

VIEWPOINT

We need better strategies to support autistic people as the COVID-19 crisis continues

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Autistic people have experienced huge disruptions over the past six months. The COVID-19 pandemic has wreaked havoc on all of our lives, but especially so for autistic people, who are often uncomfortable with swift and unexpected change and can struggle with uncertainty about the future. The pandemic has also shuttered or altered the services and supports many autistic people rely on¹.

As COVID-19 took hold earlier this year, my team — composed of autistic and non-autistic researchers — sought to discover what this moment was really like for autistic people and their families. We started talking to them and those who work with and support the autistic community about the COVID-19 lockdown back in March. We **reported our findings** two weeks ago.

We found that some individuals were surprisingly positive. These optimistic voices highlighted the immense efforts they had witnessed on the part of various programs to ensure flexibility and innovation during the crisis — for example, in schools, healthcare systems and social care programs. Some even suggested that these changes were increasing inclusivity for autistic people and their families. For example, moving services online — or “flipping the clinic,” as some colleagues in Sydney called it — made for easier access.

There were also some suggestions that autistic people are more adept at dealing with self-isolation than non-autistic people are: “We self-isolate; we do that all our lives ... autistic people are ready,” one participant told us.

After in-depth interviews with 35 autistic adults, 80 parents of autistic children (35 of these parents were autistic themselves) and 16 young autistic people about their experiences during the pandemic, however, we found that the overwhelming message was not positive at all. We heard again and again how poorly supported many autistic people have been during the crisis.

Participants reported how stressful it is to see their everyday routines “completely messed up,” and they were deeply troubled by the ever-present uncertainty. Autistic adults and young people also told us they missed seeing their friends.

These findings are striking because they fly in the face of orthodox views of autistic people — that autistic people don’t want friends, have little social motivation and prefer a life of self-isolation. Our study shows that clearly this is not the case.

Our findings also show just how important it is that all levels of government develop a targeted strategy to support autistic people as the COVID crisis continues. And autistic people themselves must be involved in developing and delivering it.

In-person connection:

Many of the participants we talked to longed for physical, embodied, face-to-face interactions. Zoom, FaceTime and Discord just aren’t enough. “My friends, I really want to see them. I want to see my friends. In person,” a participant told us.

Some children also showed in other ways that they missed their friends. “He doesn’t have a kind of communication where he tells us that he misses them,” one parent told us. “But sometimes he talks about his friends while he’s playing with little figurines. He’ll call the little figure the name of one of his school friends, so that might indicate that they’re on his mind.”

Participants also described missing broader, incidental social interactions — chats with their co-workers, neighbors, local shopkeepers and the general community.

As one woman put it, “I didn’t realize how important that incidental human contact was to me. It was so incidental that it never really registered on my radar until it was gone.”

She went on to give an example:

“Because I work with an assistance dog, right, so everywhere I go, I’ve got this giant white majestic beast next to me. So, the soundtrack of my life is, ‘Oh my God, it’s a dog. It’s a beautiful

dog. What kind is he? How old is he? What does he do?’ And, like, that drives me bananas most of the time, and I’ve actually found myself even missing that.”

Not being able to have moments of physical connection with others appeared to have a detrimental effect on people’s mental health. Some autistic adults were visibly distressed during the interviews. And many participants stopped receiving therapeutic services during lockdown, only compounding their mental health problems. They reported not wanting to talk to their psychologist, psychiatrist or even their general practitioner over Zoom or by phone.

As one young person described: “I stopped all my psychologist appointments, which was a bad call ... because if it’s an online version of a medical appointment of any sort, I just dread it. And the dread is often worse than not doing the appointment.”

For this young person and a few others, this lack of continuity of care had dire consequences. They saw a rapid decline in their mental health and were admitted to a hospital for acute psychiatric care after an attempted suicide or severe mental health distress.

Continuity of care:

In light of such outcomes, governments and healthcare systems need to ensure that face-to-face support — which is often critical to the well-being of autistic people — is not closed down without adequate alternatives put in place during the pandemic.

Telehealth and distance-learning options have not been good enough so far and desperately need improvement, our study reveals. Because continuity of care is vitally important for autistic people and their families, it must be built into emerging alternatives, such as guaranteed, regular, scheduled and individualized catch-ups with key workers.

The strategy governments and healthcare providers adopt should also help autistic people, and others, to maintain and even deepen their social relationships during these moments of crisis. We already know the huge cost of loneliness and isolation on mental health. Our research shows that it’s the same for autistic people.

The time to develop such a strategy is now. The consequences of not doing so are too serious to ignore.

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If you or someone you know is having suicidal thoughts, help is available. [Click here](#) for a worldwide directory of resources and hotlines that you can call for support.

REFERENCES:

1. Pellicano E. *et al.* (2020) *“I want to see my friends”*: The everyday experiences of autistic people and their families during COVID-19. Sydney Policy Lab. **Full text**