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Guest Editorial

Stepping Out of Isolation: Autistic People and COVID-19

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When I received the e-mail inviting me to author this editorial, I was halfway through my second day of self-imposed isolation. A COVID-19-related lockdown was not yet in place in my area, but I had developed mild cold symptoms and chosen to err on the side of caution. Between responding to e-mails and writing an ethics application, that day I found myself in tears more times than I care to admit. As an autistic adult, the sudden loss of my comfortable work routine was difficult. Coupled with the constant media coverage of illness and death, global lockdowns, and panic buying, the anxiety that I—and ∼40% of autistic people[1,2]—live with on a daily basis had peaked.

I am lucky to have enough privilege that I will likely weather this particular crisis well. I have stable employment that I can continue from home, which will afford me a regular income for the foreseeable future. I am relatively young and physically healthy, meaning that if (or when) I do contract COVID-19, I am at low risk for serious complications. Although I am disabled and usually receive support from various professionals, I am able to look after my own essential daily needs and can get by without that support in the short term to medium term, if needed. I also live in Australia, a country with a robust public health care system that, although far from perfect, is better placed to manage this pandemic than many other countries. And, by lucky coincidence, I bought a bulk pack of toilet paper a week before the panic buying broke out.

Despite all this, I am still struggling to cope with the current state of the world. Spare a thought, then, for those who are likely to fare far worse than me during this crisis.

Approximately 10% of autistic people have co-occurring physical disabilities.[3] We are known to have increased rates of various chronic illnesses and medical conditions.[4] We also show atypical immune responses,[5] and autistic people and our families have high rates of autoimmune disorder.[6] All these factors may increase our vulnerability to COVID-19. Within my own networks, among my friends, I have witnessed the sheer terror that comes with knowing that this pandemic could so easily take your life. Even in the best of times, autistic people struggle to access appropriate health care.[7,8] Now, with health workers stretched to breaking point, ensuring accessible services for autistic and other disabled people is unlikely to be a priority. The horrifying reality is that, in a massively overburdened health care system, health professionals who are forced to choose which patients to prioritize for care are likely to deem our disabled lives as less worthy of being saved.

As we face this knowledge, being able to turn to others for support becomes more important than ever. But, with ‘‘social distancing’’ a key factor in reducing the spread of COVID-19, access to social and professional support systems is increasingly limited. With autistic adults already more likely than nonautistic adults to face loneliness and social isolation,[9] and a well-established association between social isolation and mental illness,[10] any reduction in access to our often-minimal support networks may have significant mental health consequences. Even without the added isolation that will result from social distancing, the experience of a public health crisis is likely to be detrimental to mental health. Recent evidence from those affected by the 2014–2016 Ebola outbreak suggests that exposure to a pandemic may be associated with symptoms of anxiety, depression, and post-traumatic stress disorder.[11] Given that autistic people are already overwhelmingly likely to experience mental illness,[12,13] and nine times more likely than the general population to die by suicide,[14] the mental health consequences of COVID-19 may be devastating.

For some autistic people, particularly young children and those with co-occurring intellectual disabilities, it may be difficult to fully comprehend the COVID-19 pandemic and all its ramifications. For these members of our community, this will likely be a particularly challenging time. Like many of us, they will be faced with changes to safe and comfortable routines; anxious and overwhelmed family, friends, and carers; perhaps even the grief of losing a loved one. But they will also encounter additional challenges. Government advice, often unclear and rapidly changing, is rarely provided in easy-read formats. As a result, autistic adults with intellectual disabilities may be left unable to access vital public health advice. For those who live in group settings or require intensive support, social distancing may prove impossible.

Many autistic adults depend on formal or informal support for assistance with activities of daily living and a range of other needs. It is likely that formal disability services will be considered an ‘‘essential service’’ and will, therefore, remain operational during lockdowns. However, many individual disability support workers may, understandably, need or choose to self-isolate, limiting the support available to the

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disabled community. Without support, some autistic adults may be unable to implement potentially life-saving public health measures such as regular hand washing and social distancing. Others may lose support that they rely on to access daily necessities such as food and hygiene. For those who are still able to access services, the choice to maintain support arrangements may pose a concerning trade-off: by continuing to access the services we need, we run the risk of exposing ourselves (and disability services staff) to COVID-19. But for many autistic adults, particularly those with complex and high support needs, there is simply no other option.

With high rates of un- and underemployment,[15] many autistic adults are also particularly vulnerable to the economic impacts of this crisis, which will certainly be felt for long after the virus itself has passed. Although some governments have introduced economic stimulus measures in attempts to mitigate these impacts, these measures may do little to assist autistic people. In Australia, for example, people paid unemployment or student benefits will receive a ''Coronavirus supplement'' of AUD$550 per fortnight, effectively doubling their income for up to 6 months.[16] At the time of writing this editorial, those who receive disability benefits—including the 74% of autistic Australians who rely on disability benefits as their primary source of income[17]—will not be eligible for that supplement.

Underpinning much of the fear around COVID-19 is a deep sense of uncertainty. This is an unprecedented situation, and we simply cannot know what to expect as the crisis continues to unfold. Online, autistic people have astutely pointed out that this uncertainty, and the anxiety it provokes, is a part of everyday life for many of us. Those with chronic illnesses and other disabilities have observed that little in their lives will change as a result of social distancing and self-isolation measures. Similarly, some have suggested that the requirement to stay at home and self-isolate is ideal for autistic people. It is certainly true that, for some autistic and otherwise disabled people, little in our lives will change as a result of the current situation. In a world that is inaccessible for so many of us, social distancing and self-isolation can be the norm. But for most, this lifestyle is far from ''ideal.''

There is a vast difference between choosing self-isolation out of preference, and choosing—or being forced into—self-isolation out of necessity. Many autistic and otherwise disabled people live lives of isolation not motivated by preference, but motivated by self-preservation. Exclusion, bullying, harassment, and abuse; inaccessible physical and social environments; and a lack of appropriate services and supports can mean that for many, self-isolation is the only option. Now, the broader community is being faced with the circumstances in which too many autistic and otherwise disabled people find ourselves every day. I can only hope that this might engender empathy for our experiences, and prompt more allies to work together with us to build inclusive, accessible communities when this crisis eventually ends.

Encouragingly, the world is already taking steps in this direction. We have seen universities and other organizations around the world rapidly transition to online delivery of teaching and other services. Supermarkets have introduced dedicated priority grocery access for elderly and disabled people. Despite initial conflict and greed, we are now seeing communities band together to support each other, sharing kind words, animal videos, and—of course—toilet paper. These measures are necessary to help all of us get through the COVID-19 crisis. When COVID-19 is behind us, we may be tempted to return to ''business as usual,'' and dismiss these changes as temporary necessities in the face of extraordinary circumstances. But for autistic and otherwise disabled people, these measures could be beneficial far beyond the current pandemic. So before you fall back into old habits and routines, perhaps stop and consider whether your ''business as usual'' accommodates us who live our entire lives outside the usual.

As for me? Well, I have stopped crying now. With half a lifetime of experience managing mental ill-health, I have learned to prioritize self-care during difficult times. I have established a new ''working-from-home'' routine, and it is slowly beginning to fit more comfortably as I wear it in like a new pair of shoes. I am making time for exercise, finding ways to stay connected with those who make me smile, and doing the things that bring me comfort and calm. I am enjoying the extra time spent absorbing my cat's boundless affection. Like many of us, I am being productive when I can, and—perhaps most importantly—I am being kind to myself when I cannot.

In this time of uncertainty, I hope that you will also find space to be kind to yourself, and others. Remember that it is okay to not be okay during this time. While you take care of yourself and your loved ones, I encourage you to also consider what you may be able to do to support the autistic community and other vulnerable populations, both during this crisis and when we eventually emerge on the other side. In return, the autistic community may be able to teach you a thing or two about coping with isolation. Together, let us take this opportunity to create a more connected, considerate world. A world that will allow those of us who live in the margins to step out of isolation, perhaps for the first time.

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