

An Expert Discussion on Autism in the COVID-19 Pandemic

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Jacqui Rodgers, PhD,^{12,13} and TC Waisman, MA¹⁴

Introduction

WE ARE LIVING IN UNCERTAIN times. The COVID-19 pandemic, and the need to stay physically distant from each other, has required us to make very rapid changes to our everyday lives and wider society. The impact of the pandemic will likely be even more significant for autistic people—difficulties managing unexpected change and uncertainty,¹ high risk of vulnerability,² and health inequalities^{3–5} could all be magnified in the pandemic. However, with challenge and change can come opportunity. For years, disability advocates and their allies have campaigned for reasonable adjustments to enable autistic people to better access social spaces, health care, education, and employment. Adjustments we have identified and prioritized together with the autism community, such as making appointments and receiving therapy online, have not been implemented.^{6,7} However, in the current crisis, these adjustments have finally had to happen for everyone, and quickly. This could have the unintended but positive effect of finally addressing longstanding barriers for autistic people's inclusion in society that have been languishing for years.

The current extent of the impact of the pandemic on autistic adults is unknown. An important first step is to identify and discuss the challenges and opportunities that the COVID-19 pandemic poses autistic adults, incorporating a variety of perspectives. This roundtable, therefore, aims to bring together autistic adults, their families, practitioners, and aca-

demics across the fields of disability rights, public health, medicine, psychology, and mental health across different countries and contexts. Our discussion focuses on what we need to be aware of to address the issues of interest to autistic adults in the pandemic now, how we can address these issues, and make tangible recommendations to be addressed in future research, policy, and practice. We also compile a list of recommended reputable resources and initiatives to help support autistic adults in the current pandemic (Table 1).

Dr. Sarah A. Cassidy: *Today, we have brought together eight discussants with expertise and insights into the challenges and opportunities for supporting autistic adults during the COVID-19 pandemic. They each come from different disciplines, across psychology, public health, medicine, philanthropy, and lived experience of the issues at hand. Five of them are autistic themselves.*

I would like to start with asking each of us to introduce ourselves. I am an assistant professor at the University of Nottingham, and I specialize in researching mental health, suicidal thoughts, and behaviors in partnership with autistic people and those who support them.

Dr. Christina Nicolaïdis: I am here today in my role as editor-in-chief of *Autism in Adulthood*, but I am also a professor in the School of Social Work at Portland State University and an adjunct associate professor in Public Health and in Medicine at Oregon Health and Science University

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TABLE 1. REPUTABLE SUPPORT INFORMATION FOR AUTISTIC ADULTS IN THE COVID-19 PANDEMIC

<i>Organization</i>	<i>Country</i>	<i>Type</i>	<i>How to access</i>
Autistica	United Kingdom	Web hub hosting expert webinars and written guides on topics such as managing mental health, uncertainty, creating accessible online meetings, and employment.	https://www.autistica.org.uk/what-is-autism/coronavirus
National Autistic Society (NAS)	United Kingdom	Web hub with a diverse range of reputable resources for autistic children, adults, and their families, such as social stories about COVID-19, and activities to do at home.	https://www.autism.org.uk/services/helplines/coronavirus/resources.aspx
MHAutism	United Kingdom	Website dedicated to participatory mental health in autism research, including the latest research articles, organizations that offer support in the United Kingdom, autism-adapted suicide safety plans, and advice for service providers.	https://sites.google.com/view/mentalhealthinautism/resources
Autistic UK	United Kingdom	Autistic-led organization who have compiled a range of helpful resources for autistic people, including registering as a vulnerable person, benefits and money, and coping with isolation.	https://autisticuk.org/covid-19-resources-centre/resources/index.aspx
Nottinghamshire Autism Police Partnership (NAAPP)	United Kingdom	A group of autistic people, police officers, and academics from across the United Kingdom have created resources, to help police officers support autistic people during the COVID-19 pandemic, and a clear visual guide to help autistic people interpret the new coronavirus regulations.	https://www.nottingham.ac.uk/research/groups/autismandpolicing/resources/index.aspx
Thinking person's guide to autism CHIRP-LA	United States	Autism news and resources, including on COVID-19: from autistic people, professionals, and parents. 'Know Your Rights During COVID-19' guide.	www.thinkingautismsguide.com
Health Affairs	United States	Journal Blog: "Health Justice Strategies to Protect Vulnerable Communities During COVID-19", COVID-19 online toolkit hosting support resources for autistic people and their families, including a national helpline, public policy, and education resources.	www.chirpla.org/sites/chirpla.org/files/u107/Know%20Your%20Rights%20During%20COVID-19%20%28Coronavirus%29.pdf https://www.healthaffairs.org/do/10.1377/hblog20200319.757883/full/
The Autism Society of America	United States	Webinar: "Coronavirus emergency preparedness for people with disabilities and their families"	https://www.autism-society.org/covid-19/?emci=43f65fb-4078-ea11-b1e8&emdi=05701bff-4178-ea11-a94c-00155d03&ceid=837231
Disability Voices United Green Mountain Self-Advocates toolkit	United States	Plain language information on COVID-19 created by Green Mountain Self-Advocates.	http://disabilityvoicesunited.org/cv/webinar-on-coronavirus-emergency-preparedness-planning-for-people-with-disabilities-and-their-families/www.gmsavt.org

(continued)

TABLE 1. (CONTINUED)

<i>Organization</i>	<i>Country</i>	<i>Type</i>	<i>How to access</i>
AASPIRE Healthcare Toolkit	United States	Evidence-based primary care resources for autistic adults and their primary care providers, developed as part of an ongoing research project.	https://autismmandhealth.org/
CommunicationFIRST	United States	COVID-19 communication rights toolkit, developed for patients who need communication tools and supports due to speech-related disabilities.	https://communicationfirst.org/covid-19/
Autistic People of Color Fund	United States	A fund for direct support, mutual aid, and reparations by/for autistic people of color.	https://autismmandrace.com/autistic-people-of-color-fund/
Online support services and apps to stay safe and connected			
Crisis Text Line	United States/ United Kingdom/ Canada	Send a text about any type of crisis, and a live trained crisis counselor receives the text and responds.	www.crisistextline.org
Samaritans	International	Anonymous phone and e-mail support 24/7 for anyone.	https://www.samaritans.org/how-we-can-help/
Kitestring	United States	Checks up on you when you are out and alerts your friends if you do not respond.	www.kitestring.io
Circle of 6	United States	Helps to quickly alert six people close to your location if you need help.	www.circleof6app.com
Health-promoting activities to get involved with			
Coventry City of Culture	United Kingdom/ international	Community project to foster connections and belonging in the United Kingdom and internationally in these times of physical distancing. Inviting pieces describing what connections and belonging mean to you.	http://belong.coventry.domains
Mental Health America, SINCH	United States	#TextForHumanity was created to counter online negativity in the current pandemic. You send a positive message to a stranger and receive one in return.	www.textforhumanity.com
Autistica	United Kingdom	#Ways2Cope was created to help share how autistic people are coping in the current pandemic.	https://www.autistica.org.uk/get-involved/world-autism-awareness-month/my-ways-to-cope

(OHSU). My research interests are primarily around using participatory approaches to include autistic adults in research and improve their health. Clinically, I am trained as a general internist, and I practice hospital-based medicine at OHSU.

Dr. Jacqui Rodgers: I am based at Newcastle University in the United Kingdom, where I am professor of psychology and mental health. I work largely in autism research, with a focus on mental health. My main area of interest is anxiety, and particularly the role that uncertainty plays in the development of anxiety for autistic people, both children and adults. I am involved in the development of assessment tools and interventions.

Ms. Shannon Des Roches Rosa: I am the senior editor of *Thinking Person's Guide to Autism*, which is a website community and book that brings together autistic professional and family perspectives on autism. So everything that I am saying here is deeply informed by communicating with all aspects of that community, autistic people, family members, and professionals. We are also deeply invested in monitoring autism research and neurodiversity best practices for supporting autistic people.

Dr. David Eisenman: I am a professor-in-residence at University of California, Los Angeles (UCLA) in the School of Medicine, the David Geffen School of Medicine at UCLA, and also a professor-in-residence in the Fielding UCLA School of Public Health, where I direct the UCLA Center for Public Health and Disasters. I have been studying disasters and mass trauma and also climate change now for >20 years. I am also a physician in internal medicine with an outpatient practice.

Mx. TC Waisman: I am first and foremost a black indigenous South Pacific Islander who is 51 years old. I was diagnosed at 48 years old. As a result of my late diagnosis, I went back to formal education and I am now currently concluding my doctoral research at the University of Calgary regarding how higher education leaders, faculty, and staff can enhance services and outcomes for autistic students in higher education. As you can imagine, the results of COVID-19 are directly affecting my research at this time.

Dr. Clarissa C. Kripke: I am a family physician on the clinical faculty at the University of California-San Francisco. I am the primary care doctor for medically fragile and behaviorally complex patients with developmental disabilities, and I am director of the Office of Developmental Primary Care whose mission is to build the capacity of the health care system to serve transition-age youth and adults with development disabilities. I am also the parent of a nonspeaking autistic young adult.

Ms. Morénike Giwa Onaiwu: I am an autistic advocate as well as an educator and writer. I am a black woman who lives in the United States of African immigrant descent, and I was diagnosed in adulthood after my two youngest children were diagnosed. I am involved in various leadership capacities with several advocacy and disability groups, including the Autistic Women & Nonbinary Network. I am a peer researcher and I also work as a faculty member at a 2-year college where I teach developmental courses as well as employment skills. I am interested in issues related to autistic

people of color, parenting, gender minorities, meaningful community involvement, research ethics, and autistic burnout and persistence.

Dr. Steven K. Kapp: I am a lecturer in psychology at the University of Portsmouth in the United Kingdom. I research autistic people's rights and needs, including through the neurodiversity movement. An autistic activist, I also directly participate in neurodiversity and disability rights advocacy.

Ms. Bethan Davies: I work as the Events and Engagement Manager for Autistica (the UK's leading autism research charity). As well as managing our events and Discover Network, a big part of my role involves working closely with and managing our Insight Group—300 autistic adults, parents and carers who work with us and researchers, sharing insights and knowledge. I am also autistic myself, diagnosed just after university, and I am currently studying a part-time MA in Medical Humanities, looking at mental health, disability and patient advocacy.

Dr. Nicolaidis: *The first question is to Dr. Eisenman—from your perspective, what are the most important things people need to know about the pandemic right now?*

Dr. Eisenman: Let us start with taking stock of where we are. We have >800,000 cases and 38,000 deaths worldwide. It is a pandemic, but there are different hot spots in different parts of the world and different parts of the United States. Even when we get this under some control, there will likely be flare-ups in different places at different times for years to come.

Countries are using various combinations of and approaches to testing, contact-tracing, shelter-in-place, and social distancing to combat this coronavirus. In the United States, testing capacity is inadequate and social distancing is being implemented locally in some way across the majority of the United States. In fact, 250 million U.S. residents are under some sort of order to that effect.

Another front we are working on globally is trying to deal with the surge of cases that are coming into hospitals, across all countries. Health workers are overwhelmed, leading to their own higher risk of infection, also meaning then that patients do not get the quality care that they deserve, and doctors are talking about having to make decisions about who gets on a ventilator and who does not.

We are now also starting to think about how do we recover at some point from this. Until we have a vaccine, which is optimistically 12–18 months away and who knows if we will ever have an effective vaccine, the future requires some combination of widespread testing and contact tracing, use of antivirals if they are effective, protecting the most medically vulnerable from infection, and going in and out of social distancing measures.

Dr. Nicolaidis: *Thank you. So, given this context, what are the main issues to be considered for autistic adults during this pandemic?*

Dr. Rodgers: From my perspective, as someone who works largely in mental health and autism, we need to be thinking

about the impact of our current situation on mental health for autistic adults. My work shows the huge role that uncertainty has in mental health, and particularly in relation to experiences of anxiety.^{8–9} This is such an uncertain situation for everyone from a very personal level to a much more global level, where things have abruptly become very unpredictable and uncertain. We know that feelings of uncertainty underpin many mental health conditions, so this is one of the main things we need to be thinking about in relation to the pandemic.

Dr. Cassidy: I am also really concerned about the mental health impacts of the pandemic on autistic adults. In contrast to previous research that has unhelpfully suggested that autistic adults lack social motivation, we have shown that autistic adults painfully feel the effects of being socially isolated and lonely, and that has a real impact on their mental health, and risk of suicidal thoughts and behaviors.^{10–13} So I am really concerned that in this time of social distancing, what kind of impact does that have on the mental health of autistic adults? I think it is important to think about how to mitigate these effects, such as using online ways to foster connections, community projects, and what we can learn from the current situation to build a more inclusive society in the longer term.^{14–15}

Dr. Kapp: Maybe it is better to replace the term *social distancing* with *physical distancing*, because there are multiple ways for people to communicate and engage with one another, including for people to receive therapy or to meet with other people in groups or to just chat with friends and get whatever social support that people want and need. To second Sarah, I think that it is important to remember that despite our supposedly being “natural quarantiners” or whatever, that we do often enjoy engaging with other people, including sometimes in person. But there are still multiple ways of interacting with others.

On mental health, our well-being, and our sense of worth, it is important to remember that we are essential, and that government should not discriminate against autistic people and people with disabilities. The U.K. government has, for example, published the National Institute for Clinical Excellence (NICE) guidelines, which include a frailty score that discriminates against people with disabilities in how the government would ration care to fight the pandemic (especially in an earlier form that sparked backlash).¹⁶ No government should discriminate against people with disabilities.

There are potentially lessons for how society can be rebuilt around multiple points of access, such as for how people might deliver conferences and teaching and all sorts of different things that might end up offering virtual participation as an option, not just as a necessity. For some people, a remote opportunity might make the difference for whether they can participate.

Mx. Waisman: That is actually something that is top of mind for me. I know it seems odd to be discussing education at this time, but actually, when we are talking about multiple points of access and we are talking about rationing of care, the opposite is happening now in terms of rationing of care in education. The last two months, as a direct result of the pandemic, a change in student needs has really forced edu-

cation to take a giant leap. We are now experiencing multiple forms of access, which autistic students have been asking for literally for decades as accommodations. We have also been asking for multiple means of measuring outcomes and clear rubrics for all courses. These are now the new foundation of the new era of education, as a direct result of this pandemic.

Dr. Kripke: The three issues that I think are most important are first, doing what is required to stay healthy. That means avoiding disease, but it also means establishing new routines, eating healthy food, exercising, sunlight, maintaining social connections and building new connections, financial stability, having opportunities to be of service, lifelong learning, and freedom from abuse and neglect. The second critical issue is maintaining access to needed services and supports both paid and unpaid. And the third issue is emergency planning for the possibility of autistic people may get sick and suddenly need more or different help, or family or supporters getting sick, leaving autistic people with less access to needed support. We need to be proactive in monitoring evolving support needs because autistic people and family members may not be able to ask for help when they most need it.

Steven pointed out that many governments are using frailty scales as a way of rationing care.¹⁶ I think that frailty is associated with decreased life expectancy and decreased response to medical treatment if the reason for the functional problems is related to advanced disease in vital organs.¹⁷ But many autistic people may have functional problems that are not related to advanced disease and vital organs, and they benefit very greatly from aggressive medical care.

Dr. Rodgers: Just in relation to Clarissa’s point, the NICE guidelines have been clarified—the frailty scale is not validated for people under the age of 65 years and is not to be used for people who have stable physical health conditions, such as cerebral palsy, or disability *per se*, but more in line with Clarissa’s interpretation.¹⁶

Ms. Des Roches Rosa: I have been very much appreciating everything everybody is saying. I am the parent of a 19-year-old high-support autistic young man who requires one-to-one support, so I am coming at it through that lens. It is very difficult right now for many of us parents whose children require one-to-one support, and it is difficult for our autistic loved ones, too.

Thinking Person’s Guide to Autism is getting across the message that we need to be very gentle with our kids at this time, and support them through this transition, because transitions can be very very difficult for autistic people. In the parent community, we see a lot of supports that do not necessarily tune into autistic-informed ways of supporting our kids, and so we are trying to emphasize that kind of gentle and informed support. So, understanding things such as the need for safety and consistency, upping things like using visual schedules, using a calm and very warm tone of voice, because so many autistic people are what we call emotional resonators, and if somebody who is their caregiver is being agitated, then, at least in my son’s case—not everybody’s case—that is going to be exacerbated and make things worse.

Helping make sure that they understand that not everything about the way an autistic person behaves is about being autistic, being very careful, especially during this time of COVID-19, to be on top of medical conditions and how those might affect the way a person is reacting. And also being aware that autistic people do not necessarily react the same way as nonautistic people do, because of interoception and other issues, to the way that other people might respond to being ill and being very careful about that.

We also just want people to be very very chill and in tune with the way that their autistic loved one or self is dealing with pandemic-wrought changes, and give them lots of processing time, give them lots of space, make sure they have space to do their own thing, and feel safe. I think that with everybody in close quarters, it is more important than ever to be just very calm, very supportive, and let your autistic loved one—and yourself, if it is for you—be safe and have a safe space. Make sure you can do that and be reassuring to the greatest extent possible.

Ms. Giwa Onaiwu: One major concern that I have is that during this pandemic, autistic adults are facing increased vulnerability. If a person is in a situation where they might be partially dependent upon other people, in toxic, emotionally, and/or physically abusive relationships, or any type of circumstance where there is an imbalance of power, the already insufficient options and resources available to them are significantly reduced. You no longer have the ability to get away, even momentarily; you no longer have a reprieve from that life. You are, essentially, trapped there with these individuals. It is very difficult to safely and secretly obtain resources and/or seek outside intervention due to changes caused by shelter in place mandate.

There is huge economic instability. I have five children who are all home with me, two of whom are autistic, like I am, and the others have various disabilities as well. As you are at home now for an extended period of time, you are spending more money because you need to purchase larger quantities of food, drink, household products, personal hygiene items, and other necessities. Supplies might be rationed or otherwise limited due to excessive demand, which results in higher costs for certain items if you are fortunate enough to find them at all. Utility bills are likely higher than usual due to increased usage of electronic devices (for teleworking, virtual schooling, recreation, accessing telemedicine, etc.) on top of cooking, bathing, and voiding plus running the heat or air conditioner longer due to more people being at home for more hours of the day.

Job insecurity. Every day we are seeing reports on the news about the layoffs around the world, fluctuation in the stock market, businesses on the verge of bankruptcy, and record levels of unemployment. Economists are likening this period to the Great Depression. Many people do not know whether they are going to continue to have a job or not nor how this pandemic is going to impact their livelihood with regard to having a place to live and being able to have health insurance.

Another area of increased vulnerability is the prospect of heightened government encroachment in various ways. In some places they are using apps to determine whether or not a person who has symptoms of COVID-19, where they are and where they are going, whether a person is sheltering in place or not, and checkpoints if you are leaving your home. This

could put a person at risk of having more interactions with police officers, and we are individuals with communication disabilities! So this is already an uncertain time with a lot of stress and anxiety for everyone, but for us, it is heightened, and even more so if in addition to being autistic you are a nonspeaking individual and/or a person of color and/or queer and/or a person with very visible noticeable stims. Perhaps you are out trying to fill a prescription at the pharmacy or purchase food at a grocery store—all places you are allowed to go—but perhaps something goes wrong. You become overstimulated, there is considerable stereotypy in your movements, and you become ill. Anything can happen. Or perhaps you simply have a question or a concern, but you do not communicate it in a way that is clear and understood to someone who is neurotypical. Things can very easily and very quickly escalate because others may misconstrue the situation. Now you could potentially be at risk for fines, arrest, or even physical harm...all because people do not understand that we might present differently.

Mental health is another area of concern because people are inundated with information, guidelines and recommendations are constantly changing, and anxiety and depression are rampant. People face challenges accessing supports, they worry about themselves and their families, and they deal with a sense of uncertainty about what is going to happen in general.

Physical health can also be impacted. Despite protective wear, sheltering in place, and social distancing, it is still very possible to be exposed to COVID-19 at a gas station, grocery store, or through other means. However, the risks are not limited to external locations; there is the potential risk even if one does not leave the home. With more people at home for lengthier periods of time, the likelihood of an accidental fall or collision increases. People might have to skip meals or ration their medication due to limited finances or scarce resources. There is also the risk of tempers flaring due to people being in close quarters around one another all the time as well as contracting other illnesses, not just coronavirus, from one another. Many autistic people do have other health conditions outside of just our neurology as well, and with hospital emergency rooms and intensive care units overflowing with COVID-19 patients, it is hard to discern whether you should seek medical care for nonrelated physical injuries and/or psychological crises. The other day I was bitten by a spider so I got on the Internet trying to determine what to do and eventually decided, “Okay, if it was not a brown recluse, I am good,” because are you really supposed to go to the emergency room or to the urgent care or to the doctor for “nonemergency things”?

Another important issue is disrupted routine, which basically impairs productivity, executive functioning, stability, and cognition, as others have mentioned. Moreover, limited or changes in access to helpful supports can be very problematic. If you were a person who was allowed to telecommute in the past, now everyone is telecommuting. Everyone is teleworking. Now you do not really have an accommodation anymore. Now, the way you used to communicate with people is what everyone is doing, so it is overwhelming. It has changed. Maybe you cannot access certain medicines or certain foods or supplies or places that help you to self-regulate. Maybe you only eat certain things or only wear a certain brand of socks, and you now cannot get those things.

Maybe you are an autistic adult who is pursuing higher education or occupational training, and now your program has been hurriedly converted to an online program. Will it be sufficient for your needs, or will you struggle due to the change in delivery, new expectations, and/or the inability to utilize academic and/or disability resources on campus you might have benefited from before the pandemic. Perhaps you are a parent of school-aged children who are now at home with you because most schools are closed. Do you, as an autistic person, presently have the capacity, the executive functioning, the time, and the “spoons” to effectively educate them with little assistance from their school? What if said children have an individualised education plan/receive special education services and or physical, speech, occupational, or other therapies that are no longer readily accessible (everything cannot be done effectively through telehealth)?

Ms. Davies: The uncertainty—all these questions that do not have answers. A big question for many people seems to be “how long is this going to go on for?” which causes so much more long-term uncertainty, as well as uncertainty over, “Am I doing this right?” All the social rules that autistic people kind of learn to follow, like when to go in a supermarket, how you behave in a supermarket have completely changed. There is a whole new rulebook to follow now for life while social distancing.

As other people mentioned, lack of support and routine is a big issue for many autistic people and their families. So normal anxieties have been massively exacerbated because people are anxious much more about their family members, running out of food, running out of medicine, uncertainty around what is happening.

Not only have they lost access to support, but they do not have necessarily their safe foods that are of the right texture for them to eat, or they cannot go for a run, which is the way they process emotions, or they might be in a house with five other people and they cannot get alone time. So it is actually, the long-term impact of losing a lot of coping mechanisms and what that might mean for people.

Dr. Cassidy: *What was really interesting was that many of us talked about the potential opportunities that this very unusual situation has led to. It has forced us to look at alternative ways of supporting people, different forms of communication, and accessing social spaces, having now to utilize things that autistic people have been asking for decades in education contexts. Perhaps we could capitalize on these new ways of communicating and connecting with each other, which are becoming the new normal.*

What are people already doing to address the issues that we raised? How are people supporting themselves and one another? And what kind of resources is available?

Mx. Waisman: In our online autistic community, around education, there has been this discussion about how this has really irrevocably changed our case for socially just and accessible education. The common feeling has been that these accommodations that we have asked for in education have always been there, and now they are suddenly available, because able-bodied people need them. This really foregrounds the two-tiered privilege system that always existed between so-called normal students and other students. So,

what I am seeing is that this is a really great opportunity for us to be able to be included in the decision-making process for changes in policies and practices in higher education. We now have the platform of what is possible for all types of learners in education. There is evidence being collected. We can say, “This does exist.”

The infrastructure was able to come into existence very quickly and very nimbly, even though I have been told throughout my 3 years of research that it is not possible. And many autistic people have been told for many years before that that it is not possible. It is possible. What was missing just seemed to be the will to change. So, there is a great opportunity here in education, as far as I can see.

Ms. Des Roches Rosa: At Thinking Person’s Guide, we have been very grateful for many the resources that have been put out by people such as—Autistics 4 Autistics Ontario put out a plain language guide to coping with COVID-19, also with pictures. CommunicationFIRST put out a fantastic guide about supporting your rights (see Table 1).

Our local Parents Helping Parents (PHP) support group has been looking out for many of the lower income families—who do not have money, do not have Internet access, and do not have any space. PHP has been trying to raise funds to support these families. So if people need help or support, I think looking to organizations in your community is important to remember at this time.

There is another resource that autistic adults can use during this time called IAmFine.com (Table 1). It is a resource that, if the person does not check in at least once a day, it notifies people in their trusted circle that they have not checked in to make sure that somebody is monitoring that person’s well-being.

Dr. Kripke: There are things that we all know we should have done a long time ago that this crisis is forcing us to pay attention to, and one of them is emergency planning. Disability Voices United and the Office of Developmental Primary Care have come together to create a tool to help families and people with disabilities make emergency plans for themselves, and with specific advice on how to keep safe if you need service providers in your home (Table 1)

This is also a really good time for autistic people to take a look at the AASPIRE toolkit (Table 1), and to create an accommodation letter in case you need to go to the hospital, because that will be critically important if you need medical care in this time of crisis.

Dr. Kapp: The neurodiversity movement actually has mostly taken place online,¹⁸ and the term *neurodiversity* was even coined online.¹⁹ Some of my work on computer-mediated communication looked at preferred modalities of communication that people had. We found that the Internet tends to help autistic people to communicate more so than nonautistic people, for reasons such as giving people more time to think and opportunities to meet similar others, that things are written down, etc.²⁰ We also looked at modalities, such as blogs and forums, that autistic people tended to enjoy more than non-autistic people. But there is a misconception that autistic people might only prefer to communicate online rather than in person. Many autistic people still liked in-person communication strongly, but just as a group, less so than nonautistic people.²¹ I think there are opportunities for meetup groups to be online.

I think this has also been an opportunity to think about remote therapy, for example, phone or video based. It could potentially be easier, for example, to take notes if you are at a laptop, than if you are face to face with someone. So it could help autistic people who have executive functioning challenges as well as emotional regulation difficulties to keep organized. This is how some therapies that are publicly available here in the United Kingdom are being administered now, which gives me hope for my own therapy.

I was in a department meeting, and I think it went really well, actually. Being online enabled certain types of silliness or variety that we might not have had otherwise, even though it would have been nice if we could have met up in person. But it probably in some ways made it easier, no matter where we were at that time, we could all, as long as we did not have a schedule conflict, participate there in that meeting.

Ms. Davies: From an event perspective side, this has really been a huge challenge, actually having to move events, which are kind of quite a traditional conference layout online. How do we get it so people can network online and actually build those relationships with strangers, too? That is a big part of conferences. This is something which we need to solve now, which is really challenging, but also really exciting. Once we have got these ways worked out, in place, they are there forever. It is not just events, but things like focus groups, workshops, involvement opportunities, and if we are involving autistic people now, including their feedback, and sharing information during the pandemic, we are setting ourselves up for long-term improvements.

Dr. Rodgers: I agree. We have got a number of mental health intervention studies that are partway through, and so we have been trying really hard to keep going with that research. What we cannot do is see people face to face, which is what we were doing before the pandemic. So now we are looking to how we can adapt our methods and actually go to more remote delivery of psychosocial interventions, and also collecting information and undertaking assessments with participants, both autistic adults and also parents of very young autistic children. It is something that we have always thought we ought to be getting on with, and we ought to be better at this. The current situation has forced our hand, because we have a duty of care to those individuals who are in treatment trials to keep going as best we can. I think, hopefully, that will be a legacy that will remain with us beyond the current crisis, and something that we will not go back from. It really makes the whole process much more inclusive and accessible.

Dr. Eisenman: From my perspective as a public health planner, I am thinking about how during public health emergencies, the social determinants of health become social determinants of vulnerability, and that the public health response to any kind of emergency or disaster begins pretty much as a fairly blunt tool, the kinds of recommendations that issue from public health authorities. In their most basic form, they tend to overlook anybody whose overall inclusion in society is already reduced. These disasters amplify the susceptibility to harm that many people might experience on a daily basis.

As a public health planner, I am thinking about adults who have intellectual or developmental disabilities broadly who

are increasingly living independently in the community instead of living with their families, or decades ago were living in congregate care settings, and how we, as public health people, cannot rely upon the same network of support that administrators of congregate care facilities or families to prepare and protect these people. So when we are talking about these basic measures for physical distancing—which I agree is the better term than social distancing—I am thinking about, how do we reach these adults so that the messages can be implemented? How do we then balance the need for physical distance in those measures with the need for ongoing support and protection? All the social networks that people have now become also vectors of disease. Our vulnerability and our desire to help others become also a dangerous risk of hurting others, insofar as we break physical distancing or contaminate surfaces and so on. I am also asking myself—as I hear you—how do we advise such adults, their support networks, so that they can be quarantined if exposed, and what support services will they need if that happens? And then if, down the line, they have to isolate with a mild illness, because the hospital will not take them with a mild illness, what will those adults need, and who will provide it?

Dr. Kapp: Autistic advocate Ari Ne'eman has issued policy guidelines in response to the pandemic, both for access to prescription drugs and critical medical care, but also social support.^{22–24} The latter includes that the overtime restrictions for support workers should be paused, so that the support staff can work the hours that people need, and that allows family caregivers to work as support staff and to be paid for the work. This is something that people with disabilities have been advocating for many years, anyway, which acknowledges the labor that goes into natural support that many people with disabilities receive from our family members, and formalizing it a bit more, to pay people and keep families afloat.

His connected advice is to relax physical distancing guidelines enough for people with disabilities in hospitals, to enable support staff or a family member be by their side at a stressful time.²³ This could avoid someone melting down and getting agitated and unjustly physically restrained, and so on.

There have been different guidelines that I think should be looked at closely. I think where applicable these should be kept and adopted beyond this crisis period.

Ms. Des Roches Rosa: We have definitely been seeing a lot of agitation among family members of people who are living in congregate settings. The disability community has been fighting against congregate settings for a very long time, but we have to deal with the reality that people are in congregate settings, and we have to deal with how to support them now. We are seeing things like family members who live in group homes. They usually come home on the weekends, and now they cannot, and now they are not allowed to see their family for an indefinite amount of time.

If the kind of rules that Ari and Steven are talking about gets enacted, I think that would be something that could not only help ease the burden of caregiving and help people who are in these situations who are stressed out get the kind of support they need, but it could also just really help with mental health issues for people whose routines have been disrupted.

Dr. Kripke: For people who need personal support, access to protective equipment such as masks and gowns and gloves and eye protection is critically important, whether you live in a congregate care setting, or you live with family. If caregivers cannot protect themselves, then they may not be willing to provide care. Also, they are going to get sick, in which case they will not be able to provide care. That is creating different types of crises where people are abruptly removed from their home into a quarantine center or an isolation center, if we have even set one up for them, and that can create its own vulnerabilities.

I also wanted to circle back to some of the discussion about how many new opportunities there will be for education, networking, professional development, and even for accessing basic health care through telehealth. This brings up the digital divide, access to broadband Internet, and access to computers. People with disabilities, and especially communities that speak languages other than English can be very much left out of that innovation and left out of the tools that we have to connect. They can actually be cut off from medical care and basic services by not having a computer, adaptive equipment, accessible websites, and broadband Internet access. We need to solve that now.

Dr. Cassidy: *What do you recommend going forward to actually address some of the issues that we have identified?*

Ms. Des Roches Rosa: People are coming out with many guidelines and resources. I think the thing people need to realize at this point, even though the entire world has upended, is it has only been a few weeks, so this is all still fairly new for many of us. So many of these best practices are going to keep evolving. I think what we need to do is help people vet their resources, so as these resources unfold, people know what the reliable resources are, because they are going to have to keep going back to them (Table 1).

Dr. Cassidy: *We will consolidate a range of reputable resources to include in a table with this roundtable (Table 1).*

Dr. Kripke: I think that this is an opportunity for us to come together as a community for mutual support. It is an opportunity for us to really see and hear and understand each other and our various needs and to send a message that no person can be left behind in this crisis and in our community.

It is also an opportunity to think about some of our long-term policy objectives. One is the very bad policy that limits funding for Speech Generating Devices to equipment that does not have additional features beyond speech generation.²⁵ Computers and tablets in general are not considered durable medical equipment because they can be useful outside of this context. This limitation ends up costing the government much more and also restricts access to effective communication for people with disabilities by limiting reimbursement to high-end customized speech generating devices. These devices tend to cost in excess of \$10,000, whereas the advent of low-cost tablets and iPads and specialized communication apps has meant that communication access can be provided for a tiny fraction of that amount and in a much more integrated and practical manner. Centers for Medicare and Medicaid Services's (CMS's) rule is terrible public policy, and again, something that we need to address to

lower the technological and digital divide for people whose speech is not reliable.

I think that, as people are unable to go to congregate day and vocational programs, this may be an opportunity to restructure our service systems in ways that can provide more individualized program designs for better community integration.

I think that this crisis is also demonstrating why shared bedrooms are a huge safety problem. New CMS's Home and Community Based Settings regulations require people to have their own bedrooms and a locked door. This is critically important—because we cannot keep people safe in homes where they have shared bedrooms right now.

This crisis may be an opportunity to close some underperforming services and autism therapies. People may lose some therapies and realize that they were not as helpful as we thought they were, and maybe we can redirect some resources to things that are more useful and that the autistic community needs more.

Dr. Eisenman: Clarissa raises a point that is new to me. It worries me when I hear that there are going to be so many challenges for autistic adults to actually quarantine or to isolate if and when that time comes if they are sharing bedrooms for instance. We are talking about millions of cases worldwide. If the simple thing of even having your own bedroom is not standard, that means that by default those individuals are going to be put into isolation facilities and quarantine facilities.

Then you raise all the issues that were raised earlier about providing support to those people, so that family members and other support workers can help to reduce agitation. The system is just not built for that, not unless we, groups, and people advocate with their hospitals and, most importantly, their public health departments, which are going to be running those centers. It will be hard to get exceptions to the rule that family members are not allowed to be close to a sick individual. I think it is better to be proactive and to really be working with your public health directors right now, before we start to have cases like this, where people are truly physically isolated against their will from their family. They will be in quarantine centers or isolation centers, where they will congregate with people who may not know how to work with them.

Ms. Davies: I think it is quite important to get a balance in terms of helping today, next week and in the future, changing things that have been broken forever. There are many adults who have lost their entire structure, and do not see how to get to the next day. So, a big recommendation would be how can we help people tomorrow? How can we help people in the short term to use what we have available already, and adapting it to the current situation?

Dr. Rodgers: I agree with Bethan and David. Although obviously we are in the middle of this specific crisis, I think it really highlights the fact that we do need to have crisis management plans that do include and are designed for autistic people, which can be adapted to the nature of different crises. Unfortunately, what this current situation has highlighted is that there are huge gaps in provision and also in our recommendations for how to support autistic people now and in any future similar crisis. I think it has really highlighted that we are starting from a position of really not having any particular recommendations to make in relation to the kind of

public health or service level to help needed to support people. So I think that is something that we should be really recommending we develop going forward.

Dr. Cassidy: *Perhaps there is a way of combining what we are learning and the issues that people across services and across countries are experiencing, so this kind of opportunity for rapid learning is not lost, and if something like this does happen again or continues, that progress is actually made rather than still unearthing the same issues.*

Ms. Des Roches Rosa: Always make sure that your resources are informed by the autism and disability community. Even now I am seeing many articles on how to support autistic people during this crisis that are formed by normalization types of approaches as opposed to autistic-informed kinds of approaches, and that is very worrying to me.

Ms. Davies: I agree with that. Also, we find that consulting with autistic people in itself can be a type of support. I think a lot of people out there feel unheard. By giving them a voice and a chance to say what their worries are, what their thoughts are, and what support and help they actually want can be quite healing in itself. It can be a very positive thing to do.

Ms. Giwa Onaiwu: It is of critical importance that we ensure the suggestions and policies that are offered are truly inclusive. There is a lot of information about what is accessible and what is available or what people can do. But many assumptions are made: that everyone is in the type of job where they are allowed to telecommute as opposed to having to physically report to work, that everyone has unlimited access to broadband Internet and familiarity with numerous forms of technology, that everyone has the executive functioning to already have a functional contingency plan in place, that everyone has reliable transportation, that a surplus of emergency supplies will be available, that we can all easily obtain and communicate the information necessary to utilize insurance, that we can access telehealth services, etc. We should not assume everyone's socioeconomic status, communication, technology access, or family composition is the same. Instead, we should strive to think more creatively so that we can provide additional options and resources that are inclusive of all people, including those who might need more support.

There is a very white collar neurotypical view as well as a Western perspective on many of the suggestions generally found in the media and/or in the public discourse about COVID-19. Ableism is quite prevalent; it is very common for people to openly complain about having to "resort" to things such as virtual meetings, telehealth, online education, virtual gatherings, and related tools temporarily during this pandemic. Despite the fact that many of these resources are a life-changing accommodation for many people, ensure greater accessibility, can maximize productivity, and are often extremely cost-effective, there is an implication that society is only embracing these things out of desperation. They seem to be perceived as a consolation prize of sorts, because people cannot do things the way they are accustomed to, which is apparently the preferred and "real" way.

Dr. Cassidy: *How can we make sure that our recommendations that we have talked about are implemented? What*

kind of challenges and opportunities are there? What are the practical steps that we need to take right now to help us make progress?

Dr. Kapp: We can incorporate some of these online opportunities for access into universal design. The Society for Disability Studies had been debating for years about having its conference allow online participation, to remove barriers to attendance, such as the large financial and time commitment to attend a physical conference at a set time. They increasingly facilitated online participation to the point that their annual conference carried on by Zoom in early April when others cancelled.²⁶ Why should conferences not allow remote participation in general wherever they can? For teaching too, sometimes students might be ill and might not be able to come in. Maybe all of the lectures will need to be recorded. Employers and universities have had to make all sorts of accommodations and adaptations now, and have shown that they definitely can do them.

There are so many issues with congregate settings. If we think beyond autism, it is not just group homes, institutions, or developmental centers, but there are also nursing homes and even prisons. All these congregate settings are hotbeds for infection, but also for mistreatment and abuse. We all—not just people with disabilities, but also elderly people and incarcerated people—have human rights. We need to think about not warehousing people and dehumanizing them, and giving people enough personal space beyond just pandemics like this.

Ms. Giwa Onaiwu: Good point, Steven. I like the idea of incorporating certain strategies into the principles of universal design as a viable option for individuals overall, not just during this pandemic. I also agree about the problem of warehousing people. This also applies to "residential facilities" for foster care, mental health centers, those who are in the juvenile "justice" system, and immigrants too. Also, regarding government encroachment, I am very concerned about how it can disenfranchise people due to the racial and ableist biases that exist in society. People already unjustly profile and call 911 on people of color and disabled people for things that are not crimes; why wouldn't they do so if they "suspect" someone is violating a shelter in place order? I worry if this behavior is a possible precursor to quasi-martial law in some communities, keeping in mind the incidents that occurred in Ferguson, Missouri, in 2014, New Orleans in 2005 (after Hurricane Katrina), in Soweto during the apartheid era, in the Philippines in recent years, etc?

Dr. Cassidy: I agree, Morénike. Colleagues of mine in the United Kingdom are also concerned about how police will respond to autistic people and those with disabilities in the COVID-19 pandemic, who perhaps need to go out more than once a day to exercise for example. At the time, going out more than once a day contravened the new U.K. coronavirus legislation, and would have given police powers to arrest autistic people and those with disabilities who did this.²⁷ However, this legislation was challenged by autistic people, those with intellectual disabilities, and their families, compelling the U.K. government to add a clarification to the coronavirus legislation—now, anyone can travel for a medical need, including autistic people and those with intellectual disability who need to travel to a quiet location to exercise,

and more than once a day if needed.²⁸ The Nottinghamshire Autism Police Partnership (NAAP) has also developed guidance for the police, to help them be more aware of the potential impact of the coronavirus regulations on autistic people, and how to help support autistic people during this time (Table 1).²⁹ The situation is developing rapidly, and we should continue to monitor and challenge government legislation where this is discriminatory.

Mx. Waisman: I would love to see something like an Autism in Adulthood Journal think tank, like those of us who are involved here at the roundtable. We come from very different perspectives, all representing ways in which things can move forward very rapidly. I would love to see a resource where there are evidence-based suggestions for everything, for health care, for education, for movement in the medical world in real time addressing topics such as what I can do for myself as an autistic person who might have to go to a hospital, you know, things like that.

Ms. Davies: And just adding to that, I think now is the time to be experimental, too. Try things that we do not know if it is going to work, to see what might work and what doesn't. At Autistica, we are doing several different trial runs of virtual meetings to see what works best for autistic delegates for example and building that learning into resources we can share with others.³⁰

Dr. Nicolaidis: Thanks, everyone. I have been hearing many common themes today. First, each of you brought up very important concerns. Some of these issues may apply to everybody during this pandemic, but they are especially heightened for autistic adults:

- Dealing with uncertainty, changes in routine, loss of long-standing coping mechanisms, increased social isolation, and lack of connectedness stemming from physical distancing.
- Increased vulnerabilities, especially with regard to people needing to stay trapped in a toxic environment, increased economic instability, job instability, and the concerns around heightened government encroachment.
- Increases or flare-ups in co-occurring mental health issues, including anxiety.
- Challenges in recognizing acute illness or managing co-occurring physical health issues.
- Increased need for informal and formal supports, coupled with potential loss of access to regular supports.
- Challenges in providing skilled in-person supports and protecting supporters when autistic adults who need high levels of support get infected and need strict isolation.
- And concerns that rationing of health care resources may discriminate against people with disabilities by confusing measures of frailty with disability-related functional challenges.

I have been impressed with what people are already doing:

- On the personal level, just being aware of increased needs, including the need to chill.
- At an organizational level, creating, compiling, and vetting resources (see Table 1).
- Raising funds for autistic people and families who are experiencing economic hardships.

- Checking in on people living alone (e.g., using www.IamFine.com).
- And creating and disseminating tools to help people with disabilities plan for emergencies (e.g., <http://disabilityvoicesunited.org/cv/webinar-on-coronavirus-emergency-preparedness-planning-for-people-with-disabilities-and-their-families/>) or ask for accommodations in health care (e.g., www.autismandhealth.org/ahat) (Table 1).

Moving forward, the group has brought up many great suggestions:

- Being kind both to ourselves and to our loved ones who might be experiencing increased stress.
- Creating credible resources and tools that are informed by the autistic community and the disability rights community. And making sure that we are using a lens of accommodations versus normalization.
- Increasing access to remote therapies. Making sure that online events, courses, or therapies are inclusive, in terms of both disability and other social determinants.
- Being aware of and helping to decrease the digital divide; changing policies about what types of Augmentative and Alternative Communication can be reimbursed.
- Advocating for ways to pay family caregivers to work as support staff; ensuring access to personal protective equipment for caregivers; and relaxing physical distancing guidelines for autistic adults with high support needs, especially in hospitals.
- Creating short- and long-term crisis management plans for autistic people.
- And making sure that autistic people are included in developing any recommendations, policies, and guidelines.

Finally, we heard that the pandemic is also creating important new opportunities:

- For people coming together as a community.
- For making some of the accommodations that autistic people have been asking for, for years, actually happen.
- For creating alternative ways to communicate with each other and access supports, therapies, education, and social spaces.
- For ensuring that some of the remote participation options that are suddenly possible continue to be available after the pandemic.
- And for experimentation. This is a time when everybody is trying new things, and this may be a time where we can really figure out how best we can increase inclusion of autistic people in society.

Dr. Cassidy: Thank you to everyone for joining us today—we hope that the outputs of our discussion will lead to new learning, research, and changes to policy and practice to better support autistic people in the current pandemic.

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