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# A Self-Advocate's Perspective on the COVID-19 Pandemic

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## Plain Language Summary

*This article is about the impact of the COVID-19 pandemic on a self-advocate from Idaho. It talks about important issues like loneliness, mental health, and social support. This article describes how the author worked with the DD Council in Idaho to create her own support network during the pandemic.*

I go by the name D.R. I am a 30-year-old with a bachelor's degree in criminal justice and history. I am an active community volunteer, completing at least 100 hours of community service yearly. One of the organizations I am a part of is the Idaho Council on Developmental Disabilities (ICDD). It is here that I am an active Vice-Chair and state leader on policy issues that impact people with disabilities.

Having both a schizoaffective disorder alongside a small aftertaste of autism always seems to add flavor to my life, but the COVID-19 pandemic added a new level of stress and anxiety. COVID-19 may have started in China, but it soon affected everyone in the U.S. and around the world. March 21<sup>st</sup> marked the first day the Idaho Governor told everyone to remain at home and only leave for important purposes such as shopping for food or emergency situations. I started this segment of my life a week or more prior to the Governor's order.

It is a common reaction to fear death. The only place or time I have read about people not fearing death has been in the book *"Brave New World"* where they are conditioned not to. I always thought fearing death made us human...or an animal at least. Nonetheless, my experience during the COVID pandemic has changed me forever.

During the initial seclusion order, I stayed in my room. I only went downstairs or out of my room for bathroom and food breaks. I had snacks in my room along with every possible activity I would ever want to do, besides, of course, going outside or into a moving vehicle. For most people life was difficult, but for me it was a blast. I had a nook, desktop, laptop with at least 200 iTunes movies on it, phone, and other technological amazements. In addition to these, I had books galore and a chess board.

Every morning I had a similar routine. I would do exercise, eat breakfast, look at my Star Wars McQuarrie art book, write in my memoirs, write in my journal, and study Japanese or another language. During the day I would treat myself to either watching movies, study 23 vocab

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terms, or...well, buy stuff.

Though I was cut off from friends and certain locations, I still had ample opportunities to speak to them via audio or video, and I could “visit” places online. There were so many ways to communicate without being in person—the most common was Zoom. I used Zoom for DD Council meetings, story circles, and Autism Society Treasure Valley (ASTV) meetings. Unfortunately, these were not everyday events. I just met with them maybe once or twice a month, but I still looked forward to them with great anticipation.

Although I liked some parts of the pandemic, my anxiety increased, primarily because I was forced to communicate via phone and not in person. Ever since I was a child, I have had difficulties talking on the phone—although once I was on, I was superb. At times I could not stop talking. But when I was told that I could not go to Social Security Administration to discuss in person my confusion over money sent to me in the form of SSI, I grew more and more anxious. Having financial miscommunications and not being able to address it increased my anxiety to such high levels that I knew it would only lead to disaster.

As I mentioned before, I have a schizoaffective disorder and with that I would sometimes slip into an inescapable negativity. This so-called negativity occurred on Saturday May 2, 2020; it was a blissfully surreal and painful reaction to what I was going through. I still cannot believe what happened on this date. I was feeling small amounts of anxiety and occasional “life flashing before my eyes” moments. At 4pm I took a shower, thinking that would relax me further. I got out of the shower and took my Abilify and Artane medications to help further manage my anxiety, but they did nothing.

Anxiety! Anxiety! I said to myself. But from where? What can I put in my worry basket like Dr. Desai said? A week earlier I had been on a DD Council webinar where a doctor named Desai had provided a technique for us to use to manage anxiety. He said that we should “Put all your worry in a basket and put it aside until a prearranged time.” This worked well for a while, but it was not working now! Nothing seemed to help! This is not normal. This is not real. “Please let it be COVID!” I prayed to myself.

I eventually took myself to the hospital, where I tried to explain what was happening to me to four people. All they said was, “You seem to be having an acute anxiety attack.” I clutched my stomach, which was hurting, in frustration. “Why can’t I get COVID like a normal person?” I asked? Eventually, a female social worker entered my room. She spoke to me in a kind positive voice and said, “I’m going to talk to the doctor, but I don’t think you’ll be getting a prescription.” After talking to the doctor, she told me “The doctor wants you to work out your prescription with your regular doctor.” I said, “But it’s Saturday and the clinic won’t be open until Monday. What do I do until then? Can’t you give me just enough to last before then?”

She looked at me intensely but seemed to ignore me too. She said, “We need to plan what you’ll do if you don’t get a prescription. You will need to practice coping techniques.”

“What if I do every anxiety remedy known to mankind and still need medicine?”

Then she spoke the words that I most dreaded, "If you feel this again, you can come back."

I had already told her, "I don't want to bother you guys again."

She responded by saying, "We won't mind if you return."

I lowered my eyes with such intensity they could have broken. "But I will mind," I said to myself, "I will mind."

The doctor at the hospital only gave me an injection of half a milliliter of Ativan and sent me packing. After departing from the hospital, I learned that the earliest I could meet with my med manager, even on the phone, was the following Friday—6 days away!

I left a voice message at my med appointment location in hopes that they would respond to my message soon. I got no reply until Monday. They said I could not see my doctor until Friday.

"But this is an emergency!" I proclaimed in anger.

"I understand that you are in crisis, but we can't deal with crises here. If you need immediate help you'll have to go back to the hospital," the woman on the phone said.

"Would you want to?" I almost said aloud, but I kept it to myself.

Instead, I nodded my head and said those dreaded, pointless words, "Thank you."

The truly sad thing is that no one seems to believe people with mental illness, and when they do, they like to assume that you are overreacting. Who ever heard of a person with an anxiety attack go to the emergency room? Yet I did.

Anxiety attacks have the tendency to make me lose focus and forget things. So, in addition to being in quiet pain, I had to open my mouth and explain what was happening to me four times. And even then, I did not feel like they believed me.

My appointment with my med manager resulted in his agreement to all my wishes—one being to try a new medicine. All my medications are set now. Anxiety is decreasing. Most importantly, I can relax for a change.

After feeling such pain and degradation, I felt I needed to find a way to help others. On most Fridays, the Idaho DD Council hosts webinars where individuals can learn coping strategies from various professionals. My favorite session was with a Dr. Desai, who taught me about the "worry basket." He told me to "Put all your worry into your worry basket and only look back at it a few hours later."

During each webinar, there are opportunities to ask questions. I decided to speak up during a webinar about coping strategies. In the chat section of the zoom webinar, I wrote, "Why

can't we create a way for people with mental health and social disorders to correspond with each other through mail or email?" To my surprise, many people responded positively to my suggestion. A few days later, I received my first letter from a DD Council member.

I am now leading the Pen Pal Club for the Idaho DD Council. It is intended to be an opportunity to provide a chance for people to connect with others, to alleviate isolation, and open up to a person who may otherwise sleep the day away or cry because of lack of friendship. People who participate in this club provide social connection and hope through these troubled times, and this helps me too.

Although I have experienced a lot of mental anguish during the pandemic, I have found connection and support through the Pen Pal Club and I have created many new friendships. This is what I want for everyone who participates in our Pen Pal Club—to have someone they can share their joys and sorrows with. I have gained two pen pals of my own. Both are equally kind and accepting. One loves to discuss the disgusting world of politics while the other likes to discuss "Avatar the Airbender," a kid's television show. Both have helped me manage my mental health and have helped me feel connected and supported through this difficult time.

Through my personal experience, I have learned that everyone needs an outlet to share their personal stories and release pent-up frustration and pain and to realize they are not alone. Everyone is struggling during this time of crisis and everyone needs to be heard.