PRIORITY FOR COVID-19 VACCINE MUST INCLUDE THOSE WITH INTELLECTUAL / DEVELOPMENTAL DISABILITIES

Annette Majnemer and Patrick McGrath | December 4, 2020

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It was recently announced that the National Advisory Committee on Immunization, a panel of scientific advisors, has developed a priority list of groups to receive COVID-19 vaccination once approval of the vaccines is given by Health Canada (Globe and Mail, December 2).

Large scale studies have shown that persons with lifelong intellectual/developmental disabilities such as, Down syndrome, cerebral palsy, autism spectrum disorder, fetal alcohol spectrum disorder are more susceptible than the general population to develop COVID-19 infection and to suffer more severe outcomes including death from infection. Therefore, as the Government of Canada, in conjunction with provincial and local governments, develops a COVID-19 vaccine distribution strategy, it is essential that all persons with developmental or intellectual disabilities, as well as their caregivers (including personal assistants, family members, and persons working in disability-related services) are considered as priority. Although some persons with intellectual/developmental disabilities reside in long term care facilities and thus would be covered by the current recommendations, most do not.

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. This should include simple infographics and short audio or video clips that should be shared with health care professionals and community organizations to insure the information reaches all individuals with intellectual/developmental disabilities.

These key steps – of prioritizing this vulnerable population and transparent sharing of data – are supported by limited but consistent evidence.

For example, Clift et al. (2020) used 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 and found that adults with intellectual/developmental disabilities were at greater risk of death from COVID-19. There was a much greater increased risk for persons with Down syndrome (Adjusted Hazard Ratio of 10.39 [95% CI: 7.08–15.23]), exceeding that of individuals with diabetes or living in a care home.

Public Health England (2020) examined this question using data from English Learning Disabilities Mortality Review (LeDER) and the NHS England's COVID-19 Patient Notification System, Care Quality Commission (CQC) statutory notifications of deaths of people receiving social care. Anaysis of the LeDER data showed that individuals with learning disabilities (their term for intellectual/developmental disabilities) had a death rate per 100,000 adults that was 2.3 times that of the general population, while the CQC Patient Notification System data base showed the death rate for adults with learning disabilities was 3.1 times that of rates for adults that did not. Furthermore, deaths were higher for these individuals in congregate care settings than those in other living situations. Data from the USA have shown a similar pattern. For example, using data gathered from about half of the group homes in New York state, Landes et al., (2020) found the mortality rate for individuals with intellectual/developmental disabilities living in group homes was 1,175 per 100,000 compared to 151 per 100,000 for the general population. Similarly, Turkes et al. 2020 used data from the TriNetX COVID-19 Research Network platform and found that overall mortality rate was significantly higher until age 75 (i.e. ages < 17 years IDD 1.6%, without IDD < 0.01%; ages 18 to74 with IDD 4.5%, without IDD 2.7%).

Stronger on Your Own Feet, a consortium of academic and care organizations in the Netherlands, reported a high level of COVID infection and a case mortality rate of 8% for persons with intellectual/developmental disabilities (Stronger on Your Own Feet, 2020) citing higher rates of comorbidities in persons with intellectual/developmental disabilities.

Children with intellectual/developmental disabilities are also at higher risk of adverse outcomes from COVID-19. CIHR's CHILD-BRIGHT SPOR Network and the SPOR Evidence Alliance released a preliminary report of a rapid review, based on 8 studies specific to children with brain-based disabilities (intellectual/developmental disabilities), and 17 studies on children at risk of developing a brain-based disability (e.g. premature infants, congenital heart defects). It found that children with Down syndrome, with pre-existing cardiac conditions, and younger age (less than 1 year old) were at greater risk of developing severe COVID-19 disease. Furthermore, case-fatality rate appeared to be higher in younger age groups of children with intellectual or developmental disabilities, compared to children without disabilities and may be due to the frequency of comorbidities in individuals with intellectual or developmental disabilities.

The limited yet compelling evidence provides the basis for ensuring that persons with intellectual/developmental disabilities across the lifespan are not overlooked, but rather, are prioritized for vaccination.

The authors are members of a working group developing a policy brief on the impact of COVID-19 on those with intellectual/developmental disabilities. Members include: Jennifer Baumbusch, Chantal Camden, Barbara Fallon, Yona Lunsky, Annette Majnemer, Patrick McGrath, Steven Miller, Tim Stainton, John Sumarah, Donna Thomson, and Jennifer Zwicker. More information is available at <u>www.rsc-</u> <u>src.ca/en/covid-19</u>

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