

# **Mid-Atlantic ADA Center**

## **Podcast: ADA Today - Episode 1**

### **What is Accessible Medical Equipment?**

>> CALEB BERKEMEIER: Welcome to ADA Today, podcast of the MidAtlantic ADA Center. I am Caleb Berkemeier, your host, and we're coming to you from the recording studio here at TransCen Inc. in Rockville, Maryland.

This is our first episode and I just wanted to take a brief moment to talk about what we want to do with this podcast. The first thing we want to do is cover ADA related current events. So, anything that is happening in the news recently that you want to hear about and are looking for reliable, non-partisan analysis. We're hoping to use this podcast to provide that to you.

Another thing we would like to explore in this podcast is things in the area of disability studies. There is a lot of interesting stuff happening in disability culture, art, literature, philosophy that I think is really interesting and if you have an interest in that, be looking for some episodes coming in the proceeding months.

So, on December 26, 2017, the Department of Justice withdrew four ANPRMs – that is Advanced Notice of Proposed Rule Making. And one was for making medical diagnostic equipment accessible, as for setting standards for making that kind of equipment accessible.

Last year, there was an article published in the New England Journal of Medicine on this issue and we have with us today one of the co-authors of that article.

She is Dr. Lisa IEZZONI. Dr. IEZZONI, welcome to the podcast.

>> LISA IEZZONI: Thank you for having me.

>> CALEB BERKEMEIER: So, for those of – out there who don't know who you are, could you just give a brief introduction to yourself, your – your background and your – your credentials?

>> LISA IEZZONI: Sure. I am very classically pre-ADA so I have to put that right up front. I am a Professor of Medicine at Harvard Medical School and I do have an MD after my name, but I started medical school in September of 1980 and at that point, I had had four years of symptoms that had kind of been on again, off again that had started when I was twenty-two.

And I didn't realize at the time because I was young and visible and vulnerable, that in fact those were the symptoms that were telling me I had multiple sclerosis.

I was diagnosed with MS actually at the end of my first semester at Harvard Medical School because during those several months, my symptoms became such that I could no longer ignore them and think that they were going to go away.

And so, I went to the neurologist and was diagnosed with MS. Again, that was December of 1980, ten years and six months or so before the ADA was signed and it was a really rough time to be in medical school for somebody who was developing a disabling condition.

And to make a long story short, when I was in my final year of medical school and about to apply for the internship and residency that you need to do to be able to practice medicine, Harvard Medical School decided in its wisdom not to write a letter of recommendation for me.

And so, I was unable to go on to train. I never became a practicing doctor. I have my MD degree but I don't want to misrepresent myself, especially given the topic of this conversation as somebody who has actually ever practiced as a licensed physician because I never did.

I went immediately into kind of health policy related work and that is what I have done ever since July of 1984.

About twenty years ago, I kind of switched my focus to be more focused on disability related topics. I have used a wheelchair since 1988 and so I have personal experiences with what it is like to be an individual with disability.

But at that time in the late 90s, there were some intrepid researchers out there looking at disability topics, but I was really happy to join their ranks. My focus really now is on healthcare disparities for people with disability and looking at differences between people with disability and people without disability in terms of the quality of their care.

So, that is maybe more than you wanted, Caleb, but I just wanted to kind of give you a sense of the whole range of my experience around this issue.

>> CALEB BERKEMEIER: Yeah, I think that's great. And what are you doing now because you are at Harvard Medical School?

>> LISA IEZZONI: Yes. I am a Professor of Medicine. So, even though Harvard Medical School told me to go away quietly into the night back in 1984, I came back. Actually, I was recruited back in 1990 and I became a professor in 1998 and I had been here ever since.

>> CALEB BERKEMEIER: So, just to set the stage for people who might not know, we should probably just say a little bit about what is an advanced notice of proposed rulemaking or ANPRM is. Can you just give a little brief overview of that?

>> LISA IEZZONI: Sure. I did caution you that I am not an expert in this topic, but my understanding is that when the government passes laws, they need to then pass regulations to implement the law.

And so what an advanced notice of proposed rulemaking is, is kind of giving the public warning that the federal register which is this very dense volume that comes out daily and has tens of thousands of pages, that somewhere in the federal register will be posted information

about a rule that the governmental agency, in this particular instance it was the Department of Justice, will be making around a particular topic that somebody might be interested in.

>> CALEB BERKEMEIER: Now, for – so, for the ANPRM on medical diagnostic equipment, you wrote in the article that this process really got started with the Affordable Care Act. Is that true?

>> LISA IEZZONI: It did, yes. So, Senator Tom Harkin who many of you might know as a champion of the ADA since before there was an ADA, had for many years tried to implement laws to make medical diagnostic equipment accessible.

So, as you probably know, the ADA itself looks at accessibility of structures and – and items that are attached in a fixed way to a structure such as a toilet or a grab bar or a door.

But the ADA itself did not make any regulations around equipment or furnishings or the things that are within a space.

So, Senator Harkin had, for many years, been trying to pass a law to focus on medical diagnostic equipment and making it accessible to people with disabilities.

He was able to, along with other colleagues, insert a section 4203 into the Affordable Care Act that Obama signed in 2010 and Section 4203 required US Access Board along with the Food and Drug Administration to come up with standards to make medical diagnostic equipment accessible to adults with disability. It is focused on adults, not kids, but adults with disability.

>> CALEB BERKEMEIER: Could we just maybe give some examples of medical diagnostic equipment? Like, what specifically are we talking about?

>> LISA IEZZONI: Okay. Yeah. There were several classes of medical diagnostic equipment which we called MDE. The first one is exam tables, really simple, exam tables. Weight scales, again, really simple. Gurneys. You know, many people get tossed on gurneys like if they are in the catheterization lab or something like that.

And mammogram machines and then diagnostic imaging equipment.

So, exam tables, weight scales, gurneys, mammography equipment, and diagnostic imaging equipment.

>> CALEB BERKEMEIER: Okay. Yeah, and we'll get to why it's important to have standards for that in just a moment, but before we get there, I just would like to hear more about your role advising the Access Board because you were chairing a committee for that, right?

>> LISA IEZZONI: Oh yes. Okay. So, so, again, posted in the federal register I believe back in 2012 or so was a notice that the US Access Board wanted to convene an advisory committee to advise them as they were doing this rule making.

Yes, it was posted in the federal register in July of 2012 and I was fortunate enough that the Boston Center for Independent Living whose board I have served since 2005 nominated me as their representative to serve on this advisory committee.

And I was selected, again, representing the Boston Center for Independent Living, and I was honored that I was asked to actually chair the committee.

It was a fascinating committee. It was one of those classic, quote, unquote, “herding cats” committees because it had people like – I’m just kind of looking at the list of people. It had people from all of the big medical equipment makers like General Electric and Siemens. It had the bed makers like Hill-Rom Company. It also had the ADA National Network I think, advocacy group. Paralyzed Veterans in America.

It had Stryker Medical which makes gurneys. United Spinal Association. So, it had – and then it had a number of provider organizations as well and some groups that actually do some accessibility evaluations of healthcare facilities.

So, it was a very, very, very diverse group, a very committed group. I mean, we weren’t paid to do this. We did this of our own kind of very strong interest in the topic and the goals of the standard setting. But it was – it was challenging because the interests sometimes didn’t necessarily kind of align with each other if I can put it that way.

>> CALEB BERKEMEIER: Yeah, I – I actually didn’t realize just how many different people and organizations were involved in that. What were some of the points of conflict on this issue?

>> LISA IEZZONI: Oh, okay. There was one major point of conflict and in fact, I mean – again, this group met in a very devoted and dedicated way for about a year and we went through a whole range of different standards, very much guided by the very, very capable and superb staff at the US Access Board who did a lot of work researching and coming up with recommendations for standards, drawing little diagrams, so we could see what we were talking about visually.

But there was one thing that we simply could not agree on and there was general agreement that exam tables should automatically – the height of exam tables should be automatically adjustable.

So, in other words, with pressing a foot pedal or something like that. A practitioner should be able to raise or lower an exam table and should also be able to raise or lower a stretcher for example.

We could not agree on what the lowest height should be of that automatically height adjustable exam table or stretcher. The advocacy community wanted the lowest height to be seventeen inches. The manufacturers wanted the height to be nineteen inches. And for those two inches, we spent endless hours in discussing it.

And obviously for the advocacy community, having it lowered to lower heights would make it more accessible to people who might have lower height wheelchairs than others might.

For the manufacturing community, it was all a matter of engineering. Apparently, there was a sweet spot around nineteen inches and going any lower was going to be challenging for them. And so, the final rules that were actually posted in the federal register I believe it was January 9, 2017, there was one area that was left open and said that there was disagreement and no final standard and that was the lowest height of adjustable height tables.

>> CALEB BERKEMEIER: Oh, wow.

>> LISA IEZZONI: So, it could be either nineteen inches or seventeen inches. But yeah. So, that was – that was the one topic where we never reached consensus, but we did reach consensus on dozens of other standards for making diagnostic equipment accessible.

>> CALEB BERKEMEIER: Yeah, that's amazing. It's the difference that two inches makes. Wow.

So, you mentioned that final rule was published. You said in 2017?

>> LISA IEZZONI: It was published – I believe it was January 9, 2017.

>> CALEB BERKEMEIER: Okay.

>> LISA IEZZONI: Yeah.

>> CALEB BERKEMEIER: And then once that final rule is published, then what is the next step for it to eventually become an actual regulation?

>> LISA IEZZONI: Okay, so – so that is a rule. However, it just basically states what the standard should be. It does not indicate how widely implemented the equipment that meets those standards must be, okay?

So, nowhere in the rules does it say that if a clinic has ten offices, at least one or two of them have to have height adjustable exam tables.

So, that is what the rulemaking that was rescinded or put, you know, on hold in December of 2017 was all about. It was basically the Department of Justice setting the standards for what facilities needed to implement the accessible medical diagnostic equipment.

Apparently, the technical name for that is a scoping review where they basically look at the scope of facilities that might need – or might be just to these rules and decide which ones need to comply and which ones could be exempt.

>> CALEB BERKEMEIER: So, yeah, that brings us up to the withdrawal of that ANPRM and why did that happen?

>> LISA IEZZONI: It was part of a larger effort of the Trump Administration to reduce rulemaking generally. That is probably a pretty well understood aspect of the current administration, that they have tried to limit federal rules or rescind federal rules that were implemented under the Obama Administration.

As indicated, the final rule for the standards was – came out just as Obama was nine days away from leaving office and so it was just swept up in part of the effort of the current administration to do away with setting rules.

>> CALEB BERKEMEIER: So, I'm curious about why – why it is a problem that this particular ANPRM was withdrawn and maybe we can get a little bit into who this might affect or maybe would have affected as this rule was on its way to becoming a standard?

>> LISA IEZZONI: Yes. Okay. So, we know that the ADA was passed in 1990, okay? However, I suspect that people who are listening out there who are wheelchair users or who have other – other disability related barriers to accessing medical diagnostic equipment would wonder why, in 2018, soon to be 2019, they can't get up onto an exam table or can't use a mammogram machine or can't get onto a weight scale.

Even though all of these years have passed, for some reason, medical settings remain inaccessible in many instances to people with disabilities which means that people with disabilities may experience substandard care.

Now, yes. You're right that the ADA does require that patients with disability get equal, equivalent care and equitable care as to other people, but how would they do that?

For example, before the mammography equipment where I get my mammograms was made accessible, the way that that happened was that they would take a little chair and put it behind me and they would have two technicians standing on either side of me who would kind of grab me and hold me up to this equipment even though I could barely stand.

You know, so, yeah. Technically I was getting the service but it was in a way that was dangerous not only to me but also to the radiology technicians who were assisting me in doing that.

And so, the reason why I think the scoping review and the Department of Justice rules here would have been so important is that they would have made a clear statement to medical settings.

You know something, guys? It is not time for you to put accessible equipment into your facilities. You know, we're tired of having people in wheelchairs be examined in their wheelchairs which happens so often that we need to kind of make equipment as accessible as it can be for people with disabilities so they can get the same quality of care as other people get.

>> CALEB BERKEMEIER: Yeah. That makes a lot of sense. I think the big problem is that you know, on the one hand, we do have a law that says that everyone needs to get equal care, but like you're pointing out, if we don't have any sort of good measurements for that, it's really hard to tell, like, if people are really getting the same kind of care?

That was something you kind of mentioned in the article and if I read you correctly, you were saying that we don't really have a lot of good survey data for just how available this equipment is and what's going on out there. Do you have anything else that you could add to that?

>> LISA IEZZONI: Yeah. No, that is really true. I mean, there was another section of the Affordable Care Act called section 4302. So, instead of 4203, it was 4302 which is kind of confusing.

But that section had a couple of provisions in it. One provision was that the Office of Minority Health and the Department of Health and Human Services come up with a standard way to capture information on disability as well as on other attributes such as race and ethnicity and gender.

And so, the Office of Minority Health a number of years ago published six standard questions that are now to be used on federal surveys to try to capture information about disability.

But also, as part of section 4302 was a requirement that the federal government go out and determine just how accessible medical facilities were to people with disabilities and unfortunately that was never done.

And so, we do have some surveys from limited states or practice environments that have looked at this issue and we know that – that this kind of equipment is just not always routinely available.

Certainly, a classic story of somebody with a spinal cord injury is to have them asked, you know, how much do you weigh and they say oh you know, I weigh 135 pounds because that is what they weighed thirty years ago when they had their spinal cord injury because they had never been weighed since.

>> CALEB BERKEMEIER: Oh my.

>> LISA IEZZONI: It is such a common story among people with physical disabilities that they have not been able to get weighed. They haven't necessarily been able to get onto the exam table for all of the exams that a person who does not have that kind of mobility disability would have been able to do.

>> CALEB BERKEMEIER: Yeah, that is – I'm really glad you pointed that out. I think you know, I mean, as I also have gone through to try and get medical treatment as someone who is blind, I have experienced some of this stuff myself and part of me wonders like, just how many patients out there also just aren't really – aren't really aware of the fact that they might not be getting equal care either.

You know, I think the whole issue, if we knew more about it, it would be a lot easier to be able to identify where that care is falling short.

>> LISA IEZZONI: Yes, absolutely. I mean, I think that the empowered patient is a really good thing and I think historically though, people, when they are in the role as patient, and so I am speaking very specifically about that context, often do not feel empowered, often feel that professionals hold the kind of ruling hand, so they don't really question things.

For example, the fact that you are blind. If there is a blind woman who is having a mammogram and the mammography technician says okay, hold your breath when the light turns red. But you're blind and you can't see when the light turns red, then how are you going to hold your breath?

Or if the woman is deaf and the technician gives her auditory cues about when to hold her breath or if you're deaf-blind. I mean, so there are so many different contexts.

You know, and holding your breath during mammography is really important so there isn't motion artifact while the picture is being taken, so the radiographer has the best possible film to read.

And so, there are just so many instances where I think you're absolutely right, that people with disability may not be aware that they are not getting the same standard care as other people are.

>> CALEB BERKEMEIER: So, you mentioned in your article that the Department of Justice said after they withdrew this ANPRM that they are going to reevaluate whether or not regulation of this kind of equipment is necessary or appropriate.

So, just from their perspective, I mean, what do you think that they have in mind there? So, we've kind of talked about how this kind of equipment, it is kind of important for people to get the care. What do you think that they have in mind when they say necessary or appropriate?

>> LISA IEZZONI: I have no idea. I really don't. It may go to what you were saying earlier, Caleb, about is it appropriate? We already have a rule that requires equitable care and so should we just assume that this other rule covers it? I really do not know.

You know, one of the concerns that has been voices literally since before the ADA was even approved by the congress was that implementing it would be expensive.

And so, one of the things that practice settings and doctor's offices and hospitals are concerned about is that if they had to go out and buy all new equipment, it could cost a lot of money.

So, part of rulemaking is actually part of an Office of Management and Budget effort to look at what the costs of the rules are going to be. So, that could potentially, you know, obviously –

I cannot tell. I'm not part of the administration. I don't have any special knowledge of what they're thinking.

But I could imagine that there would be some practice settings that would complain, you know, that accessible table is more expensive because it's true. An accessible table, a height adjustable exam table is more expensive than a fixed type table frankly just because it has more electronics and moving parts to it.

And so, it is more expensive. But my countervailing observation would be that nurse assistants, CNAs, practice assistants have very high rates of occupational injuries from transferring patients. So, offices and hospitals have to pay for workplace injuries and worker compensation and so the costs of implementing this equipment are probably going to be complex to determine and – and – but I would imagine that that might be one of the concerns that might be voiced.

>> CALEB BERKEMEIER: Yeah. Yeah, I think that's an excellent point about the occupational workplace hazards and how much money that costs.

I mean, on the one hand, the expense to get this new equipment, I mean, that is a legitimate concern I would say from the perspective of someone who has – is running a business. But I wonder, you know, if there are any studies out there that have calculated how much it costs for disabled people to not get the same kind of care that they would be getting if there was medical diagnostic equipment that was up to the standards that – that the Access Board was proposing.

I mean, if we had a study like that – I don't know if it exists – a cost analysis, in total it might turn out that actually it is – it is worth our time as far as the healthcare system goes.

>> LISA IEZZONI: That is such a great point. However, your very clever analysis is the cost to society and all doctor's offices see it as a cost to themselves. All hospitals see is the cost to themselves.

So, however, what I would point out is for the small physician practices, there are – or at least there used to be. I expect that they still exist but, you know, we'd have to confirm that.

That there are special tax credits that are available if an office is making renovations or purchasing equipment or doing something to make it more ADA accessible or compliant.

And so, for some of the small physician practices, there would be tax advantages or tax offsets to doing that.

For the big institutions like hospitals, my response would be look at demographic trends. The baby boomers are coming. They are going to be coming with their bad knees, their bad backs. There is going to be a lot of people who are going to need assistance.

And we already have, you know, like 13% of the population we know has mobility difficulties. It is going to be very large numbers. So, don't you want your practice to be as accessible as possible, recognizing that in the future, this is going to be a very large portion of your population that you are going to be seeing?

>> CALEB BERKEMEIER: So, since it seems like we're not going to get any action on this on the federal level in the near future, is there anything that states can do about this issue?

>> LISA IEZZONI: Well, my state, Massachusetts, the Commonwealth of Massachusetts is actually – was delighted to have these standards because they had been casting around for a way to interface with the Medicaid Agency in our state to say, look, if you want to be a Medicaid provider, you need to be able to serve Medicaid beneficiaries and many people who get Medicaid have disability.

And so, when the rules came out in January of 2017, a number of legal aid organizations that focused especially on disability rights law and that kind of thing got together and went to the state Medicaid program to talk to them about having Massachusetts adopt these standards for Medicaid contracted providers.

So, you know, I am not aware of any other states that may be doing this but I suspect they might be out there. As even the ADA acknowledges, if there are states that have stronger disability rights protections than the ADA, you go with the stronger protections, the state protections.

Massachusetts looks like they are heading in that direction at least with the Medicaid program.

>> CALEB BERKEMEIER: That is great to hear. So, as we wrap up the podcast, are there any final thoughts that you would like to leave us with?

>> LISA IEZZONI: Well, I really like, Caleb, your observation about that led me to say empowered patients. I think it's just really, really important for people with disability to realize that if your friends are getting a pap test or if your friends are getting a colonoscopy or getting some other screening exam that just seems to be routinely done, if you're not getting one and if your doctor isn't saying that you should, the question is why not?

I mean, you're going to be at the same risk of developing cervical cancer or colon cancer or other sorts of conditions that are detected on screening as another person might be.

So, I think that it is just really important for people with disability to feel comfortable questioning their doctor and saying you know, why aren't you recommending that for me since all of my friends of the same age are getting that kind of test?

I think that becoming an empowered patient is going to be really something that will help you maximize your likelihood of wellness and overall quality of life.

>> CALEB BERKEMEIER: Doctor IEZZONI, thank you for joining us.

>> LISA IEZZONI: You're more than welcome. It was a pleasure.

>> CALEB BERKEMEIER: ADA today is produced by the MidAtlantic ADA Center and is part of the WADA Podcast Network.

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