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COVID-19 mortality burden and comorbidity patterns among decedents with and without intellectual and developmental disability in the US



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ABSTRACT

Background: While there is ample evidence of increased COVID-19 mortality risk among people with intellectual and developmental disability (IDD), research has not documented whether this higher risk resulted in increased COVID-19 mortality burden in the US or whether comorbidity patterns among COVID-19 deaths are similar or distinct for people with IDD.

Objective: To determine the differences in COVID-19 mortality burden between decedents with and without IDD during the first year of the pandemic.

Methods: This study uses 2020 US death certificate data to compare COVID-19 mortality burden and comorbidity patterns among decedents with and without IDD.

Results: COVID-19 was the leading cause of death among decedents with IDD in 2020, compared with the 3rd leading cause among decedents without IDD. The proportion of deaths from COVID-19 was also higher for decedents with compared to without IDD. Comorbidities resulting from COVID-19 were similar among decedents with and without IDD, but there were some differences among reported pre-existing conditions, notably higher rates of hypothyroidism and seizures among decedents with IDD.

Conclusion: The COVID-19 mortality burden was greater for people with than without IDD during the first year of the pandemic. The continued practice of postmortem diagnostic overshadowing prevents analyzing whether this difference continues through today. Action is needed by the Centers for Disease Control and Prevention to mitigate this data inequity. Out of an abundance of caution, medical providers should carefully monitor symptoms among COVID-19 patients with IDD diagnosed with hypothyroidism and/or seizures.

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A recently published science brief by the Centers for Disease Control and Prevention (CDC)¹ summarizes evidence through May 2021 from multiple countries demonstrating more severe COVID-19 case and mortality risk among people with intellectual and developmental disabilities compared to the general population. Intellectual and developmental disabilities (IDD) such as intellectual disability, cerebral palsy, and Down syndrome are conditions that occur during the developmental period and are characterized by life-long impairments in mobility, language, learning, self-care, and independent living.² Increased COVID-19 mortality risk among people with IDD has been confirmed across various geographic

contexts and sample types: population based studies in Scotland³ and Ontario⁴; hospitalized COVID-19 patients in the UK⁵; health care organization data from the US⁶; data from IDD services providers^{7,8} and states^{9,10} in the US; and COVID-19 patients in an international sample of health care data.¹¹ While many of these studies do not differentiate by specific intellectual or developmental disability status, a few do, reporting higher rates of COVID-19 mortality among people with Down syndrome^{4,5,12} and cerebral palsy^{12,13} compared to the general population.

Studies in the general population indicate older age and pre-existing health conditions as risk factors for more severe COVID-19 outcomes.¹⁴ Although evidence demonstrates that people with IDD on average die at younger ages than the general population,^{15,16} increased age has been confirmed as a predictor of COVID-19 mortality among adults with IDD in a population study⁴ as well

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as among hospitalized COVID-19 patients.⁵ In addition, there is evidence that risk of COVID-19 is higher for people with than without IDD at younger ages.^{3,4,11} Beyond age-related risk, several studies investigated the impact of comorbidities on COVID-19 risk among people with IDD. Similar to the general population, these studies document increased COVID-19 mortality risk among people with IDD with a diagnosis of hypertension, heart disease, cancer, obesity, respiratory conditions, epilepsy, dysphagia, dementia, or asthma.^{5,7,17,18} To date, age and comorbidity related COVID-19 mortality risk among people with IDD have not been differentiated by disability status.

This study used currently available death certificate data to examine cause of death patterns among people with and without IDD who died in 2020 in the United States, the first year in which COVID-19 deaths were reported. Cause of death data from death certificates are useful in determining whether certain segments or groups within the US population are at greater risk of death from specific diseases,^{19,20} essential for understanding mortality trends related to the pandemic.²¹ Analysis of cause of death data provides a better understanding of the burden of COVID-19 mortality^{22,23} on specific segments of the population such as older adults and racial-ethnic minorities.^{24,25} In addition, as illustrated by Gundlapalli and colleagues at the CDC,²⁶ death certificate data can be used to determine comorbidity patterns among COVID-19 deaths.

Both of these elements—burden of COVID-19 mortality and comorbidity patterns among COVID-19 deaths—are important to better understand the degree to which COVID-19 disparities were similar or different for people with IDD during the first year of the pandemic. Based on existing knowledge that COVID-19 resulted in greater mortality risk for people with IDD, for this analysis of death certificate data we predicted greater COVID-19 burden among people with than without IDD measured by rank order of COVID-19 among the leading causes of death, and the proportion of COVID-19 deaths. As research on COVID-19 mortality risk between people with and without IDD report that the degree of disparity varied by age, we also examined differences in the death rate by age group.

Research to date does confirm that comorbid risk factors for adults with and without IDD are somewhat similar, with greater COVID-19 severity associated with heart disease, hypertension, and chronic kidney disease, to name a few. However, pre-COVID-19 research provides clear evidence that people with IDD in general have higher prevalence of specific diseases such as respiratory disease, seizures, and dysphagia, as well as obesity, congenital heart defects, and hypothyroidism specifically among people with Down syndrome.^{27,28} Thus, while we predicted the causal chain of events from COVID-19 would be similar for people with and without IDD who died from COVID-19, we expected some specific differences in average age at death and preexisting conditions that are in line with previously documented patterns among people with IDD.

Methods

Data and measures

We used 2020 US National Vital Statistics System (NVSS) Mortality Multiple Cause data for analysis. The first reported COVID-19 death in this data occurred in January of 2020, although only 1.9% of all COVID-19 deaths reported in 2020 occurred prior to April. All cases for children and adults who died between January 1 and December 31, 2020 were included in analysis (N = 3,390,278). We created exclusive categories for intellectual and developmental disabilities commonly reported on death certificates using International Classification of Disease (ICD-10) codes from parts I and II of the death certificate: intellectual disability without cerebral palsy or Down syndrome (ICD-10 F70-79; N = 1433; here

intellectual disability), Down syndrome with/without intellectual disability (ICD-10 Q90.9; N = 2691; here Down syndrome), and cerebral palsy with/without intellectual disability (ICD-10 G80; N = 4396; here cerebral palsy). We excluded the 1547 cases that had trisomies and monosomies (ICD-10 Q91-93), autism (F84), or fetal alcohol syndrome (Q86), as well as the 15 cases that reported both Down syndrome and cerebral palsy reported on the death certificate as small cell sizes prevented analysis. The comparison category for analysis was decedents without intellectual disability, Down syndrome, cerebral palsy, trisomies and monosomies, autism, or fetal alcohol syndrome reported on the death certificate, here referred to as decedents without IDD (N = 3,380,196).

To examine leading causes of death, we used the CDC's framework for the 10 leading causes reported for 2020, inclusive of: heart disease (ICD10 I00–I09, I11, I13, I20–I51); cancer (C00–C97); COVID-19 (U07.1); accidents (unintentional injuries) (V01–X59, Y85–Y86); stroke (cerebrovascular diseases) (I60–I69); chronic lower respiratory diseases (J40–J47); Alzheimer's disease (G30); diabetes (E10–E14); influenza and pneumonia (J09–J18); and nephritis, nephrotic syndrome, and nephrosis (N00–N07, N17–N19, N25–N27).^{29,30} To examine COVID-19 comorbidity patterns, we used ICD-10 codes for all distinct comorbidities reported in Part I and II of the death certificate.

Postmortem diagnostic overshadowing, defined as reporting intellectual and developmental disabilities as the underlying cause of death is common in the US, occurring on over half of death certificates for people with these disabilities, with variation by type of disability.^{31–33} This practice “obscures” actual causes of death, unnecessarily complicating efforts to accurately identify mortality trends for this population.^{34–36} To address this problem, prior to analysis we used a sequential revision process fully detailed in a previous study³⁴ to select a valid underlying cause of death for the death certificates that had intellectual disability (17.7% of all intellectual disability cases), cerebral palsy (50.2% of all cerebral palsy cases), or Down syndrome (52.1% of all Down syndrome cases) reported as the underlying cause of death.

In order to describe the data, we included measures for age (single years, and categories [<18, 18–64, 65 and over]), sex (female, male), race-ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic other), and location of death (hospital inpatient, hospital outpatient/emergency room [ER], hospital dead on Arrival [DOA], home, hospice, nursing home, other, unknown).

Analytic strategy

We initially focused on all deaths reported in 2020 (N = 3,390,278) to better understand the burden of COVID-19 by disability status. After describing the demographic and place of death distribution of deaths, we compared the 5 leading causes of death and proportion of all deaths that were due to COVID-19 by disability status. We then computed unadjusted and adjusted (controlling for age, sex, and race-ethnicity) risk ratios using generalized linear models to examine whether the proportions of COVID-19 death were higher for decedents with than without IDD. Analysis of the proportion of COVID-19 deaths and risk ratios were repeated after stratifying by age categories.

Following the lead of Gundlapalli and colleagues,²⁶ we compared similarities and differences in COVID-19 comorbidity patterns by comparing chain-of-event conditions and contributing conditions among those who died from COVID-19 (N = 351,543). Chain-of-event conditions are comorbidities that were reported as directly contributing to death and were reported in Part I of the death certificate either on the same line as COVID-19 or on a line above COVID-19. Contributing conditions are comorbidities that

were present at the time of death but not reported as directly leading to death, and were reported on a line below COVID-19 in either Part I or Part II of the death certificate. We specifically focused on chain-of-event and contributing conditions that were reported on 5% or more of death certificates for decedents with or without IDD.

Results

Distribution of demographic characteristics and location of death by disability status for all decedents are reported in Table 1. As was expected, the median age at death from all causes was younger among people with than without IDD, with a greater difference among decedents with cerebral palsy (22 years) and Down syndrome (19 years) than intellectual disability (12 years). The age distributions of decedents further emphasized this age difference: 74.3% of decedents without IDD were 65 or over, compared to 49.1% of decedents with intellectual disability, 31.6% of decedents with cerebral palsy, and 15.1% of decedents with Down syndrome. Other differences of note were a higher percentage of male decedents and hospital outpatient/ER deaths among decedents with intellectual disability and cerebral palsy, and a higher percentage of nursing home deaths for all disability statuses (see Table 1).

The leading causes of death in 2020 by disability status are reported in Table 2. For decedents without IDD, COVID-19 was the 3rd leading cause of death, following heart disease and cancer, and followed by accidents and stroke. In contrast, the burden of COVID-19 mortality was greater for all IDD statuses. COVID-19 was the leading cause of death for decedents with intellectual disability, cerebral palsy, and Down syndrome. For decedents with intellectual disability and cerebral palsy, the 2nd through 5th leading causes of death in rank order were heart disease, pneumonitis, influenza/pneumonia, and cancer. For decedents with Down syndrome, the 2nd through 5th leading causes of death in rank order

Table 2
Top 5 causes of death by disability status, 2020 US National Vital Statistics System (NVSS) Mortality Multiple Cause Data.

Rank order	Leading cause of death by disability status	No.
No intellectual or developmental disability (N = 3,381,743)		
1	Heart disease	697,664
2	Cancer	602,775
3	COVID-19	350,334
4	Accidents (unintentional injuries)	197,316
5	Stroke (cerebrovascular diseases)	160,289
Intellectual disability (N = 1433)		
1	COVID-19	208
2	Heart disease	204
3	Pneumonitis due to solids or liquids	96
4	Influenza/pneumonia	69
5	Cancer	71
Cerebral palsy (N = 4396)		
1	COVID-19	515
2	Heart disease	423
3	Pneumonitis due to solids or liquids	336
4	Influenza/pneumonia	321
5	Cancer	179
Down syndrome (N = 2691)		
1	COVID-19	421
2	Alzheimer's disease	289
3	Heart disease	265
4	Influenza/pneumonia	209
5	Pneumonitis due to solids or liquids	162

were Alzheimer's disease, heart disease, influenza/pneumonia, and pneumonitis.

The proportion of deaths from COVID-19 and risk ratios by disability status are reported in Table 3. The proportion of deaths from COVID-19 was: 10.4% (95 CI: 10.3, 10.4) among decedents without IDD; 14.5% (12.8, 16.4) among decedents with intellectual disability; 11.7% (10.8, 12.7) among decedents with cerebral palsy; and 15.6% (14.3, 17.1) among decedents with Down syndrome. This

Table 1
Distribution of sociodemographic and place of death characteristics for all decedents, 2020 US National Vital Statistics System (NVSS) Mortality Multiple Cause Data.

	No intellectual or developmental disability		Intellectual disability		Cerebral palsy		Down syndrome	
	N	Median, IQR	N	Median, IQR	N	Median, IQR	N	Median, IQR
Age	3,380,196	76 (64–86)	1433	64 (56–73)	4396	54 (33–68)	2691	57 (49–62)
	No. (column %)		No. (column %)		No. (column %)		No. (column %)	
<i>Age group</i>								
<18	32,631 (0.97)		6 (0.42)		377 (8.58)		189 (7.02)	
18–64	837,605 (24.78)		712 (49.68)		2630 (59.83)		2096 (77.89)	
65 and over	2,509,695 (74.25)		715 (49.89)		1388 (31.57)		406 (15.09)	
Missing	265 (0.01)		0 (0.00)		1 (0.02)		0 (0.00)	
<i>Sex</i>								
Female	1,611,063 (47.66)		597 (41.66)		1973 (44.88)		1296 (48.16)	
Male	1,769,133 (52.34)		836 (58.34)		2423 (55.12)		1395 (51.84)	
<i>Race-ethnicity</i>								
Non-Hispanic White	2,495,128 (73.82)		1080 (75.37)		3157 (71.82)		2014 (74.84)	
Non-Hispanic Black	453,369 (13.41)		219 (15.287)		672 (15.29)		297 (11.04)	
Hispanic	304,443 (9.01)		113 (7.89)		448 (10.19)		309 (11.48)	
Non-Hispanic other	127,256 (3.76)		21 (1.47)		119 (2.71)		71 (2.64)	
<i>Location of death</i>								
Hospital inpatient	1,022,763 (30.26)		419 (29.24)		1335 (30.37)		941 (34.97)	
Hospital outpatient/emergency room	202,491 (5.99)		123 (8.58)		403 (9.17)		130 (4.83)	
Hospital dead on arrival	9678 (0.29)		2 (0.14)		13 (0.30)		4 (0.15)	
Home	1,125,597 (33.30)		340 (23.73)		1255 (28.55)		774 (28.76)	
Hospice	204,596 (6.05)		59 (4.12)		263 (5.98)		134 (4.98)	
Nursing home	586,276 (17.34)		387 (27.01)		941 (21.41)		553 (20.55)	
Other	228,144 (6.75)		102 (7.12)		186 (4.23)		154 (5.72)	
Unknown	651 (0.02)		1 (0.07)		0 (0.00)		1 (0.04)	

Note: Results from chi-squared tests for difference between decedents with each disability status compared to decedents without IDD were statistically significant at the p < .05 level except for sex for Down syndrome.

Table 3
COVID-19 death proportions and risk ratios, 2020 US National Vital Statistics System (NVSS) Mortality Multiple Cause Data.

	No intellectual or developmental disability (N = 3,380,196)	Intellectual disability (N = 1670)	Cerebral palsy (N = 4411)	Down syndrome (N = 2706)
Proportion of all deaths (95% CI)	10.36% (.1033, .1039)	14.52% (.1278, .1643)	11.72% (.1080, .1270)	15.64% (.1432, .1707)
Unadjusted risk ratio compared to no IDD (95% CI)	Referent	1.40*** (1.24, 1.59)	1.13** (1.04, 1.23)	1.51*** (1.38, 1.65)
Adjusted risk ratio compared to no IDD ⁺ (95% CI)	Referent	1.61*** (1.42, 1.82)	1.54*** (1.42, 1.67)	2.07*** (1.90, 2.26)
Proportion of deaths by age group				
<18	0.39% (.0033, .0046)	—	2.12% (.0106, .0419)	1.58% (.0051, .0484)
18–64	8.05% (.0798, .0810)	12.92% (.1065, .1560)	9.47% (.0841, .1065)	16.46% (.1493, .1811)
65 and over	11.27% (.1123, .1131)	16.22% (.1370, .1912)	18.59% (.1663, .2072)	17.98% (.1453, .2203)
Unadjusted risk ratio compared to no IDD (95% CI)				
<18	Referent	—	5.49*** (2.71, 11.12)	4.10* (1.32, 12.77)
18–64	Referent	1.61*** (1.33, 1.94)	1.18** (1.05, 1.32)	2.05*** (1.86, 2.25)
65 and over	Referent	1.44*** (1.22, 1.70)	1.65*** (1.48, 1.84)	1.60*** (1.30, 1.96)
Adjusted risk ratio compared to no IDD ⁺ (95% CI)				
<18	Referent	—	3.68*** (1.81, 7.50)	5.11** (1.64, 15.92)
18–64	Referent	1.69*** (1.41, 2.03)	1.60*** (1.43, 1.79)	2.30*** (2.11, 2.52)
65 and over	Referent	1.46*** (1.24, 1.73)	1.75*** (1.57, 1.95)	1.64*** (1.34, 2.02)

Notes: *p < .05; **p < .01; ***p < .001. ⁺Adjusted for age, sex, racial-ethnic minority status. Proportions and risk ratios not computed for people with intellectual disability age <18 due to small cell size (N = 6). IDD = intellectual and/or developmental disability.

higher rate of COVID-19 among decedents with IDD was confirmed with both unadjusted and adjusted risk ratios, with the severity of the difference increasing for each disability once adjusting for age, sex, and race-ethnicity. Compared to decedents without IDD, COVID-19 deaths were 1.6 times higher among decedents with intellectual disability, 1.5 times higher among decedents with cerebral palsy, and 2.1 times higher among decedents with Down syndrome. As is apparent in the lower portion of Table 3, these higher proportions of COVID-19 deaths and risk ratios persisted across age groups.

In order to better understand COVID-19 comorbidity patterns, we then turned our attention to cases in which COVID-19 was reported as the underlying cause of death. The distribution of demographic characteristics and location of death by disability status

for all decedents who died from COVID-19 is reported in Table 4. Similar to the full sample, median age at death was younger among people with than without IDD who died from COVID-19 - intellectual disability (11 years); cerebral palsy (13 years); Down syndrome (21 years). The age distributions of decedents further emphasized this age difference as well, 80.7% of decedents without IDD age 65 or over, compared to 55.8% of decedents with intellectual disability, 5.04% of decedents with cerebral palsy, and 17.3% of decedents with Down syndrome.

To examine comorbidity trends, we excluded those COVID-19 cases in which no other comorbidities were reported on the death certificate other than COVID-19 and IDD status (no IDD – 6.1% of COVID-19 deaths; intellectual disability—1.3%; cerebral palsy—6.6%; and down syndrome—6.4%). As is apparent in Table 5,

Table 4
Distribution of sociodemographic and place of death characteristics for COVID-19 deaths, 2020 US National Vital Statistics System (NVSS) Mortality Multiple Cause Data.

	No intellectual or developmental disability		Intellectual disability		Cerebral palsy		Down syndrome	
	N	Median, IQR	N	Median, IQR	N	Median, IQR	N	Median, IQR
Age	350,334	78 (68–87)	208	67 (59–74)	515	65 (53–73)	421	57 (48–62)
	No. (column %)		No. (column %)		No. (column %)		No. (column %)	
<i>Age groups</i>								
<18	127 (0.04)		0 (0.00)		8 (1.57)		3 (0.72)	
18–64	67,389 (19.23)		92 (44.23)		244 (48.04)		340 (81.93)	
65 and over	282,809 (80.72)		116 (55.77)		256 (50.40)		72 (17.34)	
Missing	9 (<.01)		0 (0.00)		0 (0.00)		0 (0.00)	
<i>Sex</i>								
Female	157,992 (45.10)		70 (33.65)		222 (43.11)		202 (47.98)	
Male	192,342 (54.90)		138 (66.35)		293 (56.89)		219 (52.02)	
<i>Race-ethnicity</i>								
Non-Hispanic White	210,045 (59.96)		144 (69.23)		370 (71.84)		280 (66.51)	
Non-Hispanic Black	56,924 (16.25)		32 (15.38)		73 (14.17)		45 (10.69)	
Hispanic	65,209 (18.61)		27 (12.98)		58 (11.26)		82 (19.48)	
Non-Hispanic Other	18,156 (5.18)		5 (2.40)		14 (2.72)		14 (3.33)	
<i>Location of death</i>								
Hospital inpatient	233,420 (66.63)		121 (58.17)		280 (54.37)		284 (67.46)	
Hospital outpatient/emergency room	11,521 (3.29)		12 (5.77)		22 (4.27)		8 (1.90)	
Hospital dead on arrival	290 (0.08)		0 (0.00)		1 (0.19)		0 (0.00)	
Home	19,330 (5.52)		18 (8.65)		33 (6.41)		36 (8.55)	
Hospice	8,999 (2.57)		9 (4.33)		25 (4.85)		14 (3.33)	
Nursing home	70,874 (20.23)		46 (22.12)		142 (27.57)		73 (17.34)	
Other	5,830 (1.66)		2 (0.96)		12 (2.33)		6 (1.43)	
Unknown	70 (0.02)		0 (0.00)		0 (0.00)		0 (0.00)	

Note: Results from chi-squared tests for difference between decedents with each disability status compared to decedents without IDD were statistically significant at the p < .05 level except for: sex for cerebral palsy and Down syndrome; and place of death for intellectual disability and Down syndrome.

the occurrence of chain-of-event conditions were similar in COVID-19 deaths across all disability statuses (no IDD, intellectual disability, cerebral palsy, and Down syndrome), with pneumonia reported in over 44.9% of COVID-19 deaths, acute respiratory failure in over 17.7%, and respiratory failure unspecified in over 14.2%. Though not as prevalent, cardiac arrest, adult respiratory distress syndrome, and sepsis were also common among COVID-19 decedents across disability statuses

There were also some similarities among contributing conditions. Hypertension was the most commonly reported comorbidity among decedents without IDD, with intellectual disability, and with cerebral palsy, and the 4th most common condition reported among decedents with Down syndrome. Also showing a pattern of similarity, diabetes, inclusive of “unspecified” and “type 2,” was one of the top four reported comorbidities for COVID-19 deaths across all disability statuses. Despite these similarities, there were also distinct differences by disability status among contributing conditions. In general, reported cardiovascular diseases (hypertension, atherosclerotic heart disease, atrial fibrillation and flutter, congestive heart failure) were more prevalent among COVID-19 decedents without IDD, while hypothyroidism and seizures (convulsions, epilepsy) were more prevalent for all disability statuses. In addition, compared to COVID-19 decedents without IDD, rates of hyperlipidemia and obesity were higher among decedents with intellectual disability, sepsis among decedents with cerebral palsy, and dementia and obesity among decedents with Down syndrome.

Discussion

Results from this study confirmed our prediction that COVID-19 deaths would rank higher among the leading causes of death for people with than without IDD, and that death would occur at younger ages. COVID-19 was the 3rd leading cause of death for those without IDD ranking below heart disease and cancer in 2020. In contrast, COVID-19 was the leading cause of death for people with intellectual disability, cerebral palsy and Down syndrome during the first year of the pandemic. Further underscoring this

difference, we found higher proportions of death due to COVID-19 across all disability statuses and ages. Examination of risk ratios clarified that this higher risk of COVID-19 death among decedents with IDD increased when adjusting for age, sex, and racial-ethnic minority status, likely due to the marked difference in the age distributions between decedents with and without IDD. These results clearly demonstrated that people who had IDD reported on their death certificate in the US experienced a greater COVID-19 mortality burden in 2020 than people without IDD, and at much younger ages.

Examination of chain of event conditions revealed that the COVID-19 related causal sequence leading to death was largely similar for people with and without IDD, with pneumonia and acute respiratory failure most commonly reported. The only caveat was that cardiac arrest was a more common chain-of-event condition among those without than with IDD. There were some similarities—with hypertension and diabetes commonly reported for COVID-19 deaths across all disability statuses—but also more distinct disability-related differences among the contributing conditions in COVID-19 deaths. The main differences among the contributing conditions for COVID-19 deaths were a higher occurrence of heart disease in those without than with IDD, and higher occurrences of hypothyroidism and seizures (convulsions, epilepsy) among all IDD statuses, and obesity among decedents with intellectual disability and Down syndrome.

Hypothyroidism is a common comorbidity for people with Down syndrome and other intellectual disability conditions, and congenital hypothyroidism can be the underlying cause for intellectual disability.²⁷ Seizures and epilepsy are also noted to be common comorbidities in many IDD conditions, with an overall prevalence of 22%.²⁷ The higher reporting in this population of both of those comorbidities is therefore not surprising. A recent systematic review and meta-analysis noted thyroid abnormalities were associated with poor COVID-19 outcomes, and that this was highly influenced by increasing age.³⁷ Since older age is not the case in the IDD population under study, the longstanding presence of hypothyroidism and possible hormonal effects on the immune

Table 5
Cause of death patterns for COVID-19 deaths, 2020 US National Vital Statistics System (NVSS) Mortality Multiple Cause Data.

	No intellectual or developmental disability (N = 329,120)	Intellectual disability (N = 205)	Cerebral palsy (N = 481)	Down syndrome (N = 394)
	No. (%)	No. (%)	No. (%)	No. (%)
Chain of event conditions				
Pneumonia (J18.9)	150,011 (45.56)	92 (44.88)	228 (47.40)	194 (49.24)
Acute respiratory failure (J96.0)	67,457 (20.50)	46 (22.44)	85 (17.67)	79 (20.05)
Respiratory failure unspecified (J96.9)	47,699 (14.49)	29 (14.15)	70 (14.55)	66 (16.75)
Cardiac arrest unspecified (I46.9)	37,141 (11.28)	15 (7.32)	42 (8.73)	34 (8.63)
Adult respiratory distress syndrome (J80)	36,550 (11.11)	18 (8.78)	52 (10.81)	36 (9.14)
Sepsis unspecified (A41.9)	20,820 (6.32)	14 (6.83)	29 (6.03)	30 (7.61)
Contributing conditions				
Essential primary hypertension (I10)	58,726 (17.84)	38 (18.54)	62 (12.89)	25 (6.35)
Unspecified diabetes (E14.9)	34,032 (10.34)	18 (8.78)	34 (7.07)	25 (6.35)
Dementia (F03)	32,353 (9.83)	14 (6.83)	20 (4.16)	45 (11.42)
COPD (J44.9)	24,916 (7.57)	3 (1.46)	26 (5.41)	4 (1.02)
Atherosclerotic heart disease (I25.1)	22,222 (6.75)	5 (2.44)	5 (1.04)	1 (0.25)
Type 2 diabetes (E11.9)	21,000 (6.38)	16 (7.80)	21 (4.37)	16 (4.06)
Atrial fibrillation and flutter (I48)	19,804 (6.02)	10 (4.88)	18 (3.74)	2 (0.51)
Congestive heart failure (I50)	16,943 (5.15)	4 (1.95)	12 (2.49)	9 (2.28)
Convulsions, not elsewhere classified (R56.8)	1721 (0.52)	32 (15.61)	54 (11.23)	26 (6.60)
Hypothyroidism, unspecified (E03.9)	3722 (1.13)	14 (6.83)	12 (2.49)	42 (10.66)
Hyperlipidemia, unspecified (E78.5)	9195 (2.79)	13 (6.34)	10 (2.08)	8 (2.03)
Schizophrenia, unspecified (F20.9)	749 (0.23)	12 (5.85)	2 (0.42)	1 (0.25)
Obesity, unspecified (E66.9)	8969 (2.72)	9 (4.39)	8 (1.66)	25 (6.35)
Sepsis, unspecified (A41.9)	13,738 (4.17)	8 (3.90)	34 (7.07)	19 (4.82)
Epilepsy, unspecified (G40.9)	317 (0.10)	11 (5.37)	16 (3.33)	4 (1.02)

system must be considered. And along similar lines, inflammatory cytokine storms from SARS-CoV-2 infection have been linked to a host of neurological symptoms, including new onset seizures.³⁸ However, much less is known about the relationship of the virus to pre-existing seizures.³⁹ Recent recommendations for management of both hypothyroidism and epilepsy is close monitoring and appropriate treatment throughout the pandemic, with or without infection.^{39,40}

While the available data do not allow an in-depth look at risks outside of medical conditions, it is important to note that other social determinants of health have been implicated in severe outcomes during this pandemic. In this death certificate data, people with IDD were noted to be living in a nursing home at the time of death at a higher percentage than those without, especially those with intellectual disability (1.6 times higher). Congregate living settings, especially when high levels of close-contact personal care support over multiple shift direct care workers are provided, are associated with poor outcomes from COVID-19, for people with¹⁰ and without IDD.⁴¹ For people with IDD, with estimates of around 13–20% of adults with IDD residing in congregate care settings,⁴² this risk cannot be overstated.

Limitations

This study has distinct limitations associated with the use of death certificates for analysis. While important to attend to differences in comorbidity patterns, it is also necessary to realize that the increased COVID-19 burden among people with IDD may at least partly be due to social factors such as a higher proportion of this population living in congregate settings, insufficient attention to care needs on a public and private level, and inequities in access to quality healthcare.^{42–44} These social factors were present prior to COVID-19 and appear to have been exacerbated during the pandemic.^{45,46} Unfortunately, we were not able to explore whether these social factors explained differences in the COVID-19 burden among people with and without IDD in this study.

In addition, it is important to realize that research shows that intellectual disability is likely underreported on death certificates.⁴⁷ This does not appear to occur as frequently with cerebral palsy or Down syndrome as these disabilities are more readily identifiable.⁴⁸ Thus, results for people with IDD in this study only describe outcomes for decedents who had these disabilities reported on their death certificate. Also related to concerns with reporting, though we know of no evidence to date, it may be that the reporting of COVID-19 as the cause of death, and reporting of comorbidities for those who died from COVID-19, may vary by disability status.

While this study highlights an increased COVID-19 burden for people with IDD during the first year of the pandemic, due to the practice of postmortem diagnostic overshadowing,^{31,36,49} we cannot determine whether these differences continue through today. The CDC provides preliminary death certificate data through the CDC Wonder site that is currently up to date through May 2022.⁵⁰ However, since postmortem diagnostic overshadowing—reporting of IDD as the underlying cause of death—occurred for 15.5% of decedents with intellectual disability, 52.3% of decedents with cerebral palsy, and 50.2% of decedents with Down syndrome in the preliminary 2021 and 2022 data, it is not possible to accurately ascertain the leading cause of death for these groups. In order to have an accurate and complete understanding of whether the pandemic continues to result in an increased burden for these groups, the CDC would need to either analyze (or release) provisional data at the decedent level with revisions to death certificates that inaccurately reported IDD as the underlying cause of death. Evidence from this

study provides further impetus for this action in order to eliminate this data inequity.

Conclusion

The burden of COVID-19 mortality was greater for people with than without IDD during the first year of the pandemic. Some of this difference may be due to higher prevalence of comorbidities among people with IDD. However, it is also important to consider the ways in which social inequities related to residential care arrangements, as well as other social determinants of health, may lead to this greater burden. To address the increased burden of disease mortality during the current, and in possible future pandemic(s), it is necessary to engage in systematic changes that address the social inequities and marginalization experienced by people with intellectual and developmental disability,^{51,52} including but not limited to the areas of public health surveillance⁵³ and action (e.g. vaccine prioritization and facilitation),⁵⁴ as well as access to quality preventive and acute medical care.⁴⁴ In addition, it is of utmost importance to realize that postmortem diagnostic overshadowing is preventing adequate surveillance of the health of this marginalized population during the ongoing pandemic. While changes are needed to the death certificate coding and revision process to address this data inequity in the long-term, in the immediate, the CDC will need to recognize this inequity and take necessary action to allow for analysis of current death certificate data at the decedent level for this population.

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Conflicts of interest

None.

Author contributions

Landes had full access to all of the collected data in the study and takes responsibility for the accuracy of the data analysis.

Concept and design: All authors.

Acquisition and analysis of data: Landes.

Interpretation of analysis: All authors.

Drafting of the manuscript: All authors.

Critical revision of the manuscript for important intellectual content: All authors.

Statistical analysis: Landes.

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