

Health Care and the ADA-Inclusion of Persons with Disabilities
Pacific ADA Center
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>> AUTOMATED VOICE: Recording in progress.

>> PAM WILLIAMSON: Hello and welcome to "Healthcare and the ADA: Including People with Disabilities" Webinar Series. My name is Pam Williamson and I'm from the Southeast ADA Center and I'm your moderator for today's webinar. This series of webinars is 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 about the Americans with Disabilities Act. You may reach your regional ADA Center by dialing 1-800-949-4232.

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Today's session, ADA National Network learning is titled "Health Equity and Disability: Impacts of Unconscious Bias and Diagnostic Overshadowing."

While everyone has an unconscious bias as a result of our own experiences in histories, biases towards individuals with disabilities can result in inequitable healthcare and poor health outcomes for these patients. Diagnostic overshadowing is rooted in unconscious bias and occurs when new symptoms are attributed to preexisting conditions. This can cause misdiagnosis, delayed or unnecessary treatments, and/or poor health outcomes. This presentation will review a variety of case study examples of the impact of biases and diagnostic overshadowing on patients with disabilities. How patients biases may impact healthcare outcomes and strategies to address and overcome biases in healthcare. Today's speaker is Holly Darnell. She is an ADA coordinator with the UCHealth in Colorado, and her role is focused on accessibility, healthcare access and equity for patients and visitors with disabilities at outpatient medical clinics. Holly, I will now turn it over to you. Thank you.

>> HOLLY DARNELL: Thank you, Pam. Like Pam said, I am an ADA coordinator with UCHealth System in Colorado. Our health system has 12 hospitals and over 150 outpatient clinics, primarily in Colorado, but we do also have some clinics in Wyoming and Nebraska. I mentioned my role in terms of the fact that I do not handle ADA accommodations for employees, only for patients. And just so you know where I'm coming from in terms of presenting this information, this is a topic that is very interesting to me and one that I have research and presented within our system to our staff, but it certainly is not something that I would consider myself an actual full-on expert in, as I do not research things like bias and diagnostic overshadowing. I just want to put that caveat out there. Please ask whatever questions you have, and if it's not something that I have the answer to, we'll try to find you an answer.

Next slide.

Today we're going to talk about unconscious bias, types of bias, and how bias might work for people or against people with disabilities in healthcare. And then we're going to spend the bulk of the time talking about diagnostic overshadowing as Pam mentioned, we have case examples that we'll use to highlight what this looks like when it's in action, but also spend some time discussing strategies to overcome this both for providers and individuals who work in healthcare but also for patients.

Next slide.

This quote comes from one of the case studies that we'll talk about in a little bit. I think it really highlights the importance of this topic. This is a patient with multiple mental illness disorders, speaking about her experience in healthcare. And she says, "I sometimes find myself tempted to leave them -- referring to her medications for her mental illness disorders -- off the list of medications that I provide to practitioners. I worry about how disclosing my medication regimen may influence the way a doctor views me. I almost never reveal I have bipolar disorder because of the stigma associated with that diagnosis."

So, for those on the call that work in healthcare, you can see how if patients are not feeling open enough and trusting enough to tell us their full medical history, that could impact the care they receive in a variety of ways. Next slide.

So we're going to start our talk on unconscious bias with a couple of examples of the way that our brain can automatically fill in information without us realizing it. I have two examples that are primarily visual. One is an auditory example. I'll do my best to describe both thoroughly for though who may not be able to see or hear the examples. The first example, you have two faces on the slide. I want you to take a minute to look at them. For most people one of these faces will appear to be more feminine and one will appear more masculine. As you look at them, see if you tend to gravitate towards one being one of those ways and then I'll explain the image in just a moment. Next slide.

So we have two faces here. Typically for most individuals they would say that the face on the left appears more feminine and the face on the right appears more masculine. However, these images are the same face. The only thing that has been changed is the contrast between the face and the skin done and some features, so that the face on the left that people would typically say is feminine has left contrast than the face on the right that people typically say is masculine. So our brains have stored information about the way that we perceive these types of features in people, and we use those things unconsciously to fill in when we don't have full information from our visual system. So these images both are only showing faces from about the middle of the forehead to the middle of the chin. We aren't getting any other information, such as hair or clothing, jewelry or other things that might give us the information on the conscious level to assign features to be more feminine or more masculine. In this case, simply changing the contrast of the skin gave us cues on a subconscious level that our brain typically uses to designate those categories. Next slide. The second visual example we have an image here, and without describing it too much, because it will spoil it at first, I'm curious to see if you can find 16 circles in this image.

When you first look at it, you may see a series of rectangles that appear to be sunk in, almost like panels of a door. I'll give a moment to look for those circles. Next slide. So this illusion is called the Coffer illusion and it relies on our brains nature and experience on what we commonly see to fill in gaps and identify objects. Most people it's the series of vertical lines and rectangles, because that's mostly what we see more

commonly in our day-to-day lives. But once you get some information and cues to look for the circles, then they tend to pop out and to appear once you have cued your brain with what you want it to look for. Once we see the circles, sometimes we go back and forth between the rectangles and the circles and even see both possibilities at the same time. So there's no one right or correct way to see the image, because it's inherently ambiguous. We can see both things at the same time or once our conscious brain knows what we want to look for, we can find things that we maybe don't automatically see in the image. Next slide.

This is our audio example. I will have the host play it and then we'll talk about what we gain from this.

>> So what you will hear is a sentence, a spoken sentence that's been transformed by a computer to sound like gibberish. So...

[computer-generated tones]

Any idea what they said?

>> No.

>> Okay. We can hear it one more time.

[computer-generated tones]

>> Now we'll hear the real sentence.

>> The constitution center is at the next stop.

[computer-generated tones]

>> Does it make sense that time?

>> Yeah. Wait, was that the same...

>> It was the exact same sentence you heard the first time.

>> No way!

>> Your brain is always using prior information to make sense of new information coming in. So once you know what the sentence is, when you go back and hear the distorted version you can apply that information and it makes sense.

[computer-generated tones]

>> HOLLY DARNELL: So in this example, as they said, we had a sentence that was changed using computers to make it to where you wouldn't know what it's saying offhand. But once you hear what it's actually saying, if you go back and rewatch this, even after the webinar, you will now likely always hear that sentence in the jumbled version of the audio because your brain has that reference to pull from.

Next slide.

So how do these exercises relate to bias? Well, first let's talk about bias and what it is. Bias, as a whole, are tendencies, inclinations or prejudices towards or against something or someone. They can be conscious. The things that we really know about people on a conscious level that we're able to acknowledge. Or they can be unconscious, things that might influence our understanding, actions and decisions in an unconscious manner. And that's really the examples we're highlighting. Based on what we have seen and experienced in our world, our brain uses that information to fill in gaps on an unconscious level without us even realizing it's happening. Next slide.

So biases are typically described as being stereotypes or prejudices. Stereotypes are fixed, overgeneralized beliefs about a particular group or class of people, while prejudices are unfavorable beliefs formed without basis. They are a prejudgment or unjustifiable attitude of one individual or group towards another. But it's important to note that everyone has biases. And biases as a whole are not inherently good or bad. Some of our biases are hard-wired into us through evolution, things like safety, recognizing animals or situations that pose a risk in igniting our fight-or-flight response. Others are learned through socialization and combination of genetics and experiences. Biases allow us to make choices in an efficient way. They can be adaptive when our decision making is enhanced by biases and maladaptive when they cause us to rely on faulty information or don't generalize to a situation in which we are applying. Typically prejudices are those maladaptive biases and are things that are maybe formed without basis or applied to groups of people where they don't actually apply.

Next slide.

So a little more on unconscious bias. Unconscious bias is an automatic mental shortcut that helps us process information and make decisions quickly. This can affect our understanding actions and decisions based on attitudes and stereotypes and the way that we perceive those. Again, unconscious bias is normal. Everyone has biases. I'm not here to say that there are people in this world who this presentation does not apply to. We all have biases. We'll talk more at the end of the presentation on our strategies and the work that we can do to recognize and address the biases that we might have. And similarly to just bias as a whole, unconscious bias is not always a bad thing. Next slide.

I like to frame this conversation with some different labels and ways we can think about unconscious bias, and we'll refer back to these as we look through the case studies. It can sometimes make it easier to pinpoint and pull out the ways that bias might be at play. And this is not an exhaustive list. There are likely other types of biases in the research. So the type of biases we'll use in the conversation today are attribution bias, or we somewhere a tendency to explain a person's behavior by referring to their character rather than situation that might be impacting that behavior. And affinity or similarity bias refers to a tendency to gravitate towards people similar to ourselves. This one is often discussed in hiring, the way bias impacts hiring process when companies or organizations or individual hiring managers have a tendency to gravitate towards people that are similar to themselves.

Confirmation bias is where we attribute our own bad acts to forces outside of our control, and other people's bad acts as indicative of who they are as a person, or sometimes this can be used to describe situations as we'll talk about in a little bit with our case study examples where we're biased towards information that confirms the things we already believe to be true.

Halo bias occurs when we perceive one great thing about a person and that affects all of our other opinions about them. Opposite of that is horns, where we generalize one negative aspect of a person to all areas of that person or to all people like that person. And then lastly the prototype bias is where we assume that someone is not the perfect fit for a role or task based on stereotyping. And like an example of this, a riddle that many of us may have heard, where if you have a son and father who are in a car accident and they arrive at the hospital, a surgeon is taking the son back to surgery and says, I can't perform the surgery, this is my son, how is that possible? Most people would then start to think of explanations such as, this is a grandfather, it's a male partner or a husband or a stepfather, and we don't necessarily always immediately think this could be the boys' mother because societal influences have led us to have stereotypes and preconceived notions about who is a surgeon and what do we think of when we picture a surgeon, and in some cases it often not immediately going towards a female. Next slide.

So, there's lots of impacts of unconscious bias. Some of those are microaggressions. Microaggressions are statements, actions or incidents that might be indirect, subtle or unintentional discrimination against members of a historically discriminated community, such as people with disabilities.

I have some examples here of people that might be considered microaggressions towards people with disabilities. Things like "I can't believe you are married." Or we don't necessarily think that someone has an identity outside of being that person with a disability. Or we don't think that they can achieve or are capable of doing the same things as others without disability.

"We all have some disability." Or "You are too young to use hearing aids." Things that deny the disability experience from an outside perspective. Or "You don't look like you

have a disability" for those with invisible disabilities, or we typically think of someone more visually presenting disability, this is one they may hear a lot.

And then doing things helping a person with a disability that doesn't need help. Treating people with disabilities like a child or doing things for them without doing, seeing someone as helpless or infantilizing by treating them like a child.

And then also there's more outward ways unconscious bias affects us. Macroaggressions of course or discrimination or ableism where things are happening more potentially at a conscious level. Discrimination is the unfair or prejudicial treatment of people and groups based on characteristics, such as disability. And ableism is discrimination based on how a person may exhibit or seem to show signs of disability, or based on the way we perceive or biases we have towards people with disabilities.

So examples of these -- and I tried to make these a little more specific to healthcare, since that is our topic today. Ableism and discrimination may occur when we have a medical clinic that only has stairs to the main entry of the build and ring and we have not taken steps for ready achievable barrier removal to make our physical location accessible. It might be someone who flat-out refuses to treat patients with a disability. Or not providing effective communication for patients with disabilities. One that we'll talk about more in our case studies is making assumptions about the quality of life of people with disabilities. This was a pretty hot topic early on in COVID, where there was concern about resource allocation when things were kind of in the worst stages of the pandemic, and how assumptions about quality of life by medical providers might impact the care that people with disabilities were receiving, and thankfully this got a lot of attention where some policies were rewritten to make sure these things were not factored in as a consideration in the decision making process for healthcare.

Next slide.

So when we think about biases specific for disability and healthcare, there is a recent study by Dr. Iazzoni, which is one I cite frequently when I present education within my system to staff and providers, because I think it's pretty eye opening for people who may not be as familiar with individuals with disabilities or the healthcare inequities for individuals with disabilities. So this study, physician in a variety of care settings, asking about their perceptions of people with disabilities and how they work with people with disabilities. Some of their findings -- this is certainly not everything that came out of that study, but these are kind of the more impactful things -- only half of physicians surveyed said they strongly agreed they would welcome people with disabilities into their practices. More than 4/5 of the surveyed physicians indicated that they think that someone with a significant disability has a worse quality of life than someone without a disability. And only 2/5 of the physicians indicated that they felt "very confident" in their ability to provide the same quality of care to people with disabilities that they provide to people without disabilities.

So this is something that could be very well-rooted in their biases. These physicians likely have biases, conscious or unconscious, around people with disabilities that is impacting both their ability to provide care but also their comfort and perception of how they could engage in care for people with disabilities. We'll see how this plays out a little bit in some of our case study examples. Next slide.

So now we're going to get into our main focus topic of today, which is diagnostic overshadowing. As Pam said in the introduction, this is occurrence in healthcare specifically that is really rooted in that unconscious bias. Next slide.

So what is diagnostic overshadowing? This is not a new topic. This is not a new thing we are looking at. This first came about in the 1980s and was centered around researching why we were missing diagnoses of mental illness in individuals with intellectual disability. This idea of diagnostic overshadowing has grown as it has been researched more and applied to other populations, so definitions in the literature vary. You can see definitions on the slide specific to individuals with physical illness, learning disability, mental illness, but I think the big kind of catch-all definition is this last bullet. It's attribution of symptoms to an existing diagnosis rather than a potential co-morbid or even new condition. Next slide.

So who can diagnostic overshadowing impact? It can impact the interactions of clinicians for patients of all ages who have physical disabilities or other preexisting conditions, such as autism, mobility disabilities, mental health conditions, neurological disabilities, and any other number of preexisting conditions.

Diagnostic overshadowing can also impact patients with other characteristics, such as those with LGBTQIA+ identities, individuals with history of substance use issues, obesity. We're focusing on disability, by mention this because often we don't just have one identity. We are people with a lot of characteristics. So if you think about the fact this can occur for these other populations, and we have a patient who has a disability plus one of these other characteristics, like low health literacy, history of substance abuse, it's like this could be happening at multiple levels.

Next slide. So as we said, diagnostic overshadowing really stems from unconscious bias, and this is really only one factor that can contribute to health inequities for people with disabilities or other health conditions. So I'm not here to say that diagnostic overshadowing is the only reason why we have health inequities. We can spend hours talking about all the different reasons that contribute to health inequities, but for the purpose of time, we're going to focus a little more on diagnostic overshadowing today. Next slide.

As mentioned in the introduction, there are potential things that can happen when patients experience diagnostic overshadowing, and this will vary greatly depending on the individual situation and things patients are experiencing. Their physical condition can worsen. It might result in decreased willingness on the part of the patient to seek care because they have this experience of feeling like they're not going to be taken

seriously. It can have an impact on quality of life if we're not able to treat and improve conditions or things are getting worse. There could be a delay in diagnosis or treatment for these other new symptoms, or potentially unnecessary or unsafe care or treatment if attributing symptoms to the wrong situation and not finding the actual root cause. Again, those inequities in care and health outcomes are certainly possible, and in worst case situations this could even result in death. Next slide.

So we're going to go into case examples. I have three case examples from different patient populations, just to give examples of ways this can occur for people in various settings.

So our first case example is mental health. This is the same individual like I mentioned in the quote at the beginning of the presentation. This is a patient who has multiple mental illness diagnoses, including borderline personality disorder and history of eating disorder. She also has a history of migraines and a syndrome that is a restriction of blood flow to fingers and toes and vascular based. So she had two situations she described. In the first one she began having episodes of crushing chest pain, went to the emergency room, or ED. They ruled out a heart attack and suggested she follow up with a cardiologist. When she followed up with the cardiologist, they said that the chest pain was due to anxiety after she describes they only spent five minutes with her in the exam room. Next slide.

So then she sought a second opinion because she wasn't very satisfied and feeling anxiety and felt the provider didn't give enough care and consideration to the symptoms she was experiencing. The second opinion included multiple testing avenues and really kind of looking for a source of this chest pain, which resulted in a diagnosis of an uncommon form of decreased blood flow to the heart. I probably will pronounce it incorrectly, but it's called Prinzmetal angina. Patient started treatment with medications which quickly resulted in decrease of frequency and severity of these attacks.

Next slide. In another situation described by the same patient she began to feel frequently nauseated and have increase stomach pain. Primary physician referred her to gastroenterology, someone who specializes in the GI tract and digestive system and that resulted in diagnosis of functional abdominal pain syndrome, FAPS, and the provider told the patient she would have to "learn to live with it." The patient researched the diagnosis only find out it's classified as a somatization disorder when a person has significant focus on physical symptoms to levels that result in major distress and/or problems functioning. So typically believed to be mental in nature and often associated with individuals with mental illness and things that maybe we don't believe there's an actual root cause to this pain, but it's being exemplified and made worse by the person's mental health.

Next slide.

So, again, this patient sought a second opinion. A new provider began a series of testing and diagnosed a small intestinal bacterial overgrowth. The patient says it took

over a year for her to regain the weight lost from having these symptoms and not getting this diagnosis, and even longer to confront the emotional toll of having her eating disorder triggered by this experience.

Next slide. So what went wrong for this patient? Likely there are biases that attributed to the providers. In both cases really kind of thinking there was a mental health cause for these things that had actual physical system causes. There is a huge prominence of stigma and negative stereotypes around mental health and that could definitely have been in play here. And also this seems like it might be a case of attribution bias where providers were attributing new symptoms to things they already knew about the patient, that they had access to her diagnoses and experiences with mental health. This was a great example of a patient who was clearly advocating for her needs, sought second opinions when she wasn't satisfied with the answers she was getting, and in doing that was able to receive accurate diagnoses to have her conditions treated. Next slide.

Our next case example is one with an intellectual disability. A 15-year-old female, moderate intellectual disability and presenting with current complaints of irritability and anger outbursts, but these have been ongoing and worsening for the past year. With her disability the patient has limited expressive language skills and predominantly nonverbal in her communication.

Throughout the past year she has become increasingly solitary, expressed irritability toward family members and often late for school. Her parents reported observing strange behavioral changes such as preferring to be alone in the bathroom for long amounts of time. When they would attempt to increase punctuality or redirect from the bathroom to other tasks so she could be at school on time, that resulted in tantrums, anger outbursts and self-injurious behaviors.

The initial treatment for this patient was focused on the irritability symptoms, and she was given medication to try and decrease the irritability. However, it didn't work. The problem behaviors continued, and resulted in significant caregiver distress on the part of her parents. She ended up being brought to this multidisciplinary team of psychiatrists, psychologists, mental health nurses, people who were a little more experienced at using a structured assessment for diagnosis, in particular with patients with intellectual disability. This is maybe not common. This might have been a rare find. In this process, they were able to get additional information from the parents about what was going on. So the parents reported that this time spent in the bathroom was for personal hygiene and that the patient was undergoing repetitive and compulsive washing of her hands. When able to complete the actions to her satisfaction, she was calm. But when the parents started to redirect her to other activities, that's when the irritability would occur.

Next slide. So this led to a diagnosis of obsessive compulsive disorder, and when that treatment began, the symptoms got immediately better. They focused on medication at first because there were limits of being able to engage effectively in cognitive therapy with the patient because of her communication difficulties. But the nursing team

provided a lot of psychosocial interventions for the parents and coping skills training for the patient. They saw symptomatic and functional improvement. So she wasn't as engaged in these obsessive behaviors, which resulted in being better able to be on time for school and to engage in other valued life activities. Next slide.

So what went wrong with this case? I like this example because when we talk about things like diagnostic overshadowing and the clinician, if you will, to attribute new symptoms to preexisting conditions, that's not always on the part of practitioners. In this case it was the parents who erroneously believed these new behaviors were manifestation of her disability, which is why these things continued to get worse for the course of a year before they began to seek help and to try to figure out what was going on. Also why they didn't initially give full information and didn't really talk about the nature of compulsive behaviors that ultimately led to that diagnosis.

Similarly, initial evaluations were really focused on the irritability. They saw that as the symptom to be treated. Without really trying to assess or ask questions to figure out why is this irritability occurring and is there a mental health or other type of condition that is contributing to that irritability which is what we actually need to treat instead of just the symptom itself.

Next slide.

A little bit more about what went wrong with this case. This is a complex situation. But it's not one that completely is unheard of, for those of you on the call who are medical providers or work in the medical field.

So there is definitely challenges with typical assessment processes for someone with communication difficulties and intellectual disability. In this particular case, the specialized care team had experience in the area and had other assessment tools they were able to use so that it gave them some extra tools in their toolbox to make this diagnosis. Their structured assessment was focused more on the onset of evolution and context of behaviors, what made them better, what made them worse, versus just talking about the behaviors at a more surface level. And that's what got them to tease out the information and make that diagnosis. So you will see in terms of our recommendations later on, sometimes we need to recognize, as medical providers, when we might not be best equipped to get to the answer and utilize our networks and referral processes to find care teams like this that might be able to tease out those types of solutions. Next slide.

The last case example is for individuals with physical disability. And this was a qualitative study that interviewed multiple people, and it was focused on how their mobility disabilities impacted the diagnosis and treatment of cancer in particular. So this is not just a one single patient. This is feedback and information and findings from multiple patients. So for one patient, they typically reported that -- sorry, not one patient. This was many of the patients reported that signs and symptoms were not always taken seriously by physicians, and that was due to assumptions in some cases

that their pain was an emotional response to their chronic health condition or their physical disability. Patients reported being told that their pain was due to depression, even if they didn't have an actual diagnosis or history of depression.

A quote from one patient that I think is pretty impactful is that she had had a colonoscopy, and the provider was a high level senior provider at the organization she was going to told her, "There's nothing wrong, you're complaining for nothing. This is your fifth colonoscopy, there's nothing wrong with you." And it was three days later from this assessment that the patient got the phone call confirming colon cancer.

Next slide.

Of the patients that were interviewed, 10 of 20 reported that the cancer diagnoses were delayed due to assumptions these new signs and symptoms were disability related. Again, in some cases that was on the part of the patient, not necessarily just on the part of the provider. Patients were, again, erroneously assuming that these were manifestations of their disability. One patient's story, which, again, is one of the more impactful ones I think was a patient with a spinal cord injury who had been losing weight for two years. Throughout the process they were diagnosed with gastroparesis and told because of their spinal cord injury they digested food slower and that was the issue causing the weight loss. This patient visited the emergency room five times over these two years and this diagnosis held, even though they reported they were never actually tested for this diagnosis. Eventually the patient's weight loss became life threatening and x-ray was done to place a feeding tube when they finally found a mass next to the patient's right lung that was stage 2 Hodgkin's lymphoma.

Next slide.

So, again, in some of these cases we have symptoms attributed to depression or mental health conditions because there were biases on the providers about the quality of life of people with physical disabilities. So this is kind of an interesting spin on this topic. It's not necessarily that these patients already had diagnoses of depression or mental health concerns, but the providers made an assumption that, well, if you have a physical disability, you must be feeling this way based on what they assumed they would feel. And then attributed new symptoms to that when that was not the cause. And other cases, patients leak their own care after attributing symptoms to physical disabilities. That patient with the spinal cord injury on the previous slide I think is a good example of confirmation bias. Here they have on the record their diagnosis, and when they went to see new providers and new cases in the ED, those providers saw that diagnosis and assumed the symptoms were confirming what they already knew instead of looking to see if there were other possible explanations or if maybe that diagnosis was incorrect

We also probably have a little bit of horn's bias happening here where people are attributing physical disability as something negative and would result in these patients

having depression or mental health conditions or lower quality of life without actually knowing if that is true.

Next slide. So we saw in some of these examples patients might also have bias when they come to healthcare and that can impact their care. That's their own attribution of new symptoms towards their preexisting condition, but there might be other biases they have that impact the care experience I want you to think about a time when you had a less than perfect experience with a doctor or store or restaurant, and how does that impact you when you think about returning back to that same place or location. For most of us that negative experience will stay with us and make us less likely to return to that exact same location or possibly even similar businesses that offer a similar service, maybe it's a chain and they're part of the same chain, and that negative experience results in a bias towards that location. So for some of these patients, and I think many patients who have experience of diagnostic overshadowing or biases towards them for having a disability, they might be less likely to seek care when new symptoms occur because of the previous experiences. Or maybe they are going to underplay what is going on and they might not be fully clear and honest with us about what it is they are experiencing or the significance of these new symptoms. So we have to be sure that we are really teasing out and asking the right questions to get the right information.

Next slide.

Additionally, they might have other biases that impact engagement with providers, and it might not be related to healthcare. We talked in the beginning how unconscious bias and some of these more negative stereotypes can apply to a variety of individuals, a variety of protected classes. You might have patients who have those types of biases and that impacts their ability to trust a provider or engage with a provider or be willing to be seen by a provider. So it's important to acknowledge that this might be impacting, again, that kind of interactive dialogue, especially with the new patient to try to figure out what was going on and recognize that that could be happening and then think about different ways we can address that. We had an example in my organization's inclusion committee that was brought up recently or was someone who was hospitalized and working with one of our neuropsychologists and told her when she walked in the room that she doesn't trust people who are a person of a certain ethnicity because she doesn't think they can understand her life experience or really understand where she's coming from as a patient.

When things like that happen we want to try to meet those patient needs and see if we have other individuals within our system we can refer them to so there can be that trusting relationship in the care. And the same could be said for individuals with disabilities. If they have had a very bad experience with a certain provider, let's get them referred to someone who maybe has more experience and comfort or has had more success in working with patients with a specific type of disability.

Next slide.

So now we're going to get to kind of the big juicy meat of the conversation, which is what we can do about this. We know this exists. We have seen examples of some pretty not-great situations. How do we stop this from happening? Next slide.

The first thing we have to, and I hope we all walk away with this today is acknowledge diagnostic overshadowing exists and occurrences can be widespread and very serious. There are lots of ways we can do this, for those. Who are healthcare providers or work in the healthcare world. If you're doing any clinical peer quality assurance reviews, reviewing specific cases or outcomes or data, keep this in mind as you are evaluating these cases and see if diagnostic overshadowing or other bias may have contributed, especially if there was adverse outcome or a patient who was unsatisfied with the outcome, and then bring that up and pose that question and get folks thinking about if this is something that was at play. Next slide.

As I said before, we're going to talk about what do we need to do to address our own biases. So, again, everyone has biases. Even if you think you might not in areas that you feel pretty confident you don't you still may. So there are tools out there. I included links here, to help us reflect and increase awareness of our own biases. I want to preface this with this is not an easy thing to do. This is hard work to really take the step to reflect and think about the ways in which we might have biases and how that might impact our daily life. The Rocky Mountain ADA Center has a training that is about managing implicit bias. There is another link here for Project Implicit through Harvard University. Both of those engage in different assessment to help you realize maybe ways that you might have biases. And when you go into doing these, if you choose to do them, it's not going to come back with results saying you are biased against people with disabilities. It's more nuanced than that and say you demonstrated a tendency towards a bias in these situations or these contexts, and it gives you a little more information there is some great courses and videos in the LinkedIn Learning if you have access to that at all. I hoped to link some or include some in the presentation but I couldn't get video to embed. But if you search for unconscious bias and some of the terms we'll review in little bit about training, there's fantastic videos that talk about how to do this work and how to reflect and think about things in your own life experiences, and how they may influence your decision making, and in the interest of being fully sharing, I'll give an example of when I kind of realized my own bias. I have been working my entire professional career with individuals with disabilities, advocating for them, helping support them to meet their life goals, both in healthcare and in other areas, and a couple of years ago, when I finally started to acknowledge that I was having issues with hearing, it was hard for me to take that step and to actually get a hearing test. Think about getting hearing aids. And take that step to acknowledge that something wasn't working right for me. Even though this has been the vast majority of my adult life that I have been in this arena and with these populations, when they apply to yourself, sometimes it gets a little harder. And it made me realize that even though this is the work that I do, I was still influenced by society and biases towards hearing loss, and who do we think of when we think of someone with hearing loss? It might not be somebody like me who was in my mid-30s at the time, but it's been a huge help and made a huge difference in my life to use these hearing aids. So think about examples

like that, even for yourself, or maybe something didn't pan out the way you thought, and when you reflect on it further, it might have been rooted in a bias, unconscious or otherwise.

Next slide. I'm not used to talking this long. I apologize my voice is cracking.

So once we build awareness the impact of bias and diagnostic overshadowing, it can make us more likely to recognize when it's happening in ourselves and others. It's easy for me to sit here and say, if you see bias, call it out and make sure it stops. But that's also a very hard thing to do. I want to give you tools about how you might be able to do that, and if you can practice and think about them when not in the moment when something is occurring, it might help us feel more prepared to act in those moments. There is a link from Johns Hopkins called "Calling Out Versus Calling in." It gives specific scenarios and specific scripting you might be able to use in those scenarios. Next slide.

So when we think about confronting bias, there's concept called "being an upstander." You may have heard well-known studies about something called the bystander effect, which is where we are less likely to act in a situation when others are around, because we assume someone else will respond. A lot of popular research in this area is around situations where something pretty significant is happening. I remember learning about one where someone was getting mugged on the streets and people were not likely to call for help or call 9-1-1 because they assumed someone else was doing it. This can also occur in situations that you wouldn't necessarily think are quite as significant. There was, again, a training video I hoped to show you that I couldn't link in through LinkedIn Learning where they set up something to be like a product demonstration. And somebody was just setting up a tent. And they did this in different phases. Some phases they had groups of 10 or 15 people, some was a group of five, and some was just one person. When it was groups of people, all but one of the individuals was in on it and was an actor. And the person who was setting up the tent was really struggling with the process and take a lot longer than you would expect it to take for someone to set up a tent, and they timed how long it took that one person that wasn't in on it to offer help or act or say something. And that time significantly decreased when there were less people around. So when it was just the person by themselves, it sometimes only took a couple of minutes for them to offer help, or when they were in a group of 15 people, sometimes it took 10 minutes for them to offer help. So bystander effect can happen in a lot of these types of scenarios. And this idea of being an upstander is a challenge to that. Someone who takes actions in these situations or the bystander effect is likely to occur. Such as when we see outward bias, microaggressions, discrimination or diagnostic overshadowing. Next slide. What does it mean to be an upstander? This training is often accompanied with three different approaches we can take in these situations. And you might use some of these interchangeably. You might use more than one in a situation. And I like it because it's not all set up to be confrontational in that moment. Some you do after the fact, which might be more comfortable for some of us or in some situations. Directly challenge something in the moment, or not in the moment. Checking in with the person who was subject of the bias

to see if they're okay. An example of this might be if you're in a healthcare situation and you're maybe not the main provider, but you're involved in the clinical decision making,ing you might say, I don't think we should assume these symptoms are related to the patient's disability without exploring other options first. If you think you might be seeing the signs of that diagnostic overshadowing or that bias towards that preexisting condition.

One of the other Ds is delegate. Tell someone else who can help intervene, a supervisor or person with authority. Depending on the situation, sometimes there's power dynamics at play to where they could be actual repercussions if we were the one to directly act in that moment, and we want to recognize that. The third D is distract. Interrupt the situation or redirect the individuals who might be at risk.

So sometimes you might use all three of these. With delegate, sometimes that might also be if you're the patient, you might delegate that to the clinic manager after the fact. Sometimes we reflect on things when we're done with an appointment and then we realize, I don't think that went the way I wanted, I'm starting to realize maybe there was some bias. Let me take that back to the manager of this clinic or this organization so they can he me navigate what to do next. And we'll talk more about how to utilize these as a patient. Next slide.

So, again, for healthcare providers, when we're doing an assessment and looking for a diagnosis, this is where I think we can have the most strategies to implement, to try to combat diagnostic overshadowing. So like we talked about with some of the case examples, using techniques that are designed to gain better patient engagement and a shared decision making process. Try to ask open-ended questions. Not just yes/no questions. Ask questions to dig and get more information. It's important to pay attention to nonverbal communication. What is the impact of the environment or physical setting on communication? And think about the context of the nature of the visit as well. If you are working in an emergency room or an urgent care where we typically see patients with emergent and new and often very painful situations, they might not be able to communicate as well as if it's a routine physical at your primary care provider. As we said many times so far, don't make assumptions about a person's quality of life or assume the quality of life is lessened by the preexisting conditions. And then we want to be sure we're assessing all aspects of health and wellness as potential root causes for behavior. Not just thinking something changed with this preexisting condition that is now causing this. Has anything changed?

Next slide. Again seeking help from outside support, we want to be sure we can understand the patient and how to communicate effectively with them and better sense of baseline behavior and changes in behavior. If you think back to the patient with the intellectual disability, it took a while to tease out what was the change in behavior and what was the cause of that change in behavior instead of just saying, she's been very irritable, we had to tease out the specifics to figure out what was actually going on. Utilizing the disciplinary teams when we can for patients with complex needs, as we saw in that example, it can be critical and key. And then I can't talk about disability and

healthcare without a plug to document disability-related needs and accommodations in our patients' charts and electronic health records. We as providers cannot know what patients need and implement what they need if we don't know and don't have it written down that that's what they need. For a system such as mine where we have lots of providers that share that electronic medical record, we want to be sure we document something super effective or accommodation need like effective communication, so that way it can be used in other settings and the patients don't have to continually ask for it and continually face that burden because that can impact how often they're coming in to our spaces.

Next slide.

So this is a video that really I think expresses these concepts we're talking about. So this is a provider who is meeting with a new patient for the first time and asking these types of open-ended questions to get to know the patient but also build that trust and to facilitate that positive relationship. I'll caveat this patient -- this video before we start. The doctor in this video is a real doctor. The patient is an actor. So they do not actually have the condition in which they are talking about, just so you know. Go ahead and play.

>> Ian is a 55-year-old male T10 paraplegic with metastatic pancreatic cancer. He's being treated with third line chemotherapy. Recent staging scans show disease progression. Ian's oncologist is unavailable due to extended medical leave, therefore a covering physician will be meeting with Ian virtually to disclose the results of the imaging studies and discuss his treatment options.

>> To be honest, I'm terrified, and I'm trying to remain hopeful. I'm not expecting the best news. I'm never eager to go see a provider, especially one who I don't know.

>> Ian, hi, my name is Katie Stowers. I know that usually you meet with my colleague, and so I appreciate you being willing to meet with me today. You know, your doctor told me a lot about the medical side of you. I would really love to learn a little bit who you are as a human and as a person.

>> Actually, that would be great.

>> Tell me a little bit about who you are and what you think is important for me to know about you as your doctor.

>> So I'm a rapidly aging middle-aged guy with a family, and a useless dog, and all sorts of stuff, and I have a bucket list that is not complete.

>> Ian, I would love to explore the bucket list with you in a little bit more detail. I'm curious if you could tell me a little bit about what day-to-day looks like for you.

>> I get up early, and I'm trying to get back into exercising. That's been a big part of my life since forever. And just trying to live each day and then do the most fun stuff, most meaningful stuff I can. My wife and I have a teenage kid, a teenager some call them. So I like to try and help out in the kitchen. I'm trying to get back into full-time work. The doctor once said, "Do you work to live or live to work?" I'm working to live.

>> Wow, Ian, I can tell there are so many aspects of your life that you have that you have such passion for and I'm curious if you could share with me some of the other things that bring you joy in your life.

>> We like to ride bikes and try to be active. My extended family is important to me. I've become a homebody, but prior to that we travel a little bit and we have strips we still want to make.

>> I appreciate you allowing me to have a little bit of a sneak peek into who you are outside of the medical record, which is the only peek that I have into you before. But I'm wondering if there's anything that you feel like I need to know about you as the doctor to be able to help care for you as best as I can.

>> I get the feeling that I'm important to you and I haven't always had that experience in the healthcare realm.

>> Well, Ian, thank you for sharing that. And I'm sorry that your experience with the healthcare system hasn't always been as positive as it could be. I think that's really helpful for me to know. If it's okay with you, maybe we'll switch gears a little bit and talk about the CT scan and where we go from here.

>> I tried to impart on Dr. Sowers that my life was full and that it was important, and I could tell by the way she responded to particular things that I said that she understood, and that made me believe that it was important to her. That nobody was going to receive better care from her than I did. I never have to doubt a provider who I trust. I never have to ask myself, would I have received different care if I didn't use a wheelchair. When I trust a provider, I can think about the treatment, I can think about getting better, I can think about recovering. And I don't have to worry about... I don't have to spend any energy at all wondering if I'm getting their best.

>> HOLLY DARNELL: I saw a comment in the chat about not being able to hear that video very well. Apologies for that. If you download the presentation, the slide and one other video, that is a clickable link that will take you to the video in YouTube if it's something you would like to refer back to or watch again. Next slide. So additional strategies for patients. We have talked about this a little throughout. But the biggest thing I want to encourage you, if you are a patient with a disability or with a different type of characteristic or protected class that you think might be factoring in with bias or diagnostic overshadowing, if you feel like that is impacting the care you are receiving, the best thing you can do is let us know. And I know that that is so hard to do. So I re-worded that phrase from our slide on upstander training about direct -- about the direct approach in terms of how you might be able to say something in that moment if you feel empowered to do so. Which is I don't think we should assume that these symptoms are related to my disability without exploring other potential causes first. Again, a lot harder to do in the moment than it is to talk about it right now. So feel free to use that too, if you really upon reflection are feeling that after the fact and you want to follow up with a provider and give them a call and convey that information. As we saw in the first case study example centered around mental health seeking second opinions when you're not satisfied with the care that you are receiving, you can sometimes be pretty impactful and life-changing if you find a provider who is better able to meet your needs. And the biggest thing that I would like to communicate to patients on the call today is to give those experiences and feedback about your experiences back to that

clinic or organization. So if it's a larger healthcare organization, not just like a single privately owned office, they very likely have someone who is in my role, either as an ADA coordinator, it might be called Section 1557 coordinator. That's part of the Affordable Care Act and part of the nondiscrimination clause of the Affordable Care Act. So the easier route to get to us would be to reach out to the manager of clinic or ask how you can get in contact with a patient representative. Patient representatives are folks within our organization, at least I know within mine, they're all clinical. I think all of them are nurses and have worked in a clinical capacity at some point before, and are the ones who receive these patient feedback, good things, bad things, and then escalate that to next steps as need. So they might be the ones that if it's a pretty significant situation and you want to file a grievance, you would start with them. But they would know who the ADA coordinator is or who within their organization has a little more experience and expertise in disability, and the ADA requirements and other things to where they can get you connected with that person. And I saw the comment about community, the hearing loss community being reluctant to request accommodations, don't know what to request or when or how. This might be the best contact for some of those patients to reach out to, if they're struggling with that process, get connected with a patient representative with an ADA coordinator, so you have someone to help navigate that with you. Because like I said, any role is fully focused on patients and making sure that patients are having their needs met, receiving equitable care, or receiving the accommodations that they need while they are in our clinics. So sometimes I don't know what is not going well if I don't hear from patients to know what we need to work on and fix and to educate or provide if we don't have it. So please feel free. Feel empowered after this conversation today to make your voice known, make that feedback known. Even if it's something good. We always like to hear the good things too. But if it's something not going well, let us know. Next slide.

That is all the content that I have for you today. I tried to go really slow and we still have quite a bit of time left for questions, which is good. I do have a number of slides at the end of this presentation as well with the references and links to some of those references, so feel free to look at those if you would like some more in-depth information about what I shared with you today.

>> PAM WILLIAMSON: Holly, thank you so much for providing this excellent information. Folks have been very appreciative in the comments and for some they said it's the first time they have ever heard this information being shared specific to the healthcare arena. So this is very exciting. Folks, we do have time for questions, and so what we would like for you to do is, if you have a question, please put it in the chat area, and I will be monitoring that for you so that you can -- I'll be monitoring the chat area and will read are the question, and then we will give Holly the opportunity to respond.

In the meantime, we do have one question that has come in, Holly. So it says, "How do you see the concept of noise?"

And in parentheses, Daniel, interacting with diagnostic overshadowing, and is it something being factored into these conversations as a separate yet related contributor to these situations?

>> HOLLY DARNELL: I would like to ask a question back, because I'm not sure I know exactly what it is you are referring to with this question, Cody. You explain the concept of noise a little bit more for me just to make sure I'm answering correctly? I feel like it's deeper than just environmental noise. So I would like some explanation, please.

>> PAM WILLIAMSON: All right. And we do have another question. Maybe later in the presentation slides do you have links to the case examples or case studies that you provided?

>> HOLLY DARNELL: I do. So there are like five slides of references. If there is one of those in particular that you are gravitating towards and you want that specific one, if it's not evident by -- this is like the formal APA format for our references, I can direct you to which one it is specifically. And as we go through this, if we go one more slide I can point them out if I see them, if I remember.

So the first one on -- what number slide is this? References 4 is slide number 51, the article was called diagnostic masking and overshadowing and intellectual disability. So that's where that intellectual disability case study came from.

The last one on this slide, my experience with diagnostic overshadowing was the mental health case study and quote at the beginning. And I don't remember off the top of my head which of these was the physical disability one. It might be -- I think slide 49 references two, the first one there. But I can double check that. So if anybody would like those articles in particular, let me know.

>> PAM WILLIAMSON: Holly, just so you know, Cody said he'd be happy to talk at later time about the information, if that would be acceptable.

>> HOLLY DARNELL: Absolutely. I want to know more about all of the things, so if there's something related that we might need to take into account as we're doing more awareness and training about these concepts within my organization or outside of it, I would love to know more about that.

>> PAM WILLIAMSON: All right. Again, if you have any questions, please put them into the chat area and I will read them aloud so that Holly can respond. So we'll give you a couple minutes to do that, in case... anyone has a question and you haven't had the opportunity to ask yet. We do have a question. It says: Are the digital charts standardized? Is there a way to have my disability, hearing loss, noted front and center of the chart?

>> HOLLY DARNELL: I wish. No, they're not standardized. It's so unfortunate. There are different companies that make electronic medical records. One of the more popular

ones is Epic. You may have heard of Epic. That's what my organization uses. And even within that organizations can customize the medical record specific to their organization. So even different organizations that use Epic might not have it set up the exact same way. What I will say is that there are a lot of initiatives around documentation of disability status, and there's people working for organizations like Epic in particular that are really focused on this and looking at it from that health equity standpoint. So trying to find ways that we can make it more prominent, that it can be more available to the staff that needs to see it. Because if it's in the chart, great. But it doesn't do any good if the staff don't see that and see what the needs are to know then what to do and what to offer that patient.

So I'll try to describe a visual of how it is with our view of Epic, when someone opens up your chart, there is a little, like, screen along the left side that is -- kind of all that key patient information. It has your photo, if we have one, and there's one part of it that says "disability needs" and it will say yes or no. If something is put in that field, it will show what it is there and you can click it to get more information. But then staff have to know to look for that. So as much as I would love to make this more universal easier thing, it's bigger than just me. And there's a lot of work happening, though can, to that effect, at some national levels and within the electronic health record organizations. So the unfortunate thing, even once documented as a patient you still might have to mention it or let people know this is documented in my chart, this is what I need for them to be able to find it. I'm hoping at some point we will have a perfect world where that is just all automated and it pops up right in their face and people won't have to continue to ask for those things.

>> PAM WILLIAMSON: Thank you so much. So we have another question/comment. Hold on a moment. I have to get back to it.

You mentioned that your hospital/organization likes to calculator to patient desires based on lived experience, E-G, the patient who only trusted providers of the same ethnic background. How you draw the line between not wanting to traumatize a patient but also not discriminating against hospital employees based upon their own identities? For example, if a patient did not want to work with Black professionals, would the hospital system grant that request?

>> HOLLY DARNELL: That is a fantastic question. So it's a very gray area, right? There is typically no hard-and-fast line to draw with some that. A lot of it will depend upon the specific circumstances of the treatment and the providers we have available, and you know, kind of the whole picture. So for that example I mentioned, where it was someone who didn't want to work with that neuropsychologist, we don't have a neuropsychologist in our system that is the same ethnicity as that patient was, because it's one of overarching-you think about that societal impacts on bias, a lot of these fields, we are typically under-represented from individuals who are not white. So finding a provider that would meet that need sometimes is just not feasible. The take-home message and fundamental thing for us in healthcare is we cannot and we will not delay care in a way that would be detrimental to a patient to meet one of these requests or

needs. So somebody expressing those types of biases we wouldn't wait for someone to be available to provide that care if it's a high-need emergent situation. I think a lot of healthcare organizations right now as well are trying to do a lot of work in this area in bias in inclusion and equity. So we have ruled out a number of trainings, including a full training on just that upstander concept for our staff to help bring awareness to these types of interactions and provide those types of upstander tools in the toolbox so that we can use when we're faced with a situation like that. So even in this example I gave, the patient expressed that concern, but it didn't mean then that that neuropsychologist did not then work with that patient. She did. She heard what the patient said. She acknowledged it. She acknowledged that she might not have the same understanding and then explained the ways that she's still there to help that patient and try to meet her needs and was able to form a bit of a trusting relationship to meet that patient's needs.

So that is kind of the approach that we would try to take. We want to hear and honor those things, but not necessarily always give in to them if it would be detrimental or in the case as you said, if someone didn't want to work with someone who was Black and it was an outward racist statement, we have ways from the upstander training we hope staff will use to mitigate that moment, or get their supervisor and somebody else higher in the chain and little more experienced to help manage what that patient is asking for. So I hope that answers the question. We don't want to open up the rains to you can request everything specific about your provider, because that just might not be possible.

>> PAM WILLIAMSON: We have another excellent question. I've seen the names like ADA coordinators in hospitals, however, lately I have started seeing other terms that are similar to ADA coordinators. What are some other names we should be aware of when we reach out for ADA coordinators at hospitals?

>> HOLLY DARNELL: Great question. So it will vary. It could be accessibility coordinator. It could be -- again, we can put this in the chat if it helps. Section 1557 coordinator. That is part of the Affordable Care Act that at one point required healthcare organizations to identify someone as being in that role and make their contact information available. That requirement has changed, as the Affordable Care Act has changed over recent years, to where I believe currently it's not currently a requirement that someone has that designation, but a lot of organizations may still have that designation. And if you're not sure about a job title to use, that's when I would say to reach out to the patient representatives and say, this is my concern, I have a disability, I'm trying to get my accommodations and my needs met. Who in your organization has more expertise in supporting people with disabilities that I can talk to? And that might cue them to find that person, if they are not identified as an ADA coordinator.

>> PAM WILLIAMSON: Thank you. Someone is interested in knowing more about your job role and where did you get your ADA education.

>> HOLLY DARNELL: Oh, that's a great question. So I think the nice thing about this type of a role is there is a variety of education experiences that someone could have that would make them succeed in this. So I by training am an occupational therapist. I

did my master's degree a number of years ago, and happened to find this position because my previous role I was doing a lot with supported employment and supported education and that's when I kind of learned more about the ADA and kind of got really interested in it. So when I knew I was ready for a change, I started searching for ADA coordinator roles, which is how I found this. That certainly is not a background everyone needs to have. The other -- there's three other ADA coordinators in my organization. We split things up. One is also an occupational therapist and the other two don't have that background. One has been an ASL interpreter, and the other started with interpreter services and then moved into this role a number of years ago. There is a training, an ADA coordinator certification training that you can do. I am guessing, Pam, you probably have a link or information about that more readily available than I do, but I did do that certification when I started that role. And that's focused on the ADA as a whole. And ADA coordinator is a role that is present not just in healthcare. State and local governments are required to have ADA coordinators. A lot of large employers will have ADA coordinators on the employment side of things, but it's very -- obviously I love the job, here talking to you so much about it, but the role and the experience that would fit that would depend on the organization and the role. But I think having experience working with the disability population and folks with a variety of types of disabilities, that you understand how that impacts their ability to engage in healthcare is pretty key.

>> PAM WILLIAMSON: And I just put the link for the ADA coordinator training certification program offered by the University of Missouri in the chat area, and that is ADAcoordinator.org.

So we have a couple more questions here. And this one says how common is psychosomatic illness? I know a lot of people with mental health issues, especially women, are not taken seriously because of physical symptoms that are overly attributed to mental health issues. How does someone know if it's physical or psychosomatic?

>> HOLLY DARNELL: That is a great question. I'm glad you mention that, because I did -- I meant to caveat that when we talked about the somatic disorders. There are genuine cases where something is manifesting as pain but not rooted in a more physical structure or system of your body. So it does happen. How frequently it happens, prevalence, I'm honestly not sure, because I'm not a mental health professional. But I think the key thing, if you're coming as a patient, and you mentioned women in pain, very true. It's even less likely to be taken seriously if you are a woman of color in pain. So if you have received one of those diagnoses and you're not sure it's accurate, that is where I think things like getting that second opinion, reaching back out to maybe your primary care provider, if you have a good one who you trust and who you like to explain the situation and see what other suggestions they have, because there might be cases where it is accurate, but there are also cases we have seen where it's not. So trust your gut and trust what your body is telling you and what you are feeling, and sometimes it might be something that for some people it makes sense and if they move more towards a mental health treatment, getting with a good therapist or

psychiatrist or psychologist, to help explore the root causes of that through more the mental health perspective will work, but that's not always going to be the answer for everybody. So that's only like half of an answer to your question. I apologize I don't know more, but I'm glad you called that out. Those are genuine things that do happen sometimes, but that doesn't mean it's all the time to every person with a mental health condition.

>> PAM WILLIAMSON: All right, we have another question. It says, what are patient rights to switch providers or fire a provider if they're not really providing good care, especially when the system has a policy that people cannot switch providers in the same practice because everyone is equally skilled?

>> HOLLY DARNELL: That is an interesting policy that an organization has. I don't know that our organization has a policy like that. I would say that as a patient you should have that right to change providers, especially if you have had a very specific negative experience that is driving that. Now, that doesn't mean -- let's say it's primary care practice with multiple providers, and you want to switch the person that is your designated primary care provider. That doesn't necessarily mean then that the health system will be able to guarantee that's the only person you're going to see for every appointment, because if you have something kind of urgent or emergent, you're trying to schedule same day, that provider might not have availability, so they might schedule you with somebody else. And I probably would not be possible or feasible to always have availability with that person. But you should be able to designate who your primary care provider is based on some on those preferences or experiences or interactions. If you have been told they have a policy where you can't do that, I would reach out a patient representative and voice your concerns about how that policy is impacting your ability to engage in healthcare with that system or with that office and ask what your options are and what you can do. And they might be the better person to help you navigate that on the internal side.

>> PAM WILLIAMSON: And I would also encourage you, if it's a person that has either Medicare or Medicaid, then they -- there's also a Bill of Rights under those health plans, and so that is another place where you can explore that, and each state has an office that manages their Medicaid, and then there's a Center for Medicare and Medicaid Services at the federal level.

All right, I believe we have time for one more question. So, I feel that the mentally challenged happen a lot to homeless and they're often overlooked. They are taken in and then released saying to come back the next day or a week later when they clearly need help right then.

So is there anything we can do about this?

>> HOLLY DARNELL: So an important thing I think that relates to this, and especially if someone is coming into an emergency room in particular for care, is there is a law called "EMTALA" and I should be able to tell you what the acronym stands for. It's

EMTALA. It's emergency medical treatment and labor act, I think. And what that says is for organizations to which it applies, which isn't going to be every single healthcare organization. For sure if an organization accepts Medicare or Medicaid, it applies to them. That is a requirement that if someone comes into our emergency room with a life-threatening condition or condition that needs treatment, we cannot discharge them until they are at a stable place. So we have to assess and find the cause and provide treatment before we discharge them. That law also says that we cannot ask questions about insurance or someone's ability to pay as a condition of providing that treatment.

So for someone like what you are mentioning who is maybe part of our homeless or unhoused population who doesn't have insurance or the financial means to pay for this appointment, legally that can't influence how they are treated medically. They still need to be given the same care and the same treatment to reach where they are considered medically stable before we are discharging them. There are definitely complexities there, because this is a population who is less likely to have a primary care provider that they can follow up with. So if they're going to have follow-up care, it's likely right back into that emergency room, right?

So just know that EMTALA is a law. It's one that, unfortunately, there is lots of violations and citations for and things don't always go as well as we want it to from a legal perspective. But if you happen to know somebody or live in an area where you know this is happening or you know of a situation where you feel like somebody was not brought to that medically stable place before they were discharged, you can raise that concern with the organization itself or with your state and medical board or your state Medicare office as a resource to go to for that as well.

>> PAM WILLIAMSON: All right. So let me check. I think we are...

This is just a follow-up comment. It says, often our Medicaid patients are pushed to the end of the line and often wait for hours for help at our local hospital and then when released they're expected to walk miles being very ill in the middle of the night.

>> HOLLY DARNELL: Yeah, is so if you happen to know those patients, see if they can advocate for maybe getting connected to social work. A lot of organizations have social workers can help connect them with resources or make sure we're not turning patients away to an unsafe situation that is going to make their health outcome worse. That is not ideal for anyone. That is very unfortunate to hear. I wish I had more answers for you for that. It shouldn't be happening is the bottom line.

>> PAM WILLIAMSON: Right. And I did just put some basic information about EMTALA in the chat for you, and it's about the rules and regulations.

So, all right, folks, we are nearing the top of the hour. So we are going to wrap up here. We know that some of you may have had questions for our speakers that we were not able to get to. However, you can contact the ADA Center at 1-800-949-4232. That number will route you by your area code to the ADA national network regional center

that serves your area. You will receive an email with a link to the online session evaluation for today. So if you can please complete the evaluation for today's program, we do appreciate your input and do take it very seriously.

I want to thank Holly again for her presentation and for her time to answer the questions, her knowledge has been valuable. And so we want to make sure that you also know that today's session was recorded and it will be available for viewing next week at ADApresentations.org/archive.php.

Thank you today, again, for attending the session. And we are wishing you all a wonderful day. Thank you!