TRANSCRIPT: JULY 13 University of Minnesota Medical School Dean's Special Lecture Series:

## "GOING FROM ABLE TO UNABLE TO DISABLED: A PHYSICIAN'S PERSPECTIVE OF CHALLENGES AND OPPORTUNITIES IN ACADEMIC MEDICINE"

Mya Wilson, DHA...: 00:03 Good morning, everyone. We are happy to have you with us this

morning. This session is recorded and will be shared out within two days after the Dean's lecture series today. For those who registered, and you will be able to find the recording on the Dean Lecture Series website. And I will post that in just a sec. I want to give others the opportunity to join. So they also have access to the link. But while we're starting, I will launch a poll for those who are with us now, so that we can take the poll. We

can see who's in the room this morning.

Ana Núñez, MD, ...: 00:46 Who's in the zoom room, huh?

Mya Wilson, DHA...: 00:48 Yes. During the session, you may have questions. We asked you

to please use the Q and A section to post your questions so that we have access to them and can share them with our speaker for today. If we are not able to get to your question and it's posted in the Q and A section, we will get the answers for you. And we will disseminate those within two days after the Dean's Lecture Series for today. Thank you very much. We still have a few trickling in the room, but I will now pass the mic over to Dr.

Ana Nuñez, who is going to introduce our speaker for today.

Ana Núñez, MD, ...:

Good morning, everybody happy July. It's still 15 hours of light outside. Isn't that wonderful. We will appreciate this, especially whenever the seasons change. I am thrilled today in terms of having us be joined by a fabulous colleague of mine, Dr. Linda

Barry.

Linda Barry, MD: Dr. Linda Barry is the associate professor of surgery, director of

the Office of Multicultural and Community Affairs and interim director of the University of Connecticut's Health Disparities Institute. Just going to tell you a little bit about her, because if I read all the good stuff she did, that would be the hour. And then we couldn't hear what she has to say. So I'm going to be short. Dr. Barry is a board-certified liver and pancreas surgeon with a unique background in both clinical and basic science research. She teaches at UConn, University of Connecticut's, Medical School and holds a position there as the director, as I mentioned, the Multicultural and Community Affairs Institute. She's the interim director of the Health Disparities Institute and a member of the editorial board for the Journal of Racial and Ethnic Health Disparities. Her professional experience and lifework has been addressing health disparities in healthcare

delivery and research. And today she's going to talk with us about going from able to unable to disabled physician's perspective of challenges and opportunities in academic medicine. So let's give her a big sort of welcome. Dr. Barry, take it away.

in my trajectory. So I always like to start talks by making sure

Linda Barry, MD: 02:59 Thank you so much. I appreciate the opportunity to speak to you and your colleagues. I'm just gonna share my screen.

Linda Barry, MD:

So I, I appreciate the opportunity to talk about this topic. I am a physician and a surgeon as mentioned, but this journey was not planned and unexpected. And I feel that there are a lot of lessons learned that I want to share with you all because we are all one accident and one illness away, particularly in the setting of COVID from developing a disability. So I just wanna make a disclaimer that I have no financial disclosures, but I also wanna say that all my comments are not too malign or impugn anyone. They are to highlight opportunities that I took the time to note

we're all on the same page.

Linda Barry, MD:

Linda Barry, MD:

04:31

05:26

Linda Barry, MD:

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So let's just define disability. It's any condition of the body, or mind, an impairment that makes it more difficult for the person with the condition to do certain activities. So you have limitations and interact with the world around them. So there are restrictions and just know that many times when we think of disability, we think of the physicality of it, but there are disabilities that are unseen as well.

The counter to disability is ableism, and it's a behavior and/or practices that discriminate against people with disabilities, physical, mental or intellectual. So it evokes a perspective that says the disabled person needs to be fixed because the standard and the norm by which everyone is measured, it's the able body. And I like this quote, because it states that ableism is connected to all our struggles because it undergirds most notions of whose bodies are considered valuable, desirable and disposable. And I think when you hear my story, you'll understand where that plays a role. So my story, I found myself navigating a brand a new world. So I'm gonna take you back way back. I am first generation American. My parents herald from this little island called Grenada and is known as the isle of spice with beautiful waterfalls and scenery.

But I'm American. I was born here and my parents came to this country and they said, "The one thing I'm giving you is their education." And so by 13 years old, I knew I wanted to be a surgeon. How? I was channel surfing on PBS, and I saw the most

disgusting thing I ever saw. I was like, this looks like a train wreck. What is this? I was the middle of the documentary, but I couldn't tear my eyes away. And what it was was a first artificial heart transplant that was being conducted on Barney Clark. And what kept me riveted was that I wanted to stay to the end to see what does that look like? And so suddenly I went from being inside somebody to seeing that whole person walking, talking, and being improved. And I was like, that's what I want to do when I grow up.

Linda Barry, MD: 06:09

So I was pre-med. I went to Yale undergrad and, you know, no one told me about the whole dissecting mice thing. And I grew up in New York City. We don't interact. But my father said, how could you take care of people if you can't even deal with one mouse? So clearly, you know, I was dared, and I took the dare and here I am. So then I go on to med school, I went to Cornell and I will be frank. It was a struggle. I had always graduated at top of my class, and I had to work really hard. Biochem kicked my butt. And I tell students about this journey, because we, we got to share the trials and tribulations that go/make us who we are. And so I, I failed biochem. They wanted me to remediate. I said, hell no.

Linda Barry, MD: 06:55

And I ate, slept and drank biochemistry. And I actually, I not only did well. I graduated with honors. So I left med school thinking I'm on top of the world. I am Wonder Woman. I can deal with the world of surgery. So I did my residency at UCSF East Bay in California. And I was the only woman out of all my intern class. And actually most of the men actually dropped out. So who would've thought that I would be the lone survivor. And again, the daring comes in again, because my mentor and my chairman asked me, "Have I ever thought about doing liver and pancreas surgery?" And I said, "No." At the time it wasn't even a formal fellowship. That was accredited, but he's like, "Don't you want to be a black woman leader in this space?"

Linda Barry, MD: 07:45

And I was like, "I don't want to be the Martin Luther king of liver surgery," but he dared me. And hence I'm a liver surgeon. I had my practice in San Francisco for a few years, but I missed teaching. And I also was caught in this transition in my field where we were going to minimally invasive approach to the surgeries I performed. So I actually left my practice and went back to do another minimally invasive surgery while I was on interview trail. I always loved to multitask. I worked on Obama's campaign. As I went around the country interviewing, I ended up at USF, South Florida. And I not only completed my fellowship, but I was very productive. I had publications, presentations. I actually created a first woman in surgery,

international surgical conference. And that led to me being recruited to where I am still today, UConn school of medicine.

Linda Barry, MD: 08:37

So imagine I went through all of this and now I'm at UConn and six months into my time, this is me now. I don't like to brag, but I just want to say I was so happy I could fit into this dress. Unbeknownst to me, the reason I could is because I was sick. And within a week later this was me. I was bedridden, and I could not walk literally in a week. I went from having pain in my elbow to my hands and in the operating room. It became such a challenge. And the thing that made me go to the doctor was the fact that I was scared to that something would happen to my patients. And literally I sat in the doctor's office and she touched me in certain parts of my body. And I felt like my skin and my body was on fire.

Linda Barry, MD: 09:26

She's like, "You cannot go back to work." I said, "I have to, I'm giving a talk to the keynote to high school students." And unbeknownst to me, whatever process was happening. I was literally standing at the podium and I felt like my legs suddenly were encased and cement and the students were unruly and I'm thinking "These kids do not know what I'm going through." By the time I got through it, it took me twice as long, but I somehow able, was able to cover it up, to get to my car. But then I couldn't lift my foot to step on the brakes. I had to sit in my car for three hours before I felt it was safe enough to drive. And by the next morning I woke up and I could not walk.

Linda Barry, MD: 10:07

So, just to cut to the chase, a fellow who noticed that I had been on minocycline for acne. And it's funny enough, my skin now is cleared. But at the time I was having these cyclical flares, and the doctors kept- every time I transitioned to a different place - said, "Oh, just stay on it." And I didn't think it was good to be on antibiotic this long, but it worked. And when I got off, I would actually have, you know, bad acne. And so trying to find out this prolonged exposure caused my body to develop antibodies against my nerves, my joints, and my muscles. So I was diagnosed with drug-induced lupus based on my physical/clinical findings and serology. And this happens about 15 to 30,000 cases per year. So it's not seen commonly, and no one ever warned me so that I could have been proactive to stop.

Linda Barry, MD: 11:01

It's rare, but again, 5% of the people take of every 10,000 patients that take the drug take it. So the standard treatment is to stop the minocycline and proceed with the standard treatment of lupus. Well, you know, nothing I do is typical because I did not present with lupus. I developed nerve

damage. One morning I woke up and my skin was on fire. The sheets were burning. It felt like they were literally burning my skin. I had been on high-dose steroids. So I thought I was having a steroid psychosis, come to find out. Studies showed that my nerve potentials were that of a 60 year old.

Linda Barry, MD: 11:44

And so I just want to, I like to include within my story, little tidbits and facts. So if I asked anyone, do you know the prevalence? How many people at your institution identify as disabled? Many of you would not know, but from the census, supposedly there are about 12.7% of the population, which equals 41 million of the U.S. Population, who are disabled. Now, there was a study that did a survey in 2021, which was reportedly, excuse me, the first major survey that did take a look at this, but it was only in practicing physicians. So there's so many physicians become disabled and cannot practice that were not measured. And so this study showed that it was about 3.1% of practicing physicians were identified as disabled. And there was another study that looked at medical students and noted it as 4.5%. Funny enough, I looked all over, even checked the ACGME website and there, I could not find any documented stats on residents.

Linda Barry, MD: <u>12:54</u>

So what does that tell you? There are a lot of factors that make this an underreport phenomenon, many people who are disabled, particularly those who have hidden disabilities do not report them. They fear judgment or that it can impact their livelihood. And so this is an area where we truly need to get a better idea of the scope of the problem. So I wanna introduce in the context of my story, the concept of disability inclusion it is when you include people with disabilities and everyday activities and encourage them to have roles similar to their peers who do not have a disability. So this would enable them by the policies and practices that are enacted in a variety of environments to fully participate. But what I felt and what I experienced felt like disability exclusion.

Linda Barry, MD: 13:45

So if you can imagine, I did not know that I was entering the world of disability. I thought this was a transitory thing. I could be treated and I could get back to operating. Come to find out, it took me almost two years to learn, to walk again. And at our institution, our faculty were in a union and that was my saving grace because being out that long, one would lose your job. And so they, because I had a variety of different safety nets, I was able to come back, but I could not practice surgery. And one of the key reasons is that I had a debilitating pain that still exists today. It manifests as arthralgias, neurologias and myalgias, and

it was not like I sit here and I talk to you and I'm in pain. I sit here and I talk to you and my skin's on fire.

Linda Barry, MD: 14:37

And the worst part of this, I mean, there's no good or bad to one's condition. I can't compare myself to others to know, but it is the uncertainty that I will have a good or a bad day. You know, when people think of lupus, they don't think that they're incapacitated and they can't walk. And in actuality, because I didn't respond to the 22 medications that were prescribed, they discerned that I don't have typical lupus. That it's atypical, which meant that we don't know how to treat you. I was offered a variety of meds as mentioned. But we got to where we hit the wall, because I could not, I was afraid I was gonna lose my job. And I was in agony every day. And the level of immunosuppression that I was being asked to take would've wiped out. I would've been the girl in the bubble and I had a choice that, of taking really high-dose immunosuppressive that may or may not work, but they also could have caused me to lose the capacity to ever have a child.

Linda Barry, MD: <u>15:38</u>

And the thing that really struck me at that time, because all my doctors, they were predominantly men never even brought it up. My condition made me always look at side effects and I was like, "I'm not really, I can't come out on the other end", and that's taken away from me. And so my doctor actually brought, I was like, well, there's one other option. It's called Benlista. And it was the first drug ever marketed to treat lupus. And it's what allowed me to walk again. But the pain syndrome remained. And so I've been on requiring ambulatory assistantce with the use of a cane ever since, but I just wanna take you a little bit into the weeds. So imagine, I woke up and I couldn't walk and text and I was on call the next day for surgery. I called the person who did a call and they're like, "Oh, you know, it's Passover due to my religious obligations."

Linda Barry, MD: 16:32

"I can't do it. So you need to find coverage." So here I am, I just started this job, and I did not wanna convey what was going on. I just said that I'm too sick. So I literally bedridden had to find my coverage. I also had not been there long enough for people to know me and know that I'm a reliable person and a good surgeon. So I asked the doctor to write a note to my chairman to kind of just let him know thatI have a real serious illness, and I'm being evaluated and I cannot go to work. Imagine my surprise when I was CC'd on this email, she told my chair who-I've only been there for six months-- said that they saw me. She gave them details about my care plan. She told them about the medication I'm on.

Linda Barry, MD: 17:18

And that like the stuff that was in this email was never told to me when I, the first time that they told me they were ruling out cancer was when, and I saw this email. And I just was like, "I cannot take, get my care." This was at my place of work. And I felt so violated and I felt like, you know, would she have done this for someone who had been a patient and this woman is greatly respected in a field of rheumatology. So I moved my care and relocated to New York for the duration of my illness over the course of the years. It became, no one knew how to treat me that I was afraid to take narcotics because of the risk of dependency and that it would incapacitate me in my job. So I went to NIH, I went to Harvard, I went to Hopkins and I went to one place and I for a consult and this doctor said, she has something that might help me.

Linda Barry, MD: 18:26

She'll send me an article. Weeks pass. I don't get an article. So I ask, "Can you please send me that article? You said there were some things that I could try based on what's written." What I actually got was a PowerPoint, and it was entitled pain and rheumatologist. Imagine my surprise when I found myself as a bullet point. Now you might think, well, this is the de-identified, how would they know it's me? Connecticut is a small state. Do you know how many black liver surgeons there are? Do you know how many black women liver surgeons who have my disease? And I was very open because I used my journey to help talk to students of color and even worse. This was at one of my Alma maters. So she did not know if I taught in front of those classes as a guest speaker or a lecturer.

Linda Barry, MD: 19:15

So I had to say something, because I felt so violated. And I said, as I reviewed the slides that I found it disconcerting to see a clinical scenario of a 41 year old surgeon, his presentation was literally like mine. I had no idea that I was contributing to your talk in that manner. It seems a bit inappropriate at the very least. I would've preferred to remain in blissful ignorance rather than see my story condensed in a paragraph and used to advance scholarly discussion. It's not truly de-identified is it? And I can honestly say that I've now experienced a true gamut of the patient experience and it's not pleasant. She wrote me back, and she apologized and said she was trying to convey to the medical students what it's like to go through this, because it could be. You tell me, I'm just going back here.

Linda Barry, MD: 20:01

How does bullet points suddenly engenders empathy? I did not feel that. And I did not. I was not. I actually felt like she forgot about me and had no treatment plan and no response. So I just wanna say that we are an academic institutions and we often use our encounters with patients to advance our scholarly

knowledge. But we also need to recognize that we are not bullet points, that we are people and that there is a way to balance both. It also reminds me about what the concept of HIPAA. It really means, right? It made me feel that you have to be cautious when you receive care, where you practice, because the lines can get blurred and crossed and beware of seeing your patient, as I mentioned, as nothing more than a bullet point or a case study. And I underscore this again. I just gave you a couple examples. There are more where I felt that I was dehumanized and a lack of empathy. And let us be clear. I say this to you as a woman of color.

Linda Barry, MD: 21:08

So I'm gonna tell you about parking. Most people jockey to get good parking at their institution. Handicapped parking is premium parking. It is normally really close to the entrance, about three to five away. And you can get five, if you don't have a handicapped tag. So when I can't park in that space, it takes more time for me to get to my destination. Okay. And at my institution come Fall when it's time to do the garden, guess where they store all their equipment and all their trucks. And when I complained, they're like, "Sell, there's handicapped parking on the other side." My office is where your truck is. Why should I park on the other side? Everything I do requires me to add more time to get to where I go and having to fight for parking is not one of them. I also get evil eye from old ladies because they look at me and they're like, you don't look like you're doing that. Do you steal the tag? So I get the ageism that comes with it. And so this is just one of those things that you might think, oh, what's no big deal. I'm just gonna park my car. There it is. It really, truly is. Because for me, when I walk, my legs could suddenly stop functioning. I just lose energy. The muscles just wear down and I 'm in an excruciating pain. And it's as if I'm back in the bed that I was several years ago.

Linda Barry, MD: 22:35

I also wanna say a lot of rough policies that we have in our institution don't always factor disabled. So a fire drill I learned is about the survival of the fittest. So when they announce on the Intercom that there's a fire drill, everyone is supposed to evacuate. So let me ask you a question. Do you check if your neighbor, particularly if your neighbor was disabled, was able to get out of their respective space to evacuate the building. It says, "Do not use the elevators. Please use the stairs." So what happens if you can't walk or you're blind or you can't hear what are your options? And I found that happen to me and we always assume that these fire drills are just a drill, but one day they will be a fire. And I was in that situation where my feet and legs and joints were so swollen, I literally could not walk.

Linda Barry, MD: 23:29

And the thought of taking stairs was I just said, "I'm prepared to die today." And I wrote to HR and I said, "I don't understand the policy of how I would get out of this building. And I just wanted let you know, my remains will be in my office." I had to be that graphic. And the response was, well, what can we do for you? And I'm not asking for me, I'm asking for anybody. It could be anybody who comes in your institution and you should have a plan. Don't leave anyone behind, you know, on the hospital side, we have to have a plan for our patients who are disabled and incapacitated.

Linda Barry, MD: 24:09

So I say this because we are, there are laws that we have to be abide that we have to abide by the Americans with Disabilities Act, right? And so this was a law, many of us know as ADA, that prohibits discrimination based on a disability, it ensures that disabled people have equal opportunities in terms of employment, in all aspects of daily life. That means that public accommodations, telecommunications and transportations, particularly state and local services and public institutions are held to a higher standard than employers. Employers must provide reasonable accommodation in any modification or adjustment to a job or the work environment that will enable an applicant or employee with a disability to participate in the application process or to perform essential job functions and disabled people have a high rate of health disparities. And it's been linked to the lack of knowledge of this policy.

Linda Barry, MD: 25:08

35% of doctors knew little to nothing about the ADA. And so they remark, "Well that's because we didn't get it in our training." And so they are unaware of the legal responsibilities and liabilities that are associated. They do not factor in what it takes for a disabled patient to walk in their door to seek care. And I think this is something that many, although we say, "Well, we have a ramp, you know, and we have, you know automated doors." That's not enough. Is the appointment that you set for that patient, knowing they have to get a handicap van best to be done in the evenings or in the afternoons? Do you or the space in your clinic accommodate the size of any equipment? Is your equipment ADA accessible? Do you have sign language options? Do you have translator options? Do you have options to treat those who are blind? So many doctors stated based on these factors that they are not confident in providing the same quality of care to disabled patients, but they assume that that is just the way it's meant to be you're disabled. So your quality of life is just not meant to be good. And I push back on that.

Linda Barry, MD: 26:18

So I'm gonna tell you about what it's like to work, travel, walk, even to go to attend a medical conference. I hate it. I feel like

I'm navigating inhospitable spaces. These list of quotes are just a sample of stuff that I have heard how many times, because of the way I look, they say, do you really need a wheelchair? And I realize, particularly when you're in an airport and you ask for a wheelchair that these transporters assume that I'm supposed to look wrecked, can't dress, right. Can't look right. I need, you know, and I need to have like a thousand gray hairs on my head in order to qualify for you to treat me so many times I'm being pushed around and they're like, "Well, you know what? Take your luggage. You can walk too" And I was like, "My legs didn't start working just because I sat in this chair."

Linda Barry, MD: 27:06

Many people have said, particularly when I'm working with finance and they're like, "Why do you need extra leg room? Why do you need to arrive at the night before?" And they don't understand that if I am spending all my time sitting in one position that my joints freeze, but why do I have to explain that to you? Do I really need a cane as if I'm faking it? And I resent that because I would love to lose a cane or what is the most egregious to me is a random stranger at work will come up to me and say, "What happened to you?" Kind of work with them. Don't know one man followed me behind and said, "I've been trying to figure out which leg is a leg." That it's a problem. And I was like, "Who are you?" We don't ask people about their cancer or any invasive question, but somehow a physical, visible disability means that you have, you're given a free pass to be in my business.

Linda Barry, MD: 28:00

No. And the worst thing is when I'm being sexually harassed in a wheelchair or someone makes some comment as if my looks in my disability somehow are inversely proportional. What, you know, this makes me very uncomfortable and trapped. And I cannot tell you how many times I've taken a wheelchair. They say, "Oh, I will be back." And they don't come back. And I'm still sitting there the last board rather than the first board. It is, you feel disempowered. I arrived at these conferences with feeling totally demoralized because it doesn't matter that I'm a doctor or surgeon when I'm sitting in that chair. I'm luggage to those people. But even at work, when they talk about, well, you know, when I came back, I couldn't work full time and I work half time. That means I work 20 hours a week. I could no longer operate.

Linda Barry, MD: 28:53

So I was in an administrative role. So why is it that you are going to have a meeting at 7 a.m. And then another meeting at four? What part of halftime does that mean? That meant that what I was doing for my health was compromised because I was constantly trying to contort to the demands of everyone. No one asked me if there's a better time, no one asked me, you

know, can I, this is before COVID, can I call in? I had to ask. And it always made me feel as if I wasn't proposing on someone. I just wanna highlight that we as physicians are more valuable than wRVUs. I felt that that's how I, my value was measured. And I'm lucky. I made an impression when I was there for a short period of time before I got sick, because I was able to transition to administrative role.

Linda Barry, MD: 29:40

And I think that is something that an academic medicine affords you that you wouldn't necessarily find in private practice. But I also realized that, when you're really sick, you don't have the bandwidth to actually deal with your loans, your taxes, you know, FMLA renewals and all of those things. And you have a benefits rep you have an ADA rep. They really need to be there to advocate as much for you as they do to make sure they don't violate any laws and everyone should be factoring the needs of disabled and be prepared if this happens to you to reassess your trajectory. But you need to learn how to market yourself because you have other skillsets that can help your organization. So what other qualities do you bring to the table?

Linda Barry, MD: 30:25

I also wanna say, you know, I didn't plan for this. There was a financial hit, you know, taking FMLA means you are only get 12 weeks and you're unpaid leave. I was out for almost two years. So I wanna say to every medical student or resident listening, get supplemental insurance and, my colleagues, get supplemental insurance because no matter what you think they pay is not enough. And so I took a hit for my health, and I would say, also be on top of your portfolio and your benefits to make sure that they're being maximized really quickly.

Linda Barry, MD: 30:58

I wanna highlight the concept of intersectionality because it plays a role here. It was a term coined by Kimberlé Crenshaw. That is a lens to which you can see where power comes and collides, where it interlocks and intersects. It's not simply that there's a race problem here. The gender problem here, or class or LGBT problem here, and Andre Law put it best. There's no such thing as a single issue/struggle because we do not live single issue lives. And so this concept has been repurposed for medicine in the context that it's an interconnected nature of social categorization, such as race, class, and gender, Billy regarded as creating overlapping and independent systems of discrimination or disadvantage. But I also wanna say, it's an advantage, because if you factor these things, when you are making policy, you don't leave us out. So we add a perspective that is necessary, that is needed at the table. So I just want to highlight the hidden disability of mental illness. This is SO425, bipolar schizophrenic depression, schizophrenia, and

depression. He was walking down the street, didn't respond to the police commands. He was shot. That's his case, Lamont Scott.

Linda Barry, MD: 32:05

He had traumatic brain injury. He had just taken his medication. He was pulled over for a traffic stop, got out of the car. People in the neighborhood said, don't mess with him. He had a traumatic brain injury. He's just, he's not a danger, had no gun. And he was shot. This is Deborah Danner, 66 schizophrenia. The police were called because she was screaming in her apartment. They came in, she swung a bat. She was shot in her room. This is Sandra Bland, 28. She had epilepsy and depression. She was found hung in her cell after she was pulled over and arrested for a traffic violation. This is Freddy Gray. He was 25. He had a developmental disability related to childhood exposure to lead paint. He was in the back of a van who was arrested for walking the wrong way and looking suspicious. And his neck was broken in the back of the van and he was paralyzed and he later died. This is Tanisha Anderson. She was 37, bipolar. She was having a psychotic break. They called 911. They sat on her. She lost consciousness and she later died.

Linda Barry, MD: 33:18

And you know George Floyd. George Floyd was not a healthy man. He had heart disease, hypertension, COVID, and a history of drug addiction. Yet that was weaponized in court. In order to say that that's the reason why he died under that man's neck. I say this all to you because these are all have the commonality of having mental illness and being black. And all those encounters showed to me that we do not exude empathy and grace to these people. When they're in crisis, they're seen as if they are a threat rather than a medical emergency and police are not equipped to deal with this.

Linda Barry, MD: 33:54

The system is not equipped to deal with this. And so I say that if you're intersectional and you have these barriers, they can enhance challenges and the barriers that ones face in the context of disability. But what is also more disturbing is I wanted to bring you data. I wanted to bring you facts. I wanted to say, well, this is what is going on. I could not find research articles written on the intersectionality of all of your identities that make up who you are, be you woman or race and disability. We already have a shortage of information on disability as a standalone issue. So there's no clear idea of the scope of this problem and the challenges that people face, but we know that they're disproportionally worsened. If you are black and disabled and you're living in poverty, or if you're a woman and you're trying to rise up the ladder and it sudden become disabled.

Linda Barry, MD: 34:45

And, you know, we could also include LGBTQ people as well. So I say this, because this quote really struck me, that "You are not obligated to do everything a healthy person does. You're not obligated to be an inspiration. You are not obligated to hide your illness in order to make other people comfortable. You're allowed to know your limits." And I would say others should be made aware of them as well. You're allowed to have bad days. You're allowed to stay in bed. If you can't get up to do anything, but go to the bathroom. It's not your fault. If other people leave you because of your illness, it is not your fault that you are sick. You do not have to apologize for something that is out of your control. And I read that and it brought a sense of clarity because as accomplished as I am, I've got promoted to associate professor and all these titles. I did the opposite, and I've always tried to conform to the norms because I never wanted to look like I was an inconvenience or disabled. I mean that my disability was a drawback rather than I bring something to the table. Let's work on trying to find a mutually acceptable solution to a meeting or situation. Right?

Linda Barry, MD: 36:05

The other things that I wanted to say is that there are resources. And so one of the things that we really need to do is enhance our education on this topic from medical students, to graduate students who are residents in public health, to our faculty and staff and the C -Suite. So this is came out from the NAC injunction with UCSF, and it puts it in the context of a clinical setting, as much as education that a disability service provider should be identified, a staff member who knows about accommodation supports and that there should be a constant assessment of how their services are received by your disabled patients.

Linda Barry, MD: 36:46

And also, I would say your disabled staff, you need to have a clear process to accommodate people and what that process means and know what is a chain and who to ask and the policies that are that identify and help those who are disabled to be clearly posted and publicized. And so and we need to also make it okay to say, "I'm having a bad day," and that does not diminish the person by saying so, and accommodating them. Last thing I want to just highlight is that, you know, there are these concepts of competency, which I always think is a miunderstood term, because no one is really, truly competent in anything there is. It takes 10,000 hours, as Malcolm Gladwell has said, to really master something. But to at least learn the premise of what it means to provide disability-competent care. It's a model of care designed to treat the whole person beyond a diagnosis condition. And it provides training in healthcare to providers in disability competencies. So there's a selfassessment for your organization and then there's a selfassessment too, for the individual and you can customize customize it for your training needs.

Linda Barry, MD: 37:56

And so there's also the core companies in the educational context and they define at least six core competencies related disabilities as listed here. So this is a good guide for you to look at and see if you can embed it in your curriculum and or identify other readings and opportunities that will expound on these competencies. So you become more proficient taking care of these people. So I wanted to close by saying that what we really need is more education because how can we expect to accommodate our colleagues who maybe get become disabled if we can't even do that for our patients? So I think everyone would benefit from having more formal education in this space. But I also think the C-suite needs to have some education in the disability competencies and the impact it has on our patients and employees to ensure that all aspects of the organization complies truly with ADA.

Linda Barry, MD: 38:49

So all policies should be reviewed from the lens of disabled person, invite them to the table, invested time and effort, but we also need more disabled people in positions of power. We need them at the table. We need more physicians. We need more students in every sector because, I think, we benefit when they are present because they will point this out rather than you learn after the fact that you did not see nor hear us or value us. I felt that I was not worth much if I couldn't operate, but I am still a surgeon at heart. And I now have a group where, every year, I have 85 women medical students want to go into surgery. My love of surgery does not go away. I sit in leadership positions in surgery. So there's value that we have. It may not always be obvious. And when you are the person going through the disability, it's hard for you to recognize that because you're drowning in your own situation and acuteness of the moment, but don't throw away your colleagues who become disabled. Find an opportunity to leverage the other great qualities they bring to the table, and you need to create a space so that they could speak up and be disabled.

Linda Barry, MD: 39:57

And whether they become disabled or they arrived in that that way. So I guess, love quote quotes. So I say based on all of this, there's nothing more debilitating about disability than the way people treat you over it. But most importantly, if you have a disability, don't let people dis your ability with that. I like to open the door for questions and I thank you for the opportunity of sharing my story.

Ana Núñez, MD, ...: 40:26

Thank you very much. So we do we have, we have sort of some questions we'll start off. One of the questions that we have, is there a solution for the fire drill or fires in terms of fire safety? And the report says, usually I can just accept that I might die on a day. I can't go downstairs. I just can't accept that. So what's the solution? How do we, how do we address that?

Linda Barry, MD: 40:57

Okay. We are not accepting the defeat disposition after this talk, you know, and there is a solution, you know, they say they're not to use elevators. You know why? Well, yes, they may not work because they're all shut down, or they're the route by which the fire people can, but they can isolate an elevator for the disabled to come. The other option which I think is less feasible because the whole thing that really bothers me is that sometimes you find yourself in a position where like you have to give up your dignity. So one solution that was posed to me is that you get a wheelchair and someone will carry you down. Well, who's the designated person, Superman, Superwoman to carry a wheelchair down the stairs. But I think I don't have the policy, an idea, you know, in all honesty, it's not my job. It is the Fireman's job. It is the hospital's job to find that policy, but there are ways to do this. We should not accept that. We're just going, you know, go up in flames literally. So hang in there.

Ana Núñez, MD, ...: 42:01

And again, sort of the comment and this has to do with our sort of lack of expertise, quite frankly, in terms of Zoom that closed captioning wasn't turned on for this, we will figure that out. And from here on all our Dean's special seminar, will have that. So thank you for noticing that the next is "Who shares, I just wanna applaud your bravery in sharing so much personal detail that you shouldn't have had to. I can tell you, I will personally continue to work, to improve my care of patients. Thank you."

Linda Barry, MD:

42:33

Thank you.

Ana Núñez, MD, ...: 42:34

Alright. And follows with also, "I'd appreciate a little training on filling out disability forms for patients I've come across some specific situations that I couldn't figure out how to fill it out. Is there, is there some intentional osification and filling out forms just to make it challenging? Or is it, or is there some special secret in terms of how to do this in a way that sort of value added that gets it done?"

Linda Barry, MD: 42:59

There is not, but I think there's some general gestalts that are kind of out there. So there are a lot of disability rights centers around the country where you can reach out, and they can give

you guidance as you kind of work through that kind of paperwork.

Ana Núñez, MD, ...: 43:17

Okay. And from Barbara Porwitt, "I have a young adult child who's been approved for SS disability support because their executive functioning is so poor. They could not keep up at minimum wage menial job, yet they have had such high intelligence and exceptional principles that they should be able to do something to contribute to the world. What place will there be for someone like my kid?"

Linda Barry, MD: 43:42

Wow. your kid has value and has something to contribute. And I think one of the things that COVID has shown us is that we can adapt to working at home. We can adapt to working in remote situations. So there's a lot of opportunities to like learn new things online you know, programming telemarketing starting your own business. You know, I think sometimes you just gotta take this opportunity and look around and see what really fits because we have shown through COVID that you can accommodate people at home. We can be productive at home. You know, and so I think that's an opportunity like Corsera. When I was lying in bed, I was like, "So what else am I gonna do? Maybe I could be like the female Sanja Gupta, because I was like, there's not that many women." So I was like, you know, I had to really think what my life would be. There are so many opportunities depending on what their person's interest is.

Ana Núñez, MD, ...: 44:42

Thanks. Alright. Martin Coyle says, "It's odd that if we see a colleague clutch, his or her chest and collapse, we immediately act if however we become injured, involved in SSE, sued, we suffer in silence. Same occurred to me after injury in my career toppled. Right. So that Martin, right?

Linda Barry, MD: 45:02

Yes. I totally, I can't tell you like we, I felt like my colleagues showed more empathy to strangers that came in as patients than they did to me and I try to give them grace. And I think that they're afraid. I actually lost some friends because I think I was young. I was just starting my career when this all happened and they see themselves in me until I learned, you know, what true friendship is, the true support is. It's unfortunate because we don't, we're not comfortable with it, but you know, people need to recognize that, because you're disabled, doesn't mean you have something, you don't have something to, you know, contribute. Right. And I think that's what we're talking about, creating space and to value each other in that regard.

Ana Núñez,	MD:	45:51
Ana Nunez,	IVID,:	45:5.

Well, and you talk about to that grace and compassion in terms of, you know, it's having sort of some limitation, isn't an infectious disease, you know, so you're not going to catch something from it. You know, it's about sort of how do we help each other? Here's a comment from an anonymous attendee, not a question. "Thank you for sharing your experience. This is a great presentation. My husband is a 30 plus year paraplegic. So much of what you presented at home. I screenshotted your next steps slide. I love the review from the lens of a disabled person."

Ana Núñez, MD, ...: 46:22

Another attendee said, "I'm very sorry to hear about all the discrimination you faced when, after you were disabled. Thank you for sharing your story. You have so much to offer, stay strong."

Ana Núñez, MD, ...: 46:33

Here's a, a comment. "How would your experience been different if lupus had hit when you were still a medical student? Can you, can you sort of conjecture about that?"

Linda Barry, MD: 46:48

Oh my God. I can't imagine. I cannot imagine. I would be, I can't sugarcoat it. I would be devastated. And I, in all honesty, I don't think I could have become a surgeon. You know, I think your, your career pathway becomes constrained because the physicality of surgery just, I mean I did 20 hour operations, right? Whipples that no one else wanted to do. And so I think you have to, you know, what your career aspirations may need to be redefined. I think one of the issues I have with medical school is that again, we don't even teach it to take care of those patients. How do we accommodate? So like, you know, I talked to my student affairs, I was like we accommodate deaf students and hearings and they may come up with a customized plan for you.

Linda Barry, MD: 47:40

But let me tell you if that student is in a fire and they can't walk or they're paraplegic, you know, blind person, do we have a plan for that person? And so I think, you know, this awareness in you as a student, if you are asking, this is to make, push our student affairs, push our leadership, to have a plan, ask them if they have a plan, because now they could be proactive. I think they are downfalls. You know, you may lose time in school. I've had students who had, you know, mental health issues and I cannot ignore that. I don't consider it necessarily, you know, a disability, but it's an illness that we need to accommodate. And one person said, "I'm bipolar. I can't become a surgeon." I said, "I'm sorry, who said that? There's medication, you finish med school." And so I think we have to sometimes re-envision who that person is in a respective field, but I'll be honest. It would be

really hard for me personally, because being I've always wanted to be a surgeon since I was 13. And I can't imagine being on the other side of the curtain, you know, and everything that I think, you know, your training is still physically and mentally demanding. So I think it depends on what kind of disability you had.

Ana Núñez, MD, ...: 48:56

Yeah. So here's a question from Jill Foster, takes you back a little bit, even to that maybe that 13 year old self. "Would you tell your teen self to still become a doctor having sort of.."

Linda Barry, MD: 49:06

Oh, heck yeah. oh, heck yeah. Because let me tell you, I think in a weird way now that I'm not practicing, I have the opportunity to reach more people as a black woman surgeon than I ever had before. I've been invited to do and participate in things that I've never had. And I have that historical experience. And second of all, I'm a ride or die surgeon. Can't imagine doing anything else.

Ana Núñez, MD, ...: 49:30

Okay. Here's a comment from one of our attendees. "I struggle with when and how to disclose my disabilities in a professional setting, mental health-related. So not visible, I'm very open with close colleagues, but less so on a larger level. So when I have a mental health flare, I use other excuses for not able being able to fully engage in certain work activities. I haven't figured out the solution to this yet that feels right for me." Thoughts, comments?

Linda Barry, MD: 49:59

I honestly will tell you on it. It's still not a safe space. We still judge people with mental health harshly. It's a shame that you have to come up with excuses like this morning. I'm blessed that I could be with you, but I had a meeting at 7:00, okay. Mornings are bad. I was like, I can't do the camera. I didn't explain to them that I could barely walk this morning. I just, I'm tired of explaining myself. But I just said, I'm not gonna be on camera. I'm gonna be late. And I may know, all apologies because they know. And so, you know, sometimes people don't need to know all your business. And if you can afford to take advantage of the time, the most important time is take care of yourself in whatever way you do and get the support you need, particularly if it's not your workplace.

Ana Núñez, MD, ...: <u>50:48</u>

Another comment, "Thank you for raising awareness, mental illness and improper crisis moment interventions as a parent to a child with invisible disabilities. It's a very real threat and daily fear." Another, "Thank you so much for your courageous talk. I've been living with my invisible health disability for a long while out of fear others limiting me by imposing their plans for my success. To me, for example, if you're in that much pain, you

should consider stop working. Can you speak to the role of importance of supervisors or systems and supporting accommodations, especially instead of encouraging people to stop working?"

Linda Barry, MD: 51:23

This is what I was saying, right? You know, when I became disabled, I'm fortunate. I knew a lot of titans in my field and I was like, "Well, what can I do if I can't operate? My brain still works." And none of them had a response and that's why I had to learn, well, what are my strengths? I had to reinvent myself. I had gone through too much for it to let it go. I think, you know, you gotta be proactive. What do you wanna do? What are your interests? What is your skillset come to the table with? These are the things I can do. And these are my limitations. How can we work together? Because they can't see, sometimes people can't see past our disability, right? And so here I can. I started as a surgeon, and now I'm an interim director of the Health Disparity Institute.

Linda Barry, MD: <u>52:07</u>

How did that happen? I'm on the board of physicians and advisor to the medical marijuana plan program. How did that happen? Right. And the funny thing is people saw things in me. I didn't see in myself, I've given talks, I've promoted. You know, I felt like my journey as a woman of color through medicine has shown me structural racism in medicine because it didn't matter that I was a doctor. It didn't matter. I had a great plan. I experienced it during this journey. And so I've been very vocal. I said, "If God allows me to walk tomorrow, I'm gonna leverage that to advocate for patients who don't know the system and because of that more opportunities have come up." And so, and then I turn around and I take those opportunities and I show them to the people at UConn. And that is why I sit before you with all those titles today. But it's, I think you have to be your own PR guy at this stage because people who don't live it don't understand it. You can't often can't see past it sometimes

Ana Núñez, MD, ...: 53:09

Just to share with you Amanda Sharp as we're fortunate to have her as sort of a resource here. "Dr. Barry, thank you for your presentation today. Access and inclusion for students with disabilities seeking to become physical therapists is her area of research and expertise. All the challenge you mentioned are consistent with those we face in physical therapy. I believe research and education are essential steps forward." And so appreciation from Amanda Sharp.

Linda Barry, MD: 53:35 Thank you.

Ana Núñez, MD, ...: 53:37

We're about four minutes left in terms of this amazing sort of presentation. I wanna thank you. This is just fantastic. So much that we need to sort of do I also wanna resonate that, you know, the "aha" moment from sort of COVID is that we learned that people can contribute remote hybrid and everywhere in between. So that flexibility that used to be, it was only one way now has sort of expanded. And as we figure out how we design our teams and how people contribute pieces the physical necessity of space plays a role. Sometimes you need it. Sometimes you don't need it in terms of sort of figuring out how do we have teams. But the other piece that you mentioned, I think, which is really important, which is about courageous leaders, asking those questions you know, whether it is if there's groups of people, you know, how do we be sort of like the military at leave, no person behind whenever there's a problem?

Ana Núñez, MD, ...: 54:35

How do we treat each other in sort of ways that they wanna be treated rather than sort of a patronizing way or a forget kind of way in terms of sort of whenever there's sort a disaster and people have to evacuate a building? We're figuring out sort of safety plans that have that flexibility so there's lots of things we have to do in terms of work. But you know, I think that your point in terms of raising that profile, asking people in terms of sort of raising their awareness and doing more education certainly is needed. Because I think that people sort of lively go by and they just see what they see and they don't notice other stuff. So thank you for your comments. Yes.

Linda Barry, MD: 55:20

I just wanna make two quick points that a lot of disability policy and practices assume the one size fits all. And so we need to always factor in the spectrum because, you know, I go and they're like, "Oh, there's a ramp." And I'm like, "Do you know much more walking? I have to do to walk up a ramp than if I just walked up and struggled three stairs, like, you know, so that's for wheelchairs." And also COVID is a canary in a coal mine for a variety of things. But with long COVID, we do not know the impact in how it will expand a disabled population, right, from children to adults. And so if we don't get ready and we don't increase our education awareness in the space, we will lose so many really productive people in our society to reaching their full potential. So thank you so much.

Ana Núñez, MD, ...: <u>56:08</u>

Thank you. Thank you very much, everybody have a great day. Enjoy the sunshine. Dr. Barry, be well, I look forward to seeing you soon.

Linda Barry, MD: <u>56:16</u> Alright.

Ana Núñez, MD, ...: 56:17 Take care, everybody.

Linda Barry, MD: <u>56:18</u> Bye.