>> Hello. Thank you for joining us for the Johns Hopkins Disability Disparities webinar series, which is a forum to share diverse perspectives about disability inequities. In today's session, Disability and COVID- , we will discuss the impact of coronavirus pandemic on people with disabilities. I'm Bonnielin Swenor, I'm an Associate Professor and Director of the Johns Hopkins Disability Health Research Center. I'm joined today by three expert panelists. Justice Shorter, who is the Disaster Protection Advisor at the National Disability Rights Network which provides legal and advocacy services to people with disability. Justice provides technical assistance and training related to natural disasters, emergency response, and humanitarian crises for people with disabilities and has served as an Advisor to the US Federal Emergency Management Agency or FEMA. Valerie Novack, who is a Disability Justice Initiative Fellow at the Center for American Progress, which is an independent policy institute. Her work focuses on gaps present in emergency preparedness and response efforts for people with disabilities. Our third panelist is Monica Schock-Spana, a Medical Anthropologist and Senior Scholar with the Johns Hopkins Center for Health Security and in the Department of Environmental Health and Engineering at the Johns Hopkins University Bloomberg School of Public Health. Her area of expertise includes community resilience to disaster, public engagement in policy-making, crisis and risk communication, and public health emergency preparedness. Thank you-all for being with us today for this important discussion. You-all have exceptional expertise in disaster and public health emergency response and I'm hoping today for each of you to share your unique perspectives on the COVID- pandemic response as it relates to people with disabilities. Justice and Valerie, I'm going to start with questions for you. There have been reports that COVID- has uniquely affected people with disabilities, and much of this data has come from residential facilities, for example. What I would like to know each of your perspectives, if you're comfortable, on how COVID- has deferentially impacted disabled people. Justice, do you want to start? >> Sure. Thank you for one for having us. It's a pleasure to be on today's panel to have such a critical conversation around the coronavirus and all of the different intersecting ways that it's impacted individuals with disabilities across the nation and the territories. In regards to residential facilities, I just want to focus for a moment on the racial disparities that we're seeing and that we've noticed in the last few months. The New York Times released an article a bit ago that mentioned if you are black or brown and you live in a nursing home, then you are twice as likely to contract the coronavirus. I'll stay away from hard statistics given that the numbers are shifting swiftly every single day. But at present, conservative estimates around nursing home infections linger around - percent. Again, those are creeping up and those are changing every single day. We've noticed that the virus has absolutely ravaged nursing homes and communities of color in particular. This is also the case for other congregate settings such as prisons and jails and ICE Detention Centers. You see advocates and activists right now all across the country combining conversations as we try to maneuver through two concurrent disasters at the same time. You have them combining conversations around police brutality as well as health inequities because both of them are steeped in a system of structural racism. The idea here is to combat structural racism wherever it appears. Whether that is emerging in hospital board rooms and in hospital bedrooms, where decisions are being made at the quality of life or the efficiency or comorbidities concerning people with disabilities, or if those conversations are happening on the streets where lives of people of color are being devalued or dismissed for any number of reasons, but primarily because folks are black and being treated with far more aggression and brutality as it relates to their interactions with the police. The underlying message in all of this is that there are systems that disproportionately impact black indigenous people of color and particular black indigenous people of colored with disabilities as well. We looked at all of these different intersecting factors when we examined the coronavirus pandemic if we really want to get down to some of the root causes and good solutions around what we can do to help make sure that these communities are not only able to survive but that we also avoid the risk of these things happening in the future in such devastating ways. >> Thank you so much Justice. Valerie? >> Yes. Hey, thank you. I'm so glad to be here. I'm glad that Justice has set the framework there on some of the racial components that we're seeing. When you asked at the beginning, Bonnielin, you'd mentioned that we see people talking about the coronaviruses as uniquely affecting the disability community and that part of that we're seeing in residential facilities. But I remember when we first started talking about this and how in addition to the racial impact that we're seeing, just the very blatant disregard that became very evident. I think we refer to ableism a lot in the disability community, but I remember the first things we started hearing when people were wondering whether or not they should be worried about getting sick with COVID- was, "Oh, well, you only need to be worried if you're older or disabled." I think right there, that beginning of this trajectory set the tone for how this experience was going to be different for people with disabilities than it might be for other people. Because from the beginning, we as a collective culture had thrown in off as something that didn't need to be worried about because it wasn't going to affect you if you were younger, if you were healthier, if you were able-bodied. I think they're very much seeing now in the conversations we're having where we're looking at people in nursing homes dying or being infected at plus percent rates. When we're seeing people talking about care rationing, we're looking and seeing wording that is very unnerving. Things talking about quality of life that is very broad and up for interpretation. We're seeing scorecards house likely as somebody to pass away of some other course in the next - years. The kind of decisions that really we would never want somebody to be making, especially somebody that doesn't know us to determine whether or not we should receive care. Those are, I think very connected to some of the things Justice was talking about when we talk about who we have built our systems to support and to allow to live life. I think part of the reason that people even feel comfortable having conversations like, "Well, if a year-old and an -year-old both come in, who should get a ventilator?" Is because we've not only in February but for our history, have made these decisions, and have thrown off these statements like, "Oh, well, it just affects disable people, I don't need to worry about it." I think we're sowing the seeds of those ablest attitudes right now by seeing these just tremendous amounts of deaths that are really targeting certain communities that we have a long history of devaluing. >> Yeah. Thank you so much. I think they're both very important perspectives. Monica, I'm going to get a turn to you now. You're an expert in building community resilience, particularly in a time of crisis. From your perspective, can you talk a little bit about what has gone right with a pandemic response from that perspective, and what has gone wrong for people with disabilities? >> Thank you so much, Bonnie, for letting me join us important panel. I thought it would be helpful to touch on what we mean by resilience. We all have a general notion that it means to bounce back. The way sociologists of disasters talk about community resilience to disaster includes two aspects of resilience. There is that ability to absorb a hit. What is it that we're doing on an everyday basis that allows us to absorb the hit of a disaster or to withstand it? Then there's that second element which is to bounce back. How do we adapt? How do we respond in the moment? It's those two elements. What is it that we're doing in our regular systems that allow us to withstand the worst? What is it that we're able to do by thinking on our feet? Our emergent behaviors that speak to the creativity of people when they're stressed in a crisis. How do they problem-solve on the fly? In terms of, from a community resilience perspective, what's gone well and what's gone poorly in regard to the disability community, I think as far as what's gone poorly and Justice was getting at this is, there are certain structural arrangements that have placed additional stresses on the disability community, and so if we think about the underpaid and uninsured workers that assist disabled individuals, and these are the home health aids, personal care aids, and certified nursing assistants, they're a workforce of about five million people, most of whom receive low wages, have no health benefits, and in the current context, have often been saddled by shortages of personal protective equipment. We have a network upon whom disabled individuals rely for material support, for moral support, for day-to-day care, and so we have communities that are being doubly stressed as a result of the way we've organized care provision in the United States. We aren't able to, from an inherent resilience, that is how we organize ourselves on a daily basis, able to deal well with something like COVID- with dramatic effects for the disabled community, as well as the individuals upon whom they rely. As far as what's gone well, so I was talking about inherent resilience, our ability to withstand something. The bounce back part or thinking on our feet or the improvisation, I think we've seen some really spectacular stuff there. I remember reading in early March, there was a blog and it was called, Half-assed disabled prepper tips for preparing for a coronavirus quarantine. Here we have this dramatic expression of self-initiative, by a woman who said, "What is it that I need to do to get through being physically distance from everyone else?" Took it upon herself to write all of her concrete actions and to provide support to others. I mean, this was an incredible display of what we call adaptive resilience. Where it is about improvising in the form of self-reliance, but more importantly, mutual aid and the sharing of critical information from person to person to person, to get through the dramatic crisis that we're now facing. >> Great. Thank you. Now I'm going to ask a question of all three of you, based on those amazing responses. What do you think we need to do to improve the response for people with disabilities moving forward? Based on what Monica just said, are there actionable steps that we could advocate for or take on right now to improve that response? Justice, I'm going to start with you. What are your thoughts? >> Absolutely. I would say first off, I agree with everything Monica just said, and she actually mentioned that some of the exact things that I was also going to reference in regards to this question. I believe one of the first things that we have to actively address, is in connection to what Valerie mentioned earlier about this devaluation of individuals with disabilities. This is really getting at the mentality of disposability, when it comes to Black, brown, indigenous, and disabled bodies. For many years, our communities have been hit with disinvestment, environmental racism, lack of green spaces, lack of adequate health resources, socioeconomic conditions that exacerbate many of these points, and those things have a very physical presentation in our bodies. That's one of the ways why you see some of the situations occur in terms of us having a more pronounced reaction to things like the coronavirus pandemic in a very physical way in terms of these underlying condition. I would say one, we have to really get at this idea that people with disabilities, Black folks, brown folks, indigenous folks are disposable and they're not worth the sacrifice of being shut down for a sufficient period of time to assure that everyone in this country is as safe as we possibly can be. That is the first thing. I would say two, we need to take full advantage of the lessons that we've learned from this pandemic. Many of the accommodations that had been openly welcomed during this pandemic, to assure access to employment and to make sure that people still had the economic engines running in their cities and in their towns, as much as possible from a remote standpoint, these are accommodations that people with disabilities have long fought for, and in many cases, are still being denied. Except in this case right now where everyone had been affected in a way that necessitated adaptation and accommodation. I hope that employers and organization now will adhere to such flexibility moving forward, and accepting the requests that come through from people with disabilities to continue working remotely, to continue having flexible hours, to continue having certain accommodations even when they are in the office to make sure that they are being as safe as they possibly can. But these accommodations I don't think need to be lost or need to be disregarded once we exit out of the current state of affairs that we are in right now in terms of the real prevalence of the virus being as heavy as it is right now. I hope that we can take all of that with us. I also hope that we can continue having multiple conversations simultaneously. I think one of the issues is the thought that we are a single problem society that we can only handle one particular problem at once, and once our attention deviates from that, then we can go look at another issue. But as Monica was mentioning, all of these things, these stressors, they are hitting us simultaneously. In order to survive, we all need to be able to address those things. Again, a lot of them are embedded in these systemic structures of oppression, and racism, and anti-blackness, and being able to unpack that and dismantle that in a myriad of ways which is absolutely necessary at this moment, I think is what will get us further towards this path of full recovery. Because resilience is rooted in representation, so individuals with disabilities, Black, indigenous, people of color needs to be at the table, not just as casual observers, but as active participants. Their lived experiences as well as their work experiences need to be valued. Their contributions need to be valued in this ongoing continual conversation, around how we can continue to make sure that we're on a path that helps us all survive in the future. >> Thank you, Justice. That was a profound response. Valerie? >> Yeah, hard to follow. I think Monica really brought in one of the things, as far as policy or government response, that really could help a lot, but it's easier said than done because, as Justice has mentioned, some of the systems. But we need to focus on home and community-based services and supporting the people who provide them. Right now we know because we're hearing it from doctors, and epidemiologists, and public health officials that we should not be in large groups. We should not be in congregate settings. Yet, we aren't taking the steps that we need to to get people out of those settings. Whether that's a nursing home, whether that's an institution, whether that's a prison or a jail, whether that's a youth home. We already know, at least on that front, what we should be doing. At this point, it's doing it. Because of a lot of the things that Monica mentioned, we know things like reimbursement rates, we know we already have an extreme shortage that's only going to increase as far as home health aid workers and CNAs, we have a lack of personal protective equipment. On one hand, that will help save a tremendous amount of lives. There's also a profound lack of investment in having made that happen prior to this moment that now has us in this position where we can't move as quickly as we need to to make sure that people can be in homes that are accessible and with the personal assistance that they need. There's also a tremendous amount of paperwork and bureaucratic administration stuff when it comes to, if you are, say, a Medicaid recipient that is living in a nursing home trying to get into your home. There's some very real barriers there. But I also think the other option is allowing people to continue to stay in these congregate settings where they are getting sick, and they're dying alone, and with no one there to care for them. Seeing family through windows and things like that, that when you try to imagine from your point of view, is just absolutely horrific to imagine either going through or watching a loved one go through, but because they're off in these settings we don't need to think about, we don't talk about it much. Even going deeper in that versus how much we've been talking about nursing homes versus this much, we haven't been talking about institutions or prisons where people are also experiencing the same thing. But because we often tend to feel like maybe a nursing home is somewhere you end up, versus a prison or an institution is you've done something to be there, that somehow it's worse of a situation if you're in a nursing home than if you're in a prison or an institution. But we're condemning people to the same thing by not focusing on how can we get people out of these congregate settings. How can we get these people so that they're also able to social distance regardless of the circumstances surrounding their confinement. Regardless of why you might be in an institution, the result of that should probably not be you dying because we wouldn't put you in a place where you could be safe. I think that's a huge thing. That is one of those government decisions that can easily be put into place, and that's a little bit reductionist, but to get people to safer places. Then I think there's personal responsibility. Like I mentioned before, I think we're seeing this line of the ableism running through where people don't want to take a little bit of discomfort to make sure somebody else doesn't have to be hurt. As far as the rest of us that are not our Congress people and are not our governors, just a little bit of discomfort on our part so that other people can be safe can really go a long way, and we're seeing that. We see the numbers, we see the studies, and the differences in states, in responses when people decide, yes, it's not fun, I don't like wearing a mask, I don't like staying home, I'd much rather be out watching football or whatever it is. Saying, but there's a lot of people out there who can get really hurt from this, so I'm going to take one for the team. That's what I need to do. I think we have very specific asks we can ask of our leaders, but there's also just very real things that we can do. I really think it comes down to supporting a lot of the people that we haven't supported before, that we don't pay living wages, that we don't provide the things they need, so that they can go on and make sure that we continue to survive and be healthy. >> Great. Thank you. Monica? >> It's wonderful to hear the great ideas from Valerie and Justice. Just to build a little bit on something that Justice had mentioned earlier, I think the principle of inclusion, joint decision-making, joint problem-solving is absolutely critical. Valerie had mentioned earlier the issue of the crisis standards of care, and the prioritized use of limited medical resources. Now, there's a history to that decision-making, and it comes from real life impossible choices. If we recall, medical staff at broken facilities in the post Hurricane Katrina chaos wrestled with these tragic decisions, with how best to treat patients entrusted to them even though they didn't have enough resources. Now, this is a very complex story. What clinicians took away from that experience and others is, they don't want to be, as individual practitioners, having to choose between person A, B, or C. That there needs to be a greater societal conversation about how it is that our policies can grapple with scarcity, if it comes to that. Those conversations are not just medical technical ones, they're totally riven with social values, and I think Valerie was getting at this. For some people, it feels as if it boils down into, particularly in light of a real history of dehumanization, into who matters and who doesn't. Those decision-making practices and processes have to be cracked open so that we have a diversity of voices, and very loudly have people with disabilities involved and engaged in those conversations so that there's clarity around the value of human life in all forms, and they can feel invested in policies that are meant to deal with unfortunate circumstances when scarcity arises. Also, to make sure we have things in place such that scarcity does not arise in the first place, because we certainly have had a lack of crisis leadership in the response to COVID- leading to scarcity that could have been prevented. But I think opening up those policy conversations and having a diversity of voices there is going to be absolutely critical. That's a key point I wanted to drive home. >> May I add something to what [inaudible]? >> Please. >> I think Monica said something that really just reminded me that I feel like because we are in a very like, everything's on fire, we're in it, that maybe we're not so much having this conversation. But I think the other side of that, when we're here sitting and talking about those conversations we need to be having as a society on inclusion, is that making sure and preparing for disaster events is often and can feel like it's at odd with profit. We need to learn to be okay with that. Spending now so we don't have to make these decisions when they come is an essential part of preparedness. As much as so many of those decisions, and I've done some research on some of this that have happened after Katrina, that led to some of these decisions. Hopefully, you would think that that would have been a sign for us to do them and to know we're going to prepare a little bit better next time. But we do operate in a way in which the bottom line is the priority, that financial bottom line, and consistently make decisions, whether this is in our personal lives, whether this is in the businesses that we operate or as a government, in which we will save the money now and deal with the problem later. We cannot continue, especially as we continue to have more disaster events, more weather events, to operate in a way where we'll do things at the least amount possible expense now and then just deal with the problem later. Because I've seen time and time again, whether it's Katrina, whether it's Sandy, whether it's COVID, the price we ultimately end up paying is people's lives because we don't want to adequately prepare for these events, because we don't want to pay a little bit extra to have a surplus of something that someday we might have a shortage of. I think that's going to take a very fundamental priority shift in the way we operate, particularly with social services and public services, in saying it's okay to have this surplus, it's okay to pay a little bit more now to make sure that the price isn't somebody not getting what they need later. >> I think that's a really strong plan. I'm just going to make one small statement that couples with that. I think we are quite primed and ready and we know how to prepare and to make sure that funds are adequately allocated in such a way because we see that happening in terms of our policing system. There is such a stark contrast when you observe police officers who are fully outfitted in military grade gear, and vehicles, and equipment, and you compare that to healthcare workers and caregivers who are literally using trash bags and rain ponchos to help protect themselves, and those who they serve, and those who they're working with and assisting on a daily basis. When we talk about funding, that has to be essentially connected to the ways in which we prepare. We can't just put things down on paper or presume that they're going to be a part of our policies and not fully flush out how they are going to be properly funded so that we can reduce this risk of scarce resources because a lot of it, as Valerie and as Monica noted, is directly attributed to whether or not it's going to have a level of economic effectiveness or it's going to be economically efficient or prudent to do so. But that there can be no direct value placed on a life, and to make that sacrifice ahead of time is absolutely imperative. We do it every day for our law enforcement and we also need to do it for the lives of everyday citizens and non-citizens across this country. >> Right. Thank you. I'm going to ask one final question. Part of my goal in this webinar series is to better connect the academic community with people outside of academics, so disability advocates such as yourself for example. Thinking about for the future, what role, if any, from all three of your perspectives, can academic institutions play in achieving the goals that were discussed and outlined today, and assisting with advocacy efforts to improve the emergency response now and for the future as we just discussed in disaster and emergency events for people with disabilities? What can we do better? Justice, let's start with you again. >> Yes. My answer will perhaps be the shortest one I've given thus far. I would say to support the work of scholars of color with and without disabilities who specialize in this work that many of whom have been doing this intensively for decades at this point, and have the wealth of content and curriculums that can be integrated and applied to universities and campuses all across the nation, and of course, in the territories as well. I would also, of course, advocate that those individuals be adequately compensated and that they not be erased from the narrative because that happens a lot as well. When folks say, "How can we help, or what can we do?" A lot of times that can lead to the appropriation or the adoption of individuals work and, of course, that doesn't necessarily include that work being attributed to those individuals who has done the research or who have gone out and who have worked within those communities and who have those case studies and those examples that are now being used in classroom settings. I would really emphasize going to those who are the most impacted, who have already been doing this work, and looking to them not as advisors but as leaders in this space, and listening, and engaging in ways that they define as going to be the most helpful as opposed to imposing what we feel or what academic institutions feel are the most important, or what will be the most helpful for those most impacted but actually listening to those individuals and taking their cue from there. >> Great. Thank you. Valerie? >> Yeah. This question actually warms my heart as I am about to jump back in yet again into the academic world. I think there's a very real applied answer to this, and then a culture shift of academia. I think I'll start with a culture shift part because of the things that Justice mentioned. I think we sometimes put so much, and rightly so, add rigorous effort into our scholarship, that we, and I am as guilty as the next person, overall can devalue lived experience, or use it as just a way to get data and not as a way to get answers. I think that when we talk about who we're having at the table and who's making these decisions, we need to stop making that differentiation and realizing that oftentimes the people who are providing us that data can also provide us those answers. Then a lot of times with the people that we're looking up in our libraries and on LexisNexis and things, have not really sometimes experienced the things to create the solutions in which we're gathering that data. Yes, to shift from maybe just studying people as groups of people or as situations, but also, like Justice says, as leaders and as people who have, through that adaptive resilience, learned to create solutions to these problems that we're now trying to write scholarship about. But I also think there's a very, very applied way. People go to college so that they can become social workers, and doctors, and nurses, and people who are part of these systems that are now being overrun, or that had to make these decisions off of something vague like quality of life, and are trying to come to really unimaginable decisions in really difficult times. When we go to the academic world to learn about these things I think as peers, as TAs, as Professors, as Provosts, we are an integral part of shaping how people see other people, and how people value other people, and the education that they take away. I think at this point, a lot of people are familiar with the University of Virginia study where they asked a bunch of med students a series of questions on racial bias. I think the number was over percent of students at least answered one of the questions saying they thought black people had a different pain threshold than other people. These are the kinds of things that we should be able to correct before those people, before those doctors get into that hospital and are administering care, or before that social worker is approving or denying somebody's application for something. I do think there's very real educational tools that we have the option and experiences to provide to students before they have to go out into the world and make some of these decisions, and that's a really important time to start addressing some of these biases and some of these devaluing attitudes that then have real racial and ableist implications in the world. >> Yeah, thank you. I honestly couldn't agree with you more, and perhaps if we had that, things would look different. >> Yeah. Hopefully, someday we will. I think we're trending there I hope. >> Monica? >> Those were spectacular answers. Just to draw out some things that struck me. The importance of community-based research and it's a relationship where there's recognition, as Valerie said, of different forms of knowledge. I liked what Valerie said about it isn't just about the data, it's about the answers. I think community-based research, which brings the best of community actors with the best of academic or university-based actors, is going to be very powerful where you have systematic pictures drawn of the resilience and the needs of various communities including disability community. That you have both the narrative and the stories that represent lived experience in addition to quantitative data, and together, you have the strength of persuasion. Whether your decision-maker wants to hear the numbers, or he or she wants to hear that human story. But both of those kinds of knowledge matter and have very strong persuasive capabilities. Researchers may have a budget, and yet community members or non-profits are silent uncompensated partners. I think Valerie was talking not just about the message of different kinds of knowledge, we have to financially value that knowledge, and this was a point that Justice was bringing up to, I believe, in that we have to build into research budgets a true validation and recognition of our community partners as co-researchers, as co-investigators. We have to value different forms of knowledge. We also have to value the efforts of community-based groups who are working alongside researchers to really advance understanding of these challenges. >> Very well said. I want to thank all three of you. Just to summarize some of the concepts I heard today it's that, it is definitely time that we value the perspectives of disability, and that we need to start to plan now for the future if we're going to do that. I'm going to say, and hopefully I say it correctly, I think this beautiful quote that Justice said which is, "Resilience is rooted in representation," and that spans all groups, and I think that's a really important message. I want to thank you again for taking the time to be with me today Justice, Valerie, and Monica in sharing your perspectives for this edition of the Johns Hopkins Disability Disparities webinar series. Thank you so much.