Adapting to life with autism during Covid

The Covid-19 pandemic has changed all of our lives. For people on the autism spectrum, change can be hard. Technology is helping people adapt and find new ways to connect. Published on July 5, 2022–8 min read



Jillian Nelson, who is on the autism spectrum, poses for photo outside of her apartment building in St. Paul, Minn., on Feb. 1, 2021. She is a Community Resource and Policy Advocate for the Autism Society of Minnesota.



Written By Chris Juhn

Did You Know?

I am a freelance photojournalist on the autism spectrum. The pandemic has meant change: the normal protest events I cover changed. The way I interacted with the world changed. And the way the world did everything seemed to change day-by-day.

People with autism have a lot of different needs and are using a variety of methods to live during this time. One common challenge people with autism face is that change can be hard. And these are changing times.

For me, my normal routine as a photojournalist is that there is no normal: my routine is always changing as I respond to news events and work odd hours. Much of my work got

canceled and there is much less structure, which is a challenge. I have had to modify some of the ways I work. I don't go close during interviews, I use Zoom meetings. Normally, I like to work in coffee shops around people and activity, so I set up a corner in my house to feel like one.

This past year has thrown a lot of unexpected things at me and the journalism community. I realized how uncommon openly disabled journalists are in this field. I realized how important it is to not only be openly disabled, but to cover issues that the disability community faces.

This a series of interviews and portraits with people on the autism spectrum. I asked most of the same questions. The goal was to understand how people with autism have adapted to the world post-pandemic and how it has changed their lives.

Interviews condensed and edited by iPondr visuals editor Angela Jimenez and contributor Sarah Stacke.



Conor O'Meara at Highland Park in St. Paul, Minn., on Feb. 10, 2021.

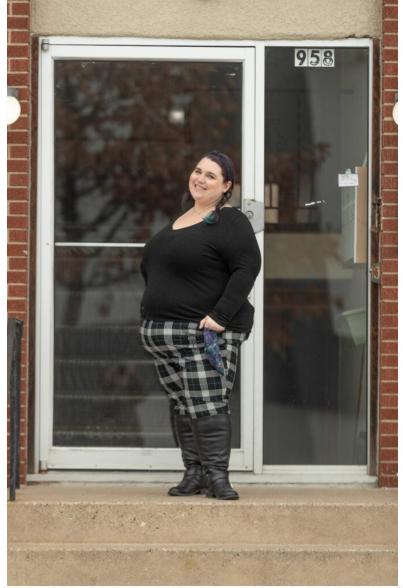
Conor O'Meara is the host of the radio program "<u>Conor's Corner</u>," which airs every Monday on WFNU 94.1 FM Frogtown Community Radio in St. Paul, Minn. For Conor, who is on the autism spectrum, Covid has swept away his usual routines. "My schedule went bankrupt," he said. Everything that anchored his days — his day program, the restaurant where he worked, his live radio show — was cancelled.

The change from a live, in-person radio show to a remote one has been the toughest. "I am not grabbing the microphone and doing interviews," he said. He is a very social person,

used to talking to people and shaking hands. He is using Facetime and Zoom, and is on LinkedIn and Facebook Live, which have helped him maintain his audience. But he misses being with people. "You have to stay inside most days," he said.

Conor's dream was to have a radio show, and he is doing it. "I'm a person with autism," said Conor. "It doesn't define me"

He has more dreams: "My plans are to expand it to a 24-hour show," he said. He wants to learn the production board, to be on MSNBC and to interview Bruce Springsteen. He would like to get some audio equipment, maybe a wireless microphone, so he can do socially distanced in-person interviews to regain that personal connection.



Jillian Nelson outside of her apartment building in St. Paul, Minn., on Feb. 1, 2021.

Jillian Nelson, a Community Resource and Policy Advocate for the Autism Society of Minnesota (AuSM), believes the world has become more accessible since the pandemic started. But these changes, she said, have not been made with disability in mind. "That was just a bonus," she said.

Jillian points to technology as the reason she's been able to adapt to the pandemic. She works online, socializes online, streams her entertainment, orders groceries online, and finds everything else she needs in a virtual environment. Jillian, who is at high-risk for infection, said, "Covid grounded me to my house. This is a big change from being a very social person."

With most of her natural supports and big level sensory activities like swimming and massage unavailable, Jillian is using social media, Zoom and FaceTime to compensate. "I fell down a rabbit hole with TikTok for social connection," she said. "I also started using Bumble to meet new people."

Though it's been a huge adjustment, Jillian thinks the technologies helping people communicate and socialize during the pandemic will benefit the autism community in the long run. "We expanded a huge potential for accessibility," she said. But, she acknowledges, "it will depend on what society is willing to hold onto." Ultimately, she hopes "the world will embrace the possible equity and equalizing effect" technology can have for people with disabilities.



Lee Samelson at Sibley Park in Minneapolis on Feb. 8, 2021.

"Despite Facebook having a significant doom scrolling aspect, it has been a key way for me to keep in touch with folks," said Lee Samelson, an organizer for Community Power, a nonprofit dedicated to expanding energy options across Minnesota. Lee said his mental health during the Covid-19 pandemic "might be worse off" without Facebook. Before the pandemic, Lee spent a lot of time biking to community events in Minneapolis that attracted people with interests similar to his. "Then one by one, all of them got cancelled," he recalls.

Lee, who doesn't drive, appreciates Zoom because there is no travel time between meetings to cause scheduling conflicts. "I can do multiple meetings one right after another," he said. He's using grocery delivery services and recently joined Gay Man Thriving, an online community committed to ending the loneliness epidemic in the gay male community through connection calls and virtual retreats. "It has people from all over the world," said Lee, adding, "it has its limitations, but it is still better than simply missing in-person gatherings."

He would like to find a virtual speed-dating event geared toward gay men. "Gay speeddating events are flat out unavailable," he reports.

Post-pandemic, Lee hopes that the normalization of virtual meetings continues so people with mobility challenges don't miss out completely or feel as left out as before Covid. Meetings with the state legislature he attends for work were sometimes cancelled at the last minute, which is easier for him now that they are online.

If there is one thing Lee wishes the world knew about autism, he said, it's this: "Everything the establishment said is wrong about us is actually what is right about us."



Shawn Weigel poses with his camera gear after photographing a Enbridge Line 3 protest at Minnesota Square Park in St. Peter, Minn., on Jan. 30, 2021.

Before the Covid-19 pandemic, music and event photographer Shawn D. Weigel was just about to put in his two-week notice at his 9-to-5 job as a painter at a factory. "Then poof, I

had nothing, all events were canceled," he said. The last concert Shawn photographed was on March 10, 2020, after two years of being busy every weekend. "It's been a very depressing time," he said.

Shawn, who was diagnosed with autism during the pandemic, hasn't adapted to popular technology services that foster online communication, like Zoom. "With my autism, I haven't been the biggest conversationalist," he said. What has changed during pandemic is his social media use. "It's increased by triple this year," he admits. Shawn recently joined an autism group on Facebook. "It makes me feel 'normal' in a way, like I'm not alone," he said. He's discovered that the autism communicate his feelings and to ask for help when he doesn't understand a situation.

With his newfound appreciation of social media, he does wish there was an app that could help autistic people navigate daily activities and how to handle interruptions in routine. For example, Sunday is Shawn's chore day — laundry, cleaning the cat box, dishes, garbage. But when a wrench is thrown into the plan, he doesn't know how to handle it. "If I had an app that I can type my thoughts in and it gave me a step-by-step process, that might help me," he said.

For Shawn, one of the hardest things about the pandemic is the lack of structure. "This week you can do that, and the next week you can't," he said. He does like the masks and that there are less people inside the stores, restaurants and new places he visits. "I enjoy wearing masks," he said. "It helps with my socializing."

"It took me 32 years to find out I'm autistic," said Shawn. "I'm just learning how to work with it."

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