

## Mental ill-health in adults with intellectual disabilities: prevalence and associated factors

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**Background** Reported prevalence of mental ill-health among adults with intellectual disabilities ranges from 7 to 97%, owing to methodological limitations. Little is known about associations.

**Aims** To determine the prevalence of mental ill-health in adults with intellectual disabilities and to investigate factors independently associated with it.

**Method** Population-based study ( $n=1023$ ) with comprehensive individual assessments modelled using regression analyses.

**Results** Point prevalence of mental ill-health was 40.9% (clinical diagnoses), 35.2% (DC–LD), 16.6% (ICD–10–DCR) and 15.7% (DSM–IV–TR). The most prevalent type was problem behaviours. Mental ill-health was associated with more life events, female gender, type of support, lower ability, more consultations, smoking, incontinence, not having severe physical disabilities and not having immobility; it was not associated with deprived areas, no occupation, communication impairment, epilepsy, hearing impairment or previous institutional residence.

**Conclusions** This investigation informs further longitudinal study, and development of appropriate interventions, public health strategy and policy. ICD–10–DCR and DSM–IV–TR undercount mental ill-health in this population compared with DC–LD.

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The prevalence of mental ill-health among adults with intellectual disabilities is unknown. Existing studies have methodological limitations, accounting for the wide discrepancy in reported prevalence rates which range from 7 to 97% (Wright, 1982; Borthwick-Duffy & Eyman, 1990; Linaker & Nitter, 1990; King *et al*, 1994). Limitations have included biased sampling; reliance upon existing case-note information or instruments designed as screening tools only; lack of information on the extent of detail within assessments, the instruments or the diagnostic criteria used; and in population-based studies, small cohort sizes. Other limitations include failure to indicate whether rates are lifetime or point prevalence; reporting combined prevalence for children and adults; reporting mental ill-health in total, but not describing or being comprehensive as to what is included; and studying selected subgroups such as adults only with verbal communication skills. These limitations prevent replication of findings, and account for the current confusion within the existing literature. Apart from behavioural phenotypes, little is known of the factors associated with mental ill-health in adults with intellectual disabilities (Smiley, 2005).

We report here the findings from a large-scale population-based study with clearly described methods, which was conducted to determine the prevalence of mental ill-health among adults with intellectual disabilities and to investigate the factors independently associated with mental ill-health.

### METHOD

#### Ethics

The project was approved by the relevant research ethics committee. Individual consent to participate was taken from each person with intellectual disabilities as far as that person had decision-making capacity

to consent, with assent given by the nearest carer when the participant lacked such capacity.

#### Case ascertainment

A process of case ascertainment was conducted in the Greater Glasgow Health Board area of Scotland. Identification of all adults with intellectual disabilities aged 16 years and over was determined through social work services for people with intellectual disabilities; local authority funding arrangements for persons receiving paid support of any kind, including day opportunities; local specialist health services for people with intellectual disabilities; the Health Board; the Scottish Executive Statistical Department; and primary healthcare services. Over the period 2002–2004, all of Greater Glasgow's general practitioners and family physicians ( $n=631$ ) worked with the project, and were paid an item-of-service fee for each person with intellectual disabilities whom they identified as registered with them and within the project remit. This process led initially to an over-identification of possible participants, such as people with IQ scores in the 70–80 range and additional complex health needs; such individuals were excluded from the research. We believe the case ascertainment process to have been comprehensive: a rate of 3.33 per 1000 adult general population was yielded, which is similar to other large-scale case ascertainment (Farmer *et al*, 1993; McGrother *et al*, 2001).

#### Process

Each participant underwent a detailed assessment by one of a team of six registered nurses, who had specialist qualifications in working with adults with intellectual disabilities and who were trained in the use of the assessment instruments, and one of three general practitioners, who had a special interest in working with adults with intellectual disabilities. They reviewed each participant's primary healthcare case notes using a semi-structured format, then undertook a detailed face-to-face assessment with each participant, supported by their paid or family carer. In all cases, assessments completed by the nurses were discussed with one of the three general practitioners. Participants identified as possibly, probably or definitely having mental ill-health were notified to the project psychiatrists, who were specialists in working with adults with intellectual

disabilities. These psychiatrists undertook in each case a review of the current and previous intellectual disabilities psychiatry, general psychiatry, child psychiatry and psychology case notes where such notes existed and (where indicated) other secondary physical healthcare case notes, and conducted psychiatric assessments of the person with intellectual disabilities, supported by one or more carers, for diagnostic clarification. Diagnoses were derived according to clinical, DC-LD (Royal College of Psychiatrists, 2001), ICD-10-DCR (World Health Organization, 1993) and DSM-IV-TR (American Psychiatric Association, 2000) diagnostic criteria.

## Materials

The assessments were conducted using the following measures.

### Primary healthcare form

A purpose-designed, semi-structured form to review primary healthcare case notes was completed to provide essential background information necessary to inform psychiatric assessment.

### PAS-ADD Checklist

The Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) Checklist (Moss *et al.*, 1998) was designed as a mental health screening tool for use with adults with intellectual disabilities. As its specificity was not relevant in this project, in order to improve its sensitivity from that previously reported (Moss *et al.*, 1998; Simpson, 1999; Sturmey *et al.*, 2005), and following a pilot exercise with 50 people (Curtice *et al.*, 2001), we used a lower cut-off threshold of any two symptoms (excluding specific phobias) or any one high-risk symptom, which we defined to include the items for suicidal attempts or thoughts, persecutory behaviour, and hallucinations or delusions, and we counted identified symptoms whether or not they were thought by the carer to be a problem (unlike the standard scoring procedure of the PAS-ADD Checklist at the time).

### C21st Health Check

The C21st Health Check (Glasgow University Affiliated Programme, 2001) includes assessment sections on mental ill-health, problem behaviours, autistic-spectrum disorders, developmental level and support

needs, as well as general physical health, and has been demonstrated to have good utility (Curtice *et al.*, 2001). It also has a section for a selected physical examination, including assessment of vision and hearing. The sections on mental ill-health, problem behaviours and autistic disorders were used to trigger referral for full psychiatric assessment of participants who scored below our cut-off value on the PAS-ADD Checklist. Assessment of physical health was necessary to exclude any possible physical cause of apparent psychiatric presentation, and measurement of physical health items provided data for statistical investigation of associations with mental ill-health.

### Demographic data

A purpose-designed demographic form was used to collect information on the demographic factors to be investigated, including full postcode information, from which an area-based measure of socio-material deprivation was derived, using the Carstairs index which is in widest use for this purpose in Scotland (Carstairs & Morris, 1989).

### Blood testing

A phlebotomy protocol was established to ensure (for example) that every person with Down syndrome had up-to-date thyroid function testing. This was necessary to exclude possible physical causes of psychiatric presentations.

### Full psychiatric assessment

Individuals who were referred for full psychiatric assessment were additionally investigated with the following instruments:

- (a) a purpose-designed semi-structured form to review case notes for essential current and background information;
- (b) a comprehensive semi-structured assessment format with consultant-level diagnoses;
- (c) the Present Psychiatric State for Adults with Learning Disabilities (PPS-LD; Cooper, 1997); a semi-structured psychopathology schedule specifically designed for use with adults with intellectual disabilities, which now allows classification of psychopathology by clinical, DC-LD, ICD-10-DCR, and DSM-IV-TR criteria;
- (d) purpose-designed instruments containing items to detect the psychopathology listed in autistic-spectrum

disorders and hyperkinetic disorders contained within DC-LD, ICD-10-DCR, and DSM-IV-TR, and also problem behaviours as defined by DC-LD; these were designed to be used within the context of a full psychiatric assessment, and suitable for use by trained psychiatrists;

- (e) the Test for Severe Impairment (Albert & Cohen, 1992); this provides an assessment of current cognitive ability, an overview of which can be compared with information available from case notes and informants;
- (f) the Vineland Scale (Survey Form) (Sparrow *et al.*, 1984); this provides a measure of current level of adaptive functioning and was also used to measure best-ever level of functioning, in cases where functional level had regressed; it was included to assess ability level in keeping with ICD-10-DCR criteria, and to contribute in part to the assessment of dementia.

### Determination of ability level

Level of intellectual ability was determined by scores on the Vineland Scale (Survey Form) and results of previous IQ tests recorded in case notes and primary care records. The C21st Health Check includes a section which measures developmental level through a series of questions on the person's skills and support needs. Total scores are highly correlated with developmental age as measured by the Vineland Scale (Survey Form): Pearson's correlation  $r=0.812$ ;  $P<0.001$ . The C21st Health Check additionally requires the professional to apply clinical judgement if the skills and support needs score is lowered because of non-cognitive factors such as cerebral palsy. A level of ability in keeping with the ICD-10-DCR classification is therefore derived. In this study, for participants who did not have a Vineland Scale (Survey Form) completed nor a record of previous IQ testing, the assessed level of ability from the C21st Health Check was used. For people whose skills had declined (e.g. because of dementia or schizophrenia), a retrospectively completed 'best-ever' Vineland Scale score was used rather than the current score.

### Determination of mental health status

The semi-structured interview format followed by the psychiatrists was comprehensive and in keeping with best practice; more

detailed information on such assessments of mental ill-health in persons with severe and profound intellectual disabilities has been reported elsewhere (Cooper, 2003). The assessment included at least one face-to-face meeting with the person with intellectual disabilities, and also with the person's main carer. If the latter was a paid carer, parents or other close relatives were also interviewed if available. Information was sought from additional paid carers as required: typically this depended upon the length of time the main paid carer had known the person and the level of detail of current and background information known to that carer. Previous and current case notes were also reviewed by the psychiatrists. The first appointment was scheduled for a 1.5 h duration, and subsequent appointments arranged as required until all necessary information had been collected about current psychopathology, its severity and duration, and differentiation between longstanding characteristics and symptoms of mental ill-health, rated within the context of the person's overall developmental level, using the rating scales. Information was also collected on the participant's past psychiatric history, previous and current medical history, current and previous drug use and mental health interventions, past and current medical and psychiatric history of family members, personal background, social circumstances and social networks, developmental history and current developmental level, and personality development. A mental state examination was conducted. Physical health had already been assessed. The information from the sources was integrated, clinical diagnoses were determined by consultant psychiatrists specialised in working with adults with intellectual disabilities, and psychopathology was classified using the three diagnostic classificatory systems.

### Analyses

Data were entered onto a personal computer and analysed using the Statistical Package for the Social Sciences version 11.5 for Windows. Frequency data were derived for point prevalence rates. Associations were investigated between each of 20 variables – age; gender; marital status; level of ability; presence of visual impairment; presence of hearing impairment; presence of epilepsy; presence of severe physical disabilities (quadriplegia); presence of mobility impairment; presence of

communication impairment; presence of incontinence of urine; presence of incontinence of bowels; type of living or support arrangement; whether previously a long-stay hospital resident, area-based measure of deprivation for the area in which the person lived; whether the person had any type of daytime occupation; number of consultations with the general practitioner or family physician within the preceding 12-month period; number of hospital admissions in the preceding 12-month period; number of life events in the preceding 12-month period; whether the person smoked – with whether or not the person had mental ill-health of any type (excluding autistic-spectrum disorder and specific phobias). Autistic-spectrum disorders were excluded from the analyses because such developmental disorders with onset in early childhood and continuation thereafter throughout life were conceived as possibly differing from mental ill-health with onset in adolescence or adulthood; participants with autistic-spectrum disorder were only included in the mental ill-health category if they additionally had a point prevalence of other mental ill-health of any type, excluding specific phobia. Binary logistic regression analysis was undertaken to determine the factors independently associated with the dependent variable 'mental ill-health of any type' (excluding autistic-spectrum disorder and specific phobias). The backwards stepwise model was used with likelihood ratio tests determining statistical significance for removal of each factor. At each step, the regressor with the smallest partial correlation was removed if it met the removal criterion, which was set at 0.05. The analyses were then repeated for the group of participants with moderate to profound intellectual disabilities only.

## RESULTS

### Cohort characteristics

Assessments were completed for 70.6% of the total eligible adult population with intellectual disabilities, among whom valid consent or assent for research was recorded for 92.7%. The resultant cohort of 1023 adults comprised 562 men (54.9%) and 461 women (45.1%) and had a mean age of 43.9 years (range 16–83). Levels of ability ranged from mild in 398 (38.9%), through moderate in 248 (24.2%) and severe in 193 (18.9%), to profound intellectual disabilities in 184 (18.0%). Of

this cohort 390 (38.1%) lived with a family carer, 467 (45.7%) lived with paid support, 102 (10.0%) lived independently of paid support and 64 (6.3%) lived in a congregate care setting, such as a nursing home designed to care for older, frail people. Most of the cohort (95.7%) were single and 96.4% were White. For 186 (18.2%) participants the cause of their intellectual disabilities was Down syndrome.

Of the 1023 adults, 552 (54.0%) were identified by the assessment as possibly, probably or definitely having mental ill-health, and 517 (93.7% of these 552 individuals or 50.5% of the whole cohort) were notified to and reviewed by the intellectual disabilities psychiatrists. Of these 552 participants, 277 (50.2%, or 27.1% of the whole cohort) were already receiving care from an intellectual disabilities psychiatrist or psychologist at the time of the assessment. The 35 (3.4%) non-notified participants had been identified at the assessment as having minor problem behaviours only.

### Prevalence of mental ill-health

Table 1 reports the point prevalence rates of mental ill-health in the cohort. Findings are presented separately for diagnoses using clinical, DC-LD, ICD-10-DCR and DSM-IV-TR diagnostic criteria. The terms used in the table to describe the diagnostic categories are not identical to those used in all the diagnostic manuals as they differ between the manuals, but the correct operational diagnostic criteria as outlined in each manual are used. Only diagnostic categories where the diagnostic criteria are operationalised were included, hence (for example) DC-LD 'other', ICD-10-DCR 'other', and DSM-IV-TR 'not otherwise specified' (NOS) categories were not included, except where criteria were cited (as these 'other' and 'NOS' categories are essentially clinical diagnoses).

Specific phobias were excluded from our prevalence rates, as were previous episodes of ill-health that had resolved by the time of the assessment, with the exception of schizophrenia/schizoaffective disorder, currently in remission, and bipolar affective disorder, currently euthymic, which we included in the reported rates. Our category of 'mental ill-health of any type' follows these same inclusion/exclusion rules. Table 2 provides details of the diagnoses within categories that were sought: no one within the cohort was found to be in episode with

**Table 1** Point prevalence rates of mental ill-health as defined by clinical, DC-LD, ICD-10-DCR, and DSM-IV-TR diagnostic criteria

Diagnostic category	Clinical diagnosis	DC-LD diagnosis	ICD-10-DCR	DSM-IV-TR diagnosis
	(n=1023) %	(n=1023) %	diagnosis (n=1023) %	(n=1023) %
Psychotic disorder <sup>1</sup>	4.4	3.8	2.6	3.4
Affective disorder	6.6	5.7	4.8	3.6
Anxiety disorder <sup>2</sup>	3.8	3.1	2.8	2.4
OCD	0.7	0.5	0.2	0.2
Organic disorder	2.2	2.1	1.9	1.7
Alcohol/substance use disorder	1.0	0.8	0.8	0.8
Pica	2.0	2.0	0	0.9
Sleep disorder	0.6	0.4	0.2	0.2
ADHD	1.5	1.2	0.5	0.4
Autistic-spectrum disorder	7.5	4.4	2.2	2.0
Problem behaviour	22.5	18.7	0.1	0.1
Personality disorder	1.0	0.8	0.7	0.7
Other mental ill-health	1.4	0.8	0.7	0.4
Mental ill-health of any type, excluding problem behaviours and autistic-spectrum disorder <sup>2</sup>	22.4	19.1	14.5	13.9
Mental ill-health of any type, excluding autistic-spectrum disorder <sup>2</sup>	37.0	32.8	14.6	14.0
Mental ill-health of any type, excluding problem behaviours <sup>2</sup>	28.3	22.4	16.5	15.6
Mental ill-health of any type <sup>2</sup>	40.9	35.2	16.6	15.7

ADHD, attention-deficit hyperactivity disorder; OCD, obsessive-compulsive disorder.

1. Includes schizoaffective disorders.

2. Excludes specific phobias.

**Table 2** Disorders included within each of the diagnostic categories

Diagnostic category	Diagnostic codes		
	DC-LD <sup>1</sup>	ICD-10-DCR	DSM-IV-TR
Psychotic disorder	3.1, 3.2	F20.0–20.3, F20.5, F22.0, F23.0–23.2, F25.0–25.2, F6.0–6.2, F10.5, F12.5	295.10–295.70, 295.90, 297.1, 298.8, 293.81–293.82, 291.3, 291.5, 292.11, 292.12
Affective disorder	4.1–4.3 (excluding 4.liv)	F30.0–30.2, F31.0–31.7, F32.0–32.3, F33.0–33.3, F34.0, F34.1, F38.0, F6.3	296.00–296.89 (excluding 296.25, 296.26, 296.35, 296.36, 296.8), 293.83, 300.4, 301.13
Anxiety disorder	5.1, 5.2, 5.4, 5.5, 5.9, 5.10	F40.0, F40.1, F41.0–41.1, F43.0–43.2, F6.4	300.01, 300.02, 300.21–300.23, 308.3, 309.81, 309.0, 309.24–309.4, 309.9
OCD	5.8	F42.0–42.2	300.3
Organic disorder	1.1–1.4, 2.1	F0.0–0.2, F1.0–1.3, F2.0–2.8, F3, F4, F5.0, F5.1, F10.4, F10.6	290.0–290.43, 291.0–291.2, 292.81, 293.0, 294.0, 294.1, 294.9, 294.10
Alcohol/substance use disorder <sup>1</sup>		F10.1, F10.2, F12.1, F12.2	303.9, 305.0, 304.3, 305.2
Pica	6.9		307.52
Sleep disorder <sup>1</sup>		F51.0, F51.2	307.42, 307.45
ADHD	7.1, 7.2	F90.0, F90.1	314.00, 314.01
Autistic-spectrum disorder	1.1, 1.2	F84.0, F84.1	299.00
Problem behaviour	1.2–1.12	F91.0–91.3	312.8, 313.81, 312.34
Personality disorder	1.1–1.7	F60.0–60.8, F7.0–7.2	301.0, 301.2–301.22, 301.4–301.83, 310.1
Other mental ill-health <sup>1</sup>		F65.0, F65.4, F95.2	302.2, 302.81, 307.23

ADHD, attention-deficit hyperactivity disorder; OCD, obsessive-compulsive disorder.

1. For DC-LD, ICD-10-DCR diagnoses included as per the instructions within DC-LD.

some of the disorders that were sought, e.g. DSM-IV-TR brief psychotic disorder and alcohol-induced psychotic disorder. Mild as well as severe problem behaviours are included in that category, accounting for the high prevalence rate in women.

Some participants met criteria for more than one disorder: 605 participants (59.1%) had no clinical diagnosis, 297 (29.1%) had one, 94 (9.2) had two, 25 (2.4%) had three and 2 (0.2%) had four clinical diagnoses. The breakdown of diagnoses within the overarching diagnostic groupings shown in Table 1 necessarily vary by the diagnostic classification used, as these differ between the systems. The following breakdown refers to clinical diagnoses. For affective disorders (6.6% of the cohort), 4.1% were unipolar depressive episodes, 0.5% were bipolar depressive episodes, 0.6% were manic episodes, 1.2% were bipolar disorder in which the

participant was euthymic at the time of assessment, and 0.3% were cyclothymic disorder. Within the psychosis category, 2.9% were schizophrenia in episode, 0.4% were schizophrenia in remission, 0.2% were schizoaffective disorders in episode and 0.9% were other types of non-affective psychosis, in episode. In the anxiety category, 1.7% were generalised anxiety disorder, 0.7% were agoraphobia, 0.3% social phobia, 0.5% adjustment disorder, 0.3% post-traumatic stress disorder, 0.2% panic disorder, 0.2% mixed anxiety and depression and 0.2% other anxiety disorders (where the breakdowns do not appear to sum to the point prevalence for the overarching category, this is owing to the figures being rounded to one decimal place).

Table 3 reports point prevalence rates of clinical diagnosis of mental ill-health for the 1023 adults by gender and by ability level. As in Table 1, specific phobias are

excluded; schizophrenia/schizoaffective disorder, currently in remission and bipolar affective disorder currently euthymic are included, but all other previous episodes of mental ill-health which were resolved by the time of the assessment were excluded.

**Associations with mental ill-health**

For the whole cohort of 1023 participants, the factors found to be independently associated with mental ill-health of any type (excluding autistic-spectrum disorders and specific phobias) were as follows: having profound intellectual disabilities; having severe intellectual disabilities; having experienced a higher number of life events in the preceding 12-month period; having a higher number of consultations with the general practitioner or family physician in the preceding 12-month period; being a smoker; living with paid carer support; not having

**Table 3** Point prevalence rates of clinical diagnosis of mental ill-health at different ability levels and by gender

Diagnostic category	Mild intellectual disabilities (n=398)			Moderate to profound intellectual disabilities (n=625)			All ability levels (n=1023)		
	Men (n=204)	Women (n=194)	Total (n=398)	Men (n=358)	Women (n=267)	Total (n=625)	Men (n=562)	Women (n=461)	Total (n=1023)
	%	%	%	%	%	%	%	%	%
Psychotic disorder <sup>1</sup>	6.9	4.6	5.8	2.8	4.5	3.5	4.3	4.6	4.4
Affective disorder	5.9	7.2	6.5	5.3	8.6	6.7	5.5	8.0	6.6
Anxiety disorder <sup>2</sup>	5.4	6.7	6.0	2.2	2.6	2.4	3.4	4.3	3.8
OCD	0	1.5	0.8	0.6	0.7	0.6	0.4	1.1	0.7
Organic disorder	0.5	3.1	1.8	3.1	1.5	2.4	2.1	2.2	2.2
Alcohol/substance use disorder	2.5	1.0	1.8	0.8	0	0.5	1.4	0.4	1.0
Pica	0	0.5	0.3	3.9	1.9	3.0	2.5	1.3	2.0
Sleep disorder	1.0	0	0.5	0.6	0.7	0.6	0.7	0.4	0.6
ADHD	0	0	0	2.0	3.0	2.4	1.2	1.7	1.5
Autistic-spectrum disorder	5.4	1.5	3.5	13.4	5.6	10.1	10.5	3.9	7.5
Problem behaviour	11.3	14.9	13.1	24.3	34.1	28.5	19.6	26.0	22.5
Personality disorder	0.5	1.0	0.8	1.1	1.1	1.1	0.9	1.1	1.0
Other mental ill-health	1.0	1.0	1.0	0.6	3.0	1.6	0.7	2.2	1.4
Mental ill-health of any type, excluding problem behaviours and autistic-spectrum disorder <sup>2</sup>	22.1	22.7	22.4	20.7	24.7	22.4	21.2	23.9	22.4
Mental ill-health of any type, excluding autistic-spectrum disorder <sup>2</sup>	29.9	34.5	32.2	36.3	44.9	40.0	34.0	40.6	37.0
Mental ill-health of any type, excluding problem behaviours <sup>2</sup>	26.5	24.2	25.4	30.7	29.6	30.2	29.2	27.3	28.3
Mental ill-health of any type <sup>2</sup>	33.3	35.6	34.4	42.4	48.7	45.0	39.0	43.2	40.9

ADHD, attention-deficit hyperactivity disorder; OCD, obsessive-compulsive disorder.

1. Includes schizoaffective disorders.

2. Excludes specific phobias.

**Table 4** Factors retained within the model as independently associated with clinical diagnosis of mental ill-health (excluding specific phobias and autistic-spectrum disorder)

Variable	Odds ratio	(95% CI)	$\beta$	P
Gender				
Male	Reference			
Female	1.333	(1.002–1.773)	0.287	0.048
Intellectual disability level				
Mild	Reference			
Moderate	1.144	(0.768–2.265)	0.135	0.487
Severe	1.583	(1.042–2.405)	0.459	0.032
Profound	1.897	(1.169–3.077)	0.640	0.010
Type of living/support arrangement				
With family carer	Reference			
Independent of support	1.319	(0.768–2.265)	0.277	0.316
With paid carer support	1.635	(1.190–2.246)	0.491	0.002
Congregate care setting	1.611	(0.898–2.891)	0.477	0.110
Number of life events in preceding 12 months	1.244	(1.127–1.773)	0.219	<0.001
Number of GP / family physician appointments in previous 12 months	1.041	(1.013–1.070)	0.040	0.004
Severe physical disability/quadruplegia				
Absent	Reference			
Present	0.394	(0.198–0.782)	–0.931	0.008
Mobility				
Fully mobile	Reference			
Immobility	0.600	(0.402–0.897)	–0.510	0.013
Urinary continence				
Fully continent	Reference			
Incontinent	1.933	(1.358–2.751)	0.659	<0.001
Smoking status				
Non-smoker	Reference			
Smoker	1.967	(1.230–3.143)	0.676	0.005

GP, general practitioner.

severe physical disabilities; not having immobility; having urinary incontinence; and being female. The other variables were not found to be independently associated with mental ill-health (Table 4).

For the 625 participants with moderate to profound intellectual disabilities, the items retained within the regression model as independently associated with mental ill-health of any type (excluding autistic-spectrum disorders and specific phobias) were as follows: having experienced a higher number of life events in the preceding 12-month period; having urinary incontinence; not having severe physical disabilities; not having immobility; being female; having profound intellectual disabilities; having a higher number of consultations with the general practitioner or family physician in the preceding 12-month period; and being a smoker. Other variables

were not independently associated with mental ill-health (Table 5).

## DISCUSSION

Mental ill-health is common among adults with intellectual disabilities. We found that more than a third – 40.9% (clinical diagnoses) or 35.2% (DC-LD diagnoses) – of our cohort had mental ill-health. These point prevalence rates are higher than those observed in the UK general population (Singleton *et al*, 2001). Many methodological factors will affect reported point prevalence rates, including the diagnostic criteria that are employed. This study is population-based and we measured a comprehensive range of psychopathology using semi-structured instruments and detailed assessments. Hence, the amount of psycho-

pathology that we detected represents that occurring in the adult population with intellectual disabilities. Operationalised diagnostic criteria have the advantage of being explicit, and thus increase reliability of diagnosis. It is, however, essential that these criteria are also valid and provide an accurate description of the presentation of each mental disorder. We conclude, in the absence of any identified diagnostic laboratory test or other elucidating research such as studies of prognostic validity, that at present the most appropriate operationalised diagnostic criteria are those that most closely resemble the current ‘gold standard’ of clinical diagnosis by a specialist, provided comprehensive assessments and measurements have been used (as outlined) and that they are conducted with a population-based sample. We found considerably lower prevalence rates using ICD-10-DCR and DSM-IV-TR diagnostic criteria, which, as highlighted by previous researchers (Sturme, 1995; Einfeld & Tonge, 1999), do not take account of the pathoplastic effect of developmental level on the psychopathology within categories of mental disorders (and so, although representing the presentation of psychopathology within mental disorders in the general population, do not accurately represent the presentation in the population with intellectual disabilities). This finding was most marked for problem behaviours and was present across all diagnostic categories, with the exception of alcohol and substance use disorders.

There are many possible biological, psychological, social and developmental factors that might account for the high prevalence rates of mental ill-health in this population, and with the exception of behavioural phenotypes, these largely have not been investigated. We identified some similarities with the general population in terms of the factors independently associated with mental ill-health – such as experiencing a higher number of preceding life events, having a higher number of preceding general practitioner or family physician consultations, being female, and being a smoker – but also some differences. Examples of these differences were the lack of association between living in more deprived areas, not having any daytime occupation, marital status and epilepsy, and mental ill-health. These differences are important, as public health interventions to improve the mental health of nations will fail to address the needs of adults with intellectual disabilities, and hence widen the

**Table 5** Factors retained within the model as independently associated with clinical diagnosis of mental ill-health (excluding specific phobias and autistic-spectrum disorder) for people with moderate to profound intellectual disabilities

Variable	Odds ratio	(95% CI)	$\beta$	P
<b>Gender</b>				
Male	Reference			
Female	1.512	(1.055–2.165)	0.413	0.024
<b>Intellectual disability level</b>				
Moderate	Reference			
Severe	1.450	(0.942–2.232)	0.372	0.091
Profound	1.921	(1.168–3.160)	0.653	0.010
Number of life events in preceding 12 months	1.262	(1.110–1.434)	0.232	<0.001
Number of GP / family physician appointments in previous 12 months	1.041	(1.005–1.077)	0.040	0.024
<b>Severe physical disability/quadruplegia</b>				
Absent	Reference			
Present	0.312	(0.148–0.658)	-1.164	0.002
<b>Mobility</b>				
Fully mobile	Reference			
Immobility	0.496	(0.316–0.778)	-0.701	0.002
<b>Urinary continence</b>				
Fully continent	Reference			
Incontinent	2.310	(1.527–3.495)	0.837	<0.001
<b>Smoking status</b>				
Non-smoker	Reference			
Smoker	2.809	(1.327–5.947)	1.033	0.007

GP, general practitioner.

**Table 6** Comparison of studies: point prevalence rates of mental ill-health

Diagnostic category	Cooper <i>et al</i> , 2006 (n=1023) %	Corbett, 1979 (n=402) %	Lund, 1985 (n=302) %	Cooper & Bailey, 2001 (n=207) %
Psychotic disorder	4.4	6.2	1.3	2.7
Affective disorder <sup>1</sup>	6.6	4.0	1.7	6.0
Personality disorder	1.0	} 25.4 <sup>2</sup>	} 10.9	} 15.1
Problem behaviour	22.5			
Anxiety disorder <sup>3</sup>	3.8	} 2.0 <sup>4</sup>	} 7.2	} 2.5
OCD	0.7			
Organic disorder	2.2		3.6	3.9
Alcohol / substance use disorder	1.0		0	1.3
Pica	2.0			
Sleep disorder	0.6			
ADHD	1.5			
Autistic-spectrum disorder	7.5	8.2	3.6	6.8
Other mental ill-health	1.4	1.3		
Mental ill-health of any type <sup>3</sup>	40.9	46.3 <sup>5</sup>	28.1	37.0

ADHD, attention-deficit hyperactivity disorder; OCD, obsessive-compulsive disorder.

1. Includes current episodes and bipolar disorder currently euthymic; excludes recurrent depressive disorder currently euthymic.
2. Text suggests that problem behaviours, personality disorder and anxiety disorders are presented as a combined prevalence of 25.4%.
3. Excludes specific phobias.
4. Text suggests that OCD and other anxiety disorders are presented as a combined prevalence of 2.0%.
5. Excludes dementia.

existing inequality gap, if they are focused only on areas that are of importance to the general population. Interestingly, having communication impairment was not independently associated with mental ill-health whereas having a lower developmental level was, suggesting that the higher prevalence of mental ill-health at lower ability levels cannot be explained by communication alone. Having previously been a long-stay hospital resident was not associated with mental ill-health, whereas having incontinence and not having severe physical disabilities nor immobility were. Whether the association between type of living support and mental ill-health is a result of cause or effect is unclear; either mental ill-health is an important cause of the requirement for expensive support packages, or mental health needs are being precipitated or not optimally managed in these settings. Either explanation highlights a need for healthcare professionals to work closely with paid support workers and managers of support-providing organisations.

Our findings offer provisional guidance to identifying people within the adult population with intellectual disabilities who are at higher risk of having mental ill-health and might benefit from more proactive healthcare approaches, and also are a step towards developing interventions that might be of benefit, such as supporting people who

experience life events, and screening for and managing incontinence.

### Comparisons with previous research

Because of the methodological limitations outlined above, there are few previously published prevalence studies with which these results can be compared. Previous small-scale population-based studies include those of Lund (1985) ( $n=302$ ); Cooper & Bailey (2001) ( $n=207$ ); and Deb *et al* (2001) ( $n=101$ ), the last of which included only participants with verbal communication skills and hence is not comparable. The larger-scale study of Taylor *et al* (2004) ( $n=1155$ ) reported data from a psychiatric screening tool only, rather than presenting psychiatric diagnoses, and hence is also not comparable. The population-based study by Corbett (1979) ( $n=402$ ) did not have the advantage of operationalised diagnostic categories, reporting by ICD-8 (World Health Organization, 1968), nor did it use clear methods of assessment. The study reported by Lund (1985) used assessment methods which, given subsequent health technology advances, would today be considered rather limited. Both studies (Corbett, 1979; Lund, 1985) include some individuals whose IQ measurements actually place them outside the intellectual disabilities range. Although we recognise these limitations in the existing literature, in Table 6 we compare, as far as possible, the findings from our study with those of Corbett (1979), Lund (1985) and Cooper & Bailey (2001). Access to the original data in the latter study has enabled us to present a prevalence rate for mental ill-health of any type, defined in the same way as in our study. This tentative comparison shows a high point prevalence of mental ill-health to be a feature of all the studies except that of Lund.

Associations have been previously demonstrated between preceding life events in adults with intellectual disabilities and 'affective/neurotic disorders' as defined by a screening tool (Hastings *et al*, 2004), and between life events and scores on the Developmental Behaviour Checklist for Adults (Hamilton *et al*, 2005), but the effect of life events in this population has received little other attention. The relationship between ability level and mental ill-health has variously been reported to be absent (Corbett, 1979), present with higher prevalence of mental ill-health at lower

ability levels (Lund, 1985; Cooper & Bailey, 2001), or present with higher prevalence of mental ill-health at higher ability levels (Borthwick-Duffy & Eyman, 1990; Bouras & Drummond, 1992); these differences are explained by the methodological limitations described above. The previous reports have also presented inconsistent and conflicting results regarding possible associations between mental ill-health and age, physical disability or epilepsy (Smiley, 2005); most studies have not found any association between gender and mental ill-health in this population, unlike the general population, although Taylor *et al* (2004) did find that women had higher scores than men on their 'affective/neurotic disorders' sub-domain, but not on their other two sub-domains. The results of our investigations therefore largely present new findings.

### Strengths and limitations of our study

The strengths of this study include its comprehensive case ascertainment procedures, the large size of the cohort, the high level of agreement to participate in the study, detailed individual assessments, and mental ill-health data reported by clinical, DC-LD, ICD-10-DCR, and DSM-IV-TR diagnostic criteria. Limitations include the case ascertainment for people with mild intellectual disabilities, many of whom require support for learning during their school years but become 'invisible' in adulthood, having gradually acquired the skills to live independently with marital and live-in partners, hold down paid employment and raise a family. Our procedures will have failed to fully identify this group, that is individuals who do not access any services or supports, and whose general practitioners/family physicians have not recognised their intellectual disabilities and who do not have a record of intellectual disability in primary healthcare case notes. For people with moderate to profound intellectual disabilities, we are confident that our procedures will have identified this population fully. In our presentation of results, we have acknowledged and addressed this limitation by presenting results separately for the group with moderate to profound intellectual disabilities, as well as for the whole cohort: the factors we found to be associated with mental ill-health were similar for both. A further limitation is the incompleteness of some previous case-note entries, limiting the amount of past history information

available. Our study is also limited by its cross-sectional design; hence we report independent associations with mental ill-health, rather than independent predictors or aetiological factors for such ill-health.

### Implications and future directions

Intellectual disability is common and life-long, with the lifetime cost (in excess of the costs for people without intellectual disabilities) in the USA for the year 2000 incident cohort being estimated at \$44.1 billion (Honeycutt *et al*, 2003). Not surprisingly, people with intellectual disabilities have been the focus of recent major national policy developments in Europe, the USA, Australia and across the high-income countries, but with little research evidence to inform these developments. Mental ill-health is a significant contributor to costs and quality of life. People with intellectual disabilities experience health inequalities compared with the general population; these include a shorter life expectancy, higher level of comorbid health needs and a higher proportion of 'hidden' comorbid health needs which fail to be met by services (Cooper *et al*, 2004; NHS Health Scotland, 2004; Scheepers *et al*, 2005). The full extent to which inequalities are accounted for by modifiable or preventable factors has been unclear owing to lack of investigation, and the study reported here is an important step towards a better understanding of the probably multiple contributory interacting factors. It will be important in future to report longitudinal cohort studies, from which predictive and aetiological factors for mental ill-health can be determined and utilised to influence the development of interventions, public health strategy, and health and social care policy, appropriate to the needs of this population.

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