

COVID-19 CASE & MORTALITY REPORT

Intellectual or Developmental Disabilities

The 2020 COVID-19 pandemic has disproportionately affected people with Intellectual or Developmental Disability (I/DD). The purpose of this study was to evaluate the impact of COVID-19 on people with I/DD across the US and to educate key stakeholders to better support people with I/DD.

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METHODOLOGY OF SURVEY DATA AND FINDINGS:

COVID-19 data from eight states through May 31, 2020 analyzed in this report suggest that although the likelihood of an individual with I/DD being diagnosed was roughly equivalent to that of a member of the general public, they are substantially more likely to die from a COVID-19 infection. Executives from state I/DD provider associations requested data from their state for individuals with an I/DD diagnosis who are on Medicaid and served by either an I/DD HCBS waiver or an ICF/IID as of May 31, 2020: the total number of confirmed diagnoses, total number of deaths, and total number of individuals served.

While state data regarding COVID-19 incidence within the general public are readily available, not all states appear to be tracking and maintaining data on incidence of infection and death specifically among individuals who have I/DD. Out of the states that were contacted, eight states included in this report provided the level of data required for a comparative analysis of COVID-19 incidence among individuals who have I/DD.

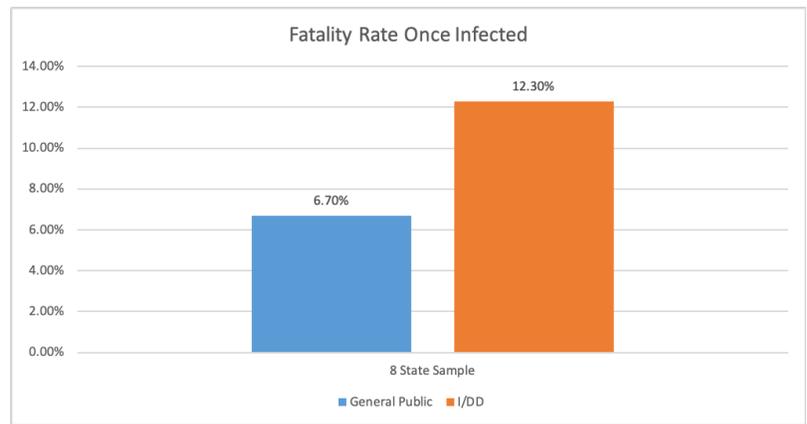
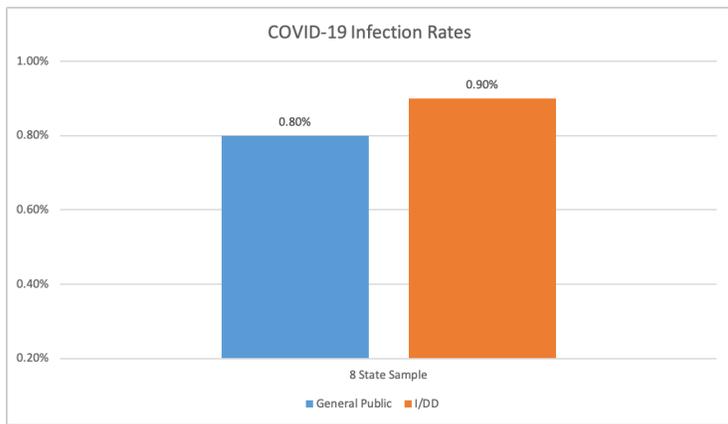
They were: California, Colorado, Indiana, Maryland, New Jersey, New York, Pennsylvania, Virginia

Researchers from the following organizations contributed to this analysis: Syracuse University, Institute on Disabilities (PA UCEDD) at Temple University, Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities, and New York Alliance for Inclusion & Innovation.

The combined population of these eight states was 107,722,117, or roughly 33% of the estimated population of the United States as of July 2019. These eight states support 611,202 people who have I/DD. As of May 31, 2020, 5,756 adults with I/DD within these eight states had been diagnosed with COVID-19, resulting in a case rate of 941 per 100,000. Comparatively, a total of 877,618 members of the general public in these eight states had been diagnosed with COVID-19, resulting in a case rate of 815 per 100,000. Our sampling indicates that 12.3% of adults with I/DD died from reasons related to the infection, while only 6.7% of members of the general public who contracted the virus ultimately died from reasons related to COVID-19. Summarizing these figures, the likelihood of an individual with I/DD being diagnosed was roughly equivalent to that of a member of the general public (1.1 times more likely). Once diagnosed, however, the individual with I/DD was 1.84 times more likely to die than an infected member of the general public. Based upon these results, it is clear COVID-19 has disproportionately impacted individuals who have I/DD. Notably, similar findings were reported in the 2017-2018 flu epidemic in The Netherlands.¹

An important consideration is that COVID-19 has spread over time across the United States. The target point for data collection of May 31, 2020 ensures temporal comparability, but it must be recognized that some states were more advanced in the pandemic than others as of this date. In fact, of the eight states, only three (New Jersey, New York, Pennsylvania) were reported to have reached their peak infection rate as of May 31, 2020, although these three states comprise about 12.5% of the population of the United States.

¹ Cuypers, M., Schalk, B. W. M., Koks-Leensen, M. C. J., Nägele, M. E., Bakker-van Gijsel, E. J., Naaldenberg, J., and Leusink, G. L. (2020). Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic. *Journal of Intellectual Disability Research*, 64: 482-488. <https://doi.org/10.1111/jir.12739>.



RECOMMENDATIONS:

The finding across the eight states in the analysis that people with I/DD have been infected by the virus at roughly the same rate as the general population demonstrates the successful work done by I/DD providers to keep people safe. **The most alarming finding was that individuals with I/DD diagnosed with COVID-19 are much more likely to die from the disease than are members of the general public.** The impact of the high rate of comorbidity among people with I/DD and the presumed older average age of the people with I/DD in the study population have been suggested as a possible contributory factors, but further analysis is required to ascertain contributory factors and caution should be exercised in offering speculative explanations.

It is clear that individuals who have I/DD are particularly at risk for severe complications from COVID-19, and thus we provide the following recommendations:

1. Given the higher risk factors associated with I/DD, service provider organizations need to receive enhanced reimbursement to provide increased compensation to the Direct Support Professionals (DSPs) who provide support to individuals who have I/DD and enhanced training.
2. Given the substantially higher death rate for individuals with I/DD, persons with I/DD and DSPs must be prioritized for receipt of any approved vaccine for COVID-19.
3. In anticipation of the continuation of COVID-19 infections (with the number of infections in some states rising lately), adequate Personal Protective Equipment (PPE) must be made available to organizations that support individuals with I/DD to ensure that both staff and individuals are protected; and the availability and funding for COVID-19 rapid testing for persons with I/DD and staff with direct contact with persons with I/DD.
4. Because of the volatility of these data, additional research would be beneficial to attempt to ascertain causal mechanisms for the apparent discrepancy in fatality rate. Caution should be exercised in attributing causation at this point in time.

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All data presented in this report were collected from provider associations in the participating states. The data are believed to be representative of information supplied to those provider associations, who reported receiving the data from their respective State governments.

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