@Risk S203 – No Substitute for Lived Experience

[Music plays]

Jodi: Hey, I'm Jodi Butts. And welcome to @Risk.

There is no substitute for walking a mile in someone else's shoes. There is no substitute for listening to and including people with different lived experiences in decision making. And there is no way to achieve equity without leaders working to overcome barriers and to take risks.

Sara Rotenberg is one such leader. Sara self-identifies as a disabled advocate. She hails from Toronto and is a DPhil student in the Nuffield Department of Primary Care Health Sciences at the University Of Oxford where she studies as a Rhodes Scholar.

Sara has worked on a diverse set of issues ranging from access to vaccines to public transportation systems. She has overcome obstacles and is helping build a more equitable and accessible world one project at a time. Please hear her story, her insights, and maybe approach your work, whatever it is, differently. And let's also grow our expectations of what good government should look like.

[Music swells, then fades out]

Okay. Thank you for joining me Sara, and welcome to @Risk.

Sara: Yeah, thank you so much for having me today, Jodi.

Jodi: Sara, how did you come to identify as a disabled advocate, and what does that mean to you?

Sara: Yeah, that's a really interesting question. So I was identified as disabled from a young age and received a wide array of supports throughout my life. And at the age of 18 I decided to move to Singapore to go to university. And I had never really encountered barriers because of my disability but started to in the educational system there, to the point where I decided to leave university for a bit.

And so learning about this inequity in education firsthand really made me see that the world isn't so accessible to everyone. And I was fortunate to live in a country and society that valued accommodations. And so this passion is really personal for me and really made me think of how I could use my experiences as a disabled person to improve advocacy around the world. And so that's something I'm really keen to do, and to sort of just move forward with this. Yeah.

Jodi: And so just tell me a little bit about your experience in Singapore. And I'm sure you raised the issue. What was the response from the university when you requested accommodations?

Sara: Yeah, it was- it was complicated. It was a new university with lots of tremendous benefits but also just different standards and rights around inclusion of people with disabilities. And so it was a real learning moment for me as an advocate trying to frame my perspective and my rights, as well as balance that with some different cultural interpretation of what disability means. And so it really expanded my view and made me want to continue working on disability advocacy.

Jodi: Excellent. And so what would you say kind of the overarching goal of your advocacy is?

Sara: Yeah, I think that my experiences have shown me that there's a lot of common sense, low cost but high impact things that can improve accessibility for people with disabilities and ultimately make our society more inclusive.

So a great example of this is I had the great privilege of working in India, working on how the Mumbai metro, which is one of the world's largest development projects in the world where they're building about 300 kilometers of metro, and trying to work with them on how to be more accessible. How this could be a tremendous opportunity to just have universally inclusive transport in one of the most largely or densely populated cities in the world.

And so one of the simple things to do this is to have consultations with people with disabilities. Ask what needs to be accessible, how the designs could be improved for accessibility. And that's just a simple thing that has a huge impact for a lot of people.

And so I think that trying to build this into our work and create a culture of accessibility as part of becoming a more inclusive world is really important.

Jodi: So forgive my ignorance, I would have thought something like large transit systems that there might be a community, a global community around the world that would share best practices and experiences with designing symptoms- sorry, systems. But it sounds like you're saying that the Singapore- er, the system in India didn't even think to kind of reach out to other transit systems.

Sara: Yeah, they had a lot of consultations with other transit systems. And there were definitely some great networks that really work on best practices in transport. But accessibility is one of those things that if there isn't someone in charge of it or a focal point, it doesn't necessarily get implemented. And so there's a huge need to sort of have accessibility leadership, or have it sort of embedded into the culture to make sure that it happens in anything from a health system to a large transit system, an education- educational institution. Whatever it is, there really needs to be a focus on accessibility.

Jodi: That strikes me as a really important point, that idea of ownership, responsibility, culture, right, leading the culture. And that strikes me as something that's really applicable in many settings.

Sara: Definitely, yeah.

Jodi: So you had not the best experience at the university in Singapore. But today you're a Rhodes Scholar. So how did you regroup from what must have been a challenging experience?

Sara: Yeah, it's an interesting story. I think second time's the charm is probably a good way to sum it up. But I think that my experiences in Singapore really motivated me to go back to school. I realized I really- I truly loved learning and being in an academic environment. So it was the right thing to do for me.

And then I also had the great privilege of going to a school like Georgetown in Washington DC where I had a lot of different opportunities. So I got to work at the Canadian embassy in the trade department. I took a lot of classes on India which eventually led me to go there for a while. I got to make furniture and really explore the area of global health, which is what I studied there.

And so all of these things and different experiences that I was exposed to really helped me to go back to education and think about applying something for something like the Rhodes.

Jodi: I think so many of us have experienced setbacks. Not necessarily to disability, but maybe other areas. Where did you find the strength to kind of regroup and re-launch, and kind of who helped you with that?

Sara: Yeah, I would say my parents for sure. I definitely am very lucky to have just really incredibly supportive parents. So they definitely get a shout out. And a community that was there to support me when I moved back home for a little bit and just took a different path.

But I always remember when I was growing up, my grandmother used to say that no means try harder. And so I think I just I grew up with a lot of resilience. And I knew I wanted to get a degree and to really make a difference about what I was passionate about which is health policy. And so I knew that going back to school was like the right- the right thing to do even if it was a little later than I expected.

Jodi: Well, that's awesome. I mean kudos to you and thankful that this community existed for you. So now you are a Rhodes Scholar. How is that helping you with or supporting your advocacy?

Sara: Yeah, there's a lot of ways that the Rhodes has definitely helped me. I think firstly just the UK is one of the most disability inclusive societies in the world. It collects a lot of data on disability inequity and has a lot of academic excellence. So being- and also a huge disabled community of activists. And so being able to live in the UK is such an immense privilege to be exposed to a culture that has really worked on accessibility and inclusion.

And then of course being at Oxford as well and being in like one of the top academic departments for public health is an incredible opportunity. So those things have definitely helped. But I also think being part of a community of future leaders, many of whom don't work on disability, has given me sort of a platform to talk about these issues and raise it to people who might not be aware how their own passions and work impacts people with disabilities and how they can be more inclusive.

But I definitely find that I'm so fortunate to be in a position of privilege within the marginalized group of being disabled. And I think this sort of duality of both having a having been marginalized and then also sort of having academic credentials to make me taken seriously when I talk about policy has really helped me advance my goals. And so very- I'm just so grateful for the opportunity to be in the UK and at Oxford, and then also sort of have this community to help me advance my goals.

Jodi: Now you have worked on a wide range of topics. It was something that immediately jumped out at me. Because we live in a world that tends to push us towards more narrow specializations, deep but narrow. And so I wanted to ask you, what has allowed you to do that? Why have you wanted to do that?

Sara: When I was little, I was just so interested in the world. And like I always used to watch videos about different countries or read books. And so I had this sort of curiosity about what went on, and then I also thought I've read the news a lot. And so I think seeing a lot of inequity made me think about how Canada, I was so lucky to grow up there. But that there was vast inequity around the world.

And so when the opportunity to move to Singapore came up, I think I really asked myself the question, if not now then when? Because I was 18, like I didn't have a family or any sort of anything really tying me down to Toronto. Though of course my parents still live there and I'm very close with them. But it sort of seemed like the perfect time to explore, especially at a time when sort of global interest in Asia is- it's really important to have some experience there right now given demographics and global power ships. And so I thought it was it was sort of a great opportunity that might not come again.

And I absolutely loved it. Like I really valued the experience I had there because I think it showed me a lot about the world. It took me outside of Canada. It allowed me to reflect critically on my experiences. And so it was a really great experience for me to move away at such a young age and just try a bunch of different things.

Jodi: That's excellent. And have you ever had the experience where your work in one area has allowed you to see more clearly a completely separate and different issue?

Sara: Yeah, I would say a lot of my work in India has really shaped how I view- how I view health systems, even though not all of my work was related to health systems while I was there. But just seeing how the bureaucracy works within transport, and how there's… If a train doesn't come on time it's a very different consequence than if a doctor doesn't show up to work. But the sort of same systems and accountability that you see in different ministries when you're talking about something as complex as a transport system, particularly one that's under development, makes it really important to understand how a health system can evolve.

Because it's not necessarily as immediate the impact but we see right now, for instance with Covid when you delay surgeries, when you have health system capacity at the brink, how it impacts other aspects. And so trying to think of how we can be more responsive in our health policy the way that you might be in a transport system has really helped help me think about my work on health policy, for instance. This is just one example but it's been super helpful to think about it that way and to have these different experiences for sure.

Jodi: Oh, that's fascinating. Thank you for sharing that. So you mentioned Covid-19, the topic we love to hate to talk about. But you have really taken on a significant leadership here in Ontario. So tell us, where has your advocacy taken you during the pandemic?

Sara: Yeah, I think we've all been just awestruck by the gross inequity in the pandemic. And I think this has been particularly true for people with disabilities. So back in March 2020, I was fortunate enough to be working with the World Bank Group in their disability team. And I've realized in my work in the last five years that there is not… There's a lot of health policy people and there's a lot of disability people, but there's not a lot of people who do both disability and health policy.

And so because I was working there and because of the pandemic and this sort of lack of crossover, I began working on some of the forecasting what some of the issues might be for people with disabilities in the pandemic.

So for instance how public health measures that we had put in place really disadvantaged a lot of people with disabilities or weren't even possible. So one example is, for instance, if you have a physical disability and require in-person care social distancing isn't possible. And so what steps need to be taken to protect you?

Or for people who rely on lip reading wearing a mask has become a huge barrier in the pandemic. And then also in the very early days, having access to information, through captions or interpreters, which a lot of governments weren't yet doing. And so trying to think of how the World Bank could help through that.

And then, as the pandemic progressed and I started my studies at Oxford, there started to be a lot of studies, particularly from the UK, that revealed the inequities among people with disabilities. So here in the UK, for instance, you saw mortality rates that were three to six times higher among people with disabilities, depending on impairment type, than people without disabilities.

In the US, for example, you saw that people with certain neuromuscular conditions and ambulatory ability were at 25 times higher risk of dying than people without.

And so this really made me think, wow, there's massive, massive inequity. This is a population that really needs protection and access to the vaccine. But when a lot of governments started rolling out the vaccine programs or talking about prioritization, there was no mention of people with disabilities, no mention of accessibility.

And so I used a lot of my work on vaccine accessibility in the past, a lot of work on accessibility and sort of my knowledge in health policy to start advocating. So writing emails, writing reports. And it most recently culminated in one of the Ontario Science Brief Table's report on how we could be more accessible in our vaccination program to ensure we reach people with disabilities who we know are at higher risk of adverse outcomes of COVID-19.

Jodi: Now, do we collect this type of data? How are we doing as a province and a country in terms of reaching people with disabilities with vaccines?

Sara: That's an excellent question, because that's one of the biggest problems actually, around the world. It's not just a Canadian problem. In Canada, we don't collect data by disability status. And so that hampers our ability to really understand how the pandemic has specifically impacted people with disabilities.

In Ontario specifically, we have some mechanisms to create measures of disability to understand the impacts, but that is not often shared publicly. Though ICES has started to release that data. But what it shows is there's still inequities in reaching these people. And so if we can really work on improving accessibility for people with disabilities, whether that's having an accommodations person on site who someone can talk to, whether that's having at home vaccination, we can really improve uptake among this community. And that's sort of the next step.

But monitoring it is definitely key to sort of understanding and then creating strategies to address that. And if we did have better data, we definitely could be a lot more proactive in our work.

Jodi: Yeah, I think this is one of the, I guess, less obvious costs of the anti vaccine movement. It's so loud, and it attracts so much attention that I think many people will look at the percentage of the population who remains unvaccinated and assume it's a choice. But I think what you're saying is there's still people who may want a vaccine, we just haven't created the systems and accessibility support to allow that to happen.

Sara: Absolutely, there are definitely still barriers to being vaccinated, though we've gotten a lot better since April when people were first- people with disabilities were first eligible in the phase two of Ontario's rollout. But yeah, I think that reaching the last 25% and really going the last mile on a lot of reaching different communities is important. But particularly for people with disabilities who do want to be vaccinated. But if some people have to organize multiple buses, buses sometimes don't show up on time. It's specialized if you're a wheelchair user, for instance. And so I think it's not- it's definitely not as easy as dismissing those who aren't vaccinated as anti vaxxers. It's more complex about how we can really support uptake in these communities for some of whom it's a lot more difficult to access vaccination.

Jodi: So has there been, do you think, growth in our understanding? When people talk about the pandemic, for sure, and I think you said this as well earlier, the inequities in our world really were brought out in relief. But are we also seeing pathways to doing better?

Sara: Absolutely. I think that there's definitely been some improvements. I think disability isn't something that often comes to people's mind, even though it impacts 15% of the world's population and 22% of the Canadian population. But I think people have started looking at the data and started to think, Okay, how can we do this?

And definitely when I talk to people about accessibility, and they're not as familiar with it, they then start thinking about how they can bring it into their practice. And I think that's an important cultural shift, right? Because you want people to think, well, of course, I want people to be on board with my cause. But also, just being able to charge people and show people accessibility isn't this sort of black box, there's a lot that can be done and that isn't so high cost or complex.

So a great example of this, for instance, is with the vaccinations, one of our main recommendations from the Science Table brief was to put an accessibility point of contact on all advertisements for pop up clinics or other clinics and ways to get vaccinated. Because sometimes it is just you have a question, it's easily answered. So for instance, is the elevator working today? And that will make you go get vaccinated rather than not.

And so I think having these more conversations about accessibility can definitely bring it into the forefront as we move into recovery and move forward from the pandemic.

But I also think one thing that's sort of a barrier here is there's a real leadership gap on disability. There's very few of our leaders, either elected or appointed, are people with disabilities themselves. And I think that when you don't have someone in the room or around the table who has that lived experience, it's very difficult to meet the needs of this large minority in Canada.

And so trying to figure out how when we talk about equity, diversity, and inclusion, how we can also bring disability into that conversation to make sure that we're addressing the needs of the 25% of Canadians who are disabled.

Jodi: Yeah, that's a really great point. My personal experience, or my personal view, is that during the pandemic and as we're hopefully coming out of it that efforts around equity, diversity and inclusion have really been lifted up. There's new momentum behind it. But having said that, it does require a lot of discussion around who is going to be lifted up by these policies. And, quite frankly, sometimes people with disabilities are left out of the discussion.

Sara: And the important thing as well is that it's so intersectional, right, because there are intersecting systems of oppression for Black and Indigenous people of color who are disabled as well. And so just trying to work on these very important initiatives in isolation isn't going to fix a lot of the structural issues that we need to work on as a country.

Jodi: Yeah, and I think your earlier comments bring up another really important point, which is everyone tries to adopt a mindset of equity, diversity, and inclusion. People want to design programs and services and goods to be accessible. But at least at this point in our evolution, very difficult to do without actually having a leader present to really provide meaningful contributions to what good accessibility looks like.

Sara: Absolutely. There's definitely… It's not something we learn about in school, about anything about accessibility practices. To be frank, it's not even something I've really learned about until my experiences in Singapore. But I think that there's a lot of work to be done around sort of the education so that we're creating a culture of accessibility, but then also really amplifying leaders with disabilities to ensure that their voices are heard in important policy and governance decisions.

Jodi: Recently in Ontario, The Draft Standards For Accessibility In Health Care were released under the Accessibility for Ontarians with Disabilities Act. And those were out for comment. And I know you have written on the importance of training in the health care system. Can you tell us a little bit about what your findings and learnings were that came out of that literature and study review?

Sara: Yeah, so good training is hard to come by in the health system and for health workers. But there's a lot of different small lessons we can learn to make sure that it becomes sort of part of the culture of medical training.

So one of the main things is including people with disabilities in it. I think that there's a great phrase that's often thrown around, it's nothing about us without us. And I think that holds true for training as well.

And then I think another part is ensuring that it's throughout the curriculum. Training is often like, on one day you go to one lecture and there's a person with a disability there, you learn about a disability, and then that's it. But there is no real sort of continuum of learning and thinking about disability.

And the last part about it, I think, is that's really siloed. So you learn about sort of the health implications of having multiple sclerosis, for instance, or being blind. But you don't learn about sort of the social things that would make any… Would make a treatment plan, or would make sort of how you perceive the world different.

And so I think trying to think about how we can really improve training, both in terms of content but also in how we work on it throughout the curriculum to ensure that we're really meeting the needs of people with disabilities. Not only their health needs, both related to their disability and other health needs. But more than that we're really working on the culture of inclusion to understand the social needs as well.

Jodi: And I would think that it's, I mean, not to be selfish, but it's an opportunity to lift all boats, right? The more we start thinking intersectionally, the more we start thinking about the diversity of experiences, the higher quality the care that we deliver is.

Sara: Absolutely. There's a recent study done in the US that said only about 40% of physicians were confident to provide care to people with disabilities. And then I think it was also about 80% thought that people with disabilities have a worse quality of life.

And so when you have those perceptions about people with disabilities, there's no causal link. But at the same time, I'm sure it impacts how you deliver care. And so if you can sort of change those attitudes, have really good policy in terms of accessibility and inclusion in the health system, and then also work on training, which I really see as like a gap in between policy and implementation, then I think you can really work on building a more inclusive health system.

Jodi: And I want to make sure that I'm appreciating the full conclusion too. So it's like, yes, when you're in the educational system, so you're in a Faculty of Health Sciences, Faculty of Medicine.

But it's through too even once your credentials and license that that training needs to continue to happen.

Sara: Absolutely, yeah. It can't just happen once and think that you'll remember it for the rest of your life. It needs to- you need continuous reminders to be able to do something. Like riding a bike, you can pick it up again, but sometimes you need that reminder to make it happen and to make it smooth and effective.

So I think, yeah, it's throughout the medical education, which I see as more continuous than just a set time when you're in school or in training. You're always learning. So that's important as well. Yeah.

Jodi: And you mentioned the UK earlier. Are there other health systems that Ontario and other provincial and territorial systems can learn from? Where would you point people to look for high quality training and a system that is designed well for accessibility?

Sara: Yeah, on the training front, I think the UK is just starting to have some more, but there's definitely a lot of work to be done. Australia has some mandatory training on intellectual disabilities and autism. But again, that this is all just starting up in more recent years. But Australia is probably of all the countries in the world has one of the most significant ones. There's a lot of work being done in India as well.

We tend to think of only looking at high income countries, but often low income countries have- low and middle income countries sorry, have really advanced topics that we haven't worked on yet. So those will be some countries for training.

And in terms of the health system, there's not one, unfortunately, that's really great, but some have different aspects that are really inclusive. So for instance, here in the UK, if you have an intellectual or developmental disability, you're invited every year for a health check. Because in the UK, they found that there's a 20 year gap in life expectancy between people with and without intellectual and developmental disabilities.

And so trying to do health checks, like just going to your general practitioner and seeing them for bloodwork and different things can help catch different comorbidities earlier and get them address. And so that's a really good example that, you know, with so many people without a family doctor in Canada, something that shows you could possibly slip through the cracks. So that's just one policy piece that could definitely come back to Canada and help, for sure.

There's a lot of international examples on different affordability mechanisms as well. Because in Canada, while we have a universal health system, we don't provide a lot of support for assistive devices or pharmacare. And so trying to work on that as well, especially as we head into a new government, can definitely improve how we're doing globally for people with disabilities.

Jodi: So during the pandemic, obviously it highlighted these inequities, as we've discussed before. Many people say, okay, you thought the pandemic was bad, wait for the increasing frequency of climate crises. The same people who bear the brunt of this virus, are also going to be more adversely impacted by increasing climate events. And I know you've written about or co-authored a piece in Healthy Debate about extreme heat events. Can you tell us a little bit about how should we be thinking about climate events? And, more importantly, preparing for climate events? How can we protect and serve our populations while knowing that this is on the horizon?

Sara: We really need to work on improving our resiliency for natural disasters for people with disabilities. And climate and heat is just one of those areas.

So for instance, when Canada was experiencing the heat dome, there's a lot of inequity that people with disabilities saw in the response. So often, people with disabilities are left on their own to sort of manage the impacts of extreme heat. But that's very difficult when there's not very many accessible shelters to, you know, escape.

There's a limited public funding for cooling. Air conditioning is still seen as a luxury. And so for people who live in poverty, that's not an option for them. And a lot of disabled people do live in poverty in Canada.

Or just inability to leave the house because of various sensory impairments that make your house more comfortable. It's very difficult to then really address those in the midst of a crisis. And what it really requires is better planning.

And so actually working on improving the infrastructure of public housing to be more resilient to climate change, and accessible. Investing in accessible shelters, or founding groups. Like in the US, there's a whole partnership on disaster preparedness and they have hotlines that specifically support people with disabilities to find accessible shelter, to find accessible transport, whether it's a flood, a hurricane, or an extreme heat event. And we don't really have those mechanisms in Canada yet, either from the government or privately, to really ensure when a crisis hits we're adequately supporting people with disabilities or other at risk populations like older persons, low socio economic groups, et cetera.

Jodi: Yeah, and I want to come back to a point that you made earlier. I used to work at Mount Sinai Hospital in Toronto, and when we would engage in disaster planning, we engaged our committee that was focused on accessibility into that discussion. Not all thoughtful design choices that heighten accessibility are expensive, but very difficult to integrate them in the context of a disaster. Easy to do ahead of time, almost impossible to do in the moment.

Sara: Yeah, investing in preparedness is… There's been so many studies that show it's so much cheaper. And it's a very similar principle with accessibility, both in in disasters and more generally. Like if you are building a building and you consider universal design principles, it's about 1% more on average, versus if you think when you when you then have to go back and renovate it and either add a ramp, add an accessible entrance, have a hearing loop, or tactile pavers for people with visual impairments. Those are quite costly. And so thinking about things from the start, I think that's a great entry point for inclusion and accessibility in particular.

Jodi: So this is the @Risk podcast, so I wanted to ask you have you ever, in terms of the incredibly rich topics that you've been engaged in and studied and throughout your advocacy work, have you ever used the vocabulary of risk or the mindset of risk in thinking about these issues?

Sara: Yeah, I think that recently we've talked… A lot of people like to use the word vulnerable to describe people with disabilities or other groups that have been adversely impacted. But I think risk is a different one because it actually doesn't have to be this way. If we really protect people and we invest in accessibility and make the world more inclusive, it's more a risk but it's not an inevitability that vulnerability suggests.

And so I think that trying to frame it in risk and manage those risks can definitely be a useful tool.

Jodi: So we've just concluded a federal election, there is an Ontario election going to happen in the spring, Nova Scotia just had one, and there's been some crises in leadership in other provinces. What should we be looking for in our leaders if we want to see greater progress on greater inclusion of people with disabilities in universal, accessible design? What do we need to hear from our leaders, and what kind of changes or indications can we look for on the ground?

Sara: Yeah, so I think there's three main things. Earlier we talked about data. I think that as we move past the pandemic, I think all provinces need to look at data systems, whether it be health, education, or economic, and just really working on that as a goal to bring Canada into the forefront of global policy making in terms of having the understanding and evidence to create better policy.

And I think that should be a goal, but it has potential consequence for people with disabilities who, because often because we don't have that data, we assume the inequity doesn't exist rather than actively working on things like accessibility. So making that a broad goal but particularly for people with disabilities will help.

Secondly, I think we need to see some more inclusion. Premiers appointing people with disabilities to panels or advisory groups to ensure that we're really including the voices of people with disabilities themselves will really push the inclusion agenda.

And then on the ground, we really need to see more accessibility. I was really disappointed in the federal election when I watched candidates and people I admire and look up to with no image descriptions on Twitter, with videos without captions. And these are very simple things to add. There weren't transcripts for speeches.

And so when we're not making it accessible for everyone, it makes politics a lot harder to engage with for a whole set of the population. So I think that working on that in the ground in our day-to-day practices and engagements with politicians will definitely help improve accessibility overall.

Jodi: Amen. Sara, what's next for you?

Sara: Yeah, that's the million dollar question, I think. Oh, if only I knew, if only I had 20/20 vision like Canada 2020. But I just really love working on health policy. I love talking about accessibility in a positive way and thinking about how we can move forward. And so any role that can allow me to do that and have impact, both for people with disabilities and for inclusion in general, is something I want to do and be a part of. So I'm not totally sure, but I just want to be able to make a difference for people with disabilities.

[Music plays]

Jodi: Sara, we'll be watching. Thank you so much for your advocacy, for all you've already achieved, and for what I'm 100% confident you'll continue to achieve in the future. Thank you.

Sara: Yeah, thank you so much for having me. It was a real pleasure.

[Music swells, then fades out]