

Briefing Note

Primary Care Guidance Regarding COVID-19 for Those Who Care for Adults with Intellectual and Developmental Disabilities

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INDEX

1.	Introduction	p. 1
2.	What's different?	pp. 2-3
3.	How is the virus transmitted?	pp. 3-8
4.	Public health measures	pp. 8-9
5.	Teaching risk reduction behaviours	pp. 9-10
6.	Giving care safely	pp. 10-11
7.	How to recognize COVID-19 illness	pp. 12-13
8.	When to get tested	pp. 13-14
9.	How to keep an adult with IDD and COVID-19 comfortable at home	p. 14
10.	Whom to call for medical help	pp. 14-15
11.	Advance care planning	pp. 15-16
12.	Contingency ('what if') plans	pp. 16-17
13.	Hospital transfer plan	pp. 17
14.	Promoting medically appropriate and ethical care	pp. 17-18
15.	Resources	pp. 18-21
	Notes and References	pp. 21-22

1. Introduction

This briefing note is for healthcare providers and caregivers of adults with intellectual and developmental disabilities (IDD). It provides primary care guidance regarding the novel coronavirus (SARS-CoV-2) and COVID-19, the disease it causes.

On Jan. 7, 2020, the novel coronavirus was first isolated. Since then, information about this virus and management of COVID-19 is rapidly expanding. As we learn more, **information in this briefing note could change.**

2. What's different? Does COVID-19 affect adults with IDD in the same ways as other adults?

Much of the medical information regarding COVID-19 for the general population (Box 1) is also relevant to adults with IDD. In applying this information, however, their specific needs and contexts of care should be considered. Preventive measures and management of COVID-19 should be focused on **holistic, person-centred care**, and not only on specialized, technical, and disease-oriented approaches to health care.¹

The COVID-19 pandemic will likely last for more than a year. While the focus of public health during this time is on preventing new infections and managing those who are ill with COVID-19, caregivers should endeavour also to promote the **total** health and wellbeing of adults with IDD as much as possible. This includes **maintaining healthy habits** of adults with IDD (e.g., diet, activity, hygiene, sleep, meaningful activities, positive relationships). It also includes continuing to **manage ongoing health conditions** (e.g., hypertension, asthma, diabetes). For both endeavours, **partnership between caregivers and family physicians**, which is important during non-pandemic times, is especially vital during the pandemic.

Some adults with IDD have physical vulnerabilities that place them at risk of becoming severely ill if they develop COVID-19:

- **Age** is one risk factor for severe illness.¹⁰ Adults with IDD generally age more quickly (on average, add 30 years to their age) than those without IDD.¹¹ According to a Dutch study, among adults with IDD who died from COVID-19, the majority (62%) were in the 40-69 year-old age range, compared to the general population in which most deaths from COVID-19 were among people above 70 years old.¹²

Box 1 General information about COVID-19

COVID-19 causes some symptoms of the common flu, but more often than the flu, leads to an acute respiratory infection (ARI). For adults with IDD, a Dutch study found that the most common symptoms are one or more of new: fever (74%); cough (68%); fatigue (61%), and shortness of breath (43%). The high prevalence of fatigue among infected adults with IDD is notable.² Some adults with COVID-19 experience gastrointestinal symptoms such as diarrhea and nausea.³ Delayed detection of symptoms could occur in older adults and those with comorbid health conditions⁴, as well as some adults with IDD who have difficulty communicating their symptoms.

There can be other medical causes of the above symptoms. Molecular or antigen tests for active novel coronavirus are used to confirm a diagnosis of COVID-19.

Symptoms usually manifest within 4-5 days, sometimes up to 14 days, after exposure to the novel coronavirus.⁵

The coronavirus causing COVID-19 spreads easily and quickly, sometimes by persons who have very mild or no symptoms of COVID-19.⁶

There are not yet:

- Widely available antibody tests to confirm whether a person following an infection is immune to future infections,⁷
- vaccines to prevent people from becoming infected,⁸
- effective and safe anti-viral or other medications to treat COVID-19.⁹

- **Co-existing physical health conditions** can increase the risk of people being severely ill from COVID-19 (e.g., hypertension, type-2 diabetes, coronary heart disease, abnormal heart rate, kidney disease, lung disease, weak immune system).¹³ Some of these health conditions are more prevalent in adults with IDD than in the general population.¹⁴
- **Delayed diagnosis:** Symptoms of COVID-19 might be missed in adults whose IDD is in the moderate to profound ranges of severity and are unable to communicate their symptoms to others or who might manifest them in less common ways than those without IDD (e.g., fatigue).

Many adults with IDD experience sensory, behavioural or mental health vulnerabilities. While this does not place them at risk of severe physical illness related to COVID-19, it does place them at risk for other complications, such as trauma, exacerbation or recurrence of mental ill health.

Many adults with IDD experience a range of environmental and social vulnerabilities that also pose certain risks. For example, those who live in congregate group-home settings are at higher risk of becoming infected if there is an outbreak in the home. Those who live independently might have difficulties accepting new precautions and resist restrictions on their outdoor or social activities, monitoring or reporting new ARI symptoms. Those who are supported by elderly or sole caregivers are at risk if these caregivers were to become ill with COVID-19 and need to self-isolate or be admitted to hospital.

3. How is the virus transmitted? What should you know?

Transmitting the novel coronavirus in communities would not be a problem if everyone kept apart from others, wore a mask, a face shield and gloves, and always washed their hands before touching their faces or eating. Short of this unattainable ideal, however, the best we can do is to help people with IDD to **learn new healthy habits** (see section 5 below) and to ensure that we and others who provide direct care **adhere to precautions** to avoid transmitting the virus to them (see section 6 below). To limit virus transmissions to or from adults with IDD, we need to understand four things:

(a) Spread

Adults with IDD often live in group homes or other congregate-living settings. In such settings, physical distancing and good hygiene practices might be difficult to practice consistently and maintain. Care providers and others who enter these settings might be carriers of the virus without being aware of this. Adults with IDD might also need support to learn new preventive behaviours and ways to better manage secretions (e.g., drooling).

Box 2 How the novel coronavirus is spread

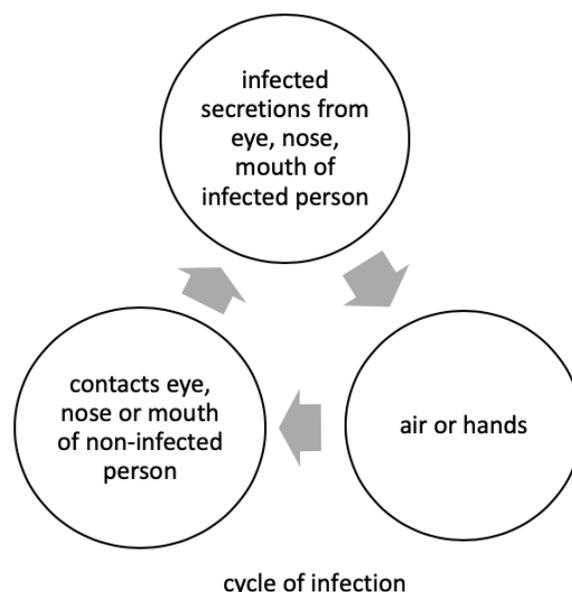
- **By mucus droplets:** A person who is infected (the host) can expel virus-laden droplets in nasal mucus, respiratory secretions or phlegm when the host sneezes or coughs.⁶ These droplets can travel through the air for a distance of about 2 meters. If they land on a non-immune person's face, this could lead to infection. A person cannot normally become infected merely by breathing.⁷ Studies suggest that although virus-laden droplets can remain suspended in the air for an hour or more, they are not at levels high enough to pose a health risk to non-immune persons unless such persons have a significant exposure to the novel coronavirus.⁸

Significant exposure to mucus droplets containing the virus depends on several factors: proximity to a host with COVID-19 and ARI symptoms (i.e., less than 6 feet or 2 meters); duration of exposure to such a host in an enclosed space (i.e., 15-30 minutes); and when the host coughs sneezes without practicing respiratory etiquette (i.e., covering his or her mouth or nose when coughing or sneezing).

When persons with COVID-19 no longer have ARI symptoms (coughing or sneezing) after their 2-week isolation period, they are no longer highly contagious transmitters of the virus through the droplet route. However, they might be transmitters of the virus by touch.

- **Through saliva:** Saliva can also contain virus-laden fluid from the respiratory tract of someone who is infected with the novel coronavirus, which can be transmitted in droplets when the host coughs.

- **By touch:** The novel coronavirus can survive for 1-3 days on surfaces, especially steel or plastic ones. Surfaces can become contaminated by the mucus or saliva of a host of the virus, when the host shakes hands with a person who is not immune and then that person touches his or her face without washing his or her hands. Infection can also happen indirectly when a person who is not immune touches a contaminated surface (e.g., door handle), even with gloves on, and that person then touches his or her own eyes, nose or mouth without taking off the gloves or without washing his or her hands.
- **Through feces:** Hosts who have gastro-intestinal symptoms of COVID-19 (alone or with ARI symptoms) can excrete the virus in their feces.



(b) COVID-19 status

To understand the scope of testing for infection with the novel coronavirus and of public health recommendations for self-isolation, we need to understand a person's COVID-19 status, which can be differentiated according to four states.

State A: Never infected and not immune

Most adults with IDD in the early phase of the pandemic are in state A. Many will likely become infected with novel coronavirus during the coming year until a vaccine is available (e.g., greater than 50% of the population).

Precautions such as isolation, which in Ontario means not leaving one's home, and physical distancing from other people when outside one's home are especially important for adults with IDD who are vulnerable to developing severe ARI symptoms due to COVID-19.

Monitoring for COVID-19 symptoms is important for those adults with IDD who might be unable to recognize or communicate those symptoms when they arise.

State B: Infected without symptoms

The novel coronavirus can be transmitted by people (including children and young adults) who have no symptoms after they become infected.¹⁵ They can transmit this virus primarily by contaminating surfaces that are then touched by others. They are most contagious just prior and following developing ARI symptoms.

Precautions such as physical distancing, respiratory hygiene and hand and surface washing should be observed especially by potential super-transmitters (see section 2 (c) below).

Testing for COVID-19 should be done on all residents in group homes where adults with IDD live as soon as one or more of them have a confirmed diagnosis of COVID-19 or a significant exposure. This testing should preferably be offered in the home and adapted as needed.

State C1: Infected with *mild* symptoms

Self-isolation and contacting health services. As soon as symptoms suggestive of COVID-19 are recognized, an adult with IDD should self-isolate, i.e., avoid contact with other members of his or her household as

much as possible until tested and found not to be infected. This person or his or her caregivers should alert the adult's family physician as soon as possible and arrange testing.

When caregivers or staff members develop mild symptoms, they should refrain from in-person caregiving. Sometimes, when there is only one caregiver of an adult with IDD, this might not be possible. Then adhering to precautions is vital (e.g., medical masks, gloves, washing hands, not giving care in small, unventilated spaces).

State C2: Infected with *moderate to severe* symptoms

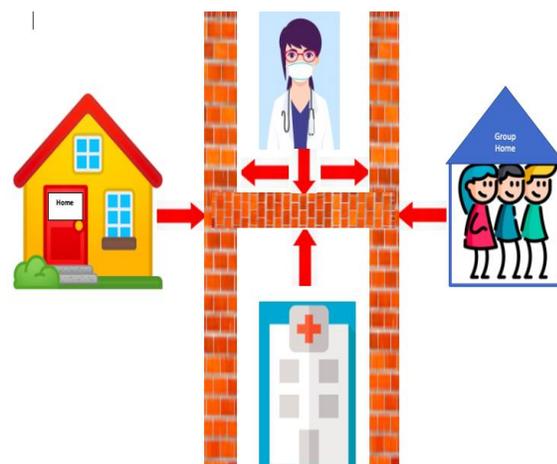
Urgent care. Symptoms such as new shortness of breath, rapid breathing or chest pain can worsen rapidly (i.e., within 24 hours). Follow up urgently with the adult with IDD's family physician or, if unavailable, engage emergency medical services.

State D: Recovered

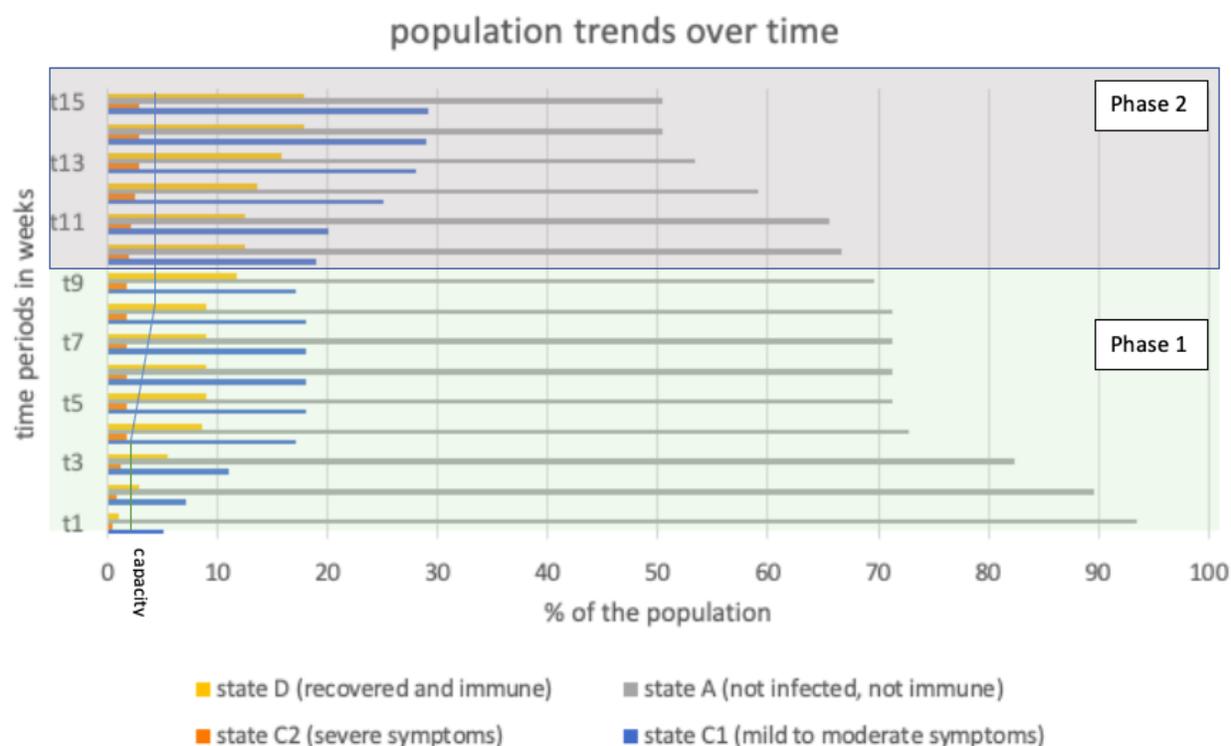
Maintain precautions such as physical distancing, respiratory hygiene, and hand and surface washing. Based on experiences with other flu-like viruses, it is expected that those who had COVID-19 and have recovered (usually by 14 days from the onset of symptoms) will likely develop immunity to re-infection with the novel coronavirus for some time. There is not sufficient evidence for researchers, however, to confirm the degree or duration of immunity. There is presently no widely available antibody test for immunity to the novel coronavirus.

2(c) Super-transmitters are people who are likely to spread the novel coronavirus to more than one person. They could include adults with IDD who live in group homes and other congregate settings as well as visiting healthcare or support professionals who have significant exposures to many people during this pandemic. Super-transmitters will often not know what their COVID-19 status is or that of others with whom they interact.

Special precautions should be taken in regard to healthcare or support professionals who could be super-transmitters (see section 6 below). Through these precautions, they can maintain a "firewall" that limits potential viral transmission upon entering and leaving the households of adults with IDD that they visit.



2(d) Population trends



During the early phase of a pandemic (Phase 1), there will be the following trends: (1) the number of people who are not infected and are not immune will be decreasing rapidly (grey bars in the chart); and (2) the number of people with new infections will increase rapidly (blue and orange bars). This rate will plateau and could even begin slowly to decrease as public health measures succeed. This is referred to colloquially as “flattening the curve”. In this model, this occurs from weeks t4 to t9. This period of plateau will enable the capacity of the healthcare system to increase.

The public health goal in this first phase is to slow down the rate of increase of people who get infected with the novel coronavirus and have severe symptoms (orange bar). This will ensure that the capacity of the healthcare system, e.g., numbers of acute and intensive care beds or the supply of personal protective equipment (PPE) as a percentage of the population (vertical line), is never exceeded. During this phase, the number of those who recover from COVID-19 and have become immune hopefully will increase (yellow bar).

If public health measures are relaxed or withdrawn too soon, the number of new infections and of people with severe symptoms of COVID-19 could surge again and risk

exceeding the capacity of the healthcare system. In this model, a resurgence of infections happens in phase 2 after public health measures are relaxed at time t_8 .

“Herd immunity” is attained when a significant percentage of the population has immunity to the novel coronavirus. One estimate is around 67%.¹⁶ Herd immunity can slow down or even stop the spread of the virus through the community. Without effective anti-viral treatments to aid recovery from COVID-19 and a vaccine, herd immunity is difficult to attain against the novel coronavirus without incurring an unacceptable death rate. Also, at this point, researchers are uncertain about the degree and duration of immunity to the novel coronavirus in people who have recovered from COVID-19.

The general point is that, in the absence of treatments and a vaccine, establishing and maintaining stringent public health measures can help significantly to slow down spread of the virus so that the healthcare system will have the time to maximize its capacity to address patients’ needs. Some restrictive public-health measures, however, cause significant hardships especially for people with IDD and their family caregivers. They are disproportionately affected by these measures and are vulnerable to experiencing both increasing needs and decreasing supports. The challenge is finding the right balance between accommodating adults with IDD who are psychologically and socially vulnerable while optimizing care of those who are physically vulnerable to developing severe symptoms of COVID-19. Often these groups overlap.

4. Public health measures

Public health measures during the COVID-19 pandemic should take into account the specific needs of people with IDD.

- **Accessible information:** A key challenge for caregivers is find ways to keep information regarding COVID-19 simple and relevant to the adult with IDD for whom they care. This is also a key challenge for primary care providers, who can be allies in this task of translating relevant specialized public health and other information into simple and meaningful messages for adults with IDD. There should be alternative ways of delivering information to those adults with IDD who do not use or have access to phones, computers or the Internet.
- **Accessible testing for active novel coronavirus infections:** Alternative means of testing could be tried with adults with IDD who cannot tolerate nasopharyngeal tests, which involve obtaining samples from deep inside the nose. Specialized testing and care areas for COVID-19 that are set up for the public should be accessible to people with limited mobility. They should be resourced to support people with behaviours that challenge. The option of in-home testing is preferable and should be requested if needed.

- **Accessible health care:** Remote primary and other health care should be offered in ways that people with IDD can access, especially those without phones or Internet.
- **Maintaining or replacing usual supports:** In-home supports and community programs that are essential or beneficial for people with IDD are likely to diminish or stop for several months. Solutions will need to be found to replace these supports. For example, personal support professionals should be included among providers of essential services during the pandemic. Supports should be offered to family caregivers, who might themselves be physically vulnerable or who might fall sick and need to self-isolate. Creative solutions should be developed to address heightened social exclusion, loneliness, boredom, helplessness, and stress, which already disproportionately affect people with IDD and their family caregivers.
- **Adapting public health measures for risk reduction:** Alternative risk reduction strategies and contingency plans should be developed as needed. For example, people with IDD for whom entirely restricting their engagement with others is unrealistic or unhealthy will need additional supports (e.g., more frequent monitoring of their health, alerting police and other public officials in charge of enforcing physical distancing measures that they are vulnerable persons).

5. Teaching COVID-19 risk-reduction behaviours

Here are examples of plain-language instructions and suggestions for teaching people with IDD behaviours to reduce risk of infections and transmissions by the novel coronavirus. For examples of videos, picture books, and plain-language information that can be used for teaching, see Resources below.

- **Respiratory (sneezing and coughing) etiquette:** Sneeze, cough or blow your nose into a tissue or into your elbow. Throw used tissues into the garbage right away. (Demonstrate using a lined garbage container.)
- **Washing hands:** Use soap and water to wash your hand for 20 seconds after being outdoors, coughing, sneezing, blowing your nose, or touching food. (Show how to do this or play video.) If you cannot wash your hands, use a hand sanitizer and let your sanitized hands dry in the air.
- **Don't share things that you use or another person uses personally** (e.g., toothbrush, towel, cell phone).

- **After touching things that others have touched**, such as tabletops, countertops, door handles, handrails, faucets or shared appliances (this is unavoidable in family households or group homes), remember to wash these surfaces and then wash or sanitize your hands.
- **Don't touch your face** (especially eyes, nose, mouth) with unwashed hands. Don't bite nails or pick your nose. These behaviours might be difficult to avoid for some people. Consider teaching an alternative behaviour, e.g., regular face washing with soap and water or using a fidget ball.
- **Physical distancing:** When you go out, keep your distance or leave a space of about three arms' length or 6 feet (2 meters) from people. Avoid touching, shaking hands, high-fives, hugging or kissing. One approach could be to teach positive behaviours in addition to physical distancing, e.g., how to offer friendly greetings at a distance and other gestures of solidarity like waving.
- **Get outside but maintain physical distancing** (e.g., to buy food, pick up medication or exercise once a day). Don't arrange to meet groups of friends or family members (no more than 2 people). Stay in touch using the phone or computer.

6. Giving care safely

Caregivers of adults with IDD will, like the person they care for, need to learn new behaviours in order to keep themselves and everyone with whom they are in contact safe. By adopting the outlined precautions, caregivers can delay or avoid transmitting the novel coronavirus. This will give them confidence to continue to support the total health and wellbeing of the adult with IDD for whom they care.

For healthcare and support professionals visiting households with adults with IDD:

- **Avoid wearing** jewelry, a watch, nail polish or anything through which the novel coronavirus could be brought into the home. If you do wear a watch, for example, clean it before and after the home visit.
- **Bring** washable over clothes, e.g., a gown, or bring a change of clothes. Also bring something disposable or washable to cover your shoes or another pair of shoes.

During a home visit:

- **Hygiene routines:** Observe respiratory etiquette and regularly wash and sanitize your hands. Carefully clean belongings such as cell phones and glasses. Avoid touching your face with unprotected hands or gloves. Disinfect surfaces before and after use.

- **Interact with anyone in self-isolation last.**
- **Personal protective equipment (PPE):** Using disposable medical (“surgical”) masks, gloves or gowns or washable coveralls or over-clothes are appropriate for activities that involve close personal contact, contact for 15 minutes or more in a small and unventilated space or contact with bodily fluids, e.g., washing, bathing or other ways of assisting an adult with IDD with hygiene routines, performing a physical assessment as a healthcare provider or in other situations where proximity to a patient or client is unavoidable. Goggles and face shields might also be appropriate depending on the task and to prevent you from touching your eyes. When wearing a medical mask, cover **your nose** as well as your mouth and avoid re-adjusting. Do not share masks or re-use masks that have not been sanitized.
- **Full PPE** (e.g., a tight-fitting N95 respirator mask, eye protection, gloves, and gown) is most important for use by healthcare providers and paramedics to protect themselves when assessing or performing certain medical procedures (e.g., those involving aerosols). For such PPE to be effective, one needs to use proper techniques when putting it on and removing it.

After a home visit:

- **Hygiene routines:** Wash and sanitize your hands. Disinfect used surfaces. Carefully clean belongings such as cell phones, badges, watches and glasses. Dispose of single-use masks, gloves and gowns in a lined garbage container and wash your hands. Take home any over-clothes, coveralls or changed clothing in a disposable paper bag and wash these items prior to the next use in very hot water with detergent. Leave shoes at the door when you return home and clean them.
- **Self-isolation:** Self-isolation means staying at home and separating oneself from other members of the household as much as possible. Healthcare providers and support workers are potentially super-transmitters. If such persons have symptoms associated with COVID-19 or have had a significant exposure (e.g., significant contact with a possibly infected person without proper use of PPE), even if they do not have ARI symptoms, they should stay home in self-isolation. Follow public health and organizational policies for the period of self-isolation (e.g., 14 days following a significant exposure). Public health authorities will advise super-transmitters regarding when it is safe for them to return to work.
- **Maintain precautions (e.g., masks and physical distancing) to avoid staff-to-staff transmission**

7. How to recognize COVID-19

- The time from exposure to developing ARI symptoms associated with COVID-19 is usually 4-5 days but can last as long as 14 days. This is referred to as the incubation period.²
- Watch for new ARI symptoms, cough (usually dry), fever and shortness of breath or any combination of these. **Other less common or atypical symptoms** associated with COVID-19 besides upper respiratory symptoms (runny nose, sore throat, headache) are lower respiratory symptoms (productive cough), fatigue, gastrointestinal symptoms (diarrhea, nausea, vomiting), reduced sense of smell, muscle aches or confusion.
- Health monitoring is important for some physically vulnerable persons with IDD without symptoms. **It is also important for adults with IDD who might be unable to communicate new ARI symptoms or might experience atypical symptoms.** Alert their primary care provider as soon as new symptoms are noticed.
- **Check for symptoms that might not be noticed or reported** (e.g., fever). Measure body temperature once or twice a day before taking medications such as Tylenol or Advil. Temperatures above 37.5°C or 1°C above the person's usual body temperature indicate a fever. Look also for the following behaviours in persons who are unable to report feeling unwell: looking flushed or pale, feeling hot or cool to the touch, being atypically fussy or groggy, having "goose bumps", shivers or tremors, diarrhea, excessive sweating and/or being more thirsty than usual.
- **Check for worsening ARI symptoms especially in people with IDD who have COVID-19 and are physically vulnerable to developing severe illness** (e.g., new continuous coughing, new shortness of breath, new rapid breathing of more than 25 breaths per minute at rest, or new rapid heart rate of more than 100 beats per minute at rest). For persons with challenges communicating, consider checking oxygen saturation levels twice daily if possible. A drop in oxygen saturation levels from usual levels of 93-100% to less than 93% (or 5% below typical levels) is significant and a reason to call your primary care provider.
- **Be attentive to changes in behaviour that might communicate heightened stress, increased anxiety or emotional distress.** Recognize that COVID-19 is bad news, and grieving can be expected. To promote mental health, encourage practices that have previously helped, e.g., talking about worries and difficult feelings or expressing feelings with drawings or other forms of art. Encourage physical

activities or exercise in the home or once a day outdoors. Encourage continuing social and spiritual practices.

8. When to get tested

Ideally, in managing the pandemic, widespread testing and follow up are optimal strategies. If resources are limited, authorities will establish guidelines for who should be tested and when, **which might be updated periodically**.

- Contact an adult with IDD's primary care provider or team for advice regarding testing (typically, they will do this by telephone) or complete an online screening test.³
- When a person with IDD has had a significant exposure to the COVID-19 virus or develops symptoms associated with COVID-19, seek referral for expedited testing. This is especially important if the adult with IDD is physically vulnerable to developing severe symptoms or is living in a congregate setting.
- For adults with IDD who might have difficulties going to and being tested in a strange setting or tolerating the usual nasopharyngeal swab test that involves obtaining a sample from deep inside the nose, ask their primary care provider about at-home testing or adapted testing (e.g., using a throat or sputum sample).
- Test results are usually ready within 24 hours but there could be a delay in reporting results if there is high demand for testing.
- Tests **confirm** the presence (positive) or absence (negative) of active novel coronaviruses. Their interpretation should always be related to **clinical assessments**. In a few instances, tests can generate false positive results (detecting viral activity where there is none) or false negative results (failing to detect viral activity). For persons who have tested negative for the novel coronavirus, if they have had no known contact with anyone with COVID-19 and an alternative diagnosis is much more likely than COVID-19 for their ARI symptoms, they do not need to self-isolate. But if they have or could have had significant exposure to the novel coronavirus or if there is no reasonable alternative diagnosis for their ARI symptoms, retesting is appropriate (e.g., within 24 hours after the prior test results).
- At a more advanced stage of COVID-19, lower-respiratory symptoms emerge (mainly frequent coughing that produces phlegm). If tested at that stage, people could have a true negative nasopharyngeal swab test result that does not pick up viral activity in their lungs. If it has been 3-5 days since the onset of ARI symptoms or if there are lower-respiratory symptoms, a sputum test and other investigations, e.g., chest x-ray, might be appropriate.

- If a person is referred to be tested at a hospital or COVID-19 assessment centre, do not use public transportation. Use reasonable precautions while travelling to and from the testing setting (e.g., the adult with IDD should use a mask, sit in the back seat, and keep the window open. The vehicle should be disinfected properly prior to being reused).

9. Keeping an adult with IDD and COVID-19 comfortable at home

See also section 7 on monitoring symptoms. Alert the person's family physician for advice as soon as new ARI symptoms associated with COVID-19 develop or if symptoms worsen.

- **Primary care support:** In general, adults with IDD and COVID-19 who are not physically vulnerable to severe symptoms can be supported at home with guidance from a primary care provider if self-isolation is feasible (e.g., staying in their own room). The primary care provider can involve others as needed. During this pandemic, most primary care providers have switched from in-person office visits to consultations by telephone or videoconferencing.
- **Medical supplies:** Maintain a 2-month stock of medications and other medical supplies (e.g., puffers, oxygen) that the person you care for regularly uses.
- **Transfer to hospital:** When self-isolation of the adult with IDD and COVID-19 is not feasible or when this person's symptoms become severe (see section 7 above), the person's family physician might propose that the person be assessed in hospital. It is helpful to have a hospital transfer plan in advance of an illness for all adults with IDD (see section 13 below).

10. Whom to call for medical help

- Caregivers' partnership with healthcare providers should always begin with the person's family physician and family health team. It is their role to involve and coordinate with others as needed. The role of caregivers of an adult with IDD during this pandemic is crucial. All healthcare providers need to recognize this role and support caregivers as much as possible. Also, be aware of the changing needs of the adult with IDD during the pandemic even prior to their getting infected. Ensure that prior supports are maintained safely and increased to meet any increasing needs.

- **Health information from media, social media or Websites:** Ask for advice from your primary care provider before trying new medications and other therapies still under investigation based on information from such sources.
- **Vaccinations:** There is not yet a vaccine for COVID-19. It is a good idea to get vaccinated for Influenza (“regular” Flu) and Pneumococcal Pneumonia (Pneumovax) to lower the risk of these possible co-infections if one becomes infected with COVID-19.
- **Medical helpline:** Use reliable helplines (e.g., Telehealth Ontario (toll-free 1-866-797-0000) if you cannot reach your primary care provider or team but contact this care provider or team for follow up when new symptoms develop or symptoms worsen.
- **Self-isolation:** In the context of COVID-19, family members, other caregivers, and group home agencies need to think about their capacity to provide health care and other supports to address the needs of people with IDD who are physically vulnerable to severe ARI symptoms and must self-isolate. This might be after a significant exposure to the novel coronavirus, after developing new ARI symptoms suggestive of COVID-19 or if the adult with IDD does not wish to go to hospital or has been discharged. This could involve working with the family physician to arrange in-home medical care and nursing support.
- **Emergency care:** When an adult with IDD is experiencing moderate to severe ARI symptoms, including difficulty breathing, chest pains, reduced level of consciousness or difficulties being roused from sleep, this is an emergency situation. Contact emergency services (911) according to the adult with IDD’s Advance Care Plan and alert their primary care provider, substitute decision maker, and others (see Hospital Transfer Plan below).

11. Advance care planning

Adults with IDD, especially those who are physically vulnerable to developing severe ARI symptoms related to COVID-19, should have an updated Advance Care Plan. This plan should specify the person who is willing and able to assume the role of Substitute Decision Maker (SDM) if and when the adult with IDD is incapable of consenting to a proposed treatment.

- The process of updating or doing advance care planning involves discussions and inputs from several people. Since this can be a time-consuming process, it is best to begin this process as soon as possible if the adult with IDD you care for is in a high-risk group.

- The Advance Care Plan includes a summary of discussions of the person's current goals and values. It can also include their input, as well as input from others, regarding treatment preferences related to COVID-19.
- It might include specific directives regarding future treatments the person would or would not want. Such an Advance Care Plan will inform the SDM's task of consenting to or refusing consent to the responsible in-hospital physician's proposed levels of care or specific treatment plan at a time when the adult with IDD is incapable of providing such consent.
- In the context of the COVID-19 pandemic, an Advance Care Plan and any related directives should envision the possibility of an ARI from which most adults with IDD will recover. This is a different context from the one envisioned when most adults with IDD might have prepared an Advance Care Plan, namely end-of-life care from a chronic and progressive health condition (e.g., Alzheimer disease). Neither an Advance Care Plan nor an Advance Directive gives or declines consent to specific treatments that might be proposed in the future. Such consent can only be given by a valid SDM whose decisions should be informed by and congruent with such plans.
- These plans should not be considered to be written in stone but rather to be updated as needed while the adult with IDD continues to be able to contribute to them.
- Such contributions do not require the adult with IDD to meet the usual capacity test needed to consent to a treatment.
- It is best to develop or review these plans with the adult with IDD and others who know them well to ensure that their goals, values, and preferences regarding emergency or hospital treatments and end-of-life care are known and can be supported (see Resources for guidance on an Advance Care Plan for Adults with IDD and COVID-19).

12. Contingency ('what if') plans

There are a number of contingencies that will need to be considered and planned for in light of specific vulnerabilities the adult with IDD whom you support that might experience and other factors, such as their environment and supporters. While Advance Care Plans relate to the adult with IDD's consent or refusal of consent to future proposed treatments, 'what if' or contingency plans relate to other circumstances that are important to imagine in the context of the COVID-19 pandemic.

- For example, what would be your plan in the scenario in which the adult with IDD for whom you care tests positive for COVID-19 and is physically vulnerable to developing severe illness? Such a plan would need to consider whether that person could be safely self-isolated in their current setting, monitored closely to identify worsening symptoms, and what should be done if the person's symptoms worsen in light of their Advance Care Plan.
- Another scenario might involve developing a plan for the adult with IDD who might have severe mental-ill health or behavioural distress without their usual supports (e.g., some people living with Autism Spectrum Disorder).
- These examples indicate the need to imagine such possibilities and develop contingency plans following discussions with the adult with IDD, their primary care providers, and others involved in their care.

13. Hospital transfer plan

Another scenario to anticipate is the need to transfer the adult with IDD whom you care for to hospital due to worsening symptoms from COVID-19. Suppose that you or others involved have activated the Emergency Medical Services (i.e., by calling 911). What health and other information should be ready to go with the adult with IDD to the hospital? It would be helpful to have such information prepared and packaged together in advance.

- **Health Passports** (e.g., *About Me*—see Resources below): People with IDD should have a health passport that informs healthcare providers and hospital staff who might not know them well about their medical history, health, and support needs. This should be included in the Hospital Transfer Package.

14. Ensuring medically appropriate and ethical care

Your biggest role as a caregiver is to advocate that the adult with IDD for whom you care receives health care that is congruent with their preferences or best interests. It is important to align your advocacy efforts with those of the adult with IDD's primary care provider, substitute decision maker (SDM), and others who know them well and are trusted by them. These alliances should begin before they become ill and are admitted to hospital. Each person matters.

- In general, you will need to weigh doing good for the adult with IDD with avoiding risk of harm to yourself and others for whom you have responsibility. You should continually seek ways to help the adult with IDD who has COVID-19

but also be well-informed regarding risks of infection and take appropriate precautions. To be avoided is refusing to provide the adult with IDD care or support when the risk that they will transmit COVID-19 virus is low with appropriate prevention. Also, to be avoided is failure to observe appropriate precautions when the adult with IDD to whom you are providing care or support has symptoms of a possible COVID-19.

- Caregivers might sometimes be faced with situations where there is incomplete compliance with appropriate preventive measures (e.g., PPE is not available or not optimal; observance of public health directives regarding isolation cannot be maintained fully in the care setting). In such situations, best efforts should still be made to reduce risks of transmitting infections (from the adult with IDD to you or other care providers, and vice versa) while providing care that the adult with IDD needs. When the risk of infection falls on the care provider, this might sometimes require a decision to act out of moral courage and compassion that goes beyond professional or legal obligations.
- When an adult with IDD tests positive for the COVID-19 virus, everyone who is likely to have had significant contact with this person at home or elsewhere should be informed quickly regarding the adult with IDD's status (usually Public Health officials track such contacts and make recommendations regarding isolation and testing).
- Public policies addressing the COVID-19 pandemic should be informed by the perspectives of adults with IDD, you and other family caregivers, and care providers. They should take into account the specific needs and barriers to health and palliative care of adults with IDD.
- Guidelines for allocating limited healthcare resources, such as access to intensive or palliative care, should not discriminate solely on the basis of the adult living with a disability or on "usefulness" to society. Such discrimination devalues people with disabilities and is unjust. There can be ethical justification for allocating limited resources based on considerations for *any* medical treatment, such as likelihood of benefit to the patient (e.g., recovery from COVID-19 and good prognosis afterwards), risks and burdens of the treatment for the patient and the patient's caregivers (e.g., as determined by the patient's goals, values, and preferences).
- The decision-making capabilities of adults with IDD should be supported to enable them to have equal access to the benefits of participating in trials of new vaccines and treatments (see Resources for guidance on a Promoting Capabilities tool).

15. Resources

General information about COVID-19

- Government of Canada: <https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19.html>
- Ontario Ministry of Health self-assessment for symptoms: <https://covid-19.ontario.ca/self-assessment/#q0>
- Oxford COVID-19 Evidence Service (synthesizes latest research): <https://www.cebm.net/covid-19/>
- Ontario Ministry of Health and Long-Term Care. COVID-19 Quick reference: public health guidance on testing and clearance: http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_testing_clearing_cases_guidance.pdf
- Public Health Ontario (news at a glance from major public health agencies): <https://www.publichealthontario.ca/-/media/documents/ncov/ncov-daily-lit.pdf?la=en>
- Toronto Region Assessment Centres: <https://www.toronto.ca/home/covid-19/covid-19-health-advice/covid-19-assessment-centres/>

Guidance for professional care providers

- Centers for Disease Control and Prevention. Interim clinical guidance for management of patients with confirmed Coronavirus Disease (COVID-19). May 15, 2020. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-guidance-management-patients.html>
- Ontario Ministry of Health guidance for primary care providers: http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_primary_care_guidance.pdf
- Ontario Ministry of Health guidance for home and community care providers: http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_home_community_care_guidance.pdf

IDD-specific COVID-19 information

- Canadian Association on Community Living:
<https://cacl.ca/coviddisability/>
- Dr. Chris Hatton, Potential risk factors for the impact of COVID-19 on health: People with learning disabilities:
<https://chrishatton.blogspot.com/2020/03/potential-risk-factors-for-impact-of.html>
- Jerome Lejeune Foundation Q&A on COVID-19 and Down syndrome:
<https://www.lejeunefoundation.org/wp-content/uploads/2020/03/2020-COVID19-DS-QA-JLF-Expanded-FINAL.pdf>

Information for family and other caregivers

- Information for those in isolation or caring for someone in isolation:
<https://www.gps-can.com.au/covid19-blog/a-guide>
- Surrey Place: <https://www.surreyplace.ca/resources-publications/coronavirus-updates-resources/>

Accessible information

- Animation on prevention:
<https://twitter.com/Stanford/status/1242508882993459201?s=20>
- Books Beyond Words: picture books to explain COVID-19
<https://booksbeyondwords.co.uk>
- Handwashing video: <https://youtu.be/O6Y5cK6D8wo>
- HCARDD: <https://www.hcarddcovid.com/info>
- Keep Safe (UK): <https://www.keepsafe.org.uk>

Tools

- *About Me* (HCARDD) –health passport
https://www.porticonetwork.ca/documents/38160/99698/About+Me_YM_Oct14_rotated.pdf/f2f436ee-63ec-4e76-ab10-c5924de5bc75
- *COVID-19 Advance Care Plan: A Guide for Caregivers of Adults with Intellectual and Developmental Disabilities*
<https://ddprimarycare.surreyplace.ca>
- *Decision Making of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities* –guide to assessing decision-making capabilities
<https://ddprimarycare.surreyplace.ca>

Notes and references

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- ⁵ Lauer SA, Grantz KH, Bi Q, et al. The Incubation Period of Coronavirus Disease 2019 (COVID-19) From Publicly Reported Confirmed Cases: Estimation and Application. *Ann Intern Med*. 2020;172(9):577-582. doi:10.7326/M20-0504
- ⁶ On May 12, 2020, Canadian federal regulators approved use of an antibody test for immunity to COVID-19 developed by DiaSorin.
- ⁷ On May 16, 2020, the federal government announced that the Canadian Center for Vaccinology will run the first Canadian clinical trials for a possible COVID-19 vaccine: <https://www.cbc.ca/news/canada/nova-scotia/first-canadian-vaccine-trials-covid-19-halifax-1.5573283>
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