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One Candle: Finding Hope in the Darkness of a Pandemic

By: Amanda Gee

As this pandemic continues and stay-at-home orders are still in place here in Ontario, Canada, I find myself reflecting on all that we have lost and what we have gained over the last fourteen months. As I do, I often hear the voices of people with intellectual disabilities with whom I work and what they have expressed to me over this time. Because of community lockdown rules, ministry guidelines, and safety protocols, many people with intellectual disabilities have been mostly at home for the past year and beyond with no clear end in sight.

As a therapist, I often start meetings, now virtual, with the words ‘What’s new?’ and then I cringe. Nothing is new really. Every day feels mostly the same. What would be better to say? ‘How was your week?’ I often settle on ‘How are you feeling?’ because the feelings are there, they are real, they are valid, and they need to be expressed. They also need to be acknowledged.

The responses are predictable: I’m bored, I’m frustrated, I’m angry, I’m sad, I’m worried, I’m ok; I miss my family, my friends, my program, seeing people. The phrase ‘When COVID is over ...’ is said as often as ‘You’re muted.’ Other times, we just laugh about it because there is still humour to be found in this unbelievable situation. Hope often comes up as well – ‘I hope when we get the vaccine ...’ ‘I hope by the summer ...’ ‘I hope my day program opens soon ...’ Through all of this, there is still hope that things will soon be better.

I work with individuals with disabilities who live in a variety of settings, some in group homes, some in supported independent living, some in family homes. The level of community access and independence varies for all these individuals for various reasons. Some had jobs, some have romantic relationships, some had large social circles, some attended day programs and rights groups, some stayed home more but left for regularly scheduled activities, which they enjoyed, all had routines. Then, in March 2020, the world came to a stop. We thought it would be for a short time – we hoped – but we were sure wrong. I can only speak for where I live and work in the greater Toronto area of Ontario where we have been in various stages of lockdown for over a year. The reality is that things are shut down, and they need to be for safety.

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A few people with disabilities with whom I work had to stop working in the community because their workplaces shut down or because of health and safety concerns. One person hasn't seen her boyfriend in person in over a year because of rules at his home and transit concerns. Another person told me that she misses playing sports and said, 'Whenever I look at that blank wall, all I see are missed goals and dreams,' referring to the fact that she isn't winning trophies and medals like she used to. Others haven't seen family much in person because of safety and distance. Others miss their social circles from their communities. 'There just isn't any place to go, and there is nothing to do' a gentleman told me the other day when talking about loneliness. For some, the days have always been long, and now they are even longer.

Some people are homebodies and prefer being at home, while others thrive on being on the go. Some people love to sit about watching TV or movies, and others have zero interest. How do we find a way to have fun at home when you never had fun at home. If you don't like TV or movies, don't like to sit around, don't have a credit card for retail therapy; what do you do? Sometimes, you sit around and feel frustrated, and depressed, and angry, and sad because you can't do what you want. And maybe you don't fully comprehend that it's not your supervisor's fault, or your staff's fault, or your fault, and you aren't being punished. There is a global pandemic, and you're right, it sucks, and it's just not fair. Sometimes, they just can't feel positive. Sometimes, there is nothing to feel positive about. Sometimes, I just have to say, 'I know, it sucks' and just be there to listen to the sadness, anger, frustration, loneliness, and all the losses.

A lot has been lost.

- **Freedom** – The freedom to just go out. The freedom to go to any store, to an event, to day program, to work. The freedom to visit with family and friends how you used to, to go for a coffee, to go to the movies, or to browse the dollar store. This is one of the hardest things for most people.
- **Choice** – This goes along with freedom. A lot of opportunities for choice have been lost with the limitations of freedom. There is limited choice of what to do on any given day. The simplicity of being able to go to the store to choose a snack or something new has been lost.
- **Connection** – A lot of our face-to-face connection has been lost. And much of what we have now is happening through masks, and face shields, and socially distanced. Friendships and casual interactions with people in the community don't happen. People try to smile with their eyes, but it is hard to convey.
- **Touch** – With social distancing and protective measures in places, touch has gone away. No more hugs from family and friends, no more handshakes and high fives, no more haircuts and manicures. Some individuals haven't seen family and friends in a long time because of protective measures, travel restrictions, and programs being closed.
- **Goals** – It's hard to work towards goals when you can't go anywhere or do anything. It's hard to think about goals when everything feels off limits in the current moment.

A lot has been lost, though hopefully not forever. With this in mind, we also need to think about what has been gained because, in all the loss, there are some great gains.

- **Technology** – A lot of learning has happened in a short amount of time. Organizations moved quickly to get the individuals whom they support connected through technology in ways they never were before. Therapy sessions quickly moved to an online platform, and many groups run online. Online shopping has been facilitated to provide choice in new purchases. It seems that, now, most people have a device of their own to be able to connect online.

To enhance this: If possible, get each individual a device they can use with ease, such as a tablet, or ensure that there are devices they can use within the home. Sit with the person and teach them how to use the device. How to mute and unmute, where the volume is, how to click on a link, get them some good headphones to allow for privacy and sound management. Make sure they know or are taught about internet safety to protect them while on the internet. There are resources and classes available online geared towards people with intellectual disabilities. If the individual is not using the internet independently, make sure to involve the person in any online shopping or planning that needs to take place for them.

- **Different Connection** – Though a lot of connection has been lost in person, so much has also been gained in other ways. New friendships have been formed through online programs between people who may not have met in person. There has been an increased social life for some because online platforms make that possible.

To enhance this: Look into rights groups or social groups that have moved online. These groups may be local or not. Some online programs have social time built right in, and people have a chance to connect and build rapport. We run an online therapeutic arts group that has been a social hub for many individuals who come to make art but also to make connection.

- **Accessibility** – Individuals who weren't able to connect with a specific group, programs, friends because of accessibility, physical limitations, distance are now able to access these services easily. For many people, online programs are a huge benefit in their ability to successfully attend. Visits with family who live far away are now possible. Going back to social lives, technology makes it easier to have a social life and hang out with friends online one on one or in a group, and you don't have to arrange things like staffing, transit, and accessible spaces.

To enhance this: Help the individual to connect online with friends and family through an online platform. There are quite a few online video platforms that are free and easy to use. Look far and wide for free or paid online programs or classes that would interest the individuals you support as the virtual world has gotten rid of distance as a barrier.

- **Creativity** – People have been very inventive, taking new and different things online. Virtual day programs, exercise classes, dinner parties, Halloween parties, art groups, cooking classes, dance parties, shows, and events. People have really tried to create new and interesting opportunities for people while being stuck at home. Staff have been amazing at connecting people and creating new opportunities in these difficult times.

To enhance this: Continue to plan creative events, host online dinner parties, and Friday night dance parties! Plan ‘An Evening Away’ to a far-off place – look online for tours of another city or country, plan a meal or snacks specific to that place, and then watch the tour while enjoying the food. Tour an art gallery or museum online anywhere in the world, visit a zoo or aquarium, or maybe go scuba diving. The possibilities are endless!

- **Hope** – We have always had it, but now it feels like it plays a bigger role day to day. Every day, individuals I work with tell me about their hopes. These hopes are often for the pandemic to end, or for what they hope to do when the pandemic ends. When future plans are mentioned, someone will always say, ‘We can hope.’

To enhance this: Keep encouraging hope and dreams. Continue to plan for the future, to have goals to achieve because things will change and can be adapted. These things don’t need to have a specific date on them but documenting them will help make them happen when possible. Work with individuals to build a ‘vision board’ or ‘dream board’ – cut out pictures or print images and make a bulletin board or poster, so that these dreams and plans are up on the wall to enhance hope for the future.

We have lost a lot but, in place of those losses, we have also gained, and I think we have learned so much. In all this, there always needs to be room for hope. Hope for the end of the pandemic, hope for the future. It comes up in conversations in talking about dreams and goals for the future, in talking about vaccines, or in smaller things like embracing spring, noticing the plants growing, and flowers blooming, the days getting brighter and warmer. There is also hope in all the new connections and new relationships that have been made through technology, new online programs, and creativity. People need connection and so much work has happened to keep people connected. These are things that I hope we continue as we move out of this in the future – keeping these new ways of connecting alive within our new normal however that may look.

About the author

Amanda Gee, RCAT, RP, RCT (she/her) has been working with individuals with Intellectual Disabilities for the past 20 years in many different capacities. Amanda is an artist and an art therapist. She is a clinician at Vita Community Living Services, a registered Canadian art therapist, a registered psychotherapist, a registered counselling therapist, and also specializes in helping people through grief and loss.

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