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COVID-19 and Pneumonia: Increased Risk for Individuals with Intellectual and Developmental Disabilities during the Pandemic

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Early evidence indicates that, compared to the population overall, individuals with intellectual or developmental disabilities (IDD) have a slightly higher risk of contracting and a substantially higher risk of dying from the novel coronavirus (COVID-19). A report in the New York Times details that, as of April 6, 2020, adults with IDD receiving services from the state of New York had a COVID-19 cumulative incidence rate of 785.7 per 100,000 population. The cumulative incidence rate was only slightly lower, at 710.1 per 100,000 population in New York State overall.[1] Differences in death rates were starker. Among individuals with IDD who receive services from the state, 105 individuals out of 1,100 confirmed cases (9.5%) died from COVID-19,[2] a death rate 2.4 times higher than the death rate for the state overall (4.0%).[1]

KEY FINDINGS

- COVID-19 death rates are higher among adults with intellectual and developmental disabilities (IDD).
- Adults with IDD are more likely to develop pneumonia (a severe complication of COVID-19) than adults without IDD.
- Medical personnel must take extra precautions in treating COVID-19 symptoms in adults with IDD.
- Those certifying death certificates need to accurately record IDD on the death certificate.

The potential impact of structural vulnerabilities: Adults with IDD are a socially disadvantaged population

The reasons for the slightly higher incidence rate but substantially higher death rate cannot be fully disentangled at this time. Both structural and health mechanisms likely inform these trends. From a structural perspective, provider organizations and their care staff - who are also typically from lower-income or disadvantaged populations - serving adults with intellectual disability have been chronically underfunded[3,4] and are currently being asked to ensure continuity of services in the midst of this pandemic. That the cumulative incidence rate is only slightly higher among those with IDD speaks to the effectiveness of their heroic efforts during this time. A lack of proper funding is not the only structural challenged faced by adults with IDD in the U.S. Adults with IDD are a socially disadvantaged population that has higher rates of co-residence with others, lower socioeconomic status,[5] and poorer access to quality medical care.[6] These are all factors that can exacerbate poor health conditions,[7] especially during a time of crisis.

The potential impact of health vulnerability: Adults with IDD are at greater risk of developing pneumonia

Adults with IDD are a vulnerable health population,[8] with a higher prevalence of certain conditions/diseases that are critical to consider during the COVID-19 pandemic. One such health risk is pneumonia. COVID-19 severity is typically related to whether infected individuals develop

pneumonia.[9] In an earlier brief, we highlighted the overall prevalence of pneumonia as an underlying cause of death for adults IDD. In this brief, we focus on the age-adjusted comparative risk of pneumonia among adults with and without IDD. To do so, we calculated the age-adjusted odds ratios of having pneumonia indicated on the death certificate, either as underlying or contributory cause of death, in 2017 for adults with IDD in comparison to adults without IDD.

Compared to adults without IDD (6.7%), pneumonia was more common for adults with each type of IDD, including intellectual disability (14.4%), cerebral palsy (15.3), Down syndrome (17.4%), and other rare developmental disabilities (9.0%). Adults across all IDD categories had greater age-adjusted odds of having pneumonia contribute to their death than adults without IDD. Specifically, compared to adults without IDD, the probability of having a diagnosis of pneumonia at the time of death were 2.9 times higher for adults with intellectual disability, 3.5 times higher for adults with cerebral palsy, 3.9 times higher for adults with Down syndrome, and 1.9 times higher for adults with other rare developmental disabilities.

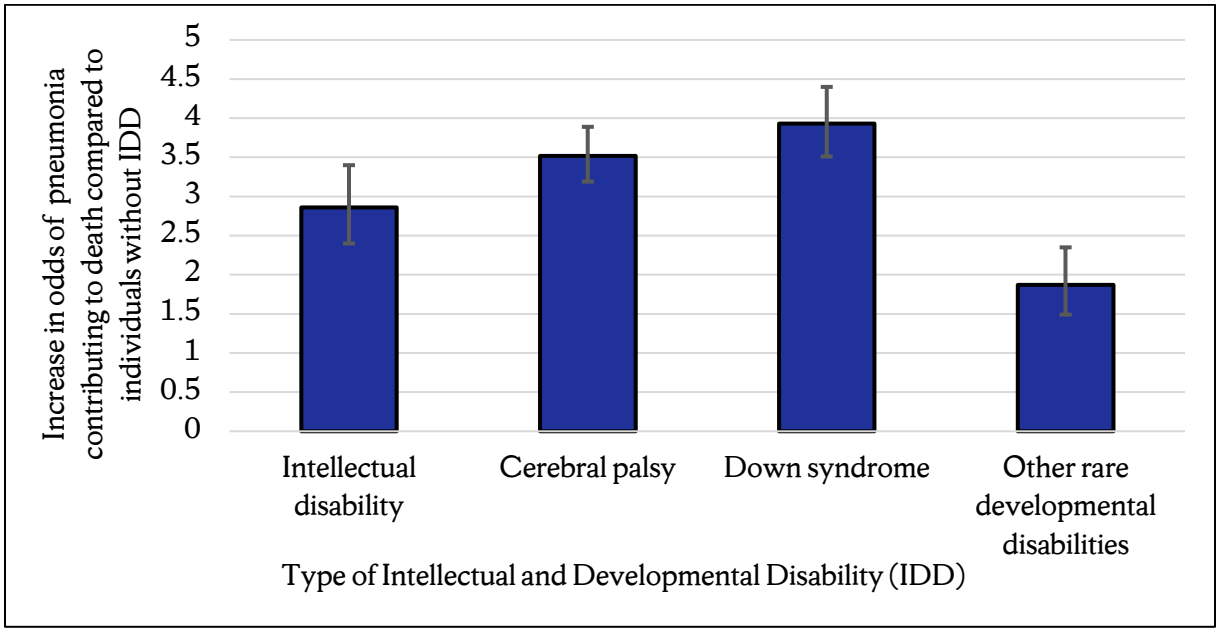

Figure 1: Odds of Dying from Pneumonia are Higher among Adults with Intellectual and Developmental Disabilities than among those Without

Data Source: National Center for Health Statistics, National Vital Statistics System 2017 US Multiple Cause of Death Mortality files, adults age 18 and over (N=2,782,834). *Note*: Error bars represent 95% confidence intervals. *Source*: Landes et al. 2020.

Extra precautions are needed in caring for adults with IDD, and accurately identifying cause of death during the COVID-19 pandemic

In light of these findings, we implore family members, care workers, and people with IDD themselves to take extra precautions to ensure the health and safety of adults with IDD during the on-going COVID-19 pandemic. Furthermore, when an individual with IDD contracts COVID-19, medical practitioners should be aware of the increased risk of pneumonia, possibly even with mild symptomatology. Difficulties with swallowing, weak or uncoordinated cough, and difficulty understanding and following instruction may exacerbate ability to clear secretions effectively.

In addition, we recommend that medical practitioners take care to accurately code the death certificates of any individuals with IDD who die from COVID-19. There has been an alarming practice in the U.S. of inaccurately coding IDD as an underlying cause of death.[10] In 2017, 56.9% of U.S. adults with IDD who had pneumonia as an underlying or contributing cause of death had their disability erroneously recorded as their underlying cause of death. Though not as common as in the U.S., these coding inaccuracies occur in other countries as well, such as the UK, Australia, and France.[11-13] This practice is not only inaccurate, but obscures actual causes of death in this population - for example, covering up higher rates of death from respiratory related diseases.[10,11] We are concerned that this imprecise coding practice may occur even when an individual dies from COVID-19. If this practice continues during the present pandemic, it will be difficult to ever know the true rate of COVID-19 death for adults with IDD.

To prevent these reporting inequities, we advise medical personnel certifying death certificates to: 1) accurately code COVID-19 as the underlying cause of death for individuals with IDD who die from this virus[14] and 2) record the IDD in Part II of the death certificate. This two-fold approach to proper death certificate coding ensures that underlying cause of death reporting is accurate and will enable researchers to eventually understand the full effects of COVID-19 on the population of adults with IDD.

Data and Methods

We used 2017 National Vital Statistics System U.S. Multiple Cause of Death Mortality data for adults age 18 and over (N=2,782,834). International Classification of Disease (ICD-10) codes were utilized to identify types of IDD, as well as pneumonia as either underlying or multiple cause of death. Odds ratios were adjusted for age at death.

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