PELVIC HEALTH MATTERS: A WEBINAR SERIES FOR WOMEN WITH MOBILITY IMPAIRMENTS
Session 4 OF 4: Access to Quality Pelvic Health Care
MAY 18th, 2016
1:00 P.M.

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>> RACHEL MARKLEY: Good morning and afternoon to everyone and welcome to the final session of the Pelvic Health Matters Webinar Series for Women with Mobility Impairments. It's exactly 1 p.m. here in Houston so we will begin. We are going to record this webinar for archiving and I will start that recording now.

Before we begin the session today, we would like to review some of the features of the webinar platform. My name is Rachel Markley, with TIRR Memorial Hermann and the Center for Research on Women with Disabilities at Baylor College of Medicine, and I will be serving as the moderator for this session. This program is brought to you as a collaborative effort between TIRR Memorial Hermann Spinal Cord Injury and Disability Research, Baylor College of Medicine and the American Congress of Rehabilitation Medicine Spinal Cord Injury Interdisciplinary Special Interest Group Women's Health Task Force and the Christopher and Dana Reeve Foundation. Individuals are joining us today using a variety of media, including the webinar platform, listening via the telephone and using realtime captioning. A copy of today's PowerPoint presentations are available at www.bcm.edu/crowd. This webinar is being recorded and it will be archived on our website soon. Our presenters will provide us with some valuable information and at the conclusion of their presentations, there will be an opportunity for everyone to ask questions.

You may submit your questions using the chat area in the webinar platform. We will address them at the end of the session, but feel free to submit them throughout the presentation. Now, I would like to introduce Dr. Margaret Nosek, director of the Center for Research on Women with Disabilities, Dr. Nosek.

>> MARGARET NOSEK: Thank you, Rachel. I would like to welcome you to the fourth webinar in the Pelvic Health Matters Webinar Series.

I would like to remind everyone that our funding is through TIRR Memorial Hermann, the Christopher and Dana Reeve Foundation through a Quality of Life grant and we also receive support from the Women's Health Task Force of the American Congress of Rehabilitation Medicine Interdisciplinary Spinal Cord Injury Special Interest Group. All of the presenters in this series have reported they have no financial conflicts of interest to disclose.

I would like to thank also our medical advisors for this project and our community advisors, who have given us valuable advice as we develop it program and continue to produce materials related to the information that we have presented in this series.

Now, our presenter that we advertised Wendy Wilkinson is an advisor to this project, and a long-term colleague of ours and a dear friend but she unfortunately is ill and won't be able to fulfill her role as the facilitator for today's program. She did, however, give us
advice and recommendation and she shared her notes. So we'll be giving you hear feedback on this topic later in the program.

She was successful in securing for us our main presenter who is Earlene Sesker. Earlene is a graduate of the University of Texas, even though she left Texas to go to Washington to join the US Access Board and she’s been there since 1993, where she serves as the training coordinator and accessibilities specialist. She gives technical assistance to government and private sector entities on the requirements of the Architectural Barriers Act of 1968, and the Americans with Disabilities Act of 1990. Earlene will be talking to us today about access to pelvic healthcare for women with mobility impairments.

>> EARLENE SESKER: As we just talked about, what I’m here to talk to you about today is the standards for the accessible medical diagnostics equipment, and how that standard is going to be applicable to all healthcare, but specifically, to access to quality pelvic healthcare for women with mobility impairments.

As we all know, this is not a new problem. People with disabilities have been having issues with getting proper medical attention for many, many years. And there have always been complaints. Well, in 2004, the Rehabilitation Engineering Research Center on Accessible Medical Instrumentation decided to fund a five-year project to evaluate the methods and technologies that are currently there to provide quality healthcare for people with disabilities, and to, hopefully, increase the access and the usability of the diagnostic therapeutic and procedural healthcare equipment. So they thought we will do this survey, five-year project, we will find out what the major problems are.

And 75% of people responded that examination tables are moderately difficult or impossible to use. And that examination table, we know, that is the major piece of equipment that’s needed when you are trying to get a pelvic exam. And 75% say they can’t use it. And so in looking at that, we then said, okay. Something needs to be done.

Well, it took a while from 2004, when that was completed, to 2010. In comes the Patient Protection and Affordable Care Act. That act included a provision that was set to add a Section 510 to the Rehabilitation Act. It's amending the Rehabilitation Act of 1973 and what this amendment did was to establish standards, gave the Access Board the authority to establish standards for accessible medical diagnostics equipment.

This provision that was written in was very specific as to what the Access Board would be looking at. First thing they wanted to make sure is that they were just looking at diagnostic equipment. Now we say this is going to be a live document. So although we started looking out at just the diagnostics equipment, this is just the first iteration of this rulemaking. After we get this one in place, then we will be moving on to other types of
equipment that might not be in the arena of diagnostic.

But this particular mandate told us diagnostics equipment, and it even was a little more specific, where it named the specific types of diagnostics equipment that it was looking for. And so it talked about examination tables and chairs, weight scales, x-ray machines, radiological and mammography equipment. But as a said today, our focus is going to be your examination tables and everything that goes along with that to ensure that quality pelvic exam.

With this, one of the things that it's important to know, although we are saying diagnostic equipment, the rule is not covering any personal, because another thing that the mandate said is that we are looking at diagnostics equipment that's used in a healthcare setting by the healthcare provider. Any personal device such as this blood sugar glucose checking device is not something that's being covered by the standards that the Access Board is writing at this time.

Another thing that's not being covered are positioning aids. What we are talking about when we talk about the positioning aids are the foam cushions and wedges that doctors sometimes have in their offices that they use on their exam tables to help position people in the appropriate position for the exam or procedure they are about to perform.

We say that positioning aids are not covered. Where it gets dicey is if those positioning aids are actually a part of that equipment, made onto that equipment and not just something that's like a pillow that's being replaced or moved, or repositioned, then it's not covered, but if it's an actual part of that equipment, then it is going to be covered.

Also with this mandate, what a lot of people don't realize and it's the third bullet there is that this standard, once it's completed by the Access Board will only be a voluntary standard and let me clarify that. When we say that, it's because the mandate gave the Access Board the authority to establish technical criteria. It did not give a mandate to establish any scoping. And what scoping is, is it tells you when equipment is required, how many pieces of equipment, what happens with existing equipment that doctors’ offices are not using, that is not accessible. None of that was in our mandate. We are specifically just giving the design criteria for the actual pieces of medical equipment.

So that's why it would be voluntary, because without that information telling people when they need to provide accessible equipment, how many pieces, there would be nothing that anyone could enforce, that anyone could actually legally do. So once we write, it's a voluntary. But the Department of Justice, who is the enforcing agency for the Americans with Disabilities Act, would be the ones to adopt this standard to make it enforceable.

They already, back in 2010, put out a notice of proposed rule-making and they talked
about equipment and in that, they talk specifically about medical equipment and they talked about the fact that the Access Board would be writing these standards and they would be looking to adopt them and they posed a lot of questions. So the push will be to get them to adopt this, once it's out as a final. They have worked very closely with us. They are on our committees and are still working with us in trying to move this along in the hopes that this will be in condition that as soon as it comes out, there won't be many changes, many problems that they have and that we can move this forward as fast as possible.

Also, the FDA. They could be an adapter of this, but the way they are looking at it is more with labeling. What the FDA is looking at is every piece of medical equipment comes through them and the manufacturers are labeling their medical equipment certain ways. In this instance, many are labeling equipment and they are already even without the standard, labeling certain pieces of equipment and exam tables as accessible. What the FDA would do in adopting this is, if you are labeling this piece of equipment as accessible, then these are the standards it has to meet. If it doesn't meet these standards then you cannot sell or label this as a piece of accessible equipment.

And in our mandate, we were also told -- and let me just sidebar here, just a little bit, because in our mandate and I didn't put it on any of the slides, probably something we don't like to talk a lot about but in our mandate this came forward in 2010 and the Access Board was given a two-year deadline to get this out as a final. As you can see from that, we are now way beyond our mandate. There were issues with what we thought we knew, and what we needed to gather more information for. So it's taken a little bit longer but we are hoping we will make up for it in the end with what we actually produce.

In that mandate, we were given federal partners and FDA, the Department of Justice, as well as the Department of Veterans Affairs have all three worked very closely with us in trying to get this to be something that's going to be workable, useful, and hopefully take us out of where we have been all of this time. As I said, there are pieces of equipment that they are saying are accessible but when you say something is accessible and you really have nothing to go on to determine or if this is really considered accessible, you may have five different doctors' offices all using different types of equipment at different heights, different sizes but they have all been labeled accessible somewhere along the line.

In looking at this, when the Access Board first started writing the guidelines, we used several documents as a starting point. In the past, what the Access Board usually writes are for the built environment, so bricks and mortar. This is the first time that we have ventured into something for equipment. We did exercise equipment at one time. But if anybody is familiar with that, we said that there needs to be a route to that and a wheelchair space beside it for someone to use. This is the first time that we are actually
looking at the design of the equipment and ensuring that the equipment will provide
independent transfers to the maximum extent feasible or possible.

And so what we looked at was the ANSI, AAME, HE75, which is the Association for the
Advancement of Medical Instrumentation. We looked at their document, because they
already had a document that they were using as they wrote this document with the intent
for it to be a design guide for manufacturers, as well as an evaluation criteria for
healthcare providers when they are actually trying to buy the equipment.

So there is a section, Chapter 16 of this document, which actually has accessibility
considerations. But one of the things that you will find with this document, is they weren't
specifically honed in on accessibility. They were just looking at human factors in general
and that meant the doctor, as he has to bend over and so we want to do ergonomically
for the doctor, as well as for the patient, and so it wasn't just a full press with
accessibility, which is what we are doing with the standard that we are looking at right
now.

We also looked at the ADA and ABA accessibility guidelines. As I said, that's what we
are used to writing and we are used to it being building guidelines so bricks and mortar.
When you look at, that we had heights for certain things. We have toilet seat heights.
We had bench heights. And so there are certain things that we could take out of that,
and apply toward what we would be doing with the equipment.

Also, we have had research projects going on for a while, that were all surrounding
anthropometric data and people sitting in wheelchairs. One of the things we have to look
at that will affect the height of these exam tables, is that when the ADA guidelines were
written initially, back in 1991, you didn't have as many people using power chairs and
other types of mobility devices. Those were written mainly with your manual chair in
mind.

So now your heights are different. We funded a research project to start looking at what
the new mobility heights are out there, what the wheelchair heights are. And then in
addition to that, we had a study of the impact on transfer. Because not only do we need
to know the heights, we need to know how people transfer, what heights people transfer
to. Is it better to transfer up or down? Is it better if it's at the parallel to where the chair is
and does that mean we need to raise our heights? All of those things needed to be
looked at. So we used those studies, as well as the HE75 document, and the ADA
standards too as our starting point for when we wrote the proposed regulation for the
MDE.

And our steps with this is, as I said, we used all of those documents. We compiled the
Notice of Proposed Rulemaking and basically what that did is it set out everything that
we were planning to write. There were questions in it, and then based on what we wrote, these were our first stab at what we thought would be workable things. We allowed a 90 day comment period to allow the public to read it, comment, tell us what's working and what is not working, what we need to do different, what we missed the mark on, what we didn't think about.

And in addition to the comments, we also held three public hearings. And that was to actually give people a chance to come in and tell us. Some manufacturers even brought in some of their exam tables and stuff so that we could look at it, so people could try transferring on and off.

And at the end of all of that, we still needed more information so we formed an advisory committee. And then the advisory committee gave us a report and based on that we are now in the throes of writing the 9 final rules for the medical diagnostics equipment.

In response to our proposed, where we did that first skew and we were saying, well, this is what we think will work. We asked the public 46 questions. And these questions were in addition to the things that we were actually posing requirements for.

These were things like, okay, we didn't have requirements in there talking about overhead lifts. Should there be an exception in the standards to say that if a company is buying a piece of equipment and they have an overhead lift, the equipment doesn't have to allow for the use of a portable lift? We had questions about transfer supports. Should we be requiring transfer supports? Should we be requiring positioning supports? And so we received actually 50 comments. The major issue that we had with our commenters is they were almost split completely down the middle how they felt about what we were proposing.

And for instance, it was in specific instances, like when we talk about the height of an exam table, we had one group that said, what you are proposing needs to be lower. We another group that was saying it needs to be higher. And I can say it was split kind of down the middle between advocates and people with disabilities and manufacturers. Manufacturers were looking at what they currently have out there and what the people with disabilities and advocates were looking at, is well, what have you currently out there doesn't work for us and obviously something needs to be done.

So then the Access Board had to stop. Now we have these comments but we can't even say the majority says one way. They were basically split down the middle. That's why we decided to convene an advisory committee. Now you saw with the steps that the advisory committee came after the proposed and so forth. Usually that's not the way it's done. Usually before the proposed is written an advisory committee is formed but at the onset, we thought, okay, we have a two-year mandate. This is a very small rule. We
have these other documents that we can use. It shouldn't be as controversial as it ended up being with our comments being split straight down the middle. So that's when it became very clear that we needed additional information. We need additional help.

We formed an advisory committee and when we do that, it's like applying for a job. We have put it out in the Federal Register that we are planning to form an advisory committee. And people submit applications or resumes to let us know and we try to balance it with an equal number of advocates, people with disabilities, manufacturers, government agencies, so that everyone is actually represented on the committee to the maximum extent possible.

We did have an advantage because we had already done the proposal. So we didn't have to just give them a document and say, we just need all of this written. We need you to come up with guidelines for all, because we had already done that, because it had already hit the streets and we knew what issues were split down the middle, we could focus the advisory group on those issues.

We were able to identify four major issues that consensus could not be reached on. And what those issues were, was the transfer surface of your exam tables, and when we talk about the surface, it was the height, as well as the size. It has to be low enough for people to transfer onto and wide enough that they are not transferring right off the other side or feel safe in their transfer.

Any permitted obstructions. How close does the person have to actually be to that table to transfer onto that? They talked about different things like your transfer supports being in the way, or trays coming out from the table or different things. And what should be permitted, if any, obstructions there? And transfer supports. It was decided they were needed but as far as where they should be located or the configuration of those, we didn't have a lot of information on that.

And then the actual depth of the wheelchair space. So if you have a wheelchair space on an elevated platform, such as a wheelchair scale, what does that need to be when we are looking at larger-sized chairs and so forth?

The advisory committee made 55 recommendations. As I said, we gave them four issues. Well, they addressed five other issues in addition to those that we gave to them, and that was armrests and a big one for us today is stirrups when you are doing the pelvic exam, lift compatibility for those people who cannot independently transfer, making sure the piece of equipment allows the use of a lift, wheelchair space, and the standing supports if someone needs to stand while the exam is taking place.

Now we'll look at a brief overview of the standards, those elements that are applicable to
a pelvic exam.

First, we'll start out with just the organization. Basically, we broke the standard into three main parts. And one is your application administration and basically that's going to tell you the purpose of it, if there's anything that needed to be defined, any tolerances and any equivalent facilitation requirements.

And then the second would be your scoping requirements. And in your scoping, as I said, we were not mandated, where we were given the authority to do scoping. So basically, what you will find in this section, it's a place holder for when the scoping comes. The only thing that the Access Board actually put in this particular section is just a provision telling you that the enforcing authority will be the ones that will specifically specify the scoping.

And then we actually organized it by the patient position that was being supported. So what we're looking at would be the supine, prone, or side lying and that's where your exam tables will fall.

And when we look at the supine, prone or side lying position, the key issues, as I mentioned with those issues that we gave to the advisory committee, were the transfer on and off of that transfer support surface, if any obstructions and any supports that may be needed to assist someone with a transfer, as well as what would need to be done to that equipment to allow the use of a lift.

As I said the height was one of the major sticking points. What we proposed was the 17 inches minimum to 19 inches maximum. And it could be a fixed height. That has what the proposed guidelines said and that 17 to 19 was taken directly from the built environment. We looked at things like the toilet seat height. We looked at benches and showers. And all of those things, since 1991, we had given a height of 17 inches minimum to 19 inches maximum. That's what we looked at in the proposal. And in looking at that, what we found is that when you say 17 to 19, and it's a fixed height, you get very little at 17. If you are telling people that the highest they can do it is 19, believe me, I have measured lots of toilets in my career, and they are usually at 19 inches. So that was the big sticking point with advocates and people with disabilities. If you tell them that they can do it anywhere from 17 to 19, then they are going to go with 19.

Manufacturers really had no problem with that, because they said right now, they don't have any tables that are below the 19. They were fine with that, but people with disabilities and advocates said, no, this is too high because you are going to end up with 19 and we would prefer the 17.

So when the committee looked at this, they ended up making a recommendation for the
high height because as I said, we had to look at the fact that people are sitting higher than they used to, and also, they added in a recommendation that we add adjustability to it. We didn’t add adjustability but the advisory committee thought adjustability and then we were looking at all of those issues too. We have wanted to get low enough for a person to transfer from their wheelchair or mobility device, as well as high enough for the exam or procedure to take place.

The problem we still had was with the low height. And even we couldn’t reach consensus with our comments and we couldn’t reach consensus at the advisory committee. So right now that’s something that we have to look at to see how that’s going to be addressed.

We had some that wanted 17, some 18, some 19. We even at one point tried to get a compromise at the 18, but there was a no-go. We couldn’t reach a consensus at a compromise. So right now we have a recommendation of the 25 for the maximum height, but we don’t have a low recommendation right now and as I said, that’s something that we are working out.

And then the size. Okay what we did is, we looked at the size of a seat versus the table. And we looked at the table being 30 inches wide. Now, a lot of our recommendations came in actually wanting the table at least 36 inches minimum wide. Not even to talk about the chair part of it, but just the exam table. People wanted it wider. Then we had manufacturers and a few others, but mainly the manufacturers, that wanted it actually smaller than even the 30 that we proposed. So this is something that the committee looked at, and when they looked at it, believe it or not, they actually did go to the lower.

They actually gave us a recommendation that it should be 28 inches minimum wide, but what they did for the width, they broke it down into two different types of equipment because they said, yes, if you are just on your plain exam table, where we would want you to transfer, would either be from the foot or the side, but if you have a table, maybe you are getting an x-ray or something else that takes place that you want to be in the middle of that table. And so they thought what we should look at is actually providing two - they called it a transfer type A and a transfer type B and having that actual transfer space be a little further up.

One of the their issues was that when we are talking about x-ray and things with boards and so forth and having to go through that, that we are talking about a table that won’t fit through there and they were looking at the actual sizes of tables and that if we got a table too wide, if you have that transfer support on the other side, that a person is still not going to be able to reach that transfer support to transfer over because it will be out of reach or even as far as a medical provider trying to reach over because now you are way out of reach in the middle this table.
So when they looked at all of those factors, they actually came and gave us a recommendation of a 28-inch minimum wide with a 17-inch depth. They increased the depth because we had 15 and basically they looked at what your standard depths are, even for the standard chair that people would be transferring into. And so they did increase that to 17 inches minimum depth.

Now, a thing I wanted to point out here, that all we are talking about here is the equipment. We realize that there needs to be wheelchair spaces beside that equipment to allow someone to transfer. Those are all things that will be addressed with the Department of Justice because that's more of the built environment issue. That's the building and right now the way ADA standards stand, there needs to be an accessible route. So all we are looking at in this standard is the equipment itself. We are not looking at the position of the equipment in the room. We are not looking at how large that room may be. We are just saying at this point that that equipment needs to be accessible, that equipment needs to be designed in a certain way. And when this is adopted, and it's told how many need to go in and where, then will be the connection of the accessible route and the wheelchair space to allow someone to transfer on.

The transfer side - I talked about our issue and one of the things the committee looked at how close does the person have to be to transfer? What can you transfer over? You see the transfer supports or the rails and what the committee recommends is that we permit temporary obstructions as long as they can be repositioned. Which is why you see that dotted line, where the other one on the other side has a solid line. The dotted line shows it will not be all the way up in that position, it can be folded down. How far away can you be? And what they recommended is that there is a 3-inch max. So there should be nothing that protrudes more than 3 inches that prevents you from getting at least three inches away from that table. You should not be further away than 3 inches when you are trying to travel onto this table, based on the recommendation of the advisory committee.

Additionally, they looked at the proposed provisions for supports. We proposed transfer supports. We talked about leg supports in the proposal, we called them stirrups. We talked about the head and the back support in the reclined position. We know we have a lot of exam tables that fold -- they move up and down. They are a chair in some instances and then you lay flat, usually when you are transferring onto that, it’s in a seated position. And we wanted to ensure that as that is reclining that there’s support there for you at all times and we looked at all of those and we did not address positioning supports. That’s something that we did ask a question about, but we did not address them, and it was something that actually once the committee finished, they did not feel the need, actually, for a particular provision talking about just positioning supports.

They felt that the transfer supports that you would be requiring would actually provide
the same type of assistance for positioning. So there would not be a need to provide both on that particular table.

When we decided on the transfer supports, we looked at what size should those transfer supports be to allow them to be useful, to allow someone to actually be able to grip that transfer support, to use like they needed to and for that, we went back to the ADA/ABA guidelines and looked at what we require for grab bars in bathrooms. And so we asked the committee the question, if we should be looking at that and the committee concurred with that and they reached consensus that we should be looking at those requirements when designing the transfer supports for the exam tables.

And in looking at that one of the things we did not do, that's in the ADA/ABA guideline is talk about the structural strength. One of the reasons, and you see the little girl, she's hanging there. Because in the ADA standards, we talked about the weight that it allows. But when we are looking at the transfer supports, the weight is not being applied in the same way it would be when you are getting up to get in the shower or on the toilet and also what we found is there are already industry standards that with certain things that have to do with the table, certain strength requirements there, and so those were sufficient without us adding on to that and they know more about what that strength requirement would be as to how the force is applied to that bar when someone is actually transferring.

Now, the location. That was a big one as to where that bar should actually be located. What side should it be located on? If the table too wide, if it's used on the opposite side, will it be used in connection with the transfer?

The committee recommended a more detailed provision than what we were looking at, because they gave us the length of 15 inches. They talked about 9 inches to 19 inches max above, and they talked about how far it should start from the actual edge.

And with that, they also recommended that it be located on the opposite side of transfer. Now issue with this is a lot of that is going to be dependent on how it's placed in the actual exam room.

So in all likelihood, what it's going to have to have is one on either side that can be folded out of the way or when that's purchased, the doctor knowing how that's actually going to be positioned in that room.

And this is what a lot of this problem is going to be. Just like we do in the world with accessibility, the drinking fountains, things can be advertised as accessible and be built as our standards say, so they are considered accessible but then be put in a room or a space and all the accessibility is taken away because of the room or how the space is.
So those things are going to be looked at by the Department of Justice.

Stirrups was a big one. We did propose stirrups and we got a lot of feedback because this was the drawing that we showed with that this was a particular model and it was more expensive. Not all places would have access to this type of stirrup. So we will forget what the picture shows but our discrepancy was, we said the stirrup should provide a method of supporting and securing the leg. When the committee came in and they looked at that, and the feedback we received was that we’re saying the stirrup should provide the method. And what they thought we needed to actually identify and make clear is that first of all, we are not requiring the stirrups. We are saying if they are provided. We know with the pelvic exam, they will be provided on the tables that we are looking at today.

And what we wanted to make clear and what the committee recommended that we make clear, is that it doesn't have to be the stirrup that provides that method. There can be something else that's purchased in conjunction with the stirrup that is going to provide that support and secure that patient's leg.

Then there's the lift compatibility. As I said, our mandate was to do what we could to the maximum extent feasible for independent transfer. We do realize that in all instances, independent transfer is not possible. So looking at that, what we then need to say is how would a person use a portable lift to access the equipment? So what we came up with were two different provisions. One around the base, because we are talking about the legs for that life, and how it will fit around to make sure that people can use the lift. We talked about, one that looked at providing space around the base, the clearance around the base and the other within the base. And this is just another view of looking at that, and the dimensions. So that if you have a piece of equipment, that's open beneath, that the lift can slide right under it. But if you have other cases where maybe it's not a small enough base that the legs of that lift can actually fit around that to then still position someone where they would need to be on that piece of equipment, on that exam table.

And I told you earlier, we asked the question about the overhead lift. This caused a lot of discrepancy back and forth with the committee also because of the fact that some wanted to include the recommendation for an overhead lift, and others didn’t. In the end, they did recommend that we provide an exception for an overhead lift in lieu of any of the base clearances, rather around or under the base of the equipment. The big thing with that is going to be how that is -- I mean, I can buy a piece of equipment. Say that it -- well, I'm going to have an overhead lift. So this piece of equipment is accessible. It doesn't have the things. So there may have to be some issues with packaging, and saying that basically this piece of equipment is only accessible if you purchase this, this, and that. If you don't purchase this, then it's not a piece of accessible equipment and not meeting the scoping requirements that the Department of Justice set forth.
On our website, you can find all of the information that I just went over with you. And that's the link for finding that information. I'm the contact on there. So if you need to ask me further questions, if you don't have enough clarification or you want to scream at me about some of the things that we are doing, and you want to contact me by email, the information is available there. It's Sesker@access-board.gov, or my direct number is area code 202-272-0022.

>> MARGARET NOSEK: Thank you very much, Earlene. I wanted to ask one question before I go to the final slides. What about materials? Could you explain to us a little bit about accessible materials for people with low vision? Are providers required to give us materials be it large print or alternative formats?

>> EARLENE SESKER: Right now, they are provided to do alternative formats but that's under just the ADA standards for alternative means of communication. They are already a requirement. As far as the equipment, what we have done is in the back part of after we get passed all of the pieces of equipment, we do have communication requirements there in the back of the standard, and that goes across all types of equipment. So it's things like if you have a piece of equipment that talks to you to tell you to hold your breath, or count to ten, that that needs to also be provided to people that have low vision, people that cannot hear, all of those things need to be provided as far as the communication.

So that part is all we are looking at with the equipment but in general, there is already a requirement in DOJ's regs about effective means of communication. If you have someone going into the doctor's office, there's an obligation to provide an effective means of communication.

>> MARGARET NOSEK: So we already have other protections under ADA?

>> EARLENE SESKER: The only thing that this new regulation, the medical diagnostics is doing is for first time we are looking at the actual pieces of equipment. There are already things out there about the treatment of people that should be being enforced.

>> MARGARET NOSEK: Thank you. And one more question. Do we have any protections under the Affordable Care Act?

>> EARLENE SESKER: Well, the Affordable Care Act is what actually gave the US Access Board the authority to write these requirements. In that act, it said we want these standards written. I want the Access Board to write these and the Department of Justice to work with them. So that act has pushed these standards into existence.
>> MARGARET NOSEK: Excellent! And so the bottom line is equity, that we have the right to get equal access to the benefit of medical services. So if anything interferes with our access, to equal quality of services, then we can say that we are facing discrimination in the delivery of those services, would that be a correct statement?

>> EARLENE SESKER: That's a correct statement. Let me also stress that just because we are just writing these standards doesn't mean that healthcare providers are not required already to provide something and what Department of Justice would say now is you just need to use whatever the closest thing that's available. That does not give them an out, because these standards aren't in place and are not enforceable yet. It does not give them an out for providing quality healthcare.

>> MARGARET NOSEK: And your standards, we're hoping that the Department of Justice would accept those and do you have a date that that decision will be made?

>> EARLENE SESKER: At this point, our goal is that by December we're hoping to have something out as a final. Because after we write it as a final it has to go to the Office of Management and Budget, they need to put something out to look at the financial impact that this is having on everything and all of that is weighed against this. We hope to have that out as a final by the end of this year and then the Department of Justice can pick it up at any time. So the push will be to get them to, as soon as it's out as a final, now it's here. Pick it up. Any push that they can be given would be appreciated. Like I said, we are already late with this and so we want to get it moving as soon as possible.

>> MARGARET NOSEK: Great. But now one important question. When -- I'm going to say when, not if, but when the Department of Justice accepts the regulations that you are recommending – will they be mandatory or voluntary?

>> EARLENE SESKER: Mandatory. Once the Department of Justice accepts them, they are mandatory and they will be putting in that scoping thing that I was saying, they will tell doctors' offices when they are required to have them and how many pieces of accessible equipment they are required to have. The issue that will be somewhat of a sticking point is whenever there's ADA requirements is when you have existing equipment because what they are not going to be doing most likely is making every doctor's office go out and buy the equipment. It will be when you replace equipment, you now have to replace it with a piece of accessible equipment until you get a number of accessible pieces that we are saying you need to have.

>> MARGARET NOSEK: Excellent. Well, that gives us more power for new equipment. New purchases have to meet these new standards.

>> EARLENE SESKER: Correct. And the Department of Justice also put in their reg and
that will be up to them, about -- I won’t say grandfathering in and saying we need to do certain things.

>> MARGARET NOSEK: That's up to us to pressure them to set that limit. Thank you. Well, stay on the line, please.

If anyone listening has any questions, please put them into the chat box and we will address them after I finish talking about our last topic for this webinar, which is self-advocacy in healthcare settings. Now there already exist a lot of materials about self-advocacy from people with disabilities in healthcare settings.

And I would like to refer you back to our website. It's, again, www.bcm.edu/crowd. We'll have that on the slide at the end, but there are also others, other pamphlets or booklets that give you a step by step guide on how to advocate for yourself, when you are in a healthcare setting. So I would suggest Googling these exact words and you will get a long list of items, including some very thorough materials developed by our colleague in Los Angeles, June Kailes. She and her team have developed some very useful materials.

On our website, if you go under the topic of healthcare, we have listed many things about how to deal with some of the barriers you are going to confront. Now, the issue in pelvic health is that we are faced with some very vulnerable situations. I mean, with you sitting there naked with your legs spread apart, it's really hard to advocate and so you have to have your knowledge ready and your strength of will ready and be prepared.

So there's as a lot of stuff you need to do before you get into that situation. And so we want to make sure that you understand that refusal to provide a patient services because a provider does not have accessible equipment is a form of discrimination under both the ADA, the Americans with Disabilities Act, and the Rehabilitation Act.

You have the power to make a difference in the accessibility and quality of your healthcare. Now, throughout this webinar series, we have been trying to make the point that you have the power to make a difference in your pelvic health, and a key element of that is how you interact with the healthcare system. So the message of this webinar is that you can make a difference in the accessibility and quality of your pelvic healthcare.

Many providers are still inaccessible, but we have to understand that they may not be aware of their obligations under the ADA or the Rehab Act, even though we are way decades after these laws have been passed, they may be oblivious to the fact that they are imposing barriers to delivering services to people who are using wheelchairs or have other types of mobility impairments.
So it’s up to us. We have to empower ourselves with information about our rights. I think just by having listened to this webinar series, and particularly this session, you will know more than your provider. You are going to know a whole lot more than your provider just by knowing that these regulations are coming down the pike. So tell your provider what assistance you need so you can receive a proper examination.

When you call to schedule your appointment, tell them about your disability, how they can accommodate you in terms of the exam table. Ask them specifically what height does it lower to? Do they have any tables that go up and down? And if they do, how low do they go and measure your own wheelchair, how low do you need it to go? If you have a disability that requires the use of a lift or a transfer board, make sure that they have that available for you.

And if you are going to need any assistance in transferring, even though they may have the equipment, then be sure to ask for that when you schedule your appointment.

But as we all know, the vast majority of physician’s offices are not going to be accessible. So how do we deal with that when we are faced with it? As I mentioned earlier, it’s better to deal with it before you end up in the office and face to face with them. So do it when you make your appointment, and ask them if they don’t have an accessible exam table, how exactly are they going to accommodate you? And you do that with expectation in your voice, not being timid about it because they have the obligation.

And if they are part of a larger institution, ask them if there are accessible exam tables in other areas where perhaps you could go for that exam. Ask how they plan to get you safely on to the table and keep you stabilized there during the exam. They are required to provide you with transfer assistance, help with undressing and dressing, and they are not supposed to be asking to you bring people to provide assistance yourself.

Now, if you are getting no as the answer to every question you ask, you do have the right to take action and even though we are waiting for these mandatory regulations to get set down as law or as regulations, we can take action, even now.

So I suggest -- and these, again, are notes from Wendy Wilkinson who is our advisor to this program, Wendy suggests that we write down the names of anyone we have spoken to in this interaction, take notes from what we discussed and what we decided to do. At the time of the appointment, bring resources on the ADA and medical equipment for the office and you can give them the website of the Access Board.

There’s a pamphlet that the Department of Justice has provided in accessing medical offices. So there are resources out there. Again, these are all on our website. Bring
online information, again, with websites or printouts of pictures with pricing. Information about accessible exam tables. They don't have to be outrageously expensive and some physicians or office administrators may have no clue about what one looks like.

Encourage them to purchase accessible equipment and make their services more accommodating for people with mobility impairments and if you are confident that what you have experienced constitutes discrimination, you have the right to file a complaint with the Department of Justice and they will send someone either to contact you or send someone out if it reaches an advanced stage of investigation to actually pursue it look into the details and provide some sanctions to the provider.

So I think we have heard very clearly here call for action. Come the end of the year, when these regulations and the recommendations from the Access Board are available and released, we have to start writing letters to the Department of Justice. Wendy used the word "asking," I would use the word "demanding" that they adopt the medical equipment guidelines so they will become enforceable. This would be the tool that we can use to apply the power that we have to advocate for this change and I have to tell you, that this is a point of really intense emotion for me. Our research at CROWD has identified inaccessible exam tables as the number one barrier for women with mobility impairments to get well woman exams. This is not a joke. This is not merely an inconvenience. This is a serious barrier.

So if you have any questions, please type them into the chat box or later, you can send an email to CROWD@bcm.edu. But I will turn it over to Rachel now. And Rachel, could you please facilitate the questions?

>> RACHEL MARKLEY: Absolutely. Thank you, both, for your presentations and for sharing your time and knowledge with us today. We would also, again, like to thank Wendy, even though she was unable to make it, we're very thankful for her help in this.

I don't see any chat messages right now, but I will give a second, if anyone has one, the chat feature is on the right-hand side. It's the second button under "leave". You can type them there and I will pass them along to our presenters.

While I give people time to type, we would like to remind you that the session was recorded and it will be available for viewing on our website within just a few days. The transcript will also be available in a couple of days.

The first three sessions of this series are already archived, and are available at our website. In just a few minutes at exactly 2:00 central, you will receive a link to an evaluation survey via email and we ask you to participate to help us identify future topics. If you could please take the survey, even if you completed a previous survey at
the end of another session, we would greatly appreciate it.

Again, we do have a lot of information on our website about pelvic health, as well as all the recordings. By the end of the week, all four should be available. We'll link them to our main pelvic health page.

I still don't see any chat messages for questions. So I would say that we could wrap up for today. Thank you both again for your presentation, and for everyone else, enjoy the rest of your afternoon.