**Down to the Struts**

Season 2, Episode 5: Physicians, Disabled Patients, and Healthcare Access

Host: Qudsiya Naqui

Guest: Lisa Iezzoni

Transcript by Qudsiya Naqui

For more information:[www.downtothestruts.com](http://www.downtothestruts.com)

**Introduction**

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Hi, this is Qudsiya Naqui and welcome to another episode of Down to the Struts. If the Coronavirus has taught us anything, it's that access to affordable high quality health care can mean the difference between life and death. Last year, as emergency rooms and intensive care units were full to capacity, physicians had to make very difficult decisions about how to distribute scarce resources. patients and their families relied on physicians to make these decisions in an unbiased, clear manner. Today, we'll listen in on my conversation with Dr. Lisa Iezzoni. Dr. iezzoni is a professor of medicine at Harvard Medical School. She recently co authored a study published in the journal Health Affairs about physician perceptions of patients with disabilities. The study found that an alarming 82% of physicians surveyed believed that patients with disabilities have a lower quality of life than non disabled patients. The study also found that less than half of the physicians surveyed believed and were confident that they could provide high quality care to patients with disabilities. We'll unpack the findings of this study what it tells us about our health care system and the necessary solutions to ensure equitable access to health care for people with disabilities. Okay, let's get down to it.

Qudsiya Naqui:

Dr. Iezzoni, thank you so much for joining me on Down to the Struts today. I really appreciate your taking the time to be with I am delighted

Lisa Iezzoni:

I’m delighted to be here with you, Qudsiya and please call me Lisa.

Qudsiya Naqui:

Thank you, Lisa, I will do that. Great. So I want I wondered if we could start off by having you introduce yourself and talk a little bit about your background and what led you to your work on and your research with centers on the experience of people with disabilities in the healthcare system.

Lisa Iezzoni:

All right, as you said, my name is Lisa Iezzoni. I identify as she her. I am a white woman, and I am pre-ADA. Okay, on this podcast, I think that that's probably one of the most important qualities about me, I have had multiple sclerosis for 44 years, I've used a wheelchair since 1988. And I am a professor of medicine at Harvard Medical School, I have an MD after my name. But if you calculate back, I actually started medical school at Harvard in September of 1980. So that's just over 40 years ago. And those of you who know that the ADA was signed July 26 1990. Well recognize that that was well before the ADA was passed. And prior to that point, I'd had about four years of kind of, on and off again, symptoms that were just weird, hard to describe, they would come they would go. But I was young, I was invincible. I was busy. And so I never really had been evaluated. But when I started at HMS--Harvard Medical School--in September of 1980, they returned with a vengeance. And I ended up not being able to ignore them from that point on, and I ended up being diagnosed with multiple sclerosis at the end of my first semester at HMS. And to make a long story short, it was pretty brutal at HMS during that time again, you know, 10 years before the ADA. Although I went through all the courses, I had to do my clerkships. I worked up all the patients I was assigned. When I got to the end of my third year and wanted to think about applying for an internship or residency, I went to one of these little functions that HMS had for its students say, had these little kind of interactions with faculty where you get together late in the afternoon, you'd have Sherry, you'd have cheese cubes, and then you'd all go into a place for dinner, and I sat at a table with a very, very top person, like the CEO of a major affiliated academic medical center at Harvard. And I said to him, Look, here's my situation. I'd like to do an internship a resident See, might it be possible to do it half time, and he paused, he pulled his fingers and said to me, at the dinner table with other people all around witnessing this, that there were too many physicians in the United States at the time for them to think about training a handicapped doctor. And so if that meant that some people got left by the wayside, so be it. So I was pretty sure this wasn't gonna work out well for me. But I several months later met with my internship advisor who told me that the medical school had decided in its infinite wisdom, that they were not going to write a letter of support for me to apply for an internship or residency. So that meant that basically, I would not be able to go on to train. And so that is, in fact, what happened. I wasn't able to go on to become a practicing or licensed physician. And I went and got my first job as a research assistant at Boston University. But from that point on, I studied health policy, I actually had a prior master's degree in health policy. However, one of the things that I really carried with me from medical school was the notion that we cannot cure you, when medicine cannot fix you. And so therefore, just don't ever talk about it. The Multiple Sclerosis Don't mention it. And so for about 12 years, I never did. And during that time, I started using a wheelchair. I, however, didn't tell my colleagues why I started using a wheelchair. It was primarily because I finally gotten some sense. You know, I was falling, I was having trouble getting around my career was kind of taking off a little bit. I was traveling to Washington a lot, again, as a health policy researcher. So starting to use a wheelchair was the best thing I ever did. Because no longer was I falling, I could travel easily. So I actually, to be honest with you, I don't know that I even noticed that the ADA was passed and signed, because, you know, I just wasn't part of a disability community. I just didn't identify as somebody with a disability even though I was using a wheelchair. But what I did know was that I was terrified the entire time of being fired, because I had a disability. And so I was a classic case of overcompensation. I just was working 24 seven, because I figured, if I wrote enough papers, if I was promoted enough, you know, the academic track, I actually went back to Harvard in 1990, I became a full professor there in 1998. So just to do the math, that's actually pretty quick. But it was because of my absolute terror of being fired because of my disability. So I felt like I had to do all this stuff. But once I became a full professor, I thought, okay, maybe they are not going to be able to fire me. There also was another little twist that I mentioned to you that I became the first female full professor of medicine at the institution at Harvard where I was, which was Beth Israel hospital, deaconess hospital, which had merged into the BIDMC. So I thought, okay, I'm the first woman full professor, it'd be hard for them to fire me. So maybe I can pause now. And just take a moment and say, Okay, what do you really want to be researching at this point in your life, and one of the things that had happened to me as I was traveling back and forth to DC, and my wheelchair was that people would talk to me in the waiting rooms. And they would say, you know, I started out with a scooter type wheelchair, because it was fabulous. I could tuck a suitcase under my legs. I had that cool little basket up front that I could put my person. And so people would come up to me and say, you know, my legs are getting a little got arthritis, it's hard for me to get around, how can I get one of those? Or my brother has a problem? How can I get one of those for him? And so I started hearing from all sorts of strangers about how their mobility is impaired. And so I said to myself, why are they talking to me? Why aren't they talking to their doctors about this? And so, I did a little research, you know, what academics do they do a lit search and found that there was very, very little in the general medical literature to train the average primary care doctor about what to do to assist people whose mobility was beginning to fail. So I said to myself, you know, something, this is what I like to study, and maybe now would be the time for me To start talking about my own disability, and I also realized that my attitude of being quiet about it of being private, of not talking openly about when I started using a wheelchair perpetuated the stigmatization of disability, I was part of the problem by not talking about it publicly. So from about 1998, or 1999, I think I wrote a paper that was actually published in JAMA, the Journal of the American Medical Association, that was the first piece I've ever written about my own experiences. And ever since then, you can’t stop me from talking about it, and here I am with you.

Qudsiya Naqui:

That is such a compelling story. Lisa, I'm really grateful that you shared it with our listeners. And there's so much of what you said that resonates with me as a blind person. I, you know, I was born in 1984, prior to the ADA, but I really came of age in the post Ada world. So your story about medical school is so jarring and shocking to me, I personally experienced workplace discrimination before in many forms, but nothing to that level. And it's just, it's a reminder of the power of laws to help protect people and, and also just this idea of feeling like your your disability was this unspoken hidden thing that was sort of your problem to deal with and couldn't be shared, I mean, the falling down, because you weren't using a wheelchair, I didn't use a white cane for a long time, because I didn't want people to see in Disha of my disability and, you know, got into some really bad scrapes myself, including falling into some train tracks. When I was in my 20s, you know, there's so much of what you said that really resonates. And, I think can resonate with a lot of our listeners. So I wanted to turn to what brought us together for this interview, which is that recently, you and a team of other researchers published a really compelling article in the journal Health Affairs, about physician attitudes towards disabled people or people with disabilities. And I was wondering if you could take some time to talk a little bit about that survey and what you found through the results of the survey?

Lisa Iezzoni:

Sure, I'd be happy to. And let me just say that for pretty much all the years before that all of my research had been very focused on people with disability themselves. I've done literally hundreds of interviews with women with mobility disability, who are pregnant with women with early stage breast cancer, who are wheelchair users with all sorts of people with different types of disability about their primary care. So I, I really understood kind of what is going on in healthcare from the perspective of people with disability. But I wanted to hear what physicians were thinking, because what I'd heard so often from patients were that doctors always make erroneous assumptions about us, they presume that they know about our lives, but they really are, frankly, clueless in many instances. And so they sometimes make recommendations that don't kind of fit with how we live our lives in any way, shape, or form. And so I wanted to really hear from physicians where their heads are when they think about caring for people with disability. So again, I did have wonderful colleagues at the Mass General Hospital, Harvard, and at the University of Colorado that I work with, and a general internist who is out of a state in Springfield, Massachusetts, my team of CO investigators that were really wonderful putting the survey together, and it was conducted out of UMass Boston by researchers there. And it was a survey that was the first ever national survey of physicians about their experiences with and perceptions of caring for people with disability. And the survey scientists would tell me, you have to be careful, you can't have too long a survey, or else people won't answer it. And so we had to design a survey that would take 15 minutes to answer. But we had lots we wanted to know. And so I'm just telling you that upfront, because our survey was very, very broad. But it was not very deep. We asked questions about a lot of topics, but we weren't able to kind of plunge deeper into why people answered the way that they did. So we have eight modules of our survey and the module that I'm going to talk about today. That was our Health Affairs paper was about how physicians perceive people with disability and whether they welcome them into their practice. So we surveyed physicians from seven different specialties and I should mention that we had funding from NIH, it's always good to thank your funding source. If you're a researcher, they generously funded this and we started the survey in the fall of 2019. So it's very, very recent data, the major findings, the top line findings that I'll mention to you now are that 82% of physicians report that people with significant disability have overall worse quality of life than other people do. That's number one. The second top line finding from my point of view is that only 41% of physicians say that they feel very confident in their ability to provide equal quality of care to people with disability. And then the third finding that I found especially striking, was just 56% of physicians strongly welcome people with disability into their practices.

Qudsiya Naqui:

That's, you know, those are really stunning data points. In particular, the first one that such a vast majority of physicians don't believe that people with disabilities have the same quality of life as non disabled people. And the third finding as well, as you were saying, what was it in particular that surprised you most about these results?

Lisa Iezzoni:

Hey, so again, I'm a person with a disability myself. I've had doctor encounters myself over the years that have been a bit troubling. And so I was pretty sure that doctors were probably going to say that people with disability have worse quality of life than other people do. But you did recognize that we did offer them the option to say that people with disability have the same quality of life or even better quality of life than other people do. But a full 82% of them said that people with significant disability have worse quality of life. And when you conduct surveys, there's something called positive response bias that respondents often answer questions the way that they expect that people want them to answer questions. They want to please the surveyors unconsciously, and they want to answer in a way that would be viewed as socially acceptable. And so I will confess that I was pretty surprised that fully 82% of physicians, so over four fifths of doctors said that people with significant disability have overall worse quality of life. What that suggests to me is that they were pretty confident that what they were saying would be kind of publicly acceptable, that the public would kind of agree with them, that people with disability have overall worse quality of life than other people. But that was still pretty striking to me.

Qudsiya Naqui:

Yeah. And I think it reinforces or it seems like it supports this idea that we've talked about on this podcast, and I know, you've commented on past episodes about sort of structural ableism in our system. But it's interesting that I wonder whether the respondents would have been as candid in their response had, they've been asked about something else, which is whether people of different racial or ethnic backgrounds have a lower quality of life, than others,

Lisa Iezzoni:

you know, I wanted to make that point in the Health Affairs paper. And so I did, as I said earlier, Qudsiya, what I always do as a researcher, is I did a literature search to see if I could find any papers or studies that have been written where physicians were asked specifically about whether people of other races, you know, people who are racial or ethnic minorities have different quality of life than do other people. I could not find a paper along those lines. But I think especially since the murder of George Floyd, that it would be pretty unlikely that the average doctor, of course, this occurred before the murder of George Floyd, that, you know, with general kind of understanding of the situation of race and ethnicity in our country, it would be very surprising to me, if 82% of doctors would say that people who are racial or ethnic minorities have worse quality of life than white patients do. And so that's just my presumption. But I think that, again, as I said earlier, I think that physicians just feel so confident in their view about people with disability that they were willing to express it.

Qudsiya Naqui:

And that relates a lot to the medical model of disability, right, versus the social model, which is this idea of the medical model talks about impairment and focuses on the disabilities themselves rather than the social structures that prevent the person from living fully.

Lisa Iezzoni:

Yes, absolutely. And I'm just going to tell you one little story because I think it all kind of solidify, one of the things that I believe as well, and that is that I think that physicians feel that because they were trained about physiology of disease, and anatomy and all sorts of kind of scientific Things about bodies that they understand what the lived experience in the body might be. And so, one day I was at a hospital that I used to work at, and one of the physicians came up to me and said, you know, how are you doing, Lisa? And I said, I'm doing fine. And I was smiling and talking with them. And they said to me, you know, you always seem so happy and cheerful when I see you. It's just so nice to talk to you, because you're always smiling. And that must be because of the inappropriate euphoria of multiple sclerosis.

Qudsiya Naqui:

Oh, wow.

Lisa Iezzoni:

Exactly. Okay, so this was at a time when, in fact, at a time when there was actually some thinking that people with MS are inappropriately happy sometimes, but still, for him to kind of like, say, to me to my face, you know, that must be because of the inappropriate euphoria of Ms. was just, ya know, kind of striking.

Qudsiya Naqui:

Yeah, I mean, because the implication is otherwise, no one who has to spend their life in a wheelchair would ever be smiling and happy. That's impossible.

Lisa Iezzoni:

Yeah. Right, exactly.

Qudsiya Naqui:

So that really like ties into something else I wanted to ask you about, you mentioned that there hasn't really been the same sort of line of questioning of physicians around their perceptions of people of racial and ethnic minorities in terms of quality of life, but there has been, you know, a significant body of research about racial disparities in terms of the delivery of care. And so how do you think that intersects with disability? So the experience of a disabled person of color, for instance,

Lisa Iezzoni:

yes, so there was a very, very prominent report that came out of the then called Institute of Medicine, I think it was in the early 90s, called :Unequal Treatment.” And that was really a touchstone type report that really highlighted the unequal treatment of racial ethnic minorities by the healthcare establishment. And it was very interesting, because in the year 2000, a very prominent federal report, there is a federal report that's called the Healthy People Report. It comes out every 10 years from the public health system in the federal government, and it's about what the public health priorities should be for the next 10 years. And Healthy People 2010, which came out in the year 2000 was the first time that people with disability were listed as a disparities population. And so by that point, there had been enough data that was also able to show that people with disabilities also experienced a lot of health care disparities. And so a lot of my work has been actually on researching healthcare disparities for people with disability. But you asked about the intersectionality of if you have both disability, and you are minority race and ethnicity, and there is some evidence, primarily more qualitative evidence. I think that that is certainly the case, I think that there's been less quantitative research done on the intersection of race and ethnicity around disparities for people with disability, although there has been some and I, as I told you earlier, I have done a lot of qualitative research with people with disabilities about what their experiences were. And I remember vividly sitting actually, in an old neighborhood Health Center, this old building in the Mission Hill part of Boston, surrounded by black patients, people with disabilities, because I wanted to hear specifically about their experiences. And mind you, as I said, earlier, I'm a white woman. I'm surrounded by black people. And it was really interesting, because I think that in the hierarchy of discrimination, it's hard to say, which is worse the color of your skin or the fact that you have a disability. But it was just interesting hearing their stories, because they would talk about, you know, they understood that I had MS because I'd introduced myself. And there was some people there who had MS as well. And we talk about going to the emergency room, for example. And they'd have unstable gait or unsteady gait because of multiple sclerosis or some other condition like arthritis that require them to use a cane. And the physicians would say, Oh, you've been drinking, haven't you? Or Oh, you must be high on cocaine, aren't you? Because there couldn't be medical reason for the fact that they might be a little unsteady on their legs? No, it had to be alcohol or it had to be drugs. And so from that perspective of the people that I was speaking to, it was just really obvious that there's just a presumption when physicians see the color of the skin of their patient in front of them. They might make different assumptions about what is going on with that patient.

Qudsiya Naqui:

And that can be, you know, truly calamitous for someone who, who needs acute care. For example, if you're making the wrong assumptions in your role as a physician or a provider, and you're not delivering the kind of care the person actually needs, because you have a wrong impression about what the problem really is.

Lisa Iezzoni:

Absolutely. And if you're going to be going to an emergency room, you probably have something that you want to talk to a doctor about. So absolutely, that could be a calamity for people.

Qudsiya Naqui:

Yeah, there was recently a Twitter thread just came out this week. And it was about a black woman who was suffering from a condition and repeatedly went to the doctor, and nothing was done about it. And then ultimately, it turned out she had some kind of severe gynecological condition and had to ultimately had to have her ovaries removed. Even if she was told had they identified this a couple of years earlier and listened to her complaints of pain, she wouldn't have lost her ovaries. And this was a black woman, and I don't believe she identified as having a disability. But I think that I think there's a lot of things at play there. There's race. And then there's also I think there's been some study about the tendency in the medical field to ignore women's pain in particulars are disparities related to gender? So yeah, I mean, I think there's so much that's right for study here that I hope you you research, because this is your area of expertise.

Lisa Iezzoni:

no, absolutely.

Qudsiya Naqui:

The next question I wanted to ask you about is related to our here and now. So we're in the middle of a global pandemic. And I'm curious about what your observations have been about, you know, what we've learned from your research about the perceptions of physicians, and what that has meant for the delivery of care to people with disabilities who have had COVID. So there's been a couple of different issues on this front that, you know, resources at various points in the height of the pandemic, where resources were scarce, ventilators and things, or oxygen was scarce. And there was a prioritization of non disabled people in the delivery. There were some stories about that. And then on the vaccine side, there's been a lot of controversy about prioritization for who gets access to a vaccine first, is it a healthy 65 year old? Or is it a younger person who has underlying conditions that render them more vulnerable to COVID? So I'm curious about what your observations have been about what you found in the survey is playing out in our real world right now, with a pandemic?

Lisa Iezzoni:

Well, those are all really, really good questions. And as soon as I started my almost now one year home isolation, which was like, March 15, I took the subway home from my office, I was like one of three people on the subway, and I haven't left since at that point, I thought, Okay, I'm going to get a lot of work done, and be quiet at home, just have so much time to get a lot done. From that point on my emails, just were overwhelmed in my inbox by people in the disability community who I knew, who were worried about what are called these crisis standards of care, which are these specific documents that are supposed to be kind of put together during times of calm, you know, when all the stakeholders can get together, everybody can figure out if there are going to be times when there's scarce resources, how should there be a fair distribution of these scarce resources to patients who might need them and what was on earth early in March of 2020, was that there were actually some states around the country that had these crisis standards of care that explicitly said that people with quote unquote, intellectual disability, or people quote, unquote, functional impairments, should go to the end of the list if there are scarce resources that are needed to treat people in a pandemic sort of situation. And so that actually forced the Office of Civil Rights within the Department of Health and Human Services and the federal government to come out with a directive at the end of March of 2020. That explicitly said that perceptions of quality of life should not be used to determine who gets the scarce resources. Because of course, you know, there were kind of rumors abounding in the disability community that this was maybe not yet happening, but people were terribly afraid that it could happen. And I actually think that our results here support those fears. Because even though the times during the pandemic when there actually was such scarcity of resources have been actually fairly rigid. sent in Southern California, when there were simply no beds in various hospitals, and people were kind of being kept out in parking lots, you know, I don't know whether it ever got to a point where people were actually being turned away for this. But I think that the decisions are supposed to be made when there are crises by people who are not the direct care providers of the patient, because there's a sense that the direct care providers might be too emotionally involved in doing that. And so you're supposed to have objective clinicians, you know, people who can step outside and don't know the person necessarily, and so can make objective decisions based on the specified criteria and the crisis standards of care. But if you've got four fifths of physicians, saying that people with disability have worse overall quality of life than other people to where are you going to find those physicians who are going to not be biased in some way?

Qudsiya Naqui:

that's a that's a real challenge. And I think that's where what HHS Civil Rights Office did, and other other sorts of safeguards in policies that prevent that sort of subjective decision making entering in to how the crisis plan is created is really critical. So that people remember that you cannot leverage someone's disability status to make decisions about whether or not they are prioritized for care.

Lisa Iezzoni:

Yes, that's, that's really so right. And you asked about vaccines. Now, as you know, vaccine decisions are being made by localities by states and local regions. And so there is guidance coming out of the CDC. But that's only recent, you know, since the Biden administration was put in place, there's been more focus on that. But what I have heard from people around the country is that different states are doing this quite differently. And in fact, in my state, it was very interesting because they prioritized health care workers, and among healthcare workers, they actually prioritize people who provide home based personal assistance services. So for example, I heard from a young woman who uses a wheelchair and has full time kind of personal assistance services, and her PA, her personal assistant had been immunized, but she hadn't yet been immunized. And that's because some people with disability had not yet been prioritize. So even though the people who provide their supports within the homes had been able to get the vaccines, the person with a disability themselves had not yet been able to. And so I think that we also know about what has happened in nursing homes and congregate living settings. And I actually was just early this morning looking at some data that has come out, that suggests that ever since nursing homes have started widely immunizing their residents, and most of the residents have some sort of disability, that there actually has been a tremendous drop in the new incidence of COVID-19 cases. And so that is simply a fact of, you know, because these places were prioritized in the vaccines work. This is something that again, I think localities are having to make decisions, but the local disability advocates are really kind of pressing for them to be more prioritized. And they've been

Qudsiya Naqui:

Yeah, I know this, really came into controversy. For example, in California, when people over 65 were blanketly prioritized without the nuance of like, there could be people younger than that age that need the vaccine more urgently. So not to say it's a zero sum game. But I think there were some some interesting questions that arose out of, for example, California's approach as well, which have been sort of like are being worked through at this point. So I wanted to kind of take a step back. And you know, again, the the findings of your study are just, you know, truly remarkable and tell us a lot about our health care system. So I'd love to hear from you about where you think we go from here, what is needed to address some of this unconscious bias and close the gap in terms of inequities of standards of care for people with disabilities.

Lisa Iezzoni:

Well, I think first of all, people need to know that this is happening. I'm not sure that that's going to fix it. There's been pretty widespread knowledge about racial and ethnic disparities. And Karen that certainly hasn't fixed that. But I think at least being conscious that people with disability do experience disparities with care and care. And the fact that perhaps physician bias might be contributing to that also So I think needs to be understood because there is a lot of education now, not only at medical schools, but also among practicing physicians about how to approach situations where your implicit biases could be affecting the care that you provide to patients. And it's not always clear how effective that education is the research that suggests that that type of education is effective is not that strong, but at least it's a starting point. One of the things though, that concerns me is that a lot of the solutions that people talk about, which is training medical students to do better in caring for people with disability, are very long term solutions. And so it's gonna take a while to put out enough young doctors who are not biased against people with disability if, in fact, we can do that to be able to care effectively for the population who needs that medical care? I think frankly, cuz Yeah, that what we need to do is to train people with disability themselves, to be their own advocates in their health care situations, and their family members or their friends or whoever they have, who can be their advocate, let me just say that every person regardless of how healthy they are, in the US healthcare system needs an advocate, simply because we know that there are errors in care, there's neglect and care, there's problems with care, everybody, regardless of whether or not they have a disability, regardless of the color of their skin needs an advocate when they get health care in the United States. And so I think the people with disability, need to feel more comfortable questioning their doctors, more comfortable making sure that they don't leave the office until all their questions are answered, and just being more proactive to try to make sure that the concerns that they come to the office with are addressed by their physicians.

Qudsiya Naqui:

Yeah, I think that there's a lot of education on both sides. And again, neither of those solutions are mutually exclusive. I think there is an incredible imperative to make sure that young physicians and medical students are educated about the social versus the medical model of disability, about the history of disability rights, and are coming out of their training with a much different perception about people with disabilities. But you're absolutely correct, that being able to engage in effective self advocacy is another area of education that's really necessary. And so relatedly you know, we talk a lot in this podcast about language and how we talk about things. And one thing that you and I had an exchange about before this interview was our I think you described it really well are asynchronous use of language. So I use identity first language, so saying disabled person, and you use person first language, people with disability. So can we take a step back? And I'd love to hear your perspective on the use of the person first language in your context, which is in you know, healthcare research?

Lisa Iezzoni:

Yes. Well, you know, that, that, I'm really glad you brought that up, because I've listened to a few of your podcasts before I joined your podcast. And so it was very, very struck by your use of language. And you actually had a great podcast was it that was explicitly about language that I learned a lot from, and I actually had to train myself to do the people first language, because again, remember, I graduated medical school, the year you were born, you confess to me, so it's classic 1984. And so the language about disability going back to those years was even kind of different than it is very different than it is now. But I use people first language because I view as my mission in life to try to educate the medical community to the best that I can, in my own little sphere of influence. And I know that physicians view disability as a failure, perhaps their failure, because they cannot cure us. You know, the medical model of disease is not named the medical model of disease, randomly, it's medical and the medical model of disability assumes that what people with disability should do is listen to their doctors and follow their instructions and hopefully be cured. That's why I feel that I would not put disability first before people when I'm talking to to my colleagues because that would be putting failure before the person who should be what they're focused on. That's why I have consciously trained myself very carefully to whenever I talk to people in my profession to use people first language. Now of course, when I'm out with people in the disability community, I use language like crictime and you know, all sorts of words. Are we within our own community can use but when I'm out trying to serve as an educator, for people in the medical field, I feel that using the people first language will be less disruptive to the message that I want to convey.

Qudsiya Naqui:

That is so illuminating, and I never thought about it in that way—this idea that physicians view disability as their own failure. As a long term goal, I would not want that to be the thinking of a physician. We have this binary right now of disease and cure, but really it’s a continuum. You rightly point out that this is ajourney—we’re on a journey that we have to go on, but for the time being, centering the person for a physician, I think makes sense to help them think less at the jump about their “failure,” which is disability. That’s so interesting. And in that episode about language, when we spoke with Dr. Sara Acevedo from Miami University, we talked about this notion that, in activism and advocacy, different language can be a tool for different ends at different times. So there’s no right answer, but using person first language in your goals, and your advocacy, and your activism is the best way of reaching your audience, so I think that’s a really interesting strategic choice.

Lisa Iezzoni:

Yes, that has been my very explicit thinking about this.

Qudsiya Naqui:

I’m so glad you shared that—that’s really, really helpful, and interesting. And important for me as someone—so I—full disclosure, I come from, I am a lawyer by training, but I come from a family of physicians, so this topic is very near to my life experience, and to what I grew up in as the child of two physician parents and the sister of a physician.So, plus a lot of extended family that are also physicians. So I very much come from this—it’s deep in my family.This is such a valuable conversation that I hope to share with my family. I just wanted to wrap us by asking you for any parting thoughts you had or advice you had for the medical community in light of the survey results that you found, and what would you say to healthcare providers about people with disabilities?

Lisa Iezzoni:

 I would say that there’s 61 million of us out there. That you cannot avoid us coming to your practices, and with the aging baby boomers—my generation—there’s gonna be more of us. And so, I’d say get ready. The one thing that I haven’t talked about is having accessible medical diagnostic equipment. I actually had the honor of chairing the national committee that provided advice to the government about setting standards for height-adjustable exam tables, height-adjustable mammography equipment. You know, getting ready. A weight scale that wheelchair users can roll onto. You know, so, I’d say to the medical community—that this is your patient population, that you want to do well by them. And so you need to learn something about their lives, and in fact, there has been some research that suggests that the more that physicians spend time with people with disability, the more comfortable they become with disability.And so, the better they’re able to provide care. For people with disability. That’s what I’d say. Do a little marketing research. Get ready. We’re coming—we’re already there, but we’re coming in bigger numbers.

Qudsiya Naqui:

That’s great. Thank you so much Lisa. And thank you so much for joining me—this has been such a great conversation.

Lisa Iezzoni:

Well, I’ve been delighted to be here with you—thank you for having me.

[jazzy piano chords, bass strumming with smooth R&B]

Qudsiya Naqui:

Thanks for listening to this episode of down to the struts. This podcast would not be possible without the energy and creativity of Adrian Kong, Ilana Nevins and Avery Anapol. To learn more about the project and access resources from this and past episodes, visit our website at www.downtothestruts.com you can subscribe rate and review the podcast on Apple podcasts, Spotify, Stitcher, or wherever you love to listen. You can also follow us on Facebook, Twitter, and Instagram. Thanks as always for your support and looking forward to the next episode so we can get back down to it.