

Dignity of Risk and Person-Centered Planning During COVID-19

Balancing Risk and Embracing Opportunity in the Face of Grave Challenges

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The United States and much of the world is currently dealing with a nightmarish pandemic. This has presented many challenges for people with developmental disabilities and those who support us to live our best lives. As we live together through this difficult time, we need to keep our eye on the prize: people with disabilities living our best lives in the community. In this short article I answer some questions about my experience in this pandemic and where I see opportunities for people to continue to work, live, and play in their communities by being supported in a way that is person-centered.



Nicole LeBlanc

What were some of your initial feelings as we learned about COVID-19 and went into quarantine/physical distancing?

Well, when news first broke that this virus was gonna be a pandemic, I was extremely scared and anxious. It raised my anxiety levels to the point that I suffered my first panic/anxiety attack in March 2020 and ended up going to the ER. I also had more anxiety-related seizures. I was especially anxious about taking paratransit and Lyft regularly to get to one of my jobs. Early on, I was thinking about how this situation shows that teleworking is good for people with

disabilities who do not drive. Being able to do my job without traveling to work helps in controlling my high anxiety levels around day-to-day routines during this difficult time.

As a person with autism, what do you think makes this crisis particularly challenging?

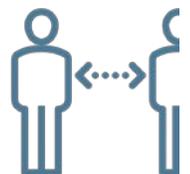
Uncertainty is one of the biggest anxiety triggers for people with autism. This pandemic has made me aware of how many day-to-day things like face-to-face contact, hugging and so forth that we all take for granted. The political and news environment during this pandemic also makes everything scarier because I find it harder and harder to know what is fact vs fake news on COVID-19. If there is one thing I have learned, it's that in crisis like this having access to factual and truthful information is more important than ever.

This crisis has made us all pay more attention to cleanliness on a day-to-day basis. Cleaning is a task I struggle with. I

have poor concentration, chronic fatigue, and sensory issues that make it hard for me to use some cleaning products – like bathroom cleaning products, which make me gag. I find it hard to keep up with cleaning demands usually. This situation makes it worse.

I am also constantly paying attention to ensuring there is enough physical distance between me and anyone else in public at places like coffee shops, the post office and the grocery store. It is exhausting to have to be extra aware of space all the time.

BEING EXTRA FOCUSED ON SPACE ALL THE TIME CAN BE EXHAUSTING.



Since I don't drive, I often have to ask allies in the disability community who I have worked with to take me to and

from my medical or dental appointments. I must say I feel safer being in cars with people I know during this pandemic than in private transit or paratransit vehicles with random strangers. Recently I had my first doctor's appointment with my neurologist via telehealth over the internet. I must say, doing doctor's appointments over the internet felt different but it was okay. The best thing about it was not having to go anywhere.

Finally, the fact that I do not get any Medicaid waiver (disability support) services plays a big role in my COVID-19 anxiety. The things that worry me about not getting services during this time is that there are many everyday tasks I could use help with – like cleaning, organizing, and getting rides to doctor's appointments, support with budgeting, and emotional support to provide reassurance everything will be okay. I recently moved to a new apartment. This was a major task and I

needed help with someone there to offer help and provide motivation for getting what needs to be done and focus on the task at hand. Since I do not have family nearby, I worry about getting support if I did catch this dangerous bug.

Dignity of risk is an important value to me. Given the current situation, all of us face choices that carry risk. However, people with disabilities may have their choices judged differently than people without disabilities.

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I think it has a lot to do with the expert or professional model of disability where professionals are seen as the ones who know what's best for us. Our habit of overprotection and seeing disability as something that is broken and must be fixed plays a big role. Our society,

culture, and systems are very ableist in the way they address and view living with a disability. This applies especially to people with intellectual disability where we are often not seen as “smart.” The risks we all face these days include ourselves or others getting sick with COVID-19.

In 2020, we all have experienced new risks related to the Coronavirus pandemic. What have we learned from this new situation?

Here are some of the most important things we have learned:



People can work from home.

This crisis is a perfect time for us to think outside the box and look at how we can get people with disabilities professional work-from-home jobs. One of the great benefits of remote jobs is that it eliminates the barrier of not having reliable, accessible, and affordable transportation to work. I hope we see a

strong movement to embrace flexible work arrangements for all. Personally, by working from home I am able to lessen my fear of crowds and getting in vehicles with people I don't know during this pandemic.



We need better access to

technology and better systems to support work and social connections, especially through peers.

COVID-19 is causing lots of social isolation, which can lead to anxiety and depression. Peer mentoring is a great way to support people to learn new life skills and offer emotional support during times of mass isolation. Given all the technology we are blessed to have access to, this service can be done virtually. Peer-to-peer connections are at the heart of the self-advocacy movement. Peers are great at telling it like it is and not sugarcoating the information. We should learn from systems that make peer support a billable service under

Medicaid and look at how virtual connections can be billed for too.



Telehealth is now and

the future. Telehealth is good for just general check-ins and going over things like blood test results for example. Now that many more people have experienced it, it can become a normal part of getting care and it can work well for people with disabilities. (MyDoc app is one telehealth example.)



People are better off living

in settings that are not institutions. This will take work on several fronts, including investing in affordable accessible housing to allow people to live in more integrated settings.

Technology could help support people, to make in-person staff less needed. It could help people to live in an apartment with nearby remote

monitoring instead of living with a home-provider 24/7. There are also tools out there that can provide verbal prompts on when to take meds or do certain daily tasks. Using Zoom or other platforms, staff can coach people with disabilities over the internet on how to cook a chicken or make a meal. Many apps out there can be set up in a way that cues the user to do various day-to-day tasks of daily living. Remote support technology is also good for adults with I/DD who have behavior or sensory issues that make living in groups and having many people working with them difficult. For example, Vermont has a program in Chittenden County called Safety Connections run by Howard Center. How it works is people living in their own apartment arm their system at night. Then someone comes over the loudspeaker to ensure they are all set. In the event the fire alarm goes off at night, or a break-in or crisis occurs, the monitor can come over the loudspeaker.

If needed, a responder on duty can rush over to help.

And it's important that we all take this virus seriously. I just moved to a cheaper apartment and I realized that in order to minimize my anxiety with this virus, it is important to choose housemates who will take the pandemic seriously and not blow COVID off like it's just a regular flu bug.

What opportunities (or chances) should we make sure people still have in the time of COVID-19?

Awesome question. On a systems level this crisis is the perfect opportunity to fight for a robust home and community-based services (HCBS) system that is truly person-centered. This is also a good time to embrace individual budgets and self-direction that allow us to have control of our supports and to be sure supports are flexible for our needs.

Living in smaller settings is important. Smaller settings also allow us to get more individualized attention than larger

(congregate) ones. When we have individualized services, it is more person-centered because we can choose our own activities and goals and not always have to do what the rest of the group does. Things that I hope to see come out of this are the creation of more supported apartment programs, increased funding for affordable housing, and exploring ways we can use technology to support people to live on their own.

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- MORE SUPPORTED APARTMENT PROGRAMS
 - INCREASED FUNDING FOR AFFORDABLE HOUSING
 - MORE USE OF TECHNOLOGY TO SUPPORT PEOPLE TO LIVE ON THEIR OWN



This crisis is a good time to work on developing social capital so that you have a circle of support you can rely on when the going gets tough. Since the

intensity of this virus began, I have been relying more on friends and allies in the disability community.

Given that scientists say being outside is somewhat safer, we should use this time to connect with nature by hiking, hugging trees, and just taking walks in the woods in places where there are no crowds. Some people are finding they can use this slower-paced world to develop hobbies like arts and crafts, run on a treadmill, or start blogging to name a few.

What about wearing masks when going out in public? Some people say they are making their own choice to not wear a mask.

As we debate the pros and cons of mask wearing we must be aware that masks can cut the risk of virus spread from person to person by up to 40+%. It is important to note that people with disabilities are more vulnerable to COVID-19 because we often have more co-occurring health issues. As citizens we all have a responsibility to ensure we

are all healthy and safe. Given that experts say it's safer to be outside vs inside, we must still stay vigilant when around other people.



If you are alone in the boonies in a large backyard and can keep away from people, then I think it's safe enough to get away without wearing masks. Avoiding crowded places and close contact with people seems to be the best way to cut the risk of getting COVID-19. Support people to explore masks or try out face-coverings made with different types of material. It does not strictly have to be the medical-type masks that you throw away. Also, in the case of people with autism, it may be good to just try wearing different types of masks, face coverings, or shields for short periods of time. Stress that if the person wants to go outside in public areas, masks are like the new seatbelt to protect us all. As parents and

professionals, it is good to use social stories and try and make it fun.

I personally think of mask-wearing as the “new seatbelt.” If we all remember when seatbelts came out it took a while to get people like my father to embrace the habit of buckling up. Ending a pandemic requires us to all embrace TEAMwork and to think about how we are contributing to our community – in this case by putting the needs of the group over the needs of ourselves. This is an important time to keep supporting people to make choices, and

to be supported to live their best lives. These days, that might include choosing to do things like wearing a mask to keep everyone healthier. Facing all the risks that we see from the coronavirus, people might need help to learn about the risks, and to make decisions about how to keep themselves and others safe and healthy.

It might take some creativity, but I think people can still be doing things that allow them to take chances and grow. This is a good time to explore interests and try learning new skills.

More resources

If you’d like to learn more, here are some trainings and resources on Dignity of Risk:

- Enabling Risk: Putting Positives First, an [online learning resource](#) and [online workbook](#) for disability support workers
- [Exploring the Concept of ‘Dignity of Risk’](#), from researchers at Monash University in Australia

NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by HSRI.

