

# The impact of COVID-19 on Canadian adults with a developmental disability: What does the research tell us and what can we do about it?

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Dr. Anna Durbin, St. Michael's Hospital

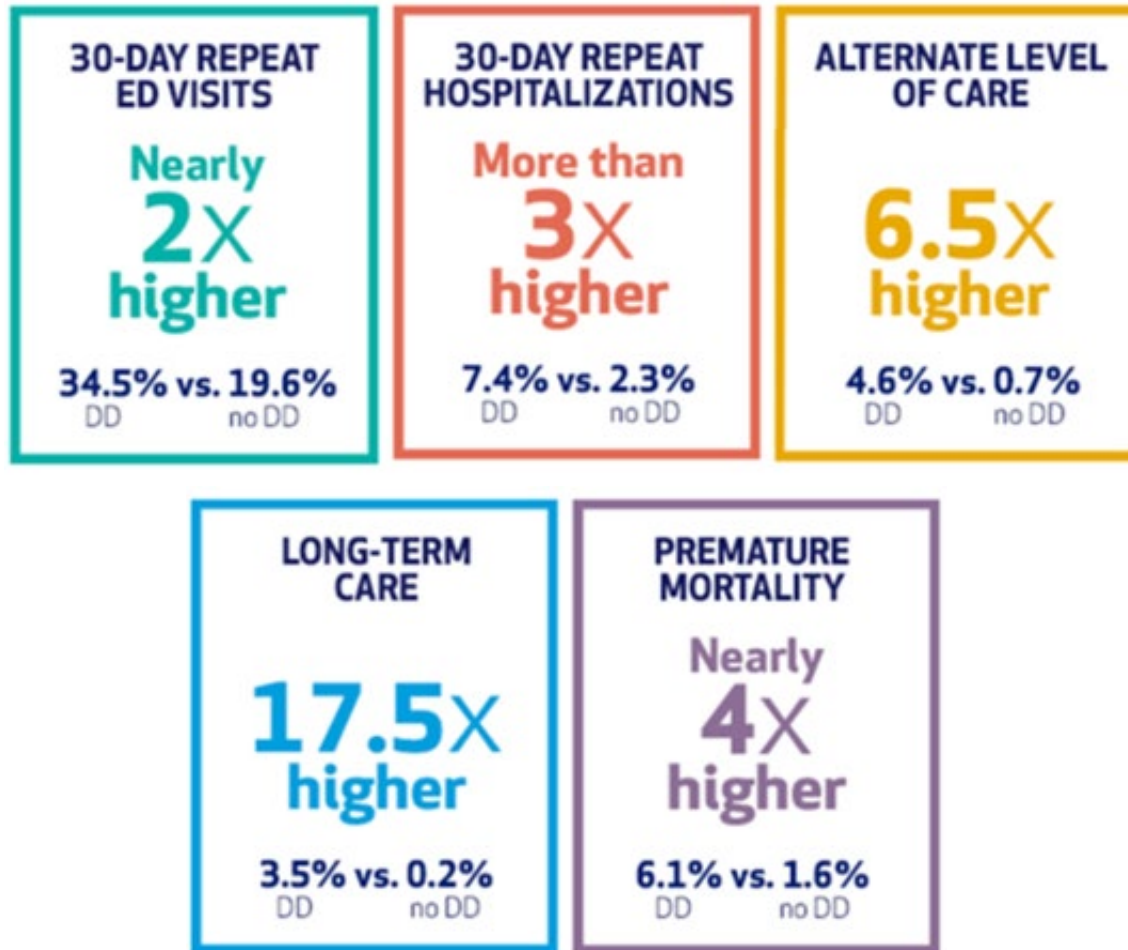
Dr. Anupam Thakur, CAMH

Professional Learning & Development Webinar  
Ministry of Children, Community and Social Services  
September 28, 2021

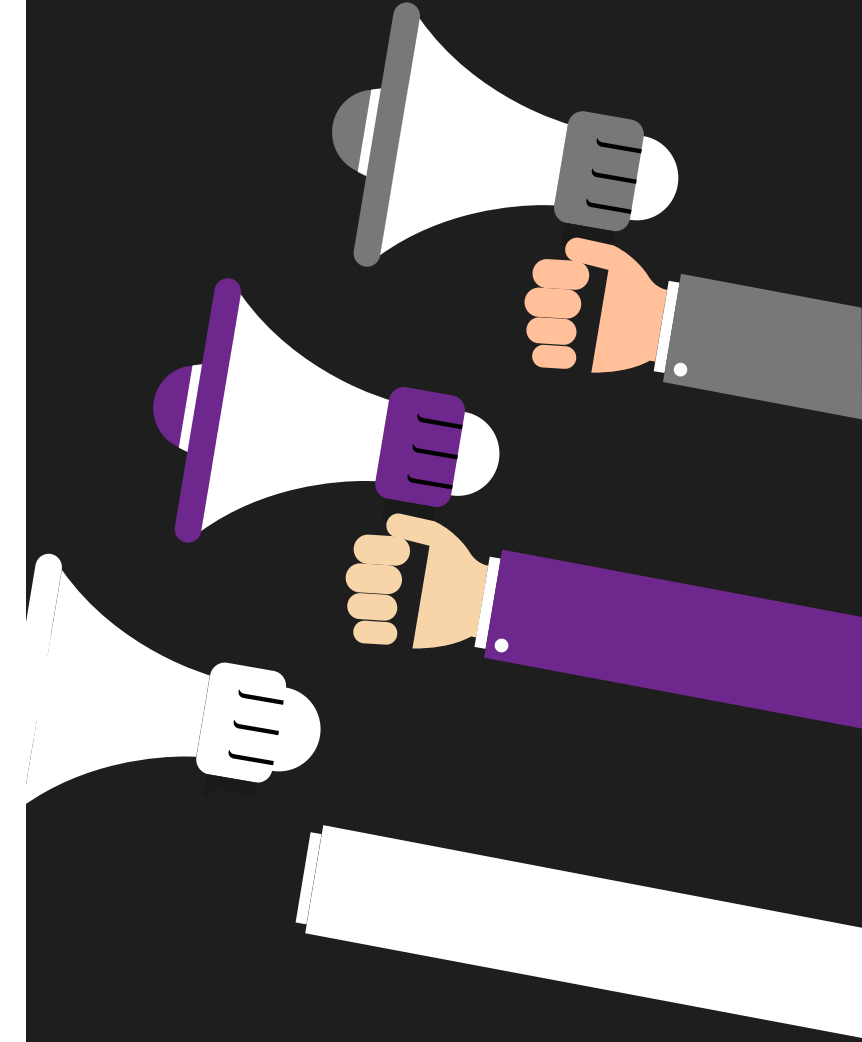


# Part 1: Population impacts of COVID-19

# Big Numbers [pre-pandemic]



Lin E, Balogh RS, Durbin A, Holder L, Gupta N, Volpe T, Isaacs BJ, Weiss JA, Lunsky Y. *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario*. Toronto, ON: ICES; 2019.



# Hospitalization and mortality rates are higher for adults with developmental disabilities during the COVID-19 pandemic

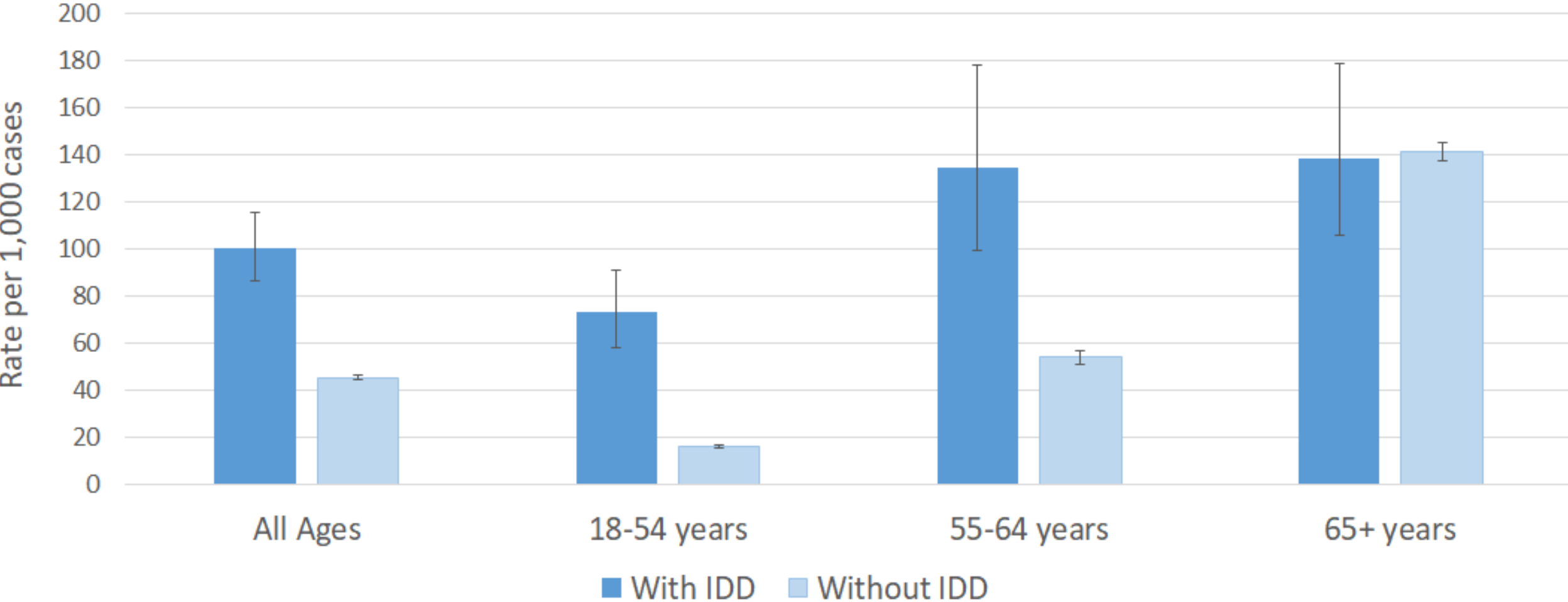


For adults with and without intellectual and development disabilities (IDD) in Ontario, researchers compared rates of COVID-19 positivity, hospitalization, ICU admission and mortality within 30 days of testing positively between January 2020 and January 2021.

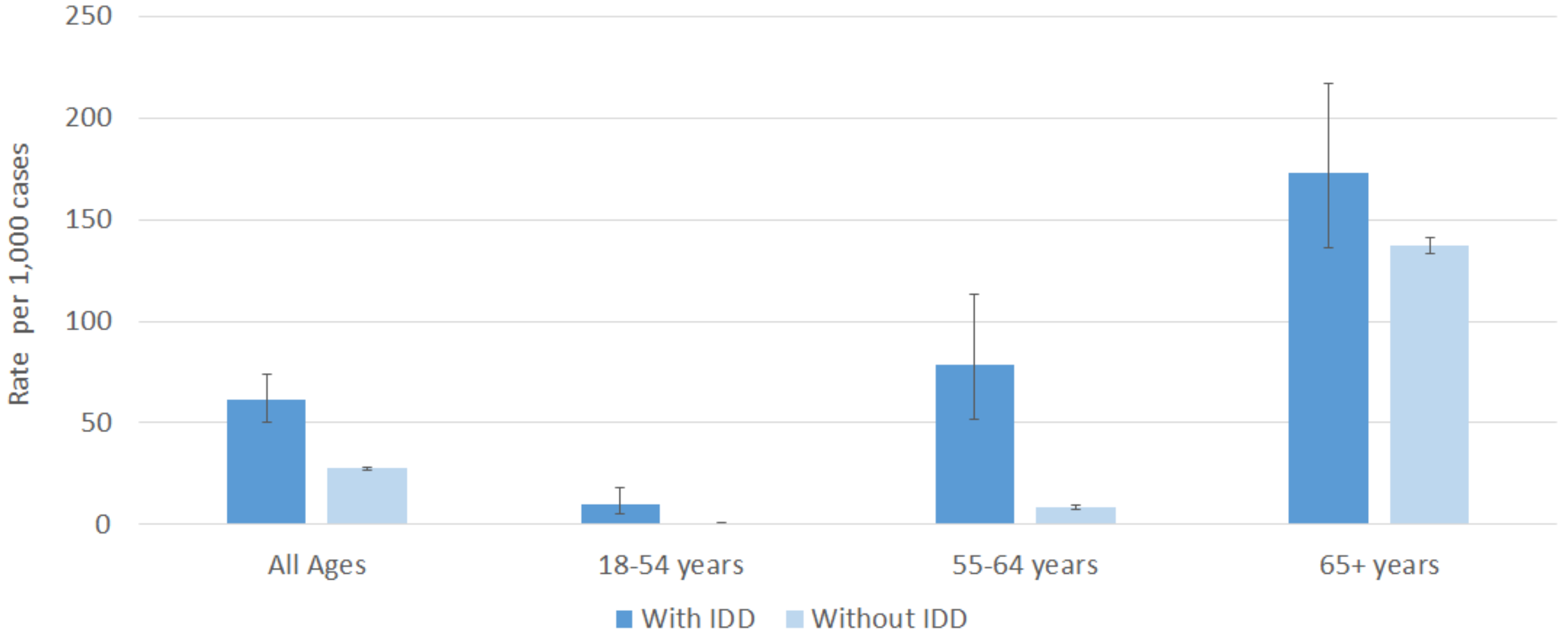
## Compared to adults without IDD:

- COVID positivity rates were:
  - **1.3 times higher** for adults with IDD
  - **1.4 times higher** for adults with Down syndrome
- Adults with IDD were **2 times as likely** to be hospitalized with COVID-19 and to die.
- Adults with Down syndrome had mortality rates that were **6.6 times higher**.

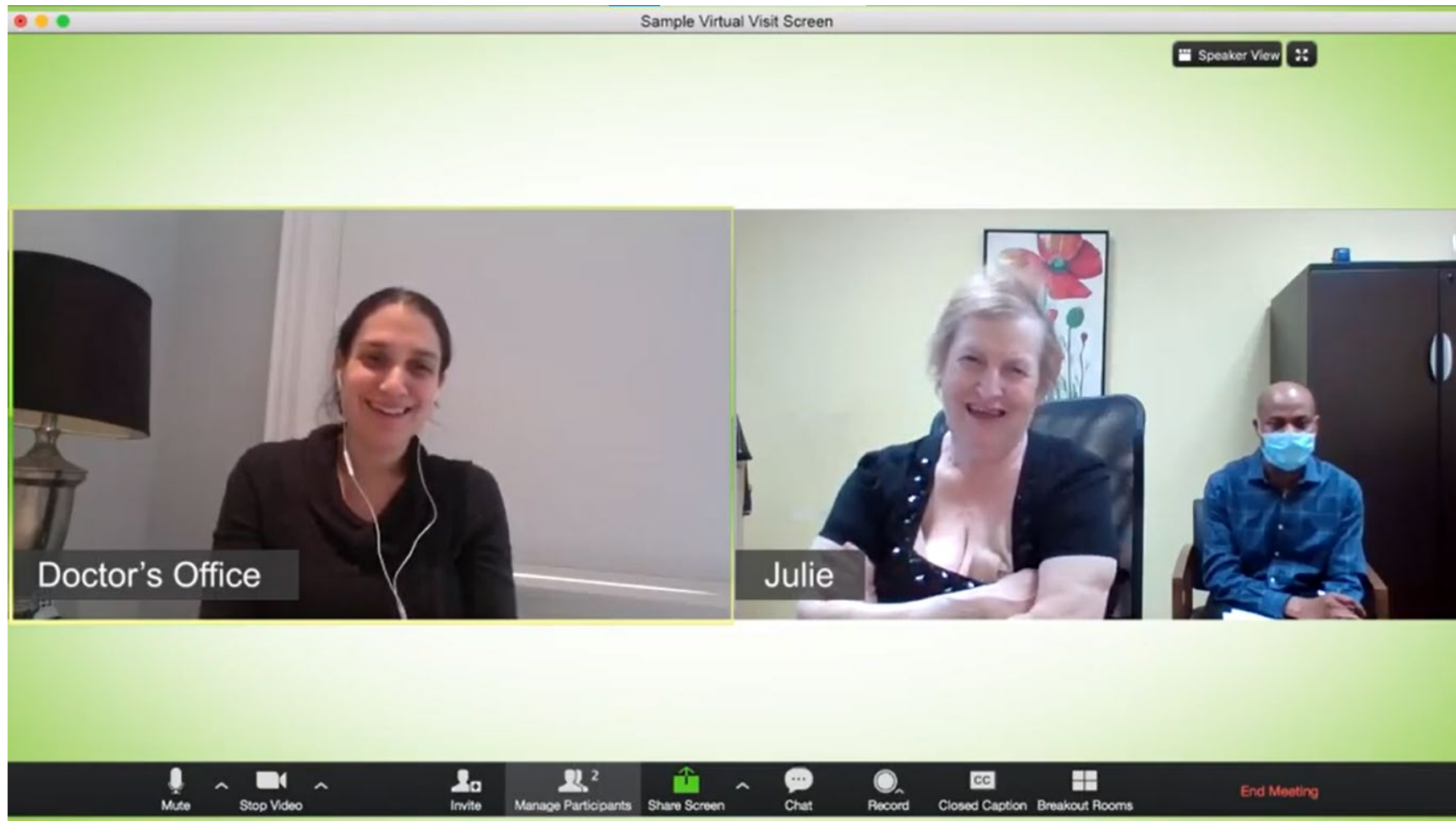
# Hospitalization rates after a positive COVID test in adults (18+) in Ontario with and without IDD, per 1,000 cases



# Mortality rates after a positive COVID test in adults (18+) in Ontario with and without IDD, per 1,000 cases



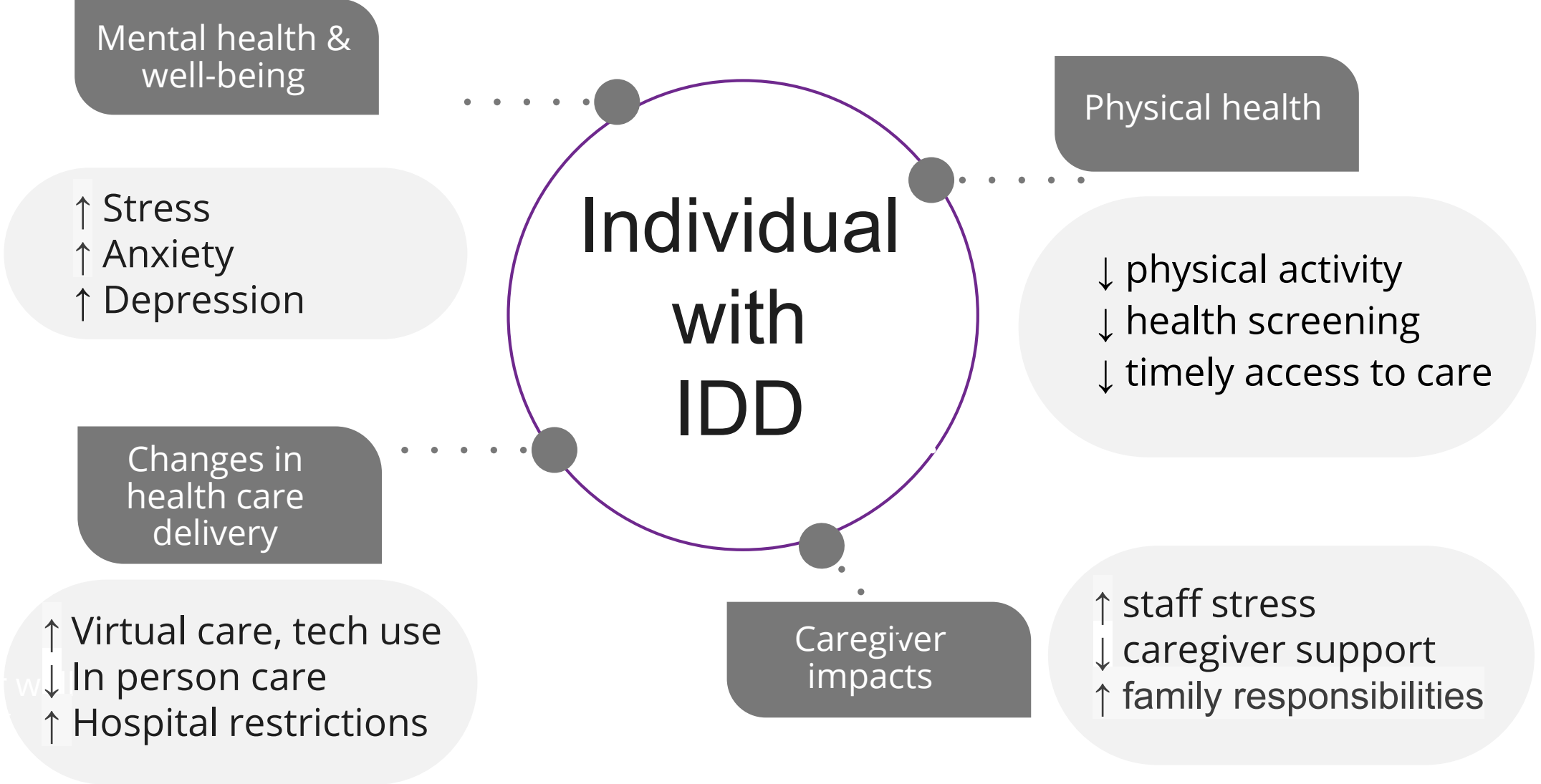
# Virtual physician visits during COVID-19 for people with IDD



# **PART 2: Impact on health**



# Factors that affect individuals with IDD during COVID-19



# What do we know from different perspectives?



Family



Staff



Individual

# What do we know about adults with developmental disabilities?



Individual

## THE IMPACT OF COVID-19 on People Ageing with an Intellectual Disability in Ireland



Evidence from Wave 4 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

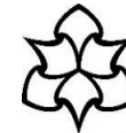


Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin



The Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing  
(IDS-TILDA)

## Coronavirus and People with Learning Disabilities Study Wave 3 Results September 2021



Manchester  
Metropolitan  
University



WARWICK  
THE UNIVERSITY OF WARWICK



UK Research  
and Innovation

## The Wellbeing and Mental Health Care Experiences of Adults with Intellectual and Developmental Disabilities during COVID-19

Johanna K. Lake , Patrick Jachyra , Tiziana Volpe, Yona Lunskey ,  
Carly Magnacca, Amanda Marcinkiewicz, and Yani Hamdani

# What do we know about adults with developmental disabilities?



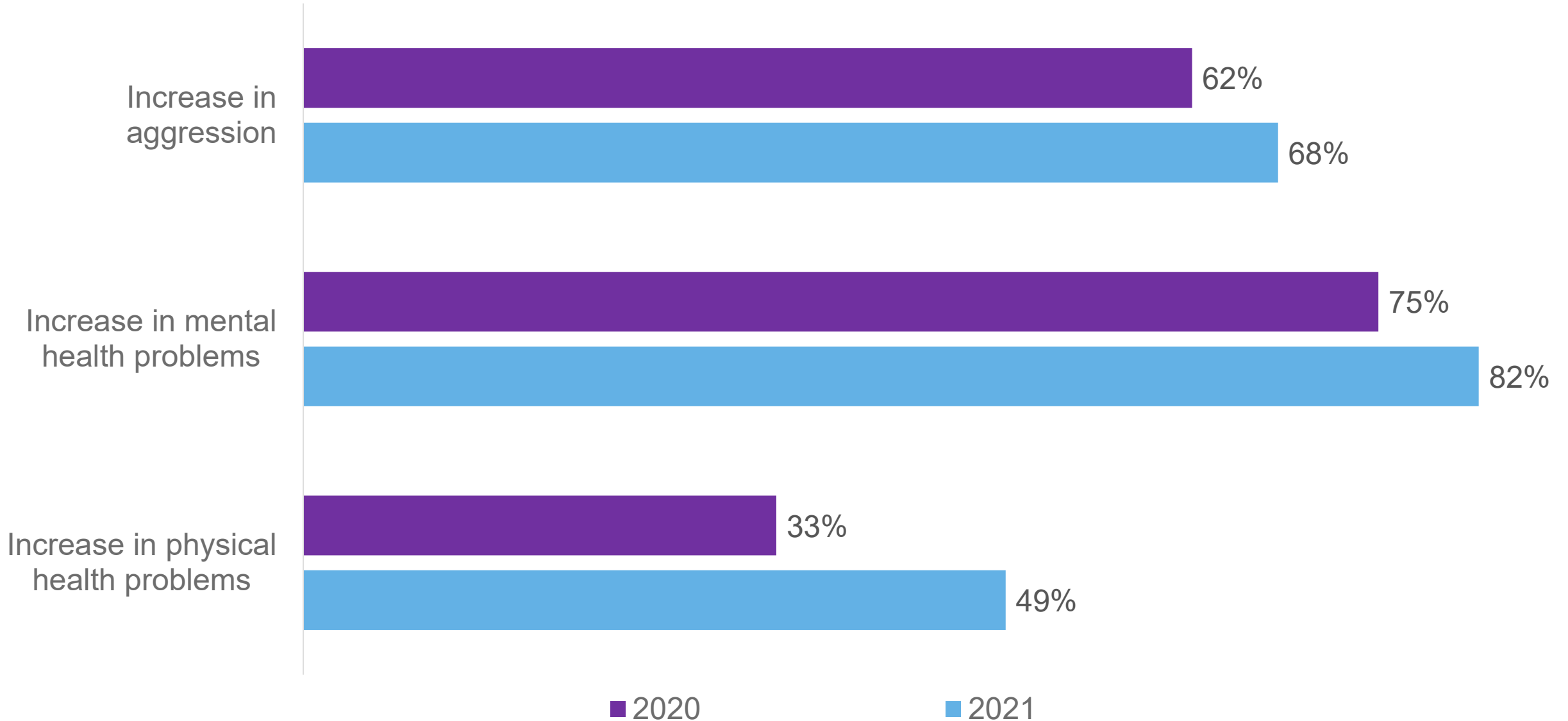
Individual

- Increased isolation & loneliness
- Heightened anxiety and sadness
- Difficulty with people they live with
- Accessing health care and support is hard
- Very few ppl have had health checks (proactive care)
- Mental health support is also limited

But also

- Some positive experiences with technology
- For some people, different pace is alright

# Impact of COVID-19 on Client Health according to Ontario staff



# What do we know about family caregivers?




Family

## Coronavirus and People with Learning Disabilities Study Wave 3 Results September 2021



Brief Report | [Free Access](#)

Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic

B. K. Redquest, A. Tint, H. Ries, Y. Lunsky 

# What do we know about family caregivers?

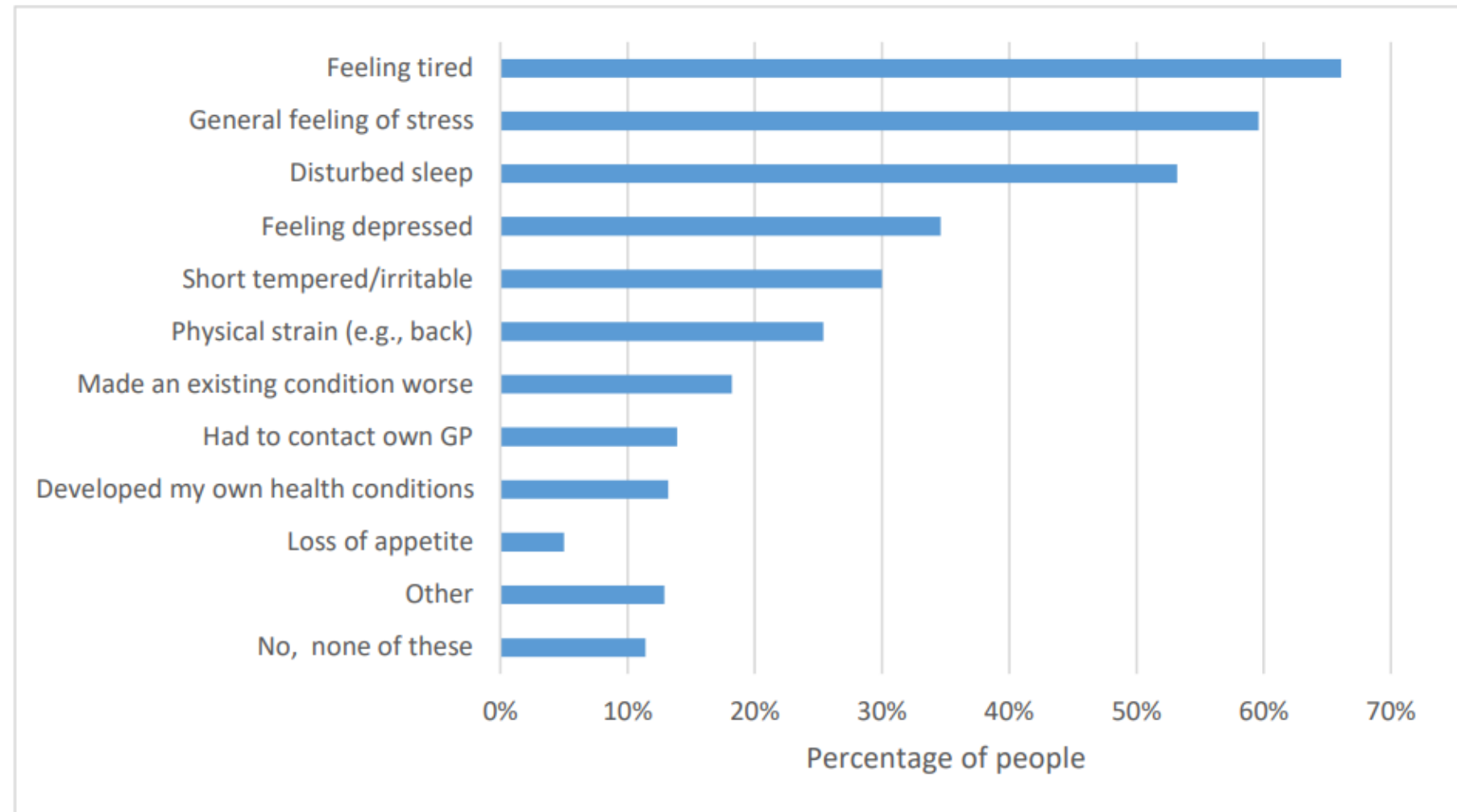


Figure 3.4. In the last four weeks, has your health been affected by your caring role in any of these ways? (Select all that apply)

From Flynn et al., Coronavirus LD Study – 3<sup>rd</sup> Wave

# What do we know about staff?



Staff

## Direct Support Workforce and COVID-19 National Report: 12-Month Follow-up



Recognizing the Mental Health  
Needs of an Essential Workforce  
Being a Direct Support Professional  
in the Time of COVID-19

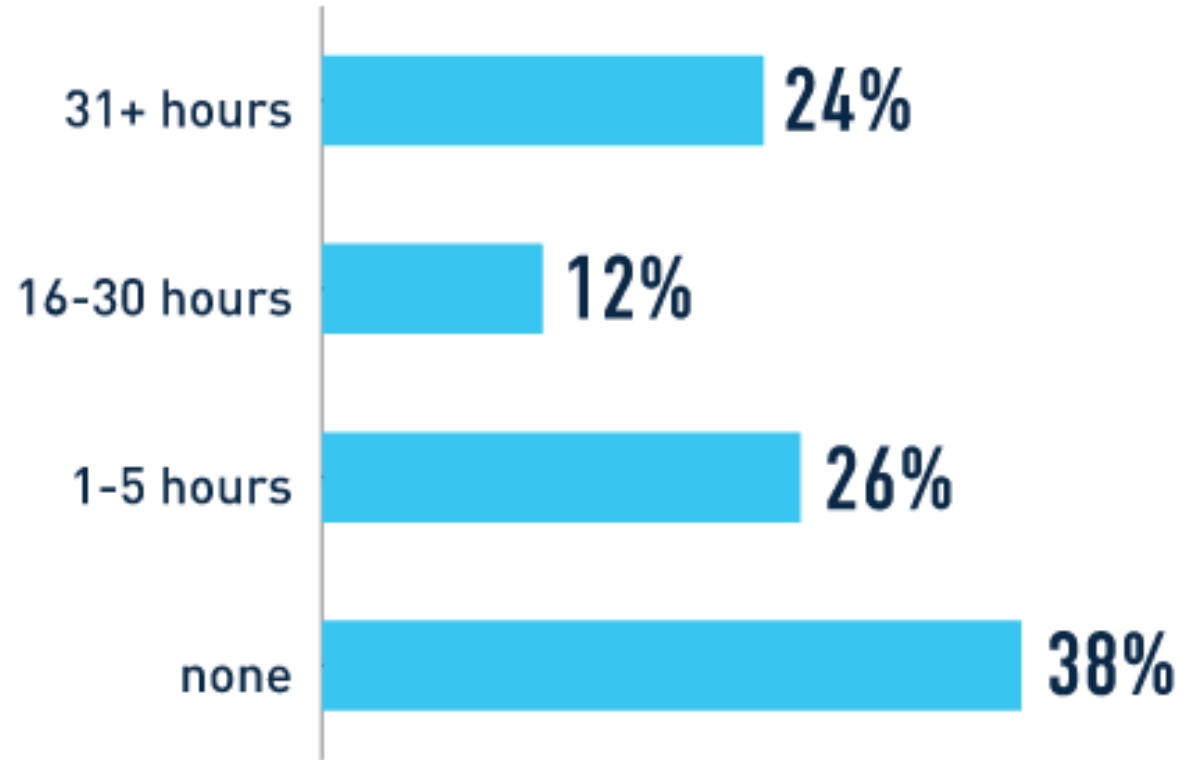


# What do we know about staff?



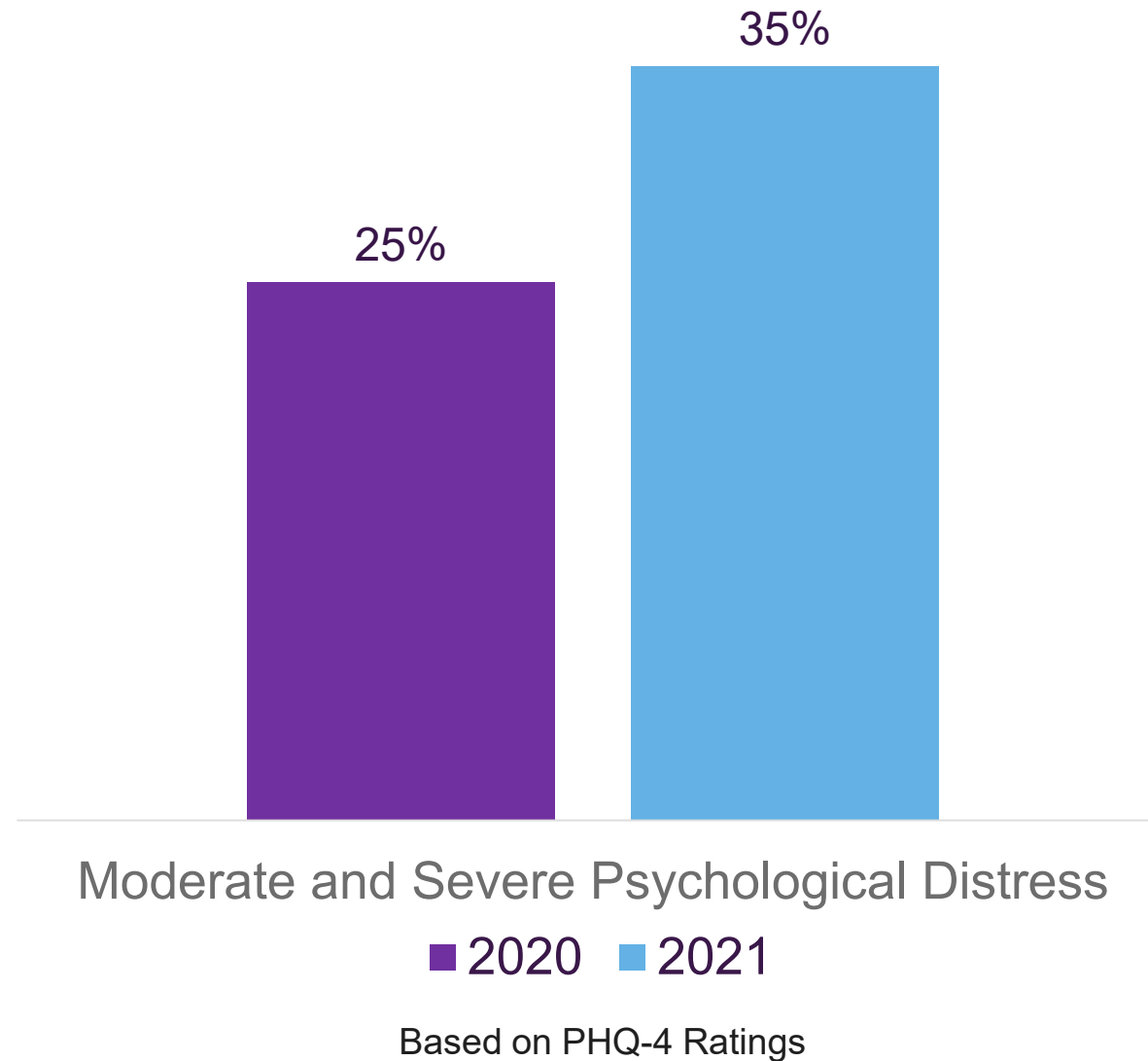
Staff

- Sub-population of staff uncertain about vaccinations
- Increased workloads



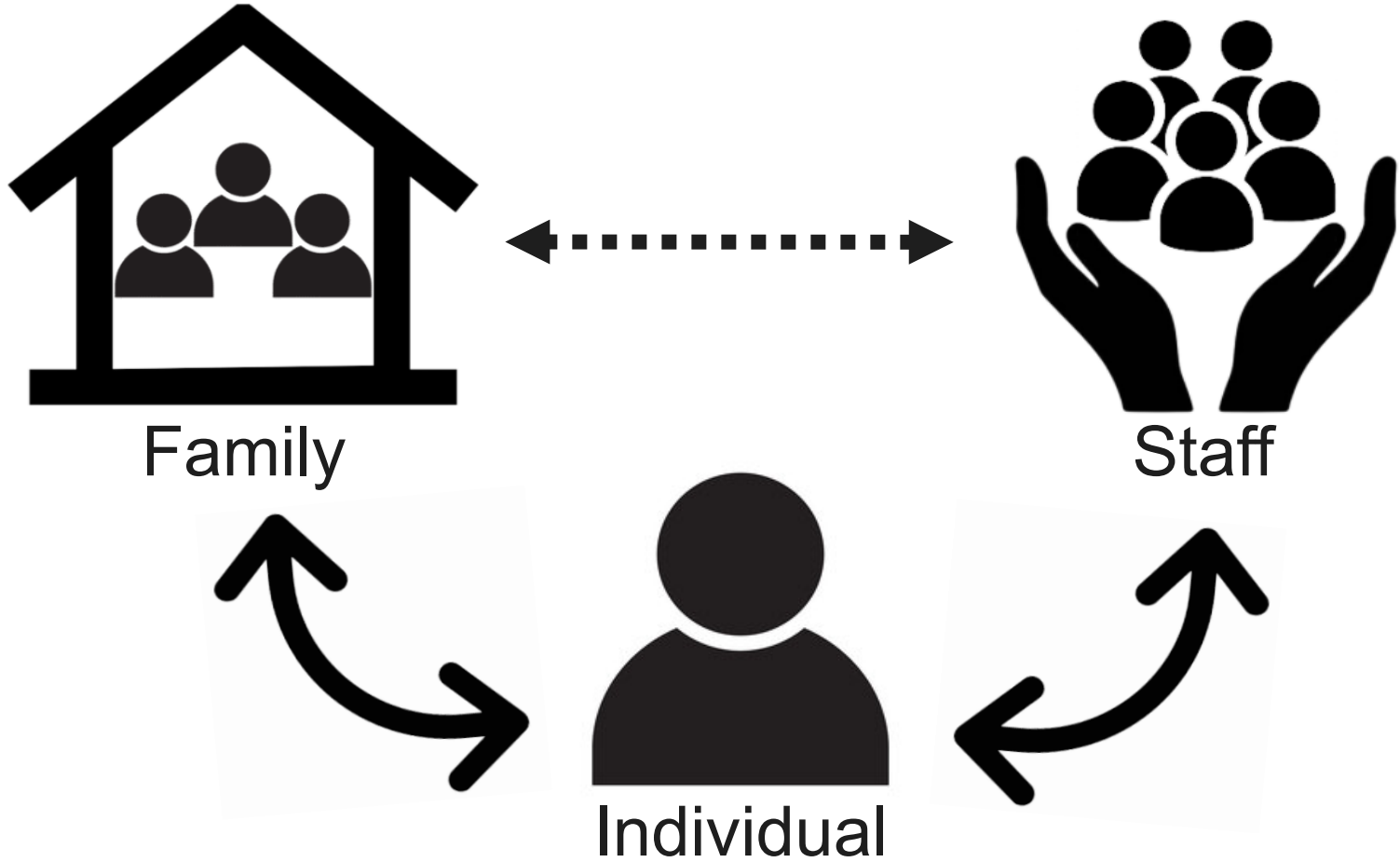
Percentage of respondents in the 12-month follow-up survey working additional hours per week due to the COVID-19 pandemic (Hewitt et al., 2021)

# Impact of COVID-19 on Ontario staff mental health



# **PART 3: What are we doing about this?**

# What do we DO from different perspectives?



# Project ECHO

Project ECHO is a “**hub and spoke**” technology enabled education and capacity building model

ECHO Core Principles:

- » Use technology to leverage scarce resources
- » Share best practices
- » Utilize case-based learning
- » Improve and monitor outcomes
- » *“All teach, all learn”*

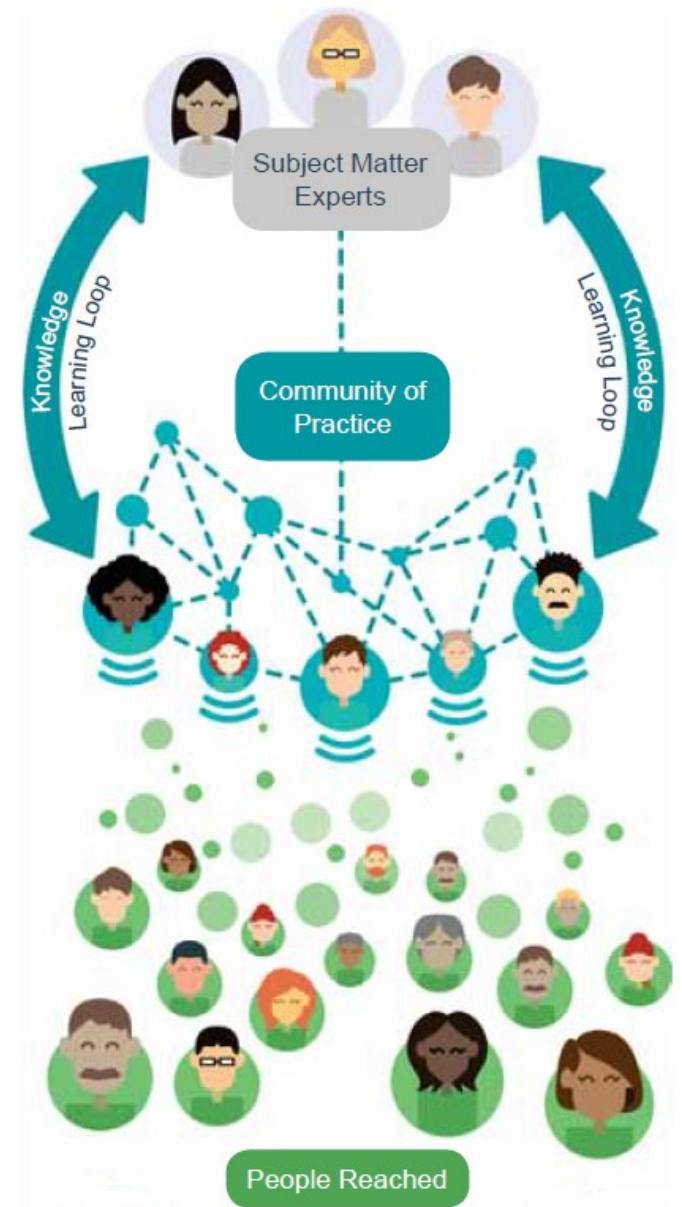


Figure 1. Project ECHO Model. From University of New Mexico School of Medicine.

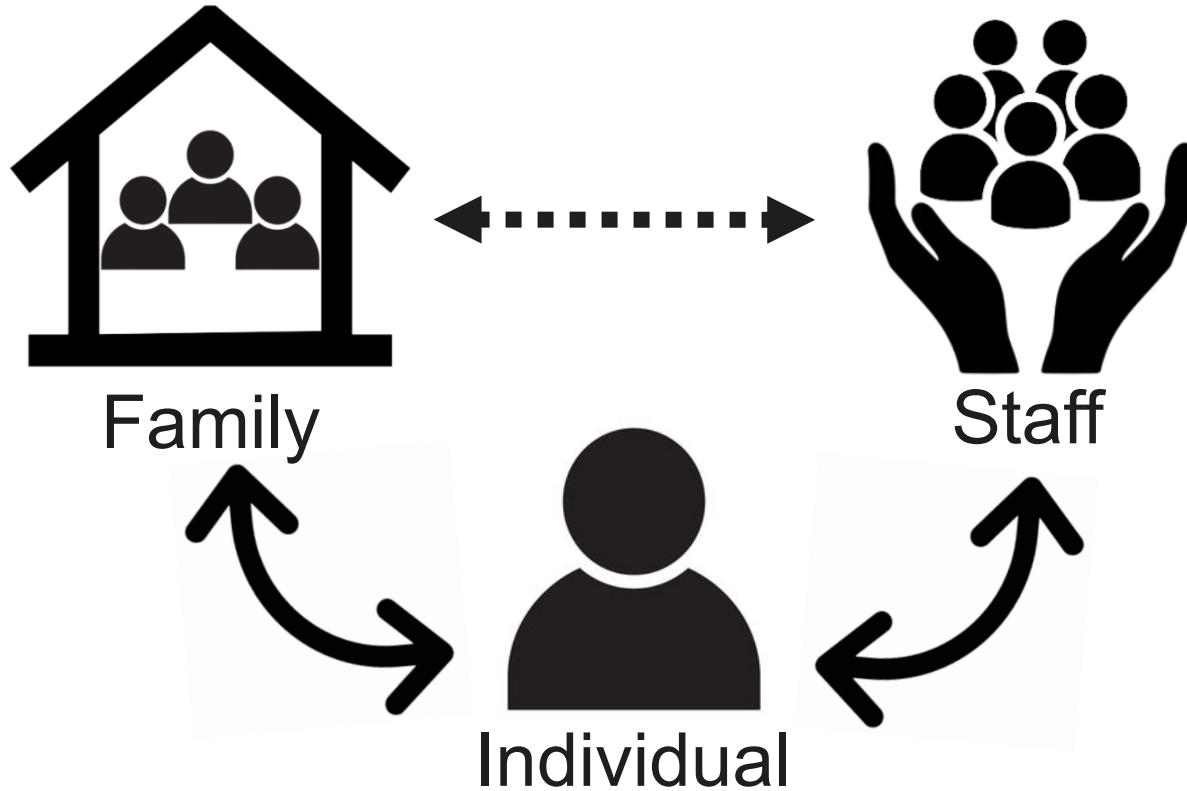
# ECHO Ontario Mental Health (ECHO-ONMH)

ECHO-ONMH helps healthcare providers build capacity in the treatment and management of [mental health and addictions](#).

Reach to date:



# CIHR National Mental Health Capacity Building Projects



6-week cycle with weekly 1.5 hour sessions

- Mindfulness activity
- Self-care & strategy sharing
- COVID-19 newsflash
- Didactic and Q&A
- Case-based learning

# ECHO Adult Intellectual & Developmental Disabilities: Mental Health in the time of COVID-19 (ECHO-AIDD)

**Focus:** Mental health challenges that the IDD population faces during the COVID-19 pandemic

- COVID MH Overview; Self-care; Depression and Anxiety; Health care decisions & planning; Supporting Families; and Grief and Loss

**Hub:** Psychiatrist, Psychologist, Family Physician, Social Worker, Occupational Therapist, Patient and Family Advisors

**Spokes:** Healthcare providers and developmental service providers who support adults with IDD and mental health concerns



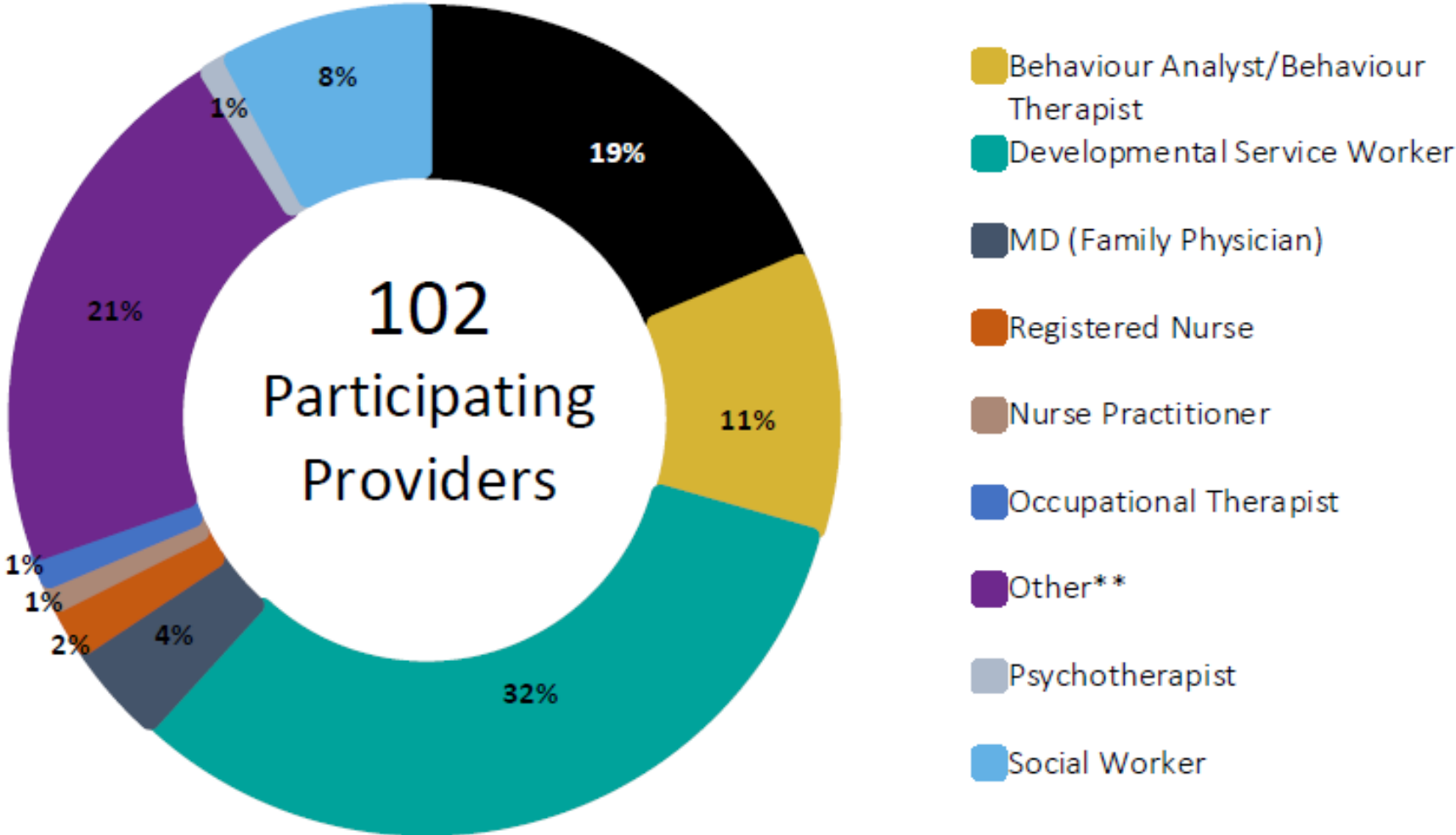
» 6-week cycle with weekly 1.5 hour sessions

- COVID-19 Overview
- Advance Care Planning
- Staff Wellness/ Self-Care
- Depression & Anxiety - Evaluating Risk
- Supporting Families, Family Interventions
- Grief & Loss



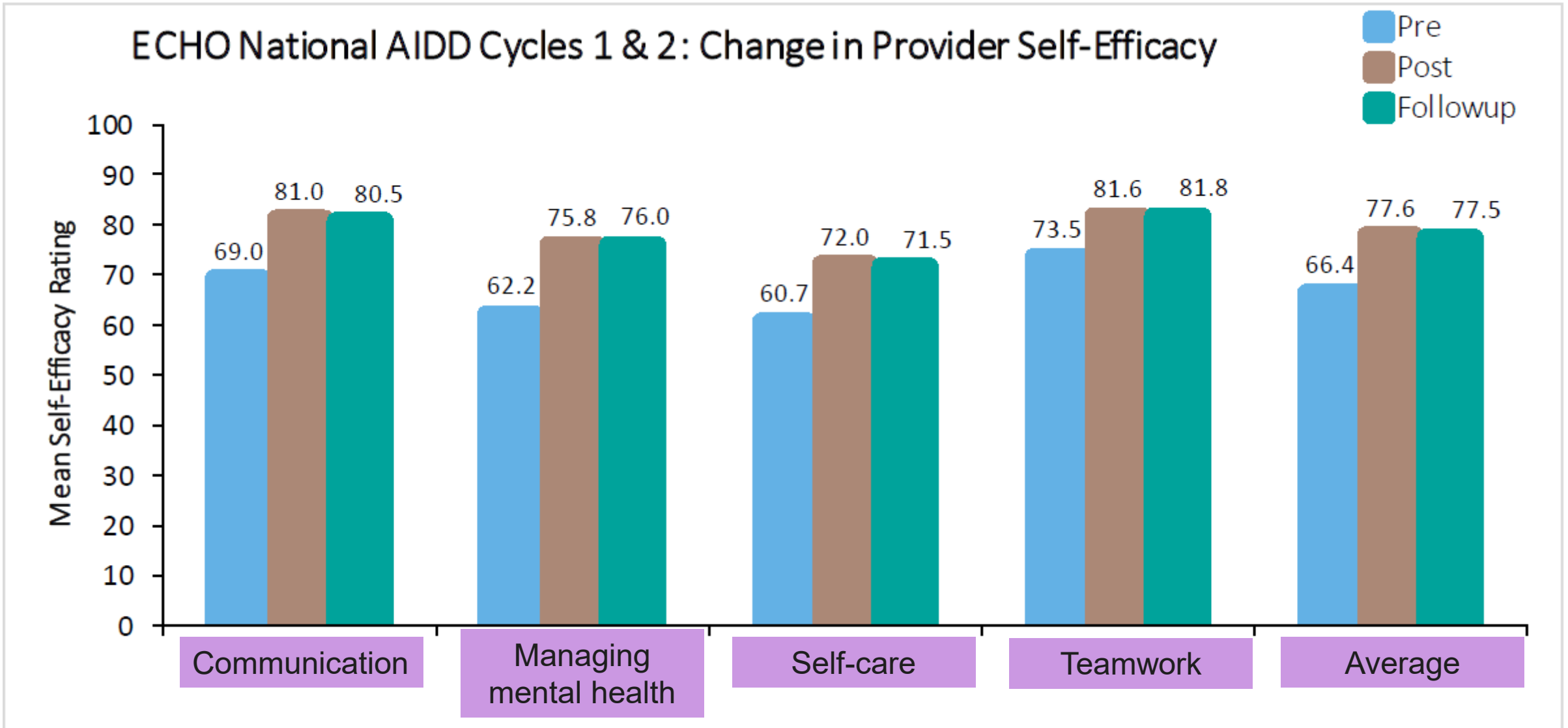
# Mental Health in the time of COVID-19 (ECHO-AIDD)

Breakdown of Participants by Profession

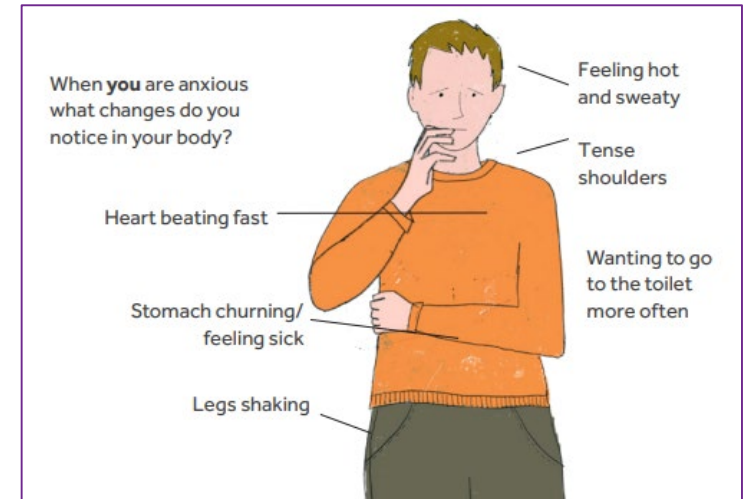


\*\*Other professions: Autism employment consultant, Human service counselor, Care Home Operator, Program coordinator, Group home supervisor, Community developer

# Self-Efficacy of Service Providers



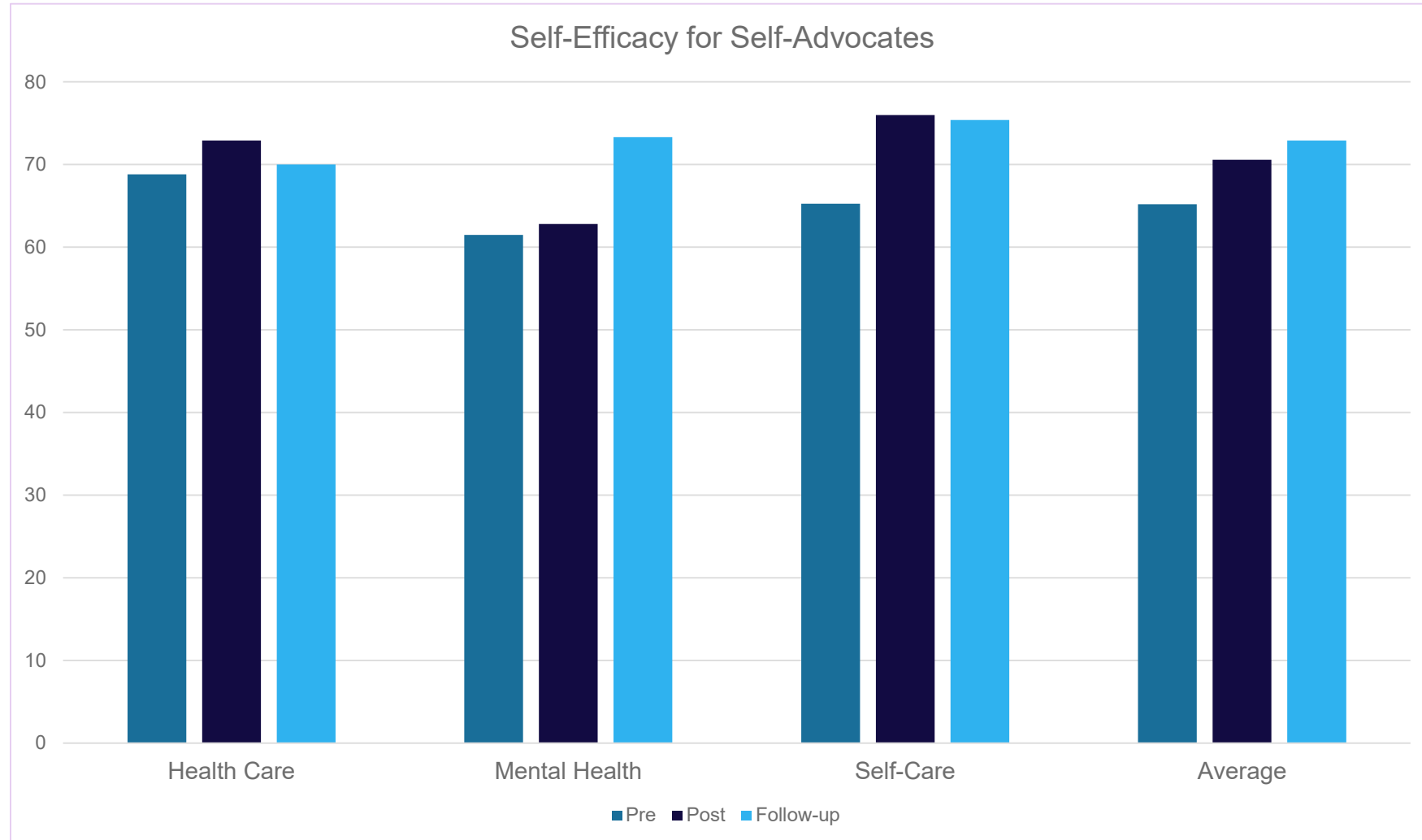
# Mental Health for adults developmental disabilities during COVID: A virtual course for self-advocates



Topics over the 6-week cycle

- » Healthcare communication
- » The COVID mental health booklets
- » Taking care of yourself
- » Grief and Loss

# Self-efficacy of Self-advocates



# Mental health for adults with developmental disabilities during COVID-19: a virtual course for family caregivers

**Mental health for adults with developmental disabilities during COVID-19: A virtual course for family caregivers**



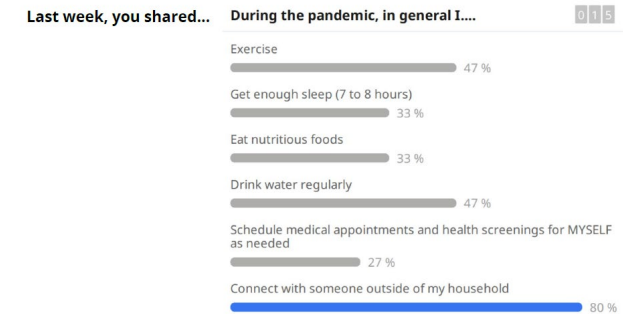
**Session 6  
Self-care: Caring for the Caregiver**  
April 21, 2021

**camh**  
Azrieli Adult  
Neurodevelopmental Centre



2 Copyright © 2017, CAMH

## Stay Strong: Physical Health

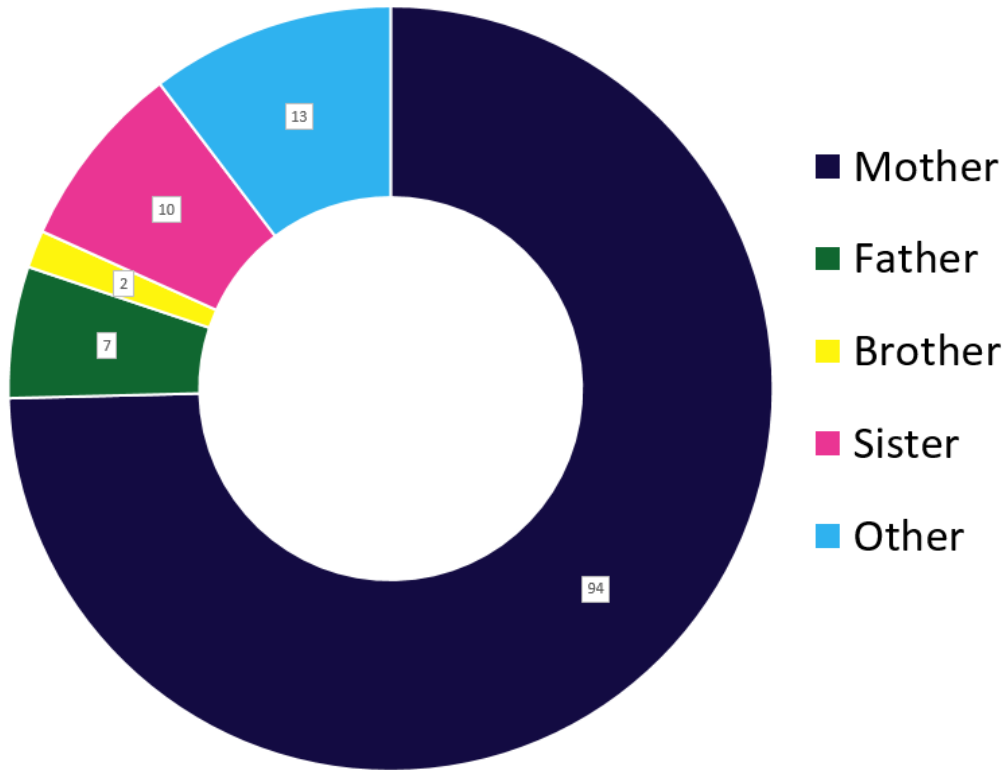


Topics over the 6-week cycle

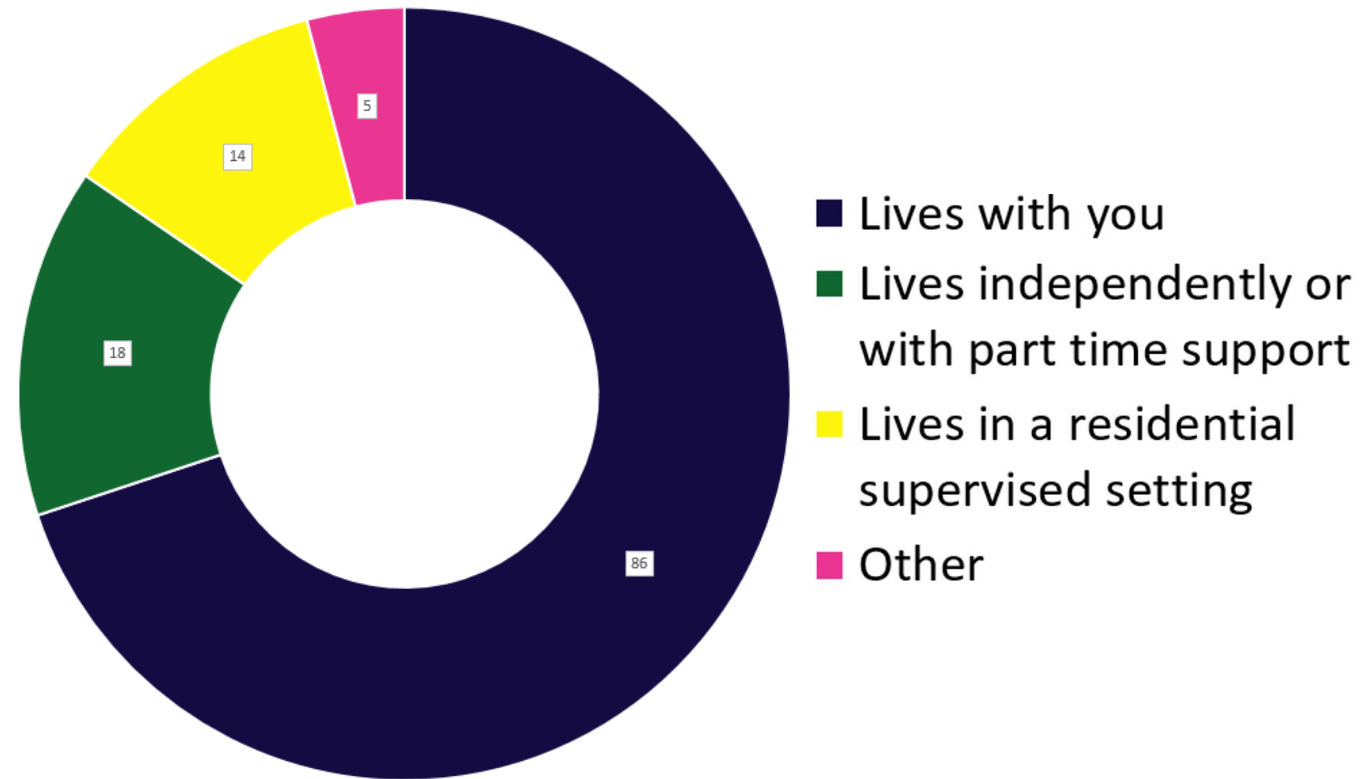
- » Getting help for mental health concerns
- » Improving healthcare communication
- » Mental Health Interventions
- » Health care planning and decision-making
- » The impact of grief and loss during the pandemic.
- » Self-care: Caring for the caregiver

# A virtual course for family caregivers

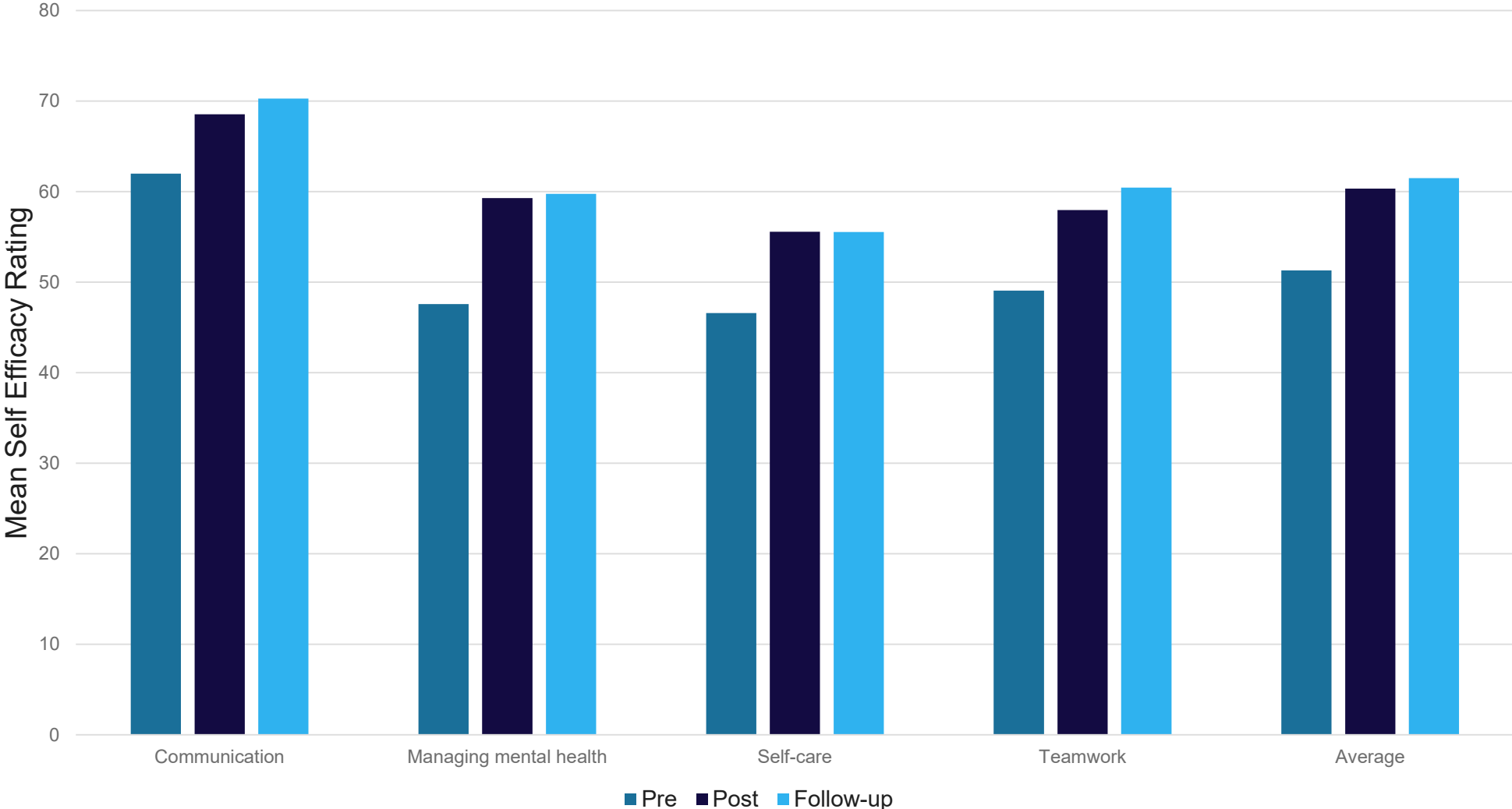
Participant (n=126) to individual with an IDD



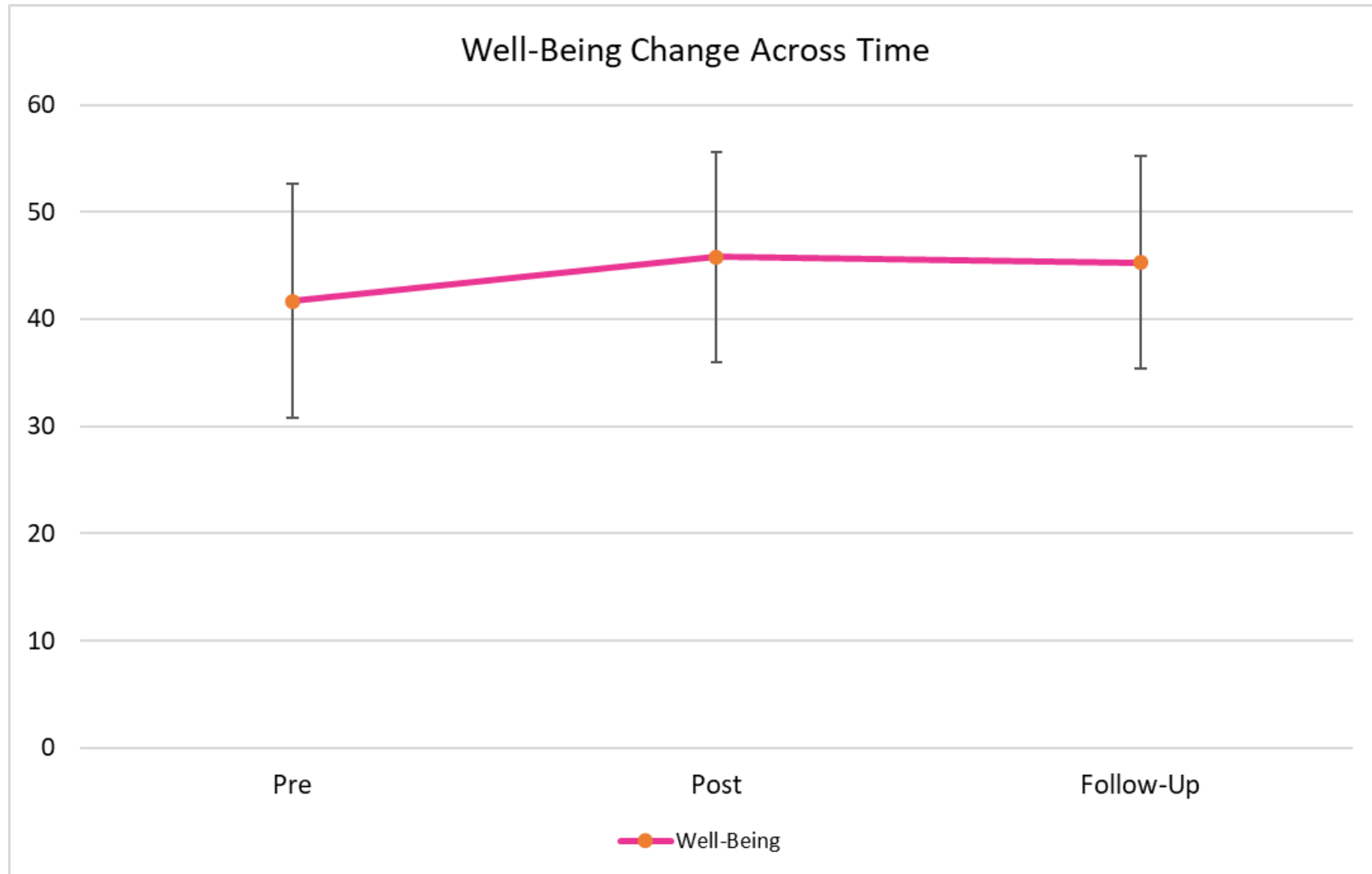
Living situation of Family Member with ID



# Self-Efficacy of Family Caregivers



# Wellbeing of Family Caregivers Over Time

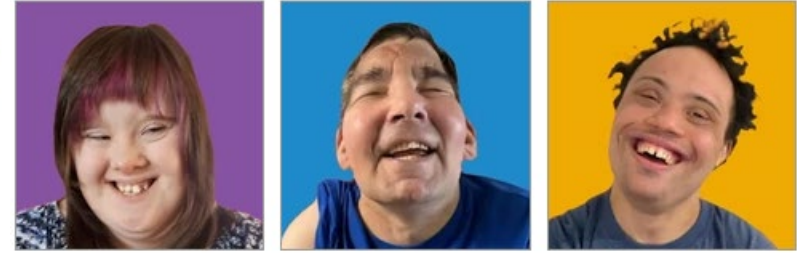




# Emerging Concerns

- Public health efforts e.g. vaccines, masks, vaccine passports, rapid testing
- Health care access and delivery

**READY**  
FOR MY  
**SHOT**



SCIENCE BRIEFS

## COVID-19 Vaccination for People with Disabilities

### COVID-19 Hospital Transfer Form for Patients with Intellectual and Developmental Disabilities

<b>Name:</b>		<b>DOB:</b>
First	Last	

**ALERTS (write detailed notes in the box below):**

<p><b>Medical</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> I have allergies (may include food, latex, medications including general anesthetic)</li><li><input type="checkbox"/> I have swallowing difficulties</li><li><input type="checkbox"/> I have a family history of complications with anesthetic</li></ul> <p><b>Attachments</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> note/summary from my family doctor</li><li><input type="checkbox"/> behavior plan</li><li><input type="checkbox"/> advance care plan</li><li><input type="checkbox"/> information about communication tools or device</li></ul>	<p><b>Important information about my care</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> I need someone who knows me well to be with me. I need this to be able to communicate with staff and/or to remain calm and keep everyone safe</li><li><input type="checkbox"/> I have communication support needs (e.g., device, board, speech impairment, ESL, deaf/hard of hearing, blind)</li><li><input type="checkbox"/> I need sedation for painful procedures (e.g., swabbing, IV, bloodwork)</li><li><input type="checkbox"/> I may hurt myself when scared or confused</li><li><input type="checkbox"/> I may hurt others if scared or confused</li><li><input type="checkbox"/> I might try to run away if I am scared or confused</li><li><input type="checkbox"/> I have a hard time staying still</li><li><input type="checkbox"/> I have physical care needs (e.g., ostomy, mobility, bathing)</li></ul>
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Health Care Access Research  
and Developmental Disabilities

# Thank you!

**camh**

Azrieli Adult  
Neurodevelopmental  
Centre

For more information and COVID-19  
resources, find us online:



@HCARDD

[hcarddcovid.com/info](https://hcarddcovid.com/info)

For more information, email [hcardd@camh.ca](mailto:hcardd@camh.ca)

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A Virtual Doctor's Visit; H-CARDD YouTube Channel: <https://youtu.be/AOKJKBSAFWA>

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