

## Disability History Association Podcast

Interview with Lisa Iezzoni

November 2022

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**Kelsey Henry:** Hello, and welcome to another episode of the Disability History Association, Podcast. I'm Kelsey Henry

**Caroline Lieffers:** And I'm Caroline Lieffers

**Kelsey:** And today it's our great pleasure to be in conversation with Lisa I. Iezzoni, a professor of medicine at Harvard Medical School. She is based at the Health Policy Research Center—Mongan Institute at Massachusetts General Hospital, where she was a director from 2009 to 2018. Dr. Iezzoni, thank you very much for joining us today.

**Dr. Lisa I. Iezzoni:** It's a pleasure to be with you two. Thank you.

**Kelsey:** So, to start. Can you tell us a little bit more about how you ended up where you are now: an MD, a professor, a health policy expert, so many different hats with expertise in disability issues. How did you get here?

**Lisa:** Sure, Well given my age I'm like a history lesson on its own. So, I was a medical anthropology major at Duke, I had no interest in going to medical school, but this was back in the mid 1970s, and health policy at the time was actually really exciting. People like Ted Kennedy were talking about universal health insurance, and there was just a sense that we needed to get costs under control, And Duke had an amazing health policy program. And so I did that, and based on my experiences there, I decided to go to Harvard School of Public Health to get a Master's of Science in health policy.

And so I moved to Boston in 1976, and that is when I started to have these little kind of eerie sensations in my body, which, I was twenty two. I was young, I was invincible, they would come, they would go. I wouldn't pay attention to them. I was really just so excited about my master's program, but I also at that time met some incredible doctors who said "Lisa, you know, why don't you consider medical school?" Well, one reason is I hadn't done any of the pre-med requirements, you know, for my science at Duke I did rocks for jocks, and I'd done biology because I thought that was fun, and I tortured my, you know, pre-med classmates there. But I finally kind of made a little yellow pad of paper with a line down the middle, and the pros and cons of going to medical school, and I finally kind of decided that the pros really exceeded the cons. And so I went back, did special, you know, student pre-med kind of thing, and got into Harvard Medical School, where I started in September of 1980. So, quite a few years ago, but notably, ten years before the Americans with Disabilities Act was passed.

And once I got to medical school, things started happening with me. I started bumping into trees while I would walk down the streets, or bump into cars, and finally, the sensations that I was having just couldn't be ignored anymore. And so I was able to get an appointment with a neurologist during my final exam week first semester at Harvard Medical School, and the neurologist, who is still a close personal friend, was very calm and very kind and said look, Lisa, given what you've told us, you sound like you have a classic history of multiple sclerosis, but come back in January, and we'll do some testing. He didn't tell me how awful they were going to be, but MRI scanners were not kind of invented for

patients at that time. So I came back in January, and had a series of terrible tests that basically ruled out things like a brain tumor, and so I was diagnosed with MS at the beginning of my second semester at medical school.

This was a period of time when you never talked about private things like your health. I mean, this was pre-Oprah Winfrey, it was pre Facebook, it was pre, before even women would talk about having things like breast cancer. That was viewed as kind of embarrassing. And so I didn't talk about it. The medical school made some accommodations for me, in terms of, like, not making you stay up 72 consecutive hours like happened back in the early 1980s. But it was pretty tough, being there at medical school at the time. People were not especially nice to me and in May of 1983, when I was thinking of applying for an internship or residency, I went to one of the dinners that Harvard Medical School arranged for their students. You know, cheese cubes and sherry, and then you'd have dinner with professors, or, kind, major people at the medical school. And I happened to sit next to a very tall man who was the head of one of the major academic medical centers affiliated with Harvard Medical School. And I described my situation, and I said, you know, could I maybe do a half-time residency at your medical school? Or can there be some accommodations for me? And he said, after pausing, "you know, there are too many doctors in the country right now for us to think about training a quote 'handicap physician,' if that means that some people get left by the wayside so be it."

And so I wasn't surprised that when I went to meet with my internship advisor in July of 1983, he said that the powers that be at Harvard Medical School had decided not to write a letter of recommendation for me to apply to an internship or residency that would allow me to be board certified. So I needed to find a job. And I did, through the help of the Dean at the Harvard School of Public Health, who kindly picked up the phone and called a friend, and I became a research assistant at BU in July of 1984, right after graduating from Harvard Medical School.

But, you know know, I had my training in health policy, and it was a great time to do health policy. In the early 1980s, there were a lot of policy changes in Medicare, and I just doggedly started doing health policy research. I had been told, you know, or taught by my medical school experiences never to talk about the fact that I had a disability. And so when I started using a wheelchair in 1988, I didn't talk about it. And I just published paper after paper after paper. I was a classic case of over compensation, and so in 1990 Harvard Medical School recruited me back. I became an assistant professor there and rose to the rank of full professor in 1998. And I realized at that point, you know, I was actually, I mean, this sounds arrogant, but this is kind of the truth, is that I was the first woman in the Department of Medicine to be promoted to professor, at the hospital where I was, which was Beth Israel Deaconess Medical Center. And so I figured it would be kind of hard for them to fire me at this point, and it also occurred to me that not talking about my disability was just perpetuating the stigmatization. You know, maybe now I had arrived enough that I could talk publicly about it.

And so in the late 1990s, I decided what would be meaningful for me to do research on, and for reasons that I won't go into, I, you know, decided this was a really good focus. I dusted off my medical anthropology credentials, this time kind of as a participant observer, and my first research project was actually visiting people with progressive mobility disability to learn about their lived experiences in their homes, and what the health care system was like for them. And I became kind of an expert in disability disparities, which I have been researching now for nearly twenty-five years. And so that's, again, I'm kind of older, so that's why it took so long for me to describe my history, but that is kind of, you know, Kelsey, an answer to your question about how I landed where I am now.

**Kelsey:** Thank you so much for sharing what amounts to is such a sprawling life history with us. You've travelled so many places professionally and personally, and I know that the both of us are so grateful that you ended up in health policy, and you ended up writing the books that you've written. But I do want to pause for a moment on the part about the story that you were telling about the ways that you were directed away from a career as a doctor in medicine. Because it made me think about just a little bit of backstory that relates to the way that I entered into your work, Lisa. I used to be a care worker. Yeah, I was a personal attendant for a woman with cerebral palsy in my late teens, and then I worked as a doula for several years, so I am absolutely fascinated by the history that you've devoted so much time to telling, and it's such an important history. But one thing that I noticed, that relates a little bit to the story you were telling about the reasons why you were excluded from a career in medicine was that there was a lot of exclusion of doulas with disabilities when I was working in the field because of the long hours, and how it physically gruelling and demanding it was. And I remember thinking what a profound shame, that we are not thinking more comprehensively about how to make clinical positions, or care positions that have to do with the care and keeping of human bodies, not making those positions more accessible to people with vast and varied experiences with embodiment, because wouldn't they be incredible care providers if we supported them in our systems, and it's something that I reflected a lot about as a care worker, and that was just coming up for me when you were talking.

**Lisa:** Well, Kelsey, first of all, I had no idea that you were a care worker when I knew that you were reading my book. What a profound thing for me to be able to learn from you about how you kind of reacted to the stories that I told. You know it is still the truth that because of technical standards, requirements for getting into medical schools, it's very hard. Especially in American medical schools. It's a little bit different overseas for people with disabilities to join the medical profession. Let me just say that, you know, the era that I'm talking about was ten years before the Americans with Disabilities Act. You know, Section 504 on the Rehabilitation Act of 1973 was in effect, but nobody really talked about it. I don't remember it being mentioned at all at the time, and let me say that I didn't take this entirely sitting down. Before, you know, when I was told by my advisor that they were not going to write a letter for me, there were two things that I'll mention to you. The first is that they said that what they were willing to do was pass the hat to other departments of medicine, to see whether they could come up with donations for a salary that they could support a position that would not be board eligible for me. They had done that, and they came up with a salary of \$3000. And at the time, you know, a starting intern's salary was \$26,000. I couldn't live on \$3000, and so I'm told that this is officially kind of constructive dismissal, or that there's a specific legal term for this that they didn't outright fire me, but they basically made it so impossible for me to continue that I kind of slunk away.

But again, I didn't make a final decision until I spoke to a man named Charlie McCabe. And the story that I'm going to tell you is a story that I tell you with his permission. And he was about to be the chief resident in surgery at Massachusetts General Hospital, which in the 1980s was considered akin to becoming God. You know, if you rise to the position of chief resident in surgery, you are God. But he was diagnosed with multiple sclerosis and became quite impaired by it, and so he himself was unable to continue as a chief resident in surgery. And I had run across him when I had done clerkships at the MGH and had seen him rolling around the emergency department in his scooter. And so I thought, okay, before I say absolutely not, I'm going to slink away, let me go talk to Dr. McCabe and see if he can give me some advice. And so I made an appointment with him, and the reason why I say that I got his permission to tell this story, is that what I'm about to say is going to be more about him than it is about me, and about what his experiences were like. And he,

sadly, I had no idea he was as ill as he was, died about three weeks after I got his permission. But I went to him, and I said, you know, Dr. McCabe, here's my story, what would you advise me to do? And he said to me, if there is anything else you could do, you should do it because they will never, ever believe with your disability that you can be a competent physician. So, you know, here is a man who is about to be God, who had the experience, where obviously, he felt that nobody ever respected his ability to be competent. He was a beloved educator, you know, education awards, teaching awards were named after him. But that's when I said, okay, you know, I, this is just not going to happen for me.

**Kelsey:** I, there's so much history, history enclosed in your life, and I know you were making kind of a joke of that, that like you, you are history, that you embody so much history because of--

**Lisa:** Yeah. I'm officially a senior citizen, but I hate that phrase, so [laughs]. It is important for those of us who were there at the time to really talk about it because we don't want this history to be lost.

**Kelsey:** Yeah.

**Lisa:** So there are wonderful people like Judy Heumann who write books about, you know, her own life and what that was like, you know, that we learn so much about.

**Kelsey:** I know that our listeners will really enjoy hearing about your life history alongside our conversation of this phenomenal book, so this will be an extra treat for them to listen to this podcast about your book, and also get to learn a little bit, like, from oral history about disability and the medical profession too. So that's really a gift.

**Lisa:** And you know, again, I felt like it was important for me to start speaking publicly, because I didn't want to perpetuate the stigmatization. But, you know, the stigmatizations still persists in medical places, and I don't know whether you experience that yourself, now, where you are in your training in your own life. But it's still there. It's better, but it isn't yet erased.

**Kelsey:** Well, I'd love to transition and hear a little bit more about your book. We've recently read your latest *Making Their Days Happen: Paid Personal Assistance Services Supporting People with Disability Living in Their Homes and Communities*, which was published by Temple University Press earlier this year. Big congratulations, it's such an impressive book. Can you tell us a little bit more about how you became interested in this topic and how that interest turned into this book?

**Lisa:** OK, thank you for that question, Kelsey, and let me just preface this by saying it might be kind of a little dangerous to be one of my friends, because I tend to get research ideas from watching what is happening to my friends, or my colleagues in the disability community more broadly. You know, so this really comes from my best friend, whose name is Michael, who I met back in 2009, when my scooter died, and that is kind of mentioned in the dedication to the book. I dedicated the book to both Michael and Nelita, who is his longest serving personal care assistant.

Michael lives in Princeton Junction, New Jersey. He was fifty-five when we met, and had had primary progressive MS since age forty-two, and had to retire at age fifty because of his severe and progressive disability. At the time we met, Michael was completely quadriplegic, with only a tiny bit of right hand function. He had divorced a while before we

met and moved into his own home alone, but he had done lots of research on how to make this very modest but accessible home, as accessible to him as possible, and he spent most of his retirement savings on adapting the new home, for example, making structural changes within it when possible, and assistive technologies like ceiling mounted lift devices. But on his fixed income, he only had enough money for three hours of personal care assistant supports per day, from 6:00 to 7:30 every morning, and from 9:30 to 11:00 at night, which he got from one of those kind of franchise personal assistance services agencies, that have sprung up nationwide and have kind of warm and fuzzy names. So during the day, he would sometimes actually go without food or water from 7:30 in the morning to 9:30 at night.

And I live outside of Boston, and so I witnessed this from 250 miles away, and I wondered how I could help. I thought, you know, here I'm supposedly this health policy person, I should know what to do to help Michael. But once I started kind of researching policies around PAS, personal assistance services, I quickly found that there were few options for someone like Michael, who at the time had only Medicare coverage and did not have family or friends to serve as the unpaid or informal care providers that provide about 75% of the PAS in in our country. So of course, I said okay, I need to research this and understand it better. So I went out and tried to get a grant to study the issue, and I was fortunate that the Gordon and Betty Moore foundation generously funded me to conduct what they wanted was a policy synthesis concerning paid PAS, but I told them that if I did this I really wouldn't understand the experiences of receiving and providing PAS, and so they permitted me to use some of the resources to conduct interviews which have led to this book.

**Caroline:** Thank you so much for that origin story, and we're going to have more questions about Michael and the interview process in just a minute. But before we move into that, I was hoping we could talk just a little bit about terminology, kind of get that sorted out before we move much further. You use the term, we just heard you say it, right, personal assistance services, or personal assistants in your book. But of course I'm sure our audience members, and you know myself also, have used terms like home care workers, or carers, or personal care attendants, and many other permutations. So how did you settle on your preferred choice of terminology, and does this term that you use, personal assistants, have any precise legal definitions or boundaries?

**Lisa:** Okay, that's a great question. And at the end of my introduction I actually have a section called note on language because you're absolutely right. The language is really really essential, not just for describing what people do, but also on the kind of respect, and where they are in terms of the kind of stigmatization that is perpetuated around both disability and this type of work. So terminology in this area differs a lot regionally, both within the United States and around the world. And so I debated about what term to use systematically throughout this book, and so I decided, based on all these interviews, I would let one of the interviewees tell me. And so, I gave everybody except Michael and Nelita, who gave me permission to use their real names, I gave them pseudonyms, and so I'm going to talk about what a very compelling interviewee, who I call Natalie told me. And Natalie's is in her early fifties. She has spinal muscular atrophy, and she has eight PAs who provide in-home ADL, or activities of daily living supports each week. And so what Natalie said to me was quote, "a lot of people refer to these workers as a personal care assistant. I'm not fond of the idea that they take care of me. I like the idea that they assist me in taking care of myself. So I tend to use personal assistant." So I thought, okay Natalie, you told me. That's what I'm going to call it. And so in certain places in the book though, I use local terminology, like where Michael lives, these personal care assistants or PAS workers are called Home Health Aides or HHAs. And so there is no universal terminology. Legal definitions tend to happen once people need certain certificates, or licenses, or specific

degrees to provide these services. And there are people who have thought about career advancement for personal assistants, but that is not yet true in the United States for PAs. That may be different in other parts of the world, but that kind of certification, certificates, or training is not yet something that's universally adopted in the United States.

**Caroline:** Thank you so much for that answer. That's really clarifying, especially for those of us who don't live in the US and may not be as familiar with the landscape. So thank you. And then there's kind of an associated question which I'm sure our audience has already anticipated, and that is, what is the preferred term that you landed on for the clients or consumers of these services? Because, I suppose some people might use the word patients, although that's not a preferred option, supervisors or perhaps employers could be an option in some cases, so talk to us a little bit about your process of working through that terminology.

**Lisa:** Yeah, that's another great question. And so I settled on the word consumer, But it also took thought, and as you say, Caroline, patients is a non-starter for me, because that's so medicalized and people aren't patients when they're sitting in their homes and just living their daily lives or going out in the community. So certainly some of the agencies that provide PAS call their clients patients, but that was not what I was going to do. So it may not be a great word but I settled on consumers because it has been used by the government and policymakers in the context of consumer self-directed personal assistance services. So consumer self-directed personal assistance services actually started in the 1970s in my neck of the woods, Boston Center for Independent Living was the second CIL that was created in the United States after the one in Berkeley. BCIL started in 1974, and it was the first instance where BCIL consumers worked with Massachusetts Medicaid to start consumer directed personal assistance services. And so that's why I decided on the word consumer for this. Although, as you say, for consumer-directed, self-directed services, often the word employer or supervisor might be used.

**Kelsey:** Thanks so much for that point of clarification, Lisa. We'd love to get into the composition of this book, because it's so, so vast and doing so many things really well. You have history, you have in-depth personal stories, you are writing about policy, you document, day-to-day issues that personal assistants and people with disabilities experience in relation to each other. But one of the things that we found most impressive and deeply moving was that you brought us into contact with so many stories of people who are involved in these care networks. In some cases it's just a brief glimpse, like the account of one personal assistant who was concerned about working in a home with bed bugs, but sometimes it's much more in-depth, looking at someone's life, like the stories of your friend Michael, like Fred's story, people who use personal assistance services and have a wealth of knowledge and experience, and so many thoughts to share. Was it really important for you to center these people and their perspectives in your book? And how did you decide on taking that approach?

**Lisa:** Absolutely Kelsey, it was foundational for me. There's just an authenticity that comes with the actual voice of people and their stories. And you get those little "aha" moments like the bed bug story. I mean, you're probably going to remember that because it's just like oh, my gosh! I had never thought about that but now I think about that. And for my health care disparities work with people with disabilities, I've done probably more than three hundred interviews, I've done projects on cancer care, on primary care, on pregnancy care, and I always try to publish qualitative research articles where the voice of the people who I interview is the primary source of data that I use in those publications. And so this is just how I've chosen to kind of write about this ever since my book about progressive walking problems that came out in 2003. It's just the way that I just feel comfortable

talking about this, is giving the people who are generous enough to tell me their stories the voice to tell their own stories.

**Kelsey:** Well, this mode of writing is extremely compelling. There's an immediacy to it, and an urgency to it that's really provocative and I'm sure supplements policy work, like for a number of readers like policymakers, historians, care workers. I don't know if you've thought about, kind of, when you're imagining your audience like all of these different audiences. But I think that the way that you tell stories by bringing in the voices of personal assistants, and the consumers or clients that are making use of their services, and intercutting that with histories of policy making, makes your book so appealing to so many different readers. And I know that I was really impressed by that.

**Lisa:** The voices are just in my head, you know, Kelsey, and I just hear them.

**Kelsey:** I get that. I get that. I'm wondering then, how did you manage to gather all of these stories? And what did that gathering process look like? Did any ethical or privacy issues come up as you were interviewing people about, really, the intimate inner workings of their day-to-day life and their bodies? Can you talk us through that process a little bit?

**Lisa:** Yeah, you're right. I was pretty bold. I asked people about very intimate things in these interviews. Okay, so, I again have done these kind of interviews for probably twenty five years now, and I have found that people who I'm talking to, especially the people with disabilities are so willing to tell their stories, and so generous in telling their stories, because they often haven't been heard, and they want their voices heard, and they kind of view me as a way to get their voices heard. So of course I have to be realistic. So, the Gordon and Betty Moore Foundation, again, generously funded me, but I only had limited dollars that I had to conduct the interview component of the project, and so I was just aiming to do about twenty interviews. So I ended up doing twenty one consumer interviews and twenty personal assistant interviews from various spots around the country. I did most of the interviews by telephone. I did a few in the Boston area in person. I was able to find these people through my own network, and also working with collaborators on the project, notably PHI, which is an organization based in New York that advocates for direct care workers. They were really helpful in helping me find, especially, personal assistants.

And my project manager, Naomi Gallopyn, was wonderful. She assisted with the recruitment process and we indicated to the interviewees that the interviews would take up to two hours, but they could stop at any time, and typically the consumers wanted to talk. And those interviews did go on for about two hours. The PA interviews typically for only about an hour. This was a research project, and so we needed to get permission from our Institutional Review Board, which, you know, they required a review of my interview protocol. But before I turn on my digital recorder, I told people about protecting their privacy, that I would assign them a pseudonym, that I would not identify specific locations, and that I would change small details about them like the number of siblings they might have, or their specific career goals, and in thanks we provided a fifty-dollar gift card to them. Unfortunately, I'm like a lot of Americans. I speak one language. I speak English. So I could not do interviews in Spanish, which is a real issue because a lot of personal assistants are immigrants and not native English speakers, and so that is one regret.

**Caroline:** Well, since this is the Disability History Association podcast, I suppose we should ask you some questions that are more specifically about history, although I have so enjoyed our conversation so far. One of the key issues that your book brings up is how domestic and companionship services were exempted from federal labor regulations that govern most other works. So these are things like minimum wage or overtime protections.

How did this happen, and then what are the consequences for PAs and folks who use their services, their consumers?

**Lisa:** Well, the quick answer to your first question about how it happened is clear, and that is racism and sexism. So there's really a long history that goes back to the arrival of the first European settlers in the continent of North America, and then later, shortly later, the transportation of enslaved people that contributed to where we found ourselves in the early twentieth century that I described in the book but won't spend as much time on here as I do there. The bottom line was that PAS was always viewed as women's work, not requiring skill, and not necessarily requiring compensation. In households, for example, it was assumed that women would, you know, provide these services. It was just simply expected of them. So you know, if we zip forward to the 1930s and the Great Depression, the public face of the great depression was largely unemployed men. Nevertheless, poor women who had subsisted doing domestic labor also suffered widespread job losses. So the New Deal's Works Progress Administration or WPA have program policies that aimed to preserve traditional gender and racial roles. And the WPA, for example, supported just one worker per family, and typically that was the male breadwinner. However, for women they created something called the New Deal Visiting Housekeeper Program that offered women employment and provide a crucial income and support to free typically white women from the demands of housework and caring for sick household members. And during its existence the WPA supported about thirty eight thousand housekeeping jobs across forty-five States and the District of Columbia, providing the major source of work relief for Black women. Now, what was interesting is that southern employers complained that these housekeeping jobs paid more than textile and agricultural work, and therefore quote unquote caused labor shortages undermining the racial caste system.

There was also kind of this little issue that they require the people who are participating in this visiting housekeeper program to undergo syphilis testing. So the women who would be coming into the homes would be officially clear of this health scourge of syphilis, and thus protect the white household. So alongside the New Deal programs to actually provide jobs, President Franklin Roosevelt, FDR, sought also broad policy changes to increase their wages. Although the Supreme Court at the time had been really brutal about that. He found that after his 1936 landslide victory, he and his labor secretary, Frances Perkins, thought that they could negotiate some legislation that could actually survive constitutional challenges and get through the Supreme Court of the time. But even in that, they had to face staunch opposition from southern legislators who fought efforts to extend labor protections to domestic and agricultural workers. So Roosevelt's ultimate strategy linked labor protections to interstate commerce where the federal government has regulatory authority in the United States. So with these restrictions and the failure to cover domestic and agricultural workers, the 1938 Fair Labor Standards Act or FLSA covered just about twenty percent of workers nation-wide, including only fourteen percent of female workers and very few Black workers.

So the phrase domestic workers has changed and evolved over time. It's encompassed a heterogeneous group of occupations that generally include people like maids and housekeepers, cooks, babysitters, home health aides, personal care aides, companions, caretakers, handymen, gardeners, chauffeurs. But what happened in World War II was that there were these new industrial jobs that white women especially could partake in, and so they happily left domestic service for more regular hours, greater independence, and higher wages. And so by one 1970, only about five percent of women workers performed domestic jobs, and the vast majority of them were women of color. In the 1960s and early 1970s, the Civil Rights movement and women's rights movements kind of intersected around

protecting domestic labor, and by 1971 the household technicians of America, for example, included dozens of locally based organizations made up largely of poor Black women, some immersed in the Civil Rights movement, and they organized to protest conditions of domestic work in which employers had overwhelming power, abuse was common, and mistreatment generally took place behind closed doors. So in 1974, Congress decided to amend the Federal Labor Standards Act, the FLSA, increasing the minimum wage and expanding the categories of protected workers. Finally they included domestic workers, but there was one exception, and that was people providing so-called companionship services. I don't know how they came up with this, but the amendment, the amended law stated that minimum wage requirements did not apply to workers who "provide companionship services for individuals who, because of age or infirmity, are unable to care for themselves." And the law viewed personal assistants as companions. So in 1975, when writing regulations to implement the FLSA 1974 amendments, the Department of Labor policy makers interpreted companionship exemption broadly to include almost all workers who provided personal care and household services to older and disabled people, and the Department of Labor also extended these exemptions to include workers who were employed by third parties like home care agencies. So workers who had actually already been included in wage and work hour protections before the passage of the 1974 amendments. So these regulatory interpretations thus led to the exclusion of hundreds of thousands of domestic workers from basic wage and work hour protections. So the companionship exemption, though, catalyzed home for workers to organize and contest these regulations. And in the 1980s unions like the Service Employees International Union began recruiting home care workers, including many who were paid by Medicaid, reasoning that they would have a strong collective bargaining position. So in his next to last day in office in January of 2001, the Clinton Administration proposed rules to give home care workers wage and work hour protections. But the incoming George W. Bush Administration jettisoned this proposal, arguing it would be too costly.

**Caroline:** Okay, that is a very sobering and may I also say frustrating history. Thank you, of course, for explaining that. But, my goodness, I mean I'm sure our audience is yeah reckoning with a lot right now, just having heard about all of that. Thank you. Can you explain where Evelyn Coke comes in to the story? She has a really important role to play here, I know. And can you tell us about who she is and what her contribution is?

**Lisa:** Okay, thank you. Yes, Evelyn Coke was a personal assistant, a PAS worker who brought a lawsuit for wage and work hour protections that went to the US Supreme Court, where she resoundingly lost. But subsequent legal actions building upon her case finally led to FLSA protections for PAS workers. So, briefly, Evelyn Coke was born in Jamaica in 1934. She worked there providing home care. She moved to the United States in 1970, living in Florida and Maryland, and still doing the home care, before settling in New York City. And she worked long hours, and she was very frugal, but she didn't get overtime pay, but her home care earnings which she saved finally allowed her in 1973 to bring her children to the United States, and in 1980 to buy a wood frame house in Queens, on Long Island, where she lived until her death in 2009. Now in April of 2002, Evelyn Coke sued her former employer, Long Island Care at Home, arguing that it had not paid her the minimum wage and overtime pay required by New York State Law and the Federal Labor Standards Act. Coke's lawsuit questioned whether Congress had truly intended to exempt Home Care Agency workers, and whether the US Department of Labor had correctly interpreted the law in specifying the companionship exemption. After various lower court rulings, Cook's case rose to the US Supreme Court with oral arguments in April of 2007. In court, the Long Island Care Home Agency asserted that being required to pay overtime would impose "tremendous and unsustainable losses," and in a friend of the court brief, New York City

estimated that paying overtime to home care workers would increase its Medicaid costs by \$250 million annually, threatening that massive services cuts would follow.

On June 11, 2007, the US Supreme Court ruled unanimously against Coke, and addressing the narrow question, though, of whether the Department of Labor had absolute authority to issue the 1974 FLSA regulations exempting home care workers. And all nine justices found that the Department of Labor had that authority. However, the unanimous 2007 Supreme Court ruling against Coke galvanized home care workers once again to pressure Congress to enact labor protections for this essential workforce, and in August of 2007, the Service Employees International Union organized a home-care visit for, guess who, Presidential candidate Barack Obama, to show him firsthand what home care workers do. Obama spent from six o'clock in the morning till nine o'clock in the morning in Oakland, California shadowing a sixty-one year old home care worker, while she assisted an eighty-six-year-old man receiving round the clock home care. She instructed Obama in lifting, bathing, and dressing her client and helping with food preparations, and Obama was really really struck by this, and by his conversations with this worker, and he announced that he would end the FLSA home care worker exemption if he became President.

It took many more years and more court cases, a convoluted story that I won't go into now, for these changes to finally occur, but the concept of companionship services does remain, but its definition now has been considerably narrowed. So, given the nature of what they do, PAS workers now fall outside this narrowed definition of companionship services. So it wasn't until a 2016 US Supreme Court case that ruled that protecting PAS workers could take effect. So they now have FLSA protections. But what has happened, and what some of the PAS workers who I interviewed told me is that payers began capping the work weeks home care workers to thirty-five hours or less, thus preventing them from getting time and a half overtime pay and limiting their potential income. And these work hour restrictions have raised concerns about reducing personal assistance quality for consumers. So getting basic labor protection for these workers remains an unfinished business and really has not necessarily achieved what the goals, intended goals, were.

**Kelsey:** Wow, Lisa! Such a fascinating history, such a frustrating history! And you were able to cover so much ground in a relatively short amount of time, very clearly. I feel like I just learned so much. I couldn't help but think as someone who perseverates on language a lot, going back to what we were talking about earlier about different associations, or like connotations that the folks that you interviewed had with the language of "care" or "attendant." The complexities that come along with terminology, that came up for me again when you were talking about this language of a companionate service in policy making. And again, thinking about gender here, and the way that gender interfaces with an informal care economy. There's so much to be said for the power of language, the way that by calling a particular kind of labor "companionate," or even like falling back on this language of care, is often feminizing, and is often a road for de-legitimizing that labor as *labor* that's deserving of compensation.

**Lisa:** Absolutely. And there's a history to that word and it's also a racialized history that the policymakers at the time, you know, many decades ago, thought of companions as typically women who would go into the homes of genteel white women and just kind of hang out with them. Have a cup of tea, you know. Prepare their meals, make sure that their hair was done properly. And the idea of the policymakers was that these quote unquote "companions" were doing this kind of almost as a labor of love. It wasn't really labor. They were basically providing friendship services, and they couldn't possibly be the sole wage earners for their families. Could they be? You know, they were companions. And

so there's this long kind of racialized and genderized history to that word that you picked up on.

**Kelsey:** Staying on this topic of disability, history, and policy, if you could tell us a little bit more about Olmstead versus LC. Um, which is another big turning point in the history that you're describing. Can you talk us through this case a little bit and explain its significance?

**Lisa:** Yes, um for people outside the US, the major um Disability Civil Rights law that covered both public and private services was the 1990 Americans with Disabilities Act, and I actually view the 1999 US Supreme Court in *Olmstead v. LC* as probably the seminal case that came from Olmstead, er, from the ADA. But that might just be my perspective. It had profound implications for institutionalization and community-based living. So the opposing sides in this case were Tommy Olmstead, who was the Commissioner of the Georgia Department of Human Resources, and two women, Lois Curtis, LC, and Elaine Wilson, who were inpatients at the Georgia Rehabilitation Hospital psychiatric unit. Both women had mental illness and developmental disability, and had agreed initially to admission to the state-run hospital. Now the ADA has several provisions within it, for example, section, well, I won't go into what the section number is. But there's a section that states quote unquote, physical or mental disabilities, in no way diminish a person's right to fully participate in all aspects of society, and a later section asserts the goal to quote, ensure equality of opportunity, full participation, independent living, and economic self-sufficiency of people with disabilities. And it was the late Justice Ruth Bader Ginsburg, who wrote the opinion, and she partially relied on these concepts in the ADA in writing the US Supreme Court's 1999 decision that held that under ADA title II, states cannot confine people with disabilities to institutions. That people with disabilities have the civil right to live within communities with appropriate supports, should they wish to do so. In this case, funded by public insurance, Medicaid.

**Kelsey:** Like so much of the history that you've discussed with us today, that translation point, or that thoroughness with which policy is translated into practice is really unfinished in the story that you're telling. So even if Olmstead was really important in principle, there have been profound challenges in its translation into the day-to-day lives of personal assistance services and consumers, people with disabilities, who are interfacing with this kind of care. How did this show up in your research?

**Lisa:** Yeah. Well, I saw it in my research, but it's also embedded within the Olmstead decision itself. And that is because Olmstead happened within the context of Georgia Medicaid. And Medicaid as people may know, is the joint federal and state health insurance program for poor people. And the US Supreme Court recognized that it actually had no jurisdiction over how states spend Medicaid dollars. Now, Medicaid is now, in the United States, the last resort for thousands of people who cannot afford home and community-based services. But gaining Medicaid coverage is often difficult. It varies across states because there are some states that have very stringent entitlement criteria. But in the mid-1970s, personal care or personal assistance services became an optional benefit for Medicaid. The 1981 omnibus Budget Reconciliation Act introduced something called the Section 1915c waiver, which permitted state Medicaid programs to cover home and community-based services, including personal care, homemakers, home health aids, and respite for family caregivers. And so the way that this came up in my project was that interviewees in different states had different levels of Medicaid PAS benefits and payment structures.

So because the Supreme Court does not have budgetary authority over how state Medicaid programs spend their dollars, it's suggested, Ruth Bader Ginsburg suggested in her opinion that putting Medicaid beneficiaries on waiting lists for home and community-based services would be acceptable if this would not generate lengthy delays. So, but, as I just said, you know, home and community-based services for Medicaid vary substantially across states and enrollment, spending reflecting different states' choices about whether they want to use a 1915c waiver, for example. And so, for example, in 2016 Mississippi put twenty-seven percent of its Medicaid long-term services and supports funding on home-based and community-based services, while Oregon allocated eighty-one percent of its Medicaid long-term services and supports dollars on home and community-based services. So Mississippi twenty-seven percent, Oregon eighty-one percent. So even in those states that prioritize these services, there can be long waiting lists. One study showed recently, you know, waiting lists from a year to fourteen years across states. A recent estimate suggests that Medicaid home and community-based services waiting lists under waiver authorities total over about 820,000 people.

So again, the Olmstead decision did not indicate what would constitute an unacceptable waiting period. And so, because there are these waiting lists, because there is not enough funding for home and community-based services, even though we have Olmstead, it may not actually be having an effect for literally, you know, hundreds of thousands of people with disabilities out there across the country. And the National Council on Disability in February 2022 released what they called their Health Equity Framework, and they have made a number of recommendations. But one of the recommendations that they made was that the Department of Justice more vigorously enforce the ADA integration mandate under Olmstead, because it hasn't really yet come to pass as originally envisioned in the original ruling.

**Caroline:** Thank you so much for that incredibly comprehensive and clear answer to our question, and I, I just have to say this is why we are so grateful that your work exists, right. For just helping to reinforce the stories of people who are fighting their way through the system and helping us I think appreciate the need to continue to advocate for change. So thank you just so much for all that you do. This is a, a bit of a big question, so I, I apologize for the capaciousness of it. But you've described our current system, maybe system's not even the right word, we might go with patchwork or dysfunction, when it comes to personal assistance services. What do you think that the state of the system right now says about our values and our priorities as a society?

**Lisa:** It's such a great question, Caroline, and it's a societal question isn't it? That we, as a society, basically, since our nation's founding have not had a sense of communal responsibility for ensuring the lives and dignity of all citizens the way that some other countries have. And so depending on a person's support needs, this kind of support, personal assistance services is just too expensive for most Americans. And seemingly intractable actuarial, costs, political, and other problems have really sunk efforts to develop a public health insurance for long-term supportive services. Some of you might remember, although it was so fleeting that you might not, that part of the Affordable Care Act that Obama administration passed in 2010 included something called the Class Act, which was Community Living Assistance Services and Supports. My late Senator Ted Kennedy was one of his kind of goals for Congress to achieve kind of long-term services and support insurance program, but it was jettisoned by the Obama administration as part of negotiation with the Republican Congress several years later, to get the budget done.

So, although the United States has signed, it hasn't yet ratified the 2006 United Nations Convention on the Rights of Persons with Disabilities which as recently has been ratified by one hundred and eighty-five other nations around the world. And the thing that's different about the UN CRPD is that it has positive rights embedded within it rather than negative rights. So what I mean by that is, that in the United States disability rights are framed in a negative—that the ADA prohibits discrimination against people with disability. In contrast, the positive rights embedded within the United Nations Convention on the Rights of Persons with Disability affirm that people should have health care. That's a positive right, you know, article 19. The title of article 19 of the UN CRPD is "living independently and being included in the community" and it calls for in-home supportive services, including personal assistance. And there's multiple other articles within the UN CRPD that describe components, positive rights, such as article 30, participation in cultural life, recreation, leisure, and sport. And so I just think that you know, in our country, the United States, it just has not been part of our national ethos to feel that we have communal responsibility, as I said, to ensure the dignity of all citizens.

**Kelsey:** I had never thought about that framing before of negative and positive rights, like formulations of rights in a negative or positive valence. And the way that in a US American context disability rights are disproportionately framed negatively. And how, how, exactly as you're saying, that's demonstrative of a larger cultural and social ethos. I had never considered that before.

**Lisa:** It isn't me. It's lawyers that I've studied who taught me that. It took me a while to figure it out, too, but it's absolutely foundational.

**Kelsey:** Well, if Caroline's last question was about the current state of affairs with personal assistance services, this question is also a big one about change in the future. So a lot of disability history fans are familiar with this really awful Medicaid - Social Security catch-22, at least in part because of Paul Longmore's work, who very famously burned copies of his book, because the income from that would disqualify him from essential Social Security benefits. So, even though some of these policies have been amended, in the story that you told some of these same problems, the same catch-22, came up for Fred. So Fred wants to be a physics professor, but his income would be too high and disqualify him for public funding for his PAS. But too low to actually afford to pay those PAS out of his own pocket. So this catch-22 consistently consigns disabled people to poverty, and prohibits them from pursuing forms of employment and work in the world that are really meaningful to them. So what would you like to see change when it comes to PAS policies and practices that relates to this catch-22, but also transcends it. And do you see these changes happening anytime soon?

**Lisa:** Yeah. The answer is, no. I think, as I've said, throughout our conversation, these changes are going to require political will and based on the founding ethos of the United States, it's just missing, and it's sadly missing today. And Fred is a twenty-year-old college student who I interviewed at the end of my project because I wanted to get the perspective of a young person. He has a severe disability. Since birth he has used wheeled mobility assistance. And, you know, he is a brilliant guy, though, and wants to be a physics professor, but he also wants to pay a living wage to his personal assistants. And I did calculations about what he might earn as, you know, a professor, and what a living wage might be, and they were, you know, off the charts different from each other. You know, one of the things that I asked all the personal assistants was how they could improve their job, and all the PAS workers I interviewed with one or two exceptions really loved their job, but they didn't love their pay. So in terms of policy changes, their recommendations had to

do with wages, wages, wages, you know, a living wage. And I think, just like so many other areas in our society, the Covid-19 pandemic and its aftermath have really, you know, upturned the rock that we knew that there were terrible things underneath. But it's really had those terrible things underneath the rock now on the surface. And we know that employers are looking for workers everywhere, and most PAS workers could find higher-paying jobs elsewhere, just down the street, perhaps even with benefits like health insurance and paid, even if limited, holidays. But where does this leave consumers? Anxious and uncertain, especially for people with consumer direction, maintaining their PAS coverage can be a full-time job.

And so I texted Michael before, you know, talking to you this afternoon, and I asked him if I could continue telling his story, and he said, go ahead. And let me just say that Michael often spends hours alone these days because of trouble finding reliable home health aides, HHAs. And so that means that Michael, who is now largely bedbound, is not being turned, thus raising risk to his skin integrity. And he's not getting his tube feeding, he's fed through a peg tube, thus risking his hydration and nutrition. And so, day after day, I get these texts from Michael: nobody showed up today. I don't have anybody today. Literally for hours. And so, you know, this is this is a really big problem, and it's something that Biden tried to address in his Build Back Better legislation that came out last spring. It had dollars in it to fund home and community-based supports for the 820,000 people who are still on the Medicaid home and community-based services waiting lists. But again, that's only Medicaid. We know nothing about what is happening to people needing PAS supports in states with restrictive HCBS coverage, or those who do not have Medicaid, and the people who don't have Medicaid live in the shadows. We don't know how many there are, or what their lives are like. So it's not a hopeful picture. I'm afraid.

**Caroline:** Thank you for that answer. It's, yeah, it's really a grave issue in many ways, and I think we're both really appreciative of the way that you're drawing attention to it. We hope that through this podcast we can contribute our small piece, right, to continuing the work of advocacy here. I think, as disability historians, we hope that history can help create change. I think many of us have that as kind of part of our grounding philosophy. That by identifying perhaps, the roots of injustice, we can then begin the process of uprooting them and creating change, right? I'm wondering if you think history has a role to play here. You do trace some of it in your book. I'm curious if there's more that we, as historians could or should be doing, to help generate the sorts of changes that are evidently needed in the system? Your answers or thoughts, here would be so welcome.

**Lisa:** I mean I'm not a historian at all. But I, I was able to, and felt strongly about putting some of the history in the book, because, as I said, the problems that we have now directly trace to, you know the origins of our country, and I think that, understanding the essential and strong links especially, to sexism and racism, helps us understand why this work has been devalued and disrespected and low-wage. The one piece that we haven't talked about but I think is also a very strong historical root is the role of immigrants in our country. Obviously there are many immigrants working in personal assistance services in the gray market, i.e. not the official market, where they make private arrangements with employers. But there, the chance for exploitation is really real, especially for people who are undocumented. But looking at the demographics of our nation in terms of birth rates, of native people, we are going to absolutely need immigrants to be able to support the home-based personal assistance services needs of an aging US population in coming decades. And so I think that if historians can contribute to understanding the very positive history of immigrants, and how they become members of our society, to get policymakers to realize that we're going to need this workforce in a selfish way, to meet our own needs, but also to

give them opportunities that then they can move on beyond personal assistance if they choose to do so. That would be a really important thread of history that is essential, a story to tell.

**Caroline:** Thank you for that a bit of a call to action, perhaps for those of us who want to find some way to contribute through our profession as historians. So thank you so much for that. Was there anything else that you wanted to mention that we haven't had a chance to talk about? Give you kind of the open stage to talk about --

**Lisa:** We have talked about a lot. But you know, and I don't want to talk about this more right now, because it's a very dense and difficult history. But I think the specific history of Medicaid, its association with poverty, its fragmented, waiver-based programs and the differences across states is a really critical history, because, trust me, somebody in Minnesota is going to be getting very different supportive services than somebody in Mississippi or Alabama, and there's just like dense and long history there that I think also needs to be told. You know, the fact that Americans, depending on the state in which they happen to be living, are going to have very different experiences if they need home and community-based supports because of their disability.

**Kelsey:** Several calls to action for historians, yes. So now that your book is out, what are you up to now? I know that you mentioned that your next project is also going to be an oral history. I'm wondering if you want to say a little bit more about that.

**Lisa:** So absolutely. So in terms of a professional hierarchy, if you will, so if we're very rigid about this. I've kind of done things backwards. I've talked about the unlicensed people who I actually think are the most important people. I actually think that the personal assistants, the PAS workers, are the most important people in supporting people with disabilities in living in their homes and communities. But health care professionals do have some role, you know, physicians and nurses, nurse practitioners, advanced practice nurses, and physician assistants, and my current project I actually started at the same time that I was doing this Gordon and Betty Moore Foundation project, and I won't go into the lengthy history of why that is. But I started kind of on the side just interviewing people in Boston who were still alive. They have to, you know, for people to be interviewable they have to still be alive. But these are people who were associated with a demonstration program that Massachusetts Medicaid conducted back in 1992 to 1996. It was called Community Medical Alliance, and it was a small capitated, in other words, per member per month payment program that had as its two populations of focus people with severe disability, so not just paraplegia, but the quadriplegia, and people with late stage AIDS. This was before the highly active antiretroviral drugs were available. And so people who enrolled in this program, who had late-stage AIDS, half of them died within six months of getting into the program.

So I just started interviewing everybody I could. I used snowball sampling, which is basically everybody who I interviewed, I asked, is there somebody else who I could interview? And many of the people who were members at the time have since then passed away and are no longer here for me to talk to. But I was able to talk, to conduct eighty five interviews and so I have those interviews literally sitting around while I've been doing other stuff. I thought during the pandemic that I was going to have all this free time, and I was going to be able to take a look into those eighty-five interviews that I did for the Community Medical Alliance History Project. But I have been very privileged and fortunate to get a Harvard Radcliffe Fellowship for the academic year 2022-2023. It started about a

little less than a month ago, and so I'm hoping during this fellowship to be able to get really kind of deep into these texts.

And there are some clues for me as to the lesson that I hope to take away from the Community Medical Alliance interviews. And that is that halfway through the demonstration program, Massachusetts Medicaid hired a group called the National Committee for Quality Assurance, and that is a group NCQA, based in Washington, that was developed to look at managed care organizations, and they came to Boston, and they interviewed people, patients and providers affiliated with CMA, Community Medical Alliance, and they came away saying, people love your program. There is something going on here. They love your program. What are you doing? You need to figure out what that special sauce is. What that secret sauce is that makes this particular managed care program beloved by the people who are members of it. And so that is one of the things that I hope to unearth in going through the eighty-five interviews that I've done.

**Kelsey:** We cannot wait for this next project. It sounds so phenomenal, so necessary. And now, of course, I'm curious about what that special sauce was. And again, when we think about what constitutes a usable history, it's so evident from the conversation that we had today that we need more histories of care and care work that really try to get at this question of when care works well within a community, what is happening in terms of labor and payment and interpersonal exchange? And how can we reproduce those conditions environmentally to ensure that more people can access the care that they need within their home communities, and that the people who are caring for them and attending to them are being compensated for that labor.

**Lisa:** Absolutely Kelsey and I apologize. I forgot to turn my cell phone to mute, and so you might have heard the little whistle. A text message. That's Michael. That's my text tone for Michael, and I thought, let me read you the text that he just wrote. He said, wow, I have to take my Tylenol because my temperature has gone up to 100.9. He just had his Covid booster shot yesterday. I'm not worried about this. This is good. But you see what this is like for me. Two hundred and fifty miles away. That in a way I'm his caregiver, you know. So it's interesting how you can play a role, you know, even if you're not physically present with somebody in providing supports for them.

**Caroline:** That's really meaningful. And I'm really glad you said that. I can absolutely understand from the perspective of politics and a fight for justice that many people want to kind of write the word care out of the equation because it has been so stigmatized, and it's associated with forms of marginalization. But I also, in a way, hope one day we can get to a point where we can bring that back into the conversation in a way that is not stigmatizing and marginalizing, but empowering and about interdependence. And you've just illustrated that so beautifully.

**Lisa:** Yeah, Yeah,

**Kelsey:** Thank you so much for joining today Lisa. I wish that we could talk for hours more and hopefully the three of us will be able to talk again in another context. There's so much more to say, and I know that our listeners will enjoy this conversation so much. Thank you for spending the evening with us.

**Lisa:** Oh, you're very welcome. Thank you for having me.

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