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HELP during COVID-19: Thoughts about meeting the mental health needs of adults with developmental disabilities and those that support them

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The good news is that direct support professionals here in Canada and around the world have worked so hard to figure out ways to protect the people they support from getting COVID-19 and, in doing so, have saved many lives. The bad news is that being responsive and proactive when it comes to COVID-19 can take a toll on our mental health.

Almost six months since we began talking about COVID-19, and over three months since we radically changed how we live our day to day, we know much more than we did about what COVID-19 is, and how to prevent its spread. But we need to talk about what it is doing to the mental health of people with developmental disabilities, and the HELP we can offer to address this.

Some pre-COVID Facts:

- Mental health IS health. How we are doing in terms of our thoughts and our feelings is just as important as any type of physical health issue. But for some reason, we find it easier to talk about physical health problems, and we feel uncomfortable when it comes to mental health.
- Mental health problems, especially anxiety and depression, were very common for people with developmental disabilities BEFORE COVID-19.
- Recognizing mental health issues can be tricky for people with developmental disabilities because they cannot always explain what they are feeling as easily as other people. Sometimes we make the mistake of thinking that a mental health issue is just part of a person's developmental disability, and we ignore it. This is called **DIAGNOSTIC OVERSHADOWING**.
- Many people with developmental disabilities take medications to treat mental health problems. These medications have side effects and need to be monitored carefully.
- Getting mental health support from people who are comfortable with BOTH mental health and developmental disabilities is really hard.
- Some people do not get help, or the only place they go to get help is the hospital because they cannot figure out who else will help them if they have a mental health problem.

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- It can be very stressful to support people who are struggling with their mental health. How we interact impacts them and us. So, we need to pay attention to our own mental health, as well as the people for whom we are caring.

Then we add a little bit of pandemic to the mix and....

So many of the very things available to people with developmental disabilities to promote and support their mental health disappear in a flash. This is hard to understand, we did not prepare for it, and we do not know when it will end or what will happen next.

So, WE need some HELP.

HELP is the acronym we use for a way to understand and respond to “behaviours that challenge” and mental health concerns. You can read more about [it here](#), and we also have [information about HELP for health care providers here](#).

H stands for Health. It is a reminder that, before we do anything else, we need to understand and investigate the physical health problems that could be causing or adding to a person’s pain or distress. People may be living with even more health issues during COVID because we are avoiding in-person medical appointments. We can also mistakenly attribute changes we are seeing to the pandemic itself and miss new physical health problems in people who cannot explain their pain very clearly. Many of the things we do to keep us healthy are harder to do in the same way, including when we go to bed, and how we sleep, what we are eating and how often, and how much exercise we are getting. Our bodies have routines that have been forced to change drastically. People may be less tired when it is time for bed or watching so much TV that it is harder to fall asleep. Eating differently and not walking to community activities each day can lead to constipation or reacting differently when taking medications. Not going to get ears or teeth cleaned, or eyes checked means there can be new problems or new pain. Not being able to access pool therapy, physiotherapy, or wheelchair seating checks may lead to increased pain and spasticity for some people. There are some very [helpful tools to monitor some of these issues](#), or you can read this article to know more about [pain](#). Importantly, we all must remember that health care is still open for business. Many health care providers are providing care virtually and still allowing in-person visits in certain situations. [This video shows how somebody with a disability’s virtual visit went, and why it is so important](#). We have to screen for medical issues and take care of health issues early on, before they become more complicated.

E stands for environment. Our environments have changed significantly during this time. For some people, the structure they relied on is gone. So, where they were once quite supported, they have less support than they require. For others, who perhaps lived with other people and had family or staff support but could also go out independently, they may have lost that freedom with new rules, so they have too much support at this time and not enough independence, which can also be frustrating. Three months in, we are seeing that some people have responded quite well to a shift in their routine and actually prefer some of the more home-based activities and structures available to them. Others, however, are no longer able to manage in their environments with the restrictions to where they go and what they do.

It makes a difference to look at the environment, and how to put structures in place. The structures put into place a few months ago may still be working, but they may no longer be enough. Activities online may need to be shorter, technology may need to be supported (and people need to be able to afford the internet connection, be able to hear things, navigate the software), and we may have to get creative about how to spend time outside and keep the environment outside of the home safe and supported. Behaviour therapists and occupational therapists can be very helpful in this regard. We all need meaningful occupations to support our day to day. Offer lots of choice! Preference assessments can be as easy as offering the choice between two activities or items. Structure access to these preferred activities and items frequently throughout the day. And make sure that everyone has a way to functionally communicate their wants and needs. Remember that All Behaviour is Communication.

L stands for lived experience, and the life events that have taken place which have an obvious impact on someone's mental health. To say that someone is depressed without recognizing that they are mourning the loss of a loved one, or the ending of a relationship, or a job they once had, fails to appreciate the impact that these events have on all of us. To say someone is anxious without appreciating that their anxiety is because of something traumatic that they experienced or witnessed, so they now understandably worry about the possibility of this reoccurring is a missed opportunity to support someone. It is our job as support people to try our best to understand how these events impact the people around us. We can normalize their experience and change our approach based on our appreciation of how they are being impacted. They still may have a depressed mood or anxiety, but now we appreciate the space they are in and why they feel that way, as opposed to just trying to fix them. **L** is also about the listening we must do for us to perform this very important work of holding space for others in their struggle.

P stands for psychiatric diagnosis. As we noted earlier, it can be quite common for people with developmental disabilities to have mental health issues severe enough that they get diagnosed as a psychiatric disorder. We need to screen for these issues with mental health providers. We treat psychiatric disorders with psychological therapies, other activities and supports to the individual and to the carers, and with medications. How we combine these different types of treatments depends on the situation and the individual. It can be hard during COVID-19 to have traditional in-person appointments with a therapist, or with a doctor to review medications. But these appointments should not stop all together, because Mental Health IS Health, even during COVID-19.

These self-help booklets, adapted to be used during COVID-19, can help people to manage symptoms of depression and anxiety and can be done with support.

<https://www.camh.ca/covid19booklets>

We need HELP too.

Supporting people in a pandemic is just plain hard, and it is a marathon, not a sprint. The thing about a sprint is we can overcommit ourselves, give it everything and make it to the finish line. Then we take some time to recover. A marathon is different. To run a marathon well, we train for it gradually, over a long period of time. So, when we do our run, we can pace ourselves and get all the way to the end. We are now running a marathon we never trained for. We have to support our own mental health if we want to stay in this race. And the challenge is we are training and running, learning as we go, all at the same time. The H-E-L-P approach applies to each and every one of us. We are no good to the people we want to support at work or at home if we do not tend to our own physical health, adapt our environments, acknowledge the impact of our own lived experience, and then ask for the help we need if we are struggling with mental health issues. An increase in sleep disturbances, worries, and alcohol or substance use may be a symptom of a mental health problem, and it is important to seek help in such situations.

Take some time each day, even a few minutes, to take care of yourself:

- Move and stretch
- Talk to someone supportive
- Laugh
- Eat something you enjoy
- Sleep
- Pray or meditate

There are many resources available to staff to support their mental health. Please take some time to take advantage of what is being offered. We are all in this together, and we all need to get our oxygen masks on first.

COVID-19 resources for DSP's

<https://nadsp.org/covid-19resources/>

<https://ici.umn.edu/product/invaluable/share-your-story>

<https://ici.umn.edu/product/invaluable/stories-from-dsps>

<http://www.camh.ca/en/health-info/mental-health-and-covid-19/information-for-professionals#>

For more information on mental health and developmental disabilities during COVID, you can also check out:

www.hcarddcovid.com/info

<https://www.camh.ca/covid19booklets>

<https://booksbeyondwords.co.uk/coping-with-coronavirus>

[And you can find H-CARDD blogs related to COVID and developmental disabilities](#) here

This article was written for health care providers about applying HELP in practice with adults with developmental disabilities: https://www.cfp.ca/content/64/Suppl_2/S23

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[To learn more about the ECHO mental health program, click here](#)

<https://echoontario.us14.list-manage.com/subscribe?u=8e45dd4c90daf383c7427c8a0&id=8b47ed41c3>

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