

Chelsey B. Coombs:

Hi there, and welcome to the Spectrum Podcast. I'm your host Chelsey B. Coombs. Since late last year, SARS COV2, known popularly as COVID-19 or just the Coronavirus, has infected at least 6.7 million people worldwide, according to Johns Hopkins University. Our lives changed dramatically, as governments put in place restrictions that left many sheltering at home and staying at least six feet away from everyone else while in public. Countries around the world are now at different stages of reopening, but researchers expect that future COVID-19 waves could send towns or even countries back into isolation. When everything was locked down, we spoke with autistic people and clinicians to understand the specific challenges they faced as a result of the pandemic, as well as some unexpected upsides.

Briony Hawkin:

Where do I start? I mean, I actually wrote down a timeline of this because it seems like it's been about 10 weeks since we started formal lockdown.

Chelsey B. Coombs:

That's Briony Hawkin, an autistic 26 year old PhD student studying synthetic chemistry at the University of Edinburgh in Scotland.

Briony Hawkin:

The restriction started with lots of bars, clubs, pubs, restaurants had to close. There was a stay-at-home period, which was enforced for at least three weeks, beginning on the 23rd of March, which basically said, throughout this period, you can't leave your home unless it's for essential purchases.

Chelsey B. Coombs:

Hawkin, who uses they/them pronouns says they got sick with what they thought was just a cold, but their bosses told them, "Stay home."

Briony Hawkin:

Four days later, they were like, right, we need to shut down the whole lab, which is a really quite technically complex operation. And because I'm a senior member of that research group, it was kind of my job.

Chelsey B. Coombs:

So Hawkin shut it down. They've been working from home ever since. They say that because of testing limitations in the UK, they weren't able to be tested. So they're still not sure if they had Coronavirus or just a regular cold.

Chelsey B. Coombs:

Raul Portales, an autistic man living in Dublin, Ireland also had a self-quarantine after being exposed at his software engineering job. In Dublin, schools closed because of the pandemic before businesses did, which Portales says was a particular challenge for his family.

Raul Portales:

My two daughters are autistic. They are six and four and not fully verbal, any of them. It's quite hard to communicate with them, to get them to understand things, follow commands. Having them at home for the winter break, which is two weeks, is already quite a stretch. Having them at home for the entire summer holidays is usually that, so we have to plan. So we were thinking if the school is canceled, we need to put something in place. After school was canceled, we figured out that we needed something that could be sustainable. So we find a tutor that came three days a week, and that helped a lot because having the tutor at home help setting a routine in the morning, very similar to the school.

Chelsey B. Coombs:

The change in routine has been tough for many autistic people and their families. That's according to Matthew Siegel, Vice president of Medical Affairs at the Autism and Developmental Disorders Service at Maine Behavioral Health Care. Here he is.

Matthew Siegel:

So most people with autism, they are quite dependent on the routines in their day, including very, very small parts of the routine sometimes, as well as supports that have usually been carefully calibrated and provided to them. With COVID, most of those things were removed, and they were removed suddenly with little warning. And the situation demands really great flexibility and reorganization and changes in how you think about things. And those are all things that are not easy for many people on the autism spectrum to do and deal with.

Chelsey B. Coombs:

Hawkin says they take routines seriously. They had worked hard to set one up in their pre-pandemic, graduate school life.

Briony Hawkin:

Getting systems of support in place, getting adjustments made at work, finding my own coping strategies, getting routines in place.

Chelsey B. Coombs:

The pandemic took it away on multiple levels.

Briony Hawkin:

To have something so sort of globally disruptive coupled with my own personal disruption and routine has been quite a traumatic event, I think. I'm still unpacking a bunch of that.

Chelsey B. Coombs:

The restrictions governments have put in place such as social distancing and wearing masks are especially difficult for autistic people who have higher support needs and may not understand why things changed so suddenly. Here's Portales, who has been with his two autistic daughters in Dublin.

Raul Portales:

We cannot do any sort of family outings now. Things as simple as being able to go to the park for the swings or the slides, so that they can't run away, they can run, blow some steam, make some exercise. That's pretty hard because now it's a place where you cannot go. We have a small space with a small

garden in the front that is shared among several houses. And usually we'll encourage them to go and socialize with the other kids. But now they have to do the opposite, and for them it's like, this is different. Why is this happening?

Chelsey B. Coombs:

Siegel says COVID-19's invisibility can make it especially hard to answer that question.

Matthew Siegel:

If you think about it, COVID and the concept of a virus is a very difficult thing to capture. You can't see it. You can't avoid it in a physical way that you can understand. And so the whole concept of there being something that can hurt you that you can't see or hear, and it can be spread in ways that are difficult to understand, is really difficult for someone who is more on the severe end of the spectrum to appreciate, or to try to explain to them. So not only is their whole world changing, but it's very hard to explain to them why.

Chelsey B. Coombs:

Jill Thaudstadt, Associate Professor of Clinical Psychology at Indiana University in Indianapolis says that lack of explanation can boost anxiety.

Jill Thaudstadt:

So there has been some individuals who we've seen an increase in problem behaviors, or just an increase in anxiety with respect to what's going on, and maybe not fully grasping the state of our world that we live in right now.

Chelsey B. Coombs:

Although autistic people have faced many challenges because of COVID-19, Hawkin And Portales say that in some ways they felt better prepared than they've seen neurotypical people be.

Briony Hawkin:

Part of me sometimes wonders if being autistic has helped me to cope with the lockdown a little better because I'm so used to having restrictions put in place on what I can and can't do, in a sense. I have a lot of disabled friends from many walks of life who are pretty used to being isolated, who may have to stay at home because of their disabilities. It certainly doesn't make it easier for the disabled community, but it's something that we are more familiar with.

Raul Portales:

And I keep seeing people around going crazy because their world is upside down. I don't know, maybe my world's been upside down all my life. But this is one of the things I was thinking, that many of these people have been struggling to make sense of the world all our life. And certainly neurotypicals are facing, no doubt, the same situation we've been facing all of our life.

Chelsey B. Coombs:

And Portales says, as his work went remote, the transition away from in-person interaction made communicating easy.

Raul Portales:

We end up in a lot of more communication over Slack, which is, for people that are not used to it, it's like WhatsApp, but for work. And for me, WhatsApp or Slack is a lot this year. There are normally language. There are no tones. There are no facial expressions. So for me, it's a lot easier than face-to-face interactions.

Chelsey B. Coombs:

Thaudstadt has seen this too, as a clinician. She says after the initial anxiety from the disruption to routine, some people's anxiety has dropped.

Jill Thaudstadt:

I have had some patients who have actually ... I know this is going to sound really funny, but actually are doing much better than they were pre-COVID, especially my autistic patients who have a lot of anxiety, a lot of social anxiety, fear of not presenting themselves in the right way or saying the wrong thing or what other people perceive them as.

Chelsey B. Coombs:

As much as the pandemic has had its silver linings for them, Hawkin and Portales are looking forward to parts of life they've been missing during their country's lockdowns.

Briony Hawkin:

I'm looking forward to seeing my partner again. I haven't seen him in a while. It's been since February, since we've seen each other. I mean, obviously we see each other over FaceTime almost every day, but it would be nice to actually hug them.

Raul Portales:

I think next week, all of the McDonald's will be open for takeaway, which will be welcome for my daughter. She's been asking for them for a while.

Briony Hawkin:

The thing I'm most looking forward to in like a couple of years when everything's back to normal, is I had ... This is going to sound a little cheesy, but I had tickets to go see BTS.

Chelsey B. Coombs:

BTS, also known as the Bangtan boys is a seven member, South Korean boy band.

Briony Hawkin:

And that was something I was really looking forward to this year. I was using that as my propelling force to get me through a bunch of difficult PhD stuff. Obviously, I don't think big stadium concerts are going to happen anytime soon, but one day, one day I'll see them in concert.

Chelsey B. Coombs:

Since we recorded these interviews, Portales has taken his daughter to McDonald's. Thankfully for public health, the BTS concert is still a ways away. Thanks so much to Briony Hawkin, Raul Portales,

Matthew Siegel, and Jill Thaudstadt for joining me to talk about their experiences. And thank you for listening to the Spectrum Podcast. If you enjoyed this episode, head to bit.ly/autismaroundtheworld to read the stories of how the initial weeks of the pandemic challenged and changed 22 autistic people and their families in 19 countries. I am Chelsey B Coombs.