

Persons with intellectual/developmental disabilities, COVID-19 and priority for vaccination

Context

Persons with intellectual/developmental disabilities (disabilities that begin in childhood and persist throughout the lifespan, including conditions such as Down syndrome, cerebral palsy, autism spectrum disorder, and fetal alcohol spectrum disorder) have been shown in large scale studies to be more susceptible than the general population to develop COVID-19 infection and to suffer more severe outcomes including death from infection. Protection of persons with developmental disabilities from COVID-19 will also require protection of their paid and unpaid caregivers and families.

As we develop a report on the impact of COVID-19 on Persons with Intellectual/Developmental Disabilities, we are sharing these recommendations in view of their timeliness toward informing ongoing deliberations regarding vaccine prioritization.

Recommendation #1: In recognition of the heightened susceptibility of persons with intellectual/developmental disabilities to severe complications and death from the COVID-19 virus as well as the disproportionate negative consequences of COVID-related public health measures on their mental health and well-being, the Federal Government, in conjunction with provincial and local governments must prioritize persons of all ages with intellectual or developmental disabilities and their caregivers (including personal assistants, family carers, and persons working in disability related services) in the distribution of COVID-19 vaccinations.

Recommendation #2: In view of accessibility challenges for this high-risk population, any information provided federally, provincially or locally about vaccinations should be shared with the public in an inclusive and accessible manner using a variety of formats to include text, simple infographics and short audio or video clips, and should also be shared with health care professionals and community organizations to reach out to all individuals with intellectual/developmental disabilities.

Background

The evidence on COVID-19 risk and outcomes for individuals with intellectual/developmental disabilities (IDD) is somewhat limited but quite consistent. For example, in a study using QResearch – a population level primary care database linked with COVID-19 data from Public Health England, hospital episode statistics, and the Office of National Statistics death registry, Clift et al. (2020) found that adults with IDD were at greater risk of death from COVID-19, with a particularly large increased risk for persons with Down Syndrome (Adjusted Hazard Ratio of 10.39; 95% CI: 7.08–15.23), even after adjusting for other risk factors and conditions such as diabetes or living in a care home. A more recent study (Hüls et al., 2021) reported that adults with Down syndrome hospitalized from COVID-19 were 2.5 times more likely to die (95% CI: 1.5-3.7), after adjusting for other known risk factors. The increased mortality rates among patients with Down syndrome began after age 40 – much younger than other COVID-19 patients.

Using different national databases (namely, the English Learning Disabilities Mortality Review (LeDER); NHS England's COVID-19 Patient Notification System; and Care Quality Commission (CQC) statutory notifications of deaths of people receiving social care), Public Health England (2020) demonstrated that the death rate from COVID-19 was two to three times higher among adults with learning disabilities (their term for intellectual/developmental disabilities) compared to the general population (2.3 times greater death rate according to the LeDER database; 3.1 times in the CQC database). Deaths were higher for individuals in congregate care settings than those in other living situations. Similar findings were reported by the Office for National Statistics (2021) in their analysis of COVID-19 deaths until the end of November 2020, which found that 6 of 100 deaths in the UK were among individuals with learning disabilities – 3.7 times the rate for adults without learning disabilities. The increased risk remained even after adjusting for other risk factors; although living in a care home was a major factor in the higher mortality rates.

Data from the USA have shown a similar pattern of higher risk among persons with intellectual/developmental disabilities. For example, using data gathered from about half of the group homes in New York state, Landes et al. (2020a) found a higher COVID-19 mortality rate for people with IDD living in group homes (1,175 per 100,000) compared to the general population (151 per 100,000). Similarly, Turk et al. (2020) analysed data from the TriNetX COVID-19 Research Network platform and found that the overall case fatality rate was significantly higher among individuals with IDD until age 75 (i.e. 1.6% vs <0.01% for ages < 17 years; 4.5% vs. 2.7% for ages 18 to 74). An analysis of California based data of people receiving IDD services (Landes et al., 2020b) found that COVID-19 outcomes varied depending on where they lived – settings with a larger number of residents had higher mortality rates.

A consortium of academic and care organizations in the Netherlands, Stronger on Your Own Feet, has reported a high level of COVID infection and an overall case mortality rate of 5% for persons with intellectual disabilities since March 2020 (Stronger on Your Own Feet, 2021a,b), citing higher rates of comorbidities among COVID-19 patients with intellectual disabilities. Data showed that the number of cases among persons with intellectual disabilities was higher in the second wave of the pandemic, but the proportion of deaths was lower compared to the first wave.

While studies among children are limited, evidence shows that children with intellectual/developmental disabilities are also at higher risk of infection and adverse outcomes from COVID-19. Findings from a preliminary report by CIHR's CHILD-BRIGHT, SPOR Network and the SPOR Evidence Alliance (Dugas et al., 2020) who conducted a systematic review of the literature including 25 studies specific to children with brain-based disabilities (intellectual/developmental disabilities) or those at risk of developing a brain-based disability (e.g. premature infants, congenital heart defects) showed that there is a greater risk of developing severe COVID-19 disease in children with IDD including Down syndrome, children with pre-existing cardiac conditions, and among younger ages (less than 1 year old). Furthermore, although mortality rates from COVID-19 are lower among children overall than adults, case-fatality rate appeared to be higher in children with IDD compared to children without disabilities. The authors noted that the higher risk may be due to the frequency of comorbidities in individuals with intellectual and developmental disabilities.

References

- Clift, A.K., Coupland, C.A.C., Keogh, R.H., Hemingway, H., & Hippisley-Cox, J. (2020). COVID-19 mortality risk in Down syndrome: Results from a cohort study of 8 million adults. *Ann Intern Med*, October 21st 2020, Epub ahead of print, M20-4986. doi:10.7326/M20-4986
- Dugas, M., Stefan, T., Lépine, J., Blouin, P., Poirier, A.A., Skidmore, B., Faust, L.E., Costello, C., Thomson, D., Majnemer, A., Goldowitz, D., Miller, S., & LeBlanc, A. (2020). COVID-19 in children with brain-based developmental disabilities: Update of a rapid review. SPOR Evidence Alliance.
- Hüls, A., Costa, A.C.S., Dierssen, M., et al. (2021). Medical vulnerability of individuals with Down syndrome to severe COVID-19 – data from the trisomy 21 research society and the UK ISARIC4C survey. *EClinicalMedicine*. <https://doi.org/10.1016/j.eclinm.2021.100769>
- Landes, S.D., Turk M.A., Formica, M.K., McDonald, K.E., & Stevens, J.D. (2020a). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York state. *Disabil Health J*, 13(4), 1-5.
- Landes, S.D., Turk, M.A., & Wong, A.W.W.A. (2020b). COVID-19 outcomes among people with intellectual and developmental disability in California: the importance of type of residence and skilled nursing care needs. *Disabil Health J*, <https://doi.org/10.1016/j.dhjo.2020.101051>
- Office for National Statistics (2021). Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020. 11 Feb 2021.
- Public Health England (2020). Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19_learning_disabilities_mortality_report.pdf
- Sterker Op Eigen Benen "Stronger on your own feet" (2021a). Radboud University Medical Center; Nijmegen, Netherlands: January 15, 2021. *Factsheet No. 14: COVID-19 in People with Intellectual Disabilities*. Accessed at: <https://www.sterkeropeigenbenen.nl/factsheet?lang=nl>
- Sterker Op Eigen Benen "Stronger on your own feet" (2021b). Radboud University Medical Center; Nijmegen, Netherlands: January 29, 2021. *Factsheet No. 15: COVID-19 in People with Intellectual Disabilities*. Accessed at: <https://www.sterkeropeigenbenen.nl/factsheet?lang=nl>
- Turk, M.A., Landes, S.D., Formica, M.K., & Goss, K.D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disabil Health J*, 13(3): 100942. doi:10.1016/j.dhjo.2020.100942

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