

*Holly J. Humphrey:*

*Welcome back to Vital Voices, a podcast from the Josiah Macy Jr. Foundation. I am Dr. Holly Humphrey, the president of the Macy Foundation. On today's episode, we will discuss an area of bias and discrimination within the healthcare system that remains a significant challenge; namely, the ableism and the healthcare disparities that Americans with disabilities experience. Increasing evidence has documented persistent disparities for people with disability, now including more than 61 million Americans. And as our population ages, this number will continue to grow. Disparities for people with disabilities have been documented in multiple areas, ranging from screening and preventive services to cancer diagnosis and treatment, to reproductive and pregnancy care. Further, people with disabilities report poorer communication with health care professionals and lower satisfaction with their overall care.*

*To help us explore this very important issue and how health professions education can help address the issue, I am joined by Dr. Lisa Iezzoni.*

*Dr. Iezzoni is Professor of Medicine at Harvard Medical School. She has spent more than three decades conducting health services research focusing on two primary areas: risk adjustment methods for predicting cost and clinical outcomes of care and healthcare experiences and outcomes of persons with disabilities. She served as director of the recently renamed Health Policy Research Center at Massachusetts General Hospital from 2009 to 2018.*

*Dr. Iezzoni is also the author of a book, [Making Their Days Happen: Paid Personal Assistance Services Supporting People with Disability Living in Their Homes and Communities](#). This book was published in the fall of 2021 by Temple University Press.*

*As always, this conversation is a follow-up to our webinar series, discussing the [Macy Conference Recommendations](#) on taking action on harmful bias and discrimination in clinical learning environments. You can find this podcast, as well as all of our webinars, the conference recommendations and other resources on our website at [macyfoundation.org](http://macyfoundation.org). And now, here is my conversation with Dr. Lisa Iezzoni.*

*Lisa, thank you so much for being with us today.*

Lisa lezzoni:

I'm happy to do this Holly.

*Holly J. Humphrey:*

*So, as you and I have discussed several times in the past, it has been over 30 years since the passing of the [Americans with Disabilities Act](#) in 1990, which at the time was really a landmark civil rights legislation for people with disability. Now, this legislation requires that healthcare professionals provide equitable care, but the population of people with disability continues to experience inequitable healthcare on so many levels. Can you describe some of the ways, both individual and system-level ways in which patients are affected and how ableism in healthcare is revealed?*

Lisa lezzoni:

Thanks Holly. I'm actually going to correct you a little bit because it actually goes back almost 50 years. [Section 504 of the 1973 Rehabilitation Act](#) was the first time that people with disability got civil rights and it required equal treatment under federal programs, which would include Medicare and Medicaid. But you're absolutely right that the civil rights laws that pertained to people with disability across all sectors really started in a big way with the 1990 Americans with Disabilities Act.

So, in response to your question, I want to underscore first that people with disability are really diverse. And so, what I'm saying might not apply across disability types. For example, you have people with intellectual disability, you have people with a mobility disability, people with hearing and vision disability, some people with what others might perceive as disabling conditions may not perceive themselves as disabled. For example, many people in the Deaf community. And that's Deaf with a capital D who speak with American Sign Language might view themselves as a linguistic minority rather than disabled.

I also wanted to precede my answer to your question by emphasizing that people with disability are really disadvantaged on average on the social determinants of health. So, you have a population that is facing a number of disadvantages, but in terms of medical care, we have to start kind of upstream. And that is that people with disability are generally excluded from the clinical trials through which the scientific evidence base is created for medical care. So, when they seek care, often the scientific evidence base is really lacking. We'll talk about this later, but healthcare professionals are not generally trained to provide disability competent care. And what I mean by that is care that looks at the root causes of disability and involves patients and experts in how the disability affects their own lives. So, in terms of some of the problems that people with disability might face, and again, disabilities are diverse and so different people might be affected by different types of problems than I'm going to talk about right now. The first one I just would like to underscore is ineffective communication accommodations. So many physicians do not even print out in large font materials for patients with vision problems. Many physicians might not hire an American Sign Language interpreter, even when the patient who is Deaf prefers that as the communication mode. You have inaccessible medical diagnostic equipment everywhere still, including exam tables that do not automatically raise and lower and weight scales that are not accessible to people with disabilities. Physicians tend to be not knowledgeable about their responsibilities under the ADA. Those are just a few of the kind of highlights of where there might be some problems for caring for people with disability.

*Holly J. Humphrey:*

*There's a lot there, Lisa.*

Lisa lezzoni:

I know.

*Holly J. Humphrey:*

*But I want to pick up on one of the things that you referred to, and that is physicians not really being adequately prepared. You and your colleagues published a [very interesting paper in February of 2021](#), so almost a year ago, on*

*physicians' perceptions and attitudes regarding patients with disability. What made you decide to look at this as an important element or an important factor in affecting the care of people with disability?*

Lisa Iezzoni:

I've been conducting research about healthcare disparities for people with disability since the late 1990s. And so, I've probably interviewed over 300 people with disability, and I like to do the interviews myself. I self-identify as somebody who has a disability. I've used a wheelchair now for 33 years. And so, I really enjoy talking to people with disability about what their experiences are like. I'd heard for years from people with disability about the stigmatized attitudes that physicians have about them and the erroneous assumptions that physicians make about their lives. And [Healthy People 2010](#), which came out in November of 2000 was actually the first time that people with disabilities were listed as a disparities population. And chapter six of that report actually attributed these erroneous assumptions about patients' daily lives, expectations and values to some of these disparities, such as an under-emphasis on wellness and disease prevention or screening. Basically, what I wanted to do was put a number on this. A lot of people with disability told me that my results weren't that surprising. And I said, "No, but at least we put a number on what the problems are."

*Holly J. Humphrey:*

*Wow. So, what were some of the key findings from that work?*

Lisa Iezzoni:

So that [February 2021 Health Affairs article](#) that you're referring to had from my viewpoint three top-line findings. The first was that 82% of physicians reported that people with significant disability have overall worse quality of life than other people. Only 41% of physicians felt very confident in their ability to provide equal quality care to people with disability. And only about 56% of the physicians strongly welcome people with disability into their practices.

*Holly J. Humphrey:*

*Wow, those are powerful. And I think very sobering. So, what can we do about this? If you could create an agenda for what health professions educators might do to address some of your findings, what would that look like?*

Lisa Iezzoni:

You know, it's interesting because I personally kind of thought that 82% was where I wanted to focus. But in fact, I think the 41% of physicians who feel very confident in their ability to provide equal quality of care is a really important place to start. It seems that 60% of physicians feel that they do not have the medical knowledge or for whatever reason do not feel strongly confident to provide the same quality of care to people with disability. And so, I think that we need to unpack that and understand that a little bit better. What is it? Is it medical knowledge? Is it cultural knowledge? What is it that is causing them not to feel strongly confident that they can provide the same quality care to people with disability? I need to understand that better. But one of the things that I would say is that about 25% of the population self-reports that they have some sort of disability. These are common conditions like heart failure and long-term diabetes, which can be profoundly disabling.

So, I think that in addition to specific training about legal requirements under the ADA, which clearly physicians need to have in addition to some training about implicit and explicit bias about disability, which they also need to have, we somehow need to build disability into all case-based training at medical schools. I know medical schools have really switched to focusing more on kind of clinical stories and clinical cases to do a lot of the teaching in the preclinical years. And so, we have to ask questions about how health conditions affect daily life, functional status measures, not just activities of daily living, but also instrumental activities of daily living to find out how health conditions and disability affect people's daily lives.

*Holly J. Humphrey:*

*Okay, well that in and of itself would be a terrific place to start, but as you know, as well as I know there's the formal curriculum where we could cover ideally some or all of the things you just outlined, but what about the hidden curriculum? Where are the opportunities to make inroads with the hidden curriculum?*

Lisa Iezzoni:

Well, Holly, thanks for asking about that question, because I have no idea. I'm not really sure.

So, one thing I can say again, because now I have a number, 82% of doctors say that people with disability have worse quality of life than other people. We also gave them the option to say that people with disability have the same quality of life or better quality of life. It seemed to me that there was no positive response bias because more than 80% of doctors felt that it was okay to say people with disability have worse quality of life. What that suggests is that people are really set in their ways of thinking, and they really did not even see their attitudes as biased or ableism. They may truly believe that people with disability have worse quality of life. That's just a foundational belief that they have. It's really, really hard to dislodge these kinds of foundational beliefs. There's a teeny-weeny bit of literature. It's pretty small, but it's kind of compelling, that getting to know people with disability actually makes them realize that they're like other people. They have the same hopes and dreams about their lives that other people do, and that they figure out how to get through their daily lives with their disability and live in the community with their disability. And so, getting to know people with disability is one place to start.

But I think actually, and this is a tough one, I haven't heard many people hugely enthusiastic about this, but I think that this is where we also need to start. And that is in continuing medical education because people always talk about, "well, let's start by training medical students." But we know that it takes seven years from the day a medical student shows up at the door of the medical school until we can have them out in practice if they're going to be an internist. We just don't have seven years to wait given the aging of the baby boomers and the increasing number of people with disabilities. We really need to bring disability training into continuing education of practicing professionals. And we need to make sure that when there are lists about improving equity and care that people with disability are included.

*Holly J. Humphrey:*

*Oh boy, once again, there's so much that you just covered that I'd love to take a little bit deeper look at. Let me just for a moment, ask you about whether one of the ways we could address this is by making the profession itself more welcoming of those with disability, because as you and I have talked before, the profession itself has historically not been welcoming in terms of our admissions processes and our accommodations in medical school, per se. Do you have any thoughts about that? I don't want to get into a long discussion because in a way that's a topic for another day, but I'd love to just hear your thoughts at a high level about that.*

Lisa Iezzoni:

Well, I'm a good example of that. I went through medical school, got my MD degree, but then was diagnosed with MS during medical school and the medical school refused to allow me to go on to train. So, I'm a good example of how back before the ADA, medical schools were not terribly, necessarily welcoming to people who were newly disabled while they were students.

I think that even with the ADA in place, that medical schools did not immediately begin to reevaluate their technical standards. And I think that that is one of the chief barriers to people with disability getting into the medical professions. And there are still barriers that are still out there now to this day because there's really not been a systematic reappraisal of what the need for the technical specifications or standards are. Especially since it's not obvious that every student who wants to go to medical school wants to be a surgeon and so it may not be necessary for them to be able to do certain manual dexterity tasks that would be required under technical standards.

So, I think that the medical educational profession really needs to reevaluate and rethink what they're training people to do. And that that is going to be a task that I'm not sure whether it happens centrally under the AAMC or whether medical schools on their own, some of which around the country have been more welcoming to students with disability, whether that would be the way that we would move into the future to get more people with disability into the profession. I will say that I was recently -- just really... it was wonderful -- I got an invitation from some medical students at UC San Diego to speak with them about disability and the medical student who invited me said, "I am an MD PhD student who uses a wheelchair." And I thought, "whoa we've really come a long way from the day

that I was a medical school." And so, it is happening out there, but just not widely enough yet.

*Holly J. Humphrey:*

*Wow. That means we have more work to do, but that background is very, very helpful, Lisa. We've spent most of our time today talking about education and what we can do differently and what we can do better. Let me ask you to share just a little bit about the system and hear your vision for what we can do with our healthcare system that would make it more welcoming and where bias and discrimination would not be present. And I think the pandemic has really highlighted many of the ways in which our system, our healthcare system really does discriminate against those with disability. So, what is your vision for what a more ideal healthcare system might look like?*

Lisa Iezzoni:

Well, framing it around the pandemic, we have to think about the healthcare system going beyond the standard kind of acute care hospital physician's offices. Because, Holly, as you know, the tragic first victims of the pandemic were residents of nursing homes, assisted living facilities and group homes. And I remember so vividly the rest of us being told, "don't worry. If you're young and healthy, you should do fine." And so implicit in that kind of language that the rest of society was being told was the message, "if you're older, if you're disabled, if you live in a nursing home, you're not going to do fine, but we're not going to talk about that." That's just part of what was going to happen in this pandemic. And so, I think that there was just a very ableist message being conveyed throughout. Even now they talk about if you're young and healthy you should do fine. It's very troubling to those of us who have disability. Certainly the crisis standards of care, which were implemented in some places around the country when resources were too scarce to care for all the COVID patients who showed up at the doors of hospitals, had explicit discrimination against people with disability, especially people with intellectual disability and those with quote-unquote neurodegenerative disorders. And a lot of them really were called on the carpet for that. And the hospitals and states had to go back and change their crisis standards of care.



But those were some very explicit discriminations against people with disability. But there were also some really interesting results. And you've probably heard of the concept of universal design that whenever you designed policies or places or procedures, you should design them thinking about all the people who would eventually use them. And so, we found through the pandemic that people who are deaf or hard of hearing who would use lip reading to help understand people who are communicating to them could not do lip reading when people were wearing masks. And so, these masks with transparent coverings over the mouths were invented, and it turns out that whoa, those transparent masks are good for other purposes, such as people interacting with small children.

And we also found that people were prevented from having relatives who are trusted caregivers at their bedside early during the pandemic, which was really a problem for people with intellectual disability. But it was also a problem for other people whose family members died without anybody at their bedside. And at some point fairly early on, at least at our hospital, it became clear that no, you had to figure out some way to allow a trusted caregiver at the bedside.

And then finally, we're talking by Zoom right now and the Zoom can be closed captioned very easily using Zoom technology. And what I'm hearing from people is that certainly people who are Deaf and hard of hearing have really valued the closed captioning through Zoom, but so have other people. It really helps for people who may not understand really well or want to multitask or whatever that the closed captioning has really helped them. Especially if it's worn over into telehealth visits that you might have with your healthcare professional. So, we're finding that universal design, things that were done to help people with disability during the pandemic are being really implemented now for other people and helping other people throughout the healthcare population receiving healthcare.

*Holly J. Humphrey:*

*Well, Lisa, those are some excellent examples to get us started. And I feel very energized just thinking about the possibility of that universal design being extended to all patients everywhere. So, thank you for those concrete examples. And most of all, thank you so much for your willingness to share your experience and your expertise with us today. There is so much that I learn from you every*

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*time I listen to you, and I look forward to more conversations in the future, but that will be it for today. So, Lisa, thank you so much for joining us on this podcast.*

Lisa lezzoni:

And thank you, Holly, for your interest in this important topic.

*Holly J. Humphrey:*

*For more on this discussion, I encourage you to read the [Macy Conference Recommendations](#) and related resources. You can find all of those on the Macy Foundation website at [macyfoundation.org](http://macyfoundation.org).*

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