

Health Care and the ADA-Inclusion of Persons with Disabilities

Pacific ADA Center

Thursday, February 23, 2023

>> Good morning and good afternoon, everyone. Welcome to the Health Care and the ADA: Including People With Disabilities Webinar Series. I am Pam Williamson, and I am your moderator for today.

The series of webinars are brought to you by the Pacific ADA Center on behalf of the ADA National Network. The ADA National Network is made up of 10 regional centers that are federally funded to provide training, technical assistance and other information on the Americans with Disabilities Act.

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Just a few housekeeping issues as we get started today. Our realtime captioning is being provided for this webinar, and the caption screen can be accessed by choosing the CC icon in the meeting control bar, and you can also toggle the meeting control bar permanently on by pressing the alt key once and then press the alt key a second time. Captions may also be accessed via a StreamText link that will be put in the chat area. As always during our sessions only speakers will have audio today. The rest of you will be able to communicate with us through the chat function.

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This Webinar Series is intended to share issues and promising practices in healthcare accessibility for people with disabilities. The series topics cover physical accessible, effective communication and reasonable modification of policy issues under the Americans with Disabilities Act of 1990.

Upcoming sessions are available at www.ADApresentations.Org under the Schedule tab. Then you follow to Healthcare. These webinars occur every other month on the fourth Thursday of the month at 2:30 p.m. Eastern time, 1:30 p.m. Central time, 12:30 p.m. Mountain time and 11:30 a.m. Pacific time. By being here you are on the list to receive notices for future webinars in this series, and the notices go out two weeks before the next webinar and open the webinar to registration.

You can follow along on the webinar platform with the slides, or if you're not using the webinar platform, you may download a copy of today's PowerPoint presentation at the healthcare schedule web page at www.ADApresentations.Org. At the conclusion of today's presentations there will be an opportunity to ask questions. You may submit your questions using the chat area within the webinar platform. The speakers and I will address them at the end of the session, so feel free to submit them as they come to your mind during the presentation.

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And now I am excited to welcome you to our Learning Session titled "State of Equitable Care for Persons with Disabilities: Fifty Years After Civil Rights Laws." Despite multiple laws requiring the provision of equitable care, research repeatedly demonstrates that Americans with disabilities experience disparities and inadequate care. Today's presenters will discuss major areas in which these disparities persist. Data gaps, effective communication, physical access to care, competency training for healthcare providers and staff, and nondiscriminatory health insurance benefit design. And each of these areas the presenters will discuss the current status of the field and promising future directions or solutions.

Today's speakers are Dr. Megan Morris, and she is an associate professor at the University of Colorado on Chutes Medical Campus and the director of the Disability Equity collaborative. The aim of her research is to advance the equity of care delivered to persons with disabilities. We also welcome Dr. Michelle Meade, who is a full professor in the departments of physical medicine and rehabilitation and family

medicine at the University of Michigan, Michigan Medicine. She is the co-director of University of Michigan center for disability, health and wellness and principal investigator on the equity and health functioning RRTC and Michigan SCI model systems. Dr. Meade's research is two-fold in working to identify and enhance individual self-management while also collaborating to identify and address systemic and environmental factors that contribute to healthcare disparities among individuals with disabilities, and particularly those from racially and ethnically marginalized and under-represented populations.

And last but not least we have also have Elizabeth Pendo, a professor of law at St. Louis University School of Law and Center for Health Law Studies. She uses a disability justice framework to study the impact of healthcare and anti-discrimination laws on health outcomes and experiences of people with disabilities.

At this time I'm going to turn it over to our speakers and we look forward to your presentation today. Thank you.

>> MEGAN MORRIS: Thank you for that introduction. My name is Megan Morris. I will get us started today. We have some slides to present, but we're going to take some pauses during our presentation for questions amongst the panel, and then we have allowed plenty of time at the end for discussion questions.

So feel free to send your questions along the way.

So the paper that we will be discussing today, or the presentation is based off a paper that was published last fall in the Disability and Health Issue of Health Affairs. And I would like to acknowledge our co-authors, Dr. Lisa Iezzoni and Dr. Mike McKee. And the link to the paper is in the chat.

So, next slide.

So just to set the stage, I think this is probably knowledge that many, if not all of you know. The research has demonstrated over and over that individuals with disabilities across different types of disabilities experience disparities in the receipt of health and healthcare services. And this can lead to poorer health and healthcare outcomes.

So I am giving a few examples here. Again, this is just a little taste of, again, the vast amount of research there is around the disparities experienced by individuals with disabilities.

So, we know that individuals with physical or cognitive disabilities have much higher rates of diabetes, 2.7 times, and higher rates of heart disease, 3 times, as compared to individuals without disabilities. And the recent COVID-19 epidemic/pandemic, there was a study that demonstrated that individuals with intellectual and developmental

disabilities were six times more likely to die from COVID-19 when they contracted it as compared to, again, individuals without disabilities who contacted COVID-19.

We know that our healthcare facilities -- and we'll go more into this -- are not accessible. As a consequence of, for example, exam tables not being accessible, women with disabilities, particularly physical disabilities, have much lower rates of preventive cancer screenings as compared to women without disabilities. We know that despite having high rates of insurance, that many people with disabilities, in this case 1 in 3 people with communication-related disabilities, reported difficulty finding a provider who would see them.

And then finally, our last graphic here, individuals with communication-related disabilities were three times more likely to experience a preventable adverse event in the hospital, again, as compared to individuals without disabilities.

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We know that there is a wide range of social, personal and environmental factors that contribute to the poor health and healthcare outcomes of individuals with disabilities. On this slide, I presented a few examples that, again, have been demonstrated in the literature. So decreased access to exercise opportunities, poor social support, lack of accessible housing, low socioeconomic status, decreased access to employment. And then what we'll be talking about today is disparities in quality and access to healthcare. So, again, I just want to acknowledge all the diverse social, personal and environmental factors that are out there, but, again, today we'll be focusing on the health and healthcare system. Next slide, please.

As was mentioned, there are multiple federal laws that require provision of equitable care to individuals with disabilities, starting with the Rehab Act of 1973. Which was then further reinforced with Americans with Disabilities Act in 1990, and then most recently the Affordable Care Act of 2010 does again, reinforce and expand the requirements for provision of equal care to individuals with disabilities. So you will hear throughout our presentation today, despite these three laws that have been around for decades, we still see pretty significant disparities and challenges with accessing high quality healthcare services.

Next slide. Last February, February of 2022, the National Council on Disability released a Health Equity Framework for people with disabilities. And in this framework, this report, they reported five different areas that were, again, core components for health equity for individuals with disabilities. So first was designating people with disabilities as a Special Medically Underserved Population. Second, designating people with disabilities as a Health Disparity Population. Three, improving data collection. Four, requiring use of accessible medical and diagnostic equipment. And five, requiring comprehensive disability clinical care curricula.

We will be covering 3 through 5 in this list, plus we added effective communication, and also nondiscriminatory private health insurance benefit design.

That is what we'll be covering in today's talk.

>> MICHELLE MEADE: Can I just stop? I think it's worth adding the increasingly executive orders coming out of the Biden administration have identified individuals with disabilities as medically underserved population, and that is definitely a population that needs to be included and addressed with any diversity initiatives.

>> MEGAN MORRIS: The piece that I wanted to mention, because I think it's a theme throughout what we talked about today, is the issue of ableism and structural ableism. Ableism is discrimination and social prejudice against persons with disabilities in favor of those who are able-bodied. And then structural ableism is the laws, policy, institutional practices and entrenched norms that create and perpetuate ableism.

I think a theme we'll talk about advertise, yes, these laws have been in place, but why have we seen more movement forward? And I would put out there that I think underlying a lot of the lack of movement and sort of the consistent disparities that are out there for individuals with disabilities really is rooted in ableism and structural ableism. So I just wanted to call that out and name that as we're going through our talk today.

>> MICHELLE MEADE: And if I can add to that, I think these are particularly problematic when it comes to healthcare systems. Medical systems are really, I think, torn between seeing individuals as patients, and people, once again, the medical model, they have to be cured, therefore the physicians, the healthcare provider is the one with the expertise, and individuals who are active collaborators both in their own healthcare as well as employees, faculty members, leaders within the healthcare system. And I think this tension very much underlies where the processes are and how, you know, these topics don't get sufficiently addressed.

>> MEGAN MORRIS: Absolutely. Next slide, please.

So I want to begin talking about our data needs. So, next slide.

So we can't improve what we don't measure. And unfortunately, historically, we have not been doing a good job of capturing who has a disability.

So this starts with in our public health data, we need in national surveys to be documenting who has a disability, so we can track quality of health and healthcare, again, at a population level. We can monitor trends. And then we can make informed policy decisions and changes.

And then at a healthcare organization, this is often discussed in terms of documenting disability in the electronic health field. Again, this has not been done historically. It is still rarely, rarely done in the healthcare setting. And we really need to be documenting and capturing a person's disability status in the electronic health record for several reasons. First, monitoring the quality of health and healthcare at an organization level. If we are implementing equity initiatives and interventions, we need to be able to, one, direct those to individuals with disabilities. And then be able to measure the effects of those interventions. And then, three, again, we'll talk about persons with disabilities are, due to the federal laws, required to be provided healthcare accommodations. Well, you don't know who needs an accommodation if you don't actually first start by asking who has a disability.

>> MICHELLE MEADE: So I'm going to jump in here, because I know Dr. Morris, you are doing a lot of work in this area. Can you say what are the best practices as related to this? And what initiatives you are working on?

>> MEGAN MORRIS: Yeah. So, if we go to the next slide...

I'll talk a little bit about what we're working on. So, like Michelle mentioned, I have been talking and thinking about this topic for a very long time, for over a decade now, and I have spent a lot of time talking with health systems and with patients and with researchers and policymakers, etc., about this topic. And as we all know, disabilities, it's challenging to measure, to document, because there are many different definitions of disability. Again, going back to the foundation in ableism, there also has been stigma associated with identifying as disabled.

So, one of the first questions I have gotten from health systems is: Well, what do patients think about this?

So, we have done some research with patient surveys, lots of qualitative work, and generally patients are pretty supportive. And they say things like, well, you're already asking me some pretty personal questions when I go to the doctor, so it's okay if you ask me if I have a hearing loss. I want my team to know this information. And so they just want to know that the healthcare system is using that data in a conscious way and not using it to, again, discriminate, but using it to inform provision of equitable care.

The next question I often get from health systems is saying, well, are we legally even, like, allowed to ask people if they have a disability? And the answer is yes. And there are some specifically Section 4302 of the Affordable Care Act talks about documenting different demographic characteristics, race and ethnicity, primary language, and disability status, for the purpose of tracking disparities.

We also have done some research talking with, again, diverse stakeholders, saying, what are your priorities for advancing equitable care for people with disabilities? And our number-one priority across all the different stakeholders, again, policymakers, health systems, patients, researchers, and consistent documentation of disability status in the electronic health record is identified consistently as the top research and policy priority.

So, what is going on? Currently. What we know is that health systems are struggling to implement, partly because there hasn't been, again, information on how to best do this in terms of best practices. Research to inform. How do you train your staff? And who should be asking? Etc.

If you could go to the next slide.

We have had some recent developments in policies, specifically July of last year the Office for the National Coordinator for Health Information Technology, so ONC, they are the federal body that oversees electronic health records. And they release requirements for interoperability for standardized disability data elements. What this says is that all electronic health records have to have a place where you can input disability status.

Now, it doesn't say to the healthcare systems you need to be using that field, but it really, again, their purview is just the electronic health record companies.

So in response to that, as part of what we have, the Disability Equity Collaborative, we have a workgroup on documenting disabilities, again, really diverse stakeholders involved. If you're interested in participating, everyone is welcome. Just go to our website disabilityequitycollaborative.org, and we put together a user guide on documenting disabilities. It's a here is where you get started. It doesn't have all the answers, by any means, but at least it takes from learning from, again, health systems that are currently working on it and puts it one place, and so, again, hopefully it is a helpful guide for health systems getting started. I hope that answered your question, Michelle.

>> MICHELLE MEADE: Sorry. It does. I would also like to add, if possible, some of the work that we are doing here at the University of Michigan, and so the -- I put an article in the chat, and hopefully it will be advanced, about a recent article published in JMIR about the disability and accommodations field. So our accessibility task force is working on a field and questionnaire within Epic that can be pushed to patients to ask about not only disability and disability accommodations, you know, once again having that knowledge beforehand so that practical steps can be taken.

This is once again, problematic, because there are questions about, do people actually identify having a disability, especially older adults and how is that seen? There's a question about do the clinicians actually know how to provide these accommodations?

And then another issue coming up is who is responsible and who needs to know this information as the patient comes in. During COVID this was particularly relevant when people were screening and not allowing folks in who did not have masks. And so it wasn't so much the front desk or the providers themselves who needed some pre-information to let them know, maybe language, communication issues, but the... you know, the folks checking people in are screening at the clinic level. And so a lot of important work. The best practices, I think it's so exciting that you are working on this, that there is more work going on at the federal level. But you know, I think it comes down to then the commitment of each healthcare system to, as you said, to pay attention to it and to use it to check on the quality of their care just as they do issues of gender or race.

>> MEGAN MORRIS: Absolutely.

>> ELIZABETH PENDO: I agree, if I could just add, there are other legal levers we can use to encourage this on the federal level. And they're starting to be more activity in that area, but as Megan mentioned, Section 4302 of the Affordable Care Act requires this information be collected and we use a standardized definition. There's actually another provision in the same area of law that requires collection of disability specific information. Where do disabilities go to get care? What barriers do they experience there? And who has accessible spaces and training. So it's right there as a requirement. It hasn't been funded and it hasn't been collected. So I think there is an opportunity to coordinate with healthcare systems in terms of collection of this information using these best practices.

>> MEGAN MORRIS: Yeah, absolutely.

I will also add, one of the challenges thus far in the ONC changes really helped prompt this is also coming from the electronic health record vendors. So one of the challenges that organizations have is that each person has to -- each organization has to develop their own fields and develop their own systems, and so we are actually working with Epic, one of the largest EHR vendors, and we currently have a grant from the -- through the National Institutes of Health to actually develop methods and develop a build for electronic health records that will be starting in the fall testing to demonstrate can these methods effectively, again, consistently get disability electronic health record and then also consistently link documentation of disability status to provision of accommodations.

>> PAM WILLIAMSON: Ladies, we've been asked if you can slow down just a little bit, because we have just a lot of information, so folks are wanting to make sure they're processing it.

>> MEGAN MORRIS: All right, will do. Thank you.

>> PAM WILLIAMSON: Thanks.

>> MEGAN MORRIS: All right, next slide.

So now I'm going to move to effective communication. So next slide.

Again, as I'm sure many of you on the call know, there is a federal requirement for provision of effective communication through provision of accommodations -- or auxiliary aids and services.

And in the healthcare setting, this means a wide range of communication, from oral communication with any member of the team work healthcare team, written communications, so patient education materials, doctor visit summaries, etc.

Telecommunication methods and electronic methods. And I think one key piece that really needs to be explored is the access to telehealth and then also patient portals. Because those are often ways that healthcare teams are now communicating with patients. And so more work needs to be done on making sure those platforms are accessible to individuals with disabilities. Next slide.

>> MICHELLE MEADE: I'm sorry, I think that just important in terms of noting not only the communication as related to sensory disabilities, which is definitely -- probably was more of an issue earlier in the pandemic, and they have done more problem-solving related to that, but those with cognitive impairments as well, and IDD. The idea of using platforms, using systems, having protocols that allow for access, and then, of course, social determinants of health, just to provide Internet access and training as resulted to -- and teller training, given the individual's background and abilities for each -- for this important healthcare tool.

>> MEGAN MORRIS: Absolutely.

>> ELIZABETH PENDO: And on the issue of web access, just something to keep our eye on, the Department of Justice has said that they will be developing legally enforceable standards for what does it mean for a website to be accessible. This is an issue with equipment too. We'll hear it's one thing to say "it must be accessible." It's another thing to develop technical standards that are legally enforceable that tell everyone what it means for it to be accessible. We have voluntary standards for accessibility of websites, but we don't have any legally enforceable standards yet. There's been a suggestion that they are going to be developed, but that process hasn't started yet, but it's definitely something to important to watch that impacts a lot of areas, but include -- but including healthcare.

>> MEGAN MORRIS: Great to hear, Elizabeth. I recently was involved in a case that is public out there, so we can talk about it, but it's *Boone v. University of North Carolina*, and it was a lawsuit brought by patients with visual disabilities and their lack of -- again,

provision of effective communication. And I will say that the federal judge did question, what are the standards out there for websites? And it is -- it's a problem of, again, who sets the standards? And right now without any federal sort of oversight on that, it's really left up to, in this case, healthcare organizations to define it.

I just really wanted to quickly just throw out there that there are lots of research around effective communication, and that when patients do not receive effective communication -- this is really any patient -- that there is a whole host of poorer health and healthcare outcomes. So, adherence to treatment, patient dissatisfaction, and lack of trust in providers. But when there is effective communication, we see, again, improved outcomes, increased adherence, less utilization of the healthcare. So if you understand when you go to the emergency room what is being told to you, you can go home and follow the treatment recommendations and you're less likely to need to come back into the hospital.

>> MICHELLE MEADE: I think this also then overlaps with later topic in terms of the provider training. And, you know, this isn't just training in terms of specific types of knowledge. It's really trying to do diversity training and address the add attitudinal environment, the implicit biases that people have, the ableism, the structural ableism that is present, and that results in providers not asking about key areas of people's lives, because they don't either value those or they don't think that individuals with disabilities are operating or interacting in those spaces.

>> MEGAN MORRIS: Absolutely. Next slide.

So as we mentioned, research has shown over and over, and I think many of us can sit here and tell stories of the lack of provision of, you know, effective communication. Really sometimes... say effective communication, any communication that, you know... I mean, I can just talk from my own personal family experience of family member who had a disability, was in the hospital, was tied down, not given a nurse call light, and was unable to, because of the medical condition, verbally communicate, and was left like that for days. I mean, that's not just effective communication. That's basic communication. And then on the other side, which, again, Michelle will talk about a little bit later, is that healthcare teams report being unprepared and uncertain how to communicate with patients with disabilities, and it goes back to that training.

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So, we do know that evidence-based solutions exist. We do know that accommodations do improve quality of communication. I will do a shout-out to Dr. Jan Blue stein at NYU and her colleagues recently had a paper that demonstrated in the emergency room, when they provided personal assistive listening devices to patients with disabilities, with hearing disabilities, that they saw a decrease in repeat visits to the emergency room.

So, again, these combinations can improve quality of care.

And then we also know that there is a range of communication strategies that the healthcare team can use. So these aren't just, here is an accommodation I'm going to hand you, but this is how I'm going to adapt how I communicate with you. And it's looking at the patient while speaking, using short phrases and sentences, etc. But, again, they're not being consistently used by healthcare teams. Often due to lack of education and awareness and in many cases biases.

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So, I often get the question of, okay, why aren't healthcare organizations providing accommodations, providing effective communication? And I put this diagram here. This is what I have -- we've done interviews with lots of health systems, and this is -- many of the main barriers they are reporting, experiencing.

The first is you have to convince your leadership and your providers and your staff on the need and importance for documenting disability status, providing accommodations, providing education, etc. And this is where oftentimes attitudes, negative attitudes and biases and ableism is coming in. Again, I can tell you stories of quotes from leadership saying, you know, they would rather just pay out ADA lawsuits than even think about trying to be accessible for patients with disabilities, and complaining that most people with disabilities are faking their disability, so why should we worry about providing them accommodations, etc.

>> MICHELLE MEADE: And this is, I think, one of the areas to me is mind-blowing. Because it's this tension of many of the people who receive care at healthcare systems, especially multiple ways have either temporary or permanent disabilities. And so it would seem to make sense that if we're going to improve population health, if we're going to really provide the best possible care to everyone, that even if it's just as patients and not as individuals with disabilities, that we think about the accommodations and strategies. And so the ableism and just the lack of awareness about, I think, this population is this is where it comes in, that we don't have the numbers. We can't provide the specific data about the effect this is having on our costs.

>> ELIZABETH PENDO: What both my fellow panelists are saying is so important. And part of it is the process that you see here on the slide. That too often within the healthcare system, disability rights, the right to accommodation, effective communication, etc., and patient outcomes are seen -- or quality of care is seen as separate. Legal requirements are seen as another thing that has to be thought about on top of providing high quality care to patients. But, in fact, they're deeply, deeply related. And part of that is like bridging different cultures of law, of medicine, of public health in different areas, and understanding how to communicate the idea that

respecting the rights of your patients with disabilities is inherently linked to providing quality care and pursuing the best outcomes. They are not separate. And I think that's why we have to think very carefully about what type of education and training is provided, and are these connections made, and is it made by, with, for people with disabilities.

>> MEGAN MORRIS: Absolutely.

So I'm going to go to the next slide and with that turn it over to Michelle.

>> MICHELLE MEADE: We may want to go back some.

>> LEWIS KRAUS: Hold on one moment. Sorry.

>> MICHELLE MEADE: Many of these topics we already talked about, and we heard the physical access to care isn't there. Do you want to go over to the next slide?

That you have both the challenges of getting to healthcare environments, particularly that are more problematic for individuals with mobility impairments, whether it is because of the ability to get transportation, the ability to have someone else take time off to go with you, just having routes or parking spots. As well as, you know, the problems with the healthcare environment themselves. The ADA has definitely improved the structural environments that are at healthcare facilities but while there have been attempted to standardize and implement legal guidelines related to the equipment, those haven't been well-integrated or uptick. And when they're there, the lack of training by providers means they're not being used. And so once again, the ACA mandated the involvement of accessibility boards to try and create standards for accessible testing, accessible environments. Exam tables. And you can just go through. But without both a follow-up, about who has this without enforcement, without the knowledge, about how to use them, and without funding. And so for the federally qualified health centers and other facilities for purchase and implement them, you just are continuing to have problems. And so with individuals with disabilities, with physical impairments, sometimes it's just a matter of getting in the door. Larger healthcare systems and more urban environments are often better, although once again, access to care as associated to insurance may be more problematic there. In rural areas, in areas where folks are repurposing houses, other structures, those adaptations that are needed to get people in the door and on the table are problematic. With the physical aspect of care, you very much have an issue of who is required to provide it. So even in large healthcare systems, you know, large budgets, you know, clinics and practitioners often think on the individual level. I don't have time to do that right now. I don't have immediate access to that. And so we're not responsible for it. So I think in terms of convincing healthcare systems and investing in this, sometimes it's connecting it to

patient outcomes and connecting it -- I don't know about financial ones, your comment, Megan, about "would rather pay out the ADA lawsuits" is really disturbing. Elizabeth, do you have specific thoughts about the legal components of the fiscal environment?

>> ELIZABETH PENDO: Yes. As you mentioned, it's one thing to require physical accessibility, which, of course, these laws do, but having those standardized requirements that everyone knows how to follow, you know, even -- let's imagine that you are a provider, you are the person who buys equipment for the provider practice, and you're aware of these laws and you want to have accessible exam tables and scales and chairs and imaging equipment, how would you know exactly what that is? The standards have been developed by the Access Board but they have not been adopted as legally enforceable regulations. Again, that process is -- there's been some signals that that process is going to start but it hasn't happened yet. Part of that is because there are so many priorities that the Office of Civil Rights and Department of Justice has even in the area of healthcare, let alone all the other areas of disability rights, that they're kind of working through the priorities as quickly as they can, but it takes a while for that to be adopted. I did see a proposed bill that has come out in a couple forms that is going to increase the tax credit. So when providers or any kind of small business purchases or expends money to make things more accessible, they can get a pretty significant tax credit. And there's a bill to increase both who can request that and the amount of it, which hopefully will address some of the concerns about the cost, because medical equipment can be quite costly.

>> MICHELLE MEADE: I think that's a great point. I see a comment in the chat about -- talking about more than physical disability access. Communication access tools for people with behavioral health issues. I think that's a combination of, you know, the communication guidelines and tools that we talked about, having spaces which allow individuals with cognitive and behavioral issues to receive healthcare in an environment that facilitates communication, which allows for appropriate connections, which allows them to really feel comfortable and safe within those settings. And it also relates to the issue of disability training. You know, that we have healthcare providers that aren't sure how to handle anyone with a disability. They would rather avoid it sometimes. And either because of the time involved or just because of implicit bias and fears that someone is not going to interact in a certain way, or that they don't have -- their quality of life isn't as good anyway, or they don't really need this. You know, the COVID pandemic really demonstrated how implicit bias led to the denial of care and very negative outcomes. And so there is much to be done as related to some of the disability competencies. So I can say a little bit more about that, but I know my colleagues have a lot to say in this area too.

>> ELIZABETH PENDO: I would add that the attitudinal barriers, stereotypes and assumptions and even just lack of knowledge becomes a self-fulfilling prophecy. I definitely have talked to providers who say, that's interesting information to know, but it's not a problem here because we don't have any patients with disabilities. And if you think 1 in 4 people in the United States according to the CDC have some kind of disability, of course, every provider should expect to see many different -- many people

with many different kinds of disabilities. But it may be that if you don't have the knowledge, if your space isn't accessible, if you don't have the practices and policies, if you don't understand how to provide accommodations, then patients with disabilities may not feel comfortable coming to you, and that reinforces the belief that this isn't necessary. It's sort of the same cycle that we experienced back in the 1970s when people with disabilities were, you know, unnecessarily institutionalized. That let people who weren't institutionalized believe that integrating people with disabilities into all aspects of community life wasn't difficult or perhaps wasn't as necessary, because a whole group of people were removed from community life.

So if these barriers are such that people with disabilities are not comfortable going to providers who they don't believe have the disability cultural competence or knowledge to treat them, then it's going to be another barrier to get that developed in those practices.

>> MICHELLE MEADE: And so I'll just say one more thing in terms about the disability training, because I do think -- at least at my institution I'm seeing some inclusion of disability as a diversity or a component. And while it's definitely there, within that context it's missing some practical supports and guidelines about how to really tailor care for individuals with disabilities that go beyond the attitudinal environment.

>> ELIZABETH PENDO: And going back to Megan's point in the beginning, this works on both an individual and a structural level. It's not a problem solely created by individual providers, right? And so it's not a problem that they can necessarily solve on their own. So understanding how both on the interpersonal care level, but also the systemic level, who buys the equipment, who is responsible for -- even in an accessible building, you can have stacks of things and equipment that -- in hallways that make it inaccessible. You know, how is the entire healthcare organization arranged around ensuring that people with disabilities can access care.

>> MICHELLE MEADE: And that provides to both patients as well as providers with disabilities. The idea is there is more work in the area to bring diversity to our workforce, and that will help improve care. I know Elizabeth still has to present her slides, so why don't we move on to those.

I'm going to switch gears a tiny bit and talk about something that is related, and that is disparities in health insurance coverage. As Megan mentioned at the top of the presentation, people with disabilities do have high rates of insurance, but there is a question to be explored about what type of insurance, because there is a large body of research showing that there are favored and disfavored forms of insurance among certain providers. So next slide, please.

Here is basic information. This was in the paper, you might be familiar with this. If we're talking about private health insurance, that is health insurance that you get through work or maybe that you purchase on the marketplace or could also be Tricare. That private type of insurance, a little under half of insured individuals who are adults with disabilities had that private insurance. That is a much smaller proportion than working age adults who do not have disabilities, as you can see, it's almost 75%. And before the Affordable Care Act, I will tell this story in chronological order, because things have been developing, and there's even more developing since our paper. Before the Affordable Care Act, it was really well known that some people couldn't access insurance at all, that insurance was fragmented, if you leave a job or go on to become eligible for Medicaid or leave Medicaid and get employer-sponsored care. The system was very fragmented. People fell through the cracks, and there were a lot of restrictions on coverage that left a lot of people, including a lot of people with disabilities without any coverage at all or underinsured. They had insurance, but the care they needed was excluded or limited, or was subject to such high cost sharing obligations that it really was not affordable, and as a result people with disabilities could not access care that they needed or medication or equipment or services. So that was the problem pre-Affordable Care Act. So, next slide, please.

Before the Affordable Care Act came the ADA, Americans with Disabilities Act in 1990. And when it was first passed, there was a lot of excitement around how it might apply to health insurance and how it might address some of these obvious problems that were mentioned in study after study and report after report. And on its face, the ADA does appear to apply robustly to insurance, right? It applies to employment discrimination. So if you get your insurance through work, you can use it to challenge discrimination. And it also seemed to apply to public entities who were discriminating on the basis of insurance, like Medicaid. And Title III also applies to public accommodations, which essentially means private businesses open to the public. So there was a lot of hope that insurers who offered these insurance plans could be covered under Title III as public accommodations. But unfortunately, as you can see on the slide, those hopes were dashed pretty quickly, actually, as the ADA was applied to health insurance, but it had these really major limitations. Before the Affordable Care Act lots of courts said, hey, the ADA doesn't require employers to offer insurance at all. So how much ability do we have to say what they should be providing? And lots of courts said, as long as they're providing everyone the exact same thing, even if it is less valuable to people with disabilities, because of the way coverage is structured that is fine under these laws. That definitely changed under the Affordable Care Act, but just talking about the ADA now. Some courts thought it didn't even apply to insurance. They thought it had to be a brick and mortar kind of store, a physical space that you could get into. And we see echoes of that, in my opinion, erroneous interpretation of the ADA echoing in a lot of the web accessibility questions that are being raised now. Does it have to be a physical space? And the biggest problem is that the ADA had a safe harbor exception that said if it's actuality justifiable, meaning it makes sense cost-wise, we're going to allow certain kinds of restrictions and exclusions even if they disproportionately disadvantaged people with disabilities.

So the ADA looked to be a powerful tool, but the way it was interpreted, and a major exception of the safe harbor, meant it wasn't the power tool to address health insurance discrimination that we hoped it could be. So let's go to next slide.

A lot of these issues were addressed by the Affordable Care Act. The Affordable Care Act has a lot of provisions that aren't specifically designed for people with disabilities but are extremely beneficial to people with disabilities, because it reforms insurance in lots of different ways. For example, preventing exclusion of pre-existing conditions. That applies to everyone, but it's particularly valuable for people with disabilities. But right now we're caught in this tug-of-war about how to interpret, how broadly to interpret a provision of the Affordable Care Act that prohibits discrimination. It's referred to as Section 1557 because that was the section number in the original bill, and it amends existing civil rights laws, including the Rehabilitation Act to say that you cannot discriminate on any of these bases in a wide variety of health programs and activities. Under the Obama-Biden administration in 2016, a really expansive regulation was passed. It was expansive in every way, but just to mention the health insurance part, they said health insurers cannot deny or cancel or limit or refuse to issue or renew a health insurance policy. You can't deny claims on the basis of disability. You can't impose additional costs or other limitations, and you can't engage in discriminatory insurance plan benefit design. People were incredibly excited to see that because it addressed this problem, this weakness, this limitation in the ADA, and said for the first time, this new provision, Section 1557 was going to prohibit health insurance discrimination.

So much rejoicing amongst disability rights advocates and people involved in health equity. But then came a change in administration. Under the Trump administration, a revised rule was issued. And it explicitly said it was going to significantly limit the original rule. It did so in a lot of ways, but in particular it removed the prohibition on discriminatory planned benefit design. So it pulled back the production protections of Section 1557 so they no longer extended into health insurance. And that is still the rule in place as of today. I checked this morning, because we're expecting a new rule at any time. The good news is that since our article was published, the Biden administration has proposed a new new rule. And it reestablishes the really broad reach of Section 1557, including the provisions related to health insurance discrimination. It reestablishes them. The notice and comment period has ended, so we're just waiting for the final rule to be issued. It could happen at any time. But if and when it does, it is expected to do so soon. It will reestablish the anti-discrimination requirement in health insurance and we can get to the issue of, well, what is disability discrimination in health insurance? These various different rules, the 2016 rule and the 2022 rule both give examples of what it might be. Sort of the classic example is drug tiering. Putting different classes of drugs in different expense categories. If you put all or most drugs that are used to treat a specific disability in the highest most expensive tier, that could be seen as disability discrimination. And we have seen a couple of cases, an administrative charge, and also a lawsuit filed against CVS related to this practice for putting drugs that are used to treat people who are HIV positive in the highest cost sharing tier.

So hopefully it's something to watch. Hopefully this rule becomes finalized. It will do many things, including ban discrimination in health insurance, but then we'll see some activity around understanding and wrapping our minds around what is disability discrimination in health insurance. And I'll stop there.

>> MEGAN MORRIS: I have been watching this 1557 as it has progressed. I watched it for a slightly different reason. I think it's under the same provision of kind of a requirement of nondiscrimination. There was also language in there that said healthcare entities with 15 or more employees have to

designate someone as their 1557 coordinator. And so we did see in sort of around that time an increase of organizations hiring these individuals and saying, all right, you're in charge of disability accessibility for our organization, which has -- I think it's been an underutilized resource in healthcare systems to providing equitable care to people with disabilities, but, yeah, I wonder if, you know, once the 2022 rule comes out if we'll see actually another sort of increase in organizations sort of designating people.

>> MICHELLE MEADE: Even when they are there -- because I know we have a 1557 coordinator. There are a lot of times putting out fires rather than doing proactive engagement. The ACA also mandated the education and then the tracking of education related to disability, but without follow-up, I don't know how many people are paying attention. I'm wondering if working on the state level with licensing laws may be more useful. But I think for me it's going to be the proactive components of everyone, patients and employees, having transparent processes for requesting accommodations, having someone specifically identified who can provide names and hold them accountable.

>> ELIZABETH PENDO: Right, because this idea of an ADA coordinator is not new. Section 1557, of course, covers discrimination based on race, ethnicity, national origin, sex or gender, age and disability. So it amends all of those existing civil rights laws. So it does put all the disadvantaged groups together in a way, which I think could be very helpful. But you're absolutely right that it's only as meaningful as it is envisioned, right? And we could have a very minimal vision of it, or we could have a very robust equity focused vision of it.

Also I wanted to mention something else that is in the 2020 proposed rule for 1557 that relates back to the data discussion we were having. Something new in that proposed rule is the Office of Civil Rights and HHS asked for comments on algorithmic discrimination. So this idea of clinical algorithms -- not that they're prohibited, but they have to be used in connection with clinical judgment rather than just adhered to and sort of acknowledging some of these data problems. Data could be biased, data could be missing, right? As we just heard. Data can be misleading. I think there's a false perception that using a clinical algorithm, like SOFA scores, or there's other types as

well, as we saw during COVID-19, there's sort of a false belief that it's more objective when, in fact, it's just moving the judgment to somewhere else. It's moving the judgment to where the data is collected. So really important putting us all on notice that this is a source of possible discrimination, and clinical decision making tools are necessary and have a role, but there is an obligation to ensure that they're not used in a way that results in discrimination.

>> MEGAN MORRIS: Yeah, I saw that, when the proposed rule came out, and I was excited about it, because, again, during COVID-19, we just saw the standards of care and sort of using these, you know, clinical algorithms to determine, you know, in theory who receives, you know, treatment and who doesn't, who gets an ICU bed and who doesn't, and I have seen some movement in discussing sort of algorithms and their biases for individuals, you know, from different racial/ethnic groups, but I... you know, it would be great to also see more research and understanding how these sort of, again, existing clinical tools and algorithmic tools are biasing against people with disabilities.

>> ELIZABETH PENDO: I'm working on a project with a colleague who does a lot of research around prescription drug monitoring systems, which are state databases that collect information on prescription of certain kinds of drugs, including certain scheduled drugs, including opioids. And the evidence that you could look at a risk score generated by a PDMP, of course, there's a lot of problems with how those are generated, and that could result in denying a patient care or denying them types of care that you would otherwise provide to them without sort of an individualized assessment. I think that is where disability rights law is really helpful. Actually for everyone, in terms of algorithmic discrimination. But you can't just take the result of the formula, right? There has to be this individualized assessment before you follow that tool.

>> PAM WILLIAMSON: Ladies, this has all been wonderful information, and we do have a few questions that have come in, so I would love for us to get to those before the end of our session today. The first question is... and I'm hoping that one of you knows what the terminology is here. It's right before COVID, I started to scratch the surface around AFN within my hospital system emergency management response. If you know of any work that has been done around this and can share, that would be really helpful in advancing the timeline and getting a program implemented.

So any of you able to respond to that?

AFN is access and functional needs. Thank you for the follow-up.

>> MICHELLE MEADE: I know we -- you know, at the University of Michigan, it's taking a lot of passionate advocates who are working on the ground to advanced rights, to connect with our leadership, to make some noise, to figure out where the connections are between the -- you know, the 1557 civil rights coordinator, between ADA coordinators, between office of patient experiences, and then thinking about providing the practical tips and policies. It's not expecting them -- the other maybe people in the system who are not as aware of disability to begin to try and integrate that into their

understanding and policies, but creating them ourselves and offering it then as a resource.

>> MEGAN MORRIS: And I will say, the University of Colorado, UC Health health system, we actually have had some great support from our equity officer. So we have a director of equity services, and she gets it, she gets disability. And so that has been wonderful and she meets with the ADA coordinators on a monthly basis and we're seeing really movement from the top of -- again, rolling out initiatives around documentation of different demographic characteristics, you know, veteran status, and has included disability in that. And so, yeah, it's this grassroots but also top-down approach of getting buy-in. I am hopeful that with health systems, many of them have new or growing equity initiatives that make sure that disability is included in those initiatives, and that we can move forward and that might be a way to get buy-in.

>> ELIZABETH PENDO: In terms of public health response in an emergency, there's been a lot of great work around the inclusion of people with disabilities, if you're interested in sort of training and language, I think there's a few statements on the national council for disabilities website around communication with people with disabilities during a pandemic or another emergency, and always including people with disabilities when we think about evacuation plans or distribution of vaccines or any activity we might engage in in response to an emergency.

And I think it's -- we learned... I think some of us were not surprised by what happened during COVID-19 in terms of people with disabilities, but other people saw things for the first time, and I think it was a really important learning moment. Not just for disability, but also for race and ethnicity and other marginalized identities. And it's really important that we not forget the lessons that we learn. There tends to be a repetitive amnesia, we learn something and then we forget it and then another pandemic and Crisis Standards of Care all over again. So really keeping the attention on these issues, as my co-panelists have suggested, is really important. Because the time to make these plans and think through the issues is not during an emergency. It's all the time. And planning ahead as much as we possibly can and not forgetting what we learned.

>> PAM WILLIAMSON: And that segues to another question we have. We've been talking about systems change and a couple of you mentioned the work of advocates. So what can individuals do to help push this so that the medical profession can better understand the disability issues?

>> MICHELLE MEADE: I think practically, in terms of when you are going in for a patient or a clinic visit, give them the heads-up. Let them know, you know, I have a disability, and so please be prepared to handle XYZ. Having that conversation. They may not be able to provide everything, but they can provide some. Continuing to advocate. I think sometimes it's easier to advocate as part of an organization than as an individual. Many individuals with disabilities are afraid of alienating or losing important healthcare providers. But disability groups, I think, those are great

communities, both for allow for discussing, recharging, and then taking practical steps, sometimes legal steps to push health systems where they need to go.

>> MEGAN MORRIS: We have a grant right now where we're testing a tool that collects patients' preferred communication strategies and then communicates that to the provider. And one of the things that we found was talking about the patients, is that they're making -- that they get nervous to say, oh, I don't want to seem like I am being pushy or I'm demanding these communication strategies, but on the other side, when we talk to providers, they say, oh, I never knew that they wanted me to use meaningful gestures while communicating. I've known this patient for years. This is really helpful.

And so, you know, sometimes giving providers a little benefit of the doubt of they want to do a good job, that they want to communicate well. They want to provide accommodations to people with disabilities. They're just in a system that doesn't set them up well to do that. And so being, you know, open to saying, hey, can I request this, this is what I need, and I think we're all so -- people with disabilities, people without disabilities, we're all nervous about being labeled the problematic patients, but if you aren't getting accommodations you need and your appointment is taking longer then you're going to be labeled as the problematic patient. So let's be upfront and say, hey, these are things that actually may make my appointment be more efficient and go better, can we make sure they're in place for my next visit?

>> PAM WILLIAMSON: Great advice. Thank you so much. We have another question. It says, to overcome the disconnect or silo mentality between legal requirements and quality outcomes, how do you appeal to the health system need to avoid reimbursement penalties for patient readmissions within 30 days?

>> MEGAN MORRIS: I will say that it is appealing to a few different things. Equity. Appealing to, you know, you got into healthcare to provide quality care and take care of people. This is a population that you also need to pay attention to. So from an equity perspective, what I do... we are seeing from some health systems that they are finding that providing accommodations upfront is, again, making the appointments go faster. This are rare, so harder with data, but there is some evidence to suggest that it decreases staff injuries because they're not having an adjustable exam table, so they're not having to manually lift someone on a table. Again, there's patient errors or patient -- like I heard stories of people being dropped on the floor when they get transferred. So some of the safe patient handling outcomes and I -- I'm a researcher, so I see it is a bit on me and my colleagues as researchers, we need to do that research to demonstrate improved outcomes and, you know, we need more of that to, again, be able to hand to our colleagues and health systems demonstrate, hey, we can decrease readmission

rates. We can decrease, you know, hospital infections. We can increase our vaccination rates if we do -- if we provide these accommodations.

>> MICHELLE MEADE: And then I think we not only have to provide that to the organizations, but also the insurance companies. And let them also make the case.

>> PAM WILLIAMSON: Excellent. So we have another question that has been asked, and it says, this is going back to the data that we have been -- that we talked about earlier. Who is collecting the data for documentation? And I would like to expand that a little bit, I know that we talked about data being included on the electronic records, so I guess part of the question is, where does it go and what difference does it make?

>> MEGAN MORRIS: I would say it is lots of people in the health system. I'm talking about specifically in the electronic health record. But as we -- as panelists have mentioned, it's best to have that information early and then counter, so the healthcare team can be prepared for the patient. So generally registration, check-in, scheduling, those are the staff members who should be documenting disability status, so it's in there, again, the team can be prepared. One thing I will say is we have really tried to separate out a documentation of disability status and like a disability diagnosis. And so those are two separate things. And so you do not need a medical -- like a trained physician or nurse to assess someone's disability.

This is a self-reported disability for, again, tracking quality of care and providing accommodations. Some organizations are integrating into the patient portal. So patients can go in and report a disability themselves.

>> ELIZABETH PENDO: This data is being collected on the federal level. The Affordable Care Act required the U.S. Department of Health and Human Services to include these disability questions in its federal health data collection projects. That is not going to filter down to individual patients as Megan was talking about having in the medical record, but it's an important source of information because it helps us identify health disparities and measure whether on a large scale our policies and practices are actually moving the needle and decreasing those disparities. So that is another kind of source where you would look. And that -- those federal data collections, as well as patient medical records are places where researchers look to do research. So if it's missing in the electronic health record, then it's missing as a resource for research, as well as for individual patient care.

>> PAM WILLIAMSON: I think we have time for one more question. And this goes back to training and the disability competency curriculum. You know, I know after reading your article and some folks have mentioned this, so that you know, it is starting to make its way into some of the educational realm for medical professionals. So what do you

see in the future if you could have your crystal ball about how it might be more prevalent in the education?

>> MICHELLE MEADE: What we're finding is that the medical students want it. And that the healthcare system, that medical schools are more likely to respond to their requests for that than they are ours as faculty member. And so we're having increasing medical student groups focused on disability. We're having them lead the conversation.

>> PAM WILLIAMSON: All right. Any other thoughts on that?

>> MEGAN MORRIS: I will just say that I agree with Michelle. Yeah, we're seeing more in medical schools, and it is often led by medical students who are asking for this curriculum and this content.

And I would just say, though, we need to make sure -- back to structural ableism, we can train medical students, but if they go into a health system that is biased and they, you know, again, structural conditions are contributing to disparities, then maybe some of that knowledge may go out the window. So we need to think about, again, all of the different stages of education, which is really tricky for a practicing clinician, especially since COVID. There's a lot of burnout and stress providers. So how do we incorporate training? But also, again, helping people just do the right thing. And that might be not sitting them down and saying -- giving them an hour lecture, but maybe working into the healthcare environment some, you know, kind of quick learning opportunities that they can, again, have some immediate successes with a patient with a disability and take that forward.

>> MICHELLE MEADE: I know one of the strategies my colleague, Dr. McKee has started doing is developing best practice alerts. And so when an individual with a disability is seen, the medical record, things will pop up about consider doing this test, because they're at higher risk of diabetes or heart disease or such. And so the just-in-time type of information and learning I think it's another way that we can begin to integrate those best practices and those training.

>> ELIZABETH PENDO: And on that structural issue, to also think of training and education for everyone involved in the healthcare enterprise. Providers, of course, but also office staff to make the appointment who can ask, do you need an accommodation, or if they're asked to provide accommodation, would understand how to handle that in the best way possible. The folks who purchased medical equipment and helped design physical spaces for large healthcare systems, right? If it's a structural issue, it means everyone needs to be aware of this to really most effectively deal with ableism.

>> MICHELLE MEADE: And if it's an equipment issue, there needs to be a resource directory about where accessible equipment testing devices, resources are located. So that those can be accessed.

>> PAM WILLIAMSON: Megan, Michelle, and Elizabeth, I wanted to thank all three of you for your wonderful information today. It has been quite informative, and I know that folks on the line, as well as myself, have benefitted from it.

And we realize that several of you may still have questions for our speakers or that you may have questions about the ADA. So if you would -- you can contact your regional ADA Center at 1-800-949-4232. And you also will receive an email with a link to today's online session evaluation. So please put the complete evaluation for today's program, because we do value your input, and we do look at these very carefully.

Again, we want to thank our speakers today for sharing their time and knowledge with us. And as a reminder, today's session was recorded and it will be available for viewing next week at ADApresentations.org/archive.php.

Thank you for attending today's session. And we look forward to having you join us next time.

>> ELIZABETH PENDO: Thank you, everyone.

>> MEGAN MORRIS: Thank you.

>> MICHELLE MEADE: Very exciting. Thank you.

>> AUTOMATED VOICE: Recording stopped.