

Steven Losorelli
Claire Rhee
Maité Van Hentenryck

Introduction: Peter Poulos

Peter Poulos:

Doctors with disabilities exist in small but impactful numbers. How do they navigate their journey?

What are the challenges? What are the benefits to patients and to their peers? And what can we learn from their experiences? Join us as we explore the stories of doctors, PAs, nurses, OTs, PTs, pharmacists, dentists, and other health professionals with disabilities. We'll also be interviewing the researchers and policymakers that drive medicine forward towards real equity and inclusion.

I am Peter Poulos and I am thrilled to bring you the *Docs with Disabilities* podcast.

Peter Poulos:

This is Peter Poulos. I am the Founder and Executive Director of the Stanford Medicine Abilities Coalition (SMAC) and I'm happy to welcome, in our inaugural launch of the Docs with Disabilities podcast collaboration between Stanford and the University of Michigan, our first guests as the founders of MSDCI, the Medical Students with Disability and Chronic Illness group at Stanford School of Medicine. The founders are Claire Rhee, Maité Van Hentenryck, and Steven Losorelli, and I wanted to invite the three of you to be our very first guests on the podcast because I feel a certain amount of indebtedness and gratitude to the three of you for founding MSDCI and for laying a lot of the groundwork for disability at Stanford Medicine. And I don't know if you guys remember the first time I met all of you in my office, it was the three of you and Richie Sapp and Zina Jawadi cramped in my tiny office

So lucky that at the time that I was starting SMAC that SDI, Stanford Disability Initiative, on the main campus, and Zina Jawadi were having their annual event. And then she basically introduced me to the five of you guys with MSDCI. And I remember, I just was asking for the state of disability at Stanford Medicine and you guys put together this like 10-page PDF document with bibliography and hyperlinks. It was everything you need to know about disability at Stanford and also what I needed to know on a national level. So that was really helpful. I'd like to ask you guys starting with Claire, what was your first impression at that first meeting?

Claire Rhee:

My first impressions were that it seemed like there was a lot of energy around disability advocacy for probably the first time that I knew of, and that partially might be just that I was ignorant of it and not as involved in it because I know disability advocacy groups at Stanford have been pretty prevalent for a while. But at the same time, it was very overwhelming because with disability advocacy, there are lots of different sectors you can go towards, especially within medicine. So, I think the advantage of the student group was that we had a sort of narrow scope which was to raise awareness of disability within medical students. And then once we sort of took it out to all of Stanford Medicine, it got so broad, I was honestly overwhelmed.

Peter Poulos:

Maité

Maïté Van Hentenryck:

Yeah, I remember thinking, I can't believe this doesn't exist yet. And thinking that when we were first talking about MSDCI how I was already surprised that that didn't exist yet. And then I was even more surprised that there seemed to be even less of a structure in place for the graduate medical side. And then remembering also feeling really lucky to be at the School of Medicine because there's a lot of resources for medical students to start these kinds of initiatives. And remember thinking, *wow, this is great. We have so many ideas of things going forward. But how are we going to actually make this happen?* I remember feeling a little bit daunted by that too.

Peter Poulos:

Steven

Steven Losorelli:

I would say that I felt overwhelmed similarly to Claire and Maïté in terms of the number of things that we came up with. Both inspired but also overwhelmed, in the sense of this is something that we're going to start that will have to be continued, because we just have too many ideas, and it could become something that's sustainable throughout Stanford Med for years to come.

Peter Poulos:

So, Claire, why did you decide to co-found MSDCI? What was your vision when you founded it? And how did your experiences play a role in its founding?

Claire Rhee:

I was involved in diversity in the medical school, and I was on crutches for the better part of my first year of medical school. And then I also have experienced a lot of mental illness in my life. So, all those things as I went through my first year of medical school, and I was surprised that there wasn't more disability advocacy. We're so involved in the spirit of diversity and we're in medicine, where disability is very much a part of our jobs and where we should acknowledge it and be more empathetic and more knowledgeable and cognizant of how to navigate that. And it just wasn't there. People would walk so far ahead of me when I was on crutches, I felt like there weren't that many accommodations available even though I didn't need that many because it was a transient thing for me.

And I couldn't even imagine what it would be like for somebody whose disability was more of a part of their life. As I went through medical school, my experience with mental illness became more of a part of my life. And it was very strange to sit in classes where people would talk about mental illness, about different diagnoses that I held, or my friend held, or that we knew people that had this diagnosis, and to hear them discuss it at such a clinical arm's length when I feel like it would behoove them and benefit their patients, if they would try to really empathize with that experience a little bit more. So, diversity was a great route to go through because there's such a robust framework for diversity and advocacy at Stanford and I thought it was a good way to raise awareness of it, get funding for this kind of work, and to paint it in a way that was almost more palatable to the general population, if that makes sense.

Peter Poulos:

Yeah, that is a very interesting word choice. And I'd like you to expand on the word *palatable*. And I know exactly what you mean by it, but I'd like to hear it from you.

Claire Rhee:

So, I feel like people, even within medicine, where we are very close to these disabilities, to seeing how they happen and see how they affect people's lives on a day to day, we're still really uncomfortable with them. I myself admit to this, I still get very nervous at the prospect of having to work my exam around someone who's a wheelchair user, even though I've taken so many classes and done so many simulations of it, I have to be very, very intentional about it. I think people are really scared to ask about what someone's disability is. And I think there's also a deeply held stigma against disability, that someone who has a disability can't live as full of life, and definitely can't be like a health care

provider, like that they're somewhat not full human beings, when there's so many people with disabilities in this world, in medicine, and a lot of the times you just don't notice or take the time to notice. And so, there's a level of discomfort around that. And there's a level of wanting to keep it at arm's length, because then you have to grapple with a lot of things that might make you feel like you're not the best human being.

Peter Poulos:

When you said, *palatable*, I think a lot of diverse populations, including those with disabilities have this sense of just being like grateful to be included, and don't want to appear too angry, or needy, or confrontational, or demand their rights. And the palatability thing, in my mind, you decided to include MSDCI in the diversity framework is because we're all just celebrating each other as part of this one, rainbow quilt. But we're not actually challenging you or any of your assumptions necessarily, but the growth comes through the challenging. And so, in my mind the palatability while it's okay to start there, it's has to move beyond that, like pretty quickly to get anything done.

Claire Rhee:

Yeah, absolutely. I think if you ask anybody, I'm not the most palatable human being. But I think in terms of navigating an organizational framework and working within the bounds of institution, it's sometimes politically expedient to get your foot in the door, however you can, and from there, start making those demands and start demanding that these institutions do better. Like I never would have been able to start MSDCI if I hadn't been able to be accepted to Stanford Medical School. And how did I do that? One could argue that I only did that by, for instance, hiding my disability. That is a conscious decision that certain people make. And it's a sad reality of the world that I've seen from sitting on different selection committees and sitting in these different rooms where people are having discussions about diversity and inclusion and seeing the different ways people try to exclude others because it's politically expedient. So maybe I'm turning into like a bad snaky, political human being. But we'll see, we'll see how it all shakes out.

Peter Poulos:

I don't think it's like bad or snaky. I think that you always have to be smart and strategic about the decisions you make and choose your battles carefully. And there's nothing wrong with that as long as you're telling the truth. So, I think you should be proud of that, instead of feeling snaky or weird about it. You already broached the disclosure issue which was my next question. But I want to give Maïté and Steve a chance to answer the question about what was your vision when you co-founded MSDCI and how did your experiences play a role in its founding?

Maïté Van Hentenryck:

Yeah, we started MSDCI kind of at the end of our first year, beginning of our second year of med school. I started med school at a pretty interesting time in my life in terms of how I viewed my disability because I'm an amputee and I kind of grew up my whole life, not thinking anything about it, just living my life and doing what I wanted to do, and thankfully grew up in a family and a community that supported that. And then the year before I started med school, I lived for a year in France, and realized just how behind all of Europe really is in terms of looking at disability.

And so, I started med school pretty self-conscious about my disability and pretty aware of my limitations. And it started even as early as anatomy when we stand for four hours, twice a week around our cadavers. And even that was really painful for me. And just doing that, and then doing the first knot tying workshops, I realized I'd have a lot of pain in my like wrist when I was trying to tie knots. And so pretty early on, I was thinking, *well, does this mean that I can't go into surgery?* And then whenever something was brought up, like I had bacterial meningitis when I was a baby, and that case came up time and time again first and second year. And every time it was brought up, I kind of looked around was like, *are people looking at me? like do people know that this is something that has like changed my entire life, that this is why I'm here?* I was pretty surprised actually by

how few people did ask me about my disability. And so, it was through these conversations with Claire and Steven first year, when we realized we're just not talking about this enough. And we really need a way to really bring awareness to this. And to kind of break this illusion that we're not - like your classmates can have these disabilities too - and that we need to talk about diseases and conditions in less of a cool scientific way and more of a *wow this is actually a disease that affects people and that really changes their whole lives beyond just, you know, whatever the genetic mutation, is beyond the pathogen, and really start to understand what that looks like for people's lives.*

Peter Poulos:

Steven

Steven Losorelli:

I have a similar story to Maïté about talking about your condition in class. So, I have microtia, which is a deformity of the outer ear and I have a fused middle ear and have reduced hearing on the right side -about 15% residual hearing. It's thought to be a brachial pouch issue and in our embryology class they put up a picture of a patient with microtia and asked if anyone that ever seen this before. And I was slouching, sweating bullets in my chair, feeling like everyone is looking at me right now. And I think that was one of the first times that, that I had always had this motivation, but I had never really considered myself to have a disability because I feel like my disability is lesser than other people's disabilities. And for that reason, I skirmished away from endorsing it in some ways. And also, the stigma that goes with disability, I guess I was avoiding. And I have to really thank Claire and Maïté, they had already gotten the ball rolling on MSDCI a little bit when they invited me in to be part of the co-founding team. And they really helped me come out to embrace my condition as a disability and identify as such, and then realize the need to be more vocal about what it's like to live with a condition and just to be an advocate for those with disabilities. I remember also, when they gave us a stethoscope, I'm like where do I put the one on the right? Do I just pretend to hear out of this thing? And that was very stressful thinking, *am I going to be able to use a stethoscope and hear heart sounds?* Fortunately, I learned that one hears enough to pretend to your heart sounds like all the other doctors.

Peter Poulos:

That's really funny. So, what did you do with the right side of your stethoscope?

Steven Losorelli:

I still just put it where the ear canal should be and pretend like I'm hearing something.

Peter Poulos:

Yeah, perfect. I mean, there's really nowhere else to put it.

Steven Losorelli:

There's nowhere else. It's not super comfortable, but it makes do.

Peter Poulos:

Do you consider yourself to be disabled or to have a disability or both?

Steven Losorelli:

Hmm, it depends on the context, I guess. Because technically I am someone who is disabled in terms of hearing loss. Although because it's only unilateral, this is also something a lot of people don't understand is that I still hear sounds the same loudness as other people. But when someone's talking on this side, I literally can't hear you if you're over there, sometimes. And I can't localize sound. So, if you're in a room with 10 people and I can't tell you where the sounds coming from. So, I guess in that sense, I do identify, although I would say disability, as we all are aware, is such a spectrum. And it's such a gray area at times, that sometimes I don't always know if I identify and other times I fully do.

Peter Poulos:

I was introduced to a woman recently, who talked about disability with a capital D. And, you know, similar to the deaf community, some people choose to call themselves capital D deaf. And she described capital D disabled as not just like having a disability, but being disabled, proud of being disabled, and culturally disabled in a sense to have a real sense of belonging to disability culture. Because I've said that, you know, I don't consider myself to be disabled, because I can still work. And I feel like disability is a work designation, whereas I clearly have a disability. But I would consider myself capital D disabled, for sure. And if somebody referred to me as a disabled person, I wouldn't object because clearly that's true. So, I think that there can be nuance for how people pick and choose how they want to call themselves and how they want to be referred to. And maybe that changes depending on the situation, or even fluctuates throughout your life. As you said, you grew to this realization, or connection to the word disabled.

Steven Losorelli:

Yeah, you know, I would say there are days when I don't think about my ear, but there are more days where I do. And so, in that sense, I would also identify as capital D disabled, because it almost is impossible for me to go a day without thinking about it or experiencing some result of it in that way. And I do want to identify, because I want to make people realize that being capital D disabled, can be a positive and have effects on your life, that I probably would not have been motivated to go into medicine if it weren't for this. And as a result, I'm now living a very fulfilling life. And I think there are many benefits that people don't consider, that are a huge add to medicine, as I've seen in both Maité and Claire.

Peter Poulos:

Claire, do you refer to yourself as disabled or having a disability?

Claire Rhee:

I do not. Because I feel like that does a disservice to the disability community. And this is where it gets really dicey because the disability community is so heterogenous. And there are definitely people who have mental illness who would identify within the disability community. But even within the sort of like chunk of people who, within the disability community who have mental illness, I feel like even like, my life is not as difficult as some of theirs is, which is simultaneously very condescending of people with disabilities in assuming their lives need to be difficult and also very minimizing of what my experience may be. And like nobody wins in the pain olympics is a favorite saying amongst our friend group, but it's very context dependent too.

Like whether or not I disclose my disabilities, whether or not I believe that my life would be somehow easier if society were shaped in a way such that it were more accommodating, it varies day by day. I face it a lot more being out on the wards and in the hospital and seeing these kids who also struggle with mental illness, and them thinking that they are alone in this and me not knowing whether or not it is helpful for me to disclose or it is harmful for me to disclose because it breaks that doctor clinician boundary. And in that sense, I wonder about mental illness and the disability community and whether or not building that community more is beneficial or even possible because there's such heavy stigma there. And it's so easy to hide, some days. Some days less, though. Some days, they're like, yeah, this is this is Claire, she's struggling. But in that it is an invisible disability, it makes it difficult for me to identify with that community. Sort of like outside of that I have like all sorts of weird poorly defined like bendy wendie joints and stuff that needs to be identified that make me go to the doctor a ton. And because it has no definition, even though I spend multiple hours of every week thinking about it and accommodating for it, I still don't think of that as a disability either. So, it's hard. And people asked me when I'm doing this work, like do you have a disability, and it's usually just easier for me to default to saying that I'm an ally.

Peter Poulos:

But you have told me that you've struggled with mental illness before and you've also confided in me that you do have physical limitations and physical symptoms, especially if they required an accommodation could definitely be considered a disability. So, it's interesting that you don't identify that way and it sounds like you just don't think it's severe enough to really merit.

Claire Rhee:

Yeah, I think the way I think of it in my head is like I am still within the standard deviations of like the normal amount of suffering one should incur in their life - the day to day lives. I think part of it is cultural. My parents don't like going to doctors, they don't like medicalizing things. And part of it is probably like some sort of protective mechanism. We're still working on it. I'm a work in progress. I'll let you know when I start actively identifying as disabled or having a disability. But you're free to refer to me however you want. You've earned that privilege Dr. Poulos.

Peter Poulos:

Oh, thanks, Claire. I appreciate that. All right, Maïté disabled, disability? Are you culturally disabled and proud?

Maïté Van Hentenryck:

Well, first, I just wanted to say I'm glad Claire brought up the pain olympics quote, because I was just gonna say that.

In terms of whether or not I identify, I do. I think it's hard not to. My disability is very obvious. I am an amputee, as I mentioned, but I walk with a pretty significant limp, and then I have various orthopedic problems. So, it's pretty obvious. Somehow, I didn't for a really long time growing up. And then since coming to med school, and just being confronted with it more every day, I've really come to embrace it as part of who I am. I think it's brought me some connections with patients that I may not otherwise have had. I've had a couple of patients with recent amputations that I've become really close to on rotations. And that's been really special. And so yeah, I think I used to just worry that if I identified as having a disability that would be admitting that I had limitations or just accepting that I couldn't do certain things. And now I have come to see it as more of a blessing or just it brings aspects to my life that I otherwise would not have had.

Peter Poulos:

Yeah, no, that's interesting. Jennifer Brea made a film called Unrest about chronic fatigue syndrome, myalgic encephalomyelitis. And she talks about this in the documentary like she says she holds two things at the same time. One is that, and I'm gonna butcher the paraphrase, one is that this disability has really messed with her life and turned it upside down. And the other side is that she's seen a side of humanity that she wouldn't have otherwise seen, and has had experiences that are beautiful. And I identify with that quite a bit. I talk about it in terms of my time machine, like, would I go back to my time machine to the day I had my accident and not have it? The flip side is that everything that I've learned and done in the last 17 years since acquiring this horrible disability, all the lessons I've learned, and all the beauty that I've seen goes away. It's like a really hard question, because it sucks so bad, having my disability, and it would be so liberating to not have it but on the other hand, like I think I'm a better person for it. And I've been able to contribute in ways that I wouldn't have been able to otherwise. So yeah, I totally see where you're coming from.

I didn't know this about you Maïté, but in reading some of the things that you wrote, and things that you've said, it's clear to me that you have a pretty strong sense of humor. You wrote this article in JAMA recently called Growing Pains, which made me extremely emotional. I don't know, it just really resonated with me it was very touching. But even in this article, this powerful article, you have like, these great lines in there just kind of sprinkled around to make it more palatable, maybe, as Claire might say, or to just make it more fun to read. You said, "I grew up healthy, with all the advantages that come with a leg I could whip off anytime I needed. I would stick it out of the car window to scare passing drivers. I once planted it in a graveyard for friends to find one night. When I played soccer, sometimes I could swing 2 goals in 1 if I got my leg to pop off at just the right moment for it to fly into the net along with the ball. I managed to distract my high school English class for an entire period

with a debate over what pattern to make my leg (we settled on tie-dye)." My question is what does humor mean to you in the context of your disability?

Maïté Van Hentenryck:

I think it's, I mean, it's just, there's just so many good opportunities, I think, for jokes with this. And I just can never really resist. The best is when people aren't really expecting me to make a joke about my disability and then I just say something and then people don't know if they can laugh or not. But I think it's a way that I use to just make it more approachable or palatable, I guess to keep using the word. I think it makes people more comfortable with it, they see that I'm comfortable with it so they're less afraid to ask

questions. And also, it's just, it's fun. I have like a series of different socks that I'm accumulating. So, I have a pair that looks like a shark is like biting my leg that I really love. And we were on a camping trip for the first-year students, like an orientation trip. Claire and I were running this group, and I was wearing my shark socks and one of the new first years was like, "Oh, I like your socks. And I was like, Oh, do you? Do you get it? Do you get why I'm wearing it? And he was like, yeah, I get it. And I was like, do you" and I think I said it like two or three times. And then it became this running joke. But I think it just made the whole group a little bit more comfortable with asking me questions about it. And I mean, we were going on a lot of hikes. And I think they were like, wanted to make sure I was okay with all of that. And it just breaks down barriers I think much more quickly than just talking.

Claire Rhee:

Can I ask a potentially invasive question?

Maité Van Hentenryck:

Sure.

Claire Rhee:

Does it cross the line when other people make jokes about it? It depends. It depends who. If it's somebody that I'm close with I tend to really appreciate it. If it's somebody that I don't know super well, it can sort of land wrong. So once in college, I was in one of the late-night dining halls one night and this guy from my Spanish class came up to me and I was wearing shorts. And I guess he had never seen my legs before. And he just came up to me he was like, "Oh, Maité, why are your legs so gnarly?" And I think he meant it as a joke. But for me, even though he was coming at it from a friendly joking way, for his first word to describe a part of my body as gnarly, was really hard to swallow. And I didn't think that we were like, we were just like, in Spanish class together. I didn't really know him very well outside of that.

Peter Poulos:

I think what he meant was, *dude, your legs are gnarly.*

Maité Van Hentenryck: Yeah, that's what everybody told me after but

Peter Poulos:

gnarly

Peter Poulos:

Steven

Steven Losorelli:

On the point of comedy. There's a quote about this independent bookstore in San Francisco and how the owner had died. And the quote was "Lawrence, he makes you laugh and then he hits you with the truth." And I think that really resonated with me in some ways, in the sense that it softens people up. Self-deprecation is a great form of making people feel endeared to you. And then once you draw them in, you can then make them see your perspective in a different way. Sometimes it's hard to balance that line between accusing people of not being supportive of a disability and coming off as very harsh. And the approach I've always taken, and it's not the only approach, is to make comedy of it. And it's also, just as a human, it feels better to laugh about things the same way we use comedy for almost any aspect of society.

Peter Poulos:

Sometimes I will let people do things to me that I wouldn't normally because I know it'll make a good story. Like this one time, it was at an airport, picking up a rental car and these people saw me sitting outside with my crutches on. And they came up to me and they asked if they could pray on me. And I was thinking, I was like, *Oh, no, you know, I'm not very religious. And I don't really want to be healed right now.* I do want to be healed, but I didn't really believe that they were going to heal me, oddly enough, but I still let them pray on me, because I thought it was funny. And I thought it would be a really good story to my friends afterwards that I got prayed on, and that they put their hands on me. And then they asked if I was better after and I said, *No, I'm sorry, nothing changed.* And they seemed a little sad.

Claire Rhee:

I though you meant *prey*, like, *predator*

Peter Poulos:

No, *pray on, pray on someone.* You can pray to someone, you can pray for someone, but if you pray on someone, that's like using your hands. I pray on this microphone.

Steven Losorelli:

I think you should have said yes, they did heal you.

Maïté Van Hentenryck:

Thrown the crutches aside and taken a few steps.

Peter Poulos:

They did. But I don't want to leave my limp behind. They healed me but I don't want to show it because I get so many perks from being disabled. Maïté, I have another question for you. In your article, you also write beautifully about words you wish you could have shared with a young girl receiving a kidney transplant but didn't get the chance to. The question is what words would you like to share today with persons with disabilities, or their allies, as they interface with the healthcare system, either as physicians, or patients, or even both?

Maïté Van Hentenryck:

I think I would say, I mean, at the end of the day, you are the expert on your condition. And just because there's a doctor with some degree after their name that is telling you these things will help you, and you should do these things, that doesn't necessarily mean it will work for you. So, finding a provider that you think will really take the time to listen to you and figure out what works for you, I think is really important. And somebody who takes the time to actually listen to your story and who actually seems to care about you and your quality of life beyond just whatever condition you may have. I think the relationship that you can have with a provider is the most important part of the whole process. And if you have somebody that is open and willing to listen to your story, and maybe be open to some things that they're a little bit less comfortable with or less familiar with, because you know that it's worked for you in the past, I think that's really important. That's what I would say to patients. Yeah.

Peter Poulos:

I wanted to ask you guys, as you contemplate your future careers, what progress in medical training with regard to disability rights and accommodations are you encouraged by and what flaws in medical training, along those same lines, are still a source of concern?

Maïté Van Hentenryck:

I think even starting first year, I feel like these conversations about disability were very few and far between in our first few months of school. And I don't think that's at all the case anymore. I think, since we started MSDCI, it's really grown. And we were initially worried about continuity of the group and that hasn't been at all a concern. The next sets of leaders have been incredible. It's been incredible to see all the things that SMAC has done and how people actually know about SMAC. Even people who don't really identify as having a disability or aren't really big parts of that community, people know what it is. And then there's just there's just little things; I think being on rotations is generally a hard time when you have a disability and finding accommodations and things like that. And I think I've been really encouraged by how many people have taken the time to ask me if stairs are okay, or just at the beginning of working with me just doing it in a very like normal non-judgmental way. Just opening up the floor if there's like anything that I want or

need from the week. I've seen just a lot of like really great progress. Maybe it's just anecdotal, maybe these things would have happened regardless, but it does feel like, since at least since starting med school, people are more aware of it. And I hope that will just continue to grow.

Steven Losorelli:

I think that one thing we've all spoken about at length at different times is what are they called, the core standards, to be a medical student. They include being able to stand for long times. It makes this case for the total ableist human being, that that may be true, if you go into a certain specialty, you need to be able to do certain physical things or not. But it definitely should not be exclusionary from all of medicine. And I think that changing those fundamental standards is important. I think many people who identify as having a disability are afraid to even go into medicine because it's such an ableist culture.

Peter Poulos:

They're called technical standards. It's true.

Okay, Maïté, what do you think is going right in medical education and medical training now in the disability rights and accommodations arena and what is not even close to being where it needs to be?

Maïté Van Hentenryck:

I can speak to Stanford, but I found that everyone has been really accommodating. When you go to the administration, when you go to the clerkship director, everyone's been really wonderful about trying to make things work for you. I think something that's hard is that disability is such a spectrum. And what works for one person doesn't necessarily work for somebody else, or the person that's tasked with helping the student find those accommodations, isn't familiar with their particular set of circumstances. So I think the onus falls a lot on the student, the person that needs the accommodations, to find the accommodations, and to find something that will work for them. And Stanford has always been super supportive and willing to make those changes, at least in my experience, but the solution always has to be driven by me, by the person asking for those accommodations. And I think that's really tiring as a person with a disability, to always have to be the one thinking of those creative solutions and be the one figuring out how the system works and how you can fit into it. I don't really know what the solution is to that because it is so hard to figure out something that will work for each person individually. But I think that's something that's worth talking about.

Peter Poulos:

Yeah, we need a team of experts who, this is all they do, is disability accommodations for people with all sorts of disabilities. And hopefully we'll get there. That's what my goal is, you know, to create a disability center and one thing that they do is give awesome accommodations to everyone.

I was going to ask what kind of accommodations have you guys asked for, or received? I say that asked for or received, because not everything you may have asked for you received as an accommodation. And if you could talk, what sorts of accommodations have worked and what have you tried that seemed like a good idea, but maybe wasn't and didn't work.

Maïté Van Hentenryck:

I am always a little bit afraid to ask for accommodations. For me, it's like things like standing for a really long time are really painful. I have like a lot of arthritis in my ankle and so especially on my surgery rotation it was really challenging when the cases were really long. Everyone was really supportive but the way that the surgery rotation is designed, you kind of end up working with all different kinds of people in a day, it's very hard to predict who you're going to be working with. So even though everyone was super supportive, and everyone I talked to you said, "you know, grab a chair just like tell people when it's too much or like go do some floor work instead of scrubbing into the surgeries" it still was hard to say no, when the attending would come in and say "okay, well, this case is starting, let's go." Or if they ask me to retract for a couple hours, it's really hard for me to say no in those situations.

And partially that's something that I should work on myself, speaking up more. But I also think it would be nice if generally people recognize that that is objectively a hard thing to do. That for everybody it's hard to stand for, you know, 12-hour days, it's hard to pull your whole-body weight on a retractor for a couple hours. And so, if there were a way to normalize just asking if that's okay to all your trainees and just checking in repeatedly and seeing how people are doing I think that would already go a really long way.

Peter Poulos:

I imagine you must feel torn though, anyways right? Because you want to learn and you might want to see that case and be scrubbed in on that case, but maybe not for five hours.

Maïté Van Hentenryck:

Yeah, yeah, totally. And I think there were definitely times where I was exhausted and just tried to make it through to the end of the day. The exhaustion maybe registered as lack of interest or just wanting to not be there anymore, and I didn't really know how to go about that differently.

Claire Rhee:

I think something that underlies a lot of this is like the physical martyrdom that people take on in medicine in general, but especially I feel like in surgical subspecialties. I remember sitting in like a surgery and like retracting for a couple hours. And then this older attending comes in and he sets up like that entire retraction kit with the ring stand and these bendy things that retract everything, I'm like, excuse me, why was I doing this? And I've spoken to other attendings and residents about it that I'm closer with or that are honestly my doctors and been like, why do you do this. And like, it's just the way the field is, and nobody likes it. But it's a rite of passage, which to me is, is really unhealthy. In general, that people take some quiet, kind of like a little bit of twisted joy in making sure that the resident can retract for four hours or the intern can retract for four hours, like it's a rite of passage. It's like hazing, but like, not legally bound to any rules.

And I wonder how many wonderful people we're keeping out of medicine by perpetuating a culture where your needs always have to come second. And even in really small ways, like the fact that everyone encouraged us as medical students to just leave when you can. But also, if you do stay, you get these like little brownie points, and everyone praises you. So, it's not necessarily that that's a penalty, but you're missing out on some kind of like learning experience in that sense. I go for appointments a lot. And every time I go for an appointment, I can't scrub into a case, or I can't see this patient, or I can't see this procedure. And no one's gonna move a surgical case for me to come back in 30 minutes. And I just wish we had more protected time off to do those sorts of things. And I just can't restructure medical education. But I think if the field of medicine were more geared towards recognizing us as humans, us as humans with health needs, it might be a little bit easier for everybody.

Peter Poulos:

Absolutely. Well said. I guess that you haven't really asked or received any accommodations it sounds like.

Claire Rhee:

I have been written for accommodations because I'm scared of retaliation if I'm suddenly viewed as not having hit certain milestones. I take a very protective approach, so I think I'm written for accommodations for like, extra bio breaks or something like that. And it doesn't come, it comes down, to me needing extra time for different appointments because I also don't want them to think that I'm somehow unprepared to be on their team, which is weird. I'm carrying a lot of stigma on myself that honestly, when I do tell my team, like, *hey, I'm having a terrible migraine*, they're like, "go home." And then I see that as a challenge, and I don't want to go home. So, there's a lot of internalization of this kind of stuff.

Peter Poulos:

Can you explain a little bit more about this strategy of being written for accommodations and how it's protective?

Claire Rhee:

If I were to go to an appointment and not have it cleared with the whole team, if they were to retaliate, and say, like, Claire didn't show up for XYZ case or didn't meet XYZ standards, it's written in there that I'm allowed to go for these appointments without facing additional repercussions. In theory. Then you get into like the whole LCME guidelines

and how many absences we're allowed to take and whether or not doctor's appointments count within those absences or are protected by the ADA and it gets really messy. It's there in case I need it. It was really helpful in the beginning when I didn't understand how to talk to clerkship directors, and I could just sort of send this paper to them that said that I needed sort of like to be treated like a delicate snowflake. And it is coded in a way such that they don't know exactly what my disability is, and they're kind of just like, okay, let us know what you need. But now I sort of am very upfront about it. And the clerkship directors in general are very accommodating. It's sort of like how much autonomy they have over the individual attendings that will be writing your evaluations and like sort of managing the team dynamic.

Peter Poulos:

I object to the snowflake choice of words.

Claire Rhee:

Someone in medical school called me a snowflake and since I've been using it very liberally to describe myself, is my way of taking ownership of the word.

Peter Poulos:

Are you using liberally as a pun?

Claire Rhee:

Not intentionally.

Peter Poulos:

There's a lot of layers to this question. But anyways, Steven, have you ever asked for or received accommodations?

Steven Losorelli:

I've asked people to speak, to sit on the left side of me if they're going to be a soft speaker and they want to have a lot of conversations. I've had several attendings, so I'm applying into otolaryngology, and so I've spent a lot of time in the O.R. And if you're standing next to somebody who's a soft speaker, and they're asking you to retract and do all these movements, I just generally ask them to let me know, or to speak louder, or let me stand on the opposite side when possible. So that's the extent that I've sought.

Peter Poulos:

What recommendations do you guys have for students applying to medical school, as far as disclosure goes?

Claire Rhee:

I have very disheartening advice; it's sometimes better not to disclose. People will sometimes see it as a merit and will sometimes use it against you. And I want to say that schools that use it against you, you don't want to be there anyways. But it's very individually based. So, you could have one person reading your application who doesn't see the journey you've gone through as a merit. And that will get you precluded from the admissions process at a program that might perhaps have been very supportive of your disability, or of your experiences in the medical field.

Peter Poulos:

So how does somebody decide whether or not to disclose? My advice I give to people is that if they don't have to disclose or feel this compulsion to disclose, that they don't have to, and they probably shouldn't because why take the chance. But I think that there are certain people whose sense of identity is so strongly tied to their disability, or their experiences with their disability have informed their decision to be a doctor, and it almost feels dishonest to them to leave it out. I would say for those people, it probably does make sense to disclose.

Claire Rhee:

Yeah, definitely. And I think if it's like strongly part of your identity and motivation, you should definitely share it. Because you want people to see the full picture of you when you're deciding what school you're going to go to. I think there are ways to spin it, and this is like snaky political Claire coming out again. Where if you spin it in a way, it's like something you've overcome, and make sure to say, the positives that have come out of it. Even if it was the most awful experience of your life, committees are more likely to look upon it more favorably.

Peter Poulos:

The O word

Claire Rhee:

What is the O word?

Peter Poulos:

Overcome

Claire Rhee:

Oh, yes. It's always about that, what is it, it's called, like inspiration porn? Am I allowed to say porn? Oh, well.

Peter Poulos:

Yeah, inspiration porn. It's a little different, but it's the same.

Claire Rhee:

A lot of these application processes want to see things that are, I think I read this article about a lot of educational constructs being rooted in white supremacy, saying things like, everything needs to be constructive. You have to think in a way that is progress oriented and thinking about how things were overcome, instead of dwelling on the things that were bad. These are a lot of educational constructs that I've also bought into and that exist within most American educational systems that are really unfair to certain people who have not had the privilege to see their experiences as something good, because an experience can truly be purely bad. And it's unfair to force somebody to see it otherwise, just because you want that to be a nicer application to read.

Peter Poulos:

Steven, do you have advice for applicants to med school?

Steve 49:31

I think like Claire mentioned, it's so person dependent. Personally, it's so linked to my entire trajectory into medicine and through medicine, that like Claire mentioned, I would feel like I was cheating myself if I wasn't honest about it. And I think for me the cost benefit of do I write this or not write this, it was outweighed that I would rather go somewhere that appreciated my trajectory. And I think I just took the gamble that the assumption that people would have about, a lot of people are not familiar with this condition, so they may not know exactly what I look like, or what I can do and what I can hear, what I can't hear. I think it's kind of a gamble still, even for me, in terms of what assumptions people are going to make and how that might affect them throwing your application in the don't read pile.

And I think every applicant has to make that decision for themselves. But I would hope that we move to a place where everyone feels comfortable disclosing if it's important to them, and that it would never adversely affect your application. It's just very optimistic. But that's what I think we are all doing MSDCI for in the first place.

Peter Poulos:

Yeah, I do you have anything to add to that?

Maité Van Hentenryck:

Yeah, I think I'm similar in that I can't really not disclose it. I don't think I would be here, I don't think I would have gone into medicine, if I hadn't spent, you know, every year of my life, going through these procedures, and just going to the Children's Hospital pretty much more days than not all growing up. And so I think when it came time to write my personal statement for medical school, it didn't even cross my mind that I couldn't, that I wouldn't disclose it. And there was no other story I could tell; this was my story. But at the same time, people would know when I came to interviews, like it's very obvious. So, there was no real way that I could get around telling it. Maybe this year, because residency interviews are all over Zoom, I could have hidden it. But I have felt like the times that I have talked about it with my teams, and when it's come up with patients, that it actually makes for a much more meaningful experience. And that felt important to me. So, it's part of who I am, and I think it's what will make me the doctor I will be. And it felt like an important story to share.

Claire Rhee:

I also want to say that being able to hide it and to choose whether to disclose is a huge privilege that I benefit from. And I think that the people who do choose to disclose whether or not they have a visible or an invisible disability, are so brave. And that is the aspirational goal, right? Is that they're able to do that and that they're able to push these programs into seeing that and grappling with that and accepting that and seeing it for what it's worth. Which is so much, like as Maité was saying, it allows for so much more connection with patients, and I think such improved patient care. Even in my short six months on the wards I've seen how people who are comfortable with, or at least 2% plugged into the disability community, how they're able to provide better care for their patients who might communicate differently. And it's so different when you're coming from that place.

Peter Poulos:

I have two thoughts. Number one, I think whether or not you disclose depends, can depend, on how strong your application is in general. And that if you're hoping, just hoping to get into one school, and you don't want to take any chance at all, then that could factor one way. Whereas if you are a stellar academic candidate, or stellar in so many other ways, then you can really afford I think, to disclose and find that school that's willing to accept you, despite of your disability or because of your disability. The second thing I would say is that it is a risky decision to not disclose, especially if you have a severe disability because they can be tempted to want to retaliate against you for not disclosing and treat you differently because you sold them something that wasn't the truth, or you weren't forthright or upfront with them. That's the risk of disclosing after the fact. So yeah, I mean, that can upset people, can upset people with a job or at a school. Like why are they only telling me this now? You know, they clearly aren't an honest person.

Steven Losorelli:

I'd say it's very therapeutic to talk to y'all about this. I think that's the reason that we all like MSDCI and we're attracted to each other as friends in the first place is because it is a very isolating experience sometimes. Especially because disability is so heterogeneous, that to find other people to commiserate about.

Peter Poulos:

I feel like we've come so far since that first meeting. I just can't even believe how far we've come with SMAC and with MSDCI. It was only in October 2018 I think when we met, so I guess yeah, two years now.

Claire Rhee:

And the fact that you've gotten protected time off to do this kind of advocacy work is incredible. That you started ERG, employee resource group. That's amazing, like you took the tiny, tiny seed, and grew it into the big, big tree that it is. So, congratulations.

Steven Losorelli:

It really is so amazing. I remember you were first talking to us and you were unaware of disability community in almost every way, and you had told us how you had never really identified and now you are leading SMAC at Stanford. So, it's just so cool.

Peter Poulos:

Culturally disabled and proud. Disabled with a capital D. You guys really motivate me because the unfairness of what happens to people on the wards just doesn't sit well with me at all. And, you know, there are students who, you know, have come to me, even recently, like within the last year with this heavy burden of being discriminated against on the wards, and it is discrimination. And they don't even know about MSDCI and they don't know about the Office of Accessible Education, like the stuff isn't posted. Especially early on, when they're first being diagnosed, they may not realize that they even have a disability. They don't know what they have, it can be very stressful and very isolating. So, I hope that we at least make people feel less alone. That was actually the proudest thing about me about the conference we had in June, was all the messaging I got around like, I finally feel like I'm not alone. And I mean, I owe so much of my success to you guys. And so, thank you for that.

Claire Rhee:

Oh, thank you so much.

Steven Losorelli:

Thanks.

Maité Van Hentenryck:

Thank you, this was great.

Peter Poulos:

Thanks, you guys.

Music Attributions:

“Aspire” by Scott Holmes