

[Music by Molly Joyce 00:00 - 00:15]

*Bonnie:*

Welcome to *Included: The Disability Equity Podcast*, brought to you by the Johns Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and news. Each season digs deep into topics, offering multiple perspectives, and will expand your view of disability. We are your hosts. I am Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

*Nick:*

I'm Nick Reed, assistant professor at Johns Hopkins University Bloomberg School of Public Health. On this episode of *Included*, we're talking with Dr. Lisa Iezzoni about her work aimed at understanding healthcare experiences and outcomes among people with disabilities. Dr. Iezzoni is a professor of medicine at Harvard Medical School and an internationally recognized health services researcher. Over the course of her prestigious career, she was co-director of research in the Division of General Medicine and Primary Care at Boston's Beth Israel Deaconess Medical Center.

After moving to the Massachusetts General Hospital, she was associate director of the Institute for Health Policy and director of the Health Policy Research Center. She's a member of the National Academy of Medicine. Dr. Iezzoni has authored numerous books, including *When Walking Fails: Mobility Impairments of Adults with Chronic Conditions* and *More Than Ramps: A Guide to Improving Healthcare Quality and Access for People with Disabilities* and has a forthcoming book to be published in the fall of 2021 entitled *Making Their Days Happen: Personal Assistant Services Supporting People with Disability Living in Their Homes and Communities*.

[Music by Molly Joyce 01:59 - 02:07]

*Nick:*

Dr. Iezzoni, thank you so much for making time to join us today.

*Dr. Lisa Iezzoni:*

Thank you for including me.

*Bonnie:*

Yes, thank you. I'm really grateful. Your work has been so important and sentinel in identifying and documenting inequities in healthcare for people with all types of disabilities. I'm hoping we can just start this conversation with you talking a little bit about that, about what kind of inequities that your work has shown. I know that's a big ask because you've done so much important work. If you could just start out, for our audience, by describing,

from your viewpoint, what some of the most important findings have been.

*Dr. Lisa Iezzoni:*

Well, Bonnie, thank you. The way that I would actually describe it is that I'm old now, *[laughter]* so I've worked for a long time and had a chance to do a lot of research with my colleagues. It's been a privilege to be able to do that. We really started out by focusing on mobility limitations. Let me just self-disclose that I have a mobility limitation. I've had multiple sclerosis now for 44 years and used a wheelchair for 33 years. In a lot of my comments today, you might hear a little bit of a subtext of a focus on mobility. Some of my research has cut across different disability areas, and so I'll highlight some of that.

Our initial work really focused on screening disparities. A lot of the reason that we focus there is that that is where the data were. My work really started with the 1994-95 National Health Interview Survey on Disability supplement. They had data on things like PAP tests and mammograms and colonoscopies that we could look at screening disparities for people with disability. What we found in doing that research is that, yes, indeed, there were disparities for people with disability compared to non-disabled populations, but they varied by disability type. It's not entirely accurate to say that there are screening disparities for all people with disability. They really do vary by different types of disability.

A next broad body of research that I've done relates to cancer. We've also used the National Health Interview Survey. We used the Surveillance Epidemiology and End Results Cancer Registry data from NCI merged with the Medicare claims. I've also done work on cancer with interviews with people. *[Laughter]* We've gone the whole way from soup to nuts on cancer, looking at incidents, outcomes, treatments, and then aspects of the patient's care experiences.

As a high overall view, what I can basically say—and this is pretty new data that we've just come out with within the last year or so—that for certain cancers, there is actually a higher incidence for people with disability than for other people. Some older work suggests that there are worse outcomes for people with disability. Not only higher rates of all-cause mortality, but also higher rates of cancer-specific mortality. We've also identified treatment disparities. Then, from some of my interview work, I found that the healthcare experiences, particularly for women with mobility disability who develop early stage breast cancer, are not quite what we would want them to be. They experience a lot of stigmatized

attitudes among healthcare professionals as well as access barriers within healthcare facilities.

Then, another large body of research that I've done relates to pregnancy. There, again, we've used survey data and found that if you control for age and if you control for marital status, women with disability are currently pregnant at the same rates that other women are, which might sound counter normative. Again, we were focused on mobility disability. In that study, I did in-depth interviews with 22 women [*laughter*] who really wanted to talk about their pregnancy experiences. We would be on the phone for, sometimes, more than two hours because they just had so much to say about how many barriers they confronted. Not only among healthcare professionals, but also societal reactions to them as they would go out in their communities as a pregnant woman in a wheelchair.

Then, we've recently completed a project funded by NIH about diagnostic overshadowing. This is the first time this has ever been looked at in the context of mobility disability. It's a concept that was, really, initially framed in Europe around intellectual disability and mental health disability. Where the basic premise is that if a person with either of those two disabilities presents with a new sign or symptom, it's assumed that, of course, that relates to their underlying disability. There have actually been studies of people coming into emergency departments with symptoms of pneumonia, and they'll be told, "No, it's just in your head. You have mental illness."

We were the first people to look at this in the context of mobility disability. This also involved a lot of in-depth interviews. We've got good hypothesis-generating data that does suggest that, yes, if people with mobility disability come in with new symptoms, their symptoms are attributed to their underlying disability, and in fact, they are not followed up on. Because of that, they can get delayed diagnoses of even something like a lymphoma or an abdominal tumor.

Then, most recently, as I know we're gonna talk about momentarily, I've had the privilege of leading the first ever National Survey of Physicians about their experiences with and perceptions of caring for people with disabilities. There's more, but that's a highlight. Let me just stop there.

*Nick:*

That's amazing. For our audience, I just love to—everybody take a moment and appreciate the breadth of all that, [*laughter*] that just

came out, and how it's scoping from these large epidemiologic surveys down to spending two hours on the phone with people to fully appreciate and understand their experience. Which fully informs all of the learning we have and all the research we have. That's just amazing. Thank you for what you do.

*Dr. Lisa Iezzoni:* Well, one of the things I really like to do, Nicholas, is I like to do the interviews myself. Number one, they're just so much fun. Number two, I do self-reveal in these interviews that I have a disability, and I know that there's some qualitative interview research questions about whether that's the right thing to do. There is some research that suggests that when you do do that, it puts people more at ease because they feel that you understand what a lot of their experiences are. In fact, I do. It's led to some really great learning from those interviews.

*Nick:* That's just fantastic to have those insights. That's amazing. We wanted to ask you, too, building off your work, the origins, really, of healthcare disparities. It's a very complex issue, and it reflects this range of issues and access, patient-centered care and communication, implicit bias. In your work, what do you see as the core drivers of healthcare disparities for people with disabilities?

*Dr. Lisa Iezzoni:* Well, one of the first documents, the first federal report that ever designated people with disability as a disparities population was Healthy People 2010. As you probably know, the Healthy People initiatives come out every 10 years. They're done by the US Department of Health and Human Services, the public health team there that looks at what should be the focus of public health initiatives over the next decade to improve the public health.

The volume that came out in November of 2000 was the first, again, that identified people with disability as a disparities population. It was chapter six. What was interesting in that chapter is that they actually attributed the fact that people with disability are considered a disparities population to erroneous assumptions about people with disability, ableist attitudes. They didn't quite use the word "ableist," [laughter] but that is what they were basically talking about.

I think that they basically said that a lot of doctors don't think that wellness services or preventative services are really that necessary for people with disabilities. They just don't understand the values and expectations about their lives that people with disability have. We also know, of course, that there's inaccessible equipment. There's inaccessible communication. One of the things that I hope

you'll let me just riff on for a second is my own personal experience about this. I really think that some of this is really hidden within the medical model of disability.

I started at Harvard Medical School in September of 1980. That was 10 years before the Americans with Disabilities Act was passed. That was also a time before people would talk publicly about health conditions that they would have. Women would be embarrassed about having breast cancer, until Nancy Reagan and Betty Ford would start talking about that. I was diagnosed with multiple sclerosis at the end of my first semester at HMS. That was in December of 1980. Although I completed all four years as I was supposed to and I was preparing to apply for an internship in residency, the medical school decided, in its infinite wisdom, that they were not gonna write a letter of recommendation for me. I decided to go on and train to become a practicing physician.

I got the distinct feeling, during that entire four years that I was at HMS, that they viewed me as one of their failures. That because they could not cure me, they could not get rid of my disability, I should just skulk away and not talk about it. *[Laughter]* That I was basically a failure of medicine. It really goes back to the medical model that started in the 1800s about how physicians really think that you're supposed to be cured or you're supposed to be significantly improved by our wonderful interventions. If you're not, you represent a failure.

I really think that that kind of ableist view really still, very much, informs medicine. We'll talk about it in a minute or so, but I fear that our recent survey supports that. You would've thought that since it's been almost 31 years since the ADA passed that, by now, physicians would've figured out something differently. *[Laughter]* No, I have a feeling that some of those attitudes still pertain.

*Bonnie:*

Thank you so much for sharing that, for sharing your story, first of all. I think this is the kind of conversation this podcast is hoping *[laughter]* to really elevate, to talk about these complex—from the perspective of individuals with disabilities—challenges and ways that the needle really hasn't moved. *[Laughter]* I think it's exactly what you said. From my experience, and I know you know this—we've known each other long enough to know—that it's that interaction of medicine and disability that we really need to push on. That has just not seemingly shifted. Relatedly, your recent article in *Health Affairs* entitled “Physicians’ Perceptions of People with Disabilities and Their Healthcare,” you have started to tackle this question, this complex paradigm by focusing on physicians, as

you indicated earlier, really, is among the first time to do so. Can you talk to us and share with the audience a little bit more about this really important study, what you found? I think you just described some of the motivation, but if you have anymore insight that you wanna share about what drew you to conduct this work.

*Dr. Lisa Iezzoni:*

Sure, Bonnie. As I told you, I've probably interviewed 200-300 [laughter] people with disabilities. Not just individual interviews, but in focus group interviews, and so I've heard a lot about their perceptions of how physicians treat them. I've never gone out in a big way. I've had a few interviews with physicians, but I've never gone out in a big way to try to learn about how physicians perceive caring for people with disability. We were very fortunate to get funding from the National Institute for Child Health and Human Development to do this survey. Although there have been some small studies, like regional studies or single-site studies about physicians' attitudes toward caring for people with disability, this is really the first survey, of which I'm aware, that looks at a national population of practicing physicians.

We're focused on adult physicians. We don't include pediatrics. We're focused on physicians who care for patients in outpatient settings. We looked at seven different clinical specialties. We looked at general internal medicine, family practice, ophthalmology, neurology, orthopedics, OBGYN, and neurology and rheumatology. We designed a survey that the physicians could answer in 15 minutes because we wanted to have a good response rate. [Laughter] Because of that, we went broad but not deep. We touched on a lot of topics, but we didn't really have the chance to ask follow-up questions to try to learn why the physicians responded the way that they did.

I'll just give you some high-level question findings. Let me just say that we went into the field with this in October of 2019. We were beginning to do our final follow ups in January and February of 2020 [laughter] when the pandemic hit. It caused a few logistical problems for our survey group that was at University of Massachusetts Boston. Because of that, they ended up closing the survey in June of 2020. The basic bottom line is that these results are pretty recent. We're talking about, again, 30 years after the ADA was passed. We're now 30 years after, and this is what the kind of responses are.

From my point of view, one of the top findings was that 82 percent of physicians feel that people with significant disability have worse quality of life than do other people. We'll pause there for just a

second. *[Laughter]* Again, 82 percent of physicians think that people with significant disability have worse quality of life than other people. Only 42 percent were very confident about their ability to provide equal quality of care to people with disability. Only 56 percent strongly welcome people with disability into their practices. A little bit over a third, 36 percent, know nothing, or just a little bit, about the Americans with Disabilities Act. Seventy percent do not know the correct approach for making accommodation decisions. Reasonable accommodations are required by Title II and Title III of the Americans with Disabilities Act for patients coming in to see their doctors.

When we're talking about people with mobility disability—and we also looked at results relating to vision and hearing and mental health and intellectual disability, but just a couple of quick ones relating to mobility disability 'cause they're just so very straightforward. Only 23 percent of physicians always or usually use an accessible weight scale for a patient with mobility disability who cannot stand on a weight scale. Only 40 percent usually or always used a height-adjustable exam table or lift device when caring for a patient with mobility disability who cannot independently transfer onto an exam table. Those are just some top-line findings.

*Nick:*

That's a lot to take in.

*Dr. Lisa Iezzoni:*

I know. It is. Lemme just point out that we did not find the typical social desirability bias that you would expect to find in a survey. Basically, survey scientists say, "Look, people are gonna answer the questions the way that they think other people in society expect them to answer them." The fact that 82 percent of doctors said that people with disability have worse quality of life suggests to me that those 82 percent of doctors thought that there was no problem with their answer, that nobody would question their belief that people with disability have worse quality of life. That's just pretty striking, especially since a lot of those responses were coming right before COVID hit. Then, of course, once COVID hit, we know so well that concerns about quality of life made the disability community terrified about whether they were going to have access to scarce resources when the pandemic hit. Resources became scarce.

*Bonnie:*

Lisa, when I read this paper, that's the part that hit me the hardest is exactly what you just said. It's that despite these *[laughter]* individuals know that they're responding to a survey, that that's still their answer. We know this. We feel this every day, as people

with disabilities. It's so truly disheartening [*laughter*] that, as you said, this is still where we are. That not only is this the answer, but the thought is this is an okay answer.

*Dr. Lisa Iezzoni:*

It is. That's why I took the opportunity of you being patient with me to tell my story a little bit. I think it's still very much the case that people with disability are still viewed as a failure of the medical community and that they really do not have imagination [*laughter*] to think about people's quality of life. In fairness to them, what you could say, maybe, is that they see—the average physician often sees patients at their worst, when they're feeling poorly. I'm not necessarily willing to give them that benefit of the doubt. It just is incumbent upon all physicians to do a social history and try to understand what their individual patients view as valuable and their expectations for their lives and what they want to achieve in their lives.

There certainly will be disabilities that do affect quality of life in a deleterious way. I don't mean to imply that there are not some disabling conditions that are profoundly painful and just devastating for people to live with. I think the majority of us—having had MS for 44 years, I don't feel like my life has been tragic. [*Laughter*] I feel very privileged in my life. I view it as a cup half full. That's why I said it was my top-line finding, Bonnie, when we got the preliminary survey results.

*Nick:*

I have to ask. You've been at this for a really long time, your line of research. You've written several articles in *Health Affairs*, and you've written very high-impact articles in *Health Affairs*. In fact, it was about 10 years ago that we found a really great article that Bonnie and I were passing back and forth when we were prepping for this. I think we had both read it, but we read it again. It was titled "Eliminating Health and Healthcare Disparities Among the Growing Population of People with Disabilities." Then we were reflecting on your most recent article. Do you think that the needle has moved at all on this issue?

*Dr. Lisa Iezzoni:*

[*Laughter*] Let's try to be a little bit of a cup half full briefly on this. [*Laughter*] That is that I think that young people with disability, including young people with disability who are the few who are entering medical school, are talking publicly about this. They're trying to educate their colleagues. They're trying to educate their professors. I do think that I'm hopeful for the future. I'm hopeful that people who are young, like you and Bonnie, are going to be able to make a difference and are going to be able to

maybe move the needle a little bit. So far, that needle has still not shifted. *[Laughter]*

One of the findings—the second finding that I emphasized was that only 41 percent of survey respondents said that they felt strongly confident that they could provide the same quality care to their patients with disability. That's suggesting to us that maybe even their medical training is not what it needs to be to be able to provide the same quality of care. We may not have only a problem with their ability to provide patient-centered care, care that respects and values the patient's perspective on how they want to live their lives and the care that they seek, but also, maybe, the medical services that they are getting may not be the highest quality.

Then, of course, we have the findings relating to accessibility of clinical settings. To design our survey, we did the—or I did 20 interviews with practicing physicians and then led 3 focus groups. *[Laughter]* The focus groups were on video, and so I could see the expressions on the faces of the people who were responding. We did one focus group with rural physicians. One rural physician said that they sent their wheelchair users to the local grain storage facilities to have their weights measured because they didn't have accessible weight scales. Another physician said that they sent their patients who are wheelchair users to the local meat processing facilities. They said this without any expressions changing *[laughter]* on their faces.

It makes you think that they don't necessarily realize that the notion of sending a person to a meat packing plant to get their weight measured is just not necessarily a respectful way to treat that person. It really does raise a lot of questions to me that I simply do not know the answers to why this is still happening. I just don't understand it. I will just confess that I'm at a loss.

*Bonnie:*

Wow. *[Laughter]* Thank you for sharing that. I think that is—it's those kinds of examples that I do think people need to understand and know about. I am with you, for sure, Lisa, in trying to be a cup half full and to not villainize individuals or physicians. I think the system has failed, has failed all of us all around in the training. It certainly failed the community of people with disabilities. I'm curious what you think could be next. I think you articulated—you just discussed some of that training and the hope for the future. What else do you think you could share with our audience that we could do to start to close these gaps? The examples you gave really are striking. This is an urgent issue.

I think, particularly at this time, when we're having these broad national conversations around health equity, around social determinants of health, around disparity populations, it feels like an important time to think about this. What else do you think people could do?

*Dr. Lisa Iezzoni:*

Well, you may not have noticed my slight of hand, but I was very deliberate in how I started out talking about my research. I started talking about the datasets that I used. One of the problems is that data on disability are not routinely available in the datasets that were used initially to look at healthcare disparities for racial and ethnic minorities and even for women. The earliest data that really looked in detail at cancer disparities were the SEER Medicare data. If you look at the articles from back 20-plus years ago, the first—and it's in the methodology is always we eliminated the under 65 and the Medicare population, which is exactly the population that we looked at.

When we went to get those data, we had to spend a year cleaning them because the contractor who made the SEER Medicare data for other researchers to use in a very highly productive way, it just wasn't on their radar screen. We had to clean the data. I think we need to start with thinking about datasets that are routinely available that can begin to tell us what's happening. If we don't have the data and if the data are not readily available, it's gonna be hard to convince the healthcare system to start spending a lot more money on new data collections around disability. We need to add it on to what we're currently doing. I think that that's really important.

The second thing is I do think it is important to have more students with disability admitted to medical schools. Have students with disability in medical schools feel empowered in their careers. I do also think—and here's where my little cup gets a little bit wobbly there—is that we have a hidden curriculum in medical schools. If 82 percent of the physicians who are teaching the medical students have implicit bias about disability or explicit bias about disability, that's gonna be conveyed to their students.

I think even though the implicit association tests are a bit ableists themselves, *[laughter]* because you have to have good hand-eye coordination to be able to take them and use them, I think that maybe going online to look at the implicit association test for disability for trainees to be able to just even—or even practicing physicians to get a sense. Do I maybe have an implicit bias that I

just wasn't aware of about disability? It might be good to have a little bit of self-awareness there.

Then, the final thing that I think is, really, absolutely, a tsunami just sitting on the doorstep are people in my age group. I'm an aging baby boomer. That's the definition of me and my cohort. Unfortunately, our age group is not as functionally healthy as our parents' generation. I think a lot of that is because of obesity. Even the smoking rates are lower than our parents' generation, the obesity has caused so much disability, diabetes, all sorts of comorbid health conditions. Every single healthcare facility is going to be just seeing giant numbers of us on their doorsteps as well as younger people, people with congenital disability who previously would've died who are now surviving. The teeny-weeny babies, the teeny-weeny newborns who are surviving with some significant disability into the age of wanting to be a mom or a dad and getting pregnant.

I just think that there's gonna be—every single practicing physician can expect to see people with disability and more of them. I just think that medical schools and continuing medical education programs, quite frankly, need to be emphasizing that physicians just don't seem to know how to care for people with disability as well as they need to. It's just imperative that they do because they're gonna be seeing more of us.

*Nick:*

That was wonderful. That was so insightful. I feel like you hit on so many themes we talk about all the time. You know what I loved about your answer is a lot of times, even people who have the disability community in mind and the best interest, we often, I think, put the answer on the back of the disability community. We often say, "Oh, if we wanna improve access, then the disability community needs to be better about telling people and disclosing," or something like that. You didn't do that once. I personally think that's not how it works. The system should be built so that everybody has an equitable experience. It's not built so that somebody has to go the extra themselves to make their experience equitable. I just wanna highlight that for our audience. I just loved the way you described that.

Unfortunately, this isn't the longest podcast in the world. I feel like we could talk to you for hours. It's been so wonderful. I just wanna ask here, as we wrap things up, is there anything else that you wanna tell our audience? Is there any other issue or piece of your work you wanna talk about? We're so just enamored to have you. We wanna hear you talk.

*Dr. Lisa Iezzoni:* [Laughter] Well, I think having conversations like this is really what needs to happen. There is a teeny-weeny thread of research that suggests that people—if physicians get to know people with disability just as people in a more casual setting and they get to know us, they feel more comfortable with us. Surprise, surprise. I think that just getting to know people with disability, figuring out some way to just hang out with us, and just not feeling embarrassed and saying, “Look”—if you feel awkward, just say, “I’m not sure if I’m gonna say this right, but how do you push your wheelchair? [Laughter] How can I help you?” If we say, “I don’t need any help. I’m cool,” that they’ll be okay with that.

I think to the extent that people can start feeling comfortable just being honest with their own discomfort and being open with it and realizing that most of us are not gonna snap your heads off. We’re gonna be thankful that you asked us what we wanted from you, if we wanted anything. I think that that would be a final thing that I would recommend.

*Bonnie:* Well, thank you so much, Lisa. I think you just opened up my friend request account.

[Laughter]

*Bonnie:* I’m grateful for it because I believe the same things you just said. I really am so grateful for this chance to learn from you, to speak for you, for our audience to hear and listen and learn from all that you’ve accomplished and researched and share with everyone. Thank you so much for all that you do. You really have moved the needle for many of us, and I’m grateful.

*Dr. Lisa Iezzoni:* [Laughter] Well, thank you so much for giving me that opportunity and for your kind words. I’m just glad that I was able to toil in the trenches.

*Bonnie:* Thank you.

You have been listening to *Included: The Disability Equity Podcast* brought to you by the Johns Hopkins Disability Health Research Center.

*Nick:* Thank you to our *Included Podcast* team and everyone that made this podcast possible, especially Sabrina Epstein, Prateek Gajwani, Curtis Nishimoto, and our guests. Music is by Molly Joyce. This

***Included Podcast Episode 17***  
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