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The prevalence of mental health conditions, sensory impairments, and physical disability in people with co-occurring intellectual disabilities and autism (both conditions together) compared with other people – a total population study of 5,295,403 people

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3 The prevalence of mental health conditions, sensory impairments,
4 and physical disability in people with co-occurring intellectual
5 disabilities and autism (both conditions together) compared with
6 other people – a total population study of 5,295,403 people
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Abstract (281 words)

Objectives: To investigate prevalence of mental health conditions, sensory impairments, and physical disability in children, adults, and older adults with co-occurring intellectual disabilities and autism, given its frequent co-occurrence, compared with the general population.

Design: Whole country cohort study.

Setting: General community.

Participants: 5,709 people with co-occurring intellectual disabilities and autism, compared with 5,289,694 other people.

Outcome measures: Rates and odds ratios (OR) with 95% confidence intervals (95% CI) for mental health conditions, visual impairment, hearing impairment and physical disability in people with co-occurring intellectual disabilities and autism compared with other people, adjusted for age, sex, and interaction between age and co-occurring intellectual disabilities and autism.

Results: All four long-term conditions were markedly more common in children, adults, and older adults with co-occurring intellectual disabilities and autism compared with other people. For mental health, OR=130.8 (95% CI 117.1, 146.1); visual impairment OR=65.9 (95% CI 58.7, 73.9); hearing impairment OR=22.0 (95% CI 19.2, 25.2); physical disability OR=157.5 (95% CI 144.6, 171.7). These ratios are also greater than previously reported for people with *either* intellectual disabilities *or* autism rather than co-occurring intellectual disabilities and autism.

Conclusions: We have quantified the more than double disadvantage for people with co-occurring intellectual disabilities and autism, in terms of additional long-term health conditions. This may well impact on quality of life. It raises challenges for staff working with these people in view of additional

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3 complexity in assessments, diagnoses, and interventions of additional health
4 conditions, as sensory impairments and mental health conditions in particular,
5 compound with the persons pre-existing communication and cognitive
6 problems in this context. Planning is important, with staff being trained,
7 equipped, resourced and prepared to address the challenge of working for
8 people with these conditions.
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20 **Strengths and limitations of this study**

- 21 • Large scale, whole country study, with a high response rate (94%), so the
22 results are representative of the whole population.
- 23 • Intellectual disabilities, autism, and additional long-term conditions were
24 enquired about systematically for everyone in the population.
- 25 • The wording of questions was tested in advance, via cognitive question
26 testing during the design of Scotland's Census, 2011.
- 27 • Limitations include proxy-reporting.
- 28 • People known to have autism/Asperger's syndrome, intellectual disabilities,
29 and the four long-term conditions were reported, rather than each
30 undergoing detailed individual research assessments which are not possible
31 in such large population studies.
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Background

People with intellectual disabilities¹⁻⁴ and people with autism⁵⁻⁷ have more mental and physical health needs than other people. A whole population study of Scotland reported that 21.7% of people with intellectual disabilities also had autism, and 18.0% of people with autism also had intellectual disabilities,⁸ so this dually diagnosed group warrant investigation. One would suspect that this population with co-occurring intellectual disabilities and autism is likely to have a high level of additional health needs, but this has received little previous attention. A higher number of additional health needs increases the likelihood of misdiagnosis, and treatment interactions, so requires more complex treatment plans. Hence it is important to investigate long-term additional health needs experienced by people with co-occurring intellectual disabilities and autism.

Some studies have investigated mental ill-health in people with co-occurring intellectual disabilities and autism. A small study of 149 adults with severe or profound intellectual disabilities and autism, living in state-run developmental centres in Louisiana, USA, compared comorbidity with 158 adults with intellectual disabilities without autism in the same centres. The former group had more symptomology for anxiety, mania, schizophrenia, stereotypies, self-injurious behaviour, eating disorders, sexual disorders, and impulse control.⁹ A study in Norway compared 62 adults with co-occurring autism and intellectual disabilities under the care of autism services, with 132 adults with intellectual disabilities only receiving intellectual disabilities support.¹⁰ High levels of psychiatric disorders were reported in both groups; 53.2% in the co-occurring intellectual disabilities and autism group, and 17.4% in the intellectual

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3 disabilities only group. An English study of referrals to a specialist intellectual
4 disabilities psychiatric service described 42% of the 137 referred adults who
5 had autism as well as intellectual disabilities to have comorbid
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8 psychopathology, most commonly schizophrenia.¹¹ A study of youth aged 14-
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11 20 years age, gender matched 36 people with co-occurring intellectual
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14 disabilities and autism with 36 people with intellectual disabilities without
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17 autism.¹² They reported the former group to have more episodes of mental ill-
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20 health, most commonly depression. A study of people aged 8-29 years with
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23 intellectual disabilities and challenging behaviour living in four residential units
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26 in England included 69 who also had autism and 13 who did not.¹³ They
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29 reported a higher prevalence of organic disorders, anxiety and stereotypies in
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32 the young people with co-occurring intellectual disabilities and autism. This
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35 literature is difficult to summarise overall, as, as well as having small sample
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38 sizes, the participants were not drawn from representative populations.
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44 A further study had the advantage of being population-based, but was still
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47 small in size.¹⁴ It compared the prevalence, and incidence, of mental ill-health
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50 in 77 adults with co-occurring intellectual disabilities and autism with 946
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53 adults with intellectual disabilities without autism, and also with 154
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56 individually age, gender, ability-level, and Down syndrome matched controls.
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59 The adults with autism had a higher point prevalence of problem behaviours
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62 than the 946 without autism, but compared with the 154 matched controls
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65 there was no difference in prevalence, or incidence of either problem
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68 behaviours or other mental ill-health.¹⁴ Three large whole population studies
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71 have reported that of people with intellectual disabilities, 21.7% reported
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74 mental health conditions;³ and of people with autism, 33.0% of adults,⁶ and
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3 7.6% of children⁷ reported mental health conditions, but did not report the
4 rates for people with co-occurring intellectual disabilities and autism.
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10 With regards to sensory impairments, of the 36 matched youth with
11 intellectual disabilities with and without autism, 38.9% with autism reported
12 having visual problems compared with 50.0% without autism, and 13.9% with
13 autism reported having hearing problems compared with 19.4% without
14 autism.¹² An intellectual disabilities register study reported that 95 of the 368
15 (25.8%) adults with intellectual disabilities who had visual impairment also had
16 markers for autism, compared with 422 of 2,674 (16%) of those who had
17 normal vision, and that 46 of the 60 (76.7%) of the adults with intellectual
18 disabilities and congenital blindness also had markers for autism, compared
19 with only 36 of the 67 (53.7%) with normal vision.¹⁵
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33 We have not identified other papers on sensory impairments or any on
34 physical disabilities in people with co-occurring intellectual disabilities and
35 autism. However, previous large whole population studies have reported that
36 of people with intellectual disabilities, 12.4% reported blindness/sight loss,
37 13.1% reported deafness/hearing loss, and 32.6% reported physical disability.³
38 Of people with autism, 12.1% of adults⁶ and 3.5% of children reported
39 blindness/sight loss,⁷ 14.1% of adults⁶ and 2.9% of children reported
40 deafness/hearing loss,⁷ and 24.0% of adults⁶ and 10.7% of children reported
41 physical disability.⁷ They did not, however, report the rates of these conditions
42 for people with co-occurring intellectual disabilities and autism.
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56 Given the frequent overlap of intellectual disabilities and autism, information
57 on the associated comorbid conditions is important, to assist policy makers,
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3 planners, and practitioners to best adapt services for individuals with co-
4 occurring intellectual disabilities and autism. This paper aims to investigate the
5 prevalence of mental health conditions, sensory impairments, and physical
6 disability in children, adults, and older adults with co-occurring intellectual
7 disabilities and autism, compared with other people.
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16 **Methods**

17 **Approval**

18 Approval was obtained from the Scottish Government to undertake secondary
19 data analysis of Scotland's Census, 2011.
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23 **Data Source**

24 Scotland's Census provides information on Scotland's population every ten
25 years, with the most recent Census on 27th March 2011.¹⁶ The Census provides
26 information on the number and characteristics of Scotland's population and
27 households on the Census date.
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31 It is a legal requirement to complete the census form and households were
32 informed that failure to make a Census return, or supplying false information
33 could result in a £1,000 fine. A very high response rate was achieved, with an
34 estimated 94% of all of Scotland's population completing the Census. The
35 Census team used a Census Coverage Survey with about 40,000 households, to
36 estimate numbers and characteristics of the missing 6%.¹⁷ The Coverage Survey
37 and Census records were deterministically matched to check for duplicates.
38 Individuals estimated to have been missed were then imputed using a subset
39 of characteristics from real individuals. The edit and imputation methodology
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3 was adapted from the Office for National Statistics rigorous and systematic
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5 guidelines.¹⁷
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10 The Census was completed by the head of each household on behalf of all
11 occupants of the household. We consider it unlikely that people with co-
12 occurring intellectual disabilities and autism completed the form, given the
13 reading age required to do so. Rather, we expect that the people who
14 completed the form on their behalf were parent-carers in family households,
15 support workers for people living in supported accommodation, and the
16 managers/key workers at communal establishments.
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26 **Variables**

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28 The census included a question to identify people with intellectual disabilities
29 and autism, as well as mental health conditions, sensory impairments, and
30 physical disabilities: 'Do you have any of the following conditions which have
31 lasted, or are expected to last, at least 12 months? Tick all that apply'. There
32 was a choice of ten possible responses to this question: deafness or partial
33 hearing loss; blindness or partial sight loss; learning disability (for example,
34 Down's syndrome); learning difficulty (for example, dyslexia); developmental
35 disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome);
36 physical disability; mental health condition; long-term illness, disease or
37 condition; other condition. For "other condition" the option of providing more
38 detail in an open text response was provided.
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54 In Scotland, the term "learning disability" is used synonymously with that of
55 "intellectual disabilities" used internationally. Importantly, the Census
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3 differentiated between intellectual disabilities and specific learning disabilities;
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5 and between intellectual disabilities and autism.
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10 During the methodology development for Scotland's Census, 2011, cognitive
11 question testing was undertaken on the questions on long-term health
12 conditions and disabilities. This was to determine whether the questions were
13 answered accurately, and to identify any changes needed to improve data
14 quality and/or the acceptability of the way questions were phrased. Cognitive
15 interviewing is a widely used approach to critically evaluate and improve
16 survey questionnaires.¹⁸ This approach enables researchers to modify survey
17 material to enhance clarity. Retrospective probing was conducted with 102
18 participants with a variety of sex, age, and health conditions and disabilities
19 (including people with more than one of the conditions). They included people
20 with autism, intellectual disabilities, dyslexia, dyspraxia, speech impairment,
21 mental health conditions (both milder and more serious), and other long-term
22 conditions.¹⁹ Using the cognitive interviewing results, the question aimed to
23 detect autism was improved and rephrased, to better capture this information.
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25 The questions on intellectual disability, mental health condition, visual
26 impairment, hearing impairment, and physical disability did not require any
27 modifications.
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48 The Census team imputed answers for the 14.7% who did not tick any of the
49 boxes in question on long-term conditions, based on their free text answers for
50 this question and answers to other health questions in the Census, which
51 increased the completion rate to 97.4%. For the remaining 2.6%, the Census
52 team assumed the most plausible explanation was that the person had no
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3 long-term condition but did not see the “No condition” check box at the end of
4 the question, and hence recorded them as having no conditions.
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11 **Data Analysis**

12 We calculated the number and rate per 1,000 population of children and
13 adults with co-occurring intellectual disabilities and autism. We then calculated
14 the number and percentage of people with mental health conditions, deafness
15 or partial hearing loss, blindness or partial sight loss, and physical disability, for
16 those with co-occurring intellectual disabilities and autism, compared with
17 individuals who do not have co-occurring intellectual disabilities and autism
18 using chi-squared (χ^2) tests. For the whole population we then used logistic
19 regression to calculate the odds ratios (OR: 95% confidence interval, 95% CI) of
20 co-occurring intellectual disabilities and autism statistically predicting the
21 binary response of having each of the four specific types of long-term health
22 conditions, adjusted for age and sex. Sex was binary, with males being the
23 reference group. Age was categorised into groups: 0-15, 16-24, 25-34, 35-44,
24 45-54, 55-64, 65-74, 75+, with 0-15 years as the reference group. We repeated
25 the regressions, including the interaction term of age x co-occurring
26 intellectual disabilities and autism, as people with the most severe disabilities
27 die earlier, which may affect the profile of additional health problems
28 differently to that seen in the general population. The same reference groups
29 were used. All analysis was conducted using SPSS software version 22.
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54 **Patient and Public Involvement**

55 The Scottish Learning Disabilities Observatory, where this research was
56 undertaken, has a specific remit for people with intellectual disabilities and
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3 people with autism. Its steering group includes partners from third sector
4 organisations and experts by experience, who approved the workplan for this
5 project prior to it commencing. Results from this study will be disseminated for
6 people with intellectual disabilities and autism in an easy-read version via the
7 Scottish Learning Disabilities Observatory website, newsletters, and
8 conference.
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18 **Results**

19 **Characteristics of the Sample**

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25 Scotland's Census, 2011, includes records on 5,295,403 people aged 0-75+
26 years. 5,709/5,295,403 (1.08/1,000) people had co-occurring intellectual
27 disabilities and autism; of whom 3,769 (66.0%) were male and 1,940 (44.0%)
28 were female. Overall, 2,362/916,331 (2.58/1,000) of the total population of
29 children (0-15 years), and 3,347/4,379,072 (0.76/1,000) adults (16-75+ years)
30 had co-occurring intellectual disabilities and autism.
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40 Compared with the population who did not have co-occurring intellectual
41 disabilities and autism, the population with co-occurring intellectual disabilities
42 and autism had more males (66.0% versus 48.5%; $\chi^2=703.5$; $df=1$; $p<0.001$);
43 were younger ($\chi^2=3894.7$; $df=7$; $p<0.001$); were more likely to have been born
44 in the UK rather than elsewhere ($\chi^2=101.9$; $df=1$; $p<0.001$), revealing lesser
45 geographic mobility; and were no different with regards to Caucasian versus
46 non-Caucasian ethnicity ($\chi^2=1.1$; $df=1$; $p=0.3$) (table 1).
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Long-term Health Conditions

Table 2 shows the proportion of people with co-occurring intellectual disabilities and autism, who had each of the four additional long-term health conditions, compared to people who did not have co-occurring intellectual disabilities and autism. Some people in the sample had more than one long-term health condition.

- Insert table 2 about here -

Mental Health Condition

Adjusting for age and sex, given the different distributions compared with the general population, having co-occurring intellectual disabilities and autism had an OR=25.553 (23.933-27.282, 95% CI) in predicting mental health conditions (table 3). When the interaction term was added (age x co-occurring intellectual disabilities and autism), co-occurring intellectual disabilities and autism had an OR=130.803 (117.131-146.070, 95% CI) in predicting a mental health condition (table 3).

- Insert table 3 about here -

Blindness or partial sight loss

Adjusting for age and sex, having co-occurring intellectual disabilities and autism had an OR=36.781 (34.212-39.542, 95% CI) in predicting blindness or partial sight loss (table 4). When the interaction term was added (age x co-occurring intellectual disabilities and autism), co-occurring intellectual disabilities and autism had an OR=65.897 (58.743-73.922, 95% CI) in predicting blindness or partial sight loss (table 4).

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10 *Deafness or partial hearing loss*

11 Adjusting for age and sex, having co-occurring intellectual disabilities and
12 autism had an OR=11.331 (10.430-12.309, 95% CI) in predicting deafness or
13 partial hearing loss (table 5). When the interaction term was added (age x co-
14 occurring intellectual disabilities and autism), co-occurring intellectual
15 disabilities and autism had an OR=21.996 (19.196-25.205, 95% CI) in predicting
16 deafness or partial hearing loss (table 5).
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31 *Physical disability*

32 Adjusting for age and sex, having co-occurring intellectual disabilities and
33 autism had an OR=61.159 (57.601-64.938, 95% CI) in predicting physical
34 disability (table 6). When the interaction term was added (age x co-occurring
35 intellectual disabilities and autism), co-occurring intellectual disabilities and
36 autism had an OR=157.535 (144.577-171.655, 95% CI) in predicting physical
37 disability (table 6).
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52 **Discussion**

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57 **Principle findings**
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3 Mental health conditions, blindness or partial sight loss, deafness or partial
4 hearing loss, and physical disability were all significantly more common in
5 people with co-occurring intellectual disabilities and autism than people
6 without these co-occurring conditions. The odds ratios after adjusting for age
7 and sex and the interaction term, were substantial, being 131, 66, 22, and 158
8 respectively. This is important as each of these conditions are disabling and can
9 significantly impact an individual's quality of life. They contribute to high rates
10 of multi-morbidity, which, on top of communication and cognitive problems
11 due to autism and intellectual disabilities, renders assessments, diagnosis, and
12 treatment of additional health problems more complex than for other people.
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27 Across all age groups, blindness, deafness, and physical disability were more
28 common in females than males with co-occurring intellectual disabilities and
29 autism, unlike the gender ratios in people without co-occurring intellectual
30 disabilities and autism. Mental health conditions were more common in males
31 than females with co-occurring intellectual disabilities and autism, except for
32 the 65+ year group, contrary to the gender ratios in other people. All
33 conditions were more prevalent with increasing age in the people with co-
34 occurring intellectual disabilities and autism, except for physical disability
35 which was more common in the children/youth and older people than in the
36 adults.
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50 **Comparison with existing literature**

51 The prevalence of these additional long-term health conditions has seldom
52 been investigated in people with co-occurring intellectual disabilities and
53 autism, particularly in comparison with other people, and never, to our
54 knowledge, as a total population study. All of the long-term health conditions
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3 were more common than in those without co-occurring intellectual disabilities
4 and autism.
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10 Smaller, less representative studies have reported a higher rate of mental
11 health conditions in adults and youth with co-occurring intellectual disabilities
12 and autism compared with those with intellectual disabilities and without
13 autism,⁹⁻¹³ but not all.¹⁴ People with autism have been reported to have more
14 mental health conditions than other people (OR=9 in adults and OR=16 in
15 children),^{6,7} as have people with intellectual disabilities compared with other
16 people (OR=7),³ using the same Scotland's Census, 2011 data as in this current
17 paper, whereas the comparable ratio we now report for people with co-
18 occurring intellectual disabilities and autism for mental health conditions was
19 OR=26. Having the co-occurring conditions therefore presents a much higher
20 risk of mental health conditions than either intellectual disabilities or autism
21 on their own.
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The previous small study of youth reported lower rates of visual and hearing
impairments in those with co-occurring intellectual disabilities and autism
(38.9% and 13.9%) compared with those with intellectual disabilities but
without autism (50% and 19.4%).¹² This was in contrast with the larger study
reporting more autistic symptoms in adults with intellectual disabilities and
visual impairments than in adults with intellectual disabilities but without
visual impairments.¹⁵ Adults with autism have been reported to have more
blindness or partial sight loss, and deafness or partial hearing loss than other
people (12.1% and 17.5%),⁶ as have children with autism (3.5% and 2.9%),⁷ and
people (children and adults combined) with intellectual disabilities compared
with other people (13.1% and 12.4%),³ using the same Scotland's Census 2011

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3 as in this current paper. This current study found the comparable rates for
4 people with co-occurring intellectual disabilities and autism for blindness or
5 partial sight loss, and deafness or partial hearing loss was 21.7% and 19.3% for
6 adults, and 16.6% and 10.3% for children. Having the co-occurring conditions
7 of intellectual disabilities and autism therefore presents a much higher risk of
8 sensory impairments than for children and adults with autism, and for people
9 with intellectual disabilities (although children were not separately studied in
10 the previous report).
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22 Regarding physical disability, 32.6% of people with intellectual disabilities were
23 previously reported to have physical disability.³ Of people with autism, 24.0%
24 of adults and 10.7% of children reported physical disability.^{6,7} These rates are
25 lower than those we report in this current study of people with co-occurring
26 intellectual disabilities and autism – 45.6% of children and 42.2% of adults.
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35 **Strengths and limitations**

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37 Strengths of the study include its large scale and general population
38 comparison group, whole population coverage and very high response rate so
39 the results are representative of the whole population. Intellectual disabilities,
40 autism, and the long-term health conditions were enquired about
41 systematically for everyone in the population. We believe the results are
42 therefore generalisable to other high-income countries. The cognitive question
43 testing during the design of the Census is a further strength. The Census had
44 clear categories to distinguish between intellectual disabilities, specific learning
45 disability (like dyslexia), and autism.
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3 Limitations include the proxy-reporting, which may, or may not reflect self-
4 reports. However, without proxy-reports, we would have no information on
5 people unable to self-report due to their disabilities, and a previous review on
6 the topic concluded that overall, proxy reports are a useful addition to
7 determine aspects of well-being in people with intellectual disabilities.²⁰
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9 Additionally, people were reported who were known to have
10 autism/Asperger's syndrome, intellectual disabilities, and the additional long-
11 term health conditions, rather than detailed individual research assessments
12 being undertaken which are clearly not possible in such large population
13 studies, and may therefore be subject to a degree of error which we were not
14 able to check.
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29 **Implications**

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31 There is a greater than double disadvantage for people with co-occurring
32 intellectual disabilities and autism, in terms of additional long-term health
33 conditions. We found that, and quantified the extent to which mental health
34 conditions, sensory impairments, and physical disabilities are more common
35 than in people without co-occurring intellectual disabilities and autism, and in
36 people with just intellectual disabilities or just autism. This may well impact on
37 quality of life. It raises challenges for staff working with people with these co-
38 occurring conditions in view of the additional complexity in assessments,
39 diagnoses, and interventions, as sensory impairments and mental health
40 conditions in particular, interact with the persons pre-existing communication
41 and cognitive problems in this context. Therefore, it is important that these co-
42 occurring conditions are planned for with staff being trained, equipped,
43 resourced and prepared to address the challenge.
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15 16 **Competing interests**

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19
20 The authors declare no competing interests.
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24 25 **Author's contributions**

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29 KD analysed and interpreted the data, and wrote the first draft of the
30 manuscript. ER contributed to data access, data interpretation, and drafting
31 the manuscript. S-AC conceived and managed the project, interpreted data,
32 and contributed to writing the manuscript. All approved the final version of the
33 manuscript. S-AC is the study guarantor.
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42 43 **Data sharing**

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45
46 Data is available via National Records of Scotland, following project approval.
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56 completed the Census.
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Table 1: Characteristics of people with and without, co-occurring intellectual disabilities and autism

	People without co-occurring intellectual disabilities and autism N=5,289,694 (100%) Number (%)	People with co-occurring intellectual disabilities and autism N=5,709 (100%) Number (%)
Gender*		
Males	2,563,675 (48.5%)	3,769 (66.0%)
Females	2,726,019 (51.5%)	1,940 (44.0%)
Age groups*		
0-15	913,969 (17.3%)	2,362 (41.4%)
16-24	631,094 (11.9%)	1,394 (24.4%)
25-34	666,725 (12.6%)	602 (10.5%)
35-44	734,304 (13.9%)	450 (7.9%)
45-54	786,355 (14.9%)	401 (7.0%)
55-64	667,157 (12.6%)	256 (4.5%)
65+	890,090 (16.8%)	244 (4.3%)
Country of birth*		
UK	4,920,614 (93.0%)	5,505 (96.4%)
Other Europe	172,160 (3.3%)	83 (1.5%)
Africa	46,708 (0.9%)	34 (0.6%)
Middle East and Asia	104,480 (2.0%)	50 (0.9%)
The Americas and the Caribbean	33,325 (0.6%)	28 (0.5%)
Other	12,407 (0.2%)	9 (0.2%)
Ethnicity		
White	5,078,910 (96.0%)	5,497 (96.3%)
Asian	140,542 (2.7%)	136 (2.4%)
Mixed/multiple ethnicities	19,775 (0.4%)	40 (0.7%)

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African	29,615 (0.6%)	23 (0.4%)
Caribbean or black	6,536 (0.1%)	4 (0.1%)
Other ethnic groups	14,316 (0.3%)	9 (0.2%)

*People with co-occurring intellectual disabilities and autism versus people without co-occurring intellectual disabilities and autism; p<0.01

For peer review only

Table 2: Prevalence of comorbidities in people with and without co-occurring intellectual disabilities and autism by age and sex

People with co-occurring intellectual disabilities and autism									
Condition	Children/youth, 0-15 years N=2,362			Adults, 16-64 years N=3,103			Older people, 65+ years N=244		
	M N=1,563 (100%)	F N=799 (100%)	Total N=2,362 (100%)	M N= 2,073 (100%)	F N= 1,030 (100%)	Total N= 3,103 (100%)	M N= 133 (100%)	F N= 111 (100%)	Total N= 244 (100%)
Mental health condition	328 (21.0%)	152 (19.0%)	480 (20.3%)	768 (37.0%)	377 (36.6%)	1145 (36.9%)	80 (60.2%)	80 (72.1%)	160 (65.6%)
Blindness/partial sight loss	214 (13.7%)	177 (22.2%)	391 (16.6%)	355 (17.1%)	220 (21.4%)	575 (18.5%)	71 (53.3%)	80 (72.1%)	151 (61.9%)
Deafness/partial hearing loss	148 (9.5%)	95 (11.9%)	243 (10.3%)	301 (14.5%)	190 (18.4%)	491 (15.8%)	73 (54.9%)	81 (73.0%)	154 (63.1%)
Physical disability	618 (39.5%)	458 (57.3%)	1,076 (45.6%)	719 (34.7%)	508 (49.3%)	1,227 (39.5%)	86 (64.7%)	99 (89.2%)	185 (75.8%)
People without co-occurring intellectual disabilities and autism									
Condition	Children/youth, 0-15 years N=913,969			Adults, 16-64 years N=3,485,635			Older people, 65+ years N=890,090		
	M N=467,543 (100%)	F N=446,426 (100%)	Total N= 913,969 (100%)	M N= 1,712,526 (100%)	F N= 1,773,109 (100%)	Total N= 3,485,635 (100%)	M N= 383,606 (100%)	F N= 506,484 (100%)	Total N= 890,090 (100%)
Mental health condition	1,861 (0.4%)	980 (0.2%)	2,841 (0.3%)	92,308 (5.4%)	95,108 (5.4%)	187,416 (5.4%)	14,760 (3.8%)	26,141 (5.2%)	40,901 (4.6%)
Blindness/partial sight loss	1,793 (0.4%)	1,439 (0.3%)	3,232 (0.4%)	24,129 (1.4%)	16,954 (1.0%)	41,083 (1.2%)	30,389 (7.9%)	49,839 (9.8%)	80,228 (9.0%)
Deafness/partial hearing loss	2,731 (0.6%)	2,225 (0.5%)	4,956 (0.5%)	70,543 (4.1%)	48,727 (2.7%)	119,270 (3.4%)	111,447 (29.1%)	114,393 (22.6%)	225,840 (25.4%)
Physical disability	3,637 (0.8%)	2,799 (0.6%)	6,436 (0.7%)	81,655 (4.8%)	82,968 (4.7%)	164,623 (4.7%)	73,759 (19.2%)	109,103 (21.5%)	182,862 (20.5%)

Table 3: Independent predictors of mental health conditions in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	25.553	23.933-27.282	130.803	117.131-146.070
Gender	Male (reference)	-	-	-	-
	Female	1.275	1.264-1.286	1.275	1.264-1.286
Sex	0-15 (reference)	-	-	-	-
	16-24	9.449	9.039-9.877	11.322	10.781-11.890
	25-34	21.168	20.285-22.090	25.305	24.134-26.532
	35-44	29.725	28.497-31.004	35.493	33.866-37.199
	45-54	29.186	27.983-30.441	34.835	33.239-36.507
	55-64	22.633	21.633-23.617	26.997	25.750-28.304
	65+	19.319	18.518-20.155	23.005	21.947-24.115
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.152	0.129-0.178
	25-34	-	-	0.101	0.083-0.123
	35-44	-	-	0.083	0.067-0.104
	45-54	-	-	0.089	0.071-0.112
	55-64	-	-	0.118	0.090-0.154
	65+	-	-	0.308	0.238-0.423
Constant	-	0.002	-	0.002	-

Table 4: Independent predictors of blindness/partial sight loss in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	36.781	34.212-39.542	65.897	58.743-73.922
Sex	Male (reference)	-	-	-	-
	Female	1.011	0.999-1.022	1.011	0.999-1.022
Age	0-15 (reference)	-	-	-	-
	16-24	1.557	1.482-1.636	1.663	1.579-1.751
	25-34	1.824	1.739-1.913	1.914	1.821-2.011
	35-44	2.548	2.439-2.663	2.687	2.567-2.813
	45-54	4.416	4.241-4.599	4.668	4.475-4.870
	55-64	7.503	7.215-7.803	7.928	7.609-8.260
Age x both intellectual disabilities and autism	65+	31.064	29.947-32.222	32.750	31.512-34.036
	0-15 (reference)	-	-	-	-
	16-24	-	-	0.433	0.354-0.528
	25-34	-	-	0.669	0.521-0.844
	35-44	-	-	0.529	0.411-0.681
	45-54	-	-	0.368	0.286-0.474
Constant	55-64	-	-	0.278	0.208-0.372
	65+	-	-	0.250	0.188-0.331
Constant		-	0.003	-	0.003

Table 5: Independent predictors of deafness/partial hearing loss in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	11.331	10.430-12.309	21.996	19.196-25.205
Gender	Male (reference)	-	-	-	-
	Female	0.687	0.682-0.693	0.688	0.682-0.693
Sex	0-15 (reference)	-	-	-	-
	16-24	1.557	1.496-1.621	1.588	1.524-1.654
	25-34	2.358	2.274-2.446	2.408	2.321-2.499
	35-44	4.237	4.099-4.379	4.347	4.203-4.495
	45-54	8.546	8.285-8.815	8.769	8.496-9.051
	55-64	18.761	18.204-19.336	19.243	18.659-19.845
Age x both intellectual disabilities and autism	65+	69.646	67.633-71.719	71.378	69.269-73.552
	0-15 (reference)	-	-	-	-
	16-24	-	-	0.633	0.507-0.790
	25-34	-	-	0.735	0.569-0.948
	35-44	-	-	0.394	0.296-0.523
	45-54	-	-	0.288	0.219-0.378
Constant	55-64	-	-	0.215	0.159-0.289
	65+	-	-	0.222	0.165-0.298
Constant		-	0.006	-	0.006

Table 6: Independent predictors of physical disability in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	61.159	57.601-64.938	157.535	144.577-171.655
Gender	Male (reference)	-	-	-	-
	Female	1.063	1.055-1.070	1.063	1.055-1.070
Sex	0-15 (reference)	-	-	-	-
	16-24	1.440	1.388-1.495	1.573	1.513-1.637
	25-34	2.603	2.519-2.690	2.857	2.760-2.958
	35-44	5.869	5.699-6.043	6.465	6.267-6.670
	45-54	10.606	10.312-10.908	11.662	11.318-12.017
	55-64	20.730	20.166-21.310	22.756	22.096-23.436
	65+	43.680	42.517-44.875	47.894	46.530-49.298
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.410	0.355-0.472
	25-34	-	-	0.344	0.287-0.414
	35-44	-	-	0.123	0.100-0.152
	45-54	-	-	0.075	0.061-0.094
	55-64	-	-	0.044	0.034-0.057
	65+	-	-	0.050	0.039-0.066
Constant	-	0.006	-	0.005	-

BMJ Open

The prevalence of mental health conditions, sensory impairments, and physical disability in people with co-occurring intellectual disabilities and autism compared with other people – a cross-sectional total population study of 5,295,403 people in Scotland

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5 compared with other people – a cross-sectional total population study of
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10 5,295,403 people in Scotland

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53 **Word count:** 4,009
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56 **Keywords:** Intellectual disabilities, autism, mental health conditions, sensory impairments,
57 vision, hearing, physical disability, co-morbidity.
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Abstract

Objectives: To investigate prevalence of mental health conditions, sensory impairments, and physical disability in children, adults, and older adults with co-occurring intellectual disabilities and autism (given its frequent co-occurrence), compared with the general population.

Design: Whole country cross-sectional cohort study.

Setting: General community.

Participants: 5,709 people with co-occurring intellectual disabilities and autism (both conditions together), compared with 5,289,694 other people.

Outcome measures: Rates and odds ratios (OR) with 95% confidence intervals (95% CI) for mental health conditions, visual impairment, hearing impairment and physical disability in people with co-occurring intellectual disabilities and autism compared with other people (adjusted for age, sex, and interaction between age and co-occurring intellectual disabilities and autism).

Results: All four long-term conditions were markedly more common in children, adults, and older adults with co-occurring intellectual disabilities and autism compared with other people. For mental health, OR=130.8 (95% CI 117.1, 146.1); visual impairment OR=65.9 (95% CI 58.7, 73.9); hearing impairment OR=22.0 (95% CI 19.2, 25.2); physical disability OR=157.5 (95% CI 144.6, 171.7). These ratios are also greater than previously reported for people with *either* intellectual disabilities *or* autism (rather than co-occurring intellectual disabilities and autism)

Conclusions: We have quantified the more than double disadvantage for people with co-occurring intellectual disabilities and autism, in terms of additional mental health conditions and impairments. This may well impact on quality of life. It raises challenges for staff working with these people in view of

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3 additional complexity in assessments, diagnoses, and interventions of
4 additional health conditions, as sensory impairments and mental health
5 conditions in particular, compound with the persons pre-existing
6 communication and cognitive problems in this context. Planning is important,
7 with staff being trained, equipped, resourced and prepared to address the
8 challenge of working for people with these conditions.
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18 **Keywords:** Intellectual disabilities, autism, mental health conditions, sensory
19 impairments, vision, hearing, physical disability, co-morbidity.
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25 **Strengths and limitations of this study**

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28

- 29 • Large scale, whole country cross-sectional study, with a high response rate
30 (94%), so the results are representative of the whole population.
31
- 32 • Intellectual disabilities, autism, and additional long-term conditions were
33 enquired about systematically for everyone in the population.
34
- 35 • The wording of questions was tested in advance, via cognitive question
36 testing during the design of Scotland's Census, 2011.
37
- 38 • Limitations include proxy-reporting.
39
- 40 • People known to have autism/Asperger's syndrome, intellectual disabilities,
41 and the four long-term conditions were reported, rather than each
42 undergoing detailed individual research assessments which are not possible
43 in such large population studies.
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Background

People with intellectual disabilities have more mental and physical health needs than other people.¹⁻⁴ People with autism also appear to have more mental and physical health needs than other people.⁵⁻⁸ A whole population study of Scotland reported that 21.7% of people with intellectual disabilities also had autism, and 18.0% of people with autism also had intellectual disabilities,⁹ so this dually diagnosed group warrant investigation. One would suspect that this population with co-occurring intellectual disabilities and autism (both conditions together) are likely to have a high level of additional health needs, but this has received little previous study. A higher number of additional health needs increases the likelihood of misdiagnosis, and treatment interactions, so requires more complex treatment plans. Hence it is important to investigate long-term additional health needs experienced by people with co-occurring intellectual disabilities and autism.

Some studies have investigated mental ill-health in people with co-occurring intellectual disabilities and autism. A small study of 149 adults with severe or profound intellectual disabilities and autism, living in state-run developmental centres in Louisiana, USA, compared comorbidity with 158 adults with intellectual disabilities without autism in the same centres. The former group had more symptomology for anxiety, mania, schizophrenia, stereotypies, self-injurious behaviour, eating disorders, sexual disorders, and impulse control.¹⁰ A study in Norway compared 62 adults with co-occurring autism and intellectual disabilities under the care of autism services, with 132 adults with intellectual disabilities only receiving intellectual disabilities support.¹¹ High levels of psychiatric disorders were reported in both groups; 53.2% in the co-occurring

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3 intellectual disabilities and autism group, and 17.4% in the intellectual
4 disabilities only group. An English study of referrals to a specialist intellectual
5 disabilities psychiatric service described 42% of the 137 referred adults who
6 had autism as well as intellectual disabilities to have comorbid
7 psychopathology, most commonly schizophrenia.¹² A study of youth aged 14-
8 20 years age, gender matched 36 people with co-occurring intellectual
9 disabilities and autism with 36 people with intellectual disabilities without
10 autism.¹³ They reported the former group to have more episodes of mental ill-
11 health, most commonly depression. A study of Medicaid claims data 2012-
12 2015 in Wisconsin, USA compared adults aged 40+years; 64 with autism and
13 intellectual disabilities and 79 with autism but no intellectual disabilities.⁸ They
14 reported no statistical difference between the two groups for claims for
15 psychiatric disorders. Claim rates were high over all (67.2% for those who
16 additionally had intellectual disabilities, and 75.9% for those who did not).⁸ The
17 authors state the autism only sample was probably skewed towards the lower
18 end of socioeconomic status of all people with autism.⁸ A study of people aged
19 8-29 years with intellectual disabilities and challenging behaviour living in four
20 residential units in England included 69 who also had autism and 13 who did
21 not.¹⁴ They reported a higher prevalence of organic disorders, anxiety and
22 stereotypies in the young people with co-occurring intellectual disabilities and
23 autism. This literature is difficult to summarise overall, as, as well as having
24 small sample sizes, the participants were not drawn from representative
25 populations.

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54 A further study had the advantage of being population-based, but was still
55 small in size.¹⁵ It compared the prevalence, and incidence, of mental ill-health
56 in 77 adults with co-occurring intellectual disabilities and autism with 946
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3 adults with intellectual disabilities without autism, and also with 154
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5 individually age, gender, ability-level, and Down syndrome matched controls.
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7 The adults with autism had a higher point prevalence of problem behaviours
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9 than the 946 without autism, but compared with the 154 matched controls
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11 there was no difference in prevalence, or incidence of either problem
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13 behaviours or other mental ill-health.¹⁵ Three large whole population studies
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15 have reported that of people with intellectual disabilities, 21.7% reported
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17 mental health conditions;³ and of people with autism, 33.0% of adults,⁶ and
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19 7.6% of children⁷ reported mental health conditions, but did not report the
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21 rates for people with co-occurring intellectual disabilities and autism.
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27 With regards to sensory impairments, of the 36 matched youth with
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29 intellectual disabilities with and without autism, 38.9% with autism reported
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31 having visual problems compared with 50.0% without autism, and 13.9% with
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33 autism reported having hearing problems compared with 19.4% without
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35 autism.¹³ An intellectual disabilities register study reported that 95 of the 368
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37 (25.8%) adults with intellectual disabilities who had visual impairment also had
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39 markers for autism, compared with 422 of 2,674 (16%) of those who had
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41 normal vision, and that 46 of the 60 (76.7%) of the adults with intellectual
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43 disabilities and congenital blindness also had markers for autism, compared
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45 with only 36 of the 67 (53.7%) with normal vision.¹⁶
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51 We have not identified other papers on sensory impairments or any on
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53 physical disabilities in people with co-occurring intellectual disabilities and
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55 autism. However, previous large whole population studies have reported that
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57 of people with intellectual disabilities, 12.4% reported blindness/sight loss,
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59 13.1% reported deafness/hearing loss, and 32.6% reported physical disability.³
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3 Of people with autism, 12.1% of adults⁶ and 3.5% of children reported
4 blindness/sight loss,⁷ 14.1% of adults⁶ and 2.9% of children reported
5 deafness/hearing loss,⁷ and 24.0% of adults⁶ and 10.7% of children reported
6 physical disability.⁷ They did not, however, report the rates of these conditions
7 for people with co-occurring intellectual disabilities and autism.
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16 Given the frequent overlap of intellectual disabilities and autism, information
17 on the associated comorbid conditions is important, to assist policy makers,
18 planners, and practitioners to best adapt services for individuals with co-
19 occurring intellectual disabilities and autism. This paper aims to investigate the
20 prevalence of mental health conditions, sensory impairments, and physical
21 disability in children, adults, and older adults with co-occurring intellectual
22 disabilities and autism, compared with other people.
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33 **Methods**

34 **Approval**

35 Approval was obtained from the Scottish Government to undertake secondary
36 data analysis of Scotland's Census, 2011.
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40 **Data Source**

41 Scotland's Census provides information on Scotland's population every ten
42 years, with the most recent Census on 27th March 2011.¹⁷ The Census provides
43 information on the number and characteristics of Scotland's population and
44 households on the Census date.
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3 It is a legal requirement to complete the census form and households were
4 informed that failure to make a Census return, or supplying false information
5 could result in a £1,000 fine. A very high response rate was achieved, with an
6 estimated 94% of all of Scotland's population completing the Census. The
7 Census team used a Census Coverage Survey with about 40,000 households, to
8 estimate numbers and characteristics of the missing 6%.¹⁸ The Coverage Survey
9 and Census records were deterministically matched to check for duplicates.
10 Individuals estimated to have been missed were then imputed using a subset
11 of characteristics from real individuals. The edit and imputation methodology
12 was adapted from the Office for National Statistics rigorous and systematic
13 guidelines.¹⁸
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29 The Census was completed by the head of each household on behalf of all
30 occupants of the household. We consider it unlikely that people with co-
31 occurring intellectual disabilities and autism completed the form, given the
32 reading age required to do so. Rather, we expect that the people who
33 completed the form on their behalf were parent-carers in family households,
34 support workers for people living in supported accommodation, and the
35 managers/key workers at communal establishments.
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46 **Variables**

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48 The census included a question to identify people with intellectual disabilities
49 and autism, as well as mental health conditions, sensory impairments, and
50 physical disabilities: 'Do you have any of the following conditions which have
51 lasted, or are expected to last, at least 12 months? Tick all that apply'. There
52 was a choice of ten possible responses to this question: deafness or partial
53 hearing loss; blindness or partial sight loss; learning disability (for example,
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3 Down's syndrome); learning difficulty (for example, dyslexia); developmental
4 disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome);
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6 physical disability; mental health condition; long-term illness, disease or
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8 condition; other condition. For "other condition" the option of providing more
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10 detail in an open text response was provided.
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16 In Scotland, the term "learning disability" is used synonymously with that of
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18 "intellectual disabilities" used internationally. Importantly, the Census
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20 differentiated between intellectual disabilities and specific learning disabilities;
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22 and between intellectual disabilities and autism.
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27 During the methodology development for Scotland's Census, 2011, cognitive
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29 question testing was undertaken on the questions on long-term health
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31 conditions and disabilities. This was to determine whether the questions were
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33 answered accurately, and to identify any changes needed to improve data
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35 quality and/or the acceptability of the way questions were phrased. Cognitive
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37 interviewing is a widely used approach to critically evaluate and improve
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39 survey questionnaires.¹⁹ This approach enables researchers to modify survey
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41 material to enhance clarity. Retrospective probing was conducted with 102
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43 participants with a variety of sex, age, and health conditions and disabilities
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45 (including people with more than one of the conditions). They included people
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47 with autism, intellectual disabilities, dyslexia, dyspraxia, speech impairment,
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49 mental health conditions (both milder and more serious), and other long-term
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51 conditions.²⁰ Using the cognitive interviewing results, the question aimed to
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53 detect autism was improved and rephrased, to better capture this information.
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56 The questions on intellectual disability, mental health condition, visual
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3 impairment, hearing impairment, and physical disability did not require any
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5 modifications.
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10 The Census team imputed answers for the 14.7% who did not tick any of the
11 boxes in question on long-term conditions, based on their free text answers for
12 this question and answers to other health questions in the Census, which
13 increased the completion rate to 97.4%. For the remaining 2.6%, the Census
14 team assumed the most plausible explanation was that the person had no
15 long-term condition but did not see the “No condition” check box at the end of
16 the question, and hence recorded them as having no conditions.
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27 **Procedure**

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29 Data was downloaded from the National Records of Scotland Census data
30 archive.
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36 **Data Analysis**

37 We calculated the number and rate per 1,000 population of children and
38 adults with co-occurring intellectual disabilities and autism. We then calculated
39 the number and percentage of people with mental health conditions, deafness
40 or partial hearing loss, blindness or partial sight loss, and physical disability, for
41 those with co-occurring intellectual disabilities and autism, compared with
42 individuals who do not have co-occurring intellectual disabilities and autism
43 using chi-squared (χ^2) tests. For the whole population we then used logistic
44 regression to calculate the odds ratios (OR: 95% confidence interval, 95% CI) to
45 estimate the effect size of the primary interest, co-occurring intellectual
46 disabilities and autism, on the binary response of having each of the four
47 specific types of long-term health conditions, adjusted for age and sex. Sex was
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3 binary, with male as the reference group. Age was categorised into groups: 0-
4 15, 16-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75+, with 0-15 years as the
5 reference group. We repeated the regressions, including the interaction term
6 of age x co-occurring intellectual disabilities and autism, as people with the
7 most severe disabilities die earlier, which may affect the profile of additional
8 health problems differently to that seen in the general population. The same
9 reference groups were used. All analysis was conducted using SPSS software
10 version 22.
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23 **Patient and public involvement**

24 The Scottish Learning Disabilities Observatory, where this research was
25 undertaken, has a specific remit for people with intellectual disabilities and
26 people with autism. Its steering group includes partners from third sector
27 organisations and experts by experience, who approved the workplan for this
28 project prior to it commencing. Results from this study will be disseminated for
29 people with intellectual disabilities and autism in an easy-read version via the
30 Scottish Learning Disabilities Observatory website, newsletters, and
31 conference.
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44 **Results**

45 **Characteristics of the Sample**

46 Scotland's Census, 2011, includes records on 5,295,403 people aged 0-75+
47 years. 5,709/5,295,403 (1.08/1,000) people had co-occurring intellectual
48 disabilities and autism; of whom 3,769 (66.0%) were male and 1,940 (44.0%)
49 were female. Overall, 2,362/916,331 (2.58/1,000) of the total population of
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3 children (0-15 years), and 3,347/4,379,072 (0.76/1,000) adults (16-75+ years)
4 had co-occurring intellectual disabilities and autism.
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10 Compared with the population who did not have co-occurring intellectual
11 disabilities and autism, the population with co-occurring intellectual disabilities
12 and autism had more males (66.0% versus 48.5%; $\chi^2=703.5$; $df=1$; $p<0.001$);
13 were younger ($\chi^2=3894.7$; $df=7$; $p<0.001$); were more likely to have been born
14 in the UK rather than elsewhere ($\chi^2=101.9$; $df=1$; $p<0.001$), revealing lesser
15 geographic mobility; and were no different with regards to Caucasian versus
16 non-Caucasian ethnicity ($\chi^2=1.1$; $df=1$; $p=0.3$) (table 1).
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31 **Long-term Health Conditions**

32 Table 2 shows the proportion of people with co-occurring intellectual
33 disabilities and autism, who had each of the four additional long-term health
34 conditions, compared to people who did not have co-occurring intellectual
35 disabilities and autism. Some people in the sample had more than one long-
36 term health condition.
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51 *Mental Health Condition*

52 Adjusting for age and sex, given the different distributions compared with the
53 general population, having co-occurring intellectual disabilities and autism had
54 an OR=25.553 (23.933-27.282, 95% CI) for mental health conditions (table 3).
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60 When the interaction term was added (age x co-occurring intellectual

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3 disabilities and autism), co-occurring intellectual disabilities and autism had an
4 OR=130.803 (117.131-146.07048.8, 95% CI) for a mental health condition
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6 (table 3).
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15 16 *Blindness or partial sight loss*

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18 Adjusting for age and sex, having co-occurring intellectual disabilities and
19 autism had an OR=36.781 (34.212-39.542, 95% CI) for blindness or partial sight
20 loss (table 4). When the interaction term was added (age x co-occurring
21 intellectual disabilities and autism), co-occurring intellectual disabilities and
22 autism had an OR=65.897 (58.743-73.922, 95% CI) for blindness or partial sight
23 loss (table 4).
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36 37 *Deafness or partial hearing loss*

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39 Adjusting for age and sex, having co-occurring intellectual disabilities and
40 autism had an OR=11.331 (10.430-12.309, 95% CI) for deafness or partial
41 hearing loss (table 5). When the interaction term was added (age x co-
42 occurring intellectual disabilities and autism), co-occurring intellectual
43 disabilities and autism had an OR=21.996 (19.196-25.205, 95% CI) for deafness
44 or partial hearing loss (table 5).
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57 58 *Physical disability* 59 60

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3 Adjusting for age and sex, having co-occurring intellectual disabilities and
4 autism had an OR=61.159 (57.601-64.938, 95% CI) for physical disability (table
5 6). When the interaction term was added (age x co-occurring intellectual
6 7 disabilities and autism), co-occurring intellectual disabilities and autism had an
7 8 OR=157.535 (144.577-171.655, 95% CI) for physical disability (table 6).
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20 *Prevalence differences*

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22 Prevalence differences are apparent from table 2. For children and young
23 people aged 0-15 years, the difference in prevalence between the population
24 with co-occurring intellectual disabilities and autism, and the rest of the general
25 population, was: 20.0/100 for mental health conditions, 16.2/100 for
26 blindness/partial sight loss, 9.8/100 for deafness/partial hearing loss, and
27 44.9/100 for physical disability. For adults aged 16-64 years, the difference in
28 prevalence between the population with co-occurring intellectual disabilities
29 and autism, and the rest of the general population, was: 31.5/100 for mental
30 health conditions, 17.3/100 for blindness/partial sight loss, 12.4/100 for
31 deafness/partial hearing loss, and 34.8/100 for physical disability. For older
32 adults aged 65+ years, the difference in prevalence between the population
33 with co-occurring intellectual disabilities and autism, and the rest of the general
34 population, was: 61.0/100 for mental health conditions, 52.9/100 for
35 blindness/partial sight loss, 37.7/100 for deafness/partial hearing loss, and
36 55.3/100 for physical disability.
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56 **Discussion**

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Principle findings

Mental health conditions, blindness or partial sight loss, deafness or partial hearing loss, and physical disability were all significantly more common in people with co-occurring intellectual disabilities and autism than people without these co-occurring conditions. The odds ratios after adjusting for age and sex and the interaction term, were substantial, being 131, 66, 22, and 158 respectively. This is important as each of these conditions are disabling and can significantly impact an individual's quality of life. They contribute to high rates of multi-morbidity, which, on top of communication and cognitive problems due to autism and intellectual disabilities, renders assessments, diagnosis, and treatment of additional health problems more complex than for other people.

Across all age groups, blindness, deafness, and physical disability were more common in females than males with co-occurring intellectual disabilities and autism, unlike the sex ratios in people without co-occurring intellectual disabilities and autism. Mental health conditions were more common in males than females with co-occurring intellectual disabilities and autism, except for the 65+ year group, contrary to the gender ratios in other people. All conditions were more prevalent with increasing age in the people with co-occurring intellectual disabilities and autism, except for physical disability which was more common in the children/youth and older people than in the adults.

There are likely to be many biological, social, and environmental reasons accounting for these results.

Comparison with existing literature

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3 The prevalence of these additional long-term health conditions has seldom
4 been investigated in people with co-occurring intellectual disabilities and
5 autism, particularly in comparison with other people, and never, to our
6 knowledge, as a total population study. While prevalence rates of mental
7 health conditions and impairments in a full country population for individuals
8 with intellectual disabilities, and separately for individuals with autism have
9 been compared to the general population, no such study has been conducted
10 on the prevalence of mental health conditions and impairments for those with
11 co-occurring intellectual disabilities and autism. We found all of the long-term
12 health conditions were more common than in those without co-occurring
13 intellectual disabilities and autism.
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29 Smaller, less representative studies have reported a higher rate of mental
30 health conditions in adults and youth with co-occurring intellectual disabilities
31 and autism compared with those with intellectual disabilities and without
32 autism,⁹⁻¹⁴ but not all.¹⁵ People with autism have been reported to have more
33 mental health conditions than other people (OR=9 in adults and OR=16 in
34 children),^{6,7} as have people with intellectual disabilities compared with other
35 people (OR=7),³ using the same Scotland's Census, 2011 data as in this current
36 paper, whereas the comparable ratio we now report for people with co-
37 occurring intellectual disabilities and autism for mental health conditions was
38 OR=26. Having the co-occurring conditions therefore presents a much higher
39 risk of mental health conditions than either intellectual disabilities or autism
40 on their own.
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57 The previous small study of youth reported lower rates of visual and hearing
58 impairments in those with co-occurring intellectual disabilities and autism
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3 (38.9% and 13.9%) compared with those with intellectual disabilities but
4 without autism (50% and 19.4%).¹³ This was in contrast with the larger study
5 reporting more autistic symptoms in adults with intellectual disabilities and
6 visual impairments than in adults with intellectual disabilities but without
7 visual impairments.¹⁶ Adults with autism have been reported to have more
8 blindness or partial sight loss, and deafness or partial hearing loss than other
9 people (12.1% and 17.5%),⁶ as have children with autism (3.5% and 2.9%),⁷ and
10 people (children and adults combined) with intellectual disabilities compared
11 with other people (13.1% and 12.4%),³ using the same Scotland's Census 2011
12 as in this current paper. This current study found the comparable rates for
13 people with co-occurring intellectual disabilities and autism for blindness or
14 partial sight loss, and deafness or partial hearing loss was 21.7% and 19.3% for
15 adults, and 16.6% and 10.3% for children. Having the co-occurring conditions
16 of intellectual disabilities and autism therefore presents a much higher risk of
17 sensory impairments than for children and adults with autism, and for people
18 with intellectual disabilities (although children were not separately studied in
19 the previous report).

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41 Regarding physical disability, 32.6% of people with intellectual disabilities were
42 previously reported to have physical disability.³ Of people with autism, 24.0%
43 of adults and 10.7% of children reported physical disability.^{6,7} These rates are
44 lower than those we report in this current study of people with co-occurring
45 intellectual disabilities and autism – 45.6% of children and 42.2% of adults.
46 Cerebral palsy is associated with intellectual disabilities, but the extent of this
47 association does not appear to account for the differences found in physical
48 disability: cerebral palsy has been reported to occur in 13% of children and
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3 young people with intellectual disabilities,²¹ and in 3.2% of general population
4 children and young people in the USA.²²
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10 **Strengths and limitations**

11 Strengths of the study include its large scale and general population
12 comparison group, whole population coverage, and very high response rate so
13 the results are representative of the whole population. Intellectual disabilities,
14 autism, and the long-term health conditions were enquired about
15 systematically for everyone in the population. We believe the results are
16 therefore generalisable to other high-income countries. The cognitive question
17 testing during the design of the Census is a further strength. The Census had
18 clear categories to distinguish between intellectual disabilities, specific learning
19 disability (like dyslexia), and autism.
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33 Limitations include the proxy-reporting, which may, or may not reflect self-
34 reports. Without proxy-reports, we would have no information on people
35 unable to self-report due to their disabilities, and a previous review on the
36 topic concluded that overall, proxy reports are a useful addition to determine
37 aspects of well-being in people with intellectual disabilities.²³ Additionally,
38 people were reported who were known to have autism/Asperger's syndrome,
39 intellectual disabilities, and the additional long-term health conditions, rather
40 than detailed individual research assessments being undertaken which are
41 clearly not possible in such large population studies, and may therefore be
42 subject to a degree of error which we were not able to check.
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56 Scotland's Census 2011 was administered 8 years ago, and so any potential
57 changes in prevalence of conditions since then are not captured by our
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3 analyses. People with intellectual disabilities and autism are both higher health
4 care users than other people and so may receive more diagnoses, but they are
5 also subject to “diagnostic overshadowing”. We do not know the extent to
6 which these factors may impact on reporting of mental health conditions,
7 sensory impairments, and physical disability at Scotland’s Census, 2011.
8 However, given the long-term nature of these conditions, any impact is likely
9 to be less than it would be for acute conditions.”
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20 The study is cross-sectional, rather than longitudinal. We acknowledge that the
21 use of odds ratios may overestimate the strength of associations in cross-
22 sectional studies where the prevalence in the general population is very low;
23 calculating odds ratios has enabled us to draw comparisons with previously
24 published results on mental health conditions and impairments of people with
25 intellectual disabilities, and of people with autism. We also present example
26 prevalence differences. It is also important to note that whilst our regressions
27 adjusted for sex and age, the effect sizes for sex and age shown in tables 3-6
28 might not be the total effect of sex and age on the four outcomes: they show
29 the proportion of the sex, age effect on the odds ratio for the four outcomes
30 that are not mediated through any sex, age effect on co-occurring intellectual
31 disabilities and autism.²⁴ Hence in our discussions of sex and age, we referred
32 to prevalence rather than odds ratios.
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50 **Implications**

51 Management of individuals with multiple health conditions or disabilities
52 presents significant challenges for health care practitioners. A review of 123
53 studies on care management for individuals with multiple chronic conditions in
54 the USA reported that these patients access services more frequently and use
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3 a larger range of services than other patients, making the coordination of their
4 care more difficult and often leading to suboptimal care.²⁵ Evidence from the
5 UK suggests that individuals with intellectual disabilities and additional long
6 term conditions receive poorer management than members of the general
7 population with the same conditions.²⁶
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16 We have shown there is a greater than double disadvantage for people with
17 co-occurring intellectual disabilities and autism, in terms of additional long-
18 term health conditions. We found that, and quantified, mental health
19 conditions, sensory impairments, and physical disabilities are more common
20 than people without co-occurring intellectual disabilities and autism, and in
21 people with just intellectual disabilities or just autism. This may well impact on
22 quality of life. It raises challenges for staff working with people with these co-
23 occurring conditions in view of the additional complexity in assessments,
24 diagnoses, and interventions, as sensory impairments and mental health
25 conditions in particular, interact with the persons pre-existing communication
26 and cognitive problems in this context. Therefore, it is important that these co-
27 occurring conditions are planned for with staff being trained, equipped,
28 resourced and prepared to address the challenge. At present, Government
29 policy and strategy in Scotland addresses needs of people with intellectual
30 disabilities,²⁷ and autistic people,²⁸ but has not yet established a framework for
31 people with these co-occurring conditions; our findings are therefore highly
32 relevant.
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52 53 54 **References** 55 56 57 58 59 60

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22 The researchers are independent from the funders.
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25 26 **Competing interests**

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31 The authors declare no competing interests.
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34 35 **Author's contributions**

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40 KD analysed and interpreted the data, and wrote the first draft of the
41 manuscript. ER contributed to data access, data interpretation, and drafting
42 the manuscript. MF provided advice on response to reviewer comments
43 regarding choice of statistical methods and contributed to the writing of the
44 manuscript. S-AC conceived and managed the project, interpreted data, and
45 contributed to writing the manuscript. All approved the final version of the
46 manuscript. S-AC is the study guarantor.
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54 55 56 57 **Data sharing** 58 59 60

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3 Data is available via National Records of Scotland, following project approval.
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5 Data are available at the following link
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7 [https://www.scotlandscensus.gov.uk/ods-web/data-](https://www.scotlandscensus.gov.uk/ods-web/data-warehouse.html#additionaltab)
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9 [warehouse.html#additionaltab](https://www.scotlandscensus.gov.uk/ods-web/data-warehouse.html#additionaltab)
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Table 1: Characteristics of people with and without, co-occurring intellectual disabilities and autism

	People without co-occurring intellectual disabilities and autism N=5,289,694 (100%) Number (%)	People with co-occurring intellectual disabilities and autism N=5,709 (100%) Number (%)
Gender*		
Males	2,563,675 (48.5%)	3,769 (66.0%)
Females	2,726,019 (51.5%)	1,940 (44.0%)
Age groups*		
0-15	913,969 (17.3%)	2,362 (41.4%)
16-24	631,094 (11.9%)	1,394 (24.4%)
25-34	666,725 (12.6%)	602 (10.5%)
35-44	734,304 (13.9%)	450 (7.9%)
45-54	786,355 (14.9%)	401 (7.0%)
55-64	667,157 (12.6%)	256 (4.5%)
65+	890,090 (16.8%)	244 (4.3%)
Country of birth*		
UK	4,920,614 (93.0%)	5,505 (96.4%)
Other Europe	172,160 (3.3%)	83 (1.5%)
Africa	46,708 (0.9%)	34 (0.6%)
Middle East and Asia	104,480 (2.0%)	50 (0.9%)
The Americas and the Caribbean	33,325 (0.6%)	28 (0.5%)
Other	12,407 (0.2%)	9 (0.2%)
Ethnicity		
White	5,078,910 (96.0%)	5,497 (96.3%)
Asian	140,542 (2.7%)	136 (2.4%)
Mixed/multiple ethnicities	19,775 (0.4%)	40 (0.7%)

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African	29,615 (0.6%)	23 (0.4%)
Caribbean or black	6,536 (0.1%)	4 (0.1%)
Other ethnic groups	14,316 (0.3%)	9 (0.2%)

*People with co-occurring intellectual disabilities and autism versus people without co-occurring intellectual disabilities and autism; p<0.01

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Table 2: Prevalence of comorbidities in people with and without co-occurring intellectual disabilities and autism by age and sex

People with co-occurring intellectual disabilities and autism									
Condition	Children/youth, 0-15 years N=2,362			Adults, 16-64 years N=3,103			Older people, 65+ years N=244		
	M N=1,563 (100%)	F N=799 (100%)	Total N=2,362 (100%)	M N= 2,073 (100%)	F N= 1,030 (100%)	Total N= 3,103 (100%)	M N= 133 (100%)	F N= 111 (100%)	Total N= 244 (100%)
Mental health condition	328 (21.0%)	152 (19.0%)	480 (20.3%)	768 (37.0%)	377 (36.6%)	1,145 (36.9%)	80 (60.2%)	80 (72.1%)	160 (65.6%)
Blindness/partial sight loss	214 (13.7%)	177 (22.2%)	391 (16.6%)	355 (17.1%)	220 (21.4%)	575 (18.5%)	71 (53.3%)	80 (72.1%)	151 (61.9%)
Deafness/partial hearing loss	148 (9.5%)	95 (11.9%)	243 (10.3%)	301 (14.5%)	190 (18.4%)	491 (15.8%)	73 (54.9%)	81 (73.0%)	154 (63.1%)
Physical disability	618 (39.5%)	458 (57.3%)	1,076 (45.6%)	719 (34.7%)	508 (49.3%)	1,227 (39.5%)	86 (64.7%)	99 (89.2%)	185 (75.8%)
People without co-occurring intellectual disabilities and autism									
Condition	Children/youth, 0-15 years N=913,969			Adults, 16-64 years N=3,485,635			Older people, 65+ years N=890,090		
	M N=467,543 (100%)	F N=446,426 (100%)	Total N= 913,969 (100%)	M N= 1,712,526 (100%)	F N= 1,773,109 (100%)	Total N= 3,485,635 (100%)	M N= 383,606 (100%)	F N= 506,484 (100%)	Total N= 890,090 (100%)
Mental health condition	1,861 (0.4%)	980 (0.2%)	2,841 (0.3%)	92,308 (5.4%)	95,108 (5.4%)	187,416 (5.4%)	14,760 (3.8%)	26,141 (5.2%)	40,901 (4.6%)
Blindness/partial sight loss	1,793 (0.4%)	1,439 (0.3%)	3,232 (0.4%)	24,129 (1.4%)	16,954 (1.0%)	41,083 (1.2%)	30,389 (7.9%)	49,839 (9.8%)	80,228 (9.0%)
Deafness/partial hearing loss	2,731 (0.6%)	2,225 (0.5%)	4,956 (0.5%)	70,543 (4.1%)	48,727 (2.7%)	119,270 (3.4%)	111,447 (29.1%)	114,393 (22.6%)	225,840 (25.4%)
Physical disability	3,637 (0.8%)	2,799 (0.6%)	6,436 (0.7%)	81,655 (4.8%)	82,968 (4.7%)	164,623 (4.7%)	73,759 (19.2%)	109,103 (21.5%)	182,862 (20.5%)

Table 3: Effect of co-occurring intellectual disabilities and autism on mental health conditions in the whole population, adjusted for sex and age

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	25.553	23.933-27.282	130.803	117.131-146.070
Sex	Male (reference)	-	-	-	-
	Female	1.275	1.264-1.286	1.275	1.264-1.286
Age	0-15 (reference)	-	-	-	-
	16-24	9.449	9.039-9.877	11.322	10.781-11.890
	25-34	21.168	20.285-22.090	25.305	24.134-26.532
	35-44	29.725	28.497-31.004	35.493	33.866-37.199
	45-54	29.186	27.983-30.441	34.835	33.239-36.507
	55-64	22.633	21.633-23.617	26.997	25.750-28.304
	65+	19.319	18.518-20.155	23.005	21.947-24.115
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.152	0.129-0.178
	25-34	-	-	0.101	0.083-0.123
	35-44	-	-	0.083	0.067-0.104
	45-54	-	-	0.089	0.071-0.112
	55-64	-	-	0.118	0.090-0.154
	65+	-	-	0.308	0.238-0.423
Constant	-	0.002	-	0.002	-

Table 4: Effect of co-occurring intellectual disabilities and autism on blindness/partial sight loss in the whole population, adjusted for sex and age

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	36.781	34.212-39.542	65.897	58.743-73.922
Sex	Male (reference)	-	-	-	-
	Female	1.011	0.999-1.022	1.011	0.999-1.022
Age	0-15 (reference)	-	-	-	-
	16-24	1.557	1.482-1.636	1.663	1.579-1.751
	25-34	1.824	1.739-1.913	1.914	1.821-2.011
	35-44	2.548	2.439-2.663	2.687	2.567-2.813
	45-54	4.416	4.241-4.599	4.668	4.475-4.870
	55-64	7.503	7.215-7.803	7.928	7.609-8.260
	65+	31.064	29.947-32.222	32.750	31.512-34.036
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.433	0.354-0.528
	25-34	-	-	0.669	0.521-0.844
	35-44	-	-	0.529	0.411-0.681
	45-54	-	-	0.368	0.286-0.474
	55-64	-	-	0.278	0.208-0.372
	65+	-	-	0.250	0.188-0.331
Constant	-	0.003	-	0.003	-

Table 5: Effect of co-occurring intellectual disabilities and autism on deafness/partial hearing loss in the whole population, adjusted for sex and age

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	11.331	10.430-12.309	21.996	19.196-25.205
Sex	Male (reference)	-	-	-	-
	Female	0.687	0.682-0.693	0.688	0.682-0.693
Age	0-15 (reference)	-	-	-	-
	16-24	1.557	1.496-1.621	1.588	1.524-1.654
	25-34	2.358	2.274-2.446	2.408	2.321-2.499
	35-44	4.237	4.099-4.379	4.347	4.203-4.495
	45-54	8.546	8.285-8.815	8.769	8.496-9.051
	55-64	18.761	18.204-19.336	19.243	18.659-19.845
	65+	69.646	67.633-71.719	71.378	69.269-73.552
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.633	0.507-0.790
	25-34	-	-	0.735	0.569-0.948
	35-44	-	-	0.394	0.296-0.523
	45-54	-	-	0.288	0.219-0.378
	55-64	-	-	0.215	0.159-0.289
	65+	-	-	0.222	0.165-0.298
Constant	-	0.006	-	0.006	-

Table 6: Effect of co-occurring intellectual disabilities and autism on physical disability in the whole population, adjusted for sex and age

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	61.159	57.601-64.938	157.535	144.577-171.655
Sex	Male (reference)	-	-	-	-
	Female	1.063	1.055-1.070	1.063	1.055-1.070
Age	0-15 (reference)	-	-	-	-
	16-24	1.440	1.388-1.495	1.573	1.513-1.637
	25-34	2.603	2.519-2.690	2.857	2.760-2.958
	35-44	5.869	5.699-6.043	6.465	6.267-6.670
	45-54	10.606	10.312-10.908	11.662	11.318-12.017
	55-64	20.730	20.166-21.310	22.756	22.096-23.436
	65+	43.680	42.517-44.875	47.894	46.530-49.298
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.410	0.355-0.472
	25-34	-	-	0.344	0.287-0.414
	35-44	-	-	0.123	0.100-0.152
	45-54	-	-	0.075	0.061-0.094
	55-64	-	-	0.044	0.034-0.057
	65+	-	-	0.050	0.039-0.066
Constant	-	0.006	-	0.005	-

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60STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract Page 1 (title)
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found Page 2
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported Pages 4-7
Objectives	3	State specific objectives, including any pre-specified hypotheses Page 7, line 9
Methods		
Study design	4	Present key elements of study design early in the paper Page 8-11
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection Page 7-8
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants Page 7-8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable Page 8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group Page 7-10
Bias	9	Describe any efforts to address potential sources of bias Page 9-10
Study size	10	Explain how the study size was arrived at Page 7-8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why Page 10-11
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding Page 10-11
		(b) Describe any methods used to examine subgroups and interactions Page 10-11
		(c) Explain how missing data were addressed Page 10
		(d) If applicable, describe analytical methods taking account of sampling strategy N/A
		(e) Describe any sensitivity analyses N/A

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed Page 11-12 (b) Give reasons for non-participation at each stage N/A (c) Consider use of a flow diagram N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders Page 11-12, Table 1 (b) Indicate number of participants with missing data for each variable of interest Page 10
Outcome data	15*	Report numbers of outcome events or summary measures Page 13-15
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included Page 12-14, Tables 3-6 (b) Report category boundaries when continuous variables were categorized N/A (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses Page 12-14
Discussion		
Key results	18	Summarise key results with reference to study objectives Page 15-17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias Page 18-20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence Page 15-20
Generalisability	21	Discuss the generalisability (external validity) of the study results Page 18
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based Page 25

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely

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available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

For peer review only

BMJ Open

The prevalence of mental health conditions, sensory impairments, and physical disability in people with co-occurring intellectual disabilities and autism compared with other people – a cross-sectional total population study in Scotland

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3 The prevalence of mental health conditions, sensory impairments,
4 and physical disability in people with co-occurring intellectual
5 disabilities and autism compared with other people – a cross
6 sectional total population study in Scotland
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Abstract (281 words)

Objectives: To investigate prevalence of mental health conditions, sensory impairments, and physical disability in children, adults, and older adults with co-occurring intellectual disabilities and autism, given its frequent co-occurrence, compared with the general population.

Design: Whole country cohort study.

Setting: General community.

Participants: 5,709 people with co-occurring intellectual disabilities and autism, compared with 5,289,694 other people.

Outcome measures: Rates and odds ratios (OR) with 95% confidence intervals (95% CI) for mental health conditions, visual impairment, hearing impairment and physical disability in people with co-occurring intellectual disabilities and autism compared with other people, adjusted for age, sex, and interaction between age and co-occurring intellectual disabilities and autism.

Results: All four long-term conditions were markedly more common in children, adults, and older adults with co-occurring intellectual disabilities and autism compared with other people. For mental health, OR=130.8 (95% CI 117.1, 146.1); visual impairment OR=65.9 (95% CI 58.7, 73.9); hearing impairment OR=22.0 (95% CI 19.2, 25.2); physical disability OR=157.5 (95% CI 144.6, 171.7). These ratios are also greater than previously reported for people with *either* intellectual disabilities *or* autism rather than co-occurring intellectual disabilities and autism.

Conclusions: We have quantified the more than double disadvantage for people with co-occurring intellectual disabilities and autism, in terms of additional long-term health conditions. This may well impact on quality of life. It raises challenges for staff working with these people in view of additional

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3 complexity in assessments, diagnoses, and interventions of additional health
4 conditions, as sensory impairments and mental health conditions in particular,
5 compound with the persons pre-existing communication and cognitive
6 problems in this context. Planning is important, with staff being trained,
7 equipped, resourced and prepared to address the challenge of working for
8 people with these conditions.
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20 **Strengths and limitations of this study**

- 21 • Large scale, whole country study, with a high response rate (94%), so the
22 results are representative of the whole population.
- 23 • Intellectual disabilities, autism, and additional long-term conditions were
24 enquired about systematically for everyone in the population.
- 25 • The wording of questions was tested in advance, via cognitive question
26 testing during the design of Scotland's Census, 2011.
- 27 • Limitations include proxy-reporting.
- 28 • People known to have autism/Asperger's syndrome, intellectual disabilities,
29 and the four long-term conditions were reported, rather than each
30 undergoing detailed individual research assessments which are not possible
31 in such large population studies.
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Background

People with intellectual disabilities¹⁻⁴ and people with autism⁵⁻⁷ have more mental and physical health needs than other people. A whole population study using the Scotland Census 2011 reported that 21.7% of people with intellectual disabilities also had autism, and 18.0% of people with autism also had intellectual disabilities,⁸ so this dually diagnosed group warrant investigation. One would suspect that this population with co-occurring intellectual disabilities and autism is likely to have a high level of additional health needs, but this has received little previous attention. A higher number of additional health needs increases the likelihood of misdiagnosis, and treatment interactions, so requires more complex treatment plans. Hence it is important to investigate long-term additional health needs experienced by people with co-occurring intellectual disabilities and autism.

Some studies have investigated mental ill-health in people with co-occurring intellectual disabilities and autism. A small study of 149 adults with severe or profound intellectual disabilities and autism, living in state-run developmental centres in Louisiana, USA, compared co-existing conditions with 158 adults with intellectual disabilities without autism in the same centres. The former group had more symptomology for anxiety, mania, schizophrenia, stereotypies, self-injurious behaviour, eating disorders, sexual disorders, and impulse control.⁹ A study in Norway compared 62 adults with co-occurring autism and intellectual disabilities under the care of autism services, with 132 adults with intellectual disabilities only receiving intellectual disabilities support.¹⁰ High levels of psychiatric disorders were reported in both groups; 53.2% in the co-occurring intellectual disabilities and autism group, and 17.4%

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3 in the intellectual disabilities only group. An English study of referrals to a
4 specialist intellectual disabilities psychiatric service described 42% of the 137
5 referred adults who had autism as well as intellectual disabilities to have co-
6 existing psychopathology, most commonly schizophrenia.¹¹ A study of youth
7 aged 14-20 years age, gender matched 36 people with co-occurring intellectual
8 disabilities and autism with 36 people with intellectual disabilities without
9 autism.¹² They reported the former group to have more episodes of mental ill-
10 health, most commonly depression. A study of people aged 8-29 years with
11 intellectual disabilities and challenging behaviour living in four residential units
12 in England included 69 who also had autism and 13 who did not.¹³ They
13 reported a higher prevalence of organic disorders, anxiety and stereotypies in
14 the young people with co-occurring intellectual disabilities and autism. This
15 literature is difficult to summarise overall, as, as well as having small sample
16 sizes, the participants were not drawn from representative populations.
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35 A further study had the advantage of being population-based, but was still
36 small in size.¹⁴ It compared the prevalence, and incidence, of mental ill-health
37 in 77 adults with co-occurring intellectual disabilities and autism with 946
38 adults with intellectual disabilities without autism, and also with 154
39 individually age, gender, ability-level, and Down syndrome matched controls.
40 The adults with autism had a higher point prevalence of problem behaviours
41 than the 946 without autism, but compared with the 154 matched controls
42 there was no difference in prevalence, or incidence of either problem
43 behaviours or other mental ill-health.¹⁴ Three large whole population studies
44 using the Scotland Census 2011 have reported that of people with intellectual
45 disabilities, 21.7% reported mental health conditions;³ and of people with
46 autism, 33.0% of adults,⁶ and 7.6% of children⁷ reported mental health
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3 conditions, but did not report the rates for people with co-occurring
4 intellectual disabilities and autism.
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10 A recent study of Medicare claims data in Wisconsin, USA, by Bishop &
11 Rubenstein (2019) compared the physical and mental health conditions for
12 adults aged 40-88 years old with a diagnosis of autism only (N= 79) to those
13 with a diagnosis of both autism and intellectual disabilities (N= 64) between
14 2012 and 2015. The prevalence of chronic medical conditions was high among
15 the entire sample, with elevated but not statistically significant prevalence
16 rates for adults with both autism and intellectual disabilities on most
17 conditions. However, odds ratios revealed a decreased likelihood of anxiety
18 and depression for individuals with both autism and intellectual disabilities,
19 and a higher likelihood of epilepsy compared to those with autism only¹⁵. As
20 the adults in this study were registered with Medicare, the sample may
21 represent a lower socioeconomic group than those with autism in the general
22 population. Given the age of the sample, and the changes in diagnostic criteria
23 for autism, this sample may not represent adults who are at the high
24 functioning end of the spectrum.
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44 With regards to sensory impairments, of the 36 matched youth with
45 intellectual disabilities with and without autism, 38.9% with autism reported
46 having visual problems compared with 50.0% without autism, and 13.9% with
47 autism reported having hearing problems compared with 19.4% without
48 autism.¹² An intellectual disabilities register study reported that 95 of the 368
49 (25.8%) adults with intellectual disabilities who had visual impairment also had
50 markers for autism, compared with 422 of 2,674 (16%) of those who had
51 normal vision, and that 46 of the 60 (76.7%) of the adults with intellectual
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3 disabilities and congenital blindness also had markers for autism, compared
4 with only 36 of the 67 (53.7%) with normal vision.¹⁶
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10 We have not identified other papers on sensory impairments or any on
11 physical disabilities in people with co-occurring intellectual disabilities and
12 autism. However, previous large whole population studies which analysed data
13 from the Scotland Census 2011 have reported that of people with intellectual
14 disabilities, 12.4% reported blindness/sight loss, 13.1% reported
15 deafness/hearing loss, and 32.6% reported physical disability.³ Of people with
16 autism, 12.1% of adults⁶ and 3.5% of children reported blindness/sight loss,⁷
17 14.1% of adults⁶ and 2.9% of children reported deafness/hearing loss,⁷ and
18 24.0% of adults⁶ and 10.7% of children reported physical disability.⁷ They did
19 not, however, report the rates of these conditions for people with co-occurring
20 intellectual disabilities and autism.
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35 This high prevalence of health conditions among people with intellectual
36 disabilities and people with autism spectrum disorders is partly attributable
37 health inequalities^{17,18}, and to the fact that certain conditions, such as cerebral
38 palsy, are associated with both intellectual and physical disabilities.
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40 Additionally, the socioeconomic status of individuals within these populations
41 is typically lower than for members of the general population^{19,20}. While
42 prevalence rates of health conditions in a full country population for
43 individuals with intellectual disabilities and individuals with autism have been
44 compared to the general population in previous work using the Scotland
45 Census 2011^{3,4,7}, no such study has been conducted on the prevalence of
46 health conditions for those with both intellectual disabilities and autism.
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3 The management of care and treatment plans for individuals with multiple
4 health conditions or disabilities presents significant challenges for health care
5 practitioners. A review of 123 studies on care management for individuals with
6 multiple chronic conditions in the USA reported that these patients access
7 services more frequently and use a larger range of services than other patients,
8 making the coordination of their care more difficult and often leading to
9 suboptimal care²¹. Existing evidence also suggests that when individuals with
10 intellectual disabilities have additional long-term conditions, these conditions
11 are more poorly managed than for members of the general population with
12 the same conditions²².
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27 Given the frequent overlap of intellectual disabilities and autism, information
28 on the associated co-existing conditions is important, to assist policy makers,
29 planners, and practitioners to best adapt services for individuals with co-
30 occurring intellectual disabilities and autism. This paper aims to investigate the
31 prevalence of mental health conditions, sensory impairments, and physical
32 disability in children, adults, and older adults with co-occurring intellectual
33 disabilities and autism, compared with other people.
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44 **Methods**

48 **Approval**

49 Approval was obtained from the Scottish Government to undertake secondary
50 data analysis of Scotland's Census, 2011.
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Data Source

Scotland's Census provides information on Scotland's population every ten years, with the most recent Census on 27th March 2011.²³ The Census provides information on the number and characteristics of Scotland's population and households on the Census date.

It is a legal requirement to complete the census form and households were informed that failure to make a Census return, or supplying false information could result in a £1,000 fine. A very high response rate was achieved, with an estimated 94% of all of Scotland's population completing the Census. The Census team used a Census Coverage Survey with about 40,000 households, to estimate numbers and characteristics of the missing 6%.²⁴ The Coverage Survey and Census records were deterministically matched to check for duplicates. Individuals estimated to have been missed were then imputed using a subset of characteristics from real individuals. The edit and imputation methodology was adapted from the Office for National Statistics rigorous and systematic guidelines.²⁴

The Census was completed by the head of each household on behalf of all occupants of the household. We consider it unlikely that people with co-occurring intellectual disabilities and autism completed the form, given the reading age required to do so. Rather, we expect that the people who completed the form on their behalf were parent-carers in family households, support workers for people living in supported accommodation, and the managers/key workers at communal establishments.

Variables

The census included a question to identify people with intellectual disabilities and autism, as well as mental health conditions, sensory impairments, and physical disabilities: ‘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 ten possible responses to this question: deafness or partial hearing loss; blindness or partial sight loss; learning disability (for example, Down’s syndrome); learning difficulty (for example, dyslexia); developmental disorder (for example, Autistic Spectrum Disorder or Asperger’s Syndrome); physical disability; mental health condition; long-term illness, disease or condition; other condition. For “other condition” the option of providing more detail in an open text response was provided.

In Scotland, the term “learning disability” is used synonymously with that of “intellectual disabilities” used internationally. Importantly, the Census differentiated between intellectual disabilities and specific learning disabilities; and between intellectual disabilities and autism.

During the methodology development for Scotland’s Census, 2011, cognitive question testing was undertaken on the questions on long-term health conditions and disabilities. This was to determine whether the questions were answered accurately, and to identify any changes needed to improve data quality and/or the acceptability of the way questions were phrased. Cognitive interviewing is a widely used approach to critically evaluate and improve survey questionnaires.²⁵ This approach enables researchers to modify survey material to enhance clarity. Retrospective probing was conducted with 102 participants with a variety of sex, age, and health conditions and disabilities

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3 (including people with more than one of the conditions). They included people
4 with autism, intellectual disabilities, dyslexia, dyspraxia, speech impairment,
5 mental health conditions (both milder and more serious), and other long-term
6 conditions.²³ Using the cognitive interviewing results, the question aimed to
7 detect autism was improved and rephrased, to better capture this information.
8 The questions on intellectual disability, mental health condition, visual
9 impairment, hearing impairment, and physical disability did not require any
10 modifications²⁶.

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22 The Census team imputed answers for the 14.7% who did not tick any of the
23 boxes in question on long-term conditions, based on their free text answers for
24 this question and answers to other health questions in the Census, which
25 increased the completion rate to 97.4%. For the remaining 2.6%, the Census
26 team assumed the most plausible explanation was that the person had no
27 long-term condition but did not see the “No condition” check box at the end of
28 the question, and hence recorded them as having no conditions.
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42 **Data Analysis**

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44 We calculated the number and rate per 1,000 population of children and
45 adults with co-occurring intellectual disabilities and autism. We then calculated
46 the number and percentage of people with mental health conditions, deafness
47 or partial hearing loss, blindness or partial sight loss, and physical disability, for
48 those with co-occurring intellectual disabilities and autism, compared with
49 individuals who do not have co-occurring intellectual disabilities and autism
50 using chi-squared (χ^2) tests. For the whole population we then used logistic
51 regression to calculate the odds ratios (OR: 95% confidence interval, 95% CI) of
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3 co-occurring intellectual disabilities and autism statistically predicting the
4 binary response of having each of the four specific types of long-term health
5 conditions, adjusted for age and sex. Sex was binary, with males being the
6 reference group. Age was categorised into groups: 0-15, 16-24, 25-34, 35-44,
7 45-54, 55-64, 65-74, 75+, with 0-15 years as the reference group. We repeated
8 the regressions, including the interaction term of age x co-occurring
9 intellectual disabilities and autism, as people with the most severe disabilities
10 die earlier, which may affect the profile of additional health problems
11 differently to that seen in the general population. The same reference groups
12 were used. All analysis was conducted using SPSS software version 22.
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27 **Patient and Public Involvement**

28 The Scottish Learning Disabilities Observatory, where this research was
29 undertaken, has a specific remit for people with intellectual disabilities and
30 people with autism. Its steering group includes partners from third sector
31 organisations and experts by experience, who approved the workplan for this
32 project prior to it commencing. Results from this study will be disseminated for
33 people with intellectual disabilities and autism in an easy-read version via the
34 Scottish Learning Disabilities Observatory website, newsletters, and
35 conference.
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48 **Results**

49 **Characteristics of the Sample**

50 Scotland's Census, 2011, includes records on 5,295,403 people aged 0-75+
51 years. 5,709/5,295,403 (1.08/1,000) people had co-occurring intellectual
52 disabilities and autism; of whom 3,769 (66.0%) were male and 1,940 (44.0%)
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3 were female. Overall, 2,362/916,331 (2.58/1,000) of the total population of
4 children (0-15 years), and 3,347/4,379,072 (0.76/1,000) adults (16-75+ years)
5 had co-occurring intellectual disabilities and autism.
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11 Compared with the population who did not have co-occurring intellectual
12 disabilities and autism, the population with co-occurring intellectual disabilities
13 and autism had more males (66.0% versus 48.5%; $\chi^2=703.5$; $df=1$; $p<0.001$);
14 were younger ($\chi^2=3894.7$; $df=7$; $p<0.001$); were more likely to have been born
15 in the UK rather than elsewhere ($\chi^2=101.9$; $df=1$; $p<0.001$), revealing lesser
16 geographic mobility; and were no different with regards to Caucasian versus
17 non-Caucasian ethnicity ($\chi^2=1.1$; $df=1$; $p=0.3$) (table 1).
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33 **Long-term Health Conditions**

34 Table 2 shows the proportion of people with co-occurring intellectual
35 disabilities and autism, who had each of the four additional long-term health
36 conditions, compared to people who did not have co-occurring intellectual
37 disabilities and autism. Some people in the sample had more than one long-
38 term health condition.
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52 *Mental Health Condition*

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54 Adjusting for age and sex, given the different distributions compared with the
55 general population, having co-occurring intellectual disabilities and autism had
56 an OR=25.55 (23.93-27.28, 95% CI) in predicting mental health conditions
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3 (table 3). When the interaction term was added (age x co-occurring intellectual
4 disabilities and autism), co-occurring intellectual disabilities and autism had an
5 OR=130.80 (117.13-146.07, 95% CI) in predicting a mental health condition
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9 (table 3).
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16 17 18 *Blindness or partial sight loss*

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20 Adjusting for age and sex, having co-occurring intellectual disabilities and
21 autism had an OR=36.78 (34.21-39.54, 95% CI) in predicting blindness or partial
22 sight loss (table 4). When the interaction term was added (age x co-occurring
23 intellectual disabilities and autism), co-occurring intellectual disabilities and
24 autism had an OR=65.90 (58.74-73.92, 95% CI) in predicting blindness or partial
25 sight loss (table 4).
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38 39 *Deafness or partial hearing loss*

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41 Adjusting for age and sex, having co-occurring intellectual disabilities and
42 autism had an OR=11.33 (10.43-12.31, 95% CI) in predicting deafness or partial
43 hearing loss (table 5). When the interaction term was added (age x co-
44 occurring intellectual disabilities and autism), co-occurring intellectual
45 disabilities and autism had an OR=22.00 (19.20-25.21, 95% CI) in predicting
46 deafness or partial hearing loss (table 5).
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Physical disability

Adjusting for age and sex, having co-occurring intellectual disabilities and autism had an OR=61.16 (57.60-64.94, 95% CI) in predicting physical disability (table 6). When the interaction term was added (age x co-occurring intellectual disabilities and autism), co-occurring intellectual disabilities and autism had an OR=157.54 (144.58-171.66, 95% CI) in predicting physical disability (table 6).

- Insert table 6 about here -

Discussion

Principle findings

Mental health conditions, blindness or partial sight loss, deafness or partial hearing loss, and physical disability were all significantly more common in people with co-occurring intellectual disabilities and autism than people without these co-occurring conditions. The odds ratios after adjusting for age and sex and the interaction term, were substantial, being 131, 66, 22, and 158 respectively. This is important as each of these conditions are disabling and can significantly impact an individual's quality of life. They contribute to high rates of multi-morbidity, which, on top of communication and cognitive problems due to autism and intellectual disabilities, renders assessments, diagnosis, and treatment of additional health problems more complex than for other people.

Across all age groups, blindness, deafness, and physical disability were more common in females than males with co-occurring intellectual disabilities and autism, unlike the gender ratios in people without co-occurring intellectual disabilities and autism. Mental health conditions were more common in males

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3 than females with co-occurring intellectual disabilities and autism, except for
4 the 65+ year group, contrary to the gender ratios in other people. All
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6 conditions were more prevalent with increasing age in the people with co-
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8 occurring intellectual disabilities and autism, except for physical disability
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10 which was more common in the children/youth and older people than in the
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14 adults.
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18 **Comparison with existing literature**

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20 The prevalence of these additional long-term health conditions has seldom
21
22 been investigated in people with co-occurring intellectual disabilities and
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24 autism, particularly in comparison with other people, and never, to our
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26 knowledge, as a total population study. All of the long-term health conditions
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28 were more common than in those without co-occurring intellectual disabilities
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30 and autism.
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36 Smaller, less representative studies have reported a higher rate of mental
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38 health conditions in adults and youth with co-occurring intellectual disabilities
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40 and autism compared with those with intellectual disabilities and without
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42 autism,⁹⁻¹³ but not all.¹⁴ People with autism have been reported to have more
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44 mental health conditions than other people (OR=9 in adults and OR=16 in
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46 children),^{6,7} as have people with intellectual disabilities compared with other
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48 people (OR=7),³ using the same Scotland's Census, 2011 data as in this current
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50 paper, whereas the comparable ratio we now report for people with co-
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52 occurring intellectual disabilities and autism for mental health conditions was
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54 OR=26. Having the co-occurring conditions therefore presents a much higher
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56 risk of mental health conditions than either intellectual disabilities or autism
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58 on their own.
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6 The previous small study of youth reported lower rates of visual and hearing
7 impairments in those with co-occurring intellectual disabilities and autism
8 (38.9% and 13.9%) compared with those with intellectual disabilities but
9 without autism (50% and 19.4%).¹² This was in contrast with the larger study
10 reporting more autistic symptoms in adults with intellectual disabilities and
11 visual impairments than in adults with intellectual disabilities but without
12 visual impairments.¹⁶ Adults with autism have been reported to have more
13 blindness or partial sight loss, and deafness or partial hearing loss than other
14 people (12.1% and 17.5%),⁶ as have children with autism (3.5% and 2.9%),⁷ and
15 people (children and adults combined) with intellectual disabilities compared
16 with other people (13.1% and 12.4%),³ using the same data from Scotland's
17 Census 2011 as in this current paper. This current study found the comparable
18 rates for people with co-occurring intellectual disabilities and autism for
19 blindness or partial sight loss, and deafness or partial hearing loss was 21.7%
20 and 19.3% for adults, and 16.6% and 10.3% for children. Having the co-
21 occurring conditions of intellectual disabilities and autism therefore presents a
22 much higher risk of sensory impairments than for children and adults with
23 autism, and for people with intellectual disabilities (although children were not
24 separately studied in the previous report).

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48 Regarding physical disability, 32.6% of people with intellectual disabilities were
49 previously reported to have physical disability using the same dataset as the
50 current study.³ Of people with autism, 24.0% of adults and 10.7% of children
51 reported physical disability in this dataset.^{6,7} These rates are lower than those
52 we report in this current study of people with co-occurring intellectual
53 disabilities and autism – 45.6% of children and 42.2% of adults.

Strengths and limitations

Strengths of the study include its large scale and general population comparison group, whole population coverage and very high response rate so the results are representative of the whole population. Intellectual disabilities, autism, and the long-term health conditions were enquired about systematically for everyone in the population. We believe the results are therefore generalisable to other high-income countries. The cognitive question testing during the design of the Census is a further strength. The Census had clear categories to distinguish between intellectual disabilities, specific learning disability (like dyslexia), and autism.

Limitations include the proxy-reporting, which may, or may not reflect self-reports. However, without proxy-reports, we would have no information on people unable to self-report due to their disabilities, and a previous review on the topic concluded that overall, proxy reports are a useful addition to determine aspects of well-being in people with intellectual disabilities.²⁷

Additionally, people were reported who were known to have autism/Asperger's syndrome, intellectual disabilities, and the additional long-term health conditions, rather than detailed individual research assessments being undertaken which are clearly not possible in such large population studies, and may therefore be subject to a degree of error which we were not able to check. Individuals who were known to have intellectual disabilities and autism are higher health care users and so are more likely to receive a diagnosis for other health care conditions than members of the general population who do not access health care services as frequently. It is also important to note that the Scotland Census 2011 was administered 8 years

ago, and so any potential changes in prevalence rates of the conditions investigated in this paper are not captured by this analysis.

Implications

There is a greater than double disadvantage for people with co-occurring intellectual disabilities and autism, in terms of additional long-term health conditions. We found that, and quantified the extent to which mental health conditions, sensory impairments, and physical disabilities are more common than in people without co-occurring intellectual disabilities and autism, and in people with just intellectual disabilities or just autism. This may well impact on quality of life. It raises challenges for staff working with people with these co-occurring conditions in view of the additional complexity in assessments, diagnoses, and interventions, as sensory impairments and mental health conditions in particular, interact with the persons pre-existing communication and cognitive problems in this context. Therefore, it is important that these co-occurring conditions are planned for with staff being trained, equipped, resourced and prepared to address the challenge.

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41 The researchers are independent from the funders.
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45 46 **Competing interests**

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49 The authors declare no competing interests.
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53 54 **Author's contributions**

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3 KD analysed and interpreted the data, and wrote the first draft of the
4 manuscript. ER contributed to data access, data interpretation, and drafting
5 the manuscript. MF provided advice on response to reviewer comments
6 regarding choice of statistical methods and contributed to the writing of the
7 manuscript. S-AC conceived and managed the project, interpreted data, and
8 contributed to writing the manuscript. All approved the final version of the
9 manuscript. S-AC is the study guarantor.
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20 **Data sharing**

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25 Data is available via National Records of Scotland, following project approval.

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27 Data are available at the following link

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29 [https://www.scotlandscensus.gov.uk/ods-web/data-](https://www.scotlandscensus.gov.uk/ods-web/data-warehouse.html#additionaltab)
30 [warehouse.html#additionaltab](https://www.scotlandscensus.gov.uk/ods-web/data-warehouse.html#additionaltab)
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Table 1: Characteristics of people with and without, co-occurring intellectual disabilities and autism

	People without co-occurring intellectual disabilities and autism N=5,289,694 (100%) Number (%)	People with co-occurring intellectual disabilities and autism N=5,709 (100%) Number (%)
Gender*		
Males	2,563,675 (48.5%)	3,769 (66.0%)
Females	2,726,019 (51.5%)	1,940 (44.0%)
Age groups*		
0-15	913,969 (17.3%)	2,362 (41.4%)
16-24	631,094 (11.9%)	1,394 (24.4%)
25-34	666,725 (12.6%)	602 (10.5%)
35-44	734,304 (13.9%)	450 (7.9%)
45-54	786,355 (14.9%)	401 (7.0%)
55-64	667,157 (12.6%)	256 (4.5%)
65+	890,090 (16.8%)	244 (4.3%)
Country of birth*		
UK	4,920,614 (93.0%)	5,505 (96.4%)
Other Europe	172,160 (3.3%)	83 (1.5%)
Africa	46,708 (0.9%)	34 (0.6%)
Middle East and Asia	104,480 (2.0%)	50 (0.9%)
The Americas and the Caribbean	33,325 (0.6%)	28 (0.5%)
Other	12,407 (0.2%)	9 (0.2%)
Ethnicity		
White	5,078,910 (96.0%)	5,497 (96.3%)
Asian	140,542 (2.7%)	136 (2.4%)
Mixed/multiple ethnicities	19,775 (0.4%)	40 (0.7%)

African	29,615 (0.6%)	23 (0.4%)
Caribbean or black	6,536 (0.1%)	4 (0.1%)
Other ethnic groups	14,316 (0.3%)	9 (0.2%)

*People with co-occurring intellectual disabilities and autism versus people without co-occurring intellectual disabilities and autism; $p < 0.01$

For peer review only

Table 2: Prevalence of conditions in people with and without co-occurring intellectual disabilities and autism by age and sex

People with co-occurring intellectual disabilities and autism									
Condition	Children/youth, 0-15 years N=2,362			Adults, 16-64 years N=3,103			Older people, 65+ years N=244		
	M N=1,563 (100%)	F N=799 (100%)	Total N=2,362 (100%)	M N= 2,073 (100%)	F N= 1,030 (100%)	Total N= 3,103 (100%)	M N= 133 (100%)	F N= 111 (100%)	Total N= 244 (100%)
Mental health condition	328 (21.0%)	152 (19.0%)	480 (20.3%)	768 (37.0%)	377 (36.6%)	1145 (36.9%)	80 (60.2%)	80 (72.1%)	160 (65.6%)
Blindness/partial sight loss	214 (13.7%)	177 (22.2%)	391 (16.6%)	355 (17.1%)	220 (21.4%)	575 (18.5%)	71 (53.3%)	80 (72.1%)	151 (61.9%)
Deafness/partial hearing loss	148 (9.5%)	95 (11.9%)	243 (10.3%)	301 (14.5%)	190 (18.4%)	491 (15.8%)	73 (54.9%)	81 (73.0%)	154 (63.1%)
Physical disability	618 (39.5%)	458 (57.3%)	1,076 (45.6%)	719 (34.7%)	508 (49.3%)	1,227 (39.5%)	86 (64.7%)	99 (89.2%)	185 (75.8%)
People without co-occurring intellectual disabilities and autism									
Condition	Children/youth, 0-15 years N=913,969			Adults, 16-64 years N=3,485,635			Older people, 65+ years N=890,090		
	M N=467,543 (100%)	F N=446,426 (100%)	Total N= 913,969 (100%)	M N= 1,712,526 (100%)	F N= 1,773,109 (100%)	Total N= 3,485,635 (100%)	M N= 383,606 (100%)	F N= 506,484 (100%)	Total N= 890,090 (100%)
Mental health condition	1,861 (0.4%)	980 (0.2%)	2,841 (0.3%)	92,308 (5.4%)	95,108 (5.4%)	187,416 (5.4%)	14,760 (3.8%)	26,141 (5.2%)	40,901 (4.6%)
Blindness/partial sight loss	1,793 (0.4%)	1,439 (0.3%)	3,232 (0.4%)	24,129 (1.4%)	16,954 (1.0%)	41,083 (1.2%)	30,389 (7.9%)	49,839 (9.8%)	80,228 (9.0%)
Deafness/partial hearing loss	2,731 (0.6%)	2,225 (0.5%)	4,956 (0.5%)	70,543 (4.1%)	48,727 (2.7%)	119,270 (3.4%)	111,447 (29.1%)	114,393 (22.6%)	225,840 (25.4%)
Physical disability	3,637 (0.8%)	2,799 (0.6%)	6,436 (0.7%)	81,655 (4.8%)	82,968 (4.7%)	164,623 (4.7%)	73,759 (19.2%)	109,103 (21.5%)	182,862 (20.5%)

Table 3: Independent predictors of mental health conditions in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	25.55	23.93-27.28	130.80	117.13-146.07
Gender	Male (reference)	-	-	-	-
	Female	1.28	1.26-1.29	1.28	1.26-1.29
Sex	0-15 (reference)	-	-	-	-
	16-24	9.45	9.04-9.88	11.32	10.78-11.89
	25-34	21.17	20.29-22.09	25.31	24.13-26.53
	35-44	29.73	28.50-31.00	35.49	33.87-37.20
	45-54	29.19	27.98-30.44	34.84	33.24-36.51
	55-64	22.63	21.63-23.62	27.00	25.75-28.30
	65+	19.320	18.52-20.16	23.00	21.95-24.12
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.15	0.13-0.18
	25-34	-	-	0.10	0.08-0.12
	35-44	-	-	0.08	0.07-0.10
	45-54	-	-	0.09	0.07-0.11
	55-64	-	-	0.12	0.09-0.15
	65+	-	-	0.31	0.24-0.42
Constant	-	0.00	-	0.00	-

Table 4: Independent predictors of blindness/partial sight loss in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	36.78	34.21-39.54	65.90	58.74-73.92
Sex	Male (reference)	-	-	-	-
	Female	1.01	1.00-1.02	1.01	1.00-1.02
Age	0-15 (reference)	-	-	-	-
	16-24	1.56	1.48-1.64	1.66	1.58-1.75
	25-34	1.82	1.74-1.91	1.91	1.82-2.01
	35-44	2.55	2.44-2.66	2.69	2.57-2.81
	45-54	4.42	4.24-4.60	4.67	4.48-4.87
	55-64	7.50	7.22-7.80	7.93	7.61-8.26
	65+	31.06	29.95-32.22	32.75	31.51-34.04
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.43	0.35-0.53
	25-34	-	-	0.67	0.52-0.84
	35-44	-	-	0.53	0.41-0.68
	45-54	-	-	0.37	0.29-0.47
	55-64	-	-	0.28	0.21-0.37
	65+	-	-	0.25	0.19-0.33
Constant	-	0.00	-	0.00	-

Table 5: Independent predictors of deafness/partial hearing loss in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	11.33	10.43-12.31	22.00	19.20-25.21
Gender	Male (reference)	-	-	-	-
	Female	0.69	0.68-0.69	0.69	0.68-0.69
Sex	0-15 (reference)	-	-	-	-
	16-24	1.56	1.50-1.62	1.59	1.52-1.65
	25-34	2.36	2.27-2.45	2.41	2.32-2.50
	35-44	4.24	4.10-4.38	4.35	4.20-4.50
	45-54	8.55	8.29-8.82	8.77	8.50-9.05
	55-64	18.76	18.20-19.34	19.24	18.66-19.85
	65+	69.65	67.63-71.72	71.38	69.27-73.55
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.63	0.51-0.79
	25-34	-	-	0.74	0.57-0.95
	35-44	-	-	0.39	0.30-0.52
	45-54	-	-	0.29	0.22-0.38
	55-64	-	-	0.22	0.16-0.29
	65+	-	-	0.22	0.17-0.30
Constant	-	0.01	-	0.01	-

Table 6: Independent predictors of physical disability in the whole population

Characteristic		Regression 1		Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)	
		Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	61.16	57.60-64.94	157.54	144.58-171.66
Gender	Male (reference)	-	-	-	-
	Female	1.06	1.06-1.07	1.06	1.06-1.07
Sex	0-15 (reference)	-	-	-	-
	16-24	1.44	1.39-1.50	1.57	1.51-1.64
	25-34	2.60	2.52-2.69	2.86	2.76-2.96
	35-44	5.87	5.70-6.04	6.47	6.27-6.67
	45-54	10.61	10.31-10.91	11.66	11.32-12.02
	55-64	20.73	20.17-21.31	22.76	22.10-23.44
	65+	43.68	42.52-44.88	47.89	46.53-49.30
Age x both intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.41	0.36-0.47
	25-34	-	-	0.34	0.29-0.41
	35-44	-	-	0.12	0.10-0.15
	45-54	-	-	0.08	0.06-0.09
	55-64	-	-	0.04	0.03-0.06
	65+	-	-	0.05	0.040-0.07
Constant	-	0.01	-	0.01	-

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract Page 1 (title)
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found Page 2
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported Pages 4-7
Objectives	3	State specific objectives, including any pre-specified hypotheses Page 7, line 9
Methods		
Study design	4	Present key elements of study design early in the paper Page 8-11
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection Page 7-8
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants Page 7-8
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable Page 8-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group Page 7-10
Bias	9	Describe any efforts to address potential sources of bias Page 9-10
Study size	10	Explain how the study size was arrived at Page 7-8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why Page 10-11
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding Page 10-11
		(b) Describe any methods used to examine subgroups and interactions Page 10-11
		(c) Explain how missing data were addressed Page 10
		(d) If applicable, describe analytical methods taking account of sampling strategy N/A
		(e) Describe any sensitivity analyses N/A

Results

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Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed Page 11-12 <hr/> (b) Give reasons for non-participation at each stage N/A <hr/> (c) Consider use of a flow diagram N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders Page 11-12, Table 1 <hr/> (b) Indicate number of participants with missing data for each variable of interest Page 10
Outcome data	15*	Report numbers of outcome events or summary measures Page 13-15
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included Page 12-14, Tables 3-6 <hr/> (b) Report category boundaries when continuous variables were categorized N/A <hr/> (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses Page 12-14
Discussion		
Key results	18	Summarise key results with reference to study objectives Page 15-17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias Page 18-20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence Page 15-20
Generalisability	21	Discuss the generalisability (external validity) of the study results Page 18
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based Page 25

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely

1
2 available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at
3 <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is
4 available at www.strobe-statement.org.
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