Episode 80 Part 1.
Dr. Peter Poullos and Dr. Neera Jain

Lisa Meeks:
Doctors with disabilities exist in small but measurable numbers. How did they navigate their journey? What were the challenges? What are the benefits to patients and to their peers? What can we learn from their experiences? My name is Lisa Meeks, and I am thrilled to bring you the Docs With Disabilities podcast.

Join me as I interview docs, nurses, psychologists, OTs, PTs, pharmacists, dentists, and the list goes on. I'll also be interviewing the researchers and policymakers that ensure medicine remains an equal-opportunity profession.

Kadesha Treco:
Hello and welcome back to another episode of the DWD podcast! In this special 2 part series, Dr. Neera Jain, senior lecturer at the Centre for Medical and Health Sciences Education at the University of Auckland and guest co-host of the docs with disabilities podcast flips the mic and interviews Dr. Poullos.

In this episode, Dr. Poullos candidly reflects on his disability identity journey and how learning from a vibrant community of diverse individuals has elevated his thinking about disability justice. He shares insight into the power of community and how forming the Disability resource group at Stanford Medicine was transformational.

Throughout the interview, Drs Jain and Poullos thoughtfully reflect on shared experiences and their roles as advocates for individuals with disabilities in medicine.

Dr. Neera Jain
So we met in 2019 for the first time at the coalition symposium. And I remember seeing your name on the list and being like, oh, somebody from Stanford, interesting. I'm interested, who's this person who I haven't heard of before? I was really intrigued by the work you were doing. At that point, I think you were maybe a year into the work, five months. Oh, because did you start it in December of 2018?

Dr. Peter Poullos
Yeah.

Dr. Neera Jain

Dr. Peter Poullos

Five months. Well, I think the coalition was in April, right? Yeah, in November.

Anyways, it was very early in my journey. And I'm so glad that was one of the... I was introduced to you and Lisa, I mean, as prominent figures in the community by Zina Jawadi is now a medical student at UCLA, but was at the time a grad student at Stanford. And she and the medical students with disability and chronic illness, as well as a lot of other people at Stanford, kind of gave me like a crash course in all things disability, because I didn't know much. You know, I was injured in 2003. And then I spent like the next years up until 2009 retraining in radiology from what I had previously done. I was very busy during that time. Frankly, didn't have that much involvement with disability sort of on purpose. I would just prefer to not think about it.

When I was around other disabled people, I felt depressed. I would get sad for people, especially that were permanent wheelchair users. I had guilt over the recovery that I made, being able to walk versus the people I was in rehab with who didn't.

You know, there was just all sorts of emotion. I had like, you know, a lot of internalized and externalized ableism to get through having been like an athlete my whole life, not like a great athlete, but you know, still like very into, you know, sports and activities and very competitive. And so I had a lot of issues.to work through. I said some things about disability early on in my recovery that make me cringe today looking back at like prior interviews and comments I'd made and I don't think I was, but I had been involved in a few things like board of directors of a nonprofit for disability and had done some like fundraisers and a few scattered things like that. I'd been interviewed for a couple of things, but you know, didn't really know much about disability culture or. philosophy. And so when I proposed doing a project on disability, I really had no idea what I was proposing even. And in fact, when they asked me what I had in mind, I just told my personal story. And, and then the group was like, “Oh, well, we should do it”. And then they said, “Pete, why don't you figure out, I don't hear the disabled– and why don't you figure out what the project would be? And as a first step, you know, you might want to consider doing a survey and to see the current status of things and, and start an affinity organization”. I mean, it wasn't even my idea really.

It was Iris Gibbs' idea. And so I sort of took it and ran, um, you know, started the organization, just looking up Googling, like, how do you start an affinity group? What are some board of directors structures? What are some like mission visions? Um, statements that I believe in that resonate with me. What do we name the group? I named it the Stanford Medicine Abilities Coalition, SMAC, not really even realizing that, like it was preferred to use “disability” as a term rather than “ability”. I thought, oh, “ability” sounds better, because “disability” sounds like “inability” or– you know, to me, had a negative connotation where ability was more inclusive and included like able-bodied allies.

Um, and so I just started meeting people around campus, talking to people, reading things, and then going to the coalition was like instrumental. Just learning about the specific area of like disability in healthcare and medicine, and then meeting you and Bonnie and Lisa and really going from like...I don't know if... it wouldn't be disability shame. I don't think it would.

Hmm. I wouldn't even refer to myself as disabled before. I mean, I understood that I had a disability and I was a person with a disability, but like the journey to saying that I'm disabled and saying it with pride took a while. It was a process.

Dr. Neera Jain
Hmm. Yeah. So I'm, I'm curious, cause I just want to go back to what you said about even starting the group. So you, you described kind of your, your journey of, you know, kind of almost being repelled by ideas of disability. How did you go from that space of kind of not engaging disability to even being in a, you know, a committee space and saying, we need something or maybe not even saying we need something, but here's an experience we should attend to.

Dr. Peter Poullos
Yeah, that's a good question. Well, I mean, I had noticed that disability wasn't being represented in diversity efforts, it wasn't being talked about or there was no visible disability presence that I noted. The students had started, um, a disability group, but I didn't even know about it. They started it like six months before I started smack. And, um, I only found about it after.

Dr. Neera Jain
Mm-hmm.

Dr. Peter Poullos
I mean, everything just kind of fell together serendipitously. I mean, the...

It was almost like I was at the center of it, but it was sort of forming around me. And it was almost, I mean, the students really drove a lot of it. You know, when I met, I didn't know much about disability at Stanford. I mean, I say this a lot that-

Dr. Neera Jain
Mm.

Dr. Peter Poullos
I'd been treated really well by the Department of Radiology that my residency experience had been mostly positive. And I thought that Stanford was a disability friendly place until I met these

students and like they were great in typical Stanford student fashion, like created a 15 page PDF with like a bibliography.

Dr. Neera Jain
Yeah.

Dr. Peter Poullos
in medicine, not just at Stanford, but nationally and giving me a primer of all these people whose readings I should absorb. And so like, I mean, the thing that got me was like that was the unfairness of the system and the negative experiences that these students were having and the discrimination that they were facing. And that just, that was the glue.

Dr. Neera Jain
Hmm.

Dr. Peter Poullos
And like the motivation for me, really that sort of lit the fire was that this should not be happening. This should not be happening at Stanford or anywhere. And so I sort of turned into a crusader at that point. That was the impetus really. The unfair system, the ableist system. And I realized that it was, I was lucky.

to have been treated like I was treated. And that had there been another residency program director or another place or different, that it could have easily been a different outcome But.

you know, using political disclosure as a way of like, you know, getting what I needed, being creative, finding win-wins, things that I've talked about in different presentations to just create an environment that I would, that would, you know, promote my success. I realized also, I realized also that this was like a natural sort of niche for me.

Not only would, did I have to do this work because if I didn't do it, maybe nobody else would, but a feeling that this could be good for my career. I mean, this is a space that, where I have maybe like the most credibility and the most potential for impact, where there's a vacuum.

And the students had a lot of great ideas where we could, like, devote our energy. Zena had a lot of great ideas. I met the disability, um, the people here at Stanford, the Stanford Disability Initiative and, um, the people who are in charge of that and part of that and the disability and access office and the office of accessible education. And, um, you know, all of the, the

Like the relationships also meant a lot. The relationships with people at Stanford and people outside of Stanford and like the warmth that I felt from the community, how welcoming all of you guys were to this dude that nobody knew.

Dr. Neera Jain
Mm, mm, mm. Well, it's interesting. I just wanna go back to what you said about kind of finding the space of leadership and it's an interesting equation because you talked about, you know, on the one hand being kind of… what's the word I'm looking for? Something like activated by the injustice that you became aware of. And I think that's kind of that critical consciousness raising moment of, whoa, like what you said about, I was lucky. Like if I had been in a different situation, if I had played the game slightly differently, if I had the wrong program director, the wrong *whoever* in the mix, my experience could be really different. And I think that's an important and powerful kind of realization that, some people might say, "oh, that's, if you knew how to do it right, you wouldn't have those problems". And what I hear you saying is something different, like, "oh, I could have easily been in that situation".

Which I think is really important. And then the other piece is the thought that this might be a space I could benefit from being a leader in. And it's interesting because we know that kind of being out, being public, taking that role can also be dangerous, right? And it may not, you know, for a lot of people, there's a fear that leading, being public will tank their careers. And it takes the courage, the viewpoint that actually this could be a good thing. You say that maybe that's selfish. But also, I think that courage, that ability to see the positive potential of it is kind of what's necessary to lead, like the combination of the recognizing the systemic injustice plus "this could be good for me and for other people", allows you to step into a space that previously you had not wanted to inhabit. I, you know, it can feel uncomfortable to talk about that, but I think it's, there's something really powerful about that, about being able to see that that's possible. And maybe part of it is that you can't hide your disability, right? It's, it's apparent. And so you're already out there. Why not? Take it up. And if you don't take it up, people are going to ask why not? Potentially.

Dr. Peter Poullos
Well, and I look at it as a duty. I mean, it's an obligation also. I feel like I really, I don't have a choice and it would be like an incredible, I would be doing an incredible disservice. And I think it would be like a failure of leadership and a failure of courage if I didn't continue doing this work.

Dr. Neera Jain
Yeah.

Dr. Peter Poullos

Like I have a title, you know, I'm a clinical associate professor of radiology at Stanford. Although that title, you know, it's not, I don't have that written on my wall. Don't look at it every day and think about, you know, how grand it is. But I, you know, it does offer me like a key to certain spaces that I wouldn't have otherwise. And it allows me to–

Dr. Neera Jain
Yeah. Hehehehe.

Dr. Peter Poullos
–to be that voice and to advocate for other people, especially people who are in lower positions of power, like students and residents. And, you know, it just, so it's a duty.

Dr. Neera Jain
Mm.

Dr. Peter Poullos
The other wrinkle in this is that I chose to not continue taking care of patients in a clinical sense. I do view my work as like directly with or for patients in radiology, reading their scans. But you know, a lot of what I... talk about when I talk about disability in medicine is like the clinical part of it, like the empathy and compassion that people with disabilities have having been in the, on the other side of the stethoscope, the other side of the curtain. And I do think that we bring a lot to that area.

Kadesha Treco:
The expectations of doctors with disabilities are both nuanced and complex. In a 2018 study aptly titled Being on Both Sides, Dr. Stergiopoulos and colleagues explore the complexity of identity negotiation for docs with disabilities citing that at a structural level practitioners engage in strategic disclosure in a medical culture which "often equates illness with weakness" and incompetence. Listen in as Drs Jain and Poullos explore the contours of this gray area.

Dr. Neera Jain
I think it's interesting what you are talking about because this is something I struggle with in terms of how we position the research and the work. You talked about one of the big arguments for doctors with disabilities is empathy, lived experience, what that can do to clinical work. And I think the danger of that argument is kind of this essentializing idea of like what it means to be a doctor with a disability. You have to be more than a doctor. You have to bring this kind of quote-unquote special ability to the encounter. And I think it's true of many doctors with disabilities, they are bringing that lived experience to the work. But what you're describing is a complicated niche, right? Like the, because you kind of hinted to feeling like you wanted to

demonstrate that you could do everything while simultaneously questioning, am I practicing safely?

Am I really doing everything that I need to be doing as a clinician? What does it mean to give that up? And yet questioning whether you could do so safely, is this even sensible to be directing someone to move your stethoscope? And feeling that conflict between here's my argument: disabled doctors can do patient care, but I'm not doing the clinical patient interactions anymore. And I think that's kind of a...there's some friction for me in the argument around what disabled doctors bring to medicine, because I think, yes, the empathy in the patient encounter, the kind of different level of understanding, the connection, the lived knowledge that comes living with a disability is incredibly important.

And yet if we essentialize that, it raises questions that it sounds like you've grappled with, which is like, what does it mean if I'm not doing that? And yet to me, it sounds incredibly sensible. It's like, you've found a niche for yourself that works well, you can practice medicine. And I mean, not that everyone needs to do this, but you are...a leader in a movement. You've taken the power that you have as a faculty member and channeled that into improving systems, raising awareness, all of those things. But yeah, I guess I'm wondering, have you thought about that kind of tension in the argument around empathy?

Dr. Peter Poullos
So this is very interesting, actually. So have you heard of ChatGPT? This AI that they say is gonna make writing obsolete and make, like, the high school essay a thing of the past.

Dr. Neera Jain
No.

Dr. Peter Poullos
Well, you should go to ChatGPT and talk to it. And I read about this and I talked to him the other night about it. And I said, “what makes doctors with disabilities more effective than those without?” This was just my question. The AI says, “it is not necessarily the case that doctors with disabilities are more effective than those without. The ability to provide effective medical care is dependent on many factors, including a doctor's training, experience, and overall proficiency in their field.”

Dr. Neera Jain
Yeah, yeah.

Dr. Peter Poullos

In some cases, doctors with disabilities may be able to bring unique perspectives and experiences to their work that can enhance their ability to provide care. But this is not always the case. Ultimately, the effectiveness of a doctor should be determined by their individual abilities and qualifications rather than their disability status.

Dr. Neera Jain
Fascinating.

Dr. Peter Poullos
Yeah. And then I said, “well, what are some of those unique perspectives?” And the AI says, “well, that's difficult to say, but, and could vary depending on the individual and their specific disability. However, you know, some possible examples may include a deeper understanding of the challenges that patients may face personal experience with accommodations and assistive technologies that can be helpful insights into the psychological and emotional impact of living with disability and how that can affect a person's health and well-being. But again, it's important to note that not all doctors with disabilities will necessarily have these perspectives and that the effectiveness of a doctor should be determined by their individual abilities and qualifications.” And I just thought that is *so* smart.

Dr. Neera Jain
ChatGPT knows.

Dr. Peter Poullos
My God, and this conversation went on. Of course, I'm not going to read the whole thing, but it was like talking to your smartest friend, really. It was just, what about, does having a disability even make a person more empathic or compassionate? The chat AI says “no”, then “not necessarily”. These are complex psychological traits.

Dr. Neera Jain
I'm sorry.

Dr. Peter Poullos
And that there are many factors that go into it. It also points out that some people without disabilities may also have high levels of empathy and compassion.

Dr. Neera Jain
Mm. Well, it's interesting. I don't know if you know Duncan Shrewsbury, but they're a doc in– a disabled doc– in the UK and they do research in the space. And they often push back on that argument about doctors with disabilities being more empathetic because they say–

Dr. Peter Poullos
like, goddamn.

Dr. Neera Jain
“Why are we basing inclusion on that argument? People have a right to participate”, and that should be central, and anything that comes after that is, as ChatGPT has told us, complex.

Kadesha Treco:
Envisioning a future of equity in medicine is a tall order, one that requires us to challenge the status quo. What would the future of medicine look like if individuals were encouraged to glean insight from their lived experience into praxis? Here Dr. Jain and Dr. Poullos explore the possibilities that could exist for the future of medicine.

Dr. Neera Jain
You know, you described yourself, like, early in your disability experience, kind of how you thought about disability, your reaction to disabled people, which was complicated. The internalized ableism that we all carry from living in an ableist society to suggest that there's an essential criticality or knowledge base that disabled people have, I think is a, is a complicated question, especially when we know that the education that medical students get is more often than not, not anti-abolist. And students are socialized into a space and asked to let go of their criticality in their training. We see the work from Dr. Yaris's team from Erene Stergiopoulos. Dr. Stergiopoulos’s work that shows, even folks who want to incorporate their lived experience into their practice and training are really wrestling with those questions of professionalism because it's not part of training to support people to do that work. And so it feels like a dangerous act, like political disclosure, it's a dangerous act to disclose to incorporate your lived experience into training. And so on the one hand, I think it's this complicated space of like, it is, I think it's a valid argument and yet it's not always valid. Should we be hanging our argument on that? And if we are hanging our argument on that, what are we doing to ensure that all trainees are supported in activating critical disability ideas in their practice?

Dr. Peter Poullos
Right. Well, it's like, why should I have to be more empathic and compassionate than someone else? Do I really have to be better than an able-bodied person at my job? Or can I just be the same or maybe even a little bit worse? I don't know. It's like I hate the curb cut argument. It's good for everyone. Even people with strollers–

Dr. Neera Jain
Exactly.

Dr. Peter Poullos

–but they're babies. It's like, why does it have to be good for everyone? Why can't it just be like a human right and good enough to be for us? You know, there is a lot of that argument going on. And I also struggle with that. I mean, taken to the extreme, I've said to, in the definitely, intentional provocativeness of this statement to say that we shouldn't even let students without disabilities matriculate to medical school because they don't have the lived experience of what it's like to be a patient.

Dr. Neera Jain
Mm-hmm. Yeah, what would that do to medicine?

Dr. Peter Poullos
Which, you know, I think, right– What would that do to medicine? I don't know. I would think that it would make it better that there would be positive changes. But again, as ChatGPT says, it depends on the individual. And it can also be true that people with disabilities can be less empathetic and compassionate than non-disabled people. Because of this idea like, what are you complaining about? Look what I have to go through on a day-to-day basis just to like get out of bed and get to work, you know?

Dr. Neera Jain
Or “I've done it, why is it so hard for you?” You know?

Dr. Peter Poullos
Right, exactly. So it can go the other way, also.

Dr. Neera Jain
And I think that's where, at least in my mind, and I don't know that we know what it would do to medicine, and I think it could do a lot of different things as you describe, like it's not a guarantee that it would improve medicine. But to me, if we started from that premise, if medicine said, you can't be a doctor unless you have lived experience, tell us your lived experience. Tell us how it influences your work. It would, on some level, that if we started from that premise, then that shifts so many things that are right now kind of core to medicine. So it might, a system that started from that premise, I would think, would look a lot different because there would be, theoretically, attention to “How do we engage that?” There would be attention to, you know, it would be destigmatized because everyone would have had some experience. So maybe it's more okay to talk about it. But I think, you know, of course I can imagine all the ways it could go wrong.

But I'd like to, you know, I think as a thought experiment, it's an interesting idea of like, what else would change in the system if we started from that point? What else could be possible through that fundamental assumption?

Dr. Peter Poullos
I mean, I have to think that it would change things for the better.

Kadesha Treco: Be sure to listen to part 2 of this important conversation. *Here's an excerpt where Dr's Jain & Poullous dive deeper and discuss the power of community and cross-movement building…*

From Part 2 of this Episode
Dr. Peter Poullos
"That's one of the most important things in this space is the relationships that you build with other leaders in the community. And one of the most gratifying aspects of the job because the people who are working in the disability and the diversity spaces are some of the coolest people I know. The most open-minded and progressive and accepting."

Kadesha Treco:
Thank you Dr.'s Jain and Poullos for this incredible conversation about disability identity and for sharing a perspective on docs with disabilities in medicine. To our audience, thank you so much for joining us, and please join us for part two of this interview. If you enjoyed this discussion be sure to subscribe to our podcast, check our previous interviews and tune in again next time. This podcast is a production of the DocsWithDisabilities Initiative and is supported, in part, by the University of Michigan Medical School Department of Family Medicine M-Disability Initiative, the Stanford Medicine Alliance for Disability Inclusion and Equity, and the Ford Foundation. The opinions on this podcast do not necessarily reflect those of the hosts, their respective institutions, or the funders. This podcast is released under Creative Commons Attribution Non-Commercial, Non-Derivative License. This episode was produced by Lisa Meeks, Kadesha Treco and Jacob Feeman

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