

The International Journal for Direct Support Professionals

Finding our way out of this hot mess called COVID-19

By: Yona Lunsky

It is now one year since the people working in this sector had to change everything. I look back at this past year, and I am stunned. Stunned that it happened, stunned that it is still happening, and stunned in a good way at the people who have held this sector together through all of it. I am writing today as a mental health researcher, a psychologist, and a sister of someone who has been reliant on direct support professionals (DSPs) to keep her safe and well for this past year spent at home. In this article, I want to focus on what we can each do in the coming months to help our sector emerge from this “hot mess called COVID-19.” People think we are going to get out of this hot mess with vaccines. This is definitely one huge essential step, a necessary and needed part of a shift that will allow help us get through this pandemic. However, we must still keep other public health practices in place to reduce spread. At the same time, it is not too early to start thinking about how things may be different, with the knowledge that hopefully soon things actually will be.

Recognizing and making space for what we have collectively lost:

The past year has impacted each of us differently, but none of us will come out of this unscathed. I think that, if we recognize how we have each been impacted by what has happened over the last year, this can help us heal and may be part of the recipe for moving forward.

We are collectively grieving what we have lost. These are the things we have to acknowledge have been lost and be sensitive to as we rockily move forward.

Lost health – When health care shut down, we stopped doing the ongoing healthcare that we all needed. This hit people with intellectual disabilities extra hard because they have more health issues than other people, and it can be harder for them to report health changes, but many of us have missed health screening appointments, as well as some of the more in-depth chronic disease management that is needed whether this is diabetes care, or mental health care. So emerging from COVID, we are less healthy than we once were. Doing things may be more difficult if we have less energy, or less muscle strength, or more anxiety

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than we had before. So, we have to slowly build up our health and our capacity ... And this will require support.

Lost trust – Many of us have experienced a sense of being let down by others, whether it is coworkers, managers, the government, the media, family, or friends. It could be trust in knowing the public values this sector of disabled people. And it could be trust in knowing that if mom says she will come visit and take me out for dinner, she means it, and then she doesn't. Things may be reopening, activities may be returning, but it can be hard to actually believe this when we thought things would be this way before, and then they weren't.

Lost joy – There were so many things that were enjoyable that have not been allowed to occur. There is a cumulative impact of not being able to do what is most enjoyable over a long period of time. It can make people feel resigned, and a bit more empty inside. I think this gets even harder when you don't have words to explain that feeling or a clear memory of what those things were.

Lost skills – There is lots of talk about the skills that children with disabilities are losing when they don't go to school, but learning doesn't end when someone turns 18, and all of us can lose skills if we don't practice them. This means that everyone, especially people with intellectual disabilities who have been stopped from practicing work skills, social skills, transportation skills, food preparation skills, shopping skills, getting up early and getting dressed to go to work skills, have a lot to re-learn. This can be on top of new skills that have to be learned as people return to spending more time in their community – like how to wear a mask, or how to avoid touching people or objects, or how to keep a certain distance from others where possible. Recognizing how we have lost skills ourselves can help us be sensitive to what it might be like for the people we support who will face new demands with less capacity than they had before.

Lost time with friends and family – In our effort this past year to take care of ourselves and each other, we had to stop spending time with people we like and even with people we love. Some of us adapted to spending a different kind of time with people, be it by phone, social media, or through virtual screen visits. In some cases, for people with and without disabilities, this has meant the development of a new set of skills and building new types of connections that are positive and rewarding. For people who struggle with getting to places in person, having more flexibility in how to connect has been welcome. But for most of us, virtual connections are not the same as in-person connections, and it has meant fewer opportunities to be with the people that strengthen us and nurture us, that make us laugh and encourage us to keep going, especially when things are hard. People who liked and loved us pre-COVID were also the people that we could hug and kiss, bump fists with, and put our arms around. What happens when all of that touch stops for a year? Some DSPs who live alone and work with people who are vulnerable had to stop that physical contact and intimacy with others. People with disabilities who live away from their families and friends had to stop that as well.

Lost opportunities to say goodbye – After a year, there will be many of us who have experienced a death, the most permanent type of loss. On top of that trauma, COVID restrictions have meant that some of us could not spend the time we wanted in close contact with someone who was ill to say goodbye, either before or after their death. This is extra complex for a group of people who have a hard time concretizing and understanding death, but

it is hard for all of us. We can still engage in rituals to mark the loss of others, even when we can't be with them, but it is not the same. So coming to terms with grief can take longer.

Building community and moving forward together:

Since the start of COVID, I have had the privilege of working with DSPs from across Ontario and Canada to teach about mental health during COVID and to learn from them about their most common struggles, as well as their innovative strategies to make things better. There are some common themes of what has strengthened or nurtured them this past year, and I think, often, it comes from engaging in meaningful activities with one another.

Exercising together – One of the biggest challenges of the past year has been the reduction in movement. We have been drawn to our couches, and our motivation to move, as well as our freedom of where we can move has been reduced. As the days get longer and warmer, we need to find ways to exercise and move our bodies, ideally outdoors when possible. Rather than save your own physical activity to after the workday ends, why not find small ways to do exercise together with the people you are supporting? Set up contests. Count how many days you can get up and get outside. Measure your strength. How many jumping jacks or arm lifts can you do? What are your best spring tunes to dance to together? Post videos, selfies, exchange ideas of how to get fit and be well.

Growing together – Now is the time to plant seeds and get ready to grow, metaphorically and literally. Some DSPs have shared stories about planting seeds of vegetables, or just flowering plants that need to be watered and cared for. These things can be done indoors and eventually be transferred to outside, or even stay indoors. But watching something small grow with sunlight and water is a reminder of what we will also be able to do ourselves. It is also about putting a nurturing skill into place. You may not have a green thumb yourself, but chances are there is a DSP in your agency who has a few ideas in this regard. There are also some very hearty plants who thrive well no matter what (RESILLIANCE), that can be good for beginners.

Touching together – We have had less physical contact since this pandemic began, but touching is one of the most important senses for our mental and physical health. As it becomes safer to allow for some touch, maybe there are activities we can resume that include a little bit of physical contact. And even if that is still not permitted, there may be activities which involve touch that are still considered safe. Is there a small animal that can be in the home, or visit the home, or even come outdoors? Petting a gentle purring cat or a furry resting dog can be so satisfying. Sitting together and applying a little hand cream to our hands, smelling it together and then feeling our own fingers one by one with the lotion is still a way to pay attention to sensations, and it can be quite soothing. Whose hands are not dry with all this hand sanitizer?

Baking and breaking bread together – One of the best parts of being part of a community is preparing food and actually sharing a meal together. This is something that had to stop during the pandemic, but are there ways to participate in some baking again? Doing a baking exchange with another home, preparing something special for family who can't yet be together? As it warms up outside, is there any eating that can be done outdoors with the right amount of space between people? Food is love for many of us, and it can be so satisfying to prepare

something with your own hands that you then get to eat or offer to someone else. At every agency, there is a DSP who has come up with a simple recipe that others can easily follow...

Walking together – The spring season gets more beautiful each day. Birds are starting to chirp, buds are opening on trees, which eventually will turn into leaves. Stores and businesses are starting to reopen. It is time to wear masks (start practicing this for people who have not been doing so) and enjoy observing the outdoor world in the sunshine. You can take a drive to a pretty place where you can easily keep your distance from other people and enjoy a walk, long or short. You can track how many steps you have taken or different places you have been to.

Creating together – Many people have been busy over the course of the pandemic with arts and crafts activities. Making jewelry, repainting a room, designing cards for loved ones. Research has shown that using one's hands to make something beautiful or just functional, actually activates parts of the brain that are associated with positive emotions.

Breathing together – Sometimes we forget to take a breath, especially when work feels so stressful. But here is one thing that every single person working in the sector and getting supported by the sector does every day. There are different audio recordings, videos and live mindfulness activities that have been designed for people with disabilities. The key is for them to be short and sweet, easy to understand, and engaging. Research has shown us that practicing meditation improves both our mental and physical health. One of my favourite mindfulness activities (and the shortest one I know) is called Just Three Breaths. If you can do nothing else, can you take a moment each day, especially when things are feeling really stressful, to stop doing what you are doing, and take three breaths together? Close your eyes if you can and savour the stillness. Notice what it feels like to breathe in and out. You can model how this is done and do it three times together.

Crying together – We have this idea in our heads that we need to be tough. But being strong for others also means being real with others. And sometimes things are simply sad. Sharing a moment when someone you support feels sad to feel sad too is one of the most important moments to have. It may even be reversed. Something may make you feel sad while you are at work. It is ok to share that with the other people in the room with you. To model that sometimes you just feel sad, and it makes you cry. And sometimes that moment of crying is healing and can help you move on to the next activity instead of hiding it or holding it in.

Laughing together – You know the expression “Laughter is the best medicine?” Whether it is watching a silly TV show, making funny faces, or just taking the time to laugh is infectious and healing. There is lots to be done, but we are all better when we can have fun while we do it. How can you make sure there is one activity each day that makes people laugh where you work? Who laughs the hardest? The loudest? The longest?

Making mistakes, forgiving, and trying again together – If I have learned one thing during this pandemic, it is to embrace all my own imperfections and to be more forgiving when I see them in others. We have all been trying our best in some fairly uncertain and sometimes impossible circumstances. There has been lots of trial and error until now, and as we try to move forward, there will be many more mistakes as we try to get it right. The important thing is to practice compassion and forgiveness, learn from mistakes, and try again.

So, to be honest, I am not certain how we will get out of this hot mess. But I am certain that if anyone knows how to make this happen, it is the incredible DSP's that have worked so hard this past year to keep the people they support safe and well. Recognizing fully what has been lost while taking actions to engage meaningfully in activities together now are two key steps to our healing. It will be a slow healing where we need to be patient and gentle with ourselves and one another. But celebrating small steps and sharing what we are learning will help. Step by step. We've got this!

About the author

Yona Lunsky is a psychologist and Director of the Azrieli Adult Neurodevelopmental Centre at CAMH and H-CARDD (www.hcardd.ca). You can find helpful COVID-19 resources at the H-CARDD COVID webpage, www.hcarddcovid.com/info and you can email hcardd@camh.ca with your ideas on how to get out of this hot mess.

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