"Everything has changed since COVID": Ongoing challenges faced by Canadian adults with intellectual and developmental disabilities during the COVID-19 pandemic

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Background

People with intellectual and developmental disabilities have unique, unmet needs that have been exacerbated by the COVID-19 pandemic due to public health restrictions and changes in healthcare access. To address their mental health needs, a 6-week virtual course was offered in Fall 2020 and Winter 2021 co-led by self-advocates and clinicians to teach practical skills and share resources/tools. We wanted to learn about what challenges self-advocates continue to experience beyond the course.

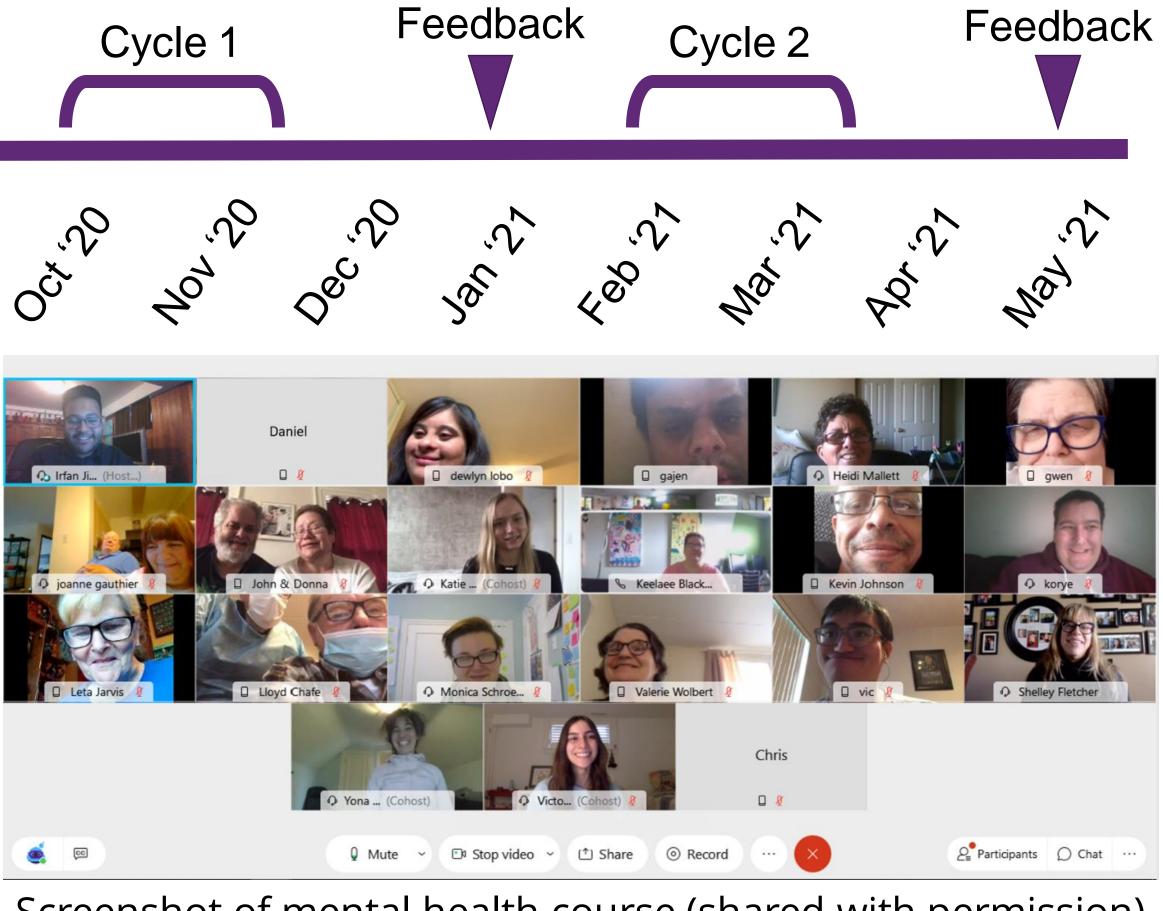
Methods

25 self-advocates were asked these two questions in each cycle of the course 6 weeks after course completion:

- 1. Please tell us about any issues or things that are difficult for you right now?
- 2. Please tell us how COVID-19 restrictions have affected you since you began the course?

Cycle 1

We used thematic analysis to analyze responses to these questions to find ongoing challenges they faced at that time in the pandemic.



Results

1) Finances

- Employment
- Government disability support

"Having enough money to pay things is hard. I am on ODSP [Ontario Disability Support Program funding]... We don't get a lot of money; it requires a lot of budgeting which is hard for *me..."* – Cycle 2 participant

2) Restrictions

- Disruptions to day programs
- Understanding changing public health updates
- Virtual health appointments
- Social connections

"Not being able to see friends or family has affected me. It doesn't make me feel happy. Not being able to go out...has been difficult...My routine has changed...there is no day program right now." - Cycle 2 participant

3) Vaccines

Cycle 2

- Anticipation for vaccine
- Waiting for prioritization
- Confusion about where and when they can get a vaccine
- Experience getting a vaccine

"I got my vaccine and I did not know where to go at first...And then, I didn't know how to fill out the forms for that." - Cycle 2 participant

"I can't find a decent job...But you can't even go try to apply because they are all closed." – Cycle 1 participant



"It is has been a long lockdown. I think we have a lockdown now. Isn't there a lockdown now?" Cycle 2 participant



for our turn. When will we know when it is our turn?" - Cycle 1 participant



Discussion

- Self-advocates found the course helpful. However, some challenges related to the pandemic remained after the course.
- These challenges are also observed in other studies.

Finances:

In many parts of the world, the employment of people with IDD was impacted by COVID. Many were laid off, some worked fewer hours, and others stopped working for health reasons¹.

Restrictions:

Many people with IDD were negatively impacted by visitor restrictions during lockdowns². In another study, social support was related to lower stress levels and higher life satisfaction during the pandemic¹.

Vaccines:

In the UK, most people with IDD were willing to take a COVID-19 vaccine in wave 1, and most had received at least one dose by wave 2^{3,4}. This is similar to what we heard from our participants.

Limitations

- We only heard from 25 participants.
- They had just taken a course to address their mental health needs during COVID.

Conclusion

It is important to understand challenges that people with IDD are experiencing during the pandemic.

These continue to be concerns as new variants and boosters emerge.

References

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Screenshot of mental health course (shared with permission)