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Brief Report

COVID-19 case-fatality disparities among people with intellectual and developmental disabilities: Evidence from 12 US jurisdictions



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ABSTRACT

Background: There is evidence from two US states that people with intellectual and developmental disabilities (IDD) are at more severe risk during the COVID-19 pandemic. Research has not explored whether this increased risk is consistent across the US.

Objective: This study compared COVID-19 case-fatality rates among people with IDD in 11 states and the District of Columbia that are publicly reporting data.

Methods: Cumulative data reported through March 31 – April 13, 2021 were analyzed. Case-fatality rates and risk ratio with 95% confidence intervals for IDD settings were compared the overall case-fatality rate for the jurisdictions from Johns Hopkins' Center for Systems Science and Engineering COVID-19 data.

Results: Settings were reported as receiving any services, community or institutional residential services, or living in own/family home. Comparison of case-fatality rates between people with IDD and their respective jurisdiction populations demonstrates that case-fatality rates were consistently higher for people with IDD living in congregate residential settings (fifteen instances) and receiving 24/7 nursing services (two instances). Results were mixed for people with IDD living in their own or a family home (eight instances).

Conclusions: These findings highlight that people with IDD, especially those living in residential settings, are experiencing higher case-fatality rates from COVID-19 than the general population across multiple US jurisdictions. Short-term and long-term public health interventions addressing COVID-19 risks will not be able to properly address the needs of people with IDD until all states begin reporting COVID-19 outcomes for this population.

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Introduction

People with intellectual and developmental disabilities (IDD) are a vulnerable health population.¹ At the beginning of the pandemic in the US, researchers warned that people with IDD may experience more severe COVID-19 outcomes due to^{2,3}: 1) higher prevalence of certain pre-existing conditions⁴; 2) persistent healthcare disparities⁵; 3) a disproportionately greater percentage of this population living in congregate settings^{6,7}; and 4) the need for personal and/or medical care that cannot be socially distanced among all people with IDD,^{3,8} but especially those living in congregate settings.⁹ Empirical results confirmed this concern.

An initial study utilizing real-time electronic medical record data reported higher prevalence of pre-existing conditions and case-fatality rates among people with than without IDD at younger ages.¹⁰ A second study reported that in New York state, case and case-fatality rates were higher among people with IDD living in group homes than in the state overall.¹¹ Adding further evidence, a third study using California data reported more severe COVID-19 outcomes among people with IDD, but with substantial variation by where the person lived and level of nursing/personal care provided. Californians with IDD living in their own or a family home had a lower case rate than the state overall, and a case-fatality rate that was only 1.5 times higher than the state. In contrast, case rates were 9–13 times higher than the state for people receiving IDD services in settings with a greater number of residents, and case-fatality rates were 8.3–10.7 times higher than the state among those receiving services in settings providing

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skilled nursing care.¹²

These early results provide evidence of more severe COVID-19 outcomes among people with IDD. However, they do not inform whether the more severe outcomes extend beyond those living in New York or California, two states with the greatest number of COVID-19 deaths in the US.¹³ To address this gap in the literature, this study compared COVID-19 case-fatality rates between people with IDD and the general population in US jurisdictions that are currently reporting COVID-19 data for people with IDD. Based on the early evidence summarized above, our expectation was that people with IDD would have higher COVID-19 case-fatality rates than the general population across US jurisdictions that are reporting data.

Methods

In order to further understand the impact of the pandemic on people with IDD, we conducted a search that identified 12 jurisdictions—11 states and the District of Columbia—that are publicly reporting updated data on COVID-19 outcomes among people with IDD. Reporting varied widely across these jurisdictions; however, all provide the cumulative number of COVID-19 positive cases and number of COVID-19 deaths through a specific date. Data on IDD COVID-19 outcomes for each jurisdiction for the time period ending March 31 – April 13, 2021 were obtained from: Arizona, California, Connecticut, District of Columbia, Illinois, Louisiana, Maryland, New Jersey, Oregon, Pennsylvania, Virginia, and Washington.

While two jurisdictions only report outcomes for all people with IDD receiving services (Washington DC, Maryland), the other ten report outcomes by type of setting. For these jurisdictions, the setting categories identified were as named in their reporting. It is important to note that each jurisdiction has definitions for each setting, and although some setting names may be the same or similar, there is no certainty that the types of services or number of residents is the same across jurisdictions. Thus, it is not advisable to engage in direct comparison of reported settings, even those with similarly described names. Instead, we used three broadly defined settings categories to describe patterns: 1) all service recipients with IDD; 2) people receiving residential services in either community or institutional settings; 3) people receiving service in their own or a family home.

We present case-fatality rates (total deaths/total cases) with 95% confidence intervals for each IDD service category in these jurisdictions. Due to the smaller sample sizes, Wilson score intervals were used to calculate the confidence interval for the IDD categories. For comparison, we used the Johns Hopkins' Center for Systems Science and Engineering (JHCSSE) data¹³ to calculate the overall case-fatality rate with 95% confidence intervals for each jurisdiction for the date corresponding to the IDD report. To better understand the disparity in case-fatality rates, we calculated the risk ratio with 95% confidence intervals using the case-fatality rates for the IDD categories compared to the JHCSSE overall case-fatality rate for the jurisdiction.

Results

All results are reported in Table 1. Distribution of the settings categories included two instances of jurisdictions only reporting outcomes for all people receiving IDD services, 19 instances of jurisdictions reporting outcomes for people receiving residential services, eight instances of jurisdictions reporting outcomes for people living in their own/family home, and one service category that we were not able to classify (Case Management in Virginia).

In the two jurisdictions only reporting outcomes for all people with IDD receiving services, analysis of the risk ratios indicated that

the case-fatality rate was between 2.4 (Maryland) and 5.5 (District of Columbia) times higher for people with IDD than for the jurisdiction, and statistically significant.

- Table 1 about here -

For people with IDD in the 15 instances in which jurisdictions reported outcomes for those receiving residential services, analysis of the risk ratios indicated that the case-fatality rates were between 1.5 and 4.8 times higher than for people with IDD than the jurisdictions, and statistically significant. For the two residential service categories that specified individuals with IDD were receiving nursing care – Intermediate Care Facilities-Nursing and Skilled Nursing Facility in California – analysis of the risk ratios indicated that the case-fatality rate for people with IDD were between 3.3 and 8.6 times higher than for the state. It is important to note that we are not able to differentiate between people with IDD who were/were not receiving nursing care as part of their residential services in the other jurisdictions. There were two instances in which differences in case-fatality rates between people with IDD receiving residential services and the state were not statistically significant: the Community Care Facility setting in California and the DDS Public Community Living Arrangements & Others setting in Connecticut.

Results were mixed for the eight instances in which states reported outcomes for people with IDD receiving services in their own or a family home. In three instances (New Jersey – Own Home; Virginia – Supportive Services, and Day Support Services), analysis of the risk ratios indicated that the case-fatality rate was higher (between 3.5 and 6.1 times higher) for people with IDD than for the state and was statistically significant. In four instances (Arizona – Family/Own Home; California – Supported Living Services; Oregon – Own Home; Virginia – Sponsored Residential Home Services), differences in case-fatality rates to the state were not statistically significant. Finally, in one instance (California – Family Home) the case-fatality rate was 65% lower than for the state.

For the one service category we were not able to classify, Case Management in Virginia, the case-fatality rate for people with IDD was 4.0 times higher than for the state.

Discussion

Concerned by early evidence that people with IDD living in congregate settings may be at increased COVID-19 risk, members of the US Senate Committee on Health, Education, Labor, and Pensions requested that the Centers for Medicare and Medicaid Services require states to collect and report COVID-19 data for people with disability living in congregate settings.¹⁴ Though not representative of all states, results from our analysis of COVID-19 outcomes through late March/first of April 2021 support this effort by adding additional evidence that people with IDD across the US, especially those living in congregate residential settings, are faring poorly compared to the general population during the pandemic. In addition, case-fatality rates were markedly higher for people with IDD receiving skilled nursing care as part of their residential services in the one state that provided this level of detailed information. Evidence from the eight instances in which states reported data on people with IDD living in their own or a family home was mixed, showing case-fatality rates that were either higher, similar to, or in one case, lower than the state. The data used in this study did not allow determination of level of services provided for those living in their own or a family home in any jurisdiction. While this study is based upon US data, it is informative to note that the increased risk of COVID-19 case-fatality among people with IDD, with variation by place of residence, is not unlike results reported from the UK.¹⁵

The finding from this study that people with IDD have a higher

Table 1
 Comparison of case-fatality rates by reported setting for the US jurisdictions publicly reporting Intellectual and Developmental Disability (IDD) COVID-19 outcomes, March 31-April 13, 2021.

State	Setting*	Category	Cases	Deaths	Case-fatality rate	95% CI	Risk ratio	95% CI
Arizona (April 13, 2021)	IDD – Family/own home	Own/family home	1678	30	1.79%	(1.26% –2.54%)	0.89	(0.62 –1.27)
	IDD – Residential setting	Residential	1108	44	3.97%	(2.97% –5.29%)	1.96	(1.48 –2.64)
	All cases and deaths for jurisdiction		850,846	17,105	2.01%	(1.98% –2.04%)		
California (April 6, 2021)	IDD – Community Care Facility	Residential	3902	75	1.92%	(1.54% –2.40%)	1.18	(0.95 –1.48)
	IDD – Intermediate Care Facilities for the Developmentally Disabled	Residential	280	22	7.86%	(2.52% –11.61%)	4.83	(3.24 –7.22)
	IDD – Intermediate Care Facilities-Habilitative	Residential	1132	30	2.65%	(1.86% –3.76%)	1.63	(1.15 –2.32)
	IDD – Intermediate Care Facilities -Nursing	Residential	582	31	5.33%	(3.78% –7.46%)	3.28	(2.33 –4.61)
	IDD – Supported Living Services	Own/family home	893	21	2.35%	(1.57% –3.57%)	1.45	(0.95 –2.21)
	IDD – Family Home	Own/family home	8512	48	0.56%	(0.43% –0.72%)	0.35	(0.26 –0.46)
	IDD – Skilled Nursing Facility	Residential	568	79	13.91%	(11.30% –17.00%)	8.56	(6.97 –10.50)
	All cases and deaths for jurisdiction		3,685,045	59,887	1.63%	(1.61% –1.64%)		
Connecticut (April 13, 2021)	IDD – Training Schools or Regional Centers	Residential	155	12	7.74%	(3.53% –11.95%)	3.16	(1.84 –5.45)
	IDD – DDS Public Community Living Arrangements & Others	Residential	67	1	1.49%	(0.26% –7.98%)	0.61	(0.87 –4.27)
	IDD – Private Providers - Statewide (Residential)	Residential	1116	49	4.39%	(3.34% –5.76%)	1.79	(1.36 –2.36)
	All cases and deaths for jurisdiction		325,689	7974	2.45%	(2.40% –2.50%)		
District of Columbia (April 13, 2021)	IDD – All service recipients	All recipients	426	55	12.91%	(10.05% –16.43%)	5.48	(4.25 –7.06)
	All cases and deaths for jurisdiction		46,016	1085	2.36%	(2.22% –2.50%)		
Illinois (March 31, 2021)	IDD – Community Integrated Living Arrangements	Residential	1903	53	2.79%	(2.05% –3.52%)	1.47	(1.13 –1.92)
	All cases and deaths for jurisdiction		1,244,499	23,579	1.89%	(1.87% –1.92%)		
Louisiana (April 2, 2021)	IDD – Intermediate Care Facilities	Residential	995	61	6.13%	(4.80% –7.80%)	2.69	(2.11 –3.43)
	IDD – Home and community based services	Residential	634	34	5.36%	(3.86% –7.40%)	2.35	(1.69 –3.26)
	All cases and deaths for jurisdiction		445,469	10,161	2.28%	(2.24% –2.32%)		
Maryland (April 2, 2021)	IDD – All service recipients	All recipients	2097	102	4.86%	(4.02% –5.87%)	2.42	(2.00 –2.93)
	All cases and deaths for jurisdiction		414,385	8319	2.01%	(1.96% –2.05%)		
New Jersey (April 4, 2021)	IDD – Licensed Community Settings	Residential	1813	112	6.18%	(5.16% –7.38%)	2.32	(1.94 –2.78)
	IDD – Own Home	Own/family home	556	51	9.17%	(7.05% –11.86%)	3.45	(2.66 –4.49)
	IDD – Developmental Centers	Residential	740	58	7.84%	(6.11% –10.00%)	2.95	(2.30 –3.78)
	All cases and deaths for jurisdiction		927,195	24,637	2.66%	(2.62% –2.69%)		
Oregon (April 12, 2021)	IDD – Residential group homes	Residential	170	11	6.47%	(3.65% –11.21%)	4.53	(2.55 –8.03)
	IDD – Own home (in-home; supported living)	Own/family home	201	4	1.99%	(0.78% –5.00%)	1.39	(0.53 –3.68)
	All cases and deaths for jurisdiction		170,850	2441	1.43%	(1.37% –1.49%)		
Pennsylvania (April 9, 2021)	IDD – Licensed Community-Based Residential	Residential	2622	131	5.00%	(4.23% –5.90%)	2.10	(1.78 –2.48)
	IDD – Intermediate Care Facilities	Residential	551	36	6.53%	(4.76% –8.91%)	2.74	(2.00 –3.77)
	All cases and deaths for jurisdiction		1,066,707	25,358	2.38%	(2.35% –2.41%)		
Virginia (April 15 2021)	IDD – Supportive Services	Own/family home	40	4	10.00%	(3.96% –23.05%)	6.09	(2.40 –15.44)
	IDD – Sponsored Residential Home Services		131	1	0.76%		0.47	

(continued on next page)

Table 1 (continued)

State	Setting*	Category	Cases	Deaths	Case-fatality rate	95% CI	Risk ratio	95% CI
		Own/family home				(0.13%–4.20%)		(0.07–3.28)
	IDD – Residential/Crisis Stabilization Services	Residential	994	43	4.33%	(3.23%–5.78%)	2.64	(1.97–3.53)
	IDD – Day Support Services	Own/family home	55	4	7.27%	(2.86%–17.26%)	4.43	(1.72–11.39)
	IDD – Case Management	Not determined	275	18	6.55%	(4.18%–10.11%)	3.99	(2.55–6.24)
	All cases and deaths for jurisdiction		641,626	10,529	1.64%	(1.61%–1.67%)		
Washington (April 12, 2021)	IDD – Community Residential Service Providers	Residential	697	34	4.88%	(3.51%–6.74%)	3.46	(2.49–4.81)
	All cases and deaths for jurisdiction		377,952	5329	1.41%	(1.37%–1.45%)		

Notes: *.Setting is identified as named in jurisdiction reporting. Each jurisdiction has definitions for each setting, and although some setting names may be the same or similar, there is no certainty that the types of services or number of residents is the same across jurisdictions. Shaded rows denote overall cases and deaths from each jurisdiction using JHCSS data. JHCSS data and IDD data from the jurisdictions report COVID-19 cases and COVID-19 deaths, but do not provide specification regarding method of case confirmation or cause of death.

Sources of data: Arizona (https://des.az.gov/services/disabilities/developmental-disabilities/vendors-providers/actions_related_to_covid-19); California (<https://www.dds.ca.gov/corona-virus-information-and-resources/>); Connecticut (<https://portal.ct.gov/DDS/General/COVID19/DDS-COVID-19-Figures-and-Trends>); District of Columbia (<https://coronavirus.dc.gov/page/human-services-agency-covid-19-case-data>); Illinois (<https://www.dhs.state.il.us/page.aspx?item=125170>); Louisiana (<https://ldh.la.gov/index.cfm/page/3959>); Maryland (https://dda.health.maryland.gov/Pages/Deputy_Secretary%27s_Webinars_on_COVID-19.aspx); New Jersey (<https://nj.gov/humanservices/coronavirus.html>); Oregon (<https://www.oregon.gov/dhs/SENIORS-DISABILITIES/DD/Pages/COVID19-Info-for-DD-Residential-Settings.aspx>); Pennsylvania (<http://www.paproviders.org/office-of-developmental-programs-odp-covid-19-report/>); Virginia (<https://dbhds.virginia.gov/covid19>); Washington (<https://www.dshs.wa.gov/dda/dda-community-residential-service-providers-confirmed-covid-19-cases>); JHCSS (https://github.com/CSSEGISandData/COVID-19/tree/master/csse_covid_19_data/csse_covid_19_time_series).

COVID-19 case-fatality rate than the general population across 12 US jurisdictions, with increased severity of difference for people living in congregate settings, especially when providing 24 h nursing care, underscores the fact that results reported in earlier studies are not unique to New York or California.^{11,12} Though we do not have data from all 51 US jurisdictions, results from this study from 12 jurisdictions representing the geographic diversity of the US provide compelling evidence that risk of more severe COVID-19 outcomes among people with IDD is likely pervasive across the US. As has been articulated in more detail in other studies,^{11,12,16} these results warrant immediate action by all persons involved in ensuring the safety and well-being of people with IDD – inclusive of self-advocate, family members, and care providers – to take all necessary steps to ensure the safety and well-being of this population during the pandemic. This is especially the case for people with IDD living in congregate settings.

In addition to the need to assure the safety and well-being of people with IDD during the pandemic, results from this study also highlight pressing concerns about data collection. The inadequate surveillance of health outcomes among the population of people with disability in the US in general, and people with IDD in particular was apparent pre-pandemic,¹⁷ and indicated at the beginning of the pandemic as a possible challenge to ensuring sufficient response to the needs of this population.^{3,18} Results from this study confirm this shortcoming, demonstrating a paucity of data sharing on COVID-19 outcomes across US jurisdictions. We are not able to determine whether the lack of data sharing in the 39 US jurisdictions not providing data is due to the lack of surveillance of COVID-19 outcomes for people with IDD in the state, or due to a decision to not publicly share collected data. Either way, the result of not engaging in adequate surveillance is detrimental to public health efforts aimed at ensuring the best possible outcomes for people with IDD during the pandemic.

In order to take the steps needed to provide optimal care for people with IDD during the pandemic, we need to better understand the disproportionate COVID-19 burden among people with IDD. This is particularly the case in regard to people with IDD residing in non-congregate settings. To do so, it is imperative that

all parties involved in providing services for people with IDD, including federal and state agencies, ensure the collection and public sharing of standardized COVID-19 data for people with IDD. At the least, data sharing should include cases and deaths by type of services provided and type of residential setting. It is important to note that beyond the immediate crisis, standardized data from the states would be critical in informing policy decisions that are likely to be debated after the pandemic in areas such as congregate living in home and community-based services, health supports and healthcare accessibility for people with IDD, and the essential roles played by family and paid direct support caregivers as frontline crisis resources.

The implications of the lack of reporting of COVID-19 data for people with IDD have been obvious at numerous junctures, including the early efforts of the CDC and states to determine and implement vaccination prioritization strategies. Based upon evidence from a study on a sample of adults with IDD living in residential group homes in New York State,¹¹ the National Academies of Sciences, Engineering and Medicine (NAS) recommended that people with IDD residing in congregate care settings, and their care staff, should be prioritized for the COVID-19 vaccine.¹⁹ While there is evidence that some states promptly heeded this advice, others either did not, or did so at a comparatively slower pace.^{20,21} In addition, there are reports that even when states did prioritize people with IDD for a COVID-19 vaccine, that individuals with IDD face obstacles in receiving the vaccine.^{22,23}

Beyond the concern that people with IDD in congregate settings and their support staff did not receive prioritization for vaccine in all states, it is critical to note that the NAS framework did not suggest prioritization for people with IDD living in non-congregate settings, such as their own home or a family home. This was a critical oversight as many people with IDD, including those living in non-congregate settings, require physically proximate personal care. It may be that the NAS report did not recommend all people with IDD for vaccine prioritization due to the lack of evidence available on people with IDD living in non-congregate settings at the time of the report. Evidence from this study on case-fatality rates among people with IDD living in their own or a family

home was mixed, with some having higher, some similar, and some lower case-fatality rates as the state. Though all states have opened COVID-19 vaccines to all adults, it is important to ensure elimination of any barriers that may prevent people with IDD, including those living in congregate settings, a family home, or their own home full access to the a COVID-19 vaccine.²²

Limitations

Although this study provides evidence of increased COVID-19 case-fatality rates among people with IDD in 12 US jurisdictions through late March/early April 2021, there are four primary limitations related to data. We cannot determine the effect of COVID-19 on people with IDD living in their own or a family home, as well as other settings, in states that have not reported data. The data currently reported by the 12 jurisdictions does not provide any information related to level of services provided within home settings, which could indicate level of health or personal needs. In addition, the data used for this study – inclusive of IDD data reported by the 12 jurisdictions and the JHCSSE data used for comparison – does not provide the age, sex, or racial-ethnic distribution of cases or deaths, factors that could explain some of the observed differences reported in this study. Finally, as reporting is not standardized across the US, we cannot determine the level of consistency present/not present in the jurisdictions reporting COVID-19 outcomes and IDD service settings. While it would be ideal to compare COVID-19 outcomes for people with IDD to a comparison group matched on age, sex, race-ethnicity, pre-existing conditions, and type of residence, data with this level of detail for people with IDD or the general population are not available for the US setting.

Conclusion

Based on findings from this study that case-fatality rates are consistently higher across the jurisdictions for people with IDD living in congregate settings, are higher for some people with IDD living in their own or family home, and the increased need for direct support that cannot be socially distanced, we concur with researchers and advocates that all people with IDD, and their care providers, should have full access to a COVID-19 vaccine. Efforts should be made to ensure that information about the vaccine is provided for persons with IDD in plain language, and that access to vaccinations are readily available and provided in such a manner that attends to any accompanying support needs. Yet, until all states report COVID-19 outcomes for people with IDD, it will be impossible to make determinations about the best possible short-term and long-term public health interventions for this or subsequent public health crises, that are germane to each state.

Author contributions

Scott D. Landes had full access to all of the collected data in the study and takes responsibility for the accuracy of the data analysis, Scott D. Landes: Acquisition and analysis of data, Concept and design, Interpretation of analysis, Drafting of the manuscript, Critical revision of the manuscript for important intellectual content, Statistical analysis. Margaret A. Turk: Concept and design, Interpretation of analysis, Critical revision of the manuscript for important intellectual content. David A. Ervin, MA: Concept and design, Interpretation of analysis, Critical revision of the manuscript for important intellectual content.

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Conflicts of interest

None.

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