



## Supporting the mental health of adults with developmental disabilities and their families during COVID-19: A national capacity building project

### What is the project about?

Pre-pandemic, adults with developmental disabilities such as Down syndrome or autism were at increased risk for mental and physical health conditions and nearly 4 times as likely to die prematurely than other adults. COVID-19 has exacerbated the challenges already faced by these individuals, placing them at greater risk of contracting COVID-19, being hospitalized and dying from it. As well, they have been severely impacted by the abrupt stop to their daily routines, recreational/vocational programs, and contact with friends and family.

This Canada-wide project addressed the urgent need to support the mental health needs of adults with developmental disabilities during COVID-19 by building a community of practice amongst self-advocates, families and service providers.

### What did we do?

We engaged self-advocates, family caregivers, and health and social service providers to participate in virtually delivered six-week courses during two cycles (fall and winter 2020/2021), targeting the mental health of adults with developmental disabilities during COVID-19. A national community of practice was created, with 279 research participants from across Canada representing all ten provinces and one territory.

We used a mixed-methods design to evaluate the impact of the virtual educational courses delivered to the three groups. Specifically, we evaluated the process (i.e. program participation and satisfaction) and outcomes (i.e. change in participants' experiences of COVID-19, learning and self-efficacy, practice and well-being) for each course. Questionnaires were administered at multiple points (baseline, 6 weeks, and 12 weeks) via an online platform (families/service providers) or individual structured interviews (self-advocates).

### What you need to know

We engaged self-advocates, caregivers, and service providers to participate in virtually delivered six-week courses targeting the mental health of adults with developmental disabilities during COVID-19. In all three groups, participation and satisfaction rates were high. Participants reported improved knowledge and self-efficacy with regard to supporting and managing mental health.

We also found that the roles of self-advocates and families as teachers were valued by course participants and team members. Our study demonstrated the value and feasibility of virtual learning and the creation of communities of practice at a time when people with developmental disabilities and caregivers need connection, support and information.

### What did we learn?

For all three groups, participation and satisfaction rates were high. Individuals in each group reported improved knowledge and self-efficacy with regard to supporting and managing mental health, self-care and working together across providers and sectors, which were maintained at follow-up.

Families reported improvements in well-being, which were maintained at follow-up. Our project also found that the roles of self-advocates and families as teachers were valued by course participants and by the teams delivering the information.

This is one of the few projects to reach people with disabilities, their families and the service providers who support them, nationally.

## About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and well-being of people with developmental disabilities through improved health care policy and services. For more information:

[www.hcardd.ca](http://www.hcardd.ca).

This study was funded by a CIHR grant, #MS2-173090. The opinions, results and conclusions in this summary are those of the authors. No endorsement by the funders or collaborators is intended or should be inferred.

## Do you want to know more?

### Read our most recent publications:

Lake J., Volpe T., St. John L., Thakur A., Steel L., Baskin A., Durbin A., Chacra M.A., and Lunskey Y. (2022). Mental health and COVID-19: The impact of a virtual course for family caregivers of adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*. <https://doi.org/10.1111/jir.12965>

St. John L., Volpe T., Jiwa M. I., Durbin A., Safar Y., Formuli F., Thakur A., Lake J. & Lunskey Y. (2022). 'More together than apart': The evaluation of a virtual course to improve mental health and well-being of adults with intellectual disabilities during the COVID-19 pandemic. *Journal of Applied Research in Intellectual Disabilities*. <https://doi.org/10.1111/jar.13024>

Thakur A, Pereira C, Hardy J, Bobbette N, Sockalingam S, & Lunskey Y. (2021) Virtual Education Program to Support Providers Caring for People With Intellectual and Developmental Disabilities During the COVID-19 Pandemic: Rapid Development and Evaluation Study. *JMIR Mental Health*. 8(10):e28933 <https://mental.jmir.org/2021/10/e28933>

## What did we learn (cont'd)?

Its virtual nature means that it did not require clinical expertise to exist in any local region. Some of the innovative aspects of our project meant that people with developmental disabilities could be supported to participate both in the intervention itself, as well as the research, when typically due to health literacy, reading literacy and digital literacy challenges, they would be excluded.

Through ongoing engagement with stakeholders, we were able to update existing resources, as well as develop new resources based on emerging issues (e.g., vaccinations) during the pandemic.

## Why is this important?

Our study demonstrated the value and feasibility of virtual learning and the creation of communities of practice at a time when people with developmental disabilities and caregivers are needing connection, support and information. Brief interventions can be valuable to each of the audiences targeted.

This project has identified current gaps and needs from multiple perspectives as well as geography. We need to improve access to adapted mental health resources.

As the pandemic continues, mental health problems will persist for this population and in many cases may worsen with a shortage of available support. Knowing how to rapidly spread valuable information and resources across the country is a valuable and important lesson.



Virtual 6-week course with ECHO hub team, including a psychiatrist, psychologist, family physician, social worker, occupational therapist, patient and family advisors.

## Additional information and resources:

- For more information, visit our [H-CARDD COVID webpage](#), [YouTube Channel](#), and [COVID-19 blog posts](#).
- [ECHO Ontario webpage](#).
- [COVID self-help booklet series](#) distributed to self-advocates across the country through People First Canada, one of our project partners. They were also translated into [French](#) and featured in a [video](#), made with DramaWay, to demonstrate how to use the self-help booklets.
- [Webinar](#) presentation, in collaboration with Partners for Planning.

## About the Team

This project was led by Drs. Lake, Lunskey and Thakur from the Centre for Addiction and Mental Health, and Dr. Durbin from St. Michael's Hospital, together with many university and community partners and collaborators from across the country.



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