Intellectual Disability and Mental Health Problems

Evaluation of Two Clinical Assessment Instruments, Occurrence of Mental Health Problems and Psychiatric Care Utilisation

BY

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Abstract

It has been suggested that persons with intellectual disabilities (ID) manifest the full range of mental health problems. The main purpose of this thesis is to adapt and evaluate two clinical assessment instruments and to investigate the occurrence of mental health problems as well as psychiatric care utilisation in persons with ID.

The psychometric properties of a Swedish version of the two instruments [Reiss Screen for Maladaptive Behaviour (RSMB) and the Psychopathology Inventory for Mentally Retarded Adults (PIMRA)] were investigated in a random, institutional and clinical sample of administratively defined (ADDEF) adults with ID (n = 199). The analyses suggest that the RSMB could be used as intended by staff as a primary screening device for the identification of mental health problems in persons with ID, and that the PIMRA had a potential to identify individuals with a specific mental disorder. The psychometric evaluation reveals that the Swedish versions of the RSMB and PIMRA measure a construct related to the diagnostic categories in the DSM-III-R and DSM-IV. This construct could be conceptualised as mental health problems.

The RSMB and PIMRA results show that the overall occurrence of mental health problems in ADDEF samples of persons with ID (175 men and 148 women) ranged from 34 to 64%.

The preliminary level of ID was mild (23%), moderate (39%) and severe (38%). The most common mental health problems were aggressive and self-injurious behaviours, depression, anxiety and adjustment disorders. In registered patients receiving out- or in-patient psychiatric care the occurrence of adults with an ICD-10 diagnosis of ID was approximately 1% (70 to 90% had a mild level of ID).

In contrast to the high frequency of mental health problems reported, psychiatric care was used infrequently. This tendency is particularly evident in persons with moderate and severe ID.

Keywords: Intellectual disability, mental health problems, assessment instruments, psychometric evaluation, psychiatric care utilisation

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Hope is the thing with feathers
That perches in the soul
And sings the tune without the words
And never stops at all,

And sweetest in the gale is heard;
And sore must be the storm
That could abash the little bird
That kept so many warm.

I’ve heard it in the chillest land
And on the strangest sea,
Yet never in extremity
It asked a crumb of me.

*Emily Dickinson*

To Ludvig, Estelle, André
and Ulf
List of Papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.


III. Gustafsson, C., Sonnander, K. A psychometric evaluation of the Swedish version of the Psychopathology Inventory for Mentally Retarded Adults (PIMRA). (submitted)

IV. Gustafsson, C., Sonnander, K. Occurrence of mental health problems in Swedish samples of adults with intellectual disabilities. (submitted)
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<tr>
<td>AAMR</td>
<td>American Association on Mental Retardation</td>
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<tr>
<td>ABC</td>
<td>Aberrant Behaviour Checklist</td>
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<td>ADDEF</td>
<td>Administratively defined</td>
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<td>APA</td>
<td>American Psychiatric Association</td>
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<td>DASH</td>
<td>Diagnostic Assessment for the Severely Retarded</td>
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<tr>
<td>DSM-III</td>
<td>Diagnostic and Statistical Manual of mental disorders 3rd edition</td>
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<tr>
<td>DSM-III-R</td>
<td>Diagnostic and Statistical Manual of mental disorders 3rd edition revised</td>
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<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of mental disorders 4th edition</td>
</tr>
<tr>
<td>ICD-8</td>
<td>International Classification of Diseases – 8th revision</td>
</tr>
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<td>ICD-9</td>
<td>International Classification of Diseases – 9th revision</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases – 10th revision</td>
</tr>
<tr>
<td>ICF</td>
<td>The International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICIDH</td>
<td>The International Classification of Impairments, Disabilities and Handicaps</td>
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<tr>
<td>ID</td>
<td>Intellectual Disabilities</td>
</tr>
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<td>IQ</td>
<td>Intelligence Quotient</td>
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<td>MR</td>
<td>Mental Retardation</td>
</tr>
<tr>
<td>PAS-ADD</td>
<td>The Psychiatric Assessment Schedule for Adults with a Developmental Disability</td>
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<td>PCA</td>
<td>Principal Component Analysis</td>
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<tr>
<td>PIMRA</td>
<td>Psychopathology Inventory for Mentally Retarded Adults</td>
</tr>
<tr>
<td>RSMB</td>
<td>Reiss Screen for Maladaptive Behaviour</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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Introduction

The relationship between intellectual disabilities (ID) and mental health problems has been the subject matter of scientific and clinical interest during the past two decades (Bregman, 1991; Matson & Sevin, 1994; Menolascino, 1965; Menolascino, Levitas & Greiner, 1986; Moss, 2001; Philips, 1967; Reid, 1989; Reiss & Benson, 1984; Sovner & Hurley, 1983; Sturmey, 1993; Szymanski & Grossman, 1984).

Moss (2001) stated that the mental health of persons with ID is an issue whose time has come and it has been suggested that the change in perspective concerning ID and mental health issues could be explained in the context of the normalisation process. The ideas of normalisation and integration have entailed a shift in the focus concerning support and services to persons with ID (Nirje, 1969). In Sweden the shift meant a break with the long tradition of institutional care that was replaced by community-based support and access to the services used by the general public. According to Ericsson (2002), this shift can best be characterised as a change from a clinical perspective with a focus on subnormal, deviant characteristics and deficiencies of the individual emanating from the institutional tradition to a citizen perspective emphasising that persons with ID should be entitled to normal life conditions in the community. In the normalisation context the importance of a normal life span is stressed in which it is assumed that persons with ID have the same fundamental human needs as persons without ID throughout their lifespan (i.e. childhood, adulthood and old age) (Grunewald, 1992). This change in perspective is related to the recognition of subjective needs and well-being of persons with ID: it is in this context that mental health issues have been raised. There is international agreement on the need to respond more adequately to mental health problems among persons with ID (Bouras, 1999; Fletcher & Dosen, 1993; Holt et al., 2000; Kebbon, 1993; Linaker, 1994; Stark, Menolascino, Albarelli & Gray, 1988). In Sweden, the legislative changes in 1985 and 1993 (SFS 1985:568; SFS 1993:387) and the subsequent organisational changes concerning support and services to persons with ID have marked a division between community-based special services and general health services. The 1985 Act on Special services for Intellectually Handicapped Persons (SFS 1985:568) and the 1993 Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387) are supplementary to the Act on Social services (SFS 1980:620) and the Act on Health and Medical care
(SFS 1985:570), indicating that a person with ID, as any other citizen, should receive medical services by the ordinary general health care system, including mental health services. Before the legislative change in 1985, persons with ID received medical care within the organisation of the special services.

Because of the complexity in assessing mental health problems in persons with ID, this organisational change has shed light on the need to enhance the competence and knowledge within the professional field and develop the provision of mental health services for persons with ID.

Research on mental health problems in persons with ID has expanded considerably in recent years. This relatively new interest of research could be explained by the way in which the relationship between ID and mental health problems has been conceptualised over the years (Borthwick-Duffy, 1994; Szymanski & Grossman, 1984; Menolascino & Fleisher, 1993). Two perspectives were dominant in the field until the beginning of the 1980s. One perspective states that individuals with ID were incapable of developing mental disorders characterised as mental illness because behaviour disturbances were attributed to the impaired development that characterised the ID. Another perspective was that mental health problems in persons with ID were of a different quality and usually of an “organic” origin and thus untreatable (Borthwick-Duffy, 1994; Szymanski & Grossman, 1984). In the 1980s a third perspective emerged, which asserts that persons with ID display mental health problems of the same kind, and thus should be treated with the same approaches as would mental health disorders among the general population without ID (Bregman, 1991, Eaton & Menolascino, 1982; Holland, 1999; Moss, 2001; Reiss, 1982; Sovner & Hurley, 1983; Szymanski & Grossman, 1984). This third perspective is closely connected to the recognition of subjective needs and well-being of persons with ID. Further, it is related to the development in the 1980s and 1990s of the classification systems of mental and behavioural disorders (APA, 1980, 1994). The current classification systems of mental and behavioural disorders remain mainly descriptive and phenomenological and are largely atheoretical with regard to specific aetiology or pathophysiological processes (Wittchen, 2001). The descriptive approach implies that the definitions of disorders are generally limited to descriptions of the clinical features of the disorders (identifiable behaviour signs or symptoms). The approach of this thesis is based on this third perspective.

It has been suggested that persons with ID manifest the full range of mental health problems and that symptoms of specific mental health disorders are essentially the same for persons with and without ID. However, the presence of cognitive and linguistic limitations in persons with ID is a serious obstacle in the assessment process. Given the complexity with assessment of mental health problems in persons with ID, particularly in persons with moderate and severe ID, there is an obvious need to use third-
party reports and observations as a complement to the traditional clinical psychiatric interview format. It has been reported that instruments designed for completion by informants can provide valuable information in the diagnostic process (Reiss, 1988, 1990; Matson, 1988; Moss, 2001; Sturme, Reed & Corbett, 1991). It is of considerable importance that any instrument that is used in the process of case recognition and as part of a clinical assessment procedure is of high quality. In Sweden, there has not been any published screening or DSM-based diagnostic instruments available for the identification of a broad spectrum of mental health problems in adults with ID.

Epidemiological research on occurrence of mental health problems and ID has been burdened by methodological problems relating to the demarcation and definition of the study population and to the definition of mental health problems in persons with ID. Reported occurrence of mental health problems range from approximately 8% to estimates greater than 50% (Fraser & Nolan, 1994; Borthwick-Duffy, 1994). In Sweden, Göstason (1985) reported on the occurrence of mental health problems in a population-based sample of adults with ID. The occurrence of DSM-III disorders was found to be 52% in persons with ID and 23% in controls in this sample. The occurrence of mental health problems in persons with mild ID was 33%. In persons with severe ID 71% had one or more mental disorders and the diagnoses were predominantly chronic psycho-organic syndromes.

After the legislative changes in 1985 and 1993 (SFS 1985:568; SFS 1993:387) and the organisational changes in the service delivery systems that followed, occurrence of mental health problems in the Swedish ADDEF group of persons with ID (i.e. receiving special services) and the occurrence of adults with ID receiving psychiatric care at general mental health clinics have not been studied systematically. Because of the reported difficulties regarding case recognition and the complexity in assessment of mental health problems, there is a need to investigate if and to what extent persons with ID have access to the general mental health services in Sweden. It is important that this vulnerable group receive assessment and adequate treatment and care according to their specific needs.

The definition of ID

ID is described as an arrest of the intellectual development, a condition that affects the brain during the developmental years (Gustavsson, 1997). The ID involves an impaired ability to arrange and rearrange, understand and remember experiences and symbols, which leads to an inferior cognitive ability. There are no specific personality and behavioural features that are uniquely associated with ID (APA, 1994).
More severe levels of ID tend to be recognised quite early in life, especially when associated with a syndrome with a characteristic phenotype (e.g., Down’s syndrome), whereas mild levels of ID of unknown origin generally are noticed later in life, typically in the school years.

ID is not a static disorder or a disease in itself but rather a dynamic condition with multiple aetiologies. Thus, the implication is that there is no single cause, mechanism, clinical course or prognosis in ID (Harris, 1995). According to Harris (1995), thoughts are not characteristically disordered and perception is not distorted in ID unless there is a concurrent mental disorder. However, the cognitive limitations associated with ID are a complex issue related to the multiple aetiologies of ID (i.e. with different effects on brain structure and function) leading to differences across syndromes and thus most likely have consequences for the neuropsychological functioning in the individual case (Mervis, 2001).

Intelligence is explained as a general mental capability involving reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly and learning from experience (Luckasson et al., 2002). IQ scores obtained from appropriate standardised intelligence tests represent intellectual functioning. After taking into consideration the standard error of measurement for the specific intelligence tests used and the tests’ strengths and limitations, the criterion for diagnosis is an individual score approximately two standard deviations below the population mean score. The psychometric definition of ID is based on the assumption that mental ability is normally distributed when culturally relevant test items of varying difficulty are administered to a large representative population. When only the psychometric criterion of IQ ≤ 70 is considered, the prevalence of ID will be around 2% of the population (Sonnander, Emanuelsson & Kebbon, 1993).

Before the development of intelligence tests there was no way to diagnose ID. At the beginning of the 20th century the concept of intellectual functioning, or IQ, was the dominant criterion for diagnosing ID (Detterman, Gabriel & Ruthsatz, 2000). Persons with ID were thought incapable of learning or acquiring other more complex cognitive skills. Research focused on cognitive deficiency and models from other areas of psychology were applied to persons with ID in an attempt to discover the underlying process responsible for ID. The two major areas that were focused on concerned memory and attention. Research suggested though that with training persons with ID could perform many tasks necessary for everyday living. Because of these findings, greater emphasis was placed on adaptive behaviour, which was considered as a criterion of ID in the beginning of the 1960s, though IQ was still considered the primary criterion.

The adaptive criterion of ID is related to social or adaptive functioning that should be assessed in relation to the individual’s background, cultural group and age. Adaptive ability has been defined as the effectiveness or
degree with which an individual meets the standards of personal independence and social responsibility expected for his age and cultural group (Grossman, 1983, Luckason, et al., 1992).

There is variation in reported studies on prevalence of ID in which criteria that should be emphasised when identifying the condition (Borthwick-Duffy, 1994). There has also been variation because of different definitions concerning the range of the upper IQ limit from a level of 70-75 to a level of 85 (Detterman, et al., 2000). Thus, it can be expected that the lack of a standardised definition over time has led to dissimilar study groups and, consequently, influenced the estimates on the number of persons with ID.

In a medical perspective ID is primarily a consequence of some kind of biological defect. The causes of ID have been classified into five main groups according to the predominating aetiological factor: (1) prenatal (before delivery), (2) perinatal (during or within 7 days after delivery), (3) postnatal (more than 7 days after delivery; before the age of 18 years), (4) psychotic group, and (5) untraceable aetiology (Gustavsson, Hagberg & Sars, 1977). The causes of ID are extremely heterogeneous and it has been estimated that approximately half of all cases with ID is due to genetic factors while the other half is due to environmental factors. According to Winnepenninckx, Rooms and Kooy (2003),

... “environmental factors include prenatal exposure of the foetus to toxic substances (e.g., alcohol, drugs), environmental contaminants, radiation, infection, malnutrition, illness of the mother (e.g., exposure to rubella, cytomegalovirus), etc. In addition, multiple problems during or after birth may cause brain damage, especially premature birth and low birth weight may predict mental retardation (MR). During childhood factors such as disease (e.g., measles), blow on the head, environmental toxins, etc., may cause irreparable damage to the brain and nervous system. Genetic factors include chromosome abnormalities, monogenetic disorders and polygenic factors.” (p. 29)

In about two thirds of cases a specific cause can be identified. The more severe the degree of ID, the greater the likelihood that the cause will be identified (Harris, 1995). It has been reported that there are about 1000 genetic causes of ID (Dykens, 1995).

Definition of ID according to classification systems
Classification systems categorise various kinds of observations into an organised schema. They are essential in the acquisition of knowledge in enhancing communication among clinicians and researchers and could be used as a component in determining eligibility for services.

The major classification systems of relevance to the field of ID are the International Statistical Classification of Diseases and Related Health
Problems (ICD-10; WHO, 1992), Diagnostic and statistical manual: mental disorders (DSM-IV; APA, 1994), Mental Retardation: definition, classification and systems of supports — 10th ed. (AAMR; Luckasson, et al., 2002), and The International Classification of functioning, disability and health (ICF; WHO, 2001). The ICD-10 (WHO, 1992), DSM-IV (APA, 1994) and the AAMR (Luckasson, et al., 2002) criteria included in the definition of ID are presented in Table 1.

Table 1. Diagnostic criteria for MR.

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<th>ICD-10</th>
<th>DSM-IV</th>
<th>AAMR</th>
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<tr>
<td>Adaptive function</td>
<td>Impairment in present adaptive</td>
<td>Concurrent impairment in</td>
<td>Limitations in present</td>
</tr>
<tr>
<td></td>
<td>functioning</td>
<td>present adaptive functioning</td>
<td>functioning</td>
</tr>
<tr>
<td>Intelligence</td>
<td>IQ of approximately 70 or below on</td>
<td>IQ of approximately 70 or</td>
<td>IQ of approximately 70-</td>
</tr>
<tr>
<td>quotient</td>
<td>individually administered tests</td>
<td>below on individually</td>
<td>75 on individually</td>
</tr>
<tr>
<td></td>
<td>Onset before age 18</td>
<td>Onset before age 18</td>
<td>administered tests</td>
</tr>
<tr>
<td>Level of MR</td>
<td>Mild, moderate, severe, profound</td>
<td>Mild, moderate, severe, profound</td>
<td>Rather than levels, categories</td>
</tr>
<tr>
<td></td>
<td>Onset before age 18</td>
<td></td>
<td>of support needs are</td>
</tr>
<tr>
<td></td>
<td>Onset before age 18</td>
<td></td>
<td>designated</td>
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ICD-10 and DSM-IV definitions of ID

The ICD-10 is the international system used for identifying diseases and physical conditions and includes codes for the various levels of ID. Although the DSM-IV classification system includes definitions and codes for levels of ID, it is primarily used to classify a wide variety of mental disorders.

The term MR is used in the ICD-10 and the DSM-IV systems and has the same connotation as the term Intellectual Disability: an intellectual and adaptive behaviour disability that begins in early life during the developmental period before the individual reaches 18 years of age.

Although both the ICD-10 and DSM-IV definitions of ID include classification by IQ scores and adaptive function, each provides a different emphasis. The ICD-10 lists MR as a disorder of psychological development and has a somewhat more extended approach than the DSM-IV in elaboration of the intelligence concept. The ICD-10 definition states that:
“MR is a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period contributing to the overall level of intelligence, i.e., cognitive, language, motor and social abilities”. (Harris, 1995, p. 96)

This view implies that intelligence is not a unitary function but should be assessed on the basis of a large number of different more or less specific skills. The scatter in abilities suggests that there are complications in the evaluation of which subgroup of level of MR (i.e. mild, moderate, severe and profound) a person should be placed. IQ levels should be provided as a guide but cannot be applied rigidly because they are divisions of a complex continuum, one that is difficult to define with absolute precision.

The DSM-IV definition emphasises adaptive functioning as an important diagnostic criterion equal to the IQ score and has adopted the criterion of significant limitations in 2 of the 10 adaptive skills areas introduced in the 1992 AAMR classification system (Luckasson, et al., 1992, 2002).

The AAMR definition
The American Association on Mental Retardation (AAMR) has had an important role in the field on definition and classification of MR and have subsequently been adopted in large part by other classification systems (Luckasson, et al., 2002).

The 1992 and 2002 AAMR classification systems are based on the intensities of needed supports. The levels of ID based on IQ scores were dropped for several reasons (i.e. ID relies on both limitations in IQ and adaptive skills, but the level of severity was based only on IQ). Thus, irrespective of an individual IQ level, needs in specified areas were classified as intermittent, limited, extensive or pervasive and the 1992 classification reflected a shift toward a functional definition of ID. The AAMR 2002 system has adopted a multidimensional model of ID, including five interrelated dimensions: Intellectual Abilities (dimension I); Adaptive behaviour (dimension II); Participation, Interactions and Social Roles (dimension III); Health, (dimension IV); and Context (dimension V). The AAMR’s theoretical model has been regarded as compatible with the ICF process model of disability (Luckasson, et al., 2002).

The ICF classification
The International Classification of Functioning, Disability and Health (ICF; WHO, 2001) is a revised version of the International Classification of Impairments, Disabilities and Handicaps (ICIDH; WHO, 1980). The ICF system is primarily a general conceptual tool for creating models of disability.

As a classification instrument the ICF is complementary to the ICD-10 classification of health conditions, diseases and disorders. However, the ICF
extends beyond the medical perspective in that it includes a societal and environmental perspective (Luckasson, et al., 2002). This system classifies functioning in terms of Body Functions and Structures, Activities, Participation and Contextual Factors and conceives functioning as an interactive person-environment process.

“It should be noted that the ICF model allows for many different patterns and directions of interactions. This is an important aspect of the conception of disability: a disability can never be explained by the mere presence of a primary impairment (e.g., significant limitations in intellectual functioning) and should always be understood within a frame of physiological and psychological as well as social and societal conditions, both past and present. Appropriate supports in any of three dimensions can influence the state of functioning of an individual and, hence the nature and degree of disability.” (Luckasson, et al., 2002, p. 105).

The ICF classification provides a frame of reference for the description of human functioning in relation to health conditions, (according to the WHO definition of health as comprising physical, psychological and social well-being not just the absence of disease). However, the ICF can be used without reference to a clearly identified disease or aetiology (Luckasson, et al., 2002).

**A Swedish model for classification**

In Sweden, Kylén (1974, 1981, and 1985) described and classified ID as a combination of biological age, intelligence and social ability. During the maturation process the capacity for abstract thinking develops in interaction between biologic maturation and environmental influences. This classification model is based on cognitive and psychodynamic theories (e.g. Piaget, 1971; Rapaport, 1963). Kylén has described three levels of cognitive functioning related to ID according to this model, which are briefly presented below.

- **A (severe):** a limited perspective of time and space, where acting and thinking are related to present time and the ability to talk is non-existent. Communication is related to signals and to some extent signs.

- **B (moderate):** can take an interest in the close surroundings and can speak and understand pictures as symbols. The ability of cognitive structure of thoughts in relation to individual experiences has been developed. Comprehension of time and the understanding of abstract concepts remain limited, however.

- **C (mild):** can learn to read and write and perform simple calculations. The ability to rearrange, structure and perform concrete cognitive operations
has been developed. Have difficulties in managing multifactorial problems.

Kylén (1974, 1981) has presented a comparison between the A-B-C model for classification of level of ID with the WHO standard classification, (Table 2).

Table 2. Level of ID according to the WHO classification, IQ scores and to the Swedish classification model of Kylén (1974, 1981).

<table>
<thead>
<tr>
<th>A-B-C (Kylén)</th>
<th>A</th>
<th>B</th>
<th>C</th>
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</thead>
<tbody>
<tr>
<td>IQ</td>
<td>10</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>WHO</td>
<td>Profound</td>
<td>Severe</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

**Administrative definition**

The administrative definition includes all persons that are receiving special services. Persons entitled to special services are persons with significant limitations in intellectual functioning, concurrent with and related to significant limitations in adaptive behaviour manifested during the developmental period. Administratively, there are cultural and historical differences related to attitudes, practices, and allocation of resources in the judgement of who should be eligible for services (Sonnander, et al. 1993).

Over the last 50 years, persons with ID in Sweden have been entitled to receive special services according to a special Act. This act has been transformed over the years. The number of individuals in Sweden ADDEF with ID across all age groups has been reported to be approximately 0.4% of the total population; an estimated majority (i.e. 75%) of those individuals have a moderate or severe ID (Grunewald, 1979, 1997). Compared with the number of ADDEF individuals reported in other countries, this is a small figure. In the US between 1 and 3% have been reported to be ADDEF and 75% were estimated to have a mild level of ID (Cooke, 1981; Grossman, 1983; Zigler, Balla & Hodapp, 1984).

**Mental health problems in persons with ID**

The definition of mental health versus mental illness is a fundamental issue in the discussion of the mental health of persons with ID. Dosen (1993) points to the subjective experiences of individuals with ID and states that feelings of satisfaction and happiness, basic components of mental health,
Menolascino (1988) stresses that basic human needs like social acceptance, social relationships and positive affection are elements of mental health important for persons with or without ID.

The behavioural and psychiatric research approaches have made separate but significant contributions concerning the definition of abnormal behaviours shown by persons with ID (Moss, 1999; Moss, 2001).

“In the broadest terms, psychiatric assessment is concerned with identifying patterns of symptoms and their clinical history and matching these patterns with those of previously defined disorders, such as depression and schizophrenia. In a behavioural formulation, on the other hand, the primary focus is on the behaviours themselves rather than on identifying an underlying psychopathology, which is thought to drive these behaviours. There is no hard fast boundary between the two approaches. Nevertheless, the differences are significant and likely to colour our view of what constitutes a mental health problem” (Moss, 2001, p. 212).

In the psychiatric approach the locus of the problem is conceptualised as being essentially within the individual. Using the behavioural approach, a behavioural analysis might indicate that the problem stems from a history of inappropriate learning and is being maintained by the responses of the people around the individual.

The terms maladaptive behaviour, behaviour disorder and challenging behaviours are often used interchangeably in research on ID and mental health problems. Emerson (1995) defined challenging behaviour as “culturally abnormal 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 serious limit use of, or result in the person being denied access to, ordinary community facilities” (cited in Moss, 2001, p. 212). In this view challenging behaviours are a social construction defined by their social impact.

According to DSM-IV the definition of mental disorder is as follows:

“Each mental disorder if conceptualised as a clinically significant behavioural or psychological syndrome or pattern that occurs in a person and thus is associated with present distress (a painful symptom) or disability (impairment in one or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability or an important loss of freedom. In addition, this syndrome or pattern must not be merely an expectable response to a particular event, e.g., the death of a loved one. Whatever, its original cause, it must currently be considered a manifestation of a behavioural, psychological or biological dysfunction in the person. Neither, deviant behaviour (political, religious or sexual) nor conflicts that are primarily between the individual and the society are mental disorders unless the deviance or conflict is a symptom of dysfunction in the person as described above. There is no assumption that each mental disorder is a
discrete entity with sharp boundaries (discontinuity between it) and other mental disorders or between it and no mental disorder”. (APA, 1994).

The current classification systems for mental disorders are largely atheoretical regarding specific aetiology or pathophysiological processes (Wittchen, 2001). Kendell (2001) states that because understanding of the aetiology of most psychiatric disorders is still rudimentary they still have to be defined by their clinical syndromes. By the use of operationalised definitions the mental disorders are grouped into diagnostic classes. However, Kendell (2001) argues that because psychiatric syndromes appear to merge into one another or into normality with no point of rarity in between, minor changes in the definitions may result in a change of diagnosis. This, in turn, will have an influence both on surveys of prevalence and in clinical practice. The DSM-IV (APA, 1994) states under the heading of MR and associated descriptive features and mental disorders that all types of mental disorders may be seen in persons with ID, and there is no evidence that the nature of a given mental disorder is different in individuals with ID. However, the diagnosis of comorbid mental disorders is often complicated by the fact that the clinical presentation may be modified by the severity of the ID and associated handicaps.

At present there is no consensus regarding which problems to include in the term “mental health problem” when applied to persons with ID. Clinical experience indicates that the existing diagnostic systems of DSM-IV and ICD-10 are not fully compatible concerning diagnostics of mental disorders in persons with ID, which may explain why the evidence-based knowledge on the assessment and diagnosis of mental health problems in this area is still scarce (Deb, Matthews, Holt & Bouras, 2001). Moss (1999), reasons that even if many problem behaviours are not diagnosable within existing psychiatric classification systems, it does not imply that they are not symptoms of mental illness; rather, it could be that the classification systems themselves are only of limited application to this particular population.

In the research on mental health problems the difficulties to apply the DSM or ICD criteria if the person has a severe and profound ID have been highlighted, but at present the knowledge in the field is insufficient to develop new algorithms (Moss, 2001; Sovner, 1986; Sturmey, 1993).

Diagnostic assessment of mental health problems in adults with ID

The diagnostic assessment in persons with ID is a complicated process and issues particularly related to this process have been reported and discussed (Sovner, 1986). *Intellectual distortion* refers to concrete thinking and impaired communication skills that will influence the clinical interview.
Psychosocial masking refers to impoverished social skills and life experiences, which could lead to an “unsophisticated” or atypical presentation of a mental disorder. Cognitive disintegration refers to stress-induced disruption of information processing that could present as bizarre behaviours. Baseline exaggeration refers to a general increase in pre-existing cognitive deficits and maladaptive behaviours.

It has been stressed that because of the difficulties to distinguish between signs and symptoms that could be the expression of underlying brain damage (e.g. excessive agitation, lack of concentration, stereotyped movement disorders and abnormal sleep) it is important to establish a baseline and to look for changes in relation to the habitual condition (Deb, Matthews, et al., 2001).

Given the difficulties with symptom identification and the assessment of mental health problems in persons with ID, there has been a focus on the development of assessment schedules over the past 15 to 20 years (Moss 1999; 2001; Russell, 1997; Sturmey, et al., 1991). There is a need for instruments and methods that could be used in the diagnostic assessment process to obtain systematic information from relatives or care staff with limited training in the mental health field.

The Reiss Screen for Maladaptive Behaviour (RSMB; Reiss, 1988), the Psychopathology Inventory for Mentally Retarded Adults (PIMRA; Matson, 1988) and the Diagnostic Assessment for the Severely Retarded (DASH) scale (Matson, Gardner, Coe & Sovner, 1991) are instruments designed to detect a broad spectrum of mental health problems in adults with ID.

The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD; Moss et al., 1993; Moss, Prosser, & Goldberg, 1996), the Mini PAS-ADD (Prosser et al., 1998) and the PAS-ADD Checklist (Moss, et al., 1998) have recently been developed for screening and diagnostics of mental health problems in adults with ID. The PAS-ADD instruments were designed to provide a flow of information from carers, through support staff to the psychiatrist and psychologists responsible for making diagnostic assessments (Moss, 2001).

In addition, schedules specifically designed to assess depression have been adapted. Kazdin, Matson and Senatore (1983), for instance, adapted the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the Zung Self-Rating Depression Scale (Zung, 1965) for use with persons with ID. Meins (1993) reported that the Children’s Depression Inventory (CDI; Kovacs, 1985) in the informant-rating version was applicable as a diagnostic and screening instrument for adults with ID.

The RSMB and the PIMRA were two of the first published and standardised instruments that identified a broad spectrum of mental health problems and maladaptive behaviours in persons with ID (Moss, 2001; Sturmey, et al., 1991). The RSMB was predominantly designed for screening and the PIMRA, which is constructed in relation to specific DSM-
III diagnostic categories, was developed for diagnostic purposes. The RSMB and the PIMRA were the only published screening instruments available when the present research project was initiated. The instruments will not be presented in the appendix of this thesis because of the regulations concerning copyright, but will be described in the following section. The author refers further to the published test manuals (Reiss, 1988; Matson, 1988).

RSMB

The RSMB is a screening instrument designed to measure the likelihood that an adolescent or an adult with ID has a significant mental health problem. Each item describes a symptom of one or more mental health disorders listed in the DSM-III-R (Reiss, 1990). The RSMB is intended to be used by non-professionals, who know the individual to be assessed well. However, the constructor stresses, “all decisions regarding treatment needs, placement and diagnosis should be made by qualified professionals who have conducted a comprehensive evaluation of the individual’s needs” (Reiss, 1988, p. 22).

A Principal Component Analysis (PCA) of the original version based on 26 items yielded seven components classified into seven subscales, each including five items: aggressive behaviour, psychosis, paranoia, depression - behavioural signs (b), depression - physical signs (p), dependent personality disorder and avoidant personality disorder. Nine items were doubled, i.e. assigned to two subscales (Reiss, 1988). More recently a confirmatory factor analysis was conducted indicating factor robustness (Havercamp & Reiss, 1997).

A system of cut-off scores yields a positive or a negative test result. The validity of the cut-off scores was evaluated in a blind test procedure involving clinical assessments 6 to 12 months post screening (Reiss, 1990). The results showed that 86.7% of the positives had mental health problems while 58.6% of the negatives were found to be without mental health problems. Difference in subscale score was related to psychiatric diagnoses obtained from individual case files, i.e. persons with a diagnosis of psychosis scored significantly higher on the psychosis subscale than did persons with a diagnosis of aggressive or affective disorder (Reiss, 1988).

RSMB was the first published standardised screening instrument with normative data and has been used both in clinical practice and in research (Havercamp & Reiss, 1997; Minnen, Savelsberg & Hoogduin, 1995; Rojahn & Warren, 1994; Sturmey & Bertman, 1994; Sturmey, Burcham, & Perkins, 1995; Walsh & Shenouda, 1999).

PIMRA

The PIMRA was designed to help mental health professionals diagnose specific mental health problems in persons with ID. The PIMRA includes 56
items and the item content is mainly derived from the major diagnostic categories schizophrenia, affective, psychosexual adjustment, anxiety somatoform and personality disorders in the DSM-III (APA, 1980). Items relating to key features of each diagnosis are included and stated in a manner relevant for persons with ID. PIMRA is available in two versions: one informant and one self-report form (the latter is recommended only when the person has mild ID). Both versions should be used in the format of an interview.

The PIMRA was developed in the US and has previously been translated into other languages and evaluated in several countries including New Zealand (Aman, Watson, Singh, Turbott & Wilsher, 1986), Great Britain (Sturmey & Ley, 1990), Norway (Linaker & Nitter, 1990; Linaker, 1991; Linaker & Helle, 1994), The Netherlands (Minnen, Savelberg & Hoogduin, 1994) and Italy (Balboni, Battagliese & Pedrabissi, 2000).

In the original study Matson, Kazdin and Senatore (1984), reported that both versions of the instrument demonstrated acceptable levels of internal consistency and test-retest reliability. A factor analysis yielded three factors for the informant version (affective disorder, somatoform disorder and psychosis) and two factors for the self-report version (anxiety and social adjustment).

The instrument has been evaluated in several studies. Most of the research performed has used the informant version. In all but one study (Balboni, et al., 2000) relatively small samples have been included when evaluating the psychometric properties of the PIMRA (sample size range: 24-168 persons). A majority of these studies have reported acceptable levels of internal consistency and low to moderate inter-rater reliabilities (Iverson & Fox, 1989; Linaker & Nitter, 1990; Linaker, 1991; Minnen, et al., 1994; Sturmey & Ley, 1990). Criterion validity has been assessed and reported regarding the psychosis and affective disorder subscales (Swiezy, Matson Kirkpatrick-Sanchez & Williams, 1995; Linaker & Helle, 1994).

Epidemiology of mental health problems among adults with ID

Several studies have shown that persons with ID manifest the full range of mental health problems and are more frequently afflicted in comparison with the general population. The reported mean frequency of mental health problems is approximately two to three times greater for persons with ID than for the general population (Borthwick-Duffy, 1994). However, the reported proportions among ADDEF samples of adults with ID range from less than 10% to more than 80%. This large variation may be an effect of the sampling procedures and assessment methods used. For example, according
to Fraser and Nolan (1994), the occurrence of major mental health problems, including both personality disorders and psychotic disorders, range from approximately 8 to 15%. When minor emotional or behaviour disorders are included, estimates greater than 50% have been reported (Borthwick-Duffy, 1994).

Different theoretical approaches have been used to explain the increased occurrence of mental health problems in the ID population (Dosen, 1993). These theories emphasise specific biological (neurological, biochemical, genetic etc), social (family interactions, cultural and other environmental variables) and psychological (cognitive development and personality variables) factors as possible explanations for the onset of mental health problems in individuals with ID.

Conflicting results have been reported concerning the occurrence of mental health problems in different age groups of adults with ID. This problem is probably due to the different research methods employed (Cooper, 1997; Corbett, 1979; Day, 1985; Deb, Thomas & Bright, 2001a; Janicki, et al., 2002; Haveman, Maaskant, Van Shrofenstein Lantman, Urlings & Kessels, 1994; Lund, 1985; Patel, Goldberg & Moss, 1993). The overall presence of mental health problems in persons with ID seems to be unrelated to gender (Borthwick-Duffy, 1994). Studies that compare the occurrence of mental health problems in persons with mild versus severe ID have not yielded consistent results (Borthwick-Duffy & Eyman, 1990; Göstason, 1985; Iverson & Fox, 1989; Jacobsen, 1982; Lund, 1985).

Overall, the majority of studies investigating the occurrence of mental health problems in adults with ID have used cross-sectional designs. However, a few longitudinal studies have been conducted. Tonge & Einfeld (2000), for instance, reported on the persistence of mental health problems over a period of 4 years in young people with ID. Thompson and Reid (2002) reported that behavioural symptomatology was persistent over a 26-year period in a cohort of adults with severe and profound ID.

Changes over time with respect to behaviour problems following transition from institutions to community living have been examined extensively (Donnelly, et al., 1996; Kim, Larson & Lakin, 2001; Nötttestad & Linaker, 2001; Saloviita, 2002; Stancliffe, Hayden, Larson & Lakin, 2002). The results are contradictory as to a decrease or increase in behaviour problems, but often showed that there was an improvement in adaptive behaviour.

Most studies describe ADDEF samples of adults with ID (i.e. receiving special services). Only a few population-based samples that have included adults or children are published (e.g. Gillberg, Persson, Grufman & Themner, 1986; Göstason, 1985; Rutter, 1976).

Reports of mental health problems in clinical samples of persons with ID frequently describe ADDEF samples referred for psychiatric assessment and treatment offered by the special services. Only a few studies have reported
the occurrence of adults with ID receiving psychiatric treatment and care by
the general mental health services (Dorn & Prout, 1993; Jacobsen &
Ackerman, 1988; Windle, Poppen, Thompson & Marvelle, 1988).

Some studies employ instruments designed to help health and social
service staff identify mental health problems among the persons for whom
they care. In the US the RSMB (Reiss, 1988) have been used in research on
occurrence of mental health problems among randomised samples of
ADDEF adults with ID (Reiss, 1990; Sturmey, Burcham & Shaw, 1996).
The occurrence of mental health problems using the informant version of the
PIMRA has been reported in one randomised ADDEF sample in the US
(Iverson & Fox, 1989) and one institutional sample of adults with ID in
Norway (Linaker & Nitter, 1990). A modified informant version of the
PIMRA was used in a UK study on mental health problems in a referred
sample of adults with ID (Bouras & Drummond, 1992).

A set of instruments that include a semi-structured guide for psychiatric
interviewing of persons with ID and their informants (i.e. the Psychiatric
Assessment Schedules for Adults with Developmental Disabilities; PASS-
ADD; Moss, et al., 1996; Moss et al., 1998; Prosser et al., 1998), has been
used in more recent studies (Deb, et al., 2001a; Roy, Martin & Wells, 1997).

Reported occurrence of mental health problems and maladaptive
behaviour

Reported overall occurrence of mental health problems in studies using the
RSMB or other maladaptive behaviour scales in ADDEF samples of adults
with ID ranges from 35 to 64% (Deb et al., 2001b; Lund, 1986; Reiss, 1990;
Smith, Branford, Collacott, Cooper & McGrother, 1996; Sturmey et al.,
1996). Studies using the PIMRA or other diagnostic scales report
percentages that range from 22 to 91% (Deb et al., 2001a; Iverson & Fox,

The samples included represent four community (Deb, Thomas & Bright,
2001ab; Reiss, 1990; Roy, et al., 1997; Sturmey, et al., 1996), one
institutional (Linaker & Nitter, 1990) and three combined samples (Iverson
& Fox, 1989; Lund, 1986; Smith, et al., 1996). The proportions according to
level of ID vary across the samples included. Linaker and Nitter (1990)
reported that the proportion of persons with mild ID was 4% and Smith et al.
(1996) reported a proportion of 12% (mild ID). In the other studies the
reported proportions of persons with mild ID ranged from 28 to 60%
(median = 46%) (Deb, et al., 2001ab; Iverson & Fox, 1989; Lund, 1986;
Reported occurrence of mental disorders

The reported point prevalence of DSM or ICD mental disorders (APA, 1994; 1987; 1980; WHO, 1992; 1978; 1971) in ADDEF samples of adults with ID range from 15 to 80% (Deb et al., 2001a; Ballinger, Ballinger, Reid, & McQueen, 1991; Cooper, 1997; Corbett, 1979; Crews, Bonaventura, & Rowe, 1994; Göstason, 1985; Lund, 1985).

The total percentage of psychotic, affective and anxiety disorders (functional psychiatric disorders) range from 7 to 23% among the studies included in the comparison. However, when any mental disorder or behaviour disorder has been included, the reported percentages were often more than doubled compared with the reported percentages that included only the functional psychiatric classifications.

The results reported by Cooper (1997), Corbet (1979), Göstason (1985) and Lund (1985) show that the distributions of psychotic and affective disorders are comparable across samples including approximately 50% of adults with severe and profound levels of ID. The reported proportions of psychotic disorders ranged from 2.7 to 6.3% and affective disorders ranged from 1.7 to 4.1%. Deb et al. (2001a) found proportions of psychotic and affective disorders within the same range in persons with mild and moderate ID.

Two institutional samples of persons with predominantly moderate, severe and profound levels of ID reported a slightly higher percentage of persons with a psychotic or an affective disorder (Ballinger, et al., 1991; Crews, et al., 1994). The reported results concerning anxiety-related (neurotic) disorders show a wide discrepancy (range = 0.6 - 16.4%) between the studies included in the comparison.

Frequency of psychopharmacological treatment of mental health problems among adults with ID

Psychotropic drugs, especially neuroleptics, are a common treatment used in behaviour problems in persons with ID and are often prescribed by primary care doctors (Ahmed et al., 2000; Wresell, Tyrer & Berney, 1990). It has been reported that 25 - 50% of persons with ID receive psychotropic drugs (Aman, Sarphare & Burrow, 1995; Göstason, 1985; Intagliata & Rink, 1985; Linaker, 1990; Lund, 1986; Reid & Ballinger, 1987; Spreat, Conroy & Jones, 1997). The higher percentages have largely been found in adults living in residential institutions.

Reported percentages of prescribed antipsychotic medication in ADDEF individuals with ID have ranged from approximately 15 to 49% (Aman, et al., 1995; Linaker, 1990; Lund, 1986; Spreat, et al., 1997; Stone, Alvarez, Ellman, Hom & White, 1989). Göstason (1985) showed that the frequency
of persons receiving antipsychotic medication was significantly higher in persons with severe (28%) and mild ID (14%) than in a control group of persons without ID (2%).

There is a lack of consensus regarding the use of psychotropic drugs in the control of aggressive, hyperactivity and stereotypical behaviour in the absence of mental illness (Santosh & Baird, 1999). The use of standard antipsychotics for treatment of chronic challenging behaviours has not shown any specific effect in the absence of a psychotic disorder (Verhoeven & Tuinier, 1999). Santosh and Baird (1999) argue that the potential side effects (e.g. tardive dyskinesia and neuroleptic malignant syndrome) make the use of these drugs controversial. Thus, further studies on newer atypical antipsychotics (e.g. risperidone and clozapine) are needed before it is possible to conclude that they may be of benefit. In addition, it has been noted that the use of antipsychotic drugs could further decrease the learning and cognitive performance in persons with ID (Sprague & Werry, 1971).

Organisation of services

Special services
The first Swedish legislation regulating services to all persons with ID was implemented in 1954. This legislation placed the main responsibility for persons with ID on the Board of Provisions of Services for the Mentally Retarded, a county council agency (Ericsson, 2002). Organisations providing support for the general population were exempted from responsibility for persons with ID. The county council authority identified and registered all persons with ID in order to channel support to the group regulated by the Act. The special services that provided for education and care were mainly institutionally based. Many persons with ID were also cared for in psychiatric institutions at this time and until the mid-1970s a series of new residential institutions was built throughout Sweden (in general one in each county).

The Social Services Act in 1980 (SFS 1980:620) marked a shift in that the basic principles of non-compulsory support and the option to avail for services were applied even to persons with a disability. With the elimination of compulsory measures in the 1980 Social Services Act, the residential institutions were no longer recognised as a service for persons with ID in the 1985 Act (SFS 1985:568) on special services (Ericsson, 2002).

The 1985 Act and the 1993 Act on special services (SFS 1985:568 and SFS 1993:387) are supplementary to the Act on Social Services (SFS 1980:620) and the Act on Health and Medical care (SFS 1985:570). This implies that persons with ID could avail for the ordinary social services in
addition to some specified special services and should be entitled to the same medical services of other citizens from the ordinary general health care system. This also includes mental health services.

Persons with a disability find themselves in a borderland between the social services and the health care system. Consequently, there is a risk that they fall between these systems when they apply for support because of the complexity of needs and the difficulties with the implementation of the 1985 Act and the 1993 Act on special services (SFS 1985:568 and SFS 1993:387) (Lewin, 1998).

One of the 10 categories of special support regulated by the Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387) includes “advice and assistance.” This primarily refers to various paramedical support measures within the health and medical care systems. Persons with ID who need advice and assistance or psychological treatment have the opportunity to get help by professionals with special knowledge in the field at the habilitation specialist services (usually habilitation centres run by the county councils). The treatment and care delivered by the habilitation specialist services are outside the scope of this thesis.

Mental health services

The provision of mental health services to persons with ID is an area of interest following the reported high prevalence figures of mental health problems. Before the legislative change in Sweden in 1985, all services including medical services provided by the special service system for persons with ID were comparable to those in many other countries. After the legislative change in 1985, medical services for persons with ID, including mental health services were to be provided by the general health care system.

A few European countries (e.g., the UK and the Netherlands) established specialist training in psychiatry related to ID in combination with provisions for specialist psychiatric services to persons with ID (Russell, 1997; Jacobson, 1999). Individuals with ID and mental health problems present unique challenges to the service delivery systems (i.e. special and mental health services) (Fletcher, 1993). Menolascino (1988) argues that persons with ID comprise a complex population whose needs are often poorly identified and who are often referred from one agency to another in a fruitless effort to obtain adequate mental health services. There is also a potential risk that these persons fall between the cracks in the delivery service systems because neither system wants to take responsibility for their care and treatment (Fletcher, 1988). One problem is the bureaucratic systemic boundaries, which means that access to the delivery system, either in mental health or special services, is based on diagnostic criteria.
In Sweden the legislation and service system characteristics necessitates studies concerning psychiatric care utilisation among persons with ID. The quoted prevalence of mental health problems varies widely and there is a need of further studies using standardised assessment instruments in defined samples of adults with ID.
Aims of the Thesis

The general aims of the present thesis were threefold: (a) to adapt and evaluate a Swedish version of two standardised instruments (RSMB and PIMRA) designed for identifying a broad spectrum of maladaptive behaviours and mental health problems in persons with ID, (b) to investigate the occurrence of mental health problems in Swedish samples of adults with ID and (c) to investigate utilisation of psychiatric care in adults with ID.

Specific objectives were:

- to investigate the occurrence of ADDEF adults with ID that were admitted to in-patient psychiatric care in one Swedish county (*Paper I*).

- to evaluate the inter-rater agreement and internal consistency of a Swedish version of the RSMB in a random sample, and to assess the criterion validity in a randomly selected sub-sample and a clinical group of ADDEF adults with ID (*Paper II*).

- to evaluate the internal consistency, inter-rater reliability and concurrent and criterion validity of the Swedish version of PIMRA in an institutional and clinical sample of ADDEF adults with ID (*Paper III*).

- to investigate the occurrence of mental health problems by using screening and diagnostic assessment instruments in Swedish ADDEF samples of adults with ID (*Paper IV*).

- to investigate the occurrence of adults with a registered diagnosis of ID among patients receiving in- and out-patient care in general mental health clinics in Sweden (*Papers I and IV*).

- to investigate the frequency of psychopharmacological treatment in a random, institutional and clinical sample of ADDEF adults with ID (*Papers II and III*).
Method

Research participants

Totally 329 persons with ID gave their informed consent to participate in the studies (*Papers II, III and IV*). Six persons were excluded because of incomplete research data. Thus, the study groups included 323 persons with ID (175 men and 148 women) between 18 and 94 years old. The distribution of preliminary level of ID indicated that 23% (n = 76) of the persons had mild ID, 39% (n = 125) had moderate ID and 38% (n = 122) had severe ID. Sample sizes and their overlap are displayed in Figure 1.

Figure 1. Sample sizes and their overlap in Papers (*II, III, IV*). The number of individuals in each study is given in brackets.
Samples
A random sample of 200 adults with ID was drawn from the total population of ADDEF adults with ID (n = 650) in one county (A) (Papers II and IV). Of this sample of 200 adults, 35 declined to participate, 22 did not respond and 3 were recently deceased. Written informed consent was obtained from the person and his or her trustee in 140 cases. Because of incomplete data in six cases, the final sample comprised 134 adults with ID (73 men and 61 women).

All persons with ID living in a residential institution (n=83) in one county (A) were invited to participate in the study (Papers III and IV). Written informed consent was obtained from each person and his or her trustee. As twelve persons declined to participate in the study, the final sample included 71 adults. Of these 71 adults, 33 were also included in the random sample.

During a period of 3 years (1995-1997) the special services for persons with ID or primary care physicians referred 44 persons with ID to the mental health services for psychiatric evaluation and treatment in county A. Informed consent to participate in the study was obtained for 27 of the 44 persons in the clinical sample (Papers II, III and IV).

Data from a Swedish unpublished study investigating mental health problems in all adults receiving special services in a second county (B) were used for comparison with the data from county A (Paper IV). Among all ADDEF adults with ID in county B (n = 174), written informed consent was obtained from 124 persons.

The study sample of adults with ID receiving special services and admitted to psychiatric in-patient care was retrospectively identified from the total population of all registered adults with ID in county A (Paper I). The study was approved by the social political board at the county council (Sociala nämnden med ansvar för omsorgerna om utvecklingstörda inom landstinget) and the director of the mental health services at the county council (ledningen för landstingets psykiatridivision). The study group included 22 men and 14 women (mean = 39 years, range 22-79 years). Level of ID indicated that 64% were persons with mild ID and 30% with moderate or severe ID.

Procedure
Adults with ID who were admitted to in-patient psychiatric care between 1985 and 1990 in county A were retrospectively identified by psychologists and social workers at each of six local agencies serving persons with ID (Paper I). The level of ID was registered from case records.

A Swedish version of the RSMB and the PIMRA (informant version) was developed and evaluated in terms of inter-rater agreement, internal consistency, item grouping, criterion and concurrent validity based on a
random sample (n=134), a clinical sample (n=21) (Paper II) and a sample of 101 adults (institutional sample n=68, random sub-sample n=20 and clinical sample n=13) (Paper III) of ADDEF adults with ID in county A.

Staff ratings of the level of ID (mild, moderate and severe) were obtained in each sample in county A using a Swedish model of intellectual functioning (Kyhlen 1974). In county B level of ID was obtained using the level of ID (mild, moderate and severe) documented in case records. DSM-III-R and DSM-IV diagnoses in case records were recorded for persons included in the clinical sample (Papers II, III and IV).

The RSMB raters were staff working in group-homes, day care centres or in residential institutions. Each rater had been familiar with the person to be rated for a minimum of 3 months in county A and for a minimum of 6 months in county B. The RSMB was completed for every person with ID by two raters independently with focus on the functioning of the person during the past 3 months. Current psychopharmacological treatment was recorded at the time of the RSMB ratings.

In county A three psychologists interviewed staff informants at the residential institution regarding a sample of 71 adults with ID, a sub-sample of 20 individuals included in the random sample and 13 individuals included in the clinical sample using the PIMRA (informant version). In order to investigate the inter-rater agreement the PIMRA interviews were completed twice, for 31 persons with ID at the residential institution. The interviewers were instructed to focus on the current functioning of the person with ID. In county B one psychologist interviewed staff informants about a sub-sample of 70 adults with ID.

The RSMB and PIMRA data were collected in 1994 (random sample and institutional sample, county A) and in 1997 (county B). The RSMB, the PIMRA data and the recorded DSM-III-R or DSM-IV diagnoses in the clinical sample were collected between 1995 and 1997.

**Clinical assessment**

Three psychiatrists examined persons with ID in a random sub-sample (n=21) using the DSM-III-R diagnostic criteria (Papers, II, III and IV). Each individual was examined by one psychiatrist. The psychiatric evaluations took place 2 to 6 months (median = 5 months) after the RSMB ratings were completed; the psychiatrists were blind to the RSMB results. The psychiatrists were instructed to (a) directly observe or interview the person with ID, (b) to interview caretakers and (c) study patient records. The psychiatrists produced a written summary including a diagnosis for each person assigned to them.

The time span between the psychiatric evaluations and the PIMRA interviews ranged from 2 weeks to 6 months (median = 3 months). The psychiatrists were blind to the PIMRA scores and the psychologist was blind concerning the results of the psychiatric evaluations on all occasions.
**Data from a local mental health care register and the national in-patient care register**

Registered cases of adults with the diagnosis of ID (according to the ICD-10 criteria) and who were receiving out-patient and in-patient psychiatric care in 2000 and 2001 were derived from a local computerised database where all patient records are registered (Paper IV). The authors of Paper 4 (Gustafsson & Sonnander) did not have personal access to the database. All data were derived in the form of individually compiled unidentified statistics concerning age, ICD-10 diagnoses and registered visits to out-patient psychiatric care (defined as consulting a psychiatrist) or admissions to in-patient psychiatric care. The adult population in county A (≥ 20 years) was 220,325 in 2000 and 222,587 in 2001, which represents a medium-sized Swedish county (Source: SCB, Statistics Sweden). The local statistics of reported cases receiving out- or in-patient psychiatric care include adult persons reported to have ID. It is not known whether all these persons received special services, however.

In 25% of the out-patient records and 2% of the in-patient records a diagnosis had not been recorded.

The Swedish national statistics on psychiatric in-patient care occasions between 1985 and 1990 for adults with ID were obtained from the national in-patient care register (Swedish National Board of Health and Welfare, Epidemiological Centre) (Paper I). The ICD-8 or ICD-9 ID diagnoses were obtained as a principal diagnoses or in combination with mental health disorders (according to ICD chapter V diagnoses).

The statistics of in-patient care in Sweden between 1991 and 2000 were obtained from the national in-patient care register in the form of aggregated data (Swedish National Board of Health and Welfare, Epidemiological Centre). The ICD-9 or ICD-10 ID diagnoses were obtained as a principal diagnosis or in combination with mental health disorders (according to ICD chapter V diagnoses). The aggregated data was compiled in the form of individually unidentified statistics concerning age, gender, and admissions to in-patient psychiatric care in each Swedish county.

The number of missing cases in the national in-patient care register is estimated to 1-2% (Source: Swedish National Board of Health and Welfare statistics, 1999).

**Psychopharmacological medication**

Current psychopharmacological treatment was recorded at the time of the RSMB ratings for 117 persons in the random sample (missing data for 23 persons), 69 persons in the institutional sample (missing data for 2 persons, 32 persons were included in the random sample) and 27 persons in the clinical sample. The total sample included 181 persons.
Drugs were aggregated to four classes: anxiolytics, antidepressants, antipsychotics and anticonvulsants. The following medications were classified as anxiolytics: oxazepam, hydroxyzine, nitrazepam, alprazolam and buspirone. Antidepressants were citalopram, clomipramine, amitriptyline, paroxetine and maprotiline. Antipsychotics included risperidone, alimemazine, chlorprotixene, clozapine, chlorpromazine, perphenazine, levomepromazine, flupentixol, melperone, zuclopenthixol, haloperidol, thioridazine, pimozide and lithium. Anticonvulsants were valproate, carbamazepine, diazepam, phenytoin, clonazepam and phenobarbital.

Instruments

The RSMB consists of 38 items. Each item is scored using a multiple criteria rating subscale (intensity, frequency and consequences of the behaviour). The raters are asked to estimate on a 3-point scale whether the behaviour is currently perceived as a problem. The RSMB yields a 26-item total score, eight subscales (aggressive behaviour, psychosis, paranoia, depression: behavioural signs, depression: physical signs, dependent personality disorder, avoidant personality disorder and autism) and six maladaptive behaviour item scores. A person who scores above any of the cut-off scores (the total score, eight subscale scores or the six maladaptive behaviour items) is considered to test “positive” for mental health problems. The RSMB manual states that a single score should be based on the average score of two raters.

The PIMRA (informant version) includes a checklist of 56 dichotomised items divided into eight subscales (schizophrenia, affective disorder, psychosexual disorder, adjustment disorder, anxiety disorder, somatoform disorder, personality disorder and inappropriate adjustment).

The interviewer assigns one point for each “yes” response to an item expressing mental health problems. A diagnosis based on PIMRA requires a subscale score of $\geq 4$ points. However, Matson (1988) points out that because some items are more central to the diagnosis than others, the “four-item” rule should be viewed as flexible and modifiable in accordance with the rules of the DSM-III manual. In actual diagnostic use the results of the PIMRA should always be considered in the context of a complete case evaluation.

The PIMRA interview should be performed with a relative or staff who knows the person well enough to make valid assessments of “behaviour, mood and emotion” and should be administered by a mental health professional “who is familiar with the basic concepts of psychopathology” (Matson, 1988, p. 2).
Statistical analyses

As in the evaluation of the original version (Reiss, 1988), the psychometric evaluation of the Swedish version of the RSMB (Paper II) was based on 26 items. Correlations were calculated using the Pearson product moment correlation coefficient. Differences between raters’ mean scores for each item were tested using paired t-tests. The agreement between the two raters on the 26-item total cut-off score (positive versus negative result on the RSMB) was computed using Cohen’s kappa coefficient. Internal consistency was explored by Cronbach’s alpha coefficient and the items were grouped by Principal Component Analysis (PCA) with orthogonal varimax rotation (SAS 1999). Overall, missing values (44 items) were substituted by the mean value obtained for each item.

The psychometric evaluation of the Swedish version of the PIMRA was based on 42 of the original 56 items (Paper III). Seven items relate to the personality disorders group on axis 2 (DSM-III; APA 1980) and seven items relate to a scale measuring inappropriate adjustment. These 14 items were dropped from subsequent analyses in that the diagnostic features of axis 1 disorders were the main focus in the analysis. Furthermore, the frequency of endorsement for one item (item 34) was zero and subsequently this item was dropped. The internal consistency was explored by Cronbach’s alpha coefficient. Inter-rater agreement between the interviewers on single-item and high versus low scores was calculated using Cohen’s kappa. PCA with orthogonal varimax rotation was used for data reduction analysis (eigenvalue > 1.5). The nonparametric Spearman rank correlation statistic was used to explore the correlation between the component and the total scores on each instrument (PIMRA and RSMB). Three persons were excluded from the correlational analyses between the PIMRA and the RSMB because only one rater returned the RSMB screening protocol. One-way analyses of variance (ANOVA) (General Linear Model procedure; SAS, 1999) with the Tukey studentized range test as a multiple comparison procedure were used to test differences between PIMRA mean scores across diagnostic groups. Missing values (1.4 % of the items) were substituted by the mode obtained for each PIMRA item. ANOVA (General Linear Model procedure) was used to test the differences between RSMB mean scores across level of ID (Paper IV). A t-test was used to test the differences between the RSMB mean scores across gender. The chi-square test was computed to test for PIMRA subscale associations across gender and level of ID. Level of statistical significance was set at p < .05.
Results and Discussion

The occurrence of ADDEF adults with ID admitted to in-patient psychiatric care in one Swedish county (Paper I)

Thirty-six adults (22 men and 14 women) with ID (64% with mild ID) in county A were retrospectively identified as having received in-patient psychiatric care during the investigated period 1985 and 1990. This figure (n=36) represented on average 0.9 % per annum of the total ADDEF group with ID in the county under investigation. In the general population in the county studied 0.9% had been admitted to in-patient psychiatric care during the year 1988.

In the general Swedish population approximately 1% per annum is admitted to in-patient psychiatric care (SOU, 1992). In comparison to Swedish national statistics on psychiatric in-patient care occasions, the subgroup of psychiatric patients who also had a diagnosis of ID represented 0.9 and 1.3% of all psychiatric in-patient care occasions reported in 1985 and 1989. In this subgroup 80% were diagnosed with mild ID (IQ > 50).

The proportion of ADDEF persons with ID in county A admitted to in-patient psychiatric care on an annual basis corresponded with the proportions of persons in the general population receiving in-patient psychiatric care. However, the estimated frequency of mental health problems in the population with ID is on average two to three times greater as compared with the general population (Borthwick-Duffy, 1994). Thus, in comparison with the general population, the higher estimated frequency of mental health problems in persons with ID would predict higher psychiatric in-patient care utilisation.

The group with ID that were identified as having received in-patient psychiatric care between 1985 and 1990 included predominantly persons with mild ID. According to national statistics, persons who received special services in Sweden were predominantly those with moderate or severe ID (Grunewald, 1979, 1997). A Swedish epidemiological study (Göstason, 1985) investigating prevalence of mental disorders in adults with ID showed that there was an overrepresentation of adults with moderate and severe ID
in the group of persons with ID and mental disorders. This overrepresentation, however, was not the case in the present study as there were fewer persons with moderate and severe ID in the group identified.

The limitation of a retrospective design cannot be ruled out. For instance, the local team professionals might have had difficulties to recall the exact number of persons admitted to in-patient psychiatric care during the six-year period. On the other hand, the professionals working in each local team were familiar with all adults with ID who received special services in their district team catchment area between the years 1985 and 1990. Another problem is that the generalisability of the results is hampered by the fact that the study was carried out in only one county: yet, it was considered valuable to compare the outcome of this study with national statistics covering all Swedish counties, although the usual limitations of register data also apply here in terms of diagnostic accuracy and validity. During the time period studied national register data were available only regarding in-patient care occasions.

In conclusion, the results indicated a low frequency of psychiatric care utilisation in comparison to the reported proportions of coexisting mental health problems in adults with ID. This finding was particularly so in ADDEF persons with moderate and severe ID as well as in comparison with the proportion of psychiatric care utilisation in people with mental health problems in the general population.

Psychometric evaluation of a Swedish version of the Reiss Screen for Maladaptive Behaviour (Paper II).

The psychometric properties of the Swedish version of the RSMB were investigated in a random sample (n =134) and a clinical sample (n = 21) of persons with ID.

The Swedish version of the RSMB had moderate-to-low inter-rater agreement on specific items (range $r = 0.28 - 0.66$, median = 0.46). The observed mean scores between the raters were not identical and differences in mean scores for each item were tested using a paired $t$-test that yielded statistically significant differences for two items (item 21, non-assertive and item 27, sadness). The inter-rater agreement of the total score was $r = 0.60$. The inter-rater agreement corrected for chance (Cohen’s kappa) between two raters on the 26-item total cut-off score (i.e. cut-off score ≥ 9 positive case, ≤ 8 negative case) was $\kappa = 0.52$, $z = 10.4$ ($p < 0.001$).

The results of the item-total correlations ranged from 0.29 to 0.62. Cronbach’s alpha coefficient of the 26-item total score was $\alpha = 0.90$ (the calculations were based on the average scores of two raters).
A PCA was conducted on the 26-inter-item correlation matrix. This analysis yielded seven interpretable components. The seven components had eigenvalues >1.00 and explained 67% of the total variance.

The correlations between the subscale scores of each component showed moderate correlations between the depression (behavioural signs) and the dependent subscales ($r = 0.54$) and between the dependent and aggressive behaviour subscales ($r = 0.54$). The depression subscale also correlated moderately with the avoidant and aggressive subscales ($r = 0.51$, $r = 0.48$). Five of the seven components yielded an alpha coefficient of $\alpha > 0.70$ (range 0.60 - 0.86).

A comparison between the psychiatric evaluation outcome (mental disorder versus no mental disorder) and positive or negative 26-item total RSMB score in a sub-sample of 21 randomly selected persons yielded an overall agreement of 81%. According to the RSMB score, persons with mental disorders as classified by psychiatrists were positives in 80% of the cases (sensitivity). Conversely, the non-cases, as classified by the psychiatrists, were negatives in 83% of the cases (specificity). Thus, the result on the RSMB was discordant with the psychiatrists’ assessments in four cases (one false positive and three false negatives). A comparison between the psychiatric assessment and positive or negative 26-item total RSMB score in a clinical group ($n = 21$) yielded the same results: one false positive and three false negatives.

In the random sample 54% (63 of 117 individuals) received psychopharmacological treatment concurrently during the course of the study (sedatives 25%, antidepressants 4%, antipsychotics 35% and anticonvulsants 22%). The results according to the 26-item total RSMB cut-off score showed that in individuals with a positive total RSMB score, 72% (33 individuals) received psychopharmacological treatment and the majority (23 persons) received a combination of drugs. Among individuals with a negative total RSMB score, 34% (30 individuals) received drugs, of which half received a combination of drugs.

The item inter-rater reliability was found to be moderate to low compared with other studies using the RSMB (Reiss, 1988; Minnen, et al., 1995; Sturmey, et al., 1995) However, the 26-item total score proved a fairly reliable measure of a high or low probability of mental health problems.

The PCA performed on the Swedish version yielded seven groups of items, all of which could be interpreted in terms of the same clinical categories that were reported by Reiss, (1988). There were at least two core items in each component in the Swedish version that corresponded with the item set included in the scales of the US version. In the first two Swedish components (aggressive behaviour and avoidance disorder) all items corresponded with the US version and in the third component (depression: behavioural signs) four of five items were found to correspond. However, concerning diagnostic categories the Swedish sample could not be
characterised as a sufficiently heterogeneous sample because of the random selection procedure.

It has been suggested that there is an association between behaviour problems (aggressive and self-injurious behaviours) and depression in persons with ID (Reiss & Rojahn, 1993; Moss, et al., 2000). The correlations found between the Swedish components (depression, dependent, aggressive and avoidant) point to the importance of including maladaptive behaviour items when using instruments for identifying mental health problems in persons with ID.

The outcome in regard to the comparison between the psychiatric evaluation and the results on the RSMB (positive versus negative results) indicates that there was a higher rate of false negatives than false positives, which is consistent with the results of Reiss, (1988, 1990). It should be noted that the small sample together with the time delay between assessments might have influenced the overall outcome. However, the diagnoses of the three persons with false negative screening results could be considered chronic mental health problems (organic personality disorder, dysthymia and cyclothymia), and except for cyclothymia, it is less likely that these mental health problems fluctuate over time. In the clinical group hospital unit staff not familiar with the person whom they rated had completed the RSMB ratings for two of the three persons with negative screening results.

A methodological problem related to this study was that the ongoing psychopharmacological treatment could have influenced the results. Among persons with a positive RSMB total score and among persons with a negative RSMB total score 72 and 34%, respectively, received drugs. This might suggest that there were no active symptoms present during the time of the present study for some persons with a negative test result and that behavioural side-effects of the psychopharmacological treatment might have affected the results. However, the overall symptom patterns obtained in the RSMB score distribution were identifiable and in accordance with previous results (Reiss, 1988, 1990).

In conclusion, the analysis of internal consistency and the amount of variance explained by the seven principal components showed that the Swedish version of the RSMB measures a coherent construct. The outcome of the inter-rater agreement analyses suggests that the total score was a fairly reliable measure of a positive versus negative result on the RSMB. The criterion validity analysis shows that the RSMB could be used as intended by staff as a primary screening device for the identification of mental health problems in persons with ID.
A psychometric evaluation of the Swedish version of the Psychopathology Inventory for Mentally Retarded Adults (PIMRA) (Paper III).

The psychometric properties of the Swedish version of the PIMRA were investigated in a sample of 101 persons with ID. To investigate internal validity, PCAs were conducted in several steps. The main focus of the analyses was the 41 items related to the diagnostic categories of DSM-III axis I disorders (APA, 1980).

A PCA based on the 41-item correlation matrix yielded nine components (eigenvalue >1.5), accounting for 55.4% of the total variance. The items in the first two components corresponded with the item set-up in the original subscales somatoform disorder and psychosexual disorder. The remaining seven components in this analysis did not correspond to the original subscales of the PIMRA. In a second step, the PCA yielded seven components including 34 items (each component comprised ≥ 3 items with a component loading of ≥ 0.40). The reliability of the seven components in terms of internal consistency based on Cronbach’s alpha coefficient was moderate to acceptable (i.e. α > 0.60; Streiner & Norman, 1995) for five of the components (range: 64 - 78). The remaining two components failed to demonstrate an acceptable internal consistency (α = 0.47 and α = 0.59) and were consequently excluded from further analyses.

The five components (including 26 items) were further analysed by PCA in a third step. The results of this analysis yielded items distributed across five groups (eigenvalue >1.5) and an explained total variance of 51%. The five components showed a high significant correlation (r ≥ 0.70) with the corresponding original PIMRA subscale. No item grouping matching the original affective disorder subscale was identified.

Analysis of internal consistency yielded a fairly high Cronbach’s alpha coefficient for the total score of the 26 included items (0.78). The range of the item-total correlations was 0.02 -0.57 (median = 0.30).

The Swedish version of the PIMRA had low inter-rater agreement on specific items. The range of the obtained kappa coefficients for 26 items was -0.08 - 1 (mean = 0.35). Items that yielded a fair to good agreement (i.e. κ > 0.40; Goldstein, 1992) were anxiety problems, auditory hallucinations, mood swings, relaxing problems, delusions, nervousness, stealing or destroying property, problems to cope with stress and frequent worrying. The inter-rater agreement on high or low total (26-item) score according to the median yielded a kappa coefficient of κ = 0.71.

The result of the concurrent validity analysis yielded a strong association between the total scores of the PIMRA and the RSMB (r₁ = 0.66), between subscales on both instruments describing psychotic symptoms (r₁ = 0.64) and between the RSMB subscale aggressive behaviour and the PIMRA subscale.
adjustment problems ($r_s = 0.60$). All components of the PIMRA correlated significantly with one or more of the components of the RSMB except for the component describing psychosexual problems. Further, all of the components of the RSMB correlated significantly with one or more of the components of the PIMRA except for the component depression (physical signs).

The outcome of a comparison of the mean scores on each PIMRA component in a selected sub-sample ($n = 33$) indicated that those persons with a mental disorder according to DSM-III-R or DSM-IV diagnoses: psychosis, affective disorder and anxiety disorder obtained significantly higher total PIMRA scores than individuals without a mental disorder.

A diagnosis based on PIMRA scores requires the presence of at least four items on any subscale (Matson, 1988). The criterion analysis showed that in 33 individuals, a comparison of the psychiatric evaluation outcome (mental disorder versus no mental disorder) and a diagnosis versus no diagnosis based on PIMRA scores yielded an overall agreement rate of 70%. Sensitivity and specificity was $19/ (19+9) = 0.68$ and $4/ (4+1) = 0.80$, respectively.

A comparison between the PIMRA component indicating psychosis and the combination of components indicating adjustment/anxiety problem with the corresponding DSM diagnoses yielded an overall agreement rate of 76% (psychosis component) and 76% (adjustment/anxiety component). The sensitivity and specificity measure of the comparison between the results on the psychosis component versus DSM diagnoses was 0.53 and 0.94, respectively. The sensitivity and specificity measure of the comparison between the results on the adjustment/anxiety component versus DSM diagnoses was 0.75 and 0.76, respectively.

A comparison of the Swedish PIMRA version with a Norwegian and Italian PIMRA version (Balboni, et al., 2000; Linaker, 1991) shows that the closest correspondence across these three national versions was for the item grouping describing somatoform problems. No item grouping corresponding to the original affective disorder subscale was found in any of these versions. One possible explanation could be that the samples in these studies include a larger proportion of persons with severe ID than in the original study and the fact that depressive symptoms manifest themselves atypically with more behavioural symptoms particularly in persons with severe ID (Dosen & Gielen, 1993; Meins, 1995; Moss et al., 2000; Kazdin, et al., 1983; Reiss & Rojahn, 1993).

Methodological problems with the present study are related to the fact that the variables were neither normally distributed (being dichotomous) nor equally distributed among the response alternatives (“yes or no”). In addition, the sample size was limited. The results of the PCA analysis must therefore be regarded as preliminary until data based on a larger and more
heterogeneous sample (including a wide range of mental health problems) become available.

The item inter-rater reliability was found to be low in the present study. It might have been possible to improve the inter-rater reliability through more training of the interviewers. Our finding of a low inter-rater reliability corresponded with a study by Minnen, et al., (1994). However, items indicating psychotic symptoms and signs of anxiety yielded a fair to good agreement and the kappa values for a high or low total score showed that the raters agreed on the amount of mental health problems in a majority of the individuals.

The time delay between the PIMRA assessments and the psychiatric evaluations, which were based on a limited sample, could have influenced the criterion analysis outcome. Furthermore, the ongoing psychopharmacological treatment could have influenced the results in that approximately 60% of the persons with a positive and 60% with a negative component score were receiving drugs. However, the overall symptom pattern obtained in the PIMRA score distribution was identifiable and confirmed in the clinical group comparisons.

In conclusion, the results indicate that the PIMRA had a potential to identify individuals with mental health problems in persons with different levels (mild, moderate and severe) of ID and identify individuals with a specific mental disorder. Thus, professionals might use the PIMRA as a complementary tool in the diagnostic assessment of mental health problems in persons with ID. In a clinical setting, however, one should always consider that the perspective of an informant could be different from that of the person experiencing the symptoms, which emphasises the importance of including a diversity of data sources and methods in the diagnostic process.

Frequency of psychopharmacological treatment (Papers II and III)

The number of ADDEF persons with ID that is receiving psychopharmacological treatment in the random, the institutional and the clinical sample is presented in Table 3.

Among 181 adults with ID in the total sample 59% received some sort of psychopharmacological treatment. The most common prescribed medication was antipsychotic drugs (41%). Among the prescribed antipsychotic drugs thioridazine (n = 34) and levomepromazine (n = 15) were the most prevalent.

Twenty-one percent (n = 38) of the adults with ID received a combination of two medications and 5% (n = 9) received three medications. The most common combinations of prescribed drugs were anxiolytics together with
antipsychotics (n = 16), anxiolytics together with anticonvulsants (n = 11) and antipsychotics together with anticonvulsants (n = 8). When persons receiving anticonvulsants as the only medication were excluded, 52% (n = 94) in the total sample, 49% (n = 57) in the random sample and 43% (n = 30) in the institutional sample still received psychopharmacological medication.

The percentage of adults with ID that were receiving psychopharmacological treatment corresponded to the figures presented in a number of studies (Aman, et al., 1995; Göstason, 1985; Intagliata & Rink, 1985; Linaker, 1990; Lund, 1986; Reid & Ballinger, 1987; Spreat, et al., 1997). The prescription of antipsychotic medications was notably high and might indicate that these drugs are used in the absence of a psychotic disorder, which is not a recommended treatment strategy (Santosh & Baird, 1999; Wiesel, 1997).

Among persons treated with anticonvulsants the majority had a prescription of anticonvulsants in combination with other drugs and the indication for treatment might therefore have been for some condition other than solely a seizure disorder. In psychiatric clinical practice anticonvulsants have been used, for example in treatment of aggressive behaviour, bipolar disorder and a psychotic disorder in combination with aggressive behaviour (Sadock & Sadock, 2000).

Table 3.
Number of persons receiving psychopharmacological treatment in ADDEF samples of adults with ID (percentage are given in brackets).

<table>
<thead>
<tr>
<th></th>
<th>Random sample (n=117)</th>
<th>Institutional Sample(^1) (n=69)</th>
<th>Clinical sample (n=27)</th>
<th>Total Sample (n=181)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiolytics</td>
<td>29 (25)</td>
<td>14 (20)</td>
<td>3 (11)</td>
<td>38 (21)</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>5 (4)</td>
<td>2 (3)</td>
<td>4 (15)</td>
<td>10 (5)</td>
</tr>
<tr>
<td>Antipsychotics(^2)</td>
<td>41 (35)</td>
<td>23 (33)</td>
<td>20 (74)</td>
<td>74 (41)</td>
</tr>
<tr>
<td>Anticonvulsants</td>
<td>26 (22)</td>
<td>20 (29)</td>
<td>4 (15)</td>
<td>50 (28)</td>
</tr>
<tr>
<td>Any psychopharmacological treatment</td>
<td>63 (54)</td>
<td>37 (54)</td>
<td>23 (85)</td>
<td>107 (59)</td>
</tr>
</tbody>
</table>

\(^1\) Thirty-two persons included in random sample.
\(^2\) Four persons received lithium.
Occurrence of mental health problems in Swedish samples of adults with ID (Paper IV).

The overall occurrence of mental health problems according to the results of the RSMB 26-item total score in the total Swedish sample (n = 294) was 37% (random sample 34%, institutional sample 36% and comparison sample 41%).

Aggression and depression (behavioural and physical signs) were the two most common mental health problems based on the percentage of individuals above the cut-off points of the specific RSMB subscale scores in the three samples. The most common maladaptive behaviour item was self-injurious behaviour.

The three most frequent RSMB items reported as a problem or a severe problem of the 38 items in the total sample (n = 294) were anxious behaviour, attention-seeking behaviour and non-assertive behaviour. Two of these items (anxious behaviour and attention-seeking behaviour) were included among the four items most frequently reported as a problem or severe problem in each sample. The RSMB items less frequently reported as a problem or severe problem in each sample were suicidal tendencies and drug or alcohol abuse.

The overall occurrence of mental health problems according to the PIMRA criteria (which require a positive subscale score of $\geq 4$ points) was 45% in the institutional sample and 64% in the comparison sample. The most common mental health problems in both samples according to the percentage of persons meeting the criteria on the PIMRA subscales were anxiety and adjustment disorders.

The analyses, according to level of ID and gender in the random and institutional sample, yielded no statistically significant differences between persons with a mild or severe level of ID or between men and women on overall occurrence of mental health problems.

The results showed that in the clinical sample (n=27) the majority were persons with mild (n=15) or moderate ID (n=10) that suffered from psychotic or affective disorders according to the DSM-III-R or DSM-IV criteria. The majority (85%) was recognised to have mental health problems according to the results of the RSMB total score. In 21 of 27 referred cases the psychiatrists had no information about the results on the RSMB before the clinical assessment. The results on the RSMB total score for those 21 persons indicated that 18 persons (86%) were identified as having mental health problems. Thus, the RSMB instrument had a good potential to identify adults with ID and coexisting mental disorders in this sample.

The percentage of individuals who met the criteria for mental health problems on the RSMB in the Swedish random and comparison samples was similar to the overall figures reported in two US studies of randomised samples of ADDEF adults with ID (Reiss, 1990; Sturmey, et al., 1996).
There were differences in subscale score profiles between the US and Swedish samples, differences that could partly be explained by sample characteristics. The Swedish samples had a larger proportion of persons with a moderate or severe level of ID and the most common reported problems in the three samples were aggression, depression and self-injurious behaviour. According to a large array of studies, there are possible relationships between severe levels of ID, self-injurious and aggressive behaviours (Collacott, Cooper, Branford & McGrother, 1998; Emerson et al., 2001; Emerson, Moss & Kiernan, 1999; Kebbon & Windahl, 1986; King, DeAntonio, McCracken, Forness & Ackerland, 1994). Furthermore, it has been suggested that there is a possible relationship between self-injurious and aggressive behaviours and signs of depression in persons with severe levels of ID (Meins, 1995; Read, 1998).

However, when the percentage of reported problems among the 38 RSMB items was compared, the result showed that anxious behaviour and attention seeking behaviour were the most frequent items reported as a problem or severe problem in all samples. This cross-cultural finding may indicate that mental health problems in persons with different levels of ID also include emotional or behavioural problems, of which some could be characterised as closely connected to the social and psychological consequences of the intellectual disability.

Although the RSMB was designed for screening while the PIMRA was primarily constructed for diagnostic purposes, a larger proportion of individuals had mental health problems with the latter tool when a comparison was done between the PIMRA scores and the RSMB scores in the institutional and comparison samples. However, the instruments were used differently (direct staff ratings versus staff interviews) and have different scoring methods, which could explain the different proportions found.

Two studies have reported the occurrence of mental health problems using the informant version of the PIMRA. Compared with the reported figure in a US random sample of ADDEF adults with ID the overall occurrence of mental health problems in the Swedish comparison sample was higher (Iverson & Fox, 1989). A possible explanation could be the differences between groups in the levels of ID (i.e. in the Swedish sample 57% had severe ID compared with 37% in the US sample). Compared with the reported figure in a Norwegian institutional sample, the overall occurrence of mental health problems in the Swedish institutional sample was lower (Linaker & Nitter, 1990). This difference might be an effect of different methodological procedures applied (i.e. patient ratings via staff interviews in the Swedish study versus direct staff ratings of patients in the Norwegian study) and the different proportions of persons with severe ID (76% in the Norwegian sample as compared with 41% in the Swedish sample). However, according to the PIMRA subscales, anxiety symptoms
appeared as the most common mental health problems in the Swedish and Norwegian samples.

The overall occurrence of mental health problems in the Swedish samples were comparable with studies using other broad-spectrum maladaptive behaviour scales in randomised or geographical total samples of ADDEF adults with ID in the UK and Denmark (Deb, et al., 2001ab; Lund, 1986; Roy, et al., 1997; Smith, et al., 1996)

The ratings of intellectual level in this study must be regarded as preliminary. Staff rated the level of ID in the random, institutional and clinical sample after a short introduction and description of the essential features of each level according to a Swedish model for classification (Kylén (1974, 1981 and 1985).

In patients receiving out- or in-patient psychiatric care in one county (A) 2000 and 2001 the occurrence of adults with the ICD-10 diagnosis of ID were approximately 1% each year and approximately 70 - 90% of these persons had a mild level of ID. It should be noted that because the data were obtained in the form of individually compiled unidentified statistics there was no information concerning the diagnostic assessment procedures that had been used. The uncertainty regarding “true cases” according to the strict criteria based on low IQ (< 70) and impairment of skills manifested during the developmental period should be particularly relevant in the group with mild ID.

Due to changes in the administrative routines, there was no register available that could identify persons receiving special services at the time this study was done. However, aggregated statistics on persons with ID receiving special services in the county according to the Act concerning support and service for persons with certain functional impairment (SFS 1993:387) were available (Source: National Board of Health and Welfare statistics, 2001). Assuming that all persons with ID who were admitted to psychiatric in-patient care or consulting a psychiatrist at out-patient mental health clinics in 2000 were ADDEF, they would represent approximately 3 and 8%, respectively, of all ADDEF persons with ID in the county. However, there is reason to believe that a large part of those individuals with mild ID registered at the mental health services had not been administratively classified as having ID since the proportion of ADDEF individuals with mild ID in Sweden always has been low (Grunewald, 1979 and 1997).

In conclusion, the overall occurrence of mental health problems in Swedish ADDEF samples of adults with ID was similar to reported overall figures in comparable studies conducted in the US, the UK and Denmark. The results show that a small number of persons with moderate and severe ID were receiving mental health services. It is not known how many persons in the three Swedish ADDEF samples with ID that actually had been referred for psychiatric assessment. However, the number of adults with ID
registered for out- or in-patient psychiatric care was low compared with the occurrence of mental health problems based on the screening results. This might imply that a large number of adults with ID (particularly moderate and severe ID) who had mental health problems had not been referred for psychiatric assessment. Thus, in the absence of specialised assessment there is a potential risk that mental health problems in persons with ID go unrecognised or are inaccurately assessed and treated.

Occurrence of adults with ID admitted to in-patient psychiatric care in Sweden

The reported cases of adults admitted to in-patient care with an ICD-9 or ICD-10 diagnosis of ID as principal diagnosis or in combination with a mental disorder during the period 1991 and 2000 in Sweden are given in Table 4.

Table 4 shows that between the years 1996 and 1997 the number of adults with an ICD diagnosis of ID admitted to in-patient care increased with approximately 148 persons (39%). This increase remained stable for men and women with different levels of ID until the last study year (i.e. 2000).

According to the Act concerning support and service for persons with certain functional impairment (SFS 1993:387) all special services are community-based forms of support and all medical services should be provided by the general health care system. The increase of adults with ID receiving mental health services could be a consequence of the organisational change in services provided to persons with ID during the past decade.

The mental health services should preferably be provided in the form of out-patient care in accordance with current Swedish mental health care policy. The total number of adults with ID receiving specialised treatment and care by the general mental health services has not been investigated because registered data on utilisation of out-patient mental health care on a national level has not been available. However, the trend concerning in-patient care indicates that adults with different levels of ID and who are receiving mental health services had increased during the 10-year study period, which might be an indication of improved recognition of mental health problems in persons with ID.
Table 4.
Number of patients in Sweden with an ICD-10 diagnosis of ID as the principal diagnosis or in combination with a mental disorder admitted to in-patient care between 1991 and 2000.

<table>
<thead>
<tr>
<th></th>
<th>Unspecified level of ID</th>
<th>Mild level of ID</th>
<th>Moderate level of ID</th>
<th>Severe level of ID</th>
<th>Profound level of ID</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>73</td>
<td>272</td>
<td>53</td>
<td>6</td>
<td>—</td>
<td>404</td>
</tr>
<tr>
<td>1992</td>
<td>77</td>
<td>234</td>
<td>53</td>
<td>5</td>
<td>—</td>
<td>369</td>
</tr>
<tr>
<td>1993</td>
<td>81</td>
<td>214</td>
<td>53</td>
<td>8</td>
<td>1</td>
<td>357</td>
</tr>
<tr>
<td>1994</td>
<td>78</td>
<td>216</td>
<td>59</td>
<td>4</td>
<td>1</td>
<td>358</td>
</tr>
<tr>
<td>1995</td>
<td>102</td>
<td>214</td>
<td>59</td>
<td>7</td>
<td>—</td>
<td>382</td>
</tr>
<tr>
<td>1996</td>
<td>86</td>
<td>234</td>
<td>50</td>
<td>4</td>
<td>2</td>
<td>376</td>
</tr>
<tr>
<td>1997</td>
<td>148</td>
<td>267</td>
<td>80</td>
<td>21</td>
<td>8</td>
<td>524</td>
</tr>
<tr>
<td>1998</td>
<td>143</td>
<td>298</td>
<td>77</td>
<td>14</td>
<td>9</td>
<td>541</td>
</tr>
<tr>
<td>1999</td>
<td>161</td>
<td>282</td>
<td>78</td>
<td>16</td>
<td>12</td>
<td>549</td>
</tr>
<tr>
<td>2000</td>
<td>159</td>
<td>281</td>
<td>66</td>
<td>21</td>
<td>12</td>
<td>539</td>
</tr>
</tbody>
</table>
General Discussion

Psychometric qualities of the Swedish RSMB and the Swedish PIMRA

The outcome of the internal consistency analyses of the Swedish versions of the RSMB and the PIMRA yielded good results, indicating that each instrument was homogeneous. It should be noted, though, that the alpha coefficient on the RSMB total score was very high ($\alpha = 0.90$), indicating a risk of item redundancy.

The relatively low measure on inter-rater reliability on the specific items for both instruments is a problem, which could put the validity of the instruments into question. However, the result indicates an acceptable agreement between the RSMB raters and between the PIMRA interviewers with respect to the amount of mental health problems in the individual case.

Any instrument should be regarded as a novel instrument when it is adapted to a new cultural setting. For data reduction analysis of the Swedish versions of the RSMB and PIMRA an exploratory procedure was used, which is commonly recommended for scale development (Comrey, 1988; Fabrigar, Wegener, MacCallum & Strahan, 1999; Floyd & Widaman, 1995; Goldberg & Digman, 1994). The results yielded an item structure for the Swedish versions that could be interpreted relatively well in terms of the same clinical sub-dimensions as in the original versions, except for the affective disorder subscale of the PIMRA. The questionable clinical diagnostic use of the sub-dimensions in the RSMB is not surprising considering that the instrument was developed primarily for screening purposes.

The problems of validity of brief screening instruments used in psychiatric research should be noted. Although many instruments have shown good internal consistency they do not cover symptoms of all varieties of mental disorders, nor do they converge closely with diagnoses based on clinical interviews and ratings (Dohrenwend, 1989). Thus, although screening instruments are easily administered and often very reliable for use in different gender, class and ethnic groups, the scales are not very precise in screening individual cases with specific mental disorders. Concerning the
use of screening instruments for diagnostic purposes they can isolate sub-
samples with much higher rates of symptoms than the general population as
a whole, but cannot provide precise rates of particular disorders in the
general population.

Criterion validity
The clinical psychiatric evaluations show that there was a variation of mental
health problems among the persons included in the clinical and random sub-
samples. The choice of clinical evaluations as a criterion in these studies
should be discussed. Criterion validity is not only limited by the reliability of
a test but also by the reliability of the criterion chosen. In the present studies
(Papers II and III) the reliability of the clinical evaluations was not measured
and the evaluations were performed without a semi-structured or structured
diagnostic interview guide. At the time the study was conducted, there was
no such interview guide available specifically designed and developed for
the ID population. The problem to find a “golden standard” concerning
diagnostics in the field of psychiatry and ID is related to the fact that
research on mental health problems in persons with ID has become an
important area of focus only in recent years. The knowledge in this field is
still in a stage of development regarding the establishment of diagnostic
criteria. The use of clinical evaluations as a criterion demonstrates how these
instruments related to a standard procedure used in regular clinical practice.

Sensitivity and specificity
Sensitivity and specificity are two vital measures on the validity of a
screening test.
A comparison between the psychiatric evaluation outcome (mental
disorder versus no mental disorder) and the positive or negative 26-item total
RSMB score show that there was a tendency of a higher specificity than
sensitivity measure, which has also been reported by Reiss (1990). In
medical practice, however, an instrument designed for screening should
preferably have cut-off points low enough to identify all persons with early
signs of a disease or illness. In practice the instrument should capture a
larger number of persons with false positive than with false negative results
(Hennekens, Buring & Mayrent, 1987). Thus, although the sample size was
small in the present study the results indicate that the cut-off score of the
Swedish version of the RSMB might be modified.

A screening test should ideally be easy to administer and impose minimal
discomfort on the individual. The RSMB has these desired properties, and in
view of the reported problems of unrecognised symptoms in persons with
ID, the RSMB is well suited as a primary screening device for the
identification of mental health problems in persons with ID.
The comparison of the psychiatric evaluation and positive or negative score (four or more items) on any of the five components of the PIMRA reveal a higher specificity than sensitivity value. Considering that the PIMRA instrument was designed primarily for diagnostic purposes, to be used by professionals as a complement in the diagnostic evaluation process, the higher specificity measure (particularly on the component indicating psychosis) should be regarded as a promising result.

Taken together, the psychometric evaluation of the RSMB and PIMRA shows that both instruments measure a construct related to the diagnostic categories in the DSM-III-R and DSM-IV. This construct could be categorised as mental health problems.

Occurrence of mental health problems

The present Swedish study and former reported figures show that the occurrence of overall mental health problems, using broad-spectrum maladaptive behaviour and diagnostic scales or any DSM or ICD diagnoses in ADDEF samples of adults with ID, was more frequent in persons with ID than in person from the general population (Deb, et al., 2001a; Hagnell, Öjesjö, Otterbeck & Rorsman, 1994; Kessler et al., 1994). However, the reported estimates of functional psychiatric disorders according to DSM or ICD criteria in adults with ID seem to be more in accordance with estimates reported in studies of the general population.

Nevertheless, caution must be advised in the interpretation of these results because the accuracy of the prevalence rates of mental health problems among adults with ID is influenced by the difficulties to apply the DSM or ICD criteria when the person has a severe or profound ID (Moss, 2001; Sovner, 1986; Sturmey, 1993).

Hagnell, et al. (1994), conclude that a common problem in the field of psychiatric epidemiology is that repeated studies on point prevalence do not reveal the unknown number of short-lasting episodes of illness that may have occurred between investigations. The present thesis has not reported incidence rates of mental health problems in the Swedish adult ID population. Accordingly, in future research it would be preferable to combine prevalence determinations with studies on incidence rates. This strategy could possible shed greater light on the difficult differentiation between chronic conditions and acute symptoms and signs of mental health problems in persons with ID.

Psychiatric care utilisation

The occurrence of psychiatric care utilisation in the administratively identified group of persons with ID shows that 0.9% per year of the total registered adult population with ID had been admitted to in-patient
psychiatric care between 1985 and 1990 in the selected county. In registered patients receiving out or in-patient psychiatric care in 2000 and 2001 the occurrence of adults with the ICD-10 diagnosis of ID was approximately 1%.

Although it is not known precisely how many in the registered ID patient group were ADDEF, these groups with ID (ADDEF and definition based on ICD-10 diagnosis) are probably overlapping, but not identical. There is reason to believe that a large part of those individuals with mild ID registered in the mental health services statistics were not administratively classified as having ID in that the proportion of ADDEF individuals with mild ID in Sweden always has been low (Grunewald, 1979, 1997). The present results indicate that psychiatric care utilisation in ADDEF adults with ID had been low during the period of organisational changes in the service delivery systems. The possibilities to generalise these findings is limited, though, because the results are based on data from one Swedish county.

The registered data of in-patient psychiatric care on a national level show that persons with a diagnosis of ID that were admitted to in-patient psychiatric care had slightly increased during the 10-year study period. This increase could be interpreted as an indication of improved recognition of mental health problems in persons with ID.

The present data on occurrence of psychiatric care utilisation were descriptive and therefore it was not possible to statistically conclude that individuals with ID utilise psychiatric care to a lesser extent than the general population. However, the data presented here generate further questions. For instance, is there a difference between the proportion of persons with ID and mental health problems and the proportion of persons with mental health problems in the general population that receive treatment and care through the mental health services? Other questions concern the findings of a high frequency of prescribed psychopharmacological drugs, particularly antipsychotic medication, in spite of low psychiatric care utilisation. The reported risk of potential side-effects, the lack of consensus regarding the use of psychotropic drugs for control of behaviour problems and the difficulties with symptom identification are all strong arguments for the need of specialists of mental health care in the assessment and treatment of mental health problems in persons with ID.

It is particularly important that this vulnerable group has accessibility to specialised assessment as well as treatment and care according to their specific needs.

The low level of utilisation of psychiatric care indicates the need of case-recognition and to develop individualised treatment and support for persons with ID and mental health problems. Current legislation does not provide a clear-cut differentiation of responsibilities between the special and mental health services in the individual case (Brusén, 2000). This lack of clarity
necessitates a cross-system approach (i.e. across the mental health system and the special services system) of services and co-operation in the assessment and treatment of mental health problems among professionals working in the medical, psychological and social fields.

There is a need of a coherent policy that utilises, existing mental health and special services in order to meet both the developmental and mental health needs of persons with ID.

Considering the present results, future research should focus on the accessibility of special tailored mental health services to help resolve problems of persons with ID in Sweden.
Conclusions

The psychometric evaluation of the Swedish versions of the RSMB and PIMRA show that both instruments measured a construct related to the diagnostic categories in the DSM-III-R and DSM-IV. This construct could be conceptualised as mental health problems.

The results show that the RSMB could be used as intended by staff as a primary screening device for the identification of mental health problems in persons with ID.

The results indicate that the PIMRA had a potential to identify individuals with a specific mental disorder in persons with varying levels (mild, moderate and severe) of ID.

The overall occurrence of mental health problems in Swedish ADDEF samples of adults with ID ranged from 34 to 64%, where the most common mental health problems were aggressive and self-injurious behaviours, depression, anxiety and adjustment disorders.

In a Swedish ADDEF sample of 181 adults with ID 59% received psychopharmacological treatment. The common prescribed medication was antipsychotic drugs (41%).

In contrast to the high frequency of mental health problems reported, psychiatric care was used infrequently. This tendency is particularly evident in persons with moderate and severe ID.
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References


community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45, 495-505.


A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to October, 1985, the series was published under the title “Abstracts of Uppsala Dissertations from the Faculty of Medicine”.)