

Prioritizing Equity video series: COVID-19 & disability

In this Feb. 11, 2021, of the AMA's Prioritizing Equity series, health justice leaders and advocates as discuss the ways in which COVID-19 uniquely impacts people with disabilities. Tune in as they share immediate and long-term improvement strategies for ensuring equity.

Panel

- **Maurice G. Sholas, MD, PhD**— Principal for Sholas Medical Consulting
- **Monica Schoch-Spana, PhD**—Medical anthropologist, senior scholar with the Johns Hopkins Center for Health Security
- **Irma Gomez**— Assistant director of the learning commons at Roosevelt University and advocate for students with disabilities

Moderator

- **Aletha Maybank, MD, MPH**—Chief health equity officer, group vice president, Center for Health Equity, American Medical Association

Transcript

Feb. 11, 2021

Dr. Maybank: Good afternoon, everyone. Welcome to prioritizing equity series. My name is Dr. Aletha Maybank and I am chief health equity officer at the American Medical Association. Thanks to you all for tuning in. This is our first episode of the new year of 2021, and just really delighted and excited to really dig into our critical conversation today that we don't have enough conversation around and very clear, nor enough action around in this country. And I would have to take some responsibility for that as well. And we're at a time when all Americans are definitely facing obstacles and concerns about the present time, as well as their future. And we know people with disabilities are being impacted in many additional ways, and it goes from anything from the ability to be able to wear masks being able to go to health care centers and all the barriers as it relates to that, whether it's for

testing or vaccinations, the inaccessibility of communication tools as it relates to telehealth and many of the other tools, even in reading and is sign available as well?

And there are so many negative consequences that happen because these accommodations are not existing and there's been tremendous advocacy to make sure that we are better responsive as a health care system, but as society overall. We know there are about 61 million individuals with disabilities within this country from all parts of society. And our White House, now that we're in 2021, they have really explicitly stated and focused on guidance and that there will be focused guidance in this COVID time for people with disabilities. And we've already seen some demonstration of prioritizing equity via their actions. So we look at the inauguration and the press briefings that have remote American Sign Language interpreters, which I think is a critical model for us all. And before we move forward, I have to acknowledge that we can do better even as the American Medical Association in centering voices and actions of people with disabilities.

This series doesn't, we don't have a sign language interpreter. And so I'm really committed to holding accountability to that in the future, and many other things as it relates to people with disabilities. And making sure that we are really centering equity in it's many different facets in ways that it needs to show up. And so to help me and to help us on this journey today, we have Ms. Irma Gomez, who is assistant director of the Learning Commons at Roosevelt University and an advocate for students with disabilities at the Harvard Graduate School of Education. And she's there as well as a student, if I'm correct. Okay. And Dr. Maurice Sholas, who I have known for a while and is principal for Sholas Medical Consulting, and from New Orleans. And he's going to tell us a little bit more about him too, when he talks.

And Dr. Monica Schoch-Spana, who is a medical anthropologist and senior scholar with the Johns Hopkins Center for Health Security. So thank you all for joining us today. What I am going to ask, what I've asked and I'm going to continue doing it because I think it really works well. I heard feedback from other physicians that during this time of COVID, it's felt very isolating. We all kind of have that understanding and isolating for probably more communities than others. And so I think it was just always meaningful to hear more personally, how are you doing at this point in time? We're almost a year, a year through all of this. So how are you all doing right now? And where are you actually physically sitting in this world or physically placed in this world?

Dr. Sholas: Yes. Great, I guess I'll start. My name is Maurice Sholas, and I'm a peds rehab doctor by training. And I am sitting in my pediatric rehab clinic that I do at Oxford Health System here in South Louisiana. Part of my job representing and taking care of kids with acquired and congenital physical disabilities, put the topic we're talking about right in front of me. I live alone, and so the COVID isolation was really, really hard, but I am blessed to have a niece and a nephew that came to stay with me because their schools were closed down for a little while. So I was blessed to have a little more company and some life in the house. I've been vaccinated with both shots, and I'm excited about that. And I've been advocating for my friends and family and people at risk to step up and get

vaccinated as well. So the angst that I have around everything related to COVID, I've channeled into advocacy. So lots of emails, lots of talks, lots of burning off nervous energy by trying to do good by my fellow man.

Dr. Maybank: Great. Thank you. Ms. Hermez? Ms. Hermes. I just mixed your first and last name. Ms. Gomez?

Gomez: Hi everyone. I'm currently in Chicago, Illinois. And as you all know, I am the assistant director of disability services at Roosevelt University. I'm currently at home because Roosevelt is all virtual.

Dr. Maybank: Got it. Thank you. And how are you doing overall? How are you a year from the start of COVID?

Gomez: Exhausted? I feel like it's definitely taken a huge toll on myself, which I could elaborate later, but I'm overall relieved that there's at least a light at the end of the tunnel now.

Dr. Maybank: Great. Thank you. Dr. Schoch-Spana?

Dr. Schoch-Spana: Well, thanks for the opportunity to join everyone today. I am with Johns Hopkins Center for Health Security, which is in Baltimore, but I work remotely from my home in Austin, Texas. And I am in Texas, the oldest daughter in a large family and was helping take care of my mother. Like Dr. Sholas had said, I've sort of thrown myself into my work as a way to cope with the stresses of the pandemic. It became very personal for me when my mother passed away a few weeks ago, not due to COVID, but the COVID conditions made it very difficult to honor her passing in a way that was comforting as it would have been in normal time. So the cremation was delayed, we couldn't have a big wake back at the house. And so those interpersonal things that can bring us comfort on a regular basis were interrupted for our family as they have been for too many families in the United States.

Dr. Sholas: Dr. Schoch-Spana, my deepest sympathies. I totally, totally identify with that. I'm in New Orleans and as everyone knows, we have so many rituals here. We have our second lines, we have our jazz funerals. We have Carnival season, which should be happening right now. And part of what makes this so difficult, and tying it into disability, is that you use rituals to sort of reestablish normalcy when you're stressed. And so the things that we use to actually cope with what's going on to us are stripped from us by the public health measures. So think about this from the eyes of a kid with autism that's accustomed to a certain schedule and accustomed to their day flowing a certain way. And we just simply can't do it that way now. And that's so incredibly disruptive to that person, but also to the entire family unit that's around them. So I put that out there to say, our condolences are definitely with our colleague on this panel, but that really underscores the meat of what we're going to be talking about today.

Dr. Maybank: Absolutely, Dr. Sholas. And yes, condolences from myself as well. Thank you for sharing at this time. So to kind of continue the conversation that Dr. Sholas started, and Ms. Gomez, I

would like for you to kind of start this off and answer as well first. During COVID and even before COVID, I think people with disabilities are often made invisible by dominant culture of ableism and oftentimes have not been prioritized. And so what have been some of the key challenges? Because again, many folks don't know and haven't seen it because for whatever various different reasons, but what are the challenges that people with disabilities during COVID have had?

Gomez: Yeah. So in my perspective, because I'm an educator, I feel like students with disabilities have had the rough end of the stick. At least here in Chicago, we've had a rough patch with CPS, so CPS is Chicago Public Schools, and the teacher's union, on whether or not schools should reopen due to safety measures. And although the COVID numbers here in Chicago have gone down from where we were in November, we were about like 12,000 cases, and now we're around like 2000, 3000, but that number is still isn't zero. So the concern for parents with students with disabilities or chronic illnesses is to choose whether or not to continue online learning where teachers might have not been given the proper support or flexibility to mold their plans to an online setting, or send their kids back to in-person where they're risking catching COVID and bringing it back home. It's not an easy decision for parents or educators because the future education and the support such as therapy are tied to an in-person environment, and students with disabilities have been in the limbo phase since last March.

Dr. Maybank: Wow.

Dr. Sholas: That's such an excellent, excellent point, Ms. Gomez, because this is a two-phase hit. Think about it. If you are a kid was cerebral palsy, and you require a device to communicate, and a device to express yourself, and another device to move yourself around in space, how does all that get cooked down to a Zoom call? How does all that get cooked down to where you can actually interact from your house? So they're missing real time, real learning because you don't have access to the equipment. The second part that comes up that Ms. Gomez made that I really want to underscore here is that there are specialized people that work in the school that do these jobs. Physical therapists, occupational therapists, paraprofessionals. If they're not working, guess what? They have special skills and can get other jobs.

So when the pandemic is over, the very people that made our school systems accessible in-person are no longer working in our school systems because they had to provide for their family. So it's not really just a matter of open-shut, in school, out of school. It's really a matter of making sure there's a space and place for kids with special needs to be able to learn and making a space and place for the people that support them to stay and endure. Does that make sense?

Dr. Maybank: And so thank you. And Dr. Schoch-Spana, do you have anything to contribute to that?

Dr. Schoch-Spana: Well, I mean, just to pick up on both of those threads, which is the workforce thread and also the importance of interpersonal contact, we know that some disabled people rely on caregivers or personal assistants to meet their daily needs, but also to provide that human-to-human

interpersonal connection that's essential to overall well-being. And where this brings in the workforce issue is that, knowing that, we have to think about disabled individuals in terms of their entire social network.

So equity issues are also surfaced by the fact that we need to protect the often underpaid and uninsured workers that assist disabled individuals. So home health aides, personal care aides and certified nursing assistants. Nearly 5 million people in the U.S., many of whom receive low wages, have no health benefits and particularly early on, were faced with shortages of medical supplies, like personal protective equipment.

So that workforce vulnerability can exacerbate the vulnerability in terms of provision of care and also human to human contact. And so, issues around relief legislation and evolving financing structures for care during the pandemic, we need to really think of these caregivers and personal aides as absolutely central to the public health response and create and sustain measures that protect economic security and personal health for the workforce that is so critical to the overall well-being of some disabled individuals.

Dr. Maybank: Thank you. That's even a more nuanced part of this whole conversation that many folks don't bring up as well. And I think it really speaks to a thread that you all have really elevated is, there's also just that emotional and social toll that it takes during this time of COVID, but also being able, the ability to care for families, the ability to care for ourselves, and what does that mean and how we're able to show up. And so, Ms. Gomez, I know you've done a lot around the area of mental health as well. And can you just speak to that, some of the work in advocacy and how you have been able to navigate some of the challenges during this time?

Gomez: Yeah. So speaking from personal experience, as someone who identifies as a wheelchair user or having chronic illnesses, I'll be honest, my mental health has been very shaky. I've had multiple sprouts of anxiety and depression from thinking if I catch COVID, will my life be deemed important enough to a doctor to save me if there's ICU and ventilator shortages? To just missing the social aspects of my life as we've kind of talked about and allude. So I haven't been able to see my friends or even my dad, because he doesn't live with me, and just taking that extra precaution of, because he continues to work that I or my mom just don't catch COVID because we do have weaker immune systems. So I've personally coped with practicing grounding methods and keeping myself occupied as well. So just with work or with school.

So I know this isn't a fix all, end all for everyone. And I do want to stress the importance of having accessible mental health resources in low income BIPOC communities. Because I want to see a counselor, living in the south side of Chicago in a predominantly immigrant community, I have to go outside of my neighborhood to access these resources and wait an additional three to four months for an intake visit. So when you think about disability, it's important to also think about people with disabilities who identify with more than one marginalized identity, and how everything combined within

society has kind of set you up for failure. And this has only become more prevalent now during COVID.

Dr. Maybank: Absolutely. And Dr. Sholas, do you want to add to that?

Dr. Sholas: That blew me away. That blew me away, Ms. Gomez and I thank you for being vulnerable that way, because this comes down to value. And I want people to pause and listen to what she said. Would her life be deemed valuable enough if there is a shortage of resources? And I think, be you from a marginalized population by your race, by your gender, by your ethnicity, by your religion, but in this case, by disability. Say we have people that are dependent on ventilators to live. If ventilators are scarce, are we going to disconnect them to provide them to someone else?

So when you're working with the stress related to COVID and managing COVID, our disabled colleagues, peers and patients are struggling with stresses we don't even think about. We don't think about as able-bodied people, will my life be valued in the same way? And when that stress is there, I think it's incumbent on our medical facilities, our social work facilities, our scientists, to really embed into the system, reassuring and acknowledging that there's real trauma in wondering if you'll make the cut. And that was very powerful thought. Thank you for indulging me with that, but I just couldn't let that pass without underscoring how powerful that was.

Dr. Maybank: Yeah, absolutely. Thank you, Dr. Sholas for doing that as well. And thank you, Ms. Gomez for sharing, for your leadership. And Dr. Schoch-Spana, I wanted to speak with you on that same vein about the work that you recently did related to the guidance for vaccination and a plan to work with communities of color during this COVID time and beyond. And specifically, I want to kind of shift a little bit to solutions. And Dr. Sholas, I'm going to come back to your article that you did write in *JAMA* as well, because I think now, it's kind of, what does it look like? What does it look like to have a society that does center so that what Ms. Gomez has elevated does not happen and is not experienced and felt. And so Dr. Schoch-Spana, can you talk about the work of that task force that you did co-chair, but also some of the key things that you've found and the opportunity that presents itself as it relates to an equity framework?

Dr. Schoch-Spana: Yes. So I co-chair the Working Group on Equity in Vaccination, which is part of the CommuniVax Coalition, which includes social scientists, vaccinologists, community advocates and public health experts, trying to grapple with equity dimensions of COVID-19 vaccination. And we just issued a national report with tools for state and local leaders to implement a COVID-19 vaccination campaign that advances equity both in and through COVID-19 vaccination. The first thing is that there is that urgent work of getting as many shots in the arms of people, particularly those hard hit, underserved, BIPOC communities, but there's a second kind of essential work, which is the trust building. And we have not built out the public health workforce to carry out that critical work stream. So we're arguing for more involvement of community health workers and community-based organizations that have roots in communities of color, so that we have connections.

The argument can also be made of course, to make sure that groups who are serving disabled persons are integral to the response and part of trust-building, especially around these issues that Ms. Gomez is bringing up about whether their lives matter or not. Secondly, is the issue of the, we are now in an acute crisis response phase, but we need to think also about the COVID-19 vaccination as not just a public health intervention under urgent conditions, but an entire economic enterprise that can be deployed in a way that offers community development and economic revitalization opportunities for hard hit communities. And so we're arguing that community capital, mostly human resources, needs to be brought together with public capital and private capital. And then lastly is the fact that, while we're in a response phase, we need to be thinking about recovery in the most holistic and complete of senses.

You know, what are the systems that have failed us and failed certain social groups in the United States, such that they are bearing disproportionate impacts, physical, psychological and financial? And what are we going to do in order to rectify those upstream causes of disproportionate impacts? And so we need to put in place a strategic recovery planning process right now. We're not going to wait. It needs to be happening at the same time as the response. And so those are some of the pieces that the Working Group wanted to make public in terms of the direction that states and local leaders are taking right now.

Dr. Maybank: Thank you. That was extremely helpful. And so in thinking about pushing upstream and moving upstream to more structural solutions, also just making sure we're addressing and going to the root causes, and then having structural solutions and policy solutions. Dr. Sholas, I would love for you to connect to that based on the piece that you wrote and had published in *JAMA* last month on children with disabilities. What are those structural opportunities? What does that look like for children with disabilities?

Dr. Sholas: Yes. Thank you. I wrote this paper with Dr. Houtrow and Dr. Apkon. My deepest, deepest appreciation to them for partnering with me on this, but the piece centers around the fact that kids with disabilities, and in a larger context, adults with disabilities, should not be an afterthought. We

have to be proactive at thinking through them. That's why I really, really liked the comments by Dr. Schoch-Spana to say, we want to build into the infrastructure accommodations and things that work for all people. And that's really what I want to talk about. Too often in the school systems and other places, we make a system that works for able-bodied and an able-bodied centric perspective. And, oh, by the way, there's some people that we have fit in here.

Nobody feels empowered or incorporated when they're an afterthought. And there's nothing that proves you're an afterthought when there's no room for you, there was no voice for you, there's no protocol for you and it's clear that nobody even thought that you mattered. So all of these processes have to start from a perspective of people matter enough to not be an afterthought. People matter enough to be thought of proactively in whatever way. And so the size that fits well for one group of problems may not fit well for another group of problems and be prepared for that.

Dr. Maybank: That's awesome. Thank you for that. And so in that, so when I hear that and I would imagine many people who are listening and will listen to this in the future, are like, "Okay, so how do we do that?" How does that happen? What do we need to do to hold ourselves accountable to doing that? So, Ms. Gomez, can you just speak a little bit to that? What does it look like and what do we need to hold ourselves accountable to doing it, as health care institutions or other systems and other institutions in this country and as people too?

Gomez: Yeah. Well, first of all, I think there's a huge lack of just conversation and asking directly the person with the disability what their needs are. Because everyone with a disability, as Dr. Sholas said, even if they have the same diagnosis, will need different resources and things to keep in mind or things to keep them afloat. So just because you've seen the same diagnosis before, it doesn't mean that the exact same formula that helped one person will apply to everyone else. So in order to think about what the future will look like, we need to start asking more people with disabilities, with varying disabilities, what their needs are so that we can build with them in mind.

Dr. Maybank: Absolutely. Anybody else want to comment? What does it look like when we prioritize equity? Because that was really helpful, Ms. Gomez.

Dr. Sholas: Sure. What it looks like to me is intentionality. For example, if you're in a rural county, or as we call them here in Louisiana, parish, and you don't have access to a speech pathologist or an occupational therapist, and that's part of what a given child needs to ascend and do well in school, there should be a mechanism for that parish to partner with a neighboring parish that does have that resource. And right now, with the walls around our various institutions, we can't do that.

A great example of this that we've done here in Louisiana is that historically, nurses, doctors and pharmacists are the only three people that can give vaccinations. Well, it turns out we have a whole other workforce out there that can do this, EMS workers. EMS workers administer medications under certain circumstances. It took some relaxation of rules to open up that entire workforce, which now means we don't have to bring the patient to the center. We have people with their own wheels, if you

will, that can take that whole vaccination process to the patient.

Dr. Sholas: That's something that prioritizes people that don't live in convenient places. I think similarly, when we're talking about disability, prioritize people that don't walk, prioritize people that don't express themselves typically and prioritize people that need accommodations to be fully whole.

Dr. Maybank: Absolutely. And as institutions, as the AMA, our wonderful employee resource group called Access, they have been partnering with Access Living in Chicago, and I think Ms. Gomez, you may be affiliated with the organization, to help bring in education for our team and staffs across the AMA to just even start developing that kind of analysis and lens and consciousness about what it means to center and prioritize and really understand what's happening in varying communities. And there's a lot more work that we have to do, but I think as folks are listening in, I always say the first part is either read, be curious, Google. There are so many ways in which we can take that first step that are really very accessible to some level to many of us. And we just have to have an intentionality, as you mentioned, Dr. Sholas to do that.

As we close out, because these conversations move by very quickly as usual, with a lot of great content and information. But Dr. Schoch-Spana, I wanted to give you a little bit of space to say anything to close out. And if you all have a word or two of closing, please be welcome to say so, but Dr. Schoch-Spana?

Dr. Schoch-Spana: Yeah, intentionality is good, concrete proof that changes on the way. It needs to be embedded in infrastructure. There needs to be resources invested. There need to be open, inclusive, participatory planning that that bring many voices to the table. And so intentionality coupled with infrastructure and investment, I think we can see the type of equitable or achieve equitable objectives that we're all interested in getting to in the United States. So thank you.

Dr. Maybank: Oh, thank you. Ms. Gomez, anything you want to say as a closeout for the audience?

Gomez: Yeah. To continue to learn about the complexity of disability. Because while I'm here with a disability, that doesn't mean that my perspective or my experience is broad spectrum to everyone with a disability. So I think that's really important to understand and yeah, to keep learning and keep voicing the people with disabilities and centering their voice.

Dr. Maybank: Thank you. And Dr. Sholas? As watching the program.

Dr. Sholas: As a New Orleanean, we are taught not to hide our crazy, but put it on a float and tell it to throw beads. I really, really think that people with disabilities are people first. And as long as you remember they are people first and we think about them as people, empowering them to have their voices, helping them find their agency, not speaking for them, we will be on a path to doing better. Intentionality matters, not just empathy, but action words matter. Because we're past the time for speeches and lofty rhetoric, and we've moved towards the time of show me what you really mean by

what you do.

Dr. Maybank: Beautiful. Thank you. And I would say lastly, accountability to the intentionality as well, and all the things that you all mentioned. So thank you for your time. I just want to elevate to the audience to remember to check out our Health Equity Resource Center site on our AMA website. Actually, before I fully close out, I did want to acknowledge, yesterday, the White House released their Health Equity Task Force names. And I was just really pleased in looking at that list. I think they did a fantastic job and a very intentional job, as well as held themselves accountable to what equity really looks like when you pull a committee together. Not only is it diverse, but they definitely have tremendous intention of centering voices of those most marginalized.

And I think Andrew Imparato, who is with the Disabilities Rights Center, I believe it is of California, is on the task force. So just, there are examples that are out there and really kudos to our government and to the chair, Marcella Nunez-Smith, who really was committed to making sure that that committee looked like that. So with that said, thanks everyone again for your time, and we look forward to talking to you more in the future.

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