

Developmental Services Planning & Advisory Council of Waterloo Region

February 15, 2021

Dr. Hsiu-Li Wang
Commissioner & Medical Officer of Health
Region of Waterloo Public Health & Emergency Services

Sent via Email to: hwang@regionofwaterloo.ca

Re: Prioritization of COVID-19 Vaccinations for Individuals Supported and Front-Line Staff at Local MCCSS-Funded Programs & Services in Congregate Settings

Dear Dr. Wang,

We are writing on behalf of the Waterloo Regional Planning Table (Developmental Services Planning & Advisory Council of Waterloo Region) to request that Waterloo Region Public Health reconsider its prioritization of COVID-19 vaccinations for individuals served and the front-line staff who support them at congregate settings which provide MCCSS-funded programs and services. In particular, this includes individuals living with developmental disabilities, the essential front-line staff who support them, and also individuals served and staff at organizations providing intervenor services.

Through our representation on the *COVID-19 Vaccine Working Group* with the Provincial Network on Developmental Services, we have learned in recent weeks that at least two Public Health units in the province have already communicated to developmental services organizations that congregate living programs in developmental services will be considered part of the Phase I vaccine distribution in their Public Health regions. As well, we have also learned that a number of developmental services agencies across the province have already received vaccinations for some persons-served, and their front-line staff.

Acknowledging that a number of our Planning Table members have previously inquired of Waterloo Region Public Health about its consideration of the unique and significant risks associated with COVID-19 exposure, transmission and infection of our persons served in congregate settings (whether congregate living / group homes, overnight respite, or in-person day programs), supported independent living and host family programs in its prioritization of COVID-19 vaccinations, we now ask that this request be reconsidered given the most current information available.

To that end, accompanying this letter is a summary of risk profiles and associated prioritization metrics for a subset of local developmental services organizations. The assessed risk and prioritization metrics are based on known high risk factors with regard to COVID-19 for the

individuals we serve in congregate settings including but not limited to: medically fragile individuals with multiple comorbidities, individuals living with complex / significant behavioural needs, older adults, individuals having diagnoses / conditions that predispose to severe outcomes of any respiratory illness, and individuals living with Down syndrome. As indicated, several organizations represented at the Planning Table have provided non-identifying information about their individuals supported in the enclosed summary.

In addition to the risk factors outlined in the enclosed summary, we also highlight the following points which have contributed to heightened COVID-19 pandemic concerns from our sector:

- With the increasing prevalence of COVID-19 variants, and indications of higher transmission rates and more severe outcomes, the morbidity and mortality risks to already vulnerable individuals supported in congregate living settings is of dire concern to their families and to the organizations providing the essential care and services they rely upon;
- Congregate living settings in developmental services accommodate individuals in both single bedrooms and shared bedrooms. With limited space and resources, it is not feasible to eliminate shared bedrooms at congregate living sites in our sector at this time, and we know that shared bedrooms in Long-Term Care have been one of the key contributors to the rapid spread of COVID-19 when outbreaks occur in LTC Homes;
- Most developmental services organizations do not employ healthcare professionals / healthcare workers (physicians, nurses, personal support workers) who would normally be best equipped to oversee, interpret and implement the heightened infection prevention and control screening measures and precautions, as well as outbreak protocols in the ever-changing environment presented by the pandemic.

For your information, we also share the following references to research, reports and studies which address the morbidity and mortality risks associated with COVID-19 among vulnerable individuals living with developmental disabilities.

Some with disabilities worry they'll die if they get COVID, say slow vaccine rollout puts them at risk

...adults with developmental disabilities are four to six times more likely to die of COVID and experience at age 50 the same level of medical frailty as someone 75 or older in the general population.

- <https://www.cbc.ca/radio/whitecoat/some-with-disabilities-worry-they-ll-die-if-they-get-covid-say-slow-vaccine-rollout-puts-them-at-risk-1.5899519>

Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis

Conclusions - Though of concern for all individuals, COVID-19 appears to present a greater risk to people with IDD, especially at younger ages. Future research should seek to document COVID-19 trends among people with IDD, with particular attention to age related trends.

- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7245650/>

Development of a frailty index for older people with intellectual disabilities: Results from the HA-ID study

Conclusion - As people with ID are getting older, the question whether additional years are spent in good health becomes salient. Here, people with ID over age 50 had frailty scores similar to most elderly people over 75 y. Future research is needed to confirm if frail elderly people with ID have an increased risk of adverse health outcomes.

- https://www.researchgate.net/publication/235895574_Development_of_a_frailty_index_for_older_people_with_intellectual_disabilities_Results_from_the_HA-ID_study

CDC – Centers for Disease Control and Prevention / People with Disabilities / People with Developmental and Behavioral Disorders

... people with developmental or behavioral disorders who have serious underlying medical conditions may be at risk of serious illness. Some people with developmental or behavioral disorders may have difficulties accessing information, understanding / practicing preventative measures & communicating symptoms of illness.

- <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>

COVID-19 Risk for People with Intellectual Disabilities

Higher rates of chronic health conditions put people with intellectual disabilities at a higher risk of serious illness and poorer outcomes from COVID-19. For example, people with Down syndrome can have compromised immune systems and smaller airways, which make them more susceptible to respiratory illnesses.

- <https://www.specialolympics.org/our-work/covid19/covid-19-risk-for-people-with-intellectual-disabilities>

Down Syndrome community at greater risk of COVID-19, pushing for vaccine priority

Canadian Down Syndrome Society's interim executive director Laura LaChance talks about the disproportionate impact of COVID-19 on the Down syndrome community.

- <https://globalnews.ca/video/7573408/down-syndrome-community-at-greater-risk-of-covid-19-pushing-for-vaccine-priority>

Including People with Developmental Disabilities as a Priority Group in Canada's COVID-19 Vaccination Program: Key Considerations

People with developmental disabilities are at greater risk of morbidity and mortality from COVID-19 in comparison to the general population and have suffered disproportionate consequences of COVID-related restrictions on their mental health and well-being. The COVID-19 pandemic raises both ethical and social justice issues for marginalized populations and our response must be bound by Canada's public health commitment to reduce health inequalities and adhere to ethical principles outlined in Canada's public health ethics framework on COVID-19. The World Health Organization's Values Framework identifies the higher rates of COVID-19-related severe illness and mortality among systematically disadvantaged or marginalized groups as a key principle when prioritizing groups for COVID-19 vaccination.

- <https://www.porticonetwork.ca/web/hcardd/news/-/blogs/research-evidence-regarding-covid-19-and-developmental-disabilities>

In closing, we respectfully request that Waterloo Region Public Health reconsider its prioritization of COVID-19 vaccinations for individuals served and the front-line staff who support them at congregate settings which provide MCCSS-funded programs and services. Representatives from our Planning Table are available and would be pleased to discuss this further at your earliest convenience.

Kind Regards,

Laura Thies, Chair
Waterloo Regional Planning Table
e: l.thies@sunbeamcommunity.ca

Brian Swainson, COVID-19 Vaccination Lead
Waterloo Regional Planning Table
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On behalf of the following Organizations:

KW Extend-A-Family – Allan Mills, Executive Director
KW Habilitation Services - Ann Bilodeau, Executive Director
Sunbeam Community & Developmental Services – Brian Swainson, Chief Executive Officer
Elmira and District Community Living - Cheryl Petersen, Executive Director
Parents for Community Living - Katherine Loveys, Executive Director
Community Living Cambridge - Lawna Paulos, Executive Director
Aldaview Services – Louise Lepp, Executive Director
Christian Horizons – Sharon Dam, Area Manager
DeafBlind Ontario Services – Amanda Mesko, Community Engagement Manager

ENCL: COVID-19 Vaccination Prioritization Metrics for Developmental Services Agencies

CC: Karen Redman, Regional Chair - Region of Waterloo
Brenda Miller, Manager, Health Protection & Investigation Infection Control
Honorable Todd Smith, Minister of Children, Community and Social Services
Rupert Gordon, Assistant Deputy Minister - Children, Community and Social Services
Harriet Taylor, Program Supervisor - MCCSS Central Region
Eva BakHebert, Program Supervisor - MCCSS Central Region
Sarah Farwell, WW COVID-19 Command Triad - Ontario Health (West)
Rob Howe, KW4 Ontario Health Team
Kristina Eliashevsky, Cambridge North Dumfries Ontario Health Team

For website posting only, the “COVID-19 Vaccination Prioritization Metrics for Developmental Services Agencies – Waterloo Region” summary enclosure is omitted due to the sensitive nature of the data involved. Data was provided by 4 local developmental services agencies, including Sunbeam Community & Developmental Services.

However, the Program Categories and Risk Profiles used in this summary are provided below for information purposes.

A. Congregate Living Sites in Waterloo Region

TABLE 1: Sites For Specialized Services for Medically Fragile / Technology Dependent and Other Clinically Complex Needs

COVID-19 Risk Profile for this Population

- All risks as identified in Table 4, plus: Complex clinical conditions and co-morbidities; high percentage of immunocompromised individuals; prevalence of diagnoses / conditions that predispose to severe outcomes of any respiratory illness; greater number of staff and essential service providers at the site to support the complex needs of persons served.

TABLE 2: Sites for Specialized Services for Complex / Significant Behavioural Needs

COVID-19 Risk Profile for this Population

- All risks as identified in Table 4, plus: Inability of persons served to comply with pandemic IPAC precautions and guidelines, and challenges for staff to support / encourage persons served to self-comply. Non-compliance of persons-served with such practices as: wearing of masks / face shields, physical distancing, frequent hand hygiene, other hygiene precautions (sneeze / cough), self-identify symptoms. This not only heightens transmission risk among persons served, but also among all who live and work at the congregate living site. Isolation protocols and stay-at-home precautions, where applicable, can be extremely difficult to implement at these sites. High prevalence of self-injurious behavior and aggressive behavior towards others often require physical interventions within behavioural support plans which also heighten exposure & transmission risk.

TABLE 3: Sites for Specialized Services for Older Adults

COVID-19 Risk Profile for this Population

- All risks as identified in Table 4, plus: Older adults (whether 50+ or 55+) living with developmental disabilities have greater morbidity and mortality risks associated with COVID-19 infection.

TABLE 4: All Other Congregate Living Sites

COVID-19 Risk Profile for this Population

- People with intellectual disabilities are considered a high-risk group for coronavirus disease (COVID-19), according to the Centers for Disease Control and Prevention.

People with developmental or behavioral disorders who have serious underlying medical conditions may be at risk of serious illness. Some people with developmental or behavioral disorders may have difficulties accessing information, understanding or practicing preventative measures, and communicating symptoms of illness. Persons with one or more of the following disability types may be at increased risk of becoming infected or having unrecognized illness.

- People who have limited mobility or who cannot avoid coming into close contact with others who may be infected, such as direct support providers and family members
- People who have trouble understanding information or practicing preventive measures, such as hand washing and social distancing
- People who may not be able to communicate symptoms of illness

Higher rates of chronic health conditions put people with intellectual disabilities at a higher risk of serious illness and poorer outcomes from COVID-19. For example, people with Down syndrome can have compromised immune systems and smaller airways, which make them more susceptible to respiratory illnesses.

People with Intellectual Disabilities (ID) are at greater risk of infection for a range of reasons that include physical health problems, social circumstances and limitations in understanding. The prevalence of comorbid physical disorders is higher among people with ID, and their life expectancy is lower than that of the general population with a standardized mortality ratio of 3.18. People with ID and genetic disorders may suffer from hereditary cardiac, inborn errors of metabolisms or respiratory conditions. Respiratory infections are the leading cause of death in people with ID especially among people with Down syndrome. The level of obesity is higher among people with ID raising their risk of

experiencing severe forms of infection with COVID-19. Overall, the prevalence of physical and mental disorders in people with ID is higher than in the general population.

B. Overnight Respite Sites in Waterloo Region

TABLE 5: All Overnight Respite Sites

COVID-19 Risk Profile for this Population

- All risks as identified in Table 4 apply, plus: Persons served are mobile between their home in the community (often with family) and their overnight respite providers. The transient / impermanent nature of respite services presents unique risks during a pandemic. This creates two residential environments for the person served, thereby increasing exposure and transmission risks. While in overnight respite (ranging from days, weeks, months depending on individual circumstances), the person served is staying in a congregate respite setting with the staff who support them, and other persons served receiving respite services. For any respite sites offering specialized MFTD services or complex behavioural supports, risks as identified in Table 1 and Table 2 apply. For older adults utilizing respite services, the risks as identified in Table 3 apply.

C. In-Person Day Programs

TABLE 6: All In-Person Day Programs

COVID-19 Risk Profile for this Population

- All risks as identified in Table 4 apply, plus: Persons served are mobile either between their congregate living / group home) site and the day program site, or between their home in the community (often with family) and the day program site. The transient / impermanent nature of respite services presents unique risks during a pandemic. This creates two environments for the person served, thereby increasing exposure and transmission risks. While attending in-person day program, the person served is supported in a congregate activity setting with the staff who support them, and other persons served attending the day program.

-END-