

PACIFIC ADA CENTER
HEALTHCARE AND THE ADA WEBINAR
2/25/21
2:10-4:00 P.M. ET

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>> LEWIS KRAUS: Welcome to the Healthcare and the ADA: Inclusion of People With Disabilities Series. I'm Lewis Kraus, your moderator for this series. This series of webinars is brought to you by the Pacific ADA Center on behalf of the ADA National Network. The ADA National Network is made up of 10 regional centers that are federally funded to provide training, technical assistance and other information as needed on the Americans with Disabilities Act. You can reach your regional ADA Center by dialing 1-800-949-4232. Realtime captioning is provided for this webinar. The caption screen can be accessed by choosing the CC icon in your meeting control toolbar. To toggle that meeting control toolbar permanently on, press the alt key once and press it a second time. As always in our sessions, only the speakers will have audio.

If you do not have sound capabilities on your computer or prefer to listen by phone, you can dial 1-669-900-918 or 1-646-558-8656 and use the webinar ID864-8854-2838. I want to also mention to you that this webinar is being recorded and can be accessed on the ADApresentations.org website in the archive section next week. This Webinar Series is intended to share issues and promising practices in healthcare, accessibility for people with disabilities. The series topics cover physical accessibility, effective communication, and reasonable modification of policy issues under the Americans with Disabilities Act of 1990, the ADA. Upcoming sessions are available at ADApresentations.org under the Schedule tab and follow to healthcare. These monthly webinars occur on the fourth Thursday of the month at 2:30 eastern, 1:30 central, 12:30 mountain and 11:30 a.m. Pacific time.

By being here, you are on the list to receive notices for future webinars in this series. Those notices go out two weeks before the next webinar and open the webinar to registration. You can follow along on the platform with the slides. If you are not using the webinar platform, you can download a copy of today's PowerPoint presentation at the Healthcare schedule page of ADApresentations.org. At the conclusion of today's presentation, there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area within the webinar platform. The speaker and I will address them at the end of the session. So feel free to submit them when you have -- when they come your mind. To submit your questions, you may type and

submit them in the chat area text box, or if you're using keystrokes, press alt-H and enter that text in the chat area. If you are listening by phone and not logged into the webinar, you can ask those questions by emailing them to adatech@adapacific.org. If you experience any technical difficulties during the webinar, you can send a private chat message to the host by typing in the chat window. Type your command in the text box and enter. If you're using keyboard, again, you can press Alt-H to access the chat box and enter your information there. Or you can email us at adatech@adapacific.org or you can call us at 510-285-5600. Today's ADA National Network session is Health Care Disparities for People with Disabilities and Potential Role of Physician Bias, healthcare disparities affecting people with disabilities and introduce recent nationwide survey of physician specialties about their experiences with and perceptions of caring for patients with disabilities. The resulting presentation will focus on physician's perception of people with disability and confidence about providing equal care to these patients and whether they welcome patients with disabilities into their practices. The survey results might contribute to healthcare disparities for people with disabilities. Today's speaker is Lisa Iezzoni. Lisa is a professor of medicine at the Harvard Medical School and based at the Health Policy Research Center, the Mongan Institute at the Massachusetts General Hospital. Dr. Iezzoni has conducted numerous studies examining healthcare disparities for persons with disability. Her first disability-related book, "When Walking Fails" was published in 2003. Her most recent book, "Making Their Day Happen: Paid Personal Assistances Services Supporting People with Disability Living in Their Homes and Communities" will appear in 2021. Dr. Iezzoni is a member of the National Academy of Medicine in the National Academies of Science, Engineering and Medicine. Lisa, I'm going to turn it over to you.

>> LISA IEZZONI: Okay. Thank you, Lewis Kraus. And Gabe is going to give me access to my slides. I think he just did. So there we are. So everybody, I notice there's 97 people here, and I'm so happy to virtually see all of you. Good afternoon from where I am. Good morning to some of you who still are right before the noon hour. And today I'm going to talk about healthcare disparities for people with disability and the potential role of physician bias. This is something that we always do at medical presentations, we first say we have no financial disclosures to report. In other words, I have no financial interest with companies or any other organizations that affect what I'm about to tell you today.

So the context. There's 61 million Americans with disability, and these numbers are growing. As the National Academy reported in 2007, disability is not actually a minority issue. In fact, disability affects today or will affect tomorrow the lives of most Americans. It's more than 30 years now since passage of the Americans with Disabilities Act and more than 43 years since regulations implementing the Section 504 regulations of the 1973 Rehabilitation Act.

So given all this, given the number of people, given how long it's been since laws have been in place, why is it so hard to make healthcare fully equitable and accessible to people with disability. Why in 2021 do people with disabilities still confront barriers and experience disparities in their healthcare? So today I would like to do four things. First I

will talk about disparities along the lines of social determinants of health, which I'll define for you. Next I'll give you examples of disparities relating to screening and preventive services, primarily. Then I'll talk about the results of our physician survey about their attitudes and perceptions of caring for people with disability. And then to ground my talk in an actual individual person's experiences, I'm going to tell you the story of Michael.

So social determinants of health. Social determinants of health is kind of a term of art these days. Basically healthcare providers and public health people use it to describe social factors that can affect physical and emotional well-being and the ability to receive healthcare services. There's increasing recognition of their role in population health. Now, on average, people with disability are severely disadvantaged and marginalized along social determinants of health. On average they have lower incomes than other people do. They have lower educational attainment than other people do. They have higher unemployment rates than other people do. They have poor housing, housing and security, or inaccessible housing. They often confront significant transportation problems. They have higher rates of food insecurity than do other people. They also are more likely to experience domestic violence, intimate partner violence, or caregiver abuse. And this pertains to people who identify as men or as women.

Sorry, my hand slipped up.

There's also a significant intersectionality between disability and race and ethnicity. Disability rates according to national surveys are 24% for whites, 30% for black Americans, 31% for Hispanic Americans, 16% for Asians, 25% for native Hawaiians or other Pacific Islanders, and a full 40% for Native Americans or Alaska natives. Sorry, I also have a disability, so my hands tremble a little bit, so you might be a little bit for giving of me if my slide movement is not as smooth as it could be.

Okay, so the coronavirus pandemic has really underscored how these minority populations with which there is this incredible intersectionality are at risk of worse outcomes. They've also underscored how the social determinants of health are also going to increase the risk for people having poor outcomes from this pandemic. And we also we know in addition to the pandemic results that ethnic and racial minority populations experience significant healthcare disparities. So there's truly a compounding effect there between disability and race and ethnicity. So let's talk about how care disparities. So every 10 years the federal government gets their public health officials together and they put together a roadmap for improving the public health over the next 10 years. It's called the Healthy People Initiative. So Healthy People 2010 was published in November of 2000 and it was looking at the decade ahead from 2000 to 2010. And it was the first time that people with disability were identified as experiencing disparities. Interestingly enough Healthy People attributed these disparities partially to erroneous assumptions and the daily lives, values and expectations of people with disability. And they said there were common misconceptions about people with disabilities that contribute to troubling disparities in the services they receive, especially an underemphasis on health promotion and disease prevention activities. Healthy People 2020, which was published in 2010 also identified disparities for people with

disability, but interestingly, its recommendations focused on addressing social determinants of health, such as improving education, improving incomes, and reducing unemployment for people with disability. So I'm just going to show you a couple of examples of data that we produced about healthcare disparities, and this first slide talks about PAP test rates. And for women without disabilities, 85% of them get PAP tests. And as you know, PAP are the screening test that has a grade A rating from the U.S. preventive services task force about early detection of cervical cancer, and thus it's really, really important to prevent deaths and serious problems from late detection of cervical cancer. So 85% of women without disability get PAP tests, but for women with mobility disability, 78% get PAP tests. 80% for women with sensory disability. 74% women with mental health difficulties. 76% with cognitive difficulties. And the lowest rates are women who report self-care limitations. Now, this slide shows PAP test rates by mobility disability level. Because from our research, one of the things that we found is that one of the reasons people don't get PAP tests, and I suspect some of the people on the call might relate to this, is that we can't get up on to exam tables. The exam tables are fixed tight and we can't get up on to them, so the doctors just choose not to do the PAP test. So women with no difficulties, again, 85% got the PAP test. Women with the least severe mobility disabilities were just 82%, so just 3% lower. Level 2, 80%. Level 3, 78%. So these numbers are going down monotonically, 72% for level 4, and then women with the most severe disability had 20% lower PAP test rates at 65%. So another thing that we -- sorry, I'm just distracted a little bit by the chat. So another thing that we found was that women with major mobility difficulties are 70% less likely to be asked by their physicians about their need for contraception. Now, from a survey data that we used to calculate these numbers, we could not tell why this was. But, of course, our presumption from just talking to women with disability and learning about what their experience is, is that physician may think that women with disabilities are asexual or not sexually active or maybe are not at risk of unintended pregnancy. And so therefore it's not at all necessary to ask them about contraception. But this is also going to be an issue when you think about PAP tests, because human papilloma viruses are the primary cause of cervical cancer. It is transmitted sexually. So if physicians think that women with disability are not sexually active, they may think it's not necessary to perform a PAP test on these women. They may think they don't have any risk of cervical cancer because they're not sexually active, which, of course, is wrong.

So here is some results from a study that we did using what is called SEER data. That's for surveillance epidemiology and end results data. Those are cancer registry data from cancer registries around the United States that were merged with Medicare data. And the way we know that women have a disability is because they're under age 65 and they're on Medicare. In other words, they have SSDI, it gets them on to Medicare. And so these results are looking at women under age 65 with stage 1 breast cancer. And what we found there was that women with disability were a lot less likely than other women to get breast conserving surgery for stage 1 cancer. So while 62% of women without disability got breast conserving surgery, only 54% of women with disability got breast conserving surgery. And with these data, we were able to account for things like age at diagnosis, race, ethnicity, tumor characteristics, like size, and how aggressive the cells were, and other factors. And even so, women with disability were

24% less likely than other women to get breast conserving surgery. Now, as of you might know, women with early-stage breast cancer have equivalent outcomes for their breast cancer if early stage -- if they get breast conserving surgery that is followed by radiation therapy. So they have the same outcomes as a mastectomy if their breast conserving surgery is followed by radiation therapy. So these analyses looked at only women under age 65 with early-stage breast cancer who had breast conserving surgery. And what we found was that women with disability were 17% less likely to get radiation therapy than were other women. And so not surprisingly, but tragically we found that women with stage 1 breast cancer and disability were 45% more likely to die from their breast cancers than were other women. So there's all sorts of causes for disparities, potential causes. So first of all, people with disabilities often have underlying health conditions that are complex, and they might have competing priorities., for example, they might say themselves, you know, I just don't really feel a PAP test is that important with everything else that I've got going on health-wise, and so it's really the patient's kind of preference. Disadvantages in social determinants we already talked about. Patients' preferences for care. There are some women or men who might feel that they don't need care because it just isn't something that they feel is part of how they want to approach their health and well-being. There's also clearly inadequate training of healthcare professionals. There's ineffective communication accommodations. So sometimes because of failure of communication patients might not fully understand what their healthcare needs are. I've already talked about inaccessible medical diagnostic equipment, such as needing to be an Olympic athlete to get up on to the exam table. Trust me, I've been there. It's kind of hard to do. And this includes weight scales. And so some of us haven't been weighed since, you know, we started being disabled. So we've got the weight we had when we were back in our 20s. And there's also, though, inadequate knowledge among physicians about ADA mandates for equitable care and providing the accommodations that you need to be able to obtain the care. But there's also, as Healthy People 2010 showed, erroneous assumptions about people with disability and ableist attitudes among clinicians. So these last two points that I make here about the erroneous assumptions about people with disability and the ableist attitudes among clinicians are really just kind of an impression that we somewhere from being out there among people with disabilities, talking to each other, we tell stories to each other. This is kind of what we feel we know from just being out there and having been around doctors. But believe it or not, there actually was not any quantitative data about how bad these attitudes were among doctors. We knew that they existed. We just didn't know how much. So, the next section of the talk is to try to quantify, put some numbers around physicians' attitudes and perceptions of caring for people with disability. Okay. So this is the first ever national U.S. survey of practicing physicians and their experiences with and perceptions of caring for people with disability. We were very fortunate to be funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, which is one of the National Institutes of Health in the NIH. And because it was... oh, there's a typo on my slide. Because it was the first national survey, we tried to cover a whole wide range of topics. And so we kind of touched on a lot of different things, but we didn't really -- yes, Eunice Kennedy Shriver was also the founder of the Special Olympics. Somebody just put that in the chat. Which is why having her name attached to this National Institute, which was

done when she was still alive, was an important honorific for her, because this is the institute that addresses childhood disability and childhood conditions. Okay, so, again, because it was the first ever national survey, we tried to cover a wide range of topics. We went shallow but not deep. So I know in the question period afterwards, you might ask me, you know, why do you think this was? Well, we asked about the attitudes but we weren't able to ask about why. Because just a little trick of survey science. Surveys have to be short for people to respond to them. And that includes doctors. And so we were trying to come up with a survey that would only take 15 minutes to apply. And so that is what we did. So what I'm going to talk to you about here today are physicians' perceptions, one module from that survey, and the data that I'm going to be reporting on this afternoon were published in health affairs, health policy journal, on February 1st. So less than a month ago. Brand-new, hot off the presses. Okay, so I would like to thank my super research team. I was the lead of team. Very privileged to have that role. Sowmya Rao our statistician, Karen Donelan, survey scientist, Nicole Agaronnik was my exceptional research assistant, now a first-year student at Harvard Medical School. Eric Campbell, another survey scientist from the University of Colorado medical campus in Aurora. Julie Ressler, a research associate of his there. The person that led the conduct of the survey, the actual mailing out of the survey was Dragana Bolcic-Jankovic at the University of Massachusetts Boston, center for survey research. And then finally we were ably assisted by Tara Lagu, an internist at Baystate Health in Springfield, Massachusetts, although she just moved to Northwestern in Chicago.

So we only had enough funding -- I won't go into budgets, but there's a lot of kind of ways you do things in these grants because of the resources you have. And we only had the resources to be able to look at seven different physician specialties. And so we looked at internal medicine doctors, general internists. We looked at family practitioners, physicians who are rheumatologists, neurologists, ophthalmologists, orthopedic surgeons, and obstetricians, gynecologists. And we chose these doctors, the primary care ones, because they should be seeing a lot of people with disability, as should physicians in the other specialties, you know, ophthalmology we'll see people who are blind, neurology will see people with all sorts of disabling conditions. We chose obstetrics/gynecology interestingly because Tara Lagu, the general internist I mentioned as one of the partners on the project had done this secret shopper survey where she called like 230 practices and she had a research team that called about 230 practices around the country and asked them if they could schedule a patient, a fictitious patient -- although, again, this was a secret shopper type of survey. It was a fictitious patient who could not independently transfer on to the exam table. And lo and behold, OBGYNs were the least likely to agree to schedule the patient. On average only 22% of physicians rejected scheduling the patient. The others agreed to. 44% of OBGYNs refused to schedule this fictitious patient. All right, so we did a lot of pre-work to develop our survey. I personally conducted 20 in-depth interviews, hour-long interviews with practicing physicians from the specialties in Massachusetts. Then we conducted three focus groups with 22 practicing physicians total across three states, across the nation, actually, and it was 17 states. So that's another typo in my slides I need to fix. We used this information to identify key topic areas for the survey. And we designed the survey iteratively. We had meetings like every two weeks where we would talk by

conference call or Zoom, although this was pre-pandemic, we actually were using Zoom back then. And so we designed the survey, you know, coming up with questions and Dragana kept saying, no, no, we can't have more questions about this. We have to make sure we're only going to be 15 minutes in length. She conducted eight cognitive interviews to make sure that the participants would understand the questions the way that we intended for them to be understood. And then 50 pilot tests of the draft survey. And so the final survey had 8 modules with 75 questions. And, again, we went broad but not deep.

Okay, so we randomly selected practicing physicians from a national list that you can purchase about the physician's practice across the country. We eliminated training, trainees, interns, residents, and fellows. We eliminated locum tenens physicians, physicians no longer practice. We eliminated physicians who had died. We eliminated a number of physicians and sampled 350 physicians in each primary care specialty and then 140 physicians in each of the five specialist groups for a total of 1400 doctors in the sample. The CSR, Center for Survey Research, mailed out the paper survey in October of 2019 with literally a crisp \$50 bill inside. Because another little secret about surveying doctors is they have to pay them. They will not answer a survey out of the goodness of their heart. You have to give them money. And so we gave them this \$50 bill. And we also offered an option to answer the survey online. And Dragana and her group at the Center for Survey Research followed up with physicians who had not answered the questionnaire, but we transitioned into the year 2020 and then people might remember what happened in February and March. And so the follow-up was actually complicated by the pandemic. Our governor, Charlie Baker in Massachusetts, you know, it's state school, U Mass Boston, they had to follow the explicit rules of the governor and they were not allowed to go into the U Mass campus to pick up envelopes, for example, of surveys that had been returned. Dragana finally figured out how to make that happen. But we ended up closing the survey in June of 2020, because by that point, you know, it was clear that we weren't going to get many more surveys. But for those of you who know anything about survey response rates, you will see that our survey response rate was 61%. Which shows that Dragana and her team at Center for Survey Research did an incredible job at tracking down these doctors and getting them to respond. So there's many findings on various topics, and as I already told you, what I'm going to focus on here is physicians' perceptions of caring for people with disability.

Okay, the major findings. 82% of physicians report that people with significant disability have overall worse quality of life than other people do. Only 41% of physicians said that they are very confident in their ability to provide equal quality of care to people with disability. Which means that almost 60% said that they aren't very confident in being able to provide equal quality of care to people with disability. And we actually thought this was a very low number. Only 56%, so a bit over half, of physicians strongly welcome people with disability into their practices. Other findings. 18% of physicians strongly agree that people with disability are often treated unfairly in the healthcare system. And 80% strongly agree that understanding their patients with disability is very valuable to them. Multivariable analysis, where we look at how different attributes of the

doctors relate to these outcomes. Women physicians were much less likely than men to report worse quality of life for people with disability. In other words, women physicians think our lives are better than men physicians do. And safety-net physicians, in other words, physicians who practice in settings that have more than 35% of their patients who get Medicaid coverage are much less likely than non-safety net physicians to report worse quality of life for people with disabilities. So, in other words, physicians who are caring for poor people are less likely to view the quality of life of people with disability as worse than that of people without disability. So we then put our multivariable analysis at work, looking at whether physicians would welcome people with disability into their practices. So you will remember that a minute or so ago I said that only about 56% of physicians said that they would welcome people with disabilities into their practices. What we found in the multivariable analysis was that women physicians are much more welcoming than men are. We also found some racial and ethnic differences, but the sample sizes for under-represented minority physicians are too small to evaluate fully. And so I just don't feel comfortable talking about those findings. It is a shocking thing to know that in 2021 only 5% of American physicians are black. Older physicians are much less welcoming than younger physicians are. Physicians in private practice are much less welcoming than physicians at teaching hospitals. And not surprisingly, physicians who value understanding patients with disability are much more welcoming of patients. And physicians who feel very confident about their ability to provide equal quality of care are also much more welcoming than other physicians. So those are our quick results. A couple slides about just kind of my take on this. First of all, something called social desirability bias was not evident. And so let me explain what that means. Survey scientists expect respondents to reply in a socially acceptable way, in the way that broader society would expect them to reply. And the survey gave physicians the option to say that people with disability have the same or better quality of life. But instead 82% of physicians responded that people with disability have worse quality of life. What that suggests to me is that these physicians are pretty sure that they're right. They're pretty sure that nobody would argue with their response that people with disability have worse quality of life. Now, of course, we're all almost 12 months into dealing with a COVID-19 pandemic. And I'm sure for some of you, your mind is racing ahead to what does this mean for the treatment of people and COVID-19, people who happen to have disability. Obviously one of the big questions early in pandemic, as we were facing down the possibility of scarce resources, and I understand in California that that has been a much more recent occurrence back in January and February, that some hospitals ran out of beds. Given the potential bias of physicians, how do we ensure that people with disability can get equal quality of care?

>> LEWIS KRAUS: Lisa, can I pause you for one moment?

>> LISA IEZZONI: Absolutely, so we can get the ASL interpreter on board? Absolutely.

>> LEWIS KRAUS: Correct. Hold on one second. Hang on one second. One moment.

>> LISA IEZZONI: Thank you for joining us. All right, so this question points number two. Only 41% of physicians feel very confident

>> LISA IEZZONI: That's pretty scary for those of us with a disability to realize that about 60% of physicians don't feel very confident in their ability to provide equal quality of care to us. And not surprisingly, those who do not feel confident are less welcoming of people with disability into their practices. And so maybe it's not so surprising that Tara Lagu's secret shopper survey found that a lot of physicians refused to schedule a fictional patient who couldn't get up independently on to an exam table. But it's pretty troubling that 30 years after, enactment of the Americans with Disabilities Act, less than half of physicians feel confident about providing equal quality of care. Clearly this must be addressed. But how quickly can that happen?

I'm going to ask you to move my slides. Because I'm having a little trouble moving them forward. Maybe my key is just getting stuck. Thank you.

>> I'm sorry to interrupt. This is the interpreter. The other interpreter is trying to get in but having problems. If you -- when she gets in, if you can make her a panelist. There she is. Gussie, if you would make her a panelist. Thank you so much. I'm sorry for interrupting.

>> LISA IEZZONI: No, of course, I'm very glad that you're here.

So the question I have is why should patients with disability need to prove to their doctor that they value their quality of life to get equal quality of care. So that's just a little set-up for the story I'm about to tell you. Next slide.

Michael's story. Next slide.

Can you go to the slide before that? This is a photograph. This slide shows a picture. This is a picture of Michael, who I am going to be talking about. And for those of you who can see, Michael is a man with a significant disability. He uses a Trac ball to operate his power wheelchair. And I am telling you this story with his permission. Next slide, please, Gabe. All right. At the time that I'm talking about, which is 2015-ish, Michael was 61 years old. He had a 21-year history of primary progressive multiple sclerosis or PPMS. Michael was born in Birmingham, England. He has a Dphil, which is the equivalent of Ph.D. in physics from Oxford University. So he's a pretty smart guy. He was in excellent physical health. He was a high altitude long distance cyclist. When he was doing his Ph.D. in physics at Oxford, he was working at the particle collider in Geneva, Switzerland, so he used to go out cycling in the Alps on weekends. He was a pretty good endurance athlete. And then he came for a post doc at Cornell University in upstate New York in 1981, and at that point he became an avid speed skater and cross-country skier. But at age 42 he was diagnosed with PPMS and he needed a wheelchair within seven years. At this point he has complete quadriplegia. He behaves like he has a spinal cord injury. He can't voluntarily move any part of his body below his

neck. He can't wiggle his toes. He can't do anything at all. And so that is as Michael was back at the time that I'm talking about and is today. Next slide. However, just show you this slide because it gives you a sense who Michael is as well. After 3.5 years of using his wheelchair, his Power Chair, his odometer read 2563 miles. Although, of course, he always calculates this in kilometers. So for those of you who are kilometer centric, it's 4,125 kilometers. Next slide, please. All right. So Michael was doing okay living at home with some personal PCA care services, but as his disability progressed, it was just really obvious that he was no longer able to afford -- he quit working at age 50 because of his disability, and he had kind of a modest disability pension. And so he was paying for about 4 hours a day of PCA care, if you meant it, he was skipping lunch and skipping food during the day. And so to obtain required PCA services and for other reasons, Michael enrolled in PACE. That's Program for All-Inclusive Care of the Elderly. Some of you may know about PACE. It's a program that involves people who are considered, quote, nursing home certifiable according to their state, they have to be on Medicare and at least age 55. And most PACE members -- PACE was actually created in the image of the unlock program in San Francisco. I forget I'm talking to Pacific coast people. So some of you may know about Unlock out in San Francisco. Most members are transported from home to adult day care and returned to their family at night. And one of the catches of PACE is that members must exclusively use PACE physicians. So some PACE leaders actually did not want Michael because he lives alone. They thought he was so disabled that he should be in a nursing home. But, in fact, there were some advocates at PACE who eventually got him in and it turned out that PACE worked pretty well for him. He had PCA coverage for 10 hours a day. He had home nursing daily. But he refused to attend the PACE adult day care. Instead he preferred to be active going out in his community, you know, doing whatever he wanted to do throughout the day and getting all those thousands of miles on to his wheelchair odometer. Next slide, please.

So Michael's cancer Number 1. In March of 2015 Michael started complaining of loss of appetite, early satiety, which means he felt full after not having eaten very much. Occasional vomiting and nausea. Reduced food intake. And change in bowel patterns. And let me just parenthetically say here, for some of you, even a first-year medical student would begin to think, you know, let's start thinking about colon cancer here, or some sort of abdominal cancer here. Even a first-year medical student with these types of symptoms. But in addition his lower abdomen grew grossly distended. He asked PACE repeatedly for a gastroenterology evaluation but the nurse practitioner failed to schedule one. Next slide.

In May of 2015 Michael's blood pressure rows to 160/100-110. And most people will know that normal blood pressure is like 120/80. And this is despite previously normal values. And this elevated pressure was not controlled by medication. In June of 2015 he started having trouble saying more than several words before needing to take a breath. And in early July of 2015 the PACE primary care doctor visited Michael at his home for his six-month checkup but did not examine him saying he could not get Michael out of his wheelchair. The doctor didn't even lift up Michael's shirt. Next slide. And this slide shows a picture of a rehab power wheelchair in its full recumbent position

showing that what this doctor said about not being able to examine Michael was just completely not true because Michael could have tilted back his wheelchair and could have been fully recumbent and the doctor could at least have lifted up his shirt. Next slide. So here I'm coming clean. You probably can already tell this. This is a photograph of Michael and me going over the George Washington bridge in New York City in our wheelchairs. Michael lives in Princeton Junction just outside of New York, and if people ask me later I can tell you how Michael and I met. Michael and I met even though I live in Boston. I take the Amtrak down to see him and get off a mile from his home and just roll over to his house. And so this is Michael and me going over the George Washington Bridge. Next slide. So I had been respectful of Michael's preference to do his own self-advocacy. As I already told you, Michael is a really smart guy. He's just a brilliant guy. Let's just say he has programmed Alexa in his house to do every possible function. You know that speaker thing that has a computer embedded within it. And health policy has little raspberry computers around his house. Anyway, he's a smart guy. And Michael, it's funny, because I was born in Boston and Michael was born in Birmingham England, but he was born exactly nine days before I was. So we are literally the same age. And Michael, in typical British fashion said to me, Lisa, we're the same age except for the Gregorian calendar adjustment. If you do the Gregorian calendar adjustment, in fact, we're actually the exact same age. I've had multiple sclerosis for 44 years. I started with a relapsing remitting type and went to secondary progressive and have been a wheelchair user since 1988, so I had a longer history of MS than Michael did, but I'm like an athlete compared to him at this point. But anyway, so I got into the habit of Michael and I got into the habit of spending our birthdays together. So his birthday is July 13th and so I went down in mid-July for his birthday visit, and he looked awful. He was haggard, unable to eat, he vomited up even his small meals. We gave him a shrimp for his birthday dinner and he vomited that up. He couldn't talk more than a word. And he had enormously distended lower abdomen, just enormously distended. Eight months pregnant distended lower abdomen. He also had grossly edematous swollen lower legs. And so at that point, before I took the train back to Boston, after my week visit, I sat Michael down and I said, Michael, look, I can talk doctor, I've got an MD after my name, I can talk doctor, can I have your permission to advocate for you with PACE? And so by the following Friday Michael had a CT scan. Next slide. Over the weekend, after the CT scan, he had a fever of 102. He couldn't eat. The visiting nurse prescribed Tylenol. Early Monday I was going crazy. You know, I was just going frantic about this. And I telephoned his PCP when I thought it was kind of a reasonable hour to do so, like 7:30 in the morning, to find out the results of Friday's CT scan. And the doctor said, Lisa, I think you should be prepared, he has a lower abdominal mass. And I said, of course he does. And I insisted with the doctor that Michael be treated at a major academic medical center in a nearby city rather than the community hospital that was affiliated with PACE. Next slide. So when Michael was admitted to that hospital he was found to have bilateral femoral vein clots. Those are the big veins that return blood back to the heart from your lower legs, and they are the veins that kind of -- you can feel -- the arteries you can feel in your groin. So the veins are right next to the arteries. So he had bilateral femoral vein clots. So on July 30th, 2015, I caught the 6:00 a.m. Amtrak out of Boston to get to Philadelphia to the hospital for noon when Michael's surgery was going to start. Because I'm his healthcare proxy, I

had to sign all the forms for him and talk to the surgeon. And that afternoon Michael had a 15-pound gastrointestinal stromal tumor, it's called a GIST, removed, and an IVC, which is inferior vena cava filter placed. It's a filter placed in the huge vein that returns blood from the whole lower part of the body to the heart to prevent clots from reaching his lungs. Within a few days his blood pressure fell to normal. His breathing patterned returned to baseline. Basically that ginormous tumor, that 15-pound tumor had been sitting on his inferior vena cava and on his veins causing the clots. It had been pressing on his artery causing the high blood pressure. It had been pushing up on his diaphragm causing him to not be able to speak more than a word or two. And so not surprisingly, once that 15-pound tumor was removed, he did well. He now takes daily imatinib, which is the treatment for GIST, and fortunately has had no side effects. And he just literally had an MRI scan about a week ago and 56 months later he remains tumor free. Next slide. So Michael's cancer Number 6. Clearly Michael got substandard care. But was there more going on? So Michael stayed in the hospital for about two weeks after his surgery. So I took the train back to Boston and then I took the train back down again when he was going to be discharged, so I could be there when he was delivered home. Because his 90-year-old mother was coming over from England to stay with him, but he was going to arrive to an empty house, so I needed to be there when the ambulance from Philadelphia brought him home. So I was there for the first few days after he was home. And so I was my usual trying to be sweet, nice, happy nice self, but my ears were open. I was listening to everything that the care providers who walked into his house said. Because I was trying to figure out what they thought had been going on. So his home care nurse, the guy, a male nurse, who had been coming into his home every day for a year had thought that Michael was simply getting fat because he does not exercise

The internists, you know, who hadn't even lifted up his shirt, I thought he might be doing something that is called diagnostic overshadowing. A lot of you -- it sounds like a technical term, but a lot you will immediately know what I'm talking about when I say that what diagnostic overshadowing means is attributing every new symptom, every new problem that you have to your underlying disability. So everything that possibly is going wrong with you has to be because of your disability. So, all right, MS causes constipation, but was it the -- was the abdominal distension -- remember, I told you he looked eight months pregnant, was the abdominal distension caused by stool? All right, severe MS can cause breathing problems, but these came on pretty suddenly. You know, was it really the MS? And I had done a PubMed search, that's what I do as a doctor person, I do this, and I could find no relationship between MS and hypertension. So let's get rid of that, that the MS probably was not causing this. They couldn't really attribute it to MS. Next slide. So it was the social worker who finally gave up the game. I asked, what do you think is going on there? And what she said to me was that PACE's goal is palliation. That Michael is so very disabled, that for him, their primary goal was palliation rather than active exploration and intervention as needed. Hopefully this attitude is rare, but let me pause there to say that I actually wrote an article about this, you know, just a short narrative. It's only about 1800 words. And to write the article, I went on to the World Health Organization website to look for the definition of palliation. The definition of palliation is not withdraw care and only provide comfort care. The

definition of palliation is try to figure out what is going on, if something is happening and fix it to make things as good as possible for that patient. So as soon as Michael had those symptoms, the first responsibility of his doctors and nurses was to figure out what was going on and do whatever they could about it. Next slide.

So, again, why should patients with disability need to prove to their doctor that they value their quality of life to get equal quality care?

And some of you will remember the picture I showed of Michael and me going over the George Washington Bridge. That was exactly a year after. That was his birthday visit in 2016, so the year after I had gone down for his cancer surgery. Next slide. So this is a picture of fireworks on Independence Day. And I always like to end my talks with a picture of Independence Day fireworks. So thank you, everybody, for listening to me this afternoon, and I look forward to answering any questions that I can.

>> LEWIS KRAUS: , Lisa, thank you so much. That was very interesting, and the personal touch was quite interesting too. Thank you so much for sharing all of that. All right, everyone, remember to submit your questions in the chat window and we'll get to those in a moment. So, Lisa, here is a first question, going back to some of the original data that you put up there. Why would older physicians be less welcoming than younger physicians when older physicians face more limitations?

>> LISA IEZZONI: You know, that is such a great observation. Of course they do. Older physicians age just like everybody else does. You know, one possibility is lack of knowledge about the ADA. They may have trained pre-ADA, which is what happened to me. So let me just parenthetically say a sense about my own -- that little MD that is after my name. I started at Harvard Medical School in September of 1980, and at that point I had had four years of symptoms of relapsing remitting MS, but I was 22, 23, 24. I was invincible. I never got it worked up. I just kept going. But once I started at Harvard Medical School all of a sudden it came back and I could no longer ignore it. So I was actually diagnosed with MS at the end of my first semester at medical school. And I went through the four years, I did everything I was supposed to do. I got a few accommodations, but I did everything, passed everything. And at the end of that time the medical school refused to write a letter of recommendation for me to apply for internship or residency. So I was never able to practice medicine. So I am of the age that some of these doctors are, and I can tell you that back in that era, I mean, disability was not something that people ever thought about. And the other possibility is that they may have older practices. They may not have the equipment, the height adjustable exam tables and so on that would make it easier for them and appropriate for them to be able to care for people with disability. But as I said, this survey was shallow but not deep. And so what I just -- the way that I just responded to that question was speculation, based on just having been around and having done all these interviews with doctors that we did in prep for the survey.

>> LEWIS KRAUS: Thank you. I do want to remind people that there have been many webinars we've had in the series, so the issue that Lisa just brought up about accessible

medical equipment and whether doctors' offices have them was the subject of a previous webinar and you can go see that in our Archives at ADAPresentations.org in the Healthcare section. All right, the next question... Do we have any understanding why people feel less confident of their ability to provide equal quality care to people with disabilities?

>> LISA IEZZONI: You know, again, our survey was shallow, not deep. We were not able to kind of dig below the surface of that question, but I suspect that they just kind of see a patient with a disability come in and they weren't trained often about how to care for people with disability. We're working on another paper right now, and lack of training is a very big problem for physicians. We looked at the correlation between lack of training and confidence to be able to provide equal quality of care, and guess what... lack of training was right there upfront. And so I have a feeling that that is perhaps one of the major reasons.

>> LEWIS KRAUS: At least one person asked if you could share the link to your Health Affairs publication. How would somebody get that?

>> LISA IEZZONI: Okay. So I am going to tell you upfront that I actually, because of copyright laws am not able to directly provide that article to you. Health Affairs owns the copyright to that. You can go on to their website, and to be honest I don't know how -- I'm embarrassed, I will confess to you I'm embarrassed that I haven't gone on to see how much they charge for a copy of it, but for those of you who have access to academic libraries, maybe one of the university libraries around there, often you can get this for free often through university libraries. So, again, I apologize about that, but my hand was slapped when I by mistake gave it out and I was reminded about the copyright requirements around distribution of that article. So I apologize about that.

>> LEWIS KRAUS: Right. So the upshot for people is go to you know, search on Health Affairs and you can go to their website and you can identify the article at that point and then do what you can to get the article from there.

>> LISA IEZZONI: Yeah, uh-huh.

>> LEWIS KRAUS: All right. Next question...

Are there any plans to make these relationships a part of a medical school curriculum?

>> LISA IEZZONI: Well, there is, actually an increasing interest among medical students, some medical students, in learning about disability. And so they are trying to introduce this to their faculty members. You know, it's kind of an interesting kind of reverse dynamic that the students are coming in. And often I will confess to you -- and I've observed this for literally decades, because it's now been 40 years since I started medical schools, so I can talk about this in decades. I have observed that the majority of young people who are interested in medical school about people with disability often have a siblings with a disability, often an intellectual disability, and so they come with a

very strong interest. And so there are scattered efforts around the country. There are some medical schools that do this, and some that don't. But there's no systematic requirements. For example, the American board of internal medicine, which board certifies people who finish their training to make them board certified internists doesn't have questions about disability. It isn't part of what the expected curriculum is. And so until some to have primary care specialties and so on do that, I think it's going to be hard to get medical schools to universally address this topic. But even so it's so frustrating to think that even if we train young physicians today, they're just starting out. We're at an age we need our doctors to know what they're doing. And so I think it's also an issue that we as patients need to educate ourselves when we behave as patients, when we're acting as patients, when we're going to a doctor to get care, we need to, to the extent we possibly can, educate ourselves so we can know what questions we want answered by our physicians.

>> LEWIS KRAUS: And someone put into the chat, and maybe we can expand that to everyone, but the American Academy of Developmental Medicine and Dentistry has a medical school curriculum initiative. So we'll put that up there. But it's true, there have been some movements towards a medical school curriculum...

What tools are available to self-advocates to use in situations like Michael's? What can we do at the person and community level to change this situation? This person says we're working with our local hospital to ensure that disabilities include in their definition of diversity and equitable health. There's so much to do.

>> LISA IEZZONI: Oh, it is such a critical question, because, you know, I think that if Michael hadn't had me that he would have been in a bit of trouble, and I was helpful to him because I had some medical knowledge. And so I was able to say -- you know, I actually said back as far early as March when Michael -- the very first time Michael said to me, I have early satiety, I don't feel like eating, I said, Michael, I don't want to alarm you, but I just want you to know that there is many reasons for that ranging from something like depression, but all the way to malignancy. So you need to be thinking about the whole range of possibilities and make sure you ask your doctors questions. So I think this is something that it would be really great for centers for independent living to be thinking about whether in peer support training or in some sort of activities they do, they can begin to think about how people with disability, when they become patients, when they need medical care can best advocate for themselves, and maybe begin to put together a cadre of people who can be consultants to those advocates. You know, call them up and say, hey, this is what I'm confronting. You know, what would you advise? Recognizing that we can't be medical practitioners. We don't have malpractice insurance, we can't be held responsible for anything, we're functioning as good Samaritans, but, you know, at least what you're doing is feeding people questions to ask to the doctors. Not coming up with the answers, but the questions to ask and then making sure if you don't feel that you're getting good answers, going up the chain you know, asking to see the specialist, in Michael's case the PACE program refused. And, in fact, apparently the nurse practitioner who refused to schedule a gastroenterologist for Michael ended up hearing about that, once his cancer was

discovered. But, you know, so there certainly will be circumstances where you're not able to get access to the next level of care, but I think just becoming empowered through practice, actually, beginning to feel comfortable asking questions and following up.

>> LEWIS KRAUS: Okay. The next question... if you were to do -- if you do further survey work, where are the areas you want to do a deeper dive?

>> LISA IEZZONI: Great question. The first thing we want to do is survey advance practice clinicians like nurse practitioners and physician assistants to see -- because interestingly, from some other analyses we've done, as many of you know, nurse practitioners and physician assistants can actually serve as the primary care clinician for some patients, and especially in rural areas where there may be an under-service of physicians. There may not be enough doctors. Oftentimes in rural areas nurse practitioners or physician assistants are serving as primary care clinician for people with disability. And so that is one thing that we want to do, so to see whether other healthcare professionals have the same kind of ideas, and if not figure out what going on here, what is different about the training and perspective? But then we're also hoping to do additional survey work and additional -- maybe not survey but in-depth interviews. And many of you know about something called the implicit association tests. Those are tests that are online that are often part of diversity training primarily focused on race and ethnicity, but there's also one for disability. And they're not perfect by any means, but, you know, getting healthcare professionals in training and physicians in training, medical students, to take an implicit bias test about disability. And see what their attitudes are. And once you know you have implicit bias, there are all sorts of training programs for helping physicians try to think about how to maybe not overcome their bias, since it's implicit it's built into your subconscious, but at least recognize that you have it. And when you confront situations where it could be at work, to try to make sure that you're aware of not making decisions based on those biases.

>> LEWIS KRAUS: Great information there. The next person wants to know if you have any good ideas of how to find those caring and knowledgeable physicians.

>> LISA IEZZONI: I saw a message on the chat, a comment, and the person who just wrote that proximity to people with disability is also a really good educational tool for doctors. And you're absolutely right, there's actually been some research about that that has shown that doctors who hang out more with wheelchair users, you know, are kind of more comfortable with disability than are others. So, Lewis Kraus, I forgot, what was your question again? I just saw the chat. My eye was just taken away while you were talking to the chat.

>> LEWIS KRAUS: So the person asked if you had ideas where to find these caring and knowledgeable physicians.

>> LISA IEZZONI: Okay, where to find these caring and knowledgeable physicians. I have no clue. I actually have really no clue. I think you do it the way you do everything

else. One of the things about finding doctors, whether you're a person with a disability or not is that you ask your friends. And you kind of just ask your friends and ask what makes that doctor good from your friend's point of view, and if those are the same characteristics you're interested in, then you go for that. But there's all sorts of health grades and online report cards and all that kind of stuff. And you can look at that. You know, I think those might be useful to look at in some circumstances. You can also call up the office and, Lewis, if you've had prior sessions on accessible medical equipment, you're going to want to make sure that the office is accessible to you, if that is something that is important given your disability. But I think just talk to people, visit the practice, see what you're feeling, the feeling to have practice is. And you might have to change doctors once or twice.

>> LEWIS KRAUS: All right. Next question... Were all the physicians in your study in private practice? This person was curious about whether doctors working in an HMO have different views about providing medical services for people with disabilities.

>> LISA IEZZONI: Okay, so as I said, academic teaching hospital physicians, so physicians based in teaching hospitals, you know, that practice out of clinics in teaching hospitals were more welcoming to people with disability and had better views of people with disability. We had relative -- so we asked physicians where they practice and we gave them lots of options. They could also list in a free text box the kind of place that they practiced. So we had a few physicians from federally qualified health centers, and a few from Indian health centers, actually from the National -- from the Indian Health Service. So we had physicians from all over, from different types of settings, but unfortunately we didn't have enough from these other less common types of settings to be able to make strong statements about them.

>> LEWIS KRAUS: I wanted to put something in the chat there from actually our funder, the Administration on Community Living. It says that they have a related grant that people might be interested in on -- at Rush University, a new grant to strengthen healthcare workforce. So you may want to look at that and address those kinds of issues.

>> LISA IEZZONI: Let me just say parenthetically that Rush University does great work on that. So congratulations to them on that project.

>> LEWIS KRAUS: Okay. Next question... How would the results relate to COVID-19 vaccine prioritization? Are you planning on covering this topic in future publications? This issue of COVID has added an extra layer to an already complex and urgent situation.

>> LISA IEZZONI: Well, some of you -- I don't know, Sylvia, whether you know -- was that Sylvia, was that you who asked that question?

>> LEWIS KRAUS: No.

>> LISA IEZZONI: I thought I saw something coming in from Sylvia. I think you might know Megan Morris at University of Colorado. She has a paper under review that I can't talk about because I don't -- you know, I just can't talk about her work. It would be unfair of me to present what she found, because these were pretty interesting findings. She looked at medical students and she looked at their views of people with disabilities. She also did implicit association tests on medical students, and she was able to do this pre-COVID and post-COVID. So there will be a tiny bit of work coming out on that. We've thought about whether we could administer a survey relating to COVID, but the problem is that there is a lot of upfront work that is required to get a survey in the field. And we're just concerned that by the time we could have gotten out in the field, once we had these results, that hopefully, you know, the pandemic will be a little bit better under control, and so the issues would be less acute. But certainly I think that one of the things I have noticed and you may have noticed it as well, is that the prioritization of people with disability for vaccine rollouts varies significantly from state to state. So, for example, I don't know what it's like in California, whether people with disability explicitly are listed as a high priority population, but in Massachusetts only certain disability types are listed as a high priority population. So I think that that is a topic that we need to keep an eye on, and advocacy out there every day.

>> LEWIS KRAUS: This may be our last question here, and it is from Sylvia. Do you think decades later, is it any easier for persons with disabilities, including people with learning or mental health disabilities to get through medical school, peers with disabilities is such a good way to foster understanding of disability among physicians.

>> LISA IEZZONI: Well, thank you, Sylvia. It's a great question. And you probably know the answer to that. Medical schools have something called technical standards. They have a series of requirements that every graduating student must meet to be passed from that medical school as a doctor who can now begin their residency and internship and become a full-fledged doctor. And there are efforts around the country to try to address the technical standards because a lot of the technical standards will prevent somebody like me from ever going to medical school, and somebody who is deaf or blind from ever going to medical school. And so -- but it's medical school by medical school. There's really no national consensus yet about what the technical standard should be at different medical schools. And different medical schools have leaderships that have very different attitudes about this. Some are more welcoming. Others less so. So I think that this is a work in progress, and the main concern is going to be making sure that whatever accommodations are made, so a person with a disability can graduate from medical school do not so fundamentally change the fund of knowledge, the amount of knowledge, the skill set that that person comes out with. And that doesn't mean necessarily physical skill set. It can be, you know, intellectual skill set, that they cannot be practicing physician. So this is something that there are people around the country actively working on right now, but we aren't there yet.

>> LEWIS KRAUS: All right. We realize that many of you may still have questions for Lisa, and apologize if you didn't get a chance to ask your questions. I will say that if your question does relate to the ADA and the issues of access under the ADA, you can

contact your regional ADA Center at 1-800-949-4232. You will all receive an email of a link to the online session evaluation. Please complete that evaluation for today's program. We value your input and want to make sure that our funder understands the value of these sessions. We want to thank Lisa again for sharing her time and knowledge with us. It was really an excellent presentation, and a reminder that today's session was recorded, and it will be available for viewing next week at ADApresentations.org in the Archive section. On our next webinar on March 25th, we will be joined by Dr. Manchanda of Boston University and the disability policy consortium for a presentation on how crisis standards of care can ensure equity for people with disabilities during times of crisis. We hope you can join us. I think it will be an excellent follow-on to this session. Watch your email two weeks ahead for the announcement of the opening of registration. And so thank you again, Lisa. And thank you to all of you for attending, and we will see you next month.

>> LISA IEZZONI: Thank you. It was really fun to do this.

>> LEWIS KRAUS: Great. All right, take care! Have a good afternoon, everyone!
Bye-bye!