The prevalence and incidence of mental ill- health in adults with autism and intellectual disabilities

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Running head

Autism and mental ill-health

Abstract

The prevalence, and incidence, of mental ill-health in adults with intellectual disabilities and autism were compared with the whole population with intellectual disabilities, and with controls, matched individually for age, gender, ability-level, and Down syndrome. Although the adults with autism had a higher point prevalence of problem behaviours compared with the whole adult population with intellectual disabilities, compared with individually matched controls there was no difference in prevalence, or incidence of either problem behaviours or other mental ill-health. Adults with autism who had problem behaviours were less likely to recover over a two-year period than were their matched controls. Apparent differences in rates of mental ill-health are accounted for by factors other than autism, including Down syndrome and ability level.

Key words

Intellectual disabilities; autism; mental ill-health; psychiatry; epidemiology; psychiatric classification.

Introduction

Autism is a neurodevelopmental disorder associated with significant lifelong impairments in communication and reciprocal social interaction (World Health Organisation, 1993; American Psychiatric Association, 2000), and now described as one of several autism spectrum disorders (ASD) with overlapping features. Epidemiological studies have described overall prevalence rates for autism spectrum disorders of 57.9- 116.1 per 10, 000, and rates for autism of 16.8- 40.5 per 10, 000 (Bertrand, Mars, Boyle, Bove, Yeargin-Allsopp & Decoufle, 2001**;** Chakrabarti & Fombonne, 2001; Yeargin-Allsopp, Rice, Karapurkar, Doernberg, Boyle & Murphy, 2003; Chakrabarti & Fombonne, 2005; Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum, & Charman, 2006).

International reports and guidelines have emphasised the need to identify and manage mental ill health[1] in people with autism (Filipek, Accardo, Ashwal, Baranek, Cook, Jr., Dawson, Gordon, Gravel, Johnson, Kallen, Levy, Minshew, Ozonoff, Prizant, Rapin, Rogers, Stone, Teplin, Tuchman, & Volkmar, 2000; Public Health Institute of Scotland, 2001; National Initiative: Autism Screening and Assessment, 2003; Scottish Intercollegiate Guideline Network, 2007), and mental ill-health has been shown to be associated with negative long term outcomes for people diagnosed with autism (Billstedt, Gillberg, & Gillberg, 2005).

There is growing evidence that children and young people with autism and intellectual disabilities experience higher rates of psychopathology[2] (Brereton, Tonge, & Einfeld, 2006), mental ill health (Bradley, Summers, Wood, & Bryson, 2004; Bradley & Bolton, 2006) and problem behaviours[3] (Bradley et al., 2004; Holden & Gitlesen, 2006), in comparison with

children and young people with intellectual disabilities who do not have autism. However, it is less clear if this is also the case in adults with autism and intellectual disabilities. Table 1 presents a summary of studies that have provided data allowing a comparison of the rate of mental ill-health in participants with autism and intellectual disabilities and a comparison sample. The conclusions that can be drawn from these studies are limited for several reasons. These include biased samples, small sample sizes, the methodology used for detection of mental ill-health, failure to distinguish between, or report if, data refers to life-to-date prevalence or point/period prevalence, use of inappropriate comparison data due to differences in sample characteristics, the diagnostic criteria used in different studies, and lack of statistical comparisons.

********** insert table 1 here**********

We are not aware of any studies reporting the incidence of mental ill-health in adults with autism and intellectual disabilities.

There is a high rate of psychotropic medication use in adults with intellectual disabilities (Robertson, Emerson, Gregory, Hatton, Kessissoglou, & Hallam, 2000). One study found that adults with autism and intellectual disabilities were more likely to be prescribed psychotropic medication, and in particular antipsychotics, compared to matched controls with intellectual disabilities who do not have autism (Tsakanikos et al, 2007). However, overall there is limited evidence about the use of psychotropic medication in adults with autism and intellectual disabilities.

This study is nested within a larger prospective cohort study of adults with intellectual disabilities of any cause. This study examines the research questions a) is there a significant difference in the point prevalence of, incidence of, and recovery from mental ill-health in adults with autism and intellectual disabilities, compared with adults with intellectual disabilities who do not have autism? b) are adults with autism and intellectual disabilities more likely to be prescribed psychotropic medication than adults with intellectual disabilities who do not have autism?

Methods

Ethical approval and consent

The study was approved by the research ethics committee. Consent was taken from each participant who had capacity to choose or refuse to participate, or for persons who did not have capacity to decide, from their nearest relative or carer in keeping with the terms of ethical committee approval.

Participants

The adult population with intellectual disabilities living within the geographical area of Greater Glasgow Health Board (total adult population of 701, 846) Scotland, was identified. The process identified all adults with intellectual disabilities who were registered with a general practitioner / family physician in Greater Glasgow (all 631 (100%) general practitioners / family physicians contributed to the ascertainment process); adults with intellectual disabilities who were receiving support of any type paid

for, or provided by, the social work department, including day services and support packages of any size; and adults with intellectual disabilities who were using specialist intellectual disabilities health services, or had done so in the past. The population ascertainment rate was 3.33 per 1,000 general population, which is similar to other, large scale ascertainments (Farmer, Rohde, & Sacks, 1993; McGrother, Bhaumik, Thorp, Watson, & Taub, 2002; van Schrojenstein Lantman-de Valk, Wullink, van den, Heurn-Nijsten, Metsemakers, & Dinant, 2006; Wullink, Van Schrojenstein Lantman de-Valk, Dinant, & Metsemakers, 2007).

Process

The adults from 11 of the 16 administrative sectors of Greater Glasgow Health Board (total adult population of 482, 734) were recruited into a longitudinal cohort at time one (T1), and data collected on demography, development, ability, and health. To examine the incidence of mental-ill-health, assessments were repeated two years later (T2).

At T1 each participant underwent a detailed assessment by nurses with specialist qualifications in working with adults with intellectual disabilities, using the *C21st Health Check* (Glasgow U.C.E.D.D., 2001). The *C21st Health Check* (Glasgow U.C.E.D.D., 2001) includes a) a screening tool to identify individuals with characteristic diagnostic features of autism, based on diagnostic criteria in the International Classification of Mental Disorders: Diagnostic Criteria for Research (ICD-10-DCR) (World Health Organisation, 1993) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychiatric Association, 2000) b) a rigorous screening process to identify symptoms of mental-ill health.

Participants were supported by carers during the assessments and information was also collected from a relative. Additionally, the primary health care case notes of the participant were reviewed using a semi-structured format to identify known health needs and diagnoses. The nurses then discussed findings with one of three family physicians specialising in working with adults with intellectual disabilities. A second stage comprehensive psychiatric assessment was then conducted with participants identified as possibly, or probably, having autism or mental ill-health.

Diagnosis of autism

Adults who were identified by the *C21st Health Check* as probably, or possibly having autism, were assessed further at a second face-to-face comprehensive psychiatric assessment by the Glasgow University Centre for Excellence in Developmental Disabilities (U.C.E.D.D.) (Glasgow U.C.E.D.D., 2001). The Glasgow U.C.E.D.D. is run by two clinical academics who are also consultant psychiatrists specialised in working with adults with intellectual disabilities, and experienced in the diagnosis of autism in adults with intellectual disabilities. In all cases, the findings were case conferenced with the consultant members of the research team to derive consensus, consultant-level clinical diagnoses of autism.

Determination of mental health status

At T1 and T2, the same process was used to identify and assess participants with mental ill-health. Participants identified with two or more items, or one "high risk" item, on the *PAS-ADD Checklist* (Moss et al, 1998), or who required diagnostic clarification of problem

behaviours, were referred for a comprehensive psychiatric assessment by the Glasgow U.C.E.D.D.. Additionally, at T2, screening questions were used to identify any episodes of mental ill-health that had occurred in the interim period between T1 and T2, and a *PAS-ADD Checklist* then completed for the episode. The same threshold was used to trigger referral for comprehensive psychiatric assessment. The psychiatric assessment process has been described in detail previously (Cooper, Smiley, Morrison, Williamson, & Allan, 2007a), and included a full clinical assessment, and information from the assessment instruments described in the section below. Medical and psychology case records were reviewed for all participants, including both primary and secondary health care records.

Episodes of mental ill-health were classified according to the criteria within the *Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities / Mental Retardation*[4] (Royal College of Psychiatrists, 2001) (DC-LD), the ICD-10-DCR (World Health Organisation, 1993), and the DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2000). The operationalised diagnostic criteria were strictly applied. For disorders where operationalised criteria are not presented within the manuals (e.g. the "N.O.S." and "Other" categories) the diagnoses were not included, as these essentially are the psychiatrists' clinical opinion. Additionally, consensus research psychiatrists' diagnoses were determined. These were diagnoses of clinically significant mental ill-health regardless of whether or not they met the full criteria required in the standard diagnostic manuals (DC-LD, ICD-10-DCR, or DSM-IV-TR. They were based on the clinical experience and training of the research psychiatrists, standardized through the consensus process.

Materials

The following instruments were used at the interviews.

1. The *PAS-ADD Checklist* (Moss et al., 1998). This is a screening tool for the identification of possible psychiatric disorders in adults with intellectual disabilities. It comprises 29 items of psychopathology commonly experienced by adults with intellectual disabilities and mental ill-health. When using the published thresholds, the reported sensitivity of the tool is only about 66% (Moss *et al,* 1998; Simpson, 1999; Sturmey *et al,* 2005). However, Simpson's study of its psychometric properties included receiver operating characteristic analyses for various possible ways of completing it. This found that when the *PAS-ADD Checklist* was completed with the person's main carer and a threshold of any two positive items was used, the tool had a 100% sensitivity to detect persons meeting criteria for an ICD-10 diagnoses with a false positive rate of 58%, and 95% sensitivity to detect persons meeting criteria for a DSM-IV diagnoses with a false positive rate of 53%. We therefore used this threshold to trigger the second stage full psychiatric assessment, as false positives would be removed at that stage. Additionally, we added six new items after a pilot study with 50 persons, to improve detection of mania and psychosis.
2. A purpose designed semi-structured demography questionnaire. This included data on age, gender, and type of accommodation.
3. The C21st Health Check (Glasgow U.C.E.D.D., 2001). This allows an assessment of health and includes sections on psychiatric disorders, problem behaviours, autism spectrum disorders, developmental level and support needs, as well as general physical health. It has been demonstrated to have good utility (Curtice, Cooper, Espie, Morrison,

Ibbotson, T. Long & Allan, 2001). There is also a section for a selected physical examination, including assessment of vision and hearing. 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. The items in the sections to assess autism, problem behaviours, and mental ill-health were also used to trigger referral for full psychiatric assessment. Inter-rater reliability has been shown to be excellent: self-injurious behaviour (kappa=1.0), verbal aggression (kappa=0.923), physical aggression to others (kappa=0.724), destructiveness to property (kappa=1.0), aggression of any of the three (verbal, physical, destructive) types (kappa=0.791), other problem behaviours (kappa=0.830), problem behaviour of any type (kappa=0.857). Intra-rater reliability has also been shown to be consistent: SIB (kappa=1.0), verbal aggression (kappa=1.0), physical aggression to others (kappa=0.791), destructiveness to property (kappa=1.0), aggression of any of the three types (kappa=0.927), other problem behaviours (kappa=0.911), problem behaviour of any type (kappa=1.0). At T1, for persons who had no record of previous testing of their intelligence quotient, ability was assessed from the development and ability section of the *C21st Health Check*, taking into account impaired communication and social skills for persons with autism, in keeping with the *ICD-10 Classification of Mental and Behavioural Disorders, Clinical Descriptions and Diagnostic Guidelines* (World Health Organisation, 1993). The scores from this are highly correlated (Pearson's correlation r = 0.812; P<0.001) with scores from the Vineland Scale (Survey form) (Sparrow, Balla, & Cicchetti, 1984). The *C21st Health Check* was also used to collect data on prescribed psychotropic drugs.

4. The *Present Psychiatric State for Adults with Learning Disabilities* (PPS-LD) (Cooper, 1997). This was used at the second stage comprehensive psychiatric assessment at both T1 and T2. It is a semi-structured psychopathology schedule specifically designed for use with adults with intellectual disabilities, and allows classification of psychopathology by psychiatrists' opinion, DC-LD, DCR-ICD-10, and DSM-IV-TR criteria. It was modelled on the *Schedules for Clinical Assessment in Neuropsychiatry* (World Health Organisation, 1992), but includes a wider range of psychopathology as required for some of the DC-LD items (e.g. tearfulness and reassurance seeking behaviour), avoids highly complex language, and places the measurement of psychopathology within a developmental perspective, including distinguishing "trait" from "state" items.
5. Purpose-designed instruments to detect the psychopathology within autism spectrum disorders, hyperkinetic disorders and problem behaviours[4]. These instruments are based on the operationalised criteria contained within DCR-ICD-10, and DSM-IV-TR for autism spectrum disorders and hyperkinetic disorders, and DC-LD criteria for problem behaviours. These are not diagnostic schedules. Rather they are specifically designed for use by trained clinicians, within the context of a full psychiatric assessment, aiming to ensure the comprehensiveness of the assessment process.

Analyses

Analysis of the data was completed using the Statistical Package for the Social Sciences Version 11.5 for Windows.

T1 point prevalence of, two year incidence of, and the two-year recovery rate from mental ill-health were calculated for the adults with autism and intellectual disabilities. The two-year incidence of mental ill-health was defined as the proportion of individuals with the onset of a new episode at any time in the two year period. The frequency of prescribed psychotropic drug use was then calculated.

Comparable prevalence and incidence data for the population with intellectual disabilities of any cause has been previously reported (n = 1,023; n = 651), using identical procedures to the ones described in this paper (Cooper et al., 2007a; Smiley, Cooper, Finlayson, Allan, Mantry, McGrother, McConnachie, Morrison, & Jackson, 2007). This data was used to calculate the standardised rate with 95% confidence intervals for point prevalence of mental ill-health. It was also used to calculate the standardised incidence ratio with 95% confidence intervals for mental ill-health.

A second comparison to a matched sample was then conducted. This was carried out since the population of adults with autism are more likely to be male, have more severe intellectual disabilities, are younger, and are less likely to have Down syndrome than the population with intellectual disabilities in general. Each of these factors has been demonstrated to influence the prevalence and incidence of mental ill-health, and could potentially act as confounding factors. Regarding cause of intellectual disabilities, matching was only carried out for Down syndrome as, unlike other genetic syndromes, it is a common cause of intellectual disabilities, and it is also know to be associated with a lower prevalence and incidence of mental ill-health and problem behaviours. Had matching for Down

syndrome not been undertaken, a larger proportion in the control group would have been expected to have Down syndrome, hence reducing the relative rate of mental ill-health in that group. Each adult with autism and intellectual disabilities was individually matched with two adults with intellectual disabilities who did not have autism for gender, ability (in the four categories of mild, moderate, severe, or profound intellectual disabilities), age within 5 years, and presence or absence of Down syndrome. Given the relatively small number of participants with autism, matching with two adults with intellectual disabilities who did not have autism was carried out to increase the power of the study (Hotopf, 2003). The χ^2 test was used to test whether any statistically significant differences in mental ill-health, and prescribed psychotropic drug use, existed between the adults with autism and intellectual disabilities, and their individually matched controls.

Results

Characteristics of participants

At T1, assessments were completed with 65.5% of the total eligible adult population with intellectual disabilities (1,023 adults). This included 77 adults with autism and intellectual disabilities; 59 (76.6%) were men and 18 (23.4%) were women; 14 (18.2%) had mild intellectual disabilities, 14 (18.2%) had moderate, 21 (27.3%) had severe and 28 (36.4%) had profound intellectual disabilities; two (2.6%) had Down syndrome. Their mean age at T1 was 37.8 years (standard deviation = 14.1 years). The 154 matched controls with intellectual disabilities who do not have autism had identical gender, level of ability, and presence of Down syndrome proportions, and mean age at T1 of 37.8 years (standard deviation = 13.6 years). One participant had a matched control that differed in age by 6

years, all others were within 5 years, and the majority (97.4%) were within 3 years. Of the participants recruited to the study at T1, 50 of the adults with autism and intellectual disabilities, and 98 of the matched controls participated at T2.

Point prevalence of mental ill-health

The point prevalence of mental ill-health for the participants with autism and intellectual disabilities at T1 is reported in table 2. The exact code numbers from each manual included within each diagnostic grouping in table 2 have previously been reported (Cooper *et al.* 2007a). Prevalence varies depending upon the diagnostic criteria employed. Forty people (51.9%) had no additional mental ill-health, 29 (37.7%) had one disorder, and 8 (10.4%) had two disorders, according to clinical diagnosis.

********** insert table 2 about here **********

Comparison of point prevalence with the whole population with intellectual disabilities, and with their matched controls

The comparable prevalence data for the whole population with intellectual disabilities reports the point prevalence of mental ill-health to be 37.0% (Cooper et al., 2007a). Hence the expected number of prevalent cases in this population with autism is 28.5 whereas the actual number is 37, giving a standard rate of 1.3 (95% confidence interval = 0.9 – 1.8). The major factor in this difference is problem behaviours, with an observed count of 29, compared with the expected 17.3 (standard rate = 1.7; 95% confidence interval = 1.1 – 2.4). The comparable prevalence data for point prevalence of mental ill-health (excluding problem

behaviours) is 28.3%. Hence the expected number of prevalent cases in this population with autism is 21.8, whereas the actual number is 16, giving a standard rate of 0.74 (95% confidence interval = 0.42-1.19).

Table 3 shows that there is no significant difference in the point prevalence of mental ill-health, between the adults with autism and intellectual disabilities and their matched controls. Of the matched controls, 92 (59.7%) had no additional mental ill-health, 45 (29.1%) had one disorder, and 12 (7.8%) had two disorders, four (2.6%) had three disorders, and one (0.6%) had four disorders, according to clinical criteria.

********** insert table 3 here**********

Incidence of mental ill-health

The two year incidence of mental ill-health of any type (excluding specific phobias) was 16.0% by clinical diagnosis (n = 8), 12.0% by DC-LD criteria (n = 6), 6.0% by DCR-ICD-10 criteria (n = 3), and 4.0% by DSM-IV-TR criteria (n = 2). No-one had more than one incident episode. The most common types of new episodes of mental ill-health were affective disorders (n = 4; 8.0%), followed by problem behaviours (n = 2; 4.0%), with one each of anxiety disorders (2.0%), and other disorders (1.3%). Three of the affective disorders were depressive episodes, and one was a mixed affective disorder. No-one had an incident episode of a psychotic disorder, mania, dementia, obsessive compulsive disorder, nor eating disorder.

Comparison of incidence with the whole population with intellectual disabilities, and with their matched controls

The comparable incidence data for the whole population with intellectual disabilities reports the two year incidence of mental ill-health to be 16.3% (Smiley et al., 2007). Hence the expected number of incident cases of mental ill-health in this cohort with autism and intellectual disabilities is 8.2, with the actual number being eight, giving a standardised incidence ratio of 1.0 (95% confidence interval = 0.4 – 1.9). For mental ill-health (excluding problem behaviours), the same comparative data gives an incidence of 12.6%. Hence the expected number of incident cases is 6.3, with the actual number being six, giving a standardised incidence ratio of 1.0 (95% confidence interval = 0.3 – 2.1). Specifically for problem behaviours, the expected number of incident cases is 2.3, compared with the 2 observed, giving a standardised incidence ratio of 0.9 (95% confidence interval = 0.1 – 3.1).

Table 4 provides comparison data for the 50 participants with autism and intellectual disabilities and the 98 matched controls who participated at T2.

********** insert table 4 here**********

Recovery from mental ill-health and problem behaviours

In table 5, the number of participants with autism and intellectual disabilities compared with the number of controls, who recovered from mental ill-health and problem behaviours during the two year period between T1 and T2 are given.

********** insert table 5 here**********

Psychotropic drugs

The use of psychotropic medications by participants with autism and intellectual disabilities, and their matched controls at T1 is shown in table 6.

**********insert table 6 here**********

Polypharmacy was common amongst both groups, and some individuals were prescribed more than one antipsychotic or mood stabilizing drug. The high use of mood stabilising drugs was due to the high prevalence of epilepsy (44.7% of the participants with autism, and 48.0% of their matched controls had epilepsy).

Discussion

Principle findings and their interpretation

Adults with autism and intellectual disabilities were found to experience a significantly higher point prevalence of problem behaviours, but similar point prevalence of mental ill-health excluding problem behaviours, compared with the whole population of adults with intellectual disabilities. However, when compared with age, gender, ability, and Down syndrome matched controls, this difference was not found, suggesting that the higher point prevalence of problem behaviours could not be attributed to the presence of autism. The incidence of mental ill-health for the adults with autism was similar to the whole population with intellectual disabilities and their matched controls. Although not statistically significant,

the data shows a trend towards a lower incidence of problem behaviours for the adults with autism compared with the controls. The recovery rate from problem behaviours was significantly lower for the adults with autism during the two year period. This suggests that the similar prevalence is due to a lower incidence, but that once present, problem behaviours are more likely to endure in the adults with autism.

This is the first study we know of to use a matched control methodology to control for the known confounding factors relevant to mental ill-health and problem behaviours. Lower ability level is associated with high rates of problem behaviours and mental ill-health in general (Borthwick-Duffy & Eyman, 1990; Cooper et al., 2007a). Female gender is associated with high rates of mental ill-health overall (Cooper et al., 2007a), depression (Cooper, Smiley, Morrison, Williamson, & Allan, 2007b), but not psychosis (Cooper, Smiley, Morrison, Williamson, & Allan, 2007c). Male gender has been reported to be associated with higher rates of problem behaviours (McClintock, Hall, & Oliver, 2003), as has female gender (Deb, Thomas & Bright, 2001; Jones, Cooper, Smiley, Allan, Williamson, & Morrison, 2008), although one study found no association with gender (Holden & Gitlesen, 2006). Finally, Down syndrome is known to be associated with low rates of mental ill-health and particularly problem behaviours (Collacott, Cooper, Branford, & McGrother, 1998; Mantry, Cooper, Smiley, Morrison, Allan, Williamson, Finlayson, & Jackson, 2007).

In the current study, there is no difference in the prevalence of mental ill-health experienced by adults with autism and intellectual disabilities, and adults with intellectual disabilities who do not have autism. This is similar to the finding reported by Tsakanikos (Tsakanikos et

al, 2006), although the sampling from clinic referrals in that study may have introduced significant selection bias. Several authors have suggested that adults with autism and intellectual disabilities experience increased rates of depression (Morgan, Roy, & Chance, 2003; Ghaziuddin, Ghaziuddin, & Greden, 2002; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006) but there is a lack of rigorous evidence to support this. Similarly, a putative association between autism and schizophrenia has been explored (Konstantareas & Hewitt, 2001) but is not supported by the findings reported here.

Two previous studies that controlled for the confounding effects of age, gender, level of ability, but not Down syndrome, on prevalence of problem behaviours (Tyrer et al, 2006; Tsakanikos et al., 2007) reported conflicting results. Although focused on single problem behaviour, physical aggression to others, similar to the study reported here Tyrer (Tyrer et al., 2006) found no increased rate of problem behaviours in the autism group, whilst Tsakanikos (Tsakanikos et al., 2007) reported an increased prevalence of problem behaviours in the autism group. A possible explanation for this discrepancy is the sampling bias introduced through the use of a clinic sample by Tsakanikos (Tsakanikos et al., 2007). Regardless of the fact that it seems that, by adulthood, autism is not an independent risk factor for problem behaviours, the high rates reported in both adults with autism and intellectual disabilities and adults with intellectual disabilities who do not have autism, emphasises the need to develop mental health promotion interventions to reduce the risk of individuals with intellectual disabilities developing problem behaviours.

The results in this study are different from those described in controlled studies of children and young people with autism and intellectual disabilities, which have demonstrated increased rates of psychopathology (Brereton et al., 2006), mental ill-health (Bradley et al., 2004; Bradley et al., 2006) and problem behaviours (Bradley et al., 2004; Holden et al., 2006). This suggests that, in childhood and adolescence, factors associated with autism have an effect on the risk of developing mental ill-health, over and above factors associated with intellectual disabilities. For example, the qualitative impairments in communication and reciprocal social interaction, and restricted, repetitive repertoire of behaviours which are central to the diagnosis of autism (World Health Organisation, 1993; American Psychiatric Association, 2000) are known to be associated with mental ill-health (Reese, Richman, Belmont, & Morse, 2005). Similarly, the sensitivities to sensory environmental factors, such as noise, light and smell commonly experienced by individuals with autism spectrum disorders (Dawson & Watling, 2000; Kern, Trivedi, Garver, Grannemann, Andrews, Savla, Johnson, Mehta, & Schroeder, 2006), have been associated with problem behaviours (Reese et al., 2005). It may be that by adulthood, with individual development of coping strategies and the provision of appropriate supports and interventions, these factors no longer have a differential effect upon the risk of developing mental ill-health, in adults with autism and intellectual disabilities and adults with intellectual disabilities who do not have autism. Although speculative, this highlights the potential benefits of early interventions for individuals with autism spectrum disorders. There is evidence that early interventions can enhance communication and social impairments in children and young people with autism spectrum disorders (Scottish Intercollegiate Guideline Network, 2007), which may be expected to reduce the long term risks of individuals developing mental-ill health. An

alternative explanation for this effect is that in childhood and adolescence, environmental factors specific to this life stage, such as transitions from schools, or parental divorce (Ghaziuddin, Alessi, & Greden, 1995) may be more likely to act as triggers for the development of mental ill-health in children with autism and intellectual disabilities, compared to children with intellectual disabilities who do not have autism. By adult life, it is possible that adults with intellectual disabilities who do not have autism have accumulated risk factors for mental ill-health, such that the differences seen in children are out-weighted.

This is the first study to report the incidence of mental ill-health in adults with autism and intellectual disabilities. Whilst there do not appear to be any significant differences compared with the matched controls, and the total study sample with intellectual disabilities, the incidence of mental ill- health reported here is greater than in the general population (Smiley et al., 2007). Further research can help to elucidate the determinants for this increased incidence of mental ill-health, and allow clinicians and academics to develop targeted interventions to reduce the risk of adults with autism and intellectual disabilities developing mental-ill health.

The finding in this study that adults with autism and intellectual disabilities with problem behaviours are less likely to recover over a two year period suggests that available interventions and service provision may be less effective for these individuals, compared to adults with intellectual disabilities who do not have autism. Few studies have been carried out examining the efficacy of interventions for mental ill-health experienced by adults with autism and intellectual disabilities, compared to adults with intellectual disabilities who do

not have autism. Compared to the literature on interventions for persons who do not have intellectual disabilities, overall there is a lack of evidence from controlled studies on the efficacy, or effectiveness, of interventions for mental ill-health in persons with intellectual disabilities. There is evidence to support the positive impact of behavioural interventions for problem behaviours (Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996, Didden, 1997; Didden 2007) in adults with intellectual disabilities. However, whilst still commonly used, there is very little robust evidence to support the use of psychotropic medication in the management of problem behaviours in adults with intellectual disabilities (Brylewski & Duggan, 2004) or autism spectrum disorders (Kwok, 2003). Furthermore, the side effects of medication can lead to psychopathology or problem behaviours, and therefore, the use of medication in the management of problem behaviours should be part of an integrated, multi-disciplinary management plan, and should be closely monitored for effectiveness and adverse effects (Deb, Clarke, & Unwin, 2006).

There is no difference in the rates of use of psychotropic medication in the participants with autism and intellectual disabilities and the matched controls with intellectual disabilities who do not have autism. This is as one would expect, given that there is no difference in the prevalence of mental ill-health between the two groups. The finding from the study reported here contrasts with the findings of Tsakanikos (Tsakanikos et al., 2007), who reported higher rates of psychotropic medication in adults with autism and intellectual disabilities. However, the adults with autism and intellectual disabilities in their study had higher rates of problem behaviours than the matched controls with intellectual disabilities who did not have autism.

Strengths and limitations of the study

This is the first population based study to compare the prevalence and incidence of mental ill-health in adults with autism and intellectual disabilities to a matched control group with intellectual disabilities who do not have autism. The study benefited from robust population ascertainment, comprehensive psychiatric assessments using structured instruments, and the use of standardised diagnostic criteria. Reporting the findings using all the standard diagnostic classificatory systems provides clarity, and enables comparison with other research, whichever criteria are used. We consider the two-year interval between T1 and T2 to be a further strength of the study; it was selected to ensure accuracy of data collection. A larger time interval might have led to missing data for persons unable to fully provide and remember their own information without carer support. This is because of e.g. the turnover of support staff and communication limitations between successive support staff, and some episodes not being brought to the attention of professionals at the time they occur.

Our study will not have included all people with an intelligence quotient less than 70. Some people in this category require additional support in childhood, but as they gradually develop, may not have impaired adaptive functioning or need for support in adult life. The latter is a required criterion in DSM-IV-TR and ICD-10, and its inclusion is estimated to half the size the adult population defined to have intellectual disabilities. Such persons are unlikely to be identified by general practitioners/family physicians (or indeed themselves) as disabled. Hence, the cohort is socially rather than statistically constructed, in keeping with both DSM-IV-TR and ICD-10 criteria for intellectual disabilities. The general practitioners/family physicians in the study were incentivised to identify adults with intellectual disabilities who were registered with them, as the Health

Board established an additional annual capitation payment to be provided to them for each person with intellectual disabilities on their list, in view of the associated additional workload. Almost everyone in the UK is registered with a general practitioner/family physician, with exceptions being the prison population and homeless persons. This population ascertainment therefore differs from "administratively" defined populations, as it was through general practitioners/family physicians, not just services provided for persons with intellectual disabilities. Reviewing the existing literature reveals that there are many contributing factors that make the prevalence of intellectual disabilities amongst the adult population far from clear, with it additionally varying with time, country and region, age group, socio-economic factors, and the definition of intellectual disabilities used (Leonard and Wen, 2002),. The population rate of 0.33 per 1,000 is in keeping with other recent population ascertainments/estimates in Europe (Farmer *et al.* 1993; McGrother *et al.*, 2001; van Schrojenstein Lantman-de Valk HM *et al.*, 2006; Wullink, Van Schrojenstein Lantman de-Valk, Dinant, & Metsemakers, 2007), and is lower than that found amongst children and young persons because of the short life expectancy of persons with intellectual disabilities, combined with their gradual skill development as described above. We consider the population ascertainment to have been robust.

The main limitation of the study is the small sample size for the participants with autism and intellectual disabilities, which led to wide confidence intervals particularly for the incidence and recovery data, and precluded investigation of factors predictive of incident mental ill-health. Additionally, we are unable to report the proportion of people with autism who

declined to participate in the study at T1, as the persons with autism were identified through assessment of each person and inspection of their medical records after gaining consent to participate in the study. Hence we reported the participation rate for the whole cohort of adults with intellectual disabilities, and assume that there is the same proportion of adults with autism who declined to participate.

The consensus, consultant-level diagnosis of autism in the study was based on a comprehensive psychiatric assessment, by psychiatrists with specialist training in the diagnosis of autism and mental ill-health in adults with intellectual disabilities. Whilst the use of a standardised diagnostic instrument, such as the ADI-R (Lord, Rutter, & Le Couteur, 1994) or DISCO (Wing, Leekam, Libby, Gould, & Larcombe, 2002) might have added to the inter-rater reliability, there is no evidence that these improve diagnostic validity compared to a gold-standard clinical diagnosis (Scottish Intercollegiate Guideline Network, 2007).

It is important to consider threats to the validity of the study findings (Cook & Campbell, 1979). There has been some interest in the idea that adults with autism and intellectual disabilities present with different patterns of psychopathology, indicative of mental ill-health, compared to adults with intellectual disabilities that do not have autism, and that measures of psychopathology specific to autism are required to reliably identify mental ill-health (Stewart et al., 2006). Therefore, a potential threat would exist if there is a between group difference in the reliability of the process to identify mental ill-health. We believe that the two stage process used in this study has similar reliability to identify mental ill-health in

the two groups of participants. The *PAS-ADD Checklist* used in the rigorous initial screening was developed for use both with adults with intellectual disabilities who do not have autism and adults with autism and intellectual disabilities (Moss et al., 1998), and is shown to have good reliability. The *PPS-LD* was developed specifically to take account of the presentation of psychopathology in adults with intellectual disabilities, assesses psychopathology from a developmental perspective, and enquires about behavioural presentations of mental ill-health (Cooper, 1997). Finally, the psychiatrists carrying out the detailed assessments have specialist qualifications and experience relevant to the assessment of mental-ill health in adults with intellectual disabilities, and autism.

Future directions

Adults with autism and intellectual disabilities, and adults with intellectual disabilities who do not have autism, experience high rates of mental ill-health. Mental ill-health is recognised to have a negative impact on long term outcomes for individuals with autism and intellectual disabilities (Billstedt et al., 2005; Bradley et al., 2006). Furthermore, problem behaviours are associated with increased family (Lecavalier, Leone, & Wiltz, 2006), and carer stress (Tyrer et al., 2006), and in adults with autism and intellectual disabilities has a strong association with the risk of being moved to an out of area placement, and increased service costs (Allen, Lowe, Moore, & Brophy, 2007). Research is required to develop an understanding of the risk and vulnerability factors relevant to the development of mental ill-health in children, young people and adults with intellectual disabilities. Large scale, longitudinal research is required to study the developmental trajectory of individuals with intellectual disabilities, and allow comparison between individuals with additional diagnoses

related to developmental disorders, such as autism spectrum disorders, and behavioural phenotypes.

To minimise the negative long term impacts of mental ill health on the quality of life of persons with autism and intellectual disabilities (Allen et al., 2007) there is a need to develop effective interventions and services. Relatively little research has been carried out to examine the efficacy and effectiveness of interventions for mental ill-health experienced by adults with autism and intellectual disabilities. As a consequence, services are less likely to be evidence based- a form of implicit discrimination. Government bodies commissioning research and grant funding bodies should consider the need to resource outcome studies for mental health interventions that include adults with autism and intellectual disabilities as participants.

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Footnotes

1. Mental ill- health is used to describe all forms of psychiatric disorders or problem behaviour, excluding autism. Problem behaviour is used as the preferred term to describe behavioural disorders or challenging behaviour. Operationalised criteria for problem behaviours are provided in the *Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities / Mental Retardation* (Royal College of Psychiatrists, 2001).
2. Psychopathology refers to any symptoms of emotional and behavioural disturbance elicited during the process of assessment. This information is then used to provide a diagnosis based on agreed criteria contained in a standardised classification system.
3. The term problem behaviours encompasses all those listed in DC-LD (Royal College of Psychiatrists, 2001) including: verbally aggressive behaviour; physically aggressive behaviour; destructive behaviour; self-injurious behaviour; sexually inappropriate behaviour; oppositional behaviour; excessively demanding behaviour, wandering behaviour and other problem behaviour.
4. The *Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities / Mental Retardation* was developed as a diagnostic classificatory system for use with adults with intellectual disabilities, in recognition of the limitations of ICD-10 and DSM-IV.

TABLE 1: Prevalence studies of mental ill-health and problem behaviours in adults with autism, and adults with intellectual disabilities

	N	Population	Assessments	Diagnostic criteria	Comparison groups	Findings
Davidson, Cain, Sloane-Reeves, Van Speybroech, Segel, Gutkin, Quijano, Kramer, Porter, & Shohan , 1994)	199	Convenience sample of referrals to a clinical service	Clinical assessment and case-note review	None	Autism= 10 Non-autism= 189 No details of between group comparability for age, gender, level of ID or Down syndrome.	No independent association with a diagnosis of autism and aggression.
Bhaumik, Branford, McGrother, & Thorp, 1997	2, 201	Register-based sample of adults with ID.	Interviewer administered carer questionnaire (items from the DAS)- autism group defined by presence of at least 4, from a possible 5, autistic traits	None	Autism= 72 Non-autism= 2129 No details of between group comparability for age, gender, level of ID or Down syndrome.	Autistic traits positively associated with problem behaviours.
Hill & Furniss, 2006	82	Convenience sample residents in 4 residential units	Interviewer administered DASH-II and ABS	None	Autism =69 Non-autism= 13 No significant between group difference in age, gender or level of functioning	Autsim group had higher scores on DASH-II anxiety, impulse, mania and stereotypies subscales.
Holden and Gitlesen, 2006	745	Administrative sample in defined geographical area.	Postal carer questionnaire- autism group defined by carer report of known diagnosis.	None	Autism=53 Non-autism=692 No details of between group comparability for age, gender, level of ID or Down syndrome.	Autism group significantly more like to experience problem behaviours

Tsakanikos, Costello, Holt, Bouras, Sturmey, & Newton, 2006	752	Convenience sample of referrals to a clinical service	Semi-structured clinical assessment. Subgroup of 224 assessed with *PAS-ADD Checklist*	ICD-10	Autism= 147 Non-autism= 605 Autism group significantly younger, and less able than the non-autism group	Psychiatric disorders less frequently diagnosed in autism group. Autism group more likely to be prescribed psychotropic medication
Tyrer, McGrother, Thorp, Donaldson, Bhaumik, Watson, & Hollin, 2006	3062	Register-based sample of adults with ID.	Interviewer administered carer questionnaire- autism group defined by presence of at least 4, from a possible 5, autistic traits DAS.	None	Autism= 68 Non-autism= 2560 Logistic regression was used to adjust for between group differences, in age, gender and estimated IQ and test independent associations.	No increase in aggressive behaviours in autism group.
Tsakanikos, Costello, Holt, Sturmey, & Bouras, 2007	168	Convenience sample of referrals to a clinical service	Clinical assessment DAS.	ICD-10 for diagnosis of autism	Autism = 69 Non-autism = 99 Participants were matched for age, gender and level of ID	Autism group significantly more like to experience problem behaviours. Autism group more likely to be prescribed anti-psychotic medication

Notes
DASH-II- Diagnostic Assessment for the Severely Handicapped II (Matson, Baglio, Smiroldo, Hamilton, Packlowskyi, Williams, & Kirkpatrick-Sanchez, 1996)
ABS- Aberrant Behaviour Schedule- Community (Aman, Burrow, & Wolford, 1995)
PAS-ADD checklist (Moss, Prosser, Costello, Simpson, Patel, Rowe, Turner, & Hatton, 1998)
DAS- Disability assessment Schedule (Holmes, Shah, & Wing, 1982)

TABLE 2: Point prevalence of mental ill-health by clinical, DC-LD, DCR-ICD-10, and DSM-IV-TR diagnostic criteria at T1

Diagnostic category	**Diagnostic Criteria (n = 77)**			
	Clinical n (%; 95% C.I.)	**DC-LD n (%; 95% C.I.)**	**DCR-ICD-10 n (%; 95% C.I.)**	**DSM-IV-TR n (%; 95% C.I.)**
Psychotic disorder*	1 (1.3)	1 (1.3)	0 (0)	0 (0)
Affective disorder	4 (5.2)	3 (3.9)	3 (3.9)	2 (2.6)
Anxiety disorder†	3 (3.9)	2 (2.6)	2 (2.6)	2 (2.6)
OCD	0 (0)	0 (0)	0 (0)	0 (0)
Organic disorder	0 (0)	0 (0)	0 (7.0)	0 (0)
Alcohol / substance disorder	0 (0)	0 (0)	0 (0.5)	0 (0)
Pica	4 (5.2)	4 (5.2)	0 (0)	1 (1.3)
Other eating disorder††	0 (0)	0 (0)	0 (0)	0 (0)
ADHD	3 (3.9)	2 (28.6)	0 (0)	0 (0)
Problem behaviour	29 (37.7)	22 (8.1)	0 (0)	0 (0)
Personality disorder	0 (0)	0 (0)	0 (0)	0 (0)
Other mental ill-health	1 (1.3)	0 (0)	0 (0)	0 (0)
Mental ill-health of any type, excluding problem behaviours†	16 (20.8; 12.4–31.5)	12 (15.6; 8.3–25.6)	5 (6.5; 2.1– 4.5)	5 (6.5; 2.1–14.5)
Mental ill-health of any type†	37 (48.1; 36.5–59.7)	28 (36.4; 25.7–48.1)	5 (6.5; 2.1–14.5)	5 (6.5; 2.1–14.5)

*Includes schizoaffective disorders
†Excludes specific phobias
††Excludes pica

TABLE 3: Point prevalence of mental ill-health for adults with autism and intellectual disabilities compared with matched controls

	Autism (n=77)	**Controls (n=154)**	χ^2	**P**
Mental ill-health of any type*	37 (48.1%)	62 (40.3%)	1.3	0.259
Mental ill-health of any type, excluding problem behaviours*	16 (20.7%)	36(23.4%)	0.2	0.656
Problem behaviours	29 (37.6%)	42 (27.3%)	2.6	0.107

*Excluding specific phobias

TABLE 4: Two year incidence of mental ill-health for adults with autism and intellectual disabilities compared with matched controls

	Autism (n=50)	**Controls (n=82)**	χ^2	**P**
Mental ill-health of any type*	8 (16%)	19 (19.4%)	0.3	0.614
Mental ill-health of any type, excluding problem behaviours*	6 (12.0%)	14 (14.3%)	0.1	0.700
Problem behaviours	2 (4%)	7 (7.1%)	0.6	0.449

*Excluding specific phobias

TABLE 5: Recovery from mental ill-health for adults with autism and intellectual disabilities compared to matched controls

	Autism	**Controls**	χ^2	**P**
Mental ill-health of any type, excluding problem behaviours*	(n=14) 5 (35.7%)	(n=31) 15 (48.4%)	0.6	0.4
Problem behaviours	(n=17) 1 (5.9%)	(n=32) 12 (37.5%)	5.7	0.017

*Excluding specific phobias

TABLE 6: Psychotropic medication use by adults with autism and intellectual disabilities and matched controls

		Autism (n=77)	**Controls (n=154)**	χ^2	**P**
Antipsychotic drugs	**Any number**	25 (32.5%)	39 (25.3%)	1.3	0.253
	One	0	32 (20.8%)	–	-
	Two	0	4 (2.6%)	–	-
	Three	0	3 (1.9%)	–	-
Antidepressant drugs		7 (9.1%)	15 (9.7%)	0.0	0.874
Lithium		0 (0.0%)	2 (1.3%)	–	0.554*
Other antiepileptic / mood stabiliser drugs	**Any number**	26 (33.8%)	57 (37.0%)	0.2	0.628
	One	17 (22.1%)	36 (23.4%)	–	-
	Two	6 (7.8%)	17 (11.0%)	–	-
	Three	2 (2.6%)	4 (2.6%)	–	-
	Four	1 (1.3%)	0	–	-

*Fisher's exact test