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ADULTS WITH INTELLECTUAL DISABILITIES. PREVALENCE, INCIDENCE, AND REMISSION OF AGGRESSIVE BEHAVIOUR, AND RELATED FACTORS

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ABSTRACT

Introduction

Aggressive behaviours can be disabling for adults with intellectual disabilities, with negative consequences for the adult, their family, and paid carers. It is surprising how little research has been conducted into the epidemiology of these needs, given the impact they can have. This study investigates point prevalence, two-year incidence, and two-year remission rates for aggressive behaviour (physically aggressive, destructive, and verbally aggressive), and investigates which factors are independently associated with aggressive behaviour.

Methods

All adults with intellectual disabilities within a geographically defined area of Scotland, UK, were recruited to a longitudinal cohort. At baseline, assessments were undertaken of demography, lifestyle, supports, development, problem behaviours, disabilities, and physical and mental health. These were repeated for a two-year period.

Results

At baseline, the participation rate was 1,023 (65.5%). After 2 years, the cohort retention was 651 adults. The point prevalence of DC-LD aggressive behaviour was 9.8% (95% CI=8.0-11.8%), two-year incidence was 1.8%, and two-year remission rate from all types of aggressive behaviour meeting DC-LD criteria was 27.7%. The factors independently associated with aggressive behaviours were lower ability, female gender, not living with a family carer, not having Down syndrome, having ADHD, and having urinary

incontinence. Incidence of aggressive behaviour meeting DC-LD criteria in adult life is similar to that for each of psychotic, anxiety, and organic disorders.

Conclusions

Aggressive behaviour is common amongst adults with intellectual disabilities, but contrary to previous suggestions, more than a quarter remit within the short to medium term. This is important knowledge for professionals as well as the person and her/his family, and paid carers. There is much yet to learn about the mechanisms underpinning aetiology and maintenance of aggressive behaviour in this population, and exploratory epidemiological investigations such as this have a role to play in progressing research towards further hypothesis testing, and trials to influence clinical practice, service development, and policy.

Key words

Intellectual disabilities, aggressive behaviour, problem behaviour, mental ill-health, epidemiology.

INTRODUCTION

Aggressive behaviour can be very disabling. Negative consequences for the adult with intellectual disabilities include difficulties integrating with and participating in the local community and in accessing resources, problems maintaining social networks, exclusion from services, break-down of support packages, and impact on self-esteem. It can also have negative consequences for family and paid carers, including injury, and carer-strain. Designing and implementing packages of support for adults who have aggressive behaviour is challenging for services, and expensive. For these reasons it is therefore important to understand the scale of this type of need, and to start to understand the factors underpinning it.

Previous research has been undertaken to investigate the prevalence of aggressive behaviour amongst adults with intellectual disabilities, and the studies which are community-based are summarised in table 1. There is considerable variation between reported prevalence rates, with all types of aggressive behaviour combined being reported to be as high as 51.7% (Crocker *et al.* 2006), rates for physically aggressive behaviour to others varying between 2.1% (Borthwick-Duffy 1994) and 27.9% (Eyman & Call, 1977), destructive behaviour to property varying between 4.3% (Jacobson 1982) and 24.0% (Crocker *et al.* 2006), and verbally aggressive behaviour varying between 5.9% (Jacobson 1982) and 37.6% (Crocker *et al.* 2006). There are several reasons for these differences, including differences in population characteristics, the different ages studied (some studies combine children and adults together, rather than reporting them

separately), the methods of data collection some of which are postal questionnaires completed by multiple informants, whether aggressive behaviour as a symptom of other physical or mental ill-health was excluded, and most importantly, the criteria used to define aggressive behaviour. For example, Crocker *et al.* (2006) specifically set out to measure all aggressive behaviour, mild or severe, whereas Tyrer *et al.* (2006) focussed only on physically aggressive behaviour to others that was frequent (more than three times per week), and/or severe. Further, Harris (1993) required physically aggressive behaviour to others to be serious and result in injury, or destructive or verbally aggressive behaviour to present serious management problems because of threat of injury to others. The recent publication of the *Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities / Mental Retardation* (DC-LD: Royal College of Psychiatrists 2001) now provides standard criteria which can be used to define categories of problem behaviours in a way that allows for comparison between future studies.

- Insert table 1 about here -

Aggressive behaviour towards others is considered to be persistent and enduring over time (Murphy *et al.* 2005), but there is surprisingly little research to confirm whether this impression is correct for adults with intellectual disabilities. Kiernan & Alborz (1996) reported that of 24 people aged 19-26 who caused physical injury and who remained living with their parents six years later, 83% still caused physical injury. However, the outcomes for an additional ten people who had left the family home in the six year time period were not reported (as the focus of the study was specifically on persons living with

their parents), so it is unclear whether or not 17% was the actual remission rate for the population overall. In a study of 118 young adults with intellectual disabilities, Leudar *et al.* (1984) reported that the presence of physical and verbal aggression directed at others remained relatively stable and resistant to change after a period of 20-24 months: it is unclear how many persons included in the study actually had aggressive behaviour. Eyman *et al.* (1981) examined Adaptive Behaviour Scale scores (Nihira *et al.* 1975) of clients accepted for a service from a regional centre in the USA. 426 out of 2,736 people were available for follow-up two years later, of whom 208 were aged 13 years or older. Eyman *et al.* (1981) do not report the proportion who had aggressive behaviour, but state that it appeared that whatever problem behaviour existed at the time of placement in institutional or community services was likely to persist regardless of age group, level of ability, or type of placement. The study is limited by the small proportion included at the second time point, and by them not presenting the numbers in support of their statement; rather, they say that statistically there was no significant time trend overall.

There have been studies investigating the endurance of problem behaviours, which included aggressive behaviour together with other types of problem behaviours. For example, an institutional cohort of adults with severe and profound intellectual disabilities were assessed for problem behaviours at two points in time, 16-18 years apart (Reid & Ballinger 1995). Of the 98 adults at the first time point, 67 were still alive and had a mean age of 51 years at the second time. Kendall's tau was used to show a correlation in severity of problem behaviours at the two time points. The frequency data presented does suggest some movement into and out of the category of having problem

behaviours, but the details of this are not presented. Further follow-up of this cohort was limited due to the extent of the attrition rate. In 1995, Kiernan *et al.* (1997) surveyed 272 children and adults who had been found to have problem behaviours in 1988. They reported that of the 179 persons who were “more demanding” in 1988, 36.9% were “less demanding” in 1995, whilst 63.1% remained in the “more demanding” category.

Hence the extent to which aggressive behaviour is an enduring condition for adults with intellectual disabilities is unclear. We have not identified any studies of the incidence of aggressive behaviour in adulthood.

The first studies of aggressive behaviour reported the frequency with which it occurred in the population, with more recent studies undertaking univariate analyses to explore the factors which were individually associated with aggressive behaviour, failing to account for the overlap between factors (McClintock *et al.* 2003). In a recent meta-analysis of people (children and adults) with intellectual disabilities, McClintock *et al.* (2003) found only two studies met their criteria to investigate gender, and suggested male gender was associated with aggressive behaviour. Level of ability was not found to be associated, and nor were communication skills, whilst autism was associated with aggressive behaviour. However, they pointed out that their tentative hypotheses that these factors are risk markers for aggressive behaviour needs further investigation, in view of the overlap between the factors which the studies had not taken into account.

Whilst three studies used logistic regression analyses to investigate factors independently associated with having physically aggressive behaviour, and destructive behaviour, the analyses were conducted only with children and adults who had some sort of problem behaviour, as no data was collected about persons with intellectual disabilities who did not have problem behaviours (Qureshi & Alborz 1992; Emerson *et al.* 2001; Lowe *et al.* 2007). We have identified only one study that included the whole adult population with intellectual disabilities and sought independent associations with having physically aggressive behaviour (Tyrer *et al.* 2006). Men, younger adults, adults with more severe intellectual disabilities, and adults living in institutional settings had a higher prevalence of physically aggressive behaviour to others, whilst people with Down syndrome had a lower prevalence. No relationship was found with epilepsy nor autistic symptoms (Tyrer *et al.* 2006). Other factors were not investigated.

This study was undertaken to investigate the point prevalence, two-year incidence, and two-year remission rates for physically aggressive behaviour to others, destructive behaviour, and verbally aggressive behaviour, amongst the adult population with intellectual disabilities, using robust methodology and the clear, operationalised DC-LD criteria. A further aim was to investigate which factors are independently associated with aggressive behaviour in this population.

METHOD

Detailed account of methodology

A detailed account of the overall methods used to conduct this study are provided in the preceding related paper which investigates self-injurious behaviour within this same cohort of adults with intellectual disabilities (Cooper *et al.* 2008). In this paper, we summarise these methods, and provide more information on the assessments undertaken to categorise aggressive behaviours over the two year period of the study.

Approval and consent

The study was approved by the three relevant research ethics committees (the multi-centred research ethics committee - Scotland A, the Glasgow Community Primary Care local research ethics committee, and the Greater Glasgow Community and Mental Health local research ethics committee), and consent to participate was sought on two occasions for each person (given the longitudinal study design), in keeping with the committees' requirements and Scottish legislation.

Participants

Previous ascertainment of adults with intellectual disabilities in the Greater Glasgow Health Board area yielded a prevalence of 3.33 per 1,000 general population, which is comparable with other ascertainments (Cooper & Smiley 2007). 100% of general practitioners / family physicians in the area participated in the population ascertainment: they were incentivised to do so as the Health Board provided an additional payment for

each person with intellectual disabilities on their list of patients, in view of the additional work required to provide quality health care. Adults were also identified through their use of health and social support services.

All adults with intellectual disabilities from a base population of 469,069 in Greater Glasgow were invited to participate, and 65.5% did so. This included both urban (Glasgow) and rural (e.g. East Dunbartonshire) areas, and geographical areas across the full spectrum of affluence and deprivation. Both participants and non-participants had a similar spread of date of birth, ranging from the 1920s to 1980s; 65.1% of men and 68.4% of women participated. Other characteristics of the non-participants are not known. The characteristics of the resultant cohort of 1,023 adults are shown in table 3. At T2, the potential cohort size was 936, of whom 651 adults participated. There was no difference between participants and persons for whom consent to participate was not gained at T2, in terms of T1 age, gender, level of intellectual disabilities, type of accommodation / support, or prevalence of mental ill-health (Cooper *et al.* 2008), nor was there for the participants with aggressive behaviour.

Process

Adults were recruited into a longitudinal cohort at the first timepoint (T1), and base-line data collected on demography, lifestyle, supports, development, problem behaviours, disabilities, and physical and mental health. Information was then longitudinally collected, with measurements of problem behaviours, mental ill-health, and supports repeated to collect information for the following two year period at the second timepoint

(T2), using the same methods, by the same research team. The problem behaviour and mental ill-health data was therefore measured at T1, T2, and for any interim episodes between T1 and T2.

Data was collected through face-to-face interviews with each adult with intellectual disabilities and their carer, followed by physical examination, and psychiatric assessment. Each participant's primary health care records were also reviewed using a semi-structured data-collection tool, as were their psychiatry, psychology, and other secondary health care records. Additionally, relatives were also separately interviewed for each adult who was assessed with the support of a paid carer. DC-LD criteria address the difficulty of diagnosing autism and ADHD when there are no living parents nor records to provide information on early childhood development; further details on psychiatrist assessments have previously been reported (Smiley *et al.* 2007; Melville *et al.* 2008).

The following process was used to identify episodes of problem behaviours or mental ill-health which occurred between T1 and T2. For all participants, contemporaneous information was taken from case records, which were scrutinised at T1, one year after T1, and again at T2 (E.S.). Additionally, at T2, participants, their family carer, and also paid carers, were specifically asked whether problem behaviours had occurred at any point in the two year period, using the 11 pages devoted to this in the data collection form, which included a series of trigger questions about a range of possible types of problem behaviours. If any possible episodes were detected, the person was referred to the Glasgow University Centre for Excellence in Developmental Disabilities (Glasgow

UCEDD) for a comprehensive psychiatric assessment of that period. This included review of paid carers contemporaneous records for the period, medical and psychology records, comprehensive discussion with the person and their carers, examination, integration of this information, ensuring a proper psychiatric and medical differential diagnosis was undertaken for the time of the episode, and then application of the DC-LD criteria for the episode (i.e. for *any* six month period within the two years). The information was checked by consensus meetings (S-A.C. and E.S.). Additionally, at the T2 interview, trigger questions were used to identify any possible interim episodes of mental ill-health, including enquiring if the person had had any mental health needs, emotional or psychological problems, or psychiatric illness, or any possible symptoms in the two year period, and whether the person had seen their GP for mental health problems, a psychiatrist, psychologist, learning disabilities nurse, or had had a hospital admission during the period. Additionally, information was sought as to whether any of 20 possible life events had occurred, and were used as trigger questions to identify any episodes of potential difficulty the person had experienced between T1 and T2. Where any possible psychiatric symptoms were identified, a *PAS-ADD Checklist* was completed for that time. If any two possible symptoms were identified, or one significant symptom, on the PAS-ADD Checklist or from the other questions, the persons was then referred to the Glasgow UCEDD for full psychiatric assessment of the possible episode.

Materials

The same instruments were used at T1 and T2:

- *C21st Health Check* (Glasgow UCEDD, 2001). This instrument was used to assess problem behaviours, development, disabilities, and physical health. It was used to trigger full psychiatric assessment for adults with possible or probable aggressive behaviour, and possible or probable autism. Inter-rater, and intra-rater reliability data was excellent, with kappa scores ranging between 0.724 – 1 (see previous paper, Cooper *et al.* 2008).
- *PAS-ADD Checklist* (Moss *et al.* 1998). As recommended by Simpson (1999), to increase the sensitivity of the tool, a threshold of two or more symptoms, or one high risk symptom triggered full psychiatric assessment. Six additional symptoms were also added.
- Purpose designed semi-structured demography and supports questionnaire.
- *Vineland scale (survey form)* (Sparrow *et al.* 1984). This instrument was used to assess ability level.

Definition of aggressive behaviour

The findings were case-conferenced by the Consultant members of the research team to derive Consultant-level diagnoses. The operationalised diagnostic criteria in DC-LD were strictly applied to define aggressive behaviour. The categories within DC-LD that were used were IIID1.3 (physically aggressive behaviour), IIID1.4 (destructive behaviour), and IIID1.2 (verbally aggressive behaviour). These are shown in figure 1. The DC-LD supplementary categories for problem behaviours that are directly caused by other disorders were excluded from our study.

- Insert figure 1 about here –

Analyses

Data were analysed using the Statistical Package for the Social Sciences Version 11.5.

The point prevalences of physically aggressive, destructive, and verbally aggressive behaviour meeting DC-LD criteria at T1, and of all three types of aggressive behaviour combined, with 95% confidence intervals were calculated. Combined rates are reported, given the known overlap between these behaviours (Crocker *et al.* 2006). The remission rate (i.e. the proportion no longer meeting DC-LD criteria) by T2, and two year incidence of new episodes (i.e. adults who did not meet criteria at T1, but subsequently did so) were calculated .

Adults with physically aggressive, destructive, and verbally aggressive behaviour were combined, in view of the known clustering of these behaviours in this population, into a single category of aggressive behaviour. In order to determine which factors were associated with being in episode for aggressive behaviour, we conducted the following analysis in three discrete stages. Initially, the distribution of being in episode with aggressive behaviour and each factor was assessed individually, with 2 tailed t-tests, χ^2 tests, and univariate regressions. Those factors found to be associated at $p < 0.05$ level were further investigated at stage 2, using multivariate logistic regressions. At stage 2, for each of the three subgroups of factors (i.e. personal factors, lifestyle and supports, health and disabilities), a backwards stepwise method was used to determine the set of factors

within that subgroup that were independently associated with being in episode with aggressive behaviour. At stage 3, the independently related factors from these three group specific models were entered into a single global model and a backward stepwise method was again used to reach the final model for being in episode with aggressive behaviour. 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).

RESULTS

Point prevalence, incidence, and remission

At T1, 100 of the 1,023 adults had aggressive behaviour that met DC-LD criteria, giving a point prevalence of 9.8%. Their characteristics are displayed in table 3. There was a high degree of overlap between the three sub-types of aggressive behaviour, as shown in figure 2.

- Insert figure 2 about here -

The two-year incidence of aggressive behaviour meeting DC-LD criteria was 1.8% (12 adults out of 651).

Sixty-five persons with DC-LD aggressive behaviour at T1 participated at T2. The two-year remission rate (i.e. no longer meeting DC-LD criteria) was 27.7%. Remission rates for individual types of aggressive behaviour were 29.4-32.1%. For the 65 adults, figure 3

shows the number at T1 and T2 who were in each of the overlapping categories of the three sub-types of aggression, demonstrating the partial as well as full remission rates. At T1, of the 65 adults, 32 (49.2%) had one type of aggressive behaviour, 23 had two types (35.4%), and ten had all three types (15.4%). At T2, of the 65 adults, 18 (27.7%) had no aggressive behaviour, 24 had one type (36.9%), 16 had two types (24.6%), and seven (10.8%) had all three types of aggressive behaviour.

- Insert figure 3 about here -

Table 2 summarises the point prevalence, incidence, and remission rates for the three sub-types of aggressive behaviour, and the combined rate for any type of aggressive behaviour. The “combined” figure is lower than that for each of the individual types of aggression, as a person had to be free from all types of aggression to be included in it i.e if a person had two types of aggressive behaviours, and remitted from one but not the other, they were not included in the combined figure.

- Insert table 2 about here –

Sixty-six percent of participants with aggressive behaviour were receiving services from the specialist health service for adults with intellectual disabilities for its management at T1.

Factors associated with aggressive behaviour

Table 3 shows the results from the initial univariate analyses, exploring the association between each individual variable of interest with being in episode with aggressive behaviour.

- Insert table 3 about here -

At the second stage of analyses (the group specific models), no-one had an incomplete data set for personal factors, no-one had incomplete datasets for lifestyle / supports, and no-one had incomplete datasets for health / disabilities. At the third stage of analyses (the global model), no-one had an incomplete dataset. Table 4 displays the results.

- Insert table 4 about here -

In summary, factors that were independently associated with aggressive behaviours were lower ability, female gender, not living with a family carer, not having Down syndrome, having attention-deficit hyperactivity disorder (ADHD), and having urinary incontinence. (Whilst bowel incontinence, not having daytime occupation, and having previously lived in long-stay accommodation were individually associated, the regression delineated that they were not independently associated with aggressive behaviour, as many of these factors overlap.)

DISCUSSION

Principle findings

The point prevalence of DC-LD aggressive behaviour was 9.8%, two-year incidence was 1.8%, and for the adults who had aggressive behaviour, the two-year remission rate was 27.7%. Prevalence is accounted for by both new onset aggressive behaviour, and enduring aggressive behaviours. It is important to note the remission rate for aggressive behaviours in this two-year period, particularly given the view in the past that such behaviours tended to be enduring. For individual sub-types of aggressive behaviour, the remission rate was, of course, higher. This shows that even for persons who do not have a full remission of their aggressive behaviour, the extent of their aggressive behaviours varies over time. In this study, all adults identified as having aggressive behaviours at T1 were offered interventions by the psychiatric and psychology clinical service if they were not already in receipt of the service. We do not know whether the remission rate would have been different if the clinical service had not been offered. The incidence of aggressive behaviour in adult life is low but not insignificant. It is similar to that previously reported for each of psychotic, anxiety, and organic disorders within the population of adults with intellectual disabilities, of which there has possibly been greater awareness (Smiley *et al.* 2007).

We specifically measured remission over a two year period. This does not necessarily mean that persons may not relapse at some future point. Indeed we suggest that for some persons, problem behaviours may well be episodic i.e. relapsing-remitting problems, as

can be the case with other types of mental ill-health, such as depressive episodes. We suggest this introduces optimism for persons and their paid and family carers, and highlights the need for treatments and interventions to improve remission outcomes.

To be included in an aggressive behaviour category in this study, participants had to be above the frequency, severity, and impact thresholds specified in the criteria. When the DC-LD working group were developing the criteria, the frequency requirement was set at a low level in order to be able to capture very severe but infrequent aggression (for forensic services). In practice, such severe, infrequent aggression is rare, and in our cohort, the individuals with aggressive episodes were experiencing aggression much more frequently i.e. our remission rate is not accounted for by persons having three episodes of aggression in the preceding six month period at T1 compared with two at T2.

Comparison with the previous literature and interpretation

The previously reported prevalence of aggressive behaviour has varied, for the reasons discussed in the introduction. The criteria we employed are stringent, and hence we expected to find a lower prevalence than that reported by Crocker *et al.* (2006), who deliberately and specifically set out to investigate prevalence including mild problem behaviours. The point prevalence we report is more in keeping with that reported by Jacobson (1982), Qureshi & Alborz (1992), and Emerson *et al.* (2001), particularly the serious/serious but controlled categories that the latter two studies used. Our lower rate than that found in some of the other studies may also be accounted for by the fact that we were able to exclude aggressive behaviour that occurred solely as part of another

disorder, in view of the comprehensive psychiatric assessments we undertook, which other studies did not.

We could not identify any previous studies of incidence of aggressive behaviour in adulthood, with which we could compare our findings.

Our findings concur with those of Tyrer *et al.* (2006) that lower ability, living with paid carer support, and not having Down syndrome is associated with aggressive behaviour, whilst there is no association of aggressive behaviour with epilepsy or autism. Contrary to Tyrer *et al.* we found that female gender was associated with aggression, not being a younger man. The criteria in the two studies differ, and the prevalence rate reported by Tyrer *et al.* is considerably higher than that which we report, which we attribute to the tighter criteria for aggressive behaviour that we used, together with the exclusion of aggressive behaviour solely due to other disorders in this study unlike the Tyrer *et al.* study. However, whether this accounts for the gender difference in the two studies requires further investigation. Gender proportions were reported in most of the studies that explored individual associations with aggressive behaviour: Eyman & Call (1977) reported each of physically aggressive, destructive, and verbally aggressive behaviour to be associated with male gender; Harris (1993) reported no gender differences for aggressive behaviour in schools or institutions, but an association with male gender in day centres; Deb *et al.* (2001) reported that 65% of adults with physically aggressive behaviour were women, although this was not significant in view of the small sample size; Crocker *et al.* (2006) found no gender difference for physically aggressive or

verbally aggressive behaviour, but male gender was individually associated with destructive behaviour.

We also found aggressive behaviour to be independently associated with having ADHD, and having urinary incontinence: other studies have not investigated this. In the past, ADHD has probably been under-recognised in this population, which may account for the lack of previous investigation. Whether the association with urinary incontinence is due to 1) a common underlying mechanism accounting for both e.g. autonomic sympathetic discharge, 2) incontinence contributing to aggressive behaviours e.g. through damaging self-esteem, 3) aggressive behaviour contributed to urinary incontinence, or 4) a spurious finding, is not clear. We think the latter suggestion is unlikely, as the finding is in keeping with previous reports of an association between urinary incontinence and both prevalence of, and incidence of, mental ill-health for adults with intellectual disabilities (Cooper *et al.* 2007; Smiley *et al.* 2007), and an association with mental ill-health in the general population. Zorn *et al.* (1999) suggest a strong association between depression and idiopathic urinary incontinence, with a common underlying pathogenesis, concluding that a reduction in serotonin function predisposes to depression and contributes to bladder overactivity. Melville *et al.* (2002) concluded that people with urge and mixed urinary incontinence are significantly more likely to have coexistent psychiatric illness. Dugan *et al.* (2000) found that the perception that urinary incontinence interfered with daily life was a significant predictor of depressive symptoms in older adults. Persons with urinary incontinence may be more likely to experience stigmatising behaviour and rejection from carers which could lead to development of poor confidence and lower self esteem,

leading to increased vulnerability for mental ill-health or aggressive behaviour. Additionally, in the general population, Perry *et al* (2006) demonstrated the relevance of emotional factors in the development and maintenance of incontinence. Our lack of understanding of the relationship between incontinence and aggressive behaviour in adults with intellectual disabilities warrants further investigation.

Study limitations and strengths

The main limitation of the study is the size of the cohort, which is too small to investigate the factors predictive of incident aggressive behaviour: we have merely investigated cross-sectional associations with aggressive behaviour. The remission rate may or may not have been affected by the fact that all adults with aggressive behaviours at T1 were offered interventions from psychiatrists and psychologists. The interventions were clinically determined, and not subject to a research protocol, i.e. the interventions were just treatment as usually offered by the local community specialist health teams for adults with intellectual disabilities, as this study was not designed to be a randomised controlled trial to determine the efficacy of a particular type of intervention.

The strengths of the study include the robust population ascertainment process, comprehensive assessments with all of the study participants, use of operationalised standard criteria to determine the presence of aggressive behaviours, the clearly specified time period, high cohort retention with similar T1 characteristics between T2 participants and persons who declined to participate, and the use of multivariate analysis to determine factors independently associated with aggressive behaviour, as recommended by

McClintock *et al.* (2003). The level of participation, and the cohort retention by T2 is good for this population for whom it is known to be more difficult to recruit / retain in studies than it is for the general population (Wadsworth *et al.* 1992; Maughan *et al.* 1999; Richards *et al.* 2001). We consider our study results to be generalizable within other developed countries, in view of the comprehensive population ascertainment, and the details of the study methodology. We have considered this point more fully in the preceding paper on self-injurious behaviour (Cooper *et al.* 2008).

We used the operationalised DC-LD criteria to define problem behaviours. Whichever criteria are used, a threshold exists. Different criteria may vary in the threshold level of frequency, severity, or impact of the behaviour required to meet criteria; hence there is a clear advantage of using fully operationalised criteria such as DC-LD.

Clinical implications and future directions

Aggressive behaviour is prevalent amongst adults with intellectual disabilities. We have found that over a quarter gain full remission in the short to medium term, with others gaining partial remission, which should help to reduce therapeutic nihilism amongst professionals, and be constructive knowledge for adults with intellectual disabilities and their families. The incidence of aggressive behaviour in adult life is low but not insignificant, and similar to that for each of psychotic, anxiety, and organic disorders. There is much yet to learn about the mechanisms underpinning the aetiology and maintenance of aggressive behaviour in this population, and exploratory epidemiological investigations such as this have a role to play in progressing this, informing work towards

further hypothesis testing, and trials to influence clinical practice, service development, and policy.

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Table 1. Prevalence of, and factors associated with aggressive behaviour in community studies of adults with intellectual disabilities

Authors	N	Population	Assessments	Diagnostic criteria	Findings
Eyman & Call (1977)	5,243	Administrative database of service users with ID aged 13 and over, USA	Selected items of the ABS completed by direct-care workers and social workers	The behaviour was rated as occurring frequently or occasionally	13+: †27.9% physically aggressive, 22.0% destructive, and 19.0% verbally aggressive. People with physical aggression were older, male, of lower ability, and institution residents. People with destructiveness were of lower ability, male, and institution residents. People with verbal aggression were older, male, of higher ability, and institution residents (χ^2 test)
Jacobson (1982)	32,112	Administrative database of service users (children and adults) with ID in one state, USA	42 item questionnaire routinely completed by staff	The general frequency of up to 3 problem behaviours could be reported	All ages: 10.9% physically aggressive, 4.3% destructive, 5.9% verbally aggressive Aged 22+: “Psychiatric and developmental disabilities” group: 18.5% physically aggressive, 6.7% destructive, 12.2% verbally aggressive. “Developmental disabilities only” group: 11.3% physically aggressive, 4.4% destructive, 6.3% verbally aggressive. Adults with physical aggression: 17.3% profound, 13.9% severe, 8.5% moderate, 5.5% mild ID. Adults with destructiveness: 6.8% profound, 5.3% severe, 3.3% moderate, 1.8% mild ID. Adults with verbal aggression: 2.7% profound, 8.4% severe, 9.8% moderate, 9.5% mild ID
Qureshi & Alborz (1992) and Emerson <i>et al.</i> (2001)	*695 (4,200)	Children and adults using ID services, in seven Health Authority areas, England	All ID services were asked to identify people with problem behaviour. Key informants were then asked to return a questionnaire on each person they identified	Interview with staff for each person who had been identified as having aggressive behaviour, on its type, intensity, and frequency	All ages: §†10.8% for all categories, or ^†6.9% for serious/ serious but controlled physical aggression, §†8.9% all categories, or ^†5.0% for serious/serious but controlled destructive behaviour
Sigafoos <i>et al.</i> (1992)	261	Children and adults using ID services in one state, Australia	Managers were asked to distribute surveys to a senior staff in each service, asking for a questionnaire completed on each person with aggressive behaviour	A two-page questionnaire listed 14 topographies of aggressive behaviour, and sought frequency as never (0) through to more than 15 times a day (7)	All ages: 261 people engaged in aggressive behaviour, cited as 11% of 2,412 service users; but the non-response rate was unclear

Harris (1993)	*168	Children and adults using ID services in one health district, England	Staff were asked in writing to identify people with aggressive behaviour; a face-to-face interview was then conducted with the staff of each person so identified	People with serious problems like biting, kicking, scratching etc. resulting in injury to others, e.g. bruising, bleeding, other tissue damage. Also actions e.g. shouting/screaming at others, or violence towards objects presenting serious management difficulties because of threat of injury	All ages: estimated 17.6% had aggressive behaviour. The highest prevalence was in the group living in hospital. In day centres, prevalence was higher for men than women, but there was no gender difference in schools or in the hospital population
Borthwick-Duffy (1994)	91,164	Administrative database of service users (children and adults) with ID in one state, USA	Routine annual report on adaptive behaviour and diagnoses completed by staff	1+ violent episodes causing serious physical injury to others (requiring immediate medical attention) in the past year. Serious property destruction and/or minor property damage on 6+ occasions within the past year	All ages: 2.1% physically aggressive, 7.1% destructive. Persons with aggression were 4.5% of the profound, 2.9% of severe, 1.8% of moderate, 1.4% of the mild ID; 1.5% of females and 2.6% of males; 2.9% of non-verbal and 2.0% with verbal skills. Persons destructive to property were 15.0% of the profound, 9.9% of severe, 6.7% of moderate, 4.4% of mild ID; 5.3% of females and 8.5% of males; 7.0% of non-verbal and 7.9% with verbal skills. 21+: 2.7% were aggressive, 8.1% destructive
Smith <i>et al.</i> (1996)	2,202	Adults (aged 20 years and over) included in an ID register for one county, England	Face-to-face interview with each person supported by their carer	Items from the DAS (aggressive behaviour rated as absent, severe and frequent {more than 3 times a week}, less severe but frequent, severe but less frequent, or lesser management problem)	†21.6% physically aggressive, 17.2% destructive. Both aggressive behaviours were individually associated with more severe disabilities(χ^2 test). The strength of other associations was not reported.
Emerson <i>et al.</i> (2001)	*264 (2,189)	Children and adults with ID in two Health Authority areas, England	All services supporting people with ID were asked to identify people with problem behaviour. Key informants were then asked to return a questionnaire on each person so identified	Individual schedule incorporating a measure of aggressive behaviour previously designed by Alborz <i>et al.</i> (1994) (serious, serious but controlled, moderate, lesser, or none)	All ages: †7.0% physically aggressive

Deb <i>et al.</i> (2001)	101	Random sample of 16-64 year olds with ID known to a social services department, Wales	Face-to-face interview with each person supported by their carer	Items from the DAS (aggressive and destructive behaviour rated as absent, severe and frequent {more than 3 times a week}, less severe but frequent, severe but less frequent.)	22.8% physically aggressive, 11.9% destructive, and 28.7% screaming/shouting behaviour. Physical aggression: 65.2% were female; 21.7% severe, 39.1% moderate, 39.1% mild ID [30% of women and 16% of men were physically aggressive; 45% with severe, 22% with moderate, and 18.8% with mild ID were physically aggressive]. Only taking psychotropic drugs was associated with physical aggression (χ^2 tests)
Tyrer <i>et al.</i> (2006)	3,065	Adults (aged 20 years and over) on an ID register, one county, England	Face-to-face interview with each person supported by their carer	Question from the DAS. Carer report of frequent (more the 3 times per week) and/or severe physical aggression to others	14% physically aggressive. Higher prevalence for men, younger adults, more severe ID, and in institutional settings; lower prevalence for people with Down syndrome. No relationship with epilepsy nor autistic symptoms (logistic regression)
Crocker <i>et al.</i> (2006)	3,165	Adults (aged 18 years and over) receiving ID services, Canada	Educators in participating agencies were sent a survey form to fill in, about aggressive behaviour over the past 12 months	MOAS. Verbal and/or motor behaviour towards oneself, environment, or others, directly or indirectly, and more or less planned. Could potentially cause physical/psychological harm to others, and may have management difficulties {0=no behaviour, 4=highest score of such behaviour}	51.8% aggressive in the previous 12 months. 24.4% physically aggressive, 24.0% aggressive to property, 37.6% verbally aggressive. No gender difference for physical or verbal aggression; men more aggressive to property (Mann-Whitney U). Mild/moderate ID more verbally aggressive (41.4% versus 29.45). Profound/severe ID more physically aggressive (31.6% versus 21%), and aggressive to property (χ^2 tests). Age was negatively correlated with physical and property aggression (Spearman correlation) for men, but not women. Highest in group homes. Physical, property, and verbal aggression were highly correlated
Lowe <i>et al.</i> (2007)	*901; 705 adults + 196 children (5,395)	Children (aged 5 years or over) or adults with ID using services in a defined area, Wales	All services supporting people with ID were asked to identify people with problem behaviour. A face-to-face interview was then conducted with the primary carer of identified persons	Individual schedule incorporating a measure of aggressive behaviour previously designed by Alborz <i>et al.</i> (1994) (serious, serious but controlled, moderate, lesser, or none)	All ages: †3.7% had serious, 1.7% serious but controlled, 5.3% moderate, 3.3% lesser, 86.0% no physical aggression. 2.3% had serious, 0.8% serious but controlled, 3.8% moderate, 3.0% lesser, 90.1% no destructive behaviour

*the number of persons on whom data was collected i.e. who had problem behaviour (the estimated denominator of number of persons with intellectual disabilities in the population)

†prevalence not reported in the paper, but calculated on the basis of other data presented

§From Qureshi & Alborz 1992; ^From Emerson, 2001

ID = intellectual disabilities; DAS = Disability Assessment Schedule (Holmes *et al.* 1982); ABS = Adaptive Behaviour Scales (Nihira *et al.* 1975); MOAS = Modified Overt Aggression Scale (Kay *et al.* 1988)

Table 2. Point prevalence, two-year incidence, and two-year remission rate for aggressive behaviours

Type of aggression	Point prevalence (n=1,023) N (%)	95% confidence interval for point prevalence %	Number of adults with this type of aggression who participated at both T1 and T2 N	Two-year remission rate N (%)	Two-year incidence (n=651) N (%)
Physically aggressive behaviour	64 (6.3)	4.9 – 7.9	38	12/38 (31.5)	4 (0.6)
Destructive behaviour	31 (3.0)	2.1 – 4.3	17	5/17 (29.4)	4 (0.6)
Verbally aggressive behaviour	77 (7.5)	6.0 – 9.3	53	17/53 (32.1)	9 (1.4)
Aggressive behaviour (combined)	100 (9.8)	8.0 – 11.8	65	18/65 (27.7)	12 (1.8)

Table 3: Results from univariate analyses: associations between individual factors and aggressive behaviour

		Whole cohort 1023 (100%)	Aggressive behaviour 100 (9.8%*)	
Group 1: Personal factors				
Age	Prevalent cases	Mean (SD)	42.2 (13.5)	0.217
	Non-prevalent cases		44.1 (14.6)	
Gender	Male	562 (54.9%)	42 (7.5%)	0.006
	Female	461 (45.1%)	58 (12.6%)	
Ability	Mild ID	398 (38.9%)	20 (5.0%)	<0.000
	Moderate ID	248 (24.2%)	23 (9.3%)	
	Severe ID	193 (18.9%)	31 (16.1%)	
	Profound ID	184 (18.0%)	26 (14.1%)	
Group 2: Lifestyle and supports				
Accommodation / support	Family carer	390 (38.1%)	21 (5.4%)	0.001
	Independent of care	102 (10.0%)	8 (7.8%)	
	Paid carer	467 (45.7%)	60 (12.8%)	
	Congregate	64 (6.3%)	11 (17.2%)	
No daytime job / occupation	Has job / occupation	767 (75.0%)	66 (8.6%)	0.029
	No job / occupation	256 (25.0%)	34 (13.3%)	
Deprivation quintile	Most affluent	228 (22.2%)	26 (11.4%)	0.734
	2	92 (9.0%)	9 (9.8%)	
	3	66 (6.5%)	4 (6.1%)	
	4	99 (9.7%)	8 (8.1%)	
	Most deprived	538 (52.6%)	53 (9.9%)	
Marital status	Married / partner	26 (2.5%)	5 (19.2%)	0.100
	No live-in partner	997 (97.4%)	95 (9.5%)	
Smoker	No	918 (89.7%)	91 (9.9%)	0.682
	Yes	104 (10.1%)	9 (8.7%)	
Life events in last 12 months	Prevalent cases	Mean (SD)	1.2 (1.4)	0.213
	Non-prevalent cases		1.0 (1.4)	
GP contacts in last 12 months	Prevalent cases	Mean (SD)	6.0 (5.1)	0.089
	Non-prevalent cases		5.0 (5.4)	

Aggressive behaviour

Emergency out of hours GP contacts in last 12 months	Prevalent cases Non-prevalent cases	Mean (SD)	0.5 (0.9) 0.4 (0.9)	0.319
Ex long-stay hospital resident	No Yes	844 (82.5%) 179 (17.5%)	72 (8.5%) 28 (15.6%)	0.004
Group 3: Health and disabilities				
Depression	No Yes	984 (96.2%) 39 (3.8%)	93 (9.5%) 7 (17.9%)	0.080
Autistic spectrum disorder	No Yes	946 (92.5%) 77 (7.5%)	91 (9.6%) 9 (11.7%)	0.557
Attention deficit hyperactivity disorder	No Yes	1008(98.5%) 15 (1.5%)	91 (9.0%) 9 (60.0%)	<0.000
Down syndrome	No Yes	837 (81.8%) 186 (18.2%)	96 (11.5%) 4 (2.2%)	<0.000
Visual impairment	No Yes	542 (53.0%) 481 (47.0%)	45 (8.3%) 55 (11.4%)	0.092
Hearing impairment	No Yes	747 (73.0%) 276 (27.0%)	80 (10.7%) 20 (7.2%)	0.098
Bowel incontinence	No Yes	767 (75.0%) 256(25.0%)	61 (8.0%) 39 (15.2%)	0.001
Urinary incontinence	No Yes	662 (64.7%) 361 (35.3%)	39 (5.9%) 61 (16.9%)	<0.000
Impaired mobility	No Yes	775 (75.8%) 248 (24.2%)	78 (10.1%) 22 (8.9%)	0.582
Epilepsy	No Yes	663 (64.9%) 349 (34.1%)	56 (8.4%) 42 (12.0%)	0.067
Special communication needs	No Yes	541 (53.0%) 480 (47.0%)	44 (8.1%) 56 (11.7%)	0.058

*Percentages for the whole cohort indicate the prevalence of the characteristic; percentages given for the group with aggressive behaviour indicate the proportion that they are of the whole cohort with that characteristic

Table 4. Factors independently associated with aggressive behaviour

		Aggressive behaviours			
		Group-specific models		Global model	
		Odds Ratio (95% CI)	p-value	Odds Ratio (95% CI)	p-value
Group 1: Personal factors					
Gender (v. male)	Female	1.891 (1.237-2.890)	0.003	1.752 (1.116-2.750)	0.014
Ability (v. mild ID)	Moderate ID	2.043 (1.094-3.816)	<0.000	2.002 (1.015-3.947)	0.011
	Severe ID	3.820 (2.106-6.930)		2.948 (1.489-5.836)	
	Profound ID	3.190 (1.725-5.898)		1.554 (0.724-3.334)	
Group 2: Lifestyle and supports					
Accommodation (v. family carer)	Independent of any care	1.495 (0.642-3.482)		2.273 (0.894-5.776)	
	With paid-carer support	2.590 (1.545-4.342)	<0.000	1.949 (1.131- 3.360)	0.030
	Congregate care setting	3.647 (1.665-7.989)		2.790 (1.208-6.447)	
No daytime job / occupation		-	-	N/A	N/A
Ex long-stay hospital resident		-	-	N/A	N/A
Group 3: Health and disabilities					
ADHD		10.570 (3.560-31.379)	<0.000	10.405 (3.242-33.393)	<0.000
Down syndrome		0.217 (0.078-0.601)	<0.000	0.210 (0.075-0.588)	<0.000
Bowel incontinence		-	-	N/A	N/A
Urinary incontinence		2.822 (1.826-4.361)	<0.000	1.995 (1.207-3.298)	0.007

Figure 1. Diagnostic criteria

DC-LD IHD1.1 General diagnostic criteria for problem behaviour

A. The problem behaviour is of significant frequency, severity, or chronicity as to require clinical assessment and special interventions / support.

B. The problem behaviour must not be a direct consequence of other psychiatric disorders, drugs, or physical disorders.

C. One of the following must be present:

1. The problem behaviour results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to restriction of his or her lifestyle, social opportunities, independence, community integration, service access or choices, or adaptive functioning.
2. The problem behaviour presents significant risks to the health and / or safety of the person and / or others.

D. The problem behaviour is pervasive. It is present across a range of personal and social situations, although may be more severe in certain identified settings.

DC-LDIHD1.3 Physically aggressive behaviour

A. General diagnostic criteria for problem behaviour are met.

B. Physical aggression must have occurred on at least three occasions in the preceding six-month period, for example the person uses or threatens physical violence. This may

be impulsive or planned, and occurs in the context of minimal or no provocation by others. Severity may range from pushing, slapping, and physically intimidating, to punching, kicking, biting, pulling the hair of others, and more serious physical assault.

IID1.4 Destructive behaviour

- A. General diagnostic criteria for problem behaviour are met.
- B. Destructive behaviour must have occurred on at least three occasions in the preceding six-month period, for example, the person damages property, such as tearing paper and fabrics, smashing furniture and glass, to more serious property damage and fire setting. This may be impulsive or planned, and occurs in the context of minimal or no provocation by others.

IID1.2 Verbally aggressive behaviour

- A. General diagnostic criteria for problem behaviour are met.
- B. Verbal aggression must have occurred on at least three occasions in the preceding six-month period, for example the person uses his or her voice in a violent or threatening manner. This may be impulsive or planned and must occur in the context of minimal or no provocation by others.

Figure 2. For the 100 adults with aggressive behaviour at T1, the number in each category of overlap between the types of aggressive behaviours at T1

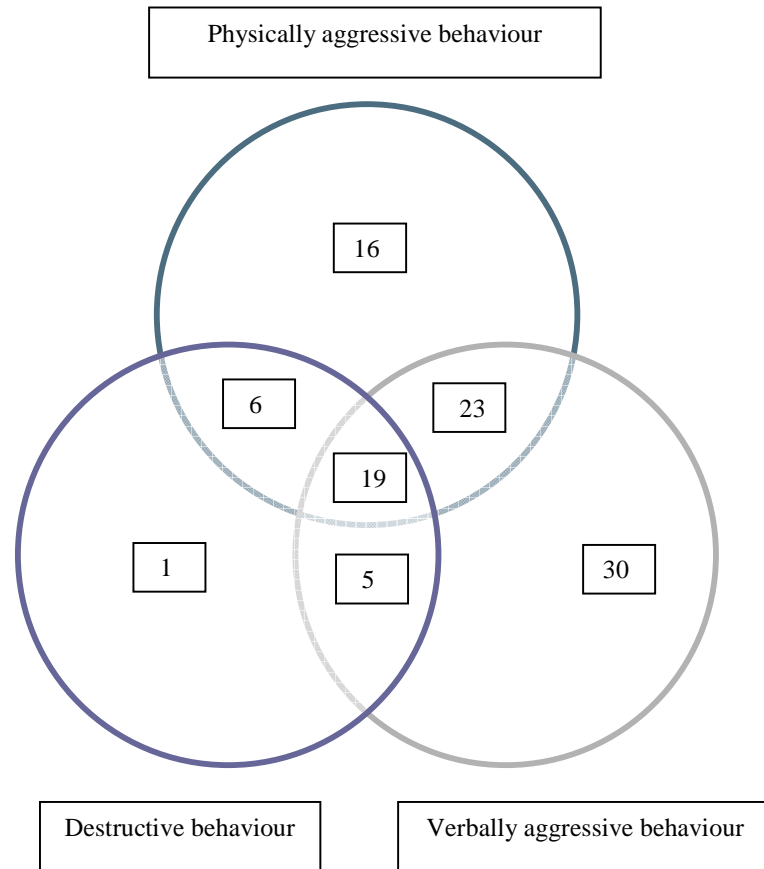


Figure 3. For the 65 adults with aggressive behaviour at T1 who participated at T2, the number in each category of overlap between the types of aggressive behaviours at T1 and at T2. T1 (T2)

