



ADA Live! Episode 90: How Public Health Monitoring During the Pandemic Can Affect Disability and Minority Populations

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Speakers: Lydia X.Z. Brown & Ridhi Shetty, Center for Democracy & Technology; Paul Harpur, the University of Queensland

Host: Dr. Peter Blanck, University Professor at Syracuse University and BBI chairman

Lydia Brown: Hi, I'm Lydia Brown.

Ridhi Shetty: Hi, I'm Ridhi Shetty.

Paul Harpur: I'm Paul Harpur and you're listening to ADA Live.

4 Wheel City: (rapping) Yo. All right, let's roll. Let's go.

Barry Whaley: Hi, everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, I want to welcome you to ADA Live.

I'm Barry Whaley. I'm the director of the Southeast ADA Center. As a reminder, listening audience, if you have questions about the ADA, you can use the online form at ADALive.org.

Marginalized communities including people with disabilities, minority populations, and people who identify as LGBTIQ+ have been the hardest hit by the COVID-19 pandemic, and historically are often the least protected from public monitoring and data outreach.

To understand the effects of COVID-19 on society and the role of technology in responding to COVID-19, the Social Science Research Council, the SSRC, a United States based international non-profit organization advancing research in social sciences and related disciplines, with support from the MacArthur and the Ford Foundation, established the Just Tech COVID-19 Rapid Response grant.

We are fortunate today to have as our guests two recipients of the COVID-19 rapid response grant. Our colleague Dr. Paul Harpur at University of Queensland in Australia and international distinguished fellow at the Burton Blatt Institute and our boss, Dr. Peter Blanck, university professor and chairman at the Burton Blatt Institute at Syracuse University.

Also joining them are Lydia Brown and Ridhi Shetty of the Center for Democracy and Technology, who'll discuss critical questions and provide a framework for technological solutions to pressing issues like remote education and public health policy. The grant project will focus on the unequal impact of social and political power on marginalized communities including people with disabilities and minority populations.

So welcome everybody to ADA Live and as always, Peter, it's my pleasure to turn it over to you.

Peter Blanck: Thank you, Barry and welcome, Paul, Lydia, Ridhi. It's really great to be with three important thought leaders today who are having real world effects at the grassroots level at a time in which we are living in a pandemic, COVID-19 pandemic, which is changing the way we all live and work and creating new norms about social, economic and civic activities that we all took for granted in many ways prior to the pandemic.

Paul, Lydia and Ridhi, each are working at different aspects of ensuring social inclusion, civic participation, fair and equal participation under anti-discrimination laws, such as the laws in Australia or here in the United States under the Americans with Disabilities Act. So welcome to you all and I would start with Paul please.

Tell us a little bit, Paul from down under, you have just received this social science research council grant which is focusing on technology and responses, rapid responses to the COVID-19 pandemic. In what ways are you focusing your research and shaping your response from a technology and other point of view to the COVID-19 pandemic?

Paul Harpur: Well, thank you, Peter. What we have been looking at is how the COVID-19 health surveillance and technological interventions are impacting on our marginalized groups such as persons with disabilities, people with LGBTQI2+ and other minority groups. These groups are the hardest hit by the virus, at the same time, the least protected by surveillance over reach by technology. So the unprecedented health, social, economics challenges created by the pandemic require analysis backwards retrospectively and also considering how can we protect these groups.

We have four overarching research questions, in this, looking at how has COVID-19 impacted, how it's altered existing social norms, regarding health surveillance in public spaces, how these new norms are creating new sites of disablement and whether people that are now essentially disabled by these new systems who previously weren't, whether they are interested in claiming the mental disability. You see that a lot with older people who don't identify as having a disability even though they could claim it in lots of situations. Finally, we're looking at how the changes brought about by the COVID-19, how norms in society will shift, how minority groups are seen by other groups.

Peter Blanck: Well, thank you, Paul. I wanted to dig deeper a bit, in a little bit on those important topics. But first, I wanted to turn to and introduce the very important work being done by Lydia and Ridhi at the Center for Democracy and technology. Like you, they are working at the leading edge of issues facing marginalized groups particularly in the area of democracy and technology. They focus very much on online algorithms driven programs, whether it's in hiring or applications to universities or in receipt of social benefits.

Thank you, Lydia and Ridhi for participating and I turn to you both as a team to explain please a little bit about your important work and how it also dovetails at a time of great trauma under the pandemic.

Lydia Brown: Thank you so much for having us, Peter. This is Lydia. Our work came out of a recognition that in the disability community, many advocates are not necessarily focused on issues caused by algorithmic or artificial intelligence based discrimination and at the same time, our communities are uniquely and particularly vulnerable to discrimination and negative disparate impact caused by algorithmic discrimination.

Likewise, the folks who are working in tech spaces often are not approaching their work with an understanding of disability, of the disabled community's priorities or experiences, or bringing a disability rights or disability justice perspective to the work that they're doing.

And while, in the last several years, there's been incredibly important conversation about algorithmic discrimination along other axes of marginalization especially around race and around gender, there hasn't been as much conversation about the impact on disabled people and particularly disabled people who live at the intersections of multiple forms of marginality, disabled people of color, disabled women, disabled queer and trans people, all of whom may face forms of hidden discrimination masked by code that affects our lives in untold ways in every aspect whether from the benefits that disabled people often rely upon to the ability to get hired for a job and to the ability to receive quality competent and respectful health care.

Ridhi Shetty: This is Ridhi. Just to add to what Lydia just described, we're seeing all these issues just being further exacerbated at this time. All the ways that we normally see algorithms being used, they're being relied upon that much more heavily now, when it seems that other options are far less available.

They're perceived as a good substitute or replacement for a lot of the in-person processes that would otherwise be handled, but right now, they're actually exacerbating a lot of the disparities that were already existing before the pandemic. As Lydia mentioned, these already existed along multiple axes and despite this perception that they are improving processes, they're actually really not.

Peter Blanck: Thank you, Lydia and Ridhi. That's really important and fascinating work. Have you heard of or seen without saying names actual cases of discrimination or instances of discrimination in this regard, since you've written that report or prior?

Ridhi Shetty: I'll just start with in particular over the past year, when it comes to benefits determinations, I think the disparity has not necessarily been specifically in the way that the determinations have been made, but in how heavily they're being relied upon and the delays that are being worsened because of staffing issues and that increased reliance on these tools.

It's not just the algorithm themselves and the kind of determination that they make, but how much the entire system is really relying on them.

Peter Blanck: Lydia, would you add to that?

Lydia Brown: I can just talk a little bit about what this feels like in real time. In just the last few months at different points, I've been part of conversations with other disabled people who talked about not being able to be hired because they think that employers' applications requiring them to complete personality tests resulted in not being able to get hired anywhere.

I was just recently part of a conversation where several dozen people shared similar stories, one after the other, where all of whom were disabled people of color who had gone up against job applications that required them to complete some kind of personality test to proceed in the application. And in all of the cases, not a single person was able to get hired. And no one can really prove what was the cause for not being hired, when there's some other reason not related to the personality test that meant that their application was not advanced and was not reviewed. Was there a specific thing that the personality test was measuring that correlated to an aspect of their disability?

No one really knows for sure, but having heard that experience from so many different people calls to question both the need for not just carefully tailored and transparent algorithms, but also for hiring decisions that are not left to people to wonder what part of this is automated, what part of this actually considers whether I can perform the tasks

required for this job, and what part of this is just some kind of a circus hoop for me to jump through?

And in another context too, I teach as an adjunct professor and I've heard from some of my colleagues that their students who are taking exams for other classes that they've been asked or required to use some kind of virtual proctoring software, some of which relies upon AI in order to prevent the use of cheating or unauthorized study materials or to make sure that the student is in fact the correct person sitting for the exam.

Now none of my students had to take exams like that for my classes, but I heard from more than one student that they felt surveilled, that they felt that their privacy had been invaded, and that they were worried that because of specific characteristics of their disability, being partially sighted or low vision, having tics because of cerebral palsy or Tourette's, or even having ADD or a gastrointestinal type of disorder would mean that they would be flagged.

In one case, a student of one of my colleagues was locked out of the exam by the AI proctoring software because of a disability related reason and had to beg a remote proctor to be allowed permission back into the online proctoring room to be able to finish taking the exam.

Because of the pandemic, more and more job applications are going to be processed online than might have been the case beforehand and more and more students are going to be asked to complete algorithmic or virtual proctoring mechanisms just to take their exams.

Peter Blanck: Wow. Before I turn back to Paul, maybe you both can briefly tell us how does the ADA protect our rights under this situation?

Ridhi Shetty: Well, especially when it comes to algorithm driven hiring tools, we've been looking at particular provisions that the ADA that govern the kinds of formats that these tools use to administer tests, the kinds of selection criteria that they rely on to evaluate applicants and also the extent to which these tools can also serve as medical inquiries prior to a job offer.

All of these provisions are especially relevant when algorithms are being used. The problem is a lot of employers or vendors kind of rely on these tools as an intermediary to shield themselves from scrutiny under the ADA, but they are very much beholden to requirements under the law, even regardless of the opaque nature of these algorithms.

Peter Blanck: That's fascinating. Paul, if I could turn back to you, clearly the implications of this important work are to public health monitoring in an era of COVID. How does this topic relate to your grant to the Social Science Research Council?

Paul Harpur: Thank you. One aspect is there's a lot of new surveillance. We've already got the... Most of our workplaces have sensors, mobiles, phones, laptops. All of these sensors. But the amount of information now the employers are gathering on employees is extensive. The health data that they now are required to get in some cases or asking for means that in a lot of cases you can no longer choose whether or not you disclose a lot of your disabilities or your health conditions, even if it's not a disability.

A good example would be you don't want to return to work right now like teachers in Chicago because you're worried about catching COVID. You might have a condition like asthma or another condition which makes you more vulnerable. You've never disclosed it because if you read statistics, if you disclose a disability, as we've already heard, your chances to getting a job is reduced. So these people may have worked for 20 years for this employer, never bothered telling them details about their medical condition that isn't relevant to their job. Suddenly they don't feel safe going to work and the only reason they can justifiably not go to work is because they have a disability. So it's forcing them to come out and disclose their disability or potentially lose their job.

Peter Blanck: Because we have you from down under, Australia of course has the disability discrimination act, I believe, the DDA, which in many ways is parallel to our ADA.

How would the DDA and perhaps as an expert on international human rights as well under the UN convention on the right to persons with disabilities, how would those legal

paradigms address this sort of issue and would it be in ways similar to the Americans with Disabilities Act?

Paul Harpur: Well, one of the first questions is whether COVID-19 is a disability, and that will depend on some countries, they regard disease as a disability. Even if COVID isn't a disability, if you look at the factors that come with COVID, a lot of the medical conditions followed would be anyway.

But trying to identify algorithmic disability discrimination, I leave that to my colleagues who run this core comprehensive reports which are amazing. In relation just to the health surveillance and the safety information, if, in a lot of cases, employers are mandated to collect this data and it's required by the government. Employers, you've got no protection. The employer has to do it or if they don't have to, it's a reasonable requirement to implement their health and safety duties.

You've got very little recourse if an employer says, "I want to know about why you're coughing," for example. "Why do you have that cough?" "Well, I've got asthma." "Can you prove it?" Suddenly, this person who had asthma, which this is a real example of a friend of mine had to establish that it was asthma. Now that was okay for the employer because the employer was good, but how do they get to work? Everyone stares at them. So it's very hard to even get to a... to pay for parking because they didn't want to use public transport, so it's a very big cost for them when going back to say, early February, they never thought themselves as having a disability, impairment. They just had minor asthma, which meant they coughed occasionally. But now it's very, very bad to have any cough.

Peter Blanck: Would the UN convention on the rights on persons with disabilities have anything to say about this situation?

Paul Harpur: Yeah, it does. Article 11 deals with times of risky humanitarian disasters. You can't say when you've got 200... the amounts of people who have died from COVID, I've got it somewhere in my notes here. It's a pandemic. It's worldwide. It's definitely an emergency. So yes, the convention does come into play. Again, the only issue there is

the CRPD, the convention of the rights of persons with disabilities, it doesn't define disability. It explains it, due to whoever drafted it, there's a lot of disagreement.

You've got an explanation in Article One, of what a disability includes and that's long term impairment. Whether it covers a disease is a maybe. Of course all of the... you could develop a second disability it definitely covers it. Just COVID itself may not, but people who have a disability already, so if you have asthma, or you're in a wheelchair and you've been negatively impacted, it definitely does cover you. But it doesn't necessarily insure you're going to get equal protected even if it's being followed because as I said, it's broadspread and widespread health and safety. It's just how these health and safety measures are implemented, it has to be done in a more human rights way where at the moment, you'll see in hospitals, people are going, "Old person, you're not worth saving. Disabled, you're not worth saving" and making choices prejudicially based upon disability, age, rather than actually looking at the person's capacity to recover. Those decisions would be impugned.

Peter Blanck: Some has been written about the potential silver linings as it were, not of the COVID pandemic of course, but of the new norms that may result in terms of work and social benefits and social interaction as a result of the pandemic. If done well, is there any potential upside to improve the inclusion and participation of persons with disabilities when we may as a society choose to use these algorithmic based solutions?

Lydia Brown: This is Lydia. I always recommend and ask people who are making policy decisions, who are designing and implementing research, or who are involved in the development and deployment of new algorithmic tools to consider how their projects can actually center and follow the leadership of actually disabled people.

Sometimes that intervention comes later in the process, much later than I would prefer. If a company has already hired a vendor to craft an AI hiring tool. If a state has already hired a vendor to craft a new algorithm to determine Medicaid eligibility for long-term supports and services, then at that point it's too later to consider disabled people's perspectives as to whether or not to implement that tool from the beginning since they've already started down the road. They've decided we're going to be using this tool. But that

doesn't mean that you can't pause and consider for what purpose will this tool be used, how widely will it be used, what limitations or other forms of control are we placing on this particular tool, and how are we auditing it, how often are we auditing it, and who is determining the standard by which it applies and what it means for it to be effective and useful, and are those people actually from disabled communities and other marginalized communities or not?

But going further back, if someone is considering should we be adopting or developing a new algorithmic tool for a particular process, that decision shouldn't be made in an absence of collaboration with and conversation with the people who will be the most impacted and therefore who will have the most to use.

If a state government is thinking about implementing a new algorithmic tool for assessment or allocation of benefits, then it is incumbent upon them not just to passively seek public input as sometimes can be the case, but to actively solicit not just the input but the leadership and the priorities of the people who are receiving those kinds of benefits already and the people who are planning to be and believe they're likely needing to require such benefits in the future in deciding whether even to implement such a tool and if so, how it ought to be used, where it fits into the process, and how it needs to be audited, and how its functionality needs to be limited as well as made transparent as well as actually accountable to the people whose lives it might affect.

The same goes for any other context. Really it just comes back to remembering that we as disabled people don't exist simply to be consulted after the fact or to be asked to provide some advice that might not actually be taken into consideration. But disabled people need to be partners in policy making, in research, in design, in programming, in coding, and in implementation and in auditing.

Peter Blanck: At the end of the day, can this be done well? Are you aware of any examples of which our listeners might look to as leading edge examples of the type of inclusiveness and participation that Lydia's talking about?

Ridhi Shetty: I think we tend to see leading edge used as more of a selling point to begin with rather than part of the analysis after the fact. Particularly thinking about it with regard to constant changes in the way that states are using benefit decision tools and in the new up-and-coming hiring tools that are becoming increasingly popular.

We haven't yet seen tools where we can confidently say that they are good or they are providing a model that people should be following. There are areas that seem to be promising, but it can be kind of premature to think now of them as foolproof or as too promising. Especially when it comes to tools that can have such dire implications if not used correctly, I think it's better to tread carefully and be cautiously optimistic rather than going ahead and endorsing any particular kinds of tools.

Peter Blanck: Thank you for that. At this point, I will say my brief interlude. As a thank you to Paul, Lydia and Ridhi, ADA Live listening audience, if you have questions about this topic or any other ADA Live topics, you can submit your questions online to www.adalive.org. Or call the southeast ADA center 1-404-541-9001.

And now as the proverbial expression goes a word from our sponsor, the Social Science Research Council.

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Peter Blanck: In the spirit of equality and the importance of the organization, perhaps Lydia and Ridhi can take a brief moment to tell us about the Center for Democracy and Technology, the CDT, which is addressing critical questions in the United States and I

believe elsewhere at this time with regard to technological advances and democratic inclusion and participation in society. Lydia and Ridhi?

Ridhi Shetty: This is Ridhi. To give a brief primer, especially over the past year in particular, as you can imagine, the Center for Democracy and technology has been not only celebrating its 25th anniversary but has been doing so focused on a lot of the evolving technology that has become especially prominent as the pandemic has hit us.

We have multiple project areas from which we're analyzing a lot of the different technology that is for us. Our project is the privacy and data project, which focuses on consumer data practices and how different private entities tend to compromise or engage in data practices that can put consumers' information at risk and the different mechanisms that should be considered in trying to protect consumer data rights.

One of the things we were pushing for is comprehensive federal privacy legislation. We're also looking at three different kinds of privacy practices from a civil rights and equity lens as well. We also look at the way that health data is used within our project and of course Lydia brought with them to CDT the AI disability project that originated at Georgetown. That's also become a big focus of the privacy and data project as well.

Across the organization, we have projects ranging from security and surveillance to free expression to open internet, internet architecture and antitrust. So as you can tell, we look at all the different evolving technology from multiple lens.

Peter Blanck: We talked a little bit about the use of law, the Americans with Disabilities Act, the Australian system, the international system. We all know that disability per se is a non monolithic concept, as is race, gender and other prior categories which have served to define people perhaps in limited ways. You, Paul, Lydia and Ridhi have talked about the nature of individuals with multiple marginalized identities. That term has become known as intersectionality. Perhaps Paul, you can start with is this an evolution of thinking about individual difference in society? Does this intersectionality concept complement the disability perspective or is it the next iteration of thinking about individual difference in our society?

Paul Harpur: Well, thank you, Peter. I think I would go so bold as to say that I think this is going to shift into a whole new way of thinking. The interest in vulnerability theory, you've got intersectionality, all of these very important theories already exist.

But if you think about COVID, we've got, what is it, about 22 million people I think in the US have acquired it last I checked. Now in Australia, we have 24 million people in our entire population. So for me, those sort of figures are dumbfounding. But if you have that many more people suddenly have a disease, then you have all those people that are associated with them have to get tested and it's such a huge impact on the population across all sectors. Of course some sectors are hit worse. Then, there's disabilities that flow from that.

I think it's going to have such a huge impact and such a tension on health that I do think it's going to unsettle norms. It creates a space where we can ask why do we build something in one way? Why do we have a health system that operates in one way? Why do we have these questions? Why does triage in hospitals, say, operate the way it does?

So I think this does create a space where questions that have really... United Nations convention of rights for persons with disabilities, the American Disabilities Act and other important documents have drawn attention to it. Nothing can compare to a pandemic for drawing attention to health differences.

Peter Blanck: You, Paul, have written prominently about mental vs. physical disability or psychosocial, psychiatric disability and the types of stigma that is born within this concept of disability.

Paul Harpur: Yeah. I was privileged to work with you Peter on that, with hierarchies of impairment and the idea that different impairment groups are treated differently. This is one of the areas I looked at that really dumbfounded me was workers' compensation. So if you're injured at work, if I'm injured at work and my arm goes into a blender and I lose it, I'm immediately treated as a person with disability. I immediately get support. I'm immediately treated well.

If I'm the person standing next to the person and I develop PTSD or a psychiatric injury, in some jurisdictions, you have to wait six months to get full protection. Then, at the end of the day, a lot of jurisdictions even say well, it has to be a higher degree of impairment for a psychiatric injury than a physical one to get payout. The treatment there, negligence also treats it different. And that's just in the law and in practice. You could just think about people walking down the street. If someone walks down the street muttering to themselves who's having twitches, people treat them or react one way. Or if I walk down the street with a guide dog and bump into someone, I've got a guide dog, actually incidentally. I can guarantee you the reaction's different.

Peter Blanck: So nicely as usual Paul led me into my next question, which was to Lydia and Ridhi, and that is number one, is there something about this new norms that are developing in the COVID pandemic that will act to shift a paradigm from a more monolithic view of disability or sexual orientation and gender identity or race to this more differentiated, intersectional self. Lydia and Ridhi, what do you think about that, that idea that this new norm or this new environment that we're living in is either an opportunity or a detriment to think differently about conceptions that we've long held?

Lydia Brown: This is Lydia. Whenever we talk about disability, we have to acknowledge and understand that everything we think we know about disability is shaped by society, by culture, by language and by other social forces and systems and structures and processes of power and domination.

All of that might sound very conceptual, very heady. Well, what that means, right, is that what we think of as a disability, who we count as disabled, who we recognize as having a disability has always shifted. Even just half a century ago, myopia or nearsightedness was widely considered to be a disability in a very different way than it is today.

50 years ago or longer, there were advertisements that shunned or looked down upon the idea of hitting somebody who wore glasses in the same way as similarly quaint, chauvinistic videos might have looked down upon the idea of a man hitting a woman, as somehow uniquely extra wrong, when of course it's wrong to hit people, right? We generally in society discourage unprovoked, unjustified violence and aggression. But

there was this idea that women should especially not be hit by men because it somehow is lower to hit a woman when it should be wrong to hit anyone. Or it was lower to hit someone who wore glasses.

Today, in 2020 and 2021, I keep forgetting we're in a new year. We've escaped that morass. We don't generally think of having myopia or being nearsighted and needing glasses as a disability even though medically, it is.

At the same time, we can see how race and class and gender all shape our ideas of what kinds of conditions are recognized and legitimized as disabilities, and therefore which types of disabled people can assert themselves under the law. So people who are more likely to have disabilities that are common in Black communities or native communities, for example, might be less likely to be identified as having a disability. Disabilities like lupus or fibromyalgia or sickle cell disease for example, disabilities that may be noticed and responded to of services, support or treatment in white people like substance use disabilities or depression or product suicidality are often deliberately rendered invisible or not responded to when they show up in Asian, Black, brown or native communities.

Similarly, what I think a lot of society is going to have to reckon with and we spoke about this a little while ago is as this pandemic continues and once it finally hopefully ends, the people who are currently being referred to as COVID long-haulers are actually now disabled. The people who have survived COVID and now have significantly reduced lung function, that now have developed conditions that mirror asthma or emphysema, that now are experiencing brain fog or cognitive impairment, that they were not experiencing prior to contracting and surviving COVID, they've now acquired disabilities. It remains to be seen in our society how will our legal, economic and health care systems adapt and respond to the increased population size of people with disabilities and particularly what opportunities and challenges that's going to present to us given that this is not going to erase structural ableism or structural racism. The ways that experiences of disability and disability discrimination have always broken down along other axes of oppression and of privilege.

Peter Blanck: Would you add to what Lydia was saying, Ridhi?

Ridhi Shetty: I think Lydia really covered it. The only thing I could possibly add is just that one thing that a lot of the disabled community has been bringing up is that the mechanisms that we see being used right now when it comes to remote work and the possibilities of technology to facilitate people who have to stay at home, whether it's because of child rearing responsibilities or health related issues. It shows that it is possible to build a society that can also work for people with disabilities but I think the question that will remain is whether when eventually all of this ends, will people remember that? Will they remember that it is possible to structure our society in a way that everybody is able to access the same kind of economic opportunities with some flexibility and with multiple options for how we work, how we study, how we function. I think the question remains then whether we will in fact see a new normal in the long run.

Peter Blanck: You led me nicely, Ridhi, into my last closing question, which I'll start with you, Ridhi and then go to Lydia and give Paul the final comment. What are we to do as individuals? in this fractured, hyper-surveillant, automated society that's coming, what is the responsibility of all of us individually, as individuals with multiple minority identities or otherwise to act and safeguard against these challenges? What would you say to our listeners?

Ridhi Shetty: I think that's going to be especially challenging on an individual level to be pushing back against the way that algorithms are used. One recurring issue that we've seen is that because of the black box issue, trade secrets, just a general reluctance to give people a glimpse into how these tools can work, it's really hard for individuals to challenge how they're being used or how they're being affected by algorithms.

I think a lot of the change will have to come kind of from the top down. We need a lot of regulations that are actually evolving along with the tech, because a lot of the guidance that we're relying on is years old if not decades old, so it no longer applies the same way. It no longer really covers the kind of situations we're looking at right now.

Of course there are ways for people to make their views heard. One thing that we talked about in the benefits termination report was that people have options for reaching out to their states through town meetings, through the notice and comment process. Those

options exist, but they aren't existing in a vacuum. They have to work along with every other stakeholder's involvement as well.

From the individual end you can push back on the tools that states are using. With employers, it's a little bit trickier when you're talking about hiring tools because you're pushing back more through private action or through the EEOC. Again, with a little bit more updated guidance. It has to be all these different stakeholders working together, not really just individuals.

Peter Blanck: Thank you. That's very well said. Lydia, why you became so passionate about this and is there anything we can be doing either at the grassroots level or as Ridhi said, at the group collective action level.

Lydia Brown: Kind of a lot. I guess as a disabled person myself, I have spent more than a decade examining and challenging the different ways that ableism shows up in our lives. A lot of my work has focused on what I usually call issues of violence, interpersonal violence or state violence that targets disabled people.

I think it might be very easy for many people to respond to that by saying, "Well, I don't really understand how an issue of violence connects to the use of algorithms. How is that related?"

I think it becomes readily apparent if we look at the real world effects of algorithmic decision making on people's lives. When people with disabilities rely on Medicaid funded services to stay alive, to be able to stay at home and to build and to sustain community connections and to be healthy and to be well, and a state implemented algorithm that creates widespread reductions and terminations of those services, that is an act of violence because that is an act of the state exercising its power to deprive disabled power who are most in need of care from receiving the care necessary to be able to live their lives.

The states adopt algorithms to make decisions about which students should be graduated or passed in classes vs. which should be flagged as fraudulent or cheating during their exams, which students are considered not a behavioral problem, which should instead be

flagged for surveillance. Any of those issues are issues of violence because we know statistically that people who are unable to complete school are more likely to experience unemployment, homelessness, criminalization, any number of other processes of deprivation and of harm that can follow someone for the rest of their life.

It may not look obvious, right? But when you start digging, all of these connections become clear. Then, all of the ways that we talk about algorithms as affecting disabled people's lives, they are all tied to ways that governments and companies are just increasingly automating decisions that relate to our health, to our freedom and to our ability to be and belong in community.

And for that reason alone, I think more folks that are invested in disability advocacy and activism need to understand just how critically important it is for us to be carefully attuned to the ways that companies and government actors in our lives are thinking of adopting or implementing new algorithmic systems. What we can do as informed members of the community to advocate against harmful adoption of algorithms and to advocate for meaningful regulation and community based and responsive auditing where algorithmic decision making tools do exist.

Peter Blanck: Well, powerfully said, Lydia. Thank you. Paul, we turn to you. The pervasiveness of ableism and other forms of discrimination, technologically or overtly in interpersonal communication and connections. What's your sense of where we're at and the opportunities ahead to overcome these barriers in attitudinal discrimination that Lydia and Ridhi have been talking about?

Paul Harpur: I wholeheartedly agree with Lydia and Ridhi. We need to look at litigation but also we need to understand that it's violence.

Another strategy that we haven't talked about is trying to look for opportunities. Algorithmic discrimination, it's a problem. But there's also potentially opportunities where education, for example, we run it over a university. They can flag people who have issues prior to the person dropping out. Maybe there's opportunities there to help identify people with a disability who may need help who haven't come forward. There's opportunities.

I don't say there's going to be a lot of positive opportunities, but I think it's worth exploring and working with people that are developing those things. Another simple one which we've already seen around web accessibility, where you have programs that go into the system and look for the errors. Blackboard does that reasonably, not fantastic at the moment. But systems that can help identify where barriers have been put into our IT systems under a network and potentially help remove them before someone with a disability hits them.

I think, as well as litigation and the social action which are both critical and often the reason we can get to the board table and to managers and say, "Look, let's try to look for opportunities." I think we have to go with the carrot and the stick, and I think both need to be utilized. Where I work at the moment, I chair a university, the University of Queensland disability inclusion group. Because of where we're at, we're able to do a lot of major changes where the university wanted to do them. Other places you don't have that, and you need to litigate first.

There's the combination of litigation and trying to find ways to be positive to help organizations go from being discriminatory to promoting ability equality as part of core business.

Peter Blanck: Well, Paul, Lydia and Ridhi, each of you have so eloquently and powerfully talked about issues that are so important to daily life today. That is fairness and equality and meaningful participation in society, not on the basis of a status characteristic, but on the basis of individual preference and self-worth and meaningful involvement.

I thank you all so much.

Barry Whaley: Lydia, Ridhi, Paul, and Peter of course, thanks to each of you for being on today. We want to thank our ADA Live listeners for joining us for this episode. Final reminder, you can submit your questions and comments for this episode online at adalive.org.

You can get access to all ADA Live episodes on our website at adalive.org. All episodes are archived with streamed audio, accessible transcripts and other resources. You can

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Finally, if you have questions about the ADA, you can use our online form anytime at adalive.org or you can contact your regional ADA Center at 1-800-949-4232. All calls are free and they're confidential.

Barry Whaley: ADA Live is a program of the southeast ADA Center. Our producer is Celestia Ohrazda with Beth Miller Harrison, Mary Morder, Emily Rueber, Marsha Shwanke, and me, I'm Barry Whaley. Our music is from Four Wheel City, the Movement for Improvement. We'll see you next episode and be safe everybody.

4 Wheel City: (rapping)

[End of Transcript]

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