

## COVID-19 DATA ON INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

### KEY POINTS

- While most states surveyed collected and reported certain key COVID-19 data for individuals with intellectual and developmental disabilities (ID/DD) (e.g., number of deaths, number of people hospitalized), data collection and reporting varied greatly across states and residential settings.
- Less than half of the states surveyed collected COVID-19 death data for the ID/DD population by race, ethnicity, and age, which limits targeted allocation of resources and interventions to those that may be disproportionately impacted by the pandemic.
- States used data to make key decisions such as targeted payment strategies for providers, service modality modifications, and vaccine prioritization and distribution strategies at the state level.
- Future federal, state, and local efforts should focus on the development and implementation of a national framework for data collection and reporting to monitor post-COVID conditions among the ID/DD population to readily analyze and respond to evolving needs, including future public health emergencies.

### COVID-19 AND INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

As of July 23, 2021, the United States had approximately 34 million confirmed cases and over 610,000 deaths related to COVID-19.<sup>1</sup> Individuals with intellectual and developmental disabilities (ID/DD) are at greater risk for infection and adverse health outcomes due to COVID-19 than individuals without ID/DD for a variety of reasons, including a high prevalence of underlying medical conditions; difficulties accessing information, understanding or practicing preventative measures, and communicating symptoms of illness; and residing in a congregate care setting.<sup>2,3,4,5</sup>

Despite the high risk of COVID-19 infection and mortality among individuals with ID/DD, there is no standardized national framework to facilitate the collection and sharing of COVID-related data for this population. An increased understanding of state collection and reporting of COVID-19 data for the ID/DD population may help inform future policies, programs, and practices that aim to reduce the risk of infection and mitigate adverse effects of COVID-19 and other infectious diseases.

### COVID-19 ID/DD DATA COLLECTION AND REPORTING AT THE STATE LEVEL

The National Association for State Directors of Developmental Disabilities Services fielded an online survey to its members (state directors of ID/DD agencies) to better understand state-level COVID-19 data collection and reporting for the ID/DD population and direct support professionals (DSPs) that provide services to individuals

with ID/DD. The online survey was fielded from January 2021 through February 2021; 28 state ID/DD agencies responded.

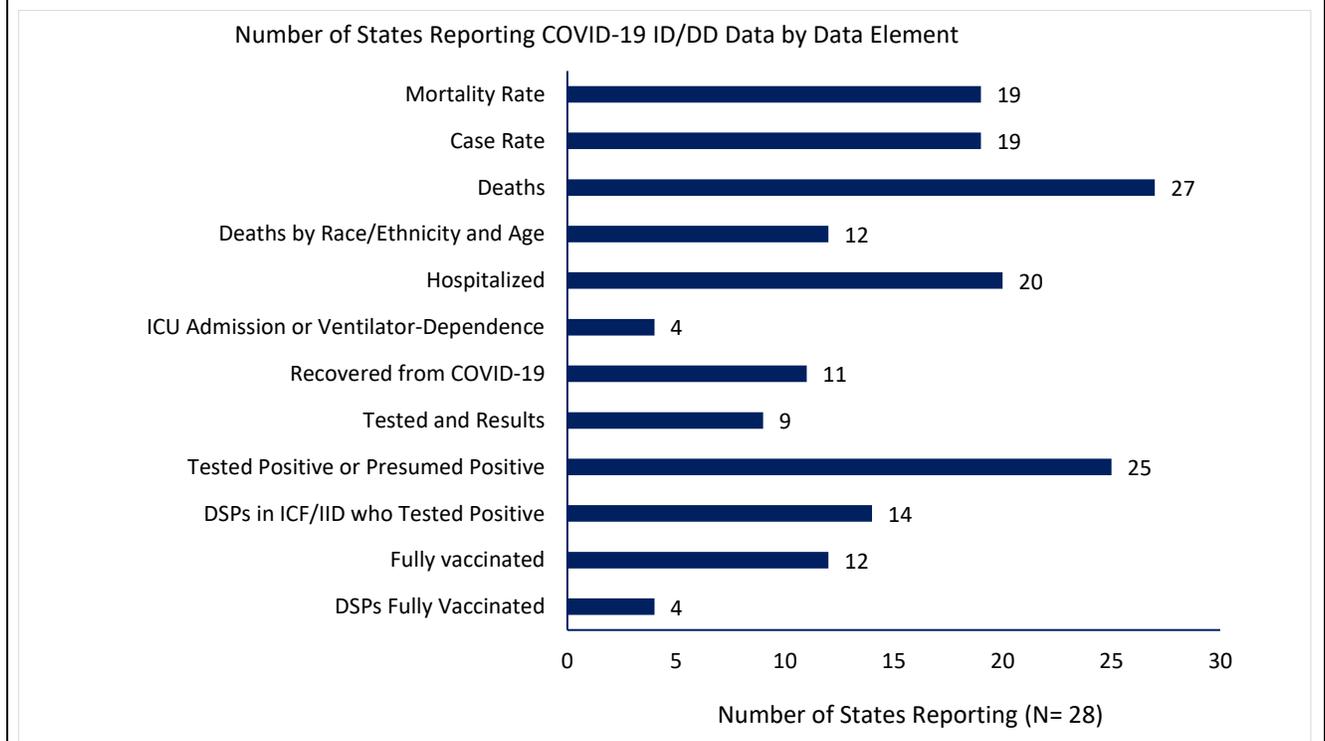
*Few states report COVID-19 ID/DD data publicly; of the states that do publicly report, data collection and reporting are inconsistent and residential setting, age, race, and ethnicity are often unspecified.*

A majority of survey respondents (i.e., the state ID/DD agencies) reported the number of deaths due to COVID-19 infection (27 states), the number of people hospitalized due to COVID-19 (25 states), and the total number of people who tested (or were presumed) positive for COVID-19 (25 states) among individuals with ID/DD.

Only 16 of the 28 responding states collected COVID-19 information on people living in their own homes or with family. Generally, data reporting requirements prior to the COVID-19 pandemic applied only to formal provider-owned and operated residential settings, resulting in a more developed data infrastructure and more comprehensive data

collection and reporting in these settings. However, unlike other types of long-term care facilities, intermediate care facilities for individuals with intellectual disabilities (ICFs/IID) were not required to report COVID-19 data to the National Healthcare Safety Network during the COVID-19 public health emergency (PHE).<sup>6</sup>

**Figure 1. Number of States Reporting COVID-19 ID/DD Data by Data Element**



\*NOTE: With the exception of the information on DSPs, all data in graph reference people with ID/DD who receive services through state ID/DD systems in the 28 states queried; all data are COVID-19 specific.

Additionally, less than half of the states (12 of 28 states) surveyed collected COVID-19 death data for the ID/DD population by race, ethnicity, and age. The lack of demographic data limits the ability of federal, state, and local officials to understand the effects of COVID-19 on persons with ID/DD across different residential settings, age groups, or racial or ethnic groups, which limits targeted allocation of resources and interventions

to those that may be disproportionately affected by the pandemic. Linking COVID-19 data to data sources that contain sociodemographic data elements, such as race, ethnicity, and residential setting, may allow for analyses to identify any disparities in health outcomes within the ID/DD population.

The vaccination rate among individuals with ID/DD differs across and within states. As of late April 2021, many states report high rates of vaccination among individuals in congregate settings, but efforts to maximize vaccine uptake continue.<sup>7,8</sup>

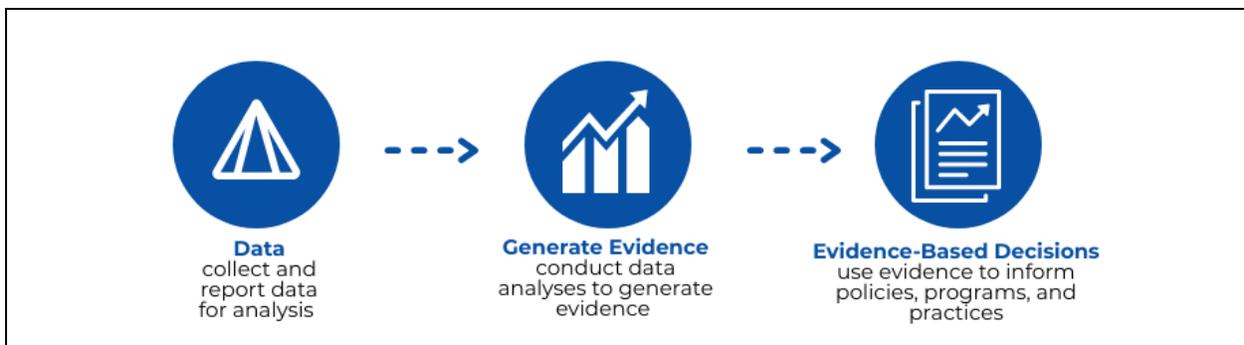
## DATA-DRIVEN DECISIONS RELATED TO THE ID/DD POPULATION DURING THE COVID-19 PANDEMIC

State ID/DD agencies, in partnership with state public health, Medicaid, and emergency management agencies, implemented data-informed responses to the COVID-19 pandemic. For example, states used exposure and infection rate data to inform targeted payment strategies for both provider agencies and DSPs to ensure continuity of service provision for individuals with ID/DD. Arkansas, for instance, instituted an enhanced tiered payment based on the acuity of individuals served who had tested positive for COVID-19.

States also used data to inform service modality modifications. Missouri's access to real-time infection rates across all local counties provided source information for the state ID/DD agency to make service modality changes, including adjusting case management in-person monitoring to remote monitoring to mitigate the risk of COVID-19 spread in areas with high levels of infection. As COVID-19 rates declined, the state permitted case managers to resume in-person visits, using social distancing and other protective measures.

Data also drove COVID-19 vaccine prioritization and distribution strategies. Some states, such as Ohio and Colorado, immediately included individuals with ID/DD and their DSPs in their top or near-top priority categories. Others, such as New York, added groups of individuals with ID/DD as information emerged and confirmed the increased risk associated with ID/DD. Prior to offering vaccines to all adults, some states continued to include only a portion of individuals with ID/DD living in their own homes and family homes depending on their other comorbidities. Emerging data contributed to a few of those states, including New York and California, adding ID/DD as a qualifying factor for vaccine prioritization (with variation regarding prioritization level).<sup>2</sup>

*Data drove **targeted payment strategies for providers, service modality modifications, and vaccine prioritization and distribution strategies at the state level.***



## BEYOND THE COVID-19 PANDEMIC: OPPORTUNITIES TO IMPROVE ID/DD DATA TO INFORM FUTURE INCIDENT MANAGEMENT AND PROMOTE DATA-DRIVEN DECISIONS

A lack of data on the ID/DD population, both prior to and during the COVID-19 pandemic, continues to limit the ability of federal, state, and local governments to understand and respond to the effects of the COVID-19 pandemic on this population. Emerging evidence suggests some people with COVID-19 experience post-COVID conditions, a wide range of new, recurring, or ongoing health problems experienced more than four weeks after first infection with the virus.<sup>9</sup> Most of the existing research on the prevalence and symptomology of post-COVID conditions has relied on voluntary self-reports from COVID-19 patients.<sup>9</sup> Self-report data mechanisms, such as telephone applications, should be accessible for all individuals with ID/DD to ensure data capture the full experience of the ID/DD population. In the near term, federal and state agencies, in coordination with service providers, should monitor both the incidence and prevalence of post-COVID conditions among those with ID/DD and the DSPs that provide services to individuals with ID/DD.

Beyond the pandemic, longer-term efforts to improve ID/DD data should be coordinated across the federal, state, and local levels and focus on the development and implementation of a national framework for data collection on infectious diseases across all service providers, including providers of long-term services and supports. Federal, state, and local governments should ensure interoperability across data systems to monitor post-COVID conditions among the population to readily analyze and respond to evolving needs, including future PHEs.

State and Local Level	Federal Level
 <p>Convene discussions between state public health and emergency management partners and discuss data sharing capabilities</p>	 <p>Convene discussions between state and federal agencies to discuss data collection to address post-COVID-19 conditions</p>
 <p>Devise uniform policies for the use of incident management systems to report suspected and confirmed infectious disease exposure</p>	 <p>Develop a national framework for data collection on infectious disease across all long term services and support models</p>
 <p>Invest in data systems that enable interoperability across state data systems</p>	 <p>Provide states financial support to build or adapt data systems to enable necessary interoperability</p>

## REFERENCES

1. Johns Hopkins University and Medicine. (n.d.). *COVID-19 Map*. Johns Hopkins Coronavirus Resource Center. <https://coronavirus.jhu.edu/map.html>.
2. J. Gleason, W. Ross, A. Fossi, H. Blonsky, J. Tobias, & M. Stephens. (2021). *The Devastating Impact of COVID-19 on Individuals with Intellectual Disabilities in the United States*. NEJM Catalyst Innovations in Care Delivery. <https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051>.
3. S.D. Landes, M.A. Turk, M.K. Formica, K.E. McDonald, & J.D. Stevens. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and Health Journal*. <https://pubmed.ncbi.nlm.nih.gov/32600948/>.
4. West Health Institute, & M. Makary. (2020). *Risk Factors for COVID-19 Mortality among Privately Insured Patients: A Claims Data Analysis*. Fair Health, Inc. <https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20-%20A%20FAIR%20Health%20White%20Paper.pdf>.
5. Centers for Disease Control and Prevention. (2021). *People with Disabilities*. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>.
6. Centers for Medicare & Medicaid Services. (2020). *Coronavirus Disease 2019 Frequently Asked Questions for Non-Long Term Care Facilities and Intermediate Care Facilities for Individuals with Intellectual Disabilities*. <https://www.cms.gov/files/document/covid-faqs-non-long-term-care-facilities-and-intermediate-care-facilities-individuals-intellectual.pdf>.
7. National Association for State Directors of Developmental Disabilities Services. (2021). *State Director and Medical Directors Call*.
8. Centers for Disease Control and Prevention. (2021). *Post-COVID Conditions*. <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>.
9. F. Salamanna, F. Veronesi, L. Martini, M.P. Landini, & M. Fini. (2021). *Post-COVID-19 Syndrome: The Persistent Symptoms at the Post-viral Stage of the Disease. A Systematic Review of the Current Data*. Frontiers. <https://www.frontiersin.org/articles/10.3389/fmed.2021.653516/full>.

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