

PACIFIC ADA CENTER
HEALTHCARE AND THE ADA WEBINAR

7/22/21

2:10-4:00 P.M. ET

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>> LEWIS KRAUS: Welcome to the Healthcare and the ADA Inclusion of Persons with Disabilities 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 10 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 toggle the meeting control toolbar on, you can press the alt key on your keyboard. Also, we have ASL interpreters at the top of the screen. You can choose to position that differently by choosing the view options. 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 1646-558-8656 and use that webinar ID of 864-8854-2838. And please note that this webinar is being recorded and will be available next week at ADAPresentations.org in the Archive section of the healthcare area. This Webinar Series is intended to share issues in 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. Then 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 web page at ADAPresentations.org

At the conclusion of today's presentation, there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area within the webinar platform. And 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 questions, just type and submit them in the chat area text box. If using keystrokes, you can use the keystroke of Alt H and enter your text. If you are listening by phone and not logged into the webinar, you can ask your question by emailing them to adatech@adapacific.org. That's adatech@adapacific.org.

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Today's ADA National Network Learning Session is entitled "Challenges and Opportunities: Lessons Learned from ADA Coordinators Working within Diverse Healthcare Organization." A growing number of healthcare organizations are hiring full-time ADA coordinators. It is unknown how ADA coordinators are integrated into healthcare organizations, including what types of roles and responsibilities they have and the types of initiatives. This presentation will present findings from interviews with ADA coordinators who represent 20 healthcare systems across the country. Specifically this presentation will show findings on the job titles and duties ADA coordinators have, the types of initiatives they lead, how they collaborate with groups within and outside of their healthcare systems, their budgetary supports and constraints, and ongoing challenges they experience.

Today's speakers are Megan Morris. Megan is an associate professor in the Division of General Internal Medicine in the Department of Medicine at University of Colorado Anschutz. Her research focuses on provider and healthcare organization level factors that negatively impact the quality of care for individuals with disabilities. Dr. Morris is a founder and director of the Disability Equity Collaborative, which you can find at DisabilityEquityCollaborative.org. Steven Lockhart is a Senior Professional Research Assistant in the Qualitative and Mixed Methods Research Core at the Adult and Child Consortium for Health Outcomes Research and Delivery Science. Also called ACCORDS. He has worked closely with Dr. Morris on multiple studies focused on outcomes for patients with disabilities in the healthcare setting.

All right, Megan and Steven, I will now turn it over to you.

>> STEVEN LOCKHART: Thank you, Lewis Kraus. I want to thank everyone for having us today. I'm excited to share some of the results from our interviews today. The title of our presentation is "Challenges and Opportunities: Lessons Learned from ADA Coordinators Working within Diverse Healthcare Organization." Next slide. I just really quickly want to acknowledge our funder for some of this work, which was PCORI and specifically the Eugene Washington PCORI Engagement Award. Just a quick disclaimer. The views presented in this presentation are solely the responsibility of the authors and do not necessarily represent the views of PCORI, its board of governors or methodology committee. Next slide. Just really quick, to go over the agenda for our talk today, I'll be going over describing the ADA coordinators as well as the healthcare organizations that they work within, talking about some of the position titles, the departments that host these positions as well as the organization structure for these positions. And then we'll highlight some of the different roles, responsibilities, and the specific initiatives that these ADA coordinators are leading. And finally, I'll highlight some of the collaboration we heard within the organization as well as outside of the organization.

And Megan will pick up from there and highlight some of the budget constraints and supports for these positions, and then dive into some of the major barriers and facilitators that these ADA coordinators reported experiencing throughout their position.

Finally, Megan will talk about Leaders, which is part of the Disability Equity Collaborative. Next slide.

Next slide. Just a quick background. I'm sure you're all very aware and familiar with these two pieces of legislation -- or three, I should say. It's just a reminder of Section 504 of the Rehab Act and ADA, really focused on requiring healthcare organizations to provide accessible healthcare to patients with disabilities. As well as 1557 of the ADA specifically prohibited healthcare organizations from discriminating against patients based on race, color, national origin, sex, age, or specifically disability. Within Section 1557 they also highlighted the requirement for healthcare organizations that have over 15 employees to specifically designate an employee to lead these efforts, which is important for our presentation today. Next slide. So just a little background about this project. We conducted 21 interviews from May 2019 to January 2021. Most of our participants, ADA coordinators were recruited by word of mouth. We worked closely with advisory committee as part of this PCORI project to help identify individuals that were needing disability initiatives at their healthcare organization. These individuals represented 18 community and/or academic healthcare organizations or hospitals across the United States. These healthcare organizations varied in size as well as geographic location. These included over 200 hospitals and ranged from systems having one hospital all the way to 40 hospitals. And we heard from individuals working on the west coast central U.S. as well as the east coast. Next slide.

So as part of these interviews, we were really curious about what types of titles these ADA coordinators had as part of their positions, and you can see from this list, it was a huge variety. And actually surprising to me at the number of different types of titles. As you can see in this table, some of these titles have parentheses with numbers, and those represent different ADA coordinators having the same title. So just to high light, it was very diverse in terms of these titles. We had one individual who their title was geriatric services director, but yet they were the person needing these ADA efforts at their healthcare organization, as well as others in places like assisted services program manager. And I'm sure some of you who are joining this call may be serving as an ADA coordinator. Maybe you have a different title as well. Next slide.

As part of this conversation, we also asked about where these positions are located, what departments are hosting these positions and supporting these positions. Again, to my surprise, there was a wide variety of departments. Some that were -- made a little more sense to us, and some that were a little surprising. Again, we had some departments that were replicated across different ADA coordinators, like interpretive services, quality and safety department, patient care services. And then we had others that were a little more surprising, like someone was -- their position was located within the call center department or facilities, continuity, human resources. Next slide. So, as part of these conversations with these ADA coordinators, we really wanted to get a better idea around the history of these positions. And what we discover were almost all of these ADA coordinators were the first person to occupy these positions. There were a couple ADA coordinators who were the second individuals in these positions. The length of time of the position also ranged. We had some individuals who were brand-new to these positions, really kind of keeping their head above water. And we had others who had been in these positions for over nine years. So a ton of experience working on these types of initiatives. Many of these positions really began as a result of

a patient lawsuit, DOJ dissent decree or a major complaint from a major patient population. And that was really the impetus for these positions at the organization. We did hear from others that these positions were a result of the ACA act, as we described earlier, 1557 required healthcare organizations with 15 or more to have someone identified to lead these efforts.

Next slide. So, as I mentioned before, one of the things we were also curious about was the structure, the organizational structure of these positions. And it really varied by healthcare organization. One thing that was consistent was in almost every case there was really only one person dedicated to improving disability accessibility within their organization. Even if they were collaborating, working closely with other individuals or departments, there was really only one position dedicated to these efforts. We also were able to put these ADA coordinators into three different types of models surrounding the structure of the position and the organization. Next slide. The first model was really kind of more of a siloed type of position and model. That was really one individual related to all efforts ADA. So as one ADA coordinator described, we have a civil rights coordinator through the requirements of Section 1557, but they, again, when it comes to anything ADA or language access related, usually those individuals will come to me for guidance and assistance in resolution. We don't have a team of ADA people. So, again, they were highlighting, despite the organization hiring someone to fulfill the requirements for 1557, this individual was still the only person dedicated to working on these initiatives and the civil rights coordinator really leaned on them for anything related to ADA. Next slide.

The second model that we discovered was still having someone leading these initiatives and efforts, but they also seem to have a team of ADA coordinators or what seems to be ADA coordinators. And as one individual described, I came in with a number of years of experience, but most of the ADA coordinators are people who have other jobs. So even though they have some support from ADA coordinators, a lot of the times these participants described ADA coordinators having other jobs and necessities that they had to fulfill before they were able to dedicate time to ADA initiatives. Next slide.

The final model for the position -- the structure of these positions was really more of what was described to us as a collaborative multi-discipline team. So even though there may be an individual leading these efforts, they have described situations where they were really working collaboratively with other individuals and other departments on different types of ADA initiatives, accommodations. As one individual described, we have a network of ADA coordinator managers in our system. The way my job works, I'm the lead...

>> LEWIS KRAUS: Steven, we lost your audio.

>> STEVEN LOCKHART: Can you hear me now?

>> LEWIS KRAUS: Yes.

>> STEVEN LOCKHART: Sorry about that.

So, again, as this individual described, it is the network of ADA coordinators, managers across our system. The way that job works, I'm a lead. Then I work in a

multidisciplinary fashion with facilities, safety, clinical and operations. Everybody takes ownership and responsibility for equal access. I'm like the quarterback. So, they may be leading the efforts but they feel it's an even playing field with support from other departments to lead some of these initiatives and efforts.

Next slide. Next I'll talk about the roles, responsibilities and initiatives from the ADA coordinators that we spoke with. Next slide. So get around the understanding of the role of these positions, we ask individuals to tell us what they saw as the goal of their position as well as what they felt the organization saw as goal of their position. And they tended to fit into two categories. One focused on remaining in compliance and meeting the requirements of laws and regulations, and on the other end really trying to create a culture focused on equal access to healthcare for people with disabilities. So for the first -- some individuals felt like their goal -- the goal of their position was really focused just on laws and regulations and remaining compliant with those. As one individual described, I would say the organization views it as a position to fulfill legal requirements, because legally we're required to have a coordinator for nondiscrimination purposes. If there wasn't a law, I don't think there would be anybody doing anything about this at this hospital. So within their position, they felt strongly that was the main purpose of their position. And without these laws in place, they felt their hospital organization would not have created resolution. On the other hand we had individuals that felt their role was really focused on creating this culture of equal access. As one individual described, I think it's really to ensure that everybody gets the care that is commensurate with every other patient in the hospital. Just to level the playing field, but every time for every one. Next slide. And in some cases, ADA coordinators described the goal of their position really being two-fold. And really covering both the legal obligations as well as promoting this idea of equal access for all individuals. So as this ADA coordinator described, I think the purpose of my job here is to make sure that we are as compliant with the rules and regulations as possible, but also that we're doing the right thing for our patients so that we can impact some of those other areas. It's not just legal obligations, but it's promoting exceptional patient outcomes, trying to reduce our readmission rate, making sure that our patients understand the discharge recommendations that we give them, making sure that our providers are able to communicate with people in a way that they understand. Next slide.

We also heard from some of our ADA coordinators that they had responsibilities that went beyond ADA and focusing just on individuals with disabilities. So some of these positions were much more broad and focused on all disparities for all populations. As one individual described, my responsibility is to grow awareness around health disparities, to create processes and systems to address those disparities and to make sure a hospital is an inclusive provider and meeting the needs of all patients we serve. So they really saw their responsibilities as much more broad and really addressing all types of patient populations. Others described additional responsibilities that really were more narrow focused and focus on specific initiatives, for example, interpretive services came up multiple times. As this individual described, I am here to provide interpreter services. I have to manage my in-house interpreters who are all Spanish speakers. I have to find contract interpreters if there are languages other than -- it's very language-based and I have ASL needs. So really the main responsibility they felt for their position was really focused on the broader interpreter services initiatives. Next

slide. These were the most common activities specific to ADA within the position that we heard from the ADA coordinators. They included things like developing and implementing policies and procedures. Responding to patient requests and complaints. Assessing facilities. Purchasing and/or providing accommodations. Conducting trainings with staff and clinicians. Providing resources and advice to staff and providers. And ensuring organization is compliant with legal requirements. Which we saw in the roles of many of the ADA coordinators. Next slide. We wanted to dive a little deeper as part of these interviews to get a better idea of what specific type of initiatives they were currently working on. And one of those that continued to come up with multiple ADA coordinators surrounded documentation of disability status. And we asked them to describe, you know, what that meant to them. And to many of these ADA coordinators, that was described as asking every patient if they needed and have a disability, and what those accommodations would be to meet those -- the desire of having appropriate accommodations for them. They felt the benefit of documenting disability status was really beneficial for staff because it would be a way for them to proactively provide these needed accommodations instead of being more reactive and waiting for these individuals to come into the hospital or healthcare setting and scrambling to try to provide the needed accommodations after they had already come in. They also described the documentation of disability status being beneficial because it will give them a better idea of who is really being impacted by the lack of appropriate accommodations and by knowing that, they can then try to figure out ways to improve the care for these populations. As one ADA coordinator described... the feedback that we've received is that the patients are very happy that they're actually asking them what their disability is at the time of registration. This is something that is unique to them. They actually expect, then, for us to be much more involved in their care. So, for this ADA coordinator, their hospital organization was already working on documentation of disability status, and they were already hearing from patients that this was really beneficial for them and it really helped them feel strongly about the type of care that they were going to be provided moving forward. Next slide.

Another common initiative that we have heard from ADA coordinators was around training and education. These trainings and education were often components of a larger system-wide type of annual employee training. So these were at times a more -- a much smaller component of a larger required training for staff. These were not trainings dedicated just to ADA or improving access for people with disabilities. As part of these trainings, the ADA coordinators described focusing on how to communicate, support, identify, and then provide the needed resources for people with disabilities. Many of the ADA coordinators describe partnering with community organizations and persons with disabilities to help lead these trainings and the benefit of having those individuals and organizations a part of those trainings. As one ADA coordinator described, it's not just now on disability sensitivity. It's really trying to engage the organization in thinking about implicit bias training. Cultural competency training but not making it transactional, really making it intentional. So they were highlighting for their organization the importance of continuing to have these trainings in education for the staff and the overall culture of the organization. Next slide. Another initiative that we continue to hear about from our ADA coordinators was around facilities and physical access. And this meant ensuring that the new and current physical spaces met ADA

requirements. And some of the examples of these type of physical access -- physical space components included things like parking lots, entrances, doors, heights of tables, and not just exam tables, and signage throughout the healthcare setting. As one ADA coordinator described in terms of this initiative, I personally go in and look at things from the aspect of a surveyor and just trying to make sure that we have things in place. If we don't, I document those things. I send them up the chain to see what kind of changes that we can make. Next slide. One of the other more common initiatives that we heard about, especially during the pandemic was around service animals. And to these ADA coordinators, it's really focusing on creating and/or updating policies specific to service animals. We heard from the ADA coordinators about staff having a lot of confusion at times about what was legal and what was appropriate and confusion around service animal policies versus emotional support animals and really not knowing what to do moving forward. So a lot of their role in these initiatives also meant training staff on these new policies or updated policies to make sure they were comfortable with how to move forward. As one ADA coordinator described, normally we don't allow animals in our building, but, of course, we want to accommodate people who use service animals. So it's important that my staff know the questions that they can ask and our responsibilities and obligations to accommodate someone who uses a service animal, and to do so in a very polite and respectable way. Next slide.

Some of the other common initiatives we heard about from our ADA coordinators included things like accessible medical equipment, which included height adjustable exam tables. It also included things like effective communication. We heard from a lot of ADA coordinators that they were working on creating or using effective communication toolkits or sensory toolkits. This also included things like large print or Braille materials, as well as things like nurse call buttons. Finally, we also heard about initiatives focused around electronic materials. And this meant making sure things like websites and patient portals were accessible for all patients. Next slide. Next we wanted to talk to our participants about the current collaboration that was happening both within the organization as well as outside of the organization. Next slide.

So when we first talked to them about the type of collaboration, it was obvious that there was frequent collaboration happening within this position with other departments. And the most common departments they were partnering with on initiatives, policies and trainings included departments like compliance and legal, patient experience, facilities, diversity and inclusion, and, finally, environmental health and safety. As one ADA coordinator described some of the collaboration happening within their organization, we implemented a system Effective Communication Policy last year. That was the result of almost a year's effort. Really working on a policy collaboratively that would make sense and be meaningful and be applicable throughout the state.

So really highlighting the impact of having important collaboration with other departments and the impact it had on the organization but also the state. We continued to hear from ADA coordinators about the importance of having buy-in from other department and how that impacted the keys to success for some of these initiatives. If they didn't have buy-in from other departments they ended up being major barriers for implementing these initiatives. Next slide. We also heard about a lot of collaboration going on outside of the organization. And the most common groups that we heard about were community advocacy organizations, local Centers for Independent Living,

ADA regional centers and national centers, as well as the Disability Equity Collaborative leaders that Megan will talk about in a little while. So within these collaborations outside of the organization, they describe collaboration in the form of grants, guidance on compliance and initiatives, as well as utilizing them for important resources, and, finally, having a space to talk with others in similar positions about lessons learned and best practices within those positions. As I mentioned previously, some of this also -- this collaboration involved persons with disabilities in trainings, making sure they were part of Advisory Committees and getting input and feedback from people with disabilities when they are developing initiatives and programs. As one ADA coordinator described, the staff not only hears about what types of things they should do but to hear about a patient's experience is most valuable. So they really felt involving persons with disabilities as part of those trainings was really influential and beneficial for the staff when conducting these trainings.

Next slide.

>> MEGAN MORRIS: Thank you, Steve. This is Megan Morris. I'm going to transition and complete the rest of our presentation now. So, one of the main topics that we talked about, or people talked about in the interviews, was budget. Budget was an important issue for them. So we'll spend a little time talking about that. Next slide, please. First I'll talk about different budget models that people discussed. So almost all of the participants we talked to reported that they did not have their own budget or budget that was carried over from year to year. They also expressed they were not necessarily the same decision maker for budget requests. Some model types, these are not necessarily independent of each other, as some people did have an annual budget, so individuals had to request funding for an item, such as accessible diagnostic equipment, one at a time. And then additionally some participants talked about how they rely on grants, outside grants, to support different initiatives at their hospital or healthcare organization. There was some confusion and variability on whose responsibility it was to fund a position and initiatives. And I think this goes back to, again, one of our first slides about the job titles of these individuals and what department they were located in. Depending on what department they were located in really contributed to whether or not they had an existing budget. And this also could differ by type of accommodation. So, for example, if a clinic in a large healthcare system needed to purchase a height-adjustable examination table, was it the responsibility of the clinic to include that in their own budget, or was there someplace in the overall healthcare system budget that that should be ordered out of? Next slide. So, like I said, budget constraints was one of the largest barriers and challenges in the position. And he talked about there was money required for one, just funding their position. Money was required for equipment and renovations. They talked about the cost of personnel time. So, for example, the cost for having all of the staff members and providers complete training. And then also the time that it took staff members to ask disability-related questions. So, for example, in call centers, many of them, their main metric is how fast you can complete a call, and by adding additional questions about disability-related accommodations lengthened the time of those calls. And then, finally, there were costs associated with other items such as accommodations or, you know, Braille format available for common forms, and also paying for interpreters.

As one participant said... "That's really it, money as the most needed resource. I think it would help if this type of position actually had its own budget, and the budget was, well, enough funded that we actually had the funding that we need so that we can provide what we should be providing. We just don't have that. Every time something is needed, I'm literally going to other people and begging to spend their money. It would be fantastic if our organization actually recognized." next slide. So, as the previous quote illustrated, participants describe constantly having to justify spending, and this often was related to a lack of support from their leadership, and to fund these initiatives. There also was competing priorities. So, again, some of these individuals had multiple roles, so it was hard for them to figure out you know, do we need to hire more Spanish speaking interpreters or ASL interpreters, and the competing priorities they experienced.

As one participant said, with my previous VP or vice president, everything was tied to money and I had to give reports and white papers on why I had to provide a deaf interpreter. Another participant reported, accessibility is expensive. Next slide. As I mentioned, leadership buy-in was really critical in terms to have whether or not they felt like they had a budget for the accessibility initiatives. The earmarked money at the upper I'd say the CEO and Board of Directors for our health system. They allocate funds in the budget every year for our ADA programs. Again, this person is talking about having that leadership buy-in and how that really facilitated them being able to enact different ADA and accessibility initiatives. Next slide.

They also stated that it was helpful when, again, leadership bought into the need for spending in this area, that then the leadership for the organization would put pressure on the departments to include our approved budget request related to the disability initiatives. As one participant said, all of our outpatient physicians group -- "All of our outpatient physician offices have purchased an effective communication kit. Their leadership basically told each site manager, this is what we recommend, this is what you need. You need to purchase it. And they did."

Next slide. Additionally, people talked about, again, how great it was when they were able to have dedicated funds and a capital budget that was allocated funds for them every single year. For the physical access and equipment, we have a disability funds budget or what we call ADA budget. Which is a pool of money that is funded through the hospital. It's capital budget that stays within the planning office. They actually oversee it, but I make all the recommendations for what we need. So you can see even when they do have a designated budget, the person, the ADA coordinator, was not necessarily the final decision maker of how that money is spent. Next slide. So next we'll talk about and go a little bit more into some of the challenges that these individuals had in their positions, and really also what made their position go well, the facilitators. Next slide.

As we have mentioned before in this presentation, I cannot stress this enough, is the importance of leadership support. So participants who felt as though they were doing well in their position, they -- when we asked why they thought things were going well, they reported feeling as though they were viewed as experts in their organization on all disability initiatives, and felt as though they had, quote, the ear of their leadership team. Participants talked about the need for leadership support across different departments

and domains since accessibility initiatives crosscut the organization. Again, the schedulers, the facilities managers, to the different clinic managers, etc. Next slide. Participants reported that having leadership support was really important to ensure that the accessibility initiatives were maintained and not just implemented for a short amount of time. So as one participant stated, leadership buy-in is huge and I would say this is probably going to be one of the most common barriers for anyone trying to push the needle when it comes to advancing disability competent care practices. Not only having that leadership buy-in, but you need their support, and you need them to be a champion. And you also need, of course, their money.

Next slide. Conversely, those who have felt as though they were constantly advocating or fighting for the recognition of the importance of their position and the importance of funding different disability accessibility initiatives, really, again, it was lack of leadership support was their main barrier. And participants talked about how many times their leaders were not necessarily aware or understood that the requirements through the ADA. And so -- the ACA. And so it was -- the participants, the ADA coordinators, then felt it was partly their responsibility to try to educate their leadership about the requirements, which was sometimes challenging because they're not necessarily in a position in which they have -- they can go directly to the CEO and advocate for this. They did, though, say that it was helpful when their legal team was backing them up when the ADA coordinators received pushback from different staffing providers. As a participant reported, leadership has to decide that this is important. You have to have a culture, you know, you have a leader who is saying this is important, we need to be doing this. And you have to put the resources to actually make it happen and then demand accountability. It can't be the flavor of the week. This is a long-term ongoing just thing we do. It's not even a thing we do, it has to be who we are. Next slide. Time resources and money. Again, coming back to that budget issue. So many of the people we talked about reported feeling overwhelmed in their position. And this was due to a few different reasons. One, they had this wide variety of different types of responsibilities, and then also a large number of responsibilities. So one person said lack of time. Because you really do have to prioritize certain things and build on them. Some of the things I would love to see us do because I have to spend time bringing other people up to speed. One of the challenges is that we have had a lot of turnover. Participants also talked about having multiple roles. And this, again, we talked about at the beginning of the presentation, is being -- leading the disability initiative might be only one part of other position. One participant reported that she only had one day a week to work on disability initiatives. Again, these are individuals who lead initiatives across many hospitals and many clinics. This participant reported, I feel like I wear so many hats that sometimes that does get put at the bottom of my to-do list. I wish I could be more available for people. And this is referring to staff. The clinics don't always have the time either to work on these disability initiatives. Next slide.

Many people were the only person in the role, which they reported as insufficient. So one participant who was responsible for all ADA initiatives across five different hospitals said, I can only do so much as one person. So it depends on others to carry out initiatives, policies and trainings. In my ideal world, I would have two or three of me. Next slide.

When participants stated that accessibility and the ADA and persons with disabilities were prioritized and the institution did things such as prioritizing accessible medical equipment, the participants reported seeing positive results from this. I think we've had a lot of success in the area of accessible medical equipment. We've bought so much equipment. We trained our staff on how to use them. We're getting really good feedback. Next slide. Again, we highlighted these individuals who, again, were leading disability initiatives did not necessarily have control over what was purchased or how much of a budget was allocated for these initiatives. We can always use more money. If I had more money, I could bring speakers in, I could do better training. It would be great to do partnerships with other systems, that sort of thing. That's the higher aspiration. And we need money to do all of that. I will always say that we need more money, more budget, more budget, more budget. Participants also reported needing systems in place. So many talked about feeling as though they were running around putting out fires, that they were -- because of a lack of funds and the lack of time and resources dedicated to their position, they were never able to proactively provide accommodations, and make sure that they were accessible, the health systems accessible, but instead they were running around addressing patient complaints. So what this participant reported... "I think what I find most frustrating than, for challenging is that we can't come up with a system on a system level to address these things. I don't care who addresses them. I don't care if they decide that it's really my job, but it would be a lot easier if there was a mechanism in place, so that I wasn't running around patching things." Next slide.

So another important factor that really facilitated this position was going back to what we had mentioned before, is documenting disability status. So, there were a lot of challenges people talked about in terms of documenting disability status, but they reported that this was a foundational step in delivering accessible care. It was important for two reasons. You needed to know who had a disability, because you needed to figure out who required disability accommodations, and then second, they needed to document who had a disability so they could measure the effect of these initiatives. So making sure that the individuals with disabilities in their organization received equitable care as compared to those without disabilities. Because if you have no idea who has a disability, you can't measure this, and the same way with documenting race and ethnicity. If you have no idea who -- what the race and ethnicity of your patients are, you can't demonstrate, oh, look, our patients with this demographic characteristic -- for example, those with hearing loss, they are -- they're not receiving vaccinations at the same rate that our patients without hearing disabilities. Well, maybe we need to think about some outreach to that community, or improve our communication with those patients about vaccinations.

So, again, despite the foundational importance of documenting disability status, majority of sites really struggled due to lack of buy-in or support from leadership for their organization. Because it did require, one, a change in the electronic health record, which is quite costly, but also required staff and providers to consistently be asking about disability status and accommodation means. They talked about priorities as one of the main barriers to documenting disability status, and they talked about a lack of research and standards in this area. They wanted more recommendations and standards on how to actually roll this out. So one participant reported, "I often get told,

there's so many different types of disability... it's such a robust project that they're not even interested in taking it on..."

And another participant reported, "It should be if we can't document it, we can't measure it, we can't improve it." next slide.

So participants reported one of the challenges is not only documenting a disability and accommodation need but then connecting it to provision of that accommodation. And so because that next step wasn't in place, oftentimes accommodations were attempted to be provided on the spot. So, again, they were not proactively identifying, hey, this patient is coming in and needs a height adjustable exam table, and in our clinic we have only one room with height adjustable exam table, so we need to make sure that patient gets scheduled into that exam room. Instead they were -- the patient who needed that exam table would come in and they would have to run back and see if the room was available. And if it was clean. I once talked with a health system, and he said that the exam room, with the height adjustable exam table also doubled as their supply closet, and so oftentimes they would have to clean out all of this extra materials and equipment to even be able to get into the room. So this participant reported documentation would make workflows easier. I think it would be more effective. How do I say it? If we don't know what a patient needs, how can I help? Next slide.

Another important piece of documentation was to demonstrate the size of the population and then therefore justify their position as an ADA coordinator, but also their budget needs, etc. So, for example, they would say that -- they would go to leadership and say, oh, we need to purchase equipment for communication toolkits, and the leadership would say, well, so few of our patients have communication disabilities, so we're not going to invest in that. So, again, having the numbers within their system of how many people would benefit from these accommodations would really be helpful. So one person said, "When I'm trying to go to the table to ask for \$100,000 to improve communication access for people with disabilities, I need to be able to show, okay, this is our member population." Next slide.

Our next barrier they encountered was staff and clinician knowledge. So participants reported that staff and clinicians were often unaware of the requirements and only saw it as a burden for providing these accommodations. This was made more difficult because, again, going back to the time, resources piece is that many participants, the only person in the role, one participant described how her organization had over 25,000 employees, and so it was challenging for her to be in charge of training every single one of those employees. Additionally, there was often turnover of staff. So how do you make sure that staff were up to date and aware of what the requirements were and how to best provide accommodations. Additionally people talked about feeling as though there wasn't necessarily training or standardized training or even standards for what training should look like.

So one participant reported, I think what I find most -- or, sorry -- I think educating and informing our staff that this is a new way of doing something, a new way of approaching an issue is probably our biggest barrier ." Next slide. Additionally, what they believed needed to happen was a culture shift for behavior change to happen. And this is really difficult. How do you change the behavior of a hospital system of a healthcare organization when they exist in a society that is incredibly biased? So, participants reported that when accessibility was integrated and was a part of the overall mission of

their organization, they believed that they saw more success in their initiatives. So it comes down to, again, how do you convince leadership to integrate accessibility as an overall piece of the mission of the organization?

The organization at all levels, again, the CEO down to every single staff member, they need to understand the need for and why you need to prioritize -- the need for and why you need to prioritize for accessible care. And participants reported that sometimes it really did take a complaint or threat of litigation to force an organization to change. One participant reported, "Even though we've been practicing and doing it for 20 plus years this way, now somebody's telling us we have to change... sometimes it's fighting a battle I feel I'm never gonna win -- battle for accessibility -- but, hey, it's the little victories that kind of keep me plugging away." Next slide. So that concludes our discussion of what we found from our interviews. I would say, again, we only talked with 18 different organizations across the country, but they did represent over 200 hospitals and thousands and thousands of clinics, and we recruited these individuals based off of where we are now. So we don't necessarily know if this is representative of all individuals who are leading ADA initiatives at their organizations, but also we talked to people who are working in organizations that have someone leading these initiatives. I suspect that there are many organizations out there who don't really have someone who is leading these initiatives, and so they are probably much further behind. So out of the need we heard from these interviews, we have been doing this work for several years now. What we decided to do, because so many of these individuals were the sole person working in their organization on ADA efforts, is to create a learning collaborative or an opportunity for these people to get together and share ideas and share challenges, but also share successes. So we created what we have described as the Disability Equity Collaborative, our healthcare leaders. Next slide.

In this leader group, it's again, a community of individuals who work -- everyone works in healthcare organizations or hospitals. They, again, have these wide variety of topics, and the focus of the group is on disability accessibility initiatives. Next slide. So our group, we currently meet every other Friday via Zoom. We were meeting once every two months or once every month prior to the COVID-19 pandemic, and then once the pandemic hit, we actually moved it to this more frequent schedule of every other Friday. This is what we have dubbed as a safe place, in which participants can exchange ideas, find solutions to problems they face in their organization and then champion each other's successes. Again, it is a place that is -- our members are just really individuals who work with healthcare organizations, and that is because organizations need an opportunity to say, hey, my hospital, we're doing a really poor job of XYZ, and not worry about someone going and filing a lawsuit or a federal complaint about them, because -- again, they want to say, hey, here is where we're not doing well. I need to work on this. Can anyone give me suggestions on where to start or what to implement?

We do often include subject matter experts as guest speakers. So if there are some particular topic that they need more guidance on. So, for example, we've had a topic like Accessible Communication for Individuals with Visual Disabilities. So we have individuals who work on that topic and were advocates or individuals who had visual disabilities, they come as guest speakers and help kind of the members work through their challenges. We additionally have an online platform that we have recently created. We use Basecamp. And through this Basecamp, they're able to send messages to

each other about, hey, this problem came up this week, does anyone have an idea or has anyone figured out a solution to this? And then we have a variety of resources available on this internal site. So, for example, some people have created at their organization policies around service animals, and others would like to see that, so we have a space for them to share proprietary information. Additionally sometimes our members have collaborated across organizations and created policies that can be shared amongst the group members.

Next slide.

So, example topics that we talk about is effective communication toolkits, documentation of disability status and accommodations, assistive technology resources for patients who are blind or low vision, service animal policies, identifying and differentiating between the roles of an ADA versus 504 versus 1557 coordinator, and then the U.S. Access Board Medical Diagnostic Equipment standards. COVID-19 topics are mask exemptions for patients with disabilities, visitor policy exemptions, and then access to clear masks. Next slide. So, we encourage you, again, you work within a healthcare organization, a setting, and you are working on leading disability initiatives and would be interested in participating in our leaders group, please contact us. So our leaders within the Disability Equity Collaborative, if you're engaging -- interested in engaging with other stakeholders on disability healthcare equity, we have other workgroups, such as documenting disability status standards, and also research in this area. We encourage you to reach out. We are working on launching a new website. I actually checked this morning. I don't think it's up, but it should be up within the next week. It's disabilityequitycollaborative.org. You can also just send me an email, megan.A.morris@cuanschultz.edu. That concludes our talk and we look forward to talking with you and seeing what questions you have.

>> LEWIS KRAUS: Thank you Megan and Steven. All right, everyone, this is your chance to send in your questions in the chat window, and we will go over those starting now. So, the first questions -- and these are kind of in chronological order from the beginning of your session. So the first question had to do with what Steven was talking about. And I'm not sure if this is so much a question as it is a statement that says: "Many people chose not to disclose -- this is when you were discussing the disclosure of disability --" Many people chose not to disclose as a number of reasons as well the need may not be associated directly with the diagnosed or visible disability. Personally I share and advocate for sharing, but many people chose not to disclose and we should still support people's challenges. Would love your thoughts."

>> MEGAN MORRIS: Yes, that is a great statement. And absolutely, it is definitely individual's right to decide not to disclose a disability. And we've done some research in this area, so, first, we actually did a survey of both people with and without disabilities and found, actually, that across both groups, 90% -- more like 95% of people with disabilities say that they're comfortable disclosing. I think part of that is you disclose a lot of personal information to your doctor. And so people saw this as just one other piece of information about them and their health. We did a study here at the University of Colorado in our health system where we actually rolled out disability status during new patient. It was six weeks long and over 3,000 patients, and we received zero

complaints about this. So no one was really pushing back. But I do absolutely think it's the responsibility of the healthcare organization and the people asking the questions to really make individuals feel comfortable with why this information is being collected and asked and how the information would be used. Absolutely there is a concern with really any demographic characteristic that discrimination could happen because someone knows about their demographic, whether it's their gender identity, or race and ethnicity or disability status. But I give the example, at the beginning of the COVID-19 pandemic, there was a push to document in all of COVID-19 reporting, that we documented patients' race and ethnicity. And because of that, for all of our COVID-related death data, we have 98% of that, we have the race and ethnicity of the patients, and we were able to identify disparities because of that. But we had no idea how the COVID-19 pandemic has comprehensively affected the disability population because they were not collecting that information.

>> LEWIS KRAUS: The next question has to do with patient responsibilities, but also revolving -- staff vendors and all peoples, universal approach and inclusion such as including eliminating implicit bias and the disability movement overall?

>> MEGAN MORRIS: I would say first off, the people we talked about, or talked with, they were the ones who were really leading patient level disability accessibility. They were not leading successfully ADA initiatives related to staff hire or working with vendors. That was another department. You know, for example, HR. So many of these individuals, they might partner with HR, but they were, as I described, drinking from the firehose of just focusing on patients. So they did not have the capacity and position to really focus beyond that. Again, there were other people in their organizations that were supposed to be in charge of that. I do think it comes back to what we talked about is how do you integrate accessibility and equity into the fiber of an organization? How do you say -- because I do absolutely think we can't ask our staff, you know, to provide accommodations and you know, work on biases if, you know, those who they're working next to, you know, the staff and providers, if they have disabilities and they're not being supported by their organization. So it really means, again, a collaborative effort that honestly comes from the top down. I'm not entirely sure how to make that happen. So if anyone has magical ways to change the culture of an organization for leadership, we would be all ears.

>> LEWIS KRAUS: That is key, isn't it? And the next two, I'm going to just read you the comments, which I'm sure are what a lot of people are feeling. One is mortified to hear that HCOs don't have the money to make things accessible for people with disabilities. And then the second comment. July 26, 2021, is the 31st anniversary of the signing of the Americans with Disabilities Act. Sad that 31 years is not enough to make the healthcare system accessible to individuals with disabilities. I think it's kind of interesting to talk a bit about that money issue. It's common for organizations to claim they don't have enough money to do the accessibility, but it is in that budgeting phase and trying to get that budgeting happening before the entire year. So I know you talked a bunch about that budget issue. Anything to add about strategies or whatnot that people were able to do to get that happening?

>> MEGAN MORRIS: Yeah, I will say -- I'll give my bias. I'm a researcher, and my bias is I actually think it's a bit on our responsibility of researchers to work on providing the evidence. Because many people talked about, if I had evidence that providing these accommodations resulted in, you know, fewer staff injuries, you know, better outcomes for our patients, like clinical outcomes, better patient satisfaction, then it would be a totally different game to get buy-in for funding for these things. So I do think we need a bit more data and better data to demonstrate this. I know Daniel Davis, a Policy Analyst with the ACL American Community Living, he talked about they actually put together some materials for making the business case for accommodations. And so the more that we can -- those of us who aren't necessarily, again, in that day and that day out role of an ADA coordinator, those who can come around and help support them and give that evidence, I think that would be very useful for those individuals. I think also, as we all know, given what has happened in our country the last year plus with the pandemic, with, you know, police related shoots and the Black Lives Matter movement, there is a huge push at hospitals and healthcare organizations for equity. But many of those conversations are not including accessibility or disability in those. Again, if anyone has bright ideas, I would love to figure out how we could convince organizations that disability equity is a part of their diversity equity inclusion initiatives. Because a lot of people are throwing a lot of money out right now. So that would be great if we could include disability as a part of that.

Next questions. Did the ADA coordinators also work with staff members requesting accommodations? Or did that tend to be a different role, and what would you recommend?

>> MEGAN MORRIS: Steve, do you want to take this? I've been talking a lot.

>> STEVEN LOCKHART: Yeah, that's a good question. You know, we heard from ADA coordinators that in some situations, they were working closely with staff members requesting accommodations, so working with schedulers and call centers to implement the initiatives. In other cases they weren't even close to implementing an initiative like that. As we highlighted throughout this presentation, the -- we continue to hear that having the buy-in from other departments like the call center department or groups like patient experience, you know, having that collaborative type of relationship for these positions really helped facilitate some of these initiatives, and really getting that buy-in from leadership, whether it's the director of the call center or, you know, leading the schedulers or those individuals who are directly contacting the patients, having buy-in from them from the top down really helped facilitate these efforts to move these forward.

>> MEGAN MORRIS: And maybe I'm reading the question differently. If the question is about different staff members and providers with disabilities requesting accommodations, that was generally not the ADA coordinator. That was generally done through HR. And I -- you know, I would recommend that get a system to work on these together. I previously worked at the Mayo Clinic, and we had a Mayo Clinic employee resource group on disability, and we often talked about how many of the staff providers within the Mayo Clinic were also patients or family members of patients who had

disabilities. So there's a lot of going back and forth. And so it seems as though it would be great to work on those initiatives together.

>> STEVEN LOCKHART: That's a good point, Megan. I see the different type of question. And we did hear from some ADA coordinators that there was someone else in a different role that was responsible for working on accommodations for employees. So they weren't necessarily the ones leading those efforts. But it depended on the organization.

>> LEWIS KRAUS: Now, coming back to your point and the previous question about trying to find good models, about getting people to leadership and organizational behavior change, did you -- were there any of the respondents showing that they were successful in doing this? Did anybody say that they were able to do it well?

>> MEGAN MORRIS: I think different organizations had different bright spots and were doing -- yeah, doing different things well. I think things that contributed to that -- again, supportive leadership, but what we also have found is that people talked about when their leadership had a family member with a disability. So they had a direct connection or sometimes the leader themselves had a disability. But that really facilitated, again, these efforts. And, yeah, it's sad to say, but, again, most of the organizations we talked to, there were lawsuits or a threat of lawsuits. And, you know, again, one of the limitations, I think in our interviews is we really talked with the systems, and I think that's probably more likely who is receiving these complaints, our larger health systems. So, you know, there are thousands and thousands of independent clinics and small private clinics that are probably not even considering ADA requirements or how to be accessible for their patients Steve, any other ideas about models that are successful?

>> STEVEN LOCKHART: I mean, that's a really good question. You know, I think thinking of the three models that we kind of group our ADA coordinators in, obviously, the first was probably the most challenging where they were really the only person reading those efforts and didn't have much support, but in terms of the other two where it was really more of a collaborative type of model with other departments having buy-in versus, you know, the individual leading the efforts with a team of ADA coordinators, it really seemed to vary by the organization. We had one ADA coordinator that really felt strongly that they felt it was easier to implement some of these initiatives without having a team of ADA coordinators, and for them it was more important to have that buy-in from other departments to really partner on these initiatives, where we spoke to others who really felt having these ADA coordinators to work with really made their job more feasible in order to meet the demand of the request of those larger organizations and possibles.

>> LEWIS KRAUS: Okay. Somebody just wrote in a little support to your answer of the previous question saying "The ADA coordinator question regarding employees can probably be summed up by the differentiation between Title I and Title III requirements. This research seemed to be focused on Title III of the ADA, not Title I.

>> MEGAN MORRIS: Yes, that's a great description.

>> LEWIS KRAUS: All right. We realize that some of you may still have questions for our speakers and apologize if you didn't get a chance to ask your question. You have Megan's email address right there if you would like to ask her a question after the session is done, otherwise if it's an ADA-related question, you can also contact your regional ADA Center at 1-800-949-4232. You will receive an email with a link to an online session evaluation. Please complete that evaluation for today's program as we value your input. We want to thank our speakers, Megan and Steven, today for sharing their time and knowledge with us. It was really interesting, I found. And a reminder to everyone that today's session was recorded. It will be available for viewing next week at ADApresentations.org in the Archive section of healthcare. And let me also point out that you may have noticed that the slides are not available yet. They will be available with the Archive next week. I think either -- it's possible that not only is Megan's website maybe not up yet and ours might have been impacted by a big down DNS down outage I guess is the term that happened today. So we'll see if that has an impact that we can get fixed.

On our next webinar on August 26th, we will be joined by the United States Department of Health and Human Services Office for Civil Rights for a presentation on disability accessibility in healthcare and recent OCR cases in review. We hope you can join us for that. Watch your email two weeks ahead of time for the announcement of the opening of registration for that webinar. Again, thank you for attending today's session. And thank you again to Steven and Megan for your great presentation today. And to all of you, have a good rest of your afternoon! Bye-bye!