THE INCIDENCE OF UNIPOLAR AND BIPOLAR DEPRESSION, AND MANIA IN ADULTS WITH INTELLECTUAL DISABILITIES. PROSPECTIVE COHORT STUDY

* Sally-Ann Cooper

Elita Smiley

Linda Allan

Jillian Morrison

*** Address for Correspondence:** Professor Sally-Ann Cooper, Institute of Health and Wellbeing, University of Glasgow, Mental Health and Wellbeing group, 1st Floor Administrative Building, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH, U.K.

Email: Sally-Ann.Cooper@Glasgow.ac.uk

ABSTRACT

Background: Incidence and determinants of affective disorder amongst adults with intellectual disabilities are unknown.

Aims: To investigate affective disorder incidence, and determinants of unipolar depression, compared with general population reports.

Method: Prospective cohort study measuring mental ill-health of adults with mild-profound intellectual disabilities living within a defined community, over two years.

Results: 70% cohort retention (n=651). Despite high mood stabilizer use (22.4%), two-year incident mania at 1.1% is higher than the general population; 0.3% for first episode (SIR=41.5, or 52.7 excluding Down syndrome). For any bipolar episode, SIR=2.0, or 2.5 excluding Down syndrome. Depression incidence at 7.2% is similar to the general population (SIR=1.2), suggesting more enduring/undertreatment given the higher prevalence. Problem behaviours (OR=2.3) and life-events (OR=1.3) predict incident unipolar depression.

Conclusions: Depression needs improved treatment. Mania has received remarkably little attention in this population, despite high prevalence and incidence (like schizophrenia), and importance of clinician awareness for accurate differential diagnosis from ADHD and problem behaviours.

Declaration of interest: None.

INTRODUCTION

People with intellectual disabilities experience health and healthcare inequalities, and a different pattern of diseases compared with the general population.[1,2] Affective disorder is prevalent amongst adults with intellectual disabilities.[3] Two general population longitudinal cohort studies suggest a higher prevalence of depressive and anxiety symptoms in adults with mild intellectual disabilities across the lifecourse compared with the general population; both also reported significantly higher prevalence of problem behaviours and emotional problems in adolescence.[4-6] However, both contain small numbers with mild intellectual disabilities (100[4], then 60[5], and 41[6]), have substantial cohort attrition for this subgroup (retention rates of 36%[4], then 22%[5], and 29%[6]), and biased cohort retention, and excluded persons with moderate to profound intellectual disabilities. They did not report findings for mania. No statistically significant factors predictive of higher depression scores were found within the mild intellectual disabilities group, other than having attended a special school, although the study was probably underpowered to investigate this. A large record linkage study in Australia reported much lower rates of unipolar depression and similar rates of bipolar affective disorder in people with intellectual disabilities compared with published general population rates, though the authors acknowledged that people with intellectual disabilities are less likely to have been assessed and treated for mental ill-health, and the database excluded contacts with primary care and private psychiatrists who conduct a notable quantity of practice in Australia.[7] Affective disorders in adults with intellectual disabilities remains a very under-studied area, and its incidence and determinants are unknown. We do not know if it is appropriate to generalise findings on affective disorders from the general population to people with intellectual disabilities, and do need to understand its epidemiology in order to effectively influence service developments and psychiatric practice.

This study was undertaken to answer the following research questions:

1. What is the incidence of affective disorders in adults with mild to profound intellectual disabilities, and compared with that previously reported for the general population?
2. What demographic, lifestyle, and health and disability factors predict incident unipolar depressive episode in the population with intellectual disabilities, and are they similar to, or different from, those previously reported for the general population?

METHODS

Participants

The adult population with intellectual disabilities (16+ years) in Greater Glasgow, U.K. had previously been identified. The process identified all adults with intellectual disabilities who were registered with a general practitioner in Greater Glasgow (all 631 general practitioners contributed to the ascertainment process: they were incentivised by the Health Board establishing an additional annual capitation payment for each person with intellectual disabilities who was registered with them, in view of the associated additional workload), and adults who were receiving support of any type paid for, or provided by, the social work department, and adults with intellectual disabilities using health services. The identified rate was 3.33 per 1,000 general population which is comparable with ascertainment rates for the adult population with intellectual disabilities conducted elsewhere.[8] Greater Glasgow includes both an urban area (Glasgow city) and rural areas (the surrounding countryside). It includes areas of affluence and deprivation i.e. across all the neighbourhood deprivation gradient.

The adults with intellectual disabilities (n = 1,023) were recruited into a longitudinal cohort at the first time point in 2002-2004 (T1).[9] Measurements were repeated to collect information for the following two year period in 2004-2006 (T2). This study presents new analyses from this cohort.

Approval and consent

Research ethics committee approval was gained. Consent was taken from each participant with capacity to decide to consent, or otherwise from their nearest relative, in keeping with Scottish law.

T1 and T2 data collection process

Face to face interviews were completed with each person supported by their carers. Information was also collected from a relative. At T1 and T2, following each interview, health data was discussed with a doctor. Individuals who had two or more, or one "high risk" symptom at the interview on the *Psychiatric Assessment Schedule for Adults with Developmental Disability* (*PAS-ADD Checklist*),[10] each had a second face-to-face comprehensive psychiatric assessment by the Glasgow University Centre for Excellence in Developmental Disabilities (UCEDD), which is run by two academics who are also qualified Consultant Psychiatrists specialised in working with adults with intellectual disabilities. In all cases, the findings were case conferenced by the Consultant members of the research team. At T2, in addition, any episodes of mental ill-health that occurred between T1 and T2 were identified at the face-to-face interview by a series of semi-structured questions, and a *PAS-ADD Checklist* was completed for that episode at the interview with the person, supported by their carers. The same thresholds were used to identify people for the second face-to-face comprehensive psychiatric assessment by the UCEDD. Persons requiring diagnostic clarification of problem behaviours also received a comprehensive psychiatric assessment by the UCEDD, as did persons who scored on items of mental ill-health on the *C21st Health Check.*[11] Medical and psychology case-notes were reviewed for all participants. Episodes of mental ill-health were classified according to the psychiatrists' clinical opinion (i.e. clinically significant mental ill-health whether or not it fully met the operationalised criteria outlined in the standard diagnostic manuals), the *Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities / Mental Retardation* (DC-LD),[12] the *ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research* (DCR-ICD-10),[13] and the *Diagnostic and Statistical Manual of*

Mental Disorders, Fourth Edition Revised (DSM-IV-TR)[14] diagnostic criteria. This approach was used in view of the well known limitations of using DCR-ICD-10 and DSM criteria with people with intellectual disabilities, due to their impaired verbal communication/understanding skills, and pathoplasticity of psychopathology at more severe levels of intellectual disabilities.

Materials

The same instruments were used at T1 and T2 interviews:

- *PAS-ADD Checklist.*[10] This is a screening tool for mental ill-health designed for use with adults with intellectual disabilities. However, when using the published threshold scores its sensitivity is only about 66%. Simpson studied its psychometric properties using receiver operating characteristic analyses, and reported that when completed with the person's main carer and a threshold of any two positive items was used, the tool had 100% sensitivity to detect persons meeting criteria for ICD-10 diagnoses with a false positive rate of 58%, and 95% sensitivity to detect persons meeting criteria for DSM-IV diagnoses with a false positive rate of 53%[15]. Consequently we used this threshold to trigger the second stage full psychiatric assessment, as false positives were detected and removed at the second stage. Additionally, we used a threshold of needing only 1 positive item if it was attempted suicide or talk of suicide, or any of the four psychosis items, and added six items after a pilot study with 50 persons: (a) lability of mood, (b) loss of social inhibitions/onset of inappropriate social behaviour, (c) increased interest in sex/sexual indiscretions, (d) excessive talking, laughing or singing, (e) tearfulness, (f) thinking that people or the television are referring to the person or giving messages or instructions. This instrument was also used to collect life events data.
- Purpose designed semi-structured demography and supports questionnaire, including post-code data to allocate individuals to quintiles of the Carstairs Deprivation Index, a Scottish area-based measure of neighbourhood deprivation.[16]
- Purpose designed lifestyle and supports questionnaire.

- *Vineland Scale (Survey Form),*[17] to measure ability.

Psychiatrist assessment followed a comprehensive semi-structured assessment format, which included using:

- *Present Psychiatric State for Adults with Learning Disabilities (PPS-LD).*[18]. This semi-structured psychopathology schedule for use with adults with intellectual disabilities measures the comprehensive range of psychopathology required for classification by clinical diagnosis and DC-LD, DCR-ICD-10, and DSM-IV-TR criteria.

Additionally, at T1, physical health was comprehensively measured using:

- *C21st Health Check*[10]. This was necessary to exclude any possible physical cause of apparent psychiatric presentation, and to provide measurement of physical health items for statistical investigation of putative predictors of unipolar depression. The *C21st Health Check* has been demonstrated to have good utility. It includes sections to collect data on prescribed medication, developmental level and support needs, as well as general physical health including epilepsy status, and includes a selected physical examination and phlebotomy protocol. For example:
    - Vision is assessed by asking a series of 9 questions to help detect any possible problems (e.g. for persons unable to self-report, carers were asked whether the person screws up his/her eyes in bright sunlight), then measured using Kay's pictures at 33 centimetres and 3 metres. Persons so detected with possible visual impairment were then referred to the University Visual Sciences Department for more detailed, specialist assessment. In this study, persons with refractive errors not corrected by spectacles (e.g. because the person wouldn't wear them) were also included in the category of having a visual impairment, but persons with a refractive error that was corrected by spectacles were not.
    - Hearing is assessed through a series of questions, then otoscopy, and if the tympanic membrane could be visualised, examination using Warblers at 1/2m at the level of

30db/500Hz, 30db/1000Hz, 30db/2000Hz, and 30db/4000Hz, with referral for specialist assessment if there was any suggestion of possible hearing impairment. If the tympanic membrane could not be visualised because of impacted cerumen, drops were first used, to clear it. In the analyses, persons were not included in the category of hearing impairment if it was fully corrected with hearing aids, but they were included if hearing remained impaired despite the use of aids, or if the person would not wear aids.

- Mobility is assessed through discussion with the person and their relative/support worker, to determine whether the person was fully mobile, walks with stick/s, frame or assistance, required a wheelchair outside only, required a wheelchair in and outside, could weight-bear to transfer only, or could not weight-bear. In the analyses, this was dichotomised to whether or not the person was fully mobile.

Statistical analyses

Data were analysed using the Statistical Package for the Social Sciences Version 22.

Potential bias amongst persons who participated at T1 but for whom consent was refused at T2 was examined using t-tests and χ^2 tests, with regards to age, gender, level of ability, type of accommodation / support, and prevalence of mental ill-health at T1.

The two-year incidence of affective disorders was defined as the proportion of individuals with the onset of a new episode at any time in the two year period. The standardised incidence ratios and 95% confidence intervals were then calculated, using published general population data.[19-22] Mania is known to be particularly rare in adults with Down syndrome,[23] and therefore, we then recalculated the standardized incidence ratios having excluded persons with Down syndrome.

The frequency of prescription of mood stabilizing drugs and lithium was then calculated, in view of the known high prevalence of epilepsy in this population, and the mood stabilizing properties of several of the antiepileptic drugs.

Putative predictors of incident episodes of unipolar depression were then investigated. (The people with incident bipolar affective disorder depression were excluded from this analysis.) Seventeen factors were investigated:

- Personal factors (4 items): older age; female gender; more severe intellectual disabilities; Down syndrome.
- Life style and supports measured at T1 (6 items): type of accommodation/support (not living with a family carer); having no employment/day opportunities; Carstairs quintile (living in more deprived areas); single status; smoking; experiencing preceding life events.
- Health and disabilities measured at T1 (6 items): visual impairment; hearing impairment; urinary incontinence; impaired mobility; epilepsy; problem behaviours.

Initially, the distribution of the outcome (incident unipolar depression) and each factor was assessed individually using chi-squared tests and t-test (after checking distributions for normality). Secondly, the individually related factors ($p < 0.1$) were entered into a multivariate model and a backward stepwise method was used to retain independently predictive factors within the model. Likelihood ratio tests were used in the stepwise procedures to determine statistical significance for removal of each factor (the removal criterion was set at 0.05). The final model was checked for goodness-of-fit using the Hosmer-Lemeshow test, in which the study sample is divided into deciles of predicted risk and the numbers of observed and expected events compared using a χ^2 test.

Involvement of people with intellectual disabilities and their carers in the study

The *C21st Health Check* was developed and piloted in a separate study funded by Greater Glasgow Primary Care NHS Trust R&D Department. This included eliciting the views of 32 people with intellectual disabilities on the experience of having the health check and its outcomes through semi-structured interviews, and the views of their 42 family and paid carers via postal questionnaire. This information led to refinements to the health check. Results from the study were disseminated to study participants and carers by sending them a purpose-made DVD as well as paper-copy information (easy-read) about the results, and also via the Scottish Consortium for Learning Disabilities. Participants and their carers are acknowledged for their contribution to the study.

RESULTS

Cohort at T2

At T2, the potential cohort size was 936 (excluding 266 people who had died or for whom *Adults with Incapacity (Scotland) Act* requirements could not be met), of whom 651 (69.6%) participated. 142 people with intellectual disabilities declined to participate, and 143 carers declined participation. The T1 characteristics of the whole T2 cohort are shown in table 2. There was no difference between participants and persons for whom consent was not gained at T2, in terms of T1 age ($p=0.76$), gender ($p=0.95$), level of intellectual disabilities ($p=0.13$), type of accommodation/support ($p=0.67$), or prevalence of mental ill-health ($p=0.73$).

Incidence of affective disorders

Table 1 reports the incidence of affective disorders. 42 (6.5%) separate people had a unipolar depression incident, and 13 (2.0%) a bipolar affective disorder incident. In addition to having an incident affective disorder, seven people had another separate incident of mental ill-health (unipolar depression and agoraphobia; unipolar depression and dementia; unipolar depression and general

anxiety disorder; unipolar depression and problem behaviour; bipolar affective disorder depression and mania; mania and problem behaviours, mania and delirium), and one person had three other incident episodes of mental ill-health (unipolar depression, agoraphobia, problem behaviour and substance abuse)

- Insert table 1 about here -

Within the general population, for 18-64 year olds, the annual incidence for depressive disorders (unipolar and bipolar combined) has been reported to be 28.5/1,000.[19] For the 16-64 year old general population, the incidence of first episode of mania was 4.0/100,000 person years, of whom 33% had previously had a depressive episode.[20,21] For the 18+ years general population, the annual incidence of bipolar disorders (new and recurrent episodes) is reported to be to be 0.5%.[22] For this intellectual disabilities population, the standardised incident ratio (SIR) for depression (unipolar and bipolar combined) is therefore 1.19 (95% CI=0.85-1.93: clinical diagnosis) or 1.07 (95% CI=0.76-1.48: DC-LD criteria). SIR of first episode mania is 41.5 (95% CI=5.0-149.8: clinical diagnosis and DC-LD criteria). SIR of bipolar affective disorder episode (new and recurrent episodes) is 2.00 (95% CI=1.06-3.41: clinical diagnosis) or 1.84 (95% CI=0.95-3.22: DC-LD criteria).

186 of the cohort at T1 and 134 at T2 had Down syndrome. Their point prevalence of depression (unipolar and bipolar combined) was 2.7% and two-year incidence was 5.2%; their point prevalence of mania was 0%, and 0% had incident mania. Excluding persons with Down syndrome from the cohort, 474 were in the age range 16-64 years: for this group the SIR of first episode mania is 52.7 (95% CI=6.4-190.5: clinical diagnosis and DC-LD criteria). 511 were aged 18+ years: the SIR of bipolar affective disorder episode is 2.35 (95% CI=1.21-4.10: clinical diagnosis) or 2.54 (95% CI=1.35-4.35: DC-LD criteria).

For 28 (51.9%) of the 54 people with incident affective disorder, the episode had both incidence and recovery within the two year period; 26 had incidence and were still in episode at T2.

As expected, the 651 people had a high use of mood stabilizers at T1, at 146 (22.4%): 10 (1.5%) lithium, 139 (21.4%) other mood stabilizer(s) (prescribed for epilepsy for 126 people, and problem behaviours for 2 people), and 3 people took both. 72 (11.1%) were taking an antidepressant. 134 (20.6%) were taking antipsychotic drugs at T1, considerably higher than the proportion with psychosis. Of the 146 people taking mood stabilizers at T1, 12 (8.2%) had incident unipolar depression, 2 (1.4%) had incident bipolar depression, 3 (2.1%) had incident mania, and 0 (0%) had incident mixed affective disorder. These frequencies are not statistically different from those of the rest of the cohort who were not taking mood stabilising drugs at T1.

Factors related to incidence of unipolar depression

The characteristics of the persons who had incident unipolar depression are shown in table 2. Table 2 also shows results from the initial univariate analyses, exploring the relationship of each individual variable of interest with incident unipolar depression. As can be seen from table 2, data was missing on daytime job/occupation for 1 person, marital status for 4 people, smoking status for 3 people, urinary incontinence for 1 person, mobility for 1 person, epilepsy for 14 people, and life events for 1 person. The dataset was otherwise complete.

- Insert table 2 about here -

For incident episodes of unipolar depression, at the second stage of analyses, type of accommodation/support, problem behaviours, and preceding life events were entered into the regression. One participant had an incomplete dataset (life events), did not have incident unipolar depression, and was excluded from the analysis. Factors at T1 that predicted incident episode of

unipolar depression by T2 were: preceding life events [odds ratio=1.30 (95% CI=1.02-1.65)], and problem behaviours [odds ratio=2.27 (95% CI=1.18-4.37)]. The Hosmer-Lemeshow statistic was χ^2=7.68 on 5 df, p=0.18, giving no indication of lack of fit.

DISCUSSION

Principal findings and comparison with the existing literature

Depression has a similar incidence in adults with intellectual disabilities as the general population, which, given its higher prevalence[3] suggests it is more enduring and perhaps undertreated. Mania occurs at considerably higher incidence in adults with intellectual disabilities than the general population. This latter finding has not been previously reported, as far as we are aware. Both these findings are further surprising, given the high proportion of the population who were prescribed mood stabilizers (mostly for epilepsy). It is important that clinicians have a heightened awareness of these facts and treat depression thoroughly, and consider mania in their differential diagnosis, given the potential misdiagnosis with ADHD and problem behaviours which are common in adults with intellectual disabilities.[9] Differential diagnosis is of fundamental importance in intellectual disabilities psychiatry due to the substantial comorbidity of physical ill-health, mental ill-health, and sensory impairments. This can be diagnostically challenging, particularly in the non-verbal population, and care is needed given that some symptoms are similar across diagnostic categories, such as distractibility, impulsivity, and overactivity, which can be prominent features of all of mania, ADHD, and problem behaviours. Heightened awareness of mania should improve diagnostic accuracy.

There has been remarkably little attention on mania in this population, although schizophrenia is known to be more common in adults with intellectual disabilities. We previously reported a high *point* prevalence of mania at 0.6% (clinical, DC-LD and DCR-ICD 10 criteria), with an additional

0.5% with bipolar affective disorder in episode with depression, and 1.2% with bipolar affective disorder in remission i.e point prevalence of 2.3% with bipolar affective disorder in total.[3] This is considerably higher than *lifetime* prevalence rates of 1.0% reported for the general population[24]. These proportions are very similar to those found by Corbett in his study of 402 persons with intellectual disabilities aged 15+ years: 1.5% had ICD-8 manic-depressive psychosis at the time of his study, and whilst he did not report the total proportion with manic depressive psychosis, there is sufficient information in his table III to calculate that it was 2.2%.[25] A lower rate of 1.2% (by the age of 38-52 years) and 1.0% (by the age of 23-37 years) was reported in the record linkage study, but with likely under-recording due to the methodology.[7] There have been few other population-based observational studies with adults with intellectual disabilities, and all are limited by small numbers of participants (n=73, n=121, n=101), which may explain why the high prevalence and incidence of mania in this population has previously been overlooked.[26-28]

Some genetic syndromes that cause intellectual disabilities are specifically associated with psychosis, such as velo-cardio-facial syndrome and Prader-Willi syndrome. Conversely, both mania and schizophrenia are rare amongst persons with Down syndrome. At T2 in our study, only one person had Prader-Willi syndrome and did not have any mental illness (due to their relatively young age; 25 years), and none had velo-cardio-facial syndrome, given the rarity of these syndromes. Hence these rare syndromes do not account for our study findings.

There is no existing literature regarding incidence, and predictors, of unipolar depression for the intellectual disabilities population with which we can draw comparisons, as far as we are aware.

We found that preceding life events predicted onset of unipolar depressive episodes. This is similar to general population findings. Unlike the general population, female gender, living in more deprived areas, not having day-time occupation, and being a smoker were not predictive of incident

unipolar depression. Age and urinary incontinence were also not statistically predictive of unipolar depression, although this is possibly due to the cohort size. This suggests it is therefore inappropriate to generalise findings from general population studies to the population with intellectual disabilities. Given the higher rate of affective disorders, this has implications for services and policy makers, and highlights the need for more health services research with this population.

Our study additionally addresses the long-running debate regarding whether or not adults with problem behaviours and intellectual disabilities are at greater risk of developing unipolar depression than other adults with intellectual disabilities. Several cross-sectional studies have reported an association between problem behaviours and depression in this population. Given the prospective cohort design of our study, we have shown that the risk for unipolar depression is higher for adults with pre-existing problem behaviours. This may be due to problem behaviours and unipolar depression having similar aetiologies, or due to problem behaviours resulting in stress, limitations and restrictions to the adult's life, predisposing to depression.

Strengths and limitations of the study

Although we have presented SIRs, it is important to note that there are differences in the studies, due to different methods of assessment and different instruments. Our confidence interval for first episode mania is very wide, due to the cohort size; however, the lower limit of the confidence interval is 5.0 or 6.4 excluding people with Down syndrome, well above 1.0 and so gives credence to the finding of the higher level of mania in people with intellectual disabilities. The American study we used as the comparator for bipolar affective disorder episodes found higher rates than European studies, and has been criticized for the use of lay interviewers, likely to overestimate rates of mania. However, we had difficulty identifying more suitable European general population data to use as the comparator for incident episodes that were not only first episodes. This may mean we

have underestimated the extent of the higher incidence of mania in adults with intellectual disabilities. It is possible the study was under-powered to detect all predictive variables for unipolar depression: there appears to be a trend towards a relationship for type of accommodation/support, age, and urinary incontinence, all of which we had expected to be related to incident unipolar depression. Additionally, the statistical relationships we found do not necessarily mean that there is a causal relationship between the T1 variables and incidence of unipolar depression, although the findings are credible. A further limitation was that cohort size precluded investigating the predictors of bipolar episodes.

Strengths of the study include the comprehensiveness of data collection and detailed psychiatric phenotyping, and longitudinal design. Studies with this population are more resource intensive than with the general population, as participants cannot easily self-report nor complete questionnaires unlike the general population, requiring data to be collected from multiple informants as well as from lengthy meetings with the participant with intellectual disabilities. This, together with the need to initially ascertain the population with intellectual disabilities from the base population, accounts for the lack of previous literature studying mental ill-health incidence in this population. With the general population it is reasonable to suspect that most episodes of mania are presented to mental health services, and hence case identification is straight-forward. However, this assumption cannot be made for the population with intellectual disabilities, as most do not hold down positions of responsibility or have partners, are subject to diagnostic overshadowing (where symptoms of ill-health are wrongly attributed to the person's underlying intellectual disabilities by paid carer and professionals), and are known to have poor access to services for a range of reasons. Hence there is no easy short-cut to identifying the incidence of affective disorders, unlike for the general population: that our methodology has fully addressed these issues is a strength of the study. Cohort retention is known to be less successful with the intellectual disabilities population than the general population, hence the high participation at T2 is a further strength. T1 and T2 are close enough in

time to reduce the likelihood of missing interim period data which is an important consideration in study design, given the population's known poor access to services when ill, the high job-mobility of paid carers, and limitations in communication skills and retention of information by many persons with intellectual disabilities themselves. Whilst there was loss to follow-up between T1 and T2, there was no difference between participants for whom consent was, and was not, gained to participate at T2, suggesting the loss to follow up did not introduce bias to the results.

We are confident that our ascertainment of the population with intellectual disabilities was comprehensive. It will not have identified all persons with an I.Q. less than 70, because some such persons on reaching adult life have successfully learned the necessary life skills to live independently of any support, marry, raise children, and hold paid employment. Such persons are not readily identified by general practitioners as having intellectual disabilities, will not be using services, and indeed do not meet ICD-10 criteria for "mental retardation", as this is a social and not purely statistical construct, being based on impaired adaptive functioning and need for support, in addition to I.Q. level. Reported prevalence of intellectual disabilities varies with the country of study, the sampling frame particularly age-range (child or adult), the definition used for intellectual disabilities, methods of assessment, and ethnic composition. Our rate is in keeping with other large scale ascertainments of adult populations in developed countries.[8]

We consider that these results are generalisable within other developed countries, in view of the robust case-identification for intellectual disabilities, the comprehensive and complete assessments, and the extent/non-bias of cohort retention.

Future research

Future study design should include more person years. We have demonstrated that results from studies with the general population cannot be generalised to the population with intellectual disabilities, and that depression in this population is more enduring (despite high use of mood

stabilizers), hence warranting further investigation of causation and interventions. This is a high-risk group for mania, warranting more detailed genetic investigation, in addition to further health services research. Inter-episode symptoms frequently occur in affective disorders in the general population; investigation of sub-syndromal symptoms and the effectiveness of affective disorder treatments for people with intellectual disabilities are clearly warranted.

ACKNOWLEDGMENTS

We are grateful to Patricia Peters, Andrew Williamson, Janet Finlayson, Alison Jackson, and the staff of the NHS Greater Glasgow primary care learning disabilities liaison team. We wish to thank study participants, and their paid and family carers. The research at T1 was funded by Greater Glasgow Health Board and the West of Scotland R&D Mental Health Programme. At T2 the research was funded by the Chief Scientist Office (reference CZH/4/96).

CONTRIBUTIONS

S-AC conceived and designed the study, analysed and interpreted the data, and drafted the first version of the paper. ES, LA, and JM all contributed to the design of the study and interpretation of the data, and revising the paper. All authors approved the final version of the paper.

CONFLICTS OF INTERESTS

None declared.

AUTHORS

Sally-Ann Cooper BSc, MB BS, MD, FRCPsych. Institute of Health and Wellbeing, University of Glasgow, Mental Health and Wellbeing group, 1st Floor Administrative Building, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH, U.K.

Elita Smiley MB ChB, MD, FRCPsych. NHS Greater Glasgow and Clyde, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH, UK.

Linda Allan RNMH, MBA. Institute of Health and Wellbeing, University of Glasgow, Mental Health and Wellbeing group, 1st Floor Administrative Building, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH, U.K.

Jillian Morrison MB ChB, PhD, FRCGP. Institute of Health and Wellbeing, University of Glasgow, General Practice and Primary Care group, 1 Horselethill Road, Glasgow, G12 9LX, UK.

ACCESS TO DATA

Sally-Ann Cooper, Elita Smiley, and Linda Allan had full access to the data. Sally-Ann Cooper takes responsibility for data integrity and accuracy of the analyses.

REFERENCES

1. Ali A, Hassiotis A. Illness in people with intellectual disabilities is common, underdiagnosed, and poorly managed. *BMJ* 2008; **336:** 570-1.
2. Cooper S-A, Melville CA, Morrison J. People with intellectual disabilities. Their health needs differ and need to be recognised and met. *BMJ* 2004; **329:** 414-5.
3. Cooper S-A, Smiley E, Morrison J, Allan L, Williamson A. An epidemiological investigation of affective disorders with a population-based cohort of 1,023 adults with intellectual

disabilities. *Psychological Med* 2007; **37:** 873-82.

4. Maughan B, Collishaw S, Pickles A. Mild mental retardation: psychosocial functioning in adulthood. *Psychological Med* 1999; **29:** 351-66.
5. Collishaw S, Maughan B, Pickles A. Affective problems in adults with mild learning disability: the roles of social disadvantage and ill health. *Br J Psychiatry* 2004; **185:** 350-1.
6. Richards M, Maughan B, Hardy R, Hall I, Strydom A, Wadsworth M. Long-term affective disorder in people with learning disability. *Br J Psychiatry* 2001; **170:** 523-7.
7. Morgan VA, Leonard H, Bourke J, Jablensky A. Intellectual disability co-occurring with schizophrenia and other psychiatric illness: population-based study. *Br J Psychiatry* 2008; **193:** 364-72.
8. Scottish Learning Disabilities Observatory. *What are learning disabilities? How common are learning disabilities?* 2016. https://www.sldo.ac.uk/media/1610/what-are-learning-disabilities-how-common-are-learning-disabilities.pdf
9. Cooper S-A, Smiley E, Morrison J, Williamson A, Allan L. Prevalence of, and factors associated with mental ill-health in adults with intellectual disabilities. *Br J Psychiatry* 2007; **190:** 27-35.
10. Moss S, Prosser H, Costello H, Simpson N, Patel P, Rowe S, et al. Reliability and validity of the PAS-ADD Checklist for detecting psychiatric disorders in adults with intellectual disability. *J Intellect Disabil Res* 1998; **42**: 173-83.
11. Glasgow U.C.E.D.D. *The C21st Health Check*, 2001. http://www.gla.ac.uk/media/media_62785_en.pdf
12. Royal College of Psychiatrists. *DC-LD [Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities / Mental Retardation]*, London: Gaskell Press, 2001.
13. World Health Organisation. *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research.* Geneva: WHO, 1993.

14. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Revised.* Washington, DC: American Psychiatric Association, 2000.

15. Simpson NJ. *Psychiatric Disorders in People with Learning Disabilities: Measuring Prevalence and Validating a Screening Instrument.* Ph.D. Thesis: p235. University of Manchester, 1999.

16. Carstairs V, Morris R. Deprivation: explaining differences in mortality between Scotland and England and Wales. *BMJ* 1989; **299:** 886-9.

17. Sparrow SS, Balla DA, Cicchetti DV. *A Revision of the Vineland Social Maturity Scale by E A Doll.* Minnesota: American Guidance Service, Inc, 1984.

18. Cooper S-A. *Epidemiology of psychiatric disorders in elderly people with intellectual disabilities.* M.D. Thesis. University of London, 1998.

19. Lehtinen V, Sohlman B, Nummelin T, Salomaa M, Ayuso-Mateos J-L, Dowrick C. The estimated incidence of depressive disorder and its determinants in the Finnish ODIN sample. *Soc Psychiatry Psychiatr Epidemiol* 2005; **40:** 778-84.

20. Lloyd T, Kennedy N, Fearson P, Kirkbride J, Mallet R, Leff J, et al. AESOP study team Incidence of bipolar affective disorder in three UK cities. Results from the AESOP study. *Br J Psychiatry* 2005; **186:** 126-31.

21. Kroon JS, Wohlfarth TD, Dieleman J, Sutterland AL, Storosum JG, Denys D, et al. Incidence rates and risk factors of bipolar disorder in the general population: a population-based cohort study. *Bipolar Disorders* 2013; **15:** 306-13.

22. Regier DA, Narrow WE, Rae RS, Manderscheid RW, Locke BZ, Goodwin FK. The de facto US mental and addictive disorders service system. Epidemiologic catchment area prospective 1-year prevalence rates of disorders and services. *Archive Gen Psychiatry* 1993; **50:** 85-94.

23. Mantry D, Cooper S-A, Smiley E, Morrison J, Allan L, Williamson A, et al. The prevalence and incidence of mental ill-health in adults with Down syndrome. *J Intellect Disabil Res* 2008; **52:** 141-55.

24. Merikangas KR, Akiskal HS, Angst J, Greenberg PE, Hirschfeld RM, Petukhova M, et al. Lifetime and 12-month prevalence of bipolar spectrum disorder in the National Comorbidity Survey replication. *Archives Gen Psychiatry* 2007; **64:** 543-52.

25. Corbett JA. Psychiatric morbidity and mental retardation. In: *Psychiatric Illness and Mental Handicap* (eds FE James & RP Snaith): 11-25. London: Gaskell, 1979.

26. Cooper S-A, Bailey NM. Psychiatric disorders amongst adults with learning disabilities – prevalence and relationship to ability level. *Irish J Psychological Med* 2001; **18,** 45-53.

27. Bailey NM. Prevalence of psychiatric disorders in adults with moderate to profound learning disabilities. *Advances in Ment Health Learning Disabil* 2007; **2:** 36-44.

28. Deb S, Thomas M, Bright C. Mental disorder in adults with intellectual disability. I. Prevalence of functional psychiatric disorder among a community based population aged between16 and 64 years. *J Intellect Disabil Res* 2001; **45:** 495-505.

Table 1. The number and proportion of people with two-year incidence of affective disorders as defined by clinical, DC-LD, DCR - ICD10, and DSM IV diagnostic criteria

Diagnostic Category	**Clinical Diagnosis N (%)**	**DC-LD Diagnosis N (%)**	**DCR-ICD10 Diagnosis N (%)**	**DSM IV Diagnosis N (%)**
Incident depression	47 (7.2)	43 (6.6)	27 (4.1)	17 (2.6)
Bipolar, depression	5 (0.8)	4 (0.6)	3 (0.5)	2 (0.3)
Unipolar, depression	42 (6.5)	39 (6.0)	24 (3.7)	15 (2.3)
Incident mania	7 (1.1)	7 (1.1)	6 (0.9)	5 (0.8)
Bipolar, mania	5 (0.8)	5 (0.8)	5 (0.8)	4 (0.6)
First episode of mania	2 (0.3)	2 (0.3)	1 (0.2)	1 (0.2)
Incident mixed affective episode	1 (0.2)	1 (0.2)	1 (0.2)	1 (0.2)
Any incident affective episode*	54 (8.3)	50 (7.7)	33 (5.1)	23 (3.5)

*Figures for “any incident affective episode” are not the sum of all the types of episodes in the table, as one person had both bipolar depression and mania during the period

Table 2. Relationship between individual factors at T1 and incident unipolar depression by T2

		Whole cohort	Incident unipolar depression	
		N=651 (100%)	N=42 (6.5%)	
Personal factors				
Age		Mean=43.6 (SD=14.2)	Mean=46.8 (SD=14.2)	p=0.135
Gender	Male Female	355 (54.5%) 296 (45.5%)	22 (6.2%) 20 (6.8%)	p=0.745
Ability	Mild Moderate Severe Profound	254 (39.0%) 140 (21.5%) 126 (19.4%) 131 (20.1%)	18 (7.1%) 12 (8.6%) 5 (4.0%) 7 (5.3%)	p=0.731
Down Syndrome	No Yes	517 (79.4%) 134 (20.6%)	35 (6.8%) 7 (5.2%)	p=0.500
Lifestyle and supports				
Accommodation / support	Family carer Independent Paid carer Congregate	258 (39.7%) 51 (7.8%) 298 (45.8%) 44 (6.8%)	9 (3.4%) 5 (9.8%) 23 (7.7%) 5 (11.4%)	p=0.058
No daytime job / occupation	Has job No job	499 (76.8%) 151 (23.2%)	33 (6.6%) 9 (6.0%)	p=0.754
Deprivation quintile	Most affluent 2 3 4 Most deprived	107 (16.4%) 54 (8.3%) 56 (8.6%) 72 (11.1%) 362 (55.6%)	7 (6.5%) 1 (1.9%) 3 (5.4%) 7 (9.7%) 24 (6.6%)	p=0.514
Marital status	Married / live-in partner No live-in partner	84 (13.0%) 563 (87.0%)	5 (6.0%) 37 (6.6%)	p=0.838
Smoker	No Yes	581 (89.7%) 67 (10.3%)	37 (6.4%) 5 (7.4%)	p=0.717
Life events in previous 12 months		Mean=1.0 (SD=1.1)	Mean=1.4 (SD=1.2)	p=0.026
Health and disabilities				
Visual impairment	No Yes	349 (53.6%) 302 (46.4%)	24 (6.9%) 18 (6.0%)	p=0.616
Hearing impairment	No Yes	457 (70.2%) 194 (29.8%)	27 (5.9%) 15 (7.7%)	p=0.354
Urinary incontinence	No Yes	436 (67.1%) 214 (32.9%)	24 (5.5%) 18 (8.4%)	p=0.141
Impaired mobility	No Yes	508 (78.2%) 142 (21.8%)	36 (7.1%) 6 (4.2%)	p=0.211
Epilepsy	No Yes	424 (66.6%) 213 (33.4%)	26 (6.1%) 16 (7.5%)	p=0.503
Problem behaviour	No Yes	506 (77.7%) 145 (22.3%)	26 (5.1%) 16 (11.0%)	P=0.010

For the whole cohort, percentages refer to the proportion of the cohort with that characteristic; for the incident depression group, percentages refer to the proportion with incident depression out of the whole cohort with that characteristic.