

Considerations and recommendations for vaccine protocols and priority of people with intellectual and developmental disabilities and others receiving in home supports in individualized residential settings other than group homes or LTC facilities.

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While individuals with intellectual and developmental disabilities residing in group homes and larger congregate care facilities have been clearly identified as part of the first or second phase of immunizations, the status of those receiving support in smaller community settings is less clear. This document is intended to identify relevant considerations regarding the priority of these individuals which represent a majority of persons with intellectual disabilities receiving support in British Columbia.

Currently there are number of support models which would fall under this category of persons. These would include:

- **Shared living**, a residential option in which an individual with IDD shares a home with someone who is contracted to provide ongoing residential support. There are two types of shared living support:
 - **Home Sharing:** This is the most common type of shared living and involves living in the shared living provider's home.
 - **Live-in support:** In this type of support model, the individual receives support in their own home.
- **Direct Funded Supports.** This would include people living in their own home, a family home as well as individuals supported through Microboards or person-centred societies.
- **Family Home.** This includes those receiving respite or other supports in the home to allow the individual with IDD to remain at home. For purposes of this document, this would include those minors 16-19 receiving in-home supports through the At Home program and adults receiving supports through CLBC.
- **Choice for Support in Independent Living (CSIL).** This is a self-directed option through the Ministry of Health for eligible home support clients. CSIL clients receive funds directly from their local health authority to purchase their own home support services.

While group homes are perhaps the most widely recognized form of residential support for people with IDD, this model actually represents a small minority of residential supports in BC. Group homes account for just over 2000 places whereas Home Share provides support to approximately 4400 persons. Direct

Funded services would account for a smaller number of supports. By far the most common residential support is the family home.

Factors Influencing Vaccine Priority

Several different and often overlapping factors influence decision making around the IDD population and vaccine priority.

Health Status and Vulnerabilities

Persons with IDD 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. 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. They found that adults with intellectual/developmental disabilities were at greater risk of death from COVID-19 and a very large increased risk for persons with Down syndrome (Adjusted Hazard Ratio of 10.39 (95% CI: 7.08–15.23) that exceeded that of diabetes or living in a care home. Using a different data set, UK data identified that adults with IDD had a crude rate of 240 deaths per 100,000 adults, 2.3 times the rate in the general population (LeDER). A second data base (CQC Patient Notification System) yielded 192 deaths per 100,000 adults with IDD 3.1 times the rates for adults without IDD. Data from the USA have shown a similar pattern of higher risk among persons with IDD. (Landes et al., 2020).

Children with intellectual/developmental disabilities are also at higher risk of infection and adverse outcomes from COVID-19. CIHR's CHILD-BRIGHT SPOR Network and the SPOR Evidence Alliance in a preliminary report on a rapid review of the literature to include 25 studies; 8 specific to children with brain-based disabilities (intellectual/developmental disabilities), and 17 included children at risk of developing a brain-based disability (e.g. premature infants, congenital heart defects), showed that there is a greater risk to develop severe COVID-19 disease in children with Down syndrome, with pre-existing cardiac conditions, and younger age (less than 1 year old). Furthermore, case-fatality rate appeared to be higher in younger age groups of children with intellectual or developmental disabilities, compared to children without disabilities. They noted that differences between children with intellectual and developmental disabilities and other children may be due to the frequency of comorbidities in individuals with intellectual or developmental disabilities.

Some of the heightened risk can be accounted for by higher rates of living in congregate settings, however the underlying health conditions associated with Down syndrome and the higher rates of comorbidity in persons with IDD indicate that residential setting is not the sole factor contributing to heightened risk.

Presence of Paid Support Staff

The vast majority of persons with IDD living in community based, non-group home settings receive regular support from external workers. These are **essential workers**. The amount of support and number of workers will vary from occasional respite staff to near full-time staff support all would face

the risk of infection from regular contact with persons outside their immediate 'bubble'. In many cases these workers would not have ready access to training on reducing risk of infection, PPE or regular testing as those in LTC and other congregate settings.

Family and Caregivers

Many individuals living in the family home, either adults with IDD or children 16-19 who are vaccine eligible have workers coming in, many do not. Regardless of staffing, there are serious impacts on the family. Many families with a member at heightened risk have limited their contact outside the family, keeping siblings out of school and reducing social contact. While this lessens the risk of contracting covid-19 it also places an extreme amount of stress on the families and can lead to significant mental health issues not only for the person with IDD but the entire family.

RECOMMENDED ACTIONS

- Current guidance on the Provincial Covid-19 website indicates that 'staff in community home support and nursing services for seniors' would be prioritized in the second phase of vaccinations beginning in February. Phase three indicates 'Adults with very significant developmental disabilities that increase risk.' ***What is not clear is when those people and their essential support persons living in individualized community settings who receive support at their community residence whose situation present increased risk will be immunized.***
- 1. We therefore would recommend that those individuals noted above be prioritized in phase three and that specific guidance is issued which clarifies that the following are to be included in phase three:**
 - People with IDD living in individualized community-based settings and their essential workers as described above;
 - Children with IDD and complex care needs age 16-19 living in the family home and those resident with them;
 - Choices in Support for Independent Living (CSIL) recipients and their essential workers.
 - 2. When priority is determined that this be clearly communicated to health authorities, relevant agencies and organizations and to individuals and families and that information be provided in accessible language and formats.**
 - 3. That the PHO and health authorities work with community-based agencies to plan and deliver vaccines in an efficient, comprehensive and accessible manner.**