

Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population

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Background

There are no previous whole-country studies on mental health and relationships with general health in intellectual disability populations; study results vary.

Aims

To determine the prevalence of mental health conditions and relationships with general health in a total population with and without intellectual disabilities.

Method

Ninety-four per cent completed Scotland's Census 2011. Data on intellectual disabilities, mental health and general health were extracted, and the association between them was investigated.

Results

A total of 26 349/5 295 403 (0.5%) had intellectual disabilities. In total, 12.8% children, 23.4% adults and 27.2% older adults had mental health conditions compared with 0.3, 5.3 and 4.5%

of the general population. Intellectual disabilities predicted mental health conditions; odds ratio (OR)=7.1 (95% CI 6.8–7.3). General health was substantially poorer and associated with mental health conditions; fair health OR=1.8 (95% CI 1.7–1.9), bad/very bad health OR=4.2 (95% CI 3.9–4.6).

Conclusions

These large-scale, whole-country study findings are important, given the previously stated lack of confidence in comparative prevalence results, and the need to plan services accordingly.

Declaration of interest

None.

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Mental ill health is unevenly distributed across the population and appears to be more prevalent among people with intellectual disabilities compared with the general population.^{1,2} An adult prevalence of 22.4% has been reported excluding problem behaviours and autism or 40.9% including problem behaviours and autism;¹ and a prevalence of 36% including problem behaviours has been reported in children and young people, compared with 8% in those without intellectual disabilities.² However, most studies have limitations. Indeed, a recent National Institute for Health and Care Excellence (NICE) clinical guideline development group³ reviewed the epidemiological evidence on prevalence of mental ill health in people with intellectual disabilities compared with the general population, and concluded they were not very confident in the results, in view of the variation in quality of the studies, and the need to include administrative samples because of limited population-based cohorts. For example, the most detailed, population-based study of adults with intellectual disabilities to date included only 1023 and no direct general population comparison group,¹ and the most comprehensive study of children and young people with intellectual disabilities, which did include a general population comparison group, included only 641 with intellectual disabilities, and was restricted to just those living in private households. Both studies had high recruitment uptake. Although other studies have also reported prevalence rates, they tend to be limited by non-representative samples and/or small study sizes.^{4,5}

Poor physical health is more common among people with intellectual disabilities.^{6–9} People with intellectual disabilities are, therefore, at high risk of comorbid physical and mental ill health. In the general population, this combination is associated with poorer

outcomes, such as premature death.^{10–12} Hence an improved understanding of the prevalence of mental ill health and its relationship with general health in the population with intellectual disabilities, undertaken on a large scale, is highly indicated.

This study's aims were to (1) describe the prevalence of mental ill health in the population with intellectual disabilities compared with those without intellectual disabilities, (2) investigate the odds of intellectual disabilities on having mental ill health when adjusted for age and gender, and (3) investigate the relationship of mental and physical health in the population with intellectual disabilities.

Method

Data source

The data source was Scotland's Census 2011. This provides statistical information on the number and characteristics of Scotland's population and households at the census day, 27 March 2011.¹³ The census is undertaken every 10 years. It includes people living in communal establishments (such as care homes and student halls of residence) as well as people living in private households. In 2011, Scotland's Census was estimated to have achieved a 94% response rate, which is close to the highest ever historic compliance rate. A coverage assessment and adjustment process was used to take account of non-response in the final Census outputs. Scotland's Census is probably one of few country censuses that identifies

people with intellectual disabilities and distinguishes these from specific learning disabilities such as dyslexia, and from autism; indeed it may be unique in this regard. Full details of the methodology and other background information on Scotland's Census 2011 are available at: www.scotlandscensus.gov.uk/supporting-information.

The Census requires the form to be completed by the head of household or joint head of household on behalf of all occupants in private households, and the manager is responsible on behalf of all occupants in communal dwellings. It is a legal requirement to complete the Census, and the Census form clearly states this, and that a head of household not completing it or supplying false information can be fined £1000. The Census team follow up non-responders and also provide help to respond when that is needed (there was not an easy-read version), hence the high 94% completion rate.

Census variables

Intellectual disabilities, mental health condition and other conditions

People with intellectual disabilities were identified by self-/proxy-reporting on intellectual disabilities from the individual questions section; question 20: 'Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? Tick all that apply'. There was a choice of 10 response options, which included:

- (1) deafness or partial hearing loss
- (2) blindness or partial sight loss
- (3) learning disability (e.g. Down syndrome)
- (4) learning difficulty (e.g. dyslexia)
- (5) developmental disorder (e.g. autism spectrum disorder or Asperger syndrome)
- (6) physical disability
- (7) mental health condition
- (8) long-term illness, disease or condition
- (9) other condition and
- (10) no condition.

For 'other condition', a prompt was included for the respondent to report the type of 'other condition'. Importantly, the question distinguishes between intellectual disabilities (for which the term 'learning disability' is used in Scotland), specific learning disabilities and autism.

General health

General health status was collected through the question, 'How is your health in general?', with a five-point response scale as follows: (1) very good, (2) good, (3) fair, (4) bad and (5) very bad.

Procedures

Following Scottish Government approval, data from Scotland's Census 2011 were analysed under the auspices of a collaborative research project with the National Records of Scotland at its premises in Ladywell House, Edinburgh. All resulting raw frequency tables of Census data were checked to ensure they did not breach statistical disclosure control thresholds and were published on the Scotland's Census website, available under the Health topic at: www.scotlandscensus.gov.uk/ods-web/data-warehouse.html#additionaltab

Data analysis

We calculated the number and percentage of people with intellectual disabilities, compared with the general population. We compared gender and age structure by Pearson's χ^2 test. We calculated the number and percentage of people with intellectual disabilities reporting a mental health condition and compared this with the general population

by Pearson's χ^2 test. We then used two binary logistic regressions to calculate the odds ratios (95% confidence intervals (CIs)) of intellectual disabilities referenced to no intellectual disabilities, in statistically predicting the dependent variable 'mental health condition', adjusted: (1) for gender and age (given the different gender and age structure in the two populations), and (2) for gender, age and general health status. Age was categorised into the following groups: 0–15, 16–24, 25–34, 35–44, 45–54, 55–64, 65–74 and 75+ years. The age group 0–15 years was the reference group for age, male was the reference gender group and good/very good health was the reference group for general health status. Next, within the population with intellectual disabilities, two binary logistic regressions were undertaken to investigate: (1) the extent to which age and gender were independent predictors of having a mental health condition, and (2) the extent to which age, gender and general health status were statistically independent predictors of having a mental health condition. The enter method was used. All analyses were conducted with SPSS version 22.

Results

Participant characteristics

Scotland's Census 2011 includes records on 5295403 people; 26349 (0.5%) with intellectual disabilities and 5269054 without intellectual disabilities. There were 15149 (57.5%) males and 11200 (42.5%) females with intellectual disabilities, compared with 2567444 (48.7%) males and 2727959 (51.8%) females without intellectual disabilities ($\chi^2=860.5$; d.f.=1; $P<0.001$). The population with intellectual disabilities were younger than those without, with 5234 (19.9%) aged 0–15 years, 18660 (70.8%) aged 16–64 years and 2455 (9.3%) aged 65+ years, compared with 911097 (17.3%) aged 0–15 years, 3470078 (65.9%) aged 16–64 years and 887879 (16.9%) aged 65+ years in those without intellectual disabilities ($\chi^2=1083.2$; d.f.=2; $P<0.001$). The prevalence of intellectual disabilities was highest in childhood, reaching its peak by age 9 years (0.7–0.8%), being 0.5% at 25–34 years, and then progressively falling from age 55–64 years to 0.2% at age 75+ years.

The population with intellectual disabilities were significantly more likely to have physical disability (32.6% v. 6.6%; $\chi^2=28316.0$; d.f.=1; $P<0.001$), blindness or partial sight loss (13.1% v. 2.3%, $\chi^2=13034.7$; d.f.=1; $P<0.001$), deafness or partial hearing loss (12.4% v. 6.6%, $\chi^2=1421.6$; d.f.=1; $P<0.001$) and autism (21.7% v. 0.5%, $\chi^2=197451.8$; d.f.=1; $P<0.001$).

Prevalence of mental health conditions

Mental health conditions were reported more often for people with, compared with people without, intellectual disabilities: 668 (12.8%) v. 2653 (0.3%) aged 0–15 years ($\chi^2=22415.3$; d.f.=1; $P<0.001$); 4370 (23.4%) v. 184191 (5.3%) aged 16–64 years ($\chi^2=11907.5$; d.f.=1; $P<0.001$); and 668 (27.2%) v. 40393 (4.5%) aged 65+ years ($\chi^2=2857.7$; d.f.=1; $P<0.001$). Table 1 and Fig. 1 show the prevalence of mental health conditions by age and gender. There are significant differences between people with and without intellectual disabilities at all ages and for both genders, most markedly so for children and young people.

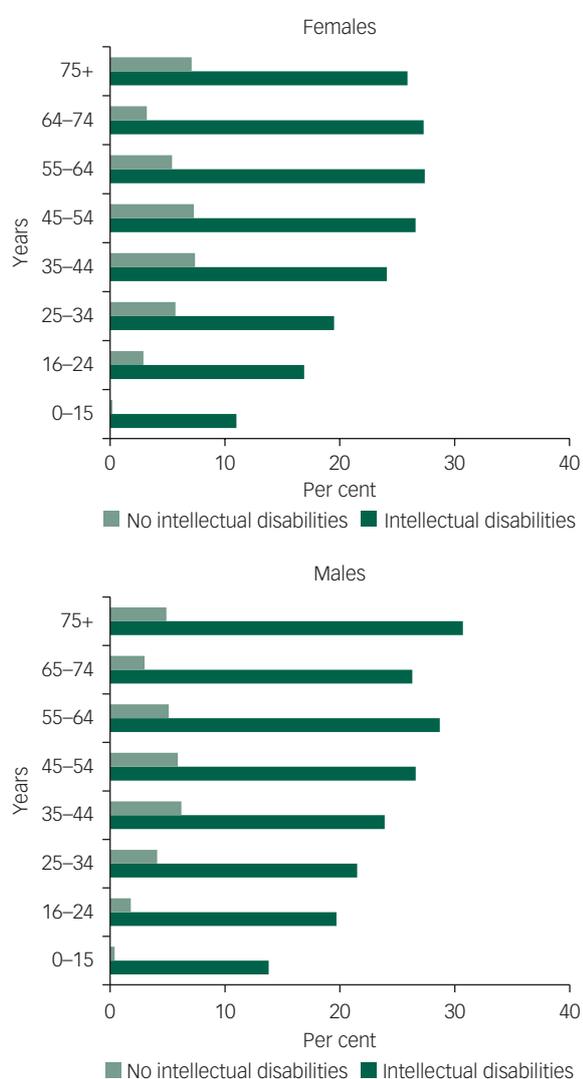
Adjusting for age and gender, given the different distributions in the two populations, intellectual disabilities had an odds ratio of 7.1 (95% CI 6.8–7.3) in statistically predicting mental health conditions (Table 2). Good/very good health, fair health had an odds ratio of 10.4 (95% CI 10.3–10.6) and bad/very bad health had an odds ratio of 25.7 (95% CI 25.4–26.0) in statistically predicting mental health conditions, when referenced against good/very good health (Table 2).

Relationship between general health and mental health

Within the intellectual disabilities population, female gender reduced the likelihood of mental health conditions. Each progressive

Table 1 Prevalence of mental ill health in the populations with and without intellectual disabilities

Age group	Intellectual disabilities, n/N (%)			Other people, n/N (%)		
	Male N=15 149	Female N=11 200	All N=26 349	Male N=2 552 295	Female N=2 716 759	All N=5 269 054
0–15	450/3253 (13.8)	218/1981 (11.0)	668/5234 (12.8)	1739/465 853 (0.4)	914/445 244 (0.2)	2653/911 097 (0.3)
16–24	492/2501 (19.7)	281/1661 (16.9)	773/4162 (18.6)	5664/314 382 (1.8)	9113/313 944 (2.9)	14 777/628 326 (2.4)
25–34	436/2025 (21.5)	286/1450 (19.7)	722/3475 (20.8)	13 552/326 582 (4.1)	19 330/337 270 (5.7)	32 882/663 852 (4.9)
35–44	529/2209 (23.9)	398/1650 (24.1)	927/3859 (24.0)	22 004/355 461 (6.2)	27 633/375 434 (7.4)	49 637/730 895 (6.8)
45–54	653/2456 (26.6)	490/1845 (26.6)	1 143/4301 (26.6)	22 723/382 061 (5.9)	29 384/400 394 (7.3)	52 107/782 455 (6.7)
55–64	442/1539 (28.7)	363/1324 (27.4)	805/2863 (28.1)	16 581/325 383 (5.1)	18 207/339 167 (5.4)	34 788/664 550 (5.2)
65–74	212/805 (26.3)	208/762 (27.3)	420/1567 (26.8)	6 776/224 557 (3.0)	8 106/255 668 (3.2)	14 882/480 225 (3.1)
75+	111/361 (30.7)	137/527 (25.9)	248/888 (27.9)	7 741/158 016 (4.9)	17 770/249 683 (7.1)	25 511/407 654 (6.3)
All ages	3325/15 149 (21.9)	2381/11 200 (21.3)	5706/26 349 (21.7)	96 780/2 552 295 (3.8)	130 457/2 716 759 (4.8)	227 237/5 269 054 (4.3)

**Fig. 1** Prevalence of a mental health condition by gender and age group.

increase in age group, up to 64 years, predicted mental health conditions compared with childhood; thereafter, the odds ratio plateaued (Table 3). Fair health had an odds ratio of 1.8 (95% CI 1.7–1.9) and bad/very bad health had an odds ratio of 4.2 (95% CI 3.9–4.6) in statistically predicting mental health conditions, when referenced against good/very good health (Table 3).

Discussion

Principle findings and interpretation

This large-scale study is the first of a whole-country population to investigate mental health and the relationship with general health in the population with intellectual disabilities at all ages, including children. It found a substantially higher prevalence of mental health conditions at all ages compared with the population without intellectual disabilities. These findings are important, given the previously stated lack of confidence as to whether people with intellectual disabilities have higher rates of mental health conditions, when excluding problem behaviours and autism.³ Few previous studies have reported mental health in comparison with the general population, and those that did had either small sample sizes or reported from general population cohort studies. The general population cohort studies are limited through being focused on mild intellectual disabilities as very few people with more severe intellectual disabilities are included in existing cohorts, and typically are restricted to private households, whereas people with intellectual disabilities are more likely to live in communal establishments than are the general population.

We found mental health conditions to be related to poorer general health status. In the whole population, this was the case for fair health compared with good/very good health and was more markedly so for people with bad/very bad health. We found the same pattern in the population with intellectual disabilities, but to a lesser extent. Contrary to the general population, however, males rather than females were more likely to have mental health conditions, highlighting the importance of specifically studying the health of people with intellectual disabilities, to provide health intelligence that is relevant to them.

The 23.4% prevalence of mental health conditions we report for adults with intellectual disabilities is very similar to the 22.4% (excluding problem behaviours and autism) reported in the previously largest study of 1023 adults who all had individual detailed assessments.¹ The Census prevalence of mental health conditions also excludes autism, as autism was separately enquired about, but it did not specifically enquire about problem behaviours, so it is unclear whether or not respondents included problem behaviours within their understanding of mental health conditions. Regarding children, the previously reported rate of 36% in 641 surveyed children with intellectual disabilities did include problem behaviours.² This is higher than the 12.8% with mental health conditions in Scotland's Census data, which may well be accounted for by problem behaviours; the substantial difference compared with the general population is apparent in both these data-sets.

Table 2 Independent predictors of mental ill health in the whole population				
Characteristic	Regression 1		Regression 2	
	Odds ratio	95% CI	Odds ratio	95% CI
Ability				
No intellectual disabilities (reference)	–	–	–	–
Intellectual disabilities	7.058	6.843–7.280	3.187	3.077–3.300
Gender				
Male (reference)	–	–	–	–
Female	1.238	1.227–1.248	1.243	1.232–1.255
Age				
0–15 (reference)	–	–	–	–
16–24	6.908	6.652–7.172	6.175	5.943–6.415
25–34	14.655	14.139–15.189	11.292	10.888–11.710
35–44	20.437	19.729–21.171	11.987	11.564–12.426
45–54	20.063	19.369–20.782	8.451	8.152–8.761
55–64	15.628	15.079–16.197	4.484	4.322–4.651
65–74	9.083	8.747–9.433	2.016	1.939–2.096
75+	18.456	17.796–19.139	2.979	2.869–3.093
General health status				
Very good/good (reference)			–	
Fair			10.445	10.328–10.563
Bad/very bad			25.702	25.387–26.021
Constant	0.003	–	0.002	

Table 3 Independent predictors of mental ill health in the population with intellectual disabilities				
Characteristic	Regression 1		Regression 2	
	Odds ratio	95% CI	Odds ratio	95% CI
Gender				
Male (reference)	–	–	–	–
Female	0.917	0.864–0.974	0.893	0.839–0.950
Age				
0–15 (reference)	–	–	–	–
16–24	1.562	1.396–1.748	1.660	1.479–1.863
25–34	1.799	1.603–2.019	1.925	1.710–2.166
35–44	2.171	1.945–2.423	2.253	2.014–2.522
45–54	2.485	2.236–2.763	2.485	2.230–2.770
55–64	2.694	2.401–3.023	2.556	2.271–2.876
65–74	2.572	2.220–2.902	2.389	2.072–2.753
75+	2.699	2.291–3.193	2.450	2.061–2.913
General health status				
Very good/good (reference)			–	
Fair			1.783	1.663–1.912
Bad/very bad			4.210	3.887–4.559
Constant	0.151	–	0.092	

Within the population with intellectual disabilities, increasing age was associated with increasing odds of mental health conditions, until age 64 years when the odds plateaued, giving some credence to a healthy survivor effect in this population.¹⁴ As the older adults start to acquire mental health conditions related to ageing (dementia), one would expect their extent of mental health conditions to increase

further. This is not observed in the data, although prevalence rates are still substantially greater than in the general population and then in the population of children with intellectual disabilities. This may be because of the premature death of people with severe/profound intellectual disabilities who have higher levels of mental health conditions, relative to people with mild intellectual disabilities.

The population with intellectual disabilities also had higher rates of physical disability, blindness or partial sight loss, deafness or partial hearing loss and autism. Despite the considerably greater burden of both mental health and physical health that we have reported in the population with intellectual disabilities, it is notable the extent to which their needs have been neglected by researchers, as shown by the limited evidence base. Clearly, more research is needed to better understand the health and healthcare needs of people with intellectual disabilities.

Strengths and limitations

This Scottish total country study is the largest and most complete population study we have identified investigating reported mental health of people with intellectual disabilities compared with people in the general population across the lifespan, and reports on general health associations with mental ill health. The advantage of Scotland's Census data is that it covers communal establishments as well as private households, and specifically, systematically, asked about the presence of intellectual disabilities for each person, distinguishing this from specific learning disabilities and autism; lack of these features has previously been highlighted as a limitation of previous research on people with intellectual disabilities conducted with large data-sets.¹⁵ Additionally, it provides a whole-country coverage, with a 94% response. It may well be unique in having all these features and, therefore, is the strength of the study.

The ascertained prevalence of intellectual disabilities by Scotland's Census is similar for adults (0.5%) to that reported in a recent meta-analysis of population-based studies of prevalence (4.94/1000),¹⁶ giving further credence to the ascertainment in the Census. However, we recognise that the country of study, sample population, age range, definition of intellectual disabilities and method of ascertainment can all impact on identified rate.¹⁷ Cohort effects result in prevalence varying with time, such that past and more recent studies of the same age ranges may well provide different rates.¹⁷ These factors become lost within a meta-analysis. For children and young people we found the prevalence in Scotland's Census varied by age, in view of the time taken for identification in childhood, making comparisons with published studies difficult. Regarding proxy-reporting for presence of intellectual disabilities, limitations have been reported with young children (e.g. age 3),¹⁵ and this is apparent in Scotland's Census data as ascertainment increases up to age 9. Adults would, of course, have been diagnosed in childhood.

We have no reason to believe the study results are not generalisable to other high-income countries.

A limitation is the lack of information on whether the responses were completed by proxies or the person with intellectual disabilities. Given the style and questions on the Census, we consider it very unlikely that people with intellectual disabilities would have been able to complete the form without help. In private households, the head of household completing the Census was most likely to be a parent of the people with intellectual disabilities, in supported living a support worker, and in communal establishments the manager. The data are, therefore, likely to be proxy-report rather than self-report for the great majority of people with intellectual disabilities. We recognise that proxy ratings could differ from self-ratings with regard to health ratings,¹⁵ but without them would have no information on people unable to self-report because of severe/profound intellectual disabilities. We note that proxy-reporting is the basis for much of the healthcare provided for people with intellectual disabilities who cannot self-report.

A further limitation is the cross-sectional design of the study. Hence, we are merely reporting associations, and causality cannot be assumed. Indeed, in the general population there is literature to suggest that mental ill health can lead to poor general ill health, and also the reverse, with poor general health leading to mental ill

health.^{11,12} A longitudinal study would be needed to untangle the preceding and precipitating factors.

Implications

People with intellectual disabilities of all ages have substantially higher rates of mental health conditions than the rest of the population, and their mental health conditions are often associated with poor general health. Their health patterns differ from those seen in the general population.⁹ These conditions are often not identified or are misattributed to the persons' learning disabilities (diagnostic overshadowing). Additionally, people with intellectual disabilities are known to experience difficulties accessing mainstream services.^{6,7} Globally, no country has comprehensive coverage of intellectual disability psychiatric services except the UK, and in the UK, there is increasing 'mainstreaming' of psychiatric care. Knowledge on intellectual disabilities and the poor general health associated with mental health is, therefore, essential for general psychiatrists and mainstream psychiatric services, as well as for carers. Without awareness of the substantial burden of mental health conditions and its co-existence with poor general health, the potential for misdiagnosis is high, and inadequate or inappropriate treatment is a risk. Health burden is also important to know for resource allocation, service planning, and to support individuals and their carers.

Clearly, given the associations we report, more research is needed to determine relationships between specific mental health problems, physical conditions and associated factors, for example, adversity, among people with intellectual disabilities, to help influence the development of appropriate interventions, and health and social care policy.

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