

Health care of adults with intellectual and developmental disabilities in a time of COVID-19

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Adults with intellectual and developmental disabilities (IDD), such as Down Syndrome and autism, are a population at risk of contracting COVID-19 and of serious illness associated with COVID-19. Members of this community are experiencing significant distress due to confusion and disruption in their daily lives. Their voice is notably absent from current discussions. Clear resources and supports explaining how to manage, along with in-person support would be helpful.

In addition, the **high rates of emergency department visits and hospitalizations** for this group even before COVID-19 may now be exacerbated. Proactive primary care in the community to address physical and mental health needs may be useful.

We can imagine challenging situations:

- A man in his forties with Down syndrome living in a group home with early signs of dementia develops a dry cough and mild fever. He is tested for COVID-19, but the test is not expedited and he is told to self-isolate for 14 days, as are his 5 housemates and all staff who have interacted with him. Being supported by a small agency where staff move between homes, and having complex needs himself, this means that many staff from this agency are now in self isolation like this man, and the 5 others in his group home. There are not enough staff in the agency to support the home now, and he and his housemates are confused and agitated about being in their rooms. The situation is no longer safe, and 9 days have passed with no test results to confirm whether it is COVID-19 or not.
- A young woman in her thirties with a mild intellectual disability lives with her aging mother (who has diabetes and asthma) in a small apartment. It is difficult for her to understand the restrictions now in place and she longs for her previous routines and connections in the community and misses meetings with her workers. She can no longer attend her day program, or the recreational activities at the local Y. She sees online that a "friend" is offering an exercise class in her home while the classes at the Y are canceled. She wants to stay healthy and be with friends, so she takes money from her dresser and leaves the house despite her mother asking her to stay home and avoid larger groups. Her mother cannot contact this "friend" (who should not be offering in person classes) and she cannot stop her daughter who travels across the city by public transportation to meet in a group setting to do exercise. She fears her daughter will become ill or bring COVID-19 into their home.

Communication, symptom monitoring, management and caregiving strategies need to consider comorbidities, special needs and the variety of settings in which adults with IDD live:

1. Some adults with IDD living in congregate care (group homes) have similar medical and behaviour concerns to many long-term care residents **despite their younger age**. Public health guidelines should provide for expedited assessment and enhanced follow-up for this group.
2. The direct care workers in group homes for adults with IDD are essential to their health care. Protocols and protections, like those for essential health care workers, should be implemented.

3. Some adults with mild IDD living independently in the community are at risk of not understanding or adhering to public health guidelines. Proactive communication and support (e.g. by phone) from knowledgeable social and health care providers is necessary to help them adhere to guidelines and manage during this difficult time.

4. Family caregivers, especially older parents, who live with and provide care for an adult with IDD, are at risk of severe COVID-related illness themselves. A crisis plan needs to be in place to continue the care of their family member in that situation.

5. If an adult with IDD needs emergency department or other hospital services, especially during the coming surge in COVID-19 cases, a partnership between family and other community-based caregivers and hospital staff will be necessary to support the communication and other special needs of the adults with IDD. Decision making supports and advanced care plans are crucial at this time. If a substitute decision maker is required for a health care decision, it is important they are accessible to hospital staff.

Resources:

A 14 minute [video presentation](#) presents a discussion of these issues.

The Ontario Ministry of Health has published a guide for staff or volunteers in group homes, "[COVID-19 Guidance: Group Homes and Co-Living Settings](#)"

The [Health Care Access Research and Developmental Disabilities \(H-CARDD\) webpage on COVID-19](#) has links to resources for patients and caregivers.

Surrey Place, a community agency in Toronto for persons with IDD, has a webpage with links to COVID information, which includes a document for educating care providers of people with IDD, "[COVID-19: Guidance for Prevention and Care](#)"

The National Health Service, England, produced a brief document with key principles, "[Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic - relevant to all clinical specialities](#)"

The "[Primary Care of Adults with Intellectual and Developmental Disabilities. 2018 Canadian Consensus Guidelines](#)" provides background health knowledge and recommendations for primary care providers.

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