

Potential Impacts of COVID-19 on Individuals with Intellectual and Developmental Disability: A Call for Accurate Cause of Death Reporting

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Recent reports suggest that people with intellectual and developmental disability (IDD) are dying from coronavirus (COVID-19) at startling rates. In New York State alone, health care providers have confirmed COVID-19 in 1,100 of the 140,000 people with IDD receiving formal disability services, 105 of whom have died.¹ Thus, the COVID-19 case fatality rate for people with IDD who are receiving services in New York State (9.5%) is 2.2 times higher than the reported overall COVID-19 case fatality rate for the state (4.4%).^{1,2} Given that the population of adults with IDD is more likely to die from pneumonia than the general population,³ and the development of pneumonia is a characteristic of severe COVID-19 cases,⁴ the higher case fatality rate is not surprising. However, it is uncertain how much this disparity will increase as deaths continue to accumulate.

KEY FINDINGS

- COVID-19 deaths will likely be more prevalent among those with intellectual and developmental disability (IDD).
- Death rates from pneumonia are between 2.2 times and 5.8 times higher among individuals with an IDD than among those without IDD, giving us a clear warning of the severity of COVID-19 among people with IDD.
- Underestimation of COVID-19 deaths is potentially more severe for those with IDD.
- Cause of death certifiers must be attentive to accurately recording IDD on the death certificate.

Pneumonia deaths: The canary in the COVID-19 coalmine?

Because COVID-19 is an acute respiratory disease, and pneumonia is one of the complications of COVID-19, we analyzed the pneumonia death rate among people with and without IDD in 2017 using U.S. mortality data to show the possible impact of COVID-19 on the population with IDD. Figure 1 displays the death rates from pneumonia among those with and without an IDD using death certificate data from 2017. The rates of death from pneumonia are between 2.2 times and 5.8 times higher among individuals with an IDD than among those without IDD, and are highest among those with Down syndrome. These pneumonia death rates from 2017 give us a clear warning of the potential severity of COVID-19 among people with IDD.

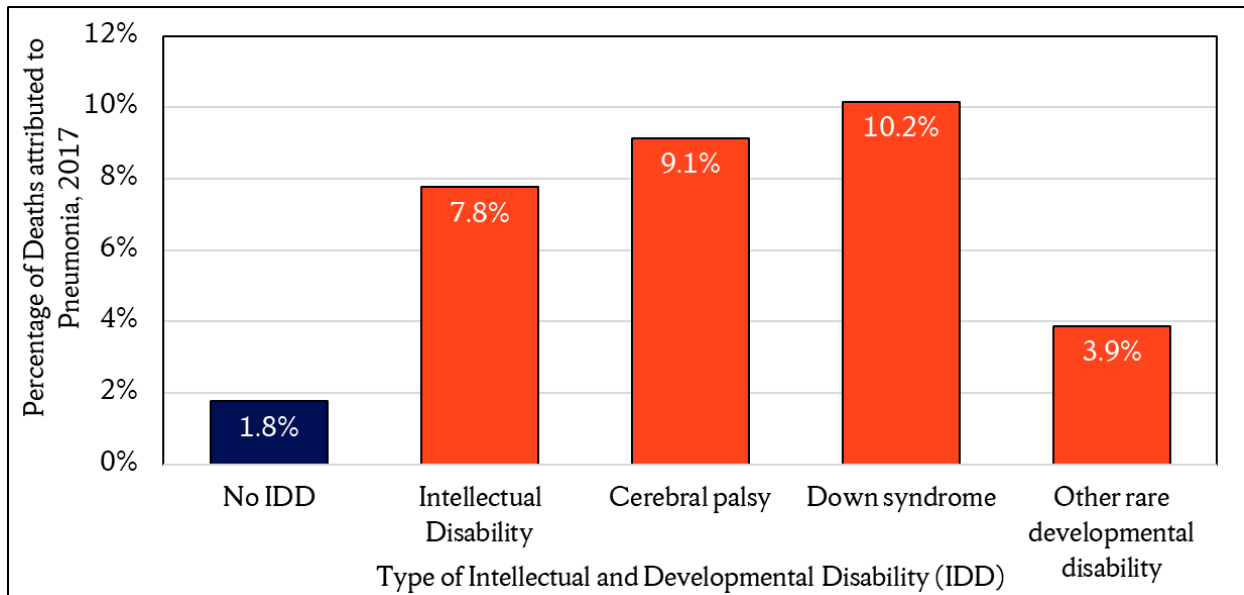


Figure 1. A Large Share of all deaths among Individuals with Intellectual and Developmental Disability are Attributable to Pneumonia

Data Source: National Center for Health Statistics, National Vital Statistics System, 2017 (among adults age 18 and older)

What is causing higher COVID-19 fatality rates among individuals with IDD?

It is not yet possible to determine the exact causal mechanism behind the higher COVID-19 case fatality rates we are now seeing among the population with IDD. The CDC suggests that people with some specific impairments (mobility, communication, cognition) are more vulnerable to COVID-19.⁵ Some disability-advocates and parents of children with IDD suggest that the higher case fatality rates may be, at least partially, due to the slow pace at which the disability service structure has responded to the pandemic.¹ Making swift and sweeping organizational change is challenging, especially during a time of severe crisis. Families of individuals with IDD and organizations that provide them with support and advocacy are often doing everything they can to survive this pandemic.^{1,6,7} However, for individuals with IDD to survive this pandemic, as well as any potential future outbreaks, it will be necessary to ensure that the IDD service system is better prepared to adjust rapidly to the challenges of providing care in the midst of severe health crises.

Accurately Identifying Cause of Death during the COVID-19 Pandemic: A Call for Better Practices and Policies

In order to identify the possible reasons that the case fatality rate from COVID-19 is higher among individuals with IDD, accurate information on causes of death for this population is essential. To date, a large and consistent problem with the mortality data for people with IDD is the [miscoding of the underlying cause of death on their death certificate](#) - arguably the most important statistic provided on the death certificate. On close to half (48%) of the death certificates of people with IDD, certifiers inaccurately identify the individual's disability as their underlying cause of death.³ If this practice continues during the COVID-19 pandemic, we will likely never be able to determine the actual COVID-19 death rate for individuals with IDD. Given low rates of testing and misclassifications of COVID-19 death early on, mortality rates from COVID-19 will be underestimated for the entire population, and underestimation is likely to be more severe among individuals with IDD. We urge individuals who are certifying death certificates to ensure they are: 1) recording COVID-19 as the underlying cause of death for adults with IDD who die from this virus;⁸ and 2) accurately recording the developmental disability in Part II of the medical certificate of death.³ Doing so is the only way we can

ensure that mortality data will accurately reflect the death rate from COVID-19 among the population with IDD.

Data and Methods

We used the 2017 National Vital Statistics System Multiple Cause of Death Mortality files for adults aged 18 and older (N=2,782,834). We used the International Classification of Disease 10th Revision (ICD-10) to identify the IDD and underlying cause of death on the death certificate. For a description of how to identify the underlying cause of death on death certificates of individuals with IDD, see this related publication.³ To determine the rates of death from pneumonia, we compared the rates of pneumonia out of all deaths reported in 2017, stratifying by IDD type.

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