Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.
Brief Report

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

Scott D. Landes, PhD a,*, Margaret A. Turk, MD b, David A. Ervin, MA c

a Department of Sociology and Aging Studies Institute, Maxwell School of Citizenship and Public Affairs, Syracuse University, Syracuse, NY, 13244, USA
b Department of Physical Medicine & Rehabilitation, SUNY Upstate Medical University, Syracuse, NY, 13210, USA
c Jewish Foundation for Group Homes, Rockville, MD, USA

A R T I C L E   I N F O

Article history:
Received 19 April 2021
Received in revised form 6 May 2021
Accepted 10 May 2021

Keywords:
COVID-19
Case-fatality
Intellectual disability
Developmental disability
US states

A B S T R A C T

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.

© 2021 Elsevier Inc. All rights reserved.

Introduction

People with intellectual and developmental disabilities (IDD) are a vulnerable health population. At the beginning of the pandemic in the US, researchers warned that people with IDD may experience more severe COVID-19 outcomes due to: 1) higher prevalence of certain pre-existing conditions; 2) persistent healthcare disparities; 3) a disproportionately greater percentage of this population living in congregate settings; and 4) the need for personal and/or medical care that cannot be socially distanced among all people with IDD, but especially those living in congregate settings. 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 IDD at younger ages. 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. 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
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) data14 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 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.

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.15 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%) | 0.89       | (0.62) |
|                           | IDD – Residential setting             | Residential               | 1108  | 44     | 3.97%              | (2.97%) | 1.96       | (1.48) |
|                           | All cases and deaths for jurisdiction |                           | 850,846 | 17,105 | 2.01%              | (1.98%) | 1.67       | (1.34) |
| California (April 6, 2021) | IDD – Community Care Facility         | Residential               | 3902  | 75     | 1.92%              | (1.54%) | 1.18       | (0.95) |
|                           | IDD – Intermediate Care Facilities for the Developmentally Disabled | Residential | 280  | 22     | 7.86%              | (5.29%) | 4.83       | (3.24) |
|                           | IDD – Intermediate Care Facilities-Habilitative | Residential | 1132  | 30     | 2.65%              | (1.86%) | 1.63       | (1.15) |
|                           | IDD – Intermediate Care Facilities -Nursing | Residential | 582  | 31     | 5.33%              | (3.78%) | 3.28       | (2.33) |
|                           | IDD – Supported Living Services       | Own/family home           | 893   | 21     | 2.35%              | (1.57%) | 1.45       | (0.95) |
|                           | IDD – Family Home                     | Own/family home           | 8512  | 48     | 0.56%              | (0.43%) | 0.35       | (0.26) |
|                           | IDD – Skilled Nursing Facility        | Residential               | 568   | 79     | 13.91%             | (11.30%)| 8.56       | (6.97) |
|                           | All cases and deaths for jurisdiction |                           | 3,685,045 | 59,887 | 1.63%              | (1.61%) | 1.64       | (1.64) |
| Connecticut (April 13, 2021) | IDD – Training Schools or Regional Centers | Residential | 155  | 12     | 7.74%              | (3.53%) | 3.16       | (1.84) |
|                           | IDD – DDS Public Community Living Arrangements & Others | Residential | 67  | 1     | 1.49%              | (0.26%) | 0.61       | (0.87) |
|                           | IDD – Private Providers - Statewide (Residential) | Residential | 1116  | 49     | 4.39%              | (3.34%) | 1.79       | (1.36) |
|                           | All cases and deaths for jurisdiction |                           | 325,689 | 7974  | 2.45%              | (2.40%) | 1.94       | (1.54) |
| District of Columbia (April 13, 2021) | IDD – All service recipients | All recipients | 426  | 55     | 12.91%             | (10.05%)| 5.48       | (4.25) |
|                           | All cases and deaths for jurisdiction |                           | 46,016 | 1085  | 2.36%              | (2.22%) | 2.05       | (1.96) |
| Illinois (March 31, 2021)  | IDD – Community Integrated Living Arrangements | Residential | 1903  | 53     | 2.79%              | (2.05%) | 1.47       | (1.13) |
|                           | All cases and deaths for jurisdiction |                           | 1,244,499 | 23,579 | 1.89%              | (1.87%) | 1.92       | (1.73) |
| Louisiana (April 2, 2021)  | IDD – Intermediate Care Facilities    | Residential               | 995   | 61     | 6.13%              | (4.80%) | 2.69       | (2.11) |
|                           | IDD – Home and community based services | Residential | 634  | 34     | 5.36%              | (3.86%) | 2.35       | (1.69) |
|                           | All cases and deaths for jurisdiction |                           | 445,469 | 10,161 | 2.28%              | (2.24%) | 2.32       | (1.52) |
| Maryland (April 2, 2021)   | IDD – All service recipients          | All recipients            | 2097  | 102    | 4.86%              | (4.02%) | 2.42       | (2.00) |
|                           | All cases and deaths for jurisdiction |                           | 414,385 | 8319  | 2.01%              | (1.96%) | 2.05       | (1.59) |
| New Jersey (April 4, 2021) | IDD – Licensed Community Settings     | Residential               | 1813  | 112    | 6.18%              | (5.16%) | 2.32       | (1.94) |
|                           | IDD – Own Home                        | Own/family home           | 556   | 51     | 9.17%              | (7.05%) | 3.45       | (2.66) |
|                           | IDD – Developmental Centers           | Residential               | 740   | 58     | 7.84%              | (6.11%) | 2.95       | (2.30) |
|                           | All cases and deaths for jurisdiction |                           | 927,195 | 24,637 | 2.66%              | (2.62%) | 2.69       | (2.63) |
| Oregon (April 12, 2021)    | IDD – Residential group homes         | Residential               | 170   | 11     | 6.47%              | (5.86%) | 4.53       | (2.55) |
|                           | IDD – Own home (in-home; supported living) | Own/family home | 201  | 4      | 1.99%              | (0.78%) | 1.39       | (0.53) |
|                           | All cases and deaths for jurisdiction |                           | 170,850 | 2441  | 1.43%              | (1.37%) | 1.49       | (1.37) |
| Pennsylvania (April 9, 2021) | IDD – Licensed Community-Based Residential | Residential | 2622 | 131    | 5.00%              | (4.23%) | 2.10       | (1.78) |
|                           | IDD – Intermediate Care Facilities   | Residential               | 551   | 36     | 6.53%              | (4.76%) | 2.74       | (2.00) |
|                           | All cases and deaths for jurisdiction |                           | 1,066,707 | 25,358 | 2.38%              | (2.33%) | 2.41       | (2.33) |
| Virginia (April 15 2021)   | IDD – Supportive Services             | Own/family home           | 40    | 4      | 10.00%             | (3.96%) | 6.09       | (2.40) |
|                           | IDD – Sponsored Residential Home Services | Own/family home | 131  | 1      | 0.76%              | (0.76%) | 0.47       | (0.47) |

(continued on next page)
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.\textsuperscript{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,\textsuperscript{11,12,15} 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,\textsuperscript{17} and indicated at the beginning of the pandemic as a possible challenge to ensuring sufficient response to the needs of this population.\textsuperscript{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,\textsuperscript{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.\textsuperscript{13} While there is evidence that some states promptly heeded this advice, others either did not, or did so at a comparatively slower pace.\textsuperscript{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.\textsuperscript{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

| State | Setting\(^{*}\) | Category | Cases | Deaths | Case-fatality rate | 95% CI | Risk ratio | 95% CI |
|-------|----------------|----------|-------|--------|-------------------|-------|-----------|-------|
| IDD – Residential/Crisis Stabilization Services | Own/family home | Residential | 994 | 43 | 4.33% (4.20%) | 1.03% | 0.97% | 1.07% |
| IDD – Day Support Services | Own/family home | Residential | 55 | 4 | 7.27% (7.86%) | 4.43% | 3.53% | 5.33% |
| IDD – Case Management | Not determined | Residential | 275 | 18 | 6.55% (17.26%) | 3.99% | 2.55% | 6.24% |
| All cases and deaths for jurisdiction | | | 641,626 | 10,529 | 1.64% (1.67%) | 3.46% | 2.49% | 4.81% |
| Washington (April 12, 2021) | IDD – Community Residential Service Providers | Residential | 697 | 34 | 4.88% (3.51%) | 1.37% | 1.45% | 1.01% |
| All cases and deaths for jurisdiction | | | 377,952 | 5329 | 1.41% (2.64%) | 3.53% | 2.64% | 4.38% |

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 JHCSSE data. JHCSSE data and IDD data from the jurisdictions report COVID-19 cases and COVID-19 deaths, but do not provide specific 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 is evidence that some states promptly heeded this advice, others either did not, or did so at a comparatively slower pace.

Sources of data: Arizona (https://www.dds.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?ItemID=125170); Louisiana (https://idh.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/sciences, engineering and medicine); Oregon (https://www.oregon.gov/dhs/SENIORS-DISABILITIES/IDD/Pages/COVID19-Info-for-DD-Residential-Settings.aspx); Pennsylvania (http://www.paperworkr.org/office-of-development让消费者 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); JHCSSE (https://github.com/CSSEGISandData/COVID-19/tree/master/csse_covid_19_data/csse_covid_19_time_series).
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 jHCCSE 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.

Funding

Research reported in this publication benefited from National Institute on Aging (NIA) Center Grant P30AG066583, Center for Aging and Policy Studies, Syracuse University. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Disclaimer

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Conflicts of interest

None.

References

1. Spong CY, Bianchi DW. Improving public health requires inclusion of under-represented populations in research. J Am Med Assoc. 2018;319(4):337–338.
2. Landes SD, Turk MA, Formica MK, McDonald KE. COVID-19 Trends Among Adults with Intellectual and Developmental Disabilities (IDD) Living in Residential Group Homes in New York State through July 16, 2020. Syracuse, NY: Lerner Center for Public Health Promotion, Syracuse University; September 16 2020. https://lernercenter.syr.edu/wp-content/uploads/2020/09/Landes_ResearchBrief_Final.pdf.
3. Boyle CA, Fox MH, Havercamp SM, Zubler J. The public health response to the COVID-19 pandemic for people with disabilities. Disability and Health Journal. 2020, 100943.
4. Fraser VP, Janicki MP, eds. Physical Health of Adults with Intellectual and Developmental Disabilities. second ed. New York: Springer; 2019.
5. Krahn GL, Fox MH. Health disparities of adults with intellectual disabilities: what do we know? What do we do? J Appl Res Intellect Disabil. 2014;27(5): 431–446.
6. Braddock D, Hemp R, Tanis ES, Wu J, Haffer L. The State of the States in Developmental Disabilities: 2017. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2017.
7. Larson SA, Eschenbacher HJ, Anderson LL, et al. In-home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration; 2018.
8. Drum CE, Oberg A, Cooper K, Carlin R. COVID-19 & Adults with Disabilities: Health and Health Care Access Online Survey Summary. report. Rockville, MD: American Association on Health and Disability; 2020.
9. Sabatello M, Landes SD, McDonald KE. People with disabilities in COVID-19: fixing our priorities. Am J Bioeth. 2020;20(7):187–190.
10. Turk MA, Landes SD, Formica MK, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. Disability and Health Journal. 2020;13(3):1–4.
11. 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. Disability and Health Journal. 2020;13(4):1–5.
12. Landes SD, Turk MA, Wong AWWA. COVID-19 outcomes among people with intellectual and developmental disability in California: the importance of type of residence and skilled nursing care needs. Disability and Health Journal. 2021;14(2):1–5.
13. Johns Hopkins University. COVID-19 Dashboard by the Center for Systems Science and Engineering (CSSE). Johns Hopkins University; 2020. Published. https://www.arcgis.com/apps/epidashboard/index.html#/bda7594747402d009423467b4e9e86. Accessed January 15, 2021.
14. Murray P, Wood Hassan M, Warren E. Congregate care data request. United states senate, committee on health, education, labor, and Pensions. https://www.help senate.gov/images/media/doc/3022019SteelCare210ert%20Help%20Congress%20-%2020October%202020.pdf. 2020. Accessed November 1, 2020. Published.
15. Ayoubkani D, Bosworth M. Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020. Office for National Statistics (ONS). https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020; 2021. Accessed May 6, 2021. Published.
16. Landes SD, Turk MA, Damiani MR, Proctor P. Risk factors associated with COVID-19 outcomes among people with intellectual and developmental disabilities receiving residential services. JAMA Open. 2021;4(6); e2112862.
17. Krahn GL. A call for better data on prevalence and health surveillance of people with intellectual and developmental disabilities. IntelDev Intirdisabil.
18. Reed NS, Meeks LM, Swenor BK. Disability and COVID-19: who counts depends on who is counted. The Lancet Public Health. 2020;5(8):e423.

19. National Academies of Sciences E, Medicine. Framework for Equitable Allocation of COVID-19 Vaccine. Washington, DC: The National Academies Press; 2020.

20. Contrera J. People with Disabilities Desperately Need the Vaccine. But States Disagree on when They’ll Get it. The Washington Post. January 13, 2021.

21. Johns Hopkins University Disability Health Research Center. COVID-19 Vaccine Prioritization Dashboard. Johns Hopkins University; 2021. https://disabilityhealth.jhu.edu/vaccine/. Accessed March 17, 2021. Published.

22. Musumeci MB, Chidambaram P. COVID-19 Vaccine Access for People with Disabilities. San Francisco: Kaiser Family Foundation; April 23 2021. https://www.kff.org/medicaid/issue-brief/covid-19-vaccine-access-for-people-with-disabilities/.

23. Brangham W, Carlson F, Zein D. Relative Invisibility Makes for Uphill Battle to Get COVID Vaccines for Americans with IDD. PBS; 2021. https://www.pbs.org/newshour/show/relative-invisibility-makes-for-uphill-battle-to-get-covid-vaccines-for-americans-with-idd. Accessed May 6, 2021. Published.