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COVID-19 infection and outcomes in a population-based cohort of 17,203 adults with intellectual disabilities compared with the general population

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Keywords: COVID-19; intellectual disabilities; infection, mortality; case-fatality; excess deaths

Abstract

Background: Adults with intellectual disabilities (ID) may be at higher risk of COVID-19 death.. We compared COVID-19 infection, severe infection, mortality, case-fatality, and excess deaths, among adults with, and without, intellectual disabilities.

Methods: Adults with intellectual disabilities in Scotland's Census, 2011, and a 5% sample of other adults, were linked to COVID-19 test results, hospitalisation data and deaths (24/01/20-15/08/20). We report crude rates of COVID-19 infection, severe infection (hospitalisation/death), mortality, case fatality; age-, sex- and deprivation-standardised severe infection and mortality ratios; and annual all-cause mortality for 2020 and 2015-2019.

Findings: Successful linkage of 94.9% provided data on 17,203 adults with, and 188,634 without, intellectual disabilities. Adults with intellectual disabilities had more infection (905/100,000 versus 521/100,000); severe infection (538/100,000 versus 242/100,000); mortality (258/100,000 versus 116/100,000); and case-fatality (30% versus 24%). Poorer outcomes remained after standardisation: standardised severe infection ratio 2.61 (95% CI 1.81, 3.40) and mortality ratio 3.26 (95% CI 2.19, 4.32). These were higher at ages 55-64: 7.39 (95% CI 3.88, 10.91) and 19.05 (95% CI 9.07, 29.02) respectively, and in men, and less deprived neighbourhoods. All-cause mortality was slightly higher in 2020 than 2015-2019 for people with intellectual disabilities: SMR 2.50 (95% CI 2.18, 2.82) and 2.39 (95% CI 2.28, 2.51) respectively.

Conclusion: Adults with intellectual disabilities had more COVID-19 infections, and worse outcomes once infected, particularly adults under 65 years. Non-pharmaceutical interventions directed at formal and informal carers are essential to reduce transmission. All adults with intellectual disabilities should be prioritised for vaccination and boosters regardless of age.

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What is already known

To date, five studies have reported mortality rates for people with intellectual disabilities compared with the general population. One English study analysed data from three different sources, with acknowledged limitations. Crude COVID-19 mortality was reported at between 2·3 and 3·1 times the general population rate. Another English study reported that people with intellectual disabilities were more than 8 times more likely to die from COVID-19 than those in the general population. A study of Welsh general practice data reported higher age-standardised mortality. One Canadian study reported that adults with intellectual and developmental disabilities were 2.23 times more likely to die and that the risk increased significantly in younger age groups. A further US study also reported higher rates of mortality in the population with intellectual disabilities when compared to the general population (8.2% vs. 3.8%) following a positive diagnosis of COVID-19.

Studies that report case-fatality rates in the intellectual disabilities population have been based on biased samples and have resulted in conflicting findings, with some studies reporting no difference between rates or as much as 2.75 times higher rates in adults with intellectual disabilities compared with other adults.

In summary studies investigating the impact of COVID-19 on adults with intellectual disabilities may indicate a higher risk of COVID-19 mortality and case fatality than other adults, but the evidence is limited and inconclusive. No studies have reported comparative infection rates.

What this paper adds

This record linkage study analysed COVID-19 mortality, case-fatality, severe infection and infection rates for all adults with intellectual disabilities compared with a 5% sample of people with no intellectual disabilities. Adults with intellectual disabilities were almost twice as likely to become infected with COVID-19, 2·2 times as likely to have severe infection, 2·2 times as likely to have COVID-19 mortality and had 26% higher COVID-19 case-fatality compared with those with no intellectual disabilities. After standardising for age, sex and deprivation, people with intellectual disabilities were 3·2 times more at risk of COVID-19 mortality and 2·6 times more at risk of severe infection relative to those with no intellectual disabilities. We also report that adults with intellectual disabilities had poorer outcomes among non-elderly age-groups particularly those aged 55-65 years, men, and those living in less-deprived neighbourhoods compared with people with no intellectual disabilities. Our data indicates that people with intellectual disabilities under the age of 65 are at significantly greater risk of COVID-19 mortality than those in the general population. The increased risk of COVID-19 infection and mortality suggests that non-pharmaceutical initiatives should be treated as vital interventions to enable carers and care-provider organisations to ameliorate the risk of infection. All adults with intellectual disabilities should be prioritised in the national rollouts of COVID-19 vaccination programmes, regardless of age, sex, or neighbourhood deprivation.

Introduction

The first case of COVID-19 was confirmed in the UK on 24th January 2020 and a pandemic declared by the World Health Organisation (WHO) on 12th March 2020. There is global concern that adults with intellectual disabilities may be at higher risk of death from COVID-19, but there are gaps in the evidence. (1) The WHO defines intellectual disabilities as impairments in adaptive, social, and intellectual functioning (IQ<70), requiring daily support, with the onset in the developmental phase (<18 years).(2) People with intellectual disabilities account for <1% of the global population,(3, 4) and about 0.5% of adults. (4) They experience substantial health inequalities, including multimorbidity,(5) and premature mortality,(6, 7) often from respiratory conditions.(8, 9) They are more likely to live in congregate settings or be in receipt of social care (10); recent studies have reported high rates of COVID-19 mortality within multi-occupancy residences.(11) However, questions remain as to whether people with intellectual disabilities are more likely to contract COVID-19, and whether they have more severe infections, and higher COVID-19 mortality compared to others.

Existing evidence is inconclusive and has limitations. Five studies have reported COVID-19 mortality compared with the general population. One population based cohort study linked data for over 17 million people on GP registers in England across two waves (01/03/20-31/08/20 and 01/09/20-08/02/21) investigating COVID-19 hospital admissions and deaths in children and adults.(12) Adults with intellectual disabilities were over 5 times more likely to have a COVID-19 hospital admission (HR 5.3, 95% CI 4.9-5.8) and over eight times more likely to die from COVID-19 (HR 8.2, 95% CI 7.2-9.4). Results were similar in wave 2 ((4.3, 95% CI 4.1-4.6 COVID-19 hospital admission; 7.2, 95% CI 6.4-8.1 COVID-19 deaths). They acknowledged their methods to identify people with intellectual disabilities may have led to possible over-estimates of HRs. A Canadian retrospective cohort study used electronic health records for the province of Ontario to investigate COVID-19 infection rates, hospital admissions and deaths between 15/01/20 and 10/01/21 for adults with intellectual and developmental disabilities, and with Down syndrome compared to the adult general population. (13) Infection rates for people with intellectual and developmental disabilities were 1.28 times higher, and 1.42 times higher for those with Down syndrome compared to the general population. For adults with intellectual and developmental disabilities the risks of hospitalisation (RR:2.21 (95%CI: 1.93,2.5)) and death (RR:2.23 (95%CI: 1.86,2.67)) were also higher compared to the general population. This study drew on administrative health data to ascertain the population with intellectual and developmental disabilities and therefore excludes those who have not been correctly classified or had contact with hospitals. A large US study of data from 547 health care organisations investigated the risk of COVID-19 infection rates, hospitalisation and deaths in people with intellectual disabilities compared to the general population, between January 2019 and November 2020. (14) People with intellectual disabilities were significantly more likely to become infected with COVID-19 (3.1% vs 0.9%, p<.001) and to be admitted to hospital (63.1% vs. 29.1%, p<.001). However, the authors recognised ascertainment of intellectual disabilities in these data was much lower than expected. One non-peer reviewed study, used three data sources in England to identify adults with intellectual disabilities who definitely or possibly died from COVID-19 from 1st February 2020 to 5th June 2020.(15) Underestimates and uncertainty around figures were acknowledged in the report, due to limitations in data sources. Analysis of two of these data sources resulted in crude COVID-19 mortality rates of 240/100,000 (2.3 times the general population) and 192/100,000 (3.1 times the general population). Welsh general practice records, 1st March 2020 - 26th May 2020, recorded 31 deaths from COVID-19 among people with intellectual disabilities, equating to a higher agestandardised COVID-19 mortality than in the general population.(17)

Five studies reported COVID-19 case-fatality rates, though with biased samples, and conflicting results. Electronic medical records from 42 health care organisations, from 30 countries, up to 14th May 2020, ascertained >30,000 patients with COVID-19 infections.(18) No difference was found in overall case-fatality rates between the 150 people with intellectual disabilities and those without, but possibly higher case-fatality rates among younger ages where deaths were generally less common.(18) A large US study using private insurance claims, between 1st April 2020 and 31st August 2020, reported higher COVID-19 case-fatality among people with intellectual disabilities compared to those without (OR 2.75, 95% CI 1.66-4.56), especially at <70 years of age (OR 3.61, 95% CI 1.89-6.93).(19) These results may not be generalisable as they did not include people with public insurance or no insurance. A large self-selected sample of English general practices covering >4 million patients reported higher COVID-19 case-fatality among people with intellectual disabilities over weeks 2-20 of 2020 (OR 1.97, 95% CI 1.22-3.18).(11) Another large study of people with intellectual and developmental disabilities living in New York state's residential settings were indirectly compared with the general population, reporting COVID-19 infection rate to be about 4 times higher, case-fatality almost double, and mortality rate 7.8 times higher.(20) Gleason et. al. (14) reported that people with intellectual disabilities were more likely to die than those in the general population following COVID-19 infection (8.2% vs. 3.8%, p<.001).

A prediction algorithm of risk of death following confirmed/suspected COVID-19 infection, was derived (24th January 2020 - 30th April 2020) and validated (1st May 2020 - 30th June 2020) using a large English primary care database of >8 million patients.(21) It reported higher fatality among adults with intellectual disabilities without Down syndrome (men: HR 1.36 (1.14-1.60), women: HR 1.36 (1.11-1.65)); and a further increase risk in the small sample of adults with Down syndrome (men: HR 9.80 (4.62-20.78), women: HR 32.55 (18.13-58.42)).(18) This led to the inclusion of Down syndrome, but not intellectual disabilities, onto the clinically extremely vulnerable list used in the UK. (22)

Adults with intellectual disabilities may be at greater risk of contracting COVID-19 and at greater risk of casefatality, though evidence for both is currently limited. This study investigated in a whole-country adult population with intellectual disabilities, COVID-19 infection, severe infection, mortality, case-fatality, and excess deaths, compared with adults without intellectual disabilities, during the first wave of the COVID-19 pandemic (24th January 2020-15th August 2020).

Methods

Population, data sources, and record linkage

We used Scotland's Census 2011 to ascertain all adults recorded with intellectual disabilities (4) and a random 5% sample of the general population (those not recorded as having intellectual disabilities or autism) linked to COVID-19 laboratory tests, hospital admissions, and death registrations. Scotland's Census, 2011 provides detailed information on Scotland's population, recorded 27th March 2011. The Scottish Morbidity Record (SMR) 01 held by Public Health Scotland (PHS), records acute hospital admissions including ICD-10 diagnostic codes. Laboratory results from COVID-19 tests are stored electronically within PHS's ECOSS database. Personal identifiers from Census 2011 have previously been linked to the NRS Indexing Spine to create a read-through index for this dataset (23) allowing Census 2011 data to be linked to health data for research.

We presented demographic characteristics for adults with and without intellectual disabilities; sex, age, and neighbourhood deprivation recorded at the time of the Census in 2011. To reduce the risk of disclosing personally identifiable information, age was categorised as adults 18- 54 years, 55-64 years, and \geq 65 years, and SIMD was categorised into two groups: more deprived (deciles 1-5) and less deprived (deciles 6-10). People <18 years in 2011 were excluded from analyses. Analysis was undertaken for the period 24th of January (first UK confirmed COVID-19 case) – 15th of August for each year of the study. When analysing all outcomes, age was calculated at time of event for those who had an event of interest, or age at 24th January in the respective year of interest for people within the denominator population who did not have any events of interest.

Outcomes

Outcomes included: COVID-19 infection (positive COVID-19 test, hospitalisation for COVID-19, or death due to COVID-19); severe COVID-19 infection (hospitalisation for COVID-19 or death due to COVID-19); COVID-19 mortality; COVID-19 case-fatality (death from any cause among those who had COVID-19 infection); and excess deaths (difference between average annual all-cause mortality rates 24/01-15/08 2015-2019 and all-cause death rate in 24/01/20 - 15/08/20).

Hospitalisation or death due to COVID-19 was defined by ICD-10 code of U07 \cdot 1 (confirmed COVID 19) or U07 \cdot 2 (suspected COVID 19) in any primary or secondary diagnostic or cause of death position, no timescale was applied.

Analyses

NRS death data up to 15th August 2020 was available and results from 24th January 2020-15th August 2020 were investigated. Crude rates (per 100,000 people) were compared for those with and without intellectual disabilities using the number of people still alive within each group on 24th January 2020 as the respective denominators. Crude outcomes included rates of COVID-19 infection, severe COVID-19 infection, COVID-19 mortality, and COVID-19 case-fatality. To take into account demographic differences between the groups with and without intellectual disabilities we performed indirect standardisation using sex, age, and deprivation. We produced COVID-19 specific Standardised Mortality Ratios (SMRs) and COVID-19 specific Standardised hospitalisation/mortality Ratios for 2020. We then produced all-cause SMRs for deaths in 2020 and separately

for deaths occurring over the previous 5 years. For each standardisation we used the 5% sample of the census population without intellectual disabilities or autism as the standard population and compared the relevant agesex-deprivation specific rates to the population with intellectual disabilities to ascertain expected and observed counts. Analyses were repeated within sex, age, and deprivation subgroups standardising each time for the other two variables.

When calculating standardised ratios for deaths and admissions occurring in 2020 we used the respective denominator populations including everyone in the original linked census cohort minus those who died before Jan 24th 2020. When calculating standardised ratios for deaths between 2015 and 2019 we counted deaths between 24th January and 15th August in each of the respective years to enable an accurate comparison with 2020. Subjects who died before the 24th January in each of the respective years from 2015 to 2019 were removed from the respective denominator populations. For all outcomes, age was calculated at time of event (not age in 2011) for those who had an event of interest (positive COVID-19 test, hospital admission, death) or age at 24th January in the respective year of interest for those people within the denominator population who did not have any events of interest.

Research Ethics Approval

This study was approved by Scotland's Public Benefit and Privacy Panel for Health (reference: 1819-0051), Scotland's Statistics Public Benefit and Privacy Panel (1819-0051), and the University of Glasgow's College of Medical, Veterinary, and Life Sciences Ethical Committee (reference: 200180081).

Results

Patient characteristics

Of the 269,771 people (24,264 with, and 245,507 without, intellectual disabilities) included in our Census 2011 cohort, 255,916 (94.9%) were linked to the NRS Population Spine. The linkage rate was 92.9% (n=22,538) among people with intellectual disabilities and 95.1% (n=233,378) of the original 5% comparison sample with no intellectual disabilities or autism. People <18 years old were excluded from the study (Figure 1) leaving a final cohort of 213,062 adults (17,203 with intellectual disabilities, and 188,634 without, intellectual disabilities or autism).

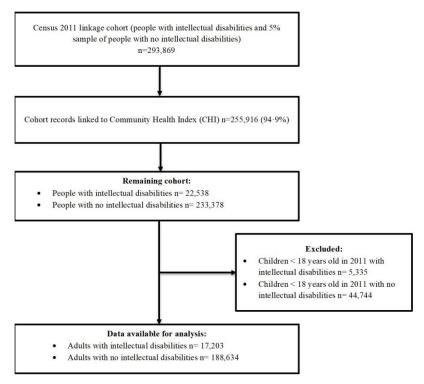


Figure 1: Participant flow diagram

As expected, there were more men than women in the intellectual disabilities population, who were younger, and more likely to live in deprived areas (Table 1).

	Adults with intellectual disabilities N=17,203		5% sample of adults with no intellectual disabilities or autism N=188,634		
	n	%	n	%	
Sex					
Male	9,565	55.6	88,863	47.1	
Female	7,638	44.4	99,771	52.9	
SIMD decile					
1-5 (More deprived)	11,099	64.5	90,406	47.9	
6-10 (Less deprived)	6,104	35.5	98,228	52.1	
Age (years) at 2011 census					
Adults ≤ 54	12,637	73.5	116,534	61.8	
55-64	2,494	14.5	31,022	16.4	
≥65	2,072	12.0	41,078	21.8	

Table 1: Characteristics of the study population in 2011

Crude COVID-19 infection rates and outcomes

Adults with intellectual disabilities were almost twice as likely as those without to become infected with COVID-19 (905/100,000 versus 521/100,000) and 2.2 times as likely to have severe infection resulting in hospitalisation or death (538/100,000 versus 242/100,000) or a fatal infection (258/100,000 versus 116/100,000) (Table 2). Following COVID-19 infection, people with intellectual disabilities were more likely to die 28.5% (95% CI 23.3%-32.3%) versus 22.3% (95% CI 20.5%-23.9%).

	Adults with intellectual disabilities			5% sample of adults without intellectual disabilities or autism		
	Ν	Crude rate per 100,000	95% CI ^a	Ν	Crude rate per 100,000	95% CI ^a
COVID-19						
Infection ^b	126	905	747, 1,061	871	521	487, 556
Severe infection ^c	75	538	417, 660	404	242	218, 265
Mortality ^d	36	258	174, 343	194	116	100, 133

^a 95% CIs calculated based on normal approximation

^b positive COVID-19 test, hospitalisation for covid-19 or death from COVID-19

^c hospitalisation for COVID-19 or death from COVID-19

^d death from COVID-19 in the population

Age-, sex-, deprivation-standardised COVID-19 outcomes

In 2020, the age-, sex-, deprivation-standardised ratio for severe COVID-19 infection among adults with intellectual disabilities compared to those without was $2 \cdot 61$ (95% CI $1 \cdot 81$, $3 \cdot 40$) and for COVID-19 mortality was $3 \cdot 26$ (95% CI $2 \cdot 19$, $4 \cdot 32$) (Table 3). The standardised ratios were slightly higher in men than women, and in less deprived areas. They were higher in people under 65 years of age and particularly high in the 55-64 year age group where the risk of severe infection, resulting in hospitalisation or death, was more than 7 times higher and the risk of death was over 19 times higher (Table 3).

Table 3. Age-, sex-, deprivation-standardised COVID-19 outcomes, overall and by sub-group

		Standardised hospitalisation/mortality ratio (95% CI)ª	Standardised mortality ratio (95% CI) ^a
Overall		2.61 (1.81, 3.40)	3.26 (2.19, 4.32)
Sex	Male	2.93 (1.85, 4.02)	3.70 (2.22, 5.18)
	Female	2.10 (0.96, 3.25)*	2.63 (1.14, 4.12)*

Deprivation	SIMD 1-5 (more deprived)	2.27 (1.43, 3.11)	3.09 (1.92, 4.25)	
	SIMD 6-10 (less deprived)	3.81 (1.74, 5.88)*	3.90 (1.35, 6.45)**	
Age (years) ^b	Adults ≤ 54	2.83 (1.08, 4.59)*	7.47 (2.29, 12.65)***	
	55-64	7.39 (3.88, 10.91)*	19.05 (9.07, 29.02)****	
	≥65	1.41 (0.67, 2.15)*	1.51 (0.72, 2.31) *	

^a 95% CIs calculated based on normal approximation

^bAge at time of event

* ratios are based on less than 20 observed events in the intellectual disabilities group

** ratios are based on less than 10 observed events in the intellectual disabilities group

***ratios are based on less than 10 observed events in the intellectual disabilities group and less than 10 observed event in the 5% sample of the general population

****ratios are based on less than 20 observed events in the intellectual disabilities group and less than 10 observed event in the 5% sample of the general population

Excess overall mortality

Overall, the age-, sex-, deprivation- standardised all-cause mortality ratio for adults with intellectual disabilities was $2 \cdot 39$ (95% CI $2 \cdot 28$, $2 \cdot 51$) over the five years prior to COVID-19, and only slightly higher at $2 \cdot 50$ (95% CI $2 \cdot 17$, $2 \cdot 81$) in 2020 (Table 4). In the sub-group analyses, the largest increase occurred in the 55-64 year agegroup where the standardised all-cause mortality ratio increased from $4 \cdot 27$ ($3 \cdot 87$, $4 \cdot 67$) between 2015 and 2019 to $5 \cdot 12$ ($3 \cdot 95$, $6 \cdot 29$) in 2020. However, the confidence intervals still overlapped.

			Standardised mortality ratio ^a	95% CI ^b
2015-2019	Overall		2.39	2.28, 2.51
	Sex	Male	2.23	2.08, 2.38
		Female	2.60	$2 \cdot 42, 2 \cdot 78$
	Deprivation	SIMD 1-5 (more deprived)	2.08	1.96, 2.20
		SIMD 6-10 (less deprived)	3.38	3.11, 3.66
	Age (years) ^c	Adults ≤ 54	4.55	4.09, 5.00
		55-64	4.27	3.87, 4.67
		≥65	1.68	1.57, 1.79
2020	Overall		2.50	$2 \cdot 17, 2 \cdot 81$
	Sex	Male	2.50	2.08, 2.92
		Female	2.51	2.01, 3.00
	Deprivation	SIMD 1-5 (more deprived)	2.18	1.84, 2.52
		SIMD 6-10 (less deprived)	3.65	$2 \cdot 82, 4 \cdot 47$
	Age (years) ^c	Adults ≤ 54	4.79	3.52, 6.04
		55-64	5.12	3.95, 6.29
		≥65	1.55	1.25, 1.85

Table 4. Age-, sex-, deprivation-standardised all-cause mortality, overall and by sub-group

^a standardised for age, sex, SIMD (whichever not used to define sub-group); referent to the 5% comparison group

^b95% CIs calculated based on normal approximation

^c Age at time of event

Discussion

Principal findings and interpretation

This is the first comprehensive study investigating COVID-19 infection, severe infection, mortality, casefatality, and excess mortality among a whole country's population of adults with intellectual disabilities compared with the general population. Adults with intellectual disabilities were twice as likely to become infected with COVID-19, 2·2 times as likely to have severe infection resulting in hospitalisation or death, and following COVID-19 infection, had a case-fatality of 30% compared with 24% in the general population. The risk of severe or fatal COVID-19 infection, relative to the general population, was higher among non-elderly age-groups and particularly high in those aged 55-64 years. Compared with the general population, risk was greater in less deprived areas due to the association of more deprived neighbourhoods with poorer outcomes in the general population, and perhaps as congregate housing for people with intellectual disabilities tends to be in more affluent areas (larger houses). Risk was also greater for men. This highlights the importance of action to reduce COVID-19 infection and mortality risks for adults with intellectual disabilities who are in both younger and older age groups, and in all neighbourhoods. The overall risk of dying from any cause was already higher among adults with intellectual disabilities prior to the COVID-19 pandemic. The net effect of COVID-19 is a slight, non-significant increase in excess deaths from any cause.

Many people with intellectual disabilities require support with daily activities meaning that public health advice on shielding has limited effectiveness as they are more likely to come into regular contact with other people. They are also more likely to be residents in communal establishments and have higher rates of multi-morbidity, resulting in more frequent contact with health-care workers. This highlights the importance of nonpharmaceutical interventions, such as social distancing, face coverings, and hand hygiene in minimising their risk of infection. It is also critical that public health policy and messaging increases awareness among caregivers and people with intellectual disabilities of COVID-19 symptoms, risks of infection, the need for carers and people with intellectual disabilities to isolate when symptomatic, and to consider hospital early to improve outcomes given the higher risk to this population, as well as the high importance of vaccination. It is critical that further comparative research is conducted to investigate any disparities or inequalities in hospital treatment following admission for COVID-19 between people with intellectual disabilities and those without.

Comparison with previous studies

Previous studies have suggested variable COVID-19 outcomes for people with intellectual disabilities including: COVID-19 mortality rates 2-8 fold higher than the general population, (12-16), increased risk of infection, (13, 14) increased risk of hospital admissions, (12-14) no difference in case-fatality,(18) overall case-fatality with OR=2.75 or OR=3.61 in the <70 year olds,(19) and all-cause mortality in those with known COVID-19 with OR=1.97.(11) A study on adults with intellectual disabilities in residential settings (compared with wholecommunity general population) reported COVID-19 infection rates to be about 4 times higher, case-fatality almost double, and mortality rates 7.8 times higher.(20) Our study of a whole nation's adult population with intellectual disabilities found they were twice as likely to become infected with COVID-19, with a case-fatality 26% higher, and COVID-19 mortality 2.2 times higher than in the general population. Poorer COVID-19 outcomes in younger adult age groups compared with the general population were expected and have also been suggested.(13, 15, 18) This is in view of premature deaths resulting in people with milder intellectual disabilities and fewer co-morbidities surviving into old age, and therefore more closely resembling the elderly general population. This difference in the age profile of COVID-19 mortality is important given the current prioritisation of ongoing vaccination boosters in the UK, and initial vaccinations internationally in countries with lesser current coverage and on those in older age groups, which will potentially lead to increased levels of potentially preventable COVID-19 mortality in younger people with intellectual disabilities who are not vaccinated.

Strengths and limitations

The study is large, including the entire country's adult population with intellectual disabilities, as well as a proportion of adults in the general population. There was a 94%, response rate. Record linkage was successful on 94.9% and provided data on a wide range of outcomes.

COVID-19 testing data is likely to be an underestimate of true community incidence of COVID-19 infection rates due to limited COVID-19 testing during the first wave of the pandemic. However this approach is preferable to the inclusion of suspected cases that may not be COVID-19. Case fatality rates were high in both groups and are likely to be an overestimate due to lack of testing of less severe infections in wave one. We did not have information on ability level, Down syndrome, or living circumstances, or data on other risk factors for COVID-19 such as comorbidities which are more common in adults with intellectual disabilities than other people. As 97.3% of the intellectual disabilities population in Scotland is white, we were unable to analyse ethnicity due to small cell sizes. In the sub-group calculations of standardised ratios of severe and fatal COVID-19 infections some cells contained less than twenty events. The Office for National Statistics (ONS) advises that, in such situations, derived rates should be interpreted as having low reliability.(24) . It is important that COVID-19 outcomes in the second and third waves are investigated as soon as this data becomes available.

Implications for clinicians and policymakers

Non-pharmaceutical interventions are critical, in minimising the transmission of Covid-19. Our findings are important for policy-makers, clinicians, and public health physicians to make evidence-based decisions about targeting preventive measures such as shielding, surveillance strategies, criteria for testing, and prioritisation for vaccination, including those providing care and support to people with intellectual disabilities. These are relevant for all adults with intellectual disabilities, regardless of age, sex, or extent of neighbourhood deprivation. The age cut-offs used in the general population for prioritising COVID-19 vaccination and boosters should not be applied to adults with intellectual disabilities who are a higher risk even at younger ages.

Contributors

AH and DK conceived the study. AH and S-AC lead on the acquisition of data for the study. AH, DK, MF, JP, S-AC, DM, CM and CH were involved in the design of the study and interpretation of the data. MF lead the analysis of the data and DM verified data. AH and DK prepared the first draft of the manuscript. MF, JP, S-AC, DM, CM and CH also contributed to the manuscript writing.

All authors approved the final manuscript.

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Declaration of interests

No conflicts of interest exist.

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Role of Funder

The funder was not involved in the collection, analysis, interpretation and presentation of the data used in this research.

Data availability

No data are available

References

1. Constantino JN, Sahin M, Piven J, Rodgers R, Tschida J. The Impact of COVID-19 on Individuals With Intellectual and Developmental Disabilities: Clinical and Scientific Priorities. Am J Psychiatry. 2020;177(11):1091-3.

2. World Health Organisation. The ICD-10 classification of mental and behavioural disorders. Clinical descriptions and diagnostic guidelines. Geneva1992.

3. McKenzie K, Milton M, Smith G, Ouellette-Kuntz H. Systematic Review of the Prevalence and Incidence of Intellectual Disabilities: Current Trends and Issues. Current Developmental Disorders Reports. 2016;3(2):104-15.

4. Hughes-McCormack LA, Rydzewska E, Henderson A, MacIntyre C, Rintoul J, Cooper SA. Prevalence and general health status of people with intellectual disabilities in Scotland: a total population study. J Epidemiol Community Health. 2018;72(1):78-85.

5. Kinnear D, Morrison J, Allan L, Henderson A, Smiley E, Cooper SA. Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study. BMJ Open. 2018;8(2):e018292.

6. Smith GS, Fleming M, Kinnear D, Henderson A, Pell JP, Melville C, et al. Rates and causes of mortality among children and young people with and without intellectual disabilities in Scotland: a record linkage cohort study of 796 190 school children. BMJ Open. 2020;10(8):e034077.

7. Cooper SA, Allan L, Greenlaw N, McSkimming P, Jasilek A, Henderson A, et al. Rates, causes, place and predictors of mortality in adults with intellectual disabilities with and without Down syndrome: cohort study with record linkage. BMJ Open. 2020;10(5):e036465.

8. Brameld K, Spilsbury K, Rosenwax L, Leonard H, Semmens J. Use of health services in the last year of life and cause of death in people with intellectual disability: a retrospective matched cohort study. BMJ Open. 2018;8(2):e020268.

9. O'Leary L, Cooper SA, Hughes-McCormack L. Early death and causes of death of people with intellectual disabilities: A systematic review. J Appl Res Intellect Disabil. 2018;31(3):325-42.

10. Perera B, Courtenay K. Mental health services for people with intellectual disability in the United Kingdom. Advances in Mental Health and Intellectual Disabilities. 2018;12(3/4):91-8.

11. Joy M, Hobbs FR, Bernal JL, Sherlock J, Amirthalingam G, McGagh D, et al. Excess mortality in the first COVID pandemic peak: cross-sectional analyses of the impact of age, sex, ethnicity, household size, and long-term conditions in people of known SARS-CoV-2 status in England. Br J Gen Pract. 2020;70(701):e890-e8.

12. Williamson EJ, McDonald HI, Bhaskaran K, Walker AJ, Bacon S, Davy S, et al. Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform. BMJ. 2021;374:n1592.

13. Lunsky Y, Durbin A, Balogh R, Lin E, Palma L, Plumptre L. COVID-19 positivity rates, hospitalizations and mortality of adults with and without intellectual and developmental disabilities in Ontario, Canada. Disability and Health Journal. 2022;15(1):101174.

 Gleason J RW, Fossi A, Blonsky H, Tobias J, Stephens M,. The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States. NEJM catalyst innovations in care delivery. 2021.
 Public Health England. Deaths of people identified as having learning disabilities with COVID-19 in

England in the spring of 2020. London2020.
16. Improvement Cymru. COVID-19-related deaths in Wales amongst People with Learning Disabilities from 1st March to 26th May 2020. In: Wales PH, editor. Cardiff2020.

17. Watkins A. COVID 19-related deaths in Wales amongst people with learning disabilities from 1st of March to 26th of May 2020. Cardiff: Imrovement Cymru; 2020.

18. Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. Disabil Health J. 2020;13(3):100942.

19. Fair Health. Risk Factors for COVID-19 Mortality among Privately Insured Patients: A Claims Data Analysis. New York2020.

20. Landes SD, Turk MA, Formica MK, McDonald KE, Stevens JD. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. Disabil Health J. 2020;13(4):100969.

21. Clift AK, Coupland CAC, Keogh RH, Diaz-Ordaz K, Williamson E, Harrison EM, et al. Living risk prediction algorithm (QCOVID) for risk of hospital admission and mortality from coronavirus 19 in adults: national derivation and validation cohort study. BMJ. 2020;371:m3731.

22. Scottish Government. Coronavirus (COVID-19): shielding advice and support 2021 [updated 15th of January 2021. Available from: <u>https://www.gov.scot/publications/covid-shielding/pages/highest-risk-classification/</u>.

23. Information Services Division. Data Linkage: Edinburgh; 2020 [26/01/21]. Available from: https://www.isdscotland.org/Products-and-Services/eDRIS/FAQ-eDRIS/#e1.

24. Office for National Statistics. Avoidable mortality in the UK QMI 2020 [Available from:

 $\label{eq:https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/methodologies/avoidablemortalityinenglandandwalesqmi.$