

ORIGINAL PAPER

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Occurrence of mental health problems in Swedish samples of adults with intellectual disabilities

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Abstract *Objective* The aim of this study was to investigate the occurrence of mental health problems in adults with intellectual disabilities (ID) and the number of adults with ID receiving care at general mental health clinics. *Method* The Reiss Screen for Maladaptive Behaviour and the Psychopathology Inventory for Mentally Retarded Adults were used to investigate mental health problems in samples from two Swedish counties. Adults with ID receiving psychiatric care at general mental health clinics were investigated via the mental health services register in one county. *Results* The overall occurrence of mental health problems in adults with ID ranged from 34% to 64%. The most common mental health problems were aggressive, self-injurious behaviours, signs of depression, anxiety or adjustment problems. The occurrence of adults with ID among patients receiving out- or in-patient psychiatric care was approximately 1%. Between 70% and 90% of these persons had a mild level of ID. *Conclusion* The overall occurrence of mental health problems was similar to reported overall figures in comparable studies conducted in the US, UK and Denmark. 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.

Key words intellectual disabilities – mental health problems – screening – psychiatric care

Introduction

Studies indicate that persons with ID exhibit the full range of mental health problems and that some prob-

lems are more frequently reported in this group than in the general population [1–6].

Figures of occurrence vary greatly between studies. The occurrence of major mental health problems, including personality disorders and psychotic disorders, range from approximately 8% to 15% [7]. When minor emotional or behaviour disorders are included, estimates greater than 50% have been reported [8].

Conflicting results have been reported concerning occurrence of mental health problems in different age groups of adults with ID probably due to different research methods employed [9–13]. The overall presence of mental health problems in persons with ID seems to be unrelated to gender [8]. Studies that compare the occurrence of mental health problems in persons with mild versus severe ID have not yielded consistent results [13–17].

Most studies describe administratively defined (ADDEF) samples of adults with ID (i.e. receiving special services). Only a few population-based samples including adults or children have been published (i.e. 15, 18).

Some studies are based on schedules designed to help health and social service staff identify mental health problems among the persons for whom they care. The first published instruments specifically designed to cover a broad spectrum of mental health problems in persons with ID are the standardized instrument Reiss Screen for Maladaptive Behaviour (RSMB; 19) and the Psychopathology Inventory for Mentally Retarded Adults (PIMRA; 20). A set of instruments that include a semi-structured guide for psychiatric interviewing of both persons with ID and their informants (PAS-ADD) [21–23] has been used in more recent studies [11, 24].

Reports of mental health problems in referred samples of persons with ID frequently describe ADDEF samples referred for psychiatric assessment and treatment within the special services directed to persons with ID. Only a few studies have reported occurrence of adults with ID receiving psychiatric treatment and care within the general mental health services [25, 26].

Persons entitled to special services are persons with

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significant limitations in intellectual functioning, concurrent with and related to significant limitations in adaptive behaviour manifested during the developmental period. The major national reforms concerning services to persons with ID have been implemented in Sweden during the last two decades. At present, all special services are community based and include ten categories of special support (e. g. housing, daily activities). Before the legislative changes in Sweden in 1985 and 1993 [27, 28], all services including medical services were provided by the special service system for persons with ID. The legislative changes entail that, in addition to community-based special services, a person with ID, as any other citizen, should receive medical services through the general health care system, including mental health services.

The occurrence of mental health problems in the ADDEF group of persons with ID and the occurrence of persons with ID receiving psychiatric care at general mental health clinics have not been studied systematically following the organizational changes in the service delivery systems.

■ Aims of the study

The aim of the present study was, firstly, to investigate the occurrence and distribution of mental health problems in Swedish ADDEF samples of adults with ID, using the RSMB and PIMRA, and, secondly, to investigate the occurrence of adults with the diagnosis of ID among patients receiving out- and in-patient psychiatric care at general mental health clinics.

Subjects and methods

The screening of mental health problems was carried out in natural settings among adults registered with the special services for persons with ID (ADDEF samples). The data collection took place in a period of transition concerning special services. In general, one main residential institution was situated in each county. The residential institutions were gradually closing down and being replaced by group homes.

In order to obtain a representative picture, samples include persons in two Swedish counties (A and B) receiving special services.

There are no special treatment facilities in Sweden for persons with ID and mental health problems. Persons with ID should get medical treatment and care within the general health care system. The documentation at the mental health care register was used to investigate the occurrence of adults with the diagnosis of ID among patients receiving out- and in-patient psychiatric care at general mental health clinics in county A.

The study was included in a project approved by the Research Ethics Committee of the Medical Faculty, University of Uppsala.

■ Samples

County A

The population of adults (≥ 18 years) was 211,992 (year 1994). The county represents a medium-sized Swedish county and includes urban and rural populations.

A random sample was derived from the total ADDEF group of adults with ID, i. e. receiving special services in county A ($n = 650$). A sample of 200 of these cases was randomly selected using a table of random numbers. Of this sample of 200, 35 declined to participate, 22 did not respond and 3 were recently deceased. Written informed consent was obtained in 140 cases. Because of incomplete data in six cases, the final random sample comprised 134 adults with ID.

In comparison with the total ADDEF group with ID in county A, there were fewer people in the random sample that were living on their own or with their families.

The random sample was representative of the national ADDEF Swedish group of adults with ID in terms of age, gender and level of ID [29].

One main residential institution was still operating in county A (apart from two smaller institutions just in the process of closing down) and all persons with ID living in the institution ($n = 83$) were invited to participate in the study. Written informed consent was obtained from 71 adults in the institutional sample. As a part of the random selection procedure, 33 of these 71 adults 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. Informed consent to participate in the study was obtained for 27 of the 44 persons in the referred sample.

County B

Data from a Swedish unpublished study investigating mental health problems in all adults receiving special services in county B were included. The population of adults (≥ 18 years) was 42,933 (year 1997) and represented predominantly a rural population. Among all ADDEF adults with ID in county B ($n = 174$), written informed consent was obtained from 124 persons. The sample ($n = 124$) was representative of all ADDEF adults with ID in county B ($n = 174$) in terms of age, gender and level of ID. Data on accommodation were not collected in county B. However, at the time of the data collection, the prior residential institution placed in the area had been closed.

Throughout the present study where the person did not have the capacity to withhold consent the trustees gave consent on behalf of the person with ID.

Characteristics of samples are presented in Table 1.

Table 1 Sample characteristics

	County A			County B
	Random sample ¹ ($n = 134$)	Institutional sample ($n = 71$)	Referred sample ($n = 27$)	Sample ² ($n = 124$)
Age (years)				
Mean	43.6	54.3	36.6	44.2
Range	21–68	34–94	18–60	22–81
Gender (%)				
Male	73 (54)	40 (56)	16 (59)	65 (52)
Female	61 (46)	31 (44)	11 (41)	59 (48)
Level of ID (%)				
Mild	37 (28)	18 (26)	15 (56)	14 (11)
Moderate	63 (47)	23 (33)	10 (37)	40 (32)
Severe	34 (25)	29 (41)	2 (7)	70 (57)
Accommodation (%)				
Living alone	6 (4)	0	2 (7)	–
Living with family	10 (7)	0	4 (15)	–
Group home	74 (55)	0	20 (74)	–
Residential institution	44 (33)	71 (100)	1 (4)	–

¹ Thirty-three persons included in the institutional sample

² Data on accommodation were not collected for the sample in county B

■ Instruments and data sources

Data were based on scores obtained with the Swedish version of the RSMB [30] rated by staff and the Swedish informant version of the PIMRA [31] based on staff interviews. The RSMB was primarily designed for screening of mental health problems among adults with ID and the PIMRA was constructed to provide specific DSM-III diagnoses [32]. The RSMB and the PIMRA were the only published standardized broad-spectrum instruments available for screening and diagnostics of mental health problems among adults with ID when the present research project started. Both instruments have been found to have acceptable psychometric properties [19, 30, 31, 33–36].

The RSMB consists of 38 items each scored using a multiple-criteria rating subscale (intensity, frequency and consequences of the behaviour). The raters are asked to estimate whether the behaviour is currently “no problem” (0), “a problem” (1) or “a major problem” (2). 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 said 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 dichotomized items divided into eight subscales (schizophrenia, affective disorder, psychosexual disorder, adjustment disorder, anxiety disorder, somatoform disorder, personality disorder and inappropriate adjustment). The interviewer should assign one point for each “yes” response to an item expressing mental health problems. When mental health professionals use the PIMRA as a structured interview, the general rule of thumb is that diagnosis requires the presence of at least four of the seven symptoms on a subscale, but the four-item rule is flexible and may be modified in accordance with the rules of DSM-III [20].

Staff ratings of intellectual level were obtained in each sample in county A using a Swedish model of intellectual functioning related to the International Classification of Disease [37, 38]. In county B, level of ID was obtained using the described level (mild, moderate, severe and profound ID) documented in case records kept by the special services for persons with ID.

To compare with the results on the RSMB and PIMRA, information about DSM-III-R and DSM-IV diagnoses [39, 40] according to the psychiatric evaluation was obtained for persons included in the referred sample.

■ Procedure

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 by two raters independently with focus on the functioning of the person during the last 3 months. Each rater in county A also rated the level of intellectual functioning (mild, moderate and severe) following a short instruction by the first author.

In county A, two psychologists interviewed 33 staff informants (concerning 71 persons with ID) at the residential institution using the Swedish version of the PIMRA (informant version). The interviewers were informed how to use the instrument by the first author and instructed to focus on the current functioning of the person with ID. In county B, one psychologist interviewed 70 staff informants (concerning 70 persons 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 data and the DSM-III-R or DSM-IV diagnoses in the referred sample were collected between 1995 and 1997.

■ Data from mental health care registers in county A

Registered cases of adults with the diagnosis of ID (according to the ICD-10 criteria [41]) receiving out-patient and in-patient psychiatric care in 2000 and 2001 were derived from a local computerized database where all patient records are registered. The authors 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 (≥ 18 years) was 220,325 in 2000 and 222,587 in 2001, which represents a medium-sized Swedish county (Source: SCB, Statistics Sweden). The ICD is the official diagnostic classification system used in Sweden concerning registered patients receiving out- or in-patient care. The local statistics of reported cases receiving out-patient or in-patient psychiatric care include adult persons reported to have a clinical diagnosis of ID. It is, however, not known whether all these persons received special services.

In 25% of the psychiatric out-patient records and 2% of the in-patient records, the ICD diagnoses were missing.

■ Statistical analysis

The results of the RSMB and the PIMRA across-sample characteristics in county A were analysed statistically. Analysis of variance (General Linear Model procedure) [42], with the Tukey studentized range test as a multiple comparison procedure, was used to test the differences between level of ID on the RSMB mean 26-item total score and subscale scores as well as the differences between age groups (21–30, 31–40, 41–50, 51–60, 61–70) on the mean 26-item total score and subscale scores. A t-test was used to test the differences between gender on the RSMB mean 26-item total score and subscale scores. The chi-square test was computed to test for PIMRA subscale associations across gender, level of ID and age groups (31–50, 51–94). A value of $p < 0.05$ was considered statistically significant.

Results

The percentages of individuals with RSMB and PIMRA scores above the cut-off points in the samples of ADDEF adults with ID are presented in Table 2.

The overall occurrence of mental health problems according to the cut-off point of the RSMB 26-item total score in the total sample (combined samples area A and B, $n = 294$) was 37% (range 34%–41%).

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

Statistically significant differences were found in the random sample across level of ID and the mean subscale scores of the aggression, autism and avoidant subscales. Persons with severe ID had a significantly higher mean subscale score (mean = 2.58) than persons with moderate and mild ID (mean = 1.40 and 1.36, respectively) on the aggression subscale [$F(2,128) = 5.14, p < 0.01$]. Persons with severe ID had a significantly higher mean subscale score (mean = 1.53) than persons with mild ID (mean = 0.67) on the autism subscale [$F(2,128) = 3.95, p < 0.02$]. Finally, persons with severe ID had a significantly higher mean subscale score (mean = 2.74) than

Table 2 Percentages of individuals with RSMB and PIMRA scores above the cut-off points in ADDEF samples of adults with ID in two Swedish counties (A and B)

	Random sample (A) (n = 134) ¹	Institutional sample (A) (n = 71) ²	Sample (B) (n = 124) ³	Total sample (A and B) (n = 296) ⁴
RSMB 26-item total score (≥ 9)	34	36	41	37
RSMB subscales:				
Aggression	11.2	14.5	16.1	13.3
Autism	6.0	5.8	7.2	6.5
Psychosis	4.5	7.2	4.8	4.8
Paranoia	2.2	2.9	6.4	3.7
Depression (behavioural signs)	3.7	5.8	6.4	5.4
Depression (physical signs)	12.7	7.2	10.5	10.9
Dependent personality disorder	3.7	2.9	2.4	3.4
Avoidant personality disorder	8.9	4.3	7.2	7.5
RSMB special items:				
Drug/alcohol abuse	0.0	0.0	0.0	0.0
Overactive	2.9	4.3	2.4	3.1
Self-injury	8.2	10.1	4.0	6.8
Sexual problem	2.2	4.3	0.0	1.4
Stealing	2.9	2.9	1.6	2.7
Suicidal tendencies	0.0	0.0	0.0	0.0
PIMRA total (≥ 4 items on any subscale)		45	64	54
PIMRA subscales:				
Schizophrenia	–	4.2	17.1	10.6
Affective disorder	–	5.6	15.7	10.6
Psychosexual disorder	–	4.2	4.2	4.2
Adjustment disorder	–	14.1	28.5	21.1
Anxiety disorder	–	18.3	37.1	26.8
Somatoform disorder	–	11.3	11.4	11.3
Personality disorder	–	4.2	11.4	7.7
Inappropriate adjustment	–	28.2	28.1	27.5

Note: The original RSMB cut-off scores and the original PIMRA “four-item rule” (a positive subscale score of ≥ 4 points) have been used in the Swedish samples

¹ Thirty-three persons included in the institutional sample

² Completed RSMB ratings n = 69, completed PIMRA interviews n = 71

³ Completed PIMRA interviews n = 71

⁴ Completed RSMB ratings n = 294, completed PIMRA interviews n = 142

persons with moderate and mild ID (mean = 1.64 and 1.23, respectively) on the avoidant subscale [$F(2,128) = 5.74, p < 0.004$]. There were no statistically significant differences across gender or age groups on the RSMB mean total scores or subscale scores, neither in the random nor in the institutional sample.

The percentages of individuals endorsing the 38 RSMB items as “problem” and “severe problem” according to the staff ratings are presented in Table 3.

The three most frequent RSMB items reported as a problem or a severe problem of the 38 items in the total sample (combined samples area A and B, n = 294) were anxious behaviour, attention-seeking and nonassertive behaviour. Two of these items (anxious behaviour and attention-seeking) 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 ≥ 4 points) was 45 % in the institutional and 64 % in the sample from area B (Table 2).

The most common mental health problems in the two samples according to percentage of persons meeting the criteria on the PIMRA subscales were anxiety and adjustment disorders.

Chi-square analyses of presence or absence of overall mental health problems according to the results on the PIMRA subscales and the two age groups (31–50 and 51–94) in the institutional sample yielded significantly different proportions [$\chi^2(1, N = 71) = 6.54, p < 0.05$]. Among those with mental health problems (n = 31) according to the results on the PIMRA subscales, 77 % (n = 24) were found to be between 51 and 94 years of age. Chi-square analyses of presence or absence of mental health problems by gender, and level of ID yielded no significant associations.

■ Referred sample

The frequency of mental disorders according to DSM-III-R and DSM-IV and individuals with RSMB total score above the cut-off point in the referred sample of ADDEF samples of adults with ID referred for assess-

Table 3 The percentages of individuals endorsing the 38 RSMB items as “problem” or “severe problem” according to staff ratings in Swedish samples of adults with ID in two counties (A and B)

RSMB item	Random sample (A) (n = 134) ¹	Institutional sample (A) (n = 69)	Sample (B) (n = 124)	Total sample (A and B) (n = 294)
Aggressive (1)	28.6	37.7	36.2	32.6
Anxious (2)	40.1	44.9	58.0	48.6
Attention-seeking (3)	41.3	38.8	39.4	39.4
Body stress (4)	27.8	24.6	40.3	32.6
Complaining (5)	17.3	13.0	25.8	20.1
Confused thinking (6)	29.3	31.3	35.4	33.0
Crying spells (7)	15.7	15.9	20.3	17.7
Delusions (8)	11.2	13.0	14.5	12.6
Dependent (9)	22.4	14.5	34.7	26.5
Destructive (10)	13.5	17.4	20.9	17.0
Drug/alcohol abuse (11)	0.7	0.0	8.9	4.1
Eating problem (12)	30.6	26.1	35.5	33.0
Echolalia (13)	8.3	4.4	12.2	9.9
Euphoria (14)	7.5	5.8	12.9	9.9
Fearful (15)	17.9	21.7	25.8	21.8
Hallucinations (16)	14.9	17.4	21.1	17.7
Hostile (17)	24.6	36.2	38.7	32.0
Impulsive (18)	34.6	32.3	39.5	35.7
Inattentive (19)	25.6	26.5	24.2	25.5
Low energy (20)	35.3	32.3	33.8	34.0
Nonassertive (21)	40.1	38.2	34.6	37.1
Object attachment (22)	20.5	17.6	25.0	21.4
Overactive (23)	12.8	17.4	15.4	15.3
Overly sensitive (24)	21.8	20.3	32.2	25.8
Paranoia (25)	19.4	14.7	22.6	19.7
Regressive behaviour (26)	12.0	10.4	15.4	12.9
Sadness (27)	19.7	10.4	21.9	19.4
Self-injury (28)	20.1	24.6	17.0	18.4
Self-stimulatory behaviour (29)	23.3	27.7	23.3	23.8
Sexual problem (30)	7.5	9.0	11.3	10.2
Sleep problem (31)	24.8	25.4	29.8	26.2
Social inadequacies (32)	28.6	16.7	33.8	28.9
Stealing (33)	9.7	8.7	16.1	12.6
Suicidal tendencies (34)	1.5	0.0	6.4	3.4
Temper tantrums (35)	32.1	37.7	41.9	36.4
Tiredness (36)	36.1	23.5	36.3	33.7
Unusual motor movements (37)	20.6	26.9	20.1	20.7
Withdrawn (38)	17.6	10.6	16.2	15.6

¹ Thirty-three persons included in institutional sample

ment to the general mental health services is presented in Table 4.

The results showed that among adults with ID referred to the mental health services the majority were persons with mild or moderate ID suffering from psychotic or affective disorders according to the clinical psychiatric assessment. The results on the RSMB total score indicated that the majority (85%) was recognized as having mental health problems. In 21 of 27 referred cases, the psychiatrists had no information of 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. Among those (3 out of 21 persons) not identified according to the RSMB total score, the co-existing mental disorder for one person with severe ID was adjustment disorder and for two persons with mild ID delusional disorder or cyclothymia according to the clinical assessment.

■ Occurrence of adults with ID among patients receiving out- and in-patient psychiatric care in county A

The registered cases of adults with the ICD-10 diagnosis of ID consulting a psychiatrist at out-patient mental health clinics in 2000 and 2001 were 61 and 64 persons, respectively. They represented approximately 1% per annum of the total registered population consulting a psychiatrist in the county studied. During the same period, 27 (2000) and 20 (2001) adults with ID were registered for admission to psychiatric in-patient care and represented 1.7% and 1.2%, respectively of all patients in the county admitted to in-patient psychiatric care.

The level of ID was registered as mild in 71% (2000) and in 76% (2001) of out-patients, and in 89% (2000) and 90% (2001) of persons admitted to in-patient psychiatric care.

The frequency of ICD-10 mental disorders in addi-

Table 4 The frequency of DSM-III and DSM-IV mental disorders and individuals with RSMB scores above the cut-off point among administratively defined adults with ID referred to a general mental health clinic (n = 27)

DSM-III-R or DSM-IV diagnoses	Mild ID n	Moderate ID n	Severe ID n	Total n (%)
Psychosis NOS	5	3	–	8 (30)
Schizophrenia	1	–	–	1 (4)
Delusional disorder	1	–	–	1 (4)
Depressive disorder	1	2	–	3 (11)
Bipolar disorder	3	2	–	5 (18)
Cyclothymia	1	–	–	1 (4)
Obsessive-compulsive disorder	1	–	–	1 (4)
Adjustment disorder	1	1	1	3 (11)
Pervasive developmental disorder	–	2	–	2 (7)
Organic mental disorder	–	–	1	1 (4)
Impulsive control disorder	1	–	–	1 (4)
Total	15	10	2	27
RSMB ¹	12	10	1	23 (85)

¹ The original RSMB 26-item total cut-off score (≥ 9) indicating mental health problems have been used

tion to the ID diagnosis among patients consulting a psychiatrist or admitted to in-patient psychiatric care during the year 2001 is presented in Table 5.

The results showed that the predominant disorders among persons consulting a psychiatrist were affective, psychotic and anxiety disorders and among persons admitted to in-patient psychiatric care psychotic and personality disorders.

Table 5 The frequency of ICD-10 mental disorders in addition to the ID diagnosis among registered ID patients consulting a psychiatrist or admitted to in-patient psychiatric care during the year 2001

ICD-10 diagnoses	Out-patient psychiatric care				In-patient psychiatric care			
	Mild ID	Moderate ID	Severe ID	Total	Mild ID	Moderate ID	Severe ID	Total
Schizophrenia	9	1	–	10	3	1	–	4
Schizoaffective disorder	1	–	–	1	1	–	–	1
Unspecified psychosis	3	2	–	5	2	–	1	3
Bipolar affective disorder	9	4	2	15	–	–	–	–
Depressive disorder	7	2	–	9	3	–	–	3
Anxiety disorder	8	1	–	9	1	–	–	1
Adjustment disorder	3	–	–	3	1	–	–	1
Eating disorder	1	–	–	1	–	–	–	–
Personality disorder	4	2	–	6	6	–	–	6
Pervasive development disorders	–	1	4	5	1	–	–	1
Organic mental disorders	1	–	–	1	–	–	–	–
Dementia	–	–	–	–	1	–	–	1
Drug/alcohol abuse	3	1	–	4	1	–	–	1

Note: For some individuals, two ICD-10 diagnoses in addition to the ID diagnosis were noted in the case-records. Mild ID includes ICD-10 diagnosis F70: mild mental retardation and F79: unspecified mental retardation. Moderate ID includes ICD-10 diagnosis F71: moderate mental retardation. Severe ID includes ICD-10 diagnosis F72: severe mental retardation and F73: profound mental retardation

Discussion

The results showed that the percentage of individuals meeting the criteria for mental health problems on the RSMB in the Swedish samples was similar to the overall figures reported in two US studies of randomized samples of ADDEF adults with ID [43, 44]. The authors have not found any previous European study using the RSMB instrument for screening of mental health problems in randomized ADDEF samples of adults with ID.

The most common mental health problems in the Swedish samples according to the RSMB subscale score were aggressive behaviour and signs of depression. The reported most common mental health problems in the two US studies were avoidant and dependent behaviour, aggression and paranoia [43, 44]. The most common special maladaptive behaviour item in the Swedish samples was self-injury and in the US samples overactivity. The differences in subscale score profiles between the US and Swedish samples could partly be explained by sample characteristics. The Swedish samples have a larger proportion of persons with a moderate or severe level of ID (72%, 74% and 89%) compared to 54% and 40% in the US samples. According to previous research, there are possible relationships between severe levels of ID, self-injurious and aggressive behaviours [45–49]. 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 [50, 51].

However, a comparison between the Swedish and US samples of the percentage of reported problems among the 38 RSMB items shows that anxious behaviour and at-

attention-seeking 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 characterized as closely connected to the social and psychological consequences of the intellectual disability.

The RSMB was designed for screening and the PIMRA was primarily constructed for diagnostic purposes. A comparison between the overall occurrence of mental health problems according to the total score of the RSMB and the subscale scores of the PIMRA in the Swedish samples showed that a larger proportion of individuals had mental health problems according to the PIMRA scores. However, the instruments were used differently (direct staff ratings versus staff interviews) and have different scoring methods (the total and subscale scores of the RSMB were based on the average scores of two raters and a diagnosis based on the PIMRA was based on a "yes" response to four items). These differences could explain the different proportions found.

The authors have found two previous studies (a randomized ADDEF and an institutional sample) using the PIMRA (informant version) for investigation of mental health problems among adults with ID. The overall occurrence of mental health problems according to the PIMRA in the Swedish area B sample was higher than the reported figure in a US random sample of ADDEF adults with ID [16]. 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). The overall occurrence of mental health problems in the Swedish institutional sample was lower than the reported figure in a Norwegian institutional sample [52]. 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 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.

Furthermore, the analyses showed that a larger proportion of older persons (51–94 years of age) in the Swedish institutional sample had mental health problems. It is likely that the older group of persons with ID living in the Swedish institution have had a long history of institutional care and behavioural or mental health problems.

The present results of overall occurrence of mental health problems were comparable with overall occurrence (range 22%–64%) in studies using other broad-spectrum maladaptive behaviour or diagnostic scales in randomized or geographical total samples of ADDEF adults with ID in the UK and Denmark [11, 24, 53–55].

Methodological limitations relating to the assess-

ment instruments and the sampling frame should be discussed. Unfortunately, it was not possible to obtain PIMRA assessments for the whole Swedish sample due to practical limitations during this transitional period of services. Problems concerning the validity of diagnoses when using the PIMRA among persons with more severe levels of ID have been reported. Another problem relating to the two instruments is that they cover different aspects of mental health problems. The RSMB include a variety of maladaptive behaviours but do not include strict diagnostic criteria (ICD or DSM). The PIMRA results were not assessed in accordance with the hierarchy of the DSM system (i.e. some diagnoses take precedence over others). The PIMRA manual states further that its use in providing DSM-III diagnoses is only in conjunction with other methods of clinical assessment and, consequently, the present study failed to consider differential diagnosis. Concerning the sampling frame (i.e. administrative definition of ID), the study was carried out in natural settings among adults with ID receiving special services. It has been reported that the probability of being known to the ID services rises with the severity of ID implying that all persons with intellectual disabilities particularly in the mild ID level range were not covered by the present sampling method [3]. Furthermore, the ratings of intellectual level in this study must be regarded as preliminary because the reported intellectual ability levels used were not based on IQ scores.

■ Referred sample

The majority of the ADDEF sample referred for psychiatric assessment had a psychotic or affective disorder according to the DSM-III-R or DSM-IV criteria and a mild or moderate level of ID. Of the 21 persons in the referred sample, in which the psychiatrists had no information of the results on the RSMB prior to the clinical assessment, the results on the RSMB total score according to staff rating showed that 86% had been identified as having mental health problems. Thus, the RSMB instrument had a good potential to identify adults with ID and coexisting mental disorders in the present study.

■ Mental health care registers

The occurrence of adults with the ICD-10 diagnosis of ID among patients receiving out- or in-patient psychiatric care in 2000 and 2001 was approximately 1% and approximately 70%–90% of these persons had a mild level of ID.

However, the restrictions and potential sources of bias concerning register data should be considered. We had no information concerning the diagnostic assessment procedures that have been used. The uncertainty regarding "true cases" according to the strict criteria based on low IQ (< 70) and impairment of skills mani-

fested during the developmental period is particularly relevant in the group with mild ID.

The results from a prior Swedish investigation of ADDEF persons with ID suggested 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 [26]. Due to changes in the administrative routines, a register identifying persons receiving special services was no longer available at the time of the present study. Consequently, it has not been possible to investigate how many of the reported cases of adults with ID according to mental health care registers were ADDEF (i. e. received special services). 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 were available [28, 56]. Assuming that all persons with ID who were admitted to psychiatric in-patient care or consulting a psychiatrist at outpatient 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 has been low [29]. This could explain the overrepresentation found of individuals with mild ID receiving out- or in-patient psychiatric care.

Conclusions

The overall occurrence of mental health problems in Swedish ADDEF samples of adults with ID ranged from 34% to 64%. The figures were similar to reported overall figures of mental health problems based on broad-spectrum maladaptive behaviour or diagnostic scales in randomized or geographical total samples of ADDEF adults with ID in the US, the UK and Denmark.

The most common mental health problems were aggressive and self-injurious behaviours, signs of depression and anxiety or adjustment problems.

The result indicated that the RSMB had a good potential to identify adults with ID and coexisting DSM-III-R or DSM-IV mental disorders.

Among adults with ID registered for out- or in-patient psychiatric care the majority had a mild level of ID. These results indicate 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 had actually 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 psy-

chiatric assessment. Thus, in the absence of specialized assessment, there is a potential risk that mental health problems in persons with ID go unrecognized or are inaccurately assessed and treated.

Future research should focus more specifically on the recognition of mental health problems in persons with moderate and severe ID and on the outcome of psychiatric treatment and care in adults with ID.

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References

- Eaton LF, Menolascino FJ (1982) Psychiatric disorders in the mentally retarded: types, problems and challenges. *Am J Psychiatry* 139:1297-1303
- Menolascino FJ, Levitas A, Greiner C (1986) The nature and types of mental illness in the mentally retarded. *Psychopharmacol Bull* 22:1060-1071
- Moss S (2001) Psychiatric disorders in adults with mental retardation. In: Glidden L (ed) *International Review of Research in Mental Retardation*, Academic Press, New York
- Reid AH (1989) Schizophrenia in mental retardation: clinical features. *Res Devel Disab* 10:241-249
- Sovner RS, Hurley AD (1983) Do the mentally retarded suffer from affective illness? *Arch Gen Psychiatry* 40:61-67
- Szymanski L, Grossman H (1984) Dual implications of "dual diagnosis". *Ment Retardation* 22:155-156
- Fraser W, Nolan M (1994) Psychiatric disorders in mental retardation. In: Bouras N (ed) *Mental health in mental retardation: Recent advances and practices*. New York, US: Cambridge University Press
- Borthwick-Duffy SA (1994) Epidemiology and prevalence of psychopathology in people with mental retardation. *J Consult Clin Psychol* 62:17-27
- Cooper S-A (1997) Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *Br J Psychiatry* 170:375-380
- Day K (1985) Psychiatric disorder in the middle-aged and elderly mentally handicapped. *Br J Psychiatry* 147:660-667
- Deb S, Thomas M, Bright C (2001a) Mental disorder in adults with intellectual disability. 1: prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *J Intellect Dis Res* 45:495-505
- Janicki MP, Davidson PW, Henderson CM, et al. (2002) Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *J Intellect Dis Res* 46:287-298
- Lund J (1985) The prevalence of psychiatric morbidity in mentally retarded adults. *Acta Psychiatr Scand* 72:563-570
- Borthwick-Duffy SA, Eyman RK (1990) Who are the dually diagnosed? *Am J Ment Retard* 94:586-595
- Göstason R (1985) Psychiatric illness among the mentally retarded. A Swedish population study. *Acta Psychiatr Scand* 7(Suppl 318):1-117
- Iverson JC, Fox RA (1989) Prevalence of psychopathology among mentally retarded adults. *Res Devel Disab* 10:77-83
- Jacobson JW (1982) Problem behavior and psychiatric impairment within a developmentally disabled population I: behavior frequency. *Applied Res Ment Retard* 3:121-139
- Rutter M, Tizard J, Yule W, Graham P, Whitmore K (1976) Research report: Isle of Wight studies, 1964-1974. *Psychol Med* 6:313-332

19. Reiss S (1988) Reiss Screen for Maladaptive Behaviour Test Manual. IDS Publishing Corporation, Worthington, OH
20. Matson JL (1988) The PIMRA manual: International Diagnostic Systems, Inc, Orland Park, IL
21. Moss S, Prosser H, Goldberg D (1996) Validity of the schizophrenia diagnosis of the Psychiatric Assessment Schedule for adults with Developmental Disability (PAS-ADD). *Br J Psychiatry* 168: 359–367
22. Moss S, Prosser H, Costello H, et al. (1998) Reliability and validity of the PAS-ADD checklist for detecting psychiatric disorders in adults with intellectual disability. *J Intellect Disab Res* 42: 173–183
23. Prosser H, Moss S, Costello H, Simpson N, Patel P, Rowe S (1998) Reliability and validity of the Mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability. *J Intellect Disab Res* 42:264–272
24. Roy A, Martin DM, Wells MB (1997) Health gain through screening – mental health: developing primary health care services for people with an intellectual disability. *J Intellect Devel Disab* 22: 227–239
25. Dorn TA, Prout HT (1993) Service delivery patterns for adults with mild mental retardation at community mental health centers. *Ment Retardation* 31:292–296
26. Gustafsson C (1997) The prevalence of people with intellectual disability admitted to general hospital psychiatric units: Level of handicap, psychiatric diagnoses and care utilization. *J Intellect Disab Res* 41:519–526
27. SFS (1985) Lag om särskilda omsorger om psykiskt utvecklingsstörda m fl. Act on special services for mentally retarded and others 568
28. SFS (1993) Lag om stöd och service till vissa funktionshindrade LSS. Act on support and services for persons with certain functional impairment 387
29. Grunewald K (1979) Mentally retarded children and young people in Sweden. Integration into society: the progress in the last decade. *Acta Paediatr Scand* 275:75–84
30. Gustafsson C, Sonnander K (2002) Psychometric evaluation of a Swedish version of the Reiss Screen for Maladaptive Behavior. *J Intellect Disab Res* 46:218–229
31. Gustafsson C, Sonnander KA (Submitted) Psychometric evaluation of a Swedish version of The Psychopathology Inventory for Mentally Retarded Adults (PIMRA)
32. American Psychiatric Association (1980) Diagnostic and statistical manual of mental disorders, 3rd ed. (DSM-III) APA, Washington, DC
33. Haverkamp S, Reiss S (1997) The Reiss Screen for Maladaptive Behavior: confirmatory factor analysis. *Behav Res Ther* 35: 967–971
34. Linaker OM (1991) DSM-III Diagnoses compared with factor structure of the Psychopathology Instrument for Mentally Retarded Adults (PIMRA), in an Institutionalized, Mostly Severely Retarded Population. *Res Devel Disab* 12:143–153
35. Matson JL, Kazdin AE, Senatore V (1984) Psychometric properties of the psychopathology instrument for mentally retarded adults. *Applied Res Ment Retard* 5:81–89
36. Prout HT (1993) Assessing psychopathology in persons with mental retardation: a review of the Reiss scales. *J School Psychol* 31:535–540
37. WHO (1968) Organization of services for the mentally retarded. WHO Techn Rep Ser, 392
38. Kyhlen G (1974) Psykiskt utvecklingshämmandes förstånd. Stiftelsen ALA, Stockholm
39. American Psychiatric Association (1987) Diagnostic and statistical manual of mental disorders, 3rd ed. Rev. (DSM-III-R). APA, Washington, DC
40. American Psychiatric Association (1994) Diagnostic and statistical manual of mental disorders, 4th ed. (DSM-IV). APA, Washington, DC
41. World Health Organization (WHO) (1992) International Classification of Diseases – 10th Revision (ICD-10), WHO, Geneva
42. Statistical Analysis System (1999) Version 8, SAS Institute Inc, Cary, NC
43. Reiss S (1990) Prevalence of dual diagnosis in community-based day programs in the Chicago metropolitan area. *Am J Ment Retard* 94:578–585
44. Sturmeijer P, Burcham JA, Shaw B (1996) The frequency of Reiss screen diagnoses in a community sample of adults with mental retardation. *Behav Interventions* 11:87–94
45. Collacott RA, Cooper S-A, Branford D, McGrother C (1998) Epidemiology of self-injurious behaviour in adults with learning disabilities. *Br J Psychiatry* 173:428–432
46. Emerson E, Kiernan C, Alborz A, et al. (2001) The prevalence of challenging behaviors: a total population study. *Res Devel Disab* 22:77–93
47. Kebbon L, Windahl S-I (1986) Self-injurious behaviour – results of a nation-wide survey among mentally retarded persons in Sweden. In: Berg JM, Dejong JM (eds) Science and service in Mental Retardation. London: Methuen
48. King BH, DeAntonio C, McCracken JT, Forness SR, Ackerland V (1994) Psychiatric consultation in severe and profound mental retardation. *Am J Psychiatry* 151:1802–1808
49. Read S (1998) Self-injury and violence in people with severe learning disabilities. *Br J Psychiatry* 172:381–384
50. Marston GM, Perry DW, Roy A (1997) Manifestations of depression in people with intellectual disability. *J Intellect Disab Res* 41:476–480
51. Meins W (1995) Symptoms of major depression in mentally retarded adults. *J Intellect Disab Res* 39:41–45
52. Linaker OM, Nitter R (1990) Psychopathology in institutionalized mentally retarded adults. *Br J Psychiatry* 156:522–525
53. Deb S, Thomas M, Bright C (2001b) Mental disorder in adults with intellectual disability. 2: The rate of behaviour disorders among a community-based population aged between 16 and 64 years. *J Intellect Disab Res* 45:506–514
54. Lund J (1986) Behavioural symptoms and autistic psychosis in the mentally retarded adult. *Acta Psychiatr Scand* 73:420–428
55. Smith S, Branford D, Collacott RA, Cooper S-A, McGrother C (1996) Prevalence and cluster typology of maladaptive behaviours in a geographically defined population of adults with learning disabilities. *Br J Psychiatry* 169:219–227
56. Official statistics of Sweden (2001) Care inputs for persons with impairments 2000. The National Board of Health and Welfare