

PACIFIC ADA CENTER
HEALTHCARE AND THE ADA WEBINAR:
INCLUSION OF PERSONS WITH DISABILITIES
9/23/21
2:10-4:00 P.M. ET

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>> LEWIS KRAUS: Welcome, everyone, to the Healthcare and ADA Inclusion of Persons with Disabilities Webinar Series. We are going to pause for a moment to determine whether the second ASL interpreter's camera is working. Can you let us know if it is working, Gussie?

>> LEWIS KRAUS: All right, we are going to proceed.

>> AUTOMATED VOICE: Recording in progress.

>> LEWIS KRAUS: Again, welcome to the Healthcare and the ADA Inclusion of Persons with Disability Webinar Series. I'm Lewis Kraus from the Pacific ADA Center, your moderator for this series. 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 ten regional centers that are federally funded to provide training, technical assistance and other information as needed on the Americans with Disabilities Act. You can reach your regional ADA Center by dialing 1-800-949-4232.

Realtime captioning is provided for this webinar. The caption screen can be accessed by choosing the CC icon in the meeting control toolbar. To turn that meeting control toolbar on, you can press the ALT key on your keyboard. We also have ASL interpreter, as you can see at the top of the screen. As always in our sessions, only the speakers will have audio. If you do not have sound capabilities on your computer or prefer to listen by phone, you can dial 1-669-900-9128, or 1-646-558-8656 and use the webinar ID of 864-8854-2838.

And I want to note that this webinar is being recorded and will be able to be accessed on the ADAPresentations.org website in the archives section of healthcare area next week.

This Webinar Series is intended to share issues and promising practices in healthcare accessibility for people with disabilities. The series topics cover physical accessibility, effective communication, and reasonable modification of policy issues under the Americans with Disabilities Act of 1990, the ADA. Upcoming sessions are available at ADAPresentations.org under the Schedule tab, and follow to Healthcare. These monthly webinars occur on the fourth Thursday of the month at 2:30 Eastern, 1:30

Central, 12:30 Mountain and 11:30 a.m. Pacific time. By being here you are on the list to receive notices for future webinars in this series. The notices go out two weeks before the next webinar and open that webinar to registration. You can follow along on the webinar platform with the slides. If you are not using the webinar platform you can download a copy of today's PowerPoint presentation at the healthcare schedule page of ADA presentations. At conclusion of today's presentation, there will be an opportunity for everyone to ask questions. You may submit your question 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. To submit those questions, you submit them in the chat area text box. If you are using keystrokes, you can press ALT and H and enter the text in the chat area. If you are listening by phone and not logged into the webinar, you may ask questions by emailing them to adatech@adapacific.org. If you experience any technical difficulties during the webinar, you can send a private chat message to the host by typing in the chat window. Again, to type your comment in the text box and then enter or use your keyboard by opening the chat box using Alt and H keys. You can also email us at adatech@adapacific.org or you can call 510-285-560 and speak to one of our technical assistants who will pass the message on to us.

Today's ADA National Network Learning Session is titled "Preparing Physicians to Care for People with Disabilities: Core Competencies and the ADA." People with disabilities represent over 20% of the American population, like other marginalized groups, people with disabilities have significant health disparities and face barriers to healthcare. Despite the passage of the Americans with Disabilities Act over 30 years ago, healthcare providers report being unprepared and uncomfortable treating patients with disabilities. To address this training gap, people with disabilities partnered with disability researchers, health educators, and healthcare advocates to create a list of six essential competencies to providing quality healthcare to patients with disabilities. Addressing core disability competencies in healthcare education will prepare the future healthcare workforce to provide quality healthcare to all patients. Today's speaker is Susan Haverkamp. Susan is a professor of psychiatry, psychology and genetic counseling at the Ohio State University Nisonger Center. She directs the Nisonger Center's health promotion and healthcare parity program. Her research focuses on health and healthcare for people with disabilities. So, Susan, I will now turn it over to you.

>> SUSAN HAVERCAMP: Thank you so much, Lewis. I'm really honored to be here and excited to be addressing you on a topic that is so important to me. Will you advance to my slides, please?

Great. Thank you. Just to start, the reason that I am talking about healthcare professionals and the importance of disability training for healthcare providers is I worry a lot about the health problems of people with disabilities and especially the significant and persistent health disparities reported among people with disabilities. I'm really troubled to learn about the barriers to quality healthcare that people with disabilities report, and I like to be part of the solution to problems, and I really believe that to the

problem of health and healthcare disparities for people with disabilities, the solution is at least in part one of education and training. So that's what I would like to talk about today. Will you go to the next slide, please? Thank you. So as Lewis mentioned, I'm at the Ohio State University Nisonger Center. The Nisonger Center is a University Center for Excellence in Developmental Disabilities. Our mission is to provide quality, interdisciplinary training, clinical care, and research in the support and inclusion of people with developmental disabilities in all aspects of community life. I'm also very fortunate to have the support of the Centers for Disease Control and Prevention to establish an Ohio Disability and Health Partnership, which seeks to improve the health and quality of life for Ohioans with disabilities as a state capacity-building program. I've been really lucky to use the support to train healthcare providers, which I look forward to talking with you about. The next slide...

The objectives of this hour, or what I really hope you come away with is an understanding that, although healthcare in this country has steadily improved, decade by decade, we still face really substantial health inequities for disadvantaged groups, and the group that I'll be talking about today is Americans with Disabilities. I also would like you to have a firm understanding that the Americans with Disabilities Act requires healthcare entities to provide full and equal access to people with disabilities. And as Lewis mentioned, this can be done through reasonable accommodations, effective communication, and accessible healthcare facilities. Next slide, please.

We understand about population health. We know that improvements in population health and health equity depend on training the healthcare workforce and helping them to provide care across different populations, different marginalized groups. Before I get too deep into it, I would like to come to a common understanding of what I mean by disability, but go to the next slide, please. The World Health Organization defines disability quite broadly and functionally. Disability denotes impairments of body functions and structures, in concert with limitations in activity related to those impairments, and also participation restrictions. And so you will notice that this definition didn't refer to specific types of disabilities or etiologies. People with disabilities are very diverse and can comprise people with mobility limitations, limitations in vision, hearing, cognition, mental health. It's very broad. Next slide, please. Research at the Centers for Disease Control and Prevention, 26% of adults in the United States has a disability. 26%. We also have some sense of diversity in that population. We know that among the 26%, the highest type of limitation is mobility limitation followed quickly by cognition. Independent living, hearing, vision, and self-care. Next slide, please.

So, at 26% of the population, people with disabilities represent the largest minority group in the country. Yet despite this, the healthcare system is not prepared to meet their health needs. Next slide, please.

We know that people with disabilities are overrepresented in the healthcare system. This is because they have health needs that are directly related to their health -- I'm sorry -- because they have health needs directly related to their disabling condition, and also people with disabilities have high rates of co-occurring chronic health conditions.

And despite having frequent need of the healthcare system, people with disabilities report barriers to accessing healthcare and quality care. Next slide, please.

So the world report on disability interviewed a lot of people with disabilities and found that compared to people without disabilities, people with disabilities reported poor access to healthcare and led to high rates of unmet healthcare needs, and when they were able to access healthcare, people with disabilities report dissatisfaction with the healthcare that they received. Next slide please. People with disabilities were more than twice as likely as people without disabilities to report finding healthcare provider skills inadequate to meet their needs. Next slide.

People with disabilities were nearly three times more likely to report being denied care compared to people without disabilities. Next slide, please.

People with disabilities were more than four times more likely to report being treated badly, treated with disrespect by healthcare providers. Next slide.

On the other side, when we ask healthcare providers, they report feeling uncomfortable and really unprepared to care for patients with disabilities. Significant training gaps contribute to healthcare disparities.

Next slide. We know that without disability training, healthcare providers, like the rest of the disabled population, tend to make certain assumptions. They have beliefs about people with disabilities that are untrue and damaging. For one, healthcare providers tend to really underestimate the size and the diversity of the disability population. They assume that they're not likely to see patients with disabilities in their practice and therefore may not be important for them to focus on people with disabilities in their training. Healthcare providers grossly underestimate the health and quality of life of people with disabilities. And this is really important, because if one assumes that a person with a disability has really minimal quality of life, they're really unhappy, pitiful, they're probably a burden to the family, to society, these beliefs, even though they may be unconscious, they have to affect the healthcare provider's care in the screenings that they recommend, in the interventions that they consider, and aggressiveness of treatment that they pursue.

The third healthcare providers hold inaccurate assumptions about the current and the future functional status of people with disabilities, very often assuming that people with disabilities are unable to do activities of daily living just because they don't know. They can't imagine how it's done, how it can be accomplished differently.

Importantly, healthcare providers tend to overlook cultural, economic, social identities of the person with disabilities and recognize social determinants of health. Because I think healthcare providers are so focused and preoccupied with the disability, that's really the novel characteristic in the room, that they overlook other identities that may be quite relevant to patient care. And at the same time they overlook health issues not directly related to the disability.

The next slide, I have some kind of headlines of articles that were published recently in the last year or so. Dr. Lisa Iozoni published a paper in Health Affairs that some of you may have seen. She found that many doctors have negative perceptions of patients with disabilities, and that those perceptions impact quality of care. Specifically she recruited 714 physicians and 82% of them reported that people with disabilities had a worst quality of life than people without disabilities. Only 40% of the physicians were very confident about their ability to provide the same quality healthcare to patients with disabilities as to patients without disabilities. Which is really concerning. Obviously, healthcare providers should be confident about being able to provide quality healthcare to all of their patients.

And, finally, just 56% of the physicians strongly agreed that they welcomed patients with disabilities into their practices. In other studies researchers asked physicians about their awareness of their responsibilities under the Americans with Disabilities Act, and by and large the physicians reported that they really didn't know anything about the ADA. They hadn't learned anything about that in their training, and many of them believed that it wasn't particularly relevant for their type of practice. And so I selected these titles because I think it underscores the importance of training of healthcare providers. Next slide, please.

Because healthcare providers across all disciplines -- and here I'm talking about physicians, nurses, social workers, psychologists, all types of healthcare will certainly encounter people with disabilities in their practice. For this reason it's important for every clinician to be comfortable and confident in treating this population, and this is why in my training I really push for training at the undergraduate medical education level before students are differentiated into their specialties. And we can talk about that later. I'm looking at my screen and imagining the audience out here, I really look forward to having a conversation at the end of this hour and hearing from you. And just to make this point one more time, a physician who sees 25 patients in a day, seven of those patients will have a disability. Whether that disability was visible or invisible, just to make the point one more time that disability is relevant to healthcare practice. Next slide, please.

So why hasn't this happened yet? Why aren't healthcare providers learning about patients with disabilities? Why isn't this a standard part of the training curriculum? I think there are several barriers. First of all, the inclusion of disability content has relied almost entirely on the advocacy effort of individual champions in individual programs at specific schools. So you can find really wonderful examples of disability training for healthcare providers, and almost without exception you can trace those innovative curricula to a person who has lived experience and a passion for making sure that the next generation of healthcare providers are better prepared. This is limiting, because as soon as that person leaves that institution, that innovative curriculum is vulnerable to all of the other constraints on time and resources and competing priorities and all of the other required aspects. And I get it. There are so many things that medical students need to learn, and we only have so many years to push that information out. It's very

difficult to make time for even something as important as disability. And so the next -- oh, and I see that my numbers are misaligned, that's not intentional. The third thing is that school accreditation requirements and the professional licensure requirements. So when programs are accredited by the American Medical Association or the association of American medical colleges, they are expected to meet certain criteria in order to have an accredited medical school. Disability is not listed in that criteria, in those criteria. Neither, when the student goes on to attain a professional license on their board exams or licensure exams, there are not disability questions. And students, you know, it's not too long in medical school before they realize they cannot possibly learn everything that is there to be learned, and they have to choose. And the students become very sophisticated about putting their effort towards the content that -- for which they'll be evaluated. And so we know that in doctoring classes, they're trying to impart soft skills about patient communication or patient care, that the students, though they love that content and they're committed to becoming the very best physician they can, they will skip that class because if they know they have an exam in something that counts towards their boards. So we need to get disability to count.

And the last thing here is a barrier to implementing training in healthcare programs has been a lack of systemic organizing framework, and I'll talk about that a little bit more, if you move to the next slide.

So as I just said, there have been some really innovative disability curricula that were developed, evaluated and published, and I have a list of citations at the end, if you're interested in the slides, they'll be available to you. And I can say that for each of these really innovative brilliant curricula, learning objectives, curricular content, and evaluation measures were developed independently for each one. So each team of health educators, it's really recreating the wheel, thinking about what is it that we need to teach our students, what do they learn about disability, how are we going to teach that and how are we going to measure the change? Which is an awful lot of effort. Up until this point there has not been any agreement on what it is to teach about disability. What should be taught? What do healthcare providers need to understand about disability?

And the next slide, so I worked with Christina Neil Boland and colleagues at the Center for Medicaid and Medicare Health CMO. Health Management -- I apologize. I wrote it down and I'm not finding it. You'll have to go to my reference to find it. I apologize -- oh, there it is. The center for Medicaid and Medicare and the Medicare Medicaid Coordination Office. A group of us got together and started thinking, well, what are the steps? If we want to build a disability competent healthcare workforce, what is it going to take? You know, where are we now? What should we be working towards collectively. And the first step we thought was to decide what it is that healthcare providers need to understand about disability in order to provide quality healthcare to patients with disabilities. The second step, once we have that, the second step is we've got to work on the training and licensure requirements, so that healthcare programs are incentivized to include disability training and that students are motivated to attend to that training, because it's a part of their evaluation. And the next two are kind of hand in hand. It's important to develop, publish, share, evidence-based disability

curricula for healthcare providers. And part of that is we really need to develop a set of robust evaluation protocols to measure disability competence. And as we're developing protocols and evaluating curricula, the curricula needs to be refined and improved so that we know how to build disability competence in our healthcare students. Once that is done, that's huge. Once we're there, we can start to evaluate the impact of disability training on the delivery of disability competent healthcare, and the impact of disability competent healthcare on patient health outcomes.

And the final step that we thought about is the importance of exploring the healthcare delivery models and different incentive structures from health plans to management organizations to promote disability competent healthcare and practice, so this is really after training, how to maintain disability competence among healthcare professionals. Okay, next slide, please. In approaching our task of building a disability competent healthcare workforce, there's advantages -- there's different approaches that could be taken. A competency-based education has the advantage of focusing first on the outcomes, the learning objectives, what we hope the learner will come away with and those objectives can be based on the health needs of the community. So when we're working to improve the health of people who receive Medicaid, Medicaid members, then we need to have a good understanding of the needs of Medicaid members, and where their gaps are. In this case, we need to have a good understanding of the healthcare needs for people with disabilities, and the first step in this process is to explicitly map the specific health needs of people with disabilities to a set of competencies for the workforce. Next slide. So in comes the Alliance for Disability in Health Care Education. The Alliance is small, a not-for-profit professional association comprised of interprofessional group of health educators who share a common passion for teaching disability to healthcare students. And formed in about 2007, this group has been meeting regularly and sharing resources and collaborating on projects, and one thing that we realized is that among the two dozen or so members, we each were developing healthcare curricula, but it was all very different. You know, one person would develop a parent patient panel. Another person would take students with them to the VA. Someone else would have people with intellectual disabilities come in and talk about their healthcare encounter. And we realized that, you know, there's a lot of strength in this diversity, but that we were trying to accomplish different things. You know, some of us were working very hard to overcome limiting assumptions and attitudes about disability. Other people were just trying to help students feel more comfortable and less afraid of people with disabilities, and it occurred to us that we really should document what the essential competencies are. So the Alliance asked, what do healthcare professionals need to understand about disability in order to provide quality healthcare to patients with disabilities? What are those kernels, those common essential baseline elements? And to do this we defined competency. Competency is the desired knowledge, skills, and behaviors that are required to successfully perform the healthcare role. And so the Alliance broke into small kind of teams of professionals and drafted core competencies on disability through these small working groups, and that draft was submitted to the membership of the alliance and approved and I will -- if you're interested in the Alliance, I hope you are, please go to their website. It's a wonderful organization, and they're accomplishing great things.

Let's go to the next slide. So the Alliance came to an agreement on what the core fundamental understandings on disability were for healthcare providers. And it was a huge accomplishment. It was not an easy task. And we felt good about it. But we recognized that this was a consensus among a pretty small group of healthcare educators. We did not have as much diversity as we would have liked among our members. We did not have as large a group of people with disabilities as we would have liked. And we recognized that in order for these competencies to have legs, we really needed a national consensus. And so at that time I was very lucky to be writing the grant to the CDC that funded the Ohio Disability and Health Partnership, and I was able to write into that grant some work on developing disability competencies and reaching out to a broad disability stakeholder group and doing a Delphi process and we were funded. I see that's really lucky, because the Alliance did not have the resources to conduct a large study like this, and this was really what was needed for the competencies to take off. And so what we did -- now I'm talking about the Disability and Health Group, we recruited a national sample, individuals with disabilities who were really mindful to reach out to as many different disability associations and advocacy groups as we could find, that we had diversity in that group and good representation of different types of disabilities. We reached out to family members, disability advocates, health educators, healthcare professionals, and disability professionals and invited them to join us to develop, refine, improve disability competencies for healthcare education. And we have a couple of hundred people signed up that volunteered to help, and what we did is send them the draft competencies that the alliance had developed and asked for their feedback. We wanted to know if they thought that these competencies captured what was needed. What did we forget? Was there anything on there that they didn't think was very important that we could skip? Was there things that were not clear or didn't really represent what they thought of as important skills or behaviors for healthcare providers, and we got so much feedback. These people were so generous in their time and threw out long comments and rationales and examples, and we collected all of that and read through them and made edits to the competencies based on this feedback. And then we sent it back to this large stakeholder group and said, now what do you think? Now what is missing? What do you think is not clear? What is important? What should be changed? And we got more feedback. And this is what is called a Delphi process. It's an iterative process where we keep asking for feedback and we keep refining the competency list until we reach consensus. And we define consensus as -- I think our goal was to have at least 75% of people who agreed that these competencies were all important, were all clear, and all reflected what healthcare providers needed to know to provide quality care to patients with disabilities. In fact, we were over 90% on each of those three metrics, and we said, we're done, that's it. We have reached consensus. There is a hyperlink on this screen and on the next one. If you go to the next screen, but please reach out to me if you don't write that quickly and you have any questions or want to access that link. Will you move to the next slide, please?

Will you move to the next slide, please?

Can you hear me?

>> Yes.

>> SUSAN HAVERCAMP: Hi. Can you move to the next slide, or is it stuck?

Seems like there's a problem with the slide. I don't know what is -- just give us a minute and we'll figure it out.

Okay. Great. There it is. Thank you so much. So, after all of this Delphi, all of this work, we arrived at a consensus, and we have the core competencies on disability for healthcare education document. This was finalized in June 2019. There is a picture of it there on the screen and link that will take you directly to the competencies. They're free. They're available online. We really encourage people to download it and to use these. But I hope that the competencies can be used to scaffold disability curricular content. And so you can pick learning objective out of the competencies and build curriculum around it. And what I will do in the next few slides is talk through what the six core competencies are and give you some examples, and like I said before, talking with you at the end of the hour. Would you go to the next slide, please?

Thank you. So these six competencies and the many, many sub-competencies define what I think is a baseline standard for disability training to improve healthcare for people with disabilities. And I'll list the six competencies here and then we'll go through each of them. The first is to obtain a contextual and conceptual framework on disabilities. The second one is professionalism and patient-centered care.

>> Sorry about that, I actually had been monitoring a webinar and asked a question, then got called to ask my question while I was away with you, and so basically I just messaged them to... because the webinar goes through 4:00, so I just said... [no audio]

>> SUSAN HAVERCAMP: Oh, sorry. Someone forgot to mute their line. I'm totally distracted now. Let me read the competencies again. Sorry about that. The first one is a conceptual contextual framework on disability. The second one is about professionalism and patient-centered care. The third one is legal obligations and responsibilities. The fourth is teams and systems-based practice. The fifth is clinical assessment. And the sixth one has to do with clinical care over the lifespan, and particularly during transitions. So I'll go through these. I'm going to save the legal obligations to the end, because I want to spend a little bit more time on that one. Okay, next slide, please.

In terms of contextual and conceptual frameworks on disability, we expect the learners to acquire a conceptual framework of disability in the context of human diversity, the lifespan, wellness, injury, and social and cultural environments. This is where we really hope to help students shift from seeing disability as an illness that should be prevented or treated, and that's how we're all trained, I think. And it takes some effort to shift that

framework to think about disability as a functional limitation that may or may not impact a person's health or quality of life. To see disability as an aspect of diversity is our goal in this competency. Next slide.

So two examples. I'm not going to share all of the sub-competencies, but I just pulled to give you a flavor of what we're talking about here. One is to -- for the students to be able to describe the civil rights and the independent living history of people with disabilities, to appreciate people with disabilities have agency, to try to move from a really paternalistic perspective on disability, recognizing that they are civil rights advocates, and to help them understand how such a history has informed our current thinking and has improved access to care and equal rights for people with disabilities. The second one I have here is about the social determinants, and I mentioned this earlier. Social determinants of health impact people with disabilities, for example, discrimination in employment, education, transportation, housing, poverty, access to healthcare, and also intersecting marginalized identities. We will touch on this competency as well.

The next slide, please. Professionals and patient-centered care. In this competency we want learners to demonstrate a mastery of the general principles of professionalism, communication, respect for patients, and to recognize that optimal health and quality of life exists from the patient's perspective. It's likely not the same as a non-disabled person's perspective. So a couple of examples of these competencies, if you go to the next slide. Students will demonstrate communication strategies to best meet the needs of the patient. Seek out and implement appropriate resources, included interpreter services to communicate effectively using clear language at an appropriate level of health literacy. And this is extremely difficult for students. They have just learned or just starting to learn these terms and the lexicon of medicine, whatever, on disciplinarian and are just starting to get comfortable with this whole new vocabulary. And in this context we're asking them to consider what is effective. You know, is bringing in your 25-cent words that you're just learning into this clinical encounter, is that going to be the most effective way to communicate with this patient and this family? And if not, let's try to reframe. Let's try to identify clear language alternatives so that your message is well-understood. I won't spend more time there. But recognizing that we may need to adjust your schedule to allow extra time for communication to really be effective. The second one an interesting nuance where the student, the learner, is to discuss issues of trust, confidence and confidentiality with respect to patients who receive support with personal care during a healthcare encounter. So if the patient comes to the healthcare encounter with an attendant or with a family member, it's important for the learner to recognize that that patient still has a right to privacy and it's up to the patient to decide whether the attendant or family member stays in the exam, during the exam, or when diagnosis and recommendations are given. So I think the point of this competency is for the learner to recognize that nuance and appreciate the rights of the patient.

Okay, next slide, please. Teams and systems based practice is particularly important for patients with complex healthcare needs and patients with disabilities. For this the learners engage and collaborate with team members within and outside of their own

discipline to provide high-quality, interprofessional team-based healthcare to people with disabilities. Next slide.

we expect students to demonstrate some skills and teamwork and we've specified what those skills are. We want the learner to demonstrate flexibility, adaptability, open communication among their peers, assertiveness, as well as conflict management among team members, the ability to recognize and execute an appropriate referral to another healthcare professional, and use of evidence-based practice to support decision making and goal setting with patients who have disabilities and other team members. The focus of the teams and system-based practice competency is the importance of keeping the patient with the disability at the very center and in charge of the team. And that's a huge adjustment for students as well. Sharing that power. Next slide, please. Thanks.

Clinical assessment, we know that good clinical management requires that accurate and relevant information about the health and function of patients with disabilities is assessed and viewed in the context of that person's life activities, their goals, and their interests. It's important to be able to confidently assess the person's health and their function. But it's also important to consider the patient's language, race, ethnicity, sexual orientation, gender, gender identity, expression, health literacy and other cultural factors in the clinical assessment. Next slide. I have a couple of examples. So the learner will respond confidently to patient's language, race, ethnicity, sexual orientation, gender identity, expression, health literacy and cultural factors. So responding confidently, the student will demonstrate an awareness of and adjust their behavior to express sensitivity to individual differences. The second one here is applies strategies and supports that could be used in the healthcare setting to accommodate patients with functional limitations. So recognizing the supports and changes that may need to be made to accommodate patients with different functional limitations. Next slide, please.

Clinical care over the lifespan and during transitions. We know that patients with disabilities may need supports and accommodations to benefit fully from clinical intervention. Transitions across the lifespan may be similar and may differ in some ways in terms of opportunities, needed supports or services for people with disabilities. For example, you may have heard a lot about the transition from pediatric to adult care, which for patients with disabilities is fraught. I'll just say it's much more difficult for many disabilities, pediatricians learn a lot more about disability and caring for patients with different functional limitations than other specialists do. In medicine, family medicine or internal medicine, they have really only a cursory understanding and maybe no intentional experience treating patients with disabilities as part of their training. And there are historical reasons for this. Back in the day when the medical school models were established, at that time many children born with disabilities didn't survive adolescence, so it never occurred to people to build that training into medical training. But the result is as children age out of pediatric practice, they find it extremely difficult to find a healthcare -- an adult healthcare provider who has experience with caring for patients with disabilities, who is willing to accept them as a patient. So that particular transition is very difficult for people with disabilities. But not to mention other everyday

transitions, graduating from high school, moving out of the home for the first time, getting married, having children, retirement, every transition can have health implications and access implications that may be more difficult for patients with disabilities. So the next slide, please. A couple examples of competencies under this one. Tailor recommended supports and interventions to the patient's cultural beliefs and values, to their time, resources, and to their preferences. They will be prepared to propose constructive solutions to possible conflicts between a patient and their caregivers, in the case of youth, and between the patient and other professionals about their goals and treatment decisions. Secondly they demonstrate skill in identifying, coordinating, referring and advocating for access to community and healthcare resources that are needed to support the treatment plan objectives.

Next slide, please. Now I would like to talk a bit about legal obligations and responsibilities. It's important, it's really critical for learners to understand their legal requirements for providing healthcare in a manner that is at a minimum consistent with federal laws, including the Americans with disabilities act or ADA, the Rehabilitation Act, and the Affordable Care Act to meet the individual needs of people with disabilities. Next slide, please. The biggest message here, and probably the hardest thing to convey to students is that accommodations are civil rights. It's not merely the right thing to do. So often a learner or healthcare professional will feel like they're being generous and doing a favor by making accommodation for a patient, and you may even hear things like, well, you know, I moved the chair so that she could have her wheelchair and it wasn't in everybody's way, and she didn't even say thank you. Well, they don't get it, right? It's because they are thinking that they are extending themselves, you know, it's a generosity that they're doing a favor for people with disabilities. They haven't shifted their thinking to healthcare as a human right. People with disabilities have a right to equal access to healthcare, and the chair shouldn't have been there in the first place. Probably the woman for whom you moved the chair was humiliated that you had to come out and move things around and rearrange the furniture on her behalf. And would have much preferred that the living room be accessible when she arrived. Okay, next slide, please.

Without training, doctors and other healthcare professionals really believe that a doctor who doesn't specialize in disability really doesn't have to learn that much about... oh, oh, I'm not going to specialize in rehab medicine, so I don't really need to learn this. Or, well, I don't specialize in your specific disability, so I don't have to take you as a patient. Well, that's not true. Not true. They assume that if a patient wants a sign language interpreter, then they'll bring one themselves. They'll make the arrangement, they know how to do that. And they'll pay for it. No, that's not what the law says. And many healthcare providers assume that the Americans with Disabilities Act is not their responsibility, because maybe they're in a small private practice or maybe they lease space, they don't own the building, so they assume it's somebody else's responsibility, and it's so very important for learners to understand that these things are not true. That they do have these responsibilities and not only that they must but to understand why they should, why it matters to provide equal access to all patients. Next slide, please.

So the ADA, as I'm sure most of you know, requires that healthcare entities provide full and equal access to people with disabilities. This can be accomplished through reasonable modifications, the policies, practices and procedures, through effective communication that makes communication in all forms easily understood. And through accessible facilities. Next slide. We'll take a minute to talk about communication. Because a lot of questions come up in this space, and it's a huge barrier for many people with disabilities. Providers must ensure that communication with patients who have hearing, vision and speech disabilities are as effective as communication with other patients. And providers must provide a qualified sign language interpreter for patients who request this, for a patient with low vision, providing a qualified reader for written communication and providing post discharge instructions and medication management in large print or virtually as the patient desires. And digital accessibility is also required. More and more we get our information from websites and digital media, and it's the healthcare entities that are responsible for making sure that this information is accessible.

Next slide, please. A couple of sub-competencies from the whole competencies legal objectives and responsibilities. Learners will identify the physical access requirements, for example, accessible exam table, mammography equipment, etc., of the ADA, the Rehabilitation Act, and related laws and policies that apply to health and the provisions of healthcare. So we like the students to think about the practice they're familiar with and recognize the barriers that may exist in that space and what the law says about changes that need to be made to become fully accessible. Secondly, ensure that healthcare providers and support staff members are trained to provide services that meet the needs of the patient with disabilities. For example, the healthcare provider and the staff should be trained on how to appropriately and safely transfer a patient with a mobility limitation to an exam table. Okay, next slide, please. Some examples of accommodations that for the most part are not expensive. I think everyone always thinks about, oh, my gosh, I have to remove walls or do heavy construction, it's going to be so expensive. Most of the time, most accommodations are really not costly, or even time-intensive. It does require a change in thinking and greater awareness. So the first one here, when scheduling, when appointment scheduling, ask all patients if they require any accommodations or any assistance to fully participate in care. Note the response in the chart so that you can plan for future care. And secondly, giving an early appointment or just after lunch appointment to a patient who has difficulty waiting or gets nervous in the waiting room, and allowing that patient to go directly to the exam room instead of hanging out for a while and bait waiting in the waiting room and exam room and waiting longer. For some patients it's much better if they can be escorted directly into the exam room. Assisting a person with a mobile disability on to the exam table or helping them position for radiography. Sending intake paperwork to the patient in an accessible format to be completed independently before the appointment. So a patient who has a vision impairment, what sometimes often happens is the patient arrives for their appointment and the clerk at the front desk gives them a sheet of paper to complete before the exam, and the patient points out that they have a vision disability

and they're not able to complete the paperwork themselves, and sometimes the clerk at the front desk will then read the questions out loud and mark down the responses, which is intrusive, particularly if that is done in the -- at the front desk and not in a private room. Far better to send the paperwork home by email to the patient and allow them to complete it and bring it with them to the appointment, or send it in.

Finally, scheduling extra time for exams with patients who require that. There is a cost associated with taking extra time with certain patients, I appreciate that, but it's also required for quality healthcare.

So that's all that I have to share about legal obligations and responsibilities. And in closing I would like to share a little bit of what we have learned. I've been very fortunate at the Ohio State University to have opportunities to collaborate with the faculty and the Department of Medicine and to integrate some disability training to the undergraduate medical curriculum, the medical students. We've got little pieces of disability content in the first year, second year, third year, and there's an elective in the fourth year, and I would like to tell you I can answer any questions, I would love to talk about what we do exactly and I would love to hear about what other people on the line are doing in this space. But I'll just share what we hear from students, if you will go to the next slide, please.

So student feedback overall is overwhelmingly positive. Students value the disability training opportunities. They report things indicating they're more comfortable with patients, they're less nervous, they're more relaxed. Specifically one student said, I'm more comfortable and less awkward seeing patients with disabilities because I learned it doesn't have to be the disability. It doesn't have to be the focus of the encounter.

I think that comfort is incredibly important. When we see students first about disability, they're so apprehensive and they don't know what to say. They don't know if it's okay to ask about the disability, what the right words are to talk about disability. They're really concerned about offending the person, and so they err on the side they think is safety by not mentioning the disability. But then they miss important information that is critical to healthcare. So I think the comfort, just allowing the students the space to slow down and get outside of their head a little bit and to talk to the person as a person I think is huge. Next slide, please. I mentioned before about the assumptions that healthcare providers make, and I think one really important outcome of disability training is to challenge these assumptions and to change them. The student said, "I think it's easy to make certain assumptions, whether consciously or subconsciously, about people with disabilities that can only really be dispelled by interacting with individuals with disabilities." And I completely agree there. Next slide, please. And finally, increased understanding of the disability experience. Students said the best takeaway I had from the encounter was that people with disabilities want their medical concerns to be addressed in a direct and straightforward way just like any other patient. I think many of the students commented on the kind of matter-of-fact approach to disability that many

people with disabilities exude and they were surprised by that and I think appreciated it. Next slide, please. Although we won't go into detail about the disability training that we offer, I will say that I believe it's absolutely critical to have people with disabilities on the training team as instructors or at least to give learners the opportunity to talk to and get comfortable with people with disabilities.

Okay, next slide. I'll share just a few disability resources for healthcare providers that I have come across, and particularly like. If you all know of other things that aren't here, please share them with me. The Alliance for Disability and Health Care Education is collecting resources and trainings to make them available to more people and I would love to have more to share with them.

Next slide.

So, these are fact sheets that specifically address legal rights and responsibilities for healthcare entities and providers from the ADA National Network. There's a really nice one from the Pacific ADA Center, our host today, and the U.S. Department of Justice. Has several that are really helpful and clear. Next slide, please.

The CDC has wonderful disability information and I didn't cite it here, but the Disability And Health Data System is a free... what is it? It's a portal where you can access data and even compare people with disabilities to people without disabilities on the behavior risk factor surveillance survey data across all 50 states. It's brilliant. The American Foundation for the Blind has a really wonderful checklist, and I'll mention them again. I just saw their training. It will be on the next slide. I recommend that. And AMA has a really nice fact sheet as well. Next slide.

These are training online asynchronous, free, really nice training. The SUNY Upstate has a beautiful disability integration toolkit with cases and trainings. We here at Ohio State University Nisonger Center have two trainings. They're each an hour long, and they're available for continuing education credit. Here is the American Foundation for the Blind. They have a series of two trainings. They're really nice, on caring for patients who have vision impairment. And finally, this is kind of a short training, it's a really nice video called Mark's Story produced by the CDC. Okay, next slide.

So I believe that we can improve healthcare and health for people with disabilities through training, and I think the next step that -- I hope we will all join together to work towards including disability competencies and professional standards for accreditation and licensure. Last slide. Thank you very much. Really appreciate your time today. It's a great opportunity for me to be with you and I'm excited to hear -- I've seen things go by in the chat but I can't multitask, and so I apologize if I have ignored people and look forward to your questions. Thank you.

>> LEWIS KRAUS: Thank you so much, Susan. Really appreciate this wonderful presentation. And you didn't really need to multitask because now is the time for

everybody, if you haven't put your questions into the chat room, now is the time to do it. And we're going to go over them together right now.

So, let's start... I do want to point out that the first couple -- I'm going to read them. I believe they are sort of affirmations of what you were saying at the very beginning about the experience of people with disabilities in healthcare. So let me go over them and then if you have a reaction to them, we can have one and you can tell us about it. Mike PCP, primary care physician referred to me as wheelchair-bound. He said that's what they taught him in school. I educated him. The next person said, did these healthcare providers do anything to increase their ability to care for people with disabilities? And the third person said, doctors have no idea of the great quality of life many of us enjoy. So I don't know... I just wanted to give you those kind of affirmations about what your whole need point you were making at the beginning.

>> SUSAN HAVERCAMP: Thank you so much for those comments. Yeah, the first one, the... I'm so glad that you educated your healthcare provider about respectful language. I'm not surprised. He may well have been taught that language in his training. I think that the next big task for us is to develop professional development training for health educators, as we're trying to develop disability content for students, it's important to bring along the faculty with them, and they too will have to unlearn a lot of things that they thought they knew. So that's a huge need.

>> LEWIS KRAUS: Okay. And just as a sideline here for everybody in the audience. If you are hitting the raising hand button, we're not going to do that this way. We are only working with your comments in the chat and we're reading them out so they get into the captioning and they get into the ASL. Okay?

So next question... what is the rationale for the resistance to including disability competency in medical school curriculum as part of the requirement by the accreditation agencies? And he says, to be clear, I'm referring to the licensure and training requirements.

>> SUSAN HAVERCAMP: That's a great question. I think we hear things like... I think the resistance really is unawareness. I think they're just ignorant of the size and diversity of the disability population. I think many people when they hear disability they think of -- they form an image in their mind and assume because they don't see that image around them very often that disability doesn't affect very many people. It's a small insignificant portion of the population, and that these rabid advocates are just pushing for too much. I think that there is an opportunity here to raise awareness, to bring the facts to the people who decide such things and to make this case. There isn't an anti-disability sentiment. And the people that I work with, the faculty, are all about including disability in their training. They are very supportive and recognize the value of patient-centered care and addressing this in the curriculum. I don't think it's mean-spirited. I think it's just ignorance.

>> LEWIS KRAUS: Okay. Let's go on to the next question and our next comment, I should say. And this is from somebody at the Downstate New York ADAPT group. And they provided their email in case anybody wants it. It's dnyadapt@Gmail.com . And they mentioned lawyer are tested on ethics and inclusion and diversity as well as having to take continuing education in these subjects. Physicians and students in many schools should have to do this. I think that's a confirmation of the same point. But I don't know if you want to add anything to that.

>> SUSAN HAVERCAMP: I completely agree with what you're saying, and also people with disabilities should be at the table, because -- they should be at the table but also because I think they could be extremely effective in making this case. The dynamics of conversation change when people with disabilities are participating, and I would love to partner with you in this effort. Thank you.

>> LEWIS KRAUS: Next question. Is it legal for doctors or hospitals or healthcare entities to kick out a patient or discharge a patient for making a reasonable accommodation request, the doctor or hospital decides not to accommodate. Can you please discuss the best practice process for providers responding to reasonable accommodation requests, including on what basis can be denied, such as cost, but considering not just that office's budget but the whole hospital's budget and how it's unlikely a hospital system with billions of yearly revenue would have an undue burden in granting many common reasonable accommodation requests.

Before you answer, let me just say that this is a great question and this is an example of the kind of question that is really centered on the ADA and can be asked by calling the ADA National Network hotline at 1-800-949-4232. You can probably -- if we don't get a great answer for you here that would be one you want to ask of the TAs that are all across the country and are skilled in being able to answer that. But I will let you take a crack at it, Susan.

>> SUSAN HAVERCAMP: Thank you so much. I am not an attorney. I'm a psychologist by training and I will not attempt to give you a legal answer. We're so fortunate that we have this network of ADA Centers and they're incredible at what they do.

>> LEWIS KRAUS: Okay, great. And the next one will be a similar one. Can you please discuss the Olmstead rights, including healthcare providers' obligations to be providing care in the community at the least restrictive setting to avoid segregation of people with disabilities in society into hospitals and institutions? And, again, I will say this is a detailed question that an ADA National Network TA specialist is going to be able to answer better than being right here. But anyway, go ahead, Susan, if you want to add something to it.

>> SUSAN HAVERCAMP: I completely agree with Lewis' answer. I will say this is part of what we hope students will learn. We have a competency on learners will since the Civil Rights Movement and the disability rights movement, and Olmstead is a huge part

of that. It's important for students to have an appreciation of how hard people with disabilities have fought for their rights, including their right to be included in the community.

>> LEWIS KRAUS: Thank you. Next question or statement. The DRJ has guidance around mobility disabilities in healthcare settings, which says for patients with mobility disabilities, it is not legal to deny care because it may take longer. It is also not legal to deny care that may take longer based on other disabilities, including, for example, patients with PTSD or developmental disabilities that may benefit from slower pacing or breaks during an exam or visit? Again, technical ADA question. I think you're going to be best handled that one at the ADA National Network hotline, 1-800-949-4232. Susan, you're welcome to take a crack at that if you would like.

>> SUSAN HAVERCAMP: I certainly hope so, but I defer to the experts.

>> LEWIS KRAUS: Okay. Let me mention a few of you asked for some general things like where can we find the slides. At the ADApresentations.org in the Schedule page today of the healthcare section. By tomorrow it will be in the archive section. It also will be in the archive section a recording of all of this, so you can go back and hear anything that you missed. And I just want to point that out. So, we're getting quite a few of these questions that are very technical questions for the ADA National Network, so I'm going to refer those to them. So let's move on to a different question here. As a disabled person, I appreciate your presentation. I feel the work you have done could create significant and possible outcomes for persons with disabilities in healthcare. I am encouraged that physicians have opportunities to learn more about communication and persons with disabilities -- with persons with disabilities and better understanding our needs.

>> SUSAN HAVERCAMP: Thank you. That means a lot to me. Appreciate that.

>> LEWIS KRAUS: Next comment. Having spent 30 years living and working with people with disabilities and having a spouse who uses a wheelchair, I think I forget sometimes how odd my experience is. The quotes from students at the end are sort of mind-boggling to me, but a great reminder of why we need to do this work. Thank you.

>> SUSAN HAVERCAMP: Yeah. Right? Yeah. You have to understand where they're coming from, you know, what their assumptions are, what they have been exposed to.

>> LEWIS KRAUS: Okay. The next one: In your implemented curriculum at OSU or just generally, how do you recommend increasing med student exposure to people with disabilities? Is face-to-face time somehow implemented within your medical training curriculum at OSU?

>> SUSAN HAVERCAMP: Yeah, thanks for asking that. In medical training, students are evaluated using what is called OSCEs. Observed structured clinical evaluation, I think is what it stands for. This is an opportunity for students to meet one-on-one with

what is called a standardized patient. What standardized patients are are actors who are given a script. They portray a patient who has certain symptoms, a certain health history that they convey to the student, and the student is tasked with interviewing them, usually trying to assess their symptoms and recommend diagnostic tests. What we did was we recruited a lot of people with disabilities to serve as standardized patients, and this is a great opportunity for them because standardized patients are well paid through our medical school. I think the rate is \$20 per hour. And they come in and meet with students one-on-one. The scenario that we're using, the patients don't portray symptoms. The students are just asked to conduct a basic social history and medical history with the patient. They have 20 minutes to interview the patient and then they take a break and the patient is able to give feedback to the student on whether the encounter was comfortable or whether they felt respected, whether they thought the student skipped over any important aspects of their social history or healthcare, and then after that feedback the students go into kind of a debrief room so that all of the students -- we have about 12 students at a time who simultaneously do these encounters. They all go into a room for a debrief with the faculty member and we answer their questions, and give them more information. That experience has been really profound. I think maybe all of the quotes that I shared with you are from students who had just completed that experience, and we're able to take some time and really talk to a person with a disability.

>> LEWIS KRAUS: Okay. Thank you so much. I'm just wanting to break in here because I realize it is past the top of the hour and I want to respect everybody's time. So I realize that many of you may still have questions for Susan and apologize if you didn't get a chance to ask your question. For all the ADA questions, please contact the regional ADA Center at 1-800-949-4232. If you want to ask Susan a question, Susan, go ahead and put your information in the contact information if you would like to receive those questions. For the rest of you, you will receive an email with a link to an online session evaluation. Please complete the evaluation for today's program because we value your input and want to demonstrate its importance to our funder. We want to thank Susan today for sharing her time and knowledge with us and reminder that today's session is recorded and it will be available for viewing next week at ADApresentations.org in the archives section of healthcare. Our next webinar will be -- we will be hosting another webinar in October and we hope you can join us. Watch your email two weeks ahead of time for the announcement of opening of registration for that webinar. Thanks for attending today's session. And have a great rest of your day!

Bye-bye!

>> SUSAN HAVERCAMP: Thank you, bye!