

The Issue

Direct support professionals (DSPs) provide services and supports to people with developmental disabilities in their homes, workplaces, and communities. DSPs have a critical role in promoting well-being and ensuring people with developmental disabilities have equitable access and opportunities to participate in their communities. A large focus for DSPs in the last two years has been to ensure people with developmental disabilities remain healthy and safe. This is important as people with developmental disabilities have higher rates of mental and physical health problems and encounter many barriers in accessing health services and community supports. Also, they have been more vulnerable to adverse COVID-19 outcomes, including hospitalizations and deaths, compared to people without disabilities. This group has also experienced disproportionate mental health impacts, in part because of the restrictions they have experienced and lack of accessible and appropriate services.

DSPs continue to work tirelessly to support the health and well-being of people with developmental disabilities in the community. However, like many

who work in front-line care roles, DSPs have experienced additional and unique stressors due to changing responsibilities, work conditions and ongoing public health measures. It is important to understand the impact of these changes on the health and well-being of this essential front-line workforce to better support them.

Our team of scientists at the Azrieli Adult Neurodevelopmental Centre at CAMH have focused on better understanding the mental health of DSPs since June of 2020. Our first report identified that *one in four DSPs in Ontario reported moderate to significant distress*. We recommended that the work of DSPs be recognized as essential and that mental health services and supports for DSPs and people with developmental disabilities be increased. Subsequent reports showed increased distress reported by DSPs, as well as by agency managers and leadership. Mental health is health for the more than 25,000 DSPs in Ontario. To promote the health and well-being of this essential workforce, it is critical to address the unique needs of DSPs as well as the people with developmental disabilities they support.



Photo credits (clockwise from top left): Reena, Participation House - Durham Region, Vita Community Services

What is the report about?

This report provides an update on the mental health of DSPs two and a half years into the pandemic.

How did we study DSP mental health needs?

DSPs from across Canada completed an anonymous survey between June and July 2022. This report includes the findings from Ontario-based respondents.

Participants responded to questions about:

- their current mental health
- COVID-related stressors faced by them and by people with developmental disabilities
- current coping strategies and needs moving forward
- barriers to receiving mental health services and supports

SURVEY



Photo credits: Vita Community Services (left), Reena (centre and right)

DSP Survey

Participants

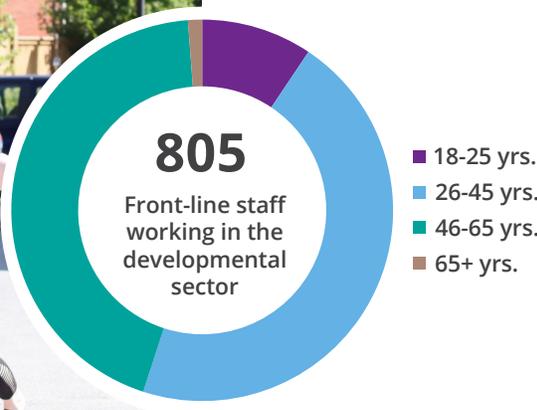
805 DSPs from across Ontario responded to the survey.

Gender

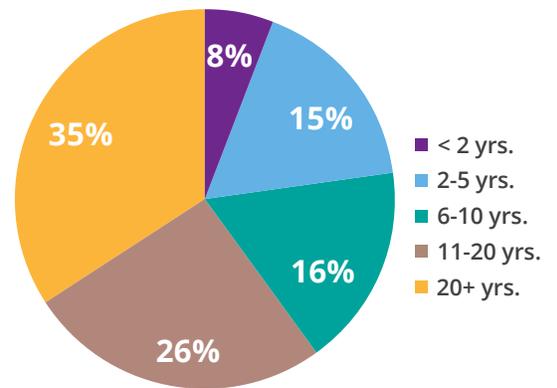


Photo credit: KW Habilitation

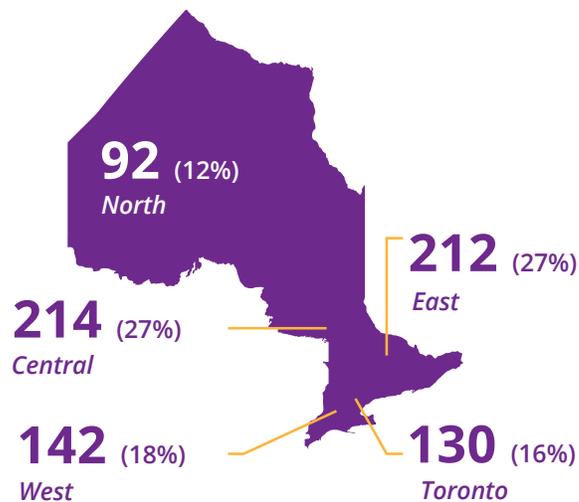
Age



Years of experience



Location of Employment



SURVEY

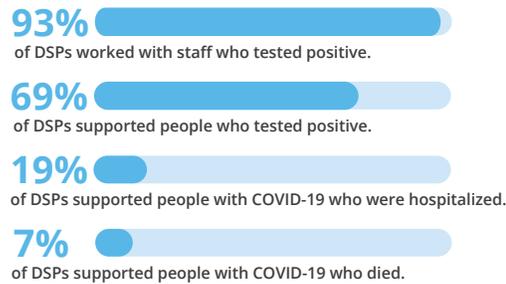
What did we learn?

The health and day-to-day lives of people with developmental disabilities and DSPs continue to be impacted by COVID-19 and pandemic protocols beyond contracting the virus.

“Providing good quality supports ... on any day can be challenging. Most days are very good. However, that wears very thin when staff are working 12-, or 13-hour shifts, day after day, after day. ...The support is still provided, but the morale becomes low and this is seen by the people we support. Care is always provided, but perhaps not done with a smile... due to fatigue and exhaustion.”

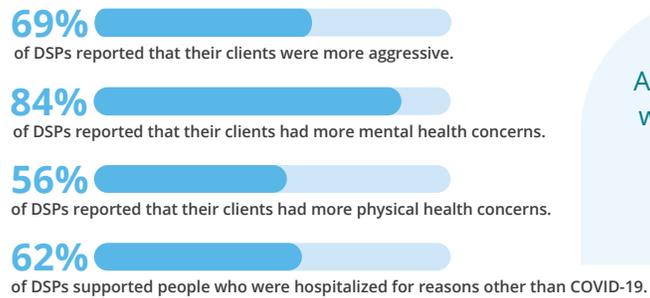
“I got serious burnout in December and ended up crying to my scheduling manager.... I wish that people realized that everyone has a breaking point and it's important to catch it before it happens to staff. Look at the signs and train your employees to recognize it in each other.”

COVID-19 testing and outcomes



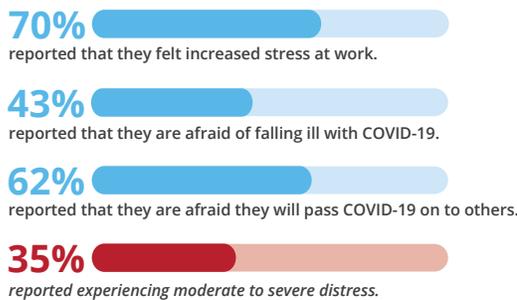
In 2020, only 10% of DSPs reported working with staff who had tested positive and 5% supported people who tested positive.

Challenges experienced by people with developmental disabilities during COVID-19



All of these challenges were more frequently reported than in the 2020 report.

DSP mental health during the pandemic



Rates of DSP distress have increased since 2020 when 25% reported moderate to severe distress.



SURVEY

Key concerns raised by DSPs related to COVID-19

- impact of pandemic on the health and well-being of people with developmental disabilities (e.g., decrease in quality of life; poor mental health; long term effects of not seeing family and friends; chronic sedentary behaviour; loss of community skills; decline in independence; fears of returning to activities, grief and trauma; staffing shortages leading to feelings of compromised care)
- impact on personal health and well-being (e.g., increased risk of burnout because of prolonged stress, grief and trauma; moral distress; difficulties accessing mental health supports).
- Structural and system challenges (e.g., compensation; challenging work environments; unpaid sick time; lack of benefits)
- Pandemic pressures at work (e.g., ongoing staff shortages made worse by COVID exposures; longer hours; lack of time off; too much time on administrative tasks that interfere with providing care)
- infection prevention and control (IPAC) procedures (e.g., IPAC fatigue; challenges with clients wearing masks; fear about increased risk of exposure in community; upset by public lack of concern about vulnerable groups)

Strategies used by DSPs to manage their stress

- maintaining social connections with family and friends **76%**
- engaging in leisure activities and hobbies **71%**
- practising self-care **61%** and seeking mental health supports **31%**
- seeking additional educational or training opportunities **25%**
- using alcohol and other drugs **23%**
- practicing their faith **19%**

When asked what would be most helpful to them moving forward, over half of DSPs endorsed

- Extra staff coverage **68%**
- Time off **63%**
- Financial compensation **63%**

Although DSPs recognized the importance of accessing mental health supports, nearly half (49%) of participants reported barriers. These included

- Financial barriers **36%**
- Having the time to seek supports **34%**
- Unsure what help is available **22%**
- Stigma **14%**

SURVEY



Photo credits: Participation House - Durham Region (left), KW Habilitation (right)



In Summary

This follow-up report highlights the ongoing impacts of COVID-19 on the mental health and well-being of DSPs, an often-invisible workforce. DSPs, other staff and leaders in the sector, and people with developmental disabilities, have been severely impacted by the pandemic. Although some of the concerns identified in the survey conducted two years ago have lessened (e.g., the uncertainty of how the virus is spread, personal protective equipment shortages), other concerns remain and have worsened (e.g., staffing shortages, the health of people with developmental disabilities). The problem of poor mental health is not going away, and staff are continuing to face significant and chronic stress in their roles. Additionally, many more people who work in and who receive supports in the sector have contracted the virus since 2020, which has had both direct and indirect impacts on people’s health and well-being.

Following release of the 2020 report, a provincial community-led initiative *Cultivating Community Wellness* was launched to support DSP mental health and foster a culture of mental health and well-being in agencies across the sector. This effort on its own is not enough to tackle the growing challenges reported by DSPs in Ontario. There are complex issues facing the sector, including a critical staffing crisis, trauma, grief and loss from COVID-19, the decline in health of many people with developmental disabilities and challenges navigating the new normal. Attention to the larger structural and system-level stressors causing ongoing staff distress, in addition to individual and organizational capacity building is needed to effectively address the mental health needs of all members of this community.

Moving forward it will be important to:

Recognize, respect and invest in this essential workforce

1

DSPs in this study identified that being recognized as essential workers by agencies, government and the public continues to be an important support strategy. Many organizations within the sector have made this a priority. However, more work can be done to understand how to attract and retain DSPs at both the organi-

zation and broader policy level. There is a current staff shortage in the sector, similar to what has taken place within health and long-term care, and investment in rebuilding the workforce is urgently needed.

Acknowledge that mental health is health for ALL people in the sector

2

The mental health and well-being of staff across the sector (including DSPs, managers, senior leadership) as well as people with developmental disabilities must remain a priority. It is evident that in the developmental services community, each group is impacted by the others which can take a toll on everyone’s mental health. At the same time, investment in the mental health of any one group will have broader benefits.

DSPs need similar access to mental health supports and resources people working in health and long term care. Communicating that DSP’s are eligible for these publicly funded supports could help to achieve greater access to them (e.g., counselling, peer support). Like other care providers, they also require sufficient paid sick time to support their ongoing mental and physical health. Furthermore, DSPs have different challenges now than they did in 2020, when our first survey



was conducted. They may not be aware of existing mental health resources especially if they are not specifically directed towards them, or the wait for mental health services is too long. Thus, more work at the sector and organization level needs to focus on communicating to DSPs about what is available and addressing barriers to mental health supports such as cost, and wait times, and competing work pressures.

Importantly, DSPs need to know that their mental health is a priority, and that their workplace can accommodate their mental health needs. Many DSPs, along with agency leadership [companion report to follow] have experienced distress over the course of the pandemic, which continues to impact them now. Workplaces must be trauma informed in their efforts to promote wellness. Comments from survey respondents highlight that what works for one individual may not work for another. Therefore, a range of resources (virtual and in person) need to be available, depending on individual circumstances and preferences.

People with developmental disabilities also need targeted mental health resources and services, as well as staff who are equipped to respond to their mental health needs. This study

suggests that many DSPs have witnessed declining mental and physical health, as well as increased aggression among this group. Initially people with developmental disabilities required mental health supports to help them adjust to the pandemic lockdown and loss of meaningful activities. Their mental health is still suffering but their needs are evolving, with continued health service gaps.

In some of our recent work with people with developmental disabilities, they have talked about the impacts of long-term isolation, the fear of what happens next, and how hard it can be to return to community activities and prior routines, after not doing them for so long. They report grieving their losses and have not always had people who recognize this and can offer support. Holding space for these emotions is important and often DSPs are the people to do that. Importantly, education for current and future DSPs can provide them with knowledge about recognizing and addressing emerging and ongoing health concerns. Tailored resources and tools have been developed to support the mental health of adults with developmental disabilities, but further investment is needed to enhance existing resources and make them available and easy to access across the province.

What's next

This work is part of a larger initiative to support the mental health and well-being of DSPs and leaders in the sector, as well as people with developmental disabilities. To learn more, and to find this report and others, as well as provincial resources, you can visit the **Cultivating Community Wellness Website** and www.camh.ca.

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To cite this report:

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