low DBC-A TBPS in two cases. In another case a cyclic mood disorder was present but the person's behaviour had recently settled.
2. In three cases the review indicated that the carers involved with each person

with an ID had tended to underrate the behaviour of the person with ID on the DBC-A. In one case the sister of a woman with Down syndrome was distressed about the possible onset of dementia, which had accommodation implications the sister was unable to accept, and in two cases the paid carers from an institutional setting who attended the appointment did not know the person with an ID very well.

This review highlights the difficulties experienced in this study of attempting to hold constant the assessment timeframe (discussed earlier), the specific difficulty of rating cyclic disorders and the less reliable ratings made by carers for a variety of reasons, but especially carers employed in large congregate care settings.

The less reliable ratings made by the paid carers and the lack of agreement between DBC-A results and clinician ratings of caseness in some cases, resulted in the AUC finding in the ROC analysis of 77%, lower than the AUC finding for the DBC-P (Einfeld & Tonge, 1992). However for screening purposes the finding was well within the range of acceptable results and not dissimilar to results for other checklists, such as the Child Behaviour Checklist (Fombonne, 1991), where the AUC finding was 78% for boys and 82% for girls.

In conclusion, Study 3 has further established the concurrent validity of the DBC-A, assessed against the results on the PAS-ADD and clinician ratings, and confirmed the checklists utility as a screening measure for emotional and behavioural problems in adults with ID.

CHAPTER 8

STUDY 4

8.1 OVERALL AIMS

Study 4 aimed to firstly, determine the reliability of the DBC-A when completed by parents or close family members and secondly, using the data from all the studies, investigate the factorial validity of the DBC-A using factor analysis techniques.

8.1.1 PART 1

Estimate the level of test-re-test reliability of the DBC-A achieved by parents or family carers of a person with an intellectual disability and estimate the level of inter-rater agreement achieved by pairs of family carers independently completing DBC-A checklists on their adult family member with an intellectual disability.

8.1.2 PART 2

To use factor analytic techniques to determine the factor structure of the DBC-A and internal consistency of the DBC-A items and the subscales (if any).

8.2 PART 1 RELIABILITY STUDIES

8.2.1 PARTICIPANTS

Participants in the reliability studies came from a study of the health and well-being of adults with an ID (the Living Well Study) conducted by researchers at the Centre for Developmental Disability Health Victoria (CDDHV) in 2001 and 2002. The Living Well Study researchers approached government and non-government organisations who provide accommodation, day activity and employment services, and organisations who support people with particular conditions e.g. Down Syndrome Association, Autism Victoria, for their assistance in distributing a booklet containing the survey questionnaires, so that participants could remain anonymous if they wished. The organisations used their own client databases to distribute the survey booklets which were accompanied by an explanatory letter from the researchers and a post-paid return envelope for participants to use to return completed questionnaires to CDDHV. Each organisation contacted by the researchers was informed about other organisations involved in the Living Well Study and asked not to send survey booklets to clients of their service who they knew were also clients of another participating organisation. This was to try and prevent potential participants from receiving, and therefore perhaps returning, more than one survey booklet.

The letter accompanying the questionnaire booklet asked the person with an ID and/or their carer (family member or employed care provider) to complete the questionnaire package. Carers were asked to involve the person with an ID in the consent process and questionnaire completion as they decided was possible and appropriate.

The Living Well Study is the first stage of a longitudinal project examining the health and well-being of adults with an ID, and aims to:

1. Describe health status and health related behaviours
2. Determine the extent of health care service utilisation
3. Examine the relationship between health care service utilisation, health status and health related behaviours
4. Investigate the association between residential setting, health care utilisation, health status and health related behaviours.

The DBC-A was made available to be used as one of the checklists in this study. Some non-identifying demographic information was also collected (e.g. age, gender, presence and level of ID, associated disorders and syndromes). Carers or participants could complete the voluntary 'contact sheet' with their names, addresses and phone contact details and return it with completed questionnaire booklets, if they wished to do so. The adaptive behaviour section of the Inventory for Client and Agency Planning (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986) was also included in the survey booklet, and the responses recorded on it were occasionally referred to if clarification of disability level was required. This occurred if information about level of disability was vague or contradictory. If information about level of ID was missing then the participant in the Living Well Study was not included in DBC-A studies.

Participants for the family carer reliability studies were the adults with an ID whose family members had completed and returned the questionnaires and contact details page in the Living Well Study.

8.2.2 METHOD

As soon as completed questionnaire booklets for the Living Well Study were received at CDDHV, family carers who had completed a questionnaire and the optional contact details form were either sent a letter describing the DBC-A family carer reliability study and asked to complete another DBC-A within two weeks or telephoned with the same information and request. If a letter had been sent to the family member, and they had agreed to participate, they were telephoned to arrange for the carer(s) to receive and complete the DBC-A. It was also determined at this stage whether there was another person in the family who could also complete another DBC-A for the inter-rater study.

Family members were offered two alternatives: 1. They could receive the DBC-A by post and return it in a post-paid envelope, or 2. They could have the DBC-A delivered by the researcher, who would wait at their home until the checklist was completed. The only exception to this was if the carer lived more than one hour's drive from the centre of Melbourne. The few carers who lived this far away were not offered the second option.

Sixty-two families were approached to participate in this study. Twenty-seven (27) families returned either one or two DBC-As in the post-paid envelope provided. Twenty-six (26) families were visited at home at a time arranged to suit them. In this situation if there was another person living in the home who also agreed to compete a DBC-A, but was not present during the visit by the researcher, then the DBC-A, consent form, explanatory document and a post-paid envelope was left in the home for them to complete and return. If any DBC-As were not returned within 5 working days carers were telephoned and asked if it was possible for them to do so. The test-retest and inter-rater agreement DBC-As were completed within two weeks of the original DBC-A being received at the CDDHV.

8.2.3 MEASURE

8.2.3.1 Developmental Behaviour Checklist for Adults (DBC-A)

The Developmental Behaviour Checklist for Adults (DBC-A) developed by the author was used. It is a 106-item checklist, constructed by modifying some items in the DBC-P for children and adolescents (Einfeld & Tonge, 1992) augmented with twelve additional items which describe the behavioural and emotional problems of adults with an ID, designed in Study 1.

8.2.4 DATA ANALYSIS

Data on test-retest and inter-rater reliability in family carers was analysed using the same techniques described in Study 2 for paid carers in a residential setting. The data was analysed using SPSS 10 (SPSS, 1999) to establish an Intraclass Correlation Coefficient (ICC) as the measure of test-retest reliability and inter-rater reliability. This was the statistic used by Einfeld and Tonge (1992) to describe the reliability of the DBC-P. It is generally regarded as a more conservative measure than the Pearson Product Moment correlation coefficient as it "takes account of the absolute as well as relative difference between the scores of two raters" (Einfeld & Tonge, 1992, p. 12).

However in test-retest reliability studies it is also illuminating to assess the absolute and relative difference separately (Achenbach, 1997), as ratings at Time 2 can be significantly higher or lower than ratings at Time 1. This was done by computing the paired-samples *t*-test statistic using SPSS 10 (SPSS, 1999).

8.2.5 RESULTS

8.2.5.1 Test-retest study participant demographics

DBC-As were completed on two separate occasions up to two weeks apart, on 52 people with ID by a close family member. The gender, ID level, age, accommodation type, and the relationship of the person completing the test-retest DBC-A is shown in Table 32. Sixty percent of people with ID were men. As expected those who lived at home with their family were in the younger adult age ranges, with a mean age of 28 years and nearly 80% had a moderate or mild ID. Their mothers were most likely to be the family member who completed the test-retest DBC-A. The few who lived in other residential settings spent time at their parents home, usually on weekends.

Table 32. Details of test-retest study (N = 52)

		Frequency	Percent
People with ID		52	100
Gender	Male	31	60
	Female	21	40
ID Level	Mild	10	19
	Moderate	30	58
	Severe	12	23
Age (years)	18 – 25	26	50
	26 – 35	14	27
	36 – 44	8	15
	45 – 50	4	8
Mean Age	28.1 years		
Accommodation settings	Home	48	92
	Community Residential Unit	3	6
	Hostel	1	3
Family member completing the test-retest DBC-A	Mother	41	79
	Father	7	14
	Other relative	4	8

8.2.5.2 Test-retest analysis

The relationship between the Total Behaviour Problem Scores (TBPS) on DBC-A 1 and DBC-A 2 was investigated using an Intraclass Correlation Coefficient. There was a strong positive correlation between the two scores (ICC = .85, n = 52, 95% CI .75 - .91) indicating high levels of test-retest reliability.

A paired-samples *t*-test was conducted to ascertain whether there was a significant difference between scores on DBC-A 1 and DBC-A 2. There was not a significant difference between the two mean TBPSs from rating Time 1(M = 34.4, SD = 23.6) to rating Time 2 (M = 34.9, SD = 24.8) *t*(51) = .25, sig.(2-tailed) .81. These results are shown in Table 33.

Table 33. Intraclass Correlation Coefficient and paired-samples *t*-test for family carer test-retest data (N = 52)

	N	Mean	Std. Dev.	ICC	95% CI	*t*	df	Sig. (2-tailed)
DBC-A 1 Living Well Study	52	34.4	23.6					
				.85	.75 - .91	.25	51	.81
DCB-A 2 Test-retest Study	52	34.9	24.8					

8.2.5.3 Inter-rater family study participant demographics

DBC-As were completed on twenty-seven (27) people with an ID by two close members of their family, who also consented to their participation in the study.

The gender, ID level, accommodation type, the mean age and age ranges of people with ID, and the relationship of the person completing the extra inter-rater DBC-A (Rater 2) is shown in Table 34. As expected in a study of family member's inter-rater reliabilities all of the people with ID lived at home, and were in the younger adult age ranges, with a mean age of 28 years. Approximately 80% had a mild or moderate intellectual disability. Their fathers were most likely to be the family member who completed the extra DBC-A (Rater 2) that provided a measure of inter-rater reliability.

Table 34. Details of inter-rater study (N=27)

		Frequency	Percent
Person with ID		27	100
Gender	Male	14	52
	Female	13	48
ID Level	Mild	6	22
	Moderate	16	59
	Severe	5	19
Age (years)	18 – 25	12	44
	26 – 35	10	37
	36 – 44	4	15
	45 – 50	1	4
Mean Age	28.3 years		
Accommodation setting	Home	27	100
Rater 2 family relationship	Mother	2	8
	Father	19	70
	Other relative	6	22

8.2.5.4 Inter-rater agreement analysis

The relationship between the TBPSs on DBC-A 1 and DBC-A 2 was investigated using the ICC (see Table 35). There was a strong positive correlation between the two mean scores (ICC = .72, 95% CI .48 - .86).

Table 35. Intraclass Correlation Coefficient for family inter-rater study (N = 27)

	N	Mean	Std. Dev.	ICC	95% CI
DBC-A Rater from Test-retest Study	27	38.0	27.7	.72	.48 - .86
DCB-A Rater 2	27	32.6	23.6		

8.3 PART TWO PRINCIPAL COMPONENTS ANALYSIS

8.3.1 PARTICIPANTS

Subjects for the Principal Components Analysis came from: Study 2, (the residents of the institution, N= 77), Study 3, (the patients referred to the CDDHV clinic, N = 70), and Study 4, (Living Well Study participants, N= 361).

A few potential participants from the Living Well Study were not included. The Living Well Study offered carers of people with ID the option of anonymity or the option of providing information about the person with ID. Consequently the database could not be interrogated to determine whether information about an individual with ID was obtained more than once. For example, this may have happened if two carers employed by an organisation completed two survey booklets for the same person with ID, unaware that another carer had also done so. Another possibility is that a carer or participant, receiving two survey booklets from two organisations, completed and returned them both, believing that this was the right thing to do.

In order to exclude 'double return' survey booklets from the DBC-A factor study, the Living Well Study database was examined for information about individual participants that appeared to be very similar. Booklets from participants with the same gender, age, level of disability and living in the same type of accommodation setting were examined, and if very similar or identical health information was contained in both survey booklets, they were excluded from the DBC-A factor study, giving a data set of 361 participants.

The total number in the preliminary data set from all studies was 579, but when missing data was taken into account data on a total of 508 subjects was available for the factor analysis.

8.3.2 METHOD

8.3.3 FACTOR ANALYSIS

DBC-A item scores and TBPSs from the three studies (N = 508) were entered into an SPSS 10 (SPSS, 1999) database.

The internal structure of the DBC-A was ascertained by principal components analysis on a matrix of polychoric correlations. An oblique rotation (Promax) was performed on the resulting 5 and 6 factor solutions. Mplus (Muthén & Muthén, 1998) was the factor analysis program used for this analysis.

This is the same form of analysis undertaken by Dekker et al. (2002), for the revision of the DBC-P factor structure and has several statistical advantages over those techniques employed in the original DBC studies (Dekker et al., 2002). In order to minimize cross loadings, only items loading at .4 or above were included in each factor. Cross loading items at .4 or above were retained in both factors in which they appeared. One DBC-A item, 68. Problems with the illegal use of drugs, was not included in the factor analysis because of a very low observed frequency of occurrence (less than .5 of one percentage point).

8.3.4 RESULTS

8.3.4.1 Participant characteristics.

There were 508 participants in the factor study (see Table 36) and fifty-nine percent were males. Nearly half (42%) of participants had a moderate intellectual disability. One quarter had a mild intellectual disability (25%), one-fifth a severe intellectual disability (20%) and a smaller group had profound intellectual disability (13%). They were all over the age of 18 years, and nearly 80% were younger than 45 years, with a mean age of 35.4 years.

Table 36. Characteristics of participants in the factor study (N = 508)

		Frequency	Percent
People with ID		508	100
Gender	Male	300	59
	Female	208	41
ID level	Mild	127	25
	Moderate	216	42
	Severe	101	20
	Profound	64	13
Age (years)	18-25	137	27
	26-35	139	27
	36-45	123	24
	46-55	72	14
	56-65	28	6
	66+	9	2
Mean age	35.4 years		

Most of the people with ID in the factor study lived in either CRU type accommodation or in their family home. The group from the residential institution comprised 14% of the total, ten percent lived in hostels in the community and a small number lived independently (see Table 37).

Table 37 Type of accommodation of people with ID in the factor study (N = 508)

		Frequency	Percent
Type of accommodation	CRU	194	38
	Family home	185	36
	Institution	69	14
	Hostel	52	10
	Independent	5	1
	Other	3	1
	Total	508	100

8.3.4.2 Principal components analysis

The analysis produced 29 factors with an Eigenvalue greater than 1. Examination of the scree plot indicated that a five or six factor solution was most appropriate (see Table 38).

Table 38. The five and six factor solution % of variance

	% of variance		% of variance
5 Factor Solution		6 Factor solution	
1	12.6	1	12.5
2	9.3	2	8.9
3	6.8	3	6.6
4	6.7	4	6.0
5	7.7	5	6.3
		6	4.0
Total variance	41.9		44.3

The five-factor solution accounted for 41.9% of the total variance. Examination of the unrotated variance components indicated that Factor 1 accounted for the most variance (12.6%) followed by Factor 2 (9.3%), Factor 3 (6.8%), Factor 4 (6.7%) and Factor 5 (7.7%). The five factors and their items are listed in Appendix K.

The six-factor solution accounted for 44.3% of the variance and examination of the unrotated variance components indicated that Factor 1 accounted for 12.5% of the variance, Factor 2, 8.9%, Factor 3, 6.6%, Factor 4, 6.0%, Factor 5, 6.3%, and Factor 6, 4.0%. The six factors and their items are listed in Table 40.

The six-factor solution was chosen because it was considered the most coherent and readily interpretable solution in relation to the clinical presentation of people with ID. The six-factor solution also accounted for slightly more of the variance. Factor 6 also contained clinically important items focussed on social relating.

The naming of factors is arbitrary and depends upon whether or not items in a factor predominantly appear to relate to the same construct. In this study the behaviours and emotions described by the highest loading items in each factor appeared to be mostly related. Five of the factors (1, 2, 3, 5, 6) could be given the same name as a DBC-P factor (revised by Dekker et al. (2002)) because they contained very similar items. The items in Factor 4, five of which were new items, describe emotions and behaviours that did not match the fourth 'Anxiety' factor on the DBC-P. The highest loading items in Factor 4 were 'Withdrawn', 'Lost enjoyment', 'Lost self-care', and 'Depressed' (not actual item wording, refer to Appendix N for full tem wording), and therefore this factor was labelled 'Depressive'.

Correlations between the six factors after promax rotation (see Appendix L) ranged from -0.425 (Communication Disturbance (5) with Disruptive (2)), to 0.359 (Social Relating (6) with Self-Absorbed (1)).

Thirty items did not load over .40 on any one of the six factors (see Appendix M), and three of these were new items (9. Bizarre speech, 40. Increased appetite, 67. Problems with cigarettes, alcohol or caffeine). Five items loaded over .4 on two factors (see Table 39).

Table 39. DBC-A items loading on two factors

	Item[a]		Factors
1	Depressed	1.	Disruptive
		4.	Depressive
7	Over-excited	1.	Self-Absorbed
		2.	Disruptive
58	Overactive	1.	Self-Absorbed
		5.	Communication Disturbance
94	Lies	1.	Self-Absorbed (negative loading)
		5.	Communication Disturbance
102	Changes	2.	Disruptive
		6.	Social Relating

[a] Brief item labels. Full item wording in Appendix N.

Table 40. The six-factor solution and items loading higher than .4

	Item[a]	Loading	DBC-P revised[b]
Factor 1	**Self-Absorbed 28 items**		
22	Pica	.80	SA
37	Hums	.80	SA
8	Bites	.78	SA
36	Hits	.75	SA
76	Screams	.71	SA
11	Chews	.71	SA
6	Bangs head	.70	SA
74	Smells	.66	SA
48	String	.59	SA
56	Noisy	.59	D
79	Stares	.55	SA
25	Twitches	.53	SA
80	Soils	.52	SA
44	Kicks	.51	D
70	Movements	.51	SA
58	Overactive [Cross-5]	.50	D
87	Strips	.49	SA
46	Laughs	.48	SA
82	Spits	.47	New[c]
30	Grinds	.47	SA
94	Lies [Cross-5]	-.46	D
19	Doesn't respond	.46	SR
103	Urinates	.45	SA
7	Over-excited [Cross-2]	.43	SA
75	Scratches	.43	-
26	Flicks	.42	SA
28	Gorges	.41	SA
83	Lights	.41	SA
Factor 2	**Disruptive 17 items**		
34	Tantrums	.69	D
42	Irritable	.66	D
38	Impatient	.62	D
106	Whines	.62	D
43	Jealous	.61	D
4	Abusive	.59	D
104	Bossy	.57	D
61	Attention-seeking	.57	D
98	Manipulative	.55	D
102	Changes [Cross-6]	.55	A
12	Cries	.51	A
1	Depressed [Cross-4]	.50	SR
96	Tense	.48	D
85	Stubborn	.45	D
97	Throws	.44	D
69	Refuses to go	.41	D
7	Overexcited [Cross-1]	.40	SA
Factor 3	**Antisocial 9 items**		
47	Fires	1.01	D
63	Panics	.58	New
33	Nightmares	.54	A
39	Sexual	.52	-
35	Hides things	.51	D
84	Steals	.50	D
64	Danger	-.46	SA
52	Gloomy	.44	New
53	Masturbates	.43	SA
Factor 4	**Depressive 10 items**		
32	Withdrawn	.79	New
50	Lost enjoyment	.72	New
51	Lost self-care	.70	New
1	Depressed [Cross-2]	.59	SR
57	Not communicating	.56	New
55	Moves slowly	.56	SR
49	Lost appetite	.51	A
78	Sleeps too much	.45	SR
31	Confused	.43	New
54	Mood changes	.41	D
Factor 5	**Communication Disturbance 13 items**		
92	Talks fast	.66	D
95	Thoughts	.62	-
89	Stands	.66	CD
88	Not capable	.61	D
90	Hallucinations	.56	-
59	Overaffectionate	.59	CD
21	Easily led	.53	D
93	Talks to self	.51	CD
58	Overactive [Cross-1]	.50	SA
14	Confuses pronouns	.45	CD
20	Distracted	.43	-
72	Echo	.43	CD
94	Lies [Cross-1]	.40	D
Factor 6	**Social Relating 6 items**		
65	Loner	.63	SR
86	Shy	.55	-
5	Arranges objects	.54	CD
102	Changes [Cross-2]	.46	A
71	Cuddled	.43	SR
3	Aloof	.41	SR

---

[a] The terms used are summary terms, not the actual wording of the items in the checklist (see Appendix N).

[b] The revised factors of the DBC-P (Einfeld & Tonge, 2002). SA = Self-Absorbed, D = Disruptive/Antisocial, CD = Communication Disturbance, SR = Social Relating. - = item did not load on DBC-P subscales.

[c] A new DBC-A item.

[Cross-1] = cross loading on Factor 1; [Cross-2] = cross loading on Factor 2; [Cross-3] = cross loading on Factor 3; [Cross-4] = cross loading on Factor 4; [Cross-5] = cross loading on Factor 5; [Cross-6] = cross loading on Factor 6.

8.3.4.3 Internal consistency

The characteristics of the sample used in the DBC-A internal consistency study are described in Table 5. Internal consistency was calculated using SPSS 10 (SPSS, 1999).

As an indicator of total item correlation, the effect on internal consistency of removing any single item was measured. Cronbach's alpha was not significantly increased by the exclusion of any item (range = .9462 - .9477).

Internal consistency of each of the factors in the six-factor solution was also calculated (Table 41).

Table 41. DBC-A total scale and subscale Internal Consistency

Factor	Internal consistency (Cronbach's α)
1. Self-Absorbed	.89
2. Disruptive	.88
3. Antisocial	.61
4. Depressive	.81
5. Communication Disturbance	.77
6. Social Relating	.62
Total scale	.95

8.4 DISCUSSION

8.4.1 FAMILY CARER RELIABILITY STUDIES

The test-retest reliability study went smoothly. Carers were easy to recruit to this study, and adequate numbers were obtained.

Recruitment to the inter-rater study was more difficult, mainly because locating intact families of adults with an intellectual disability proved to be difficult. This was in part due to the ageing of the population of carers, with the result that one parent may have died, most often the father. It was also apparent in some instances that the marriage of the parents had not survived the years, again leaving one parent as the sole or main carer, usually the mother. Sometimes another family member, such as a brother or sister, agreed to complete a checklist, and occasionally a step-parent was available and willing. Consequently the inter-rater study was relatively small, thus reducing confidence in the result.

An item-by-item review was done to explore possible causes of disagreement in the inter-rater study. This revealed discrepancies around the ratings of night time behaviour. It appeared that mothers were likely to note night time disturbance suggesting that mothers, even of grown-up children with ID, are still more easily woken from sleep than other members of a household and remain more aware of their child's night time behaviour.

However both test-retest and inter-rater reliability findings with family carers were satisfactory and compare favourably with findings in similar DBC-P studies (Einfeld & Tonge, 2002), summarised in Chapter 4. This indicates that although older themselves and now caring for an adult, family carers can use the DBC-A to reliably report on the emotional and behavioural difficulties experienced by their adult family member with an ID, and thereby make a significant contribution to a clinical assessment or research study which employed the checklist.

8.4.2 PRINCIPAL COMPONENTS ANALYSIS

8.4.2.1 Similarities and differences between the DBC-A and DBC-P

The six-factor solution was chosen, in part, because of its similarity to the revised DBC-P factor structure (Dekker et al., 2002). It was also possible to use the same DBC-P factor labels to describe five of the DBC-A factors (Table 42). Comparison of the DBC-P and DBC-A factors (Table 42) reveals that the items in the first factor of the DBC-A are very similar to the second factor of the DBC-P. Factor 1, Disruptive/Antisocial on the DBC-P separated into two factors, 2 and 3, on the DBC-A. Only one new item loaded on Factor 1 (82. Spits), none on Factor 2 and two on Factor 3. Five new items loaded on Factor 4, which related to 'Depressive' phenomena rather than Anxiety. No new items were found on Factors 5 and 6. Therefore the fourth factor on the DBC-P, Anxiety could not be identified on the DBC-A.

The somewhat different factor structure of the DBC-A which emerged from the exploratory factor analysis and the presence of eight new items within the factor structure, especially in Factor 4, Depressive, confirms the perceived necessity at the conclusion of Study 1 to change existing DBC-P items and augment the checklist with additional items.

There are enough points of similarity between the DBC-P and DBC-A to provide continuity of assessment across the age span, but enough points of difference to ensure that adult relevant behaviours and emotions are assessed.

Table 42. Comparison of DBC-A factors, DBC-P factors and factors commonly observed (Aman, 1991)

DBC-A	DBC-P	Commonly observed factors Aman (1991)
1. Self-Absorbed	2. Self-Absorbed	Social Withdrawal
2. Disruptive	1. Disruptive/Antisocial	Aggressive/Antisocial
3. Antisocial		
4. Depressive	4. Anxiety	Anxious
5. Communication Disturbance	3. Communication Disturbance	Repetitive Verbalisations
6. Social Relating	5. Social Relating	Stereotypic

8.4.2.2 Comparison with commonly observed factors

Aman (1991) described how factor analysis reveals some commonality of factor structure in a number of checklists in this area. Aman (1991) states "Five factors appear to emerge with considerable consistency across studies and across instruments" (p. 176). In the factorial study of the DBC-A these same factors are evident (see Table 42). According to Aman (1991) this similarity in findings confers factorial validity. However as checklists and rating scales in this area contain many similar items, have all been used in populations of adults with ID and analysed using the same statistical procedures, it would be surprising if substantial similarities in factorial structure were not found.

All the checklists reviewed in Chapter 3 have undergone some factor analytic exploration, with varied results. Some studies confirm a factor structure (e.g. Aberrant Behavior Checklist in studies by (Aman, Burrow, & Wolford, 1995; Newton & Sturmey, 1988; Ono, 1996)), and others produce very different findings (e.g. Psychopathology Instrument for Mentally Retarded Adults in studies by (Linaker, 1991; Matson, 1988; Watson, Aman, & Singh, 1988)). The DASH-II and PAS-ADD Checklist have had very limited investigation of their factor structure.

The DBC-P factor structure has undergone rigorous exploration in studies with substantial study populations. The original factor six-factor structure was modified, from a six to five-factor structure, by a recent re-analysis combining data on Australian (N = 640) and Dutch (N = 515) children with ID (Dekker et al., 2002). The factor findings reported here, whilst slightly different (returning to a six-factor solution) are very similar to the DBC-P and DBC-T. These findings indicate that the DBC-P, DBC-T and DBC-A have a stable factor structure even when employed in studies of people with ID of different ages and in different countries.

Further research will show whether the internal structure of the DBC-A will be replicated across larger samples of people with ID, and the factor structure can be explored further using confirmatory factor analytic techniques.

This study has both confirmed the reliable use of the DBC-A with family carers and the factor structure of the DBC-A in relation to the DBC-P and other checklists and rating scales in the area. The six-factor structure can be studied further in relation to specific psychopathological conditions.

CHAPTER 9

RESULTS SUMMARY AND CONCLUDING DISCUSSION

This thesis comprised four studies. The overall aim was to redevelop the DBC-P so that it could be confidently used with adults who have an ID. The aims of the four studies were to modify DBC-P items and to select new items for the proposed DBC-A (Study 1), to investigate the reliability and validity of the DBC-A (Study 2), to establish clinical case cut-off scores of the DBC-A and investigate its validity as a clinical assessment tool (Study 3) and in Study 4 to: (1) Investigate reliability in family members, and (2) Undertake a factor analytic study.

9.1 SUMMARY OF THE PSYCHOMETRIC PROPERTIES OF THE DBC-A

9.1.1 RELIABILITY

The satisfactory test-retest and inter-rater reliability results from Study 2, with paid carers, and from Study 4, with family carers, which established that the DBC-A is a reliable instrument, are summarised in Table 43.

Table 43. Reliability results from Studies 2 and 4

		N	ICC	95% CI	*t*	df	Sig. (2-tailed)
Test-retest reliability	Paid carers	34	.75	.55 - .86	3.88	33	.000
	Family carers	52	.85	.75 - .91	.248	51	.072
Inter-rater reliability	Paid carers	53	.48	.24 - .66			
	Family carers	27	.72	.48 - .86			

9.1.2 VALIDITY

The validity results from Study 2, Study 3 and Study 4 which indicate that the DBC-A is a valid checklist are summarised on Table 44.

Table 44. Validity results from Studies 2, 3 and 4

	N	Finding	
Total scale internal consistency		$\alpha = .95$	
Subscale internal consistency		range $\alpha = .60 - .88$	
Criterion group validity	70	$t = 4.48$	$p < 0.000$, $\eta 2 = .22$
		Cut-off score for psychiatric caseness = TBPS 60	
Concurrent validity:			
Aberrant Behavior Checklist	77	$r = .63$	$p < 0.001$
PAS-ADD Checklist	70	$r = .61$	$p < 0.01$
Psychopathology ratings	70	$r = .52$	$p < 0.000$
Readability	Flesch Grade level = 6.4		
Receiver Operating Characteristics	Area under the curve = .77		
	Specificity = 69%, Sensitivity = 79%		

9.1.3 FACTOR STRUCTURE

The findings in Study 4 are summarised in Table 45.

Table 45. Factor structure, variance and internal consistency

Factors and highest loading items[a]	% of variance	Internal consistency (Cronbach's α)
Self-Absorbed (Pica, hums, bites, hits, screams, chews, bangs head)	12.5	.89
Disruptive (Tantrums, irritable, impatient, whines, jealous)	8.9	.88
Antisocial (Fires, panics, nightmares, sexual, hides things, steals)	6.6	.61
Depressive (Withdrawn, lost enjoyment, lost self-care, depressed)	6.0	.81
Communication Disturbance (Talks fast, thoughts, stands, not capable, hallucinations)	6.3	.77
Social Relating (Loner, shy, arranges objects, changes, cuddled, aloof)	4.0	.62
Total scale	44.3	.95

[a] Abbreviated items. See Appendix M for a full description of DBC-A items

These findings establish the psychometric properties of the DBC-A and have been discussed within the individual study chapters. An overall discussion of the research follows.

9.2 CONCLUDING DISCUSSION

9.2.1 THE DBC-A IN CLINICAL SERVICES AND SERVICE PROVISION

This research has demonstrated that the DBC-A is a reliable and valid checklist with satisfactory psychometric properties. Therefore the DBC-A has the potential to make a contribution to the mental health care of adults with an ID in clinical services (assessment and intervention) and service provision.

9.2.1.1 Clinical service

9.2.1.1.1 Assessment

The DBC-A should prove to be useful in the process of assessment of emotional and behavioural problems in adults with ID as follows:

1. The cut-off TBPS for the DBC-A, indicates the likelihood of the diagnosis of a psychiatric disorder as assessed by an experienced clinician. Therefore a GP, service provider or case manager, who uses the checklist, may be encouraged to make a referral or seek out additional information. The checklist can alert clinicians to the possibility that a person with an ID may have a mental health disorder, and therefore helps to combat ignorance and the more limited, uninformed thinking that is characterised by the processes referred to in the literature as diagnostic and behavioural overshadowing (Lowry, 1997; Reiss & Szyszko, 1983).
2. The DBC-A can augment the clinical interview with a patient with an ID by providing structure and a starting point for further assessment in the carer interview. A valid and reliable carer-completed measure of behavioural and emotional disturbance will provide the clinician with valuable information about the patient irrespective of the patients' communication skills, cognitive abilities or willingness to cooperate.
3. Repeated use of a checklist such as the DBC-A may also provide the longitudinal information that indicates if baseline exaggeration (Sovner & Hurley, 1986) needs to be taken into account for a particular person. An adult with an ID is unlikely to

receive a score of zero on the DBC-A, and examining a well-documented record of a person's past emotional and behavioural difficulties would indicate whether these pre-existing difficulties had increased in severity and if new problems had emerged. The DBC-A also provides the carer with an opportunity to mention problems that may not necessarily emerge in a clinical interview.

4. The items in the DBC-A reflect the broad range of emotional and behavioural problems in adults with ID. Therefore attention may be drawn to certain problems that might be missed by the clinician unfamiliar with the life experiences of people with an ID, hence overcoming the effect of psychosocial masking (Sovner & Hurley, 1986). Psychosocial masking refers to the changed presentation of psychiatric symptoms often found in people with an ID whose life experience may have been impoverished. Symptoms are often less elaborated and more concrete in their content (Sovner, 1986). For example, it may not occur to a clinician unaware of the typical life experiences of people with ID to enquire about excessive distress that may be experienced should the person with an ID find themselves separated from familiar people (DBC-A item 23), or an intense fascination with mechanical objects (DBC-A item 62) that may be interfering with a person's quality of life.
5. The DBC-A provides an opportunity for material not covered in an assessment, or the first phase of an assessment, to emerge. A carer attending an assessment interview may wish to discuss, as a priority, those matters which in their mind have most interfered with their caring role, or which in their view impacts most negatively on the life of the person with an intellectual disability. The clinician, often pressed for time, concentrates on those matters which in their opinion are most relevant to the reason for the referral. In early studies on the DBC-P, Einfeld and Tonge (1992) report finding that the average number of symptoms elicited by questioning in the

clinical interview (9) was substantially lower than the average number of symptoms (35) selected by a carer on the DBC-P (Einfeld & Tonge, 1992). In the 70 clinical assessments in Study 3 there were a number of instances where items selected by carers on the DBC-A added important information. Three of these case examples, modified to protect confidentiality, follow:

a) In an assessment of a person with a mood disorder carers were questioned by the clinician about the signs and symptoms of a manic presentation, and could not recall any. However on the DBC-A checklist the carer selected 'Item 100. Unrealistically happy or elated.' This enabled the clinician to ask again at the next interview about periods of elevated mood and to clarify the diagnosis.

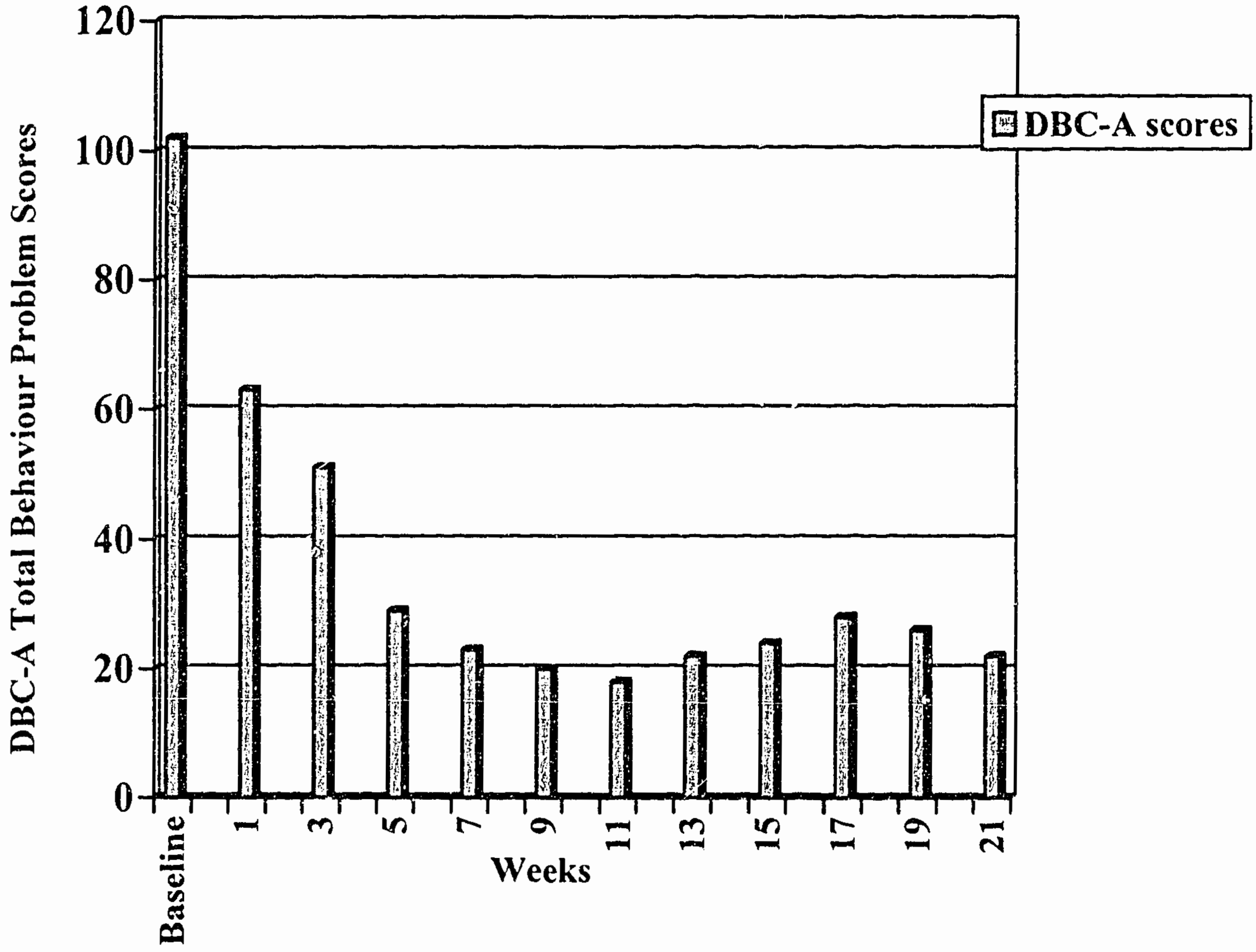
b) A person with Down syndrome in their late 30s attended a review appointment about behaviour in the Day Centre, which had been conceptualised in the initial assessment appointment as related to an anxiety disorder. However at this review appointment the carers complete the DBC-A checklist and selected items related to memory and concentration difficulties. This led to a referral to a specialist in the mental health care of people with Down syndrome for an assessment of early onset dementia.

c) The carers of a young man with autism and aggressive behaviour spoke at length in the assessment interview about their concerns and fears for their own safety and that of other clients in the same accommodation setting. Obsessional and dangerous aspects of the man's behaviour were highlighted. However items selected on the DBC-A that related to mood, sleep and appetite, led to further assessment, and diagnosis and successful treatment of a depressive disorder.

9.2.1.1.2 Monitoring interventions

Repeated use of the DBC-A to report on the same person with an ID may provide objective information to indicate whether there have been changes in the nature or severity of emotional and behavioural problems over time. Therefore the DBC-A maybe used as a tool to measure the response to various interventions and treatments. An example of the DBC-A's clinical utility as a measure of change is given in Figure 2, where a graph of DBC-A TBPS shows a reduction in a person's level of emotional and behavioural disturbance following medication treatment for an affective disorder.

Figure 2. DBC-A scores reported by carers fortnightly after treatment commenced



The results on DBC-A subscales may also assist in the choice and monitoring of intervention strategies. For example, a person with an ID may be experiencing disruptive behaviour in a particular setting. Close monitoring of carer ratings on the DBC-A Disruptive subscale could be helpful following the introduction of behavioural strategies designed to promote less disruptive behaviour in that setting.

Ratings of a selection of relevant items or a sample of items may also be used for ongoing monitoring. For example, Item 97. Throws or breaks objects, also might be a particularly problematic behaviour and could be used to monitor response to a specific behavioural management intervention. Several items relating to self-injurious behaviour exhibited by a person might be chosen to establish a baseline prior to an intervention or treatment and then as a means of monitoring progress following intervention.

The DBC-A instructions would need to be modified, so that a carer, using it for the purpose of monitoring change over time, considered the appropriate timeframe for their ratings. In addition the psychometric properties of the DBC-A as a measure of change over time have yet to be established, as has been done for the DBC-P (Einfeld & Aman, 1995).

9.2.1.2 Research

The DBC-P and DBC-T have been used in many research studies with children and adolescents with ID outlined in Chapter 4, and are summarised in the recently published second edition of the DBC-P Manual (Einfeld & Tonge, 2002). There is every expectation that the DBC-A will be able to be used in a similar manner in future studies of adults with intellectual disability, to investigate prevalence of psychopathology, in total populations or subgroups of people with specific disorders, such as autism, and genetic syndromes, to screen for disorders, such as dementia or depression, and to measure change over time.

The DBC-A is already being applied in a longitudinal study of children and adolescents with ID who have now moved on to adulthood, the Australian Child to Adult Development (ACAD) Study (Einfeld & Tonge, 1996a, 1996b; Einfeld, Tonge, & Rees, 2001; Tonge & Einfeld, 2000). Most of the study cohort is now over the age of 18 years and the use of the DBC-A will allow study of the continuity of behaviours from childhood measured by the DBC-P and also the emergence of adult psychopathology.

9.2.1.3 Service Provision

The DBC-A will potentially have a range of applications in the provision of services for people with ID.

1. Routine completion of the DBC-A by a carer who knows the person well in a service setting, perhaps on an annual basis, would provide a comprehensive 'snap shot' of a person's emotional and behavioural functioning. This would be a valuable point of comparison should that person with an ID present for an assessment of emotional and behavioural disturbance in the future. The DBC-A might be particularly useful in this respect because it is comprehensive. It is often difficult to obtain reliable retrospective information about behavioural and emotional problems, especially for adults with ID, who may find it difficult to describe their difficulties and experiences, and whose carers may be changing frequently. A checklist such as the DBC-A provides information that is structured, readily accessed and synthesised.
2. Service managers may also use DBC-A results to assist in allocating staff and resources to various program settings. Those settings catering for the needs of clients with higher DBC-A scores would arguably have greater priority for additional staffing, for staff with greater expertise in working with clients with more complex needs (McNelis, 1992) and additional training resources.

3. Another potential use of the DBC-A in service systems would be in planning the size and type of mental health services for people with an intellectual disability required to be provided in a given geographic area. There has been ongoing debate in the literature about the ideal service model for providing mental health care services to people with ID, but there is agreement on the necessity to do so (Burdekin, 1993; Day, 1994; Parmenter, 1988).

9.2.2 EPIDEMIOLOGICAL AND LONGTITUTINAL STUDIES USING THE DBC-A TO INVESTIGATE THE EMOTIONAL AND BEHAVIOURAL PROBLEMS OF ADULTS WITH ID.

The DBC-P and DBC-T have been used in many research studies with children and adolescents with ID outlined in Chapter 4, and are summarised in the recently published second edition of the DBC-P Manual (Einfeld & Tonge, 2002). There is every expectation that the DBC-A will be able to be used in a similar manner in future studies of adults with ID. The DBC-A is already being applied in a longitudinal study of children and adolescents with ID who are now grown up, the Australian Child to Adult Development (ACAD) Study (Einfeld & Tonge, 1996a, 1996b; Einfeld et al., 2001; Tonge & Einfeld, 2000). Most of the study cohort is now over the age of 18 years and the use of the DBC-A will allow study of continuity of behaviours from childhood measured by the DBC-P but also the emergence of adult psychopathology.

Table 46. Characteristics of people with ID and percentage scoring 60+ on the DBC-A (N = 579)

		Percentage
Gender	Male	59
	Female	41
Disability	Mild	24
	Moderate	42
	Severe	21
	Profound	12
Age (years)	18 – 25	26
	26 – 34	24
	35 – 44	33
	45 – 54	20
	55 – 64	5
	64+	2
DBC-A TBPS 60+	Institutional population (Study 2)	29.7
	Clinic population (Study 3)	58.6
	Community population (Study 4)	19.9
	Overall	23.5

An incidental finding of this study of the percentage of people with ID scoring above the cut-off score for psychiatric caseness of 60 or higher on the DBC-A is shown in Table 46. Across all subjects described in Studies 2, 3 and 4, 23% were selected as probable psychiatric cases. Not unexpectedly, more than twice this percentage (58%) were identified in the medical clinic group in Study 3. In the institutional population surveyed in Study 2, the rate was also somewhat higher (30%) but in Study 4, comprising mainly people with ID living in the community, the rate was lower (20%). These findings mirror those from the range of prevalence studies in adults reviewed in Chapter 2, where the prevalence rate reported varied depending on the nature of the population studied, and the ascertainment method employed. The result from the group of adults living in the community is half the 40% detected using the DBC-P in the study of an epidemiological sample of children and adolescents with ID (Einfeld & Tonge, 1996b) which did however include some children living in an institution (4.5%, (Einfeld & Tonge, 1996b)).

These studies gathered DBC-A data from a diverse population of nearly 600 people with ID but they were not an epidemiological sample. A normative study of an epidemiologically representative sample is required to ascertain the prevalence of psychiatric disorder in the general population of people with ID. An instrument with a known distribution of scores across the total population of people with ID would have enhanced value in clinical and research studies.

Valuable work has been conducted using the DBC-P to describe the behavioural phenotype (particular pattern of behavioural and emotional disturbance) of a range of disorders, such as Williams syndrome, Prader-Willi syndrome, Fragile X, Autism, and ADHD, in children and adolescents with ID. Using the DBC-A has the potential to extend understanding of behavioural phenotypes by allowing direct comparisons of DBC-P checklist scores from childhood to DBC-A scores in adulthood and into old age.

Similarly, the DBC-A maybe used in detailed studies of specific psychiatric disorders in people with ID. Some DBC-P items have been grouped to form scales, the DBC Depression Scale (Evans, Cotton, Einfeld, & Florio, 1999) and the Anxious Behaviour Rating Scale (Einfeld & Tonge, 2002). These scales could be augmented with additional items from the DBC-A and studies conducted to establish the performance of these item subsets in clinical studies with adults with an ID. Psychotic disorders often develop in the late adolescent years, and repeated use of the DBC-A within a population may indicate which DBC-A items could predict the likely development of this range of disorders.

9.2.3 FURTHER INVESTIGATION INTO THE PSYCHOMETRIC PROPERTIES OF THE DBC-A

9.2.3.1 Additional inter-rater reliability studies

9.2.3.1.1 Between groups of carers

Within Study 2 and Study 4 there was not the opportunity to conduct inter-rater reliability studies between groups of different types of carers. In Study 2 all the carers were paid employees of the residential centre, and in Study 4 the family carers were chosen for the inter-rater study because this group were not available in Study 2.

However it might also be important to understand the meaning of the differences that might be expected if two carers from two similar settings, e.g., two accommodation settings, completed a DBC-A about the same person with an ID at the same time. Such a situation would arise if a person with an ID lived during the week in a staffed residential setting, and on the weekends in a family home cared for by their parents and might point to extra stress occurring in one setting compared to the other.

Few studies of the psychometric properties of checklists in this area have examined inter-rater reliability between carers in different settings. Two notable recent exceptions are the studies on the PAS-ADD Checklist (Moss et al., 1998) and the inter-rater agreement studies undertaken by Einfeld and Tonge (2002) of the DBC-T.

In the previously discussed study by Moss (1998) 66 pairs of raters completed the PAS-ADD Checklist. Fifty-nine of these pairs were a staff member and a family member of an adult with an ID in a mixed hospital and community sample. Seven pairs of raters were both staff members as no family member was available. The resulting correlations were all significant, and between pairs of raters ranged from 0.55 to 0.79. The raters agreed in 79% of cases on the identification of at-risk individuals, which appears high (Moss et al., 1998), however when the raw data is analysed using a Cohen's kappa the level of chance corrected agreement is .55 which indicates a moderate level of agreement.

In the study of the DBC-T (Einfeld & Tonge, 2002) teachers and teachers aides of pupils in special schools and special classes rated 110 children. They achieved a lower level of inter-rater agreement (ICC = .60) than pairs of parents (ICC = .80) or nurses (ICC = .83) (Einfeld & Tonge, 2002).

9.2.3.1.2 Between carers in different settings

It is important to gather information about the ability of a range of carers to reliably complete a checklist, and to appreciate that carers who "play different roles" (Achenbach, 1997, p. 101) may have different information to contribute to an assessment (Achenbach, 1997).

Einfeld and Tonge (1992) report a lack of agreement (ICC = .30) between parent and teacher ratings on the DBC-P (parent version) and DBC-T (teacher version). This is consistent with the results of a meta-analysis of numerous reliability studies conducted by Achenbach, McConaughy and Howell (1987). Einfeld and Tonge (1992) report that teachers consistently rated children as less disturbed overall, and on each subscale, and they discuss two possible reasons for this finding: 1. Children may behave differently in the different environments of home and school, and/or, 2. Parents and teachers may use different yardsticks when judging the severity of a problem. Adults with ID may also behave differently in different settings. Future studies using the DBC-A could investigate this further with pairs of carers who know the person well in different settings.

9.2.3.1.3 Between paid carers in small accommodation settings

In the inter-rater studies conducted in this research project inter-rater reliability was not assessed with paid carers in small accommodation settings, such as Community Residential Units (CRU), which typically house 4-6 residents with ID. In this setting carers may know about the behaviours and emotions of the residents in a more detailed way than would be the case in larger institutional residential settings. Inter-rater reliability findings in a CRU type setting may be higher than those found in Study 2, with carers in an institutional environment, and could be investigated and compared to findings in other groups, such as family members.

9.2.3.2 Concurrent validity

Within the studies completed there were two opportunities to investigate concurrent validity by asking carers to complete the DBC-A and another checklist, the ABC in Study 2 and the PAS-ADD checklist in Study 3. Future validity studies could also be done with the DASH-II, the PIMRA and the RSMB. The validity of the factors could also be investigated, such as the Depressive factor with assessments of depression.

Further validity studies, especially investigating the relationship of the six factors of the DBC-A to clinical diagnoses, could shed more light on the interplay between emotional and behavioural problems of adults with ID, the standard psychiatric diagnostic criteria and the recently developed psychiatric criteria for people with ID, the DC-LD (Royal College of Psychiatrists, 2001).

9.2.3.3 Normative studies

The DBC-A would make a further contribution to clinical practice and research studies if normative data were available. Normative data for the DBC-P was derived from a community epidemiological study conducted in Australia (Einfeld & Tonge, 2002).

Designing and conducting a research study to achieve the aim of obtaining standardisation data for a sample representative of the Australian population of adults with ID may be the next priority. However the task of constructing such a sample will be difficult because many adults with mild ID are not identified as intellectually disabled, and especially since leaving school have merged into the general community (Einfeld & Tonge, 2002; Larson et al., 2001). Therefore participants in such a study who have a mild ID are probably going to be underrepresented and more likely to have associated medical conditions, genetic syndromes and behavioural and emotional problems (Einfeld & Tonge, 2002).

9.2.4 ADDITIONAL VERSIONS OF THE DBC-A

9.2.4.1 A DBC-A for the workplace and other non-residential settings

The DBC-A is intended for use by carers who know an adult with an ID in an accommodation setting. Carers' descriptions of behavioural and emotional disturbance on the adult clinic files, from which additional items for the DBC-A were derived, came mainly from carers in accommodation settings.

However a different version of the DBC-A may also be required for staff to use who care for adults with ID in other settings, such as training colleges or work places. People who may be included under this heading could be employed as workshop supervisors, job trainers or coaches, day centre supervisors or recreational officers. They will have a range of training backgrounds, such as teaching, and some may have minimal formal qualifications.

Einfeld and Tonge (1992) recognised the need to construct a separate version of the DBC suitable for use by teachers and teachers aides (the DBC-T), who have valuable information to contribute to a comprehensive assessment of psychopathology in young people with ID. The DBC-T omits items about night-time behaviour and sleep patterns and includes an additional item about behaviour in the school setting.

There are four items in the DBC-A about which carers in non-residential settings could have limited information. Three items concern sleep: 33. Has nightmares, night terrors, or walks in sleep, 77. Sleeps too little. Disrupted sleep. and 79. Sleeps too much or overly drowsy, although information about the last item (79) may also be relevant to a staff member who only saw their client during the day. The fourth item, 51. Loss of self-care skills, may also be more readily observed by a carer in an accommodation setting, because many self-care tasks (e.g. dressing, eating meals, washing, and household chores) are performed in that setting.

On the other hand staff in non-residential services may have additional information about work performance, interpersonal skills, cognitive abilities and community access skills that may not be as accessible to a carer in an accommodation setting.

Both sets of carers have valuable information about their clients, but it is possible that these two groups do not always share information with each other easily. A comprehensive assessment collates information from a range of carers, and in order to do this well another 'Day activity carer' version of the DBC-A checklist may be required, that might omit some items and include other items.

9.2.4.2 A DBC for elderly people with an ID

The clinic files of older adults were included in the item review (Study 1), and age related changes in behaviour that they may have been experiencing may be captured in some of the new DBC-A items, such as, 31. Has become confused and forgetful, and, 51. Loss of self-care skills. However there may be additional items that need to be included in a version for elderly people with ID, and perhaps a few DBC-A items may need to be excluded. DBC-A items that might not be included in a version for elderly people may be, 65. Refuses to go to college, activity centre or workplace, and, 68. Problems with the illegal use of drugs. The DBC-A in its present form, or a version for elderly people with ID, may have role in assisting with the complex assessment issue of distinguishing dementia from other mental health disorders, such as depression (Prasher, Krishnan, Clarke, & Corbett, 1994).

9.2.4.3 Self report version of the DBC-A for adults with ID

A self-report version of the DBC-A could be investigated. One of the checklists reviewed in Chapter 3, the PIMRA (Matson, 1988), has a version for self-report by the person with an ID. This version has received very little attention in the literature. Adults with a mild or moderate intellectual disability and relatively good communication skills are able to describe aspects of their own behaviour and emotions. Although some may be unable to read very well or at all, they could be assisted in their self-report by having a checklist read to them and their responses recorded by a carer or clinician.

Other researchers have modified self-report checklists developed for use by people in the general community by simplifying the response system to a yes/no response choice (McDaniel, 1997), and this could be considered. A shorter form of the DBC-A may be more appropriate for a self-report scale.

9.2.5 USAGE AND OUTCOME STUDIES

The DBC-A has several categories of potential users, but will only make a contribution if the relevant professionals find it useful in their work with people with an ID. For example, a future study could investigate the use of the DBC-A by groups of GPs, and examine the impact DBC-A use might have on GP referral decisions and clinical outcomes for their patients with ID, compared to GP settings where it is not used. The factors that influence the uptake rate of this new assessment tool could also be examined in a study such as this.

9.2.6 LIMITATIONS OF THE STUDIES

The studies reported in this thesis have a number of limitations already discussed as well as the following general issues which might bias the findings.

9.2.6.1 IQ assessment

In all four studies there is some uncertainty regarding IQ measurement. The cognitive testing of children and adults is not universal, even in a country such as Australia, well served by health and educational services. Not all adults, for whom delayed development was recognised during childhood, were formally cognitively assessed, and the more delayed they appeared to be the less likely it was that a formal IQ assessment was attempted. For the older adults in these studies it was even less likely that formal cognitive assessment results were available. For some people the results of a formal cognitive assessment had been lost to current service providers or family members, or the assessment had been done so long ago that the result would now be considered irrelevant as a measure of current cognitive function.

The studies reported here had to rely on the information supplied by carers and the procedures implemented by local service providers to determine eligibility for service provision to determine the presence and level of ID. In Victoria the DSM-IV definition of 'intellectual disability' is enshrined in law and a person is assessed against these criteria by a psychologist before they are accepted as a client of the department that provides specialist services to people with ID. Apart from 43 people with a developmental disability, defined by functional limitations in three or more areas of major life activity, originating before the age of 22, and likely to continue indefinitely (Larson et al., 2001), included in Study 1 (see Table 13), every person who entered the four studies described here has been reported by a carer or case manager to have been declared eligible to receive services from the Disability Services branch of the Department of Human Services, Victoria.

What has been more difficult to establish is the level of ID that each person has. In Study 1 and Study 2 sometimes there was little information about level of intellectual disability available on file, but in Study 2 all residents of the residential institution had low levels of adaptive functioning. In Study 3 the participants were interviewed and observed, and their carers were present and could be questioned and contacted later to provide verifying information. In Study 4 several questions were asked in the Living Well Study survey booklet about IQ, formal cognitive assessment, eligibility for services and level of ID, and the ICAP Checklist (Bruininks, Hill, Weatherman, & Woodcock, 1986) (adaptive behaviour section) was included in the questionnaire section of the booklet. Taken as a whole, answers to these questions and the level of adaptive behaviour functioning indicated by the ICAP items, generally provided enough information to be confident about the presence and level of ID. Participants of the Living Well Study, for whom there was not enough information about their intellectual level provided in the survey booklet, were not included Study 4.

Many studies of adults with ID do not report how intellectual functioning was assessed and only describe the type of service register used to recruit subjects from (e.g. Borthwick-Duffy & Eyman, 1990; Deb, Thomas, & Bright, 2001; Haveman, Maaskant, Van Schrojenstein Lantman, Urlings, & Kessels, 1994; Morgan, Ahmed, & Kerr, 2000). Two recent studies of birth cohorts (Maughan, Collishaw, & Pickles, 1999; Richards et al., 2001) identified people with a mild ID from the results of group administered tests of general ability.

Clearly it is important in studies of people with ID to be accurate about the diagnosis of ID, and in the research studies described here every effort has been made to determine the diagnosis of ID. Less precise estimates of the level of ID have been accepted. However, these studies do contain results from adults with an ID with a wide range of ability levels, age ranges and from many different accommodation settings, which is appropriate considering the aims of each study.

9.2.6.2 People with a mild intellectual disability or low average intellectual functioning

Locating adults with a mild intellectual disability presents a particular challenge to service providers and researchers alike. It is now likely that adults with a mild ID in the lower ranges (less than IQ 60) with additional social or health difficulties will be those who are identified and assisted by services. People with milder levels of ID who do not have other problems, such as behavioral disturbance, merge into the community (Larson et al., 2001). Researchers often seek the cooperation of ID service providers to help them locate potential study participants. Therefore most studies locate and enroll a lower percentage of people with a mild ID and are not fully representative of the population of people with a mild ID. The people with mild ID who do enter studies tend to be those with greater emotional and behavioural problems which introduces another source of bias in normative studies.

In the area of mental health care this may not be a significant practical problem, for it is people who have a mild ID who may be most similar to, rather than different from members of the general community, and therefore have less need of specialist assessment instruments and techniques and specialist treatment services (Sovner, 1986). However they still may have some special needs that need to be studied and appreciated by clinicians. Studies reporting findings from birth cohorts (Maughan et al., 1999; Richards et al., 2001) whose participants have all been cognitively assessed provide particularly important information about people with a mild ID, who, as a group, might not otherwise be fully represented in research studies.

Another group who may have special needs in mental health care are people who have low average (borderline) cognitive functioning (IQ 70 – 85), who receive very little special research attention (Zetlin & Maurtaugh, 1990).

9.2.7 LIMITING FACTORS IN THE USE OF CHECKLISTS

Checklists and rating scales used to assess behavioural and emotional disturbance in adults with ID have limitations. In relation to the DBC-A these include:

1. Checklists and rating scales used in clinical practice should only form part of a comprehensive assessment of the mental health of a person with an ID, and should never be relied upon solely to provide a diagnosis (Einfeld & Tonge, 2002). A comprehensive mental health assessment of a person with ID should include, wherever possible: an interview of the patient, opportunities to observe the person in a home or work setting, interviews with carers, an appropriate medical review, tests and investigations and the selective use of a range of assessment instruments. This process may take longer to complete than mental health assessments of people without disabilities. A checklist, such as the DBC-A, used for screening of emotional and behavioural disorders should be followed, where indicated, by assessment with a specialist in the area.
2. When a carer completes a checklist they are providing information that may be a biased or incomplete picture of what may be a complex situation. Some checklist developers recommend that a checklist should be completed by two carers

separately, and the results compare. (e.g. Reiss, 1988). Another way to collect information from multiple carers might be to ask them to complete the rating scale as a 'consensus document', after discussion amongst themselves. Sometimes the different information given by different carers is important clinically, and reflects real differences in the way a person behaves in different settings or when cared for by different people. If possible these differences need to be identified and understood (Achenbach et al., 1987). Nonetheless in situations where this cannot be explored, the DBC-A has acceptable levels of inter-rater agreement within groups of raters.

3. Carer-completed checklists and rating scales are not able to make a diagnosis of a specific psychiatric disorder. Aman (1991) cautioned against this use of rating scales, particularly those with subscales containing items derived from diagnostic criteria. Even when a cluster of items is selected by a carer which appears to point to a diagnosis such as depression, it does not indicate that the person actually has this disorder. They may be physically unwell, or have a related disorder, or no disorder at all. At best the checklist result might indicate the need for a clinical assessment and raise the possibility of the presence of a disorder.
4. A checklist completed at a certain time is a snapshot of the current or recent situation. A person's mental health can change even in the absence of known interventions or changes in circumstance. Therefore repeated use of the DBC-A might provide a useful method to track change. In addition the suggested rating period on the DBC-A of six months may not give a clear picture of the presentation of a person with ID. Further investigation is required to explore how the DBC-A performs as a screening instrument when an adult with an ID has a diagnosis of a disorder which is often episodic, such as mania. This issue was raised by Moss et al.

(1998) in relation to the performance of the PAS-ADD in identifying psychiatric cases, for adults with ID diagnosed with a Bipolar Disorder. It was also identified in Study 3 as a possible explanation for some instances of disagreement between DBC-A TBPSs and clinicians ratings of psychiatric caseness. A related issue may be the question of the performance of the DBC-A in instances of a deterioration in a person's functioning, such as that seen in cases of dementia. The repeated use of the DBC-A may prove useful in tracking behavioural and emotional changes related to cognitive deterioration.

5. The DBC-A was developed in Australia. When it is used in different countries, cultural differences may need to be considered. It is possible to translate the DBC-A into other language versions using the back translation method (Streiner & Norman, 1995), as has been done with the DBC-P (Einfeld & Tonge, 2002). Further validation and normative studies would be required for any other language version of the DBC-A.

9.3 OVERALL CONCLUSION

Although other rating scales which assess emotional and behavioural problems in people with ID have been developed, it has been concluded that more work and new instruments are still needed (Aman, 1991; Hurley et al., 1998; Ross & Oliver, 2003). In this poorly funded area of research (Aman, 1991) it seemed appropriate to use an existing well-developed instrument for children and adolescents with ID (Einfeld & Tonge, 1992), in order to develop a checklist for adults with ID.

The work that established the DBC-P (Einfeld & Tonge, 1992) has been continued in this series of studies to extend the use of the checklist into the adult years of people with ID. This approach has produced a checklist which not only allows the continuous study of emotional and behaviour disorders from childhood into adult life, but also describes the emergence of predominantly adult psychopathology. In modifying the DBC-P to produce the DBC-A, a priority was to preserve the comprehensive nature of the items describing emotional and behavioural problems, and ensure that the DBC-A could be used by carers who may have only completed primary level schooling.

Particular attention has been paid to the investigation of the psychometric properties of the DBC-A in diverse groups of people with ID and their carers. Reliability was investigated in groups of paid and family carers, although pairs of family carers were difficult to locate for the inter-rater reliability study. Acceptable levels of reliability were found.

Concurrent validity was established between the DBC-A and two of the 'best' instruments (ABC & PAS-ADD Checklist) available for use with adults with ID. Criterion group validity was demonstrated between groups of people with ID who were and were not defined as psychiatric cases by pairs of raters using a rating measure with demonstrated levels of inter-rater reliability. A cut-off DBC-A TBPS was determined to screen for the presence of a psychiatric disorder, with acceptable levels of sensitivity and specificity. Finally a factor analysis of the DBC-A produced six subscales with satisfactory levels of internal consistency for the total scale and each subscale.

In summary, the carer-completed DBC-A provides a broad survey of the emotional and behavioural problems of adults with ID. It has satisfactory psychometric properties and therefore can be used with confidence in clinical, research and service settings.

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APPENDIX A

ETHICS APPROVAL DOCUMENTATION

Department of Human Services

Incorporating: Health, Aged Care, Housing, Aboriginal Affairs and Community Services

120 Spencer Street
Melbourne Victoria 3000
GPO Box 1670N
Melbourne Victoria 3001
DX210081

Telephone: (03) 9637 4000
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Our Ref:
Your Ref:

ETHICS COMMITTEE
44/99

13 July 2000

Ms Caroline Mohr
Centre for Developmental Disability Health Victoria
Suite 202, 3 Chester Street
OAKLEIGH 3166

Dear Ms Mohr

Re: Determinants of Pica Behaviour Research Project

Thank you for forwarding the amended Developmental Behaviour Checklist (DBC) highlighting the changes that had been made. These changes are approved.

Yours sincerely

[redacted]

A/PROFESSOR JULIAN SAVULESCU
CHAIR

Department of Human Services

ETHICS COMMITTEE

Incorporating: Health, Aged Care, Housing, Aboriginal Affairs and Community Services

75/00

Ethics Committee Secretariat
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Melbourne Victoria 3001
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Telephone: (03) 9637 4000
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Our Ref:
Your Ref:

19 December 2000

Ms Caroline Mohr
Senior Research Fellow
Centre for Developmental Disability Health Victoria
Suite 202 Chester Street
OAKLEIGH 3166

Dear Ms Mohr

Re: Validity Studies for an adult version of the Developmental Behaviour Checklist

The Department of Human Services Ethics Committee, at its meeting of 6 December 2000 considered and approved the above project.

The Committee requests the following contact details for complaints be included in the Plain Language Statement; Executive Officer, Department of Human Services Ethics Committee, Level 17/120 Spencer Street, Melbourne, Tel: 9637 4239.

Researchers must obtain the approval of the institution at which the research will be conducted or the institution which is responsible for the care or management of the participants.

To enable the Committee to fulfil its obligations in relation to monitoring the program you are asked to provide a report within 12 months or on completion of your project whichever is earlier. Additionally the Committee requests a summary of the research findings of less than half a page, including when the study was completed.

You must ensure that the Department of Human Services Ethics Committee is notified immediately of any matter which arises that may affect the nature of the approved program.

Should you have any queries please do not hesitate to contact our Executive Officer, Ms Kay Munro on 9637 4239 or email kay.munro@dhs.vic.gov.au.

Yours sincerely

[redacted]

A/PROFESSOR JULIAN SAVULESCU
CHAIR

Department of Human Services

Incorporating: Health, Aged Care, Housing and Community Services

ETHICS COMMITTEE

40/01 **Ethics Committee Secretariat**
Telephone: (03) 9637 4239 Fax: (03) 9637 4246
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Our Ref:
Your Ref:

10 September 2001

Ms Caroline Mohr
Department of Psychological Medicine
Monash University
Centre for Developmental Disability Health Victoria
Suite 202, 3 Chester Street
OAKLEIGH 3166

Dear Ms Mohr

Re: Reliability studies for an adult version of the Developmental Behaviour Checklist
Application No: 40/01

The Department of Human Services Ethics Committee, at its meeting on 5th September 2001 considered your letter 20 August 2001 in response to queries the Committee had raised in relation to the above project.

The Committee grants full approval.

Yours sincerely

[redacted]

PROFESSOR RICHARD G FOX
DEPUTY CHAIR

State Government Victoria

MONASH UNIVERSITY

RESEARCH GRANTS AND ETHICS BRANCH

19 June 2000

A/Professor Robert Davis
Centre for Developmental Disability
Health Victoria
Suite 202. 3 Chester Street
Oakleigh Vic 316

Ms Vanessa Murray
Centre for Developmental Disability
Health Victoria
Suite 202. 3 Chester Street
Oakleigh Vic 316

Re: Project 99/340 - Determinants of Pica behaviour

Thank you for your letter of 2 June 2000 with further information as requested by the Standing Committee on Ethics in Research Involving Humans.

This is to advise that the amendments have been approved and the project may proceed according to the approval as given on 26 August 1999.

[redacted]

Ann Michael
Human Ethics Officer
Standing Committee on Ethics
in Research Involving Humans

CLAYTON, VICTORIA, 3168 AUSTRALIA FAX: (61) (3) 9905 3831 TELEPHONE: (03) 9905 3012 IDD: +61 3 9905 3012
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MONASH
UNIVERSITY

11 July 2001

Professor B Tonge
Psychological Medicine
MMC

Ms Caroline Mohr
Centre for Developmental Disability Health Victoria
Suite 202, 3 Chester St
Oakleigh 3166

2001/293 - Reliability studies for an adult version of the Developmental Behaviour Checklist (DBC-A)

The above submission was approved by the Standing Committee on Ethics in Research Involving Humans at meeting B4/2001 on 10 July 2001 provided that the following matters are satisfactorily addressed:

> A copy of approval from the Department of Human Services should be provided to the Committee.

The project is approved as submitted for a three year period and this approval is only valid whilst you hold a position at Monash University. You should notify the Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the project. Changes to the existing protocol require the submission and approval of an amendment. Substantial variations may require a new application. Please quote the project number above in any further correspondence and include it in the complaints clause which may be expressed more formally if appropriate:

You can complain about the study if you don't like something about it. To complain about the study, you need to phone 9905 2052. You can then ask to speak to the secretary of the Human Ethics Committee and tell him or her that the number of the project is ________. You could also write to the secretary. That person's address is:

The Secretary
The Standing Committee on Ethics in Research Involving Humans
PO Box No 3A
Monash University
Victoria 3800
Telephone (03) 9905 2052 Fax (03) 9905 1420
Email: SCERH@adm.monash.edu.au

Continued approval of this project is dependent on the submission of annual progress reports and a termination report. Please ensure that the Committee is provided with a report annually, at the conclusion of the project and if the project is discontinued before the expected date of completion. The report form is available at http://www.monash.edu.au/resgrant/human-ethics/forms-reports/index.html.

The Chief Investigators of approved projects are responsible for the storage and retention of original data pertaining to a project for a minimum period of five years. You are requested to comply with this requirement.

[redacted]

Ann Michael
Human Ethics Officer
Standing Committee on Ethics in Research Involving Humans

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APPENDIX B

ABBREVIATIONS

ABC	Aberrant Behavior Checklist.
AAMD	American Association for Mental Deficiency.
ABS	Adaptive Behavior Scales.
ADHD	Attention Deficit Hyperactivity Disorder.
AS	Autism Spectrum.
ASSID	Australian Society for the Study of Intellectual Disability.
AUC	Area Under the Curve.
CARS	Childhood Autism Rating Scale.
CBLC	Child Behavior Checklist.
CDDHV	Centre for Developmental Disability Health Victoria.
CDI	Children's Depression Inventory.
CHEMRA	Checklist of Emotional Problems with Mentally Retarded Adults.
DAPQ	Draw-A-Person Questionnaire.
DASH	Diagnostic Assessment for the Severely Handicapped.
DASH-II	Diagnostic Assessment for the Severely Handicapped – 2nd version.
DBC-A	Developmental Behaviour Checklist – Adult version.
DBC-P	Developmental Behaviour Checklist – Primary carer completed version for children and adolescents.
DBC-T	Developmental Behaviour Checklist – Teacher completed version for children and adolescents.
DC-LD	Diagnostic Criteria – Learning Disability.
DD	Developmental Disability.
DD-CBCL	Developmentally Delayed Children's Behaviour Checklist.
DICA	Diagnostic Interview for Children and Adolescents.
DS	Down syndrome
DSM-III-R	Diagnostic and Statistical Manual – 3rd Edition – Revised.
DSM-IV	Diagnostic and Statistical Manual – 4th Edition.
GAP-MAP	Global Assessment of Psychopathology – Managing the Assessment Process.
GP	General Practitioner.
IASSID	International Association for the Scientific Study of Intellectual Disability.
ICAP	Inventory for Client Assessment and Planning.
ICD-10	International Classification of Diseases – 10th Edition.
ID	Intellectual Disability.
IDS	Intellectual Disability Services.
IQ	Intelligence Quotient.
LD	Learning Disability.
MH	Mental Health.
MMPI	Minnesota Multiphasic Personality Inventory.
MMPI-168 (L)	Minnesota Multiphasic Personality Inventory – Short form with 168 items, adapted for people with ID.
MMS	Mini Mental State.
PAS-ADD Checklist	Psychiatric Assessment Schedule for Adults with Developmental Disability. Checklist version.
PDD	Pervasive Developmental Disorder.
PIMRA	Psychopathology Inventory for Mentally Retarded Adults.
PIMRA-I	Psychopathology Inventory for Mentally Retarded Adults – Informant version.
RSMB	Reiss Screen for Maladaptive Behavior.
SAS	Self-rating Anxiety Scale.
SCAN	Schedules for Clinical Assessment in Neuropsychiatry.
SIB	Scales of Independent Behavior.
TBPS	Total Behaviour Problem Score.

APPENDIX C

CARER-COMPLETED RATING SCALES AND CHECKLISTS FOR ASSESSING BEHAVIOURAL AND EMOTIONAL DISTURBANCE IN ADULTS WITH AN INTELLECTUAL DISABILITY

AAMD Adaptive Behavior Scale: Residential and Community Edition (Part II)	Nihira, K., Foster, R., Shellhaas, M., & Leland, H. (1975)
Aberrant Behavior Checklist (ABC)	Aman, M.G., & Singh, N.N. (1986)
Assessment of Dual Diagnosis	Matson, J.L., & Bamburg, J.W. (1998)
Behaviour Disorder Scale	Tustin, D.R., Kent, P.A., Haskell, S., & Bond, M.J. (1991)
Behaviour Disturbance Scale	Leudar, I., Fraser, W., & Jeeves, M.A. (1987)
Diagnostic Assessment for the Severely Handicapped (DASH)	Matson, J.L., Gardner, W. I., Coe, D.A., & Sovner, R. (1991)
Disability Assessment Schedule	Holmes, N., Shah, A., & Wing, L. (1982)
Health of a Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD)	Roy, A., Matthews, H., Clifford, P., Fowler, V., & Martin, D.M. (2002)
Minnesota Developmental Programming System (MDPS): Behavior Management Assessment.	Bock, W.H., & Weatherman, R.F. (1979)
Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD)	Moss, S., Prosser, H., Costello, H., Simpson, N., Patel, P., Rowe, S., Turner, S., & Hatton, C. (1998)
The Psychopathology Instrument for Mentally Retarded Adults (PIMRA)	Matson, J.L. (1988)
Psychosocial Behaviour Scale	Espie, C.A., Montgomery, J.M., & Gillies, J.B. (1988)
Reiss Screen for Maladaptive Behavior	Reiss, S. (1988)
Strohmer-Prout Behavior Rating Scale	Strohmer, D.C., & Prout, H.T. (1989)

APPENDIX D

ABBERANT BEHAVIOR CHECKLIST

ABERRANT BEHAVIOR CHECKLIST

Resident's Name: ______________________ Rater: ______________________

Unit/Villa/Ward: ______________________ Today's Date ____/____/____ Day Month Year

(complete above line for each rating)

(complete below line when requested)

Sex (circle): Male/Female

Date of Birth ____/____/____ Day Month Year

Age ______ years ______ months

M.A. ______________

I.Q. ______________ Test Used: ______________________

Degree of Retardation: (Circle number)

1. Mild 2. Moderate 3. Severe 4. Profound 5. Don't Know

Does this resident receive specialized training: Yes/No

If Yes, specify the type of training (Please circle)

1. Training center at the hospital
2. Special class (outside hospital)
3. Vocational training
4. Other (please specify) ______________________

RESIDENT'S MEDICAL STATUS (Please circle)

a. Deafness	No	Yes	?	(Don't Know)
b. Blindness	No	Yes	?	
c. Epilepsy	No	Yes	?	
d. Cerebral Palsy	No	Yes	?	
e. Psychosis	No	Yes	?	
f. Paralysis	No	Yes	?	
g. Other ______________________				

CURRENT MEDICATION (Please list medication and dosage schedule)

1. ______________________
2. ______________________
3. ______________________
4. ______________________
5. ______________________

Before completing the checklist, users should refer to the *Aberrant Behavior Checklist Manual* for more detailed instructions and descriptions of individual items.

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INSTRUCTIONS

Please rate this resident's behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the appropriate number:

0 = not at all a problem

1 = the behavior is a problem but slight in degree

2 = the problem is moderately serious

3 = the problem is severe in degree

When judging his/her behavior, please keep the following points in mind:

(a) Take relative *frequency* into account for each behavior specified. For example if this resident averages more temper tantrums than all other residents in the unit, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.

(b) Consider this resident's behavior with *all* staff, not just yourself. If he/she has problems with others but not with you, try to take the whole picture into account.

(c) Try to consider whether a given behavior interferes with his/her *development*. For example, chronic body rocking may not disrupt other residents or the management of the residential unit, but it almost certainly hinders individual development. Thus, maladaptive behavior should be taken into account as well as acting out behavior.

(d) Raters are encouraged to rely in part upon the observations of others—in particular those who know the resident especially well and those who can observe him/her in other situations such as during other work shifts, when away at school, and so forth.

Do not deliberate too long on each item—your first reaction is usually the right one.

1.	Excessively active on ward	0	1	2	3
2.	Injures self	0	1	2	3
3.	Listless, sluggish, inactive	0	1	2	3
4.	Aggressive to other patients and staff	0	1	2	3
5.	Seeks isolation from others	0	1	2	3
6.	Meaningless, recurring body movements	0	1	2	3
7.	Boisterous (inappropriately noisy and rough)	0	1	2	3
8.	Screams inappropriately	0	1	2	3
9.	Talks excessively	0	1	2	3
10.	Temper tantrums	0	1	2	3
11.	Stereotyped, repetitive movements	0	1	2	3
12.	Preoccupied; stares into space	0	1	2	3
13.	Impulsive (acts without thinking)	0	1	2	3
14.	Irritable ("grizzly" or "whiny")	0	1	2	3
15.	Restless, unable to sit still	0	1	2	3
16.	Withdrawn; prefers solitary activities	0	1	2	3
17.	Odd, bizzare in behavior	0	1	2	3
18.	Disobedient; difficult to control	0	1	2	3
19.	Yells at inappropriate times	0	1	2	3
20.	Fixed facial expression; lacks emotional reactivity	0	1	2	3

21.	Disturbs others	0	1	2	3
22.	Repetitive speech	0	1	2	3
23.	Does nothing but sit and watch others	0	1	2	3
24.	Uncooperative	0	1	2	3
25.	Depressed mood	0	1	2	3
26.	Resists any form of physical contact	0	1	2	3
27.	Moves or rolls head back and forth	0	1	2	3
28.	Does not pay attention to instructions	0	1	2	3
29.	Demands must be met immediately	0	1	2	3
30.	Isolates himself/herself from other residents	0	1	2	3
31.	Disrupts group activities	0	1	2	3
32.	Sits or stands in one position for a long time	0	1	2	3
33.	Talks to self loudly	0	1	2	3
34.	Cries over minor annoyances and hurts	0	1	2	3
35.	Repetitive hand, body, or head movements	0	1	2	3
36.	Mood changes quickly	0	1	2	3
37.	Unresponsive to ward activities (does not react)	0	1	2	3
38.	Does not stay in seat during lesson period	0	1	2	3
39.	Will not sit still for any length of time	0	1	2	3
40.	Is difficult to reach or contact	0	1	2	3
41.	Cries and screams inappropriately	0	1	2	3
42.	Prefers to be alone	0	1	2	3
43.	Does not try to communicate by words or gestures	0	1	2	3
44.	Easily distractible	0	1	2	3
45.	Waves or shakes the extremities repeatedly	0	1	2	3
46.	Repeats a word or phrase over and over	0	1	2	3
47.	Stamps feet while banging objects or slamming doors	0	1	2	3
48.	Constantly runs or jumps around the room	0	1	2	3
49.	Rocks body back and forth	0	1	2	3
50.	Deliberately hurts himself/herself	0	1	2	3
51.	Pays no attention when spoken to	0	1	2	3
52.	Does physical violence to self	0	1	2	3
53.	Inactive, never moves spontaneously	0	1	2	3
54.	Tends to be excessively active	0	1	2	3
55.	Responds negatively to affection	0	1	2	3
56.	Deliberately ignores directions	0	1	2	3
57.	Throws temper tantrums when he/she does not get own way	0	1	2	3
58.	Shows few social reactions to others	0	1	2	3

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APPENDIX E

PSYCHIATRIC ASSESSMENT SCHEDULE FOR ADULTS WITH DEVELOPMENTAL DISABILITY

©PAS-ADD Checklist

S Moss, H Prosser, H Costello, N Simpson, & P Patel

The PAS-ADD Checklist asks about problems which sometimes happen if a person has poor mental health. The checklist aims to help staff and carers to decide whether assessment of an individual's mental health may be helpful.

The person completing the checklist should have known the individual for at least six months, if possible.

If you do not have all the information you need, try to get it; for example, if you know the person only during the day, you may not know how well they sleep, and you may wish to ask someone whose information is reliable.

Before rating, it is important to ensure that the person does not have any uncorrected hearing or vision problems. Such problems can result in symptoms which may be confused with mental health problems.

Date ....

Your name (person completing the checklist) ....

Name of the person the checklist is about ....

Your relationship to the person (eg. keyworker, mother, community nurse, etc.) ....

Length of time you have known the person ....

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The University of Manchester,
Oxford Road,
Manchester M13 9PL,
UK

☐☐☐	☐☐☐	☐☐/☐☐/☐☐	☐☐	☐☐☐
1 Ref. No.	4 Setting	7 Date (dd/mm/yy)	15 Relship.	17 Months known

SECTION 1 - LIFE EVENTS

Here is a list of life events. If the person has gone through any of these **IN THE PAST YEAR**, please tick the box next to the event. If none of these events have happened, please tick the box at the end of this page.

20 ☐ Death of a first degree relative (a parent, child, spouse, brother or sister)

21 ☐ Death of a close family friend carer or other relative

22 ☐ Serious illness or injury

23 ☐ Serious illness of close relative carer or friend

24 ☐ Move of house or residence

25 ☐ Break up of steady relationship (a girlfriend or boyfriend)

26 ☐ Separation or divorce

27 ☐ Alcohol problem

28 ☐ Drug problem

30 ☐ Serious problem with a close friend, carer, neighbour or relative

31 ☐ Unemployed/seeking work for more than one month

32 ☐ Retirement from work

33 ☐ Laid off or sacked from work

34 ☐ Something valuable lost or stolen

35 ☐ Problems with police or other authority

36 ☐ Major financial crisis

37 ☐ Sexual problem

29 ☐ Any other event or change of routine which may have caused distress to the individual (Please describe briefly)

....

....

....

☐ ☐

38 39

OR

40 ☐ NONE OF THE ABOVE EVENTS

SECTION 2 - PROBLEMS

Each question asks about problems the person may have had in the PAST FOUR WEEKS. Some questions may seem similar to others, but **please answer all the questions**. Read each question carefully and put a cross in the column which gives the best answer to the question. To calculate A, B, C, D & E, add up the numbers in each of the boxes that you have ticked.

	If you cannot answer a question, then PUT A LINE THROUGH THE QUESTION and write the reason. For example, if the person does not speak well enough for you to know if they have strange beliefs, cross out that question and write that reason.	Has not happened in the past four weeks	Has happened but has not been a problem for the person	Has been a problem for the person in the past four weeks	Has been a serious problem for the person i the past fou weeks
41	**Loss of** energy, has become tired much of the time (if **known** to be due to exertion or bodily illness, put a tick in column 2)	0	0	2	2
42	**Loss of** interest and enjoyment, such as spending less time doing things that the person likes to do	0	0	2	2
43	Sad or "down" (noticed for at least three days in the past four weeks)	0	0	2	2
44	Sudden intense fear or panic triggered by **situations** or **things**, such as being alone, crowds, thunder, etc.	0	0	2	2
45	Fearful or panicky (**not** triggered by situations or things)	0	0	2	2
46	**Repeated** actions, such as checking over and over that a door has been locked, or having to do things in a particular order	0	0	2	2
47	**Too** happy or "high" (noticed for at least three days in the past four weeks)	0	2	2	2
					SCORE A: ....
48	Attempts suicide or talks about suicide	0	1	1	1
49	**Loss of** appetite and enjoyment of food (if this is **known** to be due to dieting or bodily illness, put a tick in column 2)	0	0	1	1
50	**Increased** appetite, over-eating	0	0	1	1
51	**Change** of weight, enough to make clothing fit less well (if **known** to be due to dieting or bodily illness, put a tick in column 2)	0	0	0	0
52	Startled by sudden sounds or movements	0	0	1	1
53	Shows **loss** of confidence with other people, such as repeatedly asking for reassurance	0	0	1	1
54	Suspicious, un-trusting, behaving as if someone is trying to harm them or is talking about them	0	0	1	1

If you cannot answer a question, then PUT A LINE THROUGH THE QUESTION and write the reason. For example, if the person does not speak well enough for you to know if they have strange beliefs, cross out that question and write that reason.	Has not happened in the past four weeks	Has happened but has not been a problem for the person	Has been a problem for the person in the past four weeks	Has been a serious problem for the person in the past four weeks
55 Avoids social contact **more than usual** for the person	0	0	1	1
56 Loss of self-esteem, feeling worthless	0	0	1	1
57 Delay in falling asleep - at least one hour later than the person's usual time	0	0	1	1
58 Waking too early (at least one hour before the person's usual time) and **unable to sleep again**	0	0	1	1
				SCORE B: ....
59 **Broken** sleep, waking up for an hour or more, before falling back to sleep.	0	0	1	1
60 **Less able** to concentrate on chosen activities such as watching television, reading, or other hobbies	0	0	1	1
61 Restless or pacing, unable to sit still	0	0	1	1
62 Irritable or bad tempered	0	0	1	1
				SCORE C: ....
63 Less able to use self-care skills, such as dressing, bathing, using the toilet, and cooking	0	2	2	2
64 More forgetful or confused than usual, such as forgetting what has been said or getting lost in familiar places	0	2	2	2
				SCORE D: ....
65 Strange experiences for which other people can see no cause, such as hearing voices or seeing things that other people do not	0	2	2	2
66 Strange beliefs for which other people can see no reason, such as the person believing someone or something is controlling his/her mind or that s/he has special powers	0	2	2	2
67 Odd gestures or mannerisms	0	1	1	1
68 Odd or repetitive use of language	0	1	1	1
69 Any other behavioural problem which is a **change** from the person's usual	0	0	0	0
				SCORE E: ....

Any other comments about the person's mental health:

....

....

....

☐ ☐
70 71

Scoring Instructions

Add up scores A, B, C, D and E in the combinations outlined below in order to obtain three Total Scores. Total Scores equal to or greater than thresholds indicate the need for further psychiatric assessment. This could be the completion of a Mini PAS-ADD or a GP assessment, for example.

A Total Score higher than a threshold DOES NOT imply that a person *definitely* has a particular disorder. This can only be established by a full psychiatric assessment

Regular and frequent monitoring is advised for individuals with Total Scores just below the thresholds.

Information collected in Section One (Life Events) is not included in the Total Scores, but provides useful information for further psychiatric evaluation.

TOTAL SCORE 1. Affective or neurotic disorder. ADD A+B+C = ...

Maximum possible score = 28. Threshold = 6

TOTAL SCORE 2. Possible organic condition. ADD C+D = ...

Maximum possible score = 8. Threshold = 5

TOTAL SCORE 3. Psychotic disorder. SCORE E = ...

Maximum possible score = 6. Threshold = 2

APPENDIX F

DEVELOPMENTAL BEHAVIOUR CHECKLIST – PRIMARY CARER VERSION

DEVELOPMENTAL BEHAVIOUR CHECKLIST
(DBC-P)

Some children with developmental delay have problems with their emotions and behaviour. These can sometimes be a problem for their carers.

By completing this checklist, you will help us learn more about these problems. This will assist us to know how the person might respond to help.

Name of Child or Teenager: ______________________________

Date of Birth/Age:. ______________

Sex: ______________

Person Completing Form: ______________________________

Relationship to Child: ____________

Date Completed: ______________

Is the Child: (please circle)

	Unable to see / unable to hear	Unable to speak/ speaks very little
	Unable to use arms / legs	Subject to other serious medical condition

Please describe: ______________________________

What does he/she do best?

____

What do other people like about him/her?

____

What are his/her favourite activities?

____

Is there anything you feel he/she does as well or better than others?

____

Have you sought help for any behaviour or emotional problems, apart from slow development, of the child or teenager in your care? Yes / No

If so, from whom?

____

Please continue over the page ➔

Office Use Only

Code Number: ______________

Developmental Level (circle one only)

Profound Severe Moderate Mild Unknown

Contact Person: ______________________________

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Page 3-	
Page 4	
Total	

①	②	③	④	⑤

Revised subscales 2002

Many of the following behaviours may not apply to the child or teenager in your care. For each item that does describe the person in your care, now or within the past six months, please circle the **2** if the item is **very true** or **often true**. Circle **1** if the item is **somewhat or sometimes true** of your child. If the item is **not true** of your child circle the **0**.

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

If your child is unable to perform an item, circle the **0**. For example, if your child has no speech, then for the item "Talks too much or too fast" circle the **0**

Underline any you are particularly concerned about

Office Use Only	Please Circle	
1. ⑤	0 1 2	Appears depressed, downcast or unhappy
2. ⑤	0 1 2	Avoids eye contact. Won't look you straight in the eye.
3. ②⑤	0 1 2	Aloof, in his/her own world.
4. ①	0 1 2	Abusive. Swears at others.
5. ③	0 1 2	Arranges objects or routine in a strict order. Please describe: ____________________
6. ②	0 1 2	Bangs head.
7. ②	0 1 2	Becomes over-excited.
8. ②	0 1 2	Bites others.
9. ②	0 1 2	Cannot attend to one activity for any length of time, poor attention span.
10. ②	0 1 2	Chews or mouths objects, or body parts.
11. ④	0 1 2	Cries easily for no reason, or over small upsets.
12.	0 1 2	Covers ears or is distressed when hears particular sounds. Please describe: ____________________
13. ③	0 1 2	Confuses the use of pronouns e.g. uses "you" instead of "I".
14. ①②	0 1 2	Deliberately runs away.
15.	0 1 2	Delusions: has a firmly held belief or idea that can't possibly be true. Please describe: ____________________
16. ④	0 1 2	Distressed about being alone.
17. ⑤	0 1 2	Doesn't show affection.
18. ⑤	0 1 2	Doesn't respond to others' feelings, e.g. shows no response if a family member is crying.
19.	0 1 2	Easily distracted from his/her task, e.g. by noises.
20. ①	0 1 2	Easily led by others.
21. ②	0 1 2	Eats non-food items e.g. dirt, grass, soap.
22. ④	0 1 2	Excessively distressed if separated from familiar person.
23. ④	0 1 2	Fears particular things or situations, e.g. the dark or insects. Please describe: ____________________
24. ②	0 1 2	Facial twitches or grimaces.
25. ②	0 1 2	Flicks, taps, twirls objects repeatedly.
26. ④	0 1 2	Fussy eater or has food fads.
27. ②	0 1 2	Gorges food. Will do anything to get food e.g. takes food out of garbage bins or steals food.
28. ③	0 1 2	Gets obsessed with an idea or activity. Please describe: ____________________
29. ②	0 1 2	Grinds teeth.
30. ④	0 1 2	Has nightmares, night terrors or walks in sleep.

Please be sure you have answered all items

Continue next page →

Office Use Only

TBPS

Subscales

①	②	③	④	⑤

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true
Underline any you are particularly concerned about

Office Use Only	Please Circle			
31. ①	0	1	2	Has temper tantrums, e.g. stamps feet, slams doors.
32. ①	0	1	2	Hides things.
33. ②	0	1	2	Hits self or bites self.
34. ②	0	1	2	Hums, whines, grunts, squeals or makes other non-speech noises.
35. ①	0	1	2	Impatient.
36.	0	1	2	Inappropriate sexual activity with another.
37. ①	0	1	2	Impulsive, acts before thinking.
38. ①	0	1	2	Irritable.
39. ①	0	1	2	Jealous.
40. ①	0	1	2	Kicks, hits others.
41. ①	0	1	2	Lacks self-confidence, poor self-esteem.
42. ②	0	1	2	Laughs or giggles for no obvious reason.
43. ①	0	1	2	Lights fires.
44. ②	0	1	2	Likes to hold or play with an unusual object, e.g. string, twigs; overly fascinated with something, e.g. water. Please describe: ______________________________
45. ④	0	1	2	Loss of appetite.
46. ②	0	1	2	Masturbates or exposes self in public.
47. ①	0	1	2	Mood changes rapidly for no apparent reason.
48. ⑤	0	1	2	Moves slowly, underactive, does little, e.g. only sits and watches others.
49. ①	0	1	2	Noisy or boisterous.
50. ①②	0	1	2	Overactive, restless, unable to sit still.
51. ③	0	1	2	Overaffectionate.
52. ⑤	0	1	2	Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
53. ①	0	1	2	Overly attention-seeking.
54. ③	0	1	2	Overly interested in looking at, listening to or dismantling mechanical things e.g. lawnmower, vacuum cleaner.
55. ②	0	1	2	Poor sense of danger.
56. ③	0	1	2	Prefers the company of adults or younger children. Doesn't mix with his/her own age group.
57. ⑤	0	1	2	Prefers to do things on his/her own. Tends to be a loner.
58. ③	0	1	2	Preoccupied with only one or two particular interests. Please describe: ______________________________
59. ①	0	1	2	Refuses to go to school, activity centre or workplace.
60. ②	0	1	2	Repeated movements of hands, body, head or face e.g. handflapping or rocking.
61. ⑤	0	1	2	Resists being cuddled, touched or held.
62. ③	0	1	2	Repeats back what others say like an echo.
63. ③	0	1	2	Repeats the same word or phrase over and over.
64. ②	0	1	2	Smells, tastes, or licks objects.
65.	0	1	2	Scratches or picks his/her skin.
66. ②	0	1	2	Screams a lot.

Please be sure you have answered all items
Continue over the page →

Office Use Only

TBPS ☐

Subscales

①	②	③	④	⑤

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true
Underline any you are particularly concerned about

Office Use Only	Please Circle	
67.	0 1 2	Sleeps too little. Disrupted sleep.
68. ②	0 1 2	Stares at lights or spinning objects.
69. ⑤	0 1 2	Sleeps too much.
70. ②	0 1 2	Soils outside toilet though toilet trained. Smears or plays with faeces.
71. ③	0 1 2	Speaks in whispers, high pitched voice, or other unusual tone or rhythm.
72. ②	0 1 2	Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe: ______________________
73. ①	0 1 2	Steals.
74. ①	0 1 2	Stubborn, disobedient or unco-operative.
75. ④	0 1 2	Shy.
76. ②	0 1 2	Strips off clothes or throws away clothes.
77. ①	0 1 2	Says he/she can do things that he/she is not capable of.
78. ③	0 1 2	Stands too close to others.
79.	0 1 2	Sees, hears, something which isn't there. Hallucinations. Please describe: ______________________
80.	0 1 2	Talks about suicide.
81. ①	0 1 2	Talks too much or too fast.
82. ③	0 1 2	Talks to self or imaginary people or objects
83. ①	0 1 2	Tells lies.
84.	0 1 2	Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow.
85. ①	0 1 2	Tense, anxious, worried.
86. ①②	0 1 2	Throws or breaks objects.
87. ①	0 1 2	Tries to manipulate or provoke others.
88. ②	0 1 2	Underreacts to pain.
89. ③	0 1 2	Unrealistically happy or elated.
90. ②	0 1 2	Unusual body movements, posture, or way of walking. Please describe: ______________________
91. ④	0 1 2	Upset and distressed over small changes in routine or environment. Please describe: ______________________
92. ②	0 1 2	Urinates outside toilet, although toilet trained.
93. ①	0 1 2	Very bossy.
94. ②	0 1 2	Wanders aimlessly.
95. ①	0 1 2	Whines or complains a lot. Please write in any problems your child has that were not listed above
	0 1 2	______________________
	0 1 2	______________________
	0 1 2	______________________
96.	0 1 2	Overall, do you feel your child has problems with feelings or behaviour, in addition to problems with development? If not, please circle the **0**. If so, but they're minor, please circle the **1**. If they're major problems, please circle the **2**.

Please be sure you have answered all items

Are there any other comments you would like to make?

____

____

THANK YOU

Office Use Only
TBPS
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Subscales

①	②	③	④	⑤

APPENDIX G

ABC & DBC-A ITEM COMPARISON

ABC Items		Corresponding DBC-A Items	
1.	Excessively active on ward.	58.	Overactive, restless, unable to sit still.
2.	Injures self.	6.	Bangs head.
		22.	Eats non-food items, e.g. dirt, grass, soap.
		36.	Hits, bites or injures self.
		75.	Scratches or picks his or her skin.
3.	Listless, sluggish, inactive.	55.	Moves slowly, underactive, does little, e.g. only sits and watches others.
4.	Aggressive to other patients and staff.	8.	Bites others.
		44.	Kicks, hits or injures others.
5.	Seeks isolation from others.	3.	Aloof, in her/his own world.
		32.	Has become more withdrawn.
6.	Meaningless, recurring body movements.	70.	Repeated movements of hands, body, head or face, e.g. handflapping or rocking.
		30.	Grinds teeth.
7.	Boisterous (inappropriately noisy and rough).	56.	Noisy or boisterous.
8.	Screams inappropriately.	76.	Screams a lot.
9.	Talks excessively.	92.	Talks too much or too fast.
10.	Temper tantrum.	34.	Has temper tantrums, e. g. stamps feet, slams doors.
11.	Stereotyped, repetitive movements.	70.	Repeated movements of hands, body, head or face, e.g. handflapping or rocking.
12.	Preoccupied; stares into space.	78.	Stares at lights or spinning objects.
13.	Impulsive (acts without thinking).	41.	Impulsive, acts before thinking.
14.	Irritable ("grizzly" or "whiny").	42.	Irritable.
		106.	Whines or complains a lot.
15.	Restless, unable to sit still.	58.	Overactive, restless, unable to sit still.

APPENDIX G

ABC Items		Corresponding DBC-A Items	
16.	Withdrawn, prefers solitary activities.	3.	Aloof, in his/her own world.
		65.	Prefers to do things on his/her own. Tends to be a loner.
		32.	Has become more withdrawn.
17.	Odd, bizarre in behaviour.	48.	Likes to hold or play with an unusual object, e.g. string twigs, overly fascinated with something, e.g. water.
		74.	Smells, tastes, or licks objects.
		83.	Switches lights on and off, pours water over and over or similar repetitive activity.
		81.	Speaks in whispers, high-pitched voice or other unusual tone or rhythm.
		46.	Laughs or giggles for no obvious reason.
18.	Disobedient, difficult to control.	85.	Stubborn, disobedient or unco-operative.
19.	Yells at inappropriate times.	37.	Hums, whines, grunts, squeals or makes other non-speech noises.
20.	Fixed facial expression, lacks emotional reactivity.	18.	Doesn't show affection.
21.	Disturbs other.	98.	Tries to manipulate or provoke others.
22.	Repetitive speech.	72.	Repeats back what others say like an echo.
		73.	Repeats the same word or phrase over and over.
23.	Does nothing but sit and watch others.	55.	Moves slowly, underactive, does little, e.g. only sits and watches others.
24.	Uncooperative.	85.	Stubborn, disobedient or unco-operative.
25.	Depressed mood.	1.	Appears depressed, downcast or unhappy.
26.	Resists any form of physical contact.	71.	Resists being cuddled, touched or held by close friends or family members.
27.	Moves or rolls head back and forth.	101.	Unusual body movements, posture, or way of walking.
		70.	Repeated movements of hands, body, head or face, e.g. handflapping or rocking.
28.	Does not pay attention to instructions.	85.	Stubborn, disobedient or unco-operative.
29.	Demands must be met immediately.	38.	Impatient.

APPENDIX G

ABC Items		Corresponding DBC-A Items	
30.	Isolates himself/herself from other residents.	3.	Aloof, in her/his own world.
		65.	Prefers to do things on his/her own. Tends to be a loner.
31.	Disrupts group activities.		
32.	Sits or stands in one position for a long time.	101.	Unusual body movements, posture, or way of walking.
		55.	Moves slowly, underactive, does little, e.g. only sits and watches others.
33.	Talks to self loudly.	93.	Talks to self or imaginary people or objects.
34.	Cries over minor annoyances and hurts.	12.	Cries easily for no reason, or over small upsets.
35.	Repetitive hand, body, or head movements.	25.	Facial twitches or grimaces.
		26.	Flicks, taps, twirls objects repeatedly.
		70.	Repeated movements of hands, body, head or face, e.g. handflapping or rocking.
36.	Mood changes quickly.	54.	Mood changes rapidly for no apparent reason.
37.	Unresponsive to ward activities (does not react).	55.	Moves slowly, underactive, does little, e.g. only sits and watches others.
38.	Does not stay in seat during lesson period.	58.	Overactive, restless, unable to sit still.
40.	Is difficult to reach or contact.	71.	Resists being cuddled, touched or held by close friends or family members.
41.	Cries and screams inappropriately.	76.	Screams a lot.
42.	Prefers to be alone.	3.	Aloof, in his/her own world.
		65.	Prefers to do things on his/her own. Tends to be a loner.
		86.	Shy.
43.	Does not try to communicate by word or gesture.	57.	Not communicating as much as usual.
44.	Easily distractible.	10.	Cannot attend to one activity for any length of time, poor attention span.
		20.	Easily distracted form his/her task, e.g. by noises.
45.	Waves or shakes the extremities repeatedly.	70.	Repeated movements of hands, body, head or face, e.g. handflapping or rocking.
46.	Repeats a word or phrase over and over.	73.	Repeats the same word or phrase over and over.

APPENDIX G

ABC Items		Corresponding DBC-A Items	
47.	Stamps feet while banging objects or slamming doors.	34.	Has temper tantrums, e.g. stamps feet, slams doors.
48.	Constantly runs or jumps around the room.	58.	Overactive, restless, unable to sit still.
49.	Rocks body back and forth.	70.	Repeated movements of hands, body, head or face, e.g. handflapping and rocking.
50.	Deliberately hurts himself/herself.	6.	Bangs head.
		36.	Hits, bites or injures self.
		75.	Scratches or picks his/her skin.
51.	Pays no attention when spoken to.	3.	Aloof, in his/her own world.
		74.	Stubborn, disobedient or unco-operative.
52.	Does physical violence to self.	6.	Bangs head.
		36.	Hits, bites or injures self.
53.	Inactive, never moves spontaneously.	55.	Moves slowly, underactive, does little, e.g. only sits and watches others.
54.	Tends to be excessively active.	7.	Becomes over-excited.
		58.	Overactive, restless, unable to sit still.
55.	Responds negatively to affection.	18.	Doesn't show affection.
		71.	Resists being cuddled, touched or held by close friends or family.
56.	Deliberately ignores directions.	85.	Stubborn, disobedient or unco-operative.
57.	Throws temper tantrums when he or she does not get own way.	34.	Has temper tantrums, e.g. stamps feet, slams doors.
58.	Shows few social reactions to others.	18.	Doesn't show affection.
		3.	Aloof, in his/her own world.

APPENDIX H

DEVELOPMENTAL BEHAVIOUR CHECKLIST FOR ADULTS

DEVELOPMENTAL BEHAVIOUR CHECKLIST FOR ADULTS
(DBC-A)

Some people with developmental disabilities have problems with their emotions and behaviour. These can sometimes be a problem for their carers.

By completing this checklist, you will help us learn more about these problems. This will assist us to know how the person might respond to help.

Person Being Assessed: ....

Date of Birth/Age: ....

Sex: ....

Person Completing Form: ....

Relationship to Person Being Assessed: ....

Date Completed: ....

Does the Person Have: (please tick)
Difficulties with seeing/hearing ☐
Difficulties with communication ☐
Difficulties with mobility ☐

Other serious medical conditions (Please describe)

....

What does he/she do best?

....

What do other people like about her/him?

....

What are his/her favourite activities?

....

Is there anything you feel she/he does as well or better than others?

....

Have you sought help for any behaviour or emotional problems, apart from slow development, of the person in your care?

Yes ☐ No ☐

If so from whom?

....

Please continue over the page →

---

evelopmental Level (circle one only)

ofound severe moderate mild unknown

Code number: ☐

Contact person: ☐

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Page 3	
Page 4	
Total	

Subscales	①	②	③	④	⑤	⑥

Many of the following behaviours may not apply to the person in your care. For each item that does describe the person in your care, now or within the past six months, please circle the **2** if the item is **very true** or **often true**. Circle **1** if the item is **somewhat or sometimes true** of the person. If the item is **not true** of the person circle the **0**.

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

If the person is unable to perform an item, circle the **0**. For example, if he/she has no speech, then for the item "Talks too much or too fast" circle the **0**

Office Use Only	**Please Circle**			
1②④	0	1	2	Appears depressed, downcast or unhappy.
2	0	1	2	Avoids eye contact. Won't look you straight in the eye.
3⑥	0	1	2	Aloof, in her/his own world.
4②	0	1	2	Abusive. Swears at others.
5⑥	0	1	2	Arranges objects or routine in a strict order. Please describe: ....
6①	0	1	2	Bangs head.
7①②	0	1	2	Becomes over-excited.
8①	0	1	2	Bites others.
9	0	1	2	Bizarre speech. Please describe: ....
10	0	1	2	Cannot attend to one activity for any length of time, poor attention span.
11①	0	1	2	Chews or mouths objects, or body parts.
12②	0	1	2	Cries easily for no reason, or over small upsets.
13	0	1	2	Covers ears or is distressed when hears particular sounds. Please describe: ....
14⑤	0	1	2	Confuses the use of pronouns, eg uses "you" instead of "I".
15	0	1	2	Deliberately runs away.
16	0	1	2	Delusions: has a firmly held belief or idea that can't possibly be true. Please describe: ....
17	0	1	2	Distressed about being alone.
18	0	1	2	Doesn't show affection.
19①	0	1	2	Doesn't respond to others' feelings, eg shows no response if a close friend or family member is crying.
20⑤	0	1	2	Easily distracted from his/her task, eg by noises.
21⑤	0	1	2	Easily led into trouble by others.
22①	0	1	2	Eats non-food items, eg dirt, grass, soap.
23	0	1	2	Excessively distressed if separated from a familiar person.
24	0	1	2	Fears particular things or situations, eg the dark, insects or crowds. Please describe: ....
25①	0	1	2	Facial twitches or grimaces.
26①	0	1	2	Flicks, taps, twirls objects repeatedly.
27	0	1	2	Fussy eater or has food fads.
28①	0	1	2	Gorges food. Will do anything to get food, eg takes food out of garbage bins or steals food.
29	0	1	2	Gets obsessed with an idea or activity. Please describe: ....
30①	0	1	2	Grinds teeth.
31④	0	1	2	Has become confused or forgetful.
32④	0	1	2	Has become more withdrawn.
33③	0	1	2	Has nightmares, night terrors or walks in sleep.

Office Use Only
TBPS

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Subscales

①	②	③	④	⑤	⑥

Please be sure you have answered all items
Continue over the page →

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

Office Use Only	Please Circle
34②	**0 1 2** Has temper tantrums, eg stamps feet, slams doors.
35③	**0 1 2** Hides things.
36	**0 1 2** Hits, bites or injures self.
37①	**0 1 2** Hums, whines, grunts, squeals or makes other non-speech noises.
38②	**0 1 2** Impatient.
39③	**0 1 2** Inappropriate sexual activity with another.
40	**0 1 2** Increase in appetite.
41	**0 1 2** Impulsive, acts before thinking.
42②	**0 1 2** Irritable.
43②	**0 1 2** Jealous.
44	**0 1 2** Kicks, hits or injures others.
45	**0 1 2** Lacks self-confidence, poor self-esteem.
46①	**0 1 2** Laughs or giggles for no obvious reason.
47③	**0 1 2** Lights fires.
48①	**0 1 2** Likes to hold or play with an unusual object, eg string, twigs; overly fascinated with something, eg water. Please describe: ....
49④	**0 1 2** Loss of appetite.
50④	**0 1 2** Loss of enjoyment or interest in usual activities.
51④	**0 1 2** Loss of self-care skills.
52③	**0 1 2** Makes gloomy statements.
53③	**0 1 2** Masturbates, or exposes self, in public.
54④	**0 1 2** Mood changes rapidly for no apparent reason.
55④	**0 1 2** Moves slowly, underactive, does little, eg only sits and watches others.
56①	**0 1 2** Noisy or boisterous.
57④	**0 1 2** Not communicating as much as usual.
58①⑤	**0 1 2** Overactive, restless, unable to sit still.
59⑥	**0 1 2** Overaffectionate.
60	**0 1 2** Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
61②	**0 1 2** Overly attention-seeking.
62	**0 1 2** Overly interested in looking at, listening to or dismantling mechanical things, eg lawnmower, vacuum cleaner.
63③	**0 1 2** Panics. Sweats, flushes, trembles.
64③*	**0 1 2** Poor sense of danger.
65⑥	**0 1 2** Prefers to do things on his/her own. Tends to be a loner.
66	**0 1 2** Preoccupied with only one or two particular interests. Please describe: ....
67	**0 1 2** Problems with cigarettes, alcohol or caffeine.
68	**0 1 2** Problems with the illegal use of drugs.
69②	**0 1 2** Refuses to go to college, activity centre or workplace.
70①	**0 1 2** Repeated movements of hands, body, head or face, eg handflapping or rocking.
71⑥	**0 1 2** Resists being cuddled, touched or held by close friends or family.
72⑤	**0 1 2** Repeats back what others say like an echo.
73	**0 1 2** Repeats the same word or phrase over and over.
74①	**0 1 2** Smells, tastes, or licks objects.

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TBPS
☐

Subscales

①	②	③	④	⑤	⑥

*** Deduct this item score from subscale total**

Please be sure you have answered all items
Continue over the page ➔

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

OfficeUse Only	Please Circle	
75①	0 1 2	Scratches or picks her/his skin.
76	0 1 2	Screams a lot.
77	0 1 2	Sleeps too little. Disrupted sleep.
78①	0 1 2	Stares at lights or spinning objects.
79④	0 1 2	Sleeps too much or overly drowsy.
80①	0 1 2	Soils outside toilet though toilet trained. Smears or plays with faeces.
81	0 1 2	Speaks in whispers, high pitched voice, or other unusual tone or rhythm.
82①	0 1 2	Spits.
83①	0 1 2	Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe: ....
84③	0 1 2	Steals.
85②	0 1 2	Stubborn, disobedient or unco-operative.
86⑥	0 1 2	Shy.
87①	0 1 2	Strips off clothes or throws away clothes.
88⑤	0 1 2	Says he/she can do things that he/she is not capable of.
89⑤	0 1 2	Stands too close to others.
90⑤	0 1 2	Sees, hears, something which isn't there. Hallucinations. Please describe: ....
91	0 1 2	Talks about or attempts suicide.
92⑤	0 1 2	Talks too much or too fast.
93⑤	0 1 2	Talks to self or imaginary people or objects.
94①* ⑥	0 1 2	Tells lies.
95⑤	0 1 2	Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow.
96③	0 1 2	Tense, anxious, worried.
97②	0 1 2	Throws or breaks objects.
98②	0 1 2	Tries to manipulate or provoke others.
99	0 1 2	Underreacts to pain.
100	0 1 2	Unrealistically happy or elated.
101	0 1 2	Unusual body movements, posture, or way of walking. Please describe: ....
102②⑥	0 1 2	Upset and distressed over small changes in routine or environment. Please describe: ....
103①	0 1 2	Urinates outside toilet, although toilet trained.
104②	0 1 2	Very bossy.
105	0 1 2	Wanders aimlessly.
106②	0 1 2	Whines or complains a lot.
		Please write in any problems she/he has that were not listed above.
	0 1 2	....
	0 1 2	....
107	0 1 2	Overall, do you feel the person has problems with feelings or behaviour, in addition to problems with development? If not, please circle the 0. If so, but they're minor, please circle the 1. If they're major problems, please circle the 2.

Please be sure you have answered all items

Are there any other comments you would like to make?

....

....

Office Use Only

*** Deduct this item score from subscale total**

THANK YOU

TBPS

☐

Subscales

①	②	③	④	⑤	⑥

APPENDIX I

PLAIN LANGUAGE STATEMENT

Full project title:	Validity studies for an adult version of the Developmental Behaviour Checklist
Principal researcher:	Caroline Mohr

1. Your consent

You are invited to take part in this research project, which is part of the PhD project of Ms Caroline Mohr, at Monash University.

This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read it carefully, ***or ask someone to read it to you.*** Feel free to ask questions about any information in the statement.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the consent form. By signing the consent form you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of both the consent form and this Plain Language Statement to keep as a record.

2. Description of the project

The purpose of this project is to develop a good checklist to help doctors and other health professionals assess the behaviours and emotions that concern adults with an intellectual disability and the people who know them well. The checklist is called the Developmental Behaviour Checklist (DBC). It is already used with children and adolescents who have an intellectual disability and works very well to help them.

Previous experience has shown making a good assessment of the behaviour and emotions that may concern a person with an intellectual disability and/or the people who know them well can take a long time and need special skills. Having a good checklist to use like the DBC can make this assessment faster and more accurate.

You are invited to take part in this research project because you have been referred to the Centre for Developmental Disability Health Victoria for an assessment by one of the doctors. All people referred to the Centre are being asked to participate in this project at this time, until approximately 70 assessments using the DBC have been done.

APPENDIX I

Participation in this project will involve having a person who knows you well filling out the DBC and another checklist, the PAS-ADD, about your behaviour and emotions. Caroline Mohr will observe the assessment session and she and the doctor you will see will also fill out another rating scale when the assessment is over.

3. Possible benefits

Possible benefits include you having a more detailed assessment of any problems you may have which will help the doctor decide what help to give you. However there is no guarantee that you will receive any direct benefit from this project.

4. Possible risks

The people organising this research and the doctors in the clinic do no think there is anything unpleasant or harmful that will happen to you while you are involved in this study.

5. Alternatives to participation

If you chose not to take part, your assessment with a doctor from the Centre will take place as it normally would.

6. Confidentiality and disclosure of information

Any information obtained in connection with this project that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. If you give us your permission by signing the consent form, we plan to publish the results.

In any publication, information will be used in such a way that you cannot be identified. Only information about groups of people will be used.

7. Results of the study

Information about your own checklist results will be given to the doctor who sees you at the clinic, unless you show on the consent form that you don't want this to happen. The doctor will then include these results in a report written to your own doctor. You can ask for the results to be sent to you instead. The results of the whole study will be written about in Caroline Mohr's PhD, and you can see that at the CDDHV in about two years from now.

8. Further information of any problems

If you require further information or if you have any problems concerning this project you can contact the principal researcher Caroline Mohr or Dr Bob Davis at the Centre for Developmental Disability Health Victoria on 9564 7511.

9. Other issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

Name: Professor Bruce Tonge
Position: Professor in the department of Psychological Medicine, Monash University
Telephone: 9594 1352

Or:

Executive Officer, Department of Human Services Ethics Committee
Level 17/ 120 Spencer St, Melbourne.
Telephone: 9637 4239

10. Participation is voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision about whether you take part or do not take part, or to take part and then withdraw, will not affect your routine treatment, or your relationship with the staff at the Centre for Developmental Disability Health Victoria in any way.

Before you make your decision a member of the research team will be available so that you can ask any questions you have about the research project. You can ask for any information you want. Only sign the consent form once you have had a chance to ask your questions and you have received satisfactory answers.

Before deciding whether to take part, you may wish to discuss the project with a relative or friend or local health worker. Feel free to do this.

If you decide to withdraw from this project, please notify Ms Caroline Mohr or Ms Anne O'Leary at the Centre for Developmental Disability Health Victoria.

11. Ethical guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee on the Department of Human Services, Victoria.

APPENDIX J

SENSITIVITY AND SPECIFICITY

DBC-A TBPS	Sensitivity	1 - Specificity
28.00	1.000	1.000
29.50	1.000	.969
31.50	1.000	.938
33.50	.974	.938
35.00	.947	.906
36.50	.921	.875
38.00	.895	.875
39.50	.895	.781
40.50	.868	.781
41.50	.868	.750
42.50	.868	.719
43.50	.868	.688
44.50	.868	.625
45.50	.868	.594
46.50	.868	.563
48.50	.868	.500
50.50	.842	.469
52.00	.842	.438
54.00	.842	.375
55.50	.842	.344
57.50	.789	.344
60.00	.789	.313
61.50	.737	.313
62.50	.684	.313
63.50	.658	.281
64.50	.605	.281

DBC-A TBPS	Sensitivity	1 - Specificity
28.00	1.000	1.000
65.50	.605	.250
66.50	.605	.219
67.50	.605	.188
69.00	.553	.188
70.50	.553	.125
71.50	.553	.094
72.50	.500	.094
74.50	.447	.094
76.50	.421	.063
79.00	.395	.063
81.50	.342	.063
84.00	.316	.063
87.00	.289	.031
88.50	.263	.031
91.50	.237	.031
96.50	.211	.000
100.00	.184	.000
101.50	.158	.000
103.50	.132	.000
106.50	.105	.000
111.50	.079	.000
118.00	.053	.000
127.50	.026	.000
135.00	.000	.000

The test result variable(s): DBC-A TOTAL SCORE has at least one tie between the positive actual state group and the negative actual state group.

Note: The smallest cut-off value is the minimum observed test value minus 1, and the largest cut-off value is the maximum observed test value plus 1. All the other cut-off values are the averages of two consecutive ordered observed test values.

APPENDIX K

DBC-A 5 FACTOR SOLUTION

LOADINGS GREATER THAN .40

	Item	Loading	DBC-P revised
Factor 1			
37	Hums	.83	SA
22	Pica	.80	SA
36	Hits	.78	SA
8	Bites	.77	SA
6	Bangs	.77	SA
11	Chews	.70	SA
76	Screams	.70	SA
74	Smells	.68	SA
48	String	.61	SA
25	Twitches	.55	SA
78	Stares	.53	SA
94	Lies [Cross-4&5]	-.53	D
44	Kicks	.52	D
56	Noisy	.52	D
70	Movements	.52	SA
46	Laughs	.48	SA
26	Flicks	.48	SA
87	Strips	.47	SA
19	Doesn't respond	.47	SR
88	Not capable [Cross-5]	-.46	D
7	Over-excited	.46	SA
82	Spits	.46	New
80	Soils	.45	SA
30	Grinds	.44	SA
83	Lights	.44	SA
58	Overactive [Cross-5]	.42	D
97	Throws	.42	D
103	Urinates	.41	SA
75	Scratches	.40	-
53	Masturbates [Cross-3]	.40	SA
Factor 2			
106	Whines	.64	-
98	Manipulative	.62	D
61	Attention-seeking	.60	D
42	Irritable	.58	D
4	Abusive	.57	D
34	Tantrums	.54	D
91	Suicide	.54	-
1	Depressed [Cross-4]	.54	SR
12	Cries	.51	D
104	Bossy	.51	D
43	Jealous	.50	D
52	Gloomy [Cross-3]	.49	New
94	Lies [Cross-1]	.46	D
38	Impatient	.46	D
69	Refuses to go	.45	D
60	Overbreathes	.43	SR
85	Stubborn	.42	D
Factor 3			
47	Fires	1.02	D
62	Panics	.58	New
33	Nightmares	.53	A
39	Sexual	.52	-
35	Hides things	.47	D
84	Steals	.49	D
53	Masturbates [Cross-1]	.43	SA
52	Gloomy [Cross-2]	.42	New
9	Bizarre speech	.41	New
21	Easily led [Cross-5]	.41	D
64	Danger [Cross 5]	-.44	SA
Factor 4			
32	Withdrawn	.88	New
50	Lost enjoyment	.74	New
55	Moves slowly	.64	SR
51	Lost self-care	.62	New
57	Not communicating	.62	New
1	Depressed [Cross-1]	.62	SR
33	Nightmares	.53	A
2	Avoids eye contact	.48	SR
79	Sleeps too much	.48	SR
3	Aloof	.47	SR
31	Confused	.44	New
49	Lost appetite	.44	A
54	Mood changes	.43	D
45	Lacks self-confidence	.43	D
65	Loner	.40	SR
Factor 5			
92	Talks fast	.71	D
88	Not capable [Cross-1]	.60	D
89	Stands	.58	CD
93	Talks to self	.56	CD
21	Easily led [Cross-3]	.56	D
95	Thoughts	.55	-
59	Overaffectionate	.55	CD
14	Confuses pronouns	.55	CD
20	Distracted	.51	-
90	Hallucinations	.50	-
41	Impulsive	.49	D
72	Echo	.46	CD
58	Overactive [Cross-1]	.46	D
29	Obsessed	.44	CD
64	Danger [Cross-4]	.43	SA
73	Repeats	.43	CD

[Cross-1] Cross loading on Factor 1; [Cross-2] Cross loading on Factor 2; [Cross-3] Cross loading on Factor 3; [Cross-4] Cross loading an Factor 4; [Cross-5] Cross loading on Factor 5.

APPENDIX L

FACTOR INTER-CORRELATIONS

	Factors	1. S-A	2. D	3. A	4. DP	5. CD
1.	Self-Absorbed					
2.	Disruptive	0.184				
3.	Antisocial	0.168	0.189			
4.	Depressive	0.342	0.275	0.272		
5.	Communication Disturbance	-0.307	-0.425	-0.161	-0.386	
6.	Social Relating	0.359	0.072	0.090	0.238	-0.305

APPENDIX M

DBC-A ITEMS THAT DID NOT LOAD ON SIX-FACTOR SOLUTION

Item	
2	Avoids eye contact. Won't look you straight in the eye.
9	Bizarre speech.
10	Cannot attend to one activity for any length of time, poor attention span.
13	Covers ears or is distressed when hears particular sounds.
15	Deliberately runs away.
16	Delusions: has firmly held belief or idea that can't possibly be true.
17	Distressed about being alone.
18	Doesn't show affection.
23	Excessively distressed if separated from a particular person.
24	Fears particular things or situations, e.g. the dark, insects or crowds.
27	Fussy eater or has food fads.
29	Gets obsessed with an idea or activity.
36	Hits, bites or injures self.
40	Increase in appetite.
41	Impulsive.
44	Kicks, hits or injures others.
45	Lacks self-confidence, poor self-esteem.
60	Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
62	Overly interested in looking at, listening to or dismantling mechanical things, e.g. lawnmower, vacuum cleaner.
66	Preoccupied with only one or two particular interests.
67	Problems with cigarettes, alcohol or caffeine.
73	Repeats the same word or phrase ever and over.
76	Screams a lot.
77	Sleeps too little. Disrupted sleep.
81	Speaks in whispers, high pitched voice or other unusual tone or rhythm.
91	Talks about or attempts suicide.
99	Underreacts to pain.
100	Unrealistically happy or elated.
101	Unusual body movements, posture or way of walking.
105	Wanders aimlessly.

APPENDIX N

DBC-A ITEM ABBREVIATIONS AND FULL ITEM WORDING

Item	Abbreviated Item	Full item wording
1	Depressed	Appears depressed, downcast or unhappy.
2	Avoids eye contact	Avoids eye contact. Won't look you straight in the eye.
3	Aloof	Aloof, in her/his own world.
4	Abusive	Abusive. Swears at others.
5	Arranges objects	Arranges objects or routine in a strict order.
6	Bangs head	Bangs head.
7	Over-excited	Becomes over-excited.
8	Bites	Bites others.
9	Bizarre speech	Bizarre speech.
10	Cannot attend	Cannot attend to one activity for any length of time, poor attention span.
11	Chews	Chews or mouths objects, or body parts.
12	Cries	Cries easily for no reason, or over small upsets.
13	Covers ears	Covers ears or is distressed when hears particular sounds.
14	Confuses pronouns	Confuses the use of pronouns, e.g. uses "you' instead of "I".
15	Runs away	Deliberately runs away.
16	Delusions	Delusions: has a firmly held belief or idea that can't possibly be true.
17	Distressed alone	Distressed about being alone.
18	Affection	Doesn't show affection.
19	Doesn't respond	Doesn't respond to others' feelings, e.g. shows no response if a close friend or family member is crying.
20	Distracted	Easily distracted from his/her tasked, e.g. by noises.
21	Easily led	Easily led by others into trouble.
22	Pica	Eats non-food items, e.g. dirt, grass, soap.
23	Distressed	Excessively distressed if separated from a familiar person.
24	Fears	Fears particular things or situations, e.g. the dark, insects or crowds.
25	Twitches	Facial twitches or grimaces.
26	Flicks	Flicks, taps, twirls objects repeatedly.
27	Food fads	Fussy eater or has food fads.
28	Gorges	Gorges food. Will do anything to get food, e.g. takes food out of garbage bins or steals food.
29	Obsessed	Gets obsessed with an idea or activity.
30	Grinds	Grinds teeth.
31	Confused	Has become confused and forgetful.
32	Withdrawn	Has become more withdrawn.
33	Nightmares	Has nightmares, night terrors or walks in sleep.
34	Tantrums	Has temper tantrums, e.g. stamps feet, slams doors.

APPENDIX N

Item	Abbreviated Item	Full item wording
35	Hides things	Hides things.
36	Hits	Hits, bites or injures self.
37	Hums	Hums, whines, grunts squeals or makes other non-speech noises.
38	Impatient	Impatient.
39	Sexual	Inappropriate sexual activity with another.
40	Increased appetite	Increase in appetite.
41	Impulsive	Impulsive, acts before thinking.
42	Irritable	Irritable.
43	Jealous	Jealous.
44	Kicks	Kicks, hits or injures others.
45	Lacks self-confidence	Lacks self-confidence, poor self-esteem.
46	Laughs	Laughs or giggles for no obvious reason.
47	Fires	Lights fires.
48	String	Likes to hold or play with an unusual object, e.g. string, twigs, overly fascinated with something.
49	Lost appetite	Loss of appetite.
50	Lost enjoyment	Loss of enjoyment or interest in usual activities.
51	Lost self-care	Loss of self-care skills.
52	Gloom	Makes gloomy statements.
53	Masturbate	Masturbates, or exposes self, in public.
54	Mood changes	Mood changes rapidly for no apparent reason.
55	Moves slowly	Moves slowly, underactive, does little, e.g. only sits and watches others.
56	Noise	Noisy or boisterous.
57	Not communicating	Not communicating as much as usual.
58	Overactive	Overactive, restless, unable to sit still.
59	Overaffectionate	Overaffectionate.
60	Overbreathe	Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
61	Attention-seeking	Overly attention-seeking.
62	Mechanical	Overly interested in looking at, listening to, or dismantling mechanical things, e.g. lawnmower, vacuum cleaner.
63	Panic	Panics. Sweats, flushes, trembles.
64	Danger	Poor sense of danger.
65	Loner	Prefers to do things on her/his own. Tends to be a loner.
66	Preoccupied	Preoccupied with one or two particular interests.
67	Cigarettes	Problems with cigarettes, alcohol or caffeine.
68	Drug	Problems with the illegal use of drugs.
69	Refuses to go	Refuses to go to college, activity centre or workplace.
70	Movement	Repeated movements of hands, body, head or face, e.g. handflapping or rocking.
71	Cuddled	Resists being cuddled touched or held by close friends or family.

APPENDIX N

Item	Abbreviated Item	Full item wording
72	Echo	Repeats back what others say like an echo.
73	Repeats	Repeats the same word or phrase over and over.
74	Smells	Smells, tastes, or licks objects.
75	Scratches	Scratches or picks at her/his skin.
76	Screams	Screams a lot.
77	Sleeps little	Sleeps too little. Disrupted sleep.
78	Stares	Stares at lights or spinning objects.
79	Sleeps too much	Sleeps too much or overly drowsy.
80	Soils	Soils outside toilet though toilet trained. Smears or plays with faeces.
81	Whispers	Speaks in whispers, high pitched voice, or other unusual tone or rhythm.
82	Spits	Spits.
83	Lights	Switches lights on and off, pours water over and over, or similar repetitive activity.
84	Steals	Steals.
85	Stubborn	Stubborn, disobedient or unco-operative.
86	Shy	Shy.
87	Strips	Strips off clothes or throws away clothes.
88	Not capable	Says he/she can do things he/she is not capable of.
89	Stands	Stands too close to others.
90	Hallucinations	Sees, hears, something which isn't there. Hallucinations.
91	Suicide	Talks about or attempts suicide.
92	Talks fast	Talks too much or too fast.
93	Talks to self	Talks to self or imaginary objects.
94	Lies	Tells lies.
95	Thoughts	Thoughts are unconnected. Different ideas are jumbled up together with meaning difficult to follow.
96	Tense	Tense, anxious, worried.
97	Throws	Throws or breaks objects.
98	Manipulates	Tries to manipulate or provoke others.
99	Pain	Underreacts to pain.
100	Elated	Unrealistically happy or elated.
101	Posture	Unusual body movements, posture, or way of walking.
102	Changes	Upset and distressed over small changes in routine or environment.
103	Urinates	Urinates outside toilet, although toilet trained.
104	Bossy	Very bossy.
105	Wanders	Wanders aimlessly.
106	Whines	Whines or complains a lot.